

PHN MINDS: ACHD Data Codebook

DATE CREATED: Sep23,2025

Number of Observations: 511

Number of Variables: 11

FileName	Variable_label	Variable_Name	Category	N__Percent	Mean__SD	Median_Q1_Q3	Range
eos		BLIND_ID		511(100)			
eos		BLINDED_SITEID		511(100)			
eos	B1. End of study reason:	REASON	Lost to follow-up	32(6.3)			
eos	B1. End of study reason:	REASON	Participant decision to withdraw	5(1)			
eos	B1. End of study reason:	REASON	Participant not enrolled	9(1.8)			
eos	B1. End of study reason:	REASON	Physician decision to withdraw	1(0.2)			
eos	B1. End of study reason:	REASON	Study completed	464(90.8)			
eos	C1. Was biospecimen consent withdrawn?	BIOCWD	No	498(97.5)			
eos	C1. Was biospecimen consent withdrawn?	BIOCWD	Yes	13(2.5)			
eos	C1a. Reason for withdrawing biospecimen consent	BIOREASON		498(97.5)			
eos	C1a. Reason for withdrawing biospecimen consent	BIOREASON	After serval telephone calls and email reminders, participant emailed CRC to say that ""she will not be providing saliva sample"".	1(0.2)			
eos	C1a. Reason for withdrawing biospecimen consent	BIOREASON	Called Participant To Confirm Again They Wanted To Withdrawal Biorepository.	1(0.2)			

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FileName	Variable_label	Variable_Name	Category	N__Percent	Mean__SD	Median_Q1_Q3	Range
			Participant Confirmed And Apologized For Not Sending It In.				
eos	C1a. Reason for withdrawing biospecimen consent	BIOREASON	Changed Their Mind. Not Comfortable With It	1(0.2)			
eos	C1a. Reason for withdrawing biospecimen consent	BIOREASON	No Biospecimen Collected; Lost To Follow Up	1(0.2)			
eos	C1a. Reason for withdrawing biospecimen consent	BIOREASON	Not Eligible For Study	1(0.2)			
eos	C1a. Reason for withdrawing biospecimen consent	BIOREASON	Participant And Mother Had A Discussion And Decided To Withdraw From Saliva Sample Portion.	1(0.2)			
eos	C1a. Reason for withdrawing biospecimen consent	BIOREASON	Participant Did Not Want To Do Blood Draw At Visit	1(0.2)			
eos	C1a. Reason for withdrawing biospecimen consent	BIOREASON	Participant In Med School, States He Cannot Schedule Visit At This Time. Participant Decided Not To Participate.	1(0.2)			
eos	C1a. Reason for withdrawing biospecimen consent	BIOREASON	Participant No Longer Wants To Provide Any Sampling And Withdraws Consent.	1(0.2)			
eos	C1a. Reason for withdrawing biospecimen consent	BIOREASON	Previous Coordinator Did Not Have Proper Saliva Kit At The Visit Date.	1(0.2)			
eos	C1a. Reason for withdrawing biospecimen consent	BIOREASON	Pt Did Not State.	1(0.2)			
eos	C1a. Reason for withdrawing biospecimen consent	BIOREASON	Pt Said She Was No Longer Interested In The Study.	1(0.2)			

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FileName	Variable_label	Variable_Name	Category	N__Percent	Mean__SD	Median_Q1_Q3	Range
eos	C1a. Reason for withdrawing biospecimen consent	BIOREASON	Unspecified, Withdrew Over Phone Call Before Specimen Was Collected	1(0.2)			
eos	C1c. Was the biospecimen shipped to the lab prior to consent withdrawal?	BIOWDSHIP		498(97.5)			
eos	C1c. Was the biospecimen shipped to the lab prior to consent withdrawal?	BIOWDSHIP	No	12(2.3)			
eos	C1c. Was the biospecimen shipped to the lab prior to consent withdrawal?	BIOWDSHIP	Yes	1(0.2)			
eos	C2. Did the participant withdraw consent for questionnaire, demographics, or medical history data that was already collected?	OTHWD	No	509(99.6)			
eos	C2. Did the participant withdraw consent for questionnaire, demographics, or medical history data that was already collected?	OTHWD	Yes	2(0.4)			
eos	C2a. Please select all data/questionnaires for which consent was withdrawn:	WDPROC		509(99.6)			
eos	C2a. Please select all data/questionnaires for which consent was withdrawn:	WDPROC	Demographic information (some or all); Clinical/Medical information (some or all)	1(0.2)			
eos	C2a. Please select all data/questionnaires for which consent was withdrawn:	WDPROC	NIH Toolbox Cognitive Battery; NeuroQOL Item Bank v2.0 Cognitive Function; Hospital Anxiety and Depression Scale (HADS); PROMIS Scale v1.2 Global Health; Demographic information (some or all); Clinical/Medical information (some or all)	1(0.2)			
eos	C2b. Reason for withdrawing consent	OTHREASON		509(99.6)			

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FileName	Variable_label	Variable_Name	Category	N__Percent	Mean__SD	Median_Q1_Q3	Range
eos	C2b. Reason for withdrawing consent	OTHREASON	lost to follow up	1(0.2)			
eos	C2b. Reason for withdrawing consent	OTHREASON	participant not eligible for study	1(0.2)			
eos	B2. End of study time since consent, days:	EOS_TIME		503(98)	0.08(0.2)	0(0,0.07)	0,1
eos	C1b. time since consent, days biospecimen consent was withdrawn	BIOCWD_TIME		13(3)	0.24(0.3)	0.16(0.04,0.25)	0,0.73