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# Qualitative Methods and Patient Reported Outcome Measures

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# Disclosures

- None

# Overview

- What is it?
- When is it useful?  Why do it?
- Where can I learn more about it?
- How do you do it? Not today

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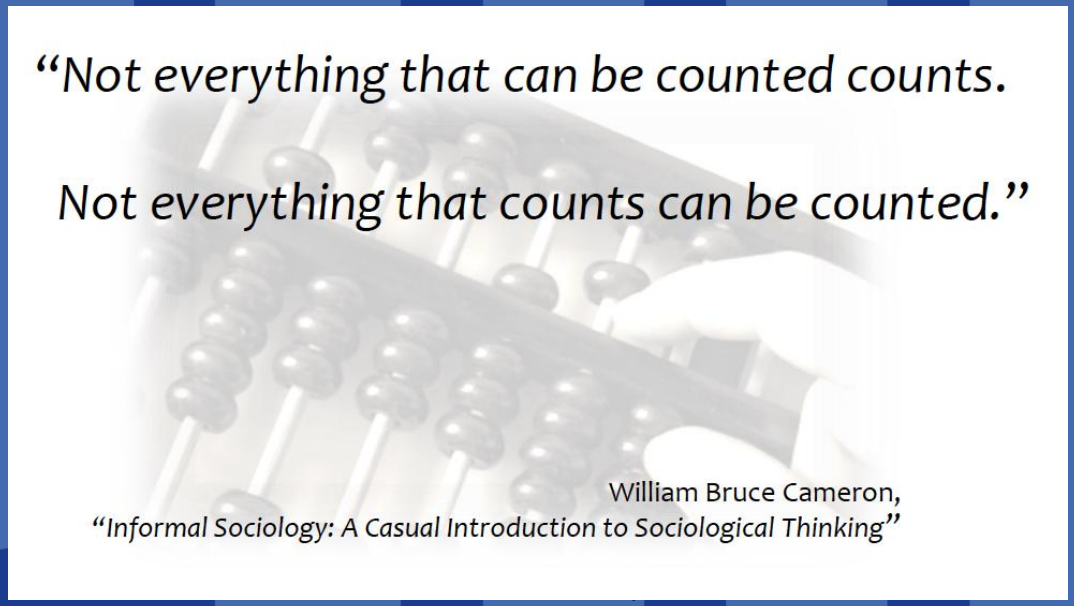
# Qualitative Research



# Qualitative Research...What is it?

- Exploratory

# Qualitative Research...What is it?

- Used to gain an understanding of underlying reasons, opinions, and motivations

# Qualitative Research...What is it?

- Provides insights into the problem or helps to develop ideas or hypotheses for potential quantitative research

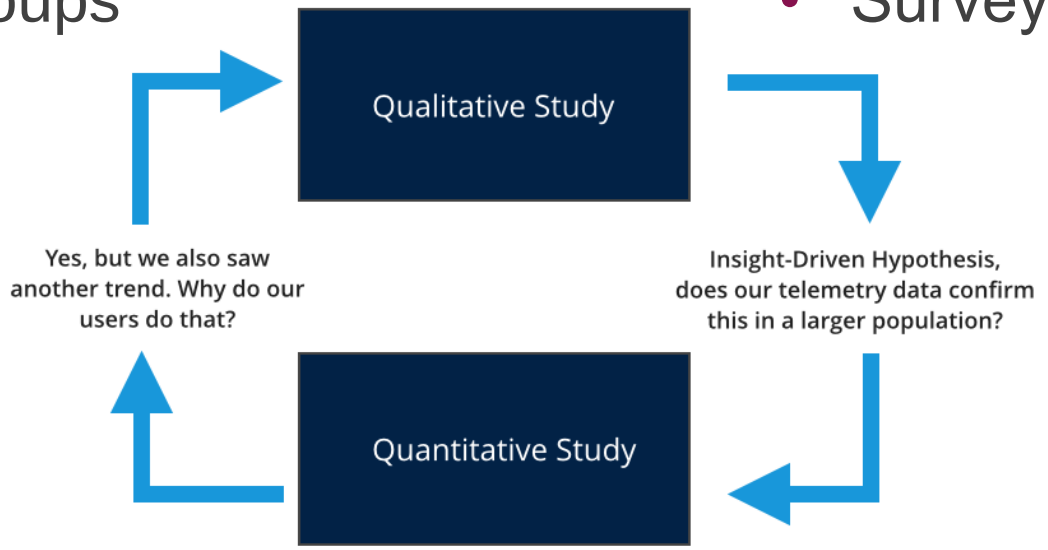
# Qualitative vs. Quantitative

## Qualitative

- Unstructured data
- Summarize, characterize
- Subjective conclusion
- Focus groups

## Quantitative

- Structured data
- Statistical analysis
- Objective conclusion
- Survey, “big data”

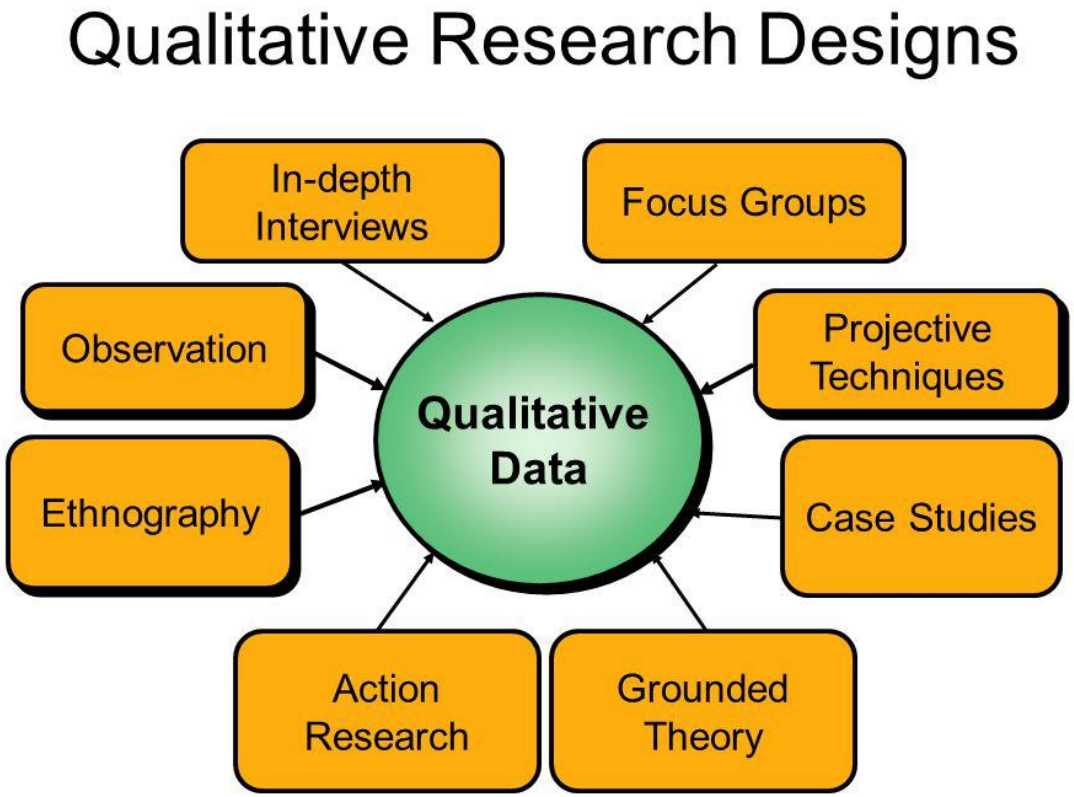


# Qualitative Research...When/why to use it?

- Answers questions like...
  - What is going on here?
  - How is this happening?

- Examines
  - Social constructs
  - Behaviors
  - Interactions
  - Group norms
  - Survey design
  - Meaning
  - Policy implications

# Qualitative Methods




Phenomenology, Content analysis, Dimensional analysis, Discourse analysis

# Qualitative Methods...Which one???

- Ex:  What do patients expect after colon surgery?
- Consult a qualitative expert
- Depends upon:
  - Question being asked
  - Context
  - Accessibility
  - Feasibility

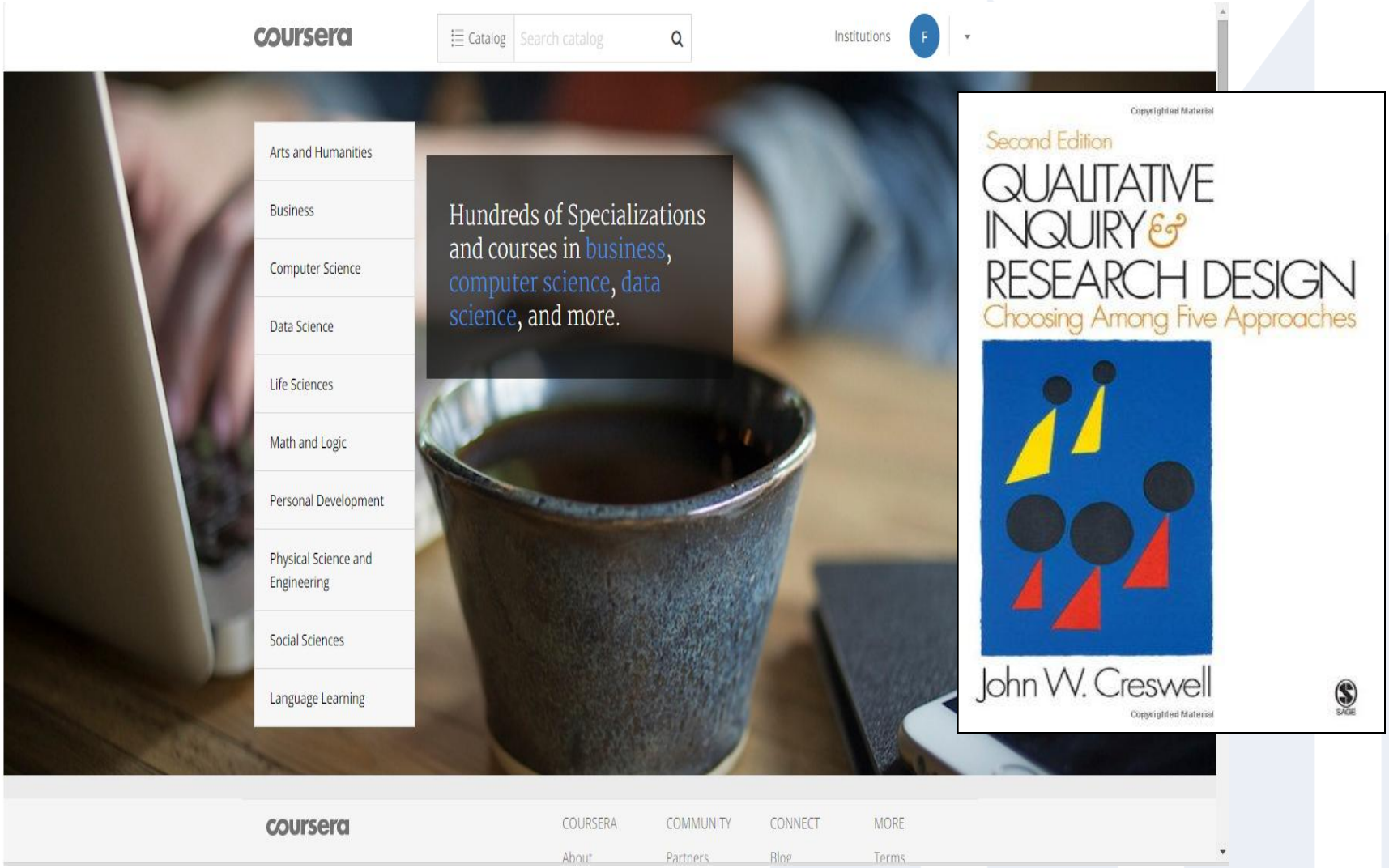
# Overview

- **Strengths**
  - Rich data
  - Explain phenomena
  - Dynamic and flexible
  - Investigate complex issues
  - Examine of feelings and motivations
  - Provides insights and generates new ideas
  - Identify/evaluate factors that help solve problems

# Overview

- **Weaknesses**
  - Volume of data
  - Time consuming
  - Reliability/replicability
  - Complexity of analysis
  - Interpretation may be subjective
  - Can’t extrapolate to whole population

# MORE INFORMATION



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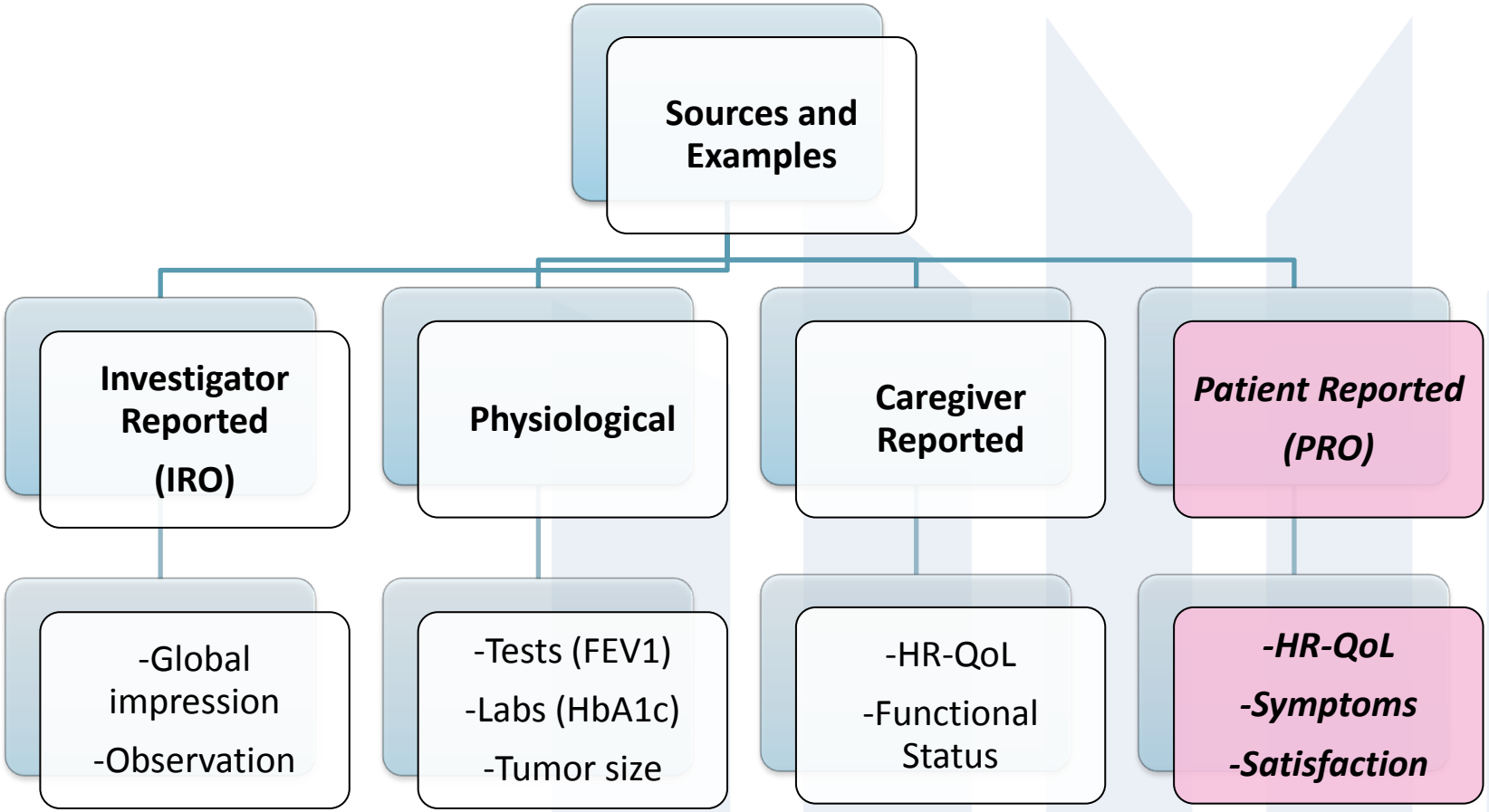
# Patient Reported Outcome Measures : PROM

# Patient-Reported Outcomes (PRO)

- Measurement of any aspect of a patient's health status that comes directly from the patient

**...without interpretation of the patient's response by a physician or anyone else**

# Assessment of Outcomes



# PRO...When to use them?

- Used to assess :
  - Symptoms (impairments)
  - Functioning (disability)
  - Wellness (health)
  - Quality of life (QOL)**

# IRO vs PRO Examples

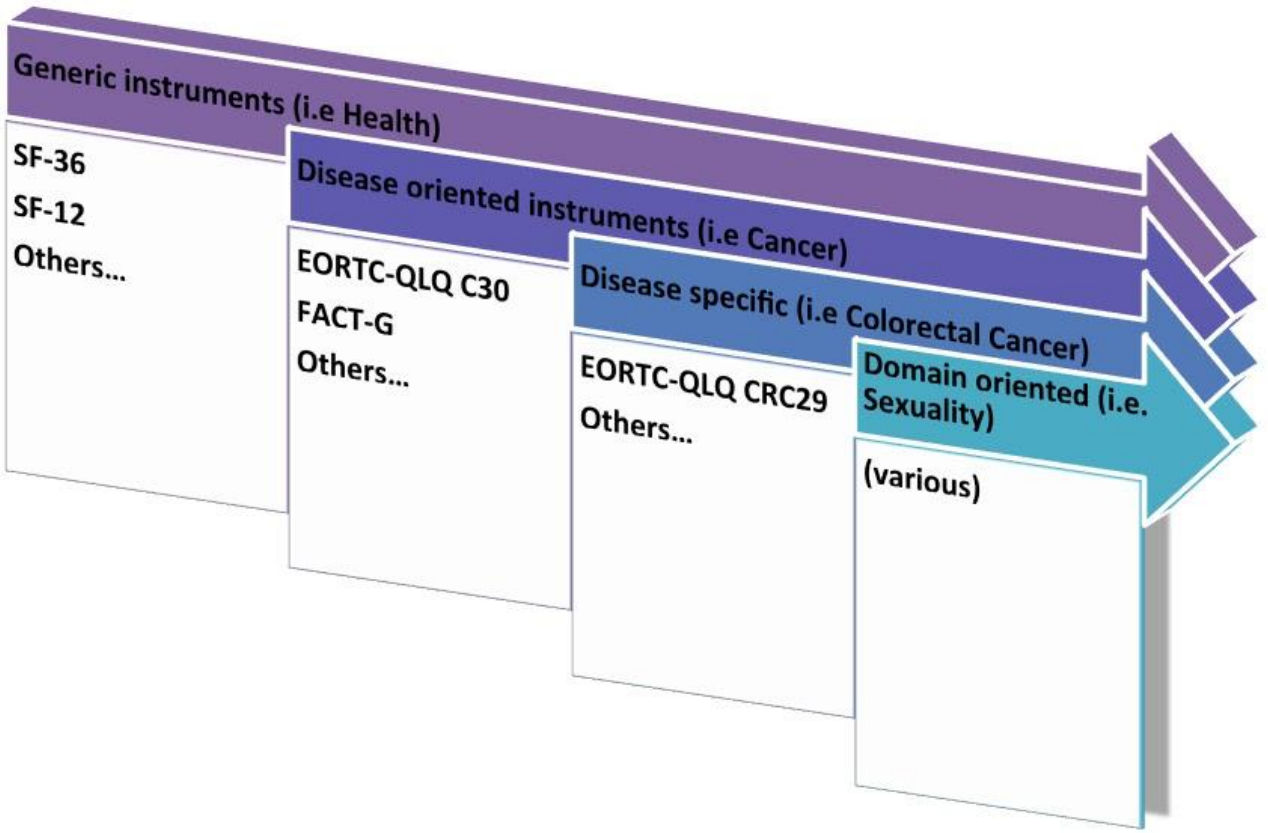
## Investigator Reported


## Patient Reported

# Generic vs Targeted PRO

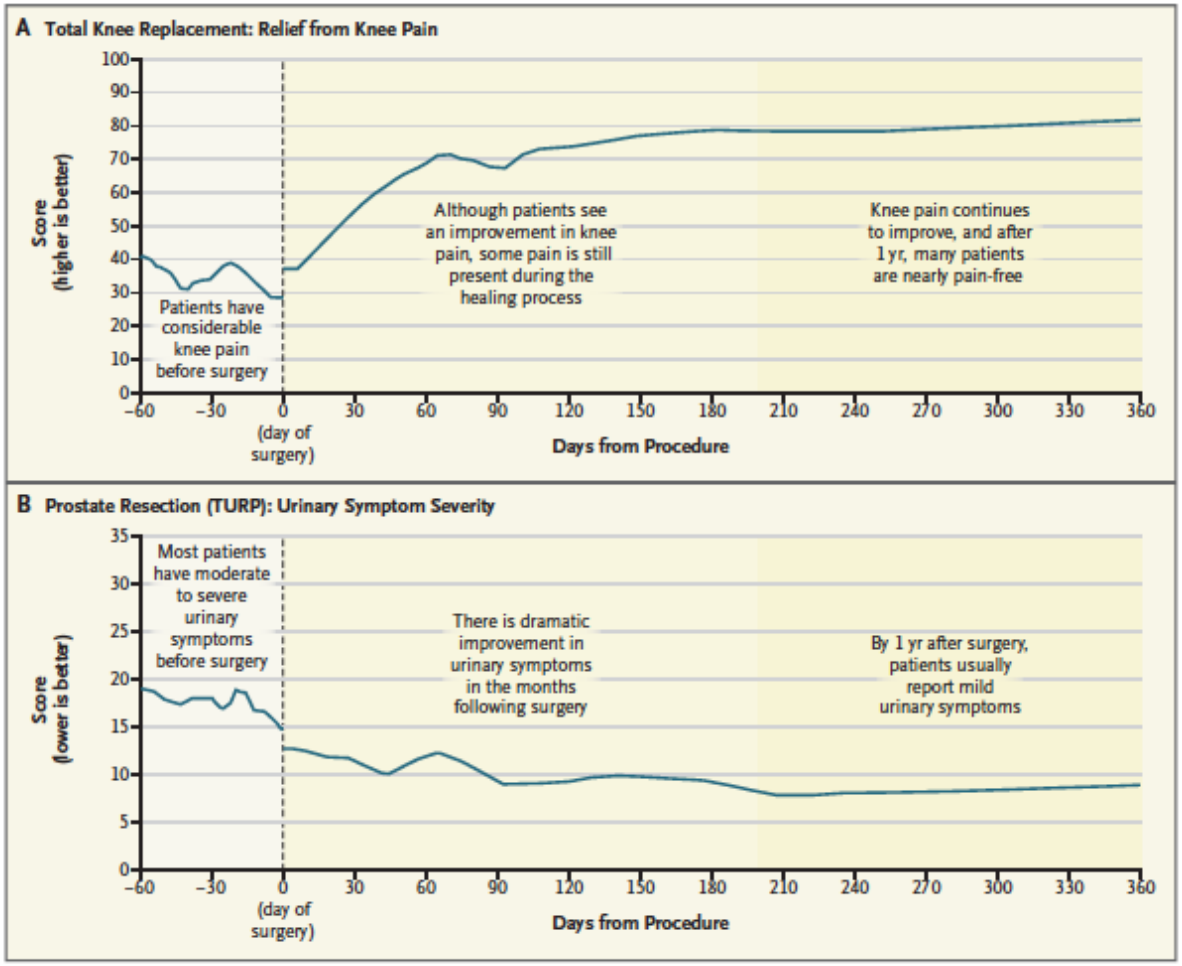
- Generic: any population and meant to cover a broad aspect of concept being measured
  - QOL: SF-36, EQ-5D
- Targeted: disease, domain, population, or setting-specific assessment of concerns most important to a given population
  - Oxford Hip, AQ20 (IBD)
  - Multidimensional Fatigue Inventory
  - QOL Profile – Senior version

# Generic vs Targeted PRO



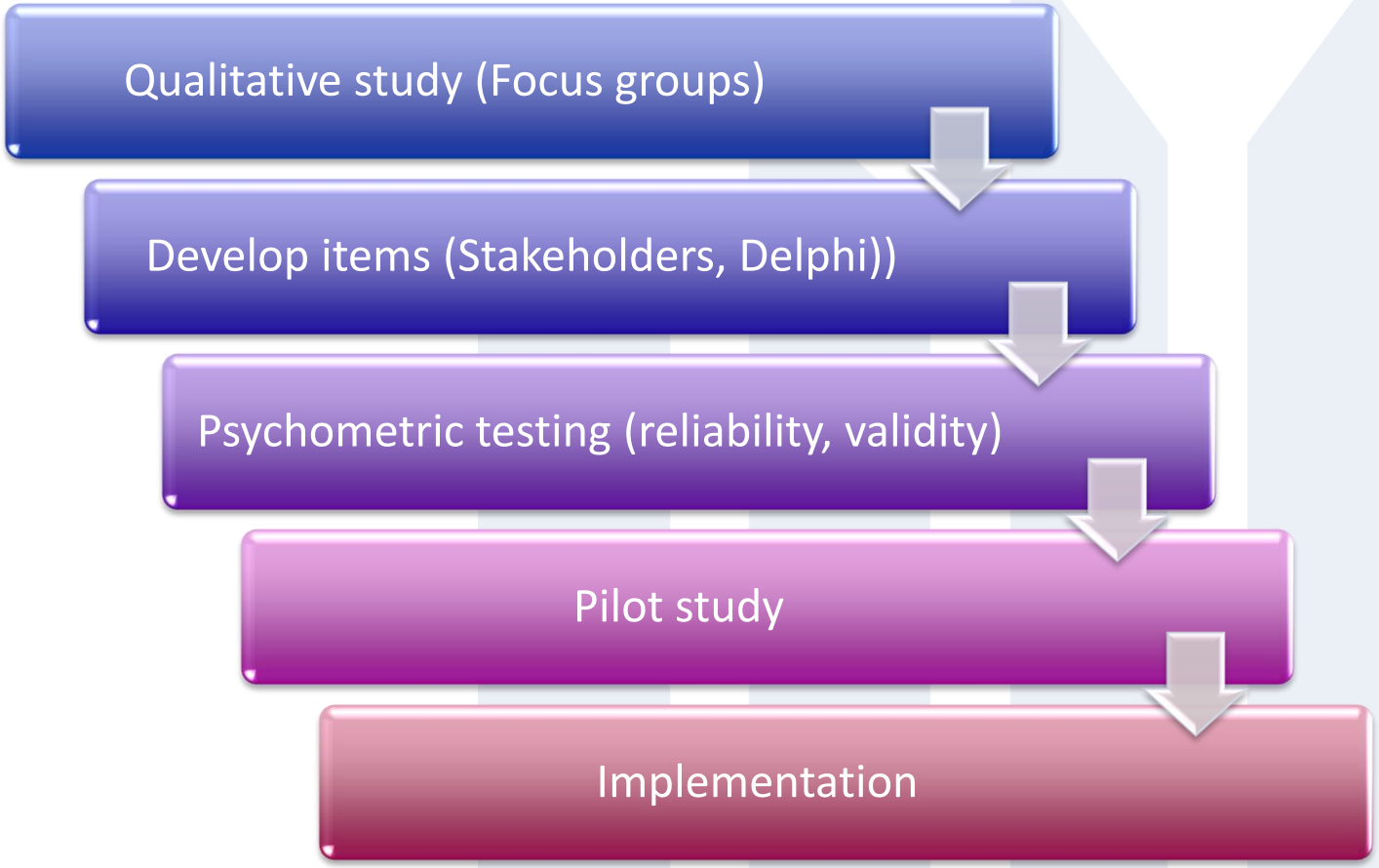
# PRO vs IRO Examples

- Total Knee
  - PRO: pain
    - General
  - IRO: DVT rate
- Prostate surgery
  - PRO: Urinary sx
    - Dz specific
  - IRO: EBL



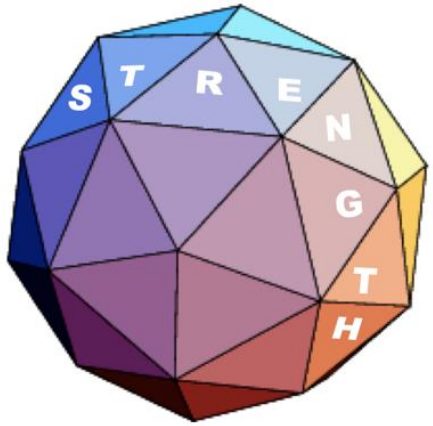

Patient-Reported Outcomes for Shared Decision-Making.

# PROM Development – PROMIS



# PROM Overview

- **Strengths**
  - Perspective on treatment effectiveness from patient's view
  - More systematic than interview
  - Some treatment effects only known to patient
  - Can be used to improved practice



# PROM Overview

- **Weaknesses**
  - Meaningfulness of scores
  - Sensitivity / Specificity
  - Poor validity
  - Unreliable

# MORE INFORMATION

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# Build Your Toolbox

- Not necessarily exclusive of one another
  - Qualitative → Survey, PRO, CER, Trials
  - PRO→ Qualitative, Survey, Trials, CER

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# Thank You!

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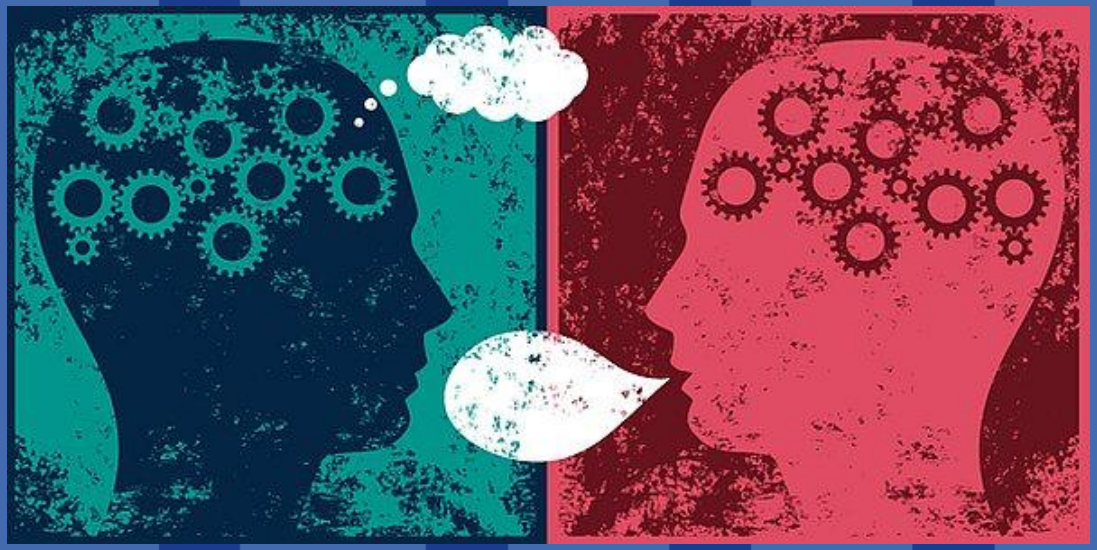

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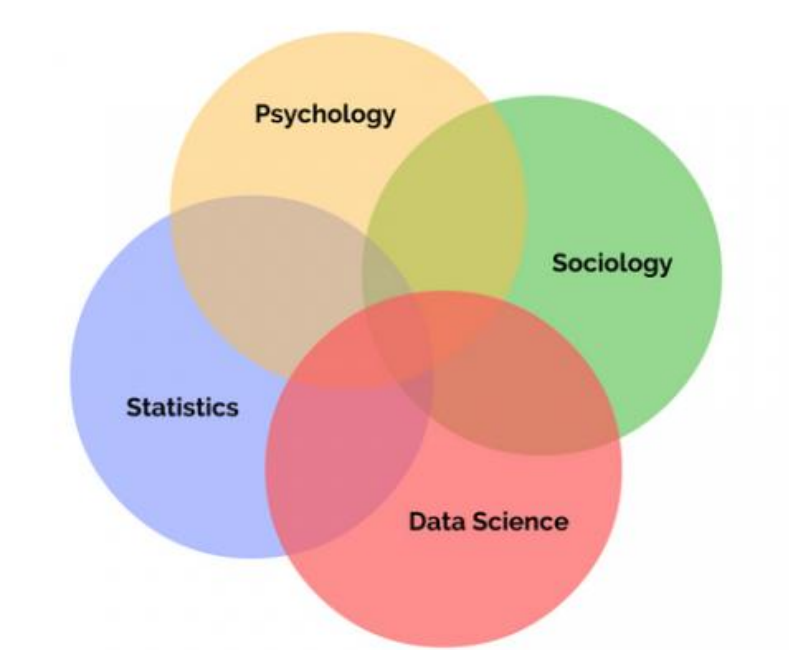
# Survey Science



# Definition

- Surveys hard to do well and expensive
  - Is there existing survey data?
  - Is the question appropriate for survey research?
  - Do I have enough funding?
- Ask someone with experience for help
  - Survey Center
  - Attending or researcher

# Existing Sources of Data

- Inter-university consortium of political and social research (ICPSR) at the University of Michigan
  - http://www.icpsr.umich.edu/icpsrweb/ICPSR/
- National health and aging trends study (NHATS)
  - http://www.nhats.org/
  - Health information national trends survey (HINTS)
  - https://hints.cancer.gov or @NCIHINTS
- Existing tools: adapt
- School of Public Health
- Survey Center

# Characteristics of a Good Survey

- Clear definition
  - Who? What? How?
- Specific content
  - Clear domains of interest
- Standardization of administration
  - Respondent receive same instructions and materials
- Standard scoring procedure

# Things to consider

- Cost: Free → $50,000
- Creation
  - Basic
  - Link to other data (respondent information, claims data, biomarkers)
- Purpose
  - Epidemiological Survey
  - Measuring of risk and protective factors
  - Outcomes measures

# Things to consider

- Types
  - Self-administered vs Interviews
- Psychometrics: Measurement of properties of a measure
  - Reliability (consistency and stability)
  - Validity: does the test measure what it was designed to measure
    - Content validity
    - Construct validity

# Overview

- Strength
  - Reach
  - Address many questions / themes
  - Return of investment (hypothesis generation)

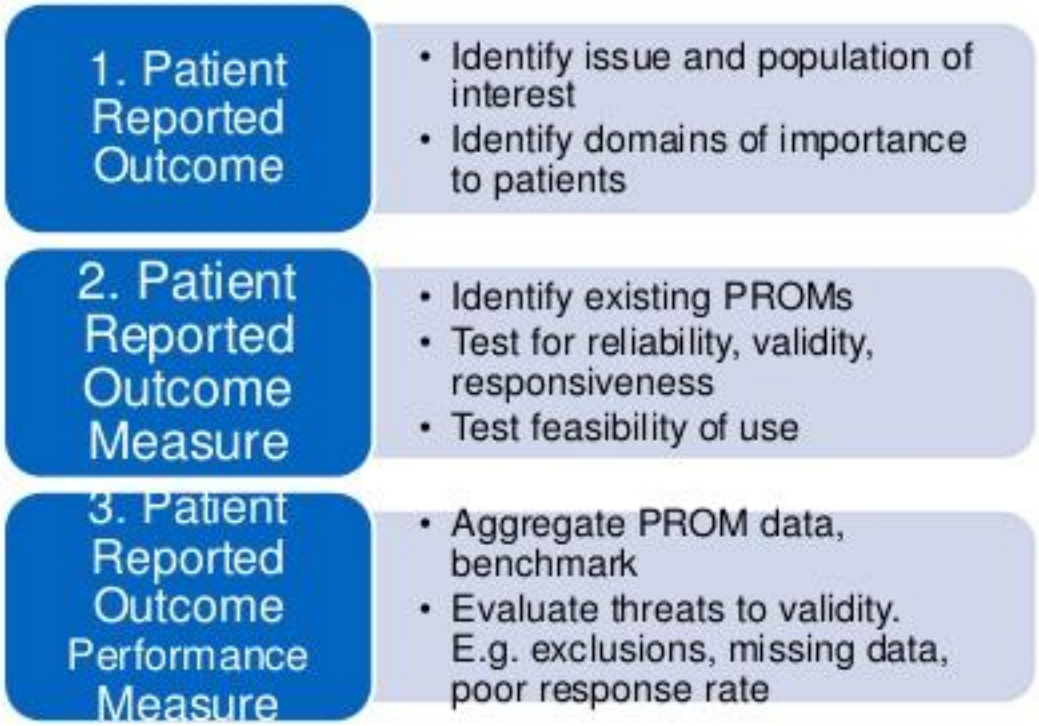
- Weaknesses
  - Lack of clarity
  - Recall
  - Return on investment (response rate)

# Important

- These tools are not necessary exclusive of one another
  - Qualitative → Survey, PRO, CER, Trials
  - PRO→ Qualitative, Survey, Trials, CER
  - Survey → Qualitative, PRO, CER, Survey

- Important to build your tool box and know how and when to use your tools

# Using patient reported outcomes




National Quality Forum. Patient Reported Outcomes (PROs) in Performance Measurement. Washington, DC: National Quality Forum; 2013


**"Leadership experience? I have 13 people following me on Twitter!"**

# PRO...When to use them?

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# Thank You!

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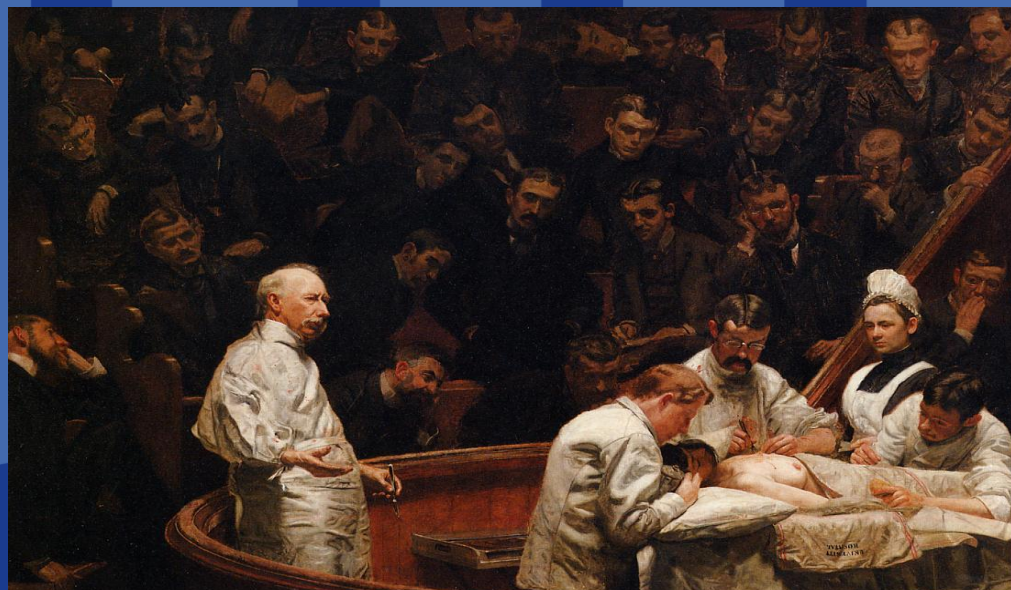
# Qualitative Research



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# Survey Science

Qualitative Study

Insight-Driven Hypothesis, does our telemetry data confirm this in a larger population?

antitative Study

# *Recap*: Qualitative Research Process

*(Maintaining Consistency)*

**1. Problem Statement**
*Gap found in the literature*

**2. Research Purpose:**
Understand
Explain
Describe
Illustrate
Explore
Conceptualize

**3. Research Question:**
Exploratory in nature

**4. Research Design:**
***Research Plan*** *- logical description of how data would be collected, and analyzed to address the research question (s)*

***Research Approach***
***Sampling Strategy***
***Data Collection Strategy***

**6. Philosophical Assumptions OR Paradigm**
Ontology (about reality)
Epistemology (about knowledge)
Axiology (about value)

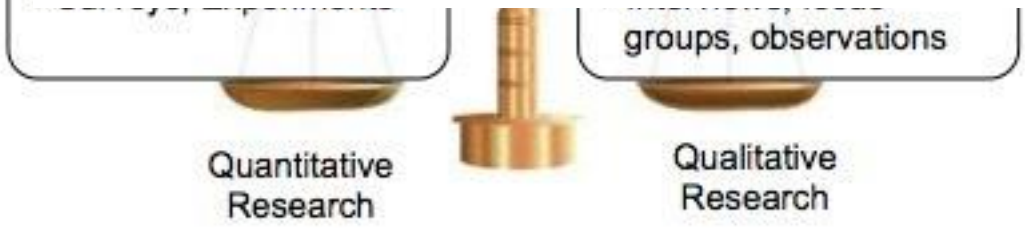
***Researcher's role(s), background, beliefs, perspectives, and biases***

**8. Analysis of Data**

**7. Quality Assurance**
Credibility
Transferability
Dependability

***9. Presentation and Interpretation of Results***

(Yilmaz, 2013)

# The Qualitative Researcher

- Adept at performing a large number of diverse tasks ranging from:
  - Interviewing to observing
  - Interpreting personal and historical documents
  - Intensive self-reflection and introspection

# Qualitative Research...What is it?

- Ex: “The goal of this study was to ...[characterize, understand, explain, explore, illustrate, describe, conceptualize]...what patients expect after surgery?”