Data Dictionary Codebook

Meaning of Screening (PID: 10282)

03/13/2025 10:37am

Instruments	
Instrument	**Form Name**
Screening And Enrollment	screening_and_enrollment
Knowledge	knowledge
Values Clarification Questions	values_clarification_questions
Demographics	demographics
Files in repository	files_in_repository

#	Variable / Field Name	Field Label *Field Note*	Field Attributes (Field Type, Validation, Choices, Calculations, etc.)
Instrument:	**Screening And Enrollment** (screening_and_enrollment)		🗨 **Enabled as survey**
1	[studyid]	Participant's ID	text
2	[eligible_date]	Section Header: *Screening Assessment* Today's Date (assessed eligibility)	text (date_mdy, Min: 2016-09-01, Max: 2017-09-01), Required
3	[group]	Randomization group	dropdown 1 | 1 - Control - Usual care information provided 2 | 2 - Interactive game - Meaning of Screening
4	[id_number] Show the field ONLY if: [group] = '2'	What is the ID number for the Meaning of Screening game?	text (integer)
5	[brochure_text]	Ask the participant, Do you remember seeing this brochure in the OB packet?	descriptive
6	[brochure]	Do you remember seeing this brochure in the OB packet	radio 1 | Yes and I read it 2 | Yes - I haven't read it 3 | No 4 | I do not remember
7	[screening_and_enrollment_complete]	Section Header: *Form Status* Complete?	dropdown 0 | Incomplete 1 | Unverified 2 | Complete
Instrument:	**Knowledge** (knowledge)	🗨 **Enabled as survey**	

8	[younger]	Section Header: *Thank you for taking the time to help us to improve our prenatal screening game called the Meaning of Screening. The following questions are about Prenatal Screening (otherwise known as NIPT - Non-Invasive Prenatal Testing, NIPS - Non-Invasive Prenatal Screening or Cell Free DNA).* The younger a woman is, the greater the chance she has for having a baby with Down Syndrome.	radio, Required 1 True 2 False 3 Dont know
9	[primary]	What is the main purpose of prenatal screening?	radio, Required 1 To see if the baby has an increased risk of Down syndrome 2 To see if the baby has a heart problem 3 To know for sure if the baby has Down Syndrome 4 To see how big the baby will grow
10	[required]	Prenatal screening is a choice offered by a prenatal care provider. Pregnant women are not required to do this screening test.	radio, Required 1 True 2 False 3 Don't know
11	[positive_screen]	What does a positive NIPT screening result likely mean?	radio, Required 1 it means there is no problem with the baby. 2 it means the baby definitely has Down syndrome. 3 it means there is an increased risk for a neural tube defect 4 it means the woman may want to get diagnostic testing because the baby has an increased risk for Down syndrome
12	[insurance]	All prenatal screening tests are covered by insurance.	radio, Required 1 True 2 False 3 Don't know
13	[false_positive]	Which of the following is an example of a false positive screening result?	radio, Required 1 The screening test shows the baby has increased risk for Down syndrome but diagnostic testing shows the baby does NOT. 2 The screening test shows that the baby has no increased risk for Down syndrome

			3	The screening test shows the baby has some other problem
			4	The screening test shows a normal result

14	[sex_baby]	The main reason prenatal care providers order prenatal screening is to find out the sex of the baby.	radio, Required	
			1	True
			2	False
			3	Don't know

15	[different]	How is a prenatal screening test different from a diagnostic test?	radio, Required	
			1	A screening test can tell for certain if a baby has Down syndrome.
			2	A diagnostic test can tell for certain if a baby has Down syndrome.
			3	Only a screening test can tell about the sex of the baby.
			4	NIPT screening tests are less expensive than diagnostic tests.

16	[sure]	A positive screening result means there could be something wrong with a baby. Further diagnostic testing is required to know for sure.	radio, Required	
			1	True
			2	False
			3	Don't know

17	[future]	Will prenatal screening give information about future pregnancies?	radio, Required	
			1	No - it only gives the woman information about this pregnancy.
			2	Yes - once the woman has had a screening test she does not need it again for future pregnancies.
			3	Yes - but only if the father of the baby is the same as the previous pregnancy.
			4	Yes - but it only gives the woman some information about future pregnancies

18	[false_positive_2]	A false positive screening result means that the screen was positive but after diagnostic testing, there wasn't a problem with the baby.	radio, Required	
			1	True
			2	False
			3	Don't know

19	[nipt]	What conditions does NIPT screen for?	radio, Required	

		1	Down syndrome, Trisomy 18, and other chromosomal problems.
		2	Twin pregnancy
		3	Neural tube defect such as Spina Bifida
		4	Diabetes

20	[separates]	Prenatal screening separates those whose baby may have a problem from those whose baby probably doesn't.	radio, Required
			1 True
			2 False
			3 Don't know

21	[higher_risk]	Which women are at a higher risk of having a baby with Down syndrome?	radio, Required
			1 Women who have never been pregnant before
			2 Women who are over 35 years of age.
			3 Women who have a poor diet during pregnancy
			4 Women who are African American or Latino

22	[tell_problem]	Will this screening test tell a woman for sure if there's a problem with her baby?	radio, Required
			1 No
			2 Yes
			3 Don't know

23	[should_happen]	What should happen if a woman gets a positive screening result?	radio, Required
			1 Nothing - she will have to wait until the baby is born to find out if the baby has Down syndrome.
			2 Her provider will recommend an ultrasound and further diagnostic testing.
			3 She should consider having a quad screen.
			4 She should do the NIPT screening test again.

24	[why_screen]	If there is no cure for chromosomal problems, why would a woman do the screening? Answer all that are correct	checkbox
			1	why_screen___1	Screening is a non-invasive way to find out if a baby is at increased risk for certain problems.

			2	why_screen___2	Many women get screened because they want to be reassured.
			3	why_screen___3	If there is a problem, many women want to have time to prepare.
			4	why_screen___4	To see if the baby has diabetes

25	[lower_risk]	How does a woman know if she is at a lower risk for having a baby with Down syndrome?	radio, Required

1	A woman is at lower risk if she has never been pregnant
2	A woman is at lower risk if she is under 35 years old.
3	A woman is at lower risk if she had no difficulty getting pregnant.
4	African-American women are at lower risk for Down syndrome.

26	[neg_screening]	A negative screening result for a condition means it is very unlikely that a baby has the condition. In general, no further diagnostic testing is necessary.	radio, Required

1	True
2	False
3	Don't know

27	[nipt_does_not]	NIPT does not directly test for individual birth defects such as spina bifida and congenital heart disease.	radio, Required

1	True
2	False
3	Don't know

28	[diagnostic]	Which of the following is a diagnostic test?	radio, Required

1	Cell free DNA test
2	Ultrasound
3	Amniocentesis
4	Maternal serum markers

29	[low_risk_high_risk]	The younger a woman is, the lower the risk. The older a woman is, the higher the risk.	radio, Required

1	True
2	False
3	Don't know

30	[chromosomal_proble ms]	Prenatal screening commonly screens for chromosomal problems such as Down syndrome and Trisomy 18.	radio, Required
			1 True
			2 False
			3 Don't know
31	[knowledge_complet e]	Section Header: *Form Status* Complete?	dropdown
			0 Incomplete
			1 Unverified
			2 Complete

Instrument: Values Clarification Questions (values_clarification_questions)   📶 **Enabled as survey**

32	[important_know]	Section Header: *Questions to help decide whether or not to have any testing:* How important to you is knowing whether or not your baby will be born with a health problem such as Down syndrome?	radio, Required
			1 very important
			2 somewhat important
			3 I am not sure
			4 not very important
			5 not important at all
33	[for_sure]	Would you choose to have a diagnostic test that would tell you for sure whether or not your baby has Down syndrome, even if it could cause a miscarriage?	radio, Required
			1 definitely
			2 probably
			3 I am not sure
			4 probably not
			5 definitely not
34	[worse]	Which would be harder for you, having a child with Down syndrome or having a miscarriage that may be caused by a prenatal test?	radio, Required
			1 definitely worse to have a child with Down syndrome
			2 probably worse to have a child with Down syndrome
			3 I am not sure
			4 probably worse to have a miscarriage
			5 definitely worse to have a miscarriage
35	[false_pos_result]	Section Header: *Questions to help choose between starting with screening or going straight to invasive testing* How important is it to you to avoid a false positive screening result?	radio, Required
			1 very important
			2 somewhat important
			3 I am not sure
			4 not very important
			5 not important at all

36	[fetus_has]	How important to you is knowing for sure whether or not your baby has Down syndrome?	radio, Required
			1 very important
			2 somewhat important
			3 I am not sure
			4 depends on my risk
			5 not important
37	[personal_risk]	Would it help you to know your personal risk (chance) of having a baby with Down syndrome before deciding whether or not to have a diagnostic test (CVS or amniocentesis)?	radio, Required
			1 definitely would help me
			2 probably would help me
			3 I am not sure
			4 probably would not help me
			5 definitely would not help me.
38	[married]	Section Header: *The next questions ask about other people's involvement in your prenatal testing decisions.* Are you married or significantly involved with a partner?	radio, Required
			1 No
			2 Yes
39	[partner_yes] Show the field ONLY if: [married] = '2'	Is your partner the father of the baby?	radio, Required
			1 No
			2 Yes
			3 Don't know
40	[partner]	Please tell us about your partner's role in your testing decision. In deciding about prenatal testing options for your pregnancy, who do you think should decide which test(s) if any you should have? Partner - here refers to your husband or significant other	radio, Required
			1 Me alone
			2 Mostly me
			3 My partner and me equally
			4 Mostly my partner
			5 My partner alone
			6 Insurance company
41	[providers_role]	Please tell us about your health care provider's role in your testing decision.	descriptive
42	[hc_provider]	In deciding about prenatal testing options for your pregnancy, who do you think should decide which test(s) if any you should have? "Health care provider" here refers to the obstetrician, nurse, midwife or family practitioner who is responsible for your prenatal care.	radio, Required
			1 Me alone
			2 Mostly me
			3 Health care provider and me equally
			4 Mostly the health care provider
			5 Health care provider alone
			6 Insurance company

43	[receive]	Please tell us about your experience receiving information about prenatal screening.	descriptive
44	[amount]	How would you rate the amount of information you just received about prenatal testing?	radio, Required 1 Much more than I needed 2 A little more than I needed 3 About right 4 A little less than I needed 5 A lot less than I needed
45	[clear]	How clearly was that information presented?	radio, Required 1 Everything was clear 2 Most things were clear 3 Some things were unclear 4 Many things were unclear
46	[balance]	How balanced (both the pros and cons) was the information in the game?	radio, Required 1 Clearly slanted (biased) toward prenatal screening 2 Slightly slanted (biased) toward prenatal screening 3 Completely balanced 4 Slightly slanted (biased) away from prenatal screening 5 Clearly slanted away from prenatal screening
47	[unable] Show the field ONLY if: [group] = '2'	Were there any tests or procedure that you were hoping to learn about but were unable to find in the program?	radio, Required 1 No 2 Yes
48	[unable_note] Show the field ONLY if: [unable] = '2'	If yes, what were they?	notes
49	[strategies] Show the field ONLY if: [group] = '2'	Were there any testing strategies that you were interested in that were not discussed by the game?	radio, Required 1 No 2 Yes
50	[strategies_note] Show the field ONLY if: [strategies] = '2'	If yes, what were they?	notes

51	[recommend] Show the field ONLY if: [group] = '2'	Would you recommend the game you played to a friend of yours who is pregnant?	radio, Required

			1	Yes - I would definitely recommend it
			2	I would probably recommend it
			3	Maybe I would recommend it
			4	I doubt that I would recommend it
			5	No - I definitely would not recommend it

52	[why_note] Show the field ONLY if: [group] = '2'	Why or why not would you recommend it?	notes

53	[groups_note] Show the field ONLY if: [group] = '2'	Please list certain groups for whom you would especially recommend the game (older women, women in their first pregnancy, etc)?	notes

54	[prenatal_screening]	Did you already have prenatal screening/testing?	radio, Required

			1	Yes
			2	No

55	[screen_type] Show the field ONLY if: [prenatal_screening] = '1'	Which type of screening/testing did you have?	checkbox

1	screen_type___1	Ultrasound for Nuchal Translucency
2	screen_type___2	First Trimester maternal serum markers
3	screen_type___3	Second trimester maternal serum markers
4	screen_type___4	Integrated Screening
5	screen_type___5	Sequential screening
6	screen_type___6	Combined screening (nuchal translucency and 1st trimester maternal serum)

			7	screen_type___7	Quad screen
			8	screen_type___8	Cell free fetal DNA
			9	screen_type___9	NIPT (Non Invasive Prenatal Testing)
			10	screen_type___10	CVS (Chorionic Villus Sampling)
			11	screen_type___11	Amniocentesis

56	[genetic_counseling]	Did you have genetic counseling by a genetic counselor for prenatal screening?	radio, Required
			1	Yes
			2	No

57	[personal_risk_down_syn]	Think about how you feel about YOUR personal risk of carrying a baby affected by Down syndrome. Do you feel it is:	radio, Required
			1	Extremely high
			2	Very high
			3	Somewhat high
			4	Neither high nor low
			5	Somewhat low
			6	Very low
			7	Non existent
			8	Don't know

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

Instrument: **Demographics** (demographics)   📲 **Enabled as survey**

59	[name_first]	What is your first name	text
60	[name_last]	What is your last name	text
61	[email]	What is your email address	text (email)
62	[phone]	What is your phone number?	text (phone)
63	[age]	What is your age?	text (number)
64	[ethnicity]	Are you Hispanic or Latino/Latina?	radio
			1	Yes - Hispanic or Latino/Latina
			10	No - Not Hispanic nor Latino/Latina
			11	Decline to answer

65	[race]	What is your racial or ethnic background?	radio	
			1	White or Caucasian
			2	Black or African American
			3	Asian
			4	Native Hawaiian or Pacific Islander
			5	American Indian or Alaska Native
			7	Multi-racial
			8	Other (specify below)
			9	Decline to answer
66	[race_other] Show the field ONLY if: [race] = '8'	Please specify your race	text	
67	[education]	What is the highest level of education you have completed?	radio	
			1	1 - No formal education
			2	2 - Less than high school
			3	3 - High school graduate, GED or equivalent
			4	4 - Some college
			5	5 - Associates degree, community college, or vocational degree
			6	6 - College graduate
			7	7 - Professional or graduate degree (MA, MBA, PhD, MD, JD, etc.)
			8	8 - Decline to answer
68	[marital]	Which of the following describes your current relationship status?	radio	
			1	Married or living with partner
			2	Significantly involved with partner but not living together
			3	Single / not significantly involved
			4	Other
			5	Decline to answer
69	[income]	What was your last year's household income (before taxes)?	radio	
			1	1 - Under $24,999
			2	2 - $25,000 - $50,000
			3	3 - $50,001 - $100,000
			4	4 - $100,001 - $150,000

				5	5 - Over $150,000
				6	6 - Not sure / Don't know
				7	7 - Decline to answer

70	[duedate]	What is your due date?	text (date_mdy, Min: 2013-08-27), Identifier

71	[prenatal_date]	What was the approximate date of your first prenatal visit (with either a nurse or doctor)?	text (date_mdy)

72	[difficult_preg]	How difficult was it for you to get pregnant?	radio

			1	Was not trying
			2	Easy
			3	Difficult

73	[know_down]	Have you ever personally known anyone who has Down syndrome?	radio

			1	Yes
			2	No

74	[relationship_down] Show the field ONLY if: [know_down] = '1'	What is that person's relationship to you? (Check all that apply.)	checkbox

			1	relationship_down___1	My child
			2	relationship_down___2	My brother or sister
			3	relationship_down___3	My other relative or member of my family
			4	relationship_down___4	A friend or neighbor
			5	relationship_down___5	Someone I worked with (paid or volunteer)
			6	relationship_down___6	Someone I took care of
			7	relationship_down___7	Other

75	[other_know_down] Show the field ONLY if: [relationship_down(7)] = '1'	Specify please.	text

76	[pregnancies]	Not including this one, how many other pregnancies have you had? *Please include ALL pregnancies, except for this one, and not just those that resulted in live births. If no other pregnancies, write 0.*	text (integer)
77	[live_birth]	How many of your other pregnancies resulted in a live birth	text (integer)
78	[miscarriage]	How many of your other pregnancies resulted in a miscarriage, tubal (ectopic) pregnancy, or stillbirth?	text (integer)
79	[abortion]	If you were told that your fetus had Down syndrome, would you choose to have an abortion?	radio 1 No - I definitely WOULD NOT have an abortion 2 I probably WOULD NOT have an abortion 3 I am unsure whether or not I would have an abortion 4 I probably WOULD have an abortion 5 Yes - I definitely WOULD have an abortion
80	[disorder_notes]	Do any of your children have a genetic disorder or chronic medical problem? Please describe.	notes
81	[game_recommend] Show the field ONLY if: [group] = '2'	Section Header: I would recommend this game to a friend?	radio 1 Strongly disagree 2 Disagree 3 Neither agree nor disagree 4 Agree 5 Strongly agree
82	[game_opinion] Show the field ONLY if: [group] = '2'	I have a positive opinion towards videogames?	radio 1 Strongly disagree 2 Disagree 3 Neither agree nor disagree 4 Agree 5 Strongly agree
83	[game_experience] Show the field ONLY if: [group] = '2'	Playing this game was a new kind of experience for me?	radio 1 Strongly disagree 2 Disagree 3 Neither agree nor disagree 4 Agree

			5	Strongly agree

84	[game_worth] Show the field ONLY if: [group] = '2'	I found the experience worthwhile?	radio 1 Strongly disagree 2 Disagree 3 Neither agree nor disagree 4 Agree 5 Strongly agree
85	[game_changes] Show the field ONLY if: [group] = '2'	What changes would you make to this game?	notes
86	[discuss_change] Show the field ONLY if: [group] = '2'	Can we contact you at a later time to discuss changes to the game?	radio 1 Yes 2 No
87	[demographics_complete]	Section Header: *Form Status* Complete?	dropdown 0 Incomplete 1 Unverified 2 Complete

Instrument: Files in repository (files_in_repository)

88	[file_1]	Analytic player usage data	descriptive (Attachment: Gapp_Analytics_5_10_2017.xlsx, Display format: Link)
89	[files_in_repository_complete]	Section Header: *Form Status* Complete?	dropdown 0 Incomplete 1 Unverified 2 Complete