Community Engagement

Selection, inclusion & access

RESEARCH MATTERS LIVE



Selection

Who to study?

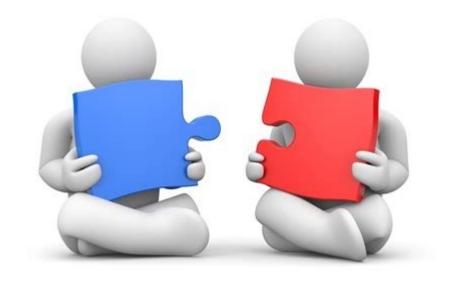
- Inclusion factors that define (frame) the generalizability of the results
- Exclusions for safety and welfare
- Exclusions for ethical reasons
- Exclusions for factors that limit interpretability of results



Recruitment

How to invite?

- Methods
- Materials



Access/"Ask us"

- As few as 3% of vaccine trial participants are Black (Warren et al., NEJFM, 2020)
- Multi-Regional Clinical Trials guidance for Achieving Diversity, Inclusion, and Equity in Clinical Research: https://mrctcenter.org/



CBPR-Applied

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RESEARCH MATTERS LIVE



HEALTH DISPARITIES RESEARCH

Health Disparities research merges my two passions in clinical health psychology and social justice/multiculturalism

Goals of Health Disparities Research

The primary aims of my research are to

- (i) identify health-related inequities/disparities
- (ii) examine and understand the biopsychosocial and sociocultural/political factors that cause and/or perpetuate these disparities, and
- (iii) develop culturally-contextualized interventions to reduce health disparities and improve health outcomes in under-represented and marginalized groups overlooked by behavioral health and psychological research.

CBPR (Community-Based-Participatory-Research) enables us to conceptualize, develop and evaluate scaled-up community based interventions that and integrated into community and clinical settings, where they can help large numbers of consumers, providers, and community systems.

Historical Research Limitations

- 1. Culture and context was ignored
- 2. Culture is viewed as a nuisance variable---rather than as a *central* contextual variable that helps to explain human behavior.
- 3. Large within-group differences are ignored
- 4. Internal validity was often favored over external validity
- 5. Culturally-diverse groups do not directly benefit from studies in which their members participate---because culture or race is ignored.

CBPR is a potential approach to eliminate many of these limitations.

<u>Today:</u> NIH and other federal funding agencies are now requiring researchers to take race, ethnicity and other demographic variables into consideration.

What is CBPR?

CBPR is a grass-roots approach to solving community health problems through community empowerment and social action.

"a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings."

Important CBPR Principles:

- 1) tailoring to meet the needs of communities;
- 2) involving participants in program development, implementation, and evaluation;
- 3) using ecological frameworks with multiple levels of analysis.
 - analyses that consider the individual, family, community, culture, sociopolitical factors, oppressive institutional policies, etc.

CBPR Partnership Example: Mercy Health Center

 Nonprofit organization that provides comprehensive care: primary care, pharmacy, dental services, health education, nutrition and exercise services, behavioral health and social service

• Small staff of 14 people, and nearly 800 volunteers



Patients have an income at or below 150% of Federal Poverty
 55% Caucasian, 25% Black, 17% Hispanic, and 3% other races, including a growing refugee population





Our UGA-Mercy Partnership



Mercy was seeing patients for medical services but removed intake questions regarding depression and anxiety symptoms.

Reason: 80% of patients endorsed severe symptoms of depression and anxiety but Mercy lacked mental health care expertise to provide required care.

Partnership first established in 2015:

 Collaborative and Service-Learning Partnership "Counseling Psychology Doctoral Practicum"



- Offered integrated, interdisciplinary behavioral health approach in Mercy Health Center
 - Behavioral Health, Interprofessional Consultation, Medication Monitoring, Triage, Interdisciplinary Treatment Team meetings----Research

CBPR Approach to Project INSPIRE

Project INSPIRE: Study examining chronic pain in patients in primary care

Characteristics of the CBPR approach include:

- (a) recognizing the community as a unit of identity
 - physicians, nurses, social work director, primary care patients
- (b) building on the strengths and resources of the community
 - EMR system, interdisciplinary approach to patient care, IPC
- (c) promoting co-learning among research partners
 - Learning about research and chronic pain
- (d) achieving a balance between research and action that mutually benefits both science and the community

Closing Thoughts on the Value of CBPR

- CBPR can promote community empowerment and social action
- Begin the process now--work on developing and establishing that partnership. Don't wait for a grant that will enable you to do CBPR.
 - 88% of successful CBPR researchers had pre-existing working relationships with the organizations that eventually became their CBPR partners.

Using Digital Methods to Promote Research Inclusion

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RESEARCH MATTERS LIVE



Digital Tools & Methods for Research

Online Recruitment Strategies

Online Screeners & Survey Assessments

Mobile App & Web Portal Use

SMS and Telemedicine Interventions

Cloud-Based Participant Management Software

Paradata & Web Analytics for Research Evaluation

API Integration

Geospatial Locators

Data Visualization & Dissemination



Evidence for a Shift Among Researchers











Selection, Response, & Social Desirability Bias

Participant Reach & Burden Cost Effectiveness

Staff Burden & Automated Data Processes

Data Quality & Evaluation

Are Digital Methodologies a Good Fit?

Study Design

- Data Collection and Analysis Plan
- Participant Management
- Recruitment Strategies

Financial Commitment

- Affordability
- Budget Limitations
- Maintenance & License Fees

Learning Curve

- Staff Expertise
- Training & Protocols
- Programming & Piloting

Intended Users

- Tech Savvy
- Literacy
- Look and Feel
- Accessibility of Stable Internet and/or Device

nstitutional Support

- IRB Approval
- BAAs
- HIPAA
- Data Security & Encryption
- IT Support
- Institutional Support









Digital Recruitment Strategies



Social Media

Facebook Instagram Twitter Snapchat Reddit



Transit

Bus Stations Bus Stops Subways/Trains Airlines



QR Codes

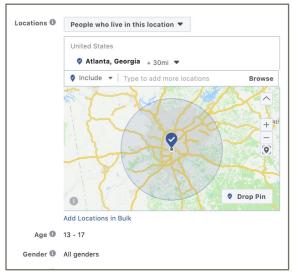
Flyers
Business Cards
Mailers
Posters/Billboards

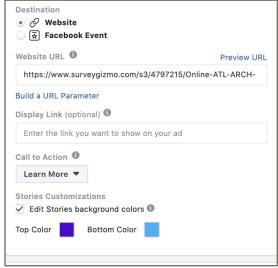


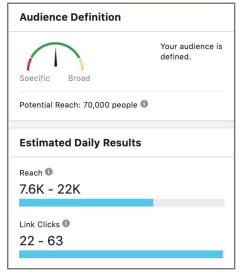
Mobile Apps

Websites Dating Apps Messaging Apps Streaming Apps

Online Recruitment Strategies



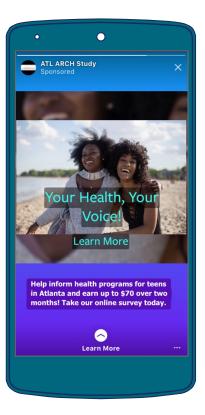




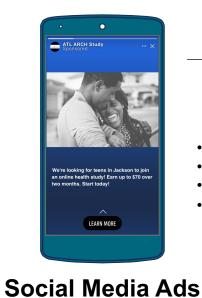
Online Recruitment Strategies







Automated Screening and Enrollment

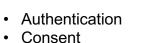


- Query strings
- Jumper links
- Hidden fields
- Unique ID Generation



Screener



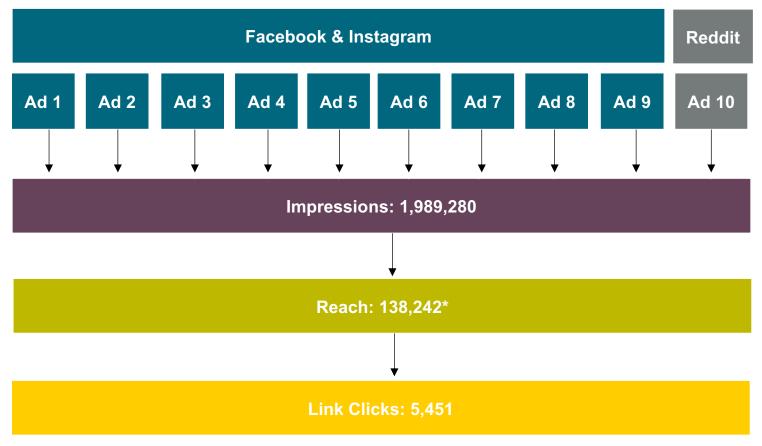


- Paradata
- **Custom Coding**
- **Data Quality** Checks



Survey Assessment

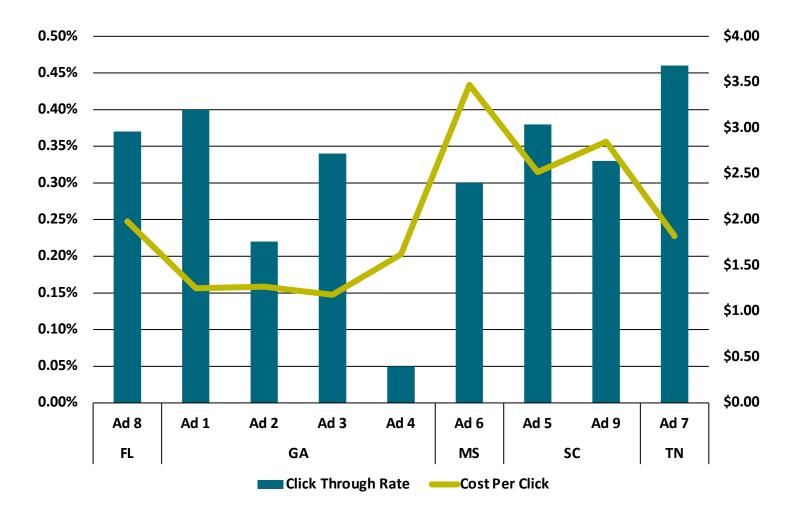
Recruitment Reach



^{*}Analytics regarding ad reach are not tracked/available through Reddit. The reported total only represents available analytics for Ads 1-9 on Facebook and Instagram.

Lambert et al., 2020

Cost Effectiveness



Lessons Learned

Feasibility of Digital Methods

Reaching Underserved and Marginalized Populations Is Very Feasible
Plan for Cost Differences Based on Population Density, Urbanicity, Community of Interest, Age, etc.
Fraud is a Consideration With Online Methods, However Many Proven Strategies to Validate Respondents
Many Communities Prefer Online Methods & Readily Have Access to Devices/Internet

Engage Community in the Process

Representation is Important
Consider Language, Imagery, and Readability
Build Trust & Relationships to Widen Reach and Increase Potential Impact
Theatre Testing & Piloting is Key

Giving Back Through Dissemination Efforts

Digital Methods Can Increase Transparency and Access to Findings, Recommendations, and Services
Dissemination Back to Communities Most Impacted Increases Collective Capacity for Change
Consider Non-Traditional Communication Channels for Dissemination to Reach More Diverse Audiences

Fishers of Men

Henry N. Young, PhD

Interim Department Head & Kroger Associate Professor Clinical and Administrative Pharmacy Department



Fishers of Men: Translating Research into Practice

Project Goal

• To implement a rural, community-based, multilevel, translational intervention to address disparate outcomes among rural men with or at risk for chronic diseases, such as cancer, diabetes, cardiovascular disease.





Fishers of Men: Translating Research into Practice

Impact of the COVID-19 pandemic



<u>USDA Opportunity – Distance Learning & Telemedicine</u> <u>Grants</u>

- Fishers of Men: On the Road to Health
- Faith-based organizations located in rural Georgia cities and towns
 - Interdenominational Ministerial Alliance (IMA)
 - Georgia Union Missionary Baptist Association (GUMBA)
- Sites are located in the following Georgia cities
 - Vienna, Montezuma, Americus, Vienna, Leslie, Hawkinsville, Fitzgerald, Unadilla, and Elko
- Projects
 - Pharmacist telemanagement service
 - Prescription drug abuse health communication campaign
 - Chronic disease self-management program

Community-Based Participatory Research

≻Guiding strategies

- Utilize the community/public outreach arm of the university to connect with rural communities.
- Create synergy around identified community health needs.
- ➤ Engage: Encourage community members to provide input into the research design to ensure the research goals reflect community values.
- ➤ Enhance the capacity of community partners. Building the capacity of community partners is important for building strong, trusting relationships.
- Follow the lead of the community.

Community & Stakeholder Engagement







UGA Campus Collaboration

- College of Pharmacy
 - Clinical and Administrative Pharmacy
 - Information and Instructional Technology
- Archway Partnership
- School of Social Work
- Possible others in the future ...
 - College of Public Health
 - College of Family and Consumer Sciences

Wrap-up

IRB tips

- Develop partnerships in the community early in project development
- Inclusion and Exclusion must be scientifically and ethically justifiable
- Ensure voluntariness
- May 4, 1:00 p.m. Consent

