Social Determinants of Health Advocacy Network (Tasmania)

*Just words…*

What we talk about when we talk about health

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Report Summary

Why this study?

In Tasmania, particularly in recent times, the term ‘social determinants of health’ has gained increasing prominence – both in the community sector and to a lesser extent in government policy. But just how well are such terms understood – and importantly how are they understood by those who are experiencing the very things we are talking about? This study used a qualitative research design and recruited people in the community across Tasmania who had little prior knowledge of the language of social determinants of health to participate in focus groups or interviews. We sought to build an understanding of how ‘everyday’ Tasmanians interpret and understand this language in the context of their own lives as well as broader society.

Main messages

- Health inequity matters to ‘everyday’ Tasmanians.

- Words are not enough – the language surrounding the concept of the ‘social determinants of health’ must lead to actions to address the social determinants of health and health inequity.

- Poor health is not simply about poor choice. It is also about the many interrelated and complex factors that influence health.

Key findings

We found that study participants:

- recognised that equality in health (i.e. equal health outcomes) is not possible, but that there are health inequities (i.e. unfair and unjust inequalities) in Tasmania, and these health inequities matter;

- clearly identified the relationship between ill health and the social conditions and resources that are available;

- believed that it was morally wrong to have low-income communities that trap individuals in ‘containers’ of disadvantage that separate them from the larger social system and deny them the resources that are necessary to live a healthy life;

- if they were from advantaged communities, were just as likely to be concerned about health inequities as people with more lived experiences of vulnerability;
identified that their concerns about health inequities related to fairness and justice, cost, stigma and discrimination;

believed that all levels of society had a role to play in addressing health inequities;

saw little value in utilising commonly used terms in health policy and academia such as ‘essential services’, ‘social determinants of health’, ‘health inequities’, ‘social gradient in health’, ‘entrenched disadvantage’ and ‘vulnerable Tasmanians’. Participants described these words as being impersonal and vilifying, contributing to stigma and blame, and they considered those who use this terminology were disconnected and out of touch;

said that it was inappropriate to simply name up health problems in this way, without actually doing something to address the problems to which the words relate;

recognised that health is influenced by many factors, which are interrelated and complex, and that access to the best possible health is a human right. They regarded Tasmanians’ health problems as being far more complex than is suggested by the current Government’s policy of “Creating the healthiest population by 2025”;

identified that the health journey can follow a convoluted path, that it is not as simple as making bad decisions, and that the concepts of perceived control and self-efficacy play a key role in personal decision-making and self-responsibility.
Report

Why this study?

When we talk about health, ‘determinants’ are the things that influence how healthy we are. There are many factors that affect our health and wellbeing. Some may appear obvious – like how much exercise we do or whether we eat enough vegetables. But others may be less obvious.

Research has shown that the houses we live in, the transport we are able to access, the level of stress in our lives, the job we have or don’t have, the social support we have around us and how much money we’ve got, have as much impact on our health and wellbeing as our genes and behaviours. These factors are known as the ‘social determinants of health’. The social determinants of health are the conditions in which people are born, grow, live, work, play and age. They are sometimes referred to as ‘the causes of the causes’ because they are the underlying reasons why people experience poor health.

In Tasmania, particularly in recent times, the term ‘social determinants of health’ has gained increasing prominence – both in the community sector [1] and to a lesser extent in government policy [2]. Related terms, such as ‘health inequities’, ‘health disparities’, ‘social gradients’, ‘proportionate universalism’ and ‘vulnerable populations’ are more frequently being used by policy writers and researchers [3-8]. The current Tasmanian government has a policy on community services that refers to ‘essential services’ and ‘hand up’ approaches for ‘vulnerable populations’ [9]. But just how well are these terms understood – and importantly how are they understood by those who are experiencing or at risk of the very things we are talking about?

In 2014, Dr Tim Senior, a GP writing on climate change and equity, noted that: “It is striking that anyone who uses the term ‘social determinants of health’ is not likely to be someone who is at risk from them.” In fact, most of what has been written about the social determinants of health is intended for scientific/academic audiences. Senior goes on to say that, “We need a language we can all understand, and we need to hear from those who are first in the queue to be harmed” [10].

One aim of this study was to help us develop a language that we can all understand and which will assist us to better engage with people that are implicated in the social determinants of health across the community. While there is research elsewhere on lay understanding about social determinants of health [11-17], to our knowledge, nothing like this had been done in Tasmania.

This report presents key findings about the language of social determinants of health, which may contribute to enhanced community engagement and more empathetic practice. We explore how community insights on social determinants of health can enhance civil/community advocacy efforts to influence policy change [1, 18-20].
Implications

The main implications arising from this study concern government and policy advisors and advocacy groups.

For government and policy advisors:

1. Health inequity matters to ‘everyday’ Tasmanians. Equity is not the same as equality ... equity is an ethical principle that encompasses the notions of justice and fairness [3]. It is not fair that there are communities in Tasmania that do not have ready access to resources necessary to live a healthy life, such as easily accessible health care services, grocery stores with fresh healthy foods and places to exercise safely. Health inequalities are pervasive and not easily eliminated [8], but we can, and should, do something about health inequity. If we recognise that health is a ‘resource for everyday life’ [21] – a human right – then it is unjust to deny people these rights.

2. Words are not enough – the language surrounding the concept of ‘social determinants of health’ must lead to actions to address the social determinants of health and health inequity. “We know enough to act. We have extremely compelling reasons, also economic ones, to act,” said WHO Director-General, Margaret Chan, when she addressed the first World Conference on Social Determinants of Health in 2011. In Tasmania, too, we have seen countless publications on our socio-economic woes, and more specifically on the dire state of our health. What we have not seen is a strategic, comprehensive and united framework for action that recognises health as the central goal. We can identify the problem but we must also offer solutions.

3. We should focus on how social determinants affect all Tasmanians (not just specific groups or socioeconomic classes). In so doing, we should identify people by shared experiences rather than by socioeconomic deficits. Using inclusive language (we, our, us) prevents artificial distancing between groups (them, they) [17, 22].

4. While individual responsibility for health is important, it is constrained by many interrelated system factors. Thus interventions should be aimed not only at strengthening individuals and communities but also at improving living and working conditions and creating healthy public policy [20].
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For advocacy groups:

1. When communicating about the social determinants of health, we need to take the time to understand our audience – this includes customising messages by selecting appropriate tools, approaches and information, rather than assuming the same message will work for all audiences. Instead of using the phrase ‘social determinants of health’, test phrases such as ‘Health starts – long before illness – in our homes, schools, jobs and communities’ and ‘Health begins where we live, learn, work, play and age’ to determine if they can relate to these concepts.

2. Unless your audience is familiar with ‘systems-thinking’, focus on communicating one thing at a time. Incorporate the role of personal responsibility, as well as the role of the social environment.

3. Use clear, plain language, rather than technical language or jargon.

4. Make issues tangible by illustrating them with analogies and stories rather than using abstract concepts or terms. Focus on the concepts behind the terminology and present messages using colloquial, values-driven, emotionally compelling language.

5. When talking statistics, break down and round up numbers, and place numbers in context. At times it will be valuable to focus on a strong, believable and compelling fact (see text box below for some examples) rather than blinding your audience with statistics [17, 22].

- There are more doctors and health services available in high income neighbourhoods than there are in low income neighbourhoods [23].
- 65% of people with mental illness do not access any treatment [24].
- Aboriginal and Torres Strait Islander people live around 10-11 years less than non-Indigenous people [25].
- The likelihood of being obese is influenced by our income, education and jobs [22].
- Living in unsafe, unaffordable or insecure housing increases the risk of many health problems [22].
- People living in lower income neighbourhoods are twice as likely to smoke as people in the highest income neighbourhoods [26].
- A good job can promote better health, self-esteem and social contacts. With a good job, we have a sense of belonging [22].
- Every day, at least six Australians die from suicide and a further thirty people will attempt to take their own life [24].
- Aboriginal and Torres Strait Islander people are more than three times more likely to report having some form of diabetes than non-Indigenous people [25].
- Warm and supportive parenting can help protect children from the negative impacts of poverty, including poor health [22].
- There is growing evidence that investing in education is a highly effective step we can take to improve health outcomes. One study estimates that having quality education available to all could save eight times as many lives as medical advances [22].
Approach

In planning this study, we sought to talk to people in the community about how they understand the language of social determinants of health - the language that they use and what is meaningful to them. Our study aimed to build an understanding of how ‘everyday’ Tasmanians interpret and understand the language surrounding the social determinants of health in the context of their own lives as well as broader society.

We used a qualitative research design and recruited people in the community across Tasmania to participate in focus groups or interviews. The study has ethics approval from the Tasmanian Social Sciences Human Research Ethics Committee.

The study involved the following steps:

1. **Targeted literature review**
   This included a review of current Tasmanian policy documents to identify the common terms that are used when articulating the social determinants of health. It also involved considering recommendations and findings from previous studies. A selected annotated bibliography of these findings is included in Appendix 1.

2. **Question development**
   The focus group questions were guided by what we found in a targeted review of the literature on lay understandings of the social determinants of health and health inequalities and a targeted scan of government policy statements/documents. The questions were pilot-tested.

3. **Recruitment of participants**
   A recruitment flyer seeking expressions of interest in participation was circulated widely among networks and community centres (see Appendix 2). Participants needed to be aged 18 years and over, and residing in Tasmania. No participants were working for the Department of Health and Human Services, non-government health (disease) organisations, or in the health or medical sciences areas of the University of Tasmania. There were no other inclusion or exclusion criteria. Our aim was to seek a wide range of views from Tasmanians living across the State in urban, outer urban, regional and rural areas. People expressing interest in participating in a focus group or an interview were provided with a written information sheet.

4. **Conduct focus groups and interviews**
   We conducted four focus groups (two in Hobart, one in an outer suburban area, and one in a rural area) with a total of twenty-four participants, and nine telephone interviews. Focus groups were held in community facilities. All focus group participants were asked to complete a written consent form prior to participation. Telephone interviewees were asked for verbal consent prior to participation.
Each focus group ran for approximately two hours. Interviews were conducted by telephone and used the same schedule as the focus groups. Interviews lasted 20-45 minutes. Focus group discussions and interviews were voice recorded as an aide-mémoire for the researchers (participants were informed about this as part of the consent process).

5. Data analysis
We used the focus group/interview schedule (Appendix 3) as a template for analysing the data from the focus groups and interviews, and developing the first set of themes. Both researchers listened to each focus group recording. The researchers independently analysed the data from the interviews and grouped it thematically. We then used the findings of research on communicating the social determinants of health from the USA [17] and Canada [22] as a basis for these themes (see below). Our independent analyses were discussed and consensus reached.

How we see health

Metaphors act as filters to unconsciously shape “everything we hear, think, say and do” [17]. Understanding how people view health has ramifications for communicating health concepts [17].

In designing our research and analysis we referred to the Robert Wood Johnson Foundation’s document, A New Way to Talk About the Social Determinants of Health, which describes how deep metaphors frame views on health. Two of the deep metaphors described in this paper are the system and the journey metaphors.

The journey metaphor is about an individual’s responsibility for their path through life and recognises that:

- journeys can be fraught with challenges or can be smooth sailing; they can be direct or divergent; and they can be unpredictable or focus on a series of steps that, if followed, will take you to a predetermined place or goal;
- society as a whole is on a long, unpredictable health journey through time but individuals themselves are on their own health journeys;
- poor health arises from bad choices along ones’ path and the inability to overcome obstacles to health that one encounters along the way;
- poor health is the result of failure to give individuals a road map of how to achieve health; and
- it is important to give individuals the opportunity and the tools to make good choices in their health journey, but at the same time we must acknowledge that they will also make their own, sometimes bad, choices.

A metaphor is a figure of speech in which a word or phrase is applied to an object or action to which it is not literally applicable.

For example: “All the world’s a stage, And all the men and women merely players” (Shakespeare).
The **system metaphor** sees health as part of an interconnected whole and recognises that:

- there are different parts that make up the whole, and that the parts of the system are interdependent and the connected parts often operate in a predictable and recurrent pattern with certain results;
- the system is held together by rights such as freedom, opportunity and equality; and health in itself is seen as a right;
- poor health is a result of a complex and interrelated system of social, cultural, economic and biological factors, and we must address social determinants simultaneously and comprehensively in order to overcome the system of interrelated factors that result in poor health; and
- if certain communities are experiencing poor health, the whole system is affected [17].

In our research we identified data that resonated with both the **systems and journey metaphors**, as well as other metaphors discussed in the paper. A Canadian publication – *Communicating the Social Determinants of Health* [22] – also used these metaphors. We have woven references to these various metaphors into our findings. We have also included references to other studies.

We believe that people’s views on health and what we can do to improve it is often tempered by their world view and which of these metaphors predominates in their thinking. How we communicate our messages needs to take these differing views into account.

**6. Write up**

This report has been subject to a peer-review process. In addition to this report, we, the researchers, are preparing an academic journal article for publication.
Inequity matters

Through exploration of a narrative/life story about health and discussion on differences in social and health indicators across Tasmania, study participants recognised that there are health inequities in Tasmania, and these health inequities matter.

Participants’ views about ‘inequality’ in health were in keeping with the journey metaphor – that people must have the opportunity to make healthy choices, but also, that they will choose their own path, which may or may not be conducive to good health. For some participants, the different paths that people choose and the resulting imbalances in health outcomes were considered a normal part of the society we live in, and the expectation that everyone can achieve the same health level was considered to be both unrealistic and misguided [22]. This view about inequality in health recognises that a lack of resources is a barrier to choosing the right path towards health. Resources are considered to be finite, and we need to be realistic that every person cannot have everything [17].

Study participants were aware that some people experience better health than others – not because of genetics or biological factors but because of the way society is constructed. When we explored a narrative of a single mother with three young children, living in an urban-fringe area, in a cold, damp house – which arguably contributed to the development of her asthma – almost all our study participants could relate to the story. Study participants were concerned that people experience different health outcomes because of factors that, in theory, ought to be controlled (in this case, housing, transport, income etc.). Participants saw a clear relationship between the ill health being experienced by this mother, the social conditions and the resources that were available to her.

“It sounds like a lot of the stories we’d hear around here.”
However, when we presented study participants with population-level data, for different local
government areas, relating to life expectancy, self-assessed health status, mortality, private health
insurance and education participation, some participants were alarmed and others were confused by
the conclusions that could be drawn from the data.

“That’s amazing... why would that be? ...I used to live in [a rural place]... and if you don’t drive and I
didn’t drive when I was up there... you have to walk everywhere and so you’d assume it would be more
healthy... I seen a lot of mums with strollers and grandparents with their grandkids and seniors just
walking so you’d assume they’d just be more healthy through walking than less healthier... I don’t
understand.”

“Is there a pollutant in the air or something?” … “Is there something in the soil?”

Once this population-level data was explained however, study participants reacted strongly. They
expressed a belief that it was morally wrong to have low-income communities that trap individuals in
‘containers’ that separate them from the larger social system and deny them the resources that are
necessary to live a healthy life such as easily accessible health care services, grocery stores with fresh
healthy foods and places to exercise safely [17].

This is in keeping with the Container metaphor – the view that low-income communities are isolated
in locations that lack the resources necessary to lead a healthy life: “...the reality for poor people is
never leaving their ‘culture of poverty’. On a psychological level this ‘culture of poverty’ traps them in
a mentality that they can never get ahead, they are unable to take advantage of the opportunities in
broader society [17].”

Study participants expressed deep concerns for the imbalance between the ‘haves’ and the ‘have
nots’. When it came to identifying how to address such inequalities or whose role it was to drive such
change, some study participants offered suggestions about the role of government and those with
more power and resources. However, overall there was a sense from participants that they believed
that everyone had a role to play. Other researchers agree that action on the social determinants of
health needs both political will and community involvement [18, 27].

“When you put people with the same issues into these little communities it’s just rife the problems...
They’re not getting the peer thing, you know, ‘oh well, we’re all the same so who cares’... They hang in
their groups.”

“The people who are rich, they don’t want to part with what they’ve earned because they say ‘we’re
comfortable, I’m alright Jack, bugger the others’.”
The more well off among us have to kind of step back and look back at what we are doing and if you can afford to pay more tax you should and I think a lot of working people are happy to pay more tax if they can see the money being spent in the correct places.

“We’re all responsible to some degree. It’s not just one person or one group or just the government.”

So, while the participants recognised that equality in health is not possible, they did recognise that there are health inequities (i.e. unjust and unfair inequalities) in Tasmania, and these health inequities matter. The main reasons identified for people’s concerns about health inequities related to fairness and justice, cost, stigma and discrimination [11].

“It matters as neighbours and friends.”

“I feel strongly about this - where a community can go on living isolated in a similar stuck situation... lacking the benefits that others have living across the river or whatever. To me that’s really problematic.”

“It matters as a tax payer because they’re going to cost a whole lot more if they don’t go to college.”

“It matters to me because of the way that stigma affects you personally and I’m just lucky that it motivated me to want to strive but if I had a reunion with most of the people I went to school with, unfortunately I could almost bet money on it that that stigma would have forced them to end up in a very different situation. I was just lucky that I didn’t allow that stigma to affect my future.”

“It sucks. Why should we suffer? No community is better than any other so why should we have to suffer?”

“It [inequity] definitely does matter... it becomes a compounding issue.”

“Those things don’t come about accidently – they are the result of human actions.”

“It shouldn’t matter where you’re born and therefore often where you end up living as to what your life expectancy or health and wellbeing should be just because of the suburb that you live in. You should have the same kind of access...just because you live in a poorer area doesn’t mean that you shouldn’t have a bike track that’s accessible so that you can go for a bike ride or walk your dog.”

“It makes me really sad and angry... It matters a lot... It’s really disturbing that there are such differences.”
Research suggests that when people are communicating about the social determinants of health, narratives and visual images are valuable tools. We should avoid further stigmatization and individual blaming [13, 28, 29]. What is most important is a shared understanding of what we are talking about and a common set of values.

The ways we view health and the factors that influence it are shaped by our values. An individual’s values affect a wide range of thought and behaviour patterns, in part generating attitudes [30]. That’s why some participants in our study talked rhetorically about ‘the glass half empty or the glass half full’ – some were more optimistic than others about health and its determinants. Such differences in optimism alone can be a source of tension between individuals or groups, which is why “understanding these basic differences in emotional response to an issue can help anticipate touch points in a conversation where communication might break down” [17].

In our study, participants articulated a range of values such as responsibility, capability, control and fairness. We found that participants drew significantly on their personal experiences to explain their views on health. Personal experiences throughout life shape our values and how strongly we hold on to them.

But unlike other studies, we did not find that people’s responses to our questions necessarily reflected their own experience of advantage or disadvantage [16]. Our focus groups and interviews were conducted in both ‘advantaged’ and ‘disadvantaged’ geographical areas in Tasmania and included participants who described themselves as being or having been ‘vulnerable’. With few exceptions, we found that people from advantaged communities were just as likely to be concerned about health inequities as people with lived experiences of vulnerability. Thus, for example, whether you grew up in a poor household or whether you were raised in a middle-income, educated family and had not personally experienced the stresses of poverty did not appear to be a determining factor in one’s views on fairness in health – there was shared recognition that the concept behind the term ‘health inequity’ mattered.

The reasons given for such inequities and what to do about them varied – again we would suggest, based on the different personal values – but overall participants in our study shared a strong sense that injustice is evident in the diverse health outcomes of Tasmanians. These finding are consistent with other research that shows people can recognise health inequities [14, 15, 31]; in particular, those living in disadvantaged areas can do so [11, 32].

“It sits right at the core of my values. That arises from teenage times. Things like that matter very much. It matters to me because everyone should have the opportunity to have a healthy life.”
Words are empty without action

Commonly used terms in health policy and academia such as ‘essential services’, ‘social determinants of health’, ‘health inequities’, ‘social gradient in health’, ‘entrenched disadvantage’ and ‘vulnerable Tasmanians’ are of limited value according to participants in our study. Participants described these words as being impersonal and vilifying, contributing to stigma and blame. Indeed, they suggested that words which reflect prejudice, that oversimplify complex relationships or that minimise history can heighten bias and exclusion [33]. Participants suggested that those who use such terminology were disconnected and out of touch. The media were also identified as contributors to the problematic use of language. While policy analysts, health workers, advocates and researchers may use such terms to describe ‘pictures’ of the health of Tasmanians and advocate for action on the underlying causes of poor health, to Tasmanians in our study these terms were empty jargon, which do nothing to improve the lives of those who are affected by poor health.

Participants said that it was inappropriate to simply name up health problems in this way, without actually doing something to address the problems to which the words related. Several people spoke about having been identified as living in a ‘vulnerable community’, yet nothing had been done to reduce this vulnerability over the course of many years. We also found that it was considered disempowering to call a community ‘vulnerable’ – a finding supported by other researchers [33].

“I don’t think anything’s changed in this community. I think the same issues are still around... transport, not enough services, people on low income... People can’t afford to feed their families but nothing’s changed... in 32 years. Those barriers... they’re still there. It’s the government’s responsibility but I don’t know how they’re going to fix it.”

“I’ve lived here all my life and it’s never changed. We’ve always had no services and the buses were always crap. They’ve yelled out for a pool for as long as I can remember to be put here but nothing’s changed...”

“We should record what we say (to politicians) and say ‘here listen to this because we’re over saying it cause you’re not listening’... They listen and care at that stage but then do nothing with it.”

“I guess they are a way of describing people but there is a risk that they can see themselves always as victims and I think quite often they may think that’s all they are and they may feel powerless and they think they can’t get out of the situation they are in.”
Participants were familiar with the concepts behind the terms listed above, and were able to describe various ‘social determinants of health’ and a broad range of ‘essential services’. Some knew they were described as ‘vulnerable’, and they were very familiar with the unfair differences in health outcomes experienced by some groups (‘health inequities’). However, the words themselves were not considered to be helpful. Participants in this study said the words were difficult to understand and created a barrier to engagement. Other studies have identified similar findings. For example, researchers in the USA, based on pre- and post-testing of people’s attitudes after their exposure to a set of messages, found that phrases like ‘social determinants of health’ failed to engage but that the concepts behind the words did resonate with audiences [17]. Canadian researchers have found that labelling populations contributes to the creation of an ‘us and them’ phenomenon. This leads to victim blaming, stigmatisation and greater power imbalances. Moreover, defining population groups by a single characteristic (e.g. low income, refugee, unemployed, low literacy) oversimplifies people’s situations – “There is always more diversity within a population group than our language can capture” [33]. These researchers suggest that a focus on disadvantage requires a similar focus on advantage, as the two coexist [33].

A GP’s view:

“This big-picture language distances us from those most affected. And it’s a pattern of behaviour. We see it in the way we talk about the so-called social determinants of health. I’ve never heard my patients talk about social determinants. I’ve never heard them mention the term “food security” either. But I’ve witnessed the tears after another racial bullying episode at work. I’ve heard people reluctantly admit that they’ve not eaten for a few days so the children can. I’ve seen stress that makes people sick from constant arguments with the housing department about getting repairs for the draughts through the house. I can go home, though, and have a sip of chardonnay, debrief with my wife, perhaps write another article for Croakey about the social determinants of health. My patients, meanwhile, have no escape. No need for the words when you live inside it. [10].”

“I don’t like it when people put words to things like this... It’s very impersonal.”

“I think [such words are] fine within the context in which they are used with policy makers and so on but as soon as you start talking with people in the wider community... they just get lost in the jargon it means nothing to them and they lose interest.”

“They use words that people in these areas don’t understand obviously so they don’t know they are being attacked... [like the word] vulnerable, I know we are but we don’t like to think we are. Communities like to think they can stand on their own two feet.”

“I’m a lawyer and I struggle to have a total definition in my head of what those phrases might mean and how they might be applied and I’ve done a lot of study so for the average person I don’t know how helpful they are because they just bamboozle people.”
“How does the government describe Sandy Bay? It shouldn’t be where you live. We’re all human.”

“There are lots of [people] who are really fed up with the negative media and the negative spin about their lives. They see lots of positive things.”

“Being called a refugee is not something you like to hear because that name puts you in the group of ‘vulnerable people’... Most refugees when they were back home in their various countries they were working... some of them have good skills but because they are being called ‘refugees’ the first thing that goes into people’s mind (is) ‘refugees, they’ve got nothing to offer’ but that’s not the truth.”

As a result of this research, we argue that the language that is currently used to describe social determinants of health in political, and health and human services fields focuses too much on vulnerability and entrenched disadvantage [5, 11, 34]. Other authors have criticised the term ‘vulnerable’ because it misrepresents the reality that vulnerability arises from a complex range of material, cultural, social and political resources [33]. For example, a recent study identified that, although there were commonalities when it came to the dominant characteristics of Tasmania’s most disadvantaged local government areas (disengaged young adults, unemployment and low family income, contact with the criminal justice system, and disability), “there was also considerable diversity regarding the prevalence of other indicators [of social wellbeing, health, community safety, access to housing, education and employment] and this variability suggests the need to be sensitive to specific local contexts” [35].

When it came to alternative language, participants in this study suggested that:

- Words should reflect rights – the right to good health and the right to access the things that can contribute to good health, such as housing and employment.
- If such language were to be used – and it was acknowledged by some that it can have its strategic uses – then there is an onus on those using the language to do something about identified problems. Other authors agree it is important not only to identify problems when communicating about social determinants of health, but also offer potential solutions [17].
- Words should be used in context, not as simple statements or titles.
Good health is more than the absence of illness

When we commenced this study we believed that governments, politicians, policy analysts and the media were largely preoccupied with a very limited definition of health – one that focuses on medical and hospital services. It is not uncommon to hear politicians justifying their focus on illness, disease and health care in terms of ‘voter demands’. We therefore considered it important to find out how members of the public viewed health and just how much emphasis they placed on ill health and treatment, in contrast to health being recognised as a “resource for everyday life” [31].

As a result of our research, we now believe that the wider community is given far too little credit when it comes to understanding the complexities of health – even if they do not use the same language as those of us who work or are educated in health policy or research. We found that study participants recognised that health is influenced by many factors, which are interrelated and complex, and that access to the best possible health is a human right. This multifactorial understanding of health is consistent with other research [16].

Although we expected our participants to describe ‘health’ as being about more than the absence of illness, we thought it was worth asking them the introductory question, ‘What is important to you for good health?’ We identified a high level of awareness of the term ‘health’ as being more than the absence of poor health/disease/illness. In fact, people who said they suffered from medical conditions did not confine their responses to our questions to the dimensions of their illnesses. In contrast to how health and its determinants are often portrayed in the media, study participants spoke far less about hospitals and health care than they did about other factors such as housing, education, social connection and so forth.

Even when hospitals and specialists were mentioned, study participants brought in equity considerations and expressed their belief that they had the right to have access to better medical care:

“I’m not so fussed if I have to go to Launceston or even to Hobart... but having to go interstate to see a [health] professional particularly if you have a family... I understand you can’t have everything in Burnie. You can’t have people to operate on hearts in Burnie because it’s probably not gonna be as good as if you do lots more in Hobart or Launceston. I’m happy to travel to see a good [health professional]... but I guess (I feel) we are kind of entitled to specialists somewhere in Tasmania.”

People spoke about health, as well as ‘wellbeing’ – a concept we would argue is often downplayed and even disregarded by the medical and health care sector. Well-being is about reaching one’s own potential, being able to cope with the normal stresses of life, being able to work productively and

“Health is dependent on so many things.”
fruitfully, and being able to make a contribution to one’s community [36].

Participants appeared to view health through both the journey and systems frames outlined earlier. In line with the journey metaphor, participants described a range of personal factors that they believed impacted on their health and wellbeing, including:

- Love – for self, and feelings of love and compassion from others towards oneself, and towards others
- Happiness
- A sense of purpose – whether that’s associated with work, volunteering or some other sense of direction in life
- Skills, knowledge, health literacy and self-efficacy – including education
- Healthy behaviours – including participating in activities that generate a sense of pleasure such as hobbies, leisure and holidaying/travel
- Resources – including financial and social resources such as housing, access to information technology
- Security – including feeling safe
- Freedom from stress.

“I don’t know what I’d do without work.”
“I think education is important.”
“When I thought of this I thought of all the obvious things like good food, getting exercise and having a pleasant environment and then I thought, a large part of my ‘wellbeing’ comes from making a contribution, that I’m useful, that I’m connected to the community... It’s a really fundamental part of my wellbeing and therefore health.”
“It’s about having choice to have good health, access to education, access to housing, access to skills and abilities and also the choice that if I don’t want any of that I don’t have to have any of that.”
“Stress is a killer...stress will kill you quicker than anything or bring on something else.”

Study participants also described the health impact of factors associated with their immediate social circle and environments, including:

- Family, relationships and friends, and a sense of connection to others and being part of community
- Connection to place – land, culture and community
- Access to resources that can support healthy behaviours such as healthy food
- The built environment including access to housing, transport and neighbourhood factors
- The natural environment such as clean air and water.
In addition to these immediate variables, study participants also identified the broader determinants of health that operate at the level of society including factors such as:

- The systems they interact with, including involvement in education and access to health services
- Freedom from stigma
- The influence of the media.

“My concern – and growing up in a low socioeconomic community myself – there doesn’t seem to be a good understanding of where these issues come from and why people do end up so disadvantaged.”

Participants recognised that the determinants of health interact. Even the personal factors listed earlier were not seen to being mutually exclusive; for example, stress experienced at the level of the individual was seen as arising from a complex interplay between a range of individual and system-wide factors.

“It’s a combination of factors that mean that (you are) a victim in that situation... and [when you’re unwell you] don’t have the energy to do what [you] could do to change those things or explore some further options.”

“I heard a politician say), ‘I know that youth unemployment is terrible in Tasmania, well why don’t these people just move’ and that’s just such a misunderstanding of how people are going to change their circumstances. I mean it’s just not as easy as that.”

Participant’s regarded Tasmanians’ health problems as being far more complex than is suggested by the current Government’s policy of “Creating the healthiest population by 2025” [37]. Indeed, recent research has shown that several “local government areas [in Tasmania] have remained depressed for long periods demonstrating the persistent, entrenched nature of the disadvantage experienced by these communities” [35].
When asked for their suggestions on how Tasmania can become the healthiest population by 2025, participants identified a broad range of opportunities, some of which included:

1. A greater focus on preventive health initiatives including a broader approach to health promotion initiatives that move beyond social marketing campaigns
2. A focus on social determinants including housing, food, employment opportunities (including responding to our changing economy), addictions, access to health services and transport
3. Focusing on key health problems including oral health and mental health
4. Addressing differences in avoidable health outcomes
5. Ensuring effective community engagement approaches
6. Building a values-based health system, with effective leadership and cross-party support
7. Enhancing environmental health standards
8. Working with children and families and through schools.

Interventions to create a fairer, healthier society are often aimed at strengthening individuals and communities, improving living and working conditions, or promoting healthy public policy [21]. We did not endeavour to undertake a consultation on how Tasmanians can be the healthiest population by 2025; however, given the breadth of ideas raised (above), we urge the government to be open to ongoing dialogue with the community about their broader health needs.

“It’s going to be hard to achieve... When politicians say something like that they should be held to account... The concept of getting something like that done in 10 years is laughable because it’s not going to happen in 10 years... it would take a lot longer. It’s entrenched in our society, that’s why.”

“I think people laugh about it because they think it’s not achievable.”
Choice and control

Participants said that individuals were not always in a position where they had control over their situations, and thus the decisions they might make. This was identified as being a crucial element in navigating the health journey. Participants talked about factors over which they had some sense of perceived control as well as those which were considered beyond their control and influence. Some study participants used the term ‘self efficacy’.

Self-efficacy is the extent or strength of one's belief in one's own ability to complete tasks and reach goals: “By determining the beliefs a person holds regarding his or her power to affect situations, it strongly influences both the power a person actually has to face challenges competently and the choices a person is most likely to make. These effects are particularly apparent, and compelling, with regard to behaviours affecting health” [38]. What some might describe as ‘health literacy’ [39] was also linked with the concept of self efficacy.

“There’s education and understanding. Whilst I might understand that I get stressed and I’ve taken yoga up to elevate that, other people... stuff happens to them and they don’t really know what’s going on. If they don’t have things explained to them about what things are doing to them, they could have bad health and not understand... It’s about personal efficacy that you can act.”

Study participants further identified that lack of perceived internal control makes individuals more vulnerable to the system. In turn, the system further erodes this deficiency, setting up a cycle of disempowerment leading to spiralling health and social problems.

“I think a lot of the things we’ve done over the years as a society is set up a dependent society that’s disempowered people...we can only do what we’ve learnt... We have a dependent part of society and they’re stuck... they know no better... we’ve created it.”

“Quite often you see people who just rely on the system, it’s just easier for them and they are used to that... That’s all they know. It doesn’t do them any favours.”

Personal values such as responsibility and self-respect for health were clearly evident in our conversations with participants. People spoke about the notion of individual responsibility, where
poor health arises from bad choices along one’s path and the inability to overcome obstacles to health that one encounters along the way [18]. This focus on poor health resulting from individual behaviours rather than structural factors is common in other research [13], especially talking about the ‘poor’ person and using the terms, ‘them’ and ‘us’ [17].

“If they’re poor they should be able to do something about it. Just find a job and get a bit more money and try and update what they’re doing, their way of life.”

“If you’re down and out, you’ve got to think for yourself and try and get yourself out of the slum because nobody else will help you... It’s up to yourself and a lot of people can’t do it... probably because of the way they’re brought up.”

Some people deserve it cause of the way they carry on but other people don’t deserve what they get... You see people they can’t afford much for their kids cause they’re single parents but they still smoke and drink don’t they?”

However, participants recognised that ill health and illness were not always as simple as making bad decisions. They talked about the importance of giving individuals the opportunities and the tools to make good choices in their healthy journey. And many people recognised that barriers such as poor experiences during childhood, lack of positive role models, poverty and its associated outcomes, and the lack of resources conducive to good health in neighbourhoods present very real challenges for people wanting to live a healthy lifestyle. Such barriers were considered to be legitimate inhibitors to personal choice and self-responsibility.

“I don’t know about ‘deserve it’. That’s a bit of a harsh word. It all depends on where they’ve come from and how they grew up.”

“[Smoking] is something [you do] to relieve stress. Having a cigarette or a drink can be a stress relief for people.”

“You can’t blame them because that’s what they think life is like.”

“I don’t have a permanent home because for various reasons I had to give up work... Now I’m on a DSP [pension]... I move around a lot... I house-sit... Given the treatments [for my health conditions], a lot of them aren’t subsidised so it would be either treatment or rent for me.”
“There’s just a lot of barriers... [They] prevent the road to recovery and wellbeing... You get this built in inertia because of all those barriers that nothing will happen and [you] get more unwell.”

Participants in our study described how people living in disadvantaged areas could become trapped by the barriers and obstacles that they encounter in their daily lives, and that this prevents them from reaching a state of optimal health and wellbeing. Participants were of the view that governments were largely responsible for creating and sustaining these ‘containers’ of disadvantage.

“You’ve got this generational thing where you’ve got people dependent on Centrelink and people think ‘I’ll never get a job’ and they’ve got no self-esteem ‘cause nobody in the family has ever had a decent job and done well you know’.”

“Looking back you could put the blame on Housing [Tasmania] for making these enclaves of houses.”

Yet, professional understandings of the social determinants of health are more focused on individual behaviours than on structural constraints. Two Canadian studies found that public and community health workers, workers in community-based organisations, child and youth advocacy organisation members, and workers in municipal governments tended not to recognise the effects of structural health determinants or issues of social justice and inequity on improving health [40, 41]. The view that individual responsibility and choice are far more complex than is often suggested by politicians and the media is strongly backed by research around the world. Take obesity, for example. The WHO Collaborating Centre for Obesity Prevention posed the question:

“Has the prevalence of obesity in Australia tripled in the last 30 years because we’ve all lost personal responsibility?” The reply: “Of course the answer is no, with all the evidence pointing to changes in the food environment [42].”

Concluding remarks

This study has shown that health inequity matters to ‘everyday’ Tasmanians. The language of health used by politicians and decision makers is empty if it does not lead to actions that do something about identified problems and address the social determinants of health and health inequity. Poor health is not simply about poor choice. Health is influenced by many interrelated and complex factors, and access to the best possible health is a human right.
References

1. Australian Health Promotion Association and TasCOSS, The Social Determinants of Health. Working together to address the social factors that affect the health and wellbeing of Tasmanians, Hobart, 2012, TasCOSS: Hobart.


Appendices
Appendix 1: Selected literature

**Government and Civil Society Action**

Addressing social determinants of health inequities: what can the state and civil society do? [27]:

“Government action can take three forms: (1) as provider or guarantor of human rights and essential services; (2) as facilitator of policy frameworks that provide the basis for equitable health improvement; and (3) as gatherer and monitor of data about their populations in ways that generate health information about mortality and morbidity and data about health equity. … Civil society takes many forms: here, we have used examples of community groups and social movements. Governments and civil society can have important positive roles in addressing health inequity if political will exists”

Cracking the nut of health equity: top down and bottom up pressure for action on the social determinants of health [18]:

“Governments need a commitment to the values of fairness and justice and an ability to cope with the complexity of responding to social determinants beyond exhorting individuals to change their behaviour. The role of civil society is crucial in advocating for governments to do this. The presence of linking social capital is also crucial to creating a social and political environment in which fairness is promoted”

**Professional views on the social determinants of health**

Perceptions of the social determinants of health by two groups more and less affiliated with public health in Canada [41]:

“We found that two groups with different affiliations to formal public health could discuss the SDOH [social determinants of health] without acknowledging the inequitable distribution of power and resources that lies at its root. We also found that those working in public health had difficulty moving beyond individual actions that they or their clients could take to improve health. … Our findings indicate that there remains work to be done in terms of translating the SDOH concept into action in Canada”.
Do great local minds think alike? Comparing perceptions of the social determinants of health between non-profit and governmental actors in two Canadian cities [40]:

“Given the importance of a shared vision in collaborative enterprises, the comparability of perceptions between the groups found here holds promise for the prospect of inter-institutional partnerships. However, the low rating assigned to more structural health determinants suggests that more work is needed from researchers and advocates to effectively advance a health equity agenda at the local level in Canada”.

Communicating the social determinants of health

Message design strategies to raise public awareness of social determinants of health and population health disparities [29]:

“Although few studies have directly tested message strategies for raising awareness of SDH [social determinants of health] and health disparities, the accumulated evidence from other domains suggests that population health advocates should frame messages to acknowledge a role for individual decisions about behavior but emphasize SDH. These messages might use narratives to provide examples of individuals facing structural barriers (unsafe working conditions, neighborhood safety concerns, lack of civic opportunities) in efforts to avoid poverty, unemployment, racial discrimination, and other social determinants. Evocative visual images that invite generalizations, suggest causal interpretations, highlight contrasts, and create analogies could accompany these narratives. These narratives and images should not distract attention from SDH and population health disparities, activate negative stereotypes, or provoke counterproductive emotional responses directed at the source of the message”.

Narratives and images used by public communication campaigns addressing social determinants of health and health disparities [28]:

“Researchers ... have ... explored strategies for raising public awareness and mobilizing support for policies to address SDH, with particular attention to narrative and image-based information. These efforts will need to overcome low public awareness and concern about SDH; few organized campaigns; and limited descriptions of existing message content. ... Certain types of SDH, including income/wealth and one’s home and workplace environment, were emphasized more heavily than others. Solutions for addressing SDH often involved combinations of self-driven motivation (such as changes in personal health behaviors) along with externally-driven factors such as government policy related to urban revitalization. Images, especially graphs and charts, drew connections among SDH, health outcomes, and other variables, such as the relationship between mother’s education and infant mortality as well as the link between heart disease and education levels within communities”.
Lay understandings of the social determinants of health

Lay concepts of the relative importance of different influences on health: are there major socio-demographic variations? [14]:

“...socio-demographic differences were less marked than might be inferred from studies of specific social groups, indicating a need for caution in health education and health promotion practice against always assuming socio-demographic differences”.

Exploring interpretation of complexity and typicality in narratives and statistical images about the social determinants of health [13]:

“Although some narratives showed potential for communicating the complex causality connecting social determinants of health (SDH) to health outcomes, contextual details sometimes disrupted generalization to a broader thematic message. Statistical images often prompted useful speculation about how the factors portrayed might be related, but tended to be regarded with suspicion and criticized for oversimplifying what were perceived to be extremely complex issues”.

Public views about health causation, attributions of responsibility, and inequality [12]:

“Participants communicated highly nuanced views about health causation and disparities, identifying layers of responsibility for health. However, individual behaviors and personal responsibility dominated the discussion and served as a counterargument to the significance of social determinants. Participants also showed limited awareness of the range of policies that could be adopted to address health disparities”.

How Do People Attribute Income-Related Inequalities in Health? A Cross-Sectional Study in Ontario, Canada [31]:

“A majority of this sample of Ontarians were willing to attribute inequalities to the social determinants of health, and were willing to accept messages that framed inequalities around the privilege of the rich or the plight of the poor. These findings will inform education campaigns, campaigns aimed at increasing public support for equity-focused public policy, and knowledge translation strategies”.
From causes to solutions—insights from lay knowledge about health inequalities [16]:

“Although generally willing to discuss health inequalities, many study participants tended to explain the latter in terms of individual behaviours and attitudes rather than social/structural conditions. Moreover, those who identified social/structural causes tended to emphasise individualized factors when describing typical pathways to health outcomes. This pattern appeared largely independent of participants’ own experience of advantage or disadvantage, and was reinforced in discussion of strategies to address health inequalities.”

“Despite the explicit emphasis on social/structural issues expressed in the study focus and framing of the research questions, participants did not display a high level of knowledge about the nature and causes of place-based health inequalities. By extending the scope of lay theorizing to include a focus on solutions, this study offers additional insights for public health. Specifically it suggests that a popular constituency for action on the social determinants of health is unlikely to eventuate from the current popular understandings of possible policy levers”.

Beyond “beer, fags, egg and chips”? Exploring lay understandings of social inequalities in health [15]:

The findings support previous research in suggesting that lay theories about causality in relation to health inequalities, like lay concepts of health and illness in general, are multifactorial. The findings, however, also illustrate how the ways in which questions about health and illness are asked shape people’s responses. In the survey reported on here people had no problem offering explanations for health inequalities and, in response to a question asking specifically about area differences in health experience, people living in disadvantaged areas ‘constructed’ explanations which included, but went beyond, individualistic factors to encompass structural explanations that gave prominence to aspects of ‘place’. In contrast, within the context of in-depth interviews, people living in disadvantaged areas were reluctant to accept the existence of health inequalities highlighting the moral dilemmas such questions pose for people living in poor material circumstances. While resisting the notion of health inequalities, however, in in-depth interviews the same people provided vivid accounts of the way in which inequalities in material circumstances have an adverse impact upon health”.

The wealthy get healthy, the poor get poorly? Lay perceptions of health inequalities [11]:

“Contrary to other research which suggests that people from more deprived backgrounds are more reluctant to acknowledge the effects of socio-economic deprivation, our findings demonstrate that, in some contexts at least, people from less favourable circumstances converse in a way to suggest that inequalities deeply affect their health and well-being”.
Location, location, location: The role of experience of disadvantage in lay perceptions of area inequalities in health [32]:

“Drawing on focus group discussions with participants from varying socio-economic backgrounds, we show, in contrast to a nascent received wisdom, how people from more deprived areas more readily discuss the adverse effects on health and well-being of structural and contextual features, whereas those with least experience of deprivation or hardship were more likely to draw on behavioural explanations of area inequalities. People living in more deprived areas also more readily accept statistics on area inequalities in health than those based in more affluent areas”
Let’s have a conversation about the language of health

*a conversation about health - where health starts - in our everyday lives*

Let’s stop and have a serious look at what it is that really keeps us healthy or makes us sick.

And we’re not just talking about whether we did some exercise or if we quit smoking - we’re talking about the things that make up our neighbourhoods, communities, as well as a the bigger wider world – the factors that influence the choices we are able to make. Think about the things that you are exposed to in your everyday life – that might cause stress and make you more susceptible to ill health, or factors that keep stressors at bay and protect your health.

Let’s have a conversation about health – where health starts – in our everyday lives.

Health is influenced by lots of factors and we want to find out what Tasmanians from all walks of life have to say about health and its determinants.

This project is being run by the Social Determinants of Health Advocacy Network – Tasmania and is being undertaken by Miriam Vandenberg (Herzfeld) & Michael Bentley.

We’ll be running a series of focus groups in March and April 2015 and are looking for people willing to volunteer about two hours of their time to be involved.

If you would like to participate in this study please contact Miriam or Michael for more information *(details followed)*

This project has ethics approval from the Tasmanian Social Sciences Human Research Ethics Committee.
Appendix 3: Focus group/interview questions

1. What is important to you for good health?

2. This is the story of Stacey. Stacey is a mother of three in her mid-30s. Stacey’s dream is to own her own home because no one in her family has ever owned their own home before. She isn’t sure how she is going to achieve her dream but she’s determined one day she will. Stacey is a single mother and lives in an outer-urban community, 40 minutes from town by bus. She doesn’t have a car and survives on Centrelink payments. Stacey has asthma. She hasn’t always had it. She doesn’t smoke but she is overweight. The asthma was diagnosed about one year ago. It was winter time, and she’d just moved into a different rental property. It wasn’t a great house but it had enough space for the kids and it was cheaper than many other rentals on the market. Stacey started to find that she was coughing a lot at night. Her chest felt tight and she noticed she was wheezing after chasing the kids around. At first she thought it was just a cold so she didn’t do anything about it. After several months, when the symptoms persisted, she decided to visit her doctor. She couldn’t get in for another couple of weeks though. But eventually she was diagnosed with asthma. The doctor placed her on medication which seemed to help initially. Thankfully she didn’t have to pay much for the medication because she has a health care card. As the winter progressed, she found her house to be very cold. The electrical heating was expensive to run. Most mornings there was moisture on the inside of the windows. She also noticed that mould was growing behind the curtains and on the ceiling. The house smelt musty. Some of the windows were jammed shut. The property owner refused to do any maintenance on the property. Her asthma continued to deteriorate but she hasn’t had the energy to go back to the doctor. She knows she will have to soon though, as she is noticing that her youngest son has also been coughing a lot lately.

   i. What does this story tell us about health?
   
   ii. Is there anything that concerns you about this story?

3. We know that where you live affects your health and wellbeing. If Stacey lives in Glenorchy or Derwent Valley Council area, she is more likely to have poorer health and die earlier than people in who live in Hobart Council. She is less likely to go on to college or have private health insurance.

   i. Does this matter?
4. In the media, when government considers stories like this one about Stacey, they sometimes use words like:
   - Stacey is a ‘vulnerable Tasmanian’
   - Stacey is an example of someone living in ‘entrenched disadvantage’

They might say:
   - Stacey needs ‘a hand up not a hand out.’

Others – such as policy writers and academics – might use words like:
   - ‘social determinants of health’
   - ‘health inequities’
   - ‘the social gradient in health’
   - ‘essential services’

i. Have you ever come across any of these words before?
ii. What do they mean to you?
iii. How do you feel about these words?

5. The Tasmanian Government wants Tasmania to have the healthiest population by 2025 – how do you think this could be achieved?
Just words... what we talk about when we talk about health