Finding Consumers and Carers
A Guide to Sourcing Consumers, Carers & Community Members for Collaborative Health Service Improvement
Legend
FINDING CONSUMERS AND CARERS

LEGEND

Type of involvement
1. responding to/commenting on papers, facts sheets, web sites, education packs
2. questionnaires and surveys
3. representatives on Boards
4. membership of advisory/steering committees/reference groups
5. focus groups
6. individual and group interviews
7. panels
8. public meetings
9. workshops/seminars/conferences
10. training/education activities
11. advocacy

Focus of involvement
a  evaluation
b  feedback
c  policy
d  quality
e  standards
f  research
g  ethics
h  strategic planning
i  service planning
j  training
k  education

Assistance required for a member/consumer and carer to participate

- payment for time at meetings and preparation time
- reimbursement of costs (travel, childcare, carer/respite, attendant carer)
- carer/respite, childcare to be offered
- responsiveness to special requirements including dietary, transport
- orientation to organisation, health system, main issues, and mentoring by a staff member
- refreshment
- administrative support
- written material in easy English and supporting documentation supplied, if the document is lengthy an executive summary needs to be provided
- translation and interpretative support
- time for reading and/or to gain input from membership/board of management
- staff, attendant carer or support person of family member to assist in travel to the project and or participation in the meeting
- hearing access (or hearing augmentation) for example an audio loop or note taker
- materials produced in a format which meets the requirements of the particular individual eg large print, audio, Braille, in an appropriate format for disk (word or plain text formats)
- meetings are held to time (often respite is booked for set times or people need to catch public transport)
- assistance with writing, and reading holding and turning pages
- payment for staff time in recruiting, selecting supporting and mentoring participants
- two consumers or carers rather than one to attend meetings
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**LEGEND**
Introduction

“Finding Consumers and Carers: A Guide to Sourcing Consumer, Carer and Community Members for Collaborative Health Service Improvement” (the Guide), is a key initiative of the Victorian Quality Council (VQC). Increasing the effective involvement of consumer, carer and community members (hereafter called consumers) in the improvement process is one component of a strategic approach to reducing the risk of harm and improving health care safety and quality in Victoria, including: Establishing a Safety and Quality Framework, Providing Improved Access to Better Data, Educating on Safety and Quality and Responding to Known Problems and Risks.

The purpose of this Guide is to assist health services to involve consumers to participate in collaborative quality and safety activities for health service improvement. The Guide is essentially a listing of consumer organisations that are interested in working with health services to improve the quality and safety of health care.

Quality and Safety Improvement

The Australian Council on Health Standards (ACHS) defines quality in health care as “the extent to which the properties of a health care service or product produce a desired outcome” (ACHS, 2002) and quality improvement as “involving activities which measure performance, identify opportunities for the improvement in the delivery of care and services and include action and follow up” (ACHS, 1998). Quality in health care can also be described by its key elements, for example, safety, appropriateness, accessibility, equity, effectiveness acceptability and efficacy (ACHS, 1998; Woodward, 2000).

The VQC “Better Quality, Better Health: A Safety and Quality Improvement Framework for Victorian Health Services” in describing safety as a dimension of quality states “a major objective of any health care system should be the safe progress of consumers through all parts of the system. Harm arising from care, by omission or commission, as well as from the environment in which it is carried out must be avoided and risk minimised in care delivery process” (VQC, 2003).

Using the Guide

To make the best use of this Guide, health services will need to develop a clear idea of what they wish to achieve by involving consumers in a particular activity. This will assist the consumer organisations to approach the most appropriate consumer to participate. It is important to remember that consumers and carers may also be referred to by other names, such as volunteers, advocates, representatives, clients, patients or members.

Structure of the Guide

“Finding Consumers and Carers: A Guide to Sourcing Consumers, Carers and Community Members for Collaborative Health Service Improvement” provides information about the various ways in which consumers from different groups and organisations prefer to participate. It will help ensure that consumers are involved in ways that are supportive and appropriate to their interests and needs and that meet the needs of health services.
Alphabetical Listings
This section lists organisations alphabetically with current contact details, aims and activities and their membership or constituency. Some organisations have different levels of membership and not all members are necessarily consumers and carers. Consumer motivation and interest in participating in quality and safety activities is indicated for each organisation, as well as their requirements regarding project proposals. Over a third of the organisations expressed an interest in, or had already been involved in a large number of the consumer participation activities either with health services or within their own organisation. Other organisations indicated that they have limited resources or abilities to respond to requests.

Codes and Explanation of their Use
Each of the organisational entries is divided into sections entitled:
- Level of involvement
- Type of involvement
- Focus of involvement
- Recruitment, selection, training, support & mentoring of members/consumers and carers
- Assistance required for a consumer/member and carer to participate

These headings and associated codes are explained below.

Level of Involvement
This refers to the level at which an organisation has an interest in being involved. Some organisations are interested at the national, state and local levels so the word “All” appears, others have a preference that is listed in order of that preference. “Local/State” would indicate they do more work at the local level and some at the state level.

Type of Involvement
This refers to the consumer participation activities the organisation believes their consumers are interested in, or have participated in, in the past. Each activity is numbered and the numbers appear in an entry to indicate that organisation’s preferences. If they are interested in all of them the word “All” appears. The number codes are as follows:
1. responding to/commenting on papers, facts sheets, web sites, education packs
2. questionnaires and surveys
3. representatives on boards
4. membership of advisory/steering committees/reference groups
5. focus groups
6. individual and group interviews
7. panels
8. public meetings
9. workshops/seminars/conferences
10. training/education activities
11. advocacy
Focus of Involvement
This refers to the main area of interest in health care delivery. For example, an organisation might be interested in policy development such as discharge management in a large acute hospital, improving an individual's care at the service planning level, such as the development of protocols for the care of colorectal patients, or providing training to staff members on the experience of a person with a sensory disability. This organisation’s entry will list the letters “c,i,j” to indicate their preferences.

The codes are as follows:

- a evaluation
- b feedback
- c policy
- d quality
- e standards
- f research
- g ethics
- h strategic planning
- i service planning
- j training
- k education

Recruitment, Selection, Training, Support & Mentoring of Members/Consumers & Carers
This section explains how each organisation recruits consumers to be involved in quality and safety activities. Some organisations describe themselves as having formal processes and others have informal processes responding to each request individually. Organisations that have a formal process tend to be those organisations that regularly access their consumers/members for quality improvement activities in their own organisation or in health service or government projects. Organisations also provide information about the availability of members and what might restrict their involvement or availability. For example, if they are carers they may need to organise alternate care, or they may have mobility issues, or work full-time. Where there is a varied membership the entry will state membership availability is varied. Each organisation states whether it can support a consumer participation project through training, support and mentoring.

Health services can improve the experience of involvement for both the health service and consumers by:

- allowing sufficient time for recruitment and orientation prior to the commencement of a project as this process can take some time
- providing a single point of contact within the health service where consumers can seek information and advice about a project they are involved in
- ensuring consumers are provided with all relevant information about the project or activity they are involved in including any constraints or limitations and
- clarifying roles and responsibilities when recruiting consumers.
**Assistance Required for a Member/Consumer and Carer to Participate**

These symbols refer to the assistance a consumer/member might require to participate effectively. For example, if the health service is running a focus group, the consumer may require their travel to be organised and/or paid for, and remuneration for attendance (SM & S), or if they are attending a meeting they may require attendant care, time for reading materials and materials produced in a format which they can understand (M, M & M). These symbols act as a guide to consumer needs but health services should check with the individual or group of consumers and carers when negotiating their involvement. The symbols are as follows:

- **SM** payment for time at meetings and preparation time
- **S** reimbursement of costs (travel, childcare, carer/respite, attendant carer)
- **M** carer/respite, childcare to be offered
- **☆** responsiveness to special requirements including dietary, transport
- **O** orientation to organisation, health system, main issues, and mentoring by a staff member
- **R** refreshment
- **A** administrative support
- **W** written material in easy English and supporting documentation supplied, if the document is lengthy an executive summary needs to be provided
- **T** translation and interpretative support
- **R** time for reading and/or to gain input from membership/board of management
- **RR** project responsiveness to individual needs of participant including, time during meetings to understand and to ask questions, acknowledgement of the ability of member and their disability, meetings held at a time convenient to use public transport
- **staff, attendant carer or support person of family member to assist in travel to the project and or participation in the meeting**
- **hearing access (or hearing augmentation) for example an audio loop or note taker**
- **materials produced in a format which meets the requirements of the particular individual e.g. large print, audio, Braille, in an appropriate format for disk (word or plain text formats)**
- **meetings are held to time (often respite is booked for set times or people need to catch public transport)**
- **assistance with writing, and reading holding and turning pages**
- **payment for staff time in recruiting, selecting supporting and mentoring participants**
- **two consumers or carers rather than one to attend meetings**

**Directories, Peak Bodies, Resource Centres and Websites**

Contact details and links for useful directories, peak bodies, resource centres and websites.

**Index**

Provides an alternative way of finding listed organisations, consumers and carers.
Examples of How the Guide might be Used

A health service will be able to use this Guide to access individual and/or groups of consumers and carers for any number of activities. Here are several examples:

1. A health service wanting to improve staff communication skills in their service provision to culturally and linguistically diverse (CALD) consumers and carers decide to engage a speaker to address hospital staff on relevant issues. By using the index of organisations that can provide speakers in this area, they identify a number of Migrant Resource Centres and Ethnic Communities Councils listed. They then refer to the specific entries for those organisations to check on the regions they cover, their particular areas of interest, and requirements for involvement and contact the specific organisation to ask for a speaker.

After hearing the representative from the Migrant Resource Centre speak and discussion with staff it is decided to focus on two ethnic groups which represent the largest percentage of CALD consumers attending the service. A quality improvement activity is then developed to address this and the staff involved seek consumers to be involved. They search the index in the Guide of organisations that can provide consumers, and find several organisations that may be appropriate. On reading the “motivation for involvement in improving the safety and quality of health care” sections for each organisation, they find that Carers Victoria have a particular interest in discharge. They contact Carers Victoria to discuss nominating a carer to sit on a committee to review current discharge policies.

3. A health service wants to improve the quality of the information they provide to consumers who have sensory difficulties. They look in the Guide index under “ear, nose and throat”, and “eye” to find organisations with expertise in the area. They examine each entry and choose those organisations with formal recruitment strategies for consumers, for example Communication Aid User Society and Blind Citizen’s. A letter is sent to both organisations, formatted according to their requirements, explaining the project in detail, and asking for their assistance in recruiting consumers for a focus group. Payment for participation and associated costs is offered as well as assistance to ensure that any particular sensory needs of participants are met.

References

Action for Community Living (ACL)
179 High Street, Northcote, VIC 3070
Tel 03 9489 2999 or 03 9489 1179 Fax 03 9489 2988
Email acl@advocacyhouse.org Website www.advocacyhouse.org
Hours Open Mon – Fri, 9am – 5pm
Contact Person Ms Libby Zerna
Geographical Area Serviced Statewide
Regional Groups & Contact Details Regional groups can be contacted through this group.

Aims and activities
To promote empowerment and independent life in the community for people with disabilities through advocacy, support and referrals.

Membership
Anyone with a disability, family members, carers and friends.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in disability and each project proposal will be considered on its merits.

Level of involvement State/Local
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation is able to provide formal recruitment and selection process to members through their newsletter, training in representation through seminars and conferences, and support as needed. Consumers and carers represent the organisation. Members may have mobility issues and may require an attendant carer or a carer may require time to arrange an alternate carer.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.

Action for More Independence & Dignity in Accommodation (AMIDA)
1st Floor, 247 Flinders Lane, Melbourne, VIC 3000
Tel 03 9650 2722 Fax 03 9654 8575
Email amida@infoxchange.net.au Website www.infoxchange.net.au/AMIDA
Hours Open Mon – Thurs, 9.30am – 5pm
Contact Person Ms Gabrielle Dickson or Ms Pauline Williams
Geographical Area Serviced Statewide

Aims and activities
To ensure additional and improved housing and tenancy rights for people with disabilities. This is achieved by involving them in the running of the organisation, providing telephone advice, information and support, direct advocacy, providing education on housing rights and a newsletter.

Membership
People who support the aims of the organisation.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in housing, deinstitutionalisation, community living, the rights and support of people who live in the community and projects that are confidential and useful to members.

Level of involvement National/State/Local
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation is able to provide formal recruitment and selection of consumers through their committee of management, a newsletter and by word of mouth. Support and mentoring can also be provided as needed. Consumers represent the organisation and most members work part-time or receive a Disability Support Pension. Many are involved with other organisations.

Assistance required for a consumer/member and carer to participate
PR $M
Alcohol Related Brain Injury Accommodation and Support (ARBIAS)

183 Gertrude Street, Fitzroy, VIC 3065
Tel 03 9417 7071   Fax 03 9417 5185
Email arbias@arbias.com.au   Website www.vicnet.net.au/~arbias
Hours Open Mon – Fri, 9am – 5pm
Geographical Area Serviced Melbourne metropolitan area and phone consultation for rural areas.
Regional Groups & Contact Details Have groups in all metropolitan regions and conducted projects in regional areas. Contact ARBIAS office for details.

Aims and activities
A community based organisation, representing the rights and needs of people of non-English speaking backgrounds (NESB) with disabilities, and their carers. Activities include advocacy, community education, information and referral, research, training and consultancy, access and equity programs, language specific carer support groups, volunteer-based in-home respite, mental health access and support programs, as well as a newsletter.

Membership
Community organisations, people with a disability from a NESB and interested others.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in short-term funded projects, which protect the interests of their clients, follow through on findings and are directly relevant to the organisation’s purpose. This being disability, NESB issues, emotional and mental wellbeing, reducing isolation of carers and clients and access to generic and specialist services.

Level of involvement State/Local
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
ARBIAS does not offer formal recruitment or training and have limited resources to support or mentor, but can provide these if the project is funded. They have a community reference group, which provides peer support and can provide recruits. All board members represent ARBIAS.
Member/consumer availability is dependant on the appropriateness of the project keeping in mind that the clients/consumers and carers come from vulnerable populations.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.

Action on Disability within Ethnic Communities (ADEC)

13 Munro Street, Coburg, VIC 3058
Tel 03 9383 5566   Fax 03 9383 5185
Email info@adec.org.au   Website www.adec.org.au
Hours Open Mon – Fri, 9am – 5pm
Geographical Area Serviced Statewide
Regional Groups & Contact Details Have groups in all metropolitan regions and conducted projects in regional areas. Contact ADEC office for details.

Aims and activities
A community based organisation, representing the rights and needs of people of non-English speaking backgrounds (NESB) with disabilities, and their carers. Activities include advocacy, community education, information and referral, research, training and consultancy, access and equity programs, language specific carer support groups, volunteer-based in-home respite, mental health access and support programs, as well as a newsletter.

Membership
Community organisations, people with a disability from a NESB and interested others.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in short-term funded projects, which protect the interests of their clients, follow through on findings and are directly relevant to the organisation’s purpose. This being disability, NESB issues, emotional and mental wellbeing, reducing isolation of carers and clients and access to generic and specialist services.

Level of involvement State/Local
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
ADEC does not offer formal recruitment or training and have limited resources to support or mentor, but can provide these if the project is funded. They have a community reference group, which provides peer support and can provide recruits. All board members represent ADEC.
Member/consumer availability is dependant on the appropriateness of the project keeping in mind that the clients/consumers and carers come from vulnerable populations.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.
Alzheimer’s Australia Victoria

Locked Bag 3001, Hawthorn, VIC 3122
Tel 03 9815 7800  Fax 03 9815 7801
Email alz@alzvic.asn.au  Website www.alzheimers.org.au
Hours Open  Mon – Fri, 9am – 5pm
Contact Person  Policy Officer
Geographical Area Serviced  Statewide
Regional Groups & Contact Details
- Ballarat Tel 03 5320 3701;
- Bendigo Tel 03 5454 7123;
- Benalla Tel 03 5762 6299;
- Geelong Tel 03 5260 3501;
- Horsham Tel 03 5381 9395;
- Moe Tel 03 5127 9141;
- Swan Hill Tel 03 5032 3120;
- Warrnambool Tel 03 5561 9386

Aims and activities
To support and educate people with dementia, their families, carers and care workers. To advocate for prevention of dementia and service enhancements through the provision of information, counselling, a telephone help line, early stage dementia support programs, education and information sessions, library, newsletter, website, resources and consumer events.

Membership
People with all forms of dementia, their families, friends, service providers, care workers and other interested people.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in short-term projects, with a relevance to dementia, aged and primary care. The project should address quality of life issues, and have a potential for positive outcomes and provision of meaningful feedback to participants.

Level of involvement  National/State/Local
Type of involvement  All
Focus of involvement  All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation trains and supports members to represent them and employs a volunteer coordinator to progress training. Members are recruited through the newsletter, newspapers and a personal approach. These are often carers, limited by their caring responsibilities and other commitments, but interested in being involved in consultations, forums and lobbying associated with dementia. Formal representatives are appointed and report back to senior management. Members are trained as speakers and individuals have presented at conferences but not as representatives of the organisation. They are currently establishing a consumer advisory group.

Assistance required for a consumer/member and carer to participate
Arthritis and Osteoporosis Victoria

263-265 Kooyong Road, Elsternwick, VIC 3185
Tel 03 8531 8000 Fax 03 8531 8022
Email Gillian@arthritisvic.org.au Website www.arthritisvic.org.au
Hours Open Mon – Fri, 9am – 5pm
Contact Person Ms Gillian van der Drift, Community Development Coordinator
Geographical Area Serviced Statewide
Regional Groups & Contact Details Regional self-help groups can be accessed through Arthritis and Osteoporosis Victoria, and their website.

Aims and activities
To raise awareness and empower people to self-manage their musculoskeletal conditions. They provide leader training and participation in self-management courses, support and self-help groups, networking, physical activity groups, advocacy education, information provision, a newsletter and magazine.

Membership
Membership is open to any organisation or individual.

Motivation for involvement in improving the safety and quality of health care
Interest in short-term funded projects with specific outcomes for people with musculoskeletal conditions. The project needs to be committed to follow-up and provide feedback to participants.

Level of involvement National/State/Local
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a number of consumer representative programs offering training in representation. They provide recruitment and selection, support and mentoring tailored to the members’ needs. They have a memorandum of understanding between their members and the organisation. Members’ availability is variable, with many members being older and less mobile. Their involvement is influenced by the location of the project and associated costs. Members can represent the organisation.

Assistance required for a consumer/member and carer to participate

Association for Children with a Disability

590 Orrong Road, Armadale, VIC 3143
Tel 03 9500 1232 or Free call 1800 654 013 Fax 03 9500 1240
Email mail@acd.org.au Website www.acd.org.au
Hours Open Mon – Fri, 9am – 5pm
Contact Person Mr Michael Gourlay, CEO
Geographical Area Serviced Statewide
Regional Groups & Contact Details Works in co-operation with Regional Parent Support Workers in each region across Victoria (contact the Association for a current list).

Aims and activities
To provide information, support and advocacy to families with a disability through the provision of free telephone advice, information booklets and a newsletter.

Membership
Parents and families with a disability and interested organisations.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects related to families with a child with a disability, education, young adults, equipment, aids and respite. Involvement will be dependent on the availability of participants and assistance provided to participate.

Level of involvement National/State/Local
Type of involvement All
Focus of involvement a,b,c,d,e,h,i,j,k

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a formal process for recruiting members, and provides mentoring and support. Members can represent the organisation but need time to make alternative arrangements for care.

Assistance required for a consumer/member and carer to participate

Association of Relatives and Friends of the Emotionally and Mentally Ill (ARAFEMI)

Suite 1, 1091 Toorak Road, Camberwell, VIC 3124
Tel 03 9889 3733 Fax 03 9889 2878
Email arafemi@infoxchange.net.au Website www.vicnet.net.au/~arafemi
Hours Open Mon – Fri, 9am – 5pm
Geographical Area Serviced Statewide
Regional Groups & Contact Details
The Loddon Mallee region group can be contacted through the Melbourne office.

Aims and activities
To promote and improve the well-being of people affected by mental illness. This is achieved through the provision of mutual support group meetings, individual counselling, a telephone support service, quarterly newsletters, library, supported accommodation and outreach support for people with a psychiatric disability. Education and information sessions for parents, carers and young people are also provided.

Membership
People who have experienced emotional or mental illness, their relatives and friends.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in short-term projects concerning policy development and service provision particularly in relation to carers' issues and mental illness.

Level of involvement State and Local
Type of involvement 1,2,4,5,6,7,8,9,10
Focus of involvement c,d,e,j,k

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has no formal recruitment or training process. Members are invited to be involved, and training is provided on an individual basis. Members have variable availability due to full-time work and/or caring responsibilities. Board members and staff can represent the organisation.

Assistance required for a consumer/member and carer to participate

Asthma Victoria

69 Flemington Road, North Melbourne, VIC 3051
Tel 03 9326 7088 Fax 03 9326 7055
Email advice@asthma.org.au Website www.asthma.org.au
Hours Open Mon – Fri, 9am – 5pm
Contact Person CEO
Geographical Area Serviced Statewide
Regional Groups & Contact Details Contact Asthma Victoria.

Aims and activities
To reduce the impact of asthma on the Victorian community through advice, education, training, general health promotion and awareness, funding research, a volunteer program and a newsletter.

Membership
Anyone with an interest in asthma.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects, which are related to asthma, with clearly articulated processes, accompanying background papers and are perceived as worthwhile to the organisation’s aims.

Level of involvement State/Local
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation will recruit, support and mentor consumers and carers through their membership list, newsletter, help line and listings of interested people. Most members work full-time and some have caring responsibilities. Members can represent the organisation.

Assistance required for a consumer/member and carer to participate


Australian Crohn’s and Colitis Association (ACCA)

PO Box 201, Mooroolbark, VIC 3138  
Tel 03 9726 9008  
Fax 03 9726 9914  
Email info@acca.net.au  
Website www.acca.net.au  
Hours Open Mon – Fri, 9.30am – 5pm  
Contact Person Ms Angela McAvoy, Managing Director  
Geographical Area Serviced National  
Regional Groups & Contact Details State Branches, regions and groups.

Aims and activities
To ensure that people with Crohn’s Disease and Ulcerative Colitis are empowered through the provision of education, awareness and information programs, confidential support, advocacy, research, self-management, a free legal service, a newsletter and resource materials.

Membership
People with Crohn’s Disease and Ulcerative Colitis, their families, health professionals and organisations.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in both short and long-term funded projects related to the promotion and education of the community and health professionals around infant feeding and breast-feeding.

Level of involvement National/State/Local
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a formal recruitment, selection, training and support process. They maintain a public relations working group and an advocacy working group. Some women train as counsellors, all are volunteers and have varying availability to participate in consumer representative activities.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.

Australian Breastfeeding Association

PO Box 4000, Glen Iris, VIC 3146  
Tel 03 9885 0855  
Fax 03 9885 0866  
Email info@breastfeeding.asn.au  
Website www.breastfeeding.asn.au  
Hours Open Mon – Fri, 9am – 5pm  
Contact Person Ms Erica Myers-Davis  
Geographical Area Serviced National  
Regional Groups & Contact Details State Branches, regions and groups.

Aims and activities
To empower women to breastfeed through mother-to-mother support for breastfeeding, information provision, community education about the importance of human milk, phone counselling, group discussion meetings, advocacy and education of health professionals.

Membership
Parents and health professionals.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in both short and long-term funded projects related to the promotion and education of the community and health professionals around infant feeding and breast-feeding.

Level of involvement National/State/Local
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a formal recruitment, selection, training and support process. They maintain a public relations working group and an advocacy working group. Some women train as counsellors, all are volunteers and have varying availability to participate in consumer representative activities.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.
Aims and activities
To provide Australian Greek persons with welfare, economic, cultural and social resources, and to engage in research, community education and information provision to promote the rights and wellbeing of Australian Greeks. The agency provides direct counselling, case work services, legal and information referral services, men’s counselling, injured worker’s support programs, aged and child care programs, drug prevention and education, volunteer programs and assistance in accessing Commonwealth funded children’s programs.

Membership
A person must be of Greek background or a partner of someone of Greek background and nominated by a member.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in issues relating to the needs of children, families, the aged, health and the impacts of social issues (drugs, gambling) in the Greek community. Before becoming involved in a project the organisation would need to know all the details including the target group, project length, outcomes and feedback mechanisms. Information would need to be culturally and linguistically sensitive. AGWS would like to be acknowledged for their participation.

Level of involvement
National/State/Local

Type of involvement
1,2,3,4,5,6,8,9,10,11

Focus of involvement
Unknown

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has an informal recruitment and selection process where assigned staff contact the community. They are able to train, support and mentor consumer representatives and regularly conduct community consultations, workshops, and focus groups to obtain information about an identified issue or emerging need. Prospective participants may need to make alternate care arrangements, may have mobility issues, and many are pensioners who are available during the day. Carers often represent the organisation.
Aims and activities
A charitable non-political organisation, which operates as a learning and family support centre. They focus on the most disadvantaged sections of the community, providing services to Vietnamese and others, regardless of race or gender, to assist the settlement of Vietnamese speaking refugees and migrants in Victoria. The organisation provides material aid, practical assistance, emotional support and counselling. Also community development, education and training, conferences and exhibitions, job search assistance, support & counselling concerning youth, women and the elderly. The organisation also assists with housing, drug treatment, Indo-Chinese offenders entering community correctional services and 3ZZZ Community Radio. There are fifteen paid staff across both offices.

Membership
Vietnamese speaking women can apply for ordinary membership; men can apply to be associate members. School children and students under 25 can apply for student memberships.

Motivation for involvement in improving the safety and quality of health care
The organisation would require all materials related to a project with a health service to be provided in both English and Vietnamese. Details about the project such as aims, purpose, outcomes, and time lines would also be required.

Level of involvement State
Type of involvement 1,2,4,5,8,9,10,11
Focus of involvement a,b,c,d,e

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a formal process to recruit and select members and can provide training in representation, support and mentoring. Members’ availability is limited as most work full or part-time. Members represent the organisation.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.
Aims and activities
To represent people affected by an Autism Spectrum Disorder, to improve community awareness and understanding and provide support to families. The organisation provides information, family support and counselling and public relations services, including media liaison, a newsletter, library and information packages.

Membership
Anyone can be a member, but mostly parents, students, clinicians, agencies and other interested persons.

Motivation for involvement in improving the safety and quality of health care
The organisation is interested in issues related to Autism Spectrum Disorders (Autism, Asperger Syndrome and Pervasive Developmental Disorder—not otherwise specified), which will increase the awareness of the characteristics of autistic disorders amongst health professionals. A request for consumer involvement would need to include project objectives, criteria for choosing participants, tasks of participants, and feedback to participants, and how the outcomes and findings will be distributed. The organisation has a protocol for all projects involving research subjects.

Level of involvement
State/Local

Type of involvement
1,2,4,5,6,7,8,9,11(systemic only)

Focus of involvement
a,b,c,d,e,f,g,h,i

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has an informal recruitment and selection process through the publishing of requests in their quarterly newsletter. The organisation can provide limited support and mentoring. Availability of members is variable and members can represent the organisation.

Assistance required for a consumer/member and carer to participate

Autistic Family Support Association (AFSA) can be contacted through Autism Victoria.
Ballarat Regional Multicultural Council (BRMC)

1208 Norman Street, Wendouree, VIC 3355
PO Box 1418, Bakery Hill, VIC 3354
Tel 03 5339 3233 or 03 5339 9817 Fax 03 5339 9817
Email brmc@netconnect.com.au
Hours Open Mon – Fri, 9am – 5pm
Contact Person Jane Mc Murray
Geographical Area Serviced Grampians region including the local government area of Ballarat and outreach service for the Shire of Pyrenees, Moorabool, Golden Plains and Hepburn.

Aims and activities
As the peak advisory body for multicultural affairs in the Grampians region the Council provides an advisory and representative role for the 15 affiliated cultural groups and 50 individual members to the three levels of government. It works in partnership with NESB Links to provide newly arrived and established migrants with culturally sensitive and appropriate support. It connects migrant women with other migrant women, and collaborates with local organisations to provide English programs, law outreach, access and equity programs; all in order to work toward reducing social and cultural isolation and loneliness of people from NESB in the region.

Membership
Any adult from Victoria.

Motivation for involvement in improving the safety and quality of health care
To act as a consumer/facilitating agency, this is supported by considerable time and effort provided by volunteers. If their members became involved in a project they would require information related to outcomes, feedback, the nature of the contact, and a clear outline of the project in question.

Level of involvement Unknown
Type of involvement 3,5,6,8,10
Focus of involvement a,b,h,i,j,k

Recruitment, selection, training, support & mentoring of members/consumers & carers
There is no formal recruitment process however if approached the organisation will distribute requests to members. The organisation can provide support and mentoring. BRMC members have varied commitments and responsibilities, some needing transport assistance.

Assistance required for a consumer/member and carer to participate

Barwon Disability Resource Council

48 McKillop Street, Geelong, VIC 3220
Tel 03 5221 8011 Fax 03 5229 5665
Email eo@bdrc.org.au Website www.bdrc.org.au
Hours Open Mon – Fri, 9.30am – 4pm
Contact Person Ms Carol Okai
Geographical Area Serviced Barwon South West region including City of Greater Geelong, Surf Coast Shire, Golden Plains Shire, Borough of Queenscliff.

Aims and activities
A voluntary body formed to represent the interests of people with a disability and provide information and advocacy.

Membership
Membership is open to anyone.

Motivation for involvement in improving the safety and quality of health care
The organisation is interested in projects, which represent the interests of people with disabilities, their families and carers, in all aspects of their lives.

Level of involvement State/Local
Type of involvement 1,2,3,4,5,6,7,8,9,10
Focus of involvement a,b,c,d,e,h,i,j,k

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation will select, recruit, support and mentor members through an informal process but will need assistance with resources if they are to do this. Members may work part-time, have mobility issues and or need time to organise a carer. Members can represent the organisation.

Assistance required for a consumer/member and carer to participate


Bear in Mind

2nd Floor, Ross House, 247 Flinders Lane, Melbourne, VIC 3000
Tel 03 9369 7222 Fax 03 9354 1057
Email bim_statewide@yahoo.com.au Website www.vicnet.ner.au/~bim

Hours Open
Mon, Tues & Thurs, 10am – 4pm,
By appointment at other times

Contact Person
Ms Lyn MacDonald or Ms Ria Strong
Geographical Area Serviced
Melbourne and surrounds
Regional Groups & Contact Details
BIM West Convenor contact Ria Strong.
Tel 03 9329 3039, or Email bim_west@yahoo.com.au
Monthly meetings in Footscray.
BIM East contact Bear in Mind statewide office.
Meetings and outings in Box Hill area.
BIM North contact John Wakefield.
Tel 03 9439 8117
Monthly meetings at Collingwood & Coburg libraries.

Aims and activities
A self-advocacy and community education group for people with acquired brain injury (ABI).
The group provides support, skill development and self-confidence to members. They try to raise
community awareness through speakers, a library, and a newsletter.

Membership
People with ABI, their carers and families, organisation and service providers.

Motivation for involvement in improving the safety and quality of health care
The organisation is interested in projects that are related to ABI, self-advocacy support and raising
community awareness. For involvement in projects members must be treated with respect, the
contact be meaningful, travel costs paid, and feedback given to the participants.

Level of involvement National/State/Local
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation can informally recruit and select members by contacting those who express an
interest. They can provide training, support and mentoring in representation. There is variable
availability of members as some work part-time and others receive pensions and are available
during the day. Members can represent the organisation.

Assistance required for a consumer/member and carer to participate

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Aims and activities
To address issues of access and equity for people from NESB and advocate on their behalf through adult learning, assisting with settlement issues for new arrivals, referral to language classes, a women’s health self-help group and a newsletter.

Membership
There are three types of membership: people from NESB and organisations; service providers who are sympathetic to the aims and objects of the Ethnic Community Council; and individuals.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects which improve access and equity for people from NESB; projects that deal with issues of social isolation such as lack of transport, address gaps in services and service delivery and increase understanding and respect for different cultures. Before a decision about a project is made they would need to know the issues to be addressed, have access to any written material and the outcomes made available to them.

Level, Type of involvement and Focus
Level of involvement National/State/Local
Type of involvement All
Focus of involvement a,b,c,d,e,f,g,h,i

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a formal process for recruiting, selecting, training, supporting and mentoring members. They use their newsletter, and direct personal contact. The executive committee approves all recruits. Membership availability for projects is variable as many work full-time and have other commitments.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.

Aims and activities
To provide services for hearing impaired people through the provision of information, independent living training, advocacy and a quarterly newsletter.

Membership
Membership is open to anyone.

Motivation for involvement in improving the safety and quality of health care
The organisation is interested in issues related to hearing impairment and deafness and each approach by a health service to participate in a project will be considered on its merits.

Level, Type of involvement and Focus
Level of involvement National/State/Local
Type of involvement All
Focus of involvement a,b,c,d,e,f,g,h,i

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation can recruit, select and provide mentoring for members through an informal process of contacting consumers by letter, word of mouth or phone. The recruitment would be related to the needs of the project. Members availability is varied, they may work part-time, have mobility issues or be aged. Members can represent the organisation.

Assistance required for a consumer/member and carer to participate
Blind Citizens Australia

13 Barrett Street, Kensington, VIC 3031
Tel 03 9372 6400  Fax 03 9376 6466
Email bca@bca.org.au  Website www.bca.org.au
Hours Open  Mon – Fri, 9am – 5pm
Contact Person  Ms Nadia Mattiazzo, Victorian Advocacy & Information Officer
Geographical Area Serviced  National
Regional Groups & Contact Details
  Melbourne Branch  Tel 03 9372 6400
  Computer Users’ Branch  Tel 03 9372 6400
  Young Blind Citizens Victoria  Tel 03 9372 6400

Aims and activities
To achieve equity and equality through empowerment, promoting positive community attitudes and striving for high quality and accessible services that meet the members’ needs. The organisation provides systemic and individual advocacy, proactively influences government policy and policymaking, disseminates information to members and provides peer support.

Membership
Full membership is available for anyone who is legally blind and associate memberships for those who are vision impaired or have an interest.

Motivation for involvement in improving the safety and quality of health care
The organisation requires projects to be sensitive to the needs of those who are blind and visually impaired. They will require time to recruit and the project should provide follow-up contact. The organisation is interested in projects which contribute towards raising community awareness of this group.

Level of involvement  National/State/Local
Type of involvement  All
Focus of involvement  All
Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a formal process for recruiting, selecting, training, supporting and mentoring. Full members can represent the organisation. Members have variable availability as some work full-time and some part-time. Members may have mobility issues which need to be catered for.

Breast Cancer Action Group

PO Box 281, Fairfield, VIC 3078
Tel 03 9878 0736 or 03 9517 2331  Email lockwood@bigpond.com
Contact Person  Ms Sue Lockwood
Geographical Area Serviced  Statewide

Aims and activities
To encourage members to contribute at all levels of decision making, promote and contribute to research, improve the experience of those undergoing treatment for breast cancer, improve consumer access to the highest quality services regardless of geographical location, social and economic status or stage of the disease, and to provide a forum for men and women to share experiences. The organisation offers advice, advocacy, liaison with breast cancer services and community services. There is a newsletter and regular meetings.

Membership
Anyone interested in breast cancer.

Motivation for involvement in improving the safety and quality of health care
The organisation will consider projects that focus on breast cancer. The project requirements need to be detailed, the project members status clarified, skills or knowledge required specified, and the frequency of meetings and length of project (i.e. commitment needed also made clear).

Level of involvement  All
Type of involvement  1,3,4,5,6,8,11
Focus of involvement  c,d,e,f,g,h,i,j,k
Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a formal process for recruiting, selecting, training, supporting and mentoring members. The availability of members is variable. Members can represent the organisation.

Breast Cancer Network Australia

PO Box 4082, Auburn South, VIC 3122
Tel 03 9805 2500 or Free call 1800 500 258 Fax 03 9805 2599
Email beacon@bcna.org.au Website www.bcna.org.au
Hours Open Mon – Fri, 9am – 5pm
Contact Person Ms Terri Smith
Geographical Area Serviced National

Aims and activities
To empower Australians affected by breast cancer individually and systemically, to influence the breast cancer agenda and to improve their care. This is achieved through advocacy, information provision and targeted support for the benefit of the whole community. The organisation recruits, trains and supports women as ‘consumer representatives’ on national and state committees and produces a quarterly national newsletter.

Membership
Anyone personally affected by breast cancer and who supports the organisation’s objectives.

Motivation for involvement in improving the safety and quality of health care
The organisation is interested in projects related to breast cancer. The health service needs to complete a form, which asks for specific information about the project. BCNA also produce kits for organisations seeking representatives, which outline the roles and responsibilities of both the requesting organisation and BCNA.

Level of involvement National
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a formal process for recruitment, selection, training in representation, support and mentoring. They have information kits for organisations (see above). The availability of members is variable and they can represent the organisation.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.

Cancer Council Victoria

1 Rathdowne Street, Carlton, VIC 3053
Tel 03 9635 5000 Fax 03 9635 5270
Cancer Help Line 13 11 20
Email enquiries@cancervic.org.au Website www.accv.org.au/
Hours Open Mon – Fri, 9am – 5pm
Contact Person Ms Doreen Akkerman
Geographical Area Serviced Statewide
Regional Groups & Contact Details Cancer support groups in metropolitan Melbourne and regional areas can be accessed by phoning 13 11 20.

Aims and activities
Cancer Council Victoria is an independent, volunteer-based charity whose mission is to lead, coordinate, implement and evaluate action to minimise the human cost of cancer for all Victorians through research, prevention, information and support.

Membership
Volunteers and constituents, not members.

Motivation for involvement in improving the safety and quality of health care
The organisation is interested in cancer research, prevention, early detection and support. Each project will be considered on its merits and the availability of the volunteers and constituents.

Level of involvement State/Local
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation provides formal recruitment, selection, training and support. It advertises surveys by health services through the newsletters and other circulars and can support representation on an as needs basis. There is varying availability of volunteers and constituents and they cannot represent the organisation.

Assistance required for a consumer/member and carer to participate
All assistance needs to be considered and negotiated with prospective participants after the Cancer Council has put them in touch with the health service.
### Carers Victoria

5th Floor, 130 Little Collins Street, Melbourne, VIC 3000  
Tel 03 9650 9966  
Fax 03 9650 8066  
Free call 1800 242 636 (Carer Resource Centre)  
Email cav@carersvic.org.au  
Website www.carersvic.org.au  
Hours Open  
Mon – Fri, 9am – 5pm  
Geographical Area Serviced  
Statewide  
Regional Groups & Contact Details  
Nine regional carer support services accessible by phoning Free call 1800 059 059. Also a database of carer support groups accessible by phoning Free call 1800 242 636.

### Aims and activities
To support carers in their caring role and increase awareness of carers and their issues. This is achieved through the provision of education, training and advocacy programs, information provision, support and counselling, support groups, a newsletter in several languages, a library, policy development and research.

### Membership
Any carer in Victoria and eligible organisations.

### Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in working on projects related to GP support to carers, discharge from acute health facilities, transition from acute to residential care, maintenance of Medicare, access to health care in rural and regional Victoria and access to health care for cultural and linguistically diverse caring families. The projects need to be outcome focused and involve meaningful consultation.

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**Recruitment, selection, training, support & mentoring of members/consumers & carers**

The organisation provides formal recruitment, selection, training, mentoring and support in presentation and advocacy. It has a ‘speakers bank’ that recruits nominees through their newsletter and individuals may be approached for specific projects. The availability of members is dependent on their area of interest and caring commitments. Members on the board can represent the organisation but must consult with the EO or board regarding decisions about the organisation. Members are actively involved in quality improvement activities through the Primary Care Partnerships and various community advisory committees and prefer short-term projects. Please note that staff participate in some of the activities with members.

### Assistance required for a consumer/member and carer to participate

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Cerebral Palsy Support Network

177 Glenroy Road, Glenroy, VIC 3046
Tel 03 9300 3901 Fax 03 9300 4057
Email cpsn@cpsn.info Website www.cpsn.info
Hours Open Most weekdays, 10am – 3pm
Geographical Area Serviced Statewide
Regional Groups & Contact Details There is a roaming support group.

Aims and activities
To support people with cerebral palsy and their families through the provision of out of school recreation programs, respite brokerage, employment of own carers, a quarterly newsletter and support groups.

Membership
Anyone with cerebral palsy or an interest in the organisation.

Motivation for involvement in improving the safety and quality of health care
Members are interested in respite, education, and awareness of cerebral palsy issues in health care. They require a proposal before they can agree to participate.

Level of involvement National/State/Local
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation provides formal recruitment and selection through the committee of management and support and mentoring of members as required. Availability of members must be negotiated. Members can represent the organisation.

Assistance required for a consumer/member and carer to participate

Choices for Childbirth

PO Box 1190, Blackburn North, VIC 3130
Tel 03 9484 6473
Email diddles@aardvark.net.au Website www.maternitycoalition.org.au
Hours Open Mon – Fri, 9am – 5pm
Contact Person Ms Di Diddle
Geographical Area Serviced Metropolitan (Brunswick and Balwyn)

Aims and activities
To support women and their partners in making informed choices about the birth of their babies through the provision of independent and accurate information, based on the best available scientific evidence. Activities include provision of resources, monthly seminars and phone consultations.

Membership
Any interested person before and during pregnancy.

Motivation for involvement in improving the safety and quality of health care
The project would need to be related to the aims of the organisation.

Level of involvement State
Type of involvement 9,10
Focus of involvement j,k

Recruitment, selection, training, support & mentoring of members/consumers & carers
The health service should first contact the Maternity Coalition (see their entry). Members are available during business hours and after hours and members can represent the organisation, as it is wholly consumer run.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.
Chronic Illness Alliance

818 Burke Road, Camberwell, VIC 3124

Tel 03 9805 9126 Fax 03 9882 7157
Email christine@chronicillness.org.au Website www.chronicillness.org.au

Hours Open Mon – Thurs, 9am – 5pm
Contact Person Dr Christine Walker
Geographical Area Serviced National

Aims and activities
To build a better focus in health policy and health services for people with chronic illness through education, research and maintenance of an email list. The email list is used to distribute information and provide a forum for discussion on particular issues.

Membership
Individuals and organisations that represent people with chronic illness.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in policy and service development affecting people with chronic illness. Members may have particular areas of interest and may wish to be involved in both short and longer-term projects with specified outcomes for people with chronic illness.

Level of involvement National/State/Local
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation provides informal recruitment and selection through individual contact and the email list, but as an unfunded organisation it is limited in the time and resources it can devote to recruitment on behalf of other organisations. Individuals are supported and mentored as required. Members’ availability depends on their other commitments and interest. Members can represent the organisation but need to report back to the board of management.

Assistance required for a consumer/member and carer to participate

Co-As-It

189 Faraday Street, Carlton, VIC 3053

Tel 03 9349 9000 Fax 03 9349 1063
Email coasit@coasit.com.au Website www.coasit.com.au

Hours Open Mon – Fri, 9am – 5pm
Contact Person Ms Emma Contessa or Mr Walter Petralia
Geographical Area Serviced Statewide

Aims and activities
To respond to the needs of the Italian community, in particular the aged, through the provision of aged care services, community development, health promotion, education, secondary consultation to mainstream service providers, Italian senior citizen’s clubs, Italian Historical Society and a resources centre.

Membership
Italians and others who identify or have an interest in Italians and their culture.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in the needs of the Italian community and the project needs to be able to subsidise staff time and guarantee arrangements are made for bilingual facilitators.

Level of involvement Local
Type of involvement 1,2,5,6,8,9,10,11
Focus of involvement a,b,c,h,i,j,k

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation will formally recruit for funded projects and would need reimbursement for staff time and resources. They do not have training or support in representation. Members may have mobility issues or need to make alternate carer arrangements. Members do not represent the organisation.

Assistance required for a consumer/member and carer to participate

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**Cochrane Consumer Network**

**Email** ccnet-contact@cochrane.de  
**Website** www.cochrane.org/consumers  
**Contact Person** Ms Janet Wales  
**Geographical Area Serviced** Worldwide

**Aims and activities**
To promote a consumer perspective in Cochrane Collaboration reviews published electronically in the Cochrane Library. The Cochrane Collaboration is an international non-profit organisation that aims to help people make informed decisions about health care, by reviewing and promoting the best available evidence on the effects of interventions and treatments. It is a charity registered in the United Kingdom and its governing body is a steering committee of members elected from the different components of the Collaboration, including two consumer representatives. The Collaboration also aims to affect the future research agenda in health, by identifying where enough research has been done, and where more is needed.

**Membership**
Any consumer interested in the aim of the organisation.

**Motivation for involvement in improving the safety and quality of health care**
The organisation is interested in developing and maintaining introductory materials, guides and a website that enables consumers to contribute to the Cochrane Collaboration, to identify and prioritise topics relevant to consumers and, to assist in linking disease and healthcare-based review groups or fields with relevant consumer groups as well as individual consumers. Consumers often serve as peer reviewers, and bring with them the perspective of a healthcare user, which provides valuable input into the design of a protocol, the outcomes, conclusions and general readability of Cochrane reviews.

**Level of involvement** International  
**Type of involvement** 1  
**Focus of involvement** All

**Recruitment, selection, training, support & mentoring of members/consumers & carers**
Consumer reviewer’s availability varies and is voluntary. They could be recruited through the newsletter.

**Assistance required for a consumer/member and carer to participate**
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.

**Collective of Self-Help Groups (COSHG)**

**PO Box 251, Brunswick East, VIC 3057**  
**Tel** 03 9349 2301  
**Fax** 03 9349 2304  
**Email** coshgmelb@yahoo.com.au  
**Website** home.vicnet.net.au/~coshg/  
**Hours Open** Wed – Thurs, 10am – 3pm  
**Contact Person** Mr Gary Gromb and Ms Christine McAuslan  
**Geographical Area Serviced** Statewide

**Aims and activities**
To develop the self-help movement through promoting and supporting self-help groups and assisting in their establishment by providing telephone information, a resource library, website, workshops for groups, help with starting a group, a Directory of Self-Help and Social Action Groups, a resource kit “In the Same Boat”, a news sheet “Collective Notes” and other publications. Members would want the requesting health service to be respectful of the process, provide clear information on the expected outcomes and purpose, plan feedback mechanisms, and indicate how much time is required including the length and location of the project.

**Membership**
Anyone who supports the aims and objectives of COSHG and is willing to be actively involved, associate membership for those not actively involved.

**Motivation for involvement in improving the safety and quality of health care**
The organisation has an interest in projects related to self-help in any area and a particular interest in broadening access to rural groups, people with disabilities and consumers of health services. Members’ availability varies and members can represent the organisation.

**Level of Involvement** State/Local  
**Type of involvement** All  
**Focus of Involvement** All

**Recruitment, selection, training, support & mentoring of members/consumers & carers**
The organisation has a formal process to recruit and select members through the news sheet “Collective Notes” and their database of members. Support is provided on an as needs basis as they do not have the resources to provide a comprehensive program. Members’ availability varies and members can represent the organisation.

**Assistance required for a consumer/member and carer to participate**
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.
### Combined Pensioners & Superannuants Association Victoria Inc.

**Trades Hall, 54 Victoria Street, Carlton, VIC 3051**

- **Tel** 03 9662 3971
- **Fax** 03 9663 5071
- **Email** cpamelb@hotkey.net.au
- **Hours Open** Mon – Fri, 9am – 1pm
- **Contact Person** Mrs J. Bidlo, State Secretary
- **Geographical Area Serviced** Statewide

**Aims and activities**
To maintain and improve the lot of all pensioners through the provision of advice and referral.

**Membership**
All pensioners of any age.

**Motivation for involvement in improving the safety and quality of health care**
The organisation would want to be informed of the outcomes and have proper feedback.

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<thead>
<tr>
<th>Level of involvement</th>
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<tr>
<td>Type of involvement</td>
<td>2,3,8,9</td>
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<tr>
<td>Focus of involvement</td>
<td>Improving services for pensioners</td>
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**Recruitment, selection, training, support & mentoring of members/consumers & carers**
The organisation has an informal process for recruiting and selecting members through the newsletter and by seeking volunteers. Members are retired and daytime projects are best.

**Assistance required for a consumer/member and carer to participate**

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### Communication Aid User Society

**269 Centre Road, Bentleigh, VIC 3204**

- **Tel** 03 9557 5551
- **Fax** 03 9557 5509
- **Email** causinc@bigpond.com
- **Website** www.users.bigpond.com/causinc
- **Hours Open** Mon – Fri, 9am – 5pm
- **Contact Person** Ms Jan Ashford, Executive Officer
- **Geographical Area Serviced** Statewide
- **Regional Groups & Contact Details** Geelong (contact through the Melbourne Office).

**Aims and activities**
To defend the right of all people with communication or speech impairment to express themselves and be listened to through the provision of advocacy, information, community education, training, secondary consultation and a newsletter.

**Membership**
Any person who identifies himself or herself as having a communication or speech impairment difficulty, family members, carers, providers and organisations.

**Motivation for involvement in improving the safety and quality of health care**
The organisation is interested in projects that progress access to: aids (augmentative and alternative forms of communication) and communication devices, appropriately trained staff, and access to speech therapy locally throughout the state. The project needs to be relevant to members, respectful and valuing of participants, provide feedback, pay costs of participation and provide an environment that is inclusive of those who may be using a communication device (which may slow down meeting times).

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<tr>
<td>Type of involvement</td>
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<tr>
<td>Focus of involvement</td>
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**Recruitment, selection, training, support & mentoring of members/consumers & carers**
The organisation has a formal process for recruiting and selecting members through knowledge of their membership and writing or visiting them to recruit. They can provide training, support and mentoring in groups or individually as required and support is geared to the member’s skills and experience. Many members are on pensions and need assistance with communication, this takes time, the requesting health service needs to allow for this time. Members represent the organisation.

**Assistance required for a consumer/member and carer to participate**
All of the assistance listed should be considered and negotiated with emphasis on the following

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Aims and activities
This peak body for continence undertakes to raise community awareness and advocates on behalf of those with incontinence, their home carers and health professional service providers from many disciplines (GPs, nurse continence advisors, physiotherapists, and specialists such as urologists, urogynaecologists and colorectal surgeons). It also works with industry (companies supplying continence-related products) and government to achieve its aim to “promote continence and manage incontinence”.

Membership
Members are consumers, carers, continence nurse advisors, physiotherapists and allied health professionals, GPs and specialists, companies, not-for-profit organisations, healthcare groups.

Motivation for involvement in improving the safety and quality of health care
The organisation has a particular interest in bladder and bowel control, which is a co-morbidity of most major diseases and health conditions.

Level of involvement: Unknown
Type of involvement: 1,2,3,4,5,11
Focus of involvement: All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The membership of consumers is small due to the sensitivity and embarrassment surrounding this health condition and therefore not easily recruited. The Foundation can access a national database of continence services, can seek consumer feedback through the help line, and promote opportunities for consumers to participate in clinical trials or research projects.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.

Aims and activities
To advocate for the rights and interests of older people through the provision of information and advice statewide, input to governments on policy issues, written submissions, development of specific projects (e.g. strength conditioning for older people; education courses on ageing and retirement).

Membership
All those 50 and over.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in all issues affecting older people, including discrimination and stereotyping and would consider each approach by a health service on its merits.

Level of involvement: National/State
Type of involvement: 1,2,4,5,6,7,9,10,11
Focus of involvement: a,b,c,d,e,h,i

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation is able to recruit and select members dependant on the particular project and can provide training in representation, support and mentoring. Staff may also represent members’ interests. Members’ availability varies and they can represent the organisation.

Assistance required for a consumer/member and carer to participate
Cystic Fibrosis Victoria Inc.

80 Dodds Street, Southbank, VIC 3006
Tel 03 9686 1811 or Free call 1800 633 685 Fax 03 9686 3437
Email admin@cfv.org.au Website www.cfv.org.au
Hours Open Mon – Fri, 9am – 5pm
Contact Person Ms Jenny Reece
Geographical Area Serviced Statewide

Aims and activities
To support people with cystic fibrosis, their families and carers through the provision of support services, counselling, information, advocacy and lobbying.

Membership
Membership is open to anyone.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in cystic fibrosis and their involvement in a project is dependent on the possible outcomes being meaningful and fed back to the members.

Level of involvement State
Type of involvement 2,3,4,9,11
Focus of involvement Unknown

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has an informal recruitment process using individual approaches to members by support volunteers and promotion via the news magazine. They provide training in representation, support and mentoring. Most members work full-time and have limited availability.

Assistance required for a consumer/member and carer to participate

Diabetes Australia Victoria

570 Elizabeth Street, Melbourne, VIC 3000
Tel 03 9667 1777 or 1300 136 588 Fax 03 9667 1788
Email mail@dav.org.au Website www.dav.org.au
Hours Open Mon – Fri, 9am – 5pm
Contact Person Ms Sue Hunt, Community Programs Manager Direct Line 03 9667 1702 Email shunt@dav.org.au
Geographical Area Serviced Statewide

Aims and activities
To represent people with diabetes in Victoria and minimise the impact of diabetes on the community, to help all people affected by diabetes and to contribute to the search for the cure. This is achieved through the provision of a range of services and programs for people with diabetes, their families, carers, health professionals and the general public by providing support and information about diabetes to the community. The services include a diabetes information and advice line, a website, group education for newly diagnosed, limited individual consultations, drop-in service, children’s camps in collaboration with Royal Children’s Hospital and Monash Medical Centre, a network of 58 community-based diabetes self-help and support groups in Victoria, advocacy, a newsletter, support of research with associated organisations, and fundraising.

Membership
Membership is open to anyone.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects concerned with diabetes, its risk factors and complications and other issues related to diabetes.

Level of involvement All
Type of involvement 1,2,3,4,5,6,7,8,9,10
Focus of involvement a,b,c,d,e,h,i,j,k

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation would use an informal process for recruitment of group members and leaders through ComNet (a network of 58 community-based self-help and support groups) or DAV volunteers or staff members (DAV also has a number of staff who have diabetes who meet on a regular basis) and in some instances board members to participate in projects. Member availability is variable. Members can represent the organisation.

Assistance required for a consumer/member and carer to participate

$ $ $ $ $ and other assistance to be negotiated
Aims and activities
A patient led self-help group made up of people with kidney failure and their families run by a volunteer committee, which offers information, support, a resource library, holiday homes, social functions, a newsletter “Shoestring”, student educational grants, social welfare program, and talks.

Membership
Anyone with kidney disease and/or their families.

Motivation for involvement in improving the safety and quality of health care
The organisation is interested in projects related to kidney disease, dialysis and transplantation, and improving services for dialysis patients. They are interested in projects, which are relevant to the improvement of dialysis and transplant patients, where confidentiality is maintained and the health service is sympathetic to the time restraints of the volunteer committee of management.

Level of involvement
All

Type of involvement
1,2,4,6,7,8,9,10,11

Focus of involvement
a,b,d,e,f,g,h,i,j,k

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has an informal process for recruiting and selecting members through the newsletter and from committee of management members. They can offer support and mentoring. Members’ availability is variable but they would probably prefer daytime. Members can represent the organisation and are willing to be speakers.

Assistance required for a consumer/member and carer to participate
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Aims and activities
To provide individual advocacy to people with disabilities and carers, to be involved in systemic advocacy, to conduct community education and training and to provide support for self-help group development through individual and systemic advocacy, community education, and a newsletter.

Membership
People with disabilities, carers and families and service providers who represent disability organisations can be full members. Associate members are service providers and interested people.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects related to access to GPs, communication with GPs and medical specialists, bulk billing, disabled parking, transport to and from appointments, respite and homecare dollars. The project would need to be outcome focused and involve meaningful consultation. Members decide which projects the organisation will accept.

Level of involvement
State/Local

Type of involvement
1,2,3,5,8,9,11 and occasionally 4,6

Focus of involvement
All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a ‘consumer bank’ composed of members who have expressed an interest in being involved. They can nominate their particular area of interest (e.g. mental health or disability affecting children). When there is a request from a health service the organisation notifies the member and they can nominate to participate if they wish. The organisation provides minimal support and mentoring as they do not have sufficient resources for this. Members’ availability is variable and dependent on other commitments and interests. Members can represent the organisation.

Assistance required for a consumer/member and carer to participate
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**Disability Employment Action Centre (DEAC)**

Level 8, 55 Swanston Street, Melbourne, VIC 3000  
Tel 03 9650 2533 or Free call 1800 332 265  
Fax 03 9650 8642  
Email deac@deac.org.au  
Hours Open Mon – Fri, 9am – 5pm  
Contact Person Mr Michael Hand or Mr Phillip Camela  
Geographical Area Serviced Statewide

**Aims and activities**

To create opportunity and choice for those with a disability and promote the integration of people in the community by providing advocacy and research skills, education and training services, employment opportunities (through the Flinders Employment Service and Women’s Employment Support Service) and rehabilitation services.

**Membership**

Full membership for people with a disability or an organisation managed by a majority of people with a disability and associate membership for people or organisations that have an interest and share the philosophy of DEAC.

**Motivation for involvement in improving the safety and quality of health care**

The organisation is interested in projects concerned with disability, employment, education and training. Project proposals need to describe the project, its aims and objectives, outcomes and location.

**Level of involvement** State  
**Type of involvement** All  
**Focus of involvement** a,b,c,d,e,h,i

**Recruitment, selection, training, support & mentoring of members/consumers & carers**

The organisation does not have a formal process for recruiting and selecting members but can place an advertisement in the members’ newsletter ‘DEAC News’. Members tend to work part-time and have mobility issues and this will influence their availability.

**Assistance required for a consumer/member and carer to participate**

**Disability Justice Advocacy**

266 Johnston Street, Abbotsford, VIC 3067  
Tel 03 9416 3488  
Fax 03 9416 3484  
Email gillian@justadvocacy.com  
Hours Open Mon – Fri, 9am – 5pm  
Contact Person Ms Gillian Meldrum  
Geographical Area Serviced Statewide within a 2-hour drive of Melbourne

**Aims and activities**

To provide individual and systemic advocacy that protects and advances the well-being, rights and interests of people who have higher support needs associated with a physical disability. Services provided include individual and systemic advocacy and a newsletter.

**Membership**

Membership is open to people with high support needs associated with a physical disability.

**Motivation for involvement in improving the safety and quality of health care**

The organisation has an interest in accommodation, personal care and transport. They would need to know the length of the project, where it is located, whether personal care is provided, how much time is required and how often, and the arrangements for confidentiality.

**Level of involvement** All  
**Type of involvement** All to be considered and negotiated  
**Focus of involvement** a,b,c,d,e,f,g,h,i

**Recruitment, selection, training, support & mentoring of members/consumers & carers**

The organisation has an informal process for recruiting and selecting members through the board, the newsletter and membership base. They can offer training in representation, support and mentoring. Mobility issues limit members’ availability, they may need transport assistance and are not available first thing in the morning. Members represent the organisation.

**Assistance required for a consumer/member and carer to participate**
Disability Rights Victoria

Aims and activities
To advocate empowerment, and independent life in the community for people with disabilities through the provision of advice and support.

Membership
Anyone with a disability, family members, carers and friends.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects related to disability and each project is considered on its merits.

Level of involvement
State/Local

Type of involvement
All

Focus of involvement
All

Recruitment, selection, training, support & mentoring of members/consumers & carers

The organisation has a formal recruitment and selection process through the newsletter. They provide training through seminars and conferences, and support is provided as required. Members’ availability varies, but if the member is a carer they may need time to make alternate arrangements or a member may require attendant care assistance. Members can represent the organisation.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.

Down Syndrome Association of Victoria Inc.

Aims and activities
To bring people together with like needs and promote improvements in the quality of life of people with Down Syndrome and to stimulate the interest and awareness of the community to their needs, abilities and rights. This is achieved through the provision of support for parents of a new baby with Down Syndrome, information and information kits, after hours telephone support, a quarterly journal, speakers, information for teachers in regular school settings who have a child with Down Syndrome in the classroom and a library.

Membership
Membership is open to anyone.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in raising awareness of Down Syndrome in the community. Members have limited time to participate in projects and would require feedback.

Level of involvement
State

Type of involvement
1,2,4,6,7,9,10,11

Focus of involvement
Unknown

Recruitment, selection, training, support & mentoring of members/consumers & carers

The organisation has an informal recruitment process using their quarterly journal “Downs’ Voice”, mail outs or through their website. They can provide support and mentoring to members who participate. Members may work full-time and may need time to organise a carer. Members can represent the organisation.

Assistance required for a consumer/member and carer to participate
All of the assistance should be considered, but particularly 🦠
Aims and activities
To provide services for people affected by epilepsy in order to achieve the best possible outcomes. This is achieved through the provision of information and support, advocacy, rural and metropolitan support groups, a newsletter, counselling and personal support, community training and education, a library, and a help line.

Membership
Anyone affected by epilepsy including families and carers.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects related to developing a national epilepsy blueprint to determine the distribution of epilepsy throughout Australia, the impact of geography on service access supports and epilepsy management and sudden unexplained death in epilepsy.

Level of involvement All
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a formal recruitment and selection process including two volunteer coordinators and a research project officer. They can provide training, support and mentoring. Membership availability is variable and they can represent the organisation.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.
Ethnic Communities’ Council of Victoria (ECCV)

150 Palmerston Street, Carlton, VIC 3053
Tel 03 9349 4122 Fax 03 9349 4967
Email eccv@eccv.org.au Website www.eccv.org.au
Hours Open Mon – Fri, 9am – 5pm
Geographical Area Serviced Statewide
Regional Groups & Contact Details

Aims and activities
The Ethnic Communities’ Council of Victoria is the peak non-government body representing ethnic communities throughout Victoria working to promote equity of opportunity. It involves itself in policy development, advocacy and information provision.

Membership
The ECCV is made up of 176 member organisations. A member organisation is an incorporated body whose primary objective may be ethnic or multicultural, and whose aims and activities are consistent with the Statement of Purposes of the ECCV.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in aged care, NESB populations and other health areas especially primary health care. The safety and quality project must have a clear purpose and outcome, make it easy to participate and benefit the ECCV by making a difference to ethnic communities.

Level of involvement National/State
Type of involvement All
Focus of involvement Primarily c,h,i less so a,b,d,e,f,g,j,k

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation provides training for organisations in working with provider organisations, leadership, strategic planning and financial management. They have an aged care mentoring and support program. They recruit members through their newsletter, by email and by inviting particular ethno-specific organisations to training programs. Members’ availability is variable. Members can be appointed by the ECCV Executive Committee or its internal policy committees to represent the organisation but they must consult and report back.

Assistance required for a consumer/member and carer to participate
All of the assistance listed should be discussed and negotiated. For small organisations associated with the ECCV payment for time to be released, and other practical assistance is required.

Ethnic Council of Shepparton and District Inc.

PO Box 585, Shepparton, VIC 3630
Tel 03 5831 2395 Fax 03 5831 3764
Email ecshepp@mcmedia.com.au
Hours Open Mon – Fri, 9am – 5pm
Contact Person Ms Rhonda Ramadan
Geographical Area Serviced City of Greater Shepparton (local government)

Aims and activities
To assist settlement, and provide child and family services for ethnic communities through assistance, referrals and advocacy.

Membership
Ethnic community representatives can be members.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in ethnic communities. Project proposals would need to specify what involvement would be required of members.

Level of involvement Local
Type of involvement 5,7,8,9,10
Focus of involvement a,b,d,e,f,g

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a formal process for recruiting and selecting members and offers training in representation. Members’ availability is limited, as they tend to work full-time. Members can represent the organisation.

Assistance required for a consumer/member and carer to participate

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Family Drug Help

1242 Glenhuntly Road, Glenhuntly, VIC 3163
Tel 03 9573 1706 Fax 03 9572 3498
Email amurnane@sharc.org.au Website www.familydrughelp.sharc.org.au
Hours Open Mon – Fri, 9am – 5pm
Contact Person Mr Alan Murnane
Geographical Area Serviced Statewide
Regional Groups & Contact Details Support groups around the state
(see website for current listings).

Aims and activities
To provide support for family members affected by drug use through the provision of a 24-hour telephone help line and support groups around Victoria for family members.

Membership
Open to anyone interested in the support needs of family members affected by a member's drug use.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in the development of strategies for family members to look after themselves. Members would need to know the length of project, where and when meetings will be held, who will be involved, what the purpose of the project is, how the outcomes will be used and the approach to the issues involved.

Level of involvement National/State/Local
Type of involvement 2,4,5,6,7,8,9,10
Focus of involvement a,b,c,h,i,j,k

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a formal process for recruitment and selection of members and training for volunteers before they begin with the organisation. However, only people with lived experience of drug use within the family (including close friends, partners) can train to work on the help line.
Availability of members is variable with a preference for daytime projects. Members can represent the organisation.

Assistance required for a consumer/member and carer to participate
need to be negotiated on an individual basis.

Geelong Ethnic Communities Council Inc. (GECC)

153 Pakington Street, Geelong West, VIC 3218
Tel 03 5221 6044 or 03 5221 6160 Fax 03 5223 2848
Email jordan.mavros@gecc.net.au Website www.gecc.net.au
Hours Open Mon – Fri, 9am – 5pm
Contact Person Mr Jordan Mavros, CEO
Geographical Area Serviced Barwon South West region
GECC is co-located with the Geelong Migrant Resource Centre www.geelongmrc.org

Aims and activities
To develop, promote, coordinate and encourage services for the region’s ethnic/migrant communities through the provision of settlement services, aged care services, employment/training, community cultural development, language services, welfare services and immigration law services.

Membership
Specific ethnic groups can be members. There are 31 affiliated communities.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in the migrant/ethnic sector cultural diversity and access and equity issues as well as disadvantaged sectors of the community (i.e. youth, unemployment and women). Any proposed project would need to specify the time involved, and the overall outcomes and expected impact.

Level of involvement State/Local
Type of involvement 1,2,4,5,6,8,9,10,11
Focus of involvement a,b,c,d,e,h,i

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a formal recruitment and selection process and can provide support and mentoring. Members can represent the organisation. The availability of members is variable.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.
Aims and activities
To overcome the challenges of genetic conditions through the provision of resources, support groups, seminars, newsletters and information, encouragement for new groups, community and professional education, and consumer feedback to providers of genetic services.

Membership
People affected by genetic conditions, their families and friends, interested health professionals and students.

Motivation for involvement in improving the safety and quality of health care
The Network has an interest in projects related to genetic conditions that are meaningful, not tokenistic and have relevance for the membership.

Level of involvement
State and occasionally National

Type of involvement
All

Focus of involvement
All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The Network has a formal process to recruit and select members and can provide support and mentoring informally and as needed. The organisation has a panel of community consultants available for genetic health service projects. For all other requests people are recruited through the newsletter. Availability of members is variable as many work full-time and many have wheelchairs. Members can represent the organisation.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual bases.
Gippsland Disability Resource Council Inc.

42-44 Fowler Street, Moe, VIC 3825
Tel 03 5127 9171 or Free call 1800 625 674 Fax 03 5127 7002
Email gdrc1@bigpond.com
Hours Open Mon – Fri, 9am – 5pm
Contact Person Ms Sue Wilson, Advocacy Coordinator
Geographical Area Serviced Gippsland region
Regional Groups & Contact Details Sub-regional advocacy groups located in Wonthaggi, Leongatha, Sale, Latrobe Valley, Bairnsdale and Warragul.
Tel 03 5127 9171 or Free call 1800 625 674

Aims and activities
To empower and create full inclusion for people with a disability, their families and carers by focusing on people's abilities and the provision of advocacy, education, information and promotion of community awareness.

Membership
Anyone with an interest in disability issues and community inclusion.

Motivation for involvement in improving the safety and quality of health care
The organisation has a particular interest in the provision of advocacy, information or referral for people with disability, their families and carers. A proposed project should have clear outcomes, feedback, and the contact with members must be meaningful.

Level of involvement National/State/Local
Type of involvement All
Focus of involvement a,b,d,e,h,i,j,k

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a formal process to recruit and select members. They provide training, support and mentoring. The availability of members is dependent on carer respite and member mobility. Members occasionally represent the organisation but usually the committee of management represents the organisation.

Assistance required for a consumer/member and carer to participate

Gippsland Ethnic Communities’ Council

RMB 4829a Hazelwood North, VIC 3840
Tel 03 5166 1502 Fax 03 5166 1888
Email george.venturini@arts.monash.edu.au
Contact Person Dr V. G. Venturini
Geographical Area Serviced Gippsland

Aims and activities
To encourage understanding, develop goodwill and promote harmony within our culturally diverse community. This is achieved by providing: opportunities for people of culturally diverse backgrounds to come together, counselling, support and advocacy services, communication and influence with government on service provision, advice to other organisations on needs of those from culturally diverse backgrounds and the development of sensitive programs.

Membership
Membership is open to anyone.

Motivation for involvement in improving the safety and quality of health care
Interest in providing opportunities for people of culturally diverse backgrounds.

Level of involvement Local
Type of involvement To be negotiated
Focus of involvement To be negotiated

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has an informal process to recruit and select members and can provide support and mentoring. Membership availability is variable.

Assistance required for a consumer/member and carer to participate

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Glaucoma Australia Inc.

PO Box 420, Crows Nest, NSW 1585

Free call 1800 500 880
Email glaucoma@glaucoma.org.au
Hours Open Mon – Fri, 8.30am – 5pm
Contact Person Mrs Beverley Lindsell, National Executive Officer
Geographical Area Serviced National
Regional Groups & Contact Details Melbourne office: Mrs Catia Sicari, Southern Australia Coordinator PO Box 1012, Lalor, VIC 3075. Tel 03 9404 2974. Melbourne Glaucoma Support Group: Maureen Boyle Tel 03 9434 3198 Email maureenboyle@hotmail.com Geelong and Swan Hill can be contacted on Free call 1800 500 880.

Aims and activities
To minimise sight disability from glaucoma by increasing community awareness, supporting sufferers, providing information to eye-care practitioners and raising funds for research through telephone counselling, a newsletter, public forums and support groups.

Membership
Any person, particularly those with an interest in glaucoma.

Motivation for involvement in improving the safety and quality of health care
The organisation would be interested in projects focused on glaucoma with clearly stated outcomes, assured feedback, meaningful contact with participants and a clearly defined purpose.

Level of involvement All
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation does not select members but would advertise the project in a newsletter. They can provide training, support and speakers. The Melbourne Glaucoma Support Group has a formal process for recruiting and selecting members. Members are unlikely to attend evening meetings and may have mobility issues. Member’s availability is variable and they require sufficient time to respond to requests. Members can represent the organisation.

Assistance required for a consumer/member and carer to participate

Grampians Disability Advocacy Association Inc.

PO Box 112, Ararat, VIC 3377
Tel 03 5352 2722
Fax 03 5352 2733
Email asas@netconnect.com.au
Hours Open Mon – Fri, 9am – 5pm
Contact Person Ms Debbie Verdon
Geographical Area Serviced Grampians region

Aims and activities
To support and empower adults with disabilities in their efforts toward independence, improved quality of life and full participation in the community through advocacy, information and referral.

Membership
Anyone with an interest in disability issues in the Grampians region.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in general disability issues. If approached by a health service they would need to know the purpose of the meeting/project, size of group required, length of the project, what happens to the information provided, and how privacy and confidentiality issues will be dealt with.

Level of involvement Local
Type of involvement 2,3,4,5,6,8,9,11
Focus of involvement a,b,c,d,e,h,i

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has an informal process for selecting and recruiting members through their newsletter and phoning appropriate members. They can provide support and mentoring. Members’ availability is variable and they can represent the organisation.

Assistance required for a consumer/member and carer to participate
**Aims and activities**

To support those living with a bleeding disorder in Victoria through advice, information, counselling, emergency support and advocacy.

**Membership**

Anyone who has a bleeding disorder, or has an interested in this disorder.

**Motivation for involvement in improving the safety and quality of health care**

The organisation has a particular interest in haemophilia, von Willebrand’s Disorder, Hepatitis C, HIV and other possible blood borne viruses. Project proposals would need to specify where, when, and who is required to participate, the time commitment required, that privacy was assured, and what outcomes and financial support was involved.

**Level of involvement**

State/Local

**Type of involvement**

2,4,5,6

**Focus of involvement**

a,b,c

**Recruitment, selection, training, support & mentoring of members/consumers & carers**

The organisation has an informal recruitment and selection process, dependant on the request. With advanced notice they could recruit by email or newsletter. Member's availability is variable and they can represent the organisation.

**Assistance required for a consumer/member and carer to participate**

- **Type of assistance needed**
  - PR
  - M

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**Headway Victoria Acquired Brain Injury Association**

86-88 Herbert Street, Northcote, VIC 3070

**Tel** 03 9482 2955  

**Fax** 03 9482 5855

**Rural free call** 1800 817 968

**Email** mail@headwayvictoria.org.au  

**Website** www.headwayvictoria.org.au

**Hours Open** Mon – Fri, 9am – 5pm

**Contact Person** Ms Merrilee Cox

**Geographical Area Serviced** Statewide

**Aims and activities**

To enable people who acquire a brain injury to continue to live as valued members of their community with access to opportunities and choices that reflect their wishes and aspirations. The organisation provides information, referral, advocacy, training, community education and policy development.

**Membership**

Anyone who supports the work of the organisation.

**Motivation for involvement in improving the safety and quality of health care**

The organisation has an interest in acquired brain injury projects where people are supported, it is not tokenistic and expectations of participants are clear.

**Level of involvement**

State/Local

**Type of involvement**

1,2,4,5,6,8

**Focus of involvement**

c,h,i

**Recruitment, selection, training, support & mentoring of members/consumers & carers**

The organisation has an informal recruitment and selection process, which involves making contact with members in the specific local area and also advertising through the newsletter. They can provide limited training in representation, support and mentoring and also access the Disability Advocacy innovation initiatives “Getting Heard Taking Charge”. Availability of members is variable and they can represent the organisation.

**Assistance required for a consumer/member and carer to participate**

- **Type of assistance needed**
  - PR
Health Issues Centre (HIC) is a non-government policy analysis group that researches health issues from a consumer perspective. It aims to help create a more equitable health care system that is more responsive to users, particularly those who are disadvantaged by current arrangements. This is achieved through research, policy analysis, project support and development, support for practice change, evaluation, training, resource development and contribution to policy development through conferences, workshops, and membership of committees.

Membership
Any organisation or individual who supports the aims of HIC.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in all aspects of health care and the health system including better complaints management practice and consumer friendly information provision.

Level of involvement
National/State/Local

Type of involvement
All

Focus of involvement
All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a Consumer Nominee Program (CNP) in which requests for consumers are included in a fortnightly bulletin "Across Our Desk", that is distributed to HIC’s database of members and consumers. Through the CNP, agencies are also provided with information, support and advice on effective consumer participation. HIC appoints consumer representatives on to committees as requested and works in close collaboration with the National Resource Centre for Consumer Participation in Health (NRCCPH). The NRCCPH have a website that provides a wide range of resources, tools and practice examples to support consumer participation in the health sector. Both the HIC and the NRCCPH have on site libraries that are available for members to use. Membership availability is variable.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.
Health Consumers of Rural and Remote Australia

PO Box 280, Deakin West, ACT 2600

Tel 02 6285 4660 Fax 02 6285 4670
Email carmel@ruralhealth.org.au Website www.ruralhealth.org.au

Hours Open Mon – Fri, 9am – 6pm
Contact Person Ms Carmel Brophy
Geographical Area Serviced Regional, rural and remote Australia

Aims and activities
Health Consumers of Rural and Remote Australia (HCRRA) is a not-for-profit organisation working to improve rural health outcomes by involving consumers in the planning, implementation, management and evaluation of health services throughout non-metropolitan Australia.

Membership
Individual membership is open to all who live in regional and remote Australia and are not employed in the provision of health services. Organisations are also eligible to join. They pay a higher membership fee and do not have voting rights.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects that promote consumer representation in the development and implementation of health policy and the delivery of health services. The project proposal would need to detail the level of commitment required from representatives, their role and responsibilities and payment available.

Level of involvement All
Type of involvement 1,2,3,4,5,6,7,9
Focus of involvement a,b,c,d,e

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a formal recruitment and selection process and offers training in representation with support and mentoring. Members of HCRRA are given the opportunity to represent the views of people who live in rural and remote Australia in the planning and implementation of a broad range of health issues that directly affect them. Members are required to give feedback on their work to the organisation for the information of other members. Member's availability is variable.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.

Heartbeat Victoria Inc.

PO Box 144, Parkville, VIC 3052

Tel 03 9367 2627
Email hbvic@iprums.com.au Website www.heartbeatvictoria.org

Contact Person Mr Joe Casha, President
Geographical Area Serviced Statewide
Regional Groups & Contact Details Regional groups can be accessed through the website.

Aims and activities
To support people and their families who have had, or plan to have heart surgery through the provision of advice, education, advocacy, accommodation, and financial assistance. They produce a newsletter and hold forums and talks.

Membership
Any person who has cardiac disease or has had a cardiac event, and their family.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in cardiac disease, focusing on improving quality of life and fund raising for cardiac equipment for hospitals. This organisation has a limited number of people available for these activities. They would be interested in projects that benefit the quality of life of their membership, future cardiac patients and hospital staff.

Level of involvement All
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a formal process for recruitment and selection using a database of members who can also be contacted personally. They offer training in representation, support and mentoring. They have an older membership whose priority are medical appointments and who would require transport assistance to attend activities in winter as the availability of public transport may be an issue. Only those on the executive can represent the organisation.

Assistance required for a consumer/member and carer to participate

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**Heart Support Australia**

**PO Box 266, Mawson, ACT 2607**

**Tel** 02 6285 2357  
**Fax** 02 6281 1120  
**Email** heartsupport@heartnet.org.au  
**Website** www.heartnet.org.au  
**Contact Person** Ms Jacqueline Stewart, CEO  
**Hours Open** Mon – Fri, 9am – 5pm  
**Regional Groups & Contact Details** Initial contact with National Office Canberra.

**Aims and activities**
To provide support, information and encouragement as a free-of-charge service for heart patients and their families through the use of volunteer trained lay counsellors.

**Membership**
Heart patients, carers, their family and other interested persons.

**Motivation for involvement in improving the safety and quality of health care**
The organisation has an interest in Heart Disease and rehabilitation following cardiac events. The criterion for involvement in projects is available from the National Office (see above).

**Level of involvement** All  
**Type of involvement** All  
**Focus of involvement** a,b,c,d,e,f,g,j,k

**Recruitment, selection, training, support & mentoring of members/consumers & carers**
The organisation has a formal recruitment process and a lay counsellor-training program. Most members are retired and can offer counselling services most hours of the day. Those that work give time after business hours and at weekends. Members can represent the organisation.

**Assistance required for a consumer/member and carer to participate**
Heart Support Australia will seek reimbursement from health services when they provide services such as consultation and document preparation.

**Hepatitis C Council of Victoria**

**Suite 5, 200 Sydney Road, Brunswick, VIC 3056**

**Tel** 03 9380 4644  
**Fax** 03 9380 4688  
**Email** hepcvic@vicnet.net.au  
**Website** www.hepcvic.org.au  
**Hours Open** Mon – Fri, 9am – 5pm  
**Geographical Area Serviced** Statewide

**Aims and activities**
To represent and respond to the needs of people with Hepatitis C, their carers, partners, friends and family members through the provision of education, information, support, training, advocacy, and a quarterly magazine.

**Membership**
Membership is open to anyone.

**Motivation for involvement in improving the safety and quality of health care**
The organisation has an interest in projects related to Hepatitis C, decreasing discrimination against those with Hepatitis C and improving access to appropriate care. The proposed project would need to allow for reimbursement of expenses.

**Level of involvement** National/State  
**Type of involvement** All  
**Focus of involvement** All

**Recruitment, selection, training, support & mentoring of members/consumers & carers**
The organisation has an informal process for selecting and recruiting members through the Council's members’ advisory group. They can offer support and mentoring. Availability of members is variable with some requiring financial assistance to participate whilst others receive disability pensions. Members can represent the organisation.

**Assistance required for a consumer/member and carer to participate**
Heart Support Australia will seek reimbursement from health services when they provide services such as consultation and document preparation.
Maltese Community Council of Victoria

Aims and activities
To keep alive Maltese traditions through the provision of welfare programs, social and cultural activities, and care for the aged.

Membership
Maltese people or people of Maltese descent.

Motivation for involvement in improving the safety and quality of health care
The organisation would need to know the time, personal commitment and benefit to the Maltese community.

Level of involvement State
Type of involvement 2,5,8,9
Focus of involvement a,b,c,d,e,i,k

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a formal recruitment and selection process and can provide support and mentoring. Members’ availability may be restricted by work commitments.

Assistance required for a consumer/member and carer to participate

Maternity Coalition

Aims and activities
The Maternity Coalition is a national non-profit umbrella organisation made up of individuals and support groups committed to advocating for the rights of mothers and improving maternity care for women during pregnancy, birth and beyond. It achieves its aims through work with the midwifery profession to expand a model of care in which midwives provide primary care and support to all women. The Coalition promotes women's control over decision-making through improved access to information, resources and support and provides forums for independent consumer driven childbirth education. It has national and state meetings, carries out lobbying and advocacy for improved maternity services, and provides a quarterly journal.

Membership
Anyone interested in issues surrounding improvement in maternity care and services.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in pregnancy, childbirth and lobbying for improved maternity services, particularly one to one midwifery care by a known midwife throughout the childbirth continuum. There is an interest in projects that lead to improved positive outcomes for women and feedback to the organisation.

Level of involvement All
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation supports consumer participation at all levels, they have an informal recruitment and selection process and can train, support and mentor consumers. Consumers represent the organisation but have limited availability, as they are volunteers.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.
Mental Illness Fellowship

Aims and activities
To decrease stigma and provide current up-to-date research-based services for people with mental illness, their families and friends. This is achieved through the provision of psychosocial rehabilitation, family support, education (community, business and counselling), support groups, advocacy, fund raising, a newsletter and volunteers. They are a registered training organisation.

Membership
Membership is open to anyone.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects related to mental illness, education, employment, mainstreaming mental illness and de-clinicalising services. They would be interested in projects with clearly stated outcomes, which provide feedback, meaningful and respectful contact with participants, and provision of a protocol for research projects.

Level of involvement
All

Type of involvement
All

Focus of involvement
All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation is able to informally recruit, but not select members through the use of staff email, a newsletter, volunteers and by word of mouth. They can provide support and mentoring as needed. Member’s availability is variable but many are unemployed.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.

Migrant Information Centre (Eastern Melbourne)

Aims and activities
To build a stronger multicultural community by providing practical solutions to barriers for accessing services and service gaps and establishing quality service delivery for migrants and their families. The organisation provides advice, support and advocacy to people and communities from culturally and linguistically diverse (CALD) backgrounds.

Membership
People and organisations that have a demonstrated interest in supporting a multicultural community in the eastern region.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects concerned with people and communities from a CALD background provided they supply the following information: what the project is seeking to achieve and how, what specific benefits will flow from the project and by when, the time commitment required, and the support offered to participants.

Level of involvement
Local

Type of involvement
1,2,4,5,6,7,9,10,11

Focus of involvement
a,b,h,i,j,k

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has an informal process to recruit and select members by contacting community leaders and individuals from CALD communities to promote the project and seek involvement.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.
Migrant Resource Centre North East

251 High Street, Preston, VIC 3072
Tel 03 9484 7944 Fax 03 9484 7942
Email mrcne@mrcne.org.au Website www.mrcne.org.au
Hours Open Mon – Fri, 9am – 5pm
Contact Person Reception
Geographical Area Serviced The local government areas of Darebin, Moreland, Banyule, Whittlesea, Nillimbuk and Yarra.

Aims and activities
To make available comprehensive migrant settlement services for newly arrived migrants and refugees living in the northern region of Melbourne. This is achieved by providing post arrival migrant settlement support and immigration advice, migrant aged services and group programs, multicultural in-home HACC services, migrant employment services, resourcing of ethnic community groups, cross-cultural training and ethnic community consultancy and education.

Membership
Residents within the northern suburbs with an interest in migrant and multicultural issues.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects concerned with migrant and refuge health and disability issues. The proposed project would need to be relevant to the issues and needs of CALD consumers and promote issues affecting ethnic communities.

Level of involvement National/State
Type of involvement 1,2,4,5,8,9,10,11
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has an informal process for recruiting members through their large regional network that is represented by the leaders of over 60 ethnic voluntary clubs. They can provide support, mentoring and leadership training to ethnic community leaders and consumer representatives. Membership availability is variable.

Assistance required for a consumer/member and carer to participate

Migrant Resource Centre North West Region

45 Main Road West, St Albans, VIC 3021
Tel 03 9367 6044 Fax 03 9367 4344
Email mrcnw@mrcnorthwest.org.au Website www.mrcnorthwest.org.au
Hours Open Mon – Fri, 9am – 5pm
Contact Person Ms Margaret Rutherford, Executive Officer
Geographical Area Serviced Brimbank, Melton, Hume - settlement services. Brimbank, Melton, Maribyrnong, Moonee Valley, Hume - community development. Western region - HACC funded programs such as social support, planned activities and disability advocacy.

Aims and activities
To provide support to people from culturally diverse backgrounds through the provision of advice and information on settlement and immigration issues. They support new and emerging communities and provide advocacy on a range of issues.

Membership
Any community member.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects related to settlement but would need to know the aims of the project and what the information collected will be used for.

Level of involvement All
Type of involvement 1,2,4,5,8,11
Focus of involvement a,b,c,h,i,k

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation can informally recruit members by linking services with ethno-specific groups. They can provide support and mentoring. Member's availability is variable.

Assistance required for a consumer/member and carer to participate

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**Motor Neurone Disease Association of Victoria**

265 Canterbury Road (PO Box 23), Canterbury, VIC 3126  
Tel 03 9830 2122  
Fax 03 9830 2122  
Email info@mnd.asn.au  
Website www.mnd.asn.au  
Hours Open Mon – Fri, 8.30am – 5pm  
Contact Person Ms Brenda Ryan, Information Officer  
Geographical Area Serviced Statewide

**Aims and activities**
To provide the best possible support and advice for people living with motor neuron disease (MND). They create and maintain support networks and programs, offer needs assessment, referral, equipment loan, telephone support and encourage and support research initiatives.

**Membership**
People with MND and other interested people.

**Motivation for involvement in improving the safety and quality of health care**
The organisation has an interest in projects related to MND that will improve services for people living with this disease.

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**Multiple Sclerosis Society of Victoria**

The Nerve Centre, 54 Railway Road, Blackburn, VIC 3130  
Tel 03 9845 2700  
Fax 03 9845 2777  
Email infoline@mssociety.com.au  
Website www.msaustralia.org.au  
Hours Open Mon – Fri, 9am – 5pm  
Contact Person Mr Glenn Mahoney  
Geographical Area Serviced Statewide  
Regional Groups & Contact Details Geelong, Warrnambool, Wangaratta, Ballarat, Bendigo and Traralgon. Other support groups are accessible through People with MS Victoria or the MS Society.

**Aims and activities**
To reduce the impact of MS on individuals, families and carers and to find a cure. The organisation provides specialist services, peer support, education, referral, information, community development and education, newsletters for members, volunteers and donors.

**Membership**
People with multiple sclerosis or another neurological condition

**Motivation for involvement in improving the safety and quality of health care**
The organisation has many interests particularly research into a cure for MS, and services enabling people with MS to live independently in their own homes and participate fully in their own community. To be involved in a project they would need to know the aims of the project, the outcomes, how issues of privacy will be addressed, how the participants will receive feedback, who is auspicing it and the support consumers will receive in order to participate.

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**Recruitment, selection, training, support & mentoring of members/consumers & carers**
The organisation has a formal process for recruiting and selecting members through their newsletter and website and through specific approaches to individuals who have expressed an interest. They have a protocol for research project participation and a privacy policy. They provide a training program in representation, support and mentoring, an ‘Ambassador Program’ which includes training in public speaking for people with MS, peer support training, and training in lobbying and community education. Availability of members is variable as some have mobility issues. Members can represent the organisation.

**Assistance required for a consumer/member and carer to participate**
Northern Mallee Migrant Services

255 Eleventh Street, Mildura, VIC 3500
Tel 03 5022 1006
Fax 03 5021 2450
Email nmmsg@hotkey.net.au

Hours Open
Mon – Fri, 8.45am – 4.30pm
Contact Person
Mr Nick Forsberg, CEO
Ms Colleen Tarrant (aged care, disability)
Geographical Area Serviced
Northern Mallee
Regional Groups & Contact Details
12 ethnic groups including Turkish, Greek, Italian, Croatian, Philippine, Tongan. The Sunraysia Ethnic Community Council is contactable through this organisation and meets bi-monthly.

Aims and activities
To maintain culture without prejudice, encourage, understand and embrace other cultures.
To promote equal access and equity in community life through referral, support, information exchange and outreach work.

Membership
This organisation supports many ethnic community groups.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects related to aged care, disability, and ethnic communities.
They require as much information as possible to be supplied before a decision regarding involvement can be made.

Level of involvement
Local
Type of involvement
All
Focus of involvement
All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation can recruit formally through their support groups. The majority of aged people who use the services are retired and may need transport assistance.

Assistance required for a consumer/member and carer to participate
### Palliative Care Victoria

**Level 2, 182 Victoria Parade, East Melbourne, VIC 3002**

**Tel** 03 9662 9644  
**Fax** 03 9662 9722  
**Email** info@pallcarevic.asn.au  
**Website** www.pallcarevic.asn.au  
**Hours Open** Mon – Fri, 9am – 5pm  
**Contact Person** Ms Margaret Box, Executive Director  
**Geographical Area Serviced** Statewide

**Aims and activities**

To understand the diverse needs of members, clients and communities, drive and influence palliative care policy, and inform and educate the community about palliative care.

**Membership**

Palliative care providers and those individuals who have an interest in palliative care.

**Motivation for involvement in improving the safety and quality of health care**

The organisation has an interest in projects related to palliative care but the project must be respectful of privacy, especially when the member is in a vulnerable position. A short time frame is preferable. Permission needs to be sought for information to be shared and agreement about what is to be done with the information is necessary.

**Level of involvement**

State/National

**Type of involvement**

1,2,5,6,9

**Focus of involvement**

c,d,e

**Recruitment, selection, training, support & mentoring of members/consumers & carers**

The organisation can informally recruit and select members through a newsletter and can supply support and mentoring as required. The availability of members is variable, but mostly they are available during the day. Members may also live in rural areas.

**Assistance required for a consumer/member and carer to participate**

Any of the assistance listed may be required and should be considered and negotiated on an individual basis.

### ParaQuad Victoria

**208 Wellington Street, Collingwood, VIC 3066**

**Tel** 03 9415 1200  
**Fax** 03 9415 1222  
**Email** hbryant@paraquad.asn.au  
**Website** www.paraquad.asn.au  
**Hours Open** Mon – Fri, 9am – 5pm  
**Contact Person** Ms Helen Bryant  
**Geographical Area Serviced** Statewide

**Aims and activities**

To support people with predominately physical disabilities by providing attendant care services, training and disability awareness, counselling services, accommodation (supported and rental), case management, volunteer services, advocacy, lobbying, and continence and aids equipment and products.

**Membership**

People with disabilities, families, carers, health professionals and students.

**Motivation for involvement in improving the safety and quality of health care**

The organisation has an interest in projects related to people with spinal cord injuries, people who have had Polio, people with high levels of disability and complex medical needs. The project proposal would need to specify the time of involvement, transport assistance provided, parking availability and disability access.

**Level of involvement**

All

**Type of involvement**

1,2,3,4,5,6,7,8,9,10

**Focus of involvement**

a,b,d,e,h,i,j,k

**Recruitment, selection, training, support & mentoring of members/consumers & carers**

The organisation has a formal recruitment and selection process through the newsletter. They provide training in representation, support and mentoring. Members’ availability is limited by work commitments and mobility.

**Assistance required for a consumer/member and carer to participate**

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People Living with HIV/AIDS Victoria

6 Claremont Street, South Yarra, VIC 3141
Tel 03 9865 6772 Fax 03 9804 7978
Email info@plwhavictoria.org.au Website www.plwhavictoria.org.au
Hours Open Mon – Fri, 9am – 5pm
Contact Person Mr Mark Thompson
Geographical Area Serviced Melbourne

Aims and activities
To provide relief from suffering, alleviate poverty, distress and financial hardship for people living with HIV/AIDS. They aim to improve life expectancy and quality of life. Services include advocacy, policy development, support and education.

Membership
Openly HIV positive people can be full members, all others can be associate members.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects related to HIV/AIDS.

Level of involvement All
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a formal recruitment and selection process. They provide training in representation, support and mentoring. They also offer public speaking and return to work training. A member with chronic and debilitating illness’ availability is limited by their health. Occasionally members will represent the organisation.

Assistance required for a consumer/member and carer to participate

People with Multiple Sclerosis Victoria Inc.

PO Box 5605, Cranbourne Park, VIC 3077
Tel 03 5996 3037 Email fredstone@bigpond.com
Hours Open Mon – Fri, 10am – 5pm
Contact Person Mr Fred Stone
Geographical Area Serviced Statewide
Regional Groups & Contact Details 31 self-help groups throughout Victoria.

Aims and activities
To represent people with MS and provide advice, advocacy, self-help support, and contact through a bi-monthly newsletter.

Membership
Predominantly people diagnosed with MS, or other neurological conditions who have no support.

Motivation for involvement in improving the safety and quality of health care
The organisation would have an interest in projects related to MS.

Level of involvement State/Local
Type of involvement 1,2,3,8,9,11
Focus of involvement a,b,j,k

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation can provide support and mentoring. See MS Society entry for other issues. Member’s availability is variable.

Assistance required for a consumer/member and carer to participate
Post and Antenatal Depression Association (PaNDa)

270 Church Street, Richmond, VIC 3121

Tel 03 9428 4600  Fax 03 9428 2400
Email panda@vicnet.net.au  Website www.vicnet.net.au/~panda
Hours Open  Mon – Thurs, 9.30am – 4.30pm
Contact Person  Ms Terrie Hollingsworth, Coordinator
Geographical Area Serviced  Statewide

Aims and activities
To support and inform women, and families affected by post and antenatal mood disorders.
To educate health care professionals and the wider community about post and antenatal mood disorders through telephone/email/letter support. They also provide information, referral and education, public speaking and professional development.

Membership
Full membership is available to all sufferers of post and antenatal depression or psychosis.
An associate membership is available for any interested person or association. Membership does not assume active participation in the organisation it may simply involve receipt of newsletters.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects related to post and antenatal mood disorders.
They would need to know the aim of the project, the process and procedures, support provided for participants including sensitivity to the impact of contact on participants and time and distance commitments required. Feedback would need to be provided to the participants as well as the organisation.

Level of involvement  All
Type of involvement  1,2,4,5,6,7,8,9,10,11
Focus of involvement  a,b,f,g,h,i,j,k

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation can recruit from their trained volunteer pool. General requests can be advertised on the website but PaNDa does not provide recruitment services in these instances. Respondents communicate directly with the organisation that is seeking participants. The PaNDa website has been used by health services to advertise activities, to disseminate information/outcomes and to recruit participants. They provide training, support and mentoring and trained volunteers frequently represent the organisation. The availability of members varies and is also influenced by their health status.

Assistance required for a consumer/member and carer to participate

O C $ M
Prostate Assist
AMA House, 293 Royal Parade, Parkville, VIC 3052
Tel 03 9347 2522 Fax 03 9347 2533
Email cvosper@contfound.org.au Website www.contfound.org.au
Contact Person Mr Cyril Vosper
Hours Open Mon – Fri, 9am – 6pm
Geographical Area Serviced Statewide
Regional Groups & Contact Details
Altona Meadows Les Mather Tel 03 9749 3681.
Frankston Frank Wood Tel 03 5985 8786.
Healesville Richard Hutchens Tel 03 5962 3093.
Heidelberg Trevor Cottle Tel 03 9458 4587.
Melbourne Cyril Vosper or Trevor Cottle, as above.
Ringwood Robert Kraal Tel 03 9725 8510.

Aims and activities
To support men with prostatitis, benign prostrate hyperplasia (BPH) and prostrate cancer.
They aim to make reliable information available to members on their illnesses so they can make
informed decisions over their futures. They provide information through leaflets and regular
meetings for information and discussion.

Membership
Any adult, but mostly men.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects related to prostate diseases and prevention with useful
outcomes, feedback, and meaningful contact with participants.

Level of involvement All
Type of involvement 1,2,6,8,9,11
Focus of involvement a,b,f,g,j,k

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation is able to informally recruit members and provide training in representation,
support and mentoring. The availability of members is variable but they are flexible and highly
cooperative. Members can represent the organisation.

Assistance required for a consumer/member and carer to participate

Reality Check Young Adults with Diabetes Inc.
13 Wreckyn Street, North Melbourne, VIC 3051
Tel 03 9328 5233
Email kate@realitycheck.org.au Website www.realitycheck.org.au
Contact Person Ms Kate Gilbert or Ms Rose Moore
Geographical Area Serviced Melbourne, Adelaide and Sydney

Aims and activities
To provide opportunities for young adults with diabetes to share their knowledge and experiences
to improve the experience of young people living with diabetes. The services provided include
educational seminars, encouraging networking opportunities, management of a website with an
interactive discussion forum, promotion of the interests and concerns of members to health
professional forums, government and the media, provision of information about living with diabetes
in a way that is accessible to young people and undertaking research into the needs of young
people with diabetes.

Membership
Primarily 17-40 year olds with Type 1 Diabetes, however membership is open.

Motivation for involvement in improving the safety and quality of health care
Due to limited availability, as stipulated below, the organisation rarely participates in general consultation.

Level of involvement State
Type of involvement 4,11
Focus of involvement c,f,g

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation plays an important role in re-engaging young people with diabetes with their
health system. In many cases people approach the organisation after many years of not seeking
adequate professional advice and support for their diabetes, having had a bad experience.
Through the organisation they receive informal referral to friendly doctors and re-enter the health
system. The organisation also undertakes activities such as participating in the formal curriculum of
medical schools by providing consumers to share their experiences with medical students each
year. The organisation can provide mentoring. The availability of members is very limited and they
can represent the organisation.

Assistance required for a consumer/member and carer to participate
Regional Information and Advocacy Council
93 Nixon Street, Shepparton, VIC 3632
PO Box 1763, Shepparton, VIC 3632
Tel 03 5822 1944 Fax 03 5831 1610
Email ceo@riac.org.au Website www.riac.org.au
Contact Person Ms Kim McCrae
Geographical Area Serviced West Hume (Mitchell, Murrindindi, Strathbogie, Shepparton, Moira) and all of Loddon Mallee.

Aims and activities
An association of self-help groups, individuals with disabilities, carers and family members who advocate for people with disabilities, their families and carers. They provide support groups, training, health promotion, a newsletter and indigenous and ethno specific workers.

Membership
Individuals with disabilities, their families and carers. Associate memberships are available for organisations.

Motivation for involvement in improving the safety and quality of health care
The organisation has a particular interest in disability, ethnic and indigenous issues and all other areas of health. Members are very interested in being involved in quality improvement activities. They are already involved in the annual self-assessment associated with meeting disability standards and some members are involved with other organisations in their QA projects. They prefer short-term projects.

Level of involvement Local/State
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a consumer representative program with a recruitment and selection process through their newsletter, the newspapers and by individual contact. They provide training in representation for specific groups and support people on an individual, as needs basis. Availability of members is variable. Consumer, carers and community members can represent the organisation but must report back to the board for any decision-making and with the minutes of the specific meetings.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.

Reinforce
Ross House Building, 247-251 Flinders Lane, Melbourne, VIC 3000
Tel 03 9650 7855
Email reinforce@netspace.net.au
Contact Person Ms Amanda Hiscoe
Geographical Area Serviced Statewide

Aims and activities
To provide advocacy assistance training, education on self advocacy and training in public speaking for those with an intellectual disability.

Membership
Membership is open to anyone.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects related to an intellectual disability but would need sufficient time and support to participate. They would require information in plain English and payment for their involvement.

Level of involvement State
Type of involvement 2,3,4,5,6,7,8,9,10
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has no formal process for recruitment or selection but members can express an interest in being involved. Members’ availability is variable.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.
Retina Australia (Vic) Inc.

4th Floor, Ross House, 247-251 Flinders Lane, Melbourne, VIC 3000
Tel 03 9650 5088 Fax 03 9650 5088
Email retina@netspace.net.au Website www.retinaaustralia.com.au
Hours Open Mon – Thurs, 10am – 2pm
Contact Person Ms Kate Giles
Geographical Area Serviced Statewide

Aims and activities
A self-help organisation made up of volunteers dedicated to helping others with retinitis pigmentosa and other associated dystrophies. The organisation provides peer support for persons affected with vision loss, a quarterly newsletter, a yearly programme called “Exploring Vision Loss”, assistance to people with any queries and fund raising for research.

Membership
Membership is open to anyone.

Motivation for involvement in improving the safety and quality of health care
The organisation is interested in projects that raise the awareness of vision loss due to inherited eye disease such as Retinitis Pigmentosa, Macular Degeneration and other retinal dystrophies. The project must also be of benefit to the members.

Level of involvement State/Local
Type of involvement 1,2,3,4,5,6,7,9
Focus of involvement a,b,c,d,e,f,g,h,i

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation is able to recruit and select informally but this is dependent on the availability of volunteers. They can offer support and mentoring. Availability of members is variable and members can represent the organisation.

Assistance required for a consumer/member and carer to participate

Richmond Fellowship of Victoria

Head Office, 2 Wellington Street, Collingwood, VIC 3066
Tel 03 9418 2300 Fax 03 9419 6100
Email semmett@rfv.org.au Website www.rfv.org.au
Hours Open 7 days, 24 hours
Contact Person Mr Stephen Emmett
Geographical Area Serviced Statewide
Regional Contacts Barwon South West, Gippsland, Hume, Loddon Mallee.

Aims and activities
To provide psychosocial rehabilitation services.

Membership
Participants are mainly people with a psychiatric disability.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects related to rehabilitation for people with a psychiatric disability. To be involved they would require the project brief to detail the infrastructure support, the purpose of consumer involvement, and how the project will ensure positive outcomes for consumers.

Level of involvement Local
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a formal recruitment and selection process and can provide support and mentoring. Members are available part-time and may have mobility issues. Members can represent the organisation.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.
Road Trauma Support Team

3c Hepburn Street, Hawthorn, VIC 3122
Tel 03 9819 9922 or Free call 1800 367 797   Fax 03 9819 6700
Email ceo@rstv.org.au

Hours Open       Mon – Fri, 9am – 5pm
Contact Person   Ms Jeanette Suhr
Geographical Area Serviced Statewide

Aims and activities
To offer counselling and support to Victorians affected by road trauma through professional counselling, volunteer support (i.e. support provided by trained volunteers who have an experience of road trauma), education and prevention.

Membership
Membership is open to all Victorians.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in road trauma and reducing the impact on individuals and the incidence in the community. They would require details of the project’s aims, time requirements for participants, and the type of involvement so mentoring and debriefing can be arranged.

Level of involvement     All
Type of involvement      1,2,5,6,7,8,9,10,11
Focus of involvement     a,b,c,d,e,h,i,j,k

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation is able to informally recruit and select members and can supply support and mentoring as needed. The volunteers/members are bereaved, carers and injured people with ABI or psychological injuries and their availability is variable.

Assistance required for a consumer/member and carer to participate

SIDS and KIDS Victoria

1227 Malvern Road, Malvern, VIC 3144
Tel 03 9822 9611   Fax 03 9822 2995
Email neridadmulvey@sidsandkids.org
Website www.sidsandkids.org
Hours Open       Mon – Fri, 9am – 5pm
Contact Person   Ms Nerida Mulvey
Geographical Area Serviced Statewide

Aims and activities
To save children’s lives through research and health promotion and to support families and community members affected by the sudden and unexpected death of a child from 20 weeks gestation to 6 years of age. The organisation provides an outreach program, bereavement support, group activities and community education.

Membership
Membership is open to anyone.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects concerned with safe sleeping and bereavement care with clear outcomes, feedback and meaningful contact with participants.

Level of involvement     All but mostly local & state
Type of involvement      2,3,4,5,6,7,8,9,10,11
Focus of involvement     All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation has a process to recruit and select parent supporters through an individual approach. Training is provided in the following areas: Speaker’s Bureau, Parent Support and Group Leadership. Availability of members is variable and consumers represent the organisation.

Assistance required for a consumer/member and carer to participate
All.
South Central Region Migrant Resource Centre

40 Grattan Street, Prahran, VIC 3181
Tel 03 9510 5877  Fax 03 9510 8971
Email mrcprah@vicnet.net.au  Website www.southcentralmrc.org.au
Hours Open Mon – Fri, 9am – 5pm
Contact Person Mr Ross Buscemi, Director
Geographical Area Serviced South central region of Melbourne

Aims and activities
To provide settlement services to newly arrived migrants and refugees through information and advice, advocacy and referral.

Membership
People from culturally and linguistically diverse backgrounds.

Motivation for involvement in improving the safety and quality of health care
The organisation would need the proposed project to have clear outcomes, feedback, and meaningful contact with the participants.

Level of involvement Local
Type of involvement 5,6 for consumers, 3,4,10 for staff & 8,9
Focus of involvement Unknown

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation is not able to recruit participants but can refer the health service to the appropriate community group.

Assistance required for a consumer/member and carer to participate

South Eastern Region Migrant Resource Centre

Level 1, 314 Thomas Street, Dandenong, VIC 3175
Tel 03 9706 8933  Fax 03 9706 8830
Email sermrc@sermrc.org.au  Website www.sermrc.dandenong.net/
Hours Open Mon – Fri, 9am – 5pm
Contact Person Ms Jenny Semple, Director
Geographical Area Serviced City of Greater Dandenong, Casey & Shire of Cardinia.

Aims and activities
To be the advocate of ethnic communities, empowering them to participate fully in Australian society. Promoting full participation of migrants and refugees from diverse cultural and linguistic backgrounds in the planning of settlement services, based on equity and justice. Services include, on-arrival migrant settlement support and immigration advice, migrant aged services and group programs, multicultural in-home HACC services, migrant employment services, assisting ethnic community groups, cross-cultural training and ethnic community consultancy and education.

Membership
Residents within the south eastern suburbs, with an interest in migrant and multicultural issues.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects concerned with migrant and refugee health and disability issues.

Level of involvement Local
Type of involvement 1,2,4,5,8,9,10,11
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation recruits members through a regional network representing leaders of many ethnic voluntary groups and associations. They can provide support, mentoring and leadership training to ethnic community leaders and consumer representatives. The members have variable availability.

Assistance required for a consumer/member and carer to participate
Southwest Advocacy Association

31 Princess Street, Warrnambool, VIC 3280
Tel 03 5561 4584  Fax 03 5561 4371
Email swaa@hotkey.net.au  Website www.standard.net.au/~swaa

Hours Open  Mon – Fri, 9am – 5pm
Contact Person  Mr Rob Dick
Geographical Area Serviced  South Western Victoria

Aims and activities
To provide advocacy on behalf of individuals with disabilities and group systemic advocacy, community education and support group development.

Membership
People of any age with any type of disability.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects related to people with disabilities that have clear outcomes, feedback and are meaningful to the participants.

Level of involvement  All
Type of involvement  1,2,3,4,5,8,9,10,11
Focus of involvement  a,b,c,h,i

Recruitment, selection, training, support & mentoring of members/consumers & carers
The activities undertaken by the organisation will need to be negotiated as needed. Members have variable availability and may have mobility issues. Consumers can represent the organisation.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.

Stroke Association of Victoria Inc.

PO Box 226, Geelong, VIC 3220
Tel 03 9760 1117  Fax 03 5278 7980
Email admin@strokeassociation.com.au  Website www.strokeassociation.com.au

Hours Open  Mon - Sun, 9am – 5pm
Contact Person  Rostered volunteers
Geographical Area Serviced  Statewide
Regional Groups & Contact Details  Can be obtained on request and from their website.

Aims and activities
To encourage communication between stroke survivors, assist with the development of new support groups on a needs basis and continue to work in partnership with like-minded organisations that assist others in need. The organisation provides information, moral and mutual support, advocacy, telephone counselling, support groups, home and hospital visits, guest speakers, information seminars, stroke awareness week, annual respite social weekend, and a quarterly newsletter.

Membership
Stroke survivors, carers and family members, interested people in stroke recovery, prevention organisations and like-minded organisations.

Motivation for involvement in improving the safety and quality of health care
The organisation has an interest in projects concerned with stroke. They must provide clear outcomes, feedback, meaningful contact with participants and useful information for the organisation.

Level of involvement  State/Local
Type of involvement  All
Focus of involvement  All

Recruitment, selection, training, support & mentoring of members/consumers & carers
The organisation is able to recruit informally through the groups and selected members. They can provide training and support. Members can represent the organisation.

Assistance required for a consumer/member and carer to participate

© © ©
**Tourette Syndrome Association of Victoria Inc.**

The Nerve Centre, 54 Railway Road, Blackburn, VIC 3130

Tel 03 9845 2700        Fax 03 9845 2777
Email tourettes@mssociety.com.au  Website www.tsavic.org.au
Hours Open  Three days per week, 10am – 3pm
Contact Person  Mail-box message bank available
Geographical Area Serviced  Statewide

**Aims and activities**

To support individuals and families with Tourette Syndrome in Victoria and maintain a useful library and a public awareness campaign. The organisation provides support meetings, a newsletter, advocacy, youth programs and a 24 hour help line.

**Membership**

Anyone with an interest in Tourette Syndrome.

**Motivation for involvement in improving the safety and quality of health care**

The organisation is interested in projects that focus on raising awareness of Tourette Syndrome in the community and the development of education systems. They prefer short-term projects where the contact with participants will be meaningful.

**Level of involvement**  Local

**Type of involvement**  2,7,8,9,11

**Focus of involvement**  All

**Recruitment, selection, training, support & mentoring of members/consumers & carers**

The organisation has a formal process to recruit and select members. Members have limited availability.

**Assistance required for a consumer/member and carer to participate**

Donation to the organisation.

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**Victorian Deaf Society**

Level 4, 340 Albert Street, East Melbourne, VIC 3002

Tel 03 9473 1111  Fax 03 9473 1122
TTY 03 9473 1199

Email info@vicdeaf.com.au  Website www.vicdeaf.com.au

Hours Open  Mon – Fri, 8.30am – 5pm

Contact Person  Mr John Paton

Geographical Area Serviced  Statewide

**Aims and activities**

To improve the quality of life for deaf and hard of hearing people by breaking down communication barriers and improving access to services, increasing the status and participation of deaf people in society, and providing specialist support and community services. The organisation provides support and counselling, independent living skills training, accommodation support, aged care services, audiology and rehabilitation services, and Auslan interpreting.

**Membership**

Anyone with an interest in the deaf community.

**Motivation for involvement in improving the safety and quality of health care**

The organisation has an interest in projects related to deaf and hard of hearing Victorians and projects that are consistent with the Victorian Deaf Society mission statement.

**Level of involvement**  State

**Type of involvement**  To be negotiated

**Focus of involvement**  To be negotiated

**Recruitment, selection, training, support & mentoring of members/consumers & carers**

The organisation can inform members through their newsletter and provide support and mentoring. Availability of members is limited and members would need interpreter access.

**Assistance required for a consumer/member and carer to participate**

Donation to the organisation.
### Victorian Mental Illness Awareness Council (VMIAC)

23 Weston Street, Brunswick, VIC 3056

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**Email** director@vmiac.com.au  
**Website** www.vmiac.com.au  
**Hours Open** Mon – Fri, 9am – 5pm  
**Geographical Area Serviced** Statewide  
**Regional Groups & Contact Details** Monthly regional group activities can be accessed through the Melbourne office.

**Aims and activities**

To enable people with a mental illness or emotional problems to have a say in decision-making using individual, group and systemic methods. The organisation provides advocacy, mutual support and self-help for consumers, and education to consumers and providers in the mental health area. They have a newsletter for members and also a web page. They provide training and support for rural and metropolitan consumer consultants.

**Membership**

Consumers and ex-consumers of psychiatric services. Other interested people may join but will not have voting rights.

**Motivation for involvement in improving the safety and quality of health care**

The organisation is interested in projects concerned with mental health.

**Level of involvement** National/State/Local  
**Type of involvement** All  
**Focus of involvement** All

**Recruitment, selection, training, support & mentoring of members/consumers & carers**

VMIAC prefer to be approached directly to nominate members to be engaged in activities. They do not have a structured consumer representation program but are aware of the skills, knowledge and interests of their membership. They are able to find a member for a project and support and train that member dependent on their needs. Availability of members varies and they can act on their own behalf.

**Assistance required for a consumer/member and carer to participate**

![Assistance Icons]

### Victorian Network on Recreation and Disability (VICNORD)

178 High Street, Northcote, VIC 3070

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<td>03 9489 6899 or 03 9489 1179</td>
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**Email** acl@advocacyhouse.org  
**Website** www.advocacyhouse.org  
**Hours Open** Mon – Fri, 9am – 5pm  
**Contact Person** Ms Libby Zerna  
**Geographical Area Serviced** Statewide  
**Regional Groups & Contact Details** Contact through this body.

**Aims and activities**

To advocate empowerment and an independent life in the community for people with disabilities. This is achieved through advocacy, support and referrals for recreational issues.

**Membership**

Anyone with a disability, family members, carers and friends.

**Motivation for involvement in improving the safety and quality of health care**

The organisation has an interest in projects related to disability and each project proposal will be considered on its merits.

**Level of involvement** State/Local  
**Type of involvement** All  
**Focus of involvement** All

**Recruitment, selection, training, support & mentoring of members/consumers & carers**

The organisation has a process to formally recruit and select members through their newsletter. They are able to provide training through seminars and conferences and support as needed. Members’ availability is dependent on their ability to make alternate care arrangements, deal with mobility issues and/or organise attendant carer assistance. Members can represent the organisation.

**Assistance required for a consumer/member and carer to participate**

Any of the assistance listed may be required and should be considered and negotiated on an individual basis.
**Aims and activities**

To provide a quality, multi-purpose women’s health service in order to improve the health status of women in the Grampians region. To assist women to make informed personal decisions on health issues, and to have more control over their lives. The organisation provides health information and referral, education services (workshops, forums, courses, information sessions), professional education to health professionals, a Well Women’s Clinic, and a lending library.

**Membership**

There are two levels of membership – full membership is available to women or organisations (the representative for voting purposes must be a woman), and limited membership is available to anyone who wishes to borrow from the library, receive newsletters or information regarding events.

**Motivation for involvement in improving the safety and quality of health care**

To be involved in a project the organisation would need to know the time commitment necessary, the expected outcomes and be reassured of feedback.

**Level of involvement**  
State/Local

**Type of involvement**  
1,2,3,4,5,6,7,8,9,

**Focus of involvement**  
a,b,c,d,e,h,i

**Recruitment, selection, training, support & mentoring of members/consumers & carers**

The organisation has an informal process to recruit and select members and is currently developing a more formal process. The organisation has access to consumers via the membership database. Membership availability varies and consumers make up the committee of management.

**Assistance required for a consumer/member and carer to participate**

![Various icons]
Aims and activities
To ensure all women have access to quality, responsive services that meet their health needs and that an understanding of women’s health is maintained and promoted from a feminist perspective. The organisation provides a clearinghouse of women’s health information. The clearinghouse collects information, literature and resources relating to women’s health and acts as an interchange point for knowledge, research and initiatives in women’s health. The organisation advocates for women, works with service providers for better health outcomes and provides statewide women’s health promotion, advocacy and health information services. They work largely in partnership with service providers to reach the maximum number of Victorian women, in particular women with limited or poor access to services.

Their advocacy to improve women’s health and well being operates principally at two levels. With health service providers to improve the translation of research and evidence into health services practice, and with public policy makers including government departments and politicians to ensure healthy public policy for women.

Membership
Individual women and organisations.

Motivation for involvement in improving the safety and quality of health care
Projects concerned with women’s health from a broader perspective.

Level of involvement All
Type of involvement All
Focus of involvement All

Recruitment, selection, training, support & mentoring of members/consumers & carers
Council members are not general members but can be involved in some activities.

Assistance required for a consumer/member and carer to participate
Any of the assistance listed may be required and should be considered and negotiated on an individual basis.
Directories, Resources, Peak Bodies & Websites
DIRECTORIES

A Guide to Services for Senior Victorians
Provides information about the range of services and opportunities available to senior Victorians from Commonwealth, State and Local Government, as well as the voluntary and community sector.

Child Health Information Centre (CHIC): Support Group Directory
Contact details and information of over 200 Victorian support groups and service providers available in the community provided by CHIC at the Royal Children's Hospital in Melbourne.
Website www.rch.org.au/chic/

Directory of Australian Breast Cancer Organisations
Provides information about state and national organisations that are relevant to all aspects of breast cancer.
Website www.isourcedirectory.com

Directory of Cardiac Rehabilitation Programs
This paper based directory contains a list of Australian-wide rehabilitation programs and support groups. It is available from the National Heart Foundation of Australia by ringing Heartline on 1300 362 787.

Directory of Self-Help and Social Action Groups
This extensive paper based directory provides immediate contact points for groups to network among themselves and build up their own links, to share information, to join together in campaigns and coalitions and a wide variety of group ventures. It is also a resource for workers in many groups and organisations, professionals, researchers, journalists, activists, libraries, and crisis intervention and information centres. The directory lists neighbourhood houses in metropolitan and rural areas, community health centres, specialist health services, women's health services, community and specialist legal centres, and migrant resource centres. It can be obtained from COSHG, PO Box 251, Brunswick East, 3057, or by phoning 03 9349 2301 or emailing coshgmelb@yahoo.com.au. Their website provides links to many of the organisations listed in the Directory.
Website www.vicnet.net.au/~coshg

Directory of Victorian Aboriginal & Torres Strait Islander Health & Community Services
Lists Aboriginal community controlled organisations and other organisations, which have Aboriginal workers, or service a large number of Aboriginal people including Aboriginal hospital liaison officers. It provides an opportunity for positive interaction between General Practitioners and Indigenous health organisations and workers. As well as information on health services, accommodation and education services in urban and rural Victoria, in keeping with an Indigenous holistic approach to health. It is currently being updated but can be downloaded from the website. For more information you can contact Daryl Nayler on daryl.nayler@ndgp.org.au
Website www.ndgp.org.au/koorihealth.htm

Disability Online
Provides information for people with a disability, their families and carers.
Website www.disability.vic.gov.au

Multicultural Services Directory
Provided by the Ethnic Communities’ Council of Victoria. A list of multicultural organisations including the Ethnic Community Councils and Migrant Resource Centres.
Website www.eccv.org.au/db/

Health Translations Directory
Enables health practitioners and those working with culturally and linguistically diverse communities to find reliable translated health information. It also provides web links to online multilingual resources across the health sector including government departments, peak health bodies, hospitals, community health centres and welfare agencies.
Website www.healthtranslations.vic.gov.au
Primary Care Partnerships Statewide Health Service Directory
Victoria's most extensive health and community support services directory. It provides access to a current database of health and associated community support services in Victoria.

Victorian Mental Health Services
Lists mental health services in the appropriate age group and area, and includes disability support services.

Victorian Multicultural Resources Directory
Provides a range of important contact details for people dealing with Victoria's many and diverse multicultural and ethno-specific organisations, communities and councils.
Website www.voma.vic.gov.au

PEAK BODIES

Carers Victoria
5th Floor, 130 Little Collins Street, Melbourne, VIC 3000
Tel 03 9650 9966 or Free call 1800 242 636 (Carer Resource Centre) Fax 03 9650 8066
Email cav@carersvic.org.au Website www.carersvic.org.au
For further information see alphabetical listing.

Centre for Culture, Ethnicity & Health
23 Lennox Street, Richmond, VIC 3121
Tel 03 9427 8766 or 03 9428 2269
Email enquiries@ceh.org.au Website www.ceh.org.au
Supports health services to become increasingly responsive to the needs of ethnic communities throughout Victoria. Provides training in cultural sensitivity and has a comprehensive library.

Chronic Illness Alliance
818 Burke Road, Camberwell, VIC 3124
Tel 03 9805 9126 Fax 03 9882 7157
Email christine@chronicillness.org.au Website www.chronicillness.org.au
For further information see alphabetical listing.

Consumer Health Forum (CHF)
PO Box 3099, Manuka, ACT 2603
Tel 02 6273 5444 Fax 02 6273 5888
Email info@chf.org.au Website www.chf.org.au
The Consumers' Health Forum of Australia Inc (CHF), established in 1987, is Australia's leading non-government organisation representing consumers on health care issues. CHF establishes policy in consultation with its members, more than one hundred health consumer organisations, and other consumers. It provides a balance to the views of government, industry, service providers and health professionals. The vision of CHF is to see consumers shaping health policy and health delivery systems in Australia. CHF's mission is to provide a respected and informed national voice for health consumers. It works collaboratively with other health consumer organisations providing a leadership role in representing the views of consumers at a national level. CHF refers requests for input at a state level to state-based consumer organisations. The CHF website lists their voting members which are the state-based organisations to which they would refer any request for consumer representatives.

Council on the Ageing (Vic)
Block Arcade, 98 Elizabeth Street, Melbourne, VIC 3000
Tel 03 9654 4443 Fax 03 9654 4456
Email cotavic@cotavic.org.au Website www.cotavic.org.au
For further information see alphabetical listing.
Ethnic Communities’ Council of Victoria
150 Palmerston Street, Carlton, VIC 3053
Tel 03 9349 4122  Fax 03 9349 4967
Email eccv@eccv.org.au  Website www.eccv.org.au
For further information see alphabetical listing.

Health Consumers of Rural and Remote Australia
PO Box 280, Deakin West, ACT 2600
Tel 02 6285 4660  Fax 02 6285 4670
Email carmel@ruralhealth.org.au  Website www.ruralhealth.org.au
For further information see alphabetical listing.

Health Issues Centre
Level 5, Health Sciences Building 2, La Trobe University, VIC 3086
Tel 03 9479 5827  Fax 03 9479 5977
Email hic@latrobe.edu.au  Website www.vicnet.net.au/~hissues
For further information see alphabetical listing.

VICSERV
370 St Georges Road, North Fitzroy, VIC 3068
Tel 03 9482 7111  Fax 03 9482 7281
Email vicserv@vicserv.org.au  Website www.vicserv.org.au
The peak body for psychiatric disability support services in Victoria. It provides support to consumers
and carers through programs such as home-based outreach, psychosocial rehabilitation day programs,
mutual support and self-help, respite and advocacy. Services to members include: sector co-ordination,
support and advocacy, training and professional development, policy, and information services.

Victorian Aboriginal Community Controlled Health Organisation (VACCHO)
5-7 Smith Street, Fitzroy, VIC 3065
Tel 03 9419 3350  Fax 03 9417 3871
Email CEO jillg@vaccho.com.au  Website www.vaccho.com.au
Represents the collective of all Aboriginal community controlled organisations around Victoria.
It serves as a channel for communities to direct Aboriginal health policies, supports locally planned
initiatives and works on behalf of members as requested. It also co-ordinates statewide opinion on
Aboriginal health issues that affect all member communities. Provides resources and links and a list
of every local Aboriginal community controlled organisation with a health function at

Victorian Council of Social Service (VCOSS)
Level 6, 130 Little Collins Street, Melbourne, VIC 3000
Tel 03 9654 5050 or Free call 1800 133 340 (rural areas)
Email pwd@pwd.org.au  Website www.pwd.org.au/links.html
The peak organisation of the social community services sector. It raises awareness of the existence,
causes and effects of poverty and inequality, and contributes to initiatives seeking to create a more
just society. It advocates on behalf of Victorians experiencing disadvantage by providing a strong,
non-political voice for the community sector through such activities as policy development and
analysis, direct advocacy to government, reliable research, reports, media releases and submissions

Victorian Mental Illness Awareness Council
23 Weston Brunswick, Brunswick, VIC 3056
Tel 03 9387 8317  Fax 03 9388 1445
Email director@vmiac.com.au  Website www.vmiac.com.au
For further information see alphabetical listing.

Women’s Health Victoria
1st Floor, 123 Lonsdale Street, Melbourne, VIC 3000
Tel 9662 3755  Fax 9663 7955
Email whv@whv.org.au  Website www.whv.org.au
For further information see alphabetical listing. The following website provides links to all the
women’s health services in Victoria www.whv.org.au/useful_links.html#vic
WEBSITES

Australian Council for Safety and Quality
Provides a list of national consumer advocacy organisations and also “10 tips for safer health care: What everyone needs to know.”
Website www.safetyandquality.org/links_consum.cfm and www.safetyandquality.org

Better Health Channel
The Department of Human Services’ on-line health information site for Victorian health consumers contains such information as articles on general health topics; a library comprising a medical dictionary, health spell checker and consumer information on prescription drugs; healthy recipes; a comprehensive directory of health services and practitioners; calendar of events; health news and an education page.
Website www.betterhealth.vic.gov.au

Carenet Family Care Incorporated
Carenet is a registered children’s charity that supports children with seriously ill brothers and sisters throughout Australia. They provide support programs using trained volunteers and an internet club for kids called “Cyber Sibs”, which is an internet based support program for kids with seriously/chronically ill siblings. The aim is to connect children for mutual support and to engender a sense of value in the group. The site can be found at www.cybersibs.org.au. Carenet is also involved in research into the psychosocial impacts of childhood illness on the siblings of the patient.
Website www.carenet.org.au

Consumer Information and Participation Program for Victoria’s Public Hospitals
The Department of Human Services provides a number of useful publications, which can be downloaded from this website including “Communicating with Consumers Series Volume 1, Well-written Health Information: A Guide”.

Council to Homeless Persons Australia
Provides a starting point for information on homelessness.
Website www.chpa.org.au/info.html

Disability Online
Provides information for people with a disability, their families and carers, including a service directory, disability and health topics, events calendar, latest news and useful links.
Website www.disability.vic.gov.au

Ethnic Communities’ Councils
All Ethnic Communities’ Councils can be accessed through the following web address.
Website www.eccv.org.au/contact_us.html

Guide to Effective Participation
An online guide for health professionals seeking to involve people in projects and programs.
Website http://www.partnerships.org.uk/guide/index.htm

Healthinsite
Provides a wide range of up-to-date and quality assessed information on important health topics such as diabetes, cancer, mental health and asthma.
Website www.healthinsite.gov.au

Health Issues Centre
Provides articles from their journal “Health Issues” plus other publications and links.
Website www.healthissuescentre.org.au

Mensline Australia
Provides a resource-link with a current database of networks, agencies, services and programs relevant to men’s interests and needs.
Website www.menslineaus.org.au
Men’s Referral Service
Provides information about an anonymous and confidential telephone service, provided for men by men. Also has an up-to-date and comprehensive listing of services that are available to men throughout Victoria.
Website www.ntv.net.au/ntv_two.htm

Migrant Resource Centres
Migrant Resource Centres in Victoria can be accessed at the following web address.

National Health Service (NHS) UK
The NHS provides an interesting website which includes the NHS Modernisation Agency which is publishing a series of Improvement Leaders Guides designed to improve patient care and improve systems of care.
Website www.modern.nhs.uk/improvementguides/patients/

National Resource Centre for Consumer Participation in Health (NRCCPH)
Level 5, Health Sciences Building 2, La Trobe University, VIC 3086
Free call 1800 625 619 Fax 03 9479 5977
Email s.robinson@latrobe.edu.au Website www.participateinhealth.org.au
A clearinghouse for information on consumer feedback and participation methodologies. A centre of excellence for advice and assistance to develop, implement and evaluate consumer participation methods and models and a centre for research and special projects on a variety of consumer participation topics. All Consumer Focus Collaboration resources can be downloaded from the NRCCPH website or a CD can be obtained by phoning the centre.

Office of the Health Services Commissioner
30th Floor, 570 Bourke Street, Melbourne VIC 3000
Tel 03 8601 5200 or Free call 1800 136 066 Fax 03 8601 5219
Email hra@dhs.vic.gov.au Website www.health.vic.gov.au/hsc/
An independent, impartial statutory authority responsible for the administration of the Health Records Act 2001. They assist with problems about unsatisfactory care, privacy of and/or access to health information, communication issues, lack of respect, dignity or privacy, and negligent or unprofessional behaviour.

Primary Health Knowledge Base
Promotes and supports effective exchange of information relevant to providers of the primary health services in Victoria.

Royal Victorian Eye & Ear Hospital Support Groups
Provides a list of a number of in-house and external support groups.

VicHealth Koori Health Research and Community Development Unit
Provides a program of community development, teaching and research that supports the work that goes on in Koori communities and organisations in the health area.

Victorian Aboriginal Corporation for Languages
Is responsible for the retrieval, recording and restoration of Aboriginal languages in Victoria. Has a useful map of the Aboriginal language areas in Victoria.
Website www.vaclang.org.au

Victorian Aboriginal Health Service Co-operative Ltd
Provides information about the Service and Aboriginal health links.
Website www.kooriweb.org/vahs/indexa.html
RESOURCES
Organisations without available members who wished to be included:

Chinese Community Social Services Centre Inc.
Suite 11, Professional Suites, Centro Whitehorse Shopping Centre, Box Hill 3128
Tel 03 9898 1965 or 03 9898 1888 Fax 03 9898 8547
Email ccssci@bigpond.net.au Hours Open Mon – Fri, 9am – 5pm
Contact Person Ms Kim Chu
Geographical Area Serviced Eastern Region
Works to promote and represent the interests of the Chinese-Australian community through the
delivery of quality social services, education and advocacy including community settlement
services, community aged care packages and home and community care programs.

Disability Discrimination Legal Service
1st Floor, 212 King Street, Melbourne, VIC 3000
Tel 03 9602 4877 Fax 03 9602 4979
Email info@ddls.org.au Website www.ddls.org.au
Contact Person Mr Jonathon Goodfellow, Coordinator
A statewide community legal centre dedicated to the elimination of discrimination based on
disability. This is achieved through the provision of free and accessible legal service, support and
casework, inclusion of people with disabilities in all law reform activities to affect systemic change,
provision of community education on disability discrimination and resource provision.

Migrant Resource Centre Westgate Region Inc.
78-82 Second Avenue, Altona, Melbourne, VIC 3018
Tel 03 9391 3355 Fax 03 9399 1796
Email WMRCA@bigpond.com.au Website www.wmrc.org.au
Contact Person Joe Caputo
Provides a safe and welcoming environment for new arrivals and the general community needing
assistance within the cities of Hobson’s Bay and Wyndham. Qualified bilingual workers and staff
offer information on settlement immigration issues, and other needs required by newly arrived
migrants and refugees.

Residential Care Rights Inc.
Suite 4B, 343 Little Collins Street, Melbourne, VIC 3000
Tel 03 9602 3066 or Free call 1800 700 600 Fax 03 9602 3102
Email rcr/rcr.org.au Website www.vic.agedrights.asn.au
A statewide service that provides quality advocacy for any person receiving a commonwealth
funded aged care service. The services include provision of information, support and advice
regarding rights and responsibilities.

SANE Australia
PO Box 226, South Melbourne, VIC 3205
Tel 9682 5933 Fax 9682 5944
Email info@sane.org Website www.sane.org
Hours Open Mon – Fri, 9am – 5pm
Contact Person Ms Barbara Hocking
Geographical Area Serviced National
SANE is a charitable foundation and any person can become a ‘Friend of SANE’ on application.
It aims to work for a better life for people affected by mental illness through campaigning and
advocacy for improved services and attitudes, community education and applied research.
The organisation’s core mission is improvement in the quality of life of Australians affected by
mental illness, through better community support and attitudes as well as provision of optimum
medical treatment.
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Please note that this will depend on the availability of a consumer or carer speaker at the time of request.

Speaker Checklist

To ensure the best experience for everyone involved it is important that speakers are fully briefed on the purpose of the event, the audience and the logistical details such as location, timing, how to get there, who will meet them etc.

Information for a speaker should include:

- who and how many are attending
- the required outcomes or aims of the event
- other speakers and their topics
- what focus or particular aspect you would like the speaker to address and for how long

Ideally speakers should have a nominated contact that can manage the whole process. Even experienced speakers may be nervous so it is important to ensure that they are comfortable with the equipment and software setup and know how to operate it or have someone to help them. It is preferable that speakers can see the venue and check presentations well before they are required to present so that any problems can be addressed. A stand for notes and a glass of water is also appreciated. Finally check how the speaker likes to be introduced. Preparing and giving presentations takes considerable time and effort and it helps to know your efforts are appreciated. An experienced chairperson who is knowledgeable in the area under discussion and has been briefed on the purpose of the forum or session should chair the session.

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Methodology used to create the Guide

Literature Review
An initial literature search was conducted using a number of search terms. The purpose of the search was to access similar Guides/Directories. Very few Guides/Directories were accessed and none with the particular criteria we had established.

Criteria for Inclusion in the Guide
The criteria established for organisations to be included in this Guide were: that the organisation participates in activities with health services, has experience of providing consumer, carer or community representatives and would like to provide consumer, carer or community representatives to health services for quality and safety improvement activities.

There are likely to be other small organisations that may fit these criteria but were not contacted due to time limitations. There are also a number of larger organisations who were unable to participate at this time either because they were undergoing restructures or were in the process of developing or redeveloping their consumer and carer participation strategies. It is hoped that some of these organisations will be included later versions of the Guide.

Contacting the Organisations
The list of organisations to be contacted grew out of other Guides/Directories, information from key informants, peak bodies and suggestions from the VQC Consumer Working Group. In addition we asked the contacts at each of the organisations, starting with peak bodies and larger consumer and community organisations, to nominate other organisations that they thought would meet the criteria and be interested in being included in the Guide.

Directories that were particularly useful in identifying groups were: the Collective of Self-help and Social Action Groups Directory; the Child Health Information Centre (CHIC); Support Groups Directory from the Royal Children’s Hospital; the Victorian Multicultural Resources Directory; and the Primary Care Partnerships State wide Health Services Directory (all are included in this Guide).

To ensure that the major disease groups were represented, we consulted the Burden of Disease and Injury study conducted by the Australian Institute of Health and Welfare (1999). The Victorian Office of Multicultural Affairs Ethnic Diversity in Victoria Information Sheet and Directory provided the main ethnic communities and language groups to be contacted. All Migrant Resource Centres and Ethnic Communities’ Councils were contacted but not all are listed in the Guide as some were unable to respond or did not define their work as directly related to health and quality improvement. Some Migrant Resource Centres and Ethnic Communities’ Councils are co-located in the regional areas. Attempts were also made to contact ethno-specific organisations from the 10 major countries of origin and language groups however we have not listed those whose work is more welfare than health oriented.

Several key indigenous workers were contacted and it was found that the Northern Hospital and Northern Division of GPs are working on updating an existing indigenous Directory (and therefore contacting organisations). It was agreed that rather than contacting organisations again, a link be provided through this Guide to the Directory of Victorian Aboriginal and Torres Strait Islander Health and Community Services. This link appears in the resources pages and index.
Collecting the Data

A questionnaire was constructed and piloted with a small number of organisations and then further refined based on feedback from the pilot. Each organisation was contacted by phone, fax and/or email and provided with an introductory letter and questionnaire (Appendix 2 and 3). Some organisations chose to complete the questionnaire independently and return it whilst others preferred a phone interview followed up by written confirmation. All organisations were sent a draft copy of their entry for the Guide to ensure the correct details were documented. Of the 230 organisations contacted by phone and/or email, 91 submitted completed entries.

In the process of creating this Guide we became aware of the vast number of organisations doing important work with their consumers and carers within their organisational structures and with health services. This Guide serves to acknowledge and build upon this work.


2 These were cardiovascular disease, cancer, mental health, nervous system and sensory disorders and respiratory disorders.
Dear Manager

RE: Development of a Victorian Consumer, Carer and Community Directory

I am pleased to introduce the work of the Victorian Quality Council (VQC) and invite you to assist us in compiling a Consumer Carer and Community Directory for Victoria.

The VQC was established in 2001 as an expert strategic advisory group to govern the safety and quality agenda for Victorian health care services. The VQC is committed to reducing the risk of harm and improving health care safety and quality. The VQC’s role is to provide leadership and direction and to identify and address gaps in safety and quality. Increasing the effective involvement of consumers in the improvement process is regarded as a priority.

One of the ways the Council is assisting health services to involve consumers, carers and community members in quality and safety initiatives is by providing them with a directory of consumer, carer and community groups interested in working with health services to improve the quality and safety of healthcare.

The Directory will provide health services with information about ways in which consumers, carers and community members from different groups and organisations prefer to participate and will help to ensure that consumers, carers and community members are involved in ways that are supportive and appropriate to their interests and needs.

We would like your help to complete the Directory by providing us with information about your organisation. Attached is a document, which asks a range of questions about your organisation. Janet Spink will phone to make a time with you to complete the questionnaire or you can complete it electronically if you wish.

If you would like further information about the project or the questionnaire please contact Janet Spink phone/fax 03 9439 8628 email jdspink@bigpond.net.au or Lesley Thornton, VQC Project Officer, phone 03 9616 1385 or email lesley.thornton@dhs.vic.gov.au

Yours sincerely

Christine Walker
Chair
Victorian Quality Council Consumer Working Group
# APPENDIX 3

## Questionnaire

### Part A General Organisational Information

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**Briefly state your organisation’s aims and objectives**

**Briefly state the activities of the organisation** *(e.g. provide advice, advocacy, support and counselling etc)*

**Who can be a member?** *(This might be age, gender, geographical, ethnic or disease based)*

**Geographical area serviced**

**Regional groups & contact details** *(if applicable)*

**Does your organisation have a particular area of interest?** *(These might be disease specific or defined in some other way such as a disability group with a focus on raising the awareness about the needs of spinal injury patients)*

**What sort of support might your members need from a health service to participate?**

- Payment for time at meetings and preparation time
- Reimbursement of costs (travel, childcare, carer/respite, attendant carer)
- Carer/respite, childcare
- Responsiveness to special requirements; dietary, transport etc
- Orientation to organisation/health system/issues, mentoring by staff member
- Refreshment
- Administrative support, written material in plain English
- Translation and interpretative support
- Time for reading and/or to gain input from membership/board of management
- Other *(please specify)*

### Part B Involvement in Health Service Quality and Safety

The purpose of this section is to find out the types of quality and safety improvement activities your members have been involved in and the kinds of activities they prefer to be involved in.

1. **Would you undertake to recruit and select members in response to requests from health services to take part in quality and safety projects/activities?** Yes/No
2. **Do you have a formal process for doing this?** Yes/No
3. **If no how would you see your organisation helping health services recruit appropriate consumers?**
Part B Involvement in Health Service Quality and Safety (cont’d)

4. Generally speaking what is the availability of your members?
   - Work full-time, available evenings only
   - Carer, need time to make alternative arrangements for care
   - Work part-time, flexible
   - Mobility issues, need transport assistance
   - Other (please specify)

5. At what levels of the health system does your organisation/members prefer to be involved?
   - National
   - State
   - Local

6. Does your organisation provide any of the following for your members?
   - Training in representation
   - Support/Mentoring
   - Other (please specify)

7. Do consumers, carer or community members ever represent your organisation? Yes/No

8. When a health service approaches you seeking consumer involvement what do you need to know from them to want to be involved? (e.g. the project will have outcomes, there will be feedback, the contact will be meaningful, short or long-term projects)

9. The tables below identify ways in which consumers can participate in improving the safety and quality of health care. Please tick those ways that your organisation/members have been involved in health services.
   - Responding to/commenting on papers, facts sheets, web sites, education packs
   - Questionnaires and surveys
   - Representatives on boards
   - Membership of advisory/steering committees/reference groups
   - Focus groups
   - Individual and group interviews
   - Panels
   - Public meetings
   - Workshops/seminars/conferences
   - Training/education activities
   - Advocacy
   - Other

9. What has been the focus of these activities?
   - Evaluation/Feedback
   - Policy
   - Quality/Standards
   - Research/Ethics
   - Strategic/Service Planning
   - Training/Education

10. Are you a member of a consumer, carer or community organisation that supports representation/advocacy and who?

Thank you for your assistance
### Application Form for Inclusion in the Guide

The Guide will be updated periodically and we would like to know if you would like to be included in the Guide. Please fill in the details below and we will contact you closer to the time to complete a proper entry for the Guide.

We would also like to hear from you if you found the Guide useful or you have any suggestions for its improvement.

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1. Briefly state your organisation’s aims and activities

2. Who can be a member?

3. Geographical area serviced

4. Regional groups & contact details (if applicable)

5. Do you have members or consumer and carer clients who are interested in participating in improving the quality and safety of health services with health services? This might include public speaking, participating in focus groups or sitting on committees to help develop policy, improve information provision or improve service delivery.

   Yes/No

6. Would you undertake to recruit and select members in response to requests from health services to take part in quality and safety projects/activities?

   Yes/No

7. Does your organisation provide any of the following for your members?
   - Training in representation
   - Support/Mentoring
   - Other (please specify)

8. Do consumers, carer or community members ever represent your organisation?

   Yes/No

Please return this completed form to:

Victorian Quality Council, Level 7, 589 Collins Street, Melbourne 3000
Tel 03 9616 1385  Fax 1300 138 933  Email vqc@dhs.vic.gov.au
APPENDIX 5

Acknowledgements

The Victorian Quality Council and project team would like to thank all those who contributed to this Guide.

Consumer, carer and community organisations that responded to our requests for information in order to construct this Guide

VQC Consumer Working Group
- Christine Walker (Chair)
- Peter Greenberg
- Jill Sewell
- Greg Pullen
- Maree Cuddihy
- Sophie Hill
- Jane Phelan
- Sandy Robinson
- Beth Wilson
- Lesley Thornton (Senior Project Officer)

Health Services
- Cathy Jones, Director Quality and Risk, St Vincent’s Hospital
- Enid Smith, Quality Manager, Hamilton Hospital
- Heather Lampshire, Quality Manager, Peter MacCallum Cancer Centre
- Helen Rohan, Child Health Information Centre, Royal Children’s Hospital
- Jennifer Thompson, Health Promotion and Community Development, Royal Victorian Eye and Ear Hospital
- Jenny Ham, Acting Operations Manager, CHERC, Bendigo Health Care Group
- Liz Bailey, Clinical Effectiveness Unit, Bendigo Health Care Group
- Mary Jane White, Quality Manager, St Vincent’s Health
- Merrin Prictor, Quality Manager, Goulburn Valley Health

Department of Human Services
- Aaron Doty
- Fofi Christou
- Jackie Kearney
- Kerry Smith
- Lois Browne
- Regina Kalb
- Sarah Wright
- Sue Casey

Other Organisations
- Annabel Barbara, Executive Manager, Centre for Culture Ethnicity and Health
- Bob Pease, Associate Professor, School of Social Planning, RMIT
- Chris Laming, Lecturer, Social Welfare, Monash Gippsland
- Christine McAuslan, Collective of Self-Help Groups
- Daryl Naylor, Aboriginal and Torres Strait Islander Liaison Officer, Northern Hospital and Northern Division of GPs
- Diane Lowther, Journal Coordinator/Administrative Officer, Health Issues Centre Inc.
- Gary Gromb, Collective of Self-Help Groups
- Helena Maher, Research and Policy Officer, Health Issues Centre
- Kay Currie, Deputy Director, Effectiveness Unit, Monash Institute of Health Services Research
- Margaret Wohlers, Information Manager, National Resource Centre for Consumer Participation in Health
- Meera Rajendran, Knowledge Manager, Health Insurance Commission
- Tatjana Bahro, Acute Care Diversity Coordinator, Centre for Culture Ethnicity and Health
- Wendy Allen, Project Manager, Centre for Clinical Effectiveness Monash Institute of Health Services Research

Your tolerance, enthusiasm and co-operation are greatly appreciated.

Researched and written for the Victorian Quality Council by Janet Spink with assistance from Christine Hill.