PANS onset
- 1 record per individual

In this set of questions we ask you to tell us about when you first noticed 's PANS symptoms. Just tell us about their symptoms to the best of your ability and use your own interpretation of how you would describe the manifestation of those symptoms.

As a reminder, for the purposes of this Registry, PANS is an umbrella term that encompasses several subgroups, including PANDAS. Survey questions that use the term "PANS" are also asking about "PANDAS".

Statistical Name	Question Text	Data Type	Required?	Branching Logic	Value	Literal	Variable Availability: Epi Baseline[long] cases	Epi Baseline[long] siblings	Epi Baseline[short] cases	Epi Baseline[short] siblings	Epi Baseline[short] controls	Epi regular follow up cases	Recruit. Only cases
onset_pattern	**Would you say your child's PANS onset was:**	List of values	Y		1	Sudden and dramatic	X		X				X
					2	A gradual progression							
onset_start	**Do you feel like you can pinpoint the day or week symptoms began?**	List of values	Y		1	Yes			X				X
					0	No							
onset_sudden_age	How old was your child (in years) at the time of sudden and dramatic onset?	Integer		[onset_pattern]==1	#	*(integer)*	X		X				X
onset_sudden_duration	Over what duration of time did his or her dramatic increase in PANS symptoms develop?	Drop-down list		[onset_pattern]==1	1	Less than 24 hours	X		X				X
					2	24-72 hours							
					3	3 days - 1 week							
					4	1 - 3 weeks							
					5	3 -6 weeks							
					6	6 weeks - 3 months							
					7	3 - 9 months							
					8	More than 9 months							
onset_sudden_symptfree	Would you say your child was ever symptom-free?	List of values	Y	[onset_pattern]==1	1	Yes	X		X				X
					0	No							
onset_sudden_earlysigns	In hindsight, do you think your child showed any early signs or symptoms of having PANS?	List of values	Y	[onset_pattern]==1	1	Yes	X		X				X
					0	No							
onset_sudden_earlysigns_age	Looking back, how old (in years) was your child when you first noticed early signs or symptoms of PANS? (Please enter '0' for less than 1 year of age)	Integer		[onset_sudden_earlysigns]==1	#	*(integer)*	X		X				X
onset_gradual_earlysigns_age	Looking back, how old (in years) was your child when you first noticed early signs or symptoms of PANS? (Please enter '0' for less than 1 year of age)	Integer		[onset_pattern]==2	#	*(integer)*	X		X				X
onset_gradual_symptfree	Would you say your child was ever symptom-free?	List of values	Y	[onset_pattern]==2	1	Yes	X		X				X
					0	No							
onset_gradual_increase	Did your child experience a dramatic increase in PANS symptoms at some point?	List of values		[onset_pattern]==2	1	Yes	X		X				X
					0	No							
onset_gradual_increase_age	How old was your child (in years) at the time of the dramatic increase in PANS symptoms?	Integer		[onset_gradual_increase]==1	#	*(integer)*	X		X				X
onset_gradual_increase_duration	Over what duration of time did his or her dramatic increase in PANS symptoms develop?	Drop-down list		[onset_gradual_increase]==1	1	Less than 24 hours	X		X				X
					2	24-72 hours							
					3	3 days - 1 week							
					4	1 - 3 weeks							
					5	3 -6 weeks							
					6	6 weeks - 3 months							
					7	3 - 9 months							
					8	More than 9 months							
	ONSET A ("sudden and dramatic" + no early signs/symptoms)			[onset_pattern]==1 & [onset_sudden_earlysigns]==0									
onsetA_physician	**Did you take your child to see a physician during your child's initial onset of PANS symptoms?**	List of values	Y		1	Yes	X		X				
					0	No							
	Which symptoms heightened in intensity during this initial onset of PANS symptoms? Please select all that apply.												
onsetA_symptoms_obsess	Obsessions (unwanted thoughts, fears, and recurring worries)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetA_symptoms_compul	Compulsions (repetitive behaviors and rituals)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetA_symptoms_foodrestr	Severe restriction of food intake	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetA_symptoms_foodincr	Unexpected increase in food intake	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetA_symptoms_bfrb	Body-Focused Repetitive Behaviors (BFRB) (including hair pulling, skin picking, nail biting)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetA_symptoms_anx	Anxiety (including separation anxiety, irrational fears)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetA_symptoms_emotlab	Emotional lability (including mood changes, depression)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetA_symptoms_selmut	Selective Mutism	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetA_symptoms_irrit	Irritability, aggression, severe oppositional behaviors	Boolean	N		1	selected	X		X				
					-1	NOT selected							

onsetA_symptoms_behavregr	Behavioral (developmental) regression (including "baby talk", temper tantrums and "clingyness")	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetA_symptoms_school	Deterioration in school performance (including deficit of certain skills, shortened attention span)	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetA_symptoms_sensabn	Sensory abnormalities (including unusual sensitivity of the senses)	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetA_symptoms_mtrabn	Motor abnormalities (inluding tics, clumsiness, motoric hyperactivity, speech disorders)	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetA_symptoms_somatic	Somatic signs and symptoms (including sleep disturbance and urinary symptoms)	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetA_symptoms_opt_other	Other	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetA_symptoms_other	What "Other" symptoms heightened in intensity during this initial onset of PANS symptoms?	Text memo	Y	[onsetA_symptoms_opt_other==1]	*text*	*(text)*	X		X			
	What do you think triggered the initial onset of PANS symptoms? Please select all that apply.											
onsetA_trigger_anxstress	anxiety or stress	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetA_trigger_infxill	infection or illness	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetA_trigger_strepppl	being around someone who is strep positive	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetA_trigger_allergfood	food allergies	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetA_trigger_allergenviro	environmental allergies (including mold exposure)	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetA_trigger_vaccs	a recent vaccination	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetA_trigger_exerc	exercise	Boolean	N		1	selected	X					
					-1	NOT selected						
onsetA_trigger_lacksleep	lack of sleep	Boolean	N		1	selected	X					
					-1	NOT selected						
onsetA_trigger_sugar	sugar or junk food	Boolean	N		1	selected	X					
					-1	NOT selected						
onsetA_trigger_denthyg	dental work or cleaning	Boolean	N		1	selected	X					
					-1	NOT selected						
onsetA_trigger_looseteeth	loose primary teeth	Boolean	N		1	selected	X					
					-1	NOT selected						
onsetA_trigger_weather	changes in barometric pressure/weather	Boolean	N		1	selected	X					
					-1	NOT selected						
onsetA_trigger_headinj	head injury	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetA_trigger_moon	full moon	Boolean	N		1	selected			X			
					-1	NOT selected						
onsetA_trigger_swim	swimming	Boolean	N		1	selected			X			
					-1	NOT selected						
onsetA_trigger_horm	hormones	Boolean	N		1	selected			X			
					-1	NOT selected						
onsetA_trigger_bugs	bug bites	Boolean	N		1	selected			X			
					-1	NOT selected						
onsetA_trigger_elec	electronics	Boolean	N		1	selected			X			
					-1	NOT selected						
onsetA_trigger_oth	other	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetA_trigger_idk	I don't know	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetA_trigger_other	Please describe the "other" trigger.	Text memo		[onsetA_trigger_oth]==1	*text*	*(text)*	X		X			
	What type of infection or illness? Please select all that apply.			[onsetA_trigger_infxill]==1								
onsetA_trigger_infx_stom	stomach virus (unspecified)	Boolean	N		1	selected			X			
					-1	NOT selected						
onsetA_trigger_infx_ear	ear infections (unspecified)	Boolean	N		1	selected			X			
					-1	NOT selected						
onsetA_trigger_infx_flu	Influenza virus ("the flu")	Boolean	N		1	selected			X			
					-1	NOT selected						
onsetA_trigger_infx_pneu	Mycoplasma Pneumonia	Boolean	N		1	selected			X			
					-1	NOT selected						
onsetA_trigger_infx_covid	Coronavirus (COVID-19)	Boolean	N		1	selected			X			
					-1	NOT selected						
onsetA_trigger_infx_strep	Strep throat	Boolean	N		1	selected	X		X			

					-1	NOT selected							
onsetA_trigger_infx_perianal	Perianal strep dermatitis	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetA_trigger_infx_impet	Impetigo	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetA_trigger_infx_scarlet	Scarlet fever	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetA_trigger_infx_lyme	Lyme	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetA_trigger_infx_staph	Staph (non-MRSA)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetA_trigger_infx_mrsa	MRSA (methicillin-resistant Staphylococcus aureus)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetA_trigger_infx_asymp	asymptomatic/never noticed symptoms - confirmed infection by blood titers or cultures	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetA_trigger_infx_oth	other	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetA_trigger_infx_other	Please describe the "other" infection or illness.	Text memo		[onsetA_trigger_infx_oth]==1	*text*	*(text)*	X		X				
	What was your residential address at the time of your child's initial onset of PANS symptoms?						X						
onsetA_street	**House number and street:**	Text memo			*text*	*(text)*	X						
onsetA_city	**City:**	Text memo			*text*	*(text)*	X						
onsetA_zip	**Zip code:**	Text memo			*text*	*(text)*	X						
onsetA_PANSneighbors	**To your knowledge, has any child from this neighborhood (not in your family) gone on to develop PANS or PANDAS?**	Drop-down list	Y		1	Yes, one	X						
					2	Yes, more than one							
					0	None that I know of							
	In this survey, we will refer to a (1) symptom-free "baseline" status and a (2) "new baseline" status characterized by reduced but persistent PANS symptoms. Some individuals recover fully from a PANS symptom flare and are symptom-free, others recover from the flare but continue experiencing mild PANS symptoms as part of their day-to-day life.												
onsetA_baseline	**Did your child return to a symptom-free "baseline" following their initial onset of PANS symptoms? Please answer this question regardless of any/what type of treatment may have been given.**	Drop-down list	Y		1	Yes, my child returned to "baseline"	X		X				
					2	No, but my child did return to a "new baseline" (persistent, mild symptoms)							
					0	No, my child has not experienced relief from these heightened symptoms							
onsetA_baseline_time	How long did your child experience the initial onset/first notable flare in PANS symptoms before he or she returned to "baseline" or to a "new baseline"?	Drop-down list	Y	[onsetA_baseline]==1 || [onsetA_baseline]==2	1	less than 1 month	X		X				
					2	1-3 months							
					3	3-6 months							
					4	6-12 months							
					5	More than 1 year							
					6	I don't remember							
					7	He or she has never returned to a baseline or "new" baseline following the initial onset							
onsetA_baseline_timetoflare	Approximately how much time passed between your child's return to "baseline"/"new baseline" and their next flare in symptoms?	Drop-down list	Y	[onsetA_baseline]==1 || [onsetA_baseline]==2	1	less than 1 month	X		X				
					2	1-3 months							
					3	3-6 months							
					4	6-12 months							
					5	More than 1 year							
					6	I don't remember							
					7	He or she has never returned to a baseline or "new" baseline following the initial onset							
	What were the persistent, mild symptoms that characterized the "new baseline" your child experienced? Please select all that apply.			[onsetA_baseline]==2									
onsetA_newbaseline_sxs_obsess	Obsessions (unwanted thoughts, fears, and recurring worries)	Boolean			1	selected	X		X				
					-1	NOT selected							
onsetA_newbaseline_sxs_compul	Compulsions (repetitive behaviors and rituals)	Boolean			1	selected	X		X				
					-1	NOT selected							
onsetA_newbaseline_sxs_foodrestr	Severe restriction of food intake	Boolean			1	selected	X		X				
					-1	NOT selected							
onsetA_newbaseline_sxs_foodincr	Unexpected increase in food intake	Boolean			1	selected	X		X				
					-1	NOT selected							
onsetA_newbaseline_sxs_bfrb	Body-Focused Repetitive Behaviors (BFRB) (including hair pulling, skin picking, nail biting)	Boolean			1	selected	X		X				
					-1	NOT selected							
onsetA_newbaseline_sxs_anx	Anxiety (including separation anxiety, irrational fears)	Boolean			1	selected	X		X				
					-1	NOT selected							
onsetA_newbaseline_sxs_emotlab	Emotional lability (including mood changes, depression)	Boolean			1	selected	X		X				
					-1	NOT selected							
onsetA_newbaseline_sxs_selmut	Selective Mutism	Boolean			1	selected			X				
					-1	NOT selected							
onsetA_newbaseline_sxs_irrit	Irritability, aggression, severe oppositional behaviors	Boolean			1	selected	X		X				

					-1	NOT selected						
onsetA_newbaseline_sxs_behavregr	Behavioral (developmental) regression (including "baby talk", temper tantrums and "clingyness")	Boolean			1	selected	X		X			
					-1	NOT selected						
onsetA_newbaseline_sxs_school	Deterioration in school performance (including deficit of certain skills, shortened attention span)	Boolean			1	selected	X		X			
					-1	NOT selected						
onsetA_newbaseline_sxs_sensabn	Sensory abnormalities (including unusual sensitivity of the senses)	Boolean			1	selected	X		X			
					-1	NOT selected						
onsetA_newbaseline_sxs_mtrabn	Motor abnormalities (inluding tics, clumsiness, motoric hyperactivity, speech disorders)	Boolean			1	selected	X		X			
					-1	NOT selected						
onsetA_newbaseline_sxs_somatic	Somatic signs and symptoms (including sleep disturbance and urinary symptoms)	Boolean			1	selected	X		X			
					-1	NOT selected						
onsetA_newbaseline_sxs_oth	Other	Boolean			1	selected	X		X			
					-1	NOT selected						
onsetA_newbaseline_sxs_other	What "Other" persistent, mild symptoms characterized the "new baseline" your child experienced?	Text memo		[onsetA_newbaseline_sxs_oth==1	*text*	*(text)*	X					
	Onset B ("gradual increase" + no dramatic increase ever)			[onset_pattern]==2 & [onset_gradual_increase]==0								
onsetB_physician	**Did you take your child to see a physician as soon as you suspected he or she had PANS?**	List of values	Y		1	Yes	X		X			
					0	No						
onset_gradual_grad_prompt	**What prompted you to consider that your child had PANS?**	Text memo			*text*	*(text)*	X					
onset_gradual_grad_whynoincr	**Why do you think your child never experienced a dramatic increase in PANS symptoms?**	Text memo			*text*	*(text)*	X					
onset_gradual_grad_flares	**Would you say your child experiences flares in his or her PANS symptoms?**	Drop-down list			1	Yes	X		X			
					0	No						
	In hindsight, what was/were the very first symptom(s) you ever noticed was/were abnormal in your child's development? Please select all that apply.											
onsetB_firstsx_obsess	Obsessions (unwanted thoughts, fears, and recurring worries)	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetB_firstsx_compul	Compulsions (repetitive behaviors and rituals)	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetB_firstsx_foodrestr	Severe restriction of food intake	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetB_firstsx_foodincr	Unexpected increase in food intake	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetB_firstsx_bfrb	Body-Focused Repetitive Behaviors (BFRB) (including hair pulling, skin picking, nail biting)	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetB_firstsx_anx	Anxiety (including separation anxiety, irrational fears)	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetB_firstsx_emotlab	Emotional lability (including mood changes, depression)	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetB_firstsx_selmut	Selective Mutism	Boolean	N		1	selected			X			
					-1	NOT selected						
onsetB_firstsx_irrit	Irritability, aggression, severe oppositional behaviors	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetB_firstsx_behavregr	Behavioral (developmental) regression (including "baby talk", temper tantrums and "clingyness")	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetB_firstsx_school	Deterioration in school performance (including deficit of certain skills, shortened attention span)	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetB_firstsx_sensabn	Sensory abnormalities (including unusual sensitivity of the senses)	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetB_firstsx_mtrabn	Motor abnormalities (inluding tics, clumsiness, motoric hyperactivity, speech disorders)	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetB_firstsx_somatic	Somatic signs and symptoms (including sleep disturbance and urinary symptoms)	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetB_symptoms_opt_other	Other	Boolean	N		1	selected	X		X			
					-1	NOT selected						
onsetB_symptoms_other	What "Other" symptom(s) was/were the very first you ever noticed was/were abnormal in your child's development?	Text memo		[onsetB_symptoms_opt_other]==1	*text*	*(text)*	X		X			
onsetB_timetoPANS	**How much time passed between that very first noticeable symptom to the time you first thought he or she had PANS?**	Drop-down list	Y		0	less than 1 day	X					
					1	1-3 days						
					2	4-7 days						
					3	1 week - 1 month						
					4	1-6 months						
					5	6-12 months						

					6	A year or more							
					7	it depends/ is hard to say for sure							
					8	I don't remember							
	What do you think triggered the very first noticeable symptom that was abnormal in your child? Please select all that apply.												
onsetB_trigger_anxstress	anxiety or stress	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetB_trigger_infxill	infection or illness	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetB_trigger_strepppl	being around someone who is strep positive	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetB_trigger_allergfood	food allergies	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetB_trigger_allergenviro	environmental allergies (including mold exposure)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetB_trigger_vaccs	a recent vaccination	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetB_trigger_exerc	exercise	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetB_trigger_lacksleep	lack of sleep	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetB_trigger_sugar	sugar or junk food	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetB_trigger_dental	dental work or cleaning	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetB_trigger_looseteeth	loose primary teeth	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetB_trigger_weather	changes in barometric pressure/weather/altitude	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetB_trigger_headinj	head injury	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetB_trigger_moon	full moon	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetB_trigger_swim	swimming	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetB_trigger_horm	hormones	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetB_trigger_bugs	bug bites	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetB_trigger_elec	electronics	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetB_trigger_oth	other	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetB_trigger_idk	I don't know	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetB_trigger_other	Please describe the "other" trigger.	Text memo	Y	[onsetB_trigger_oth]==1	*text*	*(text)*	X		X				
	What type of infection or illness? Please select all that apply.			[onsetB_trigger_infxill]==1									
onsetB_trigger_infx_stom	stomach virus (unspecified)	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetB_trigger_infx_ear	ear infections (unspecified)	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetB_trigger_infx_flu	Influenza virus ("the flu")	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetB_trigger_infx_pneu	Mycoplasma Pneumonia	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetB_trigger_infx_covid	Coronavirus (COVID-19)	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetB_trigger_infx_strep	Strep throat	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetB_trigger_infx_perianal	Perianal strep dermatitis	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetB_trigger_infx_impet	Impetigo	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetB_trigger_infx_scarlet	Scarlet fever	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetB_trigger_infx_lyme	Lyme	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetB_trigger_infx_staph	Staph (non-MRSA)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetB_trigger_infx_mrsa	MRSA (methicillin-resistant Staphylococcus aureus)	Boolean	N		1	selected	X		X				
					-1	NOT selected							

onsetB_trigger_infx_asymp	Asymptomatic/never noticed symptoms - confirmed infection by blood titers or cultures	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetB_trigger_infx_oth	Other	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetB_trigger_infx_other	Please describe the "other" infection or illness.	Text memo	Y	[onsetB_trigger_infx_oth==1	*text*	*(text)*	X						
	Onset C ("sudden and dramatic" + early signs/symptoms OR "gradual progression" + dramatic increase at some point)			([onset_pattern]==1 & [onset_sudden_earlysigns]==1) or ([onset_pattern]==2 & [onset_gradual_increase]==1)									
onsetC_physician	**Did you take your child to see a physician during the first dramatic increase in PANS symptoms (first notable flare in symptoms)?**	List of values	Y		1	Yes	X		X				
					0	No							
	Which symptoms heightened in intensity during the first dramatic increase in PANS symptoms? Please select all that apply.												
onsetC_symptoms_obsess	Obsessions (unwanted thoughts, fears, and recurring worries)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_symptoms_compul	Compulsions (repetitive behaviors and rituals)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_symptoms_foodrestr	Severe restriction of food intake	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_symptoms_foodincr	Unexpected increase in food intake	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_symptoms_bfrb	Body-Focused Repetitive Behaviors (BFRB) (including hair pulling, skin picking, nail biting)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_symptoms_anx	Anxiety (including separation anxiety, irrational fears)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_symptoms_emotlab	Emotional lability (including mood changes, depression)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_symptoms_selmut	Selective Mutism	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetC_symptoms_irrit	Irritability, aggression, severe oppositional behaviors	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_symptoms_behavregr	Behavioral (developmental) regression (including "baby talk", temper tantrums and "clingyness")	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_symptoms_school	Deterioration in school performance (including deficit of certain skills, shortened attention span)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_symptoms_sensabn	Sensory abnormalities (including unusual sensitivity of the senses)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_symptoms_mtrabn	Motor abnormalities (inluding tics, clumsiness, motoric hyperactivity, speech disorders)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_symptoms_somatic	Somatic signs and symptoms (including sleep disturbance and urinary symptoms)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
	What do you think triggered the dramatic increase in PANS symptoms (first notable flare in symptoms)? Please select all that apply.												
onsetC_trigger_anxstress	Anxiety or stress	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_trigger_infxill	Infection or illness	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_trigger_strepppl	Being around someone who is strep positive	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_trigger_allergfood	Food allergies	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_trigger_allergenviro	Environmental allergies (including mold exposure)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_trigger_vaccs	a recent vaccination	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_trigger_exerc	Exercise	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetC_trigger_lacksleep	Lack of sleep	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetC_trigger_sugar	Sugar or junk food	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetC_trigger_dental	Dental work or cleaning	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetC_trigger_looseteeth	Loose primary teeth	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetC_trigger_weather	Changes in barometric pressure/weather	Boolean	N		1	selected	X						
					-1	NOT selected							

onsetC_trigger_headinj	Head injury	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_trigger_moon	full moon	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetC_trigger_swim	swimming	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetC_trigger_horm	hormones	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetC_trigger_bugs	bug bites	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetC_trigger_elec	electronics	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetC_trigger_oth	Other	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_trigger_idk	I don't know	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_trigger_other	Please describe the "other" trigger.	Text memo	Y	[onsetC_trigger_oth]==1	*text*	*(text)*	X		X				
	What type of infection or illness? Please select all that apply.			[onsetC_trigger_infxill]==1									
onsetC_trigger_infx_stom	stomach virus (unspecified)	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetC_trigger_infx_ear	ear infections (unspecified)	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetC_trigger_infx_flu	Influenza virus ("the flu")	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetC_trigger_infx_pneu	Mycoplasma Pneumonia	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetC_trigger_infx_covid	Coronavirus (COVID-19)	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetC_trigger_infx_strep	Strep throat	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_trigger_infx_perianal	Perianal strep dermatitis	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_trigger_infx_impet	Impetigo	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_trigger_infx_scarlet	Scarlet fever	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_trigger_infx_lyme	Lyme	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_trigger_infx_staph	Staph (non-MRSA)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_trigger_infx_mrsa	MRSA (methicillin-resistant Staphylococcus aureus)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_trigger_infx_asymp	Asymptomatic/never noticed symptoms - confirmed infection by blood titers or cultures	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_trigger_infx_oth	Other	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_trigger_infx_other	Please describe the "other" infection or illness.	Text memo	Y	[onsetC_trigger_infx_oth]==1	*text*	*(text)*	X						
	What was your residential address at the time of your child's dramatic increase in PANS symptoms (first notable flare in symptoms)?						X						
onsetC_street	**House number and street name:**	Text memo			*text*	*(text)*	X						
onsetC_city	**City:**	Text memo			*text*	*(text)*	X						
onsetC_zip	**Zip code:**	Text memo			*text*	*(text)*	X						
onsetC_PANSneighbor	**To your knowledge, has any child from this neighborhood (not in your family) gone on to develop PANS or PANDAS?**	Drop-down list	Y		1	Yes, one	X						
					2	Yes, more than one							
					0	None that I know of							
onsetC_earlysigns	**Looking back, do you think your child experienced any mild symptoms (early signs) before his or her dramatic increase in PANS symptoms?**	List of values	Y		1	Yes	X						
					0	No							
	What were the early signs and symptom(s) your child experienced prior to his or her dramatic increase in PANS symptoms? Please select all that apply.			[onsetC_earlysigns]==1									
onsetC_earlysigns_sxs_obsess	Obsessions (unwanted thoughts, fears, and recurring worries)	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetC_earlysigns_sxs_compul	Compulsions (repetitive behaviors and rituals)	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetC_earlysigns_sxs_foodrestr	Severe restriction of food intake	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetC_earlysigns_sxs_foodincr	Unexpected increase in food intake	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetC_earlysigns_sxs_bfrb	Body-Focused Repetitive Behaviors (BFRB) (including hair pulling, skin picking, nail biting)	Boolean	N		1	selected	X						
					-1	NOT selected							

onsetC_earlysigns_sxs_anx	Anxiety (including separation anxiety, irrational fears)	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetC_earlysigns_sxs_emotlab	Emotional lability (including mood changes, depression)	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetC_earlysigns_sxs_selmut	Selective Mutism	Boolean	N		1	selected							
					-1	NOT selected							
onsetC_earlysigns_sxs_irrit	Irritability, aggression, severe oppositional behaviors	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetC_earlysigns_sxs_behavregr	Behavioral (developmental) regression (including "baby talk", temper tantrums and "clingyness")	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetC_earlysigns_sxs_school	Deterioration in school performance (including deficit of certain skills, shortened attention span)	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetC_earlysigns_sxs_sensabn	Sensory abnormalities (including unusual sensitivity of the senses)	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetC_earlysigns_sxs_mtrabn	Motor abnormalities (inluding tics, clumsiness, motoric hyperactivity, speech disorders)	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetC_earlysigns_sxs_somatic	Somatic signs and symptoms (including sleep disturbance and urinary symptoms)	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetC_earlysigns_sxs_opt_other	Other	Boolean	N		1	selected	X						
					-1	NOT selected							
onsetC_earlysigns_sxs_other	What "Other" symptoms heightened in intensity during this initial onset of PANS symptoms?	Text memo	y	[onsetC_earlysigns_sxs_opt_other]==1	*text*	*(text)*	X						
onsetC_timetoPANS	How much time passed between the first presentation of these early, mild symptoms to the dramatic increase in sub-acute symptoms?	Drop-down list	y	[onsetC_earlysigns]==1	0	less than 1 day	X						
					1	1-3 days							
					2	4-7 days							
					3	1 week - 1 month							
					4	1-6 months							
					5	6-12 months							
					6	A year or more							
					7	it depends/ is hard to say for sure							
					8	I don't remember							
onsetC_nosymptbaseline	Did your child return to his or her symptom-free "baseline" following their dramatic increase in PANS symptoms? Please answer this question regardless of any/what type of treatment may have been given.	Drop-down list	y	[onsetC_earlysigns]==0	1	Yes, my child returned to "baseline"	X						
					2	No, but my child did return to a "new baseline" (persistent, mild symptoms)							
					0	No, my child has not experienced relief from these heightened symptoms							
onsetC_subbaseline	Did your child return to his or her sub-acute symptom "baseline" following their dramatic increase in PANS symptoms? Please answer this question regardless of any/what type of treatment may have been given.	Drop-down list	Y	[onsetC_earlysigns]==1	1	Yes, my child returned to "baseline"	X						
					2	No, but my child did return to a "new baseline" (persistent, mild symptoms)							
					0	No, my child has not experienced relief from these heightened symptoms							
onsetC_baseline	**Did your child return to his or her symptom-free "baseline" (or sub-acute symptom "baseline") following their dramatic increase in PANS symptoms? Please answer this question regardless of any/what type of treatment may have been given.**	Drop-down list	y		1	Yes, my child returned to "baseline"			X				
					2	No, but my child did return to a "new baseline" (persistent, mild symptoms)							
					0	No, my child has not experienced relief from these heightened symptoms							
onsetC_baseline_time	**How long did your child experience their dramatic increase in PANS symptoms before he or she returned to "baseline" or to a "new baseline"?**	Drop-down list	Y		1	less than 1 month	X		X				
					2	1-3 months							
					3	3-6 months							
					4	6-12 months							
					5	More than 1 year							
					6	I don't remember							
					7	He or she has never returned to a baseline or "new" baseline following the initial onset							
onsetC_baseline_timetoflare	**Approximately how much time passed between your child's return to "baseline"/"new baseline" and their next flare in symptoms?**	Drop-down list	Y		1	less than 1 month	X		X				
					2	1-3 months							
					3	3-6 months							
					4	6-12 months							
					5	More than 1 year							
					6	I don't remember							
					7	He or she has never returned to a baseline or "new" baseline following the initial onset							
	What were the persistent underlying symptoms that characterized your child's "new baseline"? Please select all that apply.			[onsetC_nosymptbaseline]==2||[onsetC_subbaseline]==2									
onsetC_newbaseline_sxs_obsess	Obsessions (unwanted thoughts, fears, and recurring worries)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_newbaseline_sxs_compul	Compulsions (repetitive behaviors and rituals)	Boolean	N		1	selected	X		X				

					-1	NOT selected							
onsetC_newbaseline_sxs_foodrestr	Severe restriction of food intake	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_newbaseline_sxs_foodincr	Unexpected increase in food intake	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_newbaseline_sxs_bfrb	Body-Focused Repetitive Behaviors (BFRB) (including hair pulling, skin picking, nail biting)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_newbaseline_sxs_anx	Anxiety (including separation anxiety, irrational fears)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_newbaseline_sxs_emotlab	Emotional lability (including mood changes, depression)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_newbaseline_sxs_selmut	Selective Mutism	Boolean	N		1	selected			X				
					-1	NOT selected							
onsetC_newbaseline_sxs_irrit	Irritability, aggression, severe oppositional behaviors	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_newbaseline_sxs_behavregr	Behavioral (developmental) regression (including "baby talk", temper tantrums and "clingyness")	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_newbaseline_sxs_school	Deterioration in school performance (including deficit of certain skills, shortened attention span)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_newbaseline_sxs_sensabn	Sensory abnormalities (including unusual sensitivity of the senses)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_newbaseline_sxs_mtrabn	Motor abnormalities (inluding tics, clumsiness, motoric hyperactivity, speech disorders)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_newbaseline_sxs_somatic	Somatic signs and symptoms (including sleep disturbance and urinary symptoms)	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_newbaseline_sxs_opt_other	Other	Boolean	N		1	selected	X		X				
					-1	NOT selected							
onsetC_newbaseline_sxs_other	What "Other" persistent, mild symptoms characterized the "new baseline" your child experienced?	Text memo	Y	[onsetC_newbaseline_sxs_opt_other] == 1	*text*	*(text)*	X		X				