Report to the National Committee on Health and Vital Statistics on outcome data in health

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Preface

This report contains the summary of research findings and recommendations for the development of national health statistics in Australia, based on a research project commissioned by the National Committee on Health and Vital Statistics (NCHVS) through the Commonwealth Department of Health and undertaken within the Department of Community Medicine, Westmead Hospital, Westmead, New South Wales. The aim of the research was to determine the appropriate methods of measuring health outcomes and to assess the usefulness of existing data collections for this purpose.

Introduction

In 1982 the National Committee on Health and Vital Statistics commissioned, by means of a research and development grant through the Commonwealth Department of Health, a research project into outcome measures in health. The project was undertaken by a team within the Department of Community Medicine, Westmead Hospital, New South Wales.

The research team has made an examination of methods of determining measures of health outcomes and has made a number of recommendations, the implementation of which it is considered will improve these measures. The Report has been examined by NCHVS and comments have been sought regarding the issues raised by it.

The Report opens by postulating that it is measures of those aspects of health which are likely to be affected by changes in health services which are required as indicators of outcome. Two fundamental problems in the measurement of health outcomes have been identified as (i) sensitivity, i.e. those aspects of health status which are likely to be changed by particular aspects of medical care, and (ii) causality, i.e. where a change in health status is linked to the intervention of health services. It is suggested that there exist three levels of inquiry relating to the examination of the impact of health services and the health of the population. These levels of inquiry are:

- Is health status changing?
- How is it changing?
- Why is it changing and is this change due to medical care or some other factor?

To answer these questions in the Australian context, seven health data collections have been examined with a view to identifying gaps in existing knowledge of health care outcomes and providing options for filling these gaps. The seven data collections examined are:

- notifications of deaths;
- hospital morbidity data;
- cancer registries;
- infectious diseases notification;
- perinatal statistics;
- Australian Health Survey;
- Australian Bureau of Statistics *Surveys of chronic illnesses and handicap*.

In examining the Report, NCHVS has focused its attention on the tactical and enabling objectives outlined in the chapter, 'An outline of the options for priorities for the identification and collection of basic outcome data'. Specifically, all government health authorities have been asked to provide comments on the options:

- occupational coding of hospital morbidity;
- extension of hospital morbidity collections to include nursing homes;
- coding of multiple causes of death.

In relation to the option of occupational coding on hospital morbidity, the consensus was that, while occupational data would be a useful addition to the data base and was collected by some authorities, it was recognised that a number of difficulties existed. For example, a number of older patients would have their occupation recorded as *retired*, and in the case of occupation-related illness, the current occupation may differ from the occupation responsible for the illness.

In the case of the suggested extension of hospital morbidity data to include nursing homes, most authorities considered that, due to the usually extended length of stay of patients in nursing homes, a discharge-based collection such as that used for the current

hospital morbidity collections was, by itself, inappropriate. Consideration of the data base would be better served by conducting a periodic census of patients, coupled with an admission/discharge collection.

With regard to the coding of multiple causes of death, health authorities supported this concept in principle, but questioned whether the resources to undertake this coding would be available and what uses would be made of the end product.

Since this Report was written there have been two significant developments in the field of health statistics in Australia. One of these has been the convening of a workshop on national health statistics, the other, the establishment of the Australian Institute of Health.

The workshop was jointly sponsored by NCHVS and ANZSERCH/APHA and was attended by members of NCHVS, representatives of Commonwealth, State and Territory health authorities, the Australian Bureau of Statistics and other groups with an interest in improving the standard of health statistics in Australia.

As part of the preparation for the workshop the compilation of a compendium of sources of national health statistics was commenced. The purpose of the compendium, which is to be updated on a continual basis is:

- to describe all the major health statistics collections that could be identified;
- to describe as many statistical collections and data sources as could be identified that would usually be included in a national health statistics data base, and that would illustrate the wide variety of possible sources on which a national health statistics base would draw.

Arising from discussions at the workshop, a set of comprehensive recommendations was passed with the aim of overcoming the lack of sufficient, timely and appropriate data necessary for policy making; for the effective monitoring and interpretation of the nation's health; and for the planning, administration and evaluation of the nation's health services and facilities.

The Australian Institute of Health was established following a decision taken at the time of the 1984 Federal Budget and commenced operation in 1985. The aim of the Institute is to contribute to the improvement of the nation's health through orderly development of research into health and health programs. It is believed that this aim will be achieved by, among others, these functions:

- reporting on priorities and progress in research into the health status of the Australian population and the provision and use of health resources;
- developing, collating and publishing national health statistics in conjunction with relevant bodies, including NCHVS, for which secretariat services are also provided by the Institute.

This Report has, therefore, already had some impact on the health scene in Australia and is acting as a catalyst for further development.

1 Background

Many reports on the health (and welfare) systems draw attention to the paucity of data available on which to assess the use and effectiveness of health services. The Jamison Commission (Commission of Inquiry into Efficiency and Administration of Hospitals 1981) commented on the lack of information on which to base policy making and drew attention to the problems currently experienced in linking cost and performance data. The Senate Standing Committee on Social Welfare (1979) recommended an increase in the collection of health and welfare statistics. In particular, it stated:

> That the Commonwealth and State Ministers responsible for health and social welfare direct the National Working Party on Welfare Statistics and the National Working Party on Health Statistics to produce within two years, in consultation with the non-government health and welfare sector, a list of priorities for the identification and collection of basic outcome data (Recommendation 28).

This report summarised the functions of such a data collection system to be:

1 the indication of health and welfare status;
2 establishing needs for services;
3 evaluating new services;
4 meeting research requirements.

The committee also drew attention to the need for outcome measures in evaluative studies to encompass unexpected results or unplanned side-effects.

The Bailey Task Force (Task Force on Co-ordination in Welfare and Health 1977) and the Health–Welfare Task Force (Royal Commission on Australian Government Administration 1975) also commented on the inadequate co-ordination of policy development in the health and welfare area and the lack of basic data required to support policy development.

It was the concern expressed in these reports and shared by the National Committee on Health and Vital Statistics that led to the commissioning, through the Commonwealth Department of Health, of this research project.

Outcomes, in this sense, are *the effects of the utilisation of health services on the health status of the population*. This definition implies both a measure of health status and the imputing of a change to the intervention of health services, i.e. a cause–effect relationship. Outcomes, then, deal with the effectiveness of health services. It can be applied at a facility, institution or program level, as well as investigating the effectiveness of specific medical interventions.

Unfortunately, there is no single outcome measure. Death is the most clearly defined health status. Even the event of death is not an unequivocal outcome, as one can argue that there are circumstances in which prolongation of life is not a *good* outcome. The interrelationships between health, health services and other factors in the social system are unclear. An improvement in *health* may not be the outcome of health services. It is measures of those aspects of health which are likely to be affected by changes in health services which are required as indicators of outcomes.

II Objectives and terms of reference

The terms of reference as stated in the commission for this project were:

(i) to determine the appropriate methods of measuring the outcome, i.e. the effects of utilisation of health services on the health status of the population, and;
(ii) to determine the relevance and comprehensiveness of existing data for this purpose, including results of health care outcome studies already carried out or under way.

The tasks envisaged in the terms of reference were as follows:

(i) a critical review of the literature;
(ii) examination of the concepts of outcome in the health area and its assessment and measurement;
(iii) identification of outcome indicators for different health services;
(iv) outline of appropriate methods of measuring outcomes for different types of health services;
(v) examination of possible experimental designs for obtaining health services outcome data;
(vi) assessment of the scope, relevance and adequacy of existing health data collections as indicators of outcomes;
(vii) identification of gaps in existing knowledge of health services outcomes and options for filling these gaps;
(viii) an outline of the options for priorities for the identification and collection of basic outcome data;
(ix) report on (i) to (viii) above.

The Department of Community Medicine is situated in the Westmead Hospital, the teaching and referral hospital for the western metropolitan region of Sydney. Such a department has a predictable interest in health outcomes in its surrounding community, particularly as that community had been disadvantaged historically in the provision of health services. Recent developments in the region include the establishment of the hospital.

Therefore, in considering the terms of reference, we added a third:

(iii) to determine the feasibility of a study of the impact of health services on a defined population group within a specified geographic area.

The tasks envisaged were also expanded. With the increasing recognition of the limits to resource growth in health, there is a growing interest in the use of cost-benefit analysis, cost-effectiveness analysis and related techniques for evaluating the allocation of resources among health services. One of the major difficulties in the application of these techniques has been the lack of outcome measures which can be used to calculate benefits. However, there are also more fundamental problems. These arise from the theoretical basis of cost-benefit analysis. It seemed appropriate, within the terms of this project, to review and assess the application of cost-benefit analysis in health services evaluation.

Therefore, to the tasks envisaged we added:

(x) an assessment of the relevance and applicability of cost-benefit and cost-effectiveness analysis to health services evaluation;
(xi) a determination of the feasibility of a project (based on the conceptual framework developed in (i) to (v) above) to study the impact of health services on the health status of the population of a defined area of the western metropolitan health region of Sydney.

The grant was awarded on the basis of the expanded terms of reference.

III Research methods

The scope of this project, as suggested by the terms of reference, is very broad. The literature that deals with the concept and measurement of outcomes spans medicine, health care research, health administration, social statistics, economics and social research. The various attempts at conceptualising and sometimes measuring outcome rely on identifying contributions of health services to health. Thus, the investigation of outcomes could commence with the exploration of alternative definitions of health and models of the relationship between health and health services. Such an avenue, while being challenging, may contribute little to the assessment of existing health data collections.

Given the very real constraints in time and money available and the required framing of options for priorities for the identification and collection of basic outcome data, it was necessary to accept a narrowing of focus so that the project would be completed.

The definition of outcome for the project was stated in the terms of reference, 'i.e. the effects of the utilisation of health services on the health status of the population'. Acceptance of this definition suggests that the concept can be applied to the evaluation of effectiveness of health services at a facility, institution or program level, as well as investigating the effectiveness of specific medical interventions.

The starting point for this project was that there is no single outcome measure. Even the event of death is not an unequivocal outcome, as one can argue that there are circumstances in which prolongation of life is not a *good* outcome. Better *health* may not be produced by health services. The relationships between inheritance, environment, health services and other factors in the social system are still not understood. However, in the context of this project, it is measures of those aspects of health which are likely to be affected by changes in health services which are required as indicators of outcome.

The research team assembled for this project brought together skills in geriatrics, community medicine, economics, behavioural sciences, geography and health care research.

IV A critical review of the literature: development of the concept of outcomes in health

Donabedian (1966), in the classic paper describing approaches to assuring quality in medical care, defined outcome as 'recovery, restoration of function, and survival'. Shapiro (1967) gave a somewhat broader definition: 'some measurable aspect of health status which is influenced by a particular element or array of those elements of medical care'. The broader definition is consistent with the one adopted in this review. Within the clinical context, outcome measures may be applied in quality assurance programs, in clinical trials and in clinical management.

Outcome measures are also required for the evaluation of social policy and programs (Owens 1982; ABS 4101.0, 1981) and as such, measure population characteristics, as opposed to the clinical context which measures individuals' health status. In this context, indicators which are representative of a broader concept (ABS 4101.0, 1981) are used, rather than direct measurement of the underlying concept itself. While health itself is not directly measurable, infant mortality, for example, may reflect the population health status or some part of it. Social indicators are a set of statistics which focus on social well-being, rather than economic concerns (Owens 1982; UNESCO 1982) and health indicators are a subset of these.

The traditional method of measuring the health status of the population is through mortality rates indicating life expectancy and the risk of death. Within its social indicators framework, the Organization for Economic Co-operation and Development (OECD) chose life expectancy at birth, and at ages 1, 20, 40 and 60 years, and perinatal mortality as measures of length of life (OECD 1981). The WHO, in its indicators of progress towards 'Health For All by 2000', includes infant mortality, child (i.e. 1–4 years) mortality, life expectancy at given ages, maternal mortality and disease specific mortality (WHO 1981).

Fuchs (1974), Carlson (1975), Illich (1976), Taylor (1979) and others have pointed to the fairly stable death rates experienced in many developed countries over the past few decades, despite exponential increases in health spending, as indicative of the relative ineffectiveness of medicine. In response, mortality measures have been criticised for lack of sensitivity to the problems of chronic disease, disability and lifestyle associated diseases — in short all those health problems which are non-fatal (Lerner 1973; Siegman 1976; Siegman & Elinson 1977).

There are still important differences in survival between developed and developing countries. Death is a clearly defined event which is comparatively easily recorded despite some inaccuracies in death certification (particularly in the Third World; Escudero 1980). In addition, mortality figures are widely collected and have often formed the only relatively unambiguous basis of comparison between countries, and have been available in a long time series. However, survival becomes a less relevant indicator of health status as countries develop socially and economically (WHO 1981). Yet the analysis of recent trends in mortality in Australia demonstrates its continuing relevance. Mortality rates for age groups between 35 and 74 have fallen during the 1970s (Ireland & Lawson 1980) particularly for ischaemic heart disease and cerebrovascular disease (Spencer & Trickett 1980; Ring 1981). Significant differences in age–sex standardised death rates remain for population subgroups, such as Aborigines (Ring 1981), and by region (Dobson et al. 1980).

The desire to quantify the burden of non-fatal ill-health encouraged interest in measuring the incidence and prevalence of disease and disability. Measures of disease prevalence can be

obtained from the administrative data collections of health services and the cost of this *by-product* information will become less expensive with the increased use of computers (Tweedie et al. 1982). However, the information is limited, in theory, to users of the health care system, and in fact, to users of those services which collect and process morbidity data.

Household interview surveys overcome this problem of selection by covering a representative sample of the community. However, such surveys are subject to inaccurate reporting, undetected or unconfirmed diagnoses in the absence of laboratory or radiology facilities, lack of reliability and changing awareness of health/particular conditions (ABS 1982; WHO 1981).

Social surveys introduced the concept of disability days, i.e. days of work or normal activity lost due to sickness, in the nineteenth century (Katz et al. 1973). The OECD (1981) chose 'two disability measures as indicators of the healthfulness of life'. Short-term disability is disability days per person per year by level of restriction. Long-term disability is the percentage of the population suffering long-term disability by level of restriction. The WHO (1981) suggests the use of the prevalence of particular conditions, e.g. blindness, as measures of disability, but does not include a disability prevalence measure in its recommended minimum list of twelve indicators.

Some researchers have attempted to construct composite indices of population health status from mortality, morbidity and disability data (Chiang 1976; Chen 1979; Chiang & Cohen 1973; Michael et al. 1968; Miller 1970; Connop 1983). Such attempts are based on a desire to develop one summary statistic which describes the population's health; in Chen's terminology, a gross national health product which is analogous to the gross national product as a summary of economic activity.

Major problems remain with these indices in the comparability of different health status measures, the valuation and weighting of different health states (e.g. death and disability), the collection of data, the mathematical complexity of some indices, and the interpretation of single index scores.

There has been a great deal of work in the last decade in the development of standardised measures of health status of individuals, which collect data often by questionnaire (Ware et al. 1981). Many measures which have been designed for clinical decision making or as outcome measures in controlled trials fit into this category. Most of these are of limited application, being restricted to particular diseases, specialities or conditions. One of the classic examples, and one which has been widely used, is the Index of ADL (Katz et al. 1963).

More recently, work in this field has been directed to the development of indices broadly applicable across age, sex and disease groups. These instruments attempt to address 'the key area of measuring people's capability to go about their normal activities without pain or difficulty' (Williams 1975). The Sickness Impact Profile (Bergner et al. 1981), the Alameda County Survey (Breslow 1972), the Rand Corporation's Health Insurance Battery (Brook et al. 1979), the Nottingham Health Profile (Hunt & McEwen 1980), and the Duke–UNC Health Profile (Parkerson et al. 1981) encompass physical, mental and social aspects of health. The General Health Questionnaire (Goldberg 1972) has been widely used as a measure of mental health. It is notable in that it has been tested and used on Australian populations and was included in the 1977–78 Australian Health Survey (AHS).

V An examination of the concepts of outcome in the health area and its assessment and measurement

Outcome, accepting Shapiro's definition (1967), is 'some measurable aspect of health status, which is influenced by a particular element or array of those elements of medical care'. Health, whatever definition is accepted, and there are many, is a multi-dimensional concept. Therefore, there cannot be one global measure of health outcome. Different aspects of health status will be influenced by different elements of medical care at different times.

Evaluating health outcome involves determining the effect of the utilisation and provision of health services on the health status of the population. The question being asked is, what impact do health services have on the health of the population?

There are two fundamental problems in the measurement of health outcomes. One is sensitivity, the other is causality. A sensitive measure will include those aspects of health status which are likely to be changed by particular aspects of medical care and will register those changes as and when they do occur.

Evidence of causality requires that changes in health status must be measured in such a way that the intervention of health services is linked to the change in health status. A causal relationship can only be inferred when the impact of health services can be disentangled from the influence of other factors which affect health. This has led to some scepticism about the possibility of ever measuring outcomes. Even if sensitive measures are collected from a representative sample of the population, outcome evaluation requires controlled, analytic research design to untangle the larger set of events (de Neufville 1975; Murnaghan 1981).

The outcome of health services can be investigated at a number of different levels. At the most micro-level of analysis, the question can be framed in the form of a specific treatment, say, drug A *v.* drug B, or rehabilitation *v.* no rehabilitation. The patient group can be defined and circumscribed, and the measure of health status can reflect the intended impact of the treatment, be it tumour size, symptom relief or so on. At the micro-level it seems possible to define a researchable question.

However, as the analysis moves to a more macro-level, it becomes more difficult to define a researchable question. For a unit, perhaps a ward such as a geriatric assessment unit or a community health activity such as a day care program, the target group is more varied in terms of initial health status, and the intended impact is more diverse, perhaps covering quality of life rather than clinical signs and symptoms. Another level would be the evaluation of an organisation or institution, such as a hospital, a community health centre, or an Aboriginal health program. At this level, the target group would be a catchment population, and correspondingly the measure of health status required is more diverse.

Finally, the outcome of all the health services provided to a general population might be the question of concern. At this level, measures of population health status are required. The macro-level of analysis poses a question which is not specific. Stated in its most general form it cannot be answered, yet it is at this level that it is most significant. The task, then, is to structure this investigation or inquiry in a way that allows more specific questions to be posed and to be answered.

The framework that has been developed takes the major question of what impact health services have on the health of the population and approaches it in three steps. These steps have been termed levels of inquiry.

The first level of inquiry asks whether health status is changing. The simplest classification of health status consists of two identified states — alive or dead. An

elaboration of this classification gives three states: alive and well, alive and ill, dead. The first level of inquiry accepts such a crude classification. The question asked is whether in a given population the proportion in these health states is changing over time; alternatively, whether subgroups of the population have different proportions in these states at the same time.

The second level of inquiry asks how health status is changing. A change in mortality rate may be due to people getting sick less often, getting sick as often but with diseases that are not fatal, or still getting potentially fatal diseases but recovering.

The third level of inquiry asks why health status is changing and whether it is due to medical care or some other factor. A change in disease incidence or in case fatality may be due to medical improvements, or something unrelated to medical care. Given the many factors which can have an impact on health, a carefully controlled study design is required to support the causative role of health services rather than other variables.

VI The identification of outcome indicators for different health services

The framework that has been developed, of three levels of inquiry, can now be used to identify health indicators. Without this framework, it would be necessary to define and then categorise all health services to determine what aspects of health status they were attempting to change and then to identify appropriate outcome indicators. Health services can include a range of programs and activities — public health programs, environmental controls, preventive strategies, screening and early detection of disease, acute care — all of which are aimed at promoting and improving health, but in a myriad of aspects. Even within the same organisation, health services can range from health education to emergency care. Therefore, it would be inappropriate to suggest one indicator of outcome be applied to the services provided by one organisation.

The three levels of inquiry are:

1 Is health status changing?
2 What are the changes that are occurring?
3 Have health services caused these differences?

At the first level of inquiry, gross information on health status is sought. Health status is not a static attribute; people's health changes over time, both as individuals and as communities. Perhaps this question should be framed as: is the rate of change in levels of health changing? For example, in a community in which the incidence of a disease had been increasing, the stabilisation of the incidence rate would represent a change in health status.

In summary, it is important to know whether people are dying sooner or later, or becoming ill more or less often. The indicators that are likely to be useful in describing this are:

1 mortality and derived measures;
2 measures of morbidity and/or incapacity;
3 composite measures combining both mortality and morbidity.

The relevance of the continued analysis of mortality rates has been demonstrated. Community morbidity patterns can be derived from health service utilisation data; however, this will reflect differences in pattern of the use of health services as well as underlying differences in the distribution of disease. For this reason, community surveys of morbidity and incapacity are crucial.

Composite measures which combine both mortality and morbidity have as yet had little practical application. Whilst a number of conceptual problems remain, it is also important to realise that the data required in the calculation of many of these indices are not yet routinely available. These problems prompted the following comment:

> While work of this kind must certainly be pursued and is a crucial part of many health care studies, it is hard to see indices of the sort suggested having much practical application . . . Meanwhile improvements in collecting routine morbidity data need vigorous encouragement, to which expanded record linkage systems may largely be the key (*Lancet*, Editorial, 9 June 1973).

Therefore, the indicators currently required by the first level of inquiry are:

1 mortality;
2 morbidity and incapacity, from both service utilisation data and community surveys.

The second level of inquiry investigates the changes that are occurring. Health services are intended to have an impact on health status so that people become healthier, or less sick than they would have otherwise been, as distinct from being in a certain state of health or

illness. An outcome may be that people who are sick become healthy; equally, an outcome may be that people who would otherwise become sicker are maintained in a less ill condition.

A change in the population's health status may be due to people being exposed to fewer health hazards, reducing disease risk factors, getting sick more (or less) often, to people getting more (or less) severe illnesses, to people becoming ill but not deteriorating as rapidly, or to differences in the probability of death or recovery. In a population which is ageing, for example, health levels would show a decrease in functional capacity over time; in health status, an improvement would be a reduction in the decrease, or no decrease at all, in functional capacity over time.

Outcome measures need to measure changes in the levels of health, given a set of initial health states and expected changes over time. The measures that are relevant are:

1 health hazard exposure;
2 disease risk factor prevalence;
3 disease incidence rates, to measure the onset of illness;
4 disease recovery rates, to measure cure;
5 disease with chronic illness and/or residual disabilty;
6 disease survival rates and case fatality rates.

It is interesting to note that hospital administrators, at least in the nineteenth century, had something like this framework in mind when the responsibility of the hospital registrar was to record the health status of discharged patients. They were classified as dead, cured or *relieved* (see, for example, North Shore Hospital, *Annual Report*, 1896).

Mortality and morbidity, as traditionally measured, are important components of this framework. However, for the measures of recovery rates, the extent of chronic illness and residual disability, it is necessary to look at the more recently developed measures of health status.

Measures of risks to health can be developed on the basis of evidence of disease risk factors and general health hazards. However, until more is known about these patterns, attention must be directed towards measures of disease incidence and recovery.

Therefore, currently the indicators required by the second level of inquiry are:

1 disease incidence;
2 disease recovery;
3 chronic illness and residual disability;
4 disease survival and case fatality.

The third level of inquiry is the investigation of whether health services have caused the difference. The two problems of sensitivity of the health status measure and analytic study design have been outlined previously. The appropriateness of the outcome measure depends on the health service being evaluated and the changes in health already identified. Mortality and morbidity as traditionally measured will be relevant here, as will the standardised measures of health status.

The relationship between the levels of inquiry and the appropriate measures of outcome are shown in Table 1.

Table 1 Levels of inquiry and measures of outcome

Level of inquiry	*Is health status changing?*	*What changes?*	*Relationship to health services*
Measures	Mortality Morbidity Incapacity	Morbidity Incapacity Disease incidence Recovery Survival	Health status

VII An outline of appropriate methods of measuring outcomes for different types of health services

> The purpose of an information system is to improve the acquisition, processing, communication, timeliness and clarity of valid and reliable observations about a particular topic (White 1980: 296).

Few national health information systems have been systematically planned; most have grown step by step in response to differing historical, economic and political factors. The problem of inadequate and untimely information is widely recognised (McLachlan 1980; White 1980; WHO 1981). It is important to realise that complete, timely and relevant information is an unattainable ideal.

> Information available to guide policy formulation and the planning of health care is always incomplete and it is exceptional to find that information is both completely relevant and covers all questions that arise, even for the solution of relatively well-defined problems (Haro 1980: 8).

The concept of the minimum data set has evolved in response to the need to collect routinely — from several agencies or providers of health care — a set of data that can be used by a number of different users for different purposes. The uniform basic data set represents the recommended minimum collection. There are two aspects to a minimum data set: firstly, the delineation of the data to be collected; and secondly, the standardisation of measurement, definition, and classification of the data items (NCVHS 1980).

There is not a basic minimum data set that can serve *all purposes* at *all times* unless information requirements are completely rigid.

There is also a trade-off between what is practical and cheap to collect, and the comprehensiveness and validity of the information collected. The issue of practicality requires the minimisation of respondent burden, recording time and observer variation.

The basis of a health information system is a data base of routinely gathered data, collected to serve the information needs of many users. The data will be gathered by a variety of observers under the auspices of diverse organisations, but according to a uniform minimum data set. This information will form a data base which will be augmented by one-off surveys and special studies. The term, agency collected data, is used to describe multi-purpose, multi-user collections.

Agency collected data can be classified into four categories:

1 vital statistics, i.e. births and deaths;
2 health service utilisation data;
3 disease registers;
4 community surveys.

Special studies are those in which the investigators themselves collect the data required. In terms of the framework of the three levels of inquiry, agency collected data can be expected to provide the information requirements for the first two levels. The third level of inquiry will more often require special studies.

VIII An examination of possible experimental designs for obtaining health services outcome data

In this chapter a number of different problems are used to illustrate the application of the framework of the three levels of inquiry in obtaining health services outcome data. The problems considered in turn are heart disease, geriatrics, random breath testing and motor vehicle accidents, restrictive legislation on the sale of compound analgesics and discretionary surgery.

1 There have been recognised significant changes in mortality due to heart disease in a number of countries. It is reasonable to ask whether the improvement is due to increased high technology health services, such as coronary care units and intensive care ambulances, changes in lifestyle which have brought about increased exercise and improved diet, or even changes in the disease itself which have nothing to do with health services, high or low technology.

The first level of inquiry is whether health status is changing. This is readily established by an analysis of causes of death which shows that a decline in cardiac mortality has also been experienced in Australia over the last decade. The second level of inquiry would seek to identify how health status is changing; in this case, whether the decline in mortality is due to fewer people getting heart disease, or whether fewer people are dying from the disease once they have it. The third level of inquiry asks whether health services have caused the change in health status. Initially, one would investigate an association between changes in health services and changes in health status. In the case of heart disease, if case fatality had improved one would look for changes in treatment, such as the establishment of coronary care units in hospitals, or the commissioning of coronary care ambulances. On the other hand, if it were that the incidence of heart disease had fallen, one would then look for programs aimed at modifying heart disease risk factors.

2 The next example is the use of health services by the elderly. It is well established that the age group of 65 years and over are higher than average users of health services. Can this pattern of utilisation of services be expected to continue in the future?

The first level of inquiry would establish that health status is changing; in this case, the proportion of the population surviving to 65+ is increasing, and more members of that age group are reaching more advanced age. The second level of inquiry would investigate these differences: are fewer members of this group suffering from diseases that were previously life threatening, or alternatively, are the same numbers getting the same diseases and fewer dying from them? The implications of this for health planners are significant. On the one hand, the survivors may be healthier and therefore have a lower use of acute health services. On the other hand, there may be a group who survive acute disease but require ongoing care and therefore place a high demand on health services.

3 The introduction of random breath testing of drivers in New South Wales and in other States has been followed by a significant reduction in the number of traffic accident deaths. Whether this impact will be sustained and what its consequences are for health service usage, both in the short and long term, are unknown.

The fall in road deaths answers the first level of inquiry. The second level of inquiry would establish whether the total number of road accidents had fallen, or whether the fall in mortality was achieved by a decrease in the severity of the accidents that did occur. Decreasing the total number of motor vehicle accidents may well decrease the use of health

services proportionately; however, a decrease in the severity of accidents may increase the demands on the health services by increasing the number of handicapped survivors.

4 Legislation restricting the sale of compound analgesics was introduced following strong evidence linking the use of such analgesics with renal failure.

The first level of inquiry would establish whether health status had changed; in this case, whether the risk factor (average consumption of compound analgesics per capita) had changed. The second level of inquiry would establish how that change had occurred; in this case, total consumption may be significantly decreased if all users of compound analgesics reduce their intake and consequently their risk of kidney damage. It is equally plausible to suggest that total consumption may be decreased by many occasional users lowering their consumption, whilst the high risk, high consumers maintain their intake. Under this alternative, the incidence of renal failure and the consequent demand on health services may not alter.

5 Finally, the problem of significant differences in rates of elective surgery within and between population groups is considered. This illustrates how the same framework can be used to investigate differences in health service utilisation and whether these affect health status. The previous examples demonstrated the use of the framework in looking at changes in health status.

The first level of inquiry would establish the difference in utilisation; in this case, the differing rates of certain surgical procedures would be identified for different populations or population subgroups. The second level of inquiry would investigate what sort of difference in utilisation is occurring; in this case, did a higher proportion of the population have conditions which required surgical intervention, or did those who had those conditions have a higher chance of surgery? The third level of inquiry would investigate the impact of elective surgery on health outcomes.

IX A determination of the feasibility of a project to study the impact of health services on the health status of the population in the western metropolitan region of Sydney

This additional term of reference was included to demonstrate the three levels of inquiry approach and how the concepts of outcome measurement described in this report can be applied to the evaluation of a specific health service. For a Department of Community Medicine sited in a new teaching hospital, the most obvious question is, what impact does the hospital have on the health of the community it serves?

The first level of inquiry would identify the change in the provision of hospital services; in this case the commissioning of a new teaching and referral hospital, followed by a bed rationalisation program which planned for the reallocation of resources from inner city suburbs to the western growth areas.

The second level of inquiry would investigate how the utilisation of health services has changed with the introduction of the new service; in this case, the analysis of hospital morbidity data will describe the changes. For the third level of inquiry, it is necessary to identify outcome measures which are valid and sensitive measures of the changes that could be expected in health status. The development and testing of outcome measures using tracer conditions will achieve this.

Analysis of morbidity data

The changes in bed provision in metropolitan Sydney between 1978 and 1981 (the opening of the Westmead Hospital and the commencement of the hospital rationalisation program) provide an opportunity to analyse changes in utilisation patterns. The measurement of changing hospital use for selected conditions will demonstrate the effect of creating a tertiary institution in a community not previously having such a facility.

There is general agreement that relative access is a contributing factor to the use of hospital beds (McClure 1982). This has been demonstrated in rural Guatemala (Annis 1981) and has been studied in urban areas, including London and Chicago (Mayhew & Taket 1980; Morrill & Relley 1970; Hall & Gibberd 1982). However, other factors, in addition to distance, affect utilisation (Roghmann & Zastowny 1979).

In the current climate of resource restriction a conclusion is often reached that nearby communities are overserviced. Prior to the current period of constraint, the predominant concern was accessibility rather than cost containment, and the conclusion, often, was that distant communities were disadvantaged. In the absence of measures of change of health status, i.e. outcome studies, both conclusions are equally justified. The implication of overservicing is that the provision of hospital facilities does not contribute to the health of the population.

It may be considered that the effect of access on utilisation will vary with the types of conditions. Thus, for example, in acute, life threatening conditions, utilisation will not change with access. Increased diagnostic facilities may increase the rate of detection and subsequently the treatment of illnesses. For some other conditions, the pattern of management will be changed by improved access to hospital beds.

Different outcome measures will be appropriate and sensitive to different conditions or diseases. The first step in developing this approach is the analysis of hospital morbidity data to detect whether the effect of access on utilisation does differ by types of disease.

This project has now been funded by the Commonwealth Department of Health under a research and development grant.

The tracer concept

The concept of tracer conditions was introduced by Kessner et al. (1973) as a means of assessing quality of care in ambulatory health services. Tracers are discrete, identifiable conditions that, when combined in sets, illustrate the working of a health system.

The notion of a tracer is borrowed from the use of radioactive substances in examining the function of a body organ. The underlying assumption is that how well the system works in one instance is reflective of how it works in general. In the original Kessner use, the assumption is stated as 'how a physician or a team of physicians routinely administers care for common ailments will be an indicator of the general quality of care and the efficacy of the system delivering that care'.

Kessner and his colleagues were not the first to use identifiable medical conditions and their management to assess quality of care. This strategy is common to quality assurance activities from the 1960s onwards. However, the feature of the tracer method is that it is a systematic approach to the choice of conditions to be studied, whereas most quality assurance programs appear to rely on a haphazard choice. The distinguishing characteristics of the tracer method are:

1 that conditions are combined in sets;
2 that criteria for inclusion as a tracer are specified.

The definition of a tracer was extended by Sackett et al. (1974) in their evaluation of nurse practitioners to include symptoms, states, injuries and drugs. Their tracers covered the management of ten conditions and the prescription of thirteen drugs.

Despite their use in a variety of settings (Kessner et al. 1973; Spitzer et al. 1978; Nutting et al. 1981; Brook et al. 1977) the main application of tracers has been in quality assurance programs. The use of tracer conditions has been suggested by Leeder (1982) and the Commonwealth Department of Health (1981) in evaluating hospital performance.

The first step in the use of the tracer method in the evaluation of effectiveness is to develop and demonstrate a set of outcome measures which can be applied across a range of conditions treated at a teaching hospital. Conditions should be chosen to cover a range of outcomes, including survival, recovery, restoration of function and palliation. Thus, conditions chosen should include a condition which is life threatening, a condition in which loss of physical function is predominant, and a condition in which quality of life concerns are primary. The choice of outcome measures should be guided by both the treatment goals of clinicians and the impact of disease and treatment reported by patients.

X Recommendations for the use of health status measures in outcome studies

These recommendations are based on this review of outcome measurement and of health status instruments. Research projects in which an attempt is made to assess the outcome of health services should meet the following criteria:

1 Attention must be paid to the choice of outcome measures. Researchers should show how the outcome measure chosen is relevant to the service being evaluated.
2 Health status should be measured before and after the service intervention (i.e. a pre-test/post-test design should be used).
3 As far as possible, researchers should use existing health status instruments. Researchers should demonstrate a familiarity with existing instruments and, when the development of new health status measures is proposed, be able to show why existing measures are inappropriate.
4 When the development of new measures is proposed, the research proposal should not only show that validity and reliability will be tested, but *how* they will be tested.
5 Health status measures, whether standardised instruments or newly developed, should be tested in a pilot survey in the target population to ensure ease of administration and discriminative ability.

Other features which are desirable in health outcome studies are:

6 There should be a comparison with another group which does not receive the service intervention, so that the effect of the investigation itself is not attributed to the intervention (the Hawthorne effect).
7 The sample should be stratified so that known confounders including initial health status, can be distributed evenly over both groups. Random allocation offers the best chance of evenly distributing unknown confounders over both the intervention and non-intervention groups.
8 Health status measures in the intervention and non-intervention groups should be taken concurrently so that other factors which may affect health status (e.g. seasons, flu epidemics, keep fit campaigns) can be expected to operate evenly on both groups.
9 The intervention should be standardised so that it is the same for all subjects exposed.

XI An assessment of the relevance and applicability of cost-benefit and cost-effectiveness analysis to health services evaluation

Health services evaluation can address a number of questions. Can this particular service work in the best of all possible worlds (efficacy)? Does this service work in the real world (effectiveness)? What does this service cost? Is this service the best use of the money available? It is this last question to which the techniques of economic appraisal apply.

Economics is about choice where resources are scarce or limited, and where wants or goals are unlimited. Economic appraisal is the evaluation of alternative choices.

The scarcity of resources is a fundamental principle of economic analysis. Thus any activity — in this case, any health service — involves sacrifices or the resources used, and consequences or benefits. Because resources are scarce, the sacrifice involved in any particular health service is the benefit that is forgone by not providing the alternative service. This is the concept of opportunity cost. Costs are negative benefits — two sides of the same coin.

Economic appraisal compares the costs and the benefits of any intervention. It relies on two techniques — cost-benefit analysis (CBA) and cost-effectiveness analysis (CEA). Both techniques use the three steps of identifying, enumerating and valuing. Enumeration involves making estimates of the magnitude of the benefits/costs. Valuation translates the quantities estimated into monetary units.

In cost-benefit analysis both the costs and the benefits are expressed in money units, so that comparison of costs with benefits is then made in a common unit.

This allows the analyst and the decision maker to ask whether the quantified benefits of alternative activities are worth the dollar cost. Treatments or programs with different objectives, say health *v.* education, can be compared.

Some of the difficulties of CBA, particularly the dollar quantification of benefits, are alleviated by undertaking a cost-effectiveness analysis. Benefits must still be enumerated in some way, such as years of life saved, but not in dollar terms, so that cost-effectiveness analysis provides an index or a cost-effectiveness ratio by which programs or activities with the same objective can be ranked.

Cost-benefit analysis and cost-effectiveness analysis, although products of the same intellectual lineage, have quite different applications. The distinction is not always made clearly in the health care literature; many studies which are cost-effectiveness analyses are labelled as cost-benefit analyses and vice versa.

The problems of how to value the benefits of health care programs, as required by CBA, are far from resolution. Therefore, applications in the health field have drawn more heavily on CEA. The requirements of a CEA are also the elements of a sound CBA. At the current stage of development, CEA appears the more useable and useful technique (Klarman 1983).

Problems in the application of cost-effectiveness analysis arise in the lack of the information required by the technique. First of all, the analysis relies on evaluation of the effectiveness of the program or treatment under review. An evaluation of efficacy and effectiveness is often lacking; but so too may be the instruments which measure those aspects of health status which are the target of the intervention.

Secondly, estimating the costs of providing the program is not always straightforward. Identifying costs when a program provides many services is a problem which should not be

underestimated. It is not always clear that health care services are operating at least cost. There are also many problems in estimating indirect costs and costs which are borne outside the health sector.

> Costs are not immutable 'facts' scattered about waiting to be gathered and processed . . . The separation of one service from another is the essence of the analysis and there can be no single correct way of doing it. Differing systems of separation will give different insights . . . (Williams 1974).

It must also be remembered that doing a cost-effectiveness analysis has its own cost. In principle, the techniques of economic appraisal can be applied to any activity which involves resource allocation decisions. However, like research in other fields, to do it well may be costly, and to do it badly may be worse than not doing it at all. Hence the potential benefits of an exercise in economic appraisal must outweigh the costs to justify the exercise.

Williams (1974) suggested that cost-effectiveness analysis would be most fruitful when the following conditions apply:

1 sizeable amounts of scarce resources are at stake;
2 responsibility is fragmented;
3 the objectives of the respective parties are at variance or unclear;
4 there exist acceptable alternatives of a radically different kind;
5 the technology underlying each alternative is well understood;
6 the results of the analysis are not wanted in an impossibly short time.

There are more problems in applying cost-benefit and cost-effectiveness analysis that arise, not from the requirements of the analysis itself, but from the theory on which it is based. These are more fundamental shortcomings than those discussed above.

The problem that is most widely acknowledged is termed *distributional considerations*. For the most part, economists have ignored the redistribution of income/wealth within the cost-benefit/cost-effectiveness framework. Yet, the costs and benefits of a program may fall unevenly on groups within a community. Overall, some groups may end up better off and others worse off. The rationale for excluding distributional consequences is the acceptance of the proposition that the total community is better off if the gains outweigh the losses (often stated as the compensation principle if the winners would be willing to compensate the losers).

The response to this problem has been to make the analysis recognise distributional effects. A statement of the distributional consequences can be made. Drummond (1980) has suggested that different weights can be attached to the measures of costs/benefits as they affect different groups.

The next problem is the separation of components of health care services. Economic appraisal is based on the proposition that services should be provided in such a way so as to maximise return of the benefits for cost. The method of analysis relies on distinguishing one service, treatment or program and discriminating its costs and its benefits. The relevance of the analysis depends on an acceptance of the assumption that one activity, its costs, and its benefits, is separable from all other activities.

Finally, there is a basic proposition in this approach that benefits can be measured in some way. In fact, the assumption is not only that benefits can be measured, but that they can be measured in some common unit. And then, even when treatment outcomes are known and quantified, the problem of relative valuation, even in CEA, must be confronted. Does the same restriction in mobility, for example, have the same value to a professional writer as to a professional football player?

In conclusion, is there some relevance and value in cost-effectiveness (and cost-benefit) analysis in spite of the real problems, practical and theoretical, inherent in this approach?

> At this stage, therefore, the weak-spirited usually abandon the cost-benefit approach as too demanding, and return with relief to more comfortable ways.
>
> The trouble with more comfortable ways is that they foster the illusion that, if cost-benefit analysis

is not done, the issues which it poses can be avoided, whereas the reality is that these issues are all still present, and they all still have to be resolved (Williams 1974).

The techniques of CBA and CEA are generally applied to decisions about individual treatments or programs. Their intellectual roots lie in micro-economic analysis of efficiency (Williams 1967). However, the principle of the analyis, i.e. the comparison of total costs and total benefits, are applicable to health care planning on a broader scale.

The priorities for health care services can be established according to the criterion of economic efficiency, i.e. to maximise the *health* returns for the money invested. The cost of the service/program should be compared with the burden of preventable (prevented) illness. This calculation will give a cost-benefit ratio.

The burden of preventable illness is the measure of benefit/savings of prevention or improved treatment. It depends on disease incidence, cost of illness per case and the effectiveness of a new prevention or treatment program.

A recent review reports more than 200 separate cost of illness studies (Hodgson & Meiners 1982). It is generally agreed that there are three components to the cost of illness: direct costs, indirect costs and intangible costs. The direct costs are those costs occasioned by the illness itself and include expenditures on diagnosis, medical care, rehabilitation and non-health sector costs (e.g. travel to seek treatment). The indirect costs are the economic or productivity losses due to illness. The intangible costs, also called psychosocial costs or quality of life factors, are also a burden of illness but are less readily estimated. Often cited examples are pain and grief. Estimating the direct costs are less difficult than estimating the indirect costs; however, direct cost estimation is by no means problem free (Scitovsky 1982). Recent advances have been made in methods of estimating indirect costs (Hodgson & Meiners 1982) but some basic problems are not yet resolved.

Current methods of costing by disease are often based on disease prevalence. The cases existing in a given period, usually a year, are the basis of the cost analysis and the future costs of all those cases are taken into account. The prevalence cost of illness represents the current and future burden of all cases occurring within the specified period. Incidence based costing identifies the cost per case from the onset of disease to cure or death. It is this cost, rather than the prevalence based estimate, which represents the savings/benefits from prevention of a new case. There are more data requirements for incidence based costing.

Illness costing is the first step in applying the cost-benefit rationale to health planning. The data requirements are the same as for the second level of inquiry, i.e. disease incidence, recovery, residual handicap and case fatality.

XII An assessment of the scope, relevance and adequacy of existing health data collections as indicators of outcome

The health data collections selected for review are:

1 notification of deaths;
2 hospital morbidity data;
3 cancer registries;
4 infectious disease notification;
5 perinatal statistics;
6 Australian Health Survey;
7 ABS surveys of chronic illness and handicap.

These collections are considered likely to be the most relevant sources of outcome indicators. Taken together they are broadly based, i.e. not restricted to particular groups or locations; they are collected in nearly all States. However, other collections which may be potential sources of health status indicators are medical benefits claims; heart attack registers; records kept by community health centres, outpatient departments, school dental schemes, maternal and child health clinics, immunisation services, STD clinics, and Aboriginal health services; pharmaceutical benefit forms; workers' compensation statistics; nursing home benefit assessment forms; and approvals for invalid pensions, sickness benefits, handicapped children's allowances and domiciliary nursing care benefits.

Of the seven collections identified, only two (the Australian Health Survey and other ABS surveys) are surveys of the health of the community. The other information is a by-product of legal and administrative collections.

Types of collections

A system of classification of data collections will enable the comments regarding particular collections to be generalised to other collections of that class.

The distinguishing feature is that they are collected for many users and many purposes. Some data collections are routine and ongoing and every event is counted, as in the registration of births, deaths and marriages. Others are occasional, such as the Census or the Australian Health Survey. The occasional collections can also be subdivided into samples, such as the Australian Health Survey, or not sampled, such as the Census, which attempts to enumerate every member of the population.

Data collections can be primarily classified into four types:

1 vital statistics, i.e. births and deaths;
2 service utilisation data;
3 disease registers;
4 community surveys.

A further important characteristic of health status data is whether they are collected from the provider or the recipient. As Williams (1975) points out, the two may have widely differing perceptions.

The data collections are summarised and classified in Table 2. Two features deserve comment. Firstly, the data sources are predominantly provider based. Secondly, the responsibility for data collection and processing is diffuse.

Table 2 Health statistics in Australia

Type	*Collection*	*Source*	*Agency*
Vital statistics	Registration of births/deaths	Provider	Registrars-general (State)
Service	Hospital morbidity	Provider	ABS processing State health authorities for collection and further analysis
Disease registers	Cancer registries	Provider	State health authorities
	Infectious disease notifications	Provider	State health authorities
	Perinatal abnormalities	Provider	Perinatal Statistics Unit (funded by Commonwealth Department of Health)
Community surveys	Australian Health Survey	Recipient	ABS
	Survey of chronic illness and handicap	Recipient	ABS

Vital statistics

Scope, relevance and adequacy of notification of deaths

All births and deaths are registered. In addition, the registration is consistent among States (Deeble & Smith 1982). Vital statistics cover the whole population, but are restricted to only two aspects of health status (i.e. dead or alive).

The fact that differences in mortality rates in population subgroups exist highlights the importance of appropriate items to enable disaggregation. Occupation is recognised as an important factor in studying disease (Mathews 1983). *Principal* occupation during lifetime for males is recorded on death certificates. It has been common practice not to record occupation, but only marital status of females.

However, in the Census, *current* occupation is recorded. Hence, the Census and Mortality registers use different operational definitons of occupation. This makes it impossible to calculate proportional mortality rates by occupation groups by combining mortality and Census data.

Death registration allows for recording of multiple causes of death, but only the principal cause is coded for analysis.

Service utilisation

Scope, relevance and adequacy of hospital morbidity data

Hospital in-patient statistics collect data on admissions to hospitals and nursing homes, including diagnoses and surgical procedures. The unit for the collection is the stay in the institution, not the patient or the episode of illness.

Other data collected are age, sex, place of birth, Aboriginality, length of stay and discharge status. Occupation is not collected. There is provision for multiple diagnoses and procedures. These collections are limited in scope, by definition, to institutional use. They may be further limited, as is the case in New South Wales, by sampling rather than full enumeration of the population (Tweedie et al. 1982). Not all States have maintained hospital morbidity collections. Tasmania does not have a collection; New South Wales will not process 1982 data.

Hospital morbidity data are primarily a measure of hospital use. They provide diagnostic categories, but not severity or disability. For conditions in which most cases will be hospitalised, such as acute myocardial infarction, the collection has been used to estimate incidence (Reznik et al. 1982).

There has been little attempt to link data within these collections to provide utilisation information which is patient based (and thus may cover a number of admissions). However, it has been done successfully in Western Australia where such a system has operated for some years. More recently, in the Hunter region of New South Wales, patient linkage has been shown to be feasible using unit record number within hospital, and a set of identifiers excluding name, over several hospitals.

Disease registries

Scope, relevance and adequacy of cancer registries

A disease registry is a continuing systematic collection of data on the occurrence of, and characteristics associated with, a particular condition. The most prominent examples are the cancer registries in each State of Australia.

The unit on which a disease registry collects data is the incident case of the disease under scrutiny.

The scope of such collections is determined by:

1 source of data;
2 defined diagnosis of condition;
3 rate of detection;
4 community level of concern regarding the condition;
5 resources provided to maintain the registry.

For cancer, at least factors (1) to (4) favour thorough coverage of the community.

The relevance of a disease registry depends firstly on the importance of that disease as a major health problem; secondly, on the appropriateness of the items collected; and thirdly, on the timeliness with which data are available. In the case of cancer, data collected are: diagnostic items, use of hospital services and death. Cancer registries are potentially adequate as information systems covering incidence and health status. In practice, the registry's functioning depends on the resources allocated to it, and its own management of those resources. These resource problems have limited the value of the Cancer Registry in New South Wales (Tweedie et al. 1982) and possibly the same situation holds in other States.

Scope, relevance and adequacy of infectious diseases notification

Disease notification is the system of notifying the occurrence of particular conditions to a central agency for monitoring and early warning of disease outbreaks. Examples are the communicable disease notifications in each State. Their purpose is health surveillance.

Unlike disease registries, the unit of collection is the manifestation of the disease: prevalent cases rather than incident cases. Therefore, they tend not to follow up cases or to link records. The requirements of a disease register include the requirements of a disease notification system.

Disease notification systems depend on a range of data sources; however, complete reporting depends on the perceived public health risk of the disease. Given reliable reporting, disease notification systems can yield estimates of prevalence. They do not provide information on subsequent health status and hence they appear to be of little use in outcome evaluation. However, the current status of infectious disease reporting in Australia raises doubt as to the reliability and coverage of these collections.

Scope, relevance and adequacy of perinatal morbidity registry

Congenital malformations monitoring is conducted for each State and the data are processed and analysed by the National Perinatal Statistics Unit at the Commonwealth Institute of

Health, University of Sydney. Detailed information is collected on antenatal history, malformation and deaths within the perinatal period of every abnormal baby.

The scope of the collection is limited to births, still births and perinatal deaths. The collection appears to have two objectives: one being the surveillance of perinatal mortality and morbidity, the other being the collection of a data base on all births to provide, for example, national data on birthweight.

One of the major objectives of the collection is to provide early warning of suspected teratogens. However, the effect of a teratogenic agent may be seen, in addition to babies born malformed, in other manifestations, including malformed foetuses spontaneously aborted, abnormalities which are not detected in the perinatal period, and subsequent handicap or death. Abnormalities which are not apparent at birth, miscarriages, handicaps and deaths beyond the perinatal period, are excluded from the perinatal morbidity collection.

In theory, all births in Australia should come under the surveillance system; in New South Wales (where reporting is not a statutory requirement) in 1981, only 60 per cent of all births were covered and there is evidence of problems in the completeness and accuracy of the data items, particularly in regard to antenatal history (Tweedie et al. 1982). Forms completed in the medical records departments are limited to the information already recorded.

Perinatal malformations are both outcomes in themselves for the evaluation of associations between drugs, environmental agents and birth defects, and a register of health problems for which further outcome information is relevant.

Community surveys

Scope, relevance and adequacy of the Australian Health Survey

The Australian Health Survey was conducted for the first time in 1977–78, by the ABS. Its main objective was to provide data not generally available from other sources to assist in the monitoring, planning and evaluation of health services (ABS 4323.0, 1981: 3).

The survey covered private dwellings only and excluded institutions and Aboriginal settlements. This survey sought information on perceived health, usage of health services and socio-demographic characteristics. The health status data items were:

1 recent illness, physical and emotional;
2 days of reduced activity as a measure of short-term disability;
3 chronic conditions;
4 accidents, major and minor;
5 index of well-being which is, in fact, Goldberg's (1972) twelve item General Health Questionnaire (GHQ);
6 child vaccination.

Another household survey is under way in 1983. This covers a more limited range of items than the 1977–78 survey (ABS 1982–83, *Australian health survey development*, Papers 2–4). The items that are categorised as *outcome indicators* are referrals for diagnostic tests or specialist consultations, use of medications, adverse drug reactions and patient satisfaction. These are not the health status measures which have been considered as outcome indicators in this report. No measure of emotional health has been included. Health status is assessed by symptom/condition reporting and not through any standardised measure of general health status.

The health interview survey has major potential to provide population based, recipient provided data on the prevalence of disabilities and disease. However, there are major problems with the diagnostic accuracy and reliability of self-perceived illness (ABS 4323.0, 1981).

The justification for the inclusion of the GHQ in the 1977–78 survey is not clear. The GHQ is designed to detect non-psychotic, psychiatric illness, and thus the GHQ alone is not

a measure of minor morbidity and 'people's ability to go about their daily business without pain and discomfort'. The GHQ alone is far from adequate as a measure of community health status. However, even this measure has been omitted from the 1983 survey.

As with the 1977–78 survey, the 1983 survey will not cover the entire population. Institutions and Aboriginal settlements are excluded. The lack of valid and reliable health status measures within the Australian Health Survey limit the usefulness of its results. For example, do differences in the number of conditions reported by different groups within the population reflect differences in health, or differences in the population's attitude to health?

The cross-sectional survey approach is limited to a snap-shot rather than a moving picture. Thus, the Australian Health Survey shows that less than 20 per cent of the population consulted a doctor in the two weeks prior to the survey, and approximately 20 per cent had not consulted a doctor in the previous twelve months (ABS 4319.0, 1980). This does not show the frequency of consultation per capita.

Scope, relevance and adequacy of surveys of chronic illness and handicaps

Other surveys (e.g. ABS 4342.0, 1981) have been carried out by the ABS with a focus on particular conditions or disability. These surveys also lack a common method and set of health status measures. In general, they are subject to the same limitations as the Australian Health Survey.

XIII The identification of gaps in existing knowledge of health services outcomes and options for filling these gaps

The framework previously developed set up three questions or levels of inquiry. Briefly, these were:

1 Is health status changing?
2 What are the changes that are occurring?
3 Do health services relate causally to these differences?

The data that were likely to be useful at these levels were also outlined. They were:

1 mortality, morbidity, incapacity and composite measures;
2 disease incidence, recovery and survival rates;
3 measures of outcome, health services and other factors in a controlled study design.

The data collections already reviewed cannot be fitted into this framework. The relationship between levels of inquiry, measures of outcome, and existing data sources is shown in Table 3. This is illustrative and is intended to demonstrate the predominant relationships. Both the range of measures and the range of data sources should be seen as a spectrum and not as exclusive categories in their relevance to the levels of inquiry.

Table 3 Levels of inquiry and sources of data

Level of inquiry	*Is health status changing?*	*What changes?*	*Relationship to health services*
Measures	Mortality Morbidity Incapacity	Morbidity Incapacity Disease incidence Recovery Survival	Health status
Sources of data	Vital statistics Utilisation data Community surveys	Disease registers	Analytic studies

The first level of inquiry

Mortality data are collected by the State registrars-general and published by ABS. The ABS publications cover causes of death, perinatal deaths and life expectancy.

More detailed analysis of mortality data has been prevented as data tapes are not released by ABS, and researchers have experienced some difficulty in obtaining data from all State registrars-general. ABS may change or augment the data provided by the registrars-general; for example, querying a cause of death may lead to ABS changing the code. However, the augmented data are not returned to the registrars-general nor is a listing of which records have been augmented available.

Hospital morbidity data are limited to hospital usage based on separation, except in Western Australia and the Hunter region of New South Wales where record linkage has been achieved. Even with these limitations, however, the collections do provide some information about patterns of morbidity in the community. National coverage of hospital morbidity no longer exists.

Morbidity data based on health service utilisation beyond hospitals are not available.

The Australian Health Survey provides community based data on morbidity, incapacity and the use of health services. The survey is limited to private dwellings and excludes institutions and Aboriginal reserves. The validity of the reporting of morbidity and incapacity has been questioned even by ABS (ABS 4323.0, 1982). The 1983 survey does not include a standardised measure of health status.

Other ABS health surveys, e.g. *Survey of handicapped persons, Australia, February–May 1981* (ABS 4342.0, 1981), do not employ the same approach to measuring health status as the Australian Health Survey.

The second level of inquiry

Cancer registries provide the best example of functioning disease registries. These collect incidence, treatment and survival data. One of the problems faced by disease registries is the need to collect and compare data from several sources.

The infectious disease notification systems are of doubtful adequacy. The collections can vary in adequacy and scope from State to State.

The National Perinatal Statistics Unit is the only example of a national registry. It has not yet been able to achieve coverage of all births in Australia. It has not attempted to follow up cases.

The selection of those conditions which are of sufficient concern to warrant a disease registry appears to be haphazard rather than guided. A more systematic approach would be based on evidence of community mortality, morbidity and costs.

The third level of inquiry

Agency collected data are relevant to the third level of inquiry in two ways: either they provide sufficient information in themselves for a study, or they provide the sampling frame for the collection of additional data.

Either way, there are major problems with the current collections. The collections for the most part are event based (i.e. admission to hospital) rather than person based. There is a lack of time series data, due to the short period of time over which the collections have existed and due to changes and reductions in the collections. There is a lack of health status data that relates to the outcome of treatments, i.e. disease recovery and survival rates.

Linkage and linkability

Linked records identify a number of different events as relating to one individual. Thus linkage enables the development of person-based information. For example, 100 hospital separations may represent 100 people admitted to hospital once, or ten people each admitted ten times. Linked records allow these two different situations to be distinguished. Linkage is internal when records within the same data base are linked. It is external when records from different data bases are matched. An example of external linkage is a comparison of hospital morbidity data and mortality data.

The linking of records requires sufficient identifying information within each record to enable accurate matching. Matching is straightforward where there is a unique identifying item. Western Australia's hospital morbidity data is linked on the identifier of medical record number; this is possible, due to a common medical record numbering system. However, linking is feasible in the absence of a unique identifier, as demonstrated in Hunter region (New South Wales) morbidity data.

There is a very important distinction to be made between routinely linked records and linkable records. In a routinely linked data base, all records are compared and the data are transformed from an event base to an individual base. The concept of linkability does not require routine record matching, but the maintenance of sufficient identifiers to allow records

to be matched. In a linkable system, the actual matching of records is a special analysis and only carried out when justified.

The linking of records raises the issues of privacy and confidentiality. Methods have been developed to safeguard confidentiality. For example, in a data set in which numbers are used as identifiers, the identifying numbers can be changed systematically so that matching is still accurate but the person to whom the records relates is not identifiable. Linkable records are preferred on the grounds of preservation of privacy.

Responsibility for development of national health statistics

There are various governments, departments and agencies involved in the collection and processing of health information (this is well illustrated in Table 2). To some extent, this is an inevitable corollary of a federal system of government, but in Australia, in the last five years, it has impeded the development of national health information systems.

For example, the development of hospital morbidity collections was encouraged by the involvement of ABS in data collection and analysis. The withdrawal of ABS from this role has left gaps in the national coverage of hospital morbidity, with Tasmania ceasing collection altogether and New South Wales reducing to a sample rather than full enumeration. Thus, the past half decade has seen regression rather than progression of health information systems in Australia.

The improvement of national health statistics requires that there be some national view of health information systems. Currently, attention should be directed to:

1 maintenance of minimum data collections across the States;
2 development of minimum data sets;
3 development and testing of a common and consistent set of methods and measures for community health surveys;
4 development of linkability within and between data sets;
5 analysis to prompt the development of new collections and/or curtailment of existing collections in line with changing health priorities;
6 means of ensuring regular dialogue between users of the collections, and between users and agencies responsible for the collection.

Introduction of Medicare

There are two conditions associated with the implementation of Medicare which can have significant and favourable impact on the development of health information systems.

Under national health insurance each member of the population will be assigned a unique identifying number. The existence of a unique number will improve the accuracy of matching records and reduce the cost of data processing, in that comparison of only one item is required. The methods exist to protect confidentiality.

The national health insurance scheme will collect data on the use of hospital, medical and pharmaceutical services. Thus, one agency will be responsible for a data base which covers the major components of health care expenditure.

Similar provisions for data collection existed under the Medibank arrangements. However, the data collection was dismantled along with the health insurance scheme. It is important to protect health information systems from changes in health care financing.

Conclusion

The current state of national health statistics causes concern on a number of grounds; namely, coverage, timeliness, availability and accuracy.

Coverage refers to the comprehensiveness of the aspects of health status covered and the inclusion of all the population, including the identification of at-risk subgroups. Timeliness is the speed with which the data are available. Even the Federal Minister for Health, when

opening a recent conference (ANZSERCH/APHA and Biometric Society, May 1983), had to rely on statistics from 1978–79 as the latest available. Availability refers not just to the provision of summary statistics, but to access to the collections by researchers for more detailed analysis. The accuracy of most of the collections is unknown but could be investigated. Complete accuracy is not essential but it is important that the direction and magnitude of errors are known (Haro 1980).

XIV Recommendations: an outline of the options for priorities for the identification and collection of basic outcome data

The recommendations contained in this chapter have been developed as a first step in the improvement of national health information. Thus, they are the identified priorities, based on the review contained in this report, and are not exhaustive. The recommendations are presented in the format of (1) assumptions, or principles on which the following statements rely; (2) tactical objectives which are the priority areas for the maintenance and development of health statistics; (3) enabling objectives which provide the action by which the tactical objectives may be achieved.

1 Assumptions

That improved information about the effectiveness and use of health services will, through more informed research and policy making, have a favourable impact on the provision of effective and efficient health care services; and that improvements in national health information will be effected by:

1.1 maintaining and optimising the benefit to be obtained from existing data collections before establishing new ones;

1.2 reviewing on a continuing and ongoing basis, national health statistics in light of changes in policy, organisational change, developments in information technology, and research into measures of health status;

1.3 providing the means for regular dialogue between users and collectors of the data;

1.4 establishing the feasibility of proposed changes to existing collections, or the development of new collections, in pilot studies.

2 Tactical objectives

2.1 Maintain a national body, such as NCHVS, with the responsibility for the monitoring of existing collections and the development of the national health information system; and to demonstrate accountability through the publication of annual reports.

2.2 Establish a national body with the responsibility for the surveillance of the health of the nation, including monitoring progress towards national health goals; and to demonstrate accountability through publication of annual reports.

The model for this exists in the annual publication of *Health, United States* which reports on the health status of the United States. These reports present statistics concerning the health care sector and discuss current health issues. The reports have been compiled by the National Center for Health Statistics, assisted by the National Center for Health Services Research, Office of Health Research, Statistics and Technology and reviewed by the National Committee on Vital and Health Statistics.

2.3 Emphasise the health information role of mortality data by considering the following: coding of multiple causes of death, improving the reliability of the recording of occupation (principal occupation during lifetime), including occupation of females, and including Medicare number on death certificates.

2.4 Require full enumeration of hospital morbidity data in all States; to develop record linkability within hospital morbidity data, considering the inclusion of the Medicare number; and to consider the inclusion of occupation (current).

2.5 Continue the Australian Health Survey, maintaining a consistent approach so that a time series can be developed. The Survey should include a standardised measure of health status, use of health care services, other factors which influence health status (initially socioeconomic variables but including lifestyle factors as appropriate, valid and reliable means of measuring them become available).

Whilst the introduction of a health examination survey is not proposed as a current priority, the model of the United States Health Interview Survey backed up by the Health Examination Survey should be noted.

2.6 Adopt a systematic approach to disease surveillance and the establishment of disease registers. The potential for incorporating disease registers within linkable mortality and hospital morbidity collection should be investigated.

2.7 Include the National Perinatal Statistics Unit within a systematic, national approach to data collection.

2.8 Develop linkability among data collections while safeguarding privacy.

2.9 Provide regular opportunities for dialogue among users and collectors of the data.

3 Enabling objectives

3.1 In order to provide an opportunity for dialogue among users and collectors of health information, to support the maintenance of a national body on health statistics, and to support the establishment of a national health surveillance body:

- There should be a national conference on health statistics (convened by NCHVS if appropriate) within 1983–84 with a report submitted to Federal and State Ministers of Health.

3.2 In order to develop hospital morbidity data:

- There should be a federal government requirement for the collection of hospital morbidity data in all States.
- There should be a pilot study within a specific location which develops linkage between mortality data and hospital morbidity data using Medicare numbers, and which investigates the implications of a linkable system for the development of disease registers.

3.3 In order to develop the measurement of health status within the Australian Health Survey:

- There should be pilot studies of standardised health measures, including the Sickness Impact Profile, the Rand Corporation Health Insurance Study Battery and the Quality of Well-being Scale, to test their acceptability and sensitivity in Australian populations.

3.4 In order to develop the usefulness of mortality data:

- There should be a pilot study of multiple causes of death coding on death certificates.

3.5 In order to collect occupation in both mortality and hospital morbidity data:

- There should be a pilot study of the validity and reliability of occupational coding.

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