



Top Ten Tips

Practical information sheets to ensure people with cognitive disabilities have a real and equal Voice at the Table.

Voice at the Table is a project of the
Self Advocacy Resource Unit (SARU),
kindly supported by the Victorian Government



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Summary

Tip 1: Understand Consumer Participation

Consumer participation is when people with disabilities are actively involved in decision-making.

Tip 2: Be Prepared

Embed a culture of equality, respect, shared learning, listening and a commitment to action.

Tip 3: Define the Role

Be clear about the timeline, remuneration and purpose of the consumer representative's role.

Tip 4: Identify and Remove Barriers

Ask what supports are required to ensure everyone is able to have equal input.

Tip 5: Provide Accessible Information

Consider the words and formats you use. Support people to digest and understand.

Tip 6: Offer Hands On Support

Provide access to a mentor or paid one-to-one inclusion support person if required.

Tip 7: Roll Out the Welcome Mat

Ensure that consumer representatives feel welcomed and included from beginning to end.

Tip 8: Help Everyone Understand

Make the discussion accessible. Think about language, speed, and the order of conversation.

Tip 9: Give Everyone a Say

Allow time, invite all view-points and listen to everyone's ideas equally.

Tip 10: Evaluate and Do it Better

Adopt an evaluation tool to suit your organisation. Make sure you keep learning and improving.



Introduction

Voice at The Table is a project that aims to increase the number of people with cognitive disabilities (intellectual disabilities or acquired brain injury) sitting on boards, committees and advisory groups within government, service providers, community and mainstream organisations at a local, state and national level.

We offer:

- Consumer representative training for people with cognitive disabilities.
- Consumer representation and participation resources for use by service providers, governments, community and mainstream organisations.
- Inclusion and support training for staff.

SARU and *Voice at the Table* project workers can help you take the first simple steps.



Phone: 03 9639 6856



www.voiceatthetable.com.au

A comprehensive VATT Consumer Participation Kit, training and other resources are available from www.voiceatthetable.com.au.



About the Top Tips Sheets

These *Top Ten Tips* sheets provide practical tips, ideas, resources, information and web links about supporting people with cognitive disabilities to have an equal ***Voice at The Table*** within your organisation.

Amanda's Tips



Hi, I am Amanda Millear.

I am a member of the *Reinforce Self Advocacy Group*.

Reinforce is the longest running self advocacy group in Australia and it is run by people with an intellectual disability for people with an intellectual disability.

Look out for my top tips for making sure you run good meetings that include people with an intellectual disability.



You'll also find tips called **"What Brain Injury Matters Wants You to Know!"**

This information was provided by Peta Ferguson and Francesca Lee, President of Brain Injury Matters, a Self Advocacy Group by and for people with an acquired brain injury.



To hear the voice of self advocates, look out for other quotes in these blue squares.

"If they don't listen to us – then they are not going to learn what is important to us."

*Susan Arthur,
Member of Positive Powerful Parents
Self Advocacy Group*

The Voice Least Heard

The voice of people with cognitive disabilities is often the least heard. This means, more often than not, within government, services, community and mainstream organisations decisions are made **about** people with cognitive disabilities **without** people with cognitive disabilities.

Consumer participation occurs when people with disabilities are actively involved in decision-making and participate in developing, designing, implementing and evaluating policies, programs and services which impact on their lives.

Ensure people with cognitive disabilities are actively involved in all levels of decision making:

- Boards and management committees.
- Organisational and administrative activities e.g. reporting, staff recruitment.
- Policy development.
- Project development, implementation, management and evaluation.
- Resource development, training and community awareness raising activities.
- Consultations, surveys and advisory group membership.



Why Consumer Participation Matters

Civic Participation is a human right enshrined in legislation including the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

Consumers are expert in what they need and have a wealth of knowledge on how services can best be provided. Consumer participation:

- Recognises and values the lived experience and expertise of people with a disability and ensures their involvement in all levels of decision-making.
- Ensures services and policies are designed and delivered in response to the views and needs of those who use them.
- Provides first-hand feedback about the impact and outcomes of services and policies.
- Improves the quality of services, projects and programs.
- Keeps organisations informed about emerging issues, barriers and concerns.
- Exposes organisations to fresh ideas and different ways of doing things.
- Leads to new knowledge and skills development for all involved.

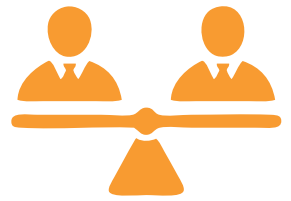
Health Issues Centre has developed resources about consumer participation and engagement.

Visit: www.healthissuescentre.org.au/health-services/consumer-engagementguide



"I would love to see a person with a disability working alongside every single politician. I just think it would be a better world".

*Colin Hiscoe,
Reinforce Self Advocacy Group*



Making Consumer Participation Work

Committing to consumer participation that involves people with cognitive disabilities requires a shift in attitudes and the way things are traditionally done.

For consumer participation to work it is important that your organisation works to actively adopt and promote a culture which ensures:

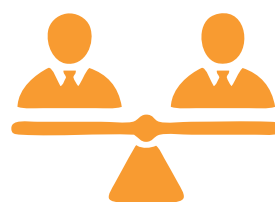
- **Equality** - all are seen and treated as equals.
- **Respect** - people are respected and valued for their contribution, and adults are treated as adults.
- **Listening** - all opinions are actively sought, listened to and considered.
- **Shared Learning** - consumer representatives and the organisation have the opportunity to learn from each other's knowledge and experience.
- **Communication** - communication between the organisation and the representatives happens in a way that builds knowledge, understanding and mutual respect.
- **Action** - participation is meaningful and influences change.

What Brain Injury Matters Wants You to Know!

"Some brain injuries impact on speech it can be all areas of speech such as speed and tone. I can't emphasise anything I don't have any modulation. Because of this people make presumptions about you before getting to know you.

ABI is called the invisible disability because sometimes people assume if you can walk and talk you are O.K.

It is important to make sure all participants on a committee are aware of ABI and its components. Prior to the meeting have the person run a session about ABI."



Consumer Participation Checklist

<input checked="" type="checkbox"/>	<h3>Checklist</h3>
	Develop a Mission or Vision Statement outlining what your organisation wants to achieve.
	Embed an inclusive culture and commit to change.
	Identify why, where, when and how you will engage consumer representatives with cognitive disabilities within your organisation.
	Write or adapt policies and procedures as required.
	Get your Chair on board. A good chairperson or facilitator is critical to running accessible and fully inclusive meetings. Ensure they support the value of consumer participation and are committed to developing a group or committee with an inclusive culture and practices.
	Provide inclusion training for staff and committee members.
	Define the role. Tip 3. Develop a clear outline of consumer representatives' roles and expectations.
	Decide how you will reimburse expenses and provide sitting fees.
	Create a checklist or script before you contact everyone.
	Ensure everyone understands organisation policies, e.g. grievance procedures, confidentiality. Tip 4. Identify and remove barriers to participation.
	Tip 5. Provide accessible information. Provide welcome information, resources and training to help consumer representatives prepare.
	Tip 10. Develop an accessible evaluation process.
	Get consent if you want to take photos or videos.



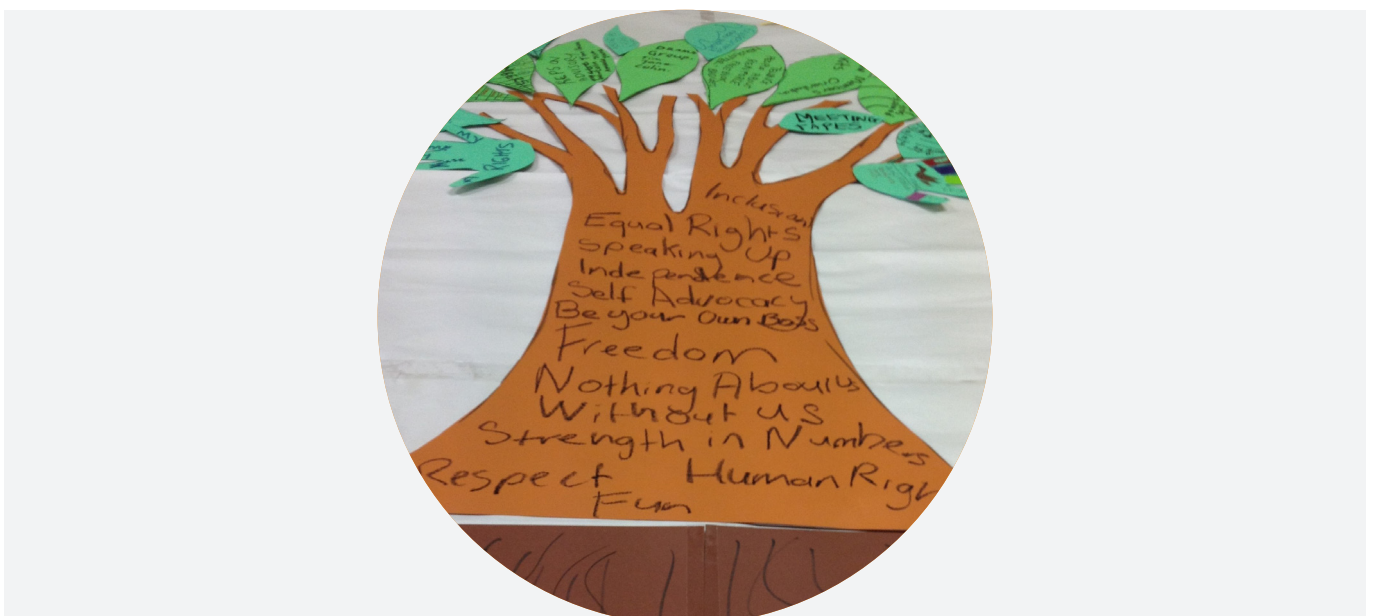
Consumer Representatives

A consumer representative is a person who voices the consumer perspective and takes part in the decision-making process on behalf of consumers.

Consumer representatives are usually appointed as a representative of a consumer organisation or as an individual who can provide a perspective based on their personal experiences and knowledge.

It is important that both the organisation and the person with a cognitive disability have an understanding of the roles of the consumer representative. These might include:

- Presenting the consumer perspective (how consumers think and feel).
- Contributing consumer experiences.
- Ensuring consumer concerns are recognised and addressed.
- Providing feedback to the committee on issues affecting consumers.
- Ensuring accountability to consumers, and reporting committee activities to consumers (if appropriate).





Consumer Representatives continued

It's also a good idea to ensure the consumer advocate understands:

- The time commitment, dates and tenure.
- How you will reimburse expenses and pay sitting fees.
- Relevant organisation policies, e.g. grievance procedures, confidentiality, etc.
- Responsibilities of the organisation, Chair and other committee members.



Amanda's Tips

Have a Code of Conduct that tells you the do's and don'ts.

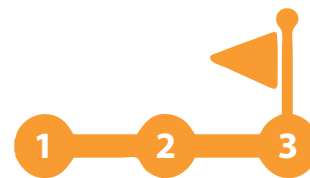
"I don't really know what my role is [on the disability advisory council] all I know is they put me, they say I am representing [a state] but I don't know it myself. I haven't really got roles. That's where I don't know and I don't really know who to report back to. Nobody bothered to tell me what my role was."

Participation in Government Disability Advisory Bodies in Australia: An Intellectual Disability Perspective. ~ Patsie Frawley



Identify & Remove Barriers

Tip Sheet 4



The First Steps

One of the first steps is to ask people about their access requirements.

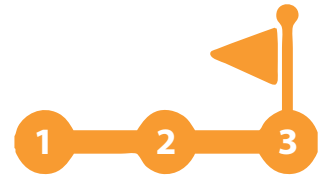
Many disabilities are invisible.

Find out from each consumer representative the accommodations and supports they require to ensure they are able to have equal input within the organisation.

Barriers to people with cognitive disabilities having a **voice at the table** can include:

1. **Information** - Information not available in accessible formats. See [Tip 5](#).
2. **Communications** - Limited access to the internet and email, difficulty speaking on the phone, difficulty reading and writing. Find out from the consumer representative how they prefer to be contacted.
3. **Social** - Organisational and/or staff attitudes and perceptions. See [Tip 2](#).
4. **Social** - Being the only consumer representative on a panel can be intimidating. Lack of confidence or unfamiliarity with the social environment can create barriers, even knowing what to wear. Wherever possible ensure there are at least two consumer representatives.
5. **Access** - Inaccessible meeting practices, including inaccessible language, e.g. jargon and acronyms - See [Tip 8](#)
6. **Access** - Support needs not addressed - See [Tip 6](#)





The First Steps

7. **Psychological** - Consumer representatives might have a history or experience that has led to trauma, a distrust of professionals or scepticism about the consumer participation process. An awareness and understanding of this can help you consider how to facilitate discussion.
8. **Economic** - There are often hidden costs associated with participation and these can create a barrier. For example, the cost of transport, food, technology, printing, phone credit or stationery. Also, some types of income can create difficulties for someone on a disability pension.
9. **Physical** - Often people with cognitive disability also have physical disabilities.
10. **Environmental** - Some people are sensitive to sound or light. Give thought to the meeting room and the seating arrangement.

What Brain Injury Matters Wants You to Know!

"Acquired Brain Injury (ABI) can be so many different things and have so many effects including physical impact . . . the need for walking sticks and wheelchairs to the unseen effects such as tiredness, memory, noise sensitivity and light sensitivity."

"One of the effects is tiredness . . . it is of paramount importance to some people with ABI to have meetings in the morning and regular breaks."



Find out each consumer representative's preferred way to access information.

Providing this information well before the meeting, to allow time for consumer representatives to digest and understand is also important.

Documents you may need to provide in accessible formats are agendas, minutes, reports and powerpoint presentations.

Some common format requests include:

- Easy English information with pictures for people who may have difficulty reading or understanding complex written information.
- Audio versions of Easy English information for people who may have difficulty reading. You could use your smart phone recorder and burn audio to CD.
- DVD versions of Easy English information, a video of a person reading aloud the Easy English information. You could use your smart phone video and burn video to DVD.
- Plain English information is different to Easy English. Plain English is a way of writing that is simple and clear. Many people prefer plain English information.
- Audio versions of the original documents for people who have difficulty reading.





Amanda's Tips ⓘ

- Send out all the information before the meeting and have someone sit with us and go through the agenda and the minutes.
- Easy English from the word go.
- Have an agenda in Big Print.

For detailed guidelines about producing easy read information in written, audio and DVD formats, visit www.voiceatthetable.com.au

More resources can be found at Scope: www.scopeaust.org.au/service/accessible-information/

"The minutes are not really that accessible to understand. No they are really complicated I think I have raised this once with them I think I said the minutes should be in Plain English and that. They said they would try. Well it would be better, then I can understand what I am reading."

Participation in Government Disability Advisory Bodies in Australia: An Intellectual Disability Perspective. ~ Patsie Frawley



Inclusion Support Person

People with an intellectual disability or acquired brain injury will often request access to a paid one-to-one support person of their choosing.

The inclusion support person is employed to work alongside the consumer representative. This can be an access need equivalent to an interpreter.

It is important that the consumer representative either selects their own inclusion support person or has the power to approve of a support worker. Support provided may include:

- Note-taking and information provision.
- Personal/emotional/moral support.
- Providing explanations and advice in meetings as requested.
- Strategic advice when requested.

The inclusion support person's role can be quite complex as it involves providing information, advice and support without unduly influencing the person.

In order to avoid potential conflicts of interest it is important that the support worker is not a member of the organisation undertaking the meetings or consultations.



Offer Hands On Support

Tip Sheet 6



Mentoring

Some government departments, boards and committees may opt to use mentors. A mentor is typically a veteran board member whose role is to assist a new member to understand their role as a board member.

Mentoring involves sharing and learning from each other. It helps new members of the board to have access to the knowledge, skills and supports they need to be effective participants. It also provides the mentor with access to the skills, experience and knowledge of people with disabilities.

Amanda's Tips

Give me a support person if I want one.

For more information about the roles and expectations of support workers visit:
www.voiceatthetable.com.au

Green Mountain Self-Advocates have also made a useful resource 'Get on Board and Make a Difference':
www.gmsavt.org/wp-content/uploads/2010/12/get_on_board_and_make_a_difference_v.2.pdf



"She writes down notes, we make a time later on and we go over what has been said. I think it [having a support worker] encourages you to have a say."

Participation in Government Disability Advisory Bodies in Australia: An Intellectual Disability Perspective. ~ Patsie Frawley



Ensure new representatives feel welcomed and included from beginning to end.

Before the meeting

The Chair or Facilitator should make contact with the new consumer representative.

- Introduce yourself and explain it is the Chair's job to make sure everyone is included.
- Let the consumer representative know it is okay to ask questions during the meeting.
- Provide information about who else will be at the meeting.
- Encourage the consumer representative to come and speak to you in the break if they have any issues or concerns they do not want to talk about in the meeting.

At the meeting

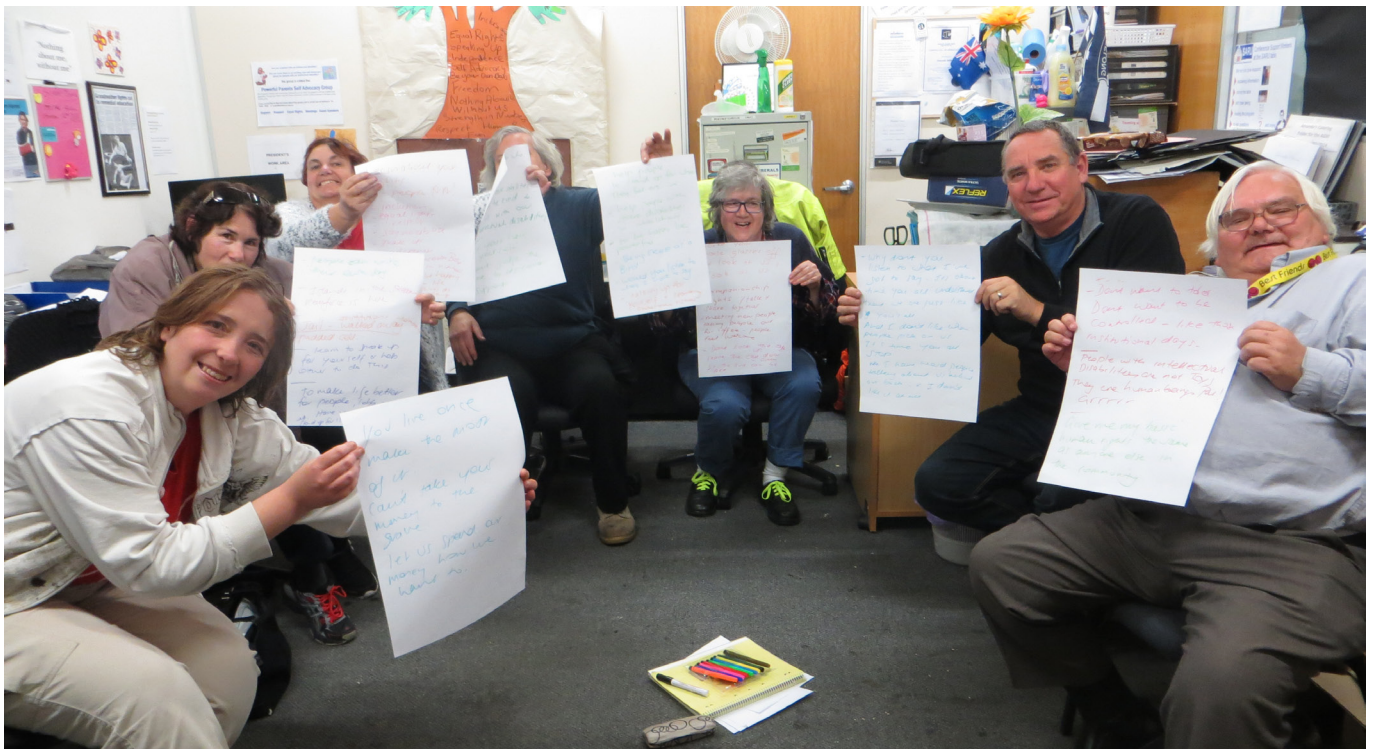
- Make sure there is someone to welcome the consumer representative when they arrive.
- Start the meeting with introductions and encourage everyone to explain why they are involved.
- Allow time for the new representatives to say a little bit about themselves, including passions, issues, why they are there and whom they represent.





After the meeting

- Say thank you.
- Ask the consumer representative how they felt the meeting went, including:
 - positive and negative feedback
 - problems which need addressing
 - whether they felt included
 - whether they got to have their say
 - whether they were listened to, and
 - whether their opinions were respected.
- Complete the feedback loop. Let the consumer representative know how their input has had an impact, and when their ideas haven't been progressed explain why not.





Help Everyone Understand

Tip Sheet 8

To make meetings user friendly the Chair and other committee members can:

- Allow time. Build it into your agenda and decide which items can be postponed if you run out of time.
- Make eye contact with the representatives.
- Ask one question at a time.
- Use straightforward language, words that everyone understands and minimise the use of jargon and acronyms.
- When it is necessary to use jargon, provide definitions, or use a glossary or 'word bank' on the whiteboard.
- Encourage everyone to speak up and ask for an explanation if they don't understand.
- Take short, frequent breaks throughout the meeting.
- Make sure the agenda is in Easy English and is clear, concise and easy to follow.
- At the start of each new agenda item, the chair should explain the topic to be discussed.
- Once an agenda item discussion is completed summarise the discussion and any decisions made.
- Ask each committee member personally if they have anything more they would like to say about each item. This enables people who may not have the confidence to speak up in the general discussion and have their say on each topic.
- If there is going to be a vote make sure everyone understands what the vote is about.
- Read out aloud any written material presented in the meeting that was not sent out beforehand.
- Avoid jumping from item to item or drifting off the topic as this can be confusing for everyone.
- Slow down, make sure the meeting is not going too fast.
- Ensure only one person speaks at a time and people do not talk over each other.



Amanda's Tips ⓘ

- Always have an agenda – sometimes I go to meetings and I feel like I am flying blind that is why I always want an agenda.
- If it is a long meeting there must be a break. I have been to meetings and my mind is splattered all over the floor, where is the break?!

What Brain Injury Matters Wants You to Know!

“A lot of information can be confusing, talking about different projects it can be hard to follow and confusing.”

“Ask the person if they need regular breaks, make sure you don’t talk over people, record minutes using dot points and don’t go off topic.”



Be aware consumer representatives may find meetings intimidating and at times disempowering. Therefore, it is important for the Chair and everyone on the committee to provide support and undertake good meeting practices from the beginning.

- Ensure everyone has an opportunity to speak and participate in discussions.
- Allow people time to ask questions and express their views.
- Listen and explore everyone's ideas equally.
- Allow time for explanations and for people to process information and think about their response.
- Avoid speaking for others – encourage people to speak on their own behalf.
- Be aware it may take several meetings before people feel confident to speak up and have their say.
- Don't jump to conclusions about what a person is saying or speak before they finish.
- Be mindful of your body language, tone of voice and other gestures that may influence a person's decision.
- Use open-ended questions rather than "yes/no" type questions.
- Let people know it is OK to disagree.
- Speak to the consumer representative with a disability not their support worker or mentor.
- Break into small groups for discussion.

Amanda's Tips

- "I have been to lots of meetings where I didn't get my say and that stinks in my opinion."
- The chair must bring the meeting to order and make sure everyone is ready to start.
- The chair has to make sure that each person at the meeting gets their say and that everyone is quiet and listens.
- If no-one is paying attention to you put your hand up to indicate you want to have a bark!



What Brain Injury Matters Wants You to Know!

- “People can be talking at you and fast while you are still trying to think of what you are going to say and then you’ve lost your train of thought.”
- “They think because you sound stupid they think you are like a child. They talk over you.”
- “Make sure the chair follows the agenda and gives everyone a chance to speak and say how they feel.”

“I don’t have much to say in meetings. I don’t think anyone does, yeah it depends how it is chaired I guess. Depends on the chairperson.

Sometimes the chairperson can talk all day,
sometimes they can be a bit quiet and let other people talk ...
the Chair over talks ... oh I think she should slow things down a bit”.

“My Knowledge Is Not As Good As Other People’s”. People with An Intellectual Disability Having An Equal And Meaningful Voice In Government Advisory Forums. ~ Patsie Frawley

“The responsibility for involving everyone in a meeting is shared by everyone at that meeting. Everyone needs to make a commitment to work together to ensure inclusion for all.”

~ Pauline Williams Co-ordinator AMIDA

Evaluation is an important part of the consumer participation process. From the beginning, it is a good idea to identify and adopt an evaluation model which best suits your organisation. It is also important to involve consumers in all stages of the evaluation, ensuring that the evaluation process is accessible too.

The following evaluation model was adapted from the Australian Government Cancer Australia website.

Types of evaluation



1

Evaluation of the **process** looks at all the processes involved in the activity as well as the immediate effects including:

- The experience for consumers.
- The consumer's level of satisfaction with the project.
- Additional activities undertaken in response to the needs of consumers.

2

Evaluation of the **impact** focuses on the short-term impacts including whether:

- The purpose, aims and objectives were achieved.
- The consumer participation strategies or activities were effective and gathered the required information.
- There were any unintended effects of the activity.

3

Evaluation of the **outcomes** identifies the long-term outcomes of an activity.

These are frequently related to the purpose, aims and objectives of a broader goal.



Evaluation Tools

A variety of qualitative and quantitative tools can be used for evaluation. These include:

- Documents such as minutes, reports, newsletters.
- Storytelling and personal narratives.
- Face-to-face, telephone and exit interviews.
- Self-completed questionnaires.
- Informal and formal feedback.
- Observation.
- Photos and videos.
- Statistics.



Creative Victoria and Effective Change have developed a useful guide called '*Evaluating Community Arts and Community Well Being*' that is available for download from:

<http://creative.vic.gov.au>