Health Literacy Case Study Highlights: Communicating complex research results

A case study from Tufts University School of Medicine, developed with the MRCT Center.

BACKGROUND

Communicating information about the effect of environmental exposures on health while retaining scientific accuracy is not a simple task. It is especially challenging when trying to share such information with non-English speaking immigrant populations. The Community Assessment of Freeway Exposure and Health Study (CAFEH) conducts community based participatory research by collaborating with immigrant communities who live near an interstate highway in Boston.

CAFEH wanted to report research results to study participants and the broader community about the biological and environmental risks of exposure to ultra-fine particles from traffic air pollution using a method that would facilitate reading and foster understanding.

APPROACH

The team used an iterative process of community engagement to communicate the research and risk results. This involved two phases. First, a focus group revealed that the prepared materials were not easy to read. In phase 2, the team engaged the community and a health literacy specialist to make the materials understandable.
**PHASE 1**

1. Drafted environmental health materials.
2. Translated materials into Spanish.
3. Conducted focus groups with study participants.
4. Revised materials based on participant feedback.
5. Reviewed with community advisory board.

**PARTICIPANT FEEDBACK**
The focus group reported that they were overwhelmed by the amount of information.

They found the information confusing, difficult to understand, and lacking information on what to do.

**PHASE 2**

1. Health literacy specialist drafted environmental health materials.
   - Applied plain language writing and design principles.
   - Added action items - “What can you do about Ultra-fine Particles?”
2. Translated materials into Spanish, Portuguese, and Haitian Creole.
3. Partnered with local adult literacy program and conducted educational programs using materials with English Language Learners.
4. Revised materials based on learner use of materials and feedback.
5. Reviewed with community advisory board.

**PARTICIPANT FEEDBACK**
- Participants found the revised information “much easier to read.”
- Larger font size and discreet sections of text improved reading ease.
ABOUT TRANSLATION

The research team worked with community partners to translate materials into Spanish, Portuguese, and Haitian Creole. They:

- Engaged English language learners to read and discuss information sheets in their own language.
- Used community expertise to ensure translation accuracy.

WHO WAS INVOLVED

Principal Investigator & Researchers

- Partnered with community organizations in the design, implementation, and dissemination of the research.

Community Advocates/Leaders from Partner Organizations

- Worked with the research team to address community needs and interests and served as community liaisons.

A Trained Health Literacy Specialist

- Applied an environmental health literacy framework to promote health literacy and plain language as a strategic response.
OUTCOMES

SUCCESSES
The team ultimately engaged with community organizations to design, implement, and disseminate information. After incorporating their feedback and applying plain language and design principles, research participants found the information much easier to read.

Partnering with adult literacy programs helped the research team promote communication and engage the community about exposure to traffic related ultrafine particles.

English language learners were eager to apply their knowledge and experience to help solve traffic-related air pollution problems in their community.

CHALLENGES
The subject matter of ultra-fine particles was quite advanced. Because of this, limiting the amount of information and using everyday language was particularly difficult.

The study team thought the first set of fact sheets were easy to read - feedback from focus groups indicated that this assumption was incorrect. This highlighted that even well-intentioned researchers can make inaccurate assumptions about the clarity of their writing for a non-professional audience.
LESSONS LEARNED

• Applying basic plain language writing and design principles helped to communicate complex research-related information in ways people could understand and act on.

• Working with a health literacy specialist:
  > Helped the team focus on the need-to-know information and use non-technical terms to do so.
  > Modeled effective teaching and community engagement in an adult literacy, English Language Learning program.

• Working with adult literacy programs holds promise for engaging communities.

RECOMMENDATIONS

Whether you want to make sure to meet your recruitment goals, or you want to return meaningful information to your study participants, engaging representatives from your intended audience when developing your materials is critical.

This is especially important in the context of translation - ensuring information is appropriately translated for non-English speakers requires involvement of members from the communities of interest.