REDCap at MCRI: 8 Years

REDCap at SLHD: 4 Years
Where might you be in another 4?

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Agenda

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About Us: Murdoch Children's Research Institute

- Located within The Royal Children's Hospital Melbourne
- Largest Children's Research Institute in Australia: 1200 researchers
- Top 5 in world for children's research
- Research areas
  - Infection and Immunity
  - Cell Biology
  - Clinical Sciences
  - Genetics
  - Population Health
- Clinical Epidemiology and Biostatistics Unit
  - Statistical support and methodological research
  - Data management support - me!
The Beginning: Why REDCap?

- A familiar story!
- Using Excel, Access etc. does not get you data that is
  - Manageable
  - Robust
  - Secure
- Commercial packages can be
  - Very complex
  - Very expensive
  - Hosted offsite or overseas
- REDCap to the rescue!
  - Usable by researchers with little support
  - Easy to set up and administer
  - Perfect price!
The Beginning: Getting Started

- Licence agreement signed July 2010
- Luke, can you set up a web server?
  - I can now!
  - REDCap version 3.3.0
  - REDCap Survey version 1.4.1
- Trial with a couple of small research projects
  - ChocHealth
    The effects of dark chocolate on children's blood pressure: a pilot randomised controlled trial
    [http://www.isrctn.com/ISRCTN60409644](http://www.isrctn.com/ISRCTN60409644)
- My first REDCap project (pid=6)
  - Storing randomisation schedules generated by statisticians in our stats group (CEBU)
  - Still going strong!
Usage Growth: Database, Files, Projects, Page Hits

- Ramping up 2010 to 2015
- Consistent growth
  - 2015 to 2019
  - Beyond...
- Indicates steady-state, market saturation
Growth: Users

- 3 broad categories
  - MCRI (LDAP authentication, user whitelist)
  - RCH (hospital staff, non-MCRI)
  - External (off-campus, external organisations)
- New internal users steady from 2015
  - Staff turnover in core usage groups
- External users consistently the largest group
- Steady state overall reached later: 2016/7?
  - Projects getting bigger, more complex?
  - Could look at fields/project by year...
Growth: Records

- Again see ramping up through to 2015/6
- Steady increase 2017 on
- Except for the sawtooth!
  - Deleted project backup
  - 120,000 aliquot records
  - "Non-traditional" usage

- Has the proportion of non-"research" vs. "research" purpose projects changed over time..?
Present: Current Situation

- REDCap is:
  - Strongly endorsed by senior management, IT, Ethics and Governance.
  - Widely accepted as the go-to platform for research data capture.
  - Also widely liked!

- Support burden is manageable with current resources.
  - 0.3 EFT direct support (user management, user helpdesk and consultations)
  - 0.2 EFT indirect (training courses, system admin, module development, community participation)

- Some capacity within my team to take on project build work with cost-recovery.
Present: Ongoing Challenges

- Capacity for training and knowledge transfer
  - 10 courses (5 basic, 5 advanced) per year, 16 participants per course
  - Remember 600-700 new users per year!
  - Internal wiki pages
  - Considering demo/seminar style sessions
- Use of REDCap by hospital (non-MCRI) staff
  - Clinicians want easy to use system for their own purposes (clinic tracking, clinical audit)
  - EMR (Epic) should be single source for patient data, but is complex, inflexible, expensive to build anything for
  - Hospital data must be on hospital servers
- Data breach* risk & compliance with GCP/NHMRC National Statement
  - "3.1.41 Researchers should adopt methods to reduce the risk of [participant] identification"
  - Participant-identifying data in research datasets (with poor User Rights management)

* Australian Privacy Act 1988, Privacy Amendment (Notifiable Data Breaches) Act 2017
Future: REDCap at Murdoch Children's

- REDCap will continue to be our primary research data capture system
- Still scope for expansion into non-traditional areas i.e. lab-based research groups
- Some reduction in non-research usage as other systems become available:
  - Project tracking (Smartsheet)
  - Sample/aliquot/inventory management (OpenSpecimen)
  - Participant relationship management (Salesforce)
- Integrations with other systems:
  - Institutional data repositories (Generation Victoria)
  - Project tracking, LIMS system, Participant relationship management
  - Epic (Electronic Medical Record) - one day!
- I'll keep building external modules :)
Future: REDCap at SLHD?

- If you're like us at 4 years...
  - REDCap will continue to be your primary tool for research data capture
  - Reaching saturation amongst potential user groups?
  - Steady-state $\rightarrow$ easier to estimate support and administration workload

- Although you're different too...
  - Escaping the hospital/research institute division
  - Cerner integration?

- But for the foreseeable future...
  - REDCap will continue to develop
  - Version 9: Alerts and Notifications
  - Version 10: ?
Thank you. Any questions?

And thanks to the REDCap team at Vanderbilt University

Title: Research electronic data capture (REDCap)—A metadata-driven methodology and workflow process for providing translational research informatics support

Author: Paul A. Harris, Robert Taylor, Robert Thielke, Jonathon Payne, Nathaniel Gonzalez, Jose G. Conde

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