Lessons learned:

Supporting major longitudinal research projects with metadata, & using metadata for rules-based data ingestion in a secure data repository

Shane McChesney shane@nooro.com



NADDI 2016 Edmonton April 7th 2016

Show, don't tell

Data Sharing and Management Snafu in 3 Short Acts

https://www.youtube.com/watch?v=N2zK3sAtr-4
- Karen Hanson, Alisa Surkis and Karen Yacobucci of NYU
Health Sciences Library

Illustrates the structured data documentation problem in a brilliant and compelling way.

Core Findings

Researchers, stakeholders: get programmers into the room!

Free course in dealing with programmers:
Bloomberg Special Double Issue
What Is Code?

http://www.bloomberg.com/graphics/2015-paul-ford-what-is-code/

Core Findings

Programmers: **keep** researchers & stakeholders

in the room...

...or at least on the call.

Get reality checks daily / weekly... okay, biweekly. (But at least twice as often as anyone thinks is necessary.)

Always be working on The Most Important Thing To Do Next

A Few Quotes

Helpful persectives for metadata implementors, interspersed between my lessons learned.

Perfect is the enemy of good.

Timelines

Anything over 2 weeks is too long.

Software projects should deliver running code on a continual basis.

Timelines

Academic / government projects seem to take 2-5x as long as business / market research projects.

Sometimes they have to... sometimes?

Teams Change

Plan for that: document, document.

Remember: "It's not about you."

Names are not codes, codes are not UUIDs

Truely unique identifiers should not be overthought, let the computer do it:

Name: Alberta

Code: AB

UUID: 170ce6e4-9f18-4432-9b6d-74b94ca8f883

Put UUIDs on everything, you'll be glad you did. Corrolary: autoincrementing integers suck.



Pain Points

"Doctor, it hurts when I do this..."

- Ralph Furley, Three's Company

"Then don't do that."

If creating metadata is a manual task after field has closed, you are doing it wrong.

It should be a condition of funding for primary researchers to provide metadata with their data.

The Cure: Start with metadata Run Data Collection Instruments Directly From Metadata

Metadata-Driven Survey Players

- 2 types of online surveys
 - Self-completed web surveys
 - In-person interviews using iPads





```
"editor class": "basic options",
    "name": "VAR014",
    "options": [
            "text": {
                "en": "Yes"
            "value": "1",
            "weight": 50
            "text": {
                "en": "No"
            "value": "2",
            "weight": 50
    "ordering": "default",
    "orientation": "horizontal_grid",
    "required": true,
    "text": {
        "en": "Do you provide at least one third of
your long-term care services (i.e., <i>at least 6
days a month</i>) in <b>{{facilityname}}</b>?"
    "type": "option"
```

Metadata-Driven Survey Players



Do you provide at least one third of your long-term care services (i.e., at least 6 days a month) in Valinor Retirement Residence (Test Site)?



(multilingual, offline capable, mobile-ready)

On Metadata Complexity



"It has been said that democracy is the worst form of government... except for all the others that have been tried."

- Sir Winston Churchill https://en.wikiquote.org/wiki/Winston_Churchill

Metadata

management can be complex, but it beats the alternative.

The good news:
The tools are always improving.

VALHUE

Value and Limitations in Hospital Utilization and Expenditures

"...one of the largest systematic collections of Patient-Reported Outcome Measures (PROMs) in Canada, and aims to evaluate the changes in patients' health status pre- and post- elective surgery."



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Vancouver Campus

Patient Reported Outcomes

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» Home » VALHUE

VALHUE

Value and Limitations in Hospital Utilization and Expenditure (VALHUE) **Project Summary**

Significance and Policy Context

There is little understanding of whether shorter wait times are associated with better clinical outcomes, and whether policy-linked initiatives to increase access to surgery are associated with consistent changes in health improvement. The literature regarding the effect of wait times on health is significantly underdeveloped. VALHUE aims to address this gap in the literature.

This study is intended to inform clinicians, Vancouver Coastal Health (VCH) decision makers, and policymakers about the nature of relationships between wait times and trajectory of change in health status, pain and depression. We expect that the results will be immediately relevant in BC and other provinces implementing changes to prioritizing health expenditures. This study is the first in Canada to examine the trajectory of patients' health while on the wait list, and also to differentiate the impact of surgical care by different types of conditions.

Funded by the Canadian Institutes for Health Research (CIHR), VALHUE is a significant PROMS project within VCH that began in January 2012. Current funding for this project ends September 2014.

Objective and Specific Aims

This joint project with the University of British Columbia aims to quantify the association between time spent on the surgical waitlist and health status. This is to be evaluated by measuring changes in health status for those patients undergoing selected surgical procedures.

The VALHUE project uses validated Patient Reported Outcome instruments to measure change in general health status, acute and chronic pain, and depression while waiting for care and after surgical treatment. This study will fill an important gap in the current understanding on the effects that changes in wait times and surgical volumes have on patients' health.

VALHUE has two specific aims:

Aim 1: Surveying patients twice prior to surgery, we will test for changes in patients' health while on the surgical wait list.

Aim 2: Surveying patients pre- and post-surgery, we will test for changes in patients' health as a result of wait times.

Tags

replacement ISOQOL UBC surgery Canada generic instruments UK health status cholecystectomy instrument selection VALHUE CHSPR Vancouver BC generic instruments pediatrics PROMs cataracts elective surgical procedures diskectomy chronic care patient experience resio HRQoL knowledge mHealth self-management condition-specific instruments pain symptom severity VCH hysterectomy Electronic PROs PREMs burden condition-specific instruments Australia conference prostatectomy patient satisfaction uveal melanoma overactive bladder

population health CAHSPR arthroplasty; hip



UBC100

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Evidence and Perspectives on Funding Healthcare in Canada

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» Home » About us *Old* » Jason Sutherland

Jason Sutherland

PhD, Statistics, Simon Fraser University, 2003 MSc, Statistics, Simon Fraser University, 1997 BA, Mathematics, University of British Columbia, 1992



Jason Sutherland joined UBC's School of Population and Public Health and the UBC Centre for Health Services and Policy Research in 2009. Dr. Sutherland is a highly regarded and recognized leader in

researching the link between financial incentives and hospital behaviours and is a Michael Smith Foundation for Health Research Scholar.

Dr. Sutherland is currently leading a CIHR-funded study of the effects of changing the incentives of hospital funding. Dr. Sutherland is also leading another CIHR-funded study investigating the links between funding policy and patient reported health outcomes (PROMS). He is currently an associate editor of Health Policy, an international journal for health policy research.

In collaboration with the Ontario Ministry of Health and Long-Term Care, Jason has led efforts to develop and implement a case mix measurement tool for inpatient rehabilitation, known as called Rehabilitation Patient Groups. Affecting a broad array of rehabilitation patients in Ontario, this health system measurement tool is applied to hospitals that treat patients with stroke, joint replacement and brain injury. This case mix measurement tool is now applied by the Canadian Institute for Health Information to hospital based rehabilitation.

Before joining UBC, Jason was an Assistant Professor at Dartmouth College within The Dartmouth Institute for Health Policy and Clinical Practice (2007-2009). From 2004-2007, Jason was an Assistant Professor in the Department of Medicine, Division of Biostatistics at Indiana University. At this time, he was also an Assistant Research Scientist at the Center of Excellence on Implementing Evidence Based Practice, Roudebush Veteran's Affairs Medical Center in Indianapolis, Indiana.



The VALHUE questionnaire is a combination of almost 30 validated health status instruments.

The appropriate path for each patient through the overall questionnaire varies based on the patient's particular diagnosis codes and the surgical procedures (ORMIS PX codes) that the patient is scheduled for.

TREC

Translating Research In Elder Care

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Translating Research in Elder Care



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Translating Research in Elder Care (TREC) is a research program focused on developing solutions for improving the quality of care provided to nursing home residents, enriching the work life of their caregivers, and enhancing system efficiency.



"A life that has been lived should not be valued less than a life that's going to be lived." -Carole Estabrooks, Scientific Director

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Home > Projects > TREC Measurement System

TREC MEASUREMENT SYSTEM

Favourable work environments lead to increased use of best practices, higher quality of care and outcomes for older people, improved staff health and well-being in long term care facilities.

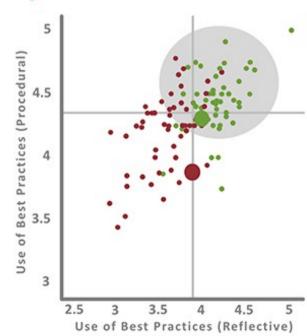
Why is it important?

We know from TREC 1.0 that context influences the use of best practices and provider outcomes (e.g., job satisfaction, burnout) which in turn can affect resident outcomes. It is possible to influence context and we want to learn more about which factors lead to positive changes in nursing home care.

What does the TREC Measurement System study involve?

The TREC Measurement System (TMS) study is a longitudinal study that explores the strength of linkages between work environments, best practice use and resident outcomes using staff survey data and RAI-MDS 2.0 data. The study will take place in 90 nursing homes across British Columbia, Alberta and Manitoba. Recruitment of sites will ensure representation across these locations, and that facilities of different sizes and owner-operator models (public, voluntary and private) are included.

Data will be collected from facilities in three waves spaced approximately 15 months apart. It will include surveys on facilities and units, and from regulated and unregulated staff. Participating facilities will play an important role in building the first longitudinal database of which we are aware of in Canada or elsewhere. We will work closely with Facility Managers, Administrator and Directors of Care to ensure that these data are collected with minimal impact on resident care.



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Knowledge Utilization Studies Program



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KUSP FYI

Health Research Data Repository

Top Ten KT Readings

KU Resource Guide

EQUATOR

Opportunities

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Knowledge Utilization Colloquia

Alberta Context Tool

Home > Resources > Health Research Data Repository

Health Research Data Repository

Based within the Faculty of Nursing at the University of Alberta, the Health Research Data Repository (HRDR) is a secure and confidential virtual research environment (VRE) created to support health related research projects, to support collaboration across research disciplines, to house health research data and meta-data throughout their life-cycle, and to promote the secondary use and re-purposing of health research data. The HRDR also has a mandate to promote and offer educational opportunities regarding research data management best practices. The mission of the HRDR is to stimulate both qualitative and quantitative health related research while building a collaborative culture of respect relating to data management and confidentiality.

KUSP currently houses research data for a number of its projects including TREC and SCOPE. We are committed to have our future data accessible in the HRDR's secure environment available to other researchers.

Contact Us

James Doiron Manager, HRDR

5-174 Edmonton Clinic Health Academy (ECHA) University of Alberta Edmonton AB T6G 1C9

Phone: 780-248-1653

Email: james.doiron@ualberta.ca



Automating Data Ingestion

Start With Metadata



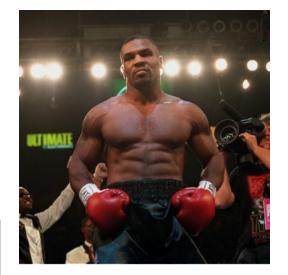


"No battle plan ever survived contact with the enemy."

- Field Marshall Helmuth Karl Bernhard Graf von Moltke https://en.m.wikiquote.org/wiki/Helmuth_von_Moltke_the_Elder

Time & Budget

...are usually that enemy.



Planning

"Everybody has a plan... until they get punched in the face."

- Mike Tyson

http://goodmenproject.com/business-ethics-2/everybody-has-a-plan-until-they-get-punched-in-the-face/

Scope Creep & Complexity

...can knock out the best laid plans.

TREC Measurement System Data Sources

- I: In-Person Interviews (CAPI)
 - Health Care Aides
 - Long-Term Care facility
 directors & other
 management for overall
 facility and care unit profiles
- trained interviewers in a carefully managed and scheduled set of on-site interviews

- II: Online Surveys
 - Nurses
 - Unit Managers
 - Allied Health Professionals
 - Practice Specialists
- controlled in-person distribution of unique links and information packages

III: Non-Survey Data: RAI-MDS 2.0 Patient Assessments



Speaking the same language for high quality care

Getting Started

Training

InterRAI Worldwide

Bibliography

Newsletter

OECD Report

Events

The 2016 WORLD interRAI CONFERENCE

April 11-14, 2016 Toronto, Ontario Canada www.worldinterrai.org



interRAI is an international collaborative to improve the quality of life of vulnerable persons through a seamless comprehensive assessment system.

Our consortium strives to promote evidence-informed clinical practice and policy decision making through the collection and interpretation of high-quality data about the characteristics and outcomes of persons served across a variety of health and social services settings. Read More >>

http://interrai.org



Long-Term Care Facilities (LTCF)

The interRAI Long-Term Care Facilities Assessment System (interRAI LTCF) enables comprehensive, standardized evaluation of the needs, strengths, and preferences of persons receiving short-term post-acute care in skilled nursing facilities as well as persons living in chronic care and nursing home institutional settings.

The interRAI LTCF (or previous versions) is currently used in Canada, Europe (Belgium, England, Finland, France, Germany, Iceland, Italy, Netherlands, Norway, Spain, Sweden, Switzerland), Asia (Hong Kong, Korea, and Japan), and Pacific Rim (Australia, New Zealand).

Admission, Annual, & Quarterly Patient Assessments

- RAI-MDS 2.0 records
 - Patient Assessments From ~90 Long
 Term Care homes
 - ~500 variables per assessment
 - 3 flavours (admission, annual, quarterly)
 - collected continuously from 2007-2020
 - administered by care providers
 - stored in several software systems
 - submitted to government quarterly
 - ~350K rows expected to be recieved in ? files at ?? times, in ??? formats from ???? distinct source systems
- by default, no care unit identifier in exports (open ended field)
- No existing metadata found...

Minimum Data Set (MDS) 2.0© Canadian Version

MDS 2.0 Form © interRAI Corporation 1997, 1999

Canadianized items Copyright © CIHI, 2002

FULL ASSESSMENT

SECTION AA and A: IDENTIFICATION INFORMATION

AA1	UNIQUE REGISTRATION IDENTIFIER				_
	RESIDENT NAME				
	ROOM NUMBER	a. Unit		b. Room #	
AA2	SEX	M. Male	F. Female	O. Other	Т
А3	ASSESSMENT REFERENCE DATE	Year	Month	Day	
ААЗа	BIRTH DATE	Year	Month	Day	
	EGLIWYLED				

Minimum Data Set (MDS) 2.0© Canadian Version

280 ▼ 281

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287 ▼

MDS 2.0 Form © interRAI Corporation 1997, 1999

Canadianized items Copyright © CIHI, 2002

FULL ASSESSMENT

SECTION AA and A: IDENTIFICATION INFORMATION

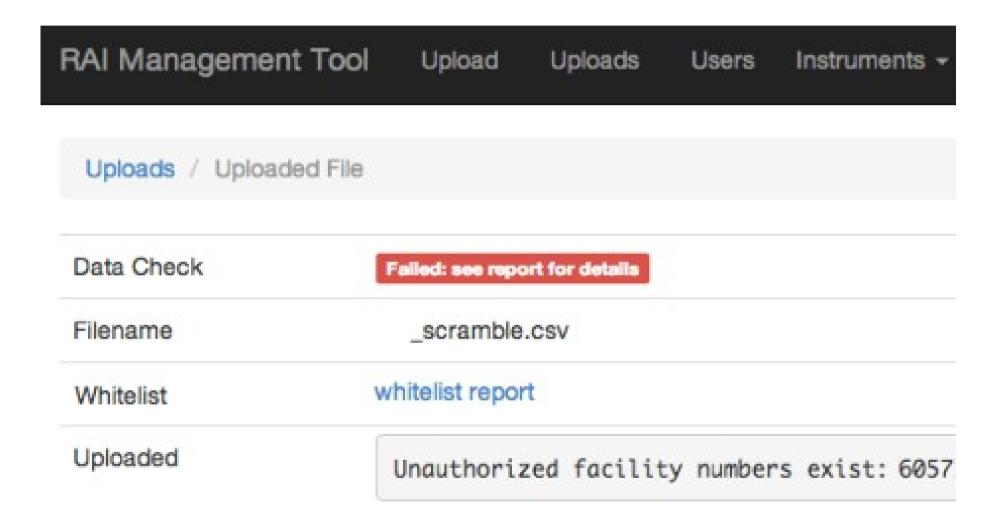
AA1	UNIQUE REGISTRATION IDENTIFIER	
	RESIDENT NAME	
	ROOM NUMBER	
		a. Unit b. Room #
AA2	SEX	M. Male F. Female O. Other
А3	ASSESSMENT REFERENCE DATE	Year Month Day
ААЗа	BIRTH DATE	Year Month Day
* * * *	EGTIWATED	

```
"name": "AA8",
    "width": 2,
    "text": "Primary reason for assessment",
    "label": "Reason for assessment",
    "start": 36,
    "valid": "01-Admission assessment",
    "values": {
        "1": "Admission assessment (before o
        "3": "Significant change in status a
        "2": "Full annual assessment",
        "4": "Significant correction of price
    },
    "type": "99"
},
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    "width": 1,
    "text": "Responsibility/Legal Guardian
    "label": "Legal guardian",
    "start": 50,
    "valid": "0, 1",
    "values": {
        "1": "Yes",
        "0": "No",
        "9": "Unknown"
    },
    "type": "9"
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    "name": "A9b",
    "width": 1,
    "text": "Responsibility/Legal Guardian
    "label": "Durable power of attorney/fina
    "start": 51,
    "valid": "0, 1",
    "values": {
        "1": "Yes",
        "0": "No",
```

Build Applications

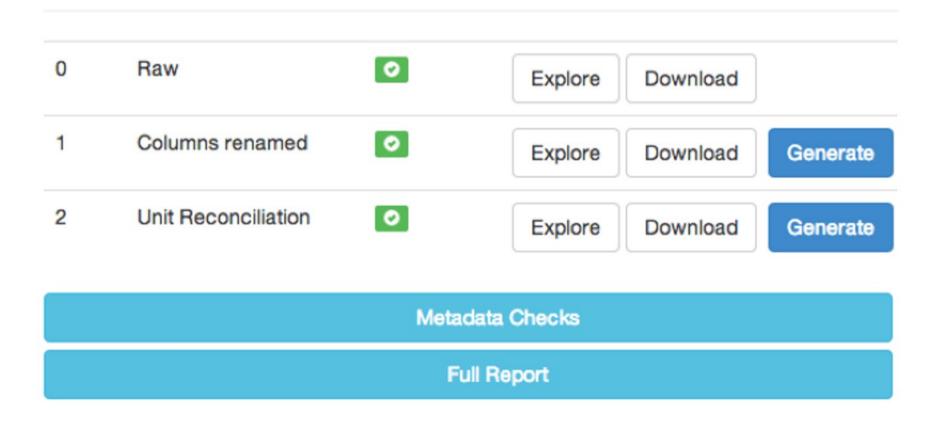
(Automate the Automatable, Control the Uncontrolled Processes)

Now We Can Identify & Reject Privacy Violations At The Point Of Ingestion...



Automate Stages of Data Scrubbing

Stages



...and add more stages as they are reduced to practice.

"Our needs are unique..."

...just like everyone else's.

Facility & Unit Reconciliation

RAI AA6 Facility Aliases

As raw RAI records are imported from many sources, you will encounter various CIHI codes and other identifiers in the incoming data that are meant to refer to this facility. Enter those known "aliases" for this facility below, one per line, so that they are permanently preserved in project metadata. The automated RAI ingestion process will use them to link new incoming

data to this facility.	Please enter a commit message to describe the change you have	
TESHT TESST TEST1	Made. Added new facility aliases found in source data today. Cancel OK	.:
Notes		
Test facility.		.:
	SAVE	
	SAVE	

Unit Definitions

The myth of the single codebook

Research Stakeholders at all stages of the GSBPM

Quality Management / Metadata Management							
Specify Needs	Design	Build	Collect	Process	Analyse	Disseminate	Evaluate
1.1 Identify needs	2.1 Design outputs	3.1 Build collection Instrument	4.1 Create frame & select sample	5.1 Integrate data	6.1 Prepare draft outputs	7.1 Update output systems	8.1 Gather evaluation inputs
1.2 Consult & confirm needs	2.2 Design variable descriptions	3.2 Build or enhance process components	4.2 Set up collection	5.2 Classify & code	6.2 Validate outputs	7.2 Produce dissemination products	8.2 Conduct evaluation
1.3 Establish output objectives	2.3 Design collection	3.3 Build or enhance dissemination components	4.3 Run collection	5.3 Review & validate	6.3 Interpret & explain outputs	7.3 Manage release of dissemination products	8.3 Agree an action plan
1.4 Identify concepts	2.4 Design frame & sample	3.4 Configure workflows	4.4 Finalise collection	5.4 Edit & impute	6.4 Apply disclosure control	7.4 Promote dissemination products	
1.5 Check data availability	2.5 Design processing & analysis	3.5 Test production system		5.5 Derive new variables & units	6.5 Finalise outputs	7.5 Manage user support	
1.6 Prepare business case	2.6 Design production systems & workflow	3.6 Test statistical business process		5.6 Calculate weights			
		3.7 Finalise production system		5.7 Calculate aggregates			
				5.8 Finalise data files			



https://en.wikipedia.org/wiki/Blind_men_and_an_elephant

Benefits Of Using Metadata for Researchers / Investigators

Reproducibility

- during & after the project

Budget

- reduce manual labour
- reduce rework

Productivity

- free resources for higher value uses

Discoverability

- online visibility = citations
- Quality Control
- Documentation

Manage Change In Dimensional Data Over Time

Tying Together Surveys & Patient Assessments in the HRDR

- **Who** carried out the research?
 - TREC interviewers
 - self completed
 - LTC staff doing patient assessments
- When did it happen?
 - survey data collected at multiple time points over 3 waves over 6 years.
 - RAI assessments done quarterly and on admission/re-admission

- Where (what location) does that data apply to?
 - Country
 - Province
 - Health Region
 - Facility
 - Unit
- All of these can change over time in surprising ways.

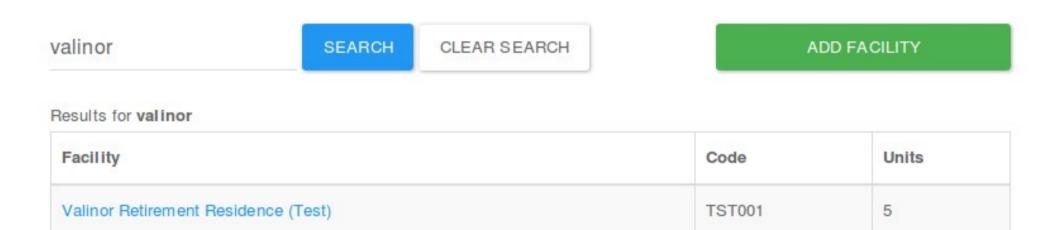
Custom Data Management Tools To Manage These Dimensions



logout nooro

Home / Facilities

Facilities



Commit Messages on All Changes... plus versioning (document history) and undo

RAI AA6 Facility Aliases

As raw RAI records are imported from many sources, you will encounter various CIHI codes and other identifiers in the incoming data that are meant to refer to this facility. Enter those known "aliases" for this facility below, one per line, so that they are permanently preserved in project metadata. The automated RAI ingestion process will use them to link new incoming

data to this facility.	Please enter a commit message to describe the change you have	
TESHT TESST TEST1	made. Added new facility aliases found in source data today. Cancel OK	
Notes		.;;i
Test facility.		.::
	SAVE	

Unit Definitions

Support

...the Field Team
During Data Collection

Subject TREC Regional Receipt Summary - XX

To shane@nooro.com

Nightly email receipts to Interviewers, reports to Regional Coordinators, summary reports to

the Data

Managers

Translating Research in Elder Care

TREC Regional Receipt Summary

Instrument: HCA CAPI Survey (Live)

Region: XX

Regional Coordinator: Shane McChesney

Activity From: 2015-03-14 12:00 AM

Activity To: 2015-03-15 12:00 AM

Uploads For Facility ABN_008

Completed Interviews

Interviewer	Interview ID	Mode	Most Recent Upload
Nooro	b08435b0	TEST	2015-03-14 09:20 AM

Managed, Versioned Recovery From User Error / Real-Life Variances



logout nooro

Home / Update Response Location

Step 1 Search for Interview by UUID

Enter a response UUID or a portion of a response UUID to find survey responses that match.

ffee26b8-538c-3389-85fa-fced4e4169cf





Home / Update Response Location

Step 2 Choose a Response

From the search results below, select the survey response you wish to update and click its "Continue" button.

Response ffee26b8-538c-3389-85fa-fced4e4169cf

CONTINUE

Interviewer Name Christine

Facility UUID 2292dbed-8372-4285-83cf-bb3746fe2bdb

Facility Name

Unit UUID c2bc6401-72f8-42a6-be40-4662430d2ff9

Unit Name Second Floor

Interviewer Comments Respondent was a little unclear about some of the questions even after I clarified using the

prompts. No appropriate unit category available on screen so I selected

She worked on 4th floor).

System Comments

Created 2014-09-22 14:54:34.071000-04:00

Max Page Reached 34

Interview Location Manitoba

Interview Context

Interview location and context are from the mobile interviewer settings view.



Home / Update Response Location

Step 3 Select New Location and Update Response

Selected Response: ffee26b8-538c-3389-85fa-fced4e4169cf

Location

Select the target location and sublocation from the combined list below. This is the information that the response will be updated to. Enter all or part of the location details to filter the list.

Filter...



Notes

This system will automatically add a note logging the details of this change, including the old and new location details. Add a note describing your rationale for this change. For example:

Commit messages! ->

Updated interview location as per 2015-04-03 email from RobJ.

Updated interview location based on interviewer comment and request from RC.

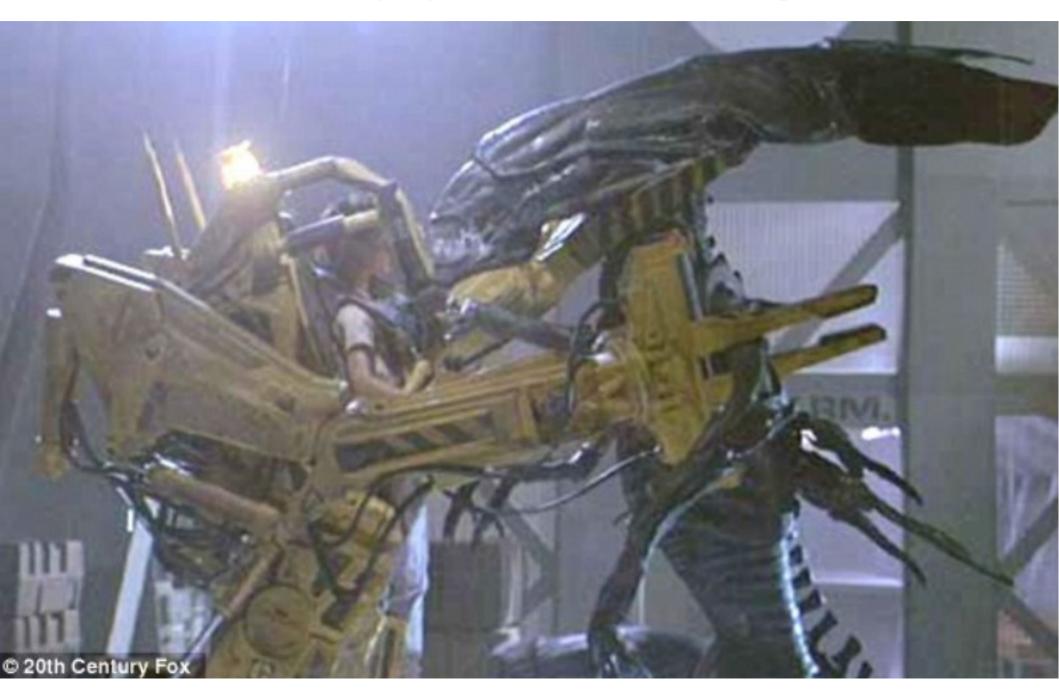
Once you have selected the desired location and entered your notes above, please click 'Apply' to save your changes, or click 'Cancel' to return to the beginning without making any changes.

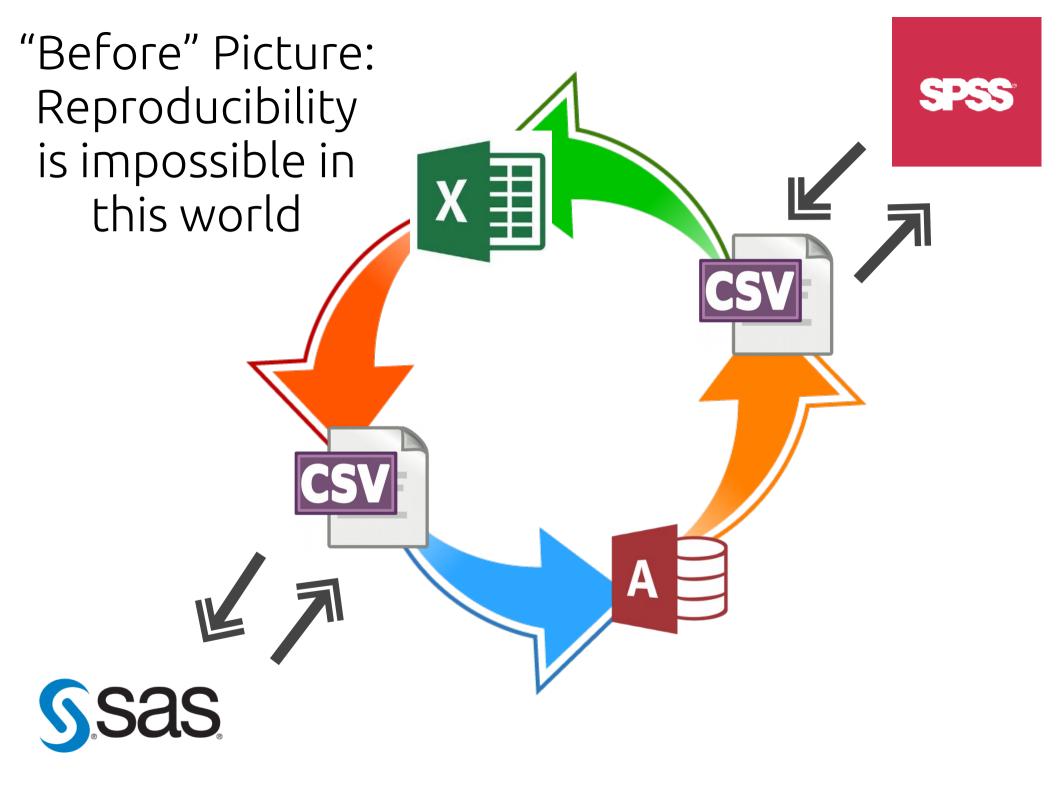
APPLY

Support

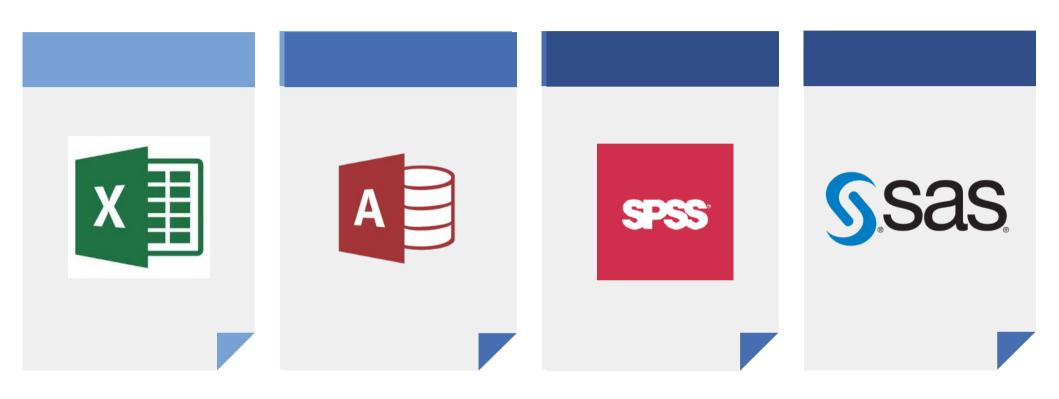
...the Data Management Team

Better Equip the Data Wranglers





Older "Windowed" Workflow / Tools



Open a rectangle

Prepare data

Manually write repetitive code

Repeat

Newer "Scriptable" Workflow / Tools



























Technical Debt

"Every line of code you write is a liability."

- Trevor Morgan

Technical Debt

"Yeah, but we'll make it up in volume!"

- Me? You?

Programmers Helping Analysts: A Quick Scripting Case Study

By doing a few simple steps in Python and collaborating with analysts on the following R code, they were able to take it and replace 1000's of lines of manually coded SAS script with a metadata-driven loop over the questions to validate all fields for missing values.

```
# Preregs: R, rjson
install.packages("rjson")
# Load the rjson library.
library(rjson)
# Read a copy of our survey definition
survey <- fromJSON(file='20150205_hca_survey.json')</pre>
# Pull a flat purpose-built JSON list produced from metadata
questions <- fromJSON(file='20150205_hca_questions_export.json')</pre>
# Open the latest data file
hcadata <- read.csv("20150205_0301_hca_all.csv", header=T)
dim(hcadata)
hcadata_frame <- data.frame(hcadata)</pre>
```

Automate It

If you build on a foundation of Open Source scripting tools like Python and R, you can create workflows that can be run automatically: nightly, for instance, or whenever a new file comes in, freeing up your knowledge workers for actual, you know, knowledge work.

Interoperability

https://ddialliance.org







- With proper metadata, processes built by one organization in one programming language can flow seamlessly into solutions built by another group in completely different language:
 - Metadata Technology is also assisting TREC with post-cleaning reporting tools.
 - Their tools in turn enable export to the broader ecosystem of DDI and traditional statistical software

- Metadata means old instruments can be brought back to life:
 - Nooro has been able to turn DDIformatted metadata into functioning online surveys in under a day (including a 1995 US Election telephone survey)
 - NADDI 2015/6 & IASSIST 2015 conference evaluations handled in DDI by Colectica and fielded by Nooro

Thank you & safe travels!

Shane McChesney shane@nooro.com



NADDI 2016 Edmonton April 7th 2016