HealthOutcomes

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From the Director, Australian Health Outcomes Clearing House

The health outcomes area has been very topical recently with the Introduction to Health Outcomes Workshop and the half-day seminar with Dr John Ware held by the Australian Institute of Health and Welfare (AIHW), followed immediately by the NSW Health Outcomes Conference. Forty people attended the introductory workshop and we already have a substantial waiting list for the next workshop to be held in December. Those interested in attending should phone Pamela McKittrick on (06) 243 4032 to have their names added to the contact list. Approximately 90 people also attended the John Ware seminar. The feedback we have received concerning these activities has been excellent and the number of participants attending these activities clearly reflects the degree of interest in health outcomes at present. I am led to believe there were over 700 participants at the NSW conference which also had an impressive array of both national and international speakers.

It was a great pleasure to have both Andrew Long (Project Director, UK Clearing House for Information on the Assessment of Health Outcomes) and Dr John Ware (one of the authors of the SF–36) visit the AIHW and have the opportunity to meet with key researchers and representatives from the Australian Bureau of Statistics, ACT Health, the Department of Human Services and Health, the NSW Department of Health, the AIHW and others. I would like to thank the Australian Bureau of Statistics (Social and Labour Division) and ACT Health (Epidemiology and Population Health) for co-sponsoring the visit of Dr Ware, which I believe was mutually productive and most useful. My thanks are also extended to all the speakers at our introductory health outcomes workshop, but in particular I would like to thank John McCallum from the National Centre for Epidemiology and Population Health and Andrew Long (UK Clearing House for Information on the Assessment of Health Outcomes) for their informative presentations and comments. I would also like to thank the participants, who coped well with a somewhat crowded environment, asked many stimulating questions and raised many important issues for discussion.

In this edition of the *Health Outcomes* Bulletin I have included an article on both the current and potential role and function of the Australian Health Outcomes Clearing House should funding for this project continue beyond the end of this year. I would welcome comments and advice from readers on these issues; however, it does need to be kept in mind that our current budget is limited and that we need to operate within these constraints.

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Notwithstanding the above, I am sure that there are many useful suggestions that readers might contribute.

Janet Sansoni
Director, AHOCH

Health system reform

(by Professor Peter Baume, Head, School of Community Medicine, University of New South Wales)

For reasons which will be argued in the paragraphs that follow, it is important that Australian medicine re-examine its purpose and priorities. It is pleasing that many Australian systems are now adopting goals and objectives which direct priority attention to health gain, rather than to illness.

It is not before time.

Our present hospital and medical systems have precious little to do with health. They are concerned, for the most part, with sickness, and with the detection and management of illness—with salvage medicine rather than with prevention or with health promotion.

Demands for curative services and for the treatment of illness are insatiable. This has something to do with the failure of most people to understand their own mortality, something to do with the glorification of youth and physical perfection, something to do with societal denial of death and dying, something to do with the expectations that have been built up by continuing advances in technology and in our technical capacity to intervene in the management of disease, something to do with the personal agendas of care-providers, and something to do

Contents

with the rhetoric of some politicians who have failed to tell the story as it is, 'warts and all'.

Regularly, we read newspaper stories about the latest technological 'achievement' —sometimes the premature reporting of preliminary results by tunnel vision enthusiasts, sometimes accounts of arcane and expensive new technologies with little relevance to the lives of most people. Amongst the technological advances are some that are critically important and worthwhile. These include coronary artery bypass grafting, modern anti-hypertensive drugs, some of the investigative techniques such as CT scans and MRI, and more. So there is no question of new technologies not being worthwhile—it is rather a question of which of the many innovations should be introduced and subsidised publicly.

Recently there appeared in a Sunday paper a story about a man who received a heart, lung, stomach, pancreas and small bowel transplant for which the paper reported he had a 50 per cent chance of survival. What was not stated in that story, but what was important for wider considerations of equity, was the question of the opportunity costs involved in the decision to carry out that extraordinary operation. Put bluntly, technological advance is not its own justification. If, to put it into effect, many other people have to be denied simple and effective care (for example, cataract extraction, hip replacement, prostatectomy), then the technology must be questioned—perhaps it is not justified to divert resources from the many to the few in ways as arbitrary as those which occur today.

Governments across Australia are in financial trouble. They have debt burdens which are now apparent and which are the subject of public debate and public concern. As one part of managing the situation, governments are reducing their financial commitment to hospital and medical services. They are demanding, and winning, efficiency gains from hospital systems and are examining ways to limit payments under open-ended fee rebate systems for medical services. While some romantics argue for still more funding for whatever it is they happen to do, this is not likely to be either possible or responsible. If it occurs, it will be at the expense of someone or something else, somewhere in the system.

While robust advocacy is accepted as part of the current system, it will have to become more sophisticated and more balanced if it is to influence governments faced with books that do not balance and with demands that are limitless. The so-called 'health' sector, representing as it does about one-quarter of the outlays of most States, will have to share in any program introduced to address continuing public sector financial crises.

This is where health system reform comes in.

For far too long we simply funded the systems we had, without examining critically any basic assumptions underpinning them. During years of sustained economic growth it was possible to maintain a fixed percentage of GDP and yet put into the hospitals and medical services more money each year in real terms. This had the effects, inter

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

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

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alia, of satisfying empire builders and of delaying consideration of basic questions of purpose and priority, questions which can be ignored no longer.

Part of the reality we face (and have faced for many years) is that rationing is part and parcel of our system of provision. What might have changed are some of the rationing mechanisms where poverty might once have limited access to care. This is now theoretically no longer the case with the right to universal access offered by Medicare (although the use of private hospitals and the private sector has been embraced, of necessity, by many needy people). The areas of interest of practitioners have served, *en passant*, to act as one rationing mechanism for if an institution favours interest A, it often is forced to ignore interests B, C or D. Other important rationing mechanisms include queues (due to many causes), the consequences of physical and social isolation, and the consequences of powerlessness. Add to all that the knowledge that power is distributed unevenly in respect to medical care—care providers are powerful compared to consumers and have used that power disparity to ensure that their priorities are the ones that are satisfied first. Power—who holds it, who wants it, who will fight to retain it, and so on—is one critical consideration in what happens in hospital systems. It has been said, often and correctly, that if one follows the likely power consequences of any proposal, one can predict who will support it and who will oppose it.

Some professional groups seem more concerned with realignment of power relationships than they are with other matters of purpose within the institutions in which they are located. While their power games might be important, they will not be sufficient in the longer run to justify the systems or their own places in them.

As well, there is a philosophical dissonance between those caring for people and those managing health systems. The former, acculturated by their medical, nursing or other professional training, are committed to the individuals they encounter, to offering those individuals best care, to responding to the problems those individuals present, with little or no regard to the opportunity costs of what they do. Philosophically they are deontologists, driven by 'the ethic of the duty of care'. That there is some element of randomness in the contacts each practitioner makes seems not to be part of the consideration.

System managers are different. They are often trained as economists and are often utilitarian in their philosophical approach. They seek 'the greatest good for the greatest number'. They look, rather more dispassionately than do care-providers, at the allocative consequences of any intervention and might determine not to subsidise one intervention in the interests of others who might need the resource for some other purpose. In Oregon, where an attempt was made to involve resident Oregonians in establishing priorities, some State subsidies were limited to some conditions on the priority list which appeared eventually.

The first reforms which are occurring now, and which are long overdue, have to do with purpose. For too long, hospital systems assumed a purpose and believed that the system was its own justification. They saw the caring professions as noble (which they are) and believed that anything done in the service of others was justified and worthwhile, and therefore that it should be funded publicly. That the care of one person might mean the denial of care to others was not traditionally a part of the thinking of care-providers. One problem is that our health outcomes, using the few crude measures that are available to us, are not outstanding—they rank sometimes behind those of Malta, Greece, Israel and Italy among others.

Some systems, notably that of New South Wales, are now moving to a 'health gain' focus, demanding that programs take into account whether they are likely to lead to any enhancement of the health of the society. This is a radical change in a system which traditionally has measured only throughput and activity—to ask it to look at results is a major change. The new Director-General of Health, John Wyn Owen, has been associated with a similar exercise in Wales and many of the ideas he has brought with him were 'field tested' there.

Add to that the facts that business was its own justification in hospitals for many years, and that many of the things we 'do' are either ineffective or downright dangerous or irrelevant to the health of society. The task is made easier for us by the work of committees, such as the Health Goals and Targets Committee, which have identified areas in which there is urgent need of activity and the likelihood of great gains to the health of society. That many of them are unfashionable or simple does not detract from their importance.

That many of the things we have done traditionally have been ineffective may come as a shock. But the history of medicine is littered with interventions that were based logically on current assumptions and which, in time, were shown not to work. Cupping, leeching and purging are but some of the older manifestations of the inappropriateness of many accepted practices—there are examples which could come easily from this century. If we continue to give financial rewards to activity whether or not it assists in the promotion of health, we will surely be guilty of compounding the problem.

Change—reform if you will—if it is to be successful must address the power relationships between individuals and groups and must also enlist the support of those who will have to bring about the change. At the very least, proposed changes should not threaten the vital interests of those it needs to enlist for change to succeed. Many of those working in the hospital and medical sectors are confused about what is happening, about what is possible, about their own futures and about what is expected of them. For health system reforms to be successful they will have to be involved and will have to 'own' the changes. For this to happen, some decisions might have to be taken to respond to the worries of many who work in the system, even if this means that powerful stake-holders are not always happy with the priorities or with the decisions.

Finally, there need be no dissonance between curative and preventive interventions in medicine. Many doctors today undertake curative and preventive activities concurrently and see the complementarity of each. It is a false dichotomy to argue for either one to the complete exclusion of the other. But it does seem that balance has been lost in recent decades, that too much has been put into curative activities at the expense of prevention and health-related interventions. Perhaps today our challenge is to ensure that the pendulum does not swing too far back the other way, to seek a balance between what are, after all, both legitimate aspects of caring and practice.

Reform is occurring. That it is driven partly by economic imperatives should not deter those of us who wish to see society the winner from what is going on and from what is yet to happen. That is the challenge of the 1990s. Meeting it is likely to see our community better off and stronger than it is today.

Aboriginal health outcomes

(by Patricia Swan and Naomi Mayers, Aboriginal Medical Service Co-operative, Redfern, and Beverley Raphael, Department of Psychiatry, University of Queensland)

Any delineation of Aboriginal health outcomes must take into account the great inadequacy of our current knowledge and the fact that where data do exist, they give clear evidence of the impact of continuing disadvantage on health status.

A recent report on Australia's health[1] has provided some of the current data on general health and noted some levels of improvement in infant mortality and life expectancy, and a lower burden of infective and parasitic disease. But rates of hospitalisation and all health outcomes remain of major concern as they exceed the corresponding rates to a significant degree for Australians generally. The age-standardised mortality rate for males is 2.8 and for females 3.8. These rates show patterns of age and sex-specific mortality which differ from the general population, for instance between 55 to 74 years the mortality rate for Aboriginal women is equal to that for Aboriginal men whereas in the general population female mortality at this age is close to half that of males. Expectation of life remains much lower for Aboriginal people, with that for a newborn Aboriginal boy who lives being 18.2 years shorter than for a non-Aboriginal and for an Aboriginal girl 19.8 years shorter. This lower life expectancy for Aboriginal people continues throughout life with adult life expectancy being much lower than for non-Aboriginal people.

Perinatal mortality remains significantly higher than for the general population with rates in the Northern Territory and South Australia being more than three times the general population rate in 1991. Similarly, while Aboriginal infant mortality has improved significantly, rates are still much higher than the general population, being more than three times the rates in the Northern Territory and South Australia.

Another area where rates remain high is in the area of maternal mortality. Despite major achievements in this area for the population generally, a significant percentage of the deaths that do occur are among Aboriginal women.

Morbidity

Morbidity patterns among Aboriginal people also reflect the impact of both disadvantage and colonisation. Deaths are accounted for by ischaemic heart disease, cerebrovascular disease, injury and poisoning. Respiratory illness, diabetes and infections and parasitic diseases are more frequent and contribute significantly to morbidity and mortality among Aboriginal people. Higher hospitalisation rates for males (71 per cent higher) and females (57 per cent higher) show further impact of poorer health outcomes.

Disability studies are few and the Survey of Disability (1986) did not provide separate data for Aboriginal people. The available data from a survey in one NSW community show one in four Aboriginal people had a disability, i.e. Aboriginal people were 70 per cent more likely to be handicapped. Loss of sight and hearing, asthma, delays of learning and development, heart disease, and diseases of the musculo-skeletal system were frequent. Chronic otitis media among children and adults is one very significant area of disability leading to other health and social problems.

Risk factors

Again data is limited because Aboriginals are under-represented in large population studies. Where data exist, they point to higher rates of smoking, high blood cholesterol, high diastolic blood pressure, obesity and harmful drinking levels.

In considering health outcomes for Aboriginal people, it is critical that there are data which allow comparison with other population groups and mechanisms to elucidate the source of adverse health outcomes such as those described above. Clearly current data are inadequate. This may relate in some instances to issues such as the failure to identify Aboriginal people in national surveys, or to sampling in ways which access their contribution. Issues of self-determination are crucial. The development of Aboriginal community controlled health organisations and medical services is increasingly providing an excellent source of care for health problems identified by Aboriginal people and in ways which not only fulfil health needs but meet cultural norms. Data exist with respect to health and health outcomes through these services but aggregation and analysis of this data in terms of health outcomes are also a matter for these organisations. Resources would need to be made available for such data to be accessed. Sensitivity exists with respect to both the publication of data and its potential for use in negative ways, and as well to racism and its implications.

Recent considerations of health outcomes instruments[2] have discussed classes of measures to be considered for multi-dimensional health profiles. These included mortality; complications/service morbidity; disease-specific measures (e.g. syndromes and symptoms), measures of service use, health-related behaviours, impact of illness measures such as functional capacity, and health-related quality-of-life. All of these measures are certainly relevant, but as indicated above, data are neither representative nor adequate. Further issues also arise in accessing many Aboriginal populations in rural and remote communities and identifying the health issues they may face.

Critical to any consideration of health outcomes is the recognition of cultural views of health and its meaning. If there are differing views, Aboriginal people generally come together to form some sort of consensus about health issues. For instance, Aboriginal people place a very strong emphasis on an holistic view of health where spiritual, physical and mental issues are interrelated and where the centrality of issues such as land and spirituality to well-being must be acknowledged. Thus the delineation of an outcomes indicator for health would have to encompass this holistic approach. Neither a symptom count nor the delineation of a degree of disability would be adequate to address impairments and handicaps faced by Aboriginal people if there were no measure or recognition of the impact of social disintegration and hopelessness on some assessment of spiritual well-being. This type of measure is not readily available in contemporary western health outcomes records. Indeed, there are no valid and adequate measures of health, especially mental health and well-being, for western health outcomes studies, let alone those sensitive to these cultural issues.

Significant delineation of health outcomes in the field of mental health has also been problematic. For instance, there have been high hospitalisation rates for psychiatric disorders. Yet it has only been in the most recent period that mental health has been identified as an issue of priority by Aboriginal people themselves, as stigma, incarceration and failure of cultural understandings made them naturally hesitant to acknowledge problems in this area. Nor have mental health systems been attuned to the special needs of Aboriginal people until recent times.

No understanding of mental health outcomes could take place without a recognition of the impact of trauma and loss for Aboriginal people.[3] This loss has undoubtedly had an impact on physical as well as mental health, yet there are no surveys identifying this risk factor in the community as a whole. Studies in one health service[4] showed that this risk factor was a key variable contributing to the high levels of psychiatric disorder found in the Aboriginal population, with a very high frequency of depression.

In suggesting appropriate health outcomes for mental health, Jenkins[5] delineates mortality and morbidity indicators, but highlights the need for questions to be focused on matters that may lead to effective intervention. She asks questions concerning specific psychiatric disorders such as: Can the incidence of the disorder be reduced? Can relapse and readmission rates be reduced? Can total disability be reduced? Is there avoidable mortality? In terms of each of these she delineates input, process and outcome indicators. This work contains matters of importance for all mental health outcomes assessment including matters of relevance for Aboriginal people. But there is also a need to encompass broader and culturally relevant issues such as the patterns of morbidity and disability that affect Aboriginal people in terms of their mental health and the risk factors associated with them.

Overriding all consideration of health outcomes for Aboriginal people must be a recognition of the effects of colonisation, racism and disadvantage in terms of poor housing, financial problems, unemployment and lack of access to resources. And health outcomes must be conceptualised in terms of cultural issues as well as in terms of an understanding of the impact of history.

Thus in addition to traditional measures of mortality and morbidity, which can only be interpreted with a recognition of the limitations of the data for Aboriginal people, risk indicators, well-being indicators and quality-of-life measures must be developed. Such measures could be developed by Aboriginal people in formats that reflect their cultural needs and understanding, with the consultative approach that is central to their way of life. They should encompass the following as a minimum:

- Mortality as outcome and its causes.
- Health care utilisation. Any such delineation should involve the views of the National Aboriginal Community Controlled Health Organisation (NACCHO) membership and the data frameworks they have evolved.
- Disability measures which

include those aspects of disability relevant to groups in different settings as well as global measures, for instance impacting on capacity to participate in prescribed cultural practices.

- Quality-of-life measures which reflect the views of Aboriginal people as to this dimension, and the contributing components of it—with particular reference to matters such as social group, land, spirituality, family.
- Risk factors. Measures need to be sensitive and specific to the impact of disadvantage generally. However, specific risk factors for ill-health need to include not only matters such as smoking and heavy alcohol intake, but also levels of exposure to loss and trauma; land and people; effects of stigma and racism; and other relevant variables.

Finally, the holistic understandings of health, while difficult to define, are central. Any measure of outcomes for Aboriginal people must ultimately reflect the integration of body, land and spirit.

References

1. Australian Institute of Health and Welfare. Australia's health 1994: The fourth biennial health report of the Australian Institute of Health and Welfare. Canberra: AGPS, 1994.

2. UK Clearing House on Health Outcomes. The potential contribution of multidimensional health profiles. Health Outcomes 1994; 2:2–7.

3. Swan P. 200 years of unfinished business. Paper presented to the National Conference, Status of the Nation, Sydney, 1988.

4. McKendrick J, Cutter T, MacKenzie A, Chiu E. The pattern of psychiatric morbidity in a Victorian urban Aboriginal general practice population. Australian and New Zealand Journal of Psychiatry 1992; 26:40–7.

5. Jenkins R. Towards a system of outcome indicators for mental health care. British Journal of Psychiatry 1990; 157:500–14.

The role of the AHOCH

In January 1994 the Australian Institute of Health and Welfare (AIHW) provided seeding funds, for one year in the first instance, to establish the Australian Health Outcomes Clearing House Project. The Institute is currently seeking funding from relevant parties to enable the continued operation of the Australian Health Outcomes Clearing House (AHOCH). The objectives of the clearing house are elaborated below with respect to both current and potential activities.

The objectives of the AHOCH are to provide a focus for activity at the AIHW and to work with others to:

- **Promote the exchange of information and views about the measurement and monitoring of health outcomes and related research.**

One of the initial aims of the AHOCH has been to establish a central information collection, dissemination and evaluation unit for health outcomes nationally and to facilitate information exchange both here and overseas among research units, researchers, clinicians, health professionals and administrators.

The AHOCH produces this quarterly bulletin (*Health Outcomes*) which aims to promote the exchange and dissemination of national and international information about health outcomes measurement and related research. As health systems in Australia adopt a health gain and health outcomes focus, health professionals, researchers, administrators and the public all require information about this change of focus and the research and measurement issues that apply to the implementation of a health outcomes focus at the national, state, service and individual levels.

The bulletin includes articles from leading researchers, health administrators and professionals from both Australia and overseas on recent trends and measurement issues. It provides reviews of current literature and conference activities and information about research centres, ongoing research activities, and the activities of the various State and Commonwealth outcomes-related units. Its national focus is to ensure that health personnel across Australia are kept up to date on health outcomes-related issues and activities and to encourage networking among such personnel.

The AHOCH also organises training activities for those health personnel wishing to adopt a health outcomes focus. An Introduction to Health Outcomes Workshop was held on 10 August and further activities of this kind will be offered in December. This is particularly relevant to those involved in regional committees and health councils in various States and also those involved in quality assurance activities within their health systems.

The clearing house also hosts seminars with international speakers (e.g. Dr John Ware) on health outcomes measurement issues, and meetings, and provides support to research networks developing instruments and indicators for health outcomes measurement. A meeting on outcomes measurement was held in Canberra on 6 July 1994 for those interested researchers attending the Health Economics Conference; a summary of this meeting is provided in this bulletin. Staff of the AHOCH present papers on health outcomes and measurement issues at related seminars, conferences and training activities.

The staff of the AHOCH also provide an advisory service linking enquirers with sources of information relevant to health outcomes and provide research support to relevant groups.

- **Establish a database of projects being undertaken which seek to measure and monitor health outcomes.**

Each bulletin has contained a research activities proforma. So far there have been over 50 responses to this proforma and many of these are listed in this bulletin. All these activities are now reported on a projects database which is continually updated. A number of key research centres have also been contacted to ascertain if there are other current research activities which need to be added to this database. Discussion has been held with officers of the NSW Health Outcomes Program concerning the addition of their funded projects, and negotiations have commenced with the UK Clearing House and the Medical Outcomes Trust concerning an exchange of information with reference to their research activities and research network. It is to be hoped that shortly health outcomes researchers from both these countries can form an international network. Similar negotiations have commenced with other organisations in the United States, Canada and New Zealand.

The project proforma/report provides details as to aims, target group and sample characteristics, nature of intervention, measures utilised, and so on. Through networking of this information, it is hoped that research activities and collaborative endeavours will be facilitated throughout Australia and that this will assist in avoiding unnecessary duplication of research effort across the States and Territories. It will also provide a useful starting point for researchers commencing activities in this field.

A bibliographical database has also been established which currently contains approximately 800 titles. Negotiations have commenced with related organisations both here and overseas to exchange information and to consolidate entries. Currently such listings are available to researchers and collaborating centres and shortly full abstract details will also be available. Databases will be made electronically accessible as soon as resources permit.

- **Develop and refine measures and descriptors of health status which may be useful in the measurement or monitoring of health outcomes.**
- **Measure and monitor the health outcomes associated with health interventions.**
- **Examine methodological issues related to the acquisition of valid and reliable information on the outcomes of interventions.**
- **Make data available to collaborative investigators to facilitate research in health outcomes where practical.**

The AHOCH is also developing a database of instruments and measures that may be utilised in health outcomes research; and through its project database of research activities is forming links and networks with key research groups with respect to the development and use of outcomes indicators. The establishment of an instruments and measures database (both generic and condition-specific) can mean that ultimately reports on instruments (and copies where copyright permits) may also be available in electronic form. The above endeavours should considerably facilitate the work of outcomes units across the States and Territories as well as the work of health professionals, administrators and health-related committees and councils.

The AHOCH is developing expertise in quality-of-life measurements, the instruments that can be used in routine care settings, and in research studies to measure quality-of-life and other psychosocial factors in the management of health conditions. Through the dissemination of discussion papers on measurement issues, it will endeavour to foster informed debate as to which measures may be most appropriate to use at population, service and individual levels. In some instances, where process is closely tied to outcome, process measures may be used as proxy indicators for outcomes measures but evaluation of such indicators will be necessary to determine whether such indicators are effective.

The AHOCH falls within the Health Services Division of the AIHW. It also has close links with the Health Monitoring Division which is responsible for both measuring and reporting on national trends in health status and monitoring health status indicators with respect to National Health Goals and Targets. AIHW databases include the National Death Index, the National Cancer Statistics Clearing House database and the National Hospital Morbidity database. The privacy provisions of the *Australian Institute of Health and Welfare Act 1987* have a number of features that would allow it to collaborate with public and private organisations in the confidential collation and analysis of information. The Act also gives AIHW the power, with approval of its Ethics Committee, to release identifying data to collaborators. The AHOCH could assist collaborating organisations gain access to AIHW and Commonwealth databases useful for health outcomes research.

The AIHW also has access to unit record data (although not identifying individuals) of Medicare claims, Pharmaceutical Benefits prescriptions, and other Commonwealth databases. Given a sufficiently strong scientific case, and with the agreement of the data holders, it would be prepared to seek from the Privacy Commissioner a public interest determination under the Privacy Act to enable it to obtain personally identified records and to link databases. In principle, personally identified hospital morbidity records could also be obtained, subject to the necessary permissions and safeguards. Linking such databases with other data collections (e.g. pharmaceutical, Medicare, hospital-based registries), where permissible and appropriate, would provide a rich data source for the development and trialling of health outcomes and outcomes-related indicators. A demonstration project may be undertaken in a key area (e.g. diabetes, hypertension, asthma) to show how available databases may be utilised in outcomes measurement and outcomes monitoring at the population level, as well as examining what measures might be useful at the service and individual levels.

Currently staff of the clearing house and the AIHW are also well placed to undertake commissioned research and analysis on best practice guidelines, instrument and indicator development and outcomes measurement.

Through these activities and through the provision of training workshops, seminars on measurement issues and the establishment of national research networks, the AHOCH is well placed to work with other organisations at both the Federal and State levels to foster national data collection and national reporting on health outcomes.

Current products

- *Health Outcomes* Bulletin
- Bibliographical listings and advice
- Research project listings
- Research networking and support
- Discussion papers and presentations
- Proposal evaluation
- Seminars and training workshops

Potential additional products*

- Instruments and measures database
- Research on the development and use of indicators
- Provision of advice on indicators for national data collection
- National collection point for outcomes data
- Analysis of national outcomes data
- Reports on national outcomes data

* assuming continued funding.

Should you require further information about current listings, reports/papers available, or forthcoming workshops, please contact Pamela McKittrick, Research Assistant, AIHW, (06) 243 4032. If you require more detailed research advice contact Jan Sansoni on (06) 243 5029.

Recent activities

Outcomes measurement issues meeting

AIHW, 6 July 1994

In attendance: Roy Harvey (Chair: AIHW); Professor Harri Sintonen (NCHPE); Dr Graeme Hawthorne (NCHPE); Dr John McCallum (NCEPH); Dr Jane Hall (CHERE); Johanna Cook (Victorian Department of Health and Community Services); Dr Bruce Shadbolt (ACT Health); Gillian MacFarland (ACT Health); Dr Ross Lazarus (Department of Community Medicine, Westmead Hospital); Dr Fiona Blyth (Department of Community Medicine, Westmead Hospital); Glenn Close (NSW Health Department); Tony Wood (ABS); Janet Sansoni (AIHW); John Goss (AIHW); Chris Stevenson (AIHW); Paul Jelfs (AIHW); Clara Jellie (AIHW).

Apologies: Professor Jeff Richardson, Professor Gavin Mooney

Summary: As it was known that a number of key researchers from the National Centre for Health Program Evaluation (NCHPE) and the Centre for Health Economics Research and Evaluation (CHERE) were attending the Health Economics Conference in Canberra, the Australian Health Outcomes Clearing House (AHOCH) used this opportunity to host an informal meeting with such researchers.

A number of researchers were utilising the SF–36 in their current research and had discussed problems encountered with its use (e.g. elderly patients' expectations and the four-week time frame) with both chronic and acute conditions. It was noted that there is now a version of the SF–36 for acute conditions available where the time frame is adjusted from four weeks to one week.[1] Concern was expressed that the SF–36 was being used almost as a de facto gold standard, and that because outcomes measurement was often viewed as difficult, there was a tendency for people to use the SF–36 without much consideration of its appropriateness in the particular context or setting or the purpose of the proposed outcomes measurement activity, or without any regard to its relative psychometric properties. While it was agreed that this instrument was a useful one, it was felt there needed to be much more informed debate about the use and merits of various instruments with reference to the purpose of the measurement activity. While there are a number of books addressing such issues, it was felt that the AHOCH might prepare a summary discussion paper, in conjunction with a steering group, recommending appropriate instruments, measures and indicators for various research contexts. Some other instruments thought worthy of further consideration included the 15D measure of health-related quality-of-life;[2] the new Rosser Index, the Index of Health-Related Quality-of-Life;[3] Torrance's Multi-Attribute Utility Scale;[4] the NCHPE Multi-Attribute Utility scale (under development); and WHOQOL[5] (although the size of this instrument is problematic).

The issue of measuring outcomes in both chronic (e.g. disability) and terminal conditions was also discussed. What might be defined as a positive outcome in such situations? A good outcome in the latter instance may be a 'good death' and research had not adequately addressed this issue. Researchers also needed to address the issue of consumer satisfaction and how best to measure this. There were a number of health authorities interested in using the RAND patient satisfaction questionnaire but as this instrument is very long there is a need to examine and recommend more manageable instruments for consistent national use.

Work on the NCHPE Multi-Attribute Utility Scale project is proceeding. The aim of this work is to obtain a single value that represents population preferences that can be used to make decisions regarding resource allocation. The researchers involved (NCHPE) believed that this could be achieved, but acknowledged that it would require much work. A draft instrument based on four dimensions of the WHOQOL has been developed, and the researchers believe that they will be piloting a version of this instrument by the end of this year. The group was divided concerning the use of a single index for quality-of-life, particularly with respect to resource allocation given that health-related quality-of-life is so diverse.

Harri Sintonen described the development and structure of his 15D instrument[2] (a measure of health-related quality-of-life) which has 15 dimensions from which a single value appropriate to quality-adjusted-life-years can be derived. Following discussion of the two-stage valuation method used to value health states, which avoided the problem of logical inconsistencies in valuation found with other methods, it was thought this instrument may compare favourably with other such indices. This instrument is also reviewed in the reviews section of this bulletin. It was also noted that there had been some recent research activity conducted overseas with regard to the development of a single index and the application of utility weights to the SF–36—while this approach may hold some promise, this research was at too early a stage to evaluate.

Participants agreed that there was a great deal of confusion regarding the use of the term 'outcomes' in recent policy documents and confusion concerning how health outcomes are related to the setting of health goals and targets, benchmarking activities and other processes. 'Outcomes' was usually not used in the strict sense as defined by the Sunshine Statement (in which changes in health status must be attributable to specific interventions), but instead was used to merely indicate a change in population health status. Again it was thought that there was a need to inform policy-makers and researchers concerning definitions and terminology as well as the relative merits of various instruments, measures and indicators of health status that may be useful in outcomes research.

References

1. Ware JE, Snow KK, Kosinski M, Gandek B. SF–36 health survey: manual and interpretation guide. Boston, MA: The Health Institute, New England Medical Center, 1993.

2. Sintonen H, Pekurinen M. A fifteen-dimensional measure of health-related quality-of-life (15D) and its applications. In: Walker SR, Rosser RM, (eds). Quality of life assessment: key issues in the 1990s. London: Kluwer Academic, 1993.

3. Rosser R, Allison R, Butler C, et al. The index of health-related quality-of-life (IHQL): a new tool for audit and cost-per-QALY analysis. In: Walker SR, Rosser RM, (eds). Quality of life assessment: key issues in the 1990s. London: Kluwer Academic, 1993.

4. Torrance GW, Boyle MH, Horwood SP. Application of multi-attribute theory to measure social preferences for health states. Operations Research 1982; 30:1043–69.

5. Sartorius N. A WHO method for the assessment of quality-of-life (WHOQOL). In: Walker SR, Rosser RM, (eds). Quality of life assessment: key issues in the 1990s. London: Kluwer Academic, 1993.

From the States and Territories

The care continuum and health outcomes of hospital inpatients: A two-year project in the ACT

(by Bruce Shadbolt, Epidemiology and Population Health, Public Health Division, ACT Department of Health)

On 7 May 1994 the Federal Health Minister, Dr Carmen Lawrence, approved funding for the ACT Ambulatory Care Research and Pilot Program, being part of a Commonwealth initiative to examine ambulatory care. The Epidemiology and Population Health Section of the ACT Department of Health, in collaboration with the National Centre for Epidemiology and Population Health (NCEPH) at the Australian National University, is conducting one of the projects in the program. The research team includes Ms Gillian McFarland (ACT Program Manager of Ambulatory Care Research), ACT Department of Health; Dr John McCallum, NCEPH; Dr Bev Sibthorpe, NCEPH; and Dr Bruce Shadbolt (Principal Investigator), ACT Department of Health. The team is investigating the care continuum and health outcomes of approximately 10,000 inpatients and their experiences prior to admission, during their hospital stay and up to six months after discharge. The project covers formal and informal service utilisation, costs across the care continuum, and health outcomes including quality-of-life, and explores cost-effectiveness models to improve the use of resources.

In recent times, Australia has been making an effort to restructure its tertiary health care system. This undertaking has been driven not only by economic incentives but also by a desire to improve inpatient health care and treatment outcomes. As part of this push, Wahlqvist and Wright[1] argue that 'outpatient' care should include an increased number of patients with complex conditions currently being cared for within a hospital using round-the-clock nursing and an expensive 'motel' infrastructure. They expect that focusing more on 'ambulatory care', especially at a tertiary level, will allow new and improved approaches to health care administration, medical informatics, biomedical engineering and clinical practice. The challenge is to identify and conserve the beneficial characteristics of inpatient and ambulatory care, and determine changes that will further improve treatment outcomes, the quality-of-life of patients and spending on health care.

The ACT care continuum project has been sparked by a dearth of research that follows hospital patients in Australia from their time of admission to their treatment outcome, and quality-of-life after they separate from hospital. Apart from studies conducted on specific treatments, such as rehabilitation and cancer treatment interventions, most of the research on hospital care and resource allocation has concentrated only on the inpatient episode. The care continuum project aims to take a broader approach by developing:

- a profile of inpatient and ambulatory care utilisation that includes the paths leading to hospital admission, the hospital inpatient stay, outpatient service use, and help from within the home
- a profile of treatment outcome and quality-of-life after discharge
- a profile of costs incurred at each stage of the care continuum
- cost-effectiveness models to help identify beneficial combinations of inpatient and ambulatory care, and achieve better resource management of other combinations that lead to undesirable outcomes
- recommendations for improving data collection systems; for instance, the care continuum project will provide insights into the types of data needed to better monitor the care of a health condition, and
- models of treatment outcomes and quality-of-life that identify key determinants or high risk groups.

In relation to the time frame for the project, pilot work is already under way to help determine the instruments that will be used in the main survey. The recruitment of patients is due to start in January 1995. After six months of recruiting and six months follow-up, a report will be produced for the Commonwealth Department of Human Services and Health showing preliminary findings. The data collection is expected to stop in July 1996, with a final report going to the Commonwealth in September 1996. The research team will continue to analyse the data, exploring issues related to resource allocation, aged care, equity and access to services, and a variety of health outcomes topics.

The number of patients in the survey will depend on the methodology decided upon as a result of the pilot work. The maximum number will not exceed approximately 10,000 people. Furthermore, the sample will be stratified, oversampling for those with more complex/serious health conditions, those with chronic diseases, the elderly and lower socioeconomic groups. At this stage, however, the coverage of inpatients has not been finalised. Given the need to reduce respondent burden and costs, a sub-sample approach will be adopted over the course of the survey—although, all respondents will be followed for the first six weeks after discharge. Within the sub-sampling, patients still receiving treatment or those who perceive that they have not recovered after six weeks will remain in the survey, while a random sub-sample of those who have 'recovered' will remain in the study for the six months follow-up. The sub-sample of 'recovered' people will ensure that the study results are not biased by the definition of recovered.

Depending on the results of the pilot, the study proposes five sources of data collection:

- An interview questionnaire, administered at the hospital, which gathers details about the paths leading to admission, as well as retrospective and current status information about socioeconomic conditions and quality-of-life.
- Standard data obtained from admission and discharge forms, including AN-DRGs, and detailed information about the treatment received by the patient and patient histories will be extracted from the hospital morbidity collection.
- Specifically collected biomedical data for particular health conditions (currently, the detail associated with this data is being negotiated with clinicians).
- A diary maintained by the patient, although filled out by the service provider, that prospectively gathers information about health services used after discharge from hospital. These data will allow a profile of service use and costs incurred, including information on the date of attendance, duration of the consultation, reason for the visit, and possibly (where appropriate) the fee for the service and treatment provided. Re-admission and transfers between hospitals will be included. Most respondents will need to keep the diary for only six weeks. Every effort will be taken to make the diary simple to use, and regular check-ups by the research team will be undertaken to ensure that patients are using them. In cases where a service provider will not fill out a diary or the patient forgets to take it with them, the respondent will be asked to fill in the missing information. Such data will be recorded as self-reported. Using a diary as a

form of data collection has been successful in dietary, exercise and labour force surveys. It is envisaged that a health service use diary also would be very successful.

- A self-completion questionnaire that collects data on quality-of-life, recovery progress, socioeconomic status and help received at home. This mail-out questionnaire will be sent to patients one week, six weeks, three months and six months after discharge. Accompanying the questionnaire will be documentation reminding patients about their diary, and asking them to return their diary with the self-completion questionnaire if they are classified as 'recovered' after either six weeks, three months, six months or not recovered after six months. In addition, a random sub-sample of 'recovered' respondents will be surveyed for the full six months.

Three out of the five collections rely on the patient to provide or at least obtain the information. Reliance on the patient has the advantage that data collection is not dependent on existing data systems and service providers. Consequently, data can be gathered from outpatient services located in the hospital right through to a visit to a local general practitioner or allied health worker, or to help received at home. Furthermore, a patient-based data collection allows the study to ask personal questions about well-being. During the pilot study great efforts will be made to ensure that collection instruments have been thoroughly tested, and processes examined to maximise the validity and reliability of the data while minimising the burden placed on respondents.

The time seems ripe to conduct this type of research: AN-DRGs have been established; more comprehensive information is being continually sought; length of stay in hospital is shortening; and health gain rather than cost-benefit is more desirable, especially within a constrained economic environment. Furthermore, Australia needs to explore innovative approaches to its delivery of health care. Certainly, types of data that provide more than administrative and counting reports should be collected. We need to develop data collections and analyses that policy-makers, hospital administrators and clinicians can use to improve both health and services. This care continuum and health outcomes project hopes to provide data and findings that will help achieve these goals. Furthermore, the ACT Department of Health sees this project as a catalyst for bringing together a broad range of people in the health care industry, leading eventually to innovative data collections that will assist in advancing Australia's health system.

Please feel free to contact Dr Bruce Shadbolt for further information on (06) 205 0834.

References

1. Wahlqvist ML, Wright C. Tertiary ambulatory care: its strategic importance in future health care. Australian Journal of Public Health 1993; 17:187–187.

Improving health outcomes in Western Australia

(by Andrew Penman, Chief Health Officer, Health Department of Western Australia)

On 1 July 1994 the structural changes in the health system foreshadowed by the Minister for Health in late 1993 were finalised. These changes instituted formal arrangements between government, health department, public health and health service providers, generally described as separating the functions of funds provider, owner, purchaser and provider in the health care system.

A leading aim of these arrangements is to ensure that the health system as a whole focuses on the achievement of health outcomes, and maximises the health gain which can be procured with available resources.

These reforms have created two major entities out of the previous Central Health Department:

- a Government Health Bureau responsible for the funds' provider/owner functions of the health system, and
- a State Health Purchasing Authority responsible for developing, through contractual agreement with providers, a regulated market in health services which ensures that services are delivered and paid for on a more open and contestable basis.

In this system, both the Government Health Bureau and the State Health Purchasing Authority have responsibility for improving health outcomes. The Bureau, through the Office of the Chief Health Officer, is responsible for assessing population health needs and trends, and canvassing opportunities for health gain through purposeful public policy and/or health service development. Through its system policy function, it determines the global approach to population resource allocation including the adjustment of the resource allocation formula to reflect health disadvantage.

The Authority is responsible for ensuring that the resources available to purchase health services on behalf of regional populations are applied in the best possible way to increase aggregate levels of access to health services, to minimise health inequality, and to ensure that contracted providers deliver nominated care of a quality which ensures a health return from the process of care, i.e. improved clinical outcomes.

Health goals and targets

Western Australia has a strong record of needs assessment and target setting in public health typified perhaps by successive editions of 'Our State of Health' in 1986 and 1991. While these documents were concerned primarily with setting of goals in health promotion and disease prevention, they established a familiarity with and a commitment to population health goals.

Western Australia has also been well served by the quality of its health information which provides essential infrastructure to the setting and the evaluation of progress towards population health goals and targets. The utility of existing databases is being expanded through increasing use of geographic information systems, and the development of additional collections such as an alcohol sales/consumption database, expanded routine injury surveillance systems in hospitals, and a cervical cytology register. The State is also developing a routine health survey which will complement existing databases by providing more comprehensive information on prevalent health states. Potentially, this will provide the State with an enhanced ability to measure health-related quality-of-life in the general population and in targeted subgroups and to assess the need for and impact of clinical services in populations.

It is envisaged that goals and targets will be developed through an iterative process in three relatively discrete areas:

- goals and targets for clinical services
- goals and targets for health risk reduction
- access and equity goals and targets.

In early July 1994 the Taskforce on State Health Goals and Targets delivered its first report on 'Clinical Health Goals and Targets for Western Australia'. This report serves a number of objectives:

- it fulfils Western Australia's obligation to the national commitment in health goals and targets
- it furnishes purchasers and providers with a set of key outcomes to be achieved through clinical services in the short and medium term
- it communicates the State Government's detailed agenda in pursuing health gain.

These clinical goals and targets have been developed through a partnership between the medical and nursing professions and officers of the Government Health Bureau and State Health Purchasing Authority. This partnership is embodied in a Taskforce on State Health Goals and Targets under the chairmanship of Dr Suzanne Dobson.

The development of goals and targets drew on the advice and input of a wide range of medical and nursing professionals and relied significantly on their assessments of needs and opportunities in clinical service, confirmed and supported by available data on health and health service in Western Australia.

The resulting report advances health goals and targets in the following areas.

Chapter 2: cancer

- Reducing mortality and improving treatment outcomes in breast cancer.
- Reducing the incidence and mortality from cervical cancer.
- Reducing morbidity of and mortality from colorectal cancer.

Chapter 3: cardiovascular disease

- Reducing incidence of and mortality from ischaemic heart disease.
- Reducing cardiovascular morbidity and mortality in the elderly through control of hypertension.

Chapter 4: disability and chronic disease

- Reducing harm associated with alcohol.
- Reducing morbidity and mortality from asthma.
- Preventing and controlling non-insulin dependent diabetes mellitus.
- Improving access to transplantation services.

Chapter 5: mental health

- Reducing the morbidity and mortality in patients and carers associated with chronic psychoses.
- Reducing deaths from suicide among persons who have previously attempted suicide or exhibited self-harming behaviour.

Chapter 6: trauma

- Improving trauma outcome in Western Australia.

The overlap between goals and targets proposed by the Taskforce and the various implementation working groups for national health goals and targets is obvious. This is to be expected given the provenance of the goals and targets agenda, and the similarity in the causes of morbidity and mortality throughout the nation. However, the document is not merely a piecing out of the national goals and targets but is distinctive in the following ways.

- It focuses exclusively on clinical services (with the exception of some risk reduction targets in alcohol).
- The structure of goals and targets differs substantially from those proposed in national documents and in particular accommodates the requirement for formalised purchasing of health services.
- Goals and targets have been developed in areas not addressed at the national level, e.g. some chronic diseases.
- Differences in emphasis and strategy are apparent. The most obvious is a firm proposal for population screening for colorectal cancer.

Measuring clinical outcomes

The Taskforce Report is clearly committed to improving the process of health care and the access to care of those people who stand to benefit from clinical services. The Taskforce has recognised that improvement in valuation and monitoring is essential if the goals and targets exercise is to have any impact. Accordingly it has recommended significant health information development. These developments include the following:

- Modification of the hospital morbidity data system to collect key items of background health status and health risk of relevance to the goals and targets, e.g. diabetes, hypertension, asthma, alcohol and injury.

- Expanded use of existing registers. The development of an in-hospital cancer registry linked to the State cancer registry, further development of the mental health register to record clinical outcomes in treatment populations, and more active use of the cervical cytology register are proposed.
- Creation of new program or disease registers. Diabetes and trauma registers are proposed as essential clinical management and program evaluation tools.
- Population surveys. The expanded use of routine population surveys for health risk and health status assessment is proposed. Furthermore the development of special surveys in specific populations, e.g. asthmatics and Aboriginal people, may be required.
- Provider reporting. The report outlines numerous areas in which provider reports to the purchaser will be critical in monitoring the achievement of health service targets.

The hierarchy of health targets proposed encompasses the need to measure health service outcomes. However, despite the availability of an array of validated clinical outcome instruments, the Taskforce found that their infrequent use militates against incorporating formalised measures of clinical outcomes in health targets at the moment.

As a result, the service targets proposed are biased heavily towards capacity, access and quality issues and less towards outcomes.

The potential for applying formalised instruments in the measurement of outcomes in clinical populations is now identified as an important research development priority within the Government Health Bureau and the Office of the Chief Health Officer.

Health outcomes research in CHERE

(by Alan Shiell, Centre for Health Economics Research and Evaluation)

Introduction

The Centre for Health Economics Research and Evaluation (CHERE) was established in 1991 with core funding from the NSW Health Department and additional support from the Western Sydney Area Health Service, Westmead Hospital and the University of Sydney. The Centre is co-located with the Department of Community Medicine at Westmead Hospital and is a department (with restricted status) within the Faculty of Medicine at the University of Sydney.

CHERE's brief is to improve the use of economic analysis among health policy-makers through teaching, research and service-related consultancy. Our interest in health outcomes arises for two related reasons. The first arises from the nature of economic cost. In economics, the cost of one activity is equal in value to the forgone benefits of the most favoured alternative. Thus economic evaluation involves a comparison of the benefits (or outcomes) of alternative courses of action. Second, a major obstacle which prevents more widespread use of economic techniques by health service decision-makers is the difficulty in measuring and valuing health outcomes.[1] It is therefore fitting that health outcomes research comprise a major part of our future plans.

An augmented 'production of welfare' model sets health outcomes into an economic framework and provides a structure for our research agenda.[2] This draws on the analogy of a production process to clarify the relationship between health inputs, processes, outputs and final health outcomes. Within this framework, outcomes-related research in CHERE takes place at a number of levels. What follows is a brief description of the range of research activities which come under the outcomes umbrella.

What constitutes an outcome?

The production of the welfare model raises issues about what should be considered as final outcomes of the health service. The use of health services does not only result in health gain or the prevention of health loss. Other non-health benefits such as the provision of information and reassurance are also important. At a conceptual level, research programs within CHERE are currently directed towards identifying what the community wants from its health service and from its doctors; measuring the outcomes of health promotion, especially community and organisational development; and exploring whether patient satisfaction is an outcome of hospital care. Each of these programs is at an early stage, and still identifying the research agenda rather than addressing the issues directly.

Measurement of health outcomes

CHERE is currently undertaking a major three-year study to investigate the cost and outcome of treatment for women with early-stage breast cancer. This study is funded by the Public Health Research and Development Committee (PHRDC) and involves an extensive evaluation of quality-of-life three months and twelve months post-surgery using a comprehensive battery of measures.

Such projects not only provide information which might be useful in guiding resource allocation and clinical practice, they also provide an opportunity to develop methods for measuring health outcomes. For example, a second PHRDC-funded project is comparing alternative ways of measuring the outcomes of cancer care. This includes a longitudinal study of changes in quality-of-life both during and after prolonged chemotherapy and consideration of the statistical problems raised in analysing such data.

Valuation of health outcomes

The multi-dimensional nature of health outcomes and the existence of non-health benefits of health service use make valuation necessary in order to determine the relative effectiveness of health services. Within the early-stage breast cancer project, the different methods of eliciting health state valuations (quality-adjusted-life-years versus healthy year equivalents) are being compared. The impact patient involvement in clinical decision-making has on the women's subjective value of their health outcome is also being assessed.

The NSW health outcomes initiative

A number of research projects have been funded throughout NSW by the NSW Health Department under its health outcomes initiative. CHERE staff have been directly involved in five of these relating to the evaluation of health outcomes in congestive cardiac failure, diabetes, opportunistic immunisation, endoscopy and gynaecological cancer. CHERE has also played a major role in providing general advice on the economic implications of the other proposals.

Evaluations of health outcomes

In addition to projects relating specifically to health outcomes, a number of economic evaluations are being carried out by CHERE staff. Such proposals are rarely accepted unless there is an assessment of health outcomes. Current projects include evaluations of domiciliary chemotherapy, team midwifery, and the treatment of prostate cancer. Typically these involve close collaboration with clinical practitioners, with CHERE responsible for carrying out the evaluation of cost and quality-of-life. Such collaboration is critical to the success of the project. It ensures the results of the evaluation are clinically relevant and acceptable to those who must implement its conclusions.

Health outcomes and planning

Health planners also need to be cognisant of health outcomes if the emphasis on health outcomes is to be translated into more effective health services. To encourage greater use of economic principles in resource allocation (including the use of health outcomes), CHERE is exploring the feasibility of using program budgets and marginal analysis.[3,4] This involves categorising the activities of Area Health Services into programs and then enabling health planners to identify the scope to reallocate resources within and between programs from activities which are least effective to those which are more effective.

Conclusion

Outcomes research is an important element in CHERE's five-year research strategy. Such research is taking place at both conceptual and applied level over both short and longer time frames. Increased awareness of the importance of health outcomes among health policy-makers challenges us to develop appropriate and useable measures of health outcomes. It also presents us with an opportunity to improve health service decision-making by encouraging and enabling managers and clinicians to take account of the effectiveness of the services they provide as well as the economic cost.

References

1. Ross J. The use of economic evaluation by health care decision makers—an Australian study. CHERE discussion paper no. 24. Sydney: University of Sydney, 1994.

2. Hall J, Shiell A. Health outcomes: a health economics perspective. CHERE discussion paper no. 19. Sydney: University of Sydney, 1993.

3. Mooney G. et al. Priority setting in purchasing: some practical guidelines. NAHAT research paper no. 6. Aberdeen: Health Economics Research Unit, 1992.

4. Shiell A. et al. Advancing health in NSW: planning in an economic framework. CHERE discussion paper no. 23. Sydney: University of Sydney, 1993.

The National Centre for Health Program Evaluation

(by Terri Jackson, National Centre for Health Program Evaluation)

With greater attention to the outcomes of health care by both government and providers, the need for evaluation tools which yield useful information for policy development and priority setting has become more urgent.

The Melbourne-based NHMRC National Centre for Health Program Evaluation (NCHPE) has set as a major goal the development of evaluation tools which go beyond individual studies of specific interventions. More rational allocation of health resources will require that policy-makers be able to assess the benefits and costs of different approaches to the same health issue; and costs and benefits of care across the range of health problems and conditions.

Established in January 1991 with funding from the NHMRC Public Health Research and Development Committee and VicHealth, the Centre has drawn together a team of nine core staff with training in health economics and health services research and evaluation. Additional project funding has doubled this to 18 researchers now working at the Centre.

A number of program areas have developed to support the aim of policy-relevant evaluation. The Disease-Based Evaluation Framework Project, for example, aims to develop a comparative framework for evaluation of the range of interventions, from primary prevention through to treatment of end-stage disease, and palliative care. Health economists, Jeff Richardson and Leonie Segal, are developing the framework using non-insulin-dependent diabetes care as the first of a series of such comparisons for specific conditions or health problems. Other projects planned for development of the framework include coronary heart disease and road trauma.

The project involves a process of preliminary ranking or options appraisal for alternatives at each level of intervention; the linkage of marginal projects by translation of outcomes into comparable units; and the use, where necessary of cost-utility analysis to achieve comparability. By assigning dollars to outcomes for various levels of intervention, policy-makers can better assess at which point in the prevention–treatment continuum additional investment might yield greater health benefits.

A second policy-focused project is the development of the Macro-Economic Evaluation Model (MEEM), a joint project with the Australian Institute of Health and Welfare (AIHW), headed by Rob Carter. The project was initiated as a way of assisting the NHMRC in assessing the economic benefits of a large number of potential health promotion and illness prevention services, and to provide a tool for the Department of Health and Human Services to use in evaluating the likely impact of health advancement initiatives.

The underlying premise of the MEEM is that judgments about priorities for illness prevention and health promotion should be based on information about three issues.

- The public health significance or burden of suffering of health problems (measured by, e.g. number of deaths, life expectancy, health expectancy, cost of illness) to clarify needs, equity and scale.
- The theoretical preventability (efficacy) and practical preventability (effectiveness) of the health problems.
- The relative cost-effectiveness (efficiency) of individual preventive measures aimed at achieving the potential for prevention.

It has been designed to attribute national health expenditure data (from databases held by the AIHW) to specific disease states and, from there, to evaluate potential savings at different levels of prevention and/or intervention across the range of possible program alternatives. Data from the MEEM will also be used to provide cost estimates for use in the Disease-Based Evaluation Framework.

One theme of both of these projects is that evaluation must itself be cost-effective. If comparison of outcomes, both within and across programs, is to be used routinely for determining directions of the health system, such evaluation must be able to be undertaken in a timely way, and making best use of available data.

Work at the Centre on primary prevention has focused on finding better evaluation approaches to broad-based community interventions. David Dunt and Neil Day, evaluating the National Heart Foundation's Shepparton Healthy Heart Project, and Penny Hawe and Jan Garrard, evaluating the VicHealth-funded Healthy Localities Project, have sought to develop indicators of culture change which go beyond risk factors as outcome measures of the success of these complex interventions.

Many of the projects to develop policy tools for evaluation have arisen from individual studies evaluating particular technologies or forms of care. For example, Michael Montalto compared patterns of care provided by general practitioners working in Community Health Centres with those of general practitioners in the Australian Morbidity and Treatment Survey (Bridges-Webb) database. Other studies have included the cost-utility of lithotripsy compared with conventional and laparoscopic cholecystectomy, patterns of intensive care unit utilisation, school-based drug education programs, and breast cancer screening programs.

One key to using existing data sources for outcomes research is risk adjustment, i.e. adjusting outcomes of care for pertinent patient characteristics. Policy-makers cannot assess outcomes of, nor providers be held accountable for, the variability in health costs and outcomes attributable to patient variability. In this area, Terri Jackson has investigated the degree of within-DRG variability in patient costs using AN-DRG data from hospital clinical costing systems. Studies in 1993 and 1994 provided the basis for the relative payment weights adopted by the Victorian Government in the first two years of DRG-based funding.

Perhaps the greatest challenge facing health economics in the measurement of health outcomes is the way in which the quantity and quality-of-life can be combined into a single unit. The National Centre's research program has investigated the practical and ethical foundations of such measurement. Jeff Richardson, Johanna Cook and Graeme Hawthorne are developing a multi-attribute utility (MAU) instrument for measuring health outcomes across multiple dimensions of health and functioning.

Empirical research undertaken at the Centre has found that existing multi-attribute utility instruments do not predict the trade-off between life and quality-of-life that would be directly selected by the public. Results of two NCHPE studies (one with the Monash Bioethics Centre) cast doubt on the empirical validity of the assumptions made by economists about the fundamental ethical views of the population, and in particular about the importance of maximising health when this conflicts with issues of social justice.

The Centre has attracted a number of respected researchers from overseas, including two national representatives in the Euroqol Group: Erik Nord from Norway and Harri Sintonen from Finland.

Centre staff also undertake work dealing with more general questions of the efficiency of the health care system, and the impact of alternative funding systems. Dick Scotton and Jeff Richardson in particular have contributed important theoretical and empirical papers to national health policy development as part of their work at the Centre.

In an effort to increase the pool of researchers trained in health services research and evaluation, the Centre has sponsored the development of a Monash University graduate diploma in health economics, a distance-education short course in health economics, and is a part of the Melbourne Universities Public Health Consortium. In addition, the Centre runs a fortnightly seminar series, and has published over 40 working papers, technical and research reports. Further information about NHCPE publications and taped seminars are available by contacting Ms Mande Falko, NHMRC National Centre for Health Program Evaluation, Yarra House, c/- Fairfield Hospital, Yarra Bend Road, Fairfield 3078, fax (03) 4813749.

The Medical Outcomes Trust

Boston, MA, USA

The Medical Outcomes Trust is a non-profit public service organisation created to provide a home for generic and disease-specific measures of health and health care. The Trust's broad goals are to:

- facilitate assessment of the effectiveness of health care delivery
- promote the continuous improvement of high quality health care
- foster the improvement of health-related quality-of-life.

The Trust was established to achieve the following three objectives:

- to assure the availability of patient or consumer-based health outcomes surveys and scoring documentation to all, free of charge
- to standardise the content scoring and labelling of these instruments to ensure their scientific validity and comparability across studies and countries
- to facilitate information exchange among users of health assessments.

Outcome measures distributed by the Trust are primarily concerned with the patient's perspective about the results of medical care. There is a broad array of measures to assess the outcomes of medical care. These measures include assessments of:

- specific diseases or treatments in terms of end points traditionally measured by clinicians
- generic measures of physical and mental functioning and well-being, social and role disability, and general health evaluations
- new disease-specific modules that measure symptoms and problems from the patient's perspective
- evaluations of specific features of health care services (access, interpersonal and technical clinician style, quality of care)
- overall satisfaction
- costs of health care.

The Trust disseminates these instruments and their scoring documentation freely and simply, making them available to everyone. Permission to use currently available instruments is routinely granted and no royalty fees are assessed. Obtaining consent to use and reproduce instruments and basic scoring algorithms may be granted by the Trust.

The first instruments available under the Trust have been the SF–36 Health Survey developed during the Medical Outcomes Study (MOS) and English language adaptations for use in other countries. Translations of the SF–36 developed through the International Quality-of-Life Assessment Project (IQOLA) are forthcoming. Other advances in assessment methods expected to be widely adopted will be added to the Trust and include health measures for children and HIV-infected individuals, in addition to measures of consumer satisfaction with health care.

Please note that the Australian Health Outcomes Clearing House has established links with the Medical Outcomes Trust, and hopes to establish a strong collaborative relationship with this organisation.

For further information, please contact The Medical Outcomes Trust, 20 Park Plaza, Suite 1014, Boston, MA 02116-4313, USA, Fax (617) 426 4131.

The Health Outcomes Institute

Bloomington, MN, USA

The Health Outcomes Institute (HOI) is a non-profit organisation established in January 1993 to encourage the development and dissemination of public domain tools and techniques for measuring the effectiveness of health care. The goals of the HOI are to:

- build consensus among physicians, managers and scientists around a standard set of data collection tools and analytic techniques for measuring the effectiveness and improving the quality of health care services
- sponsor the validation and implementation of these tools and techniques
- foster the broad-scale use of these tools and techniques as part of the Outcomes Management System

- promote the establishment and operation of outcomes data repositories to support ongoing instrument development and various clinical and management applications.

Towards this end, InterStudy began to develop the Outcomes Management System (OMS) in the late 1980s. Ongoing development and dissemination of the OMS is being continued by the Health Outcomes Institute.

The Outcomes Management System

The OMS is a collection of general and condition-specific measures of patient function, well-being and clinical status which were created in support of the routine measurement of health outcomes through data collection tools completed by patients and providers. The OMS is intended to build an ongoing observational study into routine medical care by providing a mechanism for systematically assessing, tracking and analysing health outcomes that are important to patients. To accomplish this, a system must:

- measure a patient's functional status and well-being over time, using terms understandable and relevant to patients and providers
- document changes over time in a patient's clinical condition as a result of therapeutic interventions
- ensure that data are collected in a common format
- maintain data collected from multiple sites in a single repository
- incorporate standardised and valid methods of accounting for the effects of health care organisations on health and quality-of-life.

Once established and fully implemented, the system may be used by providers to assess and choose therapies, estimate resources expended on treatment, and establish standards of treatment. In addition, policy-makers and purchasers of medical care may use the system to predict the cost of medical care, select from among the various sources of care, and design health insurance benefits. Finally, patients will be more informed about their choice of treatments.

The following are components of the OMS:

- general use survey instruments and protocols for the collection of core data to describe patients' functional status, demographic characteristics, insurance coverage, treatment setting, lifestyle, co-morbidity and satisfaction with services provided
- condition-specific functional status and clinical data collection protocols to describe changes in patient condition over the course of treatment
- a national repository for the pooling of data from all providers charged with maintaining the integrity of the database and facilitating appropriate use
- a cadre of physicians and other health outcomes managers working in provider and payer organisations, analysing the data to recommend policy changes in their organisations and/or inform colleagues of alternative practice patterns and their implications.

The OMS enables users to track the effects of ordinary medical care. The OMS is a permanent database capable of isolating the experience of individual patients or aggregations of patients by diagnosis, treatment, demographic characteristics, cost and other variables.

TyPE specifications

A principal feature of the OMS is a series of questionnaires and data collection protocols known as TyPE (Technology of Patient Experience) specifications. The system of TyPEs includes two categories of instruments. The first includes general purpose surveys used to describe patients (or non-patients) regardless of specific conditions or therapeutic measures. Data captured by these tools are used to describe individuals' personal identifiers, demographic information, health risks, co-morbidities, functional status and well-being, and satisfaction with provider services. The basic functional status and well-being instrument for adults used within the OMS is a derivative of the MOS SF–36.

The second category of instruments is condition-specific, defining a minimum set of data which must be collected to allow the description and comparison of individual patients' diagnoses, therapies and clinical outcomes. These condition-specific measures establish basic clinical and therapeutic data to be collected on patients before, during and after treatment, and also contain patient-provided quality-of-life and functional status measures uniquely relevant to the condition being assessed.

The following TyPEs are currently available: angina, asthma, carpal tunnel syndrome, cataract, chronic sinusitis, COPD, depression, diabetes, hip fracture, hip replacement, hypertension/lipid disorders, lower back pain, osteoarthritis of the knee, prostatism, rheumatoid arthritis, stroke, and substance use (disorder: alcohol).

Use and standardisation of OMS data collection

Currently, the OMS is being installed and used by multi-specialty group practices, single-specialty groups, hospitals, insurance companies, and managed health care organisations. OMS data are also being collected for collaborative projects. In one such collaboration, a consortium of six prominent group practice clinics has been cooperating to collect OMS data on hip replacement patients in all six settings. Their goal is to establish a shared data pool with which to compare the outcomes performance of the various clinics, treatments, and so on.

OMS information packets, core data sets, condition-specific TyPEs and the Health Status Questionnaire may be ordered from the Health Outcomes Institute, 2001 Killebrew Drive, Suite 122, Bloomington, MN 55425, USA, Fax (612) 858 9189.

Professional indemnity review

(by David Scholes, Professional Indemnity and Compensation Reviews, Department of Human Services and Health)

The nature and incidence of health care injuries

In recent years there has been increasing concern about the costs and implications of medical negligence. There has also been a rapid expansion of awareness about the need to maintain and improve the quality of health care. However, the specific problem of health care injury has received little attention from either perspective. There is little knowledge about the nature and incidence of injuries which are caused by or related to health care management, and which result in prolonged hospitalisation or some form of disability. However, improved understanding about the types and causes of such iatrogenic injuries is essential to developing preventive strategies for reducing the human and financial costs associated with them.

The significant involvement of government as a funding agent and administrator of health care services would seem to provide a reason for this area being given some priority.

Available data

Overseas data indicate the potential scope of the problem. The Harvard Medical Practice Study, which examined 30,121 hospital records in 51 hospitals in New York State in 1984, estimated that 3.7 per cent of hospital stays involved an adverse event and 1 per cent of discharges (or 27.6 per cent of adverse events) involved negligence.[1]

In its recently published Interim Report, the Professional Indemnity Review (PIR) raised concerns about the lack of information incidence, nature, causes and costs of adverse patient outcomes in the Australian health care system, and the inadequacies of existing data sources for collecting this information. The Professional Indemnity Review particularly expressed a range of concerns about the reliability of using E code data—currently the only possible source of information about adverse patient outcomes.

From Australian data the Professional Indemnity Review made a conservative estimate that there may be up to 146,000 adverse patient outcomes occurring in the Australian hospital system each year.[2] Their occurrence represents a significant cost to the Australian community both in human and financial terms. The 1987–88 Hospital Utilisation and Costs Study estimated that separations from public and repatriation hospitals included 44,111 cases where the main cost diagnosis related to misadventures during medical care and another 11,062 which related to drugs causing adverse effects. In total, these exceed the 54,171 separations where the main cost diagnosis related to transport accidents during the same period.[3]

In view of the perceived need to develop preventive strategies that reduce the number of adverse patient outcomes which occur, the Professional Indemnity Review is funding research such as the Australian Hospital Care Study to ensure there is an adequate base line of information for proper policy development. This will provide the basis for future data collection, analysis and monitoring. When preliminary data are available from the study, the Professional Indemnity Review recommends that relevant information from the study be made available so as to assist in the development of appropriate data items which could be collected on a national basis to give an ongoing picture in this important area. These data will not provide information about the incidence of adverse patient outcomes which occur out of hospital, such as in nursing homes and general practice. However, it is assumed that many severe adverse patient outcomes may require hospital admission, so that most occurrences could be captured by hospital morbidity data collections.

Australian Hospital Care Study

The Australian Hospital Care Study was initiated in response to this lack of information about adverse patient outcomes in the health care sector. The study involves a retrospective review of medical records in 22 New South Wales and eight South Australian hospitals to determine the incidence, causes, contributing factors, risk factors, preventability and patient disability consequences of adverse patient outcomes. It will also develop key indicators of adverse patient outcomes that can be included in national minimum data sets and focus on developing preventive strategies to reduce the incidence and severity of adverse outcomes. The definition of adverse patient outcome which has been developed for the study may be of use to the National Health Data Dictionary (see Endnotes). The study is due for completion in early 1995.

Incident monitoring

Incident monitoring is a method of collecting generally anonymous, detailed, qualitative data about any unintended incident, no matter how seemingly trivial or commonplace, which could have harmed or did harm a patient. The identification and analysis of these incidents may be used to facilitate the development and testing of preventive strategies.

The incident monitoring process uses a questionnaire with both free narrative and structured components to collect qualitative data about contributing factors and deficiencies in practices and systems. The information can be used to develop preventive strategies to monitor how the system is changing in response to the implementation of strategies for improvement. The data can be used to highlight possible predisposing circumstances or factors which could be avoided to minimise the incidence of avoidable adverse patient outcomes.

Incident monitoring pilots

As part of its focus on developing preventive strategies for adverse patient outcomes, the Professional Indemnity Review is funding the following medical specialties to conduct incident monitoring pilots:

- obstetrics and gynaecology
- emergency medicine
- endoscopic procedures
- psychiatry
- anaesthesia
- intensive care medicine
- general practice.

Final results of these pilots were reported in September 1994 and a national conference, at which results will be presented, will be held from 29 November to 1 December 1994.

Institutional incident monitoring and risk management

The Professional Indemnity Review is also funding an institution-based incident monitoring pilot to determine if the concept of incident monitoring can be applied on an institutional basis involving a range of specialties and health care professionals, and whether it can be used as an early warning system for the purposes of risk management and claims management. Preliminary results of this research, which is being conducted in several hospitals throughout Australia, will also be available at the national conference to be held in late 1994.

Conclusion

Improved understanding about the types and causes of iatrogenic injuries is essential to developing preventive strategies for reducing the human and financial costs associated with them. For this reason, the Professional Indemnity Review has commissioned the Australian Hospital Care Study and the various incident monitoring and risk management pilots. Reports on these projects should be available to provide input to the National Health Information initiative early in 1995.

References

1. Harvard Medical Practice Study. Patients, doctors, and lawyers: medical injury, malpractice litigation, and patient compensation in New York. The report of the Harvard Medical Practice Study to the State of New York. Harvard: President and Fellows of Harvard College, 1990.

2. Commonwealth of Australia. Department of Human Services and Health Review of Professional Indemnity Arrangements for Health Care Professionals. Compensation and professional indemnity in health care. An interim report: AGPS, February 1994.

3. Gillett S, Parslow R, Scholes D, Renwick M. Hospital utilisation and costs study 1987–88. Health services series no. 1. Australian Institute of Health: AGPS, 1991.

Endnotes

Adverse event: is an unintended injury which results in temporary or permanent disability, including increased length of stay and financial loss caused by health care management rather than disease process.

Unintended injury: refers to all additional morbidity that results from complications in health care management rather than a difficulty not caused by management, e.g. traumatic injury leading to hospitalisation.

Disability: refers to temporary or permanent impairment of physical function (including disfigurement) or mental function, or economic loss even in the absence of such impairment.

Causation: refers to injury caused by health care management including acts of omission (inactions), failure to diagnose or treat, and commission (affirmative actions) and incorrect treatment.

The Oregon Plan

In February of this year, the Oregon Plan for State health reform was at last implemented after a long struggle by its proponents.[1] The introduction of this plan has extended federal coverage of health care services under Medicaid to all citizens of Oregon living below the federal poverty line. This plan, to increase coverage while also containing the costs of this program, has been hailed both as a bold new initiative that goes some way towards addressing issues of equity and optimal health gain by some, and as unfair rationing of health care for the poor based on a methodologically flawed process.[2-5]

It seems almost universal that discussions of the Oregon Plan have described this initiative as the introduction of health care 'rationing' (see for example references 3-4). However, it would be more accurate to describe this plan as implementing a change in the way in which health care services are rationed. Rationing has always occurred, although previously in the United States this has occurred by restricting the number of citizens eligible for health care coverage.[2]

When Medicaid was introduced in 1965 to provide comprehensive health insurance to the poor, the intention was to provide coverage to all Americans living below the federal poverty line. However, with increasing costs of medical care in the decades since (which have not been matched with corresponding increases in the Medicaid budget), it has been necessary to restrict eligibility for Medicaid further. By 1991 Medicaid was only available to those whose family incomes were at or below 58 per cent of the federal poverty line. This amounts to approximately 40 per cent of those living in poverty, and has left a further 120,000 Oregonians living below the poverty line and ineligible for Medicaid.[2-3].

Hence, the origins of the Oregon Plan arose from a desire to provide access to health care services to all citizens below the poverty line without increasing the burden of taxpayers—that is, by limiting availability of services to those enrolled in Medicaid. Under this plan, therefore, those who were previously enrolled in Medicaid will be worse off, although it is expected that loss of population health through restricted health services will be more than offset by the health gain associated with the increased coverage of basic services. And thus began the process of defining a basic package of health services that would be guaranteed to all Oregon citizens in need.

The Oregon Basic Health Services Act

This process began with the passing of the Oregon Basic Health Services Act in 1989. This legislation established the Health Services Commission (HSC), which was given the task of 'developing a priority list of health services, ranging from the most important to the least important, according to the comparative benefits of each service to the entire population served'.[6] The legislature would then provide funding for as many items on the list (beginning from the top of the list) that available funds would cover.

The eleven-member HSC, composed of primary care physicians, other health care workers and consumer representatives, began its task by generating a list of condition/treatment pairs. Initially, each condition/treatment pair was ranked in terms of cost-effectiveness based on the calculation of quality-adjusted-life years (QALYs) for each treatment (further details regarding QALY methods may be found elsewhere[7]). The data needed for such calculations came from the following sources.

- Fifty-four panels of physicians were established to provide information on predicted outcomes after five years both with and without treatment.
- A telephone survey of 1,000 people provided information regarding preferences for different health states based on the Quality of Well-Being Scale. This survey required the valuation of ten health states on a scale of 0 (death) to 100 (full health).
- Public input through a process of community consultation. Public meetings were held in each of Oregon's 36 counties to solicit 'testimony and information' from a range of interest groups and others. Forty-seven meetings were held, representing an involvement of over 1,000 citizens.[8] The values/issues that arose as being of foremost concern in the allocation of health care resources included prevention, quality-of-life, cost-effectiveness, ability to function normally, equity and effectiveness of treatment.

Through this process a draft priority list ranking 1,600 procedures was released in May 1990. This list immediately met with widespread condemnation because of its reliance on cost-effectiveness data only (itself based on inadequate and/or inaccurate data). It did not appear to take into account community values and, because of a number of the rankings, appeared counterintuitive. For example, treatment for thumb-sucking was ranked higher than hospitalisation for a starving child.[3] Thus the HSC was forced into a change of methods in which cost-effectiveness data were abandoned and greater emphasis was placed on community values.

Using this revised method, the second list, released in February 1991, ranked 709 items. In determining this list, the HSC grouped each treatment into one of seventeen major categories, which were themselves ranked by the HSC and placed in generic categories according to whether the services were seen to be 'essential', 'very important' or 'valuable to certain individuals' only. The ranking of these seventeen categories was strongly influenced by the result of the public consultation process (thus, e.g. maternity care and dental services were ranked highly, reflecting the importance placed on these categories of care by the community). Within each grouping of services, items were prioritised based on expected QALY benefit (examples of these categories and the items contained within are provided in Table 1). A number of items were also moved 'by hand' in order to produce what appeared to be a more reasonable list.

Criticisms

Criticism of the Oregon Plan has been levelled at both the conceptual rationale for the plan and the method adopted to determine health care priorities.

At the broadest level, critics have claimed that Oregon's plans to guarantee a basic package of services to the poor does not go far enough—any reform that only rations health care provided to the poor is unethical.[2-3,9] While this view may or may not be shared, this remains an issue that can only be addressed by citizens of Oregon and of the United States.

Of wider interest are problems relating to Oregon's intention to fund all of the first priority services before considering any lower priority services. Hall and Haas[4] have stated that this method ignores

> the changes in costs or benefits for a small expansion or contraction in the number of cases treated...The relevant question is rarely: 'Should all prenatal care be stopped so that organ transplants can be funded?' Rather it is how much prenatal care with how many organ transplants will maximise the total health benefits (p. 437).

Similarly, Klein[10] writes that the Oregon Plan

> ignores the sheer heterogeneity of patients: within any broad category there will be some patients who will benefit greatly from treatment while others will not. So excluding any particular form of intervention on the grounds that outcomes are generally

> poor may also exclude individual patients with a good prognosis (p.1458).

Klein has also reported that rationing of services may not be the complete answer. Specifically,

> ...deciding that appendicitis should be treated is easy, but laying down what resources should be used during treatment (the numbers of tests, nurses, operating room staff, and so on) is difficult. In other words, the most important rationing decision in terms of resources may not be what to treat but how to treat (p. 1458).

Numerous problems relating to Oregon's method for determining service priorities have also been identified. Firstly, while the Oregon process has been praised for its involvement of the community, the success with which this was achieved has been questioned. The series of community meetings was seen as successful in terms of numbers who attended—although this audience was far from representative of the Oregon population. Fifty-six per cent of attendees were health care workers, while fewer than ten per cent lived below the federal poverty line (the target group for this legislation).[8]

Secondly, while the second list achieved general acceptance, it is clear that priorities were not solely based on clinical effectiveness and public preferences for different health states. On this list, liver transplants for patients whose liver damage was unrelated to alcohol were ranked 366, while for those with alcoholic cirrhosis, liver transplants were rated 690, despite patient outcomes being similar or equal. This suggests other criteria have also determined the placing of particular conditions and treatments on this list.[10]

Similarly, while the Oregon Plan has been hailed for its attempt to ration services based on explicit processes and the QALY methodology (which takes into account both the expected quantity and quality-of-life that results from a particular treatment), the fact that it was necessary for the HSC to rearrange some items 'by hand' on the list (based on unknown criteria) must bring into question the adequacy of this method.

Criticism has also been directed at the use of a QALY methodology and, more specifically, at the use of the Quality of Well-Being Scale to determine the community's preferences for health states.[11] Many view this methodology as being still in its infancy and with a number of conceptual problems that need still to be resolved.

The method adopted by Oregon to obtain outcomes and effectiveness data (that is, through the use of panels of physicians) has also been criticised. Even those involved in the process have admitted that 'much of this data represents a consensus by physicians rather than hard empirical outcomes data'.[6] However, in the absence of comprehensive data on the whole range of treatments and conditions assessed, this was seen as the only feasible method.

Apart from those problems outlined above, the implementation of the plan has also faced a number of political obstacles. In order to alter eligibility requirements for the Medicaid program (to embrace all citizens on incomes below the poverty line), it was necessary to receive a federal waiver of Medicaid eligibility regulations. This was initially rejected by the Bush administration in 1991, but later granted for a period of five years in

Table 1: *Categories of health services and rankings in The Oregon Plan*

'Essential' services	
1.	Acute fatal, prevents death, full recovery (e.g. repair of deep, open wound of the neck)
2.	Maternity care, including for newborn in first 28 days of life (e.g. obstetrical care for pregnancy)
7.	Comfort care (e.g. palliative therapy)
'Very important' services	
10.	Acute non-fatal, return to previous health (e.g. restorative dental service for dental caries)
13.	Chronic non-fatal, repetitive treatment improves QWB (e.g. medical therapy for migraine)
Services 'valuable to certain individuals'	
14.	Acute non-fatal, expedites recovery (e.g. medical therapy for diaper rash)
15.	Infertility services (e.g. in-vitro fertilisation)

Source: Dougherty CJ. Setting health care priorities: Oregon's next steps. Hastings Center Report 1991; May–June: 1–10 the first instance by President Clinton after a small number of modifications to the plan that ensured it did not contravene the Americans with Disabilities Act of 1990.

Americans with Disabilities Act (1990)

This issue was raised by a consortium of human rights and disability interest groups who believed that the telephone survey that was used to derive QALY weights was 'based in substantial part on the premise that the value of life of a person with a disability is less than the value of life of a person without a disability'. Proponents of the plan countered with the argument that 'Oregonians were surveyed about the impact on their own quality-of-life, not that of others'.[9]

After some negotiation, the plan was approved, contingent on a number of modifications, including that the ranking of service items was not reliant on whether a treatment 'returned an individual to an asymptomatic state'.[9] It is not clear exactly how this obstacle was circumvented, although presumably the QALY method was not seen to violate this stipulation, since the calculation of QALYs does not take into consideration the final state of the individual, i.e. a change from 0.2 to 0.6 is regarded as equal to a change from 0.6 to 1.0. Thus, treatments that produce the greatest change in QALY values are favoured—not the treatment that returns a patient to the highest absolute QALY level.

Nevertheless, as of 1 February 1994, Oregon's radical experiment has been implemented, covering 565 conditions (including dental coverage and payment of prescription drugs), with a high level of support.[1] It has been predicted that this legislation will be a stimulus to outcomes research, which will be of great interest to policy-makers as well as clinicians, administrators and researchers.[5] While the effects of this legislation, in terms of the number and range of health care services provided to groups who could previously not afford to purchase health care services, will be immediately obvious, the effects of the Oregon Plan in terms of providing health to this State's citizens will require a longer term evaluation strategy.

References

1. Roberts J. Oregon overwhelmed in its first three weeks. BMJ 1994; 308:618.

2. Callahan D. Ethics and priority setting in Oregon. Health Affairs 1993; Summer:78–87.

3. Fox D, Leichter HM. Rationing care in Oregon: the new accountability. Health Affairs 1991; Summer:7–27.

4. Hall J, Haas M. The rationing of health care: should Oregon be transported to Australia? Australian Journal of Public Health 1992; 16:435–40.

5. Stason WB. Oregon's bold Medicaid initiative [Editorial]. JAMA 1991; 265:2237–8.

6. Kitzhaber JA. Prioritising health services in an era of limits: the Oregon experience. BMJ 1993; 307:3737.

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

8. Haas M, Hall J. The Oregon plan. NSW Public Health Bulletin 1992; 3:50–1.

9. Fox DM, Leichter HM. The ups and downs of Oregon's rationing plan. Health Affairs 1993; Summer: 66–70.

10. Klein R. Warning signals from Oregon. BMJ 1992; 304: 1457–8.

11. Nord E. Unjustified use of the Quality of Well-Being scale in priority setting in Oregon. Health Policy 1993; 24:45–53.

Health outcomes projects database

The staff of the Australian Health Outcomes Clearing House Project (AHOCH) frequently receive requests for information regarding 'who is doing what' around Australia with regard to health outcomes research. In order to provide this information for others, the AHOCH have established the Health Outcomes Projects Database based on information received by researchers and others on the (pink) 'Health Outcomes Projects Database project proforma' that has been inserted in each bulletin.

To date we have received over 50 descriptions of health outcomes research projects that have been recently completed, are nearing completion, or are still in planning stages. A summary of these projects is provided in Table 2 on the following pages.

If you would like further information or detail on any of these projects, please contact staff of the AHOCH in the first instance. Alternatively, if you would like to contribute to this database, please complete the data collection proforma that has been inserted in this bulletin for each health outcomes study you are, or have been, involved in.

Cancer outcomes symposium

(by Helen Kay, Health Advisory Branch, Office of the National Health and Medical Research Council)

The Cancer Outcomes Symposium, sponsored by the Commonwealth Department of Human Services and Health and the National Health and Medical Research Council, was held on 30 and 31 May 1994 at the National Convention Centre, Canberra.

The symposium was a key element of the consultation process on the draft report 'National goals, targets and strategies for cancer control' released for discussion by the Australian Health Ministers' Council in March 1994.

Table 2: *Summary of projects received*

Researcher	**Leonie M Short**
Project team	Dr Alan Patterson
Title	Teeth for keeps
Researcher	**Patsy Kenny, Centre for Health Economics Research and Evaluation**
Project team	Madeleine King; Janelle Seymour; Alan Shiell; Bev Hunt; Alan Langlands; John Boyages
Title	Cost-utility analysis of the treatment for early stage breast cancer
Researcher	**Frank Vanclay, Centre for Rural Social Research, Charles Sturt University**
Project team	-
Title	Functional outcome measures in stroke rehabilitation
Researcher	**Dr Carmel Martin, National Centre for Epidemiology and Population Health, ANU**
Project team	Dr J Daly; Prof. RM Douglas
Title	The management of patients with chronic conditions in general practice (recipients of long-term repeat prescriptions for medication)
Researcher	**Prof. Steven Schwartz, Department of Psychology, University of Queensland**
Project team	-
Title	Preferences for health outcomes: Factors affecting health state utilities
Researcher	**Virginia Wiseman, Centre for Health Economics Research and Evaluation**
Project team	J Hall; Dr AR Denniss; Dr DL Ross
Title	Accelerated return to normal activities after acute myocardial infarction
Researcher	**Dr John McCallum, National Centre for Epidemiology and Population Health**
Project team	Dr Jim Butler; Dr Erick Kliewer; Dr Gigi Santow; Chris Raymond
Title	NCEPH record linkage pilot study
Researcher	**A/Prof. Leon Simons, Lipid Research Centre**
Project team	Dr John McCallum; Judy Simons
Title	The Dubbo study of the health of the elderly
Researcher	**Dr Fiona Blyth**
Project team	Prof. S Leeder; Dr R Lazarus; Dr D Ross; Dr M Price; Dr G Cheuk; Sr M Hewitt; Sr J Bunn; Dr J Lowe
Title	Outcomes of patients admitted to Westmead Hospital with congestive heart failure
Researcher	**Dr Deborah A Freund, Bowen Research Center, Indiana University**
Project team	Lorrie A Kalainski
Title	Assessing and improving outcomes: Total knee replacement (TKR) Patient Outcomes Research Team (PORT)

Table 2: *Summary of projects received* (continued)

Researcher	**Dr Rod O'Connor, Rod O'Connor & Associates Pty Ltd**
Project team	-
Title	Development of an instrument for assessing the degree to which environmental conditions are likely to produce ill-health (focused on Aboriginal communities)
Researcher	**Dr Rod O'Connor, Rod O'Connor & Associates Pty Ltd**
Project team	-
Title	Issues in the measurement of health-related quality-of-life
Researcher	**Jeff Richardson, Johanna Cook, Graeme Hawthorne, National Centre for Health Program Evaluation**
Project team	-
Title	Development of a Multi-Attribute Utility Instrument (MAU)
Researcher	**Dr Ashley Craig**
Project team	-
Title	Psychological consequences of spinal injury
Researcher	**Dr Bruce Shadbolt, ACT Health**
Project team	National Centre for Epidemiology and Population Health
Title	Inpatient and ambulatory care: an examination of the care continuum and health outcomes
Researcher	**Mike Langan, Australian Bureau of Statistics**
Project team	Australian Bureau of Statistics
Title	National Health Survey
Researcher	**Sara Graham, Social Policy Research Centre**
Project team	Michael Fine; Natalie Bolzan; Cathy Thomson
Title	The social care of people with disabilities, especially long-term support for people with disabilities
Researcher	**Janelle Seymour, Centre for Health Economics Research and Evaluation**
Project team	Mr Alan Shiell; Prof. David Newell
Title	The quiet revolution: reporting of health outcomes in the medical literature
Researcher	**David Gadiel, Health Care Intelligence Pty Ltd**
Project team	Australian Physiotherapy Association, NSW Branch; Strategic Human Capital Management
Title	Physiotherapy soft tissue study

Table 2: *Summary of projects received* (continued)

Researcher	**Dr John McCallum**
Project team	Dr Hal Kendig
Title	The ageing and families 7-year follow-up
Researcher	**Madeleine King, Centre for Health Economics Research and Evaluation**
Project team	Dr Jane Hall; Dr Paul Harnett; Prof. Annette Dobson
Title	Comparison of two quality-of-life instruments designed for cancer clinical trials
Researcher	**Ross Kerridge, Liverpool Hospital**
Project team	Paul Glasziou; Ken Hillman
Title	The evaluation of intensive care using QALYs
Researcher	**Mark Smith, Western Sector Public Health Unit**
Project team	Prof. SR Leeder; Dr B Jalaludin; Dr WT Smith
Title	Status report on the development of health outcome indicators for asthma
Researcher	**Dr Elizabeth Eckermann**
Project team	-
Title	Review of indicators of health status for women in the various regions of WHO: Development of indicators of health, well-being and disability more appropriate to women's experience
Researcher	**Kathy Daffurn, Liverpool Health Service**
Project team	Dr Gillam Bishop; Prof. K Hillman; Prof. A Bauman
Title	The physical and psychological sequelae found in patients after an episode in ICU
Researcher	**Colin Burrows, Monash University**
Project team	Kaye Brown
Title	Cross-cultural translation and validation of health status and social support measures
Researcher	**Colin Burrows, Monash University**
Project team	Kaye Brown
Title	Validating weights of health states for cost-utility analysis of health programs
Researcher	**Colin Burrows, Monash University**
Project team	Kaye Brown
Title	Analysis of dialysis options: cost-effectiveness and quality-of-life
Researcher	**Magnolia Cardona, Western Sector Public Health Unit**
Project team	Louisa Jorm; Abd El-Masik Malak; Maureen Grisdale
Title	Measuring health status, attitudes towards health services and health service use of the non-English speaking residents of Blacktown

Table 2: *Summary of projects received* (continued)

Researcher	**Melanie Wakefield, SA Health Commission**
Project team	David Wilson
Title	Health Omnibus Survey
Researcher	**Dr Andrew Wilson; Dr Mark Crome, Department of Social and Preventative Medicine, Princess Alexandra Hospital**
Project team	-
Title	Queensland heart attack morbidity and mortality survey
Researcher	**Alan J Crockett, Flinders Medical Centre**
Project team	John H Alpers; Josephine M Cranston
Title	A prospective study of survival and quality-of-life of patients with chronic respiratory disease referred for long-term continuous domiciliary oxygen therapy
Researcher	**Dr MD Fine, Social Policy Research Centre, UNSW**
Project team	Cathy Thomson; Dr Sara Graham; Marilyn McHugh
Title	Community support services and their users
Researcher	**Professor Arnulf Kolstad, Department of Psychology, University of Trondheim, Norway**
Project team	-
Title	Psychiatric patients in institutions
Researcher	**Mr Rob Saunders, Brisbane South Regional Health Authority**
Project team	-
Title	Joint Aboriginal and Torres Strait Islander Community Brisbane South/Brisbane North Outcomes Focused Health Service Plan
Researcher	**Andrea Henderson**
Project team	Dr Linda Worrall (supervisor)
Title	Outcome measures: validity in aphasia management
Researcher	**Eve Blair, Institute for Child Health Research, WA**
Project team	Jenni Ballantyne; Peter Chauvel
Title	Study of dynamic proximal stability splint in the management of children with cerebral palsy
Researcher	**Eve Blair, Institute for Child Health Research, WA**
Project team	Jenni Ballantyne; Peter Chauvel
Title	Lycra splinting for dysgraphia

Table 2: *Summary of projects received* (continued)

Researcher	**Eve Blair, Institute for Child Health Research, WA**
Project team	Ruth Shean
Title	Patterns of therapy delivery
Researcher	**Eve Blair, Institute for Child Health Research, WA**
Project team	Jenni Ballantyne; Peter Chauvel
Title	Lycra splinting to improve specific upper limb functional deficit in persons with traumatic head injury induced neurological movement impairment
Researcher	**Dr B. Blick, Queenscliff Child and Family Health**
Project team	-
Title	Minimum data set for Family and Child Health Community Services for NSW
Researcher	**Dr Mark J Ferson, Public Health Unit, Eastern Sydney Area Health Service**
Project team	-
Title	Suicide reduction health outcomes project
Researcher	**Shane Donnelly, Health Industry Training Board**
Project team	Julie Harris
Title	Planning for training needs of the Victorian health industry
Researcher	**Dr Robin Bell, Department of Perinatal Medicine, Royal Women's Hospital**
Project team	Sonia Palma; Professor Shaun Brennecke
Title	A randomised trial of reduced antenatal exercise to increase birthweight
Researcher	**Dr Robin Bell, Department of Perinatal Medicine, Royal Women's Hospital**
Project team	Ruth Coulson; Sue Bishop; Dr Jill Astbury; Dr Greg Rice; Professor Shaun Brennecke
Title	A randomised trial of personal counselling to reduce smoking during pregnancy
Researcher	**Barbara Murphy, Department of Psychiatry, University of Melbourne & Helen Herrman, St Vincents Hospital**
Project team	Dr Hilary Schofield
Title	World Health Organization Quality-Of-Life (WHOQOL) study
Researcher	**Richard Fordham, School of Public Health, Curtin University of Technology**
Project team	Kristine Northey; Michael Rosenberg
Title	Quality-of-life after hip fracture
Researcher	**Dr Geoff Holloway, School of Social Sciences, Curtin University**
Project team	-
Title	'Culture bound' syndromes

National health goals and targets—background

At the National Health Summit in April 1993, Health ministers agreed to work with the National Health and Medical Research Council to develop national health goals and targets in four areas: cardiovascular disease, cancer, mental health and injury.

These focus areas were selected because of the impact each has on the community and because improvements in strategies for prevention, care, treatment and palliation could and needed to be achieved. They were selected also because there were grounds to believe that changes could lead to an overall reduction in illness and premature death, and to improvements in quality-of-life among Australians.

The national health goals and targets framework is designed to achieve better health for Australians by improving the strategic direction of a broad range of activities affecting health. The national health goals and targets process is a serious attempt to reduce health inequalities and improve health care access to particular population groups. By specifying priority population groups for each of the targets, the need to reduce the gaps in health status between the most and least advantaged in Australia is made explicit.

So what can national health goals and targets offer?

They provide:

- a focus on achieving more equitable outcomes in health by addressing some of the underlying determinants of ill health—the environment in which we live, socioeconomic status, knowledge and skills
- a way of focusing the health system on outcomes, rather than incidence of the disease
- a way of involving sectors other than health in health issues.

The goals and targets process also provides an opportunity to coordinate and integrate activity at the Commonwealth, State, Territory and community levels to achieve agreed and common goals.

Implementation groups

Implementation groups were formed to develop draft reports on each of the focus areas. Membership included clinicians, State and Commonwealth Government representatives, representatives of the relevant lead agencies, people with preventive health expertise and consumers of health services.

Consultation

The draft reports were circulated widely to professional colleges and community and health consumer groups for comment. A free call telephone number was also established. As a result, over 25,000 copies of the reports were distributed.

The Cancer Outcomes Symposium was part of that consultation process. The final reports which were presented to Health ministers in June incorporated the feedback from the community consultation and from the symposium.

Cancer outcomes symposium

The major purpose of the symposium was to highlight key issues and strategies which can be addressed over the next decade to improve health outcomes in the prevention, treatment and care of cancer patients. The format consisted of short presentations followed by panel discussion. Workshops provided an opportunity for participants to provide specific feedback on goals targets and strategies for breast, colorectal, skin, cervical, lung and prostate cancer.

People with expertise in women's health, health promotion, research, prevention, management, treatment and palliation were invited to attend as well as people from cancer support groups.

An impressive range of speakers presented papers at the symposium. They included the Minister for Human Services and Health, the Honourable Dr Carmen Lawrence, MP, and the Honourable Wendy Fatin, MP, Professors Richard Smallwood, Stephen Leeder, Tom Reeve, Martin Tattersall, Ken Donald, Richard Kefford, Judith Whitworth, John Forbes, John Funder, Alan Langlands, Michael Cousins, Drs Diana Horvath, Tony Adams, Tony Green, Simon Chapman, Richard Kemp, Christine Clark, Ray Lowenthal, John Ellard, David Roder and Fiona Stanley.

Presentations addressed the major themes contained in the cancer report. These included consumer needs, best practice in cancer care, issues for cancer management, including multidisciplinary management, the research agenda and education of practitioners. A transcript of the symposium proceedings is now available and can be obtained by phoning 1800 658 616. Conference papers are also currently available.

References

1. National Health Goals and Targets Implementation Working Group on Cancers. National goals, targets and strategies for cancer control (Draft). Canberra: Department of Human Services and Health, 1994.

Editor's comments

This was the first of two recent conferences on cancer and was followed in early July by the Hospital-based Cancer Registries Conference. As the summary above suggests, there was a range of excellent speakers addressing the current state of cancer research in their areas of specialty as well as identifying the need for further outcomes-oriented research addressing quality-of-life issues and the continuing development of evidence-based best practice guidelines.

The Minister for Health, the Honourable Carmen Lawrence, spoke of the need to assess the quality and effectiveness of health care and the need to adopt an outcomes-oriented approach. She spoke of the role of the proposed National Breast Cancer Centre in extending the work on best practice guideline development and in undertaking a clearing house function by expanding the information database on interventions and their outcomes. The new centre would also have an important role in communicating outcomes information to consumers —allowing them to make more informed choices about their medical care. The minister also spoke of the proposed National Breast Cancer Foundation where the Commonwealth proposed to match contributions from industry in order to stimulate much needed research.

Consumer perspectives were also addressed by Pamela Griffith. Her description of her medical treatment was at times quite horrifying and clearly identified the need for consumers to be able to get information on their condition and the pros and cons of various treatment options that may be available to them. Although best practice guidelines under development are insisting upon the adequate provision of information to patients to inform them of 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. However, one of the choices that a patient can make is to be guided by the practitioner's view—but that choice should be overt and clear—and for those patients wanting further information and to participate in informed decision-making, it is necessary that the information provided be sufficient and that it is also provided in a way that can be understood.

The opening address was provided by Professor Dick Smallwood who reminded us that this was the second time that the Australian health system had endeavoured to adopt a goals and targets approach. He stated that, 'It was quite clear from previous experience that if the health system isn't reorientated towards outcomes, which is after all the *raison d'être* of National Goals and Targets, then nothing is going to happen again'. Let us trust he is not being prophetic. This reminds one of Leeder's address to the Public Health Association conference in 1988; this time we must endeavour to make the vision a reality.

Professor Smallwood also spoke of genetic and environmental influences in cancer and stated that 'we shouldn't neglect one approach to cancer control—understanding the fundamental biology of cancer—to concentrate exclusively on another—altering lifestyles and environment'. Nor should the focus be on cure at the cost of care, particularly palliative care, and the needs of cancer sufferers should not be neglected. He also touched upon the issue of variations in patterns of treatment practice which also arose at the Hospital-based Cancer Registries Conference.

The Hospital-based Cancer Registries Conference, organised by the Australian Cancer Society, provided information on the roles of the State and hospital-based cancer registries and the interface between these and national data collections, for example the National Death and Cancer Index. The issue of standardised data definitions for data collections at all levels arose. Some impressive examples of how such data could be used in outcomes research, e.g. cancer burden by site, stage, region; treatment patterns in relation to these factors and in relation to guidelines; adverse outcomes, and so forth, were provided by a number of presenters from South Australia, albeit that the hospital-based registries there apply only to teaching hospitals as yet. An issue that arose in discussion was whether an alternative to hospital cancer registries might be an improvement to the medical records system. Whilst viewed with some disfavour, it does raise the issue as to whether there may be a proliferation of hospital-based registries for a range of conditions other than cancer to gain the more detailed information relevant to outcomes research and whether there will be funds allocated to such endeavours. Further information about this conference may be obtained from The Project Officer, Australian Cancer Society, GPO Box 4708, Sydney, 2001.

Some relevant literature

Aharony L, Strasser S. Patient satisfaction: what we know about and what we still need to explore. Medical Care Review 1993; 50:49–79.

This is a useful review article which should be read by those wishing to administer a patient satisfaction survey to their client group. Patient satisfaction is a major concern of quality assurance and improvement activities and is also an expected outcome of care. This paper reviews the literature relating to the importance of measuring patient satisfaction, methodological problems, research on the determinants of patient satisfaction and theoretical and conceptual views of the construct. It concludes by pointing to areas for improvement and future research. Clearly this area of research is still in its infancy and much of the existing research appears to suffer from a variety of methodological flaws and a level of analysis that is largely descriptive. There is a need for a second generation of studies to investigate the relationship between satisfaction and patient outcomes, the relationship between behavioural reactance and patient satisfaction, between health employee attitudes about their jobs and patient satisfaction, as well as longitudinal studies to investigate these phenomena. The author also suggests that some studies using qualitative research methods may be useful in helping us to understand patient satisfaction processes along with a range of better designed empirical studies that investigate patient satisfaction both as an independent and as a dependent variable.

Kearsley JH. Wanted: guidelines for 'palliative' anti-cancer drug use. Medical Journal of Australia 1994; 160:723–5.

This 'point of view' article raises the general issue of what might be considered a 'good' outcome for patients with terminal conditions. Should the patient continue to be treated with cytoxic chemotherapy even where there is little evidence that such treatment may be effective for a range of tumours and where such treatment may be associated with greater morbidity and reduced quality-of-life in the remaining period of life? Might not appropriate palliative care without chemotherapy be a more positive option with treatment focused on providing better pain and symptom control measures, counselling and coping skills programs? It raises the issue as to whether a good health outcome may be a 'good' death in a palliative care setting.

The author is keen to see the development of best practice guidelines for the use of chemotherapy for patients with incurable malignancy and for anti-cancer drug use more generally. He discusses issues such as unjustifiable prescribing, *ad hoc* treatment and the need for well designed trials to explore therapeutic effects of newer therapies on 'chemoresistant' cancers. If cancer care resources are to be rationally allocated rather than just rationed, there will need to be further assessments of the cost-effectiveness of various types of cancer treatment. It may be that resources now allocated to aggressive chemotherapy for patients with terminal conditions may be better spent on the provision of compassionate and humane palliative care programs. Although this article is concerned with the treatment of cancer, this issue is of general relevance to all health professionals.

McCallum J, Shadbolt B, Wang D. Self-rated health and survival: A seven-year follow-up study of Australian elderly. American Journal of Public Health 1994; 84:1100–5.

Objectives. This study tested the hypothesis, from North American findings, that global self-ratings of health predict survival for older Australians.
Methods. A stratified sample of Australians 60 years of age and older surveyed in 1981 was resurveyed in 1988. Cox proportional hazard general linear models were constructed separately for men and women to predict survival over seven years.
Results. Better self-ratings of health had an incremental association with survival for women, but only men with poor ratings had significantly worse survival than others. After major illnesses, co-morbidities, disability, depression, and social support were controlled for, poor ratings of health for both men and women were not significantly different from excellent ratings in predicting survival. Only women's good and fair health ratings remained significant predictors.
Conclusions. People rate their health as poor on the objective basis of illness and disability. Australian findings show gender differences relative to North American results; methodological differences and site and gender variability in health profiles are discussed as reasons for the varying results. (Author abstract)

Editor's note: This paper confirms that self-rated health is an economical indicator of health defined by severe illness and disability, although it only adds finer graded information about health related to survival for women. The authors claim the specific variability observed in Australian and international findings indicates the need for further research to explore the structure of health status among elderly persons, which also includes consideration of the concept of senescence (system failure distinct from failure of body parts and specific illnesses).

O'Connor, R. Health-related quality-of-life measures need content validity. Australian Health Review 1992; 15:155–163.

Health-related quality-of-life measures are being increasingly considered as tools to aid decisions of health resource allocation, given their potential to comprehensively assess the impact of a given illness or health intervention on the individual. The development of suitable measures requires an understanding of the way external and psychological variables interact to determine subjective well-being and necessitates careful determination of those variables most important to the patient. (Author abstract)

Editor's note: This article provides a useful discussion of issues of validity pertaining to health-related quality-of-life measures. The author notes that while there is general agreement on the potential usefulness of such measures in health program evaluation there is still little agreement regarding the basic concept. Definitions of quality-of-life pertaining to health are often vague or absent. Many current instruments may lack content validity—particularly those that fail to sample adequately from the psychological and social domains which form important components of the patient's subjective sense of well-being. The author also reviews evidence indicating that a patient's view of their quality-of-life is different to the appraisal of carers and doctors. There are also differences between the valuations of health states or scenarios provided by health professionals, the general public and patients experiencing the health states concerned. Such factors raise issues of content validity with respect to the use of quality-adjusted-life-years (QALYs) in health program evaluation.

Sintonen H. 15D measure of health-related quality-of-life: the reliability, validity and sensitivity of its health state descriptive system (Draft paper). Unpublished.

The editor was given permission by the author to review this draft paper and thus it needs to be kept in mind that quite substantial rewriting may occur before its eventual publication. Professor Sintonen was recently a Visiting Research Fellow at the National Centre for Health Program Evaluation.

This paper describes the development of the 15D health-related quality-of-life measure. The current version (15D.2) asks a single question about 15 health areas (mobility, vision, hearing, breathing, sleeping, eating, speech, elimination, usual activities, mental function, discomfort, distress, depression, vitality and sexual activity) and the respondent rates their health state at one of five ordinal levels on each of these dimensions.

This style of multi-dimensional index is useful for the application of utility weights, reflecting the author's econometric orientation, but those from a psychometric or epidemiological orientation may be concerned about one clumsily written question being the only question representing each of these dimensions. The first version of this scale in translation produced some fairly quaint English as is demonstrated by Question 12: 'I am not at all in pain and/or ache' and a similar item in the second version is exemplified by Question 11: 'I have no physical discomfort or symptoms, e.g. pain, ache, nausea, itching'. One might wish to argue that while pain, ache, nausea and itching are all forms of discomfort they might be quite different aspects of this dimension and different levels of these types of discomfort may have different effects on the rating of perceived health. The editor has a particular dislike for double-barrel and multi-barrel items, but such questions seem to abound in health-related quality-of-life instruments and measures, and inevitably one must remain unsure as to what responses to these questions mean.

A variety of evidence pertaining to the reliability, validity, discriminatory power and responsivity of the first fifteen item version (15D.1) is presented and this version has been used quite extensively in Europe. It should be noted, however, that only 11 dimensions remain in common between the two instruments, many questions have been reworded, and the response categories have five levels in the second version as against four levels for some questions in the first version. The instrument was revised to form the 15D.2 version on the basis of accumulated research findings in 1993, but there is somewhat less evidence available on the psychometric properties of this current version. Given the substantial differences between versions one and two, research evidence pertaining to the first version is not really pertinent to the second version as the author appears to imply. However, this multi-dimensional index does sample a broader range of items than other instruments of this type (Euroqol, Rosser Index, McMaster Index) and includes dimensions such as vision, hearing, breathing, sleeping and sexual activity which are not covered by many of the other indices. Thus, this might be an instrument to consider using where the research questions pertain to changes in these domains. It is reported that the 15D.2 has greater discriminatory power than the Euroqol and the 15D.1.

Sintonen H, Pekurinen MA. Fifteen-dimensional measure of health-related quality-of-life (15D) and its applications. In Walker SR, Rosser RM, (eds). Quality-of-life assessment: key issues in the 1990s. London: Kluwer Academic, 1993.

This paper discusses the first version of the 15D perceived health instrument and provides more information on the valuation methods used to provide utility weights. As this 15D measure can define approximately 10 million health states (as contrasted with 243 for the Euroqol) it should increase the instrument's sensitivity but it does make for an enormous health state valuation task.

The valuation method used here is a two-stage method based on the multi-attribute utility theory. The value of a state for an individual is assumed to be a function of the value placed on the level of each dimension and the relative importance or weight attached to each dimension. The individual is asked to choose the most important dimension of health-related quality-of-life and give it a value of 100 on an adjacent 0–100 scale. All other dimensions are given a value on the scale in relation to the most important dimension. The values are then transformed to a 0–1 scale and social importance weights are formed by averaging individual weights over the sample.

Secondly, the individual is asked to give a value to the various levels of each dimension on an adjacent 0–100 ratio scale. Again the value of 100 is assigned to the most desirable level on each dimension and the other levels are valued on the scale in relation to the best level. These values are divided by 100 to attain individual level values and 'social' level values are calculated by averaging them over the sample. A computer algorithm is used to combine the social importance weights and level values to the levels ticked by the respondents on the 15D instrument and to calculate their individual score (0–1). An added benefit of the two-stage method is that it reduces the problem of logical inconsistencies that have been found using direct valuation methods with such instruments as the Euroqol.

The mean values of seven health states were found to be generally higher for the two-stage method as contrasted with three direct methods using vertical and horizontal visual analogue methods and a vertical ratio scale. It is possible to convert values derived from the two-stage method to direct values with a simple linear transformation should direct methods be preferred, but the authors point out that if there is a great number of states to be valued, it is impossible in practice to use direct methods. Thus in these situations the above conversion could be applied.

The remainder of this paper reports results of a study which compares 15D scores of coronary artery bypass candidates (operated versus unoperated) before and after operation. As might be expected, the operated group showed an enormous improvement in their score from before operation to three months after operation and a smaller improvement was found after another nine months. By contrast, the unoperated group experienced a small and continuing improvement over the year but had much lower scores than the treated group at the three-month and one-year points. The scores for each dimension did not change much for the non-operated group, whereas operated patients showed improvements in the dimensions of breathing, working, social participation, perceived health and moving but also in pain, sleeping and mental condition.

The authors conclude that further research needs to be undertaken with respect to the validity of the instrument and the valuation methods. An additive aggregation rule has been used for calculating the index score but other aggregation rules will be explored.

Ware J, Snow KK, Kosinski MA, Gandek B. SF–36 Health Survey: Manual and interpretation guide. Boston, Ma.: The Health Institute, 1993.

The Australian Institute of Health and Welfare appears to be one of the first organisations to receive this manual and I gather some researchers have experienced difficulties and delays in receiving their copies. The address for ordering is the New England Medical Centre, The Health Institute, PO Box 9178, Boston, MA 02118, USA. Fax 1 (617) 348 2994. The cost of the manual is US$45.

This is a comprehensive manual providing most of the information that users need to know concerning the instrument development, psychometric properties and validation although, of course, the normative data provided is for the US. There is a useful annotated bibliography of research undertaken using this instrument and there are also chapters dealing with its applications in population monitoring and clinical practice, and a discussion of future directions, including the development of summary health indexes. Various forms (for example, booklet, scan form) are provided in the appendices but unfortunately the appendices do not also contain the SF–6 and SF–20 which may have been of interest to researchers. There is mention of a pilot version for acute care settings, with a time frame of one week, which is currently being trialled. However, the bibliography does contain references pertinent to these versions. The current distributor of the developmental Australian version of this instrument and the Scoring Manual is Professor Rob Sanson-Fisher at the Hunter Centre for Health Advancement (Locked Mail Bag 10, Wallsend, NSW 2287 Fax(049) 246 211).

Forthcoming events

The Congress on Health Outcomes and Accountability

Sheraton Washington Hotel, Washington DC, USA, December 11–14, 1994

In one of the most significant trends in health care, purchasers are increasingly demanding information on the outcomes of the products and services they buy. This focus on accountability is revolutionising health care and spawning whole new industries. All sectors are being affected by this trend toward accountability: providers, purchasers, employers, insurers, product manufacturers, and government agencies.

Objectives for the congress include: enhancing communication about outcomes among major segments of the health care field; accelerating the development of the field while enhancing its usefulness, accuracy, meaningfulness, standardisation, and efficiency; providing a forum for the leading ideas and practices in outcomes management and related topics; bridging the gap between academic research and clinical and business practices; presenting a diverse range of viewpoints regarding this emerging and sometimes controversial field.

Registration fees will be in the order of US$795 for the full program. Please direct all enquiries to KREBS Convention Management Services, 555 DeHaro Street San Francisco CA 94107-2348 USA.
Telephone (415) 255 0497
Fax (415) 255 2244.

Seventh National Health Promotion Conference —what's working, not working and networking in health promotion

Brisbane Hilton, February 12–15, 1995

The conference aims are:

- to extend the understanding of health promotion in terms of strategies, outcomes, population groups and health issues
- to explore what does not work and increase our understanding of why not
- to identify contexts, including networks, policies and structures, that enable what works to be applied more systematically and comprehensively.

The theme and keynote speakers will contribute to debate about the direction of health promotion in Australia. Workshops and seminars are designed to improve the technical knowledge and skills of the health promotion practitioners working in various cultural and environmental settings.

Enquiries should be directed to the Health Issues Section, Department of Education, 72 Cornwall Street Annerley Queensland 4103.
Telephone (07) 896 5731
Fax (07) 896 5713.