



Consumer knowledge, skills and experience (for consumers)



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 <p>As an equal partner:</p> <ul style="list-style-type: none"> Contribute to the design, planning and implementation in the activity that has been undertaken Work effectively and cohesively as an equal partner to provide expertise and guidance 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>Q. Do I have the time needed to contribute effectively to this activity?</p> <p>A. It's important that you are informed up-front what the time and work commitment will be.</p> <ul style="list-style-type: none"> Will you be required to attend meetings on a regular basis, how often and at what time of day? Does this suit your work and/or personal life? Is it possible to attend via teleconference? <p>When you weigh this up make a list of questions to ask the project partner.</p> <p>Q. What do I need to know? Do I have enough knowledge about the area I've undertaken? What other information do I need?</p> <p>A. As a Partner, a high level of expertise in consumer and committee participation and knowledge of the health and cancer sector as well as experience in policy development and organisational governance are desirable. Your prior experience is crucial in this role not only as an effective consumer but as an equal partner.</p> <p>TIP: If you wish to brush up on these areas, consumer training generally covers these topics. See links in next column.</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 you are not the final decision maker • Review, appraise and evaluate relevant documents 	<p>Q. Do I have the time needed to contribute effectively to this activity?</p> <p>A. It's important that you are informed upfront what the time and work commitment will be.</p> <ul style="list-style-type: none"> • Will you be required to attend meetings on a regular basis, how often and at what time of day? • Does this suit your work and/or personal life? • Is it possible to attend via teleconference? <p>When you weigh this up make a list of questions to ask the project partner.</p> <p>Q. What if I don't understand the technical aspects of the discussion?</p> <p>A. Your expertise centres on bringing the consumer perspective on the issues. Ask for clarification from the relevant person in the group if you are unsure. Chances are that there will be others around the table that are unsure as well.</p> <p>TIP: Some consumer training courses cover the scientific and medical aspects of different cancer streams. Also your consumer organisation might provide useful forums and fact sheets to keep you 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 your experience and the experience of other consumers to provide an consumer perspective on issues • Astutely determine issues and offer resolutions, such as identifying 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>Q. Do I have the time needed to contribute effectively to this activity?</p> <p>A. It's important that you are informed upfront what the time and work commitment will be.</p> <ul style="list-style-type: none"> • Will you be required to attend meetings on a regular basis, how often and at what time of day? • Does this suit your work and/or personal life? • Is it possible to attend via teleconference? <p>When you weigh this up make a list of questions to ask the project partner.</p> <p>Q. What do I need to know? Do I have enough knowledge about the area I've undertaken? What other information do I need?</p> <p>A. This will depend on the task at hand. Have you been invited to critically appraise a service that you have used? If so, then your experience and your knowledge of that service are important. In areas where a more technical or medical background is required there are links provided to help you extend your knowledge.</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 you 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>Q. Do I have the time needed to contribute effectively to this activity?</p> <p>A. It's important that you are informed upfront what the time and work commitment will be.</p> <ul style="list-style-type: none"> • Will you be required to attend meetings on a regular basis, how often and at what time of day? • Does this suit your work and/or personal life? • Is it possible to attend via teleconference? <p>When you weigh this up make a list of questions to ask the project partner.</p> <p>Q. What do I need to know? Do I have enough knowledge about the area I've undertaken? What other information do I need?</p> <p>A. Your knowledge and cancer experience and the needs of cancer patients are important to your role as advocate. It is important to maintain strong links and listen to other consumers and be involved with consumer groups.</p> <p>TIP: If you wish to brush up on advocacy and representation, consumer training generally covers these topics. See links for more information.</p> <p>TIP: Avoid burnout, 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 your 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 your care and treatment • Communicate ideas and a point of view • Commit the time needed to fulfil the consumer task at hand • Ask questions and actively seek to be better informed 	<p>Q. Is prior experience in consumer engagement necessary?</p> <p>A. No. Your direct experience forms the basis of involvement at this level. Your story or experience helps to inform the service to make improvements.</p> <p>Q. My written and/or spoken English is not very good can I still be involved?</p> <p>A. Yes. It is important to hear from a diverse range of people to make sure that their needs are reflected in service delivery.</p> <p>Q. Do I have the time needed to contribute effectively to this activity?</p> <p>A. You should be informed upfront the timeframe for the activity. If you are unsure ask for more information.</p> <p>Q. What do I need to know? What other information do I need?</p> <p>A. Your experience is what matters in this instance.</p>

