

**Customer Satisfaction Survey of the NHGRI/ORD Genetic
and Rare Diseases (GARD) Information Center**

Final Report of Analyses of Survey Data

October 13, 2006

**Prepared for the National Human Genome Research Institute and
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Executive Summary

Background

The NHGRI/ORD Genetic and Rare Diseases (GARD) Information Center's information specialists respond to inquiries received primarily by e-mail from the general public, patients and their families, physicians and other health care providers. Since it was established approximately five years ago, the information specialists have passively collected information about the information center's customers and their satisfaction with their inquiry responses. To continue to operate the information center in the most cost effective manner while providing an effective, high quality service to the broadest possible audience, the NHGRI and ORD wanted to collect formal quantitative and qualitative data to draw upon to assist with identifying any needed changes to the service provided by the information center.

A customer satisfaction survey was developed to gather data to answer the following study questions: (1) What is the demographic and personal profile of information center customers? (2) How do customers learn about the information center? (3) Do information center customers find the responses effective? (4) Are information center customers satisfied with their responses? (5) What do customers do with the information they receive?

The survey was pre-tested with the target audience. Following modifications to the survey based on pretest results, approval by the Office of Management and Budget, and a training session for information specialists, the survey was conducted from March 10 through July 31, 2006. Customers who contacted the information center by telephone were asked by the information specialists to volunteer to complete the survey and given the option to complete a Web based or paper version of the survey and in English or in Spanish. Customers who contacted the information center by e-mail received their personalized Web based response with an added section, the customer satisfaction survey, and invited to complete the Web based survey. The paper and Web based versions of the survey and supporting materials (i.e., letter, reminders, personalized Web page) were available in Spanish to any inquirer who preferred the Spanish-language materials. An independent survey operations center processed all the surveys and reminders.

Survey Results

Response Rate

During the data collection period, there were 650 inquiries submitted to the information center. The overall response rate was 35.4% (n=230) from both e-mail and telephone. Some evaluation experts would consider this a low response rate. Limitations of the evaluation, which may have contributed to the lower response rate, included the lack of invitations or some means of advance notice to participate in the survey, lack of provision of incentives and length of the survey (21 questions of which 5 were demographic). Despite these limitations, the survey data did answer the study questions and survey data revealed a consistent "picture" from the pretest through the final data analyses.

While there is the ability to make inferences from the evaluation sample to the larger population of information center customers (as described below in the answers to the study questions), there is concern about bias and thus it is not with 100% confidence that the inferences are made. The bias is in the uncertainty of any differences between responders and non-responders. Included in the pool of non-responders are domestic Spanish speaking customers and approximately 20% of customers who never open their personalized Web responses.

What is the demographic and personal profile of information center customers?

Typically, information center customers are White, non-Hispanic, English-speaking females between the ages of 31 and 40 who have a post-graduate education. The customers are likely to contact the information center only once within a year and that contact is most likely to be by e-mail. English-speaking customers contact the information center from within the United States, while Spanish-speaking customers contact the information center from outside the United States. Information center customers are typically a family member or friend of the individual for whom they are seeking specific disease or condition information. The customers have done some of their own research (about the specific disease or condition of concern) prior to contacting the information center.

How do customers learn about the information center?

Customers usually get their health information over the Internet, and first find out about the information center by conducting a search using Google, Yahoo, or another Internet search engine.

Do information center customers find the responses effective?

Customers find the responses effective in that the information is new, useful, right for their personal situation, and trustworthy. For those customers who have personal contact with an information specialist, they find the specialist to be knowledgeable.

Are information center customers satisfied with their responses?

Customers are very satisfied with the responses in that the responses arrive within 5-10 business days, are right for their reading level, are clear and easy to understand, contain the right amount of information, and are easy to go through. For those customers who have personal contact with an information specialist, they are very satisfied with their experience and feel that the specialist is sensitive to their needs. Although the customers usually contact the information center only once within a year, they would definitely contact the information center again if needed and would definitely tell others to contact the information center.

Even with the high level of satisfaction with the inquiry responses, customers provided many insightful suggestions about how to improve the responses and what other services they would like to see the information center provide. Many of the suggestions were deemed feasible and are reflected in the Recommendations section of this report. There were also many suggestions that were not feasible given the mission, policies and procedures of the information center.

What do customers do with the information they receive?

Customers share or plan to share the information they receive from the information center with family members or friends. This is logical given that most of the customers describe themselves as a family member or friend of the individual for whom they are seeking information.

Recommendations

The NHGRI and ORD should consider implementing the recommendations, summarized below and described in detail in the Recommendations section of this report, to address the possible bias and to ensure that the information center operates in the most cost effective manner while providing an effective, high quality service to the broadest possible audience.

Based on the results of the customer satisfaction survey, I make the following recommendations:

Ongoing Data Collection. To obtain a better understanding of non-responders, such as domestic Spanish-speaking customers and customers who never open their personalized Web based response, and to improve the effectiveness of the responses, I recommend getting the appropriate approvals to permit the information specialist to actively collect select data from all inquirers. This data could include level of education, role as inquirer (i.e., patient, family member, physician, etc.), accessibility to the Internet, and physical location (i.e., within or outside the United States). In all cases, the response should be disseminated to the inquirer within 5-10 business days regardless if the customer provides the requested data and within a specified time period.

Outreach. For the information center to provide a service to the broadest possible audience, additional outreach activities would need to be implemented to increase awareness of the service among minority populations, such as African Americans, Asians, and domestic Hispanics or Latinos. I recommend the development and implementation of a communications plan that would identify, prioritize, and describe outreach activities aimed at reaching these groups. I recommend the use of focus groups and results from the demonstration project focused on mobilizing Latino communities around genetic information to assist in the development of the communications plan.

As another means of outreach, I recommend the development and implementation of a GARD Information Center Web site. I also recommend that increased efforts be made to contact appropriate organizations to request a link from their Web sites to the information center Web site.

Inquiry Responses.

- Increase the length of time that the personalized, Web based response is available to the inquirer.
- In the Web based response, clarify that the information was researched and drafted by an experienced information specialist (i.e., the response was not generated by a computer).

- I recommend that the information specialists “look” for clues about the inquirer’s educational level (e.g., grammar, punctuation, sentence structure) in the incoming inquiries and subsequently draft the response to the appropriate reading level. I also recommend that the information specialist query the inquirer about the level of information being sought (see Ongoing Data Collection above).
- Additional quality control measures should be implemented to ensure that customers’ questions are being addressed.
- I recommend minimizing the inclusion of basic information, as a customer may have already found such information through independent research. The information specialist should answer the inquirer’s question and then state that more information (e.g., clinical trials, advocacy groups) is available if desired. The inquirer should be instructed to contact the information center again if additional information is needed and/or be directed to the information center’s Web site for information about select topics (see Outreach above).
- Based on knowledge of the type of inquirer (e.g., health care provider), I recommend that the information specialists be selective about the type of information provided. For example, a health care provider is most likely to know about and may have already searched PubMed; therefore, providing information from a PubMed search may not be necessary.

Additional Services. I recommend the development and implementation of an information center Web site (see Outreach above). The following additional services could be made available through this Web site:

- Availability of standard responses for conditions that are requested with high frequency. I recommend that the information center continue to develop these high frequency standard responses and make them available on an information center Web site, along with a “copy” of or link to the standard responses already available on NHGRI’s Web site.
- Availability of patient information sheets. I recommend the development of patient information sheets that may be used in lieu of including certain types of information in responses. I recommend that the information center continue to develop new patient education sheets and make them available on the information center’s Web site, along with a “copy” of or link to patient information sheets already available on NHGRI’s Web site.

Evaluation. I recommend that the NHGRI and ORD conduct another customer satisfaction survey in approximately four years to again assess the level of satisfaction of information center customers and profile audiences seeking service from the information center. I suggest using the 2006 evaluation as baseline for any subsequent evaluation to help determine the effectiveness of the implementation of any outreach activities, changes to the inquiry responses and additional services.

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Background

The NHGRI/ORD Genetic and Rare Diseases (GARD) Information Center's information specialists respond to inquiries from the general public, patients and their families, physicians and other health care providers. The majority of inquiries received by the information center are by e-mail (59.5% in 2005), followed by telephone (35.9% in 2005). Other methods of contacting the information center are by fax, mail, and TTY (less than 1% in 2005). The latter group was not part of the data collection effort.

Currently at the end of its 5th year of operation, the information center has established itself in terms of policies, procedures, and standards. Over the past years, the information center's information specialists have passively collected information about the information center's customers and have received anecdotal information about customers' satisfaction with their inquiry responses. As the NHGRI and ORD embark on the next five years of maintaining the information center, they want to have formal quantitative and qualitative data to draw upon in developing and implementing plans for the information center to operate in the most cost effective manner while providing an effective, high quality service to the broadest possible audience.

Survey Development

Survey development took place during October and November 2005. The survey was designed to gather data to answer five study questions:

- 1) What is the demographic and personal profile of information center customers?
- 2) How do customers learn about the information center?
- 3) Do information center customers find the responses effective?
- 4) Are information center customers satisfied with their responses?
- 5) What do customers do with the information they receive?

Survey Pretest Methodology

Following the development of the survey, a session for the information center's information specialists was held to prepare them to recruit volunteers for the survey pretest. The survey pretest was conducted in December 2005. The target audience for the pretest included five English-speaking and four Spanish-speaking individuals who contacted the information center by e-mail or telephone. Individuals who contacted the information center by e-mail or telephone, followed by their receipt of a personalized Web based response or a standard e-mail, also received information from the survey operations center about how to access the Web based format of the customer satisfaction survey. Individuals who contacted the information center by telephone and wanted to complete a paper copy of the survey received the survey with an

addressed, postage-paid envelope. The survey (Web based and paper copy) was available either in English and Spanish.

The survey requested individuals to review the response they received from the information center before completing the survey that consisted of 21 survey questions and five pretest questions. The goals of the pretest were to: identify any needed changes to the survey such that the final survey would be most appropriate (i.e., readable, understandable) for the target audience (English and Spanish speaking inquirers); and identify any needed changes to the data collection methodology. Individuals who volunteered to complete the survey received an e-mail or paper copy reminder (English or Spanish, as appropriate) to facilitate data collection completion before January 1, 2006. The reminder system was instrumental in obtaining the survey responses in a timely manner. When the nine survey responses were received, the survey operations center posted a survey completion notice in lieu of the Web based survey. A report of the pretest survey results was delivered to the NHGRI and ORD in January 2006. A copy of that report is not included in this final report.

Following modifications to the survey based on pretest results, the survey was included in the documents required for submission to the Office of Management and Budget (OMB) for generic clearance for the Web based and paper copy survey. Clearance documents were submitted in January 2006, and generic OMB clearance approval was obtained in March 2006. A training session for the information center's information specialists was held in March 2006 to prepare them to recruit volunteers to participate in the survey.

Data Collection Methodology

The GARD Information Center Customer Satisfaction Survey was conducted over the course of five months, from March 10 through July 31, 2006.

Telephone Inquirers. After responding to a telephone inquiry, the information center's information specialists asked the inquirer (caller) if they were interested in participating in a customer satisfaction survey. If the inquirer indicated interest, the information specialists asked if the inquirer would like the survey mailed (paper survey) or if they would rather receive an e-mail with a hyperlink to the survey (Web based survey). Based on the conversation, the information specialist also would ask whether their preference was for an English or Spanish survey. Each week the information specialists forwarded the relevant mail and e-mail address information to the survey operations center for processing.

If the inquirer wanted a survey mailed, the survey operations center sent them a personalized letter on information center letterhead, the survey, and a business reply mail envelope. If the inquirer did not respond within 3 weeks, a reminder letter was mailed to them. Both the outgoing carrier envelope and business reply mail envelope were plain white envelopes with a non-descript survey operations center return address.

Online Inquirers. Inquirers who e-mailed a request via gardinfo@nih.gov received an automatic response acknowledging their request, and within 10 business days received an e-mail with an identification number and password to a personalized web page with the information sought.

During the data collection, inquirers who received a web page had an added section, GARD Customer Satisfaction Survey, inviting them to complete the survey. To access the survey, the inquirers simply responded to the question “Would you like to take the survey?” If the inquirer responded yes, they were automatically directed to the survey. All no responses were considered refusals. However, sometimes they revisited their personalized web page and completed the survey. E-mail reminders were sent to inquirers who were asked to be reminded later, never answered the question, or indicated yes and did not complete the survey.

Spanish Paper and Web Based Surveys. The paper and Web based versions of the customer satisfaction survey and the supporting materials (i.e., letter, reminders, personalized Web page) were available in Spanish to any inquirer who preferred the Spanish-language materials.

Results of Data Analyses

This section of the report provides the analyses of the data collected from March 10 through July 31, 2006.

Response Rate

During the data collection period, there were 650 inquiries submitted to the information center. The overall survey response rate was 35.4% (n=230) from both e-mail and telephone inquiries.

Of the 206 telephone inquiries received by the information center during the data collection period, only 1% (n=3) were not willing to participate in the survey. Of the remaining 203, the majority (73.9% or 150) wanted an e-mail with the hyperlink to the survey. Only slightly more than a quarter (26.1% or 53) requested that the survey be mailed.

Of those who agreed to participate in the survey, a little more than one-fifth (22.7% or 46) completed the survey. The response rate was higher for telephone inquirers who completed a paper survey than the Web based survey, 32.1% (n=17) compared to 19.3% (n=29).

Of the 444 web pages distributed during the data collection period, the majority (61.0% or 271) did not answer the question. A little less than a quarter (23.4% or 104) indicated yes to participation in the survey, and a little more than a tenth (12.4% or 55) asked to be reminded later. Despite their initial survey participation decision, slightly more than two-fifths (41.4% or 184) ultimately completed the Web based survey.

Of the 650 inquiries, a very few inquirers (2.6% or 17) completed the survey in Spanish. Of those, all completed the Web based survey in Spanish.

Study Question 1. What is the demographic and personal profile of information center customers?

Survey questions 3, 4, 5, 6, 7, 8, 17, 18, 19, 20, and 21 were designed to provide information to describe information center customers. The demographic and personal profile of the respondents was as follows:

- Of the 230 survey respondents, 92.6% responded in English and 7.4% responded in Spanish. Of the 213 English-speaking respondents, 80.8% (n=172) were female and 18.8% (n=40) were male. Of the 17 Spanish-speaking respondents, 88.2% (n=15) were female and 11.8% (n=2) were male.
- The age distribution of all the respondents was: 20 or under (0.87% or 2); 21-30 years (15.2% or 35); 31-40 years (28.7% or 66); 41-50 years (22.6% or 52); 51-60 years (23.0% or 53); 61-70 years (6.1% or 14); and 71 or over (3.5% or 8).
- Twenty-six respondents (15.5%) indicated their ethnicity as Hispanic or Latino and 145 (86.3%) indicated not Hispanic or Latino. Sixty-two respondents did not answer the question about ethnicity.
- Two respondents indicated their race as American Indian or Alaska Native, 14 indicated Asian, 8 indicated Black or African American, and 183 indicated White.
- Respondents indicated their level of education as follows: Grade school (1.3% or 3); some high school (2.2% or 5); high school graduate (11.5% or 26); some college (25.6% or 58); college graduate (27.3% or 62); and post-graduate (32.2% or 73). The response of highest frequency for the respondents who completed the survey in English was post-graduate (n=69). The responses of highest frequency for the respondents who completed the survey in Spanish were some college (n=5) and college graduate (n=5).
- Of the respondents who completed the survey in English (n=213), 93.9% or 200 indicated that they prefer to speak English. Other preferred languages were Dutch, French, Italian, Portuguese, Russian, and Swedish. Of the respondents who completed the survey in Spanish (n=17), 94.1% or 16 indicated that they prefer to speak Spanish.

Overall, 81.7% of respondents were female and 18.3% were male. Most respondents were between the ages of 31 and 40 (28.7%). The majority of respondents categorized themselves as White and not of Hispanic or Latino ethnicity. Over 90% of respondents who completed the survey in English prefer to speak English, and 94% of respondents who completed the survey in Spanish prefer to speak Spanish. Almost 60% of the respondents attained at least a college degree, with almost one-third having attained a post-graduate education.

- Eighty-two percent (82.5% or 189) of respondents contacted the information center one time in 2006; 14.8% or 34 contacted the information center two times in 2006.
- Eighty-three percent (82.6% or 190) of respondents had contacted the information center most recently by e-mail and 17.0% or 39 by phone.
- Eighty-one percent (81.1% or 172) of English-language respondents contacted the information center from all across the United States. California (n=13) and Florida (n=13) had the highest frequency. Nineteen percent (18.9% or 40) of respondents contacted the information center from other countries. Australia (n=6), Canada (n=6), and the United Kingdom (n=5) had the highest frequency. All seventeen respondents who completed the survey in Spanish completed the survey from outside the United States. The countries were Argentina, Chile, Spain, and Mexico. Argentina had the highest frequency (n=6).
- Forty-five percent (44.5% or 102) of respondents described themselves as family or friend of a patient, 31.0% or 71 described themselves as a patient, and 11.8% or 27 described themselves as a type of health care provider (i.e., physician, nurse, genetic counselor, or other health care provider) when they contacted the information center.

- Respondents most frequently (70.0% or 161) identified ‘specific disease or condition’ as the type of information they were seeking when they contacted the information center. This was followed by ‘treatment/medical care’ (41.7% or 96), ‘diagnosis for symptoms’ (39.6% or 91), ‘research study’ (34.3% or 79), ‘clinical/genetic testing’ (26.1% or 60), and ‘alternative therapies’ (23.5% or 54). The category ‘career’ was not identified by any of the respondents. Respondents completing the survey in Spanish did not identify the following categories: insurance/reimbursement, lay advocacy group, and legal/financial.
- Eighty-seven percent (86.9% or 199) of respondents indicated that they had researched their question before contacting the information center. The survey question provided an example to illustrate that the research could have been on Web sites, with health care providers, etc.

The majority of respondents who completed the survey in English contacted the information center from one of the states within the United States. All respondents who completed the survey in Spanish contacted the information center from Spanish-speaking countries outside the United States. The majority of respondents contacted the information center only once in 2006 and made the contact by e-mail. Most respondents identified themselves as a family member or friend of a patient and were seeking information about a specific disease or condition, of which they had done research prior to contacting the information center.

Study Question 2. How do customers learn about the information center?

Survey questions 1 and 2 were designed to provide information to describe how customers learn about the information center. Sixty-four percent (64.5% or 147) of respondents indicated that they usually get their health information from the computer (e.g., view information electronically on Web sites). Twenty-five percent (25.4% or 58) of respondents indicated that they usually get their health information from health care providers.

Sixty-two percent (61.7% or 142) of respondents indicated that they first found out about the information center from a search engine (e.g., Google, Yahoo, etc.). Thirteen percent (12.6% or 29) found out about the information center from the Office of Rare Diseases’ Web site, and 9.6% or 22 found out about the information center from the National Human Genome Research Institute’s Web site.

The majority of respondents gets their health information over the Internet, and first found out about the information center by conducting a search using an Internet search engine, such as Google, Yahoo, etc.

Study Question 3. Do information center customers find the responses effective?

Survey question 9 was designed to provide information to describe customers’ perceived effectiveness of their responses. A response of somewhat and yes was combined to measure degree of effectiveness. Results were as follows for question 9:

The response answered my question(s).	<i>Somewhat/Yes</i> 90.9% or 209
The response met my needs.	87.2% or 198
The response gave me new information.	86.8% or 197
The response gave me useful information.	94.3% or 215
The response was right for my personal situation.	86.3% or 195
The information specialist was knowledgeable.	88.4% or 199
The response gave me information I could trust.	93.4% or 212

Respondents thought the responses they received from the information center were effective (i.e., over 86% responded positively on each of the effectiveness questions).

Study Question 4. Are information center customers satisfied with their responses?

Survey questions 10, 12, 13, 14, 14a, 15 and 15a were designed to provide information to describe customers' perceived satisfaction with the responses they received. A response of somewhat and yes were combined to measure degree of satisfaction. Results were as follows for question 10:

	<i>Somewhat/Yes</i>
The response came within 5-10 business days.	93.9% or 216
The response was right for my reading level.	94.8% or 217
The response was clear and easy to understand.	96.5% or 220
The response had the right amount of information.	90.7% or 204
The response was easy to go through.	95.2% or 217
The response and/or information specialist was sensitive to my needs.	90.2% or 203
I was satisfied with the response I got.	92.5% or 211

Results for questions 12-15 were as follows:

- Seventy-three percent (72.9% or 167) of respondents indicated that they would definitely contact the information center again; 24.5% or 56 indicated that they would probably contact the information center again.
- Eighty percent (79.5% or 182) of respondents indicated they would definitely tell others to contact the information center; 17.5% or 40 indicated that they would probably tell others to contact the information center.
- Thirty-five respondents indicated that they had suggestions to improve the responses they received from the information center. Some suggestions were deemed not feasible given the mission, policies and procedures of the information center (e.g., give names of doctors who

treat the disease one is inquiring about, include my name on a list so others can contact me, provide a portal to talk to someone in several languages). The following suggestions were deemed feasible:

Suggestions pertaining to structure of the responses:

- “Be detail specific when giving user name and passwords and let people know that their responses are being answered by a person and not just automatic computer generated responses.”
- “Maybe have all of the Web sites within the same part of the page.”
- “When a question is sent by email have an automated response stating an answer will be coming in 2-10 days.”
- “The layout of the information was not consistent.”

Suggestions pertaining to readability of responses:

- “Perhaps query the user on what ‘level’ or ‘type’ of information is being sought. I was provided with very basic information that did not help at all.”
- “Most of it was way over my head & too many words to look up to understand it.”
- “While I understand that the information comes from medical journals or other medical sources, I would hope that there is a way to summarize the information into layman’s terms. I know this is time consuming, but it really would be helpful ...”

Suggestions pertaining to content of responses:

- “Consider that physicians know how to search in PubMed and OMIM; more information is needed about specialists or groups working on a rare disease or about family associations or data banks, etc.”
- “Provide even more articles to describe the disease in more detail.”
- “The e-mail response was abrupt and unfriendly ... the websites I was directed to were okay.”
- “The person who read my e-mail mistakenly said in their response to me that the waste in my research was from bird waste which is incorrect ...”
- “Read the questions submitted to you more carefully.”
- “Please clarify before suggesting that people contact you that no matter how detailed the information they send is, you will not be able to comment on specific treatment reoccurrence or anything other than general information that they more than likely...”
- “When trials are done think about the people who just missed it ... a summary.”
- “Maybe the information needs to be more personal in different cases.”
- “Make sure the Web addresses are up to date.”
- “Availability of all information in Spanish.”
- “Did not provide information beyond what I already had found.”
- Two respondents commented that they felt their questions were not answered/addressed in the response.
- Three respondents commented on their desire to have visuals/pictures/photos included in the responses.

Suggestions pertaining to function of the responses:

- “Make information Web site available for longer than 1 month.”

- “I need a little more time; there is so much and I want to read it all probably twice.”
- “Please do not set a time limit because when people are in need of information what they need most is time. I have an ill child that takes all my free time and therefore I do not have enough time to be on the Internet.”
- Forty-one respondents indicated that there were other services (in addition to responding to inquiries) that they would like to see the information center provide. Suggestions deemed feasible are identified with an **:
 - “Free Internet training”
 - “Library of further reading”
 - “Auto updated on health subjects by email”
 - “Continuing followup as new information becomes available”
 - “Database when possible to assist in educational planning for a child with rare chromosomal disorder”
 - “Wish service included connections with some researchers that are interested in improving quality of life/care for individuals living with rare, genetic diseases”
 - “If periodically there is a physician that can be reached, it is wonderful”
 - “Information as to how to submit new clinical information or new diagnosis of rare diseases to build wealth of knowledge at the GARD” **
 - “Have doctors in different specialties available to answer general questions”
 - “Keep me on a list for followup information”
 - “More info on diseases which come due to gene malfunctioning” **
 - “Pamphlets about physicians that treat those conditions”
 - “Patient information fact sheets” **

Many of the suggestions provided pertained to inquiry responses and not to additional services. Suggestions related to inquiry responses deemed feasible are identified with an **:

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- “Contact information for research trials.” **
- “Contacts to medical research groups.” **
- “Information & referral to practicing specialist.”
- “Information on how foreign patients can find treatment/consultation from experts in your organization/other organizations.” **
- “List of doctors and/or clinics who treat each disease.”
- “Referrals to providers for rare conditions.”
- “Provide contacts of other families with similar situation”
- “Spiritual something at this point.”
- “Help (filling out forms and transportation) for people with severe pain conditions.”
- “Treatments that were successful”
- Seventy-seven respondents provided other comments about the information center’s responses and services. The comments were positive and complimentary about the thoroughness, relevance, structure, accuracy, timeliness, validity, personalization and understandability of the responses. There were also comments that were positive and complimentary about the helpfulness, sincerity, motivation, professionalism, supportiveness, kindness, and friendliness of the information specialists. Other insightful comments were:
 - “I asked for information on what I have. I wanted a paper so I could understand more. I was told to go to a computer. I don’t own one, most seniors don’t.”

- “I would like to have the information (access to the information) available indefinitely ... not restricted to 30 days.”
- “I would like the information to be more comprehensive and concrete.”
- “Information should be clear, accurate and comprehensive to better people’s health”
- “Although the person I spoke with was helpful, I didn’t feel like the information she gave me was about my specific illness”
- “Impressed with variety and amount of very good information provided; really appreciated personal attention and information specific to my questions and problem”
- “I asked a specific question but never got a specific answer”
- “I couldn’t tell if the emails I got were automated or from a person. It took over a week to find out by your service that I had a password that I didn’t know how to use because it was a 0 instead of an O”
- “I liked receiving the information by e-mail; turn around time was faster than I expected”
- “If someone made it to your center, they are probably looking for more than what is currently available. Help patients be really knowledgeable about what questions they should be asking”
- “I was disappointed to receive basic information that I already knew about”
- “Thank you for being able to refer me to resources in Spanish or any other language”

Overall, respondents were very satisfied with the responses they received and very satisfied with the information specialists (for those who had direct contact with the information specialists). Over 90% of respondents provided positive responses on the satisfaction questions. The majority of respondents would definitely contact the information center again and would definitely tell others to contact the information center. Respondents provided insightful suggestions to improve the responses, for other services they would like to see the information center provide, and general comments about the information center’s responses and services. Those suggestions that were regarded as feasible, given the operating policies and procedures of the information center, are reflected in the Recommendations section of this report.

Study Question 5. What do customers do with the information they receive?

Survey question 11 was designed to provide information about what customers do with the information they receive from the information center. The results were as follows for question 11:

- Respondents most frequently indicated (53.5% or 123) that they have shared or plan to share the information with family members or friends.
- The statement with second highest frequency (46.5% or 107) was that respondents read (or discussed with the information specialist) the information and have made or plan to make contact with individuals and/or organizations given in the response.
- The statement with third highest frequency (41.3% or 95) was that respondents have shared or plan to share the information with their health care provider(s).

- The statement with fourth highest frequency (17.4% or 40) was that respondents read (or discussed with the information specialist) the information, but do not plan to do anything else with it.
- The statement with fifth highest frequency (15.7% or 36) was other. Responses included use of information for class, assignment or presentation.
- The statement with lowest frequency (9.1% or 21) was that respondents shared or plan to share the information with my patient(s).

Over 50% of respondents have shared or plan to share the information they received from the information center with family members or friends.

Limitations

The limitations of this evaluation were (1) The information center receives about 15 inquiries per day (i.e., low volume of inquiries as compared to other NIH information centers); (2) the information center receives about 2 to 4 Spanish inquiries per week; (3) up to 20% of Web-based responses sent by the information center are never opened despite follow-up e-mails (cause for this is unknown); (4) customers volunteered to participate in the evaluation; (5) customers were not given advance notice about the evaluation; (6) no incentives were offered for completing the survey; and (7) information center customers may be faced with stressful medical situations and/or with minimal time available. These limitations may have contributed to a lower response rate and/or to bias data.

Conclusions

Despite the limitations of the evaluation, a respectable response rate of 35.4% was achieved. The data did provide answers to the study questions. Additionally, the results of the final data analyses were consistent with the results from the pretest and interim data analyses. Therefore, there is the ability to make inferences from the evaluation sample to the larger population of information center customers.

Some evaluation experts would consider 35.4% a low response rate. The lower response rate in addition to the uncertainty about if there are differences between responders and non-responders may have introduced bias. Included in the pool of non-responders are domestic Spanish speaking customers and approximately 20% of customers who never open their personalized Web responses. Therefore, while there is the ability to make inferences from the evaluation sample to the larger population of information center customers, there is concern about bias and thus it is not with 100% confidence that the inferences are made.

I recommend that the NHGRI and ORD consider implementing the recommendations described below to address the possible bias and to ensure that the information center operates in the most cost effective manner while providing an effective, high quality service to the broadest possible audience.

Recommendations

Based on the results of the customer satisfaction survey, I make the following recommendations:

Ongoing Data Collection. To obtain a better understanding of non-responders, such as domestic Spanish-speaking customers and customers who never open their personalized Web based response, and to improve the effectiveness of the responses, I recommend getting the appropriate approvals to permit the information specialists to actively collect select data. This data could include level of education, role as inquirer (i.e., patient, family member, physician, etc.), accessibility to the Internet, and physical location (i.e., within or outside the United States). For telephone inquiries, the information specialist could gather this data at the time of the telephone contact. For e-mail inquiries, I suggest that this data be requested in a “reply” e-mail to the inquirer prior to development of the response. It should be stressed to the inquirer that this data is being requested to assist in the development of an effective response. In all cases, the response should be disseminated to the inquirer within 5-10 business days regardless if they provide the requested data and within a specified time period.

Outreach. For the information center to provide a service to the broadest possible audience, additional outreach activities will need to be implemented to increase awareness of the service among minority populations, such as African Americans, Asians, and domestic Hispanics or Latinos. I recommend the development and implementation of a communications plan that would identify, prioritize, and describe outreach activities aimed at reaching these groups. I recommend the use of focus groups and results from the demonstration project focused on mobilizing Latino communities around genetic information to assist in the development of the communications plan. The communications plan should be inclusive of activities aimed at reaching the minority populations where they are likely to congregate and seek medical care. Additionally, outreach activities should include ‘advertising’ the information center in newspapers, magazines, and on TV and radio programs that appeal to the respective groups. Survey data also indicated that health care providers (of all types) may be another audience that the information center may want to target and should be included in the communications plan.

As another means of outreach, I recommend the development and implementation of a GARD Information Center Web site. This recommendation is supported by the data, which indicated that the majority of information center customers usually get their health information from the computer and first found out about the information center by doing a Web site search. At this time, a Web site search does not bring an inquirer directly to the information center. An inquirer has to go through the NHGRI or ORD Web site to find the contact information for the information center. This is not the most effective or direct means of reaching an audience in need of information. I also recommend that increased efforts be made to contact appropriate organizations to request a link from their Web sites to the information center Web site.

Inquiry Responses. While the data support that information center customers do find the responses effective and are satisfied with their responses, I recommend the following to further improve the effectiveness and quality of the responses.

- Increase the length of time that the personalized, Web based response is available to the inquirer.

- In the Web based response, clarify that the information was researched and drafted by an experienced information specialist (i.e., the response was not generated by a computer).
- While the data indicated that the information center customers are highly educated (at least a college degree), not all of the customers are highly educated and those that are may not be well versed in medical terminology. I recommend that the information specialists “look” for clues about the inquirer’s educational level (e.g., grammar, punctuation, sentence structure) in the incoming inquiries and subsequently draft the response to the appropriate reading level. I also recommend that the information specialist query the inquirer about the level of information being sought (see Ongoing Data Collection above).
- Additional quality control measures should be implemented to ensure that the customers’ questions are being addressed.
- The data indicated that customers researched their questions prior to contacting the information center. Therefore, I recommend that information specialists minimize the inclusion of basic information, as a customer may have already found such information through independent research. Consideration should be given to reducing the amount of information provided in the response except for what is required to respond to the inquirer’s question. The information specialist should answer the inquirer’s question and then state that more information (e.g., clinical trials, advocacy groups) is available if desired. The inquirer should be instructed to contact the information center again if additional information is needed and/or be directed to the information center’s Web site for information about select topics (see Outreach above).
- Based on knowledge of the type of inquirer (e.g., health care provider), I recommend that the information specialists be selective about the type of information provided. For example, a health care provider is most likely to know about and may have already searched PubMed; therefore, providing information from a PubMed search may not be necessary.

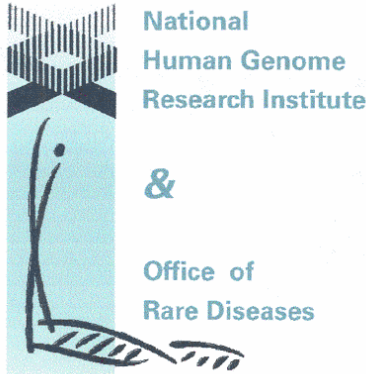
Additional Services. I recommend the development and implementation of an information center Web site (see Outreach above). The following additional services could be made available through this Web site:

- Availability of standard responses for conditions that are requested with high frequency. Some of these responses already have been developed and are available on NHGRI’s Web site. I recommend that the information center continue to develop these high frequency standard responses and make them available on an information center Web site, along with a “copy” of or link to what is already available on NHGRI’s Web site.
- Availability of patient information sheets. I recommend the development of patient information sheets that may be used in lieu of including certain types of information in responses. Some patient education sheets already have been developed and are available on NHGRI’s Web site. I recommend that the information center continue to develop new patient education sheets and make them available on the information center’s Web site, along with a “copy” of or link to what is already available on NHGRI’s Web site.

Evaluation. I recommend that the NHGRI and ORD conduct another customer satisfaction survey in approximately four years to again assess the level of satisfaction of information center customers and the profile of audiences seeking service from the information center. I suggest using the 2006 evaluation as baseline for any subsequent evaluation to help determine the

effectiveness of the implementation of any outreach activities, changes to the inquiry responses and additional services.

Appendix
English-language and Spanish-language Customer Satisfaction Survey



National
Human Genome
Research Institute

&

Office of
Rare Diseases

GENETIC AND RARE DISEASES INFORMATION CENTER

National Institutes of Health
Department of Health and Human Services

NHGRI/ORD Genetic and Rare Diseases Information Center (GARD) Customer Satisfaction Survey

Thank you for taking the time to take part in this survey. Information from this survey will be used to help us improve our responses and services to better meet your needs. No personal identifiers will be attached to your responses. Your answers will be kept confidential. Please review the response you received from the information center before completing the survey below.

Public reporting burden for this collection of information is estimated to average 17 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. **An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number.** Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0486). Do not return the completed form to this address.

The following questions will help us find out how individuals learn about the information center.

1. Where do you **usually** go to get health information? *(Select only one answer)*

- Computer (e.g., view information electronically on Web sites)
- Health care providers
- Family members
- Friends/co-workers/colleagues
- Library (e.g., view information in paper-copy from books, journals, etc.)
- Other *(specify)* _____

2. How did you **first** find out about the information center? *(Select only one answer)*

- Search engine (e.g., Google, Yahoo, etc.)
- National Human Genome Research Institute's Web site
- Office of Rare Diseases' Web site
- Another Web site *(specify)* _____
- Family member
- Friend/co-worker/colleague
- Health care provider
- Conference/meeting *(specify)* _____
- An organization *(specify)* _____
- Media (magazine, newspaper, television, radio)
- Other *(specify)* _____

The following questions will help us learn more about the individuals who contact the information center.

3. How many times have you contacted the information center in 2006? *(Select only one answer)*
- One time
 - Two times
 - Three or more times
4. How did you contact the information center most recently? *(Select only one answer)*
- Email
 - Fax
 - Letter
 - Phone
 - TTY (for the hearing impaired)
5. What country did you contact the information center from most recently? *(Select only one answer)*
- United States *(specify state)* _____
 - Other *(specify country)* _____
6. Which of the following best describes you when you contacted the information center most recently? *(Select only one answer)*
- Patient
 - Family or friend of patient
 - Physician
 - Nurse
 - Genetic Counselor
 - Other health care provider *(specify)* _____
 - Researcher/Scientist
 - Journalist/Media professional
 - Teacher or Professor/Educator
 - Student
 - Other *(specify)* _____
7. What type of information were you looking for when you contacted the information center most recently? *(Select all that apply)*
- Alternative therapies
 - Diagnosis for symptoms
 - Career
 - Genetic services referral
 - Clinical/genetic testing
 - Insurance/reimbursement
 - Lay advocacy group
 - Legal/financial
 - Newborn screening
 - Physician referral
 - Research study
 - Specific disease or condition
 - Treatment/medical care
 - Other *(specify)* _____
-
-
-

8. Did you research your question before contacting the information center most recently (e.g., on Web sites, with your health care providers, etc.)? *(Select only one answer)*
- Yes
 No

Answers to the following statements will help us learn about what individuals think of the responses they received from the information center.

9. Please select one answer for each statement below.

	<u>No</u>	<u>Somewhat</u>	<u>Yes</u>	<u>Not Applicable</u>
a. The response answered my question(s).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. The response met my needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. The response gave me new information.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. The response gave me useful information.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. The response was right for my personal situation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. The Information Specialist was knowledgeable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. The response gave me information I could trust.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Answers to the following statements and questions will help us learn about individuals' satisfaction with the responses they received from the information center.

10. Please select one answer for each statement below.

	<u>No</u>	<u>Somewhat</u>	<u>Yes</u>	<u>Not Applicable</u>
a. The response came within 5-10 business days.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. The response was right for my reading level.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. The response was clear and easy to understand.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. The response had the right amount of information.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. The response was easy to go through.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. The response and/or Information Specialist was/were sensitive to my needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. I was satisfied with the response I got.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11. Please tell us what you did or plan to do with the information you got from the information center. *(Select all that apply)*

- I read (or discussed with the Information Specialist) the information (including looking at Web sites and other sources of information given in the response), but do not plan to do anything else with it.
- I read (or discussed with the Information Specialist) the information and have made or plan to make contact with individuals and/or organizations given in the response.
- I have shared or plan to share the information with my health care provider(s).
- I have shared or plan to share the information with my patient(s).
- I have shared or plan to share the information with family members or friends.
- Other *(specify)* _____
-
-

12. Would you contact the information center again? *(Select only one answer)*

- Definitely Yes
- Probably Yes
- Probably No
- Definitely No

13. Would you tell others to contact the information center? *(Select only one answer)*

- Definitely Yes
- Probably Yes
- Probably No
- Definitely No

14. Do you have suggestions that would improve the response you got from the information center? *(Select only one answer)*

- Yes
- No

14a. If yes, what suggestions do you have?

15. Are there other services (in addition to responding to inquiries) that you would like to see the information center provide? *(Select only one answer)*

- Yes
- No

15a. If yes, what services would you like to see?

16. Other comments about the information center's responses and services?

These last questions will help us know a little bit more about the individuals like you who contact the information center so that we can better meet your needs.

17. What is your gender? *(Select only one answer)*

- Female
- Male

18. What is your age? *(Select only one answer)*

- 20 or under
- 21-30
- 31-40
- 41-50
- 51-60
- 61-70
- 71 or over

19. What is your ethnicity and race?

I do not wish to provide this information.

a. Ethnicity: *(Select only one answer)*

- Hispanic or Latino
- Not Hispanic or Latino

b. Race: *(select all that apply)*

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White

20. What language do you prefer to speak? *(Select only one answer)*

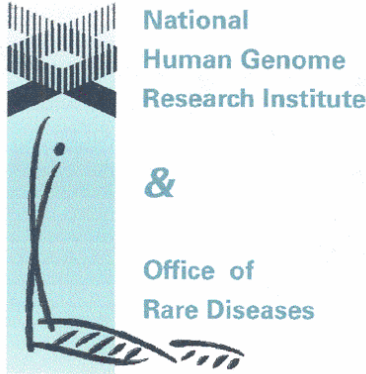
- English
- Spanish
- Other *(specify)* _____

21. What is the highest level of education you have completed? *(select one)*

- Grade school
- Some high school
- High school graduate
- Some college
- College graduate
- Post-graduate

Thank you for your time today. If you have any questions about this survey, please contact the Survey Operations Center at 1-800-441-7080.

Please return your completed customer satisfaction survey in the enclosed envelope to:
GARD Information Center Customer Satisfaction Survey
2277 Research Boulevard, MS 6Y
Rockville, MD 20850-3166



National
Human Genome
Research Institute

&

Office of
Rare Diseases

Formulario Aprobado
OMB No. 0925-0476
Caduca: 5/30/06

GENETIC AND RARE DISEASES INFORMATION CENTER

National Institutes of Health
Department of Health and Human Services

NHGRI/ORD Centro de Información Sobre enfermedades Genéticas y Raras (GARD)

Encuesta sobre satisfacción del cliente

Gracias por participar en esta encuesta. La información recopilada aquí se utilizará en mejorar nuestras respuestas y servicios para así brindarles un mejor servicio. Sus respuestas no contienen ningún código con el que pueda identificársele personalmente, las respuestas son estrictamente confidenciales y por tanto su identidad no será revelada. Por favor revise las respuestas que recibió del centro de información antes de completar esta encuesta.

La carga implícita de tiempo, para la recopilación de esta información se estima en un promedio de 17 minutos por encuesta, incluyendo el tiempo que toma en revisar las instrucciones, buscar recursos de datos y recopilar y mantener los datos necesarios además de completar y revisar la recopilación de la información. **Una agencia no debería llevar a cabo o patrocinar, así como una persona no está obligada a responder un formulario con el fin de recabar información, a menos que despliegue un número actualizado de control OMB válido.** Envíe sus comentarios en relación a este estimado de carga o cualquier otro aspecto de esta recopilación de información o sus sugerencias para reducir la carga que implica llenar esta encuesta al NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0476). Una vez lleno, No devuelva el formulario a esta dirección.

Las siguientes preguntas nos ayudarán a identificar cómo las personas se enteran sobre el centro de información.

1. ¿De dónde obtiene usted **generalmente** información sobre asuntos de salud? (*seleccione una*)

- Computadora (por ejemplo revisando páginas de Internet)
- De parte de sus proveedores de atención médica
- De parte de familiares
- De parte de amigos, compañeros de trabajo o colegas
- Bibliotecas (por ejemplo, en forma de folletos, revistas, fotocopias etc.)
- Otros medios (*especifique*) _____

2. ¿Cómo se enteró de la existencia del centro de información? (*seleccione una*)

- Motor de búsqueda electrónico (como Google, Yahoo, etc.)
- A través de la página de Internet del Instituto Nacional para la Investigación del Genoma Humano
- A través de la página de Internet de la Oficina sobre Enfermedades Raras
- Alguna otra página de Internet (*especifique*) _____
- De parte de familiares
- De parte de amigos, compañeros de trabajo o colegas
- De parte de sus proveedores de atención médica
- Conferencias o reuniones (*especifique*) _____
- A través de una organización (*especifíquela*) _____
- Medios de información (revistas, periódicos, televisión, radio)
- Otros medios (*especifique*) _____

Las siguientes preguntas nos ayudarán a identificar el tipo de persona que se comunica con el centro de información.

3. ¿Cuántas veces se comunicó con el centro de información durante el año 2006? (*seleccione una*)
- Una vez
 - Dos veces
 - Tres veces o más
4. ¿De qué forma se comunicó con el centro de información la última vez? (*seleccione una*)
- Correo electrónico
 - Fax
 - Carta
 - Teléfono
 - TTY (para personas con problemas auditivos)
5. ¿Desde que país se comunicó con el centro de información la última vez? (*seleccione uno*)
- Estados Unidos de Norteamérica (*especifique el estado*) _____
 - Otro país (*especifique el país*) _____
6. ¿Cuál de estas categorías lo describe mejor, la última vez que usted se comunicó con el centro de información?
- Paciente
 - Familiar o amigo de un paciente
 - Médico
 - Enfermera(o)
 - Consejero en genética
 - Otro tipo de profesional de la salud (*especifique*) _____
 - Investigador o científico
 - Periodista o profesional de un medio de comunicación
 - Maestro, profesor o educador
 - Estudiante
 - Otra categoría (*especifique*) _____
7. ¿Qué tipo de información estaba buscando la última vez que se comunicó con el centro de información? (*seleccione todos los puntos que correspondan*)
- Terapias alternativas
 - Diagnóstico de síntomas
 - Carrera profesional
 - Diferidos (recibir nombres o lugares en donde obtener) servicios genéticos
 - Pruebas clínicas o genéticas
 - Seguros y reembolsos
 - Organización activista popular
 - Legal o financiero
 - Exámenes de detección para recién nacidos
 - Diferidos (recibir nombres o lugares en donde obtener) servicio médicos
 - Estudios de investigación
 - Enfermedad o trastorno específico.
 - Tratamiento o atención médica
 - Otro (*especifique*) _____
-
-
-

8. ¿Hizo usted primero alguna investigación sobre su pregunta antes de comunicarse con el centro de información? (por ejemplo visitó páginas de Internet, habló con su proveedor de atención médica etc.) (*seleccione una*)

- Sí
 No

El contestar los siguientes puntos nos ayudará a saber lo que las personas piensan sobre las respuestas que recibieron del centro de información.

9. Por favor seleccione una respuesta por cada punto siguiente.

	<u>No</u>	<u>Más o menos</u>	<u>Sí</u>	<u>No corresponde</u>
a. La respuesta que obtuve contestó a mis preguntas.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. La respuesta era lo que yo necesitaba.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. La respuesta me proporcionó nueva información.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. La respuesta me proporcionó información útil.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. La respuesta era justo lo que necesitaba en mi situación específica.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. El Especialista en información era una persona bien informada.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. La respuesta me proporcionó información confiable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

El contestar los siguientes puntos nos ayudará a entender su grado de satisfacción con las respuestas del centro de información.

10. Por favor seleccione una respuesta por cada uno de los siguientes puntos.

	<u>No</u>	<u>Más o menos</u>	<u>Sí</u>	<u>No corresponde</u>
a. La respuesta llegó en un plazo de 5 a 10 días laborables.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. La respuesta estuvo acorde con mi nivel de lectura.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. La respuesta fue clara y fácil de entender.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. La respuesta incluyó la cantidad correcta de información.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. La información fue fácil de examinar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Tanto la respuesta como la persona Especialista en información se mostró sensible a mis necesidades.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Estuve satisfecho(a) con la respuesta que me proporcionaron.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11. Por favor díganos lo que hizo o piensa hacer con la información que obtuvo de GARD. (*seleccione todos los puntos que correspondan*)

- Leí (o consulté con un especialista en información) toda la información (incluso revisé las páginas de Internet y otros recursos incluidos en su respuesta) pero no planeo hacer nada más con la misma.
- Leí (o consulté con un especialista en información) toda la información y ya me comuniqué o tengo planes de comunicarme con los individuos u organizaciones mencionados en su respuesta.
- Ya compartí o tengo planes de compartir la información con mis proveedores de atención médica.
- Ya compartí o tengo planes de compartir esta información con mis pacientes.
- Ya compartí o tengo planes de compartir esta información con familiares o amigos.
- Otros planes (*especifique*) _____
-
-

12. ¿Utilizaría los servicios del centro de información de nuevo? (*seleccione uno*)

- Definitivamente que sí
- Probablemente sí
- Probablemente no
- Definitivamente no

13. ¿Les aconsejaría a otras personas utilizar los servicio del centro de información? (*seleccione uno*)

- Definitivamente que sí
- Probablemente sí
- Probablemente no
- Definitivamente no

14. ¿Tienes alguna sugerencia que nos indicaría como mejorar nuestros servicios? (*seleccione una*)

- Sí
- No

14a. De er sí, díganos su sugerencia

15. ¿Existen otros servicios (además de responder sus preguntas) que le gustaría que el centro de información le provea? (*seleccione uno*)

- Sí
- No

15a. De ser sí, ¿Qué otros servicios le gustaría que ofreciéramos?

16. ¿Algún otro comentario sobre las respuestas o servicios del centro de información?

Estas últimas preguntas nos ayudarán a conocer un poquito más sobre el tipo de persona como usted que se comunica con el centro de información para así poder servirle mejor.

17. ¿Cuál es su género, es usted? (*seleccione uno*)

- Mujer
- Hombre

18. ¿Qué edad usted tiene? (*seleccione una*)

- Menos de 20
- De 21 a 30
- De 31 a 40
- De 41 a 50
- De 51 a 60
- De 61 a 70
- Más de 71

19. ¿A qué grupo étnico o raza pertenece?

No deseo dar esta información.

a. Grupo étnico: *(seleccione una)*

Hispano o latino

No es hispano ni latino

b. Raza *(seleccione las que correspondan)*

Indio estadounidense o nativo de Alaska

Asiático

Negro o estadounidense afroamericano

Nativo de Hawai u otra isla del Pacífico

Blanco

20. ¿Cuál idioma prefiere hablar? *(seleccione uno)*

Inglés

Español

Otro *(especifique)* _____

21. ¿Seleccione el grado de enseñanza más alto que completó? *(seleccione uno)*

Enseñanza primaria

Una parte de la enseñanza secundaria

Completé la enseñanza secundaria

Algunos cursos universitarios

Graduado universitario

Estudios de posgrado

Gracias por prestarnos su atención. Si tiene alguna pregunta sobre esta encuesta, favor de comunicarse con el Centro de Operaciones de la Encuesta al 1-800-441-7080.

Una vez termine de completar la encuesta sobre satisfacción del cliente, favor de devolverla en el sobre que le incluimos a:

GARD Information Center Customer Satisfaction Survey

2277 Research Boulevard, MS 6Y

Rockville, MD 20850-3166