Defining the Authority of Online Providers of Health Information

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Hello, and welcome to the National Academy of Medicine webinar to gather information for the NAM project on principles for defining and verifying the authority of online providers of health information.

I'm Raynard Kington, and I'm head of school at Phillips Academy in Andover, and president emeritus of Grinnell College, and chair of the Project Advisory Group. I will be your moderator for today's session.

As brief background on this project, YouTube asked the NAM to identify preliminary definitions of authoritative sources of health information and the criteria by which these sources derived and maintain their authority. In response, NAM convened an expert group that will gather information and deliberate in order to publish guidance in the form of a peer-review discussion paper this Summer. This guidance will help to inform some of the ways in which YouTube identifies and elevates authoritative health information for users.

I am joined today by fellow members of the Advisory Group. First, Stacey Arnesen of the National Library of Medicine; Sylvia Chou of the National Cancer Institute; Sue Curry, University of Iowa (emeritus), David Lazer of Northeastern University, and Antonia Villarruel of the University of Pennsylvania. We are grateful to have this opportunity today to hear feedback on this important project.

Some health housekeeping items for today's session: First, please pay close attention to the chat box for logistical announcements; note that the chat box is disabled for audience use. Members of the audience should use the Q&A box to enter questions for the speakers and feedback for the advisory group. Today's webinar will be recorded, and the recording and slide presentations will be posted on the project web page. You'll receive an email notice when these materials are available.

I would also like to note that the NAM is hosting a public-comment period on the project starting today through midnight Eastern Standard Time on Friday, April 9. We encourage you to view our preliminary discussion document, which is at NAM.edu/AuthoritativeHealthSources (all 1 word),

and submit your feedback using the survey form. We also would appreciate that any information that you give us, we will include in a summary of feedback, which we will then post.

So without further ado, I'd like to introduce today's speakers. First, Dr Garth Graham, Director and Global Head of Healthcare and Public Health Partnerships at YouTube will kick off our discussion with an overview of YouTube's goals and processes for elevating authoritative information on its platform.

Next we'll hear from Brendan Nyhan, a Professor of Government at Dartmouth College, who will discuss how the environment of social media misinformation, disinformation, and echo chambers have impacted health and society in recent years.

Following PROFESSOR Nyhan will be Lisa Fitzpatrick, founder and CEO of Grapevine health, who will discuss where communities of color go for trusted health information and the health-equity implications of a content-curation strategy that doesn't consider these sources.

Finally, we will hear from Zeynep Tufekci of the University of North Carolina, who will outline some of the unintended consequences of large-scale content-curation strategies.

Following these presentations, we will have a discussion with the Project Advisory Group. Starting off, let me hand off to Dr Graham.

GARTH GRAHAM

Thanks Dr Kington. I'm going to try to do a quick overview of how we came to this: some of the background of activities that we've been doing and working on, how we came to this discussion, some of the points to be taken away from this discussion, and really talk a little bit about what YouTube has been doing in this regard around getting information out to the public, particularly information that that is relevant, scientific, and engaging. Next slide, please.

So, the overall goal here, and why we engage with National Academies and the community that you're all a part of in this discussion, is really around increasing the accessibility of authoritative health information that says, in simpler ways, “How do we get good information to people?” and

making sure that information is scientific and evidence based. It's a complicated process. You're going to hear from all of the speakers about all of these complicated dynamics that go into this, but really the overall goal is to think through, how do we get that information to communities and especially communities that need it the most. Next slide, please.

So when thinking through the opportunity, I always try to think through the scale——and that's part of the opportunities in scale and certainly a lot of the challenges are in scale as well. So on YouTube we're able to reach 2 billion logged-in viewers every month. And I often say that the world only has 7 billion people, so it's almost a third of the world population we're able to reach, and, as you can see here, all different kinds of ways in which those folks are engaged at scale. So it's a huge opportunity from a health and public-health standpoint to be able to reach people with type, timely, relevant healthcare and public-health information. Next slide, please.

And one of the other opportunities is that video is able—this again, we're speaking about YouTube context, but I also want you to think about how these platforms in general can reach people—well one of the added

benefits, in addition to scale, is that YouTube is able to take complicated clinical topics and, through the video medium, be able to explain it to people. I often say, you know, who would have ever thought that, you know, messenger RNA would be the kind of thing that you'd want the general public to understand—it's such a complicated technique in terms of developing, or development around that technique—and the truth of matter is video allowed us to be able to explain that, and explain that at scale. So video allows us to take complicated topics and make it digestible, and then the platform makes it accessible, and then this idea of the way you create the video is about how you make it culturally competent, engaging, and able to reach communities in general. Next slide, please.

And COVID-19 has been one of those opportunities that has allowed platforms like ours to be able to evolve and change quickly to meet the dynamic needs of a lot of what's needed to be delivered to communities, but also to be able to evolve our process to make sure we're meeting the needs of communities overall. As you see here, you know, with COVID-19 information, we are able to reach out to 400 billion impressions in terms of reaching people across the world, as particularly with engaging content.

But we also looked at how we evolved our processes even further, to be able to steer people away from issues related to misinformation. This snapshot, this graphic that you see at the top, is one of the Business Insider articles that just recently came out showing, culling, referring to some of the evidence that culled together how, especially more recently, the algorithm was able to steer people away from anti-vaccine videos. Now, truth of the matter is, that is an ongoing challenge, and I think, hopefully, you'll hear from some of the speakers here today about some of the prior times, especially with how algorithms can be challenging, but this is an example of just showing you how this has evolved, especially for us over a time, and now we're able to kind of move into a different phase and where we steer people more towards correct information.

We've also, um, I come from a background around Community health and social determinants of health, and we were very concerned with making sure that we were reaching communities, particularly communities who need this information and who were on the platform. And we partnered with the Kaiser Family Foundation, the Black Coalition Against COVID, Tulane University, actually some of the doctors, the Black doctors from the National Academy of Medicine, and others to be able to figure out and

create the kind of information that can reach local communities through this platform. There are a lot of different ways to reach communities; it’s not the only way—there's a lot of things that need to also happen on the ground ,but it's an example of how to utilize the platform to be able to reach communities appropriately. Next slide, please.

And, for the purposes of the next couple of things I'm going to talk to you about, I'm going to kind of talk about kind of how we're thinking about things, and then hopefully have that shape some components of this discussion. There's a lot of information on platforms like ours around kind of health in general, and some of that deals with things that are on lifestyle practices and wellness. We're not, for the purpose of this discussion, we're really talking more about information and our information quality. Let's talk about lifestyle issues, about how do you, get people information about the kinds of things that are clinically relevant, relevant from a public health perspective, and pertinent in terms of also being timely and engaging as well. So a lot of this is going to be focusing on the issue of information quality. Next slide, please.

One of the things that we've developed is a strategy for how do you deal with both misinformation, but more importantly, how do you proactively raise information. And for the purposes of what we're going to be talking about in this webinar today we're really going to try to delve a lot more in this issue of raising information, meaning how do you lift up the scientifically engaging information. You're going to hear from somebody who I consider kind of a hero in terms of the work that she's been doing with Lisa's work and others about how, you know, people are working with communities to adequately reach communities and raise information—that's one strategy. But we also have been practically working as a secret before, particularly as it involved our COVID-19 policies around removing and reducing information. And this is an ongoing issue. It’s not meant to say that the challenges are solved, but as you saw from some of the more recent data. And a lot of that is being thought through in a different realm in terms of how we kind of tackle that and make sure that we are approaching that effectively. We do want to, you know, acknowledge, especially in the past, how those kinds of processes can create challenges and hopefully you'll hear that, from one of our speakers here today, about other experiences people have had and elsewhere, etc. The whole point here is to understand how complicated this issue is. And our whole goal

here is to both engage National Academy of Medicine, and actually through this webinar, engage folks in the community to both understanding the challenges, but much like you see with heroes like Lisa Fitzpatrick, how people are able to focus on raising that information and getting that information out to communities appropriately. So moving beyond just the challenges, but how do you deal with it. You know, I spent a lot of my time in academic medicine, and I was Chief of Health Services Research at the University of Florida in addition to my role in government before recently moving over to YouTube, and one of the challenging things is, it's interesting when we are able to kind of publish and put out information about any one of the challenging public health and community health issues that affect our communities. It’s such a different issue when you're on the front lines trying to deal with it and figure it out, but actually get your hands messy with the solutions and so. Again, I kind of alluded to Lisa and others who have done this kind of work, but that kind of work, to me, is part and parcel of understanding how you are able to kind of deliver information out to communities. Next slide, please.

And this is meant to give you an example of how those kinds of things, the kinds of things we're talking about here today, how they proactively show

up for, you know, a community member, a user, a patient, or someone who is using a platform like ours. And so basically what we're trying to do here with the National Academy of Medicine is be able to more effectively identify the kinds of content that you can raise and pull from and who are the kinds of people that are producing those, that content, that we can then pull and draw from and then use the product features like here, you see here in terms of the search and some of the credibility cues, to be able to identify. You know, one of the things I found out during my journey as I've gotten to understand more about how technology interacts with community is if people are coming to the community to these, um, people are coming from the community to platforms like ours and others and asking questions, and that's the concept to understanding. I have often said, gone are the days when you would hand out flyers or put up a poster for people to receive information. Nowadays people want it in their hand, they want it quickly, they want to be able to pull up that information, and they come to a platform with questions and seeking information. Really the goal here is, within this, is how do you identify the places that as those scientifically infer…, the places where scientifically sound evidence and evidence-based information is consistent as authoritative, and then how can you pull from that and raise that in the platform and use the various

different kind of choose and credibility markers to be able to identify and showcase that. Next slide, please.

So alright, our ask and really the focus of the discussion: When you think about information, information dissemination, especially the information dissemination on a very big scale out to the public through platforms like ours, there is, it's a lot of different things we could talk about. And you know, when we were first engaging in this discussion with National Academies and I'm saying, you know part of part of my prior experiences, and I think, including folks on the committee, is when you have big problem you got to think through bite-sized chunks, like what are some of the things that we can work on and solve. I know I think about this issue around information and information dissemination, it is, there's a wealth of different challenges. There are so many different things happening, but we have to think through what are some of the initial steps we can do to kind of meet the needs of communities and be there to provide information. This is really one of those bite-sized chunks on identifying scientific evidence-based information and raising it to the top. You can get lost in all kinds of different kinds of things, but really trying to stay focus on these two questions is really the topic for discussion. So high-level definition of

categories or sources, and high-level definitions of methodologies for authority that verification and definition, is particularly important. So I want you to keep this in mind, particularly as you are, hopefully, giving us your thoughts through your comments. I want to encourage people to comment, and through, you know, give us thoughts and ideas. Because really, this is the question, the question is, are, on sources and methodologies for those sources. There are a lot of different challenges that I think we can also deal with but that we may have to save for other times, while before we get through this process initially. Next slide, please.

And so to get a sense of kind of what “definitional work” kind of alludes to… next slide, please… is it's this idea of where do you get information from. Are you getting it from medical journals? Are you getting it from WHO, CDC? Are you getting it from healthcare delivery organizations? And are these sources authoritative? Can they be trustworthy? Can you continue to lift up these sources? And then, and how do you make them engaging? And that's where it goes to the work of others who have really been working on this as I have mentioned before. This is where the concept of authoritative health sources really lie.

And I think my last slide… next slide, please… is going back to just the part of Summary. And we have this slide here twice to emphasize: The question around today is our own definition and categories of sources, high-level definition of methodologies for authority definition and the verification, and how do we then raise this information. I like to say that, you know, it's like a garden. When you think about health information, how it's out there in the world, you have a lot of misinformation and those are the weeds. And we need to pull out the weeds from the garden, but if you don't put something else back in there, then things proliferate because people are asking questions. So how do we fill in the garden with the right kinds of information, the evidence-based scientific information, to allow people to make the right decision in general. So again, we really want to focus on this particular issue for your thoughts and comments. And you know, hopefully we'll hear a little bit about the challenges that may peripherally be around this, but really, the issue is how do you get high-level, quality information to communities at scale and realize the opportunity we have to make a difference in the lives of individuals and communities? I'll stop there, Raynard.

RAYNARD S KINGTON

Thank you, Garth. So next we'll turn to Professor Nyhan.

BRENDAN J. NYHAN

All right, thank you so much. It's great to be here, and I'm very happy to share the research that my coauthors and I have been doing on this subject, which I hope can inform this discussion and provide some guidance into how authoritative, identifying how authoritative health sources might address the problems that we've seen on social media platforms, including YouTube. Next slide, please.

So I'd like to start with the following set of stylized facts, because I think they're important in a discussion like this so that it doesn't go off the rails. I've been involved in enough of these that I've seen all of these points get lost and lead to, as a result, we've, the discussions are often counterproductive, or at least unproductive. The first point that's very important to keep in mind here is that all of our social and political problems are reflected on social media platforms. And so, there's often a kind of defensiveness that the platforms express about the ways in which they're blamed for things that really are reflections of what's happening out there in the world, which we observe on social media. It's not necessarily

that social media has caused the problem. Social media did not cause political polarization. It did not cause vaccine hesitancy. It may contribute to those problems but that's a more subtle point. So it's always important to remember that social media is going to reflect what's happening in the world. And that's a point that platforms, I think, often get hung up on and get defensive about, so I think we should stipulate to that point.

The second stylized fact, which I'll share some research supporting with you, is that most people are not in so-called echo chambers of like-minded information. When people think about the problem, that interventions like what's being proposed are intended to address, that's often what they have in mind—that people are going to online sources and they're getting untrustworthy information, particularly untrustworthy information that seems to reinforce their predispositions, whether it's about health or about politics. I'll share research with you suggesting that that kind of behavior seems to be relatively rare from the best digital behavioral data that we have. However, there are small minorities of people who are deep into those kinds of digital echo chambers. And I would encourage us to separate that problem, and that small minority of people who may be consuming a lot of untrustworthy information, from the broader problem of

people going online who don't consume large volumes of belief-consistent, untrustworthy information but would like to get authoritative information when they do. Those are separate and distinct problems, and we should really think about those. You know, kind of the marginal viewer at each group is being someone quite different and the right intervention for one group may not be the right intervention for the other. And I think it's worth keeping that in mind as we think about interventions like elevating authoritative sources.

The final point is that even though social media platforms get blamed for reflecting problems, it is absolutely true that they do often amplify problematic content and that content can be harmful. We're in the midst of a deadly pandemic; people may be distrusting vaccines because of what they see on social media platforms. For instance, on the margin, right, even if platforms didn’t create vaccine hesitancy, there's the potential for real-world harms. So platforms do need to take responsibility for those harms and intervene to address them. Next slide, please.

Okay, so on the first point, that platforms get blamed for problems that exist in the world, I'll just give you one example. This teenager, who

testified before Congress a couple of years ago, and attributed the fact that he had not been vaccinated to Facebook. But he was 18 years old at the time, Facebook—at the time when his mother was making choice about whether to vaccinate him according to the recommended schedule—Facebook didn't yet exist as a general public service. It was still limited to higher education. So there's no plausible scenario where his mother was not vaccinating him because of what she was seeing on Facebook. In fact, vaccine hesitancy long predates the rise of social media. Again, that doesn't mean that there's not a problem, but it's a more specific and subtle problem than simply Facebook causing vaccine hesitancy or something like that. This is a much more general problem; it's not one that's closely linked to the rise of social media. Next slide, please. And that same principle applies to problematic content on YouTube, by the way.

Now, what is the problem? Well, one concern people have is that people are in these so-called online echo chambers that I've described. And what I would like to share with you are results from three studies that my coauthors and I have conducted documenting the fact that these digital echo chambers, to the extent they exist, are quite narrow. However, the

people who are in them are in deep and are consuming a lot of untrustworthy content. Okay, so again, the way to think about the problem is not that you know 50%, or 80%, or 90% of Americans are consuming lots of bad content online. Most of the bad content consumption is being done by a small minority of people. Okay, and to the extent that we need to address that, again, it's a different problem than the person who usually isn't consuming that kind of information but then wants to find out something about COVID, about politics, etc. Okay, next slide, please.

So the first example looked at exposure to untrustworthy websites in the period immediately before the 2016 election. As you recall, this was the time when, after the 2016 election, people were panicked that exposure to so-called fake news websites had been widespread and that supposedly might have been the reason that Donald Trump was elected. My coauthors and I were collecting digital-behavior data on the websites that people visited on their desktop and laptop computers, and while we can't see inside Facebook, what we can share with you is the websites that people visited, which is a meaningful indicator of engagement with this content. These are people who were clicking on Facebook and then, you know often, and getting there via other means and actually loading these

pages in their browser. So who is doing this? The typical story that you will hear, and we find some support for, is that people are consuming information that's consistent with their predispositions. And on the left, you can see a binary indicator of whether people went to one of these sites, depending on whether it was pro-Clinton or pro-Trump. And we're subdividing the US population there by decile of the slant of their news consumption. In other words, the 10% of Americans are the most liberal news diets on the left, the 10% with the most conservative news diets on the right, and what you'll see is that, as people have more liberal news diets in general, they're more likely to view one of those pro-Clinton sites; and then on the right tail you'll see that people who have more conservative news diets are more likely to visit one of the pro-Trump untrustworthy sites. However, when you look at the right panel what you'll see is that, as a percentage of people's news diets, exposure to these kinds of content was only substantial for the 20% of Americans with the most conservative news diets. Those are the only groups where those kinds of sites made up a substantial portion of their overall consumption. In fact, we found almost 6 in 10 visits to these kinds of sites came from just that 20% of the population. So, untrustworthy news is a big concern,

but really it's a small minority of people who are doing the bulk of its consumption, and that's a theme that will reoccur here. Next slide, please.

We then looked, using similar digital behavioral data, at data we collected between 2016 and 2019 to see what kinds of web pages people were viewing that talked about vaccines. We wanted to know specifically whether people who had mixed or negative attitudes towards vaccines were consuming large amounts of anti-vaccine content; that's a fear that people have expressed. Now we did find… So what we found was that, first of all, people don't consume very much content related to vaccines at all, and when they do, the pattern we see is what's expressed there in the graph, which is the more favorable people's attitudes towards vaccines are, as measured in a prior survey, the more vaccine-related content they consume that was not skeptical towards the safety and efficacy of vaccines. That vaccine-skeptical content you can see there was consumed more (in the highlighted box) by the people who had the least favorable attitudes towards vaccines. This is what's called a tercile split. So that highlighted group is about a third of the US population with the least favorable attitudes towards vaccines. They did consume somewhat more information that was skeptical about vaccines. But you can see that

even for that group the mean of volume of that content was very low, and in fact lower than content that wasn't skeptical about vaccine safety and efficacy. So there was no evidence of widespread consumption of anti-vaccine content, at least when it came to people's web-browsing diets. Okay, so that problem, to the extent it exists, is probably more subtle than just where people are getting their information online and what they're seeing. Next slide, please.

Most recently, my coauthors and I looked at exposure to alternative and extremist videos channels on YouTube. So these are channels that subject-matter experts and scholars had identified as either being alternative in the sense of being potential gateways to harmful content or extremists in the sense of being outright white supremacist or other kinds of really problematic content. And what we found was that about 2 in 10 of the participants we were able to recruit to install this web browser extension that visited at least one video from an alternative channel in about six months in 2020 and a little less than 1… and a little less than 1 in 10 visited one of these extremist videos. However, the people who did consume this content consumed quite a lot. Next slide, please.

Oh, in fact I don't have the slide I'm thinking of, so let me just tell you that more than about 80% of the consumption of alternative videos came from about 10% of our users, and the concentration was even more extreme for those extremist channels that I was describing. So again, there's a small percentage of people consuming a lot of potentially harmful content. The reason we might be worried about this are the predispositions that people bring to bear. You can see here that people who scored in the top third of the US population in the levels of racial resentment they express, using a standard survey scale and political science, their mean consumption of these types of videos was much higher. And, you know, something like 90% of the views of videos from these channels came from people with high levels of racial resentment. So again, small group consuming a lot of potentially problematic content. Next slide, please.

Now we know that platforms can play an important role in directing people to these kinds of content. The box, which is a little messed up, on the left there just shows that Facebook stood out as a site that people were differentially likely to have visited immediately before visiting one of these untrustworthy websites, which we took as a kind of indirect observable indicator that Facebook was helping drive people to those untrustworthy

websites during the 2016 election. We didn't see similar evidence for the vaccine…. for the vaccine-skeptical websites, however. Next slide, please.

Most importantly, because we're talking about YouTube, I want to note two findings about YouTube from that study. The first is that recommendations to these alternative and extremist channels were quite rare for our participants. You can see they made up fewer than 2% of all the recommendations they were shown. However, for people who were viewing videos from those channels, they made up a substantial fraction of the recommendations they received. So among people who would seek out those kind, that kind of content, they were potentially getting recommendations for more similar content. So it's not the simple rabbit-hole story of you're watching a cat video and something terrible happens, but nonetheless, those recommendations are being offered once you're viewing that kind of content. And we need to worry about that in the health domain as much as we need to in the domain of potential extremism. Next slide, please.

So I very much agree with the need to highlight and trust authoritative sources, and I'll just add it would be very helpful if they were trusted

sources. So just an example here from polling on the coronavirus, that Anthony Fauci is actually more widely trusted than the CDC itself, according to the polling data from Morning Consult and Politico (on the left). And, similarly, an experimental study found that a Fauci endorsement of, at that point, a hypothetical vaccine was overall the most effective at increasing willingness to take a vaccine and confidence in the safety and efficacy of a vaccine. So these trusted authoritative sources matter a lot. At this point, you know Anthony Fauci is one of the few people that there's some broad support for and agreement on. You know, you could do worse than highlighting a lot of what he said on some of these COVID topics. Next slide, please.

So I just want to wrap up by emphasizing some important principles to think about when intervening or making decisions about what content to highlight on a platform like YouTube. The first is that lines need to be drawn, even though we're talking about authoritative content, the opposite still exists. More than 50 of the extremist channels that we identified in our study are still up and present on YouTube. The second is, even for content that we think maybe shouldn't be taken down all the way, content moderation needs to exist in a conversation that's broader than simply

take down or not take down. That binary is far too simplistic. There are restrictions on monetization, recommendations, and subscriptions. For instance, that could all be implemented to reduce the incentive for producing potentially harmful content or reducing its spread. And then, finally, I want to emphasize the need to avoid fragile human solutions. And by that I mean these kind of one-off band-aids that are often implemented, where one particular search gives problematic results and some human being in a platform company fixes it up so it looks nice; but then the next one happens, and the next one, and the next one, right. So the vaccine search on Google looks pretty clean because so much scrutiny was given to it. But it would be better to have processes that are robust and new topics coming up, right, rather than people simply fixing up what content is being surfaced on a particular topic. So I just encourage whatever intervention is taken here to have a more robust approach than simply centering on a particular set of keywords. And this source-based approach, I think could be effective at that if it's implemented across topics. Next slide, please.

Okay, so just to reiterate, I know I'm, I will be wrapping up right here. Social media didn't create all these problems. Echo chambers are far

more subtle than people think, but these small groups that are consuming this harmful content that can have really significant repercussions in the real world, whether it comes to political extremism, like the violent insurrection we saw or people not getting vaccinated which can, of course, have harmful effects on many other people. And that's why it's critical that platforms do more to amplify credible sources and are moving forward to the work that this group is able to do to further that point. Thanks.

RAYNARD S KINGTON

Thank you, Professor Nyhan. Now let's turn to Dr Fitzpatrick.

LISA FITZPATRICK

Good afternoon, everyone. I appreciate the opportunity to be here. Dr Graham, I really have never been referred to on a webinar as a hero, so thank you for that. And to the Advisory Group, I appreciate the invitation to be here. Today, I want to share the experiences and lessons learned during the pandemic about this critically important topic. And throughout the pandemic, our team at Grapevine Health has been in dialogue with the public, particularly underserved communities, and we've been to two states outside of DC. We've been to New Jersey; we've been to

Pennsylvania. But the bulk of our work has been in Washington, DC, and on some of our virtual work we've had people from outside this area. But largely I'll be sharing perspectives from people we've talked to in underserved communities here in DC. But because of the lesson, the lessons we've learned today, I want to challenge the notion about who is and who isn't a credible messenger. And many of my comments will reflect back to you the questions and concerns raised from the community of our trusted and credible sources of, of information—health information. Here, and next slide.

And here is an overview, an overview of what I will cover today. I'll say a few words about how the community used traditional science messengers, let you hear directly from the community, and then I'll reflect on some of the highest priority lessons learned and offer recommendations about how we might better establish credibility, authority, and trust in the delivery of health information. Next slide.

But, before turning to the community voice, I think it's important to share a few observations from the community about traditional messengers like our government agencies. Many people we've interacted with remain

deeply skeptical of government agencies, and as a scientist and clinician it's humbling to hear how little people understand about the importance or the functions of these agencies. And I can't recall anyone being able to distinguish CDC from NIH or even broadly describing FDA's role in science. And, while some have come to know and even love Dr Fauci as we just heard, they believe he's the CDC director, and that CDC makes vaccines. In addition, responses from traditionally authoritative sources like CDC can be vague and generalized, and because they lack specificity this exacerbates distrust. Next slide.

I wanted time to community voice, so the remainder of my talk will really focus on what we're hearing in the community: what we've heard during the pandemic. But to be honest, my work focusing on health literacy and community advocacy, patient engagement, has reflected a lot of the same things we are seeing now, which are exacerbated during the pandemic. So my team at Grapevine, including several doctors, and I'll highlight doctor Fabian Sandoval who you can see in the picture at the very top; he communicates with community members in Spanish, and this will become a growing component of the work we do. And because of that, because of the work he's doing in the LatinX community, we think there's a need for

us to expand his work, especially outside the Washington, DC area. But we'll be populating the video content we create on YouTube so that more people will have access to it. But we've also been conducting virtual ask-the-doctor sessions; are responding to people via text messaging, email; and now Clubhouse, the new audio platform, we've also held sessions to answer people's questions along with many other trusted health providers; and then social media; and finally on the streets. So we've really tackled this from many, many facets. Next slide.

And the misinformation is rampant from conspiracy theories about 5G towers, Bill Gates and microchips, population control, to the pandemic being orchestrated. We've lost the trust of community, and many often turn to their trusted sources of information. Next slide.

And here's an example, a colleague of mine who is a white male researcher and medical doctor shared this example with me: After offering the vaccine to a black male patient, the patient informed him he needed to get more information. To which the doctor, my friend, replied, "Well I'm happy to answer any of your questions or provide any information you need." And this was his response, he said, "I'm not looking for *your*

information, I'm looking for my *own* information." In other words, he needed to vet the information amongst his credible sources. Next slide.

For now, I'd like to turn to, turn directly to the community's voice, and over the next few slides, I'll share a few clips with you. But first I would like to ask you, rather than to interpret the context around what you're hearing, I would like you to listen and suspend judgment, and see what you can learn from the conversations or the information these folks are sharing with us. The first two clips are audio clips from a podcast interview, the Grapevine Health podcast. And this, the next clip after the audio clips will be a small group discussion I held about trust and health information and vaccines. And the final clip is from a street-intercept interviews, a street-intercept interview I held a few weeks ago, talking to the public about coronavirus testing and the vaccine.

So, as you listen and watch these clips, again, I ask you to suspend judgment and instead seek to understand their perspective so that we can ask ourselves what it will take to establish the trust needed to ensure messages from authoritative and scientific institutions can be heard and acted upon. We should ask ourselves instead: Where have we gone

wrong, and what are missed opportunities to address the misinformation and skepticism you'll hear? Next slide.

[audio clip 1]

PODCAST INTERVIEWEE #1

What do we do when we get in the community? You go out in the community, you talk to the people that's out there and tell them what you're trying to do, and you try to bring them in, because they are the people they're gonna listen to. If they, or somebody outside tell them the sky is blue, trust me, they're gonna believe the sky is blue, 'cause that's just how people are. What I've encountered, I don't have to believe nothing you saying; but if I like you, and my friend like you, we're going with you, because we like you. It don't matter if you right, we just like you.

So what did they say different than the other person said? Oh well, that's my friend. Oh, okay, so we like her, okay; I understand. I mean that's how it is nowadays. You get a lot of likes, you're popular. No likes? You're not popular.

PODCAST INTERVIEWER

So when you hear health information on the street, how do you decide if you trust it? I heard you say, if you like the person, you believe what they're saying. But really, if you're trying to decide if, if you trust the information, how do you decide that?

PODCAST INTERVIEWEE #1

Oh well me, I research. I don't listen to what nobody says, really at all.

PODCAST INTERVIEWER

Where do you do your research? How? What's your process?

PODCAST INTERVIEWEE #1

I Google it. I ask around…

PODCAST INTERVIEWER

Who are you asking?

PODCAST INTERVIEWEE #1

Whoever say they encountered it. I’m asking everybody, “Did you ever do this before? Does this ever happen to you? What happened? Where did you go?” Like, I'm nosy, I want to know.

PODCAST INTERVIEWER

And when you go to Google, do you get the information you need in a way, you can understand it? Do you know what to do after you do your Google searches?

PODCAST INTERVIEWEE #1

Sometimes you get good information, sometimes you have to look further into it, because sometimes Google is weird—might get some weird answers sometimes.

PODCAST INTERVIEWER

So when you go to Google and it doesn't give you the clear answer you want, then what do you do? What's your next source of information?

PODCAST INTERVIEWEE #1

Oh I go to the library. And I call my mom because my mom is very resourceful.

[end audio clip 1]

[video clip 1]

LISA FITZPATRICK

Where do you get your information?

PANELIST #1

I get my information from media. It could be… I try… or the news. I don't really believe the news because they don't really tell the whole story. I really don't try to obtain information unless it's a health issue that's regarding me. I'm really connected with my doctor. I've had the same physician since I was 13, and I went to talk with her, and I felt like she just blew me off. I may look into… And I like to also cross-reference information because if you see something or hear something, it doesn't mean that it's accurate unless it's coming from… even if it's coming from a good source like a news channel.

So with the COVID, I see stuff but I'm not really… I'm not interested in receiving the vaccine. I've experienced it for myself, because I've had COVID, so my information is going off of me; because I actually had it and it didn't affect me. Not to say that it can't, or I'm invincible, but it's just that I don't take it that seriously. So I'm not looking for information. I don't even like watching the news, actually.

LISA FITZPATRICK

If you had to pick one trusted source for health information, who would it be?

PANELIST #2

I don't even trust the CDC because they went from 6 feet to 3 feet.

PANELIST #1

That's something I read off of the social media. They went from 6… this is not in the newspaper; I don't really read it. I enjoy reading, like I love knowledge, but I don't read the newspaper ever. I don't know if it's old-fashioned, but I don't read the newspaper. But I do read, so it can be on the Web, the same thing that's in the newspaper can be on the Web. And I

read that they went from 6 feet to 3 feet. And I just feel like they're just, I kind of felt like it’s planned, like everything in this world is planned.

[end video clip 1]

[video clip 2]

LISA FITZPATRICK

So if you get a COVID-19 test, what does it mean if it's negative?

WOMAN ON STREET #1

If it's negative, that means you got a problem. That you need to go to the doctor and see what's going on, if the COVID-19 is negative.

WOMAN ON STREET #2

Me personally, I don't know if it’s real … I don't know because with all the politics and everything that was going on with Trump … Personally, I feel that government sometimes oversteps its boundaries. Always felt that way. And I, sometimes I think that this is a scare tactic. I hate to say it, but I think they’re just exempting people because they can … My brother-in-law that died, not until he got in the hospital did they say he had COVID. And wasn’t nothing wrong with him. The other person I know that they said

died of COVID was feeling fine until they went into the hospital. I asked doctors, I said, “Is it real?” They said they don't know.

LISA FITZPATRICK

Really? Well, I'm a doctor and I will tell you it is real.

MAN ON STREET #1

They don't have a plan. I’m a let you know that.

LISA FITZPATRICK

Who doesn't have a plan?

MAN ON STREET #1

The FDA.

LISA FITZPATRICK

Oh.

MAN ON STREET #1

They don't have a, they don't have a serious curricular plan, for real.

LISA FITZPATRICK

Do you want to get the vaccine?

MAN ON STREET #2

At no time. I'm good.

LISA FITZPATRICK

Why not?

MAN ON STREET #2

Why should I get something that I don’t know the side effects. I might die in 30 days or 40 days.

LISA FITZPATRICK

So tell me: What questions you have about the vaccine?

MAN ON STREET #2

What's the side effects? What do it does? Who took it, and they still alive? So you was a crash dummy when you took that test.

LISA FITZPATRICK

I did.

MAN ON STREET #2

And then when you die, then what? You not coming back.

LISA FITZPATRICK

What do you do when I die?

MAN ON STREET #2

You gonna have a long, deep sleep.

LISA FITZPATRICK

Okay. Why should someone get a COVID-19 test?

WOMAN ON STREET #1

I think that, if it's real, seniors should get it because, you know, the are…

they’re exposed to a lot germs. And their, their bodies can’t fight it.

LISA FITZPATRICK

And do you know where to get information about the vaccine?

WOMAN ON STREET #3

Um, I can Google it. I can get it from my health care provider.

LISA FITZPATRICK

Okay! Thank you so much.

WOMAN ON STREET #3

You're welcome.

[end video clip 2]

LISA FITZPATRICK

So I chose these video clips because they were most instructive and comprehensively encompassing most of the things we are hearing from the community. And we've learned many lessons, but I'm just going to share a few of what I think are the top lessons we've learned that we should prioritize.

I'm going to also say, I think, there's a notion among academics and policymakers that the digital divide affects people's access to information, but our research shows, and these conversations like the ones you've heard, show us that people are very resourceful about seeking health information, especially online and using their smartphones, even if they have a doctor. You heard Dr Graham talk about YouTube being a very popular search engine. People are looking for information, they're hungry for information, but the question is: where are we, and are we communicating effectively enough for them to trust us? Next slide.

I have a few bullets on this slide.

And second, the public largely doesn't understand science or most of the information that’s being transmitted through the media, including our science agencies. And when they're confused and desperate for information, they will find it, whether it's on the grapevine. You heard Miss Juanita saying, well, when her Google search lets her down, she calls her mother, and that is a very common response we get. And so the question is, when people find information online, whether it's from these authoritative agencies or otherwise, how do we help them distinguish the

truth versus information they should trust? And ideally, we could achieve both. And, finally, people feel distrustful and disconnected from these credible institutions. Sure, people respect and listen to Dr Fauci, but even he has about a 60% approval or trust rating. So where are we going wrong? Next slide.

And I'll just end with some recommendations based on what we've heard in the community. The first, I think we have to design our messaging and ensure we are incorporating the voices, the culture, the context for people we're trying to reach. And I have a quote here from someone who told me in the community, when he told me, "Well, I don't understand what doctors are saying. And if I don't understand you I can't trust you." And I think this also applies to our academic and authoritative institutions.

Second, we must bridge trust and credibility through language and dialogue. So what language are we using? Do people understand us? We have a video—you can go to our YouTube page at Grapevine Health and the video is entitled "Do You Speak Coronavirus?" And we did this as a bit of a fun exercise because, as I was listening to the TV doctors and credible messengers on television, they were using words that I suspected

that the community didn't understand. And sure enough, that was borne out in our experience that day on the street. But the broader lesson is, we need to be thoughtful about how we message to ensure we are not isolating and alienating certain segments of the population, particularly those under-resourced and underinvested communities like we're working with. We need to educate people about the roles and responsibilities of these different agencies. People are conflating the work of CDC, NIH, and FDA—and I think that's particularly important for FDA. I can't tell you how many times I've been asked to consult to help agencies and researchers understand how to improve enrollment in clinical trials, or how do we increase the diverse participation in clinical trials? I think it starts with the basics, just helping people to understand and letting them know you want their participation. But also speaking—I can't overemphasize the importance of plain language, and speaking in language that resonates with people.

And then finally, we have to be honest. So you heard the woman—I got a kick out of what she said about CDC changing—because to the community, this appeared as if this were an arbitrary decision to change the guidance from social distancing from 6 feet to 3 feet. And if we don't

follow up with information that is relatable, understandable, and then provide access so that people can dialogue with us and ask questions so that they understand, I think we'll continue to see this problem.

And finally—next slide—I think my take-home message is: People are on social media. So you heard Brendan said, or Professor Brendan say, social media didn't create the problem; but it certainly is perpetuating the problem. And that's where people are getting their information, so we need to be in those spaces with them and we need to ensure our content is relatable. And that's certainly the path we're now on, and you can find in the upcoming weeks and months as we start to populate our content on YouTube. And I'll just leave you with this quote, “A lie can travel halfway around the world while the truth is putting its shoes on.” And that is never more true than with health information. So thank you again for having me, and I'll turn this over to the next speaker.

RAYNARD S KINGTON

Thank you, Dr Fitzpatrick. Let me also just clarify that the questions are being accumulated to help inform the work of the committee, but the

questions that are being sent in the Q&A will not be answered today. Now let me turn to Professor Tufekci.

ZEYNEP TUFEKCI

Hello.

RAYNARD S KINGTON

Welcome.

ZEYNEP TUFEKCI

Alright, so I'm assuming I'm being heard. So thank you very much. I listened to the previous ones with great interest, and I've been looking at the question and answer too. So I want to start by saying that I want to talk about one aspect of it, which is, well, how do we moderate content that's on the social media sites, and what are, sort of, some of the guidelines? Now to give us a little bit of background, I have previously written a lot about some of the harms from the business models and algorithmic models of the social media sites and how this interacts with, you know, existing societal vulnerabilities and human propensities and how it’s all a mix. So I am very much, um, I'm very much someone who has been on

the “this is concerning and this has certain effects that are not good for society” side.

But what I want to do here is highlight something that is, that interacts with how these sites operate but is somewhat outside of it, too. But it's going to come back to why and how it's really hard to fix this problem because of the way they operate, because the scale makes it very hard.

So um one thing that's come up is that there's a lot of misinformation or disinformation or incorrect stuff that circulates on these sites. You Google something, you find a lot of things that are somewhat correct, somewhat incorrect, a mix, outright misinformation of confusing, not confusing–so all of those things happen. But the question is: Well, what is the role of authorities in providing the correct information, and what is the role of authoritative sources in defining what can be allowed and not allowed in these sites? I’m going to give an example from what happened recently when Facebook was finally pushed to curb some of the health misinformation on its site. And to be clear, just like YouTube, Facebook and YouTube have been very significant in spreading an enormous amount of misinformation and even amplifying it, both by giving it a space

and also on making it easy for it to be shared, making it easy for sometimes their algorithms amplifying, so this is a problem, something needs to happen. But when you come to “what,” you realize quickly that our existing institutions aren't really equipped to draw those lines. And I'm going to go with Facebook's own guidelines as my example, but the problem is broader than Facebook.

What they decided, when finally, you know, when they were on it to act, was that they were going to take the World Health Organization as the authoritative guideline and basically declare things that were not within World Health Organization guidelines about COVID and COVID vaccines as misinformation and not allow them on Facebook. Now you quickly realize this is not going to be feasible because you essentially have to ban perhaps the first six months of the COVID newspapers—all of them—because the World Health Organization's guidelines, until like a couple months ago, until December of 2020, were saying that people did not need to wear masks separated by 3 feet indoors—I mean like 1 meter. And we know from last year, Dr Fauci was for a long time saying you don't need masks before, you know, that changed. There's a lot of information that has changed in our guidelines. And you might say, well, science got

updated and then that's how the information got changed, and when science gets updated we'll change. But that's a comfortable thing to say to ourselves. Well that's not really what happened. What happened was a fierce inter-scientific debate about airborne transmission, about role of masks and other things, in which the World Health Organization is still fairly defiant of what appears to be a good chunk of the scientific community. And today they just still published another set of ventilation guidelines that a lot of aerosol scientists and infectious disease specialists do not think goes far enough and is still behind the science. And thus, the question is, are those people allowed to speak on Facebook about this? Are we allowed to go on, you know, Facebook or YouTube and say the World Health Organization is wrong when, in fact, that does happen?

Now, so there's a difference here between inter-science debate, where scientists are debating various aspects of science with, of course, the participation of the public, and what we would like to call "misinformation" or "disinformation." And sometimes you can kind of clearly say, "You know what? I can tell the difference. If you're saying the vaccine puts you know 5G chips in your brain, that seems like clear misinformation. Whereas if you're arguing over aerosol transmission, that seems like inter-science

debate.” And I would say that makes sense, except *where* is that line and *who* decides that line? Who decides which line divides inter-science debate that's legitimate from things that are outside of science and are misinformation? And, as I just gave you as an example, you can’t easily say the World Health Organization guidelines partly because, I mean I'm not trying to blame the World Health Organization here, I'm just saying that's not what they're… that's not what they were meant to do. They issue guidelines, but that doesn't mean that everything outside of those guidelines is not science or is misinformation. That's like, that's not what that institution has been equipped to like distinguish between, “okay, this is valid science or valid scientific disagreement” versus “this is complete misinformation.” So when you come piece by piece into what we keep out, it's not at all straightforward as saying, “Let's go listen to science. Let's go listen to scientists. Let's go listen to authoritative sources.”

Also, further, even for things that I think we can easily say they're outside of science, like I would be comfortable saying that for certain things, they need to be debated and discussed to convince people, because if you basically only completely just try to block it and then you… there's a lot of… like when Facebook tried to clamp down on things, there's a lot of

things where there were genuine attempts to try to convince people about vaccine efficacy and safety that got occasionally, and sometimes very prominently, got nixed from the site because, well, how do you convince people if you're not letting the objections be aired openly? And if you're constantly just saying like "I'm just going to talk and you're just going to listen to me," is not the best way to convince people. And I think the previous presentation was very, very interesting and telling in showing, like, you need to talk to people, and you need to listen to people, and you need to earn their trust, which are not the same as, you know, we're just going to block out everything. Plus, even the Facebook guidelines, for example, I was looking at their guidelines and they had claims like, "Nobody can say the vaccine trials did not have a placebo arm. They were gonna… because apparently that's a, sort of a misinformation talking point that the vaccine trials did not have a placebo arm. So they banned that from their site, but there are current vaccine trials looking at comparing different booster regimes that do not have a placebo arm. So even there, like even Facebook's sort of authoritative health rules, I could immediately spot errors in their health rules, which kind of tells you this is not something easy. And the reason this corresponds to the business-model problem is that we can't… the problem is, if you had a small number of

sources to evaluate, you could maybe do something like, you know, form a reasonable committee of people who would say, “All right, you know what? This is outright grift and misinformation and snake oil” versus “This is inter-science debate where scientists are debating it out,” versus “It’s perhaps okay to try to have this conversation.” But on the scale of Facebook or YouTube where there's, I don't know, last I checked there were like millions of minutes uploaded every second, there's just no way for something to work on the scale of Facebook or YouTube, which creates a huge problem. Their business model would not allow it. Even if you tried to do better at it, it would be at this, I mean for me, and let's just be honest, for YouTube and Facebook, these are costs, this is not how they make their money. All moderation attempts are how they lose money, how they spend money, and if we come up with a plan that drastically ups their moderation costs, it starts hurting their costs to the point of making it implausible for them to continue. And this is why they just aren't very open to such things that essentially means that at that scale, they could not operate.

So we're at this complicated moment in which we don't have, like we keep saying authoritative sources, but our authority of sources aren't designed

for this. Our authoritative sources, even when they issued guidelines, they're not delineating the end of science. As this pandemic has demonstrated, our medical authoritative sources get things wrong. And you can't just brush over that by saying, “Oh, they had it right then, and then the science changed,” because that's not what happened, like we, that's the story we tell ourselves. And this is kind of like okay; you know, getting things wrong is part of science, but pretending it doesn't happen isn't part of science and it's not a way to help us understand how to deal with this problem. So we don't have a mechanism for that. And at this point, like when I say all of these things, sometimes people will ask me, and I'm sure it'll come up—I know we're not doing Q&A—it'll come up in that like, “What is the answer to this?” And I don't have an easy answer to this, because I don't think there's an easy answer to it. But I think we really should be realistic about the fact that the scale of these platforms makes all easy answers, or all kinds of things we say, not very feasible, and that's just our reality and we have to kind of figure out what are we going to do about this as it is, rather than making solutions for… like making solutions that just are not going to work and are either going to backfire or are going to be inoperable. And it just we're not going to be able to implement them.

I believe that, in most cases, the answer lies in authoritative sources gaining trust of people in an effective way so that they can be what people believe. Like so this is the part where I go back to you know, given all of this, I believe the answer is going to go back to like, how do we convince people that you know the authoritative sources are the right sources, rather than the other way around. So that's kind of where I would like to, you know, we ran a little over time, so I'm going to cut myself short to give the panel the time. It's a big, challenging moment and I just wanted to be the person saying I don't think we have the guidelines we wish we had Thank you.

RAYNARD S KINGTON

Thank you, Dr Tufekci. So we're going to take down the slide and we're asking the panelists to turn on their videos, and then we will start. We'll have some Q&A from the panels.

Let me start asking the first question. Professor Tufekci, while you clearly highlighted just how challenging it is to come up with a schema like the one that this is, that is being proposed, my question is, wouldn't it be better—not perfect—but better to elevate, to raise sources that are more

likely to be science based than to leave this sort of Wild, Wild West that we have now? Wouldn't it be better, not perfect, but better than what we have now?

ZEYNEP TUFEKCI

I'm sorry, it broke up a little. Was that a question directed at me?

RAYNARD S KINGTON

Yes, yes it was.

ZEYNEP TUFEKCI

Sorry, it broke up a little. So I want to say it would of course be better, but like the problem is, where do we draw that line? Like I would very much like to be a world in which the inter-science debate is, you know, full force and science is what's listened to, and the misinformation just kind of falls to the wayside. I just am trying to figure out what would be the way by which we draw that line, because most of the proposals I've seen for drawing that line are not realistic. So I'm not, like, if I had a realistic solution, I promise, I would be sharing it.

Because also the CDC and World Health Organization… I just want to make it clear. I criticize them, but they were, of course, essential, crucial institutions, but their role in the world wasn't to give us those lines by which we could moderate Facebook or YouTube. They're in the business of issuing, you know, different kinds of evidence synthesis. Their role isn't, like, “What's the right line for you to draw?” And we're kind of going at them because we don't have any other institution. I feel like we should be discussing maybe some other institution where we could give them that job and say, “Distinguish, you know, legitimate inter-science disagreement from outright misinformation,” because, again, CDC and World Health Organization necessarily do not draw that line because of what they do.

RAYNARD S KINGTON

Let me ask if any of the panelists want to comment. Dr Fitzpatrick.

LISA FITZPATRICK

Yeah, I'm sorry. I just wanted to add a perspective here. I think you know, and for those who don't know, I was trained in Epidemiology at the CDC. I worked at the CDC for 10 years. And I think there is a really important opportunity that CDC continues to miss all these years, and that is being

relatable, being accessible, really trying to provide the clarity people need so that they feel comfortable. So I think, you know, even though they might not be in a position to make these kinds of decisions, they could at least be in the spaces where people are getting their information and also adding relatable information. I mean, that's sort of my message over and over and over again. People want to hear from these credible authoritative institutions, but the messages we get are sometimes too confusing, too generalized, and they're not useful for people.

RAYNARD S KINGTON

Let me ask Dr Curry. I see your hand up.

SUE J CURRY

Yeah I know Garth came into the chat before I put my hand up, that he had a question, so I'm gonna let him ask his question and then I'll go.

GARTH GRAHAM

Or you know I'm going to defer to you. Please, I'll go after you.

RAYNARD S KINGTON

If Dr Nyan had had any comments. Have you, did you have any comments?

BRENDAN J. NYHAN

Well, look, I guess I would say that I would encourage folks to not reinvent the wheel here. We had this exact debate about Facebook and what a credible source was like four years ago. So it seems strange to me that we're proceeding as if there exists like a list of authoritative sources that one can just like staple on here and solve this problem. But I would try to build on that, I guess. You know, relative to political journalism, there is more authoritativeness. They will sometimes get it wrong. Zeynep is, of course, correct about that. I think we have to live with that, and I think the relative standard of “better than” is fine. But we, it's just thinking about where the takedown policies are being enacted, because we would have gotten this wrong, as she reminds us. So I just want to highlight that point, that it's not going to be perfect. If we say, “It won't be perfect,” then of course you can't do anything. I would encourage us to think about relative to the status quo and ways we can be robust, the kinds of mistakes that science makes is it learns about new phenomena. I'll stop there.

RAYNARD S KINGTON

And Dr Curry.

SUE J CURRY

Great, well, thanks. So actually, I have a question for Brendan and, first, I just want to thank the panelists because this was really, really, I mean you all, you know brought your top game today. It was it was really enlightening to listen to you. So, the researcher in me wants to ask this question because you showed a lot of data. It seemed to me that there was this assumption that more consumption is indicative of a stronger belief. So, people who are in echo chambers have stronger beliefs. And I guess what I'm wondering is, if people hear from somebody something that they want to verify, and they go to YouTube, and they find that one video as off the mark, or you know, unauthoritative as it might be, that confirms what they heard, I mean might they just stop there? So is there research to suggest that watching more videos makes you… is indicative of stronger, harder-to-change beliefs?

BRENDAN J. NYHAN

So I'll just respond briefly. That's a hard question to answer causally. So what we're simply doing is describing the consumption behavior and saying that these people who tend to have more extreme beliefs and more extreme information diets are often consuming the majority of this content. The causal direction between the beliefs and the viewing is hard to establish, in part because we can't run experiments on platforms. Hint hint, YouTube, hint hint. So there's lots more we could we could learn there about that. I guess I would say there are relatively few informational interventions that just tell someone something and it changes their beliefs and behavior for years and decades down the road. We think these things tend to fade. And it's, you know, we need to, you know, people need to hear things multiple times and in reinforcing ways. I'll just add that there's no evidence in our data so far of the version of that story you describe, which is something like a rabbit hole: where you watch the one video, and you become convinced, and you find a bunch of reinforcing content, and you kind of spiral off. That doesn't seem to be the model for most people. It doesn't mean it doesn't exist, but it's not, I would say it's not the first word of concern.

ZEYNEP TUFEKCI

May I add something there? I think the problem that is very hard to measure here, is that, one, the platforms themselves experiment and do A/B tests and other tests, but we don't have access to it as independent researchers. So that's problem number one. Problem number two is that these platforms have changed the whole ecology. So I know, for example, FOX news is competing with Breitbart on Facebook. So even if you're never on YouTube or on Facebook, the FOX news you watch is being influenced by the fact that the whole ecology [inaudible] in different directions. The New York Times is competing with MSNBC in some ways, which is very competing on Facebook. So, if you look just on what happens on YouTube, you'll miss this big very important shift, which is that there's only so many hours in a day, and if a very active, usually like partisans are active, you see this in primary research too, if a very active group is slightly shifting to Breitbart all the time, TV FOX news is going to change to compete with that. And all of a sudden, you think there's no effect when what has happened is that the whole ecology has shifted. And such things are very hard for social science to measure because you don't have a counterfactual Earth—Planet Earth without YouTube and Facebook in which you observe what happened to the static FOX news—

and you're just looking at, as social scientists, we can only look through fairly narrow, kind of, you know, whatever we can do.

RAYNARD S KINGTON

Thank you. I'm going to go next to Dr Chou.

WEN-YING SYLVIA CHOU (NIH/NCI) [E]

Thank you so much. I have one question for everyone and one for Brendan, and they're both quick. I think I hear a lot of repeated is the idea that trust and trusted sources is as important as just determining what's credible and what's authoritative. I'm struggling to figure out how do we take into account this notion of trust in our work, because obviously I understand the need for listening, the need for bottom up—we can't do anything top down, because we will miss a lot of people and we can further exacerbate disparities. So that's one question.

And one for Brendan. In light of all the data that shows that it's a small percentage of people that have gone into these deep rabbit holes or have fallen prey to misinformation, do you see this as a parallel to the way we look at vaccine hesitancy? There's a small group of staunch refusers, and

then there's a group that's undecided but they can be swayed. Because I'm thinking, from our perspective of communication, even all the ways platforms manage, should we think of those as two separate types of users and what do we do about that small percentage that, this is causing a lot of harm to them and, potentially, to the rest of the society? So, however people want to deal with both trust and the small fraction of extremist activities.

RAYNARD S KINGTON

Dr Nyhan, do you want to give it a shot?

BRENDAN J. NYHAN

Sure. So on trust, a simple thing one might do would be, so Facebook, for instance, I know has experimented with crowdsourced trusts in combination with other signals it uses. So one could imagine, for instance, authoritative institutions that have high levels of trust expressed by the public in surveys are gathered in ways that aren't easily gamed or manipulated, which has been a big concern with that kind of rating. Gordon Penny Cook and Dave Aranda have shown that public ratings of trust in new sources correlate quite highly with other kinds of objective

indicators of quality. Something similar might be possible when it comes to health sources to help elevate those that are likely to be trusted and, importantly, as Dr Fitzpatrick reminds, is trusted across our society: trusted broadly, trusted in communities that might be disproportionately harmed or affected. I think there's a lot that, one could do there. It could be your local hospital, it could be, you know there's lots of ways that you could imagine making that more targeted to people's needs in a respectful nonmanipulative way. On the second point, I absolutely agree. I was trying, this is exactly the partition that I was trying to recommend is to avoid making platform policies around the tiny percentage of extremists and miss how you can most effectively communicate with say the marginal vaccinator. Those are, um, the parent who has some hesitancy but we're going to be trying to convince him to vaccinate their kid in a few months, or the adult who's on the fence about whether to get a COVID vaccine now. That's really different than someone who's selectively opting out of childhood vaccines, which is, as you said, under 10% of the population. So I just want us to think about both of those problems, but to think about them separately. And the authoritative sources, I think, would be especially important for the marginal vaccinator or that kind of person. To the anti-vaccine extremists, it's more about allowing them, you know,

preventing platforms from being exploited to surface that content to more and more people and potentially harm.

RAYNARD S KINGTON

We have a couple of questions for Dr Fitzpatrick, so Dr Villarruel and then Dr Graham.

ANTONIA M. VILLARRUEL

Dr Fitzpatrick, thank you for your, and all panelists, for their talks. You in particular addressed an issue that I'm concerned about and that's differentiating the messenger from the message. Your work and your organization certainly have worked a lot on the messenger, how do we marry the message and the messengers? We're looking at finding these areas of trusted sources that will promote content on YouTube, specifically since you don't fit. And again, we need to widen the net of hospital based, professions based, librarian based, but again you're a fabulous interpreter. So what are the characteristics of your organization that we should consider as we're looking at trusted sources?

LISA FITZPATRICK

Thank you so much for that question. It's linked to a part of the response I was going to give to the previous question about trust. But first I just want to give a brief explanation for why I started Grapevine Health. So I've had almost every job you can imagine across the health sector. But in all these jobs, one thing I recognize, is that we are ineffectively communicating with people, whether it's about research, about clinical issues… Anything in health and science, we are not effectively communicating with the people I'm working with. And so we conducted a research study a couple years ago with support from Commonwealth Fund, and we asked people where they get trusted health information. And although people would say, “Well, I trust my doctor,” or, but we sampled these people from an emergency department waiting room. So these are people who have primary care providers and they were in the ER. So even though they Google—and they would sit in the ER Googling their symptoms—but the follow-up question was, “Well if you don't know what to do with your Google search results, what do you do?” Over 60% of them said they were talking to people they know, like Miss Coats said on the audio. And so, I think the challenge for us and for these institutions that we hold so dear is to find ways to listen to community and figure out where they're getting information, and then build collaborations with those organizations. So this

does include the faith community, but that's not the only solution, particularly for black communities. The people we work with, it's rare for a lot of the people we've talked to so far, and we've probably spoken to over 1000 people, it's rare for someone to say, "Oh well, you know I'm getting this information from my pastor," or "I'm getting it from my church." But that is definitely an institution that's important to partner with. But why don't we see institutional partnerships with these social service agencies that have already built trust with the communities, the people who are on the front lines providing social determinants– or social drivers–related services? I think creating, uh, building bridges with those organizations and then helping them to deliver the messages as well because… I mentioned we're doing virtual sessions during the pandemic. This includes for some of these social service organizations, and they are asking for support and for help to be able to explain these difficult concepts to the people they are serving. So I think there is a need and a hunger for this kind of collaboration and relationship. So to me it's a call to action to build that trust.

RAYNARD S KINGTON

Dr Graham.

GARTH GRAHAM

So this is another question for Lisa. I'm going to start by performing a self-critique as I give that question. You know, as someone who had thought he spent a lot of time in research and Chief of Health Services Research, and generally research, I have to tell you, it's one thing to research and write about on issues, but it’s another thing to do like Lisa's doing and be out there in the community, face-to-face with a community where they're asking tough questions. So I have a tremendous amount of respect for what it takes to be on the frontline. Because it's one thing to get a publication; it's one thing to be there in people's lives. And so, I guess my question to Lisa is along the lines of what you have learned because I really do value, I think, many of us should value those kinds of opinions much more than we do. You know, things that get citations, etc is, um… You mentioned the kind of paradox with Dr Fauci as an example of someone who is upstanding in the Community, maybe resonant with the general Community, but not resonant specifically with Black and Brown communities, in particular people on the street. And we've seen that come out of some of our activities that we've tried to do as well. Is there an example of a kind of… how you create someone that is resonant? Is there

a capacity to have resonance at scale, or is that more of a localized phenomenon and based on who community of folks are used to interacting with?

LISA FITZPATRICK

Well, thanks for that question. I mean the approach we're using at Grapevine Health, it's because of the information we were getting back from the community. They wanted to see people in the community who could answer their questions, and so I think there is a huge opportunity to scale. There are so many doctors leases on the street across the country, and there's a need to rally this group of people. We're calling them our tribe. We're trying to find more people who have, you know, and find time and resources for these people to do this work out in community, but then digitize it. So that's the importance of the videography. So that we're out in the community, answering these questions, educating people, but it's captured on video like one of the ones I showed you. And then we can put it on YouTube and then these other places, but then allow people to reach in and ask questions. I can't overemphasize how disconnected people feel from health and science, institutions, and even healthcare providers.

RAYNARD S KINGTON

Thank you. Stacey did you have a question?

STACY ARNESEN

I think it's actually been covered already, so thank you.

RAYNARD S KINGTON

Okay. Dr Chou did you have another?

WEN-YING SYLVIA CHOU (NIH/NCI) [E]

Sure. So Zeynep, your overall comment about how you feel like there are no existing mechanisms that can do this work effectively—I can really relate to that. I think it's been tried a lot of times, you know, to think about it. From the perspective of public health, though, like we're looking at certain things that I think this pandemic has given us more to think about, in terms of individual health decision making affecting the rest of the society. So it's no longer just that the Libertarian argument doesn't work very well in the cases of people wanting freedom of, you know, access to information. So is there something maybe during this pandemic that can give us a way to be, maybe a little more proactive? Because of the safety

and health of others, that could be a teachable moment to experience or experiment with something, that… different.

ZEYNEP TUFEKCI

So that's a great question because, again, I kind of try to point the finger at what's missing outside the platforms, not because I don't think there's a problem at hand. But I want to go back to what Dr Fitzpatrick was saying, which is so important, is that we don't have the tools at the scale we need to win the argument. Right? Like, you, I think you can do a lot on like the amplification side and maybe find a way to draw the line a little better and do a lot of these things, but in the end, you need to be able to convince the people by winning that argument. And I've been writing a lot publicly about the pandemic, partly because of weird circumstances. And the number of times, people come to me and say, “This is the first article I read that explained something to me.” And I'm a writer, so I write articles. I'm not going to be able to make TikTok videos, but if I could, I would do TikTok videos, to be honest, because they’re clearly more effective in that there's so much basic stuff, like really basic stuff, that we haven’t done the outreach on. And I don't care how many nice guidelines and papers you have, somebody needs to explain what on earth does vaccine efficacy

mean. And just, I write it, and I have these very grateful people saying “thank you for explaining to me” from all over the country. And I'm kind of wondering. I'm not doing something magical here; I'm just saying wait, this isn't being explained well. And that's just in writing. Like the amount of video you can do, the amount of sort of what Dr Fitzpatrick is saying, like the CDC isn’t equipped for this. I'm not blaming them; it's, you know, created so many years ago. But this is the 21st century, and we need to update these things and say how do we make them step into the space and win that argument? Because in the end, that's what's going to work more than everything else, I think, combined. Not that there isn't...

WEN-YING SYLVIA CHOU (NIH/NCI) [E]

Yeah, effective science communication, right?

Raynard S Kington

I’m going to have to shut off. Clearly, we could go on for a long time. But let me just take this. And we just barely sort of whet our appetite on these questions. So let me thank again everyone who’s participated in today's webinar. Let me particularly thank the speakers and the audience for being here and sharing insights through your questions. As just a reminder

that this session was recorded, and the recording and the slides will be posted on the project web page. We also want to remind people to submit feedback on our preliminary discussion. You can go to NAM.edu/AuthoritativeHealthSources (all 1 word), and we would appreciate any insights that you might have. And let me again thank our panelists and advisory committee for participating today. And thanks to the audience for listening. Have a good day.