# Understanding Diverse Communities and Supporting Equitable and Informed COVID-19 Vaccination Decision-Making











# Findings from Wave 2

With Support from The Robert Wood Johnson Foundation and the Horizon Foundation

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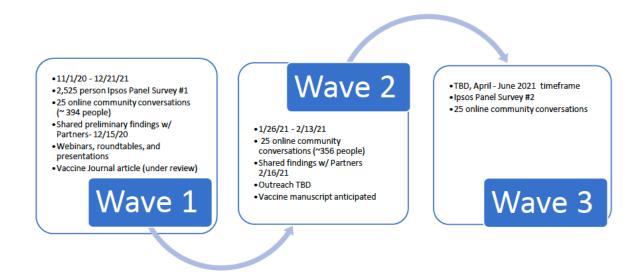
# Understanding Diverse Communities and Supporting Equitable and Informed COVID-19 Vaccination Decision-Making

#### Findings from Wave 2

Project Overview: This project, supported by the Robert Wood Johnson Foundation and the Horizon Foundation, is focused on how public health and other stakeholders can best understand and support decision-making as individuals consider if and under what conditions COVID-19 vaccination is right for them. This project recognizes that it is critical to support decision-making among those who remain undecided about obtaining a COVID-19 vaccine at this time. The project is designed in three waves, occurring between December 2020 and June 2021. Also, to foster equitable vaccine uptake, it is essential that the perspectives of communities of color, which are disproportionately impacted by COVID-19, are heard, listened to, and understood; their guidance must be followed and public health and immunization programs must meet their needs. In Wave One (November 1-December 21, 2020), we conducted a 2,525-person panel survey and hosted 25 online community conversations with nearly 400 adults. Participants in these conversations were African Americans, Latinx, and Native Americans recruited from local communities or panel survey respondents from four U.S. regions (Northeast, Midwest, South, West) who had indicated that they were undecided about their intent to vaccinate now or in the future against COVID-19.

In Wave Two (January 26-February 13, 2021), we returned to the same individuals to engage in a second set of conversations to understand what has changed for them, and whether or how these changes influenced their decision-making (Figure 1). Public considerations of COVID-19 vaccination are occurring in an environment where the disease, vaccines and national politics are rapidly evolving.

Figure 1: Project Waves 1-3 Methods and Timeline

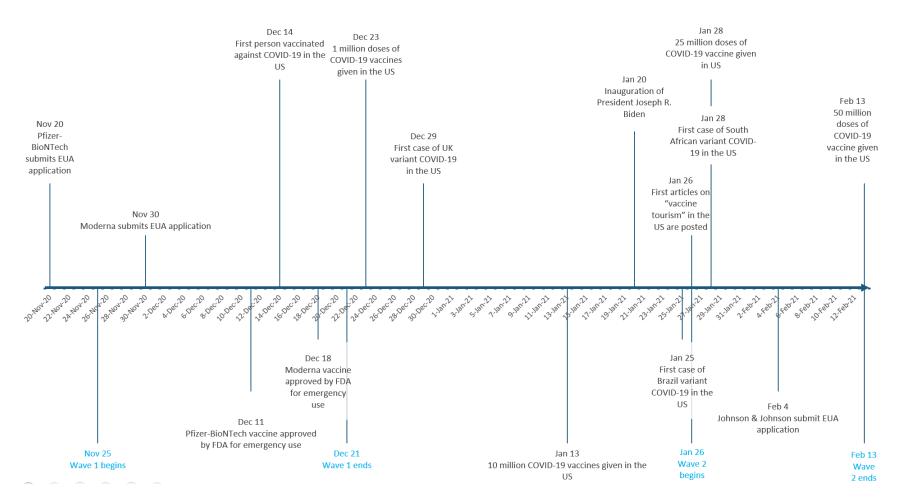


The project takes a longitudinal approach in community meetings and panel surveys to capture evolving vaccine decision-making in a rapidly evolving environment, as depicted in Figure 2.

**Project Perspective:** This project is centered on what underpins decision-making in an effort to inform strategies that serve communities based on their experiences, perspectives, and needs. The opportunities below extend beyond messaging focused on promoting vaccination to include engagement and supporting decision-making. By providing communities with information, creating neutral forums for group dialogue, and enabling people to deliberate the full range of risks and benefits in context of their culture, values, and lived experience, the project aims to assist people in diverse communities with varying needs as they make decisions about COVID-19 vaccination.

**About the Key Findings and Opportunities:** The following findings represent a snapshot of perspectives in a rapidly changing environment. The opportunities identified are considerations for implementation, with full recognition that communities have different challenges and there is no one-size-fits-all approach. The opportunities outlined are intended to support or stimulate additional thinking about how to customize approaches for a given community.

Figure 2:Timeline of Notable Milestones Surrounding Wave 1 (November 25-December 21, 2020) and Wave 2 (January 26-February 13, 2021) Community Conversations



#### Wave 1 Recap: Many Had Not Fully Formed their Views

When asked in the Wave 1 Ipsos Survey about their intent to get vaccinated:

- 50% of the survey respondents said they would definitely or probably get vaccinated as soon as vaccine was available for them (Intenders);
- 10% said they would definitely not get vaccinated (Unlikelys);
- 40% of respondents indicated they probably would get vaccinated but wanted to wait or they
  probably would not get vaccinated (Wait and Learn).

"Intenders" - This group reports intent to definitely or probably getting vaccinated as soon as they are able and represents half of the population. Intent to get vaccinated was substantially lower among African Americans (32%) and comparable among Whites, non-Hispanics (55%), Hispanics (52%) and Other, non-Hispanics (53%). Intenders also included a significantly higher proportion of men compared with women (56% vs 48%); individuals older than 60 years of age (61%) compared with younger persons; and with greater education (Bachelor's degree or higher, 63%) compared with those who had less education. Intenders were also more likely to be Democrats (63%) versus Republicans (46%) and Independents (48%). Intenders (compared to the rest of the population) were more likely to live in metropolitan than non-metropolitan statistical areas (odds ratio (OR): 1.43; 95% Confidence Interval (CI) 1.07-1.93) and have high income compared to low income (OR: 1.60; 95% CI 1.22-2.10)

Intenders (compared to the rest of the population) were more likely to report having been diagnosed with a high risk condition for COVID-19 (OR: 1.48; 95% CI 1.19-1.84), having received a flu shot in the past 12 months (OR: 3.87; 95% CI 3.17-4.73), being likely to discuss COVID-19 with their healthcare provider (OR: 6.07; 95% CI 4.61-7.99), perceiving COVID-19 as severe (OR: 2.08; 95% CI 1.70-2.53), considering a COVID-19 vaccine important to stop the spread of infection (OR: 44.37; 95% CI 18.07-108.97), and usually or almost always wearing a mask (OR: 3.20; 95% CI 2.33-4.59). Intenders were more likely to hold a communitarian worldview (vs. individualism; OR 2.74; 95% CI 2.25-3.35), support egalitarianism (vs. hierarchy; OR 2.03; 95% CI 1.68-2.46), and trust the CDC (OR 2.72; 95% CI 2.24-3.32) and local/state health department (OR 2.50; 95% CI 2.06-3.03) compared to the rest of the population. Intenders were much more likely to be confident in vaccine safety than the rest of the population (OR 10.27; 95% CI 826-12.77).

"Wait and Learn" - This group includes those who indicated they probably will get vaccinated but not right away and those who probably will not get vaccinated and represents 40% of the population. However, 52% of African Americans fall into this Wait and Learn group as do a substantial proportion of persons 60 years old and older (33%). Compared to the Intenders, the Wait and Learn group were more likely to be African American (OR: 2.51; 95% CI 1.98-3.18). The Wait and Learn group, compared to the Intenders, were less likely to live in metropolitan than non-metropolitan statistical areas (OR: 0.71; 95% CI 0.52-0.98)), report high vs. low income (OR: 0.68; 95% CI 0.50-0.90)), and to be a Democrat versus a Republican (OR: 0.58; 95% CI 0.45-0.75).

The Wait and Learn group, compared to the Intenders, were more likely to report their health being good (OR: 1.72; 95% CI 1.20-2.46) or fair (OR:1.64; 95% CI 1.07-2.52) compared to excellent, having known someone with a previous serious vaccine reaction (OR: 2.74; 95% CI 1.83-4.10), being worried about the government requiring personal information to get a COVID-19 vaccine (OR: 1.86; 95% CI 1.52-2.29) and being concerned that the government and drug companies experiment on people like me (OR: 3.74; 95% CI 3.03-4.63). The Wait and Learn group, compared to the Intenders, were less likely to report having been

diagnosed with a high risk condition for COVID-19 (OR: 0.68; 95% CI 0.54-0.85), receiving an influenza vaccine in the past 12 months (OR: 0.32; 95% CI 0.26-0.39), discussing COVID-19 vaccine with their healthcare provider (OR: 0.23; 95% CI 0.17-0.31), perceiving COVID-19 as severe (OR: 0.54; 95% CI 0.44-0.67), considering a COVID-19 vaccine important to stop the spread of infection (OR: 0.04; 95% CI 0.02-0.11), and wearing a mask usually or almost always (OR: 0.39; 95% CI 0.27-0.58). The Wait and Learn group were less likely to support communitarianism (vs. individualism - OR: 0.45; 95% CI 0.36-0.55) and egalitarianism (vs. hierarchy - OR: 0.52; 95% CI 0.43-0.64)), have trust in local/state health departments (OR: 0.47; 95% CI 0.38-0.57) and CDC (OR: 0.41; 95% CI 0.33-0.50), and to be confident in vaccine safety (OR: 0.12; 95% CI 0.10-0.16) compared with Intenders.

"Unlikelys" - This group includes those who indicate they definitely will not get vaccinated and represents 10% of the population. The Unlikelys include 15% of African American and 14% of persons with a high school education or less. The Unlikelys were less likely than Intenders to be elderly (OR: 0.38; 95% CI 0.23-0.63), have a bachelor's degree or more compared to less than high school education (OR: 0.24; 95% CI 0.13-0.44), have a high versus low income (OR: 0.46; 95% CI 0.28-0.74), and be a Democrat compared with a Republican (OR: 0.33; 95% CI 0.22-0.49).

The Unlikelys were less likely to think they will be infected with COVID-19 (OR: 0.59; 95% CI 0.41-0.85), discuss COVID-19 vaccine with their healthcare providers (OR: 0.04; 95% CI 0.02-0.06), perceive COVID-19 as severe (OR: 0.29; 95% CI 0.19-0.43), consider COVID-19 vaccine important for stopping the spread of infection (OR<0.01; 95% CI <0.00-0.01), have received influenza vaccine in the past 12 months (OR: 0.10; 95% CI 0.06-0.14), and to usually or almost always report wearing a mask (OR: 0.16; 95% CI 0.10-0.25) compared with Intenders. The Unlikelys were also far less likely to support communitarianism (vs. individualism - OR: 0.12; 95% CI 0.08-0.18) and egalitarianism (vs. hierarchy - OR: 0.37; 95% CI 0.27-0.52), trust local/state (OR: 0.20; 95% CI 0.14-0.29) and CDC (OR: 0.22; 95% CI 0.15-0.33) health authorities and be confident in vaccine safety (OR: 0.02; 95% CI 0.01-0.04) compared with Intenders.

This project assumes that community (herd) immunity will only occur if a substantial portion of those in the Wait and Learn group, chooses to be vaccinated. Current estimates are that we need at least 70% immunity homogenously across the population to control COVID-19. This estimate assumes we don't have social or geographical clustering of unvaccinated persons. New COVID-19 variants that are either more easily transmitted or the vaccines are less effective against may require higher levels of vaccine coverage or alternative approaches to vaccine administration such as booster vaccines.

# Community Conversations: Wave 1 (December 1-14, 2020) to Wave 2 (January 26-February 13, 2021):

Wave 2 focused on community conversations from vulnerable and regional groups and did not include a national survey, though polling questions were asked of community meeting participants. These online conversations invited participants from Wave 1 to continue the dialogue and share how their decision-making evolved since Wave 1. Conversations lasted 90-120 minutes and included a mix of dialogue and online polling meant to further stimulate discussion and provide a semi-quantitative, anonymous check on the conversation's outcomes. Populations, number of meetings and participants in Waves 1 and 2, and retention rate by meeting is summarized in Table 1.

Table 1: Community Meeting Population, Number of Meetings, Number of Participants in Wave 1 and 2, and Retention Rate

Population	Number of Meetings	Wave 1	Wave 2	Retention (%)
Regional Meetings	2 Northeast	39	38	97
	2 South	33	33	100
	2 West	36	31	86
	2 Midwest	38	31	82
African American	2 Baltimore City, MD	24	24	100
	2 New Orleans, LA	24	24	100
	1 Howard County, MD	23	21	91
Latinx	2 Garfield Co/Glenwood Springs, CO	34	27	79
	2 Harris County, TX	25	25	100
	2 Fairfax, VA	31	24	77
	1 Howard County, MD	23	21	91
Native American	2 Northern Plains Tribe, MT	26	22	85
	2 Great Plains Tribe, ND	22	18	82
Asian American	1 Howard County, MD	16	17*	100
TOTALS	25 Meetings	394	356	90%

<sup>\*</sup> One participant could not attend Wave 1 meeting

# Overall Findings Across Regional and Vulnerable Community Conversations from Wave 1 to Wave 2.

1. Increased comfort for many. In many cases, increased comfort regarding COVID-19 vaccination has resulted in some shifts in intention to vaccinate (Figure 3). In the second wave, 11% of persons reported having been vaccinated, with Native Americans most likely to be vaccinated, followed by African Americans, Latinx and our regional communities. Interestingly, the proportion of community members definitely not intending to get the vaccine dropped by almost half. It is unusual to see such a shift in vaccine intention among persons who seemingly had already made up their mind to forgo vaccination - this highlights both the uniqueness of COVID-19 vaccines compared with routinely used vaccines and the rapidly evolving nature of COVID-19 vaccination. There were also increases in the proportion of persons intending to definitely or probably get the vaccine as soon as they can, particularly among African Americans, Latinx and regional participants.

For many across the community conversations, knowing that millions of people, including family and friends, have been vaccinated since December has been meaningful.

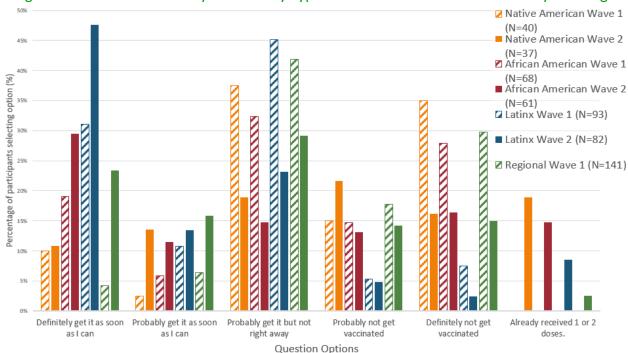


Figure 3: Vaccine Intention by Community Type in Wave 1 and Wave 2 Community Meetings

If a COVID-19 vaccine was available to you this week at no cost, how likely is it that you would get vaccinated?

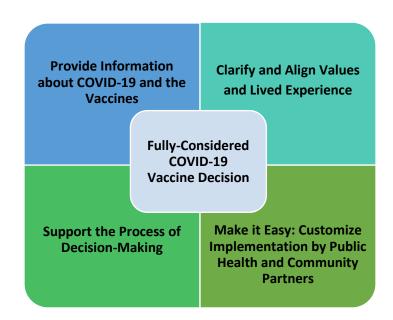
2. **Perspective and emphasis varied by community.** Many of the Latinx community members have moved from questioning *whether* to get the vaccine to questioning *how* to get the vaccine. Native American and African American community conversations experienced some shifts in perspective, but historical context and lived experience remained important lenses for considering risks of disease and vaccination. There appeared to be no major differences in regional (geographic) participants; the

same issues and concerns were raised across all four regions and there were echoes of all the vulnerable community conversations in every regional discussion.

- 3. **Safety concerns persist.** Safety concerns were focused on unknown, long-term effects and, to a lesser degree, on severe allergic reactions, particularly in people with a history of allergies.
- 4. **Information needs are evolving.** Evolving issues included COVID-19 variants, deaths following vaccination (particularly in Norway and Israel), vaccine supply and equity (particularly with people "jumping the line" or people getting vaccinated before they were eligible by, for example, traveling to another location to get the vaccine) and numbers of vaccinees by race, ethnicity, and pre-existing conditions. Questions remained regarding whether those vaccinated can still infect others with COVID-19.
- 5. Concerns about the speed of vaccine development diminished. While the speed of vaccine development was one of the top three concerns cited in Wave 1, this concern has lessened. Reasons cited for the change in their concern included having done additional research on how the vaccines were developed so quickly; having less concerns following changes to Federal Administration leadership; and seeing millions of people vaccinated without significant safety incidents.
- 6. Experience with the roll-out of vaccines has been uneven; but frustrating for many. This was mentioned to some degree across meetings, but experiences varied. Some participants shared that the roll-out was orderly and efficient for them. Those who identified issues cited supply deficiency and unpredictability, difficulties scheduling appointments, lost or wasted vaccines, technology and transportation challenges for the elderly, inconvenient hours of availability, and lack of equity or fairness in who is prioritized and gets vaccinated. Some participants experienced these frustrations first-hand while others reported the frustrations they observed from others' experiences and the media.
- 7. There is still a "Wait and Learn" approach for many. While there were shifts of perspective in many of the community conversations a large number remained in the Wait and Learn category. Some, who had characterized themselves in December as Unlikely, shifted to Wait and Learn in the second wave.
- 8. Community conversations are important to customizing support for decision-making. Many indicated they still have specific and evolving information needs while others indicated that they also need support in other ways. Some indicated that a recommendation or discussion with their doctor or other experts is important and some indicated they need more time to think about what is best for them. Others indicated they need more time to discuss information and trade-offs with family, friends, or other community members.
- 9. For those who don't want a vaccination now or maybe ever (Wait and Learn and Unlikelys), there was an interest in how else, beyond vaccination, they can help end the pandemic. There was discussion in some community conversations about how else to end the pandemic if one does not feel comfortable getting vaccinated.
- 10. **Meeting this moment.** Participants were eager to engage in respectful two-way communication about aspects that include the (1) science of COVID-19 and vaccines; (2) trade-offs related to choices they make about protecting themselves; (3) influence of their values; and (4) how various factors

impact their decision-making. While media attention has focused on public health as a transactional service provider focused on "getting shots in arms", participant perspectives from community conversations suggested that there is an opportunity for public health agencies to move beyond transactions to relationships with their communities. This could ultimately provide a platform for proving trustworthiness and true partnering for better and more equitable public health outcomes.

Beyond "Informed Decision-Making." In the public health context, leaders often indicated they want the public to engage in "informed decision-making." However, informed decision-making fails to consider what else is at play beyond an assessment of information. This project presumes decision-making about whether (and when) to take a COVID-19 vaccine is about more than information (Figure 4). A Fully-Considered Decision: As this effort has attempted to unpack decision-making, we seek to learn what a fully-considered decision is – one that is inclusive of information (Quadrant 1), a person's values and lived experience (Quadrant 2); and the extent to which people have had support, in the ways they define it, for making a decision (Quadrant 3); and how hard or easy it is to take action (Quadrant 4).



Fully Considered COVID-19 Vaccine Decision

<sup>&</sup>lt;sup>1</sup> A term to describe a **process** designed to help patients understand the nature of the disease or condition being addressed; understand the clinical service being provided including benefits, risks, limitations, alternatives and uncertainties.

Note: Sections in this memorandum report should not be generalized. These insights represent a point in time with members from specific communities and allow us to have a sense of the issues, trade-offs, and decision-making not easily understood in surveys. National-level surveys are also part of this effort and the next one will be conducted in March 2021.

#### Quadrant 1: Provide Information re: COVID-19 and the Vaccines

Community meeting participants were about evenly split on whether they had enough or needed more information to make an informed decision regarding COVID-19 vaccination (Figure 4) with variability between subpopulations (56% of Native American participants and 33% of Latinx populations report they still need more information).

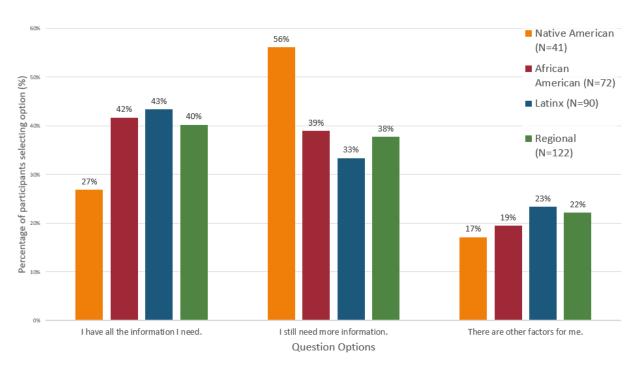


Figure 4: Information Needs by Community Meeting Population, Wave 2

Do you have the information you need?

**Information needs have evolved but continue to vary between Waves 1 and 2.** There were three topics identified as information needs in the Wave 1 discussions and survey that Wave 2 conversations explored:

- 1. Vaccine safety;
- 2. The speed of vaccine development; and
- 3. An understanding about the numbers of people who have had the vaccine.

Note: In addition to what people may have researched or learned independently between Wave 1 and 2, Wave 2 conversations began with subject matter experts sharing high level information (one slide each) on all three topics. This was done at the request made by participants in Wave 1.

1. Vaccine Safety. Common reactions, rare allergic reactions, and serious unknown long-term impacts were all raised in Wave 1 and further explored in Wave 2. In general, while questions and issues were raised about all three types of concerns, they varied in impact on decision-making. As depicted in Figure 5, the vast majority of respondents across population groups report that unknown long-term side effects make it somewhat or much less likely to get vaccinated.

60% ■ Native American (N=39)49% option (%) African American (N=65) 42% 41% ■ Latinx (N=78) 39% participants selecting 38% 35% 32% ■ Regional (N=122) 31% 26% 24% 23% 21% Percentage of It makes me much less likely to get vaccinated It makes me somewhat less likely to get It doesn't affect my decision about vaccination vaccinated Question Options

Figure 5: Impact of Possibility of Long-Term Side Effects on COVID-19 Vaccine Intention by Community Meeting Population, Wave 2

What impact does the possibility of unknown long-term side effects have on your decision to get vaccinated?

#### **Wave 2 Vaccine Safety – Key Findings from Community Conversations:**

- The possibility of long-term, unknown side effects was influential in decisions about vaccination for a majority of participants
- Approximately 1/3 of participants indicated concern regarding rare allergic reactions was a consideration and had questions about whether specific, known allergies might increase risk of a reaction to the vaccine
- Questions remained regarding ingredients, vaccine effectiveness, and to what extent vaccinated people can still spread the disease
- Questions arose regarding COVID-19 variants and whether/how vaccination would protect against them
- Many participants indicated that the safety issues seemed minimal in the general public, which led them to more specific questions regarding safety by race, ethnicity, and underlying health conditions of those who had taken the vaccine
- Questions arose about specific news stories such as the deaths in Norway among the elderly or whether fetal stem cells were used to make the vaccine.
- 2. Speed of Vaccine Development. The speed at which the vaccines were developed was cited as a major concern in every Wave 1 community conversation. In Wave 2, concerns around the speed of development decreased but was still common among a substantial proportion of participants, especially among Native American and African American communities (Figure 6).

80% Native American (N=38)71% 70% African American 64% % (N=65)■ Latinx (N=82) 54% ■ Regional (N=121) 37% 34% 29% 28% Percentage of 24% 18% 20% 17% 12% 12% 10% It makes me somewhat less likely to get vaccinated It makes me much less likely to get vaccinated It doesn't affect my decision about vaccination Question Options

Figure 6: Impact of Speed of Development on COVID-19 Vaccine Decision-Making by Community Meeting Population, Wave 2

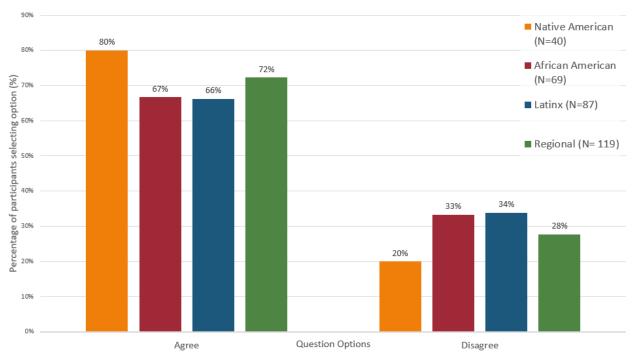
What impact does the speed of vaccine development have on your decision about vaccination?

#### Wave 2 Speed of Vaccine Development – Key Findings from Community Conversations:

Most participants indicated that a number of factors contributed to decreased concern about the speed of vaccine development, including:

- Seeing people being vaccinated without serious side effects;
- Doing their own research or learning from community conversations how the vaccines were developed in a short timeframe; and
- Change of Federal Administration, leading some to feel more comfortable with the speed of development and assurances that no corners were cut that might impact safety or effectiveness.
- **3.** Level of Comfort as it relates to millions of people getting the vaccine. In Wave 1, 56% of Ipsos survey participants would be more comfortable getting the vaccine once it has been proven safe in millions of people; community conversations yielded similar findings (Figure 7).

Figure 7: Proportion who Report they Do Not Trust a Vaccine Until it has Been Given to Millions of People by Community Meeting Population, Wave 1



I do not trust a vaccine until it has been given to millions of people

As vaccine became available between Wave 1 and Wave 2, millions of people were vaccinated in the United States and this was clearly influential in increasing comfort for some (Figure 8). The numbers of people vaccinated was less influential for Native American and African American participants with dialogue focusing on who were the millions of people and whether they were Native Americans, African Americans, or people with similar underlying conditions.

90% ■ Native American (N=40)74% African selecting option (%) American (N=65) ■ Latinx (N=81) ■ Regional 49% 5.096 (N=122)45% participants 38% 35% of 20% 2.096 18% 16% 15% 096 No Not Sure Question Options

Figure 8: Level of Comfort by Knowing Millions of People Vaccinated, by Community Meeting Population, Wave 2

Does it make you feel more comfortable to know millions of people have received the vaccine?

#### **Quadrant 2: Clarify and Align Values and Lived Experience**

From Wave 1, we know that values and lived experience are factors in decision-making about whether to get vaccinated. As depicted in Figure 4, approximately 20% of community meeting participants in Wave 2 reported there are factors other than information that impact their decision-making. Wave 2 conversations built on Wave 1 discussions of values, cultural and historical context, and trust.

#### **Wave 2 Key Findings from Community Conversations**

Impact of lived experience trust and distrust. All groups discussed the issue of trust and to what extent it was a *deciding* factor for whether to get the vaccine or not. While trust was cited as important in all cases, it varied from individual to individual on whether it was the *deciding* factor. For some, the issues of trust were mutable. For example, the changing of Federal Administration leadership in January had an impact on their trust of the vaccines and the public and tribal health systems rolling it out. For others, trust or distrust was deeply seeded in historical and cultural experience. In addition, for some, there were present-day lived experiences that contributed to whether they had trust for individuals and institutions associated with the COVID-19 vaccines.

A move toward demonstrating trustworthiness. In all cases, state, local, and tribal health, along with associated partners can work to demonstrate trustworthiness in these current conditions. There was fairly wide variability in trust issues between community meeting participants (Table 2). Three elements of

trust<sup>2</sup> further explored in the potential actionable opportunities: 1. Positive Relationships (do you "get" me and do you have my interests at heart?); 2. Good Judgment/Expertise (do you have demonstrated expertise on the issues that affect me most?); and 3. Consistency (can you be relied on and will you go above and beyond?).

Table 2: Trust Issues that Emerged in Community Conversations by Community Meeting Population. Wave 2

Community Conversations	Findings  Values, Lived Experience, Cultural/Historical Context
Regional	Regional (geographic) sessions were diverse and most of the issues discussed in the vulnerable community conversations were also raised regionally, though with varying degrees of emphasis. There were not distinctly geographic perspectives that emerged in the conversations (e.g., Northeasterners did not collectively have a certain perspective that was distinct from Westerners).
Latinx	An important finding in Wave 1 was the extent to which the Latinx participants feel a responsibility to others in their community, this remained important.
Latinx	In the majority of the Latinx Community Conversations there are strong, trusted relationships with local public health, local doctors, and others.
African American	Given the intentional abuse and neglect of African Americans' health over the past 400 years, many see the vaccine as just the latest attempt to further undermine their health.
African American	Regardless of status, wealth, or education level, African Americans who complain of pain are often ignored or dismissed by medical professionals. Healthcare and medical professionals must prove they can respond to Black Americans in pain.
African American	Many established governmental systems (education, housing, healthcare research, criminal justice and many others) have not equitably served African Americans and thus distrust has been earned.
Native American	Historical abuse and neglect of Native Americans have left indelible marks on tribes throughout the United States; infectious diseases have additional meaning for tribes given experiences with smallpox blankets (and other infectious diseases); and inadequate healthcare systems across Indian Country has led to Native Americans disproportionately experiencing the pandemic.
Native American	Native community conversations approached the pandemic and the consequences of vaccines with a multi-generational lens to include wanting to protect elders, and recognizing the interconnectedness of families and tribal members.
Native American	The issue of scarcity was raised as a result of traumatic historical experiences members. There was discussion that this lived experience results in carefully watching equity-related access issues in the roll-out of vaccines, who is prioritized, and putting a high value on things not available yet, in this case vaccines.

#### **Quadrant 3: Support the Process of Decision-Making**

From Wave 1, we understand that those in the "Wait and Learn" group may need additional support for decision-making; and Wave 2 indicates that support looks very different for people. Support for decision-making includes providing information, but also encourages communication and supports dialogue focused on deliberation. As depicted in Figure 9, community meeting participants report a broad range of factors beyond information, including getting recommendations from their doctor, talking with a public health expert, healthcare worker from their community, or family and friends. Hearing from community leaders was important for many, as was more time to think about what is best for "me" and more community conversations like the one they were participating in. Support for decision-making

<sup>&</sup>lt;sup>2</sup> https://hbr.org/2019/02/the-3-elements-of-trust

recognizes that individuals assign different weights to their perspective on personal and community risk, benefits, value alignment, cultural context, and levels of trust. The combination of these factors plus the ease or difficulty of acting on choices is influential to decision-making.

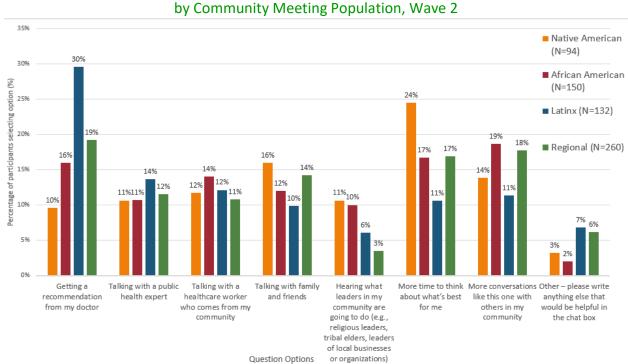


Figure 9: Factors Beyond Information that is Helpful for Decision-Making, by Community Meeting Population, Waye 2

Beyond information, what is helpful to me for decision-making?

#### **Wave 2 Key Findings from Community Conversations:**

- Across the groups there was support for dialogue-focused conversations (without the intention to persuade) "like this one," i.e. community conversations. For the Latinx community, opportunities to talk with a doctor were most important to support decision-making.
- For many, more time to think about what is best for themselves was important. This is consistent with the "Wait and Learn" profile.
- For Native Americans, talking with friends and family was important and consistent with their cultural value regarding family.

# Quadrant 4: Make It Easy: Customized implementation by public and tribal health, along with their partners

This section focuses on "making it easy" for those who do now or might want to get vaccinated at some point in the future.

#### **Make it Easy**

<u>Logistics.</u> There were a number of issues related to the roll-out of vaccination and experience varied by location. However, these were the issues that needed attention for many:

- Ensure there is equitable access and options for those who lack Internet access or the ability to monitor the computer for openings
- Let people know they are eligible for vaccination and how to make an appointment
- Ensure enough dispersed locations so that people do not need to rely on public transportation
- Customize delivery to reflect community needs, such as conducting vaccinations via drive throughs, door-to-door, and mobile units
- Explore potential for options to sharing personal information (name, address, etc.)
- Provide culturally appropriate materials
- Have materials in Spanish for Latinx communities
- Share the importance of showing up for appointments and what happens to perishable vaccines if appointments are missed
- Continue to support, encourage and celebrate all the behaviors that contribute to stopping the spread of the disease

#### Information

<u>Safety monitoring and long-term Impacts.</u> Be transparent about infrastructure and systems in place for safety monitoring for long-term impacts; the vaccine injury fund is available for serious injuries; and the importance of people reporting their side effects.

<u>Allergic reactions</u>. Discussion of the potential for an allergic reaction to the vaccine would be helpful to decision-making; in addition to recommending those with this concern get their vaccine at a medical facility location with personnel trained in addressing severe allergic reactions.

<u>Up-to-date information on variants, as they are understood.</u> There is growing interest in variants and whether and how different vaccines stack up to variants.

<u>Speed of vaccine development.</u> There is still an opportunity to share information about how the vaccines were developed so quickly; and it seemed important for many to understand this. Note: using the analogy of telephone technology building off the last version to create the next version was helpful to people.

<u>Numbers still matter.</u> In some of the community conversations, local public health authorities shared the numbers of vaccinated in their county and this was helpful to participants. State, local, and tribal health authorities should publicly share vaccination numbers (a ticker, daily counter, daily updates on the radio, tv, social media). While national and world coverage numbers are of interest, state and local numbers are more important.

#### **Values and Lived Experience**

<u>Get specific.</u> National, state, and local data on vaccine uptake parsed by race, ethnicity, and those with underlying conditions is helpful to decision-making.

<u>Customize for community.</u> State, local, or tribal health authorities should customize decision-making support based on community interests. Some may want to hear from local doctors, others from local vaccinees, and others may primarily need time and space (without pressure) to consider trade-offs or hear how others are weighing risks and benefits. Given the diverse nature of many American communities, it may be a combination of each of these. Please see pages 17-29 for specific strategies that emerged from the Latinx, African American, and Native American community conversations.

<u>Transparency regarding "jumping the line" issues as they intersect with privilege and equity.</u> While vaccine supplies are limited there's sensitivity to those "jumping the line" and whether and how that happens and the privilege it demonstrates.

#### **Support for Decision-Making**

Safe platforms to talk to experts and with each other. Supporting decision-making does not mean only supporting those who decide to get vaccinated. It also suggests that those entities involved in public health move from transactional interactions focused on shots in arms to ones focused on developing a trusted relationship where public health efforts support the timeframes and information requirements, and convene discussions about trade-offs as community members consider whether vaccines are right for them at this time. The most notable feature of the community conversations has been the safe platform they provide for participants to exchange perspectives, evolve and change their views about COVID-19 vaccines. Both those intending to and not intending to take the vaccine found satisfaction in learning more about it and discussing it with others. There is an appreciation of dialogue regardless of a person's intent to be vaccinated. Given the number of people in the "Wait and Learn" category, this outreach can support informed decision-making.

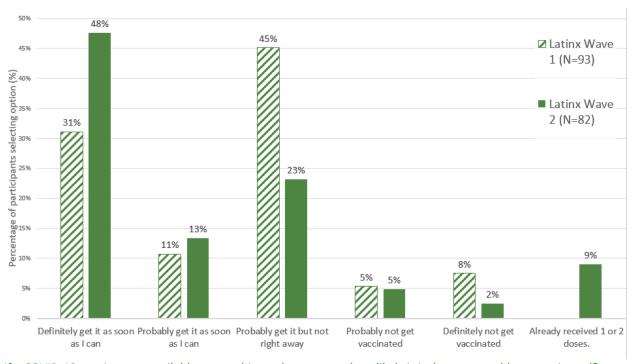
Support positive public health behaviors and decisions, beyond vaccination. Whether enthusiastic or hesitant about vaccines; all the community conversation participants believed that the current public health protocols should be followed and even enforced. In some cases, those in the "Wait and Learn" or "Unlikely" group in the meetings expressed interest in what other protective measures they could take, aside from being vaccinated. State, local, and tribal health authorities should show encouragement and appreciation for the spectrum of activities that contribute to decreased disease rates, hospitalizations, and death. To the extent it is possible, coordinated messaging on both tribal land and in the "border towns" creates more consistency with better public health outcomes.

## **APPENDIX 1**

#### At-A-Glance: What We've Learned from Latinx Communities

In the six weeks since Wave 1, the Latinx participants have an increased interest in getting the vaccine as soon as it is available to them and 9% have already received the vaccine.





If a COVID-19 vaccine was available to you this week at no cost, how likely is it that you would get vaccinated?

What has been important from Wave 1 (December 2020) to Wave 2 (January/February 2021), as articulated in our community conversations.

- Vaccine roll-out has let the community glimpse the possibility of getting "back to normal" economy/jobs, school, and family gatherings
- Hearing from local members of the Latinx community who have received vaccination has been meaningful
- Information and misinformation about the vaccines and side effects (see below)
- Information and (sometimes) confusion about how to access the vaccine
- The sense of responsibility toward community has remained strong and consistent from Wave 1 to Wave 2

#### **Evolving Information Needs**

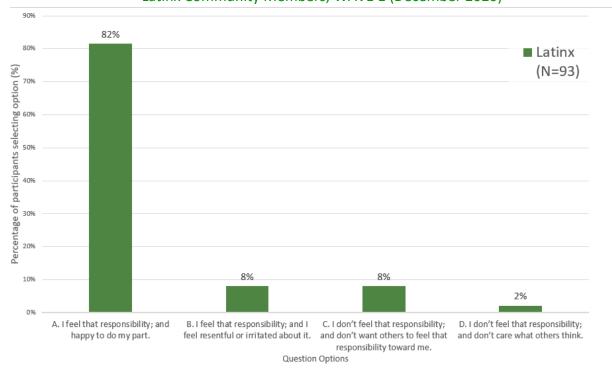
- Access to the vaccine. Many questions focused on details related to getting the vaccine in their community. Instead of questions regarding whether to get the vaccine, much of the discussion has shifted to questions about how to access the vaccine in their communities.
- <u>Safety, effectiveness, and duration.</u> Desire for information about the COVID-19 disease and vaccines mirrored all community conversations and centered on vaccine safety with a focus on understanding vaccine ingredients, emergent variants and vaccine effectiveness, duration of protection, and whether someone who has the vaccine could still pass the disease on to someone else.
- <u>Misinformation</u>. Raised in several meetings were questions about how the vaccine was made (compared to the flu vaccine), where there are fetal stem cells in the vaccine, whether those with egg allergies may have an adverse reaction to the vaccine, and views on what happened in Norway after several elderly persons died following vaccination.

**Potential Actions for Public Health and Partners:** Public health agencies should work to provide clear information about vaccination opportunities in Spanish and English. Public health, in coordination with trusted Spanish-speaking doctors (in meeting polling data indicated a doctor's recommendation was meaningful for the Latinx community) should provide information about safety, effectiveness, and duration, and seek to correct misinformation.

#### **Values and Lived Experience**

- <u>Cultural Values.</u> An important finding in Wave 1 was the extent to which the Latinx feel a responsibility to others in their community (Appendix Figure 2). This value remained a backdrop for community conversations.
- <u>Lived Experience</u>. In the majority of the Latinx Community Conversations there are strong, trusted relationships with local public health, local doctors, and others.

Appendix Figure 2: Responsibility to get Vaccinated to Protect Others in your Community,
Latinx Community Members, WAVE 1 (December 2020)



To what extent do you feel a responsibility to get the vaccine to protect others in your community?

**Potential Actions for Public Health and Partners:** Public health agencies should build upon the community value of responsibility toward others. Sharing information about the impact of following public health protocols and vaccination is likely to be helpful and support decision-making that is aligned with cultural values. Finding forums for the Latinx population to share their experience with COVID-19 vaccination will be meaningful.

#### **Supporting Decision-Making**

- Sharing realistic predictions visions about what is possible in terms of "back to normal" as communities have increased community immunity
- Spanish language materials and outreach
- Community-based experts from the medical and public health communities
- Real accounts from community members who have been vaccinated and can share their experiences with side effects
- Practical information about how to access and navigate the vaccination opportunities
- Continuing to share information about the issues of highest concern and what is known or not known at this time and when we might know more

**Potential Actions for Public Health and Partners:** Supporting decision-making is relatively straight forward for the many who have shifted toward interest in vaccination. For those who remain unsure, forums where community members can interact with Spanish-speaking local doctors and public health would help to support decision-making with information.

#### Implementation Considerations: Make It Easy.

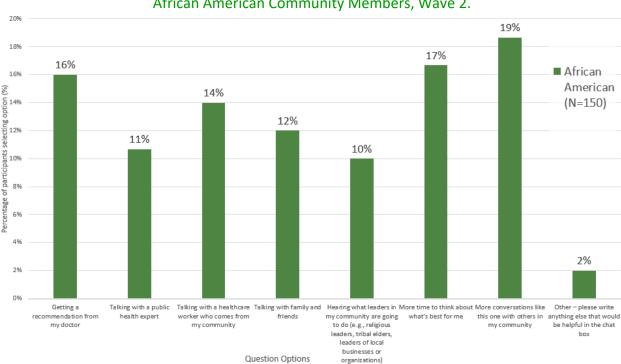
- Focus on equitable access
- Clearly share information about locations, that the vaccine is free, and whether there will be Spanish speaking assistance.

**Potential Actions for Public Health and Partners:** While Wave 2 Community Conversations explored if there were "show stoppers" that would lead participants to not get vaccinated, for many participants there was enough interest in getting the vaccine that they indicated they would overcome any barriers. Still, having multiple vaccination locations and requiring minimal personal data would ease logistical hurdles that might otherwise overwhelm those who remain undecided about getting vaccinated.

## **APPENDIX 2**

#### At-A-Glance: What We've Learned from African American Communities

African Americans in our community conversations cited a doctor's recommendation, needing more time to think about what's best for them; and more community conversations as ways to further support their decision-making (Appendix Figure 3).



Appendix Figure 3: Factors Beyond Information that is Helpful for Decision-Making,
African American Community Members, Wave 2.

Beyond information needs, what would be helpful to make a decision about getting vaccinated?

What has been Important from Wave 1 (December 2020) to Wave 2 (January/February 2021), as articulated in our community conversations.

- Information about vaccines (especially how they were developed so quickly, availability of safety data regarding side effects
- Information about the number and types of people who have been vaccinated (some cited comfort in seeing other African American receive vaccination while others felt it was most comforting to see White Americans of privilege receive it)
- Change in government leadership at the Federal Administration level has increased confidence for many in the community conversations
- Doing their own research and talking with doctors, healthcare workers, family, and others were also important factors

#### **Evolving Information Needs**

- <u>Evolving information needs.</u> Desire for information about COVID-19 and vaccines mirrored all
  community conversations and centered on vaccine safety issues (particularly regarding allergic
  reactions and unknown long-term effects), emergent variants and vaccine effectiveness, duration
  of protection, and whether someone who has the vaccine could still pass the disease onto
  someone else.
- Reactions with health conditions and medications. Given the high number of underlying health
  issues in the African American population, there is a desire to better understand how those with
  underlying health conditions (hypertension, diabetes, asthma, cancer, allergies and others) or
  those taking associated medications might experience vaccination side effects or impacts,
  especially in the long term.
- <u>Numbers and experience.</u> There is interest in understanding the number of African Americans who have received the vaccine and what their experiences have been. This is one of the most persuasive factors in the Black community's decision-making process; however, the precise number was subjective and varied by the person.
- Beyond vaccination. For those disinterested in vaccination at this time, there was a strong interest
  in knowing how else they might contribute to stopping the spread of disease, keeping themselves
  and others safe, and help improve the economy by getting people back to work.
- Questions regarding roll-out with an eye toward equity. There are emerging questions about how
  to get a vaccine; and questions about others "jumping the line" and whether their own community
  is disadvantaged when this happens.

**Potential Actions for Public Health and Partners:** Providing information that accurately shares what is known and not yet known remains important. To the extent public health is not a trusted source for information, partnering with knowledgeable community organizations will be helpful. Personal physicians, community-based "celebrity" physicians, and church leaders are trusted sources of information and safe spaces for open dialogue.

#### **Values and Lived Experience**

Historical context resulting in present-day consequences. Given the intentional abuse and neglect
of African Americans' health over the past 400 years, some see the vaccine as just the latest
attempt to further undermine their health. Some question why hypertension, heart disease, gun
violence, drug addiction and the other health and quality-of-life challenges that undermine the

Black community are not being addressed as zealously as the COVID-19 pandemic. For some, the more the vaccine is promoted, the more suspicion and anger it arouses.

- <u>Lived Experience.</u> Regardless of status, wealth, or education level, African Americans who express that they are experiencing pain following a medical intervention are often ignored or dismissed by medical professionals. The cases of Dr. Susan Moore<sup>3</sup> and Serena Williams<sup>4</sup> illustrate this point. In light of these cases, medical professionals must demonstrate they will respond to Black Americans in pain as attentively as they do to White Americans in pain.
- Historically, "establishment" systems have proven untrustworthy when it comes to equitable
  treatment of African Americans. Many established governmental systems (education, housing,
  healthcare research, criminal justice and many others) have not equitably served African
  Americans and thus distrust has been earned.

Potential Actions for Public Health and Partners: For some African Americans, the decision to get vaccinated may take more time than some might expect -- a lot more time, given their lived experience. Public health needs to exercise patience and find ways to demonstrate trustworthiness in the African American community. Three elements of trust<sup>5</sup> include: 1. Positive Relationships (do you "get" me, do you have my interests at heart?); 2. Good Judgment/Expertise (do you have demonstrated expertise on the issues that affect me most?); and 3. Consistency (can you be relied on, will you go above and beyond?). Public health authorities need to keep "showing up" and supporting the decision-making process (see below); there's a clear opportunity for public health authorities to demonstrate expertise and dedication to community health.

#### **Supporting Decision-Making**

- Safe platforms to talk to experts and each other. The most notable feature of the community conversations has been the safe platform they provide for participants to express perspectives, hear from others, and to evolve and change their views about the vaccines, if they choose to do so. Both those intending to and not intending to take the vaccine found satisfaction in learning more about it and discussing it with others. Churches were most often seen as the preferred venues for dialogue. Participants appreciated that the conversations were not conducted with the goal of inducing anyone to be vaccinated. Once the goal is perceived as a veiled attempt to promote vaccination, the value of the dialogue is severely compromised.
- <u>Support positive public health behaviors and decisions; beyond vaccination.</u> Whether enthusiastic or hesitant about vaccines; all the community conversation participants believed that the current public health protocols should be followed and, even, enforced. In some cases, "Wait and Learners" or "Unlikelys" in the meetings expressed interest in what other protective measures

<sup>&</sup>lt;sup>3</sup> https://www.nytimes.com/2020/12/23/us/susan-moore-black-doctor-indiana.html)

<sup>4</sup> https://www.nytimes.com/2018/01/11/sports/tennis/serena-williams-baby-vogue.html

<sup>&</sup>lt;sup>5</sup> https://hbr.org/2019/02/the-3-elements-of-trust

they could take, aside from being vaccinated. Public health should show encouragement and appreciation for the spectrum of activities that contribute to decreased disease rates, hospitalizations, and death.

**Potential Actions for Public Health and Partners:** Supporting decision-making does not mean only supporting those who decide to get vaccinated. It instead suggests that public health move from transactional interactions during the pandemic (shots in arms) to one focused on developing a trusted relationship where public health supports the timeframes, information requirements, and convenes and supports places for community members to discuss trade-offs as they consider whether vaccines are right for them at this time.

#### Implementation Considerations: Make It Easy.

**Potential Actions for Public Health and Partners:** Because many in the community were still in the process of decision-making, most of the dialogue focused there. Nonetheless, there were preferences mentioned:

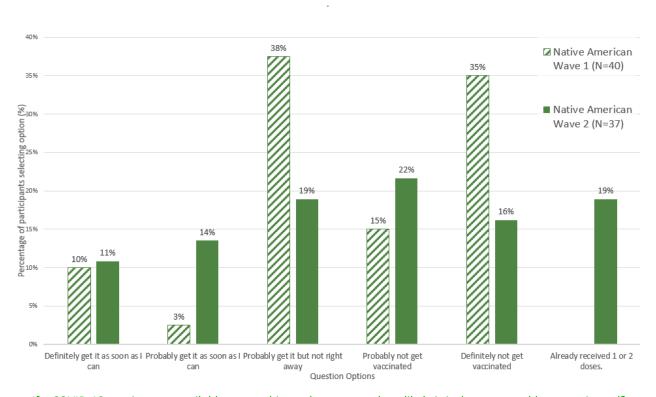
- <u>Convenient locations with a focus on equity</u>. For vaccination sites beyond a central government location, consideration should be made to having sites in neighborhoods and locations central to vulnerable communities to minimize the need to use public transportation.
- <u>Ensure equity in registration platforms.</u> Ensure registration options that account for different access to technology.
- <u>Safeguards against people "jumping the line."</u> Share the safeguards in place that prevent people from "jumping the line" and to what extent this is an issue.

## **APPENDIX 3**

#### At-A-Glance: What We've Learned in Native American Communities

There is considerable fluidity of decision-making from Wave 1 to Wave 2 as emerging information and local experience with the vaccines is considered (Appendix Figure 4).

#### Appendix Figure 4: Vaccine Intention by Wave in the Native American Community



If a COVID-19 vaccine was available to you this week at no cost, how likely is it that you would get vaccinated?

What has been Important from Wave 1 (December 2020) to Wave 2 (January/February 2021), as articulated in our community conversations.

- Seeing friends and relatives take the vaccine with no serious side effects
- Doing their own research
- Hearing from other tribes that have had similar historical experiences (resulting in distrust of the Federal government) and are also are experiencing severe COVID-19 outcomes (e.g. Navajo) and what they are deciding regarding vaccination
- Information about vaccines (especially the background of how it was developed, answering some concerns about apparent quick rollout safety data regarding side effects)
- Information about the number and types of people who have been vaccinated

- Change in Federal Administration leadership has increased confidence for many in the conversations
- Roll-out at local levels has been somewhat smooth<sup>6</sup> though issue of "no-shows" for vaccine
  appointments can lead to a chain of problematic issues as health services scrambling to find last
  minute interest so doses are not wasted.

#### **Evolving Information Needs**

- Evolving information needs. Desire for information about the COVID-19 disease and vaccines mirrored all community conversations and centered on vaccine safety issues, vaccine ingredients, emergent variants and vaccine effectiveness for those variants, duration of protection, and whether someone who has the vaccine could still pass the disease onto someone else. Specific to Native American community conversations was higher concern for short-term expected side effects, allergic reactions, and any potential for unknown long-terms impacts.
- Reactions with health conditions and medications. Given the high number of underlying health issues experienced in the Native American population, there is a desire to better understand how those with underlying health conditions (hypertension, diabetes, asthma, cancer, allergies and others) or taking medications associated with those conditions might experience vaccination side effects or impacts, especially in the long term.
- Numbers and experience. While some found it important to know that millions have now been vaccinated, there is an evolved interest in understanding the numbers and experience of Native Americans. While there is interest in understanding Native American experience overall, people also specifically wanted local information for their tribe and on people they know. They wanted to know the number of people within the tribe who have received the vaccine and possible side effects.
- Beyond vaccination. For some, who do not intend to get a vaccine at this time (or perhaps ever)
  there is an interest in knowing how else they might keep themselves healthy, contribute to
  stopping the spread of disease, and keep others safe. There is particular interest in the
  effectiveness of natural vitamins and supplements.

Potential Actions for Tribal Public Health and Partners: Providing information that accurately shares what is known and not yet known remains important, especially in local tribes. With the recognition that Native American experience and personal accounts is most important, look for opportunities for community members to share their experiences. Pairing community members with local tribal health officials who can answer questions would further support decision-making. There may be the potential for tribe-to-tribe communication and feedback sessions for those tribes that may have more experience because they were

<sup>&</sup>lt;sup>6</sup> Tribes are racing ahead of vaccination curve (indiancountrytoday.com)

engaged in clinical trials or received early doses. Caution will be necessary to protect information that a tribe may want to keep confidential about their experience with the disease and the vaccination.

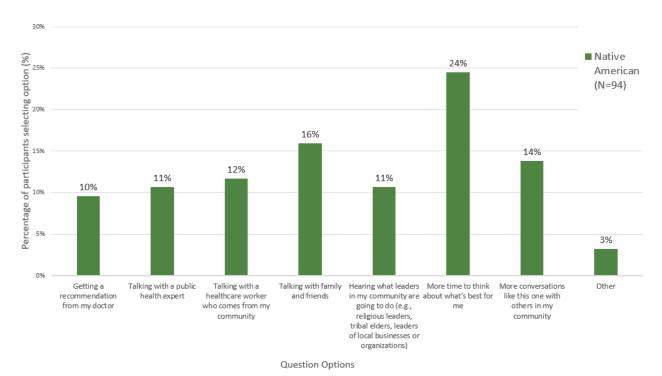
#### **Values and Lived Experience**

- <u>Historical context resulting in present-day consequences.</u> Historical abuse and neglect of Native Americans have left indelible marks on tribes throughout the U.S.; infectious disease have additional meaning for tribes given experiences with smallpox blankets (and other infectious diseases); and inadequate healthcare systems across Indian Country has led to Native Americans disproportionately experiencing the pandemic.
- <u>Values the Long Look.</u> In contrast with other vulnerable communities, Native community conversations approached the pandemic and the consequences of vaccines with a multigenerational lens. There were concerns about protecting elders, (the keepers of the language and culture) and future unborn babies (the future of the tribe). In both cases the trade-offs of the severity of the disease were weighed against any potential unknown long-term effects of the vaccine.
- <u>Values Family.</u> The tight weave of the family features importantly in the Native American community conversations. Wanting to protect elders, recognizing the interconnectedness of families and tribal members, and culturally important rituals have been challenging for individuals, families and communities throughout the pandemic.
- <u>Lived experience Scarcity.</u> The issue of jealousy and scarcity was raised as a result of traumatic historical experiences in trying to survive on handouts from the government; the resulting trauma from trying to survive these events are still painful memories for some tribe members. There was discussion that this lived experience results in carefully watching equity-related access issues in the roll-out of vaccines, who is prioritized, and putting a high value on things not available yet, in this case vaccines.

Potential Actions for Tribal Public Health and Partners: For some Native Americans, the decision to get vaccinated may take more time than some might expect given their lived experience. The extent to which roll-out approaches tend to select elders (determined by both age and roles as guardians of cultural knowledge and language) to get vaccinated first honors and acknowledges how much is at stake for tribal communities. Ensuring that there is transparency about eligible categories and equitable access to vaccines is also important to building trust. Local health services can support decision-making processes (Appendix Figure 5) and recognize the contextual backdrop that is informing decisions.

#### **Supporting Decision-Making**

Appendix Figure 5: Factors Beyond Information that is Helpful for Decision-Making,
Native American Community Members, Wave 2.



Beyond information needs, what would be helpful to make a decision about getting vaccinated?

- Safe platforms to talk to experts and each other. The most notable feature of the community conversations has been the safe platform they provide for participants to evolve and change their views about COVID-19 vaccines. Both those intending to and not intending to take the vaccine found satisfaction in learning more about it and discussing it with others. There is an appreciation of dialogue regardless of a person's intent to take the vaccine.
- Support positive public health behaviors and decisions beyond vaccination. Whether enthusiastic or hesitant about vaccines; all the community conversation participants believed that the current public health protocols should be followed and, even, enforced. In some cases, "Wait & Learners" or "Unlikelys" in the meetings expressed interest in what other protective measures they could take, aside from being vaccinated. Local tribal health should show encouragement and appreciation for the spectrum of activities that contribute to decreased disease rates, hospitalizations, and death. To the extent it's possible to have coordinated messaging on both tribal land and in the "border towns," this creates more consistency with better public health outcomes.

Potential Actions for Tribal Public Health and Partners: Supporting decision-making does not mean only supporting those who decide to get vaccinated. It instead suggests that those entities involved in public health move from transactional interactions during the pandemic ("shots in arms") to one focused on developing a trusted relationship where public health supports the timeframes, information requirements, and convenes and supports places for community members to discuss trade-offs as they consider whether vaccines are right for them at this time. Given the importance of sharing local experiences with the vaccination; it may be helpful to set up virtual conversations with tribal leaders, elders, and other members of the community who can share more about their decision-making (what were the trade-offs as they thought about whether to get vaccinated; any research they did for themselves; and what, if any, side effects they have experienced). The ability for families to attend these sessions together and then to have break-out conversations with their family members (or are encouraged to do this afterward) would be responsive to the polling data in our community conversations that indicated that "more time" and "time to discuss this with family and friends" would be helpful.

#### Implementation Considerations: Make It Easy.

**Potential Actions for Tribal Public Health and Partners:** Many indicated that the vaccination roll-outs were going relatively well in their communities. However, some suggestions were made.

- <u>Make it Easy, especially for elders.</u> Door to door or mobile units for those unable or uncomfortable traveling to a central location.
- Ensure equity in registration platforms. Ensure there are registration options that account for different access and competencies regarding technology. Rural tribal communities often do not have access to reliable wifi and therefore there needs to be alternatives to online registration.
- <u>Culturally appropriate educational materials.</u> Materials focused on information needs outlined above.
- <u>Safeguards against people "jumping the line" and what happens if people miss their appointments.</u> Share the safeguards in place that prevent people from "jumping the line" and to what extent this is an issue. Indicate what happens to the vaccine if people make an appointment and then do not show up at the scheduled time.
- Be clear about what is the next opportunity if someone is not ready right now. Given the number
  of people who have moved from "definitely not getting vaccinated" to "probably get it, but not
  right away" local agencies will want ways to check back in and let them know about future
  opportunities.