

## Executive Summary

“Ethics and Pandemic Science: A National Dialogue” was a collaborative two-day event hosted by Virginia Tech’s Community Empowerment for Pandemic Prediction and Prevention (COMPASS) Center, funded by the National Science Foundation (NSF). This event was held at the National Academies of Sciences, Engineering, and Medicine in Washington, DC, on November 12th and 13th, 2024. The purpose of the event was to bring together community leaders, scholars in pandemic sciences, representatives from federal agencies, and other members of the research ecosystem to engage in a guided dialogue about the ethical concerns about research on pandemic science topics. The goal was to leverage experiential knowledge and understand local community concerns of conducting pandemic research going forward. Participants agreed on the importance of a collaborative forum to bring together community voices that will inform pandemic science research over the next decade.

The event’s structure included roundtable and small group discussions. The format of the first day included brief scientific presentations from pandemic researchers followed by a roundtable discussion where community experts could engage the scientists directly with comments and questions. Topics ranged from surveillance of new pathogenetic threats in wildlife to testing prevention strategies with vulnerable communities and allocating resources such as vaccines during an outbreak. Building on the conversation on the first day, the format of the second day included a summary of the key ethical questions and concerns that emerged. Participants worked in small groups with a COMPASS or pandemic researcher to identify the most pressing issues within targeted research areas. The event concluded with a gallery walk during which all event participants voted on the overall most important ethical issues that community-academic partners must address.

Three core themes emerged as priority concerns for pandemic research:

1. The need to build a foundation of trust between communities and researchers;
2. The question of how the results of research can be communicated or translated so they are used for hyperlocal empowerment and action, rather than used to stigmatize and marginalize; and
3. The importance of understanding the role of communication on behavior and how this impacts the future broadly and not just in public health.

Participants further identified data collection, resource allocation, and communication as areas most relevant to their work and community. The majority of participants reported that the event was effective in fostering dialogue.

Results from dialogue throughout the event and participant feedback demonstrate the value and importance of ongoing dialogue between pandemic researchers and affected communities. The NSF COMPASS CENTER is working to host the next National Dialogue in 2026.

## **“Ethics and Pandemic Science: A National Dialogue” Summary Report**

### **Overview**

“Ethics and Pandemic Science: A National Dialogue” was a collaborative event that brought together community leaders, scholars, and scientists from across the country to engage in a guided dialogue around the ethical questions that emerge from pandemic research. The event was hosted by Virginia Tech’s Community Empowerment for Pandemic Prediction and Prevention (COMPASS) Center. The COMPASS Center is a National Science Foundation (NSF)-funded center at Virginia Tech that brings together interdisciplinary approaches to pandemic research and prevention. This event was held at the National Academies of Sciences, Engineering, and Medicine in Washington, DC. The two-day event, held November 12–13, 2024, included presentations from scientists and bioethicists, community expert roundtable dialogues, and small-group discussions and activities. The 50 participants included 28 representatives from community organizations and health departments, nine presenters on pandemic research from universities across the country, nine facilitators from Virginia Tech, and four federal government representatives.

The event’s structure was designed to foster meaningful dialogue among the many communities affected by and parties involved in the ecosystem of pandemic research. The meeting was facilitated through open-discussion roundtables and guided group activities. The roundtable conversations were structured around a central theme, with three to four pandemic prediction scholars providing presentations on their work and outlining the ethical considerations in pandemic research. Following each set of presentations, community expert participants were invited to respond to the presentations and offer perspectives about how pandemic research impacts and connects to their contexts. The initial guided group activities were designed to acquaint participants with one another and foster open dialogue. They provided opportunities for community experts and scientists to begin to understand some of the priority concerns about the ethics of pandemic research at local, regional, and national levels.

Participants brought a rich array of expertise, backgrounds, and experiences. Community experts came from local, state, and federal agencies as well as community-based organizations and healthcare institutions (see Appendix A for full participant list). Pandemic researchers’ expertise ranged from bioethics to social, computational, and life sciences. The first day centered on exploring scientific perspectives on pandemic research followed by large-group roundtable dialogue that emphasized community experts’ experiences, knowledge, and perspectives about the ethical concerns of this kind of research. The second day included a summary of the ethical questions that emerged from the discussions on the first day and concluded with small group discussions exploring those questions more in depth. Collaborating in small groups, participants shared concerns about and central priorities for pandemic research that are responsive to the experiences and concerns of communities.

### ***Overview of Day 1***

The first day began with an interactive session led by Virginia Tech’s Center for Communicating Science. Associate Director Carrie Kroehler and Co-Director of Research Jon Catherwood-Ginn led participants through two group exercises that highlighted the range of different perspectives and beliefs within the group regarding ethics around pandemic science research. Facilitated in the



*Figure 1: (left) The opening exercise, led by the Center for Communicating Science, prepared participants to engage in their own positions on a range of topics; (right) Participants respond to prompts in the opening exercise.*

large lobby space outside the meeting room, the first activity gave participants a chance to meet each other and was aimed at cutting through status markers to reveal all participants, whether academicians, government employees, or community leaders, as humans.

In pairs, participants introduced themselves by name and described something they are learning to do or are not proficient at doing. Pairs then combined to form small groups in which partners introduced each other in a more relaxed and informal setting than the official meeting room.

The next exercise moved participants toward thinking about the decision making associated with pandemic research. The facilitator asked participants to situate themselves on a spectrum of “Agree/Yes” on one side of the room and “Disagree/No” on the opposite side of the room in response to questions posed by the facilitators. The questions started with low-stakes questions such as, “Would you host family for a holiday event?” to questions that required more ethical consideration such as, “Would you consent to being tracked via phone to receive real-time notification of people near you who have contracted a virus?” After participants organized themselves on the spectrum of “Agree/Disagree,” the group was invited to discuss why they chose to stand where they did in response to the ethically challenging questions. The themes that emerged from participant responses during this activity included the importance of consent and compensation for populations being researched, different perceptions of research when conducted by the “government” versus “scientists,” and the need to conduct research in real-world contexts versus a laboratory.

The remainder of the day comprised three sessions that began with brief presentations from researchers. Sessions were organized into three themes: “Jump,” “Spread,” and “Allocate.” A roundtable dialogue with the community experts followed each session. Below is a summary of the presentations and highlights from the roundtable dialogues.

## *"Jump" Theme*

The "Jump" theme focused on the detection and identification of zoonotic viruses (viruses in animals) that can transfer to humans. The goal of this area of pandemic research is to build machine learning models for pandemic prediction that incorporate information about possible pathways by which zoonotic viruses could cause serious threats in humans. At the National

*"I feel like I never see scientists until everything is in shambles... just bring [community members] into the conversation. Being proactive would be very helpful."*

Dialogue, the first session addressed areas of the "Jump" theme related to identifying novel pathogens of pandemic potential and employing surveillance techniques via medical technologies for pandemic prediction.

Kevin Esvelt, Associate Professor at Massachusetts Institute of Technology, discussed the ethics of how scientists identify which viruses have the potential to start a pandemic. Todd Treangen, Associate Professor at Rice University, discussed the ethics of computational biosurveillance, or ways public

health can monitor and estimate the likelihood of an outbreak. Christine Johnson, Professor and Director of the EpiCenter for Disease Dynamics at University of California Davis, discussed the ethics of One Health surveillance for pandemic prediction. Common themes discussed among community partner participants centered around communication among scientists, governments, and communities, as well as issues related to federal, state, and local governments willingness to fund pandemic preparedness interventions and resources. Community experts from state organizations emphasized the importance of embedded communication, a model of community-scientist partnership in which bidirectional feedback is an organic output of research resulting from sustained partnerships between researchers and local health and services organizations. Participants described embedded communication as "a continuous relationship" that is "proactive versus reactive," moving away from transactional and temporary relationships and toward ongoing collaborations and partnerships between pandemic researchers and communities. As one participant expressed, "I feel like I never see scientists until everything is in shambles... just bring [community members] into the conversation. Being proactive would be very helpful." Community experts repeatedly referenced the importance of proactive communication (versus typical reactive communication) and highlighted the need to establish preemptive networks for information sharing and alerting the public of unfolding pandemic-related research.

Conversations shifted next to the nature, content, and timing of the communication. Some participants highlighted the need for relatable communication that is responsive to a community's context. Other participants noted the effect of fear, judgment, and lack of clarity of the content of scientific communication around the COVID-19 vaccine and quarantine guidelines. Participants discussed the precariousness around when to communicate with the public, what data should be included in those communications, and whether communication could be open to misinterpretation. Overall, the conversation explored questions about what the public needs to understand about pandemic science and what scientists need to understand about the public. Community funding was another topic discussed. Community experts commented about the lack of funding for community-led organizations and how this lack of resources limits the ability of communities to act on research findings and recommendations.

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*"Are we willing to act on the results? As a country, we are not willing to invest in prevention."*

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### *"Spread" Theme*

The second theme that the event covered was "Spread"—a theme that refers to research on the ability of a virus to spread rapidly in its physical environment and between people. In turn, the second session examined the ethical research questions regarding experimental research, governance, and tracking strategies related to studying the spread of emerging pandemic threats. Shweta Bansal, Professor at Georgetown University, discussed the ethics of modeling behavior and transmission mechanisms. Alexandre White, Assistant Professor at Johns Hopkins University, discussed the ethics of international governance of infectious diseases. Lauren Sauer, Associate Professor at University of Nebraska Medical Center, discussed the ethics of tracking emerging threats, particularly reporting and disseminating disease data. Emerging themes from the dialogue were communication about data, ethical research design, and unintentional misrepresentations of data during urgent situations. When it came to discussion about communication that does or does not come with sharing data, one participant expressed:

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*With data, you have to be careful about how it's presented and who is it presented to. There is so much misinterpretation of research results and you can apply it broadly to populations. I'm all for sharing data if you share it with an understanding of what the limitations are.*

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This idea, how research results are presented, was discussed by other participants. One community expert discussed the need to "balance the data with the context." Other participants noted that the high volume of data available can result in these data being separated from its context. Making meaning of research findings requires understanding the context in which the research was done. One participant stated, "We don't always understand the story behind the data. We have so much data, what is missing are the stories behind the data so we can do the next step." Some participants noted the value of community participation in research, emphasizing the importance of participatory design and community input from start to finish of the research process.

One participant noted that when it comes to research, "Unless people get their concerns addressed, they don't want to hear what you're talking about." Similarly, another participant

*"Most of the time the concern is 'We don't trust you.' We have to own the history of research in this country."*

expressed the importance of "bringing community together to look at the health needs of the community." Other participants discussed the importance of having lived experience in both developing research and communicating the findings of research. Another core point of discussion was the historical ways in which data have been used to justify harmful actions and the need for scientists to acknowledge that and take responsibility for that history.

### *"Allocate" Theme*

The final session of the day was titled, "Allocate" to refer to research on how human, financial, and material resources are (or should be) distributed during pandemics. The discussion in this session covered research challenges in equitable distribution of non-pharmaceutical commodities like masks, biotechnology products like vaccines, and larger systemic resources like clean drinking water. Pinar Keskinocak, chair of the H. Milton and Carolyn J. Stewart School and Professor at Georgia Tech, discussed the ethics of implementing interventions and resource allocation in pandemic research. Abbey Lowe, Associate Professor at the University of Nebraska, discussed the ethics and equity issues of pandemic research communication. In the roundtable dialogue, ongoing community partnership was brought up again, as well as the need for preparedness and infrastructure for community health work necessary during a pandemic. There were also discussions about the impact of scientific communication that lacked contextual understanding of communities. Additionally, discussions emerged about the need to pair scientific interventions (such as vaccines and testing) together with resources and support (such as food deliveries and staffing).



*Figure 2: Participants engage in a lively conversation about the risks and benefits of modeling and experimental methods.*

About the need for better infrastructure to respond to pandemics, one participant said, "You can't wait until an emergency to partner with the community." Another participant expressed, "The importance of community partners speaks to having long-standing engagement. Community engagement is not transactional when you need it, we should view it as a lifelong endeavor." This dialogue echoed earlier discussions that emphasized the importance of embedded and ongoing community partnerships, communication, and collaboration for ethical and effective pandemic research.

One participant summarized this succinctly, stating "It's so important that we work together with community-based organizations, universities, and whatever is there to support one another." The gap between pandemic science communication and understanding of the unique context of the community was discussed. One participant noted an experience where a member of their community asked, "How can we isolate when there are ten of us at home?" Participants described ways in which Covid-19 communications, at times, neglected the conditions in which many people were living (e.g., working multiple jobs, providing for themselves and family, keeping the lights on, limited access to PPE). Other participants highlighted how some community members were hesitant to test for the virus because they needed to go to work. One community expert expressed that communication that was based on assumptions of the community limited a more nuanced understanding of their actions, explaining "In some communities, there was high vaccine hesitancy and high mask compliance. People are really trying to make decisions for themselves based on what they understand."

The last theme that emerged from the discussion was the importance of allocating resources and support in tandem with medical/scientific interventions. This, participants noted, could be

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*“Sometimes we get into our siloes. One of the beauties of the pandemic is coming to help each other out and see what they do collaboratively. If we do that more as a collective, we’ll be better prepared.”*

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accomplished through community partnerships and by creating channels of ongoing communication. Participants highlighted that the allocation of interventions and resources was unevenly distributed. A community expert asked, “I have HEPA filters, but does everyone have access to that?” Another participant noted, “Access to tests was not equal.”

### *Overview of Day 2*

The second day began with remarks from facilitators with Virginia Tech. Lisa M. Lee, Senior Associate Vice President for Research and Innovation and professor of public health, discussed the role of ethics in everyday choices and the ways ethics shapes and informs research. Julie Gerdes, Assistant Professor in the Department of English, outlined the meaning of agency and its role in ethical research. Gerdes explained how in research and community contexts, “You can think of agency as power.” Lee emphasized “We do ethics every day,” and cited the common themes of engagement, collective effort, trust, and ethical preparedness that emerged during the roundtable dialogue on the first day.

Synthesizing much of the discussion of the first day, Lee concluded with “We [the researchers] have to engage now, and we have to engage before we need something in an emergency. This has to be done before we’re in a

*“We [the researchers] have to engage now, and we have to engage before we need something in an emergency. This has to be done before we’re in a panic. We want to leverage those relationships to act when we need to act.”*

panic. We want to leverage those relationships to act when we need to act.” The remainder of the day was organized into a small group activity, followed by group dialogue and a large-group discussion. The day concluded with individual reflections on the top priorities and charges for the participants and pandemic researchers.

### *Small-Group Activity*

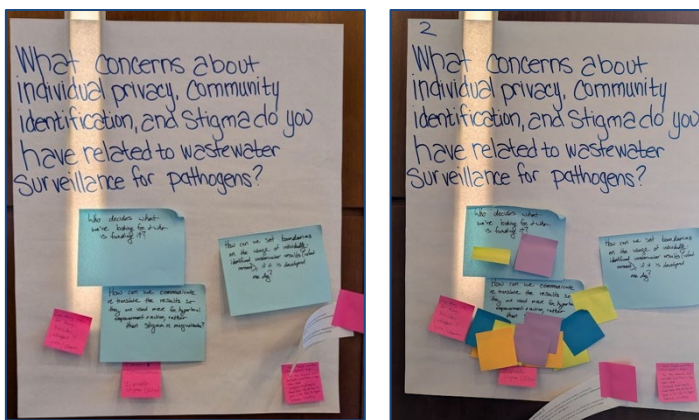
After the introductory remarks from Lee and Gerdes, Carrie Kroehler and Jon Catherwood-Ginn facilitated an activity where community experts worked in small groups to respond to nine ethical questions that connected to the researcher presentations from Day One.

Each group consisted of four to five community experts and a representative from the researchers who presented or the COMPASS Center team. Each group gathered in a different area of the building with their specific question written on large poster paper. The participants were asked to silently reflect on the question and write their responses on small sticky notes (pink). Then, groups discussed their responses and organized them into general themes related to the question, transcribed those themes onto larger sticky notes (blue), and placed those on the poster (see image):

The groups then came together, and each group poster was mounted on the walls of the main meeting room. All participants then conducted a gallery walk, reading the ethics questions and responses generated by each group. Each participant was then given three additional blank sticky notes to use as “votes” to be placed on the responses/themes they felt were most important. After voting, there was a large-group discussion where a representative from each of the nine groups shared the three main takeaways from their small group discussion.



*Figure 4: Small groups identify key ethical concerns related to specific areas of pandemic science.*



*Figure 3: Two posters illustrating outputs from the small-group meetings.*

### ***Findings: Small-Group Activity and Takeaways***

The nine questions, group-generated themes, and votes for each theme on the large posters were documented (see Appendix B). The seven highest-voted responses generated by the groups were:

1. Build a foundation of trust. This includes relationships, education, and pathways for two-way dialogue. (11 votes)
2. How can we communicate or translate the results, so they are used for more hyperlocal empowerment and action, rather than stigmatize and marginalize? (10 votes)
3. Understand the impact of communication on behavior and how this impacts the “future” broadly (not just public health). (10 votes)
4. Individual risk vs. community benefit (8 votes)

5. Whose economy? Health ripple effects. Who is put at risk for the economy? You cannot have wellness without “we,” but you can have illness with “I.” (7 ½ votes)
6. Wellness (4 votes)
7. Find, integrate, and interpret existing data. (4 votes)

For the last portion of the group activity, each of the nine groups shared three takeaways from their small group discussion.

Group 1, responding to the question, “How big does the benefit need to be to justify creating deadly viruses in the lab so that we can study them?” shared that the benefit would be greater if there was a high probability that the virus would occur and spread rapidly. They also noted the importance of preparing for how researchers would defend against the virus and treat it.

Group 2, responding to the question, “What concerns about individual privacy, community identification, and stigma do you have related to wastewater surveillance for pathogens?” asked “Who decides what we’re looking for and who finds it?” They also highlighted the importance of communicating the results of wastewater research in such a way that the results are used more for local action rather than to stigmatize minoritized communities.

Group 3, responding to the question, “How should communities be involved in deciding how data about their communities is collected, interpreted, and used?” expressed that it is the responsibility of residents of the U.S. to offer data. They also shared that questions such as “What is the scale of the collection (state, federal, etc.)?” and “Who is governing the collection?” are important to consider.

Group 4, responding to the question, “What are some of the things we should think about when we design experiments in which people are deliberately exposed to viruses for science?” articulated that motivations and intent are important when designing research, along with the risk versus reward and end goal of the research project.

Group 5, responding to the question, “How should government officials decide when and how to communicate risk when information is changing, and we are uncertain?” talked about using all the “resources at the table” (community leaders, CDC, government officials, etc.). They also highlighted the value of making decisions early and consistently while understanding the impact of communication choices in the present and the future.

Group 6, responding to the question, “How would you balance the desire for transparent information with the risk of creating panic?” talked about building a foundation of trust through relations, education, and dialogue, explaining that “Communication is relational. We don’t get to decide if we are good communicators. Address risks, and myths, and give best practices.”

Group 7, responding to the question, “What should we consider when we know the data are not representative or in the face of data scarcity?” outlined the importance of first understanding and defining missing data, expressing that “We leverage community engagement to inform us about that missing data.” They also discussed incorporating interdisciplinary approaches to better understand and remedy non-representative data.

Group 8, responding to the question, “To what extent do you think researchers should have access to personal information about how you behave in order to predict disease transmission?” highlighted equity (in data collection), engagement (self-determination to opt in and opt out), and reciprocity (how information will be shared, who has access, and for how long?) as key in collecting personal data.

Group 9, responding to the question, “To what extent should we risk the economy for the sake of health and who decides?” asked, “Why is health care viewed as a risk and not an investment?” They emphasized that the decision makers for this issue should reflect the people they make decisions for. The last group concluded with this statement, “You cannot have wellness without ‘we.’ But you can have illness if you keep focusing on ‘I.’”

### *Notecard Reflections and Survey*

The National Dialogue on Ethics 2024 concluded with a final activity. Participants (community experts, researchers, facilitators) were given index cards and asked to answer one question on each side: 1) What do you think is the most important ethical consideration of pandemic prediction and prevention research? 2) What is one charge that you have for yourself or for a pandemic researcher as a result of this event?” Thirty-seven notecards were collected and transcribed by Center for Communicating Science graduate assistant Padmaja Mandadi. Shortly after the event, a survey was sent to participants with 26 about their experience at the dialogue.

### *Findings: Common Threads from Notecard Reflections*

In response to the first prompt, “What do you think is the most important ethical consideration of pandemic prediction and prevention research?” six themes emerged (see Appendix C for the table of themes and responses for prompt 1). The themes centered on equity, trust, community relationships, effective communication, data collection, and research-related questions or approaches. For equity, respondents highlighted the importance of acceptance of others, equitable resource allocation, and research communication that acknowledges the inequality often present in scientific communication. Trust was also a frequent theme, with respondents highlighting the value of fostering and reestablishing trust with and for scientific research, noting that community member’s hesitancy toward health interventions should be acknowledged. One of the most salient themes throughout the dialogue was the importance of embedded, ongoing, reciprocal community partnerships. Closely related, the notion of effective communication between scientific research and the community was emphasized, particularly communication that is non-judgmental and accessible to the public. Another theme from the responses, as well as throughout the dialogue, was transparency related to data collection. Responses focused on questions about who has access to data, risks for people whose data are collected, and whether community input is provided when data are interpreted. Finally, the last theme covered research-related areas of focus and specific research questions, including issues like how experimental and clinical research balances the risks of individual participants in novel studies with population-wide benefits and like the relative appetite for surveillance data collection during epidemic contexts versus in non-emergency times.



Figure 5: Word Cloud of 40 Most Common Words from Responses to Prompt 1

In response to the second prompt, “What is one charge that you have for yourself or for a pandemic researcher as a result of this event?” four common charges emerged (see Appendix D for the table of themes and responses for prompt 2): engage, educate, prepare, and consider. **Engage** included responses that emphasized the need for continual collaboration and incorporation of the community. **Educate** included charges of communicating with clarity, infusing knowledge of pandemic research into dialogues, and seeking to explore questions where information is limited. **Prepare** addressed charges relating to preemptive infrastructure, partnerships, and pandemic planning. **Consider** included charges around research questions and factors to reflect on, such as considering emerging research tools and the effects of research on participants.



Figure 6: Word Cloud of 40 Most Common Words from Responses to Prompt 2

### *Survey Findings*

Twenty-three participants responded to the planning committee's follow up survey sent three weeks after the event. Of the total respondents, 61% were community organization representatives, 13% were pandemic science researchers/presenters, and 17% were planning committee members. The remaining 9% identified as "Other."

#### *Perceived Importance of Pandemic Research*

*(out of 5):*

**3.78** – before event

**4.70** – after event

On a scale of 1-5, respondents ranked the importance of pandemic science to them and their organization before the dialogue at an average of 3.78. Respondents ranked the importance of pandemic research after the event at an average of 4.70. Overall, 96% of respondents found that the event was effective at fostering dialogue about ethical concerns in pandemic research. Summative highlights from the question "What was the most impactful takeaway from the event for you?" included:

- Engaging with diverse perspectives regarding pandemic science is valuable.
- Community organizations are committed to learning and engaging in pandemic science.
- Ongoing collaboration amongst scientists and community organizations is essential.
- Ethical questions about pandemic research are important to consider and account for when working with communities.

In response to the question "Which ethical concerns discussed are most relevant to your work or community?" the following themes summarize respondents' several key concerns:

- Data Collection: purposes for, access to, and transparency of data collection.
- Resource Allocation: planning for and managing limited resource allocations.
- Communication: the need for accessible, transparent, and non-marginalizing communication.

A total of 83% of respondents answered "Yes, absolutely" to the question "Do you think that your organization, or organizations like yours, should be involved in discussions about pandemic prediction and prevention in general?" Respondents further cited the importance of including many perspectives and the collaboration necessary for an effective pandemic response.

The top three responses to the question "What community involvement or advisory role do you think the NSF COMPASS CENTER should incorporate?" were additional national dialogues (19), an advisory board that meets twice a year (15), and local community dialogues (15). Overall, respondents reported that the scientific presentations on the first day were "Easy to follow and understand" and "Informative and/or helpful." Most respondents rated the event location (the National Academies of Sciences, Engineering, and Medicine Building) highly, with most respondents selecting Washington, DC, as the preferred location for future events.

## APPENDICES

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### Appendix A Participants of the 2024 National Dialogue

Gloria Addo-Ayensu, MD, MPH, Director of Health for Fairfax County.

*Community Expert*

Kristin Adkins, Population Health Manager, Roanoke City & Alleghany Health Districts,  
Virginia Department of Health.

*Community Expert*

Shweta Bansal, PhD, Professor in the Department of Biology at Georgetown University.

*Speaker*

Mitra Basu, PhD, co-Lead for NSF PIPP Working Group.

*NSF Representative*

Sophia Booker, MSW, serves on the Court Improvement Program Advisory Committee for the  
Supreme Court of Virginia.

*NSF Representative*

Deron Campbell, MPH, Director of Community Health, Access, and Prevention at Inova Health  
System.

*Community Expert*

Jon Catherwood-Ginn, Assistant Professor of Applied Theatre and Co-Director of Research at  
Virginia Tech's Center for Communicating Science.

*Facilitator*

MacKenzie Chitwood, MPH, Prevention and Wellness Development and Evaluation Coordinator  
for Blue Ridge Behavioral Healthcare.

*Community Expert*

Pamela Chitwood, Health Equity Specialist for the West Piedmont District of the Virginia  
Department of Health.

*Community Expert*

Terry Clark, MPH, Health Equity Project Manager at the Virginia Department of Health.

*Community Expert*

Veronica Cosby, MAHS, MS, Program Manager for the Virginia Partners in Prayer and  
Prevention, Office of Health Equity, within the Virginia Department of Health.

*Community Expert*

Mindy Eckstein, MPH, Program Coordinator, Virginia Rural Health Association.

*Community Expert*

Kevin Esvelt, PhD, Associate Professor at the MIT Media Lab and Director of the Sculpting  
Evolution Group.

*Speaker*

Maurice Ferrell, MBA, PhD, Pastor at Vance Street Baptist Church in Danville, VA, and Vice  
President for Technology and CIO for the North Carolina Higher Education System.

*Community Expert*

Vilma I Ferrell, MSN, RN, Assistant Professor in Nursing at North Carolina Agricultural and  
Technical State University.

*Community Expert*

Monica Fuller, School Counselor at Ridgeview Middle School, in Dickenson County, Virginia.  
*Community Expert*

Ashley Garcia-Rivera, Policy and Advocacy Fellow at the Center for Adoption Support and Education (C.A.S.E.).  
*Community Expert*

Julie Gerdes, PhD, Assistant Professor of technical communication and rhetoric at Virginia Tech.  
*Planning Committee Member*

Joshua Glasser, Assistant Director for Combatting Antimicrobial Resistance and Integrated Health Innovation at the White House Office of Science and Technology Policy (OSTP).  
*Federal Government Representative*

Brian Hairston, 4H Agent for Youth Development in Henry County/Martinsville City at the Virginia Cooperative Extension Service.  
*Community Expert*

Brittney S. Harris, MFA, Assistant Professor of Applied Theatre and Co-Director of Research at the Center for Communicating Science.  
*Facilitator*

Kathy W. Hosig, PhD, Director for the Virginia Tech Center for Public Health Practice and Research (CPHPR) and core faculty member in the Master of Public Health program in the Department of Population Health Sciences at Virginia Tech.  
*Planning Committee Member*

La Tika Jeffery, Youth Development Specialist for Virginia Department of Social Services.  
*Community Expert*

Christine Johnson, VMD, MPVM, PhD, Professor of Epidemiology and Ecosystem Health and Director of the EpiCenter for Disease Dynamics at the University of California, Davis.  
*Speaker*

Jessica Jones, Virginia Cooperative Extension Agent and Family and Consumer Sciences Agent for Greensville and Dinwiddie Counties/City of Emporia.  
*Community Expert*

Pinar Keskinocak, PhD, William W. George Chair and Professor in the H. Milton Stewart School of Industrial and Systems Engineering at Georgia Tech and co-founder and Director of the Center for Health and Humanitarian Systems.  
*Speaker*

Troy Knighton, LPC, EdS, National Seasonal Flu & IDPIO Program Manager for the Veteran's Administration.  
*Community Expert*

Carolyn (Carrie) Kroehler, PhD, Associate Director of Virginia Tech's Center for Communicating Science.  
*Facilitator*

Stewart Lamerdin, Program Manager for the National Science Foundation, Directorate for Biological Sciences (BIO) Division of Biological Infrastructure (DBI).  
*NSF Representative*

Lisa M Lee, PhD, MA, MS, Senior Associate Vice President for Research and Innovation and Professor, Population Health Sciences at Virginia Tech.  
*Planning Committee Member*

Abigail E. Lowe, PhD, Associate Professor at the University of Nebraska Medical Center  
College of Public Health.  
*Speaker*

Amber Lowery, MLIS, Assistant Director for the Roanoke Public Libraries.  
*Community Expert*

Donald K Milton, MD, DrPH, Professor Environmental & Occupational Health at the University  
of Maryland School of Public Health.  
*Speaker*

Danielle Montague, MPH, DSL, Health and Wellness Program Coordinator with the Virginia  
Rural Health Association.  
*Community Expert*

T. M. Murali, PhD, Professor and Associate Department Head for Research in Computer Science  
at Virginia Tech and Director of the NSF COMPASS Center and the Pandemic Prediction  
and Prevention Destination Area.  
*Planning Committee Member*

Maria Murillo-Valdez, MPH, Virginia Cooperative Extension Agent and Regional Coordinator  
for the Collaborative Opioid Prevention Education Program.  
*Community Expert*

Michelle Reed, MA, Director of Client Engagement at the LGBT Life Center.  
*Community Expert*

Michelle Rodgers, PhD, Project Direct for the Extension Collaborative on Immunization  
Teaching and Engagement (E.X.C.I.T.E.).  
*Community Expert*

Roopal Saran, MA, JD, Executive Director of the English Empowerment Center in Falls Church.  
*Community Expert*

Lauren Sauer, MSc, Associate Professor at the University of Nebraska Medical Center.  
*Speaker*

Joanna Shisler, PhD, Program Director for the National Science Foundation, Directorate for  
Biological Sciences, Division of Integrative and Organismal Systems.  
*NSF Representative*

Paul R. Skolnik, MD, FACP, FIDSA, Infectious Diseases Physician, Professor, and Chair of the  
Department of Basic Science Education at the Virginia Tech Carilion School of Medicine  
(VTC SOM).  
*Planning Committee Member*

Kerry M. Smith, PhD candidate, Instructor of Record and graduate student at George Mason  
University.  
*Volunteer Recorder*

Katie Strong, MS, RD, Virginia Cooperative Extension Area Specialized Agent, Community  
Engaged Health  
*Community Expert*

Natalie Talis, MPH, Population Health Manager for the Alexandria, Virginia Health Department.  
*Community Expert*

Marco Thomas, MNS, CCHW, Lead CHW Mentor at Community Health Workers (CHW)  
Strength.  
*Community Expert*

Leslie Thornton-O'Brien, MA, Project Manager for the U.S. NSF COMPASS Center and Program Coordinator for the Pandemic Prediction and Prevention Destination Area at Virginia Tech.

*Planning Committee Member*

Todd Treangen, PhD, Associate Professor in Computer Science and Bioengineering at Rice University.

*Speaker*

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*Speaker*

C. Eric Young, JD, County Administrator for Tazewell County, Virginia.

*Community Expert*

## **Appendix B**

### **Total Votes for Small-Group Activity**

1. How big does the benefit need to be to justify creating deadly viruses in the lab so that we can study them?
  - a. How likely is the virus to cause a pandemic?
  - b. Would knowing help develop treatments faster or stop it? (1)
  - c. How big are the risks (accidents, misuse)?
2. What concerns about individual privacy, community identification, and stigma do you have related to wastewater surveillance for pathogens?
  - a. Who decides what we're looking for and who is funding? (2)
  - b. How can we communicate or translate the results so they are used for more hyperlocal empowerment and action, rather than stigmatize and marginalize? (10)
  - c. How can we set boundaries on the usage of individually identified wastewater results (without consent) if it is developed one day?
3. How should communities be involved in deciding how data about their communities is collected, interpreted, and used?
  - a. Responsibility as resident of US to offer data? (3)
  - b. Governing body: non-partisan, non-bias, appointed? (2)
  - c. Scale of collection) fed, state, local)?
4. What are some of the things we should think about when we design experiments in which people are deliberately exposed to viruses for science?
  - a. Individual risk vs community benefit (8)
  - b. Wellness (4)
  - c. Motivations/intents
5. How should government officials decide when and how to communicate risk when information is changing, and we are uncertain?
  - a. Utilize all resources (people, model, data, etc.) (3) \*
  - b. Early/consistent communication. Acknowledge what we know/don't know. (3) \*
  - c. Understand the impact of the communication on behavior and how this impacts the "future" broadly (not just public health). (10)\*
6. How would you balance the desire for transparent information with the risk of creating panic?
  - a. Build a foundation of trust. This includes relationships, education, and pathways for two-way dialogue. (11)
  - b. Communication is relational. (3)
  - c. Address risk, myths, and give best practices. (1)

7. What should we consider when we know the data are not representative or in the face of data scarcity?
  - a. Understand and define missing data. (3)
  - b. Leverage community connections to prioritize and collect data. (2)
  - c. Find, integrate, and interpret existing data. (4)
8. To what extent do you think researchers should have access to personal information about how you behave in order to predict disease transmission?
  - a. Reciprocity. How data will be stored. Who will have access to data (specific)? (1)
  - b. Engagement. Self-determination. Opt-in/opt-out. (2)
  - c. Equity. Ensure data collection is consistent across all sectors. (1)
9. To what extent should we risk the economy for the sake of health and who decides?
  - a. Risks. Who is really impacted? Why is healthcare viewed as a risk, why isn't it viewed as an investment? \*Historical mistrust. (1)
  - b. Ethics. Decision-makers should reflect the people they are making decisions for. We are all decision-makers (agency). When we don't have equal resources, we can't all make decisions for ourselves. Is that ethical? (2)
  - c. Whose economy? Health ripple effects. Who is put at risk for the economy? You cannot have wellness without "we" but you can have illness with "I." (7 ½)

**Appendix C**  
**Table of Themes and Responses for Prompt 1**

| <b>Equity</b>                                                                         | <b>Trust</b>                                                                                            | <b>Community Relationships</b>                                                          | <b>Effective Communication</b>                                                          | <b>Data Collection and Transparency</b>                                                                               | <b>Research-Related</b>                                                                                                         |
|---------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------|
| Equity means more than treatment to self but acceptance of others                     | Trust or lost of trust people have in information distributed                                           | We must create arenas of awareness; and value relationships to support wellness for all | Early communication of scientific findings that are actionable                          | Data transparency: who analyzes it and who does the sharing                                                           | Human subject research- Exposure to virus or treatments; Surveillance; Long term impacts related health issues                  |
| Most important equitable allocation of scarce resources                               | The most important Pandemic ethics issue is not addressing the concerns & hesitancy that people express | The Pandemic is real and community/ Network need to be aware of the importance          | How to communicate benefits of data without causing panic/ stigma                       | Ensure practitioners weigh in on actionable of research/data collection                                               | Balance risks of research with benefits - whose risks/ whose benefits?                                                          |
| Implementing effective health responses while acknowledging and responding inequality | Re-establishing trust and belief in science/ evidence based research                                    | Communication and building community support continuously                               | Communication that is empowering and judgement free                                     | Decide how we will require people to share data + what data needs to be collected to assist with research, Be uniform | Does "create" matter?; Spillover likelihood; Mutational/ Evolution likelihood; Pure cost/benefit?; What about prediction tools? |
| What bodies/groups are viewed as worth saving/protecting and why?                     | Fostering trust & collaboration between researchers & the public                                        | Full involvement collaboration with communities being researched                        | It is important to get the messaging out that can be understood by the community        | Risk: Automated cell phone or other automated collection of data without the consent                                  | Think deeply about ethical question that underlie pandemic research                                                             |
|                                                                                       |                                                                                                         | Increase co-creation of research agenda to include communities                          | All the issues surrounding genuine two way communication between researchers and public | When, how, and why share research with foreign entities                                                               | Considering investment over risking the lives of the people when making decisions                                               |

|  |  |                                                                                                                     |                                                             |  |                                                                                                                                               |
|--|--|---------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------|--|-----------------------------------------------------------------------------------------------------------------------------------------------|
|  |  | Put the work in before the problem arises                                                                           | Clear, accessible communication that centers equity         |  | Should we credibly identify pandemic viruses?                                                                                                 |
|  |  | What do we owe to each other?                                                                                       | calculating for equity & trust in communicating uncertainty |  | Researchers are humans too and humans need to know that!                                                                                      |
|  |  | We need more resources directed at the community funding for community health workers, NGO, and local public health | Community needs to first understand," What is a pandemic?"  |  | Resource allocation: Taking a systems perspective with data & analytics to evaluate actions and outcomes related to complex ethical decisions |

**Appendix D**  
**Table of Themes and Responses for Prompt 2**

| <b>Engage</b>                                                                                                                     | <b>Educate</b>                                                                                                          | <b>Prepare</b>                                                                       | <b>Consider</b>                                                                    |
|-----------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------|------------------------------------------------------------------------------------|
| More intentionally to bring in community members into conversations and spaces                                                    | Work to educate, even if opinions differ                                                                                | Predict                                                                              | Why am I collecting this data?                                                     |
| Develop means & engaging community members in research as collaborators                                                           | Always make clear the degree of certainty when communicating with the public                                            | Document our work better to avoid some dilemmas next time                            | Do better post-research/ longitudinal follow-up                                    |
| Ensure continuous engagement with non-research community stakeholders                                                             | People are afraid of the unknown, so communication is key                                                               |                                                                                      | How is your research localized, participating, and equitable for the participants? |
| Build a foundation of trust with community                                                                                        | Collective good is always important: I would charge myself with communicating information and concerns more effectively | Continuously building/ preparing community partnerships and seeking new partnerships | What considerations underlie building AI models to predict zoonoses                |
| The charge I have for myself is to continue to build relationships with the entire community (research community leader agencies) | To incorporate what I have learned into my work & teaching                                                              | Prepare community focused channels for stealth pandemic early warning                | Consider how to support mental health of research participants                     |
| Collaborate closely with community leaders to ensure relevance of research and dissemination of results                           | I will share that researchers are human like me because of this experience! They can be trusted                         | Starting new conversations that may become an issue later                            |                                                                                    |
| To create forums like this one that allow for dialogue, engagement, and foster trust                                              | How to better communicate how pandemic risks are understood                                                             | Revise & update pandemic planning & implementation of resources                      |                                                                                    |
| Make sure to engage communities through multiple means                                                                            | How can you communicate about a pandemic without causing panic? Is it even possible?                                    | Frame my work to include public health attributes                                    |                                                                                    |
| Continue to be intentional about building trust partnerships                                                                      | Be the person people trust for information                                                                              | Risk versus wellness should be transparently communicated in all future conversation |                                                                                    |

|                                                                                                                                                        |                                                                                              |                                                                 |  |
|--------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------|-----------------------------------------------------------------|--|
| Listening- really listening to community and providing immunization education where they are "at" and is actionable for them in a more toward wellness | 1 thing I will do is start finding out what, how people feel about the way COVID was handled | Revise & update pandemic planning & implementation of resources |  |
| Follow through with following up with this group in a timely way                                                                                       | What information could I have failed to consider completely?                                 |                                                                 |  |
| Center reciprocity in research & engagement                                                                                                            |                                                                                              |                                                                 |  |
| Encouraged                                                                                                                                             |                                                                                              |                                                                 |  |