

**Request for Approval under the “Generic Clearance for NIH Citizen
Science and Crowdsourcing Projects”
(OMB#: 0925-0766 Exp., date: 04/2023)**

TITLE OF INFORMATION COLLECTION: Share your ideas on Lived Experience Engagement in Science (NINDS)

PURPOSE:

To collect ideas from the neuroscience research community on the inclusion of lived experience engagement in research (bi-directional, mutually impactful interactions between scientists and science enablers and people who have lived experience of neurological conditions including those diagnosed, pre-manifest, recovered, caregivers, families and advocates as well as representatives of the deceased). A better understanding of support for lived experience engagement in the scientific process will help NINDS tailor our approach to developing resources, guides and best practices. Ideas from the research community, including obstacles, incentives and resources needed, will inform this understanding.

This information collection will invite responders to anonymously share ideas and to rank or vote on ideas and examples, similar to functions on popular social media applications. NINDS will launch this collaboration activity at scientific conferences, through social media posts, and online accessible via QR code. Responses collected will be used internally and not shared publicly.

DESCRIPTION OF RESPONDENTS:

Members of the scientific community, including researchers, administrators, and science adjacent professionals such as science policy and non-profit staff.

TYPE OF COLLECTION: (Check one)

- | | |
|--|---|
| <input type="checkbox"/> Data Catalogue | <input type="checkbox"/> Repository of Tools and Best Practices |
| <input type="checkbox"/> Recommendations of scientific reviewers | <input type="checkbox"/> Resources |
| <input type="checkbox"/> Call for Nominations | <input checked="" type="checkbox"/> Other: crowdsourcing ideas |

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 [X] 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 [X] No

Gifts or Payments:

Is an incentive (e.g., money or reimbursement of expenses, token of appreciation) provided to participants? [] Yes [X] 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 |
|------------------------|--------------------|---------------------------------|------------------------------|--------------------|
| Individuals | 300 | 1 | 5/60 | 25 |
| Totals | | 300 | | 25 |

| Category of Respondent | Total Burden Hours | Hourly Wage Rate* | Total Burden Cost |
|------------------------|--------------------|-------------------|-------------------|
| Individual | 25 | 43.27 | 1,082 |
| Totals | | | |

*Cite source per bls.gov if applicable, e.g., *Hourly wage rate for 19-1029 Biologic Scientist is \$43.27 (based on <http://www.bls.gov/oes/current/oes191029.htm>).

FEDERAL COST: The estimated annual cost to the Federal government is \$4,013

| Staff | Grade/Step | Salary* | % of Effort | Fringe (if applicable) | Total Cost to Gov't |
|-------------------------------|------------|-----------|-------------|------------------------|---------------------|
| Federal Oversight | | | | | |
| Health Science Policy Analyst | 14/7 | \$151,479 | 0.5 | | \$757 |
| | | | | | |
| Contractor Cost | | | | | |
| Contractor 1 | | \$130,250 | 2.5 | | \$3,256 |
| Travel | | | | | |
| Other Cost | | | | | |
| | | | | | |
| Total | | | | | \$4,013 |

*the Salary in table above is cited from <https://www.opm.gov/policy-data-oversight/pay-leave/salaries-wages/2022/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?
 Yes No

Members of the scientific community who are familiar with lived experience engagement will be invited to participate in the collaboration activity at scientific conferences, through social media, and by self-identification of interest in the topic. Initially a link will be posted on an NINDS events page for upcoming conferences.

Administration of the Instrument

1. How will you collect the information? (Check all that apply)
 Web-based or other forms of Social Media
 Telephone
 In-person
 Mail
 Other, Explain
2. Will interviewers or facilitators be used? Yes No