# A Guide for Health Staff Partnering with Consumers



# Acknowledgement of Traditional Owners

The Board and staff of Health Consumers Queensland acknowledges the Australian Aboriginal and Torres Strait Islander peoples of this nation. We acknowledge the traditional custodians of the lands on which our organisation is located and where we conduct our business. We pay our respects to ancestors and Elders, past, present and future for they hold the memories, traditions, culture and hopes of Aboriginal and Torres Strait Islander Australia.

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## Introduction

A Guide for Health Staff: Partnering with Consumers is written to help health staff develop effective consumer partnerships and complements our companion Consumer and Community Engagement Framework.

A second Guide titled A Guide for Consumers: Partnering with Health Organisations supports health consumer/ carer representatives. Together the Guides provide advice and practical information to make consumer partnerships more productive and effective.

This Guide can be used by staff in any area

and at any level of a health organisation to support partnering with consumers. Use this Guide as a quick reference tool and dip in and out as you need. It has been written to be read a section at a time.

The first section focuses on the context of consumer partnering: what it is, the standards and frameworks that guide it and some primary considerations for partnering including cultural capability and barriers and enablers.

The second section details how to partner with consumers when recruiting for formal consumer representative roles, including how to recruit, orient and support consumers.

## What is Consumer Partnering?

Consumer partnering is known by many names including consumer engagement, consumer participation, consumer collaboration and co-design. When we developed our *Consumer and Community Engagement Framework*, Health Consumers Queensland used the term "engagement", but the term "partnering" better describes the intention of the activity.

There are many ways consumers can partner with health organisations. This may include ongoing membership of a committees or in one-off activities such as focus groups, surveys, or as speakers at training. Partnering with consumers improves the outcomes, experiences and the delivery of health care by drawing on the knowledge, skills and experiences of past, present and future users of health services.

Consumer partnerships exist when health consumers/ carers influence the way health organisations plan, organise, deliver, monitor and evaluate their work. Partnerships need to be two-way, equal, respectful and cooperative.

Your role as a staff member is to enable consumer partnerships. These partnerships support the fundamental concept that the people affected by a decision have a right to participate in making that decision.

#### Why Partner with Consumers?

Health consumers expect accountability and transparency from health organisations. Many are motivated to improve their health and wellbeing as well as that of their families and communities. Research shows that partnering with consumers delivers positive results for both health organisations and health consumers/ carers, better health outcomes for all and more accessible and responsive services.<sup>1</sup>

For more detailed information on the benefits of partnering with consumers please see our *Consumer and Community Engagement Framework.*<sup>2</sup>

### Who is a health consumer representative?

A health consumer or carer representative (who we will refer to throughout the guide as a **consumer representative**) is someone who has taken up a formal role to advocate on behalf of health consumers in partnership activities within a health organisation, with the overall aim of improving healthcare for all.

Anyone who has ever used the health system can be a consumer representative. The insights and observations of consumer representatives come from their lived experience.

Ensuring the right people are at the table is one of the keys to successful consumer partnerships. Ideally, you want consumer representatives:

- who have expressed a desire to create change in the health system and are solution focused
- whose primary experience is in receiving care or being a carer of a person receiving health care
- who are past, present or potential users of the service
- who come from all walks of life with varied health and life experience
- have an interest or lived experience in the area of health that is the focus of the activity e.g. a consumer with vision impairment is a consumer partner to codesign a service specifically for people with a vision impairment.



Warwick Hospital Community Advisory Group (left to right): Julia Keogh, Chamber of Commerce; Peter Gillies, Consumer Representative; Jim Westerman, Consumer Representative; David Keenan, CEO Southern Downs Regional Council; Anita Bolton, DON/FM Chinchilla Hospital; Craig Sadler, Churches of Christ; Donna Lucas, Consumer & Community Engagement Officer DDHHS.

> Health Consumers Queensland uses the term consumer representative, but these roles are referred to in a number of ways, for example, consumer advocate, consumer advisor, community representative.

# Health staff as consumer representatives

We are all users of the health system. Health consumer representatives come from outside the system and their primary experience is that of receiving care. They bring fresh perspectives and ask questions that others within the system may not think to ask.

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.

## The role of a consumer representative

A consumer representative's role is to provide feedback and advice to health organisations to influence healthcare services, policy, systems and service change and reform from the consumer perspective.

You can expect a consumer representative to:

- Keep health consumers at the centre of all discussions
- Provide a perspective which reflects both their health journey and the collective experience of health consumers
- Raise consumer concerns and views, ask questions, test assumptions and identify gaps
- Assist the health organisation and health professionals to see beyond the clinical perspective
- Be connected and provide feedback to their own formal and informal networks
- Maintain confidentiality and disclose any conflicts of interest
- Speak up when they disagree, raise their concerns and have this formally acknowledged in the minutes or record of the activity.

You should **not** expect a consumer representative to:

- have a technical background or understand complex clinical or technical jargon
- undertake formal consumer consultation that would normally be carried out by a member of staff or a paid consultant
- be a lone consumer representative on a highly clinical or technical committee, or committee with a significant number of clinical staff such as a clinical governance steering group.

"Having a consumer on our committee has added a whole lot of merit. It opens conversations that otherwise wouldn't happen."

Keppel Schafer, Acting Director of Nursing, Women's and Families. Sunshine Coast Hospital and Health Service

## **Drivers of consumer partnering**

There are a number of charters, frameworks and standards on consumer partnerships that guide and support staff to partner successfully. These resources provide a deeper understanding of the history and context of consumer partnerships. More information on the legislative and policy context of partnering is in our Consumer and Community Engagement Framework.

#### Australian Charter of Health Care Rights<sup>3</sup>

The Australian Charter of Health Care Rights states that consumers have a right to be included in decisions and choices about their care and the right to participate in health service planning. It specifies seven key rights of patients and consumers when they are seeking or receiving health care services. It applies to all health settings in Australia (private or public hospitals, general practice and other community environments).

#### National Safety and Quality Health Care Standards<sup>4</sup>

Australian hospitals and health services, including day hospitals and dental clinics, are accredited against the National Safety and Quality Health Care Standards. A revised version of the Standards was launched in November 2017 for implementation by health organisations from 2019.

Standard 2: Partnering with Consumers aims to ensure that consumers are partners in the design, delivery and evaluation of healthcare systems and services, and that patients are given the opportunity to be partners in their own care. All actions are mandatory, and there is an increased focus on health literacy, comprehensive care planning and considering the needs of Aboriginal and Torres Strait Islander consumers (For more information on health literacy please see page 15).

#### National Safety and Quality Health Service Standards: User Guide for Aboriginal and Torres Strait Islander Health<sup>5</sup>

This user guide defines six actions that specifically meet the needs of Aboriginal and Torres Strait Islander people within the National Safety and Quality Health Service Standards. One of the six actions is partnerships with communities. It acknowledges the importance of partnerships to providing safe and high-quality care to Aboriginal and Torres Strait Islander people. The guide provides specific strategies health organisations can engage in to achieve these partnerships.

#### National Standards for Mental Health Services<sup>6</sup>

Specific health service standards exist that can be applied to all mental health services, including government, non-government and private sectors across Australia.

Within them *Standard 3: Consumer and carer participation* has seven criteria aimed at consumers and carers being actively involved in the development, planning, delivery and evaluation of services.

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#### Making Tracks toward closing the gap in health outcomes for Indigenous Queenslanders by 2033 – Policy and Accountability Framework<sup>7</sup>

This overarching policy guides the Queensland Government's efforts towards closing the gap in health outcomes for Indigenous Queenslanders to 2033. As health staff, you can use the Making Tracks Framework to help you to appropriately establish and foster long-term authentic relationships and support effective and culturally safe partnerships with Aboriginal and Torres Strait consumer representatives and communities.

#### Queensland Government: Hospital and Health Boards Act 2011<sup>8</sup>

The Hospital and Health Boards Act mandates that a health service have a consumer and community engagement strategy and must consult with consumers and community in its development. The strategy should guide and support the engagement of community and patients across the organisation and must be published and accessible to members of the public.

# Health Consumers Queensland's Consumer and Community Engagement Framework

Health Consumers Queensland's Consumer and Community Engagement Framework (Framework) orients health organisations to what underpins successful consumer and community engagement and partnerships.

"Being a member of the Mackay HHS Consumer Advisory has allowed me to contribute to the future of healthcare services for my local community. I've had many opportunities to participate in co-design projects where my contributions have been implemented. I feel valued knowing my voice is being heard and considered and making a positive difference for not only myself, but the people around me."

> Dave Conway, Mackay HHS Consumer Advisory Partner

"Dave has worked with us (the Mackay HHS) on a number of co-design projects. His contributions have helped us modify our website to be user friendly for people who are vision-impaired and use computer screen reader programs. He has also helped us review way-finding and signage and more recently been involved in training our clinical workforce by sharing his own experiences around how he has successfully prevented pressure injuries, having never had one."

> Courtney Lord, Mackay HHS Patient Experience and Community Engagement Coordinator Mackay HHS

## How to use Health Consumers Queensland's Consumer and Community Engagement Framework

Health Consumers Queensland's *Consumer and Community Engagement Framework* (Framework) outlines the building blocks for partnerships between staff in organisations and their consumer representatives. There are four elements of the Framework you can use to enable and guide partnerships with consumer representatives: where partnering can happen, when to partner, the engagement spectrum and the engagement principles. The relationship between these elements is represented in the framework diagram on this page.

#### Where partnering can happen

Consumer partnerships can happen across an organisation and system simultaneously on many different projects and initiatives. The Framework breaks down the partnership opportunities into four levels:

- Individual Engagement in individual care sees consumers as partners in their own (or loved ones) healthcare and treatment. It is often called person-centred care.
- Service Service level engagement is focused on partnerships that impact on programs and services at a facility level in a Hospital and Health Service or a unit within the Department of Health.
- Network Regional engagement processes as health organisations seek input into broader plans across their service area.
- System Engagement on health policy, reform and legislation that influences and changes the health system across local, state and Commonwealth jurisdictions.



The Consumer and Community Engagement Framework

#### When to partner

Partnering should take place across planning, implementation/ delivery, evaluation and review and is an integral part of continuous improvement processes. Good partnering happens early; at the priority setting and planning phase and can (and should) continue through to evaluation and review.<sup>2</sup> The diagram on the next page shows how you can partner with consumers at each stage of a project.

#### When to involve consumers

Below are some examples of the actions you can take at each stage of a project. Many of these actions are possible across multiple stages.

#### **Needs analysis**

 The organisation involves consumers to gather local expertise and resources to identify gaps, issues and needs that should be addressed.

#### **Evaluation and review stage**

- Consumers are part of developing the tools for evaluation and the criteria of success and are on the evaluation working group
- Consumers copresent findings at a conference

#### **Monitoring stage**

 Consumers are involved in the design of monitoring mechanisms and help decide ongoing benchmarks needed to achieve the desired outcome or goal within timeframes

Needs

analysis

Monitoring

Evaluation

and review

• Peer workers monitor how services and care are being provided and feedback from consumers is shared with the monitoring committee

#### **Priority setting Stage**

Priority

setting

Planning

- A forum is held to include a number of consumers and carers to identify priorities
  - The organisation involves consumers in developing up a matrix to help prioritise decisions and funding
    - Consumers sit on governance committees that determine the criteria for research grants and funding, so the research is focused on consumers and their needs and preferences

#### **Planning Stage**

- The organisation establishes a committee in partnership with consumers to help plan, develop and review the initiative
- A co design workshop is held with consumers to determine the model of care of the service

#### **Implementation Stage**

Implementation/ delivery

- Consumers are recruited to support the implementation and the recruitment and orientation of staff to ensure they understand the importance of the model of care from a consumer perspective
- A steering committee including a diverse range of consumers is set up to implement key recommendations

#### Why partner across all stages of the project?

- Ensures you are doing 'with' consumers and not 'to' consumers.
- Enables more safe and efficient new services, models of care and facilities (often costly) that meet a diverse range of consumers' needs and wishes.
- Leads to better person-centred care, and more appropriate and user-friendly services.

#### **The Engagement Spectrum**

Consumer and community partnership activities vary according to the level of influence that consumers have over the process, defining the problem and its solutions, and outcomes. You can use the International Association of Public Participation (IAP2) Engagement Spectrum to express and understand this.

Each 'level' on the IAP2 spectrum<sup>9</sup> from inform to consumer-led increases the level of influence from passive to active. Different levels of influence will be appropriate for specific activities, and a health organisation that is partnering meaningfully will have activities taking place across all levels of the spectrum, with more occurring at the more active levels.

The Engagement Spectrum in our Framework (diagram below) is adapted from the IAP2 spectrum. We changed the final level of engagement in the IAP2 spectrum from 'empower' to 'consumer led' to reflect the specific and active role of consumers.



#### When you are partnering:

- When planning for partnering with consumers use the spectrum to identify the level of influence consumers could bring throughout the life of the project.
- Ensure the consumers are informed about the level of influence aligned to the project.
- Be open to increase the level of influence, if identified by the consumers, as an opportunity to deliver better outcomes.

#### **Principles for partnerships**

The Framework has four guiding principles: **partnership**, **respect and dignity**, **inclusive** and **improvement** to underpin all consumer and community partnerships.

**Partnership** Working relationships between engagement partners are built on transparent and accountable processes. The purpose of consumer and community engagement is to shape service delivery to better meet consumer and community needs. Engagement takes place at all levels of the service: planning, design, delivery, evaluation and monitoring.

**Inclusive** Engagement processes are accessible, flexible and designed to promote partnerships with populations that reflect the diversity of their communities and identified health needs. The health organisation engages through outreach and is respectful of existing community resources and expertise.

**Respect and dignity** Engagement partners value each other's perspectives, knowledge and beliefs and develop relationships based on clear and open communication and shared goals. Partnerships focus on solutions and support the participation of consumers and community.

**Improvement** All engagement activities are evaluated by health staff and consumers and findings implemented for continuous improvement. Ongoing training and development opportunities are provided to support the capability building of all engagement partners.

Using the principles for partnerships can lead to:

- stronger foundations that support consumer representatives to be more informed and engaged to have influence over outcomes
- clearer expectations so there is an understanding of what is required of everyone involved
- organisational culture change

#### When you are partnering:

- Ensure that staff and management are in agreement with and, have an awareness and understanding of the principles for partnerships. You may choose to develop your own in collaboration with the consumer representatives
- Incorporate the principles into the development of your consumer and community engagement strategy.
- Let the principles guide your consumer partnering activities.

"As an inpatient nurse I saw that health care professionals have more power in the hospital environment. However, as a researcher, involving health consumers has been very different. We are working together, there was no power imbalance in the research environment. I felt we were all equal."

Nicole Gavin, Acting Nurse Researcher, Cancer Care Services, Metro North Hospital and Health Service

## Making consumer partnerships possible

## **Enablers for effective consumer partnering**

## Leadership

Organisations with successful consumer partnerships have strong leadership and demonstrated buy-in from executive, board members and the people who can make change happen. It needs to be an organisational strategic priority with budget, staff and resource allocation.

## Commitment

A genuine commitment to consumer partnerships needs to be demonstrated through engagement activities that are not tokenistic and share decision making between staff and consumer representatives. Both parties must listen to and respect each other.

### **Values**

Partnerships have to be values based: mutual respect, inclusive, transparent and respective of diversity. All staff can and should play a role in supporting and upholding the values that promote partnerships.

## Processes, training and support

Policies, procedures, training and processes that support consumer partnerships are critical to the success of engagement. By providing the right training for consumers and health organisation staff, and putting in place the right strategies to engage with a broad cross section of consumers, you are helping to set up your organisation for successful engagement.

### Staff qualities needed for effective partnerships

Partnering with consumers effectively and respectfully requires establishing and maintaining healthy relationships. Consumers have identified the qualities in staff that contribute to great partnerships:

**Open** to different ideas, ways of working and to critical feedback. Consumer partnerships can challenge existing ways of working. Staff who are self-reflective and able to be open can work through these challenges with consumers and find solutions and incorporate new ideas.

Listens and paraphrases. Listen and reflect back what has been said, what did they feel and experience? Staff can play a role in assisting other partners with different frames of reference to hear the stories and perspectives of consumer representatives around the table to ensure shared understanding.

Facilitate autonomous decision-making – Staff can enable consumer representatives to make informed decisions by ensuring they provide detailed information on areas for discussion. This may include providing the history or context of a contentious issue. Consumer representatives must be trusted to be involved to tackle difficult issues.

Advocates and mentors – Staff who advocate for consumers and consumer partnerships and speak up in support of consumer partnerships among staff are invaluable to consumer representatives. Staff can also serve as mentors and provide strong guidance to consumer partners through sharing content and system knowledge.

**Change agent** – Staff must be willing and able to make changes to models of care, systems, policies and organisational culture to ensure consumer partnerships achieve outcomes.

## Challenging the barriers to consumer partnering

Partnering with consumers may be new to your organisation. You will likely encounter barriers to implementing partnerships, but these can be overcome. Identify the change makers in your organisation who can assist you to remove barriers and work in collaboration with consumers– consumers can be powerful allies.

Below are some of the primary barriers identified by health staff and ideas on how you can challenge them:

#### No time, budget or resources

A considered and planned investment of time, resources and budget allocation will result in savings and improvements far greater than the investment.

Attitudes toward partnering You may encounter staff that believe this work is too time consuming or not a priority. The vision and values of your health organisation can be used to advocate partnering with consumers. The requirements of Standard 2 can also be a tool to support embracing partnerships. The goal is to build a culture that consumer partnering is part of everyday processes.

Lack of skilled consumers You can play an important role in developing and supporting consumers so they gain confidence and experience. Every consumer you consider 'experienced' started with no experience.

#### Not sure how to access the right consumer There is also no such thing as the 'right' consumer. There are usually

a number of consumers who would be a valuable 'fit' for what you are looking to achieve. You can be instrumental in the recruitment, training and retention of consumer representatives to support your health organisation. You want to develop a range of active consumer voices across the organisation and not rely on a few individuals to speak for the community. Refer consumers to relevant health consumer organisations such as Health Consumers Queensland to gain relevant support for consumers partnering with health services.

#### Need for training and support

to partner Identify your health organisation's "It's not enough partnering policies to attend a training and procedures on consumer engagement, and familiarise there needs to be a whole yourself with your organisational culture change organisation's about working with consumers." consumer and community Consumer representative engagement strategy. This will help clarify what the organisation has committed to doing or is doing. Know who are the engagement staff who can support your partnering as they are your first point of contact for any partnering opportunities and advice. Be aware that their role title may not have the words engagement or partnering in it. Sometimes quality, clinical governance, communications and public relations roles are responsible for

engagement and partnering initiatives. Health Consumers Queensland runs regular fundamentals and accredited training in partnering with consumers.

Lack of leadership buy-in Consumer partnering needs to be supported and championed by organisational leadership including boards, executive and middle management. No matter what your role, you can be a leader too. Take the opportunity to ask how consumers will be involved in the roll-out of a new policy or program, or advocate for consumers to be

> involved in the recruitment and orientation of new staff in your work area.

#### Fear of feedback

ement, whole change sumers." ative Receiving feedback on a project you have invested in can be difficult. Try not to take any critical feedback personally, see it as an opportunity to optimise the results. Reflect on your role in partnerships and how

you can contribute to positive relationships. Ensuring the involvement of consumer representatives from the beginning of a project or process avoids rethinking work you have already completed. Strong relationships and processes with consumer representatives will support them to give frank and constructive feedback.

## Health literacy in consumer partnering

Sixty per cent of adult Australians have low individual health literacy, which means they may not be able to effectively exercise their choice or voice when making healthcare decisions.<sup>10</sup> Low levels of health literacy affect an individual's ability to make informed decisions, which then has a negative impact on their health outcomes.

It also impacts consumer representatives in their roles. Health organisations have a responsibility to provide information and support that facilitates health literacy to ensure that consumer representatives can participate fully in partnerships.

Building health literacy in organisations and the community leads to productive reciprocal relationships. Staff can support the health literacy of consumers and organisational literacy increases from learning from the lived experience of consumers.

"Partnerships with consumers are essential for both individual health and health care and for the development of better healthcare systems. Improving health literacy ensures that consumers can fully participate in these partnerships, and that the health system and healthcare organisations are oriented to support such partnerships."<sup>11</sup>

#### What you can do:

- Identify health literacy as a key role in position descriptions of staff. All staff can take an active role to improve the health literacy of consumers and community.
- Involve, support and collaborate with consumer representatives, as they can play a key role in health literacy by informing and supporting the design of better health information.
- Use plain language and limit clinical terminology and acronyms where appropriate. Use of jargon at meetings and in meeting papers must be minimised. The use of colloquialisms is also culturally specific and can impact the understanding of culturally and linguistically diverse consumer representatives.

#### **Definition of health literacy**

Health literacy is about how people understand information about health and health care, and how they apply that information to their lives, use it to make decisions and act on it. Health literacy is important because it shapes people's health and the safety and quality of health care.

The Australian Commission on Safety and Quality in Health Care (the Commission) separates health literacy into two components:<sup>11</sup>

- Individual health literacy is the skills, knowledge, motivation and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care and take appropriate action.
- The health literacy environment is the infrastructure, policies, processes, materials, people and relationships that make up the health system and have an impact on the way in which people access, understand, appraise and apply health-related information and services.

## **Cultural capability and consumer partnering**

Both consumers and staff have identified that more work needs to be done to deepen and support engagement and partnering with diverse communities by health organisations. Authentically partnering with Aboriginal and Torres Strait Islanders and culturally and linguistically diverse (CALD) consumer representatives requires commitment by health organisations, including time, resources and development opportunities for staff to increase their cultural competence and capability.

When seeking to partner with Aboriginal and Torres Strait Islander people and CALD health consumers, staff must recognise that partnering may be an unfamiliar concept.<sup>5</sup> Time must be spent to develop relationships and to bring about the understanding that they have the right to partner with health organisations to improve and make the system better for themselves and their communities.

#### Increase your cultural capability

While it is important to prepare and support Aboriginal and Torres Strait Islander and CALD consumer representatives so they can partner, it is also equally important to prepare your organisation. When you work with people from a cultural background different from yours there are some considerations to keep in mind that will allow for a positive and productive exchange. Begin with increasing your competency.

A culturally competent staff member is likely to have:12

- a strong knowledge of their own culture and how it shapes their attitudes, perceptions and behaviours
- a willingness to value diversity and to learn about other people's cultures
- a self-reflective process to contemplate their own cultural competency and capability
- skills to feel comfortable and communicate effectively with people from diverse cultural backgrounds
- an awareness of how stereotyping individuals from certain cultures or ethnicities has limited value

A person's culture provides a framework for experiencing life and viewing the world. Culture influences people's perception of the world, the way they think, dress, speak, their beliefs, the food they eat, relationships they form, their music, their art, the way they solve problems and cope with various life situations.<sup>12</sup> It also influences the way in which people make decisions about their health.

- an awareness of cultural considerations such as attitudes to health/illness, religion, customs, attitudes to systems and authority, community participation versus individual participation
- an attitude of learning to develop an understanding of culture and diversity, through reading and research
- a willingness to ask others for feedback on their cultural competency and capability
- attended training in cultural capability and communication
- an understanding that participating in a one-off training is a good step in the right direction but is not the end, and that to develop a deeper cultural competency and capability more work is required.

The goal is to move from cultural competency to cultural capability. Building cultural capability is an ongoing process of learning, application and evaluation, or of *knowing, doing and being.*<sup>13</sup> "It aims for a workforce and a system that is responsive, innovative and reflective. While reaching competency is attaining a level of knowledge and skill which are set against certain benchmarks to ensure achievement of the desired goal. In contrast to the ongoing journey of building capability, competency implies an end point, a tick box of completion if you like".<sup>14</sup> When engagement activities, consultation, negotiation are culturally informed, you achieve better outcomes.<sup>13</sup>

#### What you can do

#### Method of partnering

- First ask what is the most effective way to partner with particular communities. Go to their community rather than bring people into your space where they are unfamiliar and may feel disempowered. You need to be open to meeting under a tree, by the river, a community hall, or a religious or spiritual meeting space. A safe meeting place enables authentic sharing of information and experiences.
- As health organisation staff you need to know about health policy frameworks and specific services aimed at increasing access and health outcomes of different population groups.

#### **Protocols**

- Find out what is appropriate and understand there may be cultural protocols, for example, young people cannot represent their elders, men cannot represent women and so on.
- Make yourself familiar with communication protocols that are aimed at conveying respect and demonstrating a genuine commitment to trying to connect and build relationships.
   These might include learning how to greet people, appropriate ways of referring to people and who are the most appropriate people to approach within a community.

#### **Relationships**

- Allow and spend time to build relationships and rapport, this means listening and finding out the true needs of the community.
- Have the intention to connect. Know that when you are meeting for the first time, it will not be the last.
- Let the consumers take the lead and guide you about what is most important for them.

- Be honest about expectations and always feed back to them about what you intend to do or cannot do.
- Be aware that the concept of time varies from culture to culture; it will be different to the time frame of your organisation and project. Build this contingency into your budget and project plan. If challenged on this, explain the risks of not doing this on outcomes and relationships in the community.

#### **Organisational Considerations**

- Create a culturally diverse workforce through the recruitment, retention and training of Aboriginal and Torres Strait Islander and CALD staff, especially the health workforce (not just administrative or operational staff).
- Ensure your health organisation is health literate. Keep in mind health literacy levels. How can you tailor messages for clearer communication?
- Work with a multidisciplinary team where diverse ideas and perspectives are encouraged, and therefore consumer partnerships will also become an important voice.

#### Language

- Ensure that interpreters are there to support your communication, if required.
- Avoid the use of jargon and acronyms.
- Keep in mind that non-verbal communication accounts for approximately 70% of communication. Aboriginal and Torres Strait Islander and CALD communities may have different non-verbal cues and they may interpret non-verbal communication differently to you.

#### Specific considerations when partnering with Aboriginal and Torres Strait Islander People

The effects of the historical colonial policies have negatively impacted the health and wellbeing of Aboriginal and Torres Strait Islander people. These colonial policies led to loss of land, family and community connections and denial of free cultural expression and growth across generations. The lasting impact of the colonial polices is seen as the disparity between the health of Aboriginal and Torres Strait Islander people and non-Indigenous Australians.<sup>5</sup>

Aboriginal and Torres and Strait Islander people define health as not being limited to just physical wellbeing, but also emotional, social and spiritual dimensions of wellbeing.<sup>5</sup> Aboriginal and Torres Strait Islander people have the right to feel confident and safe when accessing the Australian healthcare system, and the system must be able to respond to their unique needs and wishes. For this to happen health organisations need to ensure they tailor their work and services for and inclusive of the needs and wishes of Aboriginal and Torres Strait Islander people. Service provision needs to be equitable, and patient needs should drive access to the level and range of care.<sup>5</sup> Authentic and effective partnering with Aboriginal and Torres Strait Islander consumer representatives will mean that health

organisations will be able to respond to all aspects of safety – clinical, cultural, emotional and spiritual.

There is a tendency to start consultations with "we will co-design for the mainstream and then we will adjust it for Aboriginal and Torres Strait Islander people". However, if we design health services, programs and research for Aboriginal and Torres Strait Islander people we increase the chances of developing a holistic, integrated, person-centred service that meets the needs of ALL health consumers and their families. We can endeavour to get it right the first time.

#### What you can do

- Ensure that you have Aboriginal and Torres Strait Islander consumer representatives as part of your project/working group, as either group will not speak for each other. Effective partnering means asking them what their health priorities are.
- What is the best way and who can best help? Think about individual representatives versus group (advisory group). Would an individual feel comfortable sitting on a committee or is it more appropriate to have an advisory group? Who would be more appropriate; elders, women, men or young people?

- Ensure that your representative is part of the Aboriginal or Torres Strait Islander community that your health organisation services.
- Ensure that your timeframes are flexible or build in contingency, as time needs to be invested in developing authentic relationships for effective partnering.
- If there are pre-existing relationships with the local Aboriginal and Torres Strait Islander people within your health organisation, then build on strengthening pre-existing relationships to support your work.
- Use the six actions in the National Safety and Quality Health Service Standards – User Guide for Aboriginal and Torres Strait Islander Health.<sup>5</sup>

"Developing effective partnership is a long road which begins with the first step of building relationships; it's taking the time to understand each other's world views and motivations with a strong focus on working together towards mutually beneficial outcomes."

> Jermaine Isua, Queensland Health Cultural Capability Statewide

## How to partner with consumers

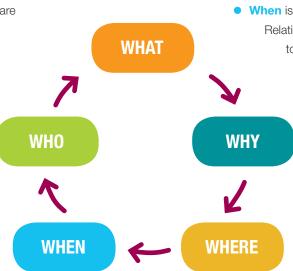
The following advice is designed to assist health staff who have identified the need to partner with consumers with specific skills and experience for a committee, working group or project.

If your organisation has a consumer and community engagement team or staff member, involve and work with them throughout the partnering process. They have the expertise to guide your activity. Health Consumers Queensland is available to support you with training, strategic advice and access to a statewide network of consumer representatives.

## **Planning consumer partnerships**

Before you begin a recruitment process, you should be clear about the purpose of the activity and the role consumer representatives will play. Here are some of the questions you can answer to plan your activity.

- What is the purpose of the partnering activity, project, or working group?
- What financial and other resources are required?
- What method of partnering will achieve the best outcomes?
- Why are you partnering with consumer representatives? How will they add value to the particular project?
- Why would consumers want to be involved?
- Where is the partnership occurring within the organisation? What level of influence will the partnership have (see p. 9–11)?



- Where will the activity take place? is it accessible for consumers? If the location limits consumer involvement, consider ways you can overcome this, such as offering videoconferencing facilities.
- When during the project cycle will you involve consumer representatives (see page 10)?
  - When is the best time to start this process?
     Relationships and trust must be established to create effective partnerships.
    - When will you schedule the activity? Some examples of things to consider are: school holidays, religious events, harvesting or tourist high season.

• Who will be involved (consumers, stakeholders and staff)? An effective partnering process needs to identify and include a range of people for it to be successful. What lived experience or cultural diversity do you need to consider?

#### **Examples of different partnerships**

As you plan for partnering here are some different ways for you to consider.

#### Consumer representation on a working group:

- Developing a new model of care or clinical guidelines/ policy
- Service planning, evaluation
- Building (re)design/refurbishment
- Patient Safety and Quality committee
- Awarding of scholarships and grants

#### Consumer representation on a steering committee:

- High level oversight of projects including budgets and policy development
- Ensure consumer engagement occurs and consumer needs are taken into consideration
- Participate in presentations on the initiative

#### Consumer Advisory Council member:

- Part of a group of consumers advising a health organisation often more strategic
- Can be chaired by a consumer
- Consumer participant on a co-design/co-production project

#### Other ways:

- One-off participation in a focus group or round of focus groups on the same subject
- Participates in training/professional development/orientation of staff and volunteers
- Staff recruitment shortlisting and selection panels
- Develop a patient journey map a diagram summarising the service experiences patients have
- Co-presenting at forums and conferences
- Involvement in research and development

#### **Elements of an effective Consumer Advisory Council**

Consumer Advisory Councils are often used by health organisations. Below are the elements of an effective Consumer Advisory Council. They have:

- a clear purpose and aims
- consumers or carers with relevant lived experience
- decision makers are members and have responsibility for actions
- consumers that feel they have a voice and are able to affect change
- effective reporting channels into the organisation
- a profile across the organisation and staff understand their role
- have a work plan in place
- periodic reviews which check progress and impact.

## Identifying and recruiting consumer representatives

#### **Consumer skills and experience**

You can identify the consumer representatives who will be most appropriate for your project based on the outcomes of the questions on page 19. To help determine the skills and experience you want in a consumer representative, consider the following:

Questions	Considerations
What skills and experience do consumer representatives need to have?	<ul> <li>Lived experience of a specific medical condition and experience receiving health care, if relevant, from a particular facility.</li> <li>Experience as a carer, especially important when working within services for children, older people, disability and mental health.</li> <li>An interest and ability to think strategically and from a systems perspective, for example for statewide roles.</li> <li>Representing a 'group' of consumers, e.g. cultural background, age, region.</li> <li>A range of experience – from significant experience to no experience.</li> </ul>
What networks and links to the community should the consumer representatives be able to demonstrate?	<ul> <li>Networks are relationships and connections to groups or individuals within communities. They can be formal or informal. For example, a mother's or local walking group is informal whereas the Australian Pain Management Association or the Pasifika Women's Association is a formal network.</li> <li>Is a part of their role to connect with others to seek their opinion?</li> </ul>
Are the right people at the table for the purposes of your work?	<ul> <li>Include consumers in partnership activities who reflect the diversity and demographics of people accessing the service.</li> <li>Is there a specific demographic that must have a voice in this activity? Who is not accessing your service? Are they from a particular region, culture or profile? You will get vital information on the barriers they face to accessing your service.</li> <li>If you are seeking consumers who may have lower literacy levels or English as a second language, consider how this might affect the recruitment process and the method of partnering chosen.</li> <li>Would it be better to design outreach processes that connect the health organisation with the community, rather than bringing consumers into the organisation for partnership activities?</li> <li>Are there key stakeholders you need to involve who may have access to appropriate consumers such as community-based organisations or Aboriginal community-controlled health services, local councils or other levels of government?</li> </ul>

#### **Recruitment of consumer representatives**

Consumer representatives can be recruited for an individual consumer perspective (lived experience), or for their ability to provide organisational advice.

Many organisations represent and have knowledge of the opinions of a large number of their consumer members, for example, Maternity Choices Australia, Cancer Voices Australia, Kidney Health Australia.

You must be clear about what will be most useful and appropriate for your activity and recruit accordingly.

Once you have completed the planning stages (what, why, where, when and who) and identified the skills and experience you are seeking from consumer representatives, you can begin the recruitment process. Some additional considerations to keep in mind are:

- Health Consumers Queensland recommends that at least two consumer representatives are recruited for each activity in order to provide support to each other, provide skills development and mentor more people to take on these roles.
- Recruitment processes provide health organisations with a valuable opportunity to grow their network of consumer representatives and stakeholders for future engagement opportunities. Distribute invitations to join the health organisation's network with recruitment advertisements.
- Staff must ensure recruitment processes are confidential to only those directly involved.

"In the Darling Downs Hospital and Health Service we are flexible in our approach in recruiting consumer representatives. We tend to identify representatives through existing connections whether that is a regular patient/carer/family member or visitor to our facilities. We conduct callouts through existing networks rather than advertising Expressions of Interest.

> We also found that allowing consumer representatives to try a committee or advisory group for a couple of meetings before making a firm commitment is also beneficial as it takes the pressure off them. They don't have that feeling of having to make an immediate decision when they may be unsure of the fit or suitability."

> > Donna Lucas, Consumer and Community Engagement Officer, Darling Downs Hospital and Health Service

# Remuneration and reimbursement of consumer representatives

Please make yourself aware of your health organisation's policies and procedures in relation to remuneration and reimbursement. Health Consumers Queensland's Position Statement on Remuneration and Reimbursement is available on our website. Share these documents with your consumers as well.

Consumer representatives engaged by health organisations may be employed or receive a pension or benefit. It is a consumer's responsibility to identify the impact of remuneration payments for representative roles on their other income. Health organisation staff cannot give financial advice and should refer consumer representatives to the Australian Tax Office for legal and financial advice. Free legal advice on Centrelink matters in Queensland can be sought from Basic Rights Queensland, 1800 358 511 www.brq.org.au. Referral information can be provided to consumers in their orientation materials.

# Health Consumers Queensland's position statement on payment of consumers

Health Consumers Queensland recommends that no consumer should be financially disadvantaged as a result of their contribution to a health organisation.

At a minimum the organisation should cover out-of-pocket expenses such as travel, accommodation, childminding, respite care costs, or printing.

Health Consumers Queensland recommends that consumers receive a sitting fee for their time, expertise and contribution.

# Create a vacancy request for consumer representative role

Advertisements for consumer representative positions should include all the information required for someone interested to make an informed decision about participating:

- the purpose, aims and scope of project or committee's work
- information on the service unit or team responsible
- staff and stakeholders involved
- the specific target group or health population being sought
- detail of the date, location, time commitment and frequency of the activity
- the skills, experience and knowledge base the consumer representative requires
- the scope of the consumer representative's role and number of representatives sought
- whether remuneration and reimbursement will be paid to consumer representatives
- a timeline and description of the recruitment process
- a contact person and their contact details

The draft Terms of Reference for the committee should be made available to consumers interested in the position. Upon appointment, the consumer representatives should also have input into the final agreed Terms of Reference.

#### Choose an appointment process

There are multiple ways to recruit consumers for partnering opportunities.

- 1. Expression of Interest (EOI) An expression of interest is a transparent method of recruitment for health organisation activities. It also gathers demographic details and identifies any additional requirements that need to be in place for the individual to participate.
  - Use the skills and experience identified in planning to develop the selection criteria.
  - Try to limit EOIs to between three to five questions.
  - Ensure questions are appropriate for all populations. Questions may need to be specially tailored for some populations. Ensure it is clear and in plain English.
  - Provide more than one way of completing the EOI, for example,

online, mailed, or an opportunity to complete the form with the assistance of staff where required.

- Allow sufficient time for the closing date, at a minimum two weeks.
- 2. Direct recruitment In limited circumstances. health organisations may directly appoint a consumer representative without completing a recruitment process. This may occur where a consumer's unique lived experience and skills perfectly match with an opportunity, and there is a tight timeframe involved.

Direct recruitment is discouraged as it:

- decreases the diversity of consumer opinions if the same consumers are often used.
- can lead to the selection of consumers not effectively representing or reflecting the community.

"We fell into the trap of thinking we only needed one consumer. It has been valuable to have a least two consumers for a better balance. You get a diversity of thoughts – we have a parent with a child and a carer of a patient. They bring different perspectives and it has been very beneficial."

> Simone Ryder, Manager, Corporate Services Division, Queensland Health

- may result in the perception that the health organisation has interest in only a small number of opinions and favours people who have existing relationships with staff.
- can lead to consumers disengaging from participating in the organisation.

#### 3. Recruitment through external

organisations – When a health organisation has not yet built a network of consumers, or has been unsuccessful in their recruitment process internally, external community and consumer organisations like **Health Consumers Queensland** can assist in recruitment.

- Health Consumers Queensland can provide a full recruitment service of consumers from our statewide consumer network.
   This includes promoting the opportunity, receiving Expressions of Interest, and shortlisting a final selection for your organisation to choose from.
- An EOI process mitigates the risk of inappropriate outcomes and allows for a transparent process ensuring the selection of the best possible person for the role.

Whatever appointment method is chosen, communicate timelines with consumers

participating in the recruitment process and inform them of any delays to processes as soon as possible.

#### **Interview considerations**

In some situations, you may want to have more than an informal phone conversation with shortlisted consumers, and invite them to a formal interview.

- Wherever possible involve consumers already partnering in your health organisation in the selection process, for example shortlisting candidates or sitting on the interview panel.
- Ensure any support considerations for the interview are in place. For example, is a translator required, do they require hearing loops or a captioner, are there any mobility issues?
- Consider budget as well. You may not have the budget to pay for the consumers to travel for the interview so a phone interview can be arranged.

Ensure the consumers are informed of the names and roles of the people on the interview panel, how long the interview will go for and contact details for a contact person.

#### **Post recruitment**

Once a decision has been made on recruitment and the successful consumers advised, inform all unsuccessful consumers as soon as possible and give feedback on their expression of interest. Invite all who applied for the role but were not successful to be part of your health organisation's community of interest group. They might be ideal for a future opportunity.

"Sometimes consumer representatives will share things that can be really challenging. I'm often the person in the middle, between the consumer and the health professionals. To maintain relationships, I have learned to keep an open mind, make no assumptions and no excuses."

Graham Reeks, Principal Engagement Officer, Sunshine Coast Hospital and Health Service

## Preparing consumer representatives for success

Supporting consumer representatives means enabling them to be more effective in their role. Lay the foundations for successful partnerships before they start their roles.

There are several touch points that you can use to ensure that you are gathering the necessary information to ensure you have the resources in place to support consumer representatives.

#### Orientation

#### What you can do

- Provide a structured and comprehensive orientation to the specific long term activity the consumer representative will be involved in.
- Provide orientation to the health organisation as well as an opportunity to meet with key people.
- Orientation is best done face-to-face but if this is not possible then aim for alternatives via phone, skype, video link or a short video.
- Develop an orientation checklist for all your partnering activities

 Find out if they need any additional support to participate fully and allow time to answer their questions and concerns.

#### Why do this?

- Well-oriented consumers will quickly become effective partners.
- Effective orientation allows consumer representatives to understand the organisation, the role and responsibilities of the position.
- Consumers have the information and resources to talk about their role and the health organisation to community members, e.g. how to use the complaints/feedback system.
- Ensures any additional supports required by the consumer representatives is budgeted for and in place.

#### Training and support for staff

#### What you can do

 Provide all health organisation staff with resources, training and support to work effectively with consumer representatives, including established committees who are new to consumer representatives.

- Ensure that all staff know the contact person for consumer partnering within the organisation.
- Show case all partnering activities within the health organisation in the organisation's communiqué and websites.

#### Why do this?

- Staff become the champions and change agents for consumer partnering.
- Embeds partnerships in the health organisation's culture.
- Training increases job satisfaction for staff.

Always ask the consumer representatives about their needs – some needs are often invisible. "Is there anything else you need? What can I do that would help you perform your role as representative better?" This demonstrates your support and desire to help them succeed.

#### Before the first meeting

Brief consumer representatives before their first meeting, if possible with the Chair, if it is a committee or working group. Ensure the consumers and staff involved in the activity are feeling comfortable and have everything they need to participate fully. Ask if there is anything consumers are not clear about or any additional support they might need.

#### What you can do

- Provide maps and directions on how to get to the meeting venue. Better still meet them at the door.
- Ensure you have catered to their needs, e.g. hearing loop, dietary requirements, medication breaks.
- Check whether there are any cultural protocols that may support respectful and effective communication and interaction.
- Ask if they would like documentation printed and mailed to them. When emailing documentation, include documents as proper attachments rather than as embedded documents.
- Identify a staff member to be the consumers' mentor/ buddy. If the consumer prefers to mentor with a certain staff member they can nominate their own. They can support the consumer by increasing their knowledge and understanding of the technical aspects of discussions.
- For pre-existing committees, provide previous meeting notes and project plans.
- Ensure other staff on the committee know the role of the consumers and their limits.

#### At the first meeting

#### What you can do

- Ensure the Chair welcomes the consumer representative(s) to the first meeting and explains the consumer role to the whole committee. Allow the consumer representative(s) to introduce themselves to other committee members and vice versa.
- Invite the consumer to sit next to their mentor or someone who can answer their questions.
- Cut out the jargon, do not use acronyms and simplify technical language and explain in full what you are talking about. Consider providing a glossary of terms with the agenda.
- Slow your speech down if content is complex. Check in with the consumer representatives during the meeting, asking for their feedback on each agenda item and checking if they need any clarification.

#### After the meeting

#### What you can do

- Check in with the consumer(s) and ask: "How did we do?",
   "What can we do better to support you?", or "Are there any questions you would have liked to ask during the meeting?"
- You can do this after each meeting to ensure the lines of communication are open between the committee and your representatives.
- You might offer to arrange a pre-meeting phone conversation with the consumer representatives a day before the next scheduled meeting to clarify any issues or answer any questions.

#### Things to consider

Recognise that there is a **power imbalance** between clinicians, health organisation staff and consumer representatives. Acknowledge this openly and find solutions together for consumer representatives to make a valuable contribution.

**Close the feedback loop**. You said, we heard, we did. Too often consumers spend time giving feedback and never hear about the outcomes of their work.



Be explicit about how you will inform the consumers about outcomes. Ask the consumer representatives how they would like to receive feedback. It could be a standing item on an agenda, a report with info-graphics, or a direct email. Consumers who have finished partnering with you should still be contacted to close the loop.

Inform consumers of project delays or when you have not achieved the outcomes you hoped for.

If you do not close the feedback loop, the next time you are recruiting consumers they may be reluctant to invest their time.

### Working with consumer representatives

Consumer representatives might be involved in a longer-term activity (more than 6 months) and over that time; there are strategies you can use to strengthen the partnership.

#### What you can do

- Offer additional training and development opportunities.
   Invite the consumer representative to attend relevant forums and conferences to increase their expertise and awareness.
- Continue mentoring the consumers and strengthen relationships.
- Look out for opportunities

- to showcase consumer contributions in newsletters and other communiques; have a celebration at the end of the year to recognise any successes.
- Consider how you are planning to evaluate your organisation's consumer and community engagement. Involve consumer representatives in the design and development of your evaluation process.

# Health organisation staff and committee members should expect that consumer representatives:

- are independent and bring a perspective that only a consumer with lived experience can bring
- will ask for clarification and more information if they do not understand
- are entitled to disagree and have this noted in official meeting records

- are paid and are not out-ofpocket
- need to be supported so that effective partnering can take place
- able to talk to other consumer representatives about the committee.

#### How to end partnerships

Projects or sitting terms end. Thinking about how to end partnerships is important. Think about the succession planning of consumers representatives who have supported your organisation for a long time and how the consumer's knowledge can continue to contribute to your service.

#### What you can do

- Be clear about the length of the representative commitment and the process for readvertisement or reappointment of the role.
   Ensure that it is an open, transparent and a fair process.
- Build and foster strong relationships so that you both feel comfortable to discuss any issues.
- Develop ways to recognise the new skills gained, e.g. training certificates, letters of support.
- Offer to become a referee for future positions.
- Explore the possibility of your experienced consumer representatives to mentor new and emerging consumer representatives.

#### Why do this?

- All parties understand the length of the partnership and manages expectations around 'ownership' of positions.
- Ensures the right people with relevant experience are at the table.
- Allows opportunities for consumer representatives to share their experience and to hear new voices.

#### Improving communication for all consumers



Peter and Jilly Lindley, being supported by a captioner Tina Fallows

#### Jill and Peter Lindley, health consumer representatives, share how communicating effectively for people with a hearing loss assists all staff and consumers to connect better.

"When people are anxious, tired and unwell it is important to slow down your speech and face them. This is essential for someone with hearing loss. It is also useful for everyone else including people who may not speak English as their primary language, who have a cognitive impairment or for people who are simply feeling overwhelmed at that moment.

In our time poor society, we are always rushing and we often rush through what we have to say. Most of the time we do not communicate what we really want to because of the rush and pressure to meet deadlines and fit everything in!

The basics of communication is that slowing our speech, not only lessens the listeners' stress levels but helps them to hear with clarity. The added benefit is that as the person talking you get the chance to really think through what you have to say. You can also support consumer representatives by using assistive devices like hearing loops and real time captioning. Best thing to do is to ask what kind of support they need."

#### When it's not working

Regular reflection may indicate that a partnership between your health organisation and consumer representative is not working for one or both partners. If this is the case, you can do a number of things.

#### What you can do

 The first step is to have a discussion with the consumer representative(s) and relevant staff members to identify the issue.

- Maintain a focus on solutions.
- Reflect if an independent mediator or support person for the consumer representatives and/or staff members will help the situation.
- Contact Health Consumers Queensland for support and advice.

Below are some questions you can ask to identify the issue(s).

Questions regarding partnering process	Questions for staff	Questions for consumer representative
<ul> <li>Is there any confusion surrounding the consumer representative role and responsibilities?</li> <li>Was the recruitment process appropriate and are procedures in place to support the consumer representative?</li> </ul>	<ul> <li>Did staff have enough support and knowledge on partnering with consumers?</li> <li>Do other staff and experienced consumer representatives have any ideas and suggestions of how to resolve the issue (while maintaining the confidentiality of the people involved)?</li> </ul>	<ul> <li>Is there any specific support that the consumer representative requires?</li> <li>Is their health affecting them? Do they not feel heard, or are they having trouble with the role or its responsibilities?</li> <li>Have they been supported to develop</li> </ul>
<ul> <li>Did the consumer representative(s) receive an orientation to their role and to the organisation?</li> <li>Did you have any committee members involved in the recruitment process?</li> <li>Were there opportunities for regular debriefs? Could you have identified and resolved the issue</li> </ul>	<ul> <li>Have they been supported to develop the necessary skills of reflective listening, hearing criticism/feedback without defensiveness and synthesising criticism into actions?</li> <li>Can they provide opportunities and access to training and resources to staff to develop strong partnering relationships?</li> <li>How can they encourage and foster a culture of consumer and community</li> </ul>	<ul> <li>the necessary skill of constructively sharing feedback?</li> <li>Is the consumer representative experiencing trauma from recalling/ reliving their health experience?</li> <li>Do they feel the need to tell their story repeatedly?</li> <li>Provide options for consumers to contact whom they wish to, to get external support.</li> </ul>

## **Evaluation of consumer partnering**

Evaluating the impact of your consumer partnerships on health outcomes and what the experience was like for all is essential to assess how successful the process was and where improvements can be made. Evaluations can reflect upon the outcomes at the end of the project or activity. Better still, you can implement processes that look at all stages of your project and ensure a reflective awareness throughout. This approach allows for the unexpected such as illness that can affect your consumer partnerships, project time lines and outcomes.

There are three levels of evaluation you can use to assess the impact of consumer partnering: Evaluation of the Process, Impact and Outcomes.<sup>15</sup> In collaboration with the consumer partners, you can evaluate, measure and analyse the results for all the elements of the project, program or activity. Consumers are focused on making a difference and will want to see the impact and outcomes of their partnering.

**Process** – Focus on the processes of partnering, and the immediate impacts. For example, how was the experience for consumers and staff, who else was involved, and their relevance to the process and levels of satisfaction.

**Impact** – Focus on the short-term impact of partnering, measuring against the aims and objectives of your project. Also, consider any unanticipated effects and how you navigated these.

**Outcomes** – Focus on the long-term outcomes, and the overall goals with a broader outlook.

Did the partnering fulfil its purpose? Did you achieve what you set out to do?

#### What you can do

- Ensure that consumer representatives are part of your evaluation process from design to analysis.
- Regular reporting on successful strategies and the key learnings must be shared at an organisational level
- Have a common location on your local intranet listing all projects focused on consumer and community partnerships so that other departments/services can benefit from your experience, knowledge and learnings.
- Consider publishing your engagement processes and outcomes, to contribute to the body of research evidence to support engagement.
- Share your learning through submitting to awards and presenting at conferences.

#### Why do this

- To know how effective and productive your consumer partnering has been.
- Ensures that you have the right resources and processes in place to optimise consumer partnering.
- Supports continuous improvement and innovation.
- Accounts for resources committed and establish a case for future partnering.

partnership is a two-way street of learning how to collaborate and set things up for success in order to do things better together"

"Consumer

Elizabeth Miller, Consumer Advisor, Metro South Health

## Thinking about the future

# Consumer partnerships are crucial to maintaining a healthy, person-centred, balanced and effective health system.

If you are partnering with consumers for the first time, consider starting with a small project to give yourself the chance to find your feet. Consumers will be willing teachers on your journey as will more experienced staff members. The most important thing to do is to start and to give it a go. Consumer representatives easily identify staff who are interested in working with them in a meaningful and effective way and value this.

If you are more experienced, find ways you can strengthen your partnerships to be more collaborative, influential and towards the more active end of the engagement spectrum. Do you have a mechanism to hear and act on ideas/suggestions coming to you from consumers and your community? Or are your partnerships always one-way? Can you offer consumers the opportunity to identify some priorities they would like to work on with you?

Think about supporting consumers with less experience to ensure that you are building capacity for the future. The ways in which we currently partner will look dramatically different in ten years' time. When everyone involved (consumer representatives

understanding of

challenges faced

by them and their

the issues and

communities.

and staff) have grown and refined their partnerships, we will be more innovative, trusting and courageous. We don't know what consumer partnerships will look like in a decade or two – but we can be assured the ways in which we partner will only be limited by our imagination.

Partnering with consumers is rewarding and can be very powerful. Consumers can often unlock doors and opportunities that staff may not be able to. To make the most of these symbiotic partnerships, you need to invest time in the relationships and increase the knowledge of the consumers about the health system and the area of health they are working in. At the same time, consumers will be increasing your

to making a difference in people's lives. All the best with strengthening your partnerships with consumers in your daily work.

## **Health Consumers Queensland**

Health Consumers Queensland is the peak organisation representing the interests of health consumers and carers in the state. Health Consumers Queensland is a not-for-profit organisation and a registered health promotion charity that believes in improving health outcomes for all Queenslanders.

### Who we are

Our priority focus is on consumer engagement that influences and leads improvements and delivers better health outcomes for all Queenslanders. We achieve this through our Queensland-wide health consumer network, tailored training and skills development programs, and maximising opportunities for consumer representation at all levels of the health system. We believe partnering with consumers is very important, as consumers see things from a different viewpoint and only they can bring that unique perspective.

## Why we wrote this guide

This guide was designed to help staff to become skilled and confident at developing and leading consumer partnership activities. It follows on from the *Consumer and Community Engagement Framework* which provides the who, what, why and when of consumer partnering. This guide for staff, and a second guide for consumers, aims to provide the 'how to' of partnering.

Health Consumers Queensland is grateful for the input from experienced and new consumers and staff who provided their feedback through discussions, focus groups and online surveys to help shape the contents of this document.

## What support can I get from Health Consumers Queensland?

Health Consumers Queensland provides strategic advice and training for health staff. Our state-wide consumer network is a register of people who are active health consumer representatives or have expressed an interest in participating in consumer representative roles. Consumer representative opportunities promoted through the Health Consumers Queensland network provide the chance to give feedback and input on health policy, planning, and service provision within Queensland and nationally. You can join the network as a staff member to access information and resources to build your knowledge about consumer partnerships.

## References

- <sup>1</sup> Health Consumers Queensland. A Guide for Consumers: Partnering with Health Organisations 2018. Brisbane: Health Consumers Queensland. http://www.hcq.org.au/our-work/framework/
- <sup>2</sup> Health Consumers Queensland. Consumer and Community Engagement Framework. 2017. Brisbane: Health Consumers Queensland. http://www.hcq.org.au/our-work/guides/
- <sup>3</sup> Australian Commission on Safety and Quality in Health Care. *Australian Charter of Healthcare Rights*. Sydney. ACSQHC, 2012. https://www.safetyandquality.gov.au/national-priorities/charter-of-healthcare-rights/
- <sup>4</sup> Australian Commission on Safety and Quality in Health Care. National Safety and Quality Healthcare Standards. Sydney. ACSQHC, 2017. Available from: https://www.safetyandquality.gov.au/our-work/assessment-to-the-nsqhs-standards/nsqhs-standards-secondedition/
- <sup>5</sup> Australian Commission on Safety and Quality in Health Care. User Guide for Aboriginal and Torres Strait Islander Health. Sydney. ACSQHC, 2017. Available from: https://www.safetyandquality.gov.au/wp-content/uploads/2017/12/National-Safety-and-Quality-Health-Service-Standards-User-Guide-for-Aboriginal-and-Torres-Strait-Islander-Health.pdf
- <sup>6</sup> Commonwealth of Australia. *National Standards for Mental Health Services*, 2010. Available from: http://www.health.gov.au/internet/ main/publishing.nsf/content/mental-pubs-n-servst10
- <sup>7</sup> Queensland Health. Making Tracks towards closing the gap in health outcomes for Indigenous Queenslanders by 2033. Policy and Accountability Framework. Queensland Health. Brisbane. Available from: https://www.health.qld.gov.au/\_\_data/assets/pdf\_\_\_\_\_file/0030/159852/making\_tracks\_pol.pdf
- <sup>8</sup> Hospital and Health Boards Act, 2011. Available from: https://www.legislation.qld.gov.au/view/pdf/inforce/current/act-2011-032

- <sup>9</sup> International Association of Public Participation (2016). *IAP2 Public Participation Spectrum*. Available from: https://www.iap2.org.au/Resources/IAP2-Published-Resources
- <sup>10</sup> Australian Bureau of Statistics. *Health Literacy, Australia*. Canberra. Australian Bureau of Statistics, 2008. Available from: http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4233.0Main%20 Features22006?opendocument&tabname=Summary&prodno=4233.0&issue=2006&num=&view=
- <sup>11</sup> Australian Commission on Safety and Quality in Health Care. *Health Literacy: Taking action to improve safety and quality*. Sydney. ACSQHC, 2014.

Available from: https://www.safetyandquality.gov.au/wp-content/uploads/2014/08/Health-Literacy-Taking-action-to-improve-safetyand-quality.pdf

- <sup>12</sup> Ethnic Communities Council of Victoria. *Cultural Competence Guidelines and Protocols*. Carlton, ECCV, 2006. Available from: http://eccv.org.au/library/doc/CulturalCompetenceGuidelinesandProtocols.pdf
- <sup>13</sup> Department of Aboriginal and Torres Strait Islander Partnerships. Cultural Capability Matters. Queensland Government Aboriginal and Torres Strait Islander Cultural Capability Training Strategy. Brisbane, DATSIP, 2016. Available from: https://www.datsip.qld.gov.au/resources/datsima/involved/cultural-capability-training-strategy.pdf
- <sup>14</sup> Jermaine Isua, Queensland Health Cultural Capability Statewide. Dec 2016. Staff quote
- <sup>15</sup> Cancer Australia. Consumer Participation Guide. (Cancer Australia. Canberra, 2009). Available from: https://canceraustralia.gov.au/system/tdf/publications/consumer\_training\_and\_mentoring1\_504af023a08ae. pdf?file=1&type=node&id=2823



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