

Health Consumers' Council (WA) INC.

Consumer Participation Program

**Policy, Guidelines, Procedures and
Supporting Documents**

Revised: April 2011

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HCC Consumer Representative Program Policy

The Health Consumers' Council (HCC) acknowledges that genuine effective consumer participation is a necessary part of a patient centred health care system. Consumer representatives play a vital role as part of many government and industry decision-making and advisory bodies. Consumer representation will ensure that these bodies have access to a wide range of views. Consumer Representatives should participate in all stages and every level of health system decision making.

Aim

The HCC aims to have consumer representatives on all key decision making committees in the WA health system

Scope

This policy covers the Consumer Representative Program of the HCC including the process for recruitment, selection, training and support of consumer representatives.

The guidelines that follow the policy are aligned with the DOCEP publications Consumer Representation on Boards and Committees: 'A Guide for Consumers' and 'A Guide for Industry and Government'

What is a Consumer Representative?

A Consumer Representative is a committee member who voices the consumer perspective and takes part in the decision making process on behalf of consumers. This person is usually nominated by, and is accountable to, an organisation of consumers.

Principles

The Health Consumers' Council supports and values consumer representatives by recognising their voluntary efforts and appreciating the meaningful contribution they make to the WA health system.

Consumer representatives will be:

1. Capable of reflecting viewpoints and concerns of consumers
2. Members in whom the HCC has confidence.
3. Aligned with the HCC Vision, Mission and Code of Conduct

Consumer Representatives fall into two categories:

- Individuals nominated by HCC but selected by the requesting organisation
- HCC representatives, selected by, and representing, HCC (an only occasional occurrence).

Consumer Representatives who represent the HCC will be approved by the HCC Board. It is not appropriate for Consumer Representatives to represent or speak on behalf of the HCC unless appointed by the Board to do so.

However if a consumer representative needs or wants to indicate an affiliation with the HCC the term member of the HCC may be used in association with their name.

If there is a degree of urgency about consumer representation a HCC staff or Board member will participate in meetings until a consumer representative is agreed upon. HCC will select the best and most appropriate person for the position.

Health rights

All Consumer Representatives will be guided in their contribution by the following set of health rights:

- The Right to safety
- The Right to be Informed
- The Right to participate
- The Right to redress
- The Right to consumer education
- The Right to respect

Adopted: 27 February 2007

Reviewed: 2009

Reviewed: 2011

HCC Consumer Representative Program Guidelines

Purpose

These guidelines are provided to give direction to HCC members who are nominated or appointed as consumer representatives.

Being a consumer representative may take a number of different forms, some of which include participating:

- As a member of a statutory body or Ministerial Taskforce
- On a range of committees including advisory committees.
- In research projects, forums or focus groups
- In meetings where policy is developed and/or action plans devised
- In evaluation of services provided
- In development of educational material
- In complaints resolution schemes

Recruitment

Consumers wishing to be considered for nomination/appointment as a consumer representative need to be:

- 1) A member of the Health Consumers' Council
- 2) Have undertaken or be willing to undertake consumer representative training by HCC (or equivalent)
- 3) Agree to abide by HCC Code of Conduct and sign the Program Agreement Form (Page 10)
- 4) Agree to report to HCC in writing at least annually (Page 11)
- 5) Participate when requested in meetings such as the Health Issues Group (HIG) or the Consumer Representatives Network Meeting.

It is a requirement of the recruitment process that applicants are made aware as to whether they are being appointed directly onto a committee by power of the HCC or nominated by the HCC to an external party.

The Health Consumers' Council will support the recruitment process by:

- 1) Maintaining a Consumer Representative Placement Register which indicates areas of knowledge, expertise and interest of consumer representatives
- 2) Ensuring that consumer representatives match the requirements of the committee as closely as possible

- 3) Promoting the Consumer Representative Program through *Health Matters*, the Non Government (NGO) sector and to all new members
- 4) Providing training for current and prospective consumer representatives as required (usually four courses per annum)
- 5) Promoting training through advertising, word of mouth and individual contact
- 6) Support and mentoring as required.

Training

The Health Consumers' Council conducts regular training courses to prepare individuals to be effective Consumer Representatives. Courses are promoted through *Health Matters*, the NGO sector and to all new members.

All Consumer Representatives, HCC members, persons from other health organisations and NGO's may attend training sessions at no charge.

The aim of the training course is to develop the skills of effective consumer representation by providing:

- 1) Knowledge of WA and Australian health system
- 2) Knowledge of rights and responsibilities in the health system
- 3) Knowledge about the work of the Health Consumers' Council
- 4) Knowledge about the philosophy of the Health Consumers' Council
- 5) Knowledge about communication, coalitions of influence and negotiation
- 6) Knowledge about the consumer concerns

Ongoing training will also be available for active consumer representatives. The HCC will hold refresher courses which all consumer representatives are required to participate in at least once every five years.

Evaluation of Consumer Representative Skills Training is done at the conclusion of each training course. The results are analysed and then influence the development of the next training course.

Ongoing Support for Consumer Representatives

Once one becomes an active consumer representative the HCC will provide ongoing support to the individual. Consumer representatives are invited to attend Consumer Representative Network meetings, to share ideas and information with other consumer representatives.

Ongoing relevant information and event invitations will be sent to consumer representatives to aid in their ongoing training.

The HCC however does not have sufficient resources to provide individual support to consumer representatives (except in exceptional circumstances). Consumer representatives may request the Consumer Participation Coordinator, the Executive Director, an experienced member of the staff or the outgoing consumer representative to accompany them on their first meeting. The decision as to whether this occurs however be will be individually assessed upon the request.

HCC Consumer Representative Program Procedures

Request for a Consumer Representative

Requests from organisations usually come in two forms, calling for a consumer representative or a HCC Representative. It is important for the Consumer Participation Coordinator to contact the requesting organisation where a HCC representative is requested to clarify the intention of the requesting organisation.

Organisations requesting the HCC nominate or appoint a consumer representative should supply the following information:

- Terms of reference of the committee
- Frequency and venue of meetings
- Expertise and/or experience required for the committee
- Provision of sitting fees, out-of-pocket expenses, etc
- Time, date and venue of next meeting
- Name and contact details of Committee Chairperson

In addition HCC should provide to the requesting organisation:

- A copy of this policy
- A copy of the Advice to Chairpersons (Page 14)
- A copy of the expectations that HCC has of the requesting committee and what they can expect from HCC (Page 12)

Procedure for Placement of Consumer Representatives

Upon receipt of a request for a consumer representative, generally expressions of interest will be called from all members who have indicated:

- (1) A willingness to be a consumer representative
- (2) An interest in/ experience of the particular health area requesting for a consumer representative (this information is held on the HCC Database)
- (3) People who have undertaken the HCC Consumer Representative Skills Training.

On some occasions, individual HCC Members will be approached directly to become a Consumer Representative.

In some circumstances it may be appropriate for staff to participate on a local/state level board or committee. The decision is a matter for the Executive Director and circumstances may include

- 1) The staff member attends one or two meeting to gain a clearer idea of the skills and experience needed by the consumer representative in order to be able to participate fully
- 2) The meeting is very important but insufficient time has been given to HCC to complete the nomination/appointment process
- 3) The board/committee has some “peak” communication function and the consumer representative is required to synthesize input from other consumer representatives and feed back the “Peak committee deliberations to consumer representatives on subordinate committees/groups.
- 4) The staff member is the best person to be on the board/committee in the light of their skills and experience
- 5) Attendance by a staff member has been specifically requested by the minister, director general of the chair of a significant board/committee

The first cases are a matter for the Executive Director to decide upon. The third and fourth examples will be decided upon by the Consumer Representatives Placement Committee following advertising of the vacancy as per the normal procedure.

If the staff member is nominated as per arrangements three, four or five is the Executive Director, then the HCC Board should be advised.

This policy however should not apply to staff members participating in any board/committee in their private time.

In order to identify trends and broader systemic issues relating to the strategic direction of the Consumer Representative Program and ensure its ongoing success the HCC will write a quarterly review. HCC will provide the review to the Board providing information regarding:

- The number of requests from external bodies for consumer representatives in the last quarter
- Number of these requests which were advertised for expressions of interest
- How the requests were advertised
- The number of expressions of interest received (i.e. in the form of “three vacancies received no expressions of interest, two vacancies received two or more expressions of interest)
- The number of requests which were for appointment (HCC decision) and the number of requests for nomination (The external body was the decision maker)
- The number of requests for letters of support/endorsement for HCC members seeking to be appointed to national committees; and
- The number of requests where a staff member had been appointed or nominated

Selection

The “Consumer Representative Placement Committee” comprises of the Executive Director, a member of HCC who is an experienced consumer representative and the Consumer Participation Co-ordinator. The HCC Consumer Representative on the committee has a two year term. This committee will be responsible for determining

appointments or nominations of consumer representatives after requests by external bodies.

The decision be decided upon based on their;

- 1) Ability to address health issues from a consumer perspective
- 2) Relationship, networks and accessibility to the people and groups they represent
- 3) Possession of good communication skills or willingness to develop these skills with appropriate training and support
- 4) Respect for diversity of consumers and fellow committee members
- 5) Ability to work effectively in a team environment
- 6) Understanding, commitment and maintenance of confidentiality when it is required
- 7) Interest in health issues and current activity in health sector
- 8) Ability and willingness to report back to HCC and provide notification of changes to committees.

Where the Executive Director is requested to participate on a committee, the Executive Director retains the discretions to approach an individual HCC member with appropriate knowledge, skills, and attitude to take on this position.

Appointment of a Consumer Representative

The Health Consumers' Council depends on Consumer Representatives to promote and articulate a consumer perspective in all parts of the WA health system. The Council is always willing to provide support, advice and information to Consumer Representatives.

Once the appointment of the consumer representative has been confirmed and the name of committee confirmed this information will be added to the Consumer Representative Database.

- The Chair or contact person for the committee will be notified of the consumer representative's name and contact details and given a copy of Advice for Chairpersons
- The consumer representative will be notified in writing of their appointment including:
 - Copy of Policy for Consumer Representatives Program
 - Information about reporting obligations including suggested format
 - Information about the Consumer Representatives Network meetings
 - Information about support available from HCC
 - Declaration on Patient-Centred Healthcare from the International Association of Patients' Organisations

Appointments will be for three years unless appointed for a set period by the committee or the term of the Committee if less than three years. After the three year period the consumer representative may expect to be reviewed by the review

committee and possible movement may result or no replacement of the consumer representative may be seen necessary.

Evaluation of consumer representatives will be undertaken by HCC every 12 months. A self-assessment survey will be forwarded to each Consumer Representative for completion and return.

Information about new committee appointments will be published in Health Matters.

Adopted: 27 February 2007

Reviewed: 2009

Reviewed: 2011

Consumer Representatives: Agreement form for Consumer Representatives
Appointed to Committees

The Consumer Representative undertakes to participate in committee and other forums, representing a broader group of like-interested members of the community. The Representative does this on behalf of, and as a member of the Health Consumers Council. The Consumer Representative agrees that their contribution as a Consumer Representative will be based on the five Health Consumer Rights:

- ❖ The Right to Safety
- ❖ The Right to Information
- ❖ The Right to be Heard
- ❖ The Right to Redress
- ❖ The Right to Community Education

In respect to the:

Name of committee, forum or other event: _____

Name of Consumer Representative:

Will be required to:

1. Attend meetings: _____
(Frequency)
2. Refer to contact person on committee:
Name: _____
Position: _____
Phone: _____ Email: _____
3. Refer to HCC contact person: _____
4. Signature of Consumer Representative: _____
5. Signature of HCC Representative: _____
6. Date: _____

Consumer Representatives: Meeting Report

One of the important aspects of consumer representation on committees is sharing the information with other consumers. As a means of doing this the Health Consumers' Council is requesting a report from each consumer representative on the activities of the committee/s they are currently or have been participating in. We are only requesting a brief report no longer than one page and in dot point format.

Representatives Name:

Name of the Committee:

Purpose of the Committee:

What have the consumer issues been?

What issues/decisions could affect Health Consumers' Council or consumers?

Has the committee discussed any items of interest to the Health Consumers' Council?

Do you have any items of interest that could be published in Health Matters?

Please return report to the Consumer Participation Programme Coordinator:

Email: info@hconc.org.au

Fax: 9221 5435

Mail: GPO Box C134 PERTH WA 6000

Expectations of the Health Consumers' Council from Committees and what committees can expect from Health Consumers' Council

What the Health Consumers' Council expects from Committees

- Sufficient and appropriate notification of meetings including changes/cancellations
- An inclusive process for out of session decisions
- The provision of meeting documents in a timely manner
- Respect for the consumer representative
- Opportunity for the consumer representative to speak at meetings
- The understanding that representatives may sometimes need time to consult with other consumers on some issues
- Reimbursement of meeting expenses as a minimum payment requirement.

What Committees can expect from HCC and the Consumer Representative

- Support and information for the consumer representative
- A large consumer network available for consultation
- Frank and fearless advice from a consumer perspective
- An interest in and knowledge of current health issues particularly those relevant to the committee
- Adequate preparation for meetings
- Understanding of, commitment to and maintenance of confidentiality when required
- Ability to work effectively in a team environment

Qualities of an Effective Health Consumer Representative

Effective consumer representatives are able to:

- Address all the issues from the perspective of the consumer;
- Develop and maintain relationships with the people and groups they represent;
- Use strong communication skills, or develop those skills with the appropriate training and support;
- Respect diversity;
- Work effectively in a team environment;
- Understand, commit to and maintain confidentiality when it is required;
- Maintain an interest in current health issues and news especially those issues relevant to health consumers and to the committees on which they sit;
- Participate in community activities that are relevant to their consumer networks;
- Have a broad community network with which to consult regularly;
- Be accessible to the consumer groups they represent; and
- Bring to the committee some understanding of the issues and health services.

Newly appointed consumer representatives may bring these attributes to the role or may be committed to developing these skills and abilities in order to effectively represent consumers.

This information is adopted from *Consumer Representation on Boards and Committees: A GUIDE FOR CONSUMERS*: Western Australian Consumer Advisory Council; Department of Consumer and Employment Protection.

Background

Your committee has recently had a consumer representative appointed to it. This document is to assist your group to gain the full benefit of having a consumer representative involved in your activities. Being a consumer representative can be a daunting experience when the consumer representative is the only lay member of a group of professionals and support from the Chairperson is appreciated and enables the consumer representative to be more effective.

Definition of a Consumer Representative

A consumer representative is a committee member who voices the consumer perspective and takes part in decision making processes on behalf of consumers. This person is usually nominated by, and is accountable to, an organisation of consumers. While their own experience as a consumer is important they are expected to take a broader perspective and represent the views of a particular group e.g. people with diabetes.

Purpose of Consumer Representatives

The three main purposes of the Consumer Representative are to;

- To bring a consumer perspective to the consultation and decision-making processes just as other members of the group bring theirs.
- To obtain better health outcomes this is the common goal of Consumer Representatives and health service providers.
- To ensure social justice for the more disadvantaged and marginalised members of the community.

Benefits of Consumer Representation on Committees

Consumer representatives provide a different view from health service providers.

Effective consumer representatives can and do add value to decision-making because they can assess problems from the consumer perspective and identify the consequences of both the problem and any proposed solutions.

If members of the group work together in bringing the knowledge and experience of each there will be a clear understanding of the consequences of particular decisions for those groups represented.

Things to Consider

There will be occasions when the consumer representative will need to consult with a wider constituency which will need additional time. However, consumer

representatives are as good as their knowledge of the people they represent so it is important that consumer representatives are allowed the opportunity to consult when necessary.

Many boards, advisory bodies, departmental working parties and committees which include consumer representation include one or two consumer representatives with 5 to 10 industry and/or professional representatives. This significant imbalance can cause problems and a sense of isolation for consumer representatives. They often find that their viewpoint is always different to the one which has to be justified and which is seen as a challenge by other members. They also find that as an individual member, they need to speak more frequently than any other because if they don't speak, the consumer perspective is not heard.

Confidentiality should also be considered. Some information can make it difficult for consumer representatives to consult with other consumers. Potential conflict between the need for confidentiality and the need to consult can be avoided if it is clarified at the meeting what matters can be discussed publicly and what needs to be kept confidential.

Expense is a barrier to participation particularly as many representatives are not in the paid workforce and may be pensioners. Reimbursement of expenses such as parking fees, fuel/ public transport costs if sitting fees are not available is appreciated by the representative. The use of email can carry with it considerable costs for printer cartridges, paper etc. If sending large documents to consumer representatives consider using ordinary mail as a means of reducing costs for the consumer representative.

How to help the Consumer Representative be most effective

There are a number of ways you can support the consumer representative be most effective in order to get the most out of your experience in working with them;

- Establish a relationship with the consumer representative
- Ensure that all members of the group treat each other courteously and that everyone's ideas are treated seriously
- Ensure that decisions are made with the whole group working together and reaching agreement
- Make sure that every member of the group has an opportunity to speak on each issue
- Apply the rules of natural justice
- Make it clear to all members precisely what is confidential and what can be talked about and suggest how this might be done
- Make sure everyone has access to the same information. This may mean making additional information available to those who are not part of the health service sector
- Build cohesion and trust within the group
- Deal immediately and effectively with conflict, difficult situations, and difficult people.

- Ensure that documents are provided to consumer representatives in good time for their meeting preparation.

References

Consumers Health Forum of Australia Inc. 2001. *Guidelines for Consumer Representatives*: Consumers Health Forum of Australia Inc.

Ministry of Consumer Affairs. 2004. *Consumer Representation: Guidelines for Chairperson Helping Consumer Representatives to be Effective*: Ministry of Consumer Affairs, New Zealand.

Adopted: October 2005

Consumer Representative Payment Policy

Background

The Health Consumers' Council supports health consumers on a number of local and state committees.

Most consumer representatives, with the exception of those appointed to State Registration Boards or involved with Divisions of General Practice, are not paid for their participation.

Mental health consumers, registered with the Mental Health Consumer Participation Program, receive payment for participating in a decision-making committee

Definition

Consumer representatives are members of a group, however titled (eg committee, working group, Board, focus group, etc.), considering health policy, planning, implementation, service and review.

A consumer representative is a person who brings a consumer perspective to matters under consideration and takes part in the decision-making process. This includes:

- Presenting how consumers may feel and think about certain issues
- Contributing the consumer experience
- Proving information about relevant issues affecting consumers

Consumer representatives should be an active member of a consumer organisation.

Rationale

HCC endorses the principle of payment to consumer representatives as an acknowledgement of their expertise and the value of the consumer input.

Remuneration/reimbursement puts the consumer representative on a similar footing to other participants and makes the consumer opinion as valuable as that of others.

HCC does not want the issue of payment to become a barrier to consumer participation and accepts the participation, not payment, is the key issue.

Policy

HCC considers the importance of acknowledgement of consumer expertise and the value of consumer input should be rewarded and thus recognised by health agencies.

Consumer representatives have the right to accept or refuse payment for their participation.

Policy Implementation

HCC will promote this policy through *Health Matters*, the Department of Health and health-related agencies.

The Council, when approached by agencies for participants to sit on health-related bodies, will encourage these agencies to consider payment for the consumer representative(s).

HCC will advocate for consumer payments.

Recommended Payment Guide

Recommended rates will include recognition of effort and out-of-pocket expenses similar to the model of the Mental Health Consumers Participation:

| | |
|--|---------|
| Minimum rate for first hour (or part thereof) | \$25.00 |
| Minimum rate for two (2) hours (or part thereof) | \$50.00 |
| Hourly rate after first two hours | \$20.00 |

Policy to be reviewed **May 2003**
Reviewed: **2003**
Reviewed: **2008**