

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: Self-Nomination for ME/CFS Research Roadmap Working Group

PURPOSE:

NINDS has formed a Working Group of the National Advisory Neurological Disorders and Stroke (NANDS) Council to develop a research roadmap for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) research. The Working Group of Council (WGC) will include ME/CFS basic and clinical researchers, leaders of ME/CFS non-profit advocacy/research organizations, and members of the public who are living with ME/CFS, are caregivers/family of people living with ME/CFS, or identify as ME/CFS patient advocates. The purpose of this proposed information collection is to collect self-nominations of members of the public who are interested in serving on the ME/CFS Research Strategic Planning WGC.

Information collected will include name, contact information, identification as a person living with ME/CFS or caregiver/care partner or patient advocate, confirmation of eligibility to participate in this research strategic planning effort, their reasons for interest in participation, their affiliations with ME/CFS advocacy organizations (if any), relevant experience with ME/CFS research, and a brief resume. This information will be used to identify individuals who represent the perspectives of people living with ME/CFS, caregivers of people living with ME/CFS, or patient advocates who could best contribute to this research strategic planning effort. From these nominations, 2-4 individuals will be invited to serve on the ME/CFS Research Strategic Planning Working Group, with additional nominees invited to serve on subgroups of the Working Group. This information will only be used internally by NINDS and the WGC.

DESCRIPTION OF RESPONDENTS:

Respondents are members of the public who are living with ME/CFS, have a family history of ME/CFS, are caregivers/care partners of people living with ME/CFS, or identify as ME/CFS patient advocates

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 checked="" type="checkbox"/> Call for Nominations | <input type="checkbox"/> 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
Totals		100		33

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

* Hourly wage rate for All Occupations is \$28.01 (based on https://www.bls.gov/oes/current/oes_nat.htm)

FEDERAL COST: The estimated annual cost to the Federal government is \$ 2246

Staff	Grade/Step	Salary*	% of Effort	Fringe (if applicable)	Total Cost to Gov't

Federal Oversight					
Health Specialist	GS12/01	\$89834	2.5%		\$2246
Contractor Cost					
Travel					
Other Cost					
Total					\$2246

*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?
[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?

We will be advertising this nomination process via emails sent directly to the NIH ME/CFS listserv, which includes members of the public who have subscribed to receive email correspondence about NIH ME/CFS activities. We will also place language notifying the public about this nomination process in the NIH ME/CFS newsletter, which is posted online and also distributed to the NIH ME/CFS listserv.

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