
National Campaign for Consumer-Centred Health Care

Strategy Paper

2012 - 2013

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Background

The ideas in this Campaign were generated at the [Consumer-Centred Health Care: Policy Innovation and Empowerment](#) conference held in Melbourne on 22-23 March 2010. This conference was convened to explore the emerging international agenda of consumer-centred health care, and how this agenda might be developed in Australia.

Since 2010, the Commonwealth Government has developed a number of tentative steps towards health reform, including a commitment to introduce a person-controlled electronic health record from 2012; a restructuring of primary health care through *Medicare Locals* and *Local Hospital Networks*; a *MyHospitals* initiative aimed at making comparative hospital performance information available to the public; several adjustments to funding arrangements for hospitals; and the establishment of preventative health agency.

The reform framework underlying the Commonwealth's initiatives is weak in both its conceptual design and its strategic intent. Its stated goals sit uneasily with its dependence upon un-reformed provider and practitioner-centred systems for the delivery of reform outcomes. In particular, the Commonwealth's goal of a less fragmented health system with a more integrated pathway of care for consumers is unaccompanied by any practical strategies for achieving this goal.

This poorly developed framework for health reform reflects a continuing pre-occupation by all Australian governments with issues of health financing rather than redesign of the content and coordination of care. This pre-occupation with system financing rather than the actual content of the consumer experience of care is a legacy of a past and now outdated era in which health priorities were built around the management of acute illness, rather than the current, more diffuse, home and community-based challenges of managing chronic illness, mental health, and aged care.

The neglect of the content and coordination of care is also a product of the thorough dominance of the health policy and reform debate by provider and practitioner peak bodies in both private and public sectors. Governments of all persuasions have taken their policy cues almost exclusively from these provider peak bodies, while consumer voices are poorly-developed, under-resourced, and almost entirely ignored in public debate. Illness-specific and institution-specific consumer representation and advisory bodies have emerged in the last thirty years but have been restricted in their function to the facilitation of consumer voice within provider and practitioner-centred systems.

The **National Campaign for Consumer-Centred Health Care** is a response to this deep structural imbalance in the Australian health reform agenda and public debate. It aims to generate a broad movement for transformational change in health policy towards consumer-centred health care, with an initial focus on the period from August 2012 to the next federal election, scheduled for October 2013.

As our Campaign proceeds, we aim to influence and extend the national health reform agenda in the direction of consumer-centred health care. We also aim to strengthen and develop the voice, capacity, infrastructure and resourcing of health consumers and consumer bodies as an integral component of the reform process.

Aims

The aims of this Campaign are threefold:

1. To develop a movement of citizens and consumers for change in the Australian health system towards consumer-centred health care;
2. To participate in the health reform debate in Australia and influence its direction; and
3. To influence the thinking of politicians, policy makers, journalists, practitioners and consumers about health care and health reform.

Principles

The Campaign is based on four principles which should underpin good health care in the 21st century. These principles provide a framework for the re-direction of reform efforts away from a narrow focus on the management and funding of acute illness to a focus on the total consumer experience of health and health care.

The four principles are:

- **My Life. My History**
Information about a person's health history and care strategies belongs to that person, and authority in management of and access to this information resides with each person.
- **My Life. My Care**
A person requiring health care interventions should be resourced with the means to acquire independent personalised information and support in making decisions about care options and coordination.
- **Self-Care and Self-Management**
A person with chronic or complex health conditions has a right to expect support from providers and practitioners in developing their capacity for self-care and self-management in their journey towards better health.
- **My Life. My Money**
A person requiring health care interventions has a right to know the price, quality and safety credentials of these interventions.

Four point agenda

The core of the Campaign consists of a four point agenda for reform. This agenda is by no means the last word in health reform. It is simply a beginning in shifting several of the key elements in the health system – information, care management, and resources – towards consumer authority and direction.

- A Person-Controlled Electronic Health Record
- A Consumer-Directed Care Coordination and Brokerage Package for every consumer with a diagnosed chronic and mental illness
- A Person-Controlled Health Management Tool
- Access to Comparative Health Care Price and Safety Information

Campaign Steering Group

The members of the Steering Group are:

Professor Debbie Kralik, *Royal District Nursing Service SA*
Dr Samantha Thomas, *Consumer Health Research Group (CHaRGe), Monash University VIC*
John Stubbs, *Cancer Voices Australia NSW*
Michele Kosky, *Health Consumers Council WA*
Professor Enrico Coiera, *Centre for Health Informatics, Australian Institute of Health Innovation UNSW*
Dr Ronald Hicks, *Newcastle NSW*
Colin Frick, *Improvement Foundation Australia, SA*
Jose Simsa, *Community Participation Committee Inner South Community Health Service VIC*
Yvonne Orley, *Self-Care Advocate QLD*
Professor Kerry Bennett, *Diabetes and Diversity in Western Melbourne, Australian Community Centre for Diabetes VIC*
Jacqui Gibson, *Prahran Mission VIC*
Debra Carnes, *Consumer Advocate TAS*
Maxine Drake, *Headwest WA*
Geoff Barry, *Sydney South West Area Health Service Consumer Community Council, NSW*
Sharon Lawn, *Chronic Condition Management and Self-Management, Flinders University SA*
Geoff Isaac, *Consumer Advocate QLD*
Professor Craig Veitch, *Community Based Health Care Research Unit, University of Sydney NSW*
Kim Smith, *Mental health Consumer Advocate, Clubhouse SA*
Hope Alexander, *Consumer Advocate WA*
Jacqui Crowe, *Family/Carer Consultant, Ballarat Health Service Psychiatric Service, VIC*
Vern Hughes, *Social Enterprise Partnerships VIC (Convenor)*

Strategies for Change

Our Campaign will employ two complementary strategies: facilitation of immediate innovation, and organisation for political support for further policy change.

1. Facilitation of innovation

Every government and health sector organisation in Australia says it is committed to innovation in health care. In reality, 'innovation' usually means amendments to work practices within provider and practitioner groups and institutions. Our Campaign will aim to facilitate innovation which is consumer-centred and oriented to enhancement of the total consumer experience of health care.

The Commonwealth's *Medicare Locals* have a stated goal of tackling the fragmentation in the health system and building integrated care. However, without a commitment to facilitate consumer-centred innovation, this objective will remain unrealised – it will result only in a plethora of service coordination meetings between providers and practitioners.

Our Campaign will work to influence *Medicare Locals* and *Local Hospital Networks* and stand alone health organisations to introduce a consumer-directed *Care Coordination and Brokerage Payment* for consumers with a diagnosed chronic and mental illness. The purpose of this *Payment* is to purchase the services of a care coordinator/ care broker/ health coach as required by each consumer to guide them through the maze of services, costs, waiting lists and information.

This is an innovation that can be undertaken locally without any enabling public policy change or new funding program – it can be done by redirecting existing pools of money and existing funding arrangements at the local level of service delivery.

Similarly, our Campaign will work to enable consumers to acquire a person-controlled health management tool, and receive training in its use. This innovation will enable the consumer, or their family or Care Coordinator and Broker, to coordinate and manage a care plan. Tools of this kind are currently available.

For system-wide innovations, our Campaign will seek to influence the Commonwealth in deepening and extending its stated commitments.

The Commonwealth has made a commitment to introduce a person-controlled electronic health record from 2012 on an opt-in basis for those consumers who want it. However, in the face of pressure from hospitals and other practitioners, the Commonwealth may introduce a watered-down version of the record without consumer-control over access. Or it may drop plans to mandate use of the record by hospitals and other providers. Or it may not permit consumers to post background information about themselves and their health experience in the Record.

Strong political pressure from our Campaign is needed to force the Commonwealth to honour its commitment to introduce a person-controlled record. Additional pressure is needed to get the Commonwealth to make it mandatory for aged care, disability and mental health providers to use the record.

Similarly, the Commonwealth's *MyHospitals* initiative is currently confined to non-health related performance outcomes such as waiting times for treatments. Our Campaign will press for the inclusion of health-related performance outcomes in this process, such as hospital errors and deaths, and hospital-based infection rates. We will also press for the disclosure of financial information by hospitals, such as hospital payments for the services of medical specialists and health fund payments for medical specialist charges. Without our Campaign, Commonwealth and State governments will defer to provider and practitioner interests who do not favour open and transparent disclosures of information.

2. Organisation of political support by federal electorate

The second strategy in our Campaign is the development of political support for further policy change.

Our Campaign will focus its effort towards political influence through the 150 federal members of the House of Representatives and their 150 federal electorates (each with 110,000 voters). In each electorate, a Campaign Coordinator will be sought to coordinate initiatives to influence their member of parliament, including personal meetings, local forums, and local media.

Individual consumers and citizens will be encouraged to participate in the Campaign as a member, and to participate in their federal electorate activity. The purpose of federal electorate activity is to influence local members of parliament in supporting consumer-centred health care. This support can be monitored and measured through a range of tools such as the number of speeches or references to consumer-centred health care made by each MP, their interest and/or support for local innovation, and their voting records in parliament.

From 2012, the Campaign will develop this activity with a view of exerting influence by the time of the next federal election in 2013.

Local Innovation

Successive Commonwealth governments have established and funded Divisions of General Practice in 110 regional areas across Australia to strengthen the place of general practitioners in the health system.

The Commonwealth over this time could have established and funded 110 Divisions of Consumers to facilitate, incubate and resource consumer-centred innovations in health care. It didn't.

Now the Commonwealth has turned these Divisions into 61 *Medicare Locals*, to improve service coordination and facilitate a more streamlined patient journey through the health system. This was the role Divisions had too, which they failed to achieve over a twenty year period.

Medicare Locals will be governed by health providers and practitioners, with a consumer representative at the end of the table. How these *Medicare Locals* will improve service coordination on behalf of the consumer is yet to be seen.

However, *Medicare Locals* will be funded to take initiatives to overcome system fragmentation and streamline the consumer experience of care. Our Campaign will aim to organise and facilitate consumer-based and directed initiatives for take-up by *Medicare Locals*. *Medicare Locals* that are enterprising and serious about reform will take up, trial and implement genuine innovations that enhance the consumer experience of care. Our Campaign aims to assist them in this task.

A map of the 61 Medicare Locals and their boundaries is available at:

[http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/content/27CE146BF54CAA47CA2579540005F656/\\$File/20120627%20-%20Australia%20Document.pdf](http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/content/27CE146BF54CAA47CA2579540005F656/$File/20120627%20-%20Australia%20Document.pdf)

Four Goals

A Person-Controlled Electronic Health Record

The Final Report of the *National Health and Hospital Reform Commission* in June 2009 recommended that by 2012 every Australian consumer should have an electronic health record which will be used by providers and practitioners across service and disciplinary boundaries. Each person should be able to authorise access to the record to the providers and practitioners of their choice.

In May 2010, the Commonwealth Government committed itself to introduce this system from 2012 on an opt-in basis for those consumers who want it.

However, in the face of pressure from hospitals and other practitioners, the Commonwealth may introduce a watered-down version of the record without consumer-control over access. Or it may drop plans to mandate use of the record by hospitals and other providers. Or it may not permit consumers to post background information about themselves and their health experience in the Record.

Strong political pressure is needed to get the Commonwealth to honour its commitment to introduce a person-controlled record. Additional pressure is needed to get the Commonwealth to make it mandatory for aged care, disability and mental health providers to use the record.

Goal 1: The Campaign will organise political influence to ensure that the Commonwealth honours its commitment to introduce a Person-Controlled Electronic Health Record from 2012.

A Consumer-Directed Care Coordination and Brokerage Package for every consumer with a diagnosed chronic and mental illness

Every consumer with a diagnosed chronic and mental illness should receive an allocation of resources in the form of a *Care Coordination and Brokerage Package*. This Package can be introduced immediately within stand-alone services, without further public policy change, where services aggregate existing funding streams and make them available to consumers in person-centred formats.

Where existing services introduce Packages by re-organising existing funding streams in person-centred formats, the size of the Packages can be a matter for local determination. However, for the purposes of our Campaign for state and commonwealth support for such Packages, we propose an initial set-up payment of \$2000 to be assigned to consumers, to be followed by an annual \$1000 payment thereafter.

This Payment would be for the purpose of engaging and purchasing the services of a care coordinator/ care broker /health coach as required by each consumer to guide them through the maze of services, costs, waiting lists and information. Payments may be made for coordination, advocacy, health literacy training, self-management training, individual or collective purchasing and tendering, contractual arrangements, and personal health and fitness coaching.

An eligible consumer would nominate a *Care Coordinator and Broker* to receive and then manage the Package on their behalf, or they may self-manage. Management tools are currently available, through innovations in disability and aged care, for consumer-directed management of these Packages.

A *Care Coordinator and Broker* may be a community health organization, an illness-specific association, a health fund, a GP or nurse or allied health practitioner, or a consumer organisation. It would be the consumer's prerogative to choose a *Care Coordinator and Broker* who has the capacity to manage the Package, enter contractual arrangements on their behalf, and manage their support and care relationships to their satisfaction.

A consumer must be free to select their *Care Coordinator and Broker*, and free to transfer from one to another annually.

Goal 2: The Campaign will facilitate the development and implementation of Consumer-Directed Care Coordination and Brokerage Packages by Medicare Locals, stand-alone health services, and Commonwealth and State Governments.

A Person-Controlled Health Management Tool

Every consumer with a diagnosed chronic and mental illness, disability and aged frailty, should have the option of self-managing a Care Plan that integrates care across jurisdictions, services, and provider and practitioner types. Eventually, every consumer should receive a payment for, and a legislated entitlement to, a person-controlled health management tool.

New technologies make it feasible and affordable for consumers, or their agents, to manage their health care through a person-controlled management tool.

This Tool can be introduced immediately within stand-alone services, without further public policy change, where consumers request to self-manage a Care Plan. Alternatively, a *Care Coordinator and Broker* may manage a Care Plan on the consumer's behalf.

The Tool would enable the consumer, or their family or *Care Coordinator and Broker*, to coordinate and manage a care plan. The Tool would enable information about health maintenance, medications, treatments and therapies available in an online format to enable co-participation in implementing the consumer's plan by relevant practitioners, nursing and administrative personnel. All providers and practitioners supplying services to participating consumers with chronic and mental illnesses, disabilities and aged frailty, would be required to enter information on the service supplied, and its cost, into the person-controlled health management tool. Commonwealth legislation will eventually be required to make it mandatory for providers and practitioners to use this tool in partnership with the consumers who seek their services.

Existing tools are available for consumer use as Person-Controlled Health Management Tools. Our Campaign will not mandate any particular Tool for use, but will develop support for the right of consumers to self-manage their Care Plan. At a policy level, we propose that every eligible consumer should receive an initial set-up payment of \$1,000 for acquisition of a person-controlled health management tool, and training in its use. Thereafter, an annual payment of \$500 would be received for maintenance and training.

Goal 3: The Campaign will facilitate the development and implementation of Person-Controlled Health Management Tools by Medicare Locals, stand-alone health services, and Commonwealth and State Governments, and will develop political support for the right of consumers to self-manage a Care Plan or assign authority for management of their Care Plan to an agent of their choice.

Access to Comparative Health Care Price and Safety Information

The Commonwealth should strengthen its current commitment to make available transparent and comparative information to consumers about the quality of health care available from various providers. It should introduce mechanisms for comparative price and service quality data on hospitals, providers and practitioners so that consumers can know what they are using and purchasing.

These mechanisms must be independent of providers and practitioners, with authority to require information from providers, insurers and practitioners for public disclosure online, including:

- Hospital errors and deaths
- Hospital-based infection rates
- Hospital payments for the services of medical specialists
- Health fund payments for medical specialist charges
- Specialist fees in private practice

Goal 4: Our Campaign will develop political support for commonwealth and state governments to introduce comparative price and service quality data on providers of health care.

Organisation

The Campaign has established a Steering Group to direct the national campaign.

The Campaign will establish a Campaign Coordinator in each federal electorate. The role of a Campaign Coordinator will be to:

- serve as a local point of contact for the Campaign
- coordinate lobbying local MPs and political candidates
- coordinate local activities with an online capacity
- coordinate contact with local media

The Campaign will establish a large membership of participants, aiming for 1000 by December 2012 and 3000 by June 2013.

Resources

The Campaign's web information and communications will be hosted by Social Enterprise Partnerships at no cost.

The Campaign will seek sources of funds for its core activity and/or specific projects.

August 2012

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