Enabling the consumer role in clinical governance
A guide for health services

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Consumer, carer and community collaboration is a key tenet of effective health care improvement. The Victorian Quality Council (VQC), in its “Better Quality, Better Healthcare: A Safety and Quality Framework for Victorian Health Services” document, nominates consumer collaboration as one of four critical organisational elements necessary for improving the quality of health services, along with Governance and Leadership, Competence and Education and Information Management.

Introduction

Improving the quality of health services through consumer collaboration

Without meaningful consumer collaboration with health services, service improvement cannot be truly consumer focused, and will be biased towards provider concerns. Health care delivery may contain inefficiencies and anachronisms based on unfounded assumptions about consumer expectations and needs. Effective consumer participation is a collaborative process between health care consumers and providers to instigate improvement activities that consider clinical, social, emotional and cultural aspects of care and services.

Clinical governance is about clear accountabilities and roles in healthcare improvement. The Australian Council on Healthcare Standards (ACHS) defines clinical governance as “the system by which the governing body, managers and clinicians share responsibility and are held accountable for patient care, minimising risks to consumers and for continuously monitoring and improving the quality of clinical care.” This paper explores both consumer and healthcare organisational roles in achieving consumer collaboration in safety and quality improvement.
Purpose of the paper
This paper expands on the information outlined in the VQC Safety and Quality Framework, “Better Quality, Better Healthcare”. Its purpose is to assist health services to better practically define the rationale and methods for collaborating with consumers to improve health service safety and quality. For the purposes of this paper, “consumers” is used as an all-encompassing term that includes carers, volunteers, advocates, representatives, clients, patients or members.

This paper should also be read in conjunction with the VQC document “Finding Consumers and Carers: A Guide to Sourcing Consumers, Carers and Community Members for Collaborative Health Service Improvement”, which not only provides a guide to sourcing consumers appropriate to various improvement activities, but also discusses issues around recruiting, selecting and working with consumers to achieve the best outcome for both parties.

The paper covers:
- Consumer roles in safety and quality
- Planning an approach to consumer participation in safety and quality improvement
- The interface between the governance of consumer participation and the dimensions of quality to be addressed
- Consumer and organisational roles in a collaborative approach
- A checklist for consumer collaboration in safety and quality.

Why support consumer and community involvement in health service quality improvement programs?
Health care consumers, and the community more broadly, have both a right and a responsibility to contribute to the quality of public health care services. Consumers and communities bring a broad range of skill, experiences and perspectives to care and service improvement. Planning and effort are required to make the experience meaningful and useful for both parties, but research does indicate that significant gains in health service quality and individual care can result from the interaction.

Consumer involvement in quality and safety improvement can enhance and guide the organisational QI program by:
- Providing a basis for dialogue between health services and consumers about improving services;
- Improving the safety, effectiveness, appropriateness and acceptability of individual care episodes;
- Providing information to health services about their impact on consumers;
- Identifying priorities, expectations and needs;
- Providing information about short and long term outcomes of health care treatment;
- Developing a culture of consumer and health service partnership;
- Improving information quality and availability and consent processes;
- Engendering consumer and community support for health services;
- Developing an understanding of the social view of health and health of communities.

How can consumer collaboration in improvement activities best be approached?
It is important to first explore and clarify the areas of the organisation in which consumer participation will be most beneficial to both consumers and providers. Consumers have a salient role to play in all aspects of quality improvement, and in some areas consumer involvement is critical to achieving comprehensive improvement, as seen in the examples of consumer roles in Table 1.
Key consumer roles in health service safety and quality improvement

Consumer and Community input into care and services via surveys, focus groups, complaints and conversations with staff

Consumer and Carer collaboration in individual care episodes, including treatment decisions and safe health care practice

Consumer advice on and development of patient information, both clinical and policy-related

Consumers sharing their first-hand experiences of care and services with providers to help improve common understanding and target areas for improvement

Consumer and community consultation on, collaboration in and carriage of planning and improvement committees and activities.

Table 1

Sustainable consumer participation in areas such as these will necessitate the development of structures, policies and protocols that embed these activities at a number of different levels of the organisation, and clear roles and responsibilities for all involved. It is critical that all parties are clear on exactly what is being improved, by whom and how. This is explored in more detail later in this paper.

The importance of training and education

There is a range of research and other guidance material available on strategies for community and consumer participation. This material will not be repeated here, except to stress that virtually any effective community and consumer involvement will require leadership, a planned approach, and education and training for both health services staff and the consumer and community members involved. Such training can help alleviate some of the difficulties that can be found in this collaboration and may include meeting procedures, orientation to hospital structures and health service decision-making processes for the consumers; and communication, consultation and participative decision-making skills for health services staff.

A planned approach

Effective consumer participation requires planning to integrate it into the organisation’s safety and quality improvement activities. Both consumer and provider involvement is required to ensure a realistic and acceptable approach. Boards, senior managers and committees with a consumer focus such as Community Advisory Committees, or other consumer-oriented groups in the health service, should monitor progress with the plan by receiving information on areas such as: demonstrated evidence of consumer involvement in feedback about service delivery; changes as a result of complaints and feedback; numbers of consumers involved in strategic and service improvement; and updated treatment, safety or service information and processes as a result of individual or collective consumer involvement.

There are some consistent themes from the literature on effective consumer and health service collaboration that may assist with this planning:

1. **Using various approaches**

Research in this area indicates that:

- Organisations that employ a variety of approaches to consumer collaboration obtain better information about their organisation from those people who use it.
- Different approaches to consumer collaboration work for different groups of consumers, not only the areas in which consumers are invited to be involved, but the level of involvement, ie, the spectrum from consumers passively receiving information through being actively consulted, jointly planning and assuming control of projects.
- Don’t use a ‘one size fits all’ approach - some approaches to consumer collaboration work better at different levels in organisations.
- Some consumer collaboration approaches work better in different clinical areas then others.
- The purpose of consumer collaboration in particular activities will determine what consumer participation approaches are needed.
- Using a variety of approaches to explore a particular problem or issue is likely to provide information that can more readily be acted on by staff.
2. Organisational characteristics
Australian hospitals undertaking consumer participation activities have reported that effective consumer participation requires:
- Board and senior management support for direct dialogue and partnership between consumers and health professionals
- Acknowledgement that consumers have an important role to play in their organisation
- A planned and monitored approach within an organisation plan
- Collaboration of staff across the organisation
- A range of ways to involve and obtain feedback from consumers
- Acknowledgement of anxieties around consumer participation for both parties and the development of a process that promotes trust
- Specific skills, resources and training for consumer participation in health services for both health care consumers and providers.

3. Providing the right environment
Information and communication
- A planned approach to the collaboration, with all parties involved clearly briefed on roles and rationale;
- Allowing sufficient time for recruitment and orientation prior to the commencement of a project as this process can take some time;
- Providing a single point of contact within the health service where consumers to seek information, advice and support about a project they are involved in;
- Organising for consumers involved in committee meetings to have a “buddy” – another consumer on the committee and/or a health services member who can assist with unfamiliar processes or jargon;
- Ensuring consumers are provided with all relevant information about the project or activity in which they are involved including any constraints or limitations.

Assistance required for consumers and carers to participate in improvement
A consumer/community member may have some requirements to ensure effective participation. For example, if the health service is running a focus group, the consumer may require their travel to be organised and/or paid for, and remuneration for attendance. If they are attending a meeting they may require attendant care, time for reading materials, materials produced in a suitable format and payment for time at meetings and preparation time. There also may be specific cultural requirements. It is important that both parties are clear about their respective requirements and responsibilities to ensure the best chance of a successful collaboration.

Consumer or carers presenting on their episode of care has been shown to be a powerful approach to directing quality improvement. This must be carefully handled, however. To ensure a useful experience for everyone involved, it is important that speakers are fully briefed on the purpose of the event, the audience, and the logistical details such as location, timing, how to get there, who will meet them etc.

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

Ideally speakers should have a nominated contact that can manage the process. Even experienced speakers may be nervous so it is important to ensure that they are comfortable with the equipment and software setup and know how to operate it or have someone to help them. It is preferable that speakers can see the venue and check presentations well before they are required to present so that any problems can be addressed. Preparing and giving presentations takes considerable time and effort and it helps to know your efforts are appreciated. An experienced chairperson who is knowledgeable in the area under discussion and has been briefed on the purpose of the forum or session should chair the session with a view to a constructive outcome for all involved.
An approach to integrating consumer collaboration into health service safety and quality improvement

This paper, as supplementary information to the VQC Safety and Quality Framework, describes a set of activities to assist health services collaborate with consumers to improve care and services. It focuses on the intersection of two key areas:

(i) the governance required to promulgate and embed consumer participation in health services, including clarification of roles and responsibilities of Board, management, clinicians and consumers and the intersection of these roles with health service structures and processes;

(ii) clarity around what is being improved, that is, the dimensions of quality that are being improved.

These two areas are described in more detail below.

i. Overview of governance roles in the organisation – who needs to be involved and how?

The Board role
The Board has ultimate responsibility for the clinical governance of a health service, and attention to this must be as rigorous as that given to other corporate Board responsibilities. Promulgation of, and ongoing support for, collaboration with consumers to improve the safety and quality of care is a key Board responsibility and they must ensure that this is implemented and reported on by Board Committees, the CEO and senior executives.

The Quality and Consumer Advisory Committee role
These Committees promote and support consumer involvement in safety and quality improvement by working together to plan, monitor and evaluate a collaborative consumer/provider approach on behalf of the Board. High-level committees such as Quality and Community Advisory Committees can promulgate consumer collaboration by:

- Clarifying the organisation’s priorities for consumer involvement
- Working with the Board and senior management to create and support a culture and environment wherein consumer participation is the norm
- Contributing to policies and protocols that embed consumer participation in the organisation
- Developing processes for involving consumers and the community in different ways in different parts of the organisation
- Assisting with the development of strategies to enable effective consumer and community participation, eg, setting clear expectations, sourcing appropriate consumer groups, developing education, presentation of information
- Facilitating consumer input into relevant policy and its implementation, for example, open disclosure.

CEO and Senior Clinician and Management role
The CEO and managers are central to operationalising clinical governance, and therefore put in place plans, protocols and procedures that embed consumer collaboration in the day-to-day work of the organisation. They also provide education and information for both providers and consumers to ensure that the collaborative processes are clear to all parties.

Healthcare Team roles
Whilst the Board, CEO and managers provide the principles, systems and resources for collaboration with consumers to improve safety and quality, it is the staff delivering services who implement and monitor these systems day to day. It is unlikely that full consumer and carer participation in their own care will can be realised until it becomes part of the routine of the clinical setting. This will require role development, supported by relevant training and senior management support.
ii. Being clear about what needs to be improved - Dimensions of quality

Dimensions of quality in health care are variously described in the literature via a number of different elements and definitions. Consumers have a salient role to play in improving each area, however described. The VQC Safety and Quality Framework, describes the dimensions of quality as follows:

**Safety** of health care: A major objective of any health care system should be the safe progress of consumers through all parts of the system. Harm arising from care, by omission or commission, as well as from the environment in which it is carried out, must be avoided and risk minimised in care delivery processes. Consumers have a salient role to play in taking responsibility for the safety of their own care, i.e., speaking up if they are offered an incorrect drug or procedure. Consumers relating their health service experience stories to providers can identify ways in which care can be made safer. Consumers can also participate in planned approaches to safety improvement, and policies that contribute to safety, such as open disclosure. Education and information for both consumers and providers is needed to develop a culture where this is acceptable and welcomed by staff as an important contributor to safety.

**Effectiveness** of health care: Consumers of health services should be able to expect that the treatment they receive will produce measurable benefit. The effectiveness of health care relates to the extent to which a treatment, intervention or service achieves the desired outcome. Consumers have a responsibility to assist health service providers to give their treatment the best chance of being effective by seeking and following information about their own care, and can help make this easier for other consumers by participation in information development and communication improvement.

**Appropriateness** of care: Essentially, the appropriateness of health care is about using evidence to do the right thing to the right patient, at the right time, avoiding over and under utilisation. It is essential that the interventions that are performed for the treatment of a particular condition are selected based on the likelihood that the intervention will produce the desired outcome, and that inappropriate care is avoided. Consumers can play a key role in advising providers on the appropriateness of treatment options being offered, both as individuals and as part of projects developed to improve appropriateness of different care and treatments.

**Acceptability** of care: Consumer and community participation should enhance the level of acceptability of services, which describes the degree to which a service meets or exceeds the expectations of informed consumers. Opportunities must be provided for health consumers to participate collaboratively with health organisations and service providers, individually and collectively, in health service planning, delivery, monitoring and evaluation at all levels.

**Access** to services: Health Services should offer equitable access to health services for the population they serve on the basis of need, irrespective of geography, socio-economic group, ethnicity, age or sex. This includes availability of services, waiting times for services and processes involved in accessing services, physical and information access. The issue of access to all health services is critical and one that consumers are well placed to advise on.

**Efficiency** of service provision: Health services must ensure that resources are utilised to achieve value for money. This can be achieved by focusing on minimising the cost combination of resource inputs in the production of a particular service as well as the allocation of resources to those services to provide the greatest benefit to consumers. Consumer advice and feedback is an important part of these decisions.

Some practical examples of enacting the intersection between the governance of consumer involvement in improving quality and safety, and the dimensions of quality that are being improved, are described in Appendix A. This list is not exhaustive by any means, and is there to prompt ideas.

A checklist to review organisational progress with structures and processes for consumer involvement is at Appendix B.

Research suggests that a predictor of strategies for improving quality being effective is the extent to which they are adapted to the individual organisation, so it is critical that health services consider these ideas in the context of their own facility. Consumer and community involvement and collaboration are vital to achieving significant and sustainable improvement in care and services, and achieving this will depend on the extent to which health services integrate this into the way they do business every day.
Appendix A

Examples of consumer and provider roles and responsibilities required to enable consumer involvement in improving each dimension of quality

1
Consumer and community involvement in SAFETY

- Health care leaders create and support a culture wherein consumer input in individual care and overall safety improvement is expected, supported by organisational policy and procedure, and respected.
- Boards create a culture where open disclosure, reporting and learning from errors and adverse events and clear accountability for and participation in safety improvement are embedded and rewarded.
- Boards and Executives encourage care and service delivery that is patient-focused, and provide an environment where consumers and the community participate equally with health services in safety improvement. Board committees have a salient role to play in this area.
- Consumers avail themselves of opportunities to participate in the monitoring and improvement of health care safety, both on an organisational and personal level.
- Individual consumers inform themselves of the risks of their care and treatment choices by reviewing available information.
- Consumers are informed of adverse events, errors and problems relating to their care and participate in review and corrective action.
- Consumers work with clinicians to improve safety by asking appropriate questions about and participating in, the care and treatment they are receiving.
- Consumers contribute to the development of consumer information about clinical safety issues such as risks and side effects, and policy issues such as open disclosure.
- Consumers take the opportunity to make complaints when dissatisfied, and provide feedback about the safety of care, treatment and services.

Consumer and community involvement in EFFECTIVENESS

- Boards and Executives are responsible for creating a culture that respects and encourages patient participation in, and contribution to, the effectiveness of the care and services provided, including provision of an environment where there are opportunities for patient input and feedback.
- Consumers have a key role to play in the effectiveness of care and services provided. This requires collaboration between consumers and clinicians on at least three levels: in direct care and associated communication; in patient information development; and between the health service and the community in planning, developing and implementing service and care improvement.
- Consumers should be involved in developing meaningful information on which to base decisions about their health and to inform participation in their care.
- Consumers and clinicians collaborating on individual care episodes should agree on a course of treatment, with both parties fulfilling their obligations to ensure the greatest chance of effectiveness.
- Processes for complaints and feedback about care and service effectiveness should be clear, user-friendly and accessible. Such feedback should be responded to in a timely fashion and incorporated into service and case review.
### Consumer and community involvement in Appropriateness

- Care that is tailored to each patient is key to appropriate treatment. This requires patients to participate in their care by providing all information relevant to treatment decisions. The patient must be provided with the means to do so, such as access to interpreters and clinical staff.
- Patients should be given the opportunity to increase the appropriateness of their care by participating in the planning and delivery of their care. This will require policies and protocols to be implemented to embed this in the routine of wards, theatres and other departments.
- Patients should be informed when inappropriate care is given.
- Consumers and community may be involved in appropriateness by assisting in information development for review of disease-specific care and services.

### Consumer and community involvement in Acceptability

- Acceptability is key to patient-centred care. Boards and Executives should develop a clear vision of what this means for the health service, in conjunction with clinical and non-clinical staff, and consumers, and put in place structures and processes for achieving this.
- These may include seeking information from Community Advisory Committees and/or other community and consumer groups regarding acceptability issues; for example, reviewing complaints and satisfaction feedback to identify problems and working with consumers to develop new processes for improving acceptability.
- Mechanisms should also be put in place for the collection and application of real-time individual consumer feedback.
- Boards and Executives should regularly review and reward practitioners and teams demonstrating high levels of acceptability in their care, and provide education and support to assist all staff to address acceptability in their day-to-day activities.
- Acceptability can form a key part of health service staff performance review and can include feedback from patients and peers.
- The Community Advisory Committee, or other consumer focused committee or group may be empowered to take the lead on acceptability of care with Board and Executive Support.
- The community in general and consumers in particular make a salient contribution to acceptability of care.
- Community participation can provide assistance to Boards, Executives and staff in health service planning, delivery, monitoring and evaluation at all levels.
- Individual consumers can provide real-time feedback about acceptability of care and services, and there will need to be a process in place whereby such information is sought, noted and fed into a review mechanism.
- Consumers should be aware of a clear, accessible complaints process that enables them to make a complaint at any time without fear, favour or prejudice. Complaints should be viewed as a valuable source of safety and quality information.
- Health service CEOs must ensure that complaints are dealt with according to a planned process, developed in conjunction with consumers. This process should be made clear to the complainant, and include investigation, resolution and follow-up of the complaint in collaboration with the complainant as equal partners in the process.
| Consumer and community involvement in ACCESS | Consumers on a personal level and the Community on a population level can offer valuable input to issues of access.  
Individual consumers can comment on their own experience of access to the service whether it be financial, geographic, physical or processes-related such as admissions, discharge and waiting time.  
Consumers can help improve and streamline access by availing themselves of relevant information regarding these processes and following instructions for arrival times, making appointments, booking interpreters and discharge procedures.  
The Community can participate in strategic decisions affecting access, such as resource allocation, reviews of physical access and service planning and process review to streamline access.  
Consumers and the Community can also inform access to information including: public information about the safety and quality of health services; appropriate use of emergency services; clinical treatment choices and options; interpreter issues; risk areas and general information about health service processes to assist consumers and staff to work together for efficient and effective care. |
| --- | --- |
| Consumer and community involvement in EFFICIENCY | Consumers and community members may participate in efficiency-related decisions regarding planning new services or reviewing existing services.  
It is important that both communities and health services are well informed to make these decisions and that discussions follow a clear and transparent process.  
Effective decision making in this complex area will depend on both the consumers and health service staff involved participating in an informed and collaborative manner. Both parties should be experienced in consumer participation at this level. |
Appendix B

Checklist for assessing health service structures and processes to facilitate collaboration with consumers in safety and quality improvement\(^1\)
APPENDIX B

<table>
<thead>
<tr>
<th>Element</th>
<th>Processes established and working effectively</th>
<th>Processes in place but need enhancement</th>
<th>Processes under development</th>
<th>No processes in place for this element</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. consumer and community participation in improving safety and quality is an accepted part of the organisation's culture and functioning</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>b. consumer and community feedback is regularly sought via a number of different channels and is integrated into improvement activities</td>
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<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>c. complaints are managed respectfully and effectively and the information fed into systems improvements</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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</tr>
<tr>
<td>d. protocols are in place on the ward and in all clinical departments to enable consumers to fully participate in their care, including flagging safety issues</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>e. consumers are made aware of the processes for participating in their care</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>f. sufficient information and opportunity are provided for consumers to participate meaningfully in their care</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>g. health service staff are aware of, and trained in, protocols and procedures for enabling consumer participation in their care, including effective communication techniques and processes such as open disclosure</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>h. consumers and community members are involved in consumer information development, both clinical and policy-related</td>
<td>☐</td>
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<td>☐</td>
</tr>
<tr>
<td>i. consumers are invited to relate their health service experiences as part of the safety and quality improvement program</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>j. consumers and community members are consulted to review and improve current services and plan new ones: formally, via membership of committees and groups dedicated to these activities, and less formally via other feedback mechanisms.</td>
<td>☐</td>
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</table>
References


Written by Dr Cathy Balding on behalf of the VQC Clinical Governance Working Group.