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SPRC: The Community Partner’s Experience

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UMass Center for Clinical and Translational Science
Mini Symposia Program
SPRC: The Community Partner’s Experience

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Disclosures

• We have no actual or potential conflict of interest in relation to this program/presentation.
Rationale for SPRC

• History of racism endured by racially and ethnically diverse communities in the past, i.e. Lacks and Tuskegee
  • Created suspicion among these community
  • Affects their willingness to participate in biomedical/clinical research
• Difficult to make results from research studies applicable to these communities
What is SPRC?

- Science Participation Resource Center
  - Goal: Increase participation of under-represented communities in clinical research
    - Under-represented: LGBT, ethnic/racial minorities, elderly, youth
  - Partnered with local community organizations to create a two way bridge between the academic and community worlds
  - Community Advisory Board (CAB) created to help strengthen relationships
Community Engagement

• Research forums/focus groups throughout the year to increase research literacy
  • Encourage dialogue and build trust
• Conquering Diseases outreach
  • Volunteer registry encourages individuals to participate in research studies at UMass

Community Engagement (cont’d)

- Public Media
  - Telegram & Gazette
- Community Forums
- Focus groups
  - Moderated by Community Representatives
Cultural Competency

- Number of barriers that lead to lack of participation
  - Informed consent process
- SCRIIPPTT was created to help find a way to break down these barriers, starting with our own research staff here at UMass
Simulation-based Community-engaged Research Intervention for Informed Consent Protocol Testing and Training

Goal: develop culturally and linguistically appropriate approaches to the informed consent process

Collaboration between community members and UMass faculty
Background of SCRIIPPTT

• Community members and faculty came together and created a 37-item checklist to train Research Assistants (RA)
  • 79% is the minimum passing score and no Core Item
• RAs were then trained on in the informed consent process, focusing on:
  • Communities of color
  • Cultural implications
  • Delivering feedback
Use of Simulation

• RAs used simulation centers to practice encounters using the techniques they learned
  • Community members were trained to act as potential research participants
• Additional community members and faculty observed via video and rated the RAs performance using the 37-item checklist
Deliberate Practice

• Deliberate practice: repetitive performance
  • Used after each encounter (total of 3)
• All observers gave feedback to the RA on their performance
• RAs used the feedback to improve on their performance while in deliberate practice
End Result

- 13 RAs were trained
- 4 did not meet the minimum passing score (79%) and were invited to come back for more deliberate practice
- All improved dramatically, compared to their baseline data
Hopes for the Future

• These results are a glimpse of how successful deliberate practice can be
• Community-engaged methods and medical simulation are novel ideas
• Simulation centers provide a safe environment for learning
Consultation Service

- UMass staff and community members meet with UMass research study teams
  - Advise with recruitment and retention strategy of under-represented populations
    - Technical support from UMass Team
    - Community feedback from network of community groups
    - Direct linking with community partners
- Open to researchers across UMass’ Network
Consultation Service: Scope

• Assist a Research Team with development of recruitment and retention protocols from inception to application
• Assist a Research Team with evaluation and adjustment of existing recruitment and retention protocols
• Offer outsourcing connections when research team is in need and within ability to include in their budget
• Our team can engage with research team and recruiting/retention agency to offer guidance based on planned recruitment and retention protocols
  • This may include training for research team and agency
• Follow up over time to aide in process of protocol application with research team and agency
Upcoming Events

• Presentation at Northeastern on May 19th to present on the work of SCRIIPPTT
• Forum on May 31st at Booth Housing Development
• Focus groups with African communities, i.e. Ghanaian and Liberian communities
Questions?