Using **REDCap** for Designing a Data Collection System in the Field

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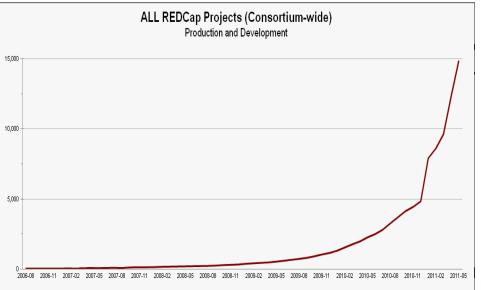


- A non-commercial use data collection and management system created by Vanderbilt University with funds from NIH
- Robust and secure repository of client-level data stored on HIPAA/FERPA-compliant servers for research projects or other applications
- Able to integrate and store respondent-level data across existing databases and any data collected in the field by home visiting program staff.
- Easily customizable and able to be configured in multiple ways to suit the needs of a given project



Map of REDCap Consortium Partners





- http://www.project-redcap.org/
- 288 active institutional partners from around the globe
- Typically, a centralized group at each institution houses REDCap to prevent infrastructure duplication
- Serves nearly 23,000 research projects and just under 33,000 end users
- Project production has grown exponentially in the past five years



- Prospective Research and Evaluation Studies
- Data Collection for Chart Reviews
- Multi-Site Data Collection (domestic and international)
- Basic Research Studies
- Behavioral Research Studies (Survey)
- CTSA-wide research studies
- (Statin Treatment for Influenza Patients Trial)
- CTSA-wide research on research studies (Committee #1 IRB + Contracts)

- Quality Improvement
- Research Operations Support (tracking databases)
- Education Support Teaching Tool
- Project Management
- Lab Specimen Tracking
- Survey can be used as a surrogate web application
- State performance management systems for home visitation

Key Considerations for Selecting





- COST: Need a cost-efficient way to collect and manage research and evaluation data
- CAPACITY/STAFFING: Need a system that evaluation staff can use with limited knowledge of data sytems
- NEW DATA: Need ability to collect new screening or clinical instruments for outcome measuring
- EXISTING DATA: Needed a way to interface with existing information management systems (if they exist)



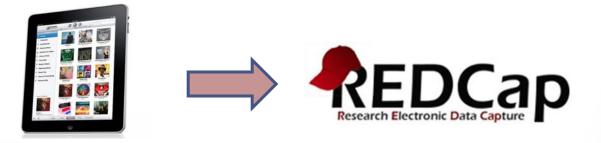
- REPORT GENERATION: Need to export data or run ad-hoc reports that are easily configurable for multiple purposes
- DATA SECURITY/CONFIDENTIALITY: Need the data to be secure when collecting, storing or importing; need a HIPAA Compliant server to transfer Protected Health Information (PHI)



- FIELD USE: Need the ability to collect and transfer screening or program data directly into MIECHV database during a home visit if desired
- FUNCTIONALITY: Need to de-identify data as needed, restrict user access to some data, create schedules, be used as a case management system (if needed), track program data
- VERSITILITY: Need it to be easy to customize, configure, or change as new program data or screening instruments are introduced



 TECHNOLOGY: Need to be able to securely interface with technology used by research assessors in their office, in the participants' homes, or on the road if needed to reduce data entry labor costs



Internet access through Wi-Fi and 3G capabilities for in the field use

Interactive use during face to face interviews



System for an Evaluation Project



- Adolescent Family Life Generations Project
 - Rigorous research and evaluation study testing the effectiveness of enhancing a home visiting program for pregnant teens with an educational support group for their parents, mental health services, and social media outreach
- Kansas' Maternal Infant Early Childhood Home Visiting (MIECHV) Program
 - Creating a Performance Management System to enable state to respond to federal reporting requirements and integrate evaluation and CQI
 - Working with four home visiting program models in each of three counties
 - Matching and integrating data from multiple agencies with different management information systems with the state's child welfare data
- Nebraska's MIECHV Program
 - Working with one home visiting program across three counties in one agency
 - Matching and integrating data from one agency's management information system with the state's child welfare data



- Generations Project Overview
- Testing the effectiveness of enhancing a home visiting program for pregnant teens with an educational support group for their parents, mental health services, and social media outreach.
- Kansas Children's Service League -Healthy Families program in Wyandotte and Shawnee Co, KS
- KU Institute for Educational Research and Public Service & School of Social Welfare

Office of Adolescent Pregnancy Programs



Generations Project Overview

TREATMENT GROUP

CONTROL GROUP

Services for Teen



KCSL Healthy Families Home Visiting



Services for Family

In-home mental health assessment & services as needed

Support Networking



Referral to Community Mental Health



Services for Grandparent

Grandparent **Education &** Support Group Social Media & facebook

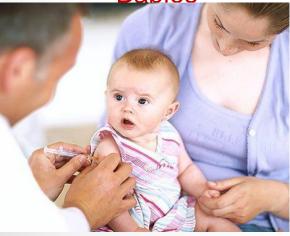


Generations Project Overview

Reduced Repeat Teen Pregnancies



Immunizations for Babies



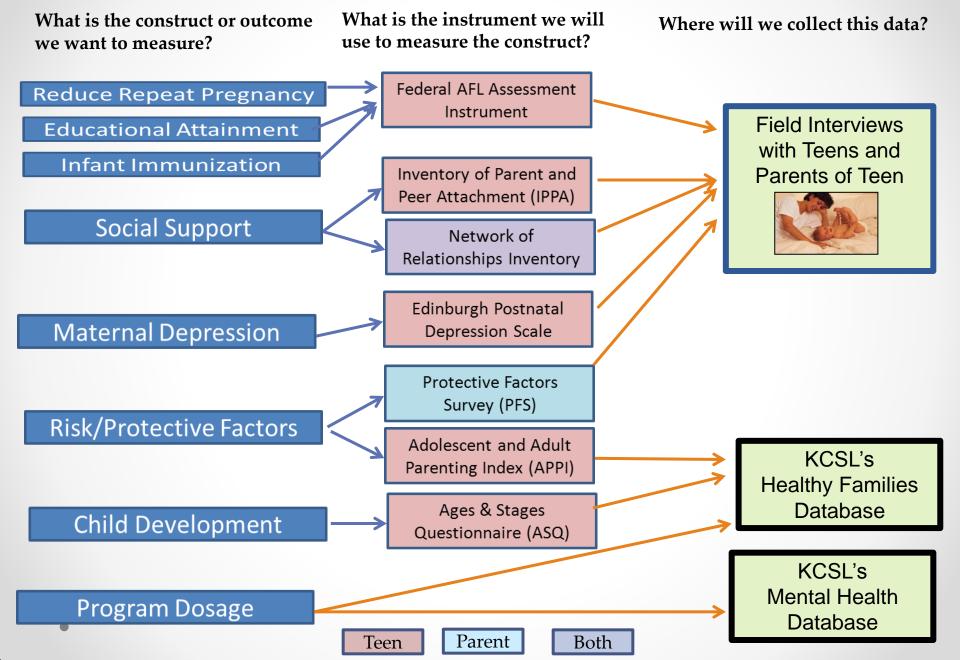
Educational Attainment for Teens



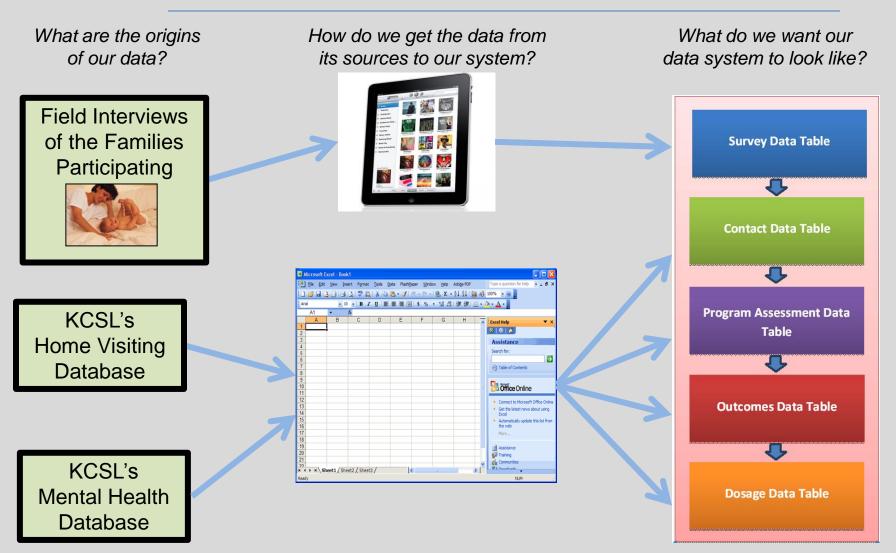
Social Support, Mental & Physical Health, Family Functioning



Generations Project Data Map



Collecting and Organizing Information





| https://redcap | rc.ku.edu/index.php? | ☆ - (C) <mark>생</mark> - spss | |
|----------------|--|--|-------------------|
| | REDCap | | Web-based |
| | Log In Please log in with your user name and password. If you are ha | ving trouble logging in, please contact <u>William Kennedy</u> . | application login |
| | User name Password: | ijbarton •••••••••••••••••••••••••••••••••••• | |

Public P

Welcome to REDCap!

REDCap is a secure, web-based application for building and managing online surveys and databases. Using REDCap's stream-lined process for rapidly developing projects, you may create and design projects using 1) the online method from your web browser using the Online Designer; and/or 2) the offline method by constructing a 'data dictionary' template file in Microsoft Excel, which can be later uploaded into REDCap. Both surveys and databases (or a mixture of the two) can be built using these methods.

REDCap provides automated export procedures for seamless data downloads to Excel and common statistical packages (SPSS, SAS, Stata, R), as well as a builtproject calendar, a scheduling module, ad hoc reporting tools, and advanced

List of current projects

REDCap

Home My Projects 📀 Create New Project 😵 Training Resources 😣 Help & FAQ 🔤 Send-It

for

Listed below are the REDCap projects to which you currently have access. Click the project title to open the project. Newly created projects begin in Development status 🖉 as you begin to build and design them. When you are ready to begin entering real data in the project, you may move it to Production status 📀 to designate the project as officially collecting data. When you are finished collecting data or if you wish to stop collection, the project may be set to Inactive status a lthough it may be brought back to Production status at any time when you are ready to begin collecting data again. Also listed is the project type, which designates if the project contains surveys 🝰, data entry forms 🧮, or both 🗮 剑

| My Projects | Records | Fields | Туре | Status |
|--|---------|--------|---------------------|------------|
| Generations Project Data Dictionary Copy | 9 | 375 | | Ì |
| Generations Project Data Dictionary Copy 2-23-2011 | 4 | 873 | | Ì |
| Webinar Test Database | 4 | 23 | E CONTRACTOR OFFICE | Ì |
| Case Management Mock Up | 6 | 103 | | Ì |
| File Upload Test | 9 | 4 | 1 | Ì |
| Generations Project FINAL | 7 | 872 | | \bigcirc |
| First Single Survey Example | 7 | 8 | 1 | Ì |
| Nebraska ACA HV Mock-up | 1 | 362 | | Ì |
| Test Database | 0 | 8 | E CONTRACTOR OFFICE | Ì |
| Nebraska ACA HV Flat File Mock-up | 19 | 1706 | | Ì |

The projects listed below are public and are accessible by anyone. No authentication (i.e. username/password) is required to access them directly

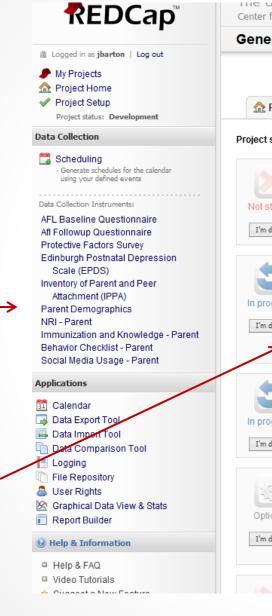
| Public Projects | |
|----------------------|--|
| Example Survey | |
| REDCap Demo Database | |

kuled

REDCap

Navigation bar on left shows the instruments and tools custom built for specific projects

Database construction tools are found under the project setup tab



| eneration | ns Project Data Dictionary Copy |
|-----------------|--|
| noject | Home Vroject Setup Dther Functionality |
| Project status: | Pevelopment |
| | Modify project settings or make customizations |
| Not started | You have created your project and are ready to begin building on it. If you would like to modify the g project settings that you set when creating the project or if you wish to make some customizations project (e.g. enable auto-numbering for new records), use the buttons below. |
| I'm done! | Go to Modify project settings or Make customizations |
| | Design your data collection instruments |
| In progress | Add or edit fields on your data collection instruments. This may be done by either using the Online (online method) or by uploading a Data Dictionary (offline method), in which you may use either me both. Quick links: Download PDF of all data collection instruments OR Download the current Data |
| I'm done! | Go to Online Designer or Upload Data Dictionary |
| 7 | Have you checked the <u>Check For Identifiers</u> page to ensure all identifier fields have been tagged? |
| | Define your events and designate instruments for them |
| | Create events for re-using data collection instruments and/or set up scheduling. |
| In progress | Go to Define My Events or Designate Instruments for My Events |
| I'm done! | |
| 1233 | User Rights and Permissions |
| | You may grant other users access to this project or edit the user privileges of current users on this navigating to the User Rights page. Additionally, if you wish to limit user access to certain records/ |
| Optional | for this project, you may want to use Data Access Groups, in which only users within a given Data A |
| I'm done! | Group can access records created by users within that group. |



| Servedu http://www.edu | os://redcap.ittc.ku.edu/redcap_v4.0.0/data_entry.php?pid=83&id=1 | 45&event_id=232&page=demographic_data | |
|--|--|--|---|
| 🛠 Webinar Test Database REDCap 🛛 🕂 | 1 | | |
| REDCap | 📰 Demographic Data | 🔁 Download for | n as PDF 🛛 🔁 PDF with saved data |
| Logged in as jbarton Log out | Editing existing Case ID 12345 | | |
| My Projects Project Home | Event Name: baseline (Arm 1: Field As | essor Data) | |
| Project Setup | Case ID | 12345 (To rename this record fo value immediately below. | r the current arm ONLY, modify the) |
| ata Collection | Case ID | (H) 12345 | |
| Scheduling - Generate schedules for the calendar | First Name | (H) Jared | |
| using your defined events | Last Name | Barton | |
| 💷 Data Entry | Date of Birth | 😬 1963-03-13 🛅 то | day |
| Case ID 12345 Event: baseline (Arm 1: Field Assessor Data) Data Collection Instruments: | Race | White Black Hispanic Native American Asian Other | |
| pplications | | Any Race | |
| 🛅 Calendar | Ethnicity | 🕒 Hispanic 💌 | |
| → Data Export Tool → Data Import Tool → Data Comparison Tool ↓ Logging ↓ Logging → File Repository ☆ Graphical Data View & Stats → Report Builder | Income Level | Under \$5,000 \$5,000-\$9,999 \$10,000-\$14,999 \$15,000-\$19,999 \$20,000-\$24,999 \$20,000-\$24,999 \$20,000-\$24,999 \$20,000-\$39,999 | |
| Reports | | ○ \$40,000-\$49,999○ \$50,000 and Over | |
| 1) Depression Scale Score | | O Unknown | reset value |
| Help & Information | | 1st Grade | reset value |
| General Help Video Tutorials If you are experiencing problems, please contact your <u>project administrator</u>. | | 2nd Grade 3rd Grade 4th Grade 5th Grade 6th Grade | |
| | | 7th Grade 8th Grade 9th Grade 10th Grade 10th Grade 11th Grade | |
| | Education Level | Ith Grade 12th Grade High School Diplom | а |

Key Point: You can build and customize the system to include any fields or data you will be collecting or that already exist in an agency database.

| | Generations Project Data Dictionary Copy 2-23-2 | 2011 REDCap | 100%1 |
|---|--|--|-----------------------|
| | redcap.ittc.ku.edu/redcap_v4.0.0/data_entry.php?pid=64 | &id=2345 C Google | |
| REDCap | Event Name: Daseline (Arm 1: Field Assessor KCSL Case ID | Data) | |
| NEDCap | As you are among the | 23456 | |
| | As you are pregnant or have recently had baby, we the answer that comes closest to how you have felt | would like to know how you and | |
| Logged in it Jbarton Log. cut | the answer that comes closest to how you have feit | IN THE PAST 7 DAYS, not just how you | I. Please check |
| My Projects | 1. In the sect | As much as I always could | reel today. |
| Project Setup | In the past seven days, I have been able to laugh and see the funny side of things. | Not quite so much now | |
| | , side of things. | O Definitely not so much now | |
| Data Collection | | Not at all | |
| Scheduling | | | |
| Oriented schedules for the calendar using your defined events | 2. In the past seven days, I have looked forward with enjoyment to things. | As much as I ever did | reset value |
| Data Entry | enjoyment to things. | Rather less than I want | |
| KCSL Case ID 23456 | | Optimitely less than I want | |
| Event baseline (Acon Scanso | | Hardly at all | |
| | | | |
| AFL Baseline Questionnaire Protective Factor | 3. In the past seven days, I have blamed myself unnecessarily when things went wrong | Yes, most of the time | reset value |
| Edinburgh Poster | unnecessarily when things went wrong. | res, some of the time | 198 - 200 - |
| Scale (EPDS) | | Not very often | |
| Inventory of Parent and Peer Attachment (IPPA) | | O No, never | |
| | 4. In the second | 6 | |
| NRI - Parent | 4. In the past seven days worried for no good | No, not at all | reset value |
| Immunization and Knowledge - | | Hardly ever | |
| Behavior Checklist - Parent Social Media Ureas | | O Yes, sometimes | |
| vadue - Parent | | Ves, very often | |
| lications | A REAL PROPERTY AND A REAL | | |
| Palendar | eft scared or panicky | Yes, quite a lot | reset value |
| EDCap n | or panicky | Yes, sometime | |
| | | No, not much | CONTRACT DESIGNATION |
| | | No, not at all | States and a state of |
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| | REDCar | 9 Software - Version 4.0.0 - @ 2011 Vanderbilt U | reset value |
| | | Version 4.0.0 - @ 2011 Vanderbis | |
| | A CONTRACTOR OF THE OWNER OF THE | Unidered and a second sec | niversity |
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| | | | |

Screening Instrument

| Edinburgh Postnatal Depression Scale (EPD) | S) 🛛 🔁 Download form as PDF | 🔁 PDF with saved data | |
|---|---|--|--|
| Editing existing Case ID 12345 Event Name: baseline (Arm 1: Field Assessor Data) | | 5. In the past seven days, I have felt scared or panicky for no good reason. | Yes, quite a lot Yes, sometimes No, not much No, not all |
| Case ID 12345 As you are pregnant or have recently had baby, we would like to know how you are feelin answer that comes closest to how you have felt <u>IN THE PAST 7 DAYS</u> , not just how you fee | | 6. In the past seven days, things have been getting on top of me. | Yes, most of the time I haven't been able to cope at all Yes, sometimes I haven't been coping as well as usual |
| 1. In the past seven days, I have been able to laugh and see the funny side of things. | As much as I always could Not quite so much now O Definitely not so much nor Not at all | 7. In the past seven days, I have been so unhappy that I have had difficulty sleeping. | No, most of the time I have coped quite well No, I have been coping as well as ever reset value Yes, most of the time Yes, quite often Not very often No, not at all |
| 2. In the past seven days, I have looked forward with enjoyment to things. | As much as I ever did Rather less than I used to Definitely less than I used Hardly at all | 8. In the past seven days, I have felt sad or miserable. | Yes, most of the time Yes, quite often Not very often No, not at all reset value |
| 3. In the past seven days, I have blamed myself unnecessarily when things went wrong. | Yes, most of the time Yes, some of the time Not very often | 9. In the past seven days, I have been so unhappy that I have been crying. | Yes, most of the time Yes, quite often Only occasionally No, never |
| | No, never No, not at all Hardly ever | 10. In the past seven days, the thought of harming myself has occurred to me. | Yes, most of the time Yes, quite often Only occasionally No, never |
| 4. In the past seven days, I have been anxious or worried for no good reason. | Yes, sometimes Yes, very often | SCORE (If a respondent's score is 10 or greater, please make appropriate contact with service staff and Healthy Families' Supervisor. Act according to Distress Respond | 17 View equation disclaimer |
| 5. In the past seven days, I have felt scared or panicky for no good reason. | Yes, quite a lot Yes, sometimes No, not much No, not at all | Protocol.) Form Status Complete? | Complete Save Record Save and Continue |
| | | | Cancel |

Key Point: Any instrument or screening tool can be added to the system and scored automatically. Can easily modify system in future to add other instruments if needed.

| | Cenerations Project Data Dictionary Copy 2-23-2011 REDCap redcap.ittc.ku.edu/redcap_v4.0.0/data_entry.php?pid=64&id=2345 C Google | |
|--|---|-------------|
| REDCap | and the second se | |
| My Projects My Projects Project Home Project Setup Data Collection | No, not at all No, not at all Yes, most of the time Yes, quite often Only occasionally No, never | reset va |
| Castle advantage of the estimate -Castle advantage for the estimate sing your datimat events Castle Entry | 10. In the past seven days, the thought of harming | reset valu |
| KCSL Case ID 21456 Event Baseline (Arie Li Field Assessor Data) Data Callestine Instrumente AFL Baseline Questionnaire Protective Factors Survey Ecologians | Participant's response to question 10 indicates that a Distress Respondent Protocol. | reset value |
| Socie (EPDS) Inventory of Parent and Peer Attachment (IPPA) Parent Demographics | (If a respondent's score is 10 or greater, please make appropriate contact with service staff and Healthy Families' Supervisor. Act according to Distress Respondent Protocol.) Form Status | ner |
| Parent | Complete? | |
| Behavior Checklist - Parent Social Media Usage - Parent Applications | Incomplete | |
| Calendar | Save Record Save and Continue | 10000 |
| The REDCap Consonium Ceimo Date | Save and go to Next Form | |
| The REDCase Consortium Offing REDCap. KU Cent The University of Kansas Lawrence, Kansas 66045 | er for Research Methods & Data Analysis Cancet | |
| | | 1000 |
| | REDCap Software - Version 4.0.0 - © 2011 Vanderbilt U | |
| | - and a Dail O | niversity |
| | | |

Preloaded Instruments

- Currently 113 Preloaded Instruments
- Agitated Behavior Scale
- Behavior Risk Factor Surveillance System (BRFSS)
- Cystic Fibrosis Questionnaire (CFQ-R)
- Center for Epidemiologic Studies Depression Scale (CES-D)
- Eating Disorders Examination Scale (EDE-Q)
- Koos Knee Survey
- Marx Activity Scale
- Pelvic Floor Distress Inventory
- Pittsburgh Sleep Quality Index (PSQI)
- Puberty Development Scale
- Short Test of Musical Preferences (STOMP Revised)

Importing Existing Data Into



Data entered by home visitors into case management system exported to CSV format data file

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| 1 | case_id | first_name | last_name | dtiindexparentdob | | | | | | | | |
| 2 | 98765 | Lady | Gaga | 3/1/1980 | | | | | | | | |
| 3 | 25814 | Weird Al | Yankovic | 8/25/1964 | | | | | | | | |
| 4 | | | | | | | | | | | | |
| 5 | | | | | | | | | | | | |
| 6 | | | | | | | | | | | | |
| 7 | | | | | | | | | | | | |
| 8 | | | | | | | | | | | | |

Key Point: The REDCap system is built using the existing variable names of data already captured in FamilyWise.

🖷 Data Import Tool

This module may be used for importing data into this project from a CSV (comma delimited) file. Below are the steps you will need to follow in order to import your data successfully into this project.

INOTICE:

This project is currently a PROTOTYPE and is in development. **Real data should NOT be entered into the project.** Any data entered thus far will be deleted when the project is pushed into production mode.

Instructions:

- 1.) Click the link below to download your data import template as a CSV (comma delimited) file. Save it locally to your computer and then open it to begin filling it with the data you wish to import.
 - Download your Data Import Template (with records in rows)
 - OR
 - Download your Data Import Template (with records in columns)
- In each column of the Data Import Template file that you downloaded, place the data for each record that you wish to import. Once all your data has been added, save the file.
 - · Be sure not to change the Variables/Field Names in the file or an error may occur.
 - Also, for all of the 'dropdown' or 'radio' fields in the project, you must make sure that the numerical value (rather than the text value) is entered in those cells, or else it cannot be processed.
 - Any empty rows or columns in the file can be safely deleted before importing the file. Doing this reduces the upload
 processing time, especially for large projects.
- Click the 'Browse' or 'Choose File' button below to select the file on your computer, and upload it by clicking the 'Upload File' button.
- 4.) Once your file has been uploaded, the data will NOT be immediately imported but will be displayed and checked for errors to ensure that all the data is in correct format before it is finally imported into the project.



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Scale Score

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encing problems, please ject administrator.

📀 Your document was uploaded successfully and is ready for review.

You are now required to view the Data Display Table below to approve all the data before it is officially imported into the project. Follow the instructions below.

Instructions for Data Review

The data you uploaded from the file is displayed in the Data Display Table below. Please inspect it carefully to ensure that it is all correct. After reviewing it, **click the 'Import Data' button at the bottom of this page** to import this data into the project.

| KEY for Data Display Table below | | | | |
|---|--|--|--|--|
| Black text = New Data | | | | |
| Gray text = Existing data (will not change) | | | | |
| (Red text) = Data that will be overwritten | | | | |
| Red box = error | | | | |
| Orange box = warning | | | | |

| DATA DISPLA | AY TABLE | | | |
|------------------------------|------------|------------|-----------|-------------------|
| case_id | Event Name | first_name | last_name | dtiindexparentdob |
| 98765 (new record) | baseline | Lady | Gaga | 1980-03-01 |
| 25814 (new record) | baseline | Weird Al | Yankovic | 1964-08-25 |

Do you wish to import the new data (displayed above) into the project? (Click the button below to import the data.)

Import Data

Key Point: Agency or data management staff can review data prior to being integrated into the REDCap MIECHV database for errors.

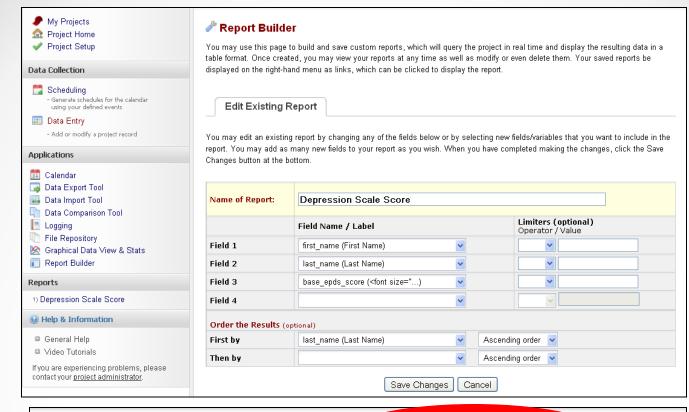
webinar Test Database

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| 📕 Demographic Data | 🔁 Download form as PDF 🛛 🔁 PDF with saved data |
|--|---|
| 🥔 Editing existing Case ID 98765 | |
| Event Name: baseline (Arm 1: Fie | eld Assessor Data) |
| Case ID | 98765 (To rename this record for the current arm ONLY, modify the value immediately below.) |
| Case ID | 98765 |
| First Name | 🕀 Lady |
| Last Name | 🕀 Gaga |
| Date of Birth | 🙂 1980-03-01 🛅 Тодау |
| | White |
| | |
| Demographic Data Ø Editing existing Case ID 25814 | 🔂 Download form as PDF 🛛 🔂 PDF with saved data |
| | |
| Editing existing Case ID 25814 | |
| Editing existing Case ID 25814 Event Name: baseline (Arm 1: F | F ield Assessor Data) 25814 (To rename this record for the current arm ONLY, modify the |
| Editing existing Case ID 25814 Event Name: baseline (Arm 1: F Case ID | Field Assessor Data) 25814 (To rename this record for the current arm ONLY, modify the value immediately below.) |
| Editing existing Case ID 25814 Event Name: baseline (Arm 1: F Case ID Case ID | Field Assessor Data) 25814 (To rename this record for the current arm ONLY, modify the value immediately below.) 25814 |

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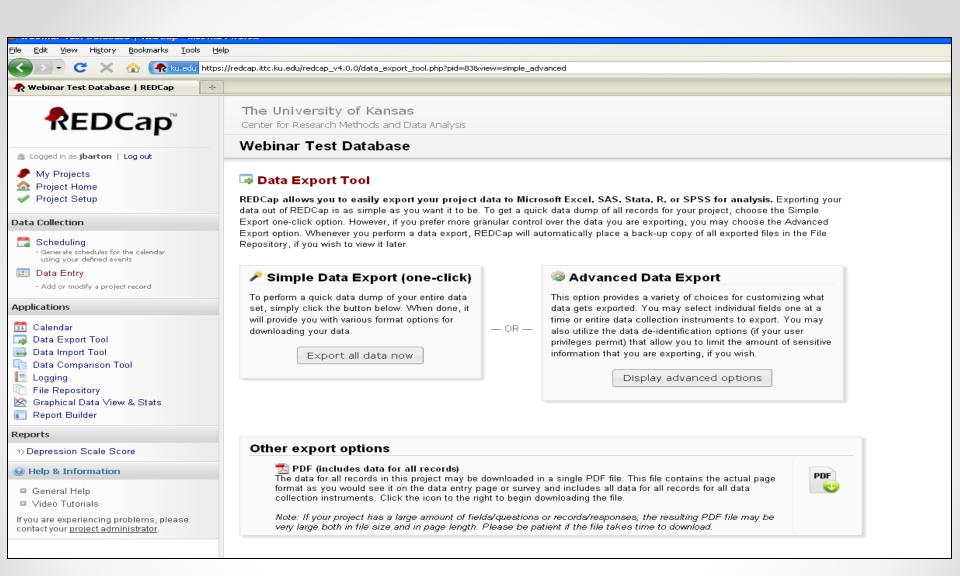


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|--|-----------------------------------|
| Number of results returned: 2 | |
| Total number of records queried: 2 ('records' = total available data across designation of the second secon | ated Events) |

Depression Scale Score

| First Name (first_name) | Lastinanio | SCORE (If a respondent's score is 10 or greater, please make appropriate contact with service staff and Healthy <i>Respondent Protocol.</i>) (base_epds_score) |
|----------------------------|------------|--|
| Jared | Barton | 17 |
| Mickey | Mouse | 15 |

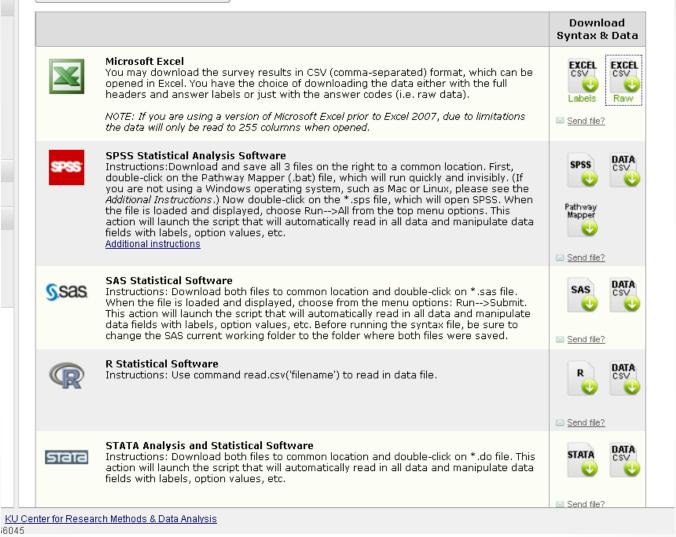




Key Point: You can select the data you want exported for reports or for analysis.

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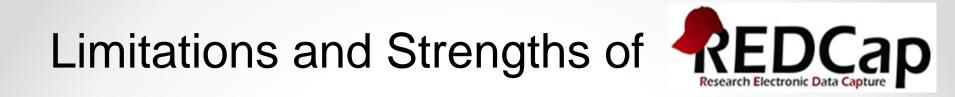
Key Point: You can export data from your system in different formats for analysis or evaluation purposes.

Limitations and Strengths of





- Limitation: The reporting function is not "pretty" there are no canned pre-formatted reports that look professionally ready for dissemination to stakeholders.
- Strength: REDCap has the ability to get out any of the data in the database in any way the user wants or needs and can be formatted in any way.



- Limitation: Requires continued data management effort to capture and integrate existing data from agencies on an ongoing basis; it is not a completely automated system.
- Strength: Using REDCap is free, upfront costs are personnel time in building a customized system to meet the needs of a given research or evaluation project. Once built, labor costs will be relatively low to manage data and build reports.



- Strength: If data changes or new screening or assessment tools are introduced later on in your evaluation, REDCap can be easily modified to capture this new data and re-launched without any loss of data
- Strength: Reduces duplicate data entry by home visitors or learning a new data system if one currently exist

The Bottom Line on RED

- It is a flexible, secure, cost-efficient way to integrate existing and new data without the need for interaction with software developers or advanced knowledge in computer programming.
- It is customizable and can be configured based on what already exists or what may be needed.
- Multi-site or cross-site merging of respondent-level data for more in-depth outcome analysis of impact across populations, sites, or communities.
- Longitudinal designs and repeated measures can be kept neatly in record for one respondent.

CONTACT INFORMATION

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