# 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:** The National Institute of Neurological Disorders and Stroke (NINDS) Common Data Elements (CDE) Project Request Form

**PURPOSE:** The Common Data Elements (CDE) are content standards that enable clinical investigators to systematically collect, analyze, and share data across the research community. The NINDS strongly encourages researchers who receive funding from the Institute to ensure their data collection is compatible with these common data elements (CDEs). The CDE Project Request form can be used by the public to propose 1) development of a new Common Data Element (CDE) for neurological disease research areas with no existing CDEs, 2) development of a new subgroup of CDEs for an existing CDE set, or 3) revising an existing CDE set. The goal is to make the CDE project development a transparent process in which all stakeholders can have the opportunity to nominate a new CDE or provide input for NINDS's internal use that would help improve the current program. NINDS only has one contract to develop one CDE per year so collecting information about research needs and the rationale for development of new CDEs or revising an existing CDE will inform NINDS efforts to prioritize those areas that address the most urgent and unmet research needs.

**DESCRIPTION OF RESPONDENTS**: Potential respondents include researchers at academic institutions, non-profit organizations, or other federal agencies, etc. that might become aware of this form via an email or a listserv advertising this form. NINDS Program staff will send an announcement about the CDE Project Request form through a listserv. Anyone among the listserv subscribers (e.g., neuroscience researchers) who are interested in submitting feedback about the existing CDEs or nominations for a new CDE can voluntarily fill out the form. Based on previous CDE evaluation data, we expect not more than 20 responses per year. The form will also be posted on the NINDS CDE Project website (https://www.commondataelements.ninds.nih.gov/) which will have a separate page where researchers will be provided with general information about the form and will be able to complete and submit it, if they desire to do so.

**TYPE OF COLLECTION:** (Check one)

[ ] Data Catalogue                          [ ] Repository of Tools and Best Practices
[ ] Recommendations of scientific reviewers  [ ] Resources
[x] Call for Nominations                     [ ] 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 <u>not</u> raise issues of concern to other federal agencies.
4. Information gathered will not be used for the purpose of <u>substantially</u> informing <u>influential</u> 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: Sophia Jeon, Ph.D. Health Science Policy Analyst, NINDS OSPP

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

**Personally Identifiable Information:**
1. Is personally identifiable information (PII) collected?  [x] Yes  [ ]  No
2. If Yes, is the information that will be collected included in records that are subject to the Privacy Act of 1974?   [x] 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 |
|---|---|---|---|---|
| Individual (Researchers) | 20 | 1 | 20/60 | 7 |
| | | | | |
| **Totals** | | 20 | | **7** |

| Category of Respondent | Total Burden Hours | Hourly Wage Rate* | Total Burden Cost |
|---|---|---|---|
| Individual (Researchers) | 7 | $40.19 | $281.33 |
| | | | |
| **Totals** | **7** | | **$281.33** |

*Hourly wage rates for 19-1029 Biological Scientists is $40.19 (based on http://www.bls.gov/oes/current/oes191029.htm).

**FEDERAL COST:**  The estimated annual cost to the Federal government is $5,133.15

| Staff | Grade/Step | Salary* | % of Effort | Fringe (if applicable) | Total Cost to Gov't |
|---|---|---|---|---|---|
| **Federal Oversight** | | | | | |
| General Health Scientist | 13/1 | $102,663 | 5% | | $5,133.15 |
| | | | | | |
| | | | | | |
| **Contractor Cost** | | | | | |
| | | | | | |

| | | | | | |
|---|---|---|---|---|---|
| Travel | | | | | |
| Other Cost | | | | | |
| | | | | | |
| **Total** | | | | | $5,133.15 |

*the Salary in table above is cited from https://www.opm.gov/policy-data-oversight/pay-leave/salaries-wages/2020/general-schedule/


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

*This will not be a focus group/survey.  There are no plans to employ statistical methods.*

**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


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?



**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

**Please make sure that all instruments, instructions, and scripts are submitted with the request.**