

Health Care Utilization & School Attendance - 1 record per individual							Variable Availability						
Health Care Utilization													
<p>In this part of the survey we'll be asking some questions related to some of the challenges around accessing health care and education for . It is our hope to gather data that can be used for advocacy purposes. Please answer these questions honestly and to the best of your ability.</p> <p>In this first set of questions, we would like to learn about 's health care utilization experience.</p> <p>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".</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
PANS_util_ins_pvt	What kind of insurance or health care coverage does your child currently have? Please select all that apply.	Private Insurance	Boolean	N		1 selected -1 NOT selected	X						
PANS_util_ins_Mcare		Medicare	Boolean	N		1 selected -1 NOT selected	X						
PANS_util_ins_Mgap		Medi-gap	Boolean	N		1 selected -1 NOT selected	X						
PANS_util_ins_Mcaid		Medicaid	Boolean	N		1 selected -1 NOT selected	X						
PANS_util_ins_schip		SCHIP (CHIP/Children's Health Insurance Program)	Boolean	N		1 selected -1 NOT selected	X						
PANS_util_ins_military		Military health care (Tricare/VA/CHAMP-VA)	Boolean	N		1 selected -1 NOT selected	X						
PANS_util_ins_ihs		Indian Health Service	Boolean	N		1 selected -1 NOT selected	X						
PANS_util_ins_state		State-sponsored health plan	Boolean	N		1 selected -1 NOT selected	X						
PANS_util_ins_othgov		Other government program	Boolean	N		1 selected -1 NOT selected	X						
PANS_util_ins_sglsvc		Single service plan (e.g., dental, vision, prescriptions)	Boolean	N		1 selected -1 NOT selected	X						
PANS_util_ins_Can		Canadian government healthcare	Boolean	N		1 selected -1 NOT selected	X						
PANS_util_ins_other		Other (not listed here)	Boolean	N		1 selected -1 NOT selected	X						
PANS_util_ins_none		No coverage of any kind	Boolean	N		1 selected -1 NOT selected	X						
PANS_util_inspct	In the past year, what percent (%) of your child's PANS-related care and treatment do you estimate is covered by your insurance or health care coverage?	Integer	Y				X						
PANS_util_expend	In the past year, how much money do you estimate you spent (out-of-pocket) to provide PANS-related care for your child (\$ USD)?	Integer	Y				X						
PANS_util_expend_most	What is the most money in any one year that you estimate was spent (out-of-pocket) to provide PANS-related care for your child (\$ USD)?	Integer	Y				X						
PANS_util_locate	Have you EVER had difficulty LOCATING appropriate care and treatment for your child's PANS condition?	List of values	Y			1 Yes	X						
						0 No							
	Have you EVER had difficulty ACCESSING appropriate care and treatment for your child's PANS condition? Please select all that may apply.												
PANS_util_access_shortsvcs	Yes, due to shortage of treatment services where I live	Boolean	N			1 selected -1 NOT selected	X						
PANS_util_access_cost	Yes, due to cost and/or lack of insurance coverage	Boolean	N			1 selected -1 NOT selected	X						
PANS_util_access_waitlist	Yes, due to wait lists	Boolean	N			1 selected -1 NOT selected	X						
PANS_util_access_shortprov	Yes, due to shortage of specialty providers where I live	Boolean	N			1 selected -1 NOT selected	X						
PANS_util_access_no	No	Boolean	N			1 selected -1 NOT selected	X						
PANS_util_apptwait	How long did you have to wait for a new patient appointment with the first PANS specialist you saw?	Drop-down list	Y			1 < 1 month 2 1-2 months 3 3-4 months 4 5-6 months 5 More than 6 months 6 NA - we never went to a PANS specialist	X						
PANS_util_numphysprePANS	Approximately how many physicians did you see (specifically for your child's PANS symptoms) before one told you your child has PANS? Enter "99" if your child has not been diagnosed with PANS.	Integer	Y				X						
PANS_util_symptime	How much time passed between first reporting neuropsychiatric symptoms to a provider and hearing from a physician that your child has PANS?	Drop-down list	Y			1 Less than 1 month 2 1-3 months 3 3-6 months 4 6-12 months 5 1-2 years 6 At least 2 years 7 my child has not been diagnosed with PANS or PANDAS by a physician	X						
PANS_util_numphys	Approximately how many physicians have you sought for treatment and management of PANS symptoms?	Integer	Y				X						
PANS_util_hosp	Has your child been hospitalized for reasons related to PANS?	List of values	Y			1 Yes 0 No	X						
PANS_util_hosp_spec	Please tell us more about this hospitalization (including your child's age, symptoms, reason for hospitalization, length of stay, outcome, etc.).	Text memo	Y	[PANS_util_hosp]=1			X						

