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Be inspired to work with data: "Innovation in Research Data"

Rory Dunbar & Jessica Workman

Desmond Tutu TB Centre

Paediatrics and Child | Faculty of Medicine and Health Sciences



Overview

- Using research data to inform operations during a research project
 - Monitor project progress
 - Plan and coordinate workload of field teams
 - Retention of study participants



The objectives

- Define community boundaries
- Define smaller zones to allocate teams
- Census
 - How many households
 - Population size
 - Basic data required
 - Gender/Age
 - Make use of local clinic...



Defining the study communities

- The need for accurate/current information
 - Demographics
 - Location of Study Populations (Clinic)
- National Census
 - Sometimes old and outdated
 - Inaccurate
- GIS and Electronic Data Capture (EDC) systems
 - Trial-specific Census
 - More up to date information (current)
 - Monitor fieldwork in community studies





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Mini Census



Data collection tools

- Mobile device
- Electronic data collection system
 - Central data storage
- Google Maps









The project setting

- Community randomized trial
- 9 Communities in the Western Cape





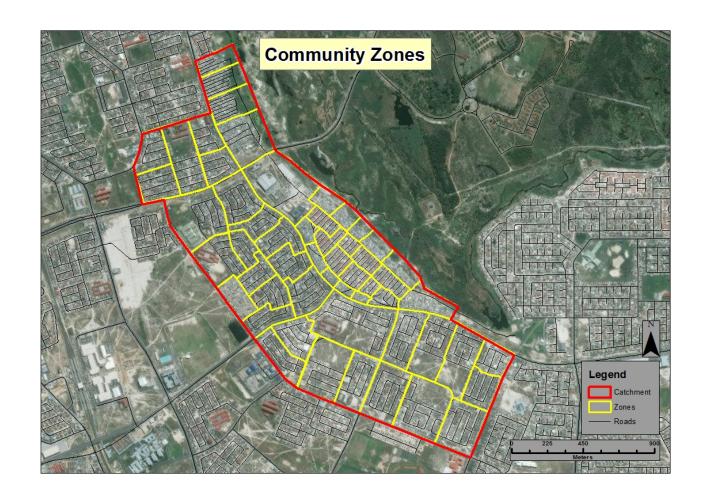
Maps created by Mark Theart

Defining the community border



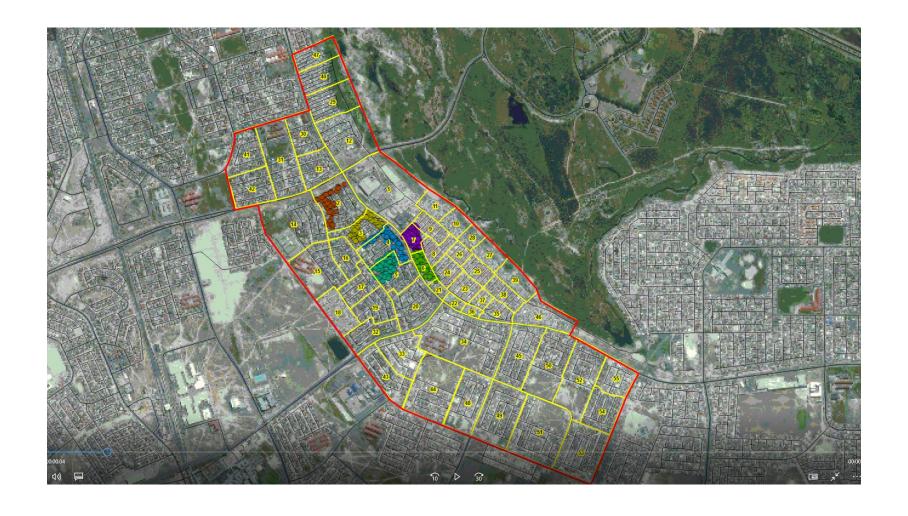


Define working zones





Monitor progress...

















Mini Census - Results

- 16 Weeks (9 communities)
 - 74 457 households
- Produced representative sampling frame for the trial
- Demographic database estimated Population of 312 473





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Monitor project progress



Retention of study participants

- Why do we loose participants
 - Withdraw consent
 - Move/Died
 - Community restructuring
 - Natural disasters



Changes in community (2013)



Informal to Formal housing (2016)





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Expanding communities



Start of study (2013)





Influx of new households (2016)





Stellenbosch University - REDCap

There are 2 instances of REDCap at SU:

- 'sandbox'/training environment: redcaptest.sun.ac.za
- production/live environment: redcap.sun.ac.za



Please feel free to contact redcap@sun.ac.za



Data Innovation in Paediatric Trials

How we're turning ourselves into a data unit of excellence



Solutions Data Can Offer





Problems we face

Solutions we build

- Budgets for cutting edge trials are small
- Leverage data to help people

Workloads are heavy

Automate manual processes

Performance must be excellent

Triggers and reminders

- Quality of data must be exceptional
- Monitor quality



Our Top 5 Innovations in Research

Automated stats

Calendar and real-time retention

Results read by a computer and sent to relevant doctors

Automated back-ups

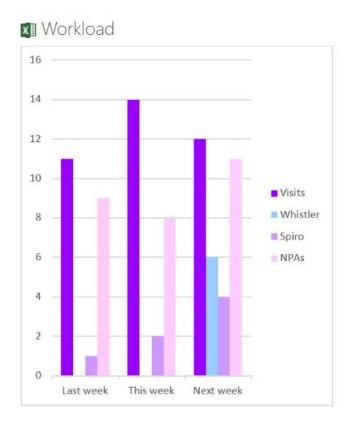


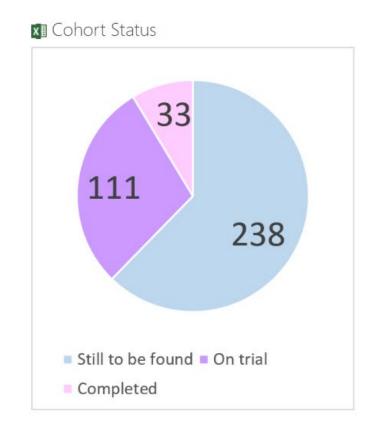
Stats for Team Updates



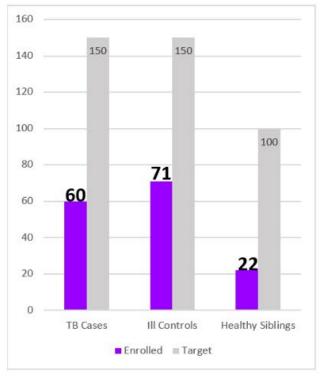


Stats for Team Updates



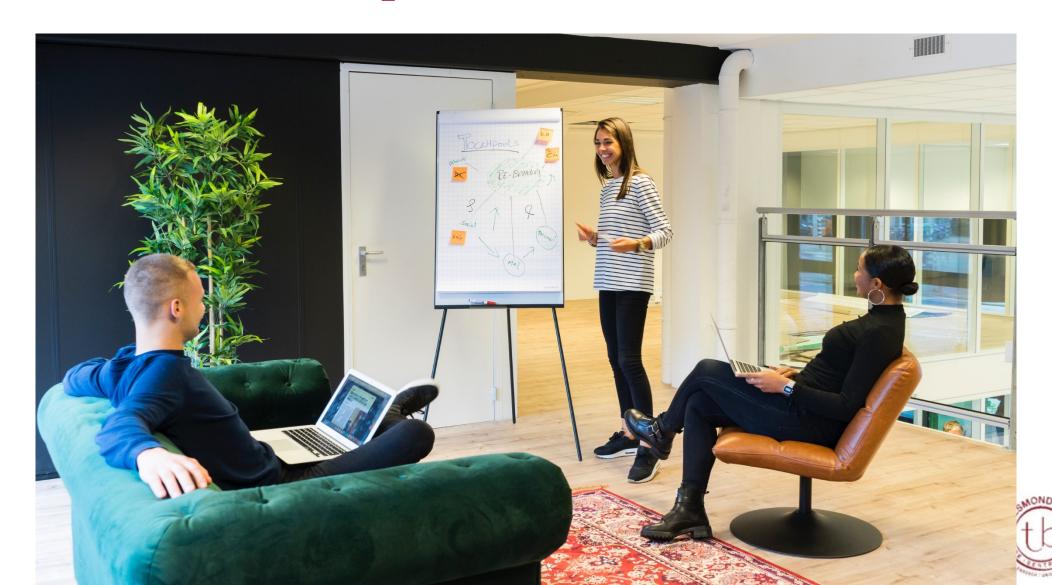








Stats for Team Updates



Calendar and Real Time Retention





Calendar and Real Time Retention

| Sunday | | Monday | Tuesda | Tuesday | | Wednesday | | Thursday | | Friday | | Saturday | |
|--------|----|-------------------------|---------------------|------------|----------------|-----------|-----------------|----------|------------|------------|-------|----------|--|
| | | | | | + New | 1 | + New | 2 | + New | 3 | + New | 4 | |
| | | | | | PUBLIC HOLIDAY | | | | | | | | |
| | | | | | | | | | | | | | |
| + New | 5 | + New | 6 + New | 7 | + New | 8 | + New | 9 | + New | 10 | + New | 11 | |
| | | ☆ U_SA0344A (wk48_m4) |) SA0374 Unsc | hedule | | | | | | | | | |
| | | ✓ U_SA0352D (wk48_m4) |) 🥯 SA0198 for a w | veight che | | | | | | | | | |
| | | ☆ U_SA0340X (wk48_m4) |) SA0276 Clinica | l Review | | | | | | | | | |
| | | ☆ U_SA0351K (wk48_m4) |) 🖈 T_SA0254E (w | k72_m4) | | | | | | | | | |
| | | ☆ U_SA0342M (wk48_m² |) 🖈 T_SA0255Z (w | k72_m4) | | | | | | | | | |
| | | +8 more | +5 mor | <u>'e</u> | | | | | | | | | |
| + New | 12 | + New 1 | 3 + New | 14 | + New | 15 | + New | 16 | + New | 17 | + New | 18 | |
| | | | /I 🥯 320 booked for | | | | T_SA0288L (wk60 | _m6) | Remind 320 | about G9 a | | | |
| | | 340 call and see if cou | | | | | | | | | | | |
| | | | | _ | | | | | | | | | |
| | | SA0326 for Drs review | | _ / | | | | | | | | | |
| | | U_SA0248R - Post-Disc | | | | | | | | | | | |
| | | +7 more | <u>+4 mor</u> | | | | | | | | | | |
| ⊦ New | 19 | | 0 + New | 21 | + New | 22 | + New | 23 | + New | 24 | + New | 25 | |
| | | Remind flandorp about | _ | | NO CLINICIANS | | | | | | | | |
| | | 320 to be admitted in | _ | | | | | | | | | | |
| | | | T_SA0217 Clini | | | | | | | | | | |
| | | | ☆ T_SA0298C (w | кь0_m4) | | | | | | | | | |
| ⊦ New | 26 | + New 2 | 7 + New | 28 | + New | 29 | + New | 30 | + New | 31 | | | |
| | | □ T_SA0358W (wk48_m4 | - | | | | | | | | | | |
| | | | | - | | | | | | | | | |
| | | | | _ , | | | | | | | | | |
| | | | | | | | | | | | | | |
| | | | . – . | _ , | | | | | | | | | |
| | | +5 more | +3 mor | <u>.</u> | | | | | | | | | |

Print Calendar



Important Results Send Themselves



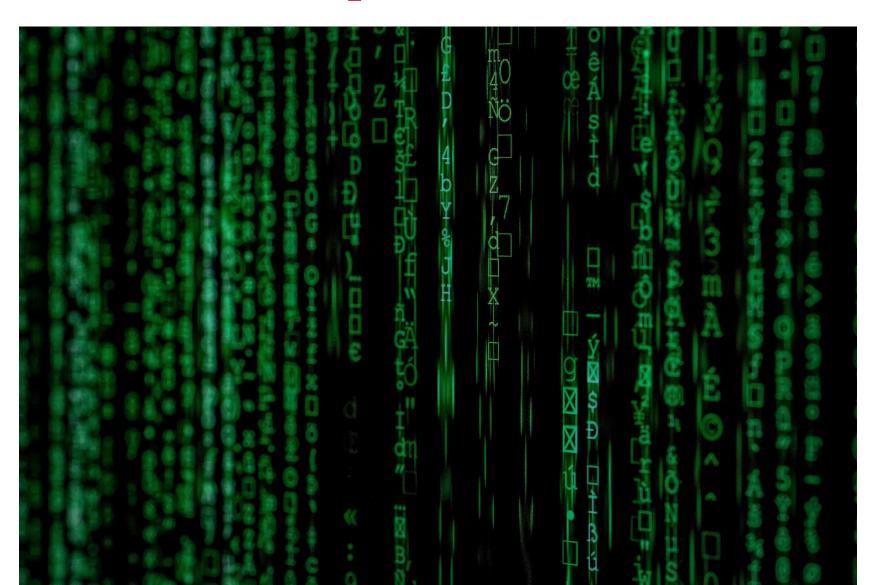


Automated Back-ups





Automated Back-ups

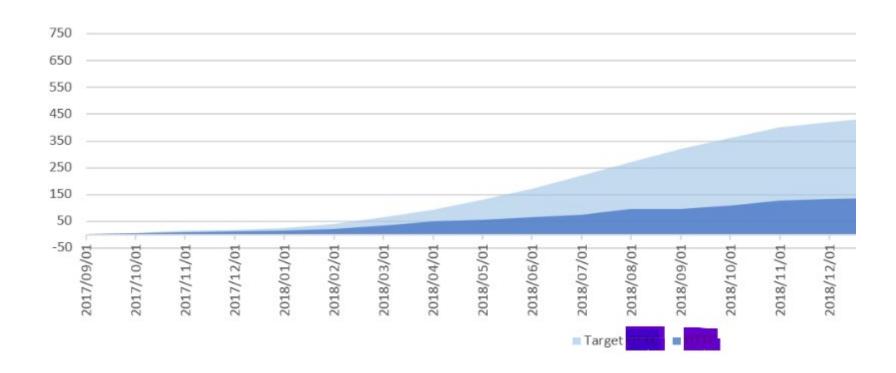




Automated Back-ups







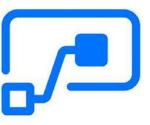






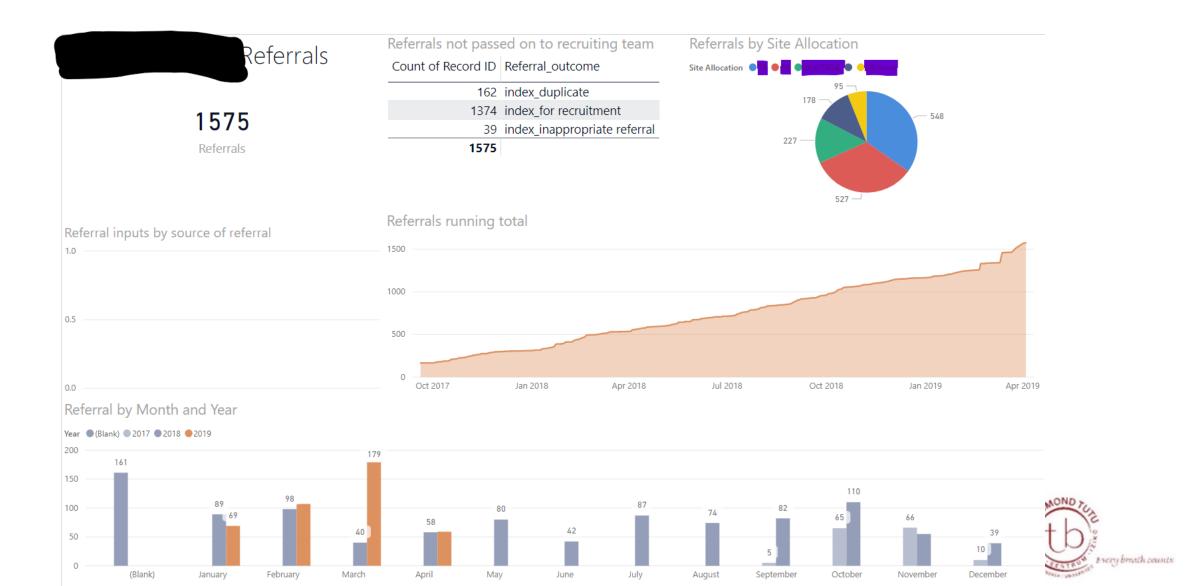
















THANKS YOU

ENKOSI

DANKIE



Free REDCap Course

https://www.coursera.org/learn/clinical-data-management?

