

Multilevel Factors in Participant Retention in Community-Based Health Studies

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Presenter Disclosures

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose

Background

- Individuals and groups most vulnerable to social inequalities and poor health may be more difficult to recruit/retain in studies.
- Groves 2006; Odierna & Schmidt 2009
- Health research is often hampered by poor retention of participants, which can bias results and lead to inaccurate findings.
- Davis, Broome, Cox 2002; Corrigan 2003

Significance

Guidelines and policies that are based on research that does not adequately retain disadvantaged populations may perpetuate health disparities - Tugwell 2006

Purpose

- Identify how characteristics of research participants, studies, and context may act as barriers to/facilitators of retention
- Provide information for investigators to
 - Develop effective multilevel retention protocols
 - Justify and allocate adequate resources for optimal retention rates

Methods

Population

Focus groups (n=54)

- 3 with current/former subjects, dropouts (n=32)
- 3 with study personnel: research coordinators, interviewers, principal investigators, nurses, receptionists, et al. (n=22)

Interviews with study dropouts (n=4)

Sites: UCSF Research Centers

1. General outpatient research (hospital)
2. Behavioral research with subjects generally considered hard to enroll and retain (community-embedded)
3. Studies of dementia, cognition, healthy aging (specialized center)

Study Procedures

Recruitment

- Staff meetings
- Flyers
- Word-of-mouth
- Cash incentives. Good food.

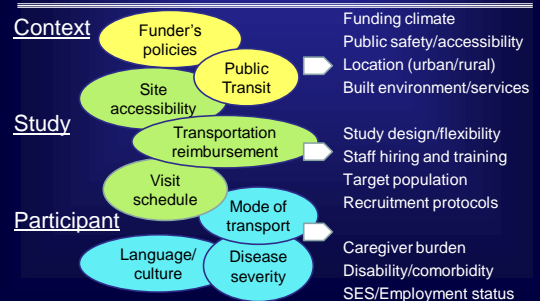
Inductive data collection and analysis

Results

Multilevel Factors in Retention

Context	Funding policies/regulations; neighborhood/area, local/regional policies, accessibility issues, and health services; built environment; workforce; catchment area; institutional reputation
Study	Study design, personnel, relationships, flexibility, institutional memory, bureaucracy, non-study services, participant/caregiver burden, incentives, transportation funds, location, retention protocols
Participant	Study implementation, sociodemographics, disease severity, employment, culture/language, treatment options, access to information/healthcare, volunteerism, altruism, salience, sense of fun/curiosity, disease family, caregivers, gatekeepers, relationships; sense of community, feeling (dis)respected.

Example: Transportation



Conclusion

The context in which research is conducted, and the characteristics of research participants and studies may interact to affect retention rates in longitudinal studies. Investigators should explore multilevel strategies to improve retention of diverse participants in health studies.

Future Directions

- Prospective studies, population- and discipline-specific issues
- Examine retention of diverse participants in drug trials and CER/PCORI
- Interactive tools to assess risk and reduce loss to follow-up

Limitations and Strengths

- UCSF-only venues
- Convenience/volunteer sample
- Limited sociodemographic data

- Real-world examples
- Multiple viewpoints
- Inclusion of study dropouts

Thanks

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