WORKSHEET 3
WHERE ARE WE NOW?

Each of the following ten items are commonly held in the literature to be keys to successful consumer participation. Complete this checklist by rating each of the following along the scale from 0 to 10. Your rating should most closely describe the current situation in your team.

**Organisational support**

The value and validity that the organisation places on consumer participation should be clear and are reflected in policies, structures and processes. Some examples include:

- organisation goals and values statements which specifically point to consumer participation
- job descriptions which include consumer participation responsibilities
- decision-making about services being devolved to the service delivery level (i.e. rather than all decisions being made centrally or at the top)
- management or advisory committees comprising consumers.

**Being open rather than closed to information from consumers**

There are a range of indicators of openness, including:

- willingness to break down the boundaries between your team and other teams
- staff members recognising and valuing the knowledge and experience of consumers (talking about consumers as experts)
- the service creates opportunities to hear consumers’ experience of the service
- there are examples of changes being made to services as a result of feedback from consumers.

**Common goals**

A clear definition of the ideals or purpose of consumer participation in your team is the basis for action. Within each team there should be agreement about:

- the team’s main service improvement issues
- which areas of the team’s operation fall within the scope of consumer participation and which do not
- the roles of staff and consumers in achieving service improvement.
**Agreed processes**

There should be clear processes for getting information from consumers about their experience of the service. It should be clear (to providers and consumers) how consumers’ issues can be placed on the agenda, how discussion will occur and how decisions will be made. The complex processes of most providers are often difficult for provider staff to understand, let alone people from outside.

**Different strategies for consumers and different purposes**

Generally, consumer participation is most effective when it is focused on a particular issue or a particular group. Different strategies will be appropriate for different issues and different consumers.

The strategies used need to be appropriate both to the goals for consumer participation and the individuals, groups or organisations involved. The influence on consumer participation of factors such as ethnicity, age, ability and consumer’s time and interest need to be carefully considered.

**Resources**

Developing and maintaining consumer participation requires staff time. This must be supported by service management as a legitimate part of people’s work. Other forms of support may also be critical to ensuring consumer participation works.

Examples include:

- workshop venues
- developing information materials which are easily understood by consumers
- respite care and/or personal care support
- administrative costs
- resources for interpreting
- transport.
Modelling participation behaviour

Openness and non-defensiveness are essential requirements for consumer participation. This means working well with people who have points of view different from your own, being open to doing things differently, being willing to make mistakes and actively sharing knowledge and skills with others.

The effectiveness with which your team works together is crucial to your effectiveness in developing and maintaining consumer participation.

Use language that everyone understands

For many consumers, the language of particular professions or services is full of mystery and jargon. It is important to:

- discuss with consumers their needs for information and the relevance and appropriateness of the information provided by the team
- identify terms that are jargon to consumers and avoid their use or explain them
- think about what will make sense to consumers in pamphlets, reports, invitations to participate and other documents
- ensure that your information is presented well and easily accessible.

Appropriate measures of effectiveness

Some measures of effectiveness such as service usage or unit costs may assess consumer participation work as an inefficient (and therefore inappropriate) use of resources. The effectiveness of consumer participation should be measured in relation to the goals of that participation. This may require quite different measures of effectiveness from those currently used.

Use available technology

The participation of consumers can be supported by the use of communication technology. Available technologies include email, teleconferencing, skype and social media.
Reconvene

Using a blank worksheet, and taking one heading at a time, starting with organisational support and develop a group picture.

Where necessary, allow time for people to explain their reasons behind the assessment they made.

Referring to your team’s ideals for consumer participation, ask each person to nominate what they think are the:

- two greatest strengths (opportunities)
- two greatest weaknesses (barriers)

to achieving your ideals for consumer participation. That is, where do you think your team should begin to focus its efforts to build on current strengths and to overcome current weaknesses?

As a group summarise your conclusions about the main barriers and opportunities to developing consumer participation in your team.

Step 3  Finding solutions

**Group activity**

As a group answer the question:

- Which of these barriers can we find answers to now, and which have no easy solution?

Then decide what action to take, either immediately or long term, to address the main barriers.

Hand out a copy of the table ‘Pathways to consumer participation’ (page 16). Give everybody an opportunity to read it through.

**Group discussion**

As a group, discuss the relevance of each column (Information Giving, Information Seeking etc.) to your team. Write into each column any examples from your own or your team’s experience.

Referring to the statement of your ideals for consumer participation and the summary of barriers and opportunities, ask each person to mark on the ‘Pathway to consumer participation’ table where the organisation is now.

**EXAMPLE**

You may currently be effective in giving information to consumers and may decide to be more effective in information seeking or you may decide to develop a consultative relationship with your consumers.

Summarise your conclusions about where you are now and where you want to be.
Step 4  Discovering who to focus on

Group discussion

Use the whiteboard to develop a list of possible issues or possible consumer groups you could focus on to engage their contribution.

Brainstorm

Get as many ideas as you can up on the board before you start to discuss them. It is so easy to get side tracked into a detailed discussion of the pros and cons of one idea.

Give each person one ‘vote’. Ask each person to choose which of the ideas on the board they are most interested in the team following up as a possible consumer participation project. Ask each person to place a ‘tick’ on the board against the idea of their choice.

As a group, identify from the ideas which have the highest numbers of ‘votes’ the consumer participation project(s) your service will pursue. Choose ideas which represent a small step for your service and be realistic.

Decide who will develop this project idea(s):

- all staff
- a small working group
- one staff member

Step 5  Planning the next steps

The person or group leading this project now needs to work through the ‘Planning Checklist’ (pages 33-35)

Decide when this will happen.

Decide how and when those responsible for this task will report back on their progress.
3.1 INTRODUCTION

This section contains practical tools to assist you in implementing consumer participation and engagement. You will find:

• a consumer participation planning checklist to assist you to plan your consumer participation projects
• a brief description of seven different tools to achieve consumer participation in service planning and improvement
• some practical steps to put each of these tools in place
• an evaluation sheet for this guide
• lists of additional resources to support you in using the tools

The seven tools include:

1. consumer and family participation in care
2. focus groups
3. forums
4. committees
5. consumer feedback
6. surveys and questionnaires
7. networking (formal & informal) and strategic alliances.
3.2 CONSUMER PARTICIPATION PLANNING CHECKLIST

Decide what you hope to achieve

Develop a brief, clear statement in plain language about what you want participation and engagement in, what kind of input is being sought and how the information gained will be used. What will motivate your consumers to participate?

Identify the issue or problem

Identify which aspects of the issue or problem you want consumers to participate in and which are outside the scope of consumer participation.

Be clear about your ideas for possible options to manage or resolve the issue or problem.

Define any truly non-negotiable aspects to the issue or problem.

At a service review time, it is expensive and time-consuming to employ a consultant to interview consumers and carers in their homes. It is also their experience that older people are grateful for the service and reluctant to criticise during such interviews. Written surveys do not generally receive a good response. The program is keen to obtain consumer’s views about a number of aspects of the program using tools other than a survey.

Consumers of this program were asked to participate in one of four focus groups to discuss the following issues:

- information provided by the programme
- quality of care from direct care staff
- complaints procedure
- role of the co-ordinator

People are more likely to talk freely in a group where they can share common experiences and build on each other’s ideas. It is important to have an independent facilitator so that the natural course of the conversation is unbiased. Support may need to be provided to consumers so that they can attend more easily.
Who will participate?
List the consumers relevant to the issue or problem
Decide who you want to participate
Do specific groups of consumers need to be engaged? (e.g. older people living alone, Aboriginal people, carers)
What are the different needs and issues of your likely participants? How will these affect the participation process or strategy?

Strategies to increase the effectiveness of consumer participation
• check your organisation’s ethical guidelines for consumer involvement in quality activities
• put together background information sufficient for the needs of participants. This information should be brief, clear, in plain language and presented accessibly
• develop a timetable which will allow sufficient time for participation to occur
• plan to actively remove barriers to participation, for example:
> use an existing forum or committee rather than set up a new one
> ensure there are a variety of ways for people to participate (not just workshops)
> address access requirements such as lack of English language skills, cultural sensitivities and adaptations for people with hearing difficulties or low vision
> address the requirements for people with dementia or cognitive decline
> respite, transport
> use appropriate ways of presenting information
> minimise the use of jargon and technical terms
> travel to rural and remote areas.
• use staff (or an external facilitator) with the appropriate skills for consumer participation, for example the skill to ensure that different or conflicting points of view are openly explored and discussed
• clarify avenues for information exchange between your team and consumer participants and ensure that they remain open throughout the process and after (information exchange is an ongoing process for all involved)
• Develop a checklist that includes all the tasks involved in organising your consumer participation strategy.

achieving:

- Develop an organising checklist.
- Write to possible participants outlining your aims and inviting their participation. People may want to be invited in person.
- Speak to each invited person to ask about their particular needs, e.g. help with transport; car parking; suitable meeting times; respite needs for carers; or personal care.

Estimating Resources

- list the resources, including staff time, that will be required
- allocate funds to meet the costs of the process and the expenses of participants.

Facilitator and minute secretary to attend the focus group (2 hours each by 4 sessions).
Facilitator to debrief with coordinator (approximately 2 hours).
Coordination of focus group planning and organisation, follow up work for coordinator (approximately 6 hours). Focus group costs (lunch, car parking, support for participants, facilitator, photocopying agendas, summary notes etc).

Reporting Back

The outcomes of consumer participation will need to be conveyed to participants as well as to staff, other teams, agencies, etc. This reporting back should include:

- key themes arising from the information received
- how the information gained has been used
- the reasoning/values behind any decisions made
- how and when decisions made will be implemented.
Evaluation

Develop an evaluation plan. The basis of your evaluation plan will be how success is defined and measured. What evaluation process/tools will you need to monitor success? Your evaluation report could include:

- what worked well and how these features could be enhanced
- what factors inhibited success and how/whether they can be overcome
- in what ways participation has been of benefit to consumers
- the outcome/what has changed as a result of consumer participation
- whether participants were satisfied with the process and with the outcomes
- how the results of the evaluation will be recorded and retained for future reference.

3.3 TOOLS FOR CONSUMER PARTICIPATION

3.3.1 CONSUMER DIRECTED CARE

What is it?

CDC acknowledges that older people have been in control of their lives throughout their lifetime and will want to remain in control even though they may now need some assistance to remain living in their own homes. If an older person is not in a position to manage their own Home Care package they may still wish to have ‘directive control’ i.e. the ability to make the key decisions about their assistance. Even people who are experiencing cognitive decline can express their preference or nominate who they would like to be their representative (family, friend, ally or advocate) in making key decisions on their behalf.

Promoting consumer direction acknowledges that people are the experts in their own lives and come to the service relationship on an equal footing with providers. The providers also have expertise to offer in relation to their professional knowledge, understanding of the service system and information about the available options for assistance. Together, providers and consumers can work to plan the best possible support arrangements within the available resources. These resources may include the community, informal networks and the funding available to purchase assistance.

It is also important to acknowledge that there will be other key people in the older person’s life who may:

- be an advocate or representative
- provide physical care
- carry out particular nursing/technical procedures
- be a partner in decision making
- provide social and emotional support
- monitor their wellbeing.

Effective consumer direction relies on:

- mutual value and respect
- clear definition of roles and expectations of each other in making support arrangements
- effective two-way communication
- ensuring the consumer and/or their representative has a say in what is provided, and how, when and by whom it is provided.
How to facilitate consumer direction:

Explore the different experiences and views amongst staff as to the value and importance of consumers having control over their support arrangements. Without the commitment of service leadership and staff you may struggle to successfully implement CDC.

1. You need to be clear that Home Care services are there to support older people to continue to have rich and meaningful lives in the community. Consumer direction is not an end in itself but a means to ensure that consumers can pursue the lifestyle of their choice and plan their support arrangements to facilitate that.

2. In order for consumer direction to be successful, consumers need all the information required to make informed decisions. They may not at first feel equipped to exercise the choices available to them and may need to build their capability and confidence to take more control of their care arrangements. Consumers should be able to negotiate the level of control that they are comfortable with, recognising that this may change over time.

3. Person-centred planning is a foundation for consumer direction at the core of which lies that you are designing the support with the older person around their needs rather than your service or staff’s needs.

4. The key to consumer direction is a positive and trusting relationship between the consumer, their informal networks and you as service provider.

5. There are many elements of your organisation’s systems and processes that will need to change in order to facilitate consumer direction and transparent budgets. However, the key change is one of mindsets to acknowledge that the consumer, not the service, is in control and that you will work together flexibly to arrive at the best possible support arrangements for the consumer to facilitate their chosen lifestyle.
What are focus groups?
A focus group consists of a small number of consumers and a facilitator to introduce and guide a discussion concerning a particular issue or service development area about which you want more information.

A focus group is useful for:
• allowing people to tell their stories in their own way and encouraging the emergence of common themes
• providing opportunities for all people in the group to contribute to the discussion
• the informal development of ideas and proposals.

It is often used as a means of establishing relevant issues you would like explored before conducting a wider survey. The focus group discussion is often recorded for later transcription and analysis.

3.3.2 FOCUS GROUPS

At the end of each focus group the facilitator reviews participant satisfaction with the outcomes and process of the session:
• a follow up phone survey of participants a week after the focus group to hear participants’ views about the outcomes and process of the session
• reporting on how the information gained in the focus group is subsequently used in service improvement initiatives
• write up the focus group outcomes and ensure it is sent to key decision makers.

TIPS
How to develop focus groups

1. Start with an issue or an area of concern in your service.

2. Develop agreement amongst staff that hearing consumers’ experience and ideas about that issue or concern is valuable and necessary. Workshop One: Understanding participation and engagement (page 19) is a way of doing this.

3. Decide which consumers to invite. You might include consumers who:
   • have already formally or informally raised this issue
   • are active members of your current networks
   • have had recent experience of your service
   • are members of a particular target group
   • you randomly select from your records.

4. Limit the number of focus group participants to 12 people. It is difficult to achieve balanced participation and in depth discussion in groups larger than 12. A minimum of six is required for good interaction.

5. Talk with your consumers about what they need to support their attendance. For example, suitable days and times for the focus group, accessible venue, providing respite for carers and assisting with preparatory information needs.

6. Plan a date and time. Two hours is a common amount of time for a focus group discussion.

7. Book a venue.

8. Book a facilitator. The facilitator should be someone who is not deeply involved in the issue so consider having a person from outside your team or service.

9. You may need to have more than one workshop with this focus group. Sometimes it is hard to know whether a second or third workshop will be necessary until you know what emerges from the first.

10. Decide how many and which staff will attend the focus group, or whether staff should attend at all. It is imperative that consumers are a considerable majority. Consider whether the presence of staff will limit consumers’ willingness to speak openly and honestly about their concerns or issues.

11. The role of staff should be to listen. It is inappropriate in a focus group discussion for staff to explain, defend or justify their service.

12. With the facilitator, develop a plan for the focus group. The most important part of the plan is clarity about what information or ideas you want to get from the consumers.

13. Any focus group should start with an opportunity for each consumer to tell their experience or ideas in their own way. You cannot expect consumers to address your agenda without first having the opportunity to address theirs.

TIP Complete the Planning Checklist (page 33). It may save you time and effort further down the track and will increase your chances of success.