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

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Recruitment and Retention Roundtable
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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

RCT’s testing the efficacy of a problem solving intervention to prevent depression among low-income 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?