### 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?

