Strategies for addressing barriers to research enrollment in an underrepresented and understudied population

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Background

- Limited diversity in research restricts the generalizability of findings and reinforces health disparities.
- Challenges in enrollment persist despite efforts to include understudied and underrepresented populations.
- Barriers to enrollment can stem from individual[1] and institutional factors[2].

Aims

- To explore strategies to address enrollment barriers for a community sample of Chinese American parents and adolescents in the Building Our Bonds Authentically (BOBA) Project, a longitudinal study on racial discrimination and mental health.
- To find solutions addressing the existing barriers to participation in research studies on underrepresented and understudied communities.

Method

Materials drew on the BOBA Project study team's reflections, focusing on recruitment challenges, community outreach efforts, and the design and adaptation of study procedures.
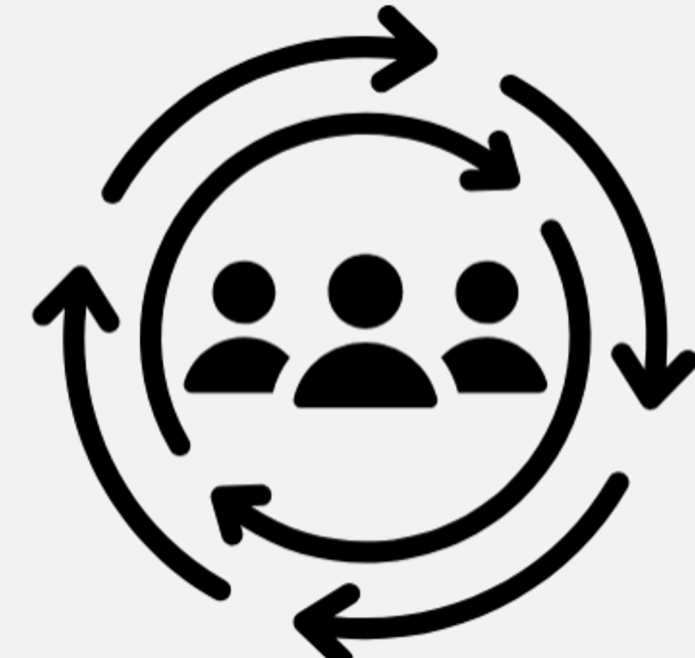
This iterative process was informed by continuous feedback from the community, participants, and potential participants, helping to refine recruitment strategies and study procedures over time.

Additional information

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Results

Participant-level barriers

- Language
- Mistrust in researchers
- Lack of exposure to research studies
- Discomfort with sensitive research topics
- Sensitivity to collection of personal information/data

Strategies implemented

- **Culturally relevant communication:** Developed bilingual, culturally tailored materials and used the communication preferred platforms (WeChat, text message, etc.)
- **Formed a Youth Advisory Board** engaged high schoolers as consultants and empowered them to educate and leader outreach initiatives
- **Minimized privacy concerns:** advocated for payment methods that do not require social security numbers or complex set up
- **Education on the merits of research:** Conducted parent webinars with community organizations

"I have communicated with my son multiple times in different ways. He [had persistent] concerns about his personal data security and [had not] agreed to participate in the study." – a potential participant

"We're happy to help share your study through our community platform and WeChat groups that we're a part of." - the leader of a community organization

"Thank you for the presentation and the important work your team has done. We are very interested in participating this study with two kids." – an attendee of our webinar

Institutional level barriers

- **Institutional limitations on non-traditional communication** and recruitment platforms (i.e., WeChat) create challenges in reaching participants
- **Cultural-related barriers in standard payment methods** (E-checks, Advarra) require participants to navigate complex setup and verification, and come with usage restrictions
- **Culturally insensitive institutional policies**, such as SSN requirements for participant compensation and community consultants. Securing an exemption required prolonged discussions with leadership and the IRB to accommodate community concerns about privacy and mistrust

Participant level barriers can and should drive change in institutional research infrastructure.

Discussion

- Including community members' perspectives is essential in ensuring recruitment approach is well-received and study materials are culturally relevant and appropriate[3].
- The identified participant-level barriers are common obstacles in research involving diverse and underrepresented populations yet viable solutions remain challenging to implement.
- Greater collaboration between researchers, community members, and institutional research offices is needed to for assessing and improving the current systems, ensuring their cultural relevance and appropriateness (i.e., integrating perspectives of community researchers and members as consultant or as staff)

References

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