

Involving consumers in your health service or facility's COVID-19 response

Involving consumers in strategic and operational decisions in healthcare has never been more important. In an unprecedented situation such as COVID-19, consumers are a key stakeholder and an essential source of advice and guidance in your work. This sheet is designed to support you to work with consumers and carers to co-design strategies, operational plans and messaging that respond to COVID-19 in a consumer-centred way.

KEY POINTS

- **It's essential to involve consumers in key strategic and operational COVID-19 decisions and communication.** If you involve clinicians in the planning and decision-making, then also involve consumers with lived experience of your health services.
- **Use established networks to find consumers quickly and easily;** contact your local LHD engagement staff and Health Consumers NSW to find out more.
- **Consumers will help ensure that you are making the right decisions** as they will understand the potential community impacts. Consumers will also help with messaging of those decisions.
- **Your engagement doesn't have to be perfect, but it's important that you try.**

WHEN TO INVOLVE CONSUMERS

Whenever decisions impact consumers, consumer and carer representatives need to be involved. **NOTHING ABOUT US WITHOUT US.** This includes all strategic decisions and the development of communications including:

- outpatient/ED/elective surgery demand management
- ethical decision making frameworks
- workforce planning
- advice to patients or carers who are currently in the health system, especially those at risk of infection
- communications and media on any of the above (statewide and local).

Remember: Early engagement is best. Outcomes will be better if all stakeholders including consumers are involved early to co-design solutions together.

WHO TO INVOLVE

The needs of all people living in NSW must be considered in COVID-19 planning, with a particular focus on those this will impact most, either through their increased vulnerability to COVID-19 or reduced access to health services.

Consider involving:

- older people
- people living with pre-existing medical conditions/multiple chronic conditions such as high blood pressure, heart disease, or diabetes, CF
- people who live in remote Aboriginal and/or Torres Strait Islander communities
- culturally and linguistically diverse populations
- people living with disability
- in-patients and out-patients
- people waiting for elective surgery
- people living in regional, rural and remote areas
- parents of immunosuppressed children and/or with chronic conditions
- survivors of COVID-19
- consumers experienced at partnering, such as
 - consumers partnering on statewide NSW Health projects
 - Health Consumers NSW
 - Local Health Districts' and Pillars' Consumer Councils and networks
 - NSW Primary Health Networks Consumer and Community Groups
 - representatives from condition-specific and population-specific organisations.

HOW DO I FIND CONSUMERS QUICKLY?

Developing partnerships with consumers is normally long-term relationship-building work. However, in times of crisis, relationships can often develop faster than normal, and in an urgent situation it is appropriate to look directly to established groups to source suitable consumers.

- Contact your organisation's consumer engagement/participation team or staff member. Health Consumers NSW can help connect you with already established consumer groups/networks.
- Look to established consumer groups within your organisation. Some of those consumers may be suitable, and already have a relationship with your organisation.
- A COVID-19 consumer group already established in your organisation.
- Contact established community groups or condition-specific organisations. Kidney Health Australia and Ethnic Communities Council of Australia are examples. Umbrella organisations that have oversight of numerous smaller organisations can be especially good points of contact. Health Consumers NSW can assist in finding and connecting to these groups.
- You may already partner with consumers on a group or steering committee. Ask them to join you.

HOW DO I ENGAGE WITH CONSUMERS WHEN WE ARE MINIMISING FACE-TO-FACE CONTACT?

You can use simple options such as video calls (such as Zoom), emails or phone. Ask your consumer engagement team or the consumers themselves what methods they recommend

KEEP THE CONVERSATION GOING

Keep the consumers you are working with informed. This can be as simple and quick as 3 dot points at the beginning of your next email to outline what has happened since you last communicated and what next steps are planned. Provide an open channel of communication so health consumers can contact you and provide information and feedback in real-time from the community.

KEY PRINCIPLES FOR CREATING STRONG PARTNERSHIPS

Following these basic principles will ensure your partnership with consumers is authentic and productive.

Partnership:

Working together to shape service delivery to better meet consumer and community needs.

Respect and dignity:

Consumers will know more than you about their personal situation, and that of their community. Be open to that, and value that contribution.

Inclusive:

If people are affected by a decision they deserve to be included in that decision. Include as many voices as possible, especially those with high social or health needs, or those who are seldom heard.

Improvement:

Use the consumers' contribution to make the COVID-19 response as good as it can be.

REMUNERATION

Health Consumers NSW recommends consumers are paid for their contribution, although every LHD and Pillar has their own policy. See Health Consumers NSW's guidelines for information.

<https://bit.ly/HCNSW-remuneration>

Your consumer partnerships are likely to involve a series of short communications. If this is the case:

- Estimate that time at the end of the month, and make one payment to cover the total, or
- Ask consumers to keep a tally of their time and send you their hours at the end of the month.
- Talk to consumers about these options before you start so it's clear what you will cover.

FURTHER ASSISTANCE

Health Consumers NSW is happy to provide additional advice and assistance in engaging consumers.

Contact us on (02) 9986-1082 or info@hcnsw.org.au.

MYTHS

MYTH: I can't involve consumers in difficult decisions, because the information is too confidential, they will get too upset, or won't understand

Making difficult decisions is exactly when you need to include consumers. Working through an ethically challenging situation with the consumers who will be affected by the decision will show you what is important and give you some viable options you may not have considered. Consumers can also guide how you communicate the decisions to the public. Testing ideas with consumers reduces the risk of getting it wrong.

MYTH: Our focus is on getting good quality information out to people, we don't have time to ask people for their input.

This is precisely the right time to bring consumers into the conversation to ensure people are getting the right messages couched in ways people will listen to. People listen (more) when their individual needs are being addressed. Partnering with consumers and consumer organisations in distributing information also ensures that people are getting the specific messages they need from a trusted source.

MYTH: It's too hard to involve consumer representatives in decisions now that we are limiting the number of people in our facilities day-to-day

Consumers don't need to be involved in planning face-to-face. You can use simple options such as video calls (such as Zoom), emails or phone. Ask your consumer engagement team or the consumers themselves what methods they recommend.

MYTH: I am overwhelmed by work right now; I just don't have time to involve consumers as well.

Involving consumers in your COVID-19 work will help lighten your load by giving you the assurance that you are making the right decisions. Your efforts will have more impact by being "road tested" by the right people before going out into the public. Many consumers are highly skilled, and all are very passionate about contributing quickly and meaningfully to this rapidly changing situation.

MYTH: I have never done this before! How am I supposed to learn this with everything else going on?

Your consumer partnerships do not need to be perfect; the most important thing is that you try. Consumers are keen to make a contribution to the COVID-19 situation as they are living this along with you. Consumers want to help you and have a strong interest in making sure better decisions are made as they are likely to be most impacted. Being inclusive and welcoming and speaking openly and honestly is very helpful.

Adapted, with permission, from: Health Consumers Queensland: *Involving consumers in your health service or units COVID-19 response*" (March 2020)