**NINDS Strategic Plan 2021-2026: RFI Response Summary**

**Background:** In response to Request for Information NOT-NS-19-079, NINDS received 95 responses from a broad range of groups, including principal investigators, researchers, trainees, patients, patient advocates, professional societies, non-profit organizations, health care providers, other research institutions, science administrators, and members of the public. Below is a summary of key themes and recommendations among responses submitted for each strategic goal.

**RFI Response Summary by NINDS Strategic Goals**

**Goal 1: Be a model of excellence for supporting and performing paradigm-changing, innovative, and rigorous neuroscience research**

| 1.1. Collaboration with governmental and non-governmental organizations. | 2 |
| 1.2. Cross-disciplinary research. | 3 |
| 1.3. Funding. | 3 |
| 1.4. Specific diseases and disorders. | 3 |
| 1.5. Grant review. | 4 |
| 1.6. Scientific rigor, reproducibility, & transparency. | 4 |
| 1.7. Basic research. | 4 |
| 1.8. Translational research. | 4 |
| 1.9. Clinical trials/clinical research. | 5 |
| 1.10. Patient engagement. | 5 |
| 1.11. Disparities in health care and clinical trials access. | 5 |
| 1.12. Rehabilitation and quality of life research. | 6 |
| 1.13. Novel devices and technologies. | 6 |
| 1.14. Data science/data sharing. | 6 |
| 1.15. Biomarkers. | 7 |
| 1.16. Gene therapy. | 7 |
| 1.17. Stem cells. | 7 |
| 1.18. Implementation research. | 7 |
| 1.19. NINDS intramural research program. | 7 |
| 1.20. NINDS strategic plan comments. | 7 |

**Goal 2. Be a model of excellence for funding and conducting neuroscience research training and career development programs and ensuring a vibrant, talented, and diverse neuroscience work force**

| 2.1. Disease- and scientific-area funding. | 8 |
| 2.2. Grant review. | 8 |
| 2.3. Trainee support. | 8 |
Goal 3: Promote the timely dissemination of accurate and rigorous information about scientific discoveries and their implications for neurological health.

3.1. Access to funded research.

3.2. Stakeholder collaborations/partnerships.

3.3. NINDS public outreach/education.

3.4. Patient community engagement.

Goal 4. Create and sustain a supportive work culture for the NINDS work force and facilitate and reward analogous efforts in the outside neuroscience community.

4.1. Overall comments.

4.2. Workplace satisfaction.

4.3. Diversity and inclusion.


4.5. Compensation and benefits.

SCIENCE

Goal 1: Be a model of excellence for supporting and performing paradigm-changing, innovative, and rigorous neuroscience research

1.1. Collaboration with governmental and non-governmental organizations. Fostering collaboration at NINDS was a high priority for many respondents. Several respondents recommended NINDS consult and/or collaborate with other NIH institutes and centers (ICs) and other federal agencies and departments, such as the DoD, CMS, FDA, CDC, VA, State, and NIDILRR, during the NINDS strategic planning process to develop a more coordinated, comprehensive national strategy and action plan to effectively address the burden of neurological disorders and conditions.

Respondents also commented that NINDS should engage and incorporate input from all relevant stakeholders involved on the bench to bedside continuum of therapeutic development, including pharma, business, law, regulatory affairs, and medicine, and encourage them to collaborate across the entire research spectrum (e.g. basic, translational, and clinical research). Respondents suggested that NINDS host workshops, provide professional development resources, and support more team science and network-type grants to help implement successful models of collaboration in the research setting.

Some respondents urged NINDS to broaden collaborations with patient-led advocacy groups and non-profit organizations by establishing partnerships to share costs for research infrastructure, research
staff, data banks, specimen repositories, and clinical trial consortia. These groups also work with patient networks and can help NINDS build, organize, maintain, and mobilize national patient registries.

1.2. Cross-disciplinary research. Respondents emphasized the need for more cross-disciplinary research to advance neuroscience. They recommended that NINDS encourage cross-disciplinary research projects to help break down research silos and bring together researchers, clinicians, engineers, and industry to work towards a common goal. To accomplish this, respondents suggested that NINDS develop funding opportunities that require co-PIs from different domains and host more cross-disciplinary meetings or symposia (similar to the BRAIN and HEAL Initiative PI meetings) to stimulate collaborations that will accelerate research progress. While it is important for neuroscience investigators to specialize, tackling complex neurological disorders requires them to be able to readily engage in cross-disciplinary research. Respondent encouraged NINDS to prioritize taking a more comprehensive approach to research involving experts from multiple backgrounds by increasing funding for large multidisciplinary projects on disease-focused bench to bedside research while maintaining funding for traditional, independent R01 grants.

1.3. Funding. Many respondents expressed concern about the limited funding available for research as NINDS remains underfunded despite moderate annual budget increases. They said that limited research funding has contributed to hypercompetition in peer review and has made it increasingly difficult for small- to medium-sized labs to compete with larger, more well-funded labs for funding. New research requirements, such as including sex as a biological variable, have also contributed to the budgetary strain experienced by investigators. Respondents suggested several potential new schema to equalize funding opportunities for all lab sizes and/or reduce hypercompetition in research, including: place a cap on the number of grants per investigator, create a sliding scale for the percentile pay lines for successful grants to make it more difficult for an investigator to receive multiple grants, limit funding for investigators supported by other research organizations, identify research grants on similar topics and encourage/incentivize those investigators to work together rather than ranking the proposals against each other, or implement a lottery-like funding model, in which all rigorous and innovative grant proposals are submitted to a random drawing for funding.

Furthermore, to reduce the time researchers spend writing grant proposals, improve productivity, and encourage rigor and innovation, respondents suggested the following strategies: fund applications based on the past performance (e.g. quality of published work, but not journal impact factor), extend R01 grants based on progress reports instead of requiring renewal grant applications, or expand the R35 funding mechanism. Several respondents also emphasized the need to increase funding for investigator-driven R01 research grants. However, other respondents encouraged increasing funding for large, coordinated programs or infrastructure, and removing funding restrictions on program project P01 grants to allow for more than 10 years of support.

1.4. Specific diseases and disorders. Many respondents urged NINDS to increase funding, conduct portfolio analyses to help determine funding priorities, align funding decisions with known disease prevalence and/or burden of disease, and invest in specific infrastructure or resources for research on specific diseases and conditions. Specific diseases and conditions mentioned include: adrenoleukodystrophy (ALD), Alzheimer’s disease, amyotrophic lateral sclerosis (ALS), cancer, central vestibular disorders, cerebral palsy, Chiari malformations, chronic pain, circadian rhythm disorders, congenital neurological conditions, diabetic neuropathy, dementia, epilepsy, frontotemporal dementia,
hypersomnia, Lewy body dementia, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), narcolepsy, neurogenic bladder, neuroinflammation, neuropsychological and neuropsychiatric disorders, pain, Parkinson’s disease, pediatric neurological conditions, psychogenic neurological disorders, restless legs syndrome, REM behavior disorder, spinal cord injuries, spinal cord disorders (e.g. syringomyelia), stroke, and traumatic brain injury. Additionally, respondents spoke more generally about funding research on behavioral disorders, common diseases, comorbidities, hard to serve medical conditions, rare and ultra-rare diseases, and secondary health effects of neurological disorders.

1.5. Grant review. Improving the grant review process at NIH was a high priority for many respondents. Some respondents were frustrated with the slow pace of the NIH grant application and funding process and urged NIH to find ways to review and fund projects faster, particularly for incurable and fatal illnesses. Some felt the review panel members are overly risk-averse and don’t place a high enough value on innovation, and that NIH should place more emphasis on rigorous design while reducing the emphasis on preliminary data. Other respondents acknowledged the importance of innovative research, but also emphasized the need for NINDS to continue its support of incremental research.

A few respondents urged NINDS to improve efforts to include relevant in-area experts for each grant under review to ensure productive reviews and useful feedback to researchers. A few respondents requested that NINDS provide better grant review feedback, especially regarding grant rejections. A few respondents expressed concerns that reviewer bias may be negatively affecting the scores for certain types of applicants, and NINDS should do more to promote fairness, transparency, and equity in the grant review process.

1.6. Scientific rigor, reproducibility, & transparency. Several respondents requested NINDS be more active in promoting rigor, reproducibility, and transparency in neuroscience research. They recommended that NINDS ensure the publication of all research findings, including null results, promote sharing of datasets, analytic code, and experimental protocols, and require researchers and publishers to notify NINDS when a paper is rescinded. Specific suggestions for incentivizing scientific rigor include creating an award for outstanding rigorous researchers, partnering with professional societies to host trainings on scientific rigor and reproducibility to educate the researchers on best practices, and creating dedicated RFAs for replication and validation studies. Respondents also suggested that NINDS promote the publication of not only original findings but also replications/corroborating results to spotlight accuracy of research findings.

1.7. Basic research. A few respondents advised NINDS to increase its support of basic research. There were concerns that NINDS had shifted its focus too heavily on translational research. Translational opportunities often emerge from basic science discoveries, and a greater focus on basic science will seed more translational opportunities in the future. Furthermore, respondents recommended NINDS fund a diverse portfolio of research using a wide array of research models. Respondents also highlighted additional research priorities for the field of basic research, which included the role of glia in neurological disorders, -omics research, microbiome, and common disease pathways underlying multiple neurodevelopmental conditions.

1.8. Translational research. Noting the importance of supporting “comprehensive bench-to-bedside-to-home” research, some respondents advocated adding a fifth strategic goal or rewording the current goals to emphasize translation of basic discoveries into therapies for people with neurological disorders.
Respondents pointed to the effectiveness of NINDS-supported translational programs, such as Translational Neural Devices, in deriving benefits to the patient population from basic and early stage translational research. Respondents also identified specific areas of translational research that they felt should be prioritized by NINDS in the upcoming strategic plan, which included the following topics: drug repurposing, drug screening programs, development and validation of animal models of neurological diseases, targeted pharmacologic therapies, cost effective research on therapeutic interventions, and therapeutics with multi-disease treatment potential.

1.9. Clinical trials/clinical research. Many respondents advocated for the continued support of clinical trials and multi-center clinical networks by NINDS. Several respondents commended NINDS’ recent efforts to increase support of clinical research and clinical trial networks, such as NeuroNEXT, StrokeNET, SIREN, rare disease networks, and the partnership program between NINDS and NCATS focused on clinical trial readiness, and urged NINDS to create a clinical trials network for pediatric trials and to ensure that children of all ages are included in clinical research. They encouraged NINDS to increase support for early phase clinical trials, large phase 2 trials that will help inform phase 3 trial design, observational studies that will be valuable for comparative effectiveness research, and clinical trial readiness activities, including longitudinal, multi-year natural history studies and biomarkers studies. To increase the efficiency and make trial results more generalizable to clinical practice, respondents advised NINDS to consider a variety of clinical trial designs, including master protocols, platform trials, basket protocols, pragmatic trials, adaptive study designs, comparative-effectiveness trials, and biomarker-guided trials. Other ideas for improving the efficiency of clinical research include increasing funding opportunities for ancillary studies of ongoing clinical trials, identifying new strategies for improving recruitment and retention of study participants, and including international researchers when updating common data elements to create a common research language globally. Additional clinical research priorities suggested by respondents include racial and geographical health disparities research, precision medicine, treatment using brain modulation, clinical neurophysiology, community and population-based studies, treatment adherence outcomes research, and large database epidemiological studies.

1.10. Patient engagement. Some respondents requested that NINDS proactively engage patient-advocacy groups, patients, and caregivers to advise on the design and implementation of research, improve patient-centered outcomes, and help identify research gaps. Respondents emphasized the need for incorporating the patient perspective in research to better tie research programs to outcomes that affect the experience and quality of life for patients, their families, and the larger community.

1.11. Disparities in health care and clinical trials access. Respondents would like to see pricing regulations or a recompense mechanism for unequal accessibility to medicines and therapies funded by NINDS. In addition, they recommended NINDS to be cognizant of providing access to foster equity in patient access to research protocols, and to require the inclusion of a diverse patient population in all clinical research studies, unless scientific or ethical reasons justify their exclusion. Furthermore, they would like to see more resources to support equitable access to low-cost, high quality diagnostic testing. A respondent advised the NINDS that increased support for Centers of Excellence, especially for low volume procedures (e.g. deep brain stimulation, spinal cord stimulation, intrathecal drug delivery, etc.) would reduce the geographical variation in and barriers to quality in the delivery of high quality health care.
1.12. Rehabilitation and quality of life research. Respondents urged NINDS to support more research on the disability, rehabilitation, and quality of life aspects of neurological conditions, which will improve the daily lives of people living with neurologic disorders and their caregivers and may help policymakers develop improved reimbursement policy for disability and rehabilitation. They recommended that NINDS increase funding for cross-cutting, multi-disciplinary research centered on 1) understanding the mechanisms of disability and rehabilitation, 2) restoring and improving functional capacity in individuals with disabilities and patients undergoing rehabilitation, 3) maintaining and preventing the deterioration of functional skills for people with disabilities, and 4) enhancing quality of life and supporting societal participation across the lifespan for individuals with disabilities while reducing health disparities. Respondents urged NINDS to include patients and their caregivers in the development of meaningful outcome measures, to fund innovative clinical trials or comparative effectiveness research by non-physician professionals with daily involvement in neurologic disease patient care (e.g. nurses or physical therapists), to support the development of novel minimally- or non-invasive treatments and therapies that can be administered in the home setting, to research methods for home delivery of treatment and rehabilitation, and to examine the effects of adaptive fitness, exercise, and nutrition on health outcomes.

1.13. Novel devices and technologies. Several respondents recommended NINDS support development of novel devices and technologies by continuing to fund the Brain Research through Advancing Innovative Technologies (BRAIN) Initiative, defining new funding streams that support early and late device and technologic development, expanding intramural and extramural opportunities for technology-related trials, supporting regulatory training and IND/IDE-enabling studies, and growing opportunities for NIH, industry, and academic partnerships. Respondents also urged NINDS to create pathways for disseminating the technologies that it develops by increasing funding opportunities for shared resources to improve investigator access to costly, novel research technologies (e.g. CryoEM, and metabolomic/proteomic resources), considering the commercialization prospect of these new technologies, and developing mechanisms to guarantee that NINDS-funded devices and technologies, in particular novel wearable technologies with clinical applications, be made accessible for use in healthcare settings, screening, and global applications.

Respondents also mentioned the following areas of emerging research to pursue and fund for novel device and technology development: wearable and smart devices, non-invasive brain stimulation, brain-machine interface, artificial intelligence, quantitative EMG techniques, continuous EEG monitoring, high-density EEG, intracranial EEG and stereo-electroencephalography, neurophysiological intraoperative monitoring, minimally invasive endovascular treatments for cerebral aneurysms, novel technological approaches to increase neuropsychological testing availability, assessment, diagnosis, and treatment, non-invasive biomedical imaging, non-invasive quantitative microstructure brain imaging, assistive technologies for neurorehabilitation, digital therapeutics, and devices for neuromodulatory treatment.

1.14. Data science/data sharing. Improving data sharing was a primary concern for several respondents. Respondents were appreciative with NINDS’ efforts to develop and support data science tools (e.g. establishing common data elements), but they felt more could be done to support data reporting, storage, sharing, and mining to enable data transparency. They recommended that NINDS create and support infrastructure and/or include additional funding line in grant budgets to ensure that all raw datasets and analytic codes, from existing and future studies, be open source and made publicly available.
accessible. Respondents also advised that NINDS consult with data science experts on how best to coordinate data sharing efforts across research institutions and how to maintain these databases. NINDS could also develop guidelines to outline best practices for data acquisition, analysis, and sharing for all types of data. Universal data formats would allow researchers to work together more effectively on collaborative initiatives, especially for big data sets. For clinical data, federal guidelines for the storage, privacy, and accessibility of clinical data for academic institutions and commercial providers would also need to be developed. Respondents noted that changing the culture to encourage and value data sharing will require funding agencies, academic institutions, and publishers to better align incentives and credit around data collection, sharing, and secondary analyses by funding data collection grants and by giving credit for good data collection not just data analysis and publications. In addition to data science, respondents also encouraged NINDS to include computational neuroscience, computational molecular modeling, and artificial intelligence in its research priorities for the upcoming strategic plan.

1.15. Biomarkers. Respondents suggested that NINDS provide more funding support for biomarker discovery and validation research to improve the diagnostic and treatment tools available for neurological diseases. The identification and development of biomarkers for different neurological diseases could potentially help health care providers identify the presence, nature, and/or severity of the disease in each patient, but also help quantify treatment response in some clinical cases.

1.16. Gene therapy. A few respondents said that it would be beneficial for NINDS to become more involved in gene therapy research, including research to validate preclinical models for gene therapy, identify the best gene therapy approach that is applicable to multiple models, and create a path for clinical development for the best approaches. This would require NIH to develop best practice guidelines to ensure fair, safe, and equitable use and access to this novel therapeutic, including developing enforceable and consistent rules to delineate permissible and non-permissible gene therapy/editing, infrastructure for sharing gene therapy and gene editing technologies, and studies of the financial and ethical considerations of gene therapy, gene editing, and other novel therapeutics. Furthermore, NIH should ensure pricing regulations for all treatments developed using NIH funds.

1.17. Stem cells. A couple of respondents commented on the need for human stem cell research. They recommended NINDS increase funding for research investigating stem cells as treatment for neurological diseases, and provide public education resources on the efficacy and safety of such uses.

1.18. Implementation research. A few respondents encouraged NINDS to expand support of implementation research via partnerships with non-profit advocacy and professional organizations. NINDS could promote or facilitate training in implementation research at national meetings and conferences.

1.19. NINDS intramural research program. A few respondents expressed support for the NINDS intramural research program (IRP). Respondents urged the NINDS IRP concentrate its efforts on projects not feasible or affordable for extramural investigators and advocated to increase funding for the IRP to focus their unique resources on key knowledge gaps underlying diseases and disorders of the nervous system. Respondents also sough greater transparency of NINDS IRP research priorities.

1.20. NINDS strategic plan comments. A respondent suggested that the NINDS consult all interested stakeholders in the development and implementation of the NINDS Strategic Plan for their input. There
was also concern about the lack of connection between the NINDS mission and the four strategic planning goals. A respondent recommended the NINDS reconfigure their strategic goals to meet its mission of reducing the burden of neurological diseases.

Training & Diversity

Goal 2. Be a model of excellence for funding and conducting neuroscience research training and career development programs and ensuring a vibrant, talented, and diverse neuroscience work force.

2.1. Disease- and scientific-area funding. Many respondents recommended the NINDS increase funding in specific diseases/conditions to attract trainees in the following areas: ME/CFS, rare diseases, pediatric neurology conditions, cerebral palsy, childhood onset-disabilities, Parkinson’s disease, and ALS. Respondents also encouraged NINDS to increase funding for training in specific scientific areas such as human neuroimaging research, data science and AI, age and disability, neurorehabilitation and care, stem cell research, early phase clinical research, behavioral health professionals and researchers, sleep and circadian function in brain health, music therapists, veterans with neurological disorders, and non-MD clinicians (e.g. psychologists, nurses, and pharmacists).

2.2. Grant review. Several respondents advised NINDS to improve the grant review process to bolster early career researchers’ grantsmanship with clear feedback and assistance navigating the grant process. Suggested activities included: a mentoring program to pair junior with experienced investigators, allow early career researchers to serve as grant reviewers, and match the grant reviewer’s expertise with both the applicant’s research and demographics.

2.3. Trainee support. Several respondents encouraged NINDS to continue their robust support of graduate and postdoctoral trainees, and a few proposed improving efforts to understand the trainee needs and to offer additional accommodations if appropriate (e.g. financial burdens of academia and friendly family policies, such as maternity leave and childcare assistance). NINDS could support postdoctoral transition to independence by expanding eligibility criteria for postdoctoral training mechanisms, training resources (e.g. grant writing workshops), and outreach about funding/training opportunities. Some respondents recommended that NINDS incentivize mentorship to enhance trainee success, such as with multi-center institutional training programs and career development awards.

2.4. Clinician-scientist support. Many respondents emphasized the need to increase funding to recruit, train, and retain clinician-scientists in the field of neuroscience. NINDS could also establish funded research opportunities during medical school and early stage residency to encourage trainees to pursue research alongside their clinical obligations. Many clinicians-scientists who may be competitive candidates for NIH funding do not pursue or stay in research careers due to non-competitive salaries. To address this, it was recommended that NIH work with medical institutions to close the salary gap between academic research and clinical practice. To increase clinician-scientist diversity, NINDS could develop outreach initiatives for underrepresented groups in medicine, such as the R25 program, and a "meet the leaders" email series showcasing successful physician-scientists from marginalized or underrepresented groups.
Respondents advised NINDS to increase support of career development training awards for clinician-scientists (e.g. K08 and K23 grants) to meet the intense need for clinical researchers, and to enhance training opportunities for clinician-scientists in clinical research design and implementation, clinical observational studies, data science, and grant writing.

2.5. Early stage investigator support. A few respondents encouraged NINDS to continue supporting new and early stage investigators (ESIs), with one recommending a separate ESI definition for clinician-scientists, as their career clinical responsibilities tend delay their first R01 application. It was also suggested that NINDS develop funding programs that would allow ESIs to maintain their research programs during times of reduced effort such as medical leave, childcare, and other personal/family responsibilities.

2.6. Diversity. Many respondents encouraged NINDS to support a diverse trainee workforce. Respondents urged NINDS to recruit, educate, and retain a vibrant, talented, and diverse neuroscience workforce by increasing funding for trainees at the level of undergraduate, graduate and professional levels, including women, minorities, underrepresented, underserved, marginalized, sociodemographic, geographical, and disabled populations. To accomplish this, NINDS could: expand outreach to and partnerships with organizations for underrepresented students in medicine, target funding to retaining trainees within these groups, and promote inclusivity within the neuroscience community.

2.7. Research training and professional development. Several respondents recommended that NINDS encourage training opportunities across the research spectrum (e.g. basic, translational, and clinical research) and across disciplines, including through workshops and other professional development activities that boost collaboration and streamline research translation (e.g. clinical and patient-center research training for basic scientists). Others recommended enhancing cross-disciplinary training in quantitative literacy, data science, and AI, to align with the NIH Strategic Plan for Data Science.

Some respondents suggested NINDS promote trainee exposure to career and professional development opportunities beyond the academic track by developing a structured curriculum for neuroscience graduate students, encouraging partnerships between academic centers and industry, and providing training in communication, which would also improve communication of neuroscience with the general public.

**Communication & Dissemination**

Goal 3: Promote the timely dissemination of accurate and rigorous information about scientific discoveries and their implications for neurological health.

3.1. Access to funded research. Some respondents urged NINDS to support open-access publishing to ease the burden of publication paywalls and enable rapid dissemination of accurate and rigorous research to all interested stakeholders, including the public. NIH could encourage grantees to publish in open-access journals by subsidizing publication costs, require journal publishers to make all publications of federally funded research be open-access, or to reduce the 12-month embargo to 6 months. However, one comment urged NINDS to help the research community and the public distinguish
between reputable publications versus predatory journals with subpar review criteria. Furthermore, to promote rapid dissemination of results, some recommended that NINDS encourage preprints articles. One respondent also commented that while timely publications are needed, it is more important to ensure publications are high quality.

**3.2. Stakeholder collaborations/partnerships.** Several respondents advised NINDS to invest in collaborative efforts to promote efficiency in research and timely dissemination of research findings through strategies already noted above (Goal 1). Many respondents urged NINDS to continue and expand communication with non-profit organizations, advocacy groups, and professional societies, which have access to large and diverse communities (including patients, caregivers, health care providers, and scientists) and often possess a robust, public relations, marketing, and social media presence. NINDS could leverage this extensive communication network and their resources to disseminate information about new NINDS discoveries and their implications for neurologic health. Partnerships with non-profit organizations and professional societies could help NINDS create and distribute educational materials about neurological disorders and stroke using modern communication formats (e.g. infographics, interactive videos, and social media platforms). Such partnerships would also enable NINDS to receive patient community input for future funding initiatives. NINDS could also utilize these communication channels to broaden their outreach to health care providers and researchers to inform them about upcoming opportunities.

**3.3. NINDS public outreach/education.** Several respondents suggested that NINDS improve the dissemination of NINDS research to lay audiences. They recommended that NINDS create a user-friendly website with lay-accessible information about funded research projects and their progress, and annotations outlining scientific advantages gained from research studies and any implications for lifestyle changes. To enhance research communication with diverse publics, NINDS could enhance the diversity of their science writers. Respondents also encouraged NINDS to collaborate with advisory boards and patient and caregiver communities to help translate complicated research topics to the public and make NIH more accessible and understandable to the general public. This would improve understanding of study implications and facilitate meaningful and accurate dialogue between patients, health care providers, and researchers. NINDS could also support science communication training programs for researchers to communicate their science to diverse audiences. A few respondents pointed out that the NINDS website, social media, or other open access platforms can be leveraged to increase media coverage of NINDS-funded research.

**3.4. Patient community engagement.** Some respondents recommended NINDS increase engagement with patient communities to develop and improve practices and policies that would better serve and anticipate their needs. They encouraged NINDS to consult with patient communities on all aspects of research including study design, feasibility and rigor, selecting study outcomes, tailoring interventions to meet patient needs and preferences, participant enrollment, dissemination of research findings, and resource allocation, as well as broader research priorities for their disease area and strategic direction of research initiatives. Respondents also requested that NINDS make a direct and concerted effort to include patient communities in the NINDS strategic planning process.

A few respondents requested that NINDS help create more accessible descriptions of clinical trials on ClinicalTrials.gov. They suggested that NINDS work to increase caregiver and patient communities access to research coordinators in neurology-related clinical trials as a way to increase the number of patients
enrolled in trials and enhance the public’s appreciation of the benefits and risks of clinical trials. Respondents also urged NINDS to return research outcomes to patients that took part in research as either partners in design and implementation or as study participants.

**Workforce Culture**

**Goal 4.** Create and sustain a supportive work culture for the NINDS work force and facilitate and reward analogous efforts in the outside neuroscience community.

**4.1. Overall comments.** Respondents were supportive of this goal, but asked that NINDS focus on the NINDS Intramural workforce. It may be impractical for NINDS to achieve this goal in the extramural community since departments and individual investigators control the local extramural workforce environments.

**4.2. Workplace satisfaction.** Some respondents raised concerns about employee burnout in the neuroscience research community. Respondents recommended that NINDS take steps to address and mitigate burnout within NINDS and the extramural neuroscience community, such as by providing tools and resources for wellness. They urged NINDS to be a model for the extramural workforce by publicly and deliberately employing and advertising workplace policies to promote work-life balance and a supportive environment, and reward and recognize the hard work of their employees. A supportive workforce culture and recognition can increase workplace satisfaction and reduce feelings of burnout.

**4.3. Diversity and inclusion.** Some respondents emphasized that recruiting and retaining a strong, bright, and diverse workforce requires NINDS to promote diversity and inclusion and a supportive work culture for all, regardless of age, gender, race, ethnicity, religion, nationality, sexual orientation, physical abilities, military status, and socioeconomic status. NINDS should model commitment to value of diversity by creating a welcoming, inclusive, and safe work environment. A respondent also urged NINDS to proactively address discrimination and harassment faced by employees in the neuroscience workforce.

**4.4. Collaboration.** Many respondents felt that encouraging collaboration can help eliminate a hostile, hypercompetitive work environment and foster more productive and meaningful scientific partnerships.

**4.5. Compensation and benefits.** Respondents urged NINDS to provide more resources to recruit, retain, and reward employees, noting that many workers in research labs are volunteers due to lack of funding to hire additional staff. A few respondents suggested that NINDS assist postdoctoral fellows and clinician-scientists with loan repayment.