**ASTC Association of Science and Technology Centers**

# Response to NIH Request for Information: Strategies for Maximizing Public Engagement in NIH Supported Clinical Research

## August 14, 2024

***NIH is seeking information to assist the agency in developing additional engagement strategies that ensure public voices are meaningfully incorporated in NIH supported clinical research studies.***

NIH is the nation's biomedical research agency, which funds research across the U.S. to make important discoveries that improve health and save lives. To accomplish this goal, NIH supports the conduct of clinical research to learn more about disease and improve health.

Patients, communities, and members of the public are essential partners to the success of clinical research. However, meaningfully engaging people and communities is not a one-size-fits-all approach. NIH believes that engagement should be tailored to the needs and experiences of people and communities, and that they should guide the direction of research that is impactful to them. This engagement should be done on an ongoing basis so that members of the public can become active leaders in all stages of the research process.

This request for information (RFI) is part of a larger NIH effort to develop a vision and framework for incorporating public voices in all phases and types of clinical research. To accomplish this, NIH asked the Novel and Exceptional Technology and Research Advisory Committee (NExTRAC) to form the ENGAGE Working Group. This Working Group includes patients, advocates, researchers, clinicians, non-profit representatives, and more.

For the purposes of this RFI, NIH is specifically seeking input about engaging the public throughout all stages of clinical research and not focused solely on recruitment or participation in clinical research and trials. The responses NIH receives to this request will help inform the development of the NExTRAC's recommendations on incorporating public perspectives in clinical research.

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NIH is requesting information from all interested parties on designing and implementing engagement strategies that sustainably incorporate public voices in NIH supported clinical research. Engagement is when people, such as patients, research participants, groups of people, communities, and/or organizations partner with researchers to work towards the success of the study. These activities can span a variety of activities, but the end goal is that the research and its outcomes are meaningful and actionable, especially for those who could benefit from or be affected by the research.

While comments are welcome on any aspects of this topic, NIH is particularly interested in hearing perspectives on the following topics from community members, patients, research participants, patient advocates, researchers, and other groups, especially those who have been historically underrepresented in research (see here for more information). **Please note that you can respond to any of the questions below and do not need to submit responses to all of them.**

1. Strategies for researchers to best partner and work with people and communities. For example, developing resources respectful of different cultures, facilitating open dialogues for decision-making, sharing results in a way that is valuable, etc.

The Association of Science and Technology Centers (ASTC), a network of nearly 600 science centers and museums—and other allied organizations committed to engaging the public with science and technology—encourages NIH to broaden its definition of "public engagement" beyond the patient advocacy community. While patients and the patient advocacy community are obviously critical components of public engagement around clinical research, there is a much wider universe of people who should be engaged.

NIH's clinical research portfolio includes not only clinical trials but a wide range of topics that will be relevant to or of interest to a broad cross-section of people, including many who are not yet aware of a future diagnosis. This commitment to *broad* public engagement means ensuring a voice for individuals of *all* backgrounds in discussions about research priorities, practices, and findings.

In addition to being the right thing to do, research from ASTC and others has shown that U.S. adults have an appetite for engaging with science, including a specific interest in medical research. For example, a nationally representative survey conducted by ASTC and ScienceCounts revealed that 29% of adults in the United States report that a medicine-related topic (including biology, the human body, genetics, psychology, neuroscience, and general medicine) was their top science-related interest.

We hope NIH will tap into the decades of work on "public engagement" in science education, including but not limited to education and outreach, diversity and inclusion, public participation in scientific research (such as "citizen science"), among other facets. By broadening the definition of "public engagement," NIH will better be able to tap into the rich body of knowledge that has proven effective for reaching diverse audiences. (For example, we suggest this resource for additional context on public engagement: https://informalscience.org/public-engagement/).

In particular, we urge NIH to proactively learn from practitioners and researchers with expertise and a long history of public engagement around scientific, medical, and socio-scientific topics. This includes—but is not limited to—our network of science centers and museums in nearly every community around the country, who are expert at meeting their audiences where they are and have deep expertise in engaging their communities around complex scientific topics, including those that may around public concern. For example, our member museums worked with a broad array of partners to cut through the polarizing vitriol around vaccines to provide fact-based understanding and enhance confidence around COVID-19 vaccination.

2. Ways for institutions performing research (e.g., academic medical centers, universities, health systems, primary care providers) to support and incentivize active, bi-directional partnerships between researchers and people/communities. Examples may include encouraging people/community members to establish shared decision-making on project milestones, prioritizing local community review of research questions and research proposals, specific research design factors, leveraging existing patient-clinician relationships, etc.

Successful engagement of the public will require developing an environment that supports shared ownership and responsibility. The individuals and communities that researchers hope to engage must feel that their input and participation is desired, integral, and ongoing. While this could mean that researchers and researchers institutions cede sole responsibility for research projects and programs, it can help foster needed transparency that goes beyond one-way communication.

A true trusting relationship between researchers and the public will likely require the involvement of an array of community partners as research institutions themselves will likely not be seen as neutral in engagement around sensitive issues. As such, research institutions would benefit from involving other organizations that can help the community have trust and confidence in the process. Science centers and museums are among the many organizations that may be helpful in convening communities, fostering engagement, combatting misinformation, building coalitions, measuring impact, and more.

3. Approaches for research funders (e.g., government agencies, non-profits, companies) to incorporate partnerships between people, communities, and researchers into their programs and priorities.

Funders like NIH can underscore the importance of public engagement by making it an expectation of research projects, clinical trials, centers, and other efforts supported by the agency. This may mean requiring investigators to discuss their plans for robust public engagement as part of future funding applications—and developing review criteria that take these needs into account. It also means ensuring that study sections and other review groups include individuals with relevant expertise in public engagement, outreach, and communications.

NIH and other funders could further promote high-quality public engagement by supporting the development of resources, training materials, examples, and suggestions of how this work should be conducted, drawing upon the expertise of those with a history of successful public engagement around health-related and other similar topics.

Encouraging these kinds of initiatives and interactions would be consistent with how other U.S. federal agencies—namely, the National Science Foundation (NSF)—think about public engagement. NSF requires all proposals to meet two merit review criteria: "intellectual merit"—the potential for the proposed project to advance knowledge and understanding within its own field or across different fields—and "broader impacts"—the potential for the proposed project to benefit society and contribute to the achievement of specific, desired societal outcomes. (See https://new.nsf.gov/funding/merit-review and https://new.nsf.gov/funding/learn/broader-impacts for additional information about NSF's merit review process.) Although broader impacts can incorporate many elements in addition to public engagement—including inclusion, STEM education, workforce development, national security, and economic competitiveness—this policy has been instrumental in creating a rich environment for scientific dialogue and public understanding of science.

4. Specific examples of things that may make people and communities **more** likely to want to engage with researchers and research institutions. Examples may include specific technologies to reduce the burden of research participation, opportunities, fair compensation, cultural competence training and/or culturally competent research models, etc.

We stress the importance of fostering a trusting relationship between the public and researchers. This means developing a sense of shared ownership and responsibility, open dialogue, transparency in decision making, and co-creation of any products, activities, or initiatives. If public engagement is merely perceived as a check-the-box activity or one-way communication from researchers to the public, engagement efforts are not likely to be successful.

It is important to meet communities where they are, being proactive in reaching out to a broad array of audiences. This can mean physically meeting communities where they are—such as by holding events or advertising opportunities within communities, rather than at the research institution. It also means providing information and data in a format and at a level that will be accessible to those without substantial training and knowledge of complex scientific and medical topics. Further, investigators will need to find ways to position the research questions it hopes to discuss in a way that will be relevant to the audience. Again, NIH and its investigators can tap into the expertise of individuals and organizations who work at the intersection of science and society to help in translating this work into a form that will be accessible to the public.

5. Specific examples of things that may make people and communities **less** likely to want to engage with researchers and research institutions. Examples may include no/unfair compensation, participation opportunities only happening during typical work hours, lack of awareness of opportunities, etc.

One of the biggest barriers to public engagement is a skeptical public who feels that researchers are not truly interested in their feedback or only pay lip-service to public engagement. As such, it is critical for researchers and research institutions to do more listening than talking and to meet their communities on the communities' terms.

More practically, this means avoiding situations where individuals are unable to speak up or feel uncomfortable doing so. It also means ensuring robust time for public input and discussion, times and locations that are accessible to public audiences and lowering the barrier to engage in the public form and one-on-one with researchers.

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Founded in 1973, the **Association of Science and Technology Centers** (ASTC) is a network of nearly 600 science and technology centers and museums, and allied organizations, engaging more than 110 million people annually across North America and in several dozen countries. With its members and partners, ASTC works towards a vision of increasing understanding of and engagement with science and technology among all people.

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