

Data Set Name: longitudinal_ds.sas7bdat

Variable Number 1 Variable maskid Type Numeric Length 8 Format . Label De-identified Subject ID

Variable Number 2 Variable Visit Type Character Length 37 Format . Label Study visit

Variable Number 3 Variable visitstudt Type Numeric Length 8 Format . Label Study visit day (days since enrollment)

Variable Number 4 Variable AgeatV Type Numeric Length 8 Format . Label Age at visit (years)

Variable Number 5 Variable UPCR Type Numeric Length 8 Format . Label Urine protein: creatinine ratio

Variable Number 6 Variable eGFR Type Numeric Length 8 Format . Label eGFR (mL/min/1.73 m2): Children - Schwartz formula, Adults - CKD-EPI formula

Variable Number 7 Variable SerumCreatinineComp Type Numeric Length 8 Format . Label Serum Creatinine (mg/dL)

Variable Number 8 Variable Edema Type Numeric Length 8 Format . Label Any edema present

Variable Number 9 Variable Edema_Ansarca Type Numeric Length 8 Format . Label Anasarca edema

Variable Number 10 Variable Edema_Facial Type Numeric Length 8 Format . Label Facial edema

Variable Number 11 Variable Edema_LowExtrem Type Numeric Length 8 Format . Label Lower extremity edema

Variable Number 12 Variable Edema_Sacral Type Numeric Length 8 Format . Label Sacral edema

Variable Number 13 Variable Height Type Numeric Length 8 Format . Label Height (cm)

Variable Number 14 Variable Weight Type Numeric Length 8 Format . Label Weight (kg)

Variable Number 15 Variable BMI Type Numeric Length 8 Format . Label BMI

Variable Number 16 Variable BMIPCT Type Numeric Length 8 Format . Label BMI percentile; Calculated based on the U.S. population BMI distribution for each child's age and sex category

Variable Number 17 Variable WeightStatus Type Numeric Length 8 Format . Label Weight status, based on BMI (BMI percentile in pediatric)

Variable Number 18 Variable BP_SitSys Type Numeric Length 8 Format . Label Sitting Systolic blood pressure

Variable Number 19 Variable BP_SitDias Type Numeric Length 8 Format . Label Sitting Diastolic blood pressure

Variable Number 20 Variable SysPct Type Numeric Length 8 Format . Label Systolic percentile for toddler and infant; Calculated based on the U.S. population BP distribution for each child's age, sex and height category

Variable Number 21 Variable DiasPct Type Numeric Length 8 Format . Label Diastolic percentile for toddler and infant; Calculated based on the U.S. population BP distribution for each child's age, sex and height category

Variable Number 22 Variable HTNStatus Type Numeric Length 8 Format . Label Hypertensive status, based on JNC 7-8 Guidelines systolic/diastolic (systolic pctl/diastolic pctl in pediatric)

Variable Number 23 Variable HTNStatus2 Type Numeric Length 8 Format . Label Hypertensive status, based on 2017 ACC/AHA and AAP Guidelines systolic/diastolic (systolic pctl/diastolic pctl in pediatric)2017 ACC/AHA and AAP Guidelines

Variable Number 24 Variable Hematocrit Type Numeric Length 8 Format . Label Hematocrit (percent)

Variable Number 25 Variable Hemoglobin Type Numeric Length 8 Format . Label Hemoglobin (g/dL)

Variable Number 26 Variable MCH Type Numeric Length 8 Format . Label MCH (pg)

Variable Number 27 Variable MCHC Type Numeric Length 8 Format . Label MCHC (g/dL)

Variable Number 28 Variable MCV Type Numeric Length 8 Format . Label MCV (fl)

Variable Number 29 Variable Platelets Type Numeric Length 8 Format . Label Platelets (k/mm3)

Variable Number 30 Variable WBC Type Numeric Length 8 Format . Label WBC (k/mm3)

Variable Number 31 Variable A1c Type Numeric Length 8 Format . Label A1c (percent)

Variable Number 32 Variable Albumin Type Numeric Length 8 Format . Label Albumin (g/dL)

Variable Number 33 Variable AlkalinePhosphatase Type Numeric Length 8 Format . Label AlkalinePhosphate (iu/L)

Variable Number 34 Variable ALT Type Numeric Length 8 Format . Label ALT (iu/L)

Variable Number 35 Variable AST Type Numeric Length 8 Format . Label AST (iu/L)

Variable Number 36 Variable Calcium Type Numeric Length 8 Format . Label Calcium (mg/dL)

Variable Number 37 Variable Chloride Type Numeric Length 8 Format . Label Chloride (mmol/L)

Variable Number 38 Variable CO2 Type Numeric Length 8 Format . Label CO2 (mmol/L)

Variable Number 39 Variable Glucose Type Numeric Length 8 Format . Label Glucose (mg/dL)

Variable Number 40 Variable Magnesium Type Numeric Length 8 Format . Label Magnesium (mg/dL)

Variable Number 41 Variable Phosphorus Type Numeric Length 8 Format . Label Phosphorus (mg/dL)

Variable Number 42 Variable Potassium Type Numeric Length 8 Format . Label Potassium (mmol/L)

Variable Number 43 Variable Sodium Type Numeric Length 8 Format . Label Sodium (mmol/L)

Variable Number 44 Variable TotalBilirubin Type Numeric Length 8 Format . Label Total Bilirubin (mg/dL)

Variable Number 45 Variable UreaNitrogen Type Numeric Length 8 Format . Label Urea Nitrogen (mg/dL)

Variable Number 46 Variable CholesterolHDL_Cntrl Type Numeric Length 8 Format . Label HDL Cholesterol (mg/dL)

Variable Number 47 Variable CholesterolLDL_Cntrl Type Numeric Length 8 Format . Label LDL Cholesterol (mg/dL)

Variable Number 48 Variable CholesterolTotal_Cntrl Type Numeric Length 8 Format . Label Total Cholesterol (mg/dL)

Variable Number 49 Variable Triglycerides_Cntrl Type Numeric Length 8 Format . Label Triglycerides (mg/dL)

Variable Number 50 Variable UrineBlood Type Numeric Length 8 Format . Label Urinalysis: Hematuria

Variable Number 51 Variable UrineProtein Type Numeric Length 8 Format . Label Urinalysis: Protein dipstick

Variable Number 52 Variable ClinSymYN Type Numeric Length 8 Format . Label Within the last 2 weeks, experienced any of the following clinical symptoms

Variable Number 53 Variable ClinSym1_SB Type Numeric Length 8 Format . Label Shortness of Breath

Variable Number 54 Variable ClinSym2_Swell Type Numeric Length 8 Format . Label Swelling

Variable Number 55 Variable ClinSym3_Fever Type Numeric Length 8 Format . Label Fever

Variable Number 56 Variable ClinSym4_CPain Type Numeric Length 8 Format . Label Chest pain

Variable Number 57 Variable ClinSym5_FUrine Type Numeric Length 8 Format . Label Foamy urine

Variable Number 58 Variable ClinSym6_Diar Type Numeric Length 8 Format . Label Diarrhea

Variable Number 59 Variable ClinSym7_Naus Type Numeric Length 8 Format . Label Nausea and/or vomiting

Variable Number 60 Variable PROMIS_Adult_Anxiety Type Numeric Length 8 Format . Label PROMIS: Adult Anxiety Score

Variable Number 61 Variable PROMIS_Adult_Fatigue Type Numeric Length 8 Format . Label PROMIS: Adult Fatigue Score

Variable Number 62 Variable PROMIS_Adult_Mental Type Numeric Length 8 Format . Label PROMIS: Adult Mental Component Score

Variable Number 63 Variable PROMIS_Adult_Physical Type Numeric Length 8 Format . Label PROMIS: Adult Physical Component Score

Variable Number 64 Variable PROMIS_Adult_PhysicalFunction Type Numeric Length 8 Format . Label PROMIS: Adult Physical Functioning Score

Variable Number 65 Variable PROMIS_Adult_Sleep Type Numeric Length 8 Format . Label PROMIS: Adult Sleep Disturbance Score

Variable Number 66 Variable PROMIS_Proxy_Anxiety Type Numeric Length 8 Format . Label PROMIS: Parent Proxy Anxiety Score

Variable Number 67 Variable PROMIS_Proxy_Depression Type Numeric Length 8 Format . Label PROMIS: Parent Proxy Depressive Symptoms Score

Variable Number 68 Variable PROMIS_Proxy_Fatigue Type Numeric Length 8 Format . Label PROMIS: Parent Proxy Fatigue Score

Variable Number 69 Variable PROMIS_Proxy_Global Type Numeric Length 8 Format . Label PROMIS: Parent Proxy Global Score

Variable Number 70 Variable PROMIS_Proxy_Mobility Type Numeric Length 8 Format . Label PROMIS: Parent Proxy Mobility Score

Variable Number 71 Variable PROMIS_Proxy_Stress Type Numeric Length 8 Format . Label PROMIS: Parent Proxy Stress Score

Variable Number 72 Variable PROMIS_Ped_Anxiety Type Numeric Length 8 Format . Label PROMIS: Pediatric Anxiety Score

Variable Number 73 Variable PROMIS_Ped_Depression Type Numeric Length 8 Format . Label PROMIS: Pediatric Depressive Symptoms Score

Variable Number 74 Variable PROMIS_Ped_Fatigue Type Numeric Length 8 Format . Label PROMIS: Pediatric Fatigue Score

Variable Number 75 Variable PROMIS_Ped_Global Type Numeric Length 8 Format . Label PROMIS: Pediatric Global Score

Variable Number 76 Variable PROMIS_Ped_Mobility Type Numeric Length 8 Format . Label PROMIS: Pediatric Mobility Score

Variable Number 77 Variable PROMIS_Ped_Stress Type Numeric Length 8 Format . Label PROMIS: Pediatric Stress Score

Variable Number 78 Variable ImmunosuppressionV Type Numeric Length 8 Format . Label On immunosuppressive at visit

Variable Number 79 Variable SteroidV Type Numeric Length 8 Format . Label On steroid at visit

Variable Number 80 Variable CTXV Type Numeric Length 8 Format . Label On CTX at visit

Variable Number 81 Variable CNIV Type Numeric Length 8 Format . Label On CNI at visit

Variable Number 82 Variable RituxV Type Numeric Length 8 Format . Label On Rituximab at visit

Variable Number 83 Variable MMFV Type Numeric Length 8 Format . Label On MMF at visit

Variable Number 84 Variable OtherIStV Type Numeric Length 8 Format . Label On other immunosuppression therapy at visit

Variable Number 85 Variable RAASblockV Type Numeric Length 8 Format . Label On RAAS blocker at visit

Variable Number 86 Variable CoagPlateletV Type Numeric Length 8 Format . Label On anticoagulants at visit

Variable Number 87 Variable DiureticV Type Numeric Length 8 Format . Label On diuretic at visit

Variable Number 88 Variable CCBV Type Numeric Length 8 Format . Label On calcium channel blocker at visit

Variable Number 89 Variable CentralV Type Numeric Length 8 Format . Label On central alpha agonist at visit

Variable Number 90 Variable VasodilV Type Numeric Length 8 Format . Label On vasodilator at visit

Variable Number 91 Variable BetaBlockV Type Numeric Length 8 Format . Label On beta-blocker at visit

Variable Number 92 Variable AlphaBlockV Type Numeric Length 8 Format . Label On alpha-blocker at visit

Variable Number 93 Variable ImmunosuppressionPrev Type Numeric Length 8 Format . Label On immunosuppressive prior to visit

Variable Number 94 Variable SteroidPrev Type Numeric Length 8 Format . Label On steroid prior to visit

Variable Number 95 Variable CTXPrev Type Numeric Length 8 Format . Label On CTX prior to visit

Variable Number 96 Variable CNIPrev Type Numeric Length 8 Format . Label On CNI prior to visit

Variable Number 97 Variable RituxPrev Type Numeric Length 8 Format . Label On Rituximab prior to visit

Variable Number 98 Variable MMFPrev Type Numeric Length 8 Format . Label On MMF prior to visit

Variable Number 99 Variable OtherIStPrev Type Numeric Length 8 Format . Label On other immunosuppression therapy prior to visit

Variable Number 100 Variable RAASblockPrev Type Numeric Length 8 Format . Label On RAAS blocker prior to visit

Variable Number 101 Variable CoagPlateletPrev Type Numeric Length 8 Format . Label On anticoagulants prior to visit

Variable Number 102 Variable DiureticPrev Type Numeric Length 8 Format . Label On diuretic prior to visit

Variable Number 103 Variable CCBPreV Type Numeric Length 8 Format . Label On calcium channel blocker prior to visit

Variable Number 104 Variable CentralPreV Type Numeric Length 8 Format . Label On central alpha agonist prior to visit

Variable Number 105 Variable VasodilPreV Type Numeric Length 8 Format . Label On vasodilator prior to visit

Variable Number 106 Variable BetaBlockPreV Type Numeric Length 8 Format . Label On beta-blocker prior to visit

Variable Number 107 Variable AlphaBlockPreV Type Numeric Length 8 Format . Label On alpha-blocker prior to visit

Data Set Name: patient_ds.sas7bdat

Variable Number 1 Variable maskid Type Numeric Length 8 Format . Label De-identified Subject ID

Variable Number 2 Variable PAT_AgeKDonset Type Numeric Length 8 Format . Label Age of onset of nephrotic syndrome or proteinuria (calculated using most recently reported date of onset)

Variable Number 3 Variable PAT_AgeV2 Type Numeric Length 8 Format . Label Age at baseline visit

Variable Number 4 Variable PAT_Hispanic Type Numeric Length 8 Format . Label Ethnic Background

Variable Number 5 Variable PAT_KDDurationMonths Type Numeric Length 8 Format . Label Duration (months) of kidney disease at enrollment

Variable Number 6 Variable PAT_Ped Type Numeric Length 8 Format . Label Age less than 18 at time of baseline visit

Variable Number 7 Variable PAT_Race Type Numeric Length 8 Format . Label Race

Variable Number 8 Variable PAT_RaceBlack Type Numeric Length 8 Format . Label Race: Black/African American

Variable Number 9 Variable PAT_Sex Type Numeric Length 8 Format . Label Patient sex from the demographic file [N1, N2]

Variable Number 10 Variable PAT_Cohort Type Numeric Length 8 Format . Label Diagnostic cohort

Variable Number 11 Variable CompRemSinceBL Type Numeric Length 8 Format . Label Patient in complete remission (UPCR \leq 0.3)after baseline visit (among active disease at baseline)

Variable Number 12 Variable PartCompRemSinceBL Type Numeric Length 8 Format . Label Partial or complete remission after baseline visit (among active disease at baseline)

Variable Number 13 Variable ESRDtxpDial Type Numeric Length 8 Format . Label End stage renal disease reached after baseline

Variable Number 14 Variable ESRDorEGFR40 Type Numeric Length 8 Format . Label End stage renal disease or 40% loss of eGFR reached after baseline

Variable Number 15 Variable PAT_FUMonths Type Numeric Length 8 Format . Label Total follow-up months from enrollment to last visit

Variable Number 16 Variable CancerratBL Type Numeric Length 8 Format . Label History of cancer at baseline

Variable Number 17 Variable CADatBL Type Numeric Length 8 Format . Label History of coronary artery disease at baseline

Variable Number 18 Variable DMatBL Type Numeric Length 8 Format . Label History of diabetes at baseline

Variable Number 19 Variable HAatBL Type Numeric Length 8 Format . Label History of heart srrhythmia at baseline

Variable Number 20 Variable HFatBL Type Numeric Length 8 Format . Label History of heart failure at baseline

Variable Number 21 Variable HTNatBL Type Numeric Length 8 Format . Label History of hypertension at baseline

Variable Number 22 Variable PVDatBL Type Numeric Length 8 Format . Label History peripheral vascular disease of at baseline

Variable Number 23 Variable RheumatBL Type Numeric Length 8 Format . Label History of Rheumatologic disease at baseline

Variable Number 24 Variable StrokeatBL Type Numeric Length 8 Format . Label History of stroke at baseline

Variable Number 25 Variable TEatBL Type Numeric Length 8 Format . Label History of thromboembolic event at baseline

Variable Number 26 Variable PAT_ChildKD_Ever Type Numeric Length 8 Format . Label Any biological children diagnosed with kidney disease

Variable Number 27 Variable PAT_FamilyDM_Ever Type Numeric Length 8 Format . Label Family history of diabetes

Variable Number 28 Variable PAT_FamilyESRD_Ever Type Numeric Length 8 Format . Label Family history of end stage renal disease

Variable Number 29 Variable PAT_FamilyHTN_Ever Type Numeric Length 8 Format . Label Family history of hypertension

Variable Number 30 Variable PAT_FamilyKD_Ever Type Numeric Length 8 Format . Label Family history of kidney disease

Variable Number 31 Variable PAT_ParentKD_Ever Type Numeric Length 8 Format . Label Biological parent diagnosed with kidney disease

Variable Number 32 Variable PAT_SibKD_Ever Type Numeric Length 8 Format . Label Any siblings with at least one common parent diagnosed with kidney disease

Variable Number 33 Variable HeightPreKD Type Numeric Length 8 Format . Label Height prior to onset of kidney disease

Variable Number 34 Variable WeightPreKD Type Numeric Length 8 Format . Label Weight prior to onset of kidney disease

Variable Number 35 Variable BTerm Type Numeric Length 8 Format . Label Birth Term

Variable Number 36 Variable BirthWgt Type Numeric Length 8 Format . Label Birth weight (grams)

Variable Number 37 Variable GestAge Type Numeric Length 8 Format . Label Gestational age weeks

Variable Number 38 Variable BMultiple Type Numeric Length 8 Format . Label Part of a multiple birth (twin, triplet, etc.)

Variable Number 39 Variable FatherAge_Years Type Numeric Length 8 Format . Label Age of biological Father at time of birth - Years

Variable Number 40 Variable FatherRace Type Numeric Length 8 Format . Label Father Racial Background

Variable Number 41 Variable MotherAge_Years Type Numeric Length 8 Format . Label Age of biological mother at time of birth - Years

Variable Number 42 Variable MotherRace Type Numeric Length 8 Format . Label Mother Racial Background

Variable Number 43 Variable WorkStat Type Numeric Length 8 Format . Label Working status at baseline

Variable Number 44 Variable StuStat Type Numeric Length 8 Format . Label Student status at baseline

Variable Number 45 Variable NumHHAdults Type Numeric Length 8 Format . Label Number adults (18 and older) in same household at baseline

Variable Number 46 Variable NumHHChild Type Numeric Length 8 Format . Label Number children (under 18) in the same household at baseline

Variable Number 47 Variable AHHIncome Type Numeric Length 8 Format . Label Gross Annual Household Income at baseline

Variable Number 48 Variable FEdLevel Type Numeric Length 8 Format . Label Highest grade/level of school completed by father (or second caregiver/guardian)

Variable Number 49 Variable MEdLevel Type Numeric Length 8 Format . Label Highest grade/level of school completed by mother (or primary caregiver/guardian)

Variable Number 50 Variable EdLevel Type Numeric Length 8 Format . Label Highest grade/level of school completed by participant

Variable Number 51 Variable UPCR_V1 Type Numeric Length 8 Format . Label Urine protein: creatinine ratio at screening/enrollment

Variable Number 52 Variable RenalBxIndication Type Numeric Length 8 Format . Label Reason for Biopsy

Variable Number 53 Variable RenalBxIndicationOther Type Character Length 300 Format . Label Reason for Biopsy Other Specify

Variable Number 54 Variable number_of_risk_alleles Type Numeric Length 8 Format . Label Number of APOL1 risk alleles