



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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 - For us
 - For you

About Us: Murdoch Children's Research Institute

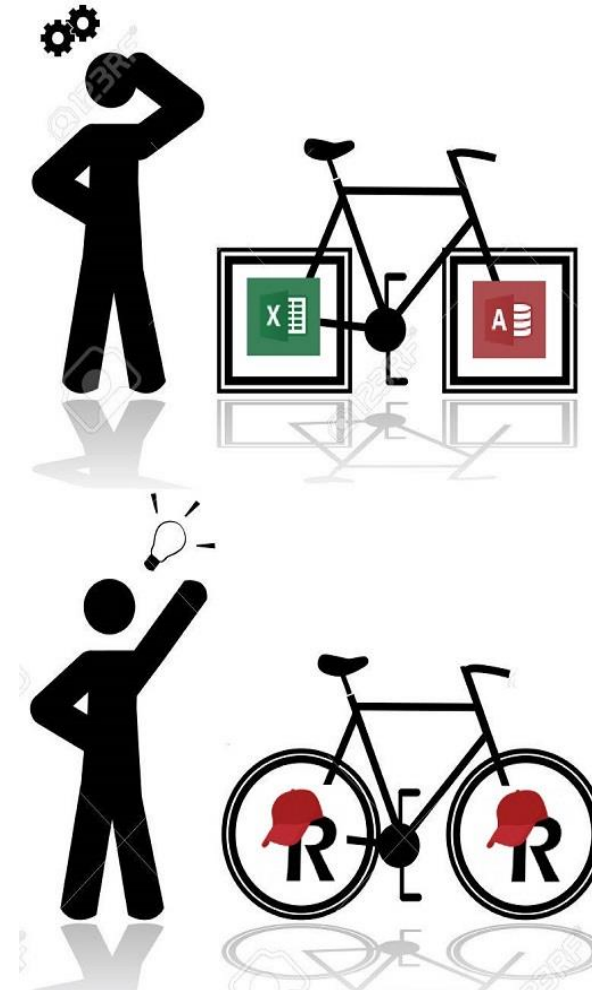


- Located within The Royal Children's Hospital Melbourne
- Largest Children's Research Institute in Australia: 1200 researchers
- Top 5 in world for children's research
- Research areas
 - Infection and Immunity
 - Cell Biology
 - Clinical Sciences
 - Genetics
 - Population Health
- Clinical Epidemiology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



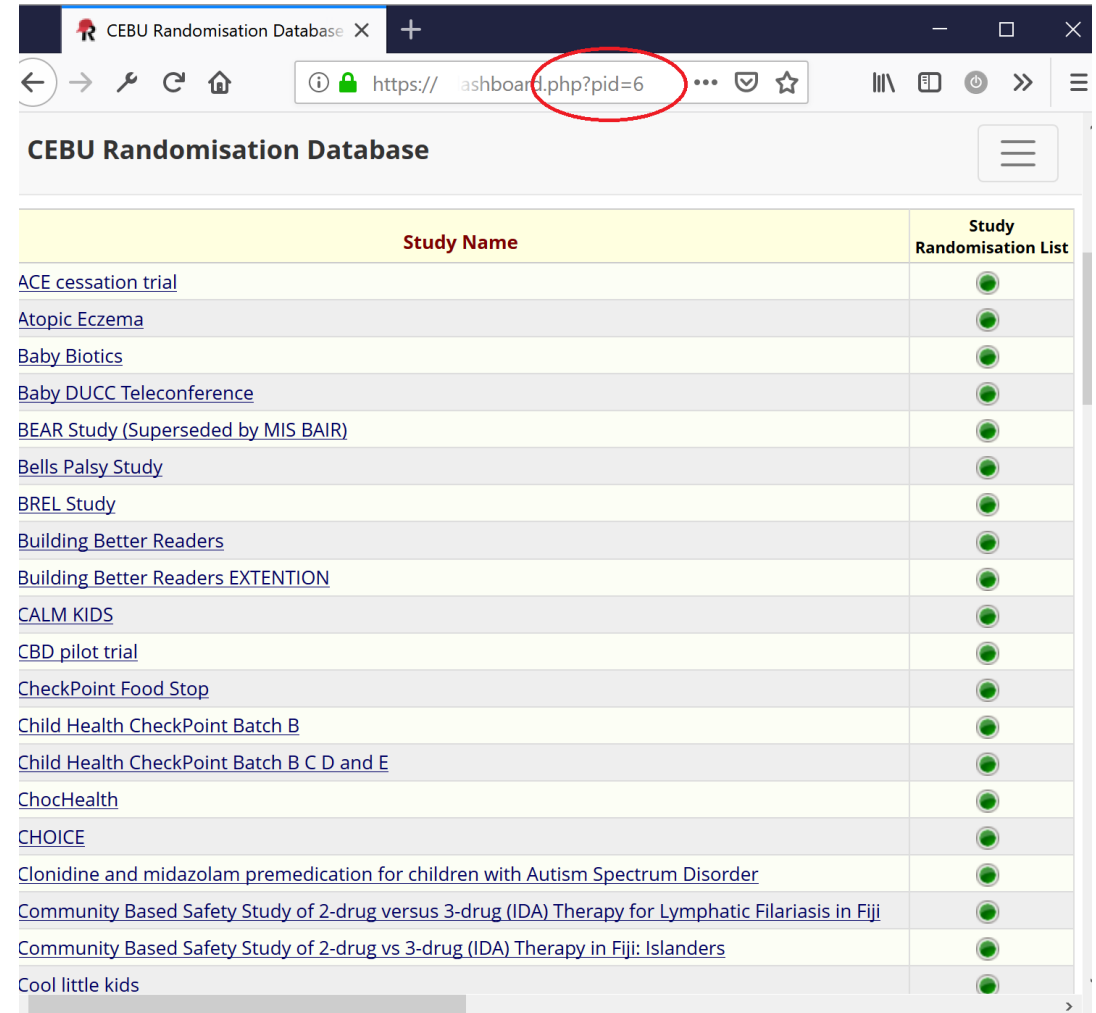
The Beginning: Why REDCap?





















- 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>
- My first REDCap project (pid=6)
 - Storing randomisation schedules generated by statisticians in our stats group (CEBU)
 - Still going strong!

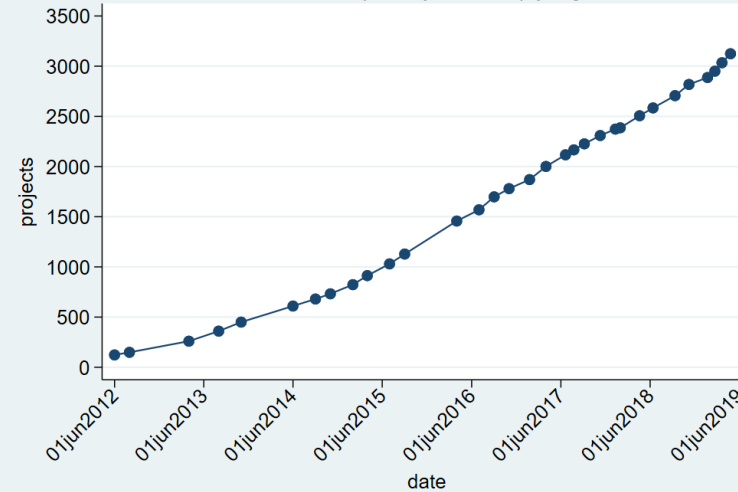


Study Name	Study Randomisation List
ACE cessation trial	
Atopic Eczema	
Baby Biotics	
Baby DUCC Teleconference	
BEAR Study (Superseded by MIS BAIR)	
Bells Palsy Study	
BREL Study	
Building Better Readers	
Building Better Readers EXTENTION	
CALM KIDS	
CBD pilot trial	
CheckPoint Food Stop	
Child Health CheckPoint Batch B	
Child Health CheckPoint Batch B C D and E	
ChocHealth	
CHOICE	
Clonidine and midazolam premedication for children with Autism Spectrum Disorder	
Community Based Safety Study of 2-drug versus 3-drug (IDA) Therapy for Lymphatic Filariasis in Fiji	
Community Based Safety Study of 2-drug vs 3-drug (IDA) Therapy in Fiji: Islanders	
Cool little kids	

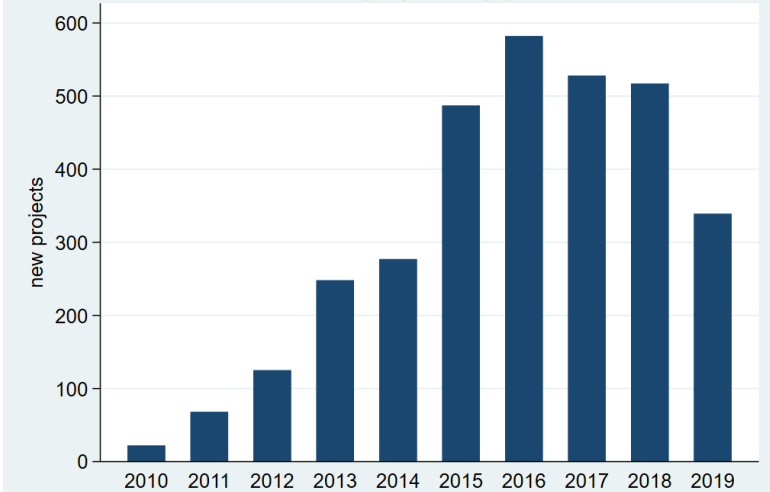
Usage Growth: Database, Files, Projects, Page Hits

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

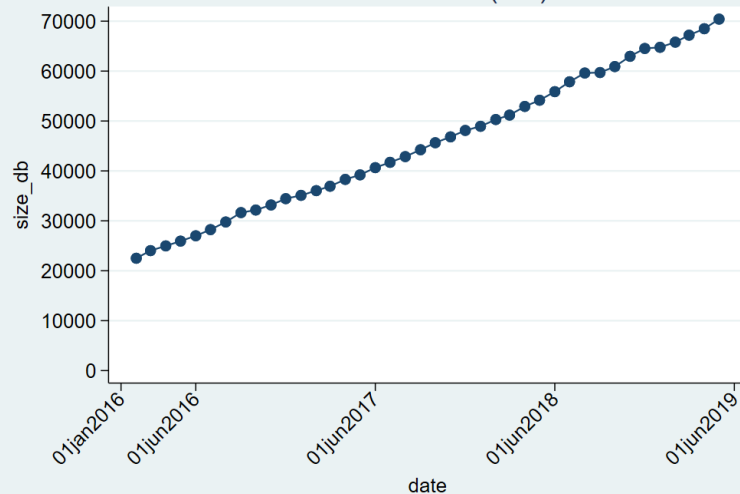
Number of (non-practice) projects



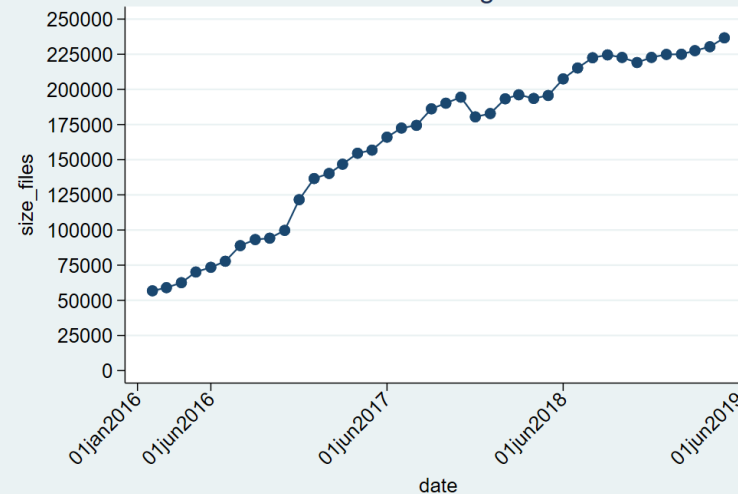
New projects by year



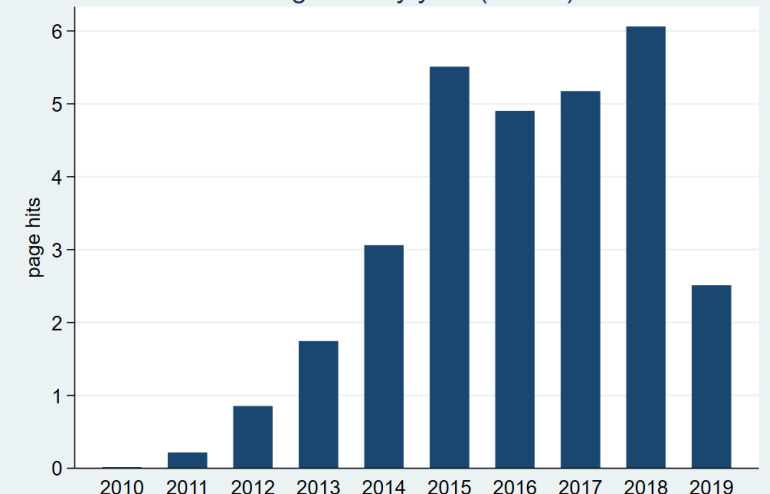
Database size (MB)



File storage

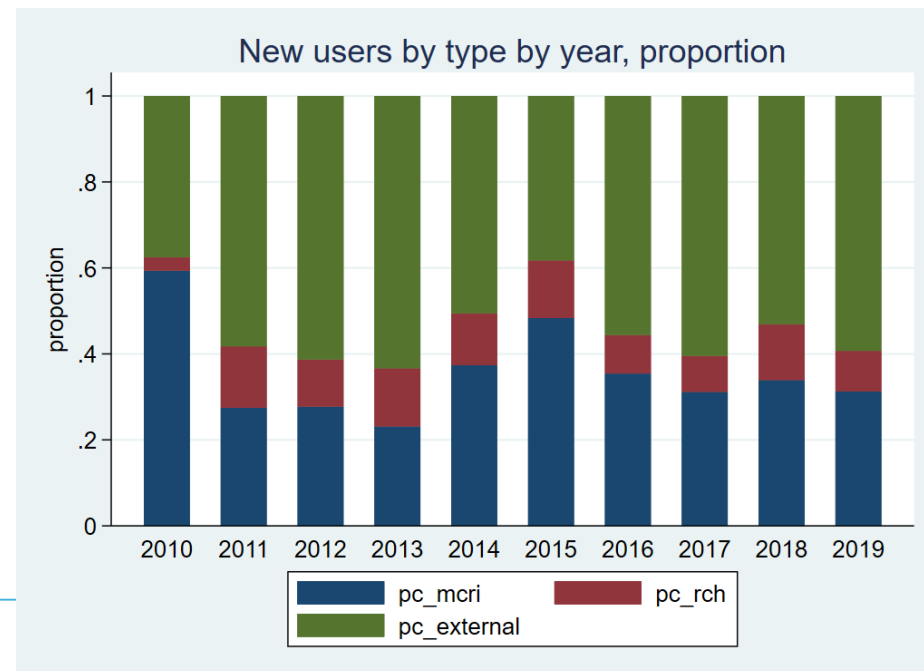
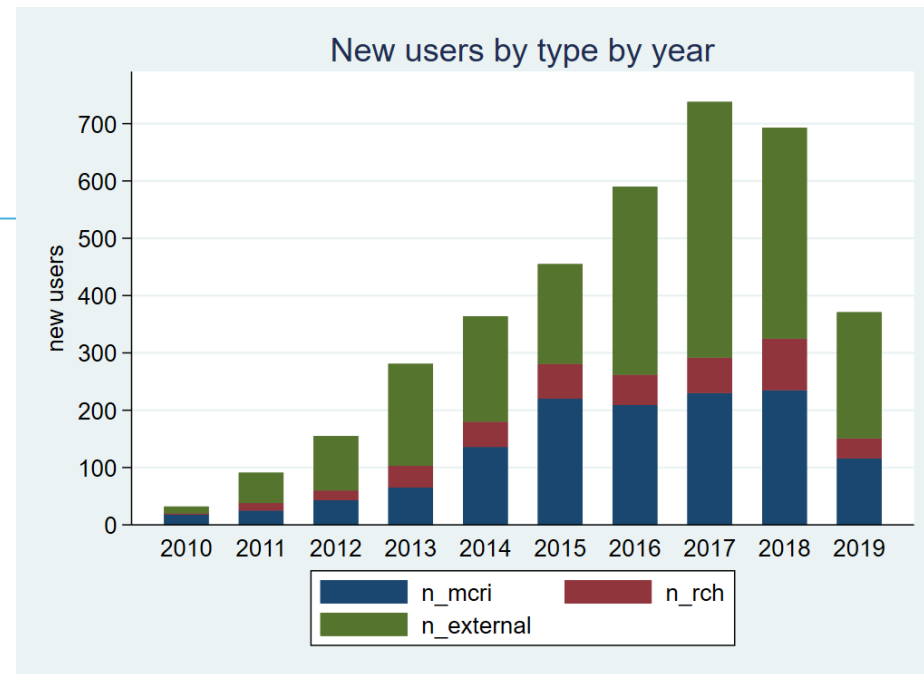


Page hits by year (million)



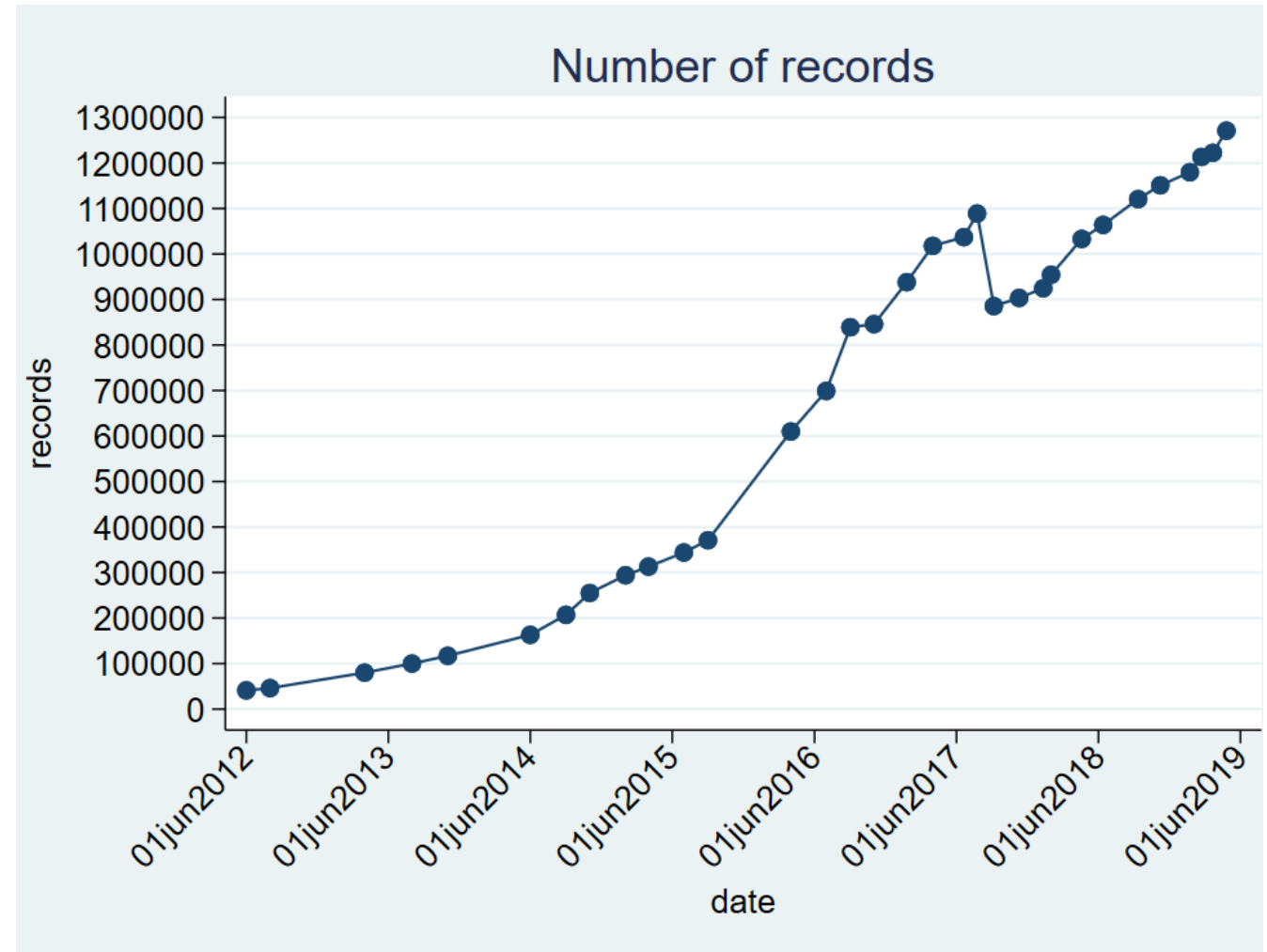
Growth: Users

- 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

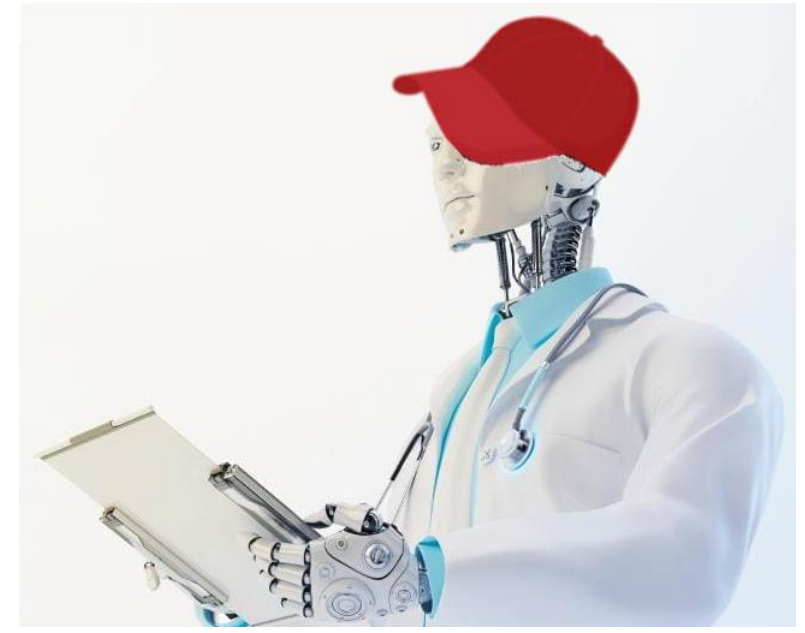
Future: REDCap at Murdoch Children's

- 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 → 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

Publication: Journal of Biomedical Informatics

Publisher: Elsevier

Date: April 2009

DOI: <https://doi.org/10.1016/j.jbi.2008.08.010>

