



# From Insights to Impact

A Blueprint for NIH  
Research Collaboration

# From Insights to Impact: A Blueprint for NIH Research Collaboration

The National Institute of Neurological Disorders and Stroke (NINDS) has pioneered a structured approach to engaging the public in research planning. That model now offers a clear blueprint for collaboration across NIH. By leveraging IdeaScale, the institute created a transparent process for collecting, organizing, and prioritizing frontline insights from outside voices. This approach has expanded externally, providing a channel for patients, advocates, and smaller innovators to participate in shaping scientific priorities in ways that traditional processes often overlook.

NINDS' experience offers a clear blueprint for how public feedback can be transformed into research roadmaps that balance scientific rigor with broader community perspectives.

## The Scale of the Challenge at NIH

The National Institutes of Health (NIH) is the world's largest public funder of biomedical research, with a budget exceeding \$49 billion in FY2025. That investment is distributed across 27 institutes and centers, each responsible for addressing urgent health challenges in their domains.

The size and complexity of this system create persistent challenges:

1. Defining priorities. Institutes must decide where to invest resources, balancing urgency with feasibility.
2. Engaging the public meaningfully. Traditional methods often limit participation to narrow channels, leaving external voices underrepresented.
3. Avoiding duplication. Without shared mechanisms for feedback, institutes risk overlapping efforts or overlooking critical needs.

NINDS addressed these challenges by creating a structured process for public input, ensuring that research priorities were informed by more relevant perspectives.



## Blueprint: Lessons from NINDS

Through its campaigns, NINDS showed how public input can move beyond consultation to become a true driver of strategic planning. Transparent collection of ideas, paired with structured review, produced research roadmaps that balanced scientific opportunity with community insight. This experience underscores a powerful truth: when public feedback is captured in a structured way, it creates clarity in priorities, minimizes duplication of effort, and lends legitimacy to the decisions that guide the future of research.

### Case Example: Public Input in the BRAIN Initiative

One of the clearest examples of this approach was the BRAIN Initiative. As NINDS sought to advance cutting-edge neuroscience, it turned to IdeaScale to gather feedback from researchers, advocates, and other external participants.

Hundreds of submissions were collected and organized into categories that highlighted both immediate opportunities and long-term scientific challenges. Leadership was able to identify areas of greatest alignment between public priorities and scientific potential.

The BRAIN Initiative showed how structured public engagement could make large, complex initiatives more transparent and responsive, ensuring that diverse voices contributed to shaping next-generation research priorities.

### Ensuring Continuity in Public Engagement

New approaches often risk fading when leadership changes or staff transition. NINDS overcame this by institutionalizing its process for public engagement. Rather than being tied to a single individual or moment, structured input became part of how the institute approached research planning.

The broader lesson is that continuity matters. Public engagement is most effective when it is consistent and repeatable, ensuring that lessons learned and operational maturity carry forward over time.

## Lowering Barriers to Participation

A defining strength of NINDS' approach was its ability to reach audiences who might otherwise have been excluded from shaping research priorities. The process brought in perspectives from smaller innovators, students, and external stakeholders outside of traditional NIH pipelines.

The ME/CFS Research Roadmap is a clear example. Using IdeaScale, NINDS collected hundreds of contributions and organized them into defined categories that balanced feasibility with urgency. This created a roadmap that not only directed internal planning but also showed external communities that their feedback carried weight.

By lowering barriers, NINDS expanded who could participate in scientific agenda-setting, and in doing so, built trust and transparency with those communities.

## Building Infrastructure for Broader Use

For public feedback to be sustainable across NIH, it requires infrastructure that makes success repeatable. NINDS' experience highlights three pillars that can be adopted by other institutes:

1. Technology. Platforms that provide secure, compliant mechanisms for broad participation.
2. Processes. Clear methods for collecting, clustering, and synthesizing feedback.
3. Oversight. Integration with advisory groups to validate and translate input into research roadmaps.

By pairing these pillars with compliance standards such as FedRAMP, NINDS demonstrated that public engagement can be both inclusive and secure.

## Looking Ahead: A Blueprint for Public Engagement

NINDS has shown that structured public feedback can clarify research priorities, build transparency, and expand participation. The opportunity for other NIH institutes is to replicate this model within their own missions.

By doing so, they can create stronger alignment between external voices and internal decision-making, reduce duplication of effort, and strengthen the legitimacy of their planning processes.

## Conclusion

From the BRAIN Initiative to the ME/CFS Research Roadmap, NINDS has demonstrated how public feedback can be turned into actionable research roadmaps. Its experience shows that engaging the public is not just about collecting input, it is about creating a transparent process that carries weight in strategic planning.

Institutes that adopt this approach will be positioned to build stronger trust with the public, set clearer priorities, and accelerate progress toward their missions.

*Learn how federal agencies are turning frontline insights into outcomes:*

<https://www.ideascale.com/gov>

- 1 National Institute of Neurological Disorders and Stroke. *NINDS Brain Initiative*. PowerPoint, U.S. Department of Health and Human Services, 2024.
- 2 National Institute of Neurological Disorders and Stroke. *Report of the ME/CFS Research Roadmap Working Group of Council: May 15, 2024*. U.S. Department of Health and Human Services, 2024.
- 3 "Transcript of the 2024 Government Innovation Summit .", 2024.
- 4 U.S. National Institutes of Health. *FY 2025 Congressional Justification*. U.S. Department of Health and Human Services, 2024.

For more information on IdeaScale's insights please contact:  
[daria.norman@ideascale.com](mailto:daria.norman@ideascale.com)  
[sales@ideascale.com](mailto:sales@ideascale.com)

September 2025  
Designed by Daria Norman, IdeaScale  
[www.ideascale.com](http://www.ideascale.com)