



ACI NSW Agency
for Clinical
Innovation

GUIDE

Participant experience focus groups: Facilitation guide

Chronic Care Network



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www.aci.health.nsw.gov.au

AGENCY FOR CLINICAL INNOVATION

Level 4, Sage Building
67 Albert Avenue
Chatswood NSW 2067

PO Box 699 Chatswood NSW 2057

T +61 2 9464 4666 | F +61 2 9464 4728

E aci-info@health.nsw.gov.au | www.aci.health.nsw.gov.au

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- NSW Agency for Clinical Innovation Consumer Council
- NSW Agency for Clinical Innovation Patient Experience and Consumer Engagement (PEACE) Team
- Directors and Managers of Aboriginal Health
- Multicultural Health Managers Group.

Glossary

Abbreviation	Description
LHD	Local health district
NHMRC	National Health and Medical Research Council
SHN	Specialty health network

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Section 1

Participant experience focus groups: Quick guide

1.1 Planning a focus group

1.1.1 Ethical considerations (including ethics approval)

A number of ethical considerations arise when conducting focus groups. Whether a focus group requires ethical approval depends on whether the project is for research or quality improvement and whether the project poses any ethical risk to participants.

The NSW Health Guideline GL2007_020 [Human Research Ethics Committee – Quality improvement & ethical review: a practice guide for NSW](#) provides advice on determining when quality improvement activities require ethical review.

1.1.2 Resources required

The following resources are typically required to organise a focus group:

- project coordinator
- facilitator
- note-taker
- observer (optional).

1.1.3 Selecting a facilitator

A focus group facilitator:

- must be empathetic, sensitive and non-judgemental, and have the ability to build trust and actively listen
- may be external or internal to the organisation (although not someone who works with participants on a daily basis).

1.1.4 Selecting a venue

A suitable venue is one that:

- is accessible (close to public transport with adequate parking and disability access)
- has minimal noise, visual and other environmental distractions
- is private.

1.1.5 Recruiting participants

When identifying and inviting people to participate in a focus group, consider:

- group size (a large group may affect group dynamics). Identify 15–20 participants to contact with the aim of having 8–12 actually participate on the day
- the target group (for example, people that have been receiving a particular program/service; Aboriginal people; frail aged)
- whether people are well enough to travel (there may be clinical reasons why someone is unable to take part)
- inviting people to participate either via telephone or face-to-face and following up with an invitation letter and information sheet (see Appendix A – Example invitation call script and Appendix B – Example letter and Participant Information Sheet)
- reimbursing people for expenses (for example, travel costs, parking).

1.2 On the day

1.2.1 Setting up

When setting up for a focus group, consider:

- technical requirements (for example, audio test if recording a focus group)
- seating in a U-shape or semicircle
- refreshments (for example, coffee, tea, water, morning/afternoon tea).

1.2.2 Participant arrival

Welcome participants and take time to develop rapport.

1.2.3 Opening the meeting

When opening the discussion, the facilitator should include:

- Acknowledgement of Country or Welcome to Country (refer to [NSW Health PD2005 472 Welcome to Country protocols policy](#))
- welcome and introductions
- housekeeping (such as location of toilets and fire exits, and duration of the focus group).

1.2.4 Consent

All participants should sign a written consent before beginning the focus group (see Appendix C – Example consent form and confidentiality undertaking) and have the option to withdraw their consent at any time (that is, during or after the focus group).

Inform the participants if the discussion is being recorded.

1.2.5 Establishing a group agreement

The facilitator may find it useful to establish a group agreement, which outlines some principles for participation (such as, being respectful and making sure conversation stays 'in the room').

1.2.6 Facilitating discussion

When facilitating discussion, it is important to:

- let the conversation flow and allow people to tell their story
- listen well and respectfully
- use verbal and non-verbal communication effectively
- use prompts and probes to facilitate conversation and explore topics in more depth.

REMEMBER! The most important thing is the safety of participants – ensure contact details are available if participants require psychosocial support. (See Appendix E – Dealing with difficult situations and troubleshooting).

1.2.7 Ending the session

To end the session:

- thank people for their time and follow up with a thank you letter (see Appendix G – Example participant thank you letter)
- provide contact details of the project coordinator in case participants have any questions
- explain what will happen with the results.

1.3 Collecting, analysing and reporting the results

1.3.1 Taking notes and recording audio

In taking written notes (and recording audio, if applicable), consider the following:

- the note-taker should sit in an unobtrusive location and record questions asked, major topics, key issues and responses, and key quotes (word for word)
- two note-takers may be required if the focus group audio is not being recorded
- recorded audio may not need to be transcribed if key issues and quotes have been recorded by the note-taker (however, the audio recording can be useful to remember what someone has said).

1.3.2 Analysing the results

When combining the participants comments from the focus groups:

- look for patterns and similarities
- group answers into key points
- consider how the responses answer the objectives of the focus groups
- write a paragraph response to each question, which may include information on how many times something was raised, to what detail, and how much emotion was expressed
- include any key quotes against questions
- develop major themes that emerged.

1.3.3 Reporting

A focus group report may include:

- the number of focus groups conducted
- the number of attendees at each focus group
- demographic information of the participants
- a description of the program/services that participants received
- major themes that emerged from results of focus groups (grouped by question)
- any quotes obtained that articulate key messages
- key learnings
- other feedback on process and learnings from conducting focus groups.

In addition, an internal report should be written that shows the quality feedback loop (that is, what will be implemented based on the findings of the focus group).

Section 2

Introduction

The NSW Agency for Clinical Innovation (ACI) Chronic Care Network is committed to empowering and enabling consumers to drive improvements in chronic care in NSW at a state and local level. In addition, the Network is keen to ensure that its activities and priorities are informed by consumer needs.

Focus groups provide an opportunity for local health districts (LHDs) and specialty health networks (SHNs) to capture consumer experience routinely. They also provide a starting point for these organisations to find ways to engage consumers and carers in programs.

The objectives of the focus groups discussed in this guide are to:

- collect information about participant experience and participant-reported outcomes following involvement in a program or service
- use this information to inform local service development and other quality improvement activities
- identify trends in participant experiences across NSW (if applied across multiple LHDs within the same setting/cohort)
- inform the priorities and activities of relevant groups, ensuring that consumer's needs and preferences are met.

In addition, focus groups are an opportunity to identify participants interested in being involved in, and proposing new ways of participating in, other initiatives or activities, such as those coordinated by ACI Networks.

LHDs and SHNs who use the information in this guide should also consider:

- informing and obtaining support from relevant LHD management/executive members and other key stakeholders locally
- how to incorporate information from the focus groups into local planning, service development and quality improvement processes
- processes to continue the capture of participant experience data routinely.

This guide has been developed to help local health districts and specialty health networks organise and deliver focus groups. It covers the following elements:

- capturing participant experience – the eight dimensions of patient-centred care
- what is a focus group?
- ethical considerations
- organising a focus group
- facilitating focus group discussion
- data collection, analysis and reporting
- cost of implementation
- conducting focus groups with Aboriginal people
- conducting multicultural focus groups
- appendices (including resources and templates to support focus group delivery).

As mentioned above, this guide includes sections on principles and additional considerations when conducting focus groups with Aboriginal people and people from culturally and linguistically diverse communities. This inclusion recognises that Aboriginal people and people from culturally and linguistically diverse communities may require a more tailored focus group approach that is accessible and culturally safe.

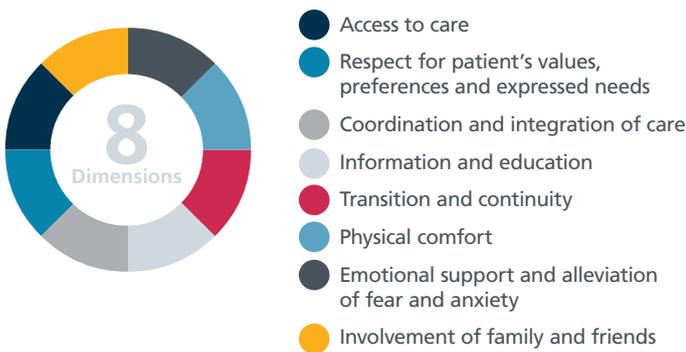
Throughout the facilitation guide, call-out boxes prompt where additional preparation or consideration should be given to ensure focus groups are inclusive and accessible for people with low literacy levels, cognitive impairment or intellectual disability. These are in line with general principles for conducting focus groups, but prompt further consideration for some elements which may otherwise present as a barrier to participation for some consumers. These additional points have been adapted from the National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability's [practical guide](#) to using focus groups as a research method in intellectual disability research.

Section 3

Capturing participant experience: the eight dimensions of patient-centred care

The consumer's perspective about their experience in health services can offer great insight to the gaps in service delivery and ways to improve it.¹

The National Research Corporation's and Picker Institute's 'eight dimensions of patient-centred care' recognise that consumer's views and experiences are integral to efforts to improve health services.² Research from the National Research Corporation and Picker Institute shows patients and carers value the following.



These eight dimensions provide a useful framework for the design and development of participant experience. During focus groups, facilitators may find it useful to introduce the dimensions of care to participants; a diagram (similar to the above) on butcher's paper or a whiteboard may support focus group discussion.

The eight dimensions of patient-centred care² are based on thousands of interviews, conducted with patients by the National Research Corporation and the Picker Institute, designed to understand what matters most to patients in the healthcare experience.

In 2015, the National Research Corporation provided the following overview of this research against each of the dimensions.² This explanation of the dimensions will help focus group facilitators ask questions and facilitate discussion according to what consumer's value in the experience of healthcare. The extent to which these principles are used to design and develop question sets will depend on the objective of the focus group.

When developing questions, write a clear statement of what is trying to be achieved. It can also be useful to involve consumers in the design of questions and resources.

In addition, all NSW Health staff have access to GEM, an online learning platform offering interactive short courses on various topics, including patient and carer experience. Staff wishing to access the platform will need to register. You can register [on the GEM site](#).

3.1 Respect for patients' values, preferences and expressed needs

Patients want to be recognised and treated as individuals. They are concerned with their illnesses and conditions and want to be kept informed.

Patients' needs can be recognised by:

- providing an atmosphere respectful of the individual patient that focuses on quality of life
- involving the patient in medical decisions
- providing the patient with dignity
- respecting the patient's autonomy.

3.2 Coordination and integration of care

Patients report feeling vulnerable and powerless in the face of illness. Proper coordination of care can ease those feelings. Patients' feelings of vulnerability can be reduced by care coordination of:

- clinical care
- ancillary and support services
- frontline patient care.

3.3 Information and education

Patients sometimes express a fear that information is being withheld and that staff may not be completely honest about their condition and prognosis. Healthcare organisations can reduce these fears by providing information:

- on clinical status, progress and prognosis
- on processes of care
- to facilitate autonomy, self-care and health promotion.

3.4 Transition and continuity

Patients often express considerable anxiety about their ability to care for themselves after discharge. Meeting patient needs in this area requires staff to:

- provide clear information regarding medications, physical limitations, dietary needs and so on
- coordinate and plan ongoing treatment and services after discharge
- provide information regarding access to clinical, social, physical and financial support on a continuing basis.

3.5 Physical comfort

The level of physical comfort patients report has a tremendous impact on their experience. Three areas were particularly important to patients:

- pain management
- assistance with activities and daily living needs
- hospital surroundings and environment.

3.6 Emotional support and alleviation of fear and anxiety

Fear and anxiety associated with illness can be as debilitating as the physical effects. Caregivers should pay particular attention to anxiety over:

- physical status, treatment and prognosis
- the impact of the illness on themselves and family
- the financial impact of illness.

3.7 Involvement of family and friends

Patients continually address the role of family and friends in the patient experience, and often express concern about the impact their illness has on their family and friends. Family dimensions of patient-centred care include:

- providing accommodation for family and friends
- involving family and close friends in decision-making
- supporting family members as caregivers
- recognising the needs of family and friends.

3.8 Access to care

Patients need to know they can access care when it is needed. Focusing mainly on ambulatory care, the following areas were of importance to the patient:

- access to the location of hospitals, clinics and physician offices
- availability of transportation
- ease of scheduling appointments
- availability of appointments when needed
- accessibility to specialists or specialty services following referral
- clear instructions on when and how to get referrals.

Section 4

What is a focus group?

A focus group is a form of group discussion that capitalises on group interaction in order to generate information.³ Focus groups are particularly useful for exploring participant experience, hence, they are commonly used to gather information on participants' experiences of disease and health services.³

Focus groups are useful because they:

- are a means of gathering in-depth information and building on ideas
- focus on experience and gaining information on what people think and feel
- are a way to generate consensus rather than diversity of opinion
- are flexible
- are face-to-face interaction
- are less time intensive than one-on-one interviews
- cost relatively little.

A focus group is different to group consultation, which consists of activities to increase understanding and awareness of a particular topic or issue.

Section 5

Ethical considerations

This facilitation guide explores a number of ethical issues associated with conducting focus groups. In addition, coordinators of focus groups will need to consider whether ethics approval is required as part of the process of setting up and running a focus group.

According to the National Health and Medical Research Council (NHMRC) *National statement on ethical conduct in human research*,⁴ the values and principles of ethical conduct shape the relationship between the researchers and research participants. These include:

- respect for human beings
- research merit and integrity
- justice
- beneficence (that is, the benefit of the research must justify any risks of harm or discomfort to participants).

All research involving humans conducted within the NSW public health system must be ethically and scientifically reviewed and approved by a human research ethics committee in accordance with the NHMRC *National statement on ethical conduct in human research*.⁴ This includes:

- clinical research
- clinical trials
- epidemiological research
- health services research
- population health research
- qualitative research.

Whether a quality improvement project requires ethical review depends on whether or not the project poses any ethical risk to participants. The NSW Health guideline GL2007_020 [Human research ethics committee – quality improvement & ethical review: a practice guide for NSW](#) provides advice on determining when quality improvement activities require ethical review.

New South Wales has 22 human research ethics committees that serve the public health system. For more information on ethics, including local ethics committee contacts, policies and links, visit the [Ministry of Health's Research ethics and governance website](#).

The NHMRC has also developed ethical guidelines for research involving Aboriginal and Torres Strait Islander peoples, which are currently under review (as at July 2016). These guidelines can be viewed on the [NSW Health Research Ethics and Governance webpage](#).

Section 6

Organising a focus group

6.1 Developing a project timeline

The focus group coordinator should put together a timeline for the project outlining the key tasks that need to be completed and timeframes.⁵ A sample timeline is included below as a guide. The coordinator is responsible for ensuring that the key tasks and timeframes are met.

Table 1

	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6	Week 7	Week 8	Week 9	Week 10
Recruit facilitator										
Secure venue and finalise date/time										
Participant recruitment										
1. Develop a list of eligible participants										
2. Phone calls/registrations										
3. Send letters and information packs										
Conduct focus groups										
Post focus group analysis										
Prepare final reports										

6.2 Selecting a facilitator

The facilitator directs and guides the discussion and is responsible for ensuring that everything runs on track.⁶ Most importantly, the facilitator is responsible for ensuring a safe and supportive consultation for participants.

The facilitator must be able to maintain the flow of the session, address problematic group dynamics (should they occur), and ensure that participants feel comfortable in discussing issues with each other. The facilitator guides the discussion but should not be the centre of the process.

It is important that you select an experienced focus group facilitator.⁵ The skills required to run a focus group differ from those needed to conduct a group consultation.

Facilitators must be empathetic, sensitive, non-judgemental and able to build trust, and facilitators must listen actively.^{5,6} The facilitator should have good knowledge of the service model and objectives of the program.

CHARACTERISTICS OF THE FACILITATOR⁶

- sensitive to the needs of participants
- non-judgemental
- respectful of participants
- open-minded
- aware of the needs of the topic
- skilled in active listening
- observant
- patient and flexible.

McHugh, Pitts and Brown, Focus group discussion facilitation guide⁶

The facilitator may be internal or external. An internal facilitator should not be a colleague or clinician who works with the participants on a daily basis, because the facilitator must be objective and comfortable discussing all experiences.⁵ Staff that work on the program may provide expertise on the program to the facilitator prior to, and on, the day. A facilitator from within the LHD can reduce the need for training or orientation to the context, and may reduce facilitation costs.

An external facilitator, or an experienced facilitator from elsewhere within the LHD, may also be used. If appointing an external facilitator, you may need to follow internal policies concerning the engagement or recruitment of an external resource.

Extra training may help facilitators enhance the participation of individuals with different types of disability. For example, augmentative and alternative communication techniques can aid the inclusion of people who have speech or comprehension difficulties.⁷

6.3 Selecting a venue

Selecting an appropriate location and venue to hold focus groups is important as it can affect the quality of data collected and the recruitment of participants.

Key issues associated with successful recruitment are:

- transport – the focus group must be easy for participants to travel to and get in and out of
- access – consider wheelchair and pram access, parking and access to public transport

The location needs to be safe for participants and facilitation staff. This also includes considering the time of day that the focus groups take place. The venue should be close to toilets and have somewhere to prepare a snack and tea and coffee. Ideally, offer refreshments before or after the focus group, as snacking during the discussion may affect participation.

Importantly, the focus group needs to be held somewhere where you will not be disturbed. Noise levels and visual and other environmental distractions should be reduced.

In terms of seating, focus groups are often conducted in a U-shape or semicircle.⁶

Provided the venue is suitable for a focus group, participants with cognitive impairment may feel more comfortable in a venue that they are familiar with, at a day and time that they would usually attend.⁷ Alternatively, you may consider inviting participants to arrive early to be shown the facility, and you could help organise travel.

6.4 Recruiting participants

As a guide, try to identify 15–20 participants who have been involved in the program or service for each focus group; aim to have 8–12 people actually participate on the day. Larger numbers may affect the group dynamics and make it difficult to ensure equitable engagement.

Some people may find it difficult to participate if the group is too large, and may be more comfortable in a smaller group (5–6 people).⁷ This may be due to fear of speaking out in a crowd, being distracted by others, or speech and hearing difficulties.⁷

Engaging with advocacy groups can be an effective way of identifying and recruiting people with intellectual disability to participate in focus groups.

As travel time may be a barrier to attendance, identify participants that live nearby or have received health services near the venue. Factor in the time that participants will need to take to travel to site. It is recommended that you consider offering to pay for travel expenses (for example, parking, public transport or mileage, see below). Make sure participants are clear about directions and travel arrangements.⁵

If possible, when conducting multiple focus groups, choose venues in different locations across the LHD to increase access for participants across geographical areas.

When recruiting participants, keep in mind the target population of the particular program or service and try to identify a diverse sample of members from that group.

Ideally, identify people who have an established history with the program or service. Be clear with participants that you are open to hearing both positive and negative experiences. In addition, identify participants that you know are well enough to travel and participate (there may be clinical reasons why someone should not be invited to take part).⁵

Having identified potential participants, the project coordinator, or another suitable staff member, should contact the participants to explain the project and create a list of those who are interested in taking part.⁵

The initial invitation to participate is best made face-to-face, or by telephone.⁵ Ideally, the invitation would be made by a member of staff who is known to the person or carer, and who is involved with the wider project so that they can answer any immediate questions or queries that may arise. (See Appendix A – Example invitation call script template.)

Send a follow-up letter to the participant or carer soon after this invitation, enclosing a detailed information sheet describing the purpose of the focus groups as well as the project of which the focus groups are a part.⁵ (See Appendix B – Example letter and information sheet.) Also advise the participants at this stage that they will need to give written consent for participation in the focus group discussion on the day.

Ensure that interested participants are given contact details of someone who can give them all of the required details about the event and answer any questions they may have.

Consider making written information available in Easy Read format, which is clear and easy to understand for people with cognitive impairment.⁸

Additional resource:

Further information on developing Easy Read information (including a guide) is available on the [New Zealand Office for Disability Issues](#) website.

Keep in mind that some participants may need a carer to accompany them. Make it clear that partners or carers of participants are very welcome to attend, if the participant would like them to.⁵

A person with cognitive impairment may need a carer or support person to assist with communication. If a carer is present, the facilitator should ensure that they are talking to the participant, not the carer. It is best if the carer or support person is seated next to the participant.⁷

For the NSW Ministry of Health committees, the NSW Health guideline suggests the following financial assistance be provided to participants:

- travel costs – for example, taxis or kilometre rate for private vehicle
- expenses for people with disabilities – for example, covering carers or papers in large print
- expenses for people with children – for example, covering child-sitting fees.

For more information, refer to [Consumers Representatives – Working with Consumers in NSW Health, Guidelines for Secretariat](#).

LHDs and SHNs should also check any local policies and guidelines regarding reimbursing consumers who participate in focus groups.

Section 7

Facilitating focus group discussion

Focus groups should ideally take place within a couple of weeks of the recruitment process,⁵ in a location where the participants will feel comfortable, and where participants' privacy is respected.

7.1 Setting up the venue

Consider the following in setting up the venue.

- Technical requirements – if you are recording focus group interviews, do a quick test of the audio in your room to make sure that the recording level is adequate for the background noise levels and for participants' natural speaking volume.⁵
- Seating – arrange seating in a U-shape or semicircle with the note-taker sitting off to the side.⁶ Have comfortable seats available.
- Refreshments – ensure morning and/ or afternoon tea will be provided and that coffee and tea facilities are available.⁶ It is a good idea to have water and tissues available.

7.2 Participant arrival

Keep in mind that some participants are likely to arrive early, so it is important to be at the venue and have the room set up in advance to be available to greet participants.

When focus group participants arrive:

- welcome them
- offer light refreshments, for example: tea, coffee, water and a snack (more extensive refreshments can be offered on completion)
- take time to develop rapport.⁶

7.3 Opening the meeting

The facilitator may use the following format to open the meeting.

1. ACKNOWLEDGEMENT OF COUNTRY

An Acknowledgement of Country is a statement of recognition of the traditional owners of the land. An Acknowledgement of Country can be given by any person, whether Aboriginal or non-Aboriginal. A suitable Acknowledgement of Country is:

'I acknowledge the traditional owners of this land that we meet on. I pay my respects to Elders past and present and any Aboriginal people who are meeting with us today.'

The facilitator or a nominated person should ensure they follow local LHD or SHN guidelines in delivering the Acknowledgement of Country.

2. WELCOME AND INTRODUCTION⁶

The facilitator should introduce themselves and make it clear that they are not part of the clinical team that directly provides (or provided) the participants' care, and that their role is as a facilitator of the discussion.⁵

3. HOUSEKEEPING⁶

Provide practical details, including:

- tea/coffee/water facilities
- location of toilets
- safety procedures (for example, fire exits)
- duration of discussion (approximately 1.5 hours).

4. OVERVIEW OF THE PROJECT⁶

Before starting, give the group an overview of the project and the purpose of the discussion based on the written information previously provided. Use a conversational tone. (An example script is provided in Appendix D – Focus group questions.)

7.4 Obtaining consent

Although consent may be implied by participants attending the focus group, all participants should sign a written consent form before the focus group discussion begins. (See Appendix C – Example consent form for participation in focus groups.)

It is important to explain why it is necessary to obtain written consent. The following is an example of the information that should be included, but facilitators should use their own words to ensure the group understands what is being said.

'Because the information you provide in this focus group is protected by the various privacy laws, we need your written permission to show that you do not object to this discussion. We also need your permission to use your experiences and opinions to inform the program and any potential improvements to service delivery. You also need to agree that others in the group may become privy to your personal and health information and all group members will need to sign that they agree to maintain the confidentiality of this focus group.'

Explain to participants that participation is voluntary and there will be no effect on care for the participant or their carer if they choose not to participate. Explain that it is okay if a participant withdraws from the discussion at any stage.

Participants may withdraw from the focus group discussion at various times, including at the start of the session, during the focus group or after the focus group.⁵ Participants who withdraw during the focus group may choose to sit quietly and listen to the rest of the discussion, or they may leave the room.

Participants should be made aware that they do not have to answer any questions they feel uncomfortable with, and that the information that is collected during the discussion will be de-identified.

The facilitator or their support person should:⁶

- hand out the consent forms
- read out the consent form to the group
- acquire the signature of each participant
- sign as witness on the form
- give all consent forms to the note-taker
- tell participants if a tape recorder is being used for the session.

Paper-based copies of consent forms should be kept and stored in a locked filing cabinet. Organisers should also keep an electronic copy of the scanned consent forms. LHDs and SHNs should refer to local guidelines regarding security and storage of data, including consent forms, collected from focus groups.

It may not always be possible to obtain written consent from participants; however, participants can still indicate that they understand the information presented to them and how the information will be used, and they can consent to being involved in the process.

Written consent may not be able to be obtained from participants where:

- the participant is unable to write
- the consent form is written in a language that the participant cannot read.

Where the need is identified in advance, consent forms should be made available in a language that the person can read. If this is not possible, an interpreter should be available to read the consent form to the participant.

Where a person is unable to write, the consent form should be signed by a support person or carer indicating that they have explained the information contained in the consent form to the person and that informed consent is obtained.

7.5 Beginning the focus group discussion

The beginning of the focus group is important as it provides the context for the rest of the discussion. It should be casual but the facilitator should inform the group that the discussion will follow a semi-structured format.⁵ If you are recording audio of the focus group discussion, you will still need a note-taker to record the path of conversation and key points and quotes. If audio of the focus group discussion is not being recorded, you should have two note-takers.

TO BEGIN THE FOCUS GROUP DISCUSSION, THE FACILITATOR SHOULD:

- explain why the participants were selected. Include the importance of their contribution to the program and the community
- make sure people understand that the session will be confidential and that discussion must stay 'in the room'. It is important that participants do not talk about the content of the focus group with anyone outside the group. This is to make sure that people in the focus group feel free to talk openly without fear that others will find out about what they have said. Ensuring a safe and confidential space for participants is paramount (some suggested words to use to explain this are included in the suggested discussion about consent)
- explain that there will be a note-taker who will be making notes of the key points, themes and quotes from the discussion
- explain how the focus group works and establish a group agreement (see below). Explain that sharing experiences of people's health can be a difficult topic to discuss so creating a safe space is necessary
- explain that this is a group discussion that is built around certain questions
- tell participants you would like to hear from all of them about their feelings on the subject. Anything they want to say is important. Remember to give all in the group the chance to speak
- ask participants to introduce themselves, noting that the focus group is to talk about people's experiences accessing the service, and that participants are not required to provide personal details, such as details about their diagnosis or medical conditions
- ask if there are any questions.

Adapted from McHugh, Pitts and Brown, *Focus group discussion facilitation guide*⁶

7.6 Establishing a group agreement

You may like to establish a group agreement including the principles of participation. As outlined in McHugh, Pitts and Brown's *Focus group discussion facilitation guide*,⁶ this could include the following:

- be respectful
- speak one at a time
- encourage space to speak
- focus on the topic
- establish and keep to a time frame
- use appropriate humour
- encourage natural discussion
- encourage everyone to say something
- keep the discussion 'in the room' (confidential)
- consider any other culturally appropriate aspects or conditions that the facilitator determines.

7.7 Facilitating discussion

The facilitator should try to keep all conversation within the group as a whole, as side conversations between group members may distract the flow of discussion. Remember that the focus of the discussion should be on gathering as much information as possible; this is not an educational session.

Different facilitators will ask questions in different ways (for example, in turn or as conversation flows) depending on what is most appropriate for the group.⁶

During discussion, pause from time to time, summarise the main points and ask participants if they have any questions.⁷

TIPS FOR FACILITATING FOCUS GROUP DISCUSSIONS

- It is important to remember that the aim of the focus group is to hear the participant or carer's story in their own words. Try to let people tell their story in their own way, but use the prepared list of focus group questions to provide some structure.
- Have a conversation – try to think 'story' rather than 'interview'.
- Listen well and respectfully. Use active listening skills to encourage the participant to continue their story.
- While listening, avoid interruption, but make a note of comments that require clarification or further exploration.
- Use open-ended prompts and probes that unpack the content and keep the flow going. Think of your task as being to help the patient or carer reconstruct the story of their personal experience. See below sections for further information on the use of prompts and probes in discussion.
- Do not keep jumping from one subject to another.
- Encourage the participant or carer with eye contact.
- Remain neutral and avoid value judgements about what you are hearing. You may like to use a whiteboard, butcher's paper or post-it notes at the front of the room to note key words or themes.

Adapted from *The King's Fund Experience-based co-design toolkit*⁵

7.7.1 Prompts

Prompts are a way of drawing new information from the group and may be helpful if there is a delay in responding to a question or where a response is brief.⁶ A prompt may be silence, which can allow participants the time to gather their thoughts to respond, or an encouraging sound, such as 'mmm' or 'uh-huh'.⁶

Suggested prompts have been included in the focus group questions. (See Appendix D – Focus group questions.)

7.7.2 Probes

Probes are a way to explore the response further or clarify a response.⁶ Often they are requests for more information, for example:

'Would you give me an example of what you mean?'

'Can you tell me more about that?'

'What do you mean exactly?'

7.7.3 Moving on

Sometimes it will be necessary to move discussion on if one person is taking a long time to share their experience, which can reduce the amount and quality of information gathered from other participants in the group. Some useful lines that may assist in moving discussion on include:

'Thank you for sharing that.'

'Let's hear from someone else.'

'Is that the case for others?'

'Does anyone have a different experience?'

'I might get you to hold that thought.'

Additional techniques to facilitate discussion include use of:⁷

- illustrations and visual aids
- word associations
- ranking exercises
- role playing
- photos.

7.8 Responding to difficult situations or feelings of distress

The facilitator may encounter difficult situations, including conflict among members in the group, an individual who continues to dominate discussion, or a person who becomes distressed. (Some tips for dealing with common situations are attached in Appendix E – Dealing with difficult situations and troubleshooting.)

The wellbeing and safety of participants are more important than the discussion itself. In some cases, participants will need to take a short break or withdraw from the discussion, and they may decline the offer of additional help. In these cases, the facilitator must provide appropriate contact details of an appropriate support person (that is, someone from the clinical team who can provide psychosocial support).⁵

If the facilitator senses that a person is distressed, the following strategies can help support that person:⁹

- ask the person what they are thinking and feeling
- listen to the person without judgement or interruption
- reassure the person that you want to hear what they have to say
- if the person is comfortable, ask open-ended questions to find out more about their thoughts and feelings, and the underlying problems behind these
- summarise what the person has said, and clarify important points to make sure these are fully understood
- express empathy and thank the person for sharing their feelings, acknowledging the courage that this takes.

When addressing the distressed person, do not:⁹

- argue or debate with the person about their thoughts or feelings
- discuss whether their feelings or experiences are right or wrong
- minimise the person's problems or experiences
- give insincere reassurance, such as 'don't worry', 'cheer up' or 'everything will be alright'
- interrupt with stories of your own
- communicate a lack of interest or negative attitude through your body language.

7.9 Ending the session

The last five to ten minutes of the focus group should be reserved to give participants the chance to add anything they haven't mentioned and to ask any questions. Thank participants for their time and explain how the results of the discussion will be used to improve services.⁵ Assure participants that the discussion has been confidential and any information will be de-identified. Make contact details available in case there are any questions after the focus group.

You can invite participants to fill out a feedback form to help identify ways to improve focus groups and other methods of consultation for participants. (See Appendix F – Participant feedback form for an example.) You may want to consider what material will be sent to, or made available to, participants following the session. For example, you could send:

- a thank you letter (see Appendix G – Example participant thank you letter)
- a hard copy of a newsletter article accompanied by a thank you note
- the results of the focus group (ensuring that the language and format are consumer-friendly).

Ensure that participants know that their time is valued by being clear about the process for feedback of results, what the information is intended for and the timeframe over which it is likely to happen.

7.10 Debriefing meeting after the focus group

The facilitator, note-taker and interpreter (if applicable) should hold a short meeting immediately after the focus group (away from the focus group) to discuss outcomes and clear up any confusion.

THE DEBRIEFING SESSION SHOULD COVER:

- whether significant things were mentioned
- group dynamics
- issues with content and process
- group norms and whether they helped or hindered the outcomes
- whether everyone had the chance to speak
- the range of views from the participants
- whether less powerful participants deferred to more powerful group members, and whether this affected the outcome
- any impact of the note-taker on the group.

Adapted from McHugh, Pitts and Brown, *Focus group discussion facilitation guide*⁶

Section 8

Data collection, analysis and reporting

It is important to record the focus group discussion in a systematic way through note-taking and, in some instances, audio recording (although this is not necessary). If audio of the discussion is not being recorded, you should have two note-takers.⁶

8.1 Taking notes

The note-taker should sit in an unobtrusive location and record details of discussion, what they observe (for example, the feel of the group, verbal and non-verbal behaviour, emotions or actions) and what participants say. Notes should include:

- questions asked
- major topics raised
- key issues/points in response to questions
- key quotes (word for word).

The note-taker can be a valuable source of feedback and may have suggestions for improving the next focus group discussion.¹⁰

8.2 Recording audio

Because of the large number of people, any audio recording must be done with a high-quality device. Audio recording should not be used in place of note-taking, but it may be useful to remember what someone has said.

Note: Organisers can decide whether or not to transcribe the focus group interview. Transcription may not be needed if the key issues and quotes have been recorded by the note-taker.¹⁰

8.3 Analysing the results

If conducting more than one focus group, it is advisable to debrief or analyse the first focus group before doing the second. The team can use the insights into potential major themes and focus group processes in an iterative process to improve or enhance the next session.

If this is not possible, analysis can be completed when the series of focus groups is completed. Analysis of results involves combining the participants' comments from the focus groups.

An example procedure follows:¹¹

1. Read through the notes taken under each question, looking for patterns and similarities.
2. Group the answers into key points. Where key points have been repeated, place a tally mark against each point. Continue listing points until every answer has been accounted for.
3. Consider what the group of answers describes and how the responses answer the objectives. Write a paragraph for the focus group question, summarising the overall response to that question. In the summary, consider:
 - frequency – how many times the key point was made by different people
 - specificity – how detailed particular responses were
 - emotions – how much emotion, enthusiasm or intensity was expressed in a particular answer.
4. Include any quotes that were noted against focus group questions to illustrate and provide insights to the summary. Ensure quotes are de-identified.
5. Develop the major themes that have emerged from the focus group results. It may take some time to let the data, information and knowledge sink in.
6. Reflect on what is not said and interpret within the context or the cohort if there are differences between results from multiple focus groups.

8.4 Implications

Consider how the insights of the participant experience drawn from the analysed results will be translated into practice. Use the key themes to develop a list of operational actions for the LHD to improve the quality of service delivery.

8.5 Reporting

Focus group reporting can occur at multiple levels. The focus group report could include the following information:

- the number of focus group conducted
- the number of attendees at each focus group
- demographic information of the participants
- a description of the program or services that participants received
- major themes that emerged from results of focus groups (grouped by question)
- any quotes obtained that articulate key messages
- key learnings
- other feedback on process and learnings from conducting focus groups. (See Appendix H – Example reporting template.)

In addition, each LHD should develop an internal report that shows the quality feedback loop, that is, what the LHD is going to implement based on the findings of the focus group.

Participants will probably want to know whether, and how, their input has affected the project. Where participants would like further information or involvement, you may like to send a letter of thanks and explanation about the main outcomes of the project.

Section 9

Cost of implementation

The cost of implementing the participant experience focus groups will depend on which of the project elements are included and whether external resources are used. That is, how much capacity and experience already exists within the organisation (for example, an experienced facilitator). Each LHD should weigh up the benefits and potential costs of the particular elements.

Typically, the following costs will be incurred when implementing this approach:

- travel (for participants and carers to attend the focus group session)
- refreshments
- staff time (project coordination, conducting interviews, transcribing and reporting)
- postage (to send information sheets to participants)
- local call costs (to invite participants to take part).

Depending on the existing resourcing and event details, the following costs may also be incurred:

- external facilitator
- professional transcription
- venue hire
- Welcome to Country (see Section 10 'Using focus groups to hear Aboriginal voices' for more information).

Section 10

Using focus groups to hear Aboriginal voices

Additional considerations apply when you are organising and delivering focus groups with Aboriginal people.

When planning the focus group, you should:

- inform directors and managers of Aboriginal Health and the Aboriginal Health Unit about the plan to engage Aboriginal people in focus groups
- in partnership, identify key stakeholders that must be informed or involved (for example, Aboriginal Lands Council, Aboriginal Community Controlled Health Services)
- with these groups and stakeholders, identify any local contextual issues that you should be aware of, and develop solutions together (for example, working with local workers to organise and run focus groups, or co-facilitating with a community representative)
- in addition to understanding local issues, understand how the broader historical context may influence discussion, and provide opportunity to explore this as part of the process
- explore whether there are any local yarning circles that could be used to promote the focus group
- consider holding focus groups in a neutral location, or across a number of locations to reflect the views of more than one local community
- ensure that the location is accessible by public transport (in line with general principles for conducting focus groups)
- consider healthy food options when organising catering
- invite one (or more) relevant support people to convey information in a way that people understand (it is possible that an interpreter may be required)
- when planning the date, be aware of any Aboriginal events or sorry business that may affect people's availability to participate

- be aware of ethical considerations when conducting research involving Aboriginal people (see Section 4 – Ethics for more information)
- consider gender issues (for example, if the discussion is likely to involve women's and men's business).

When beginning the focus group, you should:

- be clear about the purpose of the focus group. You may consider letting the participants determine the agenda topics and priority issues for discussion¹²
- understand the processes for conducting Acknowledgement of Country or Welcome to Country. (For more information on when you might conduct a Welcome to Country instead of an Acknowledgement of Country, and processes for arranging this, refer to NSW Health PD2005_472 [Welcome to Country protocols policy](#).)
- let participants introduce themselves and talk about where they are from
- consider any specific consent procedures around recording audio or video of the focus group (in addition to those already outlined in this guide).

During the discussion, you should:

- be flexible with time (in line with yarning style of conversation)
- use participatory approaches and avoid one-way processes for gathering information¹²
- avoid interrupting conversation to bring it back 'on track' as you can risk cutting out information that is highly relevant to the topic of discussion¹³
- allow the story to flow and look for links to the research topic; intervening limits the potential of information to be imparted through the storytelling process¹³
- consider how issues can be represented in other ways (for example, visually), either as part of the process or at the end
- feed back the results and explain how they will be used (in line with general principles for conducting focus groups).

Additional resources.

- NSW Health [Communicating positively: a guide to appropriate Aboriginal terminology](#) provides background information and guidance on appropriate word usage when working with Aboriginal people and communities.
- NSW Department of Community Services [Working with Aboriginal people and communities: a practice resource](#) provides additional information and practice tips when consulting and working with Aboriginal people and communities.

Section 11

Conducting multicultural focus groups

Focus groups can be a useful way to engage and understand the experiences of people from culturally and linguistically diverse communities. However, principles should be applied to ensure that focus groups are inclusive and culturally safe for participants.

Additional principles arise when conducting multicultural focus groups.

- Consider involving multicultural health workers or members of target cultural group in planning the focus group, to ensure awareness and consideration is given to cultural issues.¹⁴ These issues could influence:
 - group composition¹⁴
 - question structure¹⁴
 - style of communication¹⁴
 - group dynamics (for example, power imbalances)¹⁴
 - attendance (avoid conflicts with festivals and holy days)¹⁵
 - separate processes for different cultural groups¹⁵
 - seating and speaking protocols.¹⁵
- Written information provided to participants should be clear and use simple language, and it should be written in a language that people will understand. Some people may not be literate in either their own language or English, so engagement may need to be verbal.¹⁵
- If marketing and promotion is required to engage and recruit participants, consider culturally relevant channels, for example, local community radio, community events (organised through cultural, sport, or religious groups) or ethno-specific organisations.¹⁵
- Consider culturally appropriate dietary requirements for refreshments.¹⁵
- Consider the need for bilingual health workers and interpreters and the use of a facilitator who is a member of the cultural or community group of participants.¹⁴
- Be aware of making cultural generalisations. Individuals will be influenced by their own personal experiences and may have adapted aspects of their traditional culture to the current environment.¹⁴
- Be sensitive to the needs of people who may not be familiar with the process or understand what is expected of them (for example, new migrants and refugees).¹⁵
- Consider the possible impact of the need to obtain written consent for photography of participants, and audio and video recording. Some communities would be uncomfortable with this and may refrain from participation. In addition, the concept of privacy, and the idea that the information will not be disseminated to people outside the research team, may not be well understood in some communities.

Section 12

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Section 13

13.1 Appendix A – Example invitation call script

Hello, is this Mr/Mrs [insert name]?

[If 'no'] Is Mr/Mrs [insert name] available? [If 'no' - arrange a convenient time to call back when the participant is likely to be home].

[If 'yes'] My name is [insert name] from [insert name of hospital/facility and name of program/service]. We are interested in hearing about your experience in the [insert name of program/service] to help us identify ways to improve our services.

You are one of a group of people we would like to talk to, and the information you share with us will help us take action to improve the experience for people like you in the future. The discussion, which will be as part of a group of around ten other people, will be about your overall healthcare experience, rather than details of your medical treatment or history. Any information you provide will be kept confidential.

[Advise participant of costs that will be reimbursed, for example, travel].

Would you be interested in participating?

[If 'no'] that is no problem at all Mr/Mrs [insert name]. Your decision not to participate will not have an impact on any care that you are receiving. Thank you for your time.

[If 'yes']. Thank you. Your participation will be very valuable. The focus group will be held on [insert date] at [insert location and address] between [insert time and duration].

I will send you a letter in the post confirming these details along with an information sheet for you and your family/carer to consider before you agree to participate. Do you have any questions? [Confirm postal address with participant.]

[If participant has questions refer to the information sheet, which should provide answers to frequently asked questions.]

Thank you for your time.

13.2 Appendix B – Example letter and participant information sheet

Note: Example letter only – please consider developing plain English version.

[Local health district logo]

Name:

Position:

Postal address:

Contact number:

Date:

Dear [insert name],

Thank you for agreeing to take part in a focus group discussion as part of the [insert name of hospital/facility] improvement project.

As discussed, we are interested in hearing about your experience in the [insert name of program/service] to help us identify ways to improve our services. This is an important project which aims to improve systems and processes by focusing on the experience of people when they receive health services. You are one of a group of people we would like to talk to, and the information you share with us will help us improve the experience for people like you in the future.

We are interested in your experience before, and during, the [insert name of program/service]. The discussion would be about your overall healthcare experience rather than details of your medical treatment or history. Any information you provide will be kept confidential.

The focus group will be held on the [date] at [insert location and address] between [insert time and duration].

Attached to this invitation is a Participant Information Sheet, which gives you more information about the focus group interview and who to contact if you have any questions. If you no longer wish to participate in the focus group interview, please contact me on [insert contact numbers].

We value the feedback and appreciate you sharing your experience so that we can improve the delivery of chronic care services in [insert name of hospital/facility].

Yours sincerely,

[Name]

[Position]

[insert name] Local Health District

[Email]

[Contact number, if different to above]

Note: Example letter only – please consider developing plain English version.

Participant information sheet

Invitation

I invite you to participate in a focus group discussion as part of our project being undertaken by our local health district to improve the consumer experience of the [insert name of program/service]. We are interested in hearing about your experience so that we can identify ways to improve our service.

Before you decide whether you wish to participate in this discussion, it is important for you to understand why we would like to speak with you and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

What is the purpose of these discussions?

We would like to collect information about participants' experiences before and during the [insert name of program/service]. This information will be used to improve services in the local health district; [insert any other ways that the information may be used].

We are conducting focus group interviews with a group of approximately 10 people who have recently received health services, to understand ways to improve our services.

Why have I been invited to participate in a discussion?

You have been invited to participate in a discussion as you have recently received [insert name of program/service]. Therefore, you can provide valuable feedback regarding health services.

What if I don't want to take part in a discussion, or if I want to withdraw later?

It's fine if you don't want to take part. Whether or not you decide to participate, your decision will not disadvantage you in any way and will not affect your relationship with the hospital or community health centre, any health staff or any other aspect of your healthcare. If you decide to participate, you may withdraw your comments at any time without giving a reason.

What will a discussion involve?

The discussion will involve a series of questions that are designed to understand your experience of the service you received. This may include things such as:

- what you expected of the [insert name of program/service]
- whether you think your needs have been met
- how your life may have changed since being involved in the [insert name of program/service]
- how well you think your care is coordinated or organised (for example, how well the people providing your care work together)
- ways that you think the [insert name of program/service] can be improved.

If you are willing to tell us about your experience, we will ask you to sign the Participant Consent Form.

You are welcome to have a family member or carer with you if you wish – someone who has supported you on your journey through the healthcare system and can also offer insights about the experience. This person will also be asked to sign the Participant Consent Form.

The discussion will take approximately 1–1.5 hours. We will not ask you detailed questions about your medical treatment or results – we want to know how the health system works and communicates information to you and how you (and your carer) feel about your experience.

Will taking part in the discussion cost me anything, and will I be paid?

[Insert details of any financial assistance or reimbursement – refer to section 6.4 of this facilitation guide for more information.]

How will my confidentiality be protected?

Any information that we collect about you in connection within this discussion will remain confidential and will not be disclosed without your permission.

All participants will be required to provide written confirmation that they are aware of the confidential nature of the discussions and will maintain that confidentiality.

However, under exceptional circumstances, we may be required to disclose information you have provided. This might occur where either:

- disclosure is required by law, for example, if you were to advise us that you were the victim of a criminal act while you were receiving health services
- if mandatory policy directives within NSW Health compel us to do so, for example, if you advise us of serious misconduct or negligence by a staff member.

While these circumstances are extremely rare, these provisions exist to ensure that all unsatisfactory conduct within the NSW health system receives appropriate attention.

In sharing your insights about the health system, we will remove or change any details which may identify you (for example, your name and where you live). We will also invite you and your carer to nominate an 'alias' so that references to the information you provide us will never identify you.

What happens with the results?

Your insights about your experience will be used [insert how the information collected will be used].

While we may talk about aspects of your experience, individual participants will not be identified in any reports, presentations or papers arising from the project.

What should I do if I would like further information regarding this discussion before I decide to participate?

The name of the lead person who will meet with you is in the attached Participant Consent Form. If you have any questions after reading this information, please contact this person in the first instance. Similarly, if you would like any further information, please do not hesitate to contact this person.

Who should I contact if I have concerns about the conduct of this discussion?

If your questions are not satisfactorily answered or if you have concerns prior to, during or after the interview, you can contact the following NSW Health representative for this project:

[Insert Name]

[Insert Designation]

Phone:

Mobile:

Email:

Thank you for taking the time to consider sharing your experience within the NSW health system.

This information sheet is for you to keep.

13.3 Appendix C – Example consent form and confidentiality undertaking for participation in focus groups

Participant consent form

I agree to participate in an interview regarding my recent experience with the NSW Health system.

I understand that the interview will be conducted as described in the Participant Information Sheet and this Participant Consent Form, a copy of which I have retained. I understand I can withdraw my comments at any time and do not have to give any reason for withdrawing. I also understand that I may be contacted in the future as part of an evaluation of this interview method for patients and carers, and my telephone number has been requested for this purpose.

I understand that my personal information will remain confidential as outlined in the Participant Information Sheet.

I consent to taking part in the discussion and have understood the information contained within the Participant Information Sheet.

I understand that I may not disclose the group discussions outside the focus group and that I must treat other participants' private information as confidential.

PATIENT

Print name: Date:

Signature: Phone:

Alias:

CARER

Print name: Date:

Signature: Phone:

Alias:

I have informed the above person/s about this interview and am sure that they understand the content of both the Participant Information Sheet and this Participant Consent Form.

INTERVIEWER

Print name:

Signature:

Contact details for lead interviewer:

Name:

Position: Phone:

Email:

Address:

Contact details for director/manager:

Name:

Position: Phone:

Email:

Address:

Revocation of consent

If at any time you wish to withdraw your consent for the use of your comments, please sign below and send the form to the lead interviewer listed on the previous page. Alternatively, send this signed form to:

Address:

You do not have to give any reason for withdrawing consent.

PATIENT

Print name: Date:

Signature:

Alias:

CARER

Print name: Date:

Signature:

Alias:

13.4 Appendix D – Example of focus group questions

The following questions are designed to gather information that can be used to improve the [insert name of program/service]. They explore two key areas:

- participants' experiences and self-reported outcomes during enrolment and participation in [insert name of program/service]
- ways that participants feel the [insert name of program/service] could be improved.

Before asking any questions, the facilitator should provide an introduction that reminds participants why they are here and what they can expect. Participants should be reminded that we are here to talk about accessing health services, and that they do not need to discuss personal information, such as details of their diagnosis or medical condition. In addition, it is important to gauge the participants' current understanding of the program or service, and what services they have received as a part of that program or service. This will help the facilitator guide the discussion and determine whether and how questions may need to be tailored. The introduction and questions should be participant-friendly and avoid program-specific language (jargon) that the participants may not be familiar with. Questions should focus on participants' health-related goals and functional aspects of daily living. The following script and questions may be used to introduce the focus group and guide discussion.

Introduction

As part of the [insert name of program/service], someone would have called you to ask if you would like to be part of the [program/service]. To start the focus group, I am going to ask you a few questions about the [program/service] that you receive. I will go on to explain what the [program/service] is in a moment.

Question

1. What do you understand of the [insert name of program/service]?
2. What services have you received? What did you receive this for?

[Insert a description of the program/service. Include information on the aims of the program/service, why participants may have been referred/invited, and what participants may have received as part of the program/service for example, key program/service elements, examples of members of the care team.]

Now that I have explained what the [insert name of program/service] is, I am going to ask you some questions about the [program/service].

Question	Prompts	Probes
<p>3. What were your expectations of the [program/service] when you were first contacted?</p> <p>3.1 Have your needs been met?</p>	<p>If yes – how?</p> <p>If no – why not?</p>	<p>Has anybody else had a similar experience?</p> <p>Does anybody have anything different to discuss?</p> <p><i>Probe to explore experiences of participants who feel their needs haven't been met.</i></p>
<p>4. How has your life changed since being in the [program/service]?</p>	<p>Have you been able to do things that you had to stop doing?</p> <p>Are you more confident that you can manage your health condition on a regular basis?</p>	<p>Were there certain activities of daily living (such as dressing, showering, grooming, shopping and domestic duties) that people had difficulty with before? Has this changed?</p> <p>Were there certain personal or social activities that stopped or were difficult (such as visiting friends and family, participating in sport, hobby or social clubs, volunteering, taking part in cultural, language or faith communities?) Has this changed?</p> <p>How did the [program/service] help you to change things in a positive way?</p> <p><i>Probe to identify and explore experiences of participants who feel they have not changed and why.</i></p>
<p>5. How well is your care coordinated?</p> <p>Note: If the term 'coordinated' is confusing for participants, 'joined up' is a suitable synonym.</p>	<p>How well do the people providing your care work together?</p> <p>How often did or do you have to repeat information that you had already provided?</p>	<p>Has anybody else had a similar experience?</p> <p>Does anybody have anything different?</p> <p><i>Probe experiences of fragmentation.</i></p>
<p>6. Were you involved as much as you wanted to be in decisions about your care and treatment?</p>		
<p>7. Thinking on your experiences that you shared today, are there ways the [program/service] could be made better?</p>	<p>What works?</p> <p>What doesn't?</p> <p>If someone you knew needed help, who would you put them in contact with?</p>	
<p>8. If you could change one thing about the program/service, what would it be?</p>		<p>Does anybody else have anything different to add?</p>
<p>9. What did you value most about the program/service?</p>	<p>How come?</p>	<p>Does anybody else have anything different to add or discuss?</p>

13.5 Appendix E – Dealing with difficult situations and troubleshooting

13.5.1 What to do when you encounter a difficult situation

You may encounter several types of angry emotions, expressed in different ways, during the course of the discussion. A participant may:

- appear withdrawn and unwilling to share information, or present information in a vague manner
- be very critical or negative about aspects of their experience
- intimidate others through use of sarcasm
- appear sad or depressed.

When dealing with difficult or angry situations, it is important to remember that anger:

- is a common and normal reaction
- often results from a loss of control and feelings of powerlessness
- can be justified and should be managed accordingly.

Participant anger also has several positive features:

- it signals an important problem which needs attention
- it acts as a motivator to find solutions and bring about change.

Signs indicating that someone is angry include:

- raised voice or shouting
- withdrawal from discussion
- flushed face
- sarcasm
- wild gesticulations
- dismissive comments
- angry words
- rigid body
- gritted teeth or clenched jaw.

13.5.2 What to do when you encounter participants and carers who become emotionally distressed

Dealing with strong emotional responses can be extremely challenging. You must maintain a calm professional detachment and not become too involved or distressed or express inappropriate emotion. An inappropriate emotional response can stop you thinking and acting clearly and takes the focus away from the participant in distress. Similarly, participants will not disclose emotional content to someone who is trying to avoid discussing such content.

Therefore, always ensure that your demeanour is as comfortable as possible in order that the participant will also be put at ease.

13.5.3 Strategies for managing difficult situations

A range of strategies help with dealing with difficult situations.

Do:

- stay calm and take deep breaths
- acknowledge the emotion. Name it and recognise its origin
- focus on the issue. Take it seriously and pay full attention to what the participant is saying. Try to understand the source of their anger or distress
- acknowledge and explore the participant's emotions. Make the participant feel that you have heard what they have said and not judged them. For example, say, 'I can see that you are very upset and I would like to find out more about what happened to make you feel that way'
- listen actively and maintain eye contact. Always listen without interrupting. You can then paraphrase the information supplied and ask clarifying questions
- identify the participant's key concerns. For example, say 'Can I just check that I have heard you correctly... you said that...'
- apologise if appropriate, for example, 'I can see why you're upset and I would be too. I'm sorry that happened to you in hospital'
- move on to suggestions regarding how the problem can be overcome and the situation improved
- recognise if you have been hearing about a situation that requires further action or reporting and work with the participant or carer to support this process
- ensure you are aware of where to direct participants if they would like to make a complaint, for example, Consumer Participation Manager, Quality and Safety Manager or Compliments and Complaints Officer. Be aware of local processes to direct participants to the Health Care Complaints Commission if required.

Do not:

- take it personally as this is not about you. Participants who appear difficult or angry are acting this way as their needs have not been met. Try to visualise angry comments going through you as a messenger only
- get defensive. Do not challenge or criticise the participant. It is more important that you try to understand the root cause of the anger
- get into an argument or yell back at the participant
- be tempted to fix the problem before the participant has finished talking.

13.5.4 What to do when you encounter participants or carers who seem overly agreeable

Some participants may be too agreeable in a discussion. They may say very little, provide only positive information or provide information that they think you want to hear.

If you encounter a participant who appears to be too agreeable, it may be helpful to:

- re-focus the participant's attention on the discussion of negative as well as positive aspects of their journey and ways to improve this
- use normalisation statements to encourage a balanced discussion, for example, 'Some patients have said that they didn't have such an easy time when they came to hospital ... was that the case for you?'
- explore subtle statements like 'They are very busy ...' or 'I expect to wait ...' as they may contain deeper information
- try asking what their carer, partner or relatives thought about what happened, for example, 'Does your partner also agree that everything went well in hospital?'

13.5.5 What if the person is dissatisfied with their care and wants to complain?

First, you can reassure the person that by talking to you, they are providing direct input into a program that aims to fix the system problems they encountered and make sure that future patients and carers have more positive experiences.

Second, you can tell people they can phone or write to the manager of the service in which they experienced problems. If their complaint is about their entire journey, they can write to the Clinical Governance Unit of their LHD or SHN.

Make sure you are aware of your LHD's or SHN's protocols for handling complaints before you begin these discussions. You should be able to provide the participants with relevant contact details at the time of a discussion should they wish to lodge a complaint.

13.5.6 What if the participant reveals adverse information which requires a response?

Under prescribed circumstances, you may be required to disclose information provided by patients and/or carers in the context of a discussion, which would otherwise be confidential.

This might occur where:

- disclosure is required by law, for example, if a participant advised that they were the victim of a criminal act while receiving health services
- mandatory policy directives within NSW Health compel us to disclose information, for example, if a participant divulged details of serious misconduct or negligence by a staff member.

While these circumstances are extremely rare, these provisions exist to ensure that all unsatisfactory conduct within the NSW health system receives appropriate attention. The Participant Information Sheet that is provided to all patients and/or carers clearly conveys this information.

If, after conducting discussion, you are unsure as to whether information provided in the discussion should be disclosed, you should seek advice from your manager. The identity of the participant, and the facility involved must remain confidential until a decision is reached regarding disclosure based on the nature of information supplied.

All staff have a responsibility to be aware of relevant policy directives, manuals and guidelines governing situations which may arise in a focus group discussion. These are available on the NSW Ministry of Health site and are accessible using the following link: <http://www.health.nsw.gov.au/policies/pages/default.aspx>

13.5.7 Debriefings

For the participant

Be mindful that participants may experience a range of emotions during the course of a discussion and remain emotional at its conclusion. Where this is the case, it is important that you:

- do not leave until the participant has calmed down and you are sure they are feeling comfortable
- check on them via telephone later that day or early the next day
- follow up again via telephone for participants who were particularly distressed,
- tell your manager if you suspect that a discussion has had an adverse effect on a participant and they require additional support or assistance; your manager will be able to recommend appropriate options.

For team members

Just as patients or carers may experience a range of emotions during a discussion, it is important to be mindful of the effect that discussions have on you or your team members that may be present. It is therefore important to:

- acknowledge your own emotional state, rather than trying to fight it
- arrange for a suitable colleague or supervisor to be available for debriefings, as required
- ensure that emotionally laden material that was raised in discussions is channelled into constructive criticism and feedback to health service managers.

13.5.8 What if the participants raise other issues?

Participants and carers provide an enormous amount of valuable information during discussions and it is important that this information is not lost simply because it falls beyond the scope of your project. If a participant reveals information that is beyond the scope of the project, this information should be:

- retained for consideration at a more appropriate time

and/or

- forwarded to a more appropriate area or person for consideration.

In both of these instances, the participant's confidentiality must be maintained. Staff are responsible for ensuring that information retained or provided to another person or area could in no way identify the participant or carer.

13.5.9 What if a participant or carer changes their mind and wants to withdraw consent?

The consent form that is signed and retained by participants contains a Revocation of Consent section. If the participant or carer changes their mind about participating, they can simply sign the Revocation of Consent section and send it in, without having to explain their reasons.

13.6 Appendix F – Example participant feedback form

insert title of focus group

Thank you for attending the participant experience focus group. We hope that you can take the time to complete the questionnaire. The information that you provide will be used to improve the delivery of future focus groups.

Using the following scale, please select your best response:

1. The information provided before arrival at the focus group was sufficient.

Strongly disagree Disagree Neutral Agree Strongly agree

2. The focus group facilitator was effective.

Strongly disagree Disagree Neutral Agree Strongly agree

3. The focus group was interesting.

Strongly disagree Disagree Neutral Agree Strongly agree

4. There was enough time for discussion.

Strongly disagree Disagree Neutral Agree Strongly agree

5. The venue was suitable.

Strongly disagree Disagree Neutral Agree Strongly agree

6. My participation was worthwhile.

Strongly disagree Disagree Neutral Agree Strongly agree

Do you have any additional comments or suggestions on the way the focus group could be improved?

What are some other ways we could obtain valuable feedback from participants?

Thank you for your time and participation!

13.7 Appendix G – Example participant thank you letter

[Local health district logo]

Name:

Position:

Postal address:

Contact number:

Date:

Dear [insert name],

Thank you for taking the time to talk to my colleagues and me about your recent experience in [Insert name of program/service/hospital].

The information you gave us will make a valuable contribution to redesign being undertaken by NSW Health. By telling us about your experience, you have helped us identify ways to improve it for others in future. I will take the opportunity to remind you that your information will be kept confidential and to reiterate the importance of you keeping the contents of the discussion, including the personal information of others, confidential.

You also advised us that you would be interested in hearing more about the [insert name of program/service] project and what we have done to improve systems for patients and carers. Accordingly, we will be in contact with you towards the end of the project with further information.

Should you have any enquiries about the project in the meantime, please contact ... [name and position] on ... [contact number].

Once again, please accept our sincere thanks for so generously sharing the details of your experience.

Kind regards

[Name]

[Position]

[insert name] Local Health District

[Email]

[Contact number, if different to above]

13.8 Appendix H – Reporting template

Participant experience focus group report

PARTICIPANT – provide details about:

1. Number of focus groups conducted:

2. Number of attendees at each focus group (note a minimum of two focus groups is required):

Focus group 1:

Focus group 4:

Focus group 2:

Focus group 5:

Focus group 3:

3. Demographic details:

a. number of males:

c. number of carers:

b. number of females:

d. ethnicity and language groups:

4. Interventions participants were enrolled to receive (and number receiving each intervention):

5. Major themes and quotes that emerged from results of the focus groups and summary (please attach transcript for analysis if available):

QUESTION 1. WHAT DO YOU UNDERSTAND OF THE PROGRAM OR SERVICE?

Themes and quotes:

Summary:

QUESTION 2. WHAT HAVE YOU RECEIVED? WHAT HAVE YOU RECEIVED THIS FOR?

Themes and quotes:

Summary:

QUESTION 3. WHAT WERE YOUR EXPECTATIONS OF THE PROGRAM OR SERVICE WHEN YOU WERE FIRST CONTACTED?

Themes and quotes:

Summary:

QUESTION 3.1. HAVE YOUR NEEDS BEEN MET?

Themes and quotes:

Summary:

QUESTION 4. HOW HAS YOUR LIFE CHANGED SINCE BEING IN THE PROGRAM OR SERVICE?

Themes and quotes:

Summary:

QUESTION 5. HOW WELL IS YOUR CARE COORDINATED?

Themes and quotes:

Summary:

QUESTION 6. WERE YOU INVOLVED AS MUCH AS YOU WANTED TO BE IN DECISIONS ABOUT YOUR CARE AND TREATMENT?

Themes and quotes:

Summary:

QUESTION 7. THINKING ON YOUR EXPERIENCES THAT YOU SHARED TODAY, ARE THERE WAYS THE PROGRAM OR SERVICE COULD BE MADE BETTER?

Themes and quotes:

Summary:

QUESTION 8. IF YOU COULD CHANGE ONE THING ABOUT THE PROGRAM OR SERVICE, WHAT WOULD IT BE?

Themes and quotes:

Summary:

QUESTION 9. WHAT DID YOU VALUE MOST ABOUT THE PROGRAM OR SERVICE?

Themes and quotes:

Summary:

6. Other feedback on process and learnings from conducting the focus groups (this may include suggestions on improvements on the tools provided and development of the processes):

Report prepared by:

Name:	<input type="text"/>		
Position:	<input type="text"/>	Phone:	<input type="text"/>
Email:	<input type="text"/>		
Signature:	<input type="text"/>	Date:	<input type="text"/>