

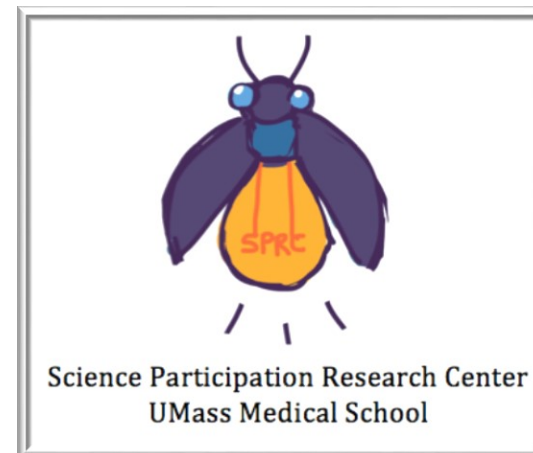
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SPRC: The Community Partner's Experience

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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



<http://www.dmnews.com/marketing-strategy/us-cellular-calls-on-community-engagement/article/416987/>



Community Engagement (cont'd)

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



Cultural Competency

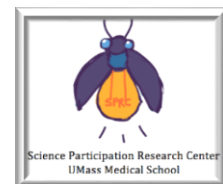


- Number of barriers that lead to lack of participation
 - Informed consent process
- SCRIIPTT was created to help find a way to break down these barriers, starting with our own research staff here at UMass



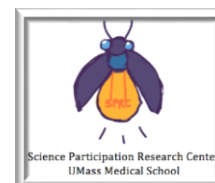
SCRIPTT

- **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 SCRIIPTT

- 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



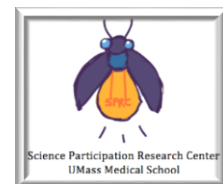
Deliberate Practice

- 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



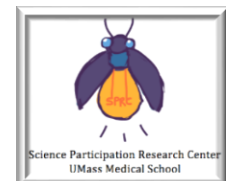
Hopes for the Future

- 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



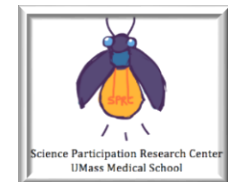
Consultation Service

- 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 SCRIIPTT
- Forum on May 31st at Booth Housing Development
- Focus groups with African communities, i.e. Ghanaian and Liberian communities



Questions?

