

A Guiding Document:

DATA COLLECTION & PROJECT MANAGEMENT

Project management and data collection are easy using REDCap due to the customizable nature of the platform. CTF is able to easily and ethically collect data without compromising the PII/PHI of the families.



WHAT IS “REDCAP?”

REDCap is a free, secure and modifiable web-based application for creating databases and surveys, distributing them to participants, and collecting and managing data.

It was developed by Vanderbilt University in 2004 and is **used by thousands of non-profit and government organizations** in the US and internationally.

In 2019, CTF adopted The Department of Health and Senior Services’ (DHSS) REDCap Data Collection to align home visiting data across entities and demonstrate the impacts of home visiting.

WHAT ARE REDCAP ‘INSTANCES’ & ‘PROJECTS’?

In REDCap, an **instance** refers to a specific REDCap application hosted on a server, while a **project** is a program or agency’s specific research study or data collection effort designed and managed within that instance.

The CTF REDCap is housed in one REDCap ‘instance.’ Each CTF-funded home-visiting program has its own REDCap project where the program records its home-visiting data and activities.

WHAT DATA IS COLLECTED?

CTF collects **data related to key metrics** to evaluate and demonstrate the effectiveness of home visiting.

CTF aligns with Maternal, Infant and Early Childhood Home Visiting (MIECHV) program requirements because of MIECHV’s emphasis on evidence of effectiveness, to reduce the data burden on providers receiving various funding streams and to demonstrate the collective impact of home visiting programs in Missouri.

CTF reviews data requirements annually to ensure we continue to require only necessary data and continually ease the data burden on providers.

HOW ARE APPROVALS & CONSENT HANDLED?

Users must be approved by a **REDCap Administrator** to access their program’s REDCap project(s) and are removed when their employment ends. Users can only access information on families they serve directly.

Program Participants (families) are informed about and sign consent forms for their data to be contained within REDCap’s secured state server when enrolling in services. Consent can be withdrawn at any time. If a family withdraws consent, any information entered during the term of previous consent is retained in REDCap, and no new information is collected.

TECHNICAL SUPPORT?

If you need REDCap assistance, contact us at redcap@oa.mo.gov.

For CTF program data or privacy questions, contact us at ctf@oa.mo.gov.



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DATA SECURITY & PRIVACY PROTECTION

The Children's Trust Fund (CTF) uses a software called **REDCap** to collect, record and report on home visiting data in Missouri.

WHO CAN ACCESS THE DATA?

REDCAP Administrators have access to all data for all programs for database maintenance, design, security and management purposes.

CTF's Data Analysts work with individual- and program-level data.

Collective Impact Coordinators can access all data for ONLY the agencies that participate in their regional data collection or referral systems. They cannot see other REDCap data.

Grant Administrators only access aggregate data.

WHO CAN USE THE DATA?

Programs that have a current contract or approval from CTF can access or enter their own data. Additionally, home visiting agencies that wish to access historical data from closed projects can contact the Children's Trust Fund to learn more.

WHO OWNS THE DATA?

CTF is responsible for the data entered on its platform and can use it for grants, contracts, agreements and evaluation.

Furthermore, providers and programs are entitled to their own data but are not able to access or view the data of other programs without said program's permission.

HOW IS DATA SHARED?

For reporting, evaluation and data purposes, CTF has established formal contracts with the following agencies:

Collective Impact Sites use their own data to evaluate impact, implement strategies and manage referral systems.

Center for Health Policy receives limited personally identifiable information (PII) to match with Medicaid data.

University of Missouri receives de-identified, individual-level Medicaid data and home visiting data related to the Outcomes Rate Card (ORC) Project as part of CTF's statewide home visiting evaluation.

CTF, DSS and DHSS share limited data regarding child abuse and neglect outcomes and maternal health and birthing outcomes for aggregate, or summarized, reporting.

IS THE SOFTWARE SECURE?

REDCap has additional HIPAA security protections built in by State ITSD beyond basic REDCap.

REDCap software has built-in securities (*i.e.* - multifactor authentication, passwords, user rights restrictions, etc.); and the database security is strengthened even further by the IT infrastructure in which the REDCap instance lives.

The CTF REDCap is stored on a web-based cloud application, AZURE GOVERNMENT CLOUD, that is housed and protected via a state server. The application is monitored by the State's Information Technology Services Division (ITSD).

CAN REDCAP USERS SEE EACH OTHER'S DATA?

No — User rights restrictions are set so users can only see their own project data or granted access-level of data.

Using a filing cabinet metaphor, the projects coexist together within the Approved REDCap 'Instance' (filing cabinets), but they do not intersect without permission. A verified user of one project (drawer) cannot access other projects (drawers) without the other program's permission.

