

Fall 12-2018

# CHAGAS DISEASE AWARENESS AMONGST TEXAS PHYSICIANS

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CHAGAS DISEASE AWARENESS AMONGST TEXAS PHYSICIANS

by

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SCHOOL OF PUBLIC HEALTH

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DEDICATION

To Crystal and Olivia Pacheco

CHAGAS AWARENESS AMONGST PHYSICIANS IN TEXAS

by

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DOCTOR OF PUBLIC HEALTH

THE UNIVERSITY OF TEXAS  
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December, 2018

## PREFACE

I am fortunate and grateful for the mentorship that first introduced me to public health and the encouragement to continue on this journey. My late father has been my inspiration throughout this degree and my public health training. He is the reason for my passion and interest in health disparities and addressing the impact of delayed medical diagnosis.

## ACKNOWLEDGEMENTS

First and foremost, I am forever grateful for the guidance, patience, and expertise of my committee. I appreciate the support from Dr. Melissa Valerio throughout my doctoral training and for pushing me to see this through. I thank Dr. John Herbold for always reminding me of the “big picture” and Dr. Jose Betancourt for his detailed feedback and encouragement. I am in Dr. David Gimeno’s gratitude, for his words of encouragement and assistance with the transcription of my qualitative data. I would like to also thank the administrative staff at the San Antonio Campus for helping me with all the logistics (and for their kind words of encouragement and faith in me!). And last but definitely not least I am indebted to Dr. Paula Stigler Granados for her mentorship, pragmatism, time, and for taking a chance with me. If she had not recruited me to assist her in her funded Chagas project, this research would not have been possible.

Next, I would like to thank the Texas Chagas Taskforce members, including: Drs. Leo Cropper and Sarah Gunter for serving as reviewers; Dr. Melissa Nolan for outreaching to her wide network of physicians to help with the recruitment; Dr. Sue Montgomery for proving her content expertise; and all of the other members who reviewed instruments and helped disseminate my questionnaires.

Finally, I would like to thank my friends and family for helping me stay on track and grounded (and stay sane!). To my wife: thank you for seeing this through and always having confidence in me, especially in those moments of self-doubt. To my family: thank you for understanding my reclusiveness and for your support.

# CHAGAS DISEASE AWARENESS AMONGST PHYSICIANS IN TEXAS

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The University of Texas  
School of Public Health, 2018

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An estimated 300,000 people in the U.S. are living with Chagas Disease (CD), many of whom may not yet know they are infected. Approximately 20% to 30% of individuals with CD are expected to develop clinical symptoms that may manifest as heart disease and result in death if left untreated. The prevalence of CD in humans is not well understood. Given its asymptomatic manifestation and the rarity in cases seen by physicians in general, CD may be under-recognized by physicians.

The purpose of this research was to explore the understanding and knowledge of CD in Texas HCP populations (cardiologists, infectious disease specialists, and general/ family practice providers) and identify provider-based education and practice recommendations to reduce the prevalence of undiagnosed CD.

Texas quarterly Inpatient Public Use Data Files (IPUDF) for 2013 to 2016 were used to identify ICD heart-related missed CD diagnosis and CD diagnosis and map the cases. Counties with a high burden of heart-related diagnosis were indicative areas with CD diagnosis, as shown by the ICD codes and by the TDSHS CD-reported cases. Heart-related diagnosis and age demographics indicate the possibility of missed CD diagnosis throughout the state.



Self-administered online knowledge, attitudes, and practice (KAP) questionnaires were used to quantify knowledge deficits by physician specialty (n= 43): family or general practice (n= 21); infectious disease (n= 19); and cardiology (n= 3). ID specialists had a greater grasp on the nuances of CD and were more confident than family providers in recognizing risk factors and the vector and were more knowledgeable overall.

Key informant (KI) telephone interviews were conducted (n= 13) among infectious disease specialists (n= 8), cardiologists (n= 4), and one family physician to explore barriers and recommendations to improve awareness and knowledge. Training and experience, according to the KI, were essential in shaping physicians' understanding of CD in Texas. Specific physician recommendations to enhance awareness and improve knowledge on CD in Texas include: 1) engage patients and physician leadership; 2) increase surveillance to better understand prevalence; 3) improve access to physician resources and how materials on CD are disseminated; and 4) improving and updating physician resources.

## TABLE OF CONTENTS

Table of Contents .....	i
List of Tables .....	i
List of Figures .....	iii
Background .....	1
Kissing Bugs and <i>Trypanosoma cruzi</i> .....	1
Geography of Vectorial Transmission to Humans.....	3
Congenital Transmission .....	4
Transmission from Blood Transfusions.....	5
Chagas as a Global Threat .....	6
Phases and Clinical Manifestations .....	7
Acute infection.....	7
Chronic infection .....	7
Chronic determinate phase.....	8
Cardiomyopathy.....	9
Epidemiology and Surveillance .....	9
Screening and Diagnosing .....	10
Drug Treatment.....	11
Prevention Programs .....	11
Role of Healthcare Providers .....	13
Health System Barriers .....	14
Patient level.....	14
System and provider level.....	15
Public Health Significance.....	17
Statement of the Problem.....	18
Frameworks.....	19
Diffusion of Innovations .....	19
Reducing or eliminating diagnostic errors .....	19
Systems-level perspective.....	21
Specific Aims.....	24
Methods.....	26
Overall Study Design .....	26
Human Subjects Protection.....	26
Methodology for Aim 1: Mapping.....	27
Data sources .....	27
Variables .....	28
Case definitions.....	28
Data collection and management .....	29
Mapping .....	31
Methodology for Aim 2a: Questionnaire.....	32

Study design and population.....	32
Instrument development.....	34
Sampling and recruitment.....	35
Sample size.....	36
Data collection and management.....	37
Data analysis.....	39
Methodology for Aim 2b: Key Informant Interviews.....	39
Study design and sampling.....	39
Interview questions.....	40
Recruitment.....	40
Data collection and management.....	41
Data analysis.....	42
Literature Review.....	44
Quantifying the Global Threat.....	44
Awareness of Chagas Disease.....	44
Among Healthcare Providers.....	44
Among the Population.....	48
Physiology and Biomarkers for Chagas Cardiomyopathy.....	51
Surveillance.....	52
United States.....	52
Texas.....	53
Journal Article 1.....	54
A geospatial analysis of diagnosed and potentially undiagnosed Chagas cases in Texas using inpatient hospital records, 2013 to 2016.....	54
Target Journal: PLOS Neglected Tropical Diseases.....	54
Journal Article 2.....	75
Shaping recommendations and healthcare provider education on Chagas disease from a mixed methods baseline exploratory study.....	75
Target Journal: American Journal of Public Health.....	75
Journal Article 2.....	76
Shaping recommendations and healthcare provider education on Chagas disease from a mixed methods baseline exploratory study.....	76
Target Journal: American Journal of Public Health.....	76
Conclusion.....	140
Main Findings.....	140
Study Strengths.....	142
Study Limitations.....	142
Recommendations.....	144
Next Steps and Implications.....	147
References.....	149
Appendices.....	157

Appendix A: IRB Outcome Letter .....	158
Appendix B: Chagas Disease Knowledge, Attitudes, and Practices Questionnaires.....	159
Appendix C: Semi-Structured Interview Scripts and Forms .....	241
Appendix D: Table of ICD-9 CM and ICD-10 CM Chagas and Cardiomyopathy Codes.....	250
Appendix E: Table of Mapped ICD Counts, by County.....	251
Appendix F: Raw Responses for Knowledge Questions, All Questionnaires	258
Appendix G: Summary of Key Informant Tracking Table.....	264

## LIST OF TABLES

Table 1: Chagas and cardiomyopathy-related ICD-9 CM and ICD-10 CM codes.....	29
Table 2: Sampling and Participation, by Specialty.....	38
Results Table 1: Participant Demographics, by Completion of Specialty Questionnaire .....	109
Results Table 2: Responses to Agreement Items, All Questionnaires.....	111
Results Table 3: Responses to Confidence Items, All Questionnaires .....	113
Results Table 4: Attitudes of Family or General Practice Physicians Questionnaire.....	115
Results Table 5: Attitudes of Infectious Disease Specialists and Cardiologists.....	116
Results Table 6: Priorities* for Managing Care in Blood Donation Letter Patient .....	117
Results Table 7: Priorities* for Managing Care for a CD Patient Potentially Exposed to a Vector.....	117
Results Table 8: Attitudes among Infectious Disease Specialists .....	117
Results Table 9: Summary of Correct Knowledge Items, All Questionnaires .....	118
Results Table 10: Summary of Correct Knowledge Items and Scores, All Questionnaires.....	120
Results Table 11: Knowledge on Screening for Cardiologists and Infectious Disease Specialists .....	121
Results Table 12: Specific Knowledge and Indexed Scores for Infectious Disease Specialists .....	122
Results Table 13: Specific Knowledge for Cardiologists.....	123
Results Table 14: Consideration of Risk Factors, Frequency by Physician Specialty .....	124
Results Table 15: Resources Physicians Reference when Managing Care of a Patient with CD.....	126
Results Table 16: Likelihood of Resources Used to Learn More about Chagas Disease.....	127
Results Table 17: Screening and Diagnosis Practices among Infectious Disease Specialists .....	128
Results Table 18: Additional Comments Regarding Screening Practices .....	129
Results Table 19: Frequency of Procedures in Patients Referred from a Blood Donation Letter .....	130
Results Table 20: Frequency of Procedures when Presenting with Idiopathic Cardiomyopathy among Cardiologists and Infectious Disease Specialists .....	132
Results Table 21: Key Informant Demographics.....	133

Results Table 22: Perceived Barriers Preventing the Management of Care for Patients with Chagas Disease .....	134
Table 3: Recommendations to Improve Chagas Disease Education at the System, Physician and Patient Levels .....	147

## LIST OF FIGURES

Figure 1: World-wide prevalence of Chagas Disease.....	2
Figure 2: Lifecycle and transmission of <i>Trypanosoma cruzi</i> in human hosts .....	2
Figure 3: Triatomine prevalence in the U.S., by state .....	4
Figure 4: Lab-confirmed Chagas cases in blood donations, 2007 – Aug. 2017 .....	6
Figure 5: Acute and chronic phases of Chagas disease infection .....	8
Figure 6: Example of Campaigns in Latin America .....	13
Figure 7: Patient barriers and strategies for coping with Chagas disease.....	15
Figure 8: Patient Engagement in the Medical Health System to Receive a Chagas Diagnosis and Treatment .....	22
Figure 9: Systems-level Conceptual Model for Barriers to Chagas Screening, Diagnosis, and Treatment .....	23
Results Figure 1: Reported Cases of Chagas Disease and County of Transmission, 2013 to 2016. ....	68
Results Figure 2: ICD Codes for Heart-Related Diagnosis, 2013 to 2016* .....	69
Results Figure 3a: Heart-Related ICD Diagnosis for 2013 to 2016, * Hispanic Population** .....	70
Results Figure 3b: Heart-Related ICD Diagnosis for 2013 to 2016*, Population Aged 20 to 59 Years of Age .....	70
Results Figure 4: Chagas Disease and Heart-Related ICD Diagnostics Codes for 2013 to 2016 .....	71
Results Figure 5: Heart-Related ICD Diagnostics Codes for 2013 to 2016, Adjusted by County Population .....	72

## BACKGROUND

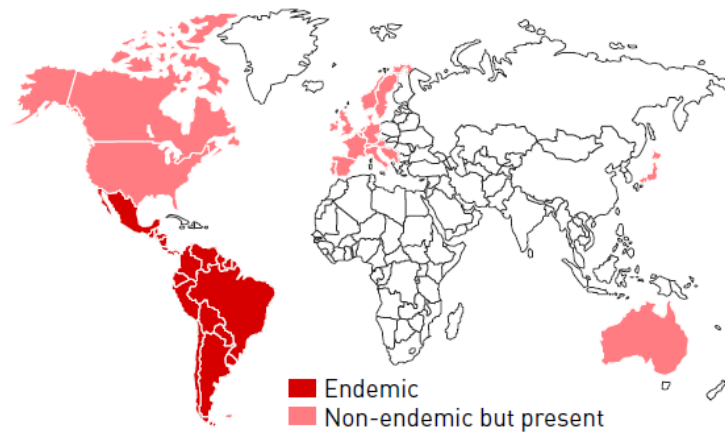
Chagas Disease (CD) is a neglected zoonotic disease<sup>1</sup> of the Americas that can be fatal if not diagnosed and treated in its early stages. CD was first discovered in 1909 by Carlos Chagas in Brazil and is endemic in Latin America.<sup>2</sup> The World Health Organization (WHO) recognizes CD as a neglected tropical disease<sup>3</sup> that continues to widen its global reach beyond the American tropics. Its impact and burden<sup>4-7</sup> are beginning to be seen in non-endemic regions from imported cases, including Europe and Asia. American trypanosomiasis,<sup>8</sup> infection from the hemoflagellate protozoan parasite *Trypanosoma cruzi* (*T. cruzi*), causes CD.<sup>1,9</sup> CD accounts for the highest burden of any parasitic disease in the 22 Latin American countries where it is endemic (Figure 1). *T. cruzi* is endemic throughout Central and South America and is found in North America, including in Mexico and in the Southern United States (U.S.).<sup>10</sup> An estimated 8 million people in Latin America have CD.<sup>11</sup> Over 28,000 people are infected each year in Mexico, Central America and South America, accounting for at least 12,000 deaths per year.<sup>12</sup>

### **Kissing Bugs and *Trypanosoma cruzi***

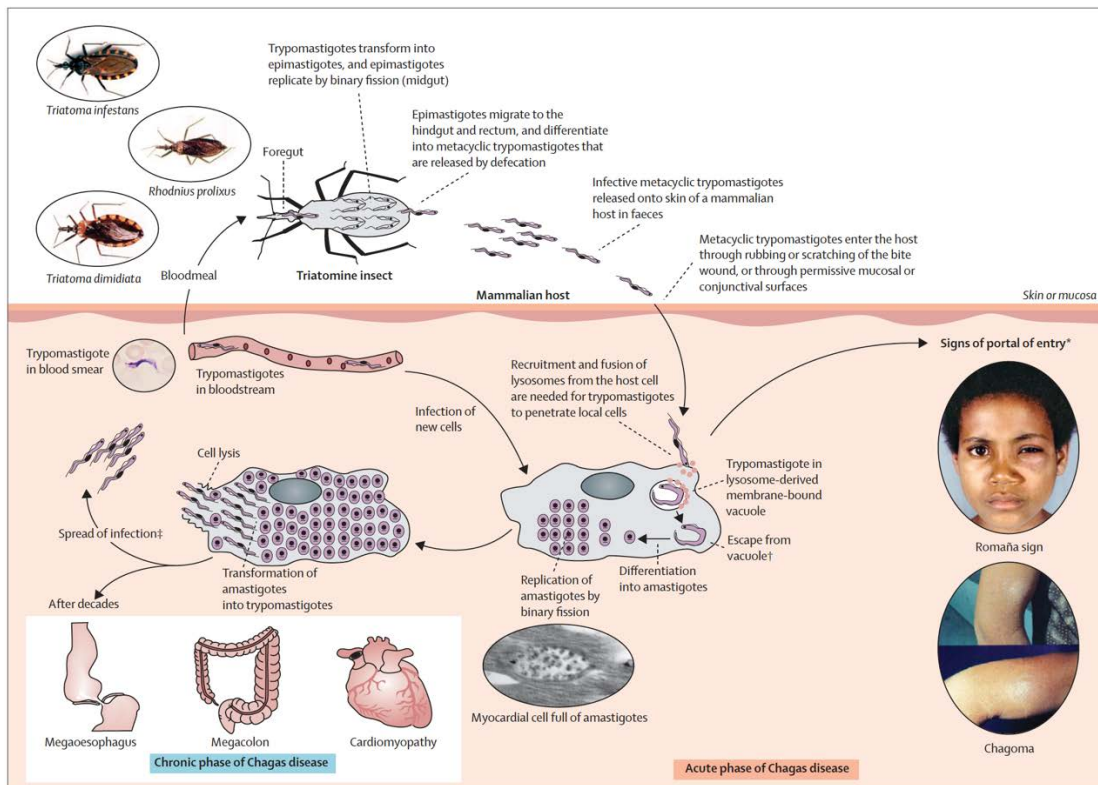
*Trypanosoma cruzi*, infects invertebrate and vertebrate hosts during its various life cycles. The complex life cycle of *T. cruzi* is described in Figure 2.<sup>8</sup> Reduviids, also known as triatomines or kissing bugs, are blood-feeding insects that transmit the parasite (mainly through their feces) that causes CD. The kissing bugs are unaffected by *T. cruzi* but act as the vector for the parasite. Kissing bugs transmit the parasite to mammals including humans,<sup>1</sup> but can also infect reservoir hosts such as canines, opossums, raccoons, and other domestic<sup>8,13</sup> and sylvatic animals.<sup>14</sup> Although CD is a zoonotic disease, the focus of this dissertation will be on the human health aspect.



**Figure 1: World-wide prevalence of Chagas Disease<sup>1</sup>**



**Figure 2: Lifecycle and transmission of *Trypanosoma cruzi* in human hosts<sup>2</sup>**



<sup>1</sup> Source: Drugs for Neglected Disease initiative (DNDi) - <https://T.cruzi.dndi.org/diseases-projects/chagas/>

<sup>2</sup> Source: Rassi et al. (2010). Chagas disease. *The Lancet*, 375: 402

## Geography of Vectorial Transmission to Humans

Vectorial transmission is most common among children and adolescents in endemic countries.<sup>8</sup> In Latin American communities, transmission usually occurs during childhood as a result of limited or nonexistent vector control eradication and screening interventions coupled with poor housing conditions.<sup>15</sup> The U.S. is not considered an endemic area, however kissing bugs infected with *T. cruzi* have been found throughout the South (i.e., from California to Georgia) and local transmission have been reported (Figure 3) in these states.<sup>10</sup> However, the burden of *T. cruzi* infections from triatomine exposure in the states where the vector has been reported (Figure 3) has not been assessed. In Texas alone, eleven different species (from the genus *Triatoma*, *Rhodnius*, and *Panstrongylus*) of the vectors are able to transmit the parasite and are found throughout the state.<sup>16</sup> Other routes of transmission include: vertical or congenital; blood-borne; organ-derived; and oral.<sup>10</sup> Kissing bugs can be found indoors and outdoors, including the following: “beneath porches; between rocky structures; under cement; in rock, wood, brush piles, or beneath bark; in rodent nests or animal burrows; in outdoor dog houses or kennels; and in chicken coops or houses”.<sup>17</sup>

**Figure 3: Triatomine prevalence in the U.S., by state<sup>3</sup>**



### **Congenital Transmission**

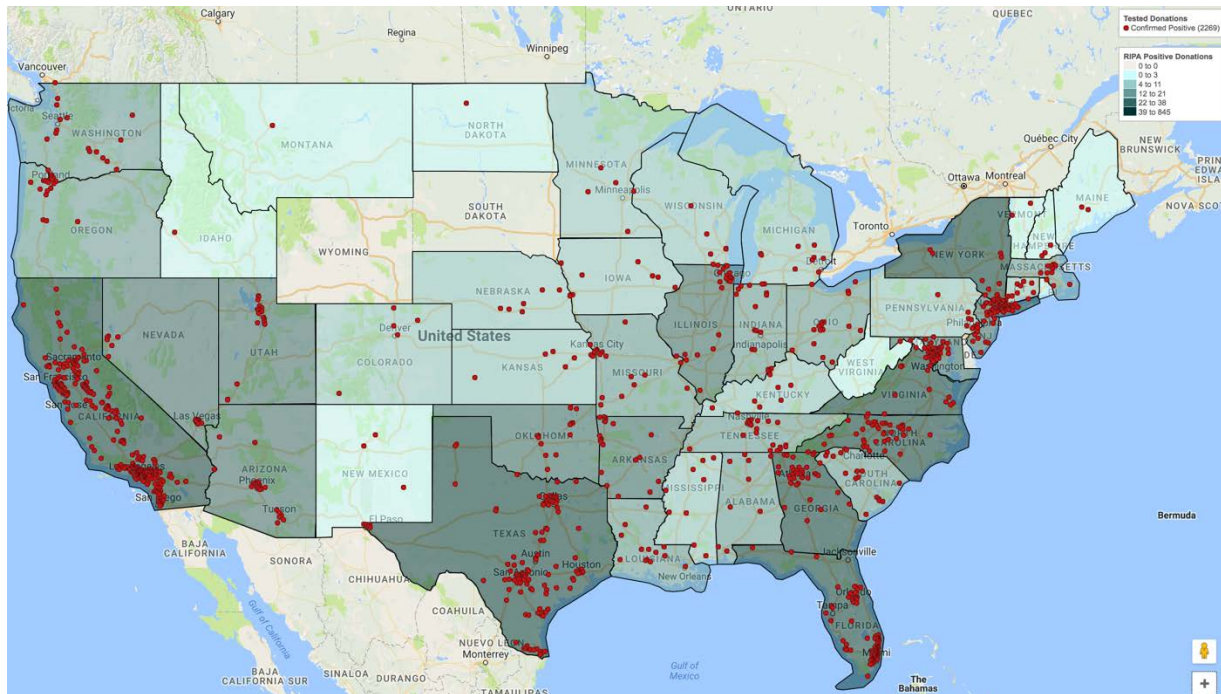
Congenital transmission occurs in both endemic and non-endemic countries.<sup>8</sup> Pregnant women are a specific concern since they may transmit the parasite to their children unknowingly. Even in Mexico, Central America and South America where CD is prevalent, residents may not be aware of their infection status nor know how or where to seek and access treatment if they believe they are infected.<sup>18</sup> In Latin America, over 14,000 congenital CD cases occur each year.<sup>19</sup> An estimated 20 to 183 congenital CD cases per year are expected in Europe.<sup>20</sup> According to Centers for Disease Control and Prevention (CDC), 63 to 315 congenital infections occur in the U.S. each year.<sup>21</sup> With an estimated 40,000 women of childbearing age infected with *T. cruzi*, the risk of transmission from an infected mother to child in the U.S. is between 1% to 5%.<sup>22</sup> In the U.S., there are no requirements, similar blood screening, or recommended guides to prompt healthcare providers (HCP's) to screen all pregnant women at risk for *T. cruzi* infection.

<sup>3</sup> Source: Centers for Disease Control and Prevention ([https://T.cruzi.cdc.gov/parasites/chagas/gen\\_info/vectors/index.html](https://T.cruzi.cdc.gov/parasites/chagas/gen_info/vectors/index.html))

## **Transmission from Blood Transfusions**

In contrast to the lack of compulsory screening and testing in the general population or with pregnant women, the blood supply in the U.S. has been screened for CD antibodies since 2007.<sup>1</sup> Blood donation screening is the most common means by which individuals learn about their CD diagnosis in the U.S.<sup>23</sup> From 2007 to 2017, a total of 2,269 confirmed serological positive donations have been identified throughout the U.S.<sup>24</sup> As shown in Figure 4, California, Texas, Georgia, North Carolina, Virginia, Florida, and New York had the highest prevalence. Nationwide, 1 in 27,500 blood donations tested positive for *T. cruzi* from 2008 to 2012.<sup>25</sup> For that same period, 1 in 6,500 blood donations in Texas were *T. cruzi* positive.<sup>26</sup> Approximately 11% of suspected cases will follow-up with a HCP to receive treatment.<sup>25</sup> In general, blood donors testing positive for *T. cruzi* will receive a letter notifying them of their potential CD serostatus. However, most infected persons (both globally and in the U.S.) are unaware of their status.<sup>1</sup>

**Figure 4: Lab-confirmed Chagas cases in blood donations, 2007 – Aug. 2017<sup>4</sup>**



## Chagas as a Global Threat

As a result of globalization, human migration has changed the distribution of CD in endemic and non-endemic countries: CD is both a re-emerging and a neglected tropical disease.<sup>4</sup> Figure 1 shows the impact to European countries, Japan, and Australia. For example, a recent literature review notes that while Japan's prevalence may reach up to 4,000 CD cases yet only 7 have been reported in medical literature.<sup>27</sup> In the U.S., both *autochthonous* (or locally-acquired) infections and imported cases from Latin America have been recorded and reported.<sup>23,28,29</sup> Two case studies presented by Hsu and colleagues describes how both CD patients were Central American immigrants identified in a New Orleans hospital.<sup>30</sup> Reports from locally-acquired infections are rare in Texas,<sup>29</sup> yet documented reports from autochthonous cases date back to the

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<sup>4</sup> Source (formerly known as) the American Association of Blood Banks (AABB): <http://T.cruzi.aabb.org/research/hemovigilance/Pages/chagas.aspx>

1930's.<sup>23</sup> Nonetheless, most infections are due to imported cases from areas of endemicity in Latin America given the prevalence of the vector.<sup>21</sup>

## **Phases and Clinical Manifestations**

### ***Acute infection***

CD includes two main phases: acute and chronic.<sup>1,2</sup> Acute infections occur up to the first two months of the initial infection, which may manifest with mild flu-like symptoms or febrile illness<sup>31</sup>. Other symptoms may include: malaise, enlarged spleen, liver, and lymph nodes; localized or generalized edema; chagomas or breaks in the skin; and result in abnormal electrocardiogram (ECG).<sup>8</sup> The hallmark characteristic, though not always present, is the swelling of the eyelids, or Romaña's sign, the site where the kissing bug feces was deposited or rubbed into the eye.<sup>11</sup> Acute infection may manifest as early as one week after exposure and may be self-limiting in most individuals.<sup>8</sup> The patient may not seek medical attention since the symptoms are mild and not unique to CD. Figure 5 shows the acute and chronic phases of a *T. cruzi* infection and the onset of the immunological response.

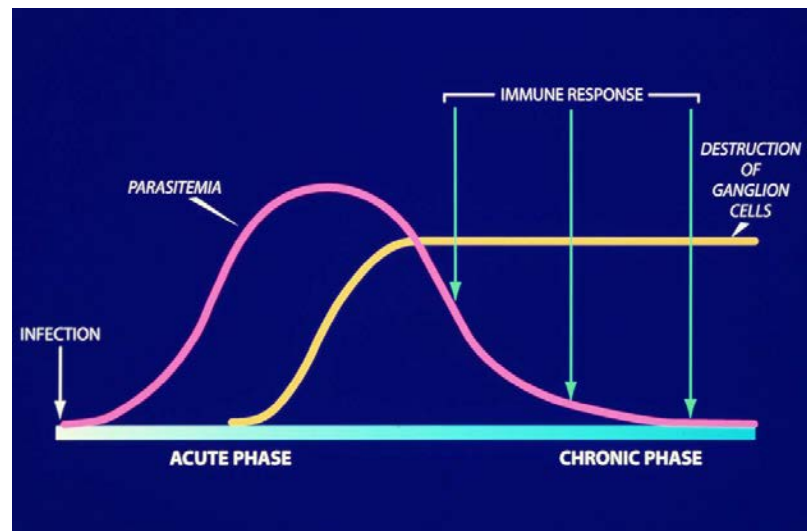
### ***Chronic infection***

During the chronic stage, two presentations are possible: the indeterminate form, which is commonly asymptomatic; and the determinate which include cardiac (e.g., cardiomyopathy, heart failure, altered heart rate or rhythm) and intestinal complications<sup>2</sup>. The majority of infected individuals (70%-80%)<sup>2,15</sup> will advance from the acute phase and remain in a latent or indeterminate chronic form of the disease (mostly asymptomatic), which may persist as a lifelong infection. The danger of this asymptomatic status is that once symptoms do manifest, eliminating the parasite becomes more difficult or impossible and often results in death.

### *Chronic determinate phase*

Conversely, only 20-30% of infected individuals will progress from the indeterminate chronic phase to a “clinically evident disease” or chronic determinate phase, months to decades after becoming infected.<sup>15</sup> Chronic determinate CD often corresponds to the organ involved (heart; esophagus; and/or colon): cardiac, digestive, or both.<sup>8</sup> The digestive manifestation is typically found mainly in South America or in persons infected in that region.<sup>8</sup> Heart failure occurs usually towards the latter phase of Chagasic heart disease.<sup>8</sup> Sudden death due to cardiac complications can occur.<sup>11</sup> The parasite is classified into six types with Strain I being wild, Strain II being domestic; both of which are “pure”, while Strains III through VI are considered hybrids.<sup>32</sup> TcI has a “wide distribution”—from the Southern U.S. to Northern Argentina and Chile.<sup>33</sup> The strain classification relates to the pathogenicity and distribution of the parasite and its association to sudden death in infected persons.

**Figure 5: Acute and chronic phases of Chagas disease infection<sup>5</sup>**



<sup>5</sup> Source: Susan Montgomery, DVM, MPH

## ***Cardiomyopathy***

For the scope of this study, heart-related symptoms were the primary focus, given that the digestive manifestation is a hallmark of South American infections. In the Southern Cone of South America (i.e., Argentina, Bolivia, Chile, Paraguay, Uruguay, and parts of Brazil) gastrointestinal CD is more common than CD cardiomyopathy, as the latter is more commonly seen in Central America and North America.<sup>34</sup> According to the National Institutes of Health (NIH), cardiomyopathy, “refers to diseases of the heart muscle...as it becomes enlarged, thick, or rigid...the heart thus becomes weaker pumping less blood and beating irregularly”.<sup>35</sup> Chagasic cardiomyopathy includes “cardiac arrhythmias, heart failure, and risk of sudden death from ventricular fibrillation or tachycardia or thromboembolic events”<sup>8</sup> and an estimated 5.4 million people will develop these symptoms.<sup>36</sup> Cardiovascular disease in CD patients is believed to be the result of “parasite persistence in cardiac tissue and immune-mediated myocardial injury.”<sup>37</sup> CD may present as idiopathic cardiomyopathy and be overlooked by many or most HCPs as a diagnosis. Some estimates considering that the Latino immigrant population is younger than the current U.S. population, suggest that, 10 – 15% of the total U.S. population (or 30,000 to 45,000 individuals) is living with undiagnosed CD cardiomyopathy.<sup>21</sup>

## **Epidemiology and Surveillance**

In the U.S., currently there is no federal mandate requiring each state to report human CD cases,<sup>38</sup> though currently it is a reportable disease in Arizona, Arkansas, Louisiana, Mississippi, Tennessee, and Texas.<sup>1,39</sup> As such, no national registry or database of confirmed human CD cases exists in the U.S., except through the case tracking and reporting by the CDC. In turn, the CDC tracking is limited by the reports they receive directly from the state health departments and individual HCP’s.



Excluding blood donor screening, no active surveillance for *T. cruzi* infections in the U.S. exists at this time.<sup>40</sup> Though reportable since 2013,<sup>2</sup> the Texas Department of State Health Services (TDSHS) currently does not actively surveil for CD, *T. cruzi* infections, or CD-related symptoms (i.e., syndromic surveillance).<sup>23,41</sup> In the absence of systematic national and State-level surveillance,<sup>1</sup> the disease burden, distribution, and populations at higher risk cannot be accurately quantified or described.<sup>10,23</sup> The lack of epidemiological data also highlights the gaps in detecting chronic Chagas cases.

The CDC estimates that 300,000 infected individuals are living in the U.S., however this is only based off of a formula using the number of Latin American immigrants in the U.S. and average prevalence found in Latin America.<sup>42</sup> Since becoming reportable in 2013, there have been 91 confirmed cases of CD in Texas. Of those cases, 20 were locally acquired, 61 were imported and 10 were from unknown origins.<sup>43</sup> In Texas, between 2013 and 2015, a total of 439 canine Chagas cases were reported.<sup>44</sup>

### **Screening and Diagnosing**

For the scope of this dissertation, screening refers to the process by which HCP's determine if further laboratory diagnostics are required. During the initial screening, the HCP discusses the patient's medical history, "including questions about travel and living conditions," and performs a physical examination and possibly an ECG.<sup>15,31</sup> The diagnosing of CD represents the clinical and serological testing required to confirm the presence of *T. cruzi*. In the U.S., the CDC requires confirmatory laboratory diagnosis for *T. cruzi* using at least two different immunoassay procedures (i.e., enzyme-linked immunosorbent assay [ELISA] and immunofluorescent antibody test) prior to treatment.<sup>15</sup> At least two different serological tests are required given the lack of specificity and sensitivity obtained from one single procedure. Such

laboratory assays are used to detect IgG or IgM antibodies to the parasite are available from major commercial laboratories (e.g., Mayo Medical Lab, ARUP, and Quest Diagnostics).<sup>45</sup> Nonetheless, no standardized protocol (at the national, State, or local/county level) is available for physicians to reference when attempting to request the laboratory codes. Recent statistical modeling demonstrates the value of screening Latin American immigrants in non-endemic countries.<sup>46</sup> Women are recognized as a target population for community screening programs in non-endemic countries in Europe (e.g., Spain and Italy) due to the risk of transmitting the parasite to their children.<sup>47,48</sup> No commercially-available rapid screening kit is available for HCP's to routinely use that provide an immediate confirmatory results for *T. cruzi*. In contrast to other chronic diseases<sup>49</sup> (i.e., type II diabetes, heart disease, cancer, etc.), screening and diagnosing for CD is not routinely performed.

### **Drug Treatment**

Antiparasitics (antitrypanosomal drugs) are currently not commercially available to the public in the U.S. and are only released by the CDC through investigational protocols. These drugs have been extensively used in Latin America. Nifurtimox and benznidazole are the two antiparastics used to eliminate *T. cruzi*.<sup>11</sup> The drugs are generally better tolerated by younger individuals because side-effects are less frequent and severe.<sup>15,31</sup> Benznidazole is the first line treatment because it has less side-effects.<sup>15</sup> Each drug has specific side-effects that tend to increase as the patient becomes older. As of 2017, benznidazole has been FDA-approved in the U.S. for use in children aged 2-12 years.<sup>38</sup>

### **Prevention Programs**

For over a century, Latin American countries have been trying to understand CD, the prevalence, and how to prevent and mitigate the adverse health outcomes. Currently, education

campaigns in Latin America primarily target rural and low-income communities and provide prevention messages. Most interventions in these regions have focused on vector control and improving housing conditions,<sup>50</sup> as highlighted in Figure 6. The *known* prevalence of CD in Latin America is likely higher than in the U.S. due to poorer housing conditions, pathogenicity of vector, and higher quantities of the vectors in large urban areas. Although CD diagnostics and eventual treatment in Latin America can be challenging due to limited resources and access to health care,<sup>51,52</sup> physicians in Latin America are more aware of CD screening and recommended guidelines for diagnosis and treatment than those in the U.S. Furthermore, international cooperation has made vector surveillance possible. The southern Cone Initiative, for example, was one of the first collaborative programs in the 1990's that focused on vector control and educating the community about kissing bugs.<sup>50</sup> Similar international efforts to the southern Cone Initiative have been sustain by Central and South American countries and have resulted in reducing the rate of new (acute) infections in some regions.

**Figure 6: Example of Campaigns in Latin America<sup>6</sup>**



### **Role of Healthcare Providers**

Due to the number of cases, its asymptomatic nature, urgency for early diagnosis and treatment and unknown prevalence in the U.S., CD should be a concern for HCP's. Many physicians currently practice medicine within their subspecialty and in isolation from other HCP specialties.<sup>53</sup> Even fewer communication exchanges occur with other scientists (i.e., veterinarians, entomologists, ecologists, policy scientists, etc.). The lack of collaboration and engagement may prevent the exchange of new ideas and innovations. In turn, this is a barrier for an accurate and timely diagnosis for a patient.<sup>53</sup> Recent epidemiological trends in the vector, or in zoonotic populations, for example, can shed light about the potential threat to human health. As we move towards a healthcare model in which the patient, as the consumer, is more informed and encouraged to participate in decision-making process, he or she may be a stronger advocate

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<sup>6</sup> Source: <http://T.cruzi.taringa.net/posts/salud-bienestar/12344378/Que-es-la-Vinchuca.html>

to improve the likelihood of testing and diagnosis, rather than rely solely on the physician as the gatekeeper for information. It is unclear how medical training and continuing education among the various specialties and sub-specialties shape how individual physicians receive, synthesize, and apply information regarding emerging or rare diseases like CD.

### **Health System Barriers**

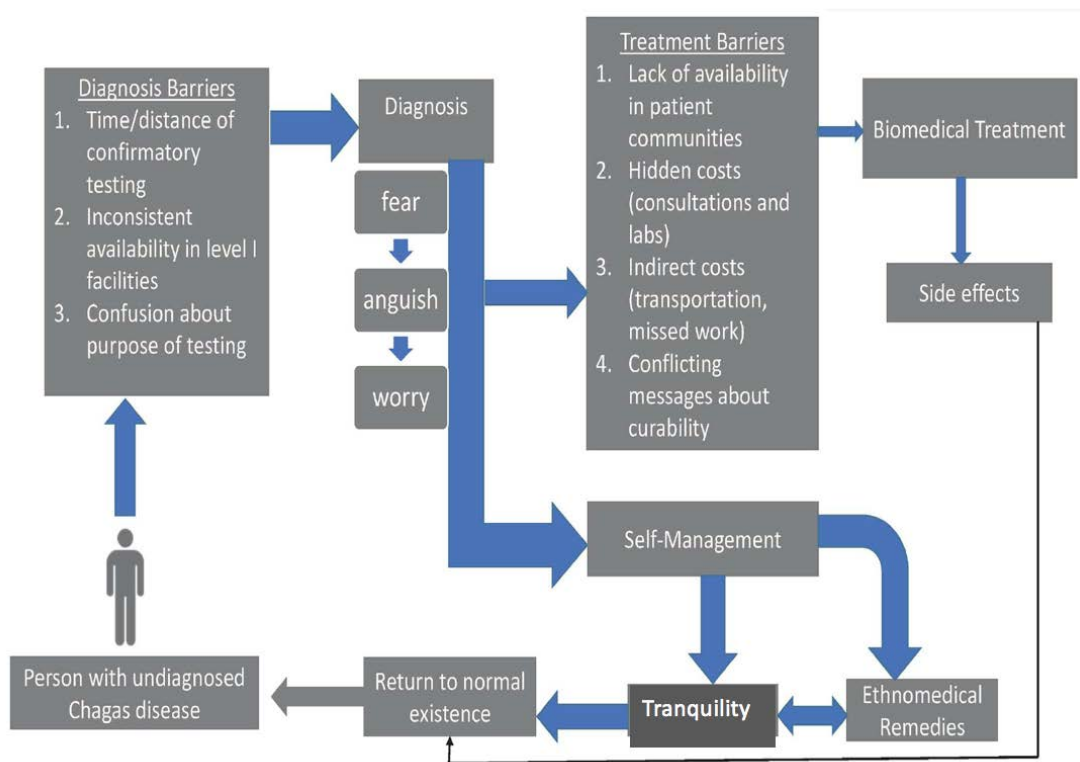
According to the WHO, an effective health system “delivers quality services to all people, when and where they need them.”<sup>54</sup> Although their configuration is diverse and specific to meet the needs of each individual country, it still “requires a robust financing mechanism; a well-trained and adequately paid workforce; reliable information on which to base decisions and policies; well-maintained facilities and logistics to deliver quality medicines and technologies.”<sup>54</sup> The emerging literature frames health system barriers to diagnosing and treatment of CD at the national, community, and individual levels, specific to the countries and population described.<sup>42,55-58</sup> Nonetheless, elements regarding the patient, provider, and health system barriers are applicable in understanding the screening, diagnosing, and treatment barriers of CD in Texas.

### ***Patient level***

The first challenge is that CD is rarely diagnosed during the acute phase of the infection.<sup>23</sup> The latency and asymptomatic nature of the disease may not prompt individuals to seek immediate medical consultation or treatment. Cultural beliefs and systemic barriers may also prevent or delay a patient from seeking medical care, particularly as documented in Central and South American groups.<sup>55,58</sup> For instance, an individual distrusts the medical system, while a systemic barrier may include the lack of drugs or HCP’s.<sup>32,48,55,56</sup> Individuals in impoverished communities in Latin America and in the U.S. lack health insurance or the means to access

medical care, even if they wanted to get diagnosed and treated.<sup>57</sup> These challenges are also reflected in the Latin American immigrants in the U.S. and other non-endemic countries. In rare occasions, individuals recognize the exposure to a kissing bug or develop clinical manifestations (i.e., a chagoma) that may prompt medical attention. Figure 7 summarizes some of the individual-level barriers.

**Figure 7: Patient barriers and strategies for coping with Chagas disease<sup>7</sup>**



**System and provider level**

Due to the rarity in reporting autochthonous cases, there is still a lack of *overall awareness* among HCP’s in the U.S., including in Texas.<sup>23</sup> HCP’s may consider CD only as a

<sup>7</sup> Source: Forsyth, C.J. (2017) “I Cannot Be Worried”: Living with Chagas in Tropical Bolivia. *PLoS Neglected Tropical Disease*, 11:1

neglected tropical disease and not recognize the risk factors for local and acquired infections in Texas. They also may not consider their patients from Latin America or from mothers from Latin America at risk if they have never encountered the disease before and know very little about it.

According to the 2015 American Community Survey, Hispanics/ Latinos represent 38.4% (which represent 10,196,367 persons) of the total population for the State.<sup>59</sup> Furthermore, in 2010, the Hispanic/ Latino population made up 37.6% of the total State population (an increase of 735,446 from 2010 to 2015).<sup>59</sup> In 2010, Hispanics/ Latinos in Texas from Mexico accounted for 31.6% (or 7,951,193 individuals) of the population, while persons from Central America accounted for 1.7% (or 420,683 individuals), and persons from South American represented 0.5% (or 133,808 individuals).<sup>59</sup> These data indicate the increase in Hispanic/ Latino immigrants in the State and also highlight the opportunities for missed screening and diagnosis for this specific population.

There are few comprehensive resources targeting HCP's that illustrate the clinical criteria used to evaluate and diagnose CD.<sup>8,15</sup> The TDSHS and the CDC have outlined general recommendations for the clinical diagnosis and treatment of CD.<sup>2,15</sup> However, there are no specific recommendations in Texas for HCP's to target screening to Latin American immigrants or women of child bearing age. A patient profile could help frame the risks of exposure to guide HCP's in deciding if further screening or serological testing is needed. No patient profile currently exists that identifies populations in Texas (or the U.S.) with a higher risk of exposure or transmission. Without such guidance, HCP's may not perform a thorough medical history (i.e., discuss potential exposure to the vector and parasite).<sup>60-62</sup> For example, the HCP's may not ask the patient about travel history or previous place of residence. Thus, even if a HCP is more *familiar or aware* of CD, s/he may have limited experience in identifying infected individuals

with the indeterminate form; performing clinical evaluations; ordering appropriate laboratory tests; or coordinating with health officials. Consequently, lack of awareness or experience may delay a patient from receiving adequate treatment.

### **Public Health Significance**

The WHO ranks Chagas as the top global neglected parasitic disease, five times greater than the number of disability adjusted life years (DALY) when compared to malaria. Although generally regarded as a rare neglected tropical disease<sup>1</sup>, current vector surveillance,<sup>28,29</sup> the increased frequency of Chagas positive blood donors,<sup>26,40,63</sup> and population migration,<sup>3,4</sup> demonstrate why more Chagas cases may be on the rise in the U.S., including Texas. It is estimated that at least 300,000 people in the U.S. are living with CD, many of whom may not yet know they are infected. Approximately 20% to 30% of individuals with CD are expected to develop clinical symptoms that may manifest as heart disease and result in death if left untreated.

With more than 60 cases of Chagas reported in Texas between 2013 and 2015 alone, it is becoming clear that HCP's must be aware of CD and not dismiss the accumulating body of evidence. HCP's may not be familiar or prepared to correctly and timely screen and diagnose suspected cases. In turn, the lack of awareness and skill may lead to underdiagnosing and under-reporting. Chagas-related deaths can be prevented if more CD cases are diagnosed and treated at the early onset of the disease.

Reducing the morbidity and mortality associated with CD is the impetus for the CDC to recognize CD as public health concern in the U.S. The CDC created a funding mechanism to support multi-site projects aimed to inform and educate HCP's about CD as well as to encourage collaboration and facilitate access to information and resources. Through community based participatory research (CBPR) and community engagement activities, the Texas Chagas



Taskforce was created in late 2015 with funding from the CDC. Various stakeholders were recruited throughout the State of Texas representing a variety of sectors, local and state health departments, organizations, and expertise.

Understanding the level of knowledge and awareness of CD among the HCP's throughout the State, specifically physicians who may routinely come in contact with those patients at higher risk, will help identify learning gaps in the medical curriculum and provide insight into how best to target HCP's serving high-risk populations. The overall objectives of this study were to: 1) examine the level of knowledge and awareness of HCP's in Texas regarding screening, diagnosis and treatment of CD; 2) describe the prevalence of reported cases in Texas; and 3) illustrate the potential missed cases for CD diagnosis in Texas.

The research expands on the knowledge of U.S. physician awareness and attitudes regarding Chagas and contribute to the literature on the frequency of diagnosis and possible missed diagnosis of Chagas. To the best of our knowledge, no other study has examined ICD-9 CD and ICD-10 CD data for both Chagas and other possibly undiagnosed forms of chronic determinant forms of Chagas (e.g., cardiomyopathy, idiopathic myocarditis). The data was mapped together to identify possible regions within the state where missed diagnoses are more likely to occur. The level of awareness of Chagas throughout the State of Texas has not been assessed previously to be able to make meaningful recommendations (i.e., convenience sampling).

### **Statement of the Problem**

Strategies and decisions derived from high-quality<sup>1</sup> and up-to date data are needed to minimize the threat of CD. However, there has been limited research on U.S. physicians' knowledge and awareness of CD despite evidence CD presence in the U.S. patient population

and blood supply. This poses the following questions: 1) what do physicians know about and understand regarding the screening, diagnosis and treatment of CD and 2) how many missed diagnoses of CD may be occurring in patients, both asymptomatic and symptomatic.

## **Frameworks**

### ***Diffusion of Innovations***

In an effort to better understand why some physicians may serve as early adopters of the idea of screening for a neglected disease such as CD, the Theory of Diffusion of Innovations may help to frame the issue.<sup>64</sup> In this model, diffusion is the “process by which an innovation or “new” practice is communicated through certain channels over time, among members of a social system,” and is then maintained or becomes accepted as practice over time.<sup>64</sup> CD is often overlooked as a possible diagnosis in part due to its asymptomatic nature, but also because of the lack of knowledge surrounding the testing and treatment, the innovation. Innovation, in this context, reflects the ideas and practices related to CD testing, screening, and diagnosing and the skills and experience needed to ensure timely diagnosis and treatment. Better understanding of how to diffuse the practice of screening patients for CD could be helpful for shaping practices and policies that prevent under or missed diagnoses of not only CD but other neglected tropical diseases that may be present on our ever-changing global environment.

### ***Reducing or eliminating diagnostic errors***

A diagnostic error is the “failure to: a) establish an accurate and timely explanation of the patient’s health problems; or b) communicate that explanation to the patient.”<sup>53</sup> The Institute of Medicine’s (IOM) recommends that in order to reduce diagnostic errors and improve diagnosis in healthcare it is important to “consider a patient-centered perspective.”<sup>53</sup> According to the IOM, the diagnostic process must start with the patient engaging in the health system. In turn, the

HCP engages in a decision process that includes gathering information to synthesize what is observed through physical examinations and discussed between provider and patient to develop a working diagnosis.

Engaging with patients is key in screening and diagnosing CD given the nature of the disease and the limited awareness by HCP's. Failure to obtain a complete medical history, for example, will yield incomplete information. Conversely, even if a complete medical history is performed, but the HCP is unable to synthesize the information, then a missed diagnosis may occur. Figure 8 illustrates the conditions necessary for a CD patient to receive treatment.

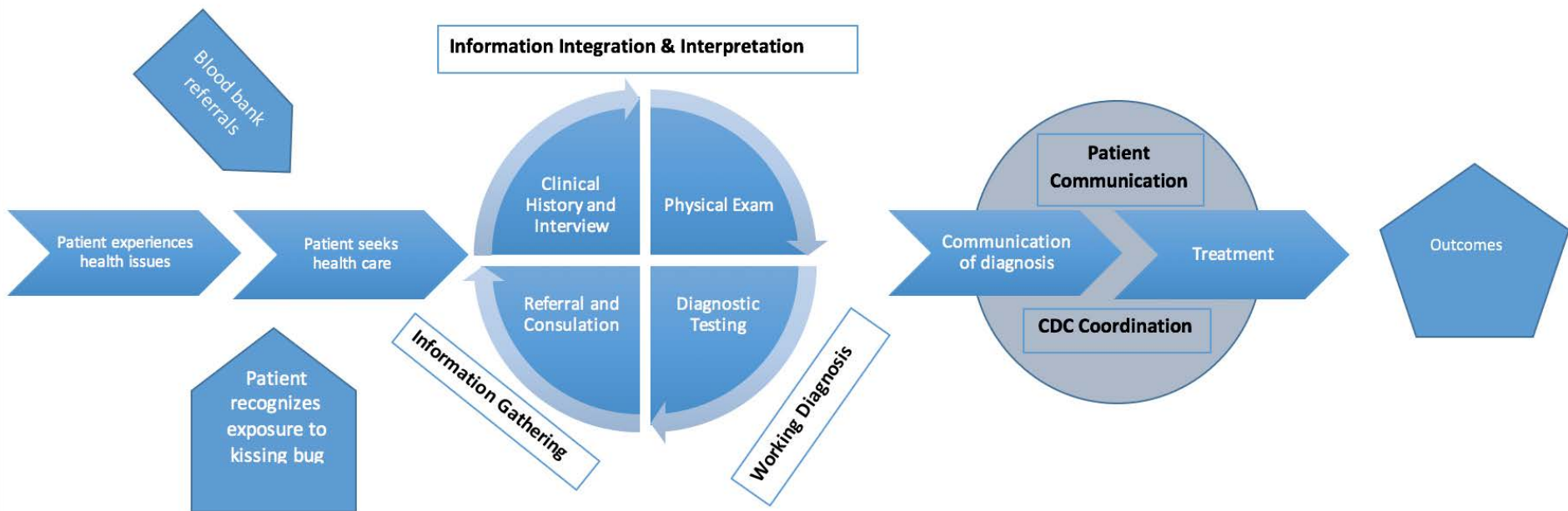
However, most physicians lack the training or have never considered risk factors specific to Texas because they have never tested a patient for CD before. These scenarios present missed opportunities in which the HCP's may not be screening patients and following up with the corresponding testing to ensure a timely diagnosis of CD. Death and morbidity from CD can be prevented if more cases are screened during the initial phases of the disease, when the drug treatment is more effective. Thus, it is crucial for infected patients (i.e., those recently exposed or with a letter from the blood-bank stating a positive screen) to get tested immediately to confirm diagnosis and receive treatment.

Furthermore, HCP's may fail to accurately describe a Chagas diagnosis using the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM).<sup>65</sup> ICD-9-CM is "the official system of assigning codes to diagnoses and procedures associated with hospital utilization in the United States."<sup>66</sup> Effective October 1, 2015 the tenth version, ICD-10-CM, replaced ICD-9-CM.<sup>65</sup> The ICD coding system may allow for estimates of incidence of diseases. The ICD-9 and ICD-10 codes can be used to specify diagnosis based on physician reimbursement coding.

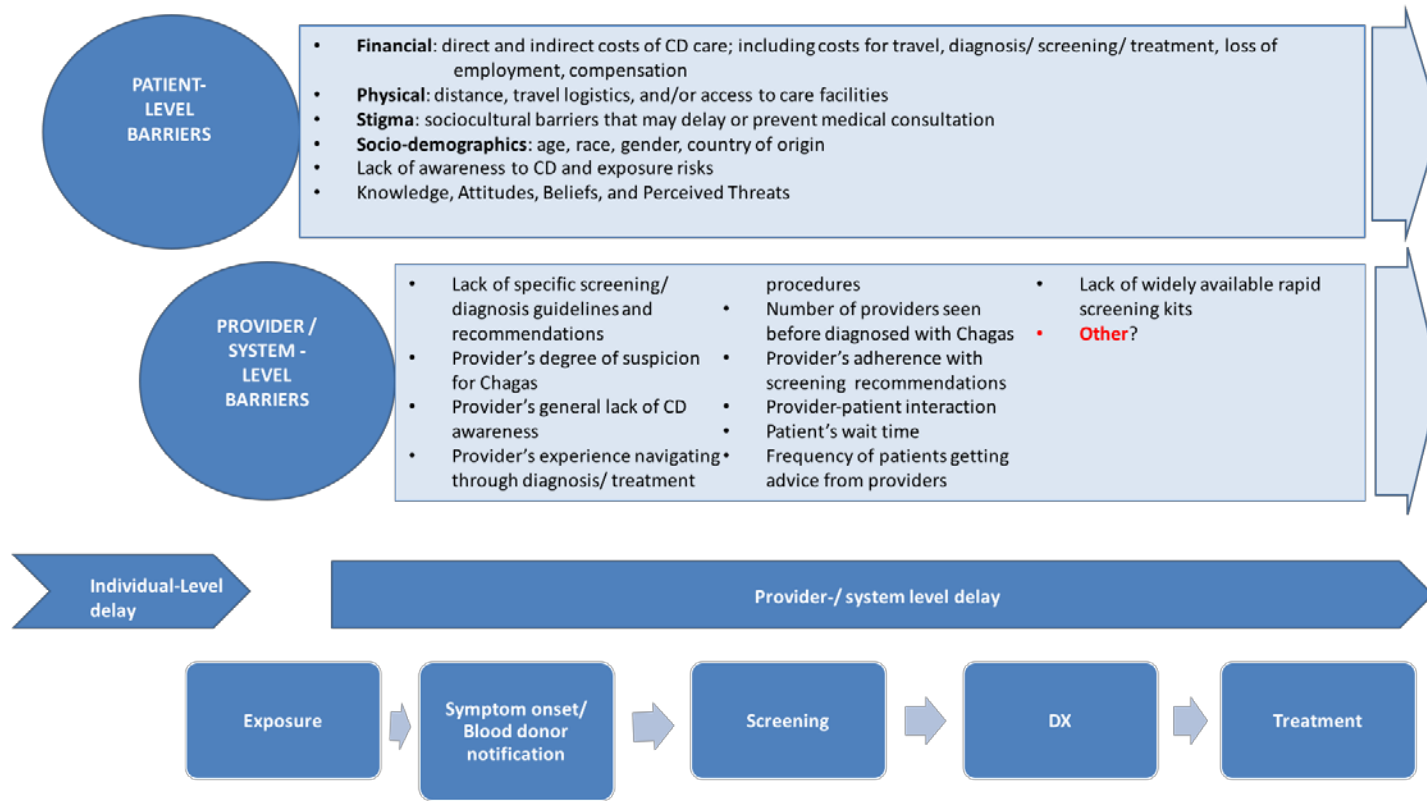
### *Systems-level perspective*

The previously discussed health system models and a conceptual model used by Yang et al frame the barriers to screening and diagnosis to CD in the continuum of treatment through a socioecological perspective. Figure 9 illustrates recurring themes at both provider and the patient levels. The figure is an adaptation of a conceptual model for delayed tuberculosis (TB) diagnosis. Both TB and CD have asymptomatic/ latent phases that as shown in the figure, and have a salient effect on the health outcome. If no symptoms overtly manifest, then the patient may not seek medical consultation in a timely manner. For CD, delayed medical consultation has deleterious impact since treatment may not be as effective once cardiac-related complications manifest. The model also illustrates how the lack of HCP awareness plays a key role in CD screening and diagnosis.<sup>67</sup> Similar to TB, HCP's lack of suspicion for the CD will delay confirmatory diagnosis and treatment.

**Figure 8: Patient Engagement in the Medical Health System to Receive a Chagas Diagnosis and Treatment**



**Figure 9: Systems-level Conceptual Model for Barriers to Chagas Screening, Diagnosis, and Treatment**



## **Specific Aims**

I posited that HCP's in Texas are generally unaware of CD as a diagnosis and therefore may miss crucial opportunities to screen and diagnose the disease amongst their patients. This remains true despite current initiatives to educate HCP's (i.e., Texas Chagas Taskforce), vector surveillance, and mainstream media attention (e.g., local media and national news coverage on kissing bugs). Because of the potential longevity of the disease and its asymptomatic (chronic indeterminate form) nature, persons with CD are more likely to remain undiagnosed by their HCP than patients with other infectious diseases that may present with clinical symptoms. Also, because only 20 – 30% of CD positive patients will ever present with symptoms (e.g., cardiomyopathy, megacolon, etc.), it can often be a missed diagnosis or go under-reported. The extent of CD knowledge deficits throughout the State of Texas remains unstudied. How, when, and if providers screen and diagnose for CD in Texas is important to understand so that missed diagnoses are prevented and prevalence of the disease is better understood. This is especially important since treatment is only available for patients who are positive for CD but are not yet symptomatic and can potentially be a life-saving treatment.

The overall objective of the study was to explore the understanding and knowledge of CD in Texas HCP populations and identify provider-based education and practice recommendations to reduce the prevalence of undiagnosed CD.

The aims of the proposed study are as follows:

1. To better estimate prevalence and possible missed diagnoses of CD, map CD cases in Texas using DSHS and ICD coding data and compare with non-CD cardiomyopathy cases using ICD diagnosis
  - a. Map all DSHS and ICD code reported cases of CD
  - b. Map non-CD cardiomyopathy ICD code reported cases in Texas along with additional risk factors (e.g. age, ethnicity)
2. Used a mixed methods design to identify and describe gaps related to knowledge, attitudes, and practices in the screening, diagnosis and treatment of CD among practicing physicians in Texas
  - a. Used an online questionnaire to quantify and describe knowledge among specialists, including: cardiologists, infectious disease specialists and family practice physicians
  - b. Conducted key informant interviews to explore the barriers to screening, diagnosis and treatment amongst physicians who have treated CD and those who have not treated CD



## **METHODS**

### **Overall Study Design**

Overall, this study included elements of a concurrent (embedded) and sequential explanatory study design. The mapping aim was embedded within the overall explanatory mixed methodology in establishing a baseline for the knowledge, attitudes, and practices among physicians. In the explanatory design, data collected from the knowledge, attitudes, and practices questionnaires were collected and analyzed first, followed by the collection and analysis of qualitative data from the key informant interviews to “help explain the initial quantitative results.”<sup>68</sup> The purpose was to identify themes related to barriers in diagnosing CD and discuss potential statewide recommendations. Also, maps were created to show the potential burden of CD in the state by comparing the overall frequency in ICD-9/10-CM reporting of idiopathic and ischemic heart disease to the confirmed TDSHS reported Chagas cases.

### **Human Subjects Protection**

There were no direct risks associated with this study. The research was reviewed by the Committee for the Protection of Human Subjects (CPHS) at the University of Texas Health Science Center (UTHealth) and approved on February 5, 2018 (HSC-SPH-17-1039). The key informant script and the online questionnaires were revised and resubmitted for IRB approval. Final approval was received on July 2, 2018.

Informed consent was obtained verbally for key informant participants prior to conducting the interview. A prompt was included in the online questionnaire to obtain informed consent electronically (i.e. a specific item with the answer choices of “Yes, I agree

to participate” “No, I do not agree to participate” was included). Administrative data from the hospital inpatient public use file were de-identified.

## **Methodology for Aim 1: Mapping**

### ***Data sources***

The Inpatient Public Use Data File (IPUDF), maintained by the TDSHS, and the number of Chagas confirmed cases data were used to create maps for this aim. The Texas Health Care Information Council (THCIC) is responsible for collecting and maintaining updates to the PUDF.<sup>69</sup> Information is collected from every licensed hospital in the state other than hospitals in a county with a population of fewer than 35,000, or those in a county with a population greater than 35,000 and with fewer than 100 licensed hospital beds and not in an area designated as an urbanized area by the U.S. Bureau of Census, or those that do not seek insurance payment or government reimbursement. Updates to the PUDF are quarterly; the third quarter for 2016 is the most recently available dataset and the earliest is 1999. Datasets contain patient demographics, hospital information and length of stay, principal and secondary diagnosis, hospital charges. However, no personable identifiable information is recorded in the reports (e.g., no dates of birth, address, social security number). CD became reportable in 2013. Thus, the hospital inpatient PUDF for 2013 to 2016 was requested. Confirmed and reported CD cases (local, imported, and unknown source of transmission) were mapped using data from TDSHS Zoonotic Control division for that same time period.<sup>44</sup> Census data (i.e., American Fact Finder web application) was used to download the American Community Survey (ACS) 5-year Texas population estimates for 2016.<sup>70</sup> This included Texas demographic data on age and Hispanic status by county. A basemap was

created by downloading the shapefile for the Texas counties from the U.S. Census Bureau (i.e., TIGER/Line Web interface).<sup>71</sup>

### ***Variables***

The following patient demographics from the raw quarterly base inpatient data files were kept: patient's age group (i.e., <18; 18 to 44; 45 to 66; 65 to 74; and  $\geq 75$ ); ethnicity (Hispanic or non-Hispanic); race (American Indian/ Eskimo; Asian or Pacific Islander; Black; White; or Other); and sex code (male or female). All of the principle diagnostic codes (i.e., 1—24) were coded to determine if that particular patient record contained any of the ICD-9 or 10 diagnostic codes of interest. Additional variables that were kept from the initial raw IPUDF included: record identification number for each hospital admission; patient's county and zip code of residence; provider ID; and type of admission.

### ***Case definitions***

A cardiologist was consulted to identify and review the diagnostic codes. Dummy variables were created using the Chagas diagnosis in the IPUDF for: ICD-9-CM (i.e., 086.0, 086.1, and 086.2) for 2013 through 2015 (third quarter); and for ICD-10-CM codes (B57.0, B57.1, B57.2, and B57.5) for the last quarter of 2015 and for 2016. These seven ICD9/10 CD diagnosis codes were collapsed as either CD-heart, or CD-non-heart related diagnosis. One additional variable for the total of all CD diagnosis was created and was used in the maps. Eight ICD-9/10 diagnostic codes were used to create the heart-related diagnosis (i.e., the proxy for potentially missed CD). Table 1 shows the diagnostic code utilized from each version.

Table 1: Chagas and cardiomyopathy-related ICD-9 CM and ICD-10 CM codes

Case	ICD Version	Diagnostic Code	Description
Chagas-related	ICD-9-CM	086.0	Chagas with heart involvement
	ICD-9-CM	086.1	Chagas with other organ involvement
	ICD-9-CM	086.2	Chagas without mention of organ involvement
	ICD-10-CM	B57.0	Acute CD, heart
	ICD-10-CM	B57.1	Acute CD, without heart
	ICD-10-CM	B57.2	Chronic CD, with heart
	ICD-10-CM	B57.5	Chronic CD with other organ involvement
Heart-related	ICD-9-CM	414.8	Other forms of chronic ischemic heart disease
	ICD-9-CM	422.91	Idiopathic myocarditis
	ICD-9-CM	425.8	Cardiomyopathy, excludes Chagas
	ICD-9-CM	425.4	Cardiomyopathy, includes idiopathic
	ICD-10-CM	I42.5	Other restrictive cardiomyopathy
	ICD-10-CM	I42.8	Other cardiomyopathies
	ICD-10-CM	I25.5	Ischemic cardiomyopathy
	ICD-10-CM	I42.9	Cardiomyopathy, unspecified

### *Data collection and management*

Initially, each of the quarterly IPDUF were exported as a comma separated value file (CSV) to Excel. Stata was used to create the indicator or dummy variables (i.e., flag the case definitions), drop variables that were not of interest for this study, denote the steps performed and run quality checks, and merge quarterly datasets to corresponding years. “If statements” were used on Stata to flag each of the *admitting*, *principal*, and *other diagnosis* codes for any Chagas or heart-related ICD 9/10 codes prior to merging quarterly datasets into the corresponding yearly datasets. Patient records that did not contain the case definitions were eliminated from the dataset. The combined raw IPUDF contained over 12 million hospital admissions, yet 3.1% were eligible for the geospatial analysis (i.e., contained a heart related

and or Chagas disease diagnosis code). Appendix D shows the frequency for each code, by year.

Four datasets (for 2013, 2014, 2015, and 2016) and the corresponding codebooks were created on Stata and Excel, respectively. Additionally, demographic indicator variables were created for age, race, ethnicity, and sex code. For age, the categories were collapsed from 22 groups to create 5 age group variables: children (individuals under 18); 18 to 44; 45 to 64; 65 to 74; and 75 and over. This re-grouping allowed for inclusion of the patient populations with HIV, alcohol, and drug use populations given their categorization into these 5 age groups. Five race indicator variables were created for: American Indian/ Eskimo; Asian or Pacific Islander; Black; White; and Other. Two indicator variables were coded for Hispanic origin and for those of non-Hispanic origin. Male and female indicator variables were created.

The tabulations by county and case definition, and by county, case definition, and demographic characteristic (i.e., age group, ethnicity, race, and sex) were inputted to an Excel spreadsheet for each corresponding year. The counties were listed as rows and the variables as numbers. An additional spreadsheet was created to summarize the sub-totals for the corresponding ICD 9/10 Chagas disease diagnostic codes (both heart and other organ involvement) and for the heart-related diagnostic codes for all four years. Thus, there were multiple iterations of data management to create a final dataset and ultimately a table with the counties by enumerating the totals for each of the cases, as shown in the Appendix E. A total of 78 heart-related Chagas codes was identified and 29 that were not related to heart-complications that could be mapped to a county. There were 366,575 heart-related diagnostic

codes that were mapped to a county. The Federal Information Processing Standard (FIPS) code was listed for each county in the final table to link up to the county shape file.

Demographic data for the state was downloaded using the American Fact Finder web application as CSV files. The five year 2016 estimates were chosen for the Hispanic population and age categories. Excel was used to import the CSV files, clean up the variables (i.e., rename columns for ArcMap usability; remove extraneous data). An Excel workbook was created for each variable. To calculate the Hispanic proportion, the number of Hispanics was divide by the total population for each county. To create the table for age groups, only the population estimates for males, females, and all, aged 20 to 59 were summed for each respective group (i.e., a column for each: males, females, and total).

### ***Mapping***

ArcMap GIS (Version 10.6.0), a software application used to map and analyze a geographic information system (GIS), was used to visualize the ICD 9/10 inpatient hospital diagnostic codes and illustrate the salience of potentially missed Chagas disease diagnoses (e.g., cardiomyopathic diagnoses).<sup>72</sup> GIS maps are useful in illustrating issues or particular situations and contextualize environmental factors.<sup>73</sup> Given that the vector is found throughout the state as demonstrated from emerging animal and entomological surveillance<sup>74</sup> this study aim can help visualize where the potential for missed diagnoses is the most prevalent throughout the state and serve as exploratory for further research to map the vector ecology with findings from this research.

A total of 5 maps were created. First, the table of Chagas disease counts reported to TDSHS (by local, imported, or unknown transmission). Each value was set to represent one

count. Next, the table with the heart-related ICD (9 and 10) total counts for each county was added in order to output a choropleth map, that is as each range of values increased so did the corresponding color intensity. The natural breaks (or Jenks) classification was initially used in order to minimize variance within groups but maximize it between them, followed by manual adjustments to categorize the data into 5 groups. The demographic tables from the ACS estimates were then loaded to ArcMap. For each map, the heart-related ICD diagnoses were represented as graduated symbols (i.e., red triangles) using the same group classification as before (e.g., Jenks). Graduated colors were used to show the proportion of Hispanics and the proportion of the county population aged 20 to 59. A final map was developed, which adjusted for the county populations and used a Jenks classification for the categories, which were per 10,000 persons. All tables were linked to the county shapefile (i.e., the basemap) using the FIPS county code.

## **Methodology for Aim 2a: Questionnaire**

### ***Study design and population***

The study design for Aim 2a was cross-sectional, in which data was collected from three online questionnaires from July 5, 2018 through October 1, 2018. Having a baseline to quantify general knowledge on CD, as well as specific diagnostic procedures, practices, and overall attitudes on CD is crucial for the development of targeted HCP educational efforts and the dissemination of resources.

Infectious disease HCP's were hypothesized to be the most aware of CD compared to cardiologists and family/ general practice physicians given their experience in diagnosing related parasitic diseases. Infectious disease HCP's were thus a focal group since other

general practice HCP's may refer patients to them. Cardiologists were hypothesized to also be aware and knowledgeable of CD since the chronic phase of the disease involves heart-related complications. However, in general, cardiologists may lack the awareness to recognize the acute or chronic asymptomatic CD cases and understand the importance or value of screening high risk populations. Cardiologists may facilitate the communication between other provider specialties, since they may be somewhat more familiar and aware of CD than other general practitioners.

In previous CD awareness questionnaires aimed at HCP's, the response rate has been between: 40.1% and 41.7%.<sup>60,61,75</sup> Finally, family practice physicians were chosen as a target population given the lack of research and thus the inability to establish a baseline knowledge among this population. Moreover, this specialty is more likely to engage with patients worried about the risk of triatomine exposure or be the first points of contact for recipients of blood donation letters, prior to consulting with ID specialists.

Thus, similar to the recent study assessing CD awareness among Ohio HCP, the questionnaires focused on cardiologists, infectious disease specialists, and family care physicians. The rationale was that these providers as are more likely to provide medical care to most patients. Although primary care physicians and other primary healthcare workers such as physician assistant and nurse practitioners act as gate keepers in referring their patients to specialized care, due to time constraints and limited resources the scope of this research was only on licensed practicing physicians in Texas who were listed with a primary specialty in cardiology, family medicine/ general practice, or infectious disease medicine. I expected the sample will be representative and reflect the knowledge, attitudes, and beliefs of



the targeted population, but findings may not be necessarily generalizable to all HCP's in Texas. However, given, the design of this research, the findings will guide future research and outreach efforts for specific HCP populations and specific Texas geographical locations. In turn, this target population will engage with patients seeking primary care as a result of vector exposure, blood donation letters, or from exhibiting clinical symptoms.

### ***Instrument development***

A questionnaire was developed to describe: 1) the overall awareness of CD; 2) screening, diagnosis, and reporting procedures; 3) and risk and exposure factors specific to Texas. Questionnaires used to collect information related to knowledge, attitudes, and practices (KAP) have been used by the WHO, particularly in developing countries to better understand the community members' perceptions about specific health concerns.<sup>76</sup> Multiple choice items and ordered-category items (i.e., Likert scales) are ways to objectively assess the knowledge.<sup>77</sup>

Prior to this research, no tool was available to assess Chagas KAP among physicians to measure specific domains (e.g., recognizing risk factors, performing screening and diagnostic practices, frequency of CD-related resources). Thus, specific questions were formulated to ensure physician attitudes about CD as well as their experience and self-efficacy in making a CD diagnosis were captured. The questionnaire was tailored to the three clinically-focused specialties. Survey questions from published research<sup>62</sup> as well as from an online continuing education course from the CDC<sup>78</sup> were used to create the items.

Questionnaire items included: physician demographics (i.e., practice type and years since graduation); clinical manifestation; risk of transmission; and whether a Latin American

immigrant population is served/ proportion served. The questionnaire will include both right/wrong items as well as self-reported level of confidence scales.

The three instruments were piloted among Texas Chagas Taskforce members, and practicing physicians (cardiologist, infectious disease specialist, and general practice provider), and non-CD experts to ensure reliability, validity of questions, and address any issues including completion time and ease of use across various platforms including smart phones. Follow-up meetings were conducted to discuss issues and revisions to questions and responses. For instance, after discussing with the physicians and other individuals who piloted the questionnaire, the response choices for various knowledge items were revised to eliminate similar or confusing answers, and thus make it easier to assess whether or not the concept was known to the physician.

### ***Sampling and recruitment***

First, the Texas Medical Association (TMA) leadership was engaged. The TMA is a professional medical society that includes over 50,000 physicians and medical students.<sup>79</sup> I will contact TMA staff and leadership about collaborating in this project to recruit questionnaire participants while pending feedback from the taskforce and from other HCP's to improve the questionnaire tool.

Two TMA staff members who were active Chagas Taskforce members served as points of contact to facilitate coordination with TMA leadership. After meeting, discussing, and reviewing the questionnaires, they agreed to forward my request via email to their respective chairs. The email provided the rationale, aims, and my contact information. A link to each specific online questionnaire was included. I did not receive access to the sampling

frame or was I copied in the direct communication to be able to follow-up with physicians. After two weeks, no new responses were initiated. I reached out to additional professional medical networks, societies and groups with access to physicians throughout San Antonio and the state (e.g., the Bexar County Medical Society, Harris County Health, Metropolitan Health District, and TDSHS, the Bexar County Health Collaborative, UT Health in San Antonio, UTHealth Tyler Population Health at the UT System). I also disseminated my request to professional colleagues who had access or worked with physicians. Finally, I reached out to physicians who participated in the Texas Chagas Taskforce webinar or workshop. A total of 5 followed up with me replying their ineligibility to participate in the research (i.e., practiced in other states; had a primary specialty that was outside the scope of this research).

### *Sample size*

In the past, TMA conducted two annual questionnaires that supported state and legislative advocacy efforts. A 2015 Questionnaire on meaningful use program for the Center for Medicare and Medicaid Services (CMS) had a 4.96% (n= 543) response rate based on 10,943 eligible participants.<sup>80</sup> However, a 2016 questionnaire on electronic health record (EHR) usage and experiences with a sampling frame of 39,165 (Texas physicians with email address in the TMA database) had a lower response rate of 2.77% (n=1,084).<sup>81</sup> Initially, response rate between 2.0 and 5.0% was expected. If the response rate within this range is not achieved, other professional medical societies will be contacted (i.e., Texas Infectious Disease Society; Texas Chapter of the American College of Cardiology).

Moreover, a 2015 physician workforce study in Texas indicated that there were 63,000 licensed physicians in Texas but only 46,953 were active in patient care.<sup>82</sup> From this research 453 practicing infectious disease specialists, 1,027 cardiologists, and 6,367 general/family practice physicians were identified for 2015.<sup>82</sup> Taking into account the number of each provider in the respective specialties and the collective TMA questionnaire response rate (between 2.0 and 5.0%), I expected the following response rate if all eligible physicians were emailed the link: 9 to 23 among infectious disease specialists; 20 to 51 among cardiologists; and 127 to 318 for family/ general practice physicians. This was a particular challenge given that a research study like this has not been previously done before to guide the decisions in statistical sampling and power. Using sample size calculations with a margin error of 10% and a confidence level of 90% resulted in a sample size of 59 for infectious disease, 64 cardiologists, and 67 general/ family practitioners.<sup>83</sup> The low threshold was to collect at least 30 participants from each group (for a total of n= 90). The reasons for the low power was that this research was explanatory in that findings would guide the development of grounded theory. In turn, specific hypotheses could be generated and tested, and the experiences of working with this challenging population could also improve sampling and response rate. No other study has demonstrated the response rate throughout the state, especially as it relates to an infectious disease specialists and cardiologists.

### ***Data collection and management***

Qualtrics (Research Core), an online application, was used to design, manage, and implement the questionnaire.<sup>84</sup> The questionnaires were anonymous and self-administered. Participants had a month to complete the questionnaire. The response rate was monitored

weekly. The recorded responses from the Qualtrics repository were exported as a CSV file for each questionnaire. The raw dataset was managed using Microsoft Excel with each question response that was initially coded as text numerically recoded to dichotomous or categorical values. Individual data dictionaries were created for each questionnaire. Copies of the original data files were saved in order to facilitate corresponding changes. A Do file (using Stata) was created for each questionnaire to denote changes made to the original dataset.

The participants' eligibility was checked. Table 2 summarizes the number of physicians sampled, the number who consented, and the number excluded. Among the 27 sampled ID specialists, 4 did not consent to participate and 3 additional participants were not licensed by the TMB. One participant indicated that s/he was a cardiologist, so the responses were grouped in the cardiology group. A total of 34 physicians were sampled for the family/general practice questionnaire. Nine did not consent, three additional participants were not licensed by the TMB, and one did not complete any questionnaire items other than the specialty. Thus a total of 11 ID specialists was excluded from the analysis. There were 11 sampled cardiologists (including the response from captured in the ID questionnaire), 6 of which did not consent and only 4 were licensed by the TMB. Only three were included in the analysis.

Table 2: Sampling and Participation, by Specialty

<b>Stage</b>	<b>Total</b>	<b>Infectious Disease</b>	<b>Family or General Practice</b>	<b>Cardiology</b>
Sampled	71	26	34	11

Consented and agreed to participate	52	22	25	5
Licensed by TMB	45	19	22	4
Included for analysis*	43	19	21	3

\*Not all of the participants answered each question, hence the missing data in the analysis.

### ***Data analysis***

Descriptive statistics were calculated as frequencies and proportions using Stata (14.2).<sup>85</sup> Pearson’s Chi square tests were used to compare differences in the response choice proportions (e.g., knowledge and attitude items), by physician group. Fisher’s exact test was used in cells with 5 or fewer counts. A p-value less than 0.05 was considered statistically significant. A summed index score<sup>77</sup> for the correct knowledge items was created that ranged from 0 to 13. No partial credit was assigned for partially correct responses, rather a “1” was assigned for identifying the correct choice.

### **Methodology for Aim 2b: Key Informant Interviews**

#### ***Study design and sampling***

The purpose of the semi-structured interviews was to explore specific domains quantified from the questionnaires, specifically regarding screening practices, as well barriers and recommendations to improve physician awareness. Initially a list of physicians (n= 24) that had treated CD patients was requested by the CDC. However, the CDC did not allow access to directly contact the physicians. Instead assistance was requested from the Texas Chagas Taskforce to identify and recruit physicians to participate as key informants. Four of the physicians listed were already part of the Taskforce and agreed to participate. An additional set of physicians (n= 10) were identified by taskforce member. Only half agreed to participate and confirmed a date and time for the call. In total, 13 physicians were identified

and recruited to participate using purposive, convenience, and snowball sampling, four of which indicated that they had not previously managed any type of care for a patient with CD.

### ***Interview questions***

As summarized by Padgett, the purpose of qualitative interviews is “to reveal key domains in which the experts add a top-down insider perspective that would otherwise be missed without their participation”.<sup>86</sup> Physicians were asked about their practice: the number of years in their specialty; whether they practice in a rural or urban area; type of medical practice (i.e., hospital, private, teaching). They were asked to describe their medical education and if they had training or medical experience in any country that is endemic to CD. Physicians were prompted to discuss their experience(s) in managing the care to CD patients (as defined by the continuum from screening and diagnosis, to treatment, to follow-up care) and elaborate on take-home messages, perceived barriers, and resources that helped them better understand CD. The script and guiding questions are shown in Appendix C.

### ***Recruitment***

Physicians listed in the sampling frame were emailed a brief description of the study. Once a physician agreed to participate, a follow-up email was sent to confirm the telephone interview. The informed consent and a summary of the key questions were attached in the email. A study identification number (Study ID) was assigned to each participant for each corresponding group. The Study ID consisted of 4 digits. The first digit starting from the left referred to the physician specialty: 0 if unknown at the time (i.e., if HCP provided contact information at a workshop or from online questionnaire); 1 for infectious disease; or 2 for cardiology. The next digit indicated whether the physician had treated for Chagas disease: 0

if it was not known at the time the Study ID was described; 1 if they had treated CD patients; 2 if they had not treated CD patients. Finally, the two out-right digits denoted the total sampling frame from 01 to 99.

A Study Participant List was created that linked the study ID to the names and contact information of the participants. A copy of the KI tracking table is shown in Appendix G. The purpose was to ensure confidentiality but be able to link physicians to their form and follow-up if needed. Initially, data collection was expected to conclude once saturation (i.e., “when additional analyses of the data bring redundancy and reveal no new information”<sup>86</sup>) was reached.<sup>87</sup> Given the challenges in recruiting physicians especially those with no knowledge of CD, or experience in managing the care of a CD patient the resulting domains and sampling strategies were homogenous. Thus, saturation was reached faster than anticipated. Interviews were conducted from late June through the end of August of 2018.

### ***Data collection and management***

Interviews ranged from 12 to 45 minutes in duration. All twelve were digitally recorded and securely stored. The script was used to guide the discussion. Notes were written down notes during the interview on the form, which were then scanned and securely stored electronically and managed via NVivo for Mac,<sup>88</sup> which is a qualitative data analysis (QDA) software used “to store data and facilitate coding and analysis.”<sup>86</sup> All of the twelve KI audio recordings were transcribed by Adept Word Management Inc.

(<https://adeptwordmanagement.com/>). The audio transcripts were emailed back as Word files and stored to NVivo. Inaudible sections were reviewed by the PI to ensure the KI’s message was accurately reflected.



### *Data analysis*

A grounded theory (GT) approach was used to guide the thematic analysis of the participant's feedback. GT is an approach that was first described by Glaser and Strauss<sup>86,89</sup> in 1967 for qualitative research with the goal of developing "new, contextualized theories"<sup>90</sup> that explain a "process, an action, or an interaction shaped by the views of a large number of participants."<sup>91</sup> A GT approach was relevant for this research given the lack of existing frameworks or models to explain the uptake of information among physicians regarding CD risk factors in the U.S. and its screening and diagnostic procedures.

GT involves "inductive coding from the data, memo writing to document analytic decisions, and weaving of theoretical ideas and concepts without permitting them to drive or constrain the study's emergent findings."<sup>86</sup> The salient feature with this approach is that the data drives the emergence of themes (i.e. inductive) rather than relying on other research to describe the phenomenon or use "prefigured codes or themes" from the existing literature.<sup>91</sup> Themes or categories are "broad units of information that consist of several codes aggregated to form a common idea."<sup>91</sup>

Using NVivo, field notes, guides/ scripts, and the audio transcriptions were reviewed. Cases were defined as the KI participants and coded accordingly. Descriptive themes were developed initially as primary nodes. The nodes were reviewed and compared to identify patterns. Axial coding was performed after the interviews were open-coded. Emerging themes were identified to describe the experiences in participating physicians that lead to screening and diagnosing CD and thus having an increased awareness (i.e., the identification of the *core phenomenon* denoted in GT). Finally, selective coding was used to weave in the

codes and propose hypotheses to describe the links between *strategies* (i.e., the actions taken in response to the core phenomenon); the *causal conditions* (i.e., the factors leading to the core phenomenon); the *contextual and intervening factors* (i.e., the broad and specific factors that influenced the strategies); and the *outcomes*.

## LITERATURE REVIEW

### Quantifying the Global Threat

Intercontinental migration (i.e., from Central and South America to North America, Europe, and Japan) has facilitated the spread of CD into previously non-endemic countries.<sup>47,92-94</sup> This globalization has resulted in CD as an emerging global disease. In countries where the vector is not present, blood transfusion, blood/ organ donations, and vertical transmission are of concern. Through computational simulation modeling, the global economic burden of CD is \$627.5 million in health-care costs and 806,170 disability-adjusted life-years (DALYs) annually.<sup>95</sup> The total net costs for infected individuals \$24.73 billion in healthcare costs, which exceeds cervical cancer costs. Bern and Montgomery estimated the possible prevalence of *T. cruzi* infections in Latin American- born individuals living in the U.S. using 2005 data. They showed there to be an estimated 22.8 million immigrants from Latin American living in the U.S. at that time and accounted for 1.31% of *T. cruzi* infections.<sup>21</sup> While Mexico accounted for the largest immigrant population, it only represented 1.03% of infections or an estimated 174,388 cases. In contrast, Bolivia represented the highest proportion (6.75%) but only represents about 4,149 cases. Thus, these estimates are likely to increase as the number of immigrants from Central and South America continue to increase.

### Awareness of Chagas Disease

#### *Among Healthcare Providers*

Given the emerging global concern, HCP's, including those in non-endemic countries in Europe must be familiar with CD etiology, screening, management, and treatment. In a

2013 study by Muñoz et al., physicians (pediatricians and obstetricians/gynecologists) and nurses in Spain were surveyed regarding their knowledge on Chagas. Eight basic questions were asked regarding the distribution, transmission in endemic countries, all routes of transmission, clinical manifestations, diagnosis, blood donation, and treatment. Physicians (n= 47) knew the least when it came to treatment and disease distribution (i.e., 57% and 60% only answered correctly) but in general answered more questions correctly compared to nursing professionals.<sup>61</sup> When compared to findings from other HCP CD knowledge studies from the U.S., this study suggests that HCP's in European countries that are seeing large waves of Latin American immigrants (i.e., Spain) are more aware than HCP's in other countries where screening and interventions are more limited, such as in the U.S. However, it is important to recognize that this study was conducted in a hospital (Poniente de Almería) that had already begun screening interventions to prevent vertical transmission.

A small study done in the U.S. demonstrated a limited awareness of CD among various sub-specialty providers. Stimpert and Montgomery showed that the knowledge, attitudes, and practices about CD were limited among a U.S. convenience sample of physicians in primary care, infectious disease (ID), cardiology, obstetrics/ gynecology (OBGYN), and transplantation medicine.<sup>62</sup> Forty-seven percent of OBGYN doctors had never heard of CD compared to 14% in primary care, 23% in cardiology, and 19% in infectious disease. Moreover, 68% of OBGYN physicians reported lack of confidence in CD knowledge being up to date, compared to infectious disease specialists who had the lowest at 27%. Additionally, 33% of OBGYN physicians did not know the cause of CD, and another big proportion (30%) of OBGYN HCP's did not know about the clinical manifestations of

disease. When asked how often the risk for CD in their patient population is considered: 34% of cardiologists, 29% of ID specialists 60% of OBGYN, 43% primary care, and 39% transplantation medicine doctors indicated that they never consider risk for CD in patients. HCP's were then asked to correctly identify the percentage of patients with chronic infection for which clinical disease develops. OBGYN (56%) had the most incorrect responses and the ID specialists the least (28%). Finally, when asked about CD symptom etiology, 48% of OBGYN answered incorrectly while ID specialists had the least incorrect responses (14%). All in all, OBGYN had the least amount of CD knowledge, while ID specialists had the most awareness regarding CD. A total of 1,142 HCP's through a national sample were surveyed. This was one of the earlier efforts to assess and quantify differences in knowledge levels by provider specialties.

Similar findings were observed in a 2010 Chagas awareness study from Verani et al. Questions were related to etiology, clinical manifestations, diagnosis, and risk for congenital transmission and represented a national sample of practicing OBGYN (n= 421). The online questionnaire was more comprehensive and focused specifically on congenital transmission risks and etiology. Over 68% of respondents self-reported a "very limited" level of knowledge regarding CD and 9% had never heard of CD.<sup>75</sup> Over a third of the participants did not know the causative agent for CD and 32% correctly identified the clinical manifestations for chronic CD. Next, an item was included about the proportion of patients seen that are immigrants from Mexico, Central America or South America. About 41% of HCP's indicated that they see 1-10% of immigrants from Latin America. Moreover, 78% and 20% never and rarely, respectively consider a CD diagnosis for immigrant patients. This

study helps to illustrate the differences in provider awareness and the need for tailored messaging that is relevant to the specialty (i.e., how to mitigate or prevent congenital transmission).

Knowledge of CD was evaluated in HCP's in six Appalachian Ohio counties with a higher proportion of Hispanic population compared to the rest of the state.<sup>60</sup> HCP specialties for this survey included cardiologists, internists, emergency department physicians, and primary care/ family physicians. Most of the HCP's (83%) had a very limited or limited level of CD knowledge. Regarding the consideration for CD in diagnosis, 46% never considered while 35% rarely did. Finally, 69% did not know the correct percentage of patients with chronic infection for which clinical disease develops. These findings contrast somewhat to the national results from Stimpert in that in general these Ohio HCP's knew less than the nationally surveyed physicians. Despite the limitations in estimating the prevalence, perhaps the disease is not as rare as perceived, thus presenting a barrier for correctly and efficiently diagnosing and treating patients. In the U.S., the CDC and health department have released educational resources aimed at healthcare providers as well as the general public<sup>31</sup>. However, the value and impact remains unseen. This study did not categorize the responses by physician specialty, and while similar questions were asked, they were not comparable to work from previous research.

A recent case report by Dolhoun and Antes illustrates the opportunity for missed diagnosis from HCP with limited experience in screening and diagnosing Chagas.<sup>96</sup> A healthy individual with no travel history to Central or South America, in a suburban residence in San Francisco, California presented with insect bites throughout a 6-week

period. He initially attempted to self-treat with over the counter medication, then contacted his primary care physician, and tried to avoid specific behaviors (i.e. not sleeping in his own bed, using a different means of transportation). His physician prescribed him sulfamethoxazole-trimethoprim and naproxen. He continued to receive new bites until he contacted a local pest management company that was able to identify triatomines in his room. This then prompted coordination with his physician and the CDC for confirmatory testing. It is surmised that the triatomines were found in the corrugated cardboard boxes that were occasionally received and stored in his room.

Assessing knowledge, attitudes, and practices (KAP) is useful in identifying “knowledge gaps and cultural barriers;”<sup>97</sup> as well as “exploring changes in the community,” including among “medical practitioners.”<sup>98</sup> Unlike the latter resource, much of the KAP guides focuses on the community-at-large in order to understand specific challenges to the uptake of a health behavior, current needs, or any other barriers to adapting or implementing interventions.<sup>97</sup>

### ***Among the Population***

Several recent studies have examined the level of CD awareness among Latin American immigrants, particularly from Bolivia. A 2014 study by Sanchez et al. assessed CD awareness among Latin American immigrants living in Los Angeles, California. Countries of birth included Mexico, El Salvador, Guatemala, or other. A total of 62% remembered seeing triatomines in their home country, yet 86% had never heard of CD. From those who had heard of CD, 81% believed that it was not a serious medical condition. This presents a

challenge in persuading high risk exposure patients to seek and follow-up with medical treatment, assuming it is accessible and available to begin with.

Bolivian immigrants in Spain were surveyed and blood samples were screened in a study by Salvador-Gil et al.<sup>47</sup> Questions related to symptoms, complications, means of transmission, and places to seek medical assistance. Out of the 96 participants, over 35% were serological positive for *T. cruzi*, but nearly one quarter did not know about CD and 71% did not know about the symptoms for CD. This suggests that not only is there high level of knowledge deficits among high risk population, but they may not know to seek medical assistance given that they may be already infected.

A similar study was conducted in Germany among Bolivian-origin residents.<sup>94</sup> CD awareness and serology was performed in 43 participants in one specific community in Munich. Less than 10% tested positive for *T. cruzi*. Nearly 70% had heard about CD, 56% were unaware of the symptoms, 30% had not knowledge on CD transmission, and 93% had never undergone testing. This research shows that even among high-risk exposure groups, there is room to better educate and inform individuals and empower them to seek medical resources.

Qualitative research further supports the quantitative results from surveys. Work from Blasco-Hernández et al., highlights how Bolivian women living in Spain perceive CD with a low-risk and may thus contribute to under diagnosis of disease.<sup>93</sup> Through key informant interviews and focus group sessions, women were aware of CD—the vector, the clinical manifestations, but were indifferent to the risk of contracting the disease and getting testing. In a different study with Bolivian women who had tested positive for CD, they



acknowledged emotional distress when diagnosed with CD but were unable to find medical treatment.<sup>56</sup>

A study aimed to identify barriers to access and treatment among Latin American immigrants in Georgia revealed consistent finding through qualitative research.<sup>58</sup> In this sample of immigrants, the majority of participants were unaware of CD but were somewhat familiar with the triatomines or *chinchas*. However, they confused the vector with other diseases not associated with Chagas. They recognized the potential to delay formal medical care, but that they trusted these remedies, especially if they consulted with family or friends still in their country. They also described “*stoically waiting*” for the illness to resolve on its own. This research helps to frame underlying cultural barriers that may delay medical consultation and engagement with the health system. If a patient does not have symptoms or does not trust doctors, then they may not be as likely to seek medical attention to get diagnosed or receive treatment.

In Honduras, a community-based surveillance pilot program that also assessed the risk awareness among children resulted in a decline in seroprevalence from 3.4% to 0.4% and improved awareness.<sup>99</sup> The success of this program indicates the feasibility and rationale for integrating vector surveillance with health education and screening.

Although, local transmission in North America is rare, specific populations who are exposed to the outdoors more frequently than other groups has been recently studied in Texas. For example, 36% of individuals enrolled in a Chagas study acquired the parasite locally via a sylvatic transmission.<sup>100</sup> Two-thirds from that proportion had reported a long

history (10 or more years) of outdoor/ recreational rural activities, thus placing this population of outdoor enthusiasts at an increased risk for infection.

### **Physiology and Biomarkers for Chagas Cardiomyopathy**

One-third to 40% of CD patients will present with cardiomyopathy with various levels of cardiac involvement.<sup>101</sup> Biomarkers are used to assess the severity of Chagas cardiomyopathy. Although Chagas cardiomyopathy and heart failure may have similar pathophysiological characteristics, the former is unique in that there are frequent ventricular arrhythmias, as well as “conduction disturbances, including sinus bradycardia, complete atrioventricular block, and right bundle block.”<sup>101</sup> High sensitive cardiac troponin is known biomarker for the diagnosis of acute myocardial infarction.<sup>101</sup> In a pilot study of *T. cruzi* positive donors in southeastern Texas, 41% had ECG consistent with Chagas cardiomyopathy and 36% were acquired through local transmission. In this study, high-sensitivity troponin serum levels increased with cardiac severity. A recent study from Echeverria et al. (2017) examined the association of *T. cruzi* infected individuals with Chagas cardiomyopathy and other biomarkers in a Colombian sample.<sup>101</sup> Findings indicated that N-terminal pro B-type natriuretic peptide (NT-proBNP) was similar to high sensitivity cardiac troponin in predicting the severity of Chagas cardiomyopathy. The clinical applications from the results of these studies thus shows the value of biomarkers in improving screening, particularly among the population with a high prevalence of CD. A recent literature review by Milei et al. concludes that chagasic cardiomyopathies can be misdiagnosed.<sup>102</sup>

## **Surveillance**

Although there is a lack of human surveillance, entomological and vector research and estimates from blood donor screening are used to estimate the prevalence.<sup>16,29,63,74,103-107</sup>

Work from Capuani et al. demonstrated an association between seropositive status and mortality in blood donors in Brazil using death certificates.<sup>108</sup> A total of 159 deaths among the seropositive donors were identified, 16% of which contained an ICD-10-CM CD cause of death (i.e., B57.0 and B57.5). In all, deaths due to CD was 17.9 times greater in seropositive donors compared to the seronegative donors.

## ***United States***

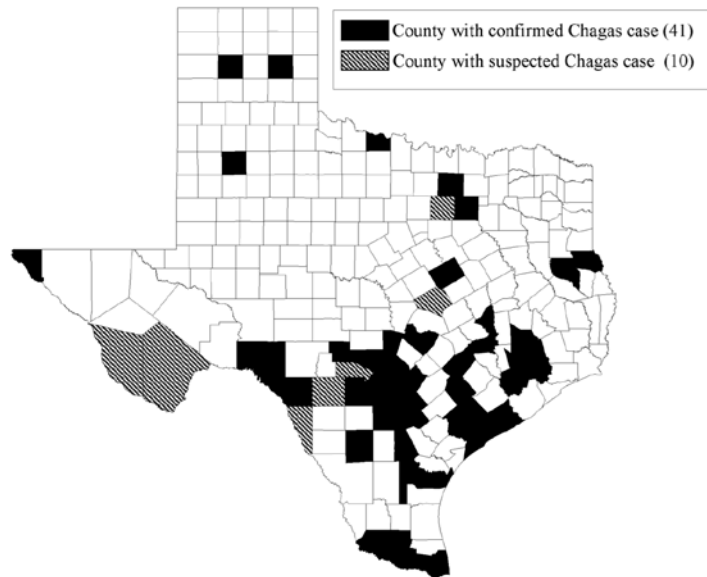
In the U.S., “relatively few resources have been devoted to surveillance, prevention, and treatment”.<sup>109</sup> Various studies throughout the last two decades have examined the potential for *T. cruzi* infection from blood donors here in the U.S. One of the earlier studies from Leiby et al., examined the prevalence of *T. cruzi* from blood donors in 1994 through 1998 in Los Angeles and Miami.<sup>110</sup> One in 7,500 and 1 in 9,000 tested serologically positive in Los Angeles and Miami donors, respectively. In a 2012 study, 41% (n=15) of the participants in Mississippi who were blood donor eligible had serologically tested positive for *T. cruzi*; out of those, 3 had reported visiting a rural area of an endemic country for less than 2 weeks, but all had previously lived where a vector has been documented.<sup>63</sup>

Additionally, 87% reported outdoor leisure or work activity. Research on *T. cruzi* infections among organ recipients from 2001 to 2011 indicated that 32 recipients received organs from 14 seropositive donors; transmission occurred in 9 recipients.<sup>111</sup> In New York, 204 donors tested positive out of 1.07 million donors between 2007 through 2011.<sup>112</sup>

## *Texas*

Public health state surveillance for CD began in 2013 in Texas. The reasons for CD surveillance includes: 1) to identify the source of infection; 2) monitor acute and chronic disease burden.<sup>39</sup> Non-human (i.e., canine cases) CD data were collected and reported between 2013 and 2016. Five locally acquired cases in southeastern Texas are described in Garcia et al. from a pilot study of positive blood donors.<sup>28</sup> Four were infected near their residence; four blood donors had a moderate to high risk of transmission from birthplace. A literature review from Garcia and colleagues indicates the first case reported of Chagas in Texas was in 1935.<sup>23</sup> Figure 10 shows a total of 51 confirmed or suspected cases that were reported in the literature between 1935 and 2015 in Texas.

Figure 10: Counties in Texas with confirmed and suspected Chagas infection from the literature, 1935 to 2015



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<sup>8</sup> Source: Garcia et al. (2015). Historical perspectives on the epidemiology of human Chagas Disease in Texas and recommendations for enhanced understanding of clinical Chagas Disease in the Southern United States. *PLoS Neglected Tropical Disease*, 9:11.

**JOURNAL ARTICLE 1**

**A geospatial analysis of diagnosed and potentially undiagnosed Chagas cases in Texas  
using inpatient hospital records, 2013 to 2016**

**Target Journal: PLOS Neglected Tropical Diseases**

## Introduction

Chagas Disease (CD) is a neglected zoonotic disease<sup>1</sup> of the Americas that can be fatal if not diagnosed and treated in its early stages. CD accounts for the highest burden of any parasitic disease in the 22 Latin American countries where it is endemic. *T. cruzi* is endemic throughout Central and South America and is found in North America, including in Mexico and in the Southern United States (U.S.).<sup>10</sup> An estimated 8 million people in Latin America have CD.<sup>11</sup> Over 28,000 people are infected each year in Mexico, Central America and South America, accounting for at least 12,000 deaths per year.<sup>12</sup>

Reduviids, also known as triatomines or kissing bugs, are blood-feeding insects that transmit the parasite (mainly through their feces) that causes CD. The kissing bugs are unaffected by *T. cruzi* but act as the vector for the parasite. Kissing bugs transmit the parasite to mammals including humans,<sup>1</sup> but can also infect reservoir hosts such as canines, opossums, raccoons, and other domestic<sup>8,13</sup> and sylvatic animals.<sup>14</sup> Vectorial transmission is most common among children and adolescents in endemic countries.<sup>8</sup> In contrast to the lack of compulsory screening and testing in the general population or with pregnant women, the blood supply in the U.S. has been screened for CD antibodies since 2007.<sup>1</sup> Blood donation screening is the most common means by which individuals learn about their CD diagnosis in the U.S.<sup>23</sup>

CD includes two main phases: acute and chronic.<sup>1,2</sup> Acute infections occur up to the first two months of the initial infection, which may manifest with mild flu-like symptoms or febrile illness.<sup>31</sup> Other symptoms may include: malaise, enlarged spleen, liver, and lymph nodes; localized or generalized edema; chagomas or breaks in the skin; and result in

abnormal electrocardiogram (ECG).<sup>8</sup> Acute infection may manifest as early as one week after exposure and may be self-limiting in most individuals.<sup>8</sup> The patient may not seek medical attention since the symptoms are mild and not unique to CD. During the chronic stage, two presentations are possible: the indeterminate form, which is commonly asymptomatic; and the determinate which include cardiac (e.g., cardiomyopathy, heart failure, altered heart rate or rhythm) and intestinal complications<sup>2</sup>. The majority of infected individuals (70%-80%)<sup>2,15</sup> will advance from the acute phase and remain in a latent or indeterminate chronic form of the disease (mostly asymptomatic), which may persist as a lifelong infection. The danger of this asymptomatic status is that once symptoms do manifest, eliminating the parasite becomes more difficult or impossible and often results in death. Conversely, only 20-30% of infected individuals will progress from the indeterminate chronic phase to a “clinically evident disease” or chronic determinate phase, months to decades after becoming infected.<sup>15</sup> Chronic determinate CD often corresponds to the organ involved (heart; esophagus; and/or colon): cardiac, digestive, or both.<sup>8</sup> The digestive manifestation is typically found mainly in South America or in persons infected in that region.<sup>8</sup> Heart failure occurs usually towards the latter phase of Chagasic heart disease.<sup>8</sup> Sudden death due to cardiac complications can occur.<sup>11</sup>

For the scope of this study, heart-related symptoms were the primary focus, given that the digestive manifestation is a hallmark of South American infections. In the Southern Cone of South America (i.e., Argentina, Bolivia, Chile, Paraguay, Uruguay, and parts of Brazil) gastrointestinal CD is more common than CD cardiomyopathy, as the latter is more commonly seen in Central America and North America.<sup>34</sup> According to the National Institutes of Health (NIH), cardiomyopathy, “refers to diseases of the heart muscle...as it

becomes enlarged, thick, or rigid...the heart thus becomes weaker pumping less blood and beating irregularly”.<sup>35</sup> Chagasic cardiomyopathy includes “cardiac arrhythmias, heart failure, and risk of sudden death from ventricular fibrillation or tachycardia or thromboembolic events”<sup>8</sup> and an estimated 5.4 million people will develop these symptoms.<sup>36</sup> Cardiovascular disease in CD patients is believed to be the result of “parasite persistence in cardiac tissue and immune-mediated myocardial injury.”<sup>37</sup> CD may present as idiopathic cardiomyopathy and be overlooked by many or most HCPs as a diagnosis. Some estimates considering that the Latino immigrant population is younger than the current U.S. population, suggest that, 10 – 15% of the total U.S. population (or 30,000 to 45,000 individuals) is living with undiagnosed CD cardiomyopathy.<sup>21</sup>

This study aims to illustrate the missed diagnosis for CD in Texas using geographical information system (GIS) mapping.

## **Methods**

### ***Data sources***

The Inpatient Public Use Data File (IPUDF), maintained by the Texas Department of State Health Services (TDSHS), and the number of Chagas confirmed cases data were used to create maps for this aim. Chagas disease (CD) became reportable in 2013. Thus, the hospital inpatient PUDF for 2013 to 2016 was requested. Census data (i.e., American Fact Finder web application) was used to download the American Community Survey (ACS) 5-year Texas population estimates for 2016.<sup>70</sup> This included Texas demographic data on age and Hispanic status by county. A basemap was created by downloading the shapefile for the Texas counties from the U.S. Census Bureau (i.e., TIGER/Line Web interface).<sup>71</sup>



### ***Variables and case definitions***

Patient demographics from the raw quarterly base inpatient data files included: patient's age group (i.e., <18; 18 to 44; 45 to 66; 65 to 74; and  $\geq 75$ ); ethnicity (Hispanic or non-Hispanic); race (American Indian/ Eskimo; Asian or Pacific Islander; Black; White; or Other); and sex code (male or female). All of the principle diagnostic codes (i.e., 1—24) were coded to determine if that particular patient record contained any of the ICD-9 or 10 diagnostic codes of interest. Additional variables that were kept from the initial raw IPUDF included: record identification number for each hospital admission; patient's county and zip code of residence; provider ID; and type of admission.

A cardiologist was consulted to identify and review the diagnostic codes. Dummy variables were created using the Chagas diagnosis in the IPUDF for: ICD-9-CM (i.e., 086.0, 086.1, and 086.2) for 2013 through 2015 (third quarter); and the ICD-10-CM codes (B57.0, B57.1, and B57.2) for the last quarter of 2015 and all of 2016. These variables were the Chagas-related cases that were mapped. Heart-related diagnosis, a proxy for potentially missed diagnosis, in the IPUDF included the following codes: 414.8, 422.91, 425.8, 425.4 (ICD-9); and I25.5 and I42.9 (ICD-10). Table 1 summarizes the ICD codes used to identify the cases.

### ***Data collection and management***

Each of the quarterly IPDUF were exported as a comma separated value file (CSV) to Excel. Stata was used to create the indicator or dummy variables (i.e., flag the case definitions), drop variables that were not of interest for this study, denote the steps performed and run quality checks, and merge quarterly datasets to corresponding years. "If statements"

were used on Stata to flag each of the *admitting*, *principal*, and *other diagnosis* codes for any Chagas or heart-related ICD 9/10 codes prior to merging quarterly datasets into the corresponding yearly datasets. Patient records that did not contain the case definitions were eliminated from the dataset. The combined raw IPUDF contained over 12 million hospital admissions, yet 3.1% were eligible for the geospatial analysis (i.e., contained a heart related and or Chagas disease diagnosis code).

The results from tabulations by county and case definition, and by county, case definition, and demographic characteristic (i.e., age group, ethnicity, race, and sex) were inputted to an Excel spreadsheet for each corresponding year. The counties were listed as rows and the variables as numbers. An additional spreadsheet was created to summarize the sub-totals for the corresponding ICD 9/10 Chagas disease diagnostic codes (both heart and other organ involvement) and for the heart-related diagnostic codes for all four years. Thus, there were multiple iterations of data management to create a final dataset and ultimately a table with the counties by enumerating the totals for each of the cases, as shown in the Appendix. The Federal Information Processing Standard (FIPS) code was listed for each county in the final table to link up to the county shape file.

Demographic data for the state was downloaded using the American Fact Finder web application as CSV files. The five year 2016 estimates were chosen for the Hispanic population and age categories. Excel was used to import the CSV files, clean up the variables (i.e., rename columns for ArcMap usability; remove extraneous data). An Excel workbook was created for each variable. To calculate the Hispanic proportion, the number of Hispanics was divide by the total population for each county. To create the table for age groups, only

the population estimates for males, females, and all, aged 20 to 59 were summed for each respective group (i.e., a column for each: males, females, and total).

### ***Mapping***

ArcMap GIS (Version 10.6.0), a software application used to map and analyze a geographic information system (GIS), was used to visualize the ICD 9/10 inpatient hospital diagnostic codes and illustrate the salience of potentially missed Chagas disease diagnoses (e.g., cardiomyopathic diagnoses).<sup>72</sup> GIS maps are useful in illustrating issues or particular situations and contextualize environmental factors.<sup>73</sup> Given that the vector is found throughout the state as demonstrated from emerging animal and entomological surveillance<sup>74</sup> this study aim can help visualize where the potential for missed diagnoses is the most prevalent throughout the state and serve as exploratory for further research to map the vector ecology with findings from this research.

### **Results**

There frequency of each ICD code by year and by diagnostic code are described in detail in Appendix D. In total, 101 CD diagnoses between 2013 and 2016 were identified. The majority of CD diagnoses were identified for 2014 (n= 22, Chagas with heart involvement) and for 2016 (n= 27, chronic Chagas with heart involvement). In contrast, only 1 acute Chagas without heart involvement was identified within the IPDF. A total of 21 occurrences of Chagas without mention of organ involvement were identified. A total of 378,592 cases of heart-related diagnoses were identified. “Cardiomyopathy, including idiopathic” and “other chronic ischemic heart disease diagnoses” accounted for the most

instances, 118,206 and 150,207, respectively. The least occurring diagnostic code was for idiopathic cardiomyopathy (n= 384).

A total of 4 maps were created. First, the table of Chagas disease counts reported to TDSHS (by local, imported, or unknown transmission). Each value was set to represent one count. Next, the table with the heart-related ICD (9 and 10) total counts for each county was added in order to output a choropleth map, that is as each range of values increased so did the corresponding color intensity. The natural breaks (or Jenks) classification was initially used in order to minimize variance within groups but maximize it between them, followed by manual adjustments to categorize the data into 5 groups. The demographic tables from the ACS estimates were then loaded to ArcMap. For each map, the heart-related ICD diagnoses were represented as graduated symbols (i.e., red triangles) using the same group classification as before (e.g., Jenks). Graduated colors were used to show the proportion of Hispanics and the proportion of the county population aged 20 to 59, given that we expected a larger proportion of the younger population with heart-related diagnosis could potentially be indicative of missed CD cases. All tables were linked to the county shapefile (i.e., the basemap) using the FIPS county code. Appendix D details the frequency for each case. In total, 366,575 heart-related diagnostic cases were created from the IPUDF and categorized into five groups: 2 to 100; 101 to 500; 501 to 1,000; 1,001 to 20,000; and 20,001 to 60,000.

Figure 1 illustrates the number of CD cases reported to DSHS between 2013 and 2016 in Texas, by transmission type. A total of 91 individual cases were reported between that time range, with each corresponding symbol representing a case. Based on the data presented in this figure, the largest clusters of imported cases were in Harris and Dallas.

Individual imported cases were reported in Potter and Wilbarger in the north, El Paso in the far west; and Shelby and Anderson towards the east. Locally-acquired cases were reported in Bexar and some in South Texas counties of Hidalgo, Brooks and Cameron.

Figure 2, a choropleth map, shows the county unweighted burden of heart-related diagnostic codes from the IPDUF. The lighter pink-colored counties represent fewer counts of heart-related counts in contrast to the darker red-colored counties that represent 1,000 or more counts of heart-related diagnosis between 2013 and 2016. Bexar, Dallas, Tarrant, and Harris, had the highest number of heart-related codes (between 1,000 and 20,000). The following counties were in the second highest category for heart-related codes: El Paso; Midland, Ector, Lubbock, and Potter moving up the panhandle; Wichita, Grayson, and Lamar along the Oklahoma border; and Zavala, Wells, Hidalgo, Cameron, and Victoria to the south. Additionally, counties surrounding Dallas and Tarrant, counties to the north of Bexar, and counties around Harris also had a high number of heart-related codes.

Figures 3a and 3b represent the ACS estimate of the Hispanic population and the proportion within that county between 20 and 59 years of age, respectively. A graduated symbology (i.e., red triangles) is shown in both maps to illustrate the potential for missed CD disease diagnosis given that a younger population might be experiencing heart complications. Counties with a high Hispanic population (75% to 99%) had a range of heart-related frequency, though the highest numbers were in El Paso, Maverick, Webb, Hidalgo, and Cameron. Counties with a lower proportion of a Hispanic population like Randall or Montgomery had large (but not the highest) numbers of heart-related diagnostic codes. The increase in the triangle symbology in the population map (Figure 3b) can be seen in some

counties with a large proportion of the population aged 20 to 59. In six counties with the largest proportion 55% to 65% in this age group (i.e., Hartley, Childress, King, Garza, Sterling, and Concho) had 100 or less heart-related diagnostic codes.

Figure 4 shows the comparison between the CD diagnostic codes (blue) and the red triangles for the number of heart-related codes. Harris and Dallas/ Tarrant, Travis, Bexar, and Cameron counties show clusters of both ICD-coded CD and higher proportions of heart-related diagnostic codes. Wilbarger had 6 CD diagnostic and only 345 heart-related codes.

Figure 5 shows the prevalence of missed diagnosis per 10,000 as adjusted by the county population. Counties with the highest adjusted prevalence included Howard, Wilbarger, Callahan, McMullen, Maverick, Fayette, Colorado, Bureson, Grimes, Robertson, Leon, Wood, Camp, Red River, and Lamar.

### **Discussion**

First and foremost, the maps demonstrate the need for statewide surveillance data in the human population to better determine populations at risk and whom to screen. However, in broad strokes, these maps begin to illustrate the systems-level and patient-level barriers and challenges to accessing and receiving care for CD. The CD cases reported to TDSHS are not homogenously dispersed throughout the state. Instead, clusters are depicted primarily in urban areas, where presumably there is increased access to physician care. Nonetheless, even with limited evidence, this dataset from TDSHS does show the potential for acquiring the infection through a vector: pockets of these locally-acquired cases were reported specifically in Bexar, Hidalgo, Brooks, and Cameron. However, no other areas, (i.e., the panhandle;

counties bordering Mexico; western Texas including the El Paso region; and the eastern parts) show locally-acquired infections.

Some counties with a high burden of heart-related diagnosis also are indicative areas with CD diagnosis, as shown by the ICD codes and by the TDSHS CD-reported cases. The reasons for the congruence in these urban hubs—Bexar, Dallas, and Harris counties—are not only due to their respective overall populations, but also reflect the availability and ability of physicians in those counties to recognize the screen factors and move through the continuum of care in screening, diagnosing, and providing treatment to CD patients. However, as indicated from the findings of an upcoming manuscript, a physician’s awareness about CD, their inclination to consider risks in their patient population, and their knowledge on specific screening and diagnostic processes is limited, even in these urban geographies in which CD cases have been reported.

Collectively, the heart-related diagnosis and age demographics indicate the possibility of missed CD diagnosis throughout the state. That is, a younger adult population with heart-related complications is indicative various chronic conditions, including chronic Chagas cardiomyopathy (CCC). The fact that there are potentially missed diagnoses in counties that do not have a major Hispanic proportion of the total population—affects everyone and should be relegated to a disease of just immigrants. It also illustrates the potential challenge in certain populations not seeking access to medical care or having a physician available to correctly and timely diagnose CD. It also highlights the significance of imported CD cases that might go undiagnosed and untreated. Ultimately, the issue remains as to whether or not the individuals with heart-related were a missed diagnosis. That is, we cannot rule out with

any level of confidence that any of those heart-related diagnoses were due to undiagnosed Chagas cardiomyopathy.

CD is currently found throughout Texas, and there is a potential for local transmission.<sup>28</sup> Five newly diagnosed CD patients are described in this 2015 case report.<sup>28</sup> All of these patients acquired CD locally and resided in rural Southeast Texas counties and were blood screened. This thus cements the possibility of persons currently not knowing that they have CD because not all cases are diagnosed. Thus physicians should not only be concerned about screening patients that come from countries where CD is endemic, but should consider local transmission in situations in which vector exposure is possible.

### ***Limitations***

This research has several limitations. This research is the first to examine statewide hospital records in order to qualify the potential for missed CD diagnosis in Texas. However, this research focused on potentially missed diagnosed cases of chronic Chagas, rather than including acute and indeterminate chronic forms of CD. Moreover, in examining chronic CD, the scope of this research was limited to CCC, rather than looking at other sequelae (i.e., gastrointestinal complications). Furthermore, establishing the criteria for missed diagnoses of CD was the greatest challenge, given the lack of research to inform specific risk factors that account for CCC. Thus the risk of misclassification is a concern.

The data sources were another limitation. ICD-9 and ICD-10 heart-related and Chagasic diagnostic codes were not completely comparable given differences in their definitions. While ICD-10 denotes the disease progression (i.e., acute or chronic), there is no code specifying the indeterminate form of CD. In ICD-9 there is a code (086.2) that alludes



to the asymptomatic, indeterminate form (i.e., Chagas without mention or organ involvement). Similarly, among the heart-related diagnostics, there is a cardiomyopathy, excluding Chagas in ICD-9 code but not one for ICD-10. Between 2013 and August of 2015, a total of 21 records indicated Chagas without mention of organ involvement.

Additionally, the Texas IPUDF was intended for administrative purposes and not intended for clinical or population health research. That is, there may be coding errors. For example, the difference in totals in Appendix D and E can be attributed to the hospitals not directly collecting the patient's county of residence or suppressing the value if a county has fewer than five discharges for that quarter. The county of residence is assigned based on the patient's zip code. For 2016, 45,008 ischemic cardiomyopathies were diagnosed but only 43,597 patient records coded a county. Thus, the statewide patterns in reported and non-diagnosed cases of CD from 2013 to 2016 are difficult to illustrate.

### ***Recommendations***

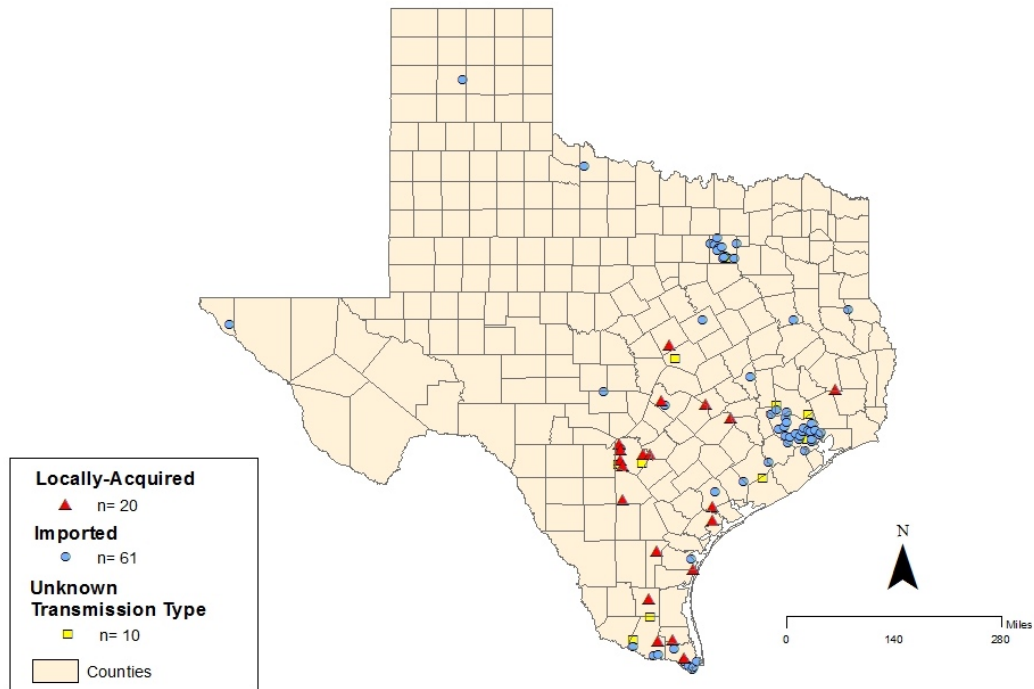
Future research can further explore the patterns of missed diagnoses within specific geographical targets (i.e., by examining and comparing urban and rural counties only in contrast to examining patterns throughout the state; or by examining differences in census tracts or zip codes). Furthermore, the case definitions for the missed CD diagnostic codes can be re-evaluated. For example, additional geospatial and statistical analyses can be performed on specific counties using only idiopathic cardiomyopathy diagnoses and comparing to other codes that accounted for the large number of heart-related diagnoses (e.g., other ischemic heart disease, ischemic cardiomyopathy, unspecified cardiomyopathy). Recent research, for example, show the promise of evaluating myocardial fibrosis using cardiac magnetic

resonance (CMR) as a predictor for CCC.<sup>113,114</sup> As such, the ICD code for unspecified myocarditis (e.g., I51.4) from the Texas IPDF can be mapped alongside specific age intervals and other patient characteristics. Additional research can map the county demographics and more specific risk factors for CCC (i.e., by narrowing the age group).

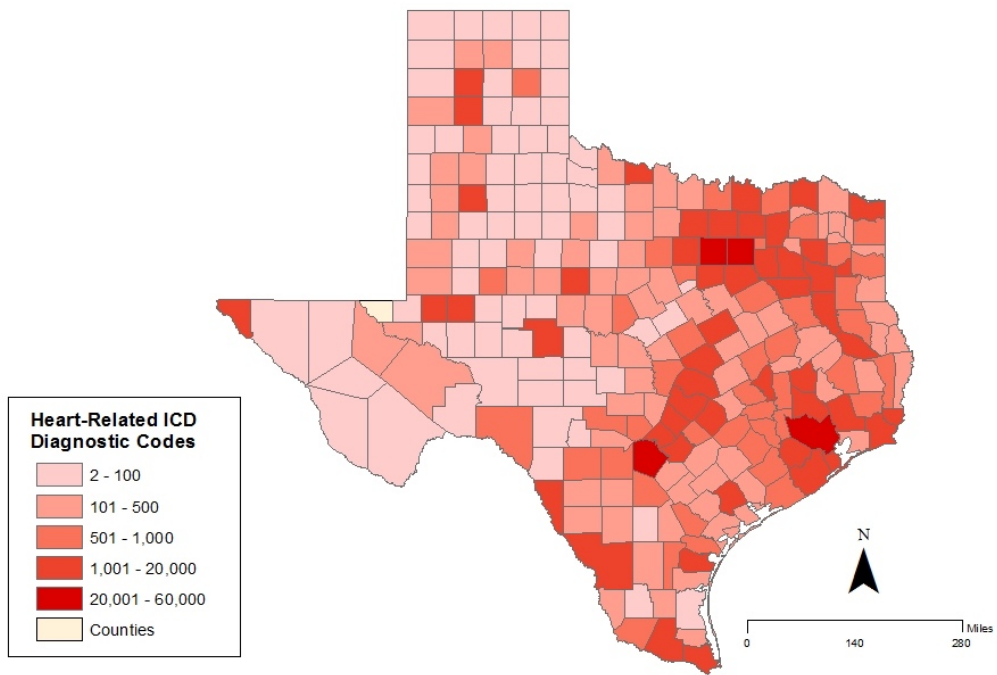
Secondly, the findings support the need for a surveillance system in the human population that would facilitate and increase the accuracy, validity, and generalizability of geospatial analysis. That is, maps that are created to illustrate the magnitude of CD cases in Texas would greatly benefit from epidemiological data that is specific to CD, rather than relying on administrative data such as the Texas PUDF.

## Figures

**Results Figure 1: Reported Cases of Chagas Disease and County of Transmission, 2013 to 2016.**

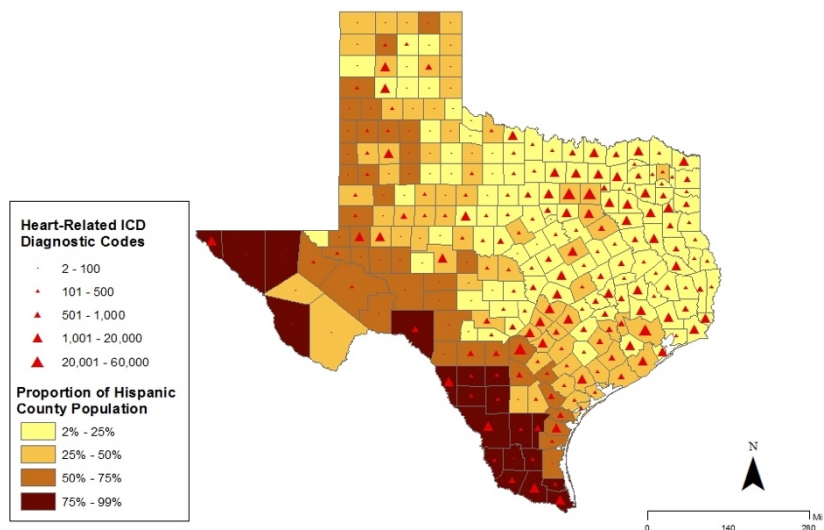


**Results Figure 2: ICD Codes for Heart-Related Diagnosis, 2013 to 2016\***



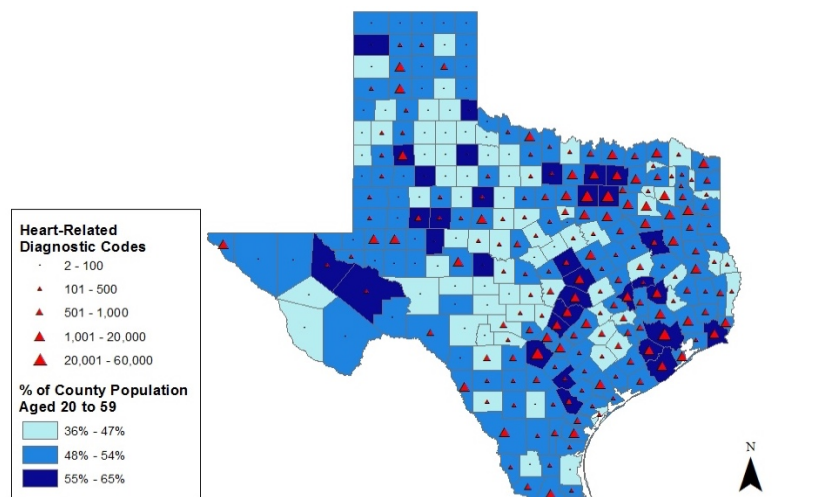
\*ICD9 and 10 diagnostic codes related to idiopathic cardiomyopathy and ischemic heart disease. For the full list of diagnostic codes used, refer to Appendix.

**Results Figure 3a: Heart-Related ICD Diagnosis for 2013 to 2016, \* Hispanic Population\*\***



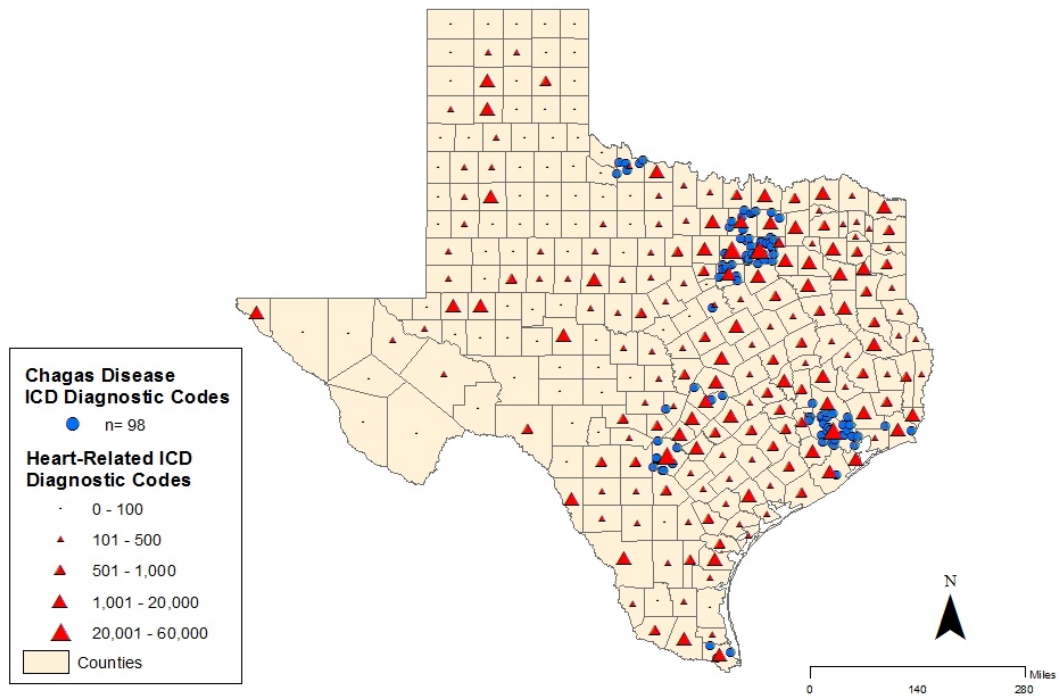
\*ICD9 and 10 diagnostic codes related to idiopathic cardiomyopathy and ischemic heart disease. For full list of diagnostic codes, refer to App  
 \*\*American Community Survey 2016 Estimates

**Results Figure 3b: Heart-Related ICD Diagnosis for 2013 to 2016\*, Population Aged 20 to 59 Years of Age**



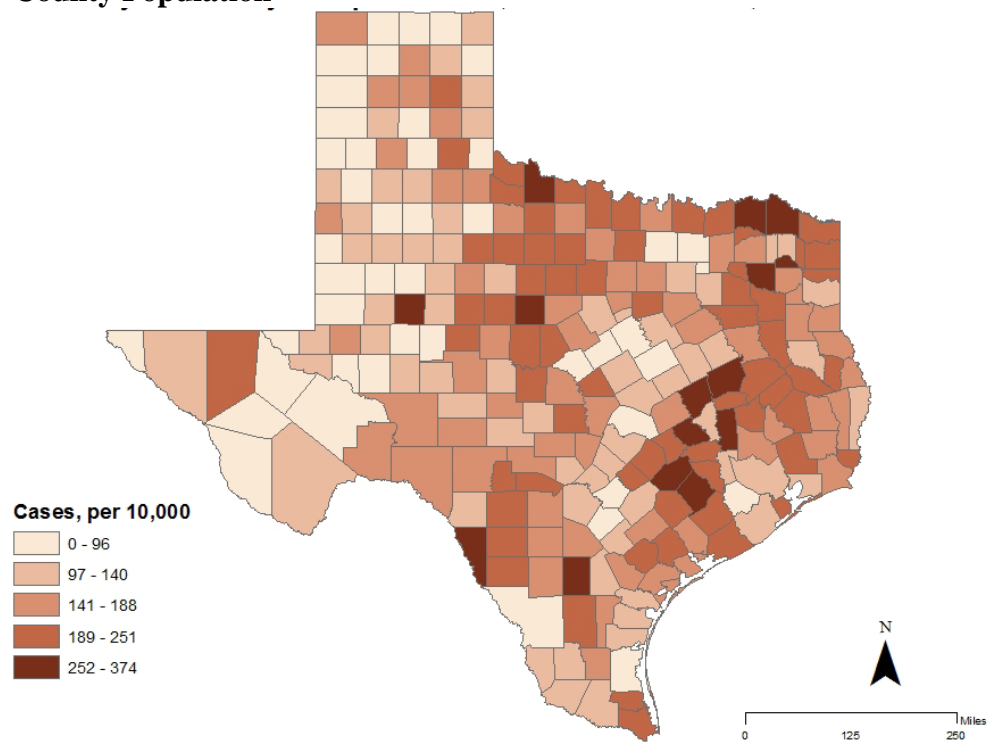
\*ICD9 and 10 diagnostic codes related to idiopathic cardiomyopathy and ischemic heart disease. For full list of diagnostic codes, refer to Appendix.  
 \*\*American Community Survey 2016 Estimates

**Results Figure 4: Chagas Disease and Heart-Related ICD Diagnostics Codes for 2013 to 2016**



\*ICD9 and 10 diagnostic codes related to idiopathic cardiomyopathy and ischemic heart disease. For full list of diagnostic codes, refer to Appendix.  
\*\*American Community Survey 2016 Estimates

**Results Figure 5: Heart-Related ICD Diagnostics Codes for 2013 to 2016, Adjusted by County Population**



\*ICD9 and 10 diagnostic codes related to idiopathic cardiomyopathy and ischemic heart disease. For full list of diagnostic codes, refer to Appendix.  
\*\*American Community Survey 2016 Estimates

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## **JOURNAL ARTICLE 2**

**Shaping recommendations and healthcare provider education on Chagas disease from a mixed methods baseline exploratory study.**

**Target Journal: American Journal of Public Health**

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## Introduction

Chagas Disease (CD) is a neglected zoonotic disease<sup>1</sup> of the Americas that can be fatal if not diagnosed and treated in its early stages. CD accounts for the highest burden of any parasitic disease in the 22 Latin American countries where it is endemic. *T. cruzi* is endemic throughout Central and South America and is found in North America, including in Mexico and in the Southern United States (U.S.).<sup>10</sup> An estimated 8 million people in Latin America have CD.<sup>11</sup> Over 28,000 people are infected each year in Mexico, Central America and South America, accounting for at least 12,000 deaths per year.<sup>12</sup>

CD includes two main phases: acute and chronic.<sup>1,2</sup> Acute infections occur up to the first two months of the initial infection, which may manifest with mild flu-like symptoms or febrile illness.<sup>31</sup> Other symptoms may include: malaise, enlarged spleen, liver, and lymph nodes; localized or generalized edema; chagomas or breaks in the skin; and result in abnormal electrocardiogram (ECG).<sup>8</sup> Acute infection may manifest as early as one week after exposure and may be self-limiting in most individuals.<sup>8</sup> During the chronic stage, two presentations are possible: the indeterminate form, which is commonly asymptomatic; and the determinate which include cardiac (e.g., cardiomyopathy, heart failure, altered heart rate or rhythm) and intestinal complications<sup>2</sup>. The majority of infected individuals (70%-80%)<sup>2,15</sup> will advance from the acute phase and remain in a latent or indeterminate chronic form of the disease (mostly asymptomatic), which may persist as a lifelong infection. The danger of this asymptomatic status is that once symptoms do manifest, eliminating the parasite becomes more difficult or impossible and often results in death. Conversely, only 20-30% of infected individuals will progress from the indeterminate chronic phase to a “clinically evident

disease” or chronic determinate phase, months to decades after becoming infected.<sup>15</sup> Chronic determinate CD often corresponds to the organ involved (heart; esophagus; and/or colon): cardiac, digestive, or both.<sup>8</sup> The digestive manifestation is typically found mainly in South America or in persons infected in that region.<sup>8</sup> Heart failure occurs usually towards the latter phase of Chagasic heart disease.<sup>8</sup> Sudden death due to cardiac complications can occur.<sup>11</sup>

For the scope of this study, heart-related symptoms were the primary focus, given that the digestive manifestation is a hallmark of South American infections. Some estimates considering that the Latino immigrant population is younger than the current U.S. population, suggest that, 10 – 15% of the total U.S. population (or 30,000 to 45,000 individuals) is living with undiagnosed CD cardiomyopathy.<sup>21</sup> For the scope of this research, screening refers to the process by which HCP’s determine if further laboratory diagnostics are required. During the initial screening, the HCP discusses the patient’s medical history, “including questions about travel and living conditions,” and performs a physical examination and possibly an ECG.<sup>15,31</sup> The diagnosing of CD represents the clinical and serological testing required to confirm the presence of *T. cruzi*. In the U.S., the CDC requires confirmatory laboratory diagnosis for *T. cruzi* using at least two different immunoassay procedures (i.e., enzyme-linked immunosorbent assay [ELISA] and immunofluorescent antibody test) prior to treatment.<sup>15</sup> At least two different serological tests are required given the lack of specificity and sensitivity obtained from one single procedure. Such laboratory assays are used to detect IgG or IgM antibodies to the parasite are available from major commercial laboratories (e.g., Mayo Medical Lab, ARUP, and Quest Diagnostics).<sup>45</sup> Nonetheless, no standardized protocol (at the national, State, or local/county level) is available for physicians to reference when

attempting to request the laboratory codes. Recent statistical modeling demonstrates the value of screening Latin American immigrants in non-endemic countries.<sup>46</sup> Women are recognized as a target population for community screening programs in non-endemic countries in Europe (e.g., Spain and Italy) due to the risk of transmitting the parasite to their children.<sup>47,48</sup> No commercially-available rapid screening kit is available for HCP's to routinely use that provide an immediate confirmatory results for *T. cruzi*. In contrast to other chronic diseases<sup>49</sup> (i.e., type II diabetes, heart disease, cancer, etc.), screening and diagnosing for CD is not routinely performed.

Due to the number of cases, its asymptomatic nature, urgency for early diagnosis and treatment and unknown prevalence in the U.S., CD should be a concern for HCP's. Many physicians currently practice medicine within their subspecialty and in isolation from other HCP specialties.<sup>53</sup> Even fewer communication exchanges occur with other scientists (i.e., veterinarians, entomologists, ecologists, policy scientists, etc.). The lack of collaboration and engagement may prevent the exchange of new ideas and innovations. In turn, this is a barrier for an accurate and timely diagnosis for a patient.<sup>53</sup> Recent epidemiological trends in the vector, or in zoonotic populations, for example, can shed light about the potential threat to human health. As we move towards a healthcare model in which the patient, as the consumer, is more informed and encouraged to participate in decision-making process, he or she may be a stronger advocate to improve the likelihood of testing and diagnosis, rather than rely solely on the physician as the gatekeeper for information. It is unclear how medical training and continuing education among the various specialties and sub-specialties shape how individual

physicians receive, synthesize, and apply information regarding emerging or rare diseases like CD.

CD is rarely diagnosed during the acute phase of the infection.<sup>23</sup> The latency and asymptomatic nature of the disease may not prompt individuals to seek immediate medical consultation or treatment. Cultural beliefs and systemic barriers may also prevent or delay a patient from seeking medical care, particularly as documented in Central and South American groups.<sup>55,58</sup> For instance, an individual distrusts the medical system, while a systemic barrier may include the lack of drugs or HCP's.<sup>32,48,55,56</sup> Individuals in impoverished communities in Latin America and in the U.S. lack health insurance or the means to access medical care, even if they wanted to get diagnosed and treated.<sup>57</sup> These challenges are also reflected in the Latin American immigrants in the U.S. and other non-endemic countries. In rare occasions, individuals recognize the exposure to a kissing bug or develop clinical manifestations (i.e., a chagoma) that may prompt medical attention. Figure 7 summarizes some of the individual-level barriers.

Due to the rarity in reporting autochthonous cases, there is still a lack of *overall awareness* among HCP's in the U.S., including in Texas.<sup>23</sup> HCP's may consider CD only as a neglected tropical disease and not recognize the risk factors for local and acquired infections in Texas. They also may not consider their patients from Latin America or from mothers from Latin America at risk if they have never encountered the disease before and know very little about it.

There are few comprehensive resources targeting HCP's that illustrate the clinical criteria used to evaluate and diagnose CD.<sup>8,15</sup> The TDSHS and the CDC have outlined

general recommendations for the clinical diagnosis and treatment of CD.<sup>2,15</sup> However, there are no specific recommendations in Texas for HCP's to target screening to Latin American immigrants or women of child bearing age. A patient profile could help frame the risks of exposure to guide HCP's in deciding if further screening or serological testing is needed. No patient profile currently exists that identifies populations in Texas (or the U.S.) with a higher risk of exposure or transmission. Without such guidance, HCP's may not perform a thorough medical history (i.e., discuss potential exposure to the vector and parasite).<sup>60-62</sup> For example, the HCP's may not ask the patient about travel history or previous place of residence. Thus, even if a HCP is more *familiar or aware* of CD, s/he may have limited experience in identifying infected individuals with the indeterminate form; performing clinical evaluations; ordering appropriate laboratory tests; or coordinating with health officials. Consequently, lack of awareness or experience may delay a patient from receiving adequate treatment.

Infectious disease HCP's are hypothesized to be the most aware of CD compared to cardiologists and family/ general practice physicians given their experience in diagnosing related parasitic diseases. Infectious disease HCP's were thus a focal group since other general practice HCP's may refer patients to them. Cardiologists were hypothesized to also be aware and knowledgeable of CD since the chronic phase of the disease involves heart-related complications. However, in general, cardiologists may lack the awareness to recognize the acute or chronic asymptomatic CD cases and understand the importance or value of screening high risk populations. Cardiologists may facilitate the communication between other provider specialties, since they may be somewhat more familiar and aware of CD than other general practitioners. The research aim is to identify and describe gaps related



to knowledge, attitudes, and practices in the screening, diagnosis and treatment of CD among practicing physicians in Texas. Specifically, through a mixed methods approach, an online questionnaire to quantify and describe knowledge among specialists, including: cardiologists, infectious disease specialists and family practice physician; Conduct key informant interviews to explore the barriers to screening, diagnosis and treatment amongst physicians who have treated CD and those who have not treated CD

## **Materials and Methods**

### ***Questionnaire***

#### *Study design and population*

The study design was cross-sectional, in which data was collected from three online questionnaires from July 5, 2018 through October 1, 2018. Having a baseline to quantify general knowledge on CD, as well as specific diagnostic procedures, practices, and overall attitudes on CD is crucial for the development of targeted HCP educational efforts and the dissemination of resources.

Thus, similar to the recent study assessing CD awareness among Ohio HCP, the questionnaires focused on cardiologists, infectious disease specialists, and family care physicians. The rationale was that these providers are more likely to provide medical care to most patients. Although primary care physicians and other primary healthcare workers such as physician assistant and nurse practitioners act as gate keepers in referring their patients to specialized care, due to time constraints and limited resources the scope of this research was only on licensed practicing physicians in Texas who were listed with a primary specialty in cardiology, family medicine/ general practice, or infectious disease medicine. I

expected the sample will be representative and reflect the knowledge, attitudes, and beliefs of the targeted population, but findings may not be necessarily generalizable to all HCP's in Texas. However, given, the design of this research, the findings will guide future research and outreach efforts for specific HCP populations and specific Texas geographical locations. In turn, this target population will engage with patients seeking primary care as a result of vector exposure, blood donation letters, or from exhibiting clinical symptoms.

#### *Instrument development*

A questionnaire was developed to describe: 1) the overall awareness of CD; 2) screening, diagnosis, and reporting procedures; 3) and risk and exposure factors specific to Texas. Questionnaires used to collect information related to knowledge, attitudes, and practices (KAP) have been used by the WHO, particularly in developing countries to better understand the community members' perceptions about specific health concerns.<sup>76</sup> Multiple choice items and ordered-category items (i.e., Likert scales) are ways to objectively assess the knowledge.<sup>77</sup>

Prior to this research, no tool was available to assess Chagas KAP among physicians to measure specific domains (e.g., recognizing risk factors, performing screening and diagnostic practices, frequency of CD-related resources). Thus, specific questions were formulated to ensure physician attitudes about CD as well as their experience and self-efficacy in making a CD diagnosis were captured. The questionnaire was tailored to the three clinically-focused specialties. Survey questions from published research<sup>62</sup> as well as from an online continuing education course from the CDC<sup>78</sup> were used to create the items. Questionnaire items included: physician demographics (i.e., practice type and years since

graduation); clinical manifestation; risk of transmission; and whether a Latin American immigrant population is served/ proportion served. The questionnaire will include both right/wrong items as well as self-reported level of confidence scales.

The three instruments were piloted among Texas Chagas Taskforce members, and practicing physicians (cardiologist, infectious disease specialist, and general practice provider), and non-CD experts to ensure reliability, validity of questions, and address any issues including completion time and ease of use across various platforms including smart phones. Follow-up meetings were conducted to discuss issues and revisions to questions and responses. For instance, after discussing with the physicians and other individuals who piloted the questionnaire, the response choices for various knowledge items were revised to eliminate similar or confusing answers, and thus make it easier to assess whether or not the concept was known to the physician.

#### *Sampling and recruitment*

Sampling and recruitment were achieved through contact and coordination with local, county, and statewide medical networks, societies and groups with access to physicians throughout San Antonio and the state (e.g., the Texas Medical Association, Bexar County Medical Society, Harris County Health, Metropolitan Health District, and TDSHS, the Bexar County Health Collaborative, UT Health in San Antonio, UTHealth Tyler Population Health at the UT System).

#### *Sample size*

In the past, TMA conducted two annual questionnaires that supported state and legislative advocacy efforts. A 2015 Questionnaire on meaningful use program for the Center

for Medicare and Medicaid Services (CMS) had a 4.96% (n= 543) response rate based on 10,943 eligible participants.<sup>80</sup> However, a 2016 questionnaire on electronic health record (EHR) usage and experiences with a sampling frame of 39,165 (Texas physicians with email address in the TMA database) had a lower response rate of 2.77% (n=1,084).<sup>81</sup> Initially, response rate between 2.0 and 5.0% was expected. If the response rate within this range is not achieved, other professional medical societies will be contacted (i.e., Texas Infectious Disease Society; Texas Chapter of the American College of Cardiology).

#### *Data collection and management*

Qualtrics (Research Core), an online application, was used to design, manage, and implement the questionnaire.<sup>84</sup> The questionnaires were anonymous and self-administered. Participants had a month to complete the questionnaire. The response rate was monitored weekly. The recorded responses from the Qualtrics repository were exported as a CSV file for each questionnaire. The raw dataset was managed using Microsoft Excel with each question response that was initially coded as text numerically recoded to dichotomous or categorical values. Individual data dictionaries were created for each questionnaire. Copies of the original data files were saved in order to facilitate corresponding changes. A Do file (using Stata) was created for each questionnaire to denote changes made to the original dataset.

Among the 27 sampled ID specialists, 4 did not consent to participate and 3 additional participants were not licensed by the TMB. One participant indicated that s/he was a cardiologist, so the responses were grouped in the cardiology group. A total of 34 physicians were sampled for the family/ general practice questionnaire. Nine did not consent,

three additional participants were not licensed by the TMB, and one did not complete any questionnaire items other than the specialty. Thus a total of 11 ID specialists was excluded from the analysis. There were 11 sampled cardiologists (including the response from captured in the ID questionnaire), 6 of which did not consent and only 4 were licensed by the TMB. Only three were included in the analysis.

### *Data analysis*

Descriptive statistics were calculated as frequencies and proportions using Stata (14.2).<sup>85</sup> Pearson's Chi square tests were used to compare differences in the response choice proportions (e.g., knowledge and attitude items), by physician group. Fisher's exact test was used in cells with 5 or fewer counts. A p-value less than 0.05 was considered statistically significant. A summed index score<sup>77</sup> for the correct knowledge items was created that ranged from 0 to 13. No partial credit was assigned for partially correct responses, rather a "1" was assigned for identifying the correct choice.

### ***Key Informant Interviews***

#### *Study design and sampling*

The purpose of the semi-structured interviews was to explore specific domains quantified from the questionnaires. Initially a list of physicians (n= 24) that had treated CD patients was requested by the CDC. However, the CDC did not allow access to directly contact the physicians. Instead assistance was requested from the Texas Chagas Taskforce to identify and recruit physicians to participate as key informants. Four of the physicians listed were already part of the Taskforce and agreed to participate. An additional set of physicians (n= 10) were identified by taskforce member. Only half agreed to participate and confirmed a

date and time for the call. In total, 13 physicians were identified and recruited to participate using purposive, convenience, and snowball sampling, four of which indicated that they had not previously managed any type of care for a patient with CD.

### *Interview questions*

As summarized by Padgett, the purpose of qualitative interviews is “to reveal key domains in which the experts add a top-down insider perspective that would otherwise be missed without their participation”.<sup>86</sup> Physicians were asked about their practice: the number of years in their specialty; whether they practice in a rural or urban area; type of medical practice (i.e., hospital, private, teaching). They were asked to describe their medical education and if they had training or medical experience in any country that is endemic to CD. Physicians were prompted to discuss their experience(s) in managing the care to CD patients (as defined by the continuum from screening and diagnosis, to treatment, to follow-up care) and elaborate on take-home messages, perceived barriers, and resources that helped them better understand CD. The script and guiding questions are shown in Appendix C.

### *Recruitment*

Physicians listed in the sampling frame were emailed a brief description of the study. Once a physician agreed to participate, a follow-up email was sent to confirm the telephone interview. The informed consent and a summary of the key questions were attached in the email. A study identification number (Study ID) was assigned to each participant for each corresponding group. The Study ID consisted of 4 digits. The first digit starting from the left referred to the physician specialty: 0 if unknown at the time (i.e., if HCP provided contact information at a workshop or from online questionnaire); 1 for infectious disease; or 2 for

cardiology. The next digit indicated whether the physician had treated for Chagas disease: 0 if it was not known at the time the Study ID was described; 1 if they had treated CD patients; 2 if they had not treated CD patients. Finally, the two out-right digits denoted the total sampling frame from 01 to 99.

A Study Participant List was created that linked the study ID to the names and contact information of the participants. A copy of the KI tracking table is shown in Appendix G. The purpose was to ensure confidentiality but be able to link physicians to their form and follow-up if needed. Initially, data collection was expected to conclude once saturation (i.e., “when additional analyses of the data bring redundancy and reveal no new information”<sup>86</sup>) was reached.<sup>87</sup> Given the challenges in recruiting physicians especially those with no knowledge of CD, or experience in managing the care of a CD patient the resulting domains and sampling strategies were homogenous. Thus, saturation was reached faster than anticipated. Interviews were conducted from late June through the end of August of 2018.

#### *Data collection and management*

Interviews ranged from 12 to 45 minutes in duration. All twelve were digitally recorded and securely stored. The script was used to guide the discussion. Notes were written down during the interview on the form, which were then scanned and securely stored electronically and managed via NVivo for Mac,<sup>88</sup> which is a qualitative data analysis (QDA) software used “to store data and facilitate coding and analysis.”<sup>86</sup> All of the twelve key informants (KI) audio recordings were transcribed by Adept Word Management Inc. (<https://adeptwordmanagement.com/>). The audio transcripts were emailed back as Word files

and stored in NVivo. Inaudible sections were reviewed by the PI to ensure the KI's message was accurately reflected.

### *Data analysis*

A grounded theory (GT) approach was used to guide the thematic analysis of the participant's feedback. GT is an approach that was first described by Glaser and Strauss<sup>86,89</sup> in 1967 for qualitative research with the goal of developing "new, contextualized theories"<sup>90</sup> that explain a "process, an action, or an interaction shaped by the views of a large number of participants."<sup>91</sup> A GT approach was relevant for this research given the lack of existing frameworks or models to explain the uptake of information among physicians regarding CD risk factors in the U.S. and its screening and diagnostic procedures.

GT involves "inductive coding from the data, memo writing to document analytic decisions, and weaving of theoretical ideas and concepts without permitting them to drive or constrain the study's emergent findings."<sup>86</sup> The salient feature with this approach is that the data drives the emergence of themes (i.e. inductive) rather than relying on other research to describe the phenomenon or use "prefigured codes or themes" from the existing literature.<sup>91</sup> Themes or categories are "broad units of information that consist of several codes aggregated to form a common idea."<sup>91</sup>

Using NVivo, field notes, guides/ scripts, and the audio transcriptions were reviewed. Cases were defined as the KI participants and coded accordingly. Descriptive themes were developed initially as primary nodes. The nodes were reviewed and compared to identify patterns. Axial coding was performed after the interviews were open-coded. Emerging themes were identified to describe the experiences in participating physicians that lead to



screening and diagnosing CD and thus having an increased awareness (i.e., the identification of the *core phenomenon* denoted in GT). Finally, selective coding was used to weave in the codes and propose hypotheses to describe the links between *strategies* (i.e., the actions taken in response to the core phenomenon); the *causal conditions* (i.e., the factors leading to the core phenomenon); the *contextual and intervening factors* (i.e., the broad and specific factors that influenced the strategies); and the *outcomes*.

## **Results**

### ***Knowledge, Attitudes, and Practices from Questionnaires***

#### *Participant demographics*

Initially, a total of 71 physicians were sampled: 10 for cardiology; 34 for family/general practice; and 27 infectious disease specialists. After excluding respondents who were not eligible to participate (i.e., did not consent to participate; or not licensed by the Texas Medical Board) and who did not respond to any other questionnaire items other than the consent, a total of 43 individual physician responses was analyzed: 21 (48.8%) for family/general practice; 19 (44.2%) for infectious disease; and 3 (7.0%) for cardiology. Over 37% (n= 16) were female and the median age was 51. Over 41% (n= 18) indicated that they primarily practiced medicine in a teaching hospital in contrast to 5 who practiced medicine in a private setting. More than 65% (n= 28) practiced in urban areas. Almost a third of participants (n= 14) indicated that they had 20 years of experience in their respective specialty. The demographic characteristics by physician specialty are summarized in Table 1.

### *Attitudes on Chagas disease*

**General attitudes:** Although the majority of participants indicated that they believed that CD is under diagnosed in Texas (a combined 76.7% of those that either strongly agreed or somewhat agreed, n= 33), nearly 19% (n= 8) were ambivalent. Similarly, whether CD is potentially misdiagnosed, 14% (n= 6) did not have an opinion for or against, yet the majority agreed with the statement. More participants (nearly third, n= 14) disagreed that in Texas, diagnosis and treatment of CD is relatively easy and with few barriers, while a quarter (n= 11) had no opinion about this statement. The difference between groups was statistically significant in that ID specialists were more likely to have some degree of disagreement as compared with general or family physicians. Over a third of family or general practice physicians disagreed to some extent that their training prepared them to recognize patients who many need to be screened. In contrast, two-thirds of ID specialists believed that their training allowed to recognize patients. Table 2 shows the breakdown for each attitudinal and Likert item, by physician specialty.

**Confidence in screening and diagnosing skills:** Collectively, nearly 70% were confident in identifying risk factors for CD in patients. ID specialists were more confident, compared to family/ general practice physicians and cardiologists. Nearly all of the ID specialists surveyed (94.7%, n= 18) were confident (either somewhat or very) in being able to recognize the vector compared to only 43% of family physicians that reported any confidence in doing so. Overall, 23% of participants were not confident in recognizing the vector. When asked about confidence in obtaining social history, few indicated having no confidence at all (11%, n= 5). More than half (53%, n= 23) reported having no confidence in

requesting the Current Procedural Terminology laboratory codes for diagnosing CD.

Moreover, less confidence was reported in coordinating with local and health departments or contacting the CDC in managing the care of a CD patient, 42% and 40% respectively. The complete list of agreement items is shown in Table 3.

#### *Additional screening attitudes*

**Family/ general practice:** Among the 21 physicians who completed the general/family practice questionnaire, there were differences in opinion regarding the screening and the diagnosis, in which 38% had neutral attitudes towards being able to either screen or diagnose through their family practice. Table 4 shows the responses. These items were only asked in this questionnaire.

**Infectious disease specialists and cardiologists:** Three additional items were asked in the ID specialist and cardiologist questionnaires, as shown in Table 5. This included 1 agreement and two confidence questions. There was a total of 22 respondents but up to 7 (28%) did not provide a response. When asked if they routinely screened who present with risk factors, 40% (n= 10) disagreed somewhat. However, 64% (n= 16) had confidence in their skills to continue to provide follow-up medical care to CD patients. In contrast, physicians were more likely to be less confident in using an ECG to screen and diagnose for chronic CD—28% (n= 7) with no confidence.

#### *Management of patients*

**Blood donation letter:** Physicians who completed the ID and the cardiology questionnaires were asked to rank the processes or steps in coordinating care to a potential patient with a blood donation letter (i.e., Table 6). Both groups prioritized obtaining social

history of patient. While ID specialists indicated that they would consult with the CDC last, two cardiologists indicated instead that they would coordinate with local or TDSHS last.

**Exposure to vector:** Similarly, family/ general practice physicians were asked to rank their priorities when managing the care of a patient who may have been exposed to a triatomine vector. Nearly 62% indicated that they would obtain the patient's social history first and almost 48% reported that they would follow-up with antitrypanosomal treatment last. Findings are shown in Table 7.

#### *Other specialty attitudes*

**Risk factors:** Among the ID specialists, nearly half were neutral on whether CD patients are more likely to present with comorbidities than non-CD patients (Table 8).

#### *Knowledge*

**Correct responses, common items:** the correct responses for the common knowledge questions are shown in Table 9. Appendix Table 1 details the full responses and questions. Collectively, the least correctly answered item was regarding treatment options (#12), in which 9% (all 4 of whom were ID specialists) indicated that benznidazole had been approved by the FDA in children, yet nifurtimox still required CDC investigational protocol. In contrast, nearly 70% (n= 30) were knowledgeable on the clinical manifestations of chronic cardiomyopathy (item #8). Less than 40% (n= 17) correctly answered that the seropositive results from two different immunoassays and/ or PCR performed at the CDC are the methods required for confirmatory diagnosis of CD (item # 11). Moreover, nearly 40% were unsure about the total number of reported CD cases to TDSHS (appendix results Table 1).

**Indexed scores:** the descriptive statistics for the summed scores for the common knowledge items are shown in Table 10. ID specialists scored the highest, with a mean unadjusted score of 69 compared to 37 among family/ general practice physicians.

**Screening knowledge among infectious disease specialists and cardiologists:** two additional questions on screening knowledge were asked in the ID and cardiologist questionnaires. Less than a third (n= 6) correctly identified all of the clinical disorders that may present in the development of chronic Chagas cardiomyopathy (table 11). Nearly 41% (n= 9) correctly indicated that a complete physical examination, ECG, and a detailed history are important elements of the clinical evaluation of a newly diagnosed chronic CD patient who is asymptomatic.

**Additional knowledge for infectious disease specialists:** Table 12 shows the variance in response choices, in which over a fifth (n= 4) correctly identified the typical manifestations of chronic Chagas cardiomyopathy, although more than half (n= 10) did not provide a response. A higher proportion of ID specialists selected all of the possible cardiac examination findings but more than half correctly answered the reactivation concern.

**Additional knowledge for cardiologists:** Table 13 illustrates the responses for the 3 cardiologists regarding additional screening.

### *Practices*

**Overview:** Only 7 participants indicated that they directly screened and/or confirmed a diagnosis for Chagas in patients in their medical care in Texas in the past five years, all of whom were ID specialists. Three indicated that they had managed the care of a CD patient who was referred to care from a blood donation. When asked about the frequency of

considering CD exposure risks, 23% never considered a mother or sibling with CD, 26% never considered the history of the patient's blood transfusions/ organ transplants, and 21% never considered the patient's travel history to areas where Chagas is endemic. Preferred resources for medical information included medical websites (23% always referred to websites such as Up to Date or Medline Plus) compared to TDSHS communiques or TMA emails that were never used by 21% of respondents.

**Practices, exposure risks consideration, all questionnaires:** all participants were asked to report the consideration of four CD exposure risks (Table 14). Non-response was a large proportion for each item. In general, overall frequency was rare or never, but the differences were noted when examining the ID group, in which more frequently reported considering mother or sibling with CD, history of blood transfusions, and travel to CD-endemic countries as exposure risks.

**Usage of resources:** When asked to indicate the frequency of resources referenced to review information on CD, participants overall used medical website more often than any of the other resource, including local or county health department or TDSHS websites or alerts from TMA, which are never used by 12% of physicians.

In addition to asking about the frequency of resources, physicians were asked about their likelihood in using other resources to learn more about CD (Table 16). Over a quarter (n= 11) would use courses as the means to learn more about CD; nearly 28% (n= 12) would use seminars; and 23% (n=10) would specifically use manuals. The highest proportion, 30% (n= 13), indicated that they would use other resources. Among ID specialists, 42% (n= 8)

identified other resources as: websites; live meetings or CME; online resources to streamline treatment; web-based materials; webinars; and brief communications.

**Direct screening and diagnosis practices:** A total of 7 ID's reported that they had directly screened and/ or confirmed a diagnosis for CD disease in patients in their medical care in Texas over the last 12 months. Two ID specialists reported screening and testing in 1 patient to confirm diagnosis; one indicated screening 15 to 20 patients; and one ID specialist screened 2 patients. Two consulted with local our county health departments in the past year, compared to 4 that coordinated with the CDC to confirm a CD disease diagnosis. Participants who completed the family practice and cardiology questionnaires did not directly screen or confirm a CD diagnosis in Texas in the past year; same was true for the cardiologists. From those that did screen, we asked them to report the frequency of coordinating with the CDC: almost half (3 out of 7) always did (compared to 3 that were not sure or that did not respond). Three also indicated that they always coordinated with the local/ county health departments (Q611 and 613). Comments regarding the screening and diagnosing of patients are shown in Table 17.

**Feedback regarding practices:** Table 18 shows the feedback from the ID specialists when asked to comment about their experience in confirming a CD diagnosis, obtaining and coordinating treatment for patients, and in coordinating with local and state health department officials. Half of the comments describe barriers in regards to the testing and diagnostics; two allude to barriers in treatment; and one about the challenges in coordinating care of a CD patient with local and state health department officials.

**Practices when a patient is exposed to a vector:** Only 1 physician indicated that they had at least one patient in the last five years that were exposed to the vector (Q65). Thus it is hard to present the practices reported (e.g., Q66\_1 to Q66\_13), nonetheless they indicated that they: 1) often perform physical examinations; b) rarely request laboratory diagnostics; c) always reviewed the travel history; d) often performed other screening differential diagnoses; e) often referred to ID; and f) sometimes consulted with TDHS to confirm vector and presence of parasite.

**Blood donation letter practices among family physicians:** Among those that completed the family practice/ general physician questionnaire, none indicated that they had provided care to a Chagas disease patient with a blood donation letter. Thus, there are no responses for Q64.

**Blood donation letter practices, infectious disease specialists:** the results are shown in Table 19, in which only 3 had experience managing the care of a patient with a positive CD diagnosis from a blood donation screening. All three indicated that they always reviewed the patient's travel history and requested the serology to confirm the CD diagnosis. One reported to have often evaluated the patient's cardiopulmonary function (i.e., performing a stress test), while another reported having performed this procedure as only sometimes, and 1 never has performed it. Two always performed cardiovascular testing to assess myocardial damage and one reported to sometimes perform this procedure. The ID specialists who have managed patients referred from a blood screening letter were more likely to consult with CDC than with the TDSHS to coordinate the patient's treatment.



**Blood donation letter practices, cardiology:** None of the three participants reported that they had provided care to CD patients with a blood donation letter over the past five years.

**Screening practices for patients with idiopathic cardiomyopathy:** Respondents to the ID and the cardiologist questionnaires were asked to report the frequency of screening procedures for patients presenting with idiopathic cardiomyopathy (Table 20). Non-responses accounted for a large proportion in each of the four items. Physicians were more likely to review travel history, look for signs of cardiac arrhythmias, and perform cardiovascular testing in patients with idiopathic cardiomyopathy more frequently than they were to evaluate cardiopulmonary function.

### ***Feedback from Key Informants***

A total of 12 physicians participated: 10 were conducted via telephone and 1 physician was interviewed in person. One physician emailed brief responses since they were not available to participate via telephone. With the exception of one physician, the remaining 10 physicians were eager and very enthusiastic to discuss their perspectives and share their insight. Appendix G denotes the participant's characteristics with their names redacted.

### ***Participant demographics***

Table 21 summarizes KI demographics. Most (61%, n= 8) were infectious disease specialists, 4 cardiologists, and 1 family provider. Seventy-seven percent had managed care to CD patients. There were slightly more KI participants that were male, and on average had been practicing for almost 12 years. The overall majority (84%, n= 11) practiced within an institution and were located either in San Antonio, Houston, or Dallas. Four indicated that

they had medical training or experience in Mexico, Central America, or South America. On average, physicians who had managed the care of CD patients had seen six patients in Texas.

### *Major categories*

After open and axial coding, 5 major categories emerged which included: knowledge on CD; other perspectives on CD in Texas; physician practices on CD; barriers to care/management of CD patients; and recommendations to improve awareness. Not surprising, the richest data were in the knowledge among physicians, their practices, and barriers.

### *Attitudes, awareness and knowledge*

Participants indicated that their peers had limited awareness and knowledge overall on CD, but also regarding the need to screen and diagnose their patients. There was a consensus that CD “might not be on their radar.” More specifically, their colleagues may not necessarily be aware of the risk for local CD transmission in Texas. According to a cardiologist, “we need to start thinking of this no longer just as a disease of underdeveloped countries or—endemic areas outside of the US, but really begin to think of it as a disease that’s more prevalent in the US, although rare.” The reasons for this lack of awareness or limited knowledge was attributed to lack of experience and training. Some indicated that CD was not part of their medical curriculum.

Participants reflected on their experiences that contributed to their better understanding of CD and how it translated to their scope of practice after they had managed the care of a patient. For ID specialists, for example, CD was either not part of their training or had very limited emphasis. However, all of the participants that had managed the care of a CD patient reiterated how that experience was the most helpful in considering CD diagnosis

afterwards, and in feeling more confident in performing the screening, diagnostics, or where to access the information needed to streamline the process. As summarized by an ID specialist, “the more you see it, the more comfortable you’ll be.” In addition to professional experience augmenting their knowledge and confidence in screening, diagnosing, and treating patients, participants indicated how colleagues influenced their level of awareness and knowledge.

Specific knowledge in screening, serology, clinical manifestations (i.e., what to look for), and local transmission in Texas was gained after managing a CD case. One cardiologist elaborated that:

*The biggest thing that I learned is about the serology because I think we told one of those patients that, “No, we did a confirmatory test. You actually do have Chagas.” And then we, of course, had to go back and say, “Well, it turns out our confirmatory test was the same one you had before. And they were both false-positives.” I think if there’s anything that I can say that I learned that is extremely important, it’s that about the commercial test being possibly the same thing.*

#### *Physician practices in the management of CD patients*

Several physicians cited Up to Date as a main resource to review screening and evaluation criteria for CD. Some referenced the CDC training module. An ID specialist said she reviewed the Mandell, Douglas and Bennett’s Principles and Practice of Infectious Diseases. Peer-reviewed journals including The New England Journal of Medicine, The Journal of the American College of Cardiology, and the Journal of the American Medical

Association, which had published the 2007 systematic review on the evaluation and treatment of Chagas disease in the United States<sup>15</sup> were additional resources. Several recognized the value of accessing CDC staff experts to confirm diagnosis and coordinate treatment. For one of the interviewed cardiologists, having the CDC as a resource “available to me was critical to my being able to manage the patient.”

Through their anecdotal experiences, physicians became more aware and knowledgeable, and thus more inclined to consider a CD diagnosis in their patients. An ID specialist detailed the following:

*So what we have done is if they have a positive screen test then we bring them over, we do history and physical, we focus on how many lived outside of the country, have lived in the more classic endemic areas, had mothers that were born in those areas, had history of having received a blood donation, lived in substandard housing, or had exposure to hunting and camping and fishing and outdoor kinds of activities; whether they have dogs on their property, whether they have seen reduviid bugs or whatever. So we kind of get into all that history, and we do a basic physical exam and do an EKG with a thirty-second rhythm strip just so we have it already, and then we—in the same visit, we just go ahead and draw CDC-confirmatory testing and send that off. So when we started this, that was like a later thing, and we would get RIPA first, and if the RIPA was negative, then we were done.*

## *Barriers*

At the systems-level, limited access to medical care and health insurance gaps in covering the patient's screening and diagnostics were some of the key barriers identified by participating physicians. Additionally, several indicated the lack of available physician resources including screening guidelines and protocols to improve screenings in populations at highest risk of CD. There were frequent remarks on the administrative challenges in accessing the antitrypanosomal drugs to prescribe to their patients. There were concerns on the specificity and sensitivity of screening and diagnostics. The limited epidemiological evidence was another barrier. Finally, few indicated that their exposure and training on CD during their Examples of the physicians' feedback on barriers are shown in Table 22.

Regarding barriers at the physician level, themes emerged regarding the lack of awareness about CD in general or about the risk for local transmission in Texas. Participants commented on how physicians in Texas have limited knowledge on CD, which in turn translates to a lack of confidence and expertise in screening and diagnosing patients. Finally, given the patient demographics, physicians were asked about their proficiency in speaking Spanish. The majority acknowledged that they could "get by" but in most cases would need to request a translator to interpret to discuss the details of the screening procedures or the treatment.

Finally, though not prompted, several participants provided patient-specific socio-cultural barriers such as refusal of medical treatment due to lacking "respect for this disorder". This theme was expanded to a separate category reflecting physicians' perspectives in which their patients did not fully understand CD. That is, their patients did

not understand that the asymptomatic phase may progress to life-threatening complications if left untreated. The adverse physiological complications and interactions with the treatment were cited as a patient barrier.

#### *Participant recommendations*

Increasing education among physicians was the most detailed and frequently discussed recommendation. Strategies to achieve that include revising the undergraduate medical education curriculum so that students gain more depth and understand that CD is not relegated to a tropical infectious disease that is of concern for specific patient populations in Texas. Another approach to increasing education in providers about CD is to engage the public, leadership within the health system, and policymakers. Concerned patients, as described by the participants, can be the vehicle of change to prompt unaware physicians to refer to the literature and other CD resources and become more knowledgeable. In contrast, another physician recommended that leadership within hospital, for example, can disseminate FAQ's and other memos that highlight the importance of considering CD in certain populations or remind physicians about the possibility of local transmission.

A few physicians proposed a peer-to-peer model in which CD experts within their respective field can “take the mantle for this cause” and help raise the awareness. In turn, specific outreach efforts include peer-review journals that are specific to those medical specialties that are more likely to be reviewed by those physicians. The proposed recommendations also highlighted not just the importance of educating providers, but having materials, resources, and the research that is up to date and accessible to physicians. Many indicated the need for epidemiological surveillance and research within the human

population to gain a better understanding of risks and prevalence. Findings from these research activities can be presented at focused conferences that will pique the interest of attendees and thus leave an impression. Participation can be incentivized with continued medical education credit.

In addition to presenting research at conferences, another approach that was discussed was story telling:

*The other way to get uptake and change people's behavior is by story-telling which is not evidence-based, so we tend not to gravitate to it. But if we have a couple of big-name cases, like if there were somebody willing to put this on television.*

Two physicians indicated the value in social media and web-based approaches to education. Similar to conferences, physicians in rural or isolated communities would benefit from webinars. Another physician proposed raising awareness about CD via Facebook ads, that can be targeted for very specific populations. Thus, these recommendations reflect the need to address the barriers discussed in the previous section.

### **Discussion**

There were differences in the level of CD knowledge by physician specialty and by domains. As hypothesized, ID specialists had a greater grasp on the nuances of CD and were more confident than family providers. The low response rate for the cardiologist questionnaire did not allow for meaningful comparisons across all three physician groups. However, the qualitative data from the cardiologists interviewed suggests that their peers are generally unaware of CD and have limited knowledge on screening and diagnostic

procedures (i.e., “I don't know that Chagas disease has registered in the minds of my heart failure colleagues, perhaps, the level that it should”).

In general, most questionnaire participants believed that CD is currently under diagnosed in Texas, but no consensus was reached regarding the ease of diagnosing and treating patients. ID specialists perceived this as a barrier, which was statistically significant, as compared to the family/ general practice physicians. Frequent references to the complexities in diagnosing patients from the KI feedback support this finding. Thus physicians perceive there are challenges and barriers to being able to screen and diagnose CD patients.

ID specialists were statistically more likely to report a higher confidence in their training, which was further explored in the interviews, that despite the “peripheral” training they received they had the “tools” given how “not uncommon for us to encounter a disease for the very first time”. No surprising, ID specialists were thus confident in their skills including in recognizing the risk factors and vectors, which was supported by the statistically significant differences. Their knowledge scores support the increased level of knowledge among ID specialists (i.e., a mean of 69.2% compared to 37.0% among family practice physicians). Findings from Stimpert and Montgomery (2010) corroborate the ID specialists’ increased knowledge.<sup>62</sup>

The utilization of physician resources on CD was further described by the qualitative data and is congruent with findings from the questionnaires. In general physicians do not reference materials disseminated by state or county health departments, but instead prefer websites such as Up to Date, CDC resources, and peer-reviewed articles. Moreover, there



seems to be some reluctance in coordinating with local and state level officials, perhaps as a result of the experiences. As one physician there was “an abundance of paperwork” that might a barrier. Another physician indicated that the health departments should provide “assistance in diagnosis and in obtaining drugs for treatment.” The qualitative data did not provide additional insight into this because the key informants, even though the majority had experience managing the care of patients, did not provide any feedback about working with local and county health departments.

These findings, particularly the feedback from the KI, complement the work by Forsyth (2017)<sup>56</sup> and Manne-Goehler et al (2015)<sup>115</sup> in contextualizing the barriers to screening, diagnosing, treatment of CD. Although the focus was on barriers in Latin American communities and the U.S. respectively, parallels can be drawn that explain the possibility for missed CD diagnosis in Texas. Accessing treatment was identified as barrier among the KI, but was considered a significant barrier by some of the questionnaire participants. However, the questions regarding the current treatment drugs and recommendations were the most incorrectly answered knowledge items, suggesting the need to educate physicians on these and thus a patient receiving treatment remains a barrier. Moreover, KI discussed socio-cultural patient barriers that are also highlighted as salient barriers that prevent the patient from engaging in the health system, including the failure in recognizing CD as a potentially life-threatening condition, or distrust in the system. Even if the patient has access to a physician, and the physician recognizes the clinical manifestations or the risk factors, and is thus willing and inclined to screen and diagnose, the patient may eventually refuse treatment.

### ***Strengths and limitations***

This is the first exploratory mixed methods study that examined differences in knowledge, attitudes, and practices among physician groups. While other research has collected KAP on CD among physicians, no studies to date have focused on examining physicians in Texas. Through the grounded theory approach and qualitative research design, further insights were discovered among this hard to reach population. However, sampling and recruiting physicians represented the biggest challenge for this study. Due to the lack of a sampling frame, the research employed snowball sampling. As such, coverage and response bias were of concern. Physician networks were consulted to recruit our participants. Thus our samples were in more likelihood, already physicians with some knowledge or interest in CD.

### ***Recommendations***

Future research is needed to address and describe and explore the reasons for CD remaining under-recognized by physicians and perceptions regarding whether or not CD is a problem in Texas. Recommendations from physicians encompass top-down and ground level strategies to improve the awareness and education, that engage both the provider, patients, and other key stakeholders (i.e., policymakers). One interesting specific recommendation was that key CD experts in their respective specialties serve as “ambassadors” to raise awareness and educate other physicians.

### ***Implications***

Follow-through on the recommendations outlined by KI will likely improve the awareness and knowledge among Texas physicians. This study provides a rudimentary baseline on which to continue to expand further research and documents the anecdotal

experiences on physicians. Additional hypotheses-driven research framed with probability sampling can better quantify differences in KAP, particularly among cardiologists and physicians with limited experience managing the care of CD patients, and among physicians practicing in rural counties.

### ***Conclusion***

Results from the questionnaires and feedback from key informants illustrate the opportunity to continue to increase the level of knowledge regarding CD in Texas. Specifically, there are knowledge gaps in understanding the screening and diagnostic processes as well as the treatment. Physician input is also invaluable in guiding how to best disseminate the latest clinical knowledge to physicians to ensure uptake and maintenance (i.e., consideration of certain CD risk exposures in their patient population).

## Tables and Figures

Results Table 1: Participant Demographics, by Completion of Specialty Questionnaire

Demographic Characteristic	Total n= 43 (%)	Family or General Practice n= 21 (%)	Infectious Disease n= 19 (%)	Cardiology n= 3 (%)
<b>Primary physician Specialty</b>				
Infectious Disease	18 (41.9)	0	18 (94.7)	0
General / Family Practice	17 (39.5)	17 (81.0)	0	0
Cardiology	3 (7.0)	0	0	3 (100.0)
<b>Secondary physician specialty</b>				
Pediatrics	3 (7.0)	3 (14.1)	0	0
Immunology	2 (4.7)	1 (4.8)	1 (5.3)	0
<b>Age,</b> Mean (S.D.)	51.1 (16.59)	48.5 (13.30)	50.2 (16.54)	52.5 (9.19)
<b>Sex</b>				
Female	16 (37.2)	10 (47.6)	5 (26.3)	1 (33.3)
Male	15 (34.9)	6 (28.6)	7 (36.8)	2 (66.7)
No response	12 (27.9)	5 (23.8)	7 (36.8)	0
<b>Medical setting</b>				
Teaching	18 (41.9)	9 (42.3)	7 (36.8)	2 (66.7)
Community	6 (14.0)	5 (23.8)	1 (5.3)	0
Private	5 (11.6)	2 (9.5)	3 (15.8)	0
No response	14 (32.6)	5 (23.8)	8 (42.1)	1 (33.3)
<b>Geographical setting</b>				
Urban	28 (65.1)	14 (66.7)	12 (63.2)	2 (66.7)
Rural	2 (4.7)	2 (9.5)	0	0
No response	13 (30.2)	5 (23.8)	7 (36.9)	1 (33.3)
<b>Years in practice</b>				
< 5	7 (16.3)	4 (19.1)	3 (15.8)	0
5 to 10	3 (7.0)	0	2 (10.5)	1 (33.3)
10 to 15	3 (7.0)	2 (9.5)	1 (5.3)	0
15 to 20	2 (4.7)	1 (4.8)	1 (5.3)	0
> 20	14 (32.6)	8 (38.1)	5 (26.3)	1 (33.3)
No response	14 (32.6)	6 (28.6)	7 (36.8)	1 (33.3)

<b>Demographic Characteristic</b>	<b>Total n= 43 (%)</b>	<b>Family or General Practice n= 21 (%)</b>	<b>Infectious Disease n= 19 (%)</b>	<b>Cardiology n= 3 (%)</b>
<b>Hispanic population served, Mean (S.D.)</b>	51.0 (27.19)	45.5 (27.31)	55.9 (28.9)	63.0 (4.24)
<b>Medical training</b>				
Mexico	1 (2.3)	1 (4.8)	0	0
South America	2 (4.7)	0	2 (10.5)	0
Have directly screened or confirmed a diagnosis for CD	7 (16.3)	0	7 (36.8)	0
Received patients via blood donation letters	3 (7.0)	0	3 (15.8)	0

Results Table 2: Responses to Agreement Items, All Questionnaires

Questionnaire Item	Total n= 43 (%)	Family or General Practice n= 21 (%)	Infectious Disease n= 19 (%)	Cardiology n= 3 (%)	p-value*
<b>CD is under diagnosed in Texas</b>					0.501
Strongly agree	17 (39.5)	7 (33.3)	9 (47.4)	1 (33.3)	
Somewhat agree	16 (37.2)	7 (33.3)	8 (42.1)	1 (33.3)	
Neither	8 (18.6)	6 (28.6)	1 (5.3)	1 (33.3)	
Somewhat disagree	2 (4.7)	1 (4.8)	1 (5.3)	0	
Strongly disagree	0	0	0	0	
No response	0	0	0	0	
<b>CD is potentially misdiagnosed</b>					0.494
Strongly agree	16 (37.2)	7 (33.3)	8 (42.1)	1 (33.3)	
Somewhat agree	19 (44.1)	9 (42.9)	8 (42.1)	2 (66.7)	
Neither	6 (14.0)	5 (23.8)	1 (5.3)	0	
Somewhat disagree	2 (4.7)	0	2 (10.5)	0	
Strongly disagree	0	0	0	0	
No response	0	0	0	0	
<b>Process required to confirm is complex and time consuming</b>					0.237
Strongly agree	6 (14.0)	2 (9.5)	4 (21.1)	0	
Somewhat agree	22 (51.2)	10 (47.6)	11 (57.9)	1 (33.3)	
Neither	9 (20.9)	7 (33.3)	1 (5.3)	1 (33.3)	
Somewhat disagree	5 (11.6)	2 (9.5)	2 (10.5)	1 (33.3)	
Strongly disagree	1 (2.3)	0	1 (5.3)	0	
No response	0	0	0	0	
<b>Few barriers in order to diagnose or treat</b>					<0.05
Strongly agree	1 (2.3)	1 (4.8)	0	0	

Questionnaire Item	Total n= 43 (%)	Family or General Practice n= 21 (%)	Infectious Disease n= 19 (%)	Cardiology n= 3 (%)	p-value*
Somewhat agree	7 (16.3)	4 (19.1)	2 (10.5)	1 (33.3)	
Neither	11 (25.6)	9 (42.9)	1 (5.3)	1 (33.3)	
Somewhat disagree	17 (39.5)	5 (23.8)	11 (57.9)	1 (33.3)	
Strongly disagree	7 (16.3)	2 (9.5)	5 (26.3)	0	
No response	0	0	0	0	
<b>Accessing treatment is not a barrier for their patient population</b>					0.772
Strongly agree	4 (9.3)	1 (4.8)	2 (10.5)	1 (33.3)	
Somewhat agree	12 (27.9)	6 (28.6)	5 (26.3)	1 (33.3)	
Neither	10 (23.3)	6 (28.6)	3 (15.8)	1 (33.3)	
Somewhat disagree	13 (30.2)	7 (33.3)	6 (31.6)	0	
Strongly disagree	3 (7.0)	1 (4.8)	2 (10.5)	0	
No response	1 (2.3)	0	1 (5.3)	0	
<b>Training prepared physician to recognize patients who may need to be screened</b>					<0.005
Strongly agree	6 (14.0)	0	6 (31.6)	0	
Somewhat agree	14 (32.6)	4 (19.1)	8 (42.1)	2 (66.7)	
Neither	4 (9.3)	3 (14.3)	1 (5.3)	0	
Somewhat disagree	13 (30.2)	12 (57.1)	1 (5.3)	0	
Strongly disagree	4 (9.3)	2 (9.5)	1 (5.3)	1 (33.3)	
No response	2 (4.7)	0	2 (10.5)	0	

Results Table 3: Responses to Confidence Items, All Questionnaires

Questionnaire Item	Total n= 43 (%)	Family or General Practice n= 21 (%)	Infectious Disease n= 19 (%)	Cardiology n= 3 (%)	p-value*
<b>Confidence in identifying risk factors</b>					<0.005
Very confident	11 (25.6)	3 (14.3)	7 (36.8)	1 (33.3)	
Somewhat confident	19 (44.2)	8 (38.1)	11 (57.9)	0	
Not at all confident	10 (23.3)	8 (38.1)	0	2 (66.7)	
No response	3 (7.0)	2 (9.5)	1 (5.3)	0	
<b>Confidence in recognizing the vector</b>					<0.005
Very confident	16 (37.2)	3 (14.3)	11 (57.9)	2 (66.7)	
Somewhat confident	14 (32.6)	6 (28.6)	7 (36.8)	1 (33.3)	
Not at all confident	10 (23.3)	10 (47.6)	0	0	
No response	3 (7.0)	2 (9.5)	1 (5.3)	0	
<b>Confidence in obtaining social history</b>					0.098
Very confident	17 (39.5)	5 (23.8)	11 (57.9)	1 (33.3)	
Somewhat confident	19 (44.2)	10 (47.6)	7 (36.8)	2 (66.7)	
Not at all confident	5 (11.6)	5 (23.8)	0	0	
No response	2 (4.7)	1 (4.8)	1 (5.3)	0	
<b>Confidence in requesting the Current Procedural Terminology laboratory codes for diagnosing CD</b>					0.309
Very confident	2 (4.7)	1 (4.8)	3 (15.6)	0	
Somewhat confident	13 (30.2)	5 (23.8)	7 (36.8)	0	
Not at all confident	23 (53.5)	14 (66.7)	7 (36.8)	2 (66.7)	
No response	4 (9.3)	1 (4.8)	2 (10.5)	1 (33.3)	



Questionnaire Item	Total n= 43 (%)	Family or General Practice n= 21 (%)	Infectious Disease n= 19 (%)	Cardiology n= 3 (%)	p-value*
<b>Confidence in coordinating and following-up with the CDC when consulting about a CD patient</b>					0.081
Very confident	8 (18.6)	2 (9.5)	6 (31.6)	0	
Somewhat confident	13 (30.2)	6 (28.6)	7 (36.8)	0	
Not at all confident	18 (41.9)	12 (57.1)	4 (21.1)	2 (66.7)	
No response	4 (9.3)	1 (4.8)	2 (10.5)	1 (33.3)	
<b>Confidence in contacting and coordinating with the local and/or state health department when consulting about a CD patient</b>					<0.05
Very confident	8 (18.6)	2 (9.5)	6 (31.6)	0	
Somewhat confident	14 (32.6)	6 (28.6)	8 (42.1)	0	
Not at all confident	17 (39.5)	12 (57.1)	3 (15.8)	2 (66.7)	
No response	4 (9.3)	1 (4.8)	2 (10.5)	1 (33.3)	

Results Table 4: Attitudes of Family or General Practice Physicians Questionnaire

Questionnaire Item	n= 21 (%)
<b>Screening for CD is possible through my general or family practice</b>	
Strongly agree	2 (9.5)
Somewhat agree	7 (33.3)
Neither	8 (38.1)
Somewhat disagree	4 (19.1)
Strongly disagree	0
No response	0
<b>Diagnosis of CD is possible through my general or family practice</b>	
Strongly agree	2 (9.5)
Somewhat agree	7 (33.3)
Neither	8 (38.1)
Somewhat disagree	4 (19.1)
Strongly disagree	0
No response	0

Results Table 5: Attitudes of Infectious Disease Specialists and Cardiologists

Questionnaire Item	Total n= 22 (%)	Infectious Disease n= 19 (%)	Cardiology n= 3 (%)	p-value*
<b>Routinely screen for CD in patients who present with risk factors</b>				0.523
Strongly agree	3 (12.0)	3 (15.8)	0	
Somewhat agree	6 (24.0)	5 (26.3)	1 (33.3)	
Neither	1 (4.0)	1 (5.3)	0	
Somewhat disagree	10 (40.0)	9 (47.4)	1 (33.3)	
Strongly disagree	0	0	0	
No response	5 (20.0)	1 (5.3)	1 (33.3)	
<b>Confidence in continuing to provide follow-up medical care to CD patients</b>				<0.05
Very confident	6 (24.0)	6 (31.6)	0	
Somewhat confident	10 (40.0)	10 (52.6)	0	
Not at all confident	2 (8.0)	1 (5.3)	2 (66.7)	
No response	7 (28.0)	2 (10.5)	1 (33.3)	
<b>Confidence in using electrocardiogram (ECG) to screen and diagnose for chronic CD</b>				0.263
Very confident	3 (12.0)	2 (10.5)	1 (33.3)	
Somewhat confident	10 (40.0)	10 (52.6)	0	
Not at all confident	7 (28.0)	6 (31.6)	2 (66.7)	
No response	5 (20.0)	1 (5.3)	0	

Results Table 6: Priorities\* for Managing Care in Blood Donation Letter Patient

<b>Statement</b>	<b>Infectious Disease n=19 (%)</b>	<b>Cardiology n= 3 (%)</b>
Coordinate with local or DSHS	4 <sup>th</sup> (42.1)	5 <sup>th</sup> (66.7)
Consult with CDC	5 <sup>th</sup> (57.9)	4 <sup>th</sup> (66.7)
Perform physical evaluation and additional testing	2 <sup>nd</sup> (42.1)	2 <sup>nd</sup> (66.7)
Confirm diagnosis via commercial serology	3 <sup>rd</sup> (31.6)	3 <sup>rd</sup> (66.7)
Obtain history	1 <sup>st</sup> (52.6)	1 <sup>st</sup> (66.7)

\*Only the largest proportion out of the total sample for each statement is shown, from most important (#1) to least (#5)

Results Table 7: Priorities\* for Managing Care for a CD Patient Potentially Exposed to a Vector

<b>Statement</b>	<b>Family n= 21 (%)</b>
Obtain history	1 <sup>st</sup> (61.9)
Consult with Texas DSHS for guidance on screening and diagnosis protocol	2 <sup>nd</sup> (57.7)
Request serology testing from a commercial laboratory	3 <sup>rd</sup> (33.3)
Perform other differential diagnosis and refer patient to infectious disease specialist if necessary	4 <sup>th</sup> (33.3)
Initiate anitrypanosomal treatment	5 <sup>th</sup> (47.6)

\*Only the largest proportion out of the total sample for each statement is shown, from most important (#1) to least (#5)

Results Table 8: Attitudes among Infectious Disease Specialists

<b>Questionnaire Item</b>	<b>Infectious Disease n= 19 (%)</b>
<b>CD patients are more likely to present with comorbidities than non-CD disease patients</b>	
Strongly agree	0
Somewhat agree	4 (21.1)
Neither	9 (47.4)
Somewhat disagree	5 (26.3)
Strongly disagree	0
No response	1 (5.3)

Results Table 9: Summary of Correct Knowledge Items, All Questionnaires

Questionnaire Item	Total n= 43 (%)	Family or General Practice n= 21 (%)	Infectious Disease n= 19 (%)	Cardiology n= 3 (%)	p-value
<b>#1. Vector transmission</b>					<0.005
Feces	23 (53.5)	6 (28.6)	15 (79.0)	2 (66.7)	
<i>Incorrect or non-responses</i>	20 (46.5)	15 (71.2)	4 (21.1)	1 (33.3)	
<b>#2. Common route of transmission in the US</b>					0.083
Vector exposure while residing in Mexico, Central or South America	29 (67.4)	11 (52.4)	16 (84.2)	2 (66.7)	
<i>Incorrect or non-responses</i>	14 (32.6)	10 (47.6)	3 (15.8)	1 (33.3)	
<b>#3. Total number of reported CD cases to DSHS</b>					1.00
Between 75 and 100	7 (16.3)	4 (19.1)	3 (15.8)	0	
<i>Incorrect or non-responses</i>	36 (83.7)	17 (81.0)	16 (84.2)	3 (100.0)	
<b>#4. Clinical course for CD</b>					<0.005
Acute for 1-8 weeks after exposure, asymptomatic for decades in most; symptomatic in a few	21 (48.8)	7 (33.3)	14 (73.7)	0	
<i>Incorrect or non-responses</i>	22 (51.2)	14 (66.7)	5 (26.3)	3 (100.0)	
<b>#5. Characteristic symptoms for acute phase of CD</b>					0.729
All of the above	23 (53.5)	10 (47.6)	11 (57.9)	2 (66.7)	
<i>Incorrect or non-responses</i>	20 (46.5)	11 (52.4)	8 (42.1)	1 (33.3)	
<b>#6. Proportion of patients with chronic CD that develop symptoms</b>					<0.05
Between 20 and 40%	14 (32.6)	3 (14.3)	11 (57.9)	0	
<i>Incorrect or non-responses</i>	29 (67.4)	18 (85.7)	8 (42.1)	3 (100.0)	
<b>#7. Symptoms that may develop in patients with chronic CD disease</b>					0.331
All of the above	28 (65.1)	13 (61.9)	14 (73.7)	1 (33.3)	
<i>Incorrect or non-responses</i>	15 (34.9)	8 (38.1)	5 (26.3)	2 (66.7)	
<b>#8. Chronic CD cardiomyopathy possible manifestations</b>					0.101
Any of the above	30 (69.8)	13 (61.9)	16 (84.2)	1 (33.3)	

Questionnaire Item	Total n= 43 (%)	Family or General Practice n= 21 (%)	Infectious Disease n= 19 (%)	Cardiology n= 3 (%)	p-value
<i>Incorrect or non-responses</i>	13 (30.2)	8 (38.1)	3 (15.8)	2 (66.7)	
<b>#9. Screening and diagnosis steps</b>					0.708
All of the above	26 (60.5)	13 (61.9)	12 (63.2)	1 (33.3)	
<i>Incorrect or non-responses</i>	17 (39.5)	8 (38.1)	7 (36.8)	2 (66.7)	
<b>#10. Social history needed to assess potential route of exposures</b>					0.628
All of the above	27 (62.8)	13 (61.9)	13 (68.4)	1 (33.3)	
<i>Incorrect or non-responses</i>	16 (37.2)	8 (38.1)	6 (31.6)	2 (66.7)	
<b>#11. Method for confirming CD diagnosis</b>					0.090
Seropositive results from 2 different immunoassays and/ or PCR performed at the CDC	17 (39.5)	5 (23.8)	11 (57.9)	1 (33.3)	
<i>Incorrect or non-responses</i>	26 (60.4)	16 (76.2)	8 (42.1)	2 (66.7)	
<b>#12. Treatment drugs</b>					0.074
Second and third choices only	4 (9.3)	0	4 (21.1)	0	
<i>Incorrect or non-responses</i>	39 (90.7)	21 (100.0)	15 (78.9)	3 (100.0)	
<b>#13. Treatment patient recommendations</b>					0.110
Always recommended for patients up to age 18 and generally recommended for patients aged 18 to 50	12 (27.9)	3 (14.3)	8 (42.1)	1 (33.3)	
<i>Incorrect or non-responses</i>	31 (72.1)	18 (85.7)	11 (57.9)	2 (66.7)	

Results Table 10: Summary of Correct Knowledge Items and Scores, All Questionnaires

Questionnaire Item	Total n= 43 (%)	Family or General Practice n= 21 (%)	Infectious Disease n= 19 (%)	Cardiology n= 3 (%)
<b>Total* Raw Score**</b>				
Mean	7.9	4.8	9.0	4.0
Median	8.0	6.0	10.0	4.0
S.D.	3.06	4.09	3.22	0
<b>Total Percentile Score</b>				
Mean	60.6	37.0	69.2	30.8
Median	61.5	46.2	76.9	30.8
S.D.	23.59	31.49	24.8	0
<b>Adjusted Raw Score</b>				
Mean	n= 34 7.0	n= 15 6.7	n= 17 8.7	n= 2 4.0
Median	6.5	7.0	9.0	4.0
S.D.	3.62	3.17	3.08	0
<b>Adjusted Percentile Score</b>				
Mean	n= 34 53.6	n= 15 51.8	n= 17 67.0	n= 2 30.8
Median	50.0	53.8	69.2	30.8
S.D.	27.8	24.4	23.67	0

\*For all questionnaire participants including those with non-responses

\*\* Score range: 1013 (i.e., lowest to highest correct number of responses). Observations with a total score of 0 were excluded. S.D.: Standard Deviation. Refer to Appendix for the question and the full response options.

Results Table 11: Knowledge on Screening for Cardiologists and Infectious Disease Specialists

Questionnaire Item	Total n= 22 (%)	Infectious Disease n= 19 (%)	Cardiology n= 3 (%)
<b>In addition to heart failure, major clinical disorders that manifest frequently and concurrently to chronic Chagas cardiomyopathy</b>			
Cardiac arrhythmias	11 (50.0)	10 (52.6)	1 (33.3)
Thromboembolism (systemic and pulmonary)	0	0	0
Chest pain syndrome	0	0	0
**All of the above	6 (27.3)	5 (26.3)	1 (33.3)
Not sure	1 (4.5)	1 (5.3)	0
No response	4 (18.2)	3 (15.8)	1 (33.3)
<b>What are the important elements of the clinical evaluation of a newly diagnosed chronic CD patient who is asymptomatic?</b>			
Complete physical examination, complete blood count, and chemistry panel	0	0	0
◆ Complete physical examination, electrocardiogram (ECG) with 30 second rhythm strip, and a detailed history	9 (40.9)	8 (42.1)	1 (33.3)
Complete physical examination, ECG with 30 second rhythm strip, chest radiograph, barium swallow, and detailed history	4 (18.2)	4 (21.1)	0
None of the above	0	0	0
Not sure	1 (4.5)	0	1 (33.3)
No response	8 (36.4)	7 (36.8)	1 (33.3)



Results Table 12: Specific Knowledge and Indexed Scores for Infectious Disease Specialists

Questionnaire Item	n = 19 (%)
<b>In general, which of the following is typical of chronic CD cardiomyopathy?</b>	
Right bundle branch block	5 (26.3)
Ventricular tachycardia	1 (5.3)
Left anterior fascicular block	1 (5.3)
◆ All of the above	4 (21.1)
Not sure	0
No response	10 (52.6)
<b>In patients with chronic CD cardiomyopathy, cardiac examination typically demonstrates which of the following?</b>	
Murmurs of mitral and / or tricuspid regurgitation	0
Wide splitting of the second heart sound due to right bundle branch block	3 (15.8)
A prominent diffuse apical thrust	0
◆ All of the above	5 (26.3)
Not sure	4 (21.1)
No response	10 (52.6)
<b>Reactivation of CD is a concern for patients who:</b>	
Are chronically infected and are receiving immune-suppressive treatment because of organ transplantation	0
Are chronically infected and have HIV/AIDS	2 (10.5)
Are chronically infected and receive a live0attenuated influenza vaccine	0
◆ First and second responses only	10 (52.6)
Not sure	0
No response	10 (52.6)

Results Table 13: Specific Knowledge for Cardiologists

Questionnaire Item*	n= 3 (%)
<b>Which of the following are typical of Chagas cardiomyopathy as evaluated using electrocardiograph?</b>	
◆ Right bundle branch block often associated with left anterior hemiblock, ST-T changes, abnormal Q waves, various degrees of AV block, sick sinus syndrome, and low QRS voltage	1 (33.3)
Mainly conduction abnormalities including first-degree AV block, left bundle branch block, and non-specific interventricular conduction delays	0
Right bundle branch block only	0
None of the above	0
Not sure	1 (33.3)
No response	1 (33.3)
<b>In patients with chronic CD cardiomyopathy, cardiac examination typically demonstrates which of the following?</b>	
Murmurs of mitral and / or tricuspid regurgitation	0
Wide splitting of the second heart sound due to right bundle branch block	1 (33.3)
A prominent diffuse apical thrust	0
◆ All of the above	0
Not sure	1 (33.3)
No response	1 (33.3)

Results Table 14: Consideration of Risk Factors, Frequency by Physician Specialty

<b>Questionnaire Item: Exposure Risk</b>	<b>Total n= 43 (%)</b>	<b>Family or General Practice n = 21 (%)</b>	<b>Infectious Disease n = 22 (%)</b>	<b>Cardiology n= 3 (%)</b>
<b>Mother or sibling with CD</b>				
Always	3 (7.0)	1 (4.8)	3 (15.8)	0
Often	2 (4.7)	0	2 (10.5)	0
Sometimes	3 (7.0)	0	3 (15.8)	0
Rarely	8 (18.6)	5 (23.8)	3 (15.8)	0
Never	10 (23.2)	7 (33.3)	1 (5.3)	2 (66.7)
No response	16 (37.2)	8 (38.1)	7 (36.8)	1 (33.3)
<b>History of blood transfusions</b>				
Always	3 (7.0)	0	3 (15.8)	
Often	1 (2.3)	0	1 (5.3)	0
Sometimes	6 (14.0)	1 (4.8)	5 (26.3)	0
Rarely	7 (16.6)	5 (23.8)	2 (10.5)	0
Never	11 (25.6)	8 (38.1)	1 (5.3)	2 (66.7)
No response	15 (34.9)	7 (33.3)	7 (36.8)	1 (33.3)
<b>Travel to Mexico, Central, or South America</b>				
Always	5 (11.7)	1 (4.8)	4 (21.1)	0
Often	2 (4.7)	0	2 (10.5)	0
Sometimes	7 (16.3)	1 (4.8)	5 (26.3)	1 (33.3)
Rarely	5 (11.6)	4 (19.1)	1 (5.3)	0
Never	9 (20.9)	8 (38.1)	0	1 (33.3)
No response	15 (34.9)	7 (33.3)	7 (36.8)	1 (33.3)
<b>Consumption of food or drinks contaminated with the parasite</b>				
Always	1 (2.3)	1 (4.8)	0	0
Often	1 (2.3)	0	1 (5.3)	0
Sometimes	4 (9.3)	1 (4.8)	2 (10.5)	1 (33.3)
Rarely	5 (11.6)	4 (19.1)	1 (5.3)	0
Never	17 (39.5)	8 (38.1)	8 (42.1)	1 (33.3)

<b>Questionnaire Item: Exposure Risk</b>	<b>Total n= 43 (%)</b>	<b>Family or General Practice n = 21 (%)</b>	<b>Infectious Disease n = 22 (%)</b>	<b>Cardiology n= 3 (%)</b>
No response	15 (34.8)	7 (33.3)	7 (36.8)	1 (33.3)

Results Table 15: Resources Physicians Reference when Managing Care of a Patient with CD

Usage of Resources	Total n= 43 (%)	Family/ General Practice n= 21 (%)	Infectious Disease n=19 (%)	Cardiology n= 3 (%)
<b>Medical websites (e.g., Up to Date, Medline Plus)</b>				
Always	10 (23.3)	7 (33.3)	2 (10.5)	1 (33.3)
Often	9 (20.9)	4 (19.1)	5 (26.3)	0
Sometimes	5 (11.6)	1 (4.8)	4 (21.1)	0
Rarely	0	0	0	0
Never	2 (4.7)	2 (9.5)	0	0
No response	17 (39.5)	7 (33.3)	8 (42.1)	2 (66.7)
<b>Official local or county health department websites</b>				
Always	1 (2.3)	1 (4.8)	0	0
Often	3 (7.0)	2 (9.5)	2 (10.5)	0
Sometimes	13 (30.2)	6 (28.6)	6 (31.6)	1 (33.3)
Rarely	3 (7.0)	1 (4.8)	2 (10.5)	0
Never	5 (11.6)	4 (19.1)	1 (5.3)	0
No response	17 (39.5)	7 (33.3)	8 (42.1)	2 (66.7)
<b>TDSHS website</b>				
Always	1 (2.3)	1 (4.8)	0	0
Often	1 (2.3)	5 (23.8)	1 (5.3)	0
Sometimes	8 (18.6)	3 (14.3)	5 (26.3)	0
Rarely	6 (14.0)	2 (9.5)	3 (15.8)	1 (33.3)
Never	5 (11.6)	3 (14.3)	2 (10.5)	0
No response	17 (39.5)	7 (33.3)	8 (42.1)	2 (66.7)
<b>The CDC website</b>				
Always	8 (18.6)	4 (19.1)	3 (15.8)	1 (33.3)
Often	9 (20.9)	4 (19.1)	5 (26.3)	0
Sometimes	5 (11.6)	2 (19.1)	3 (15.8)	0
Rarely	0	0	0	0
Never	2 (4.6)	2 (9.5)	0	0
No response	17 (39.5)	7 (33.3)	8 (42.1)	2 (66.7)
<b>Official communiques and health alerts from TDSHS</b>				
Always	2 (4.7)	1 (4.8)	1 (5.3)	0
Often	1 (2.3)	0	1 (5.3)	0
Sometimes	11 (25.6)	5 (23.8)	6 (31.6)	0
Rarely	5 (11.6)	2 (9.5)	2 (10.5)	1 (33.3)
Never	9 (20.9)	6 (28.6)	1 (5.3)	2 (66.7)
No response	15 (34.9)	7 (33.3)	8 (42.1)	

<b>Usage of Resources</b>	<b>Total n= 43 (%)</b>	<b>Family/ General Practice n= 21 (%)</b>	<b>Infectious Disease n=19 (%)</b>	<b>Cardiology n= 3 (%)</b>
<b>Email alerts from TMA</b>				
Always	1 (2.3)	1 (4.8)	0	0
Often	2 (4.7)	1 (4.8)	1 (5.3)	0
Sometimes	6 (14.0)	3 (14.3)	2 (10.6)	1 (33.3)
Rarely	8 (18.6)	4 (19.1)	4 (21.1)	0
Never	9 (20.9)	5 (23.8)	4 (21.1)	0
No response	17 (39.5)	7 (33.3)	8 (42.1)	2 (66.7)
<b>MMWR</b>				
Always	0	0	0	0
Often	2 (4.7)	0	2 (10.5)	0
Sometimes	7 (16.3)	1 (4.8)	6 (31.6)	0
Rarely	9 (20.9)	6 (28.6)	3 (15.8)	0
Never	8 (18.6)	7 (33.3)	0	1 (33.3)
No response	18 (41.9)	7 (33.3)	9 (42.1)	2 (66.7)

Results Table 16: Likelihood of Resources Used to Learn More about Chagas Disease

<b>Resources</b>	<b>Total n= 43 (%)</b>	<b>Family/ General Practice n= 21 (%)</b>	<b>Infectious Disease n=19 (%)</b>	<b>Cardiology n= 3 (%)</b>
<b>Courses</b>	11 (25.6)	6 (28.6)	4 (21.1)	1 (33.3)
<b>Seminars</b>	12 (27.9)	6 (28.6)	4 (21.1)	2 (66.7)
<b>Manuals</b>	10 (23.3)	6 (28.6)	4 (21.1)	0
<b>Other</b>	13 (30.2)	5 (23.8)	8 (42.1)	0

Results Table 17: Screening and Diagnosis Practices among Infectious Disease Specialists

<b>Screening and Diagnosing Practices</b>	<b>n= 19 (%)</b>
<b>Method(s) used to screen for CD</b>	
Physical assessment	3 (15.8)
12-lead electrocardiogram	2 (10.5)
Patient's medical and social history	5 (26.3)
<b>Lab method(s) used to confirm CD diagnosis</b>	
PCR performed at the CDC	3 (15.8)
Commercial antibody testing using ARUP	2 (9.1)
Commercial antibody testing using Mayo Medical Lab	0
Commercial antibody testing using Quest Diagnostics	1 (5.3)
Commercial antibody testing using Labcorp	1 (5.3)
Not sure	2 (10.5)
<b>Consultation and coordination with:</b>	
Local/ county health department	2 (10.5)
The CDC	4 (21.1)
<b>Classification of cases</b>	
Acute	0
Chronic indeterminate	3 (15.8)
Chronic cardiomyopathy	2 (10.5)
Chronic gastrointestinal	0
Other	0
Not sure	2 (10.5)
<b>Source of transmission</b>	
Locally acquired	1 (5.3)
Imported	2 (10.5)
Not sure	3 (15.8)
Missing	1 (5.3)
<b>Referred to other specialties</b>	
Yes (all to cardiology)	3 (15.8)
No	3 (15.8)
Missing	1 (5.3)
<b>Referred by other specialties</b>	
Yes (family med; internal; cardiology)	4 (21.1)
No	2 (10.5)
Not applicable—did not screen or diagnose	13 (68.4)

Results Table 18: Additional Comments Regarding Screening Practices

<b>Additional Comments (#)</b>	<b>Comment</b>
Experience in confirming a CD diagnosis (Q6.6)	“More than one serological test type, PCR, not finding circulating trypomastigotes, not finding cardiac amastigotes (biopsy)”
Experience obtaining and coordinating treatment for patients (Q6.12)	“I have found many patients with evidence of some form of CD disease in Central America (a project)”
Experience in coordinating with local and state health department	“Abundant paperwork”  “Assistance in diagnosis and in obtaining drugs for treatment”



Results Table 19: Frequency of Procedures in Patients Referred from a Blood Donation Letter

Questionnaire Item: Procedure	Infectious Disease n= 19 (%)
<b>Review the patient's travel history</b>	
Always	3 (15.8)
Often	0
Sometimes	0
Rarely	0
Never	0
Did not provide care to a patient with blood donation letter	16 (84.2)
<b>Request serology to confirm diagnosis</b>	
Always	3 (15.8)
Often	0
Sometimes	0
Rarely	0
Never	0
No response	16 (84.2)
<b>Evaluate patient's cardiopulmonary function (i.e., exercise stress test)</b>	
Always	0
Often	1 (5.2)
Sometimes	1 (5.2)
Rarely	0
Never	1 (5.2)
No response	16 (84.2)
<b>Perform cardiovascular testing to assess myocardial damage</b>	
Always	2 (10.5)
Often	0
Sometimes	1 (5.2)
Rarely	0
Never	0
No response	16 (84.2)
<b>Consult with TDSHS to manage treatment</b>	
Always	1 (5.2)
Often	0
Sometimes	1 (5.2)
Rarely	1 (5.2)
Never	0
No response	16 (84.2)
<b>Consult with the CDC to manage treatment</b>	
Always	2 (10.5)
Often	1 (5.2)

<b>Questionnaire Item: Procedure</b>	<b>Infectious Disease n= 19 (%)</b>
Sometimes	0
Rarely	0
Never	0
No response	16 (84.2)

Results Table 20: Frequency of Procedures when Presenting with Idiopathic Cardiomyopathy among Cardiologists and Infectious Disease Specialists

<b>Questionnaire Item: Procedure</b>	<b>Total n= 22 (%)</b>	<b>Infectious Disease n= 19 (%)</b>	<b>Cardiology n= 3 (%)</b>
<b>Review the patient's travel history</b>			
Always	4 (18.2)	4 (21.1)	0
Often	4 (18.2)	4 (21.1)	0
Sometimes	3 (13.6)	2 (10.5)	1 (33.3)
Rarely	1 (4.5)	1 (5.3)	0
Never	1 (4.5)	0	1 (33.3)
No response	9 (40.9)	8 (42.1)	1 (33.3)
<b>Look for signs of cardiac arrhythmias that may arise due to chronic Chagas cardiomyopathy</b>			
Always	4 (18.2)	3 (15.8)	1 (33.3)
Often	4 (18.2)	4 (21.1)	0
Sometimes	3 (13.6)	3 (15.8)	0
Rarely	1 (4.5)	1 (5.3)	0
Never	2 (9.1)	1 (5.3)	1 (33.3)
No response	8 (36.4)	7 (36.8)	1 (33.3)
<b>Evaluate patient's cardiopulmonary function (i.e., exercise stress test)</b>			
Always	1 (4.5)	0	1 (33.3)
Often	1 (4.5)	1 (5.3)	0
Sometimes	8 (36.4)	7 (31.6)	1 (33.3)
Rarely	2 (9.1)	2 (10.5)	0
Never	1 (4.5)	1 (5.3)	0
No response	10 (45.5)	9 (47.4)	1 (33.3)
<b>Perform cardiovascular testing to assess myocardial damage</b>			
Always	5 (22.7)	3 (15.8)	2 (66.7)
Often	2 (9.1)	2 (10.5)	0
Sometimes	6 (27.3)	6 (31.6)	0
Rarely	1 (4.5)	1 (5.3)	0
Never	0	0	0
No response	8 (36.4)	7 (36.8)	1 (33.3)

Results Table 21: Key Informant Demographics

<b>Characteristic</b>	<b>Total n= 13 (%)</b>	<b>Managed CD Care n= 10 (%)</b>	<b>Had Not Managed CD Care n= 3 (%)</b>	<b>p-value</b>
<b>Specialty</b>				0.245
Infectious disease	8 (61.5)	7 (70.0)	1 (33.3)	
Cardiology	4 (30.8)	3 (30.0)	1 (33.3)	
Family practice	1 (7.7)	0	1 (33.3)	
<b>Sex</b>				0.563
Male	7 (53.9)	5 (50.0)	2 (66.7)	
Female	6 (46.2)	5 (50.0)	1 (33.3)	
<b>Years in specialty</b>				-
Mean, (S.D.)	11.8 (9.52)	11.9 (10.73)	11.3 (5.03)	
<b>Practice setting</b>				0.577
Institution	11 (84.6)	8 (80.0)	3 (100.0)	
Community clinic	2 (15.4)	2 (20.0)	0	
<b>City</b>				0.738
San Antonio	6 (45.2)	5 (50.0)	1 (33.3)	
Houston	5 (38.5)	3 (30.0)	2 (66.7)	
Dallas	2 (15.4)	2 (20.0)	0	
<b>Training in endemic countries</b>				-
Mexico	1 (7.7)	1 (10.0)	0	
Central America	2 (15.4)	0	2 (66.7)	
South America	1 (7.7)	1 (10.0)	0	
<b>Number of CD patients</b>				-
Mean, (S.D.)		6.4 (8.04)		

Results Table 22: Perceived Barriers Preventing the Management of Care for Patients with Chagas Disease

Level	Theme	Example(s) of Participant Feedback
System	Limited access to medical care	He doesn't even live in a place with an ID doctor. He lives in the middle of nowhere in rural west Texas.
	Lack of insurance to cover diagnostic or screening tests	<p>Not every Texan is going to be able to receive—just due to, I think, maybe insurance approvals</p> <p>In other areas where people don't have access to that insurance, and you can't get an EKG or an echo or even see a provider—like you were saying, in rural areas</p> <p>When rare stuff comes up that they're not used to looking at when they're doing blood donor screening or something, there are guidelines about what to do with HIV testing, Hepatitis B testing, and Hepatitis C testing. You can look this up, but it's kind of hard to figure out if you don't know where to look. Like, what am I supposed to do with this?</p> <p>I think the most important message is that although you may not have seen Chagas Disease in your practice before, there are patients out there walking around with indeterminate Chagas Disease, and it's not a false-positive necessarily</p>
	No clear and up to date guidelines, protocols, and patient risk profile resources	<p>Well, I think that the biggest that I faced in regards to diagnosis is—determining which children should be screened for Chagas disease. There are certain high-risk situations that I think—definitely weren't testing.</p> <p>I think the biggest challenges for us were—on accessing the medications.</p> <p>It would be optimal for me, being in a teaching hospital, if it were on a formulary so that I could just say, "Give me some benznidazole."</p>
	Physician access to pharmaceutical drugs Lack specificity and sensitivity in screening and diagnostic tools	<p>Well, I guess I would say that the only real problem—getting the drug was the biggest challenge</p> <p>What I'm amazed is sort of the screening tests and how neither sensitive nor specific they are.</p>

Level	Theme	Example(s) of Participant Feedback
		Now barriers in screening are a—I guess are a concern is the right word regarding the sensitivity and specificity of commercially available test
	Lack of epidemiological evidence	EPI surveillance is pricey and not available—not systematically available with Chagas
	Outdated education during undergraduate medical education suggesting that CD should not be considered in the U.S.	The education that I had about Chagas disease as limited in medical school—medical school training—was that Chagas disease was not generally a disease present in the United States and if it were present, the cardiac manifestations are not likely to be present before adulthood, therefore on those two bases, that most of my patients are, in fact, from the U.S. and virtually none of them are in the twenty plus age range, that it's simply not a consideration. So, that—that was my attitude and opinion before I became sensitized to Chagas.
Physician	Limited knowledge or expertise to screen and/ or diagnose	Sort of—not neglected only in the sense of a tropical disease being neglected, but also neglected by physicians in the difference of diagnosis, it's kind of funny. So with that, I don't think there's a huge expertise.
		I don't know that Chagas disease has registered in the minds of my heart failure colleagues, perhaps, the level that it should.
	General unawareness	But I would still say of people and most physicians—they would—be unaware of some of it. I'm just—the more I learn with <<researcher name redacted>>, the more intrigued I am of the lack of awareness of the disease.
		They were not from an endemic area but were hunters between me and you and San Antonio—from Aliceville, from some other rural areas—who had tested positive but had not traveled outside the country. But then people were kind of interested in that component of it. And I think that they were not aware—of a potential local-acquisition disease.
		Most doctors know of Chagas disease, but especially because we don't see it a whole lot in Texas, some people might not—that might not be on their radar.
	Not knowing CD is in Texas and local transmission	I don't know that Chagas disease has registered in the minds of my heart failure colleagues, perhaps, the level that it should.

Level	Theme	Example(s) of Participant Feedback
	Language as a communication barrier	Definitely language barriers—absolutely—would be difficulties in patients, you know, receiving additional care, additional imaging I think, from a cardiovascular perspective, as well.
		I think barriers, with respect to patients not having a respect for this disorder and this disease—
Patient	Patient refusing treatment	So this one—the patient who had early cardiomyopathy, he might’ve still been a candidate for treatment because it was really super mild, but he lived in the middle of nowhere in the Valley. He was getting out of the Air Force. He was not all that motivated anyway to get treated with months of non-FDA-approved drugs
	Patient fearing to engage in the health system	definitely like racial barriers, they’re definitely just like social barriers or just, I think—I think the fear of patients who may be not appropriately documented, you know, seeking out care and that, you know, them limiting the chance of them being screened and diagnosed
		them thinking that it is truly a disease that still only exists in Central and South America, not within the United States, so they may think that they’re immune because they’re here
	Patient not understanding or “respecting” the disease	This is a really, really big problem, you know because—my case, my eighteen-year-old male, he isn’t dying, you know, he’s—he overall feels good right now
	Patient complications from treatment	Yeah, I mean, it’s a big challenge, you know, with the toxicity to the medication
		And then the second aspect that’s always difficult is the medication itself. You know, the benznidazole and the nifurtimox. It’s a two-to-three-month treatment duration. And there’s a lot of nausea and vomiting with a lot of patients. And actually, the older the patient is—which—I deal with adults. I don’t see kids. But the older the patient is, the more likely they’re probably going to have the side effects. And on top of that—I’ve never seen the neurotoxicity or the photosensitivity or any of that, but one thing we always check for is liver inflammation from the medication, and also effects on their white blood cell count, hemoglobin and platelets also. The medication can alter those.

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## CONCLUSION

### Main Findings

The maps illustrate the barriers and challenges to accessing and receiving care for CD in Texas. Particularly, they demonstrate the potential for increased CD diagnosis in urban counties. Nonetheless, CD diagnosis are possible in rural areas, as indicated by TDSHS reported CD cases data. Moreover, the maps indicate the overall likelihood of currently missed CD diagnosis throughout the state. The mapped data also visualize the potential risk of local transmission throughout the state. Thus, this begins to shed light into physicians under recognizing CD as a potential threat. The maps also stress the importance that missed CD diagnosis are due not just due to limited physician access, but maybe also due a lack of access to knowledgeable physicians who may be trained and willing to recognize the risks and follow-through with screening and diagnosis.

The findings from the questionnaires are consistent with the literature<sup>60,62,75,116</sup> and reinforce CD knowledge gaps by physician specialties, particularly among general or family practitioners. The lack or limited knowledge, as a physician or systems-level barrier, prevents or delays CD diagnosis. More than half of the participants did not answer the correct response in 6 of the 13 knowledge items. This included: the prevalence of total reported CD cases to TDSHS; the clinical course for CD; the proportion of patients with chronic CD that develop symptoms; methods for confirming CD diagnosis; pharmaceutical drugs for treatment; and treatment recommendations for patients. The questionnaire responses from the screening and diagnosis practice items indicate that only one-fifth of surveyed physicians were frequently assessing CD exposure risks among their patient populations. This is

congruent in a recent study by Edwards et al (2018). A national population of pediatric ID specialists were sampled and specific items on screening practices and knowledge in their pediatric Latino immigrant population were assessed. There was a low level of knowledge regarding congenital transmission prevalence and risk factors and rarely or ever considered a diagnosis of congenital CD in a newborn infant born to immigrants from Mexico or Central America or South America.<sup>116</sup>

This thus demonstrates the need to improve outreach and education among physicians so that more of them recognize the need to assess CD exposure risks more frequently. Interestingly, the majority perceived that CD is under diagnosed in Texas and potentially misdiagnosed. Moreover, in general, questionnaire participants believed that the process to confirm CD is complex. Access to treatment by their patient population was not seen as a barrier, yet medical training was: ID specialists believed that they are trained to recognize patients who may need to be screened as compared to family or general practice physicians.

Training and experience, according to the KI, were essential in shaping physicians' understanding of CD in Texas. Findings from a study in Spain support this, in which physicians who worked in a community clinic in which immigrant patients were screened for CD were more knowledgeable about CD than physicians who practiced in a clinic where no screening was performed.<sup>61</sup> Unpublished participant data from a 2017 Texas Chagas Taskforce workshop on CD further illustrate the value in training and educating physicians. Knowledge scores increased from 69% prior to the session to 90% after the materials were presented.

Ultimately, the emerging themes from the KI further solidify the framework for existing barriers that are congruent with other proposed frameworks<sup>115,117</sup>. Specific physician recommendations to enhance awareness and improve knowledge on CD in Texas include: 1) engage patients and physician leadership; 2) increase surveillance to better understand prevalence; 3) improve access to physician resources and how materials on CD are disseminated; and 4) improving and updating physician resources.

### **Study Strengths**

This is the first study aimed to examine CD knowledge among three specialties (infectious disease, cardiology, general/ family practice) throughout Texas. The findings build on the seminal work Stimpert and Montgomery (2010).<sup>62</sup> This study is also unique in that incorporates ICD-9 and ICD-10 coding to illustrate the potential for missed CD diagnosis. Principles of community engagement were applied to ensure to validate the tools and recruit participants. Finally, this research employed a mixed methodology that will help inform and guide future research on CD and other neglected diseases. The findings and recommendations will be disseminated through the appropriate means (e.g., Texas Chagas Taskforce meetings; updates to collaborators; and peer-reviewed articles).

### **Study Limitations**

Nonetheless, given the nested, explanatory mixed methodology design, the results do not statistically support a hypothesis or association. The generalizability of the results is limited given the non-probability sampling. Coverage error was a limitation for Aim 2a in that not all eligible physicians (i.e., within cardiology, family practice, or ID specialists) were affiliated or were members of the physician network(s) that sent out the email invitation(s) to

participate in the questionnaires (i.e., not all eligible physicians had a nonzero chance of being included in the sample). This was also a concern for the key informants, in which a new sampling frame was developed that relied on the Texas Chagas Taskforce contacts and collaborators, rather than on the CDC list of physicians who had treated for CD in Texas. Sampling error occurred as a failure to open or read the email invitations to participate in the questionnaire or KI interview. Not surprisingly, the majority of questionnaire participants practiced in urban areas, while most of the KI's were in Houston or San Antonio. Thus, physicians practicing in rural counties had very limited representation. The contextual barriers, as perceived by physicals in these rural communities, were not identified by this research, the challenge remains in the application of translating the proposed recommendations into these settings without identifying feedback from these stakeholders.

Furthermore, the recruited questionnaire participants might reflect those HCP's who might be more interested in CD, and thus be more aware or biased, and therefore more willing to participate. Furthermore, there may be response bias in answering the questions. The missing data was another limitation, that could be attributed to measurement error. Non-response bias was another limitation illustrated in the low participation from cardiologists for the questionnaires and their unwillingness to answer all the questions.

There were limitations for using administrative data for Aim 1 (i.e., the Texas PUDF). The hospital inpatient dataset does not reflect all the missed CD cardiomyopathy cases since it includes only discharge data for inpatients only (e.g., outpatient hospital data is excluded). Moreover, county names are suppressed so the enumeration of all CD diagnostics is incomplete. Although a cardiologist was consulted, a focused literature review, including

the most recent guidelines published by the American Heart Association regarding Chagas cardiomyopathy,<sup>118</sup> other recent findings on the clinical evaluation of CCC<sup>113,114</sup>, can be used to improve the definition of missed diagnosed CD cases. Finally, the implication of participant under-representation from rural counties limits the

## **Recommendations**

The impetus to continue to raise awareness and education amongst physicians in Texas remains a priority at the systems and physician levels. A multi-level approach to reducing the number of missed CD diagnosis in Texas is needed that does not rely uniquely on individual uptake of CD knowledge. Table 3 summarizes the recommendations framed at the systems, physician, and patient levels. These recommendations can be framed as responses to the barriers identified in Figure 9.

At the systems-level, curricula that discuss the specific context to CD in Texas are needed. As such, policymakers must be engaged so that they recognize the value in revising the undergraduate medical curriculum on CD. More time must be allotted to this topic to ensure physicians in training recognize the risk factors in their patient populations in Texas. Nonetheless, improved surveillance and data are needed for physicians to recognize the problem that CD is not just likely from patients who lived in endemic countries, rather that local transmission is possible and has been reported in Texas.

At the physician level, there are various opportunities to engage with physicians through the continuum of CD care, as first demonstrated in Figure 8. A physician managing the medical care potential CD patient (i.e., before performing screening or requesting diagnostics), must be able to synthesize the information received from the patient. To do that,

however, they must first recognize the potential for CD (i.e., be inclined to consider CD), have access to the latest clinical guidelines and diagnostic procedures, collaborate with other physicians (or non-physician CD experts; work outside their medical “silo”), and be able to communicate the results of the screening or diagnostics and discuss treatment options, side effects, and follow-up management. One recommendation is to have Spanish resources readily accessible for the patient in situations in which translating services are not costly or timely.

Access to resources and educational opportunities that inform or guide physician screening practices must be targeted. For example, many of the KI’s cited the pivotal JAMA article<sup>15</sup> alongside CDC materials, and Up to Date<sup>9</sup> as helpful resources. None of the questionnaire participants reported frequent usage of local, county, or health department resources. Instead, efforts, as framed by the findings, must focus on continuing medical education (CME) workshops and webinars, and conferences.

Web-based outreach is particularly beneficial for physicians in rural or remote areas. The potential for a Chagas webinar has been demonstrated in the continuing efforts from the Texas Chagas Taskforce. That is, in February 2, 2018, a total of 17 physicians participated in a CD webinar. Targeted physician recruitment through existing physician networks can further improve participation and ultimately knowledge on CD.

Additionally, experts in the field (i.e., cardiologists or IDs) must recognize the opportunity to educate physicians in other specialties about their case studies and other CD

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<sup>9</sup> Marin-Neto et al (2018). Chagas Heart Disease: <https://www.uptodate.com/contents/chagas-heart-disease-clinical-manifestations-and-diagnosis>



research. Peer-to-peer models are way to improve uptake and maximize the impact of physician awareness and education. Engaged medical leadership is a recommendation that has also been discussed elsewhere.<sup>116</sup>

Other specific outreach strategies to improve the uptake of information at the individual physician level includes the usage of peer-reviewed journals that are specific to physician specialties. For example, a recent update to the clinical management of Chagas cardiomyopathy was published by the American Heart Association and endorsed by the Inter-American Society of Cardiology summarizes and lists the current.<sup>118</sup>

The patient engagement framework (Figure 8) further demonstrates the potential impact of improving physician awareness and education. For example, a recent kissing bug and CD field guide was developed and released by the Texas Chagas Taskforce. The kissing bug field guide is available online through the TDSHS and various statewide web resources with the purpose of engaging the community at large that may be at risk of exposure to infected triatomines, and educating them about the long-term adverse health outcomes of delaying screening and diagnosing if exposed. This outreach effort had gathered statewide awareness and has empowered community members to discuss with their provider the risk of CD and be their own health advocate.

Table 3: Recommendations to Improve Chagas Disease Education at the System, Physician and Patient Levels

<b>Level</b>	<b>Recommendation</b>	<b>Strategy/ Example</b>
		Ensure that specialty journals provide updates to CD clinical care (e.g., America Heart Association)
	Improve/ facilitate access to resources for physicians	Encourage usage of Up to Date among other physicians
	Improve undergraduate medical education	Engage policymakers so that more time can be spent to contextualize CD in the U.S.
	Improve awareness within medical systems	Engage physician leadership so that briefs and alerts are disseminated throughout hospital
		Pilot studies to better understand prevalence in specific communities
	Continue research and surveillance to improve prevalence estimates and ensure physicians can access data	Conduct routine surveillance at local/ regional blood banks (i.e., not just first time donors)
Systems		Disseminate updates from TDSHS in specialty journals or TMA
	Promote collaboration between physicians/ Increase awareness/	Encourage dissemination of CD case studies/ research by physicians at local/ society conferences
		Use story telling
		Use social media including Facebook to target physicians
	Increase awareness	Use conferences to share knowledge, including available CME
Physician	Target rural or physicians in remote locations	Use webinars and other streaming educational opportunities
Patient	Increase awareness and improve education	Educate community members (e.g., Kissing Bug Field Guide)

### Next Steps and Implications

Physicians who may not consider CD as current or potential threat in Texas believe that epidemiological research and disease surveillance are needed to estimate the human

prevalence of CD and better quantify the need to screen and diagnose to guide their practices. Public health CD surveillance in Texas is needed to monitor incident cases and assess the risk of local transmission.<sup>39</sup> Texas, like the other states where CD is reportable, publish a report and update their website as the means to disseminate surveillance data. Additional dissemination methods employed by other states like Tennessee include peer-reviewed literature and targeted reports to healthcare providers. These additional strategies might help increase awareness. Interestingly, Texas is the only state out the six that currently utilized the Taskforce to increase physicians awareness.<sup>39</sup> Texas Chagas Taskforce activities are in line with the proposed recommendations, including the development and publication of a healthcare provider protocol and a testing algorithm.<sup>10</sup> However as indicated through the findings, one of the main barriers lies in the reluctance or unwillingness to access or utilize CD resources from local or county, or state health departments. Further research can explain the underlying reasons for this. The findings also support the need for improved diagnostic tools and updated physician guidelines. The uptake and impact of the recently published AHA statement and guidelines to raise the recognition of Chagas cardiomyopathy remains to be seen. Understanding the experiences and attitudes of rural-based physicians is also critical to improve the understanding of KAP of CD among these physicians and thus increase screening, diagnosis, and management of care to high-risk patients. Furthermore, additional research must explore the patient's perspectives.

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<sup>10</sup> Texas Department of State Health Services (2018). Chagas disease for healthcare providers: <http://www.dshs.state.tx.us/IDCU/disease/chagas/Chagas-Disease-Exposure-and-Testing-Flowchart-Provider-Version0918.pdf>

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## APPENDICES

Appendix A: IRB Outcome Letter



Committee for the Protection of Human Subjects

6419 River Street, Suite 1100  
Houston, Texas 77030

Mr. Gerardo Pacheco  
UT-H - SPH - San Antonio Regional Campus

**NOTICE OF APPROVAL TO BEGIN RESEARCH**

**February 05, 2018**

**HSC-SPH-17-1039** - Chagas Disease Awareness among Physicians in Texas

**Number of Subjects Approved: Target: 110 / Screen: 110**

**PROVISIONS:** This approval relates to the research to be conducted under the above referenced title and/or to any associated materials considered by the Committee for the Protection of Human Subjects, e.g. study documents, informed consent, etc.

**APPROVED:** By Expedited Review and Approval

**REVIEW DATE:** 01/20/2018

**APPROVAL DATE:** 02/05/2018

**EXPIRATION DATE:** 01/31/2019

**CHAIRPERSON:** L. Maximilian Buja, MD

Subject to any provisions noted above, you may now begin this research.

**CHANGES:** The principal investigator (PI) must receive approval from the CPHS before initiating any changes, including those required by the sponsor, which would affect human subjects, e.g. changes in methods or procedures, numbers or kinds of human subjects, or revisions to the informed consent document or procedures. The addition of co-investigators must also receive approval from the CPHS. **ALL PROTOCOL REVISIONS MUST BE SUBMITTED TO THE SPONSOR OF THE RESEARCH.**

**INFORMED CONSENT DETERMINATION:**  
Waiver of Documentation of Informed Consent

**INFORMED CONSENT:** When Informed consent is required, it must be obtained by the PI or designee(s), using the format and procedures approved by the CPHS. The PI is responsible to instruct the designee in the methods approved by the CPHS for the consent process. The individual obtaining informed consent must also sign the consent document. Please note that only copies of the stamped approved informed consent form can be used when obtaining consent.

**HEALTH INSURANCE PORTABILITY and ACCOUNTABILITY ACT (HIPAA):**  
Exempt from HIPAA: Yes

**UNANTICIPATED RISK OR HARM, OR ADVERSE DRUG REACTIONS:** The PI will immediately inform the CPHS of any unanticipated problems involving risks to subjects or others, of any serious harm to subjects, and of any adverse drug reactions.

**RECORDS:** The PI will maintain adequate records, including signed consent and HIPAA documents if required, in a manner that ensures subject confidentiality.

## Appendix B: Chagas Disease Knowledge, Attitudes, and Practices Questionnaires

# Chagas Disease Questionnaire for Cardiologists

## SURVEY FLOW

Consent and Eligibility  
Definitions  
Attitudes (5 Questions)  
Knowledge (14 Questions)  
Knowledge for Cardiologists (3 Questions)  
Practices: Actual Chagas (20 Questions)  
Practices: Other Activities- Rated (7 Questions)  
Participant Demographics (10 Questions)  
Questionnaire Conclusion and Follow-up

Q1.2 Thank you for your interest in completing the following online questionnaire. The purpose of this brief 20-minute questionnaire is to gain a better understanding of Chagas disease awareness, and practices among cardiologists, infectious disease specialists and family physicians licensed by the Texas Medical Board.

**If you would like to participate in the questionnaire, please continue to the next page.**

**If you do not wish to participate in the questionnaire, we thank you for your time and interest. You can close this page now.**

Q1.3

## INFORMED CONSENT

### INVITATION TO TAKE PART

You are invited to take part in a research project called, Chagas Disease Awareness among Physicians in Texas, conducted by doctoral candidate Gerardo J. Pacheco of the University of Texas Health Science Center at Houston (UTHealth) School of Public Health. For this research project, he will be called the Principal Investigator or PI.

Your decision to take part is voluntary. This research project has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Health Science Center at Houston as HSC-SPH-17-1039. Although we appreciate your valuable input in this questionnaire, please be advised that you may refuse to take part or choose to stop taking part, at any time. Additionally, you may also refuse to answer any question(s).

### PROCEDURES

If you agree to take part in this study, you will first confirm your consent by answering the question below. Once you consent, you will be directed to the questionnaire. It contains sections regarding your attitudes and perspectives, knowledge, and current practices about Chagas disease in Texas. At the completion of the questionnaire, you will be prompted to respond whether or not you would like to participate in a 15-

minute key informant phone interview. You will then be prompted to provide your email address if you agree to participate. Conversely, if you decline, you will be directed to a page with the answer key to the Chagas disease knowledge questions.

## PURPOSE

The purpose of this research study is to examine the level of knowledge, awareness, and practices among licensed physicians in Texas regarding screening, diagnosis, and treatment of Chagas as well as to illustrate the potential for missed cases for Chagas disease diagnosis in Texas.

## TIME COMMITMENT

The questionnaire will require 20-25 minutes to complete and will be available for up to two weeks.

## BENEFITS

The potential benefits to participating in this study include the self-assessment of Chagas disease, which will allow you as a physician to understand where your current knowledge deficits might be and if further resources should be reviewed to be up to date. In more general terms, the results from this study can help point towards statewide knowledge deficits and gaps that might be present and push towards recommendations for targeted outreach and workshops (e.g., by specialty, location, etc.).

You may receive no direct benefit from being in the study; however, you taking part may help patients receive better in the future.

An answer key is provided at the end of the questionnaire for you to review the Chagas disease knowledge section.

## RISKS AND/OR DISCOMFORTS

The risks and discomfort associated with participation in this study are no greater than those ordinarily encountered in daily life or during the performance of routine exams. The experience is expected to be informative and interesting and thus a generally positive experience.

Confidentiality: Although every measure will be taken to properly safeguard all data pertaining to this study, there is a possible risk of breach of confidentiality.

Questionnaire: You may get tired when we are asking you questions or you are completing questionnaires. You do not have to answer any questions you do not want to answer.

## STUDY WITHDRAWAL

Your decision to take part is voluntary. Although we appreciate your valuable input in this questionnaire, please be advised that you may refuse to take part or choose to stop taking part, at any time. You may decide to stop taking part in the study at any time, but you must submit in writing to the PI if you choose to have your responses excluded from the analysis.

## COSTS, REIMBURSEMENT AND COMPENSATION



If you decide to take part in this research study, you will not incur any additional costs.

You will not be paid for taking part in this study.

## CONFIDENTIALITY

Identifying information will not appear on records retained by the sponsor, with the exception of your birth year and your email address if you choose to provide that information for participation in follow-up interviews. You will not be personally identified in any reports or publications that may result from this study.

## QUESTIONS

If you have questions at any time about this research study, please feel free to contact the PI at (915) 240-2821 as he will be glad to answer your questions. You can contact the PI to discuss problems, voice concerns, obtain information, and offer input in addition to asking questions about the research.

If you have any questions or concerns about your rights as a research subject, call the Committee for the Protection of Human Subjects at (713) 500-7943. You may also call the Committee if you wish to discuss problems, concerns, and questions; obtain information about the research; and offer input about current or past participation in a research study.

## SIGNATURES

Submit your consent below to participate in this research only if you understand the information given to you about the research and you choose to take part. No signature is required to proceed if you confirm your consent below. Make sure that any questions have been answered and that you understand the study.

CPHS STATEMENT: This study (HSC-SPH-17-1039) has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Health Science Center at Houston. For any questions about research subject's rights, or to report a research-related injury, call the CPHS at (713) 500-7943.

Q1.5 If you wish to participate, please indicate below:

- Yes, I agree to participate. (1)
- No, I do not wish to participate. (2)

*Skip To: End of Survey If Q1.5 = 2*

Q1.6 Are you an MD or DO licensed by the Texas Medical Board to practice in the state of Texas?

- Yes (1)
- No (2)

*Display This Question:*

*If Q1.6 = 2*

Q1.7

Thank you for your interest. However, this questionnaire is intended for physicians.

**You may close this page now.**

*Skip To: End of Survey If Q1.7(1) Is Displayed*

Q1.8 Please indicate your primary medical specialty. If it is not listed below, select "Other":

- General Practice/ Family Medicine (1)
- Infectious Disease (2)
- Cardiology (3)
- Other (4)

*Display This Question:*

*If Q1.8 = 4*

Q1.9 If Other, please describe:

---

## Q2.1 DEFINITIONS

Definitions used for the purpose of this questionnaire:

**Screening:** clinical decision-making process or differential diagnosis to determine if further laboratory diagnostics are required.

**Diagnosis:** the clinical and serological testing required to confirm Chagas disease.

**Vector:** Triatomine or Reduviid insect that is able to transmit the parasite *T cruzi* that causes Chagas disease.

## Q3.1

### ATTITUDES ON CHAGAS DISEASE

The following sections are about your **opinions and attitudes** regarding Chagas disease.

Q3.2 To what extent do you agree or disagree with the following statements?

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
a. Chagas disease is <b>under diagnosed</b> in Texas (i.e., failure to recognize or correctly diagnose a disease or condition in a significant proportion of the population). (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Chagas disease is <b>potentially misdiagnosed</b> in patients (e.g., incorrectly diagnosed cases of chronic Chagas cardiomyopathy for idiopathic cardiomyopathy). (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. The process required to confirm Chagas disease is complex and thus time consuming. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. In Texas, diagnosis and treatment of Chagas disease is a relatively easy process with few barriers. (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q3.3 As a cardiologist, to what extent do you agree or disagree with the following statements?

	Strongly agree (1)	Somewhat agree (2)	Neither agree or disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
a. My medical training prepared me to recognize patients who may need to be screened for Chagas disease. (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I routinely screen for Chagas disease in patients who present with risk factors. (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Accessing Chagas disease treatment is not a barrier for the population I serve. (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. I have access to a 12-lead electrocardiogram with a 30 second lead to screen for Chagas cardimyopathy within my practice. (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. I have access to cardiac ultrasound equipment to perform echocardiograms to screen for Chagas disease within my practice. (16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q3.4 How confident are you in performing the following when screening for Chagas disease in your patient population?

	Very confident (1)	Somewhat confident (2)	Not at all confident (3)
a. Identifying risk factors for Chagas disease in patients. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Recognizing the vector that transmits Chagas disease. (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Obtaining a patient's social history to identify potential risk factors for Chagas disease. (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Using electrocardiogram (ECG) to screen and diagnose for chronic Chagas disease. (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Using a stress test to evaluate clinical manifestations to screen and diagnose for chronic Chagas cardiomyopathy. (16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q3.5 How confident are you in performing the following in patients with Chagas disease?

	Very confident (1)	Somewhat confident (2)	Not at all confident (3)
a. Contacting and coordinating with the local and/or state health department when consulting about a Chagas patient. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Contacting, coordinating, and following-up with the Centers for Disease Control and Prevention (CDC) when consulting about a Chagas patient. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Requesting the Current Procedural Terminology laboratory codes for diagnosing Chagas disease. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Continuing to provide follow-up medical care to Chagas patients. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q3.6 What would be the recommended sequence when managing care of a Chagas patient who has a blood donation letter? Please rank from 1 to 5 on how you would prioritize (drag and drop).

- \_\_\_\_\_ Coordinate with local health department and Texas Department of State Health Services (DSHS) to confirm diagnosis. (1)
- \_\_\_\_\_ Consult with the CDC to manage patient's treatment protocol. (2)
- \_\_\_\_\_ Perform baseline clinical workup that includes physical exam, 12-lead ECG, and additional testing if warranted. (5)
- \_\_\_\_\_ Confirm diagnosis via commercial serology testing. (3)
- \_\_\_\_\_ Obtain thorough history to evaluate potential routes of exposure. (4)

Q4.1 **KNOWLEDGE** The following sections are to help us assess Texas physicians' knowledge about the cause, transmission, and clinical aspects of Chagas disease.

Q4.2 How does the vector with the parasite transmit Chagas disease to humans?

- The infected vector penetrates the human host skin during bloodmeal, transmitting parasite through saliva. (1)
- Through infected feces of the vector, that is deposited during the bloodmeal, most commonly when the person rubs the infected feces into the bite wound while scratching the area. (2)
- The infected vector regurgitates after bloodmeal, transmitting parasite to the human. (3)
- None of the above. (4)
- Not sure. (5)

Q4.3 How do the majority of people with Chagas disease living in the United States acquire the infection?

- From drinking unpasteurized juices. (1)
- From exposure to vectors while residing in Mexico, Central, or South America. (2)
- From their mothers (i.e., congenital transmission). (3)
- From another infected person. (4)
- Not sure. (5)

Q4.4 Since becoming a reportable condition in the state of Texas in 2013, approximately how many total Chagas confirmed cases (local and imported) have been reported to the Texas DSHS, between 2013 and 2016?

- Less than 5. (1)
- Between 20 and 30. (2)
- Between 75 and 100. (3)
- More than 1,000. (4)
- Not sure. (5)



Q4.5 Which of the following best describes the clinical course of Chagas disease?

- Acute for 10 to 30 days following exposure to parasite, is self-limiting in most persons within 2 months, and rarely progresses into the chronic phase. (1)
- Acute for a week following exposure to parasite. If left untreated, it is a chronic lifelong infection 2-4 weeks following exposure to parasite. (2)
- Acute for 1-8 weeks following exposure to parasite; asymptomatic for years to decades in the majority of infected persons; but becoming symptomatic in a portion of persons infected with parasite. (3)
- None of the above. (4)
- Not sure. (5)

Q4.6 The **acute** phase of Chagas disease may be characterized by which of the following:

- Fever (1)
- Swelling at the site of inoculation (2)
- No symptoms (3)
- All of the above (4)
- Not sure (5)

Q4.7 In addition to heart failure, what major clinical disorders manifest frequently and concurrently that lead to chronic Chagas cardiomyopathy?

- Cardiac arrhythmias (1)
- Thromboembolism (systemic and pulmonary) (2)
- Chest pain syndrome (3)
- All of the above (4)
- Not sure (5)

Q4.8 Approximately what percentage of patients worldwide with **chronic Chagas** disease eventually develop the clinical (symptomatic) form of the disease?

- Less than 1%. (1)
- Between 20 and 40%. (2)
- More than 50%. (3)
- None of the above. (4)
- Not sure. (5)

Q4.9 Persons infected with **chronic Chagas disease** may develop which of the following?

- Cardiac conduction abnormalities and/ or cardiomyopathy. (1)
- Megaesophagus and/or megacolon. (2)
- Co-clinical manifestations. (3)
- All of the above. (4)
- Not sure. (5)

Q4.10 Which of the following may occur in patients with **chronic Chagas cardiomyopathy**?

- None- can present without clinical manifestations and be asymptomatic. (1)
- Dyspnea on exertion, fatigue, palpitations, dizziness, syncope, and edema. (2)
- Sudden death. (3)
- Any of the above. (4)
- Not sure. (5)

Q4.11 You should request commercial laboratory diagnostic serology tests, initiate a clinical evaluation of the patient, and conduct a thorough history in a patient who:

- Has tested positive for *T cruzi* during a blood donation or has a sibling or mother who is Chagas-positive. (1)
- Was exposed or potentially exposed to a vector in a period longer than 8 weeks. (2)
- Presents with onset of cardiac disease manifestations that are compatible with chronic Chagas cardiomyopathy. (3)
- All of the above. (4)
- Not sure (5)

Q4.12 In patients who test positive for Chagas disease after a blood donation or from a laboratory diagnostics, obtaining a social history is needed to assess potential routes of exposure, including:

- Travel to or residence in areas endemic for Chagas disease. (1)
- Previous history of blood transfusions or organ/ tissue transplants. (2)
- Possibility of congenital Chagas disease transmission. (3)
- All of the above. (4)
- Not sure. (5)

Q4.13 Which of the following best describes the method(s) for a confirmatory diagnosis of Chagas disease?

- Seropositive results from 2 different immunoassays and/or PCR performed at the CDC. (1)
- Positive serology from blood screening donations. (2)
- Detection of apolipoprotein A-1 (APOA1) upregulation in human serum. (3)
- All of the above. (4)
- Not sure. (5)

Q4.14 Which of the following describes the current treatment options for Chagas disease?

- Benzindazole and nifurtimox are available only under current investigational protocol by the CDC in children up to 18 years of age with chronic infections and in adults up to age 50 with chronic infection who have no indication of advanced cardiomyopathy. (1)
- Benznidazole has been approved by the U.S. Food and Drug Administration (FDA) for patients 2-12 years of age and is available commercially. (4)
- Nifurtimox is only available by the CDC under investigational protocol. (5)
- Second and third choices only. (8)
- Not sure. (7)

Q4.15 Should patients with chronic Chagas disease be treated with antitrypanosomal drugs?

- No, there is no evidence that antitrypanosomal treatment for chronic Chagas disease can be effective. (1)
- Yes, only patients younger than 5 years of age should be treated for chronic Chagas disease. (2)
- Treatment is always recommended for patients up to age 18 years of age and generally recommended for patients aged 18 to 50. (3)
- Only Chagas disease patients manifesting with moderate to severe cardiomyopathy. (4)
- Not sure. (5)

**Q5.1 SPECIFIC KNOWLEDGE ON CHAGAS DISEASE SCREENING & DIAGNOSTICS** The following questions are specific to you as a cardiologist in identifying the clinical manifestations of Chagas disease and screening the patient.

Q5.2 What are the important elements of the clinical evaluation of a newly diagnosed chronic Chagas patient who is **asymptomatic**?

- Complete physical examination, complete blood count (CBC), and chemistry panel. (1)
- Complete physical examination, electrocardiogram (ECG) with 30 second rhythm strip, and detailed history. (7)
- Complete physical examination, ECG with 30 second rhythm strip, chest radiograph, barium swallow, and detailed history. (8)
- None of the above. (9)
- Not sure. (10)

Q5.3 Which of the following are typical of Chagas cardiomyopathy as evaluated using electrocardiograph?

- Right bundle branch block often associated with left anterior hemiblock, ST-T changes, abnormal Q waves, various degrees of AV block, sick sinus syndrome, and low QRS voltage. (1)
- Mainly conduction abnormalities including first-degree AV block, left bundle-branch block, and nonspecific interventricular conduction delays. (6)
- Right bundle-branch block only. (7)
- None of the above. (8)
- Not sure. (9)

Q5.4 In patients with chronic Chagas cardiomyopathy, cardiac examination typically demonstrates which of the following?

- Murmurs of mitral and/ or tricuspid regurgitation. (1)
- Wide splitting of the second heart sound due to right bundle branch block. (6)
- A prominent diffuse apical thrust. (7)
- All of the above. (8)
- Not sure. (9)

**Q6.1 PRACTICES RELATED TO SCREENING, DIAGNOSING, AND TREATING CHAGAS DISEASE**

The following are about your practices related to the identification, screening, and treatment of actual Chagas disease case(s).

Q6.2 Over the past five years since becoming a reportable condition in Texas, have you directly screened and/ or confirmed a diagnosis for Chagas in patients in your medical care in Texas?

Yes (1)

No (2)

*Display This Question:*

*If Q6.2 = 1*

Q6.3 In the past year, how many patients that you suspected for Chagas disease did you screen and test to confirm diagnosis?

---

*Display This Question:*

*If Q6.2 = 1*

Q6.4 In the past year, out of those patients that you screened and/ or diagnosed, did any of them receive a positive confirmatory diagnosis?

Yes (8)

No (9)

*Display This Question:*

*If Q6.4 = 8*

Q6.5 In the past year, if you screened suspected Chagas patients, how many that were positive were confirmed by the CDC?

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*Display This Question:*

*If Q6.4 = 8*

Q6.6 Please provide additional comments regarding your experience in confirming a Chagas disease diagnosis:

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*Display This Question:*  
If Q6.2 = 1

Q6.7 In the past year, if you have screened suspected Chagas patients, what method(s) did you use to screen for Chagas disease? Select all that apply.

- Physical assessment. (2)
- 12 lead strip electrocardiogram. (3)
- Patient's medical and social history. (4)

*Display This Question:*  
If Q6.2 = 1

Q6.8 If you screened patients for Chagas disease in the past year, did you consult with local/ county health departments to coordinate treatment?

- Yes (1)
- No (2)

---

*Display This Question:*  
If Q6.2 = 1

Q6.9 If you screened patients for Chagas disease in the past year, did you coordinate with the CDC to confirm diagnosis?

- Yes (1)
- No (2)

---

*Display This Question:*  
If Q6.2 = 1

Q6.10 If you screened and/ or diagnosed patients for Chagas disease in the past year, what method(s) did you use to confirm diagnosis for Chagas disease? Select all that apply.

- PCR performed at the CDC. (1)
- Commercial antibody testing- ARUP Lab. (2)
- Commercial antibody testing- Mayo Medical Lab. (3)
- Commercial antibody testing- Quest Diagnostics. (4)
- Commercial antibody testing- Labcorp. (5)
- Not sure. (6)

*Display This Question:*  
If Q6.2 = 1

Q6.11 If you screened and/ or diagnosed patients for Chagas disease in the past year, how often did you coordinate with the CDC for treatment?

- Always (1)
- Sometimes (2)
- Never (4)
- Not sure (3)

*Display This Question:*  
If Q6.2 = 1

Q6.12 Please provide additional comments regarding your experience obtaining and coordinating treatment for patient(s):

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Display This Question:  
If Q6.2 = 1

Q6.13 If you screened and/ or diagnosed patients for Chagas disease in the past year, how often did you coordinate with the local health department and/ or Texas DSHS to confirm diagnosis?

- Always (1)
- Sometimes (2)
- Never (4)
- Not sure (3)

Display This Question:  
If Q6.2 = 1

Q6.14 Please provide additional comments regarding your experience in coordinating with local and state health department officials when diagnosing a Chagas patient(s):

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Display This Question:  
If Q6.2 = 1

Q6.15 If you screened patients in the past year and diagnosis was confirmed, please indicate the classification of the case(s):

- Acute (1)
- Chronic-indeterminate (2)
- Chronic-cardiomyopathy (3)
- Chronic-gastrointestinal (4)
- Other (6)
- Not sure (5)

---

*Display This Question:*

*If Q6.15 = 6*

Q6.16 Please describe the classification of the Chagas case(s) if "other" was selected:

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*Display This Question:*

*If Q6.2 = 1*

Q6.17 Please indicate the source(s) of transmission:

- Locally-acquired (1)
- Imported (2)
- Not sure (3)

---

*Display This Question:*

*If Q6.2 = 1*

Q6.18 Did you refer out the patient to any other specialist?

Yes (1)

No (2)

*Display This Question:*

*If Q6.18 = 1*

Q6.19 If you did refer out, please indicate to what other physician specialty:

*Display This Question:*

*If Q6.2 = 1*

Q6.20 Was the patient referred to you by another physician?

Yes (1)

No (2)

*Display This Question:*

*If Q6.20 = 1*

Q6.21 What was the physician specialty/ies that referred the Chagas patient(s) to you?

#### Q7.1 PHYSICIAN PRACTICES

The following are Chagas disease screening and diagnosing practices related to your medical specialty.

Q7.2 In general, how often do you consider each of the following as exposure risks for Chagas disease in your patients?

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Always (5)	N/A (6)
a. Mother or sibling with Chagas disease. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. History of blood transfusions or organ/tissue transplants. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Travel to Mexico, Central, or South America. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Consumption foods or drinks contaminated with the parasite. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

-----

Q7.3 In general, how often do you perform the following in patients under your medical care who present with **idiopathic cardiomyopathy**?

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Always (5)	N/A (6)
a. Review the patient's travel history. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Look for signs of cardiac arrhythmias that may arise due to chronic Chagas cardiomyopathy. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Evaluate patient's cardiopulmonary function (i.e., exercise stress test). (17)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Perform cardiovascular testing (chest x-ray, echocardiogram, etc.) to assess myocardial damage. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q7.4 In the past 5 years while practicing medicine in Texas, have you provided care to a Chagas disease patient with a blood donation letter?

- Yes (1)
- No (2)

*Display This Question:*  
If Q7.4 = 1

Q7.5 In the past 5 years while practicing in Texas, how often did you perform the following in patients under your medical care who received a positive Chagas diagnosis (i.e., letter) from a **blood donation screening**?

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Always (5)	N/A (6)
a. Review the patient's travel history. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Request serology to confirm Chagas diagnosis. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Evaluate patient's cardiopulmonary function (i.e., exercise stress test). (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Perform cardiovascular testing (chest x-ray, echocardiogram, etc.) to assess myocardial damage. (20)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Consult with the Texas DSHS to manage treatment. (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Consult with the CDC to manage treatment. (21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q7.6 In thinking about resources you reference when managing the care of a patient who may potentially have Chagas disease, how often do you access:

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Always (5)	N/A (6)
a. Medical websites (e.g., UpToDate, MedlinePlus, etc.) (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Official local or county health department websites. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. The Texas DSHS website. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. The CDC website. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Official communiques and health alerts from Texas DSHS. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Email alerts from the Texas Medical Association. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Morbidity and Mortality Weekly Report (MMWR) email updates from the CDC. (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q7.7 Which of the following would you be interested in accessing in order to strengthen your ability to help patients with Chagas disease? Select all that apply.

- Courses (1)
- Seminars (2)
- Manuals (3)
- Other resources (4)

---

*Display This Question:*

*If Q7.7 = 4*

Q7.8 If you indicated other, please describe:

---

Q8.1 **DEMOGRAPHICS** The following section is about demographics and your medical practice.

Q8.2 How many years have you been practicing in family or general practice?

- Less than 5 years. (1)
- 5 to 10 years. (2)
- 10 to 15 years. (3)
- 15 to 20 years. (4)
- More than 20 years. (5)

Q8.3 Which of the following best describes the current type of medical setting you currently practice in?

- Private (1)
- Teaching (2)
- Community (3)
- Other (4)



Display This Question:

If Q8.3 = 4

Q8.4 If other, please describe:

---

Q8.5 Which of the following best describes the setting where you practice at?

- Urbanized area (i.e., 50,000 or more people). (1)
- Rural area (i.e., at least 2,500 people but than 50,000). (2)
- None of the above. (3)

Q8.6 In your current medical practice, what proportion of total patients you see on average that are Hispanics/ Latinos?

0 10 20 30 40 50 60 70 80 90 100

Click to write Choice 1 ( )



**Q8.7 PARTICIPANT DEMOGRAPHICS- PART 2**

Q8.8 Are you male or female?

- Male (1)
- Female (2)



Q8.9 What is your year of birth? (YYYY)

---

Q8.10 Please indicate if you received medical training in any of the following places:

- Mexico (1)
- Central America (2)
- South America (3)
- None of the above (4)
- Prefer not to answer (5)

*Display This Question:*

*If Q8.10 = 2*

Q8.11 If you received medical training in Central America, indicate the country:

---

*Display This Question:*

*If Q8.10 = 3*

Q8.12 If you received medical training in South America, indicate the country:

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Q9.1

## **CONCLUSION**

Q9.2 Thank you for participating in this questionnaire. We know your time is valuable. Your responses will remain anonymous and will be used to identify a baseline of knowledge and awareness of Chagas disease throughout the state. In addition to the questionnaire, we are conducting additional research via phone interviews with practicing physicians to identify and explore additional barriers related to screening and diagnosing of Chagas disease in Texas. The goal is to understand the challenges that lead to missed Chagas diagnosis and frame recommendations to improve awareness and education among practicing physicians in Texas. Questionnaire responses will be kept separate and confidential if you do decide to provide your contact information to participate in the phone interviews.

Q9.3 Would you like participate in a 15-minute phone interview?

- Yes, I would like to participate. (1)
- No, I decline. (2)

---

Display This Question:

If Q9.3 = 1



Q9.4 Please provide your email:

---

# Chagas Disease Questionnaire for Family or General Practice Physicians

## Survey Flow

Consent and Eligibility  
Definitions  
Attitudes (4 Questions)  
Knowledge (13 Questions)  
Practices: Actual Chagas (20 Questions)  
Practices: Common, Other Activities- Rated (8 Questions)  
Participant Demographics (11 Questions)  
Questionnaire Conclusion and Follow-up

Q1.2 Thank you for your interest in completing the following online questionnaire. The purpose of this brief 20-minute questionnaire is to gain a better understanding of Chagas disease awareness, and practices among cardiologists, infectious disease specialists and family physicians licensed by the Texas Medical Board.

**If you would like to participate in the questionnaire, please continue to the next page.**

**If you do not wish to participate in the questionnaire, we thank you for your time and interest. You can close this page now.**

Q1.3

## INFORMED CONSENT

You are invited to take part in a research project called, Chagas Disease Awareness among Physicians in Texas, conducted by doctoral candidate Gerardo J. Pacheco of the University of Texas Health Science Center at Houston (UTHealth) School of Public Health. For this research project, he will be called the Principal Investigator or PI.

Your decision to take part is voluntary. This research project has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Health Science Center at Houston as HSC-SPH-17-1039. Although we appreciate your valuable input in this questionnaire, please be advised that you may refuse to take part or choose to stop taking part, at any time. Additionally, you may also refuse to answer any question(s).

## PROCEDURES

If you agree to take part in this study, you will first confirm your consent by answering the question below. Once you consent, you will be directed to the questionnaire. It contains sections regarding your attitudes and perspectives, knowledge, and current practices about Chagas disease in Texas. At the completion of the questionnaire, you will be prompted to respond whether or not you would like to participate in a 15-minute key informant phone interview. You will then be prompted to provide your email address if you

agree to participate. Conversely, if you decline, you will be directed to a page with the answer key to the Chagas disease knowledge questions.

## PURPOSE

The purpose of this research study is to examine the level of knowledge, awareness, and practices among licensed physicians in Texas regarding screening, diagnosis, and treatment of Chagas as well as to illustrate the potential for missed cases for Chagas disease diagnosis in Texas.

## TIME COMMITMENT

The questionnaire will require 20-25 minutes to complete and will be available for up to two weeks.

## BENEFITS

The potential benefits to participating in this study include the self-assessment of Chagas disease, which will allow you as a physician to understand where your current knowledge deficits might be and if further resources should be reviewed to be up to date. In more general terms, the results from this study can help point towards statewide knowledge deficits and gaps that might be present and push towards recommendations for targeted outreach and workshops (e.g., by specialty, location, etc.).

You may receive no direct benefit from being in the study; however, you taking part may help patients receive better in the future.

An answer key is provided at the end of the questionnaire for you to review the Chagas disease knowledge section.

## RISKS AND/OR DISCOMFORTS

The risks and discomfort associated with participation in this study are no greater than those ordinarily encountered in daily life or during the performance of routine exams. The experience is expected to be informative and interesting and thus a generally positive experience.

Confidentiality: Although every measure will be taken to properly safeguard all data pertaining to this study, there is a possible risk of breach of confidentiality.

Questionnaire: You may get tired when we are asking you questions or you are completing questionnaires. You do not have to answer any questions you do not want to answer.

## STUDY WITHDRAWAL

Your decision to take part is voluntary. Although we appreciate your valuable input in this questionnaire, please be advised that you may refuse to take part or choose to stop taking part, at any time. You may decide to stop taking part in the study at any time, but you must submit in writing to the PI if you choose to have your responses excluded from the analysis.

## COSTS, REIMBURSEMENT AND COMPENSATION

If you decide to take part in this research study, you will not incur any additional costs.

You will not be paid for taking part in this study.

## CONFIDENTIALITY

Identifying information will not appear on records retained by the sponsor, with the exception of your birth year and your email address if you choose to provide that information for participation in follow-up interviews. You will not be personally identified in any reports or publications that may result from this study.

## QUESTIONS

If you have questions at any time about this research study, please feel free to contact the PI at (915) 240-2821 as he will be glad to answer your questions. You can contact the PI to discuss problems, voice concerns, obtain information, and offer input in addition to asking questions about the research.

If you have any questions or concerns about your rights as a research subject, call the Committee for the Protection of Human Subjects at (713) 500-7943. You may also call the Committee if you wish to discuss problems, concerns, and questions; obtain information about the research; and offer input about current or past participation in a research study.

## SIGNATURES

Submit your consent below to participate in this research only if you understand the information given to you about the research and you choose to take part. No signature is required to proceed if you confirm your consent below. Make sure that any questions have been answered and that you understand the study.

CPHS STATEMENT: This study (HSC-SPH-17-1039) has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Health Science Center at Houston. For any questions about research subject's rights, or to report a research-related injury, call the CPHS at (713) 500-7943.

Q1.5 If you wish to participate, please indicate below:

- Yes, I agree to participate. (1)
- No, I do not wish to participate. (2)

*Skip To: End of Survey If Q1.5 = No, I do not wish to participate.*

Q1.6 Are you an MD or DO licensed by the Texas Medical Board to practice in the state of Texas?

- Yes (1)
- No (2)

*Display This Question:*

*If Q1.6 = No*

Q1.7

Thank you for your interest. However, this questionnaire is intended for physicians.

**You may close this page now.**

*Skip To: End of Survey If Q1.7() Is Displayed*

Q1.8 Please indicate your primary medical specialty. If it is not listed below, select "Other":

- General Practice/ Family Medicine (1)
- Infectious Disease (2)
- Cardiology (3)
- Other (4)

*Display This Question:*

*If Q1.8 = Other*

Q1.9 If Other, please describe:

---

## Q2.1 DEFINITIONS

Definitions used for the purpose of this questionnaire:

**Screening:** clinical decision-making process or differential diagnosis to determine if further laboratory diagnostics are required.

**Diagnosis:** the clinical and serological testing required to confirm Chagas disease.

**Vector:** Triatomine or Reduviid insect that is able to transmit the parasite *T cruzi* that causes Chagas disease.

Q3.1

## ATTITUDES ON CHAGAS DISEASE

The following sections are about your **opinions and attitudes** regarding Chagas disease.

Q3.2 To what extent do you agree or disagree with the following statements?

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
a. Chagas disease is <b>under diagnosed</b> in Texas (i.e., failure to recognize or correctly diagnose a disease or condition in a significant proportion of the population). (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Chagas disease is <b>potentially misdiagnosed</b> in patients (e.g., incorrectly diagnosed cases of chronic Chagas cardiomyopathy for idiopathic cardiomyopathy). (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. The process required to confirm Chagas disease is complex and thus time consuming. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. In Texas, diagnosis and treatment of Chagas disease is a relatively easy process with few barriers. (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Q3.3 As a general practice or family physician, to what extent do you agree or disagree with the following statements?

	Strongly agree (1)	Somewhat agree (2)	Neither agree or disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
a. My medical training prepared me to recognize patients who may need to be screened for Chagas disease. (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Screening for Chagas disease is possible through my general or family practice. (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Diagnosis for Chagas disease is possible through my general or family practice. (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Accessing Chagas disease treatment is not a barrier for the population I serve. (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q3.4 How confident are you in performing the following when screening and diagnosing Chagas disease in your patient population?

	Very confident (1)	Somewhat confident (2)	Not at all confident (3)
a. Identifying risk factors for Chagas disease in patients. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Recognizing the vector that transmits Chagas disease. (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Obtaining a patient's social history to identify potential risk factors for Chagas disease. (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Requesting the Current Procedural Terminology laboratory codes for diagnosing Chagas disease. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Contacting and coordinating with the local health department and/or the Texas Department of State Health Services (DSHS) when consulting about a Chagas patient. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Contacting, coordinating, and following-up with the Centers for Disease Control and Prevention (CDC) when consulting about a Chagas patient. (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q3.5 What would be the recommended sequence when managing care of a patient who may have been exposed to parasite (i.e., exposure to vector in Texas or in endemic areas) within an 8-week period and presents with acute symptoms? Please rank from 1 to 5 on how you would prioritize (drag and drop).

- \_\_\_\_\_ Initiate antitrypanosomal treatment. (1)
- \_\_\_\_\_ Request serology testing from a commercial laboratory. (5)
- \_\_\_\_\_ Perform other tests for differential diagnosis and refer patient to infectious disease specialist if necessary. (3)
- \_\_\_\_\_ Obtain thorough history to evaluate potential routes of exposure. (4)
- \_\_\_\_\_ Consult with the Texas DSHS for guidance on screening and diagnosis protocol. (2)

**Q4.1 KNOWLEDGE** The following sections are to help us assess Texas physicians' knowledge about the cause, transmission, and clinical aspects of Chagas disease.

Q4.2 How does the vector with the parasite transmit Chagas disease to humans?

- The infected vector penetrates the human host skin during bloodmeal, transmitting parasite through saliva. (1)
- Through infected feces of the vector, that is deposited during the bloodmeal, most commonly when the person rubs the infected feces into the bite wound while scratching the area. (2)
- The infected vector regurgitates after bloodmeal, transmitting parasite to the human. (3)
- None of the above. (4)
- Not sure. (5)

Q4.3 How do the majority of people with Chagas disease living in the United States acquire the infection?

- From drinking unpasteurized juices. (1)
- From exposure to vectors while residing in Mexico, Central, or South America. (2)
- From their mothers (i.e., congenital transmission). (3)
- From another infected person. (4)
- Not sure. (5)

Q4.4 Since becoming a reportable condition in the state of Texas in 2013, approximately how many total Chagas confirmed cases (local and imported) have been reported to the Texas DSHS, between 2013 and 2016?

- Less than 5. (1)
- Between 20 and 30. (2)
- Between 75 and 100. (3)
- More than 1,000. (4)
- Not sure. (5)

Q4.5 Which of the following best describes the clinical course of Chagas disease?

- Acute for 10 to 30 days following exposure to parasite, is self-limiting in most persons within 2 months, and rarely progresses into the chronic phase. (1)
- Acute for a week following exposure to parasite. If left untreated, it is a chronic lifelong infection 2-4 weeks following exposure to parasite. (2)
- Acute for 1-8 weeks following exposure to parasite; asymptomatic for years to decades in the majority of infected persons; but becoming symptomatic in a portion of persons infected with parasite. (3)
- None of the above. (4)
- Not sure. (5)

Q4.6 The **acute** phase of Chagas disease may be characterized by which of the following:

- Fever (1)
- Swelling at the site of inoculation (2)
- No symptoms (3)
- All of the above (4)
- Not sure (5)

Q4.7 Approximately what percentage of patients worldwide with **chronic Chagas** disease eventually develop the clinical (symptomatic) form of the disease?

- Less than 1%. (1)
- Between 20 and 40%. (2)
- More than 50%. (3)
- None of the above. (4)
- Not sure. (5)

Q4.8 Persons infected with **chronic Chagas disease** may develop which of the following?

- Cardiac conduction abnormalities and/ or cardiomyopathy. (1)
- Megaesophagus and/or megacolon. (2)
- Co-clinical manifestations. (3)
- All of the above. (4)
- Not sure. (5)

Q4.9 Which of the following may occur in patients with **chronic Chagas cardiomyopathy**?

- None- can present without clinical manifestations and be asymptomatic. (1)
- Dyspnea on exertion, fatigue, palpitations, dizziness, syncope, and edema. (2)
- Sudden death. (3)
- Any of the above. (4)
- Not sure. (5)

Q4.10 You should request commercial laboratory diagnostic serology tests, initiate a clinical evaluation of the patient, and conduct a thorough history in a patient who:

- Has tested positive for *T cruzi* during a blood donation or has a sibling or mother who is Chagas-positive. (1)
- Was exposed or potentially exposed to a vector in a period longer than 8 weeks. (2)
- Presents with onset of cardiac disease manifestations that are compatible with chronic Chagas cardiomyopathy. (3)
- All of the above. (4)
- Not sure. (5)

Q4.11 In patients who test positive for Chagas disease after a blood donation or from a laboratory diagnostics, obtaining a social history is needed to assess potential routes of exposure, including:

- Travel to or residence in areas endemic for Chagas disease. (1)
- Previous history of blood transfusions or organ/ tissue transplants. (2)
- Possibility of congenital Chagas disease transmission. (3)
- All of the above. (4)
- Not sure. (5)

Q4.12 Which of the following best describes the method(s) for a confirmatory diagnosis of Chagas disease?

- Seropositive results from 2 different immunoassays and/or PCR performed at the CDC. (1)
- Positive serology from blood screening donations. (2)
- Detection of apolipoprotein A-1 (APOA1) upregulation in human serum. (3)
- All of the above. (4)
- Not sure. (5)

Q4.13 Which of the following describes the current treatment options for Chagas disease?

- Benzindazole and nifurtimox are available only under current investigational protocol by the CDC in children up to 18 years of age with chronic infections and in adults up to age 50 with chronic infection who have no indication of advanced cardiomyopathy. (1)
- Benznidazole has been approved by the U.S. Food and Drug Administration (FDA) for patients 2-12 years of age and is available commercially. (4)
- Nifurtimox is only available by the CDC under investigational protocol. (5)
- Second and third choices only. (8)
- Not sure. (7)

Q4.14 Should patients with chronic Chagas disease be treated with antitrypanosomal drugs?

- No, there is no evidence that antitrypanosomal treatment for chronic Chagas disease can be effective. (1)
- Yes, only patients younger than 5 years of age should be treated for chronic Chagas disease. (2)
- Treatment is always recommended for patients up to age 18 years of age and generally recommended for patients aged 18 to 50. (3)
- Only Chagas disease patients manifesting with moderate to severe cardiomyopathy. (4)
- Not sure. (5)

**Q5.1 PRACTICES RELATED TO SCREENING, DIAGNOSING, AND TREATING CHAGAS DISEASE**

The following are about your practices related to the identification, screening, and treatment of actual Chagas disease case(s).

Q5.2 Over the past five years since becoming a reportable condition in Texas, have you directly screened and/ or confirmed a diagnosis for Chagas in patients in your medical care in Texas?

- Yes (1)
- No (2)

*Display This Question:*

*If Q5.2 = Yes*

Q5.3 In the past year, how many patients that you suspected for Chagas disease did you screen and test to confirm diagnosis?

---

*Display This Question:*

*If Q5.2 = Yes*

Q5.4 In the past year, out of those patients that you screened and/ or diagnosed, did any of them receive a positive confirmatory diagnosis?

Yes (8)

No (9)

*Display This Question:*

*If Q5.4 = Yes*

Q5.5 In the past year, if you screened suspected Chagas patients, how many that were positive were confirmed by the CDC?

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*Display This Question:*

*If Q5.4 = Yes*

Q5.6 Please provide additional comments regarding your experience in confirming a Chagas disease diagnosis:

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*Display This Question:*

*If Q5.2 = Yes*



Q5.7 In the past year, if you have screened suspected Chagas patients, what method(s) did you use to screen for Chagas disease? Select all that apply.

- Physical assessment. (2)
- 12 lead strip electrocardiogram. (3)
- Patient's medical and social history. (4)

*Display This Question:*

*If Q5.2 = Yes*

Q5.8 If you screened patients for Chagas disease in the past year, did you consult with local/ county health departments to coordinate treatment?

- Yes (1)
- No (2)

*Display This Question:*

*If Q5.2 = Yes*

Q5.9 If you screened for patients for Chagas disease in the past year, did you coordinate with the CDC to confirm diagnosis?

Yes (1)

No (2)

*Display This Question:*

*If Q5.2 = Yes*

Q5.10 If you screened and/ or diagnosed patients for Chagas disease in the past year, what method(s) did you use to confirm diagnosis for Chagas disease? Select all that apply.

PCR performed at the CDC. (1)

Commercial antibody testing- ARUP Lab. (2)

Commercial antibody testing- Mayo Medical Lab. (3)

Commercial antibody testing- Quest Diagnostics. (4)

Commercial antibody testing- Labcorp. (5)

Not sure. (6)

*Display This Question:*

*If Q5.2 = Yes*

Q5.11 If you screened and/ or diagnosed patients for Chagas disease in the past year, how often did you coordinate with the CDC for treatment?

Always (1)

Sometimes (2)

Never (4)

Not sure (3)

*Display This Question:*

*If Q5.2 = Yes*

Q5.12 Please provide additional comments regarding your experience obtaining and coordinating treatment for patient(s):

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*Display This Question:*  
*If Q5.2 = Yes*

Q5.13 If you screened and/ or diagnosed patients for Chagas in the past year, how often did you coordinate with the local health department and/ or Texas DSHS to confirm diagnosis?

- Always (1)
- Sometimes (2)
- Never (4)
- Not sure (3)

*Display This Question:*  
*If Q5.2 = Yes*

Q5.14 Please provide additional comments regarding your experience in coordinating with local and state health department officials when diagnosing a Chagas patient(s):

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*Display This Question:*  
*If Q5.2 = Yes*

Q5.15 If you screened and/ or diagnosed patients for Chagas disease in the past year and diagnosis was confirmed, please indicate the classification of the case(s):

- Acute (1)
- Chronic-indeterminate (2)
- Chronic-cardiomyopathy (3)
- Chronic-gastrointestinal (4)
- Other (6)
- Not sure (5)

*Display This Question:*

*If Q5.15 = Other*

Q5.16 Please describe the classification of the Chagas case(s) if "other" was selected:

*Display This Question:*

*If Q5.2 = Yes*

Q5.17 Please indicate the source(s) of transmission:

- Locally-acquired (1)
- Imported (2)
- Not sure (3)

*Display This Question:*

*If Q5.2 = Yes*

Q5.18 Did you refer out the patient to any other specialist?

- Yes (1)
- No (2)

*Display This Question:*

*If Q5.18 = Yes*

Q5.19 If you did refer out, please indicate to what other physician specialty:

---

*Display This Question:*

*If Q5.2 = Yes*

Q5.20 Was the patient referred to you by another physician?

Yes (1)

No (2)

*Display This Question:*

*If Q5.20 = Yes*

Q5.21 What was the physician specialty/ies that referred the Chagas patient(s) to you?

---

**Q6.1 PHYSICIAN PRACTICES**

The following are Chagas disease screening and diagnosing practices related to your medical specialty.

Q6.2 In general, how often do you consider each of the following as exposure risks for Chagas disease in your patients?

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Always (5)	N/A (6)
a. Mother or sibling with Chagas disease. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. History of blood transfusions or organ/tissue transplants. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. History of travel to Mexico, Central, and South America. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Consumption of foods or drinks contaminated with the parasite. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q6.3 In the past 5 years while practicing medicine in Texas, have provided care to a Chagas disease patient with a blood donation letter?

- Yes (1)
- No (2)

Display This Question:  
If Q6.3 = Yes

Q6.4 How often did you perform the following in patients under your medical care who receive a positive Chagas diagnosis (i.e., letter) from a **blood donation screening**?

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Always (5)	N/A (6)
a. Perform a physical examination. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Request commercial laboratory diagnostics. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Review the patient's travel history. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Perform other screening tests for differential diagnosis (e.g., ECG). (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Refer to a cardiologist. (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Refer to an infectious disease specialist. (15)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q6.5 In the past 5 years while practicing medicine in Texas, have you had a patient that was exposed to the vector seek medical care from you?

Yes (1)

No (2)

*Display This Question:*  
If Q6.5 = Yes

Q6.6 How often did you perform the following in patients under your medical care who **were exposed to a vector**?

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Always (5)	N/A (6)
a. Perform a physical examination. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Request commercial laboratory diagnostics. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Review the patient's travel history. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Perform other screening tests for differential diagnosis (e.g., ECG). (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Refer to an infectious disease specialist. (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Consult with Texas DSHS to confirm vector and/or presence of parasite. (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Q6.7 In thinking about resources you reference when managing the care of a patient who may potentially have Chagas disease, how often do you access:

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Always (5)	N/A (6)
a. Medical websites (e.g., UpToDate, MedlinePlus, etc.) (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Official local or county health department websites. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. The Texas DSHS website. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. The CDC website. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Official communiques and health alerts from Texas DSHS. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Email alerts from the Texas Medical Association. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Morbidity and Mortality Weekly Report (MMWR) email updates from the CDC. (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q6.8 Which of the following would you be interested in accessing in order to strengthen your ability to help patients with Chagas disease? Select all that apply.

- Courses (1)
- Seminars (2)
- Manuals (3)
- Other resources (4)

*Display This Question:*

*If Q6.8 = Other resources*

Q6.9 If you indicated other, please describe:

---

Q7.1 **DEMOGRAPHICS** The following section is about demographics and your medical practice.

Q7.2 How many years have you been practicing in family or general practice?

- Less than 5 years. (1)
- 5 to 10 years. (2)
- 10 to 15 years. (3)
- 15 to 20 years. (4)
- More than 20 years. (5)

Q7.3 Which of the following best describes the current type of medical setting you currently practice in?

- Private (1)
- Teaching (2)
- Community (3)
- Other (4)

*Display This Question:*

*If Q7.3 = Other*

Q7.4 If other, please describe:


---

Q7.5 Which of the following best describes the setting where you practice at?

- Urbanized area (i.e., 50,000 or more people). (1)
- Rural area (i.e., at least 2,500 people but than 50,000). (2)
- None of the above. (3)

Q7.6 In your current medical practice, what proportion of total patients you see on average that are Hispanics/ Latinos?

0 10 20 30 40 50 60 70 80 90 100

Click to write Choice 1 ( )	
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**Q7.7 PARTICIPANT DEMOGRAPHICS- PART 2**

Q7.8 Are you male or female?

- Male (1)
- Female (2)



Q7.9 What is your year of birth? (YYYY)

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Q7.10 Please indicate if you received medical training in any of the following places:

- Mexico (1)
- Central America (2)
- South America (3)
- None of the above (4)
- Prefer not to answer (5)

---

*Display This Question:*

*If Q7.10 = Central America*

Q7.11 If you received medical training in Central America, indicate the country:

---

*Display This Question:*

*If Q7.10 = South America*

Q7.12 If you received medical training in South America, indicate the country:

---

Q8.1

## **CONCLUSION**

Q8.2 Thank you for participating in this questionnaire. We know your time is valuable. Your responses will remain anonymous and will be used to identify a baseline of knowledge and awareness of Chagas disease throughout the state. In addition to the questionnaire, we are conducting additional research via phone interviews with practicing physicians to identify and explore additional barriers related to screening and diagnosing of Chagas disease in Texas. The goal is to understand the challenges that lead to missed Chagas diagnosis and frame recommendations to improve awareness and education among practicing physicians in Texas. Questionnaire responses will be kept separate and confidential if you do decide to provide your contact information to participate in the phone interviews.

Q8.3 Would you like participate in a 15-minute phone interview?

Yes, I would like to participate. (1)

No, I decline. (2)

*Display This Question:*

*If Q8.3 = Yes, I would like to participate.*



Q8.4 Please provide your email:

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# Chagas Disease Questionnaire for Infectious Disease Specialists

## SURVEY FLOW

Consent and Eligibility  
Definitions  
Attitudes (5 Questions)  
Knowledge (14 Questions)  
Knowledge for Infectious Disease Specialists (5 Questions)  
Practices: Actual Chagas (20 Questions)  
Practices: Other Activities- Rated (7 Questions)  
Participant Demographics (10 Questions)  
Questionnaire Conclusion

Q1.2 Thank you for your interest in completing the following online questionnaire. The purpose of this brief 20-minute questionnaire is to gain a better understanding of Chagas disease awareness, and practices among cardiologists, infectious disease specialists and family physicians licensed by the Texas Medical Board.

**If you would like to participate in the questionnaire, please continue to the next page.**

**If you do not wish to participate in the questionnaire, we thank you for your time and interest. You can close this page now.**

Q1.3

## INFORMED CONSENT

### INVITATION TO TAKE PART

You are invited to take part in a research project called, Chagas Disease Awareness among Physicians in Texas, conducted by doctoral candidate Gerardo J. Pacheco of the University of Texas Health Science Center at Houston (UTHealth) School of Public Health. For this research project, he will be called the Principal Investigator or PI.

Your decision to take part is voluntary. This research project has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Health Science Center at Houston as HSC-SPH-17-1039. Although we appreciate your valuable input in this questionnaire, please be advised that you may refuse to take part or choose to stop taking part, at any time. Additionally, you may also refuse to answer any question(s).

### PROCEDURES

If you agree to take part in this study, you will first confirm your consent by answering the question below. Once you consent, you will be directed to the questionnaire. It contains sections regarding your attitudes and perspectives, knowledge, and current practices about Chagas disease in Texas. At the completion of the questionnaire, you will be prompted to respond whether or not you would like to participate in a 15-

minute key informant phone interview. You will then be prompted to provide your email address if you agree to participate. Conversely, if you decline, you will be directed to a page with the answer key to the Chagas disease knowledge questions.

## PURPOSE

The purpose of this research study is to examine the level of knowledge, awareness, and practices among licensed physicians in Texas regarding screening, diagnosis, and treatment of Chagas as well as to illustrate the potential for missed cases for Chagas disease diagnosis in Texas.

## TIME COMMITMENT

The questionnaire will require 20-25 minutes to complete and will be available for up to two weeks.

## BENEFITS

The potential benefits to participating in this study include the self-assessment of Chagas disease, which will allow you as a physician to understand where your current knowledge deficits might be and if further resources should be reviewed to be up to date. In more general terms, the results from this study can help point towards statewide knowledge deficits and gaps that might be present and push towards recommendations for targeted outreach and workshops (e.g., by specialty, location, etc.).

You may receive no direct benefit from being in the study; however, you taking part may help patients receive better in the future.

An answer key is provided at the end of the questionnaire for you to review the Chagas disease knowledge section.

## RISKS AND/OR DISCOMFORTS

The risks and discomfort associated with participation in this study are no greater than those ordinarily encountered in daily life or during the performance of routine exams. The experience is expected to be informative and interesting and thus a generally positive experience.

Confidentiality: Although every measure will be taken to properly safeguard all data pertaining to this study, there is a possible risk of breach of confidentiality.

Questionnaire: You may get tired when we are asking you questions or you are completing questionnaires. You do not have to answer any questions you do not want to answer.

## STUDY WITHDRAWAL

Your decision to take part is voluntary. Although we appreciate your valuable input in this questionnaire, please be advised that you may refuse to take part or choose to stop taking part, at any time. You may decide to stop taking part in the study at any time, but you must submit in writing to the PI if you choose to have your responses excluded from the analysis.

## COSTS, REIMBURSEMENT AND COMPENSATION

If you decide to take part in this research study, you will not incur any additional costs.

You will not be paid for taking part in this study.

## CONFIDENTIALITY

Identifying information will not appear on records retained by the sponsor, with the exception of your birth year and your email address if you choose to provide that information for participation in follow-up interviews. You will not be personally identified in any reports or publications that may result from this study.

## QUESTIONS

If you have questions at any time about this research study, please feel free to contact the PI at (915) 240-2821 as he will be glad to answer your questions. You can contact the PI to discuss problems, voice concerns, obtain information, and offer input in addition to asking questions about the research.

If you have any questions or concerns about your rights as a research subject, call the Committee for the Protection of Human Subjects at (713) 500-7943. You may also call the Committee if you wish to discuss problems, concerns, and questions; obtain information about the research; and offer input about current or past participation in a research study.

## SIGNATURES

Submit your consent below to participate in this research only if you understand the information given to you about the research and you choose to take part. No signature is required to proceed if you confirm your consent below. Make sure that any questions have been answered and that you understand the study.

CPHS STATEMENT: This study (HSC-SPH-17-1039) has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Health Science Center at Houston. For any questions about research subject's rights, or to report a research-related injury, call the CPHS at (713) 500-7943.

Q1.5 If you wish to participate, please indicate below:

- Yes, I agree to participate. (1)
- No, I do not wish to participate. (2)

*Skip To: End of Survey If Q1.5 = No, I do not wish to participate.*

Q1.6 Are you and MD or DO licensed by the Texas Medical Board to practice in the state of Texas?

Yes (1)

No (2)

*Display This Question:*

*If Q1.6 = No*

Q1.7

Thank you for your interest. However, this questionnaire is intended for physicians.

**You may close this page now.**

*Skip To: End of Survey If Q1.7() Is Displayed*

Q1.8 Please indicate your primary medical specialty. If it is not listed below, select "Other":

General Practice/ Family Medicine (1)

Infectious Disease (2)

Cardiology (3)

Other (4)

*Display This Question:*

*If Q1.8 = Other*

Q1.9 If Other, please describe:

---

## Q2.1 DEFINITIONS

Definitions used for the purpose of this questionnaire:

**Screening:** clinical decision-making process or differential diagnosis to determine if further laboratory diagnostics are required.

**Diagnosis:** the clinical and serological testing required to confirm Chagas disease.

**Vector:** Triatomine or Reduviid insect that is able to transmit the parasite *T cruzi* that causes Chagas disease.



Q3.1

**ATTITUDES ON CHAGAS DISEASE**

The following sections are about your **opinions and attitudes** regarding Chagas disease.

Q3.2 To what extent do you agree or disagree with the following statements?

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
a. Chagas disease is <b>under diagnosed</b> in Texas (i.e., failure to recognize or correctly diagnose a disease or condition in a significant proportion of the population). (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Chagas disease is <b>potentially misdiagnosed</b> in patients (e.g., incorrectly diagnosed cases of chronic Chagas cardiomyopathy for idiopathic cardiomyopathy). (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. The process required to confirm Chagas disease is complex and thus time consuming. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. In Texas, diagnosis and treatment of Chagas disease is a relatively easy process with few barriers. (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q3.3 As an infectious disease specialist, to what extent do you agree or disagree with the following statements?

	Strongly agree (1)	Somewhat agree (2)	Neither agree or disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
a. My medical training prepared me to recognize patients who may need to be screened for Chagas disease. (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I routinely screen for Chagas disease in patients who present with risk factors. (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Accessing Chagas disease treatment is not a barrier for the population I serve. (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Chagas disease patients are more likely to present with comorbidities than non-Chagas disease patients. (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q3.4 How confident are you in performing the following when screening for Chagas disease in your patient population?

	Very confident (1)	Somewhat confident (2)	Not at all confident (3)
a. Identifying risk factors for Chagas disease in patients. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Recognizing the vector that transmits Chagas disease. (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Obtaining a patient's social history to identify potential risk factors for Chagas disease. (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Using electrocardiogram (ECG) to screen and diagnose for chronic Chagas disease. (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q3.5 How confident are you in performing the following in patients with Chagas disease?

	Very confident (1)	Somewhat confident (2)	Not at all confident (3)
a. Contacting and coordinating with the local and/or state health department when consulting about a Chagas patient. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Contacting, coordinating, and following-up with the Centers for Disease Control and Prevention (CDC) when consulting about a Chagas patient. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Requesting the Current Procedural Terminology laboratory codes for diagnosing Chagas disease. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Continuing to provide follow-up medical care to Chagas patients. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q3.6 What would be the recommended sequence when managing care of a Chagas patient who has a blood donation letter? Please rank from 1 to 5 on how you would prioritize (drag and drop).

\_\_\_\_\_ Coordinate with local health department and Texas Department of State Health Services (DSHS) to confirm diagnosis. (1)

\_\_\_\_\_ Consult with the CDC to manage patient's treatment protocol. (2)

\_\_\_\_\_ Perform baseline clinical workup that includes physical exam, 12-lead ECG, and additional testing if warranted. (5)

\_\_\_\_\_ Confirm diagnosis via commercial serology testing. (3)

\_\_\_\_\_ Obtain thorough history to evaluate potential routes of exposure. (4)

**Q4.1 KNOWLEDGE** The following sections are to help us assess Texas physicians' knowledge about the cause, transmission, and clinical aspects of Chagas disease.

Q4.2 How does the vector with the parasite transmit Chagas disease to humans?

The infected vector penetrates the human host skin during bloodmeal, transmitting parasite through saliva. (1)

Through infected feces of the vector, that is deposited during the bloodmeal, most commonly when the person rubs the infected feces into the bite wound while scratching the area. (2)

The infected vector regurgitates after bloodmeal, transmitting parasite to the human. (3)

None of the above. (4)

Not sure. (5)

Q4.3 How do the majority of people with Chagas disease living in the United States acquire the infection?

From drinking unpasteurized juices. (1)

From exposure to vectors while residing in Mexico, Central, or South America. (2)

From their mothers (i.e., congenital transmission). (3)

From another infected person. (4)

Not sure. (5)

Q4.4 Since becoming a reportable condition in the state of Texas in 2013, approximately how many total Chagas confirmed cases (local and imported) have been reported to the Texas DSHS, between 2013 and 2016?

- Less than 5. (1)
- Between 20 and 30. (2)
- Between 75 and 100. (3)
- More than 1,000. (4)
- Not sure. (5)

Q4.5 Which of the following best describes the clinical course of Chagas disease?

- Acute for 10 to 30 days following exposure to parasite, is self-limiting in most persons within 2 months, and rarely progresses into the chronic phase. (1)
- Acute for a week following exposure to parasite. If left untreated, it is a chronic lifelong infection 2-4 weeks following exposure to parasite. (2)
- Acute for 1-8 weeks following exposure to parasite; asymptomatic for years to decades in the majority of infected persons; but becoming symptomatic in a portion of persons infected with parasite. (3)
- None of the above. (4)
- Not sure. (5)

Q4.6 The **acute** phase of Chagas disease may be characterized by which of the following:

- Fever (1)
- Swelling at the site of inoculation (2)
- No symptoms (3)
- All of the above (4)
- Not sure (5)

Q4.7 In addition to heart failure, what major clinical disorders manifest frequently and concurrently that lead to chronic Chagas cardiomyopathy?

- Cardiac arrhythmias (1)
- Thromboembolism (systemic and pulmonary) (2)
- Chest pain syndrome (3)
- All of the above (4)
- Not sure (5)

Q4.8 Approximately what percentage of patients worldwide with **chronic Chagas** disease eventually develop the clinical (symptomatic) form of the disease?

- Less than 1%. (1)
- Between 20 and 40%. (2)
- More than 50%. (3)
- None of the above. (4)
- Not sure. (5)

Q4.9 Persons infected with **chronic Chagas disease** may develop which of the following?

- Cardiac conduction abnormalities and/ or cardiomyopathy. (1)
- Megaesophagus and/or megacolon. (2)
- Co-clinical manifestations. (3)
- All of the above. (4)
- Not sure. (5)

Q4.10 Which of the following may occur in patients with **chronic Chagas cardiomyopathy**?

- None- can present without clinical manifestations and be asymptomatic. (1)
- Dyspnea on exertion, fatigue, palpitations, dizziness, syncope, and edema. (2)
- Sudden death. (3)
- Any of the above. (4)
- Not sure. (5)

Q4.11 You should request commercial laboratory diagnostic serology tests, initiate a clinical evaluation of the patient, and conduct a thorough history in a patient who:

- Has tested positive for *T cruzi* during a blood donation or has a sibling or mother who is Chagas-positive. (1)
- Was exposed or potentially exposed to a vector in a period longer than 8 weeks. (2)
- Presents with onset of cardiac disease manifestations that are compatible with chronic Chagas cardiomyopathy. (3)
- All of the above. (4)
- Not sure (5)

Q4.12 In patients who test positive for Chagas disease after a blood donation or from a laboratory diagnostics, obtaining a social history is needed to assess potential routes of exposure, including:

- Travel to or residence in areas endemic for Chagas disease. (1)
- Previous history of blood transfusions or organ/ tissue transplants. (2)
- Possibility of congenital Chagas disease transmission. (3)
- All of the above. (4)
- Not sure. (5)

Q4.13 Which of the following best describes the method(s) for a confirmatory diagnosis of Chagas disease?

- Seropositive results from 2 different immunoassays and/or PCR performed at the CDC. (1)
- Positive serology from blood screening donations. (2)
- Detection of apolipoprotein A-1 (APOA1) upregulation in human serum. (3)
- All of the above. (4)
- Not sure. (5)

Q4.14 Which of the following describes the current treatment options for Chagas disease?

- Benzindazole and nifurtimox are available only under current investigational protocol by the CDC in children up to 18 years of age with chronic infections and in adults up to age 50 with chronic infection who have no indication of advanced cardiomyopathy. (1)
- Benznidazole has been approved by the U.S. Food and Drug Administration (FDA) for patients 2-12 years of age and is available commercially. (4)
- Nifurtimox is only available by the CDC under investigational protocol. (5)
- Second and third choices only. (8)
- Not sure. (7)

Q4.15 Should patients with chronic Chagas disease be treated with antitrypanosomal drugs?

- No, there is no evidence that antitrypanosomal treatment for chronic Chagas disease can be effective. (1)
- Yes, only patients younger than 5 years of age should be treated for chronic Chagas disease. (2)
- Treatment is always recommended for patients up to age 18 years of age and generally recommended for patients aged 18 to 50. (3)
- Only Chagas disease patients manifesting with moderate to severe cardiomyopathy. (4)
- Not sure. (5)

**Q5.1 SPECIFIC KNOWLEDGE ON CHAGAS DISEASE SCREENING & DIAGNOSTICS** The following questions are specific to you as an infectious disease specialist in identifying the clinical manifestations of Chagas disease and screening the patient.



Q5.2 What are the important elements of the clinical evaluation of a newly diagnosed chronic Chagas patient who is **asymptomatic**?

- Complete physical examination, complete blood count (CBC), and chemistry panel. (1)
- Complete physical examination, electrocardiogram (ECG) with 30 second rhythm strip, and detailed history. (7)
- Complete physical examination, ECG with 30 second rhythm strip, chest radiograph, barium swallow, and detailed history. (8)
- None of the above. (9)
- Not sure. (10)

Q5.3 In general, which of the following is typical of chronic Chagas cardiomyopathy?

- Right bundle branch block. (1)
- Ventricular tachycardia. (6)
- Left anterior fascicular block. (7)
- All of the above. (8)
- Not sure. (9)

Q5.4 In patients with chronic Chagas cardiomyopathy, cardiac examination typically demonstrates which of the following?

- Murmurs of mitral and/ or tricuspid regurgitation. (1)
- Wide splitting of the second heart sound due to right bundle branch block. (6)
- A prominent diffuse apical thrust. (7)
- All of the above. (8)
- Not sure. (9)

Q5.5 Reactivation of Chagas disease is a concern for patients who:

- Are chronically infected and are receiving immuno-suppressive treatment because of organ transplantation. (1)
- Are chronically infected and have HIV/AIDS. (2)
- Are chronically infected and receive a live-attenuated influenza vaccine. (3)
- First and second responses only. (4)
- Not sure. (5)

Q5.6 Which of the following describes the current treatment options for Chagas disease?

- Benzindazole and nifurtimox are available only under current investigational protocol by the CDC in children up to 18 years of age with chronic infections and in adults up to age 50 with chronic infection who have no indication of advanced cardiomyopathy. (1)
- Benznidazole has been approved by the U.S. Food and Drug Administration (FDA) for patients 2-12 years of age and is available commercially. (4)
- Nifurtimox is only available by the CDC under investigational protocol. (5)
- Second and third responses only. (6)
- Not sure. (7)

**Q6.1 PRACTICES RELATED TO SCREENING, DIAGNOSING, AND TREATING CHAGAS DISEASE**

The following are about your practices related to the identification, screening, and treatment of actual Chagas disease case(s).

Q6.2 Over the past five years since becoming a reportable condition in Texas, have you directly screened and/ or confirmed a diagnosis for Chagas in patients in your medical care in Texas?

- Yes (1)
- No (2)

*Display This Question:*

*If Q6.2 = Yes*

Q6.3 In the past year, how many patients that you suspected for Chagas disease did you screen and test to confirm diagnosis?

---

*Display This Question:*  
*If Q6.2 = Yes*

Q6.4 In the past year, out of those patients that you screened and/ or diagnosed, did any of them receive a positive confirmatory diagnosis?

- Yes (8)
- No (9)

*Display This Question:*  
*If Q6.4 = Yes*

Q6.5 In the past year, if you screened suspected Chagas patients, how many that were positive were confirmed by the CDC?

\_\_\_\_\_

*Display This Question:*  
*If Q6.4 = Yes*

Q6.6 Please provide additional comments regarding your experience in confirming a Chagas disease diagnosis:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

*Display This Question:*

*If Q6.2 = Yes*

Q6.7 In the past year, if you have screened suspected Chagas patients, what method(s) did you use to screen for Chagas disease? Select all that apply.

- Physical assessment. (2)
- 12 lead strip electrocardiogram. (3)
- Patient's medical and social history. (4)

*Display This Question:*

*If Q6.2 = Yes*

Q6.8 If you screened patients for Chagas disease in the past year, did you consult with local/ county health departments to coordinate treatment?

- Yes (1)
- No (2)

*Display This Question:*

*If Q6.2 = Yes*

Q6.9 If you screened patients for Chagas disease in the past year, did you coordinate with the CDC to confirm diagnosis?

- Yes (1)
- No (2)

*Display This Question:*

*If Q6.2 = Yes*

Q6.10 If you screened and/ or diagnosed patients for Chagas disease in the past year, what method(s) did you use to confirm diagnosis for Chagas disease? Select all that apply.

- PCR performed at the CDC. (1)
- Commercial antibody testing- ARUP Lab. (2)
- Commercial antibody testing- Mayo Medical Lab. (3)
- Commercial antibody testing- Quest Diagnostics. (4)
- Commercial antibody testing- Labcorp. (5)
- Not sure. (6)

*Display This Question:*  
*If Q6.2 = Yes*

Q6.11 If you screened and/ or diagnosed patients for Chagas disease in the past year, how often did you coordinate with the CDC for treatment?

- Always (1)
- Sometimes (2)
- Never (4)
- Not sure (3)

*Display This Question:*  
*If Q6.2 = Yes*

Q6.12 Please provide additional comments regarding your experience obtaining and coordinating treatment for patient(s):

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*Display This Question:*  
*If Q6.2 = Yes*

Q6.13 If you screened and/ or diagnosed patients for Chagas disease in the past year, how often did you coordinate with the local health department and/ or Texas DSHS to confirm diagnosis?

- Always (1)
- Sometimes (2)
- Never (4)
- Not sure (3)

*Display This Question:*  
*If Q6.2 = Yes*

Q6.14 Please provide additional comments regarding your experience in coordinating with local and state health department officials when diagnosing a Chagas patient(s):

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*Display This Question:*  
*If Q6.2 = Yes*

Q6.15 If you screened patients in the past year and diagnosis was confirmed, please indicate the classification of the case(s):

- Acute (1)
- Chronic-indeterminate (2)
- Chronic-cardiomyopathy (3)
- Chronic-gastrointestinal (4)
- Other (6)
- Not sure (5)

*Display This Question:*

*If Q6.15 = Other*

Q6.16 Please describe the classification of the Chagas case(s) if "other" was selected:

---

*Display This Question:*

*If Q6.2 = Yes*

Q6.17 Please indicate the source(s) of transmission:

- Locally-acquired (1)
- Imported (2)
- Not sure (3)

*Display This Question:*

*If Q6.2 = Yes*

Q6.18 Did you refer out the patient to any other specialist?

- Yes (1)
- No (2)

*Display This Question:*

*If Q6.18 = Yes*

Q6.19 If you did refer out, please indicate to what other physician specialty:

---

*Display This Question:*

*If Q6.2 = Yes*

Q6.20 Was the patient referred to you by another physician?

Yes (1)

No (2)

*Display This Question:*

*If Q6.20 = Yes*

Q6.21 What was the physician specialty/ies that referred the Chagas patient(s) to you?

---

#### **Q7.1 PHYSICIAN PRACTICES**

The following are Chagas disease screening and diagnosing practices related to your medical specialty.



Q7.2 In general, how often do you consider each of the following as exposure risks for Chagas disease in your patients?

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Always (5)	N/A (6)
a. Mother or sibling with Chagas disease. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. History of blood transfusions or organ/tissue transplants. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Travel to Mexico, Central, or South America. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Consumption foods or drinks contaminated with the parasite. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q7.3 In general, how often do you perform the following in patients under your medical care who present with **idiopathic cardiomyopathy**?

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Always (5)	N/A (6)
a. Review the patient's travel history. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Look for signs of cardiac arrhythmias that may arise due to chronic Chagas cardiomyopathy. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Evaluate patient's cardiopulmonary function (i.e., exercise stress test). (17)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Perform cardiovascular testing (chest x-ray, echocardiogram, etc.) to assess myocardial damage. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q7.4 In the past 5 years while practicing medicine in Texas, have you provided care to a Chagas disease patient with a blood donation letter?

- Yes (1)
- No (2)

*Display This Question:*  
If Q7.4 = Yes

Q7.5 In the past 5 years while practicing in Texas, how often did you perform the following in patients under your medical care who received a positive Chagas diagnosis (i.e., letter) from a **blood donation screening**?

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Always (5)	N/A (6)
a. Review the patient's travel history. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Request serology to confirm Chagas diagnosis. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Evaluate patient's cardiopulmonary function (i.e., exercise stress test). (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Perform cardiovascular testing (chest x-ray, echocardiogram, etc.) to assess myocardial damage. (20)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Consult with the Texas DSHS to manage treatment. (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Consult with the CDC to manage treatment. (21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q7.6 In thinking about resources you reference when managing the care of a patient who may potentially have Chagas disease, how often do you access:

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Always (5)	N/A (6)
a. Medical websites (e.g., UpToDate, MedlinePlus, etc.) (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Official local or county health department websites. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. The Texas DSHS website. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. The CDC website. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Official communiques and health alerts from Texas DSHS. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Email alerts from the Texas Medical Association. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Morbidity and Mortality Weekly Report (MMWR) email updates from the CDC. (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q7.7 Which of the following would you be interested in accessing in order to strengthen your ability to help patients with Chagas disease? Select all that apply.

Courses (1)

Seminars (2)

Manuals (3)

Other resources (4)

*Display This Question:*

*If Q7.7 = Other resources*

Q7.8 If you indicated other, please describe:

---

Q8.1 **DEMOGRAPHICS** The following section is about demographics and your medical practice.

Q8.2 How many years have you been practicing in family or general practice?

Less than 5 years. (1)

5 to 10 years. (2)

10 to 15 years. (3)

15 to 20 years. (4)

More than 20 years. (5)

Q8.3 Which of the following best describes the current type of medical setting you currently practice in?

Private (1)

Teaching (2)

Community (3)

Other (4)

---

Display This Question:

If Q8.3 = Other

Q8.4 If other, please describe:

---

Q8.5 Which of the following best describes the setting where you practice at?

- Urbanized area (i.e., 50,000 or more people). (1)
- Rural area (i.e., at least 2,500 people but than 50,000). (2)
- None of the above. (3)

Q8.6 In your current medical practice, what proportion of total patients you see on average that are Hispanics/ Latinos?

0 10 20 30 40 50 60 70 80 90 100

Click to write Choice 1 ( )



**Q8.7 PARTICIPANT DEMOGRAPHICS- PART 2**

Q8.8 Are you male or female?

- Male (1)
- Female (2)

Q8.9 What is your year of birth? (YYYY)

---

Q8.10 Please indicate if you received medical training in any of the following places:

- Mexico (1)
- Central America (2)
- South America (3)
- None of the above (4)
- Prefer not to answer (5)

*Display This Question:*

*If Q8.10 = Central America*

Q8.11 If you received medical training in Central America, indicate the country:

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*Display This Question:*

*If Q8.10 = South America*

Q8.12 If you received medical training in South America, indicate the country:

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Q9.1

## **CONCLUSION**

Q9.2 Thank you for participating in this questionnaire. We know your time is valuable. Your responses will remain anonymous and will be used to identify a baseline of knowledge and awareness of Chagas disease throughout the state. In addition to the questionnaire, we are conducting additional research via phone interviews with practicing physicians to identify and explore additional barriers related to screening and diagnosing of Chagas disease in Texas. The goal is to understand the challenges that lead to missed Chagas diagnosis and frame recommendations to improve awareness and education among practicing physicians in Texas. Questionnaire responses will be kept separate and confidential if you do decide to provide your contact information to participate in the phone interviews.

---

Q9.3 Would you like participate in a 15-minute phone interview?

- Yes, I would like to participate. (1)
- No, I decline. (2)

---

*Display This Question:*

*If Q9.3 = Yes, I would like to participate.*



Q9.4 Please provide your email:

---



## Appendix C: Semi-Structured Interview Scripts and Forms

Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ Time: \_\_\_\_\_ Study ID: \_\_\_\_ \_

### **Semi-structured Interview Script for Physicians: Managed Care of Chagas Patients**

#### **Introduction**

- *Good morning/ afternoon. Thank you for your time. My name is Jerry Pacheco. I'm a doctoral candidate at the UT School of Public Health.*
- *As part of my doctoral dissertation, I will focus on Chagas disease in Texas and the level of awareness among healthcare providers. I will be collecting primary data for my research, as part of my aims, I am collecting quantitative data (that is data from online questionnaires) as well as qualitative data—that is the data I hope to collect today through this interview.*
- *We hope that through this interview, we can dive further and explore challenges and barriers that physicians have experienced that way we can frame recommendations for improving outreach, education, and resources to physicians in Texas about Chagas disease so that the disease is diagnosed and managed on time.*
- *Thank you for agreeing to participate.*

#### **Informed consent**

Explain the risks/ benefits and confidentiality and how results will be used (refer them to form)

- *I emailed a copy of the consent. Please review and keep for your records. The risks and discomfort associated with participation in this study are no greater than those ordinarily encountered in daily life or during the performance of routine exams. The experience is expected to be informative and interesting and thus a generally positive experience.*
- *Your decision to take part is voluntary. You may decide to stop taking part in the study at any time.*
- *I would like to make an audio recording of our discussion, so that I can have an accurate record of the information that you provide to me.*
- *This study (HSC-SPH-17-1039) has been reviewed by the Committee for the Protection of Human Subjects of the University of Texas Health Science Center at Houston.*
- *If you have any questions refer to the Informed Consent Form I email you for the university research office's contact information..*

#### **Confirm provider specialty and/ or treatment of CD patients**

- *Can you confirm your specialty?*

Provider Specialty:

- Infectious Disease
- Cardiology
- Other: \_\_\_\_\_

**Demographics and type of practice**

1. How many years of have you been in your primary specialization? \_\_\_\_\_
2. How would you describe your current medical practice?
  - a. institution, community clinic, private
  - b. rural or urban
3. Did you receive any medical training or practice in Mexico, Central or South America? Please describe:  
 \_\_\_\_\_  
 \_\_\_\_\_

**Guiding Questions**

*I will be asking questions regarding the continuum of care, which includes screening, diagnosis, treatment, and follow-up of care. For the purpose of my research and this interview:*

**Screening:** *is the clinical, decision-making process or differential diagnosis to determine if further laboratory diagnosis are required.*

**Diagnosis:** *the clinical and serological testing required to confirm Chagas disease.*

1. Can you describe your experience in managing the care of a Chagas disease patient?
  - a. How many cases have you managed? Screened: \_\_\_ Diagnosed: \_\_\_ Treated:\_\_\_ Total: \_\_\_
    - i. Were they in Texas? Mexico? Central America? South America?
    - ii. When? \_\_\_\_\_
  - b. How did that patient(s) come to your care? \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_
  - c. Can you provide a brief summary, from your recollection, of the **case study/ studies**?
    - i. Local:                      Imported:
    - ii. Acute:                      Indeterminate:                      Chronic:
    - iii. Patient demographics (age, sex, Ethnicity/ race)

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d. *What resources did you review or whom did you consult with to better understand the process to screen, diagnose, or treat a Chagas disease patient?*

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e. *What was the most important lesson(s) learned from your experience(s)?*

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f. *What were the most challenging aspects or barriers in delivering care to your patient with Chagas disease?* \_\_\_\_\_

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i. **Screening specific:** \_\_\_\_\_

ii. **Diagnosis specific:** \_\_\_\_\_

iii. **Treatment specific:** \_\_\_\_\_

2. *Did you ever consider a Chagas disease diagnosis prior to your first experience in managing a Chagas patient?*

a. *Why? Why not?* \_\_\_\_\_

---

---

b. *What was your level of knowledge and skills in diagnosing patients with Chagas disease **before** your experience(s) managing your first Chagas disease patient(s)?*

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c. *What was your level of knowledge and skills in diagnosing patients with Chagas disease **after** your experience(s) managing your first Chagas disease patient(s)?*

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d. *Looking back, what are some considerations or resources that you now know of that could have been helpful during your first experience managing the care of a Chagas disease patient?*

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e. *Did you have sufficient education/ training to be able to screen, diagnose, and/ or treat Chagas disease patients? \_\_\_\_\_*

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3. *Do you think that Chagas disease is a bigger problem in Texas than other states in the U.S.?*

a. *Why? Why not? \_\_\_\_\_*

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---

b. *Do we need to increase the level of outreach and education that we provide to physicians in Texas? \_\_\_\_\_*

---

c. *How can we increase communication to physicians in Texas for them to better understand Chagas disease? \_\_\_\_\_*

---

4. *What proportion of Hispanic/ Latino population do you serve in your medical practice?*

\_\_\_\_\_

a. *What is your Spanish fluency in terms of managing Hispanic/Latino patients with Chagas disease?*

\_\_\_\_\_  
\_\_\_\_\_

b. *How do you handle patients with limited English fluency?* \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

5. *Are there any additional comments, suggestions, or feedback you would like to share?*

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

6. *Lastly, are there any colleagues, within your specialty (cardiology or ID) in Texas that I may reach out and interview about their experiences managing the care of Chagas disease patients?*

a. Name: \_\_\_\_\_

b. Email: \_\_\_\_\_

c. Phone Number: \_\_\_\_\_

d. Physician Specialty: \_\_\_\_\_

**Summary**

Recap what was discussed.

**Conclusion**

Thank the participant for their time and remind them about confidentiality and how important this qualitative data will be in framing the results from the survey and framing recommendations.

*Thank you for your time. I know your time is valuable and your responses will help frame recommendations to address current barriers and challenges that might prevent or delay the diagnosis of Chagas disease.*

Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ Time: \_\_\_\_\_

Study ID: \_\_\_\_ \_\_\_\_ \_\_\_\_ \_\_\_\_

## **Semi-structured Interview Script for Physicians: Not Managed Care of Chagas Patients**

### **Introduction**

- *Good morning/ afternoon. Thank you for your time. My name is Jerry Pacheco. I'm a doctoral candidate at the UT School of Public Health.*
- *As part of my doctoral dissertation, I will focus on Chagas disease in Texas and the level of awareness among healthcare providers. I will be collecting primary data for my research, as part of my aims, I am collecting quantitative data (that is data from online questionnaires) as well as qualitative data—that is the data I hope to collect today through this interview.*
- *We hope that through this interview, we can dive further and explore challenges and barriers that physicians have experienced that way we can frame recommendations for improving outreach, education, and resources to physicians in Texas about Chagas disease so that the disease is diagnosed and managed on time.*
- *Thank you for agreeing to participate.*

### **Informed consent**

Explain the risks/ benefits and confidentiality and how results will be used (refer them to form)

- *I emailed a copy of the consent. Please review and keep for your records. The risks and discomfort associated with participation in this study are no greater than those ordinarily encountered in daily life or during the performance of routine exams. The experience is expected to be informative and interesting and thus a generally positive experience.*
- *Your decision to take part is voluntary. You may decide to stop taking part in the study at any time.*
- *I would like to make an audio recording of our discussion, so that I can have an accurate record of the information that you provide to me.*
- *This study (HSC-SPH-17-1039) has been reviewed by the Committee for the Protection of Human Subjects of the University of Texas Health Science Center at Houston.*
- *If you have any questions refer to the Informed Consent Form I email you for the university research office's contact information.*

### **Confirm provider specialty and/ or treatment of CD patients**

- *Can you confirm your specialty?*

Provider Specialty:

- Infectious Disease
- Cardiology

Other: \_\_\_\_\_

**Demographics and type of practice**

- 4. How many years of have you been in your primary specialization? \_\_\_\_\_
- 5. How would you describe your current medical practice?
  - a. institution, community clinic, private, other: \_\_\_\_\_
  - b. rural or urban
- 6. Did you receive any medical training or practice in Mexico, Central or South America? Please describe:  
\_\_\_\_\_  
\_\_\_\_\_

**Guiding Questions**

*I will be asking questions regarding the continuum of care, which includes screening, diagnosis, treatment, and follow-up of care. For the purpose of my research and this interview:*

**Screening:** *is the clinical, decision-making process or differential diagnosis to determine if further laboratory diagnosis are required.*

**Diagnosis:** *the clinical and serological testing required to confirm Chagas disease.*

- 7. Can you confirm whether you have directly managed the care of a Chagas disease patient?
  - a. Can you please describe your experience(s) with Chagas disease? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
  - b. What resources would you use, or whom did you consult with to better understand the process to screen, diagnose, or treat a Chagas disease patient?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
  - c. What do you think are the most challenging aspects or barriers in delivering care to a patient with Chagas disease in Texas?  
\_\_\_\_\_  
\_\_\_\_\_

- 
- i. **Screening specific:** \_\_\_\_\_
  - ii. **Diagnosis specific:** \_\_\_\_\_
  - iii. **Treatment specific:** \_\_\_\_\_

8. *Have you ever considered a Chagas disease diagnosis?*

a. *Why? Why not?* \_\_\_\_\_

---

---

b. *What is your current level of knowledge and skills in screening and diagnosing patients with Chagas disease?*

---

---

c. *Do you have sufficient education/ training to be able to screen, diagnose, and/ or treat Chagas disease patients?* \_\_\_\_\_

---

---

9. *Do you think that Chagas disease is a bigger problem in Texas than other states in the U.S.?*

a. *Why? Why not?* \_\_\_\_\_

---

---

b. *Do we need to increase the level of outreach and education that we provide to physicians in Texas?* \_\_\_\_\_

---

---

c. *How can we increase communication to physicians in Texas for them to better understand Chagas disease?* \_\_\_\_\_

---

---



10. What proportion of Hispanic/ Latino population do you serve in your medical practice?

\_\_\_\_\_

a. What is your Spanish fluency in terms of managing Hispanic/Latino patients with Chagas disease?

\_\_\_\_\_  
\_\_\_\_\_

b. How do you handle patients with limited English fluency? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

11. Are there any additional comments, suggestions, or feedback you would like to share?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

12. Lastly, are there any colleagues, within your specialty (cardiology or ID) in Texas that I may reach out and interview about their experiences managing the care of Chagas disease patients?

a. Name: \_\_\_\_\_

b. Email: \_\_\_\_\_

c. Phone Number: \_\_\_\_\_

d. Physician Specialty: \_\_\_\_\_

### Summary

Recap what was discussed.

### Conclusion

Thank the participant for their time and remind them about confidentiality and how important this qualitative data will be in framing the results from the survey and framing recommendations.

*Thank you for your time. I know your time is valuable and your responses will help frame recommendations to address current barriers and challenges that might prevent or delay the diagnosis of Chagas disease.*



Appendix E: Table of Mapped ICD Counts, by County

<b>County Name</b>	<b>Chagas, Heart</b>	<b>Chagas, Other</b>	<b>Chagas, Total</b>	<b>Non-Chagas Heart- Related Total</b>
Anderson	0	0	0	978
Andrews	0	0	0	157
Angelina	0	0	0	1,704
Aransas	0	0	0	366
Archer	0	0	0	129
Armstrong	0	0	0	10
Atascosa	0	0	0	849
Austin	0	0	0	609
Bailey	0	0	0	96
Bandera	0	0	0	417
Bastrop	0	0	0	1,483
Baylor	0	0	0	73
Bee	0	0	0	521
Bell	0	0	0	3,762
Bexar	7	1	8	21,195
Blanco	0	1	1	205
Borden	0	0	0	2
Bosque	0	1	1	168
Bowie	0	0	0	2,066
Brazoria	1	0	1	3,954
Brazos	0	0	0	2,705
Brewster	0	0	0	99
Briscoe	0	0	0	7
Brooks	0	0	0	136
Brown	0	0	0	820
Burleson	0	0	0	652
Burnet	0	0	0	736
Caldwell	0	0	0	777
Calhoun	0	0	0	355
Callahan	0	0	0	347
Cameron	3	0	3	8,567
Camp	0	0	0	420
Carson	0	0	0	90
Cass	0	0	0	705
Castro	0	0	0	53

County Name	Chagas, Heart	Chagas, Other	Chagas, Total	Non-Chagas Heart- Related Total
Chambers	0	0	0	408
Cherokee	0	0	0	1,153
Childress	0	0	0	65
Clay	0	0	0	214
Cochran	0	0	0	50
Coke	0	0	0	62
Coleman	0	0	0	170
Collin	2	0	2	7,913
Collingsworth	0	0	0	38
Colorado	0	0	0	561
Comal	0	0	0	1,397
Comanche	0	0	0	216
Concho	0	0	0	44
Cooke	0	0	0	586
Coryell	0	0	0	759
Cottle	0	0	0	24
Crane	0	0	0	28
Crockett	0	0	0	57
Crosby	0	0	0	56
Culberson	0	0	0	46
Dallam	0	0	0	100
Dallas	21	5	26	34,526
Dawson	0	0	0	97
Deaf Smith	0	0	0	149
Delta	0	0	0	112
Denton	7	1	8	7,218
DeWitt	0	0	0	335
Dickens	0	0	0	29
Dimmit	0	0	0	223
Donley	0	0	0	59
Duval	0	0	0	219
Eastland	0	0	0	337
Ector	0	0	0	2,177
Edwards	0	0	0	35
Ellis	0	0	0	2,482
El Paso	0	0	0	7,777
Erath	0	0	0	451

County Name	Chagas, Heart	Chagas, Other	Chagas, Total	Non-Chagas Heart- Related Total
Falls	0	0	0	195
Fannin	0	0	0	704
Fayette	0	0	0	651
Fisher	0	0	0	58
Floyd	0	0	0	61
Foard	0	0	0	28
Fort Bend	0	0	0	6,064
Franklin	0	0	0	131
Freestone	0	0	0	219
Frio	0	0	0	276
Gaines	0	0	0	110
Galveston	0	0	0	7,049
Garza	0	0	0	79
Gillespie	0	0	0	404
Glasscock	0	0	0	7
Goliad	0	0	0	166
Gonzales	0	0	0	268
Gray	0	0	0	565
Grayson	0	0	0	2,578
Gregg	0	0	0	2,233
Grimes	0	0	0	833
Guadalupe	0	0	0	1,070
Hale	0	0	0	369
Hall	0	0	0	63
Hamilton	0	0	0	72
Hansford	0	0	0	51
Hardeman	0	0	0	92
Hardin	0	0	0	962
Harris	21	4	25	59,118
Harrison	0	0	0	769
Hartley	0	0	0	8
Haskell	0	0	0	111
Hays	0	0	0	2,068
Hemphill	0	0	0	35
Henderson	0	0	0	1,882
Hidalgo	0	0	0	11,020
Hill	0	0	0	447

County Name	Chagas, Heart	Chagas, Other	Chagas, Total	Non-Chagas Heart- Related Total
Hockley	0	0	0	266
Hood	0	0	0	907
Hopkins	0	0	0	553
Houston	0	0	0	448
Howard	0	0	0	951
Hudspeth	0	0	0	46
Hunt	0	0	0	1,624
Hutchinson	0	0	0	351
Irion	0	0	0	20
Jack	0	0	0	150
Jackson	0	0	0	271
Jasper	0	0	0	589
Jeff Davis	0	0	0	17
Jefferson	0	2	2	4,664
Jim Hogg	0	0	0	70
Jim Wells	0	0	0	653
Johnson	5	3	8	3,836
Jones	0	0	0	272
Karnes	0	0	0	179
Kaufman	0	0	0	1,505
Kendall	0	0	0	544
Kenedy	0	0	0	5
Kent	0	0	0	7
Kerr	0	0	0	899
Kimble	0	0	0	49
King	0	0	0	2
Kinney	0	0	0	50
Kleberg	0	0	0	433
Knox	0	0	0	66
Lamar	0	0	0	1,416
Lamb	0	0	0	126
Lampasas	0	0	0	459
La Salle	0	0	0	127
Lavaca	0	0	0	420
Lee	0	0	0	380
Leon	0	0	0	502
Liberty	0	0	0	1,846

County Name	Chagas, Heart	Chagas, Other	Chagas, Total	Non-Chagas Heart- Related Total
Limestone	0	0	0	234
Lipscomb	0	0	0	38
Live Oak	0	0	0	159
Llano	0	0	0	440
Loving	0	0	0	-
Lubbock	0	0	0	2,781
Lynn	0	0	0	58
McCulloch	0	0	0	191
McLennan	0	0	0	1,734
McMullen	0	0	0	18
Madison	0	0	0	344
Marion	0	0	0	220
Martin	0	0	0	70
Mason	0	0	0	54
Matagorda	0	0	0	705
Maverick	0	0	0	1,802
Medina	0	0	0	729
Menard	0	0	0	35
Midland	0	0	0	1,629
Milam	0	0	0	444
Mills	0	0	0	41
Mitchell	0	0	0	116
Montague	0	0	0	431
Montgomery	2	0	2	7,536
Moore	0	0	0	152
Morris	0	0	0	263
Motley	0	0	0	19
Nacogdoches	0	0	0	903
Navarro	0	0	0	855
Newton	0	0	0	157
Nolan	0	0	0	336
Nueces	0	0	0	4,300
Ochiltree	0	0	0	85
Oldham	0	0	0	15
Orange	0	0	0	1,586
Palo Pinto	0	0	0	612
Panola	0	0	0	405

County Name	Chagas, Heart	Chagas, Other	Chagas, Total	Non-Chagas Heart- Related Total
Parker	0	0	0	1,795
Parmer	0	0	0	73
Pecos	0	0	0	119
Polk	0	0	0	944
Potter	0	0	0	1,764
Presidio	0	0	0	59
Rains	0	0	0	258
Randall	0	0	0	1,337
Reagan	0	0	0	39
Real	0	0	0	74
Red River	0	0	0	372
Reeves	0	0	0	123
Refugio	0	0	0	129
Roberts	0	0	0	13
Robertson	0	0	0	522
Rockwall	0	0	0	840
Runnels	0	0	0	179
Rusk	0	0	0	812
Sabine	0	0	0	193
San Augustine	0	0	0	200
San Jacinto	0	0	0	451
San Patricio	0	0	0	897
San Saba	0	0	0	105
Schleicher	0	0	0	33
Scurry	0	0	0	177
Shackelford	0	0	0	65
Shelby	0	0	0	405
Sherman	0	0	0	26
Smith	0	0	0	4,176
Somervell	0	0	0	92
Starr	0	0	0	850
Stephens	0	0	0	197
Sterling	0	0	0	10
Stonewall	0	0	0	25
Sutton	0	0	0	67
Swisher	0	0	0	119
Tarrant	2	0	2	28,002



County Name	Chagas, Heart	Chagas, Other	Chagas, Total	Non-Chagas Heart- Related Total
Taylor	0	0	0	2,711
Terrell	0	0	0	13
Terry	0	0	0	158
Throckmorton	0	0	0	36
Titus	0	0	0	337
Tom Green	0	0	0	1,760
Travis	2	1	3	11,941
Trinity	0	0	0	360
Tyler	0	0	0	360
Upshur	0	0	0	595
Upton	0	0	0	31
Uvalde	0	0	0	573
Val Verde	0	0	0	700
Van Zandt	0	0	0	1,118
Victoria	0	0	0	2,038
Walker	0	0	0	1,735
Waller	0	0	0	619
Ward	0	0	0	123
Washington	0	0	0	676
Webb	0	0	0	2,365
Wharton	0	0	0	847
Wheeler	0	0	0	74
Wichita	0	0	0	3,035
Wilbarger	5	1	6	345
Willacy	0	0	0	458
Williamson	0	0	0	3,806
Wilson	0	0	0	402
Winkler	0	0	0	90
Wise	0	0	0	1,325
Wood	0	0	0	1,126
Yoakum	0	0	0	54
Young	0	0	0	366
Zapata	0	0	0	175
Zavala	0	0	0	279
	78	20	98	366,575

Appendix F: Raw Responses for Knowledge Questions, All Questionnaires

Questionnaire Item	Total n= 43 (%)	Family or General Practice n= 21 (%)	Infectious Disease n= 19 (%)	Cardiology n= 3 (%)
<b>Q1. How does the vector with the parasite transmit CD to humans?</b>				
Infected vector penetrates the human host skin during bloodmeal, transmitting parasite through saliva	5 (11.6)	4 (19.1)	1 (5.3)	-
◆ Through infected feces of the vector, that is deposited during bloodmeal, most commonly when the person rubs the infected feces into the bite wound while scratching the area	23 (53.5)	6 (28.6)	15 (79.0)	2 (66.7)
The infected vector regurgitates after bloodmeal, transmitting parasite to human	2 (4.7)	1 (4.8)	1 (5.3)	-
None of the above	-	-	-	-
Not sure	4 (9.3)	4 (8.0)	-	-
No response	9 (20.9)	6 (28.6)	2 (10.5)	1 (33.3)
<b>Q2. How do the majority of people with CD living in the U.S. acquire the infection?</b>				
From drinking unpasteurized juices	-	-	-	-
◆ From exposure to vectors while residing in Mexico, Central, or South America	29 (67.4)	11 (52.4)	16 (84.2)	2 (66.7)
From their mothers	-	-	-	-
From another infected person	-	-	-	-
Not sure	5 (11.6)	4 (19.1)	1 (5.3)	-
No response	9 (20.9)	6 (28.6)	2 (10.5)	1 (33.3)
<b>Q3. Total number of reported CD cases to DSHS</b>				
Less than 5	-	-	-	-

Questionnaire Item	Total n= 43 (%)	Family or General Practice n= 21 (%)	Infectious Disease n= 19 (%)	Cardiology n= 3 (%)
Between 20 and 30	4 (9.3)	1 (4.0)	3 (15.8)	-
◆ Between 75 and 100	7 (16.3)	4 (19.1)	3 (15.8)	-
More than 1,000	6 (14.0)	2 (9.5)	3 (15.8)	1 (33.3)
Not sure	17 (39.5)	8 (38.1)	8 (42.1)	1 (33.3)
No response	9 (20.9)	6 (28.6)	2 (10.5)	1 (33.3)
<b>Q4. Clinical course for CD</b>				
Acute for 10-30 days following exposure to parasite, is self-limiting in most persons within 2 months, and rarely progresses into the chronic phase	3 (7.0)	2 (9.5)	-	1 (33.3)
Acute for a week following exposure to parasite. If left untreated, it is a chronic lifelong infection 2-4 weeks following exposure to parasite.	1 (2.3)	-	-	1 (33.3)
◆ Acute 1-8 weeks following exposure to parasite; asymptomatic for years to decades in the majority of infected persons; but becoming symptomatic in a portion of persons infected with parasite	21 (48.8)	7 (33.3)	14 (73.7)	-
None of the above	-	-	-	-
Not sure	8 (18.6)	6 (28.6)	2 (10.5)	-
No response	14 (32.6)	10 (40.0)	3 (15.8)	1 (33.3)
<b>Q5. Characteristic symptoms for acute phase of CD</b>				
Fever	1 (2.3)	1 (4.8)	-	-
Swelling at the site of inoculation	5 (11.6)	1 (4.8)	4 (21.1)	-
No symptoms	-	-	-	-
◆ All of the above	23 (53.5)	10 (47.6)	11 (57.9)	2 (66.7)

Questionnaire Item	Total n= 43 (%)	Family or General Practice n= 21 (%)	Infectious Disease n= 19 (%)	Cardiology n= 3 (%)
Not sure	4 (9.3)	3 (14.3)	1 (5.3)	-
No response	10 (23.3)	6 (28.6)	3 (15.8)	1 (33.3)
<b>Q6. Proportion of patients with chronic CD that develop symptoms</b>				
Less than 1%	7 (16.3)	5 (23.8)	1 (5.3)	1 (33.3)
◆ Between 20% and 40%	14 (32.6)	3 (14.3)	11 (57.9)	-
More than 50%	2 (4.7)	1 (4.8)	1 (5.3)	-
None of the above	-	-	-	-
Not sure	10 (23.3)	6 (28.6)	3 (15.8)	1 (33.3)
No response	10 (23.3)	6 (28.6)	3 (15.8)	1 (33.3)
<b>Q7. Symptoms that may develop in patients with chronic CD</b>				
Cardiac conduction abnormalities and/ or cardiomyopathy	2 (4.7)	-	1 (5.3)	1 (33.3)
Megaesophagus and/ or megacolon	-	-	-	-
Co-clinical manifestations	1 (2.3)	-	1 (5.3)	-
◆ All of the above	28 (65.1)	13 (61.9)	14 (73.7)	1 (33.3)
Not sure	2 (4.7)	2 (9.5)	-	-
No response	10 (23.3)	6 (28.6)	3 (15.8)	1 (33.3)
<b>Q8. Chronic CD cardiomyopathy possible manifestations</b>				
None- can present without clinical manifestations and be asymptomatic	-	-	-	-
Dyspnea on exertion, fatigue, palpitations, dizziness, syncope, and edema	1 (2.3)	-	-	1 (33.3)
Sudden death	-	-	-	-
◆ Any of the above	30 (69.8)	13 (52.0)	16 (84.2)	1 (33.3)
Not sure	2 (4.7)	2 (8.0)	-	-

Questionnaire Item	Total n= 43 (%)	Family or General Practice n= 21 (%)	Infectious Disease n= 19 (%)	Cardiology n= 3 (%)
No response	14 (32.6)	10 (40.0)	3 (15.8)	1 (33.3)
<b>Q9. Request commercial lab diagnostic serology tests, initiate a clinical evaluation of the patient, and conduct a thorough history in a patient who:</b>				
Has tested positive for parasite during blood donation or has a sibling or mother who is CD-positive	1 (2.3)	-	-	1 (33.3)
Was exposed or potentially exposed to a vector in a period longer than 8 weeks	-	-	-	-
Presents with onset of cardiac disease manifestations that are compatible with chronic CD cardiomyopathy	-	-	-	-
◆ All of the above	26 (60.5)	13 (61.9)	12 (63.2)	1 (33.3)
Not sure	3 (7.0)	2 (9.5)	1 (5.3)	-
No response	13 (30.2)	6 (28.6)	6 (31.6)	1 (33.3)
<b>Q10. In patients who test positive for CD disease after blood donation or from a lab diagnostic, obtaining social history is needed to assess potential routes of exposure, including;</b>				
Travel to residence in areas endemic for CD disease	1 (2.3)	-	-	1 (33.3)
Previous history of blood transfusions or organ/ tissue transplants	-	-	-	-
Possibility of congenital CD disease transmission	-	-	-	-
◆ All of the above	27 (62.8)	13 (61.9)	13 (68.4)	1 (33.3)
Not sure	2 (4.7)	2 (9.5)	-	-
Not response	13 (30.2)	6 (28.6)	6 (31.6)	1 (33.3)
<b>Q11. Which of the following best describes the method(s) for confirmatory diagnosis of CD?</b>				

Questionnaire Item	Total n= 43 (%)	Family or General Practice n= 21 (%)	Infectious Disease n= 19 (%)	Cardiology n= 3 (%)
◆ Seropositive results from 2 different immunoassays and/ or PCR performed at the CDC	17 (39.5)	5 (23.8)	11 (57.9)	1 (33.3)
Positive serology from blood screening donations	-	-	-	-
Detection of apolipoprotein A-1 upregulation in human serum	-	-	-	-
All of the above	2 (4.7)	2 (9.5)	-	-
Not sure	11 (25.6)	8 (38.1)	2 (10.5)	1 (33.3)
No response	13 (30.2)	6 (28.6)	6 (31.6)	1 (33.3)
<b>Q12. Which of the following describes the current treatment options for Chagas disease?</b>				
Benznidazole and nifurtimox are available only under current investigational protocol by the CDC in children up to 18 years of age with chronic infections, and in adults up to age 50 with chronic infection who have no indication of advanced cardiomyopathy	10 (23.3)	2 (9.5)	7 (36.8)	1 (33.3)
Benznidazole has been approved by the U.S. FDA for patients 2-12 years of age and is available commercially	1 (2.3)	-	1 (5.3)	-
Nifurtimox is only available by the CDC under investigational protocol	2 (4.7)	2 (9.5)	-	-
◆ Second and third choices only	4 (9.3)	-	4 (21.1)	-
Not sure	13 (30.2)	11 (52.4)	1 (5.3)	1 (33.3)
No response	13 (30.2)	6 (28.6)	6 (31.6)	1 (33.3)
<b>Q13. Should patients with chronic CD be treated with antitrypanosomal drugs?</b>				
No, there is no evidence that antitrypanosomal treatment for Chronic CD can be effective	5 (11.6)	2 (9.5)	3 (15.8)	-

<b>Questionnaire Item</b>	<b>Total n= 43 (%)</b>	<b>Family or General Practice n= 21 (%)</b>	<b>Infectious Disease n= 19 (%)</b>	<b>Cardiology n= 3 (%)</b>
Yes, only patients younger than 5 years of age should be treated for chronic CD	-	-	-	-
♦ Treatment is always recommended for patients up to age 18 and generally recommended for patients aged 18 to 50	12 (27.9)	3 (14.3)	8 (42.1)	1 (33.3)
Only CD patients manifesting with moderate to severe cardiomyopathy	-	-	-	-
Not sure	12 (27.9)	9 (42.9)	2 (10.5)	1 (33.3)
No response	14 (32.6)	7 (33.3)	6 (31.6)	1 (33.3)

\*Rounding

Abbreviation: CD Disease (CD)

♦ Denotes correct answer for the knowledge items

\*\* Specific totals (i.e., with not all 3 questionnaire samples contained the item, thus sub-total is listed)

Appendix G: Summary of Key Informant Tracking Table

Study ID	Date and Time	Managed Care of CD patients	Institution or Affiliation	Current City	Specialty	# of Years in Specialty	Medical Setting	# of CD patients managed	Sex
2008	7/30/28; 11am	Yes	UTHouston	Houston	Cardiology	15	Inst.	5	M
2104	6/28/18, 4:30	Yes	JBSA- Lackland	San Antonio	Cardiology	3	Inst.	1	M
1105	7/2/18; 2:30pm	Yes	Children's Hospital of San Antonio	San Antonio	Infectious Disease	4	Inst.	1	M
1011	7/9/18; 4pm	Yes	Baylor College of Medicine	Houston	Infectious Disease	38	Inst.	2	F
1102	6/28/18; 3pm	Yes	.	Dallas	Infectious Disease	5	Comm. Clin	3	M
0001	7/1/18; 4pm	No	UTHealth San Antonio	San Antonio	Family/ General Practice	6	Inst.	0	M
1106	8/28/18; 1pm	Yes	UTHealth San Antonio	San Antonio	Infectious Disease	9	Inst.	1	M
1009	7/6/18; 11am	Yes	UTSouthwestern	Dallas	Infectious Disease	3	Inst.	10	F
2010	7/27/18; 7:30pm	Yes	Baylor College of Medicine	Houston	Cardiology	20	Comm. Cln.	1	F
1014	9/14; 11am	Yes	UTHealth San Antonio	San Antonio	Infectious Disease	10	Inst.	5	F
1007	7/15/18; 8:30pm	No	Baylor College of Medicine	Houston	Infectious Disease	16	Inst.	100	F
2015	7/6/18; 1pm	Yes	Baylor College of Medicine	Houston	Cardiology	12	Comm. Clin.	0	M



<b>Study ID</b>	<b>Date and Time</b>	<b>Managed Care of CD patients</b>	<b>Institution or Affiliation</b>	<b>Current City</b>	<b>Specialty</b>	<b># of Years in Specialty</b>	<b>Medical Setting</b>	<b># of CD patients managed</b>	<b>Sex</b>
1103	6/28/18; 3:45pm	Yes	Fort Sam Houston	San Antonio	Infectious Disease	12	Inst.	25	F