



Health Issues Centre
Consumer voices for better healthcare

2020

Are your COVID-19 concerns being heard?

REPORT ON COMMUNITY FORUM AUGUST 2020
DANNY VADASZ

EXECUTIVE SUMMARY

Almost 100 people attended the HIC community forum “*Are your COVID-19 concerns being heard?*” held on Thursday 27th August, with another 39 unavailable to attend but registering their interest. The Forum was opened by HIC CEO, Danny Vadasz, who spoke about the lessons learnt during the HIV/AIDS epidemic where partnerships empowering community led responses were key to building support for infection prevention measures and identifying barriers to compliance. He reflected that these lessons appear to have been forgotten. Danny then introduced Nina Fromhold, Head of Community Engagement, DHHS who spoke about the remit of her newly created office.

Following these introductory remarks, participants were invited to make general or specific statements on behalf of their organisations/communities regarding their experiences dealing with government during and about the COVID-19 pandemic response. This report is a compilation of the comments that contributed to the discussion.

Loss of trust and social licence

Attendees variously expressed bemusement, exasperation, despondency and anger at the lack of community engagement by the state government throughout the pandemic response despite their own best efforts to initiate dialogue. Examples were given of unreturned phone calls, unacknowledged emails and the cancellation of pre-existing community engagement channels such as advisory committees.

Speakers referred to these in the context of an erosion of trust between community and government.

“There needs to be significant work done to develop trust in a community relationship because for the last six months we’ve been banging on the door offering our understanding of what’s happening in vulnerable communities, and we’ve been ignored. Community engagement, consumer participation, its all been left by the wayside.” - Sophy Athan, Consumer Rep, Chair HIC.

Top-down Command and Control

Participants were universally critical of the current top-down approach to transmission control.

“Take a look at the New Zealand Prime Minister. She reached out to the community and got them engaged.” - Alan White, Consumer Rep

Prying the doors open

They spoke of their efforts to reach out to DHHS to offer practical, constructive support only to have those offers declined or ignored. Some spoke of the Department’s opacity making it impossible to know which parts of and who in the government were managing different aspects of the pandemic response. They called for the empowerment of community organisations to tailor information so that it was fit for purpose.

“At one point I was emailing DHHS every three days saying “Can I help you with this? You’ve put out comms again that use the wrong language about deaf and hard of hearing people. Here’s some resources, I’m happy to help, Call me any time” and I didn’t get a reply to these really comprehensive emails that I’d put together in good faith trying not to tell you people how to do your job but I wasn’t getting a reply.” – Maxine Buxton, Deaf Victoria

Empowering communities

Community organisations saw themselves as the trusted and natural reference point for their communities if only they were empowered to act.

“Community orgs are trusted voices. We can get evidence based and confidence inspiring info out there to support individual and overall community health.” - Patricia Schluter, Lung Foundation Australia

SPECIFIC BENEFITS OF COMMUNITY PARTNERSHIPS

The discussion covered a range of weaknesses and failings in the current COVID-19 response that could have been anticipated and addressed through community partnerships:

1. Anticipating outbreaks

Participants believed that their insights based on on-the-ground knowledge of their communities could have played a key role in anticipating infection breakouts in complex settings.

“Not enough attention paid to the vulnerable members of society given by State Government. Overseas experience demonstrated who would be at risk. Casual employment caused most of the issues in Aged Care. Why was age care not lockdown sooner?” - Lynda Andrews, Heartbeat Victoria

2. Acknowledging the fears of vulnerable communities

High risk groups feared they would be triaged out of COVID-19 care because of their pre-existing comorbidities.

“As a polio survivor myself I am fully aware of how debilitating a virus can be, and would hate to think if I were to be wheeled into Emergency, I would be rejected or discarded by reason of my disability and or age and denied full treatment.” – Shirley Glance, Post Polio, Victoria (PPV)

3. Prioritising the needs of vulnerable communities

They also felt that their needs both during and post the pandemic were not and would not be met.

“We have concerns about the role of Department in creating and ensuring (perhaps through contract arrangements) there is joint care coordination i.e there are timely and strong referral pathways from mental health providers to specialist consumer groups and vice versa.” - Patricia Schluter, Lung Foundation Australia

4. Accessing information

Representatives of high risk groups complained that they had been advised to take additional precautions but were never informed what those precautions should be.

“At the beginning of the epidemic the messages were people at high risk needed to take extra precautions but there were never any follow up about what those precautions were. The messages have always been for the general public.” – Carlie Park, Disability Advocate

It was pointed out that not only did information need to be tailored to different target audiences, it needed to be delivered through appropriate channels.

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“The Deaf Community will be more effectively reached through peer to peer information delivered by Deaf people. We can't just rely on interpreters at a press conferences.” - Maxine Buxton, Deaf Victoria

5. Cultural safety

For some groups that already felt marginalised, messages that ignore their identity reinforced their sense of being outside the system

“Its critical that the Community orgs are included in the messaging – particularly in the LGBTI community where so many have a history of discrimination and marginalisation and problems accessing health services. If they're not able to access culturally safe services and feel encouraged to do so then they won't get the services needed. - James Zanotto, National LGBTI Health Alliance

6. Unintended consequences

Several speakers highlighted unintended consequences of policy directives and government actions.

“We're on the NSW / VIC border and so many people have been terribly badly affected by the arbitrary and constantly changing Border Restrictions. This has negatively affected local people in so many ways (work, agriculture, education, caring responsibilities, access to healthcare etc) and was done without any consideration or understanding of how these border communities work. Again, the negative impacts on these communities (who have had so few cases) far outweigh any threat from Coronavirus, and their arbitrary nature has caused significant mental anguish and financial stress. - Sophie Rhys, Upper Hume Primary Care Partnership (UHPCP)

CONCLUSIONS

Consumers and community organisations believe they are in the best position to manage the communication of government information back to their communities and conversely to provide insights and feedback that can improve the outcome of pandemic management in various ways.

We call for the establishment of a clear partnership framework between government, its agencies and consumers and community groups to address the following:

- A greater transparency as to which parts of government (particularly within DHHS) have lead responsibility for different aspects of COVID-19 response management and access to those authorities;
- Establishment of bilateral pathways for communication between government and communities both to disseminate government information and to feedback barriers to compliance, service gaps, special needs and unintended policy consequences;
- Mechanism for empowering communities to advise and lead on communications initiatives and drive compliance strategies within their communities;
- Appropriate funding of community organisations to carry out this work including the commissioning of culturally appropriate resources;

INTRODUCTION

In response to the expressed concerns of many community groups regarding the lack of community consultation throughout the COVID-19 pandemic, Health Issues Centre (HIC) convened a community forum to share these concerns and consider how they could be constructively addressed.

Victorian based community organisations and community representatives engaged in consumer advisory roles with DHHS/SCV and Victorian Health Services were invited to attend.

104 registrations were received as well as a further 39 responses from organisations unable to attend but requesting to be kept informed of outcomes and future initiatives. A further 12 written submissions were received prior to the event.

While the vast majority (over 75%) of registrants were either Consumer Representatives or representatives of vulnerable communities and conditions specific groups, participants also included health system representatives, representatives of local and state governments and clinicians.

| Category | Number of participants |
|--|------------------------|
| Consumer Rep | 28 |
| Medical Professional | 3 |
| Concerned user of health | 9 |
| Community group, Charity, non-government | 38 |
| State Government | 2 |
| Health System in non-medical position | 15 |
| Local Government | 8 |
| <u>OTHER:</u> | 1 |
| Non-org Attendee | |
| TOTAL | 104 |

The Forum was opened by HIC CEO, Danny Vadasz, who spoke about the lost lessons of the HIV/AIDS epidemic where community partnerships and community led responses were key to reducing transmission rates in vulnerable communities. Danny then introduced Nina Fromhold, Head of Community Engagement, DHHS who spoke to the remit of her newly created office.

Apart from setting the context for discussion through the event theme “Are your COVID-19 concerns being heard?” HIC did not predetermine questions or topics for discussion other than to ask participants to make general observations and raise issues of specific concern to their constituents. In keeping with HIC’s *Social Listening* methodology, this report captures all the comments expressed on the day and submitted beforehand. Data includes both written statements recorded in the Chat facility and verbatim transcriptions of speaker comments. It also incorporates 12 submissions received prior to the event from organisations wishing to contribute to the discussion but unable to attend.

Because the views represented are unusually consistent, it is important to stress that no dissenting views were omitted or edited. This report authentically represents the sentiments of over 140 participants, a significant and diverse cross-section of the Victorian community sector. Editing has focussed on identifying and reflecting key themes using sentiment analysis methodology.

A LOSS OF TRUST AND SOCIAL LICENCE

A common and overarching theme raised by participants was their loss of trust in the government's management of the pandemic due to its reluctance to consult with communities, particularly "high risk" and "vulnerable" communities. Consumer representatives spoke of the suspension of long-standing advisory committees and other participatory mechanisms that they believe could have made positive contributions to the pandemic response. Community organisations related their frustration at having no line-of-sight into pandemic strategic thinking and spoke of their dismay at having their representations and offers of assistance ignored.

Rather than leveraging the trusted relationships organisations had built with their communities, the government chose to shut-down existing corridors of communication and collaboration and adopt a top-down "Command and Control" response to the pandemic.

"The biggest issue is it appears that the Government Australia wide does not seem to have learnt from the errors that have taken place over the last 6 months." - Barry Baulch, MACH

ALIENATION OF CONSUMER REPS

Harshest criticism was directed at Safer Care Victoria (SCV), the health agency that has taken the lead in promoting consumer engagement and that has responsibility for overseeing the legislative requirement for key health services to operate Consumer Advisory Committees. According to members of their own Patient and Family Council, SCV's various consumer committees have not been convened since March 2020 with no indication as to when they would be recommissioned.

"Safer Victoria State Advisory Councils not met since March 2020" - Lance Jennison, Consumer Rep, Victorian Clinical Council, Victorian Patient and Family Council, VAHI

"I find it difficult to believe that Safer Care Victoria hasn't been holding meetings. Why? Haven't they heard of Zoom?" - Alan White, Consumer Rep

The suspension of engagement with the community was seen as eroding trust and the social licence granted to government to act in the community's best interests. This has generated an unfortunate cynicism of the Department's commitment to its own consumer participation processes. The frustration and demoralisation expressed by consumers, some of whom have spent years working on advisory committees suggests there will need to be a rebuilding of damaged relationships. One speaker drew a distinction between the pandemic as a medical challenge and the real crisis which he defined as the breakdown in community trust.

"COVID is responsible for the epidemic but not for the crisis. The crisis is because of the lack of government initiative and understanding. The pandemic and the crisis is affecting all the community and the community has lost trust. It is not able to engage with and trust the government because the government isn't engaging with the community. Consumer representatives on advisory committees have not been taken seriously. DHHS has to provide a platform (perhaps legislatively) to ensure that consumer participation is taken seriously." - John – consumer rep on a health service CAC and infection control and prevention committee.

"I've been associated with SCV for a couple of years now and I've been a member of one of the Clinical Networks. That was all suspended in March but the general attitude is they just don't care. They treat people with contempt, nothing is said or done, we're just left hanging in the breeze and that's not just the general attitude of SCV but the Victorian Government. They treat us with

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contempt. The view of people in authority generally is that we the general public only exist to serve them.” – John, Consumer Rep

“There needs to be significant work done to develop trust in a community relationship because for the last six months we’ve been banging on the door offering our understanding of what’s happening in vulnerable communities, and we’ve been ignored. Community engagement, consumer participation, its all been left by the wayside.” - Sophy Athan, Consumer Rep, Chair HIC

REJECTION OF TOP-DOWN COMMAND AND CONTROL

Participants were universally critical of the top-down approach practiced to date. It was noted that by cutting itself off from community feedback, government effectively blind-sided itself from valuable information and insights that could have helped curtail community transmission. Despite this, there was a guarded optimism and good will that the creation of an office of community engagement would herald a new, more inclusive approach.

“It was a top-down approach and there was no effort to engage with the communities who knew what the vulnerabilities were. I’d really like to understand the strategy going forward. How you are going to engage with the community and how are we going to have those ongoing dialogues so that as we move forward there will be a more effective way of hearing what they are experiencing.” – Sophy Athan, Consumer Rep, Chair HIC

“Why has this position only just now been filled, it needed to have been done in the first place.”

“I’m bemused that governments (Federal and State) have adopted a total top-down approach. For example I’m doing an international online course on patient engagement and the whole structure is around consumers and patients having involvement at all levels. I’m bemused that Nina’s position is only now being created. What are people in the department being paid for? Take a look at the New Zealand Prime Minister. She reached out to the community and got them engaged.” - Alan White, Consumer Rep

“Shouldn’t have taken this long to focus on a bottom up approach. Consumer organisations have always been ready to engage.” - Christine Hunter, Hearing Matters Australia

(Re lockdown of public housing towers) “Had the government included the community they targeted they would have achieved a better outcome.” - Hoda Al-hayek, Consumer and community representative Concord Hospital NSW

The frustration felt by consumer representatives and community organisations was shared by other stakeholders

“Frustration the GP community has had in inability to be involved in planning the pandemic response. We have tried and are very thankful to have had some engagement with DHHS but not to the extent that we believe the general practice community can play the vital role in responding to the challenges of the pandemic, not just the communications but addressing inconsistent health messages, addressing what is true information and what isn’t. We’ve launched initiatives promoting the importance of expert advice but this is an activity the College has taken on itself rather than in conjunction with the Dept. A partnership model would have far greater impact in dealing with the challenges throughout this pandemic”. Kon, RACGP

PRYING THE DOORS OPEN

Some participants spoke of their efforts to reach out to DHHS to offer practical, constructive support only to have those offers declined or completely ignored. Others spoke of their frustration with department opacity when they tried to find out precisely who was managing which aspect of the pandemic response. They called for the empowerment of community organisations to tailor and deliver information that was fit for purpose.

“We have a good relationship with DHHS - we are funded to provide individual advocacy support. Nevertheless we’ve found it really, really difficult to offer feedback and support when we see that DHHS is struggling to reach out to groups with different communication and information needs. There is a need to work with particular communities to empower them to deliver tailored and targeted messages to their cohorts.”

“At one point I was emailing DHHS every three days saying “Can I help you with this? You’ve put out comms again that use the wrong language about deaf and hard of hearing people. Here’s some resources, I’m happy to help, Call me any time” and I didn’t get a reply to these really comprehensive emails that I’d put together in good faith trying not to tell you people how to do your job but I wasn’t getting a reply.” – Maxine Buxton, Deaf Victoria

“DHHS has never contacted our Assoc to see how our members are coping through Corona Virus - nor did they ever contact us through the Hazelwood mine fire - it is about time they started to make connections with the groups that are on the ground doing the hard yards”. - Vicki Hamilton, CEO of Asbestos Council of Victoria/GARDS

EMPOWERING COMMUNITIES

Participants emphasised the value of establishing partnerships with community groups, both because they are well connected with the everyday experience of their constituents and because they enjoy their trust.

“Partnerships with Community Groups are so powerful and important, and so much more timely and cost-effective.” - Sophie Rhys, UHPCP

“We want to be collaborators, but we just need people to give us some airtime, invite us to some meetings, ask us to proof-read stuff. Empower us and fund us so that we can fund expert communicators in our communities to deliver your key messages well. We’re actually trying to help reduce the burden because we don’t expect you to be experts on every type of consumer cohort – that’s our job. And we’d rather not have to come to you when mistakes are made and then you have to retrofit things.” – Maxine Buxton, Deaf Victoria

“Community orgs are trusted voices. We can get evidence based and confidence inspiring info out there to support individual and overall community health.” - Patricia Schluter, Lung Foundation Australia

“With CALD communities a priority, it has been disappointing to see the government not make more use of the network of multicultural and ethnic community associations, ethnic seniors groups etc., many of which are the most trusted organisations in their communities and have long experience working directly with their communities” - James Houghton, Ethnic Communities’ Council of Victoria

The point was made that no one expected the government to be experts about every community within society, but that expertise existed on the ground if only government would tap into it.

“We don’t expect Dept to know how to work on the ground at the grass roots level but the Dept funds a lot of agencies that know those communities on the ground. For instance the Flemington and North Melbourne High Rise communities – these are very well organised communities. If there’s a wedding or a funeral, the communication is immediate and its very smooth so it was really surprising seeing the govt not tap in to those very strong networks. Not asking agencies on the ground (like the Jesuits) who to partner with because we know. As with Maxine, our experience was of really trying to offer help and being bounced around the Dept and just not knowing who to talk to. Its like there was no entry point to say “We know how to do this. Let us help.” Its not about expecting you to do it but expecting you to support others to do it because they know how to.” - Sophie Deherty, CCEH

“Victimisation is an issue for my family. My aunties are taking on translation services, making masks. But they don’t get invited to participate. You’ve got boots on the ground willing to help. They’ve come from backgrounds where they’ve been victimised so we shouldn’t be repeating that experience now.” – Mae, (Sydney based) representing Aunties in Melbourne.

“I don’t believe that the government has even gotten started with supporting the community. The first step is to identify who is at high risk from the virus. Then to start working with these groups, to produce targeted restrictions and information, to start keeping statistics, and to roll out supports for people to take extra precautions.” - Carlie Park, Disability Advocate

BENEFITS OF COMMUNITY PARTERSHIPS

Participants highlighted a variety of ways in which community partnerships would add value to COVID-19 infection prevention and management.

1. ANTICIPATING OUTBREAKS

Participants believed that their insights based on on-the-ground knowledge of community organisations could have played a key role in anticipating infection breakouts in complex settings.

Conversely, a total reliance on hard data meant that decisions were invariably based on what had already transpired rather than what could be anticipated and therefore avoided.

“We warned about what could happen in aged care, we warned about disability and we were completely ignored and disregarded. I understand bureaucracy can be slow in responding but what I would like to see is for bureaucracy to be a lot more agile and really committed to working effectively with organisations like us.” – Sophy Athan, Consumer Rep, Chair HIC

“Not enough attention paid to the vulnerable members of society given by State Government. Overseas experience demonstrated who would be at risk. Casual employment caused most of the issues in Aged Care. Why was age care not lockdown sooner?” - Lynda Andrews Heartbeat Victoria

“The Disability Royal Commission hearing last week revealed that the government does not understand that (a) most disabled people are at a very high risk from Covid due to comorbid health conditions, high rates of poverty and discrimination impacting access to and quality of healthcare, and (b) we have different needs to the general population, and (c) we have needs that need to be prioritised.” - Carlie Park, Disability Advocate

2. ACKNOWLEDGING THE FEARS OF VULNERABLE COMMUNITIES

High risk groups feared they would be triaged out of COVID-19 care because of their pre-existing comorbidities

“Even the wait in lines for testing has been a very difficult experience for some people with significant illness and disability.” - Christine Hunter, Hearing Matters Australia

“People from NESB already feel marginalised and also feel unsafe to get tested because they feel they will be further singled out and outcasted if they test positive to COVID-19.” - unknown

“As a polio survivor myself I am fully aware of how debilitating a virus can be, and would hate to think if I were to be wheeled into Emergency, I would be rejected or discarded by reason of my disability and or age and denied full treatment.” – Shirley Glance, Post Polio Victoria (PPV)

“We have been particularly scared of catching COVID and going into hospital, particularly with information coming in that in other countries like Italy they had to make decisions about who got ventilators and who didn’t and it wasn’t us. So as a community we’ve been quite terrified of COVID and at the same time have had no information from the government as to what we should be doing about that. What I’ve seen is a lot of people in my situation going into their own lockdown. Most of us have been in some sort of lockdown since March where they are barely leaving the house. We’re only going out for absolute bare essentials like medical appointments and maybe a walk around the block. Effectively we’ve been in Stage 4 restrictions since March. Where’s the information been. Its been extremely time-consuming as an individual to have to research what measures we should be taking as a household. This should have been provided by government, not left to individuals. – Carlie Park, Disability Advocate

3. PRIORITISING THE NEEDS OF VULNERABLE COMMUNITIES

“Polio survivors must be given as of right full treatment for coronavirus infection, including use of ventilators. Moreover, PPV insists that polio survivors not be subject to enforced euthanasia through failure to provide best-practice treatment, or in any other way. It is self-evident that the medical treatment of polio survivors must not be compromised by reason of age and/or disability or on any grounds whatsoever.” - Shirley Glance, Post Polio Vic

“I’m also concerned that our needs haven’t been prioritised. So coming out of lockdown I haven’t seen anything about prioritising us in terms of getting access to health care and self-care. Things like access to swimming pools for hydrotherapy. I have a friend who is undergoing cancer treatment and cant access hydrotherapy and she says her life is literally being cut short by months but I cant see the government prioritising, giving people access to hydrotherapy as an essential health care service, access in preference to someone who just needs to go lap lane swimming. Its been really disappointing and frustrating. – Carlie Park, Disability Advocate

“A lot of us are really struggling with mental health – group therapy hasn’t moved online. I’ve heard of mental health services exiting people during this time because they’re “too distressed”. So things are being withdrawn at a time when we need them the most. No one seems to be listening”. – Carlie Park, Disability Advocate

“We have concerns about the role of the Department in creating and ensuring (perhaps through contract arrangements) there is joint care coordination i.e there are referral pathways from mental

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health providers to specialist consumer groups and vice versa.” - Patricia Schluter, Lung Foundation Australia:

“For the community on around the community centre at Wingate Avenue (that is, the Ascot Vale low rise housing estate) access to resources to support mental health, DFV and access to general social support is needed. If the community centre had a connection at DHHS to access services (or more importantly) funding for PLACED-BASED services that would be amazing. What we're seeing is the most disadvantaged being more marginalized and in extreme distress bc they're unable to work with remote services (which are understandably remote). The provision of social services (such as social workers, counsellors, food relief etc.) through the big players (such as SV, MCM, CoHealth) doesn't work for the most disadvantaged in the community, but placed-based services do work. Funding for social services, connection to DHHS and local community based working groups is what the community in the Moonee Valley area need.” - Angie (Wingate Ave CC)

“Many people who have experienced a recent amputation are being discharged from acute care to home/residential settings rather than via the traditional transition pathway to rehabilitation facilities. This leads to physical deconditioning, general malaise, mental health impacts and reduction in the physical activity needed to be fitted with a prosthesis. Consequently, people with lower limb amputations return to their home with the use of a wheelchair until they receive their interim (first) prosthesis, and often to a residence which has not yet been adequately assessed for safety or having had appropriate home modifications made.” - Fiona, Limbs for life

“We agree with masks as a society wide measure is appropriate but we would like to suggest that this is a good example of there being a really simple solution. Something as simple as a clear mask could help not just over a million Victorians with hearing loss or who are deaf but people who have additional communications needs such as seeing facial expressions – children at school needing to see their teachers, children learning to speak.” – Kaitlin Barr, Soundfair Australia

“We all live in a LGA and we need to broaden the understanding of how LGAs work. Where gaps exist we are often the first port of call to assist and where we cant we do escalate to DHHS. Understand how your local LGA is positioned to assist and how it can assist.” - David Booth: Greater Shepparton Council

MESSAGING Vs COMMUNICATION

Perhaps the major arena in which community organisations felt they could take a lead role was ensuring that government messages were differentiated and nuanced both in language and with cultural sensitivity, so as to be fit for purpose for different cohorts.

4. ACCESSING INFORMATION

It was pointed out that not only did information need to be tailored to different target audiences, it needed to be delivered through appropriate channels.

Representatives of high risk groups complained that they had been advised to take additional precautions but were never informed what those precautions should be.

“At the beginning of the epidemic the messages were people at high risk needed to take extra precautions but there were never any follow up about what those precautions were. The messages have always been for the general public.” – Carlie Park, Disability Advocate

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“There is an expectation that the consumer / citizens know where to go to get the information they need. Whilst it may there, on radio/tv but what time/channel? On the web. Trying to navigate the government health websites is a nightmare. I am sure much of what we are all asking is there in some form ... somewhere! It needs better communication.” - Denise

“Most Australians are not getting their COVID information from the Dept. of Health webpages.” - Patricia Schluter, Lung Foundation Australia:

“The Deaf Community will be more effectively reached through peer to peer information delivered by Deaf people. We can't just rely on interpreters at a press conferences.” - Maxine Buxton, Deaf Victoria

“Lack of appreciation on the part of the Department, for the role of community organisations as a trusted source of information, including tailored information to their members/supporters.... the clusters emerging in low socio economic and culturally diverse communities should demonstrate a need for tailored messaging and targeted interventions.”

“There is a need for targeted health and safety messaging that meets the needs of diverse members of our community, and developed with the community to get it right. - James Zanotto (National LGBTI Health Alliance)

5. CULTURAL SAFETY

Apart from language appropriateness, some groups called for more attention to ensure that communications were culturally appropriate. For some groups that already felt marginalised, messages that ignore their identity reinforced their sense of being outside the system.

“One of the strongest messages (research conducted by LGBTI Health Alliance) was that public health messages were not being targeted to them (older LGBTI community members). They weren't seeing themselves represented in the messages in terms of health promotion and access to services leading to a greater sense of isolation and failure to access those services.

Its critical that the Community orgs are included in the messaging – particularly in the LGBTI community where so many have a history of discrimination and marginalisation and problems accessing health services. If they're not able to access culturally safe services and feel encouraged to do so then they won't get the services needed. Research is showing LGBTI people are more likely than the general population to be suffering with mental health problems, more likely to have lost their job, more likely to be drinking more and dealing with drug and alcohol. Many of the services rely on volunteer support and many of those volunteers are no longer available.” - James Zanotto, National LGBTI health alliance

“The need for cultural safety both in the management of the response and in communications with the public (which has been exemplified by the Aboriginal community controlled sector).” - Paul Gibson, Indigenous Allied Health Australia:

“By way of example, the response in locking down the public housing towers in Melbourne missed an opportunity to support the cultural needs of residents, for example by ensuring access to familiar and culturally acceptable foods. “

“There ought be a formal role for community organisations /consumers when a public health emergency / State Displan plans are being prepared pro actively . Union organisers, members, and local Green's Mp's were most helpful .. DHSS not clearly in sight when it counted. Many residents in our public housing towers had much lived experience of living during wars, migration, poverty , and

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how to look after each other .. They ought have been treated with more respect and have more power.” – S baxandall

6. UNINTENDED CONSEQUENCES

Several speakers highlighted unintended consequences of policy directives and government actions.

“A pressing concern is suppressed demand for alcohol and other drug treatment services; elements of the sector have contracted, people may be avoiding treatment, may not be able/reluctant to engage the COVID-19 modified system and may also be increasingly engaging in at risk substance use in part due to anxiety regarding COVID-19 and associated restrictions. When/if COVID-19 subsides, it is probable that we will get a surge in demand.” - Dave Taylor, Vaada

“There’s been a drop-off of screening for non-COVID diseases for example PSA testing. There’s been no message from the government about making sure you keep your appointments up to date.” - Alan White

“The physical and mental health impacts of an ill-fitting prosthesis results in the user feeling frustrated, in pain, fearful, and at risk of trips and falls. In addition, if an ill-fitting prosthesis is being used by a person with T2 diabetes or vascular concerns, this could lead to infections and, at worst, the need for additional higher-level amputation.” - Fiona, Limbs for Life

“The Continence Foundation has fielded additional calls through the National Continence Helpline throughout the COVID-19 pandemic and particularly in relation to the recent public towers lockdown. We’re concerned that issues of incontinence can be highly personal, often stigmatized and each individual dealing with incontinence can have highly specialized needs. Concerns regarding access to products, support structures and treatments have been common and these things can be highly distressing, particularly among vulnerable members of the community. With over 5 million Australians experiencing bladder or bowel control problems we want to ensure future lockdowns consider incontinence issues and as the peak body the Continence Foundation welcomes opportunities to assist in any planning and response initiatives.” - Lane Prowd, Continence Australia

“Lots of confusion among clinicians as well.eg cancer screening being considered as "ELECTIVE" surgery.” - Kerri Easton

“Concerned about the impact of masks on clear communication, especially for people who are deaf and hard of hearing. We would have valued an opportunity early on to work with other organisations for deaf and hard of hearing people to create the environment for clearer communication.” – John Smith, Soundfair

“There is no understanding of how general rules have an impact on the day to day lives of ordinary people. People want to comply but the rules need to be framed so that they don’t have unintended consequences including deaths related to people not presenting for other conditions such as cancer treatment, family violence, suicide, drug and alcohol.” – Sophy Athan, Consumer Rep, Chair HIC

“The government has been telling off the public for not continuing to access healthcare but some of us are being literally turned away (e.g. I got turned away for having a cough though I've had it for 6 months) and some healthcare professionals have not been taking adequate precautions so we have been too scared to go. The solution is to talk to us about making services safe and accessible. To have more services delivered at home.” - Carlie Park, Disability Advocate

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“Just wanted to highlight a conflict with messaging around PPE from a disability perspective and Aged Care (entry level aged care in the home CHSP). I work in the Southern Metro Region in Melbourne and with service providers that deliver services funded by State and Commonwealth. For a service provider supporting a person with a disability is required to wear PPE including goggles but in the Aged Care sector are not required to wear goggles. These services have workers that support both groups. The messaging needs to be clarified and consistent.” – (name redacted by request)

“I have a waiting list of people who need elective surgery and often with my special needs patients its an accumulation over many years of problems and they often need a general anaesthetic to treat and of course under the current guidelines its mandatory for people to have a COVID test a week before their surgery and then isolate for the week. So there are two big issues there – firstly having someone take the test particularly if they have intellectual disability and also isolating for the whole week because of the nature of group homes and the number of carers contacting them. I don’t have a problem with the need for protection of health professionals but its really discriminating against my group of patients. With cooperation and communication and a few changes in structure that should be possible but it just needs people to work together.” - Helen Marchant, Specialist Dentist - people with disabilities –

“A lot of polio survivors are going through post traumatic stress and aren’t reaching out or being helped. From a personal perspective as a survivor I’m finding this period quite debilitating and emotionally stressful. We are also concerned about how we will be treated in hospital as a person with disability if we get COVID. Are we going to be given the same rights and privileges to care as everyone else. And we are concerned that many of us are older.” - Shirley Glance, Post Polio Victoria

“The HIV community is concerned that cluster tracing and phylogenetics of COVID will set precedents for criminalisation or civil disputes for other infectious diseases. We have seen that criminalising transmission of disease does not deter risky behaviour, but it does discourage testing.” Craig Burnett, Living Positive Victoria

“I agree Craig, criminalization doesn't deter risky behaviour.” - Mae :

RURAL AND REGIONAL ISSUES

7. BORDER COMMUNITIES

“We’re on the NSW / VIC border and so many people have been terribly badly affected by the arbitrary and constantly changing Border Restrictions. This has negatively affected local people in so many ways (work, agriculture, education, caring responsibilities, access to healthcare etc) and was done without any consideration or understanding of how these border communities work. Again, the negative impacts on these communities (who have had so few cases) far outweigh any threat from Coronavirus, and their arbitrary nature has caused significant mental anguish and financial stress.

- *The additional stress and worry for people from vulnerable communities – particularly CALD, people with disability and those with mental health challenges has been tremendous.*
- *There has been no attempt to explain the logic of why these restrictions were increasingly tightened.” - Sophie Rhys, Upper Hume Primary Care Partnership (UHPCP)*

8. BUSHFIRE RECOVERY

“We are based in North East Victoria. Badly affected by bushfires, so double whammy of bushfires and pandemic. Some of our areas super isolated, NO or few recorded cases through the whole pandemic etc., yet people currently under same ‘regional’ restrictions as Geelong, Ballarat and Bendigo. Communities still haven’t been able to get together properly since February to start the process of healing from bushfires, and the long-term implications for mental health etc., as well as economic hardship significantly greater than any threat from coronavirus.

Solutions? Create special considerations for all remote areas (perhaps based on geographical statistical areas?), but especially for those that have been through bushfires. Enable local communities to meet together, keep their businesses open etc (but fine to prevent travel to the area).” - Sophie Rhys Upper Hume Primary Care Partnership (UHPCP)

9. RURAL ISOLATION

“I live in a small community that has been locked down – the Yarra Ranges – and five kilometres is a huge limitation for me because the next community is 10 kilometres away. I don’t want the hassle of being stopped by police so in the end you simply don’t get adequate supplies or services because its too hard.” - Sophy Athan, Consumer rep, Chair HIC

“I am the Volunteer Transport Coordinator for a regional health service in Gippsland. During actual Lockdowns we are not able to use volunteers to do transport but were able to provide a limited service with paid staff who usually do group work. However, when the first Lockdown was lifted (but still a state of Emergency), I was told by senior management that the DHHS regulations were that volunteer drivers were only able to transport for 15 minutes or less, so only for short trips. Most trips we cater for are for 30 – 100km, so we were not able to provide a service for most requests.” – Anna Jones

CONCLUSIONS AND RECOMMENDATIONS

A one hour session was not enough time to allow people to vent their frustrations and to highlight their concerns, let alone workshop recommendations and solutions. However, the substance of the discussion points to consistent themes and provides clues as to how these may be constructively approached.

Consumers and community organisations clearly believe they are in the best position to manage the communication of government information back to their communities. Conversely they believe they can provide insights and feedback that can improve the outcome of pandemic management in various ways:

Supporting compliance – Ensuring that messages around testing and restrictions are communicated through language that is clear, consistent, and culturally appropriate

Identifying barriers to compliance – Identifying any economic, social, cultural or logistical inhibitors to directive compliance

Precautionary advice for high-risk, vulnerable cohorts – Identifying environments and contexts that warrant special and specific precautionary measures and self-help advice for high risk communities/individuals

Prioritising needs of high risk cohorts – Ensuring that services that have been shut down remain accessible to vulnerable communities with special needs

Unintended consequences – Providing early feedback where policy initiatives inadvertently lead to perverse outcomes

Regional and rural specific issues – Addressing the complexities of regional and rural circumstances, particularly in border communities and communities still requiring from bushfire trauma.

This report does not propose mechanisms for addressing these issues. That should be the subject of further purposeful conversation hopefully conducted in partnership with DHHS and other relevant parts of government.

It does, however, call for the establishment of a clear partnership framework between government, its agencies and consumers and community groups to address the following:

- A greater transparency as to which parts of government (and particularly DHHS) have lead responsibility for different aspects of COVID-19 response management;
- Establishment of bilateral pathways for communication between government and communities both to disseminate government information and to feedback barriers to compliance, service gaps, special needs and unintended policy consequences;
- Mechanism for empowering communities to advise and lead on communications initiatives and drive compliance strategies within their communities;
- Appropriate funding of community organisations to carry out this work including the commissioning of culturally appropriate resources;