

Consortium for Radiologic Imaging Studies of Polycystic Kidney Disease (CRISP) Data Archive

The Consortium for Radiologic Imaging Studies of Polycystic Kidney Disease (CRISP) was established to develop and implement studies to test whether imaging techniques can provide accurate and reproducible markers of progression of renal disease in patients with polycystic kidney disease. Autosomal-dominant polycystic kidney disease (ADPKD) is characterized by gradual renal enlargement and cyst growth prior to loss of renal function; however, standard radiographic imaging has not provided the resolution and accuracy necessary to detect small changes in renal volume or to reliably measure renal cyst volumes. The CRISP cohort study longitudinally observed ADPKD individuals using high-resolution magnetic resonance (MR) imaging to determine if change in renal and cyst volumes can be detected over a short period of time, and if they correlate with decline in renal function early in disease.

The CRISP data archive contains data through the CRISP 3 cycle, as well as allele frequency data.

The NIDDK Central Repository offers the following three data packages from the CRISP1 study:

1. The standard data archive, which contains a dataset compiled by the Data Center, Center for Research on Health Care at the University of Pittsburgh. The original study protocol and other descriptive documentation and the study forms are also provided in the standard data archive for reference.
2. The raw data archive, which contains the original raw data collected by the study, analysis files associated with study publications, and reports of the analyses performed by statisticians and quality control specialists at the Repository to ensure the completeness and accuracy of the analysis datasets in the Repository.
3. The genetic data archive, which contains raw and summary data collected in an ancillary study analyzing mutation-based molecular diagnostics of autosomal dominant polycystic kidney disease (ADPKD) in the CRISP population.

The NIDDK Central Repository recommends that only the standard data archive be used and it is included in the CRISP package. Requestors must ask for the genetics and/or raw data archives separately from the standard data archive.

Archive files are organized into the following directories:

- Data
- Documents
- Dataset Integrity Check (DSIC)
- Forms

The Data, Documents, and Forms directories are further organized into the following subdirectories:

- CRISP Allele (for Data folder only)

- CRISP1
- CRISP2
- CRISP3

Data

The CRISP Data directory contains the following files and datasets in Windows-based SAS and CSV formats, with corresponding codebooks.

Data/CRISP Allele

- crisp_ids_genetic_data.xlsx
- CRISP_IDS_GENETIC_DATA.CSV
- crisp_ids_genetic_data.sas7bdat

Data\CRISP1

- CRISP1_DataDictionary_Alpha_April2009.xls – This document serves as the data dictionary for the updated CRISP I analytic dataset (repository090408.sas7bdat). It also defines missing data codes and includes definitions for all derived variables.
- REPOSITORY090408.CSV
- repository090408.sas7bdat – This dataset was compiled by the Data Center, Center for Research on Health Care at the University of Pittsburgh.

Data\CRISP2\Analysis_Dataset

- CJASN_REVISIED_APRIL2014.CSV
- cjasn_revised_april2014.sas7bdat

Data\CRISP2\Collection_Forms

- FORM10.CSV
- form10.sas7bdat
- FORM11.CSV
- form11.sas7bdat
- FORM12.CSV
- form12.sas7bdat
- FORM13.CSV
- form13.sas7bdat
- FORM15.CSV
- form15.sas7bdat
- FORM18.CSV
- form18.sas7bdat
- FORM19.CSV
- form19.sas7bdat
- FORM2.CSV
- form2.sas7bdat

- FORM24.CSV
- form24.sas7bdat
- FORM27.CSV
- form27.sas7bdat
- FORM28.CSV
- form28.sas7bdat
- FORM33.CSV
- form33.sas7bdat
- FORM34.CSV
- form34.sas7bdat
- FORM40.CSV
- form40.sas7bdat
- FORM41.CSV
- form41.sas7bdat
- FORM42.CSV
- form42.sas7bdat
- FORM47.CSV
- form47.sas7bdat
- FORM48.CSV
- form48.sas7bdat
- FORM49.CSV
- form49.sas7bdat
- FORM50.CSV
- form50.sas7bdat
- FORM53.CSV
- form53.sas7bdat
- FORM54.CSV
- form54.sas7bdat
- FORM55.CSV
- form55.sas7bdat
- FORM56.CSV
- form56.sas7bdat
- FORM63.CSV
- form63.sas7bdat
- FORM64.CSV
- form64.sas7bdat
- FORM7.CSV
- form7.sas7bdat
- FORM9.CSV
- form9.sas7bdat

Data\CRISP2\Other Data Files

- CRISP12_LNTKV.CSV
- crisp12_lntkv.sas7bdat
- CRISP1_ADDITIONAL_VARIABLES.CSV
- crisp1_additional_variables.sas7bdat
- CRISP2_LONG_04172012_1.CSV
- crisp2_long_04172012_1.sas7bdat
- CRISP2_LONG_04172012_2.CSV
- crisp2_long_04172012_2.sas7bdat
- CRISP2_LONG_04172012_3.CSV
- crisp2_long_04172012_3.sas7bdat
- CRISP2_LONG_04172012_4.CSV
- crisp2_long_04172012_4.sas7bdat
- CRISP2_LONG_04172012_5.CSV
- crisp2_long_04172012_5.sas7bdat
- CRISP2_LONG_04172012_6.CSV
- crisp2_long_04172012_6.sas7bdat
- MRI_042012.CSV
- mri_042012.sas7bdat

Data\CRISP3\1 Study Data from Data Collection Forms

- 000.README.txt
- CRISP3_161116_FORM10.CSV
- crisp3_161116_form10.sas7bdat
- CRISP3_161116_FORM11.CSV
- crisp3_161116_form11.sas7bdat
- CRISP3_161116_FORM13.CSV
- crisp3_161116_form13.sas7bdat
- CRISP3_161116_FORM13_HOSP.CSV
- crisp3_161116_form13_hosp.sas7bdat
- CRISP3_161116_FORM13_NMA.CSV
- crisp3_161116_form13_nma.sas7bdat
- CRISP3_161116_FORM13_NMD.CSV
- crisp3_161116_form13_nmd.sas7bdat
- CRISP3_161116_FORM13_OMA.CSV
- crisp3_161116_form13_oma.sas7bdat
- CRISP3_161116_FORM13_OMD.CSV
- crisp3_161116_form13_omd.sas7bdat
- CRISP3_161116_FORM13_PMA.CSV
- crisp3_161116_form13_pma.sas7bdat
- CRISP3_161116_FORM13_PMD.CSV
- crisp3_161116_form13_pmd.sas7bdat
- CRISP3_161116_FORM13_PVOTPHY.CSV

- crisp3_161116_form13_pvotphy.sas7bdat
- CRISP3_161116_FORM15.CSV
- crisp3_161116_form15.sas7bdat
- CRISP3_161116_FORM18.CSV
- crisp3_161116_form18.sas7bdat
- CRISP3_161116_FORM19.CSV
- crisp3_161116_form19.sas7bdat
- CRISP3_161116_FORM2.CSV
- crisp3_161116_form2.sas7bdat
- CRISP3_161116_FORM24.CSV
- crisp3_161116_form24.sas7bdat
- CRISP3_161116_FORM27.CSV
- crisp3_161116_form27.sas7bdat
- CRISP3_161116_FORM28.CSV
- crisp3_161116_form28.sas7bdat
- CRISP3_161116_FORM28_HOSP.CSV
- crisp3_161116_form28_hosp.sas7bdat
- CRISP3_161116_FORM28_NMA.CSV
- crisp3_161116_form28_nma.sas7bdat
- CRISP3_161116_FORM28_NMD.CSV
- crisp3_161116_form28_nmd.sas7bdat
- CRISP3_161116_FORM28_NPP.CSV
- crisp3_161116_form28_npp.sas7bdat
- CRISP3_161116_FORM28_OCT.CSV
- crisp3_161116_form28_oct.sas7bdat
- CRISP3_161116_FORM28_OMA.CSV
- crisp3_161116_form28_oma.sas7bdat
- CRISP3_161116_FORM28_OMD.CSV
- crisp3_161116_form28_omd.sas7bdat
- CRISP3_161116_FORM28_PMA.CSV
- crisp3_161116_form28_pma.sas7bdat
- CRISP3_161116_FORM28_PMD.CSV
- crisp3_161116_form28_pmd.sas7bdat
- CRISP3_161116_FORM28_PRES.CSV
- crisp3_161116_form28_pres.sas7bdat
- CRISP3_161116_FORM28_PVOTPHY.CSV
- crisp3_161116_form28_pvotphy.sas7bdat
- CRISP3_161116_FORM33.CSV
- crisp3_161116_form33.sas7bdat
- CRISP3_161116_FORM34.CSV
- crisp3_161116_form34.sas7bdat
- CRISP3_161116_FORM40.CSV

- crisp3_161116_form40.sas7bdat
- CRISP3_161116_FORM41.CSV
- crisp3_161116_form41.sas7bdat
- CRISP3_161116_FORM42.CSV
- crisp3_161116_form42.sas7bdat
- CRISP3_161116_FORM47.CSV
- crisp3_161116_form47.sas7bdat
- CRISP3_161116_FORM48.CSV
- crisp3_161116_form48.sas7bdat
- CRISP3_161116_FORM49.CSV
- crisp3_161116_form49.sas7bdat
- CRISP3_161116_FORM50.CSV
- crisp3_161116_form50.sas7bdat
- CRISP3_161116_FORM53.CSV
- crisp3_161116_form53.sas7bdat
- CRISP3_161116_FORM55.CSV
- crisp3_161116_form55.sas7bdat
- CRISP3_161116_FORM56.CSV
- crisp3_161116_form56.sas7bdat
- CRISP3_161116_FORM63.CSV
- crisp3_161116_form63.sas7bdat
- CRISP3_161116_FORM64.CSV
- crisp3_161116_form64.sas7bdat
- CRISP3_161116_FORM7.CSV
- crisp3_161116_form7.sas7bdat
- CRISP3_161116_FORM7_AE.CSV
- crisp3_161116_form7_ae.sas7bdat
- CRISP3_161116_FORM7_RBF.CSV
- crisp3_161116_form7_rbf.sas7bdat
- CRISP3_161116_FORM7_RSS.CSV
- crisp3_161116_form7_rss.sas7bdat
- CRISP3_161116_FORM7_RSSM.CSV
- crisp3_161116_form7_rssm.sas7bdat
- CRISP3_161116_FORM7_RSSO.CSV
- crisp3_161116_form7_rss.o.sas7bdat
- CRISP3_161116_FORM9.CSV
- crisp3_161116_form9.sas7bdat
- DBO_VIEW_FORM10.CSV
- dbo_view_form10.sas7bdat
- DBO_VIEW_FORM11.CSV
- dbo_view_form11.sas7bdat
- DBO_VIEW_FORM13.CSV

- dbo_view_form13.sas7bdat
- DBO_VIEW_FORM13_HOSP.CSV
- dbo_view_form13_hosp.sas7bdat
- DBO_VIEW_FORM13_NMA.CSV
- dbo_view_form13_nma.sas7bdat
- DBO_VIEW_FORM13_NMD.CSV
- dbo_view_form13_nmd.sas7bdat
- DBO_VIEW_FORM13_OMA.CSV
- dbo_view_form13_oma.sas7bdat
- DBO_VIEW_FORM13_OMD.CSV
- dbo_view_form13_omd.sas7bdat
- DBO_VIEW_FORM13_PMA.CSV
- dbo_view_form13_pma.sas7bdat
- DBO_VIEW_FORM13_PMD.CSV
- dbo_view_form13_pmd.sas7bdat
- DBO_VIEW_FORM13_PVOTPHY.CSV
- dbo_view_form13_pvotphy.sas7bdat
- DBO_VIEW_FORM15.CSV
- dbo_view_form15.sas7bdat
- DBO_VIEW_FORM18.CSV
- dbo_view_form18.sas7bdat
- DBO_VIEW_FORM19.CSV
- dbo_view_form19.sas7bdat
- DBO_VIEW_FORM2.CSV
- dbo_view_form2.sas7bdat
- DBO_VIEW_FORM24.CSV
- dbo_view_form24.sas7bdat
- DBO_VIEW_FORM27.CSV
- dbo_view_form27.sas7bdat
- DBO_VIEW_FORM28.CSV
- dbo_view_form28.sas7bdat
- DBO_VIEW_FORM28_HOSP.CSV
- dbo_view_form28_hosp.sas7bdat
- DBO_VIEW_FORM28_NMA.CSV
- dbo_view_form28_nma.sas7bdat
- DBO_VIEW_FORM28_NMD.CSV
- dbo_view_form28_nmd.sas7bdat
- DBO_VIEW_FORM28_NPP.CSV
- dbo_view_form28_npp.sas7bdat
- DBO_VIEW_FORM28_OCT.CSV
- dbo_view_form28_oct.sas7bdat
- DBO_VIEW_FORM28_OMA.CSV

- dbo_view_form28_oma.sas7bdat
- DBO_VIEW_FORM28_OMD.CSV
- dbo_view_form28_omd.sas7bdat
- DBO_VIEW_FORM28_PMA.CSV
- dbo_view_form28_pma.sas7bdat
- DBO_VIEW_FORM28_PMD.CSV
- dbo_view_form28_pmd.sas7bdat
- DBO_VIEW_FORM28_PRES.CSV
- dbo_view_form28_pres.sas7bdat
- DBO_VIEW_FORM28_PVOTPHY.CSV
- dbo_view_form28_pvotphy.sas7bdat
- DBO_VIEW_FORM33.CSV
- dbo_view_form33.sas7bdat
- DBO_VIEW_FORM7.CSV
- dbo_view_form7.sas7bdat
- DBO_VIEW_FORM7_AE.CSV
- dbo_view_form7_ae.sas7bdat
- DBO_VIEW_FORM7_RBF.CSV
- dbo_view_form7_rbf.sas7bdat
- DBO_VIEW_FORM7_RSS.CSV
- dbo_view_form7_rss.sas7bdat
- DBO_VIEW_FORM7_RSSM.CSV
- dbo_view_form7_rssm.sas7bdat
- DBO_VIEW_FORM7_RSSO.CSV
- dbo_view_form7_rss.o.sas7bdat
- DBO_VIEW_FORM9.CSV
- dbo_view_form9.sas7bdat

Data\CRISP3\3 Analysis Data set for primary study publication(s)

- 000.README.txt
- BASELINE_TKV_HALT.CSV
- baseline_tkv_halt.sas7bdat
- BASELINE_TKV_PKD_MSG_7_6_2017.CSV
- baseline_tkv_pkd_msg_7_6_2017.sas7bdat
- BASELINE_TKV_SLOPE_CIC.CSV
- baseline_tkv_slope_cic.sas7bdat
- BASELINE_TKV_SLOPE_CIC_COMPLETE.CSV
- baseline_tkv_slope_cic_complete.sas7bdat
- BASELINE_TKV_SLOPE_LNHTTKV.CSV
- baseline_tkv_slope_lnhttkv.sas7bdat
- BASELINE_TKV_SLOPE_LNHTTKV_CRISP.CSV
- baseline_tkv_slope_lnhttkv_crisp.sas7bdat

- BASELINE_TKV_TEMPO.CSV
- baseline_tkv_tempo.sas7bdat
- BASELINE_TKV_TMP_CJASN.CSV
- baseline_tkv_tmp_cjasn.sas7bdat
- CYST_GROWTH_CRISP_ID_LIST.CSV
- cyst_growth_crisp_id_list.sas7bdat
- CYST_GROWTH_CYST_ANALYSIS_11_23_.CSV
- cyst_growth_cyst_analysis_11_23_.sas7bdat
- CYST_GROWTH_CYST_ANALYSIS_LONG_F.CSV
- cyst_growth_cyst_analysis_long_f.sas7bdat
- CYST_GROWTH_GENE_MSG_UPDATE1.CSV
- cyst_growth_gene_msg_update1.sas7bdat
- CYST_GROWTH_REDUCED_COPY_OF_CLAS.CSV
- cyst_growth_reduced_copy_of_clas.sas7bdat
- CYST_GROWTH_SLOPE_LNHTTCN1.CSV
- cyst_growth_slope_lnhttcn1.sas7bdat
- CYST_GROWTH_SLOPE_LNHTTCV1.CSV
- cyst_growth_slope_lnhttev1.sas7bdat
- TRAJECTORY_GFR_FIG_S6_DATA_V1.CSV
- trajectory_gfr_fig_s6_data_v1.sas7bdat
- TRAJECTORY_GFR_FIG_S9_DATA_N1.CSV
- trajectory_gfr_fig_s9_data_n1.sas7bdat
- TRAJECTORY_GFR_GFR_TRAJECTORY_4_.CSV
- trajectory_gfr_gfr_trajectory_4_.sas7bdat
- TRAJECTORY_GFR_MEDIATION_ANALYSI.CSV
- trajectory_gfr_mediation_analysi.sas7bdat
- TRAJECTORY_GFR_PREDICTION_MEAN.CSV
- trajectory_gfr_prediction_mean.sas7bdat
- TRAJECTORY_GFR_PREDICTION_MEAN_P.CSV
- trajectory_gfr_prediction_mean_p.sas7bdat
- TRAJECTORY_GFR_TRAJECTORY_DATA.CSV
- trajectory_gfr_trajectory_data.sas7bdat

Data\CRISP3\4 Study Genotype Data

- GENETICS_UPDATED.CSV
- genetics_updated.sas7bdat

Data\CRISP3\Contents\10 - Data Dictionary or Codebook

- CRISP III Data Dictionary_Combined.xlsx

Documents

The CRISP Documents directory contains:

Documents\CRISP1

- CRISP Datasets.pdf – Forms and key variables
- CRISP_Metadata.pdf – Description of the study design, goals, and outcomes
- crispMOP2003.pdf – Manual of Operations which also contains all of the study forms

Documents\CRISP2

- CRISP_2_MOP.pdf – Manual of Operations
- CRISP_2_Protocol.pdf – Protocol
- CRISP_2_Publications.pdf – List of Publications
- CRISP_2_Visit_Definitions.xlsx – Description of the visits in the CRISP2 study

Documents\CRISP2\Analysis_File_Documentation

- CJASN differences documentation.pdf
- CJASN without HALT follow-up_for NIDDK.pdf
- CJASN-Data Dictionary_derived vars.pdf

Documents\CRISP2\Codebooks

- CRISP_2_Data_Dictionary.xlsx
- CRISP_2_Long_Files_Var_Names.xlsx

Documents\CRISP3

- CRISP 3 MOP May 5 2012_to_Repo_v2.pdf
- CRISP3_protocol.pdf
- NewPub_Pres_2013_sb_to_Repo_11.11.2019.pdf

Documents\CRISP3\ 11 - Analyses file documentation (proc, programs, etc)

- BASELINE_TKV_KI paper9_13_2017_REPOSITORY.do
- CYST_GROWTH_cyst count values volume adjusted by height 10-23-2019_REPOSITORY.do
- TRAJECTORY_GFR_GFR age trajectory polynomial model without atypical 5_14_2018_REPOSITORY.R
- TRAJECTORY_GFR_GFR trajectory without atypical 5_14_2018_REPOSITORY.do
- TRAJECTORY_GFR_mediation analysis 09132018_REPOSITORY.rmd

DSIC

The CRISP Dataset Integrity Check (DSIC) directory contains:

- CRISP Allele_DSIC.pdf
- CRISP2_DSIC.pdf
- CRISP3_DSIC.pdf

- crisp_dataset_integrity_check_analysis_file.pdf
- crisp_dataset_integrity_check_baseline.pdf
- crisp_dataset_integrity_check_genetic_file.pdf
- crisp_dataset_integrity_check_volume_progression.pdf

Forms

The CRISP Forms directory contains:

Forms\CRISP1

- Registration Form (Crisp2var_Registration.pdf)
- Initial Screening Form (Crisp3var_InitialScreening.pdf)
- Baseline Visit Form (Crisp4var_BaselineVisit.pdf)
- OTC/Prescribed/Other Drugs (Crisp5var_OTCPrescripDrug.pdf)
- Reproductive History Form (Crisp6var_ReproductiveHistory.pdf)
- MR Session Information (Crisp7var_MRSession.pdf)
- GFR Collection Form (Crisp9var_GFRCollection.pdf)
- GFR Reporting Form (Crisp10var_GFRMayoReport.pdf)
- Physical Findings Form (Crisp11var_PhysicalFindings.pdf)
- Symptoms Form (Crisp12var_Symptoms.pdf)
- Follow-Up Study and Events Form (Crisp13var_FollowupStudyVisit.pdf)
- Blood Pressure Form (Crisp14var_BloodPressure.pdf)
- Family History Form (Crisp16var_FamilyHistory.pdf)
- Renal Blood Flow (Crisp17var_RenalBloodFlow.pdf)
- Study Withdrawal/Lost to Followup Form (Crisp19var_StudyWithdrawal.pdf)
- Missed Visit Form (Crisp24var_MissedVisit.pdf)
- Annual Visit - Labs (Crisp27var_AnnualVisit.pdf)
- Annual Clinic Visit (Meds and Events Crisp28var_AnnualClinicVisit.pdf)
- Current Reproductive History (Crisp29var_CurrentReproductiveHist.pdf)
- Current Symptoms (Crisp30var_CurrentSymptom.pdf)

Forms\CRISP2

- Form_2_Registration.pdf
- Form_7_MR_Session_Renal_Blood_Flow.pdf
- Form_9_GFR_Collection.pdf
- Form_10_GFR_Report.pdf
- Form_11_Physical_Find.pdf
- Form_12_Symptoms.pdf
- Form_13_Follow_UP_Study_and_Events.pdf
- Form_15_Death_Notification.pdf
- Form_18_Transfer_Form.pdf
- Form_19_Study_Withdrawal.pdf

- Form_24_Missed_Visit.pdf
- Form_27_Biannual_Clinic_Visit_Labs.pdf
- Form_28_Biannual_Med_and_Events.pdf
- Form_33_Lab_Visit_7_and_9.pdf
- Form_34_Scan_Evaluation.pdf
- Form_40_ObGyn_History.pdf
- Form_41_QualityofLifeQuesSF36.pdf
- Form_42_Pain_Questionnaire.pdf
- Form_47_UrineCollection.pdf
- Form_48_Manifest_Plasma.pdf
- Form_49_Manifest_Urine.pdf
- Form_50_Manifest_Cleve.pdf
- Form_53_Blood_Collection.pdf
- Form_54_Missing_Data.pdf
- Form_55_MRI_Status_Verification.pdf
- Form_56_Manifest_Rutgers.pdf
- Form_63_Transitional_Symptoms.pdf
- Form_64_Endpoints.pdf

Forms\CRISP3

- BiannualClinicVisitLabs.pdf
- BiannualClinVisMedEve.pdf
- BloodCollection.pdf
- DeathNotification.pdf
- EndpointsForm.pdf
- FollowUpStudyandEvents.pdf
- GFRCollection.pdf
- GFRReport.pdf
- HaltPainQuestionnaire.pdf
- IdentificationForm.pdf
- LabVisit11and13.pdf
- ManifestCleve.pdf
- ManifestMinnesota.pdf
- ManifestPlasma.pdf
- ManifestUrine.pdf
- MissedVisit.pdf
- MRIStatusVerification.pdf
- MRSessionRenalBloodFlow.pdf
- OBGYNHistory.pdf
- PhysicalFind.pdf
- QualityofLifeQuesSF36.pdf
- RegistrationForm.pdf

- ScanEvaluation.pdf
- StudyWithdrawal.pdf
- Symptoms Form.pdf
- TransferForm.pdf
- UrineCollection.pdf