

Tribal Experiences: Lessons to Guide Recruitment of Rural and Diverse Participants

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Topics to be covered:

- Some relevant literature
- Involving the community in study development
- RCT issues
- Advisory boards
- Understanding the communication channels



Cochrane Collaboration

- Meta analysis
- 27 RCTs with 26,604 participants
- Procedures that work but pose problems
 - Opt out recruitment
 - Open design – snow ball recruiting
- Telephone reminders to non responding participants

Increasing Minority Research Participation Through Community Organization Outreach

- Roger A. Alvarez, et al. Nova Southeastern University (2006)
- “For this study population of women who were HIV+ and recovering from substance abuse disorder, the authors found that establishing ***trust with community organizations*** that serve these women allows for a productive referral relationship.”

Effect of Different Incentives on Recruitment

- Nina Heinrichs, et al. (2006)
- *“Results demonstrate significant impact of payment on recruitment and initial attendance.”*
- Importance of fair compensation for time and any discomfort

Recruitment of Ethnically Diverse Populations for Cancer Nursing Research

- M. Tish Knobf, et al. (2007)
- Establish trust
- Develop an understanding of heterogeneity within and across diverse groups

Strategies

- Build community relations
- Recruit and train ethnic research team members
- Foster personal attributes of flexibility, sensitivity and adaptability
- Provide adequate compensation for recruiters
- Develop multiple strategies for recruitment

Modifications

- Tailor strategies to the study design
- Adapt materials to the target population
 - Readability
- Research mentorship of community members
- Accommodate cultural calendar of community



Recruitment of Low SES Participants

- Issues surrounding low socioeconomic status:
 - Less education, lower literacy, lower-paying jobs
 - Less flexibility with job
 - No Job: higher flexibility
 - Child care problems
 - Communication - phones
 - Life events higher priority than research participation



Cultural Sensitivity

- SAMHSA Culture Card
- What is this in real life:
 - 565 Tribes: commonalities and diversity
 - Handshake
 - Eye contact
 - Apparel: appropriate but not overdressed
 - Knowing what not to say
 - Role of religion or spirituality
 - Be yourself but modify behavior to fit culture

Involving the Community in Study Design

- Sovereign Tribal governments
 - Sovereignty is a big deal
 - Can guide thoughts on all issues
 - Spirit more important than words
- If you do not agree with a core value of the community you should not work there
 - Shared decision making

Know the Community Structure

American Indian Communities:

- Often mirror the Federal government
 - Executive, legislative and judicial: Tribal Chairman, Tribal Council and Tribal Courts
 - May have many sub-units: Chapters and Agencies
 - Some are VERY democratic: lots of participation and many votes

Know the Key Players in the Community

- How and Who: IRB or RRB or Council
- Know who has the power and who does not
 - Tribal Government versus IHS
- Do not misjudge based on appearance or education
 - Grandmothers can be powerful!
 - Status not necessarily related to education

Community Courtesy

- Arrogance is death – be open to ideas
- Make changes – respect
- Some people are very experienced
- Scientific advancement is not good enough
- Must bring immediate benefit, even if small
- Involve suggested people – huge benefit

Involve The Community In Research Design

- Examples:
 - Participant Compensation
 - Standard amounts may be established - \$20
 - Language – necessity and / or respect

Data Ownership and Sharing

- Data handling and manuscript development
- Respect the source: no surprises to community (IRB or RRB)
- The community deserves the knowledge first
 - Heads up principle
- Why? – Because they will help you recruit

Conflict and Compromise

- Some principles may conflict with the desires of the community
- Attempt to compromise when possible
- If compromise is not possible – walk away
- Do not say one thing and do another
 - We all pay for that behavior: Havasupai
 - Know the hot buttons: Genetic research

The Role of Respect

- If the study is designed without respect for the community recruitment will be impossible
- Long term approach is best
 - Flying in and flying out: you will have trouble
- No substitute for history
 - Find someone to help if you do not have any history



RCT Issues

- Randomization can incite suspicion
 - Explain how and why
- Care as usual, enhanced community services, and intervention
- We do not do research without a benefit to all study arms
 - Can be minor: materials, tooth brushes, etc.
 - If not handled carefully, it can be a disaster

Advisory Boards

- Understand the diversity of community
- Structure carefully: rely on multiple community members for help
- Make it substantive: “This ain’t no game”
- Once a decision is made stick to it
- Trust and respect produces study supporters
- Can help with recruitment

Advisory Boards

- Community resource agencies can help
- Get the right professional people to join but not dominate the board
- Have a community member as chair – when possible
- Try to avoid lists of recommendations that will not be used
 - Carefully control the discussion

Advisory Boards

- Primary reason – To increase trust
- Trust is related to recruitment and success
- Involve them in solving recruitment problems
- Listen to suggestions and implement
- Size: bigger may be better for recruitment but...



Working with Key Organizations and Community Members

- Tribal colleges, Tribal health offices, health care organizations, schools
- Identify key players
- Get the organizations on your side
- Transportation

Understanding the Communication Channels

- Involvement of community leaders can be positive but can also be negative (polarization)
- If you or your organization become known, it can be helpful
- If you are not known – hire the right person or people



Summary

- Trust
- Humility
- Local Involvement
- Time
- Respect
- Fidelity
- Flexibility
- Compromise

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Thanks!