

AUGUST 26, 2024

DATA COLLECTION PRACTICES

Allyson Calderon



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Research Outcomes in
Children's Surgery (ROCS)

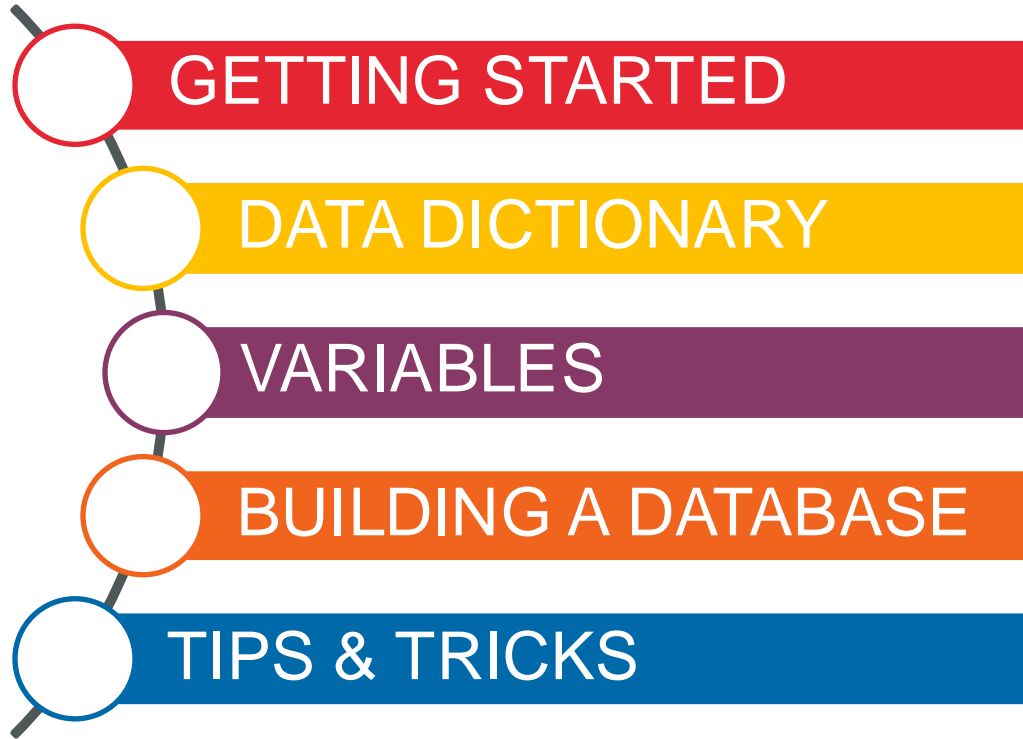
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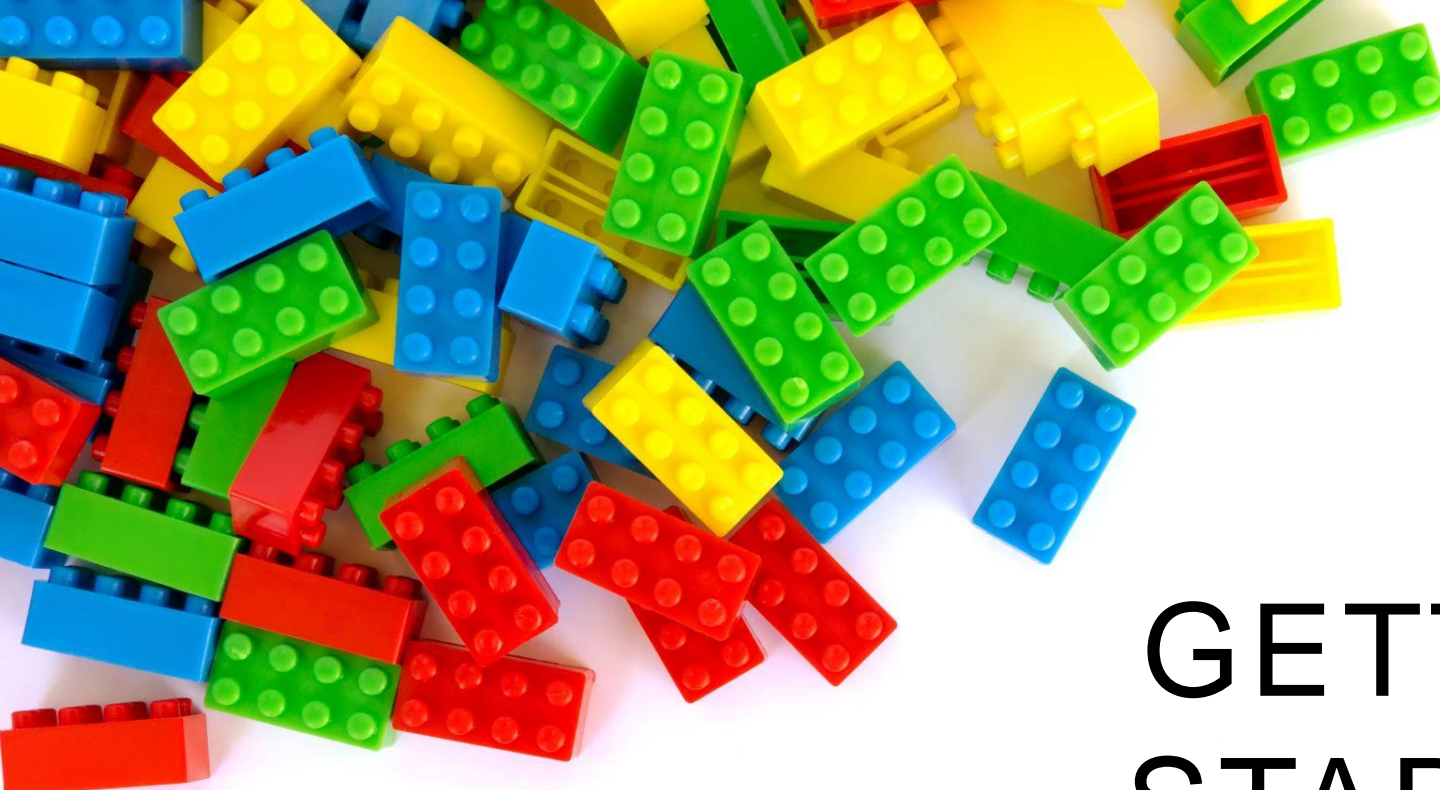


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OVERVIEW





GETTING STARTED



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REDCAP

Free with university account and CCTSI membership

- <https://redcap.ucdenver.edu/>

If you are a CHCO only employee and need InfoEd access:

- <https://research.cuanschutz.edu/comirb/home/request-poi>

For REDCap access:

- <https://redcap.ucdenver.edu/surveys/?s=5ZLmzX>

Getting Started:

1. Complete the full online REDCap tutorial
2. Online tutorial takes approx. 2 hours
3. View REDCap Resources for additional project design/setup help

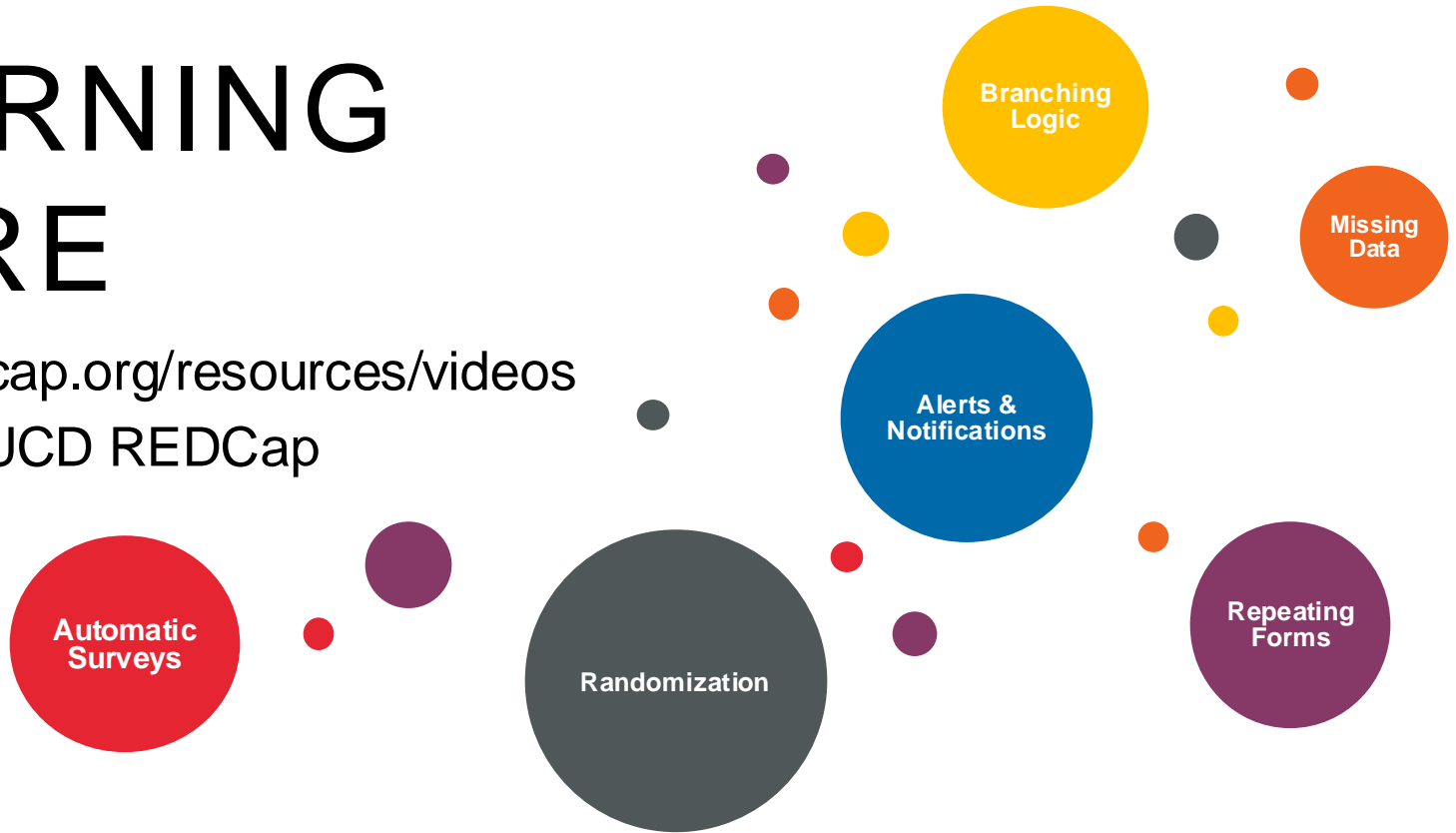
<https://cctsi.cuanschutz.edu/resources/informatics/redcap-resources>



LEARNING MORE

Projectredcap.org/resources/videos

YouTube: UCD REDCap



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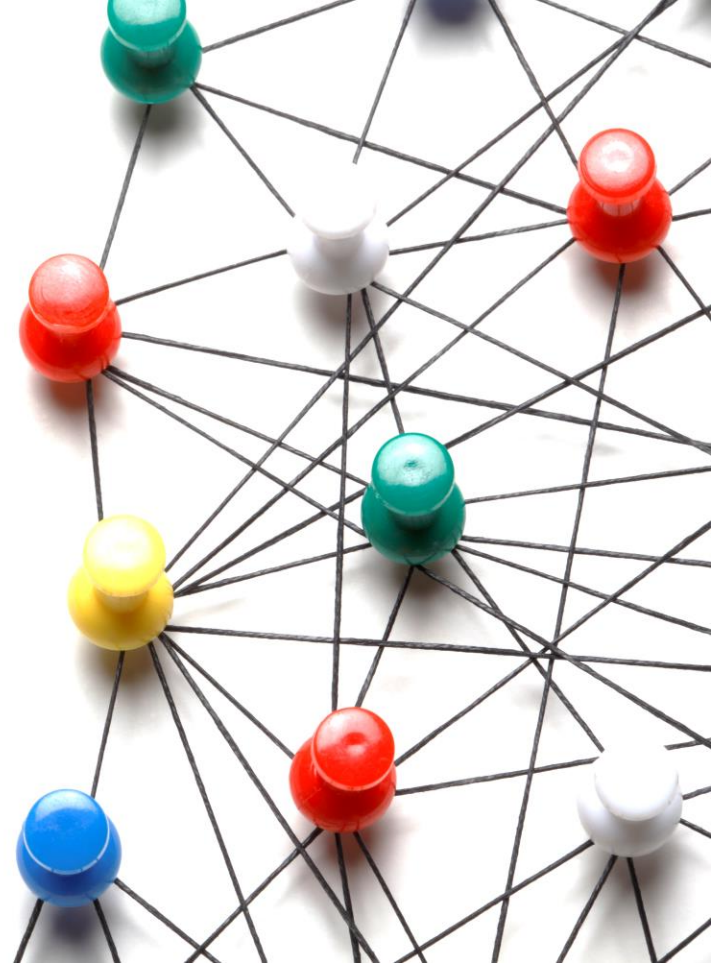
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DATA DICTIONARY



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WHAT IS A DATA DICTIONARY?

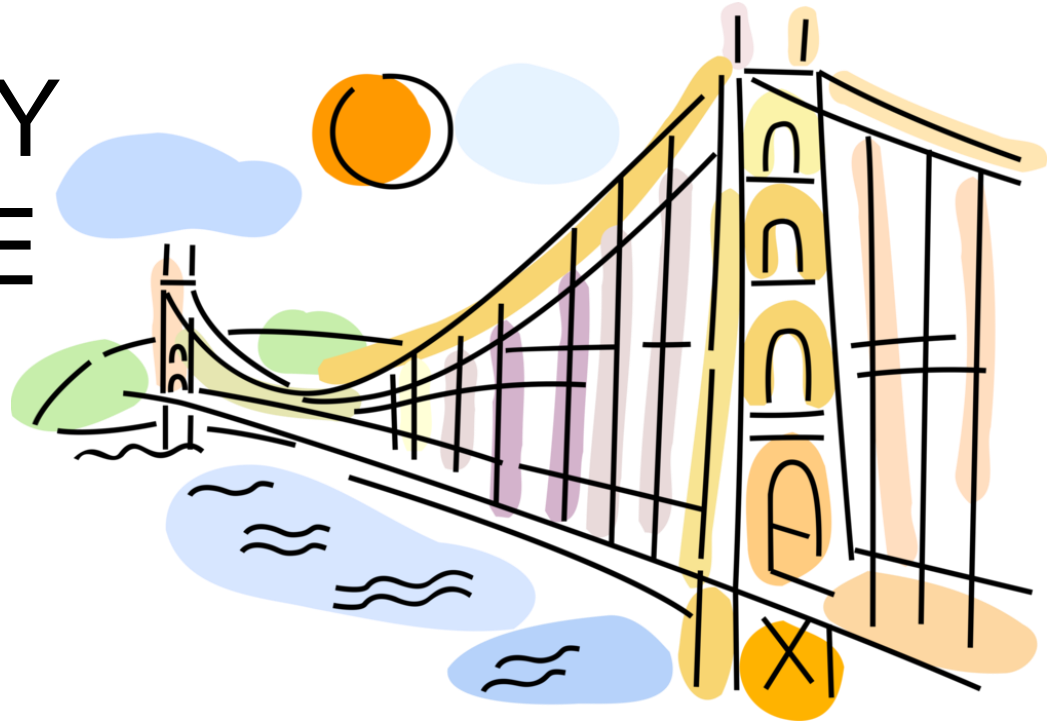
- A document, commonly .csv file, that contains your variables, labels/descriptions, choices, calculations, etc. for your database
- Download your data dictionary as excel file from the “Dictionary” tab
- View your data dictionary in the “Codebook” tab



#	Variable / Field Name	Field Label <i>Field Note</i>	Field Attributes (Field Type, Validation, Choices, Calculations, etc.)						
Instrument: Demographics (demographics) ^ Collapse									
 1	[record_id]	Record ID	text						
 	[mrn]	Medical Record Number	text (number), Identifier Custom alignment: LH						
 	[dob]	Date of Birth	text (date_dmy), Identifier						
 	[visitdate]	Date of Visit	text (date_dmy), Identifier Custom alignment: RH						
 	[age]	Age at Visit	calc Calculation: rounddown(datediff([dob], [visitdate] , 'y')) Custom alignment: RH						
 	[gender]	Gender	radio <table border="1" data-bbox="1184 773 1338 936"> <tr> <td>1</td> <td>Male</td> </tr> <tr> <td>2</td> <td>Female</td> </tr> <tr> <td>3</td> <td>Other</td> </tr> </table>	1	Male	2	Female	3	Other
1	Male								
2	Female								
3	Other								



THE DATA DICTIONARY IS A BRIDGE



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FIELDS & VARIABLES



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FIELD NAMES

     Variable: sad

SAD diagnosis? Yes No

reset

What is SAD an abbreviation for?
Seasonal Affective Disorder or
Social Anxiety Disorder?

     Variable: sad_dx

**Does the patient have a
Social Anxiety Disorder
diagnosis?** Yes No

reset

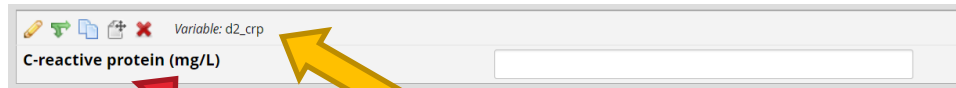
The field label is more
descriptive!



NAMING VARIABLES

- Keep it short, but descriptive
- No spaces, but can use _
- Put units and/or a longer description in the field **label** not the variable name

You want to make a field for C-reactive protein lab results. There is already a “crp” field in your Data Dictionary from Research Day 1.



The screenshot shows a data dictionary entry for a variable named 'd2_crp'. The variable name is displayed in a small font at the top left of the entry box. Below it, the field label 'C-reactive protein (mg/L)' is entered in a larger font. To the right of the label is an empty input field. A red arrow points from the text 'Units are included in field label' to the '(mg/L)' part of the label. A yellow arrow points from the text 'Variable is short, but describes the data to be entered' to the 'd2_crp' variable name.

Units are included in field label

Variable is short, but describes the data to be entered



DEMOGRAPHIC VARIABLES

AGE (What is your age?)

GENDER (Which gender do you identify with?)

Male

Female

Other _____

Prefer not to say

RACE (Which race do you identify with?)

American Indian or Alaska Native

Asian

Black or African American

Native Hawaiian or Other Pacific Islander

Latino or Hispanic

White

Two or more



DEMOGRAPHIC VARIABLES

INSURANCE TYPE

Private Insurance

State (Medicaid, Medicare)

No Insurance/Cash/Uninsured

VA/Military

Depending on population, you may need to include others



VALUABLE VARIABLES

- What information do you need to address your aims?
- Does it add important information about your study population? (gender, age, race)
- Does it fall under the scope of information you are going to analyze?
- No data fishing!



INDICATE IDENTIFIERS

Edit Field

Use the Rich Text Editor ?

Field Label
Date of Birth

Action Tags / Field Annotation (optional)

Learn about [@ Action Tags](#) or [using Field Annotation](#)

Variable Name (utilized in logic, calcs, and exports)
dob Enable auto naming of variable based upon its Field Label?
ONLY letters, numbers, and underscores

How to use [Smart Variables](#) [Piping](#) [Field Embedding](#)

Validation? (optional) Date (D-M-Y)

Minimum:

Maximum:

Tip for min/max limits: You may use the word `today` or `now` (not wrapped in quotes) for date/time fields to set dynamic range limits. Also, you may pipe a value from another field - e.g., `[visit_date]` or `[event_1_arm_1][age]`.

- or -

-- select ontology service --

Required?* No Yes
* Prompt if field is blank

Identifier? No Yes
Does the field contain identifying information (e.g., name, SSN, address)?

Custom Alignment Right / Vertical (RV)

Align the position of the field on the page



BUILDING A DATABASE



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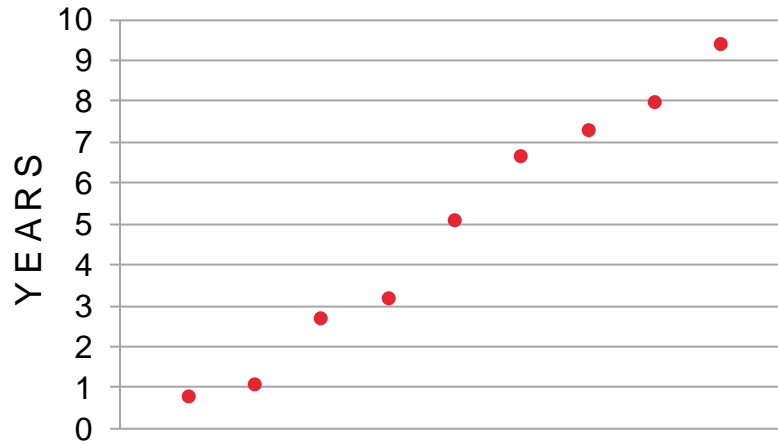


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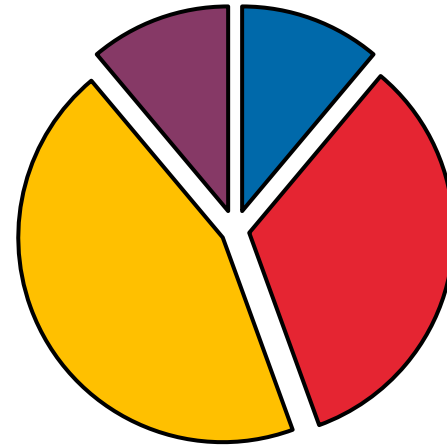
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DATA CAPTURE

CONTINUOUS



CATEGORICAL



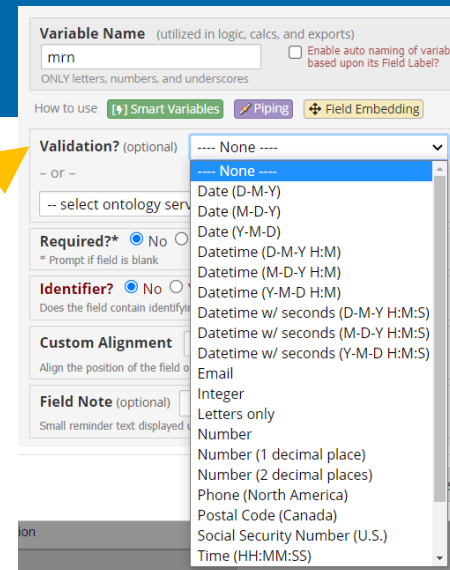
■ Under 1 ■ 1 to 5 ■ 5 to 9 ■ Over 9



CONSISTENCY

- Dates
 - D/M/Y
 - M/D/Y
- Units
- Coding Data
 - Multiple Choice vs Checkboxes

Use validation!



	record_id	mrn	dob	visitdate	age	gender	race	race_2	race_2	race_2	race_2	race_2	race_2	d2_crp	demographics_complete
1															
2	1	111111	8/8/2010	8/8/2022	12	1	1	1	0	0	0	0	0	3	2
3	2	111112	8/8/2008	8/8/2022	13	2	2	0	1	0	0	0	0	2.7	2
4															
5															



BE EFFICIENT!



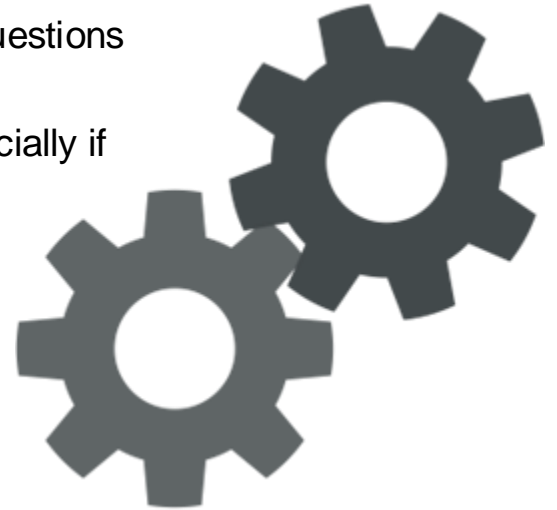
Branching Logic

- Use to “expand” answers and ask conditional follow-up questions
- Pros: Helps keep data & surveys clean
- Cons: Unintended errors in logic can happen easily, especially if there are a lot of branches



Repeating Instruments

- Use for repeat data that do not have defined time points
- Longitudinal studies



Repeating Instrument

Example

Not Repeating

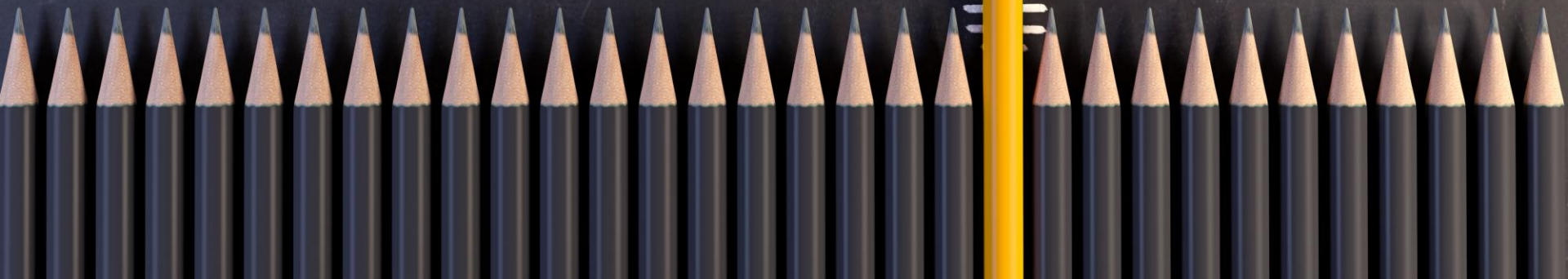
Record ID	Record ID	Enrollment Data	Demographics	Clinical Information	Week 2 Survey	Week 2 Photo	Week 4 Survey	Week 4 Photo	Week 6 Survey	Week 6 Photo	Week 8 Survey	Week 8 Photo
1	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
2	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Repeating

Record ID	Demographics	Pre-op Patient Info	Clinical Details	Post-Op Day	Hospital Discharge	Follow-up	Complications
1 (Subject ID 01-001)	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/> +	<input checked="" type="radio"/>	<input checked="" type="radio"/> +	<input checked="" type="radio"/>
2 (Subject ID 01-002)	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/> +	<input checked="" type="radio"/>	<input checked="" type="radio"/> +	<input checked="" type="radio"/>



TIPS & TRICKS



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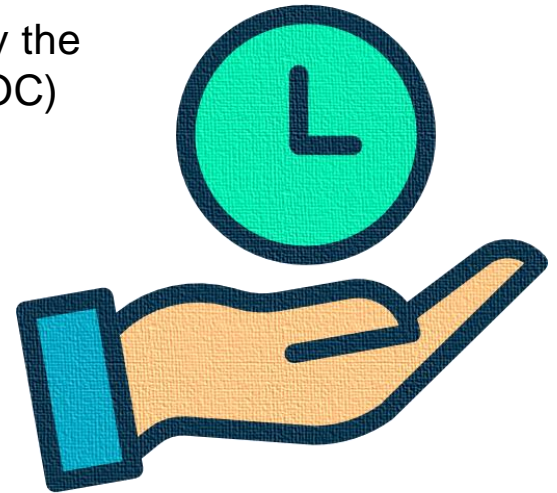
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TIME SAVERS



Shared Library

- Thousands of curated instruments approved by the REDCap Library Oversight Committee (REDLOC)
- Examples:
 - ICD10 Major Depression Inventory
 - PROMIS Emotional Distress – Anger - Short Form 8a
 - Pelvic Floor Distress Inventory Short Form 20 Scored
 - Toronto Empathy Questionnaire
- <https://projectredcap.org/resources/library/>



AVOIDING MESSY DATA

- Minimize free text fields
 - Sensitive to spaces, punctuation, spelling variations, typos, etc.
 - Use drop-downs, radio buttons, & check boxes when possible

[allergy]	Allergy	text						
[allergy_2]	Allergy	radio <table border="1"><tr><td>1</td><td>Sulfonamide</td></tr><tr><td>2</td><td>Penicillin</td></tr><tr><td>3</td><td>Tetracycline</td></tr></table>	1	Sulfonamide	2	Penicillin	3	Tetracycline
1	Sulfonamide							
2	Penicillin							
3	Tetracycline							

	A	B
1	allergy	allergy_2
2	sulfa drugs	1
3	tetracycline	3
4	sulfonamide	1
5	penicillin	2
6	tetra cycline	3
7	penecilin	2
8	sulpha	1



AVOIDING MESSY DATA

Use a “screening” question before checkbox fields – add branching logic!

Does your child have a bedtime routine?

- Yes
 No

reset

Which of the following are a part of your child's bedtime routine?
(check all that apply)

- Brushing teeth
 Reading a book
 Listening to music
 Taking melatonin
 Taking a bath/shower
 Sound machine/white noise
 Snack or drink



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DATA COLLECTION: SURVEYS



Question Phrasing

- Survey vs. Data Entry
- Cultural sensitivity



Reading Level

- Aim for <6th grade
- Flyers, educational materials



Clear & Concise!

- Avoid double negatives & double-barreled questions
- Add a “N/A” option or screening question

Ask someone unfamiliar with your study to look at your materials!



DO:

- ✓ Be consistent, clear, and concise
- ✓ Be descriptive in field labels
- ✓ Consider reading level
- ✓ Consult your biostatistician!

DON'T:

- ✓ “Fish” for data
- ✓ Use free text fields if possible
- ✓ Use double-barreled questions
- ✓ Be afraid to get an outside perspective!



THANK YOU

QUESTIONS?



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