

CRISP1 Data Archive

The NIDDK 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 Repository recommends that only the standard data archive be used. Requestors must ask for the genetics and/or raw data archives separately from the standard data archive.

The CRISP standard data archive files are organized into the following directories:

1. Documentation
2. Data

1. Documentation Directory

The Documentation directory contains the documentation from the original study.

1.1. Documents

The Documents directory contains the following three files:

- CrispMOP2003.pdf - Manual of Operations, which also contains all of the study forms, 257 pages
- CRISP Datasets.doc - forms and key variables, 5 pages
- CRISP_Metadata.doc – description of the study design, goals, and outcomes, 5 pages.

1.2. Forms

The Forms subdirectory contains the following 20 pdf files, which are the forms used in the collection of the raw data by the original study. The forms are annotated with the variable names:

- 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)

2. Data Directory

The Data directory contains the dataset compiled by the Data Center at Center for Research on Health Care at the University of Pittsburgh. It contains the updated CRISP I analytic dataset and its data dictionary:

- repository090408.sas7bdat (11.6 MB) – This dataset was compiled by the Data Center, Center for Research on Health Care at the University of Pittsburgh.
- CRISP1_DataDictionary_Alpha_April2009.xls (18 pages) – 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.

CRISP2 Data Archive

The NIDDK Repository offers the following data package from the CRISP2 study:

The CRISP2 standard data archive files are organized into the following directories:

1. Documentation
2. Data
3. DSIC

3. Documentation Directory

The Documentation directory contains the documentation from the original study.

3.1. Documents

The Documents directory contains the following three files:

- CRISP_2_MOP.pdf - Manual of Operations
- CRISP_2_Protocol.pdf - Protocol
- CRISP_2_Publications.doc - List of Publications
- CRISP_2_Visit_Definitions.xlsx - description of the visits in the CRISP2 study
- Codebooks:
 - CRISP_2_Data_Dictionary.xlsx
 - CRISP_2_Long_Files_Var_Names.xlsx
- Analysis_File_Documentation:
 - CJASN differences documentation.docx
 - CJASN without HALT follow-up_for NIDDK.doc
 - CJASN-Data Dictionary_derived vars.docx

3.2. Forms

The Forms subdirectory contains the following 28 pdf files, which are the forms used in the collection of the raw data by the original study.

- 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_Withdrawl.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

4. DSIC Directory

The DSIC directory contains the dataset integrity check that was performed on the CRISP2 data.

- CRISP2_DSIC.pdf – Dataset integrity check of the CRISP2 data using the Kidney Volume and Functional Outcomes in Autosomal Dominant Polycystic Kidney Disease publication