

Guide for Researchers Seeking to Use Data at the University of Florida Family Data Center

To access data housed at the Family Data Center (FDC), the following three steps must be completed. The process of securing permissions from the owners of the data (usually state agencies) can take up to six months. It is the responsibility of the researcher to obtain the appropriate permissions. In describing the project, the researcher will need to emphasize the utility of the findings to each state agency that owns the data. FDC offers quality review services to guide researchers in acquiring these permissions.

1. Prior to applying for permission to access data at FDC:
 - a. Obtain a certificate of completion from the Collaborative Institutional Training Initiative (CITI) training (<https://www.citiprogram.org>)
 - b. Obtain HIPAA for Researchers certification (<http://irb.ufl.edu/HIPAA/HIPAAtraining.htm>)
 - c. Consult the state agency's data dictionary to identify data elements needed to answer project's research question(s)

2. Submit study research protocol to Institutional Review Board (IRB):
 - a. Researcher's home institution, if not affiliated with UF
 - b. If researcher is UF faculty or student and request includes protected health information, apply to UF IRB-01 (<http://irb.ufl.edu/irb01>); otherwise apply to IRB-02 (<http://irb.ufl.edu/irb02>)
 - c. If researcher seeks to use vital statistic data for births, fetal deaths, or death with follow back, apply to Florida Department of Health IRB Wise (<http://florida-doh-irb.com>)
 - d. If researcher seeks to use Medicaid data, submit a Project/Research Proposal to the Agency for Health Care Administration

3. Secure Data Sharing Agreement (DSA) from state agency that owns the data. DSA stipulates that all personal identifiers will be removed from data sets supplied by the Family Data Center:
 - a. Florida Department of Health for Vital Statistics (birth, death, and fetal death certificates)
 - b. Florida Department of Health for Early Steps (Part C of IDEA early intervention program)
 - c. Florida Department of Health Children's Medical Services for medical subspecialty clinic participation
 - d. Florida Department of Health Healthy Start for Prenatal Risk Screens and Postnatal Risk Screens and services data
 - e. Florida Agency for Health Care Administration for Medicaid eligibility and claims, including pharmaceuticals
 - f. Florida Center for Health Information and Policy Analysis for hospital discharge diagnoses and charges
 - g. Florida Department of Juvenile Justice for records related to referral, adjudication, probation, detention, and intervention
 - h. Florida Department of Education for students' academic performance and behavioral referrals

Once a researcher has completed the three steps above, a contract will need to be entered into for FDC to prepare a de-identified analytical dataset.