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

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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 !