HealthOutcomes

HEALTH OUTCOMES BULLETIN • NUMBER 2 • MAY 1994

From the Director, AIHW

The response to the first *Health Outcomes* bulletin has been very pleasing. Many people have returned their pink slips (some with positive comments about the bulletin) and there have been many requests to be added to the mailing list. Details of a number of projects have been received. It is most important that the Australian Health Outcomes Clearing House (AHOCH) receives information from readers concerning projects or research activities being undertaken that are relevant to health outcomes. This will enable the AHOCH to develop a comprehensive national database which will be useful in building national information networks to assist those commencing research in the health outcomes field. It should also help in preventing unnecessary duplication of research activities across Australia.

The AHOCH is interested in all kinds of outcome studies, not just randomised controlled trials of interventions. Its interest includes studies with null findings and those that are unpublished. Please note also that the AHOCH has a broad multidisciplinary focus and is not just concerned with the outcomes of health interventions in the acute medical area. The clearing house is interested also in studies of instrument and method development as well as studies aimed at providing outcome information. The pink project proforma has been included once again in this bulletin. Please use it to tell us about what you are doing.

The director of the AHOCH, Ms Janet Sansoni, is pleased to address professional groups and conferences on health outcomes and the role of the clearing house. Ms Sansoni recently addressed the National Workshop on Consumer Outcomes in Mental Health and a brief report on this workshop, and an associated project consultancy, is included in this bulletin. Mental health is a priority topic in *Goals and targets for Australia's health in the year 2000 and beyond*[1] and the Australian Institute of Health and Welfare (AIHW) is committed to monitoring progress towards achieving the mental health component of these goals and targets.

The AIHW is also looking at other ways it can strengthen mental health information and statistics in Australia. The recently released *Better health outcomes for Australians*[2] identified strategies for goal attainment. Once such strategies are finally agreed upon it will be important for us not only to know whether the proposed health gain targets are achieved, but which of the various strategies caused, or were associated with, such health gains. Thus health outcomes research must be seen as central to these developments and the improvement of the health system.

Recently I had the pleasure of visiting the NSW Health Outcomes Program and heard of the exciting developments in that State, including the considerable funds being dedicated by the NSW Department of Health to health outcome activities. Their recently launched *Getting it Right*[3] document will be very useful for health professionals wishing to gain an understanding of and further information on health outcomes.

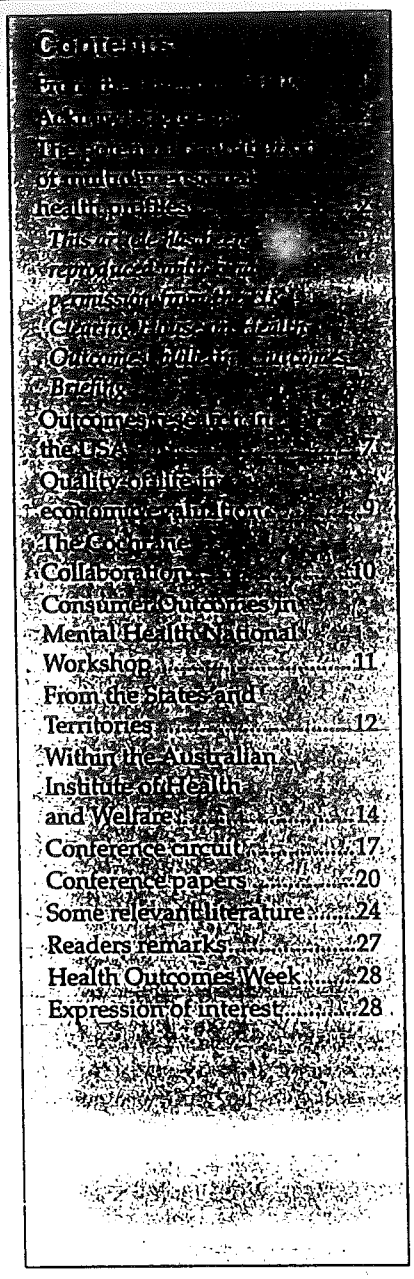
AUSTRALIAN INSTITUTE OF HEALTH & WELFARE

The NSW Health Outcomes Program is convening a major conference in Sydney later this year (12–13 August). The new Director-General of the NSW Department of Health, Mr John Wyn Owen, recently visited the AIHW. Mr Owen has long promoted a health outcomes focus and was instrumental in developing the 'health gain' initiatives in Wales.

I must mention the very great interest I have found in all parts of Australia in focusing the health system on health outcomes. I have had recent discussions on this subject in Victoria and Western Australia as well as in New South Wales.

With the moves toward the administrative separation of funding, purchasing and providing in the health system there is increasing interest in building outcome-related performance indicators into the contracts that regulate the flow of resources between these functions. Such steps focus the attention of management more and more on the outcome of health systems (i.e. the amount of health produced) rather than simply on outputs. For this to occur we need valid and accurately measured outcome-related performance indicators, but this is a subject to which I will return in future issues of this bulletin.

Recently the AHOCH successfully negotiated with the Royal Australian College of General Practitioners for Dr John Ware Jnr, to visit the AIHW in August. Dr Ware, visiting Australia to address the college, has an established reputation in health and consumer outcomes. He is one of the authors



of the SF–36 (perceived health status) instrument which is being used in health outcomes research overseas and will be administered to half the sample in the ABS 1994–95 National Health Survey. Dr Ware will present a seminar addressing these topics in Canberra on 11 August and all are most welcome to attend. The AHOCH will also be running a training workshop on health outcomes on 10 August so that participants can gain the additional benefits of Dr Ware's seminar. Further information regarding these events will be distributed once details are finalised. August looks like being a great month for health outcomes!

Dr Bruce Armstrong
Director, AIHW

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The *Health Outcomes* Bulletin is produced quarterly by the Australian Health Outcomes Clearing House (AHOCH) at the Australian Institute of Health and Welfare (AIHW). The purpose of the AHOCH is to provide a focus for activities to researchers and other parties interested in the area of health outcomes.

The AHOCH welcomes all suggestions for contributions to the *Health Outcomes* Bulletin, notification of forthcoming events and other inquiries. Please contact:

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Acknowledgments

Jenny Jefferson from the Department of Human Services and Health (Cwlth), who spent two months at the AIHW in late 1993 establishing the Australian Health Outcomes Clearing House and in preparing the first *Health Outcomes* bulletin, is to spend a year as a Senior Research Fellow at the Nuffield Institute for Health in the UK.

The UK Clearing House on Health Outcomes is located at the Nuffield Institute for Health. The AHOCH is seeking collaborative status with the UK clearing house and is grateful for the use of material from their publication *Outcomes Briefing* in the Australian bulletin.

The potential contribution of multidimensional health profiles

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Introduction

This article introduces some basic methodological questions for those of you starting out in health outcomes measurement. However, its main focus is on ways of choosing from the wide range of available measuring instruments, in particular, the strengths and limitations of one type of measure, the multidimensional profile (MDP). These have recently had a high profile in the medical literature which has tended to concentrate on their potential for clinical and public health research. This article has rather a different emphasis as it is particularly concerned with ways of choosing suitable methods and measures for

evaluating the effectiveness of routine care services, rather than uses in controlled trials or other research. Nevertheless, the issues should be of some interest to researchers and others with experience of outcomes measurement. Many of the topics mentioned here are discussed in more detail in two forthcoming Clearing House publications, on general methods for outcomes measurement and on the properties and uses of multidimensional profiles.

Instruments for outcome (or other types of) measurement

There are many different types of instruments and measures that can be used for outcomes measurement. These range from various measures of mortality, such as condition specific mortality and rates of avoidable deaths, through any topic and condition specific measures, to a number of instruments that cover several different aspects of health status and the impact of illness. Some of the types of measures are listed in Table 1. To those who are familiar with Donabedian's distinction between structure, process and outcome it may seem strange to see what are usually thought of as process measures being included in this table. This is not an encouragement to attempt more and more sophisticated process measurement, though this is urgently needed as a prerequisite to most outcomes work, but a reminder that the distinction between process and outcome is not that clear cut. Several indicators, which are usually thought of as process measures, can equally be used in outcomes measurement.

These include: readmission rates, service use and prescribing rates and levels. Measures of this kind should not be ignored. Their relative ease of collection and interpretation make them a good starting point in the many cases where there is no accepted alternative.

The possibility of using the same indicators for process and outcomes measurement is a particular example of a more general point—that none of the types of instrument in Table 1 is intrinsically an 'outcome measure'. Most of them may be used in a number of different ways such as needs assessment, screening and assisting diagnosis. What makes a measurement an outcome is not the instrument/measure, but the way in which the measurement is organised. Health outcomes measurement (of health care interventions) involves the measurement of any changes in health specifically due to those interventions, rather than those produced by other services, environmental and social influences, or simply the natural progression of the condition in the individual.

Identifying that an intervention has caused an effect, separating this from other effects and measuring it—this is the attribution problem. In clinical trials, many techniques are used to try to minimise possible effects from other factors, and control groups are used to compare the (changes in) health of those receiving the intervention with those who receive something else or nothing. Trying to measure effects during routine care delivery is that much more difficult because of the problems of trying to impose comparisons or controls. Nevertheless, this is central to achieving any sort of measurement of outcomes. Mostly this will be attempted through the design of the measurement; it is these arrangements which permit us reasonably to infer that the change in health status we are measuring has been produced by the designated health care intervention.

There are two related ways in which the measure can contribute to the likelihood that something is an outcome. First, the chosen measure should relate as closely as possible to the anticipated effects. For example, it is not worth using a measure which stresses physical mobility if this is likely to be unaffected by the intervention. It also goes without saying that the measure needs to be sufficiently responsive to detect relevant changes. Secondly, the chosen measure should not be over sensitive to other factors such as changes in the patient's social or economic status after becoming ill, or differences between patients in the extent of other help they receive. This can be a serious problem with the more general measures that are responsive to a tremendous range of influences and to a patient's general mood. If it is going to be difficult to control for extraneous influences, as is the

Table 1: *Instruments for outcomes measurement*

Some of the main classes of measure in current use for outcomes measurement:
• Mortality
• Complications / service morbidity
• Disease specific measures
• Topic specific measures (aspects of health / impact of illness)
– functional capacity
– role performance
– impact of illness
– health-related quality-of-life
• Multidimensional profiles
• Multidimensional indices
• Measures of service use
• Reported conditions and symptoms
• Health-related behaviour (outcomes of health promotion)
• Attitudes to health and health-related behaviour

Figure 1: *Main indices being used: No. of times these measures are reported*

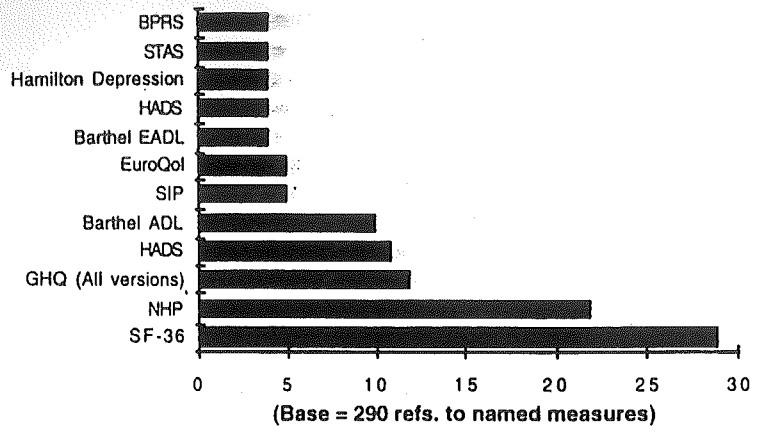
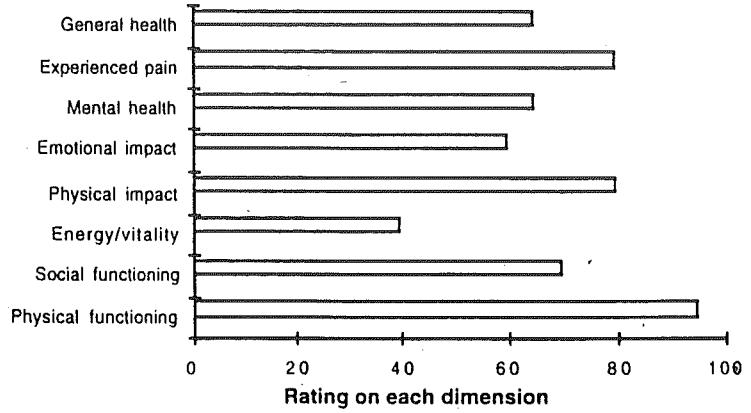


Figure 2: *Health measured with the SF–36*



case in most nonexperimental settings, then it may be best to concentrate on measures which most closely reflect the anticipated outcomes.

An introduction to multidimensional profiles

Of the measures in Table 1, one group has recently received much attention in the research literature, these are the multidimensional 'health status' profiles (MDPs). This group of measures includes several well known instruments such as the Nottingham Health Profile (NHP) and the Medical Outcomes Survey Short Form 36 (SF–36), and some which are less familiar in the UK such as the Dartmouth Co-op Charts and Duke Health Profile.

Many of the enquiries we receive at the Clearing House concern measures in this group. Two of them—the NHP and SF–36—are also the most frequently reported in our database of outcomes activities (see Figure 1).

MDPs: What are they?

MDPs are mostly self-completion questionnaires intended to measure aspects of health, illness and the impact of illness. They are sometimes described as generic health status profiles but 'multidimensional health status profiles' is a good description

Table 2: *Items and dimensions of health outcome instruments*

Name of instrument	No. of items	No. of scored dimensions
Duke–UNC Health Profile	63	4
Duke Health Profile (17-item selection from Duke–UNC profile)	17	4(6)
Nottingham Health Profile Pt I	38	6
Sickness Impact Profile & Functional Limitations Profile (UK version of SIP)	136	12(2)
Dartmouth Co-op Function Charts	49	9
McMaster Health Index Questionnaire	68	3
Medical Outcomes Survey (MOS) Full 149-item 'Functioning and well-being profile' (FWBP)	149	35(4)
MOS FWBP–C (Condensed version of full instrument)	113	20(4)
MOS Short Form–36-item instrument	36	9
MOS Short Form–20-item instrument	20	6
MOS Short Form–6-item instrument	6	6
EuroQol (6-item profile)	6	6

because it sums up two of their key features: they collect information on several aspects of health status and health-related behaviour in a single instrument; and they present the results for each aspect separately, not as some overall index of health. They are mainly intended to be generic—i.e. to cover a range of topics which is not specific to any one patient or population group.

A multidimensional picture of health

If you had just taken 5–10 minutes to complete the 36 items on the SF-36 questionnaire, you could use one of the several available scoring schemes to compute your rating on the instrument's eight dimensions.

- experienced pain—80 per cent
- social functioning—70 per cent
- energy/vitality—40 per cent
- mental health—65 per cent
- general health—65 per cent
- physical functioning—95 per cent
- physical impact on social role—80 per cent
- emotional impact on social role—60 per cent

This is not the customary answer to the conventional question 'How are you?', but it is typical of the sort of picture provided by a multi-dimensional health profile questionnaire.

Basic characteristics of MDPs

MDPs range in length from more than 140 to less than 10 questions and all but the shortest provide information on at least six different dimensions of illness and health. There are between 10 and 20 of these instruments in reasonably common use and most of these major instruments are listed in Table 2. As far as length/cost of administration/completion time is concerned they can be considered in three groups: those with less than 15 questions (normally used alongside other instruments); those with 15–50 questions; and those with more than 50 items.

Choosing and evaluating an MDP

There is a rapidly growing literature on the psychometric properties of these instruments and it is obviously important to know whether they meet basic criteria of reliability, validity and responsiveness. One should hesitate to use a measure if it fails to meet these basic requirements. However, in choosing any measuring instrument the most fundamental question is not whether the instrument has the technical properties which should follow from rigorous testing and development, but whether it PROVIDES THE INFORMATION YOU WANT in a useable form. Unfortunately, there is still relatively little debate on what these measures mean and how they have been and can be used outside of a research setting. This may support the impression that MDPs can be compared solely on the basis of their psychometric properties.

The best known MDPs differ in both the dimensions (domains) they cover and the way these are defined. If it is appropriate to use an MDP, the one chosen should be suitably sensitive to the effects of interest and sufficiently insensitive to potential confounding factors. How is it possible to tell if this is the case? Intending users of these measures may want to consider the following pointers.

- What domains/dimensions are covered/what are left out?
- How are the domains defined?
- What proportion of the instrument is taken up by each of the domains—are some covered in much more detail than others?
- What is the overall approach to health, illness and their effects: is this the same for all the domains?
- Why was the instrument developed?

What domains/dimensions are covered?/What are left out?

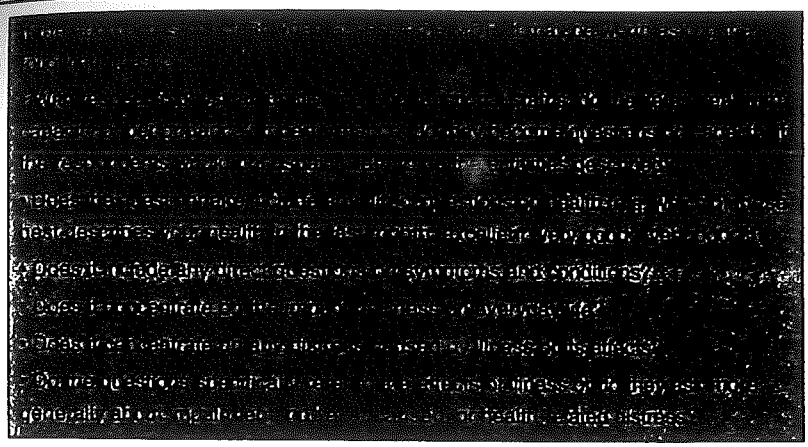
While it would be unreasonable to expect comprehensive and detailed coverage from the shortest group of instruments, the medium length profile (15–50 questions), and even the full length version, vary considerably in the domains they attempt to cover. Most MDPs have major sections on physical mobility, but nothing on impairment of sight or hearing, nor on mental acuity. This will obviously limit their suitability for a number of common applications, such as outcomes of cataract and glaucoma treatments and stroke rehabilitation. The relation between health and sleep, and the specific effects of disrupted sleep patterns are also not widely covered.

How are the domains defined?

Instruments vary widely in the ways they cover apparently similar domains. For example, the Duke 17 measures disability with a single item recording the length of any stay at home, nursing home, or hospital in the past week—this is clearly a very specific interpretation. The six NHP items on physical mobility have 'I find it hard to reach things' as their upper limit; some other instruments extend as far as the ability to perform active sports and run long distances. Apart from the wording of all the constituent items, the definition and sensitivity of a domain will depend on: the definitions of the end points, the number of items and options within each item used to cover the range and the spacing of items within the range.

What proportion of the instrument is taken up by each of the domains? Are some covered in much more detail than others?

Ten (28 per cent) of the items in the SF-36 are used to measure just one of its nine domains. Yet social functioning and pain are each measured by just two items. How was this balance arrived at and what implications does it have? Should it be inferred that the shorter dimensions are less important or that they are easier to measure?



What is the approach to health, illness and their effects: is this the same for all the domains?

In recent correspondence in the *BMJ* Sonja Hunt (one of the devisers of the NHP) argues that 'it is inappropriate to attempt to validate a health survey questionnaire (the SF–36) against a measure of perceived distress (the NHP)'. While there are some similarities in the ways the NHP and SF–36 approach certain topics, for example they use similar items for measuring aspects of functional status, there are sufficient differences to take seriously this argument that one should not be evaluated against the other. In an earlier work, the devisors of the NHP also point out that 'this distress (as measured by the NHP) may be a consequence of pathological changes requiring medical and health services, but equally may be a result of adverse social and/or environmental occurrences or conditions' (*BMJ* 1992 Vol. 305 p232). This is a different approach from that of many profiles where the questions specifically asks about the effects of illness.

Why was the instrument developed?

The point of this question is to tease out the motives and decisions underlying the development of the instrument. Knowing how an instrument was developed should help decide on the interests it embodies and the range of suitable applications. There are three key points:

- How did the developers choose the initial set of items from which the instrument was eventually developed?
- What criteria were used to select items for inclusion in the final instrument?
- What are the stated aims? These may include: to reflect the patients' interests, to contain service costs, to measure population health, and to collect information of relevance to clinicians. The principles used in compiling the measure may not coincide with the stated aims. It is common to find measures claiming to be patient centred that are obviously derived from a clinician perspective.

MDPs or other measures?

These detailed questions should only be asked after having decided that an MDP is the best type of measure for your purposes. This decision should be based on what is known of the general properties of MDPs and how they differ from other groups of measures. Four basic questions can help decide whether it is worth investigating MDPs further:

- How much data can you afford to collect?
- Do you need a multidimensional instrument or one or more single topic measures?
- Do you need data in the form of a profile or a single number?
- Do you need a generic measure, or something more specific?

Resource implications

In outcomes measurement, resources are probably more limited than the tolerance of patients. As well as the acceptability of the instruments to the patients, there will be major costs incurred in data collection analysis, interpretation and reporting, not to mention the work involved in translating findings into action. While researchers may be able to afford to use several different measures, in routine service evaluation the resources for data collection may be exhausted by a few service specific indicators, leaving no opportunity for more general measurement.

Single topic vs multidimensional measures

Single topic measures cover both bio-physical measurements such as blood pressure, and self reports of many aspects of health, illness and its impact. They are not necessarily condition specific and may deal with quite general topics such as pain, or physical mobility. All but the shortest MDPs are equivalent to small bundles of single topic measures, from which they have often been developed. It is a matter of deciding whether the measurement needs are best met by the range of domains in any one MDP, by parts of one or more MDPs (views are divided on whether it is desirable to use parts of these instruments) or a customised bundle of single topic measures.

Profile vs index

MDPs are profiles in that they separate report results for each of their constituent domains. Many of the devisers of profiles oppose attempts to collapse these scores to a single number, but there is a great deal of interest in ways of doing this. Much of this comes from purchasers, planners, administrators, policy makers and associated researchers. Their aim is to produce a single index that can summarise many major domains covered by the profiles for the purpose of comparing the health

Table 3: *Advantages and limitations of generic measures*

Advantages of generic measures

- More likely to have been extensively developed.
- Psychometric properties will be better known than for most other types.
- More likely to have supporting baseline / normative data from population and patient surveys.
- Constructs may be sufficiently general to be widely relevant.
- Provide some sort of overview of health status / impact of illness from a single instrument.
- Relatively cost-effective approach, provided the domains are independent and relevant.

Neutral

Each domain measures not more than sum of the constituent items. For example, a domain may be described as 'the impact of illness' but if this is only based on a question about the length of any periods of hospitalisation, this is all the data can be taken to mean. This might be an advantage or disadvantage depending on the relevance of the items to the intended application.

Limitations

- It can be hard to tell precisely what they mean and measure; this can present difficulties when selecting instruments or interpreting results.
- May miss critical factors for individual conditions, interventions or patient groups.
- May collect superfluous data; only a subset of domains are relevant to most applications.
- May be oversensitive to effects of confounding factors.
- They may not provide sufficiently specific information for a number of administrative and audit applications such as: evaluating quality of care, monitoring variations in protocols and interventions or planning the details of service development.

gain produced by different services, units and interventions. In one respect, indices and profiles are not radically different; most profiles use the principles of indexation to combine individual item scores within each domain. Nevertheless, this type of indexation seems more widely acceptable than collapsing the different domains into a single number. The underlying principle of single summary measures, the practical and political implications of the implied type of decision making are all being hotly debated. Regardless of whether they have been, or can ever be, successfully used and developed, some potential uses of health outcomes measurement are framed in ways that require simple global measures. Indices rather than profiles should be considered in these cases.

Generic vs non-generic approaches

The merits and drawbacks of generic measures continue to be discussed. Some of the possible advantages and disadvantages are listed here (in Table 3), though this list is itself contentious. How to weight these factors will very much depend on the intended application, but two points are probably worth noting. First, that outcomes measurement makes greater demands on instruments than most other types of uses; responsiveness to change is the main issue here. Second, that research will often give more latitude for experimenting with measures and using multiple measurement than work which has immediately and cheaply to produce service relevant data.

Conclusions

There are two overriding considerations for health outcomes measurement. First how to organise the measurement so that there will be some chance of inferring effects—this may require some type of controls and comparisons, good process measurement and, where appropriate, measurements being taken both before and after intervention. Second to choose an instrument which collects the type of data you need that is relevant to the intervention in question, not too sensitive to other factors, and gives data in a form that is useful for your purposes. MDPs are one type of measure to consider if they meet these criteria.

Outcomes research in the USA

Gornick, Lubitz and Riley[1] have identified a number of factors to account for the widespread interest in outcomes and effectiveness research in the US. Among these are the high proportion of GDP allocated to the provision of health care services (approximately 12 per cent compared to Australia's eight per cent), the perceived inappropriateness of some of the care provided, 'professional uncertainty' (which is assumed to account for a large proportion of the geographical variations in the provision of health care services that have been widely documented) and the lack of information available on the outcome of many diagnostic and therapeutic services (including many in common use).

Agency for Health Care Policy and Research

The Agency for Health Care Policy and Research (AHCPR) was established in December 1989 (replacing the National Center for Health Services Research and Health Care Technology Assessment) to undertake and promote research into the outcomes and effectiveness of different medical treatments, including the

assessment of different health care technologies.

Funding and administration of outcomes research within the AHCPR occurs primarily through the Medical Treatment Effectiveness Program (MEDTEP) which was developed to improve the 'effectiveness, cost-effectiveness and appropriateness of health care'.[2]

Specifically the AHCPR conducts and coordinates MEDTEP research activities in four areas: medical treatment effectiveness research, research database development and enhancement, clinical guidelines development, and research findings/guidelines dissemination.[3] While MEDTEP's research encompasses a range of activities, by far the most significant of these are the Patient Outcomes Research Teams (PORTs).

Patient Outcomes Research Teams

PORTs are large-scale, multisite projects conducted by multidisciplinary teams of five years (maximum) duration. The aim of PORT projects is to 'identify and analyse the outcomes and costs of alternative interventions for a given clinical condition, in order to determine the most effective and cost-effective means to prevent, diagnose, treat, or manage it and to develop and test methods for reducing inappropriate or unnecessary variations'.[4]

In the first round of funding for PORT projects the combination of literature (usually through meta-analysis) and analysis of variations in physician practice was emphasised. Those projects used large administrative databases or claims data (particularly those of Medicare, the US health insurance scheme available to all citizens aged 65 years or older), supplemented by a smaller number of patient interviews, surveys and patient records. Following dissemination of the findings, changes in physician behaviour were evaluated.

The subject areas covered by the initial PORT projects were low back pain, total knee replacements, acute myocardial infarction, cataracts, benign prostatic hypertrophy, localised prostate cancer, ischaemic heart disease, biliary tract disease, hip fracture repair, osteoarthritis, diabetes, pneumonia and obstetric practice.

Results from these studies are now available, and have been published in many sources that may be accessed using *Medline*[5] and similar resources.

PORT–IIs

In the most recent call for research applicants by the AHCPR[2] a new generation of outcome projects (PORT–IIs) was launched. In this round of funding the focus remained on condition- or technology-specific research (including both well-defined conditions as well as more general symptoms and conditions) and chronic conditions. Researchers were encouraged to adopt the most appropriate methodology for their subject area and to be creative in their research design.

The focus of PORT–IIs was to be 'on the establishment of direct linkages between practice and outcome, and on research methods that facilitate direct comparisons of alternative clinical strategies'.[2] For example, researchers may choose to compare different types of treatments (including 'watchful waiting'), different types of surgery or the type of care provided by different kinds of health professionals. The AHCPR were also encouraging (but did not require) the collection of primary data.

In particular the AHCPR was seeking research strategies that would provide results generalisable to current health care arrangements (rather than those that fell under the traditional 'efficacy' research banner), research that encompassed a broad range of outcome measures as appropriate to the condition being studied and research that emphasised the patient's perspective (such as acceptability to the patient, quality-of-life considerations and satisfaction with care).

Selection of projects for funding was to be based on a number of criteria. In particular the condition under study was to meet the following criteria:

- high incidence or prevalence in the general population or major population subgroups;
- controversy or open questions regarding the effectiveness and relative effectiveness of available clinical strategies;
- high cost, whether due to the number of people needing care, the high cost of care or high indirect costs.

While the successful applicants of the PORT–II awards will not be announced until later this year, the AHCPR expects to award US$7 million in 1994 to support the first years of 5–10 studies.

It is anticipated that the results of the PORT projects will be of relevance to a wide range of people including patients, clinicians, other health care providers and policy-makers. In addition this research will contribute directly to the AHCPR's efforts to develop clinical guidelines. Details of ACHPR projects are also published in *Research activities*,[6] ACHPR (USA).

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Quality-of-life in economic evaluation

(by Jane Hall, Centre for Health Economics Research and Evaluation)

Introduction

The literature on measuring health-related quality-of-life consists of three main strands: clinical, psychometric, economic. Each of these strands has a different disciplinary perspective and a different purpose for measurement. Clinicians have been concerned with presentation problems and evaluating the success of treatment. Therefore, they require measures which are sensitive to the particular health problems under treatment.[1] Psychometricians have been more interested in the general domain of health. Many have taken as their starting point the well-known WHO definition of health.[1] Economists are interested in issues of resource allocation and have sought to incorporate differences in quality-of-life in economic evaluation.[2] It is the purpose of this paper to describe quality-of-life measurement for economic evaluation.

Quality-of-life and quality-adjusted-life-years

The essence of economic evaluation is to compare the benefits of doing something with its costs. In cost-effectiveness analysis the benefits of health care are measured in naturally occurring 'units', most generally in the number of life years saved. Of course the problem with considering life years saved is that they do not allow for differences in the quality of those years. Many health care interventions are aimed at improving life quality rather than life expectancy.

Consequently what is needed is a measure that combines quantity and quality of life into one measure of health benefit. The resultant measure is life years adjusted or weighted to reflect quality, most generally known as a QALY (quality-adjusted-life-year). The weight used to adjust the life years for quality is sometimes called a 'utility'. The term 'cost utility analysis' is used to describe economic evaluation when QALYs are the measure of benefit.[2]

The need to combine quality and quantity of life into one measure gives rise to some special measurement properties required for QALY weights. Quality must be measured on a scale that is anchored at death (scored as 0) and at full health (scored as 1). Note that this does not preclude states worse than death. The scale must have interval properties so that a movement from 0.3 to 0.5 must be the same as a movement from 0.7 to 0.9, and both must be twice the value of a movement from 0.9 to 1.0. This ensures that 0.3 x 5 life years is worth the same as 0.5 x 3 life years (ignoring the issue of discounting).

Total QALYs are generally calculated as the sum of the (discounted) life years in each state multiplied by the weight for each state.

Where do the weights come from?

There are basically two approaches to weighting. One is to measure health state preferences directly and the other is to use an existing quality-of-life measure.[2]

In direct measurement respondents are given descriptions of the health state and asked to make some sort of trade-off with good health. The most widely used technique requires a trade-off between time in poor health and a shorter time in good health (time trade-off) or a trade-off between poor health and a gamble on good health vs. death (standard gamble). These techniques measure an individual's strengths of preference for different health states.

An already established quality-of-life measure can also provide weights. There are several hundred measures of quality-of-life but very few have the measurement properties required for the construction of QALYs. The most appropriate measures used for this purpose are the Quality of Well-Being Index (QWB) of Kaplan,[3] the Multi-Attribute Utility model (MAU) of Torrance,[4] the Rosser scale used by Kind and Williams at the University of York[5] and the EuroQol.[6] The SF-36 does not provide QALY estimates.[7]

Are QALY weights very subjective?

The purpose of QALY weights is to measure the strength of preferences for health outcomes. They are the values individuals attach to different health states and are inherently subjective.

The weights attached to different health states vary widely across individuals. Some respondents attach great value to life quality while others are prepared to put up with severe impairment of life quality for a greater life expectancy.

Subjectivity and variability are characteristics of values attached to other things than quality-of-life. Individuals are willing to pay different amounts for a good meal, a car or a painting.

Is a healthy-year-equivalent a form of QALY?

The term 'healthy year equivalent' (HYE) has also been used to describe quality-adjusted-life-expectancy.[8]

In the method described above for estimating QALYs the weight attached to a health state is independent of the amount of time spent in that state. Each year is valued independently of what went before or what follows. For example, 'being confined to bed' would have the same weight whether the person had been confined to bed for a few days or for the rest of his or her life. The

resulting total QALYs would be different because the time spent in the health state is different while the weight is the same.

Some economists argue that the weight is not independent of the duration of the state or what follows it. They argue that frequently the outcome of medical intervention is not typically one health state, but a series of transitions through a number of health states. The HYE is a measure that incorporates duration into the value derived.

Are QALYs disability-adjusted-life-years?

The term 'disability-adjusted-life-year' (DALY) was coined by the World Bank in its recent World Development Report, *Investing in Health*.[9] The DALY combines years of life lost due to premature mortality with years of disability-free life lost due to disease. The disability-free life years are weighted to reflect the severity of disability using a scale of six possible weights. These adjusted life years are then further weighted by age so that years lost at different ages are given different weights. Young adult years are weighted more highly than the very young or the elderly. Therefore a DALY is a form of QALY, but with an additional weight to reflect distributional considerations.

The estimation of DALYs required measurements of the following:

- mortality at every age due to specific causes;
- incidence of disability at every age due to specific causes;
- severity and duration of a disability.

This was based on recorded mortality data and community surveys of disability where available, professional judgement and expert opinion where not.

What about disability-free-life-expectancy?

Disability-free-life-expectancy (DFLE) counts the expected years of life free of disability or handicap. It gives a weight of 1.0 to disability-free years and a zero weight to any years with disability. It recognises differences in quality-of-life, but only allows two categories—with disability and without. If disability-free life years are used as the measure of benefit in an economic evaluation the implied assumption is that living with disability is equivalent to death.

Conclusion

There are different reasons for measuring quality-of-life and different instruments suited to different purposes. Health economists' interest in measuring health-related quality-of-life is derived from a concern with valuing the benefits of health care and health promoting interventions. This in turn stems from their concern with efficiency so that health care resources can be allocated to maximise health outcomes.

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The Cochrane Collaboration

The Australian Institute of Health and Welfare (AIHW) hosted a Cochrane Collaboration Meeting in Canberra on 4 February 1994. The first Cochrane Centre was established in Oxford in November 1992 to 'facilitate the preparation, maintenance and dissemination of systematic up-to-date reviews of randomised control trials of health care'. Since that time a number of other Cochrane centres have been established in Canada, Denmark, USA and Italy. There is current discussion concerning the establishment of such centres in Australia and the Philippines.

The first session, presented by Iain Chalmers of the UK Cochrane Centre, provided background information on the development of the Cochrane Collaboration in the UK. One of the main aims of the collaboration is to encourage the application of scientific principles in research and systematic research reviews. A number of examples were provided where popular textbooks were using treatments which the available systematic reviews had indicated were ineffective. Similarly, reviews of randomised control trials (RCTs) could indicate evidence of effective treatment strategies years before such material was included in major texts or in training curricula.

It was indicated that *Medline* searches generally only uncovered approximately 50 per cent of RCTs undertaken. This presents a bias as more research with dramatic findings is processed for publication than research with null

findings. There were enormous difficulties in locating unpublished research, including a poor response rate to letters of inquiry. Thus there was a need to establish trial registries at the inception of research while funding committees might also require evidence of a systematic review of the research literature at the proposal stage. It was also important to link the results of systematic reviews of RCTs to the review and development of clinical practice guidelines.

Professor Chris Silagy's paper followed with an outline of the structural components of the Cochrane Collaboration with differentiation of the roles of collaborative review groups, field coordination, Cochrane centres and the steering group. There are a number of Australian and New Zealand researchers involved in a range of specific interest collaborative review groups. Professor Silagy is involved in field coordination across the primary health arena. An evolving area for field coordination may be behavioural change and the dissemination of innovation as the endeavour to change and update practice is of interest across all collaborative review groups. Cochrane centres are largely administrative units established in various countries to support collaborative review groups and field coordination. They maintain registers of the following information:

(a) people involved in the collaboration;

(b) published reports of systematic reviews;

(c) systematic reviews in preparation.

The centres also play an important role in providing training; developing and preparing protocols and software; developing policies, standards, etc.; and in fostering international collaboration.

Hilda Bastian spoke of her role as a consumer representative on the steering group of the Cochrane Collaboration. One of the dilemmas that she faces is how to best involve the community given that networks between consumer organisations are relatively weak in comparison with research networks. Consumers need to be involved in setting the directions for future research and ensuring that consumers obtain value from health services. On a more pragmatic note it is difficult for consumer advocates to participate effectively without the funding to provide access to electronic mail or the travel funds to make the necessary inputs at overseas meetings of the steering group.

Following papers then examined the Australian experience with the collaboration in a range of areas (neonatal, pregnancy, childbirth, musculoskeletal and smoking cessation) and related activities (NHMRC initiatives, cancer trails register, cardiovascular trials register, calcium/osteoporosis trials and methodological issues arising from pharmaco-epidemiology developments).

In the second session Iain Chalmers spoke of the development of Cochrane centres in other countries. This was followed by an open discussion as to whether an Australian and New Zealand centre should be established. The consensus of the meeting was that a centre should be established, funding should continue to be sought and that strong links were needed with the AIHW, the NHMRC and the Department of Human Services and Health (Cwlth) to facilitate the activities of the centre at a national level. Professor Silagy identified that the Australian Institute of Public Health in South Australia was interested in hosting such a centre. Given the enthusiasm for the establishment of a Cochrane centre in Australia, it is to be hoped that the next bulletin will advise of further developments.

Consumer Outcomes in Mental Health National Workshop

20 April 1994, Brisbane

(by Ms Glenys Powell, Project Officer, National Mental Health Information Strategy)

In 1992 Commonwealth, State and Territory health ministers made a historic agreement to a National Mental Health Policy aimed at increasing the quality and availability of mental health services in Australia. A national strategy to achieve these aims has been agreed upon for the five year period from 1993 to 1998. The Australian Health Ministers' Advisory Council established the National Working Group on Mental Health Policy in 1992 to oversee the implementation of the policy.

A central theme within the policy is the need to improve the quality and quantity of information available on mental health services in Australia. Mental health consumer outcome research is one of a number of areas being targeted. At present there are no standard or agreed consumer outcome measures anywhere in Australia, nor do the States and Territories routinely collect relevant outcome data.

The long-term aim is the development of standardised consumer outcome measures for incorporation in routine service delivery and standard reporting of mental health services.

A consultancy team headed by Professor Gavin Andrews, director of the Clinical Research Unit for Anxiety Disorders (CRUfAD), will review the scope of the mental health service field and develop a project methodology for the development of national consumer outcome measures in mental health by the end of August 1994.

A national workshop on Consumer Outcomes in Mental Health was held in Brisbane on 20 April 1994. Ms Jan Sansoni,

Director of the Australian Health Outcomes Clearing House, opened the program with an outline of Australia's orientation to outcome measures in health and some of the particular problems applying to the mental health area.

The keynote speakers at the workshop were Professor John Wing, UK Royal College of Psychiatrists Research Unit (CRU) and Dr Rachel Jenkins, Principal Medical Officer (Mental Health, Elderly and Disability Policy Branch, UK Department of Health).

Dr Jenkins spoke on the development of the mental health targets in the UK Health of the Nation Strategy, a document which sets out priority areas for improving health in the UK. Mental health is one of a small number of areas focused on in the UK and three mental health targets were identified:

- Improve the health and social functioning of mentally ill people.
- Reduce the overall suicide rate (from 11.0 per 100,000 population) by at least 15 per cent by the year 2000.
- Reduce the suicide rate of people with severe mental illness by at least 33 per cent by the year 2000.

To quantify the first of these targets—improving the health and social functioning of people with mental illness—the UK health department has planned to conduct a national psychiatric morbidity survey and to develop individual consumer outcome measures, known as Health of the Nation Outcomes Scales (HoNOS).

Professor John Wing described the development of HoNOS. His team at the CRU is currently trialing a 12-item scale covering symptoms and functioning (e.g. aggression, self-harm, mood, social relationships and functional disability). The principle is that measuring the problems of users on successive occasions will measure change and therefore outcome. It is planned to incorporate the final version into routine clinical data collection and then into standard data sets.

The Australian consultants made presentations to the workshop, describing the direction of their work and uses of consumer outcome measures. The presentations provoked a lively debate on many of the issues involved in arriving at a suitable measure of consumer outcomes in mental health.

The consultants are currently conducting wide ranging consultations and would appreciate input from interested parties. Input into this project should be directed to Professor Gavin Andrews, Dr Lorna Peters or Ms Maree Teesson, c/- CRUfAD, 299 Forbes Street, Darlinghurst NSW 2010, or by telephoning (02) 332 1188—facsimile (02) 323 4316.

Further information on this project or any other mental health information projects may be obtained from Ms Glenys Powell by telephoning (07) 234 0700.

From the States and Territories

Health outcomes in Queensland

(by Sarah Muller, Epidemiology and Health Information Branch, Queensland Health)

The major activities in Queensland at this stage involve the preparation of several reports focusing on health outcomes, and national health goals and targets. These include:

- the publication in March 1994 of *Queensland progress in achieving national health: goals and targets for preventable mortality and morbidity*. This report examines trends for preventable mortality and morbidity in Queensland within the framework of the national report *Goals and targets for Australia's health in the year 2000 and beyond*. The report recommends that changes be made to several targets in the preventable mortality and morbidity chapter of the national report. The Queensland report is this State's first response to the national report. It is envisaged that in future the monitoring of trends in Queensland will be framed around national progress reports.
- the consolidation of information about health and health service outcomes research into a series of reports for wider distribution. Reports will include an overview, mortality and morbidity outcomes by major diseases, health care systems, health promotion, health outcomes, quality-of-life as a measure of health outcomes and a discussion of health service targets. The first overview report, *International health and health services comparisons*, is soon to be published.

The aim of these reports is to examine how Queensland and Australia compare with other industrialised nations in setting goals and targets for health outcomes, and also to compare the Australian health care system and health care policies with those in other countries. Currently mortality data (by cause of death) is being examined for Australia, major OECD countries, Hong Kong and Singapore. An OECD health database is also being examined exploring the demographic, epidemiological, economic and social background of 24 OECD member countries. It is intended to link this data with the mortality data to see how the background variables relate to health status.

Queensland Health also has the following projects underway in the health outcomes area:

- The Clinical Outcome Information System Project forms the first phase in the development of a clinical outcome information system for ischaemic heart disease in Queensland. Two specific aims of the study are to develop a population-based measure for acute myocardial infarction (AMI) incidence and an AMI case fatality measure which will be generalisable to Queensland hospitals. If the methods prove feasible these indicators could be used to plan and evaluate community-based prevention

programs and monitor clinical care outcomes in a standardised way.

- Aboriginal and Torres Strait Islander projects have been developed by an inter-regional health working group. The working group has brought together Brisbane South and Brisbane North health regions as well as non-government Aboriginal and Torres Strait Islander organisations in those regions. Outcome-focused projects are being developed, including one with an all Aboriginal and Torres Strait Islander working group consulting on youth drug and alcohol issues.
- In addition to the above activities, literature is being compiled outlining research in the US on Patient Outcomes Research Team projects.

The approach to health outcome assessment in South Australia

(by David Roder, Epidemiology Branch, South Australian Health Commission)

The historic role of the South Australian Health Commission's Epidemiology Branch was largely one of operating population-based disease surveillance systems for the prompt detection of outbreaks. Attention was first directed at communicable diseases, but surveillance subsequently was extended to cover:

- pregnancy outcomes;
- chronic conditions such as cancer and cardiovascular diseases;
- injuries;
- health-related behaviours and the social and environmental contexts in which they occur.

In addition data collection now covers aspects of quality-of-life.

Data of this type always have been used by the Epidemiology Branch to make judgements about intervention outcomes. Often the data have been used simply to guide judgements about the effectiveness of procedures introduced to control outbreaks of disease or about the impact of health policy changes such as recommending immunization protocols. The data also have been used in a more formal research context to obtain scientific evidence of the effects of interventions on health status.

The Epidemiology Branch promotes health outcome assessment in the following manner:

- by maintaining state-wide public health data systems that can be used for this purpose;
- by the regular publication of data giving examples of data use in health outcome assessment and indicating data availability to service providers for health outcome assessments;
- by providing epidemiological and biostatistical support to service providers or researchers wishing to use these or other data for health outcome assessment;
- by assisting the development and maintenance of registries specifically designed to link services to outcomes. Such registries include cervical cytology registries, hospital-based cancer registries, the familial adenomatous polyposis registry and a State trauma registry.
- by supporting the development of units to assist service providers assess service outcomes (e.g. clinical epidemiology units in hospitals);
- by providing advice to service providers and researchers on the processes that need to be followed for health outcome data transfer. These processes must comply with the legal requirements for privacy and the need for approval from institutional ethics committees.

Projects undertaken or supported by the branch to assess health outcomes include:

- monitoring blood lead concentrations in children to reduce contamination in domestic and general environmental interventions;
- monitoring cervical screening coverage and the incidence of invasive cancer of the cervix among populations exposed to intensive screening promotion;
- assessing case survival rates among individuals experiencing myocardial infarcts related to a range of prognostic indicators;
- monitoring the survival of corneal grafts related to prognostic indicators;
- monitoring renal transplant survival related to prognostic indicators;
- assessing cancer case survival rates related to stage at diagnosis, other prognostic indicators and, in some instances, mode of treatment;
- monitoring trauma case survival and the long-term consequences of major trauma, related to modes of retrieval and medical treatment;
- evaluating the impact of mammographic screening on stages of breast cancers at diagnosis, and monitoring the sensitivity and specificity of this screening;
- evaluating the association between homebirths and outcomes of births in hospitals of varying levels of specialization, according to birthweight and other prognostic indicators;
- monitoring immunization coverage related to promotional programmes, as for example, in the instance of childhood vaccine-preventable diseases, Q fever, and influenza.
- monitoring the prevalence of smoking and other health-related behaviour in South Australia, related to health promotional initiatives;
- monitoring self-reported levels of hypertension and biological risk factors in the context of health promotional initiatives;
- assessing deaths and near-fatal attacks from asthma related to professional and self-management practices;
- assessing perinatal and post-neonatal death rates in the context of health-related interventions;

- assessing injury rates related to preventive initiatives such as the mandated use of bicycle helmets, the reduction of hazards in the homes of the elderly, the promotion of swimming pool fencing, the improved design of bunkbeds and the reduction of playground hazards.

The branch also is a data source for extramural researchers undertaking formal research into the efficacy of health interventions, and for national and international agencies involved in health outcome assessments on a broader geographical scale.

The position taken by the Epidemiology Branch is that assessing outcomes of clinical and other health services is an important function and one that frequently should precede a broader health-economic assessment. Assessing outcomes should be just one component of an ongoing cycle of data gathering, production of health intelligence, planning and evaluation; and should not be regarded in isolation as an end in its own right.

Health outcomes in Victoria—setting the agenda

(by Martin Turnbull, Health Advancement Section, Department of Community Services and Health, Victoria)

The launch of Victoria's new Public Health Program in April 1993 signalled a major new commitment to a health outcomes orientation. Using the catchphrase 'closing the loop', Dr Chris Brook, Director of Public Health, set the agenda by emphasising that the key task facing the health system was to close the gap between health outlays and health outcomes. More explicit focus on health outcomes needed to be introduced into decision-making on resource allocation in the health care system. At the same time we needed to develop preventive, curative and other programs in a more integrated way.

To help achieve this an integrated public health branch has been established in the Department of Health and Community Services (Vic), incorporating three sections with key responsibilities for driving a health outcomes agenda.

The Monitoring and Evaluation Section of the Department of Health and Community Services (Vic) is working on a range of epidemiology projects, developing new health status measures and developing methodologies which seek to combine health outcome and economic evaluation criteria to determine optimal 'allocative efficiency'. Meanwhile the Clinical Policy and Review Section is putting considerable effort into quality assurance systems geared towards improving consistency and quality of outcomes.

The Health Enhancement Section has a brief to focus specifically on processes aimed at re-orienting the health system towards health outcomes. The section is developing strategies in particular areas such as health promotion, cancer screening, injury prevention, Koorie health and adolescent health.

The Victorian Government's Cancer and Heart Offensive provides a focus for consolidating initiatives to improve population health status with respect to cancer and cardiovascular disease, while the Victorian Injury Prevention Strategy is developing a strong agenda and broad based commitment to targeted initiatives aimed at reducing the burden of injury.

At the centre of all this work is the development of health goals and targets for Victoria. Draft goals and indicators have now been developed across eight priority health areas—the four national priorities, infectious diseases, chronic illness, child and maternal health, and dental health.

The aim of this exercise is to develop concise and detailed goals and targets to complement the national priorities and provide a framework for programs (both existing and new) relevant to the Victorian environment. Sections of the first draft are currently being reviewed by relevant experts with a view to preparing a complete paper for consultation by the end of June 1994.

A more-detailed article on these and other health outcome projects currently being undertaken in Victoria will appear in the next edition of the *Health Outcomes* bulletin in August 1994.

Within the Australian Institute of Health and Welfare

National Health Goals and Targets

In April 1993 the Commonwealth, State and Territory health ministers endorsed the development of a national health policy aimed at providing direction to the development of strategies for improving health outcomes for all Australians. The first step in this process was to develop a set of health goals and targets for areas that were most damaging to Australians. Traditional measures such as mortality, incidence, prevalence and level of morbidity were used to assess the level of impact on the community. Areas were selected if they were amenable to practical prevention, improved treatment strategies, or if the effect of the intervention strategies could be measured. The first four agreed areas of concern were injuries, cancers, cardiovascular disease and mental health.

The National Health Goals and Targets Secretariat of the Department of Human Services and Health (Cwlth) convened a committee of experts in each of the four focus areas to define broad goals, targets and strategies. The first two attempts at setting goals and targets in Australia (1988 and 1990) were generally perceived as too health-promotion oriented. There was a deliberate effort in the subsequent round to include a wider array of health professionals. The committees included Commonwealth, State and Territory health department

representatives; consumer representatives; clinicians; public health experts; peak body representatives (including the National Heart Foundation and the Anti-Cancer Council); accident prevention bodies and academics. The Australian Institute of Health and Welfare (AIHW) was invited to participate and provide advice about data availability and monitoring requirements for goals and targets set by the committees.

To assist the committees the Secretariat commissioned four reports on current activities—one in each of the focus areas. Each of the committees produced a draft report on goals, targets and strategies covering health promotion/preventive activities, medical/clinical care (including both pre-hospital, emergency and post-hospital care), rehabilitation and palliative care. The draft reports have been circulated for widespread public consultation, after which the Secretariat will prepare final reports for consideration at Australian Health Ministers' Conference in June 1994.

The AIHW has been identified as having a major role in the monitoring of goals and targets. In this discussion the terms 'goal', 'indicator' and 'target' are used as follows:

- a **goal** is a broad statement of a desired improvement in the health of the population;
- an **indicator** is a specific and measurable way of assessing progress towards a goal;
- a **target** is the value of an indicator which will be regarded as a measure of achievement of a goal.

The development of goals, indicators and targets vary according to specific health areas, and are primarily judged by subject matter experts. However, good statistical practice can ensure that goals and targets are attainable, useful health policy tools.

The choice of an indicator should reflect the object of the goal. For example, incidence measures are preferable for prevention activities that attempt to avoid new occurrences of a health problem or risk behaviour while prevalence measures are preferable for goals that aim to change risk factors, behaviours, public awareness, service access, etc. As a minimum the indicator should be measured for the current situation (providing the baseline data) and at the end of the time period to show whether the target has been reached. To enhance its use as a policy tool, the indicator should be measured regularly between current and target dates to provide monitoring data.

Developing the target involves determining the target value of the indicator and the associated target date. The targets should be specified in terms of rates, proportions or averages (means or medians), rather than as counts. Changes in the value of the indicator over time should reflect actions taken to improve the health of Australians. One way to achieve this is to express baseline values, monitoring data and target values in age-sex standardised form.

The final target value can be expressed as either an absolute value or a target percentage change. The absolute target value is generally preferred because it is unambiguous, easier to monitor and generally has a greater impact on policy makers. However, care must be taken with measuring if percentage reductions are used. The inherent variability in most indicators means that simply looking at the difference between a baseline value and a monitoring or target value may give a misleading idea of the indicator's rate of change. Some form of statistical modelling should be applied to estimate an underlying trend.

Further information on National Health Goals and Targets issues may be obtained from Edouard d'Espaignet, Population Health Indicators Unit, AIHW, by telephoning (06) 243 4005.

The National Health Information Agreement

This article outlines one of the major developments in Australian health information and statistics of recent years—the National Health Information Agreement (NHIA) between the Commonwealth, State and Territory health authorities; the Australian Bureau of Statistics and the Australian Institute of Health and Welfare. The agreement endorsed by the Australian Health Ministers' Advisory Committee came into operation on 1 June 1993.

The objectives of the NHIA are to improve national health information through cooperation on the development, collection and exchange of national health data; and to provide a national health information development and implementation structure, including a three year national health information work program.

Why develop national health information?

Health care in Australia is a major national industry; it is big business. In 1992–93 the health system accounted for some $34.3 billion (8.6 per cent of the national GDP), employed over half a million people and was present in most centres of population. As with any industry of this size and complexity; extensive information is needed for effective policy development, planning, management, monitoring and evaluation. Information is also an essential ingredient for management of the human side of the health system, the patient.

The term 'health information' is used to cover all statistics, data and derived information that are concerned with the state of health of individuals or populations; and the provision of health care services, their cost, use and outcome. This includes administrative data, clinical data and importantly, data that relate to those factors that affect health. National health information is health information that accords with agreed uniform national definitions and standards; may be aggregated to a national level and would be useful at that level for comparative analysis, planning or policy making. There remains much information that is mainly relevant to the State, area or local community that need not be collected or aggregated nationally.

Information is increasingly being recognised as a necessary prerequisite for well-managed health care. The benefits of good information flow to all levels of the health care system, including State governments, local governments, local communities, patients, care providers, managers and planners. These benefits will result from a better understanding of the elements of the system and how they interact, an ability to make valid comparisons across jurisdictions, improved management capacity at all levels, and an enhanced ability to monitor changes and evaluate outcomes. The rapid changes in health care have created further demand for information necessary to develop and monitor changes which include funding arrangements, clinical procedures and diagnostic techniques. This has led to a growing demand from clinicians, policy makers, planners and managers for consistent, timely and uniform data.

The demand has coincided with the rapid expansion of information technology into all parts of the health care system. State and Territory health authorities spend millions of dollars in developing and upgrading their information systems. This growth of information technology has seen a substantial increase in the capacity to collate, manipulate, analyse, move information and respond to demand. The disadvantage of the increased information capacity is the tendency for information to expand until it fills the capacity, but more is not necessarily better. Information should only be collected where there is a defined need and benefit (whether it be clinical or administrative, local or national).

A crucial element in the definition of good quality data is the requirement that it be uniform. The compilation of data using inconsistent definitions is useless at best, dangerous at worst. Interpretation of the data may be quite misleading, particularly if aggregating data from different sources or different jurisdictions. This push for uniformity has been a driving factor in the recent developments in health information, such as the National Health Information Agreement and the National Health Data Dictionary.

The pressure for national health information should be looked at in an Australian federal context. Australian health care has been bedevilled by an inability to compile national health statistics or make comparisons between States. This has been due to the lack of uniform data and the reluctance of some health authorities to contribute to national data collections. The analogy of the Australian railway system, with its complexities and inefficiencies, immediately springs to mind. The difficulties of comparison and transportability across State boundaries are evident in such an analogy. Some jurisdictions fear uniform national data may threaten funding through comparison with other States. Until recently basic indicators such as hospital admissions/separations were defined differently throughout Australia's health care systems.

National information does not necessarily mean large centralised data collections. The essential element for national information is the uniformity of the information collected. The question is—are the same definitions used by all health organisations that are the primary data sources?

Uniform national information provides the only reliable basis for describing and analysing health systems. This allows valid comparisons nationally or between jurisdictions and provides a solid base for national, state or regional planning and policy making. The development of uniform national health data also provides a sound statistical basis, both in consistency of definition and in providing an adequate sample size, for surveys that cross jurisdictional boundaries. It is only by using consistent national data that a sound understanding of the system and how it operates can be reached. In an environment of restructuring and micro-economic reform, the lack of such understanding is a major barrier to rational change.

Given the substantial health policy and funding role of the Commonwealth Government, nationally consistent policy and monitoring information is needed. State health authorities also now recognise the need for and benefit gained from national health information. State authorities require national information to undertake comparative analysis on a national or state basis, to measure interstate patient flows and to provide a valid statistical framework to develop such measures as patient outcomes. Uniform national statistics also assist the identification of major national health trends and broader epidemiological studies—the development of national cancer statistics and national morbidity collections, for example.

The costs associated with health information, its collection and its interpretation can be substantial. Information is not a free commodity. The collection of additional data should be undertaken when the benefits produced outweigh the costs. However, there are considerable net benefits at all levels resulting from the adoption of uniform information.

An important aspect of health information—one that underpins much of the value of national data—is the associated development of a national methodology for its use. The work of the Commonwealth Casemix Program in developing a national casemix methodology has demonstrated the significant methodological progress achieved on national issues. Developing outcome measures is a further example of where benefits will only accrue if there is an agreed national methodology.

The National Health Information Agreement

The signatories of the National Health Information Agreement are the Commonwealth, State and Territory health authorities; the Australian Bureau of Statistics and

the Australian Institute of Health and Welfare.

Objectives noted in the Agreement are:

- to promote the collection, compilation, analysis and dissemination of relevant, timely, accurate and reliable health information. This objective is concerned with the full range of health services and a range of population parameters (including health status and risks), in accordance with nationally agreed protocols and standards.
- to develop projects to improve, maintain and share national health information;
- to cooperate in the provision of resources necessary to address national health information development priorities efficiently and effectively;
- to provide the information required to research, monitor and improve health and the delivery of health services;
- to provide the information required to facilitate nationally agreed projects which promote the development and reform of the health care system;
- to promote the expansion of national health information and encourage other individuals/groups in government and non-government sectors to participate by making available information that they hold.

The agreement also aims to improve the access of community groups, health professionals, government organisations and non-government organisations to uniform health information. While the development of improved information technology access is a goal, the first priority is to improve the data collections available. An important goal is the setting of national data definitions and standards. A major outcome of the agreement is the recognition by all signatories of the National Health Data Dictionary, published by the AIHW, as the authoritative source of data definitions.

A further role for the agreement is to provide direction for the development of national health information. There are a number of health information policy issues that have broad national implications including privacy, charging, data access and data linking. It is important that such matters be addressed nationally.

In the initial stage the agreement is between governments and is mainly concerned with public sector health information issues. The rationale for this somewhat restrictive approach is that governments provide or finance approximately 70 per cent of all health services, largely fund the training of health professionals, and are also the major producers and users of health information. Obtaining the participation of and commitment from governments is therefore the first and crucial step to any national agreement.

The National Health Information Agreement recognises the need for a broader national perspective that encompasses the private sector and non-government sectors including providers, researchers and the community. Appropriate means to involve other sectors in the process and possibly in the agreement itself are being developed.

National Health Information Work Program

The major implementation mechanism of the National Health Information Agreement is a rolling triennial National Health Information Work Program of national health information activities. The activities include developing standard charts of accounts, developing health outcome measures, developing new collections (e.g. mental health), and improving existing collections (e.g. morbidity and vital statistics).

The work program lists the projects agreed to by the agreement signatories and are in accord with agreed national priority areas. These priority areas are:

- health services
  - institution-based
  - primary care
  - mental health
  - medical services
  - health service outcomes
  - pharmaceuticals
  - health insurance
  - national health expenditure
  - health labourforce
- health status
  - vital statistics
  - population surveys
  - surveillance
  - population health outcomes
- health information
  - national health information policy and infrastructure.

Work on the projects listed in the work program are currently underway or will be undertaken by one of the signatories to the agreement. Each party accepting the responsibility for a project has agreed roles and responsibilities. These include addressing the issues from a national (not Commonwealth or State) perspective, consulting broadly, reporting to the management group and using agreed national data definitions and standards.

A key element of the work program is the *National health data dictionary—institutional health care.*[1] Published in 1993 the dictionary represents a major step forward in providing an authoritative set of national definitions. The National Health Information Work Program envisages the early expansion of the dictionary to other major areas including the health labourforce, outpatients, primary care and mental health.

The next evolutionary stage of national health information is formulating a long term vision and setting in place a plan to guide health information development over the next 5–10 years.

Further information regarding the National Health Information Agreement can be obtained from Tony Greville, National Health Information Unit, AIHW, by telephoning (06) 243 5000.

Conference circuit

In this section brief summaries of recent conferences will be presented. It will include occasional reviews of papers which might be of interest to the readers. Clearly

this section cannot include all relevant conferences and activities, nor contain reviews of all relevant papers. Readers might like to assist by notifying the editor of forthcoming conferences or workshops which may have a health outcomes focus. Readers might also like to contribute brief review articles on other recent activities for future bulletins.

Harkness Health Conference

8–9 December 1993, Canberra

This conference included sessions by the following keynote speakers:

Professor R Kaplan, University of California, San Diego, on *Health outcomes as the basis for health resource utilisation;*

Dr Karen Davis, The Commonwealth Fund, New York, on *Women's health: myths and stereotypes;*

Professor R G Gregory, Australian National University, on *Some economic dynamics of Australian aged care policy;*

Dr Nicholas Hicks, Oxfordshire Health Authority, UK, on *Current issues in UK health and health care policy;*

Dr David Blumenthal, Harvard Medical School, on *Current issues in US health and health care policy;*

Professor A. J. McMichael, University of Adelaide, on *The environmental health costs of economic policy: A reverse-angle view;*

Professor Stephen Leeder, University of Sydney, on *Exploring the links between social status and health;*

Dr Lorraine Hawkins, Department of Health (NZ), on *Defining core health services and managing competition in the prototype and production model;*

Dr Jennifer Dixon, University of London, on *Rationing and politics in the new national health service;*

At this conference a range of papers were presented on current issues in health (e.g. quality-adjusted-life-years and resource allocation, women's health issues, etc.) and the characteristics of different international health systems. Requests for information or papers should be forwarded to the conference organisers, Centre for Economic Policy Research, ANU, PO Box 4, Canberra ACT 2601.

[Note: A detailed review of the Kaplan paper presented at this conference may be found in the 'Conference papers' section of this bulletin.]

Australian Association For Social Research

25–27 January 1994, University of Tasmania

The inaugural conference of the Australian Association for Social Research (AASR) was held at the University of Tasmania, Launceston, from 25–27 January 1993. The theme of the conference was 'social research and the quality-of-life'. A number of speakers addressed this issue from a diversity of academic perspectives and research methods. A small number of key papers are reviewed in the 'Conference Papers' section of this bulletin. In addition the following papers addressed the quality-of-life issue.

Atkins C. *Shared meaning of quality-of-life: perceptions of nurses who work with people with severe multiple impairments [Poster];*

Atkins C. *Symbolic interactionism: helping people with severe multiple impairments articulate their quality-of-life;*

Bennet KC, Griffin TM. *My forever child: quality-of-life issues for parents of children with intellectual disability;*

Charlton F. *Measuring the quality-of-life of older people: traps for players young and old;*

Cowan NY, Hart P, McMurray E, Wearing AJ. *Positive and negative affectivity in quality-of-life research: using structural equation models to examine the causal interdependency between personality coping and daily experiences;*

Hibbins R, Compton D. *Measuring quality-of-life: a people or place focus;*

The articles mentioned above and those reviewed are only a small proportion of those presented at the conference. While the conference theme was 'quality-of-life', there was a diverse range of topics addressed. Speakers came from many different academic backgrounds and this at times created considerable lively discussion. A number of papers focused on the application of various qualitative research techniques in social research and in particular Encel's paper, *Is there a defensible distinction between 'qualitative' and 'quantitative' research?*, caused some comment. Michael Smithson's paper, *A new approach to analysing ordinal data,* proposed an approach using inverse cumulative distributions. Smithson stated that it may be possible to perform a number of operations on ordinal data (previously thought to be untenable) without treating the ordinal responses as an equal interval scale. He also presented an introductory seminar on 'fuzzy sets' which was well-received.

It is anticipated that a journal of the key issues addressed by speakers plus other invited contributions may be produced later this year. A bulletin of conference abstracts was presented to delegates and further enquiries should be directed to Professor Wolfgang Gritching, AASR President, c/- Social Science, University of Tasmania, Launceston, PO Box 1214, Launceston Tas 7250.

Workshop on advances in the measurement of disability

21–22 February 1994, Canberra

The Australian Institute of Health and Welfare (AIHW) in cooperation with the Social Psychiatry Unit, Australian National University, organised a two day workshop in February to discuss 'advances in the measurement of disability'. The workshop was designed to promote multidisciplinary discussion of basic disability concepts. In particular the workshop discussed the concepts contained in the *International classification of impairment, disability and handicap* (ICIDH) and worked towards greater consensus within this field in Australia—or at least towards a greater appreciation of the various perspectives. The papers from the workshop are to be

published in the near future by the AIHW.

The workshop was timed to take advantage of a visit by international researchers attending the Seventh REVES International Meeting (reviewed below). There was a special focus on psychiatric disability on the second day of the workshop at which participants were able to comment on work being undertaken on the ICIDH by Professor John Cooper, University of Nottingham, UK.

Why measure disability?

Speakers revealed the wide range of potential purposes for measuring disability and handicap.

- Individual assessment and case management
- Service planning and evaluation
- Service comparisons (of needs and outcomes) to aid resource allocation

Several people attending the workshop stressed that assessment instruments should be meaningful to the consumer of disability services. Examples were provided of services which use self-assessment as a way of involving an individual with a disability in planning his or her own future.

The ICIDH

The WHO's International Classification of Impairments, Disabilities and Handicaps (ICIDH) is based on the following definitions.

Impairment: In the context of health experience an impairment is any loss or abnormality of psychological, physiological or anatomical structure or function.

Disability: In the context of health experience a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Handicap: In the context of health experience a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that individual.

The ICIDH is in the process of revision which will probably lead to a revised version in 1999. The WHO representative, Michel Thuriaux, urged those attending to make specific suggestions for improvements to the ICIDH.

The workshop discussed both the characteristics and problems of the ICIDH. There are overlaps in the way impairment, disability and handicap are conceptualised in the classification. 'Handicap' in particular was seen to need further development as the word is by definition a social construct. This poses difficulties in establishing an international standard enabling comparison among different societies and cultures. There was also discussion of the need for a fourth dimension in the ICIDH, relating to the environment and to the barriers contributing to the individual's experience of disability and handicap. Copies of the ICIDH can be obtained from the WHO Distribution and Sales Unit, 20 Avenue Appia 1211, Geneva, Switzerland, on facsimile 41 22 7880401.

The workshop reached no formal conclusions, but it seems fair to say there was a lively interest in achieving an international standard. This not only enables comparison across countries, but contains concepts robust enough to be used in different disciplines and for different purposes within the one country. Readers wishing to obtain a copy of the workshop proceedings should contact the Publications Officer, AIHW, GPO Box 570, Canberra ACT 2601, or by telephoning (06) 243 5037.

Ros Madden
Disability Services Unit, AIHW

Seventh REVES International Meeting: International Network on Health Expectancy

23–25 February 1994, Canberra

The Australian Institute of Health and Welfare (AIHW) hosted the Seventh International Meeting of the Network on Health Expectancy (Reseau Esperance de Vie en Sante—REVES) in Canberra on 23–25 February 1994. The meeting was organised by Dr Colin Mathers, Health Monitoring Division manager (AIHW), with joint funding by the AIHW and the National Centre for Epidemiology and Population Health at the Australian National University. The Australian International Development Assistance Bureau (AIDAB) also provided funding to enable a researcher from India to attend the meeting.

The Network on Health Expectancy (REVES) is an international network of researchers working on the development and application of summary health status measures. The measures combine mortality and morbidity indicators at the population level. Examples of such indicators include disability-free life expectancy and the disability-adjusted-life-year (DALY) developed by the World Bank. The network has a strong interest in population health and epidemiological trends, population ageing, and the hypothesis that levels of sickness and disability are increasing as death rates decline.

Health expectancies generalise the idea of life expectancy to talk about how long the population can expect to live in various states of health. For example women in Australia in 1993 could expect to live an average of 80.4 years, including 10.2 years with disability (4.5 years with severe handicap). The belief that health expectancies provide a powerful tool for monitoring population health and developing public policy has been a major driving force in the establishment and work of the REVES network. The network has taken considerable interest in issues such as the limits to human longevity and the compression of morbidity hypotheses.

The Network on Health Expectancy, conceived in 1988, was established the following year by the Institut Nationale de la Santé et de la Recherche Médicale (INSERM, France), the Conseil des Affaires Sociales du Québec (CAS, Canada) and the Centre for Demographic Studies (Duke University, USA) with Dr Jean-Marie Robine as its coordinator. Dr Robine visited the AIHW in

February and March to continue collaborative work with Dr Colin Mathers in the health expectancy area.

At the seventh REVES meeting, over 40 papers were presented to 63 participants from 15 countries: Belgium (two), Canada (two), Finland (one), France (eight), Hong Kong (one), India (one), Japan (two), the Netherlands (six), New Zealand (one), Norway (one), Taiwan (two), the United Kingdom (four), the United States of America (eight), Switzerland (one), Australia (23). All papers were presented in plenary session. The network has continued its tradition of not organising parallel sessions so as to avoid fragmenting the scientific debate among the different disciplines to which the members of the network belong.

Multidisciplinary debate continues to be a major strength of REVES, whose members consist primarily of demographers, epidemiologists, medical researchers, statisticians, biologists and public health professionals. Around half the participants at the seventh meeting were from universities (Amsterdam, ANU, Chicago, Colorado, Duke, Erasmus, Helsinki, Hong Kong, Kent, Kitakyushi, Leicester, Michigan, Montpellier, Pennsylvania, York, etc.) and the other half from national institutes of health (AIHW, INSERM, IHE, TNO, etc.), of demography (INED, NIDI, etc.) or statistics, mainly from health divisions (INSEE, NCBS, OPCS, Statistics Canada, etc.).

Papers and discussion at the meeting addressed a wide range of issues of importance to the health expectancy field as well as presenting new results and methods. Most papers are available on request from Dr Jean-Marie Robine (REVES coordinator in Montpellier, France) or from Dr Colin Mathers (Health Monitoring Division, AIHW). Many of the papers will also be included in the proceedings of the meeting to be published by the AIHW later in 1994.

Topics discussed at the three day meeting included:

- *The increasing number of health expectancy calculations and their harmonisation.*
- *'Compression ou expansion de la morbidité: l'accumulation d'évidences empiriques'*: 'Are we living longer but in worse health?' Are the increases in life expectancy that are occurring in developed and developed countries because we are keeping sick or disabled people alive longer or perhaps saving people from death but leaving them in states of disability and handicap?
- *Socioeconomic and other inequalities in health expectancy.* Studies presented evidence at the meeting that the social inequalities in health are much greater than have been shown by differential mortality—the poorest and the least educated not only live shorter lives but also suffer greater disability.
- *Methodological issues and the use of longitudinal data for health expectancy calculations.*
- *Policy relevance*: The potential value of a health expectancy indicator for monitoring health at the national level.
- *The disability process and relationship between disease, disability and health.*
- *Dementia-free life expectancy (DemFLE)*: Papers presented at the meeting showed that for a number of countries at a population level each elderly person over the age of 65 has an expectation of approximately one year of life with dementia. Dementia is a good example of how the use of internationally accepted diagnostic criteria may lead to a high level of standardisation in health expectancy calculations.
- *DALYs, QALYs, etc.*: Several papers examined the use of value weights to add health expectancies across a number of health states and a keynote paper examined the differences between the health expectancy and the DALY approaches to measuring the global burden of disease.
- *Biodemography*: Biological and evolutionary perspectives to the limits to life expectancy and the evolution of health expectancies were discussed.

Dr Colin Mathers
Head–Health Monitoring Division, AIHW

[Note: A detailed review of the Cadet paper presented at this conference may be found in the 'Conference Papers' section of this bulletin.]

Conference papers

Cadet B. History of the construction of a health indicator integrating social preference: The Quality of Well-Being Scale. Paper presented to the Seventh Meeting of the International Network on Health Expectancy (REVES), 23–25 February 1994, Canberra.

This paper traces the development of the Quality of Well-Being Scale (QWB) from its inception as a measure of health based on a standardised instrument applicable to the total population. To this end the authors use Sullivan's index integrating mortality and morbidity in a single continuum of health states. The QWB has two basic elements—state of health as defined as a function level (between perfect health and death) at a point in time and a set of weights corresponding to the values of social preference for each level. The functional level combines three sub-scales (mobility, physical activity and social activity) plus an additional set of problems/symptoms in order to capture 'symptomatic' disturbances such as depression. Category scaling was used for the preference of health states and this social preference was calculated on a sample of 876 persons, representative of the population of San Diego for the year 1976. Social preference for health states plus prognosis leads to a life expectancy adjusted by quality-of-life (quality-adjusted-life-expectancy, or QALE) and the unit of measure is a

quality-adjusted-life-year (QALY). More recently discounted QALEs have been used which take into account that a QALY today has a greater value than a QALY in a distant time. Programs are then evaluated, as in the Oregon experiment, by the number of QALYs gained. The ratio of cost to QALY is calculated, which classifies programs by efficiency.

Cadet notes that nearly all aspects of the QWB continue to be disputed. These include questions as to content validity, 'Is this a well-being or disability scale?', and 'Does the QWB reflect all relevant dimensions of health?'. He concludes that this lack of content validity means that the QWB is not universally applicable, lacks sensitivity and only detects major functional impact. Given inter-individual variances for a given health state the existence of social consensus is questioned. As recent literature suggests health preferences are more dependent on disease experience than on demographic characteristics it raises questions as to whose preference is to be used (healthy public or patients) and whether, in the absence of social consensus, a social preference can be built that takes individual preferences into account. In the QWB social preference of health states was measured over one day although the preference value assigned to a health state may have depended on its duration. There are also questions of measurement precision as the prognosis element within QALE is usually evaluated by experts and the general lack of available data limits the use of the model.

Questions of validity are concerned with the ability of QALE to reflect a true health preference. In practice would one prefer a program with high QALYs at the price of a reduction in the duration of life as the model predicts? It is also claimed that using QALE for resource allocation is contrary to real social choices, that the model favours persons with high life expectancy and certain social groups. QALE also targets health improvement, neglecting the start and end point and the characteristics of recipients, which is contrary to the preference of some societies where preferences are given to more disabled persons. These contradictions may be due to the indirect nature of the procedure—preferences are measured for health states, whereas they are used as preferences for programs. In the latter case factors other than health state are taken into account in allocating priorities such as age and family responsibilities.

In conjunction with these criticisms the author suggests that the benefits of this work may include the relevance of the analysis and the proposition of an operational definition of health, the ease of QALE computation, the integration of preferences for health states, and the policy relevance of this work.

Kaplan RM. Quality-of-life assessment for health resource allocation. Paper presented to the Harkness Health Conference, 8–9 December, 1993, Canberra.

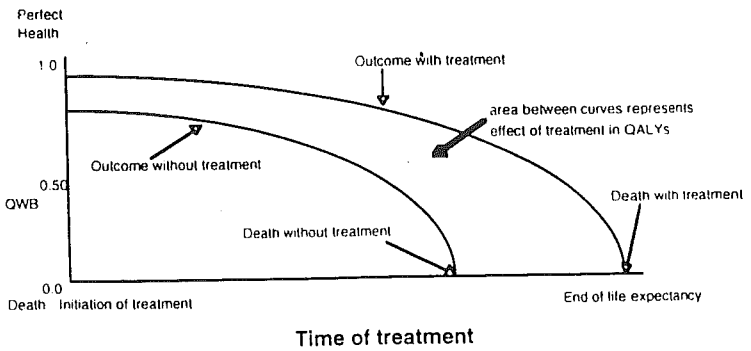
The goals of medical treatment and disease prevention are to extend life expectancy and to improve quality-of-life in the years prior to death. Typically outcomes of treatment are evaluated in terms of survival time. Although quality-of-life is often measured, interpretation of these outcomes in relation to mortality is difficult. Survival analysis places each individual into one of two categories: alive or dead. Among those alive, all individuals are considered equivalent. Thus, a patient confined to bed with severe symptoms is scored the same as someone who is active and asymptomatic. A general health policy model is proposed as a solution to this problem. The model adjusts life expectancy for diminished quality-of-life, which is measured using a standardised instrument, the Quality of Well-Being (QWB) scale. The model expresses the effect of treatment in a unit known as a well-year or quality-adjusted-life-year (QALY) as is indicated by Figure 3.

These units integrate side effects and benefits of treatment by combining into a single number, mortality, morbidity, and duration of each health state. The model has been used in a variety of different applications, including clinical trial research, and resource allocation proposals. Dividing the cost of the program by the QALY production results in an estimate of the cost-utility of the program.

The author concludes that general health outcome models can be of considerable value for analysing the costs, risks and benefits of medical therapies and of prevention programs. This information can be used to set priorities for health care resource allocation. Table 4 (following page) indicates cost/well-year estimates for a range of treatments.

[Amended author abstract]

Figure 3: *Quality-of-life assessment for health resource allocation.*



Source: Kaplan RM. Quality-of-life assessment for health resource allocation. Paper presented to the Harkness Health Conference, Canberra, 8–9 December 1993.

Table 4: *Summary of cost/well-year estimates for selected medical, surgical and preventative interventions(a)*

Program	Reference	Cost/Well-Year
Seat belt use	Kaplan (1988)	0
Ante-partum and anti-D injection(b)	Torrance & Zipursky (1984)	1,543
Pneumococcal vaccine for the elderly	Patel (1979)	1,756
Post-partum and anti-D injection(b)	Torrance & Zipursky (1977)	2,109
Coronary artery bypass surgery for left main coronary	Weinstein (1982)	4,922
Neonatal intensive care, 1,000–14,999g	Boyle et al. (1983)	5,473
Smoking cessation counselling	Schulman (1991)	6,463
T4 (thyroid) screening	Epstein et al. (1981)	7,595
PKU screening(c)	Bush et al. (1973)	8,498
Treatment of severe hypertension (diastolic > 105 mm Hg) in males age 40	Stason & Weinstein (1977)	10,896
Oral gold in rheumatoid arthritis	Thomson et al. (1987)	12,059
Dapsone for prophylaxis for PCP pneumonia(d)	Freedberg (1991)	13,400
Treatment of mild hypertension (diastolic 95–104 mm Hg) in males age 40	Weinstein & Stason (1976)	22,197
Oat bran for high cholesterol	Kinosian et al. (1988)	22,910
Rehabilitation in COPD(e)	Toevs et al. (1984)	28,320
Estrogen therapy for post-menopausal symptoms in women without a prior hysterectomy	Weinstein (1980)	32,057
Neonatal intensive care, 500–999g	Boyle et al. (1983)	38,531
CABG (surgery) 2-vessel disease(f)	Weinstein & Stason (1982)	39,770
Hospital hemodialysis	Churchill et al. (1984)	40,200
Coronary artery bypass surgery for single-vessel disease with moderately severe occlusion	Weinstein (1981)	42,195
School tuberculin testing program	Bush et al. (1972)	43,250
Continuous ambulatory peritoneal dialysis	Churchill et al. (1984)	54,460
Cholestipol for high cholesterol	Kinosian et al. (1988)	92,467
Cholestyramine for high cholesterol	Kinosian et al. (1988)	153,105
Screening mammography	Eddy (1990)	167,850
Total hip replacement	Liang (1987)	293,029
CABG (surgery) 1-vessel heart disease(f)	Weinstein & Stason (1982)	662,835
Aerolized pentamidine for prophylaxis of PCP pneumonia(d)	Freedberg (1991)	756,000

a) All estimates adjusted to 1991 US dollars
b) Treatment for Rh immunisation
c) PKU, phenylketonuria
d) PCP, pneumocystic carinii pneumonia
e) COPD, chronic obstructive pulmonary disease
f) CABG, coronary artery bypass graft

Source: Kaplan RM. Quality-of-life assessment for health resource allocation. Paper presented to the Harkness Health Conference, Canberra, 8–9 December 1993

The following are brief reviews of papers presented to the Australian Association for Social Research Conference, University of Tasmania, 25–27 January 1994.

Cummins RA, Hinchy J, Reid S, Gullone E. Comparative data using the comprehensive quality-of-life scale on adolescents, university personnel, and people with an intellectual disability.

The ComQol Scale has been developed in three parallel forms: for the general adult population, adolescents and for people who have a mild/moderate level of intellectual disability. Data include 'objective' measures of life quality as well as the subjective measures on the seven domains of ComQol (material well-being, health, productivity, intimacy, safety, place in the community and emotional well being). The scale is also multi-axial with regard to its subjective measures and each domain is rated separately in terms of its importance to the individual as well as on its perceived satisfaction. The paper presented comparative data between these three groups and while the overall pattern of data across domains is similar for the groups, differences in absolute magnitude of life quality are also apparent. *[Author abstract amended]*

Editor's Note: The ComQol is, as the title suggests, a comprehensive scale and is not particularly focused to health-related quality-of-life although containing this domain. However the approach undertaken by Cummins et al. with regard to assessing quality-of-life for people with an intellectual disability may be of particular interest to health outcomes researchers, as well as its approach in utilising perceived importance scales. The ComQol is available from the author at the Psychology Research Centre, Deakin University Toorak, 336 Glenferrie Road, Malvern Vic 3144, Australia.

Hart PM, Wearing A.J. Problems of stability and change in quality-of-life research: implications for a longitudinal model of personality, health and well-being.

This paper raised the issue as to whether people who experience more satisfying events in their life are happy, or are happy people likely to experience more satisfying events. It is really a question of whether subjective well being is a cause (top down theory) or consequence (bottom up theory) of people's interpretation of their life experiences. This study re-analysed the data of Brief et al.[1] using structural equation modelling and a methodology that enabled separation of true from spurious relationships taking into account the stability of variables over time. The conclusions drawn from these findings run contrary to those in the Brief et al. study and demonstrated that a failure to separate stability and change may lead to erroneous conclusions in quality-of-life research. The authors also suggest that in both the modelling and analysis of longitudinal data it cannot be assumed that the temporal sequence in which variables are measured will provide information about 'true' causal relationships. In order to answer the bottom up/top down question posed it is necessary to formulate models which reflect the complexity of the research question, and in particular, take into account the structure of subjective well-being. *[Author abstract amended]*

1. Brief AP, Butcher AH, George JM, Link KE. Integrating bottom-up and top-down theories of subjective well-being: the case of health. Journal of Personality and Social Psychology 1993; 64: 646–53.

Kolstad A. Quality-of-life: the concept and how to measure it

Professor Kolstad traced the history of the concept of 'quality-of-life' in the disciplines of economics, sociology and psychology and the different measures that have been derived from these perspectives. Despite the burgeoning research literature in this field, little attention has been paid to clarifying the concept itself. Hence it may be more useful to focus on clarifying this concept and its component dimensions rather than on its measurement. Issues were raised concerning cultural and sociodemographic aspects of this concept and whether existing measurement instruments might reflect middle class notions of quality-of-life, and similarly, expectations of treatments.

Kolstad A. & Viken A. Measurement of quality-of-life among people with severe psychiatric illness [Poster]

This paper described an application of quality-of-life measures. Persons living outside psychiatric institutions with severe psychiatric disorders were given structured interviews about their subjective well-being and quality-of-life as well as their living situation including social and economic circumstances. The interview results were analysed both as quantitative and qualitative data. The mean quality-of-life, assessed by two global scales, was low when compared with other groups, however, 40 per cent were 'satisfied' with their life. The social network of this group also contained some peculiarities. A number of methodological issues are raised for discussion. Such work may be of interest to those investigating mental health outcomes. *[Author abstract amended]*

McPheat D. Values, structure and life quality

Based on the work of social philosophers, classical sociologists and empirical research McPheat argues that quality-of-life is a function of values and structure. He suggests that maximisation of material wealth has incorrectly been equated with the maximisation of life quality. Actions based on maximising material wealth as contrasted with actions based on maximising life quality result in quite different social structures. He concludes that maximisation of life quality depends on finding the optimum structural combination which

depends on the prior devaluation of material wealth. *[Author abstract amended]*

Some relevant literature

Critical Public Health 1993 [Special issue on health care outcomes]; 4: no 4.

This special issue on health outcomes offers a number of perspectives on the uses of health outcomes research. The articles cover the following topics: background to the health outcomes movement; an account of the most popular health outcomes measurement instruments in use; the use of outcomes in purchasing; issues relating to health gain, rationing and choices in health care; an application of the SF-36 measure in research with the elderly; an analysis of the barriers to consumer involvement in outcomes management; a discussion of the value of death rate league tables in relation to outcomes management.

Department of Health (NSW). Getting it right: focusing on the outcomes of health service programs. Sydney: Department of Health (NSW), 1994.

The purpose of this booklet, which provides a description and rationale for the NSW Health Outcomes Program, is to:

- encourage people who work in the health system to focus their services and programs on health outcomes—whether they are involved in clinical services, preventive services or public health;
- show how outcomes information can be used in decision-making to get the best possible health results;
- demonstrate the commitment of NSW Health to this approach.

Through the Health Outcomes Program NSW Health aims to inform medical decision-makers, funding providers and consumers. The strategies that will be used in NSW to achieve this include building a health outcomes orientation into the daily life of the health system and building a strong information base. Other initiatives (such as the health outcome councils to be established in all metropolitan and rural districts) are also described.

South Australian Community Health Research Unit. Health outcomes in community health. Bedford Park, SA: South Australian Community Health Research Unit, 1994.

This is a report on the proceedings of the *Health Outcomes* seminar organised by the South Australian Community Health Research Unit. A number of papers were presented with the main papers representing both a bureaucratic perspective and a community health management perspective. The main conclusions that were drawn from the seminar are as follows: community health services must focus on the individual's health and the community's health; community health services are concerned with social, psychological and economic status as well as improving the physical health status of service users; measuring the contribution of community health services to the individual or community (both in terms of illness/health status or in capacity to prevent disease) is difficult; defining outcomes is very much a matter of a person's or group's values and of their position within the health sector.

The report also provides descriptions of current health outcome projects (in Australia and overseas), recent initiatives from within the health outcomes movement and an annotated bibliography of relevant material.

Quality-of-life issues

Guyatt GH, Feeny DH, Patrick DL. Measuring health-related quality-of-life. Annals of Internal Medicine 1993; 118: 622–9.

The article provides an overview of the use of health-related quality-of-life (HRQL) measurement instruments in health care research including clinical trials. While the authors have avoided discussion of any one particular HRQL measure, a range of issues related to the use of HRQL instruments in general is covered. These include issues related to the design, purpose and mode of administration of the instrument. In particular the psychometric properties that are required by good HRQL instruments are described including reliability, validity (especially construct validity), responsiveness and interpretability. Also discussed are the differences between generic and specific HRQL instruments and the use of HRQL instruments in clinical trials as measures of primary and secondary outcomes.

O'Connor R. Issues in the measurement of health-related quality-of-life. [Working paper]. National Centre for Health Program Evaluation, 1993.

This paper reviews the literature and examines the issues in the development of comprehensive, reliable, valid and practical quality-of-life measures. The paper considers definitions, scaling, reliability, validity and specific issues in constructing health-related measures. Four major instruments are examined: the Sickness Impact Profile (SIP), the Quality of Well-Being (QWB) Scale, Torrance's Utility Model, Rosser Classification of Illness State. The author concludes that much more research and development is needed to ensure a generic instrument suitable for general application.

Walker S, Rosser, RM, eds. Quality-of-life assessment: key issues in the 1990s. Lancaster: Kluwer, 1993.

Divided into three major sections this monograph begins with a discussion of key concepts, instruments and issues in relation to quality-of-life assessment. In this section a number of specific quality-of-life measures are described and discussed, of which a smaller selection are also reproduced within the appendix.

These are the Quality of Well-Being Scale, the Nottingham Health Profile, the McMaster Health Index Questionnaire, the Index of Health-Related Quality-of-Life, the 15D Health-Related Quality-of-Life Questionnaire and the EuroQol Valuation Task. This is followed by contributions that describe applications of quality-of-life measures on patients suffering specific diseases or causes of ill health. The final section, 'Viewpoints and perspectives', offers a range of viewpoints from others with an interest in quality-of-life measurement such as the pharmaceutical industry, policy-makers and health care purchasers.

The following series of reviews demonstrates the considerable debate that exists surrounding the use of quality-adjusted-life-years (QALYs), especially in the context of resource allocation.

Schwartz S, Richardson J, Glasziou P. Quality-adjusted-life-years: origins, measurements, applications, objections. Australian Journal of Public Health 1993; 17: 272–8.

'Quality-adjusted-life-years or QALYs are used to combine, in a single measure, information about the quantity and quality of life produced by a health intervention. They have been used as outcome measures in clinical trials and in cost-effectiveness analyses. This paper describes how QALYs are assessed and how they are used. Methodological and theoretical problems are discussed as are ethical objections to the utilitarian ethos underlying their use. It is concluded that QALYs are part of a technology that is still in development but, because of the lack of alternatives, they will certainly continue to be used. It is important to resolve the outstanding methodological issues and reach an ethical consensus to ensure that QALYs truly reflect community goals.' *[Author abstract]*

Burrows K, Brown C. QALYs for resource allocation: probably not and certainly not now. Australian Journal of Public Health 1993; 17: 278–86.

'Quality-adjusted-life-years (QALYs) have the attractive characteristic of combining morbidity and mortality into a single index which purports to measure the outcomes of health interventions. Their primary aim, when combined with cost, is to permit comparisons across candidate spending programs and thereby promote economic efficiency in the use of rationed funds. QALYs, in fact, comprise a family of measures with major differences in approach and many variations in construction, process and methods of measurement. A necessary unifying characteristic is the ethical assumption of utilitarianism. This paper examines the state-of-the-art in the development of QALY measures. It concludes that they fall far short of requirements for their advocated use in resource allocation decisions. Furthermore, their demands on measurement for this purpose are such that it is unlikely that methodological problems can be solved.' *[Author abstract]*

Editor's note: This article is a critique of the article, *Quality-adjusted-life-years: origins, measurements, applications, objections*, reviewed above. Burrows and Brown claim that the paper of Schwartz et al. argues in favour of the use of QALYs in cost-effectiveness analyses as the primary basis for rationing health expenditures. Burrows and Brown do not believe this argument can be sustained for a range of technical, administrative and ethical reasons which they discuss. Utilitarianism in QALYs is questioned as an acceptable value basis and Burrows and Brown state there are more choices in decision-making than QALYs or chaos. They claim that given the opportunity for error during the development and application of instruments the use of QALYs is unlikely to provide a simple solution.

Richardson J, Schwartz S, Glasziou PP. QALYs for resource allocation: a reply to Burrows and Brown [Letter]. Australian Journal of Public Health 1993; 17: 394–6.

As the title suggests this is a reply to the technical criticisms and issues raised by Burrows and Brown in the article *QALYs for resource allocation: probably not and certainly not now* (reviewed above). Richardson et al. do not dispute that QALYs have flaws and agree with many of Burrows' and Brown's criticisms of QALY procedures. However, Richardson et al. state that while it is important to minimise the number and impact of flaws they believe the question that should have been asked is 'Are other methods better than QALYs?'. Richardson et al. claim that Burrows' and Brown's article has misrepresented issues pertaining to QALYs and does not provide a balanced assessment of these issues. QALYs are defended because the measure represents an exchange rate between the quantity and quality of life allowing for comparison between competing options. Disease-specific quality-of-life measures are not an acceptable substitute because most have not been constructed to act as an exchange rate. Richardson et al. conclude that Burrows and Brown should be more forthcoming about how other alternatives (implicitly suggested) deal with the same problems.

The SF–36 and other general health measures

Garratt A, Ruta DA, Abdalla MI, Buckingham JK, Russell IT. The SF–36 health survey questionnaire: an outcome measure suitable for use within the NHS? BMJ 1993; 306: 1440–4.

This article reports a study assessing the validity, reliability and acceptability of the SF–36 instrument as a measure of patient outcome in a sample of 1700 patients aged 16–86 years with one of four conditions: low back pain, menorrhagia, suspected peptic ulcer, varicose veins. A comparison sample of 900 members of the general population was also used. The study found that the SF–36

instrument satisfied rigorous psychometric criteria for validity and internal consistency. The study also found that SF–36 scores were closely related to general practitioners' perceptions of condition severity. Garratt et al. conclude that the study supports the use of the SF–36 instrument as a potential measure of patient outcome within the National Health Survey (NHS). The measure seems acceptable to patients, internally consistent and a valid measure of the health status of a wide range of patients. Garratt et al. caution that the sensitivity of the SF–36 instrument to changes in health status over time should be tested before the measure is widely used. *[Reproduced with minor amendments from the UK Clearing House on Health Outcomes publication Outcomes Briefing, Issue 2, 1993]*

Editor's note: The factor analysis identified five relevant factors, with eigen values ranging from 12.8 to 1.3. The first factor appears to represent physical functioning and the second represents mental health and energy. The first factor would appear to account for a sizeable amount of the variance.

Jenkinson C, Coulter A, Wright L. Short form 36 (SF–36) health survey questionnaire: normative data for adults of working age. BMJ 1993; 306: 1437–40.

This article outlines a study to gain population norms for the SF–36 instrument in a large community sample and to explore the questionnaire's internal consistency and validity. The survey was conducted by post and investigated several items concerned with lifestyles and illness. The survey used 13,042 randomly selected subjects aged 18–64 years in Buckinghamshire, Northamptonshire and Oxfordshire. The findings indicated high internal consistency among different dimensions in the questionnaire and that normative data broken down by age, sex and social class were consistent with those from previous studies. Jenkinson et al. conclude that the SF–36 instrument is a potentially valuable tool in medical research and that the normative data provided may further facilitate validation and use of the SF–36 instrument. *[Amended author abstract reproduced from the UK Clearing House on Health Outcomes publication Outcomes Briefing, Issue 2, 1993]*

Editor's note: The age data is particularly interesting with respect to the scales/dimensions and also with respect to the postulated physical and mental health factors reported above.

McHorney CA, Ware JE, Rogers W, Raczek AE. The MOS 36-Item Short-Form Health Survey (SF–36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. Medical Care 1993; 31: 247–63

'Cross-sectional data from the Medical Outcomes Study (MOS) were analysed to test the validity of the MOS 36-Item Short-Form Health Survey (SF–36) scales as measures of physical and mental health constructs. Results from traditional psychometric and clinical tests of validity were compared. Principal components analysis was used to test for hypothesised physical and mental health dimensions. For purposes of clinical tests of validity, clinical criteria defined mutually exclusive adult patient groups differing in severity of medical and psychiatric conditions. Scales shown in the components analysis to primarily measure physical health (physical functioning and role limitations-physical) best distinguished groups differing in severity of chronic medical condition and had the most pure physical health interpretation. Scales shown to primarily measure mental health (mental health and role limitations-emotional) best distinguished groups differing in the presence and severity of psychiatric disorders and had the most pure mental health interpretation. The social functioning, vitality, and general health perceptions scales measured both physical and mental health components and, thus, had the most complex interpretation. These results are useful in establishing guidelines for the interpretation of each scale and in documenting the size of differences between clinical groups that should be considered very large.' *[Author abstract]*

Editor's note: A principal components analysis indicated that the first principal component accounted for 55 per cent of the total measured variance and correlated highly with all eight scales. Extraction of the second component increased the percentage of total variance explained from 55 per cent to 70 per cent. Rotation of these components confirmed the hypothesized physical and mental dimensions of health. However, one notes the large amount of variance accounted for by the first component with respect to this (eight scale) multidimensional instrument.

McHorney CA, Ware JE, Rogers W, Raczek AE, Lu JFR. The validity and relative precision of MOS short- and long-form health status scales and Dartmouth COOP Charts. Medical Care 1992; 30 (suppl.): MS253–MS265.

This paper summarises comparisons among four health status assessment methods: full length versions of multi-item scales (MOS); short-form multi-item scales (six of eight SF–36 dimensions); single-item global ratings; single-item COOP poster charts. These methods have been used extensively but never compared to one another. The methods were compared to determine their validity in discriminating between groups of adult patients in terms of clinical criteria (severity of chronic medical and psychiatric conditions). Relative precision estimates favoured long-form over short-form multi-item scales, and favoured multi-item scales over global and poster chart measures. Variations in relative precision were linked to differences in coarseness of measurement scales, reliability and content. These variations have implications for the interpretation of scores, the statistical power of comparisons between clinical

groups and the size of confidence intervals around individual scores. *[Amended author abstract]*

Applications and outcomes management

Bartlett J, Cohen J. Building an accountable, improvable delivery system. Administration and Policy in Mental Health 1993; 21: 51–58

'In this article, the authors describe their organisation's use of collecting outcomes data to improve managed mental health and substance abuse treatment. Three conditions that affect improvement are: the process must be ongoing; data generated must be relevant and sound; the process must become a part of an organisation's routine operations.' *[Author abstract]*

Rost K, Smith R, Burnam, MA Burns BJ. Measuring the outcomes of care for mental health problems: The case of depressive disorders. Medical Care 1992; 30 (suppl.): MS266–MS272

'To conduct effectiveness research in mental health, many non-trivial problems need to be addressed. A multidisciplinary expert panel designed an outcomes module for major depression and dysthymia to measure disease-specific outcomes, treatments routinely provided, and patient characteristics that influence treatment or its outcomes. The outcomes module was pilot-tested to evaluate its ability to identify a diagnostically homogeneous group of patients, to establish its reliability and validity, and to assess the feasibility of administering the module in a mental health setting. In a cohort of 40 patients, the module identified all 31 patients who had a research diagnosis of major depression or dysthymia (100 per cent sensitivity), and two of nine patients who did not have this diagnosis (77.8 per cent specificity). The outcomes module measured key constructs accurately enough to discriminate between groups of depressed patients expected to differ, indicating positive construct validity. High rates of instrument completion supported the feasibility of using the module in specialty settings. Extensive efforts locating patients for follow-up will be needed to draw valid conclusions about treatment effectiveness.' *[Author abstract]*

Readers remarks

Professor L Lazarus, remarking upon earlier origins of the outcomes movement, has kindly sent us an article about Ernest Amory Codman who introduced the 'End Result Idea' in 1912. The article *Stealing the golden eggs: Ernest Amory Codman and the science and management of medicine* is by Susan Reverby and was published in the *Bulletin of historical medicine.*[1] The 'End Result Idea' was 'the common-sense notion that every hospital should follow *every* patient it treats long enough to determine whether or not the treatment has been successful and then to inquire, "if not, why not?" with a view to preventing similar failures in future'.[2]

As reported by Reverby the height of Codman's campaign was the unveiling of an eight foot cartoon during a meeting arranged for the discussion of hospital efficiency. 'The cartoon depicted the Black Bay populace as an ostrich, keeping its head in a hill of humbugs, kicking golden appendicitis and other surgical eggs into the waiting arms of the Harvard Medical School faculty who are thus ignoring medical science.'[1] The Editor (*Health Outcomes*) strongly recommends reading this most entertaining and amusing article. Unfortunately as Professor Lazarus indicates, Codman suffered the consequences of being a person well ahead of his time and he was dropped as an instructor at Harvard and forced to resign his medical society position.

Professor Stephen Leeder has also written to remind us of Professor Baume's earlier contributions, those prior to 1991, with reference to the Australian focus on health outcomes. In particular he refers to Peter Baume's role as chair of the Senate Standing Committee on Social Welfare and his document, *Through a glass darkly,*[3] 'which considered very critically indeed, the absence of any formal evaluation, especially that related to outcomes, in the Australian health and welfare system'. *Through a glass darkly* provides an excellent summary of health and welfare evaluation activities prior to 1978. Recently the Editor (*Health Outcomes*) made use of a table from this 1979 document which specified 10 reasons why evaluation activity in Australia was unsatisfactory and noted that while some of these issues had begun to be addressed (e.g. a lack of national goals) it was interesting to contemplate which of these reasons may still be providing constraints on health (and welfare) evaluation activity. Recently the editor had the pleasure of meeting Professor Baume in Sydney and the professor has agreed to share his more recent thoughts on health outcomes in the next edition of the bulletin.

The Editor (*Health Outcomes*) would like to thank all readers that sent letters containing many useful tips and suggestions. The Editor (*Health Outcomes*) would also like to thank Dr Bill Buckingham and Steve Jones for the contribution of various articles.

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