

Women's perception and knowledge of prenatal screening for fetal trisomy- Survey Results Dataset

Storage Format: SPSS

Variable	Variable Name	Variable Label	Exact Wording Used	Valid Codes and Meanings
1	Survey#	Survey Number	n/a	Integer/numeral 99999: Missing
2	Age	Age	What is your age?	99999: Missing
3	Ethnicity	Ethnicity	What is your ethnicity?	1: Irish 2: Irish Traveller 3: Other White 4: Mixed Ethnicity 5: African 6: Any other Black background 7: Asian 8: Other 99999: Missing 88888: Invalid Response
4	AdditionalCommentsEthnicity	Additional Comments Ethnicity	Other _____	Open field for comment 99999: Missing
5	Children#	Children Number	How many children do you have?	0: First Pregnancy 1: One child already 2: Two children already 3: Three children already 4: Four or more children already 99999: Missing
6	PreviousMiscarriageLosses	Previous Miscarriage/Losses	Have you had a previous miscarriage or pregnancy loss?	0: No 1: Yes 99999: Missing
7	EducationLevel	Education Level	What is your highest education level?	1: Primary School 2: Secondary School 3: Third Level Education 4: Postgraduate Education 99999: Missing 88888: Invalid Response
8	ClinicType	Clinic Type	Which type of clinic are you attending?	1: Public 2: Private

				99999: Missing 88888: Invalid Response
9	ClinicianType	Clinician Type	Which type of clinician is taking care of your pregnancy?	1: Midwife 2: Hospital Consultant/ Registrar 3: Private Consultant/ Registrar 99999: Missing 88888: Invalid Response
10	BabysDNA	Baby's DNA	Overarching question: What do you understand by 'screening for fetal anomalies'? Sub-question: Blood tests to look at the baby's DNA for risk of Down syndrome.	0: No 1: Yes 99999: Missing
11	Mothersbloodlevels	Mother's blood levels	Overarching question: What do you understand by 'screening for fetal anomalies'? Sub-question: Blood tests to look at levels in the mother's blood.	0: No 1: Yes 99999: Missing
12	Ultrasound	Ultrasound	Overarching question: What do you understand by 'screening for fetal anomalies'? Sub-question: Ultrasound scan to look for signs of Down syndrome	0: No 1: Yes 99999: Missing
13	Nuchaltransucency	Nuchal Translucency	Overarching question: What do you understand by 'screening for fetal anomalies'? Sub-question: Measuring fluid on back of baby's neck	0: No 1: Yes 99999: Missing
14	Anatomyscan	Anatomy Scan	Overarching question: What do you understand by 'screening for fetal anomalies'? Sub-question: Anatomy scan (also called "20-week scan" or "detailed scan" or "the big scan")	0: No 1: Yes 99999: Missing

15	Unsure	Unsure	Overarching question: What do you understand by 'screening for fetal anomalies'? Sub-question: Unsure	0: No 1: Yes 99999: Missing
16	GP	GP	Question: Where do you go to fine information about screening tests for fetal anomalies? Option within the multiple answers to select: GP	0: No 1: Yes 99999: Missing
17	Friends	Friends	Question: Where do you go to fine information about screening tests for fetal anomalies? Option within the multiple answers to select: Friends	0: No 1: Yes 99999: Missing
18	Family	Family	Question: Where do you go to fine information about screening tests for fetal anomalies? Option within the multiple answers to select: Family	0: No 1: Yes 99999: Missing
19	Internet	Internet	Question: Where do you go to fine information about screening tests for fetal anomalies? Option within the multiple answers to select: Internet	0: No 1: Yes 99999: Missing
20	Obstetrician	Obstetrician	Question: Where do you go to fine information about screening tests for fetal anomalies? Option within the multiple answers to select: Obstetrician	0: No 1: Yes 99999: Missing
21	MidwifeatAntenatalClinic	Midwife at Antenatal Clinic	Question: Where do you go to fine information about screening tests for fetal anomalies?	0: No 1: Yes 99999: Missing

			Option within the multiple answers to select: Midwife at antenatal clinic	
22	Neversearched	Never Searched	Question: Where do you go to fine information about screening tests for fetal anomalies? Option within the multiple answers to select: I have never researched Prenatal Screening	0: No 1: Yes 99999: Missing
23	Other	Other	Question: Where do you go to fine information about screening tests for fetal anomalies? Option within the multiple answers to select: Other	
24	TestResearchAddlComments	Additional Comments on test research	Question: Where do you go to fine information about screening tests for fetal anomalies? Option within the multiple answers to select: Other_____	Open text for comment 99999: Missing
25	AllWomenOfferedTest	All Women Offered Test	I believe all women should be routinely offered a prenatal screening test, regardless of age.	1: Agree 2: Disagree 3: Unsure 99999: Missing
26	Onlywomentgt35offered test	Only women greater than 35 offered test	I believe only women over the age of 35 should be routinely offered a prenatal screening test.	1: Agree 2: Disagree 3: Unsure 99999: Missing
27	Screeningcandetectallbabies	Screening can detect all babies with disease or disability	Prenatal Screening can detect all babies with a disease or disability.	1: Incorrect 2: Correct 3: Unsure 99999: Missing 88888: Invalid Response

28	DownSyndromerate	Down Syndrome rate	How many babies are born with Down syndrome in Ireland per year?	1: 1 in 70,000 2: 1 in 7,000 3: 1 in 700 4: 1 in 70 5: 1 in 7 6: Unsure 99999: Missing
29	DetectallDS	Prenatal screening can detect all DS	Prenatal Screening can detect all babies with Down syndrome.	1: Incorrect 2: Correct 3: Unsure 99999: Missing 88888: Invalid Response
30	MostDSbabiesborntowomen>35	Most DS babies are born to women greater than 35	Most Down syndrome babies are born to women over 35 years of age.	1: Incorrect 2: Correct 3: Unsure 99999: Missing 88888: Invalid Response
31	Increasedmaternalage	Increased maternal age	Question: Which of the following factors increase a woman's likelihood of having a baby with Down syndrome? Sub-question: Increased age of mother	0: Incorrect 1: Correct 99999: Missing
32	Increasedpaternalage	Increased paternal age	Question: Which of the following factors increase a woman's likelihood of having a baby with Down syndrome? Sub-question: Increased age of the father	0: Incorrect 1: Correct 99999: Missing
33	PreviousDSchild	Previous DS Child	Question: Which of the following factors increase a woman's likelihood of having a baby with Down syndrome? Sub-question: Previous child with Down syndrome	0: Incorrect 1: Correct 99999: Missing
34	Previousmiscarriage	Previous miscarriage	Question: Which of the following factors increase a woman's	0: Correct 1: Incorrect

			likelihood of having a baby with Down syndrome? Sub-question: Previous miscarriage	99999: Missing
35	OtherfamilywithDS	Other family with DS	Question: Which of the following factors increase a woman's likelihood of having a baby with Down syndrome? Sub-question: Other family members with Down Syndrome	0: Correct 1: Incorrect 99999: Missing
36	Otherfamilywithautism	Other family with autism	Question: Which of the following factors increase a woman's likelihood of having a baby with Down syndrome? Sub-question: Other family members with autism	0: Correct 1: Incorrect 99999: Missing
37	Nofolicacidsupplement	No folic acid supplement	Question: Which of the following factors increase a woman's likelihood of having a baby with Down syndrome? Sub-question: No folic acid supplementation during pregnancy	0: Correct 1: Incorrect 99999: Missing
38	Unsure_A	Unsure	Question: Which of the following factors increase a woman's likelihood of having a baby with Down syndrome? Sub-question: Unsure	0: Not Selected 1: Selected 99999: Missing
39	PersonalriskofhavingaDSbaby	Personal risk of having a DS baby	What do you think is your own personal risk of having a Down syndrome baby?	1: Non-existent 2: Low 3: Moderate 4: High 5: Quite high 6: Unsure 99999: Missing 88888: Invalid Response

40	Yes	Yes	Question: If you were offered screening to test for Down Syndrome would you accept it? Option within the multiple answers to select: Yes	0: Not selected 1: Selected 99999: Missing
41	Yes and I had this test in this pregnancy	Yes and I had this test in this pregnancy	Question: If you were offered screening to test for Down Syndrome would you accept it? Option within the multiple answers to select: Yes, and I had this test in this pregnancy	0: Not selected 1: Selected 99999: Missing
42	Undecided	Undecided	Question: If you were offered screening to test for Down Syndrome would you accept it? Option within the multiple answers to select: Undecided	0: Not selected 1: Selected 99999: Missing
43	No	No	Question: If you were offered screening to test for Down Syndrome would you accept it? Option within the multiple answers to select: No	0: Not selected 1: Selected 99999: Missing
44	Not for DS but I would for others	Not for Down Syndrome but I would for other fetal anomalies	Question: If you were offered screening to test for Down Syndrome would you accept it? Option within the multiple answers to select: Not for Down Syndrome, but I would have screening tests for other fetal anomalies	0: Not selected 1: Selected 99999: Missing
45	Help decide about amniocentesis	Help decide about amniocentesis	Question: If you would choose screening, why?	0: Not selected 1: Selected 99999: Missing

			Option within the multiple answers to select: To help make the decision to have a diagnostic test like amniocentesis	
46	BelievehigherriskforDS	Believe higher risk for DS	Question: If you would choose screening, why? Option within the multiple answers to select: I believe that I am at a higher risk for having a baby with Down Syndrome	0: Not selected 1: Selected 99999: Missing
47	Checkifbabyhealthy	Check if baby healthy	Question: If you would choose screening, why? Option within the multiple answers to select: In order to check if my baby is healthy	0: Not selected 1: Selected 99999: Missing
48	AllowOBtohaveallinfor mation	Allow OB to have all information	Question: If you would choose screening, why? Option within the multiple answers to select: To allow my obstetrician to care for me with all the information	0: Not selected 1: Selected 99999: Missing
49	Considertermination	Consider termination	Question: If you would choose screening, why? Option within the multiple answers to select: I want to consider termination of pregnancy	0: Not selected 1: Selected 99999: Missing
50	BetterprepareforDS	Better prepare before baby is born for DS	Question: If you would choose screening, why? Option within the multiple answers to select: To allow everyone to better prepare before	0: Not selected 1: Selected 99999: Missing

			the baby is born if affected by Down syndrome	
51	Betterprepareforanother anomaly	Better prepare before baby is born for another fetal anomaly	Question: If you would choose screening, why? Option within the multiple answers to select: To allow everyone to better prepare for another fetal anomaly	0: Not selected 1: Selected 99999: Missing
52	Other_A	Other	Question: If you would choose screening, why? Option within the multiple answers to select: Other	0: Not selected 1: Selected 99999: Missing
53	AdditionalComments_B	Additional Comments	If you would choose screening, why?	Open text for comment 99999: Missing
54	Personalriskistoolow	Personal risk is too low	Question: If you would not choose screening, why not? Option within the multiple answers to select: Not necessary – my personal risk is too low	0: Not selected 1: Selected 99999: Missing
55	Notsurehowtogettest	Not sure how to get test	Question: If you would not choose screening, why not? Option within the multiple answers to select: I am not sure how to get the test	0: Not selected 1: Selected 99999: Missing
56	Thinktestisinaccurate	Think test is inaccurate	Question: If you would not choose screening, why not? Option within the multiple answers to select: I think the screening test is inaccurate	0: Not selected 1: Selected 99999: Missing
57	Worriedaboutwhattodo	Worried about what to do if baby is affected	Question: If you would not choose screening, why not?	0: Not selected 1: Selected 99999: Missing

			Option within the multiple answers to select: I am worried about what to do if the baby is affected	
58	DoNOTwanttermination	Do NOT want to consider termination	Question: If you would not choose screening, why not? Option within the multiple answers to select: I do not want to consider termination of pregnancy	0: Not selected 1: Selected 99999: Missing
59	Potentialcostoftest	Potential cost of test	Question: If you would not choose screening, why not? Option within the multiple answers to select: Potential cost of screening test	0: Not selected 1: Selected 99999: Missing
60	Mediareportsaboutinaccuracy	Media reports about inaccuracy	Question: If you would not choose screening, why not? Option within the multiple answers to select: Media reports about inaccuracy of screening	0: Not selected 1: Selected 99999: Missing
61	Amniocentesisrisktoohigh	Amniocentesis risk of miscarriage too high	Question: If you would not choose screening, why not? Option within the multiple answers to select: Amniocentesis test needed for diagnosis after screening has too high a risk of miscarriage	0: Not selected 1: Selected 99999: Missing
62	Other_B	Other	Question: If you would not choose screening, why not? Option within the multiple answers to select: Other	0: Not selected 1: Selected 99999: Missing

63	AdditionalComments_C	Additional Comments	If you would not choose screening, why not?	Open text for comment 99999: Missing
64	HighRiskLevel	High Risk Level	Screening tests report the risk of Down syndrome in your baby (1 in 200 for example). At a certain level, the woman is said to be “high risk,” and may be offered a follow up diagnostic test. What level do you think is “high risk”?	1: 1 in 2 2: 1 in 10 3: 1 in 100 4: 1 in 1000 5: 1 in 10000 6: 1 in 100000 7: 1 in 200000 8: Unsure 99999: Missing 88888: Invalid Response
65	LowriskDSmean	Low risk DS mean	What does a low risk screening test result for Down Syndrome mean?	1: Definitely does NOT have DS 2: Less likely to have DS 3: More likely to have DS 4: Definitely DOES have DS 5: Unsure 99999: Missing 88888: Invalid Response
66	HighriskDSmean	High risk DS mean	What does high risk screening test result for Down Syndrome mean?	1: Definitely does NOT have DS 2: Less likely to have DS 3: More likely to have DS 4: Definitely DOES have DS 5: Unsure 99999: Missing 88888: Invalid Response
67	Haveamniocentesis	Have amniocentesis	Women who receive an ‘increased risk’ result from a screening test may choose to undergo further tests that give a definite “yes or no” answer about conditions like Down syndrome. For example, women may choose to undergo an amniocentesis, where a very fine needle is directed through the mother’s abdomen into the womb, and a	1: Never have amniocentesis 2: Always have amniocentesis 3: Prefer a diagnostic test like amniocentesis 4: Unsure 99999: Missing 88888: Invalid Response

			sample of amniotic fluid is taken. However, this carries a 1 in 200 risk of miscarriage.	
68	Never terminate	Never terminate	Question: My views on termination for my own pregnancies are: Sub-question: I would never terminate a pregnancy	0: No 1: Yes 99999: Missing
69	Only if mother's health at risk	Only if mother's health at risk	Question: My views on termination for my own pregnancies are: Sub-question: I would only terminate a pregnancy if my health was at risk	0: No 1: Yes 99999: Missing
70	Unsure about termination	Unsure about termination	Question: My views on termination for my own pregnancies are: Sub-question: I am unsure about terminating a pregnancy	0: No 1: Yes 99999: Missing
71	Terminate only for fetal anomaly	Terminate only for fetal anomaly	Question: My views on termination for my own pregnancies are: Sub-question: I would terminate a pregnancy only because of a fatal fetal anomaly	0: No 1: Yes 99999: Missing
72	Not opposed to termination	Not opposed to termination	Question: My views on termination for my own pregnancies are: Sub-question: I am not opposed to terminating a pregnancy.	0: No 1: Yes 99999: Missing
73	Anencephaly	Anencephaly	Question: In Ireland, women can choose to terminate their pregnancy before 12 weeks. Termination after 12 weeks is only allowed if a fatal fetal anomaly is diagnosed. Which of	0: Incorrect 1: Correct 99999: Missing

			the following do you think are classified as fatal fetal anomalies? Sub-question: Anencephaly (a neural tube defect that causes abnormal development of the brain)	
74	EdwardsSyndrome	Edwards Syndrome	Question: In Ireland, women can choose to terminate their pregnancy before 12 weeks. Termination after 12 weeks is only allowed if a fatal fetal anomaly is diagnosed. Which of the following do you think are classified as fatal fetal anomalies? Sub-question: Edwards Syndrome (Trisomy 18)	0: Incorrect 1: Correct 99999: Missing
75	DownSyndrome	Down Syndrome	Question: In Ireland, women can choose to terminate their pregnancy before 12 weeks. Termination after 12 weeks is only allowed if a fatal fetal anomaly is diagnosed. Which of the following do you think are classified as fatal fetal anomalies? Sub-question: Down Syndrome (Trisomy 21)	0: Correct 1: Incorrect 99999: Missing
76	SpinaBifida	Spina Bifida	Question: In Ireland, women can choose to terminate their pregnancy before 12 weeks. Termination after 12 weeks is only allowed if a fatal fetal anomaly is diagnosed. Which of the following do you think are classified as fatal fetal anomalies? Sub-question: Spina Bifida (a neural tube defect which causes	0: Correct 1: Incorrect 99999: Missing

			incomplete development of the spinal cord)	
77	Yes_A	Yes	<p>Question: Prenatal screening tests only report on the <i>risk</i> of the baby having Down Syndrome or another condition. If the screening result shows a ‘high risk’ of Down Syndrome, this is not a diagnosis, only a risk of Down Syndrome. Would you terminate before getting a definitive diagnosis from a test like amniocentesis?</p> <p>Option within the multiple answers to select: Yes</p>	<p>0: Not Selected 1: Selected 99999: Missing</p>
78	Wouldnotterminate	Would no terminate	<p>Prenatal screening tests only report on the <i>risk</i> of the baby having Down Syndrome or another condition. If the screening result shows a ‘high risk’ of Down Syndrome, this is not a diagnosis, only a risk of Down Syndrome. Would you terminate before getting a definitive diagnosis from a test like amniocentesis?</p> <p>Option within the multiple answers to select: No, I would not terminate a pregnancy</p>	<p>0: Not Selected 1: Selected 99999: Missing</p>
79	Wantdefinitivediagnosis	Want definitive diagnosis	<p>Prenatal screening tests only report on the <i>risk</i> of the baby having Down Syndrome or another condition. If the screening result shows a ‘high risk’ of Down Syndrome, this is</p>	<p>0: Not Selected 1: Selected 99999: Missing</p>

			<p>not a diagnosis, only a risk of Down Syndrome. Would you terminate before getting a definitive diagnosis from a test like amniocentesis?</p> <p>Option within the multiple answers to select: No, I would want a definitive diagnosis through a test like amniocentesis</p>	
80	NotforDSbutforotheranomalies	Not for DS, but I would for other fetal anomalies	<p>Prenatal screening tests only report on the <i>risk</i> of the baby having Down Syndrome or another condition. If the screening result shows a ‘high risk’ of Down Syndrome, this is not a diagnosis, only a risk of Down Syndrome. Would you terminate before getting a definitive diagnosis from a test like amniocentesis?</p> <p>Option within the multiple answers to select: No, not for Down Syndrome but I would for other fetal anomalies</p>	<p>0: Not Selected 1: Selected 99999: Missing</p>
81	AdditionalComments_D	Additional Comments	<p>Prenatal screening tests only report on the <i>risk</i> of the baby having Down Syndrome or another condition. If the screening result shows a ‘high risk’ of Down Syndrome, this is not a diagnosis, only a risk of Down Syndrome. Would you terminate before getting a definitive diagnosis from a test like amniocentesis?</p>	<p>Open text for comment 99999: Missing</p>

82	Anencephaly_A	Anencephaly	<p>Question: I would only terminate a pregnancy after a definitive diagnostic test like amniocentesis came back positive indicating that my baby was affected with which of the following?</p> <p>Option within the multiple answers to select: Anencephaly (a neural tube defect that causes abnormal development of the brain)</p>	<p>0: Not Selected 1: Selected 99999: Missing</p>
83	EdwardsSyndrome_A	Edwards Syndrome	<p>Question: I would only terminate a pregnancy after a definitive diagnostic test like amniocentesis came back positive indicating that my baby was affected with which of the following?</p> <p>Option within the multiple answers to select: Edwards Syndrome (Trisomy 18)</p>	<p>0: Not Selected 1: Selected 99999: Missing</p>
84	DownSyndrome_A	Down Syndrome	<p>Question: I would only terminate a pregnancy after a definitive diagnostic test like amniocentesis came back positive indicating that my baby was affected with which of the following?</p> <p>Option within the multiple answers to select: Down Syndrome (Trisomy 21)</p>	<p>0: Not Selected 1: Selected 99999: Missing</p>
85	SpinaBifida_A	Spina Bifida	<p>Question: I would only terminate a pregnancy after a definitive diagnostic test like amniocentesis came back positive indicating that</p>	<p>0: Not Selected 1: Selected 99999: Missing</p>

			<p>my baby was affected with which of the following?</p> <p>Option within the multiple answers to select: Spina Bifida (a neural tube defect which causes incomplete development of the spinal cord)</p>	
86	Iwouldnotterminate	I would not terminate	<p>Question: I would only terminate a pregnancy after a definitive diagnostic test like amniocentesis came back positive indicating that my baby was affected with which of the following?</p> <p>Option within the multiple answers to select: I would not terminate a pregnancy</p>	<p>0: Not Selected 1: Selected 99999: Missing</p>
87	HeardofNIPT	Heard of NIPT	Have you ever heard of non-invasive prenatal tests?	<p>0: No 1: Yes 2: Unsure 99999: Missing</p>
88	NameanyNIPT	Name any NIPT	Can you name any non-invasive prenatal tests?	<p>0: No 1: Yes 99999: Missing</p>
89	AdditionalComments_E	Additional Comments	<p>Can you name any non-invasive prenatal tests?</p> <p>Additional Comments</p>	<p>Open text for comment 99999: Missing</p>
90	CostofNIPT	Cost of NIPT	What do you think non-invasive prenatal tests costs?	<p>1: 0-100 2: 101-200 3: 201-300 4: 301-400 5: 401-500 6: Over 500 99999: Missing 88888: Invalid Response</p>

91	WillingtoPayforscreeningtests	Willing to Pay for screening tests	How much would you be willing to pay for screening tests for fetal anomalies?	1: 50 2: 100 3: 150 4: 200 5: 250 6: 500 7: Any Amount 8: Nothing, it should be free 99999: Missing 88888: Invalid Response
92	Whoshouldpay	Who should pay	Who do you think should be responsible for paying for screening tests for fetal anomalies?	1: HSE 2: Hospital 3: Woman 99999: Missing 88888: Invalid Response
93	WhenWherereceiveinfo	When/Where receive info	When/where do you want to receive information about screening tests for fetal anomalies?	1: First Clinic Visit 2: GP 3: Hospital Website 99999: Missing 88888: Invalid Response
94	Additionalcomments_F	Additional Comments	Do you have any other comments or suggests regarding screening tests for fetal anomalies?	Open text for comment 99999: Missing
95	AgeCategories_recode	AgeCategories_recode	Ages clustered into three groups	1: 18-29 2: 30-39 3: 40+
96	Ethnicity_recode	Ethnicity_recode	Ethnicity groups clustered into 3 categories	1: Irish 2: Other White/Irish Traveller 3: Mixed/ African/ Other Black/ Asian/ Other
97	Children#_Recode	Children#_Recode	Number of children was clustered into 3 groups	0: First Pregnancy 1: 1-2 children 2: 3+ children
98	EducationLevel_Recode	EducationLevel_Recode	Education level was clustered into 3 groups	1: Primary/ Secondary School 2: Third Level Education 3: Postgraduate Education
99	FetalAnomaliesTests	FetalAnomaliesTests	Number of correct answers to "screening for anomalies"	0: None Correct 1: One Correct

			<p>understanding. Answers recoded to determine the how many participants could select none, some, or all of the correct answers for the question “What do you understand by ‘screening for fetal anomalies’?”. Coding was done based on the answers recorded for variables</p> <p>BabysDNA Mothersbloodlevels Ultrasound Nuchaltransucency Anatomyscan</p>	<p>2: Two Correct 3: Three Correct 4: Four Correct 5: Five Correct</p>
100	HighRiskLevel_Recode	HighRiskLevel_Recode	<p>Combined the three lowest risk levels (option 5, 6 and 7 of variable HighRiskLevel) due to the low number selected.</p>	<p>1: 1 in 2 2: 1 in 10 3: 1 in 100 4: 1 in 1000 5: 1 in 10000+ 6: Unsure</p>
101	RiskFactorsCorrect_Recode	RiskFactorsCorrect_Recode	<p>Answers to question “Which of the following factors increase a woman’s likelihood of having a baby with Down syndrome?” recoded to determine the how many participants could select none, some, or all of the correct answers. Coding was based on the answers recorded to variables</p> <p>Increasedmaternalage Increasedpaternalage PreviousDSchild Previousmiscarriage OtherfamilywithDS Otherfamilywithautism Nofolicacidsupplement</p>	<p>0: Zero Correct 1: One Correct 2: Two Correct 3: Three Correct</p>