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SA Lived Experience Leadership & Advocacy Network

We amplify the voice, influence and leadership of lived experience to be heard and drive change

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INSIGHTS REPORT:

Co-creating COVID-19 messaging & strategies with people with lived experience of distress and mental health issues

Prepared by the Lived Experience Leadership & Advocacy Network (LELAN)

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Lived experience community

Organisations that support people with lived experience

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Introduction, background & scope:

Wellbeing SA have engaged the SA Lived Experience Leadership & Advocacy Network (LELAN) to gain insights from people with lived experience of mental distress, social issues or injustice about information, concerns and strategies that would be useful to support informed decision making and access to COVID-19 vaccinations.

LELAN is working in partnership with the lived experience community to gain insight into vaccine hesitancy. These insights will guide the co-creation of messaging and strategies to support informed decision making about COVID-19 vaccinations for the lived experience community and organisations that support them, with benefit to the broader community who would also be exposed to messages.

Lived experience at the centre:

As a lived experience-led organisation LELAN centres the perspectives, collective insights and solution ideas of people with lived experience in all of our work. It is our role to listen, truly hear and amplify what people with lived and living experience of the social issue, experience or topic being enquired about share with us, resisting temptation to judge or filter what is shared because it is hard for services and systems to hear, to integrate into policy and/or practice or because resources are not available do anything about it.

Creating space for and including lived and living experience narratives in honest, visible, and influential ways matters to the people who generously share their experiences and are most impacted by the decisions made.

Listening is the oldest and perhaps the most powerful tool of healing. It is often through the quality of our listening and not the wisdom of our words that we are able to affect the most profound changes in the people around us. When we listen, we offer with our attention an opportunity for wholeness. Our listening creates sanctuary for the homeless parts within the other person. That which has been denied, unloved, devalued by themselves and others. That which is hidden. [Rachel Naomi Remen]

What we did:

LELAN invited people with lived experience to share their experiences to understand what information and messaging is important to support informed decision making about the COVID vaccination. This occurred through:

- Online survey (completed by 14 people to date)
- 1:1 in-depth conversations (9 people)
- One 3-hour co-creation session (8 people)
- Expression of Interest responses from people nominating to be Lived Experience Advisors throughout the project (11 people)

The insights below represent the perspectives of people who have received either both or one dose of the vaccine out of personal choice and/or for the greater collective good, those who felt coerced into getting either both or one dose of the vaccine (for example, mandated by their employer), those who are strongly opposed to getting vaccinated and those who want to get vaccinated but are still hesitant.

LELAN believes the various experiences and perspectives of people related to the COVID vaccine involved in this project provides rich and contrasting knowledge that will add powerful multi-dimensional viewpoints. This is what many perceive as lacking in the messaging thus far and will contribute to more valuable messaging for community moving forward.

Insights about the concerns people had/have about getting the COVID-19 vaccination:

Hesitancy around getting vaccinated stems from justified and warranted fears amongst the lived experience community. These concerns are provided in detail below but are being perpetuated through misinformation and for many, a history of being coerced, misinformed or pressured into making decisions about their health and wellbeing.

- A feeling of being forced to have the vaccine and therefore feeling like choice had been removed

You can't do this and this etc. without being vaccinated. Getting peoples backs up makes people more likely to resist.

I am not anti-vaccination, but force is not okay. It is not okay to scare people into it.

The general population are looking at me like I'm the enemy. I feel the push on TV and stuff – do it for everybody else but ignore my own needs.

- There is a general mistrust in authority, including of government and medical professionals, which was being amplified by the inconsistency and changing messaging that was confusing and scary. For example:
 - Different state leaders giving different advice
 - The experience of people who are or have in the past been forced to take medication against their will by authorities
 - Mask-wearing mandates changing

The messaging was originally that when we had hit the vaccination target rate we would not have to wear masks as there would be less chance that the vaccinated would spread it. We have hit the vaccination target but we still need to wear masks.

- The information currently out there is not helpful:
 - It is difficult to navigate, for example Government websites have so many layers before you can get to the information you need if you can find it at all

Tried to do SA Health but can't follow all the links so get lost.

- It is too complex, for example the overuse of medical jargon rather than simple wording
- It is too simple, for example the 'roll up your sleeve' campaign does not provide any information about the benefits of rolling up your sleeve

Where to find information is so confusing. Staying up to date with current information as it changes so much. I struggle with the internet my cognitive ability declines when I'm anxious I forget things.... Normal anxieties are big enough without adding to it.

- There is a distrust in the vaccine as it had been in the market for such a short time
- Lack of appropriate access for people who need access to private, quiet spaces both before receiving the vaccination and for the 15 minutes after receiving the vaccination
- There is concern and worry about the immediate impacts on health and wellbeing after getting the vaccination

I was particularly worried about the interaction of the vaccine and my body.... Worried what is going to happen to my body, worrying about the immediate impact on my wellbeing as recently I have been struggling a lot.

- Not being able to access clear information about the impact of symptoms on having NDIS provided support in their home maintained. For example, if someone with a Peer Worker has side effects such as flu like symptoms from the vaccination will they lose access to their support that is keeping them alive

I can't get a definite answer that they'll support me.

- Limited access to credible information for those that cannot be vaccinated. What messaging is out there for that group of people?

How are they being supported to live in a world that is being designed for those who are vaccinated.

Of note, these themes emerged from participants irrespective of their individual vaccination status.

Insights about the information people want/wanted to know and what information should be shared:

When asked, people with lived experience wanted access to straight-forward, open, consistent and clear information about:

- The side effects of the vaccination
- The side effects of COVID
- The benefits of getting vaccinated
- Why the Government wants people to get vaccinated
- The effectiveness of masks

There was a high need for more information about how the vaccine has been created, particularly:

- How could it be robustly tested in such a short time?
- How do we know it is safe?
- What are the ingredients in each vaccine?
- How do these ingredients react with other medications, particularly psych medication?

Insights on how information is best shared:

There was a strong belief that vaccination hesitancy would dissipate for most people if they were given agency to come to an informed choice. Currently they felt pressured, alienated or disregarded when seeking clarity around the vaccination to alleviate any anxieties they had.

Suggestions to effectively address this are shared below:

- Provide opportunities for people to have their fears listened to and addressed, for example 'What is being injected into your body? Get the facts on the Vax'
- Short, candid series of interviews and testimonials with people with lived experience honestly addressing some of the concerns they had, including:
 - What about the vaccine was worrying them?
 - What things influenced their decision?
 - How did they navigate setting boundaries around information/misinformation and people potentially perpetuating fears?
 - What supports did they put in place to make them feel safe-enough to get the vaccine?
 - What side effects did they have after the vaccination and how long did these last?
 - How are things now since getting the vaccination?

What convinced one person to get the vaccine for example, was speaking with someone whom they trusted who had been apprehensive about getting the vaccine but after receiving it described *I had the injection and now I feel on top of the world, really happy and really safe. It was so good, I'm so relieved I was so anxious but now I feel safe.*

- Multiple opportunities to speak with trusted people 1:1 and have panel discussions where people can openly and honestly have their concerns listened to and addressed without feeling stigmatised or judged. Trusted people were described as existing leaders and people of influence in the lived experience community
- Put resources such as infographics to start conversations into spaces where people go, for example cultural community spaces, sports clubs, shopping centres, etc
- Tools, guides or a flowchart to assess validity of information as there is so much misinformation

Having an open and honest conversation with someone. I needed to know the wider context and risks of contracting COVID to counteract the risk of having the vaccine. It was more prevalent than I realised. Learning about the risks helped me... I realised I was more scared of COVID. I realised that I was worried about the vaccine, but the COVID stuff I was more worried about. Vaccine seems like protective than risky thing.

Messaging needs to be:

- Visual
- Trustworthy
- Realistic
- Clear and consistent
- Tiered approach to how and the level of detail for all information that is provided. First level would present one concise sentence in simple language with the key message, the second level would be a few key dot points expanding on the one sentence, and the third level is the in depth medical information with links to even more if people wish to read further
- Free of fear, othering, scare-mongering and non-threatening
- Balanced information

Many people who responded either to the survey, in-depth conversations, participated in the co-creation session or have contributed as a Lived Experience Advisor have expressed the genuine need for creating information for those who for whatever reason are choosing to not get vaccinated.

How will those who are unvaccinated navigate the world? Do they not deserve to have a good life?

COVID-19 has caused uncertainty and fear worldwide. This is exacerbated for many in the lived experience community, even here in South Australia where we have fared much better. Confusion around existing vaccine messaging, access to non-biased and trusted information and feeling like there is no choice in decision making is impacting on people's wellbeing. Fear mongering, othering, mandated vaccinations and biased information is creating stigma, anxiety and isolation. Those who contributed to this insights report believe that unless the current messaging and strategies address the concerns described above, there is a genuine risk that people who have sought mental health support will no longer feel safe enough or be able to access these supports. Thus, potentially leading to an already over stigmatised and alienated portion of society becoming more so.

Next Steps:

As illustrated above, COVID-19 vaccinations and messaging can polarise as people have such complex and divergent opinions. LELAN's responsibility to support people with lived experience whilst being true to co-design, means that we have had to give relationship building the space and time needed to enable robust, open and honest conversations. Therefore, we have spent a lot of time creating safe-enough conditions to ensure that we are getting diverse representation and that people feel comfortable to genuinely contribute.

LELAN has explored current vaccination messaging with the lived experience community, more time is needed however to consolidate and co-create 'new' messaging and ensure the Lived Experience Advisors for the project comment on the messaging's relevance and whether it resonates with the insights expressed above.

LELAN are currently developing a slide show with the Advisors that centres messaging *by, for and with* the lived experience community. We are also designing social media tiles and fact sheets around some of the information that people wanted to know outlined above.

LELAN is hopeful that these will be ready to share with Wellbeing SA before the Christmas break, however we are conscious of our commitment to ensuring that we are co-creating messages that are meaningful to the lived experience community we represent, so it maybe early January 2022 that this can occur.

About LELAN:

LELAN's purpose is to amplify the voice, influence and leadership of people with lived experience of mental distress, social issues or injustice to drive change. The organisation has three areas of focus:

- Developing the capability and influence of people with lived experience
- Nurturing organisational and sector capacity for partnering with people with lived experience, and
- Impacting system improvement agendas to benefit people with lived experience.

As the lead lived experience organisation in South Australia LELAN has particular expertise, networks and partnerships that centre the lives, wisdom, recovery and contributions of people with lived experience. Because of our strong and trusted relationships with people in the lived experience community we are able to have deeper conversations about things that matter, drawing our collective experiences and action together in purposeful ways.

By centering the perspective, collective insights and solution ideas of people with lived experience in all of our work, as well as being immersed in the lived experience community from grassroots to strategic levels, LELAN demonstrates the principles, practices and change dynamics that the social sector is calling for and desperately needs.

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