

14 April 2020

Dear participants

*cc. Mr Paul Laris, Chair, HCASA
Ms Julia Overton, CEO, HCASA*

The future of health consumer advocacy in South Australia

We write to thank you for your participation in the workshop on the future of systemic health consumer advocacy in South Australia hosted on 28 February by the Consumers Health Forum of Australia (CHF) in collaboration with the Health Consumers Alliance of South Australia (HCASA).

We apologise for the delay in our follow-up. No doubt you, like us, have been preoccupied with responses to the current COVID-19 public health crisis given the various roles you fulfil in the health and care system. This letter provides a summary of the discussions (attached) and a suggested way to advance systemic consumer advocacy in South Australia in the future.

As you would now be aware, the HCASA Board, in consultation with members, has made the decision to wind-up as a company. This has been triggered by the withdrawal of core grant funding from the SA Government and the unsustainability, instability and level of risk associated with alternative fee-for-service and project funding. This is a disappointing outcome and leaves South Australia out of step with other jurisdictions which all have government funded peak health consumer organisations, except the Northern Territory.

CHF, as the national peak body for health consumers and those with an interest in health care consumer affairs, has a keen interest in ensuring that the Australian health care landscape values the contribution that consumer experience and insight can offer policy development, program and service design. It is this interest that prompted us to work with HCASA to convene the roundtable.

We were heartened by the level of goodwill among workshop participants. It was clear that, notwithstanding the situation faced by HCASA, participants valued and saw the urgent need for systemic consumer advocacy in SA. Participants also understood that different levels and maturity of advocacy and consumer involvement were required at state-level policy discussions through to involvement in service design, improvement and accreditation.

Under Chatham House Rules, participants agreed in broad terms that the structural change occurring across the health system in SA and the devolution of several functions to new state-wide entities and Local Hospital Networks presented an opportunity for stakeholders to co-design a contemporary fit-for-purpose 'blueprint'. The blueprint could provide a set of

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recommendations for operationalising the principles for consumer and community involvement espoused in CHF's 2018 White Paper *Shifting Gears: Consumers Transforming Health* at the state level.

Participants began to discuss several factors that could be considered and explored further in a co-design process. These included:

- the functions and roles required of the platform/model – with trust, integrity and independence as values of the model
- potential ways to fund and govern a new model such as a contributing levy from organisations with an interest in the services of a new model and the NZ trustees model
- the terminology around consumer advocacy at a service and systems level
- a sensible long-term investment model – not just HCASA, HCASA+ - with the potential for a co-investment model across the new architecture
- a collective response for the South Australian context which includes consideration of the evolving and devolving governance
- the value of consumer engagement and systemic advocacy and the impact across the system is recognised.

A number of interested SA-based organisations among the participants indicated their interest in working with CHF, who would serve as neutral broker and secretariat, to put together a blueprint for consumer and community involvement in health policy and services in SA and to working as a collective to present the plan firstly to a wider cohort of stakeholders for input and support, ultimately to government for consideration.

We would ask that those interested in working with CHF to shape the blueprint confirm their name and details with Sandra Gardam, Executive Officer at CHF on s.gardam@chf.org.au and we will endeavour to put together a short proposal for discussion and consideration at a zoom meeting to be convened at a mutually convenient time in May.

Yours sincerely



Tony Lawson
Chair



Leanne Wells
Chief Executive Officer

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Future of Health Consumer Systemic Advocacy in South Australia

Summary notes for a consultation workshop, 28 February 2020

Facilitator: Becky Hirst

Hosts: Consumers Health Forum of Australia, Tony Lawson (Chair) and Leanne Wells (CEO)

Organisational Attendees: Health Consumers Advocate members of HCASA (x2), Health Consumers Alliance of SA (Chair and CE), SACOSS (ED), Health Performance Council (Chair), Australian Medical Association (SA Branch) (President), Country SA PHN (CEO), Adelaide PHN (CE delegate), Department for Health and Wellbeing (DCE and delegate Director Safety and Quality), Commission on Excellence and Innovation in Health (CEO delegate ED Human Design), Wellbeing SA (CEO delegate), ACH (CEO delegate), Central Adelaide Local Health Network (CEO delegate ED), SAHMRI (CEO delegate), Health Translation SA (CEO delegate).

Do we need a health consumer peak body in South Australia?

1. Need for systemic advocacy

Consumers need the support from an independent organisation – for training and support to develop the collective voice.

There is a legitimacy of involvement of a health consumer peak body in decision making and systemic advocacy that is crucial to avert serious mistakes – eg ICAC, Mesh, Oakden and Chemotherapy under-dosing.

Essential to provide support for vulnerable groups to be included and to have a say.

Important to have an independent body to raise the system views – it is better to invest upstream in advocacy that to rely only on downstream complaints.

Services will always need to continue to engage, but they will come with their own view and local contexts. Consumer engagement will need to continue at the local level as well as system advocacy.

Current situation is that people don't know when the work at a system level of advocacy about an issue has saved them – and the government, from a worse outcome.

HCASA has built a major investment in a network of professional and consumer relationships – a resource that should be preserved.

Accreditation standards increasingly require evidence of consumer engagement at all levels.

2. Funding problems

Non-government organisations that do not have community awareness and electoral support are vulnerable to funding cuts.

Current reorganisation and restructure in the health system in SA has led to many organisations becoming inward-focused and not thinking about the big picture of the value of consumer engagement at a systems level. Thus system wide issues may be missed eg pelvic mesh. Two new large entities are also currently still in establishment – Commission on Excellence and Innovation in Health and Wellbeing SA.

Services are focused on their own consumer engagement and allocating their resources to support their own organisational outcomes.

The shift in the funding model from a core grant to a fee-for-service (FFS) basis has constrained HCASA's activities due to:

- not enough funding provided previously for HCASA to be a powerful voice
- FFS or project-based funding can prevent HCASA from undertaking proactive research and consultation with consumers and communities to raise concerns and areas for health system improvement with government

There needs to be funding allocated to provide sufficient resources for system oversight and to provide a platform for coordination. Pure government funding can limit the ability to have an independent voice. Alternative funding models could be explored such as a 'levy' across LHNs, health organisations and services.

What would/could systemic advocacy look like in South Australia?

If there is no health consumer peak, then there at least needs to be a 'platform' for bringing systemic advocacy and organised consumer participation into decision-making by governments and institutions. The platform should work towards a network (movement) of trained health consumers who contribute to making the health system better through a collective voice that includes local and systemic information that can be brought to focus on improvements.

The platform would need to be secure, with ongoing funding at arms-length so there is the protection of independence. This could include a number of organisations working together to make sure it happens so that it is across the system and working for all South Australians.

Funding for this platform should go across state and federal services (eg General Practice, Community Health, Hospitals) and also work at the interface with disability and ageing. The funding mechanism needs to support independence, integrity and trust (eg a levy like the banks funding the financial ombudsman).

There is a vital place for consumer advocacy to shape integrated care to complement and balance service provider views and advice. The current health funding leads services to be introverted. A separate organisation (peak body) can support health services to engage externally and be outward focused.

The economic benefit generated by including the voice of consumers and community would be recognised in a way that hasn't occurred before in South Australia. The contribution of funds is seen as an investment, not a cost.

What should the advocacy peak/ 'platform' consider for the future?

1. Health consumers are valued and can fulfil a variety of recognised roles. This includes playing a role in influencing change, improvement and innovation across the system. Such a value and appropriate methods of engagement to leverage it must be appropriately resourced.
2. The economic and community benefit is measured, documented, accepted and demonstrated through embedding into practice.
3. Equity bias in advocacy is embedded and the process of routinely engaging with the most vulnerable are embedded in the system and the learnings are actively supporting gains in efficiency and effectiveness.
4. Funding is available that is stable, consistent, mature and is mandated from across the health system and recognises the value of the functions of the platform.

5. Embedded in the process for the accreditation of health services as a system response to the standards.
6. Maturity of advocacy in that the different levels of consumer engagement and the role of systemic advocacy are valued and understood across the system.
7. Building a movement with a state level systemic advocacy organisation, comprised of engaged and involved health consumers, with a high public profile and political acumen developed through public advocacy campaigns and involvement in health service design.

Next steps – Five things for the future

Investigate other platforms/models nationally and internationally (eg New Zealand model of trustees and a levy model) that includes consideration of the following:

- The functions and roles required of the platform/model – with trust, integrity and independence as values of the model
- The terminology around consumer advocacy at a service and systems level
- A sensible long-term investment model – not just HCASA, HCASA+ - with the potential for a co-investment model across the new architecture
- A collective response for the South Australian context which includes consideration of the evolving and devolving governance
- The value of consumer engagement and systemic advocacy and the impact across the system is recognised.

Interested organisations to work together in SA on the next steps and the potential development of a blueprint for South Australian health consumer systemic advocacy.