NWABR
Northwest Association for Biomedical Research

White Paper: Actionable Strategies for Life Science Stakeholders Improving Transparency and Trust in Biomedical Research, Discovery & Therapeutics

Conclusions from the *Trusting the Science: Navigating Innovation, Misinformation & Data Frontiers* Roundtable Event

October 7, 2024 | Orin Smith Auditorium – UW ITHS, Seattle WA
Event Hosts: Northwest Association for Biomedical Research (NWABR), Washington Global Health Alliance, We Work for Health
Event Theme: Building Public Trust in Science, Drug Development, and Data Frontiers

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Executive Summary

The "Trusting the Science" roundtable convened experts to explore Challenges in public trust across three crucial domains: public health, drug development, and data security. As societal reliance on science deepens, this roundtable sought to address the trust gap between the public and scientific institutions, including academia, the pharmaceutical industry, health agencies, and data-driven AI technologies.

The event emphasized the need for greater engagement with local communities, improvement in public health communication, transparency in drug development, and ethical considerations in AI-driven healthcare solutions. This white paper summarizes the key points discussed during the three panels, drawing out lessons on how to foster trust in science while navigating the complexities of modern biomedical research.

Panel 1: Fostering Public Trust in the Science of New Discovery

Lessons learned from the COVID pandemic, combatting misinformation, and the efficacy and safety of existing test regimens

- Moderator: Melissa Tribelhorn, MPA – CEO/Executive Director, Northwest Association for Biomedical Research
- Dr. Umair Shah, MD, MPH - Secretary of Health, WA Department of Health
- CDR Jennifer Cockrill, MS, MPH - Administration for Strategic Preparedness and Response, U.S. Department of Health and Human Services

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The first panel focused on **how to build public trust in public health**. Commander Cockrill and Secretary Shah proposed three essential elements:

1. **Humility & Dialogue**: Humility is a cornerstone of building trust. Scientists and public health officials must approach their work with humility, acknowledging gaps in knowledge and the importance of learning from public perspectives. Secretary Shah highlighted the importance of identifying commonalities among diverse groups and fostering opportunities for authentic dialogue.
2. **Unity**: While society is marked by diverse opinions, the panelists emphasized identifying commonalities that unite communities. This includes fostering dialogue that transcends political or cultural divisions.
3. **Localized Engagement**: Trust-building requires more than simply educating the public. It also involves listening and finding common ground. Commander Cockrill stressed the need to engage communities by anchoring trust in shared values rather than relying solely on education or information dissemination. Public health should involve local opinion leaders who understand the specific needs of their communities. Ultimately, people will place trust in individuals and their intentions, not systems or programs, its vital that the work is done through a lens that highlights the "who" and "why" of the effort as much, or more than, the "what".

Challenges:

- Public health suffers from an "invisibility crisis"—when it works well, it often goes unnoticed.
- Science evolves – yesterday's discovery might not meet tomorrow's challenges and that's ok, but we need to communicate more explicitly about the fluidity of the process and help contextualize shifting realities.

Key Takeaways:

- Secretary Shah's "3 V's" framework—Visibility, Value, and Validation—was suggested to enhance public engagement. By raising the visibility of public health successes, the public will learn to value these services, ultimately leading to broader support and validation of public health programs and their underlying research.
- Public trust is not built solely through the dissemination of information but by addressing community concerns and fostering meaningful participation. A more

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process-driven approach to science education could shift the focus from immutable "truths" to an understanding of science as an evolving process.

Panel 2: From Idea to Market: The Roadmap of a Therapy

IP from bench science to costs to trial, promoting global access, and the irreplaceability of animal models

- Moderator: Rick Desimone - We Work for Health WA / DCG
- Marc Cummings - CEO, Life Science WA
- Sally Thompson-Iritani, DVM/PhD - AVP of Animal Care, Outreach & 3Rs, University of Washington
- Preston van Hooser, PhD - Founder & Co-Chair, Dare 2 Care: Compassion in Science, University of Washington

This panel examined the complex and lengthy journey from biomedical research to market-ready therapies, emphasizing the current gap in trust between the general public and pharmaceutical processes.

Discussion Points:

- **Financial and Logistical Hurdles**: Panelists noted that while funding for research is more readily available, development is often underfunded. The high cost of clinical trials and the limited financial incentives for rare disease therapies create barriers to innovation.
- **Public Misconceptions**: There is widespread public skepticism about the pharmaceutical industry's motives. Some panelists suggested that drug development suffers from a PR problem, with many in the general public believing researchers are driven solely by profit.
- **Supporting Researchers**: Compassion fatigue, particularly among professionals working with animal models in biomedical research, was highlighted. Organizations like Dare2Care aim to provide emotional support to these professionals to prevent burnout and promote well-being.

Challenges:

- The public may be unaware of the true costs and risks associated with drug development, which further erodes trust in pharmaceutical pricing. Structural

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issues that add out-of-pocket cost burden are often obscured in the pharmaceutical supply chain.

- The journey from research to therapy often takes up to 20 years, creating a major disincentive for innovation. Public expectations for quick and affordable treatments further complicate the process, creating a perception that pharmaceutical companies prioritize profits over public good. While development timelines are seen as excessively long, the complexity of scientific research means that rushing innovation is not feasible.

Key Takeaways:

- Greater transparency is needed in the drug development process to build public trust. Encouraging public participation in research initiatives, potentially through crowdsourcing data, could help bridge the trust gap.

Panel 3: New Data Frontiers

Clinical trial diversity, Biosecurity and data protection, and the future of open-source in a less trusting world

- Moderator: Dr. Carey Farquhar - Professor of Global Health, Medicine & Epidemiology, University of Washington
- Vishal Chaudry - Chief Data Officer, HCA
- Ramkumar "Ram" Hariharan - Director of Programs, College of Engineering and Data Science Faculty at Northeastern University

The final panel explored the ethical and practical challenges associated with the use of AI and big data in healthcare. As health data collection expands, particularly through consumer wearables and other devices, the questions of **data ownership and security** and **balancing innovation and privacy** become increasingly relevant.

Discussion Points:

- **Data Usage and Consent**: Panelists raised concerns about how data collected for one purpose might be used for another without proper consent. This ethical dilemma calls for clear guidelines on data use and ownership.
- **AI in Healthcare**: AI technologies are becoming more prevalent, but the public's trust in AI is fragile. High-profile AI tools, such as those used in diagnostics, raise

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questions about accountability and bias, especially when these systems are not transparent to users.

- **Trust in AI**: Trust can only be built if AI tools are contextually appropriate and proportionate to the risks involved. For example, there is less tolerance for error in AI-driven pacemakers than in consumer health apps. Ensuring transparency in how these technologies work, and who benefits from them, will be crucial for public acceptance.

Challenges:

- **Risk and Benefit Perception**: AI is often perceived as a threat to privacy, especially when personal data is misused or mishandled. The panelists argued for a balanced approach, with regulations that protect individuals without stifling innovation.

Key Takeaways:

- Building trust in AI requires more than technological innovation—it needs clear communication about the benefits and risks involved. Ensuring the security of personal health data, especially in an era where data breaches are common, is crucial to overcoming public skepticism.

Conclusion and Recommendations

The "Trusting the Science" roundtable highlighted the need for **transparent communication**, **public engagement**, and **ethical responsibility** across public health, drug development, and AI-driven healthcare. To build lasting trust, scientific institutions and the pharmaceutical industry must address public concerns through honest dialogue and by showing the tangible value of their work.

Key recommendations include:

1. **Increased Public Dialogue**: Scientists and public health leaders must engage with communities through localized efforts, listening responsively as much as educating.
2. **Transparency in Drug Development**: The pharmaceutical industry should demystify the lengthy and costly process of bringing new treatments to market, fostering a deeper understanding of the challenges involved.

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3. **Responsible Data Use**: Clear guidelines on the ethical use of health data, particularly in AI applications, will be crucial in maintaining public trust in technological advancements.

By addressing these challenges, we can foster a stronger, more resilient trust in science.

This white paper is based on discussions at the "Trusting the Science" roundtable on October 7, 2024, and provides a roadmap for improving public trust in the critical intersection of health, technology, and biomedical research.

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