

Attachment C: English Survey

Survey Instrument

//remove stop button for web instrument//
//insert gard survey banner//

[Landing Page]

**National Institutes of Health, National Center for Advancing Translational Sciences -
Office of Rare Diseases Research and National Human Genome Research Institute
Genetic and Rare Diseases (GARD) Information Center
Customer Satisfaction Survey**

BURDEN DISCLOSURE STATEMENT:

Public reporting burden for this collection of information is estimated to average 10 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 (0925-0648). Do not return the completed form to this address.

//Ask All//
//required response//

Lang_1. Please select your preferred language:

1. English
2. Spanish

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**National Institutes of Health, National Center for Advancing Translational Sciences -
Office of Rare Diseases Research and National Human Genome Research Institute
Genetic and Rare Diseases (GARD) Information Center
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 inquiry responses to better meet your needs. No personal identifiers will be attached to your survey responses. Your answers will be kept confidential.

Instructions:

Please read the following instructions before beginning this survey.

MOVING FORWARD:

Click on the NEXT button located at the bottom of the page to save your responses and continue to the next page.

MOVING BACK:

Use the PREVIOUS button located at the bottom of the page to view your responses on a previous page. You may change your answers to previously entered responses.

Do not use the BACK button of your browser to return to the previous page. Using your browser's BACK button may cause you to exit the survey, and your responses will be lost.

If you experience any questions about the GARD Information Center Customer Satisfaction Survey, please contact the Help Desk at 1-888-205-2311 Monday-Friday, 9:00am - 8:00pm EST or email [the GARD Information Center INFO@NIH.GOV](mailto:theGARDInformationCenterINFO@NIH.GOV) //hyperlink//.

If you experience any technical issues accessing this survey, please contact a technical support specialist at 1-301-407-6652.

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//Ask all//

//single response//

//*88 = NO ANSWER (HIDDEN)//

Q1. How did you first find out about the GARD Information Center? (select one)

1. Search engine (e.g., Google, Yahoo, etc.)
2. National Center for Advancing Translation Science (NCATS)/Office of Rare Diseases Research (ORDR) website
3. National Human Genome Research Institute (NHGRI) website
4. Other website (*specify*)[Q1_web_other] _____ // **DO NOT FORCE SPECIFY RESPONSE**//
5. Family member
6. Friend/co-worker/colleague
7. Health care provider
8. Conference/meeting (*specify*) [Q1_conf_other] _____ // **DO NOT FORCE SPECIFY RESPONSE**//

9. An organization (*specify*) [Q1_org_other] _____ // **DO NOT FORCE SPECIFY RESPONSE**//
10. Media (magazine, newspaper, television, radio)
11. Other (*specify*) [Q1_other] _____ // **FORCE SPECIFY RESPONSE**//

//Ask all//

//*88 = NO ANSWER (HIDDEN)//

//RANGE 0-1000//

Q2. How many times did you use the GARD Information Center to obtain information in 2013?

//**REQUIRE WHOLE NUMBER DURING VALIDATION; Display text "Please provide a whole number"**//

//Ask all//

//*88 = NO ANSWER (HIDDEN)//

//RANGE 0-1000//

Q3. How many times have you used the GARD Information Center to obtain information in 2014,

including your most recent effort? //**REQUIRE WHOLE NUMBER DURING VALIDATION; Display text "Please provide a whole number"**//

-----//**PAGE BREAK**//

//Ask all//

//single response//

//*88 = NO ANSWER (HIDDEN)//

The following questions refer to your most recent interaction with the GARD Information Center (e.g. Q&A website, contact with the GARD Information Center information specialist through email, telephone, fax, etc.).

Q4. Which of the following best describes you during your most recent effort to obtain information from the GARD Information Center? (*select one*)

1. Patient
2. Family or friend of patient
3. Physician
4. Nurse
5. Genetic Counselor
6. Other health care provider or allied health professional (*specify*) [Q4_provider_oth] _____ // **DO NOT FORCE SPECIFY RESPONSE**//
7. Researcher/Scientist
8. Journalist/Media professional
9. Teacher or Professor/Educator
10. Student
11. Other (*specify*) [Q4_other] _____ // **FORCE SPECIFY RESPONSE**//

//Ask all//

//multiple response//

//*88 = NO ANSWER (HIDDEN)//

Q5. What type of information were you trying to obtain? *(select all that apply)*

1. Alternative therapies
2. Clinical/genetic testings
3. Diagnosis for symptoms
4. Genetic services
5. Insurance
6. Lay advocacy group/Patient support organization
7. Legal/financial
8. Newborn screening
9. Physician/Specialist information
10. Research study/clinical trial
11. Specific disease or condition
12. Treatment/medical care
13. Other *(specify)* [Q5_other] _____ // **FORCE SPECIFY RESPONSE**//

//Ask all//

//single response//

//*88 = NO ANSWER (HIDDEN)//

Q6. Did you try to obtain or obtain information from another source before using the GARD Information Center? *(select one)*

1. Yes
2. No

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//Ask if Q6 = 1 or Q6 = No Answer//

//multiple response//

//*88 = NO ANSWER (HIDDEN)//

Q7. Where did you do your research/get your information before using the GARD Information Center? *(select all that apply)*

1. Website *(specify)* [Q7_web_oth] _____ // **DO NOT FORCE SPECIFY RESPONSE**//
2. Organization *(specify)* [Q7_org_oth] _____ // **DO NOT FORCE SPECIFY RESPONSE**//
3. Physician, nurse, or other health care provider/professional

4. Genetic counselor
5. Family member/friend/co-worker/colleague
6. Other (*specify*) [Q7_other] _____ // **FORCE SPECIFY RESPONSE**//

//Ask if Q6 = 1 or Q6 = No Answer//

//single response//

//*88 = NO ANSWER (HIDDEN)//

Q8. Overall, how satisfied were you with the information you received from those sources? (*select one*)

1. Not at all satisfied
2. Somewhat dissatisfied
3. Neither satisfied nor dissatisfied
4. Somewhat satisfied
5. Completely satisfied

//Ask if Q6 = 1 or Q6 = No Answer //

//multiple response//

//*88 = NO ANSWER (HIDDEN)//

Q9. Why did you use the GARD Information Center after researching your question/getting information from other sources? (*select all that apply*)

1. For more information
2. For more in-depth information about a specific topic (e.g., treatment options, testing centers)
3. For different information than I already had
4. To talk to an information specialist
5. Other (*specify*) [Q9_other] _____ // **FORCE SPECIFY RESPONSE**//

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//Ask all//

//single response//

//*88 = NO ANSWER (HIDDEN)//

Q10. Did you review a Q&A on the GARD website to get information you were looking for? (*select one*)

1. Yes
2. No

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//Ask if Q10 = 2 or Q10 = No Answer //

//single response//

//*88 = NO ANSWER (HIDDEN)//

Q11. How did you get the information you were looking for from the GARD Information Center? (*select one*)

1. I received a response by email after submitting the online email form located on the GARD website. (go to Q14)
2. I received a response by email after submitting a general email to GARD. (go to Q14)
3. I spoke to a GARD information specialist. (go to Q15)
4. I received a letter by regular mail or fax. (go to Q14)
5. I received a response by TTY (telecommunication device for the deaf). (go to Q14)

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//Ask if Q10 = 1//

//single response//

//*88 = NO ANSWER (HIDDEN)//

Q12. Please tell us what you think about the information you were provided on the GARD Information Center Q&A. (select one answer for each statement)

The information...

	<u>Not at all</u>	<u>Somewhat</u>	<u>Very much</u>	<u>Completely</u>
1. ...answered my question(s).	1	2	3	4
2. ...gave me new information.	1	2	3	4
3. ...gave me useful information.	1	2	3	4
4. ...gave me information I could trust.	1	2	3	4
5. ...met my needs.	1	2	3	4
6. ...was right for my personal situation.	1	2	3	4
7. ...was easy for me to read.	1	2	3	4
8. ...was easy to understand.	1	2	3	4
9. ...had the right amount of information.	1	2	3	4
10. ...was easy to go through.	1	2	3	4

//Ask if Q10 = 1//

//single response//

//*88 = NO ANSWER (HIDDEN)//

Q13. Did you contact the GARD Information Center in addition to reviewing a Q&A? (select one)

1. No
2. Yes, I submitted the online email form located on the GARD Information Center website.
3. Yes, I sent a general email.
4. Yes, I called and spoke to a GARD information specialist.
5. Yes, I sent a letter by regular mail or fax.

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//Ask if Q11 = (1,2,4, 5) or if Q13 = (2,3,5)//

//single response//

/**88 = NO ANSWER (HIDDEN)**

Q14. Please tell us what you think about the information you received in the response. (select one answer for each statement)

The information...

	<u>Not at all</u>	<u>Somewhat</u>	<u>Very much</u>	<u>Completely</u>
1. ...answered my question(s).	1	2	3	4
2. ...gave me new information.	1	2	3	4
3. ...gave me useful information.	1	2	3	4
4. ...gave me information I could trust.	1	2	3	4
5. ...met my needs.	1	2	3	4
6. ...was right for my personal situation.	1	2	3	4
7. ...was easy for me to read.	1	2	3	4
8. ...was easy to understand.	1	2	3	4
9. ...had the right amount of information.	1	2	3	4
10. ...was easy to go through.	1	2	3	4
11. ...came within a reasonable time.	1	2	3	4

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//Ask if Q11 = 3 or if Q13 = 4//

//single response//

/**88 = NO ANSWER (HIDDEN)**

Q15. Please tell us what you think about the information you received over the phone. (select one answer for each statement)

The information specialist...

	<u>Not at all</u>	<u>Somewhat</u>	<u>Very much</u>	<u>Completely</u>
1. ...answered my question(s).	1	2	3	4
2. ...gave new information.	1	2	3	4
3. ...gave useful information.	1	2	3	4
4. ...gave information I could trust.	1	2	3	4
5. ...gave information that met my needs.	1	2	3	4
6. ...gave information right for my personal situation.	1	2	3	4
7. ...gave information that was easy to understand.	1	2	3	4
8. ...gave the right amount of information.	1	2	3	4
9. ...was informative.	1	2	3	4
10. ...was sensitive to my needs.	1	2	3	4

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//Ask all//

//multiple response//

/**88 = NO ANSWER (HIDDEN)**

Q16. What did or do you plan to do with the information you received from the GARD Information Center? (select all that apply)

1. Review it, but do not do anything else with it. //exclusive response; once selected other options are no longer selectable and any previous markings in these boxes are removed//
2. Make contact with individuals and/or organizations identified.
3. Share the information with my health care provider(s).
4. Share the information with my patient(s).
5. Share the information with family members or friends.
6. Other (specify) [Q16_other] _____// **FORCE SPECIFY RESPONSE**//

//Ask all//

//single response//

//*88 = NO ANSWER (HIDDEN)//

Q17. Overall, how satisfied were you with the GARD Information Center? (select one)

1. Not at all satisfied
2. Somewhat dissatisfied
3. Neither satisfied nor dissatisfied
4. Somewhat satisfied
5. Completely satisfied

//Ask all//

//single response//

//*88 = NO ANSWER (HIDDEN)//

Q18. How likely are you to use the GARD Information Center again if you have a question related to a genetic or rare disease? (select one)

1. Not at all
2. Unlikely
3. Likely
4. Definitely

//Ask all//

//max characters 5000//

Q19. Please provide any suggestions that you feel would improve the information you received from the GARD Information Center.

//Ask all//

//max characters 5000//

Q20. Please provide any additional comments about the GARD Information Center.

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We'd like to know a little more about individuals like you who use the GARD Information Center so that we can better meet your needs.

//Ask all//

//single response//

//*88 = NO ANSWER (HIDDEN)//

Q21. Do you currently reside in the United States? *(select one)*

1. Yes *(specify state)* [Q21_state] _____ // **DO NOT FORCE SPECIFY RESPONSE//**
2. No *(specify country where you reside)* [Q21_country] _____ // **DO NOT FORCE SPECIFY RESPONSE//**

//Ask all//

//single response//

//*88 = NO ANSWER (HIDDEN)//

Q22. Which of the following best describes the area you live in? *(select one)*

1. Urban
2. Suburban
3. Rural

//Ask all//

//single response//

//*88 = NO ANSWER (HIDDEN)//

Q23. What language do you prefer to speak? *(select one)*

1. English
2. Spanish
3. Other *(specify)* [Q23_other] _____ // **FORCE SPECIFY RESPONSE//**

//Ask all//

//single response//

//*88 = NO ANSWER (HIDDEN)//

Q24. What language do you prefer for written materials? *(select one)*

1. English
2. Spanish
3. Other *(specify)* [Q24_other] _____ // **FORCE SPECIFY RESPONSE//**

//Ask all//

//single response//

//*88 = NO ANSWER (HIDDEN)//

Q25. What is your gender? *(select one)*

1. Female
2. Male

//Ask all//

//single response//

//*88 = NO ANSWER (HIDDEN)//

Q26. What is your age? *(select one)*

1. 20 or under
2. 21-30
3. 31-40
4. 41-50
5. 51-60
6. 61-70
7. 71 or over

//Ask all//

//single response//

//*88 = NO ANSWER (HIDDEN)//

Q27. What is the highest level of education you have completed? *(select one)*

1. Less than high school
2. Some high school
3. High school diploma or equivalent
4. Some college, no degree
5. Postsecondary non-degree award
6. Associate's degree
7. Bachelor's degree
8. Master's Degree
9. Doctoral or professional degree

//Ask all//

//single response//

//*88 = NO ANSWER (HIDDEN)//

Q28. What is your ethnicity? *(select one)*

1. Hispanic or Latino
2. Not Hispanic or Latino

//Ask all//

//multiple response//

//*88 = NO ANSWER (HIDDEN)//

Q29. What is your race? *(select all that apply)*

1. American Indian or Alaska Native
2. Asian
3. Black or African American
4. Native Hawaiian or Other Pacific Islander
5. White

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Thank you for your time today. If you have any questions about this survey, please contact the Help Desk at 1-888-205-2311 or the GARD Information Center INFO@NIH.GOV //hyperlink//.