

Data Management and Database Tools In Research

Presenter and Translator from English into Russian:

Elena O'Donald, PhD, MCP, CCNA

Ph.D. in Biological Sciences, MS in Computer Engineering

Bi-National Health Risk Seminar Series

Albuquerque, New Mexico

November 19, 2014

Acknowledgements

The NBCS Project Research Team:

Many thanks to the Navajo Birth Cohort Study (NBCS) Research Team: Johnnye Lewis, Becky Smith, Miranda Cajero, Esther Erdei, Jennifer Ong, Carla Chavez, Bernadette Pacheco, Chris Shuey, Jackie Morgan, Joe Hoover, Curtis Miller, Debra MacKenzie, Carol (CJ) Laselute, and Lauren Hund

Funding Acknowledgement:

CDC's (Centers for Disease Control) Award Number
for the NBCS: CDC U01 TS000135-05

Presentation Overview

Data Storage and Management Tools:

Microsoft Access Database Tool

RedCAP Online Survey Tool



MS Access Databases for the NBCS project:

NBCS BioMonitoring Database

Parsing Data

Generating Letters to Participants

NBCS Home Environmental Assessment Database

Data Collection Form



Challenges in Data Management

Data Storage and Management Tool

RedCAP Online Survey Tool

We use it primarily for: Data Entry and Data Storage

Advantages:

Security Policy Compliant

Accessible Online

No special database software needed to be installed

Fast Development of basic data entry forms and surveys

Does not require database development and programming skills to make surveys

Disadvantages:

This is *not* a Relational Database Development Tool

Data Linking Capabilities are extremely limited

This results in irrational data structure design

Form Development is Highly Restricted: limited availability of basic object types

Limited Form Design does not provide good visibility of data on larger forms

Highly Limited Query Capabilities

Design of Query Building Tools is *not* user friendly

Difficult in Managing Data

Extremely difficult in doing Data Quality Control

✓ Project Setup
Project status: **Development**

Data Collection

- Scheduling
- Generate schedules for the calendar using your defined events
- Data Entry
- Add or modify a project record

Applications

- Calendar
- Data Export Tool
- Data Import Tool
- Data Comparison Tool
- Logging
- File Repository
- User Rights
- Graphical Data View & Stats
- Report Builder

Reports

- 1) asdfasdf
- 2) sdf

Help & Information

- Help & FAQ
- Video Tutorials
- Suggest a New Feature

If you are experiencing problems, please contact your [REDCap administrator](#).

REDCap Demo Database (Longitudinal) - Drug Trial

Data Entry: Event Grid

The grid below displays the form-by-form progress of data entered into the project for one particular events. You may click on the colored buttons to access that form for that event. If you wish, you may navigating to the [Define My Events](#) page.

Study ID **SKL034**

Data Collection Instrument	Events for Arm 1: Drug A							
	Enrollment (1)	Dose 1 (2)	Visit 1 (3)	Dose 2 (4)	Visit 2 (5)	Dose 3 (6)	Visit 3 (7)	Final visit (8)
Demographics								
Contact Info								
Baseline Data								
Visit Lab Data								
Patient Morale Questionnaire								
Visit Blood Workup								
Visit Observed Behavior								
Completion Data								
Completion Project Questionnaire								

LOCK WORKFORMS

Applications

- Calendar
- Data Export Tool
- Data Import Tool
- Data Comparison Tool
- Logging
- File Repository
- User Rights
- Record Locking Customization
- E-signature and Locking Mgmt
- Graphical Data View & Stats
- Report Builder

Help & Information

- Help & FAQ
- Video Tutorials
- Suggest a New Feature

If you are experiencing problems, please contact your [REDCap administrator](#).

First Name

Last Name

Contact Information

Street, City, State, ZIP Expand

Phone number Include Area Code

Second phone number Include Area Code

E-mail

Other information

Ethnicity reset value

Hispanic or Latino
 NOT Hispanic or Latino
 Unknown / Not Reported

Race reset value

American Indian/Alaska Native
 Asian
 Native Hawaiian or Other Pacific Islander
 Black or African American
 White
 More Than One Race
 Unknown / Not Reported

Gender reset value

* must provide value Female Male

Specify the patient's mood reset value

Very sad Indifferent Very happy

Upload the patient's consent form reset value

Is patient taking any of the following medications? (check all that apply)

Lexapro
 Celexa
 Prozac
 Paxil
 Zoloft

Date of birth Y-M-D

Relational Database Development Tool

Microsoft Access

It can be used for: Entering, Storing, Querying, Managing, and Reporting Data

Advantages:

Security Policy Compliant

Database can be made Accessible Online (with limitations)

Medium Speed of Database Development

Flexibility in Designing: Database Structure, Tables, Forms, Queries, and Reports

Easy to Link Data and develop Complex Queries and Reports

Flexible Form Design allows **good visibility of data on larger forms**

Good for Data Entry, Management, and Quality Control

User Friendly Environment for Database and Visual Basic Code Development

Disadvantages:

Installation of MS Access is required

For developer: MS Access database development skills are required

For developer: MS Visual Basic Programming skills are desired

Limited Form Design Capabilities for the Online version of Database

MS Access Databases for the NBCS project

NBCS BioMonitoring Database

We currently use it for:

Parsing Data

CDC – Blood and Urine Test Results

RedCAP – Participant Information

Processing Data

We calculate 50-th and 95-th percentiles for the NBCS sample

Generating Letters to Participants

*** * * Let's now look at some of these forms * * ***

MS Access Databases for the NBCS project

NBCS Home Environmental Assessment Database

It is currently in development

It will be used for:

- Collecting Data on the Field
- Data Quality Control
- Generating Letters to Participants

*** * * Let's now look at the Data Entry Form * * ***

**Some of the Challenges
that we faced
while Managing Data**

Some organizations:

**Keep changing format of data given to us,
They inconsistently return processed data**

*** * ***

Majority of Incoming Data is *not* normalized

*** * ***

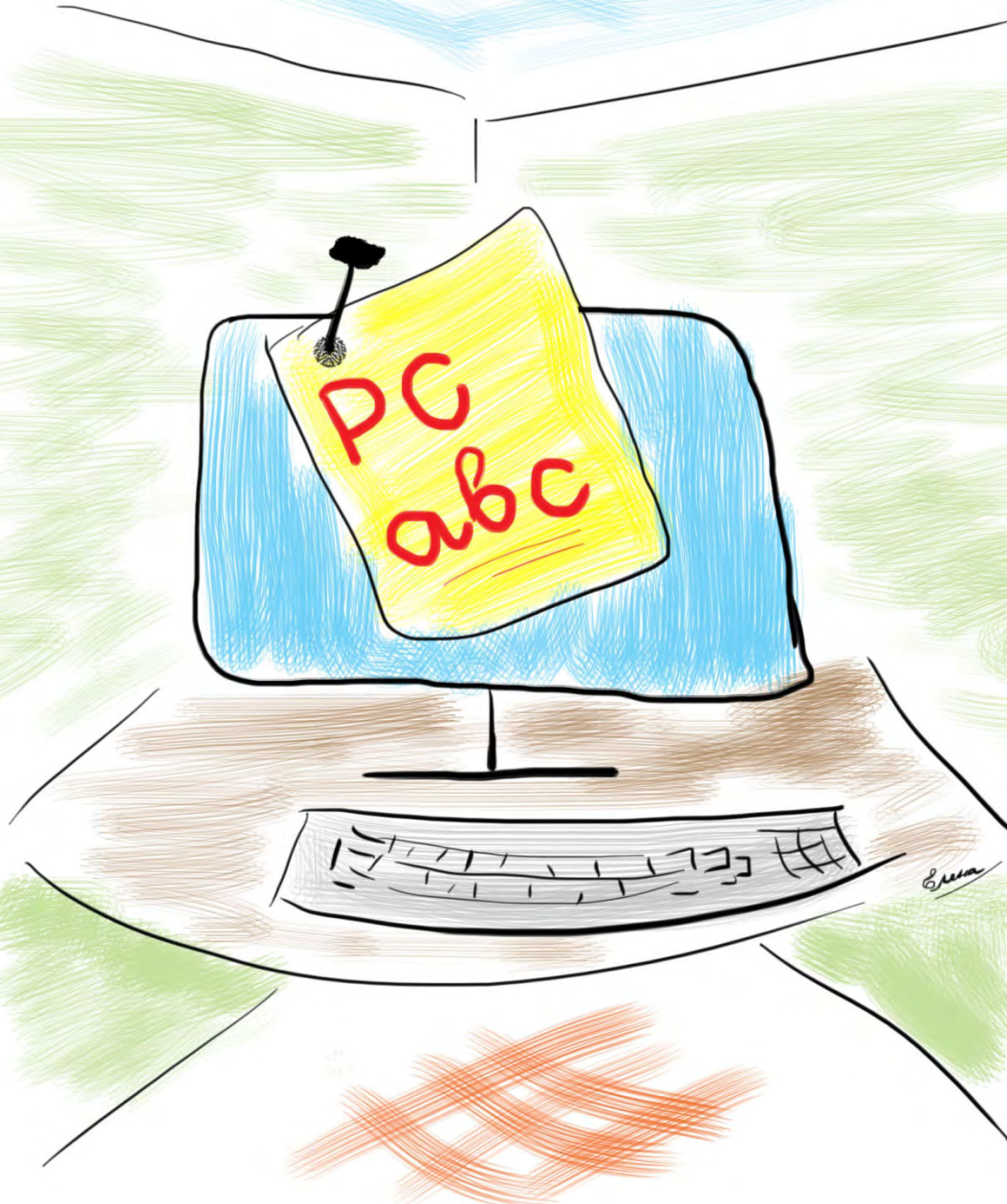
**There is no standardized process
of Data Exchange between
different organizations**

Challenge of using computers

Majority of data collection people who lived and worked at remote locations had no experience of using computers.

The off-site employees had to learn basic computer skills before starting entering the project's data.

We provided training sessions to help them and they practiced on their own until they started feeling comfortable using computers.



**Incompatible Confidentiality Protection
that is utilized by different organizations
results in the following...**

HIPAA and HSC have their own firewalls

That's why our users sometimes have to work on the two separate computers at the same time, if they want to link data located at both sites.

Notes: HIPAA = U.S. Department of Health and Human Services;
HSC = UNM Health Sciences Center



Funding is sourced to various organizations that have different policies, needs, and goals

That's why our users sometimes struggle to have the work done by partner organization's employees on time and with required degrees of accuracy and consistency.

