2017 HCA Members Forum Summary Report

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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.

Executive Summary

Health Consumers Alliance of SA Inc (HCA) held the 2017 HCA Members Forum on Monday 25 September 2017, from 3.00 to 5.00pm. Seventeen members attended.

The purpose of the forum was to provide an opportunity for HCA members to identify the priorities for HCA's advocacy and 2017/18 state election platforms.

Acting Chief Executive HCA, Ellen Kerrins, welcomed participants and summarized the work of HCA, referring to the 2017 – 2020 Strategic Directions document, and the organisation's information brochure.

HCA Board Chair, Deb Kay, facilitated the forum. She too thanked members for their attendance, and acknowledged the Traditional Custodians of Country.

Deb invited participants to introduce themselves, and outlined the forum program (attached at Appendix 1), which included small group and individual activities. She emphasized the importance and appreciation of member input to inform HCA's work and priorities.

Participants worked in four small groups to brainstorm responses to the following question: *What are the gaps or issues that HCA should influence in the next 12-18 months?*

Following a selection process, eight priority issues emerged:

1. The consumer / health system interface

2. Rural and remote health

3. Service improvement through the consumer voice

4. Aged care and older people, and health care homes

5. Social determinants of health - the needs and health care of Aboriginal and Torres Strait Islander children, and high incarceration rates, were highlighted at the conclusion of the forum. So too was the need to change the culture of the workplace to ensure a consumer focus. There was also an acknowledgement of racism in health care.

6. Consumer and carer escalation of care

7. Medication management first response and polypharmacy

8. Access and navigation of the health system, including E-Health and information technology access.

Background

Health Consumers Alliance of SA Inc (HCA) was established in 2002 as the peak body for health consumers in South Australia. We are a member-based, independent, not-for-profit organisation, funded by SA Health. We work with our members and supporters to achieve our vision: *Consumers at the centre of health in South Australia*. Our mission is to engage consumers and health services to achieve quality, safe, consumer-centred care for all South Australians.

HCA members help to strengthen the influence of consumers and communities across the state and nationally. They also contribute their diverse perspectives to shape health policy, planning, research, service delivery and evaluation.

The HCA Board and staff invited members to attend an HCA Members Forum, held on 25 September 2017, from 3.00 to 5.00pm. The purpose of the forum was to provide an opportunity for HCA members to identify the priorities for HCA's advocacy and 2017/18 state election platforms. Seventeen members attended, and collectively, they identified eight priority issues.

Forum Program

HCA Board Chair, Deb Kay, facilitated the forum and outlined the forum program (attached at Appendix 1). The process that members undertook to develop the eight priority issues is detailed below.

Identifying gaps or issues that HCA should influence in the next 12-18 months

The first activity involved participants working in four small groups to brainstorm responses to the following question:

What are the gaps or issues that HCA should influence in the next 12-18 months?

Verbatim responses follow.

Group 1 response:

1. Talk the talk vs Walk the walk.
   Seeking, acknowledging and responding to consumer advocates' input.
   How can we assist health organisations improve their consumer engagement?
   - influencing leadership and organisational culture
   - consumer involvement from commencement.

2. Develop an online forum / website to provide information on health industry framework including quality and accreditation.

3. Lack of understanding of our aged consumers and aged care, and delivery of health services to aged people in residential care, and for housebound people.

4. Health care homes for delivery of primary health care to people with chronic illness. Aged people often fall into this group.

5. Online apps for health / providers – how do aged people who are computer illiterate deal with this? As well as this is: health e-records, My Gov account, health websites etc.

Group 2 response:

1. Medication
   - focus on pharmaceutical only approaches to medicine
   - individual advocates - process re adverse reaction or negative reaction
   - consent - redress - lack of review - polypharmacy.

2. Health professionals
   - need training to respect mind body experience
   - not just physical
   - vulnerable people - culturally and linguistically diverse (CALD), aged, mental health.

3. Data
   - Emergency Department (ED) - report card - pressure valve captures people who fall through gaps in other health areas
   - can we get accurate data re presentations to ED and then focus more resources on service gaps
   - causes of death data.

4. Hospital
   - distressing experience
   - what to expect whilst in hospital
   - My Aged Care / Online services / face to face – empower consumers
   - complaints / feedback form
   - welcome kit - tells consumers about healthcare process, info re advocacy, consultancy, community visitors
   - patient advocacy - one to one
   - National Disability Insurance Scheme (NDIS).

5. Dementia.

Group 3 response:

- Clarity – to whom are we advocating?

  Health is extensive - services   - reform? what does it look like?
                       - systems   - govt / policy / organisations / service delivery / models /
                       - gaps   new roles / primary health.

- Primary health - education / expertise eg GPs with mental health expertise.

- Emergency services / response.

- Rural and remote - poorly represented / resourced / recruit / retain.

- Consumer / health interface - does it work? how?

- Consumer - silos - primary, secondary, tertiary health.

- How to navigate health?

- Consumer as "holistic case manager".

Group 4 response:

1. Sharing information about incidents that happen for rectification, not just treated as an isolated incident. HCA to monitor to address frequency and emerging patterns.

2. Communication – government departments and services to the community; consumers can access information about health services eg verifying what consumer (is) told – options available.

3. Private health, system and procedure failures handballed between hospital, admin and specialist – difficulty in resolving – tied up in 'privacy' or fobbed off.

4. Racism which is in public hospital care eg Aboriginal people, or people of lower socio-economic backgrounds – treated less favourably than others.

5. GPs - should have closer scrutiny on degree of English language literacy skills to be able to understand consumer and liaise verbally and in writing with specialists and other organisations.

Following the small group brainstorm activity, each group nominated a spokesperson to summarise for all participants the main issues identified. These were recorded on butcher's paper for viewing, and included the following:

- To whom are we advocating?

- Primary health care - selecting a GP for expertise.

- Emergency Department.

- Rural and remote health.

- Consumer / health system interface.

- Access and navigation of the health system, including E-Health and information technology access.

- Service improvement through the consumer voice.

- Consumer rep training - accreditation and standards.

- Aged care and older people / health care homes.

- Consumer influence to specialist health and private health.

- Social determinants of health, particularly the needs and health care of Aboriginal and Torres Strait Islander children, and high incarceration rates.

- Sharing consumer experiences - online.

- Health system communication with public.

- Consumer / carer escalation of care.

- Racism / discrimination (prisoners).

- Literacy and language skills of GPs.

- Medication management first response and polypharmacy.

- Data collection eg ED data, reflects whole health system, data currency.

- Individual face to face advocates.

- Advance care directives for all ages.

- Dementia.

Prioritising the issues

Individual participants then used sticky labels to indicate from these responses their personal top five priority issues.

There were subsequently eight priority issues that emerged from the selection process:

1. The consumer / health system interface

2. Rural and remote health

3. Service improvement through the consumer voice

4. Aged care and older people, and health care homes

5. Social determinants of health - the needs and health care of Aboriginal and Torres Strait Islander children, and high incarceration rates, were highlighted at the conclusion of the forum. So too was the need to change the culture of the workplace to ensure a consumer focus. There was also an acknowledgement of racism in health care.

6. Consumer and carer escalation of care

7. Medication management first response and polypharmacy

8. Access and navigation of the health system, including E-Health and information technology access.

Participants were asked to reform into four small groups, and chose priority issues to address, by considering the following questions:

- How should the issue be addressed?

- Are there organisations we (HCA) should be partnering with?

- Are there particular communities we (HCA) should focus on?

- Other comments?

Only issue 7 was not addressed. Verbatim responses are detailed below.

Issue 1: The consumer / health system interface - two groups addressed issue 1

How should the issue be addressed?

- Wide range of representation of consumers at the policy level.

- Improved <u>effectiveness</u> of consumer engagement with quality assurance and accreditation processes – involve consumers in the design of consumer assessments and feedback.

- Greater involvement and accountability in the private hospital and health system.

- Well trained, effective and knowledgeable consumer reps.

- Addressed through the health system.

- Is "Partnering with Consumers" working and how do we know that it is working?

- Note the standard is being revised / reviewed now.

- Note National Volunteer standard must by applied.

- Health literacy to improve effective consumer participation.

Are there organisations we (HCA) should be partnering with?

- SA Health.

- SA Private Hospitals Association?

- Medical Specialist Colleges.

- Disability associations eg MS Society.

- Consumer Health Forum for training.

- Regional consumer groups set up by the standard "Partnering with consumers".

Are there particular communities we should focus on?

The Adelaide Primary Health Network (PHN) and Country PHN geographic areas.

Issue 2: Rural and remote health

How should the issue be addressed?

- Awareness of country / rural issues.

- Collection of appropriate data - eg person dying in Adelaide but issue arising in rural area eg Port Pirie, Whyalla - stats do not accurately reflect issue.

- How data is collated and presented and read.

- Stop funding being cut.

- Use trained PEER people with identified communities eg Aboriginal / culturally and linguistically diverse (Country Health).
- Training of more indigenous health workers.

Are there organisations we (HCA) should be partnering with?

- Country Health SA.
- SA Health - keeping country / rural hospitals open and services available.
- Country Health Governing Council.

Are there particular communities we should focus on?

- Aboriginal and culturally and linguistically diverse communities.
- Aged.
- Mental Health.
- Disabilities.

Issue 3: Service improvement through the consumer voice

How should the issue be addressed?

- One on one advocates.
- Independent - not a patient advisor.
- Referral to counselling re trauma from illness.
- Advisory committees - hospital - feedback from advocates.
- How do complaints currently link back to improvements of service?
- Private hospital processes? - learning tool.

Are there organisations we (HCA) should be partnering with?

Council on the Ageing, Aged Rights Advocacy Service, Office of the Public Advocate, Carers Association, Statewide Mental Health Lived Experience Register (and national).

Are there particular communities we should focus on?

Vulnerable communities - mental health, culturally and linguistically diverse, disenfranchised persons, older people, living alone, homeless, cognitive impairment.

Issue 4: Aged care and older people, and health care homes

How should the issue be addressed?

Issue on how older people are treated in hospital - largest patient group. Health issues can change at home, but services are inflexible. Hidden issues eg infections overlooked. Passive - talked to. AGEISM and generalisations about age. Older people not involved in design of services - patronised.

1. More attention to mental capacity of person - full rights; and if impaired - assistance for supported decision making.

2. More use of stepdown or 'hospital at home' support to avoid hasty and expedient decisions by professionals eg residential care.

3. Responsibilities for family carer - no packages available - systemic issue - HCA to lobby.

4. More voice for older persons in design of any aged care service eg home care - little community care - some hospitals.

Issue 5: Social determinants of health

How should the issue be addressed?

- Consumer consultation at design and policy stages.

- Implementation of health implications in all policies, as proposed recently by the state government.

- Greater representation of vulnerable groups in consumer advocacy roles.

- Health advocates have a role to play in addressing emerging gaps in health service delivery arising from the NDIS.

- Literacy on social determinants of health.

- Focus on lived experience as a contribution to policy and practice.

- Create and support champions of improvements in social determinants of health.

Are there organisations we (HCA) should be partnering with?

- Organisations that represent and serve vulnerable communities and marginalised groups.

- Existing consumer advisory councils in Primary Health Networks and Local Health Networks.

Are there particular communities we should focus on?

- No – we want to ensure that all people get the health services they need, delivered in a way that is culturally safe.

- Young and aged; mental health; disability including intellectual disability and communication challenged; homeless; poverty; closing the gap; domestic violence.

Issue 6: Consumer and carer escalation of care

How should the issue be addressed?

- Health system indicator "escalation" – recognition.

- Standard part of escalation advocacy point – eg helpline
  - your rights, your responsibilities – helpline
  - point of first communication.

- Escalation from any party - consumer
  - family / network
  - health practitioners.

- Policy / protocol – education.

- Indicators eg - communication eg in hospital
  - accessing representatives eg Aboriginal and Torres Strait Islander liaison.

Are there organisations we (HCA) should be partnering with?

- Department of Health.

- Health services / networks.

Are there particular communities we should focus on?

- Aboriginal and Torres Strait Islander.

- Mental health.

- Frail aged.

- Complex health.

- Multiple diagnosis (across services).

Issue 7: Medication management first response and polypharmacy - this issue was not addressed.

Issue 8: Access and navigation of the health system, including E-Health and information technology access

How should the issue be addressed?

- 1800 phone line for consumers to verify information given by health professional to assist with process and treatment implementation.

- Example: review of public transport system to ensure inter-connectedness from their home to treatment centre – to minimise walking distance.

At the conclusion of the forum, several participants discussed the needs and health care of Aboriginal and Torres Strait Islander children, and high incarceration rates. Also highlighted was the need to change the culture of the workplace to ensure a consumer focus. There was also an acknowledgement of racism in health care.

The points raised from this small group discussion follow:

- Accessing health records - accuracy of information and being able to challenge health documentation about Aboriginal and Torres Strait Islander people.

- Accessing Aboriginal Liaison in mental health services.

- Aboriginal people - capacity to access electronic records / services.

- Aboriginal and Torres Strait Islander people in services long-term - not being addressed – managed (by) Aboriginal nurse / social worker etc.

- No recognition / knowledge of Aboriginal cultural determinants so poorly responded to.

- No recognition of at risk young people (early recognition).

- Strategies have to be implemented at first point of communication when an Aboriginal and Torres Strait Islander person presents at health service in any way – indicator of escalation.

HCA also received from two consumers the following (verbatim) contributions via email:

1. My suggestion is the creation of a registry of general practitioners who specialise (in) dealing with consumers with mental health and / or alcohol and other drugs issues, to make available to consumers to select a GP because of their specialised area.
Reason: Consumers are asked to speak with their GP as the first point of call. Many GPs have no idea of the complexity of issues surrounding mental illness and / or AOD. Enabling consumers to have more knowledge on where to go to chat with a GP who has specific knowledge within this area would give consumers the opportunity to be informed, (have) more choice and empowerment.

2. Anything that can be done to get SA to embrace digital health (like NSW is) would benefit consumers. Such as getting our public pathology results up to the My Health Record.

Conclusion

At the 2017 HCA Members Forum, participants identified eight priority issues that HCA should influence in the next 12-18 months:

1. The consumer / health system interface

2. Rural and remote health

3. Service improvement through the consumer voice

4. Aged care and older people, and health care homes

5. Social determinants of health - the needs and health care of Aboriginal and Torres Strait Islander children, and high incarceration rates, were highlighted at the conclusion of the forum. So too was the need to change the culture of the workplace to ensure a consumer focus. There was also an acknowledgement of racism in health care.

6. Consumer and carer escalation of care

7. Medication management first response and polypharmacy

8. Access and navigation of the health system, including E-Health and information technology access.

HCA will now seek more broad input from health consumers before finalising its advocacy and election strategies.

Appendix 1 – Forum Program

Time	Item
3.00pm	Welcome and acknowledgement of country
3.10pm	Brainstorm in small groups What are the gaps or issues that HCA should influence in the next 12 -18 months?
3.30pm	Prioritising the top five issues – individual selection
4.10pm	Addressing issues in small groups: How should the issue be addressed? Are there organisations we (HCA) should be partnering with? Are there particular communities we (HCA) should focus on? Other comments?
4.50pm	Report back and next steps
5.00pm	Thank you and close