**Abstract**

 Although underrepresented populations’ cultures differ from each other, these groups do share some characteristics and concerns about medical research, causing hesitancy and low clinical trial participation levels. To better benefit the health of marginalized populations, it is important to apply health communication strategies to increase clinical trial participation levels. This entry briefly describes some of the history, barriers to clinical trial participation, and particular cultural concerns of numerous underserved populations. It also suggests several health communication research strategies to respectfully address the valid cultural hesitancies of all underserved and underrepresented groups in efforts to increase their willingness to take part in clinical trials.

Keywords: underserved populations, recruitment strategies, cultural competence, minority participation, racialized populations

**Clinical Trial Recruitment: Underrepresented Groups**

Across the globe, marginalized populations look, speak, care, believe, worship, and live differently from each other. However, these groups also share some characteristics and considerations, and clearly have at least one thing in common—they all carry some degree of concern about, and are measurably underrepresented in, clinical trials (CTs). Although the sex distribution of CT participants around the world is almost evenly distributed between women (51%) and men (49%), clear evidence of CT participation disparity exists globally in other categories, such as race, ethnicity, age, and geographic distribution (U.S. Food & Drug Administration, 2021).

This underrepresentation is problematic for at least three reasons. First, low inclusion levels of underserved groups in CTs, medical databases, and biobanking translate into a lack of research benefits for those groups. Second, data resulting from CTs performed without input from these populations are not complete, and the resulting drug treatments and/or medical procedures may not be effective for all. Third, personalized medicine is being used globally and has begun to positively affect medical care. For these reasons, better inclusion of underrepresented groups is a salient factor of improved public health, and low participation creates a scientific barrier to moving forward.

Health communication scholars are well positioned to address an issue that is widely understood and recognized within the larger health research world. Successfully tackling this health problem requires developing and implementing communication strategies that will inform and influence the health decisions of not just these groups as entire entities, but their individual members as well. These strategies should integrate theoretical constructs to encourage positive changes in attitudes and behaviors. Therefore, addressing the issue of underrepresented groups in CTs is a global health communication problem.

**History**

In 1993 in the United States, President Bill Clinton signed the NIH Revitalization Act, a main tenet of which was to create guidelines for the inclusion of women and minority group members in U.S. clinical research (Freedman et al., 1995). While women are now more present as participants in CTs both in the U.S. and worldwide, very little global progress has been made regarding establishing parameters for successfully recruiting members of minoritized and other underserved groups into CTs. For the purposes of this entry, “underrepresented” and/or “underserved” groups include racial and ethnic minority populations (people of African descent, Hispanic populations, people of Asian descent, indigenous peoples, etc.); older adults (aged ≥ 65 years); socioeconomically disadvantaged individuals; rural populations; LGBTQ+ individuals; individuals with disabilities, and armed services veterans.

**Historically Well-Known Barriers to Research Participation**

Underrepresented populations’ low participation in research has been at least partially attributed to certain barriers repeatedly reviewed in the literature. Most common of these obstacles are lack of awareness of CTs (e.g., rural populations living far from research institutions, or historically excluded populations not informed by their physicians about research); lack of opportunity to participate (such as in older adults who have aged out of a trial, or individuals with comorbidities who are ineligible for the trial); and the often difficult decision to accept or decline an opportunity, as may be the case for members of minoritized populations or socioeconomically disadvantaged individuals. Other commonly cited barriers by underrepresented groups are fear, lack of trust, and concerns for safety.

**Similar/Shared Research Concerns Among Underrepresented Groups**

Distrust and lack of knowledge about CTs are main obstacles that are shared and cause varied levels of hesitancy within the affected groups. Findings of underserved populations’ distrust of medical research are ubiquitous in the global literature. Elucidated underlying reasons include (but are not limited to) histories of medical abuse of Black and Brown people by dominant cultures (Ridley-Merriweather et al., 2020), immigrants’ fears of being gathered up for experimentation or deportation (Arevalo et al., 2016), researchers’ lack of employing culturally competent communication skills in approaching indigenous peoples about CTs (Friedman et al., 2015), and fear of stigma and uncomfortable health experiences by the LGBTQ+ community (Rosa et al., 2020). Adding to the feeling of mistrust, each group’s collective medical research history can cause its population to feel socially and racially profiled and invalidated.

Underrepresented group members may display low research involvement from feeling distrustful or from having been absent from CT participation simply through having not been informed or asked to take part. These group members are often ill-equipped to make informed decisions about their health or their possible CT participation. As examples, older adults with cancer are less likely than younger individuals to be invited to take part in a cancer CT or to receive systemic treatment (Lackman et al., 2020). Members of rural and/or indigenous communities are likely to live much farther than urban residents from medical research and teaching institutions and are less likely to learn about research availability (Friedman et al., 2015). Finally, almost all groups report that neither their personal care physicians nor disease specialists talk to them about CT participation. In these situations, health communication scholars should be brought into the conversation as individuals uniquely qualified to present CT participation as an important way to benefit the participants and their community.

**Particular Concerns of Certain Underrepresented Groups**

Although many common obstacles are shared by a majority of members of underserved populations, some concerns about (and barriers to) research participation are unique to particular groups. Disparate communities that share the description “underrepresented” in research usually possess unique concerns about, and experience group-centric obstacles to, CT participation, often resulting from absent or unclear communication from the research community. For example, members of historically excluded populations have expressed fear about taking part in biomedical research. This fear in individuals of African descent is likely rooted in evidence from different countries of past abuses or lack of positive experiences in medical situations (Clark et al., 2019). Hispanics may be apprehensive about subjecting their bodies to invasive procedures or needing to show identification to register for participation (Arevalo, 2016). Members of many Asian cultures may suffer from feeling stigmatized by their disease or illness and not want to disclose it even to family members. Many indigenous groups share grave concerns about digital data generated by CTs, who owns and has control of that data, and how it is managed and used. These are all exemplars of individual cultural concerns affecting recruitment of these groups to CTs, and they are best addressed and alleviated through dedicated use of culturally competent communication practices that honor the individuals and respect their cultures and heritages.

Other underrepresented groups’ research participation hesitancy is likely centered in their own particular communication concerns. For example, older people and individuals at regional, national, and global levels, who are socioeconomically deprived, may demonstrate lower health literacy, thereby complicating their ability to fully relate to CT recruitment messaging. Currently, CT recruitment of veterans focuses on those who receive healthcare from their national government. However, it is important worldwide to develop other communication outreach strategies to include more members of this important underrepresented group in research. To help foster feelings of safety, LGBTQ+ individuals want to find queer-friendly healthcare clinicians and researchers (Rosa et al., 2020). Finally, individuals with physical disabilities may face a range of physical, mental, and logistical barriers to participation in CTs. The skilled use of interpersonal and relational communication behaviors, coupled with genuine interest in helping underserved populations, can encourage these and other underrepresented group members to become biomedical research participants (Morgan et al., 2017).

**Future Research - Health Communication-Focused Strategies to Engage and Recruit Underrepresented Groups**

 To address, navigate, circumvent, reduce, or eliminate the barriers and concerns about CT participation faced by underserved/underrepresented populations as discussed so far in this entry, several health communication strategies applicable to future research, along with recommended theoretical frameworks helpful to health communication design approaches, are now suggested (see Table 1).

**Strategy—Study and Apply Cultural Competency**

To be culturally competent is to understand and communicate with individuals across cultures, and to grow positive attitudes toward cultural differences. Globally, researchers should plan to learn and honor the cultural habits and norms of the studied group and should interact with individuals or small groups to avoid overwhelming community members. Take care to inquire about and learn any preferred group labels, as identity preference can be salient to racial/ethnic groups and the LGBTQ+ community.

**Strategy—Be Transparent, Share Information**

Some members of underrepresented groups who have previously participated in research have expressed disappointment in the lack of follow-up outreach from research teams. They desire information about study progress or findings not only for themselves, but so that their community can apply it toward making informed healthcare decisions. Researchers should plan to provide post-study (or during if study is longitudinal) outreach and messaging to both inform community members and keep them engaged.

**Strategy—Snowball Sampling**

Snowball sampling, or engaging participants in assisting with identification of other potential participants, tends to lessen feelings of distrust in potential participants and can be a successful tool for the health communication researcher.

**Strategy—Improve Patient-Clinician Communication**

A number of studies have reported that in response to described poor communication in medical settings and from medical clinicians, members of underserved communities have expressed a profound need for improved communication between patients and their clinicians or research study personnel. Lack of community participation in research can be linked to ineffective communication with medical clinicians and/or researchers.

**Strategy—Employ Community-Based Participatory Research (CBPR)**

Involving underserved community members in the health communication research process likely translates to higher probability that their needs and preferences would be part of research outcomes and improvement of healthcare delivery. CBPR is a health-focused methodology supporting collaborative interventions involving scientific researchers and community members working together to affect health disparities in underrepresented communities.

**Strategy—Involve/Engage Key Community Leaders**

Researchers engage, appeal to, and educate community leaders about the proposed research. The goal is to encourage community leaders to become early adopters, and to bring other community members along as the desired behavior gains momentum and spreads. Educating and appealing to community leaders can also signify respect and indicate researchers’ willingness to come into and engage with the community, even if logistics demand that actual study procedures must be performed elsewhere.

**Strategy—Use Message Targeting and Tailoring**

Performing rigorous formative research within an underserved community and developing population-targeted health communication messaging is an excellent strategy for successful outcomes. Tailoring the messaging to community individuals would likely create even more positive results from messaging campaigns and interventions.

**Strategy—Look for the “Why”**

Applying quantitative methods alone may not yield the depth of results needed to actually apply the findings. Researchers may find that adding qualitative explanatory findings can create the added benefits of knowing the “why” behind certain results. Health communication researchers should consider using mixed methods to help address a particularly dense or complex health communication challenge in the community.

**Conclusions**

 There are consequences to ineffective health communication for underrepresented populations, including inadequate scope of research opportunities and lack of research distribution to group members. Exhibiting cultural competence, displaying honor for these communities, and demonstrating respect for their populations is paramount. Whenever possible, messaging should not only be targeted to certain groups but tailored to in-group individuals to increase understanding and response. Finally, health communication scholars must be willing and prepared—even eager—to respectfully address the concerns of all underserved and underrepresented groups in efforts to increase the CT participation of these populations.

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**Further Reading**

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**Cross References**

See Also

IEHC0543

IEHC0785

IEHC0825

IEHC0826

IEHC0845

IEHC0849

IEHC0865

IEHC0870

IEHC0981

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| **Table 1***Strategies and Suggested Theories* |   |   |
| **Strategy** |  | **Suggested Theories** |
| Study and Apply Cultural Competency |  | critical race theory, communication theory of identity, co-cultural theory |
| Be Transparent, Share Information |  | grounded theory, uses and gratifications theory |
| Snowball Sampling |  | diffusion of innovation, elaboration likelihood model |
| Improve Patient-Clinician Communication |  | health belief model, integrated behavioral model |
| Employ Community-Based Participatory Research (CBPR) |  | integrated behavioral model, PEN-3 model |
| Involve/Engage Key Community Leaders |  | diffusion of innovation, elaboration likelihood model |
| Use Message Targeting and Tailoring |  | integrated behavioral model, PEN-3 model, health belief model |
| Look for the “Why” |   | integrated behavioral model, PEN-3 model |

**Short Bio**

Katherine E. Ridley-Merriweather, currently a doctoral student in health communication at IUPUI, is the Communication/Minority Outreach Coordinator for the Komen Tissue Bank at the IU Simon Cancer Center. She is an applied researcher whose studies on illuminating and increasing the motivations of members of racialized and underserved populations to participate in breast cancer clinical trials have been published in *Health Communication* and *Communication Education*. Additional work emphasizes the importance of identity respect and identity safety in recruiting minoritized population group members to medical research.