



COVID-19 Consumer Reference Group

Report 2: 6 May 2020

The **HCASA COVID-19 Consumer Reference Group** was convened to provide a vehicle for consumer and community feedback to government, health and community service providers and policy makers on the experiences and concerns about the impact of COVID-19 and the response strategies to minimise this impact. This report is provided to health and community service provider to better inform and support their COVID-19 decision-making.

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The Health Consumers Alliance of South Australia (HCASA) is the recognised voice of South Australian health consumers. HCASA works to ensure consumers are at the centre of health in South Australia.

Our capacity and ability, through our trusted networks, means we are well positioned to respond promptly to inform the Minister and SA Health early, and in a timely manner, and support the needs of the South Australian public through;

- Rapidly responding to requests for consumer input into COVID-19 policy, resources, strategies and implementation to ensure maximum impact and effectiveness for consumers and communities
- Dissemination 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 and other health and community services to develop information and messages that the public will understand work with consumer peak bodies across Australia to ensure consistent national information and resources
- 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 to in a timely and effective manner

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COVIDSafe APP

- The Reference Group identified the following key areas for further examination and clarification as impacting public trust in the App relating to
 - **Technology** – resulting in barriers to use
 - **Privacy** - protection of consumers individual data
 - **Misuse** – what requirements organisations may put in place
 - **Misinformation** – unsure about its status and function and how it will help/keep them safe
 - **Informed consent** - to ensure consumers are able to make informed decisions about participation

Technology

- The operating system requirements for the COVIDSafe App are not compatible with older model phones. This means that many consumers with older model phones are unable to access the App
- For those consumers who want to participate and utilise the App, this requires them to purchase new smart phones, at considerable cost dependent upon the contract they have with their phone provider. This is not an option for many consumers

- Issues about requirement for Bluetooth and the battery use
- Consumers experienced the COVIDSafe App interferes with download capacity of diabetes self monitoring Apps (eg blood glucose monitoring) and interfering with other devices that use bluetooth
- Widening of the digital divide - requires people having access to internet whereas currently 17% of SA has no internet access and no smart phone access
- Mistrust of the government based on previous tech issues, many technical issues that are not properly tested. Rushed roll out
- Consumers experienced difficulty/glitches trying to download it in the first instance so deleted it and not willing to try it again
- Concerns that it was rushed into operation ie risks - safeguards, hacking etc. Lack of overall trust in the App

Privacy

- Reference Group raised issues about data storage being contracted to US company Amazon and potential access/release of Australian data through US Law, particularly under its current unstable government and the position of the US government that is inconsistent with Australia's strategy response
- Questions about who owns the data. Little/no information provided to consumers about this
- Issues about the Bluetooth functions who/how far this will extend and talk to other devices ie how many people it will pick up in a circumference that may not be near enough the consumer for exposure
- Unsure of the legal capacity of Government to implement the App
- Concerns greater than data privacy - capacity of Government to enact legislation with potential to infringe human rights and freedoms – risk of this being maintained beyond COVID-19

Misuse

- Whilst the App is not currently mandatory, some consumers have recounted experiences where community care services (eg disability share houses) were making it mandatory for visitors and being refused access to visit family if they do not have the App
- Being mandated by some service providers for people living in retirement units
- Anecdotal information that some employers are requiring staff/consumers to sign up to App before they will be permitted to return to work
- One consumer shared that their family required them to have the App for them to be able to visit
- If poor uptake of App – will Government make it mandatory – and what are the implications of this?
- Concerns about people's loss of freedom and liberty "*if you don't do this you can't do that*". These messages aren't being taken too kindly by many people. Creates further issues of trust

Misinformation

- Early message from Government that the App would be mandatory created mistrust
- Lack of clear information to the public about the scope and function of the App. Many consumers believing that the App will warn them in real time if they are in the close vicinity of an infected person!
- Social media messaging has been stronger than government messaging. So a great deal of information to filter and little capacity to determine what is correct/accurate
- COVIDSafe – suggesting that people are safe from exposure and infection if they use it

- Lack of clear explanation of the meaning of ‘contact tracing’ – use of language and terminology that assumes the public understand. Many people do not know or understand what and how contact tracing works
- Consumers unsure what data is actually recorded and stored and believe it to record their geographical location – believe this is already being done by their smart phone so no need to use the App
- Inconsistent messaging between App being used/marketed as a social/moral incentive to increase social freedom and activity “return to normal” but subtle implications of punishment for non-compliance – “if not used may slow down lifting of restrictions”. Implies this is based on how well people behave. Related to early statement of Prime Minister that people weren’t doing the right thing – being told off

Informed consent

- Consumers have no understanding of what the App data will look like ie how much will it identify them?
- Lack of information about what data is recorded, how it is stored, who has access to it and details about what the actual function of the COVIDSafe App is a barrier to informed consent
- Concerns about deleting the App and whether data is still being gathered ie given that consumers have to actively give permission to enable the App on their device – is uninstalling/deleting the App enough? (Note: it has been clarified that uninstalling or deleting the App does not stop data recording data is still stored for 21 days. It is required that the person contact a number on the App to withdraw)
- Enactment of emergency legislation implements social infringements without public consultation or consent
- Complex information about the Apps function is outside of the capacity of many members of the community to fully understand

Poor uptake of the COVIDSafe App appears to be due in part to poor public messaging about its function and limitations. The inadvertent message appears to be that the App keeps individual’s safe and that downloading the App will ensure earlier easing of restrictions.

“I thought the message was that we would be safe if we downloaded the App but it turns out that it’s an electronic tracking device. A lot of people don’t understand this.”

Telehealth

The Reference Group confirmed their general support for the way telehealth has been implemented.

Telehealth can assist in ensuring that access to care particularly for consumers with chronic and comorbid conditions and for recurrent medical needs.

The Reference Group outlined the following experiences and matters for consideration

- Many consumers and consumer groups feel they are getting a better service delivery outcome. Some consumers are finding that they are more comfortable sharing more than they would have in a face-to-face session at a clinic. Feedback from some consumers is that
 - They are more comfortable talking over the phone
 - Feel safer in their own environment (in their own home)
 - Are not waiting for long periods of time in waiting rooms
- The Reference Group raised questions about the capacity and skills of GPs to undertake effective telehealth consults and the training being provided

- Recognition that telehealth services are only as good as the rapport and trust relationship between the consumer and their treating health practitioner/s
- Recognition that whilst this process was implemented rapidly, the quality and effectiveness of the consult was reliant on the skills of the GP to use engage over telecommunications, therefore consumers were reporting mixed experiences such as
 - Concerns remain with confused messages from health practitioners and what can and can't be provided using telehealth
 - Examples provided included
 - A GP saying that a prescription can only be provided through a video appointment (not via phone)
 - A GP refusing to provide a prescription without a face-to-face clinic appointment
 - Some GPs not offering any face-to-face appointments during COVID-19
 - Whilst other consumer experiences were very positive with health practitioners
 - Offering carpark visits so consumers do not have to congregates in waiting rooms
 - Offering outside under cover flu clinics
 - Getting consumers to wait in their car until called so that there are few people in the clinic
 - Emailing test results to consumers 24 hours prior to a telehealth appointment so that consumers had the time to clarify and ask questions
- The most effective telehealth experiences were where the GP or other health practitioner
 - Was able to engage comfortably with the consumer and treat the telehealth experience as they would in a face-to-face visit
 - Identified the best telehealth option to meet the needs of the consumer
 - Gave the consumer the choice of either clinic visit, phone or video appointment
 - Was flexible around telehealth options
 - Found creative solutions to meet consumers needs and balance the need for a more detailed assessment whilst minimising risk of exposure

COVID-19 Consumers Reference Group Recommendations

The Reference Group further supports the expansion of telehealth services beyond the COVID-19 temporary phase, as an effective strategy and tool to support consumer healthcare. The Reference Group supports telehealth as an important aspect of the COVID-19 response and identified the following priorities for telehealth services

- Ensure, where required, face-to-face physical and visual assessment and treatment is maintained and assured
- Telehealth is recognised as a tool for healthcare and does not replace face-to-face healthcare
- Telehealth appointments maintain and ensure safe, quality healthcare
- Recognise that telehealth services are best provided by the consumer's treating health practitioner/s who has access to their healthcare records, their medical history and has, where possible, an established relationship and rapport with the consumer
- Health practitioners have access to education and training to develop skills necessary for effective telehealth consultation and healthcare assessment
- Consumers be better informed of the scope and limitations of telehealth to better inform their choice and consent to using telehealth options and when/why these are beneficial
- Consumers be better informed of the requirements for payment vs bulk billing for COVID-19 telehealth services
- Consumers be better informed about their rights, including the right to refuse, telehealth services

- Actively promote and monitor that consumers ongoing healthcare needs, particularly people with chronic and comorbid conditions, and individuals and groups with high risk needs are prioritised through telehealth services
- Recognise that where consumers have access to home monitoring/measuring devices, such as BP machines, blood glucose monitors and/or health device apps is promoted and actively facilitated important additional tool for effective telehealth consultation
- Recognition that telehealth services, whilst affording greater access to rapid, flexible primary healthcare services for many people who otherwise may be disadvantaged, there remain issues of access for many others. It is important, if telehealth services in primary health are to be continued or expanded post COVID-19, that those people who are unable to access telehealth are not further overlooked.
- The Reference Group supports the expansion of telehealth services beyond COVID-19 temporary phase with
 - Appropriate consultation with consumers and the community
 - Implementation of appropriate protocols and best practice guidelines
 - Further training of health practitioners as a mandatory prerequisite for providing telehealth
 - Ensure the supports to enable access for vulnerable, high risk individuals and groups are implemented in any ongoing expansion of telehealth services

The Reference Group want to acknowledge and thank health services that have implemented telehealth options for consumers as a rapid response to ensure their ongoing healthcare needs are met.

To contact HCASA or seek the support or input of the COVID-19 Consumer Reference Group

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