TITLE OF INFORMATION COLLECTION: NLM ClinVar 2016 User Survey

PURPOSE: The goal of this survey is to collect qualitative customer service delivery feedback from users of the National Center for Biotechnology Information (NCBI) ClinVar website. This is a database containing variants and interpretations of their clinical significance for diseases. It currently has more than 200,000 submitted interpretations for more than 150,000 variants, primarily submitted from clinical testing laboratories. The information from this survey will be used to improve the design and operation of the publically accessed website.

DESCRIPTION OF RESPONDENTS: Respondents will be individual users of the NCBI ClinVar website from whom we wish to solicit customer feedback regarding features that would facilitate and improve the design and operation of this web resource.

TYPE OF COLLECTION: (Check one)

[] Customer Comment Card/Complaint Form

[] Usability Testing (e.g., Website or Software

[] Focus Group

[X] Customer Satisfaction Survey

[] Small Discussion Group

[] 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. The results are <u>not</u> intended to be disseminated to the public.
- 5. Information gathered will not be used for the purpose of <u>substantially</u> informing <u>influential</u> 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: <u>Melissa Landrum</u>

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 [X] N/A

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	300	1	5/60	25
Totals	300	300		25

Category of Respondent	Total Burden Hours	Wage Rate*	Total Burden Cost
Individuals or Households	25	\$23.23	\$580.75
Totals			\$580.75

*BLS National Occupational Employment and Wage Estimates <u>http://www.bls.gov/oes/current/oes_nat.htm#00-0000</u>

FEDERAL COST: The estimated annual cost to the Federal government is \$276.66

				Fringe (if applicable)	Total Cost to Gov't
Staff	Grade/Step	Salary	% of Effort		
Federal Oversight					
Staff scientist	T42	\$138,329	0.2%		\$276.66
Contractor Cost					N/A
Travel					N/A
Other Cost					N/A
Total					\$276.66

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?

Website respondents will be invited to take the survey via a link appearing at the top of ClinVar pages.

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.

Attachment: NLM ClinVar 2016 User Survey Instrument