

The Community Vaccine Collaborative

Mobilizing and Organizing in a Community to Promote Vaccine Equity

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Acknowledgements

- Urbankind Institute, Urban League of Greater Pittsburgh, Casa San Jose, Neighborhood Resilience Project, community co-leads of the CVC
- Elizabeth Miller, MD, PhD; co-founder of CVC
- Mylynda Massart, MD, PhD; Ken Ho, MD research co-leads of the CVC
- All members of the Community Vaccine Collaborative with whom I have had the immense privilege of partnering
- University of Pittsburgh Momentum Funds, Allegheny County Health Department, and Judy Martin, MD for providing funding



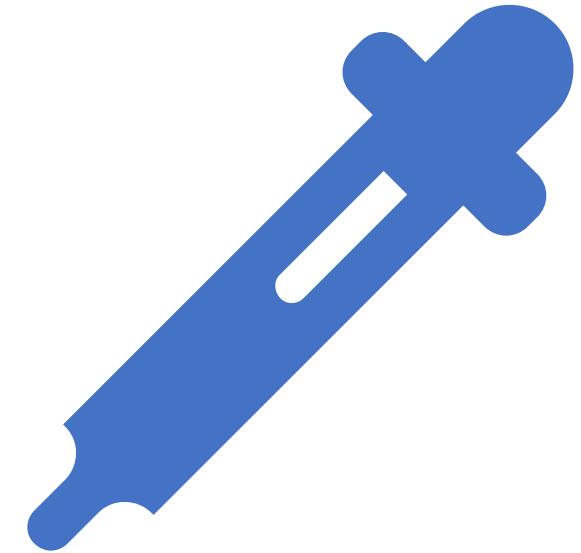
Land Acknowledgment

We live and work on the ancestral lands of the Osage, Lenape, and Shawnee people

We pay tribute and respect to their past, present, and future people, community, and culture

Agenda

- 1) Describe the mission, processes, and founding of the Community Vaccine Collaborative
- 2) Discuss key advocacy activities over the past two years
- 3) Review results from co-created research

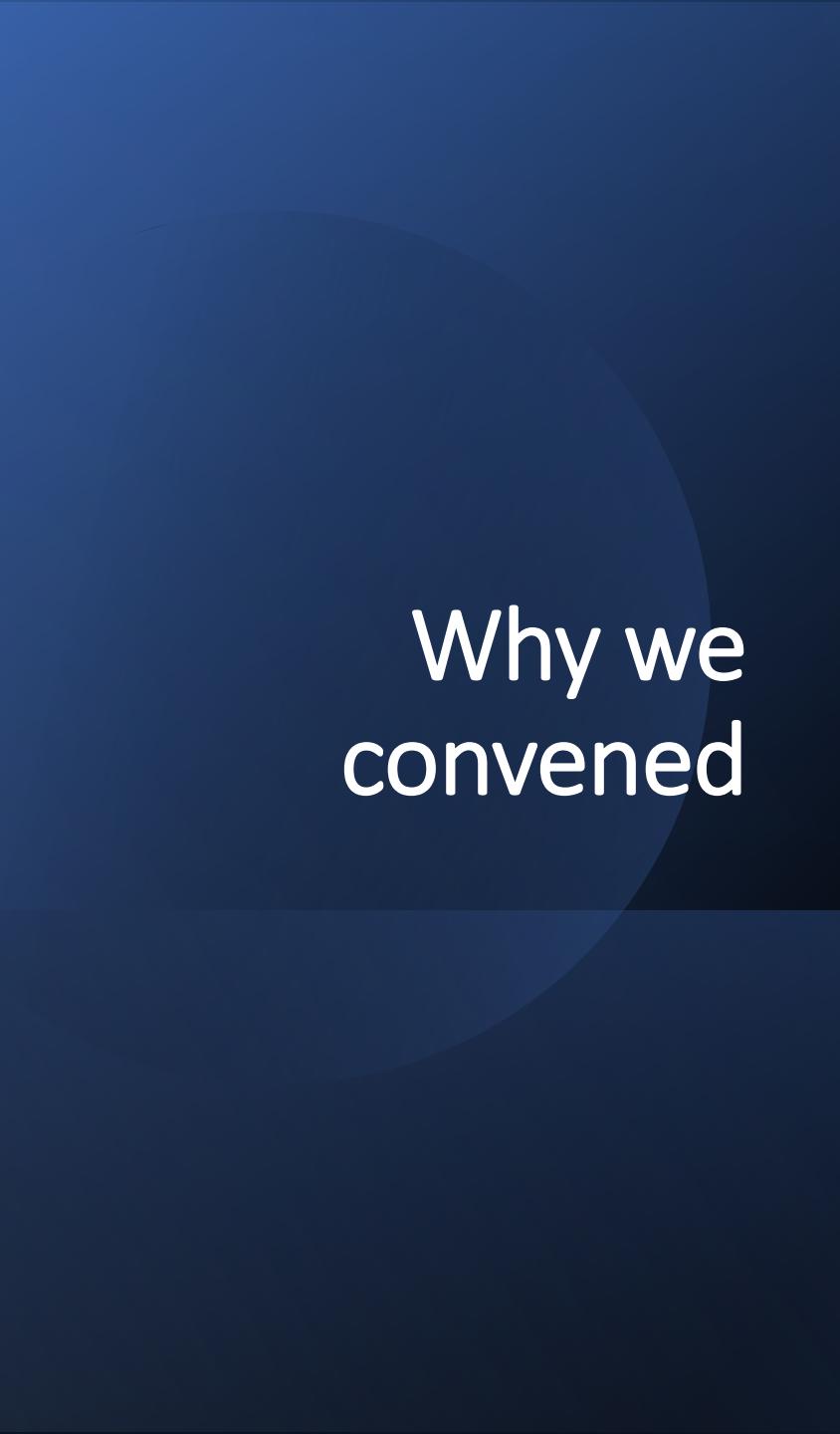


Community Vaccine Collaborative (CVC)

A **partnership** among community-based organizations, community members, researchers, health systems leaders, and leaders from public health agencies

Mission focused on dismantling COVID-19 related health inequities through promoting vaccine equity





Why we convened

Pittsburgh was a site for the COVID-19 vaccine trials and the trial site PIs wanted to put together an advisory committee

Team came together to try to do something different and reimagine community-partnered research

Context

Risk for COVID-19 Infection, Hospitalization, and Death By Race/Ethnicity

Updated June 24, 2022 · Print

Rate ratios compared to White, Non-Hispanic persons	American Indian or Alaska Native, Non-Hispanic persons	Asian, Non-Hispanic persons	Black or African American, Non-Hispanic persons	Hispanic or Latino persons
Cases ¹	1.5x	0.8x	1.1x	1.5x
Hospitalization ²	3.0x	0.8x	2.3x	2.2x
Death ^{3,4}	2.1x	0.8x	1.7x	1.8x

Los Angeles Times

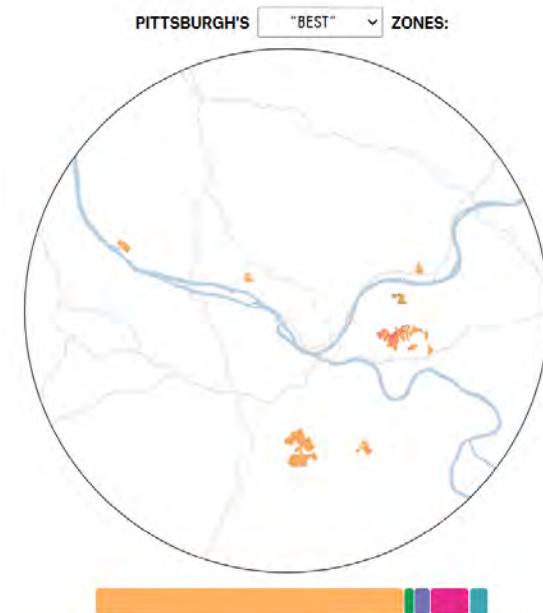
Column: 'Why won't Black folks trust us' on COVID-19? These doctors and nurses have answers

Erika D. Smith · 1 day ago



As a Black man and a nurse practitioner working at the U.S.

Department of Veterans Affairs hospital in Long Beach, Walter Perez hears a lot of cringeworthy stuff from his Black patients.



[The Lasting Legacy Of Redlining | FiveThirtyEight](#)

Black People Need Better Vaccine Access, Not Better Vaccine Attitudes

The focus on "hesitancy" as the driver of lower Covid-19 vaccination rates misses the real problem, and opportunity.

March 5, 2021

Context

Incredible
community
mobilization and
organizing



Carla Arnold, right, discussing volunteering for a coronavirus vaccine trial with Cecilia Goshay in Ms. Goshay's home.

Intentionality about our name

Advisory: “having the power to make recommendations but not take action enforcing them”

Collaborative: “produced or conducted by two or more parties working together”

Community partnered principles

Ability to anticipate and resolve problems

Committed partnerships

Sustainability

Authentic, effective, and transparent communication

Mutually respectful and reciprocal relationships

Why we sustained

COVID-19 disparities among Black, Indigenous, Latine, immigrant, refugee, rural, LGBTQ, and other historically marginalized communities rooted in cultural and structural racism

Historic and present-day inequities in power between communities and researchers

Support and center the health equity work be conducted within communities

Equitable compensation

Baseline reciprocity for partnership and leveraging expertise, time, wisdom, and trauma

Payment to our partnering organizations

Individual contracts with community members

Payment to co-create research



[This Photo](#) by Unknown Author is licensed under CC BY-ND

The CVC is led
by community-
based
organizations



Urban League of
Greater Pittsburgh

Pitt
CTSI



UrbanKind
INSTITUTE

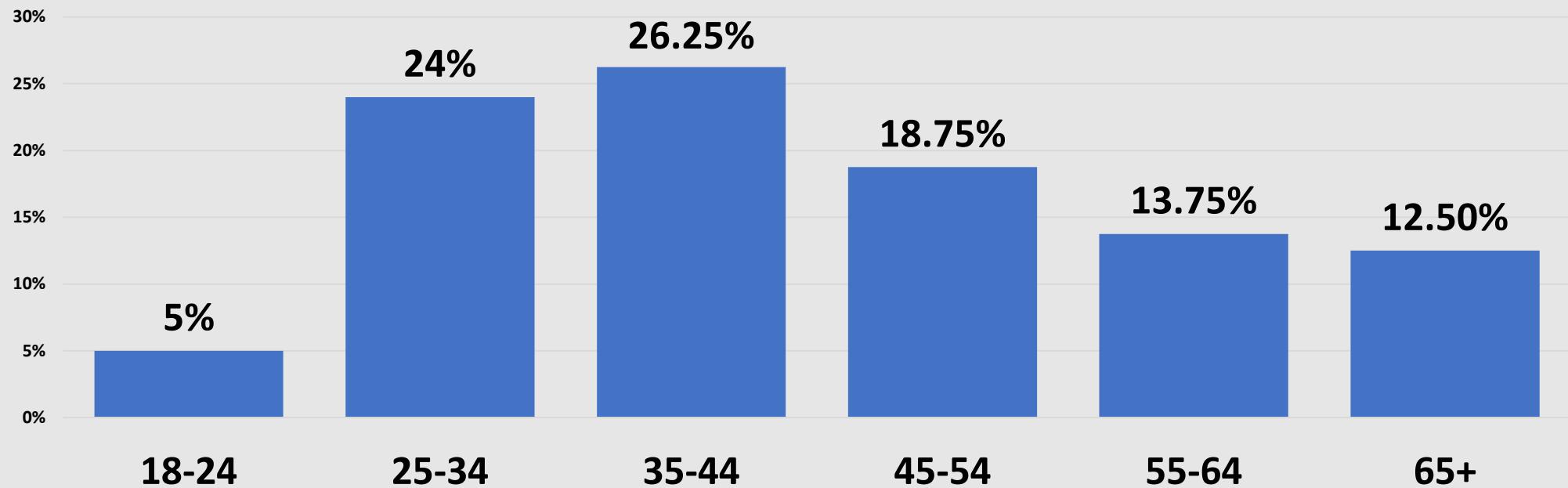
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Group meetings

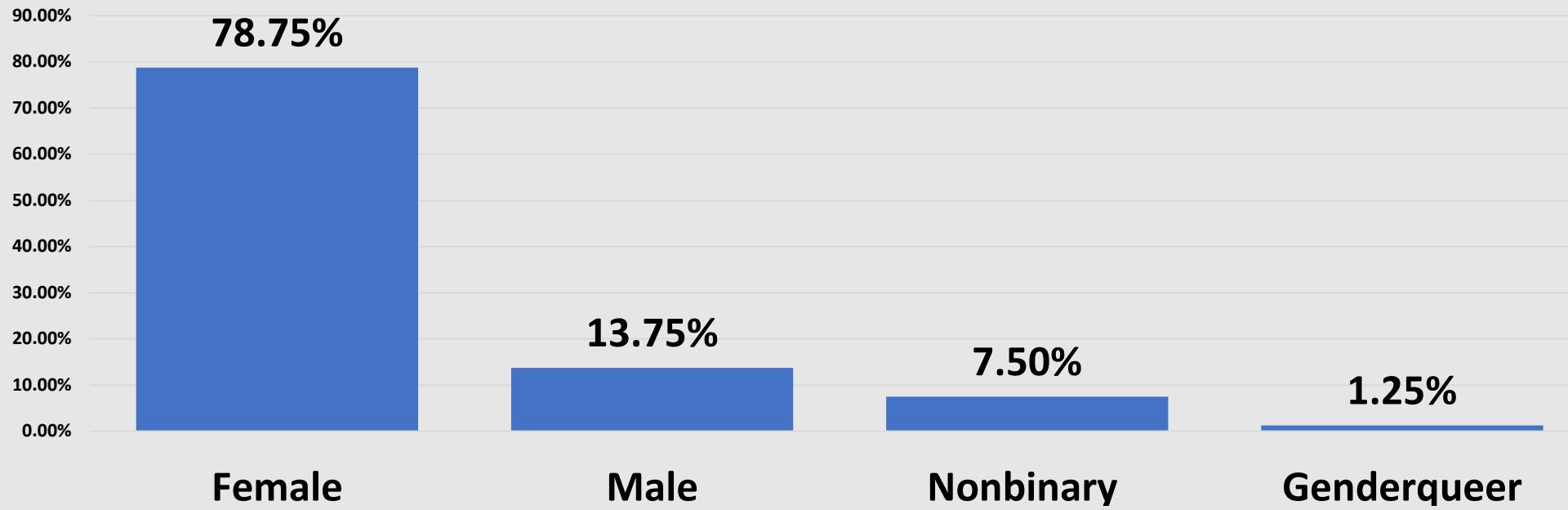
- Have met weekly from 3 to 4 PM on Wednesday since July 2020
- Attendance ranges from 20 to 40
- Mix of updates, conversations, community announcements, research presentations, reflections

CVC MEMBERS

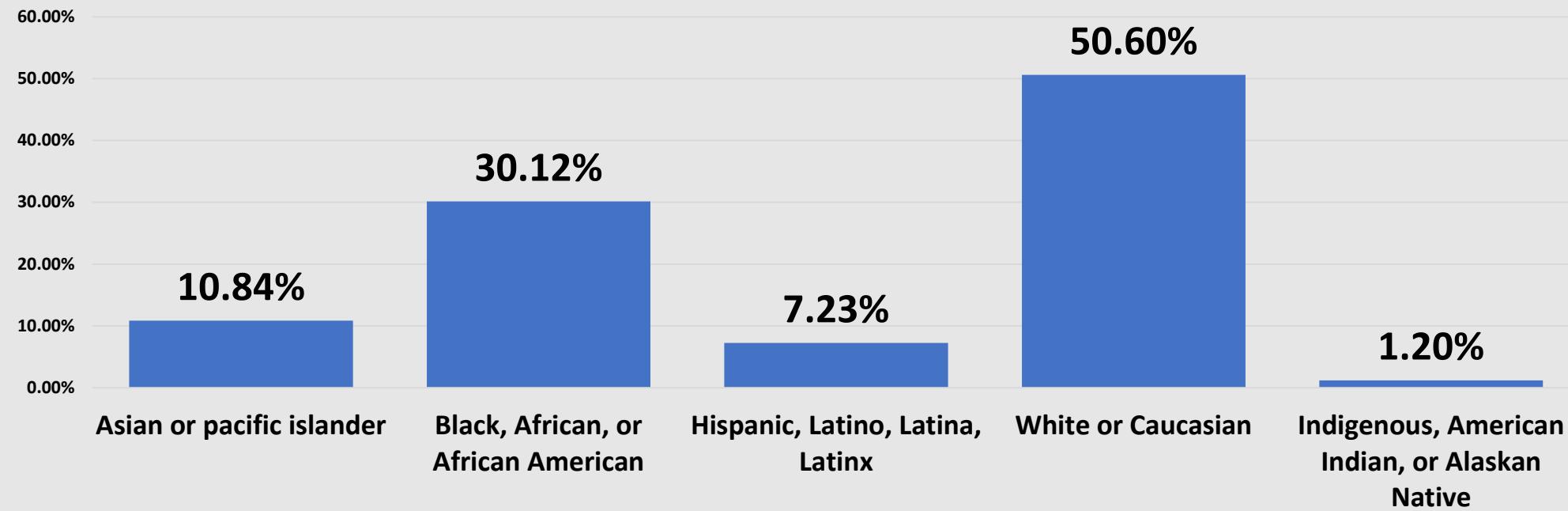
Age Breakdown



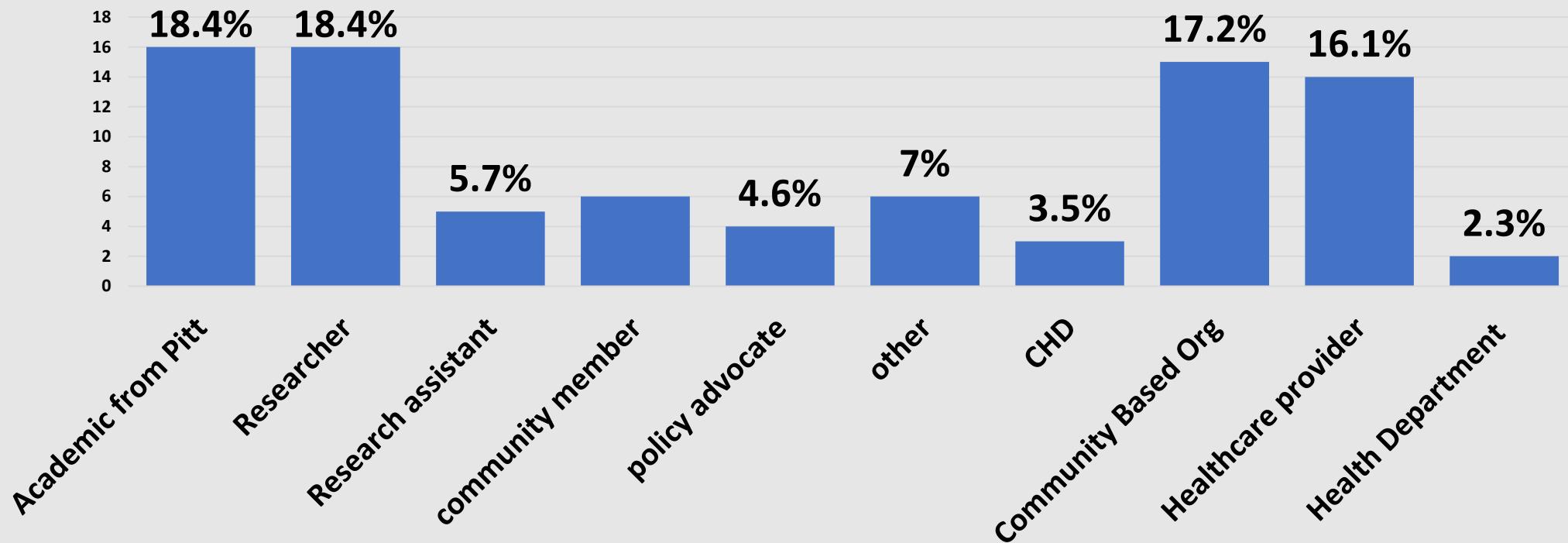
Gender Identity



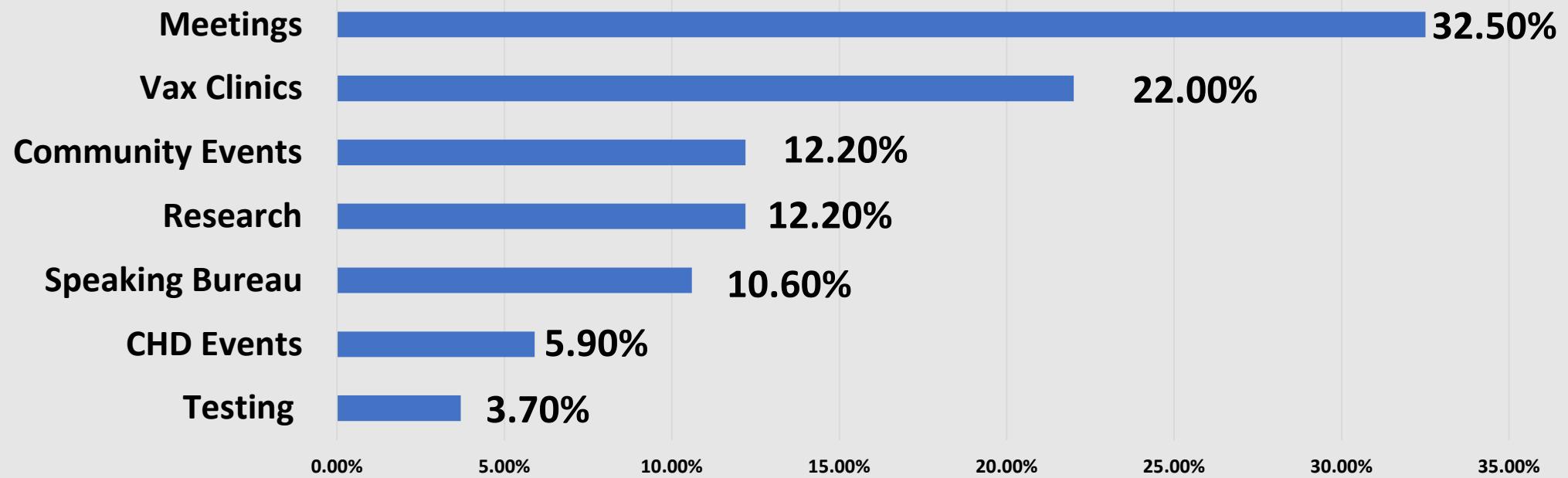
Racial and Ethnic Background



Roles of CVC members



Activities



ADVOCACY STRATEGIES

COVID-19 vaccine clinical trials



The first step is to indicate your interest in learning about the research.



A **registry** is a collection of people who are interested in being told about studies which apply to them. Being in the registry is **VOLUNTARY**. Your information is guarded with strict rules about privacy. You can stop being in the registry any time.



When you sign up in the vaccine trial registry (**PVTU.org**), this tells University of Pittsburgh researchers you might be interested in learning more about the vaccine studies in Pittsburgh.



When a study (vaccine trial) becomes available, then you may be contacted by the researchers to see if you qualify and whether you want to learn more.



To join the registry, the researchers need to ask you some questions and get your permission (consent) to review your medical conditions.

Why do researchers need this information?

The vaccine needs to be tested in people who are considered at high risk for getting COVID-19. All studies must have safety checks in place to protect people who join the study.

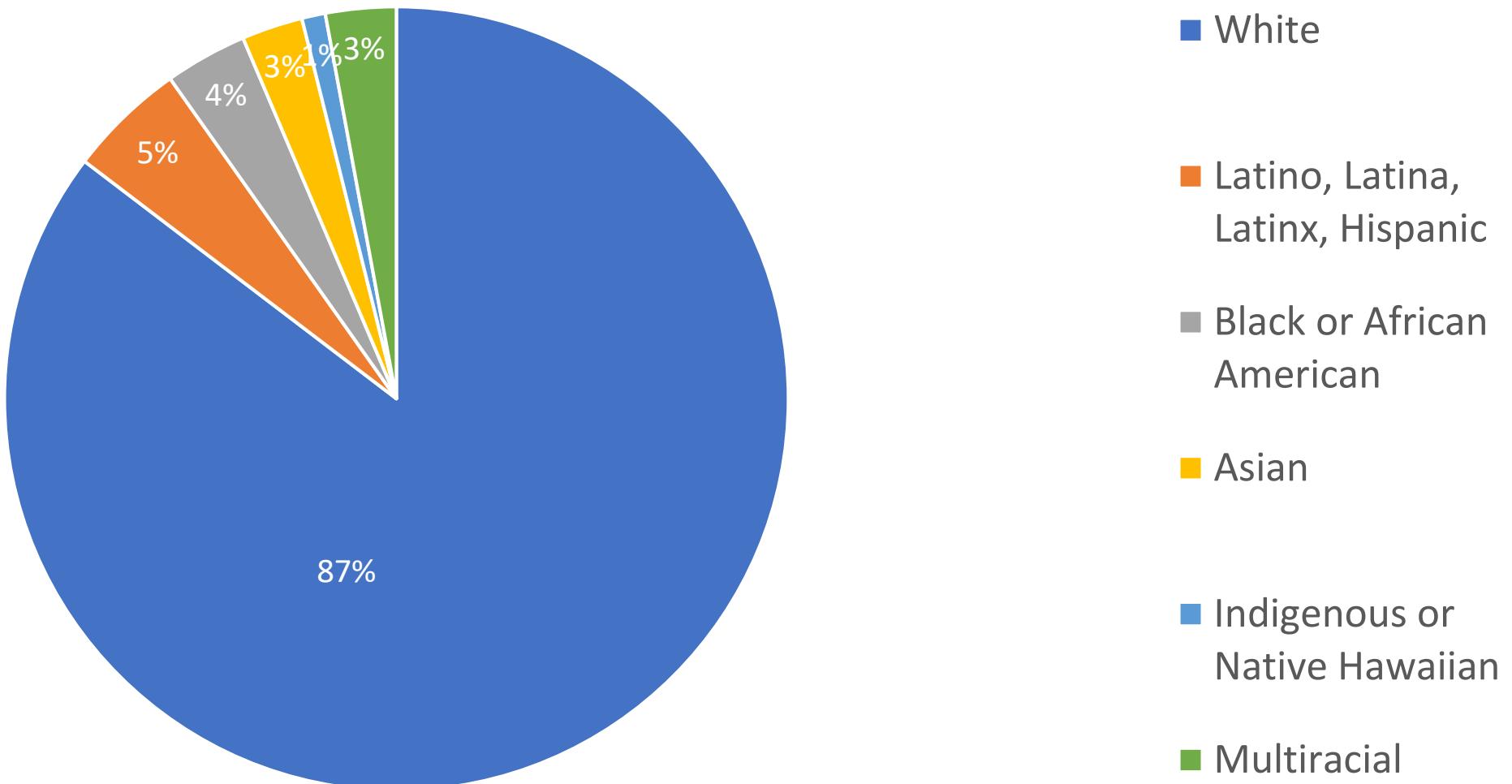


Essential workers: those working in health care, grocery stores, bus drivers, etc.



People living in neighborhoods or communities that have high levels of COVID-19

Pittsburgh Vaccine Clinical Trial Unit Registry



Community-partnered vaccine clinics

Inclusion of community health workers as Phase 1A during initial vaccine roll out

Community led clinics at community-based sites

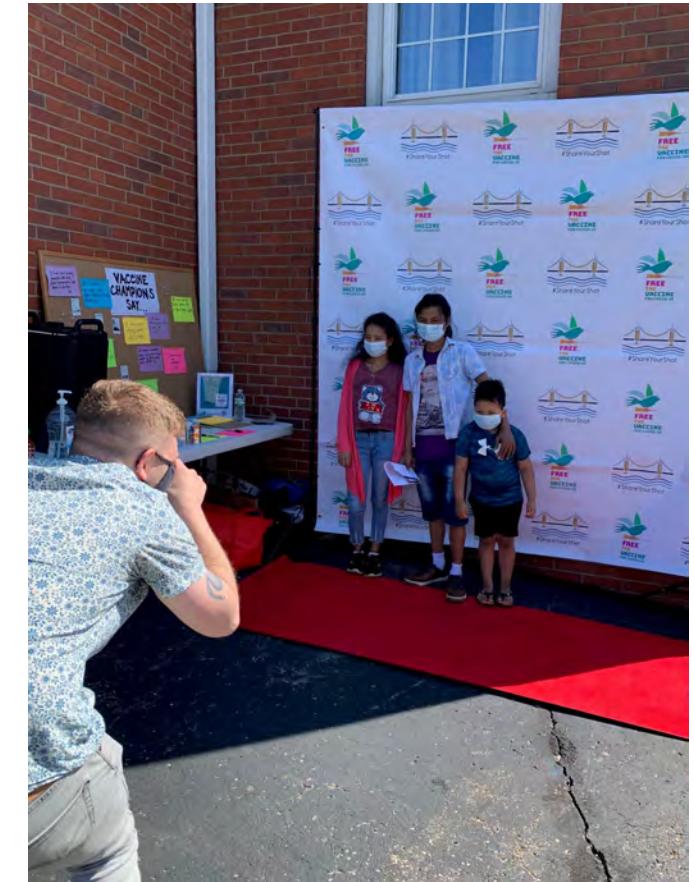
Schools, outdoor spaces, community-based organizations

Community-partnered COVID-19 vaccine access

Credit to Undervaccinated group

Type	Sessions Held	Vaccinated
Community	217	32,372
Fixed Location	884	206,606
School	368	15,903
Total	1,469	254,881

Vaccine celebrations!



Vaccine
community-
based
townhalls

VIRTUAL TOWN HALL *Meetings*



TRUSTWORTHINESS WORKGROUP

- “It would be wrong, as well as ineffective, to ask Black communities to simply be more trusting. Clinicians, investigators, and pharmaceutical companies must provide convincing evidence — sufficient to overcome the extensive historical evidence to the contrary — that they are, in fact, trustworthy.”
- Warren et al. 2020; NEJM
- Essential to addressing vaccine mistrust is shifting the burden of trust building away from the community, back to health care providers and researchers. Collaboratives must consider how to support health care providers and researchers in reflecting on and acknowledging mistrust, rather than solely “educating” communities.
- Scott et al., 2021; Health Promotion Practice

Trustworthiness workgroup activities

Open agenda time to reflect, heal, and build relationships

Co-created research

- Source of trustworthy COVID-19 information or Black and Latine adults in Pittsburgh
- Researcher perspectives about how to build trustworthiness in research

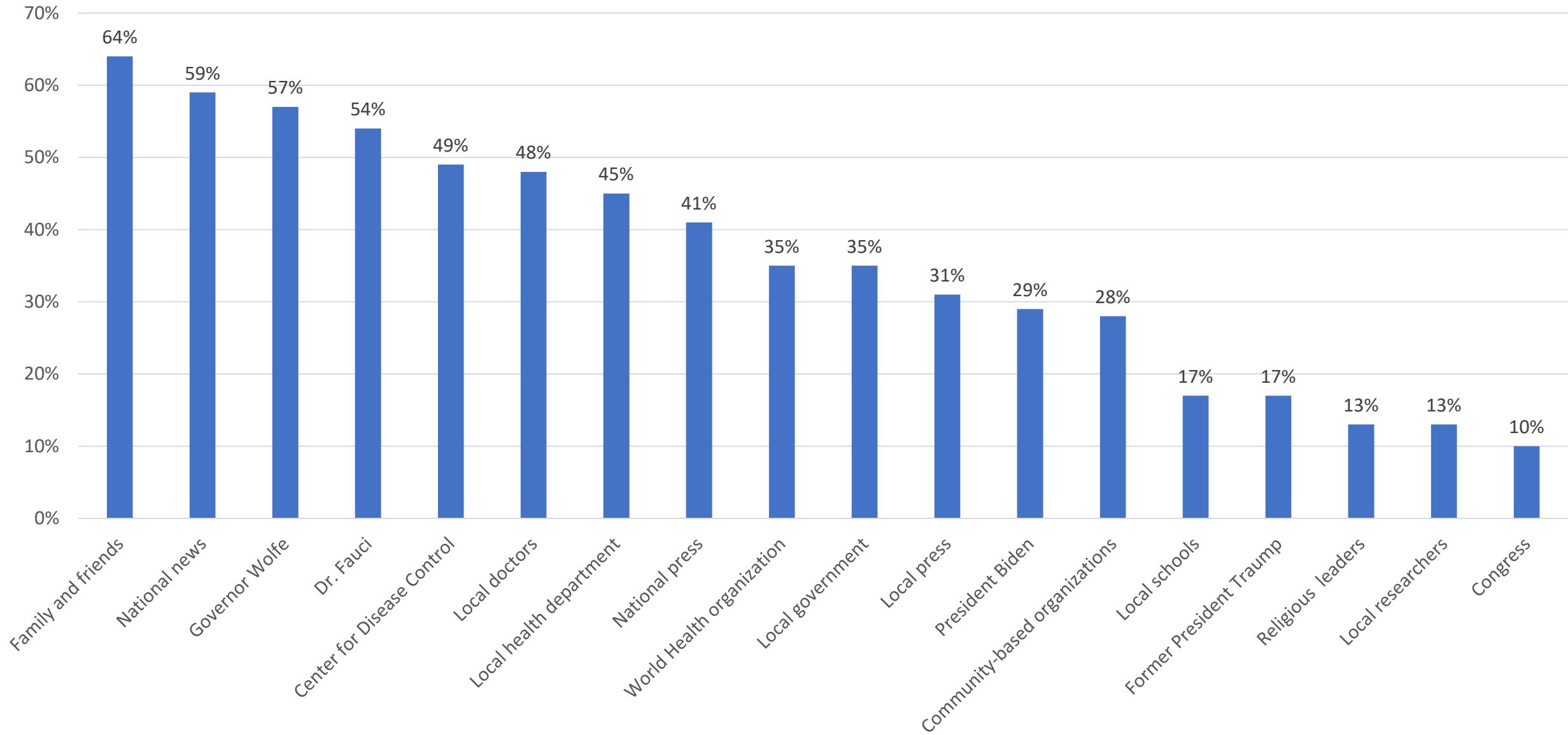


PARTICIPANT INFORMATION

Age	18-29: 89 (16%) 30-44: 219 (38%) 45-64: 173 (30%) 65-80: 71 (12%) 81 or older: 19 (3%)
Race	Black: 402 (70%) Latinx: 172 (30%)
Gender	Male: 146 (26%) Female: 422 (74%) Gender fluid/gender queer: 3 (0.5%)
Born abroad	149 (32%)
Speaks a language other than English	213 (38%)
Child less than 17	279 (49%)

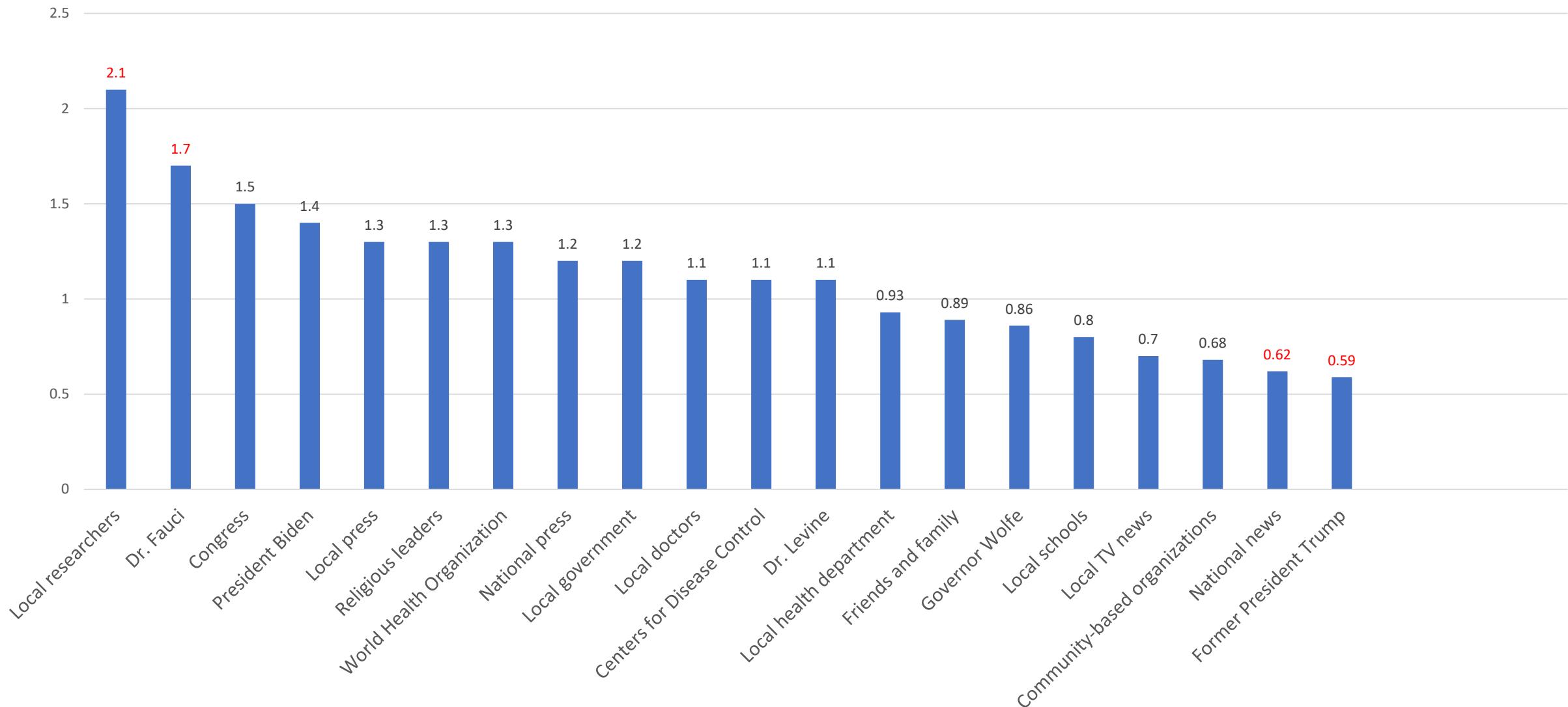


SOURCES OF INFORMATION ABOUT COVID-19



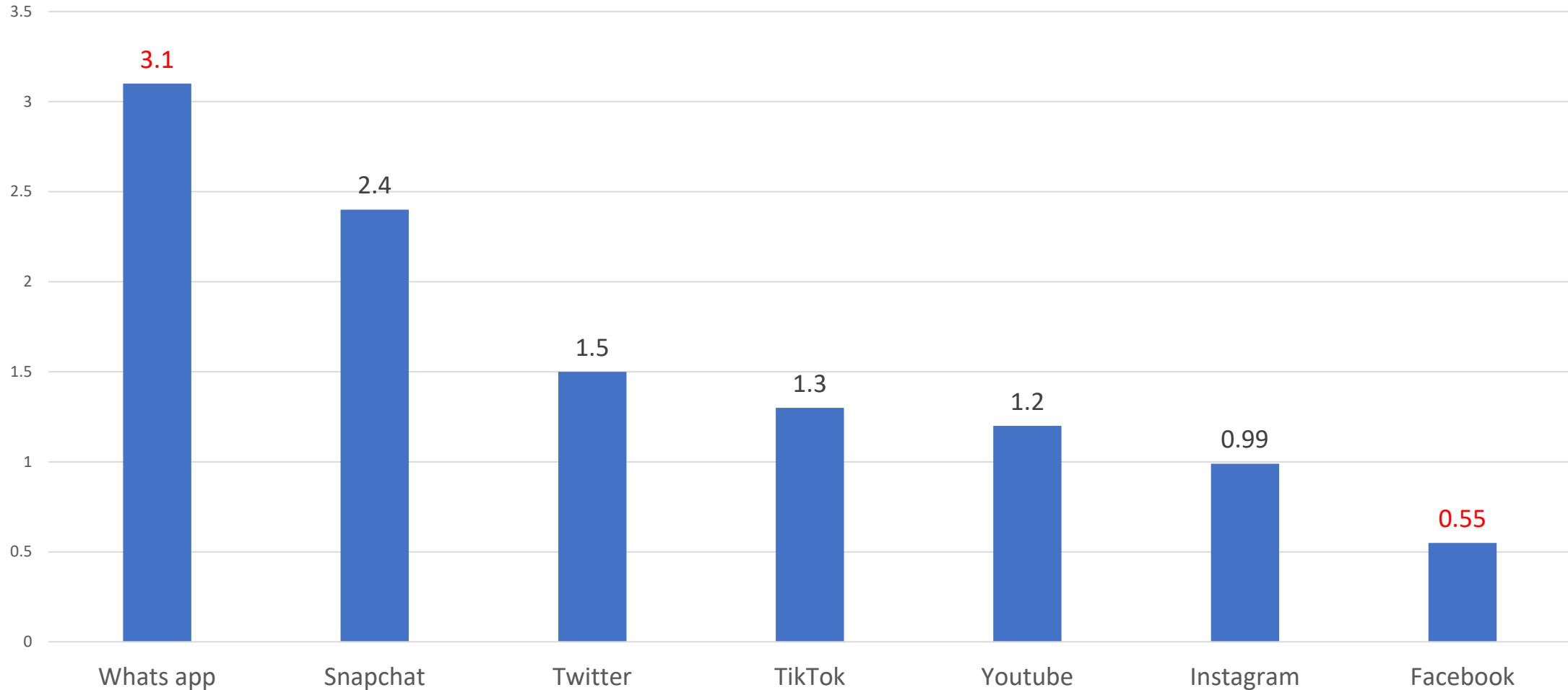


RELATIONSHIP BETWEEN SOURCES OF INFORMATION AND VACCINE INTENTION (adjusted odds ratios)





RELATIONSHIP BETWEEN SOCIAL MEDIA AND VACCINE INTENTION



Researchers' perspectives on trustworthiness

“[Trustworthiness] boils down to **really earning the trust of participants by being open and honest** and constantly self-reflective and questioning throughout the research process...I think it's something that is absolutely earned or needs to be earned. The onus is on the researchers and the medical community to not only talk that talk, but really walk that walk throughout the research process.

Institutional change related to policies and practices . . can we really make it right in the current model, or **do we need to re-imagine it?** Dismantle and re-imagine something that's bigger and better that really centers the community's needs and wants rather than being driven by funding or tenure and promotion.”

if it's difficult to identify participants from Black communities and if it's difficult to get members of those communities to trust me, then the easiest thing is just not to include them... the exclusion from research is not traumatic in the easily or usually defined sense, but it perpetuates injustice and **it perpetuates a scientific self-delusion** in the sense that we think that our results apply to all individuals, but we haven't included all individuals in our research



Principles/thoughts from trustworthiness group

Building trustworthiness takes **take time and relationship building**

Trustworthiness requires **a safe space to talk** and to get to know one another

Trustworthiness requires **consistently “showing up”** by researchers no matter what other meetings/things are happening

Reflection/listening is important, maybe even more so than agenda setting

Need the perspectives of researchers on how to build trustworthiness

Need systems/structures to hold researchers accountable

Community partners can help facilitate trust building, but they must be treated as **equal scientific partners** for leveraging their trustworthiness and social capital

IMMIGRANT AND REFUGEE WORKGROUP

MULTILINGUAL LINE



To schedule your vaccine with a language interpreter, call
833-660-2416.

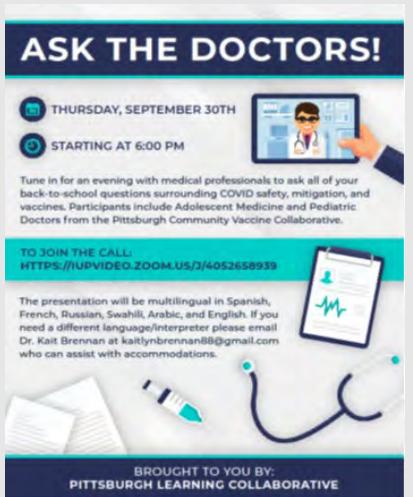
- ▶ To schedule your COVID-19 vaccine in Spanish, call **833-660-2416** and press 1
Para llamar en español para pedir su cita de vacunación contra el COVID-19,
marque **833-660-2416** y pulse la opción 1
- ▶ To schedule your COVID-19 vaccine in Nepali, call **833-660-2416** and press 2
नेपालीमा तपाईंको COVID-19 भ्याक्सिन तालिका बनाउन ८३३ ६६० २४१६ मा कल गर्नुहोस् र २ थिच्नुहोस्।
- ▶ To schedule your COVID-19 vaccine in Arabic, call **833-660-2416** and press 3
للحصول على موعد للاصابة بفيروس كوفيد-19 باللغة العربية، اتصل بالرقم **833-660-2416** ومن ثم اضغط رقم 3
- ▶ To schedule your COVID-19 vaccine in Vietnamese, call **833-660-2416** and press 4
De lay hen chich thuoc ngua bang tieng Viet Nam, Xin goi so **833-660-2416**
roi bam so 4
- ▶ To schedule your COVID-19 vaccine in Mandarin, call **833-660-2416** and press 5
需要预约新型冠状病毒疫苗中文服务请拨打**833-660-2416**, 再按 5。
- ▶ To schedule your COVID-19 vaccine in Russian, call **833-660-2416** and press 6
Регистрация на вакцинацию Ковид- 19 на русском языке, позвоните по номеру
833-660-2416 и нажмите 6

For all other languages, call **833-660-2416** and press **7**.

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Supporting language access during vaccine distribution



The immigrant and refugee workgroup

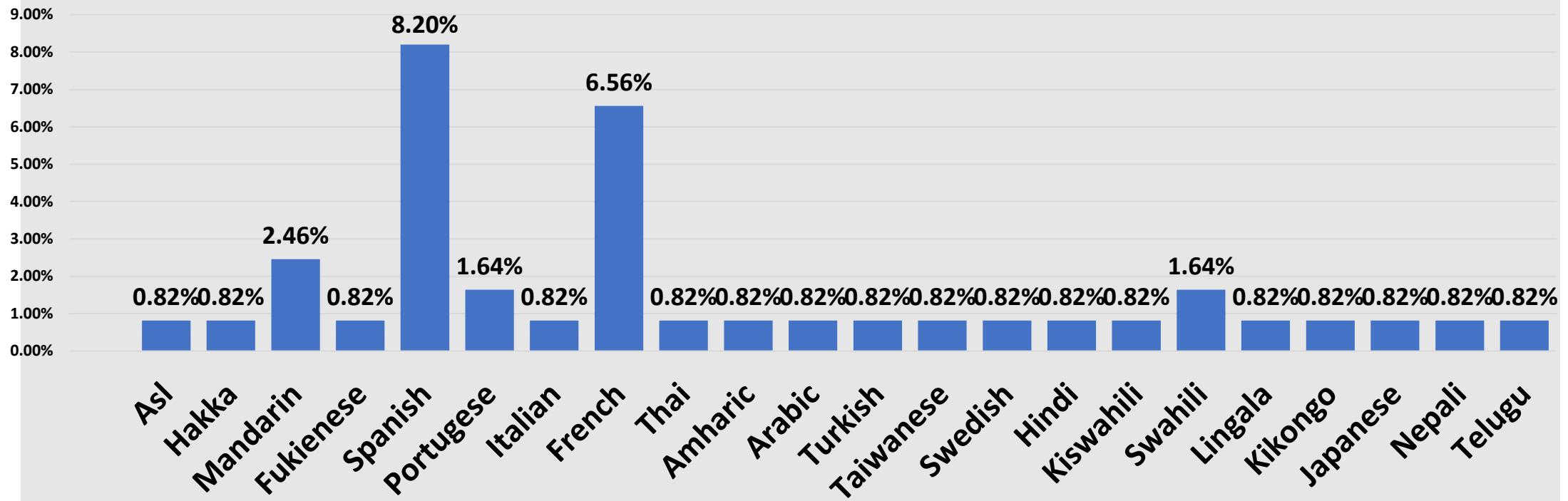
Convened as a group due to a pilot grant opportunity, which we co-wrote

Started meeting in July 2021

Starts with an open time to ask questions about the vaccine then moves into an activity

Processes are very much the same as the CVC more broadly

Languages Spoken



Main take away points

- 1) Vaccine overall trustworthy to those who have been vaccinated
- 2) Need to consider language access at all phases of the vaccine experience [particularly language brokering]
- 3) Need to limit identification requirements
- 4) Opportunities and inequities of having community-based organizations involved with vaccine clinics
- 5) Recommendations for improving healthcare to be more linguistically and culturally affirming for immigrant and refugee communities

Representative quotations

“They asked for your name and birthday. Stuff like that. And then we didn’t have social security numbers. They asked us. We said we don’t have that. They took our identity and made a copy of it.” *Mandarin focus group*

“I don’t really understand English. I can understand maybe 2 words out of 100. This is why we have our children with us who help us fill out forms and make appointments. My child played the role of interpreter there.” *Nepali focus group*

“I didn’t have the vaccine; I didn’t know where to get it. I talked to a friend, and he told me that Casa San José helped people. I decided to call them to ask them about it, and that’s how I got my Pfizer vaccine. I got the first dose.” *Spanish focus group*

SUSTAINABILITY AND NEXT STEPS

Please mark how much you agree which each of the following statements

Please mark how much you agree which each of the following statements	% Strongly Agree or Agree
The CVC maintains open, inclusive communication and shares important information, updates, and data.	95%
The CVC prioritizes community input and recognizes that neighborhoods matter.	95%
The CVC makes decisions to have positive community impact.	95%
Participation in CVC meetings is a valuable use of my time.	93%
The CVC will lead to measurable and lasting impact through relationships built	93%
The CVC acts with humility (i.e. collaborative has a modest view of itself)	93%
The CVC builds trust and shows that they care, are fair, and consistent.	93%
The Community Vaccine Collaborative connects with me with honesty, empathy and transparency.	90%
The CVC makes me feel included and connected.	88%
The CVC works together and breaks down barriers between different groups and organizations.	85%
Average	92%

Some feedback

“I really appreciate this group and how many **different backgrounds and areas of interests are brought together**. We appreciate being a part of this wonderful conversation and look forward to helping advocate with this partnership going forward.”

“We need more of such collaboratives to **promote healing and strengthen relationships** between the medical community and the general population.”

The way in which the CVC has **empowered researchers and community members alike and fostered a spirit of unprecedented collaboration** between the two stakeholder groups in a time of great crisis provides direction and hope for the future of medical research, especially as it relates to justice and equitable health care.”



How we are moving forward

- A shift from vaccines to **vitality**
- **Preserving stories** from the pandemic
- **Transdisciplinary collaboration**
- **Developing new workgroups** to meet broader equity needs
- Continued **structural processes** which has supported sustainability of the space
- **Continued focus on healing, atonement, and collaboration**

Our new name
Community
Vitality
Collaborative



Questions? Reflections?



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