Data Dictionary Codebook

Newborn Screening Residuals (Nursing pid=19) (PID: 10322)

03/13/2025 10:31am

Instruments	
Instrument	Form Name
Newborn Screening Residual Data	newborn_screening_residual_data
File Repository	file_repository

#	Variable / Field Name	Field Label Field Note	Field Attributes (Field Type, Validation, Choices, Calculations, etc.)
strum	ent: Newborn Screen	ing Residual Data (newborn_screening_	residual_data)
1	[caseid]	Study ID (Internal use only)	text
2	[format]	Questions were given in what format?	dropdown
			1 1 - Knowledge Network (pilot data only)
			2 2 - Focus groups
			3 3 - Telephone (Dan Jones)
			4 4 - Paper (PRAMS-like)
			5 5 - Knowledge Network
3	[time]	Time of survey	text
4	[composition]	Composition or make up of group	dropdown
			1 General population
			2 African American
			3 Hispanic
			4 Mothers with children less than 5
			5 Native American
5	[group]	Video or No-video group?	dropdown
			1 1 - Video
			2 2 - No-video
6	[state]	State	dropdown
			11 ME
			12 NH
			13 VT
			14 MA
			15 RI
			16 CT
			21 NY
			22 NJ
			23 PA
			31 OH
			32 IN
			33 IL
			34 MI

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35	WI
41	MN
42	IA
43	МС
44	ND
45	SD
46	NE
47	KS
51	DE
52	MD
53	DC
54	VA
55	WV
56	NC
57	SC
58	GA
59	FL
61	KY
62	TN
63	AL
64	MS
71	AR
72	LA
73	OK
74	TX
81	МТ
82	ID
83	WY
84	CO
85	NM
86	ΑZ
87	UT
88	NV
91	WA
92	OR
93	CA
94	AK
95	НІ
96	AS
97	GU
98	PR

3/25, 10	0:31 A	M	Newborn Screening Residuals (Nursing	pid=19) REDCap
				99 VI
	7	[gender]	What is your Gender?	dropdown 1 Male 2 Female -1 Refused
	8	[q1]	Section Header: Please place an [X] in the box that matches your answer 1: Did you know that these tests are done?	dropdown 1
	9	[q2]	2: How supportive are you of Health Departments doing these blood tests on all new babies?	dropdown 1 1 - Very supportive 2 2 - Somewhat supportive 3 3 - Somewhat not supportive 4 4 - Not supportive 5 5 - Don't know -1 Refused
	10	[q3]	3: Do you think it is alright that these tests are done without permission from the parents?	dropdown 1 1 - Definitely alright 2 2 - Probably alright 3 3 - Probably not alright 4 4 - Definitely not alright 5 5 - Don't know -1 Refused
	11	[94]	Section Header: Pause: Please read the screen 4: How concerned would you be if Health Departments saved the leftover blood samples from babies after the testing is done?	dropdown 1 1 - Very concerned 2 2 - Somewhat concerned 3 3 - Only a little concerned 4 4 - Not at all concerned 5 5 - Don't know -1 Refused
	12	[q5]	Section Header: Pause: Please read the screen 5: In your opinion, should Health Departments use these leftover blood samples to maintain the quality of existing tests for newborns?	dropdown 1
	13	[q6]	6: Do you think it would be alright for these leftover blood samples to be used for important research on diseases that affect mothers and babies?	dropdown 1 1 - Definitely alright 2 2 - Probably alright

3/25, 1	0.5 I A	IIVI	Newborn Screening Residuals (Nursing	piu-19) REDGap
				3 3 - Probably not alright
				4 4 - Definitely not alright
				5 5 - Don't know
				-1 Refused
	14	[q7]	7: Do you think it would be alright for these	dropdown
		[4,]	leftover blood samples to be used for important	1 1 - Definitely alright
			research on diseases that affect the general public?	2 2 - Probably alright
			pasite.	3 3 - Probably not alright
				4 4 - Definitely not alright
				5 5 - Don't know
				-1 Refused
	15	[q8]	Section Header: Pause: Please read the screen	dropdown
	13	[40]	8: Would it be alright to use these leftover	1 1 - Definitely alright
			samples for research WITH parents permission	2 2 - Probably alright
			and WITH the baby's name attached?	3 3 - Probably not alright
				4 4 - Definitely not alright
				5 5 - Don't know
				-1 Refused
	1.0		O.W. Hishardishtanandanah	
	16	[q9]	9: Would it be alright to use these leftover samples for research WITH parents permission	dropdown 1 1 - Definitely alright
			and WITHOUT the baby's name attached?	2 2 - Probably alright
				3 3 - Probably not alright
				4 4 - Definitely not alright
				5 5 - Don't know
				-1 Refused
	17	[q10]	10: Would it be alright to use these leftover samples for research WITHOUT parents	dropdown 1 1 - Definitely alright
			permission and WITH the baby's name attached?	2 2 - Probably alright
				3 3 - Probably not alright
				4 4 - Definitely not alright
				5 5 - Don't know
				-1 Refused
	18	[q11]	11: Would it be alright to use these leftover samples for research WITHOUT parents	dropdown
			permission and WITHOUT the baby's name	1 1 - Definitely alright
			attached?	2 2 - Probably alright
				3 3 - Probably not alright
				4 4 - Definitely not alright
				5 5 - Don't know
				-1 Refused
	19	[q12]	12: If the leftover blood samples are used for	dropdown
			research, how much risk would this be for babies if the baby's name is attached?	1 1 - No risk at all
1	l	I	, , , , , , , , , , , , , , , , , , , ,	

2 2 - A little risk 3 3 - Some risk 4 4 - High risk 5 5 - Don't know -1 Refused 1 1 - No risk at all 2 2 - A little risk 3 3 - Some risk 4 4 - High risk 5 5 - Don't know -1 Refused 1 1 - No risk at all 2 2 - A little risk 3 3 - Some risk 4 4 - High risk 5 5 - Don't know -1 Refused 2 - A little risk 3 3 - Some risk 4 4 - High risk 5 5 - Don't know -1 Refused 0 - Refused 0	3/25, 1	0.517	uvi	Newborn Screening Residuals (Nursing	ріц—19) ПСБОАР
20 [q13] 13: If the leftover blood samples are used for research, how much risk would this be for babies of if the baby's name is NOT attached? 1 1. No risk at all 2 2. A little risk 3 3. Some risk 4 4. High risk 5 5. Don't know 1 Refused 1 1. No risk at all 2 2. A little risk 3 3. Some risk 4 4. High risk 5 5. Don't know 1 Refused 2 2. Some risk 4 4. High risk 5 5. Don't know 1 Refused 2 2. Some risk 4 4. High risk 5 5. Don't know 1 Refused 2 2. Some risk 4 4. No trust at all 5 5. Don't know 1 Refused 2 2. Some trust 3 3. A little trust 4 4. No trust at all 5 5. Don't know 1 Refused 2 2. Some trust 3 3. A little trust 4 4. No trust at all 5 5. Don't know 1 Refused 2 2. Some trust 3 3. A little trust 4 4. No trust at all 5 5. Don't know 1 Refused 2 2. Some trust 3 3. A little trust 4 4. No trust at all 5 5. Don't know 1 Refused 2 2. Some trust 3 3. A little trust 4 4. No trust at all 5 5. Don't know 1 Refused 2 2. Some trust 3 3. A little trust 4 4. No trust at all 5 5. Don't know 1 Refused 2 2. Some trust 3 3. A little trust 4 4. No trust at all 5 5. Don't know 1 Refused 2 2. Some trust 3 3. A little trust 4 4. No trust at all 5 5. Don't know 1 1. A lot of trust 2 2. Some trust 3 3. A little trust 4 4. No trust at all 5 5. Don't know 1 Refused 4. No trust at all 5 5. Don't know 1 Refused 4. A lot trust at all 5 5. Don't know 1 Refused 4. A lot trust at all 5 5. Don't know 1 Refused 4. A lot trust at all 5 5. Don't know 1 Refused 4. A lot trust at all 5 5. Don't know 1 Refused 4. A lot trust at all 5 5. Don't know 1 Refused 4. A lot trust at all 5 5. Don't know 1 Refused 4. A lot trust at all 5 5. Don't know 1 Refused 4. A lot trust at all 5 5. Don'					
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1 Refused					
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RESEARCHER to use the leftover blood samples for research in an ethical manner? 1		22	[a15]	15: How much do you trust UNIVERSITY	dropdown
23 [q16] 16: How much do you trust PRIVATE RESEARCH COMPANIES to use the leftover blood samples for research in an ethical manner? 16: How much do you trust PRIVATE RESEARCH COMPANIES to use the leftover blood samples for research in an ethical manner? 11			[4-5]	RESEARCHER to use the leftover blood samples	
4 4 - No trust at all 5 5 - Don't know -1 Refused 23 [q16] 16: How much do you trust PRIVATE RESEARCH COMPANIES to use the leftover blood samples for research in an ethical manner? 1 1 - A lot of trust 2 2 - Some trust 3 3 - A little trust 4 4 - No trust at all 5 5 - Don't know -1 Refused 24 [q17] 17: How much do you trust FEDERAL HEALTH AGENCIES to use the leftover blood samples for research in an ethical manner? 1 1 - A lot of trust 2 2 - Some trust 3 3 - A little trust 4 4 - No trust at all 5 5 - Don't know -1 Refused				for research in an ethical manner?	2 2 - Some trust
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24 [q17] 17: How much do you trust FEDERAL HEALTH AGENCIES to use the leftover blood samples for research in an ethical manner? 17: How much do you trust FEDERAL HEALTH AGENCIES to use the leftover blood samples for research in an ethical manner? 1				· · · · · · · · · · · · · · · · · · ·	1 1 - A lot of trust
24 [q17] 17: How much do you trust FEDERAL HEALTH AGENCIES to use the leftover blood samples for research in an ethical manner? 17: How much do you trust FEDERAL HEALTH AGENCIES to use the leftover blood samples for research in an ethical manner? 1				Tor research in an ethical manner:	2 2 - Some trust
24 [q17] 17: How much do you trust FEDERAL HEALTH AGENCIES to use the leftover blood samples for research in an ethical manner? 17: How much do you trust FEDERAL HEALTH AGENCIES to use the leftover blood samples for research in an ethical manner? 1					3 3 - A little trust
24 [q17] 17: How much do you trust FEDERAL HEALTH AGENCIES to use the leftover blood samples for research in an ethical manner? 1 1 - A lot of trust 2 2 - Some trust 3 3 - A little trust 4 4 - No trust at all 5 5 - Don't know					4 4 - No trust at all
24 [q17] 17: How much do you trust FEDERAL HEALTH AGENCIES to use the leftover blood samples for research in an ethical manner? 1 1 - A lot of trust 2 2 - Some trust 3 3 - A little trust 4 4 - No trust at all 5 5 - Don't know					5 5 - Don't know
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2 2 - Some trust 3 3 - A little trust 4 4 - No trust at all 5 5 - Don't know					
4 4 - No trust at all 5 5 - Don't know					
5 5 - Don't know					3 3 - A little trust
-1 Refused					
					-1 Refused

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	25	[q18]	18: If for practical reasons parents cannot be asked for permission would it be alright for a group representing your local community to approve research using leftover blood samples?	dropdown 1
	26	[q19]	Section Header: Pause: Please read the screen 19: It may be very difficult and costly to find many parents after several years: If parents cannot be contacted, what would be the best thing to do with their baby's leftover samples?	dropdown 1
	27	[q20]	Section Header: Pause: Please read the screen	for important health research -1 -1 - Refused to answer question dropdown
			20: Do you think it is more important to	 1 1 - Provide greater privacy protection 2 2 - Allow notification of parents if something important is learned -1 -1 - Refused to answer question
	28	[q21]	Section Header: Pause: Please read the screen 21: What do you think is the best thing to do?	dropdown 1 1 - Keep samples only if parents sign a form 2 2 - Keep samples unless parents contact the Health Department to have them destroyed -1 -1 - Refused to answer question
	29	[q22]	22: Would it be alright to use your sample for research if information connecting you to the sample was REMOVED?	dropdown 1
	30	[q23]	23: Would it be alright for them to use your leftover blood sample if information connecting you to the sample is STILL ATTACHED?	dropdown 1
	31	[q24]	Section Header: Pause: Please read the screen 24: After thinking about these questions for the last few minutes, we want your final opinion: Do you think it is alright to use these leftover blood samples for doing important research?	dropdown 1 1 - Definitely alright 2 2 - Probably alright

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				3 3 - Probably not alright4 4 - Definitely not alright
				5 5 - Don't know
				-1 Refused
	32	[q26]	Section Header: Pause: Please read the screen	dropdown
			25: Have you heard about the use of leftover newborn blood samples in the news?	1 1 - Yes
				2 2-No
				-1 Refused
	33	[age]	26: How old are you (in years)?	text (integer)
	34	[zipcode]	27: What is your Zip code?	text (integer)
	35	[education]	28: What is your highest level of education you have completed?	dropdown
			, and the second	1 1 - Some high school or less 2 2 - High school diploma or GED
				2 2 - High school diploma or GED 3 3 - Some college
				4 4 - Associates degree
				5 5 - Bachelors degree
				6 6 - Graduate degree
				-1 Refused
	26			
	36	[children]	29: How many children have you ever had, not including still births?	dropdown 1 1 - One
				2 2 - Two
				3 3 - Three
				4 4 - Four
				5 5 - More than four
				6 6 - None
				-1 Refused
	37	[child_health]	30: Do any of your children have a history of	dropdown
	3,	[chird_hearen]	serious health problems?	1 1 - Yes
				2 2 - No
				-1 Refused
	38	[serious_health]	31: Is there any history of serious health	dropdown
		[56: 2605_::6026::1]	problems in your immediate family?	1 1 - Yes
				2 2-No
				-1 Refused
	39	[ethnicity]	32: Are you of Hispanic or Latino descent?	dropdown
				1 1 - Yes
				2 2 - No
				-1 Refused
	40	[race]	33: Which of the following best describes your	dropdown
			race?	1 1 - White
				2 2 - Black or African American

5/25, 1	0.3 I A	AIVI	Newborn Screening Residuals (Nursing	piu-	19) NEDCap
				3	3 - American Indian or Alaska Native
				4	4 - Asian
				5	5 - Native Hawaiian & Other Pacific Islander
				6	6 - Other
				-1	Refused
	41	[political_aff]	34: In politics today, do you usually think of	dro	pdown
			yourself as?	1	1 - Republican
				2	2 - Democrat
				3	3 - Independent
				4	4 - Something else
				5	5 - Don't know
				-1	Refused
	42	[con_lib]	35: In politics today, would you say you are?	dro	pdown
				1	1 - Very conservative
				2	2 - Somewhat conservative
				3	3 - Moderate
				4	4 - Somewhat liberal
				5	5 - Very liberal
				-1	Refused
	43	[religion]	36: What, if anything, is your religion?	dro	pdown
				1	Catholic
				2	Baptist
				3	No religion
				4	Christian
				5	Methodist
				6	Lutheran
				7	Presbyterian
				8	Protestant
				9	Pentecostal
				-	Episcopalian/Anglican
				-	Jewish
				12	The Church of Jesus Christ of Latter- Day Saints
				13	Churches of Christ
				14	Non-denominational
			15	Congregational/UCC	
			16	Jehovah's Witnesses	
			17	Assemblies of God	
				18	
				19	Buddhist
				20	Evangelical/Born Again
1	l	1	Į į	1	

22 Sevent 23 Somet -1 Refuse 44 [rel_service] 37: Aside from weddings and funerals, how often do you attend religious services? dropdown 1 1 - Mor 2 2 - Onc 3 3 - Onc 4 4 - A fer	of God h Day Adventist
44 [rel_service] 37: Aside from weddings and funerals, how often do you attend religious services? dropdown 2 2-Onc 3 3-Onc 4 4-A fee	h Day Adventist
44 [rel_service] 37: Aside from weddings and funerals, how often do you attend religious services? dropdown 1 1 - Mor 2 2 - Onc 3 3 - Onc 4 4 - A fee	
44 [rel_service] 37: Aside from weddings and funerals, how often do you attend religious services? dropdown 1 1 - Mor 2 2 - Onc 3 3 - Onc 4 4 - A fer	ning else
do you attend religious services? 1 1 - Mor 2 2 - Onc 3 3 - Onc 4 4 - A fer	d
do you attend religious services? 1 1 - Mor 2 2 - Onc 3 3 - Onc 4 4 - A fer	
3 3 - Onc 4 4 - A fee	e than once a week
4 4 - A fee	e a week
	e or twice a month
5 5 - Seld	v times a year
	om or never.
-1 Refused	t
45 [income] 38: Last year, what was your total family income dropdown	
from all sources, before taxes?	than \$20,000
2 2 - 20 to	o under \$30,000
3 3 - 30 to	o under \$40,000
4 4 - 40 to	o under \$50,000
5 5 - 50 to	o under \$75,000
6 6 - 75 to	o under \$100,000
7 7 - 100	to under \$150,000
8 8 - \$150),000 or more
-1 Refused	d
46 [date] Date of survey YYYY-MM-DD text (date_yi	nd)
Finally, do you have any comments you want to share with us about the retention and use of leftover blood samples?	
48 [age_focus_group] DO NOT ENTER DATA (place holder for calculated dropdown	_
age category, early focus group data) 1 under 1	8
2 18-21	
3 22-30	
4 31-40	
5 41-55	_
6 56-65	
7 66-80	
8 Over 80	
49 [composition_kn] DO NOT ENTER DATA (place holder for KN dropdown	
sample categories) 1 Caucasi. WY, TX a	ans from UT, CO, NM, AZ, MT, nd NV
2 African-panel	Americans from the national
3 Hispanic TX and I	s from UT, CO, NM, AZ, MT, WY,
	ans NOT from UT, CO, NM, AZ, TX and NV

25, 1	0:31 A	AIVI	Newborn Screening Residuals (Nursing	pid=19)
				5 Native American or Alaska Natives from the national panel 6 no DVD
				7 Mothers
	50	[q25]	25: How much of the movie on newborn	dropdown
		[423]	screening did you watch?	1 1 - All of it
				2 2 - Some of it
				3 3 - None of it
				-1 Refused
	51	[newborn_screening_resi	Section Header: Form Status	dropdown
		dual_data_complete]	Complete?	0 Incomplete
				1 Unverified
				2 Complete
Inst	trume	ent: File Repository (f	file_repository)	
	52	[file_1]	Imported the attached file, by mistake. I was importing into a local instance of REDCap, but did not realize that I was reimporting data into the original project.	descriptive (Attachment: NewbornScreeningResi_DATA_2015-12- 17_1640.csv, Display format: Link)
	53	[file_2]	Syntax for Logistic regression	descriptive (Attachment: LR_q20q21_with_continuous_for_manuscript_revision Display format: Link)
	54	[file_3]	Syntax for GLM	descriptive (Attachment: Core_questions_GLM_for_manuscript_revision.s Display format: Link)
	55	[file_4]	Comparing corrected dataset to original Pediatric published dataset. No meaningful changes exist.	descriptive (Attachment: Output_LR_coompare_reported_corrected_data Display format: Link)
	56	[file_5]	Comparing corrected dataset results to Pediatrics reported. No meaningful differences exist.	descriptive (Attachment: Output_glm_compare_reported_corrected_data Display format: Link)
	57	[file_6]	Dataset that Pediatrics article was developed from	descriptive (Attachment: 03_02_2011- after_recoding_online_focus_groups_without_pi Display format: Link)
	58	[file_7]	This dataset has 2 participants that have been recoded. They were in the PRAMS format but indicated they watched the video (group, and group_r variables).	descriptive (Attachment: 03_02_2011- after_recoding_online_focus_groups- for_manuscript_revision_2_Burbank.sav, Display format: Link)
	59	<pre>[file_repository_comple te]</pre>	Section Header: Form Status Complete?	dropdown 0 Incomplete 1 Unverified 2 Complete