

# Chagas Disease in a Time of Immigrant Backlash: Challenges for Expanding Access to Treatment in Los Angeles and Beyond



American Society of Tropical Medicine and Hygiene  
Annual Meeting

Baltimore, November 8<sup>th</sup> 2017

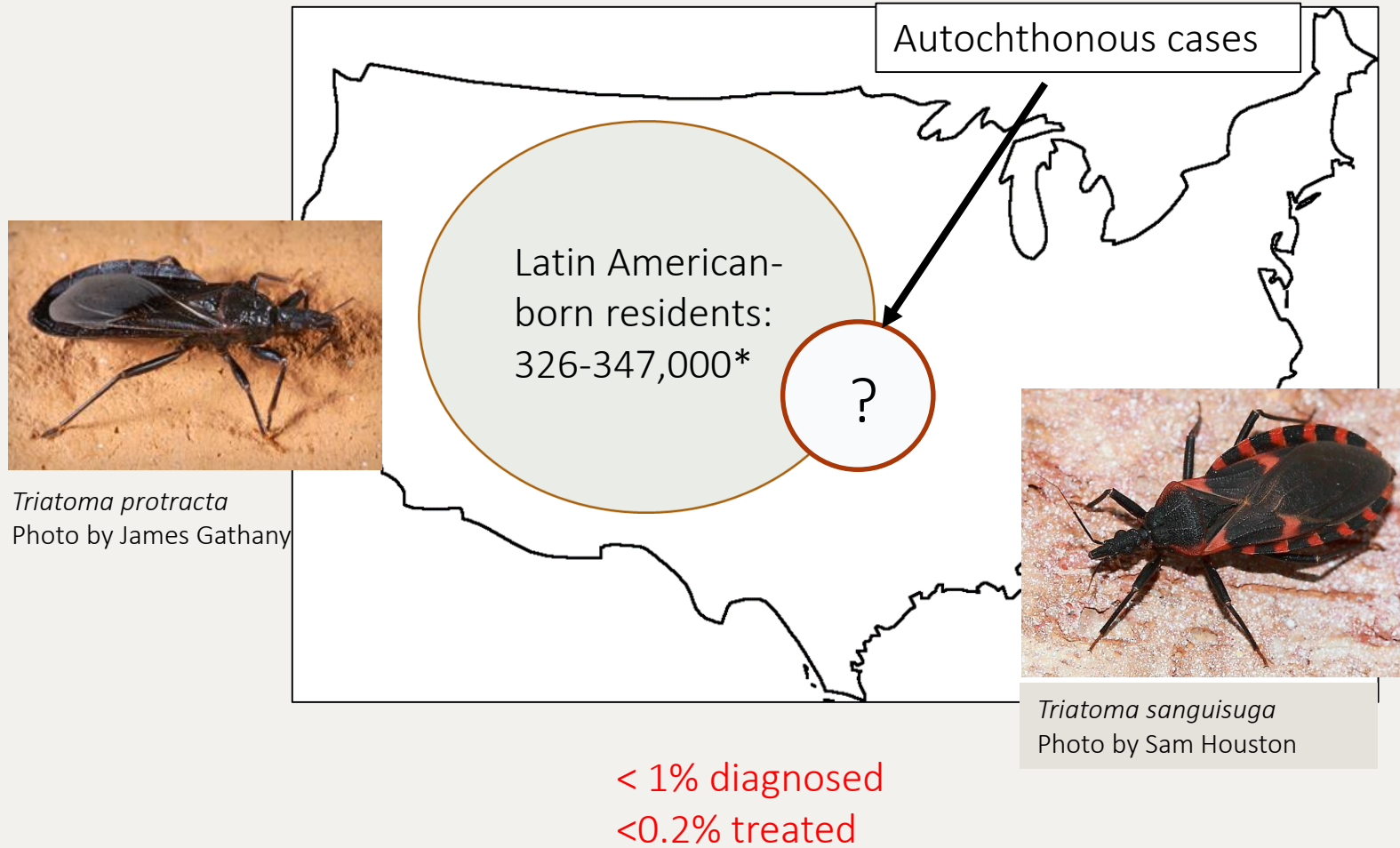
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Drugs for Neglected Diseases *initiative*



# Current Epidemiological Landscape

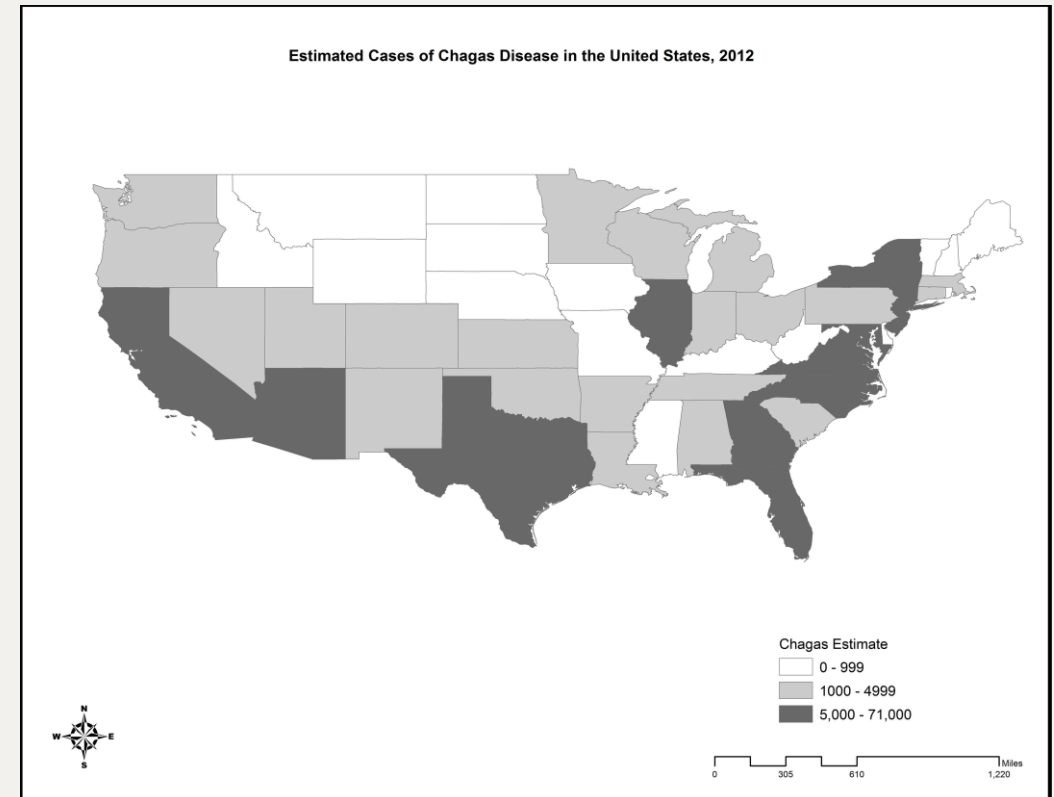


## Other transmission routes:

- Congenital
- Transfusion-transplant

# U.S. Chagas Disease: Geographic Distribution

- Total burden 326-347,000
  - State ranking by estimated cases\*:
    1. California 70,000
    2. Texas 37,000
    3. Florida 18,000
    4. New York 17,000
- \* doesn't include undocumented



\*Manne-Goehler J, Umeh CA, Montgomery SP, Wirtz VJ (2016) Estimating the Burden of Chagas Disease in the United States. PLoS Negl Trop Dis 10(11): e0005033.

# Prevalence in the Latin American-born Population of LA County: CECED Research

- Community screening program
  - 89 health fairs 2008-2014
  - 4,755 Latin American-born individuals screened
- Significant risk factors:
  - Heard of Chagas disease
  - Lived in thatch+adobe+mud housing
  - Salvadoran

Group	N	<i>T. cruzi</i> +	prevalence
All	4,755	59	1.24
El Salvador	811	28	3.45
Mexico	3,182	25	0.79
Oaxaca	86	4	4.65
Zacatecas	225	4	2.20
<high school education	3104	45	1.45
Heard of Chagas disease	394	13	3.30
Lived in thatch roof house	407	11	2.70

Source: Meymandi SK, Forsyth CJ, Soverow J, et al. Prevalence of Chagas disease in the Latin American-born population of Los Angeles. Clin Infect Dis 2017;64:1182-8.

# The Moment:

## Treatment Access for Chagas Disease in the United States, 2017

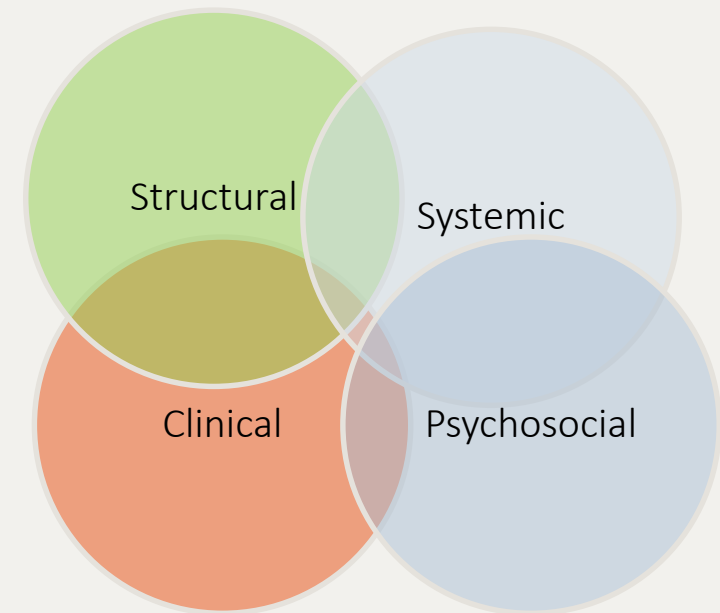
### Opportunities

- FDA approval of benznidazole August 29<sup>th</sup>
- Emerging provider-led initiatives

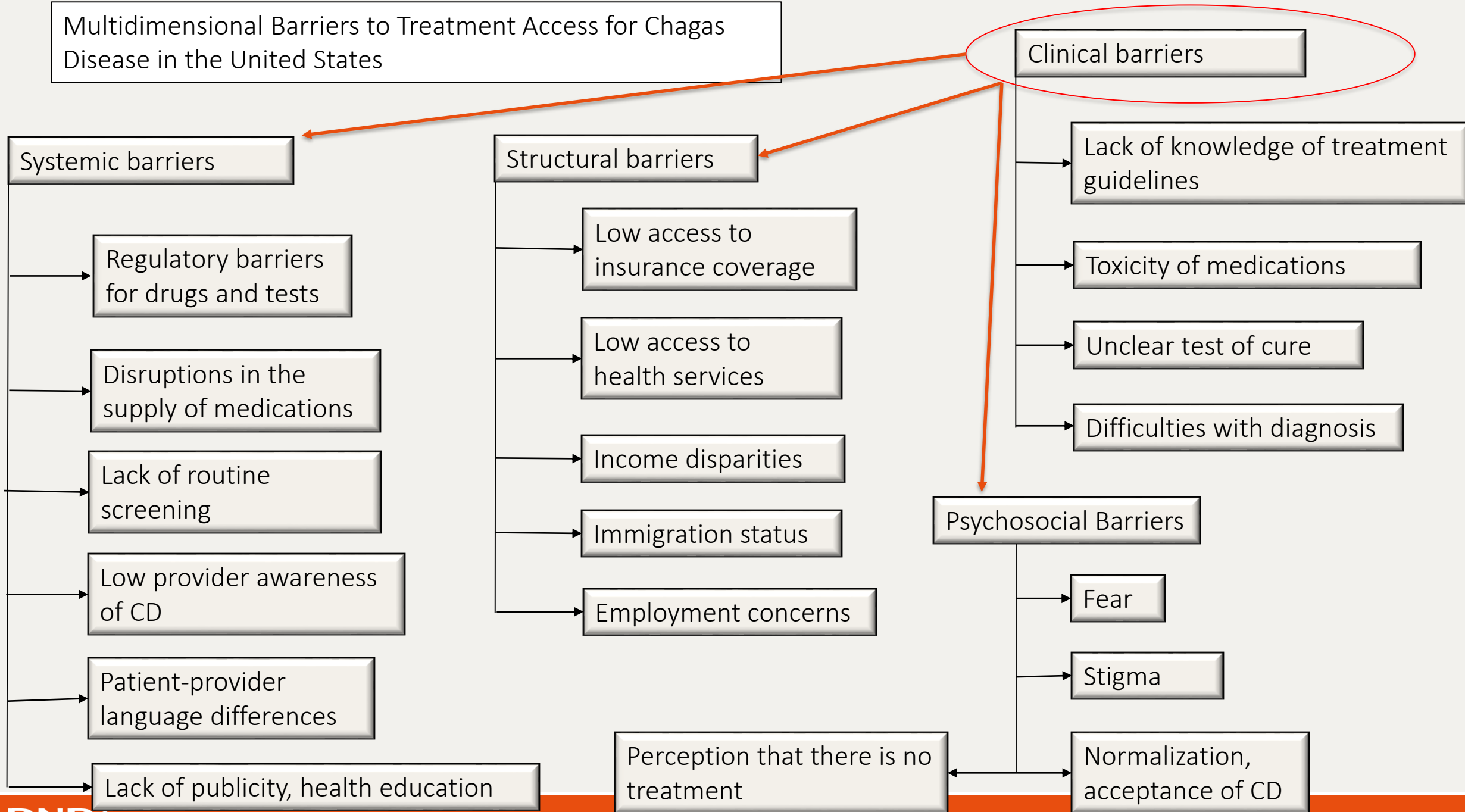
### Threats

- Anti-immigrant political climate
- Cuts to public health programs?
- Future of Affordable Care Act, Medicaid
- Tangled web of barriers

### Multidimensional Barriers to Access to Medical Services for Chagas Disease



# Multidimensional Barriers to Treatment Access for Chagas Disease in the United States





# Who are the people with Chagas Disease in the U.S.? Patients at the Center of Excellence for Chagas Disease, Los Angeles

	n	%
Sex		
Male	17	34
Female	33	66
Education		
High school graduate	20	40
<high school	30	60
Country of origin		
El Salvador	28	56
Mexico	13	26
Bolivia	4	8
Guatemala	3	6
Other (Arg, Honduras)	2	4
Occupation		
Labor/service	25	50
Homemaker	16	32
Management/professional	4	8
Retired or unemployed	5	10

- Interviews with 50 patients of the CECD, July-December 2016
- Gathered socioeconomic data, administered survey, asked patients about their experiences managing Chagas disease

	Mean	Range		Mean	Range
Age	49.5	25-72	Annual household income	30,504.36	4,800-180,000
Education (years)	8.4	0-16	Spent on healthcare in last year	894.26	0-10,000
Years in US	21.2	1-49	Number in household	3.88	2-7
Annual income, working adults	20,253.72	4800-84,000	Annual household income (per capita)	8,688	1920 – 45,000

# Structural Barriers

*Since my husband and I both work I don't qualify for Medi-Cal. And if I had Medi-Cal I know I could keep getting treated for Chagas.*  
-Zaida, 54, El Salvador

## Comparison of wealth, Latinos vs. non-Latino whites\*, 2014

	Latinos	Non-Latino Whites
Median annual income	42,491	60,256
% living in poverty	23.6	10.1

\* DeNavas-Walt C, Proctor BD. Income and poverty in the United States: 2014. Washington, DC: United States Census Bureau; 2015.

## Income and insurance coverage, CECD patients

Household income*	n	%
Below federal poverty line	26	63.4
Above federal poverty line	15	36.6
Health insurance		
Medi-Cal, Medicaid, or county program	35	70
Medicare	2	4
Private	6	12
Uninsured	5	10
Not sure/unspecified	2	4



# Structural Barriers and Patient Access

What would make it easier to go to the doctor?	n	%
Transportation	12	24
More insurance coverage	10	20
Financial support	10	20
More/easier time off	8	16
Less delays/bureaucracy in healthcare system	7	14
Services near me	4	8
Nothing/NA	14	28

*Before I couldn't go [to the doctor], because I didn't know how to drive. I had to wait for someone to take me; I depended on someone giving me a ride as a favor. And then I didn't have money to pay for the appointment or the ride, or sometimes for lack of time, and I've had to neglect other tasks so I could go to the doctor.*

-Renata, 36, Mexico

*Many [in the community] are undocumented Hispanics, and they are afraid to get treatment because they think they will get deported.*

-Sofia, 43, El Salvador

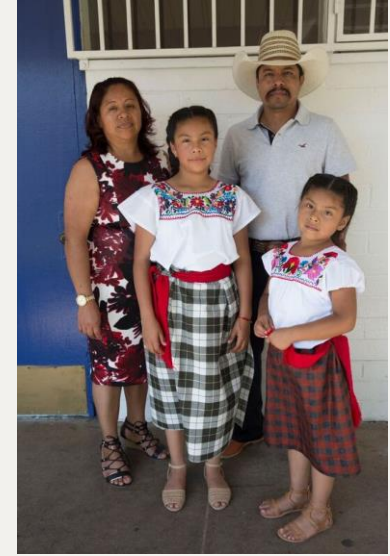
*Finding a person to give me a ride, because my daughter doesn't know how to drive and we have to go on the bus. I don't have a car so that would help me a lot.*

-Beatriz, 51, Honduras

# What is the most difficult part of adjusting to life in the United States?

## Top responses

1. The language (n=30, 60%)
2. Being far from family (n=13, 26%)
3. Finding/keeping jobs (n=13, 26%)



*Well when you get here you go about in fear, if you don't have papers here. Also language, well you know that if you don't speak the language you feel afraid and that frustrates you in the beginning.*

-Roberto, 39, El Salvador

*That was the most difficult part, the jobs. I started to get jobs here and there, and worked and worked. And then [the doctors] found out I had this Chagas disease and I had to stop working because I didn't have time to go to work. I was spending all my time in the hospital.*

-Carlota, 64, Guatemala

# Systemic Barriers: Physician Awareness

Medscape CME survey of 1142 US physicians

Response	No. (%) respondents†				
	Cardiology, n = 280	Infectious disease, n = 167	OB/GYN, n = 292	Primary care, n = 278	Transplantation, n = 125
Never heard of Chagas disease‡	63 (23)	31 (19)	138 (47)	38 (14)	35 (25)
Not at all confident of Chagas disease knowledge being up to date§	87 (44)	31 (27)	86 (68)	101 (47)	41 (48)
Did not know parasite causes Chagas disease¶	21 (16)	6 (5)	42 (33)	35 (16)	15 (17)
Did not know cardiac and/or gastrointestinal disease are manifestations of Chagas disease#	15 (8)	10 (9)	38 (30)	24 (11)	11 (13)
Never considers risk for Chagas disease in patients**	51 (34)	30 (29)	66 (60)	83 (43)	29 (39)
Did not know in what percentage of patients with chronic infection clinical disease develops††	66 (37)	30 (28)	60 (56)	93 (48)	35 (47)
Did not know Chagas disease symptoms‡‡	41 (23)	15 (14)	53 (48)	52 (27)	22 (29)

Source: Stimpert K. Physician awareness of Chagas disease, USA. EID 2010; 16:871-2.

- *The majority of doctors in the United States don't know what Chagas is. I've gone to two cardiologists... and I had to show the doctor on Google what Chagas is.*  
-Omar, 41, El Salvador
- *They explained to me I had been bitten by a chinche... and not to worry too much, to talk to my doctor, but I started to search and nobody could help me because they didn't know what the disease was.*  
-Denver, 42, El Salvador

# Systemic Barrier: Patient Awareness

- 86% of 2,677 Latin American-born residents of Los Angeles had never heard of Chagas disease (Sanchez et al. 2014)

*It's a fatal disease, and yet you don't hear anything about it, it's like a phantom disease that is killing people but nobody knows it exists, until they tell you you have it. You always hear about diabetes, cancer, but [Chagas] disease is something that's never heard anywhere, not even in the media.*

-Sara, 60, El Salvador



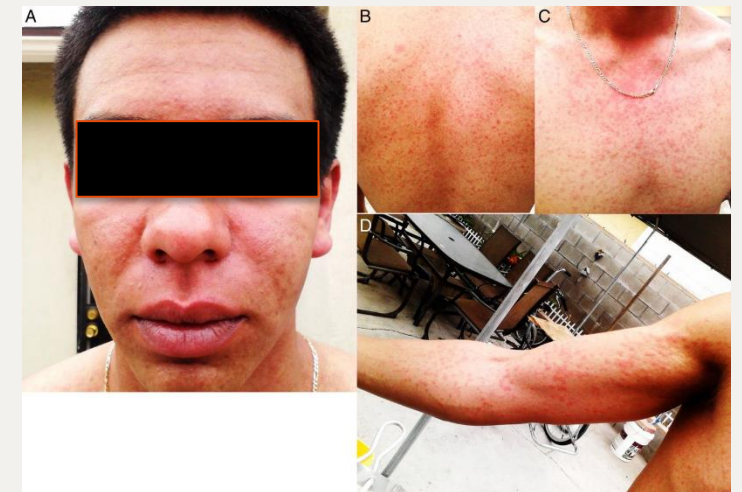
# Clinical Barrier: Adverse Effects

## CECD Research

*One went to my head, it was like it erased my mind and I think I lasted one or two weeks taking it. And then they gave me another and my hands started to swell and I got spots and a rash and all that. I also took that one two or three weeks and then I told the doctor that I wasn't going to be able to take it anymore.*

*-Cristobal, 64, Mexico*

	benznidazole (n=52)	Nifurtimox (n=53)
Mean AEs per treatment	3.5	8.2
% discontinuing treatment secondary to AEs	25	23.8
Predictors of discontinuation	AEs per 30 days	AEs per 30 days AE severity



Sources: Hernandez et al. 2017  
Forsyth et al. 2016

Case of angioedema and rash (benznidazole):  
from Miller et al. Tolerance of Benznidazole in a United States  
Chagas Disease Clinic, *Clinical Infectious Diseases*, Volume 60,  
Issue 8, 15 April 2015, Pages 1237–1240,



# Emotional Impact of Chagas Disease

*It hit me hard, because people in my family have died from Chagas... I got scared. I sought help in the hospital but they couldn't treat me because my case was chronic and treatment was more for people who had more recently acquired it... they didn't tell me in those words but what I felt was, that it was practically a waste of time. It hit me hard...*

-Victoria, 43, El Salvador

*Once I learned more about Chagas disease I started to worry...I became depressed, I felt very sad, because you don't know if you're going to die tomorrow or what... I felt down, sad, without desire to do anything, and insomnia.*

-Sara, 60, El Salvador

Study: 41% of Chagas patients exhibit depressive symptoms  
(Ozaki et al. 2010)

What mental health/social support resources are available to people diagnosed with Chagas disease?

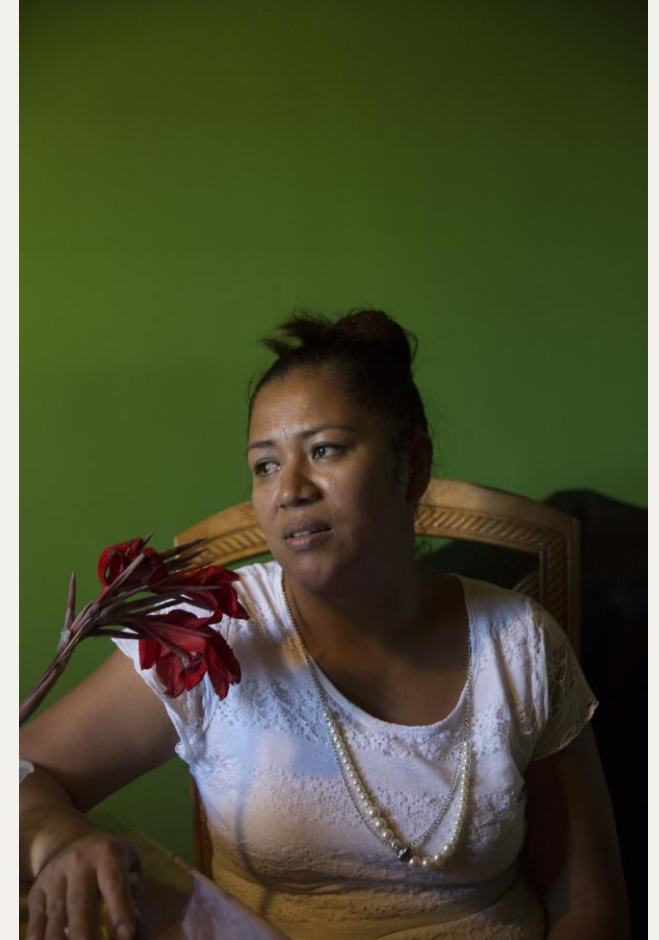
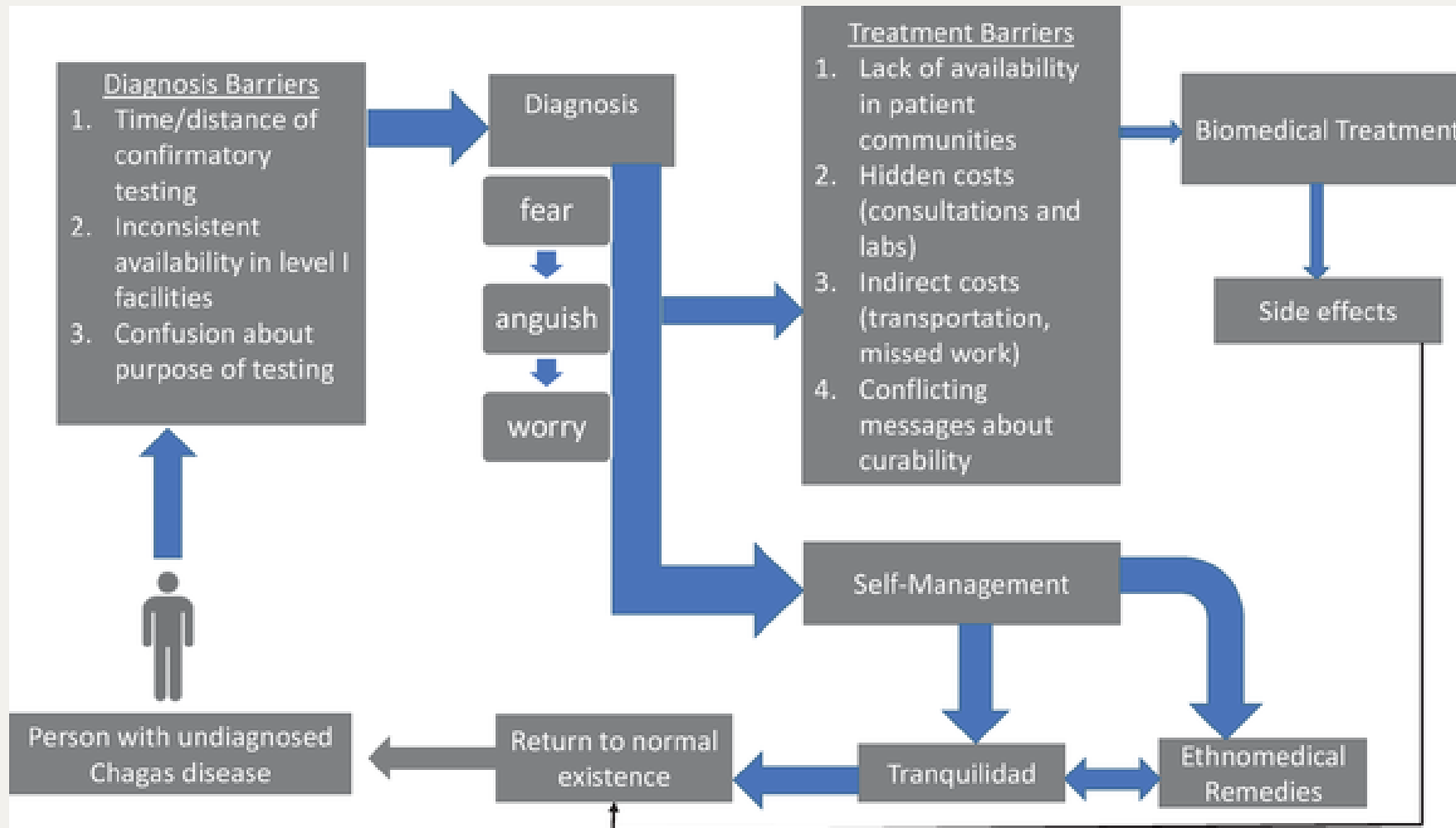




Fig 1. Patient Strategies for Coping with Chagas Disease.



*I know that nothing can be done, there's no cure, nothing, and I think the only way to go on with life is to not pay too much attention to it. I take care of myself, but apart from that nothing more can be done.*

-Abram, 55, El Salvador

Forsyth CJ (2017) "I Cannot Be Worried": Living with Chagas Disease in Tropical Bolivia. PLOS Neglected Tropical Diseases 11(1): e0005251.

doi:10.1371/journal.pntd.0005251

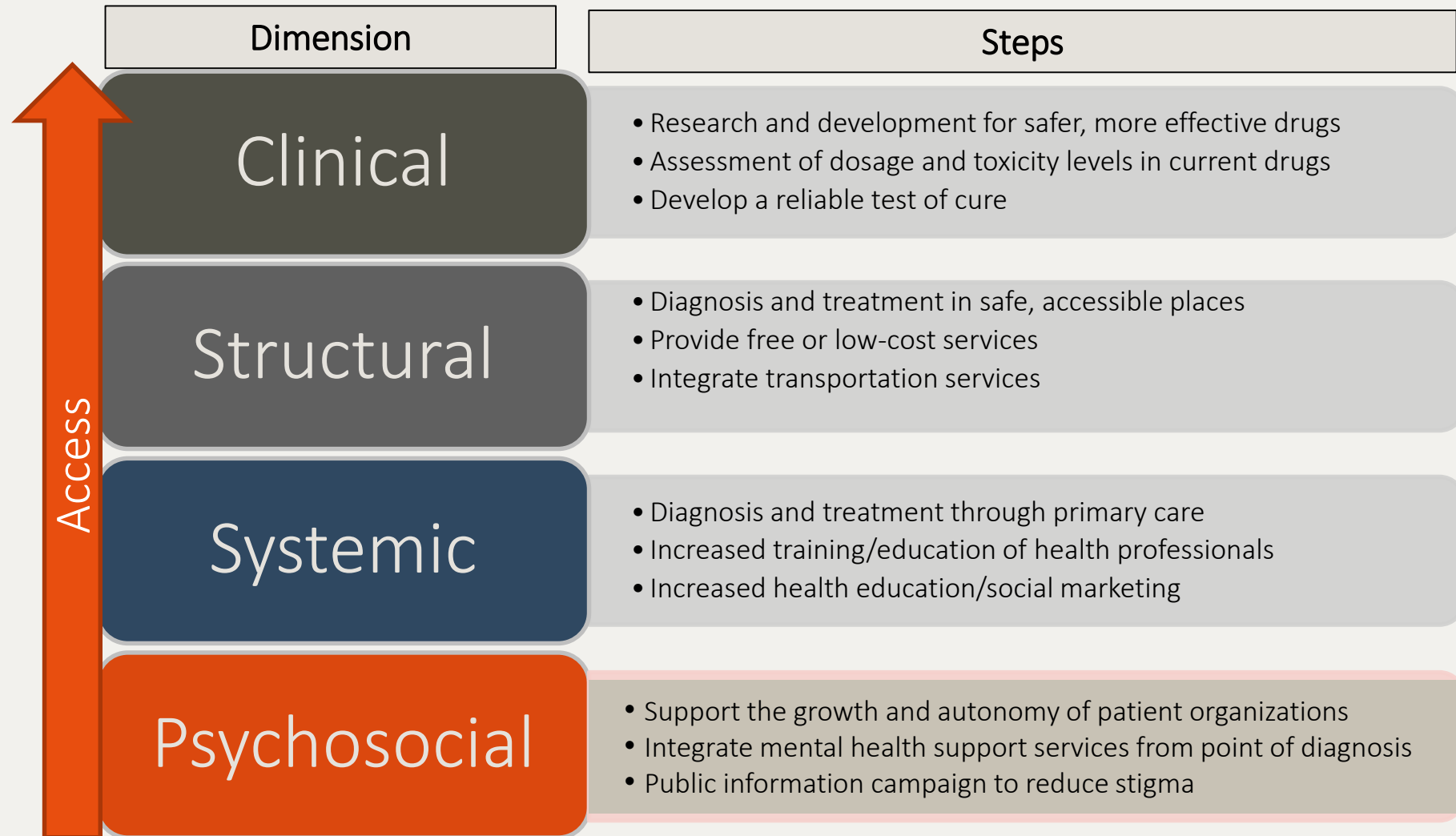
# Stigmatization: Chagas disease and anti-immigrant discourse

## Media stories stigmatizing Chagas disease, immigrants

- June 2012 “Chuck Norris warns of new border invasion”
- World News Daily, Nov. 2014: “Another deadly disease invades with illegals”
- Trump, July 2015: “Tremendous infectious disease is pouring across the border. The United States has become a dumping ground for Mexico and, in fact, for many other parts of the world.”
- Breitbart, Dec. 2015: “Why are so many diseases back decades after being wiped out in the U.S.?”
- Pitbulls and Parolees, reality TV show: “What originated in Latin America through the “kissing bug” has found its way into parts of the United States”
- World News Daily, December 2015: “300,000 CASES OF CHAGAS REPORTED IN U.S.: 'We're unwilling to stop illegals who are bringing this disease across’
- “Trump’s Open Borders Infect Thousands with Chagas and other Third World Diseases”



# Comprehensive Model to Eliminate Barriers and Increase Access to Treatment for Chagas Disease



# If you were President, what would you do about Chagas disease?

Top solutions	N, (%)	In the patients' words
Provide more information <b>N=13</b>	13 (26)	There is not a lot of awareness. I think every health center should give talks about this disease to train the nurses and everyone else because they don't have knowledge about it. (Roberto)
Find new/better medicines <b>N=13</b>	13 (26)	In my case they can't give it to me because it's very strong and if the medicine were a little milder I could take it. (Jorge)
Increase screening <b>N=9</b>	9 (18)	If I were President, I would include it in annual physicals or provide the test for free. I would find a way to provide free Chagas testing in more places. (Renata)
More facilities, providers offering treatment <b>N=8</b>	8 (16)	Make treatment more accessible. Thank God we have insurance and were able to go to this clinic, but maybe if there were clinics and better informed doctors it would be easier. Because there's just one clinic, so far away and nobody else knows about this disease. (Eleana)
Provide free or more accessible treatment <b>N=7</b>	7 (14)	I would provide free services for all people with the disease, and explain to them what the disease is and how they can survive. (Flor)

# Toypurina

