Center for Asian Health Promotion and Equity (CAHPE)

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KEY TAKEAWAY – Building trust through partnerships with community organizations and recruiting participants via trusted sources may improve Chinese American participation rates in research.

Examining Barriers and Motivators for Research Participation among Chinese American Populations in NY and NJ

Rosemary Li, MPP, Keith Chan, PhD, LMSW, Aparna Kalbag, PhD, Melissa Simon MD, MPH, Soko Setoguchi, MD, DrPH

Background

Inadequate representation of diverse populations in clinical research is widely acknowledged as a major factor contributing to health disparities affecting underserved populations. Over 5.5 million Chinese Americans reside in the US, and they represent the largest ethnic group of Asian Americans who have distinct health disparities. However, language and cultural barriers significantly hinder research recruitment efforts for this population.

Simon and colleagues (2015) developed a research literacy support (RLS) tool to improve communication and information sharing between study recruiters and potential research participants. This study aims to identify barriers and facilitators and modify the existing RLS tool using the cross-cultural adaptation framework for the Chinese-speaking population. We elicit specific concerns from this community about research participation.

Objectives

- **Aim 1**: Examine and describe barriers and facilitators to research participation for Chinese Americans residing in NY and NJ
- **Aim 2**: Culturally adapt and translate the RLS tool for the Chinese population

Study Population

Participants were recruited through CAHPE's community networks and social media posts

Inclusion Criteria:

1. Adults (18+) who live in the New York and New Jersey Metropolitan Area

2. Deep knowledge of the Chinese speaking community in the region

3. English speakers who are bilingual in Cantonese-Chinese or Mandarin-Chinese

4. Possess some knowledge of research processes

Community Engagement Core

Together Towards Health Equity: Championing Asian Health Promotion

Methods / Pilot Design

Semi-structured Interviews: Interviews: completed n=11
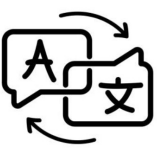
- Interviews were conducted via Zoom for 60 minutes and recorded for transcription purposes
- Interviews were conducted in English and Mandarin-Chinese

Qualitative Coding: in progress

- Qualitative interviews were transcribed, translated, de-identified, and coded for thematic analysis
- Three-member coding team to develop codebook and ensure interrater reliability

Aim 1: Preliminary Findings

Key Barriers Identified

Language barriers that lead to limited understanding of research purpose and difficulty expressing thoughts without access to well translated study materials in native language.

Limited exposure and education on research processes; and uncertainty regarding the responsibilities of research participation

Distrust and fear of sharing personal information that stems from concerns that info will be shared with other individuals or organizations

Hesitation to share information about topics they think are sensitive or private due to fear of judgement and stigma, "saving face"

Weighing the risks and benefits of participation, particularly for clinical trials, strong practical element of decision making

Key Facilitators Identified

Recruitment through trusted sources, for example, respected institutions or social networks

Collectivist culture: community-oriented research outreach and goals that align with community health concerns

Simple formatting and lay language use in study materials to ensure easier comprehension

Compensation in forms of monetary reward, health services, or benefit to the community

Conclusions

Findings from this study suggest that the Chinese American community have distinct salient and practical concerns regarding how they engage with research and choose to participate in research studies. These can include limited understanding and exposure to research processes, language barriers in particular with older adults, concerns with sharing personal information and fear of judgment from others in their community, and risks from side effects of clinical trials or other consequences. Addressing these concerns and building trust are important steps to the advancement of knowledge in research for this community. Motivators for participation can include trusted sources and networks which can be crucial to outreach and recruitment, as well as efforts from researchers to build meaningful, reciprocal connections with community partners.

Next Steps

Results from this study will inform the cultural adaptation of a research literacy tool for Chinese Americans to address Aim 2 of the study.

Cultural Adaptation:

- Use the data from interviews to inform the design and content of the RLS tool
- Translation and evaluation of language clarity, content relevance, and ease of understanding

Focus groups:

- One focus group in English and another in English and Mandarin
- Focus groups will be transcribed, de-identified, and coded for thematic analysis
- Participants to provide feedback on the cultural adaptation for multiple iterations of prototype development

Once developed, the RLS tool will be pilot tested in the community to assess feasibility of implementation in community settings. To aid dissemination, we will also develop a how-to-guide on using the tool.

Contact

PI: **Soko Setoguchi, MD, DrPH**

Co-PI: **Keith Chan, PhD**

Study Coordinator: **Rosemary Li, MPP**

Contact Email: rosemary.li@ifh.rutgers.edu

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