Recruiting Minority Adults through Electronic Technology

Center of Aging in Diverse Communities

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Outline

- Background
- Systematic Review
Background

- There is need to increase the participation of older adults and underrepresented groups in research
- Treatments are often based on studies including younger, healthier, higher functioning individuals
- It is estimated that 20% of clinical trials need to be extended because of inadequate recruitment
- Prior research has indicated underrepresentation of minorities and older adults in research
Example of recruitment of diverse groups: Registry

Example of recruitment of diverse groups: Health care setting
Recruitment: Sources of Participants

- Community Organizations
- Health Care Settings
- Population at large
Electronic recruitment methods

Methods that rely on the use of the Internet to identify or recruit participants into research studies

Potential benefits

- Increase recruitment
- Cost effectiveness
- Reach underrepresented groups
  - Ethnic/racial minorities
  - Rural populations
  - Isolated elders
  - Individuals affected by rare diseases
# Electronic recruitment methods

| Internet | ✓ General searches  
|          | ✓ Social Media (Facebook page, Twitter account)  
|          | ✓ Study blogs  
|          | ✓ Online newspapers, message boards, newsletters  
| Email    | ✓ Listings from prior studies  
|          | ✓ Listings from electronic health records  
|          | ✓ Purchased listings  
|          | ✓ Insurance listings  
|          | ✓ Use of patient portals  
| Paid Media | ✓ Social Media (Facebook Ads, Google AdWords)  
|           | ✓ Web banner ads  

What is the Rationale?

% OF US ADULTS WHO OWN THE FOLLOWING DEVICES

- Any Cellphone: 96% White, 98% Black, 96% Hispanic
- Smartphone: 82% White, 80% Black, 79% Hispanic
- Cellphone, but not smartphone: 14% White, 17% Black, 17% Hispanic

What is the Rationale?

% OF US ADULTS BY AGE GROUP

- Use of Internet:
  - 65-69: 82%
  - 70-74: 75%
  - 75-79: 60%
  - 80+: 44%

- Home broadband services:
  - 65-69: 66%
  - 70-74: 61%
  - 75-79: 41%
  - 80+: 28%

- Own a smartphone:
  - 65-69: 59%
  - 70-74: 49%
  - 75-79: 31%
  - 80+: 17%

https://www.pewinternet.org/2017/05/17/tech-adoption-climbs-among-older-adults/
Use of Facebook - 2019

http://sproutsocial.com/insights/new-social-media-demographics/
% OF FACEBOOK USERS, BY RACE/ETHNICITY

https://www.pewresearch.org/fact-tank/2015/02/03/social-media-preferences-vary-by-race-and-ethnicity/
Google Ads: How it works
Researchers as advertisers

- Determine the ad’s goal (e.g., drive people to the study website)
- Decide where to advertise (e.g., geographical targeting)
- Create a message to attract “clicks” (i.e., Words)
- Create key words
- Set the budget cap (per day, monthly cap)
- Ads appear on Google Searches based on bidding process
Example: Prostate Cancer Clinical Trials

- **Components:**
  - Matching tool with trial summaries
  - Google Ads campaign

- **Implementation:** October 2014 to April 2015

- **Languages:** English and Spanish

- **Targeted advertised campaign**
  - Ad Time: 8 weeks
  - Non-Ad Time: 22 weeks
  - $ 4000 cost; 1.49 cost per click
  - 29 matched individuals who provided information

Example: Prostate Cancer Clinical Trials

Survey Completion, Participants with Prostate Cancer, and Participants Who Left Information

Facebook ads

- Ability to target by age, geography, income, eligibility and ineligibility criteria
- Advertiser places monetary bid
- Placement is based on:
  - Feedback from Facebook users
  - Facebook evaluation
  - The advertiser with the highest combination of all three elements gets that placed
Example: Elderly Clinical Trial Enrollment

- Phase 1 clinical trial for Alzheimer's disease
- Desired recruitment: 45 individuals 60 years and older
- Traditional campaign:
  - Traditional methods (billboards, direct mailer, bus advertising, newspapers ads)
  - Yield: 6 enrolled subjects over 11 weeks
- Social Media Campaign
  - Phase 1: Black and white campaign
  - Phase 2: Typical and Altruist campaigns
Example: Facebook example: Elderly Clinical Trial

Cowie et al. (2018) The Use of Facebook Advertising to Recruit Healthy Elderly People for a Clinical Trial: Baseline Metrics

JMIR Research Protocols
## Facebook example: Elderly Clinical Trial

<table>
<thead>
<tr>
<th>Parameter</th>
<th>First Social Media Campaign</th>
<th>Second Social Media Campaign: Altruistic Campaign</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Keywords</strong></td>
<td>Alzheimer’s disease; medical research</td>
<td>Neuroscience, Clinical trial, Alzheimer’s disease research, Philanthropy, Mind games, Costco, Altruism, Medical research, Luminosity, or Lifelong learning</td>
</tr>
<tr>
<td><strong>Exclusions</strong></td>
<td>None reported</td>
<td>National Cancer Survivors Day, Diabetes mellitus type 2 awareness, Hypertension Awareness, Allergy, Prehypertension, Cancer signs and symptoms, Diabetic diet</td>
</tr>
</tbody>
</table>

Cowie et.al. (2018) The Use of Facebook Advertising to Recruit Healthy Elderly People for a Clinical Trial: Baseline Metrics JMIR Research Protocols
Evaluation of Electronic Technology Recruitment Strategies
Systematic review

- Technology based recruitment studies
- Study period 2008-2018
- Data bases
  - PubMed: EMBASE: PSYCInfo: Web of Science: Social Services Abstracts: Sociological Abstracts:
- Studies included
  - Comparative analysis of methods
  - Primarily adults
  - Registries
Why Registries?

- Useful tools to improve recruitment into health research
- Voluntary: Includes indicate interest or agree to be contacted for future research
- Type of registries
  - Rare diseases
  - Minority populations
  - Local or international
- Examples
  - Research
Systematic Review - PRISMA

5811 references after deleting duplicates

499 included by title

Registries: 34
Surveys: 40
Interventions: 220

5312 excluded by title

205 excluded by abstract

PubMed: 1209 references
EMBASE: 1613 references
PSYCInfo: 383 references
Web of Science: 914 references
Social Services Abstracts: 2061 references
Sociological Abstracts: 1510 references
Comparative studies

- Alzheimer’s disease
  - Grill et al. Constructing a local potential participant registry to improve Alzheimer’s disease clinical research recruitment (2018)

- African American
  - Green et al. Connecting communities to health research: Development of Project CONNECT minority research registry (2013)

- Rare Disease
  - Johnson et al. Evaluation of Participant recruitment methods to a rare disease online registry (2014)
Evaluation

➢ Reach (i.e. numbers of participants)
  ➢ Are electronic methods (EM) more effective at research participant recruitment than traditional methods

➢ Representation
  ➢ Do EM recruit a sample comparable to traditional methods
  ➢ Do EM recruit a more diverse sample than traditional methods

➢ Cost
  ➢ Are EM more cost effective at research participant recruitment than traditional methods
Alzheimer Disease Registry

Recruitment: Irvine California

Traditional Recruitment methods

- Earned Media (Pro-Bono public relations company)
  - Newspaper; TV; Radio
- Public Education
  - 17 Alzheimer Walks/Fairs
- Referrals
  - Friends, Research Participants, Partner Organizations, Physicians, Alzheimer’s Trial Match

Electronic Recruitment Methods

- Emails
- Internet
  - Searches, Social Media (Facebook post, Facebook campaigns, tweets)
  - News and Blogs
## Alzheimer’s disease Registry: Reach

<table>
<thead>
<tr>
<th>Intervention Type</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TRADITIONAL METHODS</strong></td>
<td>503</td>
<td>85%</td>
</tr>
<tr>
<td><strong>ELECTRONIC METHODS</strong></td>
<td>89</td>
<td>15%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Method</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Email UCI prior study</td>
<td>41</td>
<td>7%</td>
</tr>
<tr>
<td>Email UC Campus email</td>
<td>6</td>
<td>1%</td>
</tr>
<tr>
<td>Internet Search</td>
<td>25</td>
<td>4%</td>
</tr>
<tr>
<td>Social Media (15 Facebook posts, 2 paid Facebook ads and 26 tweets)</td>
<td>15</td>
<td>3%</td>
</tr>
<tr>
<td>News</td>
<td>1</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Blogs</td>
<td>1</td>
<td>&lt;1%</td>
</tr>
</tbody>
</table>

# Alzheimer’s disease Registry: Representation

<table>
<thead>
<tr>
<th>Race/ethnicity</th>
<th>N=592</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age Mean</td>
<td>63.1</td>
</tr>
<tr>
<td>White</td>
<td>88.2</td>
</tr>
<tr>
<td>African American</td>
<td>0.3</td>
</tr>
<tr>
<td>Asian American</td>
<td>6.9</td>
</tr>
<tr>
<td>Latino</td>
<td>6.3</td>
</tr>
<tr>
<td>Other/Refuse</td>
<td>3.9</td>
</tr>
</tbody>
</table>

Rare Disease Online Registry

Johnson et al. Evaluation of Participant Recruitment Methods to a Rare Disease Online Registry (2014)

<table>
<thead>
<tr>
<th>Method</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facebook page and ads</td>
<td>395</td>
<td>48.7</td>
</tr>
<tr>
<td>Google search and Google ads</td>
<td>155</td>
<td>19.1</td>
</tr>
<tr>
<td>Health Care provider</td>
<td>74</td>
<td>9.1</td>
</tr>
<tr>
<td>Academic/Government websites</td>
<td>71</td>
<td>8.8</td>
</tr>
<tr>
<td>Advocacy groups</td>
<td>25</td>
<td>3.1</td>
</tr>
<tr>
<td>Other methods</td>
<td>91</td>
<td>11.2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>811</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>
Johnson et.al. Evaluation of Participant Recruitment Methods to a Rare Disease Online Registry (2014)

<table>
<thead>
<tr>
<th>Method</th>
<th>Self-reported</th>
<th>Cost</th>
<th>Cost per participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facebook page and ads</td>
<td>203</td>
<td>771</td>
<td>3.79</td>
</tr>
<tr>
<td>Google search and Google ads</td>
<td>110</td>
<td>1447</td>
<td>13.2</td>
</tr>
<tr>
<td></td>
<td>Google Search/Ads</td>
<td>Facebook /Ads</td>
<td>Healthcare Provider</td>
</tr>
<tr>
<td>-------------------------</td>
<td>-------------------</td>
<td>---------------</td>
<td>---------------------</td>
</tr>
<tr>
<td></td>
<td>N=155 %</td>
<td>N=395 %</td>
<td>N=74 %</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>65.2</td>
<td>62.5</td>
<td>59.5</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>55.1</td>
<td>76.7</td>
<td>78.4</td>
</tr>
<tr>
<td>Black/African American</td>
<td>5.8</td>
<td>4.6</td>
<td>4.1</td>
</tr>
<tr>
<td>Asian</td>
<td>16.0</td>
<td>4.3</td>
<td>2.7</td>
</tr>
<tr>
<td>Other/More than one race</td>
<td>22.6</td>
<td>14.5</td>
<td>14.9</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>11.3</td>
<td>10.3</td>
<td>8.2</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;40</td>
<td>34.8</td>
<td>36</td>
<td>16.2</td>
</tr>
<tr>
<td>Geographic</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>USA</td>
<td>56.3</td>
<td>67.9</td>
<td>97.3</td>
</tr>
</tbody>
</table>
## Minority

<table>
<thead>
<tr>
<th>Source</th>
<th>Method Description</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Outreach</td>
<td>Community presentations Health fairs and conferences at Black churches Presentations: health topics impacting AfAm</td>
<td>268</td>
<td>44.1%</td>
</tr>
<tr>
<td>Email</td>
<td>University students, faculty, and staff</td>
<td>182</td>
<td>29.9%</td>
</tr>
<tr>
<td>Internet</td>
<td>Web enrollment</td>
<td>75</td>
<td>12.3%</td>
</tr>
<tr>
<td>Public Databases</td>
<td>Commercial sampling Telephone recruitment</td>
<td>63</td>
<td>10.4%</td>
</tr>
<tr>
<td>Existing studies</td>
<td>Prior cancer epidemiological study</td>
<td>14</td>
<td>2.3%</td>
</tr>
<tr>
<td>Earned Media</td>
<td>Radio Three regional radio stations</td>
<td>7</td>
<td>1%</td>
</tr>
</tbody>
</table>

African American

<table>
<thead>
<tr>
<th>Green et.al. Connecting communities to Health Research: Development of the Project CONNECT minority Research Registry</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Green et.al. Connecting communities to Health Research: Development of the Project CONNECT minority Research Registry</strong></td>
</tr>
<tr>
<td><strong>Community Outreach</strong> N=268</td>
</tr>
<tr>
<td><strong>Email</strong> 182</td>
</tr>
<tr>
<td><strong>Internet</strong> 75</td>
</tr>
<tr>
<td><strong>Public Databases</strong> 63</td>
</tr>
<tr>
<td><strong>Existing studies</strong> 14</td>
</tr>
<tr>
<td><strong>Earned Media</strong> 7</td>
</tr>
</tbody>
</table>

African American

<table>
<thead>
<tr>
<th></th>
<th>Time period (months)</th>
<th>Individual Reached</th>
<th>Enrollment</th>
<th>Yield by method</th>
<th>Additional costs</th>
<th>Staff time per enrolled participant (hours)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community outreach</td>
<td>54</td>
<td>8303</td>
<td>268</td>
<td>3.2%</td>
<td>$1,858</td>
<td>12.69</td>
</tr>
<tr>
<td>email</td>
<td>27</td>
<td>42,317</td>
<td>182</td>
<td>0.4%</td>
<td>.30</td>
<td>.30</td>
</tr>
<tr>
<td>Internet</td>
<td>27</td>
<td>7685</td>
<td>75</td>
<td>1.0%</td>
<td>.73</td>
<td>.73</td>
</tr>
<tr>
<td>Public databases</td>
<td>4</td>
<td>900</td>
<td>63</td>
<td>.0.7%</td>
<td>$5,813</td>
<td>4.97</td>
</tr>
<tr>
<td>Existing studies</td>
<td>2</td>
<td>500</td>
<td>14</td>
<td>2.8%</td>
<td></td>
<td>12.29</td>
</tr>
<tr>
<td>Radio</td>
<td>1.5</td>
<td>80,000</td>
<td>7</td>
<td>0.01</td>
<td>$10,000</td>
<td>2.86</td>
</tr>
</tbody>
</table>

Questions?

Comments?
Internet/Social media
  ◦ Paid—Google ads  Facebook ad
  ◦ Not paid

  ◦ Community
    ◦ Advocacy groups
Use of technology in recruitment: Considerations

- Use of technology by minorities and older adults
- Barriers to participation

- Types of studies
  - Alzheimer’s disease
  - Older adults in general
  - Specific disease that affect older adults (i.e. Cancer)
Facebook key word
Background

NIH mandate to recruit minorities women and minorities must be included in clinical research supported by NIH

In 2005 FDA required that trial participant ethnicity be documented

Prior research has indicated underrepresentation of minorities and older adults in research

older adults continue to be underrepresented in research (Mody et al., 2008). Underrepresentation has serious consequences for older adults because clinical treatments are often based on studies involving younger, healthier, higher functioning samples
Facilitators among minority participants

<table>
<thead>
<tr>
<th>Facilitators</th>
<th>African American</th>
<th>Asian American</th>
<th>Latino</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cultural congruence</strong></td>
<td>• Community education at fraternities and sororities</td>
<td>• Culturally matched research personnel and information in appropriate language</td>
<td>• Research staff that speaks Spanish and can relate to patients</td>
</tr>
<tr>
<td><strong>Benefits to participation</strong></td>
<td>• Use of culturally diverse staff</td>
<td>• No out-of-pocket costs</td>
<td>• Monetary compensation</td>
</tr>
<tr>
<td><strong>Altruism—helping family or community</strong></td>
<td>• Money or free medical services</td>
<td>• No other effective treatment available</td>
<td>• Access to medical services</td>
</tr>
<tr>
<td></td>
<td>• Access to new, better, or free medicines</td>
<td>• More information about clinical trials</td>
<td>• Sufficient or appropriate study information provided</td>
</tr>
<tr>
<td></td>
<td>• Learn about their own health</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Receive adequate information about the study purpose</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Convenience of participation</strong></td>
<td>• Contribution to future generations and community</td>
<td>• Want to help family member or Asian American community in general</td>
<td>• Help others</td>
</tr>
<tr>
<td></td>
<td>• Increase scientific knowledge</td>
<td>• Care about the purpose of the research</td>
<td>• advance medical knowledge</td>
</tr>
<tr>
<td></td>
<td>• Personal or family history of the disease</td>
<td></td>
<td>• Burden of disease on family or community</td>
</tr>
<tr>
<td></td>
<td>• Having workplace support</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Transportation compensated</td>
<td>• Childcare provided</td>
</tr>
</tbody>
</table>

# Recruitment Strategies: Traditional Methods

| Community Outreach          | • Public Education  
|                            | • Walks / Fairs 
|                            | • Brochures or fliers 
|                            | • Media outreach  
|                            |   • Newspapers, TV, Radio 
| Direct participant contact | • Mail 
|                            | • Phone 
|                            | • Provider recruitment 
| Referrals                  | • Friends 
|                            | • Research Participants 
|                            | • Partner Organizations 
|                            | • Physicians 
|                            | • Registries 
| Paid Media                 | • Publicity in news outlets  
|                            |   • Newspaper 
|                            |   • Television 
|                            |   • Radio |
Studies Linked to Web-Based and Mobile Health

Five studies included 18 years and older

Primarily smoking cessation interventions

Recruitment Methods: Facebook ads, search engines, banner ads, Google Ad words, free twitter post, forum post

Results:
- Facebook Ads cost twice as much as traditional methods
- Google ads had the highest participation yield
- Very few participants older than 55
- In some studies online participants were slightly younger
- In one case online methods reached hard to reach populations
- Google ads had the highest participation yield

Online recruitment methods for Web Based and Mobile Health Studies: Review of the literature. Lane et al J Med Internet Res 2015
ResearchMatch

Comprised of:

136,362 Volunteers
6,651 Researchers
661 Studies
163 Institutions
369 Publications

Developed and hosted at Vanderbilt University

Funded by the National Institutes of Health (NIH) Clinical and Translational Science Award (CTSA) Program grants
instagram

Gender:
- 39% Female
- 30% Male

Age:
- 13–17: 72%
- 18–29: 64%
- 30–49: 40%
- 50–64: 21%
- 65+: 10%

Location:
- 42% Urban
- 34% Suburban
- 25% Rural
Types of Ad Objectives

<table>
<thead>
<tr>
<th>Awareness</th>
<th>Consideration</th>
<th>Conversion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brand awareness</td>
<td>Traffic Snippet</td>
<td>Conversions</td>
</tr>
<tr>
<td>Reach</td>
<td>Engagement</td>
<td>Catalog sales</td>
</tr>
<tr>
<td></td>
<td>App installs</td>
<td>Store traffic</td>
</tr>
<tr>
<td></td>
<td>Video views</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lead generation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Messages</td>
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</table>