

NINDS Feedback Survey of NeuroNEXT

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Thank you for providing your feedback on your experiences with NeuroNEXT. NINDS is conducting this survey of NeuroNEXT participants to assess satisfaction with service delivery by the network and NINDS; to determine the extent to which participants feel the network has facilitated the development and conduct of high-quality exploratory trials and biomarker validation studies for neurological disorders other than stroke; and to obtain feedback relevant to program improvement.

Your participation in this survey is voluntary. Please note that your responses will not be identified with you personally or with your organization; survey results will be reported only in aggregate or de-identified form. NINDS does not plan to publish results of this survey but will use the responses received to inform future program improvements. If you have questions about the survey, or if you have any technical difficulty accessing or responding to the survey, please contact Dr. Cristina Nigro (cristina.nigro@nih.gov).

* 1. Within which component of the network are you based? Select all that apply to your current or past participation in the network.

- Clinical Coordinating Center (CCC)
- Data Coordinating Center (DCC)
- Clinical Study Site
- Non-NeuroNEXT site

* 2. What is your role within the network? Select all that apply.

- CCC/DCC Leadership
- NeuroNEXT (NN) Site PI/Co-PI/Co-I
- Protocol Principal Investigator (PPI)/Co-I
- Clinical Study Site (CSS) PI, Co-PI/Co-I
- CCC or DCC Project/Site Management/Coordination
- CCC or DCC infrastructure support
- NeuroNEXT (NN) Site Coordinator/Manager
- Protocol Principal Investigator (PPI) Coordinator
- Clinical Study Site (CSS) Coordinator/Manager
- Clinical Study Site (CSS) clinical or support staff
- NeuroNEXT Fellow
- Network Committee member
- Other (please specify)

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Overall network goals

3. What additions, removals, or changes to how the network is organized or managed would increase your satisfaction with the network's services and operations? Please list the top 3.

1.
2.
3.

4. Some of the goals from the original Funding Opportunity Announcements (FOAs) for the network are listed in the table below. Please indicate your satisfaction with how the network as a whole has addressed each of these goals:

	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	No opinion
Support for high-quality, multi-site Phase 2 clinical trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support for high-quality, multi-site clinical studies to validate biomarkers and outcomes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Efficient execution of clinical trials and studies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Develop a stable infrastructure and research capacity that is equipped to adequately serve all areas of neurology except stroke	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research training and career development for clinical investigators	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Development of public-private partnerships that engage industry and/or non-profit organizations in network research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Network portfolio

5. Please indicate your satisfaction with the extent to which the network conducts important studies that are improving treatment or will lead to treatments for neurological disorders in the next 10 years.

Very dissatisfied Dissatisfied Neutral Satisfied Very satisfied No opinion

6. Currently, the number of trials approved and being conducted in NeuroNEXT are:

Too few Just right Too many No opinion

7. Please indicate your satisfaction with each of the following items related to the network's support for a balanced portfolio of high-quality, multi-site trials and clinical studies:

Very
dissatisfied Dissatisfied Neutral Satisfied Very
satisfied No opinion

Number of studies focused on adult populations

Number of studies focused on pediatric populations

Range of disease/condition study areas

Range of intervention types

Promotion and development of a pipeline for potential future trials for the network

8. What (if anything) would you want to see done differently related to best supporting a balanced portfolio of studies?

9. NINDS seeks to support clinical networks that are open to all researchers with great ideas for new clinical studies. Please indicate your satisfaction with each of the following items related to the extent to which the network encourages investigators within the network and outside the network to **submit proposals**:

	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	No opinion
The network encourages investigators <u>within the network</u> to submit proposals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The network encourages investigators from the research community <u>outside the network</u> to submit proposals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

10. Please indicate your satisfaction with each of the following items related to the extent to which the network encourages innovative study designs and approaches:

	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	No opinion
The network supports the application of a variety of innovative study designs and approaches	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The network engages investigators with relevant expertise from <u>within the network</u> in trial design and implementation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The network engages investigators with relevant expertise from <u>outside the network</u> in trial design and implementation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

11. What (if anything) could the network do to encourage and enable innovation?

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Study execution and efficiency

12. Please indicate your satisfaction with the network on each of the following items related to efficient execution of clinical trials and studies:

	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	No opinion
Time from initial study proposal to funding (pre-award)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Time to study start-up after notice of funding (post-award)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Participant enrollment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Participant retention	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Study procedures execution	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Data quality	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Study monitoring	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

13. What (if anything) would you change to improve the efficiency of the network in executing clinical trials and studies?

14. Please indicate your satisfaction with the network in facilitating sharing best practices in enrolling and retaining diverse participants across the following demographic characteristics:

	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	No opinion
Sex/gender	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sexual and gender minorities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Race/ethnicity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Geographic distribution, including rural areas	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Socioeconomic status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

15. In what ways could the network improve in facilitating enrollment and retention of diverse participants?

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Proposal submission

* 16. If you are an investigator who has submitted a proposal for a NeuroNEXT trial, have you ever withdrawn a proposal or grant application or chosen not to resubmit an unfunded application?

Yes

No

N/A

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17. Why did you withdraw or choose not to resubmit your application for a NeuroNEXT trial? Select all that apply.

- I needed more preparation
- The network wasn't the right fit
- The network didn't provide adequate support for preparing my application for resubmission
- I chose to pursue other research directions
- The timeline for resubmitting did not fit my needs
- I found support elsewhere
- Other (please specify)

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Support from the network coordinating centers

18. Please indicate your satisfaction with network on the following functions and activities it supports during the **conceptual phase** (i.e., all activities leading up to grant submission) of potential trials funded by NINDS:

	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	No opinion
Contribute to the development of new projects for submission	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assessment of recruitment feasibility of a new study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contribute to the development of the study timeline	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contribute to the development of the study budget	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contribute to the successful submission and approval of IND/IDE's	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Statistical design support provided by the DCC	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

19. Please indicate your satisfaction with the network on the following functions and activities it supports during the **planning phase** (i.e., all activities from notice of funding approval to study start date) of trials funded by NINDS:

	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	No opinion
Rapid review and approval of new studies or amendments by the cIRB	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contribute to the selection of sites for new trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contribute to the development of plans to enhance the diversity of participant enrollment in network trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contribute to the development of the data management and monitoring plan	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

20. Please indicate your satisfaction with the network on the following functions and activities it supports during the **implementation phase** (i.e., all activities from study start to study completion) of trials funded by NINDS:

	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	No opinion
Contribute to the rapid initiation of new trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assistance with participant enrollment and retention in network trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Effective and efficient use of the central pharmacy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Effective and efficient use of the central laboratory	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assurance of safety monitoring and monitoring site performance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Efficient and effective use of the DCC centralized data management system	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assurance of data quality	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Statistical oversight provided by the DCC	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support with analysis, publication, and dissemination of results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

21. What (if anything) would you want to see done differently related to how the network provides support during the **conceptual, planning, and/or implementation phases** of trials funded by NINDS?

22. How satisfied are you with the quality of NeuroNEXT communication and collaboration activities among network components and investigators?

Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	No opinion
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

23. What (if anything) would you want to see done differently related to how the network supports communication and collaboration among network components and investigators?

Training activities

* 24. Have you participated in any training and/or professional development activities as part of NeuroNEXT?

Yes

No

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Training activities

25. Please indicate your satisfaction with the network in each of the following items related to research training and career development for clinical investigators:

	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	N/A
Site-specific NeuroNEXT Fellows program	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical Trials Methodology Course (CTMC)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Training and mentorship for coordinators	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Network-wide NeuroNEXT Fellows activities (webinar series, interviews with experts, networking opportunities)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

26. What (if anything) would you want to see done differently in terms of training activities provided for:

New clinical investigators, including NeuroNEXT
fellows

Trial PIs

Site PIs

Network coordinators and other staff

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Community engagement

27. Please indicate your satisfaction with the network in each of the following items related to community engagement:

	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	No opinion
Engages patient communities in identifying study areas ripe for answering important questions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Engages research communities across disciplines in identifying study areas ripe for answering important questions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Engages patient communities in developing study designs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Engages research communities across disciplines in developing study designs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Engages patient communities for support in participant enrollment and retention	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Engages patient communities in reviewing and interpreting results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Engages patient communities with diverse gender, race/ethnic, geographic, and other medically underserved backgrounds	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Enables partnerships between other NIH networks, non-profit organizations, industry, and/or international researchers or organizations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

28. What suggestions do you have for additional outreach or engagement with research and patient communities that would help the network achieve its goals?

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Support from NINDS

29. Please indicate your satisfaction with the following types of support you've received from NINDS program staff:

	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	N/A
Pre-submission or pre-award support (e.g., concept development, proposal development, IRB and council review, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Post-award/study execution support (e.g., milestone development, monitoring, progress reporting, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

30. What (if anything) would you want to see done differently related to support you've received from NINDS program staff? Are there other support services that NINDS program staff could have provided that would have facilitated your network-related activities?

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Lessons learned

31. We would like to know about any **positive aspects** of your involvement in the network that you consider important to the functioning, impact, or success of the network that we may not capture from other areas of this survey. Please include any details, anecdotes, or stories about anything you might wish to share about things like the benefits of participating in the network, the impact it has had on your research or career, etc. Please note that all answers on this survey are secure to the extent permitted by law.

32. It is also important for us to know about any **negative aspects** (concerns, problems, issues) of your involvement in the network that you consider important to the functioning, impact, or success of the network. Please note that all answers on this survey are secure to the extent permitted by law.

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Follow-up (optional)

33. Would you be willing to participate in a follow-up interview or group discussion? Please note that your survey responses will remain secure to the extent permitted by law, regardless of your answer to this question.

Yes

No

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34. Please provide your email address so that we may contact you about scheduling a follow-up interview or group discussion.

Email Address