Platform Development

Think Big, Build Small and Evolve:
A Recipe for INNOVATION Through Implementation

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Professor, Biomedical Informatics

Advancing Research in the Digital Age
Office of Research Informatics

- Collaborative Initiatives
  - Regulatory support/ and technical infrastructure
  - Support/ interoperability for institutional initiatives
  - StarBRITE Portal
    - Enterprise Management + Tracking and Evaluation
    - PI interface (Process/ Applications/ Resources)
  - Data management and coordination
  - Clinical information systems integration

Translational Steps

- T1: Bench to Bedside
- T2: Bedside to Bench
- T3: Proof of Concept
- T4: Site-based Research
- T5: Coordinating Center
- T6: Outcomes Implementation Science
- T7: Community Engaged Research

https://www.dtmi.duke.edu/website-administration/images/hubs_04jan13.jpg
Guiding Principles and Lessons Learned
Office of Research Informatics

- Collaborative Initiatives
  - Regulatory support/ and technical infrastructure
  - Support integration of PI interface (Process/Applications/Resources)
  - Data management and coordination
  - Clinical information systems integration

Translational Steps
- T1: Bench to Bedside
- T2: Bedside to Bench
- T3: Site-based Research
- T4: Coordinating Center

Investigator Communities
- Bench to Bedside
- Bedside to Bench
- Proof of Concept
- Site-based Research

https://www.dtmi.duke.edu/website-administration/images/hubs_04jan13.jpg
Guiding Principles and Lessons Learned

2004 Needs Assessment
Researchers needed help managing data for small/medium sized non-trial research projects (pilot, R01, PPG)

Hypothesis
Researchers will do the right thing (secure, audit trails, etc) if provided an easy way to get needed tools

Problem
Many projects, few resources
Solution:

Metadata-driven application

(no per-project programming)

2004 - First REDCap project operational at Vanderbilt
So ... I have a proposition for you ...

- Web-based
- Easy to Configure
- Free to use
- HIPAA Compliant
- Fast!
Visual Status

Data Validation

Numerous Field Types

Human Readable Labels

Auto-Variable Coding

Branching Logic

PDFs

Project History

REDCap™
Project History

Embedded De-Identification Tools

Exports Raw Data + Stats Script Files (Labels, Coding)
So ... I have a proposition for you ...

- Web-based
- Easy to Configure
- Free to use
- HIPAA Compliant
- Fast!

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Sure – I’ll have my coordinator send you our data requirements
So ... I have a proposition for you ...

- Web-based
- Easy to Configure
- Free to use
- HIPAA Compliant
- Fast!
- **One condition!**

... YOUR team (not my team) defines and maintains the study metadata
...it worked!!

RESEARCHER

REDCap™ Research Electronic Data Capture
Early Finding - Improves science

Workflow for creating projects includes all research team members and helps solidify the data management plan before enrolling the first subject.

2004 Survey --- N = 20 Early Adopters
REDCap Improves Science! (100%)
So ... how's it working so far?

It's fantastic, but could you add some sort of widget to ...
Designed For Researchers

Project History

Good ideas → new modules

Ongoing Challenge:
Add powerful features, without compromising ‘ease of use’
So ... how's it working so far?

It’s fantastic, but can I use it for my basic science studies?
Proven track record supporting diverse studies
# Measuring Impact

**Available to any student, faculty, staff member for any Vanderbilt use – no cost**

## Local @ VU

### Overall

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<td><strong>Total projects</strong> (excludes ‘practice’ projects)</td>
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<td>- Epidemiology</td>
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<td>• Quality Improvement</td>
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<td>• Other</td>
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<td>• Total user accounts</td>
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<tr>
<td>- Active users [?]</td>
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## This Week

Concurrent Users: (Past Week)

Locations of users accessing REDCap in the past week

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**REDCap™**

[Citation: REDCap™ - Vanderbilt University]
• **Protects:**
  - Institution (centralized data capture, security)
  - Data collector (data quality and continuity)
  - Participant (data security)

• **Easy to do the right thing:** easy way to get needed tools

• **Diverse:** streamlines process for collecting and managing data + supports all research domains

• **Flexible:** Single platform, many ways to configure

*Vanderbilt researchers are confident in their ability to innovate and get their research done*
Usage

- Over 28,000 Android and iOS downloads to date
- Worldwide Downloads
  - Non-US downloads in China, Brazil, South Africa, Kenya, Canada, and India

Installs by user – Top Countries

Honduras – Case/Control Study

Project Hope - Kenya

Diversity of Users/Use Cases → REDCap Innovation
Guiding Principles and Lessons Learned

#1 – Focus on A Universal Problem
All types of research require data collection and management

#2 – Design For your user (in this case – the researcher)
Make sure technical approach is sound, but design for researchers

#3 – Find and Empower Early Adopters
Good news = Free; Bad news = “You must own the process”; Good news = Empowers researchers and allows them to solve fundamental needs
Capitalize on excitement by encouraging - “Tell your friends”

#4 – Listen to End Users (a lot), then Use Input to Evolve
“This is great, but will it do ...?”
“No, but someone else asked that ... let me think about it”
#5 - Manage Expectations
Under Promise and Over Deliver

#6 – Leverage Earned Trust
“We are working on concept of X, can we get volunteers to serve on focus group, beta test group, etc?”

#7 - Promote, Promote and Re-Promote
Never turn down an opportunity to promote tools/services (e.g. IRB, Privacy, Research Skills Workshops, Courses)

#8 – Measure as You Go
Track usage of all system components for use in evaluation
Automated system/program reports saves time and effort
and let me know if you’re interested in collaborating ...
and let me know if you’re interested in collaborating ...
and let me know if you’re interested in collaborating …
and let me know if you’re interested in collaborating ...

5% for 3-Months

30% for 6-Months
and let us know if you’re interested in collaborating ...

% Effort – User Authentication
And Then ...

1 2 3 4 5 6 7 8 9 10

WE GET IT ALREADY
Consortium Partners
2,737 institutions in 118 countries
498,000 projects with 662,000 users
**REDCap Consortium Growth (By Year)**

New/More Partners yield Interesting Partnerships –
(e.g. New Local/State Health Department REDCap Working Group)
Guiding Principles and Lessons Learned

#1 – Choose Initial Partners Carefully

#2 – Remember That Technology is Always Easiest Part
   Focus on the relationships
   Biggest consortium asset = diverse, expert community

#3 – Earn and Maintain Trust
   Collaborations should Be win/win or nothing

#4 – Listen and Be Diplomatic
   More users = more GREAT ideas (and more BAD ideas)

#5 – Be Prepared To Slow Down at First
   You are probably not as ready as you think

#5 – Anticipate Issues and Problems
   When they occur, be straightforward and own them
THE Story

1  2  3  4
RIC Service Lines

Community Engagement Studio
- Conduct CES
- Training to perform local CES

Recruitment Materials
- Applications
  - Clinical Study App (New)
  - Patient Study App (New)
- Website
- Social Media (FB, Twitter, etc.)
- Printed Media
  - Letters
  - Cards
  - Pamphlets
  - Flyers

EHR
- Cohort Discovery
- Clinical Systems Optimization (Coming Soon)

Recruitment Feasibility Assessment (RFA)
- Edits/recommendations to existing RFA
- Develop an RFA
- Research & Design Studio
- Competing site review (New – Using TrialsToday)

Recruitment Plan (RP)
- Review/Recommendations to existing RP
- Develop an RP
- Training
  - ART of Recruitment
  - Community Advisory Board (CAB)
  - Consent Guidance
RIC Team Recommends Existing Tools & Service Offerings

Goal: Right methods for the right project at the right time

RIC Team Listens for Generalizable Problems → Opportunities → Innovation → New Services
Guiding Principles and Lessons Learned

#1 – Hang out with smart people & Listen

#2 – Formulate and Share Ideas

#3 – Listen again

#4 – If ideas resonate, develop/evaluate a **minimum viable product**

#5 – Watch and Listen + make objective decision to **evolve** – or sunset
**First Do No Harm ... @ Launch**

**Sign REDCap Form and Send PDF Copy to EPIC**

**Launch REDCap Form From EPIC + Transfer Some Data (LIMITED)**

**Next/Now Planning REDCap/EPIC Collaboratory Projects**

(methods abstracted for use across consortium)

1. Precision Use of REDCap Forms (the right form(s) for right patient for right user at the right time)

2. Embedding Surveys (e.g. Pre-Screening)

3. Dynamic Data Pull Real-time (Demography, CCD) + Harvesting (e.g. Labs/Vitals)
Patient-Centered Data Capture Application

Native App (iOS, Android)

Online / Offline

Researcher Authoring Toolkit – No Programming

Survey-Style Collection + ResearchKit ‘Tasks’

Data Storage = REDCap (all RC benefits)
Thank You!

References
www.projectredcap.org
www.projectmycap.org

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