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Feasibility Report

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EXECUTIVE SUMMARY

In New South Wales, routinely collected information, such as causes of death provided by the Australian Bureau of Statistics (ABS) and hospitalisation information collected by the NSW Department of Health, is commonly used to assess and report on the effect of diseases and injuries on the community. These types of information are limited in how they can be used to provide a comprehensive picture of the overall pattern of disease experienced by the population, because of limitations of coverage and ascertainment, among other things. They are particularly limited in providing an adequate description of the substantial cumulative morbidity resulting from common, long-term conditions such as depression, which often do not directly result in hospital treatment or death.

The global burden of disease study aimed to address these limitations, by developing a new summary health gap measure called the 'disability adjusted life year' (DALY), and by comprehensively assessing the complete spectrum of disease that occurs in a population. This report discusses the feasibility of conducting a burden of disease and injury study for NSW using the methodology that was used in that study and, more recently, in Australia. It presents a brief history of burden of disease studies and the main formulae used to calculate the various burden of disease components. By focusing on the Victorian study, which provides the most complete precedent for a New South Wales study, the reporting and processing steps are summarised. Finally, options and recommendations for conducting a study in New South Wales are presented.

History of the burden of disease approach

The global burden of disease study report was released in 1996, with estimates of the burden of over 100 diseases, injuries and risk factors in eight geographically defined areas of the world in 1990. Projections of burden to 2020 were also published. The aim of the study was to provide a comprehensive picture of the health status of the world population now and in the future, and to provide a foundation for applying the methodology to individual countries and smaller population groups. The methodology brought together epidemiological and health economics principles.

The global study and the subsequent burden of disease and injury studies measured the burden of disease using the Disability Adjusted Life Year (DALY), which combined burden due to premature death and burden due to disability in a single time-based measure. The mortality burden component aims to measure years of life lost due to premature death (YLL) and the disability burden component aims to measure years of life lived with disability (YLD). The additive nature of the DALY facilitated calculations and comparisons of burden across groups of diseases, health outcome, regional and demographic group and the burden attributable to risk factors. The DALY was designed to satisfy a dual purpose; quantifying the burden of disease and as a summary measure for assessing cost-effectiveness of health interventions.

Australian studies published to date include a national study, run by the Australian Institute of Health and Welfare (AIHW), and the Victorian study conducted by the Victorian Department of Human Services. These two studies were conducted in parallel and collaboratively to report the estimates of the burden of over 160 diseases, injuries, and risk factors. Within those diseases, disability burden was measured for more than 1200 disease states, stages, or outcomes. Studies have also been initiated in Queensland and the Northern Territory, but the results are yet to be published.

Calculating Disability Adjusted Life Years

The DALY aims to quantify the amount of full health lost due to illness or injury occurring in the reference period, by adding the burden arising from deaths in that period to the

burden of incident (new) cases of disease occurring in that same period. The burden is not simply the count of deaths and new cases, but is quantified by multiplying the number of incident deaths or cases by an estimate of relative severity of disability caused by the condition, known as the disability weight, and by the duration of the loss of health. The disability weight is measured on a scale of zero to one, and is constructed so that 'zero' means full health and 'one' means death. The duration of loss of life is limited by an 'ideal' life expectancy from a life table chosen for each study.

An optional discounting factor to reflect the greater importance people, on average, place on the loss of health in the near future compared with the distant future can also be incorporated into the calculation. Age-weighting to assign different weights based on the economic and social welfare value of people at different ages can also be incorporated. To be consistent with the methodology used in Australia, discounting (but not age-weighting) is incorporated into the formulae shown here.

The DALY for a cause of disease or injury is calculated separately for each age group defined in the study and for each sex. The total burden of that disease is the sum of the DALYs for all age groups and both sexes. This additive feature of DALYs is central to its application to different aggregations and disaggregations of populations and causes of disease or injury. The formula is shown below:

DALY formula

$$DALY = YLL + YLD$$

The YLL represents the number of years of life lost due to a premature cause of death in a population. It is based on estimates of the incidence of death caused by the condition and the 'ideal' life expectancy in the absence of premature death. The YLL formula for a cause of death for a given age group and sex is shown below:

YLL formula

$$YLL = D \times \frac{(1 - e^{(-r \times L)})}{r}$$

The quantities used in the formula are: D, the estimated number of deaths caused by the disease or injury in that age group and sex; L, the overall 'ideal' life expectancy of that age group and sex; and *r*, the discount rate.

The YLD represents the number of years of healthy life lost due to disability caused by the non-fatal experience of disease or injury in a population. It is based on estimates of the incidence of the condition, the average duration of the condition, and is weighted according to the estimated average degree of disability caused by the condition. The formula is shown below:

YLD formula

$$YLD = I \times W \times \frac{(1 - e^{(-r \times T)})}{r}$$

The quantities used in the formula for a given age group and sex are: I, the estimated incidence of the disease stage or sequela; W, the disability weight; T, the duration of disability; and *r*, the discount rate. The overall YLD for a disease or injury is often the sum of individual YLDs calculated for disease stages, levels, or sequelae contributing to the overall burden of that condition.

Reporting burden of disease

To help in understanding the information that is provided by burden of disease studies, this report reviews the published outputs of the Victorian burden of disease study. The *Victorian Burden of Disease Study: Mortality* presented the mortality burden of over 90 conditions aggregated variously by age group, disease group, and socioeconomic group. The *Victorian Burden of Disease Study: Morbidity* presented the total burden by its mortality and morbidity components. The results were also presented by sex and various broad age groupings, geographical region and socioeconomic status. The Victorian study took the established process a step further by calculating and reporting burden estimates for Victorian Local Government Areas (LGAs).

Processing the burden of disease

To better describe the time, effort and resources required to conduct a full burden of disease study, this report describes in detail the processing steps followed in the Victorian study.

Preparatory work included deciding on a reference (baseline) year, the list of diseases and injuries and the age and sex categories to be assessed. A discount rate, which accounts for the rate at which individuals, on average, value future health states compared to present health states, was selected, and a reference life expectancy value for each age group, against which premature mortality and disability are measured, was also calculated.

The next step was to calculate the mortality burden at the Victorian state level, which was straightforward because it involved allocating all deaths from the routinely published ABS cause of death data collection to the disease and injury list already defined. MS Excel spreadsheets were then used to calculate the mortality burden estimates for Victoria, by age group and sex. Additional statistical modelling was used to calculate the relationship between socioeconomic status, rurality, and mortality burden.

Estimating the morbidity burden was complex and time-consuming, since it required estimation of the incidence, severity, and average duration of disability for the more than 1200 non-fatal disease stages, levels, or sequelae studied. The required data were obtained or estimated from a range of sources covering disease registers, routinely collected data, published and unpublished studies, and/or expert opinion. Disability weights, which provide an index of the relative disability resulting from a disease state, were mostly obtained from previous international studies. Disease incidence, prevalence or duration was frequently modelled from available epidemiological information using a computer program, DisMod, developed by the global study researchers.

Once incidence, duration and disability weights were obtained, they were entered into MS Excel spreadsheet files. The spreadsheets files generally followed a generic framework, called a disease model, that provided a structure for the calculation of the morbidity and total burden by age group and sex.

The calculation of the burden attributable to risk factors was supplementary to the calculation of the mortality and morbidity burden. The results of the disease and injury burden calculations for all diseases that may be influenced by the risk factor must be available, as the attributable burden is calculated by applying the population attributable fraction associated with a risk factor to the mortality, morbidity, and total burden estimates already calculated. Separate Excel workbook files were created for each of the 10 risk factors considered in the Victorian study, and these contained documentation of the data sources and assumptions used as well as the data and calculations.

Projected burden of disease figures for the year 2016 for all diseases and injury causes, as well as for each of the 10 risk factors, were estimated using the baseline figures for 1996. Much of the

processing for the projected burden required use of sophisticated statistical analysis techniques to estimate trends in the incidence of deaths based on historical data. Once these estimates were obtained, Excel workbook files were used to collate and calculate the projected burden figures.

The methodology was extended to calculate the burden for local government areas (LGAs) in Victoria. These were also aggregated up to Victorian Human Services Regions. To avoid problems with small incidence counts, five years of mortality data were aggregated for calculating the LGA level mortality burden, and statistical modelling was used to estimate many of the disease incidence figures required for the LGA level morbidity burden.

Discussion

The DALY has been described as an important step forward in the development of summary population health measures, with benefits including the identification of neglected health problems and identification of the strengths and weaknesses of existing health information systems. It has fostered extensive debate on the social value choices that influence health resource allocation. The DALY has been criticised for its lack of appropriate social and methodological assumptions, the lack of good quality data, and inadequate treatment of coexisting diseases and risk factors.

Another important factor affecting the feasibility of a burden of disease study is data availability. NSW has many data collections that mirror those in Victoria. Like Victoria, there are numerous diseases for which no NSW data are available and data from other states, the literature, and/or expert opinion, would be needed. NSW is in the fortunate position of having an ongoing health survey program that could be utilised in collecting risk factor prevalence figures and prevalence or incidence figures for selected conditions. However, this would not replace sources of more accurate disease incidence information such as disease registers.

The major burden of disease studies conducted at the Australian and Victorian levels represent the culmination of an impressive commitment of time and effort from a small number of researchers. Development of the studies required the assembly and processing of detailed epidemiological descriptions of over 160 conditions, including 14 injury causes by 32 injury diagnoses.

The burden of disease approach can provide benefits by delivering a comprehensive overview of population health that reports the relationship between fatal and non-fatal outcomes of disease and injury. The resultant understanding of the epidemiology of diseases occurring at the population level should be highly regarded. Despite its appeal, acceptance of the burden of disease approach requires acceptance of many assumptions and less than ideal data sources. The apparent precision with which the results are presented can mask the imprecision and uncertainty that may be inherent in many of the estimates or the parameters used in their calculation. Further, while many resources are available from previous Australian studies, substantial development work and assembly of local epidemiological data would still be required in NSW.

Options and recommendations

Option 1: Do nothing

Reasons for choosing this option would include the lack of local epidemiological data for many diseases and doubt about the ability of the DALY methodology, with its many inherent assumptions, to provide an accurate picture of the health of the New South Wales population. Also, the completeness of disease coverage of the methodology makes it cumbersome to adapt for other purposes, such as focusing on preventable conditions or particular population groups.

Nevertheless, there remains a strong commitment to the burden of disease approach by the World Health Organization, and the methodology is undergoing continual development. A complete picture of population health in New South Wales would provide a foundation for extending the methodology into other domains in New South Wales, such as the burden of preventable disease and injury. By not pursuing burden of disease at any level in New South Wales, the opportunity to participate in its further development would be lost.

Option 2: Complete approximation of the NSW burden using Australian burden rates

The New South Wales burden would be estimated by applying Australian population rates of the mortality and morbidity burden from the 1996 study to New South Wales population counts, by age and sex. This option would give estimates of both the mortality and morbidity burden for New South Wales with minimal resources, but would give only an approximate picture of the true burden. Despite differences in magnitude in the resulting DALYs between New South Wales and Australia, the ranking of conditions and risk factors would be very similar because New South Wales had the largest population contribution to the national results. Any differences would reflect differences in the age and sex structure of the two populations, and would hide differences in other characteristics that influence disease and injury incidence.

The necessary assumption that mortality and morbidity patterns within each sex and age group in New South Wales match those at the national level would become untenable for smaller areas or sub-populations if this approach were adopted. The scope would be further limited because it would have to be based on Australian estimates as of 1996, which is now becoming quite dated. Interpretation of the results would have to be treated with caution because of the possible inaccuracies that might arise from propagating assumptions on top of assumptions already built into the burden of disease methodology.

Option 3: Full mortality burden assessment only

This option involves a comprehensive assessment of the mortality burden for New South Wales by calculating YLLs from cause of death data for New South Wales, without an assessment of morbidity. Risk factor mortality burden and LGA level estimates could be obtained using the same methods as Victoria. Availability of complete cause of death data from the ABS means that this approach would require few resources. The main disadvantage is that it would neglect the non-fatal disease burden.

Note that the mortality component represents approximately half of the total burden of disease, but requires a small fraction of the resources of a complete study. It is argued by proponents of the burden of disease approach that it is worth investing the effort into obtaining complete mortality burden estimates for the geographic area under study.

Option 4: Full mortality assessment combined with approximation of New South Wales morbidity using Australian morbidity rates

This combines option 3 for the mortality component with option 2 for the morbidity component. The mortality burden would be calculated in full, while the morbidity burden would be estimated by applying Australian morbidity burden rates to New South Wales population counts, by age and sex.

This approach would provide a substantial saving in resources, because the majority of the time and effort of a full study is expended in calculating the disability component. This approach would be restricted to an analysis of 1996 data, unless an assumption was made that the incidence of non-fatal diseases does not change over time.

Option 5: Full New South Wales-level burden of disease assessment utilising available resources from the Australian and Victorian studies

This method would use the DALY methodology to calculate mortality, morbidity and total burden estimates using Excel workbooks and disease models from the Australian and/or Victorian studies, but with New South Wales incidence data where available. This approach would have the advantages of utilising the best available data for NSW and would provide a full description of the disease burden.

Although substantial infrastructure is available from the Victorian and Australian studies, assembly and modelling of local incidence data and verifying the epidemiological assumptions built into the existing disease models remains a large task. This approach would permit extension, using the Victorian methodology, to smaller area estimates.

Option 6: Full NSW-level assessment of a reduced set of diseases and/or risk factors

This approach would focus on applying option 5 to a set of conditions considered to be of public health importance because of their preventability, such as those covered by the National Health Priority Areas. This would require fewer resources than a complete study, but would have the disadvantage of a providing an incomplete assessment of population health for NSW. It should be recognised that this approach would still require involved staff to devote a substantial amount of time and effort to becoming familiar with the methodology and the practicalities of assembling relevant data.

Option 7: Full redevelopment of the burden of disease methodology for NSW

This approach is not recommended, but is included for completeness. It would require full redevelopment of disease models, disability weights, literature review, and consultation with experts. This is such a substantial task that it is beyond the resources of a single state to conduct.

Other recommendations

1. That options be explored for establishing a national centre that provides assistance to Australian states and territories in conducting local burden of disease studies through, for example:
    - maintaining the most up-to-date epidemiological resources for completing disease models when local data sources are unavailable;
    - maintaining the MS Excel spreadsheet files and other computer resources required for conducting local studies, so that they reflect the latest epidemiological understanding of each condition;
    - providing a facility for conducting local level studies under contract to the states and territories;
    - maintaining links with international burden of disease study groups to ensure the most up-to-date methodology is being utilised; and
    - advocacy for research that will improve the epidemiological description of chronic and complex conditions at the population level.
2. That mechanisms for using the NSW Health Survey Program to provide risk factor, disease and injury prevalence and/or incidence information for use in a NSW burden of disease study be explored. It should be recognised, however, that for many long term or complex conditions, self-reported responses are often inadequate for providing accurate incidence or prevalence estimates.
3. For routine reporting of hospitalisation data in NSW, consideration should also be given to using data linkage methods to obtain incidence counts at the person level. This approach would avoid distortions that might arise when persons are counted multiple times through being readmitted for a continuing condition.

GLOSSARY

ABS	Australian Bureau of Statistics
AF	Attributable fraction; that proportion of a disease's incidence that is attributable to exposure to a risk factor
AIHW	Australian Institute of Health and Welfare
DALY	Disability adjusted life year = mortality burden (YLL)+morbidity burden (YLD); a summary measure of the fatal and non-fatal burden of a disease or risk factor in a population
DisMod	A computer program developed by the Harvard University School of Public Health for the global burden of disease study; it can be used to model the relationships among incidence, prevalence, duration, remission, and excess mortality of a condition. It can be used to obtain plausible estimates of any of those quantities when only partial information is available.
HSR	Victorian Human Services Region
LGA	Local Government Area
MS Excel	Microsoft Excel spreadsheet software
SAS	Statistical analysis software
SPSS	Statistical analysis software
STATA	Statistical analysis software
WHO	World Health Organization
YLD	Years of healthy life lost due to disability; a summary measure of the non-fatal burden of a disease or risk factor in a population; the morbidity component of the DALY
YLL	Years of life lost due to premature mortality; a summary measure of the fatal burden of a disease or risk factor in a population; the mortality component of the DALY

1 ABOUT THIS REPORT

Understanding the burden placed on the community by diseases, injuries and preventable risk factors can assist in priority setting and can guide the development of population health policy and programs. Data collected for this purpose can also provide useful information to assess the impact of such policies and programs.

In NSW, routinely collected information, such as causes of death provided by the Australian Bureau of Statistics (ABS) and hospitalisation information collected by the NSW Health Department, is commonly used to assess and report on the effect of diseases and injuries on the community.[1]

However, information collected and reported in this way cannot easily be combined to provide an aggregate 'health gap' measure of the combined effects of both death (mortality) and disability (morbidity). These types of information are particularly inadequate for describing morbidity arising from conditions such as depression that do not often lead to hospitalisation or death, but through their long term and common nature result in substantial cumulative morbidity. Furthermore, these measures are not generally prepared and reported in a way that can be easily aggregated or disaggregated to provide an internally consistent ranking of the relative contribution of diseases, injuries, or risk factors to the overall burden in a population. They may not be able to be easily compared between populations or sub-populations, because of differences in available data sources, collection methods, or ascertainment.

The World Health Organization's global burden of disease study aimed to address the limitations of more conventional measures of disease burden. Several countries, including Australia adopted the methodology of the global study. At the core of the methodology is a health gap measure called the 'disability adjusted life year' (DALY). The DALY measure incorporates the burden of premature death as well as premature disability and is used additively, making it useful for aggregating the disease burden in many different ways.

This report discusses the feasibility of conducting such a burden of disease study for New South Wales using DALYs. The most advanced burden of disease study at the state level in Australia is the Victorian study, and it will be referred to frequently in this report. The methodology and processes used in the Victorian study are used as the basis for assessing the feasibility of conducting a study in New South Wales. This approach is further justified because the national data sources used at the Victorian level are likely to have New South Wales components, and because New South Wales and Victoria have a similar range of administrative and routinely collected data sources at the state level.

By way of background, Chapter 2 presents a brief history of the development of the DALY and burden of disease studies. Chapter 3 explains how the concepts of premature death and disability are incorporated into the DALY measure by describing the formulae that are used for calculating the DALY and its components. To highlight potential reporting outcomes of a burden of disease study, Chapter 4 reviews the outputs of the Victorian study.

Because much of the time and effort involved in conducting such studies is in the data collation, preparation and processing stage, Chapter 5 reviews the processing steps of the Victorian study. Chapter 6 discusses the advantages and limitations of the burden of disease methodology, and the issues that are important in deciding how such a study could be approached in New South Wales. Finally, Chapter 7 presents the options for conducting a New South Wales study and their advantages and limitations.

The information presented in the report was obtained from several main sources:

- the global burden of disease study report;[2]
- the Australian burden of disease study report; [3]
- the Victorian burden of disease study reports and web sites;[4,5,6,7,8]
- discussions and consultation with the Victorian and other Australian burden of disease researchers.

Because there is much overlap among these reports, they are not referenced individually throughout the text. Other more specific references are given, where relevant.

2 A BRIEF HISTORY OF BURDEN OF DISEASE STUDIES

This chapter outlines the motivations of the first global burden of disease study and the development of the DALY measure of disease burden. Some of the subsequent studies are briefly described, including those conducted or being conducted in Australia.

The Global Burden of Disease and Injury Study

The global study was initiated in 1992 by the World Health Organization (WHO) and the Harvard University School of Public Health and was funded by the World Bank. The study was motivated by the desire to measure the rapidly changing global health situation and to initiate the development of a system to aid the global allocation of health resources. It aimed to provide a comprehensive picture of the health status of the world population now and in the future, and to provide a foundation for applying the methodology to individual countries and smaller population groups.

The burden of over 100 diseases and causes of injury and 10 risk factors was calculated for eight demographic regions of the world for a reference period of 1990. Projections of burden to 2020 were also published. The study took an estimated 40 person-years to complete and was published in 1996.[2] The outputs included:

- ranking of burden within geographic regions;
- comparisons of disease burden among eight demographic regions of the world;
- estimates of the global burden of non-fatal diseases;
- estimates of the burden attributable to 10 risk factors;
- projections of future global disease and injury burden.

Burden of disease studies utilising and/or adapting this methodology have since been conducted in a range of individual countries, such as Mexico, Thailand and New Zealand. Of particular note is a Dutch study that, although it did not result in a complete burden of disease study, was the source of several methodological developments that have been subsequently adopted by other countries, including Australia.

The disability adjusted life year (DALY)

Central to the global study was the development of a new time-based unit of measurement for quantifying the burden of disease and injury in human populations. The aims of the researchers in developing the measure were to:

- incorporate the combined effects of disability and premature death into a single measure;
- disentangle epidemiology from advocacy by producing a measure that was objective and demographically plausible;
- facilitate the aggregation or disaggregation of the burden for populations, demographic groups, diseases, injuries or risk factors;
- provide a unit of measurement that can also be applied to the assessment of the cost effectiveness of health interventions.

The result was the disability adjusted life year, or DALY. The DALY estimates the gap between the potential number of years that people, on average, can live in full health and the number of years actually lived, on average, after adjusting for premature disability or death. It incorporates a measure of years of life lost (YLL) due to premature death, known

as the mortality burden, and a measure of years of life lived with a disability (YLD), known as the morbidity burden. The DALY was used additively to estimate the aggregated burden for multiple diseases or injuries, risk factors, demographic groups, or whole populations, countries and groups of countries. The DALY was designed to satisfy a dual purpose: to quantify the burden of disease and to provide a summary measure for assessing cost-effectiveness of health interventions.

The core variable for calculating a DALY is an estimate of the true population incidence of disease or injury. To achieve demographic plausibility, each incidence estimate must be mutually exclusive of all other incidence estimates. Much of the effort and time expended in burden of disease studies arises from the need to utilise a range of available data sources, literature and expert judgement in an attempt to overcome under-coverage and other limitations of available data sources that might lead to erroneous or overlapping incidence estimates. The calculation of the DALY is described in more detail in Chapter 3.

Burden of disease studies in Australia

During 1998–1999, the Australian Institute of Health and Welfare (AIHW) and the Victorian Department of Human Services each conducted a burden of disease study for the whole of Australia and the state of Victoria respectively for the reference year 1996. These studies were conducted in parallel and collaboratively. The methodology used was based on the global study, but with some modifications and extensions, such as excluding the controversial practice of weighting the burden differently according to age (age-weighting), and including evaluation of the burden by socioeconomic status.

The Victorian study group went even further, and delivered estimates for small areas, including Victorian Local Government Areas (LGAs) and Human Service Regions (HSRs). This required further methodological developments, and utilised a range of additional statistical and other techniques to estimate non-fatal disease incidence at the local level. The additive property of the DALY permitted the LGA estimates to be summed to provide HSR estimates. At the time of writing, the Victorian study had occupied four to five person-years of effort, and additional work was continuing. The Australian study took approximately four person-years to complete.[9]

More recently, Queensland Health initiated its own study. They calculated the full mortality burden by the conventional method using Queensland level cause of death information. For the morbidity burden, however, they simply obtained Queensland estimates by multiplying the national age and sex-specific morbidity estimates by the age and sex-specific ratio of the Queensland to the Australian population counts. This approach assumed that the age and sex-specific incidence, duration and mortality from non-fatal disease processes for the whole of Australia also applied to Queensland. This avoided the time and effort of acquiring or estimating local level incidence figures. At the time of writing, approximately four person-months had been expended on the project, which was as yet unpublished. One senior researcher and one data analyst were employed in the task. Some adjustments were made for Queensland circumstances such as its higher incidence of melanoma.

The Northern Territory also initiated a study early in 2001. This study is important in the Australian context because of the Territory's proportionately large indigenous population. Data on the health of indigenous people is generally known to be of poor quality, though good quality deaths data is available in the Northern Territory. At the time of writing, the researchers had not yet been able to develop an adequate methodology to overcome this limitation and calculate morbidity burden estimates and the study had produced mortality burden estimates only.

Most recently, the Australian Institute of Health and Welfare established a Summary Measures Unit, which will be involved in supporting burden of disease studies at the national level. It is anticipated that the national burden of disease study will be updated every five years, in line with ABS Census schedules.

3 CALCULATING DISABILITY ADJUSTED LIFE YEARS

This chapter introduces the formula used for calculating a DALY and its components. The calculations and formulae are not essential to assessing the effort and time involved in conducting the study, as most of the effort is expended in the data collation and processing stage before the formulae are applied. However, many of the arguments for and against the DALY approach to burden of disease that will be discussed in Chapter 6, are based on concepts used in developing these formulae. The processing description in Chapter 5 explains how the components of the formulae are obtained in the preparatory and data collation stages of conducting the study.

The following sections describe the DALY formula followed by the formulae for its components—the mortality burden (YLL) and the morbidity burden (YLD). These formulae exhibit the additive nature of the YLL, YLD, and DALY. The calculation of the burden attributable to risk factors is then introduced, as these require estimates of the disease burden before the portion attributable to a risk factor can be calculated. The formulae used to calculate projected and LGA-level burden are not presented here, as these were more procedural tasks. These procedures are described in Chapter 5.

The DALY aims to quantify the amount of full health lost due to illness or injury occurring in the reference period, by adding the burden arising from deaths in that period to the burden of incident (new) cases of disease occurring in that same period. The burden is not simply the count of deaths and new cases, but is quantified by multiplying the number of incident deaths or cases by an estimate of the relative severity of disability caused by the condition, known as the disability weight, and by the duration of the loss of health. The disability weight is measured on a scale of zero to one, and is constructed so that zero means full health and one means death. The duration of loss of life is limited by an 'ideal' life expectancy from a life table chosen for each study.

In the global study, two additional factors were incorporated into the measure: discounting and age weighting. Discounting was used in a similar way to the discounting of future monetary value in economics; that is, as a compounding percentage rate. In the context of burden of disease, the discount rate attempted to quantify the decreased importance people, on average, place on the loss of healthy life in the future compared to the present. The formulation of the discount rate in the global study was based specifically on the small degree of future uncertainty over survival of human societies and to provide greater weighting to the near future than the distant future to encourage investment in health research or interventions that will provide benefits sooner rather than later. A small arbitrary discount value of three per cent was chosen in the global, Australian, and Victorian studies.

Age weighting assigned different social utility values to different ages at which disabilities or deaths are experienced, so that death or disability of a young or middle-aged adult was assigned a greater weight than for young children or the elderly. This age weighting aimed to reflect both the relative economic contribution and the broader social welfare contribution at different ages.

To be consistent with the Australian and Victorian methodology, the formulae presented here incorporate discounting but do not incorporate age weighting. Age weighting in the global study aroused considerable controversy and was therefore excluded from the Australian studies. Discounting is also optional and both the global and Australian studies calculated both discounted and undiscounted DALYs, although reporting of discounted DALYs was preferred.

The DALY

The DALY for a cause of disease or injury is calculated separately for each age group defined in the study and for each sex. The total burden of that condition is the sum of the DALYs for all age groups and both sexes. This additive feature of DALYs is central to its application to different aggregations and disaggregations of populations and causes of disease or injury. The formula is shown below:

DALY formula

$$DALY = YLL + YLD$$

The YLL term is the mortality burden component and essentially represents years of life lost due to premature death. The YLD term is the morbidity burden component and essentially represents years of life lived with disability (YLD) resulting from non-fatal incidence of a condition. Each of these terms is calculated separately and can then be summed to give the total burden for that age group and sex for the disease. These components and their formulae are described more fully in the following sections.

The mortality component of the DALY, the YLL

The YLL represents the number of years of life lost due to a premature cause of death in a population. It is based on estimates of the incidence of death caused by the condition and the 'ideal' life expectancy in the absence of premature death. The YLL formula for a cause of death for given age group and sex is shown below:

YLL formula

$$YLL = D \times \frac{(1 - e^{(-r \times L)})}{r}$$

The quantities used in the formula are:

- D, the estimated number of deaths caused by the disease or injury in that age group and sex. In Australia, the complete cause of death data collection made available by the Australian Bureau of Statistics is the source of these figures.
- L, the overall 'ideal' life expectancy of that age group and sex, obtained from the life table chosen at the beginning of the study to represent the maximum potential life expectancy pattern. This figure is a constant for all YLL calculations for a given age group and sex. It represents the duration of the loss of healthy life.
- r , the discount rate. This figure is a constant chosen at the beginning of the study.

If the discount rate is chosen to be zero, then the formula simply becomes $\boldsymbol{D} \times \boldsymbol{L}$.

The morbidity component of the DALY, the YLD

The YLD represents the number of years of healthy life lost due to disability caused by the non-fatal experience of disease or injury in a population. It is based on estimates of the incidence of the condition, the average duration of the condition, and is weighted according to the estimated average degree of disability caused by the condition.

Obtaining estimates of this morbidity component of the DALY can be an extremely complex process for many diseases. Diseases such as cancer have many distinct types and sub-types, and several stages or levels of severity within sub-types. Diseases such as diabetes have many sequelae. Injury causes result in many different injury types, with differing degrees of disability and duration. This means that YLDs for each cause of disease or injury are often aggregated from YLDs calculated for different types, stages, severity levels, and/or sequelae, depending on the way the

disease or injury progression is modelled. Other conditions are simpler and only have one stage defined, so the YLD only needs to be calculated once for each age group and sex.

Nevertheless, the basic YLD formula is applied in the same way throughout the study at the lowest level at which the disease process is defined. The formula is shown below:

YLD formula

$$YLD = I \times W \times \frac{(1 - e^{(-r \times T)})}{r}$$

The quantities used in the formula are:

- I, the estimated incidence of the disease stage or sequela for that age group and sex. This figure is obtained from a combination of available data sources, literature and expert opinion.
- W, the disability weight for the disease stage or sequela and, sometimes, age group and sex. This value is a constant between zero (perfect health) and one (equivalent to death) for the disease, disease stage, sequela or age group that has either been determined as part of the preparatory work of the study or is adopted from work done in other burden of disease studies.
- T, the duration of disability associated with the disease stage, sequela and/or age group and, in some cases, sex. This is obtained using a combination of information from available prevalence surveys or other studies, literature, expert opinion, and the use of a computer program that models the relationship among incidence, prevalence, duration, remission rate and mortality.
- r , the discount rate. This is the same constant value as used with YLLs.
- If the discount rate is chosen to be zero, then the formula simply becomes $\boldsymbol{I} \times \boldsymbol{W} \times \boldsymbol{T}$.

The processes used to obtain the quantities used in the calculation are described more fully in Chapter 5.

The burden attributable to risk factors

Calculation of the risk factor burden is an extension of the standard burden of disease calculation already described, and uses the results of those calculations as a basis. The burden of a risk factor is defined as the estimated number of DALYs that could be eliminated from a population if the risk factor was eliminated from that population.

A complication is the potentially substantial time lag between exposure to risk factors, such as smoking, and their health consequences. The approach taken in the global and Australian studies was to calculate the current burden of *past exposure* to risk factors, as this approach is less complex and less sensitive to assumptions than the alternative approach of estimating future burden of *current exposure* to risk factors.

The foundation for this work is the traditional epidemiological approach to estimating the attributable fraction of disease incidence due to exposure to a risk factor. The attributable fraction can be estimated from knowledge of the prevalence of the risk factor in the population and the relative risk of the outcome among the exposed population compared with the non-exposed population. In burden of disease studies, these quantities were obtained from the literature, from the results of available prevalence surveys that measured risk factor prevalence in the study population or comparable populations, or from expert opinion. In the Victorian study, the following steps were taken to calculate the disease burden attributable to a risk factor.

1. For each disease known to be associated with the risk factor, the attributable fraction for each age group and sex was calculated using the formula:

   Attributable fraction (AF) formula

$$AF = \frac{\Sigma_i \, p_i \times (RR_i - 1)}{\Sigma_i \, p_i \times (RR_i - 1) + 1}$$

   The quantities used in the formula were:

   - $RR_{i,}$ the estimated relative risk of contracting the disease among the exposed population relative to the unexposed population in that age group and sex, at each level, i, at which the risk factor exposure was categorised.
   - p_i, the estimated prevalence of the risk factor in that age group and sex at each level, i, at which the risk factor exposure was categorised.

2. To obtain estimates of the mortality and morbidity burden attributable to the risk factor for a disease in an age group and sex, the attributable fraction was applied to the mortality (YLL) and morbidity (YLD) burden estimates already obtained.

3. These attributable burden estimates were then summed across all diseases and injuries known to be associated with the risk factor and across age groups and both sexes to provide the aggregated total burden attributable to the risk factor. YLLs and YLDs could be separately summed to provide aggregated mortality and morbidity estimates.

4 REPORTING THE BURDEN OF DISEASE

To help in understanding the information that is provided by burden of disease studies, this chapter reviews the published outputs of the Victorian burden of disease study.

The authors of the global study envisaged that the results of burden of disease studies would:

- guide prevention of disease and injury through estimating and ranking the burden attributable to risk factors in terms of fatal and non-fatal outcomes;
- guide health service delivery through breaking down the disease and injury burden by disease in terms of fatal and non-fatal outcomes;
- guide rehabilitation policy by identifying the relationship between the fatal and non-fatal outcomes of diseases and injuries.

These objectives were reflected in the Victorian study with the production of separate mortality burden and morbidity burden reports. Generally speaking, the main results were highlighted in the body of each report, with a variety of text, graphs and tables used to communicate the results. In the main state-level reports, detailed tables were provided as appendices, showing the complete set of results by age, sex, and cause at the most disaggregated level available. Through a variety of mechanisms, including printed and/or internet reports, results were reported for the whole of Victoria, LGAs, Victorian Human Services Regions, and groupings of LGAs based on socioeconomic status. Projections of future burden were published only at the state level. The reporting of burden of disease results is described in more detail below.

The results of life expectancy calculations for each geographic area studied in Victoria were also reported. Apart from the ideal life expectancies used in the calculation of YLLs described in Chapter 3, calculation of actual life expectancies for each area was not necessary for calculating DALYs. They were, however, included as an additional summary indicator of overall population health status at the LGA level.

Victorian Burden of Disease Study: Mortality

Because the preparation of the mortality burden estimates was more straightforward than that of the morbidity burden, the first publication produced from the Victorian study was the mortality report.[4] This report concentrated on reporting the relative contribution of diseases, injuries and risk factors to premature death in Victoria in terms of the YLL figures calculated for the reference year 1996, as well projections to 2016.

Mortality burden by disease

To assess the relative contribution of diseases and injuries to the mortality burden, the results were partitioned at the following levels:

- the total of all causes of death;
- by three major disease groupings that reflected the differing pattern of health status between the more developed and less developed countries: communicable, maternal, neonatal and nutritional conditions; non-communicable diseases; and injuries;
- by seven broad disease groupings based on the national health priority areas: cardiovascular diseases, cancer, injuries, neuropsychiatric conditions, chronic respiratory conditions, diabetes mellitus, and other diseases. For some charts, only the first three of these categories were shown, with the remainder being aggregated under ‘other’;
- by 20 smaller disease groupings such as cancer, diabetes mellitus, mental disorders, cardiovascular diseases, as well as two injury cause categories, intentional and unintentional;
- by each of over 90 specific diseases and 13 causes of injury.

Each of the above partitions was also reported by sex and five broad age groups (0–14, 15–34, 35–54, 55–74, and 75 or more years). To highlight the most important diseases and causes of injury contributing to the mortality burden in Victoria, a table ranking the top 20 causes of mortality burden for each sex was also presented.

Mortality burden by geographic and socioeconomic partitions

To highlight health inequalities in Victoria, four main disease groups (cardiovascular, cancer, injuries, and other) were reported by quintiles of socioeconomic disadvantage, by rurality (metropolitan, rural towns and other rural), and by the nine Victorian Human Services Regions. These results were also reported by sex. The results of a statistical analysis that assessed the relationship among socioeconomic status, rurality and mortality burden were also presented.

Mortality burden attributable to risk factors

To assist planning and priority setting for future prevention strategies, the Victorian study reported the mortality burden attributable to six risk factors: tobacco, obesity, blood cholesterol, hypertension, physical inactivity and alcohol consumption. The effect of alcohol consumption was reported in two components; alcohol benefit and alcohol harm. These results were reported by sex and the proportional contribution of each risk factor to the total mortality burden.

Projections of future mortality burden

To provide an indication of the progression of the pattern of disease burden in Victoria over the 20 years following the reference year 1996, the estimated mortality burden for each of the seven broad disease groupings were presented for men and women for 2016. Projected changes in the ranking order of the top ten conditions for men and women were also shown.

Victorian Burden of Disease Study: Morbidity

The completion of the morbidity and final DALY component of the burden of disease processing permitted these results to be published together in the one document. The morbidity and total burden of a range of diseases, injuries and risk factors similar to those in the mortality publication were presented in this report, although a greater range of risk factors were assessed for this study (10) than were available at the time the mortality report was published (six). The morbidity publication focused mainly on describing the combined mortality and morbidity burden in terms of DALYs, and future projections of these, with a small section devoted to describing the morbidity burden.

Morbidity and total burden by disease

To assess the relative contribution of diseases and injuries to the morbidity and total burden of diseases, the results were partitioned at the following levels:

- The total of all causes.
- As for the mortality burden, by three major disease groupings that reflected the differing pattern of health status between the more developed and less developed countries: communicable, maternal, neonatal and nutritional conditions; non-communicable diseases; and injuries.
- By nine broad disease groupings that reflected the national health priority areas and other major contributors to the disability burden: cardiovascular diseases, cancer, injuries, mental disorders, neurological conditions, chronic respiratory conditions, diabetes mellitus, musculoskeletal conditions and other diseases.
- As for the mortality burden, by 20 smaller disease groupings such as cancer, diabetes mellitus, mental disorders, cardiovascular diseases, as well as two injury cause categories, intentional and unintentional.

- By each of over 140 specific diseases and 14 causes of injury.

Each of the above partitions was also reported by sex and five broad age groups (0–14, 15–34, 35–54, 55–74, and 75 or more years). To highlight the most important diseases and causes of injury contributing to the morbidity and total burden in Victoria, tables ranking the top 20 causes of mortality burden and of the total burden in each sex were also presented.

Age and sex patterns of disease burden

To describe age and sex patterns of disease burden, DALYs were reported by sex in four main age groups: children (0–14 years), young adults (15–34 years), adults (35–64 years) and older persons (65 or more years). Within these age groups, the results were partitioned by a combination of specific diseases and disease groups most relevant to that age group. Tables ranking the top 10 causes of burden in each age and sex group were also presented.

Highlighting specific disease groups

The study also provided a more detailed discussion of the seven broad disease groupings that were found to be responsible for the highest number of DALYs in Victoria: cardiovascular disease, cancer, mental disorders, neurological and sense disorders, chronic respiratory conditions, injuries, and musculoskeletal conditions respectively. Within these groups, the relative contributions of the mortality and morbidity components were discussed, as well as the contribution of specific causes within those broad groupings. The age and sex pattern was also discussed here in more detail, where relevant.

The burden attributable to selected risk factors

The extended range of risk factors assessed in the morbidity report were: tobacco, obesity, blood cholesterol, hypertension, physical inactivity and alcohol consumption, illicit drugs, intake of fruit and vegetables, occupational exposures, and unsafe sex. As in the mortality report, alcohol harm and alcohol benefit were considered separately. The report compared the contributions of each risk factor to the total disease burden in each sex, with the mortality and morbidity components distinguished.

More detailed information was provided for each risk factor, with the risk factor's contribution to individual diseases being shown in terms of YLLs, YLDs, and DALYs. The age distributions of YLLs, YLDs and DALYs for each risk factor were also presented for comparison.

Future projections of the Victorian burden of disease and injury

To assess the future pattern of the disease and injury burden and potential changes in the relative importance of conditions, the projected DALYs (expressed as rates) to 2016 were calculated and reported for all conditions and by age and sex. Projected YLLs and YLDs were reported individually only for the all-cause totals.

To assess how the importance of particular conditions is likely to change in the future, relative changes in the projected burden between 1996 and 2016 were reported for the eight broad disease groupings with the highest contribution to the total burden, and for the individual diseases within these groups. Also reported was the projected change in ranking for the top 12 broad disease categories of 1996 for each sex, and for the top 12 individual diseases of 1996 and 2016. The estimated changes in the burden attributable to risk factors was also reported, by sex, for: smoking, physical inactivity, obesity, blood cholesterol, fruit and vegetable intake, high blood pressure, and alcohol harm and benefit.

Burden estimates for Local Government Areas and Human Services Regions

The Victorian study was extended to evaluate burden of disease in Victorian Local Government Areas (LGAs) for 1996. These results were also aggregated up to Victorian Human Services

Regions (similar to NSW Health Service Areas). This generated a good deal of attention because full burden of disease analysis had not been completed at such a level of geographic detail before in the world and because health inequalities between communities were highlighted. As described in Chapter 5, the burden of disease methodology was adapted for small areas to take account of statistical imprecision and the lack of small area data for many conditions and risk factors. A preliminary LGA level study was conducted by the Southern Metropolitan Region of the Victorian Department of Human Services and the Southern Health Care Network in close collaboration with the state-level researchers.[6]

Apart from the initial report from the Southern Metropolitan Study,[6] the reports produced from these LGA level analyses were released as media briefings; one summary report for the whole of Victoria, and a separate one for each of the nine Human Services Regions.[8] More detailed data was made available as spreadsheets that could be downloaded from the Victorian Burden of Disease web site; one for each of the 78 Victorian LGAs and one for each Human Services Region.[10] These media briefings all had a similar style and the general content is described here. Microsoft Excel workbooks with more detailed results, including age-specific burden estimates for nine age groups, were also published, but are not further described here. A searchable web database of results is also available.[11]

To assess the relative contribution of disease groups to the total burden in each region, the reports showed estimated DALY counts and their component YLL and YLD counts for each of 14 broad disease groupings: cardiovascular diseases, cancer, mental disorders, neurological and sense disorders, chronic respiratory conditions, injuries, musculoskeletal conditions, diabetes, digestive disorders, genitourinary disorders, infections, congenital conditions, neonatal conditions, and other diseases.

Rates of DALYs per 1,000 population by sex for every LGA in Victoria were shown in each report. LGAs for the reporting region were highlighted, thereby permitting assessment of the ranking of LGAs both within their region and within the state. A 'burden barometer' was a novel method used in these reports to compare LGAs. It consisted of a central scale showing DALY rate per 1,000 population, with LGA names ranked vertically on the left for men, and ranked vertically on the right for women. The Victorian male and female average were also indicated on the respective side of the scale as a reference. These displays gave no indication of the statistical precision of the estimates, however. To assess geographic distribution of health status, maps of Victoria were presented, with LGAs coloured according to the following categories; highest DALY rates (157–180 per 1,000), middle range (132–156 per 1,000), and lowest (109–131 per 1,000).

To examine the pattern by LGA for important disease groupings, the same set of DALY rate displays (ranking by LGA, burden barometer, and maps) were then presented by sex for cancer, cardiovascular diseases, mental disorders, and injuries. To assess the pattern of disease burden for the National Health Priority Areas, DALY rates for cancer, diabetes, mental disorders, cardiovascular disease, asthma, injuries and other diseases, were presented for each sex and for each LGA in the region, the region as a whole, and the whole of Victoria. The media briefing also reported DALY rates for the 50 individual diseases most responsible for the burden of disease in each LGA within the Human Services region. These were shown separately for each sex, and were arranged by broad disease group.

The contributions of the 10 risk factors in each sex were also presented for the region as a whole. Again, alcohol harm and benefit were shown separately. The comparative contributions for the whole of Victoria were also shown.

5 PROCESSING THE BURDEN OF DISEASE AND INJURY

The previous two chapters introduced the formulae used and the outputs from the Victorian burden of disease and injury study. To better describe the time, effort and resources required to conduct a burden of disease study, this chapter describes the other aspects of processing required to conduct the Victorian study. Because the Australian and Victorian studies were conducted collaboratively and in parallel, the methods used were virtually identical. However, because data available at the state level in Victoria is more likely to mirror that available in New South Wales, we refer mainly to the Victorian study here. Many of these processes were originally established in the global study and were adopted by the Australian and Victorian study groups.

All of the YLL, YLD, and DALY calculations were done using Microsoft Excel workbook files. These were prepared collaboratively by the Australian and Victorian study groups and were used to store all the incidence figures assembled for the studies, as well as other parameters used in the calculations. The spreadsheet files contained all the formulae for calculating each YLL, YLD, and DALY, as well as all the aggregated results used in the reports. The Excel files used are freely available from the Burden of Disease Units at the Australian Institute of Health and Welfare or the Victorian Department of Human Services. Other computer programs, such as SPSS and STATA, were used for preparatory work to obtain figures that were needed for input into the Excel workbooks.

The processing descriptions that follow are presented in the logical order in which the processing was conducted to complete the Victorian study. Each step generally provides the basis for proceeding to the next step. Preparatory work and decisions are described first, followed by the processing required to calculate the state level mortality burden, then the state level morbidity burden, the state level risk factor burden, the projected state level burden and finally the burden for LGAs and Human Services Regions.

Preparatory work and initial decisions

Reference year

The Victorian study calculated estimates of the disease burden for 1996. This year was chosen because it was the year of the most recent cause of death information and the results of the 1996 Australian Census were available. While survey data was not considered a preferred source for epidemiological information, the availability of surveys such as the National Mental Health and Wellbeing Survey 1997 and the 1995 ABS National Health Survey (NHS) assisted in describing or verifying the epidemiology of a range of conditions.

Discount Rate

As mentioned in Chapter 3, a discount rate was used in the formula for the mortality burden (YLL) and the morbidity burden (YLD) for a disease. In the context of burden of disease, the discount rate attempted to quantify the decreased importance people, on average, place on the loss of healthy life in the future compared to the present. The formulation of the discount rate in the global study was based specifically on the small degree of future uncertainty over survival of human societies and to provide greater weighting to the near future than the distant future to encourage investment in health research or interventions that will provide benefits sooner rather than later.

A small arbitrary discount value of three per cent was chosen in the global, Australian and Victorian studies. The effect of discounting compounds over time. This means that each

year of life in the future was valued, on average, at 97 per cent of the previous year's value. The discount rate is a constant and is therefore fixed for all burden calculations.

Calculations with no discounting were also performed and recorded in Excel workbook files both nationally and in Victoria, but these were not generally reported.

Disease and injury list

Like the global study, the Victorian researchers decided to calculate the complete burden of disease and injury for the population. This required the selection of a comprehensive and mutually exclusive list of diseases and injuries for which the burden could be summed to provide an estimate of the total population burden of disease.

The global study developed a list of over 100 diseases and injury types based on chapters of the International Classification of Diseases. The level of disease delineation in the list was the result of the competing priorities of enough detail to inform health policy decisions while avoiding so much detail that the results would be uninterpretable.

The national and Victorian researchers adapted the global study list to be more relevant to the health experience of the Australian population, resulting in a list of over 160 specific causes of death and disability, including 14 causes of injury. This list defined the framework for calculating the mortality burden and a broad framework for the morbidity burden. Calculation of the disability burden further required the identification of the various stages, sequelae and severity levels within all of these conditions because of the different degrees of disability that could be experienced. This process is described below under *Disease Models*.

Age and sex partitions

To facilitate flexibility in reporting the disease burden for each sex and for different age groupings, the Victorian study calculated the burden for nine groups (0–4, 5–14, 15–24, 25–34, 35–44, 45–54, 55–64, 65–74, 75 or more years) and for each sex for each disease and injury cause. The burden for these age groupings could be summed to provide the burden for larger age groupings for a given sex and disease. Note that the mortality burden was calculated for five-year age groups, but these were aggregated up for combining with the morbidity figures to produce DALYs.

Life expectancies

As described in Chapter 2, 'ideal' life expectancies are required in the calculation of the mortality burden to provide an estimate of the potential life span of a person in the absence of premature death. The global study used Japanese life expectancies as these were the highest in the world, and could therefore be used as a reference for any country or group of countries. In Victoria, as in the Australian study, the average life expectancy figures for the whole Australian population were used.

In Australia, *cohort* life table methods were used to calculate the life expectancies, unlike the more commonly used *period* life table method, which assumes that all age cohorts alive at the time of the reference year continue to experience current mortality rates in the future. Cohort life tables aim to account for the projected future mortality experience of all age cohorts alive at the reference year. This is a more complex process than calculating a period life table, because it requires projected future mortality rates for each five-year age and sex cohort alive at the study's reference year. The ABS publishes the projected trends in age-specific mortality rates required to determine life expectancies for cohorts living up to 100 years into the future.[12]

One life table was required for each sex, and each life table provided life expectancy figures by five-year age groups. These figures could then be used in the calculation of individual YLLs for each disease or injury cause, age group and sex.

Processing the state level mortality burden

In the Australian and Victorian studies, calculating the mortality burden was a vastly simpler process than calculating the morbidity burden. This is because Australia has a well functioning death registration system in each state, and the ABS has a well established process for coding and publishing the cause of death incidence figures.

For the Victorian level YLL estimates, the ABS cause of death data collection for 1996, available as an electronic de-identified unit record file, was used to provide the required cause of death incidence figures. Deaths registered in 1996 were used rather than deaths occurring in 1996, as the delayed registrations were unavailable at the time of the 1996 release. It was considered that the small effect of this approach would be consistent over time, and that, on average, delayed registrations from the previous year would compensate for those delayed from the current year.

Counts of deaths, by sex and five-year age group, were generated for each of over 90 diseases and 13 injury causes in the disease and injury list, using SPSS statistical software. The resulting frequencies were imported into the Excel workbook file that was used to compile the final YLL, YLD and DALY summary figures. Deaths from poorly defined conditions, such as 'heart attack', were then proportionally re-allocated in the Excel worksheet to more specific causes. The proportions were separately determined using a variety of methods such as regression models, available literature, and expert judgement. Finally, the life expectancy and discount rates were applied to these adjusted death counts to calculate YLLs using the formula described in Chapter 3.

Processing the morbidity burden and total burden of diseases and injuries

Processing of the morbidity burden was substantially more time-consuming than processing the mortality burden, with the varying degrees of disability associated with the various stages, levels of severity and sequelae of each disease adding complexity to the process. The global study authors developed models to comprehensively describe the progression of each disease and its outcomes. The national and Victorian researchers adopted these models with some modifications. They then assembled and processed data and parameters from a wide variety of sources to obtain Victorian incidence estimates and other parameters to be entered into the Excel workbook files that were used to describe each disease model and calculate the morbidity estimates. These morbidity figures were then incorporated into the final summary spreadsheet file along with the mortality YLLs already calculated, to permit the calculation of the resulting DALYs for each disease and injury. These steps are described in more detail below.

Disease models

A variety of methods were used to determine the morbidity burden caused by each disease. The global study researchers developed the concept of the *disease model* to provide a framework for presenting the information brought together in calculating the morbidity burden for a disease or injury. The Australian and Victorian researchers prepared models for the more than 160 conditions in the disease and injury list. Taking into account all stages, severity levels and sequelae, there were over 1,200 disease and injury states for which incidence was assessed, including 32 injury types for each of 14 injury causes. The disease models were based on those developed for the global study, but most required some amendments based on advice from Australian experts or from more recent or more local studies.

The final model developed for each disease is fully described in the Excel workbook file used to calculate the morbidity burden for the condition. While it is not possible to generalise over all diseases, the models typically described:

- the case definition for the disease, including the severities, stages, and/or sequelae considered;
- the disease weights used for each severity, stage, and/or sequela considered and how they were chosen;
- descriptions of how the incidence figures for each severity, stage, and/or sequela were assembled and the data sources used, details of adjustments made, and any other parameters or comparative figures used in assembling or checking the figures.

The models for some diseases were very complex. For example, the model for diabetes mellitus accounted for nine possible sequelae, including: retinopathy, cataract, glaucoma, nephropathy, neuropathy, diabetic foot, amputations, ischaemic heart disease, and stroke. Cancer models accounted for the various stages and outcomes that could occur in the progression of each cancer.

DisMod

DisMod is a computer program developed by the global study researchers to model the relationship among incidence, duration, remission, excess mortality and prevalence of a particular disease. It was used for several purposes in the global study, particularly for ensuring the parameters chosen to describe these relationships were internally consistent. Most of the 40 person-years required to complete the global study were invested in the development of these internally consistent estimates.

In the Victorian and Australian studies, DisMod was similarly used to obtain internally consistent and plausible estimates of disease duration, incidence and/or prevalence when only incomplete or uncertain epidemiological information was available for a condition. It was also used to model plausible incidence estimates from prevalence figures obtained from published or unpublished results of surveys.

DisMod should not be confused with the broader disease model concept. DisMod is merely a computing tool that was used as part of the processing part of the burden of disease studies. If DisMod was used in relation to a particular disease, the disease model described in the Excel workbook file for the disease included a description of how DisMod was used.

The DisMod files created in Victoria that contained the parameters used for particular diseases were saved and are freely available along with the Excel workbook files developed.

Data sources and preparation

As described in Chapter 3, the three quantities used to calculate the morbidity burden of a disease, or its sequelae, were incidence, disability duration and disability weight. The compilation of each of these variables, and other associated parameters, is described in the following sections.

Disease incidence—Five main groups of sources were used to assemble incidence data: disease registries, population health surveys, health service utilisation data collections, epidemiological literature and opinions of disease experts. The best available data source that could provide the information required for each part of the disease model was chosen, although most models were assessed by reference to a variety of sources, including literature and consultation with experts. Within each model, incidence estimates were obtained for each sex and for the nine age groups. DisMod was used to ensure the estimates chosen were consistent with the available information on incidence, prevalence, duration, remission and excess mortality.

Where available, a disease register or surveillance system was generally considered the best choice for determining incidence estimates. Examples include the Victorian Notifiable Infectious Disease Surveillance System, the Victorian HIV–AIDS Register, the Victorian Cancer Register and the Australian and New Zealand Register of Dialysis and Transplant Patients (ANZDATA).

In the absence of a register or similar system, the next best source of data was considered to be population health surveys. These were treated with caution because of the possibility of under-reporting bias associated with self-reported disease status. Surveys used included the ABS 1997 National Mental Health and Wellbeing Survey, the 1989 National Heart Foundation Risk Factor Prevalence Survey, and the ABS National Health Survey 1995. Health surveys generally collect prevalence data, so incidence was estimated from prevalence using DisMod. Prevalence is an output from DisMod so to obtain incidence from prevalence, the Victorian researchers iteratively entered plausible incidence, duration, remission and excess mortality estimates into DisMod until the resulting prevalence was consistent with the survey estimate. Plausible estimates were obtained from literature reviews and expert clinical judgement. Survey prevalence data was also used to check the plausibility of incidence estimates from other sources and the outputs of the DisMod program.

For conditions that were recognised as generally resulting in a person seeking treatment, health service utilisation data was used as a source of incidence. Examples include the Victorian Inpatient Minimum Dataset, the Victorian Emergency Minimum Datasets (which includes injury cause surveillance data), Health Insurance Commission Medicare Claims database and the National Survey of General Practice (BEACH). For the inpatient data, Automatch software was used to match multiple admissions for the same person so that counts of people rather than admissions were obtained. This avoided the problem of multiple counting of the same person when readmitted for a continuing condition. The linkage required two person-months to complete.

In the absence of any of the above sources, published or unpublished epidemiological studies or meta-analyses provided estimates of incidence. The advice of clinical experts was also considered.

Disease duration—The duration represented the estimated average period of time a non-fatal health state was experienced after an incident case of disease occurred. It is a necessary part of the calculation of the years of life lost due to disability because the resulting burden is accumulated over time.

If estimated durations were not available from the literature, DisMod was generally used to estimate them. The duration of disease can be an input or an output of DisMod, and can be estimated by modelling the relationship among it and the incidence, prevalence, remission rate, and excess mortality from the condition. Where a condition had a range of health stages, severity levels and sequelae, DisMod was used to model the duration of each of these. Initial values of input parameters were chosen using the best available epidemiological data.

Other methods were used for certain conditions. For example, the average duration of an episode of depression was calculated using the relationship between the point prevalence and one-year prevalence estimates of depression obtained from the National Survey of Mental Health and Wellbeing. All duration estimates were checked against the literature and/or by local experts.

Disability weights—As described in Chapter 3, the disability weight is a number between zero and one representing the degree of disability experienced by a person, on average, for the duration of a particular health state. A value of zero represents full health (no disability) and a value of one represents a health state equivalent to death. For the global study, a panel of health experts from around the world assigned relative disability weights to 483

possible health states using a combination of person trade-off methods and judgement. The more recent Dutch disability weighting study developed an alternative set of weights using a similar methodology but with some enhancements, including an assessment of a greater variety of health states than those assessed in the global study.

The Victorian researchers adopted the Dutch weights where possible. Global study weights were used if a Dutch weight wasn't available. For some diseases and conditions for which neither a Dutch or global study weight were available, the Dutch methodology was used with Australian experts to derive new weights. Some weights were obtained by interpolating between existing weights, or by proportionally combining weights according to pattern of disease progression into a composite weight. Disability weights were also assessed for variation by age, where appropriate.

Calculation of the state level morbidity burden

The Australian and Victorian researchers collaboratively developed Microsoft Excel workbook files to fully document the disease models, data and data sources, assumptions and calculations performed in the process of determining the morbidity burden. This resulted in 115 workbook files, each representing a disease or disease group, and containing as many worksheets as required to fully describe the stages, severity levels and sequelae assessed. The structure and complexity of the workbooks varied considerably depending on the complexity of the disease model used to describe the disease. The calculation of the YLD figures always formed part of these spreadsheet files.

If the disease had sequelae, multiple stages or severity levels, then the morbidity burden was often calculated for each of them in separate tables or worksheets. The resulting estimates were then summed to give a morbidity estimate for the disease. However, sometimes the parameters were combined first on advice from literature or experts and the result was used in a single morbidity burden calculation. A particularly important case of this is when the literature or experts identified co-morbidities between conditions. This meant combining the weights of all co-morbid conditions. Regardless of the methods used, if a disease had sequelae, multiple stages or multiple severity levels, extra calculations were required. All pertinent data and calculations were described in the Excel workbook for the disease.

Each disease spreadsheet file contained descriptions of how the incidence counts and durations of disability were obtained. These included references to literature or experts, parameters used for DisMod if it was used, such as prevalence estimates and mortality data, adjustments made, and any other relevant information. Even though incidence counts were required for the YLD calculations, population counts and age-specific incidence rates were always presented. In many cases, this was because incidence counts were obtained by applying the available rates to the population counts. In other cases, these rates were merely presented for completeness. Population counts from the 1996 census were used. In some cases, gross incidence estimates had to be proportionally allocated among more than one age group or disease stage.

Agoraphobia is an example of a mental health condition for which epidemiological information was only available from the 1997 ABS National Survey of Mental Health and Well-being. DisMod was used to estimate its incidence and duration using prevalence figures from the survey. The literature revealed an average remission rate of six per cent, and a relative risk of death of 2.0. These values were entered into DisMod, along with plausible incidence and duration values until the DisMod prevalence rate and age distribution of prevalence closely matched the estimates from the survey. The justification for the approach was documented in the Excel workbook, along with the process used to obtain and estimate the disability weights used. The resulting incidence, duration, and disability figures were used in the final YLD calculations in the Excel workbook.

As another example, injury morbidity was assessed using incidence figures from the Victorian inpatient data collection. Injuries not treated in a hospital were considered to have negligible disability, but Emergency Department presentations were used to estimate the incidence of non-admitted, but hospital-treated, injury incidence. This was possible because the Victorian Emergency Department data collection includes detailed injury surveillance information, including cause of injury. Because the collection only covers a subset of Victorian Emergency Departments, an inflation factor was used to estimate the total incidence of non-admitted injuries.

The incidence estimates were required by nature of injury as well as by cause, because the disability weights were associated with the nature of the injury. YLDs were then calculated by injury cause by nature of injury by age and by sex, using age and sex-specific disability weights and durations. The disability weights and durations were largely taken from the global study and took into account short and long-term disabilities from each type of injury. Assumptions were made about the proportion of each type of injury resulting in short or long term consequences. The YLD calculations consisted of sum of the short term YLD and the long-term YLD values for each incidence estimate. Because there were 14 injury causes, 32 nature of injury categories, nine age groups and two sexes, a total of 8,064 individual incidence estimates were required.

Processing the total burden in DALYs

The total burden was obtained by summing the mortality and morbidity as described in Chapter 3. The final summary Excel workbook file used to collate and calculate the mortality burden figures was also used for the total burden calculations. This summary workbook was linked to the 115 morbidity workbook files to extract the relevant YLD values. The resulting mortality and morbidity burden estimates were then summed to give estimates of the total burden (DALYs) of each specific disease or injury cause in each age group and sex. These figures were then aggregated for larger age groups, both sexes, and broader disease groups. These figures were then used in the reports prepared from the project.

Processing the state level burden attributable to risk factors

The calculation of the burden attributable to risk factors was supplementary to the calculation of the mortality and morbidity burden. The results of the disease and injury burden calculations for all diseases that may be influenced by the risk factor must be available, as the attributable burden is calculated by applying the population attributable fraction associated with a risk factor to the mortality, morbidity and total burden estimates already calculated. Separate Excel workbook files were created for each of the ten risk factors considered in the Victorian study, and these contained documentation of the data sources and assumptions used as well as the data and calculations.

The burden for a risk factor was processed in three broad steps:

- identify the diseases associated with the risk factor. This information was largely obtained from available literature;
- the attributable fractions were then obtained either directly from the literature, or by calculating them using the formula described in Chapter 3. The relative risk figures used in the formula were generally obtained from the literature and prevalence figures were generally obtained from available survey results. In the absence of relevant literature or survey data, expert opinion or assumptions were used;
- the age, sex, and disease-specific estimates of risk factor burden were then estimated by applying the attributable fractions to the YLL, YLD and DALY values already available. The YLL, YLD, and DALY figures were drawn from the final summary Excel workbook

containing the final burden estimates already calculated. Links to the relevant values were created in the risk factor workbook files to avoid duplication of the data entry. The disease-specific estimates could then be summed to give the total mortality, morbidity or total burden estimates attributable to the risk factor.

Projections of future state level burden

The Victorian study calculated projected burden of disease figures for the year 2016 for all diseases and injury causes, as well as for each of the ten risk factors. Much of the processing for the projected burden required use of sophisticated statistical analysis techniques to estimate trends in the incidence of deaths based on historical data. Once these estimates were obtained, Excel workbook files were used to collate and calculate the projected burden figures.

To calculate the projected burden, projected population counts to 2016 were required. These were available from the ABS,[12] and included projections for 18 different migration and fertility scenarios. The scenario chosen by the Victorians assumed low interstate migration, low fertility and high overseas migration. This was consistent with the scenario used by the Victorian Department of Infrastructure for projections that were widely used in Victoria.

The projected mortality burden was processed in two main steps:

- the projected all-cause mortality counts for 2016 were estimated for each sex and five-year age group. The statistical computer program STATA was used to fit a Poisson regression model to the annual all-cause death rates from 1979 to 1996 to determine estimates of annual trends in death rates and the resulting trend parameters were used to extrapolate death rates using a simple exponential function. The period 1979 to 1996 was chosen because prior to 1979 an earlier version of the International Classification of Diseases was used by the ABS to code causes of death, which would have created difficulties. The projected death rates were applied to the ABS population projections to obtain projected death counts;
- a similar process was used to project death rates to 2016 for the entire disease and injury list, compressed into 51 specific causes or groups of causes. This was done by sex and, generally, five age groups (0–14, 15–44, 45–64, 65–74, and 75 or more years). Only statistically significant trend estimates were used and the remaining causes were assumed to continue at a constant rate. The resulting mortality pattern effectively gave a projected disease distribution of mortality in each age group and sex. To ensure the cause-specific death count summed to the projected all-cause counts, the projected cause-specific proportions were applied to the projected all-cause count in each age group and sex. This provided cause-specific death counts that were internally consistent with the projected all-cause death counts. These resulting counts were then used to calculate projected YLL counts for the projected mortality burden using the standard YLL formula with 1996 cohort life expectancy figures.

The projected morbidity burden was processed using two methods, depending on the particular disease or cause of injury. These calculations were performed in the Excel workbooks that were used to collate and calculate the projected burden figures. The two methods were:

- For diseases with a relatively high mortality rate, the ratio of morbidity to mortality (YLD/YLL) for 1996 was assumed to continue to 2016. The projected morbidity could be obtained by applying the ratio to the projected mortality figures. Cardiovascular disease and heroin dependence were treated differently, however, as the literature and expert opinion suggested that changes in mortality were due partly to factors other than changing incidence.

- For non-fatal and low-mortality diseases, trends in incidence were unable to be determined. Therefore, the YLD rates from 1996 were applied to the projected population counts for 2016 to obtain projected YLD counts.

For the projected risk factor burden for 2016, assumptions were made about future trends in risk factor prevalence, and these were used to calculate projected attributable fractions as for the 1996 estimates. The projected fractions were then applied to the relevant projected disease-specific burden estimates to obtain the projected risk factor burden.

Processing the burden for small areas

Because Victoria was the first place in the world to calculate small area burden estimates, the methods used at this level were considered to be preliminary approaches and expected to be subject to future revision. The methods described below were used to estimate the burden of disease for each LGA in Victoria. Regional estimates were obtained by summing the burden for the relevant LGAs. Only the 50 top ranked diseases and injuries at the state level were assessed at the LGA level. Risk factors and projections were not assessed at the small area level.

Mortality burden for Local Government Areas

To limit the effects of statistical uncertainty arising from the small numbers of deaths in some LGAs, ABS mortality data for the period 1992 to 1996 was aggregated to provide larger numbers. The resulting cause-specific proportions were then applied to the total number of deaths for 1996 in the LGA. This ensured that the resulting counts remained consistent with the state level estimates already calculated for 1996 when aggregated up.

The YLL estimates were then calculated as for the state level estimates, using the same 'ideal' life expectancies and discount rate. These were calculated by sex and the same nine age groups as for the state level estimates.

Morbidity burden for Local Government Areas

A comprehensive epidemiological description of non-fatal disease was difficult to obtain at the state level in Victoria, so obtaining it at the LGA level was even more difficult. Therefore, a range of methods were used to estimate incidence at the local area level for:

- cancers, certain mental disorders and other diseases that had registry, survey or inpatient data available, multi-variable regression techniques were used to obtain models of incidence at the Victorian level or the Australian level by rurality and socioeconomic status. Separate models were obtained for each sex. The resulting models were then used to predict the incidence in each LGA. This approach was taken to avoid problems associated with small counts at the local level. The effect of age was removed by including it as a predictor in the model.
- other conditions that were known to have a relatively high mortality rate, such as HIV–AIDS, dementia, chronic obstructive pulmonary disease and certain renal conditions, the pattern of morbidity was assumed to follow the pattern of mortality. The morbidity figures were therefore adjusted relative to the state level morbidity estimates by the same proportion that the mortality estimates differed from the state level mortality estimates;
- injuries, actual data from the Victorian inpatient data collection and the Victorian Emergency Department data collection, which collects detailed injury surveillance information, were used to determine each LGA's share of the Victorian burden of injury disability;
- the remaining conditions, such as other communicable diseases and mental health conditions, skin diseases, and oral health, state level YLD rates per 1,000 population were applied directly to the population counts for the LGA to estimate local morbidity figures.

6 DISCUSSION

The preceding chapters described the outputs and processes of the Victorian burden of disease study to provide an indication of the information offered by such a study and the time and resources required to produce those results. This chapter discusses the validity of the DALY methodology, applicability of the methods to the New South Wales situation, alternative methods that could be employed and the resources required to conduct a New South Wales burden of disease and injury study.

The validity of the DALY methodology

The DALY was described as an important step forward in the development of summary population health measures by the World Health Organization's DALY Review Group.[13,14] It was one of the first measures to combine mortality and morbidity in a single objective measure and hence was an improvement over measures of mortality burden only, such as potential years of life lost (PYLL), and more subjective measures, such as quality-adjusted life years (QALYs).[15] Other benefits ascribed to the DALY methodology include the identification of neglected health problems, identification of the strengths and weaknesses of existing health information systems and its value in encouraging the debate on the social value choices that influence health resource allocation.[16]

On the other hand, the DALY review group and others expressed concern over several aspects of the methodology, including the exclusion of social factors that have a strong impact on the 'burden' of a disease for individuals and their families; concerns over the cultural appropriateness of the disability weights across different populations; concerns that the disability weights are more an artefact of the methodology used to determine them rather than the true value judgements of the respondents who were judging them; the lack of good quality data for providing reliable estimates; and the inadequate treatment of coexisting diseases (comorbidities) and risk factors.[13,14,17,18,19] These issues have been debated at length in the literature, without firm conclusion.

Other contentious issues relate to equity. The methods used to determine the disability weights have been criticised for inherently valuing life extending health programs for disabled people less than those for healthy people.[19] Age weighting, where individuals are valued differently according to their age, and discounting have also been criticised because of their effect on the relative valuation of (healthy) life at different ages.[20] It has also been argued that the DALY methodology devalues the extra burden experienced by women due to their longer life expectancy and does not take sufficient account of differences in health service needs between men and women for non-disabling conditions, such as reproductive health care.[15]

The DALY review group concluded that, although the DALY methodology represented a forward step in the development of summary population health measures, its use to allocate health resources should be discouraged in its present form.[13] Nevertheless, the WHO remains committed to an ongoing global program of burden of disease measurement and the Global Burden of Disease 2000 study is currently in progress. Though some of these issues have been addressed since the report of the review group was published—the Australian and Victorian studies dispensed with age weighting and introduced co-morbidity adjustments—many limitations and controversies remain. The cross-cultural limitation of the methodology may be a particular barrier to studying the burden of disease in Aboriginal and Torres Strait Islander populations in Australia.

Possible approaches to a burden of disease study in NSW

It is clear from the number of diseases and the complexity of morbidity estimation that conducting a full burden of disease study for New South Wales would require substantial resources. Using the tools developed for the Victorian and Australian studies, such as the Excel workbooks, could

reduce the amount of work. However, several years have elapsed since these studies were conducted, and the reference year, 1996, is becoming outdated. A more recent reference year would be preferable, particularly when information from the 2001 ABS Census becomes available. Even though using the existing Excel files would save some time, the process of collating and entering more recent as well as any available local data into these files would still be a major undertaking. Further, it would be preferable to recheck the literature for any updated epidemiological studies and validate the existing disease models against current knowledge of disease progression and sequelae.

Queensland Health's approach of calculating the mortality burden in the standard way with Queensland cause of death data, but using the Australian study morbidity assumptions, disease models, and incidence rates, saved a great deal of time and effort. Nevertheless, the process of becoming familiar with the large array of diseases, health states and disease models still requires a substantial commitment of time. The Queensland approach requires the assumption that Queensland morbidity incidence rates at the overall state level are the same as the overall Australian incidence rates. This assumption, while somewhat plausible at the state level, would be difficult to justify if applied at the small area level in Queensland, or for particular sub-populations, thereby limiting the flexibility of this approach.

The resources required in completing a burden of disease study are largely dependent on the number of diseases and injuries chosen to study. Therefore, an alternative approach would be to reduce the number of diseases studied. The experience of the Victorian researchers was that 80 per cent of the burden was due to the top 50 most burdensome diseases. Diseases could be selected on the basis of some criterion, such as National Health Priority Areas, or other diseases of public health importance. This approach was taken in a study in southwest England that measured the 'avoidable burden' of diseases that were considered under-treated or under-prevented, using an extended methodology.[21] The disadvantage of these narrower approaches would be that the disease burden assessment would be incomplete, and proportional contributions to the total burden could not be calculated, unless assumptions about the total burden based on other Australian results were made. Further, it could undermine the reported benefit of such studies of identifying neglected diseases.

In terms of implementation, an alternative processing approach might be to dispense with the Excel workbooks and automate the processing as much as possible, using programmable statistical software such as SAS. This would have the benefit of limiting data entry errors that might arise from the large amount of manual processing required in preparing and using the Excel workbooks. However, the complexity and lack of uniformity of the disease models for morbidity processing would limit the amount of reusability that could be built into the computer programming. Furthermore, the process would be less transparent than with Excel, which is more widely understood and is more able to contain more comprehensive and flexible documentation.

Data Sources

Another important factor affecting the feasibility of a burden of disease study is data availability. New South Wales has many data collections that mirror those in Victoria, including the Notifiable Diseases Database (NDD), AIDS Database, Midwives Data Collection (MDC), Birth Defects Register, Cancer Registry, and Inpatient Statistics Collection (ISC). An exception is the New South Wales Emergency Department Data Collection, which, unlike Victoria, does not include

mandatory injury surveillance data. Like Victoria, there are numerous diseases for which no New South Wales data is available and data from other states, the literature, and/or expert opinion would be needed. New South Wales is in the fortunate position of having an ongoing health survey program that could be utilised in collecting prevalence data for many conditions and risk factors, where appropriate.

Conclusion

It is clear from the preceding review that the major burden of disease studies conducted at the Australian and Victorian levels represent the culmination of an impressive commitment of time and effort from a small number of researchers. A large portion of this work was required to disentangle the relationship between the incidence of fatal and nonfatal outcomes of diseases and the relationship among the various inter-relating factors that determine incidence and prevalence at any one time. This was done within the structure imposed by the available understanding of disease progression and available epidemiological data. Gaps in knowledge had to be filled by the best available means, which required the researchers to keep abreast of current literature and study results, as well as consulting extensively with content experts. This process had to be completed to a greater or lesser extent for over 160 conditions, which included 14 causes of injury and 32 types of injury for each injury cause. The resulting understanding of the population-level epidemiology of diseases and injuries should be highly regarded, and could provide an excellent framework for defining gaps in knowledge of disease processes at the population level.

The burden of disease approach can provide benefits by delivering a comprehensive overview of population health that reports the relationship between fatal and non-fatal outcomes of disease and injury. Because of limited data availability, more conventional epidemiological approaches to comparative disease assessment place a strong emphasis on fatal conditions and conditions that are treated in hospitals. This approach neglects certain chronic conditions, which, although infrequently fatal, may result in long periods of disability and cumulative burden. Further, hospitalisation data may be more subject to health service availability and delivery patterns than to disease incidence, and it does not capture morbidity associated with low-grade chronic conditions that may not lead to hospitalisation. The DALY approach highlights non-fatal, chronic conditions, such as mental illness, that are not captured by the more conventional approaches to descriptive epidemiology.

Despite its appeal, acceptance of the burden of disease approach requires acceptance of many assumptions and less than ideal data sources. The apparent precision with which the results are presented can mask the imprecision and uncertainty that may be inherent in many of the estimates or the parameters used in their calculation. Also, many assumptions may limit the applicability of the results to particular populations, such as indigenous people or people of non-English speaking background. The size of the burden of disease process makes it cumbersome to apply to new or specific populations. However, an important consequence of the thorough epidemiological assessment that has occurred in these studies has been the highlighting of important gaps in epidemiological data available to describe many diseases, their progression and sequelae.

To conduct a full burden of disease study for New South Wales would require somewhat less time and effort than has been required in these earlier studies, because many of the tools and much of the knowledge already developed could be implemented in New South Wales. Nevertheless, the time that has elapsed since the reference year of the earlier studies means that a substantial effort would be required to update the majority of incidence and other data. Furthermore, it would be prudent to evaluate whether the assumptions and

other decisions made in the earlier studies are consistent with the results of more recent epidemiological and other studies. Also, compiling data that is available at the New South Wales level and not at the Victorian or national levels would require substantial resources. To complete the task in-house in a reasonable amount of time and to establish a core of expertise, a Burden of Disease Unit with several staff members would need to be established. Alternatively, the task could be contracted to an external consultant.

A recommendation of this review would be to support a national resource centre, such as the newly established Summary Measures Unit of the AIHW in maintaining the disease models and Excel workbook resources for conducting burden of disease studies around Australia. Each time a burden of disease study is commenced, a core of expertise must be redeveloped to ensure that the most valid and up-to-date information can be fed in. If there was a national centre that maintained this level of core disease burden measurement expertise and tools, as well as maintaining the most up-to-date disease models based on ongoing consultative and literature review processes, then the prospect of establishing new studies would be less daunting. The centre could also maintain and update data sources that could be used to fill local level information gaps. This approach would have some important benefits, such as:

- providing support to jurisdictions in solving measurement problems of particular local relevance;
- advising research bodies, such as the National Health and Medical Research Council, on epidemiological research needed to bring greater certainty to the measurement of the disease burden in Australia.

Despite the difficulties mentioned, there are several approaches that could be taken to completing burden of disease estimates in New South Wales, with varying levels of effort and time required. Approaches requiring less effort would require a greater level of acceptance of assumptions and the applicability of the results developed by other jurisdictions

7 OPTIONS AND RECOMMENDATIONS

The options presented here for performing a burden of disease study in New South Wales are organised in order of the level of resources required. Where possible, established methodologies and resources, such as Excel workbooks from the Australian or Victorian studies could be used to facilitate processing.

Option 1: Do nothing

Reasons for choosing this option would include the lack of local epidemiological data for many diseases and doubt about the ability of the DALY methodology, with its many inherent assumptions, to provide an accurate picture of the health of the New South Wales population. Also, the completeness of disease coverage of the methodology makes it cumbersome to adapt for other purposes, such as focusing on preventable conditions or particular population groups.

Nevertheless, there remains a strong commitment to the burden of disease approach by the World Health Organization and the methodology is undergoing continual development. A complete picture of population health in New South Wales would provide a foundation for extending the methodology into other domains in New South Wales, such as the burden of preventable disease and injury. By not pursuing burden of disease at any level in New South Wales, the opportunity to participate in its further development would be lost.

Option 2: Complete approximation of the NSW burden using Australian burden rates

The New South Wales burden would be estimated by applying Australian population rates of the mortality and morbidity burden from the 1996 study to New South Wales population counts, by age and sex. This option would give estimates of both the mortality and morbidity burden for NSW with minimal resources, but would give only an approximate picture of the true burden. Despite differences in magnitude in the resulting DALYs between NSW and Australia, the ranking of conditions and risk factors would be very similar because NSW had the largest population contribution to the national results. Any differences would reflect differences in the age and sex structure of the two populations, and would hide differences in other characteristics that influence disease and injury incidence.

The necessary assumption that mortality and morbidity patterns within each sex and age group in NSW match those at the national level would become untenable for smaller areas or sub-populations if this approach were adopted. The scope would be further limited because it would have to be based on Australian estimates as of 1996, which is now becoming quite dated. Interpretation of the results would have to be treated with caution because of the possible inaccuracies that might arise from propagating assumptions on top of assumptions already built into the burden of disease methodology.

Option 3: Full mortality burden assessment only

This option involves a comprehensive assessment of the mortality burden for NSW by calculating YLLs from cause of death data for NSW, without an assessment of morbidity. Risk factor mortality burden and LGA level estimates could be obtained using the same methods as Victoria. Availability of complete cause of death data from the ABS means that this approach would require few resources. The main disadvantage is that it would neglect the non-fatal disease burden.

Note that the mortality component represents approximately half of the total burden of disease, but requires a small fraction of the resources of a complete study. It is argued by proponents of the burden of disease approach that it is worth investing the effort into obtaining complete mortality burden estimates for the geographic area under study.

Option 4: Full mortality assessment combined with approximation of NSW morbidity using Australian morbidity rates

This combines option 3 for the mortality component with option 2 for the morbidity component. The mortality burden would be calculated in full, while the morbidity burden would be estimated by applying Australian morbidity burden rates to NSW population counts, by age and sex.

This approach would provide a substantial saving in resources, because the majority of the time and effort of a full study is expended in calculating the disability component. This approach would be restricted to an analysis of 1996 data, unless an assumption was made that the incidence of non-fatal diseases does not change over time.

Option 5: Full NSW-level burden of disease assessment utilising available resources from the Australian and Victorian studies

This method would use the DALY methodology to calculate mortality, morbidity and total burden estimates using Excel workbooks and disease models from the Australian and/or Victorian studies, but with NSW incidence data where available. This approach would have the advantages of utilising the best available data for NSW and would provide a full description of the disease burden.

Although substantial infrastructure is available from the Victorian and Australian studies, assembly and modelling of local incidence data and verifying the epidemiological assumptions built into the existing disease models remains a large task. This approach would permit extension, using the Victorian methodology, to smaller area estimates.

Option 6: Full NSW-level assessment of a reduced set of diseases and/or risk factors

This approach would focus on applying option 5 to a set of conditions considered to be of public health importance because of their preventability, such as those covered by the National Health Priority Areas. This would require fewer resources than a complete study, but would have the disadvantage of a providing an incomplete assessment of population health for New South Wales. It should be recognised that this approach would still require involved staff to devote a substantial amount of time and effort to becoming familiar with the methodology and the practicalities of assembling relevant data.

Option 7: Full redevelopment of the burden of disease methodology for New South Wales

This approach is not recommended, but is included for completeness. It would require full redevelopment of disease models, disability weights, literature review, and consultation with experts. This is such a substantial task that it is beyond the resources of a single state to conduct.

Other recommendations

1. That options be explored for establishing a national centre that provides assistance to Australian states and territorries in conducting local burden of disease studies through, for example:
    - maintaining the most up-to-date epidemiological resources for completing disease models when local data sources are unavailable;
    - maintaining the MS Excel spreadsheet files and other computer resources required for conducting local studies, so that they reflect the latest epidemiological understanding of each condition;

- providing a facility for conducting local level studies under contract to the states and territorries;
- maintaining links with international burden of disease study groups to ensure the most up-to-date methodology is being utilised; and
- advocacy for research that will improve the epidemiological description of chronic and complex conditions at the population level.

2. That mechanisms for using the NSW Health Survey Program to provide risk factor, disease and injury prevalence and/or incidence information for use in a New South Wales burden of disease study be explored. It should be recognised, however, that for many long term or complex conditions, self-reported responses are often inadequate for providing accurate incidence or prevalence estimates.

3. For routine reporting of hospitalisation data in New South Wales, consideration should also be given to using data linkage methods to obtain incidence counts at the person level. This approach would avoid distortions that might arise when persons are counted multiple times through being readmitted for a continuing condition.

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