



1	2 3	4	5	6	7	8	9	10	11	12	13	14
			How old was the patient at the time of diagnosis with Phelan-McDermid									
	Has the patient been tested for any of the following conditions?										e or a SHANK3 utation?	microarray analysis array CGH, FISH, genetic sequencing etc.)
	Survey Session ID Survey Date	1 - Condition	1 - Age at testing	2 - Condition	2 - Age at testing	3 - Condition	3 - Age at testing	4 - Condition	4 - Age at testing	Age - Years	s Age - Months	s Responses
		Pervasive Developmental Disorder (PDD)									7 months	Del 22q13.31
		Pervasive Developmental Disorder (PDD)									7 months	Del 22q13.31
		Pervasive Developmental Disorder (PDD)									7 months	Del 22q13.31
		Pervasive Developmental Disorder (PDD)	2 years								7 months	Del 22q13.31
			4 years	ADHD	4 years					7 years	5 months	Del 22q13.33
		Autism	4 years	ADHD	4 years					7 years	5 months	Del 22q13.33
		_	4 years	ADHD	4 years					7 years	5 months	Del 22q13.33
		No									8 months	Del 22q13.3
		Autism	3 years	(PDD)	2 years	Other	18 years	Other	18 years	9 years	5 months	Del 22q13.31
-			2 years		5 years					2 years	6 months	Del 22q13.33
										2 years		Del 22q13.31
		Autism	3 years	ADHD	3 years	Cerebral Palsy	6 years			7 years	5 months	Del 22q13.33
				ADHD	3 years	Cerebral Palsy	6 years			7 years	5 months	Del 22q13.33
				ADHD	3 years	Cerebral Palsy	6 years			7 years	5 months	Del 22q13.33
		Autism	3 years	ADHD	3 years	Cerebral Palsy	6 years			7 years	5 months	Del 22q13.33
					3 years	Cerebral Palsy				7 years	5 months	Del 22q13.33
				ADHD	3 years	Cerebral Palsy	6 years			7 years	5 months	Del 22q13.33
					3 years	Cerebral Palsy				7 years	5 months	Del 22q13.33
_					3 years	Cerebral Palsy				7 years	5 months	Del 22q13.33
					3 years	Cerebral Palsy				7 years	5 months	Del 22q13.33
				ADHD	3 years	Cerebral Palsy				7 years	5 months	Del 22q13.33
			1 year		_		_			1 year	2 months	Del 22q13.2
			1 year							1 year	2 months	Del 22q13.2
		1	1 year							1 year	2 months	Del 22q13.2
			1 year							1 year	2 months	Del 22q13.2

dataClinical.csv

1	SubFile	Head1	Head2	IIISLEVO	neioimat	VarName	LIIIKEU	Header Patient ID
1		Patient.ID			U			
2		Survey.Session.ID			0			Survey.Session.ID
3		Survey.Date			0			Survey.Date
68	Diagnosis	Has.the.patient.been.tested.for.any.of.the.following.conditions?	1_Condition	Н	1	Condition	1	Has.the.patient.been.tested.for.any.of.the.following.conditions?_1_Condition
		Has.the.patient.been.tested.for.any.of.the.following.conditions?		Н	0	Age.at.testing	1	Has.the.patient.been.tested.for.any.of.the.following.conditions?_1_Age.at.testing
		Has.the.patient.been.tested.for.any.of.the.following.conditions?		Н	1	Condition		Has.the.patient.been.tested.for.any.of.the.following.conditions?_2_Condition
		Has.the.patient.been.tested.for.any.of.the.following.conditions?		Н	0	Age.at.testing	2	Has.the.patient.been.tested.for.any.of.the.following.conditions?_2_Age.at.testing
72	Diagnosis	Has.the.patient.been.tested.for.any.of.the.following.conditions?	3_Condition	Н	1	Condition	3	Has.the.patient.been.tested.for.any.of.the.following.conditions?_3_Condition
		Has.the.patient.been.tested.for.any.of.the.following.conditions?		Н	0	Age.at.testing		Has.the.patient.been.tested.for.any.of.the.following.conditions?_3_Age.at.testing
		Has.the.patient.been.tested.for.any.of.the.following.conditions?		Н	1	Condition		Has.the.patient.been.tested.for.any.of.the.following.conditions?_4_Condition
75	Diagnosis	Has.the.patient.been.tested.for.any.of.the.following.conditions?	4_Age.at.testing	Н	0	Age.at.testing	4	Has.the.patient.been.tested.for.any.of.the.following.conditions?_4_Age.at.testing
		How.old.was.the.patient.at.the.time.of.diagnosis.with.Phelan-						How.old.was.the.patient.at.the.time.of.diagnosis.with.Phelan-
89	Diagnosis	McDermid.Syndrome.or.a.SHANK3.mutation?	Age_Years	Н	2	Age		McDermid.Syndrome.or.a.SHANK3.mutation?_Age_Years
		How.old.was.the.patient.at.the.time.of.diagnosis.with.Phelan-						How.old.was.the.patient.at.the.time.of.diagnosis.with.Phelan-
90	Diagnosis	McDermid.Syndrome.or.a.SHANK3.mutation?	Age_Months	Н	2	Age		McDermid.Syndrome.or.a.SHANK3.mutation?_Age_Months
91	Diagnosis	What.are.the.results.of.the.patient's.genetic.test?		Н	0			What.are.the.results.of.the.patient's.genetic.test?

Structure is inferred from the file and registry structure :

second level : Section heading in the registry
third level and fourth levels : from the registry question
additional levels depending on reformatting

- first level : Questionnaire name

								.tested.for.any.of.the.				patient.at.tne.tim	
								following.conditions?			e.of.diagnosis.wit	e.of.diagnosis.wi	t
		Has.the.patient.been		Has.the.patient.been	Has.the.patient.been	Has.the.patient.been	following.conditions?			Has.the.patient.been		h.Phelan-	
						.tested.for.any.of.the.		Developmental	Has.the.patient.been				
						following.conditions?		Disorder		following.conditions?			
		_ADHD_Age.at.testi	following.conditions?	_Autism_Age.at.test	_Cerebral	_Cerebral	Disorder	(PDD)_Age.at.testin		_Other_Age.at.testin		3.mutation?	.of.the.patient's
) _/	ADHD_Condition	ng	_Autism_Condition	ing	Palsy_Condition	Palsy_Age.at.testing		g	_Other_Condition	g	_Age_Years	_Age_Months	tic.test?
							Yes	2 years				7 months	Del 22q13.31
Yes	S	4 years	Yes	4 years							7 years	5 months	Del 22q13.33
												8 months	Del 22q13.3
			Yes	3 years			Yes	2 years	Yes	18 years	9 years	5 months	Del 22q13.31
			Yes	5 years							2 years	6 months	Del 22q13.33
											2 years		Del 22q13.31
Yes	S	3 years	Yes	3 years	Yes	6 years					7 years	5 months	Del 22q13.33
		_		_					Yes	1 year	1 year	2 months	Del 22q13.2
										_	2 years		
									Yes		_	1 month	Del 22q13.2
Yes	S	5 years	Yes	2 years							2 years	2 months	Del 22q13.31
		-	Yes	2 years							4 years	11 months	Del 22q13.3
Yes	5	2 years		_			Yes	5 years			4 years	10 months	Del 22q13.31
		•							Yes	2 years	3 years		Del 22q13.33

## Clinical - Diagnosis.txt

□ □ Condition

