



# REDCap at MCRI: 8 Years

REDCap at SLHD: 4 Years

Where might you be in another 4?

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<https://doi.org/10.25374/MCRI.8187737>



# Agenda

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- About us
- The beginning
  - Why REDCap?
  - Getting started
- Past
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- Present
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  - Ongoing challenges
- Future
  - For us
  - For you

# About Us: Murdoch Children's Research Institute

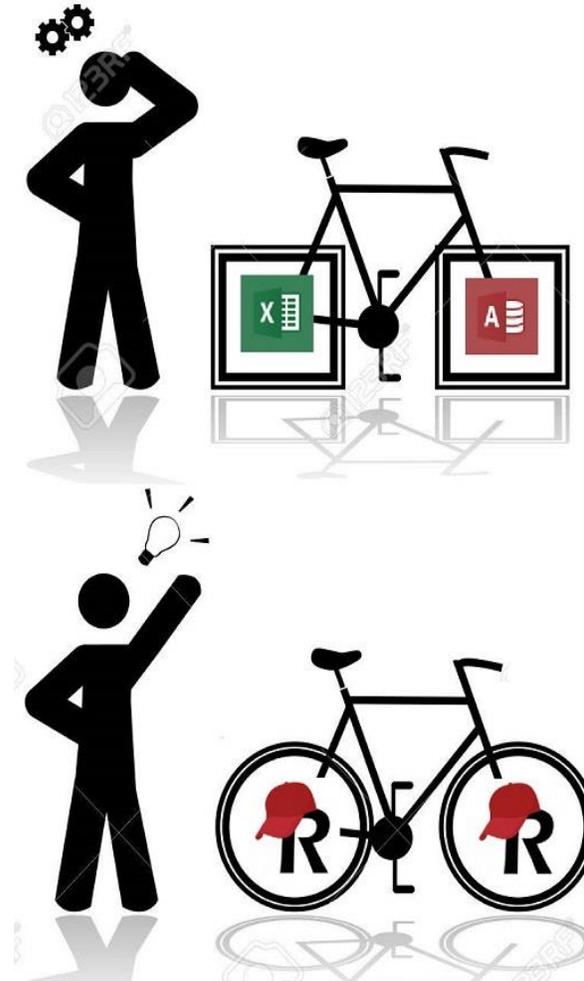


- Located within The Royal Children's Hospital Melbourne
- Largest Children's Research Institute in Australia: 1200 researchers
- Top 5 in world for children's research
- Research areas
  - Infection and Immunity
  - Cell Biology
  - Clinical Sciences
  - Genetics
  - Population Health
- Clinical Epidemiology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



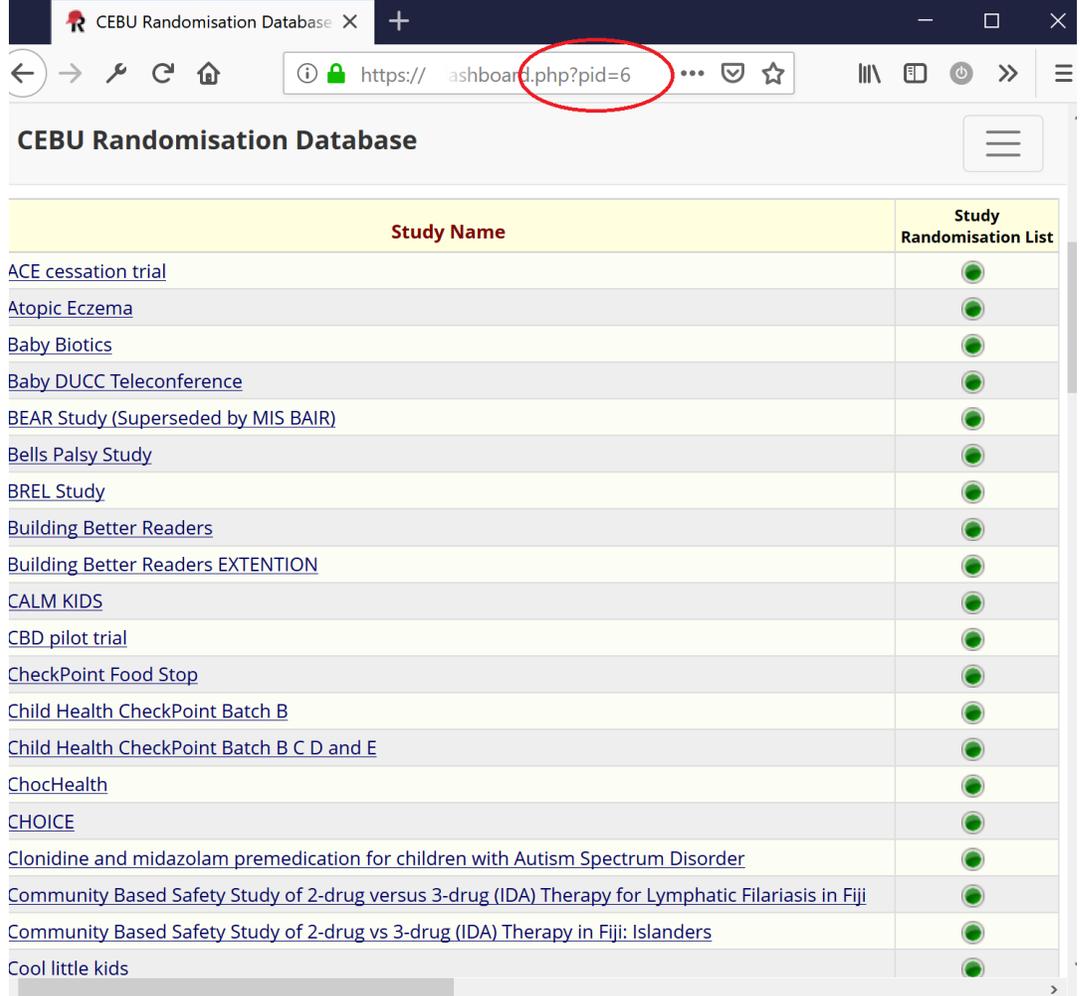
# The Beginning: Why REDCap?

- 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!

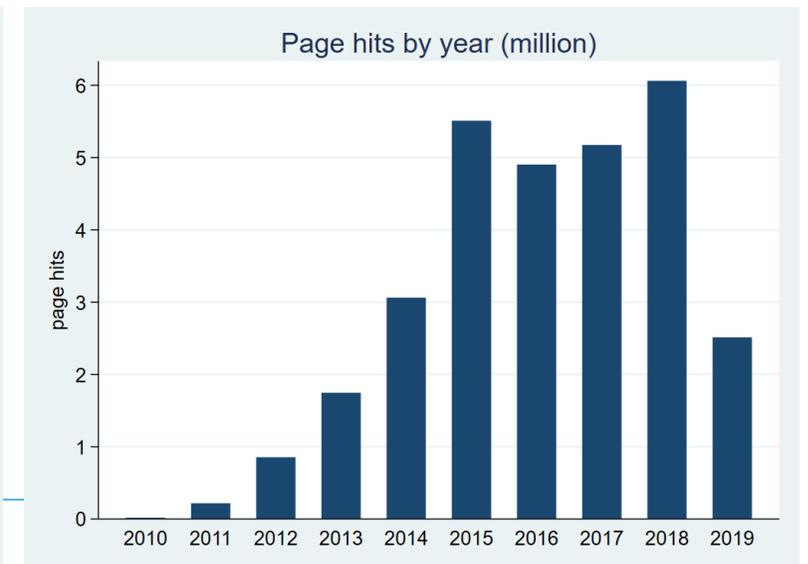
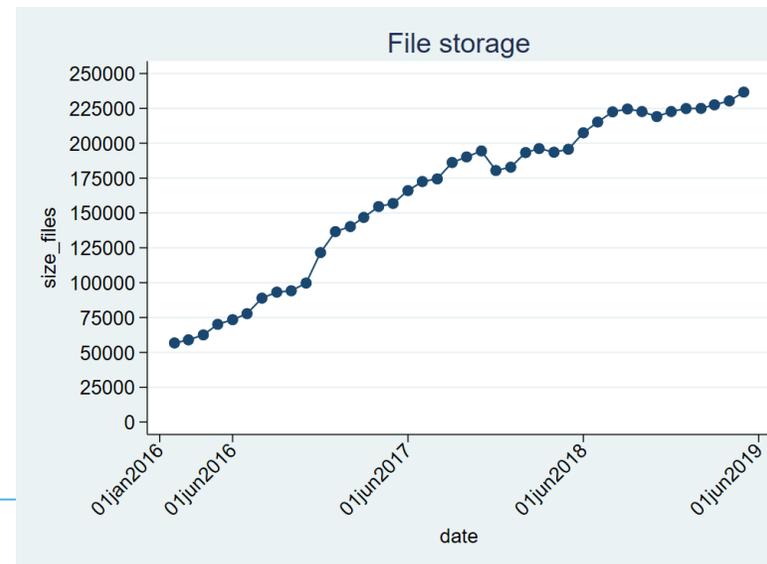
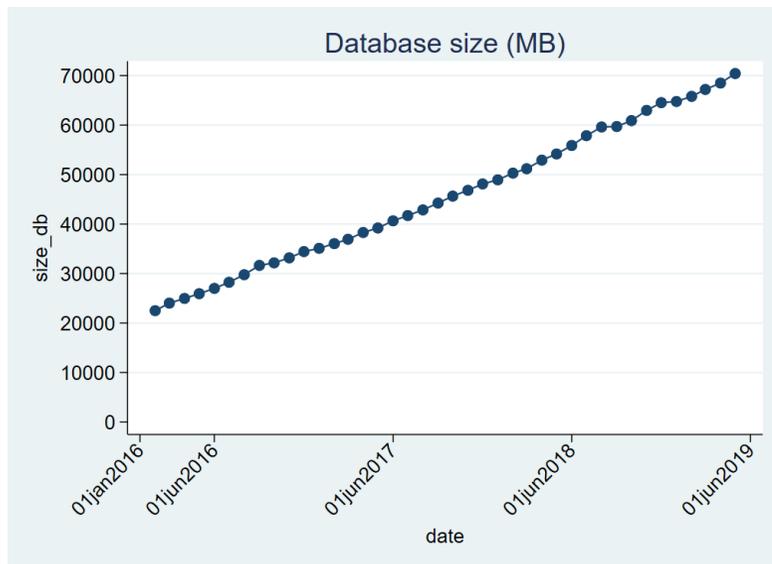
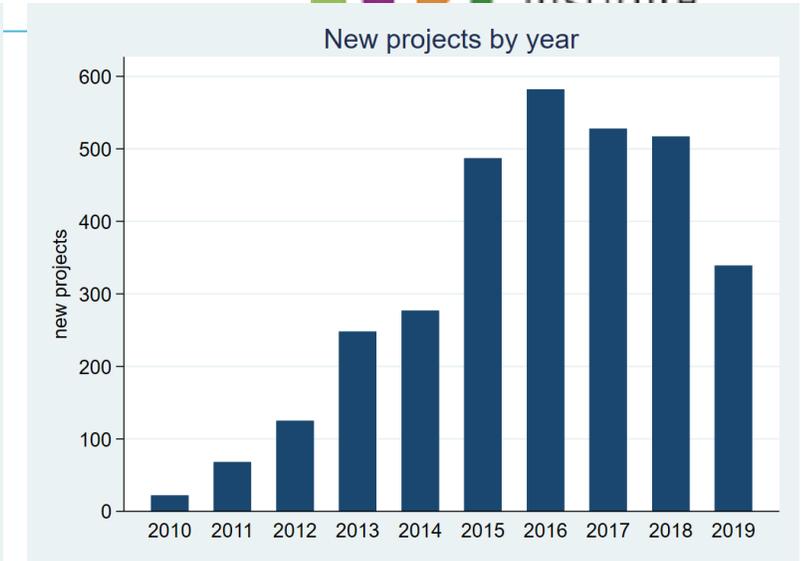
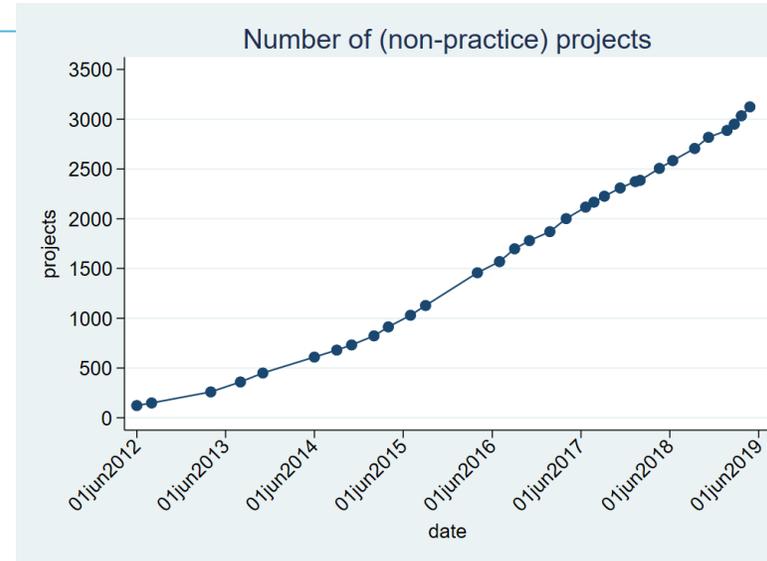


Study Name	Study Randomisation List
<a href="#">ACE cessation trial</a>	●
<a href="#">Atopic Eczema</a>	●
<a href="#">Baby Biotics</a>	●
<a href="#">Baby DUCC Teleconference</a>	●
<a href="#">BEAR Study (Superseded by MIS BAIR)</a>	●
<a href="#">Bells Palsy Study</a>	●
<a href="#">BREL Study</a>	●
<a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

# Usage Growth: Database, Files, Projects, Page Hits

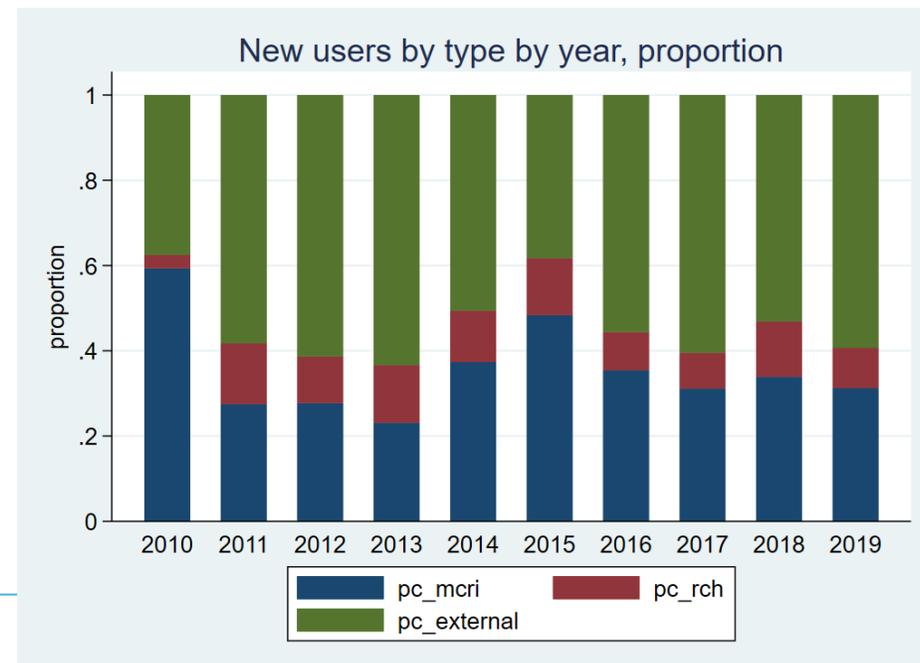
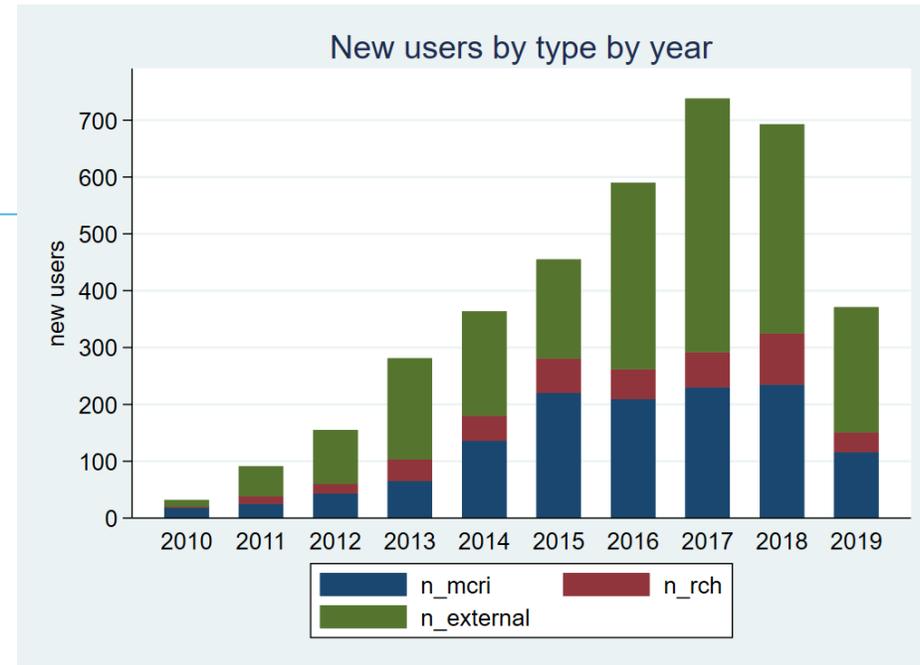


- Ramping up 2010 to 2015
- Consistent growth
  - 2015 to 2019
  - Beyond...
- Indicates steady-state, market saturation



# Growth: Users

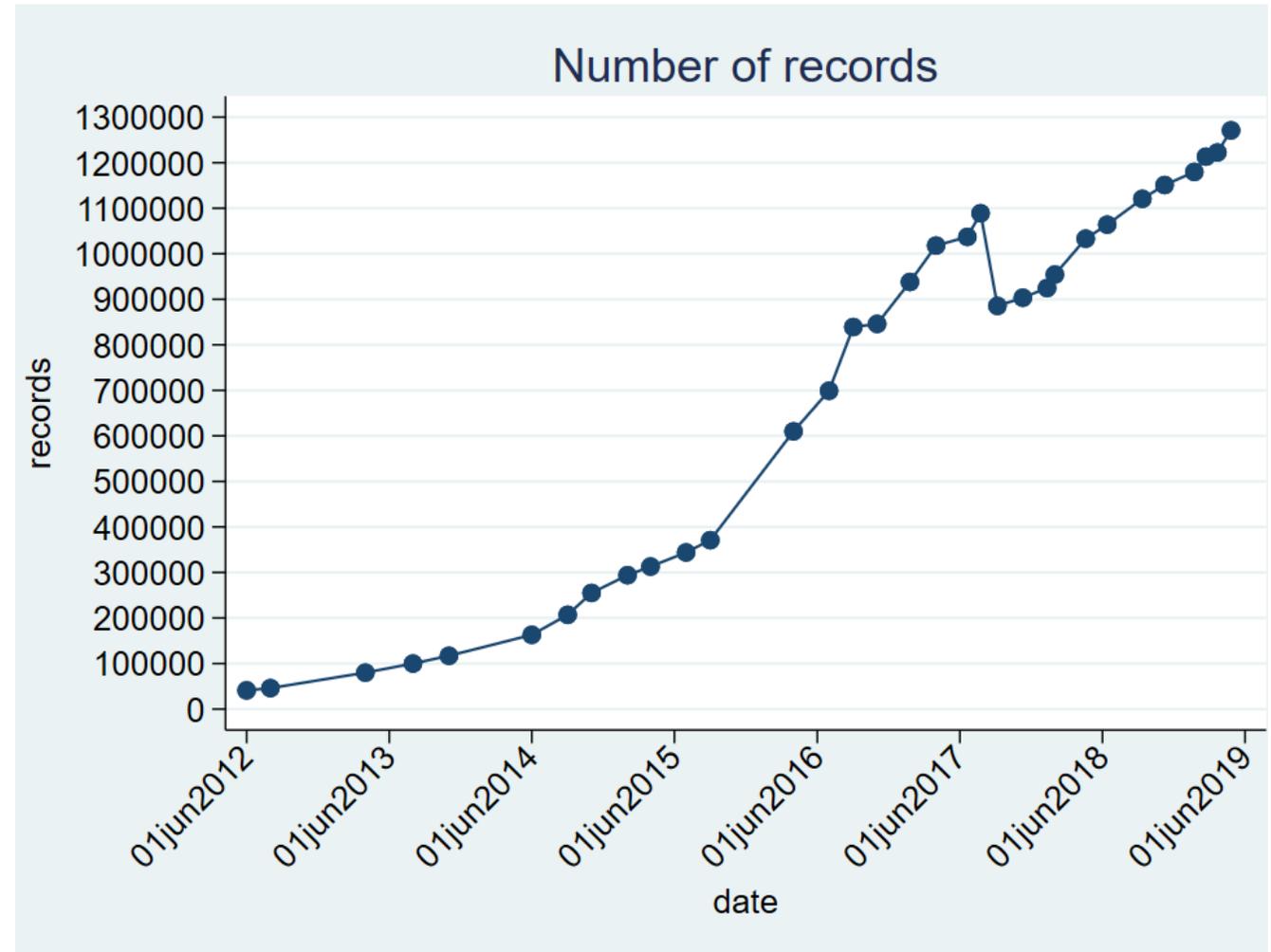
- 3 broad categories
  - MCRI (LDAP authentication, user whitelist)
  - RCH (hospital staff, non-MCRI)
  - External (off-campus, external organisations)
- New internal users steady from 2015
  - Staff turnover in core usage groups
- External users consistently the largest group
- Steady state overall 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

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- 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

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- 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)

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\* Australian Privacy Act 1988, Privacy Amendment (Notifiable Data Breaches) Act 2017

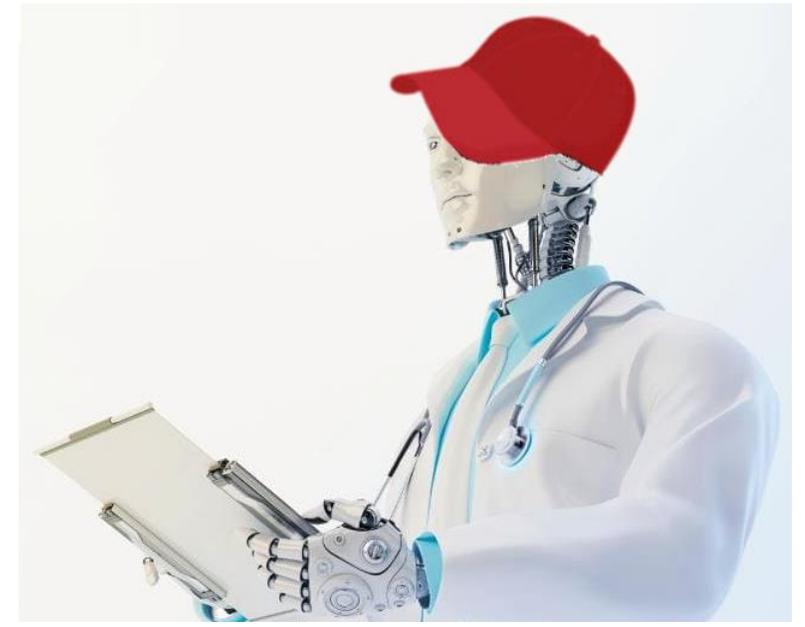
# Future: REDCap at Murdoch Children's

- 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>

