March 12, 2024

Black Americans' Experiences with Science Information: Insights from Community Conversations

Black Wisconsinites articulated strategies for and barriers to navigating science information and expressed special concern about healthcare misinformation.

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About This Project

This report is part of a multi-stage project funded by the National Science Foundation designed to understand the lived experiences of Black Americans and how those experiences shape their feelings, beliefs, communication needs, and engagement with science information.

This is one of two reports covering our findings from the first phase of the project. In the first project phase, we spoke with Black Wisconsinites about how their experiences shape their interactions with science information. During Spring 2023, our team of researchers and evaluators from UW Madison and UBUNTU Research & Evaluation held seven community conversations, online and in-person in Milwaukee, each hosting between 7 and 16 participants. The community conversations explored a range of issues related to community understandings of science and science misinformation. This report covers Black Wisconsinites' experiences with information and misinformation, and the other report covers Black Wisconsinites' broader understandings of science issues as well as their hopes and goals for participating in our community conversations.

We have been intentional about fostering partnership and collaboration between our researchers at UW –Madison and UBUNTU Research & Evaluation, and our community member participants. To honor community contributions, we have also carefully structured our process of interpreting and distilling community conversation participants' perspectives. Below, we elaborate on our research process before sharing our findings. Our discussion of our research process appears in both reports.

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Project Intentions & Research Process

Our Research Values & Intentions

We believe that how the research community thinks about the concepts of engagement with science, different communities' experiences with science, and the problem of science misinformation doesn't matter much if we don't understand how the communities impacted by science issues think about these things. We believe this to be true both from a moral perspective and from the perspective of social scientists trying to understand and make conclusions about the world as the communities within it experience it. We intend to disrupt a long history of extractive research methods and perpetuation of harmful narratives about Black communities by conducting research *with*, rather than *on* Black communities. An important aspect of our goals is identifying specific science issue areas for focus in the future, based on the assumption that working *with* Black communities is essential to ensuring that future science communication work is directed at science issues of most concern to them.

Breaking Down Our Research Process: Hosting Conversations, Interpreting Community Perspectives, Reporting Results

We have tried to implement these values both through our approach to organizing, hosting, and facilitating the community conversations, and in our approach to interpreting and reporting on community perspectives.

Organizing, hosting, and facilitating community conversations

We allow our research to move at the speed of community. This involves building trust and relationships by prioritizing our connections with community, creating space to build shared understanding (e.g., holding meet and greets), and working with community in the ways that work for them. For example, we wanted to avoid limiting accessibility to the voices that could be captured for this project. We therefore held our conversations at different times, on varied days of the week, and in two types of modalities to facilitate attendance from participants with varied needs and lifestyles. Conversations were recruited for, facilitated, recorded and analyzed by UBUNTU, utilizing their dignity-based, Afrofuturist evaluation lens with goals of fulfilling the dignity of all participants, and uplifting the voices of marginalized people.

Interpreting community perspectives

The findings of this report are our synthesis of what emerged from these conversations, including direct quotes from community conversation participants and our team's distillation of the themes that occurred within and across conversations. The process for generating these themes involved concurrent analysis by subgroups of the team based at UW Madison and UBUNTU, followed by another level of analysis by the entire team. Three researchers making up the UW-Madison subgroup analyzed each community conversation's transcript in detail, categorizing participant quotes into different themes surrounding science, information, and misinformation. Researchers at UBUNTU analyzed transcriptions, utilized notes from conversations, debrief notes, and lived experience as Black evaluators to identify and organize the data's major emergent themes. Finally, the entire team came together to compare and unify the separate structures of themes and interpretations. We recognize that

these analyses are still subject to our own biases, so whenever possible, we have tried to avoid imposing our own meaning on participants' ideas by using as much of their own language as possible, and by keeping the categories of themes we created only as detailed as we felt we were able to distinguish without imposing interpretation that relied upon unexplicit assumptions.

These ideals can seem abstract, so, to help those reading this report understand our effort to stay true to ideas explicit in community member language, we offer an example decision we made during analysis:

> A theme appearing in all conversations is the types of information sources community members use and trust. As we gathered the instances of conversation about this theme together, we first created one code (or category) under which to classify all examples of information sources participants said they used. We titled that category "trusted sources."
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> However, as we listened to more conversations, and discussed our coding, we realized we were making an assumption in classifying sources community members regularly turned to as "trusted sources." In fact, some community members specifically stated that they often turn to sources they are unsure of out of convenience or necessity. In other cases, it was unclear or unstated whether they used the source for information because they trusted it, or for some other reason. We decided it was problematic for us to assume or classify all regularly-used science information sources (that participants did not explicitly say were untrustworthy) as trusted sources. So, we coded these instances as general information sources and only coded trusted sources when individuals signaled that these sources were trustworthy. This approach allowed us to focus on what participants said, rather than our own potentially flawed assumptions.

Writing

In writing this report, we have tried to forefront community voices and perspectives, rather than hold them in contrast to scientific or academic perspectives. We have raised or compared these community perspectives to academic perspectives only when it is clear to us that academic understandings are lacking concepts that are necessary for researchers to understand the realities that Black Wisconsin communities are living with, faced against, embracing, and enduring as they relate to science misinformation.

In this report, we cover:

- Black Wisconsinites' experiences with science misinformation
  - Community definitions of misinformation & differences from academic definitions
  - Community experiences with racism as a source of misinformation
  - Science issues where misinformation is of particular concern to the community, and the impacts that misinformation has for community members
- Our research team's takeaways and goals for future conversations

Key findings: Community Experiences with Science Misinformation

Black Wisconsinite and academic definitions of misinformation differ, with community definitions offering a more nuanced view of the concept.

Both the community and academics acknowledge *incorrect and inaccurate information*, as well as *intentionally misleading dis-information*.

Community definitions of misinformation also highlight:

- Incomplete information
- Missing information
- Information that is not understandable
- Information that is not personally relevant or not applicable to life as a Black person

Community experiences individual and systemic racism as a part of science misinformation.

- Individual racism: Black communities receive misinformation because people circulate misinformation out of racist motivations or racist ignorance.
- Systemic racism: Racism shapes the structures that allow misinformation to filter through the Black community.
  - Historical racism has shaped the resources and access to information the community has.
  - Modern racism continues to shape those resources information access.

Community understandings of misinformation

"I don't trust it if no black people were involved in this research study. I don't feel like it was made for me, that's questionable to me… I don't know if it can be applicable to me in my experience."

Comm Conv., Oc. 17, 2023

"What makes information questionable will be when information is not complete like in the sense of…you're just getting a part of the picture."

Comm Conv., Jul. 24, 2023

A common academic understanding of misinformation:

Information that is inaccurate based on the best available evidence

A synthesis of prevailing understandings of misinformation in academic research[1]

"I feel to be misinformed is sometimes an act of racist, because in some communities they keep information from the Black for selfish reasons."
(Community Conv. Oct 12, 2023)

"We receive misinformation from our elders sometimes because our ancestors were lied to, and so the access that they have to specific information, they pass it down from a place of care without fully all of the time processing that misinformation is inaccurate."

(Comm Conv. Aug 28, 20)

[1] Vraga, E. K., & Bode, L. (2020). Defining misinformation and understanding its bounded nature: Using expertise and evidence for describing misinformation. Political Communication, 37(1).

Misinformation has sometimes benefited communities.

- Misinformation has sometimes circulated as a survival mechanism in response to racial disparity and lack of full access to certain types of scientific information.
- There are cultural components to some misinformation

When considering science issues, receiving accurate health & healthcare information is top priority.

- Healthcare misinformation, and other types of science misinformation that impact health are top concerns because they affect the wellbeing, livelihoods, and very survival of community members and their families.

Community members spoke, generally, of the disastrous consequences of misinformation, but particularly forcefully to the powerful harm of medical misinformation.

"When I talk about that [misinformation], I talk about generational news that has been passed down from time to time in terms of how to get rid of this, how to cure this, how to take care of this. (Comm Conv. Oct 17, 2023)

"As a black person, being misinformed to me it means disaster, destruction because if I am being misinformed, how do I have good direction?" (Comm Conv. Aug 28, 2023)

"Had she had access or lean on that access, she could have perhaps caught the early stages of breast cancer. However, she did not rely on that scientific information and so oftentimes relied on a black myth medicine." (Comm Conv. Oct 17, 2023)

"it makes me think of how at the beginning of covid and even still now, a lot of people didn't have scientifically-backed information about what was going on and that informed their decisions and either put them in situations where there was greater risk to them and to the people they were interacting with." (Comm Conv. Nov 02, 2023)

Key findings: Community Members' Strategies For & Barriers to Navigating Misinformation

Community members are motivated to fact-check science information for:

- **Themselves**
- **Their friends**
- **Their communities**

"It's something health wise or mental or something that affects my community on a daily basis, for me I'm more inclined to get to the bottom of it because it will affect everybody and the people I know" (Comm Conv. Nov 02, 2023)

Determining what information to trust is a two-step process for community members.

1. Determine if the basic information is valid & credible

"In regard where I get information from, looking it in general, I cannot know if I can trust the information I got from anyone, but it's about being able to identify when it's actually not true." (Comm Conv. Nov 02, 2023)

2. Determine if the information is applicable & relevant to MY lived experience.
    - Factors that help determine if the information is relevant and applicable:
        - Is it based on research that involved any Black people?
        - Has the person communicating the information earned my trust? Do they know anything about my communities and experiences?

The challenge of determining if the information is applicable to your experience*:*

"If you weren't trained how to think critically about the focal context or the full story of what you're being told is, it's easy to think that something pertains to you when it's shared in public but if you look deeper, you weren't included in the research, you weren't the target of the research, the information doesn't actually apply to you, and so I think knowing how to think critically about it is important and it's disheartening and frustrating." (Comm Conv. Oct 17, 2023)

The process of determining if the information is applicable to your experience*:*

"Some findings might be shared, oh it's good for you to do XYZ thing and then when you look at who was involved in that study, there aren't any black people involved in the study, so it might be good for you to wash your hair every day, but they did not have any black participants in that study, so that is misinformation for me because that information does not apply to me or was not studies for people who look like me or have my experience." (Comm Conv. Oct 17, 2023)

Elders in community networks are important sources of information.

Community members find elders to be both one of the most valuable sources of applicable, relevant information AND sometimes sources of misinformation.

"My grandparents: I get information from them. Because, although their methods might not be modern, but they have very deep insight concerning black people especially with health matters. Their methods sometimes is very effective or approaching it. Modernly, you can actually see it is not very accurate or sometimes it might have a side effect." (Comm Conv., July 24, 2023)

"They've been around long enough, so they seem to know a little bit more than me. If I need to know things about our people, I'll go ask my aunties and my uncles." (Comm Conv., Nov 2, 2023)

Communities experience both structural & individual barriers to navigating misinformation.

Individual barriers include difficulty discerning:

- How do I know what misinformation is?
- How do I know WHO to trust? (anyone could be biased)

"Some of that stuff is explicit and some of that stuff is internal. We don't even realize that a presenter or commentator or even just a journalist has anti-blackness let along racism or views that influence that they're saying or their decisions. You're trying to get something from the right person, but who is the right person?" (Comm Conv., Oct 12, 2023)

"Where they are giving actual news, some of it isn't scientific, some of it is just narrative, but it's confusing because there are times when they are giving scientific information that is correct information… it's confusing to know what's real." (Comm Conv., Nov 22, 2023)

Structural barriers include lack of access to resources, such as:

- Friends and family with the expertise to help interpret
- Time to vet information
- First-hand information
- Education
- Insurance barriers to accessing relevant resources

Mental Space & Time as a Barrier:
"Being in this age of information is being bombarded by too much information and so sometimes I can't deal with that right now or it just kind of gets added to that mental to do list." (Comm Conv., July 24, 2023)

Technology Access as a Barrier:
"They all assume that everybody has access to computers and you can access your medical records, you can access your after summary visit and it's just not true." (Comm Conv., Aug 03, 2023)

Education Access as Barrier:
"I also appreciate education, I appreciate academia and I appreciate academic research but I also recognize that due to things like capitalism and classism, everybody ain't got access to education. Everybody ain't got access to the education that we pay for or even free education." (Comm Conv., Aug 28, 2023)

Financial Resources as a Barrier:
"Insurance don't cover a botanist." (Comm Conv., Aug 03, 2023)

Key Takeaways & Future Directions

Black Wisconsinite communities and science communicators can work together to create a more complete definition of misinformation that includes important aspects of Black community experiences with misinformation.

The insights our community conversation participants have offered us can significantly expand our understandings of misinformation beyond just seeing it as information that is false or misleading, or otherwise deviates from the best available scientific knowledge on a topic. They also show us that Black Wisconsinites are using multiple strategies to scrutinize information and sift through misinformation. They are looking to not only know whether they are getting sound information but whether that information is relevant to their own lives and has Black people's dignity and livelihoods in mind. Academics, practitioners, and communicators must directly engage with information's relevance to Black life and Black communities. Without doing so, we run the risk of attempting to have conversations with Black communities that have no meaning or impact for their lives.

We have also heard from the community that racism sets the backdrop and shapes how Black Wisconsinites engage with information. Academics, practitioners, and communicators must not shy away from the impact of racism on community ability to engage with science information. Without acknowledging and confronting the impact of racism, we run the risk of ignoring the lived experiences and contexts that shape experiences with and discussions about topics related to science.

Moving forward, we want to build on what we have learned to further understand how we can work with community members to create better conversations about science information. We will focus on science issues that matter to community members, especially issues that impact community health and wellbeing. We hope to move these conversations beyond concepts of “correct vs. incorrect” information and empower Black Wisconsin communities to engage with science in ways that benefit them. And, we hope to highlight existing limitations in science information, like how relevant and understandable it is, and how well it takes the varied experiences of Black Americans into account. This means dealing directly with the relationships between racism, lived experiences, and science information. Finally, we hope to further examine and explore what it could look like to offer and deliver relevant, accurate and engaging messages about health and science to Black Wisconsinites.