## Request for Approval under the “Generic Clearance for the Collection of Routine Customer Feedback” (OMB#: 0925-0648 Exp., date: 06/30/2024)

**TITLE OF INFORMATION COLLECTION:** National Center for Advancing Translational Sciences (NCATS) Genetics and Rare Disease Information Center (GARD) 2.0 Website User Feedback Survey

**PURPOSE:** GARD is a program under the NCATS Division of Rare Disease Research Innovation at the National Institutes of Health (NIH). It provides the public with access to current, reliable, and easy-to-understand information about rare or genetic diseases in English and Spanish. The GARD website includes information on nearly 6,000 rare diseases to help people find reliable information. In the United States, a rare disease is defined as one that affects fewer than 200,000 people. The types of information presented includes symptoms, causes, how to find a specialist and information about finding a support group or obtaining financial assistance as well as other disease aspects important to a rare disease patient and their family.

Over the past two years, the GARD website has been undergoing a major redevelopment effort in terms of technology, content and user experience. A soft launch of the new site was released in the Fall of 2021, and NCATS has been routinely releasing new versions since that time. NCATS previously received approval in October 2021 under the “Generic Clearance for the Collection of Routine Customer Feedback” and has been collecting feedback on the website through an optional online survey.

We are approaching a major new release of the GARD website just prior to Rare Disease Day (RDD) NIH, to be held on February 28th, 2023. NCATS would like to slightly modify our current survey questions to collect more targeted user feedback from GARD users on the latest website release to inform our development efforts. Visitors to the GARD website will have the option of clicking a button to be taken to the survey.

**DESCRIPTION OF RESPONDENTS**:

The respondents will primarily be patients with a rare disease or one of their family members or friends.

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

[ ] Customer Comment Card/Complaint Form [ ] Customer Satisfaction Survey

[X ] Usability Testing (e.g., Website or Software) [ ] Small Discussion Group

[ ] Focus Group [ ] Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**FREQUENCY OF REPORTING:** (Check one)

[X] Once [ ] Quarterly

[ ] Monthly [ ] On Occasion

[ ] Annually [ ] 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. The results are not intended to be disseminated to the public.
5. Information gathered will not be used for the purpose of substantially informing influential policy decisions.
6. 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:\_\_\_\_\_Eric Sid\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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 [ ] 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 or households | 500 | 1 | 10/60 | 83 |
|  |  |  |  |  |
| **Totals** |  | 500 |  | **83** |

**COST TO RESPONDENT**

|  |  |  |  |
| --- | --- | --- | --- |
| **Category of Respondent** | **Total Burden**  **Hours** | **Hourly Wage Rate\*** | **Total Burden Cost** |
| Individuals or households | 83 | $28.01 | $2,325 |
|  |  |  |  |
| **Totals** |  |  | $2,325 |

# \*Source May 2021 National Occupational Employment and Wage Estimates United States <https://www.bls.gov/oes/current/oes_nat.htm#00-0000> - All occupations

**FEDERAL COST:** The estimated annual cost to the Federal government is \_$2,147\_\_\_\_\_\_\_\_

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Staff** | **Grade/Step** | **Salary\*** | **% of Effort** | **Fringe (if applicable)** | **Total Cost to Gov’t** |
| **Federal Oversight** |  |  |  |  |  |
| Program Officer | 14/2 | $133,765 | .05% |  | $67 |
|  |  |  |  |  |  |
|  |  |  |  |  |  |
| **Contractor Cost** |  |  |  |  |  |
| Lead UI/UX Designer/Manager |  | $208,000 | 1% |  | $2,080 |
|  |  |  |  |  |  |
| Travel |  |  |  |  |  |
| Other Cost |  |  |  |  |  |
|  |  |  |  |  |  |
| **Total** |  |  |  |  | $2,147 |

\*The Federal Salary in table above is cited from <https://www.opm.gov/policy-data-oversight/pay-leave/salaries-wages/salary-tables/pdf/2023/SEA.pdf>

**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 [ X] 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?

Survey respondents will be visitors to the NCATS GARD website pages who choose to respond to the survey.

**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

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