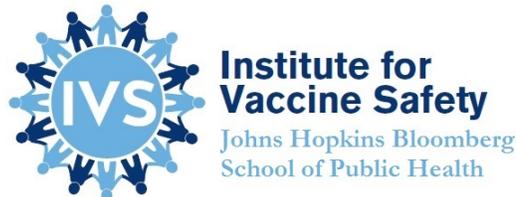


Understanding Diverse Communities and Supporting Equitable and Informed COVID-19 Vaccination Decision-Making



Findings from Wave 3

With support from the Robert Wood Johnson Foundation and Horizon Foundation

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

Findings from Wave 3 (May 1-22, 2021)

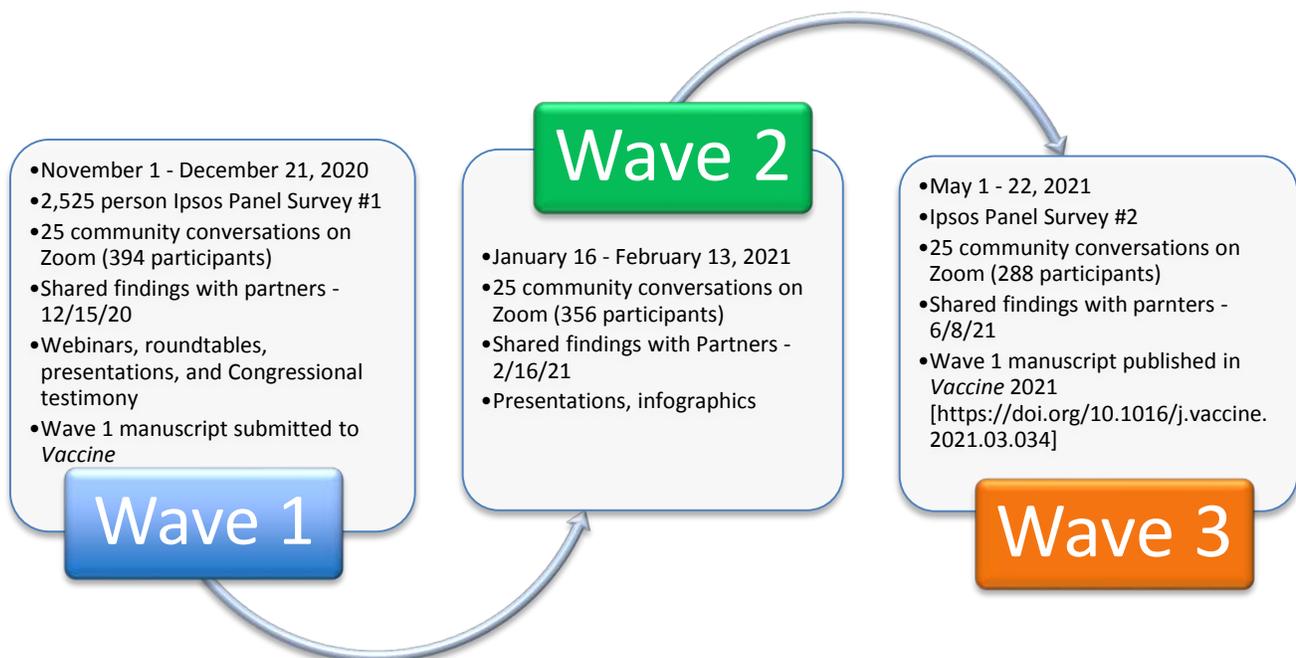
Project Overview: This project, supported by the Robert Wood Johnson Foundation and the Horizon Foundation, is focused on how public health and other stakeholders can best understand and support decision-making as individuals consider if and under what conditions COVID-19 vaccination is right for them. 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 July 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/Tribal health and immunization programs must meet their needs.

“Local is incredibly important. Respecting people’s decision-making process is very important, that people are not just cogs in a machine,” Mr. Slavitt said. “You can’t just say, ‘I want to fully process x number of people in a given day.’ You have to respect the fact that people have decision-making processes that are unique to them.”

-- Andy Slavitt, a White House Pandemic Adviser, New York Times, May 16, 2021

In Wave Three (May 1 - 22, 2021), we returned to the same individuals who participated in the first two waves to engage in a third set of conversations to understand what has changed for them, and whether or how these changes influenced their decision-making (Figure 1).

Figure 1: Project Waves 1-3 Methods and Timeline

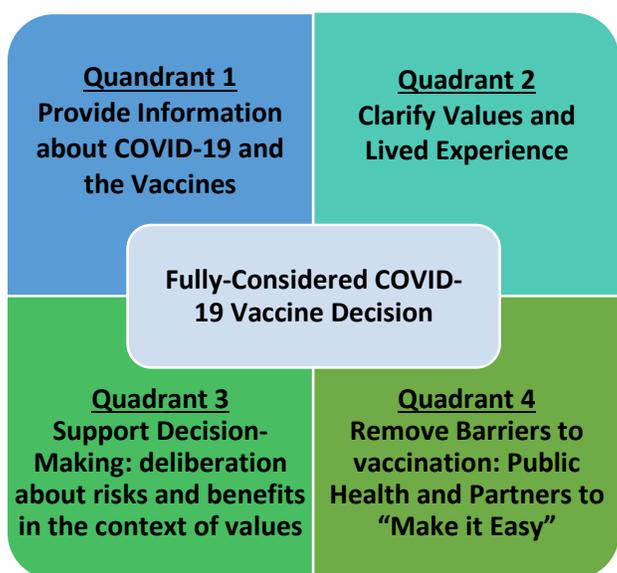


Project Perspective: This project is centered on what underpins decision-making to inform strategies that serve communities based on their experiences, perspectives, and needs. The opportunities below extend

beyond messaging focused on promoting vaccination to include engagement and supporting decision-making. The project aims to assist people in diverse communities with varying needs as they make decisions about the COVID-19 vaccination 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 the COVID-19 vaccination.

Waves 1 and 2: Moving beyond “Informed Decision-Making”¹ to a “Fully-Considered COVID-19 Vaccine Decision.” During Wave 2, with perspectives from Wave 1, we developed a framework for illustrating the decision-making factors at play for our community conversation participants, which extend beyond informed decision-making. A fully-considered COVID-19 vaccine 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**). Figure 2 illustrates the framework, along with roles that public/Tribal health and individuals have in respectively supporting and reaching a fully-considered COVID-19 vaccine decision.

Figure 2. Roles in a Fully-Considered COVID-19 Vaccine Decision



Quadrants	Public/Tribal Health Roles	Individual Roles
1	Provide information Tailor to communities, as requested	Process information about both COVID-19 disease and the vaccines available
2	Seek to understand and support without judgment	Share values and lived experience
3	Support deliberation and dialogue	Weigh values Deliberate risks and benefits
4	Remove barriers to vaccination	Communicate about barriers to vaccination

Wave 3: A Fully-Considered Decision with a Focus on Better Understanding Quadrant 3. After Waves 1 and 2, the project team felt it had a better understanding of quadrants 1, 2, 4, and less of an understanding of quadrant 3. Therefore, in Wave 3, while we asked questions pertinent to all quadrants, we focused particularly on better understanding elements of quadrant 3.

Wave 3 Community Conversations Focused on:

Quadrant 1: How have information needs evolved over the course of three additional months?

Quadrant 2: In what ways were values and lived experience pivotal in decision-making? Did vulnerable communities feel a focus on them and did that focus on equity feel appropriate and long overdue? Was it welcome or unwelcome?

Quadrant 3: What did people do to help themselves make a decision? Are there ways that public health could better support decision-making, for both COVID-19 vaccination and future public health issues?

Quadrant 4: With moving from vaccine scarcity to plentiful supply, how might public health evolve its approaches to “make it easy” and convenient for those interested in being vaccinated?

Context for COVID-19 Vaccination Decision-Making and Community Conversations:

Figure 3: Timeline of Notable Milestones Surrounding Wave 3 Community Conversations (May 1-21, 2021)

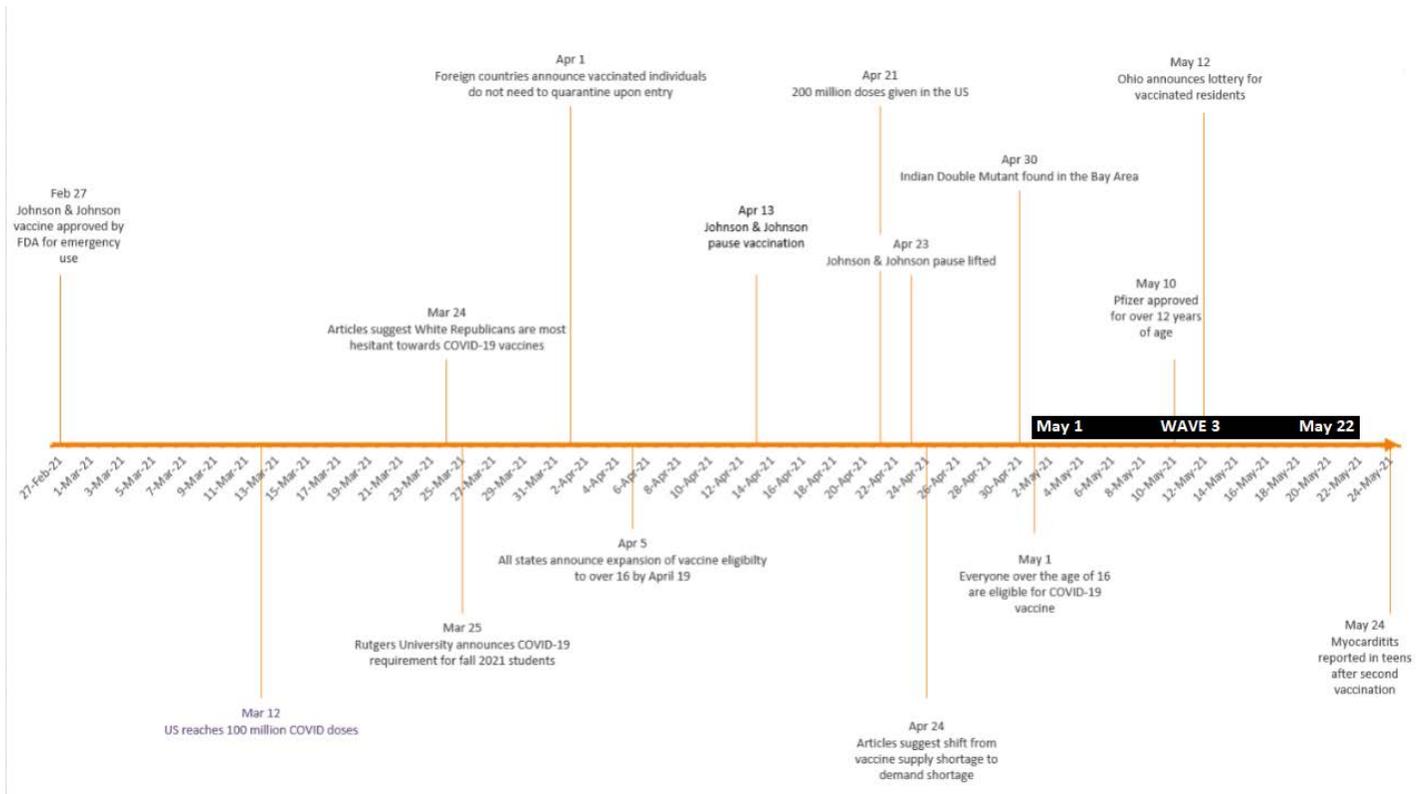


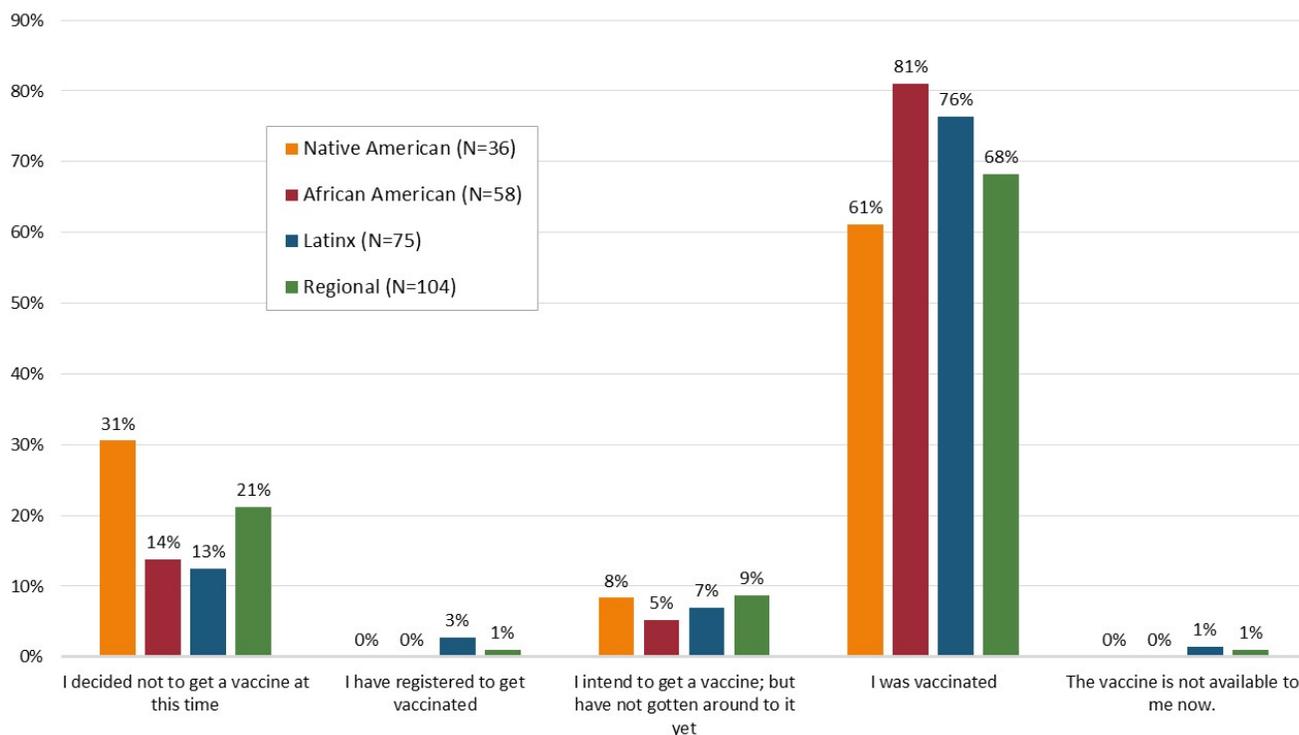
Table 1: Community Meeting Population by Number of Meetings, Wave, and Retention Rate

Population	Number of Meetings	Wave 1	Wave 2	Wave 3	Retention (%)*
Regional	2 Northeast	39	38	31	79%
	2 South	33	33	25	76%
	2 West	36	31	26	72%
	2 Midwest	38	31	27	71%
African American	2 Baltimore City, MD	24	24	20	83%
	2 New Orleans, LA	24	24	20	83%
	1 Howard County, MD	23	21	20	87%
Latinx	2 Garfield County, CO	34	27	30	88%
	2 Harris County, TX	25	25	19	76%
	2 Fairfax, VA	31	24	22	71%
	1 Howard County, MD	23	21	19	83%
Native American	2 Northern Plains Tribe, MT	26	22	17	65%
	2 Great Plains Tribe, ND	22	18	19	86%
Asian American	1 Howard County, MD	16	17	15	94%
TOTALS	25 Meetings	394	356	310	79%

* Retention between Wave 1 and Wave 3

About the Key Findings and Opportunities: The following findings represent a snapshot of themes in a rapidly changing environment. The opportunities identified are considerations for public/Tribal health implementation, recognizing 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 to foster equitable COVID-19 vaccination uptake.

Figure 4: COVID-19 vaccination status and intent by community, May 1-22, 2021



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 June 2021.

Noteworthy: Most have made a decision by Wave 3 (May 1-22, 2021).

12 Findings Across Regional Meetings of Vaccine Heisitent & Vulnerable Communities, Conversations from Wave 2 to Wave 3.

Current Status of COVID-19 Vaccine Decision-Making In Community Conversations

- 1. Decision-making was “in process” for months; now most have made a decision – overall 72% vaccinated.** There was a great deal of deliberation from December through April as individuals and communities were weighing information, cultural and lived experience, and issues of vaccine accessibility in their decision-making. However, with vaccine eligibility expanding to every adult in the United States by the end of April 2021; most have made their decision and gotten vaccinated.
- 2. High satisfaction with their decision - whether to get vaccinated or not.** For those who chose to get vaccinated, there was an overall positive attitude toward the decision, further reinforced by family and friends. For those choosing not to get vaccinated, they felt equally satisfied with their decision.

Potential Considerations for Public/Tribal Health: In some cases, access issues remain and every effort should be made to increase convenience and support such as not needing an appointment, paid time off for missing work due to side effects, etc. In other cases, approaches may need to be modified since decisions have been made to refuse vaccine (and people are highly satisfied with that decision) -- and it is likely more difficult to change a mind than to support people in the process of decision-making. This, in combination with decreasing disease rates, will further challenge vaccination programs. On the otherhand, given the continued evolving landscape of science and issues (e.g., variants, vaccines eligibility expanding to include people ages 12-15), people are likely re-visiting their decision-making as information evolves about the vaccines and disease, as they talk to more people, and as they make decisions about what they want to do in the coming year such as travel, visit family, etc). Furthermore, as many community conversation participants indicated in Wave 1 that they would (1) probably get it but not right away; (2) probably not get vaccinated; or (3) definitely not get vaccinated, it is important for public/Tribal public health to deepen its understanding of the nuanced, decision-making journey people made that ultimately led them to getting vaccinated.

Critical Factors For Decision-Making

- 3. Conversations with family, friends, and their own research.** Hearing from family and friends about their largely very positive vaccine experiences and acquiring more factual information from a variety of sources (e.g. tv, radio, online, podcasts) were very important to decision-making. Continued circulation of misinformation was influential in some communities and led to some choosing not to get vaccinated.

4. **A strong desire to return to normal life.** For some, a desire to return to normal life was central to their decision-making. Others described it as a benefit once vaccinated. However, concerns about the lack of adequate herd immunity have created uncertainty about what the near-term future will look like and doubts that life will return to the same conditions that prevailed before the pandemic. Many (including those vaccinated) felt that continued mask use and social distancing would be a part of the “new normal.”
5. **Plentiful vaccine supply and easier access had tipped fence-sitters toward vaccination.** The vaccine availability itself created a momentum in favor of vaccination. Put another way, barriers created a negative momentum and availability a positive one.

Potential Considerations for Public/Tribal Health: It is important to note that these critical factors for decision-making in Wave 3 are different than in previous waves where information about the disease, vaccine development, vaccine safety, numbers of people who have safely taken the vaccine from different communities, historical context, and lived experience all featured more prominently. While these remained important issues in current decision-making processes, the prominence of personal conversations, progress toward a “new normal”, and abundant vaccine availability during Wave 3 perhaps signals what was influential or tipped a person one way or another toward the end of their decision-making. Based on this:

- *Encourage unvaccinated people to talk with family and friends who have been vaccinated and share their journey to decision-making (not just the end result) might be helpful to a person’s decision-making. Developing materials that assist vaccinated people in having those conversations with family and friends could provide added support.*
 - *Encourage getting back to normal or a “new normal” without worry - visions of family get-togethers, being in church, vacations, and other pre-pandemic activities might also be a consideration for some as we head toward summer.*
 - *“Make it Easy” - having vaccines available where people are (worksites, entertainment sites, schools, and other locations where people congregate in their communities) during times when they are present, without lines or the need of an appointment, and opportunistically offering the vaccine to those who are bringing others to appointments has made it easier for people to consider vaccination in real-time.*
-

- *Hold public health or Tribal leadership forums, in collaboration with community-based organizations (CBOs), that offer tailored information. For tribes or other specific communities, COVID-19 data could be provided on vaccinations, infections, hospitalizations, and deaths. Additionally, host a “state of the science” introduction with break-out conversations for focused topics such as pregnancy and fertility, disabilities, other underlying conditions, distinct needs of refugees and immigrants. Team with community stakeholders (e.g., parenting groups, interest-specific associations, or other non-governmental associations) to host topic-specific engagements.*
-

Specific To Vulnerable Communities

- 6. “Lived Experience” was shaped during the pandemic and participants improvements in vaccination rollout efforts.** The early days of the pandemic and the disproportionate impact of COVID-19 hospitalizations and deaths on the Latinx, African American, and Native American populations had been indelible and traumatizing in some cases. As vaccines rolled out there were frustrations regarding registration, lack of linguistically- and culturally-appropriate materials, perception of people “jumping the line,” lack accessibility without public transportation, and other issues. Despite those circumstances, many indicated that course corrections were made in the process of the rollout that led to more available linguistically- and culturally-appropriate materials; mobile vaccination clinics that did not require people to travel by public transportation; CBOs that assisted community members with registration; and special care and prioritizing of Native American elders. A majority of community conversation participants from the Latinx, African American, and Native American communities were vaccinated and indicated they felt good about their decision.

In general, members of each vulnerable community were aware that the pandemic had created an opportunity for others to better understand the origins of distrust grounded in history and present-day experiences; and the disproportionate impact of COVID-19 on vulnerable communities due to systemic racism and resulting health disparities. There was skepticism that the focus would continue after the pandemic ends, but openness to how public health might work together on other issues that result in health disparities in vulnerable communities.

Potential Considerations for Public/Tribal Health: Findings and advice to public/Tribal health specific to Latinx, African American, and Native American communities are available in At-A-Glance documents.

Future Decision-Making Regarding COVID-19 Vaccination

- 7. Information needs continue to evolve for everyone – whether vaccinated or unvaccinated.** There was high interest in a diversity of topics, including: variants and implications for vaccine effectiveness; whether vaccinated people can spread the disease to those not vaccinated; the Johnson & Johnson vaccine and its side effects; whether there will be an annual COVID-19 vaccine shot; and COVID-19 vaccines for children. Persistent questions remain regarding if any unknown long-term side effects of

vaccination remain, including impacts on fertility. Concerns about safety related to more general topics such as the speed of vaccine development have diminished.

- 8. Increased attention on children with different information needs.** With vaccine eligibility expanding to all adults; the focus on decision-making, particularly among parents, has increasingly turned toward children. There were two specific areas of interest: (1) how effective and safe will the vaccine(s) be for children, and (2) what has been and will be the continued impact of students not being in school? A desire to have students back in school for the purposes of educational growth and mental health was central to many conversations about children. It was clear that a parent's decision to get vaccinated did not necessarily lead to the same decision to vaccinate their child. Adults cited that decisions for their children were different because children were inherently different. Participants indicated that children were (1) not at the same risk of hospitalization and death as adults; (2) different biologically and may consequently react differently to a vaccine; and (3) had a longer life ahead of them, particularly with specific considerations such as fertility.
- 9. Those "waiting and learning" or declining vaccination had specific questions, concerns, or worldviews.** There were particular concerns about the safety of the vaccine for people with specific circumstances such as pre-existing conditions, allergies, and pregnancy. Some people had heard about side effects that led to lost work and the risk of not working led them to decide against vaccination. Some also shared that they were generally against medical interventions and their excellent health, along with commitment to public health behaviors (i.e., masking and social distancing), would likely prevent them from suffering severely from COVID-19.
- 10. Those vaccinated for COVID-19 are predisposed to getting one yearly, if necessary.** Many suggested they were amenable to the COVID-19 vaccine becoming an annual vaccine; others were non-committal.
- 11. No spillover effect to how people think about routine vaccines.** Learning and thinking about COVID-19 vaccines over the past several months has not changed the attitudes of participants about other available vaccines. If they were favorable toward other vaccines, they remained favorable; if they were not interested in other routine vaccines, that also did not change.
- 12. Some support showing proof of vaccination but doubt it could be implemented successfully.** There is support for different forms of proof of vaccination; however, practical challenges led people to doubt it would be successfully implemented. Many participants expressed interest and support for using proof of vaccination as a reward for vaccinees and an incentive for unvaccinated persons to get vaccinated. However, discussion centered more on the anticipated challenges of implementing any mandates or requirements such as falsified documents, privacy invasion, and further division among highly-polarized perspectives and individuals.

Potential Considerations for Public/Tribal Health: For those who have made a decision about vaccination and for those who have not – questions persist and are evolving. Public/Tribal Health should:

- Focus on emerging issues such as: variants and effectiveness of vaccines; potential for an annual COVID-19 vaccine; and vaccines becoming available for children.
- Continue to attend to both those vaccinated and not. Among those vaccinated, some can be key partners, collaborators, and ambassadors for public/Tribal. For those unvaccinated, they continue to reassess choices with additional changes to matters such as further clarification for those with pre-existing conditions, disease rates, and vaccine safety.

Beyond the Pandemic - Future Focused Recommendations

The years 2020 and 2021 will forever link a global pandemic, a social justice movement recognizing continued systemic racism, and unprecedented polarization and political unrest in the United States. In this context, Wave 1 and 2 conversations about vaccine decision-making inevitably and necessarily led to participants sharing perspectives on health disparities, systemic racism, historical trauma, access to healthcare, and a lack of civility and place for respectful dialogue.

“The pandemic has created an opportunity to engage with communities of color, and more intentionally explore what it will take to build trust more generally.”

As noted previously, challenges that public health has faced with capacity, politicization of the response, and varying public trust meant that collaboration with community-based organizations has been important in supporting community needs. These collaborations are critical practices and should continue or expand, recognizing that community-based organizations are deeply immersed in the needs and challenges of different groups such as refugees, immigrants, church congregations, people with disabilities, and others. In coordination with public health, there was interest in exploring what might be possible and of interest outside of pandemic circumstances.

--Dr. Ben Schwartz.
Fairfax County (VA)
Health Department

With this in mind, in Wave 3 we asked questions about the preferred role of public health as it pertains to sharing information, expertise, and engaging communities in problem-solving on other public health issues.

Findings for Beyond the Pandemic

1. **Vulnerable Communities are open to future, well-intentioned, inclusive efforts focused on health equity; but they are not expecting it.** Latinx, African American, and Native American communities had various levels of awareness about the focus on equitable access to vaccination for their racial and ethnic groups. Some indicated that, while the attention and focus was very welcome, given the disproportionate impact of COVID-19 on their communities, there was little to no confidence that the effort and attention would remain after the pandemic subsides. Many in each community suggested that there were a host of other public health issues that were important to communities and could use this type of focused attention, such as chronic disease; gun violence; drug abuse; suicide; mental health; and other areas.
2. **Role of Public/Tribal Health.** Participants welcomed the following actions from public/Tribal health:
 - **Reconcile conflicting information emanating from different sources.** Public health officials are being called upon to meet this challenge. The importance of hearing consistent information was highlighted because of its value in reassuring the public and building trust in any program is being

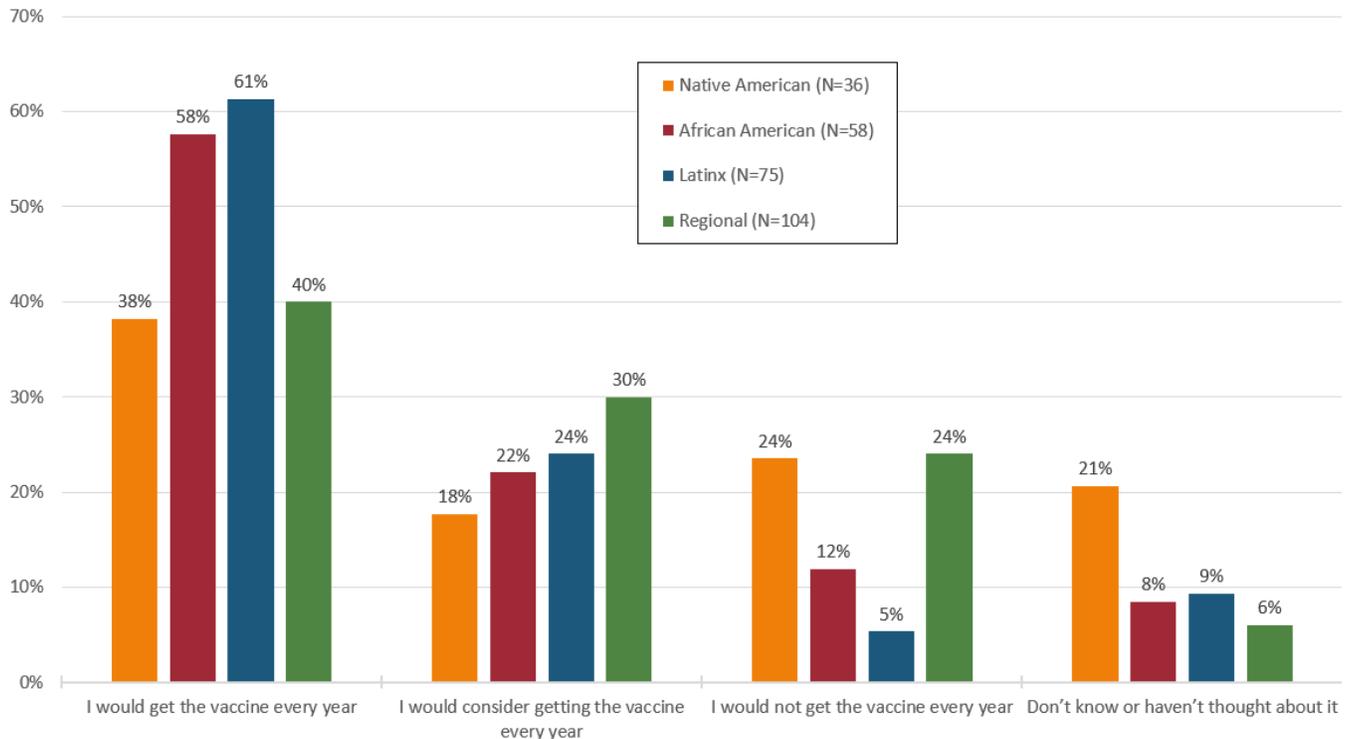
conducted. There was appreciation for public health sharing information without an intention to persuade.

- **Raise awareness that community health is everyone's responsibility.** The pandemic and its intersection with the social justice movement has made clear society's interconnectedness and our impact on each other. There is support for having public health, in collaboration with community partners, continue to share information regarding our interconnectedness on issues in the public health domain, and the responsibilities that fall to individuals in communities that care for each other.
- **Share information without focussing on persuasion or behavior change.** Participants wanted safe spaces to deliberate, talk with experts, and ultimately not be judged for decision-making where personal or community values might be weighed differently than those focused on population health.
- **Involve the public in identifying problems and potential solutions before crises appear.** Communities indicated a preference for having a relationship with public health and other partners in advance of crises. Vulnerable communities were interested in being engaged on public health issues of importance to them; and being engaged in identifying problems, as well as solutions. Working on public health issues collaboratively would create circumstances where black, Indigenous, and people of color (BIPOC) communities and public/Tribal health could demonstrate trustworthiness to each other while solving problems. These platforms and relationships would further serve communities in future crises.
- **Create places (online, in-person) for exchanging information and deliberating with others.** Forums for sharing accurate, factual information and learning through dialogue from peers and public health professionals but without being unduly influenced.

APPENDIX 1

At-A-Glance: What We've Learned in Latinx Communities - Wave 3

Figure 9: What are your thoughts about the COVID-19 vaccine if it becomes a yearly vaccine?



Noteworthy: The Latinx community is open to the potential of COVID-19 requiring an annual vaccine.

Overview – What has been important in Wave 3 (May 2021), as articulated in community conversations

- Protecting others and getting back to normal was important
- Misinformation about the vaccines was prevalent (more than in other communities where our conversations occurred)
- Questions remain about side effects, especially allergies, and long-term effects
- Increased availability and access to vaccine has helped, especially extended clinic hours
- Important barriers to vaccination are: a lack of access to healthcare and health insurance, concern about hidden costs, and the risk that side effects could lead to missing work and losing income
- Given many are recent immigrants (first or second generation), there is an appreciation and understanding of the privilege of free, widely available vaccine, afforded to everyone in the United States

Evolving Information Needs

- **Misinformation.** More extensively than in other communities, there is a great deal of misinformation about: vaccines, side effects (or deaths), and whether the government is using

vaccines as a platform to trace people, especially undocumented workers (through paperwork or microchips).

- **Specific conditions and their intersection with the vaccine.** Those who remain unvaccinated for health-related reasons often had specific questions regarding interactions with conditions such as diabetes or pregnancy.
- **How to best manage evolving social configurations.** Given cultural tendencies toward large group gatherings and a recognition that individual decisions impact others, there were questions about how to understand who's been vaccinated, how to safely be together, and how to ask questions that respect personal choice.

Values and Lived Experience

- **Cultural Values.** An important finding in Waves 1 and 2 was the extent to which Latinx individuals feel a responsibility to others in their community. This value remained a backdrop for community conversations.
- **Lived Experience.** In the majority of the Latinx community conversations there are strong, trusted relationships with local public health, local doctors, and others. Some mentioned that this differed strongly from some of the countries they emigrated from where trusting government is not a given.

Potential Actions: Local public health agencies should work to combat misinformation, particularly on social media. Vaccinated individuals could serve as information ambassadors who can help clarify misinformation. Finding ways for unvaccinated individuals to have conversations about their medical conditions and concerns about vaccine interactions will be important to some who are hesitant now. Lastly, public health could help develop culturally appropriate ways for people to approach sensitive conversations about vaccination status and the safety of convening large groups.

Supporting Decision-Making

- **Talking with others.** Conversations with others who have been vaccinated has been important.
- **Easy access has served to trigger decision-making for those who were unclear.** After-hour and easy access to vaccination sites has supported decision-making by removing a remaining barrier.
- **Focus on children and annual vaccines.** With increased focus on children getting vaccinated against COVID-19 and the potential for annual boosters, there are new decisions that need support from public health and medical experts.

Potential Actions: Supporting decision-making is relatively straightforward for many who have interest in vaccination. A number of emerging questions will need support. Many in the Latinx community conversations suggested a focus on health literacy education and on partnering with school systems.

Implementation Considerations: Make It Easy

- **Easy access has mattered.** Focused outreach by zip codes, access in super markets, at workplaces, etc. have all been helpful.
- **Transparency about the vaccination experience.** There remain questions about the mechanics of getting vaccinated. Sharing information about locations, that the vaccine is free, what type of personal information will be collected, and whether there will be Spanish-speaking assistance remain important.

Potential Actions: Multiple vaccination locations, open outside of standard work hours and requiring minimal personal data would ease logistical hurdles that might otherwise overwhelm fence-sitters. Focused efforts that go to the Latinx community instead of expecting them to come to a central location, have been successful and could be expanded.

About the Future

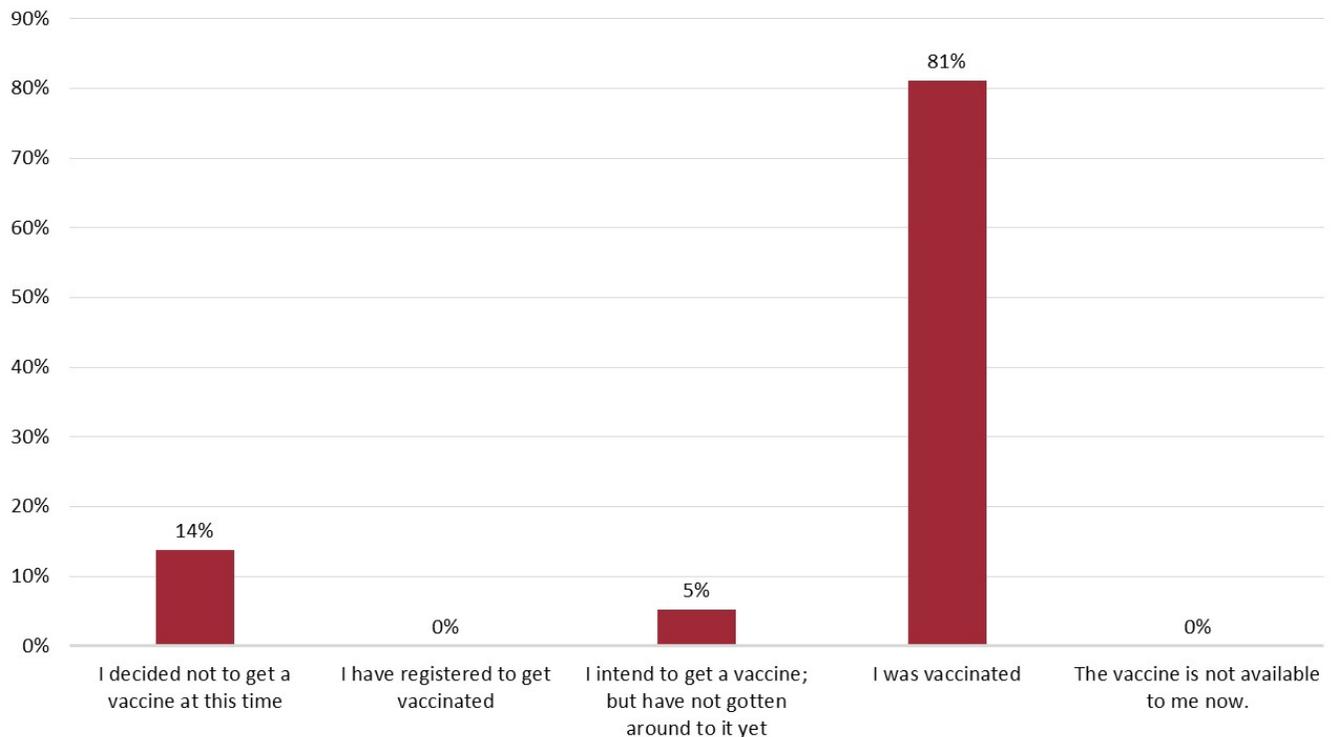
- **There is interest in well-intentioned, inclusive efforts focused on health equity.** Many in each community suggested that there were a host of other important public health issues that would benefit from the focused attention, such as: chronic disease; gun violence; drug abuse; suicide; mental health; and others. While members of the community conversations were open to (and in some cases hopeful about) collaborative efforts focused on other public health issues; there was little to no confidence that the effort and attention would remain after the pandemic subsides.

Potential Actions: To the extent there is interest and capacity, public health can build on the relationships and goodwill developed during the pandemic and bridge to other public health issues collaboratively identified by Latinx communities. Ongoing efforts would further establish working relationships where trustworthiness can be demonstrated to each other in the process of working on issues pertaining to health equity.

APPENDIX 2

At-A-Glance: What We've Learned from African American Communities - Wave 3

Figure 5: What is your current COVID-19 vaccination status?



Noteworthy: By Wave 3, the vast majority of African Americans had been vaccinated.

This varied significantly from Wave 1 where 54% of African Americans stated their intention to potentially get vaccinated at some point. See all three wave reports to better understand the evolution of their decision-making.

Overview – What has been important in Wave 3 (May 2021), as articulated in community conversations

- Seeing friends and relatives take the vaccine with no serious side effects
- Talking to family and friends (and for many, God), along with doing their own research
- Seeing a matriarch or patriarch that chose to get vaccinated and became advocates for vaccination
- Getting the vaccine for free
- Wanting to get back to life, back to normal
- In some cases, seeing people with similar values, historical context, and lived experience decide to vaccinate.
- Seeing the issue of stigma starting to emerge (i.e., how will I be treated by my community if I am unvaccinated?)

Those who refused vaccine or had lingering concerns about vaccination fell into three main categories:

- Proudful, healthy individuals who consider vaccines a “medical intervention” (i.e., “why risk having a side effect from a vaccine when I am a perfectly healthy...” or, “if I were to contract COVID-19, I’ll survive it, because of my good health...”)
- Those who were distrustful of the government and pharma or feared the medical establishment might not take them seriously if they fell ill from the vaccine
- Those who have specific medical conditions and worry about reactions with the vaccine or those with on-going concerns about side effects – long-term and short-term

Noteworthy: *In some cases, not all had decided against vaccination; some had just not gotten around to getting it yet.*

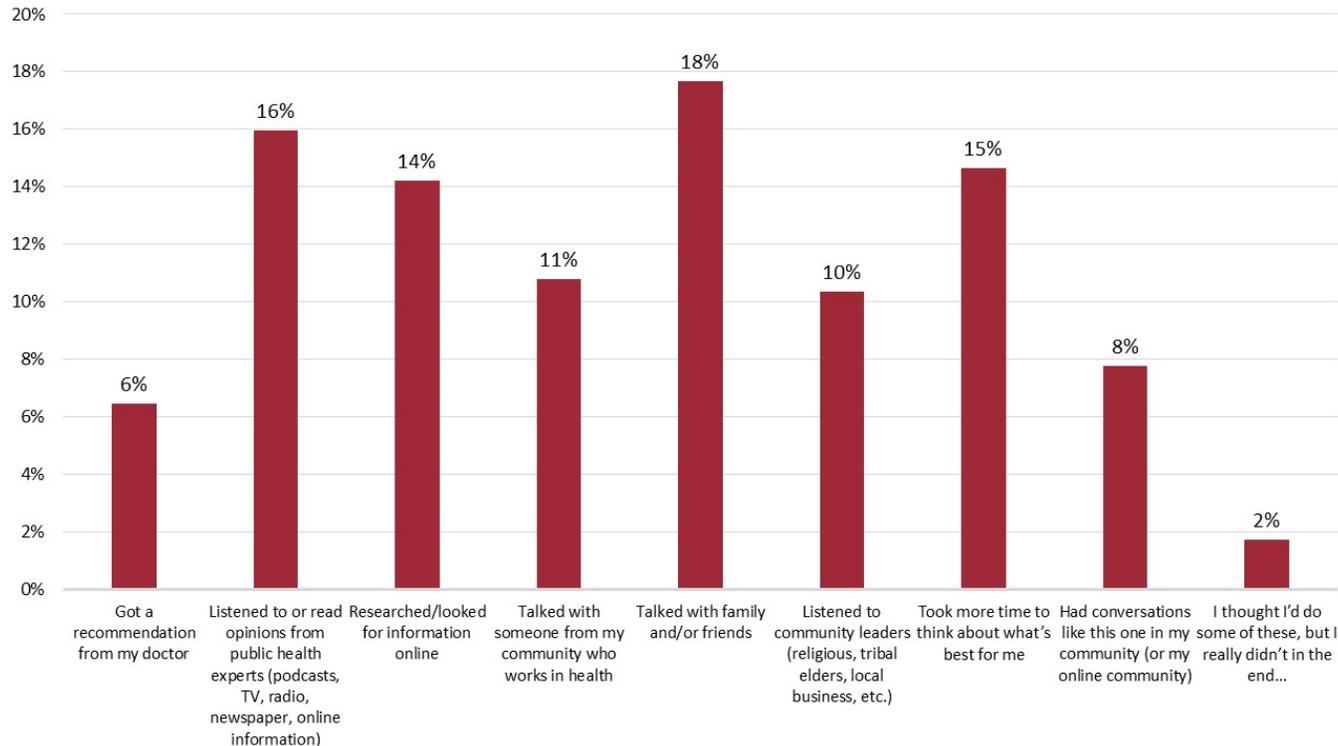
Evolving Information Needs

- **Vaccine Updates.** Remaining questions centered on COVID-19 variants, their impact on vaccine effectiveness, concerns about the Johnson & Johnson vaccine and the need for an annual vaccine. Persistent questions remain regarding any unknown long-term side effects of vaccination, especially impacts to fertility. For some, there are specific questions about individual medical conditions and potential interactions with a vaccine.
- **Misinformation.** Issues of “placebo vaccines” and “black vaccines” that are of different potency were circulating in some communities.
- **Beyond vaccination.** For those disinterested in vaccination at this time, there was a strong interest in knowing how else they might contribute toward stopping the spread of disease, keeping themselves and others safe, and righting the economy.

***Potential Actions:** Even for those in our community conversations with an 81% vaccination rate, it would be a mistake to think there were no more information needs. Because talking with family and friends is so important, those who are vaccinated or unvaccinated still have on-going information needs. With lingering questions about variants, childhood vaccines and whether annual COVID-19 vaccinations will be needed, public health and their community-based partners should keep lines of communication open and on-going. For those refusing vaccination, more customized information is needed – either in response to questions about interactions with specific medical conditions, or other issues. In those cases, life getting back to normal will allow for doctor-patient visits and conversations that did not happen during lock-downs and quarantines.*

Values and Lived Experience

Figure 6: Which of these did you do? (select all that apply)



Noteworthy: Community conversation participants did a number of things to assist their decision-making; talking to family, friends, and listening to expert views ranked high.

- Contemporary lived experience during the later days of the pandemic has been positive for many.** The early days and disproportionate impact of COVID-19 on African Americans is lasting and indelible. However, many also shared that their vaccination experience was positive (though some suffered more severe side effects than expected) and they are glad to be vaccinated. Of Wave 3 African American participants, 81% indicated they were vaccinated and feel good about the decision.

The following three bullets were shared in the Wave 2 report. We include them here as they continued to be important and influential in the Wave 3 community conversations *whether or not* a participant ultimately tipped toward getting vaccinated (and did), continuing to “wait and learn,” or refusing a vaccine.

- Historical context resulting in present-day consequences.** 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. Those who hold this view 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.
- Lived Experience.** Regardless of status, wealth, or education level, African Americans who complain of pain following any medical intervention are often ignored or dismissed by medical

professionals. The cases of Dr. Susan Moore (<https://www.nytimes.com/2020/12/23/us/susan-moore-black-doctor-indiana.html>) and Serena Williams (<https://www.nytimes.com/2018/01/11/sports/tennis/serena-williams-baby-vogue.html>) illustrate this point. In light of these cases, medical professionals must prove they can respond to African 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: Our community conversations indicate that vaccinated African Americans feel very positive about their decision to get vaccinated. Given the intrinsic trust between family and friends, public health and their community-based partners might recommend and encourage dialogue between those not yet vaccinated and those who are vaccinated. “Talking with family and friends” was the highest ranked category in both Wave 2 and Wave 3.

For some African Americans, a decision about vaccination may take more time than some might expect given their lived experience. The length of time each individual needs can also range. Public health needs to exercise patience and find ways to demonstrate trustworthiness to the African American community. Three elements of trust¹ 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 upon, will you go above and beyond?). Public health needs to keep “showing up” and supporting the decision-making process (see below). There is a clear role for public health given its expertise and dedication to community health.

Supporting Decision-Making

- **Vaccines for children and boosters for COVID-19 vaccine.** While most in our community conversations have settled into a decision at this time, there are more decisions coming regarding vaccines for children and whether to get an annual COVID-19 vaccine, if needed. Finding safe places to have conversations about upcoming decisions has proven helpful. Participants indicated a need for conversations that present information without intention to persuade and are honest about how individual actions impact community health. Churches were most often seen as the preferred venues for dialogue.

¹ <https://hbr.org/2019/02/the-3-elements-of-trust>

- **Being cognizant of stigma and supporting positive public health behaviors and decisions beyond vaccination.** The issue of stigma emerged in our conversations and how those who remain unvaccinated will be regarded in their communities. Continuing to create a welcoming atmosphere for dialogue and a range of positive behaviors, including but not limited to vaccination, was important for cohesion in communities.

Potential Actions: On-going, sustained communication will matter for the next set of decisions involving children and annual vaccines. While community conversation participants may be positively predisposed to both, it should not be taken for granted. Additionally, supporting decision-making does not mean only supporting those who decide to get vaccinated; but also supporting those who choose differently – either for the time being or permanently.

Implementation Considerations: Make It Easy

- **Convenient locations with a focus on equity and improved registration processes helped while vaccine was scarce.** There should be vaccination sites beyond central government locations with consideration to having sites located in neighborhoods and locations central to vulnerable communities that minimize the need to use public transportation. These locations should be identified in consultation with community organizations and churches with a history of serving the community.
- **With plentiful vaccines, convenience is key.** Some indicate that it was key to have increased convenience of not having to register in advance; be offered the vaccine when bringing someone else to a vaccine site, and have mobile vaccination units at churches, community centers, and other places.

Potential Actions: Increased convenience was and will continue to be very important moving forward.

About the Future

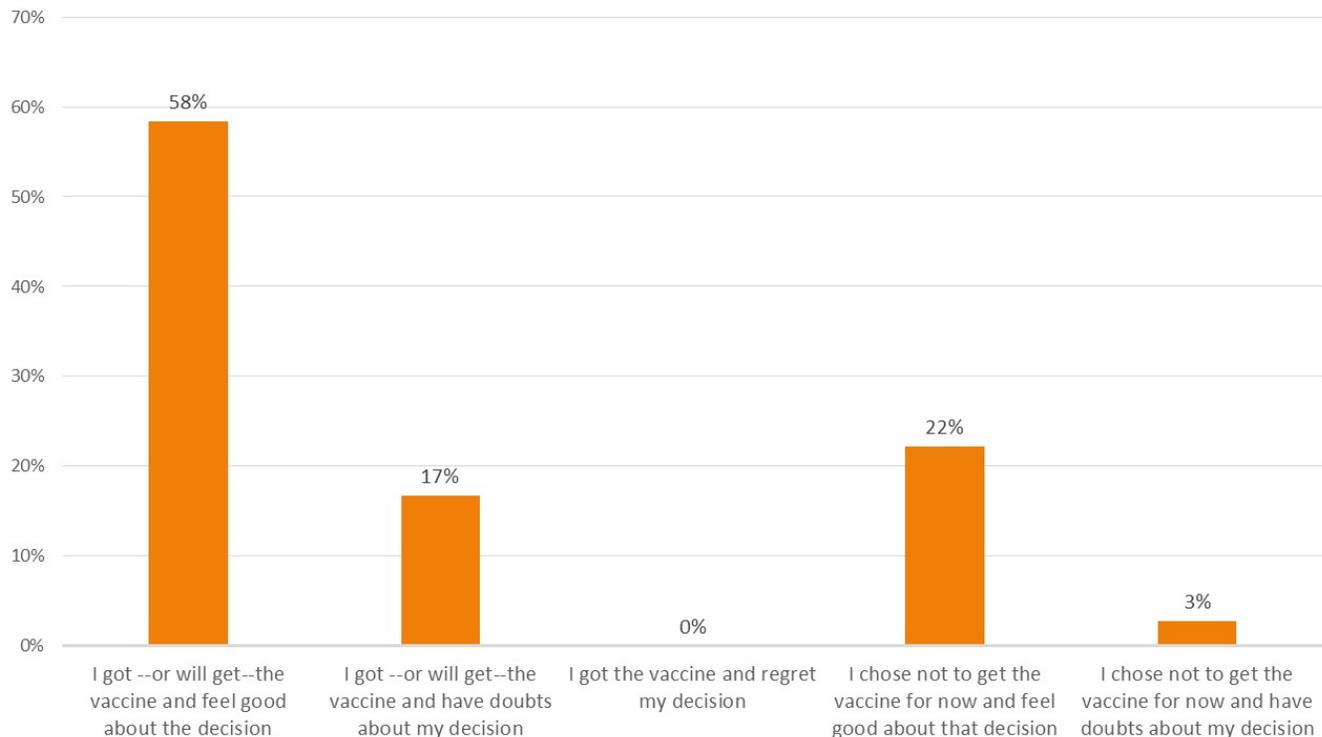
- **There is interest in well-intentioned, inclusive efforts focused on health equity.** Many in each community suggested that there were a host of other important public health issues that would benefit from the focused attention, such as: chronic disease; gun violence; drug abuse; suicide; mental health; and others. While members of the community conversations were open to (and in some cases hopeful about) collaborative efforts focused on other public health issues; there was little to no confidence that the effort and attention would remain after the pandemic subsides.

Potential Actions: *To the extent there is interest and capacity, public health can build on the relationships and goodwill developed during the pandemic and bridge to other public health issues collaboratively identified by African American communities. Ongoing efforts would further establish working relationships where trustworthiness can be demonstrated to each other in the process of working on issues pertaining to health equity.*

APPENDIX 3

At-A-Glance: What We've Learned in Native American Communities - Wave 3

Figure 7: How do you feel about the decision you have made?



Noteworthy: All had access and most had made a decision and felt a high degree of satisfaction with their decision by Wave 3.

Overview – What has been important in Wave 3 (May 2021), as articulated in community conversations

- Seeing friends and relatives take the vaccine with no serious side effects
- Doing their own research, talking to a community health worker, taking time to evolve own thinking
- Understanding the need to protect others they are living with or come in contact with
- Wanting to get back to life – school, cultural traditions and ceremonies, and work
- Convenience - no longer needing to go to great lengths to get a vaccine

Evolving Information Needs

- **Vaccine updates.** Individuals in the Native American community continued to have a strong interest in vaccine safety issues and side effects. Now that a majority of participants have been vaccinated, the concerns were more focused on unknown long-term effects. There was also concern regarding the Johnson and Johnson vaccine given reports that the vaccine caused some severe side effects. This “one and done” vaccine might have been particularly useful in remote or

rural tribal locations. Many were also worried about the impact of variants on a given vaccine's effectiveness and the implications for needing annual booster shots.

- **Pregnant women and children.** With questions answered for the general adult population, there were more specific questions regarding the impact of vaccine on pregnancy, as well as whether the vaccine would ultimately be safe and effective for children.
- **Specifics for communities.** Participants were interested in knowing statistics for their own communities. They felt they could make better decisions knowing the transmission and vaccination rates. Some expressed a lack of confidence in the numbers they heard, believing they were products of the rumor mill, and not coming from official sources.

Potential Actions for Tribal Health: Providing accurate information and data about case numbers, outcomes, outbreaks, and vaccination rates is important, as well as establishing and institutionalizing ways for tribal members to find updated information. A diversity of modalities were suggested, including: a mobile information vehicle that travels to different locations; tribal radio; social media; and tribal government communications.

Values and Lived Experience

These remained basically unchanged from previous waves, though with shifting focus:

- **Values – family and tribal rituals.** Family and the desire to get back to life was either motivating, or provided additional affirmation for a person's decision to vaccinate. Participants mentioned missing customs and rituals where tribal members could be together, as these traditions were a vital part of their way of life.
- **Support for tribe-derived mandates that protected the community.** Participants were generally supportive of the mask mandates, social distancing requirements, cancellation of tribal ceremonies and celebrations, and curfews imposed by their Tribe. The sense was that while there will always be enforcement issues, these mandates saved lives. In addition, participants felt that the Tribal government had the best interest of the community in mind, a sentiment not universally heard in other vulnerable communities.
- **Lived experience – finding allies.** Some observed an interesting benefit from the pandemic. Tribal communities have gained additional non-tribal allies who were impressed with high vaccination rates and collective approaches developed to keeping tribal communities safe. Many of these approaches were unique to that particular tribe, which is in keeping with Community Based Participatory Research (CBPR) approaches.
- **Historical context resulting in present-day consequences.** Historical abuse and neglect of Native Americans remained a backdrop across Indian Country and in all our conversations. It is an

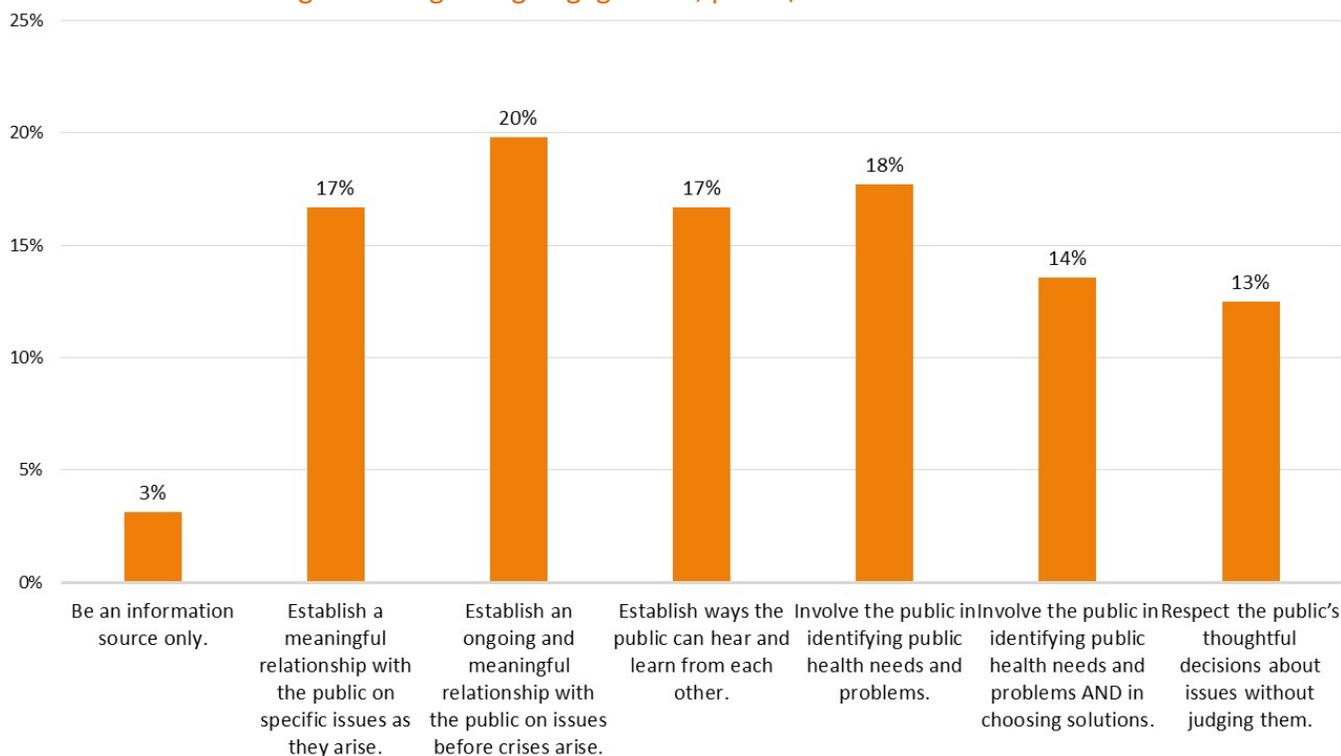
important aspect for government and public health institutions to be aware of in order to understand aspects of hesitancy and mistrust of these organizations.

- **Values – the long look.** Native American community conversations approached the pandemic and the consequences of any long-term unknown side effects of vaccines with a multi-generational lens and focus on elders (the cultural experts and knowledge keepers) to unborn children (the future of the tribal community). With adults taking a vaccination in order to protect the elders, and the elders having been vaccinated, the focus was on the safety of vaccines for children and the importance of their returning to school for both mental health and educational growth. Participants felt increased concern about the duration of the pandemic and the stress, trauma, and isolation felt by youth as they worked to keep their family members safe from disease.

Potential Actions for Tribal Health: With all participants in our community conversations having now had access to the vaccine, the role of Tribal health is shifting from a focus on access to focused focus on serving those who remain unsure or uninterested in a vaccine at this time. There is a strong desire to have reliable and current information from tribal health. Increasingly, given the duration of the pandemic, there is an increased need for trauma and mental health treatment for all tribal members, especially the youth who have been isolated and felt the burden of keeping adults safe.

Supporting Decision-Making

Figure 8: Regarding engagement, public/tribal health should...



Noteworthy: *Thinking toward future public health issues (beyond COVID-19) Native American participants are hoping for increased engagement with tribal health.*

- **Reliable information and safe platforms to talk to experts and each other – now focused on decision-making for children.** With perspectives solidifying for themselves, there is increased interest in COVID-19 vaccines for children with some participants already looking forward to it being available for children and some more cautious about its effectiveness and safety for children. Decision-making is likely a more integrated family approach in Native American households, since grandparents are often the day-to-day caregivers for children. Hence, vaccination decision-making may involve multiple generations.
- **Impact of pandemic fatigue, loosening restrictions, and “opening up” on those not vaccinated.** These community members may need additional decision-making support as they recalibrate their personal risk. Some in vulnerable communities mentioned that they were further compelled to get vaccinated as they watched others become more relaxed with masks, social distancing, and other public health measures. While most had settled into their decision and had a high degree of satisfaction with it (whether they decided to vaccinate or not), these meetings were just prior to updated CDC guidance regarding circumstances for those vaccinated (i.e., not needing to wear masks and maintain social distancing -- inside and out). This significant change in guidance and local implementation will possibly cause some to re-think their personal risk profile as they intersect with people who may or may not be faithfully following public health guidance.

- **Continued support for positive public health behaviors and decisions beyond vaccination.** Local Tribal health should show encouragement and appreciation for the full spectrum of activities that contribute to decreased disease rates, hospitalizations, and death. To the extent it is possible to have coordinated messaging on both tribal land and in the “border towns,” this creates more consistency with better public health outcomes.
- **Need for a more sustained and engaged relationship between tribal health and those they serve.** Our participants indicated that working together on a diversity of issues in advance of a crisis will better serve Tribes and improve health equity. There is a desire to work on issues beyond vaccination, including mental health, chronic disease, suicide, cancer, and other topics. As in all the vulnerable communities, participants want to be involved in identifying problems and solutions that impact their communities.

Potential Actions for Tribal Health Officials: Tribal health can continue to support decision-making by making their public health expertise available, demonstrating reliability with up-to-date information regarding infection and vaccination rates, and recognizing that the dialogue, for many, will shift to decision-making regarding children. Given the importance of sharing local experiences with vaccination and talking with family and friends, consider how to foster this engagement among tribal members. Communities are requesting engagement with tribal health on other public health issues beyond vaccination.

Implementation Considerations: Make It Easy

Potential Actions by Tribal Health Officials: Many indicated that, while roll-out went relatively well in their communities during the last few months, things likely need to shift as supply exceeds demand and as children become eligible for vaccination.

- For those less motivated to get the vaccine, convenience (and possibly incentives) is important. Whether they perceive their disease risk to be less, find registering in advance to be a barrier, or just have not gotten around to it – convenience is all the more important. Several participants said they intended to get the vaccine, but it hadn’t been convenient for them. They ask Tribal health to provide convenient locations without the need to pre-register and to offer the vaccine where communities are gathering (events, churches, grocery stores, schools). Saving a special trip to a vaccination site or office will help those who are interested make the additional effort. At the time of the community conversations, incentives were not being widely discussed. The backdrop to being “less motivated” was also mistrust of the federal government and big pharma. Those not vaccinated may also fear the vaccine’s side effects and be frustrated that there wasn’t enough information to help them understand the pros and cons.
- Find ways to make it easy for children to receive the vaccine, as well as the adult who brought them. As children are increasingly able to get a vaccine, this should be easy and accessible for parents, grandparents, caregivers. If children are getting a vaccine, the guardian could be offered

one also, increasing the convenience for the family and reinforcing the need to vaccinate for each other.

- Communicate clearly the next vaccine opportunity for those not yet vaccinated. It was clear that a number of factors (variants, infection rates, communities “opening up”) have people re-evaluating their personal relative risk and that of their families, regularly. Tribal health should check in with those who were uninterested in vaccination previously and let them know about future opportunities. They should also continue to encourage masks and social distancing, and provide this information without judgement or motives to comply.

About the Future

- **There is interest in well-intentioned, inclusive efforts focused on health equity.** Many in each community suggested that there were a host of other important public health issues that would benefit from the focused attention, such as: chronic disease; gun violence; drug abuse; suicide; mental health; and others. While members of the community conversations were open to (and in some cases hopeful about) collaborative efforts focused on other public health issues; there was little to no confidence that the effort and attention would remain after the pandemic subsides.

***Potential Actions:** To the extent there is interest and capacity, Tribal health can build on the relationships and goodwill developed during the pandemic and bridge to other public health issues collaboratively identified by Native American communities. Ongoing efforts would further establish working relationships where trustworthiness can be demonstrated to each other in the process of working on issues pertaining to health equity.*
