

Chronic Illness Policy, Health Reform, Integration and Coordination

Chronic Illness

'The Problem'

Prevention, management and treatment of chronic non-communicable diseases are major challenges facing governments this century.¹⁻³ Furthermore, the social and economic burden of chronic conditions is set to increase in western societies over the coming decades due to ageing populations, an increase in numbers of those with chronic conditions, and associated escalating health costs. In 2002 approximately 59 per cent of global death was due to chronic diseases and this percentage is projected to increase to 66 per cent by 2030.⁴ In western societies deaths due to chronic disease are estimated to be approximately 86 per cent.^{5,6}

In Australia, chronic non-communicable diseases make up 80 per cent of the total burden of illness and injury in the ageing population⁷ and account for 70 per cent of health expenditure.⁸ Because of this situation, formulating appropriate policy responses and cost effective treatment, care and management of chronic conditions will become increasingly important. Adding to the challenge, most formal health care is organised around the delivery of acute and episodic care rather than the complex, long-term care that is necessary for people with chronic diseases.¹⁻³

Policy Approaches and Suggested Solutions

The management of chronic disease has been the subject of policy-making since the mid 1980s.^{1,9} The most commonly proposed solutions involve greater service integration, coordination, flexibility and continuity, along with policy and health system changes to improve the management of chronic disease.^{3,10}

Further, it has also been observed that within health systems patients are passive recipients of care with limited opportunity to engage with health professionals or voice their concerns.³ Consequently, another emerging theme in health policy is an emphasis on what is now referred to as 'patient-centredness' – the reorientation of health services with the patient as the focus rather than the service provider as the centre of the care delivery system, an approach becoming increasingly apparent in chronic disease management.^{3,11}

However, despite these attempts to address system and other deficiencies, current literature suggests that the care provided to people with chronic illnesses continues to fall short of policy goals and that a gap remains between policy, evidence and practice in Australia.^{1,12-14} Taking account of this, the Serious Continuing Illness Policy and Practice Study (SCIPPS) is a five-year NHMRC funded research program designed to gather further evidence and assess policy and health system interventions for the care and management of people with chronic illness and to evaluate new interventions designed to enhance the quality of life for people with these conditions.

SCIPPS Studies

A qualitative study with the aim of developing an in-depth understanding of the experience of patients and carers living with and managing chronic illness was conducted by the SCIPPS team in 2007. Fifty-two patients and 14 carers were interviewed.¹ A further study consisting of focus groups with 88 health professionals – including GPs, allied health, specialists and pharmacists – was conducted with the aim of investigating this group’s reaction to patients’ perceptions of chronic health issues.⁹ Together these two studies provide a basis to propose policy and health system interventions.¹

Health System Reform

Increasing prevalence of chronic disease is a driver of health system reform both internationally and within Australia^{3,15} The costs associated with chronic illness and related disability are significant drivers for reform as they can have significant impacts, not only on individuals and households, but also on health and social welfare systems. In Australia in 2003 – 4, 2.1 million people were recipients of government disability and sickness related payments including carer and spouse allowances.^{5,16}

National policy initiatives such as the National Chronic Disease Strategy and National Service Improvement Frameworks for particular conditions identified several systemic issues: the need for service integration, problems of poor communication and access to information; the importance of patient centred approaches and; support for self-management.⁹ These problems are also identified in state and regional strategies. The impact of these strategies in reform of the management of chronic conditions has been disappointing. Reform initiatives dissipate in the complex set of funding and policy interactions between federal, state and regional health administration and implementation. The approach to policy has been central and driven by medical and managerial priorities, rather than the identified and expressed needs of patients.⁹

The Rudd/Gillard Government established the National Health and Hospitals Reform Commission (NHHRC) in 2008 with a mandate to consider major structural reforms to the health system. Several policy documents have been launched to drive this, including the National Primary Health Care Strategy and the report of the NHHRC: *A healthier future for all Australians*. Both emphasise the important role that general practitioners, nurses and other health professionals working within the primary and community care sector play in providing integrated, comprehensive primary health care. Both further emphasise the importance of this sector in the delivery of patient centred care to those with chronic and complex care needs. For example, the recommendations of the final report emphasise redesigning health care services through such things as the introduction of Comprehensive Primary Health Care Centres and Services, voluntary client enrolment with a ‘health care home’ and Regional Primary Health Care Organisations.

SCIPPS Findings – Report of the National Health and Hospitals Reform Commission

SCIPPS noted that while there had been some commentary on the extent to which the recommendations suggested by the NHHRC addressed the concerns of health professionals, little comment had been made about how the NHHRC recommendations had addressed the needs of patients with chronic illness and their carers.¹⁷ Sixty-six participants were interviewed in a qualitative research project, part of the broader SCIPPS. Participants were people with type II diabetes mellitus, chronic obstructive pulmonary disease or chronic heart failure. Family carers were also interviewed.

Content analysis was undertaken and participants' recommendations for improving care were compared with those proposed in the NHHRC final report.

Integration and Coordination

The NHHRC report recommends redesigning health services 'around people'¹⁸ (National Health and Hospitals Reform Commission 2009). **The SCIPPS qualitative studies confirmed the need for enhanced care coordination.**^{5,9} The participants who had experienced coordinated care felt satisfied with the care they received because of reduced overall amount of time spent engaging with health services. Conversely, patients who had experienced standard care suggested that coordination would greatly improve their experiences with health professionals and health services.¹⁷

The NHHRC suggested that comprehensive primary health care centres and services be established, with a range of multidisciplinary primary health care and specialist services being available. **Participants from the SCIPPS qualitative study who had encountered similar services such as GP super clinics and Aboriginal health services confirmed that these types of services improved coordination of care and access to services, and cut down transport costs and time spent accessing services.**¹⁷

Multidisciplinary Teams and Communication

Study participants suggested that multidisciplinary teams, super clinics or clinics with a variety of health professionals would increase communication among service providers. **A SCIPPS recommendation is that future reform of this type should ensure that the availability of electronic health records should go hand in hand with, not instead of, improving communication between health providers.**¹⁷

Family Carers

The NHHRC report acknowledged the role of family carers in the sustainability of the health system because of the care they provide for family members who would otherwise be cared for in the health or aged care sectors and the role of carers in keeping patients with chronic illness out of hospital and managing at home. **The report made a number of recommendations aimed at improving support for informal carers. SCIPPS noted that the report recommendations did not detail the specific mechanisms to deliver this support,** beyond a suggestion to make electronic health records of patients available to their carers.¹⁷ While the report also acknowledged the health system's continuing and increasing reliance on family carers **SCIPPS noted that there were no recommendations on how to improve financial support for family carers.**¹⁷

Health Literacy

In the area of being responsible for individual and collective health, the NHHRC report made recommendations aimed at increasing health literacy and supporting making healthier choices.¹⁸ **Participants in the SCIPPS qualitative study confirmed that their health literacy and support for making healthier choices could be improved by the provision of more written information via pharmacists or general practitioners, and if health professionals provided information in easy and practical terms,** particularly concerning dietary management. Recipe books that catered for disease related dietary needs, instructions for managing exacerbations; and support for management in the home, especially on discharge from hospital were other suggestions made by SCIPPS participants. Indigenous patients suggested that brochures and written material were not an effective way of

providing health information to them while immigrant participants reinforced these suggestions as they wanted timely access to information in plain English or their native languages.¹⁷

The NHHRC recommendations called for patient care to be managed locally through hospital networks and primary care networks. Incentives are emerging to provide better care for patients who fall within majority groups and highly visible groups that represent high financial burden to the health system, such as patients with chronic diseases.¹⁹ **Now is the time to ensure that the particular needs of immigrants, people with multiple conditions and family carers are not forgotten during the reform process. Their voices, as well as those of all patients and families, must remain central to system reform and implementation.**¹⁸ The NHHRC has looked at crucial issues in health systems but income and social policy, both important determinants of health and health adequacy, remain outside their terms of reference. **Extending and clarifying the NHHRC reform recommendations, evidence from experiences of people in the SCIPPS qualitative study confirm that unless effective mechanisms for cross jurisdictional planning and action are enacted, patients will continue to be short changed and the system will continue to fall short of its aspirations.**¹⁷

SCIPPS Findings – Focus Groups with Health Professionals

As part of SCIPPS, a series of focus groups were conducted to gain insight into health professionals' perspectives concerning care of people with chronic illness.⁹ Health professionals in this study included doctors, nurses, allied health staff and pharmacists (n = 88). These health professionals identified the need for national reform, although there was little agreement on the detail of what this reform should entail. They argued that Medicare should provide greater resources to those treating the chronically ill but this was thought of only as an increase in funding rather than a reform that would reshape or change the way resources are allocated. **Simply demanding increases in the volume of current services is unlikely to yield good results in the face of growing workforce shortages and mounting numbers of people with chronic illness.**⁹ **Improving integration and coordination of care for the chronically ill requires more than just an increase in MBS items relating to these conditions. It may also require structural and workforce change.**

Integration and Coordination

Improved integration and coordination of health services are essential if the various constituent parts of the health system are to work in more cooperative, flexible manner to plan and deliver a continuity of appropriate care to those with chronic illnesses. The Australian Government Coordinated Care Trials attempted to address issues of lack of coordination and integration. The evaluation of this national initiative suggests that collectively these trials led to individuals' improved access to services, sense of security about their health and interventions, and health related empowerment.²⁰ However, to date there is yet to be a national approach supported by policies in other sectors addressing the wider whole-system issues.¹

Since the release of the National Chronic Disease Strategy in 2005 there have been various initiatives and strategies at both federal and state levels to address the problem of service fragmentation – a lack of coordination and integration. **Evidence from the SCIPPS studies suggest continued efforts to improve integration and coordination of health services for those with chronic illnesses “have yet to be proven sufficient to the challenge”.**⁹

SCIPPS Findings – Focus Groups with Health Professionals

The SCIPPS study confirmed that service fragmentation was a term understood and used by the health professionals to describe the many components of the health system operating independently with limited communication or commonality of goals, inadequate access to services for patients, lack of continuity and “dysfunctional healthcare culture”.⁹ Other views on fragmentation generally from health professionals included that services operated across jurisdictions with no common planning or shared approach to care, that the streaming of care into clinical specialties created multiple lines of responsibility whilst removing overall accountability and that fragmentation was a consequence of time and resource constraints and trying to meet unlimited needs with limited capacity.⁹ Some health professional thought the solution to these problems was intervention at national level. **However, SCIPPS also noted that “policy questions of accountability and cooperation are difficult to resolve by central mandate and there appeared to be little appetite to address it locally”.**⁹

Relationships between Health Professionals

Health professionals thought that lack of integration and coordination was a local problem that was caused by difficulties in negotiating relationships between the various professions and services that contributed to each patient’s care. They described health services as “tribes operating entirely independently of each other, with little and erratic communication and minimal teamwork”.⁹ However, health professionals also acknowledged the importance of teamwork and multidisciplinary care but they could provide few details as to what this would mean in practice: who, for example, would be doing what, and who would be paying for it. SCIPPS found that the most commonly expressed view was that some other health professional should do something differently such as send more timely letters of referral or discharge, better communicate changes to colleagues or consult before making changes to care.⁹

Information

Health professionals saw non-collaborative decision making as a result of poor communication between service providers which in turn was a consequence of problems moving information around the system “in a timely and helpful way”⁹ and also a lack of access to a common and easily accessible patient information store. Nurses, allied health staff and GPs would like to have seen increased use of electronic tools and technical support provided to improve access to information for patients and health professionals. Pharmacists saw the need for core patient information to be available to mitigate medication problems.⁹

Assessment and Referral

Health professionals’ thought fragmentation of services led to multiple assessments by different service providers for assess to similar services. Health professionals were of the view that “rigid access pathways and competing jurisdictional accountabilities were exacerbated by the current remuneration structure”.⁹ **GPs reported difficulty in referring because information about referral processes was often hard to access and that they “were frustrated by circuitous and formal routes of referral and barriers to appropriate care”.**⁹

GPs as Care Coordinators for the Chronically Ill

SCIPPS found that GPs thought they were the obvious starting point for co-ordinating care of patients with chronic illnesses as continuity of care started from the continuous relationship of individual patients to their GP. GPs argued that “enrolling people with chronic illness in an agreed program of care with a named primary care practice would ensure that the time-consuming care needs of patients with long-term conditions were met as well as adequately compensating the practitioner”.⁹ **However, SCIPPS noted that delivering coordinated care for people with chronic illnesses been hard to achieve in Australian general practice because of heavy patient workloads and patients’ freedom of choice of GP.**⁹

Fee for Service Versus Salaried Health Professionals

Many health professionals were of the view that increased remuneration was necessary to cover the time and complexity of managing chronic illnesses. However, those working on a fee-for-service basis, GPs and retail pharmacists, “stressed time pressure within the current rate of remuneration – patients needed more time therefore appropriate care could only be provided if remuneration increased. Salaried health professionals, on the other hand, were more likely to argue for additional resources to increase services”.⁹

SCIPPS Findings – Interviews with Patients and Carers

Patients identified the health system’s inability to work efficiently and collaboratively in providing care. Patients and the family carers talked of the time and money costs of service fragmentation and its affect on their ability to balance competing demands and manage co-morbidity. They resented and were confused by the inability of the health system to provide an integrated service, expressing frustration at poor communication and contradictory messages from health care workers.¹ The complexity and number of services and organisations providing care presented significant barriers to meeting peoples’ needs.⁹

References

1. Jeon Y-H, Jowsey T, Yen L, Glasgow NJ, Essue B, Kljakovic M, Pearce-Brown C, Mirzaei M, Usherwood T, Jan S, Kraus SG, Aspin C. Achieving a balanced life in the face of chronic illness. *Aust J Prim Health* 2010; 16(1): 66–74.
2. World Health Organisation. Innovative Care for Chronic Conditions: Building Blocks for Action: Global Report. Geneva: WHO, 2002.
3. Nolte E, McKee M (Editors). Caring for People with Chronic Conditions: A Health System Perspective. Berkshire (UK): McGraw Hill Open University Press, 2008.
4. Mathers C, Loncar D. Updated Projections of Global Mortality and Burden of Disease, 2002-2030: Data Sources, Methods and Results. Evidence and Information for Policy Working Paper. Geneva: WHO, 2005.
5. Jeon Y-H, Essue B, Jan S, Wells R, Whitworth JA. Economic hardship associated with managing chronic illness: a qualitative inquiry. *BMC Health Serv Res* 2009; 9: 182 – 193.
6. Lopez A, Murray C. The Global Burden of Disease, 1990-2020. *Nat Med* 1998; 4(11): 1241-3.
7. National Health Priority Action Council (NHPAC). National Chronic Disease Strategy. Canberra: Australian Government Department of Health and Ageing, 2006.
8. Australian Institute of Health and Welfare. Australia's Health 2004. Cat. no. AUS 44. Canberra: AIHW, 2004.
9. Yen L, Gillespie J, Jeon Y-H, Kljakovic M, Brien J, Jan S, Lehnbohm E, Pearce-Brown C, Usherwood T. Health professionals, patients and chronic illness policy: a qualitative study. *Health Expect* 2011; 14(1): 10-20.
10. Zwar NA, Harris M, Griffiths R, Roland M, Dennis S, Powell Davies G, Hasan I. A Systematic Review of Chronic Disease Management. Canberra: Australian Primary Health Care Research Institute, 2006.
11. Coulter A, Parsons S, Askham J. Policy Brief: Where are the Patients in Decision-Making about their Own Care? World Health Organisation on behalf of the European Observatory on Health Systems and Policies, 2008.
12. Armstrong B, Gillespie J, Leeder S, Rubin G, Russell L. Challenges in health and health care for Australia. *Med J Aust* 2007; 187(9): 485-9.
13. Glasgow N, Zwar N, Harris M, Hasan I, Jowsey T, Managing Chronic Conditions: Experiences in Eight Countries, Observatory Studies Series No. 15. (Eds E Nolte, C Knai, M McKee), European Observatory on Health Systems and Policies, World Health Organisation, Copenhagen, 2008: 131–160.
14. Harris M, Zwar N. Care of patients with chronic disease: the challenge for general practice.

Med J Aust 2007; 187(2): 104–7.

15. Productivity Commission. Australia's Health Workforce, Research Report. Canberra: Productivity Commission, 2005.
16. Australian Institute of Health and Welfare. Australia's Welfare 2005. Cat. No. AUS 65. Canberra: AIHW, 2005.
17. Jowsey T, Yen L, Wells R, Leeder S. National Health and Hospital Reform Commission final report and patient-centred suggestions for reform. *Aust J Prim Health* 2011; 17: 162–8.
18. National Health and Hospitals Reform Commission. A Healthier Future for All Australians: Final Report June 2009. Report No. P3–5499. Canberra: Commonwealth of Australia, 2009.
19. Department of Health and Ageing. A National Health and Hospitals Network: Further Investments in Australia's Health. Contract No. P3-6523. Canberra: Commonwealth of Australia, 2010.
20. Commonwealth of Australia. The National Evaluation of the Second Round of Coordinated Care Trials Final Report. Barton (ACT): Commonwealth of Australia, 2007.