

PANS flares - 1 record per individual							Variable Availability						
<p><i>For the purposes of this Registry, a flare episode is defined as a heightened intensity/exacerbation of symptoms following a trigger.</i></p> <p><i>In this section we ask you to tell us details of your observations around 's flare episodes.</i></p> <p><i>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"</i></p>							Epi Baseline ^{long}		Epi Baseline ^{short}			Epi regular follow up	Recruit. Only
Statistical Name	Question Text	Data Type	Required?	Branching Logic	Value	Literal	cases	siblings	cases	siblings	controls	cases	cases
flare_descript	Please describe what flare episodes look like for your child.	Text memo	Y			text (text)	X						
flare_number	How many flare episodes would you say your child has experienced in total?	Drop-down list	Y			1 1 2 2-5 3 6-10 4 More than I can remember	X						
flare_freq	How often does your child tend to experience a flare?	Drop-down list	Y			1 ~ once/month 2 ~ once/3 months 3 ~ once/6 months 4 ~ once/year or less 5 ~ once/year or more 6 My child remains symptomatic (chronic)	X		X			X	X
flare_dayspermonth	On average, how many days per month is your child flaring (experiencing a heightened intensity/exacerbation of symptoms)? Indicate "0" if less than 1 day/month on average.	Integer	Y			# (integer) 0 1 2 3 4 5 6 7 8 9 10 + MISSING	X						
flare_physician_opt	Do you usually take your child to see a physician during a flare episode? Please select one.	List of values				1 Yes, always 2 Yes, sometimes 3 Yes, but rarely 4 No - I used to, but don't anymore 5 Never missing	X						
	Please select all PANS symptoms your child has EVER experienced.						X						
	Please select all PANS symptoms your child has experienced in the past 6 months.											X	
flare_symptoms_obsess	Obsessions (unwanted thoughts, fears, and recurring worries)	Boolean	N			1 selected -1 NOT selected	X					X	
flare_symptoms_compul	Compulsions (repetitive behaviors and rituals)	Boolean	N			1 selected -1 NOT selected	X					X	
flare_symptoms_foodstr	Severe restriction of food intake	Boolean	N			1 selected -1 NOT selected	X					X	
flare_symptoms_foodincr	Unexpected increase in food intake	Boolean	N			1 selected -1 NOT selected	X						
flare_symptoms_bfrb	Body-Focused Repetitive Behaviors (BFRB) (including hair pulling, skin picking, nail biting)	Boolean	N			1 selected -1 NOT selected	X					X	
flare_symptoms_anx	Anxiety (including separation anxiety, irrational fears)	Boolean	N			1 selected -1 NOT selected	X					X	
flare_symptoms_emotlab	Emotional lability (including mood changes, depression)	Boolean	N			1 selected -1 NOT selected	X					X	
flare_symptoms_selmut	Selective Mutism	Boolean	N			1 selected -1 NOT selected						X	
flare_symptoms_irrit	Irritability, aggression, severe oppositional behaviors	Boolean	N			1 selected -1 NOT selected	X					X	
flare_symptoms_behavregr	Behavioral (developmental) regression (including "baby talk", temper tantrums and "clinginess")	Boolean	N			1 selected -1 NOT selected	X					X	
flare_symptoms_school	Deterioration in school performance (including deficit of certain skills, shortened attention span)	Boolean	N			1 selected -1 NOT selected	X					X	
flare_symptoms_sensabn	Sensory abnormalities (including unusual sensitivity of the senses)	Boolean	N			1 selected -1 NOT selected	X					X	
flare_symptoms_mtrabn	Motor abnormalities (including tics, clumsiness, motoric hyperactivity, speech disorders)	Boolean	N			1 selected -1 NOT selected	X					X	
flare_symptoms_somatic	Somatic signs and symptoms (including sleep disturbance and urinary symptoms)	Boolean	N			1 selected -1 NOT selected	X					X	
flare_symptoms_oth	Other	Boolean	N			1 selected -1 NOT selected	X					X	
flare_symptoms_other	Tell us more about the "other" symptoms your child has ever experienced.	Text memo	Y	[flare_symptoms_oth]=1		text (text)	X						
	Please select all of the symptoms that tend to be CONSISTENT across flare episodes.												
flare_consistentsymptoms_obsess	Obsessions (unwanted thoughts, fears, and recurring worries)	Boolean				1 selected -1 NOT selected	X						

flare_triggers_oth	other	Boolean	N			-1 NOT selected 1 selected	X	X			X	
flare_triggers_idk	I don't know	Boolean	N			-1 NOT selected 1 selected	X	X			X	
flare_trigger_other	Please describe the "other" trigger.	Text memo	Y	[flare_triggers_oth]=1		text (text)	X					
flare_trigger_infx_stom	stomach virus (unspecified)	Boolean	N	[flare_triggers_infxll]=1		1 selected -1 NOT selected		X			X	
flare_trigger_infx_ear	ear infections (unspecified)	Boolean	N			1 selected -1 NOT selected		X			X	
flare_trigger_infx_flu	Influenza virus ("the flu")	Boolean	N			1 selected -1 NOT selected		X			X	
flare_trigger_infx_pneu	Mycoplasma Pneumonia	Boolean	N			1 selected -1 NOT selected		X			X	
flare_trigger_infx_covid	Coronavirus (COVID-19)	Boolean	N			1 selected -1 NOT selected		X			X	
flare_trigger_infx_strep	Strep throat	Boolean	N			1 selected -1 NOT selected		X			X	
flare_trigger_infx_perianal	Perianal strep dermatitis	Boolean	N			1 selected -1 NOT selected		X			X	
flare_trigger_infx_impet	Impetigo	Boolean	N			1 selected -1 NOT selected		X			X	
flare_trigger_infx_scarlet	Scarlet fever	Boolean	N			1 selected -1 NOT selected		X			X	
flare_trigger_infx_lyme	Lyme	Boolean	N			1 selected -1 NOT selected		X			X	
flare_trigger_infx_staph	Staph (non-MRSA)	Boolean	N			1 selected -1 NOT selected		X			X	
flare_trigger_infx_mrsa	MRSA (methicillin-resistant Staphylococcus aureus)	Boolean	N			1 selected -1 NOT selected		X			X	
flare_trigger_infx_asymp	Asymptomatic/never noticed symptoms - confirmed infection by blood titers or cultures	Boolean	N			1 selected -1 NOT selected		X			X	
flare_trigger_infx_oth	Other	Boolean	N			1 selected -1 NOT selected		X			X	
Has your child ever had a confirmed positive test result for a viral or bacterial infection prior to/during a flare? Please select all that may apply.												
flare_pos_infx_test_covid	Coronavirus (COVID-19)	Boolean	N			1 selected -1 NOT selected		X			X	X
flare_pos_infx_test_hhv6	Human herpesvirus 6 (HHV-6)	Boolean	N			1 selected -1 NOT selected		X			X	X
flare_pos_infx_test_ebv	Epstein-Barr virus (EBV)	Boolean	N			1 selected -1 NOT selected		X			X	X
flare_pos_infx_test_coxa	Coxsackie A	Boolean	N			1 selected -1 NOT selected		X			X	X
flare_pos_infx_test_coxb	Coxsackie B	Boolean	N			1 selected -1 NOT selected		X			X	X
flare_pos_infx_test_myscopneu	Mycoplasma pneumoniae	Boolean	N			1 selected -1 NOT selected		X			X	X
flare_pos_infx_test_strep	Group A Streptococcus (GAS, Strep)	Boolean	N			1 selected -1 NOT selected		X			X	X
flare_pos_infx_test_lyme	Lyme	Boolean	N			1 selected -1 NOT selected		X			X	X
flare_pos_infx_test_parvob19	Parvo B19	Boolean	N			1 selected -1 NOT selected		X			X	X
flare_pos_infx_test_cmv	Cytomegalovirus (CMV)	Boolean	N			1 selected -1 NOT selected		X			X	X
flare_pos_infx_test_variczost	Varicella Zoster	Boolean	N			1 selected -1 NOT selected		X			X	X
flare_pos_infx_test_flua	Influenza A	Boolean	N			1 selected -1 NOT selected		X			X	X
flare_pos_infx_test_flub	Influenza B	Boolean	N			1 selected -1 NOT selected		X			X	X
flare_pos_infx_test_rose	Roseola	Boolean	N			1 selected -1 NOT selected		X			X	X
flare_pos_infx_test_bab	Babesia	Boolean	N			1 selected -1 NOT selected		X			X	X
flare_pos_infx_test_mrsa	Methicillin-resistant Staphylococcus aureus (MRSA)	Boolean	N			1 selected -1 NOT selected		X			X	X
flare_pos_infx_test_bart	Bartonella	Boolean	N			1 selected -1 NOT selected		X			X	X
flare_pos_infx_test_oth	other	Boolean	N			1 selected -1 NOT selected		X			X	X
flare_pos_infx_test_none	none of the above	Boolean	N			1 selected -1 NOT selected		X			X	X
flare_seasonal	Do you notice a seasonal pattern to your child's flare episodes?	List of values	Y			1 Yes 0 No	X					
flare_seasonal_increase_winter	Flares seem to increase in (please select all that apply): Winter (~December through ~February)	Boolean		[flare_seasonal]=1		1 selected -1 NOT selected	X					
flare_seasonal_increase_spring	Spring (~March through ~May)	Boolean				1 selected -1 NOT selected	X					
flare_seasonal_increase_summer	Summer (~June through ~August)	Boolean				1 selected	y					

flare_seasonal_increase_sept	Autumn (~September) - within a month of school beginning	Boolean				-1 NOT selected									
						1 selected	X								
flare_seasonal_increase_autumn	Autumn (~October through ~November) - more than a month after school begins	Boolean				-1 NOT selected									
						1 selected	X								
						-1 NOT selected									
flare_remission	Do you consider your child to be in remission (symptom free) now?	Drop-down list	Y			1 Yes, with ongoing treatment/medications	X		X				X	X	
						2 Yes, without any treatment/medications									
						0 No									
flare_remission_time	How many months has your child been in remission? (enter '0' for less than 1 month) 	Integer	Y		[flare_remission]=1 [flare_remission]=2	# (integer)	X		X				X	X	