Celebrating the Achievements of Health Services Research in Australia and New Zealand

2001-2011
Editors

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Contents

4 Introduction
6 Author biographies
8 The Health Services Research Association – our history
10 A decade of health system reforms in New Zealand
12 Health reform and evaluation in Australia
14 Primary care data: opportunities and limitations for health services research
16 Achieving a stronger primary health care system and better integrating care in New Zealand
18 Funding models
20 Health insurance through the ages
22 Priority setting in health: looking back over ten years
25 Priority setting developments within the New Zealand health system
28 You can’t always get what you want: the state of play in the economic evaluation of Australian health services
31 Quality of life in health services research: some issues and challenges
35 Patient perspectives
36 Māori health, and health services research: ten years of growth
38 Choice experiments in health services research
40 10 years on: using data linkage and cohort studies for health services research
42 Building on the achievements of the last ten years: “now is the time”
Introduction

This publication represents the tangible celebration of the 10th anniversary of the Health Services Research Association of Australia and New Zealand. Bringing together a set of papers looking back over the past 10 years in terms of both research and policy seems a fitting means of commemoration for an Association whose purpose is to facilitate communication across researchers, and between researchers and policymakers, to promote education and training in health services research, and to ensure sustainable capacity in health services research in Australia and New Zealand.

We began the process of thinking about which topics might be suitable by looking back at the subjects discussed at the first two Health Services Research and Policy conferences held in 1999 (Sydney) and 2001 (Wellington). We wanted to see which issues were perennial and unchanging and which had changed and developed over time.

The range of issues discussed by the authors of the papers illustrates just that. Health reform (Robin Gauld (NZ) and Jane Hall (Australia)) was discussed at those inaugural conferences and remains a firm favourite along with funding models (Tony Scott), private health insurance (Stephen Duckett) and economic evaluation and priority setting (Tony Harris, Rob Carter and Cathrine Mihalopolous (Australia) and Marty de Boer (NZ)).

Although reform in primary health care was already underway in New Zealand at the time of those first conferences, it has continued and evolved over the past 10 years (Jacqueline Cumming). Although not as wide reaching or comprehensive as the NZ reforms, the primary health care sector in Australia has seen many changes in this time (Elizabeth Comino). A common theme in both countries is the need to evaluate the impact and outcomes of such reforms using high quality data.
Although the Association has always recognised the need for Indigenous health services research (and researchers), it was not as strong a theme at the original conference as it has been over the past two or three meetings. Amohia Boulton’s essay demonstrates the impressive gains made by Indigenous health services researchers in New Zealand.

But perhaps the most obvious advances have been made in the areas of “the patient’s perspective” in Australia and in the availability of complex data for health services research. Karen Luxford and Graeme Hawthorne illustrate different aspects of shifting the focus of health care towards the patient. On the other side of the coin, Stephanie Knox and Louisa Jorm describe the use of data at the patient level to evaluate what is delivered to whom, with what effect (and sometimes at what cost) and how to understand patients’ choices and preferences.

We are very grateful to all the authors who so willingly provided excellent essays in a relatively short time with only minimal guidance. Sarah Green kept us all on time (more or less) and on budget and dealt efficiently with the myriad of administrative issues which inevitably arise in the coordination of a project such as this.

Happy 10th Anniversary and Happy Reading!

Jacqueline Cumming (President),
Jane Hall (Past-President) and
Marion Haas (Vice-President)

Health Services Research Association of Australia and New Zealand
Author Biographies

**Amohia Boulton** (Ngāti Ranginui, Ngati te Rangi, Ngati Pukenga) is a Senior Researcher at Whakaaee Research for Māori Health and Development, an iwi (tribal) research centre in Whanganui. She is also a Visiting Senior Research Fellow at the Health Services Research Centre, School of Government, Victoria University of Wellington. Amohia’s research interests include all aspects of Māori health services research however, she has a particular interest in understanding the relationship between, and contribution of, government policy, contracting mechanisms, performance monitoring and accountability frameworks to improving health outcomes for Māori. Amohia is a member of the Māori Health Committee of the Health Research Council of New Zealand and sits on the Executive of the Health Services Research Association of Australia and New Zealand.

A Professor Elizabeth Comino, is an epidemiologist who works with the UNSW Centre for Primary Health Care and Equity. Her research interests include access to best practice, primary care, equity, research methods in primary care, and use of administrative data collections for research. She currently leads two research programs: the Gudaga Research Study, an NHMRC funded birth cohort study of Aboriginal Children in an urban environment that is systematically describing their health, development, and services use; and a Diabetes linkage study, an NHMRC funded record linkage study investigating best practice health care for older people with diabetes. Elizabeth Comino is also the inaugural director of the south west Sydney Health District Primary and Community Health Research Unit.

Rob Carter is Head of Deakin Health Economics (DHE) and Deputy Director of the Deakin University Strategic Research Centre in Population Health. Rob has held a number of senior research positions, including: Head of the University of Melbourne Health Economics Group (2000-2006); Deputy Director of the Monash University Health Economics Unit (1993-1999); and Head of the Economics and Evaluation Unit within the Technology Assessment Branch at the Australian Institute of Health and Welfare (1990-1993).

Rob is widely recognised for his expertise in economic appraisal and in recent years has focussed his research on priority setting. His contributions to priority setting have been widely recognised, including five Awards for Research Excellence.

Dr Jacqueline Cumming is an Associate Professor and Director of the Health Services Research Centre in the School of Government at Victoria University of Wellington, Wellington, New Zealand. She has qualifications in economics and public policy, worked for many years as a policy analyst/economist with various New Zealand government agencies (including the Ministry of Health), and has worked as a health services researcher for the past 18 years. Her main interests are in health systems performance, primary health care access to services, equity, and priority setting. She is currently President of the HSRAANZ.

Marty de Boer works for the Ministry of Health as a Principal Advisor within the Executive Team of the National Health Committee. He has a BSc in Mathematics (Operations Research) and a Masters of Public Health. He has worked a variety of roles within the New Zealand health sector since the 1980s, including with the National Health Statistics Centre, Public Health Commission, KPMG, Central Regional Health Authority, Health Funding Authority and Hutt Valley District Health Board.

Stephen Duckett, an economist, is a Professor in the Schools of Public Health at LaTrobe University and the University of Alberta. In 2006 he was awarded the degree of Doctor of Science by the University of New South Wales on the basis of his publications, including his publications on health insurance. He is a Fellow of the Academy of Social Sciences in Australia.

Robin Gauld is Associate Professor of Health Policy and Director, Centre for Health Systems, Dunedin School of Medicine, University of Otago. He is author or editor of ten books, including The New Health Policy which was awarded first prize in category at the 2010 British Medical Association Medical Book Awards, and around a hundred journal articles and book chapters. Present research interests are in health system performance improvement and clinical governance.

Professor Marion Haas is a leading health services researcher in Australia. She has extensive policy and research based experience of health services funding and financing in Australia. Her research interests are in the use of economic evaluation, undertaking and applying the results of economic evaluation to health care services and understanding the preferences and behaviour of providers and consumers/patients in relation to health care. Dr Haas is a Co-Director of the Australian Technology Network of Universities (ATN) Centre for Metabolic Fitness, a multi University collaboration undertaking a wide range of research and evaluation projects related to obesity and the metabolic syndrome. Dr Haas is the leader of a UTS team, which, in collaboration with researchers from UNSW, is the recipient of an NHMRC Health Services Research Program grant and is CIR on a UTS-administered NHMRC Capacity Building grant. She is the Program Manager for the newly established Cancer Research Economic-Support Team which has been funded by Cancer Australia to provide advice and support to all Cancer Clinical Trial Groups in Australia. Dr Haas is currently Vice President of HSRAANZ.

Jane Hall is Professor of Health Economics in the Faculty of Business at the University of Technology Sydney; and the founding Director of the Centre for Health Economics Research and Evaluation, a position she has held for twenty years. She is a Fellow of the Academy of Social Sciences in Australia. She was President of the International Health Economics Association in 2006-7, and was President of the Health Services Research Association of Australia and New Zealand until 2007.

Jane has a wide range of research interests, including health technology assessment, the nursing workforce, and health funding. She is involved in health policy issues in Australia and internationally through her involvement with the Commonwealth Fund International Program in Health Policy and Practice. Her recent contributions include a position as an external advisor to the Commonwealth of Australia for Cambridge University Press Private Health Insurance and Medical Savings Accounts: Lessons From International Experience; and on the economics of prevention for the Oxford University Press Handbook of Health Economics, both due to be published shortly. She has a long standing commitment to the use of economic analysis in policy.
A/Prof Graeme Hawthorne is a Principal Research Fellow in the Department of Psychiatry at Melbourne University. Much of his research over the past 20 years has focussed on the development and/or validation of participant reported outcomes, including co-authorship of major generic outcome measures (e.g. the Assessment of Quality of Life (AQoL), the WHOQOL-OLD) as well condition-specific measures (e.g. the Friendship Scale (FS) for assessing social isolation, the Quality of Life after Brain Injury (QOLiBRI) or the Short Assessment of Patient Satisfaction (SAPS)). He has also published population norms for the SF-36, WHOQOL-BREF and AQoL. His current research includes population mental health, depression prevalence, quality of life research (QoL), traumatic brain injury, mental health post-acute-care, suicide prevention, physiotherapy in intensive care, hospital readmission reduction and health care resource use.

He is head of the World Health Organization’s (WHO) Quality of Life Australian Field Centre, an Associate Editor of the Journal of Medical Economics, the Journal of Happiness Studies, and a former Associate Editor of Quality of Life Research. He was an invited member of the COSMIN (Consensus-based Standards for the Selection of Measurement Instruments) project. He recently served on the Board of the International Society for Quality of Life Research, the International Economics of Incontinence Committee and the Advisory Committee, National Centre for Mental Health, China Centre for Disease Control, China.

Louisa Jorm is the Foundation Professor of Population Health in the School of Medicine at the University of Western Sydney. She also holds the part-time position of Principal Scientist at the Sax Institute. She is an epidemiologist who prior to taking up her current post, spent more than 15 years in senior positions in public health policy and Service roles. Her areas of expertise include data linkage, use of routinely collected health data and facilitating the policy and practice uptake of research. She is Chief Investigator of the Outcomes, Services, Policy for the Reproductive and Early Years (OSPREY) capacity building program, which has been funded by the NHMRC to build methods and capacity for the analysis of linked health datasets to answer policy-relevant questions about the health of mothers, babies and children. She also leads the NHMRC-funded Indigenous Health Outcomes Patient Evaluation (IHOPe) project, which is using linked data and multilevel modeling to investigate the influences of individual, geographic factors on hospital outcomes for Aboriginal people. In her role at the Sax Institute, Professor Jorm leads the NSW node of the Population Health Research Network, which has been funded through the National Collaborative Research Infrastructure Strategy, to build national infrastructure for research using linked health data.

His most recent work has been an analysis of international drug reimbursement decision making, evaluation of cost effectiveness within clinical trials, econometric analyses of the impact of chronic disease on labour market outcomes in Australia, and the demand and supply of acute and emergency public hospital care.

Stephanie Knox is a research fellow at CHERE with more than 12 years of experience across a range of health research disciplines in Australia, including public health, epidemiology, psychometrics and health economics. Stephanie leads the Bettering the Evaluation and Care of Health (BEACH) program at CHERE, and has been funded by the NHMRC to build methods and capacity for the analysis of linked health datasets to answer policy-relevant questions about the health of mothers, babies and children. She is currently principal investigator on Australia’s first large scale longitudinal survey of doctors (MABEL: Medicine in Australia: Balancing Employment and Life).

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The Health Services Research Association - our history

Jane Hall, Professor of Health Economics, Faculty of Business, University of Technology Sydney and the founding Director of the Centre for Health Economics Research and Evaluation
Jacqueline Cumming, Associate Professor and Director, Health Services Research Centre, School of Government, Victoria University of Wellington, New Zealand

The Health Services Research Association of Australia and New Zealand (HSRAANZ) officially came into being in December 2001, when a general meeting was held within the Health Services Research and Policy Conference in Wellington, New Zealand. The conference brought together researchers and policy makers to consider health services research evidence and current policy issues. The purpose of the conference and the newly formed Association was not to debate or advocate particular policy stances, but rather to understand the development and implementation of health services policy; and to consider how evidence and evaluation could better inform that. That remains the purpose of the Association, now celebrating its tenth anniversary, and the conference, which is held biennially in Australia and New Zealand.

This 2001 meeting was not the first conference. Two years earlier, the first meeting was held in Sydney, attracting around 400 participants. It provided the opportunity to focus on health services research and policy, an opportunity that most involved in the meeting had seen lacking in the conference scene in both countries. From that meeting, an executive group was formed; and with some funds granted by the Commonwealth Department of Health, the work of continuing the activities and forming an Association began.

Why was there a need for a new conference and a new Association? The idea of health services research and evaluation was not new. Australia was in the midst of the co-ordinated care trials, an attempt to establish pilot schemes of funds pooling and budget holding at the primary care level. Evaluation of the pilots was an integral component. Developments in various aspects of service delivery, such as hospital-in-the-home, early discharge programs and telehealth services were all linked to evaluation studies. Health Technology Assessment was well established at the Commonwealth level; the economic evaluation requirement for new drugs listed on the PBS had been operating for almost a decade; and a new Medical Services Advisory Committee applying the same approach to medical interventions on the MBS was commencing. Health services research had been strongly supported through the 1980s by the Commonwealth Department of Health through the Research and Development Grants Advisory Scheme though this waned during the 1990s.

In New Zealand, regional health purchasing authorities in the early 1990s followed by the single national health funding authority established in the late 1990s had increased interest in health services research and evaluation to support purchasing decisions and to assess new service developments, such as shared care in mental health, integrated care, clinical priority assessment criteria, etc. PHARMAC was becoming well established and assessing medicine’s funding priorities. In addition, the many reforms to the structure of the New Zealand health system were opportunity for research and evaluation, to identify what works well and what does not, and how the health system’s performance could be improved.

In both countries, the precursor to the Public Health Association (PHA) was ANZSERCH, the Australian and New Zealand Society for Epidemiology and Research into Community Health. ANZSERCH took a broad approach with Community Health encompassing health services as well as social and biological determinants of health. But the advent of public health and the PHA changed that focus to population health – infectious diseases and social factors influencing health and disease. Indeed, the Special Interest Group which focussed on health services research and health policy was abolished by PHA Australia in the mid-1990s. The Australian Health Economics Society provided a forum for health economics research. The Case-mix Conference developed the niche around classification of health service activity and associated issues; and the Health Outcomes Conference developed a different but still specialised focus on measuring health outcomes. Nonetheless, there was a great deal of work for which those conferences were not the natural forums for dissemination; there were 260 different presentations made at those first two health services research and policy conferences, so there was certainly no lack of work underway. But there was no obvious venue for the presentation of research on broad issues of health service delivery.

The early years of HSRAANZ were marked by enthusiasm and a great deal of voluntary effort. The Centre for Health Economics Research and Evaluation (CHERE) was able to provide some administrative support, and each conference generated sufficient funding to bankroll the next conference. Together the Association and the conferences made visible the health services research constituency; and the extent of work underway often with meagre support. For example, at the 1999 conference, a plenary speaker asked how many of the audience had continuing employment contracts or contracts for 5 years or longer; only one hand was raised. By 2004, the Association had 112 individual members and 14 corporate members; around one third had five year
contracts, but another third had contracts of one year or less [1]. At that time, members nominated as major issues for the field: the building of health services research capacity in Australia and New Zealand; funding for training and career development; funding for research with longer time horizons; and the need to strengthen links between research and policy.

The Association has worked very hard to raise the profile of health services and health policy research. In Australia, health services research is now recognised by the NHMRC as the fourth pillar of research, the other three being biomedical, clinical and public health. The NHMRC now has a Grants Review Panel for health services research; and has funded several initiatives such as Centres of Research Excellence in Health Services Research. The ARC also funds some health services research through its disciplinary groupings. In New Zealand, health services research continues to fall under the category of public health research, and an increasing focus on clinical research continues to make access to health services research funding difficult.

A real turning point for the Association came in 2006. By that time, the Association, primarily through the success of its conferences, had accumulated sufficient funds to employ a part-time Executive Officer. Sarah Green joined and quickly initiated a wide range of activities aimed at both existing and potential members and at raising the profile of the Association and health services research within the broader research funding and policy communities. Gradually, the range and scope of funded health services research has expanded. Health services researchers have had some success in gaining support from training and people support schemes of the funding agencies. As well as short term, defined research projects, there has been some success in gaining some programmatic funding support for a more topic driven research effort with five year time horizons.

While some congratulation are in order, health services research continues to face real challenges. The scope of health services research remains poorly conceptualised, and for many it is another name for clinical research, so scarce funds are not directed as intended. There is little support for doctoral and post-doctoral fellows, and poor recognition of the varied career paths that bring researchers to health services research; rarely is it a straight line from undergraduate enrolment to post-graduate study. Experienced staff continue to work on soft funding, with few or no career options available. The success rate for health services research project applications remains low, even compared to public health research. Longer term strategic research is difficult to undertake where funding remains inadequate and largely allocated on a project-by-project basis.

The strengthening of links between the world of research and academia, and the world of bureaucracy, policy and clinical practice, the third of mid-decade major issues, has seen little progress. While translational research has become a major focus of funding agencies in Australia, and to a lesser extent in New Zealand, it is still conceived of as taking research findings from the laboratory to the bedside. The many important issues that New Zealand faces - in relation to identifying where the best spends in health are and developing tools to assist in such decision-making, whether and how reforms in primary health care are delivering the outcomes desired, the effectiveness of clinical networks and leadership, changes in workforce policies, where productivity gains have been made, and whether quality of care and safety are improving – all require research and evaluation on the ground rather than in laboratories or through clinical trials. Australia has embarked on the most far reaching health reforms since the introduction of Medicare in 1984 [2]; this will encompass establishing new governance arrangements for public hospitals, establishing organisations for primary care, developing and implementing new forms of activity based funding for service provision, establishing incentive schemes to reward targets achieved, operationalising a preventive health agency, ensuring accountability, sound management and strong clinical leadership.

So let us celebrate this tenth anniversary by taking stock, while acknowledging there is so much to do to build evidence based health policy, we have some achievements to recognise from working together, and let us face the challenges with renewed resolve to make a difference.


A decade of health system reforms in New Zealand

Robin Gauld, Associate Professor of Health Policy, Director, Centre for Health Systems, Department of Preventive and Social Medicine, Dunedin School of Medicine, University of Otago

BACKGROUND

New Zealand has built a reputation for regular reform of its health care system, which is around 80% government-funded from general taxes. The remaining funding is from out of pocket copayments for primary medical care and prescribed pharmaceuticals, and from patients bearing the full-cost of private services. Through the 1990s and 2000s, successive governments variously restructured the organizational arrangements for planning, funding and providing New Zealand’s health services [1, 2]. These reforms have been the focus of various presentations delivered at HSRAANZ events and evaluations by Association members [3-12].

In line with trends elsewhere, particularly in the English NHS, the focus of reforms in the 1990s was on stimulating competition at both the purchasing and provider levels of the health system. Four new purchasing agencies were created with public hospitals to function like private businesses. This had mixed success; a single national purchasing agency was then created, and by the latter part of the 1990s the policy focus had shifted to service integration, national consistency in terms of purchasing decisions and service access, prioritization, reducing inequalities, and improving primary care. A new centre-left government was elected in 1999 and then, around the time the HSRAANZ was formed, introduced a population-health focus via a series of national health goals [13]. Structural changes included replacing the single purchaser with 21 local District Health Boards (DHBs), each composed of elected and appointed members supported by a chief executive and secretariat. DHBs were designed to democratise and decentralise planning and decision making, as well as run public hospitals and fund all other public health services for their regional populations. From 2002, this government also oversaw creation of over 80 primary health organizations (PHOs) [14]. Evaluations by HSRAANZ members, including some that involved collaborations with government agencies, suggested the new system was bedding down but that both it and the change process had been complex, as predicted early on [15], and that local and national goals did not necessarily chime with one another [3, 6-8].

By the time of the 2008 general election, several questions about health system performance had emerged [2]. 21 DHBs and 80 PHOs seemed excessive, with wide-ranging concerns about duplication, variation in size, efficiency and service access. Clinical staff had become alienated from management and policy makers. While the aims of the system seemed reasonable, the design and its implementation appeared sub-optimal. The election produced a new centre-right government concerned with clinical engagement, productivity, quality improvement, and service access - especially to electives and cancer treatments [16]. This contrasted with the prior government’s focus on community involvement in governance, local decision making, public health and primary care. The new government commissioned a Ministerial Review Group to review the system, with its prescription for change released in 2009 [17].

The group’s diagnosis was of a system with deep-rooted problems, including too much bureaucracy and insufficient focus on ensuring adequate access to front-line health services, of considerable funding increases over several years yet no evidence that clinical service capacity or efficiency had improved, and a lack of national coordination especially around issues such as quality and service integration [17]. The general solution has been a wide-ranging series of reforms now in implementation.

NEW INSTITUTIONAL ARRANGEMENTS

Core principles underpinning the new directions are reducing bureaucracy including duplication of ‘back office’ functions of the DHBs, improving coordination, and reducing waste within the health system [17]. The keys to this are seen to be quality improvement, comparative-effectiveness research, and nationalisation of various functions such as information technology (IT) planning. A series of new institutional arrangements have been created, with considerable borrowing of initiatives from abroad, especially the English NHS, but also other health systems concerned with quality improvement and efficiency.

At the central government level, a new National Health Board has been established to assume operational oversight functions formerly the responsibility of the Ministry of Health. Thus, the National Health Board, in the end established as a business unit within the Ministry of Health, has responsibility for all matters pertaining to monitoring, funding and organization of the DHBs. The National Health Board’s job is improve DHB performance, ensure a national focus for the DHBs, reduce duplication and bureaucracy and, with almost a quarter of funding (for primary care, maternity, some mental health and other services) never devolved from the Ministry to DHBs, work out which services should be centrally or locally purchased. Meanwhile, legislative changes mean DHBs must now plan together regionally especially for services, such as cancer and pediatric sub-specialties, that are difficult to staff and provide for geographically disparate populations. In the interim this is creating a more complex set of administrative layers, but the longer term aim is that the silo structures of the DHBs should reduce. A 2010 merger between two DHBs mean there are presently 20 DHBs. Other mergers could follow.

In keeping with its policy of ‘better, sooner, more convenient’ services, the government has funded a series of pilot primary care-based Integrated Family Health Centres [18]. While still in planning, these largely aim to bring together primary care practitioners offering 24 hour service access with advanced diagnostic and some specialty services. PHOs, themselves, are enduring a period of consolidation with the Minister of Health seeking mergers. There are currently around 36 PHOs.

Other national agencies have been created for specific tasks (see Box). Reporting directly to the National Health Board is the IT Health Board, created to drive coordination of IT purchasing and planning, presently done by 20 DHBs and a myriad of PHOs and other organizations. While New Zealand has had comparatively high usage of IT, especially in primary care [19], interoperability is low with limited connectivity between primary and hospital providers. The IT Board aims by 2014 to have a portable, patient-accessible, electronic patient record for every New Zealander and is also pursuing a range of projects around e-prescribing and referrals, the primary-secondary care interface, and national IT system architecture. The National Health Board also houses Health Workforce New Zealand, created to focus on workforce planning and sustainability as New Zealand has a serious health workforce shortage [20]. New independent agencies include Health Benefits Limited, whose goal is to reduce funding for non-clinical services by $700 million over five years. It aims to nationalise back office functions such as payroll and, in seeking to emulate the successes of Pharmac, the national drug purchasing agency, use monopsony power through national procurement of medical and other equipment (presently done by individual DHBs). A new Health Quality and Safety Commission is designed to support and stimulate quality improvement activities across the health sector, with interests in everything from safe prescribing systems and adverse events through to promotion of ‘lean’ process design. The long-lived National Health Committee, formerly focused on providing advice to the government on various issues, is being reconfigured to undertake comparative-effectiveness research.
Central to all of the new arrangements has been a government commitment to ‘clinical governance and leadership’, with Ministerial directives that DHBs must facilitate this [21]. Clinicians had long felt sidelined in planning and decision making, with the prior government disregarding general practitioners in its PHO policy development process and DHB management frequently offside with hospital staff [22]. In contrast, the present government has involved clinicians in all of its decision making structures with the boards of all the above-mentioned new agencies clinically dominated. In keeping with quality improvement theory and practice elsewhere, clinical governance and leadership are also seen as pivotal to health system performance improvement [23]. This said, initial research shows DHBs need to do more to promote clinical governance [24].

Driving the activities of the 20 DHBs have been six new health targets. Pre-2008, a New Zealand Health Strategy had focused the health sector on a multitude of population-based goals many of which lacked specificity [8]. The present government’s six targets have specific goals (e.g. treat emergency department patients within six hours; treat cancer patients within four weeks) and are published quarterly in league tables comparing DHB performances against benchmarks and one another. This has driven considerable competition and some improvement in these areas.

A PROMISING NEW COMPLEXITY?
The post-2008 reforms represent a considerable change in the configuration for planning and funding of New Zealand’s health services. It is difficult to say how well the new system is likely to perform as the changes are under implementation. This said, a few observations can be made. As noted, the reforms chime with developments elsewhere focused on efficiency and quality improvement. Several policy initiatives look as though they were directly borrowed from the English NHS (albeit prior to the present NHS changes focused on devolving commissioning to GP consortia), from the creation of new central agencies dedicated to specific issues, to the promotion of a national IT infrastructure, clinical governance and primary care integrated centres (similar to the ‘polyclinics’ the NHS commissioned). In many ways, the reforms aim to recreate a ‘national health system, with strong central oversight and coordination, following several years of devolved planning and decision-making which, the government’s advisors argued, exacerbated variation and produced poor health system performance [17].

However, there remains considerable continuity of institutional arrangements with many organizations and power-bases unaffected at least in the interim. The 20 DHBs, for instance, are each led by their own board and chief executive. While now required to coordinate regionally, they are able to resist various central demands, promote alternative agendas in policy discussions, and do not necessarily act in unison. This has driven considerable competition and some improvement in these areas.

In 1999, there was not much to say about Australian health care reform; it was almost an oxymoron. The structure of Australian health care had remained the same, since the advent of Medicare in 1984. Public hospitals were owned and operated by the States, with the Commonwealth’s share of cost funding determined through 5 yearly agreements; all Australians were entitled to free public hospital treatment. Medical services were subsidised through the Medical Benefits Schedule, fee for service and private practice were enshrined. The Pharmaceutical Benefits Scheme provided universal access to a comprehensive range of prescription drugs at a standard co-payment. The rest of the world was moving away from subsidised private practice while in the Netherlands the idea of its engagement with the forces of competition. The UK had instituted the NHS with a funds pooling model and evaluate its implementation.

By 2000, the Australian Co-ordinated Care Trials had completed the first phase and were reporting. The Trials were a systematic attempt to develop a funds pooling model and evaluate its implementation.

Today, health reform is a national program. In the 2007 national election, won by Labor under the leadership of Kevin Rudd, health policy was a major issue, but the focus had moved from publicly subsidised private insurance to the funding and governance of public hospitals, and the ‘blame game’ between the Commonwealth and State/Territory governments. To what extent, if any, did health services research and evaluation influence the changing agenda? There has been quite a body of research on insurance, the impact of the incentives on take-up of insurance (see Stephen Duckett’s commentary), the type of new entrants encouraged by the incentives, and their use of public hospitals. At least, the impact of this was to raise doubts about the efficiency and effectiveness of insurance subsidies. This body of work probably helped move attention to other aspects of health system finance and organisation.

The precursors of the support for health reform can be found in the growing pressure on public hospitals. State governments were able to exert budgetary control, whereas the MBS and the PBS are largely open-ended commitments. Public hospital workloads were steadily increasing (and continue to do so), in numbers and complexity. Public concern with the state of the health system is focussed on waiting times in emergency departments and for elective surgery. State governments were facing voter dissatisfaction, and funding public hospitals was imposing an increasing burden on increasing State Treasuries. Faced with this, some State Premiers began to entertain a Commonwealth take-over of responsibility for public hospitals, encouraged by several policy commentators.

The Rudd Government established the Health and Hospitals Reform Commission to tackle the long term reform plan which would provide sustainable improvements in performance. The Commission’s report was made public in 2010 with recommendations for a major restructuring of inter-governmental funding, and a move to managed competition. The Commonwealth government’s response, announced in March 2010 was for greater local control of hospital governance with the Commonwealth funding 60% of public hospitals. This required the States’ agreement to a clawback of the GST revenue paid to the States. Western Australia refused to sign the Agreement, making it a much less than national deal. The change in Prime Minister led to a new round of negotiations with a national Agreement reached in August 2011. The Commonwealth will fund a lower share of hospital costs but the States do not give up their GST revenues. National Health Reform encompasses hospitals, primary care, aged care, mental health, standards and performance, workforce, prevention and eHealth. However, the major focus is still funding public hospitals. By mid 2012, activity based funding (case-mix) will be provided from a national funding pool directly to Local Hospital/Health Networks. A new agency is being established to set efficient prices: The Local Networks are small groups of hospitals, primarily geographically based, constituted as independent legal entities. Alongside them are Medicare Locals, to develop out of the Divisions of General Practice but to encompass all primary care services, and to take a population health focus. Another feature is increased accountability and public reporting.

Has health services research influenced the push for reform or the development of the reform plan? The sense that things would be better if there were one level of government responsible for health funding appealed to common sense. But like many dilemmas in health policy, to every complex problem, there is a simple and common sense solution – and it is generally wrong. There was little research evidence to support the one level of government view, and indeed the Coordinated Care Trial results showed that gains in terms of better health outcomes and lower costs were not that
easy to achieve. The Health and Hospitals Reform Commission worked primarily on a submission and consultation basis, not from a review of research evidence. So its own deliberations were largely uninfluenced by research. It did, however, in its final report draw attention to the need for a self-improving health system which used the results of research to deliver improved health outcomes. This has been used to focus attention on the gap between biomedical research results and their application in routine health care, while the need for learning from social experiments – and every new social policy is a form of experiment – has not been identified. The subsequent development of the government response relied even more heavily on consultation and photo opportunities for the Prime Minister in public hospital wards and emergency departments.

There are, though, examples of research with direct influence on the development of policy and its evaluation, such as the evaluation of the safety net arrangements. The Extended Medicare Safety Net was introduced in 2004 to address the issue of rising out-of-pocket expenses. The Safety Net pays 80% of out-of-pocket costs for Medicare reimbursed medical services provided out of hospital, once a certain threshold for families (and lower for singles) has been reached. The 2009 independent review, undertaken by a team at CHER, found that this led to a significant increase in fees; a conservative estimate was that around 40% of the expenditure under the Safety Net went to providers, and most of that to obstetrics and assisted reproductive technology. Guided by these findings, the government introduced caps on certain Medicare items; meaning that there is a maximum limit on the amount of benefit to which a patient is entitled. A further review demonstrated a marked impact on Safety Net expenditure.

Health reform will present many such challenges which are amenable to research and evaluation. The new national hospital pricing authority will have to determine exactly how to pay on an activity basis. In general, hospitals have high fixed costs and low marginal costs, activity based funding sets strong incentives to admit additional low cost patients, rather than treat them in alternative settings. Research can investigate the impact of these incentives in the Australian setting, and provide the basis for adjusting the levels to ensure desired outcomes. The new national health performance authority is to provide the community with valid information on the performance of their health services. Yet, according to a recent WHO review, almost nothing is known about how to present this information to providers, funders and the general public so that it is useful and used. Here research can identify what information should be presented; and how different methods of presentation affect its comprehension and use. The setting up of the new Local Hospital Networks is based on the argument that local decision making will improve efficiency, quality and outcomes. New approaches have been developed to evaluate reforms in the UK, such as the investigation of the effect of competition on mortality. Here is a great opportunity to use similar approaches to evaluate the Local Networks.

But let us not expect to be able to trace direct links between one research project and a policy action. The virtuous cycle of the NHMRC, in which research investment creates new knowledge which is then applied through policies and clinical practice to result in healthier Australians, and greater national wealth then supporting further research investment, is not a useful model for research into health care financing and organisation. Health policy, particularly at the level of system wide financing and organisation, is very much driven by ideology and vested interests. Research evidence is but one input to the contest of ideas but without it there can be no intelligent approach to policy.

Primary care data: opportunities and limitations for health services research

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INTRODUCTION

When I began this career in about 1990, electronic data collections were in their infancy. My MPH treatise investigated Leptospirosis in kennelled Greyhounds as a public health issue. I spent many hours trawling through microfich data files looking for ‘cases’. Health service data was at best patchy or non-existent. We dreamed about the possibility of expanded electronic data collections. I went on to develop my interest in primary and community health research and have developed a substantial research program using administrative data collections to explore access to primary health care with a strong interest in equity.

This document provides a personal perspective on the development of electronic primary health care (PHC) data collections in Australia in recent years, and a discussion of current opportunities to enhance the availability and comprehensiveness of electronic PHC data collections. These provide exciting opportunities to enable health services researchers like myself with an interest in access to and equity of PHC with opportunities to explore more interesting and complex questions.

WHY PRIMARY HEALTH CARE?

Barbara Starfield defined primary health care as ‘first-contact, continuous, comprehensive, and coordinated care provided to populations undifferentiated by gender, disease, or organ system[1]’. PHC is that section of health care that is provided wholly or partly in community based settings through a complex network of services, providers, and funding mechanisms. It is provided through a range of organisations including general practice, community health services, private non-medical and allied health services, and non-Government organisations and by a range of health care professionals including doctors, nurses, dentists, pharmacists, allied health care providers and health workers. PHC is delivered in a number of settings including traditional settings such as a general practice, dental surgery, or community health centres, as well as other settings such as work places and schools. Overseas research has demonstrated that there is a close association between the strength of the PHC sector and population health[2].

PHC plays a key role in Australia’s health system. Through PHC, Australians generally have good access to episodic care (that is, one-off care for acute or short term conditions), health promotion and disease prevention, early detection and management of chronic health conditions, co-ordination of care for patients with complex care needs and advocacy through links to other sectors and outreach to vulnerable and marginalised populations with special needs. For example, we know that about 85% of Australians consult a GP at least once a year and have an average annual rate of 5.3 consultations[3]. Less is known about the range of other PHC services that Australians use.

Nevertheless, ensuring that Australians have access to appropriate and affordable health care is an integral component of Australian health care policy[4]. Although Australians have access to universal publicly funded medical, public hospital, and some community health services care under Medicare, the PHC system is fragmented through multiple funding and service delivery mechanisms, the exclusion of many PHC services from Medicare funding, and uneven distribution of services. Consequently, there is unequal access to PHC driven by factors such as out of pocket costs, availability of services, and distribution of services. Growing awareness of the importance of PHC in delivering equitable and cost-effective care is creating interest in better understanding and addressing issues of access to PHC.

SOURCES OF PHC DATA

Although it has been estimated that PHC comprises about half of total public and private health care expenditure, information about this sector is largely underrepresented in health care statistics due to the lack of a comprehensive, reliable PHC data collection[5]. Information derived from these data are of potential interest to governments who are responsible for health policy and for public funding, health care and professional organisations with responsibility for ensuring practice standards, and consumers and health service providers with an interest in ensuring access to best practice PHC. Data support planning to determine need for services, highlight barriers to access to health care including availability and appropriateness of suitable services, ensure implementation of ‘best practice’ PHC, enable evaluation of outcomes of PHC care such as ambulatory care sensitive admissions, and support policy development.

Yet although PHC data has been and remains fragmented, there have been huge advances during the last decade or so. Electronic data collections, where data collections exist, are now the norm. For example, most GP practices now use electronic medical record systems for billing or prescription writing, and many community health nursing services have changed to or are planning to change to electronic medical records. Where services receive publicly subsidised funding such as GP and pharmacy, electronic claims systems are contributing to administrative data collections containing information on aspects of PHC.

Available PHC data collections can be grouped into three general categories: Administrative data eg Medicare data; specific data collections eg GP activity data, register data; and Population health surveys.

Administrative data provide a record of services used and are a source of information on people who use services. The major source of administrative data for PHC currently available in Australia is Medicare Australia data. These data include a record of claims for reimbursment for GP and other health professional services funded wholly or partially through the Medical Benefits Scheme (MBS), and for substituted cost of pharmaceutical products dispensed that exceeds a predetermined threshold (PBS)[6]. These data collections have evolved over the last decade with the introduction of direct electronic claiming for MBS in 2011 and for PBS in 2004. In 2012 the PBS data will include all PBS items dispensed. Although these data are a potentially rich source of data on GP and pharmacy, access is limited and subject to stringent approvals and adherence to privacy guidelines. MBS and PBS data do not include information on the underlying medical condition, are limited to eligible MBS/PBS items, and exclude many aspects of PHC services. There are other sources of electronic administrative data in PHC that are used within practices or by community health services. Although there has been a significant expansion in their use in recent years, coverage remains variable, practice based for internal purposes, and not collated for research and other purposes.

The Bettering the Evaluation and Care and Health (BEACH) data collection is a continuous paper-based survey of GP activity in Australia that commenced in 1997. The collection comprises information from GPs who provide information on reasons for and content of consultations. These data are an important source of information within GP including trends over time. However, participation is low, limited to GPs in practice, and the data are not able to be linked internally or externally.
**Disease registers** have a role in GP. The CARDIAB data base for example is a GP diabetes register developed for and maintained by Divisions of General Practice[8]. It was widely used for patient care to monitor control of diabetes and recall patients for review, and for research[8]. CARDIAB use has lapsed in recent years with wider use of practice based patient management systems which are collated for research purposes[9].

**Population based health periodic surveys** are widely used by government to seek information on demographic and socioeconomic characteristics, risk and preventive factors, health and health services use of participants[10]. Surveys provide general information on the prevalence and treatment of a range of health conditions. Specific surveys, for example the AusDiab survey enable more indepth exploration of specific issues[11], including a health check and biological testing to supplement self-reported data.

**Cohort studies** are a development of surveys and include additional follow up over time enabling examination of lifestyle, development, health and health service use among other factors over time. There are an increasing range of cohort studies in Australia including large cohorts such as the 45 and Up Study[12] and smaller ones such as the Gudaga study, a unique study of a birth cohort of Aboriginal children[13].

In summary, although there has been an expansion in available electronic data sources on PHC, activity, none provide a comprehensive view of PHC. However all have a greater or lesser capacity to generate information on PHC that is of use for health service planners, policy advisors, practitioners and researchers. Their limitations include their stand-alone nature, focus on limited aspect of health care, inability to link patient needs directly to health service use, and their accuracy and reliability. These data also exclude information on health services that are not covered by public funding, including dentists, allied and other health providers. Barriers to building more comprehensive PHC data collections include availability of data, capacity to identify individuals in data, consent to use the data for purposes other than it was collected, data custodian issues, privacy guidelines, and system design and software/hardware compatibility. New developments in data collections provide opportunities to address some of these issues.

**EMERGING RESEARCH OPPORTUNITIES**

Our research using various PHC data collections has contributed to aspects of PHC[14],[15]. Emerging opportunities are enabling us to explore more complex questions about access to PHC and the relationship between processes of care in PHC and health outcomes. These include new population based data collections and enhanced capacity to link unit record data. The first opportunity is the establishment of the Centre for Health Record Linkage (CHEReL) in NSW and the ACT in 2006. The CHEReL is an independent facility that is able to link electronic data on the basis of personal identifiers at person level, create linkage keys and return these to data custodians. The data custodians are able to release clinical information to researchers. Using a CHEReL linkage, we are currently completing research using linked data from a CARDIAB Register and the NSW Admitted Patient Data Collection. This research is enabling us to explore the nature of the relationship between processes of care and control of diabetes in GP and admission; research that is of interest to health care policy advisors and planners as diabetes is regarded as an ambulatory care sensitive condition. Record linkage will enable exploration of such questions of clinical and health service importance.

The second opportunity was the establishment of a large population health cohort, the 45 and Up Study, comprising 267,000 NSW residents aged 45 years and over[12]. Potential participants were identified from the Medicare database. The baseline data collection provides data on participant demographic characteristics, socioeconomic status, behavioural risk factors, health status including health related quality of life, presence of certain health conditions, and treatment of these conditions. These data are able to be linked directly to available Medicare data including MBS and PBS claims for reimbursement for services provided through Medicare Australia and indirectly to hospital data through the CHEReL. The cohort and linkage will enable us to create comprehensive PHC data collections not currently available and to explore questions of national significance. We have attracted NHMRC funding for this research.

A third opportunity involves research led by Professor Siaw-Teng Liaw at the Centre for Primary Health Care and Equity[16]. We are working with primary care providers including general practice and community health to extract clinical data from clinical record systems. This research is in its early stages. It has potential to enable significant clinical research into specific ambulatory conditions such as diabetes.

**CONCLUSION**

Governments, professional organisations, and providers in many developed countries including Australia are grappling with the high costs of health care provision, especially for expensive secondary and tertiary care. There is an increased interest in and focus on research to better understand the roles and functions of the PHC sector improve health care provision. Developments in electronic data collections in the last 10 years in Australia are extending available data collections to support this research. Our understanding of PHC is benefiting from the development of electronic administrative and clinical record systems and from enhanced capacity to link these to address issues of wider clinical and policy interest.

[16] Liaw ST, Taggart J, Dennis S, Yeo AET. Data quality and fitness for purpose of routinely collected data – a case study from an electronic Practice-Based Research Network (ePBRN). Proceedings of the American Medical Informatics Association Annual Symposium 2011, Washington DC.
Achieving a stronger primary health care system and better integrating care in New Zealand

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New Zealand’s health system has been largely publicly financed since the 1930s, but there has always been a gap in coverage for primary health care (PHC) services. PHC services have traditionally been only partially financed by government, with service users paying increasing out-of-pocket fees (co-payments) to use PHC services. This has led to major, long-standing concerns about poor access to and use of PHC services in New Zealand, with a suspicion that this in turn results in both over-use of expensive hospital services and poorer health, particularly for Māori and Pacific populations, and for people on low incomes[1-3].

In 2001, when the HSRAANZ was being established, New Zealand had released its first ever national PHC Strategy[4]. In an environment of rising health care costs, chronic diseases requiring new ways of delivering services, and increasing international evidence that a strong PHC system should deliver better health, reduced inequalities, and be a cost-effective means of providing health care[5] [6], the PHC Strategy was a multi-pronged approach aimed at improving access to PHC services, as well as improving health and reducing inequalities in health.

The Strategy’s implementation involved a significant increase in the funding provided to support PHC services, with a view to reducing the out-of-pocket costs incurred by patients and expanding PHC service provision. It also encouraged the development of new Primary Health Organisations (in New Zealand, usually funded as a result of the PHC Strategy) which were intended to function as meso-level primary care organisations to facilitate the development of PHC services. Capitated funding was to be allocated to PHOs on a population basis, weighted for need, and a performance management programme was also to be introduced to ensure a focus on quality of care.

The first test of the new Strategy revolved (as always in PHC policy in New Zealand) around whether general practices would be able to continue to set the level of co-payment charged to individual patients, in spite of the significant increases in funding being provided by the government[7]. Eventually, the government agreed that this practice could continue; at which point, the reforms took off. Within a few years, 80 PHOs were established, and most of the New Zealand population were enrolled with a PHO (through a general practice).

A very early formative evaluation focused on key aspects of implementation[8]. Importantly, the Ministry of Health, the Health Research Council of New Zealand and the Accident Compensation Corporation then funded a multi-year evaluation of key aspects of the Strategy, while the Ministry of Health also funded a number of other evaluations of specific components of the Strategy, one of the very few times such major reforms have had specific funding for evaluation set aside in this way. Various monitoring reports and evaluations show that the PHC reforms have achieved much: there have been reductions in the co-payments charged to patients for PHC services[9] [10]; a reduction in unmet need with respect to PHC services[11]; an increase in the delivery of services by nurses[9]; and increases in consultation rates for PHC services amongst New Zealanders[9] [10]. There have also been improvements in performance amongst PHOs in achieving key targets (e.g. breast and cervical cancer screening rates, flu vaccinations and child vaccination rates)[12].

Reports on and evaluations of the reforms also identified a number of issues with the reforms. First, there were concerns that not enough of the new funding being provided to reduce co-payments was in fact being used by policy makers[7]. A result of this time, the government produced guidelines for co-payment increases each year, established a ‘review’ process which could be used by the District Health Boards (DHBs) if DHBs believed that co-payment increases were too high, and provided increased funding to those PHOs that would agree to charge below certain co-payment levels in order to keep co-payments affordable[7]. Second, there were concerns over the number of and variation in PHOs[13]. Originally, PHOs ranged in size from fewer than 5,000 members to over 300,000 members; their governance arrangements differed (including in relation to whether Board members were paid or not); they differed in terms of the range of providers they worked with; and they differed in terms of their expectations of their role[13]. Third, there were concerns over the lack of clarity in the roles of PHOs[13]. Finally, there were concerns that perhaps too much attention had been paid to establishing new structures with community governance arrangements and a broader public health profile, and insufficient attention had been given to developing a more comprehensive approach to the delivery of PHC services[14].

The desire for a more comprehensive PHC service in part reflects concerns over the fragmentation of health care delivery in New Zealand. New Zealanders have long noted the importance of achieving more ‘integrated’ or ‘co-ordinated’ care, with better collaboration and co-operation between providers, both within PHC service delivery and between PHC and hospital service delivery. However, a major stumbling block to more integrated care has been that PHC services have always been on the edge of the publicly-financed health care system in New Zealand, making it difficult to build more integrated care initiatives around a strong PHC system[15].

The strengthening of PHC services in recent years, including as a result of the PHC Strategy, has now enabled an increased focus on actually delivering more integrated care. Demonstration projects during the 1990s (a number of which were also evaluated) found ways to improve co-operation between providers; and make the most of agreed pathways and guidelines, shared information, and shared care arrangements, to improve patient care[16] [17]. Unfortunately, however, evaluations were generally not funded to assess integration from a patient perspective, show improved health outcomes or demonstrate relative cost-effectiveness[16]. Later evaluations of projects in Counties Manukau resulted in and demonstrated some important achievements and improvements in health (including statistically significant changes in diabetes care, blood pressure and cholesterol)[18] [19].

Towards the end of the 2000s, seven years after the introduction of the PHC Strategy, the concern became that not much had changed in terms of actual PHC service delivery to patients, and that much more needed to be done to achieve more integrated care. Thus, in its 2008 pre-election health policy, the New Zealand National Party asserted that the previous government had “failed to deliver on the Primary Health Care Strategy” with “little if any progress in developing multi-disciplinary health teams, better co-operation with hospitals, or more minor surgery”[20]. If elected,
the National Party pledged to provide “Better, Sooner, More Convenient Healthcare”[21]. In government, it would maintain PHOs and advance the PHC Strategy, but deliver a patient-centred health system where individuals are active partners with health professionals in the management of their own treatment and care[21], the development of integrated family health centres (IFHCs) and co-location of multi-disciplinary teams to deliver a wider range of services in PHC settings, and the devolution of services from hospital providers (DHBs) to primary health care settings[21].

Following the election of a National-led coalition government in late 2008, a Ministerial Review Group was established in January 2009 to review the health system and recommend how its quality and performance might be improved. Its subsequent report made recommendations around nine key themes, the first of which was, “New models of care which see the patient rather than the institution as the centre of service delivery and which aim to promote a more seamless patient journey across community, primary, and hospital sectors, greater use of primary and community care, and the shifting of care ‘closer to home’”[22]. The report also suggested that PHOs should further develop their management capability and encouraged to develop new models of care. In terms of new models of care, in September 2009, a request for expressions of interest for the delivery of Better, Sooner, More Convenient Primary Health Care was released[23]. More than 70 responses were received, with nine (subsequently called ‘Alliances’) selected to develop business cases and subsequently proceed to implementation[24].

These reforms have seen further changes in the PHC landscape. First, there has been a significant reduction in the number of PHOs in New Zealand, from around 80 in 2010 to around 30 in October 2011[21]. Second, in terms of the Alliances, there are new regional macro-level networks in Auckland and the Canterbury regions, involving a wide range of organisations in planning, funding and delivering services; new networks of PHOs, with four PHOs working together in the Midlands region, and a National Māori Primary Health Organisation Coalition bringing together 11 Māori PHOs; and in four districts, PHOs have amalgamated, with a Pacific-led PHO formed in Auckland to co-ordinate services and develop a critical mass in Pacific health, and a single PHO now planning and funding all PHC services in each of the three other districts[26].

Overall each Alliance is focusing on a range of initiatives, including devolving services from New Zealand’s publicly-owned hospitals (run by DHBs) into the community; greater co-ordination between PHC services and hospitals; IFHCs; an increased focus on nurse-led services and multi-disciplinary teams; improved co-ordination for Pacific PHC services; and the new whānau ora (family wellbeing) models of care to improve Māori health[26][27].

Overall, New Zealand has made significant progress in strengthening its PHC services in recent years. However, some significant issues remain.

First, although major increases in funding to support PHC services were provided to the health sector during the 2000s, the economic climate has now changed, making it more difficult to fund further change. The out-of-pocket costs to patients when they use services continue to increase each year (historically by around 6% per annum in nominal terms)[10], and it is not clear how the present Government intends to ensure good access to services in the light of such increases in co-payments.

Second, it is not clear what impact the amalgamations of PHOs are having on their ability to bring about change and their overall performance. There are concerns that larger PHOs may not successfully engage well with their providers, making them less, rather than more, likely to succeed. Unlike the original PHC Strategy, we are not aware that any evaluations of recent changes have yet been funded. This means that very little is known about what differences, if any, the most recent reforms resulting in fewer PHOs have made; there is a pressing need to better understand the different models of PHOs and if their make-up has an impact on their overall performance.

Finally, very little is known about the implementation of the Better, Sooner, More Convenient plans, with DHBs expected to devolve services to PHC level, and for Alliances, DHBs and PHOs to work to develop new models of service delivery, including through IFHCs. These developments need to be much better documented and evaluated in terms of the features and policy settings that are facilitating change (and those that are not), as well as gaining some understanding of what is meant by more ‘integrated care’, how it might be assessed including by patients, and how the new models of care are improving health, reducing inequalities in health and improving the relative cost-effectiveness of PHC services. With such knowledge, we can better share lessons and encourage effective and cost-effective innovation over time.

[27] Ryall HT. Nine short listed for next steps in primary care, 4 November 2009.
Funding Models

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INTRODUCTION

The aim of this paper is to briefly review the contribution of health services research in the area of the funding of health services in Australia. The aim is to pick out some key changes in the way in which health care has been funded or proposed to be funded in Australia in the last 10 years, and give my view about the contribution of health services research to either the design or evaluation of these changes. There will also be a comment on the future.

Funding changes can be fundamental in changing the structure of health care services and the behaviour of health care organisations and individuals within them, to meet the stated goals of the health care system. Changes in financing also influence the behaviour of patients and those seeking access to health care services.

The last 10 years in Australia can be characterised by a number of changes to way in which health care is financed and funded.

1) A single change at the beginning of the period around 2000 with the introduction of large subsidies for those taking out private health insurance;
2) Change at the end of the period in 2011 where Australia is on the brink of implementing major changes to national public hospital funding, the public release of performance data, and the piloting of capitation payment and pay for performance for diabetes in primary care.
3) Sandwiched in the middle there has been the usual tinkering around the edges with Medicare funding rules and schemes, often resulting in cost blowouts that the Federal government did not predict, which also reflect its lack of understanding of the behaviour of both providers and patients.

CHANGES TO FUNDING THROUGH MEDICARE

The Centre for Health Economics Research and Evaluation was commissioned by the Department of Health and Ageing to investigate the effects of the Extended Medicare Safety Net. This is an additional subsidy of 80% of Medicare out of pocket costs if these costs are over certain thresholds. This research has gone on to directly inform legislated changes to the design of the scheme in 2009 that capped the benefits paid for some Medicare items. This evaluation was unusual in that an annual ongoing evaluation by an ‘independent academic institution’ was legislated and is required to report directly to parliament each year on the operation of the scheme. If only evaluation was legislated for all new programs and funding changes.

Other programs have also been subject to evaluation by health services researchers including the evaluation of the Better Access to Mental Health scheme, with key components led by the Centre for Health Policy Programs and Economics at the University of Melbourne. The evaluation was supportive of the scheme and the scheme continued, though some areas of Medicare funding were restricted in the 2011 budget.

Only through these tenders have researchers been able to access Medicare data, which has limited the ability to conduct independent research on changes to Medicare. Though data linkage is improving this slightly, such linkage is usually linkage to surveys of specific populations or linkage to administrative datasets, the latter of which has only successfully occurred in WA. Furthermore, these data are at the patient level and what is required are data at provider level to examine the response of providers to funding changes. Australia lags behind other countries in access to these types of data.

Overall, the extent to which health services researchers have been involved in the initial design of these policies is disappointing. Health economics in particular has a potentially large role to play in using theory to predict the effects of changes in funding and incentives on behaviour, which could potentially be used in policy simulation, and then policy design. Evidence-based policy design is something we could become more involved with.

PRIVATE HEALTH INSURANCE

A key success has been the involvement of health services researchers and health economists in the evaluation of the changes to private health insurance subsidies early in the last decade. These changes included tax incentives (Medicare Levy Surcharge), a direct 30% subsidy of premiums, and age-related premium discounts (Lifetime Health Cover). Expenditure on the 30% rebate alone was $4.7 billion in 2010-11. A large literature has developed that has evaluated the impacts of these changes, with most research during the period being conducted by the Centre for Health Economics Research and Evaluation (CHERE) and the Australian Centre for Research on the Economics of Health (ACERh), with notable contributions from health services researchers in WA amongst others. Some of this research has yet to be published, but has formed a solid body of independent evidence on the impact of the subsidies and the factors influencing the decision of individuals about whether to purchase and use their insurance, and the impact of the subsidies on public hospitals. Bills in Parliament in late 2011 are making further changes to the subsidies, mainly in the form of means testing the rebate and the Medicare Levy Surcharge, and these changes should encourage further research.
OPPORTUNITIES FOR THE FUTURE

Of course the involvement of health services research and health economists in the thinking behind the National Health and Hospitals Reform Commission proposals was more obvious, including through the membership of the Commission itself, and in the discussion papers that were commissioned. Some older ideas, eg Dick Scotton’s managed competition model, did not get up, but a version of it, Medicare Select, was suggested as an option but subsequently not adopted by government. These proposals were based around the idea of competition amongst health insurers and payers, including governments, and relied on individuals choosing an insurance package from a range of alternatives. Often these ideas were viewed as too radical. Many ideas adopted by the Commission were a clear reflection of reforms and research that had occurred from overseas. Australian academic health services research certainly did not obviously dominate the ideas of the Commission, and were less prominent compared to the National Health Strategy of the early 1990s. As the health reforms progress, there are new opportunities for health services researchers to be involved in the design, implementation and evaluation of funding reforms.

Activity-based funding. The biggest funding change is the introduction of activity-based funding (ABF) though there were few academics presenting at the National Casemix Conference in September 2011. Though the scheme has been designed, there has been little critique of it in terms of how hospitals will respond to the new incentives. Setting efficient prices will be a key area of work informed by research, in addition to evaluating the impact of ABF on costs and quality of care. Consultants are already embedded within government agencies and are likely to end up running these evaluations given the high level of risk-aversion in government. Health services researchers and health economists from Universities should be a major part of this and need to find ways to win these tenders, or to conduct higher quality and independent research through NHMRC and ARC.

Moving to blended systems of payment for doctors. The Commission and a separate National Primary Care Strategy also coalesced previous discussions around the role of pay for performance, with a number of reviews of the literature in this area, including a new Cochrane review authored by Australian researchers from The University of Melbourne. The recommendations of the Commission and Primary Care Strategy led to the coordinated care pilot for diabetes, with 2011 devoted to designing the pilot, including the capitation and pay for performance payments, with the pilot and evaluation to begin in 2012 and to last 2 years. This is being led by McKinsey with involvement from health services researchers from the Baker IDI and Flinders University. It is unclear whether the opportunity to conduct a randomised trial has been taken, and the extent to which evidence is being used to inform the design of the new financial incentives. As far as I am aware there are no health economists involved in the design or evaluation of these new funding arrangements. This is important as key problems with the economic design of these payment systems have arguably been a major reason for their perceived failure in other countries. This includes i) rewarding providers for measured improvements rather than achievement of one or two high thresholds, ii) risk adjustment to reduce the unintended consequence of cream-skimming, whilst ensuring appropriate sharing of financial risk to providers who have high cost patients, and iii) avoiding other forms of ‘gaming’ and unintended consequences through careful design.

CONCLUSION

The last 10 years have seen a handful of funding changes in which health services researchers and health economists have been involved in evaluating, though there was little obvious involvement in their design. In addition, there was some, but not a lot, of involvement in the recommendations proposed by the NHHRC. Key lessons include trying to become involved in the design, as well as evaluation, of these schemes. A poorly designed funding scheme is unlikely to be effective. In addition, our involvement in evaluation has been rather ad hoc, largely due to patchy and unpredictable funding, and competition between academic researchers and consultancy firms. There are not enough health economists working in the area of financing and funding models in Australia, and building capacity in this area is essential so we are better placed to engage in the future. A final key lesson is that the last 10 years have been characterised by poor quality and unlinked data. The promise of data linkage can help here only if this includes linkage to provider-level data (eg the characteristics of doctors, medical practices, and hospitals), as well as patient-level data which is the focus of current data linkage efforts.

During the period, there has been some growth in HSR and health economics capacity through NHMRC funding (Health Services Research Grants, Capacity Building Grants, and Centres of Excellence in Health Services Research) which should place us in a stronger position to evaluate current funding reforms. However, much uncertainty remains, with new health economics expertise being either imported from overseas or obtained from economics departments. Neither of these avenues are sustainable in the longer term without a co-ordinated effort to train more economists to become involved in the design and evaluation of funding reform. The future looks better than it did 10 years ago, but there is still some way to go.
Health insurance through the ages

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My favourite quote on health insurance is from the 1969 Nimmo report on health insurance which concluded that private, voluntary health insurance was ‘needlessly complex and beyond the comprehension of many’. Plus ça change, plus c’est la même chose! Government interest in and support for private health insurance has waxed and waned over the intervening period in line with political cycles: waxing in periods of Liberal government, waning in the Labor years. Carter and Chapman (2001) have looked at one slice of the debate about private health insurance over the last couple of decades: the introduction of the rebate for private health insurance. They identified six frames for the debate:

- For proponents of the rebate these were labeled ‘The end is nigh’ (about the decline of private health insurance); ‘Make my day’ (right of government to govern); You get what you deserve’ (rewarding people who make provision for their health needs) and the private interest, ‘What’s in it for me?’
- Opposing frames were ‘It won’t work and it’s not fair’ and ‘Bribery and corruption’

Similar framing is still at play at the time of each attempt by the current government to wind back some of the current subsidies and compulsions which have led the private health industry to have greater levels of government subsidy than agriculture, mining and manufacturing combined. In contrast to these other industries, the private health industry (mainly private health insurance, but through them, private hospitals) has been able to avert addressing structural change by garnering extraordinarily generous public subsidies. ‘The end is nigh’ continues to be part of the framing of those who resist winding back industry support in this area.

But what I want to focus on here is the way in which health services researchers at the time.

There have been many studies which have looked at private health insurance in Australia over the last couple of decades, with few exceptions they have focused on this ‘headline’ number (or the equivalent from household surveys) examining issues as diverse as adverse selection to the link between the decline in insurance, or the insurance prevalence increase following introduction of life time cover and the (lack of) impact on public hospital utilisation.

But what is wrong with this picture? The first point is that despite the rationalisation of health insurance products post-Nimmo, there are still multiple insurance products and the headline graph disguises the fact that there are different trends occurring in different products. Second, there is a break in the series in 1995 and the pre and post headline numbers are reporting different types of insurance.

Medibank transformed the Australian health financing landscape. Until its introduction, except in Queensland, public hospital use for most people attracted accommodation charges. Insurance was available against these charges (known as ‘basic table’ insurance), and that is what is the vast majority of people took out. Insurance was also available for the higher costs involved in accommodation in private hospitals; data on the prevalence of this type of insurance became available in 1978.

The figure below is taken from the fourth edition of my Australian health care system book (now co-authored with Sharon Willcox), it is an update of the third edition graph.

REPORTED TRENDS IN PRIVATE HEALTH INSURANCE COVERAGE

Private health stakeholders (private health insurance, private hospitals) have been successful in persuading the media (and through them the public) and the occasional gullible Labor minister that there is a coincidence of interest between private and public health: specifically that a decline in private health insurance leads to increased reliance on public provision with consequent impacts on waiting times. The evidence usually starts with something like the following figure, published by the Private Health Insurance Administration Council on the front page of their website (www.phiac.gov.au accessed 16 September 2011).
What this graph shows is that the percentage of people who had insurance for private hospital care was remarkably stable over the 1980s and 1990s: the nadir was in the June quarter of 1983. The introduction of Medicare seems to have been associated with an increase in the proportion of people covered for private hospital care. However, the big take-away message is that there was no significant decline over this period in the proportion of the population insured for private hospital care.

The insurance decline was essentially because of people dropping cover for public hospital care, a rational choice as the basic table product covered accommodation costs for private care in public hospitals. Most private care was provided in private hospitals and care in public hospitals was now available without direct charges for everybody so private insurance was no longer necessary. By 1994 a mere 2% of the population had only basic table insurance, the vast bulk of those with private insurance took out higher levels of coverage. It made logical sense from a statistical point of view for published statistics to discontinue that distinction in the nature of the coverage.

One should not expect that the steady decline in the headline number would have any impact on demand for public hospitals: those with basic table insurance were probably always intending to use public hospitals, dropping insurance only converted them from private patients in a public hospital to public patients. Although this is not how the debate was framed, in spite of the comments of health services researchers at the time. The revised reporting post 1995 introduced a distinction between those who had private insurance which covered everything (no co-payment, no deductible i.e. no requirement to pay the first $1000 or whatever) and those who faced a gap between charges and coverage. Policies with deductibles and copayments were cheaper than policies without these requirements.

In 1997 almost three in every four policies was for 'full coverage' but there was a steady divergence and by 1999 (immediately pre-life time cover), the ratio had fallen to 60%. Post-life time cover the ratio declined below 50% and continues to decline. Practically all the increase in private health insurance coverage following the introduction of life time cover was people who took out policies requiring co-payments or deductibles, possibly because these products were cheaper and those compelled into private insurance wanted to spend the least possible and were not expecting to benefit from use of the product. Similarly for the impact of the Medicare levy surcharge which appears also to have elicited purchase of products with deductibles, again with the possible expectation of no benefit from use but rather benefit from tax reduction. Unfortunately, there has been no research published which tests these hypotheses.

Deductibles and co-payments should reduce the likelihood of private hospital use which creates an out-of-pocket obligation vs. public hospital use with no out-of-pocket costs. Uptake in private health insurance should therefore not have been expected to correlate directly with changed public hospital use. Despite the doom and gloom predictions one hears in parliamentary debates, the reverse is also true: mitigating the incentives for the wealthy to take out private insurance is unlikely to have much impact on use of public hospitals either.

THE PLACE OF HEALTH SERVICES RESEARCH
Health services research has a weak place in the academic sun in Australia: the vast bulk of NHMRC funds still go to biomedical research. Even with the research that has been done, little finds its way into the public debate portrayed in the media. Regrettably, the policy debates of 2012 are still being framed in similar terms to the late 1990s: private health insurance is a homogenous product and support for private health insurance still masquerades as support for public hospitals.

Will more research help? One can live in hope that more research will lead to a more rational policy debate. But the positions of the policy participants are generally values-based, and shifting frames and values is hard. Data may help, but may not.

But I'm a data nerd and believe, possibly unjustifiably, that more data can only help the policy process. Researchers, though, obviously need to use more refined measures of health insurance coverage in their analyses. This is possible to do using aggregate data, but users of the national health survey and like instruments face a tougher time. Health insurance products are second only to phone plans in their opacity and complexity and I doubt whether survey respondents could give reliable answers to a question about the level of their coverage, no matter how carefully phrased the question.

There are many researchable questions about private health insurance as with any other aspect of the health system. The design of optimal regulation for example, to encourage health insurers to operate more efficiently, is a worthy goal, regardless of your position on the importance of private health insurance to the public hospital sector. Analysing the impact of different types of deductibles or co-payment structures on people in different circumstances might also help in public policy formation, so too for tracking the impact of changes in industry structure (de-mutualisation, foreign involvement). Looking behind the headline numbers is a must: who has health insurance, what type and where do they live? What is the incidence of the subsidy; who wins, who loses? How does churn work in the industry?

Insurers also face knowledge gaps about how they might impact utilisation, optimal product design, what works in terms of preventive interventions over a reasonable investment horizon for a market-based organisation.

So my conclusion looking back is:
• The (political) debate about private health insurance is as still as uninformed as ever, and it is difficult to see the march of progress – in terms of informing public debate - in this field;
• Researchers (myself included) could have addressed this issue better;
• But, as with every other topic covered in this volume, more research is still needed into an area which is, after all, a big slice of the health pie.
Priority-setting in health: looking back over ten years

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INTRODUCTION
While the pressure on health care budgets and the inevitability of difficult choices continues to be a feature for the health sector, the last ten years has seen an encouraging growth in the methods for priority-setting. Three factors continue to dominate: the growing evidence that the deployment of current resources is far from optimal [1]; the continued growth in health care expenditures [2]; and doubts about the “free market” as the mechanism of choice to allocate health sector resources and to determine access to services [3]. Of these, the increasing cost of health care in particular, is making it difficult for governments to provide comprehensive high quality health care to all citizens, irrespective of their ability to pay. The need to bring growing community aspirations and the scarcity of resources closer together is a common theme in the literature [4].

The issues that underlie the debate about priority-setting approaches have not changed much, viz. the merits of ‘implicit’ versus ‘explicit’ approaches; the role of ‘due process’ versus ‘technical analysis’ in explicit approaches; the need to match approach to the different levels of decision-making in the health sector; and the issue of who to consult, particularly attempts to consult and involve the public [5]. There is also a growing recognition that one-off economic evaluations can be inadequate to influence more general health policy [6]. There have been several attempts to set priorities in public health systems; most noticeably in Oregon in the USA, the general health policy [6]. There have been several attempts to set priorities in public health systems; most noticeably in Oregon in the USA, the Netherlands, Sweden, Norway, New Zealand, Israel, Uganda and the United Kingdom [7-13]. Each of these countries adopted a different approach and most continue to amend their processes as they strive to find satisfactory solutions. Some jurisdictions attempted to specify ‘core services’ (Netherlands; Oregon; Israel; New Zealand initial approach); some identified broad principles, but provided little guidance to agencies on how to implement them (Norway; Sweden); some focused on the development of evidence-based guidelines to ration access to health care (New Zealand; United Kingdom). One notable area where explicit priority setting approaches have continued to dominate is in the provision of publicly financed pharmaceuticals, though other sectors of health are also starting to adopt such approaches (such as the Medical Services Advisory Committee (MSAC) in Australia).

Importantly, progress has been made in the last ten years in establishing a set of criteria which define an “ideal” approach to priority setting [14]. While checklists have existed in some areas for more than ten years (such as economic appraisal [15, 16], assessing fairness in decision-making [17]; and assessing likely impact on decision-making [18]), significant recent developments include criteria for Program Budgeting and Marginal Analysis [19] and health technology assessment [20], as well as a checklist regarding the “ideal” approach to priority setting [14].

Other areas where significant change has occurred include: i) the development of data bases (such as DALYs and DCIS [21, 22]) that facilitate the inclusion of economic appraisal as an integral part of priority setting exercises (as opposed to reliance on existing studies with attendant issues of methodological confounding); ii) the development of approaches to assist resource allocation in less developed countries [23, 24]; and iii) an increase in the number of practical applications of explicit priority setting methodologies, particularly at a disease/risk factor specific level [14].

In this short review piece, we will focus on key issues for priority setting emerging from the growing number of practical applications, together with user considerations for decision-makers.

LESSONS FROM EMPIRICAL EVIDENCE
The experiences of the US State of Oregon, The Netherlands, New Zealand, Sweden, Israel, the UK and the Nordic countries, over the last decade or so, exemplify the emergence of explicit priority setting as a national initiative [8, 9, 25]. In each of these countries priority setting entered the national health policy agenda as the scope of publicly financed health services came under review. In New Zealand this has resulted in greater cost containment and affordability in comparison to the UK and Australia, particularly for publically provided pharmaceuticals [26]. In Australia there have been no similar systematic efforts to establish a national framework in which explicit criteria are clearly laid out, with ethical values established through community consultation. There are, nonetheless, relevant empirical experiences in priority setting from which lessons can be drawn [14, 27-37].

The empirical evidence available suggests that while the various technical approaches have undoubtedly made an important contribution, no country has adopted a purely technical approach. The role of economic evaluation in the countries reviewed has reflected the significance afforded efficiency as an objective of their health care systems, together with difficulties encountered in the practical application of economic evaluation techniques. All countries reviewed, including Sweden, embraced efficiency as an important objective, but clearly not the only objective, and often not the most important objective. For most countries, the importance placed on different objectives reflected their underlying ethical values (such as effectiveness, solidarity/fairness, severity and efficiency). All countries have come to recognise that if their decisions were to have legitimacy for patients, for providers, and for the general public, then a balance had to be struck between techniques and decision rules drawn from disciplines like economics, and a concern for due process and consultation [8, 9, 11].

In relation to evaluation techniques, most countries recognised that the broader the priority setting task attempted, the more likely economic evaluation would encounter technical problems. Several countries (New Zealand, Nordic countries) preferred to focus economic evaluation on vertical priority setting (i.e. on interventions for dealing with the same disease or problem) and/or within the context of guidelines or dealing with new technologies. The Australian experience is similar. The use of economic evaluation within a restricted role, such as assisting the decisions of the Australian Pharmaceutical Benefits Advisory Committee (PBAC) or the Medical Services Advisory Committee (MSAC), has been generally well regarded. Experienced evaluators have questioned the suitability of available economic evaluation techniques in application to entire domains of health care. Those initiatives that have sought a much broader application (such as Oregon [8], the Health Benefits Group/Health Resource Group approach [38] and the Health Sector Wide Disease Model [39]), have encountered significant data problems that have limited their usefulness [40]. These approaches have sought to make the task more tractable by either limiting the scope of the research question; restricting the role of economic evaluation; or by withdrawing from priority setting to a more general planning and scenario assessment role. Techniques such as Program Budgeting and Marginal Analysis (PBMA), which provide a structure in which evidence and values can be brought together, have grown in popularity, particularly in Australia, New Zealand, Canada and the UK. In
Australia, the early appeal of the consensus-based approaches reflected their focus on due process, particularly the effective involvement of participants in the decision-making process [27-29].

Finally, priority setting is not just about making one set of decisions, but recognising “the complex interaction of multiple decisions, taken at various levels...” [41, 42]. In New Zealand, for example, it was unclear how well recommendations from their guidelines development process matched purchasing recommendations from their PBMA process [31]. In the UK, the National Institute of Clinical Excellence (NICE) has been criticised for not taking into account the cost of its recommendations on regional bodies that are meant to implement them. While there are ongoing concerns that NICE recommendations will distort efforts to establish priorities at the local level [43], there is little doubt that NICE has been influential to the continued growth of health technology assessment internationally [25]. The empirical evidence thus highlights the reality that explicit rationing at all levels involves both the use of techniques and the application of judgement. The empirical experience also confirms that there are no simple solutions to the challenges posed by the need for priority setting. Complexity is inherent in the range of stakeholders involved; the various levels at which decisions are taken; the need for both vertical and horizontal priority setting; and the importance attached to ethical values and principles.

USER CONSIDERATIONS
Attempts to make priority setting more explicit have also revealed the difficulty of defining a basic package of services by excluding some treatments from public funding. The “exclusion” approach ignores the variation in cost-effectiveness ratios with patient needs, population sub-groups, program size, program design and health service setting. There are few treatments that are wholly effective or wholly ineffective and the challenge is to ensure that the services that are funded are provided to those patients who stand to benefit. Those charged with the responsibility for rationing have usually declined to use the exclusion approach. The experience to date suggests that where exclusions have been achieved they have tended to be interventions involving minor ailments and/or interventions for which the evidence was lacking. They are all marginal to mainstream health care. While not preparing detailed lists of the type adopted in Oregon, several countries have adopted health service classification systems based on illness severity/perceived importance, that have proven to be useful (Sweden, Norway, Finland, and Denmark) [44].

The natural consequence of the difficulties inherent in rationing by exclusion is the increasing interest being shown in setting priorities by drawing up guidelines for the provision of services. The focus has changed from which services or types of care should be provided, to which patients should be selected for what kinds of treatment and at what level of intensity. The focus on rationing by guidelines also reflects the wider movement to strengthen the scientific basis of health care and the associated concern to reduce variations in clinical practice patterns.

EMERGING ISSUES IN APPROACHES TO PRIORITY SETTING
Non economic approaches
Surveys across a number of countries suggest that a common approach to resource allocation in health is to base funding decisions on what has been funded in previous years [45], pro rating allocations up or down based on changes in health service costs and/or demographic changes. While this approach is still widely used, reliance on it is slowly falling. There is now growing evidence that managers and clinicians find little satisfaction with approaches where implicit values and politics dominate, rather than evidence of effectiveness, sound judgment and explicit decision-making processes [45].

Another commonly used means of setting priorities is through the assessment of need employing various epidemiological techniques. Needs assessment, for example, has been utilized by purchasers in the UK and by many public health units in various states of Australia [46]. Early enthusiast

asm for needs assessment, however, has reduced over the last 10 years, due to the size of research effort involved and the lack of guidance such studies provide into which specific services or interventions should be funded. While needs assessment can play an important role in focusing attention on specific areas with large unmet need (for example, the hidden disease burden associated with mental disorders), they are most useful when integrated with economic evaluation.

Interesting endeavours at explicit consensus-based approaches to priority setting have also been conducted in Australia over the last ten years [27-29]. One example involved the development of priority areas for health promotion for women in the Hunter region of NSW [27]. In this approach, epidemiological data on disease incidence and distribution, views from the community and advice from experts were synthesized using a nominal group approach. These consensus models clearly have advantages in terms of their potential to achieve legitimacy in the eyes of stakeholders, but there are also weaknesses that compromise their potential to guide resource allocation decisions. These relate principally to the type of information provided (e.g. no resource cost information) and the primary focus on the size of the problem rather than on health gain. There is little published information to assess the frequency of such approaches, though we would presume that Delphi and similar consensus-based approaches remain popular in institutional settings.

Economic approaches
There are also many economic approaches to priority setting. Three approaches are selected here to illustrate the range of issues involved.

Program Budgeting and Marginal Analysis (PBMA) is an approach to priority setting specifically designed as a practical guide for decision-makers in the planning and provision of health services. The starting point for most PBMA studies has been to examine how resources are currently spent before focusing on incremental gains and costs of changes in that spend, through comparison across or within programs. It is clear from a growing literature on PBMA [45-48] that substantially different evaluation approaches have emerged within this overarching framework. More recently, there has been a shift towards improving the evidence base of PBMA [14, 34, 36] in line with the growing acceptance of the evidence-based medicine movement. Many of the criticisms of PBMA reflect more the “growing pains” of an evolving technique, than fatal flaws in its underlying structure or rationale. Criticisms such as lack of measurement rigour, inadequacies in option selection, narrow perspective and poorly developed marginal analysis [44, 49, 50] are all resolvable as evidenced by the Assessing Cost Effectiveness (ACE) work, which sits arguably within the PBMA genre.

The ‘ACE’ approach reflects an endeavour to develop an approach that satisfies criteria for an “ideal” approach to priority setting, particularly the challenge of finding an appropriate balance between technical rigour and due process [14]. The approach has been applied in a series of case studies funded through competitive grants [37] or commissioned by government [34, 36]. The decision context for most ACE evaluations has been the possible adoption Australia-wide of options to improve the efficiency of current health services and to inform policy makers about the best bundle of interventions, given alternative levels of budget availability. In the ACE approach economic evaluations are undertaken as part of the priority setting exercise, based on economic/epidemiological modelling techniques that utilise best available data and extensive uncertainty analysis. The technical analysis is then placed within a broader decision-making framework that includes ‘equity,’ ‘strength of evidence,’ ‘feasibility of implementation,’ ‘acceptability to stakeholders’ and other study-specific considerations, called ‘2nd stage filter’ analysis. The information is assembled by a multi-disciplinary research team, preparing briefing papers to a standardised format agreed by a Working Group of stakeholders who are involved throughout the study.
Finally, it was common practice in economic approaches to priority setting for the results of individual economic evaluations to be brought together to provide a "league table", in which the interventions are ranked in order of their cost per quality adjusted life year (QALY) results. While this approach has intrinsic appeal for priority setting, economists have urged caution against their simplistic use for reasons associated with their potential for methodological confounding and the frequent inclusion of studies from a range of settings. More recently, the trend has been to a more sophisticated use of league tables which give regard to inherent uncertainty and minimization of methodological confounding. The development of methods such as ACE, and even the World Health Organisations (WHO)’s CHOICE methodology [23], have assisted in this.

REFLECTIONS ON TEN YEARS OF PRIORITY SETTING

Over the last ten years there has clearly been some important progress in the development of explicit priority setting methodologies along the lines involved in PBMA and ACE. Unfortunately, such approaches are still not commonplace. By and large, interventions or programs still continue to be considered individually (e.g. within the NICE context or the PBAC context). This means that broader implications in terms of allocative efficiency are not adequately dealt with. Management, whether in government or elsewhere, will need time (and encouragement) to trust explicit approaches to priority setting, particularly if they are time and resource intensive. This is particularly so when explicit approaches have implications for current financial reporting practice (e.g. program structure and associated cost centres); for current data collections (e.g. the collection of activity and outcome data); for research activity (e.g. establishing the evidence base); and the validity of decisions. There needs to be recognition that explicit approaches to priority setting require infrastructure, a long-term commitment from senior management and the courage to confront vested interests. Decision-makers need to have confidence; therefore, not only in the technical results, but also that the policy recommendations include a consideration of the broader factors that impinge on them. The key question will remain the extent to which technical appraisal and due process is used and the respective emphasis on these different approaches. Approaches that combine both have much to recommend them.


Priority setting developments within the New Zealand health system

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INTRODUCTION

Priority setting is an inevitable consequence of trying to meet population health demands within limited resources. Priority setting helps to inform decisions on the allocation of resources to meet these pressures and competing demands, ideally in a way that maximises population health gain in a fair and equitable way.

Pressures on funded services include:

- increasing prices for the labour and supplies required to deliver services;
- increasing demand, through population growth, aging and rises in chronic diseases;
- increasing scope and coverage from technological developments, service expansions, increasing sector and public expectations, and Government policy decisions.

To understand developments in the area of priority setting within the New Zealand health system over the last decade requires some knowledge of their antecedents during the 1990s. I trace some of the key developments in health sector prioritisation from the 1990s through the 2000s and describe some recent developments to show the continuity of their evolution through ongoing system change.

Through the 1990s there was a move from focusing on the need for prioritisation, through developing the principles under which it should be conducted, towards developing the processes and tools to do it. Over the last 10 years the focus has been more on how to achieve consistency and collaboration in prioritisation, with moves now towards further developing capability and capacity.

THE 1990s

A key early development was the establishment of an independent Ministerial Advisory Committee in 1992, commonly known as the Core Services Committee (CSC). Following examination of international approaches and extensive public consultation the Committee found it difficult to establish a philosophical foundation to initiate practical work[1] and they rejected the notion of identifying a ‘core’ list of services that should be publicly funded[2]. Instead the CSC recommended progressively and systematically identifying terms of access and quality standards for services already funded. In this way the CSC believed a more rational, explicit and evidence-based approach to what services should be publicly funded could be developed incrementally.

Work was undertaken within the HFA to develop a process for prioritisation based on their five decision-making principles[3]. Following the international literature of the time, the initial focus was on a cost-utility analysis approach (CUA) using the quality-adjusted life year (QALY) as the base measure. However, there was concern that a focus on maximising the benefits from health care neglected an adequate consideration of who receives them. An amended approach proposed a process of programme budgeting and marginal analysis, incorporating cost-effectiveness analysis while taking into account the principles of equity, Māori health and acceptability (as well as health and disability gain priority areas). The aim was to have adequate analytical support to maintain a pool of proposals for the ‘next best spend’ of new funding, given that allocative efficiency was constrained due to budget ring-fences in different service areas. An NHC-commissioned review of the HFA’s proposed prioritisation, while supporting the general objective, raised a number of concerns around methodological and practical problems and recommended the use of pilots as a programme for continual learning[4].

From public consultation, however, the CSC derived four principles to guide decisions about resource utilisation[2], which informed a set of Purchasing Principles for Regional Health Authorities (RHAs)[3]. Work on these by Midland RHA subsequently formed the basis for a principles-based approach to decision making within the Health Funding Authority (HFA) and added the promotion of Māori health to the CSC principles of effectiveness, equity, acceptability and efficiency[3]. CSC public consultation also resulted in a focus on acceptable waiting times for non-urgent surgery[2]. The CSC called for the introduction of a booking system to replace the use of waiting lists and worked with RHAs to develop clinical priority access criteria. They advocated for the use of evidence-based guidelines as the basis for determining access to services and were responsible for the establishment of the New Zealand Guidelines Group.

A political development of note during this period was the introduction of Mixed Member Proportional Voting for general elections in 1996. This has seen smaller political parties in coalition governments with Associate Health Minister appointments in specific portfolio areas, providing opportunities to influence Government priority setting.

Following the disestablishment of the central Public Health Commission (PHC) and the regionalisation of its functions, the CSC’s scope was expanded to include advice on public (population) health in 1996[1]. In response to the formation of the HFA, in 1998 the CSC was given a revised terms of reference, expanded its work programme into the area of service reviews and became known as the National Health Committee* (NHC). The consideration of the wider social, cultural and economic determinants of health resulted in a new focus on inequalities, disadvantaged groups and health impact assessment, although priority setting continued to remain a theme within the NHC’s work[2].

Work was undertaken within the HFA to develop a process for prioritisation based on their five decision-making principles[3]. Following the international literature of the time, the initial focus was on a cost-utility analysis approach (CUA) using the quality-adjusted life year (QALY) as the base measure. However, there was concern that a focus on maximising the benefits from health care neglected an adequate consideration of who receives them. An amended approach proposed a process of programme budgeting and marginal analysis, incorporating cost-effectiveness analysis while taking into account the principles of equity, Māori health and acceptability (as well as health and disability gain priority areas). The aim was to have adequate analytical support to maintain a pool of proposals for the ‘next best spend’ of new funding, given that allocative efficiency was constrained due to budget ring-fences in different service areas. An NHC-commissioned review of the HFA’s proposed prioritisation, while supporting the general objective, raised a number of concerns around methodological and practical problems and recommended the use of pilots as a programme for continual learning[4].
Concurrently in 2004, three other sector groups were working in the perceived weaknesses[10]. While response to the content was generally positive, there were also An NHC evaluation of pilot sites using the prioritisation tool found that the information together in order to make prioritisation decisions[9]. A benchmark for progress in priority setting in other service areas might be to reach a stage where robust comparison between pharmaceutical and non-pharmaceutical interventions is possible regarding the next best spend of health funding.

THE 2000s

A change in government in 1999 ushered in another set of structural health reforms that resulted in the establishment of DHBs and a move back towards localised planning and funding decision-making. Launched in 2000, the New Zealand Health Strategy[6] (NZHS) provided the framework within which DHBs and other sector organisations were to operate. In the NZHS, thirteen priority population health objectives were chosen on the basis of their amenability to improve health outcomes and reduce disparities in the short to medium term.

DHBs are required to assess and prioritise the needs of their communities within the constraints of their funding and in the context of the NZHS. In prioritising they must follow a principle-based framework that links directly to the principles of the NZHS and to clearly document[7]:

1. Why decisions were made;
2. Who the decision makers were;
3. What the decision making process was;
4. How the community was involved in the decision making process.

Annual letters of Ministerial expectation are used to convey current Government priorities. These inform the development of DHB planning and accountability documents, which include indicator performance measures with negotiated targets. At the national level the Ministry of Health runs the annual budget process, which includes a mixture of funding to meet DHB pressures, for the development of new services, and for Ministerial priorities.

From the outset a variety of tools were developed by individual DHBs to help weigh the needs between national and local priorities and to assist their Boards in decision-making (e.g. Hutt Valley DHB[8]). A joint DHB/Ministry initiative began in 2003 to provide guidance on a common approach to prioritisation, building on the work of the NHC and HFA, as well as international work. This resulted in the production of a framework and resource material on how to identify and analyse services and bring the information together in order to make prioritisation decisions[9]. An NHC evaluation of pilot sites using the prioritisation tool found that while response to the content was generally positive, there were also perceived weaknesses[10].

Concurrently in 2004, three other sector groups were working in the areas of service planning and change, technology assessment and collaborative decision-making. These included joint Ministry/DHB work initiated by the National Capital Committee, sector clinical work initiated by the Minister, and NHC work. The NHC identified a number of deficiencies within the DHB system[11]. They recommended that priority be given to the development of robust inter-DHB processes and improved assessment capacity and capability. The culmination of bringing the three groups’ work together was the development of a Service Planning and New Health Intervention Assessment (SPNIA) framework for collaborative decision-making[12].

The aim of SPNIA was to provide prioritisation at a national level to assist in health services changes that required a collective decision and to overcome problems created when the actions of individual DHBs impacted on others or were contrary to the national interest. SPNIA governance was intended to be through a joint Ministry/DHB group under the auspices of a National Service and Technology Review (NSTR) committee. Secretariat support for NSTR and some funding for expert advice were provided by the Ministry, while DHBs were responsible for maintaining regional forums and contribution of assistance and expertise to the development of business cases that NSTR accepted on the basis of referrals received. While NSTR completed a number of assessments, governance became split between the Ministry and DHBs, resulting in difficulties in consensual decision-making, particularly around funding issues.

National health targets were introduced in 2007/08 and developed as a publicly accessible and published tool to drive provider performance[13]. These have been successful in maintaining DHB focus on a set of Government determined priority areas. While the use of targets is not new (e.g. there were health goals in AHB days[14] and the PHC developed health outcome targets), their success may be attributed to their focus on short-term outputs, level of publicity (DHB performance is published in newspapers) and the degree of Ministerial backing.

A Ministerial Review Group (MRG) was commissioned in 2009 to provide advice on improving the quality and performance of the public health system[15]. It found that the SPNIA framework had struggled to address the issues previously identified by the NHC due to its governance structure and lack of influence over funding decisions. The issues identified by the NHC included a lack of systematic processes for assessing new interventions, limited stakeholder involvement beyond clinicians, and decisions around their introduction largely made independently by individual DHBs (or service speciality areas within them). This led to duplication of effort, lack of comparison of relative benefit and unintended consequences on other services and DHBs. The MRG considered that these issues could only be addressed by a single national agency separate from both DHBs and the Ministry, and recommended that the NHC assume the role of prioritising all significant new diagnostics and interventions.

The MRG recommended that the NHC be strengthened to have the capability to conduct evidence-based assessments of the clinical safety and cost-effectiveness of new and existing procedures and interventions and be responsible for determining the conditions under which they should be publicly funded. This included the replacement of existing interventions as a result of new ones being recommended, as well as the assessment of others that appear to be lower priority (e.g. uncertain or low
benefit). Having considered international and New Zealand experiences in trying to prioritise across all services to identify a publicly funded 'core', the MRG concluded that such an exercise was unlikely to succeed in the current environment. Instead they recommended focusing service prioritisation "at the margin" (i.e. on new things to be added or old things to be dropped).

Other MRG recommendations (and their implementation) included:

• establishing a national shared service agency (Health Benefits Limited, HBL);
• that PHARMAC assume responsibility for medical devices (exploratory work currently underway between PHARMAC, HBL and the NHC);
• transferring the planning and funding for national services, strategic planning for IT, facilities and workforce, and monitoring of DHBs into a new agency (the National Health Board and Business Unit established within the Ministry);
• establishing an independent national quality agency (the Health Quality and Safety Commission);
• requiring DHBs to plan on a regional basis (Regional Plans now a legislative requirement).

RECENT DEVELOPMENTS

By August 2011 the NHC had been reconfigured with new terms of reference and membership[16]. Like many of the other entities established as a result of MRG recommendations, early tasks involve identifying decision-making criteria and developing operational processes. Both international (particularly Canadian and Australian) and local experiences are influencing this. Recognising that it will be an evolving process to build stakeholder relationships and to develop assessment capacity and capability, the Committee have selected a small number of initial projects to trial their approach on and to provide early lessons. The Committee have also invited the sector to make referrals for candidates for their 2012 assessment work programme.

At the time of writing, the NHC is in the process of seeking sector feedback on proposals received for potential assessment. This will help inform the development of a work programme aiming to provide maximum value to the sector, within the Committee’s scope, available resourcing and current stage of development. Key features are planned to include:

• A service-wide assessment perspective over a number of domains (clinical, ethical, societal, economic and financial) within the context of the New Zealand environment;
• Engagement with networks, building of partnerships and iterative engagement with stakeholders in undertaking assessments;
• The development of implementable recommendations, including around funding, provision and monitoring.

Other work planned by the NHC includes facilitating sector linkages and identifying potential pathways for proposals that do not make it onto their assessment work programme, developing Health Technology Assessment capability and capacity within New Zealand, and building a horizon scanning programme with both local and international links.

Acknowledgements

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You can’t always get what you want: the state of play in the economic evaluation of Australian health services

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INTRODUCTION
It seems to be generally accepted that resources are finite and that we can’t provide all of the health services that people want. Rationing takes place in the private market through prices and in the public system through decisions on eligibility and the timing of access. At a political level it has become increasingly common to demand that new services provide some evidence of net social value prior to funding. The last ten years have seen both a widening of the scope of services subject to a form of economic evaluation, and a deepening in the attention paid to the quality of evidence on the net benefits of new health services over current practice.

Australia has a comparatively long history of requiring such evidence, particularly in pharmaceuticals where formal economic evaluation of new medicines prior to reimbursement on the Pharmaceutical Benefits Scheme has been mandatory since 1993. The last decade has seen both a strengthening of the evidentiary standards required for coverage decision for drug therapies and a widening to include vaccines[1]. The period has also seen the beginning of a formal system of economic evaluation prior to funding for medical services under Medicare[2]. We have been less systematic outside of these two areas and although there has been some ad hoc widening of the scope of economic evaluation to include prevention and health promotion programs as well as some hospital based services, these have tended to be one off commissioned pieces, often reviews of existing programs[3], or academic papers not linked directly to funding initiatives[4], or what might seem like post hoc justification for decisions already made[5].

There have been few if any pre-planned economic evaluations of major health initiatives outside of the Pharmaceutical Benefits Scheme (PBS) or Medicare Benefits Schedule (MBS) that have led to any major revision or curtailing of initiatives. In general while the sophistication of academic papers using economic evaluation has increased considerably in the last ten years it is not clear that the use of economic evidence in policy making has increased with it. The mantra of evidence based decision making has led to the inclusion of sections on cost effectiveness in many reports on new services but with a few rare exceptions it is less clear that these have been instrumental in determining any aspect of delivery. Even in the area most obviously affected, drug reimbursement, it is difficult to show that the more formal use of economic considerations since 1993 has resulted in improved health or financial outcomes compared to a counterfactual of informal negotiation with pharmaceutical companies on subsidy levels as in earlier years. There is no doubt that economic evaluation has made a difference to the likelihood of a particular drug indication pair being subsidised at a particular time[6] but it is less clear that the price is lower than it would be otherwise or that the flow on effect to “me too” products and generics is advantageous. Information on value for money provided by an economic evaluation gives information to both sides of the market – government and industry – information that is valuable in negotiating the distribution of the value of the net benefits of the product. It shows the maximum price the funder will pay but not the minimum the supplier will take. The point is not that economic evaluation is harmful to decision making or that we should not expand it to include all health services but rather it matters how you use the information to get what you need.

There is a strong case for expanding the breadth of services that we routinely evaluate to include not only public hospital services (a glaring omission) but also preventive services[7]. From a public policy perspective there is also a case for greater public provision of evaluation evidence of private expenditures and activities on for example nutrition and alternative or complementary therapies. With so little assessed and so little has been acted upon there is scope for both improving health by doing more in some areas, although it is less clear that there are savings to be made by doing less in others as some have argued[8].

STRENGTHENING DECISION MAKING
From a methodological perspective perhaps the single most influential contribution to the development of economic evaluation of health services in Australia has been the development of the Pharmaceutical Benefits Advisory Committee (PBAC) guidelines 1. The guidelines from their inception have influenced the way in which economic evaluation has been performed in Australia. By what they encouraged, and provided them with the wider methods for formal analysis of that uncertainty in cost effectiveness analysis in the form of confidence intervals[9] or the construction of a cost effectiveness acceptability curve (CEAC)[10]. Economic evaluation has embraced formal analysis of that...
uncertainty with the development of Bayesian flavoured techniques that make distributional assumptions about the parameters of models such as the quality of life in particular health states; or the cost of hospital services. These so called probabilistic sensitivity analyses allow a number of different ways of presenting uncertainty around a point estimates of cost effectiveness using either frequentist statistical methods (confidence intervals or p-values) or Bayesian methods (posterior probabilities of cost effectiveness or acceptability curves). In quasi Bayesian terms the CEAC shows the probability of the intervention being cost effective at different threshold levels of social willingness to pay for a health gain. By the nature of the analytical choices made, modelling of economic costs and outcomes involves uncertainty beyond that of just the uncertainty inherent in sampling for experimental evidence. The approach has the apparent advantage of summarising much of the uncertainty inherent in an economic evaluation and presenting this to decision making bodies without being prescriptive about the money value of the health gains or the potential health gains from denying coverage of one particular service but spending on another. Rather than a unified Bayesian approach with its risk of potential obfuscation, the 2008 PBAC guidelines suggest adopting a staged approach to uncertainty, expanding the information presented on uncertainty to considerable length with detailed descriptions of modelling assumptions and data quality and assessment of uncertainty at each stage. It seems that Australian authorities have not wholeheartedly embraced the use of acceptability curves as enthusiastically as academic authors and other jurisdictions have. It appears that far from finding them informative they find the filtering of multiple sources of uncertainty into a series of correlated probability distributions that are then compounded into a single distribution of the ICER, somewhat unilluminating.

**COST EFFECTIVE EXPERIMENTS**

Another reflection of the demand from decision makers for high quality evidence on which to base decisions has been an increase in the number of experimental based cost effectiveness studies in Australia. While the majority of studies on the cost effectiveness of health services have been based on simulations of patient experience using decision analytic models based on parameters from a variety of sources [11][12], there have been a small number of experimental studies in Australia that measure effectiveness and cost in a sample of patients or providers [13]. These are usually randomized clinical trials that collect data on resource use and quality of life in each arm. The apparent advantage of collecting information in this way is that it avoids the strong assumptions embedded in most decision analytic models, but it can do so at the cost of narrowing the scope of the analysis and thus limiting its generalizability beyond the sample and study timeframe. Some have combined the short run within trial results with modeled longer term outcome [14] while other trials have been of a considerable duration with relevant long term outcome measured appropriately[15][16]. It seems likely that the demand for high quality evidence will change the balance at least in clinical areas such that economic evaluation will increasingly be collected as a routine part of clinical studies in the future. A feature of these experimental studies has been the increase in sophistication in the statistical analytic techniques used in cost effectiveness analysis and a convergence in methods between econometric techniques, biostatistics and other social sciences. This is particularly noticeable in the analysis of pragmatic trials where statistical controls for observed and unobserved confounding and selection, similar to those used in traditional longitudinal observational studies in economics are beginning to be applied. It seems likely that we will see more of this convergence particularly as analysts move into broader program evaluation where randomized trials are not generally feasible. This is an area that is underdeveloped in Australia. It is rare to see economic evaluation of larger health programs either prospectively or retrospectively. The econometric analysis of existing health services programs has become more common overseas but there are few examples here. In part this is a data issue as we do not have access to large longitudinal linked datasets that might allow us to analyse the costs and benefits of major health programs and we are forced to rely on modeling with a minimum of statistical analysis. This might change in the future with greater access to linked PBS, MBS, hospital and longitudinal survey data that will allow us to look at causal questions and evaluate outcomes and costs of programs. However we do not need to wait for this as there are plenty of new health services out there where value for money is not being assessed. It may be that in terms of data quality we can't always get what we want, but there are observational data to give us what we need.

**BEYOND A COST PER QALY**

The spread of economic evaluation studies to areas beyond clinical applications has highlighted some of the limitations of cost effectiveness analysis. These include the need to have a single homogeneous outcome measure across interventions for whom there is a single budget to allocate. Where there are outcomes that are not easily summarised in a single measure, such as the widely accepted quality adjusted survival, or where there is not a single budget that is affected by the intervention, cost effectiveness analysis is restricted in offering policy advice. Some authors have attempted to widen the scope of outcomes for example in diagnostic or screening tests to include things not part of a health related quality of life measure such as information or re-assurance. They have used experimental techniques to determine subjective preferences (individual changes in welfare or its money equivalent) [17] and to predict usage [18]. This work, although increasingly sophisticated with a strong theoretical framework, remains even after 35 years experimental and not fully integrated into health economic evaluation in practice. As Lancsar and Louviere [19] note there has been an upsurge in the number of Discrete Choice Experiments (DCEs) in the last 15 years mostly in eliciting preferences particularly for non-health outcomes and process characteristics or predicting uptake (and occasionally in valuing health outcome in money terms), but I am not aware of any published examples of DCE derived outcomes being directly used in a cost effectiveness or cost benefit evaluation in Australia and none internationally that go beyond a feasibility study.

There appears to be considerable inconsistency across sectors in the attributes of outcomes that are important to decision makers[20]. It is hardly surprising that the context in which health gains take place are as important to decision makers as they are to the wider society. The advantages of simplicity and comparability over time that cost effectiveness analysis brings to priority setting within a given budget, in pharmaceuticals or medical services, does not extend to a comparison across sectors for example to health promotion, transport or the environment or indeed to how much of our resources we devote to the health sector. In addition it may be that these areas involve more complex important health and non-health outcomes. This has led some to argue that we might revisit the arguments for a full cost benefit approach in health services evaluation, with individual preferences for health expressed in money rather than in quality of life [21]. Others have argued for a return to a kind of social accounting...
matrix approach that includes cost effectiveness. For example the ACE prevention project [22] insofar as they included issues of equity and acceptability as qualitative subjective criteria in addition to cost effectiveness is an example of a more traditional social accounting matrix approach to multiple outcomes, in what has been called a cost consequence analysis.

In that specific case it was not clear why the attributes were chosen and no attempt was made to quantify these let alone weight them to allow them to be combined with the effectiveness information in a fuller cost benefit analysis. Some recent attempts have been made to derive weights at least for aspects of equity [23]. However both the implementation of a weighted multi-attribute outcome within a cost effectiveness analysis, or the possibility that we are prepared to accept individual stated willingness to pay from experiments in a cost benefit analysis remain experimental [24].

A focus on equity (for example needs weighted QALYs) might change some of our priorities [25], but while there may be support in principle for greater weighting of QALYs provided to patients with severe conditions or for some disadvantaged people for whom health services are a priority, and where traditional cost effectiveness analysis may not be adequate to demonstrate the net social gains from action, there is currently no robust evidence in the literature to support a particular magnitude of weighting [26]. Rather than distort the hard won political acceptance of cost effectiveness in health service evaluation it might be better to treat these as special cases. This might not get us what we want but as the resigned pragmatism of Mick Jagger and Keith Richards suggests it might get us what we need.


Quality of life in health services research: some issues and challenges

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ABSTRACT

An historical review of the reasons behind the development of participant-reported outcomes (PROs) in health-related quality of life (HRQoL) shows four key drivers: respect for patient views, evidence of health care intervention success at the patient level as well as at the program level for policy setting, and evidence of cost-utility analysis for resource allocation.

Aging from these diverse perspectives are some key difficulties. There is no definitive agreement on the nature of the HRQoL construct: it is whatever a researcher wishes it to be — a situation which has not significantly changed in 30 years — and which has led to some commentators recommending abandonment of the term altogether. Reflecting this, throughout the 1990s there was considerable diversity in the development of HRQoL instruments, including the publication of numerous generic health function measures, multi-attribute utility measures and disease-specific measures. The relationship between these different instrument types, however, was uncertain. During the decade following 2000, however, a discernable pattern in instrument development and validation has emerged. This decade has been marked by continued publication of disease-specific measures and the search to make these clinically relevant. In the same decade, no new major generic HRQoL instruments have been published. Instead, there has been considerable effort to develop crosswalks between disease-specific or health function measures and utility measures, which may reflect a profound belief that imputed evidence is sufficient for economic analysis at the policy level.

These observable changes may be consistent with disillusionment of the promise of PROs and they may mark a re-assertion of a boundary around medical science which is a response to external social forces seeking to ‘meddle in medicine’. Whether these changes reflect such a paradigm shift in the conceptualization and operationalization of HRQoL is debatable.

Within the health care industry, there are four key drivers for health-related quality of life (HRQoL) research. First advocated in the 1960s and developed into fully-fledged arguments by the late 1980s, these are at the patient/clinical level: (a) respect for patient views and experiences as opposed to clinical evidence — often referred to as patient reported outcomes (PROs) that can be used by patients and clinicians to assist with clinical decision-making under the therapeutic alliance model; (b) evidence that medical care has protected or restored the HRQoL of patients; and at the policy level (c) the need for evidence regarding program outcomes; and (d) evidence to assist with the allocation of resources between competing possible interventions (1-4).

Understandably, given these very different perspectives, HRQoL has become a catchword covering all different kinds of research activities and measurement instruments. The term ‘health-related quality of life’ appears to have been first used by Kaplan and Bush (5) who differentiated between ‘quality of life’ (QoL; including all the circumstances of living) and HRQoL (wellbeing as a function of health) for the purposes of evaluating the effects of health care interventions for policy development. The term was popularized by Patrick and Erickson (3 p152) who defined it as “the value assigned to opportunity, perception, functional status, impairment and death associated with... disease(s), injuries, treatments, or policy”. In the 20 years since the Patrick and Erickson paper, little has changed in the definition of HRQoL. For example, in 2009 Anderson et al defined HRQoL as “the aspects of quality of life that specially relate to a person’s health, and can be defined as self-perceived multidimensional health status” (6 p330).

These definitions of HRQoL stand in stark contrast with definitions of QoL. As noted above, QoL covers all aspects of life, including social, health and wellbeing indicators (7). In 1993 the World Health Organization defined Quality of Life Group (WHOQoL) defined QoL:

...as an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment. (8 p153)

Implicit in this definition is that QoL may not be congruent with health status, health function, impairment or disability. For example, Walsh et al (9) defined a good QoL after total abdominal colectomy surgery as being the number of daily successful bowel movements — a definition that equates bodily function with QoL, but that would be incompatible with the WHOQoL definition. The problem, of course, is that these are not necessarily related at all; a situation that has become known as the disability paradox, viz., that a person can have a severe disability or have poor objective health yet enjoy a high QoL (10). Elsewhere, the SF-36 is commonly described as a QoL instrument, even though the instrument developers deny that it assesses QoL at all (11). This confusion in conceptualization and definition is rampant throughout the health care sector.

Reflecting this confusion, in an early review of the term QoL in medical research, Bergner (12, p150) reported that “Quality of life as it is used in clinical research is a vague term without conceptual clarity. It is what the investigations mean it to be!” Ten years later in the late 1990s, Leplege et al reported similar difficulties, finding that definitional confusion had created technical, conceptual and ethical dilemmas; they recommended abandoning the term QoL in medicine altogether and replacing it with ‘subjective health status’ (13, p50). Dikkers, two years later, in a review of QoL was scathing in his comments, referring to QoL definitions as a “…tower of Babel or ‘quagmire’... the disarray results from the fact that QoL is a highly abstract concept, and very fundamental values and philosophical issues are tied up in its measurement” (14 p286).

In the 20 years since Bergner’s comments and the 10-12-years since the Leplege et al and Dikkers’ reviews, the situation has not improved, or improved marginally at best. McDowell, whilst acknowledging some improvement, reported that “…there is no clear distinction between quality of life (QoL) measures and ... general health measures” (15, p520). In 2010 Hill et al (16 p438) in a review of QoL instruments used in spinal cord injury noted that “a clear definition of QoL has yet to emerge...” In fact, the terms HRQoL, QoL and health status are often used interchangeably and are seldom defined. A recent review of HRQoL in vestibular schwannoma (17)
reported that none of the reviewed studies had defined HRQoL/QoL, but simply assumed it was being assessed by whatever measures were used in the study, which ranged from the SF-36 to a single item “I am content with the quality of my life now”.

The second issue that has arisen in the past 10 years is highly related to the quality of my life now” simply assumed it was being assessed by whatever measures were used in reported that none of the reviewed studies had defined HRQoL/QoL, but macro level whereas disease-specific measures have most value at the generic HRQoL/QoL measures are most likely to be used at the util-

sures are focused on a narrow range of outcomes which ignore the wider resistance to questionnaires, it is easier for short measures to be isomor-

in their review of health status and HRQoL measures reported that across the 1990s there was exponential growth in the number of annual disease-specific reports. Since around the year 2000, however, there have been no major new generic HRQoL/QoL measures developed. In contrast, research into the development of new disease-specific measures has continued unabat-

This fundamental change in the nature of HRQoL/QoL research over the past 10-15 years raises critical questions in relation to why this shift has oc-

Although social scientists, program evaluators and health economists are comfortable with the axioms behind HRQoL instruments – including both psychometric and decision-making theory – these are largely outside the experience of most clinicians who are familiar with signs, symptoms and disease classifications. Whilst a fundamental axiom of HRQoL research is that the patient perspective provides additional information not available from clinical indicators (35), a recurrent theme through the HRQoL/QoL liter-

The second reason, closely related to or consequent upon issues of demonstrat-

Kuhn (63) argued that changes in scientific paradigms occur slowly, almost invisibly, based on increasing malfunction of the current scientific para-

Kuhn (63) argued that changes in scientific paradigms occur slowly, almost invisibly, based on increasing malfunction of the current scientific para-

CONCLUSION

The original arguments for the development of PRO HRQoL/QoL instruments have, in the past 10-15 years, been challenged. The justification for the development and use of HRQoL/QoL instruments was to capture the patient perspective alongside the clinical perspective, it was to enable cross-condition evaluation of different interventions, and economic cost utility evaluation providing evidence-based information for use in setting health priorities and policies. The pattern of publications over the past 20 years suggests a paradigmatic shift in the purpose and operationalization of HRQoL research. Increasingly, new HRQoL/QoL instruments are justified on the grounds that they assess issues of concerns to clinicians as either part of the therapeutic alliance or that they provide disease-specific information which can be used in evaluating alternative clinical interventions within a disease. The implication is that PROs are increasingly likely to be biased assessments of the patient perspective. Additionally, in the past 10 years there has been a loss of interest in publishing new, generic instruments for use at the policy level and a large research effort into imputing utility values from disease-specific or health function measures.

Worldwide, there are a handful of generic multi-attribute utility (MAUs) instruments designed for use in CUA; the AQLQ (18), EQ5D (19), HUI3 (24), IHQI (21), 15D (20), QWB (25), and SF6D (27). Their purpose is to elicit the value the people place on HRQoL and for these utility scores to be used in the calculation of Quality-adjusted Life Years (QALYS) for use in CUA. By definition CUA is about the benefits of Treatment X in Condition Y when compared with Treatment A for Condition B. For example, if the cost per QALY-gained is AUD$40,000 for Treatment X and AUD$20,000 for Treat-

ment A, then Treatment A is to be preferred in that the community will get better health outcomes for spending on Treatment A to help Condition B, subject to the rule of rescue. I.e. utility instruments must be generic if they are to do their job.

The concept of a disease-specific MAU is incompatible with this funda-

mental purpose of MAUs (equal comparison between different interventions for different diseases) because it introduces bias into the measure-

ment – a point that was recognised 20 years ago (33). Disease-specific MAs can only be used to compare new HRQoL/QoL instruments – but CUA is not needed to do this anyway; any disease-specific measure can do this and a cost-effectiveness analysis performed. Yet, there are calls in the litera-

ture for the use of disease-specific MAUs for economic evaluation (54, 55). Additionally, once considered infeasible or invalid (56, 57), over the past 10 years there has been considerable research effort into developing crosswalks which map disease-specific or health measures onto MAUs (e.g. 58, 59-62). Implicit in these crosswalks is the assumption that there is no need to collect original MAU data and that imputed data will suffice for CUA policy-level evidence.
private interpretation of the observed trends above is open to discussion. Equally, whether these shifts are leading to losses in the voice of patients and the quality of evidence at the policy level is a legitimate question for debate. Certainly it will be fully played out over the next decade.
PICTURE THIS: An elderly Italian woman is hospitalised for several days and refuses to eat or comply with treatment or take medicine as part of the care plan prescribed by her doctor. The patient is progressively deteriorating. Staff are at their wits’ end - they have run out of ideas and patience. The clinical team finally resort to a conference with the family members to say that the elderly woman is dying despite their perseverance to deliver best standards of care. After going over the details of modes of care delivery, the family put ‘two and two’ together and work out the old lady is too proud to receive ‘things for free’ and that she has a personal culture of having always ‘paid her way’. The nursing staff proceed to make up false currency notes on the colour photo copier and slip them into the elderly patient’s purse. The next day when food and medicines arrive, she is told if she wants she can ‘pay’ and she does so now with a happier disposition. Suddenly she is ‘compliant’ and makes a quick recovery to the pleasure of staff and family concerned. I heard this story recently – it is a true story from a NSW hospital. It highlighted to me the need to understand patient perspectives and how we continue to treat the disease and not the person.

This story also made me think, how much of what we do in health services research is from a policy, clinical, economic or academic perspective? To what extent do we consider the patient perspective not only in our delivery of care but in the way in which we evaluate care? Where have we come from? Where to from here?

In 2001 - coinciding with the birth of the HSRAANZ - the Institute of Medicine (IOM) in the USA released the Crossing the Quality Chasm: A New Health System for the 21st Century. [1] This sentinel document laid down the dimensions of quality health care and was the first to clearly recognise the importance of ‘patient-centredness’ as a dimension in its own right. In the last 10 years in Australia, we have witnessed a slow but growing recognition of the importance of a ‘patient-focus’ in health care. Depending on which type of service you are involved with, the rhetoric has included the need to strive for person-centred, patient-focused, client-oriented services. But when we examine our approaches to studying and improving health care services, how far have we really come in ten years towards including patient perspectives?

These dimensions of patient-centredness are:

- respect for patients’ preferences and values
- emotional support
- physical comfort
- information, communication and education
- continuity and transition
- coordination of care
- the involvement of family and friends
- access to care.

For the first time, this framework clearly defined the patient’s perspective and served as the foundation for the measuring patient experiences of health care.

Just preceding the IOM report, Mead and Bower [3] (2000) proposed 5 dimensions to person-centred health care including: bio-psycho-social perspective; patient as a person; sharing power and responsibility; therapeutic alliance; and doctor as a person. Similarly, Lutz and Bowers [4] in 2000 described patient focused care as “a collaborative effort consisting of patients, patients’ families, friends, the doctors and other health professionals…”

Have we been taking the same approach in the way in which we research health care services? To what extent have we investigated service user perspectives here in Australia? To what extent is the ‘patient perspective’ included in the identification and measurement of the outcomes of health care? We have some evidence from state-based and international surveys of patients. But to what extent do the expectations prior to a patient’s experience of health care align with their satisfaction after the fact? [5]

Interestingly, it is also about 10 years ago using health services research that we worked out that health administrators were most likely to accurately estimate the service expectations of patients, while medical and nursing students were most likely to underestimate them. [6]

Yet we would be doing ourselves a disservice to solely relegate the need for understanding of patient perspectives to the business managers. Although we know that a customer-focused service is important for service recovery, operational benefits[7] and market share, more recent research within health services indicates an important link between delivering patient-based care and clinical outcomes including decreases in mortality[8],[9], rates of hospital-acquired infection[10], surgical complications[11], improvements in patient functional status[10] and higher quality clinical care. [12]
Gaining and understanding patient perspectives assumes that we will use these insights to drive improvement in our health care delivery. Increasingly, we are now turning to measuring care from the patient perspective in new ways, moving beyond patient surveys to real time feedback and patient reported outcome measures (PROMs). We are starting to put more value on n = 1 through the inclusion of patient stories, family ‘health talk’ and narratives to compliment quantitative data. [13]

Encouragingly we have also witnessed the emergence of a focus on diversity and a move away from the generic ‘patient’ view to considering cultural competence and investigating difference. Important bodies of work have emerged in indigenous health, understanding individuals from culturally and linguistically diverse communities and aged and community care settings. Indeed some of the seminal work in this field has come from mental health care.

Not only do we need to study and analyse patient perspectives but we need to engage patients in our work and give them a voice at the table in determining research agendas and driving quality improvement. In Australia, we have a proud history of consumer engagement in policy arenas. We need to expand on the engagement in research development that we have witnessed in clinical areas, such as oncology trials and health technology assessment, to a broader approach to engagement to ensure that our work remains relevant at the coal face.

And if we don’t include these perspectives in our work, not only are we missing half the story but we will drive patients to seek alternative avenues, such as social media, to make their perspectives known.

As researchers in the health care services arena, we can lead a greater engagement with individual patients and consumer organizations to gain their perspectives to better inform our directions. As we listen more carefully, new research questions will arise. Respecting different perspectives may lead us to new research methodologies. We have come a long way in 10 years – but we still have a way to go.

The elderly Italian patient had a different perspective but it was her perspective as a patient. She didn’t ‘park it’ at the door when she entered health care. Our challenge is how do we include her perspective, her views, her needs in making health care all about the patient.

PS – I’m relying on you not to tell the Mint about the forgery story!

Māori health, and health services research: ten years of growth  
Amohia Boulton, Senior Researcher, Whakauae Research for Māori Health and Development

Health services research (HSR) is a multi-disciplinary research activity with the objective of improving the health services that patients and consumers receive. In the New Zealand context, Māori comprise a unique and significant proportion of these consumers; unique because as the indigenous peoples of New Zealand and partners to the Treaty of Waitangi, Māori are guaranteed a level of health status that is at least equivalent to that of non-Māori; and significant because for a myriad of reasons, as a population Māori fail to meet this level of health, experiencing on average “the poorest health status of any ethnic group in New Zealand” (Ministry of Health 2002).

As health services researchers, concerned with applying the results of our research to effect improvements in health care financing and delivery, it is essential that we not only engage with Māori as research participants but also as research partners so that we may inform improvements that are both timely and appropriate.

In reflecting back over the ten years since the Association came into being, it is evident New Zealand has witnessed significant changes in Māori health research and Māori health services research more generally. The changes can be grouped according to three key themes: the growth in the number of “research active” Māori health providers and practitioners; an emergence of new sites of health research activity; and an increase in the number of Māori scholars at post graduate level trained in health and health services research. Each of these themes is discussed more fully below.

THE GROWTH IN THE NUMBER OF “RESEARCH ACTIVE” MAORI HEALTH PROVIDES AND PRACTITIONERS

One of the most noticeable changes in our field of research has been the growing awareness of, and interest in research displayed by Māori health providers, clinicians and practitioners. Prior to the first Health Services Research Conference in 1999 Māori health service provision was in its infancy, Māori providers having emerged as health service provision entities in their own right after the health reforms of 1993 and 1997 (Boulton, 2005). Whereas in 1993 there were as few as 20 Māori health providers, by 2004 this number had risen to some 240 (King, 2004). Few Māori health providers, if any, in those early years were routinely evaluating programmes or initiatives, undertaking research for service improvement, or using their own evidence-based research to justify the need for additional funding or the re-prioritisation of funding.

By comparison, in 2011 many Māori health providers are conducting their own research and evaluation in order to validate their models of health care; ensure programmes and initiatives are meeting the needs of specific population groups; or answer questions of importance to their specific community; questions which may or may not be of national concern. The last ten years has seen the growth of Māori health practitioners and clinicians engaging in health services research activity on a localised scale in order to advance community concerns and address whānau (extended family), hapū (sub-tribe), iwi (tribe) or community-identified needs. While excellent examples of local-level health services research led by Māori providers for the benefit of their respective communities abound, few are ever published in academic journals and only rarely are results publicised at academic conferences. For our Association, promoting the work of Māori providers, so that other indigenous services may learn from their experiences, is a real challenge. Māori providers have little in the way of discretionary income to allow staff to attend academic conferences and few have the time or need to write the results of their research up into academic articles. Other forums for knowledge sharing and engagement to promote the indigenous health services research activity occurring in our communities may be required in the future.

AN EMERGENCE OF NEW SITES OF RESEARCH ACTIVITY

As interest in research has grown amongst Māori health providers, and the potential benefits of research activity become clear, so too have we seen an increase in the range and variety of locations and institutions undertaking health services research. Where once HSR may have been the preserve of the hospital-based clinician or University-based academic researcher, in 2011 a myriad of institutions now engage in the activity of health services research, and particularly in Māori health services research. While the traditional sites of health service research activity remain, many Universities are now actively seeking to partner with Māori providers, Māori tribal authorities and even marae (traditional gathering places) in order to develop health services research projects that are relevant and appropriate for Māori communities and Māori as a population group. Large scale, multi-method, resource-intensive studies tend to remain concentrated within mainstream research centres within New Zealand universities, but other smaller studies can, and are, being conducted outside of the traditional academic setting.

An initial review of sites of HSR activity indicates that in addition to mainstream university-based research, health services research is being conducted by at least six additional types of organisations: University-based Māori Health Research Centres; Community-based Research Centres; NGOs/Māori Health and/or Social Service Providers; Independent Consultants; Rūnanga (Tribal Authorities); and those which fall outside any of these categories (Other).

Health services research conducted by a university-based Māori health research centre is quite distinct from that undertaken by Pākehā- or non-Māori-led research conducted within a university setting. Often-times the principles and values which underpin Māori health research centres within the mainstream setting derive from a kaupapa Māori philosophy or Māori worldview. The questions that are asked, the methods by which data is collected, the analysis that is undertaken gives primacy to Māori worldviews and privileges Māori knowledge. Similarly, community-based research centres, those established under the auspices of tribal authorities and even to a degree, consultations, will operate from a distinct, even idiosyncratic kaupapa Māori philosophy. Consequently, health services research in New Zealand is now more diverse and varied, benefitting from the inclusion of a different perspective, one that is firmly grounded with an indigenous epistemology. Harnessing this distinct perspective; building better collaborations; and developing health services research projects which are capable of honouring both indigenous and non-indigenous views are important challenges for our membership as we move into the next ten year cycle. One means by which e can harness the growing interest in indigenous health services research is for our Association to attract new and emerging health services researchers. It is perhaps appropriate then to turn to the final theme: that of the growing Māori health research workforce.

“Rata Marae, Ngāti Hauiti, Rangitikei”
Table 1: Sites of Māori Health and Health Services Research Activity

<table>
<thead>
<tr>
<th>Type</th>
<th>Currently Active Research Organisations</th>
</tr>
</thead>
</table>
| University-based Maori Health Research Centre | • Te Rāpata Rangahau a Eru Pōmare, University of Otago, Wellington  
• Research Centre for Māori Health and Development (RCMHD, Massey University, Palmerston North)  
• Te Whānau a Tū  
• Te Whānau o Arotora  
• Tāmaki Tū Māori Health Research Centre, University of Auckland  
• Taupou Wāhiao, Auckland University of Technology  
• Whariki, Massey University, Auckland  
• Te Kupenga Hauora Māori, Auckland University  
• Māori/Indigenous Health Institute (MiHI), University of Otago, Christchurch |
| Community-based Research Centre | Whakauae Research for Māori Health and Development  
• Te Atawhai o Te Aro  
| NGO/Maori Health and/or Social Service Provider | • Te Runanga o Kōkiri  
• Te TūMana Whaine  
• Ngati Porou Hauora  
| Consultancy/Company/Independent | Kaitai Ltd  
• Tumana Research Services  
• Māori and Indigenous Analysis Ltd (MIAA)  
| Runanga (Tribal Authority) | • Te Runanga o Ngati Awa  
• Te Rānanga o Te Rarawa  
| Other | • Māori Women’s Welfare League  
• Amokura Family Violence Prevention Consortium |

Disclaimer: This list is by no means exhaustive. The list is derived from an analysis of research host institutions in receipt of Māori Health funding from the HRC in the last five years.

INCREASE IN GRADUATE SCHOLARS, DOCTORATES AND POSTDOCS
Since the 1990s there has been a significant effort made on the part of universities and tertiary institutions to improve the numbers of Māori students moving into postgraduate study and, by extension, to increase the number of doctoral and postdoctoral completions. According to Middleton & McKinley (2009) the number of Māori doctoral students enrolled in New Zealand universities has increased dramatically from 77 in 1994 to 275 in 2005. A number of universities have employed specific strategies to increase Māori postgraduate student numbers. Massey University for example, set a goal of having 25 Māori students’ complete doctoral degrees in ten years. A recent article indicates that since the inception, in 2002, of the Te Amorangi National Māori Academic Excellence Awards (an annual event that acknowledges Māori PhD graduates across the country), some 239 Māori PhD graduates have received this award (Te Puni Kōkiri, 2011).

Of course not all of these graduates completed degrees in fields traditionally associated with health services research. It would be a complex exercise, given current reporting mechanisms, to accurately gauge the exact number of graduates working in a health services research-related field. However we do know from Health Research Council of New Zealand data that in Māori health, some 26 Master’s scholarships, 28 doctoral scholarships, and 30 postdoctoral scholarships have been awarded since 2000. This cohort of almost 90 indigenous emerging health researchers represents a significant contribution to the health research workforce. Importantly, given the skills and experience of the Māori able to supervise at PhD and postdoc level, and the types of research that Māori generally gravitate towards, it is likely that the majority of these students have undertaken their research in a health services or a closely aligned field. Ensuring these new and emerging graduates are not lost to either health services research or to health research more broadly is another key challenge of the sector and one which our Association is currently actively working on through initiatives such as the ERGO group and scholarships to assist PhD students attend our biennial conference.

CONCLUSION
Our Association has much of which it can be proud, as it looks back over the last ten years. The inaugural Health Services Research Conference held in 1999, included only a few papers on Aboriginal health, and little in the way of indigenous participation. Since these early beginnings conference committees for each biennial conference have made sure to advance and promote indigenous participation by, amongst other things encouraging the submission of papers on aspects of Aboriginal and Indigenous health; including Aboriginal and Indigenous panel sessions, themes and streams; and including appropriate cultural protocols according to conference location. Now in 2011, in conjunction with an increase in the number of presentations being given by the indigenous presenters themselves, indigenous conference delegates will have the opportunity of a separate pre-conference satellite meeting to network and prepare for the conference.

As an Association we have made a number of advancements in supporting indigenous health services research and researchers. Building on the highly successful indigenous panel session at our 2009 conference, the Association has invited two indigenous health researchers to be co-opted onto the Executive Committee: Dr Amohia Boulton (Ngāti Ranginui, Ngāi Te Rangi and Ngāti Pukenga) and Ms Kim O’Donnell (Malyangapa/Barkindji, NSW). Their role is to advise and assist the Association to engage better with indigenous health researchers and to create an Association that values and respects indigenous health researchers’ knowledge and skills. The Association has supported the development and adoption of a policy statement which outlines the Association’s guiding principles in respect of indigenous health services research and sets the Terms of Reference for the Indigenous Health Services Research Interest Group (IHSRIG). This document, and more information about the IHSRIG, can be found on the association website: http://www.hsraanz.org/Files/Indig%20Group%20ToF%20Ref%20final%20.pdf

Reflecting back on the last ten years and indeed, the “first” ten years of this Association’s existence, we cannot afford to sit on the laurels of our success, simply because we cannot afford to ignore the significant inequalities between indigenous and non-indigenous peoples in our respective countries that were alluded to at the outset of this paper. However, it is appropriate to take the time to consider where we have come from and in that moment reflect on the hard work, determination and effort of those who have brought our Association to where it is today. We have made great gains in our first ten years; our on-going challenge is to do so again.

“I climb to the summit of my mountain, to see the lands of my ancestors” Piki atu ki te taumata o tōku maunga, ka kite au i te mana, i te ithi o te whenua nei nō ōku tīpuna [7].

Over the last two decades discrete choice experiments (DCEs) have become a popular tool in health services research for eliciting patient and community preferences for non-clinical outcomes of health care that are not routinely investigated in clinical studies. Examples include the value that the community places on access to services, travel and waiting times or choice of provider. In patient populations DCEs are useful for understanding trade-offs that patients might make between the usual direct clinical outcomes of treatment and other aspects of treatment such as side-effects, convenience and invasiveness. Understanding consumer preferences for non-clinical aspects of care allows these aspects to be included in any evaluation of a health service.

Early Australian studies that applied DCEs in the area of health services research included the evaluation of immunisation programs, screening programs, and genetic testing. Many early DCEs in Australia focussed on community preferences for health services. In the last 5 years there has been growing interest in using DCEs to gauge patient preferences for assessing value patients place on non-clinical aspects of treatment. Examples include patient preferences for asthma treatment, cancer treatment, screening services and access to primary care services. There are fewer published DCE studies from New Zealand. However recent work includes DCEs to explore patient and community preferences for public and private surgery services and community attitudes to pre-birth genetic testing.

Health services research in Australia and New Zealand has mainly focussed on the application of DCEs to answer empirical questions about health and related outcomes. However there has been an increasing contribution from Australian and New Zealand researchers, including those in health services research, to new methodological developments and applications in choice experiments. A number of early DCE reviews and methodological papers in health service research came out of Australia. More recently health service research has been at the cutting edge of the application of new methods in the design and analysis of DCEs and related choice experiments.

The Choice Task
In a discrete choice experiment, the respondent completes a series of hypothetical choice tasks. In each task the respondent is shown a scenario with two or more alternatives, each described by levels of a set of relevant attributes and asked to choose his/her preferred option. The levels of the attributes across alternatives and choice sets are systematically varied by the design of the experiment.

Many DCEs involve choosing between two or more generic products or services each described by levels of a common set of attributes. However the choice set could also include an "opt out" or status quo option, for example choosing whether or not to undergo a genetic test as described in the choice scenario. It is also possible to label the options in terms of a named service or treatment, for example private or public hospital. Labelled options allow respondents to express their prior preferences for or against a particular service, and above the included attributes that describe that service.

Choice of attributes
Recent methodological work has focussed on the importance of the selection of attributes included in a DCE. The numbers of attributes, the range of levels and the framing of the descriptions of attributes and levels can all have an effect on the respondent’s choices. Existing studies have selected candidate attributes based on literature reviews, focus groups, and interviews with clinical experts. In the last 5 years there has been an increasing emphasis on the role of formal qualitative work in selecting attributes and framing the description of levels. There is as yet no consensus on what qualitative approaches are best for selecting an optimal set of attributes.

The cognitive burden placed on respondents is also a consideration when finalising the set of attributes. The researcher may need to reach a compromise between a comprehensive set of attributes and minimising respondent burden.

Constructing the choice sets
Once the set of attributes and levels has been decided upon the question becomes how to create choice sets so that all effects of interest are identified. Perhaps one solution is to use all the combinations of attribute levels in the complete factorial and insist that each appear in at least one choice set. However for experiments that include a large numbers of attributes and levels the number of choice sets of reasonable size (say at most 4 options) required to do this is just too large and so the treatment combinations in a fractional factorial design need to be used to construct the choice sets. In the 1990s many of the DCEs in health research used strategies to construct choice sets from fractional designs that have since been demonstrated to be inadequate for identification of the effects of interest. Since then there have been significant advances in the formal theory and methods for selecting the right design fraction and creating choice sets to allow the efficient estimation of all effects of interest.

One approach developed by Streit & Burgess (2007) is to create choice sets from a fractional factorial design where the effects of interest are orthogonal (uncorrelated) to each other and therefore estimable. A starting design that can estimate the effects of interest is selected from a design catalogue. The starting design forms the first option in the choice sets and other options in each choice set are then generated by systematically shifting the attribute levels of the starting design. The matrix properties of the final choice sets are analysed to gauge the efficiency of the design. The usual measure of efficiency is the D-efficiency, where the generalised variance of the parameter estimates is minimised. For competing designs the one with the greatest efficiency is generally chosen.

Other approaches use computer search algorithms to construct efficient designs. Recent strategies include Bayesian approaches which relax the design requirement of orthogonality of effects and instead use the distribution of prior parameter estimates in constructing an efficient design. Constructing efficient Bayesian designs can be very computer intensive and to date there are few examples of the use of Bayesian DCE designs in health services research.

Current research is underway on the empirical comparison of designs constructed using the different strategies and their relative performance under different model specifications.

Analysis of DCEs
Discrete choice models are used to analyse respondents’ choices and the model coefficients indicate the relative utility of attribute levels. The multinomial logit (MNL) model is the starting point for exploring the specification of models to estimate utility weights. However the MNL model has well-known limitations for modelling consumer choice behaviour. The MNL model cannot account for heterogeneity in consumers’ choices nor capture variable substitution patterns between more or less similar products. Both these aspects of choice behaviour are of empirical and theoretical interest in modelling preferences.
There are now a large number of models that can be estimated to account for heterogeneity and flexible substitution patterns. These include latent class models, random parameter models and multinomial probit models. Of these models, the random parameters or mixed logit model proposed by McFadden & Train (2000) has become one of the most widely used models for analysing DCEs. The mixed logit models the distribution of individual taste heterogeneity, estimating the mean preference and the standard deviation of individual preferences for attribute levels specified as random. Flexible substitution patterns can be captured by allowing correlation across random parameters.

There has been a recent debate, however on whether respondent heterogeneity is due to individual differences in taste or whether the observed heterogeneity is better explained as individual differences in the variance of the error term, known as scale heterogeneity.

A very recent model, the generalised multinomial logit (GMNL) model was developed by Fiebig et al (2010) to identify both forms of heterogeneity so that residual taste heterogeneity can be estimated after accounting for heterogeneity in the scale of the error term. The first application of the GMNL model in health services research was forecasting the uptake of new contraceptive products in Australia.

FUTURE DIRECTIONS

Best-Worst Attribute Task

A relatively new variant of choice experiment the Best-Worst Scaling (BWS) task has recently been gaining popularity in health services research. In a BWS task the respondent is shown a single profile of a product or service described by levels of relevant attributes. The respondent is asked to choose the best feature (attribute level) of the described profile and then the worst feature of the profile. So instead of choosing between options as in a standard DCE, the respondents indicates what they most like and dislike of a proffered treatment or service.

The BWS task has been shown to be less cognitively demanding than choosing between complete profiles. The BWS task has an added advantage of allowing all levels across all attributes in an experiment to be ranked relative to each other on a common scale of best to worst. This is achieved by setting a single level of one attribute only as the base case and then coefficients are estimated for all the other levels of all attributes. This is in contrast to a standard DCE the where the base case contains an omitted level for every attribute which are each normalised to zero. Therefore the BWS can provide some information on the relative ranking of complete attributes (not just levels within attributes) which is not available in standard discrete choice experiments.

One shortcoming of the BWS is that it does not involve the respondent making choices that trade off preferred attribute levels. Current research on BWS tasks in the area of health services research in Australia includes constructing optimal designs for BWS tasks.

QALY weights.

Quality adjusted life years (QALYs) are used in economic evaluation as a summary measure of survival and quality of life. One early rationale for using DCEs in health economics was to incorporate other dimensions of health care into economic evaluation that was not captured by QALYs. Recent research however, has returned to the DCE as a method to estimate (QALY) weights for valuing health states. Although still at the exploratory stage this approach to estimating QALY weights has been demonstrated to be feasible and may have advantage of being less cognitively demanding than the usual QALY evaluation methods of time trade-off or standard gamble.

RCTs

There are recent examples of DCEs used in randomised control trials to understand the value patients place on the process of care, such as travel time and convenience. There have been some concerns expressed about the extra burden placed on patients undertaking DCEs in trials. However patient groups have shown themselves willing to participate and a DCE performed during a trial increases the validity of estimated preferences and can improve the evaluation of the study.

On-line administration

Currently most DCEs in health are conducted in face to face interview and for patient populations this may be the best approach. For community samples however, on-line administration has shown to be feasible, with advantages in terms of cost and ease of administration. There are some questions about the generalisability of results from on-line samples. Nevertheless with an increasingly computer-literate population the future may see more DCEs conducted on-line.

Summary

Interest in using choice experiments in health services research in Australia and New Zealand continues to grow. The last decade has seen many developments in the theory and method of designing, conducting and analysing choice experiments. For the researcher undertaking a choice experiment today, there is more theoretical and empirical research available on methods of design and analysis, which has clarified some aspects of best practice in conducting choice experiments. There is however, also greater awareness of the uncertainties and limitations of conducting choice experiments. When conducting choice experiments careful planning is now expected for each of the key stages of the choice experiments; setting the context, attribute development, design, administration and analysis. When publishing a choice experiments study, the authors need to provide clear details on the approach to each of these key stages. Over the last decade the bar has been raised for executing a good choice experiment and researchers need to carefully design and conduct their choice experiments in a way that clears this bar.

The past 10 years have seen huge growth in two basic raw materials for health services research in Australia: (i) administrative data that can be linked together for individuals across services and over time; and (ii) population-based cohort (panel) studies that collect detailed individual data on factors that drive the use and outcomes of health services, including socioeconomic status and health behaviours. Researchers have made use of these new resources, in increasingly sophisticated ways, to evaluate and model the outcomes of health policies and models of service provision. But their effective use has been limited by a prevailing project-based, “cottage industry” approach to health services research, compounded by research workforce shortages in biostatistics and health economics, and by frustrating bottlenecks in processes for access to data. Recent investments in relevant research infrastructure—in technologies, policies and people—have the potential to deliver an (industrial) revolution in large-scale, data-intensive health services research in the decade to come.

**LINKED ADMINISTRATIVE DATA: 10 YEARS ON**

Australia has one of the most comprehensive collections of population-based administrative data in the world, capturing complete information about use of services including those funded through Medicare (Medical Benefits Schedule [MBS] and Pharmaceutical Benefits Scheme [PBS]), public and private hospital services and community-based and residential aged care. These are supplemented by other data that are routinely collected by government agencies, including vital statistics and disease registers (birth registrations, death registrations, mortality data, cancer registries, communicable diseases), adverse incident reporting systems and surveys of patient satisfaction. Over many decades, these routinely collected data have underpinned the measurement of population health status and health system performance by government agencies including the Department of Health and Ageing, state government health departments, and the Australian Institute of Health and Welfare (AIHW).

Such uses traditionally have involved calculation of age-standardised rates using population denominators derived from the five-yearly Australian Census, often without consideration of the likelihood that single individuals will contribute multiple events. Although most routinely collected data contain complete or partial personal identifiers, presenting the potential to link records for individuals together across datasets and over time, person-based longitudinal analyses have been only rarely used in routine reporting. Up until the mid-1990s, this was attributable to factors including privacy concerns, fragmented regimes for data governance, technical challenges in linking very large data sets and methodological inertia.

But from 1995, the landscape changed with the establishment of routine, systematic linkage of administrative health datasets through the Western Australian Data Linkage System (WADLS). WADLS implemented a privacy-preserving (or ‘best practice’)[1] system of data linkage whereby the personal identifiers (name, address etc.) used for linkage were split off from the rest of the health record for the processes of linkage, and researchers were supplied only with de-identified health records. Neither staff involved in data linkage, nor researchers, ever have access to both personal identifiers and health details for individuals. Data linked through WADLS supported burgeoning numbers of research projects through the late 1990s, culminating in more than 700 research outputs by the year 2003[2].

Despite the successes of WADLS, data linkage work in other Australian states took off only slowly. It was largely limited to development of innovative technical approaches to linkage[3] and to supporting discrete research projects (e.g.[4],[5]) until 2006, when the Centre for Health Record Linkage (CHeReL) was established to link health-related data for New South Wales and the Australian Capital Territory.

Things snowballed from there. In the same year, the Australian Government, through its National Collaborative Research Infrastructure Strategy (NCRIS), allocated $20M in funding for population health data linkage. Following a consultative process to develop an investment plan for the NCRIS funds plus an additional $32M in cash and in-kind contributions from state governments, the Population Health Research Network (PHRN) was set up in 2009. This has a mission of expanding health data linkage in Australia. The establishment of the Centre for Data Linkage (CDL) at Curtin University, SA/NT DataLink, Health LinQ (Queensland) and Victorian Data Linkages (VDL) followed in short order.

In 2011, the Sax Institute launched the PHRN Secure Unified Research Environment (SURE) remote access data laboratory for the analysis of linked health data. The Australian Government has signalled that its linked data (including MBS, PBS and aged care data) will generally only be available to researchers through such secure remote access facilities, or on-site data laboratories. In the same year, a Cross-Portfolio Data Integration Committee was established to provide leadership regarding the use of Commonwealth data assets in data integration projects for statistical and research purposes[6]. And again in 2011, the Australian Government allocated additional funding of $10M from the Education Investment Fund (EIF) Super Science Initiative to further development of PHRN-related infrastructure, including building data linkage capability in the AIHW.

Australia now has excellent, though still emerging, infrastructure for research using linked administrative data.

**COHORT STUDIES: 10 YEARS ON**

Longitudinal studies are needed to understand the complex factors that drive trajectories of health and wellbeing throughout the lifespan. They provide the best evidence regarding the key determinants of health and how these interact, about potential points for intervention to improve life trajectories, and for assessing the impact of interventions, services and programs. Although linked administrative data facilitate longitudinal analyses for entire populations, in general these data contain only very limited information about key determinants including socioeconomic status and health behaviours, and key outcomes including mental health status, functional status and wellbeing. This is where high-quality cohort studies can contribute.

Australia has an impressive collection of such studies[7]. These have made critical research contributions including demonstrating the role of sleeping position in Sudden Infant Death Syndrome (SIDS)[8] and the link between using inhaled steroids and developing cataracts[9]. Key Australian cohort studies include the Busselton Study (established in 1966), the Dubbo Study (1988), the Tasmanian Infant Health Study (1988), the Melbourne Collaborative Cohort Study (1990), the Blue Mountains Eye Study (1992), the Australian Longitudinal Study of Ageing (1992) and the Australian Longitudinal Study on Women’s Health (1995).
Most of these longstanding cohorts have continued to collect data, through active follow-up and/or data linkage, and to yield substantial research outputs, in the decade since 2000. The same period has seen the establishment of important new cohorts, including the Longitudinal Study of Australian Children (2004) and the 45 and Up Study (2006). The 45 and Up Study is Australia’s largest cohort study to date, with more than 265,000 participants aged 45 years and over, and incorporating extensive linkages with routinely collected data. The last 10 years has also seen the initiation of significant Aboriginal child cohorts including Footprints in Time - the Longitudinal Study of Indigenous Children (2008) and the Study of Environment on Aboriginal Resilience and Child Health (SEARCH, 2008).

Australia’s cohort studies are managed by diverse entities, mainly universities or independent research institutes, and have a wide variety of access models. In general, they have grown out of a tradition of grant-funded investigator-initiated research and have been used primarily for risk factor or aetiologic epidemiological studies. Their potential to support health services research has not been fully realised, even though most of the more recently established cohorts have sought participant consent for linkage with administrative data. This value has been well-demonstrated, though, for example through recent outputs from the Australian Longitudinal Study on Women’s Health that used linked MBS data to evaluate policy change[10]and from the 45 and Up Study that used linked data to investigate models of service provision in community care[11].

Currently many large Australian cohort studies rely on short-term project funding to support their maintenance, follow-up and tracking activities, challenging their long-term sustainability. They are ripe to benefit from the sort of systematic investment in infrastructure that has so strengthened the data linkage landscape.

THE NEXT 10 YEARS

Australia is poised to consolidate its position as an international leader in health services research using linked administrative data. The scope and population coverage of our existing data resources supports research to explore health differentials, geographic and spatial aspects of health, and the effectiveness of health services, that is not possible anywhere else in the world.

If we can capitalise on current potential and developments, the next 10 years will see a dramatic increase in our large-scale data resources for health services research. Existing routine linkages will expand to incorporate ongoing linkages with: (i) a wider range of administrative data, including data relating to community-based and residential aged care services, education, child protection, crime and forensics; (ii) key population cohort studies; (iii) stand-alone registers relating to disease, treatments and devices; (iv) data from clinical trials; and (v) data from emerging systems for electronic health records. Research using these expanded data resources will inform the reconfiguration of human services towards a person-centred, lifecycle, approach, and will drive action to reduce the use of harmful or ineffective treatments, and to redirect resources towards cost-effective options.

Ensuring that we achieve this potential will require continuing investment in three areas: technologies, policies and people.

Technological advances have delivered new methods to protect privacy and improve data security, but also new data mining methods that can be used to defeat existing privacy preservation measures. Over the next 10 years, significant additional investment will be required to up-scale SURE and similar secure analysis facilities to meet growing demands from a broader group of researchers. We will need more investment in systems for the secure storage, management, transfer and archiving of data, and for performing data linkage. New technologies will also potentially assist in supporting the efficient ongoing operation of cohort studies and registries, including shared, secure infrastructure for cohort recruitment, maintenance and tracking. These systems will be able to make good use of the forthcoming National Broadband Network.

Health services research using administrative data will not happen without good governance, a robust policy framework, and strong community support. Incorporation of data from cohort studies, registers and clinical trials into routine data linkage will require the development of new mechanisms to govern and manage these data as an open-access resource while still maintaining appropriate arrangements with regard to intellectual property[6].

Finally, data-intensive health services research is highly dependent upon capabilities in biostatistics and health economics, both of which are current areas of workforce shortage in Australia. We urgently need good models for building workforce capabilities in these areas, in the face of strong demand from other workforce sectors that are crying out for quantitative and computational expertise.

According to the Australian Productivity Commission “There is a case for maximising the benefits that the community achieves from the data it has paid for. More extensive research and analysis of these data collections could deliver significant improvements in the efficiency and effectiveness of health care”[12]. HSRAANZ members can help to make this happen over the coming 10 years.

This publication demonstrates that health services research is now well established in Australia and New Zealand; and that the last ten years have seen substantial progress across a range of issues and methodological developments. Nonetheless its base is a toehold rather than a secure position. For example, of the 756 research projects funded by the NHMRC in Australia in 2010, only 24 were health services research. Identifying health services research in New Zealand is more difficult, but an even lower proportion of health services research projects is likely there. Many researchers in this field struggle with short-term employment contracts, and even senior researchers leading complex research programs and responsible for varied educational programs are expected to bring in their own salaries. Research centres in Australia and New Zealand have been crucial in developing new researchers, in supporting a range of professional activities – including this Association – and in building research infrastructure through data and methods development. But the centres also rest on a vulnerable funding base, reliant on the vagaries of competitive funding largely from the NHMRC in Australia and the HRC in New Zealand. In both countries, it has proven difficult to build and maintain focussed research programs around relevant policy issues. Researchers and centres depend for their survival on successful grant raising, and this comes at the expense of long term research priorities. Health expenditure in Australia has now exceeded $120b per annum; it represents almost 10% of our economic activity and employs 1 in 9 Australian workers. It is staggering that only 3% of projects, the preeminent funding scheme of NHMRC, are committed to improving how that much expenditure is allocated.

There are numerous definitions of health services research; generally the field is considered to encompass the effectiveness, efficiency and equity of service delivery; it can focus on organisation and management, financing, workforce, utilisation and evaluation; it will include health services delivery and health system development. Both the NHMRC and the HRC require applications to be assessed against significance, defined as the extent to which the proposed research will directly lead to improved health outcomes. As a result of this narrow frame of reference, successful applications are much more likely to be focussed on improvements in service delivery at the clinical interface. Contributions to how the health system is financed and organised, the inherent incentives in that, and the evaluation of system level policy are often overlooked. Yet this focus on health systems research is also crucial. According to WHO, this broader level and focus of research is “the brains of the health system”. WHO has called for major investment in developing capacity to develop and evaluate health system policy, simply because more return will be realised from strengthening health systems through research and evaluation than higher investment in the discovery and development of new interventions. Each country should have earmarked funding, and focussed organisations for learning from health system development.

There are plenty of challenges facing our health systems. Societies and governments are concerned about the increasing cost of health care and the extent to which these costs will be considered affordable in the future. Ageing populations will require better co-ordination between health services and aged care, while significant inequalities in health and access to health services must continue to be a key focus of attention. There are rapid developments in new technologies which will bring additional costs to adopt. According to the Productivity Commission, recent technological advances have been responsible for over one-third of recent increases in our health care spending, more than twice the contribution of population ageing; so determining whether all new technologies provide value-for-money will become more pressing. There have been rising out-of-pocket payments, increasing the potential burden on patients and the chance that they will skip treatment due to cost. The way we pay for our health care was designed when hospitals, medical services and pharmaceuticals were separate and distinctly different elements of care; now more flexible funding approaches and new ways of delivering services are required to ensure better co-ordination of these and other services.

Health services and health systems research has already demonstrated its worth in contributing to health policy design. In Australia, a key component of current reform is the move to activity-based funding for public hospitals. The base work on the development of case-mix classification commenced in the 1980s, initiated by academic researchers, then given great impetus by sustained and continued funding for development under the Medicare Agreements. The National Co-ordinated Care Trials demonstrated the difficulties in imposing flexible funding and care co-ordinators at the primary care level onto the existing inflexible and unco-ordinated system. The adoption of the requirement for economic evaluation by the PBAC was only possible because of preceding developments in the methods, including developments in quality of life. In New Zealand, health services researchers have demonstrated the impact of adverse events in hospitals, leading to a number of new activities aimed at reducing harm. They have shown the complexities involved in contracting for services, including contracting in indigenous health, in priority setting for elective services, in reforming the funding and delivery of primary health care services, and, as in Australia, better integrating care.

So why is health policy research a virtual desert in our countries, as described by the editor of the Medical Journal of Australia? Even the best, high quality, timely-focused research may not influence policy. There are many influences on policy and policy making: Sax listed political factors, and the drive to win elections; the philosophy of the political party; pressure groups; the influence of mass media; the prevailing climate of social opinion; history – and existing policies; feasibility of implementation; and information, including but not limited to research evidence. According to Roos, “policy relevant health care research almost inevitably arouses differences of opinion in which ideology, commonly held myths, and self-interest all play significant parts”. And why is health services and systems research only relevant when directed by policy makers? Invaer found that while high quality research was nominated as important by decision makers, equally important was that the research recommendations confirmed the current policy direction. Surely this underpins the recommendation for academic independence in this field of research, as recognized by WHO.

It is not as though the need for this research has gone unidentified. In 1986, the Kerr White Review of health and medical research funding...
recommended the establishment of a national centre for Technology and Health Services Assessment. A subsequent review almost ten years later commented that "Health services and health systems research is not well funded in Australia" and recommended earmarked funding. The Grant Review in 2004 criticised the delay in implementing Wills' recommendations for the establishment of 5-7 centres with $10m per annum in population health and health systems research. However, in 2004 the NHMRC established Health Services Research Program Grants, not anything near Centre funding, but a means to support a longer-term research program around a broad topic. But these were discontinued after three rounds of applications. In 2008, the NHMRC introduced partnership project grants and capacity building grants in public health and health services research (now discontinued). Partnership projects have continued so far, but with a strong emphasis on service delivery. "NHMRC Partnership Projects should focus on the design and uptake, at the population or community level, of interventions which are known to be effective at the individual level." Nothing that deals with financing, incentives, measuring system performance. The idea of independent Centres does seem to have been lost, with the original Wills-Grant recommendation having been transformed into Partnership Centres. These were to be introduced in 2008, but have been withdrawn and subject to further consultation several times. However, the current information available states there will be a further announcement late in 2011. In New Zealand, little attention has been paid to health services research funding and policy; a separate health and disability services management portfolio existed for a while with the HRC, with limited funding available, but even this no longer exists and the emphasis now appears to be moving towards more clinical research. As the role of indigenous providers also grows in New Zealand, new research funding is also needed to better understand their roles and effectiveness.

New Zealand has already been through major health system reforms and re-organisations over the past twenty-five years and significant reforms are continuing particularly in primary health care. Australia is just now embarking on an ambitious reorganisation of its health service delivery. How can either country assure good stewardship of its investment in its health systems, how can it develop evidence-based policy, and how can it learn and correct policy settings without a much greater investment in learning about health systems? As the WHO has already urged, 'now is the time'.
