

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 Office of Rare Diseases Research 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 over 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, available treatments, 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.

The GARD website is currently undergoing a major redevelopment effort in terms of technology, content and user experience. Before launching the new website, NCATS would like to collect targeted user feedback on the draft new pages to inform our development of the new website. When visiting pages on the current GARD website, users will have the option of clicking a button to be taken to a preview page of the website. On that preview page there will be a link to provide feedback by responding to a series of questions.

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)

- | | |
|---|---|
| <input type="checkbox"/> Customer Comment Card/Complaint Form | <input type="checkbox"/> Customer Satisfaction Survey |
| <input checked="" type="checkbox"/> Usability Testing (e.g., Website or Software) | <input type="checkbox"/> Small Discussion Group |
| <input type="checkbox"/> Focus Group | <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. 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	\$29.08	\$2,414
Totals			\$2,414

*Source https://www.bls.gov/oes/current/oes_47900.htm - All occupations

FEDERAL COST: The estimated annual cost to the Federal government is \$2,134

Staff	Grade/Step	Salary*	% of Effort	Fringe (if applicable)	Total Cost to Gov't
Federal Oversight					
Program Officer	13/3	\$107,670	.05%		\$54
Contractor Cost					
Lead UI/UX Designer/Manager		\$208,000	1%		\$2,080

Travel					
Other Cost					
Total					\$2,134

*the Salary in table above is cited from <https://www.opm.gov/policy-data-oversight/pay-leave/salaries-wages/salary-tables/21Tables/html/SEA.aspx>

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

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 NCATS GARD website pages who choose to view the preview of the draft new version of the page and wish to respond to the survey by selecting the “Feedback Form” button. See attached for sample.

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