



Qualitative Methods and Patient Reported Outcome Measures

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Disclosures

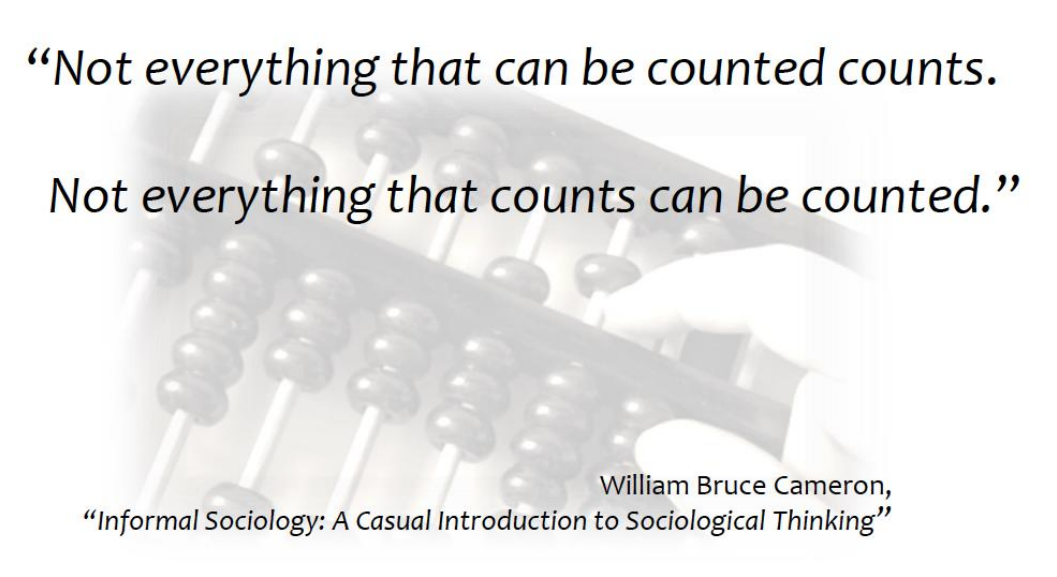
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Overview

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

Qualitative Research



*“Not everything that can be counted counts.
Not everything that counts can be counted.”*

William Bruce Cameron,
“Informal Sociology: A Casual Introduction to Sociological Thinking”

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



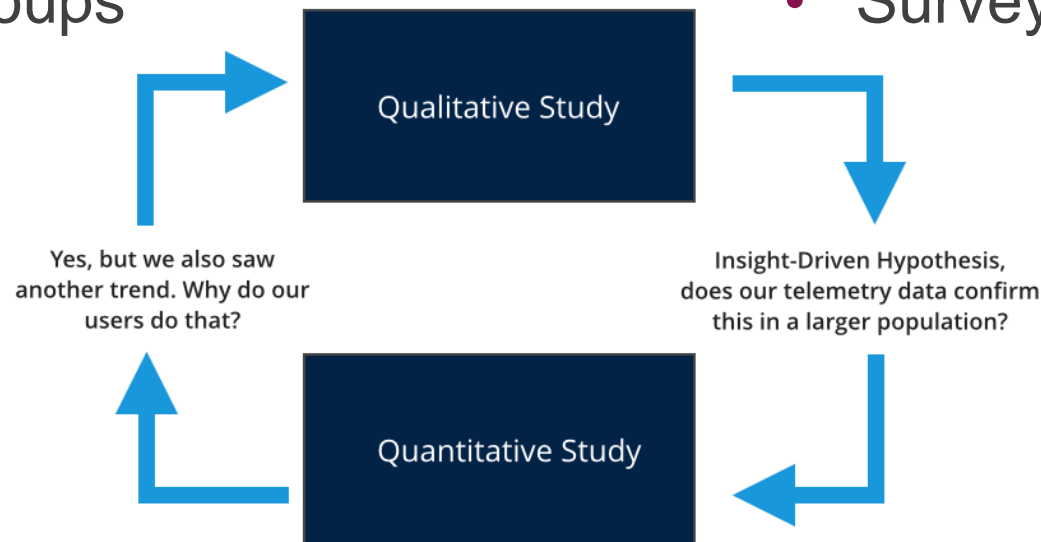
Qualitative vs. Quantitative

Qualitative

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

Quantitative

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

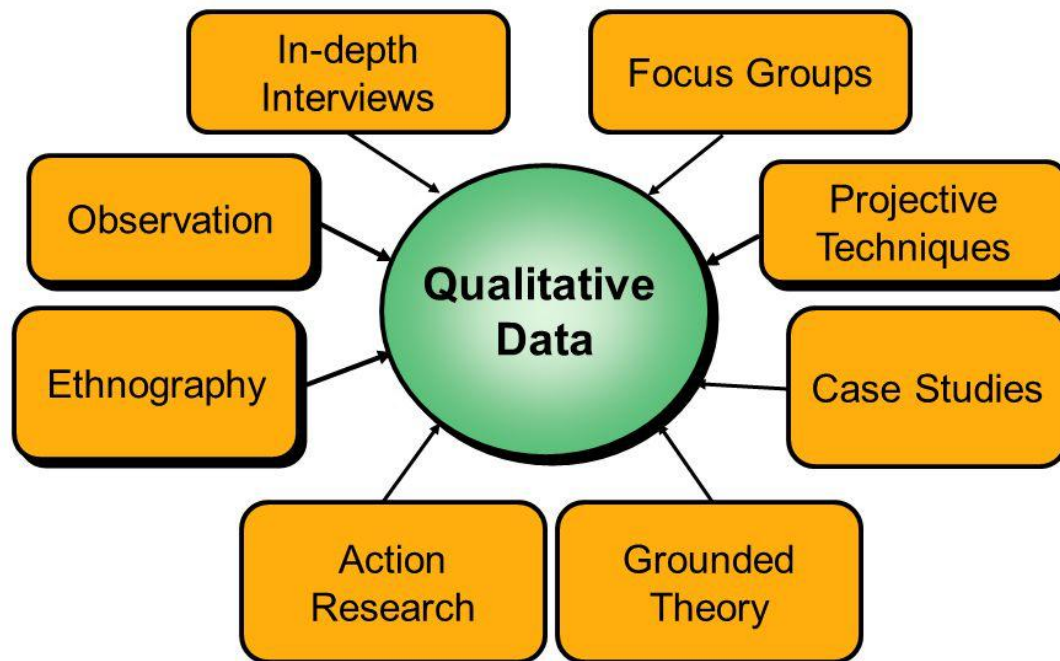


Qualitative Research...When/why to use it?

- 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 Research Designs



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



- **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

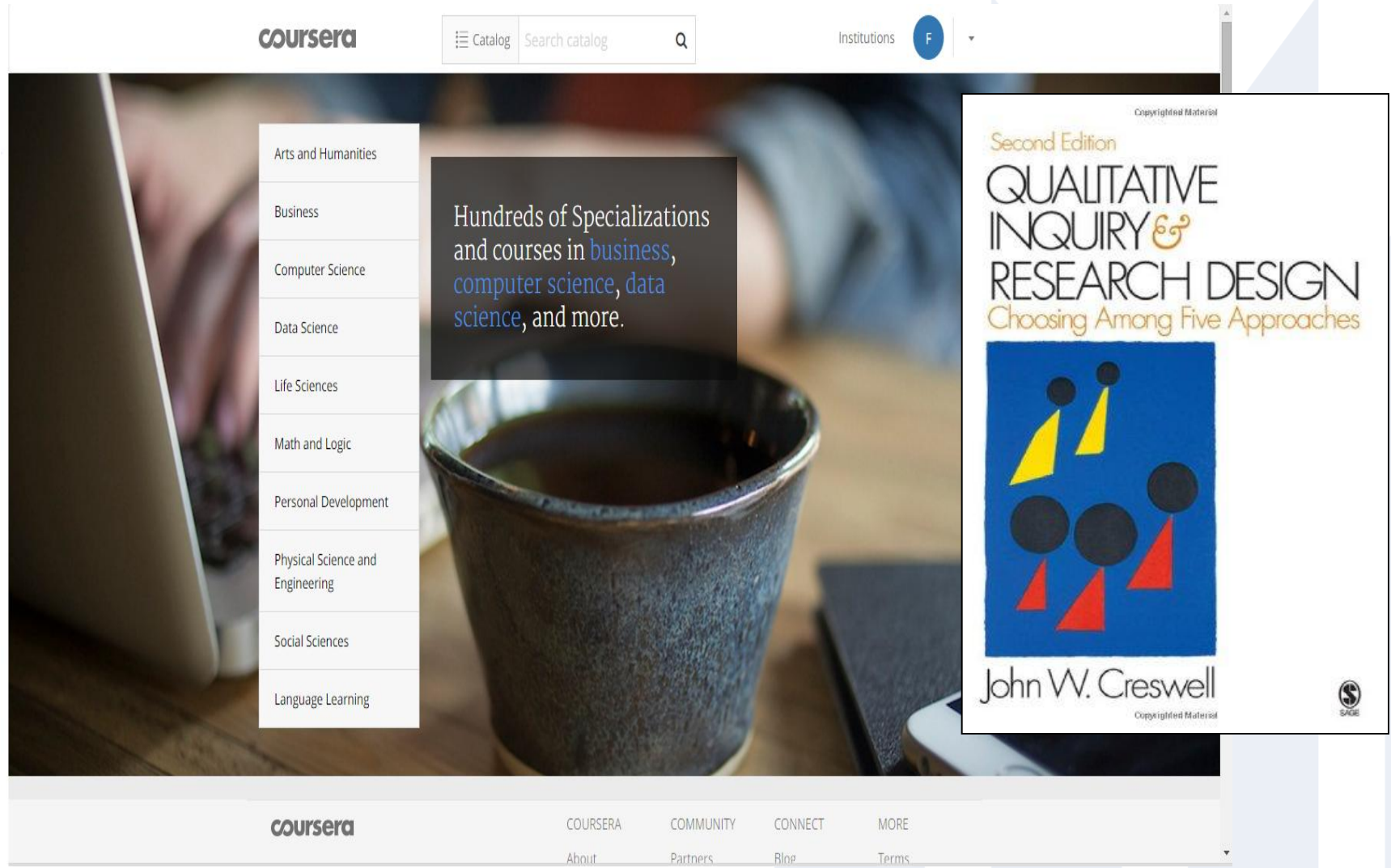


- **Weaknesses**

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



MORE INFORMATION



The image is a screenshot of the Coursera website. The background is a blurred image of a person's hands typing on a laptop keyboard next to a dark, textured ceramic cup. Overlaid on the left side is a vertical menu with the following categories: Arts and Humanities, Business, Computer Science, Data Science, Life Sciences, Math and Logic, Personal Development, Physical Science and Engineering, Social Sciences, and Language Learning. In the center, a dark grey box contains the text: "Hundreds of Specializations and courses in **business**, **computer science**, **data science**, and more." The top of the page features the Coursera logo, a search bar with the text "Catalog Search catalog", and a dropdown menu for "Institutions" showing the letter "F". The bottom of the page has a navigation bar with links for COURSERA, COMMUNITY, CONNECT, and MORE, followed by a secondary row of links: About, Partners, Blog, and Terms. On the right side of the page, there is a white rectangular box containing the cover of the book "Qualitative Inquiry & Research Design: Choosing Among Five Approaches, Second Edition" by John W. Creswell, published by SAGE. The book cover features a blue background with abstract yellow and red shapes and the author's name at the bottom.

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Second Edition

QUALITATIVE INQUIRY & RESEARCH DESIGN

Choosing Among Five Approaches

John W. Creswell

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About Partners Blog Terms

Patient Reported Outcome Measures : PROM

which of the following, if any, represents your
single biggest concern
right now...

 personal relationships <ul style="list-style-type: none">• Family• Friends	 monitoring health <ul style="list-style-type: none">• Testing blood sugars• Checking feet	 emotional health <ul style="list-style-type: none">• Sad• Anxious• Other emotional concerns	 money <ul style="list-style-type: none">• Cost of medicine or supplies• Paying for care	 health behaviors <ul style="list-style-type: none">• Diet• Exercise• Sleep
 medicine <ul style="list-style-type: none">• Taking medication• Managing side effects	 getting health care <ul style="list-style-type: none">• Finding a provider to talk to• Scheduling appointments	 work <ul style="list-style-type: none">• Schedule• Environment• Managing your health condition at work	 physical health <ul style="list-style-type: none">• Pain• Fatigue• Physical difficulties	 something else

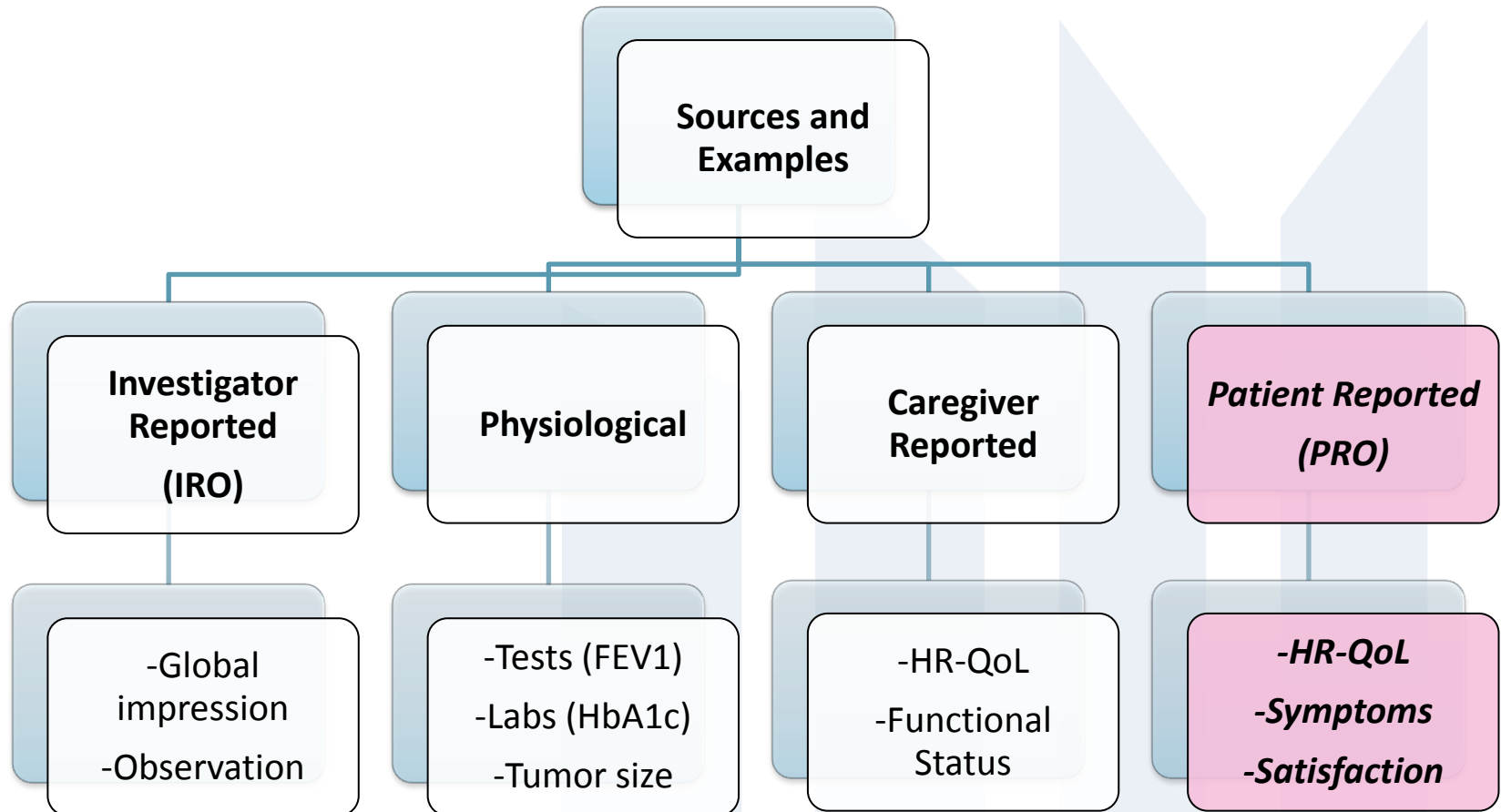
Patient-Reported Outcomes (PRO)

- 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



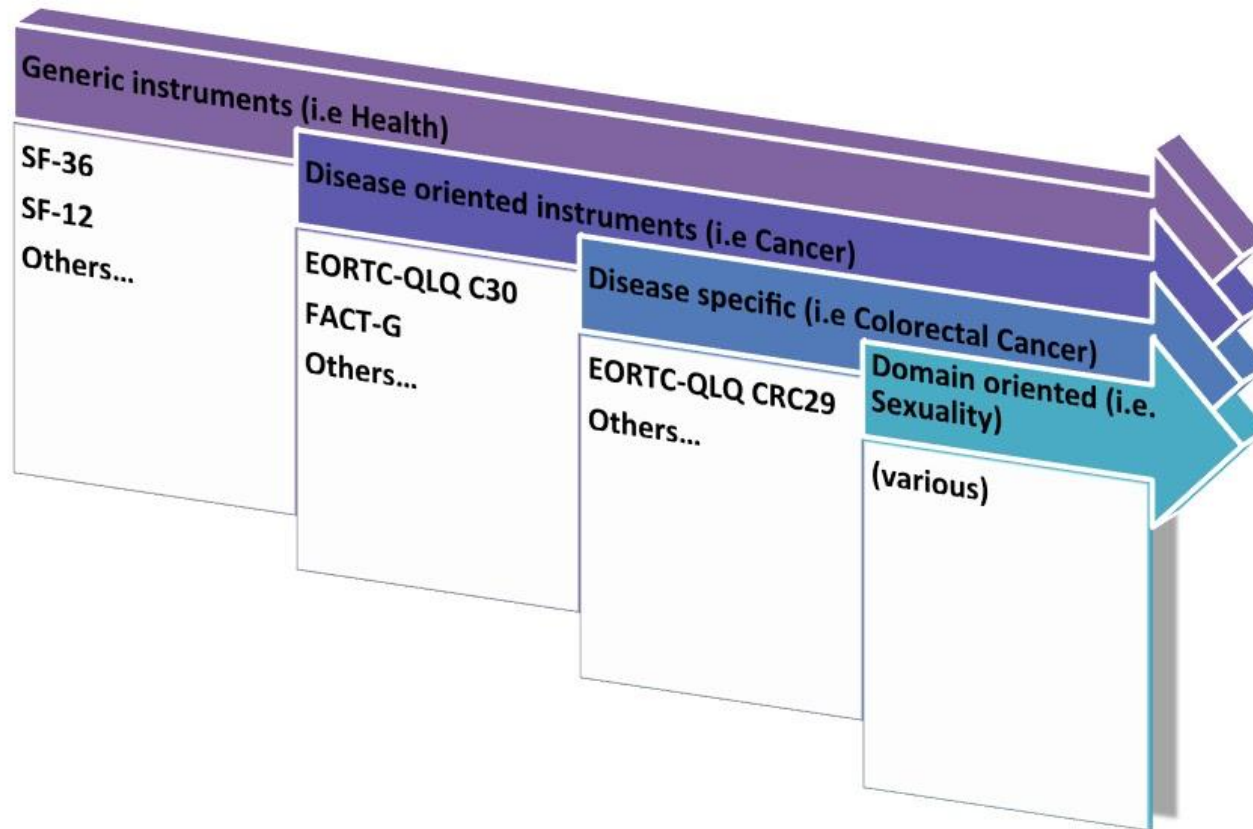
Patient Reported



Generic vs Targeted PRO

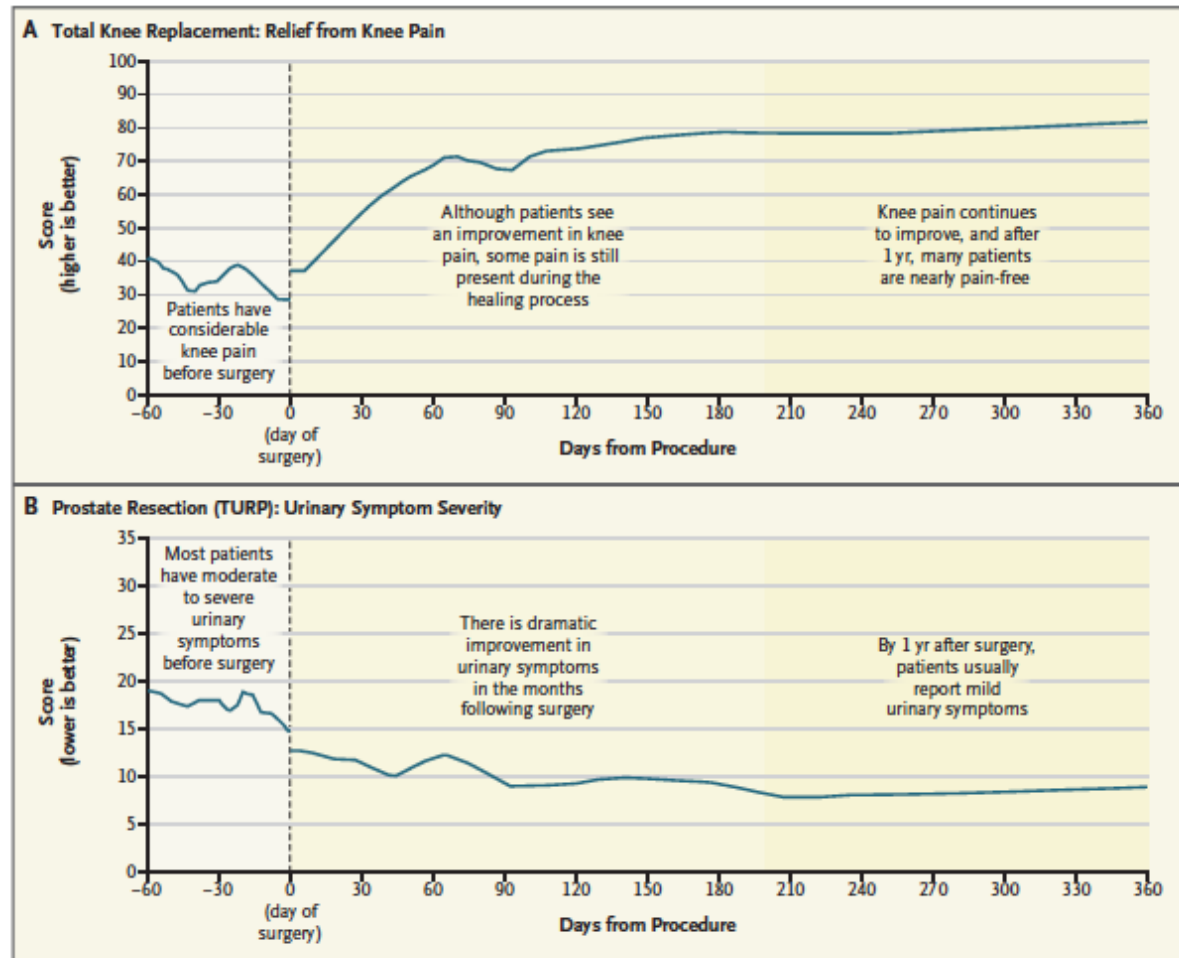
- Generic: any population and meant to cover a broad aspect of concept being measured
 - QOL: SF-36, EQ-5D
- Targeted: disease, domain, population, or setting-specific assessment of concerns most important to a given population
 - Oxford Hip, AQ20 (IBD)
 - Multidimensional Fatigue Inventory
 - QOL Profile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

Generic vs Targeted PRO

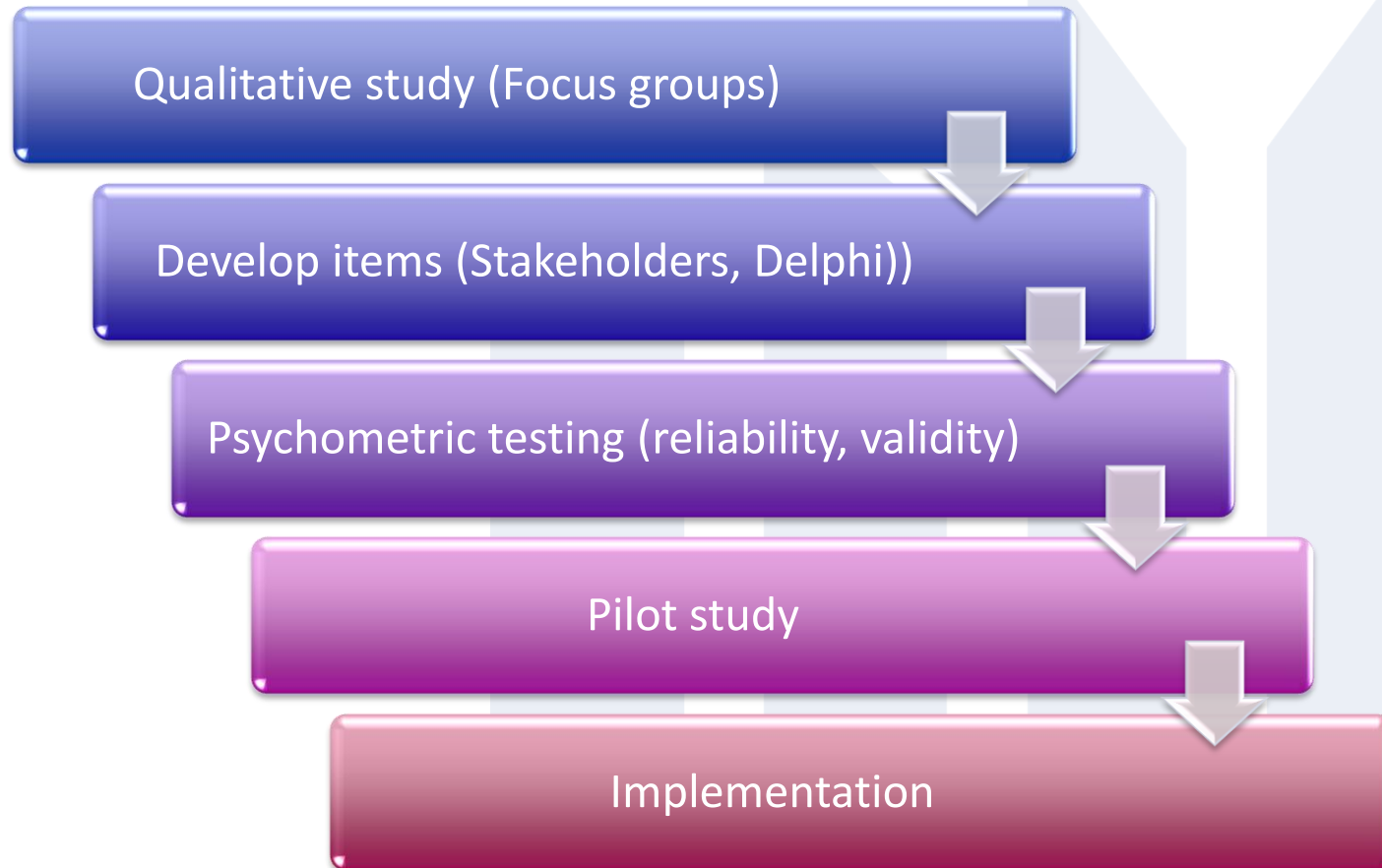


PRO vs IRO Examples

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



PROM Development - PROMIS



- **Strengths**

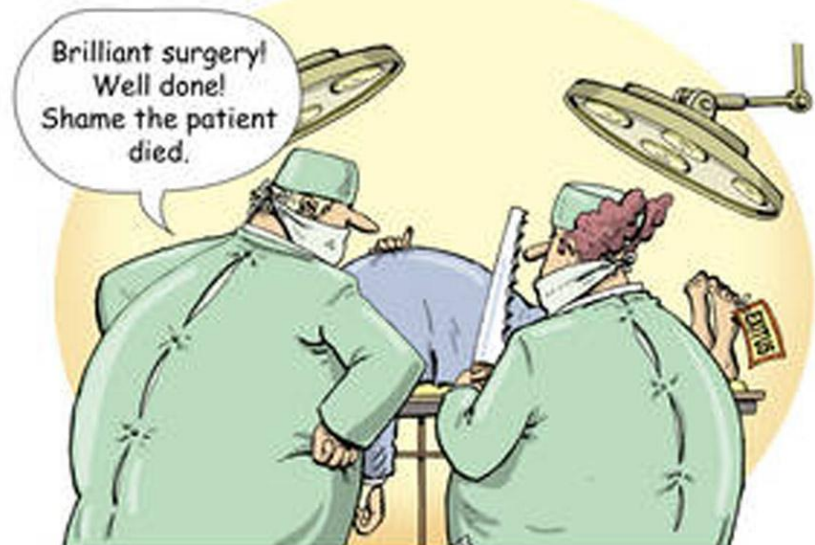
- Perspective on treatment effectiveness from patient's view
- More systematic than interview
- Some treatment effects only known to patient
- Can be used to improved practice



- **Weaknesses**

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

Do outcomes matter?



MORE INFORMATION



Build Your Toolbox

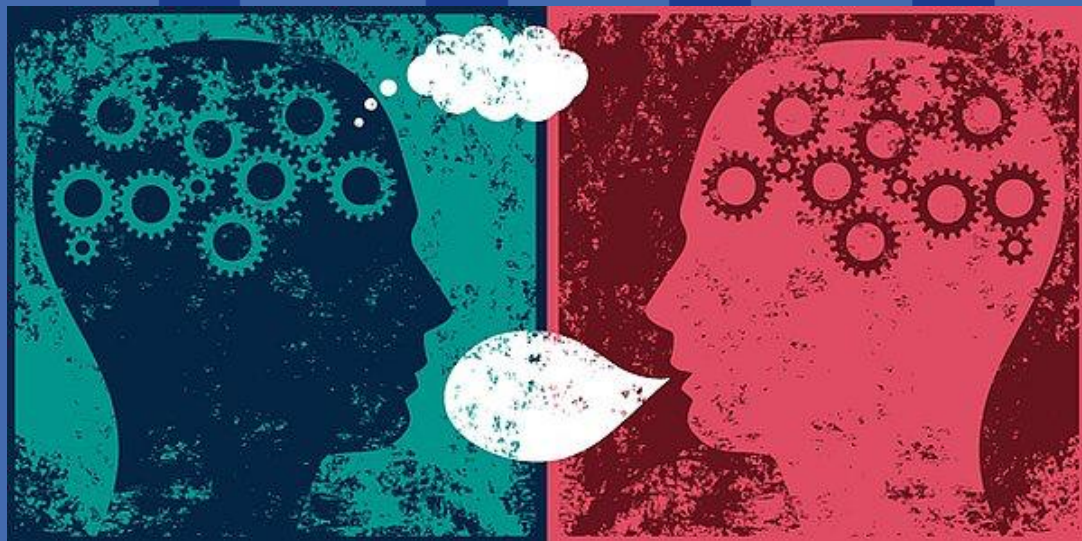
- Not necessarily exclusive of one another
 - Qualitative → Survey, PRO, CER, Trials
 - PRO → Qualitative, Survey, Trials, CER



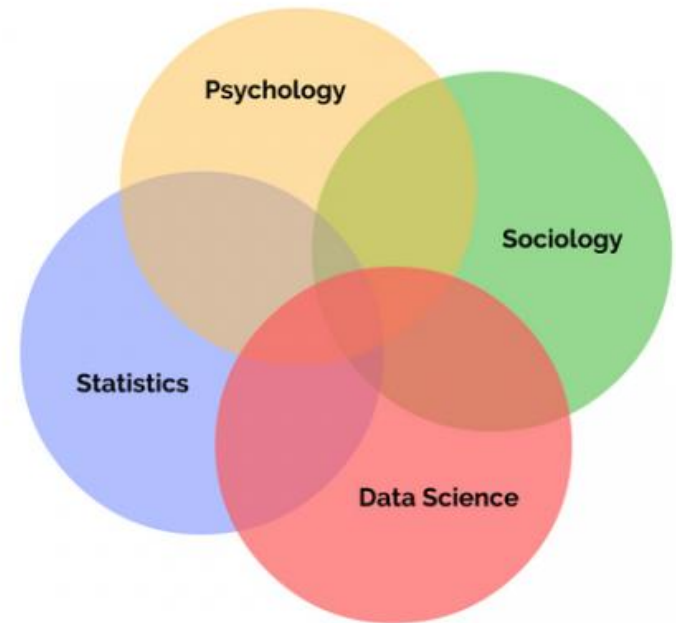
Thank You!

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Survey Science



Disciplinary Components of
Survey Methodology

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

- Strength
 - Reach
 - Address many questions / themes
 - Return of investment (hypothesis generation)
- Weaknesses
 - Lack of clarity
 - Recall
 - Return on investment (response rate)

- 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

1. Patient Reported Outcome

- Identify issue and population of interest
- Identify domains of importance to patients

2. Patient Reported Outcome Measure

- Identify existing PROMs
- Test for reliability, validity, responsiveness
- Test feasibility of use

3. Patient Reported Outcome Performance Measure

- Aggregate PROM data, benchmark
- Evaluate threats to validity. E.g. exclusions, missing data, poor response rate



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

PRO...When to use them?

PROs

- ✓ Health-related quality of life (HRQOL)
- ✓ Symptoms
- ✓ Function
- ✓ Satisfaction with care or symptoms
- ✓ Adherence to prescribed medications or other therapy
- ✓ Perceived value of treatment



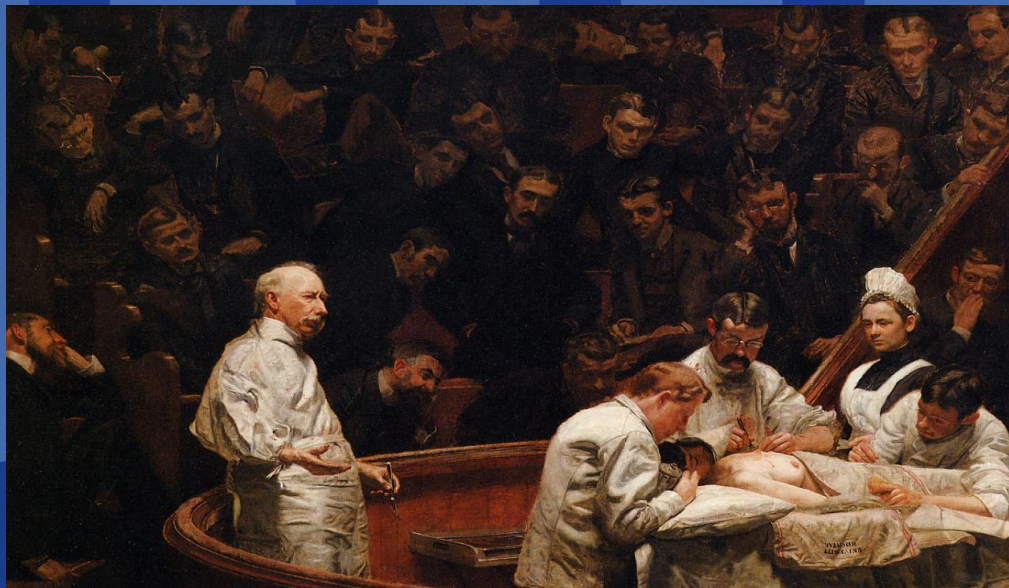
Thank You!

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Qualitative Research



Survey Science



Qualitative 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

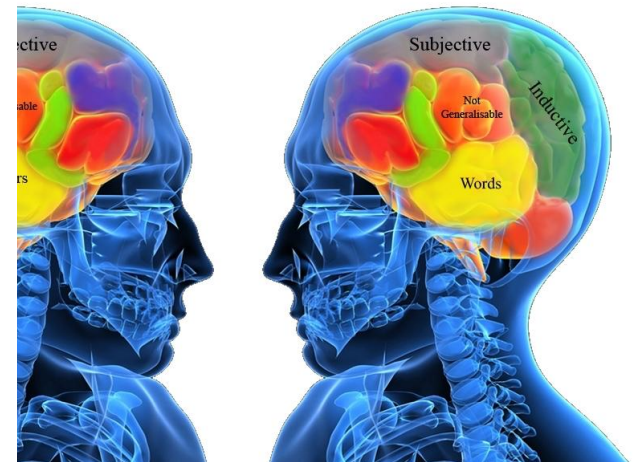
Credibility
Transferability
Dependability

9. Presentation and Interpretation of Results

(Yilmaz, 2013)

Quantitative Study

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



groups, observations

Quantitative
Research

Qualitative
Research

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?”