



Focus Group Updates

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WRAIR



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This report summarizes findings from three focus groups composed of Black DC-MD-VA (DMV) participants during December 2020. Groups of 5-15 participants led by Dr. Lisa Fitzpatrick discussed COVID-19 testing and vaccinations, clinical research, and WRAIR initiatives. Participants shared their experiences and recommended action steps for promoting community engagement around COVID-19 and wider research efforts. These conversations generally identified persistent institutional miscommunication and abuse as a driver of distrust. Takeaways reflected these themes, emphasizing the necessity for community-led collaborations in building lasting, productive relationships.

COVID-19 Experience

Growing needs drove intense emotions in an unfamiliar and unfriendly environment. Participants commonly reported disruptions to the following dimensions of their lives:

Work

- Participants who had worked in customer-facing, service sector jobs had generally lost their jobs. One such individual, who had previously worked in food service, reported that the unemployment support available exceeded their pre-pandemic monthly income.
- Participants connected to businesses reported staff reductions. One individual had started a cleaning business before the pandemic, which had slowly lost customers over the past several months. Another participant reported that their company had lost service contracts in the entertainment sector, forcing them to cut dozens of jobs.
- One participant, who had occasionally been going into their office, reported that proper precautions were not being taken.

Social Life

- Many participants reported feelings of isolation.
- We heard that seniors were having an especially difficult time. One participant, who worked at a senior home, reported that they were combating this by introducing seniors to online multiplayer games with laptops obtained with grant money. Their seniors also enjoyed bike rides.
- Holidays were reported to be especially difficult, as many families could not gather as they normally would.

Spirituality

- One participant emphasized that not being able to worship in groups weighed on her. While some faith centers are doing outreach and hosting online services, these replacements do not seem to provide the same sense of community as in-person gatherings.

Physical Safety

- Accounts of general criminal activity varied widely. Some participants felt as though crime was decreasing; others reported it increasing.
- Heightened emotions were often cited as a driver of aggressive behavior. Many participants reported a reluctance to speak up when people around them were not following social distancing guidelines. Correcting non-compliant people in stores was

seen as risky because it could provoke aggressive retaliation. Participants strongly preferred when store workers enforced precautionary measures.

- Several people reported more loitering than usual.

Physical Health

- While only a few participants had been infected with COVID-19, nearly all participants knew someone who had been infected at some point. Some participants were able to quarantine apart from their households and others were not. Every case we heard described was different, and one became pneumonia.
- A few people reported gaining weight. There was general confusion around “safe” activities, so some may not have been exercising due to the associated settings.

Mental Health

- Many participants reported feelings of depression and anxiety due to prolonged isolation, loss of security, and feelings of helplessness.

Across the board, we heard that experiences were worsening along with the passage of time. Participants were exhausted, and didn't seem to believe that there could be an end in sight.

Trust

Perhaps the most common experience was that of information overload. Communication of evolving scientific information, testing and treatment options, and local regulations was confusing and often misleading. As more traditional trusted authorities became unreliable sources for accurate information, participants turned to their communities for support. Generally, participants felt as though they could only trust themselves to decide what information could be trusted from which sources.

Trusted Sources

- Participants in every focus group cited [Dr. Anthony Fauci](#) as a trusted source of reliable information.
- Most participants cited [friends or family members](#) as regular sources of health information. These connections were often frontline health care providers or worked in an adjacent field, including the pharmaceutical industry.
- Most participants consumed health information disseminated by [social media influencers](#). Participants noted that they rarely followed public health or governmental institutions on social media, instead consuming content shared by their friends, families, and popular accounts on [Instagram](#), [Facebook](#), [TikTok](#), and [Twitter](#). This effect may be somewhat platform-specific, however; one participant reported following [Kaiser](#), [Donald Trump](#), and [Joe Biden](#) on Twitter. Popular Instagram accounts included [Saudia Shuler](#), [The Shade Room](#), [DMV Hood News](#), [Murder Mayhem DC](#).
- Many participants cited their [primary care providers](#) (PCP) as reliable sources of trusted health information. However, not all participants were under the care of a PCP, and not all participants reported trusting their PCPs. Trust was earned based on how providers treated patients, and extended beyond COVID-19 information. Many participants reported withholding health information, mainly related to substances, from their

providers. Participants who reported trusting their physicians did so because of their medical education.

- Many participants referenced their own research efforts as a main source of health information during COVID-19. Information was sourced mainly from online literature and recorded seminars.
- Several participants cited churches as consistent sources of health information.
- Lesser-cited sources of trusted information included local resources, including a local health department's website, a senior wellness center, reports from the mayor and council members, and newsletters.

Less-Trusted Sources

- Many participants referenced TV news channels as sources of information, though perceptions were somewhat channel-dependent. CNN was trusted by a few participants. MSNBC was also viewed favorably. Apple News was mentioned as a source. A participant who did not trust TV information said they felt this way because the news makes things more dramatic to scare their viewers. Another said that the news would be negative regardless of the information, and so they preferred other sources.
- Participants generally reported dimming views of the reliability of public health institutions. While some would still obtain information from the CDC, they questioned whether its information was reliable and up-to-date. Similarly, the WHO seemed to have fallen somewhat out of favor with these focus groups.
- Participants had conflicting and generally weak opinions of bus stops, fliers, and radio stations as sources of information.

Distrusted Sources

- A few participants referenced Donald Trump as a source of misinformation. His "fake news this, fake news that," narrative influenced at least one participant's shift from trusting traditional sources of information.

Institutions

While some participants trusted their health providers to varying degrees, the vast majority shared a common distrust of the overall healthcare system. Many participants cited the poor treatment of Black and Brown patients in the medical system as a significant deterrent to engaging in care or clinical research. Several participants agreed that providers often didn't listen to or understand their concerns, resulting in treatment mistakes. Because providers were not always fully partnered in care, one participant emphasized the necessity of advocating for themselves based on their own research rather than taking a provider's word as "the law." Another participant, who worked as a physical therapist, stated that they saw the degree to which good intentions could result in poor outcomes depending on who administered medical interventions.

Likewise, the government's historical abuse of Black and Brown people was a significant point of concern for participants. The Tuskegee Syphilis Study came up in every focus group as an example of lawful abuse by institutions which Black and Brown people had little recourse to reform. Many participants voiced concerns around being treated like test subjects or lab animals without their informed consent. Some expressed distrust in government institutions

because of their perceived track record for failing to fully acknowledge and address such past harms.

In all conversations, participants pointed to a persistent underrepresentation of their interests in truly shaping decisions or policies as a source of institutional distrust. Many mentioned deep concern over institutional oversight, questioning whether the government, healthcare systems, and pharmaceutical companies would be held accountable for any harms caused directly or indirectly related to COVID-19. Generally, participants felt as though there was little evidence that previous patterns of institutional behavior would change. On the contrary, several participants felt as though institutional handling of COVID-19 proved that nothing would change, and seemed to reinforce previously-held beliefs.

- Because the government had failed to solve other critical issues, many participants saw no reason to trust it with a COVID-19 vaccine. Some discussed concerns with dissemination of accurate, reliable information, and many were frustrated with testing infrastructure. These persistent failures undermined participants' confidence in the government's ability to develop or administer a safe and effective COVID-19 vaccine. Additionally, several participants cited historical abuses as a significant deterrent from trusting vaccines produced by the government.
- Poorly-communicated status updates compounded with unexplained resource rationing to reinforce distrust in the healthcare system. Participants expressed frustration over clinicians refusing to test them when they reported feeling unwell, as well as confusion over test accuracy and interpretation. Because nuances in test function and allocation were not widely understood, some participants reported decreased trust due to apparent inconsistencies and mistakes in medical treatment. Because of the variance in COVID-19's symptoms and presentation, one participant expressed skepticism that systems knew enough about the virus to test for it, let alone vaccinate against it. Collectively, the breadth of complex, evolving information around the virus and medical options, often communicated in confusing, misleading, or inaccurate ways, deepened existing distrust in the healthcare system.

COVID-19 Knowledge

Several points of confusion became apparent. Participants had questions about COVID-19 transmission, pathology, and testing.

Transmission & Pathology

- Some participants did not understand surface transmission. One participant asked specifically about the logistics of surface transmission in driving, opening doors, and safety pumping gas.
- Several participants did not understand airborne transmission. One participant reported having a karaoke night with some of their friends, one of whom later tested positive. Out of the eight other attendees, only two tested positive. The participant asked how that could have been possible, since they were all singing right next to each other.

- Some participants were unclear on the relationship between exposure and infection. Specifically, the amount of viral exposure required for an infection was unclear.
- Some participants asked about whether temperatures affected the virus, likening it to a germ that might be killed with hot water.
- Some participants did not understand the transmission period.
- Several participants were confused about why COVID-19 infections “disappear[ed]” after a few weeks.
- A few participants asked about the duration and strength of the protective immune response associated with prior COVID-19 infection.

Prevention

- Many participants did not understand the connection between preventive measures, including masking and social distancing, and viral transmission. One participant asked if it was safe to go for walks or sit in parks, and whether masks need to be worn outside. Another asked if they could safely go to the grocery store, and whether they needed to wipe down groceries.
- Some participants asked about the effectiveness of Lysol vs other disinfection methods. Lysol’s packaging states that it protects against coronaviruses, leading some to believe that it was the only product that protects against coronaviruses. They asked about safe replacements.
- A few participants asked about the effectiveness of wearing gloves in preventing infection.

Tests

- Many participants did not demonstrate an understanding of the nuances between different types of COVID-19 tests. This resulted in confusion around results due to variations in test availability, options, accuracy, administration technique, methodology, interpretation, and sensitivity over time. When participants discussed tests in relation to their friends’ and families’ infections, they often did not know what kind of tests those people had received. This widespread conflation of test types fueled confusion and distrust, as interpretations of results varied widely.
- Many participants expressed distrust based on stories they had heard about testing availability, distribution, and interpretation. One participant reported being refused a test because a physician interpreted their symptoms as more indicative of ovulation than COVID-19 infection. Another reported their sister testing negative twice in the ER, taking care of her own symptoms at home, and then testing positive once the illness had cleared.
- Many participants were confused about the circumstances which would prompt them to get tested for COVID-19. Because of the mixed public guidance, they were unsure of whether they should wait until they felt sick or if they should be tested after a suspected or confirmed exposure.
- A few participants noted care quality gaps between private and public testing. Participants who had private insurance reported positive overall experiences. Participants who had been tested publicly expressed mixed feelings. One participant had gone to a public testing site at a fire station in DC and reported that the line got so

long that people left before being tested. Another reported no problems at a public testing site near the DC arena.

- Some participants also reported variations in test administration across different locations and health care workers. One participant in particular was very frustrated by having to demonstrate administration of a nasal swab to a worker.

COVID-19 Vaccines & Clinical Trials

Many participants expressed concern over the speed at which the vaccines had been developed and did not understand why the timeline had been so dramatically accelerated. Many felt that there was no way to tell whether these vaccines were safe, and were concerned about both the long-term unknowable effects and the short-term side effects. Some participants had heard about adverse effects connected to the COVID-19 vaccine trials, including paralysis, death, and allergic reactions.

A few participants also expressed concern about pharmaceutical companies' motives in vaccine development, and whether data reported by the news could be trusted. One participant was wary about rising stock prices after good COVID-19 vaccine trial data had been released. A few participants asked whether pharmaceutical companies would be held accountable for adverse reactions.

Some participants did not understand why so many vaccines were being developed, and asked how to pick the best one once they were more widely available. A few expressed decreased confidence in vaccine effectiveness due to their administration, stating that they "must not work that well if you have to get two shots." We've found that a widespread misunderstanding around mRNA fuels significant distrust of COVID-19 vaccines and clinical trials. A few participants were concerned about the composition and mechanism of the vaccines, and asked if the vaccines would permanently alter their DNA. Many participants asked whether they would have to be vaccinated against COVID-19 every year. Some participants were unclear as to whether a vaccine would prevent someone from being infected or infecting others with COVID-19, and whether they could get as sick from COVID-19 after being vaccinated.

Many participants expressed concern over racial and ethnic disparities in vaccine safety and effectiveness. Several participants asked whether Black people were represented in clinical trials, both as volunteers and in vaccine development. Many participants asked whether the vaccine worked differently across racial groups. One participant asked whether the vaccine worked differently for persons with African American chemical makeup than it did for persons with European chemical makeup. They reasoned that, because Black people have different health challenges, including hypertension and diabetes, than other groups, the vaccine might not affect a Black person the same way it would affect a white person. Similarly, some participants asked whether the vaccine would be suitable for those with chronic conditions.

One participant was concerned about microchips.

Vaccine Acceptance

Few participants said they would take a vaccine as soon as it was made available.

- One had already volunteered for the Moderna trial.
- One was comfortable taking it because they didn't have a history of bad reactions to vaccines or allergies. This participant had been raised in the Caribbean and studied in the US for several years, and noted that they had a different perspective than African Americans.
- One said they would take it and would have been interested in enrolling in clinical trials, but that they had seen marketing that specifically excluded residents of 6, 7, and 8 from the COVID-19 trials.

Most commonly, participants were not interested in receiving a COVID-19 vaccine at all.

- Several merely said that they wouldn't take the vaccine unless they had to.
- One had heard that people had died from the vaccine and cited their distrust in the government and a belief that the process valued profit over lives.
- One said that they would refuse the vaccine for themselves and their child because they didn't know what was in it. They mainly referenced doctors contributing to the confusion by spreading misinformation in videos, and said that there was "so much fake news" about the vaccine. This participant was also deterred by perceived DNA alterations caused by the vaccine. Additionally, they expressed distrust in the military, stating that soldiers couldn't be trusted to obey orders.
- One expressed frustration over likely having to take the vaccine to travel overseas. They likely would not take it unless it was made mandatory, and were willing to forego their usual travel. They were also suspicious of the stock price jumps of the "two main companies" with successful vaccines, though they didn't know why the share prices rose.
- One specifically did not want to feel like an "animal" or "test dummy," and stated that the vaccines were developed too quickly.
- One did not want the vaccine because of their underlying conditions.
- One had already recovered from a summer COVID-19 infection that had become pneumonia and required them to quarantine for two months away from their children. Additionally, they had come down with the flu after taking the flu shot. They were uninterested in the vaccine because of those experiences.

Several participants were between these two groups. These participants were not interested in receiving a vaccine immediately once one was made available, but did not completely rule out taking a vaccine. They wanted to see how early adopters responded to the vaccine, generally in case there were any common adverse events or safety issues.

Several participants felt that a COVID-19 vaccine would not be worth the associated risks unless it had been proven to be 90%, 95%, or 99.9% "accurate," "safe," or "effective." They said both 60% and 65% efficacy rates would be too low.

Research Trials & WRAIR

Few participants were willing to participate in clinical trials.

- Participants who were not interested in enrolling in clinical trials did not want to be treated like “research subjects,” “test dummies,” “animals,” or “guinea pigs.”
- The few participants who were willing to enroll in clinical trials tended to have personal or family backgrounds in science or health.
- Some participants were between these two groups, and would only be interested in enrolling in clinical trials if their lives were personally threatened. These participants typically said they would enroll themselves or their children if their primary care physician recommended doing so.

Trial site did not seem to have a consistent effect on participants’ interest in clinical trial enrollment beyond a strong preference for heavy physician and scientist involvement. Participants who were not interested in enrolling typically reported that the site would not impact their interest, or were unsure of the extent to which the site would impact their interest.

- Participants typically cited medical distrust as the main driver of research hospital avoidance.
- Many participants cited Tuskegee-related perceptions of government abuse and coverups as drivers of military research avoidance. A few participants reported suspicion while acknowledging that it made sense for the military to be conducting research because of their interest in keeping their soldiers and workforce healthy. These participants were curious about military accountability to enrollees and the public, and inquired about existing oversight measures. A few participants pointed out that soldiers weren’t guaranteed to follow orders, which could impact trial results.
- The few participants with some personal or familial connection to the military were generally more accepting of WRAIR-conducted research. One participant had previously encountered military physicians at the NIH, which had positively influenced their opinion of all military medical research.

Recommendations

We asked participants to share their recommendations for improving community engagement. They focused on building trust by meaningfully improving transparency, simplifying communications, and ensuring that all interests were represented throughout the entire research, development, and distribution process.

- Make educational resources relatable. There are gaps in conveying information to people in ways they can understand. Simplifying information and messaging through personally-meaningful contacts, such as PCPs, could improve care quality. Additionally, explicitly connecting pieces of the health puzzle with simple language may improve comprehension. For example, explicitly connecting how masks prevent COVID-19 infection and protect frontline health workers without using scientific jargon.
- Improve information accessibility. People want accurate information, they just don’t always know how to assess content quality or access experts. Participants

recommended holding smaller forums and focus groups where people could come to learn and ask questions. One participant shared they wished they'd had more information from their employer, their employer's health team, or their personal provider. Another participant said they'd find personalized letters from their primary care provider outlining the pros and cons of vaccination very helpful, emphasizing the importance of breaking down complex concepts so that everyone can follow logical progressions.

- Develop community-specific communication strategies. Such strategies should be sensitive to how different cultures process, understand, and analyze information differently, and tailored to improve community acceptance of information. One participant had immigrated from the Caribbean, and emphasized the importance of taking “motley” approaches to outreach.
- Partner with community members. Community health workers understand nuanced population needs, navigate resources effectively, and make complex information relevant. Their involvement may also improve provider-patient relationships. Community-led enrollment may improve communication around risks and benefits by using only clear, understandable language. A few participants recommended that community advocates accompany enrollees to trial appointments so that they could clarify and support more hesitant volunteers.
- Leverage social media. Almost everyone spends time on social media, yet institutions have been reluctant to build active, reliable, relatable presences to disseminate information. Participants in every focus group advocated for building strong social media presences and collaborating with established influencers to reach people in their digital communities.
- Improve transparency. Close collaboration with community partners can help reduce anxiety around technical processes. Several participants wanted to follow the experiences of those vaccinated for weeks to months to know what to expect. Some participants wanted to hear testimonies from early vaccine adopters with a variety of underlying chronic conditions. A few participants emphasized the importance of knowing their options for recourse in the case of an adverse event.
- Invite stakeholders to the table. Shaping decisions around community members' input was the most important step in cultivating strong relationships. Many participants advocated for more “faces that look like us” -- people whom they trusted to represent their best interests at every level in the system.

Tuskegee

One group, composed of educated Black professionals, offered suggestions on how to approach deeper concerns around Tuskegee. They felt that a genuine public apology, underscored by meaningful, collaborative action, would help convey institutional commitment to more equitably improving processes. These participants emphasized the need for a formal acceptance of responsibility and acknowledgement of change for reconciliation conversations to carry weight.

Collaborators

Participants in a few groups recommended partnering with churches to reach their congregations. Because faith communities are largely well-connected environments in which people already feel safe and respected, co-hosting events or distributing information through trusted points of contact, including pastors and faith leaders, may improve perceptions and connectivity.

Participants in one group also recommended partnering with Howard and other HBCUs. HBCUs are generally very connected to Black and Brown communities through alumni and international student associations, new graduates, and outreach efforts. Because of these connections and established trust within communities, Howard was specifically recommended in the DMV as a good hub for information dissemination.

Very few specific organizations were mentioned. One participant mentioned that Community of Hope was giving away masks in the early afternoons on Mondays and Tuesdays.