

PANS diagnosis - 1 record per individual						Variable Availability							
<p><i>This is likely the longest component survey included in the Registry, but perhaps also the most important as we'll be asking you detailed information about 's' experience with PANS.</i></p> <p><i>If you get tired, you can take a break, and when you return, continue from where you left off. However, it is very important that you complete the entire survey so that everyone in the community has answered the same questions.</i></p>						Epi Baseline <sup>long</sup>		Epi Baseline <sup>short</sup>			Epi regular follow up	Recruit. Only	
Statistical Name	Question Text	Data Type	Required?	Branching Logic	Value	Literal	cases	siblings	cases	siblings	controls	cases	cases
pansdx_aware	How did you first hear about PANS?	Drop-down list	Y			1 a friend/family member 2 my doctor 3 the internet 4 a therapist 5 school 6 other	X						
pansdx_aware_other	From what "other" source did you first hear about PANS?	Text memo	Y	[pansdx_aware]==6	text	(text)	X						
pansdx	Has a physician formally diagnosed your child with PANS or PANDAS?	Drop-down list	Y			1 Yes 0 No	X		X				X
	What do you suspect your child has? Please select all that apply.		Y	[pansdx]==0									
pansdx_no_PANS		PANS Boolean				1 selected -1 NOT selected	X		X				X
pansdx_no_PANDAS		PANDAS Boolean				1 selected -1 NOT selected	X		X				X
PANS_dx_year	What year was it the first time a physician told you this?	Integer	Y	[pansdx]==1	#	(integer)	X		X				X
pansdx_physname	Please list the names of all physicians who have diagnosed your child with PANS or PANDAS and who have subsequently confirmed this diagnosis.	Text memo		[pansdx] == 1		text	X						
	What specific diagnosis has a physician given your child? Please select all that apply.			[pansdx] == 1									
pansdx_yes_PANS		PANS Boolean	N			-1 NOT selected 1 selected	X		X				X
pansdx_yes_PANDAS		PANDAS Boolean	N			-1 NOT selected 1 selected	X		X				X
	How did the physician make this determination? Please select all that apply			[pansdx] == 1									
PANSdx_basis_clinobs	Clinical observation	Boolean	N			1 selected -1 NOT selected	X						
PANSdx_basis_tests	Tests	Boolean	N			1 selected -1 NOT selected	X						
PANSdx_basis_oth	Other	Boolean	N			1 selected -1 NOT selected	X						
PANSdx_basis_idk	I'm not sure	Boolean	N			1 selected -1 NOT selected	X						
PANSdx_basis_other	Please describe the "other" approach a physician used to make this determination.	Text memo	Y	[PANSdx_basis_oth]==1		text	X						
	What tests were relied on to make this determination? Please select all that apply.			[PANSdx_basis_tests]==1									
PANSdx_tests_lab	Lab work	Boolean	N			1 selected -1 NOT selected	X						
PANSdx_tests_mri	Magnetic Resonance Imaging (MRI)	Boolean	N			1 selected -1 NOT selected	X						
PANSdx_tests_lumb	Lumbar Puncture	Boolean	N			1 selected -1 NOT selected	X						
PANSdx_tests_eeg	Electroencephalogram (EEG)	Boolean	N			1 selected -1 NOT selected	X						
PANSdx_tests_oth	Other	Boolean	N			1 selected -1 NOT selected	X						
PANSdx_tests_idk	I am not sure	Boolean	N			1 selected -1 NOT selected	X						
PANSdx_tests_other	What "other" tests were relied on?	Text memo	Y	[PANSdx_tests_oth]==1		text	X						
PANSdx_code	For insurance billing purposes, what diagnoses (and codes, if known) has the physician recorded for your child?	Text memo		[pansdx] == 1		text	X						
PANSdx_parentexpln	In your opinion, what do you think is the most likely explanation for how/why your child has PANS? In other words, what do you think led your child to get PANS?	Text memo	Y	[pansdx] == 1		text	X						
PANSdx_parentdisruptscale	How disruptive would you say PANS has been in your child's life (at the most severe times) on a scale from 1 to 10 (10=extremely disruptive)?	Integer	Y	[pansdx] == 1		text	X						
PANSdx_parentsevscale	Knowing what you do about PANS, how severe do you think your child's case has been (at the most severe times) on a scale from 1 to 10 (10=most severe)?	Integer	Y	[pansdx] == 1		text	X		X				
comor_puberty	Has your child entered puberty?	List of values	Y			1 Yes 0 No	X	X	X			X	X
cormor_puberty_effect	How would you characterize the effect of puberty on your child's PANS symptoms? If responding for a control, please select "NA".	Drop-down list	Y	[comor_puberty] == 1		0 No effect 1 More dramatic symptoms after puberty 2 Less dramatic symptoms after puberty 3 NA - my child was diagnosed with PANS after going through puberty 4 NA - I am reporting on a control	X	X	X			X	X
medrecs_cunningham	Has your child had a Cunningham Panel?	List of values	Y			1 Yes 0 No 2 I can't remember/unknown	X		X				X
<b>Cunningham Panel Sub-Form</b> <i>multiple records per individual possible</i>													
medrecs_cunningham_sub	Please record the Cunningham Panel results. If multiple panels have been done, continue clicking the + Cunningham panel results (iPad) or + ADD OCCURRENCE (laptop) button below until you've recorded ALL results. On an iPad, you can use the Left/Right arrows to scroll through your entries to make sure they are complete.			medrecs_cunningham==1		NA							
cunningham_date	Date of the Panel:	Date				date (yyyy-mm-dd)	X						







	Creatine																		
comor_table_creat_low		low	Boolean					1 selected -1 NOT selected		X	X								
comor_table_creat_high		high	Boolean					1 selected -1 NOT selected		X	X								
comor_table_creat_norm		normal range	Boolean					1 selected -1 NOT selected		X	X								
comor_table_creat_notest		never tested	Boolean					1 selected -1 NOT selected		X	X								
	Protein																		
comor_table_prot_low		low	Boolean					1 selected -1 NOT selected		X	X								
comor_table_prot_high		high	Boolean					1 selected -1 NOT selected		X	X								
comor_table_prot_norm		normal range	Boolean					1 selected -1 NOT selected		X	X								
comor_table_prot_notest		never tested	Boolean					1 selected -1 NOT selected		X	X								
	Ceruloplasmin																		
comor_table_cerul_low		low	Boolean					1 selected -1 NOT selected		X	X								
comor_table_cerul_high		high	Boolean					1 selected -1 NOT selected		X	X								
comor_table_cerul_norm		normal range	Boolean					1 selected -1 NOT selected		X	X								
comor_table_cerul_notest		never tested	Boolean					1 selected -1 NOT selected		X	X								
	CDS7																		
comor_table_cd57_low		low	Boolean					1 selected -1 NOT selected		X	X								
comor_table_cd57_high		high	Boolean					1 selected -1 NOT selected		X	X								
comor_table_cd57_norm		normal range	Boolean					1 selected -1 NOT selected		X	X								
comor_table_cd57_notest		never tested	Boolean					1 selected -1 NOT selected		X	X								
	Alkaline phosphatase																		
comor_table_alk_low		low	Boolean					1 selected -1 NOT selected		X	X								
comor_table_alk_high		high	Boolean					1 selected -1 NOT selected		X	X								
comor_table_alk_norm		normal range	Boolean					1 selected -1 NOT selected		X	X								
comor_table_alk_notest		never tested	Boolean					1 selected -1 NOT selected		X	X								
	Zinc																		
comor_table_zinc_low		low	Boolean					1 selected -1 NOT selected		X	X								
comor_table_zinc_high		high	Boolean					1 selected -1 NOT selected		X	X								
comor_table_zinc_norm		normal range	Boolean					1 selected -1 NOT selected		X	X								
comor_table_zinc_notest		never tested	Boolean					1 selected -1 NOT selected		X	X								
	Immunoglobulin A (IgA)																		
comor_table_IGA_low		low	Boolean					1 selected -1 NOT selected		X	X								
comor_table_IGA_high		high	Boolean					1 selected -1 NOT selected		X	X								
comor_table_IGA_norm		normal range	Boolean					1 selected -1 NOT selected		X	X								
comor_table_IGA_notest		never tested	Boolean					1 selected -1 NOT selected		X	X								
	Immunoglobulin M (IgM)																		
comor_table_IGM_low		low	Boolean					1 selected -1 NOT selected		X	X								
comor_table_IGM_high		high	Boolean					1 selected -1 NOT selected		X	X								
comor_table_IGM_norm		normal range	Boolean					1 selected -1 NOT selected		X	X								
comor_table_IGM_notest		never tested	Boolean					1 selected -1 NOT selected		X	X								
	Immunoglobulin G (IgG)																		
comor_table_IGG_low		low	Boolean					1 selected -1 NOT selected		X	X								
comor_table_IGG_high		high	Boolean					1 selected -1 NOT selected		X	X								
comor_table_IGG_norm		normal range	Boolean					1 selected -1 NOT selected		X	X								
comor_table_IGG_notest		never tested	Boolean					1 selected -1 NOT selected		X	X								
	Immunoglobulin E (IgE)																		
comor_table_IGE_low		low	Boolean					1 selected -1 NOT selected		X	X								
comor_table_IGE_high		high	Boolean					1 selected -1 NOT selected		X	X								
comor_table_IGE_norm		normal range	Boolean					1 selected -1 NOT selected		X	X								
comor_table_IGE_notest		never tested	Boolean					1 selected -1 NOT selected		X	X								
	Antinuclear antibody (ANA)																		
comor_table_ANA_low		low	Boolean					1 selected -1 NOT selected		X	X								



