Data Dictionary Codebook

Utah Genome Project - Informed Consent (PID: 3050)

03/13/2025 10:39am

Instruments	
Instrument	**Form Name**
Participant Info	participant_info
Pre-video	prevideo
Video	video
Teachback	teachback
Genetics	genetics
Informed Consent	informed_consent
DCS	dcs
Process Hallinan - form	process_hallinan_form
Process Hallinan	process_hallinan_4f98
Video only questions	video_only_questions
Coordinator Completes	coordinator_completes

	#	Variable / Field Name	Field Label *Field Note*	Field Attributes (Field Type, Validation, Choices, Calculations, etc.)
Instrument: **Participant Info** (participant_info)				
	1	[record_id]	Record ID	text
	2	[f_name]	first name	text
	3	[l_name]	last name	text
	4	[date_cgs]	Date of CGS visit	text (date_mdy)
	5	[email_2]	email	text (email)
	6	[approach]	Date of approach	text (date_mdy)
	7	[consent]	Did participant agree verbally to the Informed Consent Study?	radio 1 Yes 2 No
	8	[group]	Which group does the participant belong to?	radio 1 Standard of care (original consent, no movie) 2 Intervention (new consent, with movie)
	9	[gift_date]	Section Header: *Compensation* Date gift card given	text (date_mdy)
	10	[gift_code]	Gift card code	text
	11	[gift_notes]	Notes	notes

| 12 | [participant_info_complete] | Section Header: *Form Status*
Complete? | dropdown
<table><tr><td>0</td><td>Incomplete</td></tr><tr><td>1</td><td>Unverified</td></tr><tr><td>2</td><td>Complete</td></tr></table> |

Instrument: **Pre-video** (prevideo)   📱 **Enabled as survey**

| 13 | [pre_video] | Thank you for your interest in research. Please click on the submit button below to begin watching a short (14 minute) video about genetics, and the Utah Genome Project. | descriptive
(Attachment: video.png, Display format: Inline image/PDF) |
| 14 | [prevideo_complete] | Section Header: *Form Status*
Complete? | dropdown
<table><tr><td>0</td><td>Incomplete</td></tr><tr><td>1</td><td>Unverified</td></tr><tr><td>2</td><td>Complete</td></tr></table> |

Instrument: **Video** (video)   📱 **Enabled as survey**

15	[group_number]		calc Calculation: [group] Field Annotation: @HIDDEN-SURVEY
16	[video]	Consent in Genetic Research	descriptive (Media URL: https://player.vimeo.com/video/161992203 autoplay=1, Display format: Inline)
17	[ic_page_1]	Section Header:	descriptive (Attachment: ic_improved_1.png, Display format: Inline image/PDF)
18	[ic_page_2]		descriptive (Attachment: ic_improved_2.png, Display format: Inline image/PDF)
19	[ic_page_3]		descriptive (Attachment: ic_improved_3.png, Display format: Inline image/PDF)
20	[video_complete]	Section Header: *Form Status* Complete?	dropdown <table><tr><td>0</td><td>Incomplete</td></tr><tr><td>1</td><td>Unverified</td></tr><tr><td>2</td><td>Complete</td></tr></table>

Instrument: **Teachback** (teachback)

| 21 | [tb_start] | Start Teachback Process - Click Now button | text (datetime_seconds_mdy) |
| 22 | [tb_purpose] | Section Header: *INTRODUCTION: Now I'm going to ask you to describe in your own words a few key points about the research. This is so I can be sure the information was clear. In your own words, what is the purpose of this research? [Preferred answers will include something about studying the effect of genes on health.]* | radio
<table><tr><td>1</td><td>Yes</td></tr><tr><td>2</td><td>No</td></tr></table> |

		Understand first time?	
23	[tb_purpose_review]	Did you review the material again?	radio 1 Yes 2 No
24	[tb_purpose_reasses s]	How is their understanding after review?	radio 1 Good 2 Satisfactory 3 Poor 4 Did not re-assess
25	[tb_todo]	Section Header: *How would you describe what you would be asked to do if you take part in this research? [Preferred answers include filling out a questionnaire, giving a blood or saliva sample, and maybe some tissue from a procedure.]* Understand first time?	radio 1 Yes 2 No
26	[tb_todo_review]	Did you review the material again?	radio 1 Yes 2 No
27	[tb_todo_reassess]	How is their understanding after review?	radio 1 Good 2 Satisfactory 3 Poor 4 Did not re-assess
28	[tb_costs]	Section Header: *How would you describe the costs to you for taking part in this research? [Preferred answers include; none or no costs.]* Understand first time?	radio 1 Yes 2 No
29	[tb_costs_review]	Did you review the material again?	radio 1 Yes 2 No
30	[tb_costs_reassess]	How is their understanding after review?	radio 1 Good 2 Satisfactory 3 Poor 4 Did not re-assess
31	[tb_stored]	Section Header: *From the information you've been given, what is your understanding of how long your information and blood or tissue samples will be stored for research? [Preferred answer is indefinitely or for years to come.]* Understand first time?	radio 1 Yes 2 No

32	[tb_stored_review]	Did you review the material again?	radio 1 Yes 2 No
33	[tb_stored_reassess]	How is their understanding after review?	radio 1 Good 2 Satisfactory 3 Poor 4 Did not re-assess
34	[tb_risks]	Section Header: *How would you describe possible risks from this research? [Preferred answers will include loss of confidentiality or privacy.]* Understand first time?	radio 1 Yes 2 No
35	[tb_risks_review]	Did you review the material again?	radio 1 Yes 2 No
36	[tb_risks_reassess]	How is their understanding after review?	radio 1 Good 2 Satisfactory 3 Poor 4 Did not re-assess
37	[tb_benefit]	Section Header: *How would you describe the possible benefits for others from this research? [Preferred answers will include: improved understanding of many diseases or more discoveries about cancer.]* Understand first time?	radio 1 Yes 2 No
38	[tb_benefit_review]	Did you review the material again?	radio 1 Yes 2 No
39	[tb_benefit_reasses s]	How is their understanding after review?	radio 1 Good 2 Satisfactory 3 Poor 4 Did not re-assess
40	[tb_expect]	Section Header: *What information do you expect to get after your participation in this research? [Preferred answers will include: nothing or general information in a newsletter but NOT personal results.]* Understand first time?	radio 1 Yes 2 No
41	[tb_expect_review]	Did you review the material again?	radio

			1	Yes
			2	No

42	[tb_expect_reassess]	How is their understanding after review?	radio	
			1	Good
			2	Satisfactory
			3	Poor
			4	Did not re-assess

43	[tb_end]	Section Header: *What questions do you have for me?* End of Teachback process - Click Now button	text (datetime_seconds_mdy)

44	[tb_time]	Time of Teachback Process *Minutes*	calc Calculation: datediff([tb_end], [tb_start],"m","dmy")

45	[teachback_complete]	Section Header: *Form Status* Complete?	dropdown	
			0	Incomplete
			1	Unverified
			2	Complete

Instrument: Genetics (genetics)   👤 **Enabled as survey**

46	[inheritance]	What is true about the relationship between parents' genetic information and their children's genetic information?	radio	
			1	The children have twice as much genetic information as each of their parents.
			2	The children have genetic information that is identical to their father for boys and identical to their mother for girls.
			3	The children have genetic information that is identical to one of their parents. Whether the parent is male or female does not matter.
			4	The children have a combination of genetic information from the mother and the father. The amount of information from each parent is random.
			5	The children have a combination of genetic information from the mother and the father. Half always comes from the mother and half always comes from the father.
			6	The children have most of their genetic information from one

				parent. From mothers for daughters and from fathers for boys.

47	[traits]	How are a person's traits determined? Most are determined by:	radio	
			1	genes only.
			2	one's sex (girl or boy).
			3	the environment only.
			4	both genes and the environment.

48	[dna]	The information in DNA molecules provides instructions for the following:	radio	
			1	Building a product that has a function inside the body.
			2	Building a product that has a function outside the body.
			3	Building genes, which have a function inside the body.
			4	Building genes, which have a function outside the body.
			5	Rearranging genes, which have a function inside the body.
			6	Rearranging genes, which have a function outside the body.

49	[genome]	A person's genome:	radio	
			1	provides the instructions for an entire organism.
			2	Is a complete set of a person's genes.
			3	Is a complete sequence of a person's DNA.
			4	Includes all of the above.

50	[set_genes]	What is a set of genes that provides the instructions for an entire organism called?	radio	
			1	Genetic variation
			2	A genome
			3	A DNA sequence
			4	A genetic sequence

51	[mutation]	Mutation is a process that causes changes in DNA. What is true about MOST mutations?	radio	
			1	They improve people's health.
			2	They cause diseases in most people.
			3	They are not harmful.
			4	They cause diseases in some people and not in other people.

				5	Once they are discovered they can be fixed.
52	[health]	Most common diseases, like heart disease and diabetes, are caused by:	radio		
				1	a variation in only one gene. The variation always causes the disease.
				2	a variation in only one gene. The variation sometimes causes the disease.
				3	variations in many genes. Each variation has a large effect on disease.
				4	variations in many genes. Each variation has a small effect on disease.
				5	common diseases are not caused by variations in genes.
53	[research]	Human genetic research can provide information about all of the following, EXCEPT:	radio		
				1	how to treat diseases.
				2	how to prevent diseases.
				3	how to develop tests for diseases.
				4	how long a person will live.
				5	how the environment affects health.
54	[sequencing]	DNA sequencing is used to identify gene variations. It can ALWAYS be used for the following, EXCEPT	radio		
				1	identifying variations that may cause a specific disease.
				2	identifying variations which provides an accurate diagnosis for a disease.
				3	comparing variations among family members.
				4	comparing variations among people in populations.
55	[sequencing_2]	DNA sequencing is used to identify variations in genes. It can be used for the following, EXCEPT to:	radio		
				1	identify variations that may cause a specific disease.
				2	identify variations that can contribute to causing a disease.
				3	identify variations that may increase a person's risk of developing a disease.

				4	identify variations that can always be used to diagnosis a disease.
				5	compare variations among family members
				6	compare variations among people in populations

56	[sequencing_3]	How can DNA sequencing be used to study health conditions and disease?	radio		
				1	It can be used to rearrange DNA to prevent a certain disease.
				2	It can be used to identify variation in genes that may cause a specific disease.
				3	It can be used to insert DNA into a healthy gene to prevent a certain disease.
				4	It can be used to identify variation in genes but it cannot be used to determine the genes involved in health and disease.

57	[sequencing_4]	DNA sequencing always provides an accurate diagnosis for a disease?	radio		
				1	True
				2	False

58	[genetics_complete]	Section Header: *Form Status* Complete?	dropdown		
				0	Incomplete
				1	Unverified
				2	Complete

Instrument: **Informed Consent** (informed_consent)			👤 **Enabled as survey**		
59	[text_informed_consent]	Based on your understanding of the study information, please choose "True" if you agree with the statement and "False" if you disagree with the statement. Please choose "I Don't Know" if you are not sure.	descriptive		
60	[genes]	I am providing information about my genes in this research.	radio (Matrix)		
				1	True
				2	False
				3	I don't know
61	[future]	Information I provide will be available for future research.	radio (Matrix)		
				1	True
				2	False
				3	I don't know

62	[one]	This research is about one specific health problem.	radio (Matrix) 1 True 2 False 3 I don't know
63	[questionnaire]	This research does not involve a questionnaire.	radio (Matrix) 1 True 2 False 3 I don't know
64	[blood]	I might give a blood sample for the research.	radio (Matrix) 1 True 2 False 3 I don't know
65	[paid]	I will get paid for taking part in this research.	radio (Matrix) 1 True 2 False 3 I don't know
66	[fee]	I do not pay a fee to be in this research.	radio (Matrix) 1 True 2 False 3 I don't know
67	[directly]	The research will directly benefit my health now.	radio (Matrix) 1 True 2 False 3 I don't know
68	[improve]	The research might improve knowledge about diseases.	radio (Matrix) 1 True 2 False 3 I don't know
69	[service]	If I decline to participate in this research the service I get from my health care provider will be affected.	radio (Matrix) 1 True 2 False 3 I don't know
70	[cancer]	All people involved in this research have some form of cancer.	radio (Matrix) 1 True 2 False 3 I don't know

71	[stored]	Your research information is stored with your medical information.	radio (Matrix)
			1 True
			2 False
			3 I don't know

72	[identify]	By participating in this research many people and organizations may have access to information that identifies you.	radio (Matrix)
			1 True
			2 False
			3 I don't know

73	[not_support]	The purpose of this project is to build a resource for research, which types of research would NOT be supported by this resource:	radio
			1 genetic research
			2 cancer research
			3 toxins in the environment
			4 financial impact

74	[major_risk]	What is the major risk from participation in this research?	radio
			1 loss of confidentiality
			2 side effects of cancer therapy
			3 infection
			4 pain from a blood draw

75	[withdraw]	Which of the following statements are true?	radio
			1 you can withdraw anytime
			2 you have to inform in writing to withdraw
			3 data that has been already used from your bio-specimen cannot be removed
			4 all of the above

76	[informed_consent_complete]	Section Header: *Form Status* Complete?	dropdown
			0 Incomplete
			1 Unverified
			2 Complete

Instrument: DCS (dcs)   👥 Enabled as survey

77	[option]	Which option do you prefer?	radio
			1 Participating in the Cancer Genetics Study
			2 Declining to participate in the Cancer Genetics Study
			3 Unsure

78	[available]	Section Header: *Considering the option you prefer, please answer the following questions:*	radio (Matrix)

		I know which options are available to me	
			0	Strongly Agree
			1	Agree
			2	Neither Agree Nor Disagree
			3	Disagree
			4	Strongly Disagree

79	[benefit]	I know the benefits of each option	radio (Matrix)
			0	Strongly Agree
			1	Agree
			2	Neither Agree Nor Disagree
			3	Disagree
			4	Strongly Disagree

80	[risk]	I know the risks and side effects of each option	radio (Matrix)
			0	Strongly Agree
			1	Agree
			2	Neither Agree Nor Disagree
			3	Disagree
			4	Strongly Disagree

81	[benefit_matter]	I am clear about which benefits matter most to me	radio (Matrix)
			0	Strongly Agree
			1	Agree
			2	Neither Agree Nor Disagree
			3	Disagree
			4	Strongly Disagree

82	[risk_matter]	I am clear about which risks and side effects matter most to me	radio (Matrix)
			0	Strongly Agree
			1	Agree
			2	Neither Agree Nor Disagree
			3	Disagree
			4	Strongly Disagree

83	[clear]	I am clear about which is more important to me (the benefits or the risks and side effects)	radio (Matrix)
			0	Strongly Agree
			1	Agree
			2	Neither Agree Nor Disagree
			3	Disagree
			4	Strongly Disagree

84	[support]	I have enough support from others to make a choice	radio (Matrix)

			0	Strongly Agree
			1	Agree
			2	Neither Agree Nor Disagree
			3	Disagree
			4	Strongly Disagree
85	[pressure]	I am choosing without pressure from others	radio (Matrix)	
			0	Strongly Agree
			1	Agree
			2	Neither Agree Nor Disagree
			3	Disagree
			4	Strongly Disagree
86	[advice]	I have enough advice to make a choice	radio (Matrix)	
			0	Strongly Agree
			1	Agree
			2	Neither Agree Nor Disagree
			3	Disagree
			4	Strongly Disagree
87	[choice]	I am clear about the best choice for me	radio (Matrix)	
			0	Strongly Agree
			1	Agree
			2	Neither Agree Nor Disagree
			3	Disagree
			4	Strongly Disagree
88	[sure]	I feel sure about what to choose	radio (Matrix)	
			0	Strongly Agree
			1	Agree
			2	Neither Agree Nor Disagree
			3	Disagree
			4	Strongly Disagree
89	[easy]	This decision is easy for me to make	radio (Matrix)	
			0	Strongly Agree
			1	Agree
			2	Neither Agree Nor Disagree
			3	Disagree
			4	Strongly Disagree
90	[informed]	I feel I have made an informed choice	radio (Matrix)	

				0	Strongly Agree
				1	Agree
				2	Neither Agree Nor Disagree
				3	Disagree
				4	Strongly Disagree

91	[important]	My decision shows what is important to me	radio (Matrix)
			0	Strongly Agree
			1	Agree
			2	Neither Agree Nor Disagree
			3	Disagree
			4	Strongly Disagree

92	[stick]	I expect to stick with my decision	radio (Matrix)
			0	Strongly Agree
			1	Agree
			2	Neither Agree Nor Disagree
			3	Disagree
			4	Strongly Disagree

93	[satisfied]	I am satisfied with my decision	radio (Matrix)
			0	Strongly Agree
			1	Agree
			2	Neither Agree Nor Disagree
			3	Disagree
			4	Strongly Disagree

94	[dcs_complete]	Section Header: *Form Status* Complete?	dropdown
			0	Incomplete
			1	Unverified
			2	Complete

Instrument: Process Hallinan - form (process_hallinan_form) 🔁 **Enabled as survey**

95	[text_process]	Now we want to understand how satisfied you were with the consent process. For the following items please rate them form 1-5 with 5 being you completely agree and 1 being you were completely disagree.	descriptive

96	[form_under]	The words in the consent form were easy to understand.	radio (Matrix)
			1	Completely disagree
			2	
			3	
			4	

| | | | | 5 | Completely agree |

97	[form_words_read]	The words in the consent form were easy to read.	radio (Matrix)
			1	Completely disagree
			2	
			3	
			4	
			5	Completely agree

98	[form_read]	The consent form was easy to read.	radio (Matrix)
			1	Completely disagree
			2	
			3	
			4	
			5	Completely agree

99	[not_detail]	There was not enough detail in the consent form.	radio (Matrix)
			1	Completely disagree
			2	
			3	
			4	
			5	Completely agree

100	[too_detail]	There was too much detail in the consent form.	radio (Matrix)
			1	Completely disagree
			2	
			3	
			4	
			5	Completely agree

101	[movie_word] Show the field ONLY if: [group] = '2'	The words in the movie were easy to understand.	radio (Matrix)
			1	Completely disagree
			2	
			3	
			4	
			5	Completely agree

102	[movie_too] Show the field ONLY if: [group] = '2'	There was too much detail in the movie.	radio (Matrix)
			1	Completely disagree
			2	
			3	
			4	

			5	Completely agree

103	[movie_not] Show the field ONLY if: [group] = '2'	There was not enough detail in the movie.	radio (Matrix) 1 Completely disagree 2 3 4 5 Completely agree
104	[process_hallinan_form_complete]	Section Header: *Form Status* Complete?	dropdown 0 Incomplete 1 Unverified 2 Complete

Instrument: Process Hallinan (process_hallinan_4f98)   📲 **Enabled as survey**

105	[time]	I had enough time to think about this research before signing the consent form.	radio (Matrix) 1 Completely disagree 2 3 4 5 Completely agree
106	[rushed]	I felt rushed to sign the consent form.	radio (Matrix) 1 Completely disagree 2 3 4 5 Completely agree
107	[person]	The words the person used that gave me the consent were easy to understand.	radio (Matrix) 1 Completely disagree 2 3 4 5 Completely agree
108	[friendly]	The person that gave me the consent information was friendly.	radio (Matrix) 1 Completely disagree 2 3 4 5 Completely agree

109	[helpful]	The way the consent form and information was given to me was helpful.	radio (Matrix)
			1 Completely disagree
			2
			3
			4
			5 Completely agree

110	[encouraged]	I was encouraged to ask question about what I was consenting to participant in.	radio (Matrix)
			1 Completely disagree
			2
			3
			4
			5 Completely agree

111	[review]	I was able to review the consent materials independently.	radio (Matrix)
			1 Completely disagree
			2
			3
			4
			5 Completely agree

112	[hci_trust]	I trust Huntsman Cancer Institute to use the Resource's samples for research in an ethical manner?	radio (Matrix)
			1 Completely disagree
			2
			3
			4
			5 Completely agree

113	[process_hallinan_4f98_complete]	Section Header: *Form Status* Complete?	dropdown
			0 Incomplete
			1 Unverified
			2 Complete

Instrument: Video only questions (video_only_questions)

114	[email]	Did you receive an email about this study before you came into the clinic today?	radio
			1 Yes
			2 No

115	[movie]	How much of the movie did you watch?	radio
			1 None of it
			2 Some of it
			3 Most of it

				4	All of it

116	[consent_read]	How much of the consent form did you read?	radio		
			1	None of it
			2	Some of it
			3	Most of it
			4	All of it

117	[video_only_questions_complete]	Section Header: *Form Status* Complete?	dropdown		
			0	Incomplete
			1	Unverified
			2	Complete

Instrument: Coordinator Completes (coordinator_completes)

118	[consent_cgs]	Did participant sign yes to the Cancer Genetic Study?	radio		
			1	Yes
			2	No

119	[notes]	Please write any notes here	notes

120	[coordinator_completes_complete]	Section Header: *Form Status* Complete?	dropdown		
			0	Incomplete
			1	Unverified
			2	Complete