Consumer and Community Engagement Council THS South

Attention: Minister for Health
Hon Sarah Courtney

Dear Minister,

Consumer and Community Engagement Council (CCEC) THS South appreciate the opportunity to provide feedback on the Healthcare Futures document. Members of the CCEC would appreciate the opportunity to contribute to ongoing discussions and initiatives that arise from this Healthcare Futures consultation. We look forward to ongoing engagement at all levels of the Department of Health Tasmania and Tasmania Health Service (THS) as partners in improving healthcare outcomes in Tasmania.

Yours sincerely,

Dr Heather Gluyas

Chair
Consumer and Community Engagement Council THS South

4th February 2021

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FEBRUARY 4, 2021

RESPONSE PAPER TO OUR HEALTH CARE FUTURES 2020

CONSUMER AND COMMUNITY ENGAGEMENT COUNCIL THS SOUTH

Introduction

This paper has been developed and is submitted by the Consumer and Community Engagement Council (CCEC) THS South. The submission is based on various resources including research literature, Government and Health Consumers' websites, and lived experience and professional knowledge of the members of the CCEC. As part of our submission we highly recommend the Health Consumers Tasmania (HCT) discussion paper submitted in response to the *Healthcare Futures* consultation request. We fully support and endorse the HCT recommendations. Our response has been developed independently and adds further support to the HCT recommendations and discussion.

The paper is presented in the following sections:

- Section 1: Better Community Care
- Section 2: Modernising Health System ICT infrastructure
- Section 3: Strengthening the Clinical and Consumer voice
- Summary
- Full list of Recommendations

There are eight recommendations for action presented. These are embedded within the body discussion of each section. The recommendations are then presented in totality at the end of the paper.

Section 1: Better Community Care

There is more than a quarter of a million people admitted to hospital for illnesses that could have been prevented or managed in the community [1]. In the main these admissions are for patients with chronic conditions, many of which are related to type 1 and 2 diabetes, obesity and smoking. The experience of these admission for potentially preventable acute admissions is reflected in the statistics for 2017-18 where approximately 50% of all people admitted to hospital were for chronic conditions [2]. Tasmania is disproportionally represented in these statistics, having the third highest percentage nationally of Type 1 and 2 diabetes, with 63% of Tasmanians overweight and, the worst prevalence of smoking nationally. Combining this with the other factors that impact on the prevalence of chronic diseases such as the ageing demographic of the Tasmanian population; the percentage of Tasmanians who live in areas ranked as most disadvantage (33%); high unemployment; and, financial barriers such as the lack of bulk billing GPs, it is imperative that the THS identifies strategies to address these challenges [2].

The current network of Community and Health Services and Multipurpose Service (MPS) centres throughout Tasmania, which on the face of it, should be providing effective access for primary and community care. These type of integrated care centres provide a mixture of services from home based nursing, health assessments and referrals, child health centres, community nursing, allied heath such as physiotherapy, podiatry and mental health services. As well, in the case of MPS centres, aged care residential, respite and some subacute and acute care are provided to the communities they serve. However, given the feedback collected by HCT [2 pp. 7-8], it would appear that there are barriers to access and utilisation that

are not being recognised. Levesque et al. [3] provide a conceptual model (see Figure 1) that captures the enablers and barriers to access and utilisation of community health services.
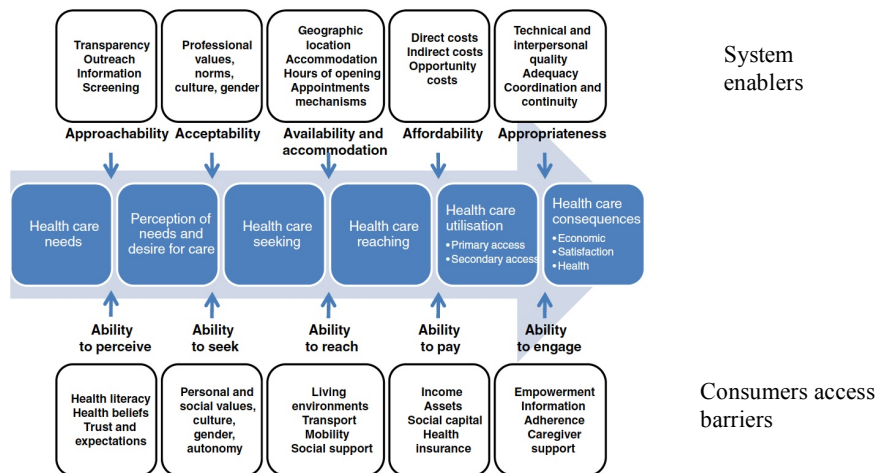

System enablers

Consumers access barriers

The enablers of an effective community service provision are that the consumer needs to know that the service exists (approachability); that the service is acceptable and appropriate socially and culturally for the population it is serving (acceptability); that the service is able to be accessed geographically, physically and in a timely manner (availability and accommodation); that it is economically possible for the consumer to attend (affordability); and, that there is a match between the service provided and the consumers health care needs (appropriateness).

The barriers to consumers accessing community care are that the consumer may not be able recognise and understand their need for care (ability to perceive); that they may not have the capacity, autonomy to recognise the need for care or the manner of health care provision may be culturally or socially unacceptable to the consumer (ability to seek care); that the consumer may not have the transport, time or mobility to attend community care (ability to reach); that the consumer does not have the financial or time resources to attend for care (affordability); and, that the consumer has the health literacy and confidence to participate actively in discussion of care and treatment options that suit their wishes and values(ability to engage) [3]. The ability to engage is also often frustrated as the consumer does may not know the question to ask. While this is a feature of health literacy it is more about knowing what to ask in order to get the right direction, not necessarily the correct answer.

An important step in increasing access and utilisation is to recognise that health service enablers and the individuals' utilisation barriers are not discrete but rather they interact with each other and differently for each episode of care for each individual health care consumer.

Consideration could be given to implementing a model that extends the current Community and Health Services and Multipurpose Service centres and District Hospitals to provide more outreach care for chronic and complex care, increased subacute beds for early intervention for deterioration in chronic conditions, extending the current the North West Rapid Response service. Increasing the use of nurse practitioners, midwives and other allied health practitioners in GP practices and other primary care settings would allow consumers access to a "one stop shop". Finally, further investigation to the use of a health care workforce whose

primary role is to help health consumers navigate and connect with appropriate health care providers. These are termed in other jurisdictions and countries as health navigators, lay workers, peer supporters, care facilitators and health connectors.

The voice of consumers from the region is critical for the design and delivery of the services in the particular region, and in the on-going monitoring and evaluation of the arrangements, especially to ensure the decentralised health services remain appropriate given inevitable changes in the delivery of community services and in the patient needs.

Recommendation 1: Implement a community health model to provide more outreach care for chronic/complex cases. This proposal would be a comprehensive improvement to the current Community and Health Services, Multipurpose Service centres and District Hospitals and North West Rapid Response service.

Recommendation 2: In consultation with the local community and consumers of each metropolitan, rural and regional area, identify and address the barriers related to approachability acceptability, availability and accommodation, affordability, and appropriateness, which are affecting current access and utilisation for the particular community.

Section 2: Modernising Health System ICT infrastructure

An effective digital health program offers enormous possibilities to improve care including better coordination of care for complex and chronic conditions, reduced duplication of tests, better informed health professionals and consumers when considering treatment options, giving consumers control of their health and care, less errors in care and, reduced hospital admissions [4]. Federally a 10-year digital project is being rolled out to all States and Territories. However, this would appear to be piecemeal, with a focus on pilot projects. As an example, if we look at the "My Health Record" program, at the beginning of 2020 more than 90% of Australians have a record created, noting that it was an "op out" system and thus creation was automatic unless you opted out. However, only just over half of those have anything uploaded into them. The registration to use "My Health Record" statistics for GPs (90%), public hospital (93%) pharmacies (69%) is better, but with only half the records having anything in them, it is clear that registering to use doesn't mean it is being used. To add to this only approximately 1 in 10 consumers have ever logged in to view their record [5; 6]. Given the identified benefits that would flow from an effective and well implemented digital health program it is incumbent on the Department to identify the barriers to the use of current initiatives and implement strategies to implement an effective digital health program in Tasmania.

Covid has provided a unique opportunity for growth within the general and medical and allied health professional communities' knowledge and acceptance of electronic communication (tele and videoconferencing) for advice and consultation using the telephone and applications such as Zoom & Microsoft Teams. While this would, and should, not replace face to face interactions entirely, this acceptance of the technology could be harnessed to decrease wait times by dealing with such things as initial consultations, appointments for referrals, sick notes, prescription renewals. The option of extending tele and videoconferencing is supported by Health Consumers Forum of Australia survey in March/April 2020 in which 82% found telehealth services to be excellent or good quality.

There were however barriers reported that included unreliable internet, affordability, awareness of the option, access to required technology and availability [7]. So, if this service was to be extended these barriers would need to be addressed. As well, these consults would need to be Medicare funded as they have been during Covid to ensure acceptability to the community and health professionals.

These non face-to-face consults could also be used for specialist appointments so that people are not faced with travelling to the main centres to access these appointments. The regional and remote areas of West Australia and Queensland offer a model that could be adopted in Tasmania. In this model the patient attends a local regional or community clinic where video conferencing has been put in place. The doctor in the metropolitan area consults with the patient over the video conferencing facility in the presence of a nursing or allied health. The nurse or allied health professionals undertakes any physical observations required (e.g. Blood pressure, temperature etc…) the information to the doctor. The travel cost and time for both the patient and the doctor are minimised.

Recommendation 3: Invest in information technology to provide a seamless, efficient and effective process, for any member of the community, accessing any health facility across Tasmania. This includes investigating the barriers to uptake of current digital health initiatives and implementing strategies to overcome those barriers. This should also look into extending and improving electronic video and telecommunications between patients and health professionals.

Section 3: Strengthening the Clinical and Consumer voice

There is much rhetoric around the need to involve patients and their families (consumers) in their care, as well as encouraging consumers to participate in the decision making around service provision, governance and policy making. Intuitively it makes sense that at the individual care level patients should play a key role in choosing treatment options. This would increase the likelihood that treatment is appropriately administered, monitored and adhered to, and in the prevention of adverse events occurring during their treatment and care. It also makes good sense to have consumers actively involved in the organisation of health services from service level through to a governmental and policy development. While there is increasing evidence that active involvement of consumers at all levels has a positive effect on quality of care and outcomes, it is also important to recognise that users of the health service have a legitimate and valid role in contributing to decisions about the delivery and planning of healthcare.

Recognising the importance of consumer involvement, the ASQHCS standards emphasise a central tenet that health care services require stronger involvement of consumer involvement at all levels of healthcare service delivery and planning. However, despite this recognition, progress in involving consumers is patchy and sluggish and is in the main concentrated at the lower end of involvement – that is informing and consultation rather than collaboration, involvement, partnership, co-design and, shared leadership with consumers [8; 9; 10]. While some health professionals and healthcare organisations may not embrace the idea of collaboration and power sharing with consumers, many more are committed to consumer involvement. However, a commitment at senior governmental and health service executive level to resourcing, educating and supporting healthcare professionals and organisations to

share power and to view consumers' views and values as equally important in discussions and decision-making is required. Without this commitment, progress in harnessing the invaluable contribution that consumers can contribute to ensure effective, efficient and quality healthcare delivery will remain a lost opportunity

Clinical Senates

An effective Statewide Clinical Senate could provide the link between decisions about healthcare reforms or initiatives at the Department of Health and Healthcare executives and the clinicians responsible for delivering care at the local service level. A clinical senate would bring together multidisciplinary health professionals from different clinical streams and service areas and consumers, to discuss and make recommendations about health care options and programs accords the spectrum of healthcare. The senate would require administrative and research support to ensure the topics of discussion are informed by the latest research and evidence. The advantage of this type of forum is that clinicians and consumers, who must be engaged and committed for any reforms to come to fruition, are involved in the decision making and understand the evidence and research factors that underpin the identification of priorities and decision pathways. As well, the executives are hearing firsthand what clinicians believe is doable in the reality of service delivery, and what consumers value and require from a healthcare service [11].

If the Department of Health Tasmania proceeds with this model, consumers should be involved from the beginning in developing the framework for the Clinical Senate. Subsequent consumer membership should not be a tokenisation e.g. 1-2% representation, but rather a meaningful percentage with the capacity to undertake leadership roles within the senate. Consumer representation is vital as clinicians are focussed on actions drawn from their own disciplines or on actions that can be achieved jointly with other clinicians, while the consumer is focussed on the situation from the individual's perspective to see the broader social or community ramifications. However, the consumer participants would need to be able to provide a broad range of views from groups representing the aged, special needs, culturally and linguistically diverse, rural, regional and metropolitan, mental health, chronically ill and primary perspectives. While diverse representation as described would be challenging we would suggest that there is a core membership of consumers on the Clinical senate with others seconded to represent different areas depending on the particular focus of the Senate at the time.

Recommendation 4: Implement an effective State-wide Clinical Senate ensuring that:

- **Consumers are involved in the planning, implementation and evaluation of a Tasmanian Clinical Senate.**
- **Consumers have significant representation on the Clinical Senate with the opportunity for leadership roles as members of the Tasmanian Clinical Senate**

Meaningful consumer engagement at higher levels of organisation design and governance, and policy making

The comments above in regards to Clinical Senate should be considered in relation to this question, especially in relation to consumer engagement at a system level. There needs to be consumer representation at all levels of health planning, delivery and quality improvement from government health policy, governance and planning, through to health service

governance and planning and clinical service delivery. This range of consumer representation would support consumers' experiences and perspectives being integrated into the design and governance of services.

Carman et al [12] describe three levels of engagement being direct care, organisational design and governance and, policy making (see Figure 2). At each of those levels there is increasing levels of consumer involvement with low level engagement identified as consultation, where information is principally unidirectional such as patient information pamphlets, surveys, feedback or complaints). The second level of involvement has two-way information sharing and, at the highest level consumers are involved as partners, co-designers, sharing in leadership and decision-making.
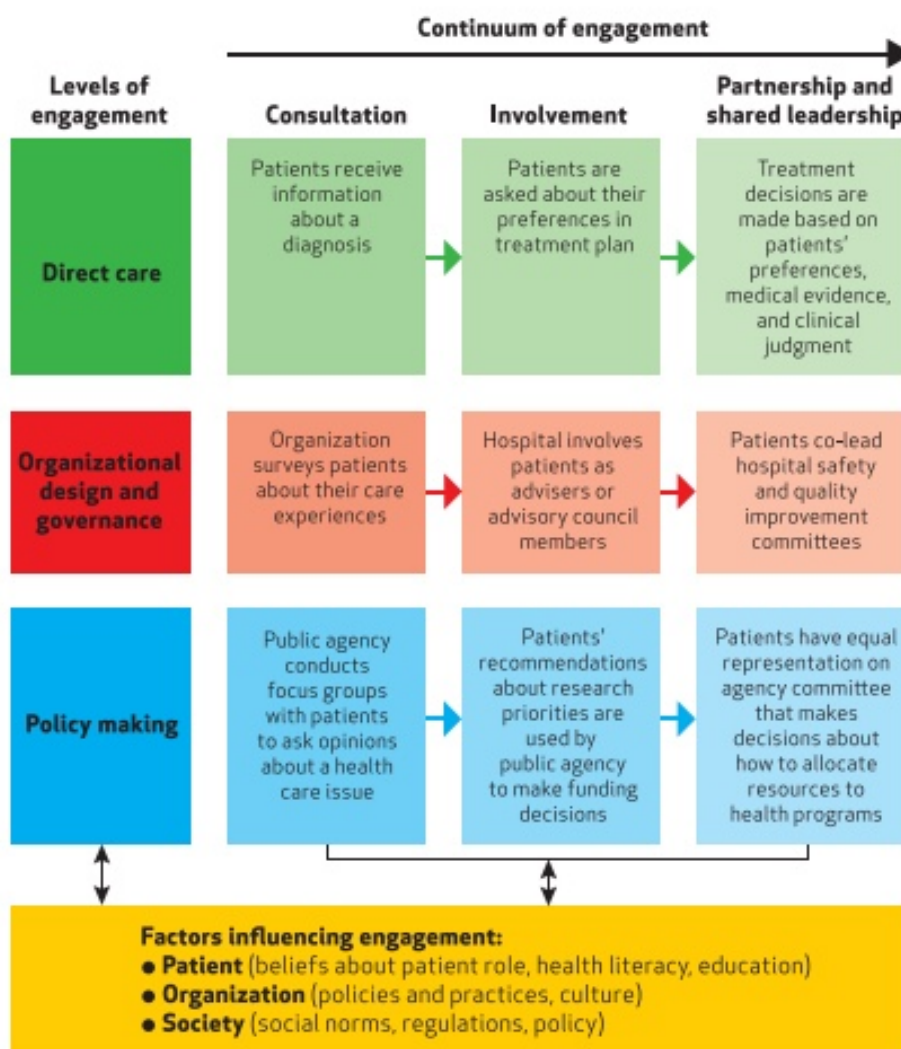

Figure 2: Continuum of consumer engagement. (Carman et al; pg. 225) (12). Used with permission of Project Hope/Health Affairs Publishers

Current consumer participation from direct care through to policy making across the Tasmanian Health Service (THS) is mainly at the level of unidirectional communication consultation level, with pockets occurring at the bidirectional communication involvement

level, with little evidence that there is much involvement at the shared decision making higher levels [2]. If the Department of Health Tasmania is committed to better and more effective engagement, then strategies to increase consumer engagement at higher levels need to be implemented. To identify strategies there needs to be a greater understanding of the barriers that exist that influence the lack of consumer engagement.

The barriers of language, culture, poor health literacy and health professional attitudes and behaviours are issues that impede consumers from being involved at health service design and governance and policy making levels. Moreover, there are other barriers that consumers themselves identify as impacting on their willingness to be involved. These include:

- Perception that there was inaction or no outcomes achieved while being a consumer representative
- Tokenism – in terms of whether their involvement was genuinely wanted and valued
- Feeling uncertain about how to undertake the role and their capacity to fulfil expectations as representing "all" consumer views
- The time, financial and technological "costs" of being involved
- Ability to deal with conflict when there was a division between what consumers wanted and what the organisation wanted
- Experiencing intimidation, discrimination, rejection or humiliation, and disrespect by health professionals [13]

If the Department of Health Tasmania is going to embrace the rhetoric that commits health care organisations and professionals to involving consumers in the planning, provision and evaluation of care delivery systems then there must be a firm commitment to addressing the barriers that hinder their involvement.

Recommendation 5: Improve the current consumer engagement processes to make it more effective, efficient and seamless across the State. This includes:

- **Committing to a goal of increasing consumer involvement across the three levels of consulting, involving and partnership/ shared leadership engagement.**
- **An explicit consumer involvement framework and strategy covering all levels of engagement from direct care, organisation design and, governance and policy making**
- **Further investment in staff resources, for a more effective consumer engagement process**
- **Investment in customer care systems and resources for improved research into consumer feedback, including evaluation and reporting back to the community**
- **Inclusion in all THS job descriptions and performance indicators that consumer involvement is a priority in the planning, implementing and evaluation of health care delivery**

Opportunities to strengthen and optimise consumer engagement in person's own care

Any episode of patient care may involve multiple sectors (primary, residential, secondary and tertiary and many health professionals in each of those contexts (doctors, nurses, allied health, paramedics). However, the only person who is going to be there for the whole episode of care is the health care consumer. Consumers then are uniquely placed to provide

information and perspectives that will contribute to a positive outcome. The consumer also has a high investment in seeking the best health outcome. There are multiple areas that a consumer can be involved in their care including but not limited to the following:

- Helping to reach an accurate diagnosis – consumers can provide clinicians with information about their illness (symptoms, duration, onset, location, alleviating or precipitating factors etc.…) that will increase the likelihood of an accurate diagnosis.
- Informed consent about treatments and procedures - consumers should be involved in decision about their treatment options. They are absolutely familiar with their own circumstances, values and preferences and given accurate information about the harms and benefits of treatment options the decision about treatment choices should be shared between patients and the clinicians.
- Medication management – consumers who are informed about their medication regime, including expected action and possible side effects are then able to inform staff about their response to the medication.
- Checking medical records – while the practice of consumers having access to their medical records is uncommon, if this practice became widespread the benefits would be two-fold in terms of checking accuracy of the records and also in patients giving a greater understanding of their health status.
- Involving patients in open disclosure processes when an adverse event happens. This is a unique opportunity for the organisation and health professionals to provide their perspective of the events, which can be utilised in planning to minimise similar incidents occurring in the future [14].

As noted in previous sections, language, literacy levels, gender attitudes and health beliefs can be major hurdles for effective consumer involvement and collaboration. Consumers may not understand how to access appropriate services, but if they do, they may not understand the treatment options or the care plan that is instituted. Health professionals may not appreciate the difficulties that these factors cause and make assumptions about health choices, and care plans that do not meet the needs of the individual consumer [14].

The lack of health literacy can inhibit consumers from being involved in their care. Not knowing the terminology, or having a professional or personal background that gives the consumer some knowledge of medical terminology, medical conditions or the health care environment, can lead consumers to be overwhelmed and unable to question or discuss their care options and make decisions. A recent survey by Consumers Health Forum of Australia found 73% of respondents stated they had had occasions when they had struggled to understand what a health professional was saying [15]

A perception of a paternalistic or non- caring attitude is a powerful barrier to consumer involvement. Patients can feel powerless and vulnerable faced with a directive and dominant attitude in their interactions with health professionals. Especially if they feel excluded in discussions about their health as can occur when staff are discussing a patients care plan when handing over care or doing medical "rounds". This can also occur when staff discuss the patient care with relatives and the patient is not included in the discussion.

Consumers also perceive the structure of the work environment and care delivery framework as a barrier for involvement in their care. Multiple health professionals providing care can prevent active engagement as the consumer tells the same story multiple times, answers the same questions repeatedly and finds there is a lack of consistency and continuity in the plan

and management of their care. Having to interact with a multitude of different health professionals may mean that the consumer does not have the opportunity to form a meaningful trust relationship with any particular health professional which makes it very difficult for them to have input and involvement in the planning of their care

Health professionals require education and training in understanding the barriers that prevent consumers being active participants and how paternalistic medical model of care undermines consumers' power and abilities to be equal partners in decision making.

Recommendation 6: **Implement education and training for all health professionals that focuses on communication, cultural change, consumers as partners, and shared values based decision making.**

Consumer feedback on care provision

The direct voice of the patient and their carers (community) is currently limited. Prime sources are from feedback offered at the time the service is received, from complaints and compliments, and from THS-initiated surveys. None of these sources alone offer a significant contribution to the services offered or delivered.

Apart from the community engagement in any roll-out of regional service hubs, mentioned above, there are many areas where consumers can be invited to give valuable feedback by the use of clear and encouraging questions. For example:

- After your recent stay in hospital what could have been done to make it easier?
- Do you believe you received adequate medical care and your needs attended to?
- What do you believe could improve any future hospital admissions and/or care?
- What do you think could have been asked, but was not, during your last admission process?
- Did you get help and information you think you needed when you were being discharged?
- What do you think would best assist or improve your care in hospital?
- What would you like to happen when you are being discharged and when would you like that to occur? *This could be asked the day before, on the day of discharge or through contact after discharge at home - particularly for those who are elderly, have a number of health issues and/or live on their own with little to no at home care.*

Peer workers, non-clinical staff, and consumer volunteers (who are trained and appropriately screened) in a hospital setting can help "sell" the feedback form and questions through conversation and engagement, to give consumers a sense of trust. This approach can educate the consumer as to their value, and that of their opinion, and give assurance that their voice is heard and can make a difference.

The Royal Hobart Hospital (RHH) is currently collecting comprehensive patient feedback post discharge by mail out however, with a 28% response rate there are obviously challenges in getting responses returned. While this is an excellent initiative there is are still opportunities to gather focusing more on qualitative data with face to face interviews as described above.

Recommendation 7: Investigate the opportunities to increase consumer feedback using peer workers, non-clinical staff, and consumer volunteers to interview consumers face to face.

Three suggested Models of consumer engagement and participation

1. *Tasmanian Health Service Community and Consumer Engagement Councils*

The CCEC THS South, North and North West are actively engaged within their health services in organisational design and governance and policy level at both a consultation one-way feedback) and involvement (bidirectional feedback). As well, the Chairs of these groups meet with the Department secretary to provide feedback. The model is an excellent example of effective consumer engagement and participation. Of course, it is hoped that this engagement will continue and overtime will lead to lead to engagement at the higher level of partnership and shared leadership.

It is important to note that in the main there is genuine commitment by clinicians and senior managers and the THS Strategy and Planning Unit and Quality and Patient Safety teams to engage with consumers and the work program of the CCEC. Yet, as the profile of the CCEC members and their contributions within the THS grows, the workload for the members of CCEC and the THS Strategy and Planning Unit, and the Quality and Patient Safety Teams in coordinating and supporting the CCEC teams, is also growing. It is thus imperative that the increased workload of THS Strategy and Planning Unit and Quality and Patient Safety Teams in supporting the CCEC teams are resourced adequately to support CCEC members ongoing engagement in the multitude of activities.

2. *Co-design Methodology to Improve Health Care Services*

A further model of engagement that is in its infancy but is developing is the co-design methodology. This model uses patient experience and staff experience as equal partners to design change processes to improve care [16]. The methodology has been used in many countries including Australia, Canada, England, New Zealand and the United States for projects in many clinical areas including emergency medicine, drug and alcohol, cancer services and mental health. [16]. An example of this model of engagement was used in Victoria in the CORE Study (see https://medicine.unimelb.edu.au/research-groups/general-practice-research/mental-health-program/the-core-study) between 2013-2017. It led to the development of a purposive engagement model to work with people experiencing severe mental illness. New Zealand which has a similar healthcare system to Australia provides further examples of successful co-design projects. Examples of co-design tools utilised, projects and project evaluations are available at the following websites:
https://www.healthcodesign.org.nz/ and
https://www.hqsc.govt.nz/our-programmes/partners-in-care/work-programmes/co-design/

Co-design methods are demonstrating very successful health service delivery change projects at a time when demand and health resources are becoming increasingly challenged. The Co-design method provides an excellent model that could be used successfully to improve care and health outcomes throughout the THS.

3. Peer workers

Peer workers have been mentioned previously in this paper in the context of community care models and consumer engagement and feedback. However, the subject of a peer workforce model, who are involved in the care delivery, deserves a separate section. Currently this model is almost exclusively with in the mental health field of care both in Australia, and other countries including New Zealand, Canada, Hong Kong and the United Kingdom [17].

Peer workers are consumers who have lived experience of either mental health illness and recovery or as family member or friend who has supported a person with mental health issues. They draw on this lived experience to undertake a variety of roles within the mental health services including individual and systemic advocacy, peer support, health promotion, education and training, research and innovations, coordination and management, and increasing engagement and participation in treatment [17]. This model of peer worker support has proved successful and sustainable within the mental health sector and is actively embraced in the Tasmanian Mental Health Sector [18]. However, there is no reason why this could not be extended to other areas, especially within the primary care and community sector.

Recommendation 8: Other consumer engagement processes are implemented to derive maximum benefits to the community. Including:

- **Ensuring continuation of the current engagement model of Consumer and Community Engagement Councils and encouraging moves to mature the model to one of partnership and shared leadership. This will also require that the THS Strategy and Planning Unit, and Quality and Patient Safety teams are adequately resourced to maintain the required support to CCEC members and their activities.**
- **Adopting the co-design model for use in the design, implementation and evaluation of the health care service improvements in Tasmania.**
- **Investigates and trialling a peer workers support program in other areas of the primary and community health sector**

Summary

The CCEC THS South appreciate the opportunity to provide feedback on the Healthcare Futures Document. It is hoped that this is received and actioned mindful of the experience of consumers in regards to tokenism and lack of outcomes summarised in the sections above. Members of the CCEC would appreciate the opportunity to contribute to ongoing discussions and initiatives that arise from this Healthcare Futures consultation. We look forward to ongoing engagement at all levels of the Department of Health Tasmania and Tasmania Health Service (THS) as partners in improving healthcare outcomes in Tasmania.

RECOMMENDATIONS

Recommendation 1: Implement a community health model to provide more outreach care for chronic/complex cases. This proposal would be a comprehensive improvement to the current Community and Health Services, Multipurpose Service centres and District Hospitals and North West Rapid Response service.

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Recommendation 6: Implement education and training for all health professionals that focuses on communication, cultural change, consumers as partners, and shared values based decision making.

Recommendation 7: Investigate the opportunities to increase consumer feedback using peer workers, non-clinical staff, and consumer volunteers to interview consumers face to face.

Recommendation 8: Other consumer engagement processes are implemented to derive maximum benefits to the community. Including:

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