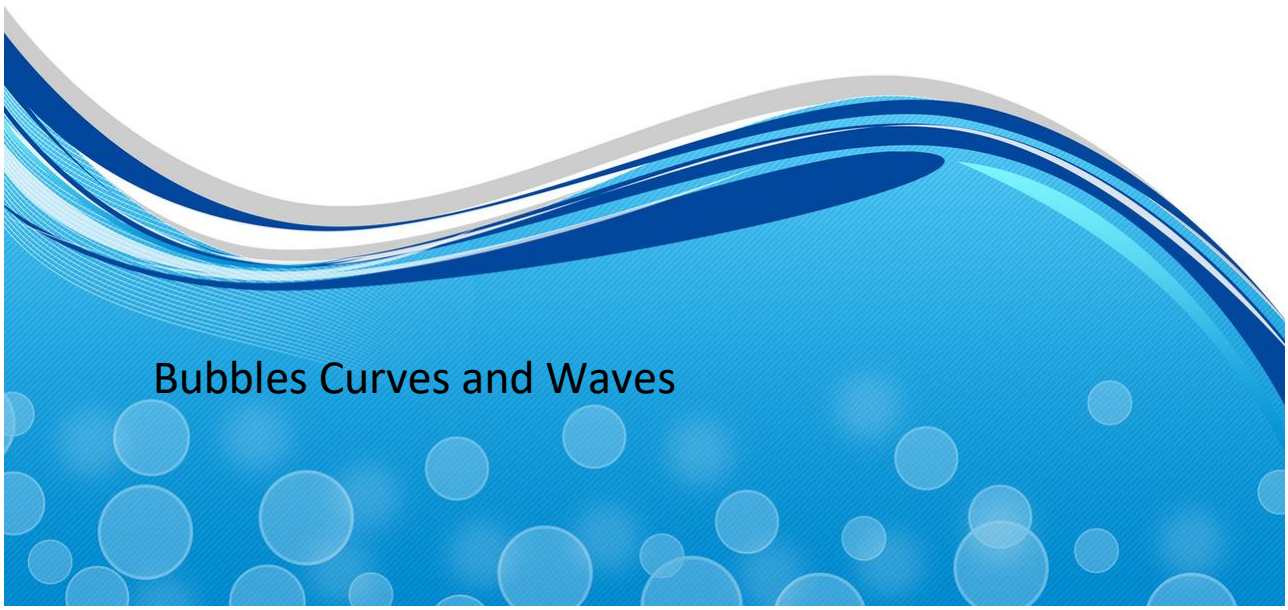
Executive Summary Report

Evaluation of the Impact of Consumer Engagement during COVID-19

January 2020 to January 2021



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Evaluator

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Robyn is an independent consultant and has over 30 years of experience in social and cultural planning and project management within private and public sectors. She has held management and social planning roles in Local Government, Primary Health, Community Services, and Education and Training. Robyn has a Masters Degree in Program Management and is a member of the Australian Evaluation Society. She has conducted evaluations for government and non-government agencies on a range of issues such as suicide prevention, Indigenous youth justice programs, social housing design, cultural exhibition programs, emergency management responses, and health promotion programs. Robyn has worked in rural and remote and urban communities to develop structured partnerships and community based responses to social issues, and she was awarded a Churchill Fellowship to further her practice and experience in community based primary health. Robyn has experience with disaster management and in particular has worked in community recovery roles in Queensland and NSW.

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.

1. Introduction

This report summarises the activities, approach and outcomes of the evaluation of consumer engagement during the COVID-19 pandemic in 2020. This mixed method evaluation was conducted by an independent evaluator with the participation of Health Consumers Queensland (HCQ), consumer representatives and Queensland Health staff. The evaluation is focussed on the process and quality of consumer engagement, and the outcomes of engagement during the pandemic. HCQ Principles of Engagement: partnership, respect and dignity, inclusiveness, and improvement provide a basis for measuring effectiveness and quality in this evaluation.

The contextual understanding for this evaluation is essential as the parameters and scope of the project derive from circumstances that are not considered business as usual and required legislated authority and operational changes for all governments, organisational parties, and the community. The operational management of the pandemic continued to evolve during 2020 as the state of emergency moved back and forth through phases of disaster management: prevention and preparedness, response, and towards recovery.

Language to communicate about the pandemic evolved with “bubbles” (such as restrictions around travel, borders, households), “curves” (flattening the number of COVID-19 cases), and “waves” (exponential increases in the number of COVID-19 cases) depicting the social behaviours and restrictions, the data and trends, and even the emotions of fear and caution. These terms were absorbed into public messages and became as much a part of life as the daily weather reports during 2020.

The Queensland Government was quick to declare a public health emergency and to legislate the authority to manage restrictions and directives required under the Whole of Government Pandemic Plan (2020). Queensland Health is the lead agency and is structured to ensure continuity of business for the Department and a capacity to manage the Statewide responsibilities for pandemic management.

HCQ is the peak organisation representing the interests of health consumers and carers in Queensland. They pivoted their business to ensure consumers were involved and had a say at this critical time within the health system. This required significant adaptation for HCQ staff with limited financial resources. There has also been a high level of commitment from the consumer network that engaged at all levels of the system to partner with Queensland Health to optimise health and safety for Queenslanders. Consumers conveyed vital information about impacts on individuals and services within the broader health and social service networks.

HCQ was assertive, advocating from the outset that consumer voices and representation was a strategic component in the pandemic response. This action early in the pandemic, and the trusted relationships that existed between HCQ, clinicians and the Queensland Health leadership team, ensured the inclusion of consumer voices and representation at strategic levels in the pandemic response. Senior leadership in Queensland Health responded to the call for consumers to have a voice and invited HCQ representation on Queensland Health working groups and committees. HCQ provided a conduit for consumer voices into complex and sensitive operational settings.

HCQ identified population and service gaps and elevated relevant concerns and advice to a strategic level with Queensland Health. The strengthening of alliances with HCQ, Queensland Health and other NGO agencies directly relevant to the pandemic event, benefited the consumer groups they represent (e.g., Aged Care and Advocacy, Palliative Care, Disability). Consumer representation in Queensland Health working groups and committees resulted in the identification

of population and service gaps in pandemic response initiatives such as COVID-19 Testing, hospital visitation, and quarantine, and this supported Queensland Health to connect with relevant population groups to address their needs (e.g. international students, prisoners, RACFs, homeless people).

HCQ partnered with Queensland Health to improve communications with the community and create information and resources to assist consumers to navigate health system changes. HCQ moved rapidly to design and facilitate an online communications platform, conducting Consumer Conversations that were fit for purpose during the pandemic restrictions and praised by the Chief Health Officer (CHO) for its contribution to supporting Queensland Health and the community. HCQ supported Queensland Health to improve their communications and messages to the community by providing access to diverse consumer networks, quick response reviews and bespoke consultation, and engagement with experienced and trained consumer representatives. HCQ partnered with clinicians, health staff and NGOs to develop resources that build consumer confidence to navigate the health system during pandemic conditions (e.g. telehealth, Compassionate Conversation Guides, RACF guide, Know Your Rights).

HCQ extended the outreach and distribution of trusted and reliable pandemic information into regions and back to relevant central leadership areas of the Department. Best practice in disaster management includes "intelligence" or "on the ground" information through engaging with local communities. HCQ's considerable effort during the pandemic response has resulted not only in bringing consumer voices to the table with Queensland Health, but also the development of trusted channels of communication from consumers around kitchen tables, in regions, and in online conversations. Participants in this evaluation spoke of the benefit of receiving trusted, timely and relevant information for them to pass on to their communities and networks.

HCQ documented issues arising, and solutions proposed, for pandemic relevant topics and ensured the documents were circulated in targeted and open ways. This contributed to respectful feedback and a shared voice for consumers and the Department. The documentation of Issues Papers provided a consistent and accessible mechanism for all participants to distribute appropriate and relevant information across networks.

This evaluation has identified high levels of satisfaction from consumers, HCQ and Queensland Health staff with regard to the contribution of consumers and engagement with Queensland Health during the 2020 pandemic. HCQ adapted their engagement practices to effectively support consultation online, Queensland Health executive staff and clinicians provided opportunities for engagement, new partnerships were formed with other NGO advocacy peak agencies, and there was an increase in the diversity of consumers and their direct engagement across the State. There were also challenges highlighted that will inform system improvements for the ongoing and future engagement of consumers in pandemics.

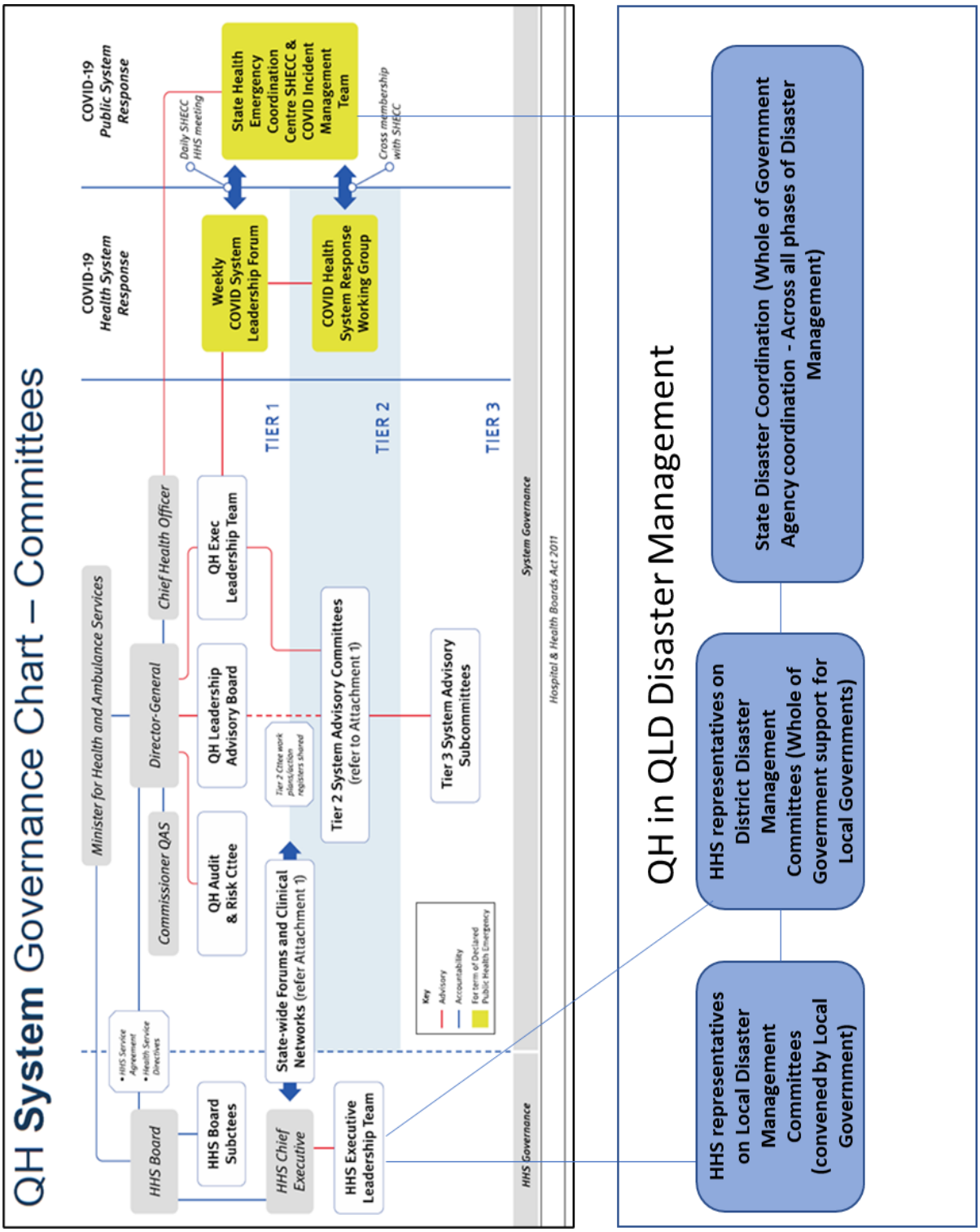
2. Background

2.1 Queensland Government Pandemic Management

The Queensland Government passed urgent amendments to the Public Health and Other Legislation (Public Health Emergency) Amendment Act 2020 on 18 March 2020, strengthening the powers of the CHO and emergency officers appointed under the Act for the COVID-19 emergency. Appointments were made to act in the position of Deputy Director General of the Prevention Division to ensure business continuity whilst the CHO has been the State Health Incident Controller for the management of the COVID-19 Pandemic response. Queensland Health reviewed their organisational structure to reflect the changes in Executive roles and identified the senior leadership committees for the duration of the pandemic and linked to the structure of the Department (Figure 1). The defining of roles has been important for business continuity for Queensland Health, and it also highlights the change in scope from Queensland Health specific operational responsibilities to Whole of Government lead responsibilities across the wider community. Business continuity planning is recommended in the Queensland Disaster Management Guideline (2018. p.33) and the recommendation applies to both Government and non-government agencies as a critical element in preparedness. The creation of distinct roles in Queensland Health for leadership of the State response to the pandemic, and ensuring the continuation of health service delivery, impacted relationships and formal structures for health consumer engagement.

The defining of responsibilities for the State Government included running parallel systems with Queensland Health being responsible for service delivery and business continuity as impacted directly by COVID-19, and the CHO being responsible for the public health response through the State Disaster Management structures (Figure 1). The structures within Queensland only represent a part of the overall pandemic management system which also includes National and interstate coordinated responses. Figure 1 is a simplified version to describe the alignment between Queensland Health and Queensland Disaster Management only.

Figure 1. Parallel systems – Queensland Health and Queensland State Disaster Management



The Queensland *Whole of Government Pandemic Plan* (2020) is based on existing State Government Disaster Management structures, legislation and guidelines. It emphasises that disaster impacts in Queensland are generally experienced more intensely at district levels as the State is accustomed to cyclone and flood events. Pandemics differ in their impact and can be over a longer period of time

and across the whole State. With the differences in scale and timeframes, the plan states that "*Disaster management responses developed to deal with smaller level, localised disasters may require further planning to adapt to the need for large scale response." (p. 6. 2020.)*

The structures that are in place for disaster management are identified in the Queensland *Whole of Government Pandemic Plan* (p.8. 2020). The plans indicate that: "*Across the prevention, preparedness and response phases of a pandemic (Figure 2), the type of specific assistance required will be identified by Queensland Health as the lead agency and requested via the State Disaster Coordination Group or via the State Disaster Coordination Centre (when activated) who will then coordinate with the relevant entities. The support provided by disaster management groups must align with the State Disaster Management Plan and/or requirements of the State Health Emergency Coordination Centre (SHECC) and their relevant HHS. As the response phase escalates, it is envisaged that Local Disaster Management Group's and District Disaster Management Group's response would move to 'stand up' in support of their relevant HHS as the lead agency."*

Figure 2. Queensland Whole of Government Pandemic Plan – Emergency Management Framework

Table 1 Emergency management framework – AHMPPI, QHDISPLAN and QSDMP

AHMPPI Stages	AHMPPI Sub-stages	Characteristics of the disease that inform key activities	Queensland response arrangements
Prevention	Prevention	No novel strain detected or emerging strain under initial investigation	Prevention
Preparedness	Preparedness	No novel strain detected or emerging strain under initial investigation	Preparedness
Response	Standby	Sustained community person-to-person transmission overseas	Alert Lean Forward
	Initial Action Targeted Action	Cases detected in Australia Initial - When information about the disease is scarce Targeted - When enough is known about the disease to tailor measures to specific needs	Stand Up
	Stand Down	Virus no longer presents a major public health threat	Stand Down
Recovery	Recovery	Virus no longer presents a major public health threat	Recovery

**Prevention and recovery are not the primary focus of the AHMPPI. It is acknowledged that the consequence management arrangements for recovery may be in play before the move to 'recovery'.*

The phases of emergency management for the pandemic response situate this evaluation during the response phase of this pandemic event. The impacts and activities have, and will vary through the phases of prevention, preparedness, response and recovery and this is important in understanding the organisational structures, relationships and roles of relevance to consumer involvement.

2.2 Health Consumers Queensland

HCQ is a peak organisation that represents the interests of health consumers and carers in the State of Queensland. The team is small with less than 8 full time staff, and it is a not-for-profit organisation and registered health promotion charity. Queensland Health fund HCQ to ensure the Department of Health, and the HHSs, involve consumers in planning and policy decisions that impact them.

During 2020 and the COVID-19 pandemic the HCQ Board decided to pivot business and focus on working directly with Queensland Health to ensure consumer engagement in the response. The HCQ Consumer and Community Engagement Framework identifies four principles of consumer engagement which provide a basis for evaluating the effectiveness and quality of involving consumers in the pandemic response. The principles are partnership, respect and dignity, inclusive, and improvement (Figure 3).

Figure 3. HCQ Principles

3. Evaluation project design

3.1 Objectives

The objectives of this evaluation were:

a) To evaluate the effectiveness of consumer engagement that has occurred during the COVID-19 pandemic in Queensland.
b) To contribute to evidence that assists with embedding consumer partnerships in the health system across Queensland for ongoing and future pandemics.
c) To identify improvements to enable growth and maturity of consumer partnerships between Queensland Health and Queensland consumers and carers based on the response to the COVID-19 pandemic.

3.2 Scope

The evaluation included the period from January 2020 to January 2021. Due to the project timeframes and resources, data collection for the evaluation was limited to the Queensland Health pandemic leadership team as identified by Queensland Health. The Hospital and Health Services (HHS), primary care, and private hospital sectors were not identified as direct data sources for this evaluation, although some participants have referred to these areas as relevant to their responses. Disaster management plans refer to phases of prevention, preparedness, response and recovery and this evaluation considered all phases based on participant experiences during the COVID-19 pandemic in 2020.

3.3 Method

HCQ is the peak organisation representing the interests of health consumers and carers in the State, and the principles of engagement are fundamental to all activities. Consumers have been engaged in the codesign of this evaluation and its conduct and implementation. The evaluation project governance included consumer, HCQ Board, HCQ staff and Queensland Health staff representation on the Evaluation Reference Group with clearly established Terms of Reference, evaluation project meetings, and regular online communication. Consumers were appointed to the Evaluation Reference Group following an open Expression of Interest to consumer representatives on HCQ's data base.

This evaluation adopted a participatory and mixed method approach. Semi structured interviews, open form questionnaires, a survey and two focus groups captured the observations, opinions and comments of over one hundred and thirteen participants. The analysis of this provides a documented record of activities and proposals for continuous improvement in consumer engagement practice during pandemics.

Data was collected through an online consumer survey with 60 participants, anonymous questionnaires with eight Queensland Health staff and eleven HCQ staff and Board members, interviews with six consumers, three HCQ staff and Board, and four Queensland Health staff. There were also two focus groups: one with five representatives from NGO peak advocacy agencies and the other with fifteen representatives of the Health Consumers Collaborative of Queensland. Anonymity and confidentiality for all participants has been an important ethical consideration in the conduct of this evaluation. The only participant who agreed to have direct statements attributed to them was the Chief Health Officer (CHO).

3.4 Program Logic

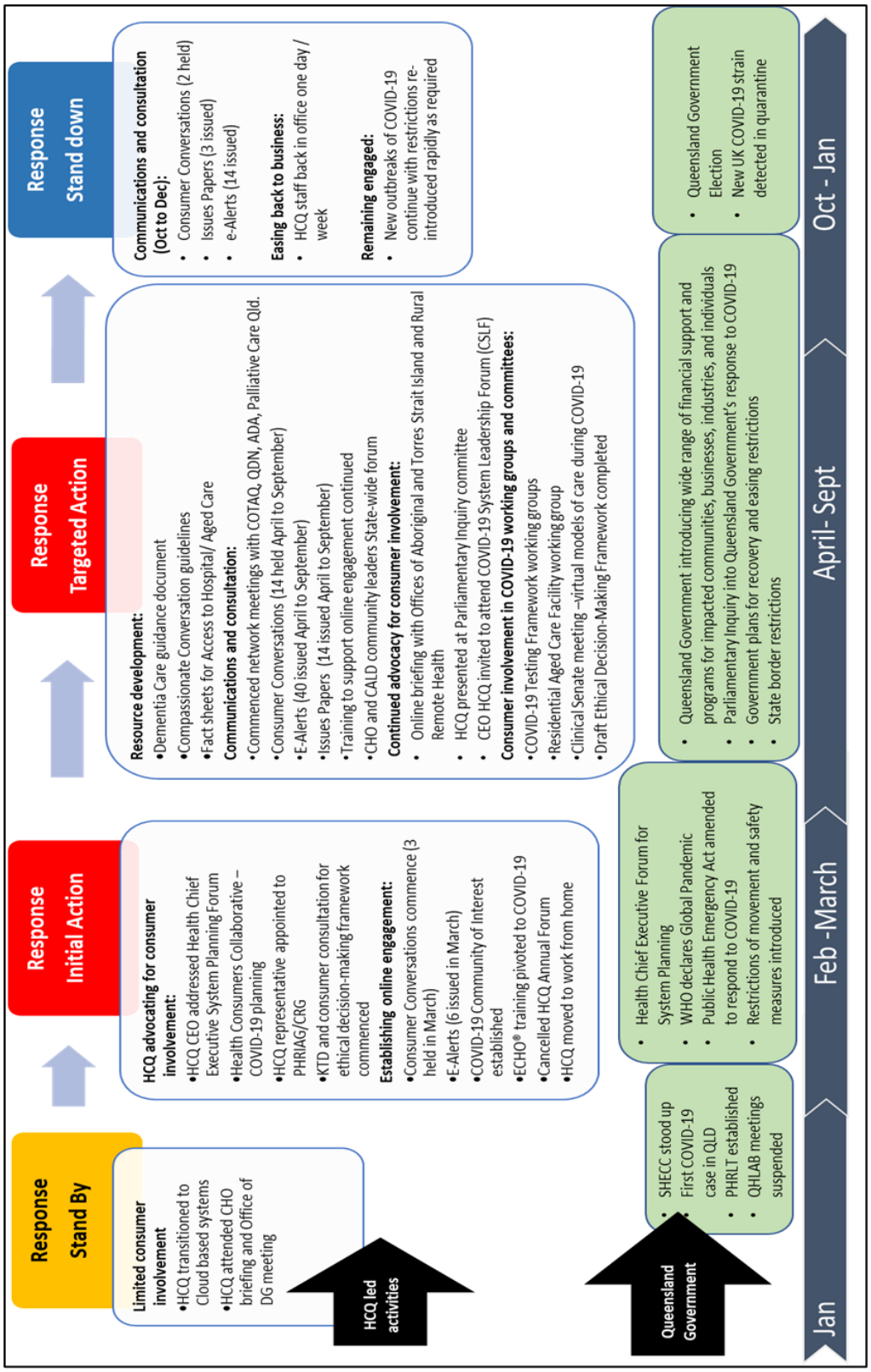
The Evaluation Reference Group identified the outcomes and impacts relevant to the activities of HCQ during the pandemic. They are summarised in a Program Logic (Figure 4). The evaluation included data collection to summarise the activities of HCQ and resources developed during 2020, and the findings from data collection have been aligned to the outcome areas and impacts in the program logic.

Figure 4 Program Logic

4. Activity Mapping

The activities of HCQ and consumers during the pandemic in 2020 were collated and summarised in a timeline (Figure 5). The timeline is aligned to the phases of pandemic management (Figure 2).

Figure 5 Consumer engagement during the pandemic in 2020



Committees and working groups within Queensland Health became important for the inclusion of consumer perspectives. HCQ representation on senior level committees was not immediate and evolved during the pandemic response through strong advocacy, existing, and new relationships with key leaders in Queensland Health. During 2020, Queensland Health included representation from HCQ through the CEO and Chair positions, and this opened further opportunities during the year to invite consumers onto additional working groups. HCQ is now represented on the COVID-19 System Leadership Forum (CSLF), all Tier 2 Advisory Committees, the Queensland Clinical Senate and some Statewide Clinical Networks, and the Health Consumers Collaborative of Queensland.

HCQ staff and Board and consumer representatives participated in a number of Queensland Health Committees and working groups during the pandemic in 2020 including:

- Reform Planning Group
- Clinical Reference Group (CRG) formerly Pandemic Health Response Implementation Advisory Group (PHRIAG)
- COVID-19 System Leadership Forum (CSLF)
- Pharmacy-based COVID-19 testing working group
- Maternity Clinical Excellence Queensland (CEQ) and Consumer meeting;
- COVID-19 Testing Framework (and related working groups)
- COVID-19 Testing Booking and Triage Solution Committee
- COVID-19 vaccine governance oversight committee;
- COVID-19 Disability Service Clinical Advisory Group;
- COVID-19 Residential Aged Care Facility Clinical Advisory Group;
- COVID-19 Working Group – Residential Aged Care;
- COVID-19 in a Residential Aged Care Facility Analytics Advisory Committee Queensland Health;
- Vaccination consumer engagement group.

With an increase in collaboration directly with Queensland Health, HCQ also worked closely with key business areas in response to COVID-19. Existing relationships were maintained and strengthened with the Social Policy and Legislation Branch (including the Disability and Multicultural Health Unit), the Queensland Clinical Senate, and the Queensland Clinical Networks. At the outset of the pandemic two new divisions of the Office of Rural and Remote Health and First Nations Health had been established and HCQ strengthened relationships with senior leaders in these areas. New relationships were developed with the SCB as this was a critical function within the pandemic conditions.

Queensland Health and HCQ created opportunities for bespoke and detailed consultation with consumers on a number of topics during the pandemic including:

- Listening to the voices of vulnerable Queenslanders prior to the pandemic.
- Maintaining health and wellbeing during COVID-19.
- COVID-19 contact tracing App.
- Breast Screening – impact of COVID-19 suspension on services
- COVID-19 messages for CALD audiences.
- Targeted Communications for First Nations and rural and remote communities - Consumer engagement
- Bereavement Guides – For CALD and Aboriginal and Torres Strait Island consumers.
- Rural and Remote workforce continuity plan
- Care in Rural areas
- Document review for community management of mild COVID1-19 illness in rural Queensland

- Mental Health and Wellbeing website review
- Help Us Help You
- Kindness and Inclusiveness Always
- Know Your Rights
- Patient communications
- On-going management of COVID-19 positive patients and their treatment options including care in the home, medi-hotel and hospital (including dedicated COVID hospitals). The main options discussed were: Hospital in the home; dedicated COVID positive hospital; and Hotel quarantining

Resources were developed by HCQ and partner agencies to support consumer navigation of the system and Queensland Health staff including:

- Ageing and Dying video
- Communication checklist: Residential care facilities (aged care, disability and community support)
- COVID-19 Outbreak Management Preparing and responding — Guidance for Residential Aged Care Facilities in Queensland
- Consumer guide to e-health care terms
- Compassionate Conversations guides: Communicating virtually and using an interpreter in virtual communication
- COVID-19 Safe App decision making guide
- Know Your Rights - A guide for people with disability to get the hospital care they need during COVID-19
- COVID planning tool kit
- Tip Sheet developed for Queensland Health staff– Involving consumers in the COVID-19 response
- Frequently Asked Questions: Queensland Health COVID-19 Online booking and triage system
- Draft Ethical Decision-Making Framework
- Digital Health Charter

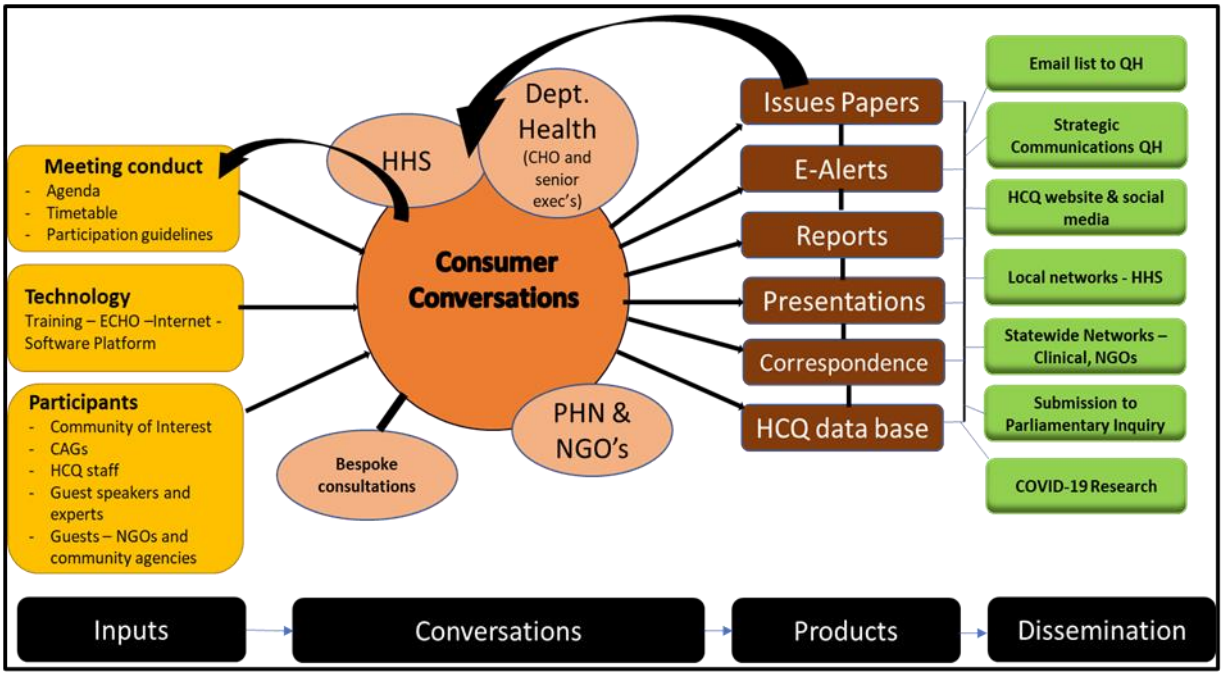
5. Consumer Conversations

Since the beginning of COVID-19 in mid-March 2020, HCQ has been conducting regular Consumer Conversations. These online sessions have been central to the flow of information and the creation of a collective voice for consumers and carers. Consumers have had the opportunity to hear from key people in health, and to have their voices heard on health issues relevant to COVID-19. The pandemic conditions prompted a need for operational changes including online communications, rapid responses to changing topics and circumstances, open self-selective participation, and trusted connections to evidence and authority.

Consumer Conversations have been a method to seek the input of a wide range of consumers on particular topics. The conversations were held regularly, and early in the year they were more frequent to ensure information was timely and current. The conversations are an example of the pragmatic approach taken by HCQ staff when the decision was taken to pivot business to focus on COVID-19 during 2020. It provided a more efficient mechanism for HCQ staff to bring together a few consumer groups that would ordinarily have met separately. This allowed more frequent meetings, strengthening the networking of information, and more diversity in the participation of consumers. The Consumer Conversations were continuously improved and designed to be central to engagement during 2020. Diagram 1 provides an overview of the process.

There were 19 Consumer Conversations during 2020 with an average consumer participation of 22 consumers per session and over 500 consumer attendances. Staff from Queensland Health were regular observers or guest speakers and other participating organisations included Primary Health Networks (PHNs) and NGO peak advocacy agencies.

Figure 6 Consumer Conversations Process



Summary highlights of the Consumer Conversations and Issues Paper case study:

- Demonstrated leadership from HCQ Board by **pivoting business** to focus on COVID-19 and making **changes to operations** such as bringing existing meetings and forums together into the Consumer Conversations.
- **Leadership** from senior and executive Queensland Health staff who participated directly in the Consumer Conversations and applied information received from the Issues Papers and Consumer Conversations.
- Inclusion of HCQ and consumers through existing **relationships and trust** developed over time through formal committees – such as the Queensland Clinical Senate and Queensland Clinical Networks, Health Consumers Collaborative of Queensland, HHS Consumer Advisory Groups.
- Adaptation founded on consumer **engagement principles, practices and training**.
- Applying **technology and skills** to bring engagement practices online. Project ECHO® was identified as being an advantageous and timely basis for online engagement.
- **Structure and consistency** in the conduct of the conversations and reporting on their outcomes.
- Continuous attention to the inclusion of participants from a range of locations, cultural backgrounds and experiences to maintain **diversity and** inclusion in the conversations.
- Flexibility in the agenda to ensure **responsiveness and relevance** in a rapidly changing environment.

6. Program logic outcomes

Short term outcomes as outlined in the Program Logic (Figure 4) were reviewed from the perspective of each of consumers, HCQ staff and Board, Queensland Health, and NGO advocacy peaks. Key outcomes aligned to each are:

a) Queensland Health pandemic lead team and HCQ partnering to support consumer navigation of the health system during the pandemic.

There is evidence that HCQ and Queensland Health have partnered due to executive level support from health staff, and assertive and persistent advocacy by HCQ to ensure that consumers were involved. This was necessary as the disruption of committees where consumers were usually represented, effectively closed off channels of engagement and the flow of timely and relevant information early in the pandemic. The relationships that had been established with leaders in Queensland Health and HCQ prior to the pandemic, engendered trust and facilitated the inclusion of HCQ and consumers.

Once systems were established by both HCQ and Queensland Health, consumer input improved. This is evidenced by the Consumer Conversations as a consultation platform meeting the needs of consumers and Queensland Health, HCQ representation on key pandemic management committees such as the CSLF and CRG, and consumer representation on working groups for engagement in systems such as COVID-19 Testing Frameworks. The input of consumers was focussed on reviewing and crafting communications, and reviewing systems design with considerations of consumer access, diversity and vulnerable populations.

Navigation of the system was complicated throughout by confusion and complexity within the system due to Federal Government and State Government responsibilities and jurisdictions. Consumer involvement was identified as a benefit as consumers were able to operate across jurisdictional and line accountable boundaries within the health system. There was also confusion due to a lack of understanding about the structures for pandemic management within Queensland at State, District and Local levels and the links between the health system and the disaster management systems.

b) Health system changes introduced during the pandemic delivered through tele-health and digital communications were consumer centred.

The adaptation of engagement to online mechanisms was generally viewed by all participants as positive. The changes through HCQ were made quickly and with high levels of praise about their support to consumers and Queensland Health by establishing engagement practices online that were respectful, inclusive, and responsive and in accordance with HCQ Engagement Principles (Appendix 1). The systems for online engagement were continuously improved through feedback from participants.

Telehealth was also generally viewed positively. There was confusion about the roles of the Federal Government and State Government in the use of telehealth and there were comments about the need to ensure quality in the standard of General Practice and other health services provided through telehealth. There were also concerns about the need for choice, access and reliability of internet, and the digital divide for those who do not have adequate equipment or training.

c) Queensland Health pandemic lead team provided opportunities for consumer involvement and influence.

The support of senior Queensland Health staff was reported as an enabler in creating opportunities for consumer engagement. This was very well received by consumers and there are many remarks about the importance of direct access between consumers and Queensland Health senior staff and the Minister. However, there are also many comments indicating the role of consumers is not universally accepted within Queensland Health, and that without systemic embedding of formal links and consumer engagement policy, there is an over-reliance on individuals to broker the opportunities.

There has been a range of research conducted into the challenges that health systems have faced during the COVID-19 pandemic. The benefits reported emphasise the critical importance of involving consumers to enable the resolution of ethical and practical changes to health service delivery (Straiton et al., 2020), and to build community support and capacity to meet pandemic responses and directives (CDAC Network, 2020).

d) Queensland Health and HCQ systems established to measure outcomes and provide feedback on consumer involvement.

HCQ quickly established Issues Papers and e-Alerts as documented and shared evidence of the issues that were raised, solutions and suggestions to inform key participants during the pandemic. The measurement of outcomes has been referred to by HCQ staff as problematic, in that their systems are not set to assist with monitoring in a consistent way. There were very few examples of Queensland Health staff providing feedback or keeping record of consumer involvement the outcomes of their input. Where consumers were participating in committees and working groups they would sometimes be informed about the progress and outcomes of the work, however it is not always allowable for the consumers to disseminate information outside a committee or to know what the outcomes of their input has been. Ensuring a simple, feasible and consistent method of monitoring data will be an important step in ensuring continuous improvement and quality in the engagement process for both HCQ and Queensland Health.

e) HCQ contributing to changed communication flow and network strength through new partnerships and processes that empower collective and diverse consumer voices.

HCQ made significant changes to their role by linking directly with consumers, opening the doors to opportunities with new sections of Queensland Health, building relevant alliances with NGO advocacy peaks, and ensuring information was being directed both to and from Queensland Health. There are many comments about the significant contribution made by HCQ and their ethical and assertive approach to ensuring consumer voices were heard. The new partners have indicated they want to continue to build on the short-term outcomes and strengthen the alliance.

7. Evaluation conclusions

The evaluation findings are summarised under the three evaluation objectives including suggested improvements for consumer engagement during pandemic emergencies. This evaluation is focussed on HCQ and the pandemic leadership team in the Department of Health, and it has not included direct data collection from the primary health, private health, or HHS segments of the health system. Where participants and background research for the evaluation have identified aspects of the pandemic response that is out of scope for this evaluation, suggestions for further investigation have been included.

7.1 To evaluate the effectiveness of consumer engagement that has occurred during the COVID-19 pandemic in Queensland.

The evaluation has identified strong evidence that the existing culture and practices of HCQ enabled the organisation to respond in a rapidly changing environment with the sound foundation of engagement principles, inclusive practices for online engagement, a primed and trained consumer network, and strategic connections within Queensland Health. HCQ adapted and redesigned engagement processes to optimise operations during COVID-19 pandemic conditions and developed platforms for communications and bespoke consultation that met the needs of all stakeholder groups including consumers, Queensland Health, and other health and social service providers. The ability of HCQ staff to identify and respond to consumer's concerns and needs early in the pandemic has been identified as a strength and a characteristic of the flexibility intrinsic to the way that HCQ functions. This agility was identified as a positive contribution during the pandemic enabling consumers to support solutions and communications across jurisdictional and reporting lines of responsibility.

The quality of processes to engage with consumers has been evaluated with reference to the HCQ Principles of Engagement (Figure 3). **Partnership** was demonstrated through working relationships between Queensland Health, consumers and HCQ, with the purpose of delivering pandemic responses and changes to health services that met consumer and community needs. The three evaluation case studies (Consumer Conversations, COVID-19 Testing Framework, and the Draft Ethical Decision-Making Framework) demonstrate engagement to provide and receive information, consult, and collaborate at senior and operational levels in the health system. In all three cases, consumer involvement was reported to have improved the understanding of underlying concerns for consumers; refined communications, and messages; facilitated the transfer of information to regions and vulnerable population groups; and importantly provided a supportive partnership between health service staff, clinicians, HCQ and consumers during a rapidly changing and stressful event.

The partnership between Queensland Health and HCQ was derived from strong advocacy on the part of HCQ and leadership by senior staff and executives within Queensland Health. Participants in the evaluation have reported high levels of satisfaction with HCQ's advocacy for their involvement and to have voices heard, as well as being at the table to share in creating solutions to technical and sensitive issues arising. 77% of participants in the online consumer survey responded that HCQ's advocacy for consumers during COVID-19 was good or excellent. Consumer representatives were highly satisfied with HCQ brokering relevant consumer opportunities with Queensland Health during the pandemic and with the senior executive Queensland Health staff being directly engaged with consumers.

There is evidence that where relationships had been developed the perspectives and knowledge of both consumers and staff were valued by each other. Comments that the relationship was "symbiotic" demonstrated a respectful understanding that there were common goals to ensure

better health outcomes for consumers within the constraints of the pandemic event, and that this was mutual between clinicians, Queensland Health staff and HCQ consumers. There is also evidence in the evaluation that the acceptance of consumer involvement was not shared in all areas of the Department or by all staff. There were new alliances formed during 2020 based on a strategic need to address issues with communications, COVID-19 testing, ethical considerations, and supporting vulnerable populations. The progress made with these relationships is a positive indicator towards cultural change and a better understanding of the benefits of consumer engagement.

Most consumers reported respectful consumer engagement online and in working groups and identified support from HCQ and Queensland Health staff. Some identified the technical nature of the information as being challenging however, where there were supportive staff and mentors to assist with building the capacity and knowledge of the consumer representatives the experience was reported as very positive. One example of effective consumer engagement in technical and sensitive issues partnering closely with clinicians, hospitals and health services was the consideration of ethical decision-making. Investing in building the capacity and knowledge of consumers by both Queensland Health and HCQ, provides the basis for efficient, informed, and vital consumer engagement as transformation partners during rapidly changing and sensitive pandemic conditions.

Respect and dignity were also demonstrated through clear and open communication. Most consumers have praised HCQ for their feedback on consumer engagement outcomes during the pandemic. HCQ provided feedback through Consumer Conversations, e-Alerts and documentation through Issues Papers. The participants in the online consumer survey indicated that the e-Alerts (80% of participants) and Issues Papers (68% of participants) were always or mostly informative and relevant. Engagement became more accessible for some during COVID-19 and HCQ was well prepared to move to online engagement. This provided new opportunities for consumers and staff to be involved in pandemic responses. HCQ redesigned and continuously improved their online engagement practices based on consumer and participant feedback during 2020 to meet principles of inclusion, conduct of meetings, training and upskilling of all participants (staff, guest speakers, and consumers). The practices were reported by all participants as meeting the needs of both consumers and Departmental staff. The CHO in particular commented on the flexible, responsive and effective support that HCQ provided to bring all parties together online, and that this improved the depth and continuum of communications between consumers and the Department during the pandemic.

Inclusive practices to ensure engagement was accessible to as many consumers as possible, flexible to meet the needs of participants, and assertively outreached to engage diverse populations, were all reported as being positively addressed by HCQ. The demands of pandemic restrictions creating "bubbles" of physical distancing and social isolation were significant challenges that HCQ reportedly met with high levels of success, although there were many suggestions about areas for continued development and network strengthening. HCQ's partnering with NGOs and openness to improve connections with young people and Aboriginal and Torres Strait Island people through COVID-19 projects are examples of strategic approaches to addressing identified gaps.

Benefits and impacts attributable to consumer involvement during the pandemic in 2020 need to be considered in the context of a complex system and as a continuum of relationships and partnership development between HCQ consumers and Queensland Health. Cultural change in a complex system is a long-term outcome, and this evaluation of the current pandemic response was designed to identify short term outcomes and incremental indicators of change. The evaluation has identified many examples of the impact of consumer engagement indicating progress towards the short-term aspirational outcomes in the Program Logic (Appendix 4). The logic identified activities and products that contribute to short term outcomes across five domains as reported in Section 15.2.

Queensland Health staff have demonstrated an openness to build on existing relationships with HCQ during 2020 by installing consumer representation on a range of pandemic response committees and working groups at all levels of the system. The representation of consumers on Queensland Health committees increased during 2020 and relationships in key areas such as SCB and Prevention were also reported to have had increased levels of contact with HCQ and improvements in understanding the role that consumers can play during a pandemic to support the public health response. The Director General, CHO, and Queensland Clinical Senate were identified as providing critical strategic leadership by responding to HCQ's advocacy for consumer involvement.

Improvements suggested for consumer engagement during a pandemic:

7.1.1 HCQ should continue to fill gaps in recruitment to their consumer networks with priorities being young people, Aboriginal and Torres Strait Islander people, families and working age people, and people in rural and remote areas. These gaps may be addressed through individual consumer engagement and through partnerships with other advocacy agencies. HCQ is actively working to improve the inclusion of young people and Aboriginal and Torres Island communities in specific project initiatives.

7.1.2 HCQ and Queensland Health undertake communications planning with specific and early inclusion of vulnerable groups and attention to the range of languages, communication channels and tools as this is critical at all phases of the pandemic. The communication plans need to include consumers, and key community organisations as they enable knowledge transfer through the duration of a pandemic. Some population groups, such as CALD, Disability and Aboriginal and Torres Strait Islanders have established relationships through internal Queensland Health business units. Ensuring strong formal links with HCQ and these Department branches during pandemics should also be included.

7.1.3 HCQ should review the structure of engagement through committees and activities applied during the pandemic to streamline and coordinate links between regions (HHSs, KTD hosts in regions, Clinical Networks, CAGs) and State-wide coordination (Queensland Health committees such as the CSLF, CRG, Tier 2 Committees, Queensland Health Consumers Collaborative etc) to support consumers and Queensland Health with consistent consumer input during a pandemic.

7.1.4 HCQ should build the capacity of the consumer network through consumer team-based mentoring, to reduce reliance on HCQ staff during high demand peaks such as the pandemic.

7.1.5 HCQ should establish processes that record the time and effort of participants and ensure the staff and consumer networks are monitoring fatigue and building hand-over, buddy-system, rotational, or stand-down care arrangements during extended periods of a pandemic response. Participants were reporting fatigue for both consumers and staff during this extended and continuing pandemic.

7.1.6 The move to online engagement created barriers for some consumers and a potential "digital divide". A review of who "missed out" and the quality improvement suggestions made by consumers in the online survey should be undertaken. The costs to individuals and organisations to participate in online engagement such as equipment, programs, training and internet access was reported as prohibitive for some. Information and advocacy to assist consumers to access funded programs that contribute to the costs of technology should be included.

7.1.7 Queensland Health should work with HCQ to improve feedback loops on consumer input and to codesign an outcomes framework and tools that can apply in rapid response pandemic conditions. This could then contribute to Queensland Disaster Management plans and procedures for future pandemics, and reporting systems ongoing for consumer outcomes.

7.1.8 Where Queensland Health committees include consumer representatives, HCQ and Queensland Health should upskill secretariats to contextualise consumer commitments serving on a committee. (Such as the Consumer Guide for Clinical Networks)

7.2 To contribute to evidence that assists with embedding consumer partnerships in the health system across Queensland for ongoing and future pandemics.

The evidence gathered from this evaluation regarding embedding consumer involvement in pandemics relates to two key aspects: the rationale or imperative for formal and strategic consumer input; and the structural and practical mechanisms that ensure consumer engagement is sustained. Sections 14 and 15.3 of this report detail the responses from participants and focus group regarding the experience during the 2020 pandemic and rationale, risks and suggestions regarding embedding consumer involvement.

Benefits reported by all cohorts, that support formally embedding consumer engagement and building a sustained basis for involvement during pandemics include:

- Existing relationships between HCQ and key parts of the health system (Clinical networks, HHS, Department Executives, Corporate Services etc), as well as HCQ skills, consumer networks, policies and practices, provided the foundation for trusted, well informed, networked partnering in a pandemic event.

- Consumers formally engaged as partners, provide vital information ensuring consumer-centred design and planning, during a pandemic where health service delivery can change rapidly. Understanding the potential impact on people with consideration of personal circumstances, population vulnerabilities, access issues, and communication needs can create efficiencies and improve health outcomes.

- Consumers operate with a level of flexibility that is not afforded paid employees and in pandemic conditions the benefits of such agility are paramount to finding and contributing to rapid response solutions that meet community needs. Consumer engagement was reported to have enabled information provision, consultation and collaboration across jurisdictions and line accountable “silos”. This was seen to be a significant benefit in pandemic conditions that warrant rapid, confidential and effective communications and action.

- Understanding the complexity of the health system added to HCQ’s capability to respond rapidly and engender trust with Queensland Health.

- Consumer engagement provided ready access for Queensland Health to consumer networks wider than the Department’s usual connections, and pro-active identification of gaps in vulnerable population groups relevant to pandemic directives and responses.

Barriers identified that need to be considered for successful embedding of consumer engagement:

- All participants in the evaluation reported confusion at the beginning of the pandemic within Queensland Health about roles, responsibility, authority and that this was gradually addressed through strong advocacy, persistent engagement, and commitment. The confusion is evidence of a lack of preparedness, Health and Disaster Management system knowledge, information, and practice, which is largely attributable to a pandemic of the scale and duration of COVID-19 being unprecedented in “living memory”.

- HCQ and State peak advocacy agencies are small organisations with limited resources, and they fulfill critical roles at a time when pandemics trigger a need for system wide service

disruption, policy and procedural amendments, and effective and accessible communications.

Rationale for embedding engagement

The leadership shown by Executives and clinicians within Queensland Health, coupled with strong and persistent advocacy from HCQ, has been instrumental in assuring consumer involvement during the pandemic in 2020. However, this outcome has been dependent on individuals and the embedded systemic inclusion of health consumers has been identified as important by evaluation participants. The following provides a background rationale for embedding consumer involvement:

- In contemporary practice consumer engagement in health systems is regarded as best practice, and the participants in this evaluation refer to Standard 2 (Australian Commission on Safety and Quality in Health Care, 2012) as providing a guide to embed engagement.

- In Emergency Management practice the engagement of communities is fundamental to operational efficiency and community recovery. The Queensland Government pandemic response has been structured on the existing emergency management system and the inclusion of community representatives and agencies, however consumers are not included in those plans and committees.

- Communications was one of the main themes in the evaluation. The involvement of communities and consumers in a pandemic provides an important additional source of "intelligence" in addition to medical and technical data, in crafting clear and relevant messages and resources. Communications are more effective if they are two-way and not simply messages out to an "audience".

- The COVID-19 pandemic has continued beyond the timeframe of this evaluation and as such suggestions and learnings will continue to be relevant during the current pandemic response.

- Reasons for embedding consumer involvement during pandemics were identified and supported by the Health Consumers Collaborative of Queensland including the need to ensure the automatic inclusion of consumers in the formal system pandemic response to enable representation, commitment, feedback and continuous improvement.

This evaluation has revealed the need for an improved understanding of the systems that were activated to manage the pandemic. There are National, State, District and Local levels of authority, and parallel systems within Queensland (Figure1) that were stood up during the pandemic. In order to propose the embedding of consumer involvement in ongoing and future pandemics both the Queensland Health structures, and the Queensland Disaster Management structures are relevant. Embedding is also reliant on the extent to which Queensland Health is prepared, and structured committees and terms for operation are formally established, to identify where to include consumer representation. It is important that HCQ consumer representation is strategic and aligned to its purpose of ensuring health outcomes for consumers. There is a caution in that HCQ has a limited capacity and needs to be positioned for best effect and outcomes for consumers within existing resources.

Improvements suggested to embed consumer engagement in pandemic management:

HCQ in liaison with Queensland Health and the SHECC should consider:

7.2.1 Distinguish the role of a consumer/carer within a pandemic response. Health consumers are not identified in any of the Queensland Health pandemic management plans or documentation, although they may be "assumed" within broader stakeholder or community engagement terms. Consumers fulfill a role in more detailed bespoke and collaborative engagement as demonstrated in this evaluation, and that will be beneficial in any pandemic where health systems and services are disrupted or changed, or where there is an impact on consumers and carers.

7.2.2 This evaluation has not directly included HHS or the Disaster Management committees for data collection and it is therefore not clear where consumers would be most strategically placed without further investigation. Within Queensland Health the evaluation indicates key areas that will enable consumer engagement in ongoing and future pandemics include governance level committees, SCB, prevention, and social policy branches. HCQ should be formally included ongoing in the committees that they have been placed on during the pandemic including the CSLF, and consideration should be given to including a representative on the SHECC. However, it is not clear that committees such as the CRG and CSLF are standard/ embedded Queensland Health committees for future pandemics. It is suggested that HCQ liaise with Queensland Health to review and identify the most appropriate committees for inclusion in pandemic planning.

7.2.3 HCQ should review and plan for business continuity to ensure flexibility to scale up and down as pandemics are prolonged by nature.

7.2.4 Review the overarching plans and Disaster Management frameworks (including the Australasian Inter-service Incident Management System (AIIMS)) to include consumer engagement. Ensure consumer engagement is included in all phases from preparedness to response to recovery. Current concerns expressed by participants were that consumer and community consultation should also be included in a recovery phase. Consultation with consumers and community stakeholders was suggested about pandemic impacts such as mental health, consumer access to health services, and consideration of the financial and service delivery impacts on the health system.

7.2.5 HCQ and Queensland Health should continue to build the capacity and capability of consumer representatives and staff by incorporating training and information regarding Queensland Health's pandemic management system and structures. This should also include an understanding of the communications, committees, and roles and procedures at National, State, District and Local levels.

7.3 To identify improvements that enable growth and maturity of consumer partnerships between Queensland Health and Queensland consumers and carers based on the response to the COVID-19 pandemic.

The development of new and improved partnerships, organisational level networks, and collaborative outcomes facilitated by HCQ during the pandemic include:

- HCQ identified areas of Queensland Health that they had not previously liaised with, and new relationships were formed during COVID-19. Participants identified the need to strengthen relationships with some key areas such as the SCB and the Prevention team to ensure continuity and a smooth transition through phases of emergency management including both “stand up” and “stand down”.

- HCQ brokered new partnerships with other NGO peak advocacy agencies, and this was reported to have bridged system gaps such as “in home or community based” residential settings, aged and disability care services etc.

- Consumers and clinicians reported the strengthening of relationships during 2020 and a recognition of common interests for patients and carers to ensure a health system that attends to both staff and patients’ health, wellbeing, and rights.

- Collaborations have created resources that have informed and supported consumers and the community during the pandemic. These resources may be useful in future public health crises and should be built on as part of the emergency management materials and tools applicable to all emergency management in Queensland.

- There are reports of significant work that consumers were engaged in prior to the pandemic that has been deferred or sidelined during the pandemic and an assessment needs to occur of pre-existing initiatives to ensure relevant work continues. This includes pandemic relevant policy work, such as the (draft) Ethical Decision-Making Framework, that involved consumers and was commenced during the pandemic but has not been officially approved.

Improvements in partnerships and networks:

7.3.1 HCQ should work with the NGO peak agencies partnered with during the pandemic, to strengthen and maintain the alliance and build resources and capacity to contribute to pandemic responses. The suggestion that this alliance could be linked to the Clinical Senate should also be investigated.

7.3.2 Queensland Health and HCQ should identify resources that have been developed that contributed to informing and supporting consumers and the community and establish a clearing house with the areas of Queensland Health and Disaster Management to retain publication as a support for future pandemics.

7.3.3 Queensland Health and HCQ should review policy work that was deferred or incomplete during the pandemic to provide feedback to consumers and stakeholders on the status and progress of the projects.

7.3.4 Conduct a review of the effectiveness in Queensland Health of the program of training and information to strengthen knowledge about consumers, their roles, and contributions. The review could specifically consider ways to engage during a pandemic to continue to engender best practice and engagement.

7.3.5 HCQ should conduct a mapping and consultation process in liaison with Queensland Health to explore Disaster Management and community links (such as Red Cross, Lifeline, Local Government) as well as other NGO networks (such as CALD, Disability, Aboriginal and Torres Strait Island people, Mental Health) for the purpose of reviewing information and consultation flow, and access and training for technology/ online engagement during the pandemic. This should then inform future planning for networking and communications.

8. Acronyms and Glossary

Carer	A person who provides care and support to someone with health issues. They could be family, friends, or community members.
Consumer (health)	Current health consumers and potential health consumers, carers and organisations representing consumers' interests.
Consumer and Carer Representative	A person who has taken up a formal, specific role to advocate on behalf of other consumers.
ADA Australia	Aged and Disability Advocates Australia
ATSICCHO	Aboriginal and Torres Strait Islander Community Controlled Health Organisations
CAG	Consumer Advisory Group
CALD	Culturally and Linguistically Diverse
CEO	Chief Executive Officer
CEQ	Clinical Excellence Queensland
CHO	Chief Health Officer
CHQ	Children's Health Queensland
COTA Queensland	Council on the Ageing Queensland
CRG	Clinical Reference Group
CRM	Customer Relationship Management (system)
CSLF	COVID System Leadership Forum
DG	Director General
DDG	Deputy Director General
ECHO®	Extension for Community Healthcare Outcomes program – see references
GP	General Practitioner
HCQ	Health Consumers Queensland
HHS	Hospital and Health Service
Kitchen Table Discussions (KTD)	Kitchen Table Discussions are community consultation sessions led by local people for local people. They allow small groups to participate in consultation at a time of day, and in a place, that suits them. The Kitchen Table Discussions also enable health consumers, carers and community members who do not ordinarily participate in healthcare consultation to have their say in a safe and supportive environment.
Networks	This term is applied in two contexts: the Statewide Consumer Network which is all consumers on HCQ's database; and organisational level networks which include health consumer peaks in other States and Territories, and NGO peaks, and others within the health system such as HHSs, PHNs.
NGO	Non-Government Organisation
PHN	Primary Health Network
PHRIAG	Pandemic Health Response Implementation Advisory Group
PPE	Personal Protective Equipment
Private Providers	Private Hospitals
QCS	Queensland Clinical Senate
QDN	Queenslanders with Disability Network
QH	Queensland Health
RACF	Residential Aged Care Facility
SCB	Strategic Communications Branch (Queensland Health)

SHECC	State Health Emergency Coordination Centre
Tier 2 System Advisory Committees	Key governance committees that report to the Queensland Health Executive Leadership Team with a connection to the Queensland Health Leadership Advisory Board; both of these two groups report to the Director-General of Health. There are HCQ representatives and consumer representatives on all Tier 2 committees (See Appendix 2)
WHO	World Health Organisation

9. References

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