

Transforming Health Consumer and Community Engagement Committee

Activities Report

2015 - 2017

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About the Health Consumers Alliance of South Australia

Health Consumers Alliance of SA Inc (HCA) was established in 2002 as the peak health consumer organisation 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.

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

Executive Summary

The May 2014 federal budget resulted in major funding cuts to health services. Following this, the SA Health Minister initiated a review and reform program, eventually known as Transforming Health. It was described as an opportunity to focus on the quality of health care by creating efficiencies and building the sustainability of our public hospital system, with the vision:

‘South Australians deserve consistent, quality healthcare: best care, first time, every time.’

SA Health released the Transforming Health Discussion Paper in October 2014, followed by a Summit held in November 2014 and a related Proposals Paper issued in February 2015. The Delivering Transforming Health – Our Next Steps paper was released in March 2015.

In response to this change agenda, Health Consumers Alliance of SA Inc (HCA) held two consumer and community forums on Transforming Health in November 2014 and May 2015, with over 150 people informing HCA’s work on Transforming Health.

Following recommendations from the May 2015 Consumer Forum, HCA established in July 2015 the Transforming Health Peak Consumer and Community Engagement Committee, with support from SA Health. Committee members were selected via an application and interview process, with organisations representing priority target populations also being asked to nominate a representative.

The Committee met monthly, chaired by Michael Cousins, HCA Chief Executive (CE), with staff from HCA providing executive and project support, and SA Health staff providing information and receiving advice from the Committee.

The purpose of the Committee was to provide SA Health with broad, strategic and representative consumer and community engagement as the peak consumer and community advisory body for Transforming Health.

The Committee was connected to the Transforming Health Ministerial Clinical Advisory Group (MCAG) through the Committee chair, HCA CE, as a member of MCAG.

A Committee review in June 2016 resulted in clarification of the role of the Committee, and the word ‘peak’ being removed from its title.

The Committee developed a work plan with a focus on:

- Consumer and community engagement
- Access
- Vulnerable populations
- Information provision, community education and health literacy
- Measures, indicators and evaluation
- Primary health and prevention

The key driver for the work of the Committee was consumer-centred care. The Committee hosted three forums, and influenced the evaluation of Transforming Health with the development of a Consumer Experience Theme in the evaluation. Early and authentic consumer engagement, effective and timely communications and access, were common themes in the advocacy undertaken by the Committee.

The Minister for Health and Ageing announced in July 2017 that the Transforming Health program would end with the opening of the new Royal Adelaide Hospital, and the closure of the Repatriation General Hospital. The Committee subsequently began plans to conclude, with the development of an activities report. The purpose of the report would be to document the work of the Committee, the experience of its members and recommendations for consumer engagement in health reform into the future.

As part of the Committee’s final review process, HCA prepared four questions, and in August 2017 distributed these by email for members’ responses:

- What were the impacts of the Committee?
- What worked well for you?
- What were the challenges?
- How could things work better in the future?

The Committee clearly identified that its biggest challenge was that consumers were not engaged right from the beginning of Transforming Health, and that it took twelve months to clarify the Committee's role and purpose.

The Committee found that the opportunity to sit around the table with some of the decision makers in SA Health was integral to its success. One of the key impacts of the Committee was the change in the relationship between consumers and SA Health at the strategic level. The robust, challenging and respectful relationships that have developed through this Committee have flowed on to increase consumer engagement in other areas of SA Health.

Committee members were clear that health consumer engagement in the future needs to start from the beginning and have a clear purpose, with links to real decision making. They would like "Nothing about us, without us" embedded in SA Health at all levels. Their recommendations are detailed below.

Recommendations

1. That HCA present a consumer engagement proposal to the Minister for Health and Ageing to address future health strategy and reform. That proposal should include:
 - development of a consumer and community engagement committee to provide advice on health strategy and health reform.
 - committee membership including individual consumers and community representatives from community stakeholder groups.
 - representation by senior executives from SA Health on the committee, along with other relevant SA Health staff who would be equal members of the committee to reflect true partnership.
 - representation from Primary Health Networks.
 - consumers being engaged from the start of any reform process, utilizing co-design principles and processes.
 - HCA and a consumer should co-chair the committee, with HCA adequately resourced to provide executive and project support to the committee.
 - the committee should have a clearly articulated purpose and scope.
 - the committee should have links to the Partnering with Consumers and Community Committee and Local Health Networks.

Overview

Background of Transforming Health

The May 2014 federal budget resulted in major funding cuts to health services. Following this, the SA Health Minister initiated a review and reform program, eventually known as Transforming Health. It was described as an opportunity to focus on the quality of health care by creating efficiencies and building the sustainability of our public hospital system, with the vision:

‘South Australians deserve consistent, quality healthcare: best care, first time, every time.’

SA Health released the Transforming Health Discussion Paper in October 2014, followed by a Summit held in November 2014 and a related Proposals Paper issued in February 2015. The Delivering Transforming Health – Our Next Steps paper was released in March 2015.

The Transforming Health Summit:

- endorsed the approach of operating in partnership with clinicians and consumers at the core of our health system, to increase the likely success of Transforming Health.
- affirmed that evidence-based, high quality patient-centred services are required across primary and secondary care, considering the needs of all health consumers, regardless of background and individual circumstances.
- recommended that the continuum of experience for the consumer, from prevention to palliation and end of life care, should be seamless.

The Summit noted the gap in outcomes for vulnerable South Australians, including Aboriginal communities, mental health consumers and country communities. It recognized transformation is complex, requires significant resources, and must involve change management with genuine engagement and consultation.



Committee meeting workshop

Establishing the Transforming Health Consumer and Community Engagement Committee

Health consumers expressed the desire to be involved and constructively challenge the health system about service principles, safety and quality, equity, access, sustainability and performance.

Improving the safety and quality of health care involves everyone: politicians, administrators, doctors, nurses, allied health professionals and support staff. Importantly, the values, needs and preferences of consumers, families, carers and communities should be central to any change agenda.

Transparency and openness to other knowledge, experiences, perspectives and values is critical for high quality health care. This can only be achieved if our health system is consumer-centred.

As the peak health consumer organisation in South Australia, Health Consumers Alliance of SA Inc (HCA) supported consumer-centredness as the first quality principle adopted in Transforming Health.

Following recommendations from the May 2015 Consumer Forum, HCA established in July 2015 the Transforming Health Peak Consumer and Community Engagement Committee, with support from SA Health.

Members participated in a reflective review in July 2016, then adjusted the terms of reference and changed its name to the Transforming Health Consumer and Community Engagement Committee (the Committee).

As the consumer and community advisory body for Transforming Health, the purpose of the Committee was to provide SA Health with broad strategic and representative consumer and community engagement.

The last meeting of the Committee was held in September 2017, as Transforming Health was retired and health reform became business as usual.

Committee process 2015 - 2017

Committee Membership

Committee members were selected via an application and interview process, with organisations representing priority target populations also being asked to nominate a representative. The mix of individual and representative members was found to be beneficial, with individual members taking a more prominent role in engaging in the model of care working groups, and the representative members providing the linkages with Local Health Networks (LHNs) and priority populations. The Aboriginal Health Council was asked to nominate a member, however it advised that broad consultation and engagement would be more effective than an individual representative. HCA then engaged with the Health Performance Council's Aboriginal Health Leaders Group, and supported the development of the Aboriginal Experts Reference Group that reported to the Ministerial Clinical Advisory Group (MCAG).



Members of the Transforming Health Consumer and Community Engagement Committee with staff from HCA and SA Health, including Dr Dorothy Keefe, Clinical Ambassador for Transforming Health

Table 1: Committee Members

	Member Name	Position	Date Appointed	Date Resigned	Organisation
1	Michael Cousins	Chair	29/07/2015		Health Consumers Alliance SA
2	Anne Burgess	Member	29/07/2015		Council on the AgeingSA
3	Helena Kyriazopoulos	Member	29/07/2015		Multicultural Communities Council SA
4	Dean Fyfe	Member	29/07/2015		Central Adelaide LHN Consumer
5	Juli Ferguson	Member	29/07/2015		Individual consumer
6	Kathleen Gregurke	Member	29/07/2015		Country Health SA LHN Consumer
7	Lynda Whiteway	Member	29/07/2015		Individual consumer
8	Chris Lemmer	Member	29/07/2015		Veterans' Health Consumer
9	Melissa Cadzow	Member	29/07/2015		Women's and Children's Health Network Consumer
10	Vickie Castle	Member	29/07/2015		Individual consumer
11	Allan Patching	Member	29/07/2015		Northern Adelaide LHN Consumer
12	Amanda Porter	Member	29/07/2015	13/06/2016	Individual consumer
13	Lyn Woodforde	Member	29/07/2015		Carers SA
14	Diana Voss	Member	29/07/2015		Southern Adelaide LHN Consumer
15	Alison Smith	Member	24/07/2016		Adelaide Primary Health Network
16	Jenny Philip-Harbutt	Member	25/05/2016	10/01/2017	Country SA Primary Health Network
17	Inara Beecher	Member	22/02/2017		Country SA Primary Health Network
18	Peter Blacker	Proxy	29/07/2015		Country Health SA Local Health Network Consumer

Table 2: SA Health and HCA Representatives who attended meetings as observers and informants to the group.

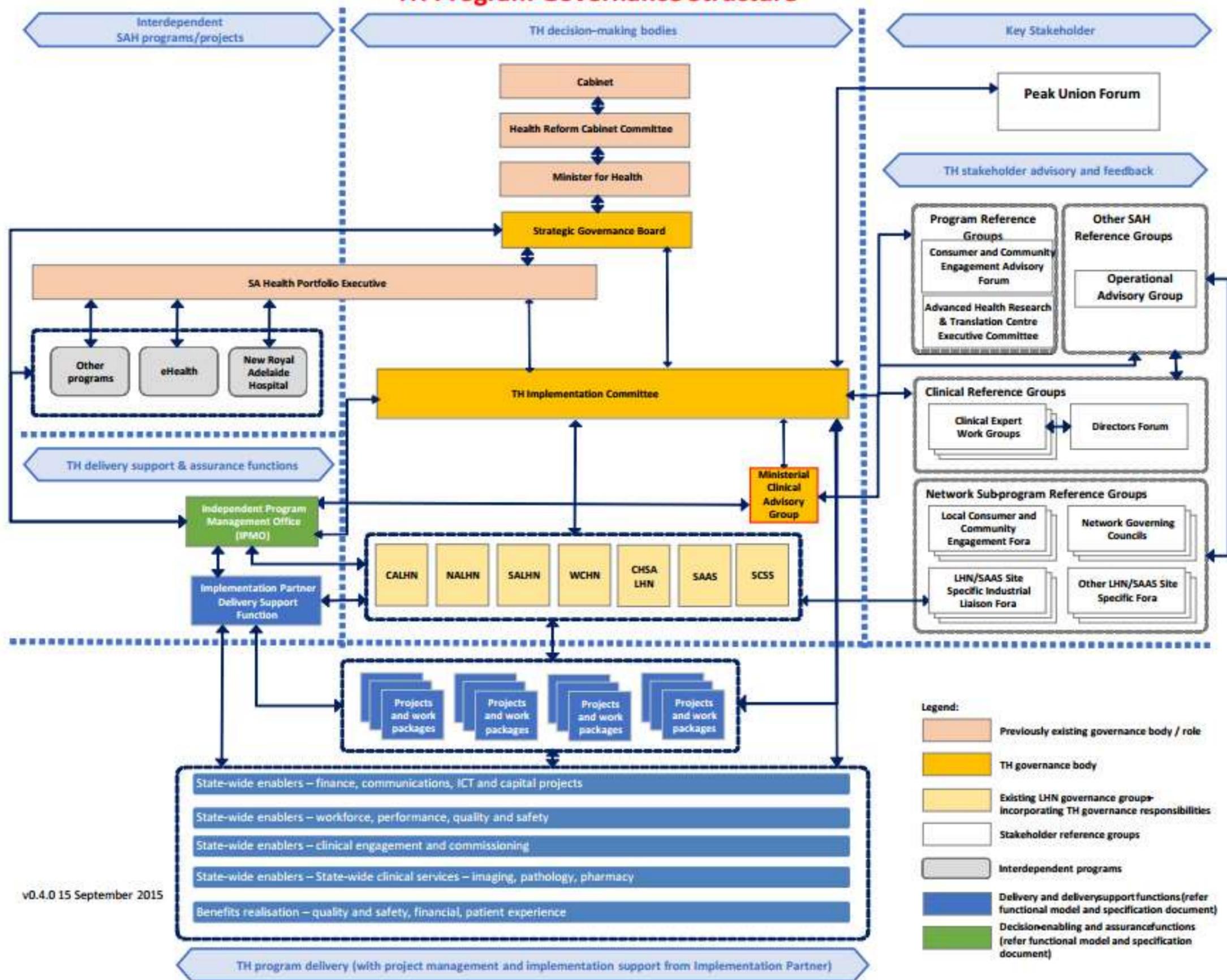
	Representative Name	Organisation	Position
1	Vickie Kaminski	SA Health	Chief Executive, SA Health
2	Penny Thyer	SA Health	Manager, Clinical Improvement and Engagement Transforming Health
3	Lynne Cowan	SA Health	Deputy Chief Executive, Transforming Health
4	Michele McKinnon	SA Health	Executive Director, Quality, Information and Performance
5	Thaao Woolfe	SA Health	Communications Advisor, Marketing Communications
6	Ellen Kerrins	HCA – Committee support	Manager Policy and Advocacy
7	Kathy Mickan	HCA – Committee support	Manager Consumer Engagement
8	Karen Shepherd	HCA – Committee support	Project Officer

The Transforming Health Governance Structure (September 2015)

The Committee was connected to the Ministerial Clinical Advisory Group (MCAG) through the Committee Chair, HCA Chief Executive Michael Cousins, also a member of MCAG.

At each Committee meeting, a MCAG update was a standing agenda item. The Committee’s representative was able to pose questions to MCAG on behalf of the Committee, as well as provide the Committee with updates on MCAG activities and priorities.

TH Program Governance Structure



v0.4.0 15 September 2015

Terms of Reference and Review of the Committee

Terms of Reference October 2015

The Committee's Terms of Reference were endorsed on 28 October 2015 with the following role and scope.

Role

The purpose of the Committee is to provide SA Health with broad, strategic and representative consumer and community engagement as the peak consumer and community advisory body for Transforming Health. The Committee will communicate with consumers and communities; actively identify and communicate concerns and solutions across Transforming Health work groups; and match the intent of Transforming Health with community aspirations for best care, first time, every time - in the manner communities prefer.

Scope

The Committee will address hospital and inpatient services as they relate to Transforming Health. A work plan with priority actions will guide the operation of the Committee. This Committee will also keep a watching brief on primary health and other aspects of the health system as they become part of the Transforming Health agenda.

Committee Review June 2016

A Committee review was conducted in June 2016. It involved telephone interviews, a member survey and an independently facilitated workshop. The purpose of the review was to identify what was and was not working for the members, and to decide on a clear strategic forward direction for the Committee.

The review resulted in the following recommendations:

- Amend the terms of reference to reflect changes indicated and agreed at the session by the Committee.
- Remove the term 'Peak' from the title of the Committee.
- Ensure the Chair of the Committee and Transforming Health leadership provide timely advice, reports and challenges for the Committee.
- Finalise the Committee's consumer and community engagement theme plan and progress consumer consultation about Transforming Health changes and concerns.
- Continually reflect on the diversity of individual expectations of the Committee and what can and has been achieved.
- Ensure the Committee's communique is retained and refreshed.

The Committee also agreed to retain a focus on:

- MCAG Dashboard and SA Health progress.
- input and feedback from the Primary Health Networks (PHNs).
- broader advice and information from SA Health
- access and equity issues, for example progressing engagement with culturally and linguistically diverse (CALD), Aboriginal and Torres Strait Islander (ATSI) and other vulnerable consumers.
- summaries or reports from the Chair, following Ministerial meetings.

- maintaining the communicate and refreshing it.
- finding a way for the Committee to provide advice to minimise negative impact on consumers.

The Committee was also keen to create and promote:

- balance between receiving information and turning information into strategy or recommendations.
- expanding current SA Health reporting, with a consumer filter where and when consumers are involved.
- SA Health using the Committee as a brains trust and bringing Transforming Health work to the Committee.

Terms of Reference July 2016

As a result of the review, the Committee was subsequently renamed the Transforming Health Consumer and Community Engagement Committee, removing the word 'Peak' from the title. The Committee's role was amended as detailed below, while the scope remained unchanged.

Role

The purpose of the Committee is to provide SA Health with broad, strategic and representative consumer and community engagement as the consumer and community advisory body for Transforming Health. The Committee will communicate with consumers and communities to inform, consult and engage consumers in Transforming Health, and actively identify and communicate concerns and solutions through Transforming Health work groups and to the MCAG.



Committee members engaging in discussion as part of the review

Committee work plan 2015 - 2017

Based on the outcomes of the event *Transforming Health: a Workshop for Health Consumers and Carers*, held in May 2015, and in collaboration with SA Health, the Committee developed a work plan. Many of the recommendations and strategies were implemented by HCA staff on behalf of, and in collaboration with, the Committee. The table below summarises the priority issues for the Committee, the strategies to address those priorities, and any outcomes or outputs that were achieved.

Goal/issue	Strategies	Outcomes/ Outputs
Peak Committee establishment	Establish the Peak Committee in line with the principles, terms of reference, and selection criteria recommended at the May 2015 consumer and community workshop.	<ul style="list-style-type: none"> • Recruited membership • Established the Committee 2015 - 2017 • Endorsed the terms of reference • Reviewed the Committee and terms of reference 2016 • Last meeting of the Committee held in September 2017
Consumer and community engagement	Develop a consumer and community engagement strategy that includes: <ul style="list-style-type: none"> • promoting consumer participation in Transforming Health (TH) workshops and working groups • mixed media communication strategies and channels • community forums on diverse topics, held in a variety of locations • a statewide register of consumers and community members interested in contributing to health system improvements • information, education and health literacy. 	<ul style="list-style-type: none"> • Established a TH page on the HCA website • Used HCA's eNews to promote the Committee, projects, media and the communiques • Used HCA's Facebook for additional promotion • Members linked back to their representative community or LHN • Recruited attendees to workshops via eNews • Held three forums • Provided advice to HCA on their submission to the Senate Select Committee • Developed position statements on issues of priority

Goal/issue	Strategies	Outcomes/ Outputs
Access	<p>Identify, consult on and analyse key issues impacting consumer and community access to metropolitan hospitals including:</p> <ul style="list-style-type: none"> • transport • accommodation • disability access • rural and remote community access • information, education and health literacy. 	<ul style="list-style-type: none"> • Provided information and advice to SA Infrastructure on parking, access and facility design issues • Worked with SA Dental Services on access issues • Collaborated with RAH and nRAH on accommodation for country consumers • Committed to a focus on consumer-centred care as the key priority in addressing issues • Advocated for a better access solution to what already exists, and is being planned for, at the Queen Elizabeth Hospital • Lobbied the TH leaders to continually inform consumers about the infrastructure progress and its challenges • Disseminated via the HCA website infrastructure information provided to and requested by the Committee
Vulnerable populations	<p>Identify vulnerable population groups and develop specific engagement strategies for these groups, including:</p> <ul style="list-style-type: none"> • older people • people with a disability • Aboriginal communities • CALD communities • veterans • young people • people living with a mental illness • carers • identified priority populations. 	<ul style="list-style-type: none"> • Held ‘A conversation about Transforming Health’ CALD Forum • Requested statistics on the demographics of hospital users • Encouraged consistency in data collection and reporting in relation to demographics across the LHNs • Liaised with SA Health Aboriginal Leaders Network • Collaborated with Frank Lampard, Commissioner for Aboriginal Engagement • Collaborated with the Health Performance Council and joined the Aboriginal Leaders Group • Supported the establishment of the Aboriginal Experts Committee reporting to MCAG • Addressed mental health through a forum agenda • Promoted advocacy from membership, particularly around rehabilitation services reform • Advocated for the needs of country people using metropolitan hospitals • Provided specific support for Veterans Health Service reforms

Goal/issue	Strategies	Outcomes/ Outputs
		<ul style="list-style-type: none"> • Conducted a forum for the SA Mental Health Strategic Plan • Advocated in collaboration with Carers SA • Reviewed the SA Health Partnering with Carers Policy Directive
Information provision, community education and health literacy	Identify and develop health literacy strategies and opportunities that can be incorporated into Transforming Health.	<ul style="list-style-type: none"> • Conducted forums • Published communiques • Reviewed communications materials • Initiated a health literacy strategy and resources
Measures, indicators and evaluation	Partner with researchers and academics to identify, develop and promote evidence-informed performance indicators, measures and evaluation relevant to consumers and the community.	<ul style="list-style-type: none"> • Participated in two evaluation workshops • Held a members' workshop to inform the key consumer experience questions for the TH evaluation • Joined the TH Evaluation Working Group facilitated by SA Health and Medical Research Institute (SAHMRI) • Led the patient experience evaluation theme
Primary health and prevention	Monitor TH for the opportunity to connect to the primary health and prevention sector.	<ul style="list-style-type: none"> • Advocated for Adelaide Primary Health Network (APHN) and Country SA (CSAPHN) membership • Advocated for elevating primary care focus • Introduced Health Pathways at the Working Together Forum

Committee Meetings

The Committee met monthly on 23 occasions between July 2015 and September 2017. The average rate of attendance was 77 percent. Meetings were initially scheduled for three hours, however were reduced to two hours from October 2016 as a result of the Committee review.

Committee Forums

The Committee hosted three forums, including a CALD Communities Forum, a Local Health Network Forum, and a Working Together Forum.

CALD Communities Forum – A conversation with Lynne Cowan

The CALD Communities Forum was hosted in July 2016, in partnership with Multicultural Communities Council SA, with approximately 50 attendees.

The purpose of the forum was to provide an opportunity for CALD communities to engage with the Transforming Health program, and learn about the goal of this work. It also provided an opportunity to consider the issues raised by the CALD community as needing action. Three priority issues were identified:

- the ongoing requirement for robust comprehensive data
- the identification of CALD consumer needs on admittance to hospitals
- the gap in the current provision of interpreter services and the need for a *Use of Interpreters Policy*.

SA Health's Safety and Quality Unit has established a working group to conduct a proof of concept project to address issues around identification of CALD consumers and data management. HCA and Multicultural Communities Council SA are represented on this group. No progress has yet been made in relation to a *Use of Interpreters Policy*.



Attendees at the CALD Communities Forum

Local Health Network (LHN) Forum

Fifty-eight people attended the LHN and Transforming Health Consumer Engagement Forum, held on Wednesday 30 November 2016. Participants included Committee members, consumers and representatives from LHNs, the HCA team, and members of hospital consumer and community committees.

The overarching theme of the forum was: *'What do consumers have to look forward to in Transforming Health over 2017?'*

The Committee convened the Forum, with the purpose of providing information updates on what consumer networks could expect from Transforming Health in 2017, and to share the lessons learned and solutions developed at that point. It was also timely to collaborate with consumers in the early development of the Transforming Health Evaluation Framework, with particular reference to how consumer expectations and perceptions would be captured. HCA also saw this as an opportunity to gauge interest about intent and ways LHN consumer groups could engage in the future.

Two recommendations from the forum were endorsed by the Committee:

- That future forums such as this one are conducted either three to six-monthly, with an interactive format.
- That improvements are made when communicating to consumers and community about the upcoming Transforming Health events and changes.

Recommendation one has not been followed up. The Committee felt that there was not energy for another forum, and that one should not be planned unless there was a clear purpose. There was also a sense that Transforming Health was coming to an end, and the uncertainty impeded the ability to have a clear purpose.

Recommendation two was actioned through having an item on Transforming Health communications on the Committee's meeting agenda, and advocating for improved collaboration between SA Health's communications team, LHN communications teams and consumers.



Attendees at the Local Health Network Forum

The Working Together Forum – Mental Health, Primary Health and Transforming Health

Forty-seven people attended the Working Together Forum held on 17 February 2017. The forum was a collaboration between HCA and the Committee. Participants included consumers and carers, health professionals, general practitioners, non-government organization representatives, volunteers, students, SA Health staff, HCA's team and members of the Committee.

The forum focussed on the overarching theme, *Working Together: Mental Health, Primary Health and Transforming Health*.

HCA and the Committee convened the forum, with the purpose of providing an insight into how aspects of the consumer experience of health services connected and focused on consumer-centred care.

The forum objectives were:

- To inform consumers and the non-government sector about changes and priorities across the primary health, mental health and hospital sectors
- To identify opportunities for engagement and collaboration.

There was general agreement to focus on two recommendations:

- To work towards community empowerment through health promotion and health literacy, by collaborating with the Primary Health Networks and the relevant theme of the Thinkers in Residence program, which is facilitated by the Don Dunstan Foundation.
- To use this type of forum to build collaborations and address capacity building in the community.

These recommendations have been progressed, with HCA developing and sharing resources relating to health literacy for consumers and health care providers.



Panel of speakers at the Working Together Forum – Mental Health, Primary Health and Transforming Health

Committee communications

In October 2015, the Committee circulated its first communique. The purpose of the communique was to provide information to the community about Transforming Health and the activities of the Committee. The circulation of the communiqués included promotion through HCA eNews, LHN consumer advisory committees, and other organisations represented on the Committee.

The content of communiqués was agreed at the end of meetings, then drafted by HCA staff and circulated to the membership for editing before public circulation. Sixteen communiqués were circulated through the term of the Committee.

Committee members' individual experiences 2015 - 2017

As part of the Committee's final review process, HCA prepared four questions, and in August 2017 distributed these by email for members' responses:

- What were the impacts of the Committee?
- What worked well for you?
- What were the challenges?
- How could things work better in the future?

Ten of the 14 Committee members eligible to provide feedback contributed to the review. A selection of comments is included below.

What were the impacts of the Committee?

Almost half the Committee members considered that the biggest impact made by the Committee was on SA Health. Their thoughts are best summarised by these comments:

"I think the main impact was reminding SA Health to take note of consumer perspectives on the changes they were making. Issues that may have seemed trivial to them in the scheme of major change (eg parking) gained more prominence. Also, it reminded them of the need to be accountable to consumers and the community."

"Helped bring consumer engagement to the table across SA Health and recognise the importance of the consumer voice in planning, evaluation and co-design."

Several other members were not certain that the Committee had any real impact, although some valued the connection to the model of care working groups.

"To be honest I don't think we had any impact on the how the TH changes went; if anything, it gave us the platform to be invited to other workgroups that then had an impact."

What worked well for you?

The connection that the Committee had to SA Health executives, the Ministerial Clinical Advisory Group and the Health Minister was considered vital to the effectiveness of the Committee. The relationships with SA Health executives were valued for the two-way communication, as evidenced by these comments:

"I liked the fact that SA Health always sent at least one senior member of their workforce to our meetings. I felt that we were listened to and that some of our suggestions were picked up and acted upon. Having that opportunity to interact with Vickie Kaminski and Lynne Cowan on matters that were important to us was invaluable."

“The ability to sit around the table with some of the decision makers in SA Health ie Vickie Kaminski, Lynne Cowan, Michele McKinnon, Penny Thyer, and share information, concerns and receive correct information directly.”

“The ability to escalate concerns to the Transforming Health Ministerial Clinical Advisory Committee.”

Others valued the opportunity to network with consumers from across local health networks and other parts of the health system.

What were the challenges?

The most significant challenge for Committee members was the time that it took to get clarity on the role of the Committee. It was felt that neither SA Health nor the Committee members really had clarity on the role and purpose of the Committee for the first year, and that consumer engagement was considered an afterthought. All decisions around infrastructure were decided without any consumer engagement. At times, members felt that their participation was tokenistic. This is best summed up by the following member feedback:

“The main challenge, I think, was what was our role from the Department’s and HCA’s perspective? Should we have consulted more with consumers and the community? Were we there to comment on an agenda put to us or should we have raised issues ourselves? To what extent were we expected to communicate out to the community? At times, I felt we were ‘consulted’ on issues already determined. We clearly saw communication re TH as a major concern but it took a long time to get a communication strategy underway. The department representatives were diligent, honest people who often spoke frankly but it was hard to see our suggestions and concerns influencing outcomes.”

“I think this group was doomed before it started. The consumer voice was only brought to the TH project part way through. To engage consumers correctly they need to be at the table from day one. This would (have given) the Committee more purpose and it may have been able to do more than look at reports and be told what has been decided and how it will work.”

“I felt the communication flow between planning, outcomes and evaluation were difficult and we couldn’t see the difference we made sometimes – I still wonder if we DID make a difference!”

How could things work better in the future?

The main message that Committee members contributed about health consumer engagement in the future is that engagement needs to start from the beginning and have a clear purpose, with links to real decision making. This is reflected in the following comments:

“We need to continue to lobby strongly for the value of including consumers in front line decisions in health that could affect them, and deliver on well thought out and substantiated input. Also, I think we need to not just be grateful that we’re included, but stand firm for clarity on our role and expected outcome. I saw glimpses of this but it’s a challenge for the future!”

“Earlier engagement with consumers and community to ensure that partnering occurs from the start.”

“Acknowledgement that consumers and community are amorphous and therefore early thought about how best to access; in particular vulnerable groups, such as Aboriginal & Torres Strait Islanders.”

“Realisation of true partnerships not tokenism at ALL levels.”

“Better linkages with program, advice and outcomes – wasn’t always clear exactly what impact we had on the progress.”

SA Health staff experiences of the Committee 2015 - 2017

SA Health staff were asked to respond to the same four questions provided to the Committee members. Five staff were approached with three providing input.

What were the impacts of the TH CCE Committee?

Feedback from SA Health staff reflects the perspective of the Committee members who indicated that the Committee provided an opportunity for SA Health staff to learn to work more collaboratively with consumers, and that the opportunity to develop relationships was important. They also recognise that consumer engagement did not start early enough. This is reflected in the following comments:

"I think the Committee provided an opportunity for regular dialogue between its members and very senior staff.... in SA Health re Transforming Health. There was a valuable opportunity to build relationships and be continually reminded/awareness raised regarding what constitutes successful consumer engagement and how to work in partnership. Prior to this I don't recall us having a forum which allowed consideration (the balcony view) and dialogue across multiple projects which have had consumer representation."

"I think sometimes we use the Committee to "legitimize" our actions and we need to be better at earlier discussion and involvement, not asking for endorsement once a decision has already been made."

"Having a dedicated Committee was an integral part to the success of consumer engagement in Transforming Health as it required accountability of SA Health staff who attended and reported on progress but also enabled regular discussions on the consumer aspects."

"It was a safe environment which allowed robust discussions, and this then ensured a better outcome. I felt members could contribute to full potential whereas often in committees people can hold back if it doesn't feel safe."

What worked well for you?

The level of trust in the Committee, the connections to the Local Health Networks (LHNs) and Ministerial Clinical Advisory Group (MCAG), and members' contributions to the development of models of care were highlighted by SA Health representatives as working well. This is reflected in the following comments:

"I think there was an effective level of trust and respect established to support the partnership between this Committee and Department staff. Members of the Committee who were also members of LHN Consumer Advisory Committees were important in my view as they provided the best opportunity to tie in what was occurring in LHNs with regard to Transforming Health."

"Participation in the gallery walks, the development of models of care and the representation at MCAG."

"Having a regular high level committed Committee ensured that we had the input needed - but it also kept us honest."

What were the challenges?

SA Health representatives indicated the late engagement of consumers in Transforming Health, and a lack of role clarity presented challenges to the effectiveness of the Committee. This is reflected in the following comments:

"Earlier involvement of consumers and more meaningful involvement- not just a "tell and sell" opportunity."

“What we asked the Committee to do for SA Health and what was needed for Transforming Health was sometimes blurred. Sometimes it was not clear regarding what were the concrete pieces of work versus what was advice and/or advocacy. An additional challenge was that we were creating the framework for consumer engagement and co-design in Transforming Health as we were already going through the Transforming Health program, which creates risk and opportunities.”

“At times, I felt that the frequency of once a month was a little too much, perhaps bi-monthly would have worked better particularly in the latter stages. I also felt that LHN level understanding within the specific TH project teams responsible for TH projects was not impacted as much as it could have been.”

How could things work better in the future?

In the future, SA Health representatives would like to see involvement happen earlier, and across management committees, not just at project level. They would also like to engage with consumers at a deeper co-design level, where they can take risks and be more innovative, as evidenced in the following comments:

“Addressing the earlier involvement piece”.

“Having a better understanding of what consumers can offer a process like this and how ascertaining consumers want to be involved, instead of us deciding what that involvement will look like.”

“There has been a maturing in the relationship between SA Health and HCA as well as a building of capability in consumer engagement and co-design due to Transforming Health. In the future SA Health needs to ensure that consumers are included in management committees as well as at project level.”

“As part of this I would like to create a safe space to take additional risks in the projects around how we work together. I would like to set up innovative projects where we can be safe to fail. Then we can take more risks in how we conduct the project instead of always designing them conservatively to be fail safe.”

Conclusion

With the initiation of the review and reform program known as Transforming Health in 2014, the delivery of hospital services in Adelaide, South Australia were put under the spotlight. Fifty two clinical standards were identified as being unmet due to the configuration of the public hospital system. The development of a review and reform program, based on clinical data and evidence was a much-needed response to reduce avoidable deaths and injuries in South Australian hospitals.

Consumer and community engagement is an essential element of a contemporary health system. Consumer engagement in Transforming Health would have benefitted from earlier implementation, a clearly articulated purpose and more integrated application. Involvement of consumers in the review and development of new models of care was well regarded.

The purpose of the Consumer and Community Engagement Committee was to provide SA Health with broad, strategic and representative consumer engagement and advice. In the first year of its term the potential of the committee was not met. Early and authentic engagement with effective links to decision makers in SA Health will improve collaboration in future health strategy and reform.

HCA thanks all involved in consumer engagement in Transforming Health. We particularly thank the consumers and community members who volunteered their time and provided their wisdom on the Transforming Health Consumer and Community Engagement Committee.

Recommendations

It is recommended that HCA present a consumer engagement proposal to the Minister for Health and Ageing to address future health strategy and reform. That proposal should encompass the following:

- Development of a consumer and community engagement committee to provide advice on health strategy and health reform.
- Committee membership should include individual consumers and community representatives from community stakeholder groups.
- Senior executives from SA Health should attend, along with other relevant SA Health staff who would be equal members of the committee to reflect true partnership.
- Primary Health Networks should also be represented.
- Consumers should be engaged from the start of any reform process, utilising co-design principles and processes
- HCA and a consumer should co-chair the committee, with HCA adequately resourced to provide executive and project support to the committee
- The committee should have a clearly articulated purpose and scope
- The committee should have links to the Partnering with Consumers and Community Committee and Local Health Networks.

Appendix One: Transforming Health Consumer and Community Engagement Committee Terms of Reference July 2016



Transforming Health Consumer and Community Engagement Committee Terms of Reference

1. Background

SA Health has committed to working with and through the Health Consumers Alliance (HCA), the Local Health Network Governing Councils and Consumer Councils, and the Health Advisory Councils to consult with consumers, consumer representatives and communities. The Committee will be the key mechanism for enhanced consumer and community consultation and engagement in Transforming Health.

HCA as the peak body for health consumers in South Australia has been invited by SA Health to convene and chair the Consumer and Community Engagement Committee for Transforming Health.

The principles, membership, selection criteria, methods of engagement, priority actions and recommendations to establish the Committee were developed by community participants at a workshop held in May 2015.

The top ten principles recommended to guide the establishment and operation of the Committee and Strategy are:

1. Consumer centred and directed
2. Authentic partnership not tokenism
3. Accountability
4. Diversity and Inclusion
5. Equity
6. Accessibility
7. Evaluation and continuous improvement
8. Transparency
9. Trust, integrity and respect
10. Wellness and prevention.

Health literacy will be integral to the operation of the Committee and the strategies it recommends.

2. Role

The purpose of the Committee is to provide SA Health with broad, strategic and representative consumer and community engagement as the consumer and community advisory body for Transforming Health. The Committee will communicate with consumers and communities to inform, consult and engage consumers in Transforming Health and; actively identify and communicate concerns and solutions through Transforming Health work groups and to the Ministerial Clinical Advisory Group.

3. Scope

The Committee will address hospital and inpatient services as they relate to Transforming Health. A work plan with priority actions will guide the operation of the Committee. This Committee will also keep a watching brief on primary health and other aspects of the health system as they become part of the Transforming Health agenda.

4. Chair

The Chief Executive, Health Consumers Alliance will chair the Committee. In the absence of the Chair, the Deputy Chair will be a representative of Health Consumers Alliance SA as nominated by the Chair.

5. Membership

The membership will consist of up to 16 health consumers and community representatives with interest and experience in consumer and community participation in health, in addition to the Chair.

Membership will be selected through an open recruitment process including representatives nominated to represent particular populations or LHN's. The Committee can also invite individuals to join as needed. Membership will be reviewed annually by HCA.

SA Health and HCA staff will attend as observers and supporters of the Committee, however they do not have voting rights.

A quorum will be 8 members or half plus 1 of the active members, whichever is the lesser.

6. Membership criteria

- understanding of consumer and community experiences of service access, safety and equity issues
- understanding of the public hospital clinical and service systems
- ability in group work
- ability to take on an area of interest and link with consumer groups or priority populations
- understanding of Transforming Health and its principles
- participated in recent consumer advocacy or representative training.

7. Participation requirements

- Attendance and participation at regular committee meetings
- Following 3 absences, a member will meet with the Chair to discuss membership
- Provision of oversight, advice on and review of Transforming Health initiatives, activities and documents to ensure they reflect the best interests of consumers and community.

8. Reporting and Communication

Committee minutes or activity reports will be made available to SA Health executives and the Minister for Health.

The HCA Chief Executive and HCA Board Chair meets with the Health Minister bi-monthly and may engage with the Minister on issues raised through the Committee.

The Committee will agree on issues to be included in a Communique for communicating with member networks and the wider public. HCA to draft the communique and circulate within one week of the meeting so that member feedback can be incorporated into the final communique that is circulated with the meeting minutes.

Members are advised to refer requests for comment from the media or requests external to their networks to the Chair of the committee.

The meeting agenda will provide opportunity for members to provide information on the activities and outcomes of the Ministerial Clinical Advisory Group (MCAG) work groups.

The Chair represents the Committee on MCAG and the Manager, Clinical Engagement and Strategy, Transforming Health provides a formal link with MCAG.

9. Frequency of Meetings

Meetings will be scheduled every month. The Chair may convene additional meetings to consider business which may require urgent consideration. If necessary, the Committee may also make decisions out of session electronically. The Committee may also opt to schedule consultation Forums with specific communities if required.

10. Meeting Papers

The Chairperson will set the agenda. The agenda and supporting papers will be circulated to members at least one week prior to each meeting. Minutes will be circulated within two weeks of meetings. Standing agenda items and a work program with measurable goals will drive the proceedings of each meeting.

11. Proxies

Members requiring a proxy must nominate their proxy to the Chair and ensure they are kept informed about the business of the Committee. The Chair must be notified in advance if a proxy will attend a meeting.

12. Reimbursement

Consumer and community members will be reimbursed for reading time, meeting attendance, carers leave, and costs associated with travelling to the meeting. This reimbursement will be in accordance with the SA Health policy for the Government of South Australia. Non- Employee Reimbursement forms will be provided at each meeting.