

Consumer Leadership

Report of the findings of a literature review and
consultation process into consumer leadership
February 2007



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

February 2007

This booklet is also 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.

Printed on sustainable paper by Impact Printing, 69-79 Fallon St.,
Brunswick, 3056.

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



Executive summary

The Victorian Quality Council (VQC) identified consumer, carer and community collaboration as a key tenet of effective health care improvement. The VQC commissioned this research project to provide advice on developing consumer leadership uptake and capacity in healthcare quality and safety improvement.

The project comprised a literature review and consultation with individuals and representatives of community and consumer organisations, government departments, academic institutions and health services. Its purpose was to identify research, evidence and opinion on leadership, consumer leadership and health consumer participation. The literature review and the consultations informed each other, with a discussion paper developed early in the literature review process. This paper provided a basis for the targeted consultations.

Executive summary

Consumer leadership: emergence and forms

The definition, characteristics and structures of consumer leadership were consistently articulated in both the literature review and the project consultations. The literature suggests that community leadership has a strong focus on social responsibility and not on personal or organisational benefit, arising from interactions at the community level. It is relationship based and representative of a constituency and their shared concerns and needs.¹

Similarly, consultation participants spoke of consumer leadership as being motivated by a form of altruism, that is, being focused on and representing the views of a broad range of people's experiences and concerns, and linked to a constituency of consumers. They also confirmed the difficulties and barriers experienced by consumer representatives who, in representing their constituency, find themselves challenging the operation and culture of the health care system.

The literature and project consultations concurred that consumer leadership is organic - that it arises from and is embedded within a community of interest, consumer organisation or network, with knowledge and expertise derived from that group. It is accountable and responsible to that constituency, its needs and concerns and retains a sense of responsibility to other consumers. In addition, its purpose is transformational. It has a shared, articulated vision providing strategic guidance in a complex and diverse environment, demonstrating courage, and networking and building alliances for change.

It is also clear that the organic nature and transformational purpose of consumer leadership is particularly evident in health consumer leadership, and that this brings with it a complexity of relationships and accountabilities to both the consumer sector and the health service sector that must be understood if health consumer leadership is to be effective in informing and enhancing health care quality and safety.

The project established that effective health consumer leadership is firmly embedded in consumer participation in health. Promotion and development of consumer leadership therefore relies on ongoing and effective development of consumer participation strategies and mechanisms within the health sector.

Consumer health leadership: characteristics and skills

The recognition of the fundamental need for consumer leaders to be embedded within, supported by and accountable to, the consumer constituency is essential if the complexities and difficulties for consumer leaders are to be addressed.

From both the literature review and the consultations, there is a consensus that the characteristics of leadership that are significant for effective sustainable consumer leadership are: setting of strategic direction or vision, changing the status quo and energising others by swaying their expectations, aspirations and commitments.² Leaders act as role models to attract and create trust in others, generate a shared vision and inspire effort from members of the group. They build alliances that work toward a better health system for all and continue in the face of opposition.

The necessary skills for effective consumer leadership include communication, negotiation, conflict management, ability to work with a range of people individually and in groups, critical reading, ability to see a broad view, and personal organisation. Knowledge of the health care system, its issues for consumers, decision-making processes and the context within which health consumer leaders are working is also needed.

Furthermore, support is needed for consumer leadership to emerge and develop. That support includes the expansion of consumer participation activities to provide opportunities for consumer leadership to emerge, support for consumer organisations, providing information about the health system and leadership education and training.

Consumer leadership in health services: models and programs to develop consumer leadership and health service capacity

It was widely accepted across the literature and the consultation process that structured education and training is necessary for the development of emergent leadership and effective consumer participation in improving the safety and quality of care.

A small number of programs for the development and support of consumer leadership within health services were identified. A range of leadership development programs was also identified in health and community sectors and in community organisation models. These courses all provide structured education and training in the theory of leadership, in leadership skills and qualities, in the technical issues of the environment in which the consumer leadership is located, and in ways in which leaders work for system change and improvement.

Until the mid to late 1990s, most of the opportunities for health consumer activists to provide leadership were provided from within the organised consumer sector. However, structured health consumer leadership roles are now being provided by some health care organisations and services. These leadership roles are usually established to provide a representative consumer presence or influence within health care organisations. This is particularly evident in mental health services where consumer consultants are employed by some services. These consumer consultants often play a leadership role in quality and safety improvement and in fostering opportunities for consumer participation. A consumer academic position has also been created within the Centre for Psychiatric Nursing Research and Practice, and is actively encouraging and developing further consumer leadership.

There are now a few examples of models that engage consumers as structurally equal partners in the provision of care. This is particularly evident in the mental health sector in the USA where there has been a proliferation over recent years of consumer-run mental health services and networks.

The project identified that effective and sustained consumer participation and health consumer leadership required structured and sustained support. Those arrangements need to address the barriers to participation arising from the meeting of two different cultures - the egalitarian culture of consumer and community groups and organisations and the hierarchical nature of providing health care. An environment that encourages and supports the emergence of consumer leadership in health service provision is one in which:

- there is clear and visible commitment and support from the health organisation's governing body and senior management
- staff concerns about consumer participation are identified and addressed
- both consumer leaders and health professionals have education in understanding the role of consumer leadership, in the relationships between consumers and professionals, and in the operation and objectives of the health service and health system, including the legislative and other broader contexts relevant to the health service
- quality information, orientation and briefings about the issues and the work of the committees or other fora in which consumers are engaged is provided
- infrastructure and resources for participation for both the health service and relevant consumer organisations are provided.

Conclusion

This project identified that there were a variety of strategies that are effective in developing leadership capability in the community and health sectors. Thus there are opportunities to further develop health consumer leadership capacity using such strategies. The strategies found to be most effective are:

1. consumer leadership programs that incorporate elements of formal learning, peer support and mentoring for nominated and applicant leadership candidates from consumer organisations and from health service organisations
2. peer support networks for consumer leaders involved in safety and quality activities that include local, regional and statewide meetings, in partnership with statewide and major metropolitan and rural health consumer organisations and networks
3. guidelines for development and support of consumer leadership within the health system to ensure effective participation and leadership



Contents

1. Introduction	7
1.1 The context for the project	8
1.1.1 Victorian Government initiatives	9
1.1.2 Consumer leadership	9
1.1.3 The Victorian Quality Council	9
1.2 Project approach	10
1.2.1 Literature review	10
1.2.2 Consultations	10
1.3 The report	11
2. Consumer leadership: definitions, emergence and forms	12
2.1 Definitions and forms of leadership	13
2.1.1 Structured and organic leadership	14
2.2 Recognising consumer leadership	15
2.3 Emergence of consumer leadership	15
2.4 Consumer leadership and leaders: issues for the consumer sector	16
2.5 The role of consumer leadership in health service safety and quality	18
2.5.1 Health consumer leadership in action	19
2.6 Summary	20
3. Consumer health leadership: context, characteristics, skills and support	21
3.1 Characteristics of consumer leadership	22
3.2 Skills for consumer leadership	22
3.3 Support for emergent leadership	22
3.3.1 Support for consumer organisations	22
3.3.2 Provision of information	23
3.4 Education and training for consumer leadership	23
3.4.1 Environmental activism	23
3.4.2 Disability sector	24
3.4.3 Health	25
3.5 Leadership development for consumers and professionals	27
3.6 Summary	28

4. Consumer leadership in health services: models and programs to develop consumer leadership and health service capacity.	29
4.1 Structured leadership opportunities	30
4.2 Health service capacity to involve consumers in leadership roles	31
4.3 Summary	32
5. Conclusion	34
6. References	36



1. Introduction

Section 01

The Victorian Quality Council identified consumer, carer and community collaboration as a key tenet of effective health care improvement. The VQC commissioned this research project to provide advice on developing consumer leadership uptake and capacity in healthcare quality and safety improvement.

NOVA Public Policy was commissioned to undertake the literature review and consultation for this project. This report presents a summary of the current literature relevant to consumer leadership in health and the outcomes of consultations with individuals and organisations in health and other industry sectors in which consumer involvement is a major driver of program/service improvement.

The project comprised:

- a systematic literature review
- a discussion paper to inform consultations with a broad range of individuals and organisations with experience of consumer participation and leadership
- a program of consultation interviews with individuals and organisations in health and in other industry sectors where consumer involvement has been a major driver of program/service improvement.

This report provides a synthesis of the areas of consensus and the major themes that emerged from the literature and the consultation program.

The project was conducted between April and August 2006. The literature review and the consultation phases were conducted concurrently. Throughout the development of the project, members of the NOVA project team and the VQC Governance and Leadership Working Group met to discuss the information and issues emerging and to consider the final report and recommendations.

1. Introduction

1.1 The context for the project

It is now widely accepted that the involvement of consumers in healthcare is an important component of effective healthcare improvement. This involvement ranges from making individual decisions about their own care to involvement in broader service delivery and planning.

Healthcare consumers and their carers are increasingly recognised by themselves, by health services and by the community as well placed to describe the quality of services received by them and to advise and assist in improving that quality. While the recognition of consumer capacity to effectively inform health care and health services is increasing throughout the health care system, the development of principles and mechanisms to support such engagement and influence is recent and limited.

Individual consumers and organised consumer groups have, for many years, raised issues about the safety and quality of health care, primarily about adverse events. Until recently however, there were limited ways for consumers to alert the health care system to problems with safety. In the 1990s the health system began to develop reporting mechanisms for consumers who had experienced an adverse event. In Australia, state and territory-based health complaints services developed over time and are now well established. More recently consumer organisations and individual consumers have increasingly argued for other constructive opportunities and ways to provide information and feedback to the health service or service provider and, commonly, to ensure their experience improves the experience of others.

In parallel, governments and health care providers have increasingly recognised that health care consumers, unlike consumers of other goods and services, do not have capacity to influence the quality of health care through market forces. Health care consumers rarely have the market power to choose or not to choose to use a service based on the consumer view of the adequacy, appropriateness or safety of the service. Similarly, governments and

consumer organisations have become more aware of the need for increased transparency and accountability in the overall health care system.

A means by which the community and governments can assess overall performance and make decisions about the safety and effectiveness of services, procedures and treatments is therefore now being provided.

The Quality in Australian Health Care Study, published in 1995, provided evidence about the incidence of preventable errors in the Australian health care system.³ Since then Australian state and territory governments have made considerable investments in structures and strategies aimed at improving safety and quality of health care. Governments have also recognised the importance and potential of involving consumers in decisions about health care at a number of different levels:

- in their own care - at this level consumers can be empowered to make choices and decisions about their own health care and to work in a more equal partnership with the health care providers
- at the systemic level - at this level consumer representatives participate in policy, planning, delivery and evaluation of health services through direct involvement in committees or through a variety of consultation mechanisms. There is also a greater emphasis on understanding and learning from the experiences of a range of consumers to inform policy and service provision.
- at the system-wide level - at this level consumers, as citizens and funders of services, have access to more information about the safety and performance of the health care system and its component parts.

1.1.1 Victorian Government initiatives

In Victoria, the State Government introduced a number of initiatives to promote and support consumer involvement in service development, quality improvement and health policy developments. All metropolitan public health services and five regional health services are required by legislation to establish community advisory committees (CACs) and to develop community participation plans. The Victorian Department of Human Services produced non-statutory guidelines for community advisory committees to assist health services to establish CACs.⁴

The department has also developed a statewide consumer, carer and community participation policy that covers participation at the:

- individual consumer or patient level
- department/ward/program within the health service level
- health service organisational level
- Department of Human Services level.⁵

The department provides guidance and support to health services regarding consumer and community involvement through workshops and the publication of guidelines for CAC's. Performance indicators regarding consumer participation are also being developed.

The Victorian Government provides support for the Health Issues Centre (HIC), a non-government organisation that has promoted consumer perspectives in the Australian health care system for over 20 years. HIC is funded by the government to run a consumer nominee program that trains and links consumers to government and health services to increase consumer participation.

1.1.2 Consumer leadership

In recent decades a number of health consumer leaders have emerged from consumer organisations and the broader community. These individuals have played a key role in focussing the attention of policy makers and health services on consumer concerns

about the safety and quality of health care and the need for and value of involving consumers in service and system wide reform.

Health consumer leaders represent the consumer interest group or communities from whom they have emerged and engage with a health service or system on their behalf. Consumer leadership in recent years has demonstrated intellectual and strategic influence and has often acted as a bridge or a translator between the community and the health service. Health consumer leaders have demonstrated their ability to communicate the experiences and concerns of the community and to actively collaborate with policy makers and service providers to address those concerns.

The current international and national policy focus on quality and safety in health care provides the context and imperative for policy attention to the capacities and characteristics of health consumer leadership that can contribute to and advance the quality and safety agenda.

1.1.3 The Victorian Quality Council

In 2001, the Victorian Government established the Victorian Quality Council (VQC) as a ministerial expert strategic advisory group to lead the safety and quality agenda for Victorian health care services. The VQC identified consumer, carer and community collaboration as a key tenet of effective health care improvement and aims to strengthen the consumer role in quality and safety improvement of healthcare through enhancing consumer leadership capacity across Victoria. In 2004, the VQC published a paper on the consumer role in clinical governance.⁶ The purpose of this paper is to assist health services to better define the rationale and methods for collaborating with consumers to improve health service safety and quality. A key result area in the VQC's 2005-2008 strategic plan is to 'enhance leadership in healthcare quality and safety'.

The VQC consumer leadership project was commissioned to understand consumer leadership and identify strategies to build consumer leadership capacity.

1.2 The project approach

The project comprised a literature review to identify research, evidence and opinion on leadership, consumer leadership and health consumer participation and a targeted consultation program. More than 50 individuals and representatives from community organisations, government departments, academic institutions and health services were consulted regarding issues identified early on in the literature review and formalised into a discussion paper.

The major themes, areas of consensus and concepts identified in the literature review and the consultations are presented in this report.

1.2.1 Literature review

The aim of the consumer leadership literature review was to:

- define and describe the characteristics of consumer leadership in the context of health care
- identify possible models or programs for developing consumer leadership capacity
- identify the skills, knowledge, experience or other prerequisites for consumers to participate in a leadership program
- provide evidence of models, programs and examples of effective consumer leadership in health care improvement
- identify opportunities for consumers to work with health services in a leadership capacity to improve the safety and quality of care
- identify ways of supporting health services to involve consumers in leadership roles to improve the safety and quality of care.

The full report of the literature review is available at: www.health.vic.gov.au/qualitycouncil/

1.2.2 Consultations

Consultation participants were approached from a range of sectors including health, financial, disability and environment. Most of the participants had a wide range of experience drawn from different roles within the sectors and were targeted to provide this project with a diverse and rich range of relevant experience and opinion.

The aim of the consultations was to identify:

- models or programs for developing consumer leadership capacity
- skills, knowledge and experience or other prerequisites for consumers to participate in a leadership program
- opportunities for consumers to work with health services in a leadership capacity to improve the safety and quality of care
- the ability of health services to involve consumers in leadership roles.

The consultations were conducted using a semi-structured interview schedule. Most interviews were conducted by telephone with some undertaken face to face.

Prior to the consultations, participants were provided with a brief discussion paper summarising the literature on leaders and leadership in general and in the community and consumer sectors.⁷ The paper identified the following six main areas of investigation:

- definitions, qualities and characteristics of consumer leadership
- 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, quality and improvement of services
- models for enhancing the capacity of service providers to work in partnership with consumers on safety and quality improvement.

The full report of the consultation process and the major themes emerging from the discussions, is published separately at: www.health.vic.gov.au/qualitycouncil/

1.3 About this report

This report presents the findings of the literature review and consultations. It provides an analysis of the role and potential role of health consumer leadership as well as opportunities and strategies for engagement with the health sector. The information and major themes that emerged through the literature review and the consultations are synthesised to:

- define and describe consumer leadership
- describe the characteristics and skills that are required for consumer leadership in health care
- identify opportunities for consumer leadership in health and the environment within which it should be fostered.





2. Consumer leadership: definitions, emergence and forms



Section 02

The literature review and consultations identified a consensus of opinion on the definition, characteristics and structures of consumer leadership. Research evidence on consumer leadership and, more particularly, health consumer leadership was limited; however there is a vast pool of descriptive analysis and opinion from the field that, together with the consultations, established that health consumer leadership is emerging as a concept.

2.1 Definitions and forms of leadership

There has been a long-term debate in literature about the nature, values, qualities and characteristics of leadership and how these distinguish a leader from all others. Much of this literature derives from organisational management theory and observation and recognises the close links between leadership and management.

In this context, leadership delivers the organisation's objectives through leading teams, employees or individuals within the organisation. Managers and leaders are generally identified as those who make strategic decisions that contribute to the organisation's goals. They develop and inspire those they lead to implement those decisions. Recently there has been discussion on the differences between leadership and management in the manner of 'management is doing things right: leadership is doing the right things'.⁸ Other literature focuses not on differences in what is done but on how leaders and managers perform identical tasks.²

Leadership is commonly understood as the capacity to lead or motivate and is focussed on change rather than maintenance of a *status quo*. Leadership is recognised by behaviour that generates a shared vision and goals, and creates trust. Leaders are role models who inspire and support effort from others, exceeding the capacity of the group acting individually or without that leadership. Theoretical approaches to describing and analysing leadership can be categorised into four main approaches,⁹ these are:

- trait theories - qualities that leaders were believed to have
- behavioural theories - behaviours were grouped into leadership styles e.g. task or people focussed, directive or participative
- contingency theories - leadership as a combination of the style and the situation in which it occurs
- transformational /charismatic theories - where leaders motivate others to do more than they thought possible.

Characteristics of transformational leaders include:

- idealised attributes - leading by means of charisma; behaviour that encourages a follower to identify with the leader
- idealised behaviours - leading by acting as an influential role model and encouraging followers to share a common vision and goals
- inspirational motivation - leading through a visionary approach; raising workers' expectations and beliefs about the mission and goals through appeals to their emotions
- intellectual stimulation - leading by appealing to workers' sense of inquiry; challenging them by questioning assumptions and encouraging creative problem solving
- individualised consideration - leading by focusing on the individual and providing coaching and mentoring.¹⁰

Leaders that demonstrate transformational leadership qualities are perceived to be both more effective and more satisfying to work for and are promoted more frequently; they generate better productivity rates, produce more innovative products and receive a higher level of volunteer effort from associates.¹¹

Other research approaches have reviewed the characteristics that denote an outstanding from a good leader and identified:

- seizing the future - the ability to plan for the long term
- political astuteness - awareness of and ability to manage diverse interest groups
- leading change through people
- effective and strategic influencing - using a number of strategies to achieve goals.¹²

These qualities and characteristics were also identified by the consultation participants.⁷

2.1.1 Structured and organic leadership

Much of the leadership literature describes formal organisational hierarchies common in commerce, industry and the services sector. In this form, leadership is structurally provided, role-based, attainable and institutionally recognised. It has status and there are expectations of performance. However attainment of or incumbency in such a position does not of itself generate leadership. Structured leadership positions are then created and mandated by an organisation. They are vested with roles and responsibilities and can be attained by merit or aspiration, by selection or by candidature.

In contrast, recent literature on community movements and activity identifies leadership that arises from the initiative and activism of individuals within groups or organisations of people acting together with a common purpose. This form of leadership is organic, emerging from within a community of interest or membership. It is self-generated and acquired through recognition by, and the respect of, others within the group. Leadership in the community context is about listening and articulating what a community has to say:

'... leadership is about giving voice to people's concerns, their fears and their needs. Not someone else telling them what concerns them. Listening and hearing their concerns and what makes them afraid and what they need, but [sic] taking up their voice and propelling it onto a larger stage.'¹

The consumer sector is a discreet sector that shares some of the purpose and characteristics of community groups. There is a substantial history of consumer activism that has been instrumental in improving the quality and safety of products and services. Actions taken by individuals or groups of consumers include:

- lodging complaints with manufacturers and providers about faulty products and services
- taking legal action against individual manufacturers of faulty products and services
- working with governments to improve government policy and regulation
- working with manufacturers and service providers to improve quality and safety systems
- using the media to draw public attention to concerns about products or services.¹³

Activism as consumer leadership is little recognised, acknowledged or respected in the consumer literature. Consumer leadership in sectors as diverse as environmental movements, financial, retail and health (such as breast cancer and HIV/AIDS) is documented in literature in terms of advocacy, activism, social participation and social change. In health in particular, the focus is on consumer participation rather than leadership, although in a proportion of the literature this includes roles and activities that could be seen as having some leadership characteristics.

Recognition of leadership by consumers is now emerging, often within the concept of the empowerment of consumers. The Massachusetts-based, National Empowerment Centre Inc. commissioned a guide for consumer organisation leadership. This guide describes leadership as 'the capacity of an individual to lead an organisation', a capacity that is learnt and based on knowledge, skills and motivation and not on innate talent.⁸ The author of the guide quoted five themes of effective leadership:

- challenging the current way of doing business
- bringing people together around a common vision
- helping others take action
- setting an example
- recognising accomplishments.

Consumer leadership tends to be organic, emerging from within a community of interest to represent the views and concerns of that community. Within each group there may be some structured leadership roles, generally those of office bearers and paid staff positions. In recent years structured leadership roles have been established within health services for consumer representatives. Consumers who hold such structured leadership positions have commonly moved into those positions as a consequence of their emergence as leaders within their consumer group, network or organisation. However not all consumer leaders will be engaged within the health system. Many will provide vision, strategic and tactical analysis and a broad consumer perspective within the group that others draw on in their representative roles.

The literature and the project consultations agree that consumer leadership is organic: arising from and embedded within a community of interest, consumer organisation or network, with knowledge and expertise derived from that group. It is accountable and responsible to that constituency; its needs and concerns and retains a sense of responsibility to other consumers. In addition its purpose is transformational: having a shared, articulated vision, providing strategic guidance in a complex and diverse environment, demonstrating courage, and networking and building alliances for change.

2.2 Recognising consumer leadership

Although the literature review found a lack of material directly related to leadership in the consumer sector, it did find a lively discussion about community leadership, much of which is directly relevant to the health consumer sector. This literature suggests that community leadership has a strong focus on social responsibility and not on personal or organisational benefit. It is seen as relationship based, coming from interactions at the community level and representing the concerns and needs of a constituency.¹

Similarly, consultation participants spoke of consumer leadership as being motivated by a form of altruism. They described it as being focused on and representing the views of a broad range of people's experiences and concerns and being linked to a constituency of consumers. They also confirmed that consumer representatives experience difficulties and barriers when, to represent their constituency, they challenge the operation and culture of the health care system.

The consultations echoed the literature, with many consultation participants questioning traditional concepts of leadership as they apply in the corporate and government sectors and which denote seniority or higher 'rank'. That stereotype was seen to inhibit recognition and development of leadership capacity in all types of people. It is clear that in the community and consumer sectors, leadership is a more inclusive concept. It is seen as operating in many different ways and at many different levels. It recognises that leadership qualities can be held and exercised by ordinary people if they are provided with an environment that enables leadership to emerge and the right sorts of support. This leadership is then 'exercised day by day by thousands of humble people in modest roles - using their ingenuity to surmount problems and running calculated risks when it seems right to do so'.¹⁴

Much of the engagement of consumers occurs at the interface between a service and the community, whether in health care or other consumer-focussed services such as education and retail. While it is possible to assert that there are influential consumers who have provided leadership for the consumer movement within services sectors, this is poorly documented. There is a body of health research on the nature and characteristics of consumer participation in health. This participation ranges from representation of the individual consumer experience of health care quality and safety, through research in health care and health services, to strategic policy and planning issues relevant to users of the health system.

Consultation participants acknowledged there has been a lack of recognition of the concept of consumer leadership, stressing that the ethos in the consumer community has traditionally been to work on a more inclusive model. As a result, the literature and discussions about the health consumer have been more about advocacy, activism, social participation and social change than leadership.

The literature review and consultation discussions for this project indicate that consumer leadership as a concept in the health sector is now emerging as a 'paradigm shift' from that of consumer participation, for both consumers and for health services. This is particularly noticeable in New Zealand, where there is recognition of the need for consumer leadership and governance in mental health services in order to shift from a focus on illness to a focus on recovery.¹⁵

2.3 Emergence of consumer leadership

An understanding of how and where consumer leadership emerges is fundamental to any strategy to encourage and develop leadership capacity. The literature review undertaken for this project was particularly useful in identifying the basis of leadership by consumers and what groups or contexts give rise to it, as well as understanding what sustains it and its constituencies and purposes.

It is clear that consumer leadership emerges from participation in groups or organisations of consumers. Consumer organisations provide the means to develop collective consumer voices and thus to facilitate engagement between the health sector and consumer views and issues.^{13, 16, 17} The empowerment of consumers is recognised as leading to improved health outcomes. It is a viable public health strategy and based on participation that is

augmented by strategies that build the capacity of community organisations and individuals. Features of empowered and therefore effective participation are: access to information, inclusion in decision making, capacity to make demands on the organisation and organisations that are accountable to the public.¹⁸

So, an understanding of the characteristics and structures of effective consumer participation offers a basis for consideration of the characteristics and structures relevant to the emergence of effective consumer leadership.

The review identified three primary areas of consumer participation in health from which consumer leadership may emerge:

- involvement in own care - the consumer as client or carer receiving or experiencing clinical care or experiencing the manner in which the health service engages with the consumer
- group member or advocate - the consumer acting at the systemic level in respect of the experience of a group with specific characteristics such as a community of place (local community, whether neighbourhood, metropolitan, rural, regional or remote) or a community of interest (specific health condition, particular health concern, disability, cultural, linguistic or racial)
- consumer group acting on behalf of the whole population in respect of the health service or system (at the system-wide level).

The findings of the literature review were broadly substantiated by views expressed in the consultations. The participants equated consumer participation in health service reform with opportunities for emergence of consumer leadership. The existence and role played by health consumer organisations is the basis on and context in which opportunities for leadership emerge. Many organisations have effectively advocated for consumer participation within health services and worked with services to help them engage with their communities. Consumer organisations also play a role as training grounds for consumers to participate within the group and develop the confidence and skills that individuals need to participate as influencers or agents of change in the health system.

2.4 Consumer leadership and leaders: issues for the consumer sector

The literature and discussions within and about the health consumer sector have focussed on advocacy, activism, social participation and social change.

The consultations confirmed there is a lack of recognition of the concept of consumer leadership amongst the consumer sectors. This appears to arise at least in part from the consumer ethic of an inclusive and supportive group of equals. Traditional concepts of leadership have not been considered because of the connotation of elitism and hierarchies that are inimical to the culture of the sector.

Consumer participants in the consultations stressed that the ethos in community and consumer sectors is that of 'bringing others along', with the health consumer sector working within an inclusive model that includes amongst its conventions the regard of all health care consumers as equals. Some in the community sector consequently regard the traditional structured model of leadership common in the corporate world with concern:

'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.'

However it is worth noting that publications generated within the health consumer sector contain a number of articles about individuals and organisations that implicitly recognise the leadership role they play. In addition a number of consumer advocates have been nominated from within the sector for awards that recognise the leading roles they have played.¹⁹

The risk taking characteristics of leadership were also recognised through the consultations, with the contrast between management and leadership identified by some who consider management to be a much safer role.

'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.'

Community and consumer sector leadership is demonstrated in many forms and at many different levels. Consultation participants considered that leadership was demonstrated by individuals and by organisations in grass roots and the wider public arena. Some who have played leading roles in consumer advocacy do 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.'

Within the consumer sector the relationship between people who are seen to be 'leaders' and the people they 'lead' is not distinct. Consultation participants emphasised that in this sector it is important to recognise and accept that there are:

'... multiple leaders at different times based on expertise, mutual leading, educating and informing.'

In addition stereotypes associated with illness, disability and culture can and commonly do, inhibit recognition of leadership capacity. This was particularly identified for people with disabilities and people with mental health disorders. Another issue particular to leadership by people within Aboriginal and Torres Strait Islander communities is that the term 'consumer' is not one that is commonly used in discussions about indigenous health, and this can obscure health leadership within indigenous communities. Health consumer leadership therefore is widely regarded as not identified within the sector and is further compromised by the perceptions of others about the abilities and capacities of people who are health care consumers.

For the consumer sector generally there are tensions inherent in the exercise of leadership in relation to two distinct spheres. Consumer leaders are accountable to the community of interest from which their leadership emerges and yet must effectively influence the sector or organisation that is the target of that leadership. Consultation participants cited by way of example the expectations of some grass roots members of consumer organisations who want to see their representatives take a high profile in the media without understanding that this can undermine relationships with other stakeholders.

To understand health consumer leadership in order to promote and support it, the conflicting dual pressures on leaders must be recognised and catered to. The skills required to bridge those different sets of values must be identified and developed. As one consultation participant who occupies a structured leadership position within a consumer organisation said:

'You are in a much more vulnerable place than one where I just have one set of people behind me.'

Consultation participants considered there are different roles for consumer leaders to bring about change. Some leaders need to stand outside the system and point out its shortcomings in the public arena. This can inhibit a direct dialogue between those particular consumers and the health services but it does act as a means of opening the door for other consumer leaders to engage in negotiations with governments and service providers around service improvement issues.

Consumer leaders appointed to structured positions within health services are considered to be less effective when they are not informed by or accountable to a constituency that provides the basis for the leaders knowledge and capacity to represent the current experience concerns of consumers.

Consumer leadership also included those who do not necessarily have a high public profile. Consultation participants observed that the history of consumer leadership includes many who are not visible to others:

'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.'

2.5 The role of consumer leadership in health service safety and quality

The VQC Safety and Quality Improvement Framework²⁰ places the consumer at the centre of all models of health care improvement. A quality-oriented health service will encourage and enable consumers to participate in their own care and treatment and the planning, delivery and evaluation of health services. The framework outlines six dimensions of quality: safety, effectiveness, appropriateness, acceptability, access and efficiency, and processes for the involvement of consumers in all these dimensions.

There is an increasing level of consumer participation with independent agencies that assess and measure implementation of quality improvement systems in Australian health care facilities. Consumers are represented on the boards of agencies such as the Australian Council for Health Care Standards and Australian General Practice Accreditation. They are involved in reviewing and setting standards and are increasingly being involved as accreditation surveyors for health services and in clinician training programs. Some agencies have now set standards that require some degree of engagement with consumers at the service-wide level.

In Victoria consumer participation in health services is being directed by government, with a clear commitment through its statewide consumer, carer and community participation policy launched early in 2006.⁵ The policy incorporates and builds on consumer participation policies and strategies developed in specific service areas and for specific populations, including people from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Island people, mental health services, primary and community health and cancer care.

The strategic location of consumer leaders within health services could be expected to encourage an increasing number of opportunities for consumer leadership to emerge by demonstrating and enabling

increasing levels of effective consumer participation within the health sector. The literature review and consultations identified many areas where engagement between health services and consumers occurs, thus providing opportunities for emergent leadership. These areas include:

- clinical care:
 - quality assurance and safety
 - research - both clinical and consumer driven research
 - clinical education and training
 - services delivery service, design, implementation and review
 - illness prevention
- health service-community interface:
 - service planning
 - health policy
 - health financing.

There are now a variety of opportunities from which leadership can and should emerge as implementation of consumer participation strategies proceed and as services develop and implement community participation plans.



2.5.1 Health consumer leadership in action

Below are three examples of health consumer leadership in action, engaged at each of the three levels of participation.²¹

1. Involvement in own care

Dream, Believe, Achieve is the name of a self-management program developed by two stroke survivors, John Norton and Peter Richardson. When the two men left hospital after their strokes, they found they had no 'road map' to help them live with the physical and emotional effects of the stroke, and its impact on their daily lives. They saw the need for a self-management program to help stroke survivors deal with the devastating impact it can have on people's lives.

John and Peter live in Bendigo and worked in collaboration with the Bendigo Health Care Group in Victoria to refine their ideas and develop the program. They applied for and received funding from the Australian Council for Safety and Quality in Health Care to pilot test the program. The excellent results of the pilot attracted further funding from the Australian Government Department of Health and Ageing. The National Stroke Foundation Self Management Education Project is now being conducted under the auspices of the National Stroke Foundation, who employed John and Peter as consumer consultant project officers to the project.

The revised program now includes a leader-training program to teach health professionals and consumers how to deliver the program, and is being further tested. It is expected the program will help stroke survivors to develop practical strategies to get on with their lives, monitor their health in partnership with their health care providers, and enable the consumer to become the expert in his or her long-term recovery.

2. Group member or advocate

Ann Revell was nominated by a leading consumer organisation to represent consumers' interests on a national committee within a specialist medical college. The committee's task was to guide a program that is aimed at improving the use of particular procedures. Other members of the committee are specialist clinicians, most of whom had little experience in working with consumer representatives. The committee has set a plan for the future work of the program and is now involved in the implementation of the strategy.

Ann has the support of two consumer organisations, but it is difficult for them to give her a detailed brief or provide anything other than broad guidance for her work. However, her membership of these organisations gives her access to a range of consumers' needs and perspectives she can draw on to inform her work on the committee.

Ann saw an opportunity for the college, through the program, to conduct some innovative work that she believed, based on her own experience and knowledge of a range of consumers perspectives, would be of benefit to consumers. It involved a project on multidisciplinary care. Ann seized the opportunity and put her idea forward. Although a consumer representative generated project proposal represented a new and challenging prospect for the college, Ann's reasoning convinced the committee and the secretariat of its merits and the proposal received unanimous support.

The college is also impressed with the work that Ann does in reporting back to her consumer constituency. She has now accepted an invitation from the college to contribute an article to the college magazine. It will be the first time that it has contained an article from a consumer representative.

Ann has taken considered, interactive and interpretative risks in fulfilling her consumer role on the college committee. During meetings and out of session she has made judgements and decisions based on her own experience, knowledge and skills. She has broken new ground for consumers and in doing so has demonstrated leadership on behalf of consumers to the specialist college and the clinicians with whom she has worked.

3. Acting on behalf of the whole population

In the early 1980s Hilda Bastian was a young mother looking for a playgroup for her children. She joined up with other mothers and was soon involved in the planning of a national conference, which aimed to establish a national homebirth organisation. It was apparent the voices of mothers and their experiences of childbirth and the early years of motherhood needed to be shared and nationally focused. In 1987, The Maternity Alliance was conceived, with Hilda in the thick of it.

She became interested and concerned for consumer information and evidence about the safety of health interventions, particularly around childbirth. This led her to focus on research and on developing an understanding of the role consumers must play if research outcomes are to be meaningful for them.

At about this time, the Consumers' Health Forum of Australia (CHF) was established and became an important vehicle through which some of the broader maternity issues could be promoted. The representative mechanisms CHF was establishing provided an opportunity for some homebirth and maternity issues to be introduced into national policy and research committees. Hilda saw the possibilities and seized the opportunities. She became a consumer member of an NHMRC committee dealing with mortality in childbirth. She developed an understanding of research methods and moved the homebirth debate through the NHMRC by working on guidelines for quality management of homebirths and hospital transfers. In doing this she opened up its process for reviewing maternal mortality and highlighted the inequitable outcomes for Aboriginal mothers.

Her research interests and passion about providing good evidence for consumers led to Hilda playing a leading role when the Cochrane Collaboration was first established, and she became the convenor of its consumer network. She also conducted training programs to help consumers understand the work of the collaboration and the development of systematic reviews. Hilda is now head of the Patient Information and Research Department in the German Institute for Quality and Efficiency in Health Care.²²

2.6 Summary

Consumer leadership in health has not been well recognised within either the consumer or health services sectors, nor received significant attention in the literature. However the enthusiasm of those who participated in the consultations for this project indicated that both the health service and consumer sectors are now keen to recognise leadership by consumers as it operates in relation to the health sector.

From both the literature review and the consultation discussions, it is evident that consumer leadership can be described or defined as organic: that which emerges from within its own grouping and as transformational: that which seeks to achieve change.

It is also clear that the organic nature and transformational purpose of consumer leadership is particularly evident in health consumer leadership.

For health consumer leadership to be effective in improving safety and quality in health the complexity of relationships and accountabilities to both the consumer sector and the health sector must be understood.

Consumer participation in health provides significant opportunities for emergent consumer leadership in the health sector. Promotion and development of consumer leadership therefore relies on ongoing development of effective and empowering consumer participation strategies within the health sector.



3. Consumer health leadership: context, characteristics, skills and support



3. Consumer health leadership: context, characteristics, skills and support

3.1 Characteristics of consumer leadership

The literature review established that leadership as a role is commonly understood as the capacity to lead or motivate and is focussed on change or development rather than maintenance of a *status quo*. Although there is debate about whether leadership can be taught or is innate, the literature describing transformational leadership and leadership demonstrated in community and consumer sectors is recognised and characterised by:

- setting of strategic direction or vision
- changing the *status quo*
- energising others by swaying their expectations, aspirations and commitments.²

These characteristics are achieved by behaviours that:

- attracts and creates trust in others
- are a role model to and generates among others a shared vision and goals
- inspires and supports effort from others that exceeds the capacity of the group acting individually or without that leadership.

The literature review and the consultations produced a consensus that consumer leadership is characterised by:

- articulating a shared vision
- the ability to build inclusive networks and alliances to bring about change
- altruism and a sense of social responsibility to improve the health system for everyone
- ability to comprehend the issues for both consumers and health services
- courage and commitment to continue in face of opposition.

3.2 Skills for effective consumer leadership

A range of skills and knowledge required for effective consumer leadership were identified through the project. Those skills can be summarised as:

- communication - the ability to represent and assert consumer issues in a diversity of environments and to actively listen to and communicate constructively with diverse stakeholders
- negotiation and conflict management
- understanding how to work with people to achieve, including the dynamics of groups and meeting procedures
- ability to locate and critically analyse information
- ability to see a broad view - being able to translate individual experiences into system-wide issues
- personal organisation including time management, record keeping and management of information.

3.3 Support for health consumer leadership

The emergence and development of consumer leadership also requires a range of support.

Leadership is embedded in and arises from consumer participation, communities of interest, community organisations or networks. Both consumer communities and the health sector are environments in which participation can enable leadership to emerge. For health consumer leadership to be effective, both consumer communities and the health sector need to provide opportunities for effective participation and to recognise that participation promotes and develops leadership.

3.3.1 Support for consumer organisations

For consumer leadership to engage effectively with health professionals, health services and the health system, the characteristics and capacities of that leadership must be recognised by both consumers and their organisations, and health professionals and services.

Both the literature review and the consultation process identified the role of consumer organisations in facilitating the development of consumer leadership and in providing a support base for the leader to draw upon. There is a wide range of consumer organisations including population-based groups,

self-help and support groups and advocacy organisations. Although governments provide some funding for some organisations and a few receive some corporate support, consumer organisations mostly rely on voluntary efforts. Thus the extent to which consumer organisations can develop and support leaders is constrained by the resources available to them. This may be further inhibited by the culture, capacity and knowledge of health professionals, health services and systems.

3.3.2 Provision of information

Lack of shared knowledge between health services and consumers can disempower and exclude consumer leaders. For emerging consumer leaders, whose participation has arisen from their own experience of health care, the operation and structure of the health system is commonly invisible. Thus their capacity to represent and assert consumer experience and concerns to health service providers and leaders is accordingly reduced.

For health consumer leadership to be supported and resourced, health services and providers engaging with health consumer communities, organisations and networks, need to provide timely, current and instructive information about the health system and services. This includes individual services such as mental health; funding sources and arrangements; common medical language; safety and quality issues and strategies; internal processes and how decisions are made.

For consumer leaders to be effective in representing the experiences and concerns of consumer constituents, they need to have access to reliable, rigorous scientific advice and knowledge about issues. Examples of such sources include those established for environmental groups by working with scientists and in the Breast Cancer Network of Australia (BCNA). This network has a Medical and Scientific Reference Group comprised of clinicians and researchers who provide reliable and rigorous advice to the organisation and its representatives. Another example cited by the project's consultation participants is the Cochrane Collaboration, which has a strong internal consumer network that provides results of systematic reviews in consumer friendly formats.

3.4 Education and training for consumer leadership

A number of consumer and community organisations offer leadership development programs to their members.

3.4.1 Environmental activism

In a different area of consumer activism and leadership promotion in the USA, the Environmental Leadership Program (ELP), through a fellowship program, provides training, project support and a peer network to 20-25 people each year who are engaged in environmental and social change work. The ELP website describes ELP as 'committed to fostering a reflective, diverse environmental movement capable of responding to our complex social and environmental challenges'.²³ ELP fellows come from non-profit organisations, businesses, government, tribal government and higher education. The organisation offers a two-year fellowship to emerging leaders who are defined as practitioners and are relatively new to the environmental field, identified as approximately three to ten years' involvement.

Applicants for the Fellowship must participate in four one-week retreats over two years, with ELP covering all retreat travel and accommodation costs. Topics covered at the retreats include communications, fundraising, organisational development and conflict resolution. There are discussions on the role of all types of diversity in the environmental movement, the current state and future of environmental movements and the complexities of building diverse coalitions. Participants also have opportunities to discuss environmental and leadership issues with established environmental leaders.

On completion of the two-year fellowship, they become part of a network of Senior Fellows, which seeks to further public dialogue on what it means to be an environmental leader and how environmental leaders can partner with new constituencies in the interest of environmental protection and social equity.

3.4.2 Disability sector

There is an established commitment to the development of leadership skills and opportunities for people with disabilities, which are particularly illustrative of the significance of education and training as well as mentoring by professionals for the development of consumer leadership.

In Victoria, Leadership Plus is a community organisation that promotes people with disabilities as leaders, through intensive leadership courses, mentoring, internship and a leaders' network. The focus is on civic participation and inclusion as citizens in Australian society. The organisation's objective is to foster leadership in people with disabilities by engaging those people with a disability who are already leaders, developing the leadership potential of people with a disability, creating leadership opportunities for leaders with a disability, and ensuring the sustainability of Leadership Plus.²⁴

Leadership Plus works in partnership with the Office of Training and Tertiary Education, the Royal Melbourne Institute of Technology (RMIT) TAFE and the participants themselves, to provide an accredited set of leadership competencies for 25-30 people with a disability. A range of sponsors also supports the workshops and seminars. The Leadership Program has three core elements: theory (delivered by RMIT), witnessing Leadership (Guest Speakers), experiencing Leadership (Syndicates).

Leadership Plus offers:

- mentoring programs that involve leaders from the business, community, cultural, social, environmental and local government sectors in a relationship with emerging leaders from the disability advocacy sector, including matching students with a disability, who are in their final year of tertiary study, with a mentor in a company or organisation in the area in which the student hopes to establish their career
- Leadership in Advocacy mentoring, which gives people with a disability the opportunity to work with leaders in mainstream advocacy organisations
- Leadership through Mentoring 79 project, which works with the 79 local governments in Victoria to provide people with disabilities with a one-day mentoring program with councillors, chief executive officers and senior managers

Leadership Plus Internship Program, which connects a person with a disability with a high-profile Victorian leader from politics, the public service, business or the community sector.

Partners in Policymaking, established by the state of Minnesota in 1987, is a well-evaluated competency-based leadership-training program for adults with disabilities and parents of young children with developmental disabilities. The program aims to teach best practices in disability and to teach the competencies of influencing public officials. Partners programs have been widely implemented across the USA and overseas, and the website states that '...more than 13,000 Partners' graduates are part of a growing national and international network of community leaders serving on policy making committees, commissions, and boards at all levels of government.'²⁵

'The program teaches leadership skills and how to develop positive partnerships with elected officials and other policy makers who are concerned with service delivery. It aims to assist people to become advocates for themselves and for others and to be leaders in the disability field and the public domain.... The program also offers opportunities to learn from experts about lobbying, policy development and service delivery.'

The program is interactive, runs over eight weekend sessions, involves a range of practical tasks, and is free to participants. Each group of 20-30 is selected to represent diversity of location, ethnicity, gender and type of disability, and the program aims to help people to develop networks across this diversity. The course and course materials are altered to suit the local political or cultural environment.

In New Hampshire, sponsored leadership courses for people with disabilities and their family members have been provided since 1988. The Institute on Disability at the University of New Hampshire, in collaboration with a range of other organisations including the Developmental Disabilities Council, the New Hampshire Division of Mental Health and Developmental Services, the New Hampshire Department of Education and People First, provides training courses that produce leaders 'who have a clear vision, knowledge about state-of-the-art supports for individuals with disabilities, and skills necessary for advocating with service providers.

They know how to use the legislative process to achieve change, and how to organise communities to support inclusion. The Leadership Series enhances the ability of people and families to change laws, persuade schools and businesses to include individuals with disabilities, and educate communities about the importance of welcoming and including every member.²⁶

3.4.3 Health

An Australian example of such education and training is the Consumer Focus Collaboration (CFC) formed in 1997. The CFC aims to facilitate the provision of high quality information to consumers in appropriate formats; active consumer involvement in health service planning, delivery, monitoring and evaluation; and to improve health service accountability and responsiveness to consumers. The collaboration also has a priority commitment to promote education and training that supports active consumer involvement in health service planning and delivery.

An extensive consultation project²⁷, identified the following areas in which education for consumer participation was needed:

- how the health system works, from national to local
- social and ecological views of health, to complement the limited biophysical perspective
- committee operation and training for Chairs
- group dynamics
- communication skills, including assertiveness, active listening, conflict management
- terminology and jargon-busting
- emerging issues/new technical skills - for example, how to deal appropriately with commercial-in-confidence papers, how to undertake criteria ranking
- organisation orientation manuals
- values clarification and exchange
- skills in analysis/audit.

The consultations consistently indicated that, 'one-off education has a very limited impact'. The CFC project identified the following characteristics of successful education and training programs:

- bringing consumers and providers together
- containing a mix of information provision and practical exercises
- based on experience
- including peer support elements
- providing information which was relevant to participants' needs
- using credible, skilled presenters.

The final report of the CFC project summarised the research and development undertaken by the project to produce the *Resource Guide for Education and Training for Consumer Participation in Health Care* as 'essentially a guide to what other people have done in relation to education and training for consumer participation in health care policy, planning, service delivery and evaluation'.²⁷

The report noted that:

'Building learning organisations, networks, and communities, in the health sector ... promotes an opportunity for innovative collaboration and partnership between providers and consumers in addressing the challenge of the new century. ... A learning organisation focus provides an opportunity for consumers and providers in health care to develop a new vision for the future together, bringing a wide range of learning strategies into a single learning environment. This, in turn, develops a capacity for health organisations to adapt in the present environment of exponential change. The capacity to work together to bring about positive changes presents a critical challenge where consumers and providers share a common interest.'²⁷

In developing a conceptual model, the researchers identified a number of important assumptions underpinning the project:

- effective and efficient health care requires consumer participation in the planning, service delivery, monitoring, quality improvement and evaluation of health services
- consumer participation in health services benefits the services, their administrators and service providers as well as consumers

- for consumer participation to be effective, all participants in the process need to respect the different skills and expertise of the other participants
- effective participation is facilitated by the development of mutual trust, respect, integrity and goodwill between participants
- effective participation can be enhanced through many different forms of learning, including education, training and other less formal learning processes
- consumers, providers and administrators of health services can all benefit from learning about the planning, delivery, monitoring and evaluation of health services.

Particularly significant is the report's finding that health professionals benefited as much from education and training about the health system as did consumers and that shared education and training advanced the participation and contributions of both:

'Often those who have thought about training and education to make consumer participation more effective have only focused on consumer needs. However, as the research showed, such programs need to include health service providers and administrators, as well as consumers, because these groups strongly influence how effectively consumers can participate.'²⁷

The Breast Cancer Network of Australia encourages its consumer representatives to complete a Breast Cancer Advocacy and Science Training Program where possible, to equip them with the knowledge, skills and confidence to become effective breast cancer advocates and consumer representatives. While it is not a prerequisite to being a consumer representative, it is expected that those who have not undertaken the program will do so when the opportunity presents.

The NSW Cancer Council, in partnership with Cancer Voices NSW, runs two-day cancer consumer advocacy training workshops designed to assist people with cancer and their families/carers, to become effective consumer advocates for improved health policies and systems. The aims of the workshops are to:

provide participants with the skills and knowledge required to become active and effective advocates for improvements to cancer policies and systems

provide the skills and knowledge to effectively represent the interests of cancer consumers in a range of forums

empower cancer consumers to fully participate at all levels where cancer decisions are made

enhance participants' understanding of how to influence government, the health delivery system, clinicians, research institutions and cancer organisations and support providers.²⁸

In the USA, women who have or have survived breast cancer are offered leadership training through Project LEAD[®] (Leadership, Education and Advocacy Development). The National Breast Cancer Coalition (NBCC) web site describes Project LEAD[®] as:

'A science training course developed by the National Breast Cancer Coalition designed to help breast cancer activists influence research and public policy processes. As an extensive four-day program, Project LEAD[®] prepares advocates for participation in the wide range of forums where breast cancer research decisions are made.'²⁹

Since 1995, Project LEAD[®] graduates have served on influential research boards and committees in the United States' federal and state governments, universities, hospitals and private industry. Graduates are expected to seek out and participate in the breast cancer research process. They are also expected to work closely with NBCC and other Project LEAD[®] graduates to encourage and strengthen consumer participation in breast cancer research. Through NBCC, graduates join a nationwide Project LEAD[®] network that provides ongoing support and a forum to exchange ideas with other activists in the breast cancer research community.

The project particularly emphasises technical and clinical training for leadership participants:

'Project LEAD[®] strives to provide a foundation of scientific knowledge on which participants can strengthen and empower themselves as activists. Participants will:

- learn the language and concepts of science
- discover how to critically appraise scientific literature
- acquire study skills necessary to remain educated on scientific aspects of breast cancer
- study how breast cancer research decisions are made
- become familiar with the wide range of consumer advocacy opportunities
- gain confidence to speak up, ask questions and find common ground with scientists'.

The Project LEAD[®], leadership-training course is presented by scientists from academic and research institutions. The course covers:

- basic science, such as the biology of cancer, basic genetics, the roles of DNA, RNA and proteins and development of cancer at the molecular level
- basic epidemiology such as biostatistics, descriptive studies, analytic studies, clinical trials, causality, meta-analysis and screening
- leadership and advocacy development skills and how to participate in the scientific community as a breast cancer advocate.

Requirements for acceptance to the course include:

- experience with breast cancer advocacy in one's community - consumer advocates must demonstrate a dedicated commitment within their community to educate others about breast cancer advocacy
- interest in learning the language and concepts of science - Project LEAD[®] trains breast cancer advocates to participate in the design and evaluation of research and policy

a clear personal connection to breast cancer - while a special emphasis is placed on training breast cancer survivors, this is not a requirement for Project LEAD[®]

a commitment to continue learning about scientific concepts. Graduates of Project LEAD[®] are encouraged to join LEAD Grads Online, serve on government and hospital research panels, become or remain active within local breast cancer organisations, lobby members of congress on important issues affecting breast cancer research and attend Project LEAD[®] graduate courses

a willingness to prepare for, and actively participate in, the entire four-day course - applicants must attend every session of the course. There are no exceptions.

3.5 Leadership development for consumers and professionals

It is widely accepted across the literature and is emerging in recent consumer empowerment strategies that education and training is an essential foundation for effective consumer participation in improving the safety and quality of health care.

While consumer leadership is developed within some areas of the community sector, the capacity for that leadership to achieve its potential within health sector is constrained by the consumer context and resources and by the culture, capacity and knowledge of health professionals, health services and health systems.

Structured and strategic approaches to consumer leadership development are effective where these are framed as empowerment strategies that are explicitly based on collaboration and equal partnerships between health professionals and health care consumers. Working in a collaborative arrangement with consumers can be a new and challenging experience for health care providers and they need support and training to enable them to work in different ways.

Education and training for both health professionals and consumers that addresses the context, experiences and prior knowledge of each substantially increases the success of these collaborations. Each group needs to be made aware of the benefits, opportunities and obligations for improving healthcare safety and quality through effective collaborations and partnerships.

The education of both consumers and providers should be recognised as a dynamic process, one in which participants mix formal learning with experience and reflection, as summarised in the Consumer Focus Collaboration report:²⁷

'Learning is now recognised as a dynamic and active concept which is a lifelong activity... It is also now recognised that learning, even at an unconscious level is a cyclical process. This involves the stages of undergoing an experience, reflecting on that experience, making decisions about how to do it differently next time and then testing out the different approach at the next opportunity'.

During the course of this project a range of leadership training programs were examined including those in environmental activism, disability, cancer, HIV/AIDS, primary care and mental health.

Consistent across these education and training programs were elements of:

- formal training
- peer support and mentoring
- opportunities to learn from established leaders in diverse fields, including business, community, local government and advocacy organisations
- the passing on of skills and knowledge acquired by participants in the programs to other consumers.

A number of programs, particularly those in the mental health sector, have developed education and training directed at both health professionals and consumers. This education aims to develop mutual understanding of the roles and responsibilities of consumer and professional leadership and a shared knowledge of the technical and specific environments in which consumer and professional leaders function.

3.6 Summary

Both the literature review and the project consultations established the importance of understanding the opportunities for and barriers to consumer leadership in health and the need for deliberate education and training for both consumer leadership development and for the development of equitable and effective partnerships between health professional and health consumer leadership.

Recognition of the fundamental need for consumer leaders to be embedded within, supported by and accountable to their consumer constituency is essential if the complexities and difficulties for consumer leaders are to be addressed.

Consumer leadership education and training programs that are cited as effective and as producing sustained leadership by consumers, all include selection or intake criteria for course participants that emphasise personal knowledge and experience, strong connections to a consumer group or network, and demonstrated interest in active participation. The courses all provide structured education and training in the theory of leadership and characteristic skills and qualities, the technical issues of the environment in which the consumer leadership is located and in ways in which leaders work for system change and improvement. A range of education and training programs also provide or emphasise mentoring by professionals and by established leaders.


The emergence of consumer leadership is enhanced by the existence of peer support that informs and supports health consumers in taking a leadership role.

There is evidence that education and training for health consumer leadership is increased in its effectiveness and sustainability when it is provided to both consumer and health professional leadership and provides shared education and training strategies for leaders in both sectors.

Many consumers are now participating in health system and service reform in Victoria where there are increasing opportunities for consumer leadership roles within health services. This capacity would be further enhanced by the provision of leadership programs that develop and enhance the characteristics and skills identified in this report.



4. Consumer leadership in health services: models and programs to develop consumer leadership and health service capacity



Section 04

Through the literature review for this project, a small range of models, programs and examples of structured approaches to the development and support of consumer leadership within health services were identified. Consultation participants also pointed to a range of models and programs of relevance to the project. A range of leadership development programs were identified in environmental activism, youth services, disability services, HIV/AIDS and mental health services, and in community organisation models.

4. Consumer leadership in health services: models and programs to develop consumer leadership and health service capacity

4.1 Structured leadership opportunities

Until the mid to late 1990s, most of the opportunities for health consumer activists to provide leadership were provided from within the organised consumer sector. Those positions included senior staff and board positions within consumer organisations.

Increasingly, structured health consumer leadership roles are being provided by health care organisations and services. These leadership roles are usually established to provide a representative consumer presence or influence within health organisations or services. This is particularly evident in mental health services where consumer consultants are employed by some services and can often play a leadership role in quality and safety improvement and in fostering opportunities for consumer participation.

In 2000, the Centre for Psychiatric Nursing Research and Practice (CPNRP) created a consumer academic position. It aimed to create a mechanism through which a consumer perspective could influence the strategic direction of the CPNRP. The role includes teaching within the Postgraduate Diploma in Advanced Clinical Nursing (Psychiatric Nursing). The position was supported and guided through a partnership of the CPNRP and the Melbourne Consumer Consultants Group (MCCG). This ensured that the consumer academic would receive input and advice from consumer colleagues to provide a broader view of consumer perspective.

The consumer academic has established and convenes the Psych Action and Training (PAT) group. The membership of consumers and senior nurse educators are dedicated to strengthening and promoting the consumer perspective in research and in the training and education of mental health practitioners. One of the aims of PAT is to provide resources and support for a consumer educator workforce. Training workshops have been developed for consumers to enhance their skills in the areas of training and research.

The strategy aims to build capacity for consumers to work collaboratively with mental health professionals in the areas of education, training and research.³⁰⁻³³

A second example of an innovative structured leadership position within a mental health service in Victoria emerged during the course of this project. Spectrum - the Personality Disorder Service for Victoria³⁴ - recently created a position for a consumer leader with lived experience of being a mental health consumer and involvement in the consumer movement at state level. This management advisory position is to lead, plan, organise and monitor the implementation of effective community consumer strategies at a statewide level.

Both of these structured leadership positions have well defined and ensured linkages between the consumer leader and the represented constituency.

Some Victorian health services have mandated consumer advisory committees (CACs) that provide a form of structured health consumer leadership. The role of the CAC is specified in the Community Advisory Committee Guidelines. One of the roles is, 'to provide direction and leadership in relation to the integration of consumer, carer and community views into all levels of health service operations, planning and policy development.' In order to meet these objectives, the selection and appointment of consumers with established links to consumer groups is essential. CACs must achieve partnerships with consumer groups and networks that facilitate the engagement of consumer leaders who emerge from and are firmly located within the relevant consumer constituencies.

They can therefore be seen as having a structured relationship role that should, through increasing the level of consumer participation, provide more opportunities for the emergence of health consumer leadership.

Consultation participants identified that, while not all CACs are successful in meeting the objectives set out for them, those that are successful have become 'a leadership organisation that builds leaders as well. Structurally it's a leadership group influencing other groups.'

The literature review and consultation participants emphasised the need for structured and sustained strategies to enable consumer participation and thus promote and support health consumer leadership. Those strategies need to address barriers to participation arising from the meeting of two different cultures. These arise mainly from lack of understanding about the purpose and role of consumer participation and knowledge of how to engage with consumers other than as passive patients.

The literature review established that health consumer leadership within health agencies and organisations is facilitated and supported when:

- consumer participation is included in organisations' policies and business planning
- there is executive support and champions
- the change management process is well managed
- there is accountability to the consumer sector
- adequate resources are allocated such as:
 - education for staff
 - financial - dedicated budget
 - work space.

4.2 Health service capacity to involve consumers in leadership roles

Most of the barriers to consumer participation and leadership in health services arise from the differing cultures of the consumer and health sectors. Consumer participation in health is relatively new, dating mostly from the 1990s. In this comparatively short space of time, there has been increasing acceptance of engaging with consumers as a key strategy in improving the safety and quality of care. However that involvement generally has not been one in which there has been explicit recognition that consumers can and should play a leadership role.

There are now a few examples of models that engage consumers as structurally equal partners in the provision of care. This is particularly evident in the mental health sector in the USA where there has been a proliferation over recent years of consumer-run mental health services and networks. In Australia efforts are being made to encourage the health system and services to become more outward looking and to engage more closely with their communities. This is particularly evident in Victoria where a systematic approach is being taken to build and enhance consumer participation throughout all public health services. It can now be seen that some of the basic structures are being put in place to enable consumer participation and consumer leadership.

Consumer participation has been increasing over the past decade and is an evolutionary process. A number of consultation participants stressed that there is now considerable experience of consumer participation and that evaluation of processes and outcomes is required.

What is now understood is that consumer participation and consumer leadership involves a relationship between two different and distinct sectors and cultures. Examination of a range of

programs and models that enhance health service capacity to involve consumers in leadership roles suggest that key features of successful models include:

- clear articulation of and agreement to the purpose and philosophy of consumer participation and leadership between parties
- explicit and equal commitment by both parties to the purpose, processes and outcomes of the relationship
- articulated and agreed roles, relationships, responsibilities and accountabilities for leadership and engagement for both consumers and service providers
- investment in education, training and supports such as mentoring that recognises the individual consumer and service provider characteristics, skills and capacities
- investment in communication (feedback, comment and inquiry) and in peer recognition and acknowledgement of achievement and effective leadership.

Development of models that incorporate these features will need to take account of the:

- power imbalances in relationships between consumers and health service providers and the need for structures that deliberately create equity of power and influence
- need to broaden participation and leadership opportunities
- need to provide resources to develop and sustain relationships with consumer constituencies
- need to provide an enabling environment within health services so that maximum advantage is gained from consumer participation and leadership.

4.3 Summary

An environment that encourages and supports the emergence of consumer leadership in health is one in which there is:

- education and training for both consumer leaders and for health professionals that includes an understanding of the role of consumer leadership, the relationships between consumers and professionals and the operation and objectives of the health service and system including the legislative and other broader contexts relevant to the health service
- clear, visible commitment and support from the health organisation's governing body and senior management
- provision of quality information, orientation and briefings about issues and the work of the committees or other fora in which consumers are engaged
- provision of infrastructure and resources for participation, including office space, equipment and project officers: for both the health service and relevant consumer organisations
- operational support for the consumers who are involved, including appropriate and accessible meeting venues, office support for the consumers and resources to support consumer involvement
- a process to identify and address staff concerns about consumer participation.

The four key factors identified as enabling the success of the consumer academic position at the Victorian Centre for Psychiatric Nursing Research and Practice have been consistently confirmed through the literature and the consultations as critical to effective consumer leadership. These are:

- partnership and commitment to equal representation
- support - the project team supported the consumer academic throughout the development of the role. The team initially met fortnightly, meeting less frequently as the role developed.

- scope - the consumer academic role was not confined to specific and discrete activities or projects, in order to introduce and maintain a consumer perspective into all activities of the CPNRP. The activities of the consumer academic broadly related to the areas of education and training, research, and consultancy.
- autonomy - the CPNRP sought to avoid tokenism with its appointment of a consumer academic, and provided the position with complete autonomy so that the academic was not required to seek approval through line management prior to voicing an opinion or engaging in specific activities.³⁵

These four factors should be regarded as fundamental principles in the implementation of consumer leadership promotion and development strategies within individual health services and organisations, and across the health system. The effective contribution of health consumer leadership within the health sector and health services is reliant on an enabling environment and the development of effective relationships between the health service and groups of consumers.





5. Conclusion

Section 05

This exploration of issues relating to consumer leadership has entered new territory. Consumer leadership in health has not been well recognised nor has it received significant attention in the literature. It is not a concept that is well recognised within the ethos or culture of the health consumer sector. However the enthusiasm of those who participated in the consultations for this project indicated that both the health service and consumer sectors are now keen to recognise and advance leadership by consumers within the health sector.

There are two forms of consumer leadership - organic leadership and structural leadership - and most consumer leaders must operate within both forms. The interactions of these dual types of leadership and the complexities that arise have not been consistently understood or addressed. Effective consumer leadership in health is organic in its origin and credibility. Effective consumer leadership within the hierarchical structure of health services must be resourced and supported to to engage with and manage the the complexities of being accountable to both the consumer constituency of origin and the health service constituency of operation.

Dynamic and effective consumer leadership in health is enabled to make a sustained contribution to the quality and safety of health services by supports such as consumer leadership training and peer support networks.

Opportunities exist to further develop health consumer leadership capacity using strategies identified through the project. The strategies found to be most effective are:

1. consumer leadership programs that incorporate elements of formal learning, peer support and mentoring for nominated and applicant leadership candidates from consumer organisations and from health service organisations
2. peer support networks for consumer leaders involved in safety and quality activities that include local, regional and statewide meetings, in partnership with statewide and major metropolitan and rural health consumer organisations and networks
3. guidelines for development and support of consumer leadership within the health system to ensure effective participation and leadership.



6. References



1. Nossell G. 2003, Leadership for the health of communities: where and how does it expand community control? *Communities in Control*. Melbourne. Available at: <http://www.ourcommunity.com.au> Accessed 8 June 2006.
2. Lipshitz R, Mann L. 2004, Leadership and decision making: William R Ruckelshaus and the Environmental Protection Agency. Available at: <http://www.mbs.edu/index.cfm?objectid=951E3C5F-123F-A0D8-42933A770483B51A> Accessed 26 May 2006.
3. Wilson RM, Runciman WB, Gibberd RW, Harrison BT, Newby L, Hamilton JD. 1995, The Quality in Australian Health Care Study. *The Medical Journal of Australia*, Vol 163, November, pp 458-471.
4. Department of Human Services 2006, Community advisory committee guidelines: Victorian public health services. Department of Human Services, Rural and Regional Health and Aged Care Services Division. Available at: <http://www.health.vic.gov.au/consumer>
5. Department of Human Services 2005, Doing it with us not for us. Department of Human Services, Rural and Regional Health and Aged Care Services Division.
6. Victorian Quality Council 2004, Enabling the consumer role in clinical governance: a guide for health services. Department of Human Services, Metropolitan Health and Aged Care Services Division.
7. Victorian Quality Council 2007, Consumer Leadership - Consultation Report. Department of Human Services, Rural and Regional Health and Aged Care Services.
8. Ten Hoor WJ. 2002, *A guide for consumer organisation leadership: principals for practice.*, National Empowerment Center Inc.
9. Doyle ME, Smith MK. 2001, Classical Leadership. *Infed* 2001. Available at: http://www.infed.org/leadership/traditional_leadership.htm . Accessed 27 December 2006.
10. Sinclair A, Wilson V. 2002, New Faces of Leadership. *Leadership Victoria - Articles* Vol 2002. Available at: http://www.leadershipvictoria.org/articles/article_sinclair2002spring.pdf Accessed 7 June 2006.
11. Sarros J, Moors RJ. 2001, *Right From the Top: Profiles in Australian Leadership*. Australia: McGraw-Hill; 2001.
12. Hay Group 2001, NHS Leadership Qualities Framework. NHS Institute for Innovation and Improvement, National Health Service-UK. Available at: <http://www.nhsleadershipqualities.nhs.uk/> Accessed 27 December 2006.
13. Smith S. 2000, ed. *In the Consumer Interest: A selected history of consumer affairs in Australia 1945-2000*. Melbourne: Society of Consumer Affairs Professionals in Business.
14. Mant A. 1997, *Intelligent Leadership*, Allen and Unwin.
15. Gordon S. 2005, The role of the consumer in leadership and management of mental health services. *Australasian Psychiatry*, 13(4), pp 362-365.
16. Coney S. 2004, Effective Consumer Voice and Participation for New Zealand: A systematic review of the evidence. New Zealand Guidelines Group. Available at: http://www.nzgg.org.nz/guidelines/0086/050511_Consumer_Report.pdf Accessed 8 June 2006.
17. Newman J, Vidler E. 2006, Discriminating customers, responsible patients, empowered users: Consumerism and the modernisation of health care. *Journal of Social Policy*, Vol 35, pp 193-209.
18. Wallerstein N. 2006, What is the evidence on effectiveness of empowerment to improve health? World Health Organisation Regional Office for Europe. *Health Evidence Network report*; <http://www.euro.who.int/Document/E88086.pdf>

19. Consumers' Health Forum Australia. CHF announces its first life membership awards. *Consumers' Health Forum*, Available at: http://www.chf.org.au/Docs/Downloads/Media_release_2005_CHF_AGM.pdf Accessed 23 January 2007.
20. Victorian Quality Council 2003, Better Quality, Better Health Care, Victorian Government Department of Human Services, Metropolitan Health and Aged Care Services Division. Available at: <http://www.health.vic.gov.au/qualitycouncil/>
21. Australian Council for Quality and Safety in Health Care 2005, Partnerships for Health in Action: Promoting Consumer and Community Involvement in Health Care Improvement. Australian Council for Safety and Quality in Health Care. Available at: [http://www.safetyandquality.org/internet/safety/publishing.nsf/Content/C06811AD746228E9CA2571C600835DBB/\\$File/consumrept0705.pdf](http://www.safetyandquality.org/internet/safety/publishing.nsf/Content/C06811AD746228E9CA2571C600835DBB/$File/consumrept0705.pdf)
22. Graham J. 1997, The First Bastian, *Health Forum*, 40.
23. Environmental Leadership Program - undated. ELP Fellowship. Available at: <http://elpnet.org/fellowship.php> Accessed 17 June 2006.
24. Leadership Plus - undated. Leadership Network - Become a Member. Available at: <http://www.leadershipplus.com/index.cfm?siteaction=network#becomemember> Accessed 17 June 2006.
25. Johnson K, Frawley P, Hiscoe C, Strong R. 2002, *Supporting leadership opportunities: a report to the disability affinity group*. Melbourne: Leadership Plus, October. Available at: http://leadershipplus.com/documents/Supporting_Leadership_opportunities.pdf
26. Institute on Disability 2006. The New Hampshire Family and Consumer Leadership Series. *University of New Hampshire*. Available at: http://iod.unh.edu/projects/consumer_leadership.html
27. Global Learning Services Pty Ltd. 2000, Education and Training for Consumer Participation in Health Care. Commonwealth Department of Health and Aged Care, Consumer Focus Collaboration. Available at: <http://www.participateinhealth.org.au/clearinghouse/Docs/cfcedandtrainreport.pdf> Accessed 11 June 2006.
28. Cancer Council of NSW - undated. Cancer Consumer Advocacy Training Workshop. Available at: <http://www.cancerCouncil.com.au/editorial.asp?pageid=974> Accessed 26 June 2006.
29. National Breast Cancer Coalition - undated. Project LEAD. Available at: <http://www.natlbcc.org/bin/index.asp?Strid=483&btnid=4&depid=7> Accessed 10 June 2006.
30. Happell B, Pinikahana J, Roper C. 2002, Attitudes of post-graduate nursing students towards consumer participation in mental health services and the role the consumer academic. *International Journal of Mental Health Nursing*, 11(4), pp 240-250.
31. Happell B, Pinikahana J, Roper C. 2003, Changing attitudes: the role of a consumer academic in the education of post-graduate psychiatric nursing students. *Archives of Psychiatric Nursing* 17(2), pp 67-76.
32. Happell B, Roper C. 2002, Promoting consumer participation through the implementation of a consumer academic position. *Nurse Education in Practice* 2(2), pp 73-79.
33. Happell B, Roper C. 2003, The role of a mental health consumer in the education of post-graduate psychiatric nursing students: the students' evaluation. *Journal of Psychiatric and Mental Health Nursing*, 10(3), pp 343-350.
34. Spectrum 2006, The Personality Disorder Service for Victoria. *Spectrum - The Personality Disorder Service for Victoria*.
35. Happell B, Roper C. 2006, Promoting Genuine Consumer Participation in Mental Health Education: A Consumer Academic Role. Accepted for publication in *Australian e-journal for the Advancement of Mental Health*.

