

Submission to the National Health and Hospitals Reform Commission from the Menzies Centre for Health Policy

MENZIES CENTRE FOR HEALTH POLICY

The Menzies Centre for Health Policy (MCHP) is a joint venture between the Australian National University and the University of Sydney, established in 2006 through a competitive grant from the Sir Robert Menzies Memorial Foundation.

The MCHP seeks to explore various aspects of the Australian health care system, the better to understand prevailing health policy and to offer suggestions, based on observation and research, to the policy debate which may help the health service to achieve optimal use of resources set aside for health gain. It organises its inquiry and observation by major domains: the quest for equity; optimal health service governance; the future and; the health workforce.

We have chosen to study the health policies that guide the allocation of resources to the care of patients with serious and continuing illnesses (SCIs), not only because of the indisputable need for better care for people with these problems and the growing demand that these conditions place upon the health system, but also because the complexity of care for these people raises serious policy questions in the principal domains mentioned above – equity, workforce, the future and governance.

THE SURGE OF SERIOUS AND CONTINUING ILLNESSES

The rising prevalence of serious and continuing illnesses in the Australian community has provoked interest and concern from many quarters. Diseases such as Type 2 Diabetes, which is strongly related to obesity, have achieved epidemic proportions in recent years in this country and the demand from the affected community for strong action is undeniable. Not only are serious questions raised by the public about the way the health system responds (or fails to respond) to SCIs, but also there is great concern about the lack of effective prevention. Those who know about the ghastliness of Indigenous illness understand that SCIs are the dominant expression of the fractured and ruined social conditions in which many Indigenous people live and die, and that, whatever else, access to services for the care of these problems is urgently needed if the 17 year gap in life expectancy is to be closed.

Health service executives are increasingly aware of the allocative inefficiencies, administrative shambles, IT luddism (pieces of paper float around the patient moving between home and hospital in desperately inadequate ways, failing to communicate), that characterise contemporary care of people with SCIs. We are, in the main, blissfully unaware of how hard it is for people with these disorders to get about, to come to hospital or doctors' rooms, and how little reserve they have to cope with delayed or cancelled appointments or with the classical non-arrangements made by many hospitals for patient parking. Many managers in the system give the impression that they perceive the

problems of SCIs as simply a burden on their hospitals, rather than a major group of patients needing care. Patient focus is foregone: what counts is to keep these people out of hospital – the GOMERS (Get Out of My Emergency Room) of Samuel Shem’s 1978 entertaining but devastating account of life and death in the U.S. emergency room in his book *House of God*. Care for patients with SCIs in Australia at present is neither homely nor godly.

THE SERIOUS AND CONTINUING ILLNESS POLICY AND PRACTICE STUDY (SCIPPS)

The Menzies Centre for Health Policy has been awarded a 5 year NHMRC Health Services Research grant that is being conducted at two sites – Sydney West Area Health Service and the Australian Capital Territory. The Serious and Continuing Illness Policy and Practice Study (SCIPPS) aims to find policy and health systems solutions for people with SCIs and those who care for them. SCIPPS is a study of three prototype conditions - cardiovascular disease, complicated diabetes, and chronic obstructive pulmonary disease - in people aged 45-85.

One distinctive feature of the study is that it starts from the patient with the problem. We have completed in depth interviews with patients with these problems and their carers, paying special attention to patients for whom English is an unfamiliar language and Indigenous Australians living in urban settings. Our study is thus patient focussed: we intend to use the information that we gather to discuss policy responses with health professionals, alone and in professional groupings such as divisions of general practice, health service executives and state and Commonwealth health policy officers.

SCIPPS takes account of existing health financing arrangements such as Medicare and seeks to assess the adequacy of current Medicare arrangements for the care of people with SCIs. We have special interest in the way SCIPPS subjects use medications and the utility of the Pharmaceutical Benefits Scheme in assisting such people with the procurement of continuing, prescribed medication. Data for the study can be brought to bear upon policy questions relating to medical care and medication prescription and use.

Observations from SCIPPS

SCIPPS has been running for over eighteen months and has gathered rich detailed qualitative data from more than sixty people living with an SCI in both study sites. These data provide vital insights into the management of SCIs as well as the implications that these have for the development of effective policy to overcome the challenges posed by chronic illness management.

Living with a serious and continuing illness

People with an SCI face significant challenges that require them to balance the demands of their illness with a multiplicity of other factors such as economic hardship, co-morbidity, negotiating the complexities of the health system, and understanding the complex health messages related to their condition. People with these illnesses are often

overwhelmed and bewildered by the multiple and diverse demands placed on them by health systems and health professionals.

The role of carers

These demands are further compounded for carers of people with an SCI, many of whom are not trained to carry out the demanding and complex tasks required of them. Carers often have a familial connection with the person they care for and this can lead to tension over matters such as decision-making and financial management and this in turn can contribute to reduced health and well-being of the carer.

Co-morbidity

Many people with an SCI experience some form of co-morbidity and this contributes to difficulties with managing medication and recognizing the symptoms associated with individual illnesses.

Health systems

By and large, people with an SCI tend to have negative impressions of health services and the people who work in them. The systems are overwhelmingly complex and lack coordination while the people in them are perceived as poor communicators who are overloaded with patients and together, these contribute to poor quality of care and delays in treatment. As a result, many people with an SCI refuse to engage with certain services and health professionals and this contributes to their less than optimal health and well-being.

Health literacy

The breadth of knowledge acquired by patients in the course of living with, or caring for someone with a chronic condition is immense. For many patients this can be overwhelming, something that most health care professionals do not acknowledge. Patients are expected to know about disease processes, medications, co-morbidities, services available, the financial implications of their condition, and associated lifestyle factor modification such as diet, exercise and smoking. The complexity and diversity of this knowledge can lead to confusion and bewilderment.

Economic impact

Economic hardship is a major barrier to good health for people with an SCI to the extent that they experience reduced quality of life, often with limited social engagement and an inability to afford both illness management requirements and everyday living expenses. Economic hardship means that patients often have difficulty engaging in disease prevention and self-management through healthy eating, regular exercise and seeking timely medical attention.

Resources uncovered by SCIPPS that may be of interest to the National Health and Hospitals Reform Commission

1. The model operated by Aboriginal Medical Services, with a shared record, shared site and focus on the health and well-being of the person, their family and the community is considered to be helpful and effective.

2. Health professionals believe that improvements can be made by allowing patients to manage their own health care and by providing different models of care. These need to be community-based and patient focused with systems in place that facilitate effective communication and knowledge sharing.
3. At the same time, health care providers believe that patients and carers do not have sufficient knowledge to manage their condition effectively and that benefit would be gained from providing a means by which this deficiency could be rectified.
4. A "one-stop shop" approach to medical and social services would help to alleviate financial hardship. This might include access to specialists, dentists, podiatrists, lab-tests, affordable exercise and nutrition programs; and funding for rehabilitation programs through existing gyms in the community.
5. Health care providers felt that lack of trust and confidence between different medical professionals and between hospital and community staff affected quality of care. The issue was particularly prominent in the case of general practitioners (GPs), and this resulted in reduced trust in the GP. Channels of communication and trust between clinician and patient need to be improved significantly if there is to be improvement in the self-management of SCIs.
6. Patients with an SCI say that their learning about the intricacies of the health system and their own health within that context occurs in stages. They need to be given ample opportunities to ask questions of clinicians and other health care providers so that they can expand and build on their knowledge over time. This means that patients often need more than a quick ten minute consultation.

IMPACT OF THE CURRENT HEALTH SYSTEM STRUCTURE

There is a widely held view that the problems we face are not merely the consequences of poor choices of individual policies, but stem from broader structural failures. While there are many useful and cost effective changes that could be made immediately, and would improve outcomes and satisfaction levels for those using the system and those providing services, these large structural problems will come back to haunt us.

Fissures in the system

We face a series of fissures in the system, with a variety of origins:

State and federal

The federal state divide is commonly seen as the largest of these breaks – the prime source of 'blame games', cost shifting and fragmentation of service delivery. Over many years the Australian health system has developed a unique pattern under which the 'public sector' – those areas where governments are directly involved in managing and delivering services – have become entirely the province of state and territory governments. The Commonwealth is largely responsible for purchasing services from the

private sector, through Medicare, the PBS and subsidy of the state-managed publicly delivered sector.

It is important to note that this division has a long history and caused very little political and health care concern until the 1980s. For most of the post Second World War era, the public sector covered short episodes of acute care, general practice, primary care and gatekeeping access to more expensive services. Most political and health policy debates focused on access to the system and other questions of equity – not the content of its services. In Australia, as with other developed countries, this comfortable consensus has been broken by the shifting burden of disease. As the weight of demand moved from short sharp episodes of acute illness to long term management of SCIs, structural problems began to appear. Australia was not alone – and the experience of the United Kingdom and New Zealand suggest that the strains over divided sovereignty were not the cause of the fundamental problem.

A realistic and achievable model of health reform will need to avoid easy assumptions that there is a single cause of problems in the health system. ‘Blame shifting’ is a constant in every political system. An approach that locates particular problems will be less dramatic, but more politically realistic than attempts to rewrite the constitution.

Cross sectoral within government

Many of the same structural problems that beset federal/state relations have affected other long-established institutions. Australia’s welfare state was one of the first to take account of the strains imposed by long term illness on families and carers, through disability and veterans’ pensions. The former were always closely aligned with the needs of labour markets, and this emphasis has been intensified in recent decades, with ‘active labour market’ policies. The only attempts to align them with priorities drawn from health policy have been with age groups and conditions likely to return to active employment. Although withdrawal from employment due to ill health is an early signal of the need for assessment and intervention, there has been little apparent communication between the health and welfare systems.

These cross sectoral divides also mark the civilian and veterans’ systems. The latter has recently attempted to use entry to disability benefit as a signal for activation of intervention of health professionals. With health, especially hospitalization and pharmaceutical costs and disability support met from the same budget, incentives have driven a more unified approach. Interviews with health care providers in SCIPPS have found Department of Veterans’ Affairs Gold Card holders are seen as easier to case manage, because DVA has begun to bridge some of the chasms in the system.

Costs of health services, public expectations and sustainability

Health literacy – the ability of citizens to navigate through a complex system and contribute to the identification and management of health problems before they get out of control – is the key to a sustainable future. It is difficult to see this happening without a greater public dialogue over expectations and attitudes towards the system. The Menzies-Nous Survey of Attitudes to the Health System is a CATI investigation of

questions of satisfaction and views on health reform. It is due to be conducted later this year and we expect it will inform discussions in these under researched areas.

Even the best medical care for chronic conditions is still shaped by traditional medical attitudes towards disease. ‘Cure’ is unlikely, management of the continuing condition so that the patient enjoys a tolerable life and avoids repeated hospitalisation are the best possible outcomes of conditions that will last until death. The Commission’s Challenge: ‘Caring for and respecting the needs of people at the end of life’ would be easier to achieve if the artificial barrier between chronic care and palliative care were reconsidered.

Public and private

The Australian health system has always been a hybrid with public and private streams of funding and provision. Over the last decade, the Commonwealth’s expansion of private health funding has created strains within the system – shifts of hospital services from the public to the private. Rigid regulatory systems have prevented private funds from attempting innovative experiments. The effect has been to deliver the worst of both worlds, growing barriers to access to elective procedures now largely in the private sector with little of the experimentation and innovation that competitive pressures should deliver. Community rating rules have been used to suppress innovation and the repeated delays in reinsurance reform have blocked incentives to take on the management of more difficult long term illnesses.

How should barriers be approached?

Reform of Australian health care should start from the problems driving current systemic strains. Most of these structural fissures only became real problems with the change in disease burden. Solutions that start from symptoms – blame and cost shifting – etc may do more harm than good.

Evaluation and policy learning have been sadly undeveloped in Australia. While a considerable amount of experimentation with imaginative resolutions to these problems is already underway, it is difficult to learn what is being tried, let alone what works. Policy borrowing between states is a haphazard and process, with little systematic evidence available. A classic defence of federal political arrangements is the scope they offer for creative competition and innovation. A freer flow of information – with national leadership – could revivify federal forms. At a time when most developed nations are looking at ways to decentralize and ‘federalize’ health services we should be wary about easy centralizing fixes.

Steps to be taken to bridge gap between above principles and reality

The Commonwealth government has a unique opportunity to take a leading part in each of these areas. Change will be gradual – shifting professional boundaries and integrating health and welfare policies are major undertakings. However, these reforms will never happen without decisive changes in some policy settings. The Commonwealth is in the best position to remove barriers to change and provide tools to those working for change.

Solutions to these structural problems – most of which have developed over decades – may make slow inroads, but this process is doomed without national leadership.

The policy instruments available at the national level include:

- Strategic direction of workforce development: It is crucial not just to fill gaps in service provision but also engage in long-term planning and build new cooperative relationships to transform professional boundaries, professional roles, professional attitudes and flexibility in roles. The Productivity Commission's 2006 report, *Australia's Health Workforce*, made a series of recommendations around these issues however many remain unaddressed.
- Information and communications technologies (ICT): Data linkage has been a victim of federal/state rivalries. Data linkage and the establishment of national standards to allow wider take-up of the new generation of broadband based ICT services are national responsibilities.
- Funding mechanisms: New service models need to be funded and the reform of obsolescent systems require reshaping of existing incentives.
- Health literacy: Effective interventions to address this serious health policy issue will require a greater knowledge of how learning and effective navigation of the system occurs.
- Innovation: There is a lack of evaluation and cumulative learning in the Australian health care system. A mass of experimentation is conducted at the local level, through, for example, Divisions of General Practice and area health services but information on successful innovations is spread haphazardly, with no systematic evaluation. National leadership is needed to transform local successes in to initiatives that operate across the health system.

A WAY FORWARD FOR THE NATIONAL HEALTH AND HOSPITALS REFORM COMMISSION

Making the Federation work better in providing health services for the Australian people is a high priority. While inevitably there will be scope for blaming and shaming in any complex system where funding and accountability are blurred, there is much room for improvement.

A simple place to start would be in transparency and accountability on all sides. The First Report of the National Health and Hospitals Reform Commission (NHHRC) provides key areas to measure the overall performance of the health system. While many of these areas are currently lacking agreed measures of the performance, the NHHRC framework provides a good basis for moving forward to a nationally agreed health return performance measurement system.

An urgent task, therefore, is to fill out the framework provided by the NHHRC. This process would focus the health policy debate around what is important, measurable and achievable. Accountabilities across the health sector would become clearer and the debate should be widened to include not just the accountabilities of the funders but also of the professionals who provide services, the industries who provide the

pharmaceuticals, devices and other products that support good health care and health consumers themselves.

The process of developing a realistic health performance measurement system could be phased. The first stage would be to agree a reporting and accountability structure for the elements of the NHHRC accountability framework that are already available, e.g. some throughput, access and performance quality measures in the acute sector and some quality measures in the primary care sector.

The next stage, which would proceed in parallel, would be to develop progressively specific measures for areas where there are no indicators at present, e.g. consumer satisfaction and most measures in primary care.

CONCLUSION

The Menzies Centre for Health Policy, its affiliates and partners have an established reputation as independent conveners that can extract consensus on controversial issues and seek understanding of the range of opinions and concerns on topical public health issues.

We welcome the opportunity to further discuss our submission and offer our services to the Commission. We have national and international networks of people interested in and committed to the formation and implementation of evidence-based medicine and policy development in a wide range of health areas. MCHP staff have a wealth of experience in health policy and health system reform, epidemiology, management, mapping and strategic planning, health service and professional development, clinical effectiveness, nutrition policy, working with industry and consumer issues. The Centre is able to facilitate workshops and consensus development across a range of issues and portfolios.

The Serious and Continuing Illness Policy and Practice Study provides a rare insight into the deficits in policy in the care of patients with serious and continuing illnesses. We would be pleased to make available to the Commission further insights derived from this study.

For further information please contact:

Professor Stephen Leeder
Co-director
Menzies Centre for Health Policy
University of Sydney
Tel 02 9036 5412
Mob 0419 209 569
steve@med.usyd.edu.au