2018 REDCapCon Poster Competition

When is the poster presentation session?
Tuesday, August 21 in Exhibit Hall from 3:45 – 5:15 pm

How do I vote?
Check your e-mail after 3:00 pm on Tuesday, August 21. You will receive a survey invitation. In the survey you can rate each poster on a 1-10 scale.

What criteria should I use in rating each poster?

1. Methodology: Are objectives stated clearly? Are findings included and do they correspond to the objectives?
2. Usefulness: Can the information be applied elsewhere? Is it interdisciplinary and generalizable?
3. Clarity of Content: Is the poster well written? Is text easy to read?
4. Visual Impact: Is the poster well organized and easy to follow? Does it make good use of graphics?
5. REDCap Contribution: How has this project benefited from REDCap support? Is the role of REDCap clear?
6. Overall Reaction: Considering the above criteria, what is your overall reaction?

How many posters do I have to rate?
There are 24 posters and 22 of them are competing. So you will need to assign a rating to the 22 competing posters.

How long do I have to submit my voting survey?
Voting ends at 9 am on Wednesday, August 22.

What's in it for me?
A voter will be chosen at random to win a tech prize. The random voter will be announced after the poster winners are announced.

When are the winners announced?
The top three highest scoring posters are announced on the last afternoon of the 'Con (Wednesday, August 22.)

Health Information Exchange in REDCap

Leila Deering, BA and Chris Kadolph, BS
Marshfield Clinic Research Institute, Marshfield, WI

Contact Information
deeringl@marshfieldclinic.org
kadolphc@marshfieldclinic.org

Introduction

Marshfield Clinic's Office for Computing and Analytics was tasked with finding a solutions for the following.

- ✓ Ability to share patient information, across a 5 county region.
- ✓ View patients with an ordered list by follow up date and time
- ✓ Ability to view all patient data in an easy to read format which includes.
  - ✓ Patient visits
  - ✓ Referrals
  - ✓ Case assessments
  - ✓ Real time reporting
- ✓ Case management

Creation

The Application Analyst works with the business, gathers requirements and creates mock ups.

The Programmer created plugins as replacements for Record Home (RH) and Record Status Dashboard (RSD). Hooks were then developed to redirect users from RH and RSD to their respective plugins, and in appropriate context.

The development process, initially took 18 months. With the development of a framework The process has become more efficient. Most time is consumed with learning the business process flows to ensure the redirects and buttons match the workflows in the expected manner.

Simple dashboards can now be created within days, while more complex dashboards (as shown on right) can take a few months or more, depending on the requirements.

Process Flow

Click project bookmark → Opens List dashboard for records. Click "Open" on the record you want to view → Record Detail Dashboard displays data from REDCap data entry forms. Click on the custom buttons to open data entry forms. → Completing a form will redirect the user back to the detail dashboard, instead of the built-in record home

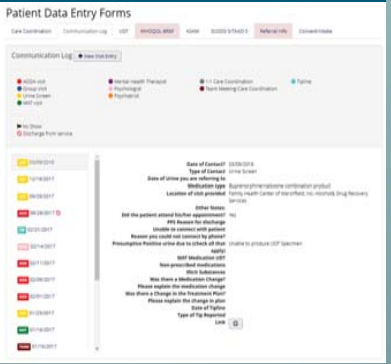
Implementation

Follow-up List Dashboard

- ✓ Prioritized work list
- ✓ Table data tailored to business requirements
- ✓ Column sorting
- ✓ Variety of filtering & search options
- ✓ Color-coding based on status

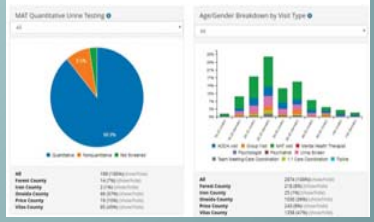
Record Detail Dashboard

- ✓ Aggregate data from all forms across the record
- ✓ Buttons to navigate to specific forms (and instances)
- ✓ View patient communication log entries by date
- ✓ Visual indicators to show patients progress or decline based on data entered.
- ✓ Ability to refer to other resources within the patient context
- ✓ Date driven alerts to indicate when assessments need completion.



Custom Reporting

For these projects the business requested to view data in real time. A custom reporting environments was created using c3js frame work to view the data in real time.



Conclusion

We were able to find a solution to all the required tasks requested by the business through custom plugin development. Having the ability to communicate across counties and with other organizations has improved patient care and outcomes.

REDCap is supported by Vanderbilt University with funding from NCATS grant UL1 TR000445. The Marshfield Clinic Research Institute Biomedical Informatics Research Center receives support from NCATS grant 9U54TR000021. Funding for the specific projects described was provided by Family Health Center of Marshfield, Inc. and grant support awarded to the Marshfield Clinic Center for Community Outreach. Marshfield Clinic Center for Community Outreach staff actively use all the REDCap systems described and continue to work with Marshfield Clinic Research Institute staff to test the limits of REDCap functionality in community programs.

RESEARCH TECHNOLOGIES
INDIANA UNIVERSITY
University Information Technology Services

REDCap-ETL (Extract, Transform, and Load)

Automating data workflows and accelerating research

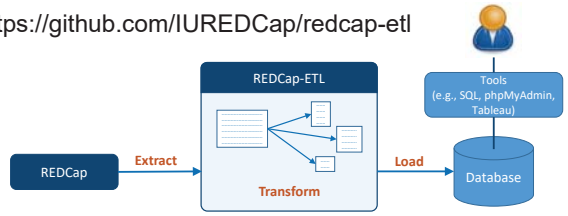
Jim Mullen, Andrew D. Arenson, Catherine Bauer-Martinez, Ryan L. Long, Abhijeet Malatpure, Richard F. Meraz

PERVASIVE TECHNOLOGY INSTITUTE
INDIANA UNIVERSITY

Overview: What is REDCap-ETL?

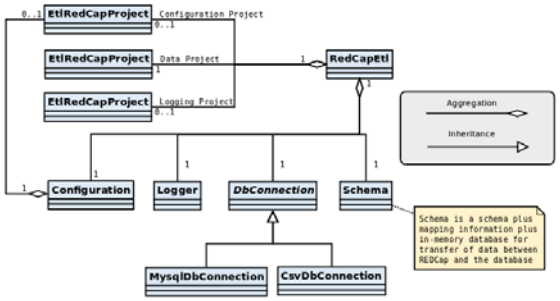
Uses simple rules to automate the process of extracting data from REDCap, transforming it, and loading it into a relational or other database for analysis and reporting.

https://github.com/IUREDCap/redcap-etl



- **Handles a variety of scenarios**
  - Suffixes (name1, name2, name3, etc.)
  - Events (6mos, 12mos, 18mos, etc.)
  - Repeating Instruments, Repeating Events
  - Events:Suffixes, Events & Repeating Instruments

- **Supports MySQL and CSV - Extendable to others**



- **Transformation Rules can be auto-generated**

```
TABLE Patient, record_id, ROOT
FIELD first_name, FirstName, string
FIELD last_name, LastName, string
…

TABLE Contact_Info, Patient, 1;2;3
FIELD phone, Phone, string
…

TABLE Contact_Attempts, Patient, REPEATING_INSTRUMENTS
FIELD attempt_date, DateAttempted, date
…
```

Value: How does REDCap-ETL help?

A faster, easier, reliable way to transform your REDCap data for data analysis.

Use instead of repetitively exporting and reorganizing data.

Examples: Who is already benefiting?

OPTIMISTIC – Improving care for nursing home residents via embedding a collaborative clinical team in nursing facilities.

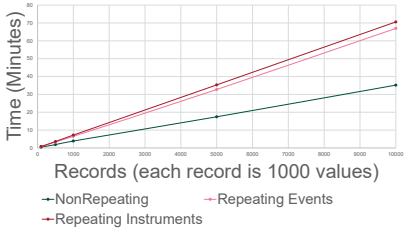
- *"Without the ETL process our daily and weekly reports would not be feasible."* – Ravan Carter, Data Analyst
- Funded via grant 1E1CMS331488, Centers for Medicare and Medicaid Services

Indiana Alzheimer Disease Center – Multi-disciplinary research program on causes, early detection, and treatment

- *"REDCap-ETL has allowed for ease of extracting, transforming, and loading into a relational data model with the use of a very simple, but robust transformation rules engine."* – Bob Davis, Director of Clinical Data Management
- Funded via grant P30 AG10133, National Institute of Aging

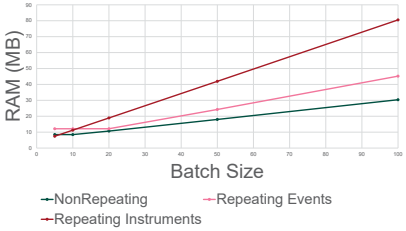
Performance Analysis: How fast is REDCap-ETL? How much RAM dose it use?

Project Size vs Time (Batch size of 50)



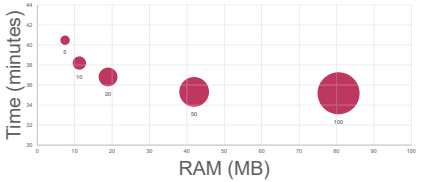
- **Repeating elements take more time to process**

Batch Size vs. RAM (5000 records)



- **Repeating instruments require more memory to process than repeating events**

Time vs RAM by batch size (Repeating Instruments, 5000 records)

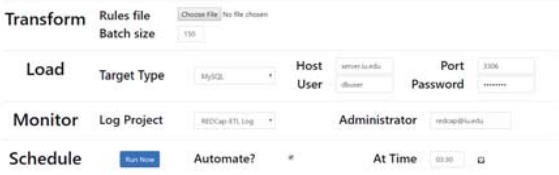


- **Batch size can exchange time for RAM, but with diminishing returns**

Formal Testing: Assuring reliability

Future: How will REDCap-ETL improve?

Available as External Module



Performance Improvements; 100% Test Coverage

REDCap External Module – *Form Render Skip Logic*

Philip Chase, BS[1], Taryn Stoffs, MS[1], Stewart Wehmeyer, BS[1], Prasad Lanka, MS[1], Dileep Rajput, BS[1], Tiago Bember Simeao, BS[1]
[1]UF Clinical and Translational Science Institute, Gainesville, Florida

What is Form Render Skip Logic (FRSL)?

Branching/skip logic for ENTIRE REDCap forms and surveys!

FRSL provides a means for hiding or displaying entire forms/surveys based upon one or more control fields or conditions.

FRSL hides unneeded forms for a specific record on the list of *Data Collection Instruments* due at each event, and grays out the colored buttons on the *Record Status Dashboard* and the *Record Home Page*.

What is a control field?

A control field is a single REDCap data or metadata field whose value will be tested to determine which forms will be displayed. If the condition evaluates as true, the forms listed under the condition will be displayed. If the condition is false, and no other true condition displays them, the forms will be hidden.

Condition fields can utilize event names, piping and Smart Variables.

The FRSL conditions and control fields can also be restricted to specific events in longitudinal projects.

Can some forms be displayed universally?

Yes, any form that is not configured within the FRSL module will display for all records.

Can I define multiple conditions or control fields?

Yes, multiple control fields or conditions can be defined to control the display of non-overlapping sets of forms.

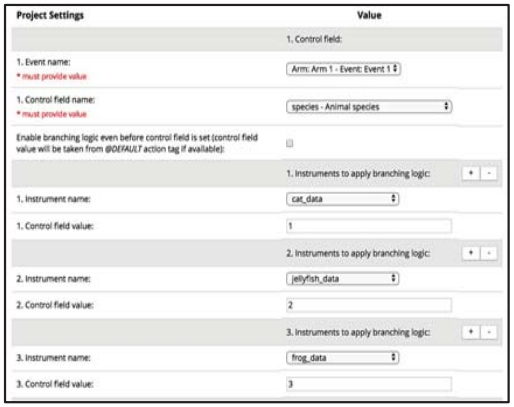
Does FRSL work with surveys?

Yes! FRSL allows you to use the 'Auto-continue to the next survey' survey-termination feature even if the 'next' survey should not be administered to the subject.

What are some use cases of FRSL?

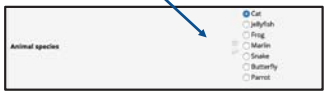
- Avoid putting records into separate arms if subjects have different CRFs and/or time and event tables (i.e., controls vs. interventions).
- Make subsequent forms 'unavailable' if subject is not eligible or withdraws from the study, to avoid further data collection.
- Make site-specific forms available only when a record is assigned to a DAG (i.e., site-specific Informed Consents).
- Eliminate the need to use the *Survey Queue* when not all subjects will receive the same set of surveys.

A Simple Example of FRSL in Action

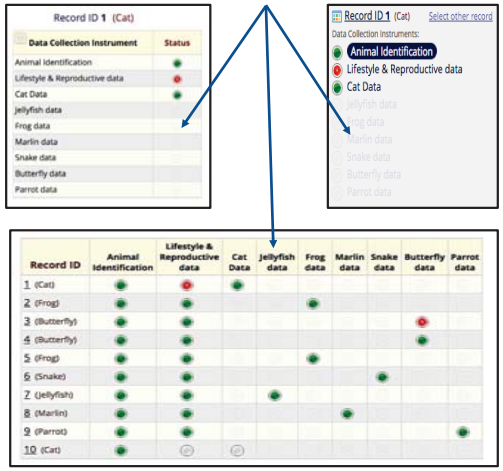


Configuration of the FRSL Module

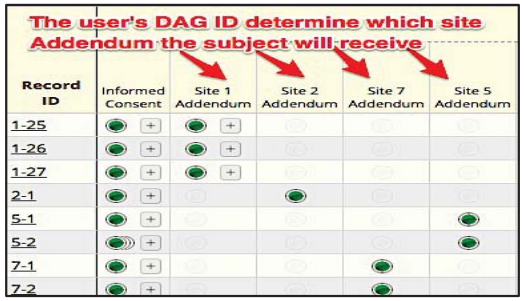
Control Field

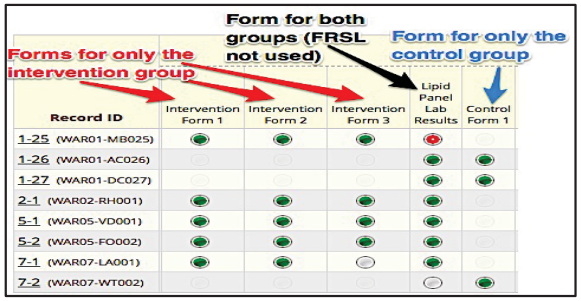


Unneeded forms are hidden



Further Examples Using Smart Variables or Multiple Conditions





Where can I download the module? Form Render Skip Logic is released under an open source license. It's available at https://github.com/ctsit/form_render_skip_logic and in Vanderbilt University's REDCap Repo.

Clinical and Translational Science Institute UNIVERSITY of FLORIDA

This work supported in part by the NIH/NCATS Clinical and Translational Science Awards to the University of Florida UL1TR001427, KL2TR001429 and TL1TR001428.

Experiences in running an offline electronic data capture system in a large-scale population trial in Nepal and Bangladesh

Yama G Farooq[1*], Olga Mazur[1], Katherine Theiss-Nyland[1], Rachel Colin-Jones[1], Merryn Voysey[1], Mujtaba Ghulam Farooq[1], Xinxue Liu[1], Andrew J Pollard[2], Mila Shakya[3], Anup Adhikari[4], Ashesh Chhetri[4], Bhola Prasad Koirala[4], Nirod Chandra Saha[5], Prasanta Kumar Biswas[5].

[1]Oxford Vaccine Group, [2]University of Oxford, UK. [3]Oxford University Clinical Research Unit - Patan Academy of Health Sciences, Kathmandu, [4]Nepal Family Development Foundation, Nepal. [5]International Centre for Diarrheal Diseases Research, Bangladesh.

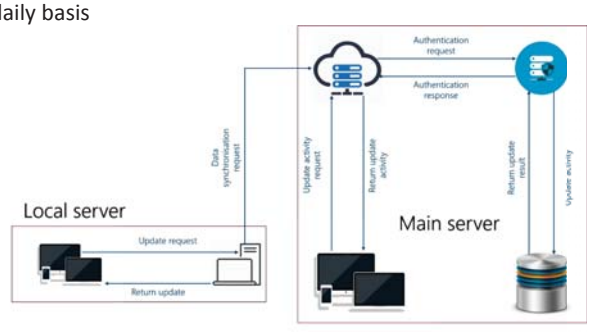
Background

- TyVAC is a partnership between the Centre for Vaccine Development at the University of Maryland, the Oxford Vaccine Group at the University of Oxford, and PATH, an international non-profit organisation. TyVAC aims to accelerate the introduction of new typhoid conjugate vaccines (TCVs) into Gavi (the Vaccine Alliance) eligible countries in order to reduce morbidity and mortality caused by Salmonella enterica serovar Typhi.
- Two main data collection issues faced by TyVAC were:

1. Traditional data collection and data management methods
   - are labour intensive
   - result in poor quality data collection[1]
   - increase data cleaning time
2. The REDCap mobile application does not support
   - repeatable instruments
   - randomisation
   - dynamic SQL queries
   - large projects (>1000 fields)

Methods

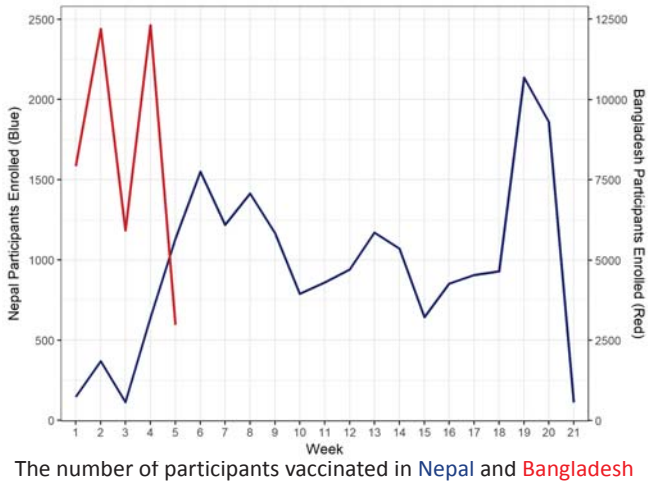
- Portable servers accessible through the intranet were developed to overcome the limitations of the REDCap mobile application and enable generation of high volume quality data.
- Case report forms were developed in REDCap and were deployed to all local servers.
- Data from local servers were uploaded to the main server on a daily basis



- Scripts to check data quality were written in C# and R programming languages and run regularly to enhance data quality
- Database reports and descriptive analyses were auto-generated weekly
- We assessed efficiency and quality of the process by quantifying accuracy and volume of data and data entry time during the course of the vaccination campaigns.

Results

Number of participants vaccinated per week



- The number of participants vaccinated in Nepal and Bangladesh were 20,019 and 41,344 in 21 weeks and 5 weeks respectively.
- Data entry was carried out by 123 staff in Nepal and 100 in Bangladesh.
- The overall percentage of correct data ranges from 97 to 99%. The median rate of error encountered ranges from 1 to 3%
- Accuracy values meet the acceptable quality threshold of 50 errors per 10,000 data point recommended by the Society of Clinical Data management[2].

Conclusions

- The data capture system used in TyVAC Nepal and Bangladesh
  - is robust and easy to use
  - allows high volume data collection over short time period
  - has low error rates
  - allows data access in real time
  - facilitates data quality checks and data validation
  - is adaptable for use in other similar clinical trial studies

REFERENCES:
1. James M. Galliher, PhD1,2,3 Thomas V. Stewart, BA1 Paramod K, Data Collection Outcomes Comparing Paper Forms With PDA Forms in an Office-Based Patient Survey
2. Pomeratseva V, Ilicheva O. Clinical Data Collection, Cleaning and Verification in Anticipation of Database

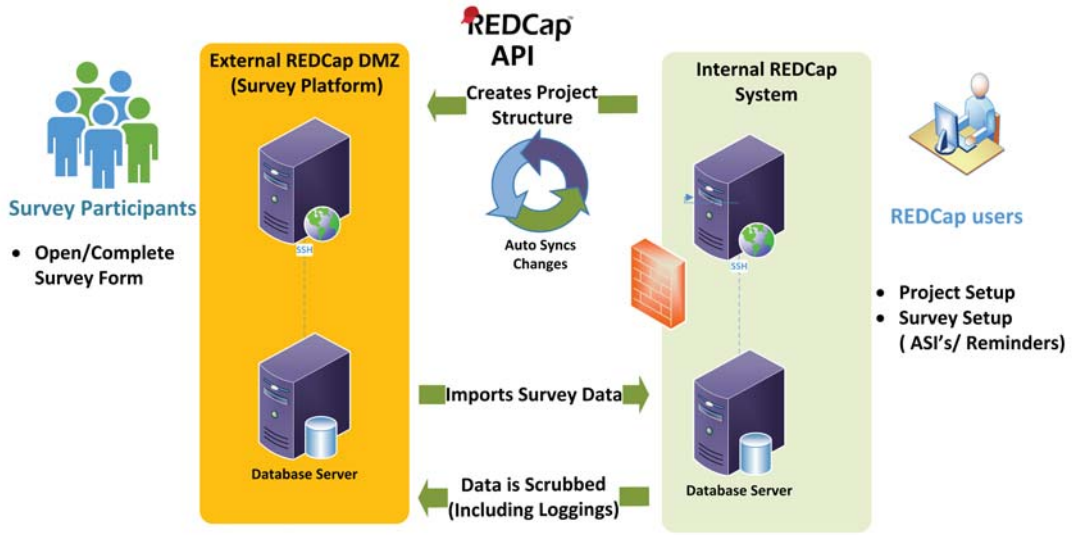
FUNDING: TyVAC is funded by the Bill and Melinda Gates Foundation, grant number OPP1151153

Implementation of a highly secure REDCap infrastructure that retains world-wide survey capabilities

Naveen Karduri, Samantha Walkow, Ashley McKerrow, Anastasia Dropol, Fontayne Wong, Halley Cote, Gurm Dhugga, Elodie Portales-Casamar
BC Children's Hospital, Vancouver, BC, Canada | redcap@bcchr.ca

ABSTRACT : BC Children's Hospital Research Data Management team has implemented a clinical REDCap infrastructure (Database & Web servers) that is not exposable to external networks while retaining the functionality to send surveys world-wide. Personal health information is stored in a dedicated clinical REDCap platform only accessible to clinicians/staffs within the hospital network. A separate REDCap survey platform in the DMZ is used to generate and send the survey links as well as receive survey data back from respondents. All data from the survey platform is passed through the firewall to the clinical platform according to programmed rules and triggers with SSL encryption using the DET-API feature of REDCap. All data is scrubbed from the survey platform immediately upon transmission to the clinical platform. The implementation retains REDCap survey functionalities, including survey invitations, survey reminders, and survey queue.

Architecture



Developer Tools

New REDCap API Methods

Additional to REDCap Core API Methods:

- Import and Export Survey Settings
- Export Public Survey Link of Project
- Import Record as Survey Complete (Includes Completion Time)
- Export Record Details by Survey Hash Code
- Export and Import Survey Queue Settings

Plugins

- **External Survey Setup**
  This plugin is designed to copy a full project structure in external REDCap System from the push of a button in the internal REDCap System. This includes survey settings, survey queues.
- **Data Transfer from External to Internal Systems (DET)**
  This plugin is designed to transfer the data to the Internal database server when a survey is completed on the external system and deletes the data on the external database server.

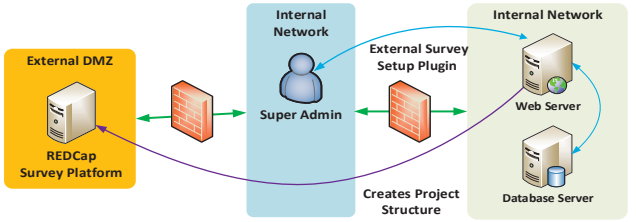
Future Direction

- **Import and Export Survey Login Settings**
  This method will allow you to import and export survey login settings of a project.

Data Work Flow

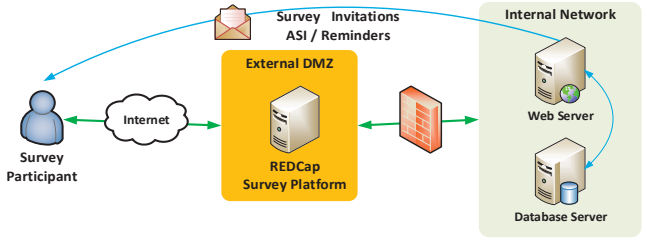
Step 1 – External Project Creation

Initial Setup: A Super Admin runs a REDCap plugin on the **REDCap internal server** to create a new project structure without data on the **REDCap external DMZ server**.



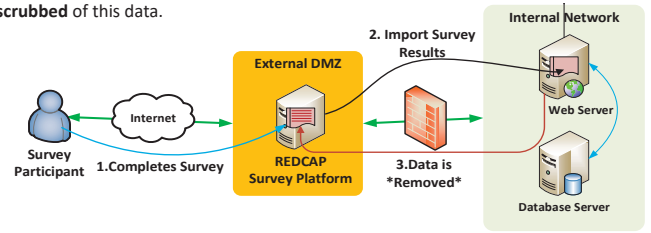
Step 2 – Survey Links Sent to Participants

Emails from the **REDCap internal server** are sent to the participants, the survey links contain a URL to the **REDCap External DMZ server**.



Step 3 – Participant Completes Survey and Data is Scrubbed

Participant completes the survey on the **REDCap external DMZ server**, the data is then pushed to the **REDCap internal server** and the **REDCap external DMZ server** is **scrubbed** of this data.



The Ever-Expanding Functions of REDCap – Successfully Administrating Investigator-Initiated Research Studies

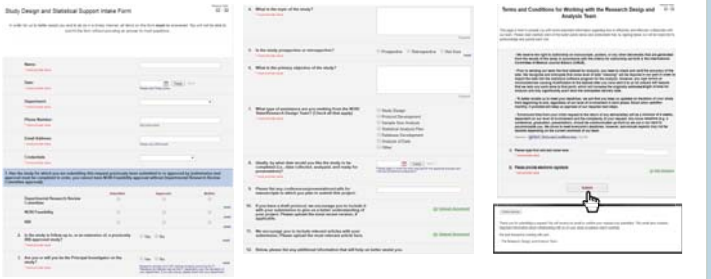
Hope Kincaid, MPH, CPH and Jennifer Macfarlan, MPH
Network Office of Research and Innovation, Lehigh Valley Health Network

ABSTRACT

Before the days of REDCap, the Research Design and Analysis Team's (RDAT) process for investigator-initiated research studies was lacking the support needed and not sufficient for the complexity and quantity of projects. This problem persisted throughout the lifecycle of the project. The old process started with a simple group email serving as the ticketing system, followed by MS Access as the tracking system, and it ended with an often very dirty Excel file, requiring significant cleaning before analysis. LVHN's adoption of REDCap (in 2016) has allowed us to streamline our process and has enhanced the work flow. The following is the series of events involved in the new process that transpire over the lifecycle of a project.

1. PROJECT CONCEPTUALIZATION

2. TICKETING SYSTEM

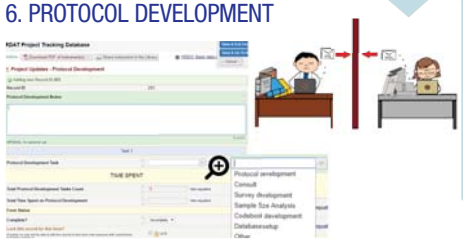


3. YOU'VE GOT MAIL!

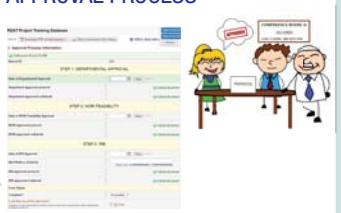
4. INITIAL STUDY MEETING

5. TRACKING DATABASE

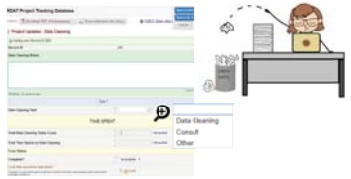
6. PROTOCOL DEVELOPMENT



7. APPROVAL PROCESS



8. DATA CLEANING



9. STATISTICAL ANALYSIS

10. FINAL PRODUCTS DEVELOPMENT

11. DISSEMINATION OF RESULTS

Lehigh Valley Health Network
LVHN.org

THE UNIVERSITY of NORTH CAROLINA at CHAPEL HILL

Let Your PIs Manage the Expiration Date

UNC SCHOOL OF MEDICINE
North Carolina Translational and Clinical Sciences Institute

Introduction

Assigning the *User Rights* privilege in REDCap grants users the ability to perform numerous tasks: creating a role, adding users to the project, assigning users to a role, and setting an expiration date for users. Giving REDCap *User Rights* to a member of a project allows complete control such as an administrator would have. At UNC-Chapel Hill, we historically have not assigned *User Rights* to anyone other than REDCap administrators since it would allow them to delete data. Therefore, the responsibility of performing administrative tasks has fallen to REDCap administrators.

In order to provide the task management of renewing user access to the Principle Investigators and their project managers, we have developed new plugins which allow them to update their project users' expiration dates without needing to assign them REDCap *User Rights* privileges.

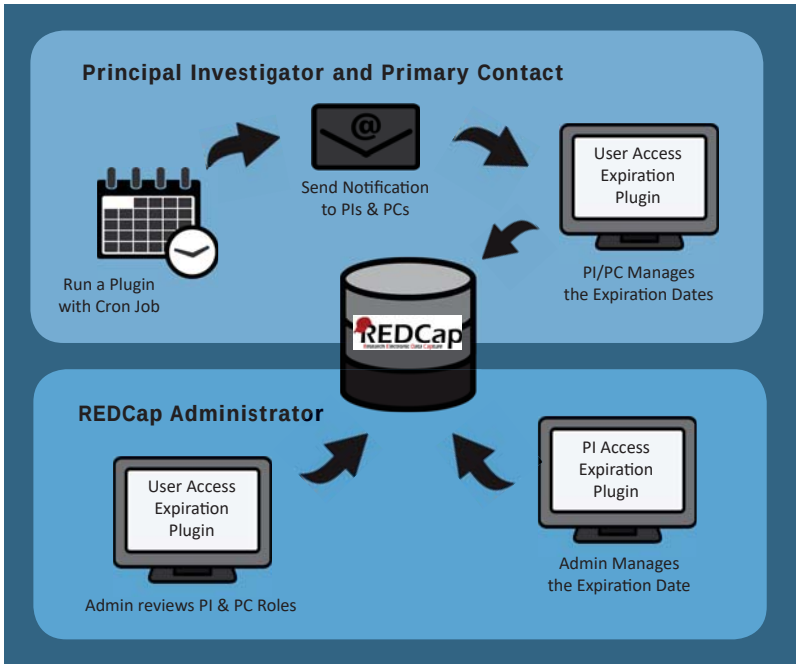
Prerequisite Role

- Principle Investigator (PI) roles : pi_data_mgr, pi_read_export
- Primary Contact (PC) role : data_mgr_primary

The *Expiring* plugins look for users with the above roles and identify who has permission to manage project users' expiration dates. They may renew user access for those accounts expiring within this month or that have expired in the past 90 days. A PI role may renew user access for anyone on the team except their own. A PC role may renew anyone except themselves and the PI.

Send Notification to PIs & PCs

First, we gather the redcap_user_rights table data to find users from the "Development" and "Production" projects whose expiration is in the past 15 days or next 30 days from the date of running the query. From the generated data, we send emails to PIs and PCs with links to the projects in which users are expiring. If the PIs or PCs have never logged in, the email is sent to username "at" standard UNC email server. These emails are sent on the 15th and 25th of each month, providing two reminders to PIs and PCs before user access expires. They will only receive one email with all project links even if they have multiple projects.



PI/PC Manages the Expiration Dates

Principle Investigator and primary contact users will receive emails with the following link:

https://{REDCap URL}/plugins/expirations.php?pid={project id}

The link from this email takes the PI/PC to the *User Access Expiring* plugin. The choices are "Let Expire", "Expire Today", "Renew 1 Year," or a specific date. Because they are required to renew annually, they may only pick dates within a year. They then choose the appropriate action and certify compliance with required HIPAA training. Selections are logged, so if they choose "Let Expire" or "Expire Today", those users will not be displayed in subsequent views for the next 32 days. The default view is "recently expired" and "expiring soon". They may select different time frames of either "expiring in 90 days" or "view all".

Admin Reviews PI & PC Roles

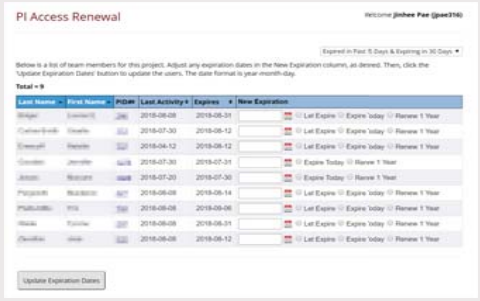
For the REDCap administrator, the *User Access Expiring* plugin displays a list to ensure the PIs and PCs are listed on every project with a user expiring within the month. This feature is included in the *User Access Expiring* plugin because it makes it easy to navigate among projects. If roles are missing on projects, this can easily be determined from the list, and the admin will add them.

Admin Manages the Expiration Date

Those who are assigned PI and PC roles may manage their project users' expiration dates, but they cannot update their own expiration date. The PIs should renew PCs, while a REDCap administrator will update the PIs' expiration dates using the *PI Access Expiration* plugin.

https://{REDCap URL}/plugins/expirations_pi.php

This list shows the PIs and PCs who are expiring within a selected time frame, providing a way to review project activity to ensure they are still active while renewing PI access. The projects that are set to "Archived" or "Inactive" are not displayed. Development projects are reviewed separately to determine if they need additional assistance.



Where and How to Get the Plugins

Go to **tracs.unc.edu/redcap-plugins-manage-users-expiration**

OR

1. Go to **tracs.unc.edu**
2. Click on **Resources**
3. Click on **ShareHub**
4. Click on **Informatics**
5. Click to **Download** the "REDCap plugins - Manage Users Expiration"

Note : need to create an account and login

Using REDCap to Stop the Data Chaos

Roya Hamadani, MFA, MPH, Lehigh Valley Health Network, Allentown, Pa.

The Health Advocacy Project (HAP) is a program designed to meet the social and economic needs of patients from Community Clinics a Lehigh Valley Hospital–17th St.

- College interns are trained to become Health Advocates (HAs) and serve average 3-4 months.
- HAs complete an Intake to identify patient's social needs.
- HAs refer patients to appropriate community resources.

To show the impact of the program, HAs must document

- All contacts (telephone and face to face) with patient
- All resource referrals made
- All contacts between patients and resources, when they occurred, and the result of those contacts (patients' self report)

In Year 1 our REDCap Project focused on collecting the data we needed, rather than aiding the HAs correctly collect and enter the data we needed. By the time HAs had mastered the work flow, their internships were almost over. And trying to analyze the data on the back end was…chaos.

We were able to identify common mistakes to inform our second project design in Year 2. We used the new features to reduce training time and errors, while increasing accuracy:

- Branching logic and piping through the series of forms for each client guide the referrals HAs make and the follow up questions they ask.
- Reports and Custom Dashboards allow us to identify common errors so that specific concepts can be quickly re-iterated as needed.

USING BRANCHING LOGIC AND PIPING TO GUIDE BEHAVIOR

HAs should give resources based on location. However most HAs are from out of the area, and it takes time to learn what is available and where.

- Populating resources according to city saves training time, and prevents duplications.

1. The HA chooses "Allentown" from the drop down menu on the Demographic form.
2. If the city on the Demographics form is "Allentown" and the Intake form indicates the client has food insecurity, then food banks and pantries located in Allentown will appear on the Referrals Made form. For every resource the HA chooses, they are also prompted to enter the date.
3. We also track # connections to resources and # satisfied clients per month. For that reason

- All the resources chosen and dates entered on the Referrals Made form will appear on the Follow Up forms to remind HAs to ask the patient if they have contacted the resource(s).
- Previous to this feature, HAs toggling between screens would often forget to ask about every resource.

USING REPORTS TO CONTROL ERRANCY

4. We use many quality check (QC) reports to keep HAs on schedule.

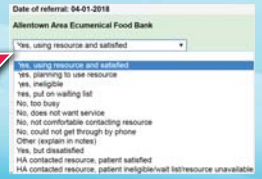
- Example: This report allows us to quickly find instances where follow up call was not attempted within the required 7 days of the first referral or service provided by HA.

USING CUSTOM DASHBOARDS TO IDENTIFY SOURCES OF CONFUSION

5. Custom Record Dashboards allow us to quickly see which cases are missing the required completed forms.

- Example: This dashboard allows us to quickly identify errors by number of instances and status of forms. Here we can see that Big Bad-Wolf is missing a completed Provider Update form.

Since using these features, training has become more efficient, HAs reach proficiency sooner, and reports are more accurate, thereby stopping the data chaos. (Now it's more of a slight muddle. Much more manageable.) The fight continues!



CURRENT PROJECT: **893** fields ➤ **8** forms ➤ **42** reports

BRANCHED AND PIPED THROUGH 2 FORMS: **95**

Captured over 21 months...

PATIENTS REFERRED TO RESOURCES: **240**

REFERRALS MADE BY HAs: **997**

SATISFIED PATIENTS: **153**

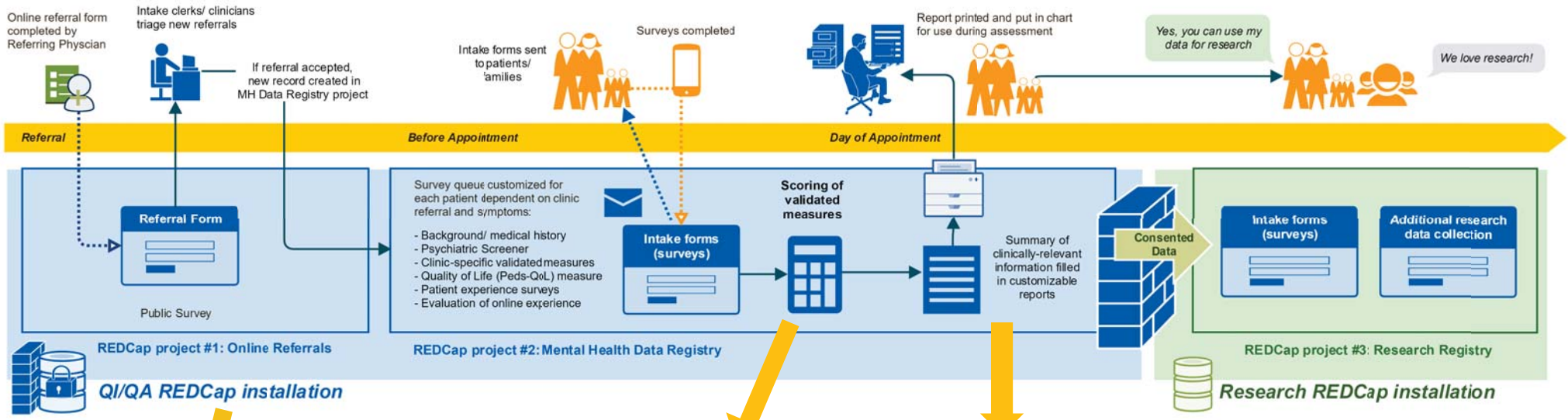
Lehigh Valley Health Network

LVHN.org

An integrated toolbox to collect and deliver clinically-relevant information on-demand

Fontayne Wong, Naveen Karduri, Nelson Chan, Samantha Walkow, Ashley McKerrow, Halley Cote, Anastasia Dropol, Ashley Lee, Stephen Fung, Gurm Dhugga, Elodie Portales-Casamar
BC Children's Hospital, Vancouver, BC, Canada | redcap@bcchr.ca

Background: BC Children's Hospital Research Data Management team developed a set of custom tools and REDCap plugins to enhance collection and delivery of referral and patient/ family-reported information to clinicians and administrators in Mental Health programs at BC Children's Hospital and BC Women's Hospital + Health Centre. This fills a need for secure, standardized data collection across different clinics in the program and provides infrastructure for both program evaluation and integrated research.



"Clinical" REDCap platform behind firewall that is only accessible by clinicians and staff within hospital networks. Survey functionality is retained by an additional external REDCap platform that passes encrypted (SSL) data through the firewall using DET-APIs and promptly deletes data after it is transferred.

See our other poster for details:
Karduri N, et al. Implementation of a highly secure REDCap infrastructure that retains world-wide survey capabilities. Poster presented at: REDCapCon 2018 (hosted by the University of Chicago). 10th Annual Conference of the REDCap Consortium; 2018 Aug 19-22; Chicago, IL, USA.

Scoring Look-up (plugin and DET-APIs)

- Uses the raw score of measures (calculated on REDCap) to look up and import appropriate T-score, percentile, and classification back into the record using DET-APIs

Step #1: Determine if conditions met for look-up

Scoring Scheme	Eligible Age Range	Eligible Gender
BRIEF Parent Form	5 <= Age < 19	Both Male and Female
BRIEF Self Form	11 <= Age < 19	Both Male and Female
CBCL	6 <= Age < 19	Both Male and Female
Conners Parent Form	6 <= Age < 19	Both Male and Female
SDSC	N/A	N/A

Step #2: Obtain scoring, percentile from CSV files containing scoring tables by passing raw score to ScoreLookup script

subtest	gender	age	rawscore	tscore	percentile
bri	m	5	28	33	1
bri	m	6	28	33	1
bri	m	7	28	33	1
bri	m	5	29	34	3
bri	m	6	29	34	3
bri	m	7	29	34	3
bri	m	5	30	35	6
bri	m	6	30	35	6
bri	m	7	30	35	6

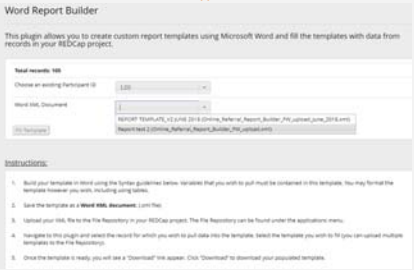
Step #3: Import scoring, percentile, classification, accept flag value back into record (DET-API)

Word-Template Report Builder (plugin)

- Allows end users to pull REDCap data (e.g. patient-entered intake information and calculated scores on measures) into custom templates formatted as Microsoft Word XML files

Step #1: Create XML template in MS Word and upload to File Repository

Step #2: Navigate to plugin on REDCap and select template and record ID. Link to download filled XML file will appear.



Supports:

- Classic and longitudinal projects
- IF conditions (nested up to 10 levels)
- Combined logical operators (AND/ OR/ =/ <>/ >/ </ <=/ <=value<=)
- Display and hiding of rows/ tables based on IF conditions
- Flexible formatting and design of template in MS Word

Future Directions: We will explore creating a patient portal (with login) to house the intake surveys and appointment information, integration with our EMR, and sending personalized resources to patients and families based on their responses to the intake questionnaires.

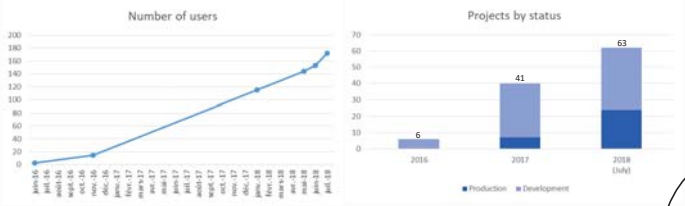
REDCap at Institut Pasteur illustrated by a use case with offline constraints

M. Sanchez [1], T. Obadia [2], B. Dupont [1], S. Demey [1]
[1]EvoSI Group, IT department, Institut Pasteur, Paris, France
[2]Malaria Parasites & Hosts Unit, Department of Parasites & Insect Vectors, Institut Pasteur, Paris, France

REDCap at Institut Pasteur

Research areas

REDCap indicators



Our data collection areas

Limited/Unreliable network coverage Good network coverage

Use Case ACT-Radical Study

A comparison of two artemisinin combination therapies (ACTs) in combination with primaquine for radical cure of *Plasmodium vivax* malaria in the Solomon Islands.

Study methods

- 3-arm Randomized Controlled Trial with 2:2:1 block-randomization
- 6-month active follow-up with 16 scheduled visits
- Initial assessment of demographic covariates, regular collection of biological samples, microscopy and PCR detection of parasites
- Passive follow-up when patients go to their local health center for possible Adverse Event or any other illness
- Primary endpoint: time to first *P. vivax* relapse

Data collect

A multiple project approach

① Sick patient visits local health center

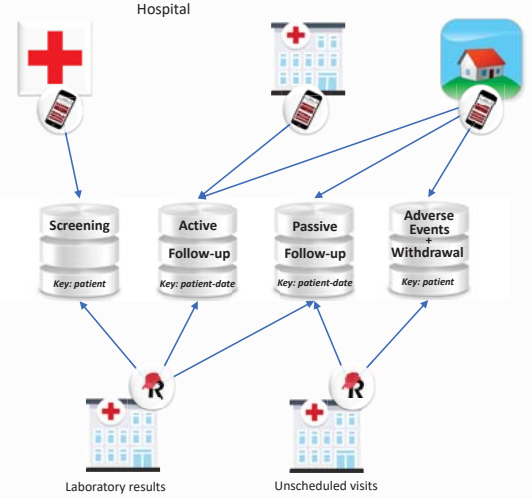
② Local health center contacts ACT-Radical regulator for possible relevant case

③ **Screening team** goes for patient initial assessment

④ **Screening team** brings back eligible patient to Good Samaritan Hospital

⑤ **Enrollment team** validates inclusion, patient is randomized and treated

⑥ **Follow-Up team** meets with patient at 15 different scheduled visits over the next 6 months



Technical challenges

- Staff is not computer-literate
- Poor and unreliable internet coverage
- Concomitant screening and enrollment by different teams on different mobile devices
- Lab results not available in real-time
- Integration of unscheduled visits in a longitudinal setting

Challenges addressed

Patients are attributed a screening ID that should be reported when they are enrolled. Regardless, critical data from screening is collected again after enrollment.

To keep the possibility to enroll multiple patients simultaneously, the bloc-randomization list was prepared ahead of study and is not handled in REDCap.

Strict procedures were developed for project initialization, data collection and synchronization steps with data safety as first priority. Daily review of data allows for early detection of errors and rapid clarification requests.

Conclusion

Efficient use of multiple REDCap projects is a good way to address complex study designs. Regular data uploads are critical for day-to-day collection in a longitudinal setting, yet challenging when internet access is of poor quality. Emergency dumps and project logs provide robust backups.

Contact: redcap@pasteur.fr

REDCapCon: Hosted by University of Chicago August 19 – 22, 2018

An Interactive Multimedia Consent Process Using a Website and Videos

Suzanne M. McCahan, PhD[1,2], Chris Pennington, MS[1], H. Timothy Bunnell, PhD[1], Kathryn Blake, PharmD[1]

[1]Nemours Biomedical Research, Wilmington DE, and Jacksonville FL; [2]Jefferson Medical College, Thomas Jefferson University, Philadelphia PA

INTRODUCTION

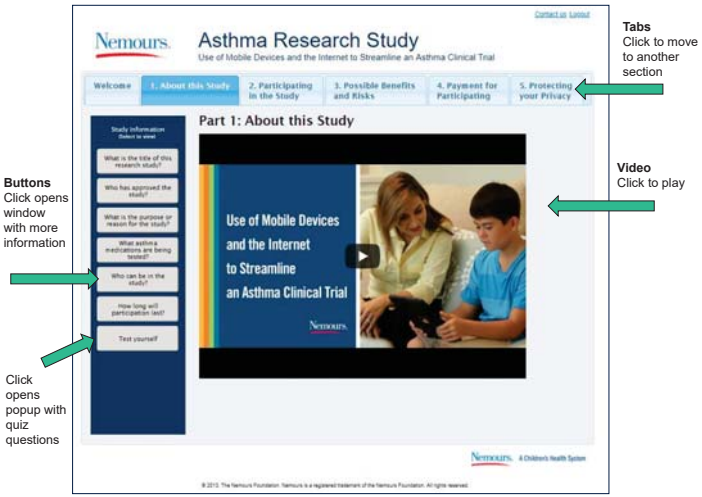
A pilot pediatric asthma clinical trial was performed to investigate novel methods for obtaining consent. Participants were randomized into two arms. In one arm, the parental permission/assent process was conducted via traditional means. In the other arm, the parental permission/assent process was delivered over the internet via a dynamic interactive multi-media format. This multi-media format included a website and videos. Participants' access to the multimedia material was controlled via username and password stored in REDCap and interaction with the multi-media materials was tracked and stored in REDCap. This pilot study was designed as a noninferiority study and tests if the multi-media format is not inferior to the traditional format.

OVERVIEW OF STUDY DESIGN

- Two arms
  - LASST – traditional paper consent form
  - MICT – multimedia presentation of trial information and documentation of consent
    - Website with trial information
    - Consent documented in MyNemours (Nemours branded EPIC MyChart)
- Assessment for comprehension of consenting information
  - Parent and adolescent (12-17 yo) interviewed separately (voice recorded)
  - 17 item verbal questionnaire
    - Responses rated by two evaluators
    - Correct answer 3 pts; Partially correct answer 2 pts; Incorrect answer 1 pt

PARTICIPANTS' WEBSITE EXPERIENCE

- Access to website controlled
  - Potential participants were given a username and password
  - Login credentials were stored in REDCap and accessed via API
  - Each entry into the website required a report of who was viewing the website (parent/guardian, child or other)
- Video (15 minutes total length)
  - Separated into 5 parts, each part was presented on a separate tab
- Side bar buttons
  - Click on button opened window with information about the study
  - Specific buttons were referred to in the video
  - Selected buttons changed color when referred to
- Quiz questions
  - Completion required before information on next tab could be viewed
  - Positive feedback for correct and incorrect answers given as each question was answered
- Final video section paused
  - Participants were instructed to complete the quiz questions for this section and then come back to video
- Participants were free to navigate back to review previous material and to return to the website



DEVELOPMENT OF VIDEO CONSENT AND WEBSITE

- Office of Human Subjects Protection and Institutional Review Board
  - Provided feedback on video and script as they were developed
  - Approved waiver for:
    - Replacement of paper consent document with video and multimedia website
    - Having a person-to-person telephone interaction instead of a face-to-face interaction with the researcher
    - Documentation of informed consent electronically instead of using an ink signature on paper (EPIC and MyChart at Nemours were compliant with federal regulations)
- Consent video and website designed based on principles of human cognition and learning (sensory-modality view, coherence, signaling, redundancy and personalization)
- Web pages coded in PHP, JavaScript, CSS, HTML
- All activity (clicks) on website tracked; data was stored in REDCap via API
- Video files stored on YouTube (unlisted channel)

PUBLICATIONS

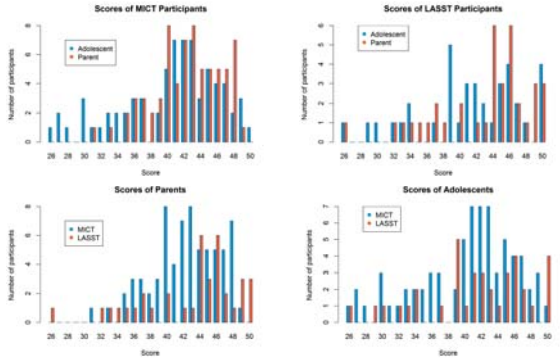
- Antal H, Bunnell HT, McCahan SM, Pennington C, Wysocki T, Blake KV. A cognitive approach for design of a multimedia informed consent video and website in pediatric research. J Biomed Inform. 2017 Feb;66:248-258. PubMed Central PMCID: PMC5381728
- Blake K, Holbrook JT, Antal H, Shade D, Bunnell HT, McCahan SM, Wise RA, Pennington C, Garfinkel P, Wysocki T. Use of mobile devices and the internet for multimedia informed consent delivery and data entry in a pediatric asthma trial: Study design and rationale. Contemp Clin Trials. 2015 May;42:105-18. PubMed Central PMCID: PMC4450122

ASSESSMENT SCORES

Assessment scores for participants in the MICT and LASST arms

Highest possible score = 51; Lowest possible score = 17

	MICT		LASST	
	Parent	Adolescent	Parent	Adolescent
Average	43.1	41.1	43.7	42.1
Std Dev	4.09	5.98	5.85	6.13
n	70	71	37	37



USE OF VIDEO CONSENT AND WEBSITE

- 71 Participants signed consent to MICT arm
- 2 participants only had quiz answers tracked
- 1 parent only clicked 'Start'
- 1 parent didn't view website (only adolescent did)
- 4 adolescents didn't view the website (only parents did)
- 1 participant only indicated 'Other' viewed the website

Number of MICT participants who viewed the video

Section of Video	Parent	Adolescent
1	62	59
2	60	55
3	60	56
4	62	57
5	61	56
Viewed All	59	52
At least one section not viewed	10	17

ACKNOWLEDGEMENTS

We thank Kathleen Norton (Nemours Marketing and Communication) for her work on creation of the consenting video and design of the Consent Web Site; Yang Li, MS for her programing work; and Tim Wysocki, PhD and Holly Antal, PhD for their contributions to the development of the content and assessment.
This work was supported by NIH/NHLBI grant 1R01HL114899 and the Nemours Foundation.

A Linear Data Entry Workflow for REDCap and the WARRIOR Investigation

Philip Chase, BS[1], Taryn Stoffs, MS[1], Surya Prasanna, MA[1] , Prasad Lanka, MA[1], Dileep Rajput, BS[1], Tiago Bember Simeao, BS[1], Stewart Wehmeyer, BS[1], Mike Conlon, Ph.D[1], Dr. Eileen M. Handberg, Ph D, ARNP-BC, FACC[2], Dr. Andre Rogatko, PhD[4], Dr. Rhonda Cooper-DeHoff, Pharm.D., M.S., FAHA, FACC[2], Jane-Anne Norton, BS[2], Brittney J Roth, MPH[2], Dr. C Noel Bairey Merz, MD[3], Dr. Carl J. Pepine, M.D., MACC[2]
[1]UF Clinical and Translational Science Institute, Gainesville, Florida; [2]UF Health, Gainesville, Florida; [3]Smidt Heart Institute, Cedars-Sinai Medical Center; [4]Cedars-Sinai Biostatistics and Bioinfomatics Core

Problem

The WARRIOR Investigation is a pragmatic clinical trial of the effects of aggressive therapy in women with nonobstructive coronary artery disease. The trial was designed with a streamlined clinical workflow to proceed directly from consent, through eligibility assessment, randomization, data collection, recommendations for therapy, and delivery of prescriptions to the study pharmacy. This workflow requires strict enforcement of data collection rules to allow decision making and therapy.

REDCap is more permissive than the WARRIOR Investigation workflow. Data entry rules in REDCap's non-survey forms are not enforced. Required fields are not enforced. Data entry workflow can skip steps. Decision-making is not possible without all the required inputs.

Solution

Force forms to be filled in sequence. Enforce data entry rules and required fields to progress through forms.

Outcomes

Rules can recommend eligibility and RXes based on inputs from case report forms. Fewer retrospective data quality checks are required. Less missing data. Required configuration work is minimal. Software tools are generically useful.

How we did it

Write a REDCap External Module.
- Project-level activation, configuration, and form knowledge make the REDCap External Module framework perfect for the task.

Let project metadata and events drive the workflow.
- Present forms in the order described in the Data Dictionary.
- Present events in the order described in Define My Events tab.
- Enforce the form's required field data.
- Enforce the form's data constraints.

Use each form's *Form* Completed field as the gatekeeper.
- Do not allow a form to be marked *Completed* if a required field is missing or a data entry constraint fails.
- Require a form to be marked *Completed* to move to the next form.

Apply these rules in every view that allows access to a form.
- Record Status Dashboard
- Record Home
- Data Entry Form

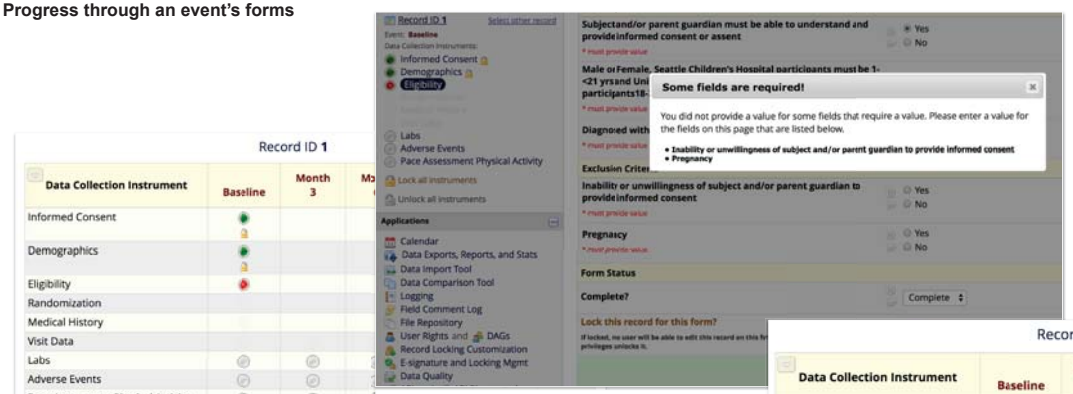
In production since February 2018

By-products of the project goals

Auto-locking of forms on completion
- Once the forms are completely filled in and the data quality checks are met, automatically locking a form is the natural next step. This feature is configurable by role so only study coordinators experience the automatic lock event.

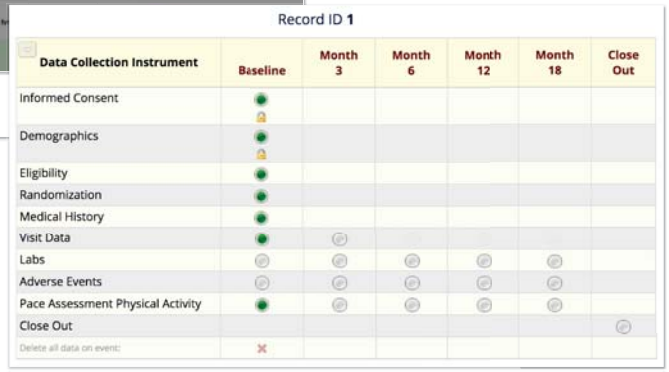
Generically useful, fully configurable, free software
- The software is fully configurable for use in any project on any REDCap system. It is available on Github and the REDCap Repo.

Progress through an event's forms



Honoring required fields
An attempt to save a form as completed will cause rechecks of data quality rules and field requirements.

Record Home – Baseline incomplete
Completed forms have allowed access to *Eligibility*. As it is incomplete, *Eligibility* blocks access to *Randomization* and so on.



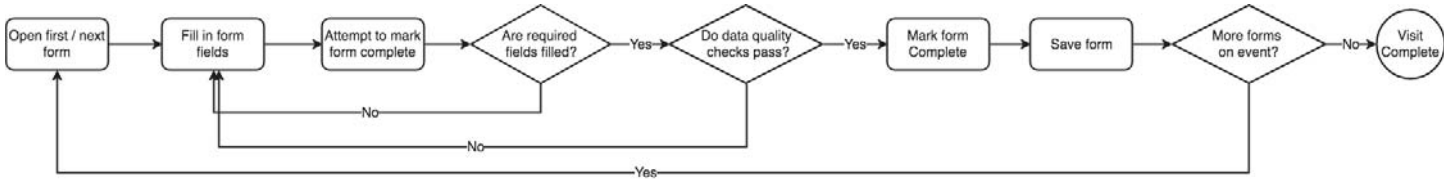
Record Home – Month 3 accessible
With *Baseline Visit Data* completed, *Month 3 Visit Data* becomes accessible.

How to get it

Linear Data Entry Workflow is released under an open source license. It's available at https://github.com/ctsit/linear_data_entry_workflow and in Vanderbilt University's REDCap Repo.

DOI 10.5281/zenodo.1341977

Typical Workflow

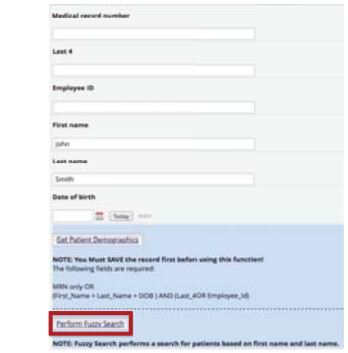


This work supported by the NIH/NCATS Clinical and Translational Science Awards to the University of Florida UL1TR001427, KL2TR001429 and TL1TR001428, the University of Florida Clinical and Translational Science Institute, the United States Department of Defense, the University of Florida College of Pharmacy, the University of Florida College of Medicine.

Creative REDCap Integration Projects:
Using REDCap to Solve Problems Beyond Data Entry

Adie Fridman, Edward Kowalewski, Brian Tep, Matthew McLaughlin, Harold Moyse, Mahendra Yatawara, Spencer Soohoo
Research Informatics & Scientific Computing Core (RISCC) | Cedars-Sinai Medical Center | Los Angeles

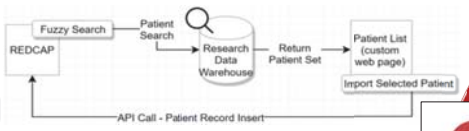
Non-DDP EPIC Data Interface



RECORD	MRN	FIRST NAME	LAST NAME	DATE OF BIRTH	CITY	
0	200723435	John	Smith	29-JUN-3I	ORANGE	Update Record 0
1	200000614	John	Smith	09-MAY-1I	LOS ANGELES	Update Record 1
2	200328596	John	Smith	23-OCT-1I	LOS ANGELES	Update Record 2
3	200411345	John	Smith	20-AUG-1	LOS ANGELES	Update Record 3

Problem: Inability for researchers to immediately pull demographics data from the EMR for patients who came in for their clinic visit and only their full name/date of birth were available.

Solution:. We built a custom PHP script so users could type in the patient's name and perform a fuzzy search through REDCap to find the patient in our EMR. This function performs an API call to a Patient table in our Research Data Warehouse. A list of patients is returned based on the possible matches and renders a webpage with the list of matches. Users would then select the correct patient and click 'Update Record' to execute an API call to import and save the record back into REDCap with all of the patient's demographic information populated.

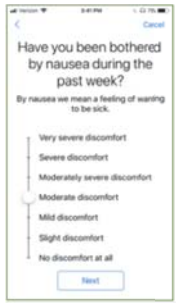


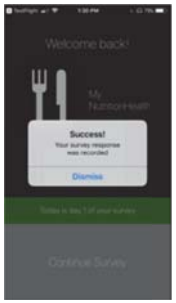
Technologies Used: PHP, Oracle SQL Developer, REDCap API

Dynamic Displays via ResearchKit/ResearchStack

Problem: Rather than using REDCap's Automated Survey Invite feature to schedule daily surveys to be sent, researchers wanted to create a user-friendly method to conduct surveys and collect daily responses.

Solution: We used ResearchKit (iOS)/ResearchStack (Android) and REDCap's API to create a custom mobile app. We wrote a script to dynamically pull survey questions built into the corresponding REDCap project and display them through the mobile app for participants to respond to. The responses were then stored and viewable through REDCap.





Record ID	Mynutritionalhealth
1512784938.05051	
1512785044.22654	
1512789535.37952	
1512790101.38877	
1512801317.61315	
1512801390.99613	

Technologies Used: ResearchKit/ResearchStack, REDCap API

REDCap
Research Electronic Data Capture

Talend ETL for Tableau Displays

Problem: Researchers needed to visualize specific elements of their REDCap data in a quick and easy-to-understand dashboard in Tableau. However, the data feeding into the dashboard required a daily manual export to reflect any new data entered into REDCap.

Solution: Using the application Talend, we built a job to automate a daily API pull from REDCap with the Talend component 'tRest,' used to call a PHP function. The data is then inserted into an Oracle database which we subsequently connected to the Tableau dashboard.

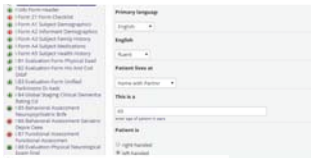
Technologies Used: Talend, Oracle SQL Developer, Tableau, PHP, REDCap API

Text Transformation for Physician Notes

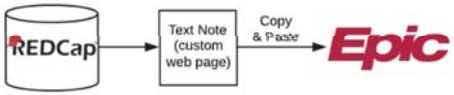
Problem: Eliminate the need for double data entry into both the physician note in the EMR and the patient's REDCap record.

Solution: Using PHP and REDCap's API, we were able to render a custom physician note by concatenating strings and filling in values with previously entered patient data in REDCap. We used a REDCap project bookmark to call the PHP script and create a comprehensive text note which the physician could then easily copy and paste into the patient's electronic medical record.

1. Complete Patient's REDCap Record



3. Text Note is Generated



2. Execute PHP Script by Clicking on REDCap Project Bookmark

Link #	Link Label	Link URL / Destination	Link Type	User Access	Opens new window	Append record info to URL
1	Generate Physician Note	https://risce.csmc.edu/redcap/export_records.php	Advanced Link	All users / Selected users	☑	☑

Technologies Used: PHP, REDCap API

Outcome

- We were able to incorporate the REDCap platform into more projects due to the ease with which we could use REDCap's API
- Automating these tasks allowed us to increase efficiencies by reducing non-value added tasks in research areas
- By successfully completing these creative projects, we were able to increase the userbase for REDCap

A multi-language enrollment, data collection and tracking application in REDCap supporting a family strengthening intervention trial for refugee families in New England

Peter MacIsaac, MD, MPH, FRACGP, FACHI [1] , Rani Dalgin, M.S.W., M.Ed[2] , Jenna M. Berent, MPH[3], Theresa Betancourt, ScD, MA3

1 MacIsaac Informatics (formerly REDCap manager Hunter Medical Research Institute)
2 Boston College School of Social Work Research Services
3 Research Program on Children and Adversity, Boston College School of Social Work,

Study data were collected and managed using REDCap electronic data capture tools hosted at Boston College]

Supported by NIMHD Grant R24 15860

Refugee youth are at increased risk for mental health problems compared to other youth in the United States. The Family Strengthening Intervention for refugee families uses a Community Based Participatory Research (CBPR) approach to strengthen community ties and bridge cultural barriers, while addressing the mental health needs of refugee youth and families through home visiting sessions.

300 families and several thousand individuals will be enrolled and assessed in the next phase of the trial.

The research assistants and intervention community health workers are drawn from Somali Bantu and Bhutanese Lhotshampa refugee communities in New England.

All data will be collected in the family homes on tablets using REDCap – without internet connection in real time

Aims of Customized REDCap tool:

- A record for each family unit enrolled
- A record for each individual family member enrolled
- Demographic details on each participant enrolled
- The automatic creation of a unique family identifier and individual identifier that is customized to incorporate community membership, gender, and role of individual
- Randomization into group at the family level (intervention vs care-as-usual)
- Five sets of psychosocial batteries, incorporating a total of over 40 different scales, which will be administered at 3 time points
- Data & process tracking of status, workflow notes, and referrals throughout the 10 module intervention

Technical challenges - *strategies*

- Users: 2 refugee communities, with 4 languages, adults and children ***– multilingual extension***

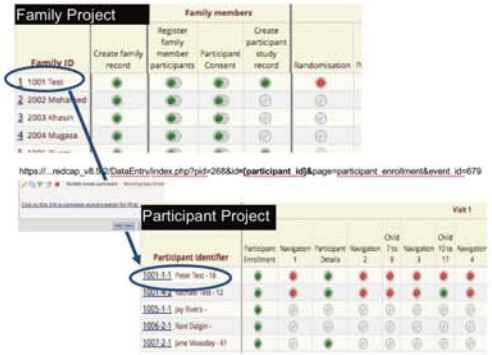
Multilingual

Questions

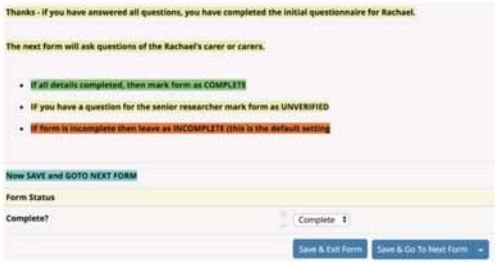
English	In the past 30 days, how much d
Nepali	विगत ३० दिन भित्रमा तपाईको बच्चालाई ध
Somali	30-kii maalmood ee ugu dambee
Maay Maay	sodonk beri luso dhaafi meega j

- Use of structured IDs **– *@DEFAULT concatenation (new concatenation extension not sufficiently functional)***

- Dealing with 2 subjects of interest – family & individual
  – dual projects with shared linkage key based on project 1's family and participant record_ids
  – automated registration of participant in project 2 with URL containing record_id piping



- Complex form navigation**–*end of form pop up "signposts" and navigation links***



- Hiding non-relevant forms for some participants **– *Form Render Skip Logic extension***
- Enhanced record search **– *Orca Search extension***

- Reduction of cognitive load **– *extensive use of piping and calculated fields***
- Handling of "fuzzy" age **– *input options for date, month/year, year, estimated age –single field reconciliation***

- Mobile app not used **- *internet needed for real time function using mobile "hotspot"***
- Multilanguage extension "breaks" data dictionary - as leading "@" export limited to 255 characters **– *hack to add $ to start of each field via project XML edit.***
- Use of " " in text breaks csv output for data dictionary **– *removed offending text and for extension developers to "escape" protected text.***
- Delivery of complex requirement using standard REDCap **– *external support for in-house team***

Improving Patient Enrollment Process using REDCap and HIE: The Generations Project-Environmental Influences on Child Health Outcomes (ECHO)

Dorota Gruber, DHSc, CGC[1,2] , Lorraine Verdade[2], RN, Kelly Duarte[2], Ashley Jones[2], Aneesha Manji[2], Elena Kowalsky, CCRC [2], Kedar Radhakrishna, MD[3], Ismael Rodriguez[4], Rajani Julooru[4], Shreya Sanghani[4], John Chelico, MD[4], Betty Diamond, MD[5]. Peter K. Gregersen, MD [2] , Eitan Kimchi[4] Svetlana Kerman[4], Darshan Shinde[4]

ECHO Environmental influences on Child Health Outcomes
A program supported by the NIH

Northwell Health℠

Background

- Autism Spectrum Disorder (ASD) is reported to affect 1 in 67 live births in the United States. Several studies report 78% increase in ASD prevalence between 2002 and 2008.
- There are currently very few predictors of ASD and therapeutic approaches are inadequate. The current literature strongly suggests that the presence of maternal autoimmunity can have a profound influence on the neuro development of the child.
- The Generations Project-ECHO (GPE) cohort is one of the 35 cohorts participating in the ECHO Program funded by the NIH. The GPE is a prospective, population-based, longitudinal study of approximately 4,000 infants born at either Long Island Jewish Medical Center or North Shore University Hospital, and their mothers, recruited during the prenatal period over five years.
- The main goal of the GPE is to understand the contribution of in-utero exposure to maternal autoimmune and inflammatory factors to risk for neurodevelopmental outcomes in the offspring of mothers with evidence of these exposures.
- In effort to replace a tedious manual process, we developed a seamless integration between HIE, REDCap and LIMS (Laboratory information management system) using hooks, plugins and API's.The integration of multiple and varied sources of clinical information can provide tremendous benefits in the pre-screening and enrollment of patients. This resulted in securing the consent of higher numbers of subjects as its real-time monitoring and management services are able to quickly connect researchers with more potential subjects who would have been missed .with less effective processes.

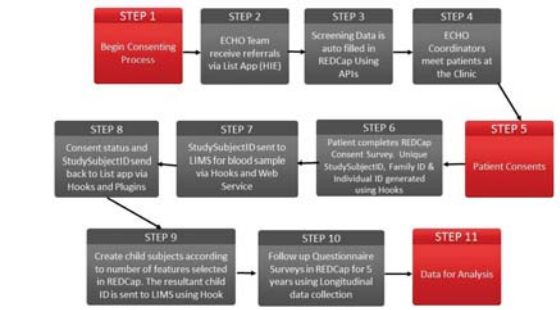
Significance

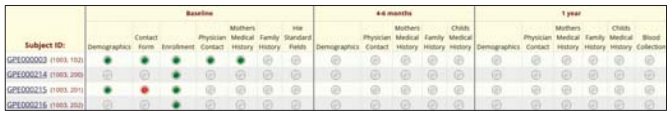
- Such prospective longitudinal data supporting a role of the intrauterine environment on risk for ASD, will fundamentally alter our understanding of ASD pathogenesis and will lead directly to potential diagnostic approaches and strategies for disease prevention. Meeting recruitment, sample collection, and subject retention goals in the study of this magnitude could be challenging and requires novel approach utilizing various IT solutions.
- We report on our approaches to meeting these challenging goals for recruitment, sample collection, and follow-up, including the utilization of novel IT solutions.

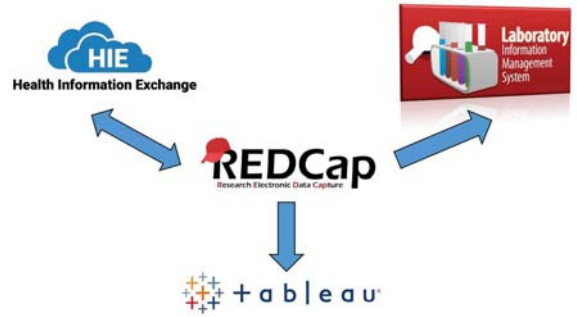
Methodology/Schedule of Activities

Week 10-27 (1st and 2nd Trimester)	Week 28 (3rd Trimester)	Postpartum , 4-6 months and 1 year	Child 2-2.5 yrs	Child 3.5-4 yrs
Prenatal care Research Coordinator OB/GYN Nursing Staff **Recruitment** **Signing formal consent** **Questionnaire (Baseline)** • Enrollment • Demographics • Medical hx • Family hx **Sampling** • Blood (2nd Trimester) (Plasma DNA Serum, RNA)	**Prenatal care** Research Coordinator OB/GYN Nursing Staff **Sampling** • Blood (Plasma, DNA Serum, RNA)	**Hospital/Clinic/Home** Research Coordinator Labor and Delivery Nursing Staff **Sampling child** Immediate post partum • Placenta biopsy • Cord blood **Sampling mother** Blood at one year (Serum) **Questionnaire (update)** • Contact info • Demographics • Medical hx • Family hx *Edinburgh Postnatal Depression Scale*	**Home** Research Coordinator **Questionnaire** • Development/ Autism risk scoring (PEDS and PEDS DM) and M-CHAT-R) • Contact info (update) • Medical hx (update) • Demographics (update) • Family hx (update) **Clinical/Dx testing for those who screen positive (Physician)** Developmental-Behavioral Intake Assessment, ADOS-2, BASC3, Bayley Scales of Infant/Toddler Development-III, Achenbach Observation Assessment	**Home and Clinic** Research Coordinator and Physician **Questionnaire (Coordinator)** • Development/ Autism risk scoring (PEDS and PEDS DM) • Contact info (update) • Medical hx (update) • Demographics (update) • Family hx (update) **Clinical/Dx testing for those who screen positive (Physician)** Developmental-Behavioral Intake Assessment, ADOS-2, BASC), Achenbach, WPPSI-IV, CBCL (Preschool)

Project Workflow







ListApp(HIE) and REDCap

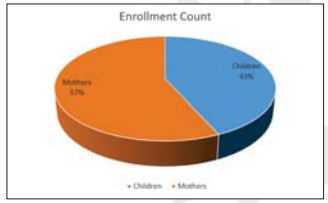
ECHO Subject Outreach Screen

ListApp(HIE) and REDCap

ECHO REDCap Enrollment Form

Results

- **Enrollment**
  - Start Date April 1, 2017
  - To date, there were 1037 participants enrolled into GPE
    588 mothers (ages 19-45) and 449 children



Limitations and Proposed Solutions

- **Limitations**
  - Enriching for autoimmunity
  - Integrating ECHO-wide measures

Conclusion

Seamless integration of **REDCap** and Health Information Management System (HIE) into the Generations ECHO operation allowed us to successfully initiate recruitment of our new cohort and to exceed our recruitment goals from the originally anticipated slow start up of 50 pregnant mothers to 150 within the first quarter of recruitment (**588 mothers and 499 newborns** enrolled within 1 year). It also allowed for timely sample collection and tracking. Similar solutions are being implemented by other active research studies at Northwell Health.

References

1. 2012. Prevalence of autism spectrum disorders--Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008. Morbidity and mortality weekly report. Surveillance summaries 61:1-19.
2. Boyle, C.A., Boulet, S., Schieve, L.A., Cohen, R.A., Blumberg, S.J., Yeargin-Allsopp, M., Visser, S., and Kogan, M.D. 2011. Trends in the prevalence of developmental disabilities in US children, 1997-2008. Pediatrics 127:1034-1042
3. Patterson, P.H. 2012. Maternal infection and autism. Brain, behavior, and immunity 26:393.
4. Choi, G.B., Yim, Y.S., Wong, H., Kim, S., Kim, H., Kim, S.V., Hoeffer, C.A., Littman, D.R., and Huh, J.R. 2016. The maternal interleukin-17a pathway in mice promotes autism-like phenotypes in offspring. Science 351:933-939.
5. Brimberg, L., Sadiq, A., Gregersen, P.K., and Diamond, B. 2013. Brain-reactive IgG correlates with autoimmunity in mothers of a child with an autism spectrum disorder. Mol Psychiatry 18:1171-1177.
6. Estes, M.L., and McAllister, A.K. 2016. IMMUNOLOGY. Maternal TH17 cells take a toll on baby's brain. Science 351:919-920.

[1]Department of Pediatrics, Pediatric Cardiology, Cohen Children's Medical Center of New York; [2]Robert S. Boas Center for Genomics & Human Genetics, Feinstein Institute for Medical Research; [3]OCIO Information Services, Northwell Health; [4]Research IT & Informatics, Northwell Health; [5]Department of Autoimmune Disease, Feinstein Institute for Medical Research, Northwell Health

TECHNISCHE UNIVERSITÄT DRESDEN

Center for Information Services and High Performance Computing (ZIH)

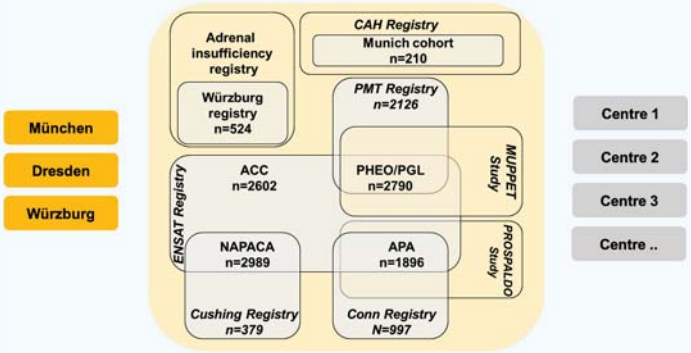
DESIGN OF A VIRTUAL RESEARCH ENVIRONMENT FOR ADRENAL RESEARCH

M. Schulze[1], J. Conway[1], G. Eisenhofer[2], S. Bornstein[3], R. Müller-Pfefferkorn[1], W. Nagel[1], R. Grunzke[1]

1 Technische Universität Dresden, Center for Information Services and HPC, Dresden, Germany
2 University Hospital Carl Gustav Carus, Institute of Clinical Chemistry and Laboratory Medicine, Dresden, Germany
3 University Hospital Carl Gustav Carus, Department of Medicine III, Dresden, Germany

Background

- The adrenal gland is the central organ of the human stress response system and plays a major role in stress-related diseases.
- The recently established collaborative research center CRC/TRR 205 "The Adrenal: Central Relay in Health and Disease" aims to understand both adrenal function and dysfunction.
- REDCap has been chosen as the VRE for the entire CRC.
- It will enable the efficient integration of the heterogeneous data sources such as new and existing patient, subject and animal model data sets, including their eCRFs, imaging and omics data.



Schematic presentation of the research environment including existing and proposed registry structures.

CAH: congenital adrenal hyperplasia, ACC: adrenocortical carcinoma; PHEO/PGL: pheochromocytoma / paraganglioma, APA: aldosterone producing adenoma, NAPACA: non-aldosterone producing adrenal adenoma

Objectives

Conversion of Excel Files to CDISC ODM

- To import existing studies into REDCap, we developed a tool that enables Microsoft-Excel-based studies to be converted to CDISC ODM (see column on the right).
- The tool has been utilized to import the Prospective Monoamine-producing Tumor study, including patient eCRFs (32 sheets, 2500 patients, 500 variables), genetic testing and tumor specimen related lab data that was previously kept in disparate Excel files.

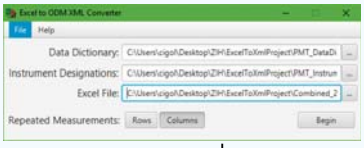
Publication-ready Plots

- To enable REDCap to produce publication-ready plots it needs to be expanded to include measurement unit support.
- A REDCap text entry field used for the value of a measurement will be linked with a dropdown menu to select the appropriate unit.
- This value-unit pair can then be used for plots, unit conversion and automatic determination of resulting units of calculated fields.
- Together with additional statistical functions such as hypothesis tests and survival analyis this will allow REDCap to produce publication-ready plots.

A Simple Way to upload Excel Files to REDCap

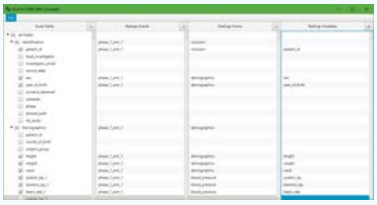
Visit the GitLab: http://bit.do/xlsx-xml

How to use it

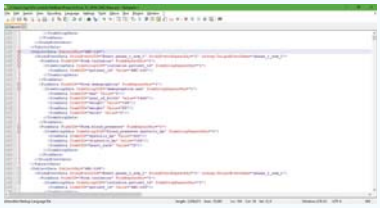


Step 1.
Select your Data Dictionary, Instrument Designation, and Excel File for conversion.
Choose also whether the Excel file has repeated measurements across its rows, or its columns.

Step 2.
Select which sheets and fields from the Excel file you wish to convert.



Step 3.
For each sheet or field, select a corresponding REDCap event, form, and variable.



Step 4.
When you're ready, simply press convert and the program will turn your Excel file data into ODM XML format that can be uploaded to REDCap.

Mitglied im Netzwerk von: DRESDEN concept

gefördert durch: DFG Deutsche Forschungsgemeinschaft

ZIH

Optimizing REDCap for a Longitudinal Multi-site Medical Research Project (Cancer Registry) in Australia

Liman J[1], Holland J F[2]

[1]Health Data Platform;[2]Cancer Research Program, Public Health and Preventive Medicine
Monash University, Australia

BACKGROUND

REDCap is used by the Upper Gastrointestinal Cancer Registry (UGICR), a clinical quality registry that is managed by Public Health and Preventive Medicine, Monash University, Melbourne, Australia. A clinical quality registry collects health information on groups of patients to monitor the quality of care provided. The UGICR began in 2016 and collects data from patient medical records about diagnosis, treatment and outcomes of individuals with an upper gastrointestinal cancer (pancreatic, esophageal, stomach, bile duct or primary liver cancers) who are cared for at a participating hospital. This data is used to measure the quality of care provided by hospitals and report on areas where improvements could be made.

CHALLENGES

The UGICR receives monthly data extracts (in the form of MS Excel files) from the Victorian Cancer Registry (VCR) a government dataset and directly from hospitals. These data extracts are used to identify new potential participants for the registry. The UGICR uses an opt-out approach for recruiting participants. This approach includes sending an invitation letter to eligible potential participants, who then have two weeks to contact the registry if they wish opt out before they are formally recruited into the registry. If a potential participant is deceased at the time of checking registry eligibility they are automatically recruited to the registry.

A problem identified with the UGICR's method of processing of potential participants for the registry was that it relied largely on manual processes of data manipulation and data processing using MS Excel spreadsheets. These manual processes were not only time-consuming but that they also posed a risk to data integrity. For example, there was a risk of patient may receive the letter twice if a person had duplicate record that was not identified, or an invitation letter may be sent to the wrong address if contact details were entered into the wrong line in a spreadsheet

AIM

1. To improve the efficiency and accuracy of adding new potential participants, from government cancer registry data and hospital data extracts by reducing the number of manual processes in managing new data.
2. To integrate with existing document generation software to further streamline mail out processes and to automate record updates once a letter has been sent to improve data completeness and accuracy.

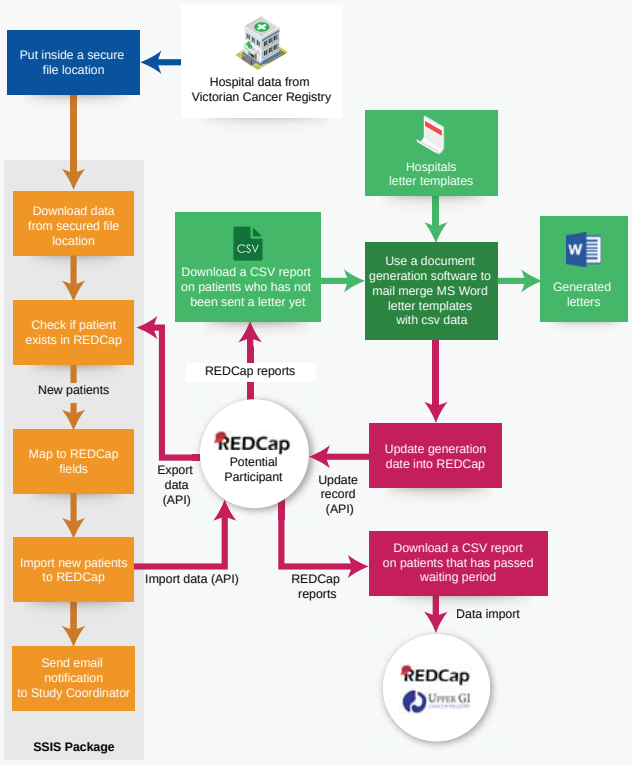
SYSTEM DESIGN

1. A new REDCap Potential Participant project was created to replace the existing MS Excel master list of potential participants. This new REDCap project would be used to keep a single record for each potential participant identified to the registry and to record data related to eligibility screening and participant invitation mail outs.
2. An SQL Server Integration Services (SSIS) package was developed to read the MS Excel file extracts received from the VCR, compare new data with the existing data from the REDCap Potential Participant project via API to filter out new patients. The SSIS package then transforms the MS Excel data for new potential participants to match the import template format, and imports the new patients into the REDCap Potential Participant project. The package is scheduled to run on regular basis.

SYSTEM DESIGN (cont.)

3. A REDCap report can then be run to download a list of potential participants that require an invitation letter to be generated and sent. This downloaded CSV report file is used as an input to custom built document generation software. Once a batch of letters is generated, the software triggers the REDCap API to update the REDCap Potential Participant record for each potential participant with the 'Date letter sent'.
4. Another REDCap report is also created to download list of patients which has passed the waiting period. This report is used as an import file to the UGICR's REDCap.

PROCESS FLOW



The UGICR is supported by
the Victorian Government,
Pancare Foundation,
Specialised Therapeutics Australia,
Shire Australia, and
Eli Lilly Australia

Scan me

PROCESS COMPARISON

	OLD		NEW	
Process	**Process Type**	**Tools Used**	**Process Type**	**Tools Used**
Receive new list of potential patients from VCR	Manual	MS Excel	Manual	Ms Excel
Download and save a copy	Manual		Manual	
Identify new patients	Manual	MS Excel	Automated	REDCap Potential Participant project/ REDCap API/SSIS
Check patient eligibility	Manual	MS Excel	Manual	REDCap Potential Participant project
Generate list of patients that need to be sent with letter	Manual	MS Excel	Semi Automated[1]	REDCap report
Print and send letter	Manual		Manual	
Update patient data to indicate letter has been sent and waiting period began	Manual	MS Excel	Automated	REDCap API
Check if patient has passed the waiting period	Manual	MS Excel	Semi Automated[1]	REDCap report
Prepare import file to main UGICR REDCap project	Manual	MS Excel	Semi Automated[1]	REDCap report

[1] Semi automated – a much less complicated manual task, e.g. clicking a button to download the report.

RESULTS

Time Efficiency – As time consuming manual tasks are automated or made simpler, the efficiency of adding potential participants to the registry has been improved.

Streamlined Processes – With the integration with existing document generation software with REDCap API, the process to generate letters has been made simpler and more streamlined.

Data integrity – The reduction of manual manipulation of data is expected to result in improved registry data integrity.

FUTURE DEVELOPMENT

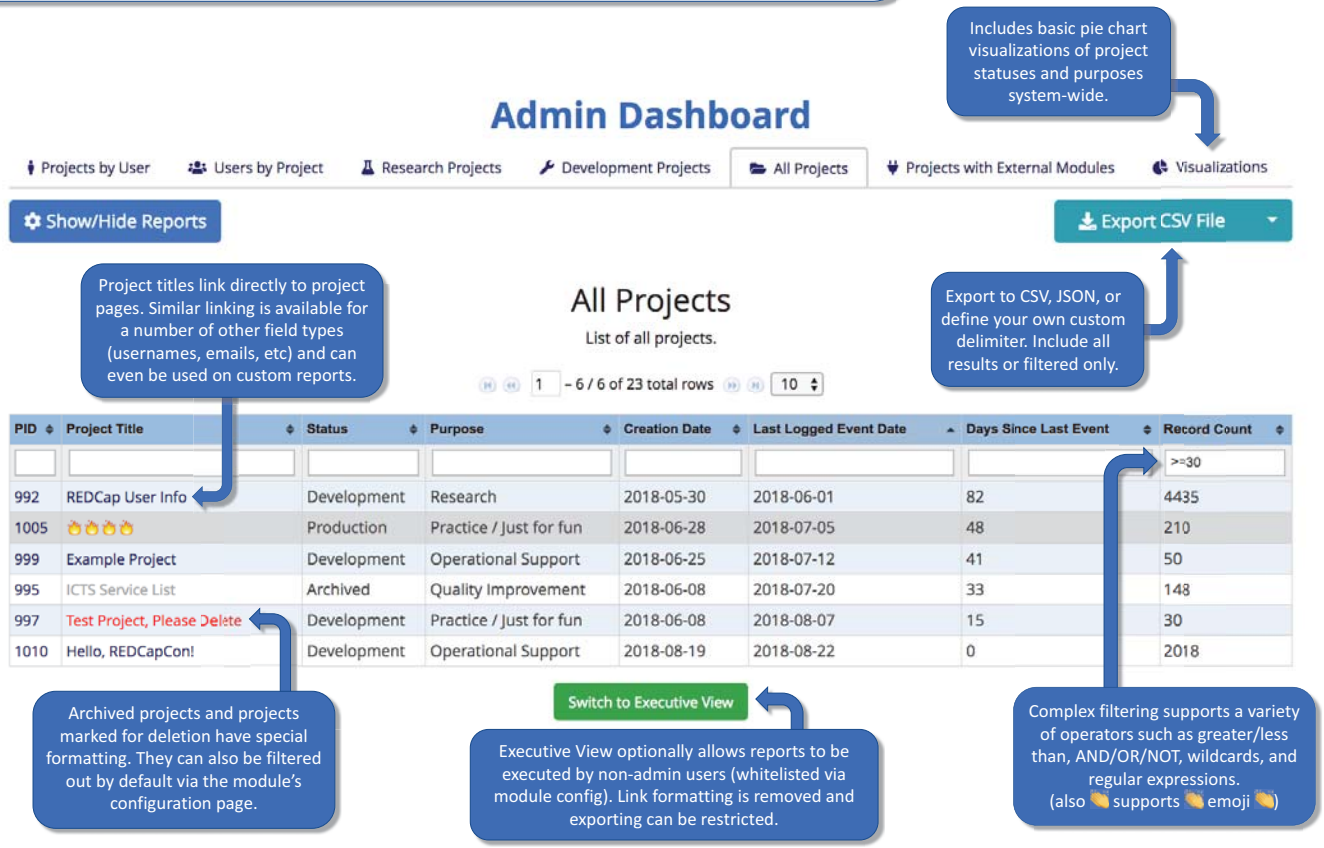
- Automate the process of downloading the new MS Excel data files from the VCR.
- Create a new SSIS package that runs daily to check patient waiting period and automatically import new participants into REDCap UGICR Registry project when the waiting period has elapsed.
- Work with participating hospitals to set up automatic uploads of new potential participants to the REDCap Potential Participants project using a similar process to the VCR new participant process.

REDCap Admin Dashboard

The REDCap Admin Dashboard is an External Module that provides a sortable table view of various reports on REDCap metadata (users, projects, etc). It includes 5 ”default” reports that cover most basic information as well as some optional reports for less common use cases. Additionally, custom SQL queries can be easily integrated, allowing the Dashboard to report on any data or metadata stored anywhere in REDCap’s database.

The University of Iowa | Institute for Clinical and Translational Science

Eric Neuhaus
eric-neuhaus@uiowa.edu



Default Reports

- **Projects by User** – List of users and the projects to which they have access.
- **Users by Project** – List of projects and the users which have access.
- **Research Projects** – List of projects that are identified as being used for research purposes.
- **Development Projects** – List of projects that are in Development Mode.
- **All Projects** – List of all projects.

Optional Reports

- **Login Credentials Check** – Reports to search for strings related to usernames/passwords in projects.
- **Projects with External Modules** – List of External Modules and the projects they are enabled in.

Custom Reports

Include your own **custom SQL queries** (SELECT only) and take advantage of Admin Dashboard’s ease of access, complex filtering, special formatting, and export options

Bridging the Communication Gap with the Holistic REDCap Human Subject Toolbox for Research Institutions

Theresa Baker, MS; Maxx Somers, MA; Warren Welch; Michael Wagner, PhD
Cincinnati Children's Hospital Medical Center

The Research Cycle:

- The Human Subject Tool box is an effort to encourage research teams to consider a more systematic approach and to consider the full scope of research projects when planning data capture and study management systems.
- REDCap's users have developed a variety of task specific tools to assist in various stages of the research cycle.
- A publicly available comprehensive systematic approach to research studies inspires confidence in researchers and clinical research coordinators, standardizes an approach to study management, and provides tools to manage researcher need in study management documentation.
- Cincinnati's CCTST REDCap purposes the REDCap Human Subject Toolbox as a tool to improve, standardize, and save time across an institution's study management workflow.

Define the system: Human Subject Research

- Allows principal investigators to identify the appropriate REDCap tool for the research task.

Identify Stakeholders:

- Allows roles and responsibilities for the study to be assigned at any step of the process.
- Seamless transition between roles throughout the research cycle.

Leveraging REDCap:

- Each step in the process is a possible leverage point for REDCap to effectively assist in the implementation of research studies.
- Many REDCap users successfully customize their databases to be study specific or to accommodate a study team's style. However, most institutions approach the study management as a research team's or administrator's silo and only overlap roles for verification or auditing.
- Often databases are developed without considering the whole system. By adjusting databases to accommodate the whole system, REDCap is able to facilitate the implementation of study protocol in a swift and accurate manner while saving institutions and studies financial AND resource capital.

IRB Protocol Review & Approval
Facilitate the study protocol's interaction with IRB.

Preparation of Study File

Delegation of Authority Log
Document study personnel's roles and responsibilities throughout the life of the study.

Train Study Team Members

Participant Contact & Schedule Log
Document potential participant contact & facilitate pre-visit tasks.

eRegulatory Binder
Organize essential study specific documentation to facilitate knowledge transition of study activities & information.

Training Documentation Log
Tracking log to provide a comprehensive list of all training completed by study staff.

Assemble Research Team

CCTST Center for Clinical & Translational Science & Training

REDCap Research Electronic Data Capture

- The purpose of the REDCap Human Subject Toolbox is to bring together a group of standardized templates that can be customized to effectively implement each stage of a research study while serving all stakeholders.
- By standardizing a set of templates, the institution has provided seamless transition for stakeholders to move between studies, allowing choose between well tested/optimized tools, thus decreasing the burden on all stakeholders.

Study Closure Log
Track institution's studies log and their current status (Pre-approval, In-progress, Closing, Closed)

Study Personnel Log
Record and track study personnel credentials.

Study Completion and Termination

Recruit Participants

Grant Management Log
Record study's grant progress.

Enrollment Log
Track participants enrollment status. (Current, Finished, Withdrawn)

Monitor Study Progress

eScreener
Mechanism for determining eligibility of potential participants and facilitate the recruit-to-enroll process.

Study / Follow-up visits

Study Monitoring Log
Record all monitoring visits to provide a comprehensive list of oversite actions.

eConsent
Document informed consent electronically.

Study Specific Database(s)

Benefit Management Log
Facilitate the distribution and recording of study benefits.

Takeaway:
REDCap Human Subject Toolbox can assist the researcher at every stage of the study and is user-friendly to each stakeholder.
- PI, Research Team, Participant, Research Administrator, & Monitor

For copy e-mailed to you or our contact information.

Supporting Clinical Processes and Clinical Research for Autism Patients and the Kansas Intellectual and Developmental Disabilities Research Center (KIDDRC) via REDCap

Angelica Allen[1], Li Huang MPH[1], Sean Swindler[2], Brenda Salley PhD[2], Maren Wennberg[1], Lemuel R. Waitman PhD[1]
[1]Center for Medical Informatics and Enterprise Analytics, Department of Internal Medicine, [2]Pediatrics and Center for Child Health and Development
University of Kansas Medical Center, Kansas City, KS

Introduction

The clinical processes and advanced testing provided by state autism centers often lie outside the routine workflow of commercial electronic medical records (EMR) and tailoring the EMR to these processes may lag behind other health system priorities. At Kansas, REDCap has been used to manage 1) family intake, assessment, and follow up for the autism center, 2) a healthy volunteer baby registry for developmental research (BabyLab), and 3) provide an environment to facilitate recruitment by integrating data for the KIDDRC from i2b2-based Data Repositories, EMR supplemental data regarding mother-baby linkage, and eligibility screening by the study teams.

Autism Center Data Collection

Background: The Center for Child Health Development (CCHD) family intake, assessment, and follow-up data was previously stored in two databases: VELOS and REDCap.

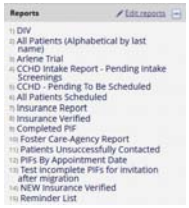
Goal: Clinicians and researchers want one unified database for all CCHD data and to link this data to EMR data

CCHD Data to REDCap

Created combined REDCap project to house data imported from VELOS with data originally collected in REDCap

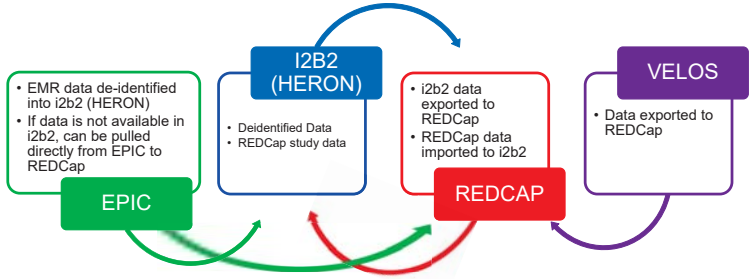
- Manually mapped VELOS data to align with REDCap data import format
  - Imported 7,738 Records
- Instrument: 36 forms & 2 surveys
- 3,392 unique patients and 4,630 data collection fields
- 79 hours for REDCap Development
- 30 hours for Study team review & update

Data Collection Forms Assigned to 3 Visits Longitudinally

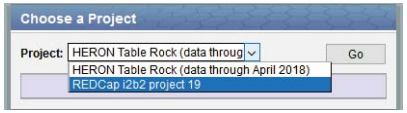


Clinic Staff Use REDCap Reports to Track Patients

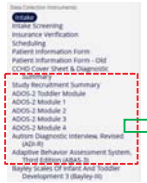
Integrated CCHD Data into i2b2 Data Repository (HERON)



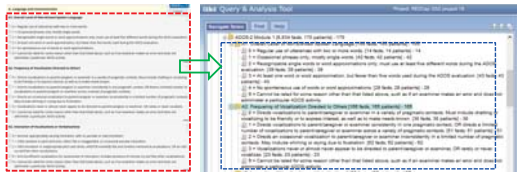
- Data from REDCap was integrated into the de-identified i2b2 data repository (HERON) which also contains data from the EMR and other patient registries
- Each record in the REDCap project has an MRN associated with the patient. This MRN is used to link the patient to the EMR data
  - During the HERON ETL process the MRN is masked and each patient is given a unique de-identified number visible for HERON end-users
- All CCHD REDCap fields marked as "identifiers" are not brought into HERON



HERON Users May Choose REDCap to Search REDCap Data Alongside EMR Data



CCHD Data Collection Forms Available as Folders in HERON



Autism Data Collection Fields from REDCap are Available in HERON

BabyLab and Subject Recruitment

Expand and provide access for KIDDRC investigators to a pediatric clinic registry for recruitment of typically-developing (TD) participants.

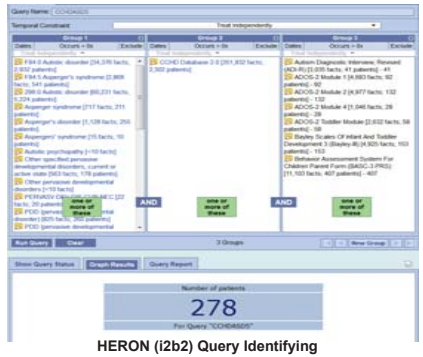
- I2B2 (HERON) allows users to identify newborn infants based on specified criteria
- Mother and infant records can be linked using the data warehouse and EMR
- Infants newly presenting in the system from i2b2 (HERON) are loaded into REDCap HERON Master Database
- Combine newborn infant data from multiple sources into a unified REDCap Master Database

Process to Create CCHD Database and Link with EMR Data

Child Psychology Recruitment

Expand, maintain, and provide access to HERON and the Frontiers Participant Registry for investigators to:

- Identify eligible subjects defined by case, control and geographic areas
- Investigators uses REDCap to manage subject screening
- Investigator uses REDCap to manage research data collection



HERON (i2b2) Query Identifying Patients with Autism

Future Work

- EPIC integration for CCHD initial Intake and Patient Information Form
- EPIC import into REDCap using FHIR for immediate availability.
- Provide researchers with patient's upcoming scheduled appointments via Clarity or FHIR

Acknowledgements

This work was supported by a KIDDRIC grant and CTSA grant from NCATS awarded to the University of Kansas for Frontiers: University of Kansas Clinical and Translational Science Institute (# UL1TR002366) The contents are solely the responsibility of the authors and do not necessarily represent the official views of the NIH or NCATS.

Expressing observations from electronic medical record flowsheets in an i2b2 based clinical data repository to support research and quality improvement.
Waitman LR1, Warren JJ, Manos EL, Connolly DW.
AMIA Annu Symp Proc. 2011;2011:1454-63. Epub 2011 Oct 22.
Serving the enterprise and beyond with informatics for integrating biology and the bedside (i2b2).
Murphy SN, Weber G, Mendis M, Gainer V, Chueh HC, Churchill S, Kohane I.
J Am Med Inform Assoc. 2010 Mar-Apr;17(2):124-30. doi: 10.1136/jamia.2009.000893.

THE UNIVERSITY OF KANSAS Medical Center

Diseases Registries & REDCap at KFSH&RC

Epilepsy Registry - Example

Saleh Al-Ageel

BACKGROUND

Disease registries is a powerful tool that can drive significant practice change, improve the health of the patients, and over time to increase our understanding about the disease.

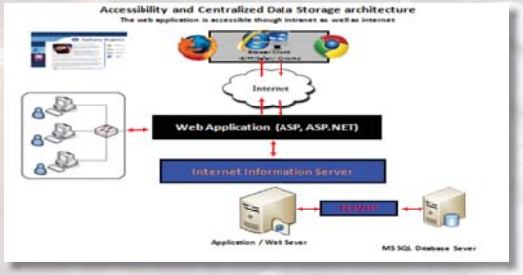
King Faisal Specialist Hospital & Research Centre (KFSH&RC) has been alerted to the importance of the Disease registries for that reason Registries Core Facility (RCF) established in year 1989 in the Department of Biostatistics, Epidemiology and Scientific Computing (BESC), which is in charge of setting up, maintaining, and development of hospital-based registries. It contains 13 registries, including Epilepsy Registry.

EPILEPSY REGISTRY

In 1999, the Department of Neurosciences and the BESC collaborated to establish the Epilepsy Registry. Major aims of this program are to collect, analyze and disseminate accurate and timely data of patients referred to the KFSH&RC, Riyadh. Pertaining to their demographics, medical history on risk factors, diagnosis, treatment and outcome to the researchers and health care providers.

SOFTWARE USED BEFORE REDCap

Microsoft Internet Information Server (IIS) was used to store and manage the registry data. The centralized web-databases can be accessed through the Internet from anywhere. The registry software are designed and developed in-house by the BESC. Access to the registry data is password protected and is restricted to an unauthorized access.



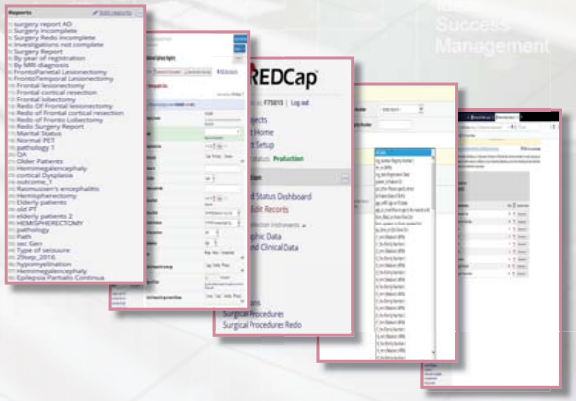
WHY WE CHOSE THE REDCap

- Access to REDCap is authenticated
- Secure hosting and regular data backups
- Allows multi-site access
- Researchers can build databases rapidly
- Importing data from different resources
- Export data to a variety of statistical analytics packages

DEVELOP REDCap DATABASE FOR THE EPILEPSY REGISTRY

- Started the development of the epilepsy registry using REDCap data capture software November 2014.
- The data collection instruments are:
  - Demographics data
  - History and clinical data
  - MRI
  - PET
  - Medications
  - Surgical procedures
- Tested the new system by entering some data.
- Imported the registry data from the old system to the new REDCap software.
- Moved to production on July 2016.

EPILEPSY REGISTRY WITH REDCap



CONCLUSIONS

- REDCap is a good choice for the registry.
- REDCap is less dependent on programmers.
- Easy to create an immediate simple reports.
- Easy to give a user's access with different privileges.

CTSI Pilot Management System

Christine Zeller: CTSI Pilot Program Manager, Mark Oium: CTSI REDCap™ Administrator

Background

The CTSI of Southeast Wisconsin has offered pilot grants since our inception in 2008. In the beginning the program was managed mostly through emails between CTSI staff, the PIs, and potential reviewers – gathering proposals from PIs, finding reviewers and processing their reviews, notifying of award statuses, etc.

Until 2014 we mainly used REDCap to collect Progress Reports for those PIs that were awarded. These Progress Report projects would then be copied for the next cycle's awardees.

As our Pilot Program grew, so did the number of proposals that we needed to process annually. As a result, the burden and complexity of managing the Program became so great it was difficult to maintain our cycle's timeline. There was some resistance to exploring ways REDCap could make Pilot administrative tasks more efficient and so the full benefits of REDCap remained untapped. Instead, projects were copied from year to year rather than adopting a longitudinal model. As the number of projects – and redundancy – increased, becoming unwieldy, I was finally able to convince management to consolidate into 1 main system.

The system proved so successful we adapted it for other institutional seed grant programs and have shared with our consortium partner CTSA institutions.

Objective

To develop a comprehensive system that allows for yearly proposal submission, multiple, integrated reviewer submissions, progress reporting once awarded, all in one REDCap project that will greatly reduce the administrative overhead associated with managing a large and growing program.

Acknowledgements

The project described was supported by the National Center for Advancing Translational Sciences, National Institutes of Health, Award Number UL1TR001436. The content is solely the responsibility of the author(s) and does not necessarily represent the official views of the NIH.

Two Connected REDCap™ Projects

CTSI Pilot Reviewers

Reviewer project is populated yearly prior to the Pilot cycles. Each new record receives a survey asking if they are willing to be a reviewer for the upcoming CTSI Pilot cycle and how many proposals they are willing to review.

Instrument name	Fields	View PDF	Enabled as survey
Contact List	21		Enable
CTSI Pilot Reviewer Invitation Survey	11		
Participation	11		Enable

CTSI Pilot Management System

Pilot project uses a public survey link for the Intent to Apply submission. If accepted, a unique and customized Grant Application survey is sent and completed by the applicant. Potential Reviewers are then selected based on area of expertise and asked to disclose any Conflict of Interest. Suitable Reviewers are then sent the full Reviewer scoring survey with a PDF of the Grant Application attached via a hook. Scores are then compiled & calculated automatically within REDCap. Awardees then continue to use REDCap to submit pre-award requirements and the program manager uses REDCap to track these submissions. From there post-award Progress Report surveys are collected.

Instrument name	Fields	View PDF	Enabled as survey
Intent to Apply	94		
LOI Approval	4		Enable
Grant Application	302		
Aims and Objectives	28		Enable
Admin Reviewer Request	53		Enable
Reviewer Request 1	9		
Reviewer Request 2	9		
Reviewer Request 3	9		
Reviewer Request 4	9		
Reviewer Request 5	9		
Reviewer Request 6	9		
Application Admin	38		Enable
Study Team	1		Enable
Reviewer 1	41		
Reviewer 2	38		
Reviewer 3	38		
Reviewer 4	38		
Award Status	32		Enable
Regulatory Admin	36		Enable
Initial Check-in	17		
Budget Check-in	11		
Benchmark	385		

REDCap™ Hooks Used

redcap_data_entry_form – javascript is used to parse the selected text of sql dropdowns when selecting a specific reviewer on a record
redcap_save_record – parse data from certain instruments and send survey invitations with compiled attachments about the proposal to selected reviewers
redcap_survey_complete – used to send confirmation emails to multiple people with the completed survey pdf attached

Results

In 2017 we created an innovative method for the Pilot proposal review process which allowed us to enhance our Reviewer Database and link it to our online application system using REDCap. This resulted in administrative efficiencies such as: the ability to generate automated reminders to those who had not yet completed the review; increased accuracy in eliminating manual compilation; improving the quality of the feedback by requiring comments for each criterion score; ability to generate instant and accurate reports and score calculations. We also were able to improve the number and quality of proposal reviews. For the first time we successfully obtained at least three reviewers per proposal who were experts in the field while at the same time screening for Conflict of Interest. This system also enabled us to efficiently track review submissions using a new dashboard tool (Tableau), with an outcome that 100% of all 120 assigned reviews were returned by deadline. The system also allowed us to maximize our reach with experts across the country, making it easy for all to conduct the reviews online. The 120 reviews were conducted by 91 individuals across 23 different institutions; 56% of reviews were conducted by reviewers at institutions other than MCW and all but 6 proposals had at least one external reviewer. We evaluated this new review process and in addition to the measurable improvement in administrative efficiency, 90 out of 91 Reviewers felt the online system worked well for them.

WWW.GLOBALSURG.ORG

Crowd-sourcing surgical data

Riinu Ots, Thomas M. Drake, Catherine A. Shaw, Stephen R. Knight, Kenneth A. McLean, Roseline Antai, Cameron J. Fairfield, Ewen M. Harrison + GlobalSurg Collaborative

Contact: R.Ots@ed.ac.uk or enquiry@globalsurg.org

Funded by NIHR

Introduction

GlobalSurg was established to represent practising surgeons from around the world and support collaborative international research into surgical outcomes by fostering local, national and international research networks.

GlobalSurg 3

Quality and outcomes in global cancer surgery: a prospective, international cohort study

Any hospital anywhere in the world

4-week data collection periods between April & October 2018

All consecutive patients undergoing surgery for breast, gastric or colon cancer

PubMed citable authorship for all collaborators

REDCap Access:

2000+ users

800+ DAGs

Registration (public survey)

Up to 3 team members, must submit one registration form per team.

Admin instrument for:

indicating duplicates (based on ORCID IDs, marked by a CRON-RScript);

curating new hospitals (if selected: "My hospital is not listed");

any other administrative notes based on email correspondence.

Records - REDCap API + R

DAGs and User Rights - SQL

Authorship

Curated copies of **Registration** forms (i.e. the public survey). Record IDs in Authorship are a subset of record IDs in **Registration**.

One Data Access Group (DAG) per hospital, e.g. gb_edin_royalinf.

Registration Violations

Collaborators changing hospitals (common for trainee surgeons/residents).

Team members registered separately or same member on multiple registration forms (which would have been marked as a duplicate).

Etc.

Take home message

An intricate yet intuitive set-up of interlinked **REDCap projects** and **Shiny apps** can be used to globally crowd-source patient-level surgical outcomes data.

REDCap Shiny by RStudio

data.globalsurg.org

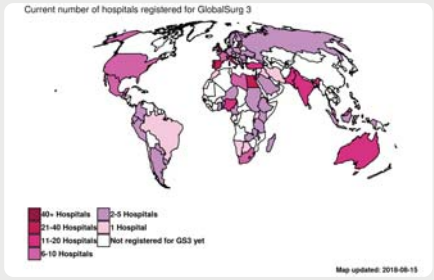


Figure 1: Current number of hospital registered for GlobalSurg 3 (updated 15-August 2018).

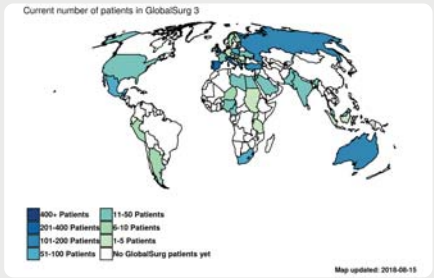


Figure 2: Current number of patients in GlobalSurg 3 (updated 15-August 2018).

Monitoring and Evaluation

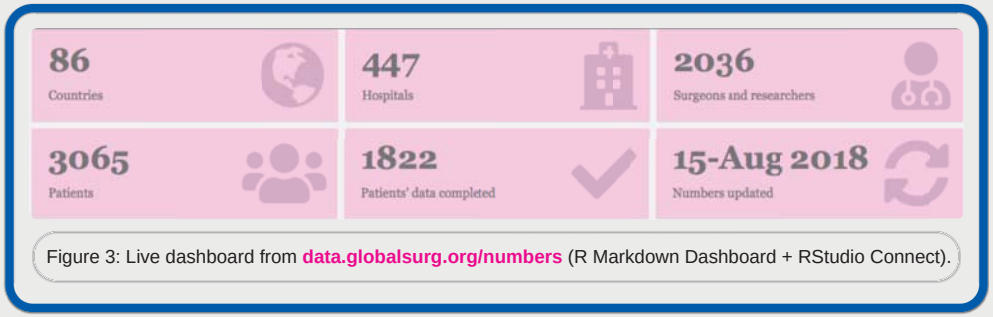


Figure 3: Live dashboard from **data.globalsurg.org/numbers** (R Markdown Dashboard + RStudio Connect).

Data

Teams in different DAGs: e.g. **gb_edin_royalinf_01**, **gb_edin_royalinf_02**

Real-time execution of 57 Data Quality Rules.

~100 variables per patient (depending on cancer type)), 5 instruments (including 30-day outcomes).

Validation

One independent validator per hospital, case ascertainment + accuracy (based on a subset of variables).

National Leads

Country, Name, ORCID ID

National Leads app

Monitor Registrationn and Data collection at hospitals from your country. Password protected - not public like the main Live Dashboard.

Assign Hospital Leads from registered Teams.

Hospital Leads

Country, Hospital, Name, ORCID ID

Add new hospitals

Hospitals

A dynamic and curated list of hospitals that have taken part in any of our studies (~800 hospitals).

For example:

Record ID: 2080038	208 is UK's Globalsurg country identifier, 0038 is n-th hospital from this country in our list
Country: United Kingdom	Country names pulled from the Countries project
ISO2: GB	We use these 2-letter codes in the DAG label, e.g. this listing becomes gb_edin_royinf
City: Edinburgh	
Hospital: Royal Infirmary of Edinburgh	
DAG: edin_royinf	"city_hospital", max 12 characters (as need to add gb_ and team ID, e.g. _01)

Countries

A list of 217 countries.

For example:

GlobalSurg country unique identifier (Record ID): 208

Country: United Kingdom

ISO2: GB

HDI 2016: 0.909

HDI rank 2016: High

For women who are positive for human immunodeficiency virus and children who are born, Integration of clinical information and construction of follow-up system using REDCap

National Center for Global Health and Medicine

KOJI Kitajima [3], YASUHARU Sasaki [3], HIROSHI Ohtsu [2], MIZUE Tanaka [1]

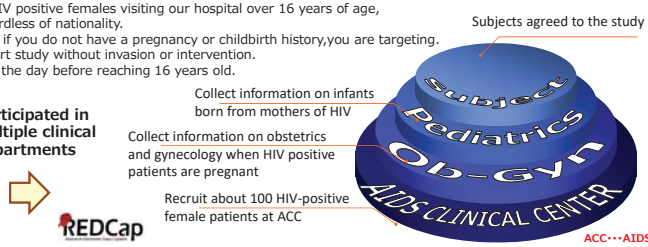
1), Department of pediatrics 2),Department of Clinical Study and Informatics, Center for Clinical Sciences 3),JCRAC Data center, Department of Data science, Center for Clinical Sciences

Introduction／protocol

The rate of mother-to-child transmission from HIV-infected mothers is considered to be about 30%. In 1994, a mother-to-child transmission prevention protocol consisting of preventive administration of anti-HIV treatment directed to mothers, optional caesarean section and zidovudine (AZT) for children was established, and the mother-to-child transmission rate in Japan increased It fell to an extremely low level of 0.5%.
However, there are few reports of long-term follow-up of infected or infected neonates born to HIV-positive mothers or long-term effects of maternal HIV infection on the growth and development of the body.
In the case of infected infants, because there is continuous medical treatment, it is possible to grasp the long-term prognosis, but in non-infected children there is no stipulation in the follow-up period, the median observation period is as short as 2 years, accurate long-term prognosis is grasped It was difficult.
On the other hand, deformity and SIDS (sudden infant death syndrome) frequently occur in uninfected children, and it is necessary to further study the influence of maternal HIV infection and antiviral drugs.
In addition, about 13% of women infected with HIV are infected, which is a small number.
According to the National Research Report on HIV / AIDS (2014), it was found that 857 cases of HIV pregnancy had occurred by the end of 2013.
Although women have life events such as pregnancy and childbirth, although there is a physical difference, in Japan the prognosis of the infected women is hardly elucidated and more precisely born from HIV female and HIV positive pregnant women in Japan I think that a cohort survey is necessary to grasp the long-term prognosis of children.
By conducting this survey, it is expected that not only the long-term prognosis of HIV-positive women and their born babies will be clarified, but also the revision of prevention measures for mother-to-child transmission in line with Japan's current situation will be helpful.
As of July 2016, about 2,000 HIV patients are being consulted at our hospital ACC, of which about 200 are female.We aim to register about 40 cases per year, about 100 cases in 3 years, we decided to conduct a cohort survey with October as observation date every year.

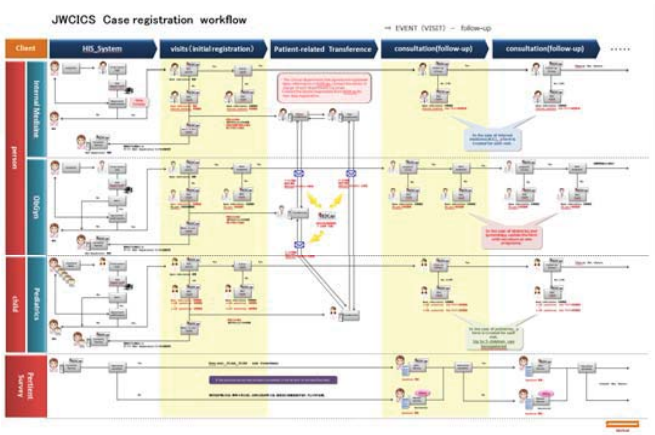
Past Research findings	Infected child	Non-infected child
Clinical cases (e.g.)	27	229
sex (M:F) ratio	15 : 12	116 : 112
Last observation age	Median: 14year and 10month	Median: 2year and 10month
nationality (Jpn:Fc)	7 : 19	104 : 124
Death toll	4	6
Malformation	0	5 (mouth,ear,fingers)
Congenital heart disease	0	VSD : 3 PDA : 1 Tricuspid : 1
Growth disease	4	3
Developmental disease	5	16

Target conditions
・All HIV positive females visiting our hospital over 16 years of age, regardless of nationality.
・Even if you do not have a pregnancy or childbirth history,you are targeting.
・Cohort study without invasion or intervention.
・Until the day before reaching 16 years old.



ACC･･･AIDS CLINICAL CENTER

Workflow



First, I will organize the flow of work.
Although it is the same facility this time, there are different input timings in different departments.The input itself was not a problem if REDCap was used.
But,HIV positive patients are being consulted at ACC Center → When the patient gets pregnant, Obstetrics and gynecology → When giving birth it flows with pediatrics department.Also, at the time of pregnancy or when a child finds HIV positive, we will introduce it once to ACC and give feedback to each department after acquiring consent at ACC.
Although the coordinator nurse attempted to unify information by inputting at ACC, it was not possible to announce to each department afterwards, and it was the most troubled part in operation.

Registration Form(Basic Infomation)
・When the consent is obtained, when the basic information is registered, a mail of registration completion is transmitted to the target person. Confirmation and have the completion operation done (Survey_Mail Regist).
In addition, a mail of registration completion is sent to the doctor at each window of this research participation department.
・ If this subject is not related to pregnancy, registration physician will listen and register pregnancy history (GPAC) information as well.

Registration Form(Internal Medisine)
・Follow-up items are registered for each follow-up observation day from October to February every year.The contents to be registered at the time of the first time and the time of the follow-up are switched automatically.

Registration Form(Ob Gyn, GPAC)
・Registered within 3 months immediately after childbirth.
If there is an outcome register pregnancy information (GPAC) as pregnancy history this time.

Registration Form(Pediatrics1~5)
・Register for each child. Register up to 5 people. Follows every 3 months until 1 year and a half and followers every year for over 1 year and over.
・Follow-up items are registered for each follow-up observation day from October to February every year. The contents to be registered at the time of the first time and the time of the follow-up are switched automatically.

Registration Survey(Questions)
・Every year in April, October twice a year Survey Mail is sent automatically and questionnaires about the current situation.

Method／REDCap

I cohort women themselves and their children with HIV positive women as the key.
By using a woman with a consultation history as a key, it became possible to simplify the association with the electronic medical record system in the hospital, and to register both infected and uninfected children.
REDCap is built and operated only with the basic functions of REDCap, this time REDCap can use repeatable form / event function by using Ver. 7.0.11, input of pregnancy history information and obstetrics and gynecology information more It became easy to do. Until now, the e-mail notification to the project user to urge the input which the secretariat had manually corresponded,
After introducing the latest Ver. 7.4.7, it is possible to send simultaneous messages to project users using the messenger function, so it became a slight improvement by successfully using this function.

Conclusion／Consideration

For the real world data／evidence

We are started to collect a patient information (registry) though multi-clinical department doctors using REDCap / REDCap surveys.
next year, we hope to be able to expand this research project at multi-center research.
This trial's aim is collect of "REAL WORLD" data/evidence for the patient.
We are trying to the next cohort study though this registry data. We want to share between registry and cohort without stress. (such as utilization of external modules and hook functions.)
We think there are many technical problems to use REDCap.

・This research is subsidized for fiscal year 2016 Health Labour Sciences Research Grant／ Integration and analysis of clinical information of infants born from pregnant women infected with HIV and construction of follow-up system. (member of research project : M.D. mizue tanaka).
・Conflict of Interest (COI) of the Principal Presenter : No potential COI to disclose

・Contact information.Email:kkitajima@hosp.ncgm.go.jp