

## Integrated Chronic Disease Management Fact Sheet

# Consumer, Carer and Community Consultation and Participation – Resources and Case Studies

## A Resource for Primary Care Partnerships

**This resource has been developed to assist Primary Care Partnerships (PCPs) that are considering the options for consumer participation, especially with regards to their Integrated Chronic Disease Management (ICDM) initiatives. It highlights some key resources and describes some successful work in this area from around Victoria.**

Consumer participation is essential to planning, designing and evaluating the quality and effectiveness of health care services.

There is extensive literature about consumer participation: theory, models, evidence and examples. This fact sheet does not aim to summarise all approaches to consumer participation, however, it provides a starting point for PCPs endeavouring to enhance or commence this important activity, with a focus on those approaches which have been used to inform and develop integrated chronic disease management.

This resource commences with a selection of key resources for planning consumer participation, both general and specific to ICDM, followed by examples and case studies of consumer participation in PCPs against three of the five types of consumer participation outlined in the DHS 'Doing it with us, not for us' policy: information, consultation and partnership. There are few examples of the remaining two forms of participation, delegation and control, at present. *Further information about these types of consumer participation are available in 'Doing it with us not for us.'*

The focus of this resource is consumer participation at the program or department level and the health service organisation level. *Participation at the individual care level and Department of Human services level are addressed further in 'Doing it with us, not for us'.*

Contents of this resource:

1. [Resources for planning consumer participation](#)
2. [Resources specific to integrated chronic disease management](#)
3. [Examples of Information](#) (needed for participation)
4. [Examples of Consultation](#)
5. [Examples of Partnership](#)
6. [Contacts for further information](#)

# 1. Resources for planning consumer participation

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## **Department of Human Services policy and resources**

The Victorian Department of Human Services supports a range of initiatives which promote and support consumer involvement in decision-making about their treatment and care, in service development and quality improvement and in health policy developments.

Since 2006, this support has been guided by the '[Doing it with us not for us](#)' policy. The Department developed the policy in partnership with health services, consumers, carers and community members. Two key initiatives of the policy are the biennial *Participate in Health* conference and the *Evaluating Effectiveness of Participation* project grants.

A new comprehensive suite of **standards and indicators for consumer, carer and community participation** are currently in development. The indicators will cover all health sectors: acute, sub acute, mental health, primary health and public residential aged services. The Health Issues Centre is leading this piece of work on behalf of the DHS Statewide Quality Branch, and the indicators will be launched at the Participate in Health conference in September 2009. They consist of five standards with a series of supporting indicators.

These indicators will be able to be used to complete the Quality of Care reports, which community health services are mandated to complete from 2007-08 and metropolitan and rural health services complete annually to describe the systems and processes in place to monitor and improve quality.

**Visit:** [www.health.vic.gov.au/consumer/](http://www.health.vic.gov.au/consumer/)

## **The Health Issues Centre**

The Health Issues Centre (HIC) is an independent, not-for-profit organisation that promotes consumer perspectives in the Australian health system. It has a number of key services including:

- **Primary Health Consumer, Carer & Community Participation Resource** is a publication resulting from a series of training workshops with primary health agencies and Primary Care Partnerships across Victoria in 2006-07. The references (pp28-29) relevant to consumer participation in chronic disease, organised in categories of articles, case studies, and tool kits will be especially useful.
- **Victorian Consumers Participate in Health** - The Health Issues Centre maintains the Participate in Health website ([www.participateinhealth.org.au](http://www.participateinhealth.org.au)), providing information on what consumer participation means, frameworks and models and how to plan and evaluate consumer participation. The site provides practical advice and resources for agencies planning to implement consumer participation and consultation.
- **Consumer Nominee Program** recruits consumers, carers and community members for consultation and partnership activities
- **Support to organisations engaging consumers** on committees, consultations or events, including advertising opportunities or positions, making nominations of consumers, training and support for consumers, and training and support for organisations about consumer participation.

**Visit:** [www.healthissuescentre.org.au](http://www.healthissuescentre.org.au)

**Consumers Health Forum of Australia** is the "national voice for health consumers". It provides and supports consumer representatives to more than 230 national committees with a health remit. The CHF website provides useful advice on the role of consumer representatives and skills required (including a self-assessment form).

**Visit:** [www.chf.org.au/consumer\\_reps\\_program](http://www.chf.org.au/consumer_reps_program)

## Resources for planning consumer participation (cont'd)

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### **Victorian Quality Council**

The Victorian Quality Council provides several resources and services to support consumer involvement, including:

**Consumer Leadership Training** - A large challenge in developing good consumer engagement and consultation in chronic disease services is a lack of strong and enthusiastic advocates and consumer representatives. The Victorian Quality Council is piloting a consumer leadership course.

**Visit:** [www.health.vic.gov.au/qualitycouncil/activities/consumer.htm](http://www.health.vic.gov.au/qualitycouncil/activities/consumer.htm)

**Directory of consumer organisations** - organisations who have confirmed their interest in providing consumer representatives.

**Visit:** [health.webcentral.com.au/consumers/](http://health.webcentral.com.au/consumers/)

**Centre for Health Communication and Participation** at La Trobe University was established in 2009 and has a mission to improve communication with and participation by consumers and carers, through evidence-informed policy and decision making. The Centre's focus currently includes evidence for different modes of consumer participation.

The centre includes the **Cochrane Consumers and Communication Review Group** that coordinates the preparation and production of systematic reviews of interventions which affect consumers' interactions with healthcare professionals, services and researchers.

**Visit:** [www.latrobe.edu.au/chcp/](http://www.latrobe.edu.au/chcp/)

**The Picker Institute Europe** specialise in measuring patients' experiences of healthcare and using this information to improve the provision of healthcare. It works with patients, professionals and policy makers to promote understanding of the patient's perspective at all levels of healthcare policy and practice. They undertake research, development and policy activities which aim to "make patients' views count".

Some of the resources available from the Picker Institute include:

- a practical toolkit for gathering, understanding and using patient feedback to bring about improvements to healthcare services, "based on what patients say is important, and what healthcare staff tell us works"
- A Good Practice database of practical examples that have improved the patient experience
- Fact sheets on a range of useful topics

**Visit:** [www.pickereurope.org](http://www.pickereurope.org)

**Centre for Culture, Ethnicity and Health** provides training and a range of free resources about Consumer Participation and Culturally and Linguistically Diverse (CALD) Communities.

**Visit:** [www.ceh.org.au](http://www.ceh.org.au)

### **ICAP (Improving Care for Aboriginal and Torres Strait Islander Patients) Resource Kit**

developed by the Victorian Aboriginal Community Controlled Health Organisations (VACCHO) and the Department of Human Services includes suggested models and local examples of aboriginal communities' participation in health services, including:

- involving Aboriginal people in governance and advisory roles and processes
- partnerships with Aboriginal organisations
- cross-cultural training programs - a starting point

**Visit:** [www.health.vic.gov.au/koori/icap/contents](http://www.health.vic.gov.au/koori/icap/contents)

## 2. Resources specific to Integrated Chronic Disease Management

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### **Chronic Illness Alliance**

This national alliance represents over 50 consumer and advocacy groups on matters of common concern. They have considerable experience in consumer consultation and provide a consultancy service to undertake consultation exercises on behalf of organisations.

**Visit:** [www.chronicillness.org.au](http://www.chronicillness.org.au)

### **Patient Assessment of Chronic Illness Care**

In recognition that understanding patients' experiences of the health system is crucial to improving chronic illness care, the MacColl Institute developed the PACIC, a self-report instrument for assessing the extent to which patients with chronic illness receive care that aligns with the Wagner Chronic Care Model. The PACIC is the only tool currently available which audits organisational systems for chronic care from the patient's perspective.

The tool could be handed or posted to patients to complete and return to an agency, or completed as part of a consultation with a health professional. It could be used in a snapshot survey, for example, given to all clients attending a specific service which is being evaluated within a defined time period such as week. It can become part of ongoing evaluation of a new service or program. All or some questions could be added to existing patient feedback mechanisms. It has also been used in a focus group format (see case study below).

**For more information and to download the tool, visit:**

[www.improvingchroniccare.org/index.php?p=PACIC\\_Survey&s=36](http://www.improvingchroniccare.org/index.php?p=PACIC_Survey&s=36)

### **Chronic Care Models and Frameworks**

Some community advisory groups or the like have found it useful to reference the materials about consumer participation and partnerships with consumers which are contained within the major chronic disease models.

#### **Wagner Chronic Care Model – 'Community Resources'**

This model states that 'by looking outside of itself, the health care system can enhance care for its patients and avoid duplicating effort. Community programs can support or expand a health system's care for chronically ill patients, but systems often don't make the most of such resources.' The literature around this component of the Wagner model provides useful principles for consumer participation in health.

**Visit:** [www.improvingchroniccare.org/index.php?p=The\\_Community&s=19](http://www.improvingchroniccare.org/index.php?p=The_Community&s=19)

#### **Expanded Chronic Care Model**

This model integrated Wagner's Chronic Care model with principles of prevention and health promotion, by expanding on those aspects which are outside of the health system by adding some new elements. The concepts and principles behind 'Create Supportive Environments' and 'Strengthen Community Action' in this model may provide useful reference points.

**Visit:** [www.ncbi.nlm.nih.gov/pubmed/14674182](http://www.ncbi.nlm.nih.gov/pubmed/14674182)

### 3. Examples of Information

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Key tools of this strategy include public information campaigns and health consultations where staff are trained and educated in patient-centred communication.

The objectives of information that supports participation are usually:

- to support participation;
- to convey facts; and/or
- to educate.

#### Self-management poster and postcard



This poster (pictured, left) was developed by Knox and Darebin Community Health Services in 2006 to raise community awareness of the principles of chronic disease self-management, and the changes that clients were likely to see through the implementation of the Early Intervention in Chronic Disease initiative. Consumers at both organisations were consulted about the design and messages of the poster during their development.

Posters were placed in waiting rooms of community health services, consulting rooms of key clinicians and also provided to general practices in the surrounding areas.

The artwork is available for other health services to use and adapt.

**For further information, contact Carolyn Hines at Darebin Community Health on 03 9290 6604 or email [carolyn.hines@dch.org.au](mailto:carolyn.hines@dch.org.au) or Anne Parkes at Knox Community Health on 03 9757 6284 or [anne.parkes@kchs.org.au](mailto:anne.parkes@kchs.org.au).**

### 4. Examples of Consultation

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Consultation is only considered to be participation when the information is used to make or change policy, planning, research, care or treatment.

The objectives of consultation are usually:

- to find out people's views and ideas;
- to use people's views and ideas to improve; and/or
- to increase acceptance.

Where a priority has been identified by the PCP and its member agencies, focused consultation with local people who are affected by that issue (e.g. a medical condition) has been found to make a very useful contribution alongside consultation with others groups such as health service managers and health professionals.

#### **Consumer engagement can unify and drive system change – Inner East PCP Improving the Journey for People with Type 2 Diabetes project**

The Inner East Primary Care Partnership (IEPCP) and the Outer East Health and Community Support Alliance (OEHCSEA)'s joint initiative, Improving the Journey for People with Type 2 Diabetes, included in its development a consumer consultation exercise, alongside clinician-led service reviews, data mining and broad partnership and consultation work.

## 5. Examples of Consultation (cont'd)

### ***Consumer engagement can unify and drive system change (continued)***

As this project has progressed, consumer engagement has emerged as an invaluable tool for strengthening partnerships between diverse agencies, facilitating 'whole of system thinking' and ultimately driving systems change.

The initial consumer consultation exercise included 119 telephone interviews, three focus groups and six individual interviews of people living with Type 2 Diabetes. The consultation proactively engaged people who had 'dropped out of the system' by contacting people who had once attended, but then not been in contact with, some member agencies for 18 months.

The report from the consultations included the key themes identified through the consultations, as well as pictorial representations of a selection of the consumers' journeys which has proved a powerful communication tool.

**For more information, see the full case study at:**

[www.health.vic.gov.au/communityhealth/cdm/resources.htm](http://www.health.vic.gov.au/communityhealth/cdm/resources.htm)

Consulting with a group of consumers who represent a catchment as a whole is another, slightly different, consultation approach. In this case, there is no specific project or initiative which the consultation is designed to inform.

### **South East Healthy Communities Partnership Client Journey Project**

In 2005, South East Healthy Communities Partnership (SEHCP) contracted HOW Projects to undertake the Client Journey Project on its behalf. A series of interviews were undertaken over an eighteen month period with 22 members of the community. Initial interviews were conducted with a health service provider present.

Key findings from the project were wide-ranging, and included:

- A number of participants expressed concern regarding their lack of involvement in their discharge planning and ongoing decision making about their care
- Comprehensive assessment to identify all the service needs was lacking
- Unrecognised high levels of support provided by family members and carers

This information has been used by SEHCP to inform planning and project implementation in partnerships development, service coordination, integrated chronic disease management and integrated health promotion. It has also been used as a quality improvement tool within agencies and for orientation of new staff.

**For more information, contact SEHCP Executive Officer by email to [wendy.mason@southernhealth.org.au](mailto:wendy.mason@southernhealth.org.au) or phone 03 9793 3768.**

### **Increasing use of existing Consumer Consultation findings – Hume Moreland & Moonee Valley Melbourne PCPs**

At an ICDM planning session, the need for consumer involvement in service redesign to improve chronic illness care in the region was identified as a priority.

A group representing many different health and community services identified that there had been several pieces of consumer consultation undertaken in recent years, of which other agencies that were present were not aware.

Subsequently, an opportunity was identified to ensure that consumer consultation which is undertaken is available and widely accessible. PCP websites were identified as potential locations. It was also proposed that all recent consultations be analysed to identify themes and used to inform work in the region. This work is ongoing.

**For more information, contact Hume Moreland PCP on 03 9300 3082 or Moonee Valley Melbourne PCP on 8325 1855.**

## 6. Examples of Consultation (cont'd)

### **Community Conversations based on Wagner's Patient Assessment of Chronic Illness Care – Hume Moreland PCP**

The Hume Moreland PCP's Integrated Chronic Disease Management Alliance (ICDMA) undertook a process to gather local information to inform their identification of priority areas of action around ICDM in 2008. One aspect of this was to have community health services in the area complete the Wagner Organisational Assessment of Chronic Illness Care (ACIC). The Alliance also sought to obtain consumer perspective of chronic illness care in the region, The 'Patient Assessment of Chronic Illness Care'\* (PACIC) was identified to be the most relevant tool to use given its consistency with the ACIC tool that had also been completed.

The PACIC is designed to be completed by patients/consumers as a written survey. The Alliance identified some issues with this methodology including language and literacy barriers amongst community members. The developers of the PACIC tool in Seattle, USA were consulted about its use in a group discussion format and whilst they were not aware of it having been done before, they supported the initiative and asked to be kept abreast of the results. It was subsequently agreed to conduct community conversations throughout the Hume-Moreland PCP catchment based around the PACIC questions. It was also identified that the conversations would be best facilitated by independent people, such as PCP staff.

Community health services in the area organised and recruited participants to three community conversations, and a fourth was conducted with a local diabetes support group, with a total of 25 community members. PCP staff and the DHS ICDM Industry Advisor facilitated the discussions.

Generally the PACIC tool worked well as a discussion format. For the final group session, the facilitator re-ordered the questions to a more logical flow – this amended version of the PACIC is an Appendix to the final report at the link below.

Some of the findings identified included:

- Most aspects of patient activation rated very low, including providing clients with copies of treatment/care plan, or individualised list of things, to do were not evident
- Goal setting and problem-solving approaches were not evident
- Access to programs in the community was generally self-refer, not via health providers
- Participants valued their involvement in support groups and other peer learning opportunities highly for receiving the information and support that they required.

The full findings of the community conversations were presented to a planning day and usefully informed the development of ICDM priorities for Hume Moreland PCP.

**For more information, see the final report from the community conversations at [www.humemorelandpcp.org.au](http://www.humemorelandpcp.org.au).**

\* The PACIC is "a brief, validated patient self-report instrument assessing the extent to which patients with chronic illness receive care that aligns with the Chronic Care Model (CCM) — measuring care that is patient-centred, proactive, planned and includes collaborative goal setting, problem-solving, and follow-up support". Wagner, E., et al, Practice Change: PACIC Survey, Improving Chronic Illness Care website, [http://www.improvingchroniccare.org/index.php?p=PACIC\\_Survey&s=36](http://www.improvingchroniccare.org/index.php?p=PACIC_Survey&s=36) , Accessed 9 December 2008.

## 7. Examples of Partnership

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In partnership, there is a move towards joint decision making.

The objectives of partnership are usually:

- to make joint decisions;
- to agree on process; and/or
- to collectively own the outcomes.

Several PCPs have formed Consumer References Groups or Community Advisory Groups, or include consumer representatives or nominees on their governance structures.

### **Community Advisory Group - Inner South East Partnership in Community & Health**

Inner South East Partnership in Community & Health (ISEPICH)'s Community Advisor Group (CAG) comprises up to twelve community members drawn from the three local government areas of the PCP catchment (Glen Eira, Port Phillip & Stonnington). Membership is diverse and inclusive across age, gender, ethnicity, abilities and work and life experience.

**Purpose:** To provide an informed consumer, carer and community perspective on health and wellbeing issues raised by members of the group, or matters referred to it by the ISEPICH Executive or Working Groups.

**Decision making:** CAG members are represented on the ISEPICH Executive, Working Groups and sub-committees, and attend relevant forums and workshops whenever possible, including service co-ordination, chronic disease management, health promotion and partnership events and meetings.

**Achievements:** Participation of CAG members has contributed significantly to:

- ISEPICH member agencies developing more responsive client and community focused service delivery;
- a range of proactive integrated health promotion actions and strategies;
- the ISEPICH partnership's social inclusion and acceptance of diversity through their "bottom up" grassroots experience and extensive connections with local communities.

**Examples of recent significant contributions include:**

- **review of reception and intake services** across four sites of a community health centre; and
- initiation of a **community forum** about privacy, health services and e-referral.

ISEPICH pays an honorarium to CAG members when participating in ISEPICH meetings, working groups and for attendance at stakeholder forums and meetings.

**For more information visit:**

[www.port Phillip.vic.gov.au/isepich\\_participation.html](http://www.port Phillip.vic.gov.au/isepich_participation.html)

The DHS 'Doing it with us not for us' policy document on consumer participation in health has been used as the key resource for this publication, and provides a range of further information. See [www.health.vic.gov.au/consumer/](http://www.health.vic.gov.au/consumer/).

**For further information, contact:**

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