



Respondent Burden

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The Topics

- Burden from the Respondent perspective
 - IRB Constraints
 - Suggestions/Solutions
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- All information in this presentation is based on secondary sources. See References.

Burden, What is it?

- Perceived: different for different people at different times
- Time length of interview (perceived length)
- Subject matter, privacy issues (HIPPA/biological specimens)
 - i.e. abortion(s), pregnancy, HIV, abuse (physical/sexual)
- Effort or difficulty
- Frequency (longitudinal)
- Significance
- Fear of computer
- Repetitiveness of questions

Example of multiple follow up questions

- Q14 "Have you ever tried to quit or reduce your smoking?"
- Q15 "How many times since the end of the study have you tried to quit smoking?"
- Q15a "Since the end of the study, what was the longest period you quit smoking?"

Best Mode/Best Time

- Computer self interview
- Telephone – most burdensome, interrupting blindly
- In person – most satisfying to respondents

- No time is “best” for everyone
- Retired and/or at home, want contact during day
- Shift workers
- Don't call at work/school

Language is burdensome

- Complex convoluted sentences difficult over phone
- Individual hearing issues
 - Accents can be difficult
 - Physical ability to hear (deafness)
- Specialized/technical lingo
 - Computer lingo
 - Acronyms
 - Slang
 - Medical terminology

Example

- Language for Medical Professionals would not be appropriate for non medical professionals
 - "An electronic medical record (EMR) is a computer-based patient medical record. Not including billing records, does your practice use electronic medical records, part electronic and part paper medical records, or all paper medical records?"

IRB, Internal Review Board

- Primarily ethical point of view
- Justice -- historically arose from unethical treatment of subjects for medical and behavioral research
- Review payments/incentives (can't be coercive)
- Beneficence -- balance between risk and benefit
- Protection for those with diminished autonomy

IRB Continued

- IRB ensures human subjects protection against sensitive questions and enforces appropriate guidelines.
- Boundaries between biomedical and behavioral research
- The selection of research subjects needs to be scrutinized to choose the right criterion.
- Monetary incentives shouldn't be the main factor to persuade economically disadvantaged persons.
- Minimize risk associated with the study population and ensure their well-being.
- Review the inclusion/exclusion criteria for the study population.

IRB Example

- Disparity in incentives is inappropriate
 - "Thank you for your time. We will send you the \$200 check as soon as we verify your contact information. You should expect to receive the check within two to three weeks."
 - "Thank you for your time. We will send you the \$10 check as soon as we verify your contact information. You should expect to receive the check within two to three weeks."

Suggested Solutions to Reduce Burden

- Simple question wording
 - Mutually exclusive response options
 - Close ended questions (easier for respondent)
- Stick to the topic
- Keep the length appropriate
 - Pilot studies to test the length
 - Adhere to the time in the informed consent
- Survey appropriate population
- Appropriate approved incentives

Suggested Solutions Continued

- Convenient/flexible interview time
- Provide survey results
- Panel maintenance, lead letter, newsletter, website
- Good tracking records
 - Respect refusals
 - Make sure completions are not re-called
 - Keep scheduled appointments
 - Limit calls over a fixed period of time

Summary

We cannot completely eliminate respondent burden, however, we can reduce the burden to the participants by:

- Following IRB regulations and rules
- Simplified question wordings
- Keep the length appropriate
- Survey appropriate population
- Appropriate approved incentives
- Convenient/flexible interview time

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