

Negotiating Contradictions Between Research and Service Goals at the UFO Study

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Definition of Issue

- Epidemiological and bio-medical research studies of vulnerable populations often embody contradictions between the studies' scientific goals and the service needs of study participants.
- Resolving the contradictions sometimes occurs as a dialectical process resulting in synthesis.
- Personal standpoint: Writing from my position as a front-line worker, as a counselor/interviewer and coordinator for UFO. Involved in various aspects of injection drug user health since 1994. Currently naloxone prescription project coordinator for the Drug Overdose Prevention and Education (DOPE) Project and board co-chair, San Francisco Needle Exchange. Member of the North American Users' Union during its existence.

The UFO Study

- The UFO Study (UFO) is a series of community-based studies of viral blood borne infections in young adult injection drug users (IDUs) in San Francisco.
- Over the last 8 years, UFO has reported on the epidemiology of HIV, HCV, and HBV infections, as well as opiate overdose and methods to improve HBV vaccine adherence in young and often homeless IDUs.
- The UFO research team includes principal and other investigators, as well as front-line staff, including: project directors, interviewers/test counselors, outreach workers, phlebotomists, and nurses.
- The UFO Study has a long research and collaborative history.
- It was initiated in 1997 with funding from the California Universitywide AIDS Research Program (UARP) as one of the first "HIV

Community Collaborative Research" Awards as a collaboration between the Haight Ashbury Youth Outreach Team (HAYOT), a program of the Haight Ashbury Free Clinic, Inc. and researchers at UCSF.

- The collaborative grant process was the first to emphasize equally both programmatic and research goals, and some saw this as a unique opportunity to mix services with research for an especially vulnerable and underserved population.
- Since 2000 the UFO Study(ies) have been funded by a series of grants from NIH, UARP and UCSF with changes in research questions and priorities.
- Community partners and providers have changed over time due to changes in fiscal, political and public health priorities, also resulting in changes in service provision to young IDU.
- The emphasis on community collaboration was no longer a directive by study funders but members of the study team, especially front-line staff remained strongly committed to providing services to study participants.

The Issue

Negotiating the gap between research priorities that construct "subjects" as objects of knowledge and service priorities that construct "subjects" as patients or clients.

Expanding Services at UFO

Conflict between service and research goals often presents as field staff wishing to expand the services provided to UFO participants.

Negotiated Issues

Problem/Challenge	Staff Perspectives	Researcher Perspectives
Multiple service needs	Expand medical, mental health and social services.	Institutional constraints; limited resources.
Laboratory tests and diagnostics	Disclosure of all research testing results.	Regulatory constraints regarding diagnostic vs. experimental tests.
Access to prevention	Full availability of prevention, e.g. clean injecting equipment.	Regulations prohibiting use of federal funds for NEP.
Study instruments and tools	Staff input: lexicon changes, cultural competence.	Measurement priorities: concerns for internal and external validity
Research questions	Experience driven	Hypothesis driven

Problem/challenge: Instrument design

- UFO field staff reads the instrument before it is finalized and makes suggestions in content, language, and cultural competence.
- Field staff also advocates for research areas to be included in the instrument.
 - Overdose
 - Police harassment and incarceration of participants

Problem/challenge: Disclosure of experimental HCV laboratory results

- Enzyme immunoassay (antibody test: EIA III), Recombinant immunoblot assay (confirmatory antibody test: RIBA), and transcription mediation amplification (viral nucleic amplification test: TMA) test results originally only used for research purposes.
- Field staff questioned the ethics of withholding results from participants, particularly results that could indicate that the participant has cleared the virus.
- Research staff struggled with the ethics of disclosing experimental test results not approved for clinical use.
- These results are now disclosed to UFO participants.

Problem/challenge: Syringe distribution

- Funds from federally funded grants are not permitted to be used for syringe exchange.
- Field staff questioned the wisdom of giving money to young injectors, which they will probably use to purchase injectable drugs, without giving them new syringes.

- One UFO project now provides the standard of care for IDUs by giving participants new syringes and injecting equipment.
- One UFO project has syringe exchange volunteers on site to provide syringes and other injection equipment to participants.

Problem/challenge: Expanded HCV diagnostic testing for participants in all UFO studies.

- HCV is epidemic in the population and expanded testing leads to better knowledge and potential for prevention.
- Staff wants expanded access to sophisticated HCV testing for young IDU participating studies where HCV is not the principal focus, for instance: HCV RNA and viral load, and liver function tests.
- Research protocols limit tests due to resource and study priority constraints.
- Negotiated results: no expanded testing services.

Problem/challenge: Expanded medical services for participants at UFO research sites

- Field staff advocates for increased access to medical resources.
 - Diagnosis and treatment of illness, including prescriptions.
 - Incision and drainage for abscesses.
 - Healthcare related to the questions in the interview.
 - More comprehensive injection related healthcare.
 - Workshops for vein care, abscess prevention, overdose prevention
 - Naloxone prescription
- Research staff limit direct provision of medical care based on resources, safety, institutional constraints including liability, and other needs.

Challenges to Successful Negotiations

- Breakdown in communication between research and field staff.
- Financial constraints.
- Concern that providing services may bias study results.
- Competing forms of knowledge.
 - Team members have different understandings of and responsibilities to UFO participants.

Competing Forms of Knowledge

- **Epidemiological** – Understands participants as members of population samples; goal is to gather appropriate data to direct public health policy.
- **Medical** – Understands participants mainly as bodies that can be diagnosed and treated.
- **Psychosocial** – Understands participants as individuals embedded in a society that often does not meet their basic needs.
- **Street** – Participants have direct experience and knowledge of their own lives.
- These forms are not necessarily mutually exclusive, particularly in practice.
- UFO in practice = bricolage.

Opportunities for Better Negotiation

Communication between field and research staff is key.

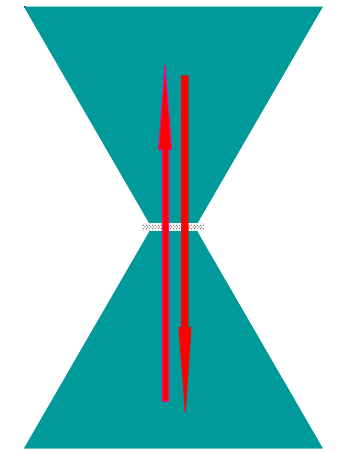
- Establish channels of communication between frontline and research staff.
 - Regular meetings with both research and frontline staff in attendance.
 - Field staff input in meeting planning and agenda important.
 - Project Director crucial for successful negotiation.

Future Issues to Address and Negotiate

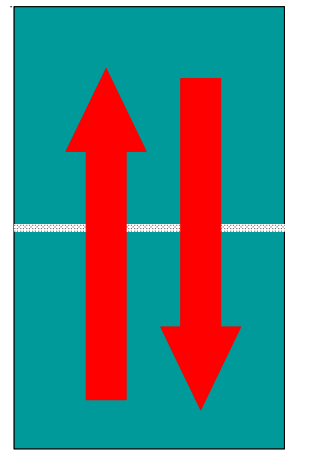
Expanded participant input in research.

- Currently no mechanism to incorporate participants' research priorities.
- No official method to ask participants what issues they believe to be most important to study.
- Community advisory board that includes participants.

Communication between research and frontline staff mediated exclusively by a Project Director: limited, but focused



Unmediated communication between research and frontline staff: more open, may lack focus



Factors for Successful Negotiation

- Clear and frequent communication between field and research staff.
- Changes in knowledge leading to shifting research and service priorities.

Outcomes and Lessons Learned

- Trust and an open dialogue between investigators and front-line staff are critical to successful negotiation. Negotiation can close the gap between research priorities that construct "subjects" as objects of knowledge and service priorities that construct "subjects" as patients or clients.

Fellow Aliens of UFO "Praxis makes perfect"

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