TITLE OF INFORMATION COLLECTION:

NLM GHR User Study Screening Survey

PURPOSE:

The purpose of this survey is to collect customer service delivery information from users of the National Library of Medicine (NLM) Genetics Home Reference (GHR) website. This online information collection will be to identify participants for a usability study of GHR resource that provides consumer-friendly information about genetic conditions and the gene or chromosome changes responsible for those conditions. The screening survey will be used to choose a diverse sample of GHR users to be interviewed in greater depth about their experience with this resource and their suggestions for improving it. No similar studies have been carried out for GHR users and the data collection. The second participant interview phase of this study will be subsequently submitted to OMB for authorization to conduct that information collection pending approval of this initial screening survey.

DESCRIPTION OF RESPONDENTS:

Respondents will be users of the Genetics Home Reference website over age 18, including patients, students, and health professionals.

TYPE OF COLLECTION: (Check one)

[] Customer Comment Card/Complaint Form

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

[] Focus Group

[] Customer Satisfaction Survey

- [] Small Discussion Group
- [X] Other: <u>Online user screening survey</u>

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>Stephanie Morrison</u>

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

Personally Identifiable Information:

- 1. Is personally identifiable information (PII) collected? [] Yes [X] No
 - Limited contact information for respondents will be collected by the contractor so they can reach selected users for interviews. The data will be de-identified by the contractor before it is sent to NLM; no PII will be made available to the government.

- 2. If Yes, is the information that will be collected included in records that are subject to the Privacy Act of 1974? [] Yes [X] 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
Individuals or Households	150	1	10/60	25
Private Sector	50	1	10/60	8
Totals	200	200		33

Category of Respondent	Total Burden Hours	Wage Rate*	Total Burden Cost
Individuals or Households	25	\$23.23	\$580.75
Private Sector (Healthcare workers)	8	\$37.40	\$299.20
Totals	33		\$879.95

*BLS National Occupational Employment and Wage Estimates http://www.bls.gov/oes/current/oes_nat.htm#00-0000 Healthcare Practitioners and Technical Occupations http://www.bls.gov/oes/current/oes290000.htm

FEDERAL COST: The estimated annual cost to the Federal government is: <u>\$1,594.00</u>

Staff	Grade/Step	Salary		Fringe (if applicable)	Total Cost to Gov't
Federal Oversight		S and J			
Information Research Specialist	GS-13/4	\$101,361	0.4%		\$405.00
Contractor Cost		\$1,189	100%	N/A	\$1,189.00
Travel					N/A
Other Cost					N/A
Total					\$1594.00

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?

This screening survey will be used to identify a diverse group of Genetics Home Reference users to be interviewed in greater depth as part of a usability study. A link to this survey will be provided on each page of the Genetics Home Reference website. The full text of the survey is attached.

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.