



Cancer screening and Hepatitis B education during COVID19 in Melbourne's Northwest Corridor

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## **Table of contents**

INTRODUCTION	1
PROGRAM DESIGN	1
ACTIVITIES	2
Information sessions	2
Resources distributed	2
FACTORS THAT AFFECTED UPTAKE	ERROR! BOOKMARK NOT DEFINED.
Experienced bicultural workers	3
2. Project timing during active outbreak	4
3. Health literacy and education	5
4. Superstition, stigma and taboo	5
4. Creating a comfortable learning environment	6
5. Digital literacy and access	7
6. Gender	8
CONCLUSION	9

# **Acronyms**

Hep B Hepatitis B

COVID-19 Coronavirus disease of 2019

ACPCC Australian Centre for the Prevention of Cervical Cancer

NWMPHN North West Melbourne Public Health Network

### Introduction

Cervical, bowel screening and Hepatitis B testing are some of the most effective tools available to prevent cervical, bowel and liver cancer developing or treat it in the early stages. During COVID-19, the number of people screening and testing in Victoria reduced. The community in Northwest areas of Melbourne were particularly impacted by COVID-19, with high case numbers and large populations of priority groups from culturally diverse backgrounds.

To counteract this trend, Cancer Council Victoria worked with community organisations to raise awareness in priority communities about cervical and bowel screening and Hep B testing. Bicultural workers designed and delivered tailored community engagement activities both online and remotely with their communities between July and August 2021. The project included many activities, but this report focuses on the work done by bicultural workers and their reflections on what worked well when delivering education remotely during a pandemic.

This project was funded by the Victorian Department of Health and formed part of a bigger project. The Australian Centre for the Prevention of Cervical Cancer (ACPCC) and North West Melbourne Public Health Network (NWMPHN) delivered the professional facing activities that encouraged health professionals to promote screening and testing.

## Program design

Cancer Council asked community-based organisations in North West Melbourne for their advice on what was the best way to reach as many people as possible in a COVID-19 safe way. They recommended two main approaches: education sessions led by bicultural workers and distributing resources. Cancer Council partnered with four organisations that had established bicultural worker programs<sup>1</sup> to recruit 20 bicultural workers with community connections to 10 priority language groups:

Country/ region of the target audience	Languages
East Africa (North Sudan, Eritrea, Ethiopia)	Arabic
South Sudan	Dinka
Ethiopia	Amharic
Somalia	Somali
Syria	Arabic
India	Telugu, Hindi
Burma	Hakha Chin, Karen
Tibet	Tibetan
China	Mandarin, Cantonese

<sup>&</sup>lt;sup>1</sup> Wyndham Community Education Centre, Adult Multicultural Education Services, Chinese Cancer and Chronic Illness Society and Cohealth

### **Activities**

The bicultural workers selected to talk about cervical screening, bowel screening or Hep B testing depending on the age and gender of their networks. Some delivered a combination of topics if their audience was more diverse. Bicultural workers decided what type of session suited their audience best and what kind of resources they should use. Their plans had to be adapted to deliver the project safely during Victorian lockdown five (15-27 Jul 2021) and beginning of lockdown six (5 Aug - 21 Oct 2021).

### Information sessions

The project was divided up into three periods depending on the pandemic restrictions: open (large in person groups), medium (small in person groups or individual support) and lockdown (fully remote activities). This project had an exceptional reach of 2052 people, considerably exceeding the 1100 target.

Open	Only two in person presentations to larger groups were implemented before the pandemic lockdown reaching 72 people.
Medium	In the intermediate period before lockdown, bicultural workers held nine smaller in person informal groups in homes and one in a café reaching 82 people.
Lockdown	When full lockdown came into force, activities were adapted to remote delivery with larger online Zoom groups reaching 1113 people, recording YouTube videos or livestream on social media reaching 1127 people and providing personalised support over the phone or opportunistically as part of other work reaching 631 people.

#### Resources distributed

On top of the education sessions, bicultural workers planned to hand out hard copy resources to an additional 1000 community members. Only one organisation was able to hand out 109 hard copies to the Mandarin speaking community outside a grocery store before the lockdown came into force. To adapt to full lockdown, bicultural workers shared the resources over Facebook, WeChat, Telegram, WhatsApp, Facebook Messenger, email and over text message depending on their community's preference. 824 people were reached remotely with resources, bringing the total number of additional community members directly receiving resources to 933.

### **Bicultural worker reflections**

Cancer Council spoke to three (100%) project managers and 13 (65%) bicultural workers to reflect on the project. They described seven factors that influenced implementation: having experienced bicultural workers, project timing during an active outbreak, health literacy and education, superstitions and taboo, creating a comfortable learning atmosphere, digital literacy and access and gender.

### 1. Experienced bicultural workers

Partnering with established migrant support organisations was an effective way of recruiting highly skilled bicultural workers that were already trained in community engagement and were active members in their community. Most of the workers had many years of experience doing community engagement, some specifically on cancer screening. Bicultural workers reflected that the relationships built from this previous experience as well as their position as community leaders meant that the community turned up for sessions and listened to the information being delivered:

"Because the information came through other community member like me they take it in, but if [you] just come and knock the house they will be suspicious. But when I come and talk to them, they say ok, if you tell us we will trust you... because we trust each other." (South Sudanese bicultural worker)

Overall, the bicultural workers and project managers reflected that this style of tailored community engagement project raises awareness and motivates people to get tested.

"You notice the difference between when the information sessions starts and when it ends. At the beginning you know everyone is sceptical: 'No, no, no. We don't want this we have enough of all these things'... And at the end of the session you will find ...the group encouraging each other: 'No no we have to do it, this is for our own good'... So they change their minds at the end of the session." (Project manager)

They gave positive examples of the community contacting them to say they had acted on the information and sought treatment:

"When she called me and she said- thank you because of this information I did [the test] ... and I had surgery and now I am doing well I am safe- It was like a gift for me, I was very happy." (Syrian bicultural worker)

## 2. Project timing during active outbreak

#### Bicultural workers time

This project was difficult for bicultural workers to deliver as it had short deadlines and the lockdown meant activities needed to be adapted for remote delivery. This project was planned as part of North West Melbourne's recovery from COVID19. However, as the pandemic transitioned back into active outbreak in July 2021, bicultural workers needed to pivot back to COVID-19 response instead of recovery. This meant they had less time to focus on the project.

Bicultural workers were under pressure to quickly redesign and implement remote alternatives to their planned in person activities. Their extensive community engagement experience and good rapport with the community meant they could recruit participants and deliver sessions quickly, even online and in the short timeframe. However, they felt less experienced workers would have struggled to get things off the ground so quickly. They reflected that with more time, they could have delivered something more creative that would have had a bigger impact.

#### Openness of the community to messages

Running a recovery focused project during an active outbreak was seen as both a positive and negative in communities. Some communities welcomed the sessions as they offered a break from COVID-19:

"I think it was a good break to hear about something else besides Covid, vaccines and testing. I think it was different... I think it was refreshing for the group that I witnessed... I think it took their mind off the current situation we are in right now." (South Sudanese bicultural worker)

However, the Hakha Chin, Syrian and Indian community were less open as they were overloaded with COVID-19 response information and news of violence in their home country. Zoom fatigue was also prevalent in the Somali and Northern Sudanese community as well as for parents supporting online learning.

"Your iPhone, your mobile, email, full of action, book your vaccine... all this it is too much. I think it wasn't the right time to make people think about something else because I think we are at the top now of corona. We are a long-time lockdown and the curfew and everyone is sick of this. It was a big challenge to talk about something else." (Syrian bicultural worker)

Some communities also felt singled out by the project, which may also have affected openness to messages. For example, the South Sudanese and Somali community felt the government was checking on them or thought they were spreading infection.

## 3. Health literacy and education

Openness to messages was also linked to health literacy and education. For example, the Hakha Chin bicultural worker felt the high health literacy and education level of their younger audience meant that they could take on board new information and were motivated to get tested. Other bicultural workers, for example those from the South Sudanese and Somali community, were surprised by the low level of health literacy in their community. They felt that despite explaining the information clearly to the community, they were still suspicious and confused:

"And if you literally mention any vaccines, they automatically think of COVID. Like Hep B as a virus, I was trying to explain it to them, they just got really scared even though Hep B was around before COVID." (Somali bicultural worker)

They reflected that it was possible these communities needed more foundational health sessions to overcome misconceptions about cancer, viruses and vaccinations in general before they could take on board the cancer screening and Hepatitis B testing messages.

Community members could also be closed to the messages if their health literacy and education level were very high. For example, some participants in the Indian Zoom presentations felt they already knew the information or knew where to find it themselves online. To adapt to this, the bicultural worker adjusted the messaging to try to convert this awareness into action: "If you know about this, then why don't you do it?".

## 4. Superstition, stigma and taboo

Superstitions and taboo surrounding cancer are barriers that affected participation, attendance and uptake of resources. For some communities, for example in the orthodox Indian community, storing the bowel test sample in the fridge is culturally unacceptable. Some people from the Ethiopian, South Sudanese and Somali community were very reluctant to engage with the project because "...they were very superstitious, they basically believe... if you speak it into existence it will happen to you..." (Somali bicultural worker). This stigma was also evident in the Chinese community:

"One of the ladies when I tried to hand her over the materials and she had a look at the titles and saw that it was something about cancer screening and she said 'oh this is nothing to do with me... if I've got cancer then that is bad luck... I'd rather not know about it if I've got cancer.' I was quite surprised." (Chinese bicultural worker)

Bicultural workers had noticed a generational shift away from cancer stigma, but despite this positive shift for younger people, these beliefs will take a long time to overcome. They suggested that continued education sessions were the best solution for overcoming the stigma and normalising conversations about cancer.

## 4. Creating a comfortable learning environment

Despite delivering a suite of great adapted remote activities for this project, the bicultural workers expressed disappointment that they could not implement in person events. All bicultural workers and project managers felt strongly that in person strategies were the most effective way to increase awareness about cancer screening and hepatitis B testing and crucially were much more effective in translating awareness into action.

"It would have felt less formal. Maybe we would have gotten a little refreshment ... We could have helped make the atmosphere more comfortable for them to speak out if they have any questions." (Somali Bicultural Worker)

Having participants share their stories was the most powerful and effective way to change minds and spark action. A bicultural worker gave an example of how the personal story of a respected community member created a major shift in understanding and attitude in the room:

"It was amazing, people said OK it is close to us it is not on the TV the disease, someone like us can have it. So, it is more powerful for the groups" (Syrian bicultural worker)

Some bicultural workers were able to foster a comfortable atmosphere in the Zoom setting and this encouraged engagement and questions. In the Arabic speaking East African sessions, there was so much discussion and questions that the sessions went for three hours. Bicultural workers used the following strategies to create a comfortable environment online:

- Recruit established online groups where people feel comfortable with each other.
- Consult the community about their preference for separate genders and time.
- Send the materials beforehand so people can prepare questions.
- Spend time at the start with introductions to give people a chance to come online.
- Use their language so they can express themselves fully and not feel shy.
- Use visuals to increase understanding of people with low literacy.
- Make it short and allow plenty of time for discussion.
- Make people feel valued and respected by asking them to share their experiences: "If you let people talk about themselves, about their experience, about how they feel how they think I think they will feel they are a part of the session they are a part of the whole work. You give them the ownership." (Arabic speaking East African bicultural worker)

## 5. Digital literacy and access

#### Online sessions

When full lockdown came into effect, many of the bicultural workers chose to deliver presentations with groups on Zoom. Presenting in existing online support groups was easier because participants were used to meeting online and had been supported by the group leaders or volunteers to develop their digital skills:

"Some people are not used to talking on zoom. It is much better now because there is a lot of Zooms and this is how they get information and people try to adapt themselves. Computer skills and this takes time" (Arabic speaking East African bicultural worker)

Bicultural workers reflected that Zoom had the advantage of a wider reach as the whole family would attend the Zoom session, while only one representative would attend an inperson presentation. Bicultural workers reached older people with low digital literacy through their children, who had been supporting their families to access technology since the beginning of the pandemic.

One bicultural worker harnessed the high digital literacy in the Indian community to present and record a livestream session on Facebook. They felt this strategy worked better than a Zoom presentation as it was more interactive and conversational. Other effective online strategies included making a video and posting it to social media.

#### Lower tech options

Despite these promising developments of digital literacy and established family support, there are still some groups and people that did not have the skills or resources to get online. This means the project may have missed the most vulnerable who have never been tested. Bicultural workers overcame these barriers by including low-tech options like calling participants individually or small groups on using platforms more familiar to the participants like the phone, WhatsApp video call or Facetime. This strategy had the benefits of privacy but could be challenging because it was time consuming and meant that bicultural workers could receive calls back outside their working hours.

One on one conversations were also initiated opportunistically as part of the bicultural workers' other roles. For example, when doing casework over the phone in the South Sudanese community, the bicultural worker would also talk about screening. The bicultural workers reflected that this kind of one-on-one support could be more effective than the group setting because you can really gauge people's understanding and they feel comfortable asking questions. They also felt this type of support was even more effective in person, as you can help them book an appointment right there and then follow up to ask if they acted on the information.

### 6. Gender

Gender was an important factor for many bicultural workers when planning their strategies. The Hakha Chin, Karen, Tibetan, Chinese and Indian community found that running the sessions together was the best approach. For the Chinese community, mixed gender was more acceptable on Zoom than in person because the participants felt more anonymous. For the South Sudanese community, the opposite was true with mixed gender being more appropriate when meeting in person but not on Zoom.

For other communities, having gender segregated groups was important. For example, the Karen groups could cover Hepatitis B together, but bowel and cervical screening needed to be separate. In the East African Arabic speaking community, everyone was invited to the same session, but men were asked to leave for the final section on cervical screening. For the Somali community, it was important to have full gender segregation for sessions and topics.

"I'm not sure bowel cancer, some men they don't want to talk about their conditions, some women definitely don't want to talk about in front of the men." (Karen bicultural worker)

For some communities, it would be inappropriate for a male presenter to talk about cervical screening to women. It was more acceptable for a confident female presenter to run the male sessions.

Gender segregation was very important for communities where female genital cutting or mutilation (FGC/M) is common (Somalia, North Sudan and Eritrea). Bicultural workers reported that women who have experienced FGC/M are reluctant to discuss their experiences in front of women from communities that do not practice FGC/M and are not comfortable talking to their GPs:

"Some women because of the circumcision they feel shy, they feel embarrassed, they don't feel comfortable talking about those things and some women they don't even know their rights to ask about a female doctor to do that for them" (Arabic speaking East African bicultural worker)

One of the ways Hepatitis B can be transmitted is through unprotected sex and this can be difficult to discuss, especially in mixed gender sessions, because it implies a connection between Hepatitis B and what the community considers to be sexually immoral behaviour. This could mean people were less likely to share their experiences with Hepatitis B because they did not want people to think they had contracted the disease through sex. An effective way to overcome this was by framing testing as something you do to keep your family safe. They also felt the video with the map that showed the regions of high prevalence helped explain why they were being targeted and reduced the stigma.

### Conclusion

This community engagement work was a success because of the team of highly experienced bicultural workers who adapted to an evolving and challenging environment to deliver screening messages to communities that really needed to hear them. While many bicultural workers expressed disappointment that the planned in person activities could not go ahead, the creative and tailored strategies designed by the bicultural workers meant the project could still be a delivered during a difficult period. The diverse projects delivered and range of engagement from the communities demonstrates the importance of investing in tailored responses rather than a one size fits all approach to maximise awareness about screening equitably for all Victorians. Culturally diverse communities are diverse in themselves, and projects need to respond to each community's needs and preferred approach.

The bicultural workers and their project managers did an exceptional job overcoming the challenges of a very short timeframe and delivering community engagement during an active COVID19 outbreak. While the bicultural workers and project managers should be commended for their fast adaptation to an ever-evolving COVID19 landscape, the project steering group should consider whether it would have been more effective to pause community engagement until the pandemic status had transitioned back from active outbreak to COVID19-recovery.

The reflections in this summary provide important information about which strategies work best and the factors that contribute to effective message sharing, while also highlighting why some strategies were less effective. The high quality of the evidence gathered about the project is a testament to the bicultural workers' willingness to openly share their community engagement expertise and both the successes and challenges of their strategies. Cancer Council looks forward to using this information to improve strategies for future projects and building on these relationships with organisations, bicultural workers and communities to promote cancer screening and hepatitis B testing in future.