
NINDS Strategic Planning Discussion Panel

Communications Panel Meeting Summary

October 31, 2020

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Introduction

NINDS convened a panel discussion on October 30, 2020, to gather perspectives from a group of 12 stakeholders on challenges and opportunities facing our Institution in its communications and outreach to scientific researchers across all career stages.

Small groups of participants met in a series of three pre-convening calls held between October 8 and 15, 2020, in which each stakeholder had a chance to express their thoughts on major themes that would be most fruitful to discuss during the panel conversation. The facilitator, Dr. Brie Linkenhoker, used these inputs to develop four areas of focus: communicating a sense of belonging, evaluating communications channels, the importance of personal contacts in career advancement, and communicating the mission and value of NINDS.

This report synthesizes the ideas, reflections, and recommendations shared by participants in the pre-call and panel discussions.

Communicating a Sense of Belonging

Belonging emerged as a high-level theme in relation to ongoing conversations about inclusion, diversity, and equity at universities and research institutes across the country. Panelists acknowledged groups that have been historically disenfranchised or poorly engaged in federally-funded scientific efforts, and they encouraged efforts to bring more diversity to the NINDS community, as these efforts are likely to strengthen NINDS's scientific and translational endeavors, and its capacity to serve the needs of *all* Americans.

Panelists recognized the convening of this panel itself as a great example of how to build community and encourage a sense of belonging. Panelists appreciated NINDS' commitment to soliciting input and feedback from a diverse range of stakeholders across career stages and roles, and to continually improving its communication and outreach efforts. They highlighted the importance of diverse representation in helping more Americans interested in science feel that they can be a part of the NINDS mission

Multiple discussions touched upon the idea that communicating NINDS' commitment to inclusion, diversity, and equity alone would not be as effective as a strategy that actively aimed to encourage belonging. While the former conveys an appropriate commitment to a level playing field, the latter actively encourages and solicits participation from community members who may not have the academic pedigree, personal relationships, directly relevant research interests, or funding history that have made engaging with NINDS easier for those who do.

Panelists differed in their perceptions of how much they felt they “belonged” in the NINDS community, and in their judgments of NINDS' success at creating a sense of belonging. Some panelists perceived NINDS as a “distant funding source,” especially early in their careers, while others highlighted the importance of experiences like internships and direct interactions with NINDS leaders as creating a greater sense of belonging. Personal relationships—with POs, NINDS leaders, and scientists, peers, and

mentors currently funded by NINDS—emerged as a critical component of belonging, and panelists identified repeated connections with peers and mentors across a series of events as the most effective path to developing such positive relationships.

Among the suggestions to NINDS for strengthening belonging were: 1) continuing to send representatives to universities and conferences (and increasingly, into online forums) to answer questions about NINDS opportunities and practices, 2) encouraging grantees to involve their trainees in NINDS online and in-person events and in conversations with POs as a way to build familiarity with NINDS in early career stages, 3) building relationships with minority-serving institutions, and sponsoring community building events designed to introduce under-represented groups to NINDS, its mission, and its activities, 4) reflecting on NINDS successes in engaging diverse patient and disease communities, among whom NINDS is seen as a “pillar of consistency” in its engagement efforts, 5) publicly highlighting stories and profiles of scientists, trainees, and technology entrepreneurs that showcase NINDS’ *aspirational diversity and inclusion*, 6) supporting networking and community building activities among stakeholder groups (e.g. underrepresented minority students across multiple universities, or clinicians looking for research opportunities relatively late in their medical training), and 7) making the roles of program officers and their modus operandi more transparent (more on this below).

Communications Channels

Panelists unanimously found the NIH and NINDS websites to be rich and thorough sources of information about funding opportunities. However, while they recognized the NINDS website as being one of the more organized among its peer institutes, panelists noted that it can still be an intimidatingly dense and technical resource, in part because navigation often involves jumping back and forth between NIH-wide and NINDS-specific sites. As a result, panelists said, visitors need significant foreknowledge of program offerings and structure to take advantage of available web resources and doing so often requires more effort than it should.

Importantly, panelists suggested that most researchers treat the NIH and NINDS websites as technical reference manuals to be consulted once an opportunity has been identified through other means. These means most often include word-of-mouth communication from well-connected peers or research colleagues, curation, and dissemination of career-stage specific opportunities by university administrators, and listserv and social media communications (discussed below). Panelists generally agreed that the NINDS website meets the needs of providing needed reference and technical information after an opportunity is identified, but that it could do a better job of serving people coming to the website to discover new opportunities and/or specific insights or “how-tos” that may not be relevant for all audiences.

Information overload surfaced as a major challenge for communications. Researchers and trainees receive many communications about funding opportunities, but inconsistent use of acronyms and lack of audience targeting can hamstring these efforts. Panelists cited some NINDS materials, such as the ‘Building Up the Nerve’ podcast, as high-quality and effective (in this case, for clarifying how study sections work), but potentially hampered by limited distribution or awareness. One panelist suggested

that concise video content could be very helpful for more visual learners who have trouble sifting through the mass of written information available. Another suggested that providing “thinned down” website content with a clear map relating opportunities to career stages and life events could facilitate information retrieval and navigation. Adding more interactive interfaces could also help provide more career-stage or interest-specific paths through NINDS content. Whatever the approach, panelists agreed that brief, targeted, timely, and curated communications are most effective in reaching busy researchers when “pushed” out to specific audiences, and that some website re-design could be helpful for making exploration more efficient.

Multiple panelists (especially younger ones) cited Twitter as the best source of relevant, timely, curated information about scientific funding opportunities. Campaigns aimed at strengthening connection and community among subgroups on Twitter (e.g., #BlackinNeuro, #BlackinSTEM) have been very successful in disseminating information and advice. Twitter threads grown from specific questions, like a postdoctoral researcher who is searching for grant opportunities, provide a convenient and contextualized way for other community members to identify opportunities. While the transience and brevity of Twitter may limit its potential as an information repository, it has real power as a community center where real-time, personalized interactions take place. This can be particularly powerful for reaching under-represented minorities, for example, through live discussions or personal outreach by NINDS staff. Dr. Marguerite Matthews’ work, including her solicitation of direct messages from the community, was cited as a successful example. Another strength of Twitter is the potential for well-targeted messages to reach specific stakeholder groups. A well-pitched tweet with appropriate wording and tags may be amplified by relevant networks and community organizations, allowing information to reach broader audiences, and providing opportunities to shape conversations across a broad swath of social media.

Suggestions for improving NINDS communications channels and their effective use include: 1) experimentation with Twitter as a primary tool for information dissemination, community building and engagement, and amplification of other communication efforts (e.g., the NINDS podcast), 2) user testing of the website to assess its efficacy in fulfilling search versus exploration needs, leading to some redesign or added navigational elements, 3) development of a network of university-based curators, potentially via social media, who can disseminate timely, relevant information to their university communities, and 4) continued research and discussion related to the channels used by different NINDS stakeholder groups at different career/life stages.

Personal Contacts

The importance—and perceived mystery—surrounding program officers (POs) was a central theme of discussion. Panelists relayed that the quality of relationships grantees had with POs seems to vary widely, and that these relationships have a major impact on the success of applicants for research support. Some panelists reported very familiar, personal relationships with their POs, accompanied by high levels of confidence about how to reach them, and about what was appropriate to discuss or communicate. Others felt uncertain about the roles of POs in review processes and funding decisions, and about the expected manner, nature, and desired frequency of communication with them. For example, several panelists expressed surprise at the idea that their POs would want to know about

upcoming publication of NINDS grant-funded research. Panelists with deep experience communicating with their POs noted that NINDS POs generally have deep and thorough knowledge of their portfolios and the broader research space around them, and that they are more willing to spend time directly assisting applicants than those from some other institutes. But universally, panelists wanted more transparency into the roles of POs, what they want and expect and when, and how best to functionally engage them (email, phone, etc.).

Panelists suggested that NINDS provide more guidance on when and how to interact with POs in order to help grantees access their expertise and guidance more consistently. One panelist suggested that POs could actively reach out to some applicants, especially those new to NINDS. Another suggested that POs could host occasional “office hours” where applicants could ask POs questions about the application and review processes. Several panelists recognized that the presence of POs at major conferences was invaluable for facilitating communication with trainees and junior scientists, and this value could be extended by having them visit more universities, particularly those that serve minority populations.

Panelists also emphasized the career impacts of early personal interactions with knowledgeable scientific mentors on future success in applying for NINDS funding. These relationships are most frequently with PhD or postdoctoral supervisors, or with senior mentors of junior faculty. Some panelists expressed concern that unequal access to relationships with “people who know people” or “people who know the system” could amplify systemic inequalities in funding, especially for trainees at smaller institutions, institutions that receive proportionally less federal research funding, and/or for trainees moving into relevant areas of brain research from non-traditional fields.

Panelists recognized that NINDS probably cannot directly influence mentoring relationships outside of its intramural program, but one panelist suggested that NINDS could learn from the example of the Chan Zuckerberg Initiative, which actively connects researchers applying for funding or carrying out research within a specific topic area. They also reportedly ask that mentors bring a trainee to meetings so they can develop relationships with the broader community and have their voices heard in conversations. These measures seem to be successful in developing a supportive and integrated research community. Other panelists suggested that peer support could, in some cases, bolster weak mentor networks, and that NINDS could support peer engagement programs in person and on social media.

Communicating the Mission and Value of NINDS

Panelists encouraged NINDS to communicate a clear, regularly updated mission from which its funding priorities and engagement activities flow. This would enable investigators to more easily judge whether or not their own research goals are aligned with NINDS’ goals and could also encourage collaborations between research groups that might not otherwise work together due to administrative or personal roadblocks. The ability to catalyze such novel -- and occasionally adversarial -- collaborations through the incentive of funding may be one of NINDS’ most powerful assets.

Several panelists encouraged NINDS to communicate more clearly the value it creates for the American public, and for the scientific community at large. Panelists recognized efforts like webpages that highlight NINDS contributions to approved therapies, but suggested NINDS could do more to communicate its role in discovery, translation, and treatment to broader public audiences in plain language across social and other media channels frequented by non-scientists. One panelist highlighted the NINDS role in supporting development of anti-seizure drugs as a success story worth amplifying to the general public. Panelists encouraged the use of more compelling multiple media to drive interest in historical, and especially contemporary, narratives of NINDS' contributions to brain science and health.

The NINDS website has fact sheets which offer condensed information about diseases and the research being carried out on them, and staff indicated that these are already some of the most-visited pages. There may be an opportunity to share these fact sheets (or related content) directly with online discussion groups and further develop them based on feedback. Visual content such as infographics or videos conveying similar information may also be particularly impactful due to their shareability and digestibility, especially by less scientifically fluent or more visual learners. By iterating and promoting clear and accessible resources based on community feedback, NINDS could become the first and foremost place for the public to go when seeking information about neurological disorders and stroke, thus connecting back to an overarching recommendation from panelists to communicate that the NINDS really is for *all* Americans.

Panelists also explored the idea of NINDS investing in training and resources to help grantees better communicate their own scientific undertakings and findings. Although the 'broader impact' sections of NSF grants can provide some sense of direction for NINDS to follow, the broader impacts requirements often do not include effectiveness metrics, and many scientists may not have the skill sets or breadth of experience to imagine what "broader impacts" could look like in relation to their research. By providing tools, training, and other useful resources, NINDS could facilitate the adoption of modern science communication principles and techniques, and thereby improve the quality of outreach activities being carried out in relation to the science and technology development work that the Institute supports.

As a publicly funded institution, NINDS has the opportunity—and perhaps even the obligation—to serve communities that have not always had a voice in shaping research priorities, and/or who have not been well-served by public engagement campaigns. Some panelists suggested that strategic stakeholder analyses could help identify specific concerns, needs, and interests of these groups and communities. Such analyses could help eliminate unrecognized bias in communications and ensure that program activities are meeting the needs of the widest possible range of citizens. This effort could start with outreach to self-organized patient and family groups, industry organizations, and affinity groups in science. Over time, input from a more diverse set of stakeholder voices could influence NINDS' mission and the ways it aims to create more value for more Americans.

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