



Survey Research Group

Conducting Research on Vulnerable and Stigmatized Populations

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What Do You Mean, Vulnerable and Stigmatized?

- Groups that if identified as research participants based on their status might be subjected to:
 - Shame, scorn, ridicule or discrimination
 - Damage to financial standing, employability, or reputation
 - Civil liability, criminal penalties or administrative actions
 - Physical danger, persecution, threats reprisals
- Status may be unknown to family, friends, employers, neighbors and others

Examples

- Have stigmatized medical conditions or had stigmatizing medical procedures
- Engaging in illegal or socially unacceptable behaviors, including sexual behaviors
- Victims of crime or stalkers who do not wish to be identified
- “Under the radar” in financial dealings, immigration status
- May be situational – OK in some circumstances, not in others (terrorist vs. freedom fighter)

Why is There Research Interest?

- Interest in how numerous they are
- Concern for their safety and well-being
- Concern about risks they may pose to others
- Interest in how policies affect them or how policy changes might affect their behavior
- General interest in individual and social behaviors
- Interest in methodological challenges

Sampling Approaches

- Identify them within a larger population
 - Ask directly, may be OK in context
 - Make in indirect inference
- Seek them out as the focus of the study
 - Standard probability sampling methods, time/location, “watering hole”
 - Chain referral sampling, RDS
 - Identified indirectly, through informants
- Criteria – Are they known to each other? Can others identify them? Are they willing and able to identify themselves?

Why Would They Participate in Research?

Not different from other respondents

- A story to tell – and fewer opportunities to tell it
- Enjoy respectful interaction with researchers
- Desire to further their interests and help others in the same situation
- Sponsorship credibility
- Financial incentives

Burden Takes on a New Meaning

- Length of survey, time for participation, cognitive burden
- Psychological cost – negative appraisals of self
- Cost of disclosing identity
 - Legal or social penalties
 - Risking reprisal
 - Risks of being judged or not respected
- Interviewers need to be well trained and supported

Keeping Respondents Legally “Safe”

- Anonymity – no record of who respondents are
- Researchers may be asked or compelled to reveal confidential information like respondent identities, failure to do so risks being jailed for contempt
- No blanket legal protection for research, but:
 - Authorizing legislation from some federal agencies allows data protection
 - Federal Certificate of Confidentiality
- Moving contact information out of the U.S. does not ensure protection

Gaining Access to Vulnerable Groups

- Break the “we/they” barrier through meaningful research participation
- Advocacy groups are common
 - Extent to which they are representative of the group is unknown – even to them
 - Often suspicious of researchers
- Helping groups or enforcement agencies may assist
 - Medical treatment facilities, assistance groups
 - Law enforcement, licensing, etc.

Do You Have to be a Horse to Judge a Horse Race?

- Frequent suggestion that only people in the group are suitable data collectors
 - Able to engage other group members
 - Able to ensure the accuracy of information
- This is rarely a necessary and causes problems
 - Introduces “expert” bias in the data
 - Compromises confidentiality in social networks
 - Strained or distracting social interactions between interviewer and respondent
- Use self administration for very private information

Ethical Issues

- Prisoner protections under IRB regulations
 - To what extent do protections extend to people on parole or probation or “at risk”
 - Detainees with ambiguous legal status
- Warnings of requirements for disclosure
 - Intent to harm self or others
 - Child or elder abuse
- When is deception or incomplete disclosure of elements of consent allowable?

Conclusions

- Vulnerable and stigmatized individuals behave like other respondents in many respects
- Special issues apply in protecting them from research risks, including disclosure
- Thought, research and planning make it safe and successful – subject experts, population experts, survey and sampling experts
- Benefits are potentially substantial for a well-conducted study to have significant impact



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