

Save HCASA campaign strategy research

Top line report
December 2019



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Background

The Health Consumers Alliance of South Australia is the peak health consumer organisation in South Australia. Working with members and supporters, HCASA exists to ensure users and potential users are at the centre of health in South Australia.

After being supported by State Government funding since beginning its work in 2002, HCASA was taken by surprise when the government announced in Sept 2018 that all of its core funding would be cut following the end of their service agreement in June 2019. This makes South Australia the only State in Australia to not have a government-funded peak body for health services consumers.

HCASA is now operating on an unsustainable fee-for-service model and will need to begin the process of closing down by the end of March 2020 if there isn't a reversal of the SA Government's decision, a significant influx of funds or a new reliable ongoing revenue stream established.

HCASA has a small group of individual and organisational members who pay a small fee. Ideally, HCASA would be able to grow this membership base to create an engaged, passionate movement of health services consumers that not only provide financial sustainability beyond the uncertain decisions of changing governments but would also increase HCASA's power, independence and ability to create change that would improve health outcomes for all South Australians.

The role of this research is to test assumptions regarding proposed consumer messaging.

Objectives

Explore consumers' current awareness and understanding of HCASA

Evaluate proposed messaging in support of HCASA

Understand the viability of a short term consumer facing campaign to save HCASA

Methodology

N=2 1.5hr focus group discussions in Adelaide as follows:

	Date	Location	Detail
Group 1	Tuesday 17th December @ 6pm	Adelaide	9 participants Mix of men and women Aged 40-70 years
Group 2	Tuesday 17th December @ 7.45pm	Adelaide	8 participants Mix of men and women Aged 25-40 years

NOTE: Findings in this report are based on a very small sample of people and should be treated as indicative only. Quantitative research is necessary to verify the extent to which the views expressed in focus groups are shared by the wider public

- All participants have personally, or have an immediate family member with, a chronic health condition (mental or physical) that requires ongoing treatment and access public health care services at least every 2 months.
- Each participant was paid a \$90 incentive for taking part

Executive summary and implications

1. The **health care system in SA is under pressure**. Good care is available but you have to learn to navigate the system and often have to wait to be seen.

2. Beyond some awareness of a Health Ombudsman there is **no awareness of any specific groups focussed on advocating** on behalf of health consumers in SA.

3. That said, health consumers **see value in a 'consumer voice'** as they feel largely powerless personally and as a broader group to affect real change in the system.

4. There is **no awareness of HCASA** and so no idea of what the organisation does or who it represents.

5. As a result, the prospect of it ceasing to operate is largely met with **indifference**.

6. In the absence of tangible evidence of the value that HCASA provides for them or South Australians generally, there is **no motivation to support them financially or otherwise**

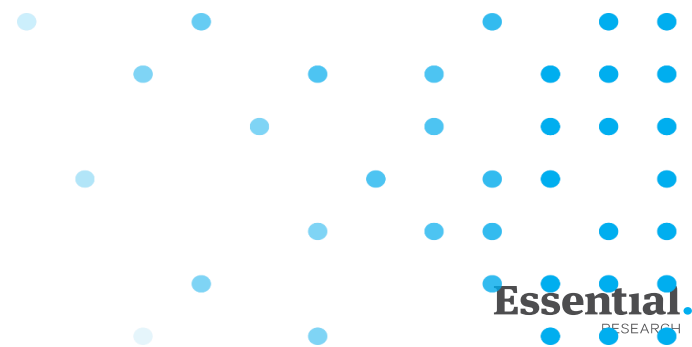
7. It is important to note that this research was conducted among a very small group of South Australian health consumers and so we caution against extrapolating the learnings to the broader community. That said, given the HCASA's timeline and available budget, **a consumer directed campaign is not recommended**. The low levels of awareness of the HCASA makes building ground up support sufficient to save the organisation extremely difficult.

As a secondary campaign audience, speaking to consumers using tangible examples of the value HCASA has provided and speaking to the support of SA Health are likely to be most impactful.

Key findings



Attitudes to health care in South Australia



Health care in South Australia is under pressure



Health consumers are unanimous in their belief that the system is under pressure. They are able to access services and are generally positive about the care they or their family members are receiving but are acutely aware of challenges in the system which they believe are largely driven by a lack of funding and connected to that, a shortage of staff:

- Ambulance ‘ramping’ at the hospitals
- Long delays to see specialists in the public system and so problems can become more serious as you wait
- Over worked staff
- Costs increasingly being passed on to consumers

There is also some concern expressed about sub-optimal communication between different health care providers and the need to often re-explain your case history. Despite the challenges most feel they are doing a reasonable job of navigating the system and getting what they need albeit slowly and sometimes not without frustration.

That said health consumers feel largely powerless to affect change. They don’t believe they have any say in how the system operates or any power to change how they access or receive health care services.

Positive stories or quick service is often attributed to being ‘lucky’.

“Well at the moment we’re experiencing high levels of ramping, a true indicator that it’s not in a good state at this particular point in time”

“Unless you’re kind of private, public seems to be really long to wait for things”

“Often I’ve found myself going into the emergency with him and on occasion you know they might not have access to records that are kept in the building next door which I find a bit frustrating. So having to go over and over the same story again”

“Yeah I think generally when you’ve got some serious illness, they usually treat you, you know, urgently if there’s an emergency there. But you know other cases might be slow, but overall it’s good”

“I’ve always known that the staff, especially in emergency, are massively under a huge amount of pressure and constantly checking things with you over and over again just to make sure that they’ve got the correct information. So that’s one thing I would say that they’re stretched to the max”

“The thing is the juggling of departments. Like when I ring up trying to get through to whoever handles it – like everybody, you know like ‘ah that’s not my department / we don’t Yeah. Waiting lists, I think, as well, particularly for major stuff like surgery and whatever. Like, I went to the doctor three weeks ago. I’m still waiting for my referral to come through to go see someone about it have that on record’ and then you get hung up on”

“We don’t have a say”

“Yeah, you get what you’re given – there’s no choice, there’s no ‘I’ll take the adult role / I’ll choose this particular room / I would like to have that doctor over there’ – you just get it dished out”

Health Consumers Alliance South Australia



Consumer advocacy has a very low profile

Beyond some awareness of a Health Ombudsman there is no awareness of any specific groups focussed on advocating on behalf of health consumers in South Australia. Some see organisations like Diabetes Australia or the Cancer Council as advocates of sorts for their specific medical conditions but recognise no broader organisation at work.

Among these health consumers there is no awareness of HCASA and so no idea of what the organisation does or who it represents. As a result, the prospect of it ceasing to operate is largely met with indifference though a few wonder whether we might miss out on something if only we knew what it was. On the whole most feel that on the basis that there is no evidence of the HCASA having done anything of significance they are not concerned that it may cease to exist. The prospect that HCASA may be doing important work in the background but failing to communicate with the public is not completely discounted though seems unlikely to most given their reasonably heavy involvement in health services.



“I think the hospitals themselves they actually do have patient advocacy groups that I’ve dealt with before that help you with choices and that sort of thing but they were very difficult to get to engage in processes”

“I’m thinking community organisations like say Diabetes Australia or Diabetes SA or like those sorts of asthma, cancer councils – they play an important role”

“I don't know any”

“The health ombudsman”

“I think the thing is we don’t know; we don’t know what they’ve done so we’re just hanging out like puppets at the moment not knowing. So I think it’s disappointing if that does happen if they have been backing things and supporting it”

Support for the general principle of representing consumers

Health Consumers Alliance of SA is the peak health consumer organisation in South Australia. They are a member-based, independent, not-for-profit organisation that works with members and supporters to having consumers at the centre of health in South Australia.

HCA's mission is to engage consumers and health services to achieve high quality, safe, consumer-centred care for all South Australians.

They seek to promote and strengthen the voices, wellbeing, rights and leadership of health consumers.

They advocate that consumer engagement policy and practice is embedded across the SA health care system. This includes public, private and non-government health service providers.

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

The aim here was not to test this particular description with consumers but rather to give consumers some understanding of the role of the HCASA given their own low levels of knowledge.

Exposure to this description shows that consumers are very supportive of the general idea though unclear as to how it plays out in practice. What do HCASA actually do? It sounds like a lobby group but do they in fact work more closely with individual consumers, both of which they see as important roles in the system. Being independent and not-for profit are clear benefits.

Without understanding more about the work of the HCASA and in the absence of tangible examples of what they have achieved it is difficult to get behind the organisation.

While everyone recognises they are the 'consumer' the word is a little strange to most because it implies a choice to buy something which they don't feel they have when it comes to needing medical help.

“Where are they?”

“So they’ve been around for a while?”

“There’s definitely a need for that sort of group. It’s just, like they say, their mission is ‘to engage consumers’ but they haven’t engaged consumers much”

“Because if we are the consumers, we can choose not to consume and, if we did that, we’d either be worse off or we’d die. So it’s not really a choice, is it?”

“So is that a State Government-run initiative?”

“Hopes and dreams because, like, there’s nothing concrete in it about what they actually do and how they do it, what they’re connected with, where their voice is”

“If I could see that they’ve had a big win, and were able to implement something or planning or allocation or budgetary stuff, then I’d be more inclined to support them. But as it stands, I don’t know anything about them and I don’t know what they do”

“If they want to present us I think they need to come up a bit more anyhow because so far I haven’t heard of them. You know I think social media and newspapers and so on – I’ve never heard of them at all to be honest”

“I would like to know what their achievements have been and what their future plans are and how they’re effective, yeah, what have they done?”

“What can you lose? Can you lose something that you never had?”

Narrative and messaging

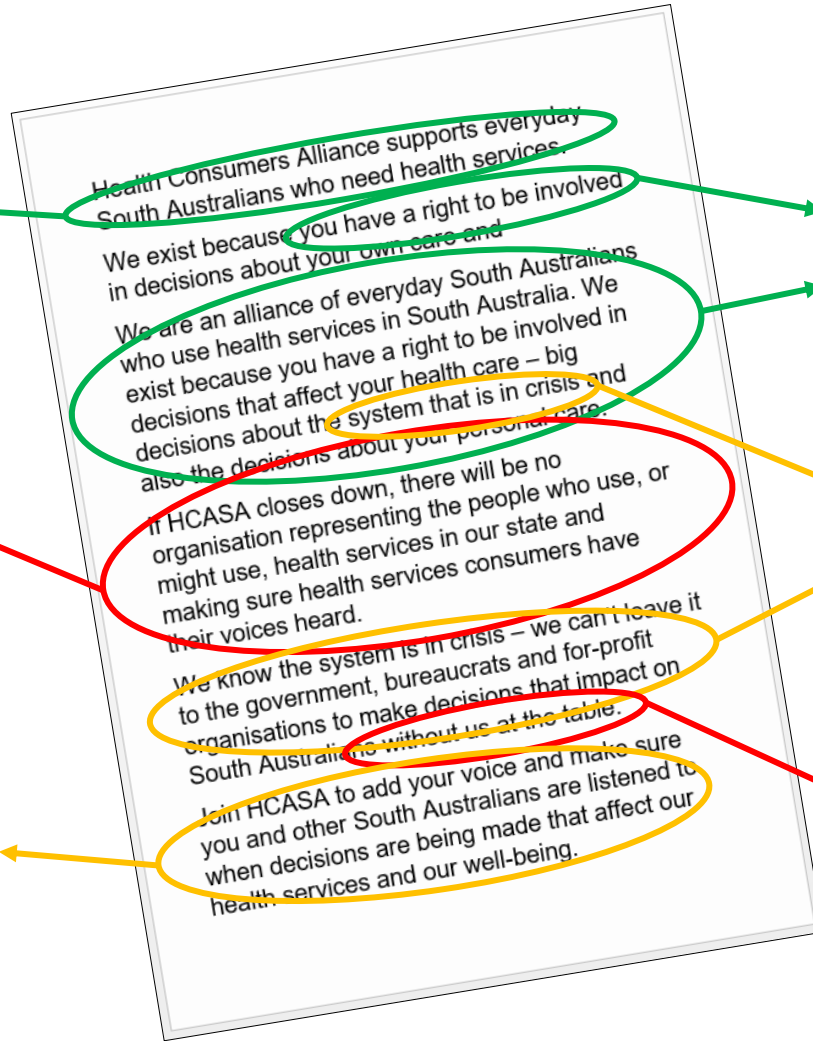


The narrative has some positive elements

Like the idea even if they don't know it's true

Not believed, particularly if they are aware of the Health Ombudsman. Hospital advocacy services, MPs and social or mainstream media are also options

Sounds like a Union's call to action. Falls flat because the case for supporting the HCASA isn't made



Strong support particularly for the idea that they have a right to be involved in decisions affecting their health care

Agreement that the system is under pressure but crisis is too strong for some. Governments are the ones that make the decisions

No evidence of the importance of having HCASA at the table

....but lacks supporting evidence to make it compelling

Consumers agree with the broader principles outlined in the narrative; the value of a consumer advocate and having a consumer voice in the system, a right to be involved in decisions about their healthcare. However, the narrative lacks any compelling evidence; facts, data or examples of how the HCASA has tangibly had an impact and made a difference to health outcomes in South Australia. Dealing with and trying to influence the government is a tough ask so evidence of impact is important. As a result the call to action fails to elicit support and the notion of joining the HCASA or donating financially is rejected.

"I still think it's too generalised. Don't think it's enough to really stick a pin in what they are and why we need them. So physically, if they leave, potentially someone else might come up and they might do better work, so..."

"Why is there - like, can't they put a graph saying this is the percentage of help that we have done? They could easily say "We've helped 80 per cent of Australians find doctors in outback South Australia." There's no proof. There's no record of anything"

"They lost me in just the first sentence because "supports everyday South Australians". None of us have heard of them"

"I just, I just think do they really have an impact on Government decisions? That, you know like do we really need them?"

"Are they a union?"

"I think for me it's like proof is in the pudding, we need to see a big pudding"

No proposed messaging triggers reappraisal

You have a right to be involved in decisions about your own healthcare and about the health services available to you and your family. Health Consumers Alliance ensures you have a voice about how health services are delivered in South Australia.

When the health system in South Australia is under so much pressure, South Australian's need an independent peak body to amplify their voice to influence the big decisions about the SA Health system.

With no ongoing funding South Australians will no longer have an independent consumer voice to influence decisions about health service planning, development, delivery or monitoring. Health Consumers Alliance exists to provide a voice for all South Australians to ensure they access to health services that meet their needs.

Health Consumers Alliance no longer has ongoing funding. If we close down there will be no independent organisation representing your voice about the health care decisions that affect you or your family.

If Health Consumers Alliance is not here....your voice is not heard when government makes decisions about your health care. We need your support to ensure your voice is heard. We exist to strengthen your voice and ensure you receive the health care you want and need.

Our mission is to put you at the centre of health in South Australia...where are you if we are no longer here? We know the health system is under pressure – we can't leave it to the government, bureaucrats and for-profit organisations to make decisions that impact South Australians without consumers at the table.

All South Australians have a right to be involved in how health services are designed and delivered. When you are not able to access the health services you and your family need, Health Consumers Alliance presents your voice to ensure better care.

“We can’t leave it to the Government, bureaucrats’ – I prefer let’s not allocate blame.

Yes.

I agree with you, I’m so sick of that sort of thing”

“How we can benefit? How the community can benefit? So those statements there that are more focused on the consumer, is what I’d think, ‘what’s in it for us.’”

“Not just being negative – you know it’s going to be terrible if we’re no longer here and you know you don’t want Government making decisions without us”

“For me, how it says at the end that “they provide a voice for all South Australians”. If they provide a voice, how come no-one told my Nona about it when she went to hospital for breast cancer every day for over a year now, you know? “

...but focussing on consumer benefits works best

The general lack of facts and clear expressions of what value the HCASA delivers meant that none of the proposed messages was particularly strong. However, those messages which focus on what they as health consumers would gain or spoke to a possible benefit for them are certainly preferred.

The messages which are rejected out right are more focussed on the HCASA talking about itself, what it needs, that suggests there is no other body that can do what they do or that consumers need them or trying to make consumers feel guilty about not supporting them.

"It's like that guy going, "I'm quitting. Who's with me?" And everyone just looking at him going, "What?" "

"It was all very Adam Sandler. Just middle of the road and there's just nothing in it"

"It all sounds great but you know when it comes to the crunch 'what are you going to do for me?'"

The claimed support of SA Health is valuable

Across both groups the news that South Australia would be the only state without a Health Consumers Alliance is met with little surprise, further evidence of a feeling that South Australia often misses out on a national level. That said, there are a few for whom this is something of a concern even without really being clear on what the HCASA does.

In the second group only, consumers were exposed to some additional information:

- Despite the State Government cutting it's budget, SA Health is supportive of HCASA continuing: That SA Health would support the work of the HCASA gives the HCASA considerably more credibility and is to some extent evidence that they must be making a positive contribution to health care in South Australia. That the government is cutting services comes as no surprise nor that there is a disconnect between the politicians and those delivering services.
- Simplified examples of the HCASA's role in Oakden, the J&J mesh case, having representatives on Boards/committees in hospitals: these are seen as tangible examples of what the HCASA does which help to explain it's role and start to build a case for the value of keeping it going. It is the type of evidence that consumers need to get behind the HCASA.

“I wouldn’t want to be the only State that didn’t have them. So if we do miss out then...”

“I think it's bad after you've explained all those things. Yeah. It's definitely a bad thing, but there's - like with bad thing that you mentioned before, there's a whole number of things that SA is behind the other states. We always have been”

“I think even if we did, assuming we do know what they do, you still wouldn’t want to be the only, let’s say that they were really active and they were doing all these things we still wouldn’t want to be the only State”

“It's infuriating. If that's the only, you know, non-profit organisation that's trying to, you know, speak for people, then that makes me so angry that they're going. The Government's not trying to help them or anything. It's so crap....In saying that, there must be pretty poor if not one of us here has heard of it”

“Oh, okay. I like these guys then”

“I think it's really encouraging that they [SA Health] say help them to keep going. They obviously don't just view them as a pain in the arse. They obviously really value their input and their obviously, you know, on the right track. I'm sure SA Health didn't ask for their budget to be cut”

There is no real interest in donating to the HCASA

Lack of awareness of the organisation and in the absence of any understanding of what the HCASA does for them, there is little concern about operations ceasing and no motivation to support them financially.

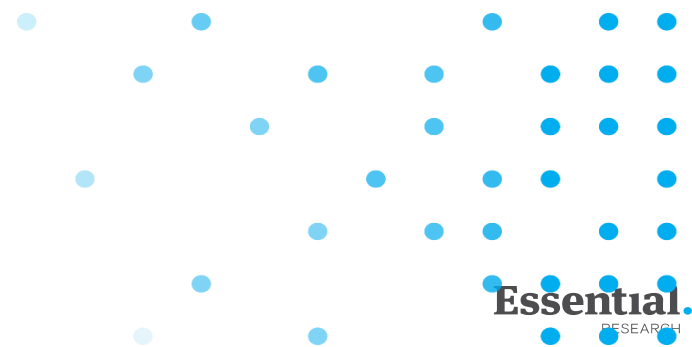
“Not going to happen”

“If I knew that I was going to pay something just random, 20 dollars a year to be a member right, and that was going to, they were going to be the voice between the hospital to go ‘okay, we’re going to fund enough money, that we get enough money from our consumers to help with medication costs (or whatever)’ – that 20 dollars is nothing compared to the thousands I’m paying”

“We just don't have enough faith in, yeah, the brand to put our money - put our own money to it because most of us are exhausted financially, whether we're supporting a family member or whether we've got a condition ourselves. You know, our money's pretty tight. We're already skipping therapies and skipping, you know, a lot of extra care that can be done”

“I don't think there's enough brand awareness for them to call people to pay money a month”

Appendix: Discussion guide



HCSA Discussion Guide (11/12/19)

Introduction (5 min)

Welcome/Independent researcher/ no right or wrong/ want honest opinions/ hear from everyone/share air time/ anonymity/ recording and viewing /may interrupt or look at notes/ help themselves to refreshments/any questions before we start? / introduce themselves

Health care in SA (15 min)

- Tell me about the current quality of health care in South Australia?
- What's working well?
- What are the challenges? For patients? For families and carers?

- How is the voice of the consumer, your voice, currently heard in the health care system?
- How is the consumer's voice currently captured in decision making about health care in SA?
- How well is it working currently?
- Who or what group, if any, advocates for consumers in health care in South Australia?
- Do you think of yourselves as health 'consumers'?

Health Consumers Alliance SA (20 min)

- Have you heard of the Health Consumers Alliance?
- What do you know about them? heard about them?
- What do they do?

SHOW/READ OUT DESCRIPTION.

Health Consumers Alliance of SA is the peak health consumer organisation in South Australia. They are a member-based, independent, not-for-profit organisation that works with members and supporters to having consumers at the centre of health in South Australia.

HCA's mission is to engage consumers and health services to achieve high quality, safe, consumer-centred care for all South Australians.

They seek to promote and strengthen the voices, wellbeing, rights and leadership of health consumers.

They advocate that consumer engagement policy and practice is embedded across the SA health care system. This includes public, private and non-government health service providers.

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

- How do you feel about this organisation?
- How important is it to have an organisation like this?
- What would be the benefits of having an organisation like this?
- What should they be doing?
- What concerns or questions does it raise for you?

- What would happen if it didn't exist?
- What would we lose as South Australians?
- How would it impact you personally? How might it?

- How would you feel if I said funding for the organisation runs out this coming March and without new funding it will stop operating?
- Does it matter?
- How interested would you personally be in donating to it to keep it going? PROBE donating \$10 a month/Getting out in support to meetings/Writing to MPs/ Sharing posts in social media/Signing petition

Narrative (15 min)

HAND OUT NARRATIVE SHEET. Here is one possible argument in favour of supporting the HCA. Without discussing it at this stage, please underline what you agree with and put a line through what you disagree with or don't think is true.

Health Consumers Alliance supports everyday South Australians who need health services.

We exist because you have a right to be involved in decisions about your own care and

We are an alliance of everyday South Australians who use health services in South Australia. We exist because you have a right to be involved in decisions that affect your health care – big decisions about the system that is in crisis and also the decisions about your personal care.

If HCASA closes down, there will be no organisation representing the people who use, or might use, health services in our state and making sure health services consumers have their voices heard.

We know the system is in crisis – we can't leave it to the government, bureaucrats and for-profit organisations to make decisions that impact on South Australians without us at the table.

Join HCASA to add your voice and make sure you and other South Australians are listened to when decisions are being made that affect our health services and our well-being.

DISCUSS RESPONSES

- Overall, how good an argument is this for supporting the HCA?
- How strong are those arguments?

Key messages (25min)

We're going to break this down a bit and look at different ways of talking about this.

FOR EACH MESSAGE (7):

- How do you feel about this?
- What do you agree/disagree with?

RANK ORDER IN TERMS OF STRONGEST ARGUMENT

1. *You have a right to be involved in decisions about your own healthcare and about the health services available to you and your family. Health Consumers Alliance ensures you have a voice about how health services are delivered in South Australia.*

2. *With no ongoing funding South Australians will no longer have an independent consumer voice to influence decisions about health service planning, development, delivery or ~~expanding~~. Health Consumers Alliance exists to provide a voice for all South Australians to ensure they access to health services that meet their needs.*
3. *When the health system in South Australia is under so much pressure, South Australian's need an independent peak body to amplify their voice to influence the big decisions about the SA Health system.*
4. *Health Consumers Alliance no longer has ongoing funding. If we close down there will be no independent organisation representing your voice about the health care decisions that affect you or your family.*
5. *If Health Consumers Alliance is not here...your voice is not heard when government makes decisions about your health care. We need your support to ensure your voice is heard. We exist to strengthen your voice and ensure you receive the health care you want and need.*
6. *Our mission is to put you at the centre of health in South Australia...where are you if we are no longer here? We know the health system is under pressure – we can't leave it to the government, bureaucrats and for-profit organisations to make decisions that impact South Australians without consumers at the table.*
7. *All South Australians have a right to be involved in how health services are designed and delivered. When you are not able to access the health services you and your family need, Health Consumers Alliance presents your voice to ensure better care.*

REVIEW FINAL RANKING.

Were there any points in the initial sheet you read that belong at or near the top of this ordering?

Final thoughts (5 min)

- If it was your job to get people to donate \$10 a month to HCA to keep it going, what do you think are the most compelling arguments for doing it?
- What do people need to know or hear to get behind it?

THANKS & CLOSE

INCENTIVE

Stimulus requirements:

1 x A3 Board with HCA description

18 x A4 sheets with narrative

7 x A3 Boards with key messages