



Narratives from African American/Black, American Indian/Alaska Native, and Hispanic/Latinx community members in Arizona to enhance COVID-19 vaccine and vaccination uptake

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Abstract The state of Arizona has experienced one of the highest novel coronavirus disease 2019 (COVID-19) positivity test rates in the United States with disproportionately higher case rates and deaths among African-American/Black (AA/B), American Indian/Alaska Native (Native), and Hispanic/Latinx (HLX) individuals. To reduce disparities and promote health equity, researchers from Arizona State University, Mayo Clinic in Arizona, Northern Arizona University, and the University of Arizona formed a partnership with community organizations to conduct state-wide community-engaged research and outreach. This report describes results from 34 virtually-held focus groups and supplemental survey responses conducted with 153 AA/B, HLX, and Native community members across Arizona to understand factors associated with COVID-19 vaccine hesitancy and confidence. Focus groups revealed common themes of vaccine hesitancy stemming from past experiences of research abuses (e.g., Tuskegee syphilis experiment) as well as group-specific factors. Across all focus groups, participants

strongly recommended the use of brief, narrative vaccination testimonials from local officials, community members, and faith leaders to increase trust in science, vaccine confidence and to promote uptake.

Keywords COVID-19 · African American/Black · Indigenous · Latinx · Vaccine hesitancy · Medical mistrust · Vaccine uptake

Background

Across the United States (U.S.), the coronavirus disease 2019 (COVID-19) pandemic has amplified the social and health inequities with disproportionate burdens of prevalence, hospitalizations, and deaths among racial/ethnic minority populations (Gross et al., 2020; Ravi, 2020; Stokes et al., 2020; Webb et al., 2020). These disparities are due to social determinants of health such as having a lack of access to both medical care and to culturally appropriate health information (Kim et al., 2020; Millett et al., 2020; Thakur et al., 2020; Wadhwa et al., 2020). To date, all Americans are encouraged to receive the COVID-19 vaccine and booster in order to prevent serious illness, hospitalizations, and death from the virus and its variants (CDC, 2021). However, general mistrust of vaccine benefits and related side effects can be barriers to achieving population immunity through vaccination, particularly among racial/ethnic minority groups (Paul et al., 2021). Vaccination hesitancy and refusal are often shaped by multi-level factors including religious and political beliefs at the individual level, a lack of effective communication and engagement strategies at the community level, and social inequities, including access, at the structural level (Dutta et al., 2021; Omer et al., 2021). Additionally, individuals who have experienced discrimination and racism

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based on their racial/ethnic status from health care systems or governmental agencies may feel increased mistrust toward the same structures that have contributed to their experiences of marginalization and discrimination (Burgess, 2021; Dutta et al., 2021; Khan et al., 2021). Therefore, bringing an end to the COVID-19 pandemic will require on-going trust-building via information sharing among researchers, health advocates, health systems, and community members through engaged and respectful listening sessions focused on vaccine concerns, addressing and responding to specific fears, and working to counter disinformation (Khan et al., 2021). These efforts must ensure that those who have been disproportionately impacted by COVID-19 have a voice in the development of culturally relevant strategies intended to serve them. Listening to, understanding, and responding to their needs through their perspectives are important steps toward increasing trust in science and enabling individuals to make informed health-related decisions.

As of early January 2022, Arizona (AZ) reported more than 1.6 million cumulative COVID-19 cases, comprising nearly 23% of AZ's population, and 25,429 deaths (AZDH, 2022). As of early January 2022, 27% of COVID-19 cases in AZ were among HLX people, 5% of cases were among Native people, and 4% were among AA/B individuals (AZDH, 2022), that respectively, make up 31%, 5%, and 5% of the AZ's total population (U.S. Census Bureau, 2021). However, vaccination rates in these population groups in AZ are lagging behind those of Whites, especially among HLX people. Based on the most recent available data by race/ethnicity from January 2022 (Kaiser Family Foundation, 2021a), 58% of the White population in AZ had received at least one vaccine dose compared to only 40% of the HLX and 47% of the AA/B population. Of those having received at least one COVID-19 vaccine dose by early 2022, 4.3% were Native people (AZDH, 2022), who represent 5% of AZ's total population (U.S. Census Bureau, 2021). COVID-19 related deaths are estimated to be higher among Native people in AZ (9%) than their proportional share of the population (Kaiser Family Foundation, 2021b). However, data from the Navajo Nation (Navajo Nation, 2022), one of the largest tribes in AZ, suggest that a similar proportion of those eligible in the Navajo Nation have been fully vaccinated (72.5%) compared to 71.5% in AZ overall (AZDH, 2022). In response to nationwide COVID-19 disparities, the National Institutes of Health (NIH) established the Community Engagement Research Alliance (CEAL) Against COVID-19 Disparities initiative as a research consortium across multiple states, including AZ, to address the urgent needs related to the inequity of the COVID-19 pandemic and its far-reaching effects (Webb et al., 2020). Active community involvement and collaboration through inter-organizational partnerships is essential to increase trust in science, medicine, and policy makers among communities

that have historically been excluded and continue to be marginalized. Academia-community partnerships in particular, have become more widely recognized as being effective in addressing issues of trust and underlying health disparities (Dutta et al., 2018). The national CEAL initiative leverages community partnerships among diverse entities such as academia, public health departments, community and social service agencies, health systems, and grassroots organizations. The national CEAL initiative also serves as an alliance of interlinked community-engaged research projects across the U.S. to develop an evidence base for deployment of effective strategies that aim to enhance awareness and uptake of preventive health measures to mitigate the pandemic, as well to promote outreach and inclusion in COVID-19 research in underserved communities.

The AZ COVID-19 CEAL Consortium (AC3) is composed of transdisciplinary and geographically dispersed teams and their community partners, housed across four AZ institutions: Arizona State University (ASU), Mayo Clinic in Arizona, Northern Arizona University (NAU), and the University of Arizona (UA). The AC3's overarching goal is to conduct community-engaged research to increase COVID-19 awareness among AZ communities disproportionately affected by COVID-19, to understand their experiences, concerns, needs, and reduce misinformation, to ultimately help promote vaccination uptake. These research efforts are guided by a community engagement framework (Ahmed & Palermo, 2011) that underscores the importance of establishing mutual respect, mutual understanding, and power-sharing between researchers and the communities of focus, promoting equity, having flexible timeframes, and addressing needs within community contexts. In this effort, the AC3 formed a Community Task Force that acted as a Community of Practice to prioritize community needs, co-develop educational materials for dissemination, and ensure representation and inclusiveness (Wenger et al., 2002). The Task Force included representatives from social service agencies, local faith-based organizations, community health centers, community health worker associations, and county and state public health departments. The rapid deployment and success of the AC3, including the formation of the Community Task Force, was possible because of the existing relationships across all four academic-medical institutions and their extensive and often over-lapping partnerships with state, county, and tribal agencies, as well as with health care systems, patients, and community members from rural, border, tribal, and inner-city communities. Some Community Task Force members were recruited from existing community advisory boards of participating institutions. Overall, these partnerships helped to align the goals of the project from the beginning through shared values, existing partner trust, and by being responsive to community-identified priorities across the state of AZ.

Because the COVID-19 pandemic presented a new and emerging crisis that did not warrant a priori assumptions about people's experiences and concerns, we used focus groups to uncover specific and cross-cutting themes reflecting AA/B, HLX, and Native community members' experiences in AZ. The group process used in focus groups creates a context for collective sense-making in a safe environment that was particularly well suited for this purpose (Liamputtong, 2011). Consistent with a community engagement framework, focus groups allow for the perspectives and voices of participants to be heard in their own language and engages them as experts in their own communities. The AC3 team aimed to identify multi-level factors (including individual, group, and structural factors) associated with COVID-19 vaccine uptake, as well as any other factors that represented the "needs, preferences, and values of specific racial and ethnic populations" (Durlak & DuPre, 2008, p. 343).

Methods

Participants and procedures

The AC3 Community Task Force and partners of the four academic-medical consortium members (e.g., existing community advisory boards) assisted with the recruitment of participants for community-based focus groups by sharing recruitment flyers and through word of mouth advertisement to explain the purpose of the study to potential recruitment sites (e.g., community-based agencies) and participants. Additionally, we used snowball sampling. Once an interested participant contacted the research team, a "family and friends" approach was used to recruit additional participants via the interested participant's family and network. Although this meant that some focus group participants knew each other, this approach was adopted to create a trusted space for participants and to increase opportunities for participation as focus groups were conducted virtually. Furthermore, a "family and friends" approach allowed participants to share an internet connection, computer equipment, access to the Zoom video conferencing platform, and come together safely in a shared space or household if so desired. This approach also helped to ensure digital access, which tends to be lower in HLX, Native, and AA/B communities, and was particularly important in this study to increase inclusiveness.

Eligibility criteria included being 18 years of age or older, identifying as a member of the AA/B, HLX, or Native community, residing in AZ, and having an email address to receive a link to an online survey as well as the incentive. Individuals were screened for their language preference (i.e., English or Spanish). Focus groups were conducted with participants from the same racial/ethnic group only (e.g., only

Native participants in one group, and AA/B participants in another). Although we did not collect data on the specific cultural origins of HLX focus group participants, most HLX focus group participants were likely of Mexican ethnicity given that the majority (88%) of HLX residents in AZ are of Mexican ancestry (U.S. Census Bureau, 2019).

Additionally, participants came from three primary geographic regions: Maricopa County (greater Phoenix metropolitan area), southern Arizona (including Tucson), and northern Arizona (including Flagstaff). Participants were also invited to complete an anonymous, online survey before the focus group meeting. The online survey was used to collect demographic information which included a "HLX" as a race/ethnicity category that was defined as including Hispanic and Latino identities, or individuals of Spanish origin, such as Mexican, Puerto Rican, Cuban and other identities. Data about individuals' vaccination status and experiences were also asked to supplement the qualitative focus group data with descriptive information about individual participants.

Enrolled participants were emailed the following: (1) an overview of the study, (2) a copy of the consent form in English and Spanish, (3) a link to an anonymous online survey via REDCap, (4) the Zoom link for the focus group with an optional call-in phone number, and (5) a \$45 e-gift card after completion of the focus group to encourage and thank participants for their participation. Participants consented to the online survey electronically and gave their verbal consent at the beginning of each focus group. To maintain anonymity of participants, no names, contact (including email address), or other identifying information were linked to the survey or focus group data. Only team members not directly involved with focus group data collection (and without access to contact information) analyzed the online survey data. Of the 153 focus group participants, 137 completed a survey. Table 1 shows a full list of questions on the survey.

All procedures for this study were approved by the University of Arizona Institutional Review Board (Protocol # 2,011,244,240). Native participant data includes responses from those who were living in urban areas and on sovereign tribal lands. For participants living on tribal lands, tribal permission to collect data was authorized via tribal memorandum of understanding (MOU) agreements secured through study team partners with existing tribal partnerships at NAU prior to the start of data collection.

Data collection

Focus groups

Between February and August 2021, a total of 153 participants took part in 34 focus groups (10 with AA/B participants, 10 with Native, and 14 with HLX.). Nine of the HLX

Table 1 Descriptive statistics of focus group survey respondents

	Hispanic/Latinx (HLX) (<i>n</i> = 63) % (M ± SD)	African American/Black (AA/B) (<i>n</i> = 42) % (M ± SD)	American Indian Alaska Native (Native) (<i>n</i> = 32) % (M ± SD)
<i>Gender^a</i>			
Man	31.7	26.2	25
Woman	68.3	73.8	75
Transgender female or trans woman	0	0	0
Transgender male or trans man	0	0	0
Age	(40.6 ± 12.5)	(51.7 ± 15.9)	(40.1 ± 17.3)
<i>Education level</i>			
Less than high school	17.5	0.0	0.0
Some high school	8.8	0.0	0.0
High school graduate or GED	28.1	16.7	22.6
Associates or technical degree (for example, AA or AS)	19.3	9.5	16.1
Bachelor's degree (for example BA, BS, or AB)	15.8	21.4	38.7
Graduate degree (for example MA, PhD)	10.5	52.4	22.6
<i>Annual income for 2019</i>			
Less than \$15,000	8.9	3.3	14.8
\$15,000–\$19,999	8.9	10.0	7.4
\$20,000–\$24,999	13.3	0.0	14.8
\$25,000–\$34,999	8.9	0.0	0.0
\$35,000–\$49,999	17.8	20.0	22.2
\$50,000–\$74,999	22.2	3.3	7.4
\$75,000–\$99,999	2.2	26.7	3.7
\$100,000 and above	17.8	36.7	29.6
<i>Health insurance</i>			
Uninsured	36.4	5.0	25.9
Private health insurance through a job or school	36.4	40.0	37.0
Insurance bought through a government exchange such as healthcare.gov	3.6	2.5	0.0
Insurance bought from a health plan or company	5.5	12.5	3.7
Medicare	7.3	22.5	7.4
Medicaid	10.9	12.5	7.4
Military health care	0.0	5.0	0.0
Indian health services	–	–	18.5
Received Covid-19 vaccine	38.7	61.9	93.8
<i>How likely to get a Covid-19 vaccine^b</i>			
1 = Not at all likely	21.1	12.5	0.0
2	10.5	18.8	0.0
3	5.3	0.0	0.0
4	5.3	18.8	0.0
5	5.3	6.3	0.0
6	0.0	6.3	0.0
7 = Very likely	52.6	37.5	100.0
<i>Reasons to get a Covid-19 vaccine?^b</i>			
I want to keep my family safe	65.8	68.8	–
I want to keep my community safe	47.4	56.3	–
I want to feel safe around other people	47.4	50.0	–
I don't want to get really sick from COVID-19	28.9	62.5	–

Table 1 (continued)

	Hispanic/Latinx (HLX) (<i>n</i> = 63) % (M ± SD)	African American/Black (AA/B) (<i>n</i> = 42) % (M ± SD)	American Indian Alaska Native (Native) (<i>n</i> = 32) % (M ± SD)
I believe life won't go back to normal until most people get a COVID-19 vaccine	39.5	37.5	–
I have a chronic health problem, like asthma or diabetes	13.2	18.8	–
My doctor told me to get a COVID-19 vaccine	5.3	12.5	–
<i>Reasons NOT to get a Covid-19 vaccine?</i>			
I don't know enough about how well a COVID-19 vaccine works	47.4	31.3	–
I'm concerned about side effects from the vaccine	36.8	62.5	–
I don't trust that the vaccine will be safe	31.6	18.8	–
I don't think vaccines work very well	10.5	18.8	–
I don't like needles	7.9	6.3	–
I'm not concerned about getting really sick from COVID-19	7.9	12.5	–
I don't believe the COVID-19 pandemic is as bad as some people say it is	5.3	0.0	–
I don't want to pay for it	2.6	6.3	–
I'm allergic to vaccines	0.0	0.0	–
<i>Trusted sources for Covid-19 Information (% reporting "a great deal" of trust)</i>			
Your doctor or health care provider	74.6	82.9	100.0
Arizona Department of Health Services	62.9	61.0	75.0
The U.S. Coronavirus Task Force	60.7	67.5	75.9
Your close friends and members of your family	31.7	65.0	61.3
The U.S. government	44.3	23.1	41.4
Your faith leader	40.0	47.2	56.3
News on the radio, TV, online, or in newspapers	32.3	27.5	31.0
People you go to work or class with or other people you know	12.1	19.4	35.5
Your contacts on social media	8.3	7.7	14.3

^aNo participants selected categories: gender nonbinary, genderqueer, or genderfluid

^bOnly asked of those unvaccinated. Only 2 Native participants reported being unvaccinated, thus reasons to and not to get vaccinated are not reported for them for confidentiality reasons

focus groups were conducted in English and five in Spanish. The average group size was 4 participants (range = 2 – 9), which is smaller than traditional, in-person focus groups. However, we followed recommendations for virtual focus groups of 3–4 participants per group (Dos Santos Marques, 2021) and found that the smaller size helped to facilitate the online discussion among participants, especially given the sensitive nature of the topics (i.e. historical trauma). Group sizes varied because we aimed to overrecruit to account for potential no-shows. In total, we had three groups with only two participants. Despite being below our targeted group size, we opted to conduct those groups to honor the commitment of those participants who showed up on the scheduled day.

Focus groups lasted between 60 and 90 min, were audio recorded, and were each led by a facilitator and co-facilitator. Consistent with culturally responsive focus group methodology (Rodriguez et al., 2011), focus group facilitators

and co-facilitators were PhD and Masters level researchers who identify as AA/B, HLX, or Native and reflected the cultural identities and communication styles of participants. For example, HLX facilitators and co-facilitators were bilingual and were able to conduct focus groups in both English and Spanish language. Matching participants' racial/ethnic identities and linguistic preferences with those of the facilitators helped to build trust and collect reliable and valid data. This approach is particularly important when conducting research on stressful experiences (e.g., associated with the COVID-19 pandemic), personal or controversial topics (e.g., vaccines), and with participants from groups that are marginalized and historically underrepresented (de la Rosa, et al., 2007). A copy of the consent form in English and Spanish was emailed to participants ahead of time and verbal consent from each participant was obtained at the start of each focus group in accordance with the approved human subjects protocol and tribal MOUs.

Focus groups were conducted using semi-structured questions developed by the AC3 team. Focus group participants were first asked to describe their general experiences during the COVID-19 pandemic (e.g., How has COVID-19 affected you, your family, and your community? Has the pandemic affected you differently because of your race/ethnicity?). Other questions centered on COVID-19 vaccine perceptions, readiness, and information sources (e.g., What are your thoughts about the COVID-19 vaccines? Who do you trust most to learn about the COVID-19 vaccines? Where do you hear about COVID-19 vaccines? Where do you access health care?). Participants were also asked about COVID-19 related health messaging (e.g., What kinds of messaging would your community need to know the vaccines are safe? What are some ways to communicate updates for the vaccines? What ways can community leaders build and maintain trust with communities?).

Data analysis

Audio recordings of the focus groups were professionally transcribed verbatim. Spanish transcripts were translated into English. All identifying information was removed from transcripts, including any tribal names and affiliations mentioned during the sessions. We used a thematic analysis approach to identify themes that were common and unique across the three racial/ethnic groups (AA/B, HLX, Native) (Nowell et al., 2017), and coding for each of the three racial/ethnic groups were conducted by the same two team members (6 facilitators and coders in total). Coders used an iterative process to identify themes as new information was collected (Mills et al., 2009). Intercoder agreement was established through debriefing sessions where any discrepancies in codes or themes were reviewed by a third coder to ensure consensus among coders (Lincoln, 1985).

Results

Characteristics of focus group participants based on responses to the online survey are shown in Table 1. The majority of participants in all three ethnic/racial groups (AA/B, HLX, Native) were female (between 70 and 75%) and came from varying socioeconomic contexts. AA/B participants tended to be more highly educated and had higher incomes than participants from the other two groups and consistently, a much smaller proportion of AA/B participants were uninsured; and because they were slightly older (on average, 52 years compared to 41 years for the other two racial/ethnic groups), more of them were insured through Medicare.

Common focus group and online survey themes across racial/ethnic groups (AA/B, HLX, Native)

Focus group findings across all three racial/ethnic groups (AA/B, HLX, Native), revealed similar themes regarding vaccine hesitancy grounded in culturally specific factors. Prominently, AA/B and Native groups described medical mistrust as a factor of their own or their community's vaccine hesitancy due to experiences of historic and contemporary medical and research abuses (e.g., past measles and smallpox epidemics experienced by Native populations and the Tuskegee syphilis study with AA/B men). Among HLX participants, the cultural importance of religion and religious beliefs and values played a key role in either getting vaccinated or not. Furthermore, online surveys indicated that the vast majority of Native respondents (93.8%) and almost two-thirds of AA/B participants (61.9%) were vaccinated prior to participation in focus groups, compared to only 38.7% of the HLX participants (Table 1). Therefore, focus group conversations with AA/B and Native participants centered on their decision-making processes and as to what degree their behavior influenced others to get vaccinated.

Overall, findings from the online survey indicated hesitancy was not reported as particularly strong or widespread among any of the racial/ethnic groups, though somewhat more varied among HLX participants. Of those not vaccinated, all Native respondents reported on the survey that they were "very likely" to get the COVID-19 vaccine. A higher percentage of HLX participants (52.6%) than AA/B participants (37.5%) reported they were "very likely" to get the COVID-19 vaccine, yet a higher percentage of HLX participants (21.1%) than AA/B participants (12.5%) also said they were "not at all likely" to get the COVID-19 vaccine (Table 1). This variation was also observed in focus group conversations (described below).

Additionally, there were also similarities across racial/ethnic groups (AA/B, HLX, Native) regarding reasons to get vaccinated. Both unvaccinated AA/B and HLX participants most commonly reported on the survey that their reasons to get vaccinated were to keep their family (AA/B = 68.8%; HLX = 65.8%) and their community safe (AA/B = 56.3%; HLX = 47.4%) and to feel safe around others (AA/B = 50.0%; HLX = 47.4%). However, a majority of AA/B survey participants also reported not wanting to get really sick from COVID-19 (62.5%) as a reason to get vaccinated as compared to only 28.9% of HLX participants. Because only 2 Native focus group participants who took the survey were unvaccinated, we do not report their reasons for or against getting vaccinated to protect their confidentiality.

Other similarities among all participants who completed an online survey reported "a great deal" of trust (85.8%) that their doctor or health care provider would provide correct information about COVID-19. Other highly trusted

information sources for all three racial/ethnic groups (AA/B, HLX, Native) were the U.S. Coronavirus Task Force as well as the AZ Department of Health Services (Table 1). Almost two-thirds of AA/B (65.0%) and Native (61.3%) participants also trusted that their close friends and family members would provide correct information about COVID-19, compared to less than one-third (31.7%) of HLX participants. Overwhelmingly, no group trusted their contacts on social media (AA/B = 7.7%; HLX = 8.3%; Native = 14.3%). The survey results were echoed in focus group conversations as participants from all three racial/ethnic groups (AA/B, HLX, Native) discussed placing more trust in those who were in their immediate circle (e.g., family and friends) and who were vaccinated.

Vaccine hesitancy and confidence in Hispanic/Latinx (HLX) focus groups

A theme unique among HLX participants was that vaccine hesitancy stemmed from religious beliefs and values, as well as placing trust in God to guide life's decisions, including to get vaccinated. As examples, HLX participants who expressed vaccine hesitancy said:

I work in the medical field, and I have contact with a lot of COVID patients, and I did see them on a regular basis, and their progression and anything from young, who were not far from my age, or my parents' age. And so you hesitate where you think, well, I don't want to catch this, and maybe I'm going to be that one type. But at the same time, I have to have faith. And so I prayed about it a lot, and I asked for a sign and I asked God to just give me a clear cut sign and direction on what he wanted for me. Now, I know that doesn't necessarily work for everybody, but I just asked him for a sign for me on what to do. And when I got that sign, I knew that the vaccine was not for me. ...the only one who knows when or not, he [God] was going to take me when he's going to take me...that's just kind of how I felt about it. (HLX participant)

...he [said he] is not going to get it because the vaccines are made with fetal waste. And the other day I heard it on the news too. Also, the other day I heard from an archbishop, a bishop, too, who said the same thing. He was a Catholic bishop; I am a Catholic too. (HLX participant)

Other participants described their family or community members' resistance to getting vaccinated due to their religious beliefs.:

Well, I have heard many things [from religious people]. Some link it to such an apocalypse event...which there is not biblical basis to argue that COVID-19 vac-

cine is related to that theological stance, that is out of place. But there are some groups that do believe it and tell their congregants not to do it [get vaccinated], because this is coming [and] behind all this it's the devil and they are preparing the ground for...the Apocalypse...but that is being misinterpreted. (HLX participant)

...we are a large family ... one of my brothers became ill. Some of them are Evangelical Christians and they don't believe in the vaccine. (HLX participant)

However, other participants discussed how God and religion helped them during and after they received the vaccine:

I put myself in the Lord's hands and I didn't want to get it [the vaccine] [...] I got it in [...], my daughter got it yesterday. I got a little scared, but nothing is going to happen to me. You hear a lot of things, a lot of very, very negative things, right? And that's why people don't want to get it. I got it, but as I tell you, I am in the hands of the Lord and everything is fine. (HLX participant)

I was vaccinated yesterday, the first dose... I believe that God gives us wisdom, and thank God that we have doctors, scientists, teachers, the entire sector that is giving, that is working for humanity. (HLX participant)

These findings suggest that religiosity, trust in God, and specific religious beliefs contribute to vaccine hesitancy and/or confidence among HLX focus group participants, as the same factors that increase hesitancy can also help to increase confidence, comfort, and provide guidance to get vaccinated. This theme did not emerge in focus groups with the other two racial/ethnic groups (AA/B and Native).

Vaccine hesitancy in American Indian/Alaska Native (Native) focus groups

Two themes emerged among Native focus group participants, representing possibly conflicting perspectives: vaccine hesitancy and deep mistrust due to historical and contemporary traumas, as well as having a desire to trust Western medicine to fulfill cultural responsibilities and protect family. Among many Native participants, vaccine hesitancy and mistrust were tied to past histories of measles and smallpox epidemics first introduced by Europeans that resulted in the loss of entire tribal nations. Other participants expressed mistrust toward COVID-19 vaccines as they evoked fears of being used as medical test subjects without consent:

I think it [vaccine] just brought back the history of measles and smallpox. (Native participant)

When it first came out, there was a lot of hesitancy because a lot of people had the idea that we were being

used as guinea pigs for the government once again. (Native participant)

I felt like such a short time had gone by...they're trying to kill off our people, they're testing us, and that's what I told my dad, I was like, "you don't know what's in this vaccine...for all you know they're trying to get rid of you." (Native participant)

Some participants also reported wanting to trust Western science in order to return "back to normal." Reflecting on the multiple losses experienced within their community, participants identified their cultural responsibilities, respecting elders, and listening to trusted medical scientists as reasons for wanting to get vaccinated:

I got both shots, and I was the type of mother that was against vaccinations... because of just the history of our people... I had such mixed feelings because I'm like, "our people aren't guinea pigs." It's really sensitive to talk about or to even think about, how we can help our people as ourselves, without the help of Western medicine. It's kind of a double-edged sword. (Native participant)

I come from a family that does not have a lot of trust with Indian Health Service... so yeah, the hesitancy was pretty deep. Yet at the same time, because of everyone who passed, and the elders in the family were just like, "get the vaccine now, now, now!" They pushed us all to do it for them. It's still my motivator, keeping safe and wearing a mask even though I'm vaccinated. (Native participant)

I think the fear of losing more family members led to my decision of wanting to take the vaccine. And I did, I'm fully vaccinated and I feel fine. And I think that was kind of a consensus with my friends and also my family, just knowing how quickly we lost family members to COVID, like we all took the opportunity because we don't want to have to go through that again. (Native participant)

Being Native, we understand the history of disease and how it spreads and I feel like it was taken more seriously. And the fact people who may be more privileged didn't view it with the same severity that we did—was difficult. (Native participant)

My whole mind has just been totally changed because of all the things we have learned listening to [Doctor Anthony] Fauci and listening to the medical professionals and the scientists and the people that are reasonable. (Native participant)

Many Native participants described hesitancy as a tension, holding opposing views, while deciding to get vaccinated. Across groups, Native participants identified immediate family members, cultural values (e.g., love for their

community), and protecting elders as turning points in their decision to get vaccinated. Additionally, participants alluded to the sentiment, as one stated, that Native people "understand" the spread of diseases, meaning because Native people know their history of dealing with past epidemics, prevention measures are critical for individual, cultural, and community survival.

Vaccine hesitancy in African-American/Black (AA/B) focus groups

AA/B community members described vaccine hesitancy and mistrust as a consequence of historical and contemporary experiences with social and historical racism, including research abuses as well as the legacy of disparate health outcomes experienced by AA/B community members. When asked about their hesitations related to the COVID-19 vaccines, many participants cited not wanting to be a "guinea pig" or provided a one-word response, "Tuskegee," a coded reference to the U.S. Tuskegee syphilis study (Brant, 1978):

...it is an earned caution. Poor people and minorities have earned the suspicion of it, we have definitely been tested from Puerto Rico to Tuskegee, we've definitely have an earned hesitancy. (AA/B participant)

...with a disease that is killing people, it reminds me too much—it's very analogous to the Tuskegee syphilis experiment. And I don't want to have the thing, and then they aren't treating me for the thing. Or I don't want to be exposed to the thing and they gave me the placebo and now I die. Yeah, that would never be me. (AA/B participant)

And then of course...with the Tuskegee experiment... there were some African Americans who felt like with all the history of being abused by the science that they felt that this just was not for Black [people], that we should not get this vaccine, because it was going to do something: it was an experiment.... (AA/B participant)

More so than in HLX and Native focus groups, AA/B participants expressed a "wait and see" attitude due to uncertainty created by disinformation, the speed of vaccine development, and the associated concerns about potential side effects of the vaccine. This finding is supported by evidence from the online survey, which showed that 63% of AA/B respondents who had not yet received the vaccine said that they were concerned about side effects from the vaccine, compared to only 36.8% of unvaccinated HLX participants who cited this a reason for not getting vaccinated (Table 1). Many AA/B participants who contemplated getting vaccinated described that they wanted more time before deciding:

I think part of the hesitancy, I mean, just all of the misinformation that we've had...and then the fact that

the vaccine came so quickly...and so [we] really do not know what the long-term effects could possibly be. And I think that was one of the big concerns for me...I was thinking, "Maybe?" No, no, no, "I'll wait." (AA/B participant)

I don't want to have adverse reactions to something that's new. Don't get me wrong. When you take a medicine, [over the counter name brands], or whatever, you can have an adverse reaction, I get that. But it's been around long enough for them to work out the quirks and the kinks. It's like electronics. You don't buy the phone as soon as it comes out, or the flat screen, you wait. Let it get going, let some years or months or whatever - so they can work out the kinks. So, I have that same thought process on anything that's new. (AA/B participant)

My only problem right now is the fact that we have so many people, including a lot of my own family that are still hesitant on taking it, just wait and see. (AA/B participant)

People feel like they developed the vaccine too quickly. Or they feel like they need more time. They're waiting to see how it's going to affect people who have taken the shot. (AA/B participant)

Overall, AA/B participants described an openness or desire to getting vaccinated similar to Native participants, that was less expressed in HLX focus groups. The greater vaccine hesitancy among HLX individuals is also reflected in the online survey data indicating fewer HLX participants were vaccinated and a greater proportion was very unlikely to get vaccinated (Table 1). Taken together, these findings suggest that there may be greater need, as well as different barriers to increasing vaccine confidence and uptake among HLX compared to Native and AA/B community members in AZ.

Use of testimonies from local officials, community members, and faith leaders to increase vaccine confidence

Focus group participants were invited to share their thoughts on strategies to increase vaccine confidence among their fellow community members. Participants from all three racial/ethnic groups (AA/B, HLX, Native) strongly recommended using community-based testimonials from local leaders, local elected officials (e.g. tribal leaders), local elders, faith-based ministers or traditional/tribal healers, other religious leaders, and other community members who have received the COVID-19 vaccine and are able to encourage others in their community to do the same:

We had our fraternal organization chapter meeting a few weeks ago, another participant...she says at a

church, which is an African American church, "they are giving out COVID vaccines...you need to get over there!" (AA/B participant)

I've been repeating my faith leader in the things that I'm saying, which now because of COVID, I attend a church which is a spiritual center in Los Angeles, it's huge. I mean, he's worldwide. And I have been influenced by what he says.... (AA/B participant)

They actually made a small video of our [tribal] vice president getting the vaccine. It was effective because he's what you would call a traditionalist. I think that's an effective strategy, if there was some sort of video that collectively shows people from all kinds of different [Native] nations saying, "I got my vaccine, and why I got it, and this was my experience," so people can relate and say, "well, they got it and there're okay, so maybe I should think about getting it too." (Native participant)

I think messages from our Native physicians carry a lot of weight as being trusted leaders and healers in the community. And maybe even some of our trusted Medicine people to also support [getting vaccinated] and encourage it. (Native participant)

Our [Local Community Health Center name] are the ones that they are informing the people. They have a program on [social media site] called: "We love [City]," and the doctor appears every week in that program and gives the numbers, explains to the people why is it necessary to get the vaccine, it also gives ..., encourages them, [he] also asks them about the vaccine, why they got [vaccinated], how it was, ...reasons why they [got the vaccine], and people are informed because I do see it on [social media site]. (HLX participant)

The greatest confidence was given to me by this infectious disease doctor who is also a pastor, who has a lot of experience and who is an expert on these types of issues. This is how we were convinced that it was okay to do it, we did it and I think that what needs to be done in this case is to give people deep, clear information, so that they can really know how the vaccine is made and why it suits us. (HLX participant)

While specifics varied by community and trusted sources, vaccination testimonials from local trusted individuals and organizations clearly emerged as a preferred source of information on the COVID-19 vaccines. This recommendation contrasts the results from the online survey. For example, when asked how much focus group participants trusted various sources to provide correct information about COVID-19 in general, but not specifically regarding the vaccine, the majority of respondents from all three communities (60–100%) indicated that they most trusted their doctor or health care provider as well as official state or national

organizations such as the AZHS and the U.S. Coronavirus Task Force (Table 1). A majority of AA/B and Native participants (65% and 61%, respectively) indicated on the survey they trusted their friends and family a great deal to provide correct information about COVID-19; however, among HLX survey respondents, only 32% did. More HLX participants trusted the U.S. Government (44%) and their faith leaders (40%) than their friends and family. Together, these results suggest that official channels such as public health departments and health care providers play an important role in keeping all members of the population informed about COVID-19 in general. However, when it comes to increasing vaccine confidence among AA/B, HLX, and Native communities in AZ, targeted, locally-relevant and trusted messengers may be more effective.

Discussion

Despite generally increasing vaccination rates in AZ, COVID-19 and its variants continue to circulate as infections, hospitalizations, and deaths endure among communities disproportionately affected by COVID-19. Findings from focus groups with 153 members of AZ's AA/B, HLX, and Native community members indicate that COVID-19 vaccine hesitancy is multi-faceted, influenced by personal perceptions of vaccines, family and community relationships, as well historical and structural factors. Among HLX participants, religiosity was a key factor contributing to either vaccine hesitancy *or* confidence behaviors, whereas AA/B and Native participants underscored vaccine hesitancy that is grounded in a deep-seated mistrust toward governments and the medical establishment due to historical traumas, including racist research and medical abuses. Several important findings emerged from the AC3 research efforts, which can help to inform strategies in AZ, and potentially in other states across the country.

Although there may be similar underlying concerns, the focus group results indicated vaccine hesitancy is shaped by factors unique to each racial/ethnic group (AA/B, HLX, Native) that will require tailored messaging strategies for each community. For AA/B and Native communities, vaccine messages may need to be rooted in an acknowledgement of the harmful legacies from past and current medical and research abuses that these communities have experienced to alleviate fears of being test subjects without consent. Messaging strategies for HLX communities in AZ, which are predominantly of Mexican origin, may need to consider how faith and religious beliefs shape vaccine hesitancy. The HLX focus group findings suggest that values and beliefs, in the context of religion and God, play an important and collective role in the lives of many HLX individuals, families, and communities, which can be both a source of vaccine

hesitancy, as well as confidence. Messages may need to acknowledge the importance of faith among HLX persons and/or potential HLX sub-groups when making decisions. HLX participants' references to their religious beliefs, God, or religion were often discussed as a source of strength utilized during difficult times and when making important life decisions, and these factors need to be recognized as such. Public health approaches may want to draw on trusted religious leaders to deliver accurate information about COVID-19 and provide encouragement to get vaccinated to increase vaccine confidence in HLX communities. In Arizona and other states with a large HLX population, this can potentially be an important strategy as vaccination rates are particularly low among HLX groups.

Across all three racial/ethnic groups (AA/B, HLX, Native), focus group participants recommended that brief personal testimonials from leaders and elders, including religious leaders, elected officials, and other community members who received the COVID-19 vaccine, who represent their racial/ethnic group and local community, and who would most effectively engage and encourage others in the community to get vaccinated would be highly beneficial. This is consistent with theory and research on health behavior change suggesting that the use of "narratives" to increase vaccine confidence may be particularly helpful as confidence often hinges on issues connected to one's religion, values, morals, complex social relationships, and other issues where appeal to logic and reason has limited effect (Hinyard & Kreuter, 2007). For example, participants identified both individual- and culturally-specific reasons for not wanting to get vaccinated in the context of the broader social-structural factors experienced by their racial/ethnic community. Specifically, among AA/B participants, many described structural racism (i.e. 'Tuskegee') as a reason to not trust the government and/or not get vaccinated. Furthermore, narratives are more likely to "immerse" the audience, reducing the reaction to want to counter-argue key messages. Moreover, because narratives are often more personal, emotionally resonant, and memorable than non-narrative communication approaches, they are more likely to influence attitudes and beliefs (Hinyard & Kreuter, 2007). Deploying a range of tailored COVID-19 vaccine testimonies from trusted sources, across a large-scale, can potentially reach multiple segments of communities where different patterns of health literacy, experiences, and values exist (Burgess et al., 2021).

Moving forward, more research is needed to develop and evaluate the use of narrative interventions among the three racial/ethnic groups (AA/B, HLX, Native) in AZ to promote COVID-19 vaccine confidence and to encourage vaccine uptake. A more fine-grained analysis of focus group data could help to identify additional sub-themes or specific issues impacting sub-groups for each of the three racial/ethnic groups. Furthermore, to strengthen knowledge

generation, it will be essential to collaborate with other state-based NIH-funded CEAL consortia who share common goals and are also using local approaches to promote trust in science and confidence for the use of COVID-19 vaccines and other therapies among underserved communities. Examinations of narrative approaches may also need to include testing of various delivery modes, including social media, radio, and printed materials to increase our understanding how messages can quickly and effectively be disseminated to underserved populations. Ultimately, knowledge derived from implementing, evaluating, and refining a narrative approach could help to reduce the prevalence of COVID-19 and eventually improve health outcomes. Future studies could consider exploring narrative approaches as a means to promote health equity across AZ's communities and across the country.

Limitations

This study had several limitations. First, best practices of community-engaged research aim to foster and build trusting relationships via meetings to explain the study, answer questions, and recruit participants in person. However, face-to-face meetings were not possible due to pandemic-related safety concerns and shut-downs of community-based organizations. Instead, we conducted recruitment via flyers, email, and conducted online focus groups using the Zoom platform. This may have limited recruitment to more technologically-competent and connected participants and may have made it more difficult for some community members to participate in the study. However, our ability to draw on existing relationships with community partners and advisory board members, while using a "friends and family" approach to recruitment may have alleviated potential recruitment and participation limitations. Second, the focus groups were conducted over a period of approximately seven months between February and August 2021 during which the pandemic changed, vaccines became available, state and local mandates were installed and then lifted, with prevention recommendations actively shifting. Therefore, data from early focus groups may not be comparable to later focus groups. Third, the majority of study participants were from urban areas in AZ. It is unclear if and how these themes and findings may resonate with residents living in rural, borderland, reservation, and other tribal areas. Lastly, survey data were used to supplement focus group information. However, a few participants chose to participate in the survey, but not the focus group, and vice-versa, but reasons for this were not elucidated. Thus, the online survey sample cannot be interpreted as representing exactly the same individuals who participated in focus groups.

Conclusion

Our AC3 community-engaged research aims were to identify factors, with an emphasis on culture and community, that contribute to COVID-19 vaccine hesitancy and confidence, as well as identify trusted messaging strategies. Findings revealed multi-level factors contributing to COVID-19 vaccine hesitancy including underlying social-structural factors (e.g., historical trauma and racism) specific to AA/B, and Native communities. Among AA/B and Native participants, hesitancy was tied to questions about vaccine effects, speed of development, and concerns of being used as test subjects given the historical legacy of medical and research harms experienced. For HLX participants, spiritual or religious factors are indicated as important considerations. Furthermore, our findings across all three racial/ethnic groups (AA/B, HLX, Native) strongly suggest an effective way to promote trust in science and increase COVID-19 vaccine confidence is through the use of community-based testimonials or narratives from local leaders, local elected officials, local elders and other community members who have received the COVID-19 vaccine and who are able to encourage others in their community to do the same. While more research is needed to test narrative messaging to increase COVID-19 vaccine confidence and uptake, it holds the promise of informing effective strategies in AZ, and potentially informing strategies in other states and across the country.

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Availability of data and material All authors ensure data and materials support their published claims and comply with field standards.

Code availability The data and code to support findings of this study are not openly available yet and are available from the corresponding author upon reasonable request.

Declarations

Conflict of interest The authors have no relevant financial or non-financial interests to disclose.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was approved by the University of Arizona Institutional Review Board (Protocol # 2011244240). For participants living on sovereign tribal lands, consent was provided via tribal memorandum of understanding (MOU) agreements secured through Northern Arizona University.

Consent to participate and publication Informed consent was obtained from all individual participants included in the study.

Human and animal rights and Informed Consent All procedures followed were in accordance with ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.

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