



Guide to engaging diverse consumers in organisational and governance structures

June 2022



Contents

Introduction	3
Background	4
Definitions	6
Key considerations for engaging with diverse consumers.....	8
Purpose	8
Organisational readiness	8
Policy, frameworks and work plans	8
Challenges and how to address them.....	10
Factors affecting effective consumer engagement	12
Terminology	14
Planning a consumer engagement process	16
Stage 1 - Planning.....	17
Stage 2 - Organisational and secretariat support.....	18
Stage 3 - Recruiting diverse consumers.....	19
Stage 4 - Undertaking the engagement process.....	21
Stage 5 - Reporting and closing the loop	23
References	24
Appendices:.....	25
Appendix 1: Template to write a consumer engagement policy.....	25
Appendix 2: Template to write a consumer engagement plan	27
Appendix 3: Template to write Terms of Reference.....	28
Appendix 4: Consumer Confidentiality and Conflict of Interest Statements - SAMPLE	31
Appendix 5: Template for consumer position description	33
Appendix 6: Template for consumer position advertisement.....	35
Appendix 7: Interview guide for consumer positions –SAMPLE.....	36
Appendix 8: Template letters to successful and unsuccessful candidates	37
Appendix 9: Induction/orientation kit for consumers on health service committees - SAMPLE	39
Appendix 10: Consumer remuneration template.....	42
Appendix 11: Consumer engagement methods	43

This resource was originally published in September 2021 and reviewed in June 2022 after it was trialled by several health services.

Introduction

Safer Care Victoria (SCV) commissioned Health Issues Centre (HIC) to develop and deliver a strategy to engage diverse consumers in healthcare partnerships. This *Guide to engaging diverse consumers in organisational and governance structures* (the Guide) was designed for services staff charged with planning and implementing consumer engagement in general – but with reference to diverse consumers in particular.

Adhering to the Partnering in Healthcare Framework (PiH), the Guide addresses consumer engagement in decision making and healthcare partnerships at the **service** or **systems** level.

Service level - Consumers participate in service design, delivery and quality improvement. Health services partner with consumers in decisions about the design and delivery of services, including through community advisory committees, working groups, quality and safety committees, and service design working groups. Consumers provide feedback, ideas and personal experiences to drive change

System level - Consumers, carers, and communities participate in system-wide quality and safety improvement in healthcare organisations and the Department. Healthcare organisations partner with consumers in governance, planning and policy development, including through hospital boards and clinical governance. Government organisations partner with consumers in governance, planning and policy development. ¹

When should this Guide be used?

This Guide should be used when consumers are invited to be part of internal structured processes and systems as partners in decision-making and in healthcare partnerships. If you are seeking to engage diverse consumers in **formal service, organisational** or **governance structures**, this step-by-step Guide includes descriptions of the processes, planning stages and methods for engaging with consumers from diverse backgrounds.

This Guide outlines the main considerations when planning engagement of consumers in health service governance, design, development, implementation and evaluation.

How should this Guide be used?

You can read the Guide from the beginning, or you can click on the hyperlinks to go to the specific sections of the Guide that may interest you.

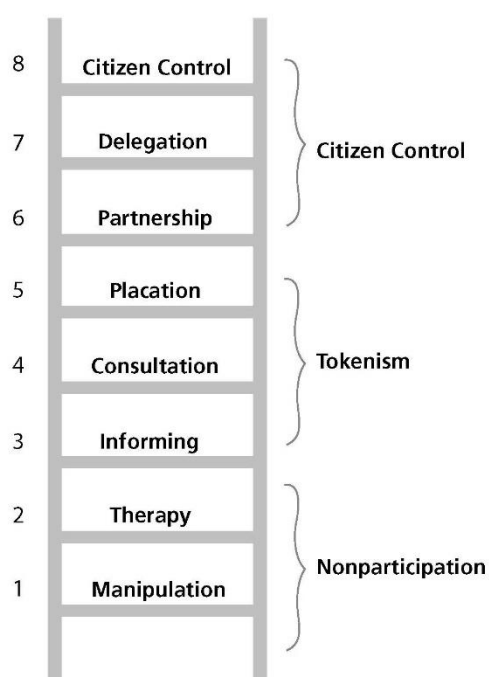
We encourage you to copy and adapt the templates available to meet your organisational needs. We ask that you credit Health Issues Centre when repurposing any of the materials included in this Guide.

This Guide can be used in conjunction with its companion Guide for inclusive community consultations. This Guide includes planning tools and consultation methods for community consultations and consultation methods for specific diverse communities.



Background

Health services are encouraged to engage with consumers in healthcare partnerships when undertaking health service design, service development, implementation and evaluation. This level of engagement corresponds to the upper rungs of the classic **Arnstein's Ladder of Participation**². This is, "partnership", "delegation" and "control" which operate at the decision and policy making processes and within the governance structure of an organisation. For those organisations that use the IAP2 Public Participation Spectrum³, this aligns with the "collaborate" and "empower" end of the spectrum.



Arnstein's Ladder (1969)
Degrees of Citizen Participation

(Image source: [The Citizen's Handbook](#))

Traditionally, organisations invite consumers to engage in the lower rungs of the Ladder of Participation. This is, at the "informing" and "consultation" levels. Or at the "inform", "consult" and "involve" end of the IAP2 Spectrum. Rarely consumers are engaged in the upper rungs of the Ladder. Often engagement at these higher levels, when it takes place, is based on consumer representatives or advisors engaged in organisational formal structures such as committees. Historically, this type of engagement has often been tokenistic and poorly managed although improvements have been seen in recent years.

Most often - if consumers are engaged - their contribution is not adequately recorded, acknowledged and evaluated. There are very few evaluations and publications about the benefits or outcomes of consumer engagement at the higher levels of engagement and in formal structures such as committees.^{4,5,6,7} Furthermore, engagement in these higher rungs of the Ladder of Participation is usually with consumers who do not necessarily represent the diversity of the consumer population that a health service serves.

Engagement in the upper rungs of the Ladder of Participation is by definition "inward-facing" as it is about health services partnering with consumers in decision-making processes, policy development and the governance of the organisation through formalised structures. As such, consumers are invited to engage with the health service in a way that locates them within the internal context and structures already in place in the organisation. For example, in boards, executive teams, committees, co-design teams, working parties or research teams.

This context is not necessarily conducive to engagement with diverse consumers who may prefer to engage with health service design, implementation and evaluation through engagement methods other than formalised committee structures. Hence, special consideration needs to be made with regards to supporting diverse consumers who may find it hard to engage in formalised engagement structures and/or other engagement methods should be offered.⁸ For information and examples on how to engage consumers in alternative ways, we recommend reviewing the companion resource - companion **Guide for Inclusive Community Consultations** [hyperlink].

Some best practice planning, methods of engagement and evaluations of consumer engagement in partnerships, delegation and control – and methods that encourage effective engagement of diverse consumers - are emerging in the 'co-production' and 'consumer engagement in research' areas.

Co-production resources

- Social Care Institute of Excellent – [Co-production in social care: what it is and how to do it](#)
- 1000 Lives Improvement - [Tools for improvement: Co-producing services, co-creating health](#)
- Involve – [Co-production](#)
- Nesta – [Co-production catalogue](#)

Consumer engagement in research resources

- The British Medical Journal – [Evaluating patient and public involvement in research](#)
- Cochrane Training – [Patient and public involvement in research: What, why and how?](#)
- Bio Med Central - [Patient and public involvement in research: from tokenistic box ticking to valued team members](#)
- RAND Corporate - [Patient and public involvement in research: Enabling meaningful contributions](#)

Aims

This Guide aims to:

- Capture best practice consumer engagement at the higher levels of the Ladder of Participation – partnership, delegation and control – for health service design, development, implementation and evaluation.
- Address engagement of consumers in general and of diverse consumers in particular
- Outline how to best plan consumer engagement in decision making, policy development, and governance
- Describe consumer engagement methods to be applicable to the PiH's levels of engagement: organisational or service level and policy or systems level.

The Guide also provides links to other resources that may help health services to broaden their menu of options to undertake consumer engagement in healthcare partnerships.

Definitions

Consumer engagement

HIC has adopted the definition of consumers engagement from the Australia Commission on Safety and Quality in Healthcare⁹. This definition provides context to the Guide and helps to locate the engagement of consumers at the organisational governance, policy and decision-making levels and it describes consumers as partners.

“Consumer engagement is an informed dialogue between an organisation and consumers, carers and the community which encourages participants to share ideas or options and undertake collaborative decision making, sometimes as partners.”

Consumer advisor

Consumer advisors are those consumers, carers or family members who are current or past users of a health service. It is expected that by sharing their personal experiences of the health service, they can assist to improve patient experience and ensure the patient perspective is considered in service improvements.^{10,11}

Consumer representative

According to the Consumer Health Forum of Australia¹²:

“A consumer representative is a member of a government, professional body, industry or non-governmental organisation committee who voices consumer perspectives and takes part in the decision-making process on behalf of consumers. This person is nominated by, and is accountable to, an organisation of consumers.”

Consumer perspective

The opinions, views and experience of consumers, carers and communities are unique; they are different to other stakeholders engaged in health services. The Consumer Health Forum of Australia¹³ states that:

“Consumer representatives often hear other committee members say that they are also a consumer and can act as a consumer representative. Everyone is a consumer, but not every committee member can represent consumers. Other committee members such as service providers, researchers or professionals are usually placed on the committee to represent those perspectives. They cannot possibly do this and represent consumers at the same time. Only those people whose primary experience is as a consumer can represent a consumer perspective because their judgment is not clouded by another perspective”.

Diversity

HIC has adopted a definition of diversity and a classification of diverse consumers from the Diversity Council of Australia¹³. This definition and classification provide context to the Guide’s content and helps to identify the main diverse consumers that health services could engage with more effectively. Diversity refers to:

“All the differences between people in how they identify in relation to their age, caring responsibilities, cultural background, disability, gender, Indigenous background, sexual orientation, and socio-economic background (Social Identity), and their profession, education, work experiences, and organisational role (Professional Identity)”.

Diverse consumers

Aboriginal and/or Torres Strait Islander consumers

Consultations with Aboriginal and/or Torres Strait Islander consumers should be based on respecting

their communities' history, culture and social determinants of health. Effective consultations with these consumers must be mediated by and in collaboration with local indigenous organisations.

Age

Undertaking community consultations with diverse aged cohorts is challenging, especially with children, young people and the elderly. Effective engagement strategies exist to engage with people affected by specific aged-related conditions such as dementia, and effective engagement methods are available to consult with children and young people.

Gender

Method of engagement should take into consideration people's gender identity, their social roles and status for example in relation to parenting, working life and experiences and responsibilities. This moves beyond a gender binary – that people identify with either male or female and is inclusive of someone's own internal sense of self and their gender.

Carer status

Many people provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged. Strategies for engaging these consumers require careful consideration of their situation and time availability.

Culturally and linguistically diverse background consumers

Engaging consumers from culturally and linguistically diverse backgrounds requires consideration of cultural identity, ancestry, ethnicity, migration or refugee history, sub-cultures, language, and English literacy. Effective engagement with these communities must be mediated by and in collaboration with local ethnic communities' councils, associations and grass roots organisations.

Disability

When undertaking engagement with consumers with disabilities, it is important to make the necessary adjustments to respond to sight or hearing impairment, communications and speech impairments, and any other considerations that may exclude individuals from participating in the engagement.

Sexuality

Consultations with LGBTQAI+ consumers should take into consideration gender identity and sexual orientation and particular care needs to be taken in the use of language.

Geographical isolation – Rural areas

Consultations with consumers living in small rural and regional urban centres is complex but can be achieved by establishing contacts with local communities and services.

Seldom heard groups or communities

The Institute for Research and Innovation in Social Services¹⁴ in the UK defines seldom heard groups as:

“Under-represented people who use or might potentially use social services and who are less likely to be heard by social service professionals and decision-makers. They are often referred to as 'hard to reach' groups, though this term has been criticised for implying that there is something about these people that makes their engagement with services difficult. 'Seldom-heard' places more of the emphasis on agencies to engage these service users, carers and potential service users”.

Key considerations for engaging with diverse consumers

When considering undertaking an engagement process with consumers and choosing an engagement method or methods in general - but specifically when undertaking engagement initiatives with diverse or seldom heard communities - the choice of methods must be made within an overall design that will ensure effective engagement. The choice of consumer engagement method or methods will depend on an understanding of the purpose, the context, and the process that would ensure that the level of engagement sought is clear, realistic and well implemented.¹⁵

Purpose

When undertaking consumer engagement, it is essential to be clear what the engagement aims to achieve. The purpose of the engagement process should be explicit and clear to the consumers and organisational staff engaging with them. Ideally, the purpose should be agreed from the beginning by those that will be invited to engage and the organisation. Establishing relationships with consumer organisations, peak bodies, and community groups early in the planning process will facilitate buy-in and full participation of consumers engaged in these organisations. Having a clear purpose and relationships with the consumers and the community groups or organisations they are engaged with will contribute also to the choice of consumer engagement method or methods.

Organisational readiness

Engaging diverse consumers in health service design, service development, implementation and evaluation should be framed within the organisation's commitment to consumer engagement. This commitment will be showed by having a policy, a framework and a work plan for consumer engagement and clear expectations for consumers engaged in the policy and decision-making processes and the organisation's governance.

Policy, frameworks and work plans

There is usually confusion about what is a policy, a framework and a consumer engagement strategy or plan. Many consumer engagement policies include a consumer engagement framework; sometimes consumer engagement frameworks are developed in the absence of a consumer engagement policy; and consumer engagement work plans, or strategies are developed without a policy or framework as context. Organisations should have a policy, a framework and a work plan for consumer engagement.

A **consumer engagement policy** outlines the overall commitment and vision for consumer engagement of the organisation and how the policy relates to other organisational policies. It is a document that describes the long term aims and objectives, accountability and reporting requirements, the stakeholders (internal and external) and the resources available to support consumer engagement in the organisation. A consumer engagement policy should be linked to the organisational strategic plan, OHS policies, volunteer's policy, and other relevant policies such as consumer remuneration and reimbursement and confidentiality policies. A template to write a consumer engagement policy is in [Appendix 1](#).

Samples of consumer engagement policy are: [Early Start Australia Consumer Engagement Policy](#) and [DHHS Tasmanian Consumer, Carer and Community Engagement Policy](#).

A **consumer engagement framework** outlines the overall strategy the organisation has in place to implement its consumer engagement policy. It outlines the internal context, structures, personnel (staff), consumer engagement methods (including within the organisation and outreach and community initiatives) and resources dedicated to consumer engagement. It is a long-term document to be used in conjunction with the policy. Samples of consumer engagement frameworks are: [Cancer](#)

[Australia Consumer engagement strategy](#) and [Calvary Care Consumer and Community Engagement Framework](#).

A **consumer engagement plan** describes the specific initiatives, activities, responsibilities, human and financial resources (budget) and timelines to implement consumer engagement across the organisation. This is a short-term document that can last one to three years. Consumer engagement initiatives take time and ideally the work plan should take into consideration the need to plan and develop relationships with consumers and communities the health service seeks to engage. See a template to write a consumer engagement plan in [Appendix 2](#).

Challenges and how to address them

Each consumer engagement initiative will take place within an internal organisational context. The internal context will present challenges and constraints but also opportunities for the engagement process to be successful. It is important to identify the potential internal issues that may affect the engagement. The organisation should be able to demonstrate

- Leadership support and commitment to consumer engagement
- A clear understanding about the past experience of the organisation and of the staff that will engage with the consumers; their perception of risk related to engaging consumers¹⁶
- How potential barriers and challenges will be managed
- How meaningful engagement will be ensured
- How well the organisation and staff understand the consumer role.

The below suggestions to respond to organisational barriers and challenges have been adapted from Consumer Health Queensland's [Guide for Health Staff Partnering with Consumers](#).

- **“We’re struggling with lack of leadership buy-in”**
Consumer engagement needs to be supported and championed by organisational leadership including boards, executive and middle management. Staff can be leaders by asking how consumers will be involved from the beginning, and in an ongoing way in the development and production of any new policy, service or program.
- **“We don’t have the time, budget or resources”**
This is a very real and common barrier across health services with competing demands and stressors. Addressing this barrier requires unwavering buy-in and leadership from executive leadership and an acceptance that the process of engaging with consumers does take longer, but for good reason. A considered, and planned investment of time, resources and budget allocation will result in savings and improvements far greater than the investment. Making sure that consumer engagement is an ongoing item in the organisational budget, will ensure that human and financial resources are available when engaging with consumers.
- **“We have other priorities, partnering with consumers will need to come later”**
The vision and values of the organisation can be used to advocate for partnering with consumers. The goal is to build a culture that promotes consumer engagement as everyone’s responsibility and part of everyday processes.
- **“Consumers don’t have the necessary skills”**
Staff can play an important role in developing and supporting consumers, so they gain confidence and experience. Every consumer considered ‘experienced’ started with no experience. Seek expert advice, training and coaching according to consumers’ needs. It’s also important to acknowledge the skills that consumers do bring and to tailor engagements to tap into these.
- **“I’m not sure how to access the right consumer”**
There is no such thing as the ‘right’ consumer. There are usually a number of consumers who would be a valuable ‘fit’ for what the organisation is looking to achieve. It is important to establish mechanisms to ensure a range of active consumer voices across the organisation and not rely on a few individuals to speak for the community. For example, establish relationships

with consumer organisations and peak bodies that represent consumers and build a consumer register.

- **“We need more training and support”**

Identify organisation’s consumer engagement policies and procedures and the organisation’s consumer and community engagement strategy. This will help clarify what the organisation has committed to doing or is doing. Arrange training for staff and consumers as needed.

Reader highlight

Consumer engagement should not be undertaken purely with the purpose of responding to external requirements such as meeting accreditation standards or funding requirements. Tokenism must be avoided at all costs. Consumer engagement should respond to a thought-through and trustworthy process by which the organisation seeks to gain the consumer perspective in decision and policy making processes and in the governance of an organisation and their contribution is seriously incorporated into decision-making. Organisations must strive to work in true collaborative partnership.

Factors affecting effective consumer engagement

Consumer engagement in policy and decision-making and organisational governance is demanding and several factors must be taken into consideration for it to be effective. Special consideration to these factors is required when planning consumer engagement with diverse communities and seldom heard groups. For example, engagement on committees and other formal structures such as boards and working parties, may be challenging to consumers that may not be familiar with meeting-driven organisational processes.

Some of the issues include

- Meetings are conducted at a pace that may be challenging for some consumers
- Some consumers have said that there is not enough thinking time or that communication in meetings is too fast
- There is too much reliance on computer-based communication and not enough thought given to other forms of communicating
- There is also the issue of the content of communication, for example, the extent to which different parties have different perspectives or are on different wavelengths.

Other factors affecting effective engagement in structured settings are:

- Lack of interpreters
- Poor acoustic environments for communication, for example too much background noise
- Lack of accessible transport and finance for it
- Documents that are too long, complicated and not in plain language
- Difficult group dynamics and relationships, for example one or two dominating persons
- Lack of clarity about the role of the consumers on the committee and how much power and influence the consumers have in decision-making processes.

Process

The design of the consumer engagement process should follow closely the purpose of the engagement and the understanding of the internal context where the engagement will take place. The process of engagement is based on the purpose - this is, deciding what is to be achieved - and which methods should be used. The process of engagement will be strengthened if the organisation has the human and financial resources to support the engagement process.

For example, having

- Allocated staff time to support the internal process to engage with consumers and to support the consumers engaged
- An item for consumer engagement in the budget
- A policy regarding reimbursement and remuneration of consumers engaged.

Example templates and tools to budget for consumer engagement costs, and reimbursement guidance are available in Victorian Comprehensive Care [Centre's Consumer Remuneration Factsheet for staff and organisations](#) and Safer Care Victoria's [A guide to consumer remuneration](#).

The process will be strengthened if the organisation makes it clear to consumers that they are invited to engage in internal organisational decision-making processes and governance. These settings may present certain constraints and necessary confidentiality requirements which should be clear to the consumers from the beginning. Clear expectations and roles, Terms of Reference (ToR) or "rules of

engagement” and confidentiality statements should also be made clear from the beginning. Templates for ToR and confidentiality statements are found in [Appendix 3](#) and [Appendix 4](#). Efforts should be made to ensure that appropriate recruitment and selection processes are in place and that support is provided to the consumers engaged. Templates for consumer position descriptions, advertisements, selection interview questions, letters to successful and unsuccessful candidates, orientation kit, and remuneration and reimbursement policy, are in [Appendix 5](#), [6,7,8,9](#), and [10](#).

Support

Support for consumers should be in place to ensure that the engagement is meaningful and that consumers are acknowledged and informed of the results or impacts of their engagement. Support for consumers engaged across the organisation to meet and share experiences should also be made available. For example, acknowledging consumer contributions in Annual Reports, inviting consumers as co-presenters at conferences, inviting consumers to present their contributions to the board, thanking consumers for their contribution via intranet, on websites and staff meetings etc.

Consumer self-assessment and organisational assessments tools must be used on an ongoing basis to ascertain the effectiveness of the consumer engagement processes. Necessary amendments and changes are undertaken to address any difficulties or barriers to meaningful engagement.

Additional HIC resources

The following resources are available on HIC’s Website to enable the engagement process and support for consumers:

Guide for consumer to self-assess their engagement in healthcare organisations

This guide is for consumer representatives or advisors to self-assess the quality of their engagement in healthcare organisations.

Consumer Mentorship Program Manual and Guide

These two resources will provide the background information and step-by-step guidance to establish, implement and evaluate a mentorship program in a health or community service.

Terminology

Advisory committees, advisory groups, working parties, consumer councils and consultative committees are terms used to refer to formal or structured consumer engagement initiatives in an organisation. These types of formal structures of consumer engagement should be one of the many consumer engagement methods used by the organisation and they should be embedded within the organisation’s consumer engagement strategy and framed by the consumer engagement policy.

These formal consumer engagement initiatives respond to different aims or objectives. For example,

- **Advisory group** provides strategic expertise, usually to the whole organisation. As the name suggests, ‘advisory groups’ are for ‘advice’ and are not usually decision-making bodies.
- **Working groups** are set up to progress certain tasks.
- **Reference groups** are like advisory groups in form, but they tend to have a narrower focus. Where advisory groups are often at the organisational level and operate across a number of projects or services, reference groups are usually restricted to a single service or program within an organisation or a specific research project.
- **Steering committees** represent a higher level of engagement. The key difference between a steering committee and a reference group is decision-making capacity. As the name suggests, ‘steering committees’ direct programs, services and research projects and have substantial or even full control of decisions.¹⁷

Table 1 shows some of the terms used and below there are definitions that may help the health service to decide which modality to establish according to the consumer engagement policy and framework’s aims and objectives.

NOTE: The Victorian public health services Community Advisory Committees (CACs) established in Victoria under the Health Services Act 1988 have their own definitions and Terms of Reference. See the CAC Guidelines here [SCV CAC Guidelines](#)

Table 1: Terminology		
Stakeholder	Objective or role	Type
Consumer	Advisory	Committee
Carer	Reference	Group
Community	Steering	Council
Consumer, Carer and Community	Consultative	Working party
For example: <i>Community Advisory Committee</i> <i>Consumer and carer advisory committee</i> <i>Consumer, carer and community reference group</i> <i>Consumer and carer advisory council</i> <i>Consumer and community advisory panel</i> <i>Consumer and carer working party</i> <i>Consumer consultative committee</i>		Panel

Terminology explained

The following descriptions have been adapted from Health Consumers Queensland's [Guide for Health Staff Partnering with Consumers](#).

What is a project advisory or reference group?

Project advisory or reference groups are set up to advise on a specific project. They are often small groups of four to six members of the public who help with all stages of the project from developing aspects of the project design through to disseminating the results.

What is an advisory council?

Advisory councils can identify opportunities for improving the patient and family experience, advise on policies and practices to support patient and family engagement, and recommend how to better measure, quantify, and evaluate patient and family engagement. Specific roles of council members may include serving as a sounding board for new initiatives; generating ideas; sharing best practices; planning and evaluating programs; and providing input on institutional policies, programs, and practices.

What is a steering group?

Steering groups are made up of experts who oversee a project to ensure that protocol is followed and provide advice and troubleshoot where necessary. Their role is to provide input based on their direct experience of the topic of the project. The steering group usually meets at key stages during the course of a project and influences strategic decisions. A steering group is usually made up of high-level stakeholders or experts who provide guidance on key issues. Usually not representative of the broader demographic, a steering group is more a panel of experts who guide decision-making.

What are working group's or working parties?

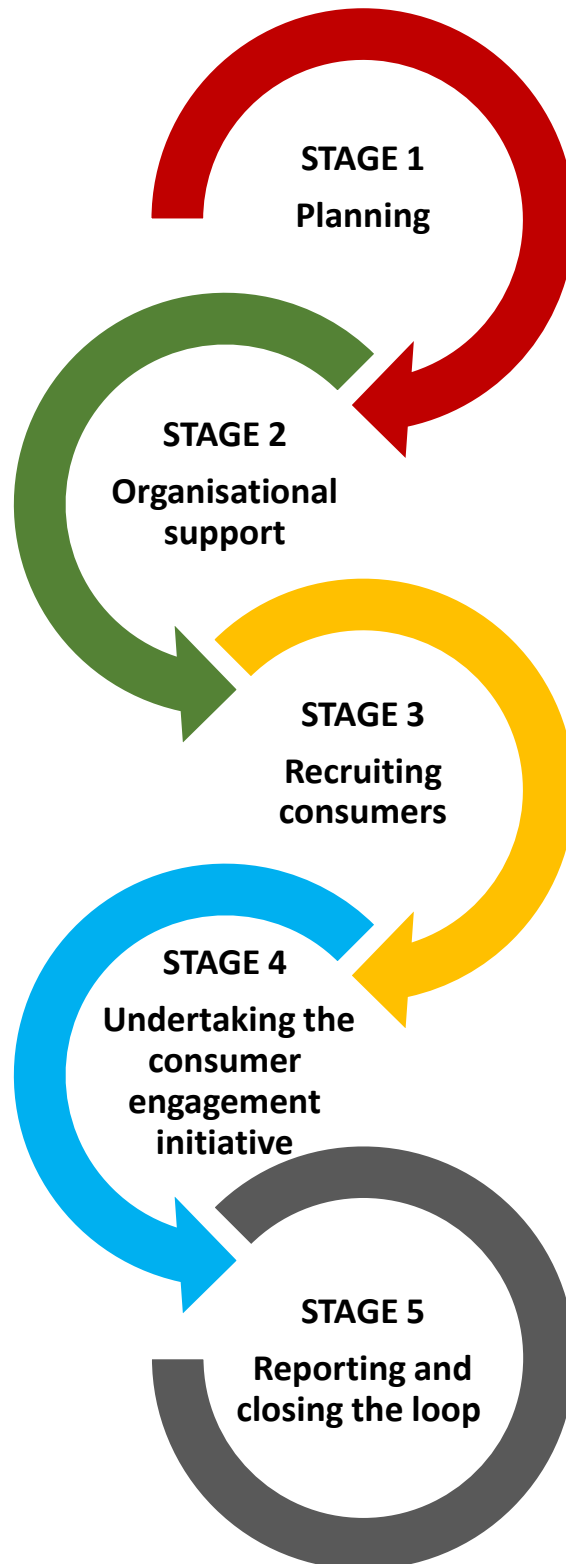
A working group, or working party, is a group of experts working together to achieve specified goals. The groups are domain-specific and focus on discussion or activity around a specific subject area.

What is a community consultative committee?

A community consultative committee is a group comprised of local residents, business owners, service providers and interest groups who can help a project team have meaningful and effective communications and discussions with the community affected by the project. In essence, a consultative committee is a partnership between a project team and the local community impacted by the project.

Planning a consumer engagement process

A successful process of consumer engagement should take into consideration the following stages:



Stage 1 - Planning

The questions to make sure to ask at this stage include:

- ✓ *What are the reasons and the rationale to engage consumers?*
- ✓ *Is there leadership understanding, support and commitment to consumer engagement?*
- ✓ *What are the issues, concerns or processes that the organisation is seeking the consumer perspective about?*
- ✓ *Will there be tangible outcomes as a result of the engagement process?*
- ✓ *Have the potential risks and benefits of the engagement been identified?*
- ✓ *Has the organisation engaged consumers in the past, if so, what has been the experience of this?*
- ✓ *Does the organisation have a clear understanding of the diversity of the consumers they seek to engage?*
- ✓ *Does the organisation have a clear position description, recruitment and selection processes and specifications of the attributes required from consumers?*
- ✓ *What support for staff and consumers is available to ensure consumer engagement is successful?*
- ✓ *What other stakeholders will need to be engaged in the consumer engagement process?*
- ✓ *Do the members of the board, the executive team, staff, committee or working party see the value and benefit to partnering with consumers?¹⁸*

Engagement on committees or advisory groups

During this planning stage it is also recommended to think about the most appropriate and effective ways to engage consumers. Would it be most effective and efficient to engage consumer representatives or advisors on a committee; or would it be more effective to organise a group of consumers in an advisory group which can provide consumer perspectives to the committee but from outside the meetings of the committee.¹⁹

Areas of engagement

Areas of consumer engagement in a health service may include:

- Information, communication and health literacy
- Policy
- Quality and safety
- Patient experience
- Research
- Community engagement
- Governance, leadership and culture

Additional HIC resource

Consumer Model – Partnering with Healthcare Organisations

This model shows how consumers at any stage of development or level of experience can play an active role across each of the about activity areas.

Methods of engagement

Selecting the most appropriate method to engage consumers is critical. This should be considered carefully during the planning stage and should be appropriate to the consumers being invited to take part.

A thorough overview of different engagement approaches is included in Appendix 11: Consumer engagement methods which health services can use as a guide.

Stage 2 - Organisational and secretariat support

Ideally, there is a staff member allocated to the consumer engagement initiatives across the organisation who provides secretarial support to staff and consumers.²⁰ This will mean that there is a dedicated person who takes responsibility for building relationships with the consumers and supports the different teams that seek to engage consumers. The secretariat staff:

- Acts as both the point of contact for the consumers and as a bridge, supporting consumers to fully integrate and partner with the organisational staff and other consumers.
- Organises and encourages meetings between all consumers engaged in the diverse committees and formal structures of consumer engagements across the organisation.
- Are responsible for facilitating and navigating recruitment and orientation of the consumers along with supporting ongoing communication and administrative needs.
- Ensures that potential barriers to the engagement of consumers are identified and addressed (i.e., meeting accessibility, hearing or visual impairments, childcare, travel arrangements, reimbursement, etc.).
- Helps the consumers to prepare for meetings and meets with consumers after engagement activities regularly to answer questions, acknowledge contributions and further develop relationship with the consumers.
- Helps in the resolution of challenging situations or communication issues
- Tracking and assessing the contributions of consumers from the perspective of both the staff and consumers.
- Communicates internally and externally about the consumer engagement initiatives and helps acknowledge and celebrate the consumers contributions.

If resourcing does not allow for a dedicated secretariat across all consumer committees, the committee should allocate a staff member do take on secretariat duties and develop supportive relationships with the consumer(s) on that committee. This still requires a dedicated consumer engagement lead at the organisational level.

Support to consumers on committees

When engaging consumers on committees, it is important to:

- Be clear about the role, purpose and benefits of the engagement.
- Provide clear guidance on the role, including time commitment, accountability and identifying conflicts of interest.
- Clarify the role to the rest of the committee and their status as an equal member. If it is a voting body, be clear about the rationale for including or excluding the consumer vote.
- Avoid unnecessary technical terminology or provide abbreviations and acronym lists.
- Provide interpreters, AUSLAN, or disabilities and visual aids if required.
- Make it clear which papers and sections of meetings contain confidential information.
- Be clear about confidentiality of patient-sensitive information, data protection requirements and how to handle media contacts.
- Provide financial or other recognition arrangements, reimburse out-of-pocket expenses, cover carer or personal assistant costs if required.
- Acknowledge consumer contribution in reports, Annual Report and conference presentations
- Acknowledge time constraints, consumers should have equal time to anyone else involved in the committee, time meetings conveniently, send papers at least one week ahead of the meeting.
- Ensure consumers have information, training and support, including IT skills.²¹

Stage 3 - Recruiting diverse consumers

Understanding the communities served

To undertake a successful engagement of diverse consumers to governance and decision-making processes in an organisation it is necessary to identify the diverse consumers, especially those from seldom heard groups, that are served by the health service. To do this, organisations should identify the demographics of the community they serve.

Ways to do this include using

- the [Australian Bureau of Statistics \(ABS\)](#) data by region
- the [Australian Health and Welfare Institute \(AHWI\)](#) reports and data
- the [Household, Income and Labour Dynamics in Australia \(HILDA\) Survey](#)
- the Victorian State Government's [Discover Victoria's diverse population](#) data

Diversity

Some of the diverse consumers to engage may be:

- those who do not speak English as a first language
- people from Aboriginal and Torres Strait Islander backgrounds
- children and young people
- Older adults
- LGBTQAI+ consumers
- People living with chronic illnesses
- People with disabilities (including sight and hearing impaired and people affected by speech impairments)
- People affected by mental illness
- Asylum seekers
- Those living in rural and regional urban centres.

They should also come from different backgrounds in terms of

- Educational attainment
- Socioeconomic status
- Religious beliefs and cultural values
- Employment history
- Contact with the justice system
- Experiences with the healthcare system

Strategic approach

The main strategy to engage with diverse consumers and seldom heard groups is to identify the main stakeholders and community organisations that represent these consumers. For example, peak bodies, advocacy organisations, or gender or LGBTQAI+ specific groups or associations, local community groups, condition specific organisations and peer-support groups, citizens and senior citizens clubs, sport and recreation organisations, churches and local places of worship, and charities.

Once the key organisation, community groups and key stakeholders or contacts for these groups are identified, the health service should contact these key people and establish communication about the intention to invite consumers to be engaged in the health services internal process and governance structures. At this early stage it is valuable to discuss what is expected to be the impact and benefits of the engagement. At this point, it would also be advisable to consult with key contacts about any previous engagement of consumers from their organisation, if there are any preferences or needs, and if there are any potential risks or barriers to the engagement of consumers from their group, peak body or organisation.

Identifying “what’s in it for them” is important. The organisation should consider and discuss with the key contacts what they want to get out of the process of engaging a consumer from their group, peak body or organisation and what could prevent them from participating. If motivations and challenges can be clarified at the beginning of the engagement process, there will be less confusion and participants will be satisfied with the outcomes.

One useful strategy to engage with local community groups and organisations is to make a list of these groups in the health service catchment area and seek invitations to attend their meetings. Local councils, health promotion programs and advocacy organisations usually hold list of the community groups on geographic area. A comprehensive list of condition-specific organisations is held by [Consumer Forum of Australia](#). Making a presentation about the health service and the specific engagement the health service seeks at these meetings will promote the initiative. Members of the group can then be invited to express their interest in getting engaged.

Reader Highlight:

An effective consumer engagement process with diverse consumers or seldom heard groups seeks to engage consumers through establishing relationships with consumers and organisations, peak bodies and organisations that represent them.

Stage 4 - Undertaking the engagement process

Participants

Deciding who will be invited to engage in organisational decision-making processes and governance will depend on the purpose and context of the engagement, which will set the parameters for which recruitment process to undertake. Engagement at the higher levels of the Ladder or Participation requires that those invited to engage are familiar with their community and the issue affecting them as well as the requirements of the board, executive team, committee or working party they have been invited to be a member of. It is expected that the consumers are holders of the specific information which is sought and that they are able (if required) to confirm with others to inform the consumer perspectives they bring to the table. Some caution needs to be applied when determining if staff or board members of a health service could serve as consumer representatives or advisors.

Health Consumers Queensland (2018) state “A staff member serving as a consumer representative may have a conflict of interest between their organisational role and their consumer role. This may cause confusion for other consumer representatives and committee members who are not clear whether their feedback or ideas come from the perspective of a consumer or a staff member. It may also prevent them from seeing barriers and solutions to issues and make it difficult to speak up where other staff are present. It is advisable that staff do not take on the role of a consumer representative within their own health organisation”.

Deciding who to engage

HIC's [Consumer Model - Partnering with Healthcare Organisations](#) (Consumer Model) describes the roles, characteristics and capabilities required of consumers who engage in healthcare partnerships. The Model is based on the five PiH dimensions and a continuum of engagement comprising of three stages of development that consumers align with - “emerging”, “evolving” and “excelling”. This taxonomy aims to represent the breadth and depth of the roles required of consumers to operate across key activity areas and within diverse contexts while at the same time respecting the contributions that consumer makes as they develop in their role.

Broadly speaking, most consumers go through a developmental process as they engage. Initially consumers are engaged as: expert patients, contributors, representatives and advisors; in time they develop skills and have knowledge to be considered also as: policy advisors, educators and community mobilisers; and at a more advance level of engagement, consumers are also considered: policy influencers, co-designers, decision-makers and deliverers of projects.

Health services can use this taxonomy and the roles, characteristics and capabilities outlined in the **Consumer Model** to help inform who will be best suited to engage in engagement activities targeting policy, decision-making, and governance.

Ideally health services should seek to engage at least two consumers on boards, executive teams, committees and working parties. Having just one consumer engaged is not recommended. Two consumers can support each other, brief and debrief before and after meetings, share the load of reading material and prepare for meetings, and one can attend if the other cannot attend a meeting.

Defining the role of a consumer representative or advisor

In Australia there are different terminologies to refer to consumers that engage in health service's governance, policy, and decision-making processes. The Consumer Health Forum of Australia (2021), for example, refer to ‘consumer representatives’ as those consumers who are invited to engage as representatives of professional bodies, peak bodies, advocacy groups, non-governmental organisation (NGOs) or community and local groups. While some health services refer to ‘consumer advisors’ as

those consumers, carers or family members who are current or past users of a health services and are invited to share their personal experiences of the health service (Alfred Health 2021, Mercy Health 2021). Their experience would assist to improve patient experience and ensure the patient perspective is considered in service improvements. Other commonly used terms include 'Consumer Advocate', 'Consumer Partner', 'Lived Experience Expert', or 'Lived Experience Advisor'. Health services should decide and discuss with consumers the preferred term which reflects best the role to be performed.

The consumers who were involved in the co-design of the **Consumer Model** developed the following broad definition for their preferred term 'Consumer Advisor':

"Someone who is interested in using their knowledge and experience to influence change in the health system can choose to become a Consumer Advisor. Consumer Advisors volunteer their time to health services, researchers, or government agencies and become important partners in improving outcomes for consumers. Consumer Advisors bring an outsider perspective to health organisations and are the voice for what really matters to health consumers and their communities.

Consumer Advisors can take on many different roles within the health system depending on their interests, skills, and level of experience. They may draw on their lived experience of being a health consumer. They may also contribute other relevant personal and professional experience that helps them to effect change. More experienced consumers can use their position to advocate for or represent broadly the needs of health consumers."

It is important that the health service engaging with diverse consumers agree on a definition and have a written statement regarding the status of the consumers engaged and if they will be consumer representatives – representing a constituency – or if they will be consumer advisors – providing the personal experience of healthcare. This is important also because it will determine the recruitment process to be undertaken. For example, contacting peak bodies and community groups and organisations to seek consumer representatives; or advertise in local newspapers or community boards; or advertise internally through information boards and relevant staff to seek consumer advisors from the users; or past users of the health services, their carers and family members.

In the case of engaging with diverse consumers, especially seldom heard groups, it is best to engage through community groups or peak bodies or organisations that represent them.

Logistics and administrative support

Staff should be allocated to provide briefing and debriefing before and after meetings and/or liaise with the relevant staff managing or providing secretariat to the board, executive team, committee or working party, and ask them to provide this support to the consumers engaged. Maintaining ongoing contact and communications with the consumers in person (when possible) and telephone calls and emails will be useful. Be mindful that some consumers may have differing levels of experience of acting as a consumer representative or advisor. Some will need more support than others.

Sometimes consumers will not be able to attend meetings. It is best practice to follow up with consumers when they miss meetings (i.e., send the minutes, phone to follow up). Let them know that their presence was missed, and their participation is valued. Provide opportunities to include their perspective outside meetings if possible, such as holding a conference call with the secretariat of the board, executive team, committee or working party, forward written minutes, resources and materials, etc.¹⁸

Stage 5 - Reporting and closing the loop

Identifying who should know about the consumer engagement initiatives will help to determine the type of report to be prepared and submitted. Summaries of the number of engagement initiatives and numbers of consumers engaged would be most suitable for boards and executive teams, while more detailed reports may be required for external funders and for others in the organisation who would be interested in detail data and analysis. Consumer-friendly summary reports would be useful for those consumers who participated in the engagement initiatives and their community groups, peak bodies or organisations (if nominated by them to engage).

Evaluation of consumer engagement

Evaluating the impact and outcomes of consumer engagement in the organisation is as important as evaluating the process of engagement. The main questions to answer when evaluating consumer engagement initiatives are:

- ✓ *Has consumer engagement improved the quality and safety of the health services offered to the community?*
- ✓ *Has it had a positive impact upon the design, implementation and evaluation of health services?*
- ✓ *Has it led to more consumer-focused policy and decision-making processes and the governance of the organisation?*

Below is a brief outline and possible questions to ask in a process, impact and outcome evaluation process that has been adapted from Cancer Australia's [Evaluation of consumer involvement](#).

Evaluation of the process: emphasis is on looking at all the processes involved in the activity as well as the immediate effects.

- How were consumers recruited and supported?
- How was the experience for consumers and what were the immediate effects for them?
- How was the experience for staff and what were the immediate effects for the organisation? (e.g., board, executive team, committee or working party?)
- Who were the consumers and how well did they represent the target group?
- What was the consumers' level of satisfaction with the engagement?
- What additional activities were undertaken in response to the needs of consumers?

Evaluation of the impact focuses on the short-term impact of the activity and is usually related to the objectives of the activity; normally includes unanticipated effects.

- Were the purpose, aims and objectives achieved?
- Were the activities effective to achieve the objectives of the engagement?
- Was the implementation of the activity achieved within the budget and timelines?
- Were the skills of consumers sufficient to implement the engagement initiative adequately?
- Were the skills and organisational support (human and financial) adequate?
- Was the feedback loop closed and all involved in the engagement initiative informed of the outcomes of the engagement?
- Were there any unintended effects of the activity?

Evaluation of outcomes identifies the long-term outcomes of an activity that are frequently related to the purpose and aims of a broader goal (e.g., consumer engagement policy). The long-term effects of an engagement initiative are usually the endpoints of an integrated approach to an issue. Thus, outcome evaluation would assess whether a consumer engagement initiative had achieved its main aim, the conditions required to implement this aim successfully in the future, and whether the conditions to successfully achieve an aim can be reproduced in the future.

References

- ¹ Horvat, L 2019. Partnering in healthcare for better care and outcomes, Safer Care Victoria, State Government of Victoria, Melbourne
- ² Sherry R. Arnstein. 1969. A Ladder of Citizen Participation. *Journal of the American Planning Association*.35: 4. pp. 216-224.
- ³ IAP2 International Federation. 2018. [IAP2 Spectrum of Public Participation](#).
- ⁴ Nathan S, Braithwaite J and Stephenson N. 2014. The scope and impact of community participation: The views of community representatives in an Australian health service, *Journal of Health, Organisation and Management*, 28: 405 – 42.
- ⁵ Edelman N and Barron D. 2016. Evaluation of public involvement in research: time for a major re-think? *Journal of Health Services Research & Policy*. 21(3): 209–211.
- ⁶ Boivin A, Richards T, Forsy L, Grégoire A, L'Espérance A, Abelson J and Carman K. 2018. Evaluating patient and public involvement in research. *BMJ*. 363:5147.
- ⁷ Pollard K, Donskoy AL, Moule P, Donald C, Lima M and Rice C. 2015. Developing and evaluating guidelines for patient and public involvement (PPI) in research. *International Journal of Health Care Quality Assurance*. 28 (2):141-155.
- ⁸ Kennedy, L.A., Rafferty, M. and Price, A. 2017. Service user, family member and carer engagement in mental health services in Ireland – A review of the literature. Mental Health Engagement Office. HSE. St Loman's Hospital. Palmerstown. Dublin.p.31
- ⁹ Australia Commission on Safety and Quality in Healthcare. 2008. Development of a consumer engagement statement for the commission. Consultation Report. p.3.
- ¹⁰ Alfred Health. 2021. [Become a Consumer Advisor](#).
- ¹¹ Mercy Health. 2021. [Consumer Engagement](#).
- ¹² Consumer Health Forum of Australia. 2021. [Consumer representation – the big picture](#).
- ¹³ Diversity Council of Australia. 2020. [D&I 101 - Conducting diversity survey](#).
- ¹⁴ Institute for Research and Innovation in Social Services. 2011. [Effectively engaging and involving seldom-heard groups](#).
- ¹⁵ Involve. 2005. [People & Participation. How to put citizens at the heart of decision-making](#).
- ¹⁶ Institute for Patient and Family-Centered Care. 2010. [A checklist for attitudes about patients and families as advisors](#).
- ¹⁷ The National Mental Health Commission. 2017. [Consumer and carer engagement: a practical guide](#).
- ¹⁸ Alberta Health Services. 2014. [A Resource Toolkit for Engaging Patient and Families at the Planning Table](#).
- ¹⁹ Health Consumers Queensland. [A Guide for Health Staff Partnering with Consumers](#).
- ²⁰ Consumer Health Forum of Australia. 2018. [Fact Sheet. Information for Consumer Representatives](#).
- ²¹ Gilbert D. 2012. [Working with lay members and patient representatives](#).p.14.

Appendices:

Appendix 1: Template to write a consumer engagement policy

Policy number:		Date adopted:	
Written by:			
Authorised by:			
Date last reviewed:	Reviewed by:	Date of next review:	
Policy context: This policy relates to:			
National standards	[Insert national standards relevant to the policy]		
Accreditation	[Insert accreditation requirements relevant to the policy]		
Legislation or other requirements	[Insert legislation relevant to the policy]		

Vision: Organisational vision for consumer engagement

Principles: Set of principles which will underpin consumer engagement across the organisation

Purpose/Rationale: Why do we have a participation policy?

Scope: This policy will apply to [indicate who the policy is for (consumers, carers, communities)] and definitions

Policy statement:

- Insert a general statement about the commitment your organization has about consumer engagement
- Also insert a list of actions the organization will undertake to implement this policy. These will be detailed further in your procedures.

Procedures

- Information strategies to ensure understanding of consumer engagement practice in your organization
- Support to participate. List of strategies used to support consumer engagement in the organization
- Strategies to involve consumers in service development and organisational governance and management
- Strategies to involve consumers in the planning and delivery of services

Other related policies and procedures

Documents related to this policy	
Related policies	
Forms or other organisational documents	

Review processes

Policy review frequency:	Responsibility for review:
Review process:	
Documentation and communication:	

SOURCE: Adapted from Queensland Council of Social Services. 2010. Participation policy template. Standards for Queensland Non-government Community Service Organisations (Standard 3)

Prepared by Health Issues Centre
February 2021

Appendix 2: template to write a consumer engagement plan

Organisational commitment

- Purpose of the consumer engagement plan - should align with the consumer engagement policy and framework
- Values and principles that will guide the plan
- Staff/stakeholders you need to help define the purpose of the consumer engagement plan
- Your team, section and organisation's current consumer engagement understanding and practice
- Your team or section's position in terms of work, time availability and other competing needs
- Involvement of key others within the organisation, a staff champion and management

Consumer engagement plan

Objective(s)	
Priority or focus areas	
Consumer engagement tools, methods, activities or approach to use (e.g. consultations, advisory groups, workshops, etc.)	
Budget (for internal costs and remuneration or reimbursement of consumers)	
Timeframes	
Training/coaching/mentoring for staff and consumers	
Communication strategy (internal and external)	
Potential risks and risk assessment	
Evaluation	

Prepared by Health Issues Centre
February 2021

Appendix 3: Template to write Terms of Reference

Terms of Reference (ToR) are important for any committee. Below is a suggested list of things you might want to include. Use this as a guide only, as ToR are best tailored to the particular group and written with their full participation. The less jargon and legalistic terms you use, the more useful you will find your ToR. It should be a tool to help you achieve, not an obstacle.

Mission statement or Vision

This is normally a short statement, preferably one or two sentences, stating what you hope to achieve, and your 'big picture' idea. For example, Starbucks' Mission Statement is: *'our mission is to inspire and nurture the human spirit – one person, one cup and one neighbourhood at a time.'* This really has nothing to do with making coffee – that comes later. What do you hope to achieve, broadly, as a group?

Purpose

This is a statement of the things the group can do. If there are policies, procedures or legislation that affect the group, mention them (briefly) here. If there is anything obvious that's outside the group's scope, mention it here. For example: 'The advisory group does not respond to individual patient and family complaints.'

Activities/specific issues to be addressed

In preparing this list (dot points are good), clarity is essential to provide focus and direction for the group. Be specific and realistic. This can be updated periodically as the scope or nature of the work progresses, so don't worry about trying to include everything.

Terms of membership

The terms of membership could also include the number of members, skills and experience required or preferred. For example, the group may decide that a specified number of members need to be users or former users of the health service.

You will want guidelines regarding timeframes for membership. For example, what is the term-length for members? Is there a limit to the number of years a person can be a member? Can long-term members be rolled over into a 'consumer emeritus' status which would allow them to be brought in for advice or to provide peer support without continuing as a member?

Resignation and dismissal of members

Normally a member of the consumer advisory group may resign at any time. It is helpful to incorporate into the Terms of Reference a system for eliciting feedback from a resigning member through an exit interview. This feedback is essential for understanding sources of dissatisfaction or disenchantment among members.

The organisation, or the advisory group itself, may choose to remove a person from the consumer advisory group if they decide it is not in the interests of the organisation (or the group) for the person to remain a member. This is obviously a decision which should not be taken lightly and should be done in conjunction with the consumer leaders among the group. If the organisation or group intends to make such a decision, they must give the member written notice setting out the intended decision and the grounds on which it is based.

There may be a number of possible reasons for dismissal of a member which you may wish to spell out. Some examples:

- the person is not working at the required standards (and is unable or unwilling to do so)
- they have contradicted the aims of the group
- the person has lost the trust and confidence of the other members

The organisation may also choose to add a clause which allows them to remove a person from the consumer advisory group if, without reasonable excuse, that person fails to attend a specified number of consecutive meetings.

Timeframes

- Expected duration of the group: Is it permanent? Or will it last only through a particular project?
- Are there any significant or obvious milestones along the way? Does the completion of these affect the membership of the group? For example, completion of one stage of a large project may mean it's necessary for members to change roles or there may be a need to recruit new members with a different set of skills or experience.
- Are the timeframes set in concrete or are they negotiable? If negotiable, under what circumstances?

Meetings

- Schedule and duration of meetings (e.g., monthly for 1.5 hours)
- Process for setting up periodic meetings and if meetings may be required other than those listed above
- Process to select a Chair and/or if Chair is to be rotating. This might include whether or not the Chair must be a consumer, the option of co-Chairs, etc.
- Position description for Chair. Will this role include administrative duties or will the organisation manage those?
- Who will determine the content of agendas? This is a very important issue as it will inevitably shape the focus and direction of the group.
- How will the minutes be recorded and distributed? Who is responsible for this?

Resources and training for members

- Reimbursement of out-of-pocket expenses will need to be covered in the Terms of Reference. For example, will members receive a sitting fee? Will other support for attendance be provided, such as travel costs, accommodation, parking, childcare, carer respite, etc.?
- What resources are available to the group and how they will be accessed? For example, secretariat and clerical, computer access, word processing, telephone, photocopying, catering for meetings, etc.
- Is there an orientation program for group members? If so, what is included in that program or information packet?
- Will there be any training provided for group members? This might include sessions on committee protocol or storytelling.

Reporting guidelines

Develop and include in the ToR a reporting structure, no matter how simple, for the group. Who will they report to, how and how often? Who will write or present these reports? This is essential not just for practical purposes, but because developing good reporting systems will help to increase the group's influence and ability to shape organisational policy.

Grievance procedure

Consumer members have the right to make a complaint in relation to the activities and operation of the group. The organisation may want to put in writing its commitment to resolving complaints fairly, reasonably and promptly. A complaint may be made in person or in writing. The first point of call should be the Chair of the group, then the person responsible for the group within the organisation (a member of the staff) and then the CEO of the organisation, before engaging in a formal grievance procedure.

The formal grievance procedure should follow standard procedures that the organisation has in place for management of complaints for staff and board members.

Review of the Terms of Reference

Establish the timelines for reviewing the ToR and the process to be undertaken. How often will they be reviewed and who will conduct the review? Ongoing groups may choose to allocate a time during a specific meeting every year for this process to occur.

Additional items

Some organisations have specific policies around confidentiality and/or a Code of Conduct for committee members and staff. You may need to cite these within the Terms of Reference.

Prepared by Health Issues Centre
February 2021

Confidentiality and Conflict of Interest statement for (insert title of the committee and organisation)

This agreement is made between [insert name of the organisation] and [insert full name], member of the (insert name of the committee).

I understand that:

Confidential Information means all information made available to me as a member of the (title of the committee) for the purposes of participating in the committee, whether orally or in writing, and includes information that it is by its nature confidential or is designated by [insert name of the organisation] as confidential.

Conflict of interest includes any conflict of interest, any risk of a conflict of interest and any apparent or perceived conflict of interest arising through my engaging in any activity or obtaining any interest that is likely to conflict with or restrict me as a member in performing the work of the committee fairly and independently.

CONFIDENTIALITY

I undertake to maintain the confidentiality of any material and information that may come into my possession and confine discussions of this material and information to meetings of the committee. This information may be related to personal and health information collected for the purpose of patient care, or for administrative or statistical purposes. I will ensure that such information, whether in the form of paper documents, emails, computerised data or in any other form is stored in a secure manner and place.

Signing your name means that you have read and understood the information above, that you have had a chance to ask questions relating to this statement, and that you agree not to share protected health information outside the committee in any written, verbal, or email communications.

Name of Member

Signature of Member

Date:

Name of Witness

Signature of Witness

Date:

CONFLICT OF INTEREST

I attest to the best of my knowledge and after making diligent inquiry, at the date of signing this Statement, no conflict of interest exists or is likely to arise in the performance of my duties as a member of the committee. If, during the period of my appointment to the committee, a conflict arises in respect of my membership, I will notify the Chair of the committee and withdraw from any discussion or decision concerning such a matter.

Signing your name means that you have read and understood the information above and that you have had a chance to ask questions relating to this statement and understand that you must declare any conflict of interest to the Chair of the committee and withdraw from discussions if this is the case

Name of Member

Signature of Member

Date:

Name of Witness

Signature of Witness

Date

Other resource: Consumer Health Forum of Australia. Confidentiality guidelines.
<https://chf.org.au/publications/confidentiality-guidelines>

SOURCES: Department for Health and Ageing, Government of South Australia. 2012. Guideline Consumer and Community Advisory Committee / Group (CACAC / CAG) Policy Guideline and Toolkit; Agency for Healthcare Research and Quality. 2017. Working with Patient and Families as Advisors Implementation Handbook; Nepean Blue Mountains Local Health District. 2013. Consumer Representative Information Package.

Prepared by Health Issues Centre
February 2021

Appendix 5: Template for consumer position description

POSITION TITLE	[Consumer/Carer/Community Representative/advisor]
REPORT TO	[Insert name and position of direct staff responsible for the committee management]
POSITION PURPOSE	[insert description from the committee's Terms of Reference]
MEMBERSHIP TENURE	[Insert time of tenure – commencement and finish dates and if the position could be extended for another period. E.g. Fulfill a two-year term with possible extension]
KEY RESPONSIBILITIES*	[List the key responsibilities. See below possible options regarding role descriptions. Key responsibilities should match the committee's Terms of Reference]
SKILLS and EXPERIENCE*	[List the expected skills and experience of the candidate. See below some suggestions]
CONFIDENTIALITY AGREEMENT	[See template sample]
CONFLICT OF INTEREST	[See template sample]
REVIEW PERIOD	[Insert when the position description will be reviewed. E.g. every 2 years]

***KEY RESPONSIBILITIES**

This is a list of possible key responsibilities. Not all have to apply. You may choose from the list the options that best address the committee's Terms of Reference.

- Presents a broad consumer, carer or community perspective
- Provides a consumer perspective which is informed by feedback and the experiences and opinions of other consumers as well as their own experience and opinions
- Provides an important perspective to priority setting, discussions and decisions
- Has knowledge and understanding of the health system
- Has knowledge and understanding of health services governance structures
- Protects the interests of consumers
- Identifies and advocates for consumer perspectives in decision making
- Reports the activities of the committee to consumers according to confidentiality agreements
- Ensures that there is communication and dialogue between the committee and other consumers across the organisation
- Demonstrates ability to attend meetings and other meetings as negotiated
- Shows ability to work as a member of a committee of consumers
- Participates in self-assessment and review of committee proceedings as required
- Demonstrate commitment to safety and quality improvement in health services
- Show commitment and ability to consult with a broader consumer constituency
- Prepare and read materials and documents provided in preparation for meetings
- Comply with agreed upon terms of reference, confidentiality and conflict of interests
- Provide a satisfactory police record check if required

***EXPERIENCE**

This is a list of possible experience required. Not all have to apply. You may choose from the list and/or add other experience that best address the needs of the committee.

- Must have had a healthcare experience within the last 10 years
- Must be users of the health service or care for someone who uses the health service or be an interested members of the community where the health service is located
- If affected by a health condition, there must be two years since the initial diagnosis
- Have experience working collaboratively with other consumers, carers and community members, health practitioners, health system administrators and managers
- Has previous experience as a consumer representative/advisor in a health field

***SKILLS**

- Demonstrates consumer leadership skills
- Demonstrate ability to positively influence others and build consensus
- Demonstrates effective management of time and self-care
- Applies verbal communication skills
- Is able to present ideas and comments to the group
- Demonstrates an open mind on issues and awareness of own prejudices
- Applies negotiation and conflict management skills
- Has ability to problem-solve and resolve issues
- Brings energy and enthusiasm to the position
- Has ability to seek help or assistance when unsure or concerned about any issues

SOURCES: Department for Health and Ageing, Government of South Australia. 2012. Guideline Consumer and Community Advisory Committee / Group (CACAC / CAG) Policy Guideline and Toolkit; Institute for Patient- and Family Centred Care. 2019. Creating Patient and Family Advisory Councils; One Island Health system. Engagement tool. Health PEI.

Prepared by Health Issues Centre
February 2021

Appendix 6: Template for consumer position advertisement

Health service	
Program/Project	
Committee	
Purpose of the committee	
Role of the consumer on this committee	
How many consumers are required?	
Skills, interests or experience the consumer should have	
Where meetings will take place	
Time commitment	
Commencement date	
Length of appointment	
Remuneration/reimbursement	
Supporting information	
How to apply	
Contact information	

Prepared by Health Issues Centre
February 2021

Appendix 7: Interview guide for consumer positions –SAMPLE

Below are some possible interview questions for when you are selecting consumers to be engaged as consumer representatives or advisors in your organisation. It would be unusual to use all of these – and probably somewhat intimidating. We recommend choosing several from the list and using as is or adapting to meet your particular position requirements.

General questions

- What appeals to you about this position or committee?
- What is your understanding of the role?
- How do you think you can best contribute to our work?
- How might your personal consumer experience be relevant or useful?
- Have you (or a family member or a friend) had an experience of health care in the last five years?
- Have you been diagnosed with a health condition in the last two years?
- Have you been involved as a consumer representative or advisor and with which organisation (s)?
- How confident are you in representing the needs of others as well as your own?
- Are you engaged in a consumer advocacy organisation or a community group?
- What are your areas of interests?
- Are there areas that you wish to develop skills in?
- Do you anticipate particular challenges or frustrations with this work?
- How would you like to receive information/communicate with the health service?
- What communications and computer technology are available to you? i.e. do you have access to a phone and the internet?
- Is there any other information that you think might be important for us to know about you?

Competency based questions

Communication

A part of this role involves discussing and evaluating options or ideas in a limited timeframe. Can you discuss a time when have you had to present an idea to a group of people for their feedback? How did you do it? What was their response?

What to look for: Actively listens, checks understanding, expresses ideas clearly, uses appropriate language.

Teamwork

What sort of teams or committees have you been involved in? What was your role?

What to look for: Encourages a supportive environment, encourages free exchange of ideas, encourages feedback.

Innovation and initiative

We are always looking for better processes or ways of doing things. When have you identified a new, unusual or different approach to solving a problem or facing a task?

What to look for: Generates solutions, uses novel approaches, suggests ideas for improvement.

Appendix 8: Template letters to successful and unsuccessful candidates

Applicant's name
Street address
Suburb, state, postcode
Date

Dear [Applicant's name]

Thank you for your application for the position of [insert position].

I would like to personally congratulate you on your great interview on the [insert date]. I would at this time like to offer you the position of [insert position].

We look forward to you joining our team. Please notify [insert name and contact details] of your intention to accept this offer.

Should you accept the position, as conveyed during the interview process, you will be required to complete an induction meeting. Additionally, we will at this time commence our engagement verification process by asking you to obtain a police check [if required].

Thank you for your interest in joining us at [insert name of health service] and for taking the time to submit an Expression of Interest and attend the interview.

Yours sincerely

Name of health service representative
Title

Date

Applicant's name

Street address

Suburb, state, postcode

Dear [Applicant's name]

Thank you for your application for the position of [insert position].

We have received many applications from well-qualified and experienced candidates.

Unfortunately, on this occasion your application for the [insert position] was unsuccessful.

Nevertheless, we at [insert name of health service] offer many other opportunities to engage with consumers and you may be interested in joining us in another capacity.

If you are interested in joining us in other of our consumer engagement initiatives, please contact [insert name, position and contact details].

We wish you well in your future endeavours and encourage you to get in touch with us and apply again in future if a suitable position becomes available.

Yours sincerely

Name of health service representative

Title

Prepared by Health Issues Centre
February 2021

Appendix 9: Induction/orientation kit for consumers on health service committees - SAMPLE

Introduction

Welcome to *(insert name)* Committee. We are delighted you have decided to help us improve the services within *(name of health service)* and look forward to your contribution.

There is evidence that active consumer participation in health service planning improves the quality of health care and the effectiveness of health systems as a whole. Your role as a consumer representative or advisor is really important to us and will assist us to meet the needs of the communities we serve.

We will do our best to assist you in your role as a consumer representative or advisor on a committee and to support you in any way we can.

About *(insert name of health service)*

- *[Insert information about your health service]*
- *The vision and goals of the organization*
- *Consumer engagement policy, framework and plans*

Definitions

Consumer

“Consumers include people, families, carers and communities who are current or potential users of health services. This includes children, women and men, people living with a disability, patients, carers, clients, people of diverse cultural, linguistic and religious experiences, socioeconomic status and social circumstances, sexual orientations, sexes, genders and gender identities, health and illness conditions. The term also includes people who choose to get involved in decision-making; health consumer representatives who provide advice on behalf of consumers, with the overall aim of improving healthcare; and carers who often have an important role in health care decision making and care giving. Different health settings use terms such as: patients, people/persons, families, carers, clients and residents”.

Consumer engagement

“Consumer engagement reflects an approach involving the development of meaningful relationships with a shared focus. Consumer engagement is underpinned by trust and mutual respect, a commitment by all involved and active two-way dialogue. The term consumer engagement indicates that action is more than simply taking part.’

Consumer representative

“A health consumer representative is a health consumer who has taken up a specific role to provide advice on behalf of consumers, with the overall aim of improving healthcare. A consumer representative is often a consumer member of a committee, project or event, who voices consumer perspectives and takes part in decision-making on behalf of consumers. A health consumer representative may be nominated by, and accountable to, a consumer organisation. Usually the person works with a health service or consumer organisation, but they may also operate independently in some activities”.

[Insert other definitions as required]

Reporting

(Insert information about whom the committee reports to and is supported by)

Your role as a consumer on a committee

The role of the (insert name of committee) is outlined in the Terms of Reference. A copy of this document is attached.

Your role as a consumer member of this committee is to ensure that the perspective of our consumers is included in all of the committee's discussions, decisions and recommendations.

It is important that we are always conscious of the impact our decisions will have on the people who are using our health service.

Being on a committee is about working in collaboration with the health services. As a member of the committee, you need to think not just about your views and issues but about the broader community and the collective impact on all consumers.

Support for consumers on committees

Your support person/people for the *(insert name of committee)* is *(insert name and contact details)*. He/she should be your first point of contact for any questions, feedback or other issues.

The Chair of committee has the responsibility to help all members of the committee to participate in decision-making. The Chair plays a significant role in the business of the committee including keeping track of decisions made, action taken and ensuring that all members are treated fairly and respectfully. The Chair will introduce you to other members of the committee when you commence your role.

The Secretary of the committee is in charge of sending out the papers and making sure items are put on to the agenda. The Secretary will usually send out the agenda prior to the meeting.

Participation in meetings

Before the meeting

Read the agenda and minutes of the last meeting. It might be worth meeting with your contact person on the committee prior to the meeting, to ask any questions about anything that is new to you, or you don't understand.

If there is any jargon or medical terminology that you do not understand, ask for an explanation. Make some notes about any points or questions you would like to raise.

At the meeting

Feel free to ask questions about anything you don't understand. You can also join in the discussion and make comments.

Clarify if you can add items to the agenda, whether this be at the beginning or end of the meeting. If items are dropped, use 'other business' to have them put on the agenda for the next meeting.

After the meeting

If you had any difficulties with the meeting, make a time to discuss them with your support person on the committee as soon as possible.

Frequently asked questions

How do I make sure I am clear about my role and expectations?

The Terms of Reference has been provided to you. If you have any questions about your role, your support person will be available to discuss this with you.

What training and support will I receive as a consumer to support me in my role?

[Insert your information here] e.g. training; mentoring and coaching; meeting with other consumers; briefing and debriefing before and after meetings, etc.

What are my entitlements as a consumer committee member?

[Insert your information here] e.g. reimbursement for out-of-pocket expenses; remuneration; participation in conferences and workshops, etc.

Who do I talk to if I am having difficulties in my role?

If you are having any difficulties, please talk to someone who you feel comfortable discussing it with. This could be your support person on the committee, another member of committee or the Chairperson. Do not be afraid to voice your concerns. We want to ensure that you have every opportunity to fulfil your role.

Resources

Websites - Websites that you may find useful in your role as a consumer committee member:

- [Health Issues Centre](#)
- [Safer Care Victoria – Partnering with consumers](#)
- [Australian Commission on Safety and Quality in Healthcare – Partnering with consumers](#)

Attachments *(information from your health service)*

- Terms of Reference
- Consumer position description
- Site map/s
- Organisational chart
- Confidentiality and conflict of interest statements
- Reimbursement and/or payment information
- Additional relevant organisational information (e.g. Strategic plan, CPP plan)

Prepared by Health Issues Centre
February 2021

Appendix 10: Consumer remuneration template

A **consumer remuneration and reimbursement of consumers policy or guidelines** describes the way the organisation will offer remuneration or reimburse consumers for out-of-pocket expenses they may incur to be able to perform their representative or advisory role

Consumer name:

Program and activity	Date	Amount	Code (office use only)

Consumer signature:

Date:

Approved by:

Signature

Date:

Prepared by Health Issues Centre
February 2021

Appendix 11: Consumer engagement methods

The consumer engagement methods presented in the following tables describe consumer engagement methods that can be used to undertake engagement in healthcare partnerships with consumers. It aims to capture best practice consumer engagement at the higher levels of the Ladder of Participation – partnership, delegation and control – for health service design, development, implementation and evaluation. It also aims to describe consumer engagement methods to be applicable to the PiH’s levels of engagement: service level, or systems level.

Some of the descriptions of methods listed below have been adapted by HIC from the original sources.

CONSUMER ENGAGEMENT METHODS

Service level



Co-led redesign of health services

Co-led redesign involves the collection of quantitative data for assessing the current systems and the collection of qualitative data through patient, family, and staff interviews to determine the barriers to patient satisfaction. Consumer involvement in organisational design and governance provides an opportunity for patients to partner with health care providers in planning, delivering and evaluating health care. Interviewing patients and their families allows them to identify gaps and strengths of the system and influence the redesign of health care services.

SOURCE - Prior SJ, Campbell S. 2018. [Patient and Family Involvement: A Discussion of Co-Led Redesign of Healthcare Services](#). J Participant Med. 10 (1)e5

Experience based co-design

Experience-based co-design involves gathering experiences from patients and staff through in-depth interviewing, observations and group discussions, identifying key “touch points” (emotionally significant points) and assigning positive or negative feelings. A short, edited film is created from the patient and staff interviews. This is shown to staff and patients, conveying messages about how patients and staff experience the service. Staff and patients are then brought together to explore the findings and to work in small groups to identify and implement activities that will improve the service.

SOURCE - Australian Healthcare and Hospitals Association (AHHA) and Consumers Forum of Australia (CHF). 2017. [Experience-based-co-design. A toolkit for Australia.](#)



Patient-reported experience measures (PREMs)

Patient-reported experience measures (PREMs) are used to obtain patients’ views and observations on aspects of health care services they have received. This includes their views on the accessibility and physical environment of services (for example, waiting times and the cleanliness of consultation rooms and waiting spaces) and aspects of the patient–clinician interaction (such as whether the clinician explained procedures clearly or responded to questions in a way that they could understand).

Consumers can be invited to review this data and then be involved in to implementing quality improvement projects.

SOURCE - Australian Institute of health and Welfare. 2018. [Patient-reported experience and outcome measures.](#) Australia’s Health 2018



Walkabout

Conducting a walkabout from the patient and family perspective. The walkabout focuses attention on the expertise that consumers bring to the table and helps build trust in and comfort with the collaborative process. The walkabout and related meetings can also be beneficial for patients and families to build their understanding of staff and clinician perspectives and to help them understand care processes and the environment of care. The walkabout process also allows consumers to begin to get a broader view of the positive elements of the system of care as well as areas for quality and safety improvement.

SOURCE - Agency for Healthcare Research and Quality. 2017. [Working with Patient and Families as Advisors Implementation Handbook](#), p.35-37

Patient-reported outcome measures (PROMs)

Patient-reported outcome measures (PROMs) capture a person's perception of their own health through questionnaires. They enable patients to report on their quality of life, daily functioning, symptoms, and other aspects of their health and well-being.

Responses to PROMs questions help hospitals and healthcare services to provide the care that patients need and want. These measures aim to fill a vital gap in our knowledge about outcomes that matter to patients.

Health services should bring consumers together to review this data and then collaboratively set goals with the health service to improve patient experience and health outcomes.

SOURCE - Australian Commission on Safety and Quality in Healthcare. 2021. [Patient-reported outcome measures](#)





Consumers as teachers

Partner with consumers to deliver curriculum by, for example, using patients and families as faculty or mentors and including patient and family feedback and perspective as key parts of learner assessment.

SOURCES - Carman KL, Dardess P, Maurer ME, Workman T, Ganachari D and Pathak-Sen E. 2014. A [Roadmap for Patient and Family Engagement in Healthcare Practice and Research](#).

*American Institutes for Research, Gordon and Betty Moore Foundation. Palo Alto, CA. p.21
Doubleday Centre for Patient Experience .2021. [Get involved](#)*

NHS England, Nesta and the Health Foundation. 2016. Realising the value. [Ten key actions to put people and communities at the heart of health and wellbeing](#)

Consumer activated rapid response teams

The Rapid Response Team invites consumer to serve as members of the working group to advise on the planning, implementation, and evaluation of patient and family activation of Rapid Response Teams.

SOURCES - Institute for Family and Patient centre Care. 2009. [Applying Patient- and Family-Centred Concepts to Rapid Response Teams](#).

Institute for Healthcare Improvement. 2021. [Delivering Great Care: Engaging Patients and Families as Partners. Improvement Stories](#)



Consumers involved in staff selection

Partner with patients and families on hiring and staffing issues, for example, by having them interview candidates for leadership positions and participate in other hiring decisions and performance evaluations.

SOURCES - Carman KL, Dardess P, Maurer ME, Workman T, Ganachari D and Pathak-Sen E.2014. [A Roadmap for Patient and Family Engagement in Healthcare Practice and Research.](#)

*American Institutes for Research, Gordon and Betty Moore Foundation. Palo Alto, CA. p.31
Baxter s, Clowes M, Muir D, Baird W, Broadway-Parkinson A and Bennett C.2017.*

Supporting public involvement in interview and other panels: a systematic review. Health Expectations.20:807–817



Systems levels



Community researchers

Community researchers are consumers who provide a link between the health service, patients and the wider community by researching local needs, identifying gaps in provision, gathering feedback and disseminating information to the community. Consumers are given training and support to provide consumer perspectives into the design and delivery of services. They connect with existing local organisations and community groups and libraries, schools, neighbourhood houses, etc. as well as visiting people in their homes and connecting with other service providers and volunteers.

SOURCE - NESTA. 2013. [By us, for us: the power of co-design and co-delivery.](#) Innovations Unit. UK. P. 12-13

Consumer advisory groups/councils – CACs

Community advisory committees provide a formal way for health services to work with their communities and listen to their needs. They serve the role of advocating for their community and advising the board on the community needs. The committee is accountable to the health service board, which in turn is accountable to the Minister for Health

SOURCE - Safer Care Victoria. 2020, [Building your healthy community A guide for health service community advisory committees.](#)



Consumers involved in research prioritisation

Partner with patients and families to determine organisational research priorities and design organizational research projects.

SOURCE - Carman KL, Dardess P, Maurer ME, Workman T, Ganachari D and Pathak-Sen E. 2014. [A Roadmap for Patient and Family Engagement in Healthcare Practice and Research.](#) American Institutes for Research, Gordon and Betty Moore Foundation. Palo Alto, CA. p.31



Consumers involved in the health service board

Consumers sit on the governing body of the health service or board of management.

SOURCES - Kennedy, L.A., Rafferty, M. and Price, A. 2017. [Service user, family member and carer engagement in mental health services in Ireland – A review of the literature.](#) Mental Health Engagement Office. HSE. St Loman's Hospital. Palmerstown. Dublin.

Carman KL, Dardess P, Maurer ME, Workman T, Ganachari D and Pathak-Sen E. 2014. [A Roadmap for Patient and Family Engagement in Healthcare Practice and Research.](#) American Institutes for Research, Gordon and Betty Moore Foundation. Palo Alto, CA. p.3



Consumers presenting at conferences

Invite patients and families to participate in conferences and meetings as keynote speakers or participants on panel presentations.

SOURCE - Carman KL, Dardess P, Maurer ME, Workman T, Ganachari D and Pathak-Sen E.2014. [A Roadmap for Patient and Family Engagement in Healthcare Practice and Research](#). American Institutes for Research, Gordon and Betty Moore Foundation. Palo Alto, CA. p.55



Engage consumers in research

For research projects, such as clinical trials, comparative effectiveness research, health services research, and quality improvement, partner with patients and families to formulate research questions and study design; implement and monitor the study; analyse and interpret results; plan and disseminate findings; prioritise research topics and questions for funding; and review grant applications.

SOURCE - Carman KL, Dardess P, Maurer ME, Workman T, Ganachari D and Pathak-Sen E.2014. [A Roadmap for Patient and Family Engagement in Healthcare Practice and Research](#). American Institutes for Research, Gordon and Betty Moore Foundation. Palo Alto, CA. p.37



Engage consumers in data information – public data reporting

Work with patients and families to identify and report the quality, cost, and safety data that are most important to them and for all patients and clinicians.

SOURCE - Carman KL, Dardess P, Maurer ME, Workman T, Ganachari D and Pathak-Sen E.2014. [A Roadmap for Patient and Family Engagement in Healthcare Practice and Research](#). American Institutes for Research, Gordon and Betty Moore Foundation. Palo Alto, CA. p.41



Reference group – Older people/aged

A group of older people regularly provide feedback and support to government and provides the views of older people directly into government policies and programs.

SOURCE - Government of South Australia, Office for the Ageing (OFTA) and Department of the Premier and Cabinet (DPC). 2016. Better Together: A Practical Guide to Effective Engagement with Older People [Better Together Guide to Engage with Older People](#)



Ideas groups

Using ideas groups will help to brainstorm issues and related ideas for improvements. It is an easy, fast, fun way of scoping potential improvements and innovations.

SOURCE - Boyd H, McKernon S, and Old A. 2010. [Health Service Co-design: working with patients to improve healthcare services](#). Auckland: Waitemata District Health Board. pp 70-72



Stakeholder needs table

A stakeholder needs table shows you what different stakeholders need and what improvements will help more than one stakeholder. Useful to compare one stakeholder's needs against those of another. For example, patient needs and ideas can be identified and compared to managerial, clinical and other stakeholder needs.

SOURCE - Boyd H, McKernon S, Old A. 2010. [Health Service Co-design: working with patients to improve healthcare services](#). Auckland: Waitemata District Health Board. pp 74-77

Youth reference committee – Young people

A group of young people regularly meet to provide feedback and support to government and provides the views of young people directly into government policies and programs.

SOURCE - Government of South Australia, Office for the Ageing (OFTA) and Department of the Premier and Cabinet (DPC). 2016. Better Together: A practical guide to effective engagement with young [Better Together. Guide to engaging with young people](#)

