



From Ideas to Outcomes



How NINDS Uses Frontline
Insights to Set Research Priorities



Introduction

NIH and IdeaScale have established a long-standing collaboration that supports NIH's mission by turning frontline insights into research priorities with measurable impact. At NINDS, this collaboration has reshaped how priorities are set — making the process more transparent, inclusive, and aligned with the scientific community. Neurological disorders are complex, often chronic, and affect millions of individuals and families. Federal research investment must be carefully targeted to accelerate the path from discovery to clinical trials.

In the past, many research institutes, including NINDS, often relied on traditional tools such as Requests for Information (RFIs). While these methods allowed patients, caregivers, and researchers to share feedback, the process generally offered only one-way communication and lacked opportunities for dialogue, prioritization, and consensus-building. To address these limitations, NINDS turned to IdeaScale, a platform that enables two-way engagement with communities, structured input collection, and transparent prioritization of ideas.

The result was a repeatable process where input from subject matter experts was synthesized into actionable research roadmaps. These roadmaps not only guide internal planning but also create legitimacy by showing that NIH priorities reflect both scientific opportunity and the insights of the broader research community.

The Challenge of Priority Setting in Neurological Research

Neurological diseases range from epilepsy to chronic fatigue syndrome to rare brain disorders. Each community has urgent needs and unique perspectives. For an institute like NINDS, determining what deserves funding priority is not a theoretical exercise. It is a balancing act between feasibility, scientific momentum, and patient urgency.

Campaigns often produced hundreds of ideas that then had to be distilled into a handful of clear, consensus-driven priorities. The process required more than collecting suggestions, it demanded structured mechanisms for reviewing, synthesizing, and translating them into strategic guidance.

Input Collection as a Two-Way Dialogue

With IdeaScale, NINDS introduced a more interactive forum where stakeholders could contribute, build on one another's ideas, and help shape priorities. Instead of relying solely on one-directional feedback methods, the platform created opportunities for genuine dialogue. This shift created more energy around campaigns and gave participants the ability to see how their voices were being heard. Transparency built trust by allowing communities to observe which ideas resonated most widely and how input was being used.

Turning Input Into Actionable Roadmaps

The strength of NINDS' model lies in how input moves from volume to clarity. Campaigns begin by gathering hundreds of ideas. These ideas are then organized, clustered, and prioritized through community commenting and structured expert review.

The end product is a research roadmap, a forward-looking plan that guides funding, scientific exploration, and advisory council decision-making. For example, the ME/CFS Research Roadmap was developed through a process where IdeaScale collected perspectives from experts, which were then synthesized into clear categories of priority.

This roadmap allowed the community to understand which priorities NIH was most interested in supporting, making transparent what was most likely to move toward clinical trial readiness.

The ME/CFS Research Roadmap

- Hundreds of submissions collected via IdeaScale.
- Priorities distilled into a formal roadmap presented to NINDS advisory council.
- Balanced urgency with scientific feasibility to set clear direction.

Leveraging Expertise at Every Stage

Community input plays a critical role in surfacing new priorities, but translating that input into strategy requires structured review. At NINDS, submissions were evaluated by expert working groups to determine feasibility, relevance, and alignment with broader research goals.

NIH planning depends on convening diverse working groups of clinicians, researchers, individuals with the disease, people with lived experience, and caregivers. This layered process helps transform raw input into actionable research roadmaps that balance urgency with scientific rigor.

Meeting Communities Where They Are

One of the clearest lessons from NINDS' experience is that no two communities engage in the same way. The ME/CFS community, with many participants housebound, welcomed online participation as an accessible lifeline for contributing. In contrast, epilepsy communities initially struggled with digital platforms and required additional outreach and support to feel included.

These differences highlight a critical truth: effective public engagement depends on designing approaches that match the realities of the population. Understanding a community's needs, abilities, and communication preferences is not a detail — it is the factor that determines whether a campaign succeeds or stalls.

Essentials for Engagement that Works

- **Tailored outreach.** Customize methods to reflect each community's strengths and challenges.
- **Iterative design.** Pilot, measure, and refine questions to ensure clarity and relevance.
- **Inclusive access.** Provide digital and non-digital options to maximize reach.

Security and Continuity

Adopting new engagement tools in a federal environment requires strong compliance. Security and continuity were essential considerations when bringing IdeaScale online. FedRAMP certification provided confidence that sensitive processes could remain compliant while enabling broader participation.

Conclusion

By combining broad community engagement with expert review and secure infrastructure, NINDS created a repeatable process for turning ideas into roadmaps. These campaigns demonstrated that input collection is not just a method for feedback but a strategy for legitimacy, transparency, and alignment.

NINDS has shown that when structured properly, input collection can bridge the gap between stakeholder voices and scientific planning, ensuring that federal research priorities reflect both urgency and opportunity.

Works Cited

National Institute of Neurological Disorders and Stroke. NINDS Brain Initiative. PowerPoint, U.S. Department of Health and Human Services, 2024.

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.

"Transcript of the 2024 Government Innovation Summit ."2024.

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

Sales@ideascale.com

September 2025

Designed by Daria Norman, IdeaScale

www.ideascale.com