



Consumer knowledge, skills and experience (for organisations)



Partner:

Consumers are considered equal partners with essential knowledge for health reform, research and policy development and system change.

| Participation | What experience do I need? | Some tips and key questions |
|---|---|--|
| <p>Possible areas of involvement:</p> <ul style="list-style-type: none"> health reform research policy development system change <p>Types of participation:</p> <ul style="list-style-type: none"> Committees (e.g. safety and quality, research team; ethics committee) Working groups Boards Project teams or groups | <ul style="list-style-type: none"> Network with specific groups, individuals and/or cultural organisations to understand consumer issues and viewpoints Ability to evaluate issues from a consumer perspective and make relevant recommendations Understand policies, procedures and other documents relevant to the work that is undertaken Review, appraise and evaluate relevant documents Influence decision-making to support the needs of the consumers Task manage to set goals and prioritise | <p>It's important that consumers are informed up-front what the time and work commitment will be.</p> <ul style="list-style-type: none"> Will consumers be required to attend meetings on a regular basis, how often and at what time of day? Does this suit their work and/or personal life? Is it possible to attend via teleconference? <p>As a Partner, a high level of expertise in consumer and committee participation and knowledge of the health and cancer sector and experience in policy development and organisational governance are desirable.</p> <p>Consumer's prior experience is crucial in this role not only as an effective consumer but as an equal partner.</p> <p>TIP: If consumers wish to brush up on these areas, consumer training generally covers these topics.</p> |



Examples of consumer involvement



Expert:

Consumers participate on organisational boards or in high-level advisory committees or major projects and are invited for their high-level expertise as a consumer.

| Participation | What do I need to be involved? | Some tips and key questions |
|---|---|--|
| <p>Types of participation:</p> <ul style="list-style-type: none"> • Committees (e.g. safety and quality, research team; ethics committee) • Working groups • Boards • Project teams or groups | <ul style="list-style-type: none"> • Network with specific groups, individuals and/or cultural organisations to understand consumer issues and viewpoints • Ability to evaluate issues and new ideas from diverse consumer perspectives and make relevant recommendations • Use links and networks to consult with relevant consumer organisations • Understand the concept of 'consumers' interests' as much broader than relying on one's individual experiences as a consumer • Have an appreciation of the context of the issue/s being addressed, such as funding allocation, staffing, who makes decisions, etc. • Use expertise to provide options rather than single solutions • Contribute to policy decisions and recommendations if called upon. Also understands that consumers are not the final decision maker • Review, appraise and evaluate relevant documents | <p>It's important that consumers are informed up-front what the time and work commitment will be.</p> <ul style="list-style-type: none"> • Will consumers be required to attend meetings on a regular basis, how often and at what time of day? • Does this suit their work and/or personal life? • Is it possible to attend via teleconference? <p>Consumer's expertise centres on bringing the consumer perspective on the issues.</p> <p>In areas where a more technical or medical background is required, you can support consumers by providing them with the relevant information, offering them training or mentoring them.</p> <p>TIP: Some consumer training courses cover the scientific and medical aspects of different cancer streams. Also consumer organisation might provide useful forums and fact sheets to keep consumers up-to-date, informed and relevant. See links for more information.</p> |



Examples of consumer involvement

Advisor:

Consumers participate in government policy or cancer services to provide advice and to influence final decision.

| Participation | What do I need to be involved? | Some tips and key questions |
|---|---|--|
| <p>Types of participation:</p> <ul style="list-style-type: none"> • Committees (e.g. safety and quality, research team; ethics committee) • Working groups • Project teams or groups | <ul style="list-style-type: none"> • Be able to analyse and evaluate information to determine its effect on consumers • Use their experience and the experience of other consumers to provide an consumer perspective on issues • Identify the main issues for service improvements • Imagine the consequences of decisions, in the short- and long-term • Canvass what consumers see as important • Keep up-to-date with current issues affecting stakeholder groups • Review, appraise and evaluate relevant documents | <p>It's important that consumers are informed up-front what the time and work commitment will be.</p> <ul style="list-style-type: none"> • Will consumers be required to attend meetings on a regular basis, how often and at what time of day? • Does this suit their work and/or personal life? • Is it possible to attend via teleconference? <p>The knowledge and information consumers need will depend on the task at hand. Have consumers been invited to critically appraise a service that consumers have used? If so, then the consumer's experience and consumer's knowledge of that service are important.</p> <p>In areas where a more technical or medical background is required, you can support consumers by providing them with the relevant information, offering them training or mentoring them. There is also help at hand by contacting the organisations listed in the next column.</p> |



Examples of consumer involvement

Advocate:

Consumers represent the broad views and experiences of a range of people affected by cancer.

| Participation | What do I need to be involved? | Some tips and key questions |
|--|--|--|
| <p>Types of participation:</p> <ul style="list-style-type: none"> • Committees (e.g. discharge committee, research team; ethics committee) • Working groups • Project teams or groups | <ul style="list-style-type: none"> • Reflect the broad views and experiences of those consumers represent; moving away from personal opinion to a viewpoint that takes into account the diverse experiences and needs of the consumer • Network with specific groups, individuals and cultural organisations • Canvass consumers to ascertain what they see as important • Locate information and identify key issues • Good negotiation and interpersonal skills • Be open to: new ideas, different points of views, all possibilities and be willing to reassess own views • Problem solve or seek help to solve problems • Analyse and evaluate information to assess validity and reliability • Ask and prepare questions for clarification | <p>It's important that consumers are informed up-front what the time and work commitment will be.</p> <ul style="list-style-type: none"> • Will consumers be required to attend meetings on a regular basis, how often and at what time of day? • Does this suit their work and/or personal life? • Is it possible to attend via teleconference? <p>Consumer's knowledge and cancer experience and the needs of cancer patients are important to consumer's role as advocate.</p> <p>It is important that consumers maintain strong links and listen to other consumers and be involved with consumer groups.</p> <p>TIP: If consumers wish to brush up on advocacy and representation, consumer training generally covers these topics. See links for more information.</p> <p>TIP: a great risk for advocates is burnout – help them by suggesting they practise self-care.</p> |



Examples of consumer involvement

Personal engagement:

Consumers actively participate from their personal perspective and provide feedback to services through sharing stories and participating in focus groups and targeted working groups.

| Participation | What do I need to be involved? | Some tips and key questions |
|--|--|--|
| <p>Types of participation:</p> <ul style="list-style-type: none">• Focus group• Feedback on services• Survey• Communicate about own health care needs | <ul style="list-style-type: none">• Reflect on consumer's personal experience to provide constructive feedback that will assist with service improvement• Engage in activities to assist services to recognise what is working well and what needs to be improved from an end user's direct experience• Shows an interest and/or willingness to provide verbal or written feedback• Use information to make informed decisions about consumer's care and treatment• Communicate ideas and a point of view• Commit the time needed to fulfil the consumer task at hand• Ask questions to seek information and be informed | <p>Q. Is prior experience in consumer engagement necessary?</p> <p>A. No. consumer's direct experience forms the basis of involvement at this level.</p> <p>Consumer's story or experience helps to inform the service to make improvements.</p> <p>Use several methods for engagement at this level, such as inviting consumers to tell their stories or write them; invite them to participate in focus groups or fill in surveys.</p> <p>TIP: If consumers wish to become more involved as a consumer representative, suggest them to join consumer groups or organisations listed in the next column.</p> |

