

Culture-centered community-led testing

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ABOUT CARE

The Center for Culture-centered Approach to Research and Evaluation (CARE) at Massey University, Aotearoa New Zealand, is a global hub for communication research that uses participatory and culture-centered methodologies to develop community-driven communication solutions to health and wellbeing. Through experiments in methods of radical democracy anchored in community ownership and community voice, the Center collaborates with communities, community organizers, community researchers, advocates, and activists to imagine and develop sustainable practices for prevention, health care organizing, food and agriculture, worker organizing, migrant and refugee rights, indigenous rights, rights of the poor, and economic transformation.

Gayle Moana-Johnson is the Community Research Assistant working with the community advisory group on the CARE's Highbury Project in New Zealand.

Mohan J. Dutta is the Director of CARE and author of books such as *Neoliberal Health Organizing*, *Communicating Health*, and *Voices of Resistance*.

Culture-centered community-led testing

Abstract:

This white paper outlines the key principles of culture-centered community-led testing that are voiced by the advisory group of community members in Highbury, anchored in the principle of representing the most “in-need” members of the community (referred in the rest of this white paper as the “margins of the margins”). The key ideas in this white paper are developed as anchoring principles for the partnership between the community advisory group and the Health Hub Project New Zealand (HHPNZ).

Universal access

- Testing should be available to everyone in the community, especially those at the “margins of the margins” of the community.
- Addressing challenges with mobility is a key concern. Some community advisory group members suggest having a testing hub in Highbury will be good for the Highbury Community so that those who

cannot make it into town or other places to do test can do so as it is close. Others suggest setting up vans for transporting community members to the testing site.

- Meeting the needs of the “margins of the margins”: Concerns voiced that the Highbury community will miss out and our margins will fall through the cracks again. To address community needs, our advisory group will communicate the criteria as well as identify those at the margins of the community that meet the criteria.
- Mobile services, especially for those in need eg. Hapū mama, caregivers with child/ren, those who have a mental or physical disability, elderly/kaumatua, those with no transport (some people cannot even make it to the supermarket). This will be safer than whanau having to travel out more times than needed.
- Consider test design for the margins: Sit in car option (for instance, for single parent with young child). Consider testing options for whanau in culturally-centered, contextually-embedded forms.

Transparent and Universal access to information

- Transparently communicate the criteria and do so through open dialogue with the community. Ideally, criteria should be simply if people felt they needed the testing (not only having symptoms, based on the evidence that not every infected person is symptomatic). The community understands that there might be need for rationing, with limited tests available. If this is the case, communicate so transparently with an open channel of communication.
- If symptom-specific testing, communicate the symptoms clearly, transparently, and in culturally-centered forms. Our design team will work with the clinical and medical research teams at HHPNZ to culturally center the message. Message will be disseminated through digital hub and word-of-mouth, in our community networks.
- Clearly communicate how many tests have been conducted and how our Highbury community is doing (aggregate data). This will be

driven by continual dialogue with HHPNZ.

- Give community control on information regarding infections in the community. That is integral to ensuring community-based democratic access to communication. This is also critical to addressing potential media stigmatization.

Cultural context

- If testing is done at a designated HHPNZ location, we need to know a safe way of doing this and how. Where can people call, express their needs, and then be instructed on the process in a mana enhancing/culturally appropriate way. Community feeling safe is important. Highbury community organizer and advisory group should play a key role in bridging.
- Address the question of cultural targeting. Some community members expressed concern that this testing is happening - are we not doing okay? Should tests have started ages ago? So far, there has been a large focus on our elderly. It is good that

they are opening up more to all, and at the same time, the trust of our whanau needs to be carefully negotiated. Whanau sovereignty and community sovereignty are both important.

- Address the question of informed consent and gathering of DNA-based information. Is DNA-based information going to be stored? Clearly communicate information around DNA for individual consent as well as community knowledge.
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