Addendum to the 2010 Annual Report: A Brief History of the CHSD

In 1993 the Centre for Health Service Development was established within the Department of Public Health and Nutrition, Faculty of Health and Behavioural Sciences, University of Wollongong (UoW). It is a research centre that investigates how the health system works; it undertakes evaluation projects, designs tools for service development and constructs programs for routine outcome measurement.

The overall aim of CHSD is to make the health system work better. We borrowed our motto 'Combining Realism with Rigour' from a paper in Australian Health Review (1990; 13(2): 144–50, http://www.ncbi.nlm.nih.gov/pubmed/10109120), called *Evaluations of health promotion: combining realism with rigour*. The paper offered guidelines for planners and administrators, who "should be realistic about the limitations of program evaluations and avoid the traps of either attempting to adhere to inappropriately high standards of scientific rigour or of abandoning any attempts at evaluation."

CHSD begun with a strong bias towards applied research, and had a large project to manage – the sub-acute and non-acute casemix classification study (SNAP) – that was run over 104 participating sites and collected 30,604 episodes, with 14,742 staff keeping a daily log of time to give a profile of each episode. Since the SNAP study, CHSD has kept a core of expertise in a contingent of casemix experts producing educational materials, simulations and models, and tools for measuring the patient characteristics that mainly drive the cost of providing their care.

Because of the way it was designed with useability in the field as well as research in mind, a number of tools for outcome measurement were grown out of the 1994–1996 SNAP study. The 'AN-SNAP system' reflects the goal of management, rather than the patient's diagnosis, as the main organising principle, so a change in functional status or improvement in quality of life needs to be captured, not just their principle diagnosis. It was designed to complement the existing AN-DRG classification with four case types of subacute care, for both overnight and ambulatory care, and one case type of non-acute care:

- palliative care
- rehabilitation
- maintenance care.
- psychogeriatric care
- geriatric evaluation and management

This broad classification of types of care beyond those provided in acute hospital settings guided a longer-term research and development pathway. The relationships developed to carry out such a complex study also formed the basis for the Centre's alliances that make possible the long-term and sustainable changes in the health system. It also involved building practical tools for collecting data and systems for managing information that have proved useful in the field. This marked the beginning of the Centre's strategy for health service development that aimed to be sustained beyond the immediate time period of any particular project, program or research study. Rather than a 'grand theory' it relied on a number of coherent research 'themes' to guide work programs that were planned and developed for the longer term. At the same time CHSD was also refining and investigating new areas of research by undertaking evaluations, organisational and literature reviews and population-based health assessments, interventions and planning projects.

Projects Guided by Research Themes

While establishing its more long-term sustainable programs of work, CHSD was also continuing its roles as a self-funded health services R&D centre. CHSD completed 335 R&D projects over a 15-year period between 1995 and 2010. Figure 1 shows how the thematic content of the Centre's projects looks over time. However, the figure does not show the relative size of the projects under each theme or the specific research areas where large projects like evaluating national trials or complex interventions may be undertaken over a number of years.

Figure 1: CHSD Projects by Research Theme 1995–2010
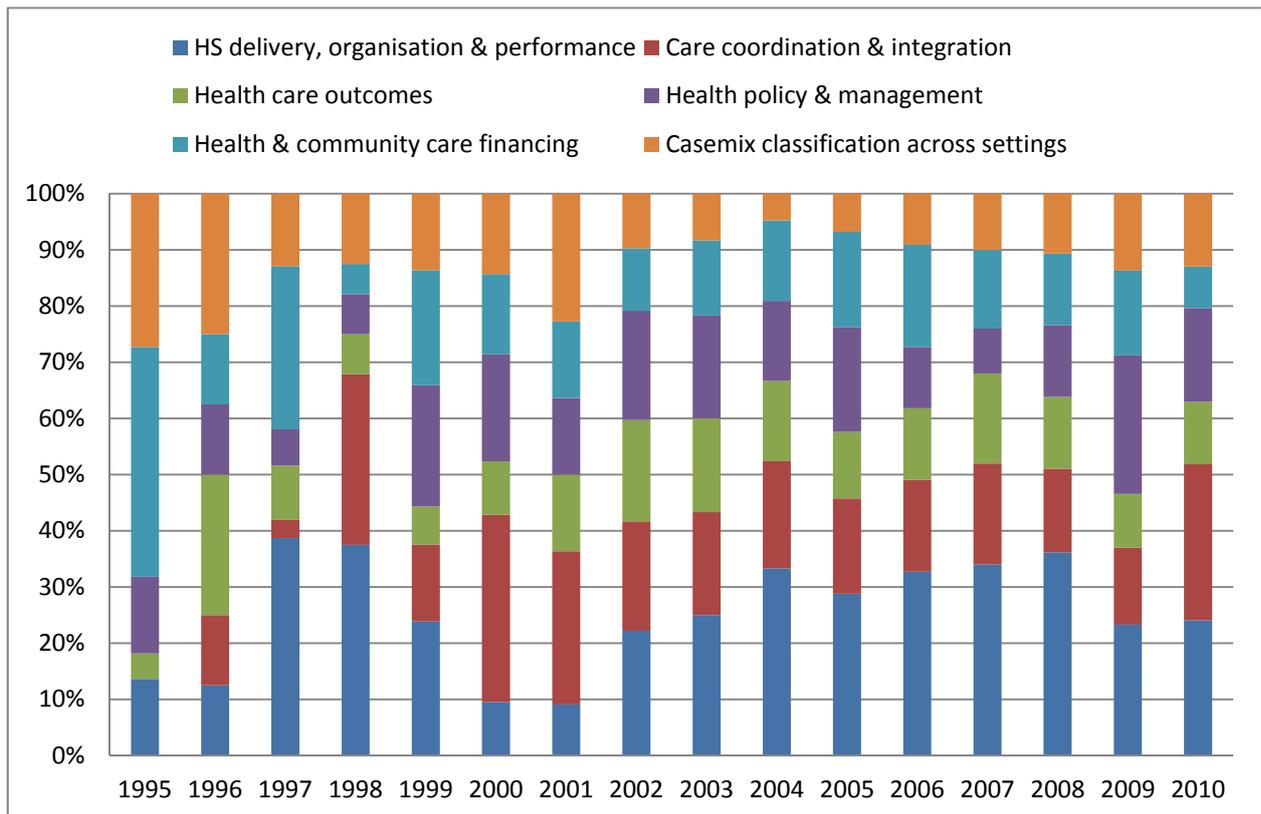
There were 100 evaluation projects completed in that time across a range of settings and of different time scales from short organisational and methodological reviews, to three-year national and state program evaluations. There were also projects on reviews of evidence and current practice in specific service areas like mental health, emergency and ambulance services, intake assessment in community care, carer interventions, models of care in chronic diseases and aged care. The result was a mix of big and small, international, national, state and local projects that represents an accumulated body of useful knowledge, only some of which can easily get published in mainstream or specialist journals or quickly translated into changes in the system.

CHSD has consolidated the 'working capital' accumulated through projects by a research agenda guiding its commissioned work. The research themes give a framework to shape the public profile of the Centre for potential commissioners of research projects:

- Casemix classification development
- Health and community care financing
- Health policy and management
- Health care outcomes
- Care coordination and integration
- Health service delivery, organisation and performance.

This longer-term consistency created by the themes helps the Centre to manage its workloads. Short-term trends in the availability of projects relevant to the Centre's expertise can influence workloads and the development of the themes have been useful in both guiding the choice of the research that is tendered for and in explaining the expertise we can offer to commissioners of research when making bids for projects.

Longer term projects are preferable in terms of planning the Centre's workload and they can offer opportunities to broaden the experience of staff members by bringing them in for assisting in particular tasks like field consultations or for undertaking targeted literature reviews or data analyses. Total R&D income has not been a straightforward progression but has also been influenced by the CHSD's own strategic decision-making at crucial points. The decision to grow the Centre from 2002 was taken because it was clear that competition for health services research funds would come from large consulting firms as well as other universities, and it was also a way to manage the risks of internal competition in the University of Wollongong environment.

Figure 2: CHSD R&D Income 1995-2010
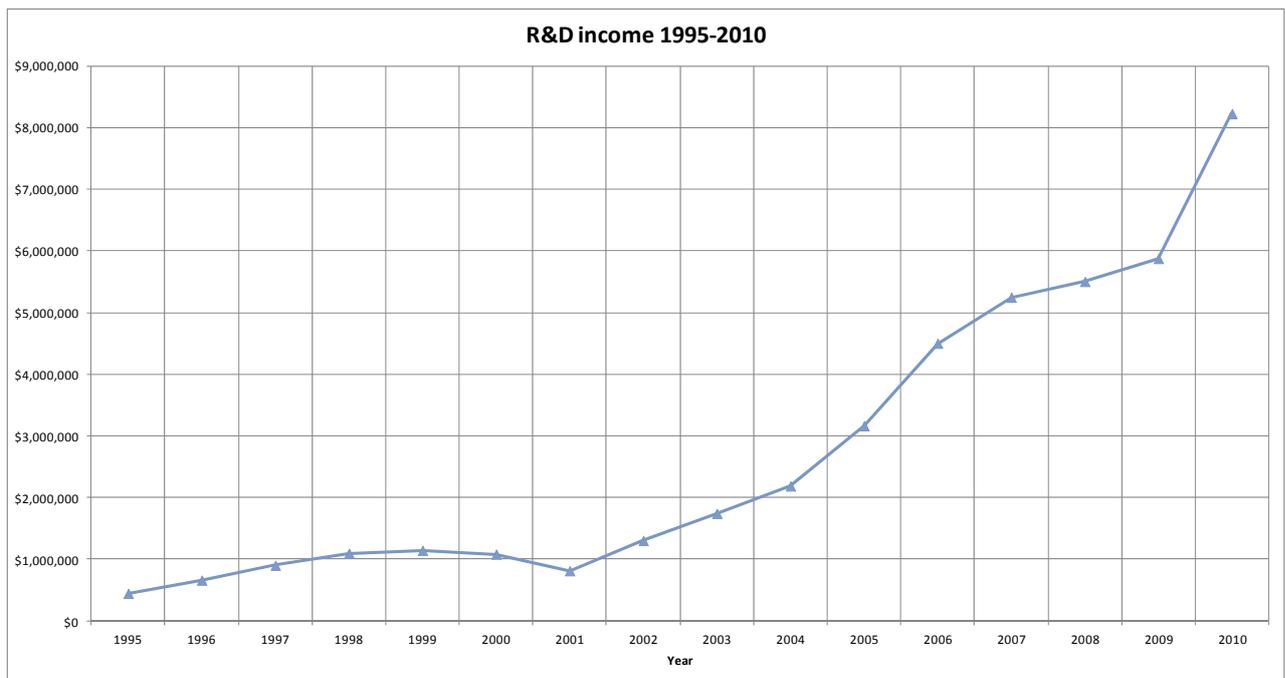
Total R&D income reflects the number of individual projects, but also the growth of the Centre's programs. Figure 2 shows that total income increased significantly in 2010 at a point where a major casemix program began. The development of long term programs of work has become a significant strategy that has been built on the experience of a large number of related projects. The ability to contract for major pieces of work in support of health reform reflects the depth of the Centre's accumulated technical expertise that it has built up through the research it has undertaken, guided by the research themes.

The Purposeful Development of Programs

In July 1997, the *Australian Health Outcomes Collaboration* (AHOC) transferred to CHSD from the Australian Institute of Health and Welfare. AHOC was the first program-based sub-centre developed to consolidate a research and development theme, with its focus on using evidence from research papers, conferences and the analysis of tools for outcome measurement, and carrying out its own evaluation contracts.

Building on the alliances from the SNAP study and with clinical experts interested in the development of a R&D agenda in outcome measurement; in July 2002 the *Australasian Rehabilitation Outcomes Centre* (AROC) was established in a joint venture with the Australasian College of Rehabilitation Physicians as another sub-centre of the CHSD. There are approximately 180 Australian inpatient rehabilitation units in Australia and 25 in New Zealand and 184 units submitted data in 2010. AROC members submitted more than 64,000 episodes in 2010 and more than 500,000 episodes of data have been submitted since 2002. AROC has developed five roles:

- A national 'data bureau' that receives and manages data on the performance of rehabilitation services in Australia.
- The national 'benchmarking centre' for medical rehabilitation.
- The national certification centre for the Functional Independence Measure (FIMTM) instruments (designed to measure functional needs and outcomes).
- An education and training centre for the FIM_{TM} and other rehabilitation outcome measures.
- A research and development centre that develops research proposals and collaborates in international research and service development agendas.

While rehabilitation is a good example of secondary prevention, in restoring functional abilities, the primary prevention end of the continuum of population need is also important for the longer term. In January 2005 the *Australasian Occupational Science Centre* (AOSC) was established to promote an occupational perspective of health, which focuses on what makes and keeps people well. The Centre is based the Shoalhaven region and works in the field of Occupational Science, which is an inter-disciplinary field concerned with the study of human occupation in relation to health in daily living, including the social policies, culture and geography that are part of the social determinants of health.

At the other end of that same continuum of health resources is end of life care, where thinking about health outcomes takes on a different dimension. Also growing out the original SNAP study, in July 2005 the *Palliative Care Outcomes Collaboration* (PCOC) was established as a national voluntary program based in four universities, utilising standardised validated clinical assessment tools to benchmark and measure outcomes in palliative care. Participation in PCOC enables palliative care service providers to improve their practice and meet the *Standards for Providing Quality Palliative Care for all Australians*. By the end of 2010, 108 palliative care services were collecting PCOC data and a further 28 services had agreed to join PCOC. All other specialist palliative care services across Australia (approximately 180) are at various stages of follow up, with most expected to join.

In February 2009, another opportunity arose to develop a work program around standardising clinical information, taking advantage of the availability of key experts, to support e-health initiatives and assist the health information industry with broader classification and information management issues. The *Australian Centre for Clinical Terminology and Information* (ACCTI) was established to build and maintain a work program in this highly technical area in relation to the Australian Government's policy commitment to the development of the Personally Controlled Electronic Health Record (PCEHR), a key element of the emerging health reform agenda.

The aim of ACCTI is develop and tailor purpose-built clinical terminologies, specifically using SNOMED CT, the endorsed national standard clinical terminology. SNOMED CT is a tool that is essential for developing a common terminology to allow the linkages that are required for electronic health records and the PCEHR in particular. The aim of this work program is similar to AHOC, AROC and PCOC in seeking to enhance the quality and reliability of research and routine data collections which rely on consistent, current and reliable clinical documentation.

The up-front investments made in establishing ACCTI through 2009 paid off in July 2010 when the *National Casemix and Classification Centre* (NCCC) was established. The NCCC was formed following the successful bid by CHSD and ACCTI to develop the Australian Refined Diagnosis Related Group (AR-DRG) Classification System. The CHSD/ACCTI bid was successful in winning the contract let by the Dept of Health and Ageing, beginning in April 2010 and operating through to the implementation phase in July 2013. The contract is to develop the '*AR-DRG System*' that consists of the Australian Modification of the International Statistical Classification of Diseases and Related Health Problems, the Australian Classification of Health Interventions, and the Australian Coding Standards. With the NCCC's highly technical work program set out for a tightly-defined period, the experience of CHSD's statisticians is crucial for managing the complex data sets and understanding the inter-relationships involved.

The *Centre for Applied Statistics in Health* (CASIH) was established at the end of 2010. The creation of CASiH recognised the key role played by the CHSD statisticians in maintaining the quality of the products in the various other Centre programs as well as in the Centre's many shorter-term research and evaluation projects. CASiH also has the capacity for consulting work and joint projects with other parts of the University, as members of CASiH have good links to the Centre for Statistical and Survey Methodology and expertise in all areas of applied statistics, including classification development, time series, statistical modelling, regression analysis in its many guises, survey design and analysis and experimental design. Consolidating and supporting statistical expertise across projects and programs cuts both ways; the statisticians can work in new and interesting areas and develop their own career paths and interests; and using their statistical expertise in managing the NCCC, AROC and PCOC data sets, and in working within evaluation and review projects, means the quality of the quantitative side of CHSD's work remains consistently high.

By the end of 2010, after more than 15 years of purposeful and strategic development, a cluster of research centres with their own particular areas of expertise had been created within the umbrella of the Centre for Health Service Development:

- Australian Health Outcomes Collaboration (AHOC 1997)
- Australasian Rehabilitation Outcomes Centre (AROC 2002)
- Australasian Occupational Science Centre (AOSC 2005)
- Palliative Care Outcomes Collaboration (PCOC 2005)
- Australian Centre for Clinical Terminology and Information (ACCTI 2009)
- National Casemix and Classification Centre (NCCC 2010)
- Centre for Applied Statistics in Health (CASiH 2010)

The purposeful development of this set of programs was guided by a practical theory; that more standardised information collected in the initial contact and as part of a continuous client record can be used for the purposes of measuring the outcomes of services or interventions. The development pathway for the Centre's programs was also in part opportunistic in the sense of making good use of available expertise and the opportunities arising from current and evolving themes in health and community care policy.

Building the Centre's R&D Programs for the Long Term

Building programs and the expansion of staff numbers and funding sources are not ends in themselves. Their purpose is to provide a basis for durable changes in complex systems and ultimately to improve the prospects of better health outcomes in the population, whether it is through national or state-level programs or planning and evaluating more localised initiatives.

CHSD's pragmatic 'realism with rigour' approach has affiliations with health promotion evaluation as it was formulated in the 1990s and with a rapidly evolving body of more contemporary work on evaluating complex interventions and *population health intervention research*. The CHSD is based on the consistent working hypothesis that more sustainable impacts on the health system will be achieved by promoting a program focus and in particular by a focus on the systematic measurement of outcomes.

Unpacking the practical theory behind our work suggests that health service research and evaluation will have more sustainable impacts by promoting more *standardised* assessment systems, capable of being used *routinely* in clinical and community support settings. Research studies and evaluation projects help refine the tools for systematic outcome measurement. Building a *program* structure within the Centre was seen as an important long term strategy to manage the complex politics of standardisation and to guide the redesign of clinical systems, all within a health system context that is undergoing continual change, not always in a strategic or carefully planned way.

The point of building programs is to secure this greater continuity over time in more specialised service areas, to build the 'D' in R&D' as well as to provide a basis for consolidating the lessons of more time-limited or project-driven research work. The

Centre's programs have emerged logically from its themes and draw on the existing body of casemix and evaluation research as well by the programs undertaking new research agendas of their own. The growth of programs within CHSD has been a logical progression from the research themes; casemix and financing, informing policy and management, with a clear focus kept on understanding outcomes, aiming to improve health service delivery, organisation and performance. The 'bigger picture' of CHSD and its various Centres represents a set of related strategies, aimed at improving how the health system functions by building effective partnerships. The programs and research projects are planned interventions in the various levels the health system towards that end.

Building a program structure inside the Centre was also seen as a way to address the practical problem of achieving a critical level of infrastructure. As well as support from the University of Wollongong, from 1998 CHSD had benefited from an infrastructure grant from NSW Health, but there were risks involved in too heavy a reliance on single funding sources, so with advice from the CHSD Board, the management team set out to grow the Centre over a planned period of expansion. That meant the next logical steps were more and bigger projects and a diversification of funding sources.

Figure 3 shows CHSD R&D income between 2002–2008 over the planned rapid growth period, broken down by infrastructure, projects and programs. It shows the accelerated rate of growth and how by 2008 program income had overtaken projects and our dedicated infrastructure funding was a relatively smaller proportion of the total.

Figure 3: Planned rapid growth period: Components of CHSD R&D income 2002–2008
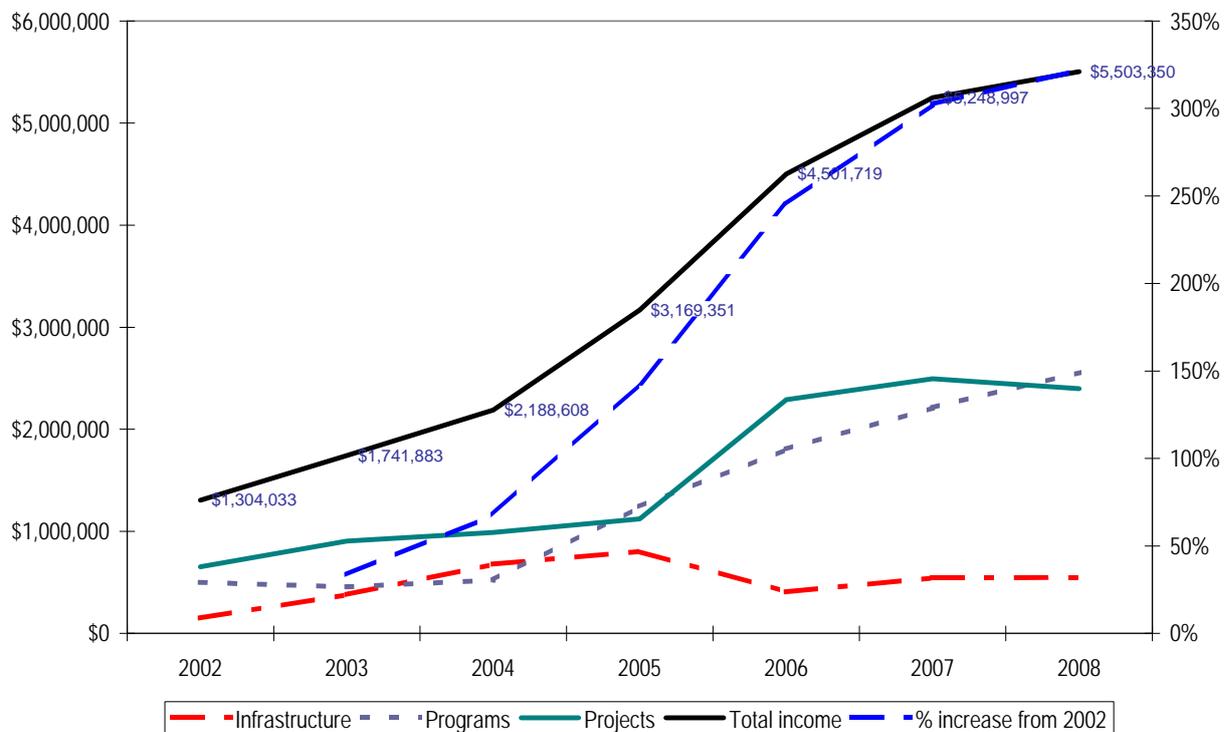
The shift from a reliance on projects to the development of programs was consistent with the Centre's themes of coordination, integration and measuring outcomes and the planned rapid growth period was also a strategy to manage the risks of a more competitive University and health services research evaluation and commissioned research environment. It was a way of ensuring that the Centre could be large enough to be competitive, plus offer career pathways, which project-based employment does not provide, so as to attract experienced researchers and planners as well as capable new staff.

The bigger picture of which the programs make up important parts is the improvement of the health of the population at national, state and local levels. Better services help, but don't necessarily ensure other basic needs are met or the causes of illness and disability are addressed, or that help is provided where it is needed most. A lot of the Centre's research projects contribute to planning a better mix of services, including the development of models to fairly allocate resources and promote care coordination and integration at local level.

Accommodating our Expansion

From its early days with just five full-time staff members up to 1996, CHSD was located in a small cottage adjacent to the University's main campus.   From 1996 to 2000 with more projects to manage and more staff members to accommodate, it relocated to the main campus (Building 38), sharing the space with a Nursing teaching laboratory. After the University's Research Policy Office moved out of the old Principal's Residence (Building 29) at the Western end of the campus, in Easter 2000 we relocated to a space that gave us some capacity to expand as the number of staff members increased.

From 2000 to 2010 CHSD operated moderately comfortably in Building 29 and with the help of Buildings and Grounds we were able to fit into an increasing number of demountables as our programs grew and as the number of projects and staff steadily increased. With the advent of organisational and management changes in the Faculty of Health and Behavioural Sciences, and in order to provide the best prospects for growth, in January 2002 CHSD moved within University to be managed within the structure of the Faculty of Commerce. Then in September 2005 CHSD left the Faculty of Commerce along with the Graduate School of Business (now Sydney Business School) when it became a separate graduate faculty and it made good organisational sense for CHSD to move with it as one of its research arms.

So by 2010 the 15-year R&D strategy within CHSD had resulted in a strong organisational structure that included seven programs (somewhat confusingly also called 'Centres' within the Centre), each with dedicated core staff members and a range of support staff, operating in a number of settings including Sydney, Brisbane, Perth and Adelaide as well as Wollongong and the Shoalhaven.

Building 29 was well past its 'use by date' by the time we moved in and with five demountables and only two toilets (!) it was clearer than ever that a more purpose-built environment was necessary. After lengthy consideration of the range of alternatives, by the

end of 2010 CHSD decided that a move to the University's new Innovation Campus would be the best way to consolidate our Wollongong-based activities. The new buildings going up on site in Fairy Meadow included the Sydney Business School and an adjacent building provided an opportunity to design our own space. This meant that the design could suit the multi-disciplinary way we were already working as well as be able to accommodate future developments; and so the move to new premises was planned to take place in early 2011.

CHSD built up a critical mass of expertise and the specialised skills necessary to deal with the complexity of the health services and social research issues faced by government, providers, patients and carers. Our expanded size also meant we would be in a better position to compete for and undertake larger and longer-term projects. That also meant we could offer more job security for staff and the prospect of more interesting career pathways, and it also had the advantage of providing more continuity over time and between projects and programs so that our areas of expertise could be consolidated.

Understanding our own Impacts and Outcomes

The CHSD has itself been a complex intervention in the health system, based on the consistent working hypothesis that more sustainable impacts on that system will be achieved by promoting a program focus in parallel with commissioned research, and in particular by a focus on the systematic measurement of outcomes.

Our approach has useful implications for research at local, state and national levels, where policies and new models are designed to be implemented in the short term on the assumption that they will be able to create more lasting changes to routine practice. The sustainability issue has been an important focus for the Centre in its evaluation projects, leading us to promote continuity between successive research projects and underlining the importance of maintaining relationships over time with policy-makers and the specialist cohorts of managers and clinicians.

Making an impact on complex systems means intervening to change how questions are asked and answered, not just offering learned commentary. It requires specialist as well as generalist research skills in evaluation, statistical analysis, personalised assessment (mainly of functional abilities). It involves active engagement in building information management tools, and funding and resource allocation models. Broadly conceived, this is an R&D agenda in understanding the health and support needs of populations and what drives the costs of providing their services, and then setting up the means to do something about it.

The resulting number of programs and projects has meant we have kept very busy, but we know from the content of the work we do that the amount of activity *per se* is not so interesting. It is only a part of the 'bigger picture' and begs the question of 'so what?' The more important indicators are those to do with impacts and outcomes.

We think there are a number of measurable ways of looking at our own impacts and outcomes as applied researchers, evaluators and system designers. We have contributed to

the re-design of clinical services by evaluating 'best practice' models, trials and demonstrations through time-limited and one-off studies. We have built assessment tools and clinical information management systems and achieved progress in standardising outcome measurement systems, and built up ongoing organisations to collect useful clinical information in the course of routine practice.

So we can look for evidence of building our capacity to do good quality research and of making our contributions sustainable within the Centre and within the health and community care sectors. We can also see evidence of our efforts in supporting local system developments through research of practical significance to the health of the population of the Illawarra region.

Evidence of Making an Impact

It is a truism that Australian health and community care systems are inherently complex; local, state, federal and national programs, a mix of public and private providers, often competing comprehensive and selective primary health care strategies, the resulting integration conundrums, the recurring crises in acute care institutions, quality and workforce issues in community and residential care. A 'strife of interests masquerading as a contest of principles' remains an apt characterisation of the current era of health reform, much as it was in 1984 when Sid Sax, Australia's pioneer of population health planning and health services research, first borrowed the phrase as the title of his book on the history of health policy. It came from a Thesaurus of Quotations as a definition of 'politics', echoing Rudolf Virchow's pithy statement from 1848 in Germany, that "medicine is a social science, and politics is nothing more than medicine in larger scale".

Within this context of CHSD has benefited from a set of consistent working hypotheses that more sustainable impacts on the health system will be achieved by a strong bias towards 'evidence- based' and 'data-driven' solutions. We have also benefited from promoting a longer-term program focus within the Centre and in particular by programs for the systematic measurement of the health outcomes of service users. We can show we have contributed to measurable improvements in standardisation and routine clinical monitoring systems. But some impacts and outcomes can take years to become evident.

This longer-term impact of building routinely used measurement systems and evaluation research reflects a similar analysis to the 2008 *WHO Report of the Commission on the Social Determinants of Health* (the Michael Marmot Report). This analysis suggests that services are useful for improving health but there is more to addressing the causes of health inequalities than simply providing better access to good quality services. So CHSD's approach has been to also be conscious of the existing dynamics in health systems that mean that some services are more likely to be better resourced than others.

Macro level system processes have therefore become a focus of CHSD's work. In the evaluation literature this is also known as *formative research*. It is useful to be as explicit as possible about the purpose of this level of evaluation because the research process has become *part of the intervention* and may be part of the reason for its effect. So if helping to

build and evaluate a new model of care includes examining its system-level impacts and questions of integration and coordination with social supports as well as other services, then health service research is contributing to population health research and planning for the needs of a geographic area.

Research, Planning and Partnerships

Arising from the 'realism and rigour' promoted by its research themes, CHSD has as a guiding principle to use scientific methods to produce knowledge about policy, programs and clinical interventions that have potential to *change the underlying reasons for the distribution of health risks*. Building strong partnerships is important because one Centre can't expect to achieve much in this direction on its own. So our partnership with rehabilitation clinicians in AROC (through the College of Rehabilitation Medicine) and with three other universities in palliative care quality improvement (through PCOC), as well as our 'formative' evaluation methods in individual projects, all involve not only a level of technical research ability, but also a capacity to involve service sectors or individual organisations in a shared understanding of what our research means.

The Centre worked on regional systems for GP-level early detection of public health problems, tools for better waiting list management, and a framework for population health in the local Area Health Service. Local evaluations have examined the benefits of a community midwifery model, coordinated care for the frail elderly and integrated case management across the human services. We also worked on state-level systems to improve how resources are allocated through health Resource Distribution Formulae, by advocating 'funding levers' for public health, and devising systems for population group planning for ageing and disability. These are all concerned with not just improving the efficiency of service provision but they are also strategies to promote greater equity of resource allocation in order to improve the local population's access to care and support.

From a planning perspective, efficiency has to be understood in terms of questions of *allocative* and *dynamic* efficiency, not just a concern for *technical* efficiency that is mostly about increasing the throughput of traditional acute care services. Within the various service sectors, the policy aims of addressing the needs of a geographic area as well as personalising service provision implies a systemic capacity for understanding the *full* range of a person's needs, as well as their goals in seeking a particular form of assistance and has to be informed by an analysis of what resources are available across the continuum of care from prevention and early detection, through acute and restorative care to palliation.

The step beyond improving access to a service system is ensuring that the service response can be commensurate with the person's level of need, which implies a consistent way of measuring that need. A body of research, levering off the Illawarra Coordinated Care Trial, the refining of dependency data items in community care, assessment pilots in various jurisdictions, was carried out over more than a decade, using local partnerships and collaborations. The aim of this health research is to inform planning, most usefully at the local level, to support decisions about how resources should be allocated, how priority of

access can be assigned in a fair way and what alternative interventions and substitutions of service and support types can be made in order to address health needs most efficiently.

The Centre's research agenda has included local projects with broader lessons and implications; as microcosms of bigger national challenges and research questions. It has addressed questions where the answers go beyond specific types of services. Why do people turn up in emergency departments? How do different service sectors integrate their efforts in support of those most in need of help? Why can one older person with chronic heart disease and diabetes live independently in the community, but another can't? Why does one person with cancer need oncology, but another need palliative care?

The methods and tools we use to understand these bigger, population-level questions include patient classification schema, data management methods for use in planning systems, evaluation frameworks with 'system-level' indicators and economic evaluation that includes social interventions designed to promote health and reduce inequalities.

The logical extension of addressing these bigger questions in a more localised context highlights the need for a regional collaboration to build a *Population Health Information Platform* for the purposes of integrating the mosaic of data sets, using informatics applications and data linkages, producing profiles of important sub-populations, and then tracking changes in those profiles over time. This enables us to work out if specific interventions have useful outcomes and provide the basis for understanding if there are wider influences on health that can only be understood through creative data linkages.

Building a regional capacity for this type of research will involve long-term strong regional partnerships. What we can show so far is how we are working towards a coordinated 'R&D' approach to key regional priorities, moving outwards to the whole population over time. So progress will be measured in areas like improvements in Aboriginal health and well-being, chronic disease management and in promoting the health of older people across a continuum of levels of need from prevention to the 'front end' or 'gateway' to services, through to end-of-life care.

Impacts on the Service System – SNAP and Beyond

Improving equity of access to services is a valuable longer-term aim, but just as important is the development of systems to improve the equity of health outcomes, and that implies systems capable of measuring the outcomes of interventions. Using casemix classification methods and developing useful tools for understanding what drives the need for care were logical strategies that grew out of the 1994-96 SNAP study. The AN-SNAP classifications and definitions, the SNAPshot software, the non-diagnosis based methods of defining episodes of care and the continual refining of the patient classifications has formed a continuous work program for the Centre. This CHSD research agenda has had a very direct impact as the basis for the routine outcome measurement systems in rehabilitation (AROC) and palliative care (PCOC) that are now well embedded in clinical practice in Australia and having an influence as models for similar developments in international settings.

Our work in palliative care evaluations through a series of national programs has informed publications on evaluation methods and tools (the Palliative Care Evaluation Toolkit), research ethics (A Guide to the Human Research Ethics Committee process) and quality improvement strategies, leading to the formation of PCOC in 2005. The PCOC database as at December 2010 contained data on approximately 76,000 patients with 94,600 episodes of care and 197,600 phases of care. The maintenance data quality and the analysis of symptom scores (e.g. pain and severity) by the phases of care gives the empirical basis for the comparison of quality and outcomes between facilities and services, which are practical tools for service improvement.

In rehabilitation there are national and international networks that use the information management tools and benchmarking reports that have been developed by CHSD since its beginnings in 1994. In Dec 2010 the AROC database contained data describing approx 530,000 inpatient episodes of rehabilitation from Australia and New Zealand, and just over 6,000 ambulatory episodes. In the calendar year 2010 there were just over 76,500 inpatient episodes and 4,000 ambulatory episodes reported. With the statistical expertise available, this data set can be managed ethically, analysed by impairment types and other groupings of patient characteristics, and used for comparisons between facilities with designated rehabilitation programs.

The impact of this long-term strategy was evident in the National Partnership Agreement on Hospital and Health Workforce Reform (2009) where national and State and Territory jurisdictions signed-off a five-year via the Council of Australian Governments. Schedule A of that Agreement (Activity-Based Funding – A13) requires a common casemix classification and costing methodology in Emergency Departments, Sub-acute Care, Outpatients and Community Health and page 12 of the Schedule has this being implemented under Stage 3 from 2012-2013. Schedule C (Sub-acute care – C5, p.24) commenced from 2009 and required "Agreements ... in working with national data collection agencies (such as AROC and PCOC)".

What Drives the Need for Care in the Community?

There is common ground with population health and sub-acute and non-acute patient classification in asking what drives the need for health care and support services in the community? The policy aim of personalising service provision implies a systemic capacity for understanding the full range of a person's needs, as well as their goals in seeking a particular form of assistance. The health and community service system, from the point of initial assessment through to the development and review of care plans and case closure, should then be able to better organise and provide a range of more individualised responses to meeting a person's identified needs.

The Centre's Illawarra Coordinated Care Trial evaluation (1998-2000) generated an assessment system for community care that has had a lasting legacy in subsequent projects on client and carer assessment, priority rating and care planning. Our work in coordinated care and integration also informed the development of the CHSD approach to carer assessments and the Home and Community Care Program (HACC) nine-item Functional

Screening Tool which has been built into the Program's Minimum Data Set and is the basis for a routine system for assigning a priority rating for clients and allocating resources in the NSW Home Care Service, the largest HACC provider in Australia.

The HACC Functional Screen has also formed the core of the routine assessment system for young people with disabilities leaving school (Post School Programs) and the Ongoing Needs Identification (ONI) system for primary and community care. The ONI and its variations has been used in devising an intake module for regional disability services for the NSW Ageing, Disability and Home Care Agency (ONI-IAM) and in the Australian Community Care Needs Assessment (ACCNA) and the Carer Eligibility and Needs Assessment (CENA) tools that were commissioned by the Australian Government in 2007 to form the basis for a standardised 'front-end' to aged and community care. The planned introduction of routine and standardised measurement of functional abilities constituted the first step on a longer development pathway leading to a common system for outcome measurement in community care programs.

We know from our many research projects that it is possible to use that system to both measure individual client need and also to inform program-level and resource allocation decisions. Each new generation of such a system would progressively include more useful variables for classification and outcome measurement purposes, but getting national agreement on a coherent strategy has been difficult and the area of community care outcomes is a good example of how some impacts and outcomes of our work can take years to become evident.

Improving the capacity for outcome measurement in community care is an intervention in a complex system; it needs a technical, data-driven strategy that responds in practical terms to the policy aims. The response starts with better organised assessment information at the intake point where some client characteristics are more useful than others for the purposes of measuring outcomes. More standardised and intelligently designed information collected in the initial and ongoing processes of assessment then forms part of a continuous client record inside client information systems. If the same data elements are collected at different points, then the 'change scores' can be used for the purposes of measuring the outcomes of services or interventions.

A decade and more of projects, demonstrations and trials have helped define what is most useful to collect in community settings. It is the client's functional abilities (the physical and mental abilities that everyone needs to live independently) that predicts who will need community care and/or more active service models like rehabilitation and also how much that care will cost. And the personal and social context of those abilities also needs to be understood. So information on carer status, care network sustainability, social isolation and/or other factors useful for measuring well-being, can be standardised and routinely collected and used to understand the outcomes achieved over time.

One question that still needs to be asked and answered is how best to build a data repository function with a stable longer term work program that can be supported for such a diverse service sector. It is not possible to simply borrow systems from other sectors because community care information has to be organised in its own coherent and logical way.

A 'grand synthesis' of our findings on what drives the need for care would suggest it is possible to build and support a set of systems that can routinely capture a manageable number of key indicators that can be used to plan and deliver individual care and also provide a good picture of how well the service system is doing, not only how many services of different types are provided.

Putting Research into Practice

The production of our research outputs is easy enough to measure, but their distribution and use are more difficult to gauge in reliable ways. Academic publications are an indicator of impact but only in a limited way when the Centre's aims are to influence routine clinical practice and improve quality in real-world systems. Conducting formative and process-oriented evaluations, building prototypes and data management tools, testing and refining outcome measurement systems may not be so attractive for many of the traditional high 'impact factor' specialist journals, but we have begun to analyse our approaches more systematically and target our publishing efforts at some of the high quality evaluation journals.

With that caveat in mind we have managed to write our share of peer-reviewed publications in journals and book chapters – totalling 254 over the period 1995-2010. This is about 20% of our grand total of 1243 written outputs over that period in all publication types including commissioned reports, conference papers, literature reviews and written briefings. Examples of this practice literature are our evaluation frameworks that have been adapted and refined through a range of projects in coordinated care, mental health integration, rural palliative care, hospital avoidance, best practice models in residential aged care, clinical services redesign and asthma management.

Sometimes these reports in the practice literature can be consolidated into a body of useful knowledge in one sector. Our evaluations of the Griffith Area Palliative Care Service, Rural Palliative Care, Caring Communities and Care Planning Programs have informed our Palliative Care Evaluation Toolkit and our Guide to Research Ethics – both of which were turned in useful booklets and web publications for the National Palliative Care Strategy. The large national evaluation project on Evidence Based Practice in Residential Aged Care has likewise produced a significant body of lessons and stronger evidence to guide the planning of useful interventions in the sector.

Other examples of where we have been able to leave useful tools behind or distribute them more widely after a series of studies are the SNAP software in sub-acute and non-acute care and the routine clinical data sets for rehabilitation and palliative care managed by AROC and PCOC. In a similar but less comprehensive way the HACC functional screen has generated a

number of reports and publications but its use is hard to gauge even though it is collected routinely in the Program's Minimum Data Set. It is used in assigning priority for service in NSW Home Care and in assessing the functional capabilities of school leavers with disabilities and forms the basis for the annual training that is carried out for the assessors within this NSW state-wide disability program. The ONI/ACCNA community care assessment systems containing the functional screen are also supported by a number of our own published papers and commissioned reports and their data elements are built into a range of care management systems now routinely used in different jurisdictions.

Our literature reviews for specific projects help to inform how our evaluations are carried out but can also find a useful place in the practice-based literature. Our *Review of Effective Caring* in its full report form is able to be accessed on the Department of Health and Ageing website and our own, and a more 'user-friendly' product was published in the Australian Institute for Family Studies journal, Family Matters. Subsequently the Benevolent Society of NSW commissioned us to turn the work into one of their Research into Practice Briefings and that summary has been incorporated into a commercial publisher's educational resource book entitled Carers: Ageing and Disability, which is part of their *Issues in Society* series.

A good example of CHSD working to assist strategies for health gain is the five years of producing evidence summaries for programs promoting child health in Victoria, now incorporated into the *Victorian Child and Adolescent Monitoring System* (VCAMS) which freely promotes the distribution of the findings. This work was undertaken in support of the Child Wellbeing and Safety Act 2005, after which the Victorian Government endorsed 35 outcomes for Victoria's children which were expected to be of most importance to their present and future lives. VCAMS provides a comprehensive overview of the way in which the service system, the community and the family all interact to determine the wellbeing of children, and provides a sound basis for government planning and intervention. In 2006, CHSD was commissioned by the Victorian Department of Human Services to develop a catalogue of evidence-based strategies for the health and wellbeing of children aged 0-8 years.

The catalogue is distributed through the Department's website a key element in VCAMS, providing practical guidance to policy makers and program developers. The original catalogue was created for the *Best Start* program, which had a particular focus on prevention and early intervention with vulnerable families, including socially disadvantaged families, Aboriginal and Torres Strait Islander (ATSI) families, people from culturally and linguistically diverse (CALD) backgrounds, and families living in rural areas. Subsequently, the Victorian Department of Education and Early Childhood Development commissioned the *Catalogue of Evidence-Based Strategies* with regular updates by CHSD.

In 2010 we revised narrative reviews and, where necessary, new catalogue entries were provided for the 12 indicators originally reviewed in 2008. The task in updating the catalogue was to check whether any relevant, new evidence had emerged in the academic or grey literature for each of the indicators being reviewed. This meant adding a new

strategies and catalogue entries for an indicator, instead of, or in addition to existing strategies. The indicators updated in this work in 2010 included seven adolescent indicators linked to prevention of school disengagement and promotion of success for young people at risk of leaving school early, and in addition, updates were provided for four child and adolescent indicators:

- Hospitalisation rate for asthma
- Low birth weight
- Proportion of children with emotional or behavioural difficulties
- Proportion of families who are food insecure

While our research output plays only a small part in these complex preventive interventions, we see the distribution of the products as good examples of making an impact on the wider system. But to be realistic in terms of putting our research into practice by measuring our own outcomes, we are still at an early stage of becoming more systematic and are little more than anecdotal in how we understand the effects of what we do. Measuring our own impacts is a continuous undertaking and as well as keeping up with how our work is disseminated, we need to reconcile our understanding with academic and international perspectives through peer reviewed publications as well as national and state and territory views of what are useful outcomes, in terms of policy and program refinements and organisational changes promoting health service development.

Where to From Here?

This brief history serves several purposes. It is a way to take stock and learn from past experience. When we look back over our series of CHSD Annual Reports we can see a lot of activity, much of it arguably useful, represented by roughly $25 million worth of earned income, 335 project reports publications and presentations, successful completion of 100 evaluations big and small and a range of other outputs,

Looking back lets us see how busy we have been, but is more useful to examine strategies and set directions which can take us beyond expecting to do 'more of the same'. When we look forward with expectations of being better supported by our infrastructure and with improved prospects for career paths as well succession planning, then other possibilities open up. We can expect to do both more and different local and international work as well as building on our casemix development, benchmarking and outcome measurement, assessment and integration themes.

The direction of health reform implies that hospital service planning will need to translate into Local Hospital Network (LHN) Service Agreements to help determine the service mix, volumes, pricing, and risk management that has to be part of their planning. But finding ways to promote growth funding for new activity that is not hospital-based will be the hard and interesting work ahead.

Ways of carving up State funding between LHNs will still be required and integrated capital and service planning will be critical. So needs-based funding models (Resource Distribution

Formulae) will be required and help to do integrated capital and service planning will be critical, as will smart purchasing of hospital activity and knowing what to buy or deliver, not just what to pay, will be an important part of planning in the obvious next steps in health reform.

Getting the interfaces right between State and new Commonwealth-funded entities, between LHD, Medicare Local, Aged Care, hospital discharge and chronic disease management programs will also be important for local planning. So will getting the interfaces right between state-funded services like housing, education, police etc, which are also going to be important for better allocative and dynamic efficiency, which also implies a strategy to shift of the focus away from hospitals.

The potential for strengthening local and regional planning, with implications for wider lessons to be drawn in implementing health reforms, is likely to increase in the near future. This direction builds on our health services focus and our approach to working in strong partnerships with those delivering health care. We see it as a way to use scientific methods to produce knowledge about policies, programs and strategies that have the potential to improve the way services and preventive strategies can work together better.

We also see this development as a longer term impact on evaluation research of the analysis that went into the 2008 WHO Report of the Commission on the Social Determinants of Health (the Michael Marmot Report), aimed at offsetting the emphasis in public and population health research of increasingly fine analytic descriptions of increasingly sick populations. This type of work, which we are very familiar with, is driven mainly by concerns to reduce acute care costs rather than the longer term aim of reducing demand for services and improving the health status of people who may not yet be service users.

The potential for a Centre strategy in strengthening planning and building partnerships is in promoting new research in areas where more investment is going to be needed as health reform is implemented. Local primary care and hospital-based organisations will need to understand the type of interventions that will reduce health inequities in the long term, not just alleviate some distress, change health service access or change the eating patterns of people suffering from inequity today. This implies different types of interventions from those familiar to health services, i.e., interventions that have grown out of inter-sectoral strategies like between education and health for nutrition issues, and integration strategies and information management tools to share across other community-based sectors.

With the advent of the Australian Government's Medicare Locals, the University's regional focus now coincides with the same geographic area boundaries of the Local Health District (LHD) and we all share a broad and as yet under-developed role in promoting, protecting and maintaining a healthy community. This suggests there may be potential for creating new opportunities for CHSD in building on and using our staff members' practical experiences in population-level planning as well as our accumulated expertise in evaluating complex health service and health system-level interventions.

A strategic shift in this direction is a logical extension of what CHSD does and may also require a degree of 're-framing' of the Centre's profile to include partnerships and planning issues as another one of our programs, working towards a coordinated local R&D approach. This would have national significance given the shape and expected directions of the health reforms and would be relevant at the same time to key regional priorities, where we would promote the strategy of starting with areas of inequity and high need, and moving outwards to the whole population over time: Aboriginal health and well-being, chronic disease management; and older people across a continuum of levels of need.

If we were to create a new program in the longer term, there would be significant infrastructure costs to consider (well beyond our own internal capacities to fund), including the need for a regional collaboration to build a *Population Health Information Platform*. The program would ideally be supported by work on improving data linkages, integrating the mosaic of data sets, producing profiles of important sub-populations and an ongoing capacity in tracking changes in those profiles over time.

The long term aim of developing a program of work in this area would be to develop a more consolidated set of tools to support a regional research focus with national significance, what we called (in our 2008 NSW Community Health Review, borrowing a description from Julian Tudor Hart) a 'periphery of excellence'. It would not just be about research for its own sake but would take our regional role to a new level where we build tools to help researchers within and beyond CHSD work out if new service models, routine health service activities and population health interventions do actually have useful outcomes for the populations they are meant to serve.

Selected References

Benevolent Society of NSW (2010) Research to Practice Briefing 5: Working with and supporting informal carers http://www.bensoc.org.au/uploads/documents/research-to-practice-briefing5-informal-carers.pdf

Commission on Social Determinants of Heath (2008) Closing the gap in a generation: Health equity through action on the social determinants of health. World Health Organisation Press, Geneva.

Eagar K (1998) The Establishment of a Division of Population Health within the Illawarra Health Area Service. Centre for Health Service Development, University of Wollongong.

Eagar K, Cranny C and Fildes D (2004) Evaluation and palliative care: a guide to the evaluation of palliative care services and programs. Centre for Health Service Development, University of Wollongong. ISBN 0 642 82472 X www.palliativecare.gov.au

Eagar K, Watters P, Currow DC, Aoun SM and Yates P (2010) The Australian Palliative Care Outcomes Collaboration (PCOC) – measuring the quality and outcomes of palliative care on a routine basis. Australian Health Review, 34: 186–192.

Hawe P, Degeling D, Hall J. Evaluating Health Promotion. A Health Workers' Guide. Sydney: Maclennan and Petty, 1990.

Hawe P, King L, Noort M, Gifford S and Lloyd B (1998) Working invisibly: health workers talk about capacity-building in health promotion. Health Promotion International, 13, 285–295.

Hawe P and Potvin L (2009) What is population health intervention research? Canadian Journal of Public Health, 100, 1: 8–14.

Leutz W (2005) Reflections on Integrating Medical and Social Care: Five Laws Revisited. Journal of Integrated Care, 13, 5: 3–12. October 2005.

McCaffrey N, Karnon J, Currow D and Eckermann S (2010) The Old Dog and the Poor Relation: Informing funding decisions in palliative care with cost-consequence analysis in the cost-disutility plane. Palliative Medicine, 2010; 24(4): S207.

Masso M, Dodds S, Fildes D, Yeatman H and Eagar K (2004) Ethical research in palliative care: a guide through the Human Research Ethics Committee process. Centre for Health Service Development, University of Wollongong ISBN 0 642 82473 8 www.palliativecare.gov.au

Owen N and Magnus P (1990) Evaluations of health promotion: combining realism with rigour. <u>Australian Health Review</u>, 13(2): 144-50, <u>http://www.ncbi.nlm.nih.gov/pubmed/10109120</u>

Pluye P, Potvin L and Denis J (2004) Making public health programs last: conceptualizing sustainability. <u>Evaluation and Program Planning</u>, 27: 121-133.

Sax S (1984) <u>A Strife of Interests. Politics and policies in Australian health services</u>. George Allen and Unwin, Sydney.

Stevermuer TL, Owen A, Williams K and Masso M (2007) Priority rating for community care. <u>Australian Health Review</u>. 31 (4): 592-602.

Tudor-Hart J and Smith G (1997) Response rates in south Wales 1950-96: changing requirements for mass participation in human research. Chapter 1 in Maynard, A and Chalmers, I (Eds) <u>Non-random Reflections on Health Services Research: On the 25th anniversary of Archie Cochrane's Effectiveness and Efficiency</u>. BMJ Publishing Group, London

Turner-Stokes L, Khan F, Stevermuer T, Simmonds F and Eagar K. Comparison of rehabilitation outcomes for long term neurological conditions: A cohort analysis of the Australian Rehabilitation Outcomes Centre Dataset. <u>Journal of Neurology, Neurosurgery and Psychiatry</u>, 2011 (In press).

Victorian Child and Adolescent Monitoring System (VCAMS) – Catalogue of Evidence-based Strategies.
<u>http://www.eduweb.vic.gov.au/edulibrary/public/earlychildhood/healthwellbeing/catalogue ofevidence-technicalreport.pdf</u>