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