Consumers
Health Forum
of Australia

REPORT ON STAGE 1 OF THE ESTABLISHMENT OF A HEALTH CONSUMER ORGANISATION IN TASMANIA: DEVELOPMENT AND SCOPING PHASE

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May 2016

EXECUTIVE SUMMARY

Primary Health Tasmania provided funding to the Consumers Health Forum of Australia (CHF) to develop, scope and establish a peak health consumer organisation in Tasmania. Currently, Tasmania and the Northern Territory are the only two jurisdictions who do not have a state-based organisation through which consumers are involved in shaping and influencing health policy. Consumer-centred care is at the heart of a contemporary health care system. Therefore, health consumer organisations need to reflect the changing role of consumers in the health system by building consumer capability and capacity to partner with health care providers and policy makers in influencing and shaping the system of health care. This includes equipping consumers to be more informed and enabled to make the cultural shift from a pure 'advocacy' approach to one of collaboration and partnership.

Tasmania is in the process of transforming its public health system with the establishment of a single Tasmanian Health Service with a newly appointed CEO and a statewide Governing Council. Although health services and hospitals will still be delivered through the 3 key geographical areas, there is a single mechanism established now to provide a statewide approach. At the same time, the Australian Government has restructured primary health care organisations to be better aligned with local health districts. In Tasmania, this has meant the formation of a single Primary Health Network, Primary Health Tasmania which provides a statewide approach and which will commission services to be delivered through the 3 geographical hubs. The establishment of a single public health service and a single primary health care organisation together with a major private hospital provider creates a climate for better co-ordination and integration of health services across the state. It seems very timely to be considering the establishment of a statewide mechanism or organisation that can bring together the consumer voice to partner with the Tasmanian Health Service and Primary Health Tasmania to improve the health outcomes of Tasmanians.

A Project Steering Committee was established to guide and provide strategic advice to the Project. Consultations were undertaken with members of the Steering Committee, external stakeholders and consumers. Thirty two consultations were held, **9** with committee members, **15** with external stakeholders and **8** consumers. This included **19** face to face consultations, **8** teleconferences and a focus group for consumers. The aim of the consultations was to assess the need for a peak health consumer organisation in Tasmania, explore the benefits and challenges, discuss the activities or potential core business of the organisation, the linkages and interface between organisations, funding and governance. The consultations were designed to assess the degree of support that exists to establish a peak health consumer organisation and what gaps it might fill. As well as consultations undertaken in Tasmania, consultations were held with all 6 state and territory peak health consumer organisations in Australia.

There was overwhelming support for the establishment of a health consumer organisation for Tasmania from the Committee, external stakeholders and consumers. This report provides the outcomes of Stage 1

of the project which is the development and scoping phase. It includes an overview of the international and national policy context driving a new era of health reform and consumer engagement, an overview of the existing state and territory peak health consumer organisations in Australia and the outcomes of the consultation process. A proposed model for the health consumer organisation in Tasmania is outlined which identifies 10 components across 6 domains and suggests a series of recommendations for the implementation phase.

Tasmania is in an enviable position with an exciting opportunity to establish a contemporary health consumer organisation aligned with current best practice in consumer engagement and participation. This will enable the organisation to drive system change in partnership with public, private and primary health care services to improve the health of all Tasmanians.

1. INTRODUCTION

Primary Health Tasmania provided funding to the Consumers Health Forum of Australia (CHF) to develop,scope and establish a peak health consumer organisation in Tasmania. Currently, Tasmania and the Northern Territory are the only two jurisdictions who do not have a state-based organisation through which consumers are involved in shaping and influencing health policy. In particular, there is an increasing emphasis on consumer-centred care and greater recognition of the consumer experience as an element of high quality health care which the health system must be better equipped to address. Currently in Tasmania, there are a number of organisations that provide consumers and families with condition specific advice and support, and there are other organisations which advocate on health issues relevant to their particular membership base, and in communities more broadly. A state-based consumer group which focuses on the health system and where health care providers and professionals can go to seek consumer input on their policies and services is missing. The aim of this project is to establish an independent alliance of existing health consumers and health consumer organisations and those with an interest in health consumer affairs that could work across the system building on the existing networks, interest and local expertise.

The project has two stages: Stage 1: the development and scoping phase and Stage 2: establishment and implementation phase. It is anticipated that Stage 1 will be completed by April 2016 and Stage 2 by mid to late 2016.

This report provides a summary of the aims and objectives of Stage 1 of the project, the methodology undertaken and the outcomes. A proposed model for the organisation is outlined with issues for discussion as well as a number of recommendations relevant to the implementation phase (ie Stage 2).

2. STAGE 1 : SCOPING AND DEVELOPMENT PHASE

Stage 1 of the project involved undertaking a scoping and development phase to assess the need for such an organisation and to develop a model that would suit Tasmania and be aligned with contemporary trends and best practice in consumer engagement.

2.1 AIMS AND OBJECTIVES OF THE PROJECT

The aim of the overall project is to establish an organisation that will have the support of the Tasmanian health system and will have the ability to:

- Grow an organised consumer movement in Tasmania
- Provide health planners and decision makers in Tasmania with informed strategic policy, health system and service development advice
- Provide independent systemic health consumer advocacy and representation

- Facilitate, promote and support health consumer advocacy, networking and leadership
- Raise awareness of issues of interest to Tasmanian health care consumers through engagement, information dissemination and training.

The objectives of Phase 1 were to:

- Gain an understanding of contemporary trends in the health consumer sector
- Gain an understanding of the Australian context in relation to health consumer organisations
- Gain an understanding of the Tasmanian health system and landscape in relation to health consumer issues and advocacy
- Consult with key stakeholders and consumers in relation to the benefits, challenges and type of organisation that needs to be developed
- Develop a model based on the outcomes of the above processes
- Provide some recommendations for the implementation phase.

2.2 METHODOLOGY

The methodology used to undertake the scoping phase included:

- Reviewing models of existing health consumer peak bodies in Australia and internationally through desktop analysis, teleconferences and interviews
- Undertaking telephone and face to face interviews with key stakeholders in the 3 areas of Tasmania (ie North, North West and South)
- Undertaking a focus group with consumers and telephone consultations.

A Project Steering Committee was established to guide and provide strategic advice to the project. (Refer **Appendix 1** for Terms of Reference and Membership of the Steering Committee)

3 INTERNATIONAL/NATIONAL POLICY CONTEXT FOR CONSUMER HEALTH

For several decades now there has been a recognition of the need for a more active role for consumers in health care, what is often referred to as consumer 'choices' and consumer 'voices' with the aim of improving service delivery, consumer experience and consumer outcomes. The impetus behind consumer involvement in health care has continued to grow and change over the decades. Although a number of patient/consumer organisations have been active since the 1950s, momentum built in the 1960s and 70s with the emergence of the patients' rights movement as part of a larger scale citizens' and human rights movement. These movements included both a general focus on the role of patients and consumers, and more specialised foci on specific advocacy areas (ie HIV –AIDS).

In more recent years, three additional factors have led to more active engagement of consumers. These include:

- Changing nature of patient profiles, in particular the increasing number of individuals living with chronic and complex conditions
- Large scale reforms to the health system which have swept most developed countries

- Involvement of consumers in the consumer safety and quality agenda, that is, monitoring and developing strategies for responding to medical errors and adverse events; contributing to service development and strengthened system governance.

These factors have led to a shift in consumer activity and input from a focus on rights and advocacy to a greater role in understanding and promoting health literacy, self-management, shared decision making and consumer-centred care. This shift is also demonstrated by greater responsibility placed on the individual for their health outcomes and to the health system in providing quality, responsive and accessible care and treatment options. This has led to changes in the power relationship between the providers and the consumers from 'medical' dominance to a more democratic partnership approach.

A twenty first century health system is characterised by partnership with consumers. Partnering with consumers is about health care organisations, health care providers and policy makers actively working with consumers to ensure that health information, systems and services meet their needs. There are lots of terms used to describe the concepts that underpin partnership with consumers such as consumer-oriented care, consumer engagement, consumer participation and citizen engagement. Essentially, partnership with consumers happens when:

- Consumers are treated with dignity and respect
- Information is shared with consumers
- Participation and collaboration with health care providers is encouraged.

Consumer-centred care is at the heart of a contemporary health care system. It will increasingly be the case that hospitals, community health services and primary care settings will be accredited and held to standards that uphold the principles and practices of consumer centred care. Consumer-centred care is defined as, 'an approach to the planning, delivery and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients and families' (ACSQHC, 2011).The dimensions of consumer-centred care identified by the ACSQHC (2011) include:

- respect
- emotional support
- physical comfort
- information, communication and education
- continuity and transition
- care co-ordination
- involvement of family and carers
- access to care

Contemporary health consumer organisations need to reflect the changing role of consumers in the health system by building consumer capability and capacity to partner with health care providers and policy makers in influencing and shaping the system of health care. It includes equipping consumers to be more informed and enabled to make the cultural shift from a pure 'advocacy' approach to one of collaboration and partnership.

For example, in the UK, *National Voices: people shaping health and societies* is a coalition of health and social care charities in England. It is a registered charity and a company limited by guarantee and aims to integrate person-centred care across the health and social care sectors. They have gone a step further from consumer-centred care focusing solely on health care to person-centred care focusing on a whole system of care across sectors. It currently has 140 charity members and 20 professional organisations as associate members. National Voices have developed 5 narratives that define what person-centred care looks like in different health and social care services (refer www.nationalvoices.org.uk)

3.1 CHANGES IN THE DELIVERY OF HEALTH CARE AND IMPLICATIONS FOR CONSUMERS

Over the last decade there have been pervasive changes to the health care systems in the developed world. The drivers of these changes have been largely financial (the increase in chronic diseases and in life expectancy) and therefore a greater fiscal burden on the health system, the rising costs of hospital based care, the need for more coordinated, multi-disciplinary approaches and more holisitic care. This has led to countries like the UK, USA and Australia to rethink their health systems and engage in significant reform processes.

The UK have embraced the social determinants of health and recognised that the drivers of health sit outside the health system and by integrating health, local government, housing and other services across a geographic area (which could be a city, region, town or neighbourhood) the system can be reengineered to secure better health outcomes and be more sustainable in the future. They define this as 'place-based health'.

As stated in the *Forward of Get Well Soon: Reimagining Place Based Health* (2016) *"If we are to take Sir Michael Marmot's call for a focus on the broader determinants of health seriously, people must be put at the heart of reform. This means reimagining a new health and wellbeing system which promotes personalisation, supports healthy decisions, enables physical activity and encourages responsibility"* The *Five Year Forward View* (NHS 2014) is, for example, "quite clear about the need for a 'radical upgrade' in prevention and public health, a blurring of care settings and silos, and a more diverse delivery model that has citizen voice and experience at its heart." Place based health is not seen as something that happens in a clinical setting but in the settings of everyday life.

Health Foundation and Nesta,(2015) in a report "*At the Heart of Health: Realising the Value of People and Communities*", cited evidence from high quality international health systems and early findings from integrated personal commissioning and small-scale studies from areas such as Greater Manchester that support the idea that early intervention and prevention improves outcomes and potentially saves money in the longer term. For example, Nesta (Health Foundation and Nesta 2015) estimated that over £4 billion could be saved with more direct involvement of patients, families and communities in the management of long-term conditions.

The USA Health System which is quite different from the NHS in the UK and the federated system of Australia has strongly linked consumer-centred care to health insurance. From a USA perspective, a consumer-centred health care system is designed to maximize value for individuals and families so that they receive more benefit and results for their health care dollars, both as patients and consumers buying health insurance. There is a strong push in the USA to make the patient the focus of the American health care system and the consumer, the key decision maker. This leads to the concept of consumer-directed care where consumers hold the funds for their health care and then make the decisions about where they wish to purchase services. This has implications for the way the National Disability Incentive Scheme (NDIS) may be implemented in Australia.

There has been significant reform at the national level in Australia in primary health care with the establishment of 31 Primary Health Networks (PHNs) across Australia. These PHNs are commissioning organisations and are responsible for identifying health needs, planning, coordinating and commissioning services and ensuring quality monitoring and evaluation. All PHNs are required to have Community Advisory Councils to enable community input and feedback on primary health care needs and services. Mental Health Reform in Australia also focuses on strengthening early intervention and prevention and shifting the focus from acute care to primary care and community intervention with PHNs assuming a much greater role in coordinating services for people with mental health issues. The Australian Commission for Safety, Quality in Health Care (ACSQHC) has developed the National Safety and Quality Standards (NSQS) and Accreditation. Standard 2 requires the involvement of consumers in the organisational and strategic processes that guide the planning, design and evaluation of health services.

KPMG Global Health Care (2014) explored the global healthcare industry to determine the factors that contribute to the inherent value that better patient involvement and community input improves care. In their report *Creating new value with patients, carers and communities* (2014) they identified" 9 different questions or areas to be asked of the system:

- *Is there work to create a new culture centred on the patient culture?*
- *Is there patient input into service design?*
- *Are there systems to support shared decision making?*
- *Are there models to support self-care and help the professionals adapt?*
- *Are patients assets mobilized?*
- *Can patients get and use information?*
- *Are patients involved in teaching and research?*
- *Are the assets that communities can contribute mobilized?*
- *Are there measurement systems to support this?"*

In their report, they cite examples from all around the world to answer the 9 questions and have developed a maturity matrix by which healthcare organisations can assess their progress.

Changes in the healthcare system in the developed world over the last decade are moving to having consumers and the broader community at the core of the system. Enabling consumers and communities

to gain greater control over, and contribute to better health outcomes, involves reorienting or reengineering the system to focus on the enablers (ie health literacy, access to shared information, shared decision making) and the settings in which this will take place.

3.2 CONSUMER PARTICIPATION AND ENGAGEMENT

Underpinning the consumer -centred focus of health reform is the need for effective consumer and community engagement and participation. Travaglia and Robertson (2011) as cited in Joyner (2015) identified 3 levels of consumer and community engagement. These include:

Micro: Consumer to clinician, where consumers are seen as experts/equal partners in the delivery of care; where consumers have an active role in assessing and directing the quality and safety of their own care or their family members care or where consumers directly participate in research. (for example, this type of engagement is common at the **INDIVIDUAL** level).

Meso: consumer and community engagement in service and information planning and delivery; in designing, directing or governing research (including through ethics committees); in evaluating the effectiveness of services; and or in developing or directing information about health care issues. (for example, this type of engagement is common at the **ORGANISATIONAL** level).

Macro: consumers are engaged as part of the health system consumer councils; in state or national (countrywide) committees and advisory councils; in patient safety enquiries or on professional boards and bodies in setting professional and service standards; and on accreditation boards. (for example, this type of engagement is common at the **SYSTEMWIDE** level**).**

Within each of these levels of engagement are a range of strategies and techniques that are employed based on the suitability to the respective contexts. The literature has identified a number of different spectrums of engagement and participation.

SPECTRUM SOURCES	LOWER		DEGREE OF ENGAGEMENT		HIGHER
IPA2	Inform	Consult	Involve	Collaborate	Empower
CHF	Inform	Listen	Consult	Partner	Govern
NSQHS Std2	Inform	Consult	Partner	Delegate	Consumer/Community control
Centre for Disease Control(CDC)	Outreach	Consult	Involve	Collaborate	Shared Leadership

Table 1: Spectrum of Engagement/Participation

The *Public Participation Spectrum* (2006) developed by the International Association of Public Participation (IPA2) is frequently cited as a starting point for most spectrums ranging from inform to empower. The Consumers Health Forum (CHF), 2014 supports a slightly different spectrum that recognises and differentiates listening from consulting and the particular role of consumers in governance. CHF focuses on the role for consumers in decision-making. ACSQHC (2012) Standard 2 cites a similar spectrum that shows increasing control of consumers in decision making but also notes that regardless of which model is used the standard 'aims to improve' consumer engagement and participation within health services. The spectrum outlined by the Centre for Disease Control (CDC), 2011 in the USA is of relevance to working with marginalised or hard to reach populations. The spectrum focuses on increasing community involvement, impact, trust and communication flow. In particular, inform is replaced with outreach and empower becomes shared leadership.Selecting a spectrum is ideally done in collaboration with key consumers and community stakeholders. It plays a strategic role in that it sets boundaries and expectation for an organisation's engagement program.

A report published by the Centre for Clinical Governance Research, Australian Institute of Health Innovation, Faculty of Medicine, University of NSW in 2012 in which they reviewed the literature on Consumer and Community engagement, concluded that "*It is difficult to extrapolate a clear model for engagement which is evidenced based. Rather, what emerges from the evidence is an 8 stage model for consumer and community engagement. It is clear that attempts at engagement at each level of the health system, micro, meso and macro need to take these stages into account to plan, execute and evaluate consumer and community engagement strategies*." In a recent review of the implementation of the National Safety and Quality Health Standard 2: Partnering with Consumers, the ACSQHC (2014), identified strategies employed by Australian and international health services who have successfully partnered with consumers. The detail of these stages and strategies can be found in the references.

However, what may be most relevant for this project is a set of recommended best practices outlined in the WentWest model of Consumer and Community Engagement, (Joyner 2015). These practices are very relevant for the establishment of community based health consumer networks or organisations.

1. **Ensure consumer engagement is a priority**
    - Involving consumers from the start
    - Support for engagement from senior management
    - Consumers involved in governance

2. **Address organisational facilitators**
    - Internal governance for engagement
    - Built in opportunities for consumers and communities to initiate engagement

3. **Actively include disadvantaged/marginalised groups**
    - Recognition of the systematic nature and impact of health inequalities
    - Employing specific strategies to engage with disadvantaged/marginalised groups

4. **Build the capacity of consumers to engage**
   - Provide training to consumers
   - Support consumers who engage
   - Develop the capacity of consumers and community members to engage

5. **Build the capacity of staff to support engagement**
   - Provide staff with training
   - Support staff to effectively engage with consumer

6. **Focus on outcomes and evaluation**
   - Consumer Experience data
   - Evaluate engagement
   - Focus on the outcomes of engagement

These best practices although relevant for organisations seeking to partner with consumers are also relevant for consumer networks and organisations leading consumer engagement.

4 AUSTRALIAN CONTEXT: HEALTH CONSUMER ORGANISATIONS

One of the key components of the scoping phase was to review all the existing state and territory peak health consumer organisations in Australia. Currently there are 6 organisations at the state and territory level with one national organisation, Consumers Health Forum of Australia. These are:

- Health Consumers Alliance of South Australia (HCASA)
- Health Consumers Queensland
- NSW Health Consumers
- Health Consumers Council (WA)
- ACT Health Care Consumers Association
- Victoria Health Issues Centre

Although networked, the organisations are all autonomous and are not part of a federated system. Consultations were held with the existing state and territory peaks in Australia. The purpose of the consultations was to understand the model that was established for each jurisdiction, the impetus and rationale, the key objectives and an analysis of key successes, challenges and future opportunities. The following people participated in the consultations:

- Michael Cousins, CEO, Ellen Kerrins, Policy Manager, **Health Consumers Alliance of South Australia (HCASA)**
- Melissa Fox, General Manager**, Health Consumers Queensland**
- Anthony Brown, CEO, **NSW Health Consumers**
- Pip Brennan, Executive Director, **Health Consumers Council (WA)**
- Eleanor Kerdo, Senior Policy Manager, **ACT Health Care Consumers Association**

- Danny Vadasz, CEO, **Victoria Health Issues Centre**

The key areas that were explored as part of the consultations included funding, governance, membership, role and function, staffing, key programs, successes, challenges, opportunities and learnings.

4.1 OVERVIEW OF THE STATE AND TERRITORY HEALTH CONSUMER ORGANISATIONS

A summary table has been provided for each jurisdiction which outlines the outcomes of the consultation against each of the consultation areas explored.

	SOUTH AUSTRALIA
Establishment	Established in 2002 following a consultation process and discussion paper
Funding	Receives core funding from SA Health Department. Other income streams include fee for service, project based funding and membership fees
Governance	Incorporated Association. Membership based. Voting members vote the Board members in. Moving to a skills based Board
Membership	Types of members: Full/Associate and Voting/Non-Voting
Role and Function	Strategic policy advice to health planners and decision makers, systemic health consumer advocacy and representation, facilitation, promotion and supporting consumer advocacy, networking and leadership, training of consumers and health providers, Information and health literacy and strategic partnership development
Staffing	4 FTE as well as consumer advocates
Key programs	Systemic Advocacy and Strategic Policy Advice, Training for consumer representatives involved in consumer consultation or advisory groups in the health system Consumer input to health reform processes in South Australia, Partnership Development
Unique features	Strategically well positioned to influence the health reform agenda in South Australia

	QUEENSL AND
Established	2008 was set up as a Ministerial Advisory Committee 2012 established as an independent organisation
Funding	Split funding model: core funding provided by Qld Health for state health funded services, purchasing Model for PHNs
Governance	Company limited by Guarantee: 7 Member Board. Registered Charity
Membership	Not a membership based organisation
Role/Function	Systemic advocacy, maintaining and supporting a diverse consumer network, training for consumers and service providers and co-ordination of consumer representation as required
Staffing	5.2 FTE
Key Programs	Consumer network meetings and support including an Annual Forum, Participation on a high level Consumer Collaborative statewide Committee (Qld Health), Partnership development and provision of training for consumers and service providers
Unique Features	Governance and Funding Model

	NEW SOUTH WALES
Established	2010 following a consultation process
Funding	Core funding from NSW Ministry of Health. Other income derived from training and consultancies
Governance	Membership Association .Board voted in by members 10 Board Members. Registered Charity.
Membership	Individual and Organisational membership
Role/Function	Systemic advocacy, supporting and building capacity of consumers and health services
Staffing	3.5 FTE
Key Programs	Training for consumers (Developed a 2 day package) Provision of customised training on a fee for service basis or cost recovery

	Consultancy with Went West to develop a framework for consumer engagement
Unique features	Developed a conceptual framework for consumer engagement

	WESTERN AUSTRALIA
Established	Established in 1994
Funding	Core funding from State Department of Health. Also receive commonwealth funding for Aboriginal advocacy
Governance	Membership Association. Board voted in by members 10 Board Members
Membership	Individual and organisational membership
Role/Function	Individual Advocacy, Aboriginal Advocacy, Systemic Advocacy and Consumer Engagement
Staffing	8 FTE
Key Programs	Individual advocacy Training for consumers and health providers Co-ordination of a consumer representative service Aboriginal advocacy program Provision of a print based newsletter
Unique features	Individual Advocacy and Aboriginal Advocacy

	AUSTRALIAN CAPITAL TERRITORY
Established	Established in 1978
Funding	Core funding from ACT Health. Also receive project funding for specific projects
Governance	Membership Association. Board voted in by Members
Membership	Individual and organisational membership
Role / Function	Coordinating and facilitating consumer participation and representation,systemic advocacy, policy Influence and response, Influencing health infrastructure development and health services planning
Staffing	6 FTE
Key Programs	Policy including response to submissions through facilitating policy forums, focus groups, Health Policy Steering Committee and Reference Groups Consumer Representative training Health Infrastructure program Multicultural program
Unique features	Community controlled organisation

	Strongly influence health infrastructure planning and receive funding for it Strong policy infrastructure Multicultural program

	VICTORIA
Established	Established in 1980s
Funding	Core funding from DHHS supplemented by fee for service, consultancies, projects Diversified funding model
Governance	Membership Association. Board voted by members. 12 Member Board. Registered Charity
Membership	Individual and organisational membership
Role/Function	Agent of transformation of the health system in Victoria, facilitation of consumer partnerships in health, influencing policy, developing consumer capability through support, training and provision of resources and systems advocacy
Staffing	8 FTE
Key programs	Provision of accredited training for consumer leaders and health professionals Customised training for organisations and health services on a fee for service basis Consultancies for health services and training colleges Accredited training program
Unique Features	Resources and tools Building consumer partnerships as agents for cultural change in the health system

4.2 ANALYSIS OF THE STATE AND TERRITORY PEAK HEALTH CONSUMER ORGANISATIONS

There are a number of consistent features across all the organisations. These include:

- All receive core funding from their respective state/territory health departments and supplement this in various ways through membership fees, project based funding, cost recovery for training and consultancies
- All are relatively small organisations (ie under 10 FTE)
- All are membership based organisations with the exception of one which is a Company, Limited by Guarantee
- All are engaged in systemic advocacy, consumer engagement, training for both consumers and health professionals and policy work

- All are committed to a consumer-centred approach to health service delivery and aim to improve consumer participation in health service planning and delivery
- All are represented on high level committees in their respective state/territory health departments (ie health reform, consumer collaboration, integrated care, health infrastructure planning)
- All are involved in capacity building of both consumers and the health sector
- All support the principle that better health outcomes will be achieved through more improved consumer participation at all levels in the health system

The differences across the organisations include:

- All have different names
- All at different stages of development (3 relatively new, 3 well established)
- Even those who have membership models, have different types of membership and voting processes
- Not all are registered charities
- Only one organisation is involved in individual advocacy
- Even though all receive core funding from their respective state/territory health departments, funding agreements are all different
- All have different processes and approaches to training, facilitating consumer representation and policy responses
- All have different approaches or position themselves differently as a 'peak' organisation

4.2.1 Key success factors and learnings so far

There are a number of key success factors and learnings that the consultations with the state and territory peak health consumer organisations have identified. These centre on the following themes:

- Need for good and effective governance
- Strong and visionary leadership
- Long term sustainability
- Respected and valued by government
- Contemporary approach to consumer engagement
- Strong connection with constituent base and transparent decision making
- More improved networking nationally

Need for good and effective governance

A recurrent theme in the consultations was good governance as this is seen as a major factor impacting on the credibility and reputation of the organisation. As most of them are member based organisations the challenge has been to have a skills based Board while still being representative of the constituent base. For those organisations who are well established, they certainly commented on variation in the quality of their governance over time and the steps they have taken to resolve this.

It is essential in drafting the constitution of a membership based organisation to enable a skills based Board to be established otherwise the quality of governance may be seriously compromised.

Strong and visionary leadership

Along with good governance, another success factor is strong and visionary leadership. The consumer role in the healthcare system is changing and although there are increasingly more mechanisms in place for that to happen, there is still a risk of tokenism. Leadership is critical in engaging a wide range of stakeholders to value and respect the role of consumers as partners in the health care system. It requires strong communication and networking skills, the ability to engage and be respected by consumers, health providers, management and government along with the wider stakeholder base. It also requires visionary and strategic thinking to engage and inspire people to do things differently or to change if that is required.

Long term sustainability

The sustainability of consumer organisations is a recurrent theme. All the existing organisations are dependent on government funding for their core functions so maintaining this over a period of years can be a challenge. They are all not for profit community based organisations. All of the organisations attempt to diversify their funding base but they are limited in what they can achieve because of their resource base. Most of them recognise the importance of partnerships and strive to establish joint funding arrangements for certain activities. Consideration also needs to be given to a range of organisations outside of government that could contribute to such an organisation because of the mutual benefit.

This is a significant issue that needs to be considered from the outset is to ensure that the business model that is established enables a range of income generating activities. Several of the state and territory organisations have gained charitable status in order for them to receive tax concessions and other benefits for potential donors. A clear business strategy needs to be developed early to address the long term sustainability of the organisation.

Respected and valued by government

Clearly, all the organisations have a funding agreement with their respective jurisdictional health department and contribute to high level committees and policy advice. All the organisations commented that it is essential for the Health Consumer Organisation to have a strong connection with the government if they are to influence policy and effect change. South Australia, for example, leads the consumer consultative committee for Transforming Health, SA Health’s key reform agenda. Similarly in Queensland, the consumer organisation is a member of the high level Queensland Health Consumer Collaboration Committee while the ACT is provided with funding to enable consumers to provide input to all health infrastructure planning.

Contemporary approach to consumer engagement

Those organisations who are well established commented on the need to modernise their organisations and bring them into line with new technologies, different generations of consumers and different expectations. However, they are facing challenges in trying to achieve this. The world is a different place in the twenty first century to what it was in the 1980s and 90s with new technologies, increasing multiculturalism, increasing incidence of chronic disease, decentralised health services and an ageing population. It is important for health consumer organisations to consider multiple strategies for engaging consumers across the population spectrum from young people to adults and older people as well as population groups with specific needs.

It is also important to be abreast of current best practice and the evidence base in consumer-centred care so that capability and expert knowledge can be developed. A contemporary approach focuses on promoting and leading transformational change underpinned by an evidence base rather than the personality driven adversarial approaches of the past. This links to the earlier success factor of strong and visionary leadership.

Strong connection with constituent base and transparent decision making

Most of the organisations commented on the need to keep strongly connected to the membership, particularly consumers and ensure that consumers are involved in the decision-making processes of the organisation. This includes recruitment of staff, planning, implementation and evaluation of activities, advocacy and policy response. Some of the organisations had much stronger connection to their constituent base than others. It is important for credibility as a consumer organisation to maintain that representation of the consumer voice and have transparent policies and processes regarding decision-making.

More improved networking nationally

As mentioned previously, whilst there is not a federated system of organisations, CHF is taking a leadership role in fostering closer networking and sharing of resources between the organisations. As all are small organisations with limited resources, this is helpful both in preventing the need for reinventing the wheel and ensuring benefit from the experience of others. All the organisations are keen to support and help Tasmania in the establishment and ongoing development of its health consumer organisation.

5 THE TASMANIAN CONTEXT

The Tasmanian health system is currently being transformed with the aim of integrating services both within and between the public, private and primary health care sectors to ensure better health outcomes for all citizens. Although a small jurisdiction, Tasmania has a heavily decentralized population with health and other services being delivered through three key geographical areas known as the South (Hobart and regional environs), North (including Launceston and outer regional areas) and the North West (including

the major towns of Devonport, Burnie and Ulverstone). Each of these three areas have at least one major public hospital, some components of private health and prior to 2012, three Divisions of General Practice or Primary Health Organisations (North, North West and South). The advent of a single Medicare Local for Tasmania in 2012, supported unified action in the primary care space, but this work was hampered by a regional approach to State Health service delivery. This resulted in system fragmentation and lack of a strong, coordinated and integrated statewide approach.

Currently, the public health system in Tasmania is moving to a single organisation – the Tasmanian Health Service –with a newly appointed CEO and a statewide Governing Council. Although health services will still be delivered through the three key geographical areas, there is now a single mechanism established to provide a statewide approach. At the same time, the Australian Government has restructured primary health care organisations to be better aligned with local health districts. In Tasmania, this has meant the formation of a single Primary Health Network, Primary Health Tasmania (PHT), which provides a statewide approach and which will commission services to be delivered through the same three geographical hubs.

Furthermore, the Australian Government has provided funding to the University of Tasmania, Health Service Innovation to help implement clinical redesign in the Tasmanian public health system in order to achieve better quality health care and improved outcomes for consumers. The Health Partners Consortium has been established with key partners and aims to provide support to Health Services Innovation Tasmania through expert guidance, advice and local leadership.

The health consumer sector in Tasmania has largely displayed some of the hallmarks of the previous health system which was best characterised as fragmented, not well coordinated and lacking a statewide approach. Each of the major hospitals in Hobart, Launceston and Burnie has had a Consumer Advisory Committee to provide advice, feedback and input to the planning and delivery of services. These committees have all been in the process of change recently and are reconfiguring as: Community Advisory Council (one in both the North and North West), and Community Engagement Committee (South). PHT has also established a formal Community Advisory Council which is a requirement of its funding agreement and supplements a number of other consumer roles and engagement mechanisms in the organisation. It is interesting to note that these committees are broader in their focus now to represent a community perspective rather than just consumer voices. Calvary Care Private Hospital Lenah Valley has a Consumer Advisory Committee which provides advice, input and feedback on service planning and delivery as well as input into developing patient information and resources. Currently, there is a community representative on the Health Partners Consortium, Health Services Innovation, University of Tasmania.

FLOURISH, the mental health consumer network of Tasmania is funded by the Department of Health and Human Services and has a statewide function. In many ways, FLOURISH undertakes many of the activities that would be expected of a peak health consumer organisation except that it is specifically for mental health. FLOURISH provides systems advocacy, training and support for consumer advocates and co-ordinates a consumer representative service as well as providing high level policy advice.

As well as these specific consumer/community advisory mechanisms and organisations, there are a range of non-government organisations in Tasmania that provide advocacy and policy advice in the health area from a consumer perspective. The following table provides an overview of the NGO landscape in Tasmania. It is by no means inclusive of all NGOs but provides a picture of some of the key organisations and peak bodies.

TYPE	ORGANISATIONS
Health Specific	Heart Foundation Tasmania Diabetes Tasmania Cancer Council Tasmania Arthritis and Osteoporosis Tasmania
Specific Population Groups	COTA (Council on the Ageing) Aged Care and Housing Disability Voices Tasmanian Aboriginal Centre (Community Controlled Organisation) Tasmanian Aboriginal Health Reference Group Carers Tasmania YNOT (Youth Network of Tasmania) Migrant Resource Centre
Broader Health and Social Care	Neighbourhood Houses Inc TASCOSS (Tasmanian Council of Social Services) Anglicare, Baptacare, Centacare, Salvation Army and other similar charities
Advocacy	Advocacy Tasmania Health Ombudsman Health Complaints Commissioner
Peak Bodies	Mental Health Council of Tasmania TASCOSS COTA Tasmania Tasmanian Chronic Disease Prevention Alliance

Table 2: NGO Organisations in Tasmania

The establishment of a single public health service and a single primary health network, together with a major private hospital provider, Calvary Care, creates a climate for better coordination and integration of health services across the state. It seems very timely to be considering the establishment of a statewide mechanism or organisation that can bring together the fragmented consumer voice to partner with THS, PHT and Calvary Care.

6 OUTCOMES OF THE CONSULTATION PROCESS

6.1 CONSULTATION PROCESS

Consultations were undertaken with members of the Steering Committee, external stakeholders and consumers. External stakeholders were identified in collaboration with the Steering Committee and consultations were undertaken with a representative group across the different categories noted in in Section 5 above. Consumers were identified in collaboration with the Steering Committee and **8**

consumers were nominated. These consumers represented the THS Community Advisory Councils, Primary Health Tasmania Community Advisory Council, Health Partners Consortium, COTA and the Heart Foundation of Tasmania**. Six** participated in a focus group and **two** by individual teleconference. In all, **32** consultations were conducted. Table 3 below provides a breakdown of the consultations.

	Face to Face	**Teleconference**	**Total**
Steering Committee	7	2	9
External Stakeholders	12	3	15
Consumers	5	3	8
TOTAL	**24**	**8**	**32**

Table 3: Consultations conducted in Tasmania

The aim of the consultations was to assess the need for a health consumer organisation in Tasmania, explore the benefits and challenges, discuss the activities or potential core business of the organisation, the linkages and interface between organisations, funding and governance. The consultations were designed to assess the degree of support that exists to establish a consumer health peak organisation and what gaps it might be filling.

The list of stakeholders and consumers consulted with can be found in **Appendix 2.** As can be seen from the list, consultations were held with stakeholders and consumers from across the three key geographical hubs. The consultation questions for the stakeholders and consumers can be found in **Appendix 3.**

6.2 OUTCOMES OF THE CONSULTATIONS

There was overwhelming support for the establishment of a health consumer organisation for Tasmania from the committee, external stakeholders and consumers.

6.2.1 Benefits to Tasmania

The benefits to Tasmania that were identified included the following:

a) Having a statewide approach to bringing the consumer voice together and having an organisation totally focused on the consumer perspective. This also includes training and support of consumers to be informed advocates.

"Better co-ordination of the consumer perspective. Its currently very fragmented, not well coordinated or consistent. Even the 3 TasHealth Committees don't meet"
Consumer

b) An independent, well informed consumer voice that can provide high level strategic advice and expertise will be of enormous benefit to improving the health system.

"Development of a literate, informed consumer voice would help to build a consumer oriented system of health care rather than a service provider centric one that exists now." Committee Member

"Long term improved health outcomes for Tasmanians through improved health services" Consumer

c) Provides an opportunity for engaging with a diverse group of consumers and building a body of knowledge and expertise on consumer oriented care that can contribute to the way health services are delivered in the future.

"Greater opportunity for a diversity of consumers and including the voice of vulnerable groups" Committee Member

d) Provides a central mechanism for other organisations to work with in relation to consumers.

"Having a one stop shop to go to for independent, informed consumer expertise and advice" Stakeholder

"A well supported structured health consumer mechanism that creates greater accountability" Committee Member

Consumers commented on previous attempts at developing a consumer organisation and the barriers to success. These included parochialism, personality driven approaches which were not representative of the collective consumer voice and an adversarial approach at times which created fear in some consumers in relation to the backlash they might receive. The consumers were much more encouraged by a refreshed approach which positioned the organisation as strategic, system focused and providing leadership and expertise underpinned by a strong evidence base.

6.2.2 Activities of the Organisation

The activities of the organisation identified in the consultations were similar across the different groups. The activities fell into four main groups:

- ***Capability building of both consumers and service providers***
  - Education and training of consumers and service providers
  - Support and mentoring for consumers
  - Developing policy and standards for consumer representation including remuneration etc
- ***Advocacy and advice***
  - Systems advocacy
  - Providing advice on safety and quality

  - Policy response and advice
- ***Consumer Engagement and development of a Consumer Network***
  - Providing a statewide consumer representative service including coordinating a central register of consumers
  - Facilitating consumer consultations
  - Leading consumer engagement strategies for government
- ***Information and resources***
  - Providing a clearing house: central repository of resources
  - Building consumer expertise : evidence base, national/international policy
  - Developing health literacy

In terms of activities that should not be part of this organisation, most people were of the view that individual advocacy should not be undertaken nor should the work of other organisations be duplicated. The Ombudsman was very clear that this organisation should not deal with complaints but refer them on.

> *"There are already clear legislative policies and protocols in place to address complaints within the health system" Ombudsman*

6.2.3 Linkages with other organisations

All the external stakeholders viewed this organisation as value adding. With the exception of FLOURISH, none of the organisations consulted were purely consumer organisations so they viewed the consumer perspective as the gap. They all spoke of the benefit of being able to have an organisation that could provide a consumer perspective and which provided an informed view based on training, support and mentoring of consumers. In terms of the potential interface, the stakeholders identified the following as important:

- Needs to have a partnership approach and not duplicate
- Needs to engage in joint projects and joint approaches to submissions and policy responses
- Provide a centrally coordinated training program for consumers
- Provide a coordinated consumer representative service for the state

The overall view was that if the health consumer organisation could provide a central mechanism for training and coordinating consumer representation, then consumer advocacy would become more consistent and well informed and that standards for consumer participation could be developed. There were significant benefits to be gained from a central organisation coordinating the training and the consumer representation across the state.

> *"This organisation would have added value to the Health Partners Consortium in providing support in the identification of consumer/community representatives, and also providing the HPC with information on their role, remuneration and how to integrate them into the Consortium (where the community representative is the only non-health representative) and perhaps also provided a great point of contact for me as the community representative to make contact with*

other representatives and prepare myself for the role (which has been a 'learn as I go' experience." (Consumer)

Clearly, there are a lot of synergies with the work of FLOURISH so early discussions on collaboration will need to be considered.

6.2.4 Funding and Governance

There was a unanimous view from the consultations that the state government needed to fund the organisation in the first instance which is consistent with the existing state and territory health consumer organisations. However, there were quite a few people who thought that Primary Health Tasmania which is funded by the Australian Government should also contribute funding.

"*If this organisation is co-funded by DHHS, TasHealth and Primary Health Tasmania it demonstrates State and Commonwealth commitment". (Stakeholder)*

Given that there is now one health service and one primary health care organisation in Tasmania, this seems to be a sensible option. Nevertheless, regardless of the funding arrangements, most people consulted with commented on the sustainability of the organisation and that the business model needs to enable diversified income streams.

In relation to the governance structure, most thought it should be a membership-based organisation with a skills-based board. Several made comments about auspicing and what organisations could fill that role but all were unanimous in their support for it to be independent. There were some real risks to the perception of independence if some organisations took on the auspicing role.

"*The auspicing agency would need to be aligned to the values and the core business of the organisation and would have to be careful for it not to be seen as part of the auspicing agency to protect its independence" (Stakeholder)*

One stakeholder wondered whether it might be worth considering the organisation to be an affiliate of one of the other bigger state and territory organisations due to the size and potential resource allocation available for this in Tasmania. Another suggestion was that maybe CHF would be an appropriate auspicing agency as it would be perceived as independent of Tasmania and has the corporate knowledge of health consumer organisations in Australia.

7 PROPOSED MODEL

Following the review of the existing state and territory health consumer organisations in Australia, consultations with key stakeholders, consumers and Steering Committee members in Tasmania and informed by international and national developments in consumer participation in health, a proposed model for a health consumer organisation in Tasmania is outlined below. The key components of the model are articulated and for each component, the rationale and evidence for the component is provided. Where appropriate, considerations are also be identified that will require further discussion and debate.

7.1 KEY COMPONENTS OF THE MODEL

The model includes 10 key components grouped around 6 domains:

	HEALTH CONSUMER ORGANISATION TASMANIA
Purpose	Statewide, value-adding organisation specifically focused on the consumer perspective in health and which provides independent, well informed expertise and advice
Funding	Funded by government (preferably state and commonwealth)
Governance	Independent organisation Membership based organisation with skills based Board
Role and Function	Facilitate the development of a statewide consumer network and to coordinate and lead statewide consumer engagement ensuring a diverse consumer voice Build capability of consumers and service providers to work in partnership to drive system change
Approach	Work in partnership with existing organisations Is contemporary, underpinned by a strong evidence base, and working in alignment with current health reform processes
Focus	Is strategic, systems-focused and statewide Focuses on prevention and early intervention as well as treatment

1. Independent Organisation

Independence is an essential component of the model, as having an organisation that is enabled to provide an independent voice will be seen as credible if health services are to be improved and system change effected.

Rationale: Consumers will not engage with an organisation that is not deemed to be independent nor will other stakeholders. A critical component of transforming the health system is empowering the consumer

voice and enhancing capability. Creating an organisation that empowers consumers to provide that independent advice and voice conveys respect and valuing of their views and insights and begins to demonstrate the change in power relations between consumers and health service providers. It creates a climate for collaboration and shared decision making.

Evidence: The evidence is overwhelming from the consultations and the literature. ACSQHC Standard 2 certainly supports the need to value, respect and empower the consumer voice. Independence signifies trust which is the foundation for any effective working relationship.

Considerations: Consideration needs to be given to the framing of the funding agreement and the drafting of the constitution to ensure the ability to provide an independent voice is enshrined.

2. Membership Based Organisation with a skills based Board.

It is proposed that the governance structure for this organisation is membership based. It will be important for consumers to "own" the organisation and participate in the decision making process. This is consistent with the previous feature of independence. However, it is also critical to the success of the organisation to have good governance so the ability to have a skills based Board will be essential. This means that several positions on the Board can be taken up by non-members that meet the gaps in the skills required at the Board level.

Rationale: This governance structure enables consumers to feel a sense of ownership of the organisation and be involved in the decision making while at the same time enabling good governance. Having a skills based Board ameliorates the risk of compromising governance in an effort to remain community controlled.

Evidence: The experience of the existing state and territory health consumer organisations would indicate that membership organisations with skills based boards are more effective. They have all been transitioning to this structure if they were not established in this way from the start. The consultations provided strong support for this type of governance structure.

Considerations: Consideration needs to be given to the legal structure that will best support the activities of the organisation. The choice will inevitably be between an Incorporated Association or a Company Limited by Guarantee. Both are the most common types of community based not-for-profit legal structures. Choosing the right incorporated structure is a very important legal decision as it has consequences for where the organisation is allowed to operate, the costs of operating the organisation, who the organisation must provide information to and what level of detail. Other considerations include applying for charitable status and Board membership and composition. This has implications for the drafting of the Constitution particularly in relation to types of membership, voting rights and the skill mix of the Board. (Refer www.nfplaw.org.au/legalstructure)

3. Statewide, value adding organisation specifically focused on the consumer perspective in health and which provides independent, well informed expertise and advice

This component of the model pertains to the purpose or value proposition of the organisation. It fills the gap in the existing landscape of services by being focused solely on the health consumer perspective. It needs to be seen as value adding to the existing organisations and health services by taking on a statewide, coordinating role.

Rationale: The health consumer sector in Tasmania is currently very fragmented, not well coordinated and doesn't have a statewide approach. FLOURISH is the only consumer network which has a statewide approach but focuses on mental health specifically. There is a need to develop a statewide organisation that adds value, coordinates and facilitates consumer representation, consumer training and support and provides high level advice.

Evidence: There was unanimous support for a health consumer organisation for Tasmania because it does fill a gap. Most of the consumer advocacy is either linked organisationally, to a population group or a condition. There is no organisation that specifically focuses on consumers.

Considerations: Consideration will need to be given to whether the organisation is referred to as a 'peak' or whether it is referred to as a coalition or forum. The latter is the preferred option of consumers and some stakeholders in that it acknowledges the existing organisations and working with them rather than the establishment of a new entity that organisations have to work with.

4. Facilitate the development of a statewide consumer network and to coordinate and lead statewide consumer engagement ensuring a diverse consumer voice

This component reflects one of the key functions of the organisation, to develop and facilitate a statewide consumer network which is inclusive of diverse consumer populations. The organisation will also be a leader in consumer engagement and develop and promote best practice in this area.

Rationale: It will be important as a first step in the establishment of the organisation to develop and implement a consumer engagement strategy with a view to establishing a statewide consumer network. It will be important for the network to include a diverse range of consumers including vulnerable groups, young people, older people and culturally diverse consumers.

Evidence: The consultations provided strong support for engaging with vulnerable groups as well as consumers across the lifespan. This is also supported by the literature, particularly the recent work in the UK and the consumer engagement literature.

***Considerations*:** Consideration will need to be given to connecting with consumers who are hard to reach and partnering with peak bodies already engaged with specific population groups.

5. Build capability of consumers and service providers to work in partnership to drive system change

Building capability of both consumers and health service providers needs to be a key function of the organisation. This involves education, training, support and mentoring to develop skills and capability to work in partnership.

Rationale: It will be just as important to build capability with the service providers to collaborate and work with consumers as it will be to support and enhance capability of consumers. It requires an attitudinal shift and a change in culture to develop the foundations of trust, respect and valuing of the respective positions for collaboration to occur.

Evidence: The evidence is clear from the literature, is supported by Standard 2 in the ACSQHC the work of the existing state and territory health consumer organisations and the consultations.

6. Working in Partnership

Another key component of the model is working in partnership. This component acknowledges there are existing organisations in Tasmania that play a role in consumer advocacy and participation and need to be linked into the work of this organisation.

Rationale: The organisation will not be able to achieve its goals without a partnership approach. Partnership will be really important in coordinating policy advice and response, engaging with specific population groups, developing a consumer engagement strategy and coordinating a consumer network. It will also be important not to duplicate the work of other organisations. It will also be helpful in promoting consistency and best practice across organisations in consumer engagement and participation.

Evidence: There was overwhelming support from the stakeholders in the consultations for a partnership approach. Partnerships ranged from working together on policy submission and joint projects to assisting this organisation to assume responsibilities they could benefit from (ie consumer training and support, consumer representative service) as well as partnering with the organisation to benefit their own constituent base. State and territory experience is that sustainability will be dependent on the development and establishment of strong partnerships.

Considerations: One of the first tasks of the organisation will be to undertake a partnership mapping and engagement strategy to clearly identify the partners and how they will work together and the type of partnership that needs to be established. Developing a collaborative partnership with FLOURISH is an important priority due to the synergies in role and function and given it already receives core funding from DHHS.

7. Is contemporary underpinned by a strong evidence base and working in alignment with current health reform processes

This is a really important component because it relates to intent and approach. The health consumer organisation needs to be a contemporary organisation which is reflected in its approach, strategies and resources. It needs to utilise current technologies, take a multi-dimensional evidence-based approach to consumer engagement and develop expertise and a body of knowledge on consumer-centred care. The consumer voice needs to be embedded in an evidence-based approach to lead and influence change.

Rationale: The health system is changing and the evidence base is increasing for a new and enhanced role for consumers to play. Old school advocacy strategies which rely on individual stories, personality driven, adversarial approaches need to be replaced with a representative, strategic voice which is well informed, educated and underpinned by an evidence base. Consumers need to be the leaders in consumer oriented care.

Evidence: Strong and growing evidence base for consumer- centred care and a growing appetite from consumers to be engaged in meaningful collaboration with the health system where they can engage in shared decision making and shape the future.

8. Is strategic, systems focused and statewide

This component is self-explanatory. The key focus will be to build capability to influence change and shape the future health system. Therefore, priority needs to be given to systems advocacy, providing a statewide view on consumer issues and ensuring a level of coordination across the system. Working in partnership and collaboration is inextricably linked to this component.

Rationale: There are already mechanisms for consumer advocacy, input and advice operating at local or organisational levels. What is currently missing in Tasmania is the overarching statewide view across a range of consumer population groups, settings and conditions. Ensuring co-ordination across health, disability and social care sectors is also needed.

Evidence: The evidence to support this component came from the existing state and territory organisation where the majority, focus on systems advocacy and from the consultations in Tasmania.

9. Focuses on prevention and early intervention as well as treatment

Ensuring access to and knowledge regarding interventions that will help prevent serious illness, complications or hospitalisations is as important as providing high quality accessible treatment when required. Influencing the health system to prioritise prevention and early intervention interventions as well as acute care needs to be a focus of this organisation in order to enhance the health and wellbeing of all Tasmanians.

Evidence: The evidence is strong from the UK that the health system needs to increasingly be cognisant of the social determinants of health and provide more holistic care across a wider variety of settings of everyday life. The recent outcomes of Mental Health reform in Australia (Commonwealth of Australia, 2015) stress the importance of focusing on early intervention and prevention in addressing mental health issues. Several stakeholders and a consumer strongly supported community development approaches to build community capacity for health and wellbeing. Encouraging and supporting health literacy, self-management and shared decision making were also mentioned by stakeholders and Committee members.

Considerations: Prevention and early intervention covers a broad area and begins to move into other sectors beyond health. Consideration will need to be given in any planning process on the role this organisation can play in this area and define specific areas of activity and roles and responsibilities.

10. Funded by Government

It is proposed that core funding for the establishment of the organisation is sought from the State Government Department of Health and Human Services (DHHS) and the Australian Government through PHT.

Rationale: The state government and PHT are the key beneficiaries of a health consumer organisation and will need to work in partnership with this organisation to drive system change and reform that is currently proposed. As they have responsibility for the public and primary health care system in Tasmania it is highly appropriate they contribute and support its establishment. It also gives legitimacy to the organisation and enables it to have a statewide 'whole-of-system' mandate. It gives a strong message to the community that it values the consumer voice.

Evidence: All the existing state and territory health consumer organisations receive core funding from their respective state health departments and all the participants in the consultations support the view that the state government should contribute funding. The consultation process also supported PHT being a co-funder.

***Considerations*:** Sufficient resourcing will be essential for the organisation to achieve its purpose and carry out its functions so consideration needs to be given to this. The length of the funding agreement also needs consideration in terms of ability to attract and retain good staff and sustainability.

8 RECOMMENDATIONS

The evidence supporting the development of a statewide health consumer organisation for Tasmania is overwhelmingly clear. The following recommendations are provided to inform the establishment and implementation phase providing there is agreement and support for this to proceed.

RECOMMENDATION 1: Consumers must be involved in all aspects of the implementation phase as partners

Consumers need to be involved in co-designing the organisational model and the implementation phase. The proposed model outlined in the previous section of the report outlines the key components but decisions will need to be made around the operationalising of those components (ie name, type of legal entity, membership model, skill mix on Board). It will be imperative to have consumers comprise at least 50% of the membership of any Steering Committee or Advisory Group overseeing the implementation phase. The consumers involved in the consultation process are well positioned to be champions of this new organisation as they represent the various segments of the consumer health sector in Tasmania and they are already well respected by their peers.

An important next step following the scoping phase will be to conduct a workshop with the consumers involved in the scoping phase consultations, the external stakeholders and the current Steering Committee to discuss the proposed process from here forward, components of the model and the implementation phase. It will also be important to then establish an Implementation Advisory Committee that will oversee the establishment and implementation phase.

RECOMMENDATION 2: The Independence of the organisation is ensured

In supporting the establishment of a health consumer organisation in Tasmania, everyone consulted was unanimous in their feedback that it must be seen as independent and not an instrument of government. It will be essential to ensure that the funding agreement and the constitution enable the organisation to represent an independent voice. Governments need to be held accountable and this organisation needs to have the ability to partner with government but also challenge them in ensuring that they shift towards consumer-centred care.

RECOMMENDATION 3: Consideration be given to CHF auspicing the establishment of the Health Consumer Organisation in Tasmania

There is merit in considering an organisation to act as an auspicing agency to provide support, mentoring and guidance through the establishment phase. The auspicing agency would work with the proposed Implementation Advisory Committee to establish the organisation and build its capacity to be independent. It is anticipated that the auspicing role would be at most for about 2 to 3 years.

Given that the perception of independence is such an important priority, the appointment of an auspicing agency is also significant in ensuring that the independence of the organisation is safeguarded. CHF should be seriously considered as the auspicing agency for several reasons. Firstly, it is the national peak body and therefore brings with it a wealth of knowledge and expertise in both the evidence base for consumer-centred care but also the experience of developing similar organisations in Australia. Secondly, CHF has the benefit of facilitating the network of state and territory health consumer organisations in Australia, and so can leverage resources to support Tasmania in a way that no local organisation in Tasmania can do.

Furthermore, CHF also has the national and international networks to assist in recruiting the right person to lead this organisation in Tasmania. Finally, although there are some peak organisations in Tasmania that could auspice this organisation, none have the strong consumer base and values that CHF has. Even the organisations that may have the infrastructure to auspice this organisation, were concerned regarding their capacity as well as the perception of independence which is regarded by everyone as essential to the success of the organisation. Tasmania is also in the enviable position of establishing a contemporary health consumer organisation aligned with current best practice in consumer engagement and participation and given CHF is driving the national policy reform in this area, makes it a good fit.

If CHF were to auspice this organisation, a specific auspicing contract would be developed between CHF and Tasmanian funders. CHF would then employ an interim General Manager, based in Tasmania to work in collaboration with the Implementation Advisory Group to establish the organisation. Although employed by CHF, this person would work under the auspicing contract with CHF CEO and Board which would enable this position to work more autonomously. CHF would be accountable through the auspicing contract to Tasmanian funders.

RECOMMMENDATION 4: Implementation is staged to enable the development of a consumer network and partnerships with stakeholders

Consideration needs to be given to a staged implementation process with the first stage being sourcing the funding, drafting the constitution, establishing a Board and recruiting a CEO. This would be followed by a phase of undertaking two foundational pieces of work: a consumer engagement strategy to develop a consumer network and a partnership mapping and engagement strategy to identify the partners and build a coalition of organisations that have a consumer health focus. There were some key organisations that were not consulted with as part of the scoping phase but will need to be included in this phase such as Neighborhood Houses, Youth Network of Tasmania (YNOT), Migrant Resource Centre and some of the charities such as Anglicare.

Following this, the organisation will be ready to embark on its core business of building capability within the system for partnering with consumers. It is very important to get the foundations in place because without consumers and partners, there is no organisation. This was certainly the advice from FLOURISH, the mental health consumer network during the consultations. Their feedback was that time needs to be taken in developing the constituent base before engaging in the core activities of the organisation.

RECOMMENDATION 5: There needs to be a communication strategy developed to inform community, consumers and stakeholders of the implementation process

Once the funding agreement is in place and the work in establishing the organisation begins, a communication strategy needs to be developed to inform consumers, stakeholders and the broader community of the implementation process. This would be the role of the auspicing agency in collaboration with the proposed Implementation Advisory Committee overseeing the implementation. Keeping the

broader consumer and stakeholder network informed of timelines and developments will help manage expectation and enhance confidence in the process.

RECOMMENDATION 6: Development of a Strategic Plan for the Organisation and a Business Plan that addresses sustainability need to be undertaken early in the implementation process

Once the foundational work has been completed a strategic plan will need to be developed for the organisation which outlines its core business, value proposition and key deliverables. It will be important for this to be undertaken early so that the organisation has clear guidelines to work with and can remain focused on its niche market.

Similarly, the Board will need to consider a business plan to address sustainability early so that strategies can be put in place over time to diversify the funding base and grow the organisation without complete dependence on government funding in the long term.

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APPENDIX 1 STEERING COMMITTEE TERMS OF REFERENCE

BACKGROUND

Primary Health Tasmania has provided funding to the Consumers Health Forum of Australia (CHF) to develop, scope and establish a peak health consumer organisation in Tasmania.

Most states and territories have a state-based peak healthcare organisation through which consumers are involved in shaping and influencing health policy - with Tasmania and the Northern Territory the two exceptions. In particular, there is an increasing emphasis on consumer -centred care and greater recognition of the consumer experience as an element of high quality health care which the health system must be better equipped to address. Currently in Tasmania, there are a number of organisations that provide consumers and families with condition specific advice and support, and there are other organisations which advocate on health issues relevant to their particular membership base, and in communities more broadly. A state-based consumer group which focuses on the health system and where health care providers and professionals can go to seek consumer input on their policies and services is missing. The aim of this project is to establish an independent alliance of existing health consumers and health consumer organisations and those with an interest in health consumer affairs that could work across the system building on the existing networks, interest and local expertise.

This project we hope will lead to the establishment of an organisation that – with full support of the Tasmanian health system – could:

- grow an organised consumer movement in Tasmania
- provide health planners and decision makers in Tasmania with informed strategic policy, health system and service development advice
- provide independent systemic health consumer advocacy and representation
- facilitate, promote and support health consumer advocacy, networking and leadership
- raise awareness of issues of interest to Tasmanian health care consumers through engagement , information dissemination and training

The Project will have two stages, Stage 1 will be the development and scoping phase which will include a consultation process and workshop. CHF have engaged a consultant Jennie Parham to undertake this phase. Stage 2 will be the establishment or implementation phase which will be undertaken by CHF in collaboration with the Steering Committee. It is anticipated that Stage 1 will be completed by April 2016 and Stage 2 by mid to late 2016.

PURPOSE OF THE COMMITTEE

The purpose of the Committee is to:

- Provide high level strategic input and advice to all phases of the project
- Provide advice and work closely with CHF and Consultants during the consultation processes undertaken as part of the Project
- Promote and support the Project's aims and objectives in existing networks
- Ensure that all stakeholders have been able to contribute to the development of the model in the most appropriate way
- Provide feedback and comments on discussion papers and other documents as required in a timely manner

- Partner with CHF to ensure implementation of the agreed model

MEMBERSHIP

Membership of the Steering Committee will include the following:

- Phil Edmonson (CEO, PHT)
- Annaliese Caney (PHT)
- Maree Gleeson (PHT)
- Pip Leedham (DHHS)
- Anthony Lawler (DHHS)
- Richard Eccleston (University of Tasmania)
- Graham Peterson (University of Tasmania)
- Judi Walker (THS Governing Council)
- Kym Goodes (CEO, TASCOSS)
- Kathryn Berry (CEO, Calvary Care)
- Leanne Wells (CEO, CHF)
- Jennie Parham (Consultant , Stage 1)

MEETINGS

The inaugural meeting of the Steering Committee will be held face to face with subsequent meetings on a "as needs basis" and may be face to face or teleconference.
Members will be required to participate in consultation processes and workshops as required and to provide feedback on discussion papers in relation to the scoping phase.
Summary notes of each meeting will be circulated following the meeting.

APPENDIX 2 LIST OF STAKEHOLDERS AND CONSUMERS WHO PARTICIPATED IN CONSULTATIONS

STEERING COMMITTEE

Phil Edmondson	CEO	Primary Health Tasmania
Maree Gleeson	Manager, Collaborative Population Health Planning	Primary Health Tasmania
Greg Peterson	Deputy Dean, Faculty of Health Co-Director, Health Services Innovation	UTAS
Richard Eccleston	Director, Institute for the Study of Social Change	UTAS
Pip Leedham	A/Deputy Secretary Director, Community Planning and Strategy	DHHS
Judi Walker	Member	Tasmanian Health Service (THS) Governing Council
Kathryn Berry	CEO	Calvary Care
Kym Goodes	CEO	TASCOSS
Leanne Wells	CEO	CHF Australia

EXTERNAL STAKEHOLDERS

Susan Powell	General Manager	Primary Health Tasmania
Connie Digolis	CEO	Mental Health Council Tasmania
Maggie Boughton	Senior Policy Officer	FLOURISH Mental Health Consumer Network
Sue Leitch	CEO	COTA
Darren Mathewson	CEO	Aged and Community Care Services
Graeme Lynch	CEO Chair	Heart Foundation Tasmanian Chronic Disease Prevention Alliance
Caroline Wells	CEO	Diabetes Tasmania
Richard Connock	Ombudsman and Health Complaints Commissioner	Office of the Ombudsman and Health Complaints Commission
Kate Fish	Operations Manager	Advocacy Tasmania
Judy Clarke	Chair	Tasmanian Aboriginal Reference Group
June Sculthorpe	Policy Officer	Tasmanian Aboriginal Centre
Kate Hiscock	Policy Officer	Local Government Association of Tasmania
Janine Arnold	CEO	Carers Tasmania
Theresa Hinton	Senior Research and Policy Officer	Anglicare, Disability Voices

David Alcorn	CEO	Tasmanian Health Service

CONSUMERS

Stuart Auckland	Chair	Community Advisory Council, Primary Health Tasmania
Alison Lai	Community representative	Health Partners Consortium Health Services Innovation, University of Tasmania
John Regan	Chair	Community Engagement Committee, THS South
Peter O'Sullivan	Member	Community Advisory Council THS North
Norma Jamieson	Member	Community Engagement Reference Group, THS NW
Fran Thompson	Consumer	COTA
Mary Parssissons	Consumer	COTA
Kris Todman	Consumer	Heart Foundation , Tasmania

APPENDIX 3 CONSULTATION QUESTIONS

STAKEHOLDERS AND COMMITTEE

1. Can you give me a brief overview of your organisation and in particular, engagement with consumers?

2. What does your organisation see as the benefits to Tasmania of establishing a consumer health organisation?
3. What activities should such an organisation undertake and what should be their role? (ie core business). How would this be different to the role and function of your organisation ?
4. Does your organisation have a view on what this organisation **should not do ?**
5. What gaps would this organisation fill?
6. What would the benefits of such an organisation be to yours and how would you perceive your organisation relating to this organisation once established. How would it add value?
7. Have you any thoughts about the type of governance this new organisation should have (ie membership, company etc)?
8. What are the challenges that need to be considered?
9. Does your organisation have a view on who should fund it and own it ?
10. Who is most appropriate to auspice the new organisation initially and why?
11. Any other comments?

APPENDIX 3 CONSULTATION QUESTIONS

CONSUMER FOCUS GROUP

1. What do you see as the benefits to Tasmania of establishing a consumer health organisation?
2. What activities should such an organisation undertake and what should be their role? (ie core business). How would this be different to the role and function of the organisation you represent ?
3. Do you have a view on what this organisation **should not do ?**
4. What gaps would this organisation fill?
5. How would you perceive the organisation you represent relating to this organisation once established. How would it add value?
6. Have you any thoughts about the type of governance this new organisation should have (ie membership, company etc)?
7. What are the challenges that need to be considered?
8. Who should fund it and own it?
9. Who is most appropriate to auspice the new organisation initially and why?
10. Any other comments?