Practice Based Research:
Patient engagement, subject recruitment, and data collection

William J. Sieber, Ph.D.
Professor, Division of Family Medicine
Research Director & Associate Director of Collaborative Care
Patient Engagement

- Engagement versus recruitment

- Reasons to engage patients
  - Identify blindspots/biases
  - Better understand needs/barriers
  - Grantsmanship (PCORI)

- When to engage patients (even if retro data extraction)
  - Focus groups/patient interviews/Patent Advisory Committees (PACs)
  - Inform design, method, and/or outcomes
  - Recruitment
Subject recruitment I

What is patient’s incentive?
- Often over-estimated (graduate student mentality)
- Financial
- Clinical
- Altruistic
- Burden of involvement (e.g., time, transportation, discomfort)
- Privacy concerns
Subject recruitment II

Recruitment methods (how might sample be biased), IRB

- Community/newspapers
- Flyers in waiting rooms, bathrooms (critical wording? Tear-aways and drop-box minimize effort; patient consultants)
- Waiting room/staff approach
- Registries
- My Chart (allows identification of eligibility)
- Physician-identified (too busy, make easy to identify and refer, warm hand-off)
- Physician incentives and concerns? (CMMI, Scribe, depression screening)
Data Collection I

What?

- Content (what is primary, what is secondary?)
- PROs
- Clinical markers
- Attitudes, knowledge, intentions
- Behaviors (e.g., utilization)
- Standard scale versus home grown: benefits & drawbacks
Data Collection II

• What is hypothesis & purpose?
  • Reducing anger or knowledge of anger mgt skills
  • Satisfaction: with provider, clinic, health
  • Perception vs. behavior (key with self-report)

• How has it been measured in the past?

• What needs to be added?

• Modify existing tools
  ◯ Normative data, known psychometrics
  ◯ Goldilocks is never satisfied!
  ◯ Back away from the questionnaire!
Data Collection III:
Level of data determines (almost) everything!

Types of scales
- Nominal (categorical)
- Ordinal: measures magnitude (relative ranking)
- Interval: equal intervals
- Ratio: absolute zero
Data Collection IV

• Type or level of data limits sensitivity of data analysis
  • Diabetes: yes/no → non-parametric statistics, whereas comparing A1c of two groups allows more options with more powerful statistics (i.e., data reduction lowers power)

• “Higher” level can often be ‘reduced’ to a “lower” level (e.g., continuous vs. dichotomous) but ‘you can’t go back’

• Are you willing to sacrifice sensitivity for convenience (↑ items → ↓ participants, ↑ cognitive demand → ↑ missing data); ‘delay data reduction as long as you can’ - -- so go for ‘item efficiency’

• Is expected distribution of phenomenon captured by your format? (magical DBP of 90, ‘4 or more’ MD visits/year would exclude phone calls to clinic & not be utilization)
Data Collection V: Bias

- Method of collection: Phone, face-to-face, mail, internet
- Selection/response bias
  - Socio-demographic
  - Clinical variables (sick people visit clinic waiting rooms)
  - on-line = ageism? Digital divide
Data Collection VI: Response bias in PROs

- Social desirability

- Recall bias
  - Rare/significant events have longer decay curves (frequency of behavior last week, month, year)
  - Behaviors are less prone to bias (brushing teeth) than subjective impressions/ratings (generous, kind)

- Response set: changing valence (+ -) periodically

- Cognitive dissonance: “I felt so much worse than before this remarkable treatment!”
Data Collection VII

How? (entered & collected)
- Patient report: psychometric issues
- In clinic/US mail
- Email/My Chart
- Clinically relevant/flowsheets

When?
- How often expect change? (PHQ-9, A1c, weight, sustained change)
- Patient burden/attrition: privacy, costs/postage, # questions
Key Points

- Wording is very important …get a consult
- Pilot testing is critical …get a consult
- Make it shorter …get a consult
- Scoring is hard …get a consult
- Every step of the way…get a consult…..from patients, from statisticians, from researchers!