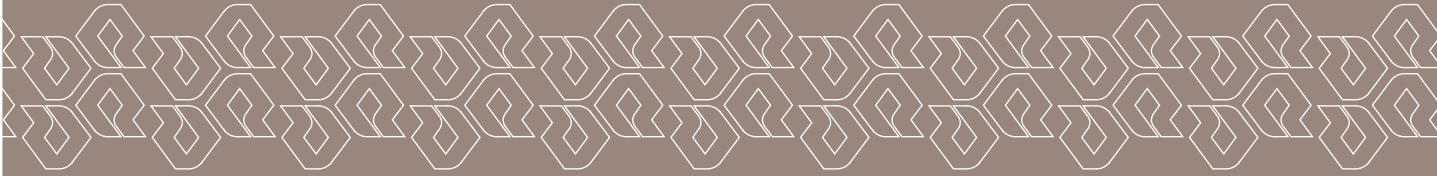


Consumer Leadership

Consultation report
May 2007



Published by the Rural and Regional Health and Aged Care Services Division,
Victorian Government Department of Human Services, Melbourne, Victoria.

May 2007

This booklet is available in pdf format and may be downloaded from the VQC
website at www.health.vic.gov.au/qualitycouncil

© Copyright State of Victoria, Department of Human Services, 2007

This publication is copyright. No part may be reproduced by any process except
in accordance with the provisions of the *Copyright Act 1968*

Authorised by the Victorian Government, 50 Lonsdale St., Melbourne 3000.

rcc_070517

Victorian Quality Council Secretariat
Phone 1300 135 427
Email vqc@dhs.vic.gov.au
Website www.health.vic.gov.au/qualitycouncil

Contents

1. Introduction	2
2. Overview	4
3. Leadership and leaders	6
4. Characteristics of consumer leadership	9
5. Supporting consumer involvement in service improvement	14
6. Effective consumer leadership	21
7. Developing consumer leadership capacity	24
8. Opportunities for consumer leadership in health care	26
9. Enhancing partnerships between health services and consumers	29
10. References	32
11. Appendix 1 – Consultation participants	34
12. Appendix 2 – Consultation guide	37
13. Appendix 3 – Advocacy training programs	40

1. Introduction

Section 01

1. Introduction

The Victorian Quality Council (VQC) identified consumer, carer and community collaboration as a key tenet of effective health care improvement and aims to enhance leadership capacity and consumer involvement in health care quality and safety improvement across Victoria. To inform the development of consumer leadership, the VQC commissioned a research project to identify strategies to facilitate consumer leadership in quality and safety improvement in health services.

A targeted consultation process comprised a major part of the project and was undertaken concurrently with a literature review that is the subject of a separate report. The literature review is available at: www.health.vic.gov.au/qualitycouncil

The aim of the consultations was to identify:

- characteristics of consumer leaders
- models or programs for developing consumer leadership capacity
- opportunities for consumers to provide leadership in safety and quality and to work with health care services to improve services
- the ability and capacity of health services to involve consumers in leadership roles.

During June and July 2006 more than 50 people from community and consumer organisations, government departments, academic institutions and health services were interviewed. Participants came from a range of sectors including health, financial services, disability and environment. Most had considerable experience within their sectors and drew widely upon that experience to inform this project. A list of participants is included in Appendix 1.

Prior to the consultations, participants were provided with a short discussion paper about community and consumer sector leaders and leadership. Six main areas of investigation were identified:

- defining the qualities and characteristics of consumer leadership
- identifying the support and encouragement required for consumer involvement in service improvement
- the skills and knowledge required for effective consumer leadership – for both consumers and service providers
- models for developing the capacity of consumers to play a leadership role
- models to provide opportunities for consumer leadership in delivery of safety and quality improvement of services
- models for enhancing the capacity of service providers to work in partnership with consumers on safety and quality improvement.

These six areas formed the basic structure for all interviews.

The consultations were conducted as semi-structured interviews. Most were carried out by telephone, with some face-to-face meetings.

This report provides an overview of the major themes arising from the consultations, and then summarises the major points and views expressed in the interviews. It does not seek to analyse, interpret or draw conclusions, but rather sets out the views of a range of stakeholders about consumer leadership and how it is best encouraged and developed.

2. Overview

Section 02

2. Overview

Consultation participants differed widely in their knowledge and experiences of consumer advocacy and participation and in their perceptions of the Australian health care system; however, some common themes emerged from the interviews. All consultation participants responded positively to the project and to discussion about consumer leadership. Many saw it as breaking new ground.

The consultations revealed broad support for investigating this topic and a sense that it would be a constructive contribution to improving the safety and quality of care. Research in this area is not yet widely reported.

Consumer leadership in health was not seen as being embedded in a few high-profile individuals. Rather, it was seen as something that is inherent in many people and can emerge and be developed given the right combination of an enabling environment and appropriate support, including training.

There was broad agreement that consumer leadership is usually organic (arising from a community of interest), but that it can also be structural. Consumer leadership was seen as being linked to consumer participation and many respondents did not differentiate between the two.

There was a wide recognition of the need to support and develop consumer leadership. Structured training programs were recognised as being an important component of leadership development, although some respondents were cautious about an over-reliance on formal, traditional training. They stressed the need for a range of different strategies that recognised the backgrounds and diversity of consumers.

Health services were seen as having an important role in enabling consumer leadership to emerge and providing an environment within which it could develop and grow. Many respondents stressed the need for health services to be more open and engaged with their communities and to provide a variety of fora through which consumers could engage at different levels with health services. Increased participation would then enable consumer leadership to emerge.

There was recognition of the tensions that can be inherent when dealing with two, sometimes divergent, populations and the need for consumer leaders to have particular characteristics and skills.

Victorian consumer advisory committees (CACs), were seen by some as having the potential to foster consumer leadership and to play a leadership role within health services. Some CACs were nominated as being successful; however, there were also concerns about lack of diversity in CAC membership and that many services were not encouraging CACs to achieve their potential.

Respondents stressed the need for health services to provide an enabling environment within which leadership can emerge and develop. Such an environment is characterised by demonstrated support for consumer participation from the highest levels of the organisation, clarity about roles, and providing appropriate support and training to enable consumers and providers to work collaboratively.

3. Leadership and leaders

Section 03

3. Leadership and leaders

Some respondents saw a confusion or conflict between management and leadership. While there is a tendency to talk about those concepts together, one respondent strongly made the point that management is a much safer task:

‘Leadership is a high risk area and there can be an attrition rate – it takes a toll on people and requires more energy than management’.

Consumer and community leadership was seen as differing from the traditional concept of leadership demonstrated by people in senior positions in the corporate sector. Many respondents indicated that in the community and consumer sectors, leadership is demonstrated in many forms and at many different levels: in individuals and organisations; at grass roots and in management positions; in people or groups working in the wider public arena; and in people in governance positions.

‘Leadership relies on people relinquishing power and accepting multiple leaders at different times based on expertise, mutual leading, educating, informing, and providing a learning environment.’

Some participants who played leading roles in consumer advocacy did not identify themselves as leaders:

‘I don’t feel I have anything more than lots of years of experience in mental health politics. I do not see myself as a leader other than sharing what I have learned’.

Others spoke of the traditional stereotype of a leader as inhibiting recognition of leadership capacity. This was particularly so in regard to people with disabilities or mental health issues. The opportunity to look at what it takes to develop leadership capacity for all sorts of people, rather than one individual, was welcomed.

Some respondents, particularly those in the community and consumer sectors, spoke of the lack of explicit recognition of leadership in those sectors.

‘The ethos in the consumer/community sector is to bring others along. If we followed corporate sector models of leadership we could easily undermine our own people. We work on a more inclusive model. We are so careful about this that we don’t let our leaders shine.’

A respondent from the disability sector observed that, intellectually, leadership comes from the corporate sector, and that traditional portrayals of leaders have ‘put it outside our box’.

Some also spoke about the relationship between people who are seen to be leaders and the people they lead. They spoke about the importance of recognising and accepting that there are ‘multiple leaders at different times, based on expertise, mutual leading, educating and informing’.

Some respondents spoke of the difficulties inherent when exercising a leadership role within two distinct and sometimes conflicting groups: the groups from which consumer leadership often emerges and the health care sector that is to be influenced through consumer leadership positions. They pointed out the issue that consumer leadership cannot be divorced from consideration about how and who is being led and that groups may be competing and have differing needs and values. For example, many grass roots members of consumer organisations want to see their representatives take a high profile in the media without understanding that this can undermine relationships with other stakeholders. Therefore, in understanding consumer leadership, it is important to recognise the conflicting pressures on leaders. There is a skill in being able to bridge those different sets of values. There was also some discussion about the perception that people who are leaders must have a high public profile. The point was made that:

‘... consumer leaders are not necessarily the people who are in your face all the time – the people who get wheeled out to speak in public. They are often people who are thinking about the essential issues to do with consumer perspectives. Leaders are

often people who are doing the thinking and the writing and the conversations and the publishing around why health needs the consumer perspective’.

Several respondents spoke of the need for different strategies to bring about change. Some consumer leaders need to stand outside the system and point out its shortcomings in the public arena. While this can inhibit a direct dialogue between those particular consumers and the health services, it does act as a means of opening the door for other consumers to engage in negotiations with governments and service providers around service improvement issues.

Many respondents emphasised that leadership operates in many different ways and at many different levels – from involvement in formal and informal groups at local, state and national levels or working on specific issues relating to a specific service, to dealing with system-wide issues.

Some participants also expressed concerns about the process for selecting consumers to leadership positions within health services: being hand-picked. The point was frequently made that the effectiveness of the leadership position is weakened when they are not informed by, or accountable to, a constituency that can provide a foundation for their work through access to a representative range of consumer experiences and perspectives.

Some respondents also emphasised that not only individuals demonstrate leadership; it can also be demonstrated by organisations. Established organisations can demonstrate leadership by supporting emerging organisations with practical help and advice, role modelling and mentoring.

Several respondents were involved in enhancing the relationship between services and people from Aboriginal and Torres Strait Islander backgrounds. They took a somewhat different view of consumer leadership; it was pointed out that the term ‘consumer’ is not one that is commonly used in discussions about indigenous health. Rather, their emphasis was on working with the whole community and on establishing and using dedicated, structured positions within services to educate other health workers about working with indigenous people. It was also on training indigenous people to work in the community to help people to prevent illness and care for their own health.

4. Characteristics of consumer leadership

Section 04

4. Characteristics of consumer leadership

Questions about the qualities and characteristics of consumer leadership elicited many ideas and discussion. There was a remarkable consistency in responses and there did not appear to be any substantial disagreement with the qualities and characteristics identified in the literature review and provided in the discussion paper. However, respondents elaborated and expanded on the underlying qualities needed for consumer leadership.

Consumer leadership was seen as driven by the following.

- Having a bold vision – a sense that it was possible to change things.
- Motivation – mostly identified as being altruistic and being about improving the health system so that others might benefit rather than a sense of grievance. There was also some acknowledgement that a general interest in the issues could develop into leadership.

‘A leader is someone who can think along the lines of how you help many others.’
- Commitment – this was expressed as a ‘total commitment to getting the best deal for consumers, but balanced with the need to take into account the public and general interest’. This included remaining independent and accountable to consumers – learning how to avoid being co-opted to other people’s agendas.
- Passion – consumer respondents particularly saw this as the core of what consumer leadership is about; it’s what drives a person. For some it is the determination that ‘what happened to me should never happen to anyone else!’

Others cautioned against relying on passion alone as a driver for leadership, noting that if people are selected because of their personal mission, then it is difficult for them to be held accountable because they perceive themselves as holding a high moral ground, which no-one can question because it is personal. Passion and commitment have to be balanced by a transparent, open and accountable system. Another respondent cautioned that prejudice could arise from passion and from

the way in which the particular needs of particular groups of consumers can skew the allocation of health dollars.

Leadership qualities and characteristics were seen as the ability to do the following.

- Be inclusive – the ability to bring and keep people together in a cohesive group around a particular purpose or issue. Some participants stressed the importance of being able to work with a range of people with different skills, experience and motivation so that everyone in the group felt their contribution had worth.
- Encourage and motivate others – to help them refine and develop ideas. Understanding and accepting the many reasons why people join a group and allowing people to participate in their own way. They understand people’s motivations, accept that they may only be interested or able to make a small contribution and understand that some people just have a little picture while others have a broader vision.
- Work with diversity – consumers’ needs and views can vary widely and at times, even be in conflict. Effective leadership involves the capacity to work with and to bring people together to find common solutions to what appear to be diverse needs.
- Inspire and energise other people to participate and develop leadership capacity – several respondents stressed that good leaders are not necessarily out in front. Effective leadership is often about being on the ground, leading with or behind other people.
- Be trusted and trustworthy – several participants stressed the importance of being able to trust people in leadership positions. Leadership is about being trusted by the people who are led: ‘... our leaders are the people that others trust and who do not alienate others.’
- Be representative and accountable – a number of respondents spoke passionately about the need for those whose task is to represent consumers in different fora, and who advocate publicly for consumers’ interests to be truly representative.

'An essential quality of a leader is someone who does not just have a vision and keep ahead of the pack – but has a commitment to all those they are meant to be leading – and understands they have to represent everyone.'

There was substantial criticism of processes that led to appointing people to consumer representative positions not being chosen by the people they were supposed to represent. This was regarded as a process that is more likely to lead to a poor outcome because it does not effectively engage with a range of consumers.

- Be courageous – a number of consumer respondents spoke of the need for consumer leaders to have courage and be brave. They must be prepared to raise things that won't be popular, utilise tactics that make them appear naive and at times, to cope with being bullied or intimidated.

'A small number of clinicians are supportive of consumer participation, but many are passive-aggressive – waiting for consumer representatives to make a mistake, questioning whether they are a 'real' consumer. Consumer leaders have to be able to cope with these attitudes and to work their way through the internal politics of an organisation or committee.'

'It is about being brave enough to hold the space that says that the consumer perspective must be part of every relationship and every action that happens in health decision making and service delivery. It does not necessarily mean that the consumer leader fills that space – but holds the space that demands the consumer perspective must be taken seriously and not be tokenistic. It's about being strong and brave about holding that space.'

- Network and build alliances – the importance of making and nurturing connections in order to make a difference.

For consumer respondents, formal and informal networks with other consumers were seen as providing an important basis for information, encouragement, peer support, mentoring and a place in which to debrief.

However, consumer leaders also needed to develop networks and alliances with a range of people such as health professionals, service managers, government officials, researchers and scientists and facilitate bringing people together on key issues of interest. The alliance between the Breast Cancer Network of Australia and its scientific committee was nominated as a good example of an alliance that has underpinned successful advocacy and leadership.

Building networks of people with similar issues was identified as being particularly important for groups of people who have been marginalised. Good networks provide a ground for developing identity and a recognition that people are not 'on their own'. They also help to identify common issues and develop a community of interests.

- Be confident – effective leadership involves people having 'faith in themselves and valuing the knowledge and expertise they bring to the committee, because others on the committee may not.' It's about 'intelligent people asking naive questions'.
- Be knowledgeable – '... have an enquiring mind'.
- Have a good knowledge of the health system, how it operates and how change is achieved as well as consumer needs and experiences of health and illness.

One respondent from a consumer organisation stressed 'our people need to understand the system *and* the political agendas. We have to be strategic in selecting advocates.'

Also emphasised was the importance of consumer organisations that deal with a particular condition and to be knowledgeable about that condition including existing and potential treatments and to have access to scientific information and advice from trusted sources.

- Communicate – consumer leaders have to be able to communicate and interact both within their consumer constituency and the organisation they are trying to influence. Listening was emphasised as a vital part of communication. The ability to talk with a wide range of people including people in government departments, health service managers and providers, as well as a range of consumers.

Consumer leaders use individual experiences 'to transcend and help a broader group within the community'. It is not only about being able to lobby but 'also to listen and hear what the issues are – understanding who and what we are trying to change'.

'... it's an ability to make connections, to be open and say what you think in a non-threatening way. If you have a confrontational side you get locked out.'

- Be strategic – knowing 'where you want to go and how to do it'.

This was seen as 'having political nous' and being able to 'recognise where you should go, and who you contact – to get the most for your buck. It's partly instinctive but you can learn it.'

Being strategic also involves having 'an ability to run with an issue – to sort out what is important'. It was described by one respondent as:

'... having the ability to harness what can be a volatile environment – where there is anger and where people have burning issues – to use that, turn it around from anger to solutions. It's about making people feel OK about expressing their emotions, and then using that to take the issue forward and not get stuck. Leaders have magic touches – they make people feel they are part of the solution – not just the anger.'

Some respondents in management positions within consumer organisations pointed out 'the vision may be different from what the funder wants you to do, or what the sector you are influencing wants you to do – so this is a particular skill in consumer organisations'.

- Take a broad view – this was described as valuing and using their own story, but being 'able to see outside their own world' and appreciate and understand others' experiences so that they can represent a broader view.
- Maintain a sense of humour – an essential characteristic that enables a consumer leader to keep going in the face of adversity.

'The ability to maintain a sense of humour under assault and the ability to work with comrades, to debrief, to do those sorts of things after an attack – after the grenade is thrown either at you or by you. They are the bad cops. What qualities do you need if everyone hates you? You need self-esteem and conviction and you need your friends.'

- Be humble – several spoke of the need for humility in effective leadership:

'... the ability to eat humble pie and not be arrogant ...'

'... not get caught up in your own self-importance. It's about knowing that you have been invited to fill that space by other consumers and that you have a responsibility to them. It's to know that you are not necessarily the leader.'

Humility was also seen as being about people knowing their limitations and being able to recognise the expertise in others in the group or organisation. It is a necessary prerequisite for being strategic in the interests of the wider group 'to know when to pass something on to someone else – to not comment on things they know nothing about'.

One long-term, high profile, consumer respondent stressed that it is:

'...vital for all of us, but particularly figureheads, to know that the figurehead skills are the ones you have – but that does not necessarily make you the leader – the leaders are in many different places'.

Another respondent in a leadership position in a consumer organisation suggested that 'if you make a mistake, everyone should learn from it. It's been hard for me but good for me at the same time.'

- Be resilient, tenacious and patient – many spoke about leadership needing to deal with the frustration of the slow pace of change and improvement and about the need to 'not get exasperated – to deal with the frustration that things aren't going as fast as you want or in the way you want'. The

importance of recognising that change is achieved slowly and usually in small chunks: '... it's chipping away at it'.

Leadership involves being able to stick with it no matter what: '... it's hard not to get disenfranchised and be unenthused'. There is frustration when the target audience – service providers, government officials and corporate representatives – frequently changes, and arguments have to be repeated over and over again. They pointed out that keeping themselves and others enthused is a challenge.

'It is difficult to maintain the rage.'

- Be self-aware – seen as important for resilience. People need to know themselves well enough to manage not to burn out. Consumer leaders should also get enough out of what they are doing to sustain and keep them going.

'Other consumers need to give them energy rather than take.'

- Focus on what is being achieved – described as 'optimism' by several respondents.

'... in the constant battle we forget what we have achieved.'

'Without it, it is easy to become disheartened. You have to believe that you will succeed. It gives you a sense of purpose.'

5. Supporting consumer involvement in service improvement

Section 05

5. Supporting consumer involvement in service improvement

Consultation participants identified a range of supports and encouragement required for consumer involvement in service provision.

Opportunities for leadership to emerge

There must be opportunities for leadership to emerge: ‘... you can’t just go out and train up a whole lot of leaders.’ They discussed the need to look at how services engage with their communities and how those services could create more opportunities for consumers to become involved, such as holding a range of public fora for members of the community to talk about services and health concerns.

It is important that the health system alone does not define what opportunities should be available because that will in turn define and constrain consumers’ interest in health. Some participants emphasised that consumers have always played a big role in health promotion and prevention of harm.

‘People are really interested in their own health and are into prevention of disease – and this provides a better model of a health system.’

‘It’s important to get people at the grass roots level and to provide support before the problem gets too big.’

It was emphasised that people often do feel powerless about the health care system: ‘... it appears scientific and distant’. Other participants spoke of the need for health services to be part of the broader community and be recognised as such.

‘It comes down to having to have a sense of community. People feel disenfranchised from the health system – you have to have a community place where people gather – to engender a feeling of belonging and then people will start to speak out.’

There was also a concern that there should be greater public awareness about the opportunities that are available for consumers to contribute to the health service system with one participant suggesting that

this needed to be addressed by government health departments. This would include ensuring that a range of groups such as small self-help groups knew about how they could contribute.

Encouraging more spontaneous formation of support groups or groups around particular concerns such as child health or access to a particular drug or treatment was seen as important. Such groups provide essential opportunities for consumer leadership to emerge.

Another place where leadership emerges is within the staff of consumer organisations.

‘There is a need for clarity around the place of staff. In our organisations there is not a corporate structure or career paths, and we have a lot of short-term placements. In the corporate sector if you are good you would develop expertise and see opportunities for career and for skills development. But those pathways do not exist in the community sector.’

Support for consumer organisations

Well-organised and consumer organisations with resources were identified as playing a critical role in supporting and encouraging consumer involvement in service development and delivery. One participant emphasised:

‘There have to be consumer organisations, and they have to be supported in each state and territory, and then possibly even in each area health service. There has to be a structure and a process so that there is clarity about how you can recruit consumers and provide training etcetera. It provides confidence about representation.’

Another participant stressed that:

‘... we [government departments] don’t give recognition to consumer leaders – and we should. One of the things we don’t do well is recognise the role of community organisations – they were set up by consumers for specific reasons – often

to pick up the pieces. We do not acknowledge the role of organised consumers and their evolution into consumer organisations. It's a barrier we put up because once you get too organised you are not considered a consumer anymore. We need more opportunities to develop relationships with consumer organisations.'

A number of government, provider and consumer respondents pointed out that involvement in consumer and community organisations provide a 'training ground', through which leadership can emerge and be identified: '... they bring people together and act as talent spotters'. Through involvement in consumer organisations, people become knowledgeable and confident about working in groups and familiar with group processes such as meeting procedures, debate around particular issues and advocating on a particular issue.

Several respondents spoke of the importance of working in groups and sharing tasks and knowledge.

'Chairs and staff are often good at these things, but can't do everything. So we have a collective focus on developing expertise in groups. We have a sort of peer review system where you work as a group and share your skills and abilities. We use the strength of the group. After all, no one person displays leadership all the time.'

Many consumer organisations also provided formal training programs aimed at developing the skills and knowledge to enable consumers to participate in health system and service committees. They also provide a source of formal and informal mentoring for consumers.

Consumer organisations were seen as providing a basis for representative consumers and consumer leaders because they offer a constituency that provides a knowledge base for the representatives to use in their advocacy of consumer issues and a means of accountability back to other consumers for their work.

Support for consumer organisations could be provided through core funding – both government and corporate sector – and access to skills-development opportunities. It could also include providing opportunities and resources to network with other organisations, including those representing consumers, providers and service managers.

Information about the health system and services

The need for consumers to have access to information about how the health system and individual services work was emphasised repeatedly. It was stressed that without an understanding of how the health system works it is difficult for consumers to influence and bring about service improvement. The point was made that for those who do not work in health services, the health system is 'somewhat of a mystery'.

'The health system is an incredibly complicated machine that no-one understands and where no-one is in charge.'

Participants suggested that services should be encouraged to work within their communities to 'demystify the system and the services'. Activities would include holding open days, putting signs in local shops, liaising with local media and producing community newsletters.

Providing tours of hospitals and other services and orientation sessions for consumers who are, or want to be, involved in service development and improvement were also suggested. It was emphasised that this could 'build understanding and break down barriers' by explaining system issues and processes and terminology in ways that people could understand – such as the use of the word 'triage' in emergency departments.

Access to 'trusted' sources of knowledge

Consumers need access to trusted sources of knowledge about their issues of concern. Without trust, reliable evidence may be dismissed. An example was given of a group of parents who were concerned that children in a public school were suffering higher incidences of respiratory diseases because the school was located next to an industrial site. The health department provided evidence that there was no impact from this site on the respiratory health of the children, but parents were not convinced because they did not trust the source of the advice. An independent source of evidence was suggested as a solution to this problem.

Examples of consumers having access to reliable scientific advice from trusted sources were cited: the Breast Cancer Network of Australia which, in the early days of its formation, built alliances with medical researchers and clinicians, and has now formalised this alliance by establishing a medical and scientific

reference group; and the Cochrane Consumer Collaboration providing systematic reviews in consumer-friendly formats, available to all Australians through the National Institute of Clinical Studies.

Consumers could be supported to access peer reviewed journals in health. These journals are already available to clinicians and could be made available to consumers who participate within their service and to the consumer organisations with which they have a relationship.

Creation of a consumer knowledge base

The need to create and develop a consumer knowledge base was seen as a significant issue. There is currently no academic basis for collecting and analysing the knowledge about consumers' perspectives, needs and experiences. It is therefore difficult to build a conceptual basis for the work of consumer leaders. There has been some discussion within consumer groups about this but it has been difficult to pursue because of a lack of funding.

This thinking is particularly well developed in the mental health sector, and a copy of a funding submission for a National Centre for Consumer Perspective Studies in Mental Health was provided. That submission envisages that:

'Such a centre should be attached to a university as a shared commitment between that university and the Commonwealth and State and Territory governments'.

It argues the centre is needed to nurture consumer history as well as promote current consumer priorities and future initiatives. It is conceptualised as being 'akin to an Aboriginal studies centre or a women's studies centre. As such, it would have a variety of roles but it would also be symbolic in the sense that it would be tangible recognition that not all the 'players' in the mental health sector start from the same place in relation to resources, power to implement government policy or to influence practice and research, opportunities to develop intellectual heritage and the sharing of knowledge and expertise.'

An enabling environment for consumer involvement

Many participants nominated the need for services to provide a respectful enabling environment as an essential prerequisite for effective consumer involvement.

'An environment needs to be created where there can be rapport between disparate groups – to develop a respectful understanding of all positions and a collaborative working together.'

Effective consumer involvement occurs 'within a framework that promotes the value of consumer input as part of service delivery'. Services need to be genuine about consumer involvement and see it as 'just good management practice'. Important components of that environment were seen as:

- top down commitment from government
- clear commitment and support from senior management
- operational support for the consumers who are involved, including appropriate and accessible meeting venues, office support and providing resources to support that involvement
- providing good quality information, orientation and briefings about the issues and the work of the committees or other fora in which consumers are engaged
- structures that are linked and provide information back to consumers about what is happening in other areas related to the for in which consumers are engaged
- respect for the particular expertise that consumers bring
- having at least two consumers on all committees – to provide support for each other and to ensure breadth of representation.

Several participants emphasised the need for services to be aware of, and take account of, all the things that enable people to get involved such as the physical location, transport, remuneration or reimbursement of expenses, interpreters, attendant carers, meeting support personnel.

'It's not just about individuals, if you are running a process, understand you could be locking people out – so make sure it's inclusive and that meetings work for everyone, language, alternative formats, communication.'

The role of the committee Chair was nominated by some as being critical to providing an enabling environment for consumer involvement. Effective Chairs could engender a respectful environment where consumers could feel safe about raising issues that might cause some discomfort to other committee members.

The community resource officers (CROs) were nominated by respondents who had direct experience of the Victorian health service community advisory committees (CACs) as being an important part of an enabling environment. Effective CROs can help to provide the right sort of supportive structures within which consumer leadership can emerge and be encouraged. They also provide valuable advice to the CAC about the service within which they are working and ensure the group's advice is conveyed and responded to by the service.

A number of respondents nominated some of the CACs as now providing good models through which consumer leadership is developing.

'Our CAC is a forum for leadership – it's a leadership organisation that builds leaders as well. Structurally, it's a leadership group influencing other groups. People on it have a mixture of advocacy, carer and health backgrounds – it makes it a dynamic forum.'

The work of the CACs is not so well developed in all health services; they are seen as being there 'simply to comment'. The factors that enable development of leadership through the CACs included:

- the CEO and Board Chair attending meetings on a regular basis
- clear guidelines about the role of the CACs
- strong endorsement of the CAC from the top of the organisation – it gives a message to the CAC and the rest of the organisation that the work of the CAC is important
- being clear about what they need to achieve and to 'align it with what is possible'
- developing a clear, agreed work plan
- identifying information needs

- providing relevant, timely and accessible orientation and information by the health service
- providing support to those committees through a good CRO who understand the potential role of the committee and how to help develop that potential.

'The appointment of the organiser of the CAC who understands leadership and capacity building is critical.'

Consumers need to feel safe in the health service environment in order to be involved. When consumers are dependent on a service, they often do not feel able to air criticisms because they fear there may be repercussions in terms of their access to and treatment by the service.

Similarly, consumers sponsored to attend a safety and quality conference were supported by a nominated official for the duration of the conference, providing access to expertise and advice as well as the network of other consumers.

In addition, ensuring CAC membership sufficiently represents the diversity in the community was raised as an issue. Only one health service has an Aboriginal person on their CAC and there is an overall lack of young people involved in CACs.

Working with diversity

Consumers are not a homogeneous group, they have different educational, cultural and employment backgrounds, age groups, differing health needs and differing understandings and experiences of the health system. This needs to be recognised by health services so that the many levels at which consumers can and feel able to contribute are supported.

'We need a whole range of levels that people can engage at – an evolutionary hierarchy where people can develop and learn how to change policy and have a big impact.'

For example, several participants stressed the need for input from young people to be supported through appropriate consultation techniques and opportunities. An example was given where young people were able to influence the way in which health promotion was delivered. The service established a number of discussion groups so that people could come in their own time with their own issues, and they influenced the sort of health promotion activities that were undertaken.

Other respondents emphasised the need to do more to engage indigenous people within the services.

'An ideal service would engage with Aboriginal issues – they would employ a consumer advocate in a similar way to the mental health system. You could employ them to work in connection with the Victorian Aboriginal Health Service – it would need support and could develop into an advisory team ... There should be Aboriginal representation on community advisory committees.'

Peer support and consumer networks

Peer support and access to networks of consumers was seen as critical to supporting and encouraging consumer participation.

Involvement in a network of other consumers was seen by many respondents as being valuable in a number of ways: it provides a wider basis for consumers to learn about a range of other consumers' needs, experiences and perceptions, which in turn enriches the input that consumers are able to provide. It also helps to build confidence in people's ability to work within groups and in their capacity to participate in a range of health service forums. One participant talked about an informal network of consumers in another jurisdiction that had developed through involvement in clinical committees. Those individual consumers were helped to come together by the health department and were then able to learn from each other, and to provide information and advice to the health department and other stakeholders about improving health services and how to enhance consumer participation.

Consumers and a health service manager from the ACT pointed to the networking activities that can be facilitated through consumer organisations. In that jurisdiction the Health Care Consumers' Association provides opportunities for consumer representatives to meet together to discuss issues and the work of their committees. This enables the consumers to learn from other representatives and to make connections between the areas they are working in and other areas of the health system, thereby enabling them to take a broad view of the system.

A number of people involved in CACs also nominated the peer support network for CAC Chairs as being an invaluable resource for consumers. This network is supported by government. Another participant spoke of the need to find new ways for consumers to network with each other, such as electronic web-based tools.

Formal and informal mentoring and other forms of peer support were nominated by many consumers as being a critical means of support and encouragement and developing a new generation of leadership.

A number of consumer respondents also spoke of the critical importance of being able to debrief with other consumers – particularly after a difficult experience of participating in a health service or system meeting or conference. Debriefing is important to help analyse what went well, what didn't go well, and why. It is also important to maintain confidence and the energy to keep going.

'We need to recognise that cups of coffee together are not a waste of time.'

Payment for consumer participation in committees

Many participants raised the issue of payment for consumers to sit on committees. Some emphasised the need for consumers to be paid a sitting fee in recognition of the time, the work and expertise they are providing. Payment should be at the same rate as other committee members, as a lesser payment indicates a lesser regard for consumer input and was seen by some participants as 'insulting and degrading'. The issue that accountability and expectations of performance come with payment was also raised as was the concern that payments may 'increase effectiveness but create a vested interest' because of responsibility. At the very minimum, respondents felt that expenses incurred by consumers participating in committees and other forums should be reimbursed, consumers 'should not be out of pocket'.

Other participants raised the issue of time. There were a lot of people who had the potential to be effective consumers but they lacked the time available, often because of work commitments. They pointed out that funding would help to reward consumer involvement.

Feedback to consumers

Many respondents emphasised the need for consumers to receive feedback about the input and advice they have provided. Many consumers have experiences where they provide input but have no idea whether it was used or how or why or what happened as a result of its use. Such information is essential to nourish and encourage consumer participation and to ensure that the advice and input just does not disappear into a vacuum: '... people need to understand that they are being heard'.

Role modelling and mentoring

A number of respondents spoke of the value of having good role models available and a number of high-profile consumer leaders were nominated. They are people who have provided inspiration to motivate other consumers as well as demonstrating how good leadership can be achieved.

Many people nominated formal and informal, consumer mentoring by consumers who are experienced in participation and leadership as a useful method of developing leadership. Some respondents also spoke of the value of using a wide range of community leaders, in addition to health consumer advocates, as mentors.

Some respondents also spoke of the need for mentoring at an organisational level where an established community or consumer organisation is partnered with an emerging organisation. A number of respondents nominated the relationship between Women's Health Victoria and the Victorian Women with Disabilities Network as an example of a good mentoring arrangement.

Succession planning

The need to be constantly developing new leaders was emphasised by many participants.

'We should be thinking cogently about mechanisms to bring younger people along to learn what we have learned and bring their own knowledge and skills.'

'It's about a better use of current leaders – harnessing commitment and knowledge to grow a new generation of leaders in consumer protection broadly.'

'For me, a leader has to be nurturing others to take over, if you are not you are not a leader – it's about sharing for the future.'



6. Effective consumer leadership

Section 06

6. Effective consumer leadership

In addition to the characteristics already reported, consultation participants nominated a range of skills and knowledge for effective consumer leadership.

Skills

- Negotiation – so that barriers and obstacles to change can be identified and dealt with.
- Being able to translate individual stories into system issues – so that personal experiences can be used to demonstrate what works well and what needs to change.
- Working in groups – understanding how to work with other people to achieve change. This involves working with groups that are only made up of consumers as well as working with a range of other stakeholders.
- Critical reading – being able to read documents in a way that enables both an understanding of what is being said and identification of what is not being said and what the underlying issues could be.
- Being well organised – involves time management and the management of information, including meeting papers.
- Assertiveness – the ability to argue a point confidently but not aggressively, and to maintain confidence in oneself and the issue, despite opposition.
- Use of media – understanding how and when to use the media and the problems and pitfalls.
- Meeting skills – involving an understanding of formal meeting processes, as well as tactics that can be used within meetings.
- Research skills – how to find information using tools such as libraries and the internet – and how to organise, assess, analyse and use information.
- Remaining independent and accountable to consumers – learning how to avoid being co-opted to other people's agendas.
- Use of tactics – several people emphasised the need to adopt different approaches at different times and in different situations and having

the ability to know which strategy to use in what situation.

'It is the capacity to test the waters and change a little bit and the ability to get cross when you have to – and articulate that and not take it home with you.'

One consumer described a recent occasion when she had had a 'strategic tantrum' with the result that the other party acknowledged and understood the problem and apologised. 'It's about knowing when and how to do it, and when not – and sometimes being truthful to your own feelings – not always trying to please people. You don't always succeed by appeasing everyone – you are not there as a consumer to do that even if it makes you comfortable.'

One respondent from a consumer organisation pointed out that in general, 'a shotgun approach will not give us as much return as a targeted approach. We have to use our limited resources to give us the most return'.

Knowledge

Consultation respondents also identified a range of knowledge that is needed to underpin effective consumer leadership. However, the point was made that 'it should not necessarily be the responsibility of the person to have all the skills and knowledge. If the organisation the consumer is engaging with is truly wanting to provide opportunities, then it has the responsibility to identify the knowledge, and to make it available and accessible to consumers.' An example was given of a service that wanted the input of young people into a grants selection process. To prepare them for this task, the young people were provided with information about the process, objectives and selection criteria through a series of workshops.

Participants identified the following topics on which knowledge is required and education provided.

- The health care system and the service – consumers need to know enough about the health care system and services to get beyond asking the

basic questions and not to be sidetracked by side issues. This knowledge should enable consumers to understand the system and its impact on consumers in general.

'A lot of us come in with issue specific interest. A measure of how well we have been supported is our capacity to move to higher level thinking.'

The types of information required include:

- health system generally including specific services such as mental health and alcohol and other drug services
- funding sources and arrangements
- individual health services
- common medical language.
- Consumer issues – consumers need to know what makes health care safe and good for consumers. They also need to know about the experiences of other consumers 'so there needs to be consumer research out there'.
- Processes – how decisions are made and how to get the consumer voice heard in that decision-making process, and where to get the information from.
- Context within which they are working – so that they understand the pressures on the system and barriers to change. This includes knowledge about the culture of the organisation and culture in which health care is delivered.

Some respondents referred to a proposal to engage consumers in an infection-control program by asking them to ask providers if they had washed their hands. Some consumer advisory committees had rejected this proposal because it did not take account of the existing power differential in the individual provider-consumer relationship, and could have adversely affected the desired relationship of trust between consumers and the people who provide health care.

Many respondents emphasised the importance of recognising that consumers are not a homogeneous group, and that many people have already developed considerable skills in their private, community and working lives. Some may need more or differing types of support and training according to their backgrounds and their needs.

'People work at different levels – there should be formal education plus informal opportunities. The education is primarily to understand why consumer perspectives

are important and that is the stuff that gives us courage. It is not about how to sit on a committee. It's about engendering the confidence and basis to actually sit on a committee and to make a difference. A secondary concern is to provide more structure around practical things like meeting procedures.'

7. Developing consumer leadership capacity

Section 07

7. Developing consumer leadership capacity

Some participants were able to identify programs or models for developing the capacity of consumers to play a leadership role. However, many cautioned that a range of different strategies were needed and that there should not be a reliance on a 'one-size fits all' approach to developing leadership. Nor should the entire focus be on training consumers to fit into the existing medical system.

The important role that local councils can play in fostering consumer participation and the development of consumer leadership was highlighted. The Leadership Plus and Leadership 79 program that involves people in local government providing mentoring for people with disabilities were given as examples. Another local government program involved establishing youth councils.

Structured training programs were recognised as being an important component of leadership development. It was also suggested that such training should link-in to national accredited training. Some respondents felt strongly that such training programs must be led and owned by consumer organisations, with one government respondent stating that:

'It is important to have a structured training program that is totally controlled by consumers – using the resources of government, academia and health services to help. The governance of the curriculum must be entirely controlled by the consumer movement.'

However, some respondents were cautious about an over-reliance on formal, traditional training. Any training should equip consumers to handle, and make judgements about how to handle, the difficult situations they can face when participating in a health service or system, how to retain confidence and commitment when 'spreading the message that no-one wants to hear'² and how to avoid the problem of being co-opted to a health service agenda.

Other components of a model were suggested as:

- the development of consumer networks – 'being able to link consumers up with each other – to share experiences.' This was seen as being through a variety of channels, including fora, web-based chats, and face to face opportunities

- content education as including 'education on issues of importance for consumers from trusted sources and delivered in an acceptable way'
- the use of arts and culture as helping people to develop confidence. Tools such as playback theatre and forum theatre 'brings another dimension to informing debate'
- mentoring.

Evaluation was also seen by respondents as an important component of any model to develop consumer leadership. They emphasised that consumer participation is happening, and leaders have emerged, and it was seen to be important to capture the lessons from the experience. It should be seen as a 'work in progress that we should continually evaluate so that we know what works and what needs to be developed'.

The need to establish a research base on which to develop models and to test interactions was emphasised by some respondents. It was stressed that consumers are already involved in theoretical debates, but the academic basis for development of conceptual models is not there.

Some of the advocacy and participation skills programs and models that were specifically mentioned by respondents are listed in Appendix 2.



8. Opportunities for consumer leadership in health care



Section 08

8. Opportunities for consumer leadership in health care

Consultation respondents felt that consumer participation in health services is now generally accepted as 'a good thing', and that this should offer opportunities for consumers to provide leadership in a range of ways and at a range of levels within the health services.

It was emphasised that consumer participation takes time to develop – but there has now been a lot of experience. One provider respondent suggested that most providers have learnt that consumer participation should not be seen as token 'rather that 99 per cent of people are saying this should not be lip service – it is crucial'. The same respondent went on to stress that 'as this movement grows and matures, it is broadly accepted that it is a good idea, but systems for doing it are different in different places – we need to continually evaluate what works and what doesn't.'

Many respondents spoke of the need to involve consumers at all levels of the health care system. They also spoke about the need for services to open up to their communities and to create more opportunities for consumer participation; to be creative in the ways they do it and open to enabling greater diversity of involvement. 'The consumers are out there – it's more about opening the system up to use the consumers effectively.' Respondents generally saw that the more opportunities there are for involvement, the greater are the opportunities for consumer leadership to emerge.

Safety and quality was not seen as being confined to one particular silo of the health care system, particularly by consumers. For them, quality encompasses most facets of health care including access to services, continuity of care, discharge planning, appropriateness and safety of care and it was suggested that a 'whole-of-portfolio' approach to consumer leadership is necessary. Therefore, consumer leadership in delivering safety and quality involves leadership in, and of, a broad spectrum of the service's activities.

Some of the specific areas that were nominated include:

- planning and design of facilities and services
- boards and board sub-committees
- quality committees and activities
- clinical services committees
- development of clinical guidelines and protocols
- aged care
- community services
- audit committees
- reporting and analysis of adverse events
- accreditation activities
- research, including both clinical and consumer research
- education of clinicians
- education of health professionals at both undergraduate and postgraduate level
- self-management programs
- rehabilitation and recovery programs
- cultural awareness programs
- illness prevention and awareness raising.

One respondent raised the issue of consumer involvement in staff selection, suggesting that while this has generally not been an area of consumer activity, some CAC members have been involved in staff selection. This sends a signal to the hospital about the openness of decisions and services.

Consumer involvement in the reporting and analysis of adverse events was raised by some respondents. They felt that having consumers involved brought another 'pair of lens' to scrutinise the systemic problems leading to the event. Although investigation and analysis requires some expertise, it was pointed out that it would not be difficult to train consumers in the analysis process, and that indeed this has happened in at least one other jurisdiction. One respondent suggested that analysis of adverse

events was another forum through which consumer leadership in safety and quality could emerge. Involving consumers would bring another sort of lens to the analysis of serious adverse events and it could be a means of educating consumers about the sort of systemic issues that the health system needs to deal with.

Another respondent pointed to the achievements of the Adverse Medicines Events Line – a national phone line initiative funded by the Australian Council for Safety and Quality in Health Care. This is a system through which consumers can report adverse events arising from their medicines and data on these events is collected by the Therapeutic Goods Administration and provides a useful model for collecting data on things that go wrong, which in turn should be used to identify and implement reforms to health system processes.

Several respondents also stressed the need for consumers to participate in and publicly 'own' some of the hard choices that have to be made in providing health care services, such as around service rationalisation and closures. Others also nominated health financing as a key issue for consumers. There had been some early work done by consumer organisations when the consumer movement was first becoming active in the 1980s and early 1990s.



9. Enhancing partnerships between health services and consumers



Section 09

9. Enhancing partnerships between health services and consumers

Many participants, particularly consumers, stressed the need for the health care system to become outwardly looking and to engage more fully with the broader community. Some stressed the positive benefits that could come from the health services having better links with communities. It would enable them to be more in touch with community needs and to provide services that focus on the needs of their consumers.

‘A consumer-focused health service is one that values, seeks and responds to feedback from its customers at every possible point.’

Some also stressed that services need to take more of an illness prevention approach, because the starting point for most consumers is about staying well.

More outwardly focused health services could learn from a range of other services about quality, safety and efficiency. For example, one consumer who has been frustrated with the inflexible and inefficient appointments booking systems within his hospital drew an analogy with hairdressers’ appointment systems. He pointed out to the hospital that hairdressers did not just make appointments and expect their customers to turn up – as the health service often did. The hairdresser first informed customers about what appointment times were available, and then allowed the consumer to make the decision about what was convenient for them.

Indigenous respondents emphasised the need for services to be culturally aware, to focus on preventing illness and to make people feel comfortable about using them when they need it.

‘If the service is not culturally friendly they won’t use it.’

The potential role of health services in providing opportunities for effective consumer leadership to emerge was stressed.

‘Opportunities need to be provided for participation experience – for example, encouraging people to come to fora at a local level to build up the experience of participating. Services need to invite

people to events where people have a say, and learn through experience. People need to be told about opportunities to participate, and how you acquire skills, training and mentoring. We need to put an investment into developing the expertise.’

‘Service providers need to provide opportunities for advocacy organisations but also need to take on a broader public participation framework – so that there are opportunities for all.’

Some saw a role for government in providing leadership by setting an agenda that expects health services to seek and welcome community input. One participant indicated a way in which health services can model good leadership in consumer participation such as the New Zealand Mental Health Commission, which is led by three commissioners, one of whom is a consumer.

A number of consumers expressed frustration with the slow pace of change in regard to improving the safety and quality of services:

‘Consumers are dealing with a system that is harm tolerant – it tolerates a worrying degree of harm in spite of the professed ethos of ‘do no harm’. It is a system that does not count outcomes – it counts throughput’.

Some respondents identified the need to train health professionals to be more team based in connecting people to consumer groups so that patients have access to consumer leadership as part of their recovery or rehabilitation.

A number of respondents suggested that some basic structures are in place to enable consumer participation and emergent consumer leadership. However, there were some concerns that more attention is needed to implement consumer participation processes and then to evaluate the processes. Some of the Victorian CACs are seen to be working effectively, although it was suggested that many are still just providing advice and are not properly resourced or used.



There were also concerns about the transparency of appointment processes for CAC members, especially the adequacy of members' linkages to consumer groups from whom they could draw knowledge, support and a membership base that could be enabled to participate in service improvement.

'The services decide who is on the committee and they get the people they want and they hear what they want.'

It was suggested by one respondent that a centralised community consultative committee is needed to make the appointments to the individual CACs. Some respondents were also concerned that CAC membership was on a purely voluntary basis and that this could be a disincentive for people to apply for appointment.

Overall, there did not appear to be a sense that a new model for enhancing the capacity of service providers to work in partnership with consumers on safety and quality improvement was necessary. Rather a number of participants suggested that 'consumer participation is an evolutionary process' and that we 'have to get on and do it'. The basic frameworks and tools were seen to be in place, and there are some good examples of consumer and community participation in services in Victoria that provide good models from which other services can learn.

'The barriers within services are unconscious – few people are now consciously resistant. But they haven't had enough experience of what a well-organised consumer movement can contribute and don't recognise the adjustments that are needed to be made to incorporate consumers.'

'We need simple, clear policy positions and policy guidance. Working with consumers needs to be built into stakeholder management – it can be included specifically within performances agreements and elicit elucidation of stakeholder management that includes consumers.'

'Bureaucratic inertia will go away with time, but the consumer movement needs to influence CEOs and ministers, and to set out the minimum core standards for consumer engagement.'

A number of participants stressed the need to evaluate consumer participation strategies. Different strategies are being employed in different jurisdictions and it was important to learn about what works well and what doesn't, and then to make changes based on that learning.



References

Section 10

10. References

1. Bland, R (2005) National Practice Standards for the Mental Health Workforce Implementation Plan: Report prepared for the National Practice Standards Implementation Group 2005, University of Tasmania
2. Nossell G (2003) Leadership for the health of communities: where and how does it expand community control? Communities in Control, Melbourne.



Appendix 1:
List of consultation
participants



Section 11

11. Appendix 1: List of consultation participants

Name	Organisation or affiliation
Barracrough, Liz	Balcombe Estuary Rehabilitation Group
Bloomfield, Rita	Chair, CAC Shepparton, Goulburn Valley
Bond, Carolyn	Centre for Credit and Consumer Law
Braithwaite, John	Foundation for Effective Markets and Governance, ANU
Brown, Robin	Consultant in consumer issues
Clarke, Margaret	Victorian Aboriginal Controlled Health Organisation
Corbin, Teresa	Executive Director, Consumers Telecommunications Network
Cormack, Mark	Deputy CEO, ACT Health
Cox, Darlene	Emerging consumer leader, ACT
Coine, Lester	Aboriginal Policy and Planning Officer, St Vincent's Hospital
Cristou, Fofi	Department of Human Services, Victoria
Draper, Mary	Quality Manager, Royal Women's Hospital
Dwyer, John	Former Chair, Australian Healthcare Reform Alliance
Epstein, Merinda	Consumer, former member of Consumer Advisory Committee to Australian Council for Safety and Quality in Health Care
Evans, Frank	CEO Upper Murray Health and Community Services
Fermanis, Suzanne	Secretariat for Primary Health Consumer Advisory Committee
Ferrari, Georgie	Executive Officer, Youth Affairs Council of Victoria
Flanagan, Kerry	Upper Murray Health and Community Services
Graham, Janne	Consumer; former Chair, Consumer's Health Forum of Australia
Happell, Brenda	Centre for Psychiatric Nursing Research and Practice, Melbourne University
Harmer, Cath	Program Manager, Consumer Participation and Information, Department of Human Services, Victoria
Hassard, Julie	Breast Cancer Network of Australia
Hopkins, Helen	Executive Director, Consumers Health Forum of Australia
Horey, Dell	Health Issues Centre
Kennedy, Mike	Victorian AIDS Council
Kosky, Michele	Health Consumers Council of WA
Kroschel, Jon	Consumer Consultant, Alfred Psychiatry

Lawler, Bill	Rural Access Worker, City of La Trobe
Maher, Helena	Consumer Participation Coordinator, Royal Women's Hospital
Malowney, Tricia	Consumer Advisory Committee, Royal Women's Hospital
McBride, Tony	Health Issues Centre
Moore, Gary	Former Executive Director NSW Council of Social Service
Naksook, Charim	Health Issues Centre
Newell, Christopher	Consumer representative on Australian Commission on Safety and Quality in Health Care; disability advocate, Tasmania
Newby, Liza	Victorian Quality Council
Oliver, Janet	Environmental advocate
Petrie, Christine	Community Development Officer, Bayside Health
Roper, Cath	Consumer Academic, Centre for Psychiatric Nursing Research and Practice, Melbourne University
Rose, Sally	Secretariat for Primary Health Consumer Advisory Committee
Sjardin, Helen	Motor Neuron Disease Association
Small, Yosef	Consumer Advisory Committee, Bayside Health
Sorrell, Linda	Victorian Quality Council; CEO, Southern Health
Spencer, Brian	Executive Director, Community Services and Health Industry Training Board
Sylvan, Louise	Deputy Chair, Australian Competition and Consumer Commission
Tennant, David	CARE Inc Financial Counselling Service
Thom, Clare	Disability Advisory Council of Victoria
Tito-Wheatland, Fiona	Consumer; PhD scholar, ANU; expert in safety and quality in health care
Walker, Christine	Victorian Quality Council; CEO, Chronic Illness Alliance
White, Mary-Jane	Quality Manager, St Vincents Hospital
Willis, John	Senior Project Officer, Improving Care for Aboriginal and Torres Strait Islander Patients Program
Wilson, Kim	Office for Youth, Department of Victorian Communities

Section 12


Appendix 2: Consultation guide

11. Appendix 2: Consultation guide

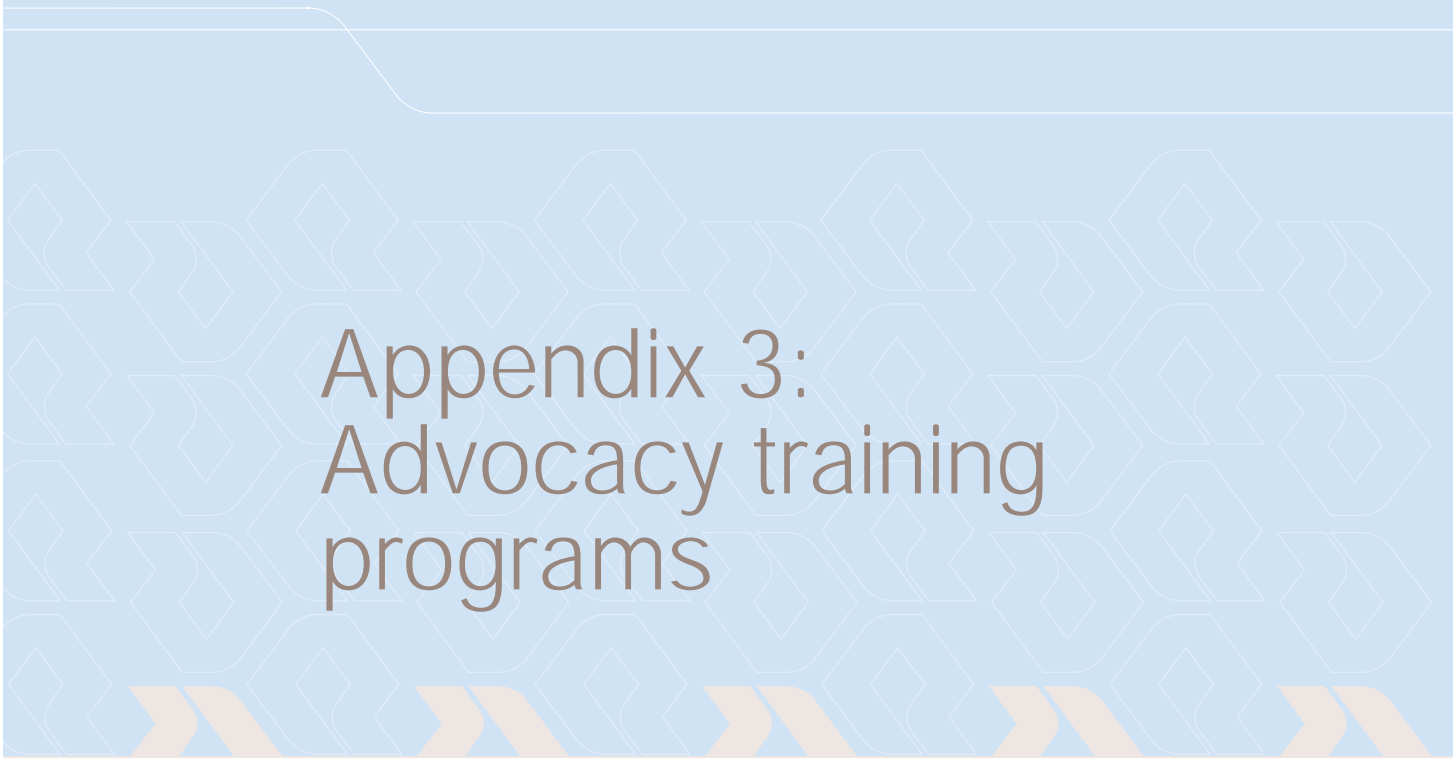
Consumer leadership in health care: aspects and issues	Interview questions
Defining the qualities and characteristics of consumer leadership	<ul style="list-style-type: none"> ○ How would you, or do you, define consumer leadership? ○ What do you think are important components of consumer leadership? ○ How would you describe the role that consumer (or community) leaders can play? ○ How would you define consumer leadership in health care and health service delivery? ○ What do you think are/would be the key characteristics and qualities of effective consumer leadership in health?
The support and encouragement required for consumer involvement in service improvement	<ul style="list-style-type: none"> ○ In what ways do you think consumers have provided or could provide leadership in safety and quality improvement in the health system? ○ Are there any other areas of health care and health services that consumers could provide leadership? ○ Do you consider there are barriers to consumers exercising leadership within the health care system? ○ What barriers do you think are most significant? <ul style="list-style-type: none"> ○ In health services ○ In health consumer activities ○ In health professionals
The skills and knowledge required for effective consumer leadership (for both consumers and service providers)	<ul style="list-style-type: none"> ○ What do you think are desirable personal qualities or capabilities of health consumer leaders? What would you add to or subtract from this list? ○ What do you consider have been the most significant attributes or characteristics of consumers who have successfully influenced the production and delivery of products and services (not necessarily health care or services)
Models for developing the capacity of consumers to play a leadership role	<ul style="list-style-type: none"> ○ What factors in the consumer sector do you consider are significant in allowing consumer leadership to develop? ○ How can the health care sector best develop and support consumer leadership? ○ Do you have any knowledge of successful leadership development programs for consumers? ○ What skills, knowledge and experience do you think would be necessary for consumers to participate in a leadership program?



Consumer leadership in health care: aspects and issues	Interview questions
Models to provide opportunities for consumer leadership in delivery of safety and quality and improvement of services	<ul style="list-style-type: none"> ○ What do you consider would be the key elements of an effective health services approach to developing and supporting consumer leadership in health?
Models for enhancing the capacity of service providers to work in partnership with consumers on safety and quality improvement	<ul style="list-style-type: none"> ○ What skills and capabilities do you think service providers need in order to shift to a model of working in partnership with consumers on quality and safety issues? ○ What changes to operational arrangements would be required?



Appendix 3:
Advocacy training
programs



Section 13

12. Appendix 3: Advocacy training programs

Alfred Psychiatry Consumer Participation program

This program is an integrated program that has an active consumer membership of over 100 consumers. So far, consumers have worked or are currently working in a range of capacities including evaluation teams, staff training teams and consumer newsletter teams. Participation is consumer driven, staff-consumer collaborative, and resourced and supported by management. www.participateinhealth.org.au/ClearingHouse/Docs/cappsalfredproceduresreportweb.doc

A Seat at the Table – Breast Cancer Network Australia

This was nominated as the best model of breast cancer consumer advocacy in the world – and the BCNA is keen to take it out into the more general consumer population. In this program 25 women are selected to undertake the three-day advocacy program, which includes some basic science training. The course covers the structure of the health system, use of media and good advocacy. It explains what is involved in sitting on a committee and provides confidence to take on those roles. The program includes guest speakers and there is a program coordinator who links with various other organisations such as the National Breast Cancer Centre.

www.bcna.org.au/cms/details.asp?NewsID=56

Consumers' Health Forum of Australian consumer representatives training program

CHF is a national organisation that has 90 voting members representing nearly one million health consumers across a wide range of health interests and health system experiences. It provides government and policy makers with a consumer perspective on health issues, and seeks to balance the views of health care professionals, service providers and industry.

One of CHF's major activities is to nominate, train and support consumer representatives to sit on government and professional committees. The organisation now provides consumer representatives to over 230 Department of Health and Ageing portfolio and related committees and other working groups with a health focus. For the past three years, DoHA has provided CHF with special funding to run training workshops for consumer representatives.

www.chf.org.au/

Health and Community Services Industry Training Board Competency standards

Since the national Vocational Education and Training (VET) system was formed, a range of industry advisory bodies (industry skills councils) have been the key conduits of advice and information between the VET system and industry. The Community Services and Health Industry Training Board aims to create a culture of training and learning for the community services and health industries that positions training and skill development as a key ingredient for business success in the new millennium. They have developed a set of competency standards on advocacy and representation.

www.intraining.org.au/about_us.htm

Health Care Consumers' Association of the ACT

The Health Care Consumers' Association provides a voice for consumers on local health issues. It does this by working with health services to achieve services that are responsive, respectful, accessible and affordable to all, encouraging direct consumer involvement in health decision-making, and lobbying and advocating on behalf of ACT health consumers.

Within the association consumers work together to share their understanding, their experiences and views, to identify shared priorities and goals, and to represent these views to the ACT Government. The association also runs training programs for potential

consumer representatives. These programs cover knowledge of the health service, advocacy and meeting skills.

www.hcca.org.au/

Health Consumers Council of WA

The Health Consumers' Council is an independent community-based organisation representing the consumers' 'voice' in health policy, planning, research, and service delivery. The council advocates on behalf of consumers to government, doctors, other health professionals, hospitals and the wider health system.

The Health Consumers' Council undertakes recruitment, training, and support for consumer representatives in metropolitan and rural health services, and provides information and training programs for consumer representatives.

www.hcc-wa.asn.au/

Health Issues Centre

Health Issues Centre delivers training programs and education sessions, and conducts seminars and workshops on a diverse range of topics focused on consumer, carer and community participation in health including health care, health research and health service planning, development and evaluation. In order to increase the capacity of health services to involve consumers, carers and community members at all levels of the health service, Health Issues Centre works with organisations to develop training programs targeted at the particular needs of the organisation.

www.healthissuescentre.org.au/training/index.asp

Hume region public tenant participation model

The Social Housing Advocacy and Support Program (SHASP) is a newly funded program delivering advocacy and support services to social housing tenants (comprising public, long-term and common equity housing) and applicants. Rural Housing Network Ltd commenced SHASP in January 2006 operating from office locations in Wodonga, Wangaratta, Shepparton and Seymour. SHASP tenant support workers provide support and advocacy.

SHASP also maintains a focus on tenant participation, and in conjunction with the Office of Housing, works to expand participation opportunities, develop tenant

skills, and provide avenues for tenants to participate in decisions that affect their housing. The discussions, initiatives and enthusiasm coming from the Hume Region Regional Tenant Council, Tenant Advisory Group, district tenant groups, and the ever-expanding number of community-based tenant groups highlight the importance and success of tenant-based participation. Both the Rural Housing Network Ltd and the OoH have employed tenant participation workers to support and foster further tenant involvement within participation-based initiatives.

www.mc2.vicnet.net.au/home/hrtpf/web/rural.html

Leadership Plus: Mentoring 79

Leadership Plus is a community organisation that promotes people with disabilities as leaders in Australian/Victorian society. The Leadership Plus Leadership Program accepts participants with a variety of disabilities who can demonstrate through a selection process that they have leadership potential. Candidates are sought from a wide range of backgrounds (including business, public sector, rural, arts, unions and volunteers). It offers participants the opportunity to talk to a cross-section of today's leaders, to hear their frank opinions and concerns and learn from their experiences. It allows participants to meet, exchange ideas and work together at regular intervals.

www.leadershipplus.com/index.cfm?siteaction=network

National Consumer Council of the UK

The National Consumer Council's strategy and work priorities are overseen by a Chairman and part-time Board members, who are appointed by the Secretary of State for Trade and Industry. Members bring a wide range of experience and expertise to the formulation and development of consumer policies. The strategic objectives for 2005-08 are to:

- put users at the heart of public services
- make markets work for consumers
- ensure that disadvantaged and vulnerable consumers get a fair deal
- achieve more sustainable consumption.

www.ncc.org.uk/about/board-members.htm

Victorian Women with Disabilities Network and Women's Health Victoria

The Victorian Women with Disabilities Network and Women's Health Victoria are working together in a mutually beneficial partnership that will assist the organisations to jointly progress an advocacy agenda on issues critical to women's health and women with disabilities. Their model uses a health promotion multi-strategy approach that includes:

- policy advocacy
- influencing mainstream providers
- influencing disability organisations around gender awareness and responsiveness
- supporting the development of leadership and advocacy skills amongst women with disabilities.

www.whv.org.au/partnerships.htm

