

Health Consumers Alliance SA response to South Australian Health and Wellbeing Strategy 2019-2024: Summary framework for consultation

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Level 3, 12 Pirie Street, Adelaide SA 5000 | GPO Box 2248, Adelaide SA 5001

T: 08 8231 4169 E: info@hcasasn.au W: www.hcasasn.au

Facebook: HealthConsumersAllianceSA Twitter: @HealthConsumers ABN: 90 294 720 079

HCA 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.

Health Consumers Alliance of SA Inc

Health Consumers Alliance of SA Inc (HCASA) was established in 2002 as the peak health consumer organisation in South Australia as a direct result of grass roots community lobbying. We are a member-based, independent, not-for-profit organisation. We work with our members and supporters to achieve our vision: **Consumers at the centre of health in South Australia.**

Health consumers are people who use, or are potential users of health services, including their family and carers.

HCA'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. We advocate that consumer engagement policy and practice is embedded across the SA health care system.

We believe that consumer engagement results in better planning and policy-making. This leads to better health outcomes and community wellbeing.

HCA is part of a network of state/territory peak consumer organisations that promote and facilitate consumer voice to the health systems across Australia.

HCASA submission

HCASA's response to the "South Australian Health and Wellbeing Strategy 2019-2014: Summary framework for consultation" is informed by our work with consumers, community and health services, and feedback from our Consumer Advocate Network, members and organisational members.

We acknowledge that HCASA was included as part of the process to develop the draft strategy and that in excess of 20 consumers were included in that important initial conversation.

Discussion

Vision

Wellbeing implies good physical and mental health, life satisfaction, social engagement and a sense of meaning. It is unclear how this vision addresses these broader issues. The focus of the Draft Strategy appears to be on collecting and analysing data to "build the capacity of individuals to take care of their own health". There is acknowledgment of the importance of the environment and social and cultural determinants of health, but no indication for action to address these.

The vision infers competition against other States rather than a call for achieving good health for South Australians. "South Australians experience excellent health and wellbeing" could be an alternative.

Providing people with information to enable them to manage their health is important, however we must avoid stigmatising or stereotyping people with poor health and worsening health inequity. It is also important to demonstrate acknowledgement of the fact that health literacy is not just about consumers improving (individual health literacy). The workforce also requires a good level of health literacy in terms of creating the right environment for consumers and to improve the health literacy of health services (health literacy environment).

SA Health's website has a reputation for being difficult to navigate and a lack of useful, consumer friendly information readily accessible. Our health system can improve its health literacy by co-designing consumer information with consumers with relevant experience remembering that consumers are the ones that travel the entire journey - health practitioners are often only involved in their part of the journey. Building the health literacy re environment is crucial and advice from consumer representatives can assist in building this capacity. They can encourage the use of techniques such as "teach back" to ensure that consumers (and their families) understand how to manage their own care.

There is opportunity for the Vision to reflect the importance of our health systems and services being more

consumer-centred. Consumers have a right to care that considers their values, preferences and experience and to be considered as having skills, knowledge and experience. Having trained consumers engaged at every level of the health system ensures consumers are at the centre of decision making at the system and service level.

Trusted

It is important to understand the distinction between consumers, and the local and broader community. A consumer is recognised as a user or potential user of health and/or community services. In a holistic context. A consumer includes the person's family, carers and other members of their support network (as identified by the person) who often have an important role in health care decision-making and care giving.

Community refers to consumers who may, at any time, act as a collective of individuals, populations, networks or organisations, who represent or bring a collective voice of the interests of health consumers and of specific affected communities.ⁱ While some communities may connect through a local, regional or group interest in health, others may share a cultural background. Some communities may be geographically dispersed but linked through an interest in, or experience of, a specific health issue (eg by the internet, or some other means)ⁱⁱ.

Requiring LHN's to engage only local community in the planning, design and evaluation of services undervalues the experience of people using services may not be inclusive of other discrete communities who are more likely to experience disadvantage.

It is recommended that addressing patient harm from treatment should be addressed here, not only from medical error, hospital acquired infection etc, but also side effects of medication, and the use of products such as medical mesh without informed consent. Ensuring that consumers are fully informed of risks enables them to make fully informed decisions.

Integrity and honesty amongst health professionals is also essential. Consumers place a lot of trust in health professionals, and they expect that they are making professional judgements and decisions based on evidence and the best outcomes for the patient, and not on either financial or non-financial benefits, resistance to change or personal or professional bias.

Establishing systems and standards for communicating effectively when things go wrong in the delivery of care is also an important trust factor. Trust is eroded when things go wrong but is destroyed when communication following an incident or poor experience is not timely, respectful or responsive. This requires a culture and practice of open disclosure and standardised processes for responding to consumer complaints and feedback.

Trust in the health system also comes from knowing that there is a true commitment to ensuring that services are based on contemporary evidence and national or international best practice. The practice of making decisions based on doctors or others receiving benefits, or because it is how things have always been done need to end.

Targeted

In addition to developing strategic plans addressing eating disorders and personality disorders, a strategic plan should be developed to address trauma. Addressing trauma experienced through abuse, violence, workplace exposure or war can prevent the onset of other physical or mental health conditions. This can improve individual health and wellbeing, increase productivity, and reduce demand for more expensive tertiary health services. A trauma informed approach to providing health care, particularly in emergency departments can reduce the likelihood of health services re-traumatising people.

Targeted services should not only focus on individuals, but on some of the key health issues affecting our communities. For example, if targeting dementia, a focus should be on investing in research, providing community education and health promotion, creating dementia friendly communities, providing appropriate early intervention and treatment services, addressing the needs of carers, and educating the health workforce on how to work effectively with people living with dementia.

The engagement of consumers at the individual, service and system level is integral to addressing emerging challenges and variations in health experiences and outcomes. This should be reflected in the deliverable action areas and indicators.

Tailored

The supporting statement is too strongly focussed on technology. Health services that are tailored to the needs of individuals, families and communities, are listening to people and respecting their values, preferences and experiences. Technology has huge potential to drive, enable and enhance consumer centred care. Used well, it can enable new types of information sharing, development of innovative care model and facilitate consumer involvement and leadership over their own care. It is critical that use of technology is driven by the goal for improving consumer experience and outcomes – as opposed to use of technology for technology's sake, which does not contribute to better care.ⁱⁱⁱ

Developing systems for the recording and reporting of patients reported experience measures (PREMs) and patient reported outcome measures (PROMs) should be reflected in the action areas. If the system does not record and report on consumer informed measures, then they will never be more than tokenistic measures, poorly and sparsely applied.

Models of care should be co-designed with consumers, with informed consumers as equal partners in decision making processes. Developing workforce capability to engage effectively with consumers at an individual, service and system level will be integral to improving health services and should be reflected in the action areas.

Putting consumers at the centre of health, would mean that consumers receive tailored care, rather than focussing on services and what they deliver. From the consumer perspective the actions should be much broader, addressing integration of tertiary health services with primary care, prevention, as well as the aged care and disability sectors.

Tailoring care to consumer needs will also address the comprehensive care needs of people with co-morbidities, including those experiencing both physical and mental health issues. This includes making health care accessible to people who are housebound because of their physical and/or mental health conditions.

Services must be tailored to meet the needs of communities as well as individuals. Aboriginal communities, Culturally and Linguistically Diverse Communities, and rural and remote communities experience poorer health outcomes and require tailored strategies to ensure that health services are accessible and appropriate to their needs. In developing action plans that will bring this strategy to life, it will be important to work collaboratively with organisations such as Health Consumers Alliance SA, Multicultural Communities Council SA, Aboriginal Health Council and the Rural Doctors Workforce Agency, Adelaide Primary Health Network and County SA Primary Health Network.

Timely

Ambulatory care is unlikely to be a term well understood by the public. The use of clear language is important and consumers felt a term such as community-based care could be a useful descriptor.

In order to provide timely services, it is important to resource prevention and health promotion strategies. Aboriginal Community Controlled Health Services have excellent examples of empowering communities to improve health outcomes which ultimately relieves pressure on hospitals.

Improving patient flow into and out of hospitals is imperative to improve the timeliness of care, and to achieve this the strategy needs to address working with the primary health sector to minimise the number of people attending emergency departments when their health concerns could be addressed in a primary health care setting, as well as improving connections with the aged care and disability sector.

Our health system needs to reflect that people get sick or injured at anytime of the day or week. People should be able to access the care they need, when they need it. This applies to in and out of hospital services and includes GP services. SA Health should be advocating for improved after/extended hours GP Services or working in partnership with GP practices in close proximity to hospitals, to encourage people to attend the GP rather than an emergency department when a GP would be appropriate.

End of Life care is mentioned only in relation to palliative care. The strategy should be clear that End of Life care and palliative care are different and need to take into account the needs and views of patients, consumers and their families in the delivery of End of Life care (and palliative care).

Final thoughts

The summary framework is a good start for addressing some issues in the health system that have been important to consumers for many years. The themes have generally been addressed well at a service level, however it lacks system level themes, actions and indicators.

The South Australian government needs to address the social determinants of health at a whole of government level to achieve real improvements in health and wellbeing. SA Health also need to work collaboratively with other parts of the health system in order to achieve improved health outcomes, particularly for people experiencing higher levels of disadvantage, or with complex health needs.

This document refers to our ageing population profile, our poor performance in relation to asthma and mental health, and the need for a better connected health system and integrated care, however the actions and indicators do not reflect these important factors. South Australia is currently the only state without Asthma Australia funding. At a system level, we should be advocating for federal funding for this important work. South Australia is also about to be the only mainland state without a Mental Health Commission when we have higher rates of mental health conditions than the Australian average. We have higher than average rates of adverse events, and yet we are about to become the only state in Australia to not have a centrally funded health consumer organisation to steer the system to being more consumer centred in its delivery of care and response to adverse events, or to train consumers to engage with health services so they can inform safety and quality improvements.

To make lasting and impacting change, we need to add system level themes with corresponding indicators. Consumers want to know that our public health system integrates with the primary health system, the private health system, aged care system, NDIS, and the mental health system.

Indicators for an 'Integrated' theme would include MOU's between different parts of the system, collaborative service planning, joint resourcing of positions or services to increase integration. At a service level, the indicators would be rates of discharge summaries, comprehensive care plans, case conferencing and PREMs relating to service integration.

Consumers should be viewed as enabling resources to help improve the health system, not just sick people needing health services. The needs of carers also need to be acknowledged and addressed as the unpaid caring they provide in the community saves millions of dollars for the health system every year.

Our final point is that there must be accountability built into the strategy. How will achievements against this strategy be measured and reported? Without accountability, this strategy will lack credibility.

ⁱ Canadian Institutes of Health Research. Strategy for Patient-Oriented Research - Patient Engagement Framework. Ottawa 2014

ⁱⁱ Developing a consumer and community engagement strategy: a toolkit for Hospital and Health Services, Health Consumers Queensland, July 2012

ⁱⁱⁱ Review of key attributes of high performing person-centred healthcare organisations ACSQHC 2018