

## **Request for Approval under the “Generic Clearance for the Collection of Routine Customer Feedback” (OMB Control Number: 0925-0648)**

**TITLE OF INFORMATION COLLECTION:** Genetic and Rare Diseases Information Center Customer Satisfaction Survey

### **PURPOSE:**

The purpose of the Genetic and Rare Disease (GARD) Information Center is to help people find information about rare and/or genetic diseases. GARD provides access to experienced information specialists who furnish current and accurate information - in English or Spanish - about rare and/or genetic diseases.

The GARD Information Center goals are to:

1. Provide and enhance knowledge and understanding of specific genetic and/or rare diseases through the provision of information to requesters (via telephone, mail, or email) and on the GARD Information Center website.
2. Maintain high quality service by ensuring that requesters are satisfied with the service.
3. Fulfill critical needs, especially for patients with rare diseases where little information may be readily available, without duplication of efforts of other entities/organizations
4. Fulfill needs in an efficient and cost-effective manner

OMB Generic Clearance is being requested to gather feedback from the public that utilizes GARD information services through a web and telephone satisfaction survey. The purpose of this customer satisfaction survey is to determine if GARD is providing a service that satisfies its customers and to identify ways in which GARD can improve its service.

The objectives of this survey are to:

1. Identify who is being served by GARD.
2. Identify how individuals learn about GARD
3. Identify the reasons why individuals are seeking information.
4. Identify the type of information being sought.
5. Assess customers’ satisfaction with GARD services in terms of effectiveness (e.g., quality, usefulness, personal applicability, utility, timeliness, understandability, sensitivity, amount of information, and format of delivery) of responses provided by information specialists. Similarly assess satisfaction with the information available on the GARD website, either through the overall content of the site and through the Questions and Answers (Q&As) sections.
6. Determine where else customers might have sought information to ascertain possible duplication or overlap and possible future collaborations.

### **DESCRIPTION OF RESPONDENTS:**

From 2002 to 2011, GARD received more than 30,000 inquiries concerning more than 5,000 separate diseases. In 2012, GARD received an average of 383 inquiries per month. Inquiries are received by email, website contact form, phone call, or letter/fax. Of the 383 inquiries, approximately 6 per month (2%) were from Spanish-speaking individuals to which the Information Specialists responded in Spanish. GARD responses are sent in 2 – 10 business days (unless a request was urgent). Requesters for information include patients (35%), family members and friends (38%), health care professionals (11%), educators and students (6%), and others or not specified (10%).

In 2012, the GARD Web pages received an average of 160,000 visits per month, representing 55,000 unique visitors. The Web pages with Spanish Q&As received about 3,126 visits per month, representing 521 unique visitors. Thus far in 2013, there has been a steady increase in site traffic; in August the site had 127,278 unique visitors and 447 requests.

It is expected that the survey respondents will have similar characteristics and in similar proportions.

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

- |  |  |
|--|--|
| <input type="checkbox"/> Customer Comment Card/Complaint Form          | <input checked="" type="checkbox"/> Customer Satisfaction Survey |
| <input type="checkbox"/> Usability Testing (e.g., Website or Software) | <input type="checkbox"/> Small Discussion Group                  |
| <input type="checkbox"/> Focus Group                                   | <input type="checkbox"/> Other: _____                            |

The survey will be hosted on ICF’s server. When an individual clicks on the survey link, he/she will be redirected to the survey pages.

Invitations to participate in the survey will be as follows:

- In the case of individuals visiting the GARD website, a pop-up will invite the person to take the survey and ask if he/she wishes to take the survey. If the respondent selects “no”, the pop-up will disappear and not reappear again. If the respondent selects “yes”, a new window will open taking them to the survey.
- Individuals who contact GARD by email or the online contact form will receive [in addition to the response to their question(s)] a footnote indicating that they will receive a follow-up email inviting them to take the survey. A second email will be sent later that same business day, explaining the purpose of the survey and containing the URL to the survey.
- Individuals who contact GARD by phone will be invited to complete the survey by phone or online (in this case, the URL will be provided verbally to the individual, as well as instructions on how to access the survey on the GARD website). If the individuals indicate that they would like to complete the survey, their names and contact information will be collected by the GARD information specialist. This information will then be transferred via a secure web portal to an ICF-trained interviewer, who will call respondents and administer the survey. If the respondents do not want to take the survey, no information will be collected.
- The survey will consist of 29 questions 27 of which are closed-response (i.e., pre-coded) questions and 2 open-ended. During survey development, the Evaluation Contractor collaborated with the Technical Contractor to ensure that the survey format is compatible with the data collection system.

**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: **Thomas Brassell**

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

**Personally Identifiable Information:**

1. Is personally identifiable information (PII) collected?  Yes  No

**Note:** Name and phone number will be collected for up to 200 respondents who agree to complete the GARD survey via telephone. The PII collected will never be associated with the respondent’s survey responses, and will be destroyed at the conclusion of data collection.

2. If Yes, is the information that will be collected included in records that are subject to the Privacy Act of 1974?  Yes  No

**Note:** The name and phone number collected will only be used to make follow-up calls, and will not be attached to any records of survey responses.

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

**BURDEN HOURS**

Category of Respondent	No. of Respondents	Participation Time	Burden Hours
Individuals	576	10/60	96
<b>Totals</b>	<b>576</b>	<b>10/60</b>	<b>96</b>

**FEDERAL COST:** The cost to the Federal government is **\$79,950.52**

**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?

Individuals who contact GARD by email, website contact form, phone, letter or fax, or visit the Q&As on the GARD website are the target population for the proposed study. The target population includes individuals for whom English is their primary language (comprise 98% of the population) and individuals for whom Spanish is their primary language (comprise 2% of the population). The approximate average size of the population (per month) that contacts GARD by email, website contact form, phone, letter or fax is 390. The approximate size of the population (per month) that visits the Q&As on the GARD website is 55,500. This number represents the average number of unique visitors to the Q&As per month. We expect that the population is predominantly female (60%). Similarly, approximately 70% of the target population identifies itself as patients/individuals or family members/friends at-risk for genetic and/or rare disease.

Convenience sampling will be used to collect the data for the proposed study. All individuals who contact GARD (online contact form, email, phone, letter/fax, or website visit) will be invited and will self-select to complete the survey. The total number of survey respondents that will be needed in order to perform the analysis is 576.

### **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