

Deportation Fears Are Putting A Damper On Diverse Medical Research

But one organization is dedicated to keeping Latinos in the clinic.

By Erin Schumaker

Medical research subjects skew white and male, meaning that the most effective treatments are designed for and tested on white men. Doctors prescribe these standard treatments to female, black and Latino patients, but they are doing so without patient-based evidence they'll be effective.

One prime example: In 2015, the Food and Drug Administration approved Addyi, a drug designed for women with low libido, based on a study of 23 men and 2 women, meaning researchers couldn't definitely say whether it was safe for women to drink alcohol while taking Addyi.

Enter the Sangre Por Salud biobank, a collaboration between Mountain Park Health Center and the Mayo Clinic in Arizona. Sangre Por Salud collects blood samples from Latino patients at Mountain Park who consent to donate, so that future studies (and the precision medicine that results from them), will include Latinos — who, like black and female patients, are underrepresented in medical research.

Valentina Hernandez is the director of integrated nutrition services at Mountain Park, which is essentially a one-stop shop for primary care services — including pediatric and women's health care, labs, a pharmacy and health education classes — in the Phoenix area.

Hernandez, who also oversees Sangre Por Salud's operations, talked with HuffPost about some of the biggest challenges she faces when recruiting Latino patients to donate to the biobank.

HuffPost: Who is eligible to donate blood to Sangre Por Salud? Do you have to be a U.S. citizen to participate?

Any patient who self-identifies as Latino or Latina can be included in the biobank. We enroll patients that come into the clinic. We don't ask them their immigration status.

They go to see their doctor, we approach them and we invite them to participate in research. We explain what it is, what we're doing and why, and if they want to participate, then they come in and give a blood sample that is stored for future research.

Why focus specifically on the Latino population?

It's the fastest-growing demographic in the U.S., and there's a huge need for more research for this community, because their health factors are different than other communities that have been researched.

That's why it's so important that we include them in research, to understand their health status and what treatment they are going to respond to or not respond to.

A lot of them might struggle with a condition like diabetes, or they have family that does. They see it as a way of helping research advance so that their children, grandchildren, great-grandchildren, might not have to struggle with it as much. It's very altruistic. If you talk to our participants, they really want to help future generations. They completely understand the value of what it is they are doing.

What are some of the barriers to enrolling Latinos in the Sangre Por Salud biobank?

There are a few barriers that we see all of the time, for any type of initiative that we do at Mountain Park, like transportation and time away from work.

In research, what we have seen is that there's more fear of sharing their personal information. And every time that we have different immigration climate change and there's a different initiative out there to try to scare or identify people who might be undocumented, we see a decline in participation.

We talk a lot about the undocumented participants, but we've seen that fear [among] participants that might be here legally or might even be citizens, because their families are mixed.

That's a huge barrier. You might have status or be a citizen, but if your wife, your husband, your niece, someone who is with you is not, your fear is equal to theirs. The risk you're taking can impact them.



SANGRE POR SALUD

Valentina Hernandez (back row, second from right) with staff from Mountain Park Health Center, the Mayo Clinic and Sangre Por Salud, a blood biobank that aims to include more Latino patients in medical research.

President Donald Trump has waged an intense deportation campaign during his first months in office. Is it harder to recruit patients now that Trump is president?

It's been a little more difficult to recruit patients. In the past, in order to meet our weekly goal, we had to approach 60 patients a week. Now we have to approach between 70 and 75 patients to get to our goal.

Since the beginning of this year, our participants are saying they're more afraid. They don't want to share their information or leave their homes.

We've seen more fear. Just driving a car across town might put them in a situation where they might be pulled over or asked their immigration status. They don't want to risk going to the

grocery store. The fear of being out in public and being in the wrong place at the wrong time is scary.

What do you tell potential biobank participants who are worried about participating?

Mountain Park Health Center has been in the community for more than 30 years. That is our strongest currency, the trust our patients have in us.

Sangre Por Salud has also obtained a certificate of confidentiality that protects the researcher and the study from being forced to disclose identifying information. It's a federal protection. We explain that to all of our participants.

And if the patient says, "You know I'm really afraid to leave my house. I don't want to drive my car," we say, "We'll send you a cab."

What could happen to the Sangre Por Salud project if gets increasingly difficult to recruit Latino participants?

The strength of the research is in the number of participants you have. If you have a biobank of 5,000 patients versus a biobank of 3,000 patients, your 5,000-patient biobank is going to be a lot more valuable.

We want it to be valuable, so we want to meet our goals. Otherwise it might not be as attractive for researchers to want to study that group.

We're about 10 percent behind where we should be.

How do you feel about the next four years and beyond? Are you hopeful about the biobank's future?

I'm going to remain hopeful as long as I can. It's important work and the entire nation is going to benefit from it.

In Arizona, the immigration climate can change from week to week. There have been immigration sweeps in the city of Phoenix or in Maricopa County, and during those times we see a decrease in participation.

I've been with Mountain Park for about 15 years. We've weathered a lot. Joe Arpaio. S.B. 1070. In Arizona, it's a cycle. This is no different. We're just going to keep moving forward.