

Tools: Sample Contact & Demographic Questions

This tool provides sample questions you might include on your registry data collection form. Also indicated is the question format for each question and whether answering the question should be required. Note that these sample questions and answers were developed using data standards established by the [Clinical Data Interchange Standards Consortium \(CDISC\)](#) and [United States Core Data for Interoperability \(USCDI\)](#).

Section I. Patient & Contact Information			
Field #	Question Format	Question (*= required)	Answers
1	Checkboxes	What is your relationship to the patient(s) living with the rare disease? *	I am the patient. I am the parent/legal guardian/caregiver of the patient. I am related by blood to at least 2 patients who have a RD but I do not have the RD.
2	Short Answer	Patient's first name*	
3	Short Answer	Patient's middle name	
4	Short Answer	Patient's last name*	
5	Calendar	Patient's date of birth*	
<i>Insert the description below for questions 6-8.</i>			
If you are filling the form for the patient, please fill in YOUR information below.			
6	Short Answer	First Name	
7	Short Answer	Middle Name	
8	Short Answer	Last Name	
<i>Insert the description below for questions 9-16.</i>			
If you are the patient, enter your information below. If you are the patient's parent/legal guardian/caretaker, enter YOUR information below.			
9	Short Answer	Street address	
10	Dropdown	City	
11	Dropdown	State/Province	
12	Short Answer	ZIP code or postal code	
13	Short Answer	Country	
14	Short Answer	Email*	
15	Short Answer	Confirm email*	
16	Short Answer	Telephone number*	
Section II. Permissions			

17	Checkboxes	May we contact you about (select all that apply):	News and events
			Disease-related or research news
			Future research trials
Section III. Patient Demographic Information (OPTIONAL SECTION)			
Field #	Question Format	Question	Answers
18	Multiple Choice	Sex: What is the patient's sex?	Male
			Female
			Unknown
19	Multiple Choice	Ethnicity: Is the patient of Hispanic, Latino/a, or Spanish origin?	Yes
			No
20	Checkboxes	Race: What is the patient's race? (Select all that apply.)	American Indian or Alaska Native
			Asian
			Black or African American
			Native Hawaiian or Pacific Islander
			White
			Other: (please specify)
21	Multiple Choice	Primary Language: How well do you speak English?	Very well
			Well
			Not well
			Not at all
Section IV. Diagnosis (OPTIONAL SECTION)			
<i>Note: Be selective about the questions you decide to include in your form. Too many questions can dissuade people from completing the form and joining your registry.</i>			
22	Checkboxes	How was the patient diagnosed (select all that apply)?	<i>Create a list of the tests and procedures used to diagnose the disease (e.g., clinical evaluation, laboratory tests, imaging tests, or diagnostic procedures).</i>
23	Short Answer	At what age was the patient diagnosed?	
24	Short Answer	What is the name of the doctor who diagnosed the patient?	
25	Dropdown	What is the medical specialty of the doctor who made the diagnosis?	<i>Create a dropdown menu containing the names of different types of medical specialists. For examples of some of the different types of medical specialists, see Types of health care providers page from MedlinePlus.</i>
26	Short Answer	Name of medical center, practice, or hospital where patient was diagnosed?	