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Front cover: A word cloud of the principles proposed by workshop participants. The bigger the word the more popular the principle.

Summary

This report provides the advice, priority actions and recommendations from the Community Workshop held on 7 May 2015 to establish the Peak Consumer and Community Engagement Forum for Transforming Health. Over ninety participants joined the Minister for Health, the Acting Chief Transformation Officer, the Health Consumers Alliance Board Chair and Chief Executive, members and staff of Health Consumers Alliance of SA (HCA) and SA Health staff.

Workshop participants identified the principles, selection criteria, methods of engagement, priority actions, recommendations and initial strategy advice to establish the Forum as an integral part of Transforming Health. They are as follows:

Principles to inform and guide the establishment of the Forum and Strategy

The top ten principles recommended to guide the establishment and operation of the Forum 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.

Selection criteria for Forum membership

It is recommended, that there be a limit on membership, and the Forum should ensure a diverse mix of consumer and community representatives through a structured process including:

- Aboriginal communities; multicultural communities; young people; older people; veterans; rural communities; lesbian, gay, bisexual, transgender and intersex communities; and carers
- Priority populations and communities encompassing a diverse mix of health consumer experience including, but not limited to: people living with chronic illness and complex conditions; people living with a disability; people living with a mental illness; and other vulnerable communities or populations
- Local Health Networks: Governing Councils, Consumer Councils and Health Advisory Councils
- Relevant peak consumer and community organisations.

Knowledge, skills and experience:

1. Understanding of public hospital clinical and service systems
2. Understanding of consumer and community experience of service access and equity issues
3. Understanding of consumer and community engagement

4. Competency in consumer leadership, advocacy and representation
5. Capacity to link to a larger consumer or community constituency
6. Capacity to take on an area of interest and link with consumer groups or priority populations.

The Forum may establish sub committees, networks, communication platforms, strategies with specific focus as required, and may co-opt consumers, community members and representatives with relevant experience as needed.

Methods of engagement

Participants recommended innovation and evidence informed engagement methods, including a mix of communication mechanisms ranging from regular face to face forums, through to electronic consultation and deliberation. Participants also identified the need for proper committee structures and governance processes to be established and for the Forum to be appropriately resourced. In this section of the report are further details about the specific actions, processes and resources recommended in establishing the Forum.

Priority actions and recommendations

Priority actions recommended include:

- endorsement of and adherence to the principles identified
- development of an engagement strategy and communications plan
- development of an action plan with goals, timeframes and performance indicators to be reported publically
- development of a terms of reference for the Forum
- confirmation of the Forum's position in the governance for Transforming Health.

Participants also voiced strong opinion that all four groups established to govern the implementation of Transforming Health should have consumer representation and overlapping terms of reference and access to their reporting mechanisms.

HCA will engage with the Minister, SA Health and Transforming Health team to discuss the following outcomes from the conference:

1. The top ten principles to inform a Terms of Reference and guide the Forum
2. Forum membership selection criteria and recruitment process
3. Priority actions and other recommendations for the Forum
4. Forum processes to achieve the priority principles, including communication and accountability mechanisms.

HCA thanks all who participated in this important step in Transforming Health.

Introduction

The Health Consumers Alliance (HCA) and SA Health invited consumers and community members to attend the workshop held on 7 May 2015, to inform the establishment of the Peak Consumer and Community Engagement Forum and Strategy. Over ninety participants joined the Minister for Health, the Acting Chief Transformation Officer, the Health Consumers Alliance Board Chair and Chief Executive, members and staff of HCA and SA Health staff. As the peak body for health consumers and health consumer organisations in South Australia, HCA facilitated the conference and will chair the Peak Consumer and Community Engagement Forum (the Forum) in Transforming Health.

The purpose of the workshop was to gain information and advice on the first steps required in establishing the Forum. The first section of the workshop program comprised an update from the Minister of Health and SA Health on the Transforming Health program and its implementation. The latter section of the conference was structured around the participants providing advice and feedback on what could be the principles, membership, key actions and recommendations for the Forum.

This report brings together all the information contributed on the day with some thematic analysis and recommendations for the next steps. Appendix 1 provides the questions raised and comments made by the participants over the day, they relate to the Health Minister's presentation, the presentation by the Acting Chief Transformation Officer and thoughts stimulated that were not specifically aligned to the structured program.

Background

The Delivering Transforming Health – Community Information Summary released in February 2015 outlines SA Health's commitment to creating a health system where what is best for health consumers comes first and where consumers will be central to every aspect of designing and delivering Transforming Health. SA Health will work with and through the Health Consumers Alliance of South Australia, the Local Health Network of Governing Councils and Consumer Councils, and the Health Advisory Councils to consult with consumers, consumer representatives and communities. Through consultative processes they will identify issues that are important to our community and solutions for how to deliver the best care, first time, every time.

In the Community Information Summary document SA Health stated its commitment to undertaking the important and necessary work with consumers and communities to make the best health system that we can for South Australia. If decisions are difficult but necessary, they will be worked through so that whatever we do improves the health and outcomes for South Australians.

"Whilst this phase of Transforming Health is about improving our metropolitan hospital system, there is also commitment to planning and developing strategies with our partners in primary health care, to keep people healthy and out of hospital"

"We will develop, foster and maintain a truly community and consumer centered healthcare system by setting up a Peak Consumer and Community Engagement Forum for Transforming Health to guide and direct how we engage with consumer and community groups. This will assist

us design and deliver health services that reflect the values and needs and preferences of health consumers, carers and the community”¹

HCA has been invited to Chair the Forum.

HCA understands the purpose of the Forum will be to provide SA Health with broad, strategic and representative consumer and community engagement: communicating with consumers and between communities; to proactively identify concerns and solutions; and match the intent of Transforming Health with community aspirations for best care, first time, every time – in the manner that communities prefer.

In accordance with advice received from the 7 May conference, and as informed by research evidence, it is proposed that the Forum work primarily with and through existing consumer structures and representative bodies. HCA recommends a related consumer and community engagement strategy is established and resourced to sustain the Forum initially through to 2018.

¹ Community Information Summary – Delivering Transforming Health Proposals Paper, February 2015

Transforming Health – Commitment to Consumer and Community Engagement: Minister for Health, Hon Jack Snelling MP

The following is a summary of the Minister's address to the conference with an overall response to participants.

The Minister recognised the day as an important step in developing an inclusive engaging and collaborative governance structure for Transforming Health and thanked the strong turnout of passionate and enthusiastic South Australians.

He noted that since he was last invited to speak at the Health Consumers Alliance Annual General Meeting in November 2014 a lot of progress has been made in putting quality first in our healthcare system.

He referred to The Delivering Transforming Health – Summary document that was released in March 2015 which outlines the next steps for Transforming Health, "These are based on extensive input, feedback and ideas provided by the community, our staff and the industry"

"At the broadest level, the South Australian Government places a special emphasis on community engagement and conversation – involving people in the decisions that affect their lives and giving them a genuine role in making such decisions".

He noted programs such as the Better Together Program bringing the community's voice into Government decision-making.

"Better Together enables the South Australian Government to make better decisions by bringing the voices of citizens and stakeholders into the issues that are relevant to them.

He also recognised the more specific work in SA Health, the development of *A framework for active partnership with consumers and the community* to ensure there are mechanisms in place to actively engage with consumers and the community in order to meet their needs, and develop appropriate services.

"However we want to do more to formally embed consumer engagement in the governance structures that will support Transforming Health.

We propose that the Peak Consumer and Community Engagement Forum for Transforming Health is established to guide and direct how we engage with consumer and community groups"

The Minister described SA Health's successful partnership with Health Consumers Alliance. As the peak body for health consumers in South Australia, the Health Consumers Alliance supports the South Australian community through:

- Improving health literacy and the recognition of health consumer rights;
- Advocating for consumer centred health policy and practice; and
- Supporting consumer advocates in partnering for planning, design and evaluation of health services.

"The Health Consumers Alliance is uniquely placed to assist SA Health in facilitating community engagement in the health system, and I have every confidence in their ability to work with consumers to co-design an effective Peak Consumer and Community Engagement Forum and Strategy for Transforming Health".

“In summary he stated Transforming Health is about delivering a system focused on continuous improvement, a system that supports innovation and a system that is committed to quality.

We cannot achieve these goals without the participation of consumers and the community”.

An overview of the Minister for Health’s response to questions:

- Clinical engagement structures in SA Health are being reviewed to align with the governance structures and clinical priorities of Transforming Health.
- The consumers who have contributed through the Clinical Networks and all our other mechanisms are dedicated, passionate individuals and we have every intention of making sure they remain engaged and have multiple opportunities to be involved in Transforming Health
- Under Transforming Health there are many clinical improvement projects that need to be developed.

Transforming Health – Current status including governance and timeline: Acting Chief Transformation Officer SA Health Naomi Dwyer

Adjunct Professor Naomi Dwyer provided current Transforming Health program information, congratulated consumers on the advice received so far, and forecast the challenges she expected in this exciting time of Transforming Health.

Following is a summary of major points from her presentation:

“Going forward from today and over the following four years transformational effort will be required. We know we have wonderfully dedicated staff, and many areas of clinical excellence, but we also recognised significant opportunities for improvement”

Naomi acknowledged the many consumers who took the opportunity to share thoughts throughout the Transforming Health consultation process, providing thoughtful reflections and recommendations about the values and governance attributes that characterise high performing health systems.

“You told us that:

- Reform must put patients and patient outcomes first;
- The transformational effort must extend beyond metropolitan hospitals to the full continuum of the health and related care systems;
- Consumers and community should be integrally involved in co-designing, evaluating and monitoring the reform;
- Reconfiguration of services should not happen until capacity is created.
- Cultural change, backed up by resource and system changes will be pre-requisite enablers;
- There had been effective communication, not to be mistaken for engagement, and arising from this, and
- A mechanism to inform and ground TH in a patient directed, continuum of care, and whole of system mode is required.”

Naomi stated these views were heard, and significantly influenced the commitments that were subsequently made in the next steps of Transforming Health to a truly consumer and community centred system of healthcare

“In this early stage of a 4 year transformation program our efforts have been focused on putting in place the essential pillars of success – that is, the accelerated clinical redesign process to support the expected surge in activity this winter, creating the framework for key stakeholder engagement, developmental work on priority models of care with clinicians and consumers, and capital planning for the significant investment in new and improved facilities”

“No aspiration to transform a healthcare system can be realized without an authentic partnering with consumers and community”

SA Health is well advanced on this journey. Its commitment is expressed through state-wide policy, the partnership with the Health Consumers Alliance, and the empowered consumer structures and representative bodies embedded within existing Networks.

There is a clear commitment through TH to maintain, foster and develop a truly consumer and community centred system of health care, with a number of assertive actions to translate this intent into practice.

“We have left the how of our consumer and community engagement strategy for Transforming Health deliberately open, and that is so it could be co-designed with you”.

Naomi acknowledged that “today is about exploring the principles that will shape our consumer and community engagement, what it looks like, how it is facilitated, how it applies across our services, our engagement methods such as social media and other platforms, the role of health literacy, consumer involvement in the design of new models of care and hospital design and building initiatives, how we ensure respectful and innovative practices for Aboriginal and other vulnerable populations, how we will measure and evaluate the impact and success of TH, and share this with community” She also reminded us to consider how we sustain and nurture the excellent engagement that already exists, and not burden it with non-value adding overhead.

In summing up she thanked everyone for attending and trusting in this process and quoted Roosevelt:

“It’s about keeping our eyes on the stars and our feet on the ground.”

Transforming Health: Overview of the Community Conference Program: HCA Chief Executive Michael Cousins.

The Chief Executive of HCA, Michael Cousins welcomed the consumers and community members for joining HCA and SA Health to contribute to the program and in particular to advise on the next steps in establishing the Peak Consumer and Community Engagement Forum.

He said “Now is the time for peak consumer and community representative bodies, Local Health Network governing councils, consumer councils and Health Advisory Councils to get more involved in Transforming Health by engaging with their constituents and communities of interest, partnering with the health system to co-design the solutions to the challenges raised by the Transforming Health advisory committees so we can ensure the consumer and community voice and views are heard and incorporated”

Michael outlined the purpose and goal of each of the three conference workshops and introduced the table leaders who will guide the activities.

The first workshop is designed to establish the principles that will inform and guide the Forum and Strategy.

The second conference workshop will focus on the membership of the Forum, Michael reminded participants about best practice size of such working groups, which is around 10 or 12 members. Given this advice, the other task of this workshop was to carefully consider and define the Forums methods of engagement, the ways these 10 or 12 members could work inclusively, effectively and efficiently with diverse consumer and community representatives.

He described the final conference workshop as less structured and more about coming up with good ideas and advice on what the priority actions and key issues could be for the Forum and Strategy.

In summing up Michael concluded "Health consumers, carers and the community understand the health budget is finite and are keen to work with the Government, SA Health and clinicians to develop a sustainable, world class health system that places consumers at the heart of health care. Health consumers have expressed the desire to become a central part of the solution and constructively challenge the hospital system about service principles, quality, equity, access and performance"

Workshop 1: Principles for the Forum

What principles should inform and guide this Consumer and Community Engagement Forum and Strategy?

Participants were asked to identify the principles they thought important to inform and guide the operation of the Forum and Strategy. Ten tables of participants were then asked to prioritise the top five at each table.

Table 1: Top five principles from each of the ten tables

Accountability	Trust and mutual respect	Authentic partnership	Equity of outcomes not just equity of access	Equal weight to all voices
Accountability for roles, structure, communication, evaluation	Equity: Wellness and population health focus	Forum has a public voice	Partnership	Proactive cultural change facilitate it in the system
Diversity of cultural experience	Self determination	Integrated access: broad definition of health	Person centred not patient centred	Focus on vulnerable people
“Real” based on lived consumer experience	Transparent	Accessible	Inclusive	Engaging
Authentic not Tokenistic: Literacy about the Forum	Accountability linked to Transparency	Respectful valuing of consumers	Diversity of representation	Partnership: building capacity
Diversity of Engagement	Patient and Consumer centred	Accessible: access to information	Partnership: respect existing representative bodies	Support to participate and shared decision making
Integrity: Do what you say you will	Equity and Inclusion	Treat the person not the problem	Consumer and patient directed health systems	Invest in Prevention
Accountability and Transparency	Champion for the users of Transforming	Consumer is the captain of consumer	True partnership in the design of Transforming	Ensuring the public understand what

	Health services	centred care	Health	the Transforming Health Quality Principles mean
Consider consumer, person and family centred care: patient is hospital	Dignity: information: what are my needs?	Diversity accessible safe care	Authentic equal respectful engagement	Effective efficient outcomes: measures to be defined, improvement feedback
Patient centred care	Continuous improvement: measure evaluate, improve	Accountability, Transparency	Partnership not Tokenism	Broad representation

Top ten principles recommended

The top ten principles recommended by workshop participants to inform and guide the operation of the Forum and Strategy are:

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

Participants made other suggestions for principles to guide the work of the Forum which were not prioritised in the top ten – these are attached in appendix 2.

Workshop 2: Forum membership and methods of engagement

Following an overview from the HCA Chief Executive on some of the thinking around membership (appendix 3), and on what best practice numbers are likely to be for such a committee, participants identified the membership they considered appropriate.

Table 2: Suggested Forum membership

Aboriginal Health Council SA
SA Council of Social Service
Multicultural Communities Council SA
Youth Affairs Council SA
Council of the Ageing
Carers SA
The metropolitan and country Local Health Networks Consumer Councils
Adelaide and Country SA Primary Health Networks
Veterans Health Advisory Council
SA Ambulance Service Consumer Council
Health Consumers Alliance SA

More so, participants opted to provide advice on the selection criteria to appoint members to the Forum.

Table 3: Criteria for consideration when selecting members for the Forum

Members should be consumer groups not service providers	Mental Health consumer representation is required
Line of access for disengaged young people	Representation of community engagement research
Ability to constantly refer back to bigger constituency through both peak bodies and Forum events	Members need experience as a consumer representative and links to the community
Members need links to parts of SA Health being affected by Transforming Health	Members need to represent drug and alcohol consumer organisations
Members need to take on the role of diversity for example the refugee voice	Members experiencing family violence
Members should have to apply and not be nominated	Ensure it is not just peak body representation
Members must have drive, commitment, passion and connection to community groups	Members should have some relevant expertise and knowledge of the SA Health System
Members should respect diverse and adverse opinion	Accountability of members that they need to feedback to the consumers and community
Membership must be across those with cognitive impairment	Membership needs to work out how everyone will have access to their work
Membership needs to align with the principles developed today: authentic and representative	Members should be from existing mechanisms and networks
Members should value add to existing good practice	Membership should consult with the State Commissioner for Aboriginal Community Engagement
Members must be interested in reducing beurocracy and improving health literacy	Membership takes on portfolios of interest
Membership should be clear about reporting mechanisms	Most disadvantaged in our population should be represented by the members
All those applying should have knowledge	Members need to be from new blood not the same outcome from the usual SA Health

and commitment to vulnerable populations	structures
Membership need to avoid the same people representing same consumer issues who are not solutions focussed	In the first cut of membership geographical distribution needs consideration
While carers have the right to speak out they are not suited as Forum members	Membership needs capacity to co-opt as needed
Membership does not need to duplicate the LHN Governing Councils with the Consumers Councils	No need for representation from the PHC networks at this point
Caution against using the guiding diagram as it is exclusive	Membership needs to ensure it has a grass roots connection and not just government sponsored organisations
Membership needs to include a mix of skills with consultative skills a priority	Members needs to value evidence based community engagement work

Selection criteria for Forum membership

From the discussion and written feedback on the day, It is recommended, that there be a limit on membership, and the Forum should ensure a diverse mix of consumer and community representatives including:

- Aboriginal communities; multicultural communities; young people; older people; veterans; rural communities; lesbian, gay, bisexual, transgender and intersex communities; and carers
- Priority populations and communities encompassing a diverse mix of health consumer experience including, but not limited to: people living with chronic illness and complex conditions; people living with a disability; people living with a mental illness; and other vulnerable communities or populations
- Local Health Networks (Governing Councils, Consumer Councils and Health Advisory Councils)
- Relevant peak consumer and community organisations.

Knowledge, skills and experience should include people with:

1. Understanding of public hospital clinical and service systems
2. Understanding of consumer and community experience of service access and equity issues
3. Understanding of consumer and community engagement
4. Competency in consumer leadership, advocacy and representation
5. Capability to link to and represent a larger consumer or community constituency

6. Capability to take on an area of interest and link with consumer groups or priority populations.

The Forum may establish sub committees, networks, communication platforms and strategies with specific focus as required, and may co-opt consumers and community members with relevant experience as needed.

Links to the Primary Health Networks will be sought at a later date, when they are established.

Methods of engagement

Participants recommended innovation and evidence informed engagement methods, including a mix of communications mechanisms be utilised ranging from regular face to face forums, through to electronic consultation and deliberation. Participants also identified the need for proper committee structures and governance processes to be established and for the Forum to be appropriately resourced.

Specifically participants recommended:

Communications and media:

- Use local communication networks
- Strategic Partnerships at an organisational level
- Must be web focussed
- Develop an online patient network
- Have quarterly Transforming Health Community Forums similar to community cabinets
- Need a social media strategy
- Develop a NESB communication strategy
- Develop virtual subcommittees
- Ensure there are technology tools for consultation like 'Bang the Table', Assess the ACCC, "Like your Say"
- Develop advertising strategy and material, articles and news items
- Ensure the Forum has a system to educate and improve Health Literacy
- Don't waste money on leaflets and flyers – no one reads them!
- Develop an on line chat focus
- Consult with key CALD groups, use the ethnic media
- Use website as an engagement tool, webinars
- Use ways of engaging with people who use not IT platforms

Process:

- Use a strategic approach by starting with the TH strategic plan deliverables to structure the consultation
- Have an agenda or engagement plan that is issues and outcomes based
- Engagement outcomes
- Some face to face meetings
- Ensure key people support the Forum and Strategy and are available for questions
- Consolidate existing Forums

- Develop the terms of reference to match the achievable goals
- Ensure the chair is to make this an accessible and open engagement Forum
- Ensure the agenda has standing items
- Use existing Forum mechanisms
- Ensure the Aboriginal representation is broad
- Early construction of materials for consultation purposes
- The Forum operation needs to be authentic of politics and power.
- The Forum won't have all the expertise, develop task forces and networks
- Community forums with community groups
- Have a stakeholder gathering such as this every three months
- Take advantage of all communication methods
- Develop innovative ways of meeting and the meeting process
- Consider weekend workshops with plenary structures
- Governance structure of the Forum to be clarified, will it have working groups, specific population focus
- Members will need induction, training, support, board experience
- Community will expect a proper process of appointment
- Forum members will expect to do meaningful work
- Ensure the meeting has an agenda and minutes.

Resources:

- Ensure adequate resources are allocated to meet the expectations of the Forum's
- Make sure there are resources allocated for the Forum that meet the needs of the deliverables
- Quality of the engagement is dependent on the resourcing
- This must be funded.

This advice and recommendations on methods of engagement will be provided to and assessed by the Forum's membership when it is established.

Workshop 3 Priority Actions and Recommendations for the Forum and Strategy

Priority actions and recommendations

Priority actions recommended include: the endorsement of and adherence to the principles identified; development of an engagement and communications plan to enable strategy; development of an strategic action plan with goals, timeframes and performance indicators reported publically; development of terms of reference for the Forum; confirmation of the Forum's position in the governance for Transforming Health.

The participants also voiced strong opinion that all four groups established to govern the implementation of Transforming Health; Research, Clinical, Union and Consumer and Community; should have consumer representation and overlapping terms of reference and access to their reporting mechanisms.

Table 4: Describes the top five priority actions for the Forum

Develop a timeframe and action plan	Ensure clinicians understand consumer centred care	Important there is a clear briefing for the Forum from TH Board	Collate Information to develop action plan	Identify the required resources
Communicate Communicate Communicate	Define the outcomes required	Define the "so what" according to consumers	Develop the reporting publically mechanism	Use qualitative stories and experiences of consumers
Design a Forum that has high levels of engagement with marginalised groups	Set up the TOR to match the TH requirements of the Forum	Develop an action plan with outcomes, a communications plan and a monitoring and evaluation strategy	Make sure members have the capacity to engage	HCA to establish an information hub
Vigilance to keep it real and not singular consumer experience	TOR focus on the cultural change required for person centred care	Have a Forum member on the TH Board	TOR has members' responsibilities and two way communication	Members appointment for 12 months and then review
Formalised system for engagement	Settle the principles and governance	Move from rhetoric to action	Communicate the outcomes this	Develop the role and job statement

and consultation	structure		workshop	for the members
Engagement plan to have Goal, purpose, strategies, KPIs and review and evaluation	Collate a more comprehensive list of all consumer groups in SA with a health focus	Begin as you mean to continue - co design with consumers	Establish expectations of LHNs	Copy the Uni Jam concept use the Citizens Jury, Survey monkey, Bang the table
Make the Forum visible media events	Appoint an inaugural group, build the plan and profile, review and extend the members	Develop a comprehensive map of where consumers sit in TH	Design the evaluation process for the Forum and TH	Ensure the Forum infrastructure is sound

Participant's provided the following recommendations for the Forum and Strategy:

1. Endorse principles of engagement for the Forum and ensure they are applicable to all the decisions being made in relation to Transforming Health
2. Develop a sustainable and efficient engagement strategy for all of Transforming Health governance
3. Seek a direct report to the Minister of Health from the Forum
4. The Forum should be central to the Transforming Health governance structure
5. All four advisory groups established to govern the implementation of Transforming Health should have consumer representation and overlapping terms of reference and access to their reporting mechanisms
6. Must be a Deliberative Democracy Process eg: Fund my Healthcare
7. Make this a consumer exercise embedded in the process of cultural change
8. Promotion of Health Literacy through the Forum and Transforming Health
9. Explore ways of communicating about getting people to take responsibility for health
10. Engagement starts at every interaction: Front of house
11. The Forum should report publicly and to the Transforming Health Board
12. Ensure consumer priorities are held accountable by the Forum
13. How will the Forum know what it does not know? Surveys should support the development of the Forum agenda
14. Ensure everybody has a voice!
15. The Forum needs to be accountable for doing only meaningful work
16. Require an early assurance of an open relationship with the Chief Transformation Officer

Conclusion

The Health Consumers Alliance and SA Health invited consumers and community participants to attend the workshop held 7 May 2015, to establish the Peak Consumers and Community Engagement Forum and Strategy. Over ninety participants joined the Minister for Health, the Acting Chief Transformation Officer, the Health Consumers Alliance Chief Executive and Board Chair, and members of the HCA and SA Health teams. As the peak body for health consumers and health consumer organisations in SA, HCA facilitated the workshop.

HCA will chair the Peak Consumers and Community Engagement Forum and highly regards the clear, rich and diverse advice from workshop participants. These recommendations and advice will provide a framework to guide the establishment of the Forums including principles, membership, terms of reference, agenda, and operational roles in engagement and communication.

HCA will engage with the minister, SA Health and the Transforming Health team to discuss the following outcomes from the workshop:

1. The top ten principles to inform the Terms of Reference and guide the Forum
2. Forum membership selection criteria and recruitment process
3. Priority actions and other recommendations for the Forum
4. Forum processes to achieve the priority principles including communication and accountability mechanisms.

HCA thanks all who participated in this important step in Transforming Health.

Appendix 1: Questions and Comments relevant to establishing the Forum

In her opening remarks the HCA Board chair invited participants to record relevant questions and comments on the coloured cards provided on the ten tables. Given the time limitations on the day, this strategy will facilitate tracking of the issues and ideas the participants have for the establishment of the Forum. Over sixty questions and comments were received and the ones not already reported in the Principles, Membership, Priority actions and Recommendations include:

- Is there any possibility of inclusion of additional therapies such as Art Therapy and Complementary therapy such as energy medicine and acupuncture in the TH program?
- What is the commitment to enhancing consumer's experience of health systems, by understanding these systems, and the systems being clear to consumers about what they can offer?
- Medical Jargon and Clinical specific knowledge needs to be translated for meaningful understanding of consumers
- Health workers and Administrators need to be skilled up to understand consumer ideas and how to influence co design
- Will there be consumer and community members form the Peak consumer and community engagement group on the TH Board? If not why not? They must be part of the highest Governance process
- Transforming Health: **What disappeared:** PHC services; Health promotion; Public health expertise; Community health services; Community development; Community health research? **What appeared:** A huge new tertiary level hospital; a huge new medical research centre; huge increases in medical salaries and award conditions?
- Better together, noted by the Minister: co framework for active partnering with SA Health. How is Better Health being utilised in TH in particular co design and community engagement?
- Better together does not do consumer engagement as it does not allow consumers to attend.
- Tap into the 8000 people the Minister quoted as using the SA Health services every day. Needs to be fundamental data not satisfaction surveys
- Minister we heard "yes we like you and want you to be involved" but we still are not clear on the consumer role and co design
- Response to Naomi Dwyer: Genuine in her passion for consumers
- What is the story form Generational Health Review to TH? How can we link all of this work and the associated principles?
- Don't believe that carers should be excluded as their knowledge and experience are invaluable and many spend a lot of years advocating for better services and supports. Family carers have a great deal to offer and their opinions are important. Often they are the voice for the loved one they care for.
- In regard to TH what exactly is the aim of consumer engagement?
- Health Literacy is integral to this process. The Minister alluded to the Government having no plans in increasing health literacy but is shifting that responsibility to HCA. This is not good enough or appropriate so what plans will government come up with to address health literacy?

- There is still a concern that the Minister hasn't a genuine understanding of including consumers is vital
- Person centred care is great but the system must support CALD specific needs with targeted approaches. What will these targeted approaches include?
- How will we know that TH is delivering patient outcomes? What are the measures? Who will define these? Can we measure shift of resources including from hospital to community care?
- How will we make sure the hospital bit of the journey interacts efficiently with the rest of the patient's life – including both formal services and informal services?
- What new initiatives will improve transport between and within and to and from hospitals?
- Some people cynically say hospitals and clinicians cannot transform themselves to be patient centred. They will always be self-centred and self-serving. How do we protect against this instinct?
- Concerning the New RAH, can the public be advised of the car parking arrangements for the disabled and will there be any changes to the public bus services to make it easy for elderly patients to go to the hospital?
- Will dental services move to the new RAH?
- There is no information in the TH papers about dental services. Dental Health is extremely important and the waiting time in the public system is too long.
- When the Minister held his meetings with the doctors about TH were there any consumers represented?
- Prevention and early detection is essential to divert people from the hospital system. Government has been reducing its commitment to prevention, early intervention and harm reduction over the years. This will impact on contact with hospitals. If you reduce the hospital system while reducing funding to prevention and early intervention the responses will have negative impacts on consumers
- Some doctors think they are god and can improve on the creator by doing operations. Before someone undergoes an operation the alternatives should be explained first this could eliminate most operations
- There is a downfall with surveying consumers in that they give responses that they believe the system wants to hear, people are scared that their answers will affect how they will be treated.
- If the implementation of TH is over 4 years what then? Change of government? Does the baby get thrown out? The health system should not be party or government owned system. It belongs to the community!
- Why has the mental health review finalised and released in November 2013 been overall ignored and not implemented?
- Why is SA Health not investing in Drug and Alcohol services, care and rehabilitation?
- Why does SA Health continue to implement the same practices in EDs? And expect a different result? Stop blaming consumers for the poor and inefficient use of good and committed staff
- Spend time implementing the good policy documents SA Health has produced.
- From this day forward can we now unanimously agree to use the phrase "person centred" and drop the "patient" word from all communication?

- Concern that decisions have been made without wider community consultation
- Community wanted PHC and prevention however they have been cut
- How do you reconcile rhetoric around strong consumer and community engagement with highly and increasingly centralised management structures which exclude community involvement?
- Provision of a detailed engagement list for Aboriginal involvement
- How are we going to manage power differences between patients and clinicians? And between acute hospital sector and PHC?
- When will TH recognise the importance of PHC and health promotion?
- On the current proposed TH governance structure, consumer and community engagement looks isolated and tacked on rather than central and an influential role
- How will the various current consumer engagement strategies and the new Forum interact, avoid duplication?
- In regards to the Ministers speech these issues require solutions: Transport, rural and remote access to metro services: challenge of the state and Federal funding focus: no tokenism or sidelining of consumers engagement
- Response to the Ministers presentation: It's a job for SA Health: It's a life for consumers (or not)
- I am concerned about how TH is addressing PHC concerns and preventative health issues. Is there going to be adequate funding? There seems to be many projects that have been in place and working for many years that are coming to an end due to funding. Why is the breastfeeding unit at the WCH closing? Where will women go to receive expert assistance? There needs to be a preconception health clinic for pre-existing health issues can be addressed before a woman becomes pregnant.
- I think many decision have been made by politicians re TH without public consultation that is the changes are going to happen whether we like them or not. We are being told this is how it is going to be and why. It is a great idea to have a Peak consumer and community engagement Forum but this should have been set up before implementing TH.
- How to win over the clinicians in the system who has said to me that they need to design the health system first before asking consumers what they think. No! It's about meaningfully involving highly skilled consumers in the design from day one!
- Don't give consumers of the Forum "busy work: it needs to be meaningful and making a difference
- Make sure this work is value adding – do not disrespect what is working for consumer groups in the LHNs.

Appendix 2: Additional suggested principles not recommended in the top ten

Participants made other suggestions for principles to guide the work of the Forum that were not prioritised in the top ten.

- Direct access to decision making
- Outcomes measured in people terms not clinical terms
- Goal driven consultation
- Influence through feedback
- Governance: consumers are integrated into all organisational governance structures
- Ethical behaviour
- Collaboration: mutually beneficial outcomes
- Mutual respect
- Right of response
- Kindness
- Dignity of care
- Easy understanding and navigation
- Prevention focus
- Empowering consumers
- Outcomes driven
- Listening and reflecting
- Empathy for clinicians
- Health literacy
- Social Determinants of Health
- Holistic Health
- Lived experience
- Supporting and Educating the consumer and the community
- Responsibility
- Self determination
- Inclusivity of cultural diversity
- Views of young people as future leaders
- Strong implementation system
- Flatter hierarchies
- Affirmative inquiry
- Open disclosure
- Bi partisan support for continuity and longevity
- Forum must have an educative role
- Including consumer and community narratives
- Consumer acknowledgement at all levels of governance
- Evidence of sustained and meaningful engagement
- SA Health to promote the behaviour of respect for consumer engagement.

Appendix 3: Possible Forum membership

