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Lifting up the voices of older Black and Hispanic adults: Perspectives on the COVID-19 pandemic and vaccination



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Introduction

Why this Research?

Data is clear that COVID-19 disproportionately impacts Black and Hispanic¹ adults 60+ years of age, and these adults have received vaccinations at significantly lower rates.² ³ Centuries of inequalities in social determinants of health along with structural conditions and racism have created significant health disparities.⁴ ⁵ In addition, considerable obstacles to effective communications exist for these communities. For example, COVID-19 communications strategies have relied on the Internet as a communications channel. However, a Pew Research study found that 25% of adults 65+ years of age indicate they never use the Internet, a rate that is up to twice as high for Black and Hispanic older adults and low-income adults. ⁶ 7 8 9

HelpAge USA commissioned this research to better understand the experiences of older Black and Hispanic adults during the COVID-19 pandemic and what is important to them in their decision-making regarding the vaccination. This will help organizations tailor strategies so that people can feel supported and informed.

The following considerations guided our approach:

- **In-depth understanding:** We wanted to understand the "why" behind people's views, the underlying beliefs and values that influence their decisions.
- The impact of the pandemic: We wanted to better understand the many ways the pandemic has affected individuals and their families.
- **Representation:** We focused on a group of older adults whose views are often left out of public opinion research. We sought geographic representation through different regions in the United States.
- **Community co-researchers**: Members of the community co-led this research including leading the focus groups, participating in the analysis, and writing this report.
- A range of perspectives: We considered all perspectives meaningful to help better understand what factors are most important to people in their decision-making.
- **Community-based partners:** We recognized the importance of working with public health and community organizations as trusted intermediaries and the critical role they play in informing and implementing recommendations from the research.

Approach

Collaborative

We believe that knowledge and meaning are created through our conversations and relationships. This research represents a collaborative approach that "equitably involves all partners in the research process and recognizes the unique strengths that each brings". ¹⁰

Creating a Research Team - We created a research team that was co-led by older adults. It also included graduate students in social work and organizational partners. This research team was an important part of the entire research process including:

- research focus and design,
- recruitment of participants,
- facilitating the focus groups,
- participating in analysis and report writing, and
- sharing the findings.

Partnering with Community Organizations - We identified community organizations and workgroups that were committed to the focus of this research: Rush University Medical Center, Chicago Department of Family and Support Services, the Contra Costa Family Justice Center, The Black Neighborhood, Contra Costa Alliance to End Abuse, Contra Costa Latinx COVID-19 Workgroup, Contra Costa Older Adult COVID-19 Workgroup, COVID-Aging Taskforce for Contra Costa County Health Department, Contra Costa African-American COVID-19 Workgroup. We learned about their efforts and how this research might help them reach their goals of better supporting older adults of color in their community.

Lifting Voices

The focus of this research is to elevate voices with regard to COVID-19 vaccination efforts. It provided older adults with a forum to share their experiences during this time and their decision-making process about the COVID-19 vaccination.

Recruitment - We focused on communities where we had partnerships with community organizations and leadership of our older adult research team. Our intention was to engage focus group participants who are Black and Hispanic from different parts of the country - east and west, north and south, rural and urban. We also held Spanish-speaking focus groups.

Focus Groups - We designed a focus group method with a mix of four participants in each session, to gather different perspectives and stimulate conversation, while ensuring that

people's voices were heard. The focus groups were conducted remotely (over Zoom and by telephone) with participants across the country to ensure that technology access would not be an obstacle for anyone to participate. Buddy Moore and Irma Angulo facilitated the sessions. In total, twenty-two people (three men and nineteen women) participated in focus groups from Washington, D.C., South Carolina, North Carolina, Contra Costa County, CA. Sixteen people identified as being African American/Black and six people identified as being Latinx/Hispanic. Ages ranged from 55 – 89 years old. The focus groups were completed in March 2021.

Disrupting Patterns

There is a history of distrust of the health system among many members of Black and Hispanic communities that stems from historical wrongs such as the Tuskegee syphilis study and the experience of Henrietta Lacks and continues to be reinforced by how people of color are treated in the health system. In our analysis of the focus groups, we strived to stay as close as possible to the words participants used, and to not superimpose our voices on what they had to say. It is critical that we listen deeply to people's voices as we work to improve systems that better serve and support them. In this research, we sought to disrupt a pattern of mistrust by listening with empathy, challenging our assumptions, and paying attention to the stories that were emerging from the focus group conversations. We invite you to join us by reflecting on any assumptions you bring as you read this report.

Analysis - Thematic analysis of the focus group conversations involved an iterative approach of collaborative coding with the research team and students, sharing initial themes with the co-researchers for refining and continued exploration, and holding a conversation with focus group participants to reflect on findings and get input.

Sharing Findings - A collaborative approach continues with sharing findings. In preparation for a presentation to the Chicago ASA Roundtable, the co-research team worked collaboratively on the main messages, and the presentation was given by Buddy Moore and Kristin Bodiford. The co-research team provided valuable input to this report and it has been distributed to all focus group participants. Presentations were also given to Contra Costa County workgroups. The findings report was shared with participants and community partners.

Ethical Protocol - This study received ethical approval from the Dominican University Institutional Review Board (IRB). All participants were provided informed consent forms and were informed that they were free to withdraw at any time. Participants consented to the recording of interviews, which were subsequently anonymized and transcribed.

Key Findings

The analysis produced four key findings.

Challenging Experiences - In the beginning of the pandemic, many people felt a sense of panic, fear, uncertainty, and anxiety. Participants learned to take greater precautions in order to stay safe. Most also experienced abrupt changes, disruptions, and a loss of what was normal in their lives. Several experienced decreasing access to healthcare along with other personal challenges. There was also a common concern for the well-being of others.

Building Resilience - Positive experiences such as humor, appreciation, gratefulness, optimism, spirituality, and empathy are as much a part of this story as disruption, loss, grief, and sadness. Participants often reframed negative experiences into a more positive outlook. There was a determination to make it through this time. Many tapped into their strengths and knowledge and learned new skills. They used their strengths and skills to adjust and cope with challenges. For many, this time supported them to slow down, taking time for reflection, increasing self-awareness, and re-evaluating priorities. Some people learned to use technology to communicate. The use of technology brought people together with friends and family in some cases even more than before the pandemic. Social connections helped people feel less isolated and helped bring them peace of mind.

Considering Vaccination - Some participants didn't have to think about whether to get vaccinated. It was a "no-brainer." Others spent considerable time researching about the vaccines in order to feel comfortable with its safety. Several people found it challenging to get the information they needed to make a decision. A few chose to get vaccinated when they heard of others dying from COVID-19. Most shared that they want to live their lives more fully. Many waited to see others get vaccinated and learn more about the side effects and safety before choosing to be vaccinated themselves. Several found reassurance in comparing the COVID-19 vaccination to other vaccinations (flu, shingles). Participants viewed Dr. Fauci, African American scientific and medical experts, and their own personal doctors as highly trustworthy. Several wanted to be advised about their own health conditions and concerns as they relate to COVID-19 and the vaccination. People shared that being able to talk with others, share their concerns, and hear other perspectives has been valuable.

Equity & Access - Participants are also concerned about equity and access to the vaccine for others, and many encountered barriers themselves. Some wanted to make sure other generations and groups of people facing challenges receive the vaccination first. While there are feelings of mistrust stemming from historical inequities and unethical treatment, (e.g., Tuskegee), many trust the science and scientists.

Themes

This section digs deeper into the significant themes.

Experiencing Challenges

Participants experienced feelings of **panic**, **uncertainty**, **worry**, **anxiety**--especially in the beginning of the pandemic --which created a need to feel safe and secure. They began to spend more time alone. Most talked about how abruptly things changed. They experienced **postponements**, **delays**, **disappointments**, **frustrations**, and an inability to plan.

"My experience has been like a roller coaster. Originally it was like a caged bird for me."

"I feel like I have been a hostage in my own house because I don't drive so that means that I catch the bus and the subway to go where I want to go."

"My experience has been a lot of delays and postponements and frustrations but finding new ways of functioning. My needs are being met, it's just slow in coming. So that's very frustrating. But it's just a new way of doing things, of seeing things."

Participants began to **take more precautions**. For example, adopting practices like wiping things down, letting things sit. Washing hands and wearing a mask became standard practice. Some practices were initially seen as a burden but became to be accepted over time. While others such as not hugging others or not seeing family or people who are at risk, was very difficult for most.

"I assumed the responsibilities that had to be assumed. The caring of hands, protection with the mask, not having contact."

"But that [giving hugs] is not possible now, and I had to come to grips with that. And I had to help other people come to grips with that because overnight we were thrust into a situation that is not normal."

Participants shared that **safety** was important to them. They wanted to feel safe with their families, young and old. They wanted kids to feel safe to go to school. They wanted to feel safe in the doctor's office and in public around other people. They had specific concerns about the impact of the virus because of their age. They want for public health organizations and others to keep communicating safety guidelines - to wash hands, wear a mask, socially distance - to do the right thing.

"I think we all have that need, the need to feel secure when we are going around family members, especially older. Or when we ourselves are being approached and the encounters we have with the younger people. You know - that peace of mind."

Participants talked about an increased **sense of loss**, things that were planned were

being cancelled, loss of social connections and physical contact. Most missed going to church and regular family events. They also shared a loss of freedom and independence. They shared about how their limited ability to get around affected their level of exercise. They were unable to go grocery shopping and essential things simply took longer.

"I know my grandchild mentioned 'I miss my friends' and I can see why because I hear people from the center always saying we miss each other, because that was an outlet for everybody, young and old, to participate with their loved ones, their friends, and their families."

"I go everywhere on the bus. So, when all of this happened, and I knew that I couldn't take the bus, it was just not good. It took all my independence away. Because that means I had to ask people, that sometimes didn't want to give me a ride but did because I do things for them."

There was a **decreased access to healthcare**. These restrictions limited some participants' abilities to support others such as attending hospital appointments or treatments with them. People shared concerns and anxiety about health care settings, often avoiding appointments and delaying treatments and routine medical care. Others eventually did virtual appointments.

"The first 6 months I would not have gone for an appointment. Most of them were being cancelled anyway, so it didn't matter."

"My husband was diagnosed with cancer during this time and that meant he had to get chemotherapy treatments. Well, I'm used to going with him to his appointments, but I couldn't go with him, I had to be on virtual while he's in the appointment with the doctor. It was pretty scary, because now he had to wear a mask and I had to be careful about whether he was bringing something home from the hospital."

Participants experienced other **significant challenges.** One person was sick with COVID and is still challenged with health effects. Another person experienced chronic anxiety, which was made more severe during this time. For those who were working, COVID affected their ability to work and survive economically. Several others had children or grandchildren in their home and were challenged with adapting to the new requirements of learning online.

"I got infected in November of last year. I went to the hospital for 13 days. Thank God I have good family support and I speak English. Thanks to God, I am alive. And with the help of my children, I was able to continue paying for my medical treatment because I still have, like in the lungs, I have an inflammation that I am undergoing treatment for. I finish my treatment in summer."

"The impact of the pandemic was very critical. In my work they told me 'We are not going to continue; you are not going to continue working'. I did not know what to do and I started looking for alternatives to survive economically. I even applied to unemployment and that was all a collapse of anguish and the despair of feeling, 'what am I going to do at this moment that I lost my job? In the different processes that we, the different immigrants, are in'. In my particular case, I am in an immigration process during all of this."

"I also have a 12-year-old granddaughter living with me and it was very disturbing for her because all of a sudden her young life was disrupted. And then my granddaughter was on Zoom. Zoom and all that was new to me. What affected her mentally during this stage affected me too because I have to consider her feelings and help her out during this time of transition and caring for this."

Many shared a **concern and worry for others**. They worry about people who need support or family members who don't have health insurance, families in need. Several discussed their concern about other older adults who don't participate in a senior center and don't have anyone reaching out to check on them. One person shared a concern about others' isolation and mental health. Many shared a concern about children not being in school. Several shared a concern about young men involved in street activity/selling drugs or people who are experiencing homelessness being able to access the vaccination. In general, people were concerned about others impacted by COVID.

"Those who live with many people, you know, who cannot be separated from their home. Those who lose their jobs and lose their apartments because they have no money to pay. These are all poor families of different languages."

"There are people who need someone to check in on them. In the city of San Pablo, the members of the senior center, the staff, talk to them, check with them on what they need. But I am talking about people who do not participate in the senior centers."

Building Resilience

One of the strongest messages from the focus groups was the importance of **positivity**. Participants often reframed negative experiences into a positive learning or frame of mind and often communicated gratefulness, appreciation, optimism, and hopefulness. There was often a sense of humor in the conversations, with people sharing how important humor was to their well-being.

"I feel grateful for the things that we do get to enjoy every day in life and these formats that we're enjoying them in, talking to people." "I am trying to look at things in a positive way. Everybody is calling me, first thing in the morning they are calling to make sure I am alright or to tell me what they have going on. And that I appreciate."

"These are the stories that I love, they are the stories that make me cry, they are the stories that I grieve with others, and then I participate in the humor that other people have".

Spirituality was important to many participants. Some say they have found themselves praying more and counting on their spirituality. While they were not able to attend church in person, many attended churches online. Church members also were an important source of support.

"I lived in a lot of tranquility, putting my family, my friends, and the whole world well, humanity - in prayer. And I calmly lived through it."

"I prayed, I prayed some more, and I prayed some more. Reading the bible has been my way out."

Coping was a strong theme. Participants were resourceful and had a sense of resolve and persistence to get through this time by making their lives as normal as they could. Though many activities were limited, they found what they *could* do.

"It has been scary, and at the same time, it has been encouraging as we have worked our way through the last year."

"I think this has strengthened my coping skills. I was working on that anyway from a personal standpoint, but it's brought me a new level of maturity even in my elderly years. I am learning to cope even better."

Several also increased their **wellness practices**, including activities like yoga, meditation, breathing, exercise, going for a walk, focusing on a healthy diet, and cooking new recipes. Some limited news exposure as a way of reducing anxiety.

"I've learned to get more into myself and things that I used to do and learn new hobbies. I have a lot of time on my hands to do things that I didn't think about before, things that I used to do in the past. I've also learned to cook instead of the restaurants and this fast-food stuff. I learned to cook like I used to, and I learned to do things the way my grandmother did, as far as preparing everything fresh and taking your time and just cooking from scratch."

Many participants shared that this time offered them an opportunity to **slow down**, with more time for **self-reflection/ self-awareness and reevaluating priorities**. They also mentioned taking time for themselves and engaging in other interests and hobbies. For many, this was a time of personal growth and learning.

"I had to slow down. In some ways I think it was good. It gave me a chance to back up, reflect, and say 'What is it that you are trying to do?' And I thought about it and said this is great, I am not anxious anymore, I can sit back and relax and plan my life 2021, 2022 etc. That has been a good thing and has taught me to be patient and slow down."

"People are stopping to smell the roses. We tend to be so busy we don't stop to take note of what is important in life".

"Both of us came to this country to reinvent ourselves since we arrived. Then with COVID, we had to continue to reinvent ourselves."

"I gave myself the opportunity to reflect on my life and I have a different perspective on my life now...deciding how I am going to continue my life at 71 years old."

Technology was an important resource. Those who were resistant to technology before learned how to use it, which increased opportunities to connect and drew people closer. Many also used it to order groceries and food. Most found technology offered assurance and support in their lives.

"I always would tell my children, don't get me an iPad now because I haven't learned the telephone yet. But this thing has helped me a lot. I really do enjoy it. Because I have 10 children, I really need it to keep up with them and for them to keep up with me. So, we do the Zoom calls and that has been a real blessing. I would chase them from my iPad right now. I think all old people need to have one."

"I am very grateful to Zoom, that we have that format, and you don't lose contact."

"For me, technology was a blessing because it was a way to unite, a way to break, in a way, the fear. Although I will not replace technology with human contact which is very important to me."

"The only downfall we could not attend church, but with Zoom I was able to attend many churches."

"Grandpa, you really need to learn how to use the computer because we want to talk to you, we want to talk to you, and we just want to call you."

While participants increased their sense of self-reliance and independence, they also learned how to accept help and sought ways to support each other, noting they appreciated that they were able to rely on others. Through a strong sense of **empathy and mutual concern and caring for others**, many shared stories about how they have experienced helping each other get through this time. People communicated a concern for others—children in school, young people, people who are experiencing homelessness. Many felt grief and connection to a collective experience of loss.

"We haven't been to church, but we keep in contact by texting each other and keeping in contact with each other that way but it's still hard. It is also very hard because our church has lost a lot of people and you don't know what to do. You can't go to the house, yet you want to go see them, or hug them or bring stuff to them."

"I have to manage my feelings about that, my grief about the loss of life. But I am happy to be concerned if that makes any sense because that's my human connection.

"We have to help each other get through it."

"We need to really engage the young people and say we love you and you are going to have a future, but you can't have a future if you are not protected."

Staying connected and communicating with others was important to most participants. People appreciated increased communication and connectedness with family and friends. Several shared that during this time they were learning to listen better. They appreciated the opportunity to listen to others' perspectives and felt comfort in knowing everyone was going through this together. Supporting and listening to others, hearing their stories, helps shift negativity into positivity.

"Communicating with other people that I care about, that helps a lot. Just being able to talk to family and friends about what is going on and getting different perspectives."

"I thought I had all the questions and answers, giving advice here and there and I found out that I wasn't really listening to the other person. When I began to listen, I could empathize with the fact that they might have lost a loved one during this time, they have lost a lot."

"On the positive side it drew my family closer with Zoom. We took trips and celebrated anniversaries and birthdays. It drew us closer because due to the wintertime sometimes we [normally] weren't able to see each other. But with Zoom we had baby showers and all types of celebrations.

Participants appreciated support that family and others provided.

"I probably appreciate support groups even more than when I was able to participate face to face, I look forward to that, that keeps my voice active, that keeps me participating, that keeps me connecting with other people."

"My daughter says 'Mom, take care of yourself' and she also collaborated a lot with me."

"I go to meetup.com for a group to talk in Spanish every Friday."

Participants shared the need for **peace of mind**. They wanted reassurance and comfort, having someone to share feelings with who cares about how they feel. Several people said

they wanted someone checking in on them. They wanted to be able to discuss information together to develop solutions and provide mutual support. Often people shared they also just wanted a hug.

"My grandson is 10 years old, and he'll come over, and he'll walk toward me and then he'll look at his mother like 'can I, may I?' It's heartbreaking. So that's what I need, I need someone there to hug."

"Early in the morning they are calling me first thing in the morning to make sure I am alright or to tell me what they have going on, and that I appreciate."

Participants shared there were **unanticipated benefits** during this time such as saving money. They also appreciated changes that have been made in the health system to support their safety. People also re-evaluated their priorities and were inspired to do other things, build other interests.

"We can save some money during the pandemic because we're not engaging in some of the activities that we normally would be engaging in that cost us money, things like shopping and travel."

Decision Facilitators

Most recognized the decision about the vaccination as a **personal choice**. They feel people need to have the evidence that is most useful to them to support their choice and that it is important to address people's concerns. Many put a lot of thought into the decision, others didn't even need to think about it. Most were clear this was their decision to make for themselves. Several people also shared a **sense of collective responsibility** by receiving the vaccination.

"There is an African American doctor that visits African American Churches, not to persuade them, that is an individual decision, but to make sure they have the best information possible."

"My granddaughter and niece didn't want me to take it. I had people in my ear, which you know, they don't make decisions for me. So, I was determined, and I knew I was going to take it. Yesterday I had my first one and I am thankful for that."

"If I take the vaccine, I will be helping myself and my community."

Feeling well-informed helped support participants' decision making. As they considered taking the vaccination, information on side effects was important. They shared that Dr. Fauci, African American doctors, and personal doctors play an important role in providing credible information. Several prioritized understanding the vaccination in the context of one's own health/conditions before making any decisions, being mindful and addressing specific medical concerns.

"The bottom line is that I need information, I need to look into your face and for you to tell me what is really going on with me."

"I'm going to have a talk with my primary and cardiologist just to get their feedback about my underlying problems before I make that decision. I really would appreciate more medical data about this vaccine before I decide to take it."

While there was recognition of the history of medical research for Black participants related to Tuskegee, most **trusted the science**. Some did extensive research. Others also relied on informal sources and word of mouth.

"I know what happened at Tuskegee, but I have a lot of respect for science and for Dr. Fauci. I guess he is one of the first doctors that I haven't met personally that I could say 'I trust this man'. There is something about his spirit that I trust."

Some shared they decided to get the vaccination to **avoid sickness and death** after knowing people who have died. They also decided it was similar to receiving the flu vaccine in order to avoid getting sick. They normalized the vaccination just like other practices to avoid disease. Some felt a sense of urgency and wanted the vaccination to address high risk situations with their own health or living with others at higher risk.

"I saw all these people talking about the body bag, and so many people dying in New York. Then when it reached home and so many people passing away and when it hit family, I said 'I will take that shot, I can't wait.' You know, I said 'well I had the flu shot, pneumonia one, shingles one, why not this one?"

"Two friends passed from Covid who were the same age and healthy. And I said 'Wow here I am, in the same age bracket, I have a lot of health problems, and I live in that atmosphere with seniors, and I really need to do something for myself. I need to protect them, and I need to protect myself.""

Many participants shared that the idea of the vaccination **instilled a sense of hope** and new possibilities. Several made the decision to get the vaccination to "live life." They communicated having goals, doing things they wanted to do like travel, and passing on their wisdom to others. They also wanted to stay independent.

"That is why I have to take the vaccination. I wonder, what do I want to do with my life? You know, I have children, grandchildren, and a great-granddaughter. I can give them more time and pass my wisdom on to them."

"I am going to turn 89 next month and I don't have time to waste. I got to be well because I have things to do."

Many who said they waited in the beginning or still hadn't decided **wanted reassurance from watching others**, seeing what the side effects are and that others respond OK. Some

wanted reassurance of how vaccines were developed and what "approvals" mean. Several were encouraged by family or friends, which made a difference for them. People also shared they were comforted when there were practices in place during the vaccination process like social distance guidelines.

"But that was after I've seen a few friends and my brother, and you know other people that I could relate to being administered the vaccine, and I felt more confident about it."

Children, grandchildren, neighbors, and organizations played an important role in helping make decisions and accessing the vaccination. Sometimes family members made vaccination appointments for participants. In another situation, someone from the local council office called to schedule an appointment and made sure the location was convenient. In some cases, staff and members at the senior center or church checked in. One person received a message to sign up for vaccination on their phone. Others received information from trusted organizations (e.g., the Latina Center) on their Facebook pages.

"I have a friend who is panicky and told me 'No, I am not going to get vaccinated because we are guinea pigs.' The only way to help her was saying 'I already got it, and everything is fine' and that is important."

"I was going on the computer (to schedule a vaccination appointment) and every time I would get to the end it said, 'We are out of it'. And I just said to my daughter 'Maybe I'm just too slow with the computer.' So, my daughter said 'Okay, you go on the computer at your house, I'm going on at my house, and we'll see what we can do.""

"My 89-year-old mama was very hesitant with concerns (about the vaccine). She has congestive heart failure, diabetes, and high blood pressure. I was able to make an appointment for her by calling several times. She was very upset with me. She said that if she died, she's going to come back and haunt me. We put her on a three-way call with her primary care physician who strongly recommended it, and with her heart specialist. They were strongly recommending that she have the vaccine. She had it this past Tuesday."

Decision Barriers

Except for the few that didn't even need to think about receiving the vaccination, almost all participants had **concerns about the vaccination**. Most were worried about side effects and wanted to see how it might affect others. Some had reactions or allergies to other vaccinations in the past. A few were concerned about their underlying health conditions. A couple had family members that were concerned and who advised them not to get the vaccination. Several also shared they were worried about their exposure to others during the vaccination process. A fear of needles was expressed as a barrier by some people.

"I really don't like the point that they're putting all these celebrities out taking pictures,

like the baseball player Hank Aaron took it and then two weeks later...but that's not saying it was from the vaccine. But for people like me that gives me pause of doing that."

Sometimes participants felt **skeptical about the data** and didn't feel they understood the development or approval process. Some didn't feel they had the information they needed to feel comfortable or were not clear about the evidence or were confused by the information they were receiving. They acknowledged hearing **mixed messages** from social media and from other generations.

"I did get a mixed message from some of the younger people when I told them I was getting the vaccine. They were like, 'No, you don't need to do that', because they're getting their information from other places, you know from the social networks, social media and so forth, and sometimes those are not the most positive messages or the most informed messages."

The **negative history** of medical studies like Tuskegee made some participants wary. Several also had a fear of organizations taking their personal data at the vaccination locations due to their different immigration situations. There were also confusing rules by federal, state, and county governments.

"I remember Tuskegee. I was a little girl, and I haven't forgotten."

"I also think for a little bit that it may be fear because they will take my data, because they will have my address."

Equity and Access

One of the biggest challenges was **knowing how to access the vaccination**. Not knowing how to or being able to register by phone or online or lacking technology were barriers. The process to sign up in multiple places and then some places calling participants was confusing. Others found it difficult to get to the vaccination location and needed something closer to where they lived due to mobility or transportation barriers. The issue of limited supply of vaccines also made it difficult.

"I have an 80-year-old friend, she and her family decided to get the vaccine and she can't get an appointment. She's been calling and calling. She is readily capable of registering herself. She is very savvy on the internet and phone. She is a very calm person, but I heard the frustration in her voice just trying to get an appointment."

Strategies for Action

The following are several proposed strategies for action from focus group participants:

- Reduce sensationalism in the media and increase objective sources with good information to counteract myths. Be clear with scientific, concrete information from real sources to reduce uncertainty.
- Develop a campaign about people's experiences receiving the vaccination including public leaders/officials who are role models along with a diverse group of people who can give testimony and communicate directly to the community— spreading voice.
- Provide tips by specialists, coaches, psychologists.
- Place signs in public places that people are exposed to.
- Engage trusted people in communities to do outreach.
- Create messages in a culturally appropriate way that enable people to connect.
- Share information flyers about the vaccination at the food pantry.
- Identify older adults who are alone and need support and match them with a volunteer who can reach out with well-checks.
- Make available hotlines in Spanish and other languages.
- Provide alternatives for people who cannot make vaccination appointments due to lack
 of access to technology. Provide in-person outreach with brochures for many people
 not on Zoom or social media.
- Coordinate with organizations joining together to provide well-checks.
- Give clear information on the news that doesn't scare and leave people with anguish and uncertainty.
- Provide knowledge of the new vaccine for older adults from Latin American countries who may have a different understanding of the way vaccines were developed.
- Partner with organizations that deliver food for people who live in apartments and cannot go out. Focus on multipliers of resources (for example when they were doing census outreach, they provided COVID testing information.)
- Ensure vaccine access and efficiency of process for registration for all people, ensuring equity of availability and access.
- Address technological barriers and access to technology.
- Provide mobile vans and other strategies to reach out to seniors, people with disabilities, and those without access to technology. Sending flyers to all homes was a strategy people suggested to ensure all people had access to the information they needed.
- Offer rides to the grocery store and doctor's appointments with trusted people.

Several people shared they wanted to take action to volunteer, to reach out to others, do well-checks, send flyers. Some have already taken actions to help others to sign up for and access vaccinations.

"I really need to feel comfortable that people who want the vaccine can get it."

"I gave myself the opportunity to register over 60 people. Since I have lived here for 50 years, I know the community, I went to some apartments where I knew there were many older and disabled people. I connected with the property manager and there we started. We signed them up and arranged the transportation."

"Send me a flyer and I'll take copies at the pantry for people to see."

"I realized that soon after participating in my focus group conversation, I began to seek out people who had not been vaccinated and offering to find them appointments. Oftentimes it meant spending a great deal of time at various periods of the day and night searching for vaccine appointments available through state and local providers and with third party providers. I didn't realize how much time I was putting in until I started getting up at 3:30 AM and staying up until 7AM searching my computer for available vaccine appointments. To date, I've personally helped 19 people get vaccinated. One of my neighbors has helped 15 others."

Highlights

The following are highlights that focus group participants, students, and community partners found most important. We end with a call to action and with a renewed commitment to continue strengthening relationships and connectedness in communities as a source of support and resilience.

Connection & Community

People were able to build connections and a sense of community. These connections and community provided reassurance and support.

Voice & Stories

Ensuring everyone's voices and stories are heard and valued in a brave space can be a powerful tool for addressing inequalities in communities.

Empathy & Compassion

Empathy, understanding, and compassion for all will get us through the pandemic together.

Resilience & Growth

People's stories reinforced their resiliency throughout hardships. People were able to grow and develop new strengths and skills during this time.

"Even though we were isolated during the time of COVID we seemed to be shifting our focus from ourselves to others. While we are developing these new skills, we are still thinking about others who might need to get a vaccination, who might need a ride to the grocery store, who might need to get a telephone call, who you want to hug. Even though we are in a pandemic and people are afraid and learning to do things in different ways it comes down to thinking of others and expanding relationships."

Call to Action

Strengthening connections to family, friends, and community has helped us get through these challenging times. We have an opportunity to build on these important connections to be even more organized than before in our collective efforts to rebuild community and address inequities.

01. Advocacy & Partnership

Access to trustworthy information and to receiving the vaccination was one of the biggest challenges that many people faced. It will be critical for organizations to join together in advocacy, with a continued commitment to actively elevate the voices of those most impacted and inform the issues in collaboration with community partners and older Black and Hispanic adults. The way forward is through strengthening relationships between systems and Black and Hispanic communities. In a system with historical racism and injustice, simply designing new messages is not enough. Authentic engagement from the community is essential.

02. Empowerment

Empowerment is a process through which people gain greater control over decisions and actions affecting their own health and well-being. From this perspective, older Black and Hispanic adults are not seen as passive actors but rather active partners in creating solutions and helping to promote innovation and systems change. These changes are then informed by their experience and their voices.

03. Equity

Over the next 20 years, the U.S. will continue to become both more diverse and older.¹¹ ¹² The foundation Commonwealth Fund asserts that in order to reduce health disparities, it is essential to acknowledge that race and racism factor into health care.¹³

"Efforts to improve health outcomes, ones for instance that fail to consider the particular factors that may lead to worse outcomes for Blacks, Hispanics, or other patients of color, may not lead to equal gains across groups — and in some cases may exacerbate racial health disparities. (Commonwealth Fund 2018)"

Intersectional inequity, developed by Kimberlé Crenshaw, Professor at Columbia Law School, states the intersection of different experiences such as racism, economic inequalities, ageism, ableism, nativism, and sexism can create disadvantages for groups of people.¹⁴

These interactions shape social determinants of health and produce major differences in peoples' lived experiences. Focusing on intersectionality requires flexibility to meet the unique needs of people with specific attention to structural factors that create barriers or risks. Addressing the intersections of experiences that create disparities requires us to look at root causes of inequities.

Limitations and Future Research

This intention of this research was to provide insights for vaccination communications efforts. Given the time sensitivity of this issue, we worked to balance the need to conduct and share the research rapidly while staying true to the values embedded in the research of collaboration, lifting voices, and disrupting patterns.

The sample size is limited to twenty-two participants. While we attempted to get a cross-section of representation such as people who are Black/Hispanic, from rural/urban areas, differing access to technology, there were limitations in our ability to engage in outreach and recruitment. Many of our focus group participants had already received at least their first vaccination. We had few participants who had significant concerns about the vaccination.

Building on this research, it is important for future research to explore the root causes of inequity in health systems and communications/accessibility efforts in order to develop solutions addressing structural factors that cause barriers and risk. Our commitment is to continue this inquiry and action in collaboration and partnership with communities most impacted.

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This research was co-led by C. Buddy Moore and Kristin Bodiford. Buddy is a member of the D.C. Multimodal Accessibility Advisory Council and Outreach Coordinator for the D.C. Ward One Senior Wellness Center. Kristin is Principal of Community Strengths, adjunct faculty at Dominican University, research affiliate at Portland State University Institute on Aging, Senior Fellow at Generations United, and advisor to HelpAge USA.



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"We feel we will be more empathetic and compassionate in our careers in social work.

Learning about how other populations are impacted helped open up our perspective. We want our older adult partners and participants to know their participation was purposeful and their involvement will help a lot of people. Your voices and stories will help many others. We also appreciate research more, being able to hear your individual stories."

Through this research students experienced the possibility of what change research can bring for communities who are impacted most. Working as a team with others was the foundation of this research. Their experience also reinforced that social workers play an essential role in advocating for the needs of the community.

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Citations

- 1. Please note, a decision was made to use the term Hispanic in this report. We recognize the term Latino is also often used to describe people with Latin American roots, with Latinx as a more gender-neutral description.
- 2. Ford, Reber & Reeves (2020) Gaps in COVID-19 deaths are even bigger than they appear. Brookings https://www.brookings.edu/blog/up-front/2020/06/16/race-gaps-in-covid-19-deaths-are-even-bigger-than-they-appear/
- 3. Ndugga, et. al (2021) Latest Data on COVID-19 Vaccinations Race/Ethnicity. Kaiser Family Foundation. https://www.kff.org/coronavirus-covid-19/issue-brief/latest-data-on-covid-19-vaccinations-race-ethnicity/
- 4. Rogelio Sáenz, PhD, Marc A Garcia, PhD, The Disproportionate Impact of COVID 19 on Older Latino Mortality: The Rapidly Diminishing Latino Paradox, The Journals of Gerontology: Series B, gbaa158, https://doi.org/10.1093/geronb/gbaa158
- 5. Ray, Rashawn (2020) Why are Blacks dying at higher rates from COVID-19. Brookings https://www.brookings.edu/blog/fixgov/2020/04/09/why-are-blacks dying-at-higher-rates-from-covid-19/
- 6. Anderson, Perrin, Jiang & Kumar (2019) 10% of Americans don't use the internet. Who are they? Pew Research Center https://www.pewresearch.org/fact-tank/2019/04/22/some-americans-dont-use-the-internet-who-are-they
- 7. Anderson & Kumar (2019) Digital divide persists even as lower-income Americans make gains in tech adoption. Pew Research Center https://www.pewresearch.org/fact-tank/2019/05/07/digital-divide-persists-even-as-lower-income-americans-make-gains-in-tech-adoption/
- 8. Smith, Aaron (2014) African Americans and Technology Use: A demographic portrait. Pew Research Center https://www.pewresearch.org/internet/2014/01/06/african-americans-and-technology-use/
- 9. Perrin & Atske (2021) 7% of Americans don't use the internet. Who are they? Pew Research Center https://www.pewresearch.org/fact-tank/2021/04/02/7-of-americans-dont-use-the-internet-who-are-they/
- 10. Kellogg Community Health Scholars Program. (2001) Stories of Impact: Kellogg Community Health Scholars Program.
- 11. The share of the older population who is at least 65 will increase from about 1 in 7 today to about 1 in 5 in 2030, while the number of people who are at least 85 years old are expected to increase two-fold. The United States will likely be majority people of color by 2045.
- 12. The United States will soon be bigger, older, and more diverse (2018) APM Research Lab. National Equity Atlas
- 13. Commonwealth Fund (2018) In Focus: Reducing Racial Disparities in Health Care by Confronting Racism. https://www.commonwealthfund.org/publications/2018/sep/focus-reducing-racial-disparities-health-care-confronting-racism
- 14. Crenshaw, K., 1989. Demarginalizing the intersection of race and sex: a Black feminist critique of anti-discrimination doctrine, feminist theory and anti-racist politics. University of Chicago Legal Forum, 1989(1), pp.139-167.