

HIV Research Involving Adolescents: Drug Abuse and Other Stigmatizing Behaviors

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Stigma

- Noun: A mark of disgrace associated with a particular circumstance, quality, or person: "the stigma of mental disorder".

Stigmatizing Behaviors

- Drug Use/Abuse
 - Specific drugs
 - Modes of administration
 - Consequences of drug use
- Sex
 - Specific practices
 - Partner number/selection

Other Areas of Stigma

- Disease
 - HIV/AIDS
 - STIs
 - Mental Disorders
- Fashion
 - Clothes
 - Activities
- Social group
 - Peers
 - Activities

Issues for Stigmatized Populations

- Consent
- Justice
- Confidentiality

Consent

- Social Desirability
 - Need/desire for acceptance
 - Fear of refusal
- Culture of Exploitation
 - Expectation of rejection
 - Habituation to negative consequences



Justice

- Need for extra protections?
- Need to correct/compensate for past injustice?
- Individual vs. systemic intervention?
- Parallel with civil rights movements?

Confidentiality

- Review of Confidentiality
- Consequences of Violating Confidentiality
- Special Topics in Confidentiality
- Confidentiality for Special Populations
- Confidentiality Issues for Different Types of Data Collection



Review of Confidentiality

- Confidentiality vs. Anonymity
- Importance varies by culture
- Identifying Information
- Federal Certificate of Confidentiality
- Violations of Confidentiality

Confidentiality vs. Anonymity

- Confidentiality = keeping a secret
- Anonymity = not knowing the secret

Culture

- Concept of confidentiality, privacy
- Protections available
- Researcher's vs. subject's culture
 - Whose definition prevails?

Identifying Information

- It's more than just a name
- “Identifying” depends on who has the information
- Computer based identifiers
 - IP addresses
 - Data mining
- DNA



Federal Certificate of Confidentiality

- Legal protection
- No protection from harassment by police
- No protection from social consequences



Violations of Confidentiality

- Almost always well-intentioned
 - To help a research participant in distress
 - Out of concern for a research participant's well-being
 - To further the aims of an important research study

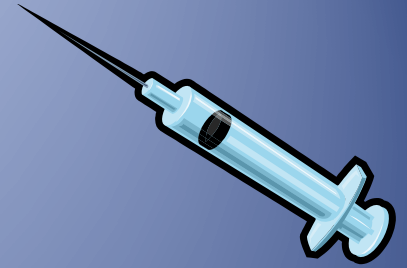
Consequences of Violating Confidentiality

- Arrest
- Physical harm (even death)
- Shame/Emotional Distress
- Relationship Distress
- Harm to the Participant-Researcher Relationship
 - For specific study/researcher/institution
 - For research in general

Issues for Specific Populations

- Injection Drug Users
- Youth
- MSM

Injection Drug Users



- Illegal Behaviors (not only drug use)
- Capacity for consent when using
 - Is an addicted drug user more/less able to consent when high or when in withdrawal?
- Compensation
 - Paying for drugs
 - Preventing other money-raising practices
- HIV risk for participant and others

Youth

- Parental Consent/Assent
- Youth Consent/Assent
- Emancipated Minor Status
- Risks in getting consent from parents/guardians



MSM

- LGBTQ is really L, G, B, T and Q
- Internalized Stigma
- HIV risk for participant and others



Individual Interviews

- Interviews in public/semi-public locations
- Interviews in private locations identified with specific populations
 - Health clinics (including specialized clinics)
 - Research field sites



Focus Groups

- Confidentiality among participants
- Group composition
- Power dynamics

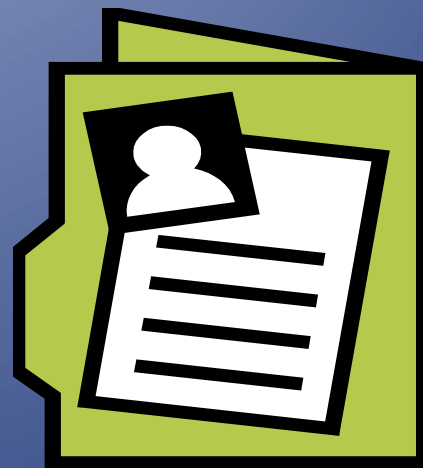


Ethnography

- Participant-Observation
- Boundaries

Clinical Chart Reviews

- Identification of individuals with study topics
- Disclosure of research information to clinic staff



Internet-Based Research

- Hidden identifiers
 - IP address
 - Facebook information
- Veracity
 - Subject
 - Researcher
- Inability to read verbal and nonverbal cues
 - Distress
 - Honesty
 - Capacity



Case Studies

- IDUs
- Youth
- MSM

