

## Questionnaire Development and Testing

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Complementary and  
Integrative Health

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## Acknowledgments

- Gordon Willis, Ph.D.  
Applied Research Program, NCI
- William T. Riley, Ph.D.  
Director  
Office of Behavioral and Social Sciences

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## Outline of Lecture

- Self-report measures
- Data collection methods
- Main questionnaire development steps
  1. Determine analytic objectives
  2. Put together draft questionnaire
  3. Cognitive testing
  4. Field pretesting
  5. Translation
- Qualitative Research
- Mixed Methods Research

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## Data Sources for Health Research (other than self-report)

- Birth and death records
- Medical records at physician offices, hospitals, nursing homes, etc.
- Medical databases housed within various agencies, universities, and insurance companies
- Physical exams and laboratory testing
- Registers of diseases

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## Self-Report Measures

- Used in questionnaires
- Some information can be gathered only by asking people questions (i.e. **not easily observable**)
- Self-report measures are **estimates** of true scores
  - True score + Measurement error = Survey response

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## What are the Pitfalls of Self-Report?

Susceptible to the respondent's:

- Mood
- Motivation
- Memory
- Understanding



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## What are the Pitfalls of Self-Report?

Also susceptible to:

- Context of interview
- Social desirability

Thus, importance of *rigorous* methods

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## Common Types of Questions

- **Open-ended**
  - What health conditions do you have?
- **Closed**
  - Which of the following conditions do you currently have? Say yes or no to each.
    - Diabetes?
    - Asthma?
    - Hypertension?

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## Common Types of Questions

- **Response options**
  - Nominal – unordered (e.g. male, female)
  - Ordinal – ranked (e.g. excellent, good, fair, poor)
- **Type of information**
  - Factual – Objectively verifiable
  - Subjective – Knowledge, perceptions, feelings, judgment

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## Data Collection Methods in Surveys

- **Computerized vs. paper surveys**
  - Computerized: desktop, laptop, web, smartphone, tablet
- **Interviewer vs. self-administered**
  - Interviewer: Face-to-face or from centralized location
  - Occasionally interactive voice response

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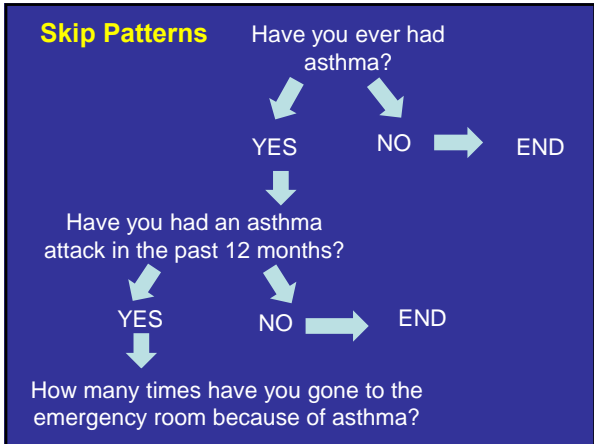
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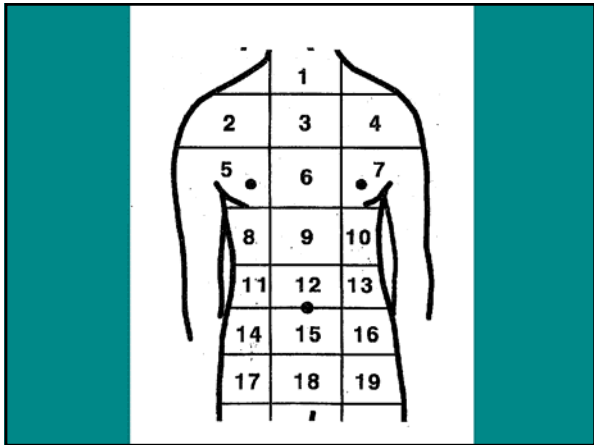
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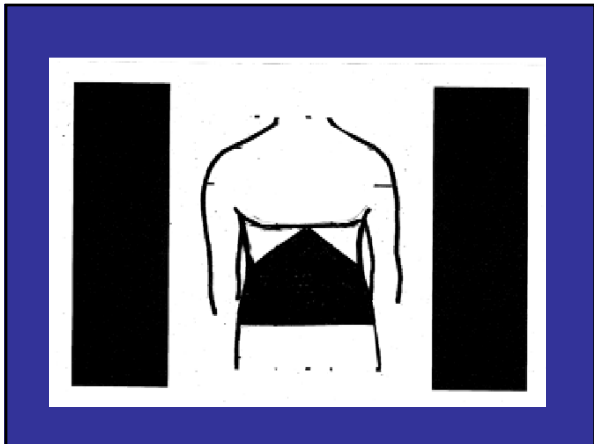
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## Computerized Surveys



### Pros

- Faster data availability
- Can handle complex *skip patterns*
- Can help to eliminate skip errors (**but not always**)
- Can be tailored to severity of symptoms or situation

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## Computerized Surveys

### Cons

- Data can get lost if system crashes
- Requires power source

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## In-Person Interviewer Administered

### Pros

- Interviewer can answer questions
- Can administer to illiterate/low reading level
- Can reach people who can't come to you
- Can build rapport
- Higher response rates
- Can use visual aids

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## In-Person Interviewer Administered

### Cons

- Expensive
- Geographic limitations
- Longer data collection period
- Interviewer presence can bias results
- Interviewers may use inconsistent techniques

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## Telephone Interviewer Administered



### Pros

- Lower Costs
- Can ensure uniform data collection
- Shorter data collection period
- Good geographic coverage

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## Telephone Interviewer Administered

### Cons

- Omit people without phones (2% of US)
- 4 in 10 U.S. adults are cell phone only (complicates sampling)
- Cannot use visual aids
- Lower response rates compared with in-person

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## Web/Smartphone/Tablet Self-Administration



### Pros

- Lower costs
- Timely data
- Anonymity (good for sensitive items)
- Flexible in design options (can use visual aids, long lists, complex skips)
- Convenient for respondents (any time/location)
- Can cover large geographic area

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## Web/Smartphone/Tablet Self-Administration

### Cons

- Varying degrees of computer skills, access, connection speeds
- Samples reflect select online groups
- Difficult to verify informed consent
- Difficult to track non-responders

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## Paper and Pen Self-Administration

### Pros

- Anonymity for sensitive questions
- Can use long, complex response categories
- Can use visual aids
- Appearance consistent
- Can cover large geographic area
- Length easy to see (*plus or minus?*)



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## Paper and Pen Self-Administration

### Cons

- Requires good reading/writing skills
- Cannot have complex skip patterns
- No quality control
- Does not always save money

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## Effects of Data Collection Method on Response

- Multiple methods increase response rates (but at what cost?)
  - Spoken vs. Visual
    - Spoken questions produce more positive responses

“How would you describe your health, would you say excellent, good, fair or poor?”

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## Effects of Data Collection Method on Response

- Questions tailored to method:
  - Yes/No for telephone
  - Long list of check boxes for web
  - Long scales for self-administered/ shorter scales for telephone
  - Vast array of visuals/graphics available for computerized surveys
- Be careful combining/comparing

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## Main Development Steps: 1. Determine Analytic Objectives

- What are the general concepts to be covered/research questions?
  - Literature review
  - Expert panels, think tanks
  - Patient input

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### 1. Determine Analytic Objectives

What Type of Data Will Answer the Research Question?

| % of respondents who used yoga in past 12 months | % who took a yoga class in past 12 months | % who had insurance coverage for cost of yoga class |
|--|---|---|
| Men (X%)   | (X%)                                      | (X%)  |
| Women (X%)                                       | (X%)                                      | (X%)  |

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### Main Development Steps: 2. Put Together Draft Questionnaire

Use existing instruments

- **National Field Surveys:**
  - National Health Interview Survey (US)
  - National Health And Nutrition Examination Survey (US)
  - National Health Service Survey (UK)
- **Research Electronic Data Capture (REDCap):**
  - Shared library of data collection instruments

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### Put Together Draft Questionnaire

**HealthMeasures.net** (sponsored by NIH/  
developed with best practices)

- Patient Reported Outcomes Measurement Information System (**PROMIS**)
- Quality of Life in Neurological Disorders (**Neuro-QoL**)
- Adult Sickle Cell Quality of Life Measurement Information System (**ASCQ-Me**)
- NIH **Toolbox**

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### Put Together Draft Questionnaire

- Pay attention to aesthetics
- Draft new questions using known criteria

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### Put Together Draft Questionnaire

- Literacy < 9<sup>th</sup> grade U.S.
- Specific better than broad
- Culturally sensitive
- Scales consistent
- Terms well-defined
- Instructions clear
- Reference periods clear
- Response options match question
- Multiple concepts separated

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### Put Together Draft Questionnaire

- Interpreted accurately by people with range of demographic characteristics
- Capturing what researcher intended

#### Avoid

- Social desirability effects
- Negative wording
- Double barreled
- Jargon
- Ambiguous
- Leading

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### Main Development Steps: 3. Cognitive Testing

- Cognitive Testing

*Technique to study the way in which respondents understand, process, and respond to survey questions*

- Probing techniques to determine how respondents interpret questions

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## Cognitive Testing

- All components tested (stem, response categories, instructions, question ordering)
- Qualitative analysis performed to find common themes
- Performed in laboratory by trained research team
- Can be beneficial to travel to respondents (hard to reach populations)

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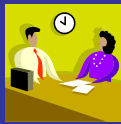
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## Cognitive Testing



Participants:

- Based on target population
- Start to lose focus after 1 hour
- Usually paid

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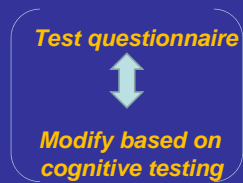
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## Cognitive Testing

Iterative Process



- Goal: Find and fix sources of **Response Error**

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## Sources of Response Error

- Respondent does not know the information
- They cannot recall it, although they do know it
- They do not understand the question
- They do not want to report the answer in the survey context

(Fowler F. (1991). *Survey Research Methods*, Sage)

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## Actions Taken Based on Cognitive Interviews

- Accept original question
- Accept original question with minor edits
- Accept original question with major edits
- Drop question/draft new question



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## Examples of common questionnaire problems: *Too Broad*

### *Original*

Would you be more inclined to use complementary therapies if your medical doctor or other conventional health care provider recommends it?

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**Examples of common questionnaire problems: *Too Broad***

***Final***

During the past 12 months, did you use [therapy] because it was recommended by a medical doctor?

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**Examples of common questionnaire problems: *Too Complex***

***Original***

During the past 30 days did you use any of the following vitamins and minerals for your own health or treatment? Be sure to include ALL vitamins that you use. If you take a SINGLE vitamin or mineral supplement, such as niacin, that is not part of a combination multi-vitamin/mineral supplement, include it separately.

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**Examples of common questionnaire problems: *Too Complex***

***Final***

The next questions are about any vitamins and minerals you may take. Have you ever taken any vitamins or minerals listed on this card?

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**Examples of common questionnaire problems: *Double-barreled***

***Original***

What was the reason you chose to use acupuncture...was it to treat a specific health problem or just to stay healthy or well?

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**Examples of common questionnaire problems: *Double-barreled***

***Final***

Did you use acupuncture for any of these reasons? Please say yes or no to each.

**For general wellness or general disease prevention?**

**For one or more specific health problems, symptoms, or conditions?**

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**Examples of common questionnaire problems: *Information Unknown***

***Questions dropped***

- Do you currently see a practitioner for homeopathy more, less, or about the same as you did one year ago?
- At what age did you first start using [complementary therapy]?
- During the past 12 months, did your child pray for his/her own health?

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**Examples of common questionnaire problems: *Terms Undefined***

***Original***

During the past 12 months did you use **movement therapies** for your own health or treatment?

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**Examples of common questionnaire problems: *Terms Undefined***

***Final***

Have you ever practiced any of the following movement or exercise techniques?

- Alexander Technique?
- Feldenkrais?
- Pilates?
- Trager Psychophysical Integration?

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**Examples of common questionnaire problems: *Cultural salience***

- Have you ever switched from a stronger to a lighter cigarette?



- ***(Original)*** During the past 12 months, did you see a practitioner for/use [therapy] because it is **how you were raised**?
- ***(Final)*** During the past 12 months, did you see a practitioner for/use [therapy] because it was **part of your upbringing**?

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**Examples of common questionnaire problems: *Inconsistent response categories***

- NHIS: 10-fold increase in children reported to have cerebral palsy 2004-2006
  - 311-353 cases in 2004-2006 vs. 34 cases in 2003
- Caused by interviewer error when survey moved to new screen design

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Looking at this list, has a doctor or other health professional ever told you that {child name} had any of these conditions?

- (00) None
- (01) Down's syndrome
- (02) Cerebral Palsy
- (03) Muscular Dystrophy
- (04) Cystic Fibrosis
- (05) Sickle cell anemia
- (06) Autism
- (07) Diabetes
- (08) Arthritis
- (09) Congenital heart disease
- (10) Other heart condition

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**Examples of common questionnaire problems: *Ordering effects***

**Original**

Have you ever had a sigmoidoscopy?  
When was your most recent?

Have you ever had a colonoscopy?  
When was your most recent?

**Final**

Order reversed

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## Pay Attention to Length

- Ideally
  - < 30 minutes for face-to-face
  - <15 minutes for phone or web
- Too long will increase costs/decrease response rates
  - Interviewers rush
  - Respondents get tired
  - Interviewers may cheat (keystroke data)



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## Main Development Steps: 4. Field Pretesting

- Survey administered in realistic setting to similar study population
- **For Interviewer-administered surveys**
  - Experienced interviewers
  - Nearly final instrument
  - Designers/sponsors observe
  - Rating forms to record issues
  - Debriefing

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**Field Pretesting**

- **For Self-administered surveys**
  - Respondents interviewed after they complete survey
  - Observe respondents as they fill out survey

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**Field Pretesting**

- **Tabulated data used to:**
  - Design closed response categories from open-ended questions
  - Collapse/eliminate response categories
  - Alter skip patterns
  - Drop items

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## 5. Translation



### PROMIS Approach

- **Harmonization:** different words/ languages must mean the same
  
- **Universal approach:** One language version for multiple countries
  - People from various countries/dialects involved

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### Translation (PROMIS approach)

1. 2 English to target lang. translations
2. Native speaker of target lang. reconciles
3. Back translated by native English speaker
4. Review by project manager
5. 3 native target lang. experts review (linguists and healthcare professionals)
6. Review by project manager

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### Translation (PROMIS approach)

7. Native target lang. speaker reviews history of items/determines final version
8. Review by project manager
9. Formatting/typesetting/proofreading
10. Cognitive testing with native target lang. speakers
11. Compilation of comments and finalization

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## Qualitative Research

*The systematic collection, organization, and interpretation of textual material derived from talk or observation.*

*(Malterud, 2001)*

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## Qualitative Research

### Quantitative

- Begin w/ hypotheses
- Specific research questions
- Analysis after data collection

### Qualitative

- Generate hypotheses
- General research questions
- Analysis ongoing during data collection

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## Qualitative Research

### Data collection:

- Data sources: interviews, observations, videos, diaries, memoirs, biographies
- Requires sensitivity to pick up on non-verbal cues
  - Familiarity with literature can enhance sensitivity
- Context is important

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## Qualitative Research

### Data collection:

- Interviews audiotaped/transcribed later
- *Interview protocol*
  - Data about date, time, location
  - Questions to be asked during interview
- Additional questions asked spontaneously

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## Qualitative Research

### Data Analysis:

- Begins with 1<sup>st</sup> piece of data
- Coding: assigning themes to data
- Each piece of data compared for similarities/differences
- Conceptually similar segments grouped to form categories
- Concepts form basis of analysis

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## Qualitative Research

### Data Analysis:

- Coding scheme evolves
- **Saturation:** no new piece of data challenges categorical structure
- Both an art and a science
- More than one story can be derived from data
- Qualitative data analysis software (e.g. MAXQDA, ATLAS, Nvivo)

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## Mixed Methods Research

*Integrating or combining qualitative and quantitative methods to draw on strengths of each*

### Reasons for using

- View problems from multiple perspectives
- Contextualize information
- Develop more complete understanding

### Challenges

- Teamwork, resources, sample size, interpretation

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## Mixed Methods Designs

- **Qualitative → Quantitative:** Qualitative research used to develop outcome measures or intervention
  - Most pertinent to questionnaire development
  - Qualitative data used to ensure instrument is grounded in views of participants

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## Mixed Methods Designs

### Example:

- Patient Reported Outcomes Measurement Information System (PROMIS):

Expert review → focus groups → cognitive testing → administer survey → psychometrics

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## Mixed Methods Designs

**Quantitative → Qualitative:** Qualitative used to help explain the quantitative data

**Example:** Do positive views on aging influence health?

- First questionnaires used to determine *if* there are associations
- Then qualitative interviews used to determine *specific* barriers and resources that impact health behaviors

*Craciun et al. (2015)*

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## Mixed Methods Designs

**Qualitative and Quantitative used Concurrently:**  
Both methods used at the same time to answer the same research question

- Example:** Sought to better understand cause of distracted driving by commercial truck drivers
- Qualitative interviews identified how supervisors might distract drivers
  - Surveys focused on decision-making by drivers in near crashes
  - Synthesis of these guided interventions

*Swedler et al. (2015)*

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## Mixed Methods Research

### NIH Clinical Center Example

- Brain imaging study with Fibromyalgia patients and healthy volunteers
- Subjects given experimental heat on leg using thermode, and asked to rate their level of pain
- Qualitative component added to learn how patient's determine pain ratings (looking for differences between FM and HV)

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## Mixed Methods Research

### NIH Clinical Center Example

- **Qualitative data used to explain peculiarities in quantitative data:**
  - Identified subjects who were confused/did not follow directions
  - Identify subjects who had trouble focusing/fell asleep
  - Identify subjects who had pain other than FM

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## Summary



- Questionnaire development requires careful planning
- Use existing validated instruments when possible
- Rigorous methods will reduce response error

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## Suggested Resources (Textbooks)

- Cognitive Interviewing (Willis, 2005/Sage)
- Survey Research Methods (Fowler, 2014/Sage)
- Basics of Qualitative Research 3e (Corbin and Strauss, Sage/2008)
- Designing and Conducting Mixed Methods Research (Creswell and Clark, 2007/Wiley)
- Mail and Web Surveys (Dillman, 2007/Wiley)

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## Suggested Resources (Internet)

- Question Appraisal System (Willis & Lessler, 1999)
  - ([appliedresearch.cancer.gov/areas/cognitive/qas99.pdf](http://appliedresearch.cancer.gov/areas/cognitive/qas99.pdf))
- NIH sponsored health measures
  - ([healthmeasures.net](http://healthmeasures.net))
- Patient Reported Outcomes Measurement Information System (PROMIS)
  - ([nihpromis.org](http://nihpromis.org))

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## Suggested Resources (Internet)

- NIH Toolbox
  - ([nihtoolbox.org](http://nihtoolbox.org))
- Quality of Life in Neurological Disorders
  - ([neuroqol.org](http://neuroqol.org))
- Adult Sickle Cell Quality of Life Measurement Information System
  - ([ascq-me.org](http://ascq-me.org))

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## Suggested Resources (Internet)

- United Health Service Surveys (U.K.)  
([nhssurveys.org/](http://nhssurveys.org/))
- Centers for Disease Control and Prevention (CDC) Surveys
  - ([cdc.gov/nchs/surveys.htm](http://cdc.gov/nchs/surveys.htm))
- REDCap Shared Library
  - ([project-redcap.org](http://project-redcap.org))

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