



**Health Issues Centre**  
Consumer voices for better healthcare

**2022-23**

**Victorian Pre-Budget Submission**  
*Towards consumer-centred healthcare*





## Contact

**Andrew Mosley (he/him)**

Head of Policy and Advocacy  
Level 1, 255 Bourke Street  
MELBOURNE VIC 3000

**T:** (03) 8676 9050; 0402 909 345

**E:** [andrew.mosley@hic.org.au](mailto:andrew.mosley@hic.org.au)

## Introduction

Of the many lessons learned through the two years of the COVID-19 crisis, none have been more important than the realised value of ongoing community engagement, not just to promote public health advice, but to better understand the enablers and barriers to the adoption of that advice.

COVID-19 reinforced the value of partnering with communities to achieve optimal public health outcomes.

Over the last few years, the principles of partnering through a consumer-centred approach have been applied to the delivery of individual patient care, to systems improvement in policy, service design and monitoring and in the context of translating medical research to ensure the public derives measurable benefit from its considerable investment.

Consumer-centredness has become a key organising principle at all levels of the health system: <sup>i,ii</sup>

- The Victorian Government mandates the operation of Consumer Advisory Committees in its health services
- ACSQHC has embedded 'Partnering with consumers' as a core National Safety and Quality Accreditation Standard, and
- Key research funding bodies now require consumer engagement plans as a necessary and integral precondition of funding applications.

Yet in practice, embedding consumer participation across the health sector is still a work-in-progress. <sup>iii</sup>

### ***Consumer and community engagement***

As yet there are no consistent methodologies or best practice models or strategies to engage with those who are seldom heard – the disadvantaged, the marginalized and the vulnerable.

Despite best intentions to bridge discrepancies in health access and equity, our most marginalized and vulnerable communities are being left behind by this pivot to consumer involvement. COVID-19's uneven impact on disadvantaged Victorians<sup>iv</sup> provides ample evidence of the uneven nature of consumer engagement.

This shouldn't be surprising because the very social determinants that loom as barriers to equitable access are also barriers to participation. What is needed is a new approach that ensures that the vulnerable, the marginalized and the seldom heard also get to influence the decisions that determine their health outcomes.

Such a model of Consumer Driven Outcomes has been prototyped by the Health Issues Centre and it now seeks support to turn its proof of concept into a normalised model of best practice.

### ***Consumer Centred Care***

Health Services embrace models of care delivery that acknowledge patients as partners, rather than as passive recipients of care. But patient centredness is more than a compassionate approach to care delivery. It requires shared decision making which in turn requires consumer activation, health literacy and informed consent so that consumers can play a meaningful role in self-managing their health.

As a trusted advocate for the consumer voice, HIC understands the enablers and barriers to the active participation of consumers in their own health care and seeks support for its efforts to make the health system truly patient centred.

## ***Consumer driven health and medical research***

The pandemic has highlighted the critical role medical research plays in our health and wellbeing.

It is acknowledged that consumer involvement in research leads to better, translatable outcomes that improve healthcare. These benefits and the importance of consumer input into health and medical research are well-documented,<sup>v</sup> and accepted by key research funding entities such as the NHMRC<sup>vi</sup> and MRFF.<sup>vii</sup>

HIC welcomed this Government's 2020 appointment of Victoria's first-ever Minister for Medical Research and subsequent financial commitments.<sup>viii</sup> Victoria can cement its place as Australia's medical research hub by strengthening the researcher-consumer connection. But this needs direct investment in both sides of the partnership, not the current reliance on trickle-down consumer capacity building through investment in research institutions.

This is why our submission recommends a package of measures to better-enable consumers and researchers to collaborate, including establishing a pool of 'research-ready' consumers able to engage effectively in health and medical research.

## ***Towards a truly consumer-centred health system***

Embedding consumer-centric approaches to healthcare policy, design and delivery is the next frontier – and a key opportunity – in further improving our healthcare system.

Our submission contains cost-effective measures that will further strengthen healthcare and Victorian communities.

As Victoria's recognised peak consumer advocacy body, HIC is committed to working constructively with all sides of politics to improve health outcomes for all Victorians – regardless of where they live.

Our insights are informed by our ongoing engagement with Victorian healthcare consumers. In the past year, we have engaged with thousands of Victorians and their communities across a broad range of contemporary health issues.

We would welcome the opportunity to provide further detail or advice on enhancing consumer-centred health, utilizing our extensive network of consumers and their experiences.



**Danny Vadasz**  
**CEO**

## Who we are

Health Issues Centre (HIC) is Victoria's recognised peak consumer health advocacy body. We are registered as a charity and have been operating for over 35 years.

We champion the voices of everyday people in all aspects of our healthcare system and **represent the millions of Victorians experiencing care**. Importantly:

- People living in low SES areas experience poorer health
- Almost 50% have one or more of the 10 most common chronic conditions – 80% for people aged over 65.
- One in seven people do not feel they can make sense of health information.<sup>ix</sup>

We continuously engage with health consumers to:

- **Policy** – Advocate on behalf of health consumers, particularly those who currently have no influence on the decisions that define public health policy.
- **Service design** – Identify emerging needs and market failures and ensure that consumers get to influence, service design so that healthcare meets their needs and delivers quality and safety improvements.
- **Health literacy** – Deliver a range of consumer training courses including Australia's only nationally accredited consumer training. We have trained 3,000 people in the last five years alone.



## *Summary of recommendations*

**1** Boost Government's local engagement capability by trialing and adopting HIC's consumer-driven outcomes approach to community engagement [\$600K over three years]

**2** Improve research outcomes by investing in consumers' and researchers' capacity to collaborate as partners in research [\$900K over three years]

**3** Partner with Health Issues Centre to develop a 'Charter of digital health rights' [\$120K over two years]

**4** Establish a Youth Health Council to drive youth engagement on healthcare issues [\$100K over two years]

**5** Embed consumer perspectives in healthcare by supporting HIC to deliver its training for consumers and services online [\$200K over two years]



# 1

## **Boost Government's local engagement capability by trialing and adopting HIC's consumer-driven outcomes approach to community engagement - \$600K over three years**

*"The systems we put in place are supposed to serve people – not the other way around"*  
– Participant, HIC consumer health forum<sup>x</sup>

### **CHALLENGE:**

#### **Most community consultation processes, though well-intentioned, do not hear from vulnerable or marginalised voices and communities**

- Effective community engagement is critical to good policy development, successful implementation, avoiding unintended outcomes, and facilitating community uptake
- COVID-19 has reinforced the utility of place-based and local healthcare approaches<sup>xi</sup>
- The Victorian Government's Place-based Framework (2020) recognises that:<sup>xii</sup>
  - "Inclusive and accessible engagement results in diverse voices being heard by decision-makers and the broader public"
  - "We need to see [opportunities and challenges] from a local perspective and work with local people and communities"
- The Victorian Public Health and Wellbeing Plan 2019 –2023 acknowledges:<sup>xiii</sup>
  - "We need a public health and wellbeing system that is appropriate for and responsive to Victoria's diverse population"

#### **BUT**

- Standard public consultation processes seldom reach beyond educated, highly health literate, activated consumers.
- Despite a broad consensus that consumer input is vital to achieve person-centric health care, policy and service delivery reform and translatable research, there are no models for how the consumer voice can be embedded in a timely, economic and genuinely inclusive manner.
- The same social determinants that create barriers to equitable healthcare access also act as barriers to participating in consultation. Consultation innovations such as the EngageVic website do not overcome these barriers.
- The Government's draft Public Engagement Framework notes "our challenge is to make [public engagement] a whole of government priority and lift the quality of our engagement activities."<sup>xiv</sup> Consultation closed February 2020, but the final Framework has not been released.
- The Victorian Government has also acknowledged:<sup>xv</sup>
  - 'Interventions planned, funded and coordinated centrally by government are not enough to deal with the complex challenges that some Victorians face'
  - 'Government can better support place-based approaches that partner with local communities in decision-making'

## Proposed solution – What are we asking government to do?

***Invest in a trial of HIC's pre-developed Consumer Driven Outcomes Model on a range of population and condition-specific groups to inform a 'how-to guide' and toolkit for government, developed by HIC, to boost participation in underrepresented groups.***

The resulting model will be an operational guide to implementing the vision and aspirations of Government's draft *Public Engagement Framework*.

The model will ensure that engagement activities will enable rather than deter the participation of marginalised and vulnerable Victorians in influencing policy and service design outcomes.

### Impact and benefits

- **Better community engagement.** HIC's model ensures that data collection includes input from marginalised and vulnerable Victorians irrespective of their literacy levels, socio-economic background or health status. It ensures accessibility to a deliberative phase, and uses human-design principles to ensure that solutions reflect collectively defined needs. Victoria's Chief Health Officer has identified redressing disadvantage exacerbated by COVID-19 as a recovery priority,<sup>xvi</sup> and this proposal helps deliver the means to enable meaningful community engagement on how best to achieve this.
- **Better healthcare outcomes.** Governments acknowledge, and reviews have shown, that consumer-centric health care generates optimal outcomes.<sup>xvii,xviii</sup> Health services are often structured around the needs of service providers, rather than consumers.<sup>xix</sup> This proposal will deliver better outcomes by ensuring that the consumer experience is the organizing principle around which health care is designed and delivered.
- **Support Government's healthcare framework objectives.** The need and requirement for public engagement is enshrined in legislation and policy.<sup>xx</sup> This proposal strongly aligns with Victoria's:
  - *Victorian Public Health and Wellbeing Plan 2019–2023* – “We need a public health and wellbeing system that is appropriate for and responsive to Victoria's diverse population”<sup>xxi</sup>
  - *Place-based Framework* (2020) – Recognises the need to engage local people as ‘active participants in development and implementation.’<sup>xxii</sup>

## This funding would cover:

- HIC collaborating with priority populations and condition-specific groups – where those people live and congregate – to customise the model to their unique circumstances.
- Expanding HIC’s model into a robust, scalable replicable mechanism that can be used by Government and other organisations as a model and guide to ‘best practice’ community engagement
- Evaluation
- Providing training to allow government departments, health services and other stakeholders to apply the model to their own needs.
- Development of:
  - Handbook with steps and key information
  - Decision-making matrix
  - Communications guide – image and language guidelines; other languages; audio tapes; and video

## Case Study – Redesign of women’s health service delivery

A regional district health service in Victoria recognised the need to move beyond the limitations of standard consultation processes when designing their Women’s Health and Wellbeing Centre, and engaged HIC to deliver its consumer-driven outcomes approach.

Initial community consultation was by short survey and open conversation using a combination of paper based, social media, local print media and kitchen-table conversations. Initial data analysis revealed two cohorts were not represented – young pregnant women, and older women with dementia. HIC then facilitated conversations with older people (and their carers) at participating residential age care facilities and collaborated with the local Priceline (which had been identified as a popular teenage meeting place) to offer “Free makeover” sessions to connect with and hear from pregnant girls.

The suite of activities to capture routinely-absent voices included:

- ‘Ten for tea’ events in their homes
- Supported playgroup sessions
- Social media conversations
- “Casual encounter” conversations conducted by intercepting shoppers at local retail outlets and Farmers Markets.

As a result, HIC reached hard-to-reach communities.

This yielded input from over 400 women – 5% of the total population – on the health issues affecting them, and potential solutions.



# 2

## ***Improve research outcomes by investing in consumers' and researchers' capacity to collaborate as partners in research [\$900K over three years]***

### **CHALLENGE:**

#### **Consumer input improves research outcomes, but bilateral support for consumers and researchers is needed if we are to develop a truly collaborative partnership model**

- Evidence demonstrates the clear benefits of involving consumers in research <sup>xxiii,xxiv,xxv</sup>

#### **AND**

- There is growing institutional recognition of the importance of consumer input into health research (e.g. NHMRC <sup>xxvi</sup>; MRFF <sup>xxvii</sup>)

#### **BUT**

- Community health outcomes – and the needs, experiences and priorities of consumers – are not always reflected in choices about what research is undertaken and/or funded <sup>xxviii</sup>
- Barriers include communication barriers, <sup>xxix,xxx</sup> time and cost <sup>xxxi,xxxii</sup>
- Evidence shows researchers benefit from training courses to best engage with consumers <sup>xxxiii,xxxiv, xxxv</sup>
- To achieve a true consumer-researcher partnership, investment is needed in consumers, not just research institutions to better prepare consumers to engage in the research process.

## Proposed solution – What are we asking government to do?

### ***Fund HIC to deliver a package of measures to foster a partnership relationship between consumers and researchers.***

To prepare consumers to be partners in research, HIC would:

- Provide recruitment and mentoring of consumers as potential research advisers/participants
- Establish a pool of “research ready” consumers for emerging research projects
- Provide skill-specific training to consumers for the various stages of the research cycle

To support researchers, HIC would:

- Train researchers on the principles and in the practice of community engagement
- Provide Consumer Engagement support packages i.e. develop and manage consumer engagement programs for individual research projects

To foster a research partnership between the research community and consumers, HIC would:

- Develop a standard set of principles that defines the mutual obligations, rights and roles of researchers and the communities that are the objects or beneficiaries of research
- Ensure that research protocols (including ethics frameworks) balance consumer access and protections to optimise participation.
- Establish an institutional capacity to advocate for the consumer perspective in research strategy and planning

‘Consumer-driven research’ is the first-listed priority in the new draft Australian Medical Research and Innovation Priorities (November 2021).

As consumer input is increasingly valued, recognised and mandated, both researchers and consumers require support to embed this into research practices – including when prioritizing research activity, designing research, interpreting results, communicating findings and ensuring that research is translated into better public health outcomes.

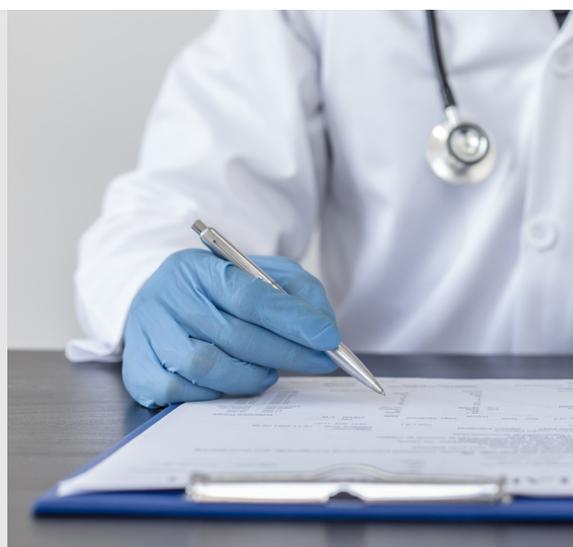
## Impact and benefits

- **Improve research outcomes**
  - Better quality studies
  - Better translation of findings into practical solutions and community benefits
  - Improved recruitment and retention of research study participants
  - Improved research dissemination and research translation
  - Time saved through pool of “research ready” consumers
  - Greater accountability of public investment in research
- **Victorian leadership in consumer-driven research**
  - Improve the quality, relevance and acceptability of health and medical research
  - Cement Victoria’s position as Australia’s medical research leader
  - Opportunity to establish national best-practice (and possibly world best-practice) in research/community collaboration
- **Deliver needed support to consumers and researchers**
  - Consumers will be readily available for research projects
  - Upskilled consumers
  - Support for researchers to meet increasing expectations that consumer input will be included in research processes
  - Development of consumer engagement pathways for individual research projects, i.e. run researchers’ consumer engagement for them

## This funding would cover:

- Establish a pool of “research ready” consumers for emerging research projects
- Provide training for consumers
- Delivery of a service connecting researchers to consumers (for researchers)
- Develop a standard set of principles that defines the mutual obligations, rights and roles of researchers and the communities that are the objects or beneficiaries of research
- Consumer and industry online portal of a series of community conversations, research forums and research showcase to recruit interested community members

*“It is particularly useful to hear about the experiences and ideas around consumer engagement from other researchers. I am now planning to extend my research and speak to carers of patients with cerebral palsy about their experiences of sleepless nights. I hope this will compliment my research on carer’s fatigue”*  
**Robert, a clinical researcher**



### 3 **Partner with Health Issues Centre to develop a 'Charter of digital health rights' [\$120K over two years]**

*"Weak governance of digital technologies is causing health inequities and compromising human rights"<sup>xxxvi</sup>*  
– *The Lancet*

#### **CHALLENGE:**

**Rapid digital health uptake is outpacing consumer privacy expectations and inclusive, equitable healthcare access.**

- Digital health provides opportunities for improved, person-centred consumer healthcare
- Most consumers agree that sharing clinical information could potentially improve health treatment<sup>xxxvii</sup>
- Digital health requires trust and buy-in for the rollout to be truly successful
- Proper structures provide greater assurance<sup>xxxviii</sup>

#### **BUT**

- Consumers have told HIC in ongoing consultations that:
  - they do not want the benefits digital health brings to compromise basic consumer rights<sup>xxxix</sup>
  - they are concerned they will lose control of their personal health data, e.g. the right to opt in or out of participation,<sup>xi</sup> and
  - privacy is particularly important for people with blood-borne diseases, mental health diagnoses and/or a history of being a victim of domestic violence<sup>xli</sup>
- 83% of Australians want government to provide more data privacy protection<sup>xlii</sup>
- Vulnerable Victorians are missing out and risk being left behind:
  - There is a marked 'digital inclusion' divide between metro and non-metro areas
  - Digital inclusion increases with education, employment, and income<sup>xliii</sup>



## Proposed solution – What are we asking government to do?

***Partner with Health Issues Centre to develop a 'Charter of digital health rights' articulating consumer digital health rights and establishing a set of principles to guide governments when designing services.***

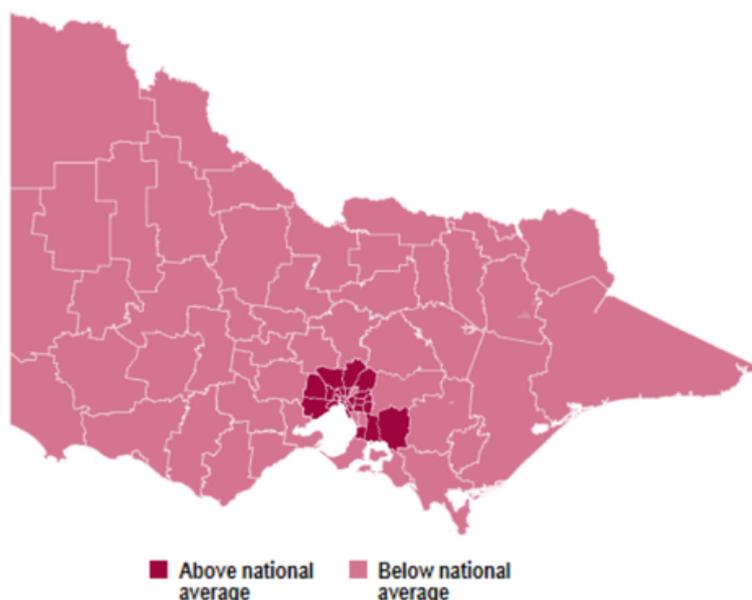
The Charter would provide additional assurance that the safety and needs of consumers are respected and protected, and include privacy rights, access rights, and digital safety and the requirement for new digital solutions to be subject to Privacy Impact Assessments.

Consumers have emphasized the importance of articulating digital health rights and rules, especially as the uptake of digital health accelerates. HIC is well-placed to continue working with our consumer network and Government to develop a Charter.

### Impact and benefits

- **Safety and needs of consumers are respected and protected.** Consumers want to feel confident that data is stored securely, in the right jurisdiction within Australia and to know their access rights – it is not sufficient to simply dial-up punitive measures for breaches.<sup>xliv</sup>
- **Increased consumer trust.** Social license is important for acceptance. Engagement with and uptake of new technologies are heavily influenced by consumer trust.<sup>xlv</sup>
- **Help improve equitable healthcare delivery.** The Charter would include inclusivity principles. The Charter will cover rights to equitable digital engagement and the right not to be disadvantaged by a lack of digital access. We welcomed the Government's \$625.8 million Digital Futures Now program, but digital inclusion is still lagging for disadvantaged and vulnerable Victorians:

The Australian Digital Inclusion Index (2021)<sup>xlvi</sup> demonstrates the rural/regional and metro divide...



...with rural areas being the three 'least included' and inner metro areas being the three 'most included':

Local Government Area	Score	Gap
Loddon	58.0	-13.1
Buloke	60.0	-11.1
Gannawarra	60.0	-11.1
Port Phillip	79.0	+7.9
Stonnington	79.0	+7.9
Yarra	80.0	+8.9

### **This funding would cover:**

- Consumer forums and consultation, leveraging HIC's large and diverse consumer network.
- Development of a 'Charter of digital health rights' that will articulate consumer digital health rights and a set of principles that government should consider when designing services.

# 4

## ***Establish a Youth Health Council to drive youth engagement on healthcare issues [\$100K over two years]***

### **CHALLENGE:**

**The voices of young people are often missing from health policy debates and decision-making**

- Young people should be empowered to take a leadership role on the health issues that impact them.

### **BUT**

- There is no designated independent forum or coalition of young people for health issues in Victoria
- While there is an active consumer voice advocating for health reform, young people's voices are seldom heard. They also often feel unable to engage in discussions about their health.
- HIC research has shown that:
  - 80% of Consumer Health Representatives are over the age of 60.
  - Young people experience feelings of confusion, disenfranchisement and a lack of respect when accessing health services or health information (recent consultation forum by HIC with young people (179 registrants) for VicHealth). This tends to be worse across regional areas.
- Initiatives such as VicHealth's Future Healthy program and government support for Youth Affairs Council Victoria are welcome, but independent community-driven input and advocacy can provide valuable grassroots insight to inform policy and implementation.

### **Proposed solution – What are we asking government to do?**

***Partner with the Health Issues Centre, as the State's peak health consumer body, to establish a Youth Health Council in Victoria to seek and promote youth voices on youth health issues and to ensure a youth voice is heard on all community health matters.***

With Government support, HIC is well-placed to facilitate and promote the voice of young people on the issues that affect them. This will include routine health users along with young people who have chronic conditions and long-term healthcare needs.

The Victorian Youth Health Council will complement the Commonwealth's funding commitment to establish a national Youth Health Forum.

## Impact and benefits

- **Empowered young people.** Young people often feel unable to engage in discussions about their health, or their input is limited by prescriptive consultative processes. HIC's engagement activities go beyond standard consultation methods and provide grassroots, tailored insights.
- **Better-informed policy on the health issues that affect them.** Entrench the voices of young people into healthcare policy deliberations and development. We will feed back our findings to VicHealth and other government entities.
- **Solution-focused insights.** Working with young people can lead to cost-effective or cost-neutral insights and solutions to health services, strategies, and programs. Frequent health users deal with the system day-in and day-out, and they often have the best insight into what is working and what needs improvement.

## This funding would cover:

- Establishment of the Youth Healthcare Council by HIC
- Establishing designated spaces for young people to contribute, discuss and advocate for health issues that are important for them
- Provide a reference point so that any policy initiative can access a youth perspective
- Creating a gold-standard model of co-design and consumer engagement that can be used by health providers and government to promote meaningful and effective consultations.

## **5** *Embed consumer perspectives in healthcare by supporting HIC to deliver its training for consumers and services online [\$200K over two years]*

### **CHALLENGE:**

**Many consumers do not feel empowered to engage in civic discussions about their healthcare and some services do not feel confident engaging with consumers**

- Consumer input strengthens healthcare delivery
- Consumers have the right to be involved in any decision making on health issues that affect them (Australian Charter of Healthcare Rights)<sup>xvii</sup>
- Consumer engagement is increasingly being mandated (e.g. NHMRC Guidelines<sup>xviii</sup>)

### **BUT**

- Consumers need to be better supported to feel more in control of their health care<sup>xix</sup>
- Health services find 'Partnering with consumers' the most challenging of the National Safety and Quality Health Service Standards to implement<sup>1</sup>
- Some staff are still hesitant about engaging with consumers<sup>ii</sup>
- Learning opportunities are difficult to come by for those who are immobile and/or live in rural communities

### **Proposed solution – What are we asking government to do?**

***Embed consumer perspectives in healthcare by funding HIC to deliver its consumer training online (\$200K over two years).***

HIC is a recognised leader in consumer and community engagement training. We deliver the only accredited courses in Australia.

This funding would be used to refresh HIC's accredited training, but also to deliver new contemporary and interactive content, develop self-paced online modules, and develop the capacity to deliver the training online.

## Impact and benefits

- **Empowered consumers.** Consumers will feel more confident and better-able to engage in decisions about their own – and others’ – healthcare.
- **Upskilled practitioners.** Practitioners will feel more confident dealing with consumers and incorporating their input.
- **More equitable training delivery.** Face-to-face training can be difficult for people in rural and regional areas to attend. Online, self-paced delivery provides another, flexible delivery option for people to enhance their skills and confidence.
- **Better healthcare outcomes.** Empowering consumers and better-equipping practitioners helps incorporate consumer needs in healthcare design and delivery. The training helps services meet the second National Safety and Quality Health Service Standard – ‘Partner with Consumers.’

## This funding would cover:

- Development of new digitally-delivered content
  - for consumers to improve their skills in engaging with health service providers, and
  - for healthcare providers to enhance their consumer engagement skills
- Consumer and provider access to an online platform to host our online training sessions
- Incorporation of a peer-to-peer support tool into the online content.

*“This kind of course and the way it is run sparks my initiative to stand up and voice how I think and feel about health care. There were many skills I acquired while completing the course which I have since utilised by engaging with my new representative role for people with disabilities.”*

*– Consumer course attendee*

## Case Study: Engaging better with communities

Mark was among a group of around a dozen community engagement coordinators undertaking the Graduate Certificate in Consumer and Community Engagement (10164NAT) at Health Issues Centre.

"It's important for us as an ambulance service to get feedback from people about what's working and what isn't," he said. "We need to talk to people who represent groups and have a broad knowledge and get feedback from people using our services."

"The course has been really good for us because it's giving us a lot of insight," he said. "How we engage people and groups shows us who's representing the group as opposed to when we're talking to someone from the group about their own experiences in isolation – which is a really important distinction."

"I'm feeling really positive about it. It's welcomed."

Tim said he also welcomed the opportunity to walk in the shoes of his stakeholders and also to benchmark his own activity against that of his peers.

"The course takes the perspective of actual consumer advocates and it's so important for us to connect with who our stakeholders are," he said.

Shea said the course had been very practical.

"This course highlights for me the importance of consumer and community engagement," she said.

"The tools we have been given will assist in doing that as we progress in our roles as community engagement coordinators."



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