

Clinical researchers learn about NIH interpretation and translation services

By Eddy Ball

To be truly inclusive as NIEHS steps up community-engaged clinical research, researchers must understand the language needs of a quickly changing demographic.

That was the take home message of a talk Nov. 17 at NIEHS by two NIH Clinical Center experts — Brenda Robles, coordinator of the Language Interpreter Program, and Adrienne Farrar, Ph.D. head of the Social Work Department. Their talk, “Communicating With Non-English Speaking Study Participants,” was the latest in an NIEHS Clinical Research Seminar Series on “Practical Applications and Regulatory Considerations in Human Research.”

“As we do more outreach into the community, we really need language services,” said Joan Pakenham, Ph.D., director of the NIEHS [Office of Human Research Compliance](#), who hosted the talk. “We have to make a real effort to accommodate other languages and ethnicities.” She also emphasized the importance of cultural competencies as part of interpretation and translation.

Setting effective communication as the goal in research and treatment

Robles has been on the front lines of communicating with people who have limited English proficiency at NIH since 2006. She began her talk by tracing the legislative background of her program back to the Civil Rights Act of 1964, through the NIH Revitalization Act of 1993 and Executive Order 13166 in 2000, up to the [NIH Language Access Plan](#), (<http://edi.nih.gov/consulting/language-access-program/about>) which is in its final stages of implementation this year.

“Health care is communication dependent,” Robles told the audience, as she described the ethical and legal requirements for providing patients and research subjects with the best possible interpretation and translation services. Robles made a clear distinction between translation from one language to another and the much more complex process of interpretation. Along with the words themselves, cultural differences, body language, and educational level can be important considerations in effective interpretation.

For the estimated 55 million Americans who speak a language other than English at home, poor communication can be at worst a life or death matter (see [text box](#)). At best, the outcomes of ineffective communication can lead to inappropriate diagnosis, confusion over how to take medications, and failure to give human patients and subjects meaningful access to treatment and research.

Translation and interpretation — the right thing and the required thing to do

After Robles presented her strong case on the basis of ethics, Farrar spoke directly to the practical needs of the NIEHS Clinical Research team, as it designs projects that will pass muster with Institutional Review Boards (IRBs). She said researchers must preplan the language needs of human participants in clinical studies and provide them with fully translated consent forms, validated research surveys, and questionnaires, presented in ways that are culturally appropriate.

At the Clinical Center, that has meant building a professional bilingual staff of certified health care interpreters. The Language Interpreter Program in Bethesda, she said, has grown from a few volunteers in 1990 to a professional staff. Members include full-time-equivalent certified interpreters, contractors, bilingual linguistics, science or health care student interns from the Hispanic Association of Colleges and Universities (HACU), tested and vetted volunteers, and telephonic interpreter services.

In these ways, the program has served the majority of the 2,200 patients speaking over 60 languages in fiscal year 2014, in person or by telephone. Farrar also noted the importance of hiring bilingual staff and care providers, not to act as interpreters, but to perform their jobs in the language of the patients they serve.



“We really need this talk,” Pakenham said in her opening remarks, “because we’re moving toward an asthma clinic with many people who need this service.” (Photo courtesy of Steve McCaw)



Robles gave several examples of potential pitfalls when clinicians fail to communicate effectively. Instructions to take one pill daily could be misunderstood by Hispanics, for example, because the word once (on-say) in Spanish means eleven. (Photo courtesy of Steve McCaw)

“It’s a constant back and forth,” Farrar said of the process of meeting legal and administrative requirements, beginning with determining an individual’s preferred language for medical communication. She reinforced Robles’ call for comprehensive data collection and documentation, as well as the need for acknowledging and becoming sensitive to cultural differences.

“If acceptable plans are not in place,” she said, “Good luck with getting IRB approval.”

The NIEHS Clinical Research Branch currently has [several studies](#) underway or in enrollment at the Clinical Research Unit in Research Triangle Park, North Carolina. NIEHS clinical researchers also perform studies at the [NIH Clinical Center](#) in Bethesda, Maryland.



Clinical endocrinologist Janet Hall, M.D., gave an example of why cultural sensitivity can be so important in her research. How can researchers ask important questions in reproductive medicine studies, such as how many sexual partners a subject has had, if they rely on family members for interpreting, she asked. (Photo courtesy of Steve McCaw)



Virtually everyone with ties to the NIEHS clinical research program turned out for the talk, including Acting Director Stavros Garantziotis, M.D. Early in Robles’ talk, Garantziotis shared his own experience trying to communicate through a patient’s family member. “It’s hard to tell if you’re being understood,” he said. (Photo courtesy of Steve McCaw)



One essential for building an effective language interpretation program, Farrar told the audience, is getting buy-in from leadership. (Photo courtesy of Steve McCaw)



The talks were especially relevant for Craig Wladyka, left, and Jane Lambert, who work with NIEHS IRB approvals. As the Clinical Research Division designs more and more community-engaged studies, ensuring that subjects are giving truly informed consent will become increasingly essential to when a study goes forward or not. (Photo courtesy of Steve McCaw)

The case of Willy Ramirez

[\(http://healthaffairs.org/blog/2008/11/19/language-culture-and-medical-tragedy-the-case-of-willie-ramirez/\)](http://healthaffairs.org/blog/2008/11/19/language-culture-and-medical-tragedy-the-case-of-willie-ramirez/)
— a treatment fiasco based on a single word

In 1980, Ramirez suffered an internal brain hemorrhage that was ignored for two days because of failure by staff at a south Florida hospital to understand the difference between the Spanish word intoxicado and the English word intoxicated.

When emergency room personnel asked Ramirez what was wrong, he told them he was intoxicado, which in Cuban Spanish is a kind of an all-encompassing word that means there's something wrong with Ramirez because of something toxic he ate or drank. Thinking instead that he was intoxicated by alcohol or drugs, hospital staff failed to order a neurological exam, treated him for drug or alcohol overdose, and let him remain unconscious for more than two days, as his hemorrhage continued to bleed.

By the time doctors had realized their mistake, it was almost too late. The damage left Ramirez paralyzed from the neck down. In an out-of-court settlement of the subsequent malpractice suit, Ramirez received a lump sum payment of \$3.4 million and monthly payments for the rest of his life, according to a [story](#)

[\(http://news.google.com/newspapers?nid=1346&dat=19831105&id=bEdNAAAIBAJ&sjid=mvSDAAAIBAJ&pg=6965,1458953\)](http://news.google.com/newspapers?nid=1346&dat=19831105&id=bEdNAAAIBAJ&sjid=mvSDAAAIBAJ&pg=6965,1458953)

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