

# Request for Approval under the “Generic Clearance for NIH Citizen Science and Crowdsourcing Projects”

(OMB#: 0925-0766 Exp., date: 04/2023)

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**TITLE OF INFORMATION COLLECTION:** Self-Nomination for Funding Opportunity Special Emphasis Panels Managed by NINDS

**PURPOSE:** The National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health is increasingly working to add people with lived experience of neurological disorders to its special emphasis review panels. This information collection will collect self-nominations from people with lived experience of neurological disorders to serve as reviewers on Special Emphasis Panels (SEPs) assembled for peer review of research grant applications submitted to NINDS Funding Opportunity Announcements (FOAs). For example, NINDS will use this form to seek self-nominations from persons living with Amyotrophic Lateral Sclerosis (ALS), caregivers for persons with ALS, or persons at risk of developing ALS to serve on a SEP being assembled to review applications responding to the FOA titled: Amyotrophic Lateral Sclerosis (ALS) Intermediate Patient Population Expanded Access (RFA-NS-23-012). NINDS will use the same form for self-nominations from persons with lived experience of other neurological disorders for other FOAs for which NINDS will include such members as reviewers.

The information sought will be the same for each use of the form, and only the name of the relevant disorder and the title and number of the corresponding FOA will be modified for each use. As such, we are submitting the form as it will appear for FOA RFA-NS-23-012, and we have highlighted in yellow where specific details will be modified for subsequent FOAs. Information collected will include name, contact information, identification as a person with lived experience of a neurological disorder, confirmation of eligibility to participate in review, their reasons for interest in participation, their affiliations with advocacy organizations (if any), and relevant experience. This information will be used by NINDS to identify individuals who represent the perspectives of people with lived experience on a SEP. From these nominations, NINDS will invite 1-10 individuals to serve on a given SEP and contact information of others will be used for future engagement opportunities, if the respondent chooses. Responses collected will be used internally and not shared publicly.

## DESCRIPTION OF RESPONDENTS:

Respondents are members of the public who are living with the disorder relevant to a FOA, have a family history and/or genetic predisposition of the disorder, are caregivers/care partners of people living with the disorder, and/or identify as patient advocates.

## TYPE OF COLLECTION: (Check one)

Data Catalogue

Recommendations of scientific reviewers

Call for Nominations

Repository of Tools and Best Practices

Resources

Other: \_\_\_\_\_

## CERTIFICATION:

I certify the following to be true:

1. The collection is voluntary.
2. The collection is low-burden for respondents and low-cost for the Federal Government.
3. The collection is non-controversial and does not raise issues of concern to other federal agencies.
4. Information gathered will not be used for the purpose of substantially informing influential policy decisions.
5. The collection is targeted to the solicitation of opinions from respondents who have experience with the program or may have experience with the program in the future.

Name: Cara Long, NINDS Office of Science Policy and Planning

To assist review, please provide answers to the following question:

**Personally Identifiable Information:**

1. Is personally identifiable information (PII) collected?  Yes  No
2. If Yes, is the information that will be collected included in records that are subject to the Privacy Act of 1974?  Yes  No
3. If Applicable, has a System or Records Notice been published?  Yes  No

**Gifts or Payments:**

Is an incentive (e.g., money or reimbursement of expenses, token of appreciation) provided to participants?  Yes  No

**ESTIMATED BURDEN HOURS and COSTS**

Category of Respondent	No. of Respondents	No. of Responses per Respondent	Time per Response (in hours)	Total Burden Hours
Individual	100	1	20/60	33
<b>Totals</b>		100		<b>33</b>

Category of Respondent	Total Burden Hours	Hourly Wage Rate*	Total Burden Cost
Individual	33	\$28	\$ 924
<b>Totals</b>	<b>33</b>		<b>\$ 924</b>

\* Hourly wage rate for All Occupations is \$28.01 (based on

[https://www.bls.gov/oes/current/oes\\_nat.htm](https://www.bls.gov/oes/current/oes_nat.htm))

**FEDERAL COST:** The estimated annual cost to the Federal government is \$ 2,514

Staff	Grade/Step	Salary*	% of Effort	Fringe (if applicable)	Total Cost to Gov't
<b>Federal Oversight</b>					
Health Science Policy Analyst	13/1	112,015	.5		\$ 560
<b>Contractor Cost</b>					
Contractor 1		130,250	1.5		\$ 1,954
Travel					
Other Cost					
<b>Total</b>					\$ 2,514

\*the Salary in table above is cited from <https://www.opm.gov/policy-data-oversight/pay-leave/salaries-wages/2023/general-schedule/>

**If you are conducting a focus group, survey, or plan to employ statistical methods, please provide answers to the following questions:**

**The selection of your targeted respondents**

1. Do you have a customer list or something similar that defines the universe of potential respondents and do you have a sampling plan for selecting from this universe?

[X] Yes [ ] No

If the answer is yes, please provide a description of both below (or attach the sampling plan)? If the answer is no, please provide a description of how you plan to identify your potential group of respondents and how you will select them?

For each instance that the form is used, NINDS will advertise the self-nomination opportunity through listservs, email lists, and connections with non-profit organizations focused on relevant disorders that allow us to contact the target audience. Example email attached.

**Administration of the Instrument**

1. How will you collect the information? (Check all that apply)

- [X] Web-based or other forms of Social Media
- [ ] Telephone
- [ ] In-person
- [ ] Mail
- [ ] Other, Explain

2. Will interviewers or facilitators be used? [ ] Yes [X] No