Data Dictionary Codebook

Assessing the financial burden of genetic testing (PID: 10283)

03/13/2025 10:34am

Instruments		
Instrument	Form Name	
Consent	consent	
Demographics	demographics	
Genetic Testing	genetic_testing	
Utility	utility	
Thank you	thank_you	

#	Variable / Field Name	Field Label Field Note	Field Attributes (Field Type, Validation, Choices, Calculations, etc.)
Instrun	nent: Consent (co	ensent) 🛂 Enabled as survey	,
1	[record_id]	Record ID	text
2	[consent]	Assessing the Financial Burden of Genetic Testing: a patient survey	yesno 1 Yes
		By selecting "yes" to the right, you will proceed to the survey and consent to the study. By selecting "no" you will not continue to the survey.	0 No
		The purpose of this research study is to assess patient experiences and attitudes toward genetic testing. We are doing this study because we hope to improve future genetic counseling session for patients or the parents or guardians of patients who are minors who pursue genetic testing.	
		I would like to ask you to complete this online questionnaire. The risks associated with this study are potential feelings of sadness, anger, frustration, and guilt. We hope the information from you will help patients make better decisions about genetic testing even if there is no direct benefit to you.	
		If you have any questions complaints or if you feel you have been harmed by this research please contact Katelyn Swade, genetic counseling student at the University of Utah, at katelyn.swade@utah.edu.	

Contact the Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at irb@hsc.utah.edu.

It should take 15-20 minutes to complete this study. Participation in this study is voluntary. You can choose not to take part. You can choose not to finish the questionnaire or omit any question you prefer not to answer without penalty or loss of benefits. By returning this questionnaire, you are giving your consent and authorization to participate and allow us to use information from your medical record, as described below.

AUTHORIZATION FOR USE OF YOUR PROTECTED HEALTH INFORMATION

Agreeing to this document means you allow us, the researchers in this study, and others working with us to use some information about your health for this research study.

This is the information we will use and include in our research records:

- Name
- Address
- Telephone number
- Family medical history
- You and your child's personal health information including prior medical history, tests or records. How we will protect and share your

information:

- Study information will be kept in a secured manner and electronic records will be password protected.
- In order to conduct this study and make sure it is conducted as described in this form, the research records may be used and reviewed by others who are working with us on this research:
- o Members of the research team and authorized members of the University of Utah and Primary Children's Hospital

Assessing the financial burden of genetic testing | REDCap o The University of Utah Institutional Review Board (IRB), who reviews research involving people to make sure the study protects your rights; • If we share your information with groups outside of University of Utah or Primary Children's Hospital we will not share your name or identifying information. We will label your information with a code number, so they will not know your identity. • If you do not want us to use information about your health, you should not be part of this research. If you choose not to participate, you can still receive health care services at University of Utah and Primary Children's Hospital. What if I decide to Not Participate after I agree to the Consent and Authorization Form? You can tell us anytime that you do not want to be in this study and do not want us to use your health information. You can also tell us in writing. If you change your mind, we will not be able to collect new information about you, and you will be withdrawn from the research study. However, we can continue to use information we have already started to use in our research, as needed to maintain the integrity of the research. This authorization does not have an expiration date. You have a right to information used to make decisions about your health care. However, your information from this study will not be available during the study; it will be available after the study is finished. Your participation in this study is greatly appreciated. Section Header: Form Status dropdown

3 [consent_complete]

Complete?

0 Incomplete
1 Unverified

			2 Complete
strum	ent: Demographics	G (demographics) 🛂 Enabled as surv	rey
4	[filling_for]	Section Header: This questionnaire is about genetic testing you received from Intermountain Health system/Primary Children's Hospital. We want to know how we are doing in meeting your healthcare needs. Section 1: Demographics The following questions will ask questions about you. You do not need to answer questions you don't feel comfortable answering. Are you filling this survey out for:	radio, Required 1 You as the patient 2 Your spouse or partner as the patient 3 Your child as the patient 4 Other 5 Prefer not to answer
5	[filling_for_child] Show the field ONLY if: [filling_for] = '3'	What is your relationship to the child who received genetic testing?:	radio, Required 1 Parent 2 Legal guardian, but not parent 3 Foster parent 4 Other 5 Prefer not to answer
6	[filling_for_child_ other] Show the field ONLY if: [filling_for] = '3' and [f illing_for_child] = '4'	other:	text
7	<pre>[filling_for_other] Show the field ONLY if: [filling_for] = '4'</pre>	other:	text
8	<pre>[patient_name]</pre>	Name of the patient: Note: Patient name will be used to view the patient's medical record information regarding genetic testing. Information from this survey will not be entered into the patient's medical record and will not be available to anyone but the PI and research team.	text, Identifier
9	[sex]	Sex of the patient	dropdown (autocomplete), Required 1 Male 2 Female 3 Other 4 Prefer not to answer
10	[sex_other]	other:	text

[sex] = '3'		
11 [age]	Age of the patient:	text (number), Required
12 [state]	State of residence of the patient:	text, Required
13 [race]	Race/ ethnicity of the patient:	checkbox, Required
		1 race1 African-American/ Black
		2 race2 Asian/ Pacific Islander
		3 race3 Hispanic/Latino
		4 race4 Native American/ American Indian
		5 race5 Caucasian/ White
		6 race6 Not listed
		7 race7 Prefer not to answer
14 [race_not_lis	ted] not listed:	text
Show the field	ONLY	
if: [race(6)] = '1'		
15 [household_si	Number of individuals living in the household of the patient:	text (number), Required
16 [household_pa	rent] Number of parents living in household the patient:	of text (number), Required
17 [household_ir	come] Total household income per year:	radio, Required
		1 \$0-\$25,999
		2 \$26,000-\$51,999
		3 \$52,000-\$74,999
		4 \$75,000-\$99,999
		5 \$100,000-\$124,999
		6 \$125,000 or more
		7 Prefer not to answer
18 [household_en	ploye Number of household members who a employed, full or part-time:	re text (number), Required
19 [househol_edu		radio, Required
n]	the household:	1 No schooling
		2 Elementary/middle school
		3 Some high school
		4 High school degree or equivalent (GED)
		5 Some college

		i		
				6 Associate degree
				7 Bachelor's degree
				8 Professional degree
				9 Master's degree
				10 Doctorate degree
				11 Other:
				12 Prefer not to answer
	20	[household_educatio n_other]	other:	text
		Show the field ONLY		
		if: [househol_education] = '11'		
	21	[health_insurance]	Does the patient have health insurance?:	radio, Required 1 Yes 2 No 3 Prefer not to answer
	22	<pre>[insurance_name] Show the field ONLY if: [health_insurance] = '1'</pre>	What is the name of the patient's insurance?	text, Required
	23	<pre>[demographics_compl ete]</pre>	Section Header: Form Status Complete?	dropdown 0 Incomplete 1 Unverified 2 Complete
Ins	trum	ent: Genetic Testin	g (genetic_testing) 🛂 Enabled as su	rvey
	24	[remember_testing]	Section Header: Section 2: Genetic Testing Genetic tests are a type of medical tests that can take a blood or saliva sample and look for changes in a patient's genetic makeup, or DNA. DNA is the genetic material that provides instructions for what our bodies look like and how we function. Examples of names of genetic testing include, but are not limited to: chromosomal analysis, microarray, single gene testing, panel testing, or whole exome sequencing. The following series of questions will ask about your knowledge of genetic testing services that you (or the patient) received through the Intermountain Healthcare system/Primary Children's Hospital. Do you remember having genetic testing done for the patient through the	yesno, Required 1 Yes 0 No
			done for the patient through the Intermountain healthcare system?	

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	25	<pre>[name_of_test] Show the field ONLY if: [remember_testing] = '1'</pre>	What was the name of the genetic test? If more than one genetic test was ordered, list all names:	text, Required
	26	<pre>[inpatient_or_outpa tient] Show the field ONLY if: [remember_testing] = '1' [provider]</pre>	At the time your genetic testing services were completed, was the patient admitted in a hospital or were you a patient at one of the Intermountain outpatient facilities? Who did the patient meet with about genetic testing before it was ordered?	radio, Required 1 Inpatient 2 Outpatient 3 Don't remember 4 Prefer not to answer radio, Required
		Show the field ONLY if: [remember_testing] = '1'	genetic testing before it was ordered:	Neurologist (physician who specialized in the brain and nervous system) Geneticist (physician who specialized in DNA and the inheritance of disease)
				3 Genetic counselor (a health care provider who is trained in genetics and focuses on the education and decision making process for genetics in a family)
				4 Cardiologist (physician who specializes in the heart)
				5 Other:
				6 No one
				7 Don't remember
				8 Prefer not to answer
	28	<pre>[provider_other] Show the field ONLY if: [provider] = '5'</pre>	other:	text
	29	<pre>[out_of_pocket] Show the field ONLY if: [remember_testing] = '1'</pre>	The out of pocket cost includes the amount of money charged to the patient for the genetic testing services alone (the amount you had to pay after the help of insurance companies or other funds). How much were you charged out-of-pocket for the genetic testing the patient received?	text (number), Required
	30	<pre>[out_of_pocket_expe cted]</pre>	How would you rate the out-of-pocket cost paid for genetic testing for the patient?	radio, Required 1 More than I expected 2 About as much as I expected

/25, 10:34 AN	/1	Assessing the financial burden of genetic	c testing NEDCap
	Show the field ONLY if:		3 Less than I expected
	[remember_testing] = '1'		4 Prefer not to answer
31	<pre>[remember_results] Show the field ONLY if: [remember_testing] = '1'</pre>	Do you remember receiving the results of the patient's genetic testing?	radio, Required 1 Yes 2 No 3 Prefer not to answer
32	<pre>[results_delivery] Show the field ONLY if: [remember_results] = '1'</pre>	How did you receive the results of the patient's genetic testing?	radio, Required 1 Phone call from provider 2 Meeting in person with provider 3 Internet 4 Other 5 Prefer not to answer
33	<pre>[results_delivered_ other] Show the field ONLY if: [results_delivery] = '4'</pre>	other:	text
34	<pre>[results_descriptio n] Show the field ONLY if: [remember_results] = '1'</pre>	In your own words, what were the results of the genetic testing?	notes, Required
35	[diagnosis] Show the field ONLY if: [remember_testing] = '1'	Does the patient have a diagnosis of a genetic condition?	radio, Required 1 Yes 2 No 3 Prefer not to answer
36	[diagnosis_result] Show the field ONLY if: [diagnosis] = '1'	Was that diagnosis made because of a genetic testing result?	radio, Required 1 Yes 2 No 3 Prefer not to answer
37	<pre>[name_of_diagnosis] Show the field ONLY if: [diagnosis] = '1'</pre>	What is the patient's diagnosis?	text, Required
38	[diagnosis_service s] Show the field ONLY if:	What, if any, additional services has the patient been able to receive because of their diagnosis?	notes, Required

	[diagnosis] = '1'		
39	[month] Show the field ONLY if: [remember_testing] = '1'	Did the month of the year genetic testing was ordered matter for insurance purposes?	radio, Required 1 Yes 2 No 3 Prefer not to answer
40	[genetic_testing_complete]	Section Header: Form Status Complete?	dropdown 0 Incomplete 1 Unverified 2 Complete
	ent: Utility (utility)		
41	[involved]	Section Header: Section 3- Utility and Decision Making Do you feel as though you were involved in the decision making process when you were deciding to get genetic testing services for the patient?	radio, Required 1 Yes- completely my choice 2 Somewhat- my provider highly recommended testing 3 Not at all- I was told by my provider to get testing 4 Prefer not to answer
42	[question] Show the field ONLY if: [involved] = '3' and [i nvolved] = '2'	At any point, did you question your provider's request to get genetic testing for the patient?	radio, Required 1 Yes 2 No 3 Prefer not to answer
43	<pre>[involvement_explai n]</pre>	Explain:	notes, Required
44	<pre>[results_checkboxe s]</pre>	Check all that apply for the patient and their family. Having a genetic test result has allowed us to	checkbox, Required 1 results_checkboxes1 make th uncertain of risk clearer
			2 results_checkboxes2 discuss results with a physicia
			3 results_checkboxes3 have oth family member tested
			4 results_checkboxes4 better prepare the futu
			5 results_checkboxes5 be motivate

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				to take actions to decrease risks
				6 results_checkboxes6 other:
				7 results_checkboxes7 prefer not to answer
	45	[free_testing]	cost, would you now want genetic testing	radio, Required 1 Yes
			done?	2 No
				3 Not sure
				4 Prefer not to answer
	46	<pre>[adequately_informe d]</pre>	Section Header: Please answer the following questions about your decision to get genetic testing. Please indicate to what extent each statement is true for you AT THIS TIME. I was adequately informed about the different options available for genetic testing	radio (Matrix), Required 1 Strongly Agree 2 Agree 3 Neither Agree nor Disagree 4 Disagree 5 Strongly Disagree 6 Prefer not to answer
	47	[best_decision]	The decision I made was the best decision possible for me personally	radio (Matrix), Required 1 Strongly Agree 2 Agree 3 Neither Agree nor Disagree 4 Disagree 5 Strongly Disagree
				6 Prefer not to answer
	48	<pre>[carry_out_decisio n]</pre>	I expect to successfully carry out (or continue to carry out) the decision I made	 radio (Matrix), Required 1 Strongly Agree 2 Agree 3 Neither Agree nor Disagree 4 Disagree 5 Strongly Disagree 6 Prefer not to answer
	49	[input]	I had as much input as I wanted in the choice of genetic testing	radio (Matrix), Required 1 Strongly Agree 2 Agree 3 Neither Agree nor Disagree

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			4 Disagree
			5 Strongly Disagree
			6 Prefer not to answer
50	[satisfied_decisio	I am satisfied with the decision that was	radio (Matrix), Required
	n]	made about genetic testing	1 Strongly Agree
			2 Agree
			3 Neither Agree nor Disagree
			4 Disagree
			5 Strongly Disagree
			6 Prefer not to answer
51	[resources]	Do you feel that genetic testing allowed	radio, Required
		you or the patient to have more access to resources?	1 Yes
			2 No
			3 Prefer not to answer
52	[explain_resources]	Explain:	notes, Required
53	[worth]	Do you feel that it was worth it to receive	radio, Required
		genetic testing?	1 Yes
			2 No
			3 Prefer not to answer
54	[explain_worth]	Explain:	notes, Required
55	[why_test]	Why did you pursue genetic testing for the patient?	notes, Required
56	[right_decision]	Do you feel you made the right decision	radio, Required
		in getting genetic testing for the patient?	1 Yes
			2 No
			3 Prefer not to answer
57	<pre>[explain_right_deci sion]</pre>	Explain:	notes, Required
58	[anything_else]	Is there anything else you would like to add to tell us about your experience with genetic testing through Intermountain Health Services?	notes, Required
59	[utility_complete]	Section Header: Form Status	dropdown
		Complete?	0 Incomplete
			1 Unverified
			2 Complete
	l .		

60	[incentive]	Section Header: Section 4- Thank You Thank you for participating in my research project. The first 200 participants will be offered \$10 for participating. Would you like to receive \$10 for your time? This decision will not be linked to your survey or medical records in any	yesno, Required 1 Yes 0 No
61	<pre>[thank_you_complet e]</pre>	way and is completely optional to you. Section Header: Form Status Complete?	dropdown 0 Incomplete 1 Unverified
			2 Complete