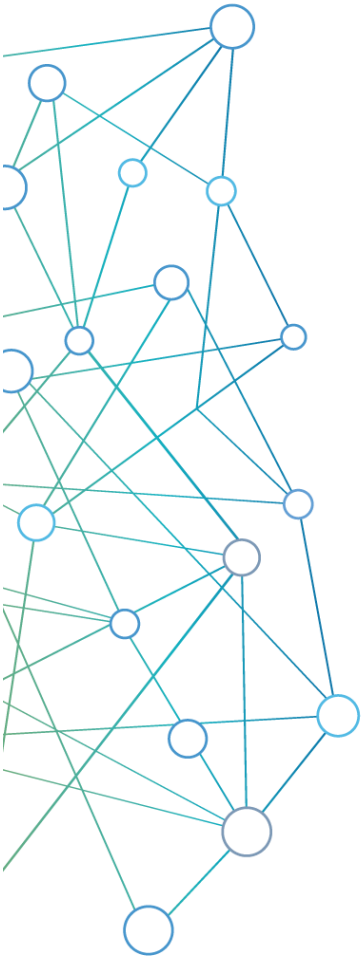
THOUGHTFUL DATA COLLECTION: GETTING THE BEST DATA FOR YOUR STUDY, BY DESIGN

ITHS | Institute of Translational Health Sciences

Accelerating Research. Improving Health.

Who We Are

ITHS IN A NUTSHELL



One of 62 NIH-funded CTSA sites to support translational research

160 faculty and staff across all health science disciplines

$17 million annual funding

Reach extends to 5 states: Washington, Wyoming, Alaska, Montana, Idaho

UNIVERSITY of WASHINGTON

UW

Seattle Children's

Seattle Children's
HOSPITAL · RESEARCH · FOUNDATION

Fred Hutch

FRED HUTCH
CURES START HERE

What We Do:
Enable translation



Lab → **Clinic** → **Community**

Accelerate science to the clinic for the benefit of patients and communities

Turning observations into interventions

Learning objectives

Describe how to match the appropriate data collection method to your study populations

What type of data collection should you pick for your study?

Apply best practices to maximize data quality and quantity to real life scenarios

Learn about best practices about data collection and how they relate to data analysis

Use various REDCap features to improve data collection

Get acquainted with some of the more specialized features in REDCap

Practice evaluating your data needs

Put all this new knowledge to work

Een goed begin
is het halve werk!

- Dutch Proverb -

A good start is half the job!

- Rough translation -

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Your data collection does not live in a vacuum

Your data is the lynch pin in your study

- Principal investigators
- IRB's
- Funding sources
- Participants
- Your employees or coworkers
- University / Departments

So where to start?

Let me tell you how I work…

What's your ultimate goal?

Answer a specific set of research questions

The classic research model

Creating a repository for future studies

Collecting simple contact information and/or consent might be beneficially to future studies

To get funding for my next research project

Larger grants sometimes want to see pilot data

"Fishing expedition"

Collecting as much data as possible in the hope that something will be relevant and/or significant

Determine some basic aspects of your study

Target population

Available resources

Target sample size

Variables

Sites

Ballpark estimates are the goal during this phase

Target population

- General age
- Willingness to participate
- (Computer) literacy
- Tolerance of contact
  - Number of encounters
  - Timing of encounters
- Location
  - Where do your subjects live?

Available resources

- People
- Time
- Money
- Tools
- Internet availability

Resources

People

Time

Money

Tools

Internet Availability

People

- Available FTE
- Expertise
  - Study design
  - People skills
  - Computer savviness
- Compensation

- Participants can be resources!

Resources

People

Time

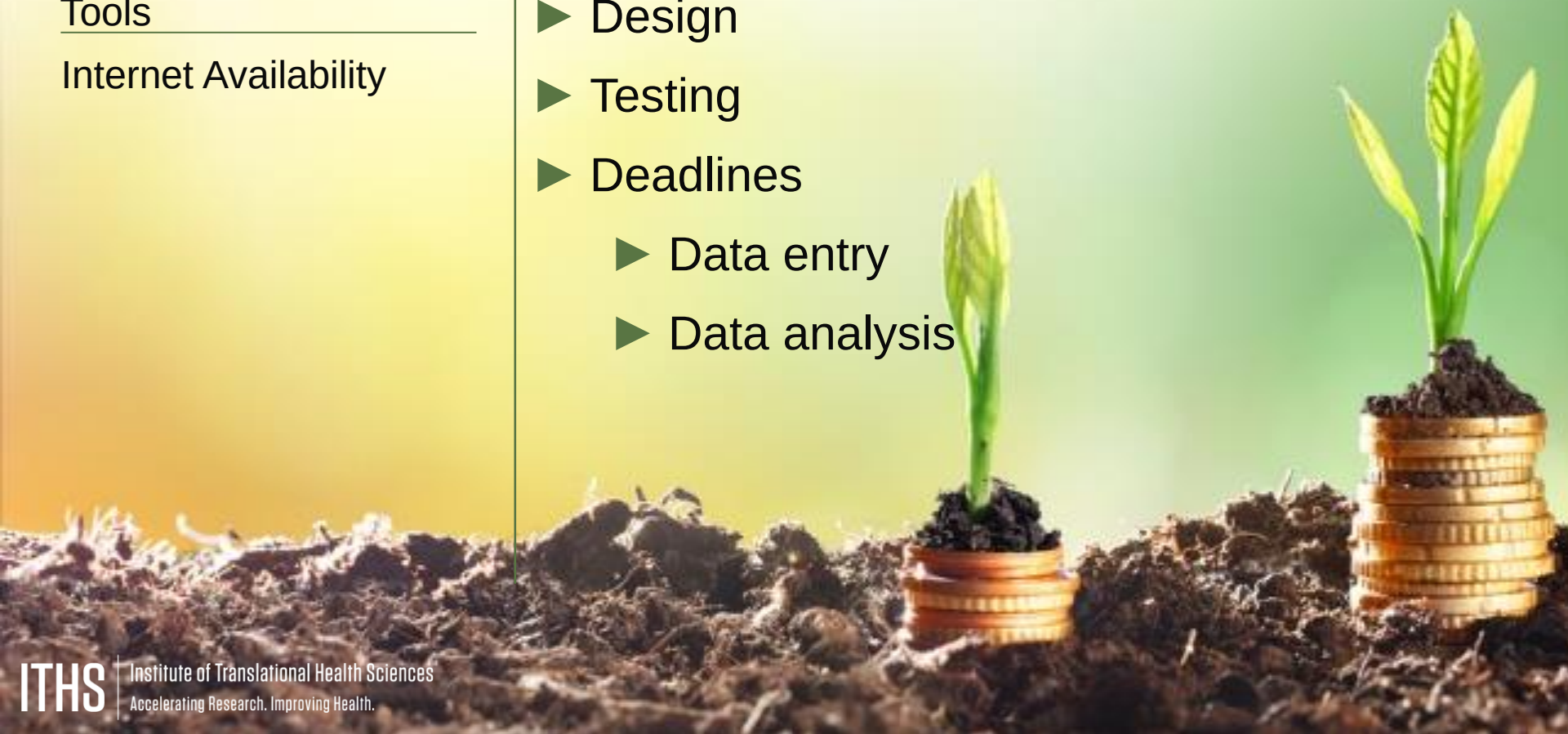
Money

Tools

Internet Availability

Time

- Timeline of your study
  - When are you collecting data?
- Design
- Testing
- Deadlines
  - Data entry
  - Data analysis



Resources

People

Time

Money

Tools

Internet Availability

Money

- Operating costs
  - Hardware
  - Licensing
  - Office supplies
  - Paper
  - University “Cut”
  - Salaries
  - Consulting fees
- Participant compensation

Resources

People

Time

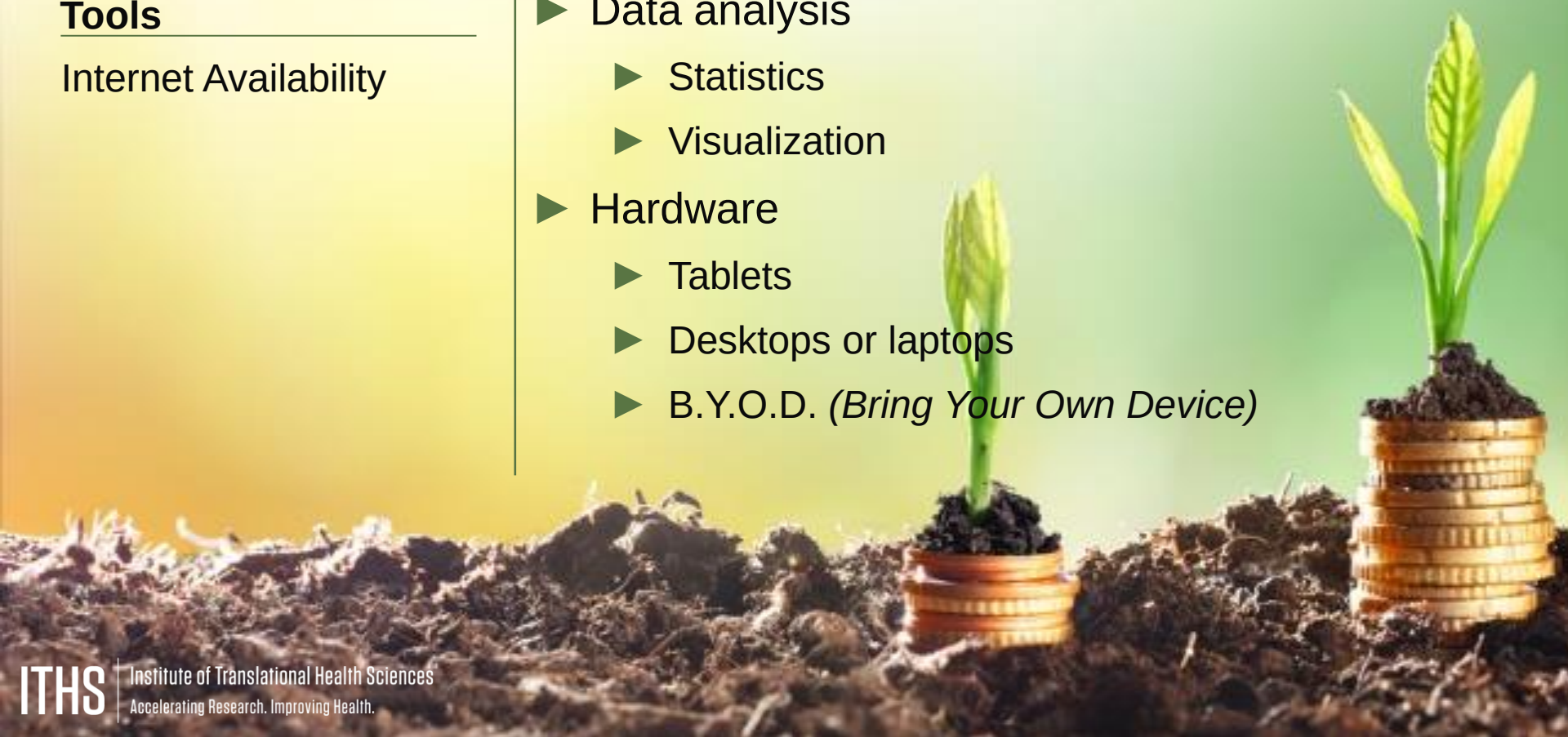
Money

Tools

Internet Availability

Tools

- Data capture tools
  - REDCap, Catalyst, Excel or Access
  - Paper
  - Industry SaaS options
- Data analysis
  - Statistics
  - Visualization
- Hardware
  - Tablets
  - Desktops or laptops
  - B.Y.O.D. *(Bring Your Own Device)*



Resources

People

Time

Money

Tools

Internet Availability

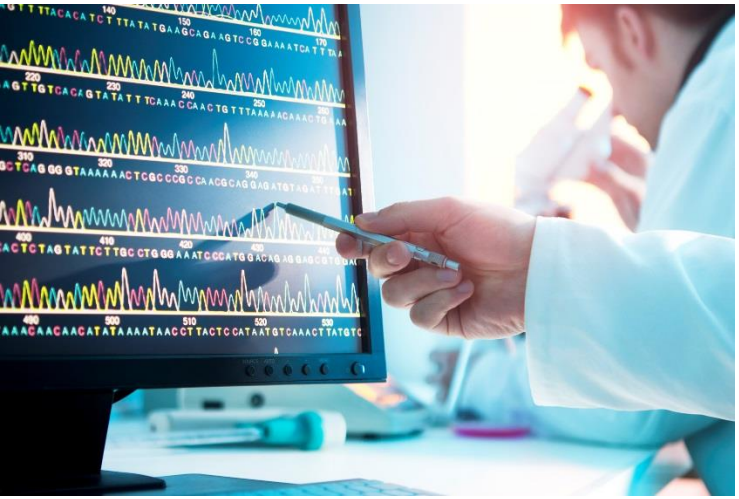
Internet availability

- Online
  - Reliability
  - Speed
  - Email capability
- Offline
- Hybrid
  - Access depends on:
    - Location
    - Time
    - Costs

Target sample size

- Quantity
- Quality
- Ease of recruitment
- Enrollment ratios
- “Finishers” ratios
- Statistical power

Variables



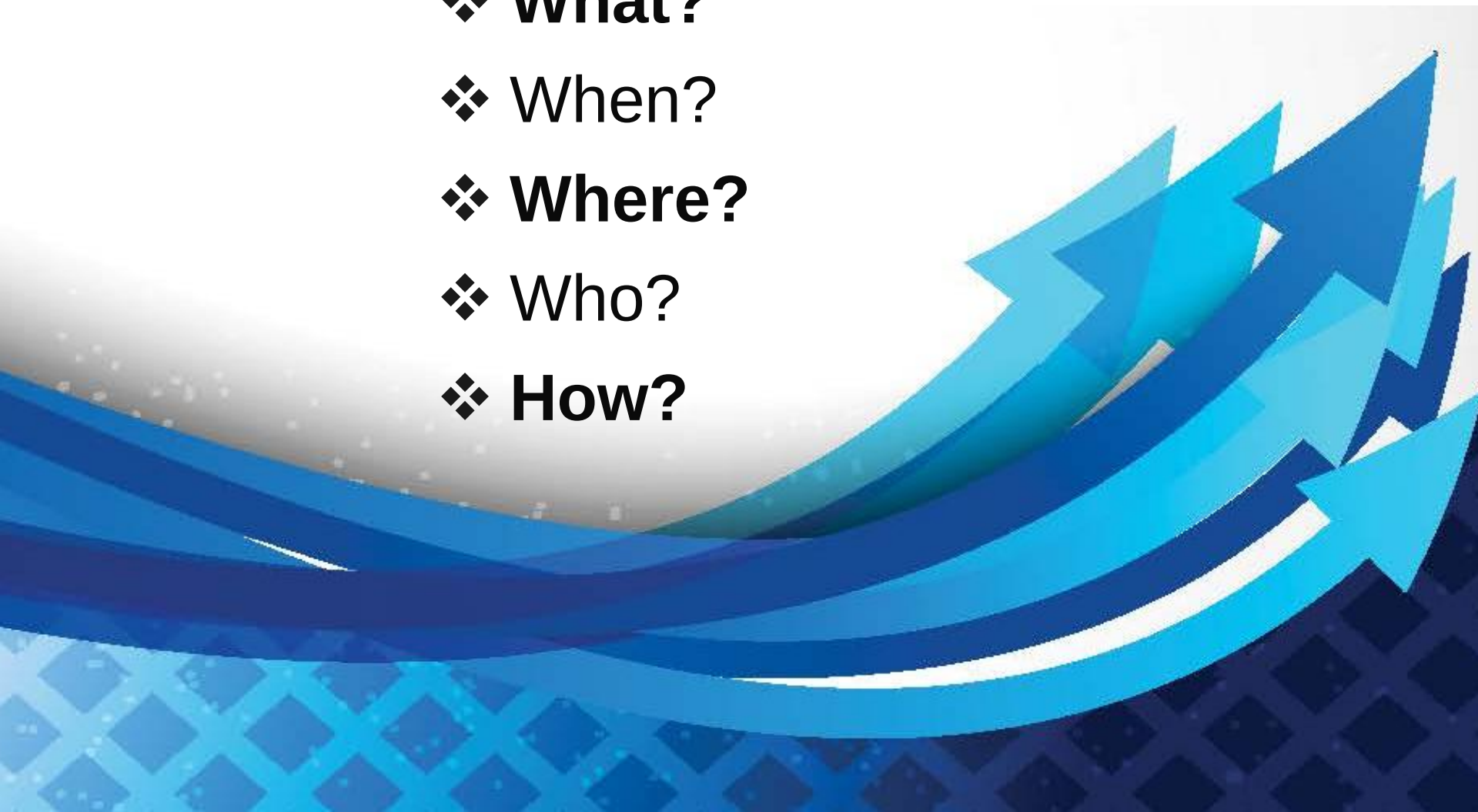
- Essential vs Optional
  - Hypothesis crucial
  - Legally mandatory
- Anonymous vs identified
- Nature of variables
  - Low risk
  - Personal Health Information (PHI)
  - “Super” PHI

Sites

- Single site
- Multiple sites
  - Stakeholders
    - Local politics
    - Multiple IRB's
  - Location
    - Local, National, International
  - Language
  - Data model
    - Federated
    - Spider in a web

Choosing your workflow

- **What?**
- When?
- **Where?**
- Who?
- **How?**



Choosing your workflow

What?

When?

Where?

Who?

How?

What are you collecting?

- Variables
  - Number
  - Type
  - Nature
- Time commitment *(average)*
- What are your targets?
  - People
  - Events
  - Things (diagnoses, medications, devices)

Choosing your workflow

What?

When?

Where?

Who?

How?

When are you collecting it?

- Collection points
  - Total number
  - Intervals
  - Triggers
    - Time
      (Daily, weekly, monthly)
    - Event based
      (When participant visits ED)

Choosing your workflow

What?

When?

Where?

Who?

How?

Where are you collecting it?

- Online
  - Desktop
  - Mobile
    - Text message
    - Browser
    - Phone call
- Offline
  - In-person
  - Paper
  - REDCap Mobile App
- Extraction from a medical system

Choosing your workflow

What?

When?

Where?

Who?

How?

Who is doing the collecting?

- Participants
- Study personnel
- "Hearsay" people
  - Clinicians
  - Parents
  - Social workers
  - Teachers

Choosing your workflow

What?

When?

Where?

Who?

How?

How are you doing your collection?

- Electronic Data Capture *(REDCap)*
  - Data entry
  - Survey
  - Data import
- Paper forms
- Machine generated
  - Images *(MRI, CAT, Ultrasounds)*
  - “Fitness trackers”
  - Data dump from a database *(EMR)*
- All of the above

Example Cases

- Long Acting Reversible Contraception (LARC)
- Soccer Traumatic Brain Injury (TBI)
- Headache Clinic
- Autism Center

Long Acting Reversible Contraception (LARC)

What?	• EMR Medical data (~500 variables) • Targets: Women with IUD's
When?	• *Retrospective over the last 3 years*
Where?	• *Extraction from the EMR data warehouse, the EMR itself*
Who?	• *Data analyst & research coordinators*
How?	• *EMR data dump & manual abstraction*

Soccer Traumatic Brain Injury (TBI)

What?	• *Mental state, trauma data, scoring tools (150 variables)* • *Targets: 7 to 14 year olds that play soccer*
When?	• *Single time point. At various soccer tournaments*
Where?	• *On location, Online via mobile devices*
Who?	• *Research coordinators, parents, children*
How?	• *Questionnaires on tablets or phones*

Headache Clinic

What?	• *Headache symptoms, scoring tools (100~200 variables)* • *Targets: Adult patients with chronic headaches*
When?	• *Multiple time points. Generally before a clinic visit*
Where?	• *Online*
Who?	• *Study participants*
How?	• *Questionnaires via email invitation, choice of desktop or mobile*

Autism Center

What?	• *Social history, scoring tools (200~300 variables)* • *Targets: Parents, patients*
When?	• *Multiple time points. During clinic visits, online follow up surveys*
Where?	• *In clinic, online*
Who?	• *Study coordinators, parents*
How?	• *Questionnaires via email invitation, choice of desktop or mobile, manual data entry online*

Questions?


Workshop

Workshop Case (Marathon)

Goal	*Track the wellbeing of the Marathon runners*
Target Population	*Marathon runners doing the 2017 Seattle marathon*
Available Resources	*UW Medicine MD, First aid workers, mobile laboratories, tablets*
Target Sample Size	*~7.000 runners*
Variables	*Injury details, medical history, demographics*
Sites	*14 first aid tents spread out over the course*

Workshop Case (Marathon) example solution

What?	• *Medical history, injury history, local lab results, demographics* • *Targets: Marathon runners*
When?	• *Pre-race, during the race, post race*
Where?	• *14 First aid tents, online*
Who?	• *Marathon runners, first aid workers*
How?	• *Questionnaires via email invitation, choice of desktop or mobile, REDCap mobile app during the race on tablets*

Thank You

Questions?

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