Strategies used to meet recruitment goals and retain >90% of low income mothers in a yearlong RCT

Jenna Sandler Recruitment and Retention Roundtable November 30, 2016

Learning Objectives

- 1. Understand the challenges to engaging diverse populations in research
- 2. Implement strategies to meet recruitment milestones
- 3. Develop approaches to maintain high participant retention in research

Discussion question

• In your own work, what do you see as barriers to participation of vulnerable populations in research?

Common barriers to participation of vulnerable populations in health-related research

- Mistrust
- Competing demands
- Unintended outcomes
- Lack of access to information
- Stigma
- Health insurance coverage
- Legal status in the United States

George, S., Duran, N., & Norris, K. (2014). A Systematic Review of Barriers and Facilitators to Minority Research Participation Among African Americans, Latinos, Asian Americans, and Pacific Islanders. *American Journal of Public Health*, *104*(2), e16–e31.

Project Solve Context



- RCT's testing the efficacy of a problem solving intervention to prevent depression among lowincome urban mothers
- Study population:
 - Low income
 - Very diverse (75% racial or ethnic minority; about 50% born outside the US)
 - At risk for major depression
 - Over 50% had a history of trauma
 - Majority single mothers

Project Solve Research Assessments

- Research assessments every 2 months over a one year follow-up period
 - By phone: 2, 4, 8, and 10 month
 - In person: Baseline, 6 and 12 month
- In person assessments conducted in the home or other community location

Project Solve Staffing Structure

- Three distinct teams of research staff that work across projects
 - Recruitment team
 - Intervention team
 - Follow-up team

Recruitment strategies

Proactive outreach

- Incorporating screening for study into current practices
- "Loopback" recruitment strategies to capture missed referrals
 - Continuously obtain data on missed referrals and get permission to contact
- Opt out letters

Getting in touch with potential participants

- Flexible research staff
 - Evening, weekend hours
- Call as soon as possible after receiving a referral
- Loop back to referring provider about non-working numbers
- Recognize that people are busy. Be persistent but respectful
 - On referral form, ask for preferred times to call and for preferred methods of contact
- Call from non-BMC number
 - Staff cell phones

Building rapport

- Re-visit the recruitment script often
- Bilingual/bicultural staff are key

High quality informed consent process

- Two way discussion
- Provide opportunities for questions
- Offer time for family to discuss and think it over

Recruitment of sites

- Identify a champion at each site
 - Someone who cares about the research aims
 - Talk with this person every month
 - Go to them to troubleshoot as issues arise
- Give back
 - Use research team's expertise to provide educational opportunities and resources

Close monitoring of recruitment progress

- "Diagnose" why you're not getting people into the study in the way you want to
- Systematically track study flow from referral to enrollment
- Make changes as needed

Retention Strategies

Prep to retention

- Ensure that research participants fully understand what is involved in the study
 - MacCAT-CR tool
- Screen out families who plan to move or travel for extended period of time
- If possible, have several steps before randomization
 - 1. Contact on phone to gauge initial interest
 - 2. Conduct home visit to conduct informed consent and baseline
 - 3. Call next day to randomize (remind participants of what is involved and confirm that they would like to move forward)

Training RA's

- Importance of "being human" during research assessments
- Personalize visits
- Be understanding about no-shows and cancellations
- Same RA should do all visits for a participant to build a relationship

Be accommodating

- Flexible hours/days
- Flexible methods (phone, in-person, email)
- Allow for rescheduling
- Offer to skip a research assessment and call again for the next one

Strategies for keeping in touch

- Utilize all methods you have permission to use
 - Text
 - Email
 - Alternate contacts
 - Social media (with appropriate permissions and steps to protect privacy)
 - If possible, provide cell phones to participants

Documentation

- Maintain accurate and thorough contact information, including alternate forms of contact
- Permission to access EMR
- Update contact information at EVERY time point
- Detailed contact logs

Strategies for keeping in touch

- Consistent point person for each participant
- Reminder calls, especially if there is a gap between visits
- Send birthday cards/holiday cards
- Last resort strategies
 - Certified letter to tentatively schedule an interview
 - Find participants at clinic visits
 - Partner with another provider to coordinate a visit

Continuous quality improvement

- Ask participants for feedback
 - If participant withdraws, ask for feedback and learn from the experience
 - Qualitative interviews at study completion
- Track major issues very closely
 - Loss to follow up
 - Participant withdrawals

Maintain accurate tracking systems

- Interview "windows" with start and end date for each research assessment
- Create a data tracking system that can easily query interviews that are currently due
 REDCap
 - Don't rely on Excel for big studies
- Someone should be looking at the tracking systems daily
- Weekly meeting with PI to review follow-up rates

Take home points

- Most valuable strategies for Project Solve:
 - Discussion-based informed consent process
 - Flexible, dedicated research team with strong interpersonal skills and language capacity
 - Home visits
 - Texting
 - Alternate contacts
 - Meticulous tracking

Questions?

