



Health Consumers Queensland submission

Queensland Parliament

Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee

Inquiry into the Queensland Government's health response to COVID-19

3 July 2020

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About us

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, and we believe in improving health outcomes for people in Queensland.

Consumers are people who use, or are potential users, of health services including their family and carers. Consumers may participate as individuals, groups, organizations of consumers, consumer representatives or communities.

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.

Consumer engagement is when health consumers actively participate in their own healthcare and in health policy, planning, service delivery and evaluation at service and agency levels



Our Six Strategic Objectives

1. Enabling health consumers and healthcare staff statewide

We build consumer, staff and system capacity to design a health system together through collaborative, integrated and consumer-centred approaches by providing support, strategic advice, training and advocacy.

2. Acting as an agent of change for consumer-centred health care

In partnership with consumers and healthcare staff, we act as a strong voice on system wide issues to influence key decision makers, policies and models of care to deliver a high quality consumer-centred health care system for all Queenslanders.

3. Enhancing effective partnerships

We develop and grow effective organisational partnerships locally, nationally and internationally to achieve consumer-centred health care for all Queenslanders.

4. Building and using evidence

We support consumers and staff to be involved in co-creating the evidence base for health system development and transformation. We act on the evidence of the human lived experience of the health system to build capacity of consumers and to leverage system change.

5. Being transparent and enduring

We demonstrate transparency and responsiveness on behalf of consumers, community and our funders. We maintain strong leadership and governance to assure organisational sustainability and longevity. We support the passion, energy and courage of our staff and members of our Network.

6. Addressing the social determinants of health

We acknowledge that systemic reform of the health system requires recognising the social determinants of health and co-designing models of care that address them.

Areas of Focus

Our areas of focus in implementing our strategic objectives

In partnership with consumers (including vulnerable groups) and staff, we act as a strong voice on system wide issues such as:

- **Healthcare Rights:** Breaches of healthcare rights which prevent fair, just and affordable access to healthcare;
- **Quality & Safety:** Where quality and safety and/or consumer experiences are of concern;
- **Healthcare Standards:** Embedding healthcare standards around consumer engagement, comprehensive care and health literacy; or
- **Systemic Issues:** Complex, difficult or contentious systemic issues.

1. Introduction

Our organisation welcomes the opportunity to provide an organisational response to the Committee. The Chief Executive, Melissa Fox, is also available to give evidence before the Parliamentary Committee.

Our staff, who are not health care providers, work closely with consumer and carers from across Queensland in their day-to-day work and the knowledge gained from these daily interactions has helped to inform our organisational response to the Inquiry into the Queensland Health's response to COVID-19.

2. Looking back: Consumer Perspective - How effective has the Queensland Government's response to COVID-19 been?

Via Health Consumers Queensland's COVID-19 Community of Interest, Facebook page and a survey, consumers and carers were offered the opportunity to respond to the following:

How effective do you think Queensland Health's COVID-19 response has been? If we had our time over again, what do you think they could do differently?

21 consumers from the COVID-19 Community of Interest discussed the topic at the weekly Consumer Conversation via videoconference; 2 responded via survey; 1 responded via social media.

Key Points

Queensland Health Response

- Overall, **consumers are impressed with Queensland Health's big picture response**, citing low infection rates and case numbers as the main indicator.
- **In relation to vulnerable groups, regional areas and communication, the response could have been improved.**
- In comparison with other states, **Queensland Health has done really well to involve consumers**, listen and act on their ideas, views and concerns.
- **Queensland Health has demonstrated openness and transparency** around information sharing.

Queensland Health's COVID-19 Response

Response to the "Big Picture"

When discussing the information Queensland Health broadcast to the community, consumer involvement, and low infection rates **consumers rated the response very positively, particularly when compared with other States.**

"The QH response overall has been really good overall from macro level - taking care of everyone within the ICU, as a consumer, telehealth switchover has been quite good, regional perspective parents healthcare has continued well. Overall happy."

“QH response has been really great. Swift, precise. Proof in pudding with low case rates and infection rates.”

“Was QH response perfect? Not at every state of the game, yes could have done better, but did QLD do better than 90% of the rest of the country? 90% of the time - yes.”

“I think QLD has done exceedingly well”

“Well, proof in the pudding, our case rates low, pretty easy access to testing.”

“Things can always be improved and we are all wise with hindsight but in this case the QH response has been above expectations.”

“I know in certain health services it hasn't been an ideal story but what HCQ and QH has done in including everyone and asking for consultation has been really good.”

Favourable Comparison to Federal and Other States: Consumer Involvement the Key

Many respondents are involved in health consumer activities interstate and federally, so were well-placed to judge their local experiences in that context. Conversations with interstate counterparts and observation of the national response highlighted for them the effectiveness of Queensland's response.

Without exception, the experience of Queensland consumers was viewed as significantly better than those of other states. Queensland Health's openness to consumer involvement and transparent communication was credited for this success, and consumers were grateful for it.

“Here in QLD have been included and asked for our opinions. All because of HCQ and advocacy you do in promoting the consumer voice and why QLD is seen as Gold Standard of consumer voices during pandemic. Meeting with DG of QH was good.”

“Other states more private and not information sharing freely. Why was it private? With COVID 19 thought everyone would want to share information and get into it.”

“I think we [Queensland] were the best.”

“I was really quite shocked to speak to some consumers in other states to hear how excluded they are in their own HHS equivalent committees especially around Standard 2 - Working with Consumers and shutting consumers out from any (video) meetings during the pandemic.”

“QLD has done demonstrably better in terms of other states in terms of consumer representation without any question.”

“WA consumers have been completely cut out. When they've asked they've been told no. Here in QLD have been included and asked for our opinions.”

Supporting the consumer view, Queensland has done this better than any other jurisdiction in Australia according to an opinion piece in Croakey: <https://croakey.org/governments-urged-to-engage-in-community-consultation-as-part-of-pandemic-response/>

Suggestions for Improvement

While consumers were very happy with the response generally, many still had areas of concern. **Inclusion of vulnerable groups, a focus on the south-east corner, effectiveness of communication, and fears of a recurrence of infections were all on respondents' minds.** People are keen that we learn from this period to be well-prepared in the event of future outbreaks.

Vulnerable People Left Out

"People with disabilities and those with poor mental are two groups which have been left behind when they should have been priorities."

"The hierarchy of testing and access to medical treatment could have been better eg. the testing criteria was not created using scientific criteria but a criteria deciding who was "worth saving first". I didn't qualify as a disabled woman back in March 2020 in QLD."

"Mental health and disability voices still need to be heard."

Too Much Focus on South East Corner

"Perhaps the action was concentrated too much QH wise around the metropolitan area. Some visibility driving action from QH in regional, rural and remote areas may have added to an already great response."

"As someone from the regions [...] I have felt that the concentration has been somewhat metropolitan. Maybe someone up top could have given the regions a nudge to find out what the consumers had to say for their locals."

Looking Forward: Applying What We Have Learned

"Preparedness for another pandemic - think about how we improve services for vulnerable groups including older people living at home on their own, people coping with domestic violence."

"We need to fund those services we KNOW we need to do better in eg. Mental health, domestic violence, child care, health care, education, access to vaccinations, access to home delivery for groceries for vulnerable groups, local manufacturing for PPE."

"There is a lot more work to be done with Qld Health on what has worked and what has not, so that we can develop an effective response in this area."

Communication

"QH needs to be careful about an over-reliance on digital communication. Consumers have not received any information about COVID-19 as hard copy, written information by post and this needs to be re-considered."

"QH needs to remember to close the feedback loop when involving consumers."

"QH could be doing better at proactively establishing and communicating what the bigger picture is now."

“It was great to meet with DG. It would be good to meet with Queensland's CHO. Victoria's CHO has been more open, upfront and accessible to consumers.”

“Information dissemination for vulnerable groups eg. people who can't access the internet or don't have electricity. eg. elderly people need notices in PRINT FORM MAILED OUT. YES. IN 2020. - It took WAAAAAY tooooooo long for them to use an Auslan interpreter. And they still don't produce information in Easy Read.”

Testing and fears of reoccurrence

“I would like to see randomised testing of people without symptoms to see if there are many people who are carriers. ”

“We still haven't had population scale viral load estimation, by either serological or wastewater methods, both of which we know QH have in their toolkit.”

“The widespread testing effort gives confidence, but it still is based on symptoms and even then, people with symptoms don't get tested.”

“I would like to see randomised testing of people without symptoms to see if there are many people who are carriers.”

“Govt should urgently put shoulder to wheel to get some epidemiological data out about levels of virus in community, with either/both serological testing and waste water testing that will give us some idea of what we really are facing.”

Looking forward

Rapid expansion of telehealth and virtual care has emerged as one of the positive outcomes from COVID-19. Now is clearly the time to harness the potential of telehealth and address the gaps and inequities of this model of health service delivery.

While talking about funding priorities for the next financial year, it is clear that health consumers have an appetite for major changes in health. Consumers have suggested major reforms to long-held ways of providing health care. Identified reforms are:

- to the way patients are categorized for care
- re-imagining HHS borders
- funding healthcare
- collaborating with consumers to design new models of care, service improvements and
- funding models to actively address the social and cultural determinants of health and the systems barriers that keep some people in a cycle of poverty and ill-health.

3. Looking back: Health Consumers Queensland Organisational Perspective - How effective has the Queensland Government's response to COVID-19 been?

At Health Consumers Queensland, we have never seen the health system work this hard and this collaboratively to care for its consumers.

At the same time consumers have valued having their voice heard and seeing how that shapes the system's response to COVID19. "Being heard and having our input providing value during COVID-19 has helped the hospitals and health systems understand what the community needed from them. "

The relationships between Health Consumers Queensland, consumers, clinician peak groups and Queensland Health decision makers have strengthened and demonstrated the value and perspective that each brings to the table to adapt in complex situations as well as design best outcomes. All have navigated sensitive and challenging conversations with maturity and grace, so that each party felt heard and developed outcomes that could only be achieved through the collaboration.

Challenges during the height of the response

For a public health system that has prided itself on being a networked system that works in collaboration with stakeholders, it was our observation it was very challenging to have a networked, joined up response early on and during the height of the emergency. Regular and meaningful stakeholder input at a high level into the public health response and advising on public health messaging/implementation, was almost impossible during the early days.

This was due to both policy constraints (informed by the Australian Health Protection Principal Committee AHPPC and decided on by National Cabinet), and time constraints (the evolving pandemic was a rapidly moving situation, with issues changing by the hour).

Whilst crisis may lead to a more closed and rigid command and control approach to leadership, this does not result in adaptive solutions that fully meet the needs of the consumer it seeks to serve, as it blocks the important feedback loop about how outputs are being received. There was no national mechanism at in the early stages for all the Chief Medical Officers to listen to consumers. This resulted on 26th March with the coalition of state health consumer groups calling on Australian Governments to invoke maximum precautionary measures to halt the exponential growth of COVID-19 infections in Australia, including mass testing, contact tracing, closure of all non-essential services, and lockdown of neighbourhoods with infection clusters. This was followed in days by a national policy approach which reflected this call.

We do acknowledge this was the first time the health system was faced by such a challenge as COVID-19 and how well the system has worked to protect the health and wellbeing of Queenslanders. However, what it also showed up was:

- the gaps in planning and preparedness for such situations, including a consumer, clinician and stakeholder engagement plan
- system leadership support for consumer involvement was not consistent across the system
- the need for consistent, targeted and honest communication with Queenslanders

WATCH: A set of three videos talking with older consumers about their experience during COVID-19 in Queensland

<https://www.youtube.com/playlist?list=PL0hT8LUg95rSWpi-GwEwuXTgdeGg5pPGx>

Opportunities and challenges overcome

The system did mobilise several mechanisms to overcome these challenges, including communication mechanisms such as a Primary care & NGO stakeholder group, and appointing our CEO to a new Pandemic Health Response Implementation Advisory Group (PHRIAG). This enabled the ability for consumers to input into public hospital system response.

The Queensland Clinical Senate and the Clinical Networks also demonstrated the benefit of respectful, responsive and collaborative work that led to improved actions and practices.

The system also welcomed our pivoting of our activities to amplify the consumer voice to inform the COVID-19 response (see p. 10).

Looking forward

Health Consumers Queensland commends Queensland Health on their response to COVID-19, the initiatives they have put in place, the opportunities they have presented to consumers to influence decisions and the way in which they have worked to support the health and wellbeing of all Queenslanders.



EMPOWERED ENGAGED
LUCKY APPRECIATIVE
BREATHING
HEARD VALUED INCLUDED
PRIVILEGED GRATEFUL
TELEHEALTH

A networked system needs to get input and insight from the front line and users of the system and bring to the system decision making and direction setting areas. This needs to be a full feedback system that needs to be maintained and enhanced.

Additional enablers which should underpin the future of our networked, collaborative health system include:

- Recommitment by leadership and the system to a networked system that includes genuine partnership with clinicians and consumers across all parts of the response, including public health
- Behavioural science and culture change to influence lack of capacity and attitudes driving behaviours that will support partnering and collaboration as “must haves” for every part of the system

- Whole of system governance and oversight of Reform Planning Group reform priority opportunities implementation by the Queensland Health Leadership Board, with public health engaged and open to partnering.
- Communications to the user needs to be tested with the user (or agreed agent of them i.e. carer) about the outcomes that they need and prioritise. To achieve this, we need more effective feedback mechanisms and embedding of those insights.

Health Consumers Queensland's COVID-19 Response

MID-YEAR SNAPSHOT 2020



125 DAYS
of our **COVID-19**
RESPONSE

Health Consumers Queensland, consumers and Queensland Health work together to deliver a consumer-centred public health system response to COVID-19



500+ CONSUMERS
SHARE THEIR VIEWS
WITH QLD HEALTH

26 CONSUMER
CONVERSATIONS WITH
6 CONSUMER GROUPS



151 MEMBERS OF OUR
COVID-19 COMMUNITY
OF INTEREST

80+ CONSUMERS IN
FIRST NATIONS AND
RURAL & REMOTE FORUM



20 FAST-TRACK
CONSULTATIONS WITH
100+ CONSUMERS

KEY TOPICS

COMMUNICATIONS | **MENTAL HEALTH**
ACCESSING CARE | **TELEHEALTH**
TESTING | **WHO IS BEING LEFT BEHIND**



Health Consumers Queensland responded early to the onset of COVID-19. In early March we pivoted our work to support consumers and the health system to collaborate on solutions to challenges not seen before.

Our early action and involvement in key initiatives has played a key role in ensuring a consumer-centred public health system response to COVID-19.

At the outset of the pandemic just prior to the lockdown requirements, HCQ hosted a Health Consumers Collaborative of Queensland meeting which involved workshopping the main themes arising in the immediate and longer-term response to the pandemic from consumer, clinician and health system manager perspectives. Due to the long standing relationship of trust and collaboration that we have built over the years of the Collaborative we were readily able to develop practical and time sensitive insights, advice and recommendations that formed priorities for the system response.

Through our work since March, Queensland Health has been able to hear from many hundreds of Queenslanders with significant health needs and use that intelligence to form a more wide-reaching response than otherwise possible.

Consultation during this time has been undertaken with informed and less informed consumers, and at the grassroots level with the broader community. Consultation has occurred with remote, regional and rural communities and vulnerable population groups including: older persons, Aboriginal and Torres Strait Islander people, people with chronic conditions, people with mental health and disability or living in social housing, people from non-English speaking backgrounds and those who identify as culturally and linguistically diverse, and people directly impacted by COVID-19.

This work saw real growth in partnerships between consumers, clinicians and health services. These were enabled by the existing trusted relationships, which were strengthened. At times this was driven by consumer and clinician focused forums and organisations having opportunity to respond to needs that it sees and influence.

Queensland Health and clinician led organisations partnering with HCQ have stated that the continuous engagement and collaboration with consumers and HCQ on issues during COVID19 has improved decision making agility and confidence that these decisions are fit for purpose. It has reduced fear, risk aversion and inertia) and improved speed and outcomes.

Health Consumers Queensland's initiatives to support the Queensland COVID-19 response have included:

COVID-19 Consumer Community of Interest Group

- Creation of a new Community of Interest Group of 150+ diverse consumers and carers across the State interested in COVID-19. These consumers are invited to our weekly Community of Interest Consumer Conversations to discuss consumer related issues and concerns about health care and messaging during the pandemic. We have been able to track and instigate change on issues the group has raised. We turn to the Community of Interest Group when we are asked for rapid consumer consultation on behalf of Queensland Health.

Consumer Conversations

Health Consumers Queensland has been hosting regular consumer conversations by videoconference several times per week since 25 March. We have held 26 Consumer Conversations with more than 500 consumers across the state.

This provides regular opportunities for consumers to raise concerns, identify gaps they see and work with the health system to strengthen the COVID-19 response. The conversations are held with different cohorts of consumers including:

- COVID-19 Consumer Community of Interest members
- Experienced consumers – including State-wide HHS Consumer Advisory Group leaders, consumer members of the Health Consumers Collaborative of Queensland and HCQ's own consumer advisory group
- State-wide Clinical Networks consumer representatives
- Queensland's Primary Health Networks consumer representatives

Health Consumers Queensland wrote and distributed issues papers that summarised key consumer issues from these conversations. These were distributed to Queensland Health leaders, clinicians and our Consumer Network and published on our website for consumers and staff. Topics included:

- o Consumers delaying healthcare (early in the pandemic)
- o Queensland Health funding priorities including consumer insights about telehealth and virtual care
- o Rebalancing the health system (in light of some surgeries recommencing)
- o Positives and innovations consumers want to keep beyond COVID-19
 - For a full list of issues and summary of key themes look at our Issues Papers on our website (www.hcq.org.au).
 - See attached for a summary of themes we have heard across the 26 Consumer Conversations during COVID.

Consumer Consultations & Forums

To facilitate consumer involvement in key decision making, Health Consumers Queensland has supported consumers being involved in 20 rapid consultations during the COVID-19 response (involving more than 100 consumers) for Queensland Health projects and initiatives including:

- Funding priorities and models
- Community media/communications campaigns including for culturally and linguistically diverse consumers, Queenslanders generally and around a mental health and wellbeing campaign.
- Reviewing form letters and SMS messages to patients when elective surgery delayed, and then again, when reinstated
- Health and Wellbeing Queensland's website.
- Strategic Communications Branch utilised insights from health consumers directly into their work and influenced key messages – including the move away from “social distancing” to “physical

distancing”. A small but important change that consumers championed understanding the benefits of social connection more than ever before.

- We held a one-off on-line forum for First Nations peoples and those who live in rural and remote communities.
- We have also successfully converted the Kitchen Table Discussion methodology to work on-line (rather than face-to-face). Eleven (11) community hosts conducted kitchen table discussions with 69 participants during COVID-19 to hear the voice of the wider community in relation to learning what level of communication they would expect from Queensland Health during the pandemic and what they would expect of patient centred care.

Ethical Decision-Making Framework for Queensland

In March 2020 and in the early stages of the COVID-19 pandemic, an Ethical Decision-Making Framework for Queensland was developed with the support of clinicians and in partnership with health consumers and other key stakeholders. The framework guides decision-making during a pandemic and is built upon a set of underpinning ethical values that align with the Human Rights Act in Queensland.

Health Consumers Queensland and consumers were involved throughout the framework development, and also were enabled to facilitate rapid consultation with informed consumers and the broader community. More than 80 consumers and carers were consulted or involved in the framework development and review process.

Queensland is the first and only state or territory to develop their framework in partnership with consumers.

- See attached for a full snapshot of HCQ initiatives to support Queensland’s COVID-19 response.

4. Looking back: How effective has Health Consumers Queensland’s response to COVID-19 been?

We invited consumers to respond to the following question:

We also invite you to be our critical friends: how would you rate Health Consumers Queensland’s response? Do you feel we have helped facilitate a good response by Queensland Health?

Key Points

Health Consumers Queensland's Response

- **Consumers were extremely happy with Health Consumers Queensland's response**, believing it to be a key factor in inclusion of marginalised voices and high consumer involvement by Queensland Health.
- **More activity in regional areas** was one of the few suggestions for improvement.

Consumers were overwhelmingly positive about the COVID-19 response from Health Consumers Queensland, with many feeling that the COVID-19 Community of Interest gave consumers the opportunity to have their voices heard, and gave them the information they needed to support themselves, their families and their communities. More importantly, **consumers saw the influence they had on Queensland Health** and were mindful of how unique that is in Australia.

Throughout the discussion, participants had a strong sense of this period setting the standard for consumer involvement in healthcare decision-making and were optimistic that genuine progress has been made in cementing a consumer voice at the table.

Overall Reaction to Health Consumers Queensland's Response

"From my high school chemistry days a catalyst was something that promoted a reaction but remained unchanged by it. In this case HCQ was a highly effective catalyst and improved itself in action and reputation through it."

"[Health Consumers Queensland's work] has helped empower us to get our voices out there and get us involved in QH. Believed it has helped QH to have the response it has had."

Key to Ensuring the Needs of Vulnerable People are Met

Participants have expressed concern for vulnerable groups throughout the Consumer Conversations series, and **credited Health Consumers Queensland with providing the means for the voices of marginalised people to be heard.**

"Including disabled people like me in this community of interest has been fantastic and given disabled people of QLD a voice to QLD Health - Including a voice to the Director general of QLD Health for the very first time. This has been the work of Health Consumers QLD."

"[Health Consumers Queensland] have tried to ensure they are including a diverse range of viewpoints and listening to groups of people who wouldn't normally have a voice. Now to get QLD Health to make the changes we consumers are talking about in the sessions."

"Thank you to Health Consumers QLD for ensuring a voice for the vulnerable people of QLD"

What Could We Have Done Better?

While the reaction to Health Consumers Queensland's response was extremely positive, greater reach into the regions was an area for improvement.



“As a consumer in regional Queensland I would have liked to have seen HCQ having some outreach beyond the metropolitan area and influencing some joint health area and consumer action the various health areas.”



23 June 2020

HCQ listening to consumers during COVID-19: What's working & what's not

CONSUMER THEMES THROUGH COVID-19

Health Consumers Queensland has been facilitating Consumer Conversations since 25 March to hear directly from consumers during COVID-19. Since then we have held 26 sessions with more than 500 consumers. The early conversations were during a lot of uncertainty as public health restrictions were being imposed and we simply asked “what is working, what isn’t and what are you concerned about?” As the curve began to flatten, we refined the conversations to focus on specific topics, based on what we were hearing from consumers. Consumers routinely identified early key issues for the community, which we were able to feed through to the health system. This enabled the system to respond in the knowledge of consumer insights and expectations.

Since mid-April, HCQ has been writing an Issues Paper based on each week’s Consumer Conversations. These are all [available on-line](http://www.hcq.org.au) at www.hcq.org.au and include:

- Mental health
- Telehealth and virtual care
- Who is being left behind?
- Positives and innovations consumers want to keep
- Consumers delaying healthcare during COVID-19
- COVID-19 Testing
- QLD Health funding priorities 2020/21
- Safety in healthcare during COVID-19
- Re-balancing the health system: Providing care and being prepared for COVID-19

SUMMARY OF KEY THEMES FROM ALL THE CONSUMER CONVERSATIONS

Valuing the consumer voice and co-designing system responses

In a time of rapid change and uncertainty, consumers intuitively understand that their involvement in system-wide and local Hospital and Health Services (and other health provider) responses can help to increase the chances that the right decisions will be made, and communicated effectively, to consumers and community. Consumers understand that their living experience and insights can improve and strengthen the health system response during a global pandemic.

Consumers value the chance to come together regularly to discuss their living experience of receiving healthcare (or not) during these times, their concern for other priority population groups and to hear the perspectives of other health consumers in different circumstances.

Consumers want to co-design system-wide and local HHS (and other health provider) responses and decisions regarding policy, planning, service delivery, communication and more. Consumers understand that their collective experience is critical to the implementation of an effective pandemic response (while at the same time balancing the needs of those who continue to require healthcare that is not COVID-19 related).

Consumer representatives from across Department of Health committees and HHS committees report a variability of their involvement during COVID-19. Some consumers are more involved than

ever before on very important decisions, and some committees have completely excluded their consumer reps from critical decision-making.

Recommendation: Collaborate with consumers more.

Strong desire to use the disruption of a global pandemic to transform the health system

Consumers would like for the health system to use this opportunity to make significant changes to the health system including:

- the way in which consumers are viewed (from passive users of the system to active decision-makers of the system and of their own care). Consumers want to be actively involved in their own care as well as system-wide planning, policy and decision-making.
- more collaborative decision-making that is timely and less bureaucratic.
- decision-making that is collaborative, transparent, and focused on the greatest good. They are happy to see the demise of decision-making that is siloed, slow and overly bureaucratised.
- a more balanced perspective on risk. Pre-COVID-19 it seemed that decisions took a long time to be made as key health leaders worried about the risk of those decisions. During COVID-19 the view of risk shifted, with health leaders understanding that there was more risk in doing nothing. Consequently they made decisions knowing that if they didn't work out, they could adapt them, tweak them, learn from them. Consumers valued this responsiveness that saw telehealth suddenly unblocked and clinicians trying new ways of providing care.
 - In the early days of the pandemic there seemed to be a greater autonomy for clinicians and local service providers to do what they needed to do to ensure they were prepared for any over-demand on the health system.
- consider new ways of funding healthcare that focuses on people's health outcomes and experiences more than on just 'doing something'
- reprioritising the way people wait for surgeries and treatments so that those people can be involved in those discussions – currently it is all based on clinical need without looking at the impact on the whole person/family unit.

Recommendation: Capitalise on this major disruption and transform health care by working in strong partnerships with consumers.

Communication and consumer informed decision making about accessing care:

- People living with chronic conditions, or with complex care needs, or with a disability, identified in the early days of the pandemic they were not receiving the information they needed in order to keep themselves safe, and to help with their decision-making about when and where to receive care. Key messages were being largely prepared for healthy Queenslanders, not those people who were already 'in' the health system. We have fed this into various parts of the Department, however it continues to be an issue. The system needs to communicate the right individualised and localised messages to people with extra health care needs, for as long as COVID-19 is a threat.
- Improved levels of health literacy in the community as a result of COVID-19 require health staff to have different conversations with consumers. COVID-19 has required us all to become more comfortable with ambiguity, and consumers want to hear their options and make informed decisions about care together.

- Consumers are keen to hear the evidence behind decisions, not just what the latest rules, guidance or policies are.
 - Currently consumers want to know what groups of people are getting surgery, which aren't, what is being done to manage wait lists and to re-prioritise care if needed and the evidence/rationale for these decisions.
 - Consumers hear that hospitals are safe, but before going to hospital they want to know how they are being made safe, what screening measures are in place, the physical changes being made to waiting rooms etc. It's not enough to just 'trust' the system that adequate measures are in place.

Recommendation: Recognise the social capital and connections available from the consumer-world and tap into these to inform communication, particularly communication aimed at those who require focused health attention and are likely to be impacted most by these decisions.

Communication – mass

Consumers are keen to lead the next phase of messaging to show the importance of physical distancing for vulnerable people – consumers would like to put a face on what vulnerable looks like. One consumer said he is walking a fine line “between diligence and paranoia” and would like to contribute to messaging for people to understand the continuing importance of physical distancing, particularly when restrictions have eased for the mainstream community.

In fact, consumers have been very keen from the on-set of COVID-19 to be more involved in message framing. Consumers have been able to review messages and community campaigns once they are complete but are not involved in the early phases of the development. They are keen for this to change.

Consumers in regional areas have also highlighted that in previous emergencies such natural community members hear from trusted, authoritative locals. Receiving communication from trusted sources is important, and for many people those trusted sources vary. Consumers would like more opportunity for local health providers (whether it's a HHS or an Aboriginal and Torres Strait Islander Community Controlled Health Organisation) to tailor messaging specific to their local community, while noting the importance of consistency of messages between local, state and national sources. People from First Nations and culturally and linguistically diverse communities have a particular reliance on established trusted sources of information. Ensuring a mechanism that allows for consistent messaging across Queensland but using the right spokespeople is critical to ensure the messaging is understood and acted upon.

Recommendation: Create communication campaigns with consumers playing a leading and active role.

Concern for others – an inclusive and equitable system

Many consumers are concerned for people who are being forgotten about or left behind during COVID-19. This includes people living with a disability and/or chronic condition including people who are immune-suppressed. It also includes First Nations consumers who are also living with a disability and/or chronic condition, and culturally and linguistically diverse consumers.

Consumers are also concerned about others whose circumstances have changed and created new challenges for them including those people who are at risk of homelessness, international students or new arrivals who do not have access to Medicare-funded health services, and people who have recently lost their livelihoods/incomes.

The digital, financial and communication divide can increase the risks for those who are already vulnerable. Those who need to remain in isolation to protect their own health as restrictions ease for others are of particular concern. This needs to be actively monitored and measured, and those groups included in decision-making wherever possible.

Recommendation: Monitor and measure the impact COVID-19 is having on the people most at risk of being left behind. Involve these consumers in co-design to ensure the health response meets their needs.



JUNE 2020

Health Consumers Queensland's COVID-19 response: A snapshot

BACKGROUND

About Health Consumers Queensland:

- Peak organisation representing the interests of health consumers and carers in the state.
- A small (7.2 FTE), not-for-profit organisation and a registered health promotion charity.
- We work with health consumers and health staff to improve health outcomes for people in Queensland.
- Funded by Queensland Health to ensure the Department of Health and the Hospital and Health Services (HHS) involve consumers in planning and policy decisions that are going to impact them.
- 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.

OUR COVID-19 RESPONSE

Health Consumers Queensland responded early to the onset of COVID-19. In early March we pivoted our work to support consumers and the health system to collaborate on solutions to challenges not seen before.

Our early action has played a key role in ensuring a consumer-centred public health system response to COVID-19. Through our work, Queensland Health has been able to hear from hundreds of Queenslanders with significant health needs and use that intelligence to form a more wide-reaching response than otherwise possible.

1. COVID-19 Consumer Community of Interest Group

Creation of a new Community of Interest Group for consumers interested in COVID-19 (132 members, as of 21 June). These consumers are invited to our weekly Community of Interest Consumer Conversations to discuss consumer related issues and concerns about health care and messaging during the pandemic. We have been able to track and instigate change on issues the group has raised. We turn to the Community of Interest Group when we are asked for rapid consumer consultation on behalf of Queensland Health.

2. Consumer Conversations

Health Consumers Queensland has been hosting regular consumer conversations by videoconference several times per week since 25 March. We have held 26 Consumer Conversations with more than 500 consumers.

This provides regular opportunities for consumers to raise concerns, identify gaps they see and work with the health system to strengthen the COVID-19 response. The conversations are held with different cohorts of consumers including:

- COVID-19 Consumer Community of Interest members

- Experienced consumers – including Statewide HHS Consumer Advisory Group leaders, consumer members of the Health Consumers Collaborative of Queensland and HCQ's own consumer advisory group
- Statewide Clinical Networks consumer representatives
- Queensland's Primary Health Networks consumer representatives

We have also held a one-off on-line forum for First Nations peoples and those who live in rural and remote communities. We are hopeful we can continue to collaborate with the Aboriginal and Torres Strait Islander Division in the Department of Health to continue these conversations regularly.

3. Bespoke consumer consultations

To facilitate consumer involvement in key decision making, Health Consumers Queensland has supported consumers being involved in 20 rapid consultations (involving more than 100 consumers) for Queensland Health projects and initiatives including:

- Funding priorities and models
- Community media/communications campaigns including for culturally and linguistically diverse consumers, Queenslanders generally and around a mental health and wellbeing campaign.
- Reviewing form letters and SMS messages to patients when elective surgery delayed, and then again, when reinstated
- Health and Wellbeing Queensland's website.

We have also successfully converted the Kitchen Table Discussion methodology to work on-line (rather than face-to-face). Eleven (11) community hosts conducted kitchen table discussions with 69 participants during COVID-19 to hear the voice of the wider community in relation to learning what level of communication they would expect from Queensland Health during the pandemic and what they would expect as patient centred care.

4. COVID-19 Resource Development

- Development of [factsheet for Queensland Health staff](#) on involving consumers in decision-making during a pandemic. This has been adapted by state/territory consumer peaks across the country. Safer Care Victoria have requested to adapt this resource.
- Health Consumers Queensland's pilot of Project ECHO training was adjusted to be COVID-19 responsive – we were the first in the Asia-Pacific region to deliver this training from homes and the first in the world to use Project ECHO to build skills in consumer engagement.
- Development of a [COVIDSafe tracing app decision guide and FAQs](#). Health Consumers Queensland understands we are the only state/territory consumer peak organisation in Australia to have developed a decision-making guide for consumers.
- Write and distributed [issues papers that summarise key consumer issues](#). These are distributed to the Public Health Response Implementation Advisory Group, to QH leaders and on our website for consumers and staff. Topics have included:
 - QH funding priorities including consumer insights about telehealth and virtual care
 - Rebalancing the health system (in light of some surgeries recommencing)
 - Consumers delaying healthcare (early in the pandemic)
 - Positives and innovations consumers want to keep beyond COVID-19

For a full list of issues and summary of key themes look at our [Issues Papers](#) on our website.

MILESTONES/ACHEIVEMENTS

Health Consumers Queensland has a seat on key QH committees, so are able to speak up on behalf of consumers across Queensland.

HCQ has facilitated and advocated for Queensland Health to involve consumers in their COVID-19 responses. Queensland has done this better than any other jurisdiction in Australia according to an opinion piece in Croakey: <https://croakey.org/governments-urged-to-engage-in-community-consultation-as-part-of-pandemic-response/>

Strategic Communications Branch include consumer insights from health consumers into their work and influencing key messages – including the move away from “social distancing” to “physical distancing”. A small but important change that consumers championed understanding the benefits of social connection more than ever before.

Consumers have valued having their voice heard and see how that shapes the system’s response to COVID19. “Being heard and having our input providing value during CVOID19 has helped the hospitals and health systems understand what the community needed from them.” Another consumer recommended people join the HCQ networks “So we can all be a part of change and make our health system great.”

LOOKING FORWARD

- CEO of health Consumers Queensland is an expert member on the [Reform Planning Group](#)
- Training for health staff and consumers: Health Consumers Queensland has plans to provide training for staff and consumers over the next 12 months that will further embed strong consumer partnerships and system-wide engagement. Lunchtime sessions will be held with QH staff in the Department of Health and across HHSs. Experienced consumers will get the opportunity to take part in our successful Project Echo training sessions that build peer support and mentoring and training all into one.
- Health Consumers Queensland will continue to listen to and amplify the consumer voice and will be looking at ways to better partner with young people.