



Chronic Conditions Self Management 2008-2010 Project

**National Consumer Representative and Stakeholder
Planning Workshop Report**

August 2008

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Introduction

On 27 August 2008, the Consumers Health Forum of Australia (CHF) held a national consumer representative and stakeholder planning workshop to commence work on its *Chronic Conditions Self Management 2008-2010 Project* (the project). This project is funded by the Australian Government Department of Health and Ageing under the *Australian Better Health Initiative*.

The workshop was attended by 21 consumer representatives, as well as six stakeholders from a range of organisations with an interest in the area. A full list of participants is provided at Attachment A. The workshop was facilitated by Ann Porcino of PRP Consulting, who prepared a subsequent workshop report on which this final report is based.

The aim of the workshop was to inform consumer networks about and involve them in the CHF project. Objectives for the meeting were:

- To inform consumer networks about the objectives and proposed activities of the CHF project in the context of the Australian Government *Australian Better Health Initiative*
- To develop a dialogue between health consumers and health professionals to work together to support chronic conditions self management
- To obtain input on the direction of project activities, including development of a publication to support consumers in self management of chronic conditions, consultation activities in partnership with Divisions of General Practice and professional development activities with health professionals and consumer representatives
- To obtain input on an evaluation framework for the project.

Workshop program

The agenda for the workshop is provided at Attachment B. The meeting commenced with two presentations to provide background information to participants – the first by CHF and the second by a representative of the Australian Government Department of Health and Ageing (the Department).

Following this, a panel of consumer representatives spoke briefly on consumer perspectives on self management of chronic conditions and took questions from participants. Panel members were Sheila Rimmer from the Council on the Ageing (COTA), John Daye from the National Association of People Living with HIV/AIDS (NAPWA) and Russell McGowan, Chair of the Project Reference Group.

The remainder of the workshop was devoted to small group and plenary discussions designed to draw out the views of participants on the following questions:

- What does good self management look like?
- What tools and systems do consumers need in order to self manage?

- What existing self management tools and models should CHF be aware of?
- What should this project deliver?
- How will success of the project be measured?

This report summarises key themes and messages arising from the small and large group sessions of this workshop around these topics.

Evaluation of the workshop was undertaken by the facilitator, a summary of which is provided at [Attachment C](#).

Understanding self management

Participants agreed that the project will need to describe chronic conditions self management and contribute to defining common language for discussing self management that is easily understood and widely recognised by consumers. Participants described the central elements of a self management approach that works for consumers:

- Consumers own self management and are at the centre of it. They are in control of their health care and take responsibility for health promoting activities
- Self management is holistic, incorporating the physical, emotional, social and lifestyle factors critical to good health and well being
- Consumers are appropriately prepared for self management and feel confident in their ability to communicate with health professionals about their care. Training in self management starts with young people, so that they approach the health system more empowered and with the view that they are the drivers of their own health care
- Consumers are 'health literate'; they have ready access to the best available information about their condition and the health system
- Consumers understand and are able to evaluate the impacts and risks of the choices they make and their choices are respected
- Consumers are supported to self manage by a team of health and other professionals, as well as carers, family members, friends and the wider community. An appropriate health professional coordinates care planning
- There is quality control of health interventions, so that no harm is being caused to the consumer by self management.

Participants were eager to record that self management is not about shifting blame, responsibility and costs to the consumer. Instead, it is about empowering the consumer to drive their own health and well being. It may also lead to a change in emphasis on where resources are placed in the health system; for example, instead of increasing numbers of health professionals, some resources could instead be expended on the development of self management support tools and on changes that result in a system ready to support self management.

What consumers need to self manage their chronic conditions

Workshop participants described a variety of tools and systems that are needed to support chronic conditions self management, as discussed below.

Skill development training

Consumers need a range of personal skills to assist them to effectively self manage, including assertiveness and communication skills, and skills to build partnerships with service providers.

Self management tools

Tested and evidence based tools that assist consumers with various aspects of the self management processes are needed, including:

- Decision aids to assist consumers to weigh up the benefits and risks of the various health care options open to them
- Navigational tools to assist them to find their way around the health system and to access services in and outside the health system that lead to optimal health outcomes
- Tools that facilitate communication between the consumer, health professionals and other members of the care team, such as checklists.

Access to good quality health care

Unless consumers can get the health care they need from a range of health professionals and other providers, they are unlikely to be able to effectively self manage. Consumers must have access to services with a minimum of gate-keeping. This means having multiple entry points, not always through a general practitioner (GP), and access regardless of where the person lives or their capacity to pay.

Access to effective care planning

To facilitate self management, care planning processes need to work effectively. This requires that a GP or another health professional takes responsibility for the coordination of care provided by the team involved in the care plan.

Access to good quality health information

To build health literacy, consumers need access to accurate information that helps them to understand their condition. Information must be relevant to the needs of the consumer, including being presented in languages and formats that are meaningful to them.

Access to peers

For many consumers, the information and support provided by others with similar chronic condition(s) is an invaluable aspect of self management. Consumers need access to peer support groups and peer workers who are themselves trained in providing support. Consumers would like their health professionals to have information on relevant consumer networks and self help groups to link them into such supports.

Consumer involvement in development of self management policy and service delivery

To ensure that systems and services are effective for consumers, it is vital that consumers and consumer organisations are meaningfully involved in negotiations about policy and service development, delivery and evaluation.

Health system reform

Changes to the health system more broadly are needed in order to encourage and facilitate approaches that support consumers' capacity to self manage. These changes include:

- **Improved electronic communication mechanisms, such as an electronic health record:** These are critical in facilitating the flow of information required for self management amongst care teams and between the consumer and health providers.
- **Increased dialogue about the benefits of self management, from an evidence base that includes consumer experience:** This dialogue is needed at the highest levels of the public, private and non government health systems to inform how the system must adjust to resource this approach.
- **Development of a range of evidence based models of self management:** What will work for one consumer might not work for another. For this reason, there needs to be a range of evidence based models of self management in the system to support consumers and health professionals to take up appropriate initiatives.
- **Professional development:** Health professionals must be aware of the importance of self management and that it is the consumer, rather than the health professional, that drives self management mechanisms. Professional training and development programs based on this approach are needed to change the attitudes, knowledge and skills of some health professionals around self management.

Existing effective self management tools and models

Workshop participants were asked to provide examples of existing good self management tools and strategies that the project can build on. The ideas provided by participants are outlined in [Attachment D](#).

What this project can and should deliver

Participants were given an overview by CHF of the expected broad deliverables of the project, as follows:

- Development of a consumer resource that assists consumer self management
- Work in three demonstration communities in Australia, to link health professionals and consumer groups and build capacity of the community in the area of chronic conditions self management. This will be facilitated through partnerships with three Divisions of General Practice and involvement of consumer networks at the local level
- Three state workshops run in the locality of the selected demonstration communities towards the end of the project. These workshops will enable those involved in the project to share lessons learnt and reflections with other consumer groups and health professionals, and in this way, build skill development around chronic conditions self management
- Consumer engagement in 'encouraging active patient self management' – to complement health professional education and training under the *Australian Better Health Initiative*
- Promotion and support for national consumer representation on professional education and training committees

- Strengthening the capacity for consumer networks to contribute and respond to policy and program developments on chronic conditions self management
- National communication on self management, including an information paper, a dedicated project page on the CHF website, newsletter articles and use of an e-list
- A national workshop for peak organisations in year two of the project to engage these organisations in the project, advocate for greater consumer involvement in self management and promote any resources produced during the project
- Project evaluation.

Participants were asked to give their views and guidance on the first three of these deliverables – consumer input to which is particularly valuable at this stage of the project. Participant views on these prioritised deliverables are summarised below.

Development of a consumer resource

Participants gave the following suggestions on what kinds of resources, or resource components, would be of use to consumers to assist them to manage their chronic conditions:

- **An agreed definition of self management:** This would include providing a clear description of what self management is, justification for using this approach including benefits to consumers, and discussion about who pays for self management. The meeting agreed that the ideal outcome from the project would be the production of a consensus statement, across all stakeholder groups, which defines self management in clear and unambiguous terminology.
- **A peer education training resource on chronic condition self management:** This resource would train consumers in how to talk with other consumers about self management and how to assist them in self management skills development.
- **A risk assessment framework for engagement in self management:** Such a framework could be used by consumers, with appropriate support, to assess their capacity to self manage. It would include tools that could be used by consumers, carers or health professionals to explore the potential costs and benefits of a person becoming involved in a self management approach to care.
- **Collection of consumer stories about successful self management:** Such a resource would give consumers ideas about what good self management looks like and how it can be approached.
- **Analysis of current self management resources and practices:** This could involve an audit of self management resources and projects already in existence, with identification of those that have been most successful – leading to a publication of best practice examples of chronic conditions self management for consumers and professionals.
- **Resources on working with your health care team:** This could include articulating what consumers should expect from their GPs and other care team members, and practical information on how to use the health system and other services effectively for self management (e.g. Medicare Benefit Schedule item numbers that can be used by eligible service providers to support self management).
- **Strategies that facilitate communication between consumers and their health professionals – particularly GPs:** Participants agreed that CHF might not necessarily produce such communication strategies, but could contribute to the

development of these. For example, CHF could work collaboratively with other organisations to develop a component of GP training on chronic condition self management to be delivered from a consumer perspective.

- **Information on where to get help for self management:** This resource would, for example, refer consumers to the sources of condition specific information or support groups.
- **Adaptation of the ‘Australian Charter of Healthcare Rights’¹ to encompass self management.** This Charter was recently released by the Australian Commission on Safety and Quality in Healthcare.

Participants recommended that as well as producing a new chronic condition self management resource, CHF could also link consumers to existing resources throughout the project. New resources should come from a ‘strengths’ not a ‘deficiency’ perspective, be in plain language and culturally sensitive, and be delivered in a variety of formats (e.g. web-based, written, pictorial) to reach a diverse range of people.

Consumer and health professional engagement in local communities

Participants recommended that this element of the project focus on learning about *practical* strategies for improving opportunities for consumer participation in chronic conditions self management. Activities should seek to engage a broad range of relevant organisations and groups within the community, including allied health professionals, GPs, practice nurses, community nurses, community health centres, self help groups, disease specific medical specialists and community based (including culturally diverse) organisations.

Participants suggested that the three communities selected for this project could include:

- At least one urban centre
- At least one rural town where transport and access to health services is poor at the moment
- Different types of communities, including at least one community with a significant culturally and linguistically diverse population, Indigenous population and/or populations experiencing significant disadvantage
- Different types of Divisions of General Practice, with particular attention to two variables: the level of resources in local practices (e.g. practice nurses, size of practice overall, administrative support) and the existing level of knowledge and commitment to chronic conditions self management
- Communities in which consumer groups already exist in order to support project initiatives
- Divisions that have either a good consumer engagement process or a good chronic conditions project through which they are committed to building in consumer involvement.

State workshops for consumers and health professionals

Participants recommended that these State workshops be tailored to meet the needs of the local community and participants. They supported the idea that the workshops be run towards the end of the project – allowing participants to reflect on and share benefits, lessons learnt

¹ Available from the Commission’s website: <http://www.safetyandquality.gov.au> (accessed November 2008)

and challenges from the project. They further supported that these workshops (and perhaps some of the other activities of the project) have an element of health professional training or encourage the community to pursue health professional development activities as appropriate.

Measuring success of the project

Workshop participants were invited to discuss the project evaluation and to identify the types of tangible outcomes they would expect to see from the project. Participants agreed that it is unrealistic to expect measurable outcomes in consumer health from the two year project.

Participants brainstormed a range of ideas for what outcomes might demonstrate the success of this project, as follows:

- The project produced and delivered specific training initiatives for health professionals and consumer groups on chronic condition self management, and evaluated these initiatives
- The project produced and delivered an important consumer resource (such as those suggested earlier) to assist them in managing their chronic conditions that was supported by peak organisations and consumer groups
- Consumers and health professionals engaged in the project demonstrate better understanding of chronic conditions self management, including the barriers to self management. This might be measured by:
 - evidence that there is greater consistency in the language consumers and health professionals use to describe self management
 - measurement (pre and post project) of the number of people who have heard about self management and who can describe what it is
 - consumers reporting of the use of chronic conditions self management approaches and of confidence in using these approaches (pre and post project)
 - evidence of an increase in availability of chronic conditions self management materials in general practices and elsewhere in the three communities that have been the focus of the project
- Evidence of better communication and connection between consumers and health professionals in the three communities. This might be measured by:
 - the number of joint activities undertaken in these communities
 - the extent of consumer involvement in a range of projects in these communities
- Consumers give positive feedback when asked to evaluate components of the project, such as this workshop
- Divisions of General Practice give positive feedback about their involvement in the project
- Evidence that marginalised groups of consumers have been engaged in this project (e.g. culturally and linguistically diverse people, Indigenous people and people living in rural and remote communities)
- Evidence that CHF has influenced policy on chronic conditions self management.

Conclusion

This workshop provided an invaluable opportunity for consumers to inform the directions and focus of the CHF *Chronic Conditions Self Management 2008-2010 Project*. Participants clearly articulated, from a consumer perspective, what good self management involves and

what consumers need in order to self manage. Participants emphasised that self management is about consumers being in control of their health and well being. The role of health professionals, family, carers and community networks in this picture is to support the consumer. Workshop discussions highlighted the important role of community supports, including peer support groups and networks, in facilitating self management. They also identified the need for consumers to have access to quality information, multidisciplinary and coordinated health care, and tools that increase the skills and confidence of consumers to self manage.

This guidance will enable CHF to move forward in establishing linkages between consumers, health professionals and community organisations to inform the implementation and evaluation of this important project.

Contact Us

Further information on this workshop and activities under this CHF project can be found at:

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This report reflects discussion at the CHF 'Chronic Conditions Self Management Project 2008-2010' Consumer Representative and Stakeholder Workshop in Canberra on 27 August 2008 and does not necessarily reflect the views of the Consumers Health Forum of Australia, the Australian Government Department of Health and Ageing, nor other presenters at the workshop.

**Chronic Conditions Self Management 2008-10 Project
National Consumer Representatives and Stakeholder Planning Workshop
27 August 2008, Old Parliament House, Canberra**

Participants List**Consumer Representatives**

First Name	Last Name	Member Organisation
Diana	Aspinall	Arthritis NSW
Gary	Carr	Consumer Representative
John	Daye	National Association of People Living with HIV/AIDS
Corinne	Dobson	Federation of Ethnic Communities' Councils of Australia
Tricia	Greenway	Consumer Representative
Robin	Grindrod	Association for the Wellbeing of Children in Healthcare
Elizabeth (Beth)	Hunter	Queensland Self-Management Alliance
Anton	Keijzer	OCD Support Service
Valerie	Lee	Cancer Voices
Isabelita	McRae	Mackay Division of General Practice
William (Bill)	Morris	Health Consumers Council WA
Sheila	Rimmer	Council on The Ageing (COTA)
Ann	Roberts	Haemophilia Foundation Australia
Margaret	Springgay	Mental Illness Fellowship of Australia
Merle	Thompson	Post-Polio Network (NSW) Inc
Robin	Toohey	Shoalhaven North Health Consumers Action Group
Lerma	Ung	Arthritis Victoria
Sharon	Van der Laan	Genetic Support Council WA

Reference Group

First Name	Last Name	Member Organisation
Russell	McGowan	Health Care Consumers Association of the ACT
Noel	Muller	Bundaberg Consumer Advisory Group Inc Queensland Alliance
Christine	Walker	Chronic Illness Alliance

Stakeholders*

First Name	Last Name	Organisation
Christine	Ashley-Coe	Australian Nursing and Midwifery Council
Sharon	Lawn	Flinders Human Behaviour and Health Research Unit
Bo	Li	Australian Psychological Society
Leanne	Wells	Australian General Practice Network

*2 stakeholder names withheld on request



Chronic Conditions Self Management 2008-2010 Project

National Consumer Representative and Stakeholder Planning Workshop
Wednesday 27 August 2008
9am – 5pm

Venue: Old Parliament House, Canberra

Aim: To inform consumer networks about and involve them in the CHF *Chronic Conditions Self Management 2008-2010 Project*

Objectives:

- To inform consumer networks about the objectives and proposed activities of the CHF project in the context of the Australian Government *Australian Better Health Initiative*
- To develop a dialogue between health consumers and health professionals to work together to support chronic conditions self management.
- To obtain input on the direction of project activities, including development of a publication to support consumers in self management of chronic conditions, consultation activities in partnership with Divisions of General Practice and professional development activities with health professionals and consumer representatives
- To obtain input on an evaluation framework for the project

Facilitator: Ann Porcino, RPR Consulting

Program

9.00am	Registration	
9.20am	Welcome and introductions	Russell McGowan Reference Group Chair
9.40am	History of consumer involvement in chronic conditions self management	Helen Hopkins CHF Executive Director
10.10am	Overview of the <i>Australian Better Health Initiative</i>	Australian Government Department of Health and Ageing representative
10.30am	What active consumer involvement in self management of chronic conditions means for consumers	Panel session
10.50am	Morning Tea (30 min)	

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11.20am	<p>Setting the scene: important consumer questions for discussion</p> <ol style="list-style-type: none"> 1. What does it mean to self manage? What does good self management look like? 2. What tools and systems do consumers need in order to self-manage? 3. What's happening in practice? What works? What doesn't work? 	Facilitator, groups and whole of room
1.00pm	Lunch (1 hour)	
2.00pm	Reflections on key elements of chronic conditions self management. What can be addressed through the CHF project?	Facilitator, groups and whole of room
3.00pm	Identifying and engaging with key stakeholders	Facilitator and whole of room
3.30 pm	Afternoon Tea (20 min)	
3.50pm	<p>How we will know we have been successful in the CHF project</p> <ol style="list-style-type: none"> 1. What are the key evaluation questions? 2. How will we measure them? 	<p>Joy Russo CHF Senior Policy Advisor Facilitator, groups and whole of room</p>
4.30pm	Next steps, including strategies for ongoing consumer involvement in this project	Facilitator, groups and whole of room
5.00pm	Close	

Workshop evaluation

Workshop participants were asked to complete an evaluation at the end of the day and 21 evaluations were completed. Overall, there was excellent feedback about the workshop itself and evident excitement and enthusiasm for the Project. A comment by one participant sums up the sentiment of participants:

Congrats on this exciting project. This is a wonderful time for putting many years of work together.

Aspects or components of the workshop nominated as most valuable by participants included:

- sharing of experiences between participants with incredible breadth and depth of perspectives (10 participants)
- the background sessions provided by CHF and DoHA (6 participants)
- the small group sessions and plenaries (6 participants)
- the opportunity to learn about self management and the project (3 participants)
- the whole workshop (3 participants)
- the meeting was a safe place to share ideas (2 participants).

Thirteen participants had no comment or replied ‘nothing’ when asked about what was least valuable about the workshop. Those who did respond raised a range of matters including domination of some participants, lack of depth in some of the presentations and discussions, and concern about lack of attention to the needs of consumers in rural and remote regions.

Participants were very pleased with both the facilitation of the workshop and the venue and catering.

Participants suggested areas of improvement to inform future CHF project planning days, as follows:

- incorporate examples of good practice in self management, including information on self management models such as the ‘Flinders model’, either through the agenda or by distributing articles in advance (4 participants)
- distribute the information paper and copies of power point presentations earlier so that participants can bring the ideas from the paper into discussions (4 participants)
- provide information in advance about parking and entry via the back door if held in the same venue (3 participants)
- ensure disabled parking is close to the workshop room (4 participants)
- make the small groups even smaller (maximum of five participants), nominate participants in advance to ensure a good mix and provide a CHF facilitator for each group to make sure that discussion does not go off track (2 participants)
- give more opportunities for quiet people to participate (2 participants)
- ensure that people speak loudly, or that there is a roving microphone, so everyone can hear (1 person)
- shorten the initial presentations so that people get to the discussions earlier when they are less tired (1 person)
- ensure panels are better prepared so their focus is clearer (1 person)

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- inform participants early in the day that a report will to be prepared from the workshop and when/how they will receive it (1 person)
- provide warm food for lunch and ensure fruit is provided earlier (1 person each).

In summary, the workshop was enjoyed and felt to be worthwhile by all the participants who completed evaluations.

What good self management tools and strategies are you aware of?**Specific tools mentioned**

- Websites:
 - Whitehorse and Peninsula Division of General Practice website
 - Arthritis Foundation website
 - Mary Ellen Copeland website
 - Victorian Department of Human Services (DHS) website describing how Medicare Benefit Schedule item numbers can be used in primary care
 - National Association of People Living with HIV/AIDS website, publications and telephone counselling
 - 'Health Insite' website
 - National Health and Medical Research Council website 'Geninsite'
 - CHF website
 - National Prescribing Service website
- Arthritis NSW
 - 8-18 year old annual camp
 - 'Moving On' – chronic illness self management resource
- Picker Institute in the UK
- 'WRAP' – mental health self management resource from a strength perspective
- Flinders University
 - risk assessment tools for lifestyle advisors with the South Australian Department of Health
 - capabilities tool kit for primary health care professionals
- Stamford chronic illness self management course
- Victorian DHS Hospital Admission Risk Program (HARP)
- Starlight Children's Foundation 'Livewire' Program
- Chronic Illness Alliance of NSW consumer position paper on self management
- Chronic Illness Peer Support (CHIPS) – Westmead Children's hospital 'mentor' program
- Greco's patient satisfaction measurement tools
- Mental Illness Recovery Journey – consumer delivered for consumers
- Lorig Licence, utilised by
 - Canning Division of General Practice
 - SHOUT Canberra (with support from ACT Health)
- Wellway Course – a researched peer delivered national program (university in Victoria) with a short program for people in rural settings
- Post polio consumer tool to facilitate communication with health professionals

Generic tools mentioned

- Tools for risk analysis and self assessment, e.g. risk assessment framework
- Condition specific support groups in each state
- Community health centres that provide self-management services

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- Telephone coaching by practice nurses
- E-groups as a mechanism for information sharing
- Non government organisation fact sheets
- Vocational education and training and the tertiary sector – emphasis on chronic disease self management



Background information

The Consumers Health Forum of Australia Inc (CHF) is the national voice for health consumers. As an independent non-government organisation, CHF helps shape Australia's health system by representing and involving consumers in health policy and program development.

Health consumers have a unique and important perspective on health as the users and beneficiaries of health care and, ultimately, those who pay for it. CHF takes consumers' views to government and policy makers, providing an important balance to the views of health care professionals, service providers and industry to achieve a health system that reflects the needs of all stakeholders.

CHF member organisations reach millions of Australian health consumers across a wide range of health interests and health system experiences. Health policy is developed through wide consultation with members, ensuring a broad, representative, health consumer perspective.

Current priorities include safety and quality in health care, safe and appropriate use of medicines and health care for people with chronic conditions. CHF also facilitates the appointment of consumer representatives on over 200 national health-related committees.

CHF believes all consumers should receive affordable, safe, good quality health care at the time they need it. The best outcomes are achieved when consumers are involved in decisions about and management of their own health care. Consumers should receive health care information when they need it in a form they can understand, particularly about using medicines.

Established in 1987, CHF receives funding from the Australian Government Department of Health and Ageing and membership fees. It seeks external funding for priority projects.

With its ability to access a variety of health consumer networks and extensive knowledge of consumer issues, CHF is a respected and influential contributor to the Australian health debate.

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