

Summary of stakeholder and consumer consultations

1) Introduction:

Consultations are underway to inform the design of a health consumer-based organisation for Tasmania. To date, over 45 individual meetings and four larger group meetings or briefings have occurred.

This document provides a high-level summary of the consultations and highlights some of the reasons **why** Tasmania should have an independent, peak consumer organisation and commences the discussion on **what** a new organisation should or could focus on.

The stakeholder engagement diagram in section three outlines the three broad phases or steps underpinning the engagement process.

The first phase involves a situational analysis with the aim to review and assess the Tasmanian landscape and determine the priorities behind a Tasmanian organisation. Progress against this phase is summarised under the commentary **why**. The discussion provides an overview of the issues that have arisen through the consultations and groups them into five broad themes. The text in bold provides an observation or conclusion to the points being raised.

The second phase involves the drafting of an implementation plan and developing an agreed approach or focus for the organisation. Section four commences this conversation which will be concluded through a proposed stakeholder workshop scheduled for February 2019.

This document builds on and confirms the findings from a scoping report undertaken by Consumers Health Forum of Australia (CHF) in May 2016.

Date: 2 November 2018

2) Background

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.

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

- Changing nature of patient profiles including 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 agenda, that is monitoring and developing strategies for responding to medical errors and adverse events.

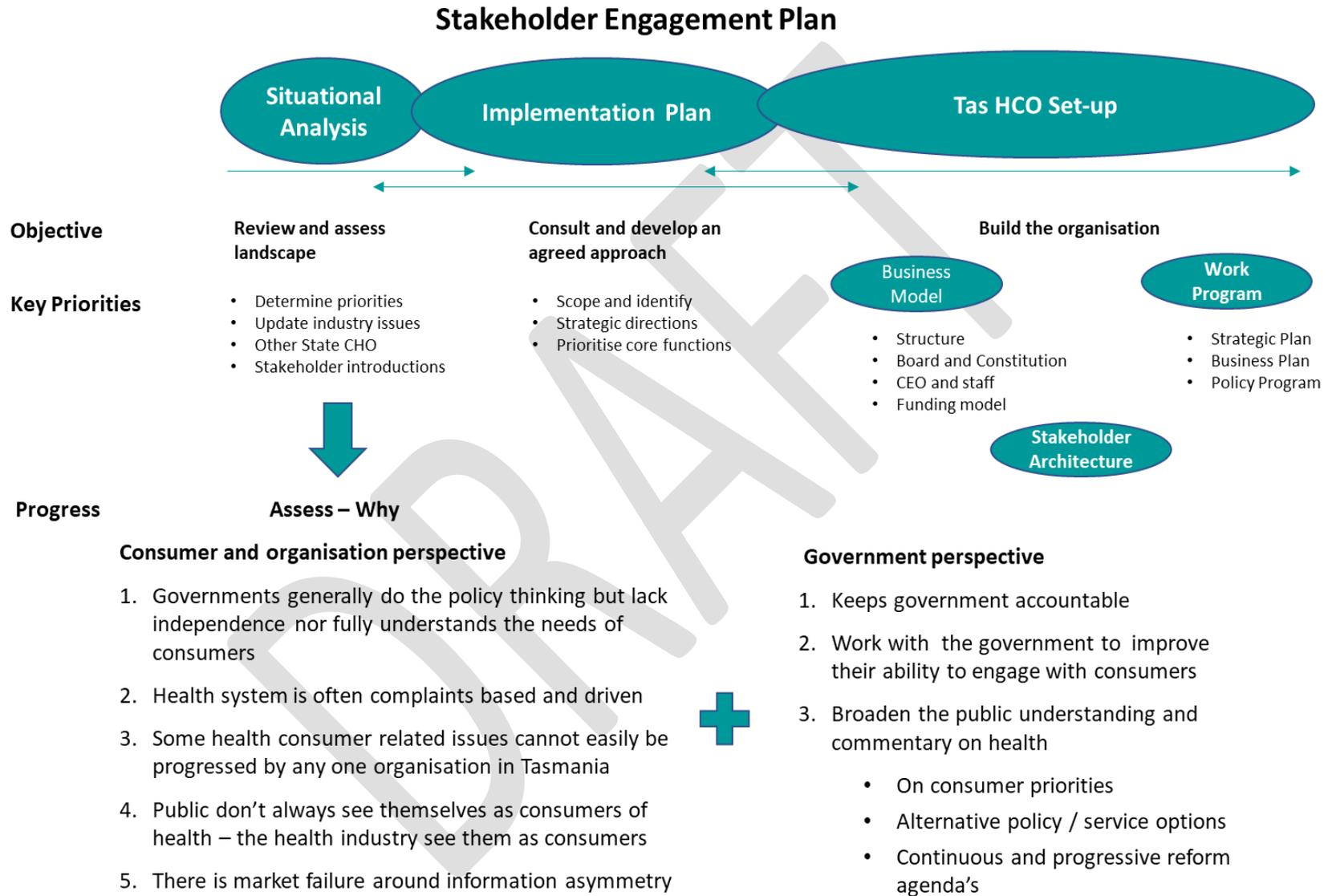
These factors have led to a shift in consumer activity and input from a focus on rights and advocacy to a greater role in understanding and promoting shared decision making and consumer-centred care.

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 scoping report undertaken by CHF in May 2016 into the establishment of a peak health consumer organisation in Tasmania confirmed there was overwhelming support for the establishment of an organisation in Tasmania. The report recommended a model incorporating ten key components summarised below:

	Key components of a Tasmanian health consumer-based organisation
Funding	1. Funded by government (preferably state and commonwealth)
Governance	2. Independent organisation 3. Membership based organisation with skills-based Board
Purpose	4. State-wide, value-adding organisation specifically focused on the consumer perspective in health and which provides independent, well informed expertise and advice
Role and Function	5. Facilitate the development of a state-wide consumer network and to coordinate and lead state-wide consumer engagement ensuring a diverse consumer voice 6. Build capability of consumers and service providers to work in partnership to drive system change
Approach	7. Work in partnership with existing organisations 8. Is contemporary, underpinned by a strong evidence base, and working in alignment with current health reform processes
Focus	9. Is strategic, systems-focused and state-wide 10. Focus on prevention and early intervention as well as treatment

3) Draft Results



WHY do we need to build a new health consumer organisation?

..... A consumer and not-for-profit sector perspective

1. Govt departments generally do the policy thinking - they are not necessarily independent or understand the views of the consumer / community

[There is an opportunity to strengthen the broader public policy conversation and analysis by ensuring the consumer voice drives both the agenda and shapes the solutions]

- Advocate for systems change – not necessarily individual advocacy unless there is a gap in the system
- Identify and promote alternative consumer driven solutions to health care: for example, explore and promote consumer driven
 - placed based or community-based health care
 - whole of person-centred care

2. Health system is complaints based and driven

[Therefore, consumer advocacy and organisational response is directed into specific areas where the need is visual and often time dependent]

- There is an opportunity to identify and build a longer-term, strategic and proactive position or voice on health from a systems-based perspective.
- Often disadvantaged and marginalised groups are unable to voice their views on standards / services or lack of services

3. There are health issues that can't necessarily or easily be progressed by one organisation alone as they incorporate and involve many different sectors within health

[service delivery is on the most part siloed and fragmented – therefore this directs consumer advocacy, consumer input and a consumer response which mirrors this environment]

- There is a need for consumer representation that is larger than any one sector, includes but is broader than both the lived experience and sector-based consumer advocacy but importantly strengthens and amplifies both these voices
- Ensure consumers are aware of direct and indirect issues or factors that contribute to being healthy and that the health debate is not just about acute care provided through hospitals. For example, the conversation covers
 - the social determinants of health
 - incorporates the issue of preventative health
 - whole of life perspective including meaningful health services across all phases of life

- Understand the inter-relationships and opportunities for collaboration across the specific membership-based organisations, whether they be placed based, condition based or demographic based
 - There is a need to support both the public advocacy and behind the scenes influencing role – in effect amplify the current activity
4. Public don't necessarily see themselves as consumers of health – the health industry see them as consumers

Consumer defn: free to choose and purchase a product or service (generally singular product/service)

significant legal framework around consumer protection that is understood

[This is a cultural issue and has implications on a range of factors including:

- **service provider – patient/consumer relationships;**
- **degree to which the industry will accept and invite community engagement;**
- **degree to which consumers understand their role and responsibility to provide input**
- **ability to access, and equality of access to health services]**

There are opportunities to support, train and mentor both

- the consumer - to be able to voice their viewpoint and feedback
- the service provider – to be able to listen, respect and act on the consumer voice to shape service delivery
- health system – decision makers and policy managers and funders are able to listen to the needs of the community to identify community requirements, design a system to meet the needs and then continually improve the system
- increasing the accountability of the health system and providers.

5. There is a market failure around Information asymmetry and this exists at many levels.

[This occurs in many forms, for example:

- **Information and communications between communities / consumers and the industry or service provider and also across different service providers]**

Opportunities therefore exist to

- Strengthen both the capacity (resources) and capability of health service provider to engage meaningfully with the consumer
- Strengthen and improve the health literacy of the broader community
- Greater collaboration and two-way information sharing between service providers and consumers
- Greater collaboration and two-way information sharing between policy and decision makers and across service providers

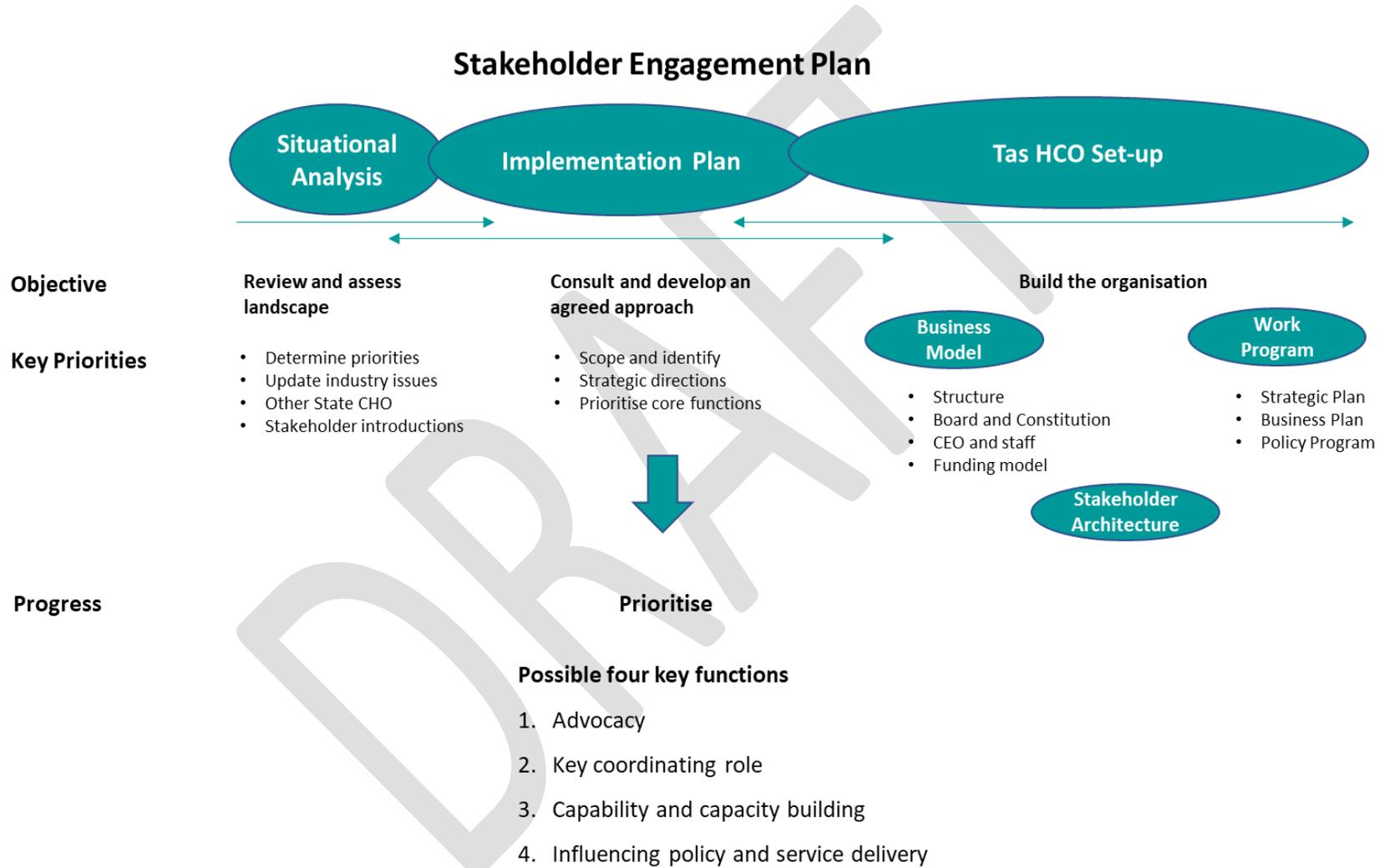
..... A government perspective

The Government's (both state and federal) have outlined a number of reasons why they would like to see the Tasmanian HCO be established:

They require an organisation that

- Can make the Department, and hence the Government more accountable to the public
- The Department acknowledges it needs to improve how it works with consumers and require external and independent advice on how best to engage consumers
- Specifically, the Department would like to strengthen a consumer perspective on prevention, non- acute and community health reform more so than on acute health, where there has been a longer standing series of arrangements for consumer input.
- The Departments require consumer engagement across a range of areas ranging from larger systems-based issues through to local service level-issues.
- Lacking across Tasmania is a coordinated consumer voice that can:
 - provide advice on consumer priorities for health state-wide
 - influence a range of public health reforms
 - provide advice on what Government isn't doing and new opportunities
 - provide advice on how to best deal with alternative policy and service delivery approaches
 - in the longer term, engage the consumer voice into the big public health debates and be proactive in advocating for continuous and progressive reform.

4) What a new organisation should or could focus on



What a new organisation should or could focus on

Possible four key areas of focus for the new organisation

Why	What
1. Governments generally do the policy thinking	i. Advocacy <ul style="list-style-type: none"> a. On big health issues, alternative consumer driven solutions with a long-term focus b. Building evidence to support system-based change c. Government budget influencing
2. Systems are complaints driven	
3. Health issues that can't be progressed easily by one organisation	ii. Key coordinating role <ul style="list-style-type: none"> a. Developing overarching messages and identify opportunities to support and amplify existing messaging b. Ensure all voices across the health system are incorporated <ul style="list-style-type: none"> - eg marginalised or disadvantaged c. Process to communicate back to stakeholders and out to the community
4. Community – service provider relationship	iii. Capability and capacity building <ul style="list-style-type: none"> a. Training and support for <ul style="list-style-type: none"> - Policy makers - Decision makers - Consumers b. Support to existing organisations to help strengthen their consumer engagement capabilities
5. Information Asymmetry	iv. Influencing policy and service delivery <ul style="list-style-type: none"> a. Ensure decision makers have consumer input into policy and service delivery b. Health literacy