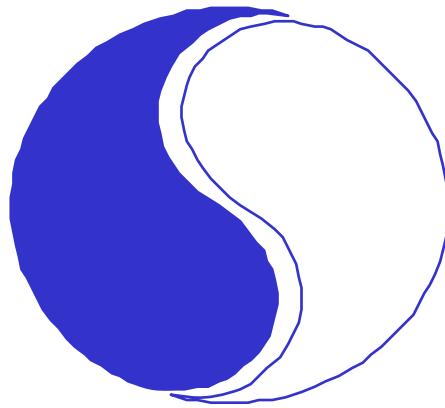


An Overview of the Health Outcomes Approach: An Australian Perspective



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Health Outcomes: A Framework

Health systems and hospitals in Australia and overseas have traditionally evaluated their activities on inputs and outputs and continue to do so. Casemix funding, for example, has largely focused on the efficiency of service throughputs, not the effectiveness of interventions. It is only relatively recently that health system evaluation has also focussed on evaluating processes and now, outcomes. While we are benchmarking hospital services with regard to cost, we may also wish to increasingly benchmark these services with regard to indicators of quality, and to undertake these activities in an integrated way. The assessment of quality and health outcome must become an integral feature of the model of care.

The health outcomes focus is about health system reform and a cultural change within the health system. It is concerned with the need to know which health interventions work, as against those that produce little or no health benefit, and to know which treatment alternatives for a condition are the most cost effective in producing health gains. This focus needs to be incorporated at all levels of program management; at health system, service and at clinical practice levels. It should also be noted that the 'outcomes' focus has spread to related sectors such as community services and allied health and thus one could increasingly speak of a health and community care outcomes focus. An integrated health system would require continuity of care to be provided across these sectors. Recent government initiatives such as the Sharing Health Care projects and the second round of the co-ordinated care trials emphasize the need for continuity of care to be provided across sectors.

Assessing the relative effectiveness of alternative interventions for the same condition is extremely important when considering the allocation and distribution of health resources throughout Australia at the system or the service level. Similarly it is important to ascertain, in hospital systems, whether efficiency drives to reduce the length of stay are at the cost of quality or the longer term health outcomes of the patient.

The Outcomes Context

As elsewhere, the Australian focus on health outcomes has derived from a number of interrelated factors. These factors are as follows:

1. The increasing proportion of expenditures going to health care and/or the need for cost containment.

Cost containment has been more of a problem in the US than Australia, where health expenditure as a proportion of the economy has remained relatively stable in recent years. It was about 8.4% of GDP (AIHW, 1994; Ross et al., 1999) in the nineties and recently was estimated to be about 9.5% of GDP (DFAT, 2006). Cost containment, however, will always be a necessity particularly given the ageing of the Australian population. There is also a desire by health systems to allocate funds so that health gain for the community may be maximised. In order to do that, one needs health outcome information concerning the relative effectiveness and costs of various health interventions.

Also, in those health systems where there has been a split in funding between purchasers and providers (UK, NZ) there has been an increasing interest in outcomes of health services, in order to advise purchasing choices and to justify service provision.

There are also large unexplained differences in health expenditure by region without any observable differences in health outcomes. For example in Australia, the Hospital Utilisation and Costs Study (AHMAC, 1996) recorded more than two-fold variations in cost per bed-day for hospitals of similar size and apparently similar case loads.

2. The recognition of the serious limitations of available information about the effects of many services and treatments.

There are claims that approximately 80% of commonly used medical interventions have never been demonstrated in control trials to provide benefits to patients (Kingman, 1994), and even fewer have been shown to be effective in routine practice.

As indicated by Harvey (1995) the usefulness of randomised control trials as the 'gold standard' for medical practice has been questioned by Bunker (1988) and others. The criticism was two-fold: firstly, few treatments were evaluated because of the costs of the method and secondly, the populations on which they were conducted were almost always different to the groups for whom the treatments were intended, and there was generally little evaluation of how well treatments worked in routine practice.

There has also been increasing recognition that best practice 'consensus' statements may be a weak foundation on which to base practice (Reinhardt, 1990). Guidelines for the Development and Implementation of Clinical Practice Guidelines (1995) by the NHMRC Quality of Care and Health Outcomes Committee, differentiate between evidence-based and consensus-based guidelines as well as identifying the need for guidelines to indicate areas where no consensus may be reached. Both the revision of *A Guide to the Development, Implementation and Evaluation of Clinical Practice Guidelines* (NHMRC 1999) and the *Health and Medical Research Strategic Review* (1999) suggest an increased emphasis on guideline implementation and dissemination and on applied health research that will assist in transferring research knowledge into practice.

3. The perception of large hospital variations in the use of medical procedures between geographical areas and between physicians.

Examples would include the inability to explain the observed variations in surgery rates, hospital admissions and diagnostic interventions, (Wennberg, 1987) and documented levels of inappropriate interventions for major types of surgery (Leape, 1989). In NSW it has been noted there are variations in the frequency of common surgical procedures across hospitals, which also require some explanation (NSW Health Department, 1994). There have also been concerns expressed concerning surgical rates for mastectomy (as contrasted with the preferred procedure of lumpectomy relative to stage) as these rates are apparently much higher in rural than in urban regions (Craft et al., 1996). Similarly large differences in hysterectomy rates have been recorded across the States and Territories (Mishra, 1997) and between rural and urban areas (Reid et al., 1999). In the USA it has been estimated that only a third of operations for endarterectomy, a half of coronary artery by-pass grafts and two fifths of pacemaker implantations are carried out on patients likely to benefit from the procedure (Enthoven 1990, as cited in Bowling, 1995).

4. Concerns as to whether new technologies are actually improving patients' well-being.

The use of less invasive laser surgical techniques for some conditions may lower the threshold at which the surgeon decides to undertake surgery, leading to an increase in the number of surgical procedures. There has also been an associated increase in surgical complication rates for some conditions (Hirsch et al., 1994). Another example may be the earlier debate over whether medical rebates should apply to expensive technologies such as medical resonance imaging – whether these could be justified in terms of the technology's contribution to the health outcomes of patients when more widely available and less sophisticated technologies may achieve similar outcomes for less cost. A similar topical issue is the same debate concerning medical rebates for PET and scans for particular diagnostic conditions.

5. Concerns about the quality of care.

As Harvey (1994) indicates, the quality of care provided has been called into question. Brennan (1991) found that 3.7% of patients hospitalised in New York State experienced adverse events due to medical care, over half of which were avoidable and over a quarter were due to negligence. In Australia, McLaws (1988 a, b) found that in 1988, hospital acquired infections would have added \$180 million to hospital costs and that 'clean wound' infection rates associated with surgery would have cost \$60 million: in both cases significant reductions were possible. The Australian Hospital Care Study reported similar findings with respect to potentially avoidable death and disability (AHMAC, 1996). Issues concerning safety and quality in Australian health care are becoming of increasing importance to Australian health departments as a number of recent reports suggest (Australian Council for Safety and Quality, 2000).

6. The increasing empowerment of consumers/patients.

Harvey (1995) also notes there has been a rise in 'consumerism' amongst patients in the USA and Australia. One of the manifestations has been the rapid growth in medical malpractice suits/settlements in both countries, and the assertion of patients' preferences for mode of treatment, initially in areas such as child birth.

Research into patient assessment of outcomes of care has found significant differences between patient and clinician assessment of outcomes (Wennberg, 1990) - contributing to a decline in the notion that 'the doctor knows best'.

Entwistle (1995) from the NHS Centre for Reviews and Dissemination, University of York, also refers to the necessity of honesty concerning areas of certainty and uncertainty when communicating with the public on the effectiveness of health interventions. Many of these issues are concerned with the questioning of the scientific basis of medicine and in association with this, a questioning of the "medical model" of health care. In our current models of care, we can no longer assume that doctor knows best; it needs to be demonstrated that the health intervention does actually produce health benefit. This means that outcome measurement and monitoring should become a routine part of quality assurance activities and be integrated within the model of health care.

The increasing emphasis placed on consumer issues and consumer participation in health service management and evaluation can also be evidenced by the number of recent publications addressing consumer issues listed on the Commonwealth Department of Health and Ageing web site at www.health.gov.au

Definitions

Before the measurement of health outcomes commences, it is always useful to check on definitions. In Australia the operational definition is known as the 'Sunshine Statement' which defines a health outcome as:

'A change in the health of an individual, or a group of people or population, which is wholly or partially attributable to an intervention or series of interventions.' (AHMAC February 1993, Modified NHIMG 1996.)

Given the key notion of attribution in this definition it might have implied to some that the only level of evidence one might consider is that provided by a randomised control trial. Clearly there are different levels of research evidence that may be useful in examining health outcomes, particularly in routine health care settings. Randomised controlled trials are not the only form of research design one might wish to use, even if this were always possible (for example it is not ethical to withhold treatment in certain circumstances). In some situations, particularly when gaining information on the performance of health services (rather than the change in health status of individuals which can be aggregated), the term health outcome-related performance indicators (or process and quality indicators) has been used. The following definition has been proposed by Bruce Armstrong:

'An outcome-related performance indicator in the health and welfare field is a statistic or other unit of information which reflects, directly or indirectly, the performance of a health and welfare intervention, facility, service or system in maintaining or increasing the well being of its target population.' (Armstrong 1994.)

It is also useful to differentiate between those health interventions that have a direct effect on a health outcome (for example, the repair of a broken leg) as against those that may alter risk factors (for example, smoking rates). These may have a longer term effect on health outcomes and are sometimes referred to as 'intermediate outcomes'. These in turn can be differentiated from health outcome-related performance indicators (for example, rate of avoidable adverse events, hospital acquired infection rates, time to treatment rates, return to theatre rates, readmission rates etc.).

Outcome-related performance indicators often measure aspects of process (e.g. practice variations). Some process indicators, however, such as some hospital quality indicators (e.g. unplanned readmissions) may not always be effective indicators of outcome, since these may be influenced or confounded by other factors (e.g. hospital policies on initial length of stay, bed availability, etc.). In the literature, outcome-related performance indicators are also referred to by a range of other names (e.g. process outcomes, quality indicators).

Health Status Monitoring and Health Outcomes

Health outcomes should be differentiated from the related area of population health status monitoring - which is concerned with the provision of statistics about the health status of Australians over time but which is not directly concerned with the issue of attribution *per se*.

An example is the death rate for coronary heart disease from 1983-1993. There has been a major reduction in the death rate for males (Abrahams et al., 1995), but it is unsure as to what factors are responsible for this trend. It is quite possible that this is strongly associated with the decline in major risk factor determinants of health such as smoking rates. Some of this 'health gain', however, could also be due to lower fat diets, reduced serum cholesterol, and males taking more exercise in recent times. Without sophisticated causal modelling, or the evaluation of strategies used to modify such risk factors,

the relative contribution of our health interventions to such health gains remains unknown. Changes in population health status over time, are not examples of health outcomes research unless we can make some level of attribution to an intervention, or interventions that may have been responsible for this change.

System wide approaches to health information such as the National Health Indicators Performance Framework (NHPC, 2000) include health status measures, health outcome measures, measures of health determinants and health outcomes related performance indicators within the framework, as clearly all such sources of information will be required to reflect on both population health and health system performance. However, when examining such 'system' frameworks it still remains important to distinguish between the different types of information each of these indicators can provide – some measures and indicators will be related to outcome while others will not. Many of these indicators at the national level will be population health status measures.

Where interventions have resulted in modifications to behavioural risk factors it is usually referred to as an intermediate outcome (e.g. reduction in smoking incidence and prevalence), as it will be some time before such population risk factor changes will result in reduced mortality or morbidity for particular diseases or conditions.

The Health Evaluation Cycle

Much of the confusion concerning health outcomes arises because this term is not placed in its evaluation context. Formative and summative evaluation and review mechanisms may be embedded within each phase of the evaluation cycle. It is important to continue to undertake evaluation activities at all phases of this cycle. The health outcomes focus is about including the evaluation of outcome in our evaluation activities, as for too long this has been ignored. Just as inputs, processes and outputs can be examined at the system, service and practitioner levels - so may outcomes. The different indicators and measures currently utilised for health evaluation are placed within this framework so that outcomes are seen as one part of the evaluation cycle with ultimately outcomes, in turn, leading to inputs. Ultimately reliable outcomes information should be informing resource allocation (inputs) so that we allocate our resources where they will produce the most health gain for the community.

The current challenge, however, is to develop valid, reliable and responsive health and welfare outcome measures and outcome related indicators, and to endeavour to get some uniformity in the use of measures at system and service levels to allow for comparability of results.

Donabedian (1980, 1992) did not see much merit in debates of 'process versus outcomes' but saw them as necessary and related links in the chain. It is important to improve processes and to set standards and benchmarks by gaining evidence and/or consensus about best practice, but, this is not enough as outcome evaluation will also be required.

Outcomes

It can be seen that it is possible to have performance measures at various stages in the evaluation cycle (e.g. input, process and output indicators) but these should not be confused with measures of the ultimate outcome, which is a change in health status that can be attributed to an intervention. Where research is unclear or unavailable with respect to attribution, some outcome-related performance indicators may reflect upon, predict or be associated with outcome. It is desirable to measure outcomes/outcome-related performance indicators with respect to all phases of the treatment and service cycle from primary prevention through screening, diagnosis, treatment, rehabilitation, palliative care to community service use.

Health Outcomes and Guidelines, Benchmarking, Quality Improvement and the Continuum of Care

As the purpose of health outcomes measurement is to ensure better health outcomes for our patients it is important to ensure health outcomes measurement activities are integrated with our quality improvement processes.

In the United States, Batalden et al. (1994) have noted that outcomes measurement, process improvement and continual quality improvement all have been used to improve quality in health care, but note that these complementary approaches have been used primarily in isolation from each other. They suggest the use of a 'Serial V' approach as an integrative strategy to incorporate these approaches to create a comprehensive way to evaluate, institute and reflect on change aimed at improvement within

the hospital sector. Such an approach integrates continuous measurement of outcomes, satisfaction and cost assessment throughout the clinical path of care.

Similar approaches have also been expanded to cover treatment across the continuum of care, as has been exemplified by the natural history of disease approach. A promising approach that was developed in NSW examined a framework for the natural history of the disease or condition (e.g. the diabetes prototype) and identified interventions and their processes and outcomes at each stage of care from primary prevention through to palliative care (NSW Health, 1994).

There is a need to identify outcomes indicators across the continuum of care and not to focus only on outcomes of acute care in isolation. It is for this reason that models of care that focus on co-ordination of care and shared care are becoming increasingly popular and of interest to funders, as is indicated by the national co-ordinated care trials and the establishment of a range of chronic disease self management projects.

For example, an earlier 'in house' study indicated that there was considerable time lag (an average of eight years) between patients' presentation to hospital based rehabilitation programs and their presentation to tertiary rehabilitation services. In the intervening years these patients had often been unemployed or had become increasingly unemployable, and experienced less than optimum health outcomes, due to a lack of appropriate links between secondary and tertiary rehabilitation services.

Asthma is another example where effective links between acute and ambulatory care can assist in reducing the number of avoidable admissions to hospital (which is both in the interests of the individual and the community). This is an example where a health outcomes focus can lead to cost savings and greater efficiency as well as effectiveness.

A major study in the ACT by Shadbolt et al. (1996, 1997) tracked a large sample of patients from admission through discharge to six months post discharge in the community. This study examined both service utilisation and the health related quality of life outcomes of approximately 6000 patients. Assessing the health outcomes of health interventions will often necessitate tracking patients post discharge from hospital, which will increasingly require co-ordination between community and acute services, common data definitions and compatible information systems.

Similarly, there is a growing emphasis on the implementation of evidence based best practice guidelines to improve practice (NHMRC, 1999). As Harvey (1995) indicates, the Guidelines for the Development of Guidelines (NHMRC, 1995) document also recommends that known adverse outcomes from treatments should be documented and should be incorporated into specific quality assurance processes by hospitals, colleges and others who certify and re-certify health professionals. It recognises that unless guidelines are used, and the results of their application are collected and reviewed, practice will not improve.

The uptake of guidelines will often be influenced by both their credibility (commercial or government sponsored) and whether key stakeholders have been involved in their development. In the USA the implementation of guidelines was found to be much better for asthma specialists than for general practitioners, as the latter had been excluded from the development process and thus found some aspects of the guidelines impractical for local implementation. Similarly as Ken Harvey (2003) suggests some of the recent increase in pharmaceutical expenditure in Australia may partly be due to inappropriate prescribing patterns and again there is a need for GPs to become involved in guideline development and implementation through initiatives such as the Quality Use of Medicines (QUM). It is also important that up to date guidelines for prescribing are integrated within prescribing software systems.

Implementation is also influenced by accessibility. In 1997 the US Agency for Healthcare Research and Quality established the National Guidelines Clearinghouse. This clearinghouse serves as an international electronic repository of clinical guidelines, although most guidelines currently included have been developed in the United States. The mission of the National Guidelines Clearinghouse is to provide physicians and other health care professionals, health care providers, health plans, integrated delivery systems, purchasers and others an accessible mechanism for obtaining objective, detailed information on clinical practice guidelines and to further their dissemination, implementation and use (Slutsky, 1998). The Clearinghouse provides structured abstracts, tabular comparisons of abstracts, syntheses of clinical guidelines on similar topics, full text of guidelines or ordering information, electronic discussion groups and annotated bibliographies. To satisfy inclusion criteria all guidelines must meet the Institute of Medicine definition of a clinical practice guideline (Field & Lohr, 1992), show proof of a substantial literature search and a review of the current scientific evidence and have been developed or revised in the last five years. As long as guidelines meet the evaluation criteria they are placed on the site; no

other formal endorsement procedure exists for those guidelines. The Guidelines Clearinghouse can be found on the internet at www.guidelines.gov.

There was some earlier interest in the development of an Australian Clinical Guidelines repository to work in collaboration with the National Guidelines Clearinghouse (Harvey & Sansoni, 1997; Sansoni, 1999). The NHMRC web site provides access to a range of guideline documents developed in association with the NHMRC in Australia, and the NSW Health Department web site (CIAP) also contains guideline information.

The monitoring of practice variations in relation to guidelines can be viewed as outcome related clinical benchmarking. For example, as mentioned earlier there is a higher rate of mastectomy for earlier stages of cancer in the rural as opposed to the urban areas of Australia, when lumpectomy should be the preferred procedure (Craft et al., 1996). The colleges may wish to address such issues through the monitoring of practice and then provide educational programs to ensure greater compliance with the guidelines. The Australian Rehabilitation Outcome Centre has been established to undertake outcome benchmarking activities in this sector (Marosszeky & Eagar, 2001) and the Australian Mental Health Outcomes and Casemix Network is fulfilling a similar role for the mental health sector.

Although the best practice guidelines under development are insisting upon the adequate provision of information to patients to inform their choice of treatment alternatives, practitioners and health professionals often state that many patients neither want this information nor desire to make the choice about treatment alternatives. It is claimed that patients rarely have the required medical knowledge to evaluate the information they may be given. One of the choices that a patient can make, however, is to be guided by their practitioner's view. This choice should be overt and clear, and for those patients wanting further information it is necessary that this is provided in a way that can be understood.

Dr Vikki Entwistle (NHS Centre for Reviews and Dissemination, University of York) has been involved in trials concerning the evaluation and development of information provided to consumers in the UK. Entwistle (1995), as indicated earlier, stressed the need to involve consumers in making choices and to be honest concerning the areas of certainty and uncertainty concerning interventions, whereas frequently health professionals want control over what information is given to the consumer. For example, if information concerning the pros and cons of various treatments for glue ear is given to patients/carers then it may be that surgical rates will decline which may then make surgeons somewhat unwilling to distribute this information.

To incorporate a health outcomes focus in quality improvement activities the following will be required in Australian hospitals and health services:

- a client centred consumer focus;
- staff training in health service evaluation;
- good information technology systems and common data definitions;
- a commitment to patient-based assessment of health outcome, e.g. health related quality of life and satisfaction rather than just survival;
- a commitment to undertaking some patient follow-up post discharge;
- greater continuity and co-ordination of care across the continuum of care (e.g. across the primary, acute care, rehabilitation and palliative care settings);
- a commitment to evidence based practice and to change practice when there is evidence that an alternative treatment/intervention produces greater health benefits; and
- a preparedness to assess the relative cost effectiveness of new technologies compared with other methods rather than to adopt such technologies because they are the latest thing.

Some System Initiatives

The National Health Performance Committee has recently published the National Health Performance Framework Report (NHPC, 2001), which has been derived from the Canadian Health Information Roadmap Initiative Indicators Framework (CIHI, 2000). The stated goals of this report are to promote benchmarking based on national health performance indicators; to improve the quality of care of health services; and to extend the national performance indicators framework to include such areas as community health, general practice and public health. The framework is presented below. The framework proposes a range of indicators in such areas as health status and health outcomes, health determinants and system performance indicators – but only some of these indicators will be outcome related.

National Health Performance Framework

Health Status and Outcomes				
<i>How healthy are Australians? Is it the same for everyone? Where is the most opportunity for improvement?</i>				
<i>Health Conditions</i>	<i>Human Function</i>	<i>Life Expectancy and Wellbeing</i>	<i>Deaths</i>	
<i>Prevalence of disease, disorder, injury or trauma or other health-related states.</i>	<i>Alterations to body, structure or function (impairment), activities (activity limitation) and participation (restrictions in participation).</i>	<i>Broad measures of physical, mental, and social wellbeing of individuals and other derived indicators such as Disability Adjusted Life Expectancy (DALE).</i>	<i>Age and/or condition specific mortality rates.</i>	
Determinants of Health				
<i>Are the factors determining health changing for the better? Is it the same for everyone? Where and for whom are they changing?</i>				
<i>Environmental Factors</i>	<i>Socioeconomic Factors</i>	<i>Community Capacity</i>	<i>Health Behaviours</i>	<i>Person-related Factors</i>
<i>Physical, chemical and biological factors such as air, water, food and soil quality resulting from chemical pollution and waste disposal.</i>	<i>Socioeconomic factors such as education, employment, per capita expenditure on health, and average weekly earnings.</i>	<i>Characteristics of communities and families such as population density, age distribution, health literacy, housing, community support services and transport.</i>	<i>Attitudes, beliefs knowledge and behaviours e.g. patterns of eating, physical activity, excess alcohol consumption and smoking.</i>	<i>Genetic related susceptibility to disease and other factors such as blood pressure, cholesterol levels and body weight.</i>
Health System Performance				
<i>How well is the health system performing in delivering quality health actions to improve the health of all Australians? Is it the same for everyone?</i>				
<i>Effective</i>		<i>Appropriate</i>		<i>Efficient</i>
<i>Care, intervention or action achieves desired outcome.</i>		<i>Care/intervention/action provided is relevant to the client's needs and based on established standards.</i>		<i>Achieving desired results with most cost effective use of resources.</i>
<i>Responsive</i>		<i>Accessible</i>		<i>Safe</i>
<i>Service provides respect for persons and is client orientated and includes respect for dignity, confidentiality, participation in choices, promptness, quality of amenities, access to social support networks, and choice of provider.</i>		<i>Ability of people to obtain health care at the right place and right time irrespective of income, physical location and cultural background.</i>		<i>The avoidance or reduction to acceptable limits of actual or potential harm from health care management or the environment in which health care is delivered.</i>
<i>Continuous</i>		<i>Capable</i>		<i>Sustainable</i>
<i>Ability to provide uninterrupted, coordinated care or service across programs, practitioners, organisations and levels over time.</i>		<i>An individual's or service's capacity to provide a health service based on skills and knowledge.</i>		<i>System or organisation's capacity to provide infrastructure such as workforce, facilities and equipment, and be innovative and respond to emerging needs (research, monitoring).</i>

National Health Performance Framework Report (NHPC 2001) *[Derived from Canadian Institute for Health Information (CIHI) and Statistics Canada, Canadian Health Information Roadmap Initiative Indicators framework 2000 (www.cihi.ca)]*

As indicated earlier, many of the higher level indicators will be population health status measures for the purposes of benchmarking performance between the States and Territories. While it may be interesting to know whether the death rate for a particular condition varies across States it is important to undertake outcomes research to determine the factors that are associated or may cause this difference before improvements to quality of care can be undertaken. Apparently the ACT had a higher death rate for breast cancer than other States (AIHW, 2001). This may, however, be quite unrelated to the quality of care provided in the ACT but could possibly reflect socio-economic differences in the population mix or be associated with such factors as older maternal age. Thus follow up outcomes research will be required to elucidate the reason for such variations in these benchmarking activities.

Many of health system performance indicators relate to structure, process, and output/throughput variables, and only some aspects within each cell may be related to outcome. Clearly 'effectiveness' of interventions is primarily outcome focussed, whereas many of the 'efficiency' indicators will be output focussed. Many of the State health systems are now mapping their data collections and indicators to the cells in the framework - which is a challenging task. While there is general acceptance that health determinants influence health status and health outcomes, the causal pathways are not always clear. Further work is also required to develop appropriate indicators in such areas as community capacity and health inequalities.

SECTION 2: HOW DO WE MEASURE OUTCOMES?

Typology of Outcomes Measures and Instruments

Mortality and period of survival are commonly used population health outcome indicators but they are not particularly responsive to the change in delivery of health care, as for many conditions it may take some years for the reduction in mortality, or increase in years of survival, to become apparent. More recently there has been greater interest in the quality of life following a health intervention. One may be cured of a disease, but have residual disabilities and handicaps, and these incur costs to the individual and society. There are a range of instruments and measures that are used to assess such factors.

Various Australian population surveys have included items on morbidity and changes in behaviour related to risk factors (e.g. incidence, prevalence and levels of smoking and drinking behaviours, dietary factors). Presumably one might also expect that with improved co-ordination of care, there may be changes in such risk factors. Similarly, a reduction in infectious disease notifications and an increase in immunisation rates might be a product of better co-ordinated care. Stage of disease at diagnosis could also be a measure of earlier intervention associated with improved co-ordination, as could the reduction in later stage complication rates for some diseases (e.g. limb amputation for diabetes).

Health outcome related process style indicators that may be of relevance might include hospital acquired infections, admissions and readmissions to hospital or health services.

There are also well-being outcomes other than health that one may wish to consider, for example well-being indicators such as housing, employment, service utilisation and access, satisfaction with co-ordination of services and degree of participation by the community.

TYPOLOGY OF HEALTH AND ASSOCIATED OUTCOME MEASURES

Quantity of Life Mortality	Process Based Outcome Measures	Quality of Life Health related quality of life Dimensions of health			Satisfaction with Health Care - Patient satisfaction surveys
		Physical	Social	Mental	
Avoidable premature mortality	Re-admission rates Relapses Complications	Measures of impairment Disease specific measures Pain scales Measures of functional status Measures of handicap	Measures of social support Measures of disability	Measures of depression Measures of social adjustment	
Multi-dimensional health status profiles and indexes cover many of these dimensions in a single instrument					

Figure 1: Aspects of Health and Associated Measures (This diagram appeared in the article "Issues in Outcome Measurement" in *Outcomes Briefing*, UK Clearing House for Information on the Assessment of Health Outcomes, Nuffield Institute for Health, Introductory Issue, Spring 1993, p. 11)

Health, Health-related Quality of Life, Quality of Life and Well-being

Historically, health has usually been referred to negatively as the absence of death, disease and illness. The World Health Organisation (WHO) has recommended the development of measures of positive health and defined health as:

'a state of complete physical, mental and social well-being, and not merely the absence of disease or injury' (WHO, 1981).

Although this definition is somewhat broad and idealistic, and has been criticised because of the difficulty of defining and measuring 'total' well-being, it has also focussed attention on a more positive concept of health. In order to conceptualise and measure positive health, researchers have developed multi- dimensional models of health, involving more than one health concept or 'dimension' (Kaplan et al. 1976; Rosser, 1988; Ware & Sherbourne, 1992). Health concepts most frequently included in such models are:

- morbidity (disease or impairment);
- limitations to functional abilities (disability);
- role limitations because of health problems (handicap);
- bodily pain;
- mental health (psychological distress and psychological well-being);
- vitality (energy/fatigue); and
- general perception of health (eg. excellent/good/fair/poor).

Although some of these concepts relate to personal, economic and social well-being, broader concepts of well-being have not usually been included in such multi-dimensional models of health or the instruments developed to measure them. Such concepts are dimensions of another imprecisely defined term 'quality of life' (Harvey, 1991; Kolstad, 1994). Quality of life is generally understood as a broader concept than health, but the concept means different things to different people, reflecting differences in experience, perceptions and values. It is equivalent to the term total well-being and may include:

- health;
- social well-being;

- economic well-being;
- environmental well-being (sustainability);
- life satisfaction;
- spiritual or existential well-being; and
- other characteristics valued by humans.

These dimensions overlap with each other, therefore in measuring life satisfaction one may also measure aspects of health and social well-being, and in measuring social well-being there are large overlaps with health and economic well-being.

It has become common to equate non-clinical dimensions of health (such as disability, handicap, psychological well-being, general perception of health) with 'quality of life'. This is likely to be a source of conceptual confusion (Bowling, 1991; Harvey, 1991), and it is recommended that, if the term must be used in relation to aspects of well-being that relate to health, then the terms 'health related quality of life' or 'health status' be preferred. There is an increasing trend to also refer to instruments that measures such aspects as 'patient reported outcomes measures' or 'patient reported health outcomes measures'.

Well-being or Health-related Quality of Life?

For practical reasons, instruments of perceived health status or health-related quality of life usually measure the domains of health mentioned above. Instruments that focus on quality of life more broadly, such as those developed by Becker (1993) and Cummins (1993), include a greater coverage of the social, economic and employment domains of well-being, but they usually do so at the cost of having a less extensive coverage of the health domain. Focussing on the health aspect of total well-being, however, should not mean the other aspects of total well-being are ignored. Clearly an impact of a disability may be to reduce one's material well-being, which may in turn have a profound effect on quality of life. Having reduced material circumstances (e.g. loss of employment) can clearly affect one's health either directly, or indirectly through lesser access to treatment (equity issues). Many of these welfare outcomes may be particularly important with reference to conditions resulting in long term residual disabilities.

One of the first decisions that needs to be made when endeavouring to measure quality of life outcomes for particular conditions is whether to focus on a broad measure of quality of life, or a measure of health-related quality of life. A broader measure may tap some aspects of health and welfare outcomes for health conditions and these may be of particular significance for some conditions, or may be particularly related to the questions of the study.

Generally researchers choose to measure health-related quality of life, as invariably the choice of instruments involves a trade off between depth, breadth and utility. As mentioned earlier, instruments addressing quality of life more broadly usually have very few items addressing health, which is obviously limiting when evaluating medical/health interventions.

Physical	Impairment	Disease, Symptom	Single Dimension
Mental	Disability	Condition Specific	Multiple Measures
Social	Handicap	Generic Measure	Profiles/Indexes

Figure 2: Some different dimensions relating to the focus and type of health-related quality of life measures

The next question to decide is whether to use a 'generic' measure of perceived health status/health-related quality of life, or a disease specific measure.

Health Status/Health-related Quality of Life Measures

Health-related quality of life measures are classified as either **generic**, namely a common measure that can be used for comparisons across conditions, such as the multi-dimensional profiles and indices (e.g.

SF-36, Nottingham Health Profile, Sickness Impact Profile, Quality of Well-Being Scale, AQOL, EQ-5D).

Alternatively, measures can be **disease or condition specific** quality of life measures which focus on particular aspects of health (e.g. symptoms) and health-related quality of life that are relevant to each health condition. Examples of the latter instruments include the Arthritis Impact Measurement Scale (Meenan et al., 1980), Living with Asthma Questionnaire (Hyland, 1991), the Functional Living Index for Cancer (Schipper et al., 1984), and may include symptom checklists such as the Rotterdam Symptom Checklist (de Haes et al., 1990). McDowell (2006) provides reviews of many of these instruments.

Disease Specific Measures

Measures can be disease specific – for example those developed for diabetes or asthma. These types of measures are useful for more detailed measurement of symptoms and the impact of symptoms for particular health conditions, but have the obvious limitation that comparisons cannot be made across health conditions. Disease specific measures can include clinical indicators and physiological measures such as blood pressure or serum cholesterol, but they can also include symptom checklists and ‘Type’ indicators. Some of these instruments exemplify the trend for disease specific measures to try to cover as many dimensions of health as general health profiles, as well as including condition specific items or symptom checklists. Increasingly such instruments may be displaced by modular packages combining a general health profile with a complimentary disease/condition specific element. The Health Outcomes Institute in the US (Radosevich & Husnik, 1995) markets and evaluates such TYPE modules which contain sets of condition or disease specific clinical indicators, a generic health related quality of life instrument (HSQ 2.0 – many common items to SF-36) and a core set of other relevant indicators (demographics, co-morbidities etc). Clearly there are a range of condition specific clinical outcome indicators that need to be assessed along with aspects of perceived health status, but to incorporate these elements in the one instrument may lead to other psychometric inadequacies, (e.g. inadequate item representation on generic domains) and prohibit comparisons across conditions.

Condition Specific Measures

These might include a range of functional status or disability measures used to assess the health of a particular population group such as the elderly or those with mental health problems. Some brief mental health measures such as the Kessler 10 have also been used in population mental health surveys (Kessler, 1997; ABS 1997). Condition specific measures do not focus on a particular disease but to a health condition or state. For example, a recent Australian project (Thomas et al., 2006) has been undertaken to develop an outcomes measurement suite for incontinence conditions.

Mental Health:

The HoNOS scales for assessing the mental health status of individuals could be considered a condition specific rating scale in that it may be used for a variety of mental health conditions; however it is not specific to *particular* disorders such as schizophrenia, depression or anxiety disorder. In fact it is a 'in between' measure, in the sense that it is a generic instrument for a variety of mental health conditions but would not be used for non-mental health conditions. The HoNOS has 12 scales; aggressive or disruptive behaviour, suicidal thoughts & self injurious behaviour, alcohol or drug use, memory, orientation & understanding, physical disorders, mood disturbance, hallucinations & delusions, other mental or behavioural problems, social relationships and social environment (Wing et al., 1994).

The HoNOS is a clinical rating scale rather than a self report inventory and will require reasonable knowledge of the patient and training in the use of the scale before the rating can be made. Whilst generally there is a preference for self report inventories rather than doctor or carer ratings (when self report and carer ratings are compared they often differ significantly), clearly if the patient is in an acute episode, with some concerns as to the accuracy of their own assessment, rating scales can be a good alternative. There are a number of Australian studies that have used this instrument (Clarke, 1996; Boot, 1996; Stedman et al., 1997; Brook, 1999) and it has also been used in mental health case classification systems (Eagar, 1996) and for the routine monitoring of mental health inpatients through the Australian Mental Health Outcomes and Casemix Collection Network (AMHOCCN). There were some indications and concerns that this instrument may not be particularly responsive to change and thus have limitations as an outcomes measure (Hooke, 1998; Brook, 1999; Bebbington et al., 1999)

although more recent findings appear to have overcome some of these concerns (Sansoni and Tilley, 2005). However, many practitioners have informally expressed that they find this instrument useful and useable particularly as an assessment device (Stedman et al., 1997).

The HoNOS is now a mandated measure for mental health in-patient services. This has enabled the benchmarking of treatment outcomes across mental health services. This enables services not only to routinely monitor the outcomes of their patients but also allows them to compare the patient outcomes from their service with similar services and thus can provide very useful feedback to assist quality improvement. However, to compare services it is necessary to standardize outcome results to take into account the mix of patients/consumers –for example some services may have patients with more severe problems than other services. Thus services are compared in relation to Casemix Adjusted Relative Mean Improvement Scores.

As part of the AMHOCCN initiatives a consumer self-report measure is also completed. The recommended measures were the Mental Health Inventory, the Basis -32 and the Kessler -10. Again these measures could be classed as condition specific measures for mental health. Each State has chosen a self report measures to be completed by their inpatient and ambulatory mental health services. Including both clinical ratings, self report measures and other clinical indicators allows a triangulation of perspectives on patient outcomes.

Functional Limitations and Activities of Daily Living

There are a number of instruments that are used to assess activities of daily living (e.g. self care tasks such as bathing, dressing, toileting, grooming, feeding etc) and instrumental activities of daily living (e.g. shopping, transport and housekeeping). Many of these instruments are used to assess the maintenance/improvement/deterioration of such skills in the elderly or for those with chronic conditions or undergoing rehabilitation. These instruments could be considered to be condition specific (e.g. focussed on ageing, medical rehabilitation).

Some of the commonly used instruments are the Barthel Index (Mahoney & Barthel, 1995) and the more recent modifications of this; the Functional Independence Measure (FIM) (Stineman et al., 1994), the Index of Independence in Activities of Daily Living (ADL) (Katz et al., 1959) although the latter instrument is somewhat dated. The disability dimension of the Health Assessment Questionnaire (Fries et al., 1980; Ramey et al., 1995) has been used in chronic disease management studies (Lorig et al., 1996; Stanford Sample Questionnaire, 2000). While some of these instruments have been available for quite some time there is surprisingly little published literature available concerning the psychometric properties of some of these instruments (Thomas et al., 2006).

The choice of these instruments will probably depend on the setting in which it is to be used. Within its limitations of scope, the Barthel Index is considered to be one of the best brief assessments of basic ADL available (Wilkin et al., 1992) and has been incorporated in the Health and Community Care (HACC) Assessment tool (CHSD, 2001). Katz's index of ADL has been extensively used with the elderly or for those with chronic conditions but is better suited to institutional settings rather than primary care. The FIM forms part of a uniform dataset for medical rehabilitation in the USA (Granger et al., 1993) and a number of Australian hospitals are making use of this dataset as well (Marosszecky, 1995, 1997). There is Australian normative data for this instrument and its psychometric properties are good. However, again this instrument is better suited to inpatients or those with fairly severe conditions, as there are likely to be ceiling effects (scoring at the top of the scale) in outpatient populations such as tertiary rehabilitation. Many of these instruments are used with the elderly or people with disabilities to assess need for services, and for some instruments there are options for administration which include self report/ interview, or as a rating scale.

Multi-dimensional Profiles: Generic Measures

Instruments designed to measure multi-dimensional health status profiles cover several dimensions of health which previously might have been measured using separate instruments (eg. pain or mental health). They usually include items on physical functioning, role functioning, mental health perceptions and pain, but other instruments will include domains such as sleep and social and sexual functioning.

Currently most researchers are using such multi-dimensional health status measures/profiles (for example the SF-36 (Ware & Sherbourne, 1992), the Nottingham Health Profile (Walker & Rosser, 1993) and the Sickness Impact Profile (Bergner et al., 1981)), combined with other condition or disease specific clinical measures, as generic instruments may miss critical factors for individual conditions, interventions or patient groups. Some comprehensive recent reviews of these instruments have been

undertaken by Nick Marosszecky (Thomas et al., 2006) and some reviews are available at www.uow.edu.au/commerce/ahoc.

The SF-36

There has been much recent outcomes work using multi-dimensional profiles, particularly the SF-36 (Ware & Sherbourne, 1992). This instrument has been utilised with a 50% sample in the 1995 National Health Survey (ABS, 1997), which has enabled the linking of data on health differentials to this measure of perceived health status. It has also been used in a variety of population health surveys across the United States and has also been trialed in a variety of clinical settings (Sanson, 1995, 1996, 1997). Critical reviews of this instrument have been prepared by Sanson (1995) and Dixon et al. (1994) and Marroszecky (1997, 2005). Generally the SF-36 is considered to be one of the better multi-dimensional health profile instruments as there is increasing evidence of its reliability, validity and responsiveness in a range of studies both in Australia and overseas (Shadbolt, 1996, 1997).

There are a range of standardized versions available for languages other than English. It was recommended as the generic measure of health status for the non-Aboriginal Co-ordinated Care Trials and was utilized in the ACT Continuum of Care Study of approximately 6000 patients across a variety of conditions. There is Australian normative data for Version 1 of this instrument (ABS, 1997) and Version 2 (Hawthorne, 2006) and an increasing collection of data pertaining to condition profiles and self reported morbidity.

A revised version of this instrument is now available (Version 2, Ware & Kosminski, 1996; Ware et al., 2000). There have been minor changes made to the wording to develop a more 'international' version, the layout has been refined and made more user friendly and there are more levels available in the response categories for the role functioning scales (5 point vs. 2 point response categories). Thus the role functioning scales are now less prone to floor and ceiling effects. This is relevant to its use with some population groups (elderly, those with chronic disease and multiple morbidities) as elderly patients with multiple morbidities may be more likely to score near the floor of some items. Norm based scoring has also been introduced to ease clinical interpretation. Sanson and Costi (2001) outline the changes made and discuss the pros and cons of using the different versions of this instrument in the Australian context.

The revisions encompassed in Version 2 appear to have led to a greater precision of measurement particularly for the role functioning scales (Jenkinson et al., 1999; Ware et al., 2000; Sanson & Costi, 2001). Unfortunately Version 2 of the SF-36 has not been validated for Australia although it has been for the United Kingdom (Jenkinson et al., 1999). The version made available for Australian use is the same as the 'international version' with only changes to the metric (kilometres and metres vs. miles and yards) for some items (Sanson & Costi, 2001). Recently the SF-36V2 has been included in a special SA Health Omnibus Survey (Harrison Health Research, 2004; Hawthorne 2006) to collect normative data for norm comparison purposes, and until this Australian normative data is published one cannot apply the norm based scoring method to any data collected. It is anticipated these norms will be made available very shortly (Hawthorne & Sanson, 2004; Hawthorne 2006). As Australian normative data, until recently, has only been available for Version 1 (albeit that it is now possibly out of date) most Australian research has made use of the earlier version.

Australian Use of the SF-36

In Australia, the SF-36 continues to increase in popularity, and details of outcomes projects are continually entered on the AHOC Research Activities and Instruments Database (RAID). There is also an annotated bibliography for the SF-36 available which lists all international studies up to and including 1996 (Ware et al., 1996).

There are extensive, long term studies using the SF-36, such as the Women's Health Australia study, which involves a longitudinal study of 1500 women in each of three age groups over a period of five years (Lee, 2002). Other examples of the types of applications for the SF-36 are hospital based studies, such as the Gynaecology Oncology Outcomes Project (Stenlake, 1996) and the ACT Health Outcomes and Continuum of Care Project (Shadbolt, 1996). It was also used in the National Coordinated Care Trials as a generic measure of health status and health outcome. Sanson (1997, 2004) and Thomas et al. (2006) have provided an overview of the major population surveys that have used this instrument.

Concerning the use of the SF-36 in Australia a number of points emerge:

- the SF-36 has been used in a variety of population groups including non-English speaking groups, elderly patients and patients with psychological disorders;
- the SF-36 is frequently used in conjunction with disease or condition specific measures.

The SF-36 has been administered in a number of ways, for example a self administered postal questionnaire, by personal interview and by computer assisted telephone interview (CATI). Care needs to be taken, however, to check on the mode of administration before making any comparisons between data sets.

Substantial Australian normative data is available for Version 1 of the SF-36 (English Language Adaptions) and interim Australian norms for Version 2 are now available (Hawthorne 2006 in press)

the SF-36 has been found to be responsive to changes in health status in a range of acute care clinical settings including both surgical and medical treatments (Shadbolt et al., 1997) . The SF-36, however, may not be sufficiently sensitive to detect change arising from more subtle health care interventions such as a change in health care management practices (e.g. coordinated care). It is more likely that disease, symptom specific and patient satisfaction measures may be more sensitive to change in these contexts.

Multi-dimensional Indices

Health outcomes also have a major economic focus, although we are some way as yet from resource allocation based on health outcomes. While it is important to know which interventions lead to an improvement in health status, it is also useful to know the relative costs and benefits in comparison to alternative treatments for the same condition. Such information is extremely useful in setting priorities and directions for health expenditure. This has led to the development of multi-dimensional indices. Multi-dimensional profiles need to be distinguished from multi-dimensional indices, as scores on the latter are aggregated to form a single index or number, whereas this is not the case for multi-dimensional profiles.

There has been much research on multi-dimensional indices which may be used to generate QALYs (Quality-Adjusted Life Years) and DALYs (Disability-Adjusted Life Years) which, together with information on costs, enable cost-utility analyses and thus cost and benefit comparisons across conditions. Given that health resources will always need to be rationed, such approaches compare the health gains to be made and their community valuation in relation to costs across health interventions, and claim to generate more rational models for health service resource allocation than is true of current resource allocation. QALY units 'integrate side effects and benefits of treatment by combining, into a single number, mortality, morbidity, and duration of each health state' (Kaplan, 1993). Harvey (1991), commenting on the costs associated with breast cancer screening, notes that if women were screened annually rather than biennially that an additional 14% of life years could be saved for a 70% increase in expenditure.

The base scales for health status assessment used in such multi-dimensional indices usually contain about five questions with each question representing one domain, (e.g. physical mobility, role functioning, pain, mental health), with the aim of such indices being to compress this information into a single number. While economists see this as entirely desirable, psychologists and others may wish to question how representative each of these questions can be of the domain they supposedly represent. Thus the validity issue of the extent to which items are representative of the health domains chosen is even more pertinent to the multi-dimensional indices than for the multi-dimensional profiles.

There are many other concerns with regard to QALYs (especially surrounding methods for valuing health states and the use of QALYs for resource allocation) and Cadet (1994), in critically reviewing the Quality of Well-being Scale (Kaplan et al., 1976), raises many issues which are also pertinent to other indices such as the EuroQol/EQ5D, Rosser Index, Sintonen's 15-D instrument and Torrance's Multi-Attribute Utility model (Torrance, 1987). Brazier (1997) developed a utility scale, the SF-6D based on items from the SF-36 instrument, and an international study is currently refining and assessing the usefulness of this measure. A recent report by Hawthorne in Thomas et al. (2006) compares a number of health indexes with reference to a range of evaluation criteria for the purposes of selecting a utility index for studies of incontinence. Two measures, EQ5D and the AQOL received the highest ratings although the HUI 3 also performed well. These instruments were further assessed in relation to

incontinence status in a special edition of the SA Health Omnibus Survey (2004) and a current recommendation is to use either HUI 3 or the AQOL for cost utility studies in this field (Hawthorne & Sansoni, 2004)

It should be noted, however, that there is still much interest in developing and refining models making use of QALY algorithms, and one such modelling exercise was been undertaken by Professor Hindle and associates in the Illawarra (Cromwell et al., 1995). Such work raises interesting issues as to the prioritisation of case loads for hospital systems. Is it more cost effective to spend your resources on six tattoo removals or on one coronary artery bypass graft, and what are the relative health benefits to be gained by the region?

Recently there has been much interest in the notion of disability adjusted life years (DALYs) which could also form a base for more rational priority setting and funding at the national or system level than has been the case for historical approaches (Murray & Lopez, 1996). Currently studies are underway in Australia at the AIHW and the Victorian Department of Human Services to examine these burden of disease approaches in the Australian context (Mathers, 1999).

Other Measures: Self – Efficacy Measures

In health promotion and chronic disease management settings there has been an interest in self-efficacy measures to assess the outcomes of educational interventions concerning health care self-management. Although there have been attempts to develop generic self-efficacy measures, given the task and behavioural specificity of self-efficacy it is not recommended that one general instrument is used to assess this construct (AbuSabha & Achtenberg, 1997; Dwyer et al., 1998; Mailbach & Murphy, 1995). Further, purportedly generic measures have been criticised on the grounds that they are domain specific or cover a very limited range of domains (Woodruff & Cashman, 1993).

A range of self-efficacy measures are available, such as the scales developed by Lorig et al. (1996) and the Stanford group (Stanford Sample Questionnaire, 2000) for chronic disease management, the Self Care Self Efficacy Scale (Lev and Owen, 1996) and the Chronic Pain Self Efficacy Scale (Anderson et al., 1993). Abu Sahba et al. (1997) and Dwyer et al. (1998) provide information on a range of other self-efficacy measures pertaining to nutrition and exercise.

Another approach that has been undertaken is to design disease specific efficacy scales. Various scales have been designed for assessing patient attitudes to self-management of asthma (Bowling, 1995). For example, an Asthma Self Efficacy Scale has been designed by Tobin et al. (1987), and a self-efficacy scale for sickle cell disease has also been developed recently (Edwards et al., 2000). However, there is limited information about the psychometric properties of these instruments (Bowling, 1998). The question arises as to whether self-efficacy may be more specific to tasks within a domain to manage specific symptoms (e.g. managing breathing or exercise) and whether there is sufficient generality for self-efficacy to apply across a disease or health condition.

Outcome Measurement Suites

A recent approach has been to develop outcome measurement suites for a range of conditions (e.g. chronic disease management, dementia, incontinence conditions, assessment and monitoring of the elderly and asthma) or for particular situations (assessment and monitoring in primary and community care). Outcome measurement suites are a collection of measures and other information items that are seen as relevant for the outcomes monitoring of these conditions. They will usually contain patient information items, medical history, medicinal use, service use, clinical indicators and generic and disease/condition specific measures.

The Stanford Sample Questionnaire (2000) is an example of an outcomes measurement suite for chronic disease self management studies. An initial needs assessment battery for primary care has been collated (CHSD, 2001) which has the potential to be used as a health outcomes monitoring suite for this area. An outcome measurement suite for incontinence conditions has been developed (Thomas et al., 2006) and one for dementia and associated conditions has recently been completed (Sansoni, 2007). A similar approach was undertaken by the Health Outcomes Institute in the US (Radosevich & Husnik, 1995) in the development of their TYPE modules. These modules contain sets of condition or disease specific clinical indicators, a generic health related quality of life instrument and a core set of other relevant indicators (demographics, co-morbidities etc).

It is important to consider the issue of redundancy in the development of outcome measurement suites, as many of the scales may have overlapping items. It is desirable to avoid respondent burden for the clients in such studies, as otherwise one is likely to find both sample attrition and a preponderance of missing data. It is interesting to examine the evolution and refinement of the Stanford Sample Questionnaire (2000) from that proposed by Lorig et al. (1996) in their earlier work. The later questionnaire deleted a number of items and areas that had not proved useful. Often a tiered approach or a decision tree model may be useful in the development of outcomes measurement suites. The CHSD has a range of measurement suites that can be examined on their web site at www.uow.edu.au/commerce/chsd and these publications also contain some excellent reviews of relevant instruments. The recent development of an outcomes measurement suite for continence conditions (Thomas et al., 2006) also contains a number of reviews of condition specific and generic instruments related to this condition.

Criteria for Selecting Instruments and Measures

The dimensions below are those one must consider in selecting instruments and measures:

RELIABILITY (Accuracy of measurement, for example, internal consistency and test/retest reliability.)

VALIDITY (Does the instrument measure what it claims to measure? There are different types of validity –content, construct, criterion, concurrent, convergent, discriminant etc.)

DISCRIMINATORY POWER (Is the instrument able to discriminate well between groups, for example, healthy public versus terminally ill.)

RESPONSIVENESS (Can the instrument detect change in health status over time?)

TYPE OF INSTRUMENT (Generic health status measure, condition or disease specific measure, profile or index.)

STYLE OF INSTRUMENT (For example, is it better to use a self report instrument or a rating scale or a combination of both? Is a self report inventory the best instrument to use with severely disturbed patients?)

PRACTICAL UTILITY (Is the instrument too long/short, is it easy to administer and use, is it easy to score, will there be respondent burden, etc?)

FREEDOM FROM CONFOUNDING FACTORS (For example, social desirability of responses, inappropriate questions associated with missing data, literacy level of the survey etc.)

RELEVANCE and SUITABILITY OF APPLICATION (For example, one might ask the question of whether the SF-36 may be the most appropriate instrument to use in palliative care or with persons with sensory conditions. Are there versions of the instrument suitable for use with children?)

MODE OF ADMINISTRATION (Self reported or structured interview, telephone administration etc.)

AVAILABILITY of COMPARATIVE DATA (For example, are there norms and clinical reference data sets?)

CULTURE, GENDER and AGE APPROPRIATENESS (Are there translations/adaptions for other cultural groups, are all items gender appropriate, are there versions suitable for use with children?)

Some Selected Applications of the Health Outcomes Approach

Applications to Primary and Community Care

The health outcomes approach has already gained much acceptance in the acute care sector. However, there are a number of issues that need to be addressed when translating this approach to other sectors, such as primary and community care.

Professor Alan Hutchinson (1998), with reference to outcomes monitoring in general practice, strongly recommends the KISS approach, or 'keep it simple stupid!' His view is that it is unrealistic to expect that busy general practitioners would have the time to routinely monitor the outcomes of their patients using instruments that assess health related quality of life. Ware (1995), however, has indicated that a number of GPs in the USA do in fact use the SF-36 to monitor individual patients and there are local practitioners such as Price (1998) who would also enthusiastically recommend such an approach.

Earlier, Sansoni (1995) and Dixon et al. (1994) suggested that the psychometric properties of the instrument would not recommend its use for individual patient monitoring although increasingly it does seem a fairly robust and responsive instrument for both group comparisons and for monitoring patient groups pre and post intervention.

A more realistic approach in general practice has been to use such instruments with particular groups of patients where a specific intervention is being assessed, rather than as a matter of routine. Sometimes some of the preferred instruments may be too long for use in routine care but now approaches such as Item Response Theory can be used to cross calibrate items from similar scales, to refine measures and to make them suitable for computerised adaptive testing (Ware, 2003). In the latter situation patients/clients are only given the minimum number of items that are necessary, through statistical inference, to determine their final score and thus in these situations respondent burden is far less likely. These approaches hold great promise for the refining of many commonly used standardised measures in the future.

The use of health outcomes performance indicators as proxies for the outcomes of patients and of patient management may be a more practical approach to adopt in primary care settings. Indicators might include such items as the proportion of patients that have been appropriately immunised, the proportion of female patients that have been appropriately screened for cancer of the cervix, the number of hospital admissions for patients with asthma, the presence and routine monitoring of asthma management plans, and the appropriateness of prescriptions with respect to best practice guidelines.

A similar approach can be undertaken in community care settings. Outcome related performance indicators pertaining to the particular service can be more informative concerning patient outcomes than the measures of throughput and output (such as the number of occasions of service performed) that are now used as performance indicators by many health departments. Output measures may reflect efficiency and the volume of service, but do not give any indication of the quality or appropriateness of the services provided. One way to address this issue is to examine the desired outcomes of the particular strategy or health intervention and then pose the question as to what readily available information might reflect whether the intervention is obtaining the desired outcome. For example, a tertiary rehabilitation service could examine indicators concerning the proportion of clients returning to paid and unpaid work or study. Nancarrow (1999) and Rubenach (1999) provide some examples of the application of this approach in a range of community care and allied health settings and one of these is outlined below.

An Allied Health Example

Nancarrow (1999) applied Benson's (1992) Ambulatory Classification Model in a podiatry application known as The Footpath Project. This project was a primary health initiative designed to prevent unnecessary lower limb ulceration or amputation, primarily in people with diabetes, but also in people with peripheral vascular disease or other causes of foot problems (Nancarrow, 1999).

Health outcome measures for the Footpath Project

Outcomes Type	Foot Health Indicators	Effectiveness Goal	Quality Action Point	Data Source	Frequency of Review
Disease specific outcome	Prevention of pressure (neuropathic) foot ulceration	90% of all patients with peripheral neuropathy remain free of pressure ulcers	80%	Medical Records	Annually
General Health outcome	Foot health status questionnaire	90% of patients report that their foot status is excellent or very good	70%	Questionnaire to 33% of patients who receive foot health care	6 monthly
Patient Performance Outcome	Patient knowledge of risk factors for lower limb ulceration	90% of patients able to demonstrate understanding of lower limb factors	80%	Chart audit – 1% medical records (or patient survey)	6 monthly
Patient satisfaction outcome	Patient satisfaction with level of care they	90% of patients express satisfaction with the level of care	80%	Survey administered to 100% of patients	6 monthly

	receive for foot complications	they receive for foot complications			
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- The **indicator** is based on what the intervention is trying to achieve within the scope of the service. A number of indicators may be identified, and these should be prioritized into those aspects of care which are most important for the service.
- The **effectiveness goal** is the level to which the organization is going to aim to achieve the chosen indicator. The **effectiveness goals** and **quality action points** are arbitrary and ideally, should be based on the evidence of the effectiveness of interventions as shown by research.
- The **quality action point** is a predetermined threshold that is used to flag the need to introduce quality improvement activity to improve performance on the indicators.
- The **data source** requires careful consideration to provide the level of information required in the most effective way. Data collection can form a major cost in a quality improvement process. Therefore consideration must be given to the availability of the data, the method of data collection, how much data is required to provide meaningful results and, the value of the data in terms of providing useful information.

It can be seen the advantage of this model is that indicators can be built into many areas of routine clinical practice.

Some Selected Issues and the Health Outcomes Approach

Cultural Adaptation of Instruments

In 1996 AHOC was asked to convene an expert working group to recommend measurement instruments for both the Aboriginal and non-Aboriginal components of the Co-ordinated Care Trials.

The SF-36 was recommended for the non-Aboriginal component of the Co-ordinated Care Trials. This was because it was assessed as being the most valid, reliable and responsive of the generic measures of health outcome of those available (Shadbolt, 1996). As there are a number of standardized versions for other languages it was also considered to be appropriate for use with people from a non English speaking background.

However, the expert group workshop considered that the SF-36, as it is, would not be suitable for Aboriginal and Torres Strait Islander populations, especially those in remote areas. A popular example of the cultural inappropriateness of the questions is illustrated by question 3a, which asks if your health limits you in activities such as climbing a flight of stairs. Obviously this question is redundant in communities where buildings do not have stairs. Other inappropriate questions mention activities such as vacuum cleaning, playing golf and bowls which are also unlikely to be routine activities in remote rural communities. Thus it is most important to find instruments that are appropriate to the group being assessed.

An individual's perception of his/her own health status may also be influenced by the general health status of the community in which they live. If the community, as a whole has a poor health status, then a person may see themselves as being more healthy than their companions and rate themselves accordingly, when their actual health status, as seen by an outsider is low. This factor was observed in the NATIS Survey of 1994. The NATIS Survey indicated that a similar proportion of Aboriginal peoples reported their health as being good to excellent as for a sample from the general Australian population, yet if objective criteria are used (incidence and death rates associated with various diseases) it is clear that the health of the indigenous population is not as good as that for the Australian population overall. This would tend to suggest that cultural relativities may be taken into account when people complete 'perceived' health status measures. Whilst perceived health status measures are often good proxies for a direct measures of 'health' and are an important component of the construct of health, 'perceived' and 'actual' health status may be not quite the same thing.

One could modify the items of the SF-36 to make them more comprehensible (Henderson & Gray, 1994) or substitute items such as going hunting and fishing as examples of moderate physical activities, change the time frame, etcetera, as has been suggested. Making such modifications, however, would mean that the reliability and validity of this modified instrument would need to be re-assessed. There is also the problem that the construct of health implicit in this scale is based on the perceived dimensions

of health that are relevant to white middle class Americans. Studies by Senior (1999) and Scott et al. (1999) raise serious questions about such assumptions. Tinkering at the edges will not solve the issue of cultural inappropriateness and insensitivity.

Senior (1999) indicates that the construct of 'health' may have a different meaning and different dimensions than is the case for middle class non-Aboriginal people on whose health construct such standardised scales have been developed. For example, that Aboriginal and Torres Strait Islander communities might consider such factors as environmental sustainability, spirituality and kinship, and a sense of self esteem and self control as major components of their health construct (Senior, 1999). Senior's interviews about domains of quality of life in Lulaluk and Minmarama Park strongly indicated there was a need to develop an entirely new measure of quality of life for the Aboriginal people in this community. Senior (1999) found that even the WHOQOL-BREF (World Health Organization, 1996), an instrument designed to be applicable across different cultural groups, omitted domains relevant to quality of life for these groups, and various items were also subject to misinterpretation by the community participants.

Although this brief discussion has focussed on issues relevant to indigenous peoples there are many other pertinent examples. Consider the assessment of those with dementia conditions from culturally and linguistically diverse backgrounds (CALD). It is suspected that later diagnosis and misdiagnosis is more likely to occur due to communication difficulties, cultural misunderstandings, culturally inappropriate assessment tools and the lack of available interpreters (Black, LoGiudice, Ames, Barber & Smith, 2001). It is also noted that second language skills also tend to be lost early in Dementia. Thus cultural appropriateness will be an important consideration for a broad range of groups

Gender Sensitivity and Specificity

Papers by Broom (1998), Eckerman (1997), Tilley (1997), Sansoni (1996) and Sansoni and Rubenstein (1997) have examined issues of gender in relation to outcomes assessment. One can gain the impression in the health arena that 'women's health' until recently has been overly concerned with female reproductive functions - as though these are the only aspects of women that differentiate them from men!

Sansoni (1996) and Sansoni and Rubenstein (1997) also note that many drug trials have not included female subjects, severely limiting the applications of these findings, and there also is a growing body of evidence indicating that there are practice variations in medicine pertaining to gender – such as less timely treatment for myocardial infarction (Tilley, 1996).

Gender appropriateness of items is also an area that has sometimes been ignored by those developing standardised instruments used to assess health related quality of life. Sansoni (1996) refers to an example where an instrument used to assess the sexual functioning of men was 'cosmetically' adapted for women without any consideration as to whether these domains of sexual functioning (e.g. frequency of intercourse, achievement of orgasm) were as pertinent to women.

The above examples are used to highlight the fact that one must consider the gender appropriateness and sensitivity of proposed outcomes indicators and assessment devices when designing outcome data sets. It is also important in developing data collections to ensure that the data can be gender disaggregated.

Conclusions

In conclusion, it would seem there are some promising approaches to developing more integrated and co-ordinated approaches to health care and to the routine assessment of patient based health outcomes. It is to be hoped that the current health outcomes focus in Australia may act as a catalyst for us to integrate the various efforts that are already being made to improve the quality of our health systems and hospitals. It is only by evaluating our services that we can become both more effective and more efficient in the delivery of health care. It is also essential that health outcomes evaluation should become integrated within our quality improvement systems – there is not much point in evaluating patient outcomes unless we use this information for service improvement and to improve patient outcomes.

The Australian Health Outcomes Collaboration

The Australian Health Outcomes Clearing House (AHOCH) was established in 1994, and served as a site for the dissemination of information about health outcomes research, practice and policy in

Australia and overseas. In 1997 the Clearing House became the Australian Health Outcomes Collaboration (AHOC).

The primary aims of the AHOC are to:

- To disseminate information about health outcomes research
- To maintain an active network of collaborators in health outcomes research
- To maintain a database of health outcomes projects, literature and instruments
- To provide advice of the selection of measures for health outcomes assessment
- To assist with the distribution of measures/instruments used in health outcomes assessment and information concerning these measures
- To provide health outcomes education and training
- To organize national and international conferences and seminars
- To facilitate health outcomes research throughout Australia

Visit the web site at www.chsd.uow.edu.au/ahoc for further information about the AHOC and the annual health outcomes conference and workshop activities. The Australian Health Outcomes Collaboration can also provide advice and assistance concerning the implementation of the health outcomes approach and the measurement tools that might be used.

References

- Abraham B, d'Espaignet E and Stevenson C (1995) *Australian Health Trends 1995*, Australian Institute of Health and Welfare.
- AbuSahba R and Achtenberg C (1997) *Review of self-efficacy and locus of control for nutrition- and health-related behaviour*. Jnl. American Dietetic Assoc. Vol. 97, No. 10,
- AHMAC, February (1993). As quoted in: *Health Outcomes Bulletin*. No. 1, February 1994, 5.
- AHMAC (1996) *The Final Report of the Taskforce on Quality in Australian Health Care*. AGPS, Canberra.
- Anderson KO, Dowds BN, Pelletz RE, Edwards WT (1995) *Development and initial validation of a scale to measure self-efficacy beliefs in patients with chronic pain*. Pain. Vol. 63, pp.77-84
- Armstrong B (1994) *Getting health outcomes into state and national health policy, a national perspective*. NSW Health Outcomes Conference. Sydney, 12-13 August 1994.
- Australian Bureau of Statistics (1997) *1995 National Health Survey: SF-36 population norms, Australia*. Cat No 4399.0. ABS, Canberra.
- Australian Council for Quality and Safety (2000) *Safety First: Report to the Australian Health Ministers' Conference*. DHAC, Canberra.
- Australian Institute of Health and Welfare (1994) *Health expenditure highlights*. Health Expenditure Bulletin. No. 10, p.1.
- Australian Institute of Health and Welfare (2001) *Cancer in Australia 1998*, Australian Institute of Health and Welfare and Australasian Association of Cancer Registries, Canberra.
- Australian Hospital Care Study (1995) *Interim Report Task Force on Quality in Australian Health Care*.
- Bebbington P et al. (1999) *Validation of the Health of the Nation Outcome Scales*. Br Jnl of Psychiat. Vol. 174, pp.389-394.
- Batalden P, Nelson E and Roberts J (1994) *Linking outcomes measurement to continual improvement: the serial "v" way of thinking about improving clinical care*. Journal of Quality Improvement. Vol. 20, No. 4, pp.167-180.
- Becker M, Diamond R and Sianfort F (1993) *A new patient focused index for measuring quality of life in persons with severe and persistent mental illness*. Quality of Life Research. Vol. 2, pp.239-251.
- Benson DS (1992) *Measuring Outcomes in Ambulatory Care*. American Hospital Publishing, Inc.
- Bergner M, Bobbitt RA, Carter WB and Gilson BS (1981) *The Sickness Impact Profile: development and final revision of a health status measure*. Medical Care. Vol. 19, pp.787-805.
- Black K, Lo Giudice D, Ames D, Barber B and Smith R (2001) *Diagnosing Dementia*. Alzheimer's Association of Australia.

- Boot B (1998) *Outcomes of acute admissions to psychiatric units*. Integrating Health Outcomes: Measurement In Routine Health Care Conference. Canberra, 13-14 August 1998.
- Bowling A (2001) *Measuring Disease (2nd ed.)*. Open University Press, Buckingham.
- Bowling A (2005) *Measuring Health: A Review of Quality of Life Measurement Scales (3rd ed.)*. Milton Keynes, Open University Press.
- Brennan TA et al. (1991) *Incidence of adverse events and negligence in hospitalised patients: results of the Harvard Medical Practice Study*. New England Journal of Medicine. Vol. 324, No. 6, pp.370-376.
- Broom D (1998) *Gendering health outcomes*. Integrating Health Outcomes: Measurement In Routine Health Care Conference. Canberra, 13-14 August 1998.
- Brazier J (1997) *Developing a utility index from the SF-36*. Conference Proceedings: Managing and Measuring Health Outcomes: From Policy to Practice. Australian Health Outcomes Collaboration, Canberra (CDRom).
- Brooks R (1999) *The reliability and validity of the Health Of the Nation Outcome Scales*. Conference Proceedings: Health Outcomes: Integrating the Elements. Australian Health Outcomes Collaboration, Canberra (CDRom).
- CIHI (2000) *Canadian Health Information Roadmap Initiative Indicators Framework 2000*. Canadian Institute for Health Information and Statistics, Canada.
- Cadet B (1994) *History of the construction of a health indicator integrating social preference: The Quality of Well-Being Scale*. Seventh Meeting of the International Network on Health Expectancy (REVES). Canberra, 23-25 February 1994.
- CHSD (2001) *Pilot Testing of Tools: Guidelines for Undertaking Initial Needs Identification and developing a Service Coordination Plan*. Centre for Health Service Development, University of Wollongong and Australian Institute for Primary Care, La Trobe University. Available at <http://aipc.latrobe.edu.au/pcpssc/>
- Clarke R (1996) *Field test: selected measures of consumer outcomes in mental health project*. Integrating Health Outcomes, Measurement in Routine Health Care Conference. Canberra, 13-14 August 1996.
- Council of Australian Governments (COAG) Meeting, Communique, 11 April 1995, Canberra.
- Consumers' Health Forum (1993) *Paying for Health: Consumers and the Health Care System*. Proceedings of a national conference, December 10-11, 1992, Canberra: CHF, 1993.
- Craft P, Primrose J, Lindner J and McManus P (1996) *Patterns of surgical treatment of primary breast cancer in Australian women in 1993: analysis using medicare statistics*. 23rd Annual Scientific meeting of the Clinical Oncological Society of Australia inc. Brisbane Convention and Exhibition Centre, 27-29 November 1996.
- Cromwell D, Haball J, Viney R and Hindle D (1995) *Illawarregon, Development of a Model to Assist Priority Setting by an Area Health Service*, Centre for Health Service Development, Wollongong.
- Cummins RA (1993) *Comprehensive Quality of Life Scale for Adults (4th ed.)*. Deakin University, Deakin.
- De Haes JC, Van Knippenenberg FC, Neijt JP (1990) *Measuring psychological and physical distress in cancer patients: structure and application of the Rotterdam Symptom Checklist*. British Journal of Cancer. Vol. 62, pp.1034-1038.

- Department of Health and Aged Care (1999) *Health and Medical Research Strategic Review*, AusInfo, Canberra 1999.
- Dixon P, Heaton J, Long A and Warburton A (1994) *Reviewing and applying the SF-36. Outcomes Briefing*. Vol. 4, pp.3-24.
- Donabedian A (1980) *Basic approaches to assessment: Structure, process, and outcome*. In
- Donabedian A (1980) The Definition of Quality and Approaches to its Assessment: Explorations in Quality Assessment and Monitoring. Vol. 1. Health Administration Press.
- Donabedian A (1992) *The role of outcomes in quality assessment and assurance*. Quality Review Bulletin. November, pp.356-360.
- Dwyer JJ, Allison KR and Makin S (1998) *Internal structure of a measure of self-efficacy in physical activity among high school students*. Soc. Sci. Med. Vol. 46, No. 9, pp.1175 –1182.
- Eager K (1996) *Linking funding to health outcomes*. Integrating Health Outcomes: Measurement In Routine Health Care Conference. Canberra, 13-14 August 1996.
- Eager K (1995) *Purchasing Health Gain*. Seminar presented at the AIHW, Canberra, June 15.
- Eckermann E (1996) *Towards a new gendered and 'differentiated' social epidemiology*. paper prepared as part of a consultancy undertaken for the AHMAC Subcommittee on Women and Health, Department of Health and Family Services, Canberra, November 1996.
- Edwards R, Telfair J, Cecil H and Lenoci J (2000) *Reliability and validity of a self-efficacy instrument specific to sickle cell disease*. Behaviour Research and Therapy. Vol. 38, pp.951-963.
- Entwistle V (1995) Paper delivered to Cochrane Collaborative Review Group on Communicating Effectively with Consumers, sponsored by the Public Health Division, Melbourne, 2-3 May, 1995.
- Field M and Lohr K (1992) *Guidelines for Clinical Practice: From Development to Use*. Institute of Medicine, National Academy Press, Washington DC.
- Fries JF, Spitz P, Kraines RG et al. (1980) *Measurement of patient outcome in arthritis*. Arthritis Rheum. Vol. 23, pp.137-145.
- Granger CV, Cotter AC, Hamilton BB and Fiedler RC (1993) *Functional Assessment Scales: a study of persons after stroke*. Arch Phys Med Rehab. Vol. 74, pp.133-138.
- Harrison Health Research (2004) *South Australian Health Omnibus Survey (HOS) Report*. South Australia Department of Health, Adelaide.
- Harvey K (2003) "Saving" the Australian Pharmaceutical Benefits Scheme. Monash, HEU, 26/11/03 at <http://users.bigpond.net.au/medreach/downloads.htm>
- Harvey R (1991) *Making it Better: Strategies for Improving the Effectiveness and Quality of Health services in Australia*, Background Paper No. 8, National Health Strategy, Melbourne.
- Harvey R (1994) *A Pilot Study to Integrate Health Outcomes and Health Interventions*, AIHW.

- Harvey R (1995) *Health Outcomes, quality assurance and information: 'Doing the do-able' or 'You've got to start from here!' part 1.* Health Outcomes Bulletin, Spring, No. 6, p.22.
- Harvey R and Sansoni J (1997) *Options and Costs for a Clinical Guidelines Repository*. A report prepared for the NSW Health Department, 1st edit., NSW Health.
- Hawthorne G (2004) *Multi attribute utility measures of quality of life*. In Thomas et al. (2006) *Continence Outcomes Measurement Suite*, DHA.
- Hawthorne G (2006) *Measuring incontinence in Australia*. Australian Government Department of Health and Ageing, Canberra (In Press).
- Hawthorne G and Sansoni J (2004) *Incontinence and quality of life*. Health Outcomes 2004: Perspectives on Population Health. Canberra, 15-16 September 2004.
- Hirsch N et al. (1994) *Minimal Access Surgery: an Update*. A Discussion Paper, AGPS.
- Henderson G and Gray A (1994) *The Tharawal Aboriginal Family Environmental Health Survey*. Australian Institute of Aboriginal and Torres Strait Islander Studies, ANU, Canberra.
- Hooke G (1998) *HoNOS versus the rest*. Implementing the Health Outcomes Approach Conference. Canberra, August 1998.
- Hyland ME (1991) *The living with asthma questionnaire*. Journal of Respiratory Medicine. Vol. 85 (Suppl. B), pp.13-16.
- Jenkinson C et al. (1999) *Assessment of the SF-36 version 2 in the United Kingdom*. J Epidemiol Community Health. Vol. 53, pp.46-50.
- Kaplan RM, Bush JW and Berry CC (1976) *Health status: types of validity for Index of Well-being*. Health Service Research. Vol. 11L, pp.478-507.
- Kaplan RM (1993) *Quality of life assessment for health resource allocation*. Harkness Health Conference. Canberra, 8-9 December 1993.
- Katz et al. (1959) *Index of independence in activities of daily living (ADL)*. In Wilkin D, Hallam L, and Doggett MA (eds.) (1992) Measures of Need and Outcome for Primary Health Care. Oxford Medical Publications, UK.
- Kessler R (1997) *Kessler's Psychological Distress Scale*, Department of Health Care Policy, Harvard Medical School, Boston.
- Kingman S (1994) *Quality control for medicine*. New Scientist. Vol. 143, pp.22-26.
- Kolstad A (1994) *Quality of Life: the concept and how to measure it*. Australian Association for Social Research Conference. University of Tasmania, 25-27 January, 1994.
- Lee C (2002) *Women's Health Australia, seven years on: Contributions to the evidence base for health outcomes policy and practice*. Health Outcomes 2002: Current Challenges and Future Frontiers. Canberra, November 2002.
- Leape LL (1989) *Unnecessary surgery*. Health Services Research. Vol. 24, No. 3, pp.351-407.

- Lev EL and Owen SV (1996) *A measure of self-care self efficacy*. Research in Nursing and Health. John Wiley and Sons.
- Lorig K, Stewart A, Ritter P, Gonzalez V, Laurent D and Lynch J (1996) *Outcome Measure for Health Education and Other Health Care Interventions*, Sage Publications, 1000 Oakes CA.
- Mahoney FI and Barthel DW (1965) *Functional Evaluation: the Barthel Index*. Md State Med J. Vol. 14, pp.61-65.
- Mailbach E and Murphy DA (1995) *Self-efficacy in health promotion research and practice: conceptualization and measurement*. Health Education Research. Vol. 10, No. 1, pp.37-50.
- Marosszky JE, Granger CV and Marosszky NEV (1995) *The uniform data system for medical rehabilitation: first admissions in Australia for 1992-1993*. Health Outcomes Bulletin. Vol. 6, pp.29-30.
- Marosszky JE and Eagar K (2001) *The Australian Rehabilitation Outcome Centre (AROC)*. Health Care in Perspective 2001 – Incorporating the 13th National Casemix Conference. Hobart, 16-19 September 2001.
- Marosszky N (2005) *Reviews of SF-12, SF-36, WHOQOL-100, WHOQOL-Bref*. In Thomas et al. (2006) *Continence Outcomes Measurement Suite Project: Final Report*, DHA.
- Mathers C (1999) *Australian Burden of Disease – implications for priority setting*. Conference Proceedings - Health Outcomes: Integrating the Elements. Australian Health Outcomes Collaboration, Canberra (CDRom).
- Meenan RF, Gertman PM and Mason JH (1980) *Measuring health status in arthritis: the arthritis impact measurement scale*. Arthritis Rheumatism. Vol. 23, No. 2, pp.146-152.
- McLaws M et al. (1988a) *The Prevalence of nosocomial and community acquired infections in Australian Hospitals*. Medical Journal of Australia. Vol. 119, pp.585-590.
- McLaws M et al. (1988b) *Predictors of surgical wound infection in Australia: a national study*. Medical Journal of Australia. Vol. 119, pp.585-590.
- Mishra G (1997) *Hysterectomy and incontinence in middle age women*. Conference Proceedings: Managing and Measuring Health Outcomes: From Policy to Practice. Canberra, 31 Oct – 1 Nov, 1997.
- Murray CJL and Lopez AD (1996) *The Global Burden of Disease*. The Harvard School of Public Health on behalf of the World Health Organisation and The World Bank, Harvard.
- Nancarrow S (1999) *Health Outcomes: issues for community care*. Workshop: Health Outcomes and Community Care. Canberra, 26 February 1999.
- NHMRC (1995) *Guidelines for the Development and Implementation of Clinical Practise Guidelines*. 1st ed., AGPS.
- NHMRC (1999) *A Guide to the Development, Implementation and Evaluation of Clinical Practice Guidelines*. Commonwealth of Australia, AGPS.
- National Health Performance Committee (NHPC) (2001) *National Health Performance Framework Report*, Queensland Health, Brisbane.
- NSW Health (1994) *Report on the 1993 NSW Diabetes Outcomes Workshop (NDOW)*, NSW Health, Sydney.
- Radosevich D and Husnik M (1995) *An abbreviated health status questionnaire: HSQ-12*. Update. Vol. 2, No. 1.

Ramey DR, Raynauld J-P and Fries JF (1992) *The Health Assessment Questionnaire 1992: status and review*. Arthritis Care Res. Vol. 5, pp.119-129.

Reid B et al. (1999) *Relative Utilisation Rates of Hysterectomy and Links to Diagnoses*, DHAC, Canberra.

Reinhardt UE (1990) *The social perspective*. In Heithoff KA and Lohr KN (eds.) (1990) Effectiveness and outcomes in health care. National Academy Press, Washington DC.

Ross B et al. (1999) *Health Expenditure: Its Management and Sources* (Occasional Papers: Health Financing Series Vol 3), DHAC, Canberra.

Rosser RM (1988) *A Health index and outcome measure*. In Walker SR and Rosser RM (eds.) (1988) Quality of Life: Assessment and Application. MTP, Lancaster.

Rubenach S (1999) *Health outcomes for the elderly: community and domiciliary care*. Workshop: Health Outcomes and Community Care. Canberra, 26 February 1999.

Sansoni J (1995) *Quality of life: Measure for Measure*. In Health Outcomes and Quality of Life Measurement: Conference Proceedings. Australian Institute of Health and Welfare, Canberra, August 14-15 1995.

Sansoni J (1996) *The Centrality of Health Outcomes Measurement*. In Integrating Health Outcomes in Routine Health Care Conference Proceedings. Australian Institute of Health and Welfare, Canberra, August 13-14 1996.

Sansoni J and Harvey R (1996) *Integrating the Health Outcomes Focus*. Health Outcomes Workshop. Bendigo, 1996.

Sansoni J and Rubenstein L (1996) *Women's Health Outcomes Project*. AHMAC Subcommittee on Women and Health, Department of Health and Family Services, Canberra.

Sansoni J (1999) *Options and Costs for a Clinical Guidelines Repository*. NSW Health Department, (2nd edit), NSW Health.

Sansoni J (1997) *The use of the SF-36 in population health surveys: The Australian experience*. In Proceedings: State of the Art Health Outcomes Conference. MOT, San Francisco, May 1997.

Sansoni J and Costi J (2001) *SF-36 Version 1 or Version 2: The Need for Australian Normative Data*. Proceedings of Health Outcomes 2001 - The Odyssey Advances: 7th Annual national health outcomes conference. Canberra, 27/28 June 2001.

Sansoni J (2004) *The use and value of HRQOL measurement for the Australian health system*. Harmonizing International Health-Related Quality of Life (HRQOL) Research, *11th Annual Conference of the ISOQOL*, October 16-19, Hong Kong.

Sansoni J and Tilley L (2005) Health Outcomes 2005: Making a Difference: Conference Proceedings. Australian Health Outcomes Collaboration, University of Wollongong, Canberra, 2005.

Sansoni J, Marosszeky N, Jeon Y-H, Chenoweth L, Hawthorne G, King M, Budge M, Zapart S, Sansoni E, Senior K, Kenny P, Low L (2007) *Final Report: Dementia Outcomes Measurement Suite Project*. Centre for Health Service Development, University of Wollongong.

- Schipper H, Clinch J and McMurray A (1984) *Measuring the quality of life in cancer: the Functional Living Index-Cancer, development and validation*. Journal of Clinical Oncology. Vol. 2, pp.472-483.
- Scott KM, Sarfati D, Tobias MI and Haslett SJ (in press) *A challenge to the cross-cultural validity of the SF-36: A comparative factor analysis in Maori, Pacific and New Zealand European ethnic groups*.
- Senior KA (1999) *Cross cultural issues in measuring health and community care outcomes*. Workshop: Health Outcomes and Community Care. Canberra, 26 February 1999.
- Shadbolt et al. (1996) *Selecting Instruments and Measures for the Co-ordinated Care Trials Workshop*. Canberra, July 1996.
- Shadbolt et al. (1996) *First Report from the ACT Continuum of Care Project*. ACTH&CC.
- Shabolt B, McCallum J and Singh M (1997) *Health Outcomes by Self-report: Validity of the SF-36 among Australian Hospital Patients*. ACT Department of Health and Community Care, Canberra.
- Slutsky J (1998) *Guidelines and outcomes: AHCPR's National Guideline Clearinghouse*. In Sansoni J and Tilley L (Eds.) Implementing the Health Outcomes Approach (Conference Proceedings). AHOC, November 1998
- Stanford Patient Education Research Center (2000) *Sample Questionnaire for the Chronic Disease Self-Management Program*. Palo Alto, CA.
- Stedman T, Yellowlees P, Mellsop G, Clarke R and Drake S (1997) *Measuring Consumer Outcomes in Mental Health*. Department of Health and Family Services, Canberra, ACT.
- Stenlake A (1996) *A Workshop Approach to Outcomes Assessment in Gynaecological Cancer Care*. February 1996.
- Stufflebeam D (1984) *Resource materials for an evaluation workshop*. West Michigan University, Michigan.
- Thomas S, Nay R, Moore K, Fonda D, Hawthorne G, Marosszeky N and Sansoni J (2006) *Continence Outcomes Measurement Suite Project (Final Report)*. Department of Health and Ageing, Canberra.
- Tilley L (1996) *Measuring women's health outcomes: gender differences in health outcomes and implications for health practice*. AHMAC Subcommittee on Women and Health, Department of Health and Family Services, Canberra.
- Tobin DL et al. (1987) *The Asthma Self Efficacy Scale*. Annals of Allergy. Vol. 59, pp.273-277.
- Torrance GW (1987) *Utility approach to measuring health-related quality of life*. Journal of Chronic Disease. Vol. 40, No. 6, pp.593-600.
- Walker SR and Rosser RM (eds.) (1992). *Quality of Life Assessment, Key Issues in the 1990's*. Kluwer Academic Publishers, Hingham, USA.
- Ware JE and Sherbourne CD (1992) *The MOS 36-item short form health status survey (SF-36): 1, Conceptual framework and item selection*. Medical Care. Vol. 30, pp.473-483.
- Ware JE et al. (1996) *The SF-36 Health Survey Annotated Bibliography: First Edition (1988-1995)*. The Health Institute, NEMC, Boston.
- Ware J (2003) *Standardizing health metrics: The SF-36 Health Survey and beyond*. In Sansoni, J and

- Tilley L (Eds.) Conference Proceedings: Health Outcomes 2003: The Quest for Practice Improvement. Canberra, 20-21 August, 2003.
- Ware JE and Kosinski M (1996) *SF-36 Health Survey (Version 2.0) Technical Note*. The Health Institute, Boston, MA.
- Ware JE, Kosinski M and Dewey JE (2000) *How to Score Version 2 of the SF-36 Health Survey*. QualityMetric Inc., Lincoln, RI.
- Wennberg JE (1987) *The paradox of appropriate care*. Journal of the American Medical Association. Vol. 258, No. 18, pp.2568-2569.
- Wennberg JE (1990) *On the need for outcomes research and the prospects for evaluative clinical sciences*. In Andersen TF and Mooney G (1990) The Challenges of Medical Practice Variations. McMillan Press, London.
- World Health Organization (1996) *WHOQOL-BREF*, Geneva.
- Wilkin D, Hallam L and Doggett M (1992) *Measures of Need and Outcome for Primary Health Care*, Oxford University Press, Oxford.
- Wing J (1994) *Health of the Nation Outcome Scales: HoNOS Field Trials*, 9, B9.
- Woodruff SL and Cashman JF (1993) *Task, domain, and general efficacy: A re-examination of the self-efficacy scale*. Psychological Reports. Vol. 72, pp.423-432.
- World Health Organisation (1981) *Program Evaluation: Guiding Principles*. Health For All. Series No 6, WHO, Geneva.