



Consumers at the centre of health in South Australia

Consumer Engagement in South Australia during COVID-19

A Consumer Survey Report

April 2020

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HCASA acknowledges the Traditional Custodians of Country. We pay respect to Elders past and present, and recognise that their cultural heritage, beliefs and relationship to Country are important for sustaining health and wellbeing.

The role of Health Consumers Alliance of South Australia (HCASA)

HCASA is the peak body for health consumers in South Australia. We are a member-based, independent, not-for-profit organisation. We work with consumers and health services to position consumers at the centre of care. Health consumers are people who use, or are potential users of health services, including their family and carers.

HCASA's mission is to engage consumers and health services to achieve high quality, safe, consumer-centred care for all South Australians. We seek to promote and strengthen the voices, wellbeing, rights and leadership of health consumers.

HCASA works in partnership to provide the information, training and services people, services and policy makers need to ensure consumers have a powerful influence on the health services they pay for, use and expect to support the health and wellbeing of all South Australians. HCASA advocates for health and human rights for all South Australians; is informed by the lived experience of health consumers, carers and the community; provides evidence-based consumers representation in health policy and planning and works collaboratively with consumers and health service providers to build the capacity for meaningful consumer engagement. We work to ensure consumer centred policy and practice is embedded across the SA health care system. This includes public, private and non-government health service providers.

The evidence supports the fact that consumer engagement results in better health service design, planning, delivery, policy making and evaluation, leading to better health outcomes and community wellbeing. Consumer engagement has been considered critical to improving the quality of care provided by health care services. Consumers' perspectives are unique given their firsthand experience at every stage of the care pathway. Consumers are legitimately positioned, through this experience, to evaluate the care and services received in terms of whether their care goals, needs and expectations have been met, and their outcomes of care. Consumer feedback provides a valuable source of insight into safety and quality related problems within healthcare organisations.

HCASA has the capacity and is well positioned, through our trusted consumer and community networks, to respond promptly to inform SA Health and to support the needs of the South Australian public through:

- Dissemination of COVID-19 resources and messages (including from the Minister and SA Health)
- Providing reassurance and consistent messaging to individuals and the public
- Developing and promoting individual and community health literacy and active change behaviour about COVID-19
- Supporting SA Health to develop information and messages that the public will understand
- Working with consumer peak bodies across Australia to ensure consistent national information and resources and
- Transferring our focus quickly to provide individual advocacy to support individual consumers who may be isolated, anxious or in crisis and link them to the right services as quickly as possible.

Through our consumer and community networks HCASA can also provide feedback on the effectiveness of the health system response by consolidating multiple lived experiences of health care consumers into system issues that SA Health and other government agencies can then respond in a timely and effective manner.

Consumer Advocate Survey

As part of HCASA's consumer strategy in response to the COVID-19 pandemic, we undertook an online survey (via Survey Monkey) of Consumer Advocates across South Australia. The survey sought to identify the role consumer advocates are playing in supporting the SA Health COVID-19 response. Feedback was sought from consumer advocates who are current members on SA Health and other community health service committees, including but not limited to clinical governance, consumer advisory and safety and quality committees. Consumer Advocates were asked to respond to a range of questions relating to how health services had consulted with them in the statewide response to COVID-19.

The HCASA Consumer Advocates Networks (CAN) has 230 registered members. HCASA utilises the support of CAN as part of its consumer and community engagement strategies to; inform policy and decision-making; provide consumer advocate feedback and response to key state and national health policy; inform strategic priorities and provide rapid response to key issues.

A online survey was undertaken between 1 April to 6 April 2020. CAN members were notified by email. It is recognised that not all consumer advocates will have been aware of the survey if they were not checking emails during this time. Forty consumer advocates sitting on current SA Health and other health and community services, responded to the survey. It was however an opportunity to gather rapid response on feedback we were informally hearing from consumers. This report is framed as a themes and trends analysis of the responses received.

Consumer advocate participation in early stages of the COVID-19 response

Most consumer advocates identified that, from the commencement of the South Australian COVID-19 response, their participation in ongoing committees had been cancelled. Many committees, although moving to online platforms, offered little or no support to assist include consumer advocate members to online access. Many consumer advocates were unsure whether the committees had been cancelled or whether they were ongoing but had effectively excluded consumer members.

When asked if their consumer advocacy role had been impacted by the early stages of the COVID-19 pandemic, 76% of consumer advocates stated that their advocacy had been impacted; 2% said it had not; and 21% stated it was too early to tell or were unsure. Of those impacted, 70% identified that their role on committee meetings had been cancelled with one consumer advocate stating that they felt organisations and services were *“too busy to include consumers in decisions”*.

“I am really concerned that whilst I can understand COVID-19 needs to be top priority, I’m concerned we are forgetting other issues and this in turn will delay things to happen or lose the window of opportunity”

“When things get hard, consumer engagement goes out the door. We have a lot of skills to offer health in these tough times.”

Consumer advocates noted that given the seemingly sudden onset and rapid escalation of the COVID-19 pandemic, it is to be expected that consumer engagement would not be perfect, however many noted that consumer and community engagement appear to have dropped off the page entirely.

“This is the time when advocacy and oversight is imperative, and it is almost impossible. We all understand the reasons for restrictions/exclusions, but who is ensuring safety and quality adherence and that human rights are being upheld?”

Many expressed frustrations at their committees simply being cancelled or continuing without them. One consumer stated the following:

“Listening to and employing voices of consumers and carer’s lived experiences in creating all new policies and documents. Not negating lived experience and consumer groups by cancelling them all – a lot of lost ground for the mental health consumer movement. Very disappointing.”

It is recognised and acknowledged that some health services have continued to ensure consumer advocate involvement and consumer advisory committees are ongoing. Some services have been forward thinking in enabling consumers to participate using online platforms. It is unclear however whether these services are ensuring consumers are part of the COVID-19 decision-making.

Access for consumer participation

Consumers noted that while many organisations have moved meetings to online formats (Zoom, Microsoft teams etc) not all organisations are providing clear and easy-to-follow instructions or have offered tech support consumers may need to access these platforms. Some consumers were offered the option of

phoning into meetings, where they did not have the computer or internet access required. This was however not an option offered across all health services. Many consumers noted that some committee meetings have simply been cancelled indefinitely with no alternative for consumer participation during the COVID-19 pandemic. Many consumer advocates stated that no communication or support has been offered at all.

When asked about access options for consumer participation consumer advocates responded that while 64% of committee meetings had moved to an online format, 32% of these organisations and services had not made sure that these online meetings were accessible to consumer advocate members. Consumers responded that *“they have assumed that consumer advocates have the required infrastructure”* and *“meetings are restricted to relevant staff.”*

Consumer advocates recognised that whilst many non-essential committees would likely be cancelled, they are not being co-opted onto priority COVID-19 response committees or decision-making.

A concern HCASA has is that decisions such as these will degrade the relationship between organisations and services and consumers, we hope to partner with these services and organisations to ensure this doesn't occur.

Other ways consumer advocacy role has been impacted

When asked in what other ways consumer advocacy and participation may have been impacted, many consumer advocates shared their concerns that consumer engagement was coming to a complete halt in a time when it is most needed.

“There has been less communication in regard to consumer work in the hospital and that still being a primary objective. While I understand the need to limit physical contact, I worry there will be a failure in the system without continued work in this area.”

Consumer advocates expressed further concerns about the shelving of key projects and committees and the ongoing impact that this would have and the potential for this momentum to be lost and not resumed at a later date. These concerns, consumers advocates felt, come from a lack of communication with consumers involved and little reassurance that their work is valued and will be continued post COVID-19;

“the closure of some projects until COVID-19 has passed effectively means that projects have been shelved for months or even years...”

Overall, consumer advocates believed health and other community services that they are involved with are informing them rather than consulting and or involving them in their COVID-19 response. Many reported they were receiving emails and communication to say what the organisation as whole was doing, but not with consumer engagement projects *per se*. One consumer quoted Health Consumers Queensland to further their sentiments;

“Involving consumers in strategic and operational decisions in healthcare has never been more important. In an unprecedented situation such as COVID-19, consumers are a key stakeholder and an essential source of advice and guidance in work.”

Many consumer advocates provide support to inpatients, outpatients and emergency services through patient visiting support. They are frequently able to reassure consumers in highly stressful and anxious times and relay, in real time, concerns raised by patients about their care. Although consumer advocates understand health services priority need to ensure their safety, they remain committed to the importance of this role being able to continue this role as soon as possible.

Consumer participation in statewide strategies

When asked whether they believed consumers had been involved in the state response to COVID-19, 60.5% felt that consumers had not been consulted and consumer participation in decision-making and strategies for containment was not considered in the state's response.

“National and state level government responses to COVID-19 have been made without health consumer, ageing and disability representation. This means that government responses have been at times unhelpful and thoughtlessly impractical.”

“I don’t feel it has been considered enough. I don’t know of, or I am not aware of any consumer consultation regarding major changes such as self-isolation, closing gyms and parks etc. I know it needed to be done but I don’t know if any consumers or consumer groups were involved in these decisions.”

Consumers felt there was little or no evidence of any consumer or community shared decision-making;

“... a bit of a mess as this (consumer engagement) has not been considered... from my perspective, it’s non-existent.”

What would consumer engagement look like as part of the COVID-19 response?

Consumers confirmed their fear that the almost total cessation of consumer and community participation in COVID-19 response decision-making will result in less transparency and accountability within health services and state and national strategic responses to COVID-19 at a time, like no other in recent history, when it is so essential.

They expressed fear for how services plan to reengage with consumers and the community in the step down and post COVID-19.

Consumers believe engagement in decision-making is crucial. Merely being informed through a one-way communication is not good enough. They expressed the clear belief that consulting with consumers would help in assessing what information and support is needed by the community and how such information should be provided most effectively.

Consumers expressed deep disappointment that their experiences, perspectives, values and priorities were no longer being voiced in advisory and clinical governance committees. They recognised this as a lost opportunity to build a better COVID-19 response. Consumers felt that their participation would help guide the response rather than get in the way.

One consumer responded;

“As per SA Health policy, there would be consumer representation on all decision-making bodies.

The engagement needs of people who do not have internet access would be considered - note that for many people the local library was where they accessed computers, and local libraries have closed their doors. This disproportionately affects vulnerable groups, including the elderly and people living in poverty.

Work on ongoing key projects would continue, but with extended timelines (e.g. the SA disability and health consultation) to allow for additional COVID-19 workload.”

Recommendations

HCASA identifies the following recommendations in relation to consumer participation in the SA COVID-19 response. It is essential to:

- maintain a commitment to consumer engagement throughout the COVID-19 pandemic
- involve consumers in key strategic and operational COVID-19 decisions and communications
- involve consumers in ethically challenging COVID-19 decision-making
- involve consumers to assist in identifying clear and consistent community messaging, including for diverse communities
- involve consumers early, in modelling and preparing for transition post pandemic
- use established consumer and community networks, through HCASA and other organisations, to access consumer feedback and input quickly and reliably

- Keep the consumers health services that are already working fully informed
- Provide an open channel, through consumer engagement teams, so that health consumers can contact the health service and provide real time feedback from the community
- establish alternative consumer access including digital and online formats
- engage with consumers from diverse health and community groups particular those and higher risk due to comorbidities
- reinstate funding for Health Consumers Alliance of South Australia as the peak body for health consumers in South Australia

Conclusion

HCASA tenders this report and hopes to provide insight and advice on how consumers can be engaged as this crisis progresses. The value and importance of engaging consumers at all levels, particularly in moments of crisis, cannot be undervalued. The almost unanimous response from consumer advocates through this survey resoundingly confirmed that consumers are not involved at an organisational, service or state level in the COVID-19 response.

The community is finding it difficult to filter and identify credible and important information as invalid and inflammatory misinformation about COVID-19 grows rapidly on social media.

Involving consumers in developing key government and health messaging during COVID-19 is essential to community understanding and compliance. Consumers know best what information they need and how they need to receive it to be most effective. Using community channels for information distribution is more targeted and filters out dangerous misinformation and limits alarmist information.

In such times of health, social and economic crisis, the need for consumer engagement is even more critical to achieving meaningful and successful outcomes. Consumers want to participate and help. Decisions made in response to COVID-19 impact on every member of the community. Compliance with social distancing and other strategies is strongest when communities are actually engaged in the decision-making process. This is not the time to revert to vertical decision-making structures that exclude involvement of those that bear the outcome of these decisions.

Many consumers are highly skilled and experienced in working with health services. Involving consumers can support health services to understand and identify the best decisions for different individuals and groups, especially ethical decisions about limited resources and outcomes of care. Involving consumers in these enables more informed acts as a check and balance and enables testing of, service responses and priorities as well as, effective messaging and early identification of critical response gaps. Consumers are motivated and willing to respond quickly when called and to help shoulder the responsibility for decision-making.

HCASA has convened a Consumer COVID-19 Reference Group to enable rapid feedback and advice to COVID-19 response strategies and operational decision-making.

HCASA calls for active engagement with the community in responding to the Covid-19 pandemic in-line with evidence-based safety and quality practices. There is an urgent need for open and transparent accountability from government and health services, which must include consumers and community groups and organisations at the table in developing the ongoing COVID 19 response, particularly communities of higher risk.

The South Australian public has a right to be involved in decisions that affect their health and safety *including the government's response to COVID-19*. To date, there has been limited recognition of these rights in supporting the design, development and implementation of responses at both a systemic and service level. Consumer and community groups and organisations are best placed to inform this decision-making and channel clear, targeted information to the South Australian community. Ignore consumers, and COVID- 19 responses will continue to risk creating these gaps.

“When things get hard, consumer engagement goes out the door. We have a lot of skills to offer health in these tough times.”