

KEY TAKEAWAY – The Research Literacy Support tool was culturally adapted into Simplified Chinese through an iterative process, ensuring that the language, content, and visuals were thoughtfully tailored to be relevant and informative for the Chinese-speaking population.

Culturally Tailoring the Research Literacy Support Tool for the Chinese-speaking Community

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Background

Inadequate representation of diverse populations in clinical research is widely acknowledged as a major factor contributing to health differences 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 1) identify barriers and facilitators and 2) modify the existing RLS tool using the cross-cultural adaptation framework for the Chinese-speaking population. This poster will report on Aim 2.

Objectives

Aim 1: Examine and describe barriers and facilitators to research participation for Chinese Americans residing in NY/NJ through conducting key informant interviews.

Aim 2: Culturally adapt and translate the RLS tool for the Chinese-speaking population through conducting focus groups and interviews, using an iterative adaptation process. Key informants from Aim 1 were invited to participate.

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

Selection of RLS Tool Cards:

- Use the data from Aim 1 interviews to inform the design and content of the RLS tool
- Translation and evaluation of language clarity, content relevance, and ease of understanding
- Participants provide feedback on the cultural adaptation for multiple iterations (two focus groups and one individual interview) of prototype development
- Develop finalized version of the RLS tool

Qualitative Coding:

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

Results

Aim 1 Key information interviews (n=11), Aim 2 Cultural Adaptation (n=7), 4 participants dropped out due to time conflict or travel

- First Focus Group: n=5
- Individual Interview: n=7
- Second Focus Group: n=6

Aim 2 Finding: Adaptation Feedback

Translation

- Use lay language and simplified descriptions of research processes
- Use concise wording/phrasing and limit placeholder words from the English version
- Some words/phrases become nonsensical with literal translation, rather, ensure meaningful and contextual translation

Content

- Adding relevant images and visuals to the target population
- Limit the length of the tool and prioritize critical content

Presentation of the Card

- Arrange the information in a comprehensive order
- Visually make key takeaways stand out amongst other information (i.e., highlight, font styling, draw a box)
- Larger print for better readability

Usage

- Make clear the purpose of the tool (i.e., recruitment, advocacy, education)
- Identify events/settings and how the tool would be effectively used

参与健康研究前我需要了解的事 (1)

1 为什么招募亚裔人群参加健康研究?

健康研究是指对人身健康与疾病的研究。

开展针对亚裔群体的相关研究可以帮助我们更深入地了解亚裔群体，验证现有的理论，并提升亚裔群体的医疗水平。

- 由于不同群体对治疗的反应可能不同，我们希望通过招募亚裔参与者，找到对亚裔群体更有效的治疗方法。
- 所有研究在招募参与者时都有特定的入组标准。研究目的不同，标准也会有所不同。
- 参与者需要同意才可以参与研究。

Center for Asian Health Promotion and Excellence

RUTGERS HEALTH
Institute for Health, Health Care Policy and Aging Research

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2 什么是知情同意?

知情同意是指：参与者在被告知研究的所有信息后，自愿同意参与的过程。

请您在充分理解知情同意后，再做出是否参与的决定。之后您仍可随时更改并退出研究。

- 在此期间：
 - 研究委员会向您解释同意书的全部内容，包括参与者的权利、风险、获益和其他长期作用
 - 在收到同意后，您可以单独或与家人朋友一同阅读并充分了解后，再决定是否参加。
 - 如有任何疑虑，请务必向研究员提出。

3 作为患者/健康人群，我参加研究的必要性是什么?

原因包括以下但不限于：

患者： 获得更加有效的治疗方法，并获得经济补贴。

健康群体： 提升对亚裔群体健康的认知，并获得经济补贴。

不管是健康群体还是患者，您都在帮助推进针对亚裔群体的健康研究：

- 1) 了解为什么特定药物对亚裔人群有效，而对其他人群无效。
- 2) 了解为什么亚裔人群更容易患有特定疾病。

研究员会与您一起探讨该研究能如何对您有益。



Three versions of the RLS tool developed for different purposes:



Infographic: for mass distribution



Slideshow: for presentation



Flashcard: for one-on-one use

Next Steps

Limitation: 1) Small sample size, and 2) Did not have sufficient participants who could read/speak Chinese to adequately adapt a Cantonese version of the tool

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

This tool can also be culturally adapted to assist other underrepresented communities in research.

Contact

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