A Guide to Setting Up Screening for Chagas Disease in Outpatient Settings

A Tool Created By the Implementing Novel Strategies for Education and Chagas Testing (INSECT) Team

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Abbreviations

- BPA: Best Practice Advisory
- Chagas: Chagas disease
- CMS: Centers for Medicare and Medicaid Services
- ECG: Electrocardiogram
- EMR: Electronic Medical Record
- Epic: A type of EMR
- ID: Infectious diseases
- INSECT: Implementing Novel Strategies for Education and Chagas Testing
- IT: Information technology
- LIS: Laboratory Information System
- QI: Quality Improvement

Contact Us

If you have questions or would like any help from the INSECT team, please reach out to us at chagas@bu.edu or by phone at 617-358-5907. For more information and resources visit our website: www.bu.edu/chagas/

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Section I

When to Implement a Screening Program

Many factors should be considered to determine whether to implement Chagas disease (Chagas) screening. These factors include:

- If your community has immigrants from Mexico, Central, or South America (or patients who have spent time more than 6 continuous months living in these countries/regions)
- If you are caring for more than one patient with Chagas
- If you live in a U.S. state where triatomine bugs are found (see Appendix 1).

Understanding the Burden of Disease

When considering the implementation of a Chagas screening program in your clinic, it is important to assess the potential burden of Chagas. While Chagas is markedly under-diagnosed in the United States, it is also important to set expectations around how many cases you may find. Data from existing screening programs in the US have shown a prevalence of 1-2% in patients from Chagas endemic regions. This may mean there are few patients who will have positive test results among your patients but diagnosing and treating this neglected population can greatly improve patient quality of life, reduce future healthcare costs and burden, and save lives.

In addition to assessing the burden or potential burden, it can be helpful to have a baseline estimate of Chagas in your community prior to implementing a screening program. This will help you track the effectiveness of your screening program.

Review Current Institution Data

If you have an electronic medical record (EMR) system, query that system to document the number of cases of diagnosed Chagas disease. If your clinic has a dedicated IT team, they may be able to help you with this. Even if you see many at-risk patients, this number may be low due to a lack of previous screening. If the numbers of diagnosed Chagas cases are low, this should not be a deterrent to starting a screening program.

If you are interested in a methodology called synthetic estimation to better approximate the Chagas burden in your area, please refer to Appendix 2.

Section II

Identify Chagas Champions and Other Supporters

Engaged and enthusiastic Chagas Champions as well as other supporters are one of the most important pieces of a successful screening program.

General Principles

Chagas Champions are people who will take the lead on advocating for Chagas disease screening in your clinic. Chagas champions can help ensure a smoothly running cascade of care for Chagas patients. A cascade of care refers to the steps taken to care for a patient with a particular disease or condition, including diagnosis, treatment, and follow-up. Your Champions could help develop, streamline, and implement your screening program. These individuals/team members will be a great resource for other providers to turn to with questions. Some activities that Chagas Champions can help with include:

- Delivering regular talks to their colleagues and other providers to raise Chagas awareness
- Develop educational materials that are appropriate for their patient population
- Facilitating relationships with their colleagues, clinic managers or administrators to set-up screening
- Encouraging colleagues at other institutions to become involved in screening for Chagas

Who Should You Recruit?

Chagas Champions should be healthcare personnel who can help establish and maintain screening in your setting. These providers do not have to be attending physicians; they can be students, residents, fellows, physician assistants, nurse practitioners, nurses, laboratory technicians, managers, and anyone else who is involved in patient care or running of your clinic/hospital in some way. If you work in a larger clinic/hospital, your screening team should ideally involve multiple Chagas Champions from different practice areas.

How to Recruit

- Consider starting small by talking to people in your department or among colleagues you think may be interested. Explain the importance of this underdiagnosed disease – the potential complications for infected individuals, the potential for sudden cardiac death, and the possibility of transmission from pregnant mother to infant. Case presentations of patients seen at your facility can help emphasize that this disease is relevant for your patients. Informational emails, pamphlets, or newsletters can also be used for follow-up.
- If you have regular department meetings, ask if you can give a presentation about Chagas where you introduce the disease and screening process and mention that you are looking for Chagas Champions. It may be effective to include Chagas under the broader umbrella of immigrant health – people may be more familiar with those issues and thus more likely to participate.
- If you are having difficulty recruiting Champions, start the screening program and slowly enlist help over time.

How to Engage

- Schedule recurring meetings, at least quarterly, where you can discuss perspectives, address barriers, and identify solutions to increase Chagas screening.
- Centers for Medicare and Medicaid Services (CMS) require clinics to perform yearly quality improvement (QI) projects. Considering satisfying this requirement by approaching screening as a QI project with the Chagas Champions.

- If funding is available, offer a small stipend to offset any time spent by the Chagas Champions and to further incentivize them to continue to participate.

How to Retain

- Retain Chagas Champions by keeping them involved in the process of setting up screening. Give them regular updates on the impact of their work and ask for feedback.
- Offer opportunities for career advancement related to Chagas or immigrant health such as presenting at meetings, publishing manuscripts, or submitting abstracts to conferences.

Additional Suggestions for Recruitment

- Hold educational talks to advertise your screening program. Additional interest will provide you with more potential Champions.
- Consider reaching out to affiliate health centers or peers who may be interested. Your collaborative team can be multisectoral.
- If your healthcare system is too small to create a full team of Champions, you can always opt to start small and use the personnel you have at hand. You can add new Champions in the future if the opportunity arises.
- If you have any students, residents, or fellows who need to complete a project, assess their interest in focusing on Chagas screening.
- As previously mentioned, framing Chagas screening within immigrant health can help to attract more supporters.

Section III

Hold Chagas Disease Informational Talks/Sessions

Ways to Educate

Teaching providers about Chagas is one of the most important steps in this process. Education can begin with grand rounds, department-level talks, lectures at the medical school, or residency lectures. We have created PowerPoint presentations that you can access on our website; we also have pre-recorded lectures available on our website that you can access, listen to, or share with colleagues. Some departments may appreciate hearing from their colleagues in other departments (i.e., someone from OB/GYN could present to the Family Medicine department). Consider inviting external speakers if that may attract a larger audience. If you prefer, someone from our team would be happy to assist with educational efforts. We can be contacted at Chagas@bu.edu

Our research shows that one of the most important things to keep in mind when developing talks for providers about Chagas (or any neglected disease) is to use case studies and include actionable steps that can be implemented in clinic immediately. This is what providers report being most effective for their learning.

Emphasize Positive Test Results

One of the most important topics to emphasize as you educate providers is whether you are identifying cases and what the rates of positive Chagas tests are in your community. If you do not have data yet about your patient population, then synthetic estimation can be useful here. In addition, if rates seem low then it can be helpful to include information about other diseases that are routinely screened for in the United States and have similar or lower rates, such as syphilis and gonorrhea.[3]

Additional Educational Opportunities

If you would like to learn more about Chagas, there are many educational opportunities available. Many of these are currently available online and free of charge. For example, the CDC offers a continuing education course (CME accredited) that you can access on your own time. The link to this course and other resources can be found on our website.

Educating Other Providers

If you become your healthcare system's expert on Chagas, here are some tips for providing high-quality education to others:

- Case-based presentations are often the best approach for this kind of learning to maximize engagement and retention.
- Find ways to offer CME credit or direct them to CME opportunities.
- Consider using recorded seminars so providers can access them on their own time.

Section IV

Confirm Logistics

Determine Insurance Procedures and Costs

Insurance coverage of Chagas screening tests varies from state to state and insurer to insurer. Likewise, the cost of running the initial test may vary though most laboratories such as Quest Diagnostics will charge approximately $100. In some states, such as Massachusetts, the screening tests are fully covered by insurance and by Medicaid (MassHealth). This website may be helpful in trying to determine Medicaid coverage in your state. The INSECT team is happy to assist with figuring out costs, as well, and can be reached at chagas@bu.edu.

Set-up the Laboratory

See Appendix 3: Laboratory Procedures Guide

Establish a Referral System for Positive Patients

Identify a point of contact in the department or section of infectious diseases (ID) who can direct or assist with care for any identified Chagas patients.

You will want to talk to your ID colleagues to see if any have a particular interest in Chagas or tropical medicine. If so, it will be good to discuss a strategy for timely referrals. If there is no one in your area with a particular interest/expertise in Chagas, you can contact one of the providers listed in the US Chagas Providers Network or contact the INSECT team, who can facilitate a referral or provide guidance.

Gain Administrative Approval

You may need permission from your hospital/clinic administration to begin a Chagas screening program. Even if it's not required, it may be beneficial to have their support or to at least make them aware of your plans.

Make Your Case

There are many benefits to screening for Chagas:

- For the patient:
    - Preventing possible progression to cardiomyopathy, stroke, and sudden cardiac death
    - Avoiding perinatal transmission from mother to infant
    - Identifying other at-risk individuals (such as family members)

- For the institution/community:
    - Chagas screening increases health equity for minority, immigrant populations, which have traditionally been underserved. By addressing an issue that primarily affects Latin American immigrants, your hospital/clinic will bolster the health of these communities. In screening for Chagas, which has many potential complications, you will be advocating for the health of these individuals and may have a major impact on their communities. Chagas screening programs can serve as a stepstone for a broad immigrant health screening program.
    - By using country of origin as a tool for determining screening procedures, this may provide opportunities to screen for other diseases endemic to these regions beyond Chagas Disease.

- Screening in community-based health care centers has been shown to be cost-effective, particularly for maternal and neonatal screening.
- Screening in a hospital system has potential financial benefits to the hospital:
    - Diagnosis and treatment of Chagas requires a significant number of procedures (echocardiograms, EKGs, blood work, and serologic testing) and potential referrals (ID, cardiology) that may indirectly benefit the hospital/clinic.

Establish a Point Person(s)

Ideally, 1-2 people should serve as the clinical point person(s). The point person(s) is often also a Chagas Champion, but their role includes tracking of individuals who tested positive and managing referrals. The point person(s) can be responsible for all contact and communication with the patient's primary care provider to ensure that they are referred. Ideally, this person(s) could also share information around trends or statistics on screening in the clinic and country of origin and/or give periodic information sessions on Chagas and the importance of screening for it.

Identify a Patient Navigator

If possible, it is best to recruit a patient navigator or add Chagas to any current patient navigator's role. People diagnosed with Chagas often face many barriers to accessing care and staying in treatment such as lack of flexibility in their jobs for appointments, lack of transportation, low literacy, etc. The patient navigator can help ensure that patients make it to their appointments, link them with other services (if available), and, ideally, be a culturally competent ally for the patient. Their role includes tracking of individuals who tested positive and managing referrals. They often will work with the point person to ensure that the patients are properly referred for treatment.

Set-Up Patient Tracking and a Data Monitoring System

Tracking Patients Using Electronic Medical Records

The screening program should have a way to track patients who have been screened. Depending on the needs of your institution and the community you serve, it may be possible to adapt your EMR to track patients. The EMR can also be amended to add alerts/reminders to providers to test for Chagas and can be used to streamline the documentation process for providers (e.g., using "dot" phrases).

Country of Origin

Collection of patients' country of origin data is important to identify those individuals who should be screened for Chagas.

- If your hospital/clinic routinely collects country of origin data:
  - Double-check them for accuracy
  - Cross-reference with your administration or registration personnel by checking a sample of patients to make sure country of origin matches across the EMR

- If you do not routinely collect country of origin data from your patients:
  - It is recommended that you start this process, ideally within the EMR

- If your providers struggle to remember to collect country of origin:
  - Consider using a system through your EMR software that will make this easier, such as a dot phrase or best practice advisory. Providers will have different preferences, so talk with them to get a sense of what would be most helpful.
  - Create an informational/education session to communicate the importance of country of origin collection to providers. If a new software tool will need to be used, include this in the

session to train providers how to do so. Feel free to contact the INSECT team for help and resources for this session.

Order Templates and Dot Phrases

If your EMR software allows for templates, this can be a useful tool to ensure a particular standard of care for screening. Similarly, dot phrases in Epic can help providers fill out their note and ensure they are collecting the recommended screening tests. For those who use Epic, we have Epic templates and dot phrases geared toward screening of immigrants, including Chagas testing. Please contact the INSECT team and we will share those templates with you. You may need help from your IT department to implement these templates and/or to create your own if you use a different EMR.

Best Practice Advisory Alerts

Best practice advisory (BPA) alerts in EMR software such as Epic can be helpful reminders to screen patients. If you can link a BPA to country of origin for your patients, this may be helpful, especially for monitoring cases in your community. Be cognizant of the fact that providers will have differing opinions on alerts and some providers may find them annoying. Nonetheless, they can also increase screening, particularly for new or less well-known tests.

Pooling of Patient Data Through EMR

Another useful tool for tracking Chagas patients is the pooling of patient data through an EMR system. This is also something that can be developed with the help of IT personnel. This is outlined in further detail below.

Data Monitoring System Guide

Recording and regularly reviewing data on Chagas testing in your hospital/clinic will help you to identify any trends or changes in the population. This will also provide a resource to follow-up with Chagas disease patients to make sure that they have received the appropriate care and treatment.

Setting Up the System

Setting up a data monitoring system is most useful if it is geared toward the specific needs and wants of the clinicians who will be using it most. At a minimum, the information that should be collected includes:

- Medical record number
- Date of screening positive
- Whether the confirmatory test was sent
- Whether the patient has been referred to ID

One Boston area clinic, East Boston Neighborhood Health Center (EBNHC) has set up a tracking system that their personnel have built into the software of Epic. While this process will differ between EMR software, the teamwork between physicians and the IT team is paramount to its success.

How to Begin Screening Patients

If you have identified a patient who is considered at risk for Chagas disease, it is recommended that you briefly discuss the role of screening for Chagas disease. It is reasonable to assess the patient's awareness of Chagas and if they are aware of any family members with a diagnosis of Chagas. If the patient is agreeable to proceeding with testing, then a *Trypanosoma. cruzi (T. cruzi)* serologic test should be ordered (most commercial laboratories in the US offer a *T. cruzi* serologic test). In order to make a diagnosis of Chagas, two different positive serologic assays are required. If the initial serologic test is positive, then a specimen should be sent to the CDC for confirmatory testing. If this is positive, then it confirms the diagnosis of Chagas. The patient should be informed and referred to an infectious diseases specialist with experience treating Chagas.

Holding Community Engagement Events

It may come as a surprise that knowledge about Chagas is generally very low even among endemic populations. Once you have successfully established a screening program in your hospital or clinic, it would be an asset to the community to hold some community engagement events around Chagas or immigrant health more broadly. We strongly recommend waiting to do this until you know that the community members will be able to access screening and care.

Some examples of community engagement events include:

- Booths or stands at health fairs
- Posters or other advertisements in the community about screening opportunities
- Informational sessions and screening at church gatherings or community centers
- Interviews on local radio or tv channels, particularly those consumed by at-risk populations
- Opinion pieces or short articles in local newspapers, particularly those that serve at-risk populations

Maintaining Provider Buy-In

Regular Department Meetings

Holding regularly scheduled meetings within departments or clinics may be helpful. You can use these opportunities to report back on the number of patients screened and identified and discuss things that are and are not working within your cascade of care. These meetings will also help to keep Chagas disease on the forefront of providers' minds. When possible, use actual cases (preferably your own patients) to work through issues. Working through real examples of cases is an effective tool that will help providers retain information and apply it to their own practice. Since most providers have very busy schedules, keep these occurring in a pattern which best enables all your team to be present.

Chagas in Health Care Provider Curriculums

If you're affiliated with a medical/PA/nursing school or program, consider involving Chagas in the curriculum to get them interested in the topic and potentially involved.

External Collaborations for Chagas Disease

Please contact us if you are interested in collaborating with us or would like us to connect you to the broader Chagas network.

Appendix 1

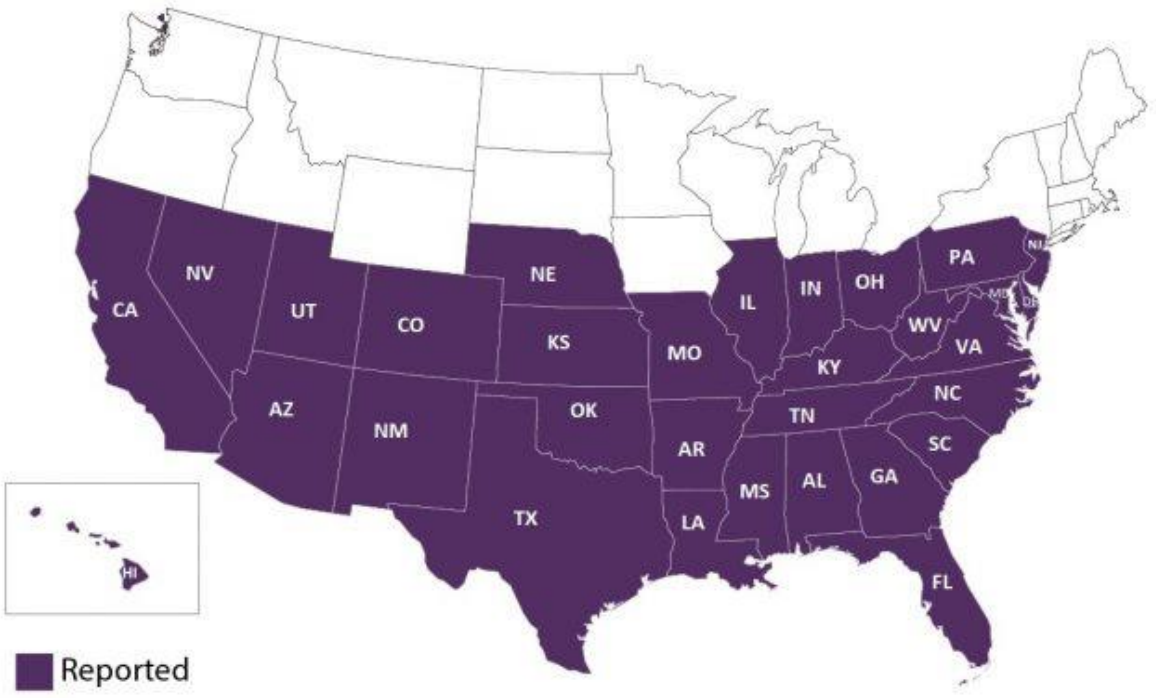
Local Transmission

Local transmission of Chagas disease is not a current priority due to the lack of incidence. Rates in the United States are very low, and it is likely not cost effective to screen the general population if they have no other risk factors. Therefore, screening should be focused on immigrant cases. However, it should be noted that local transmission is possible. Here is some additional information on triatomines in the U.S. if you are interested in local transmission.

Triatomine bugs, the vectors which transmit *T. cruzi,* have been found in 29 of the 50 U.S. states. Of those states, Texas, New Mexico, and Arizona have the most species and findings of kissing bugs. Here is a list of states known to have the highest proportion of triatomine species:

1. Alabama
2. Arizona
3. Arkansas
4. California
5. Colorado
6. Florida
7. Georgia
8. Kansas
9. Kentucky
10. Louisiana
11. Maryland
12. Mississippi
13. Missouri
14. Nevada
15. New Mexico
16. North Carolina
17. Ohio
18. Oklahoma
19. South Carolina
20. Tennessee
21. Texas
22. Utah
23. Virginia

Map of US States with Triatomines



Source: https://www.cdc.gov/parasites/chagas/gen_info/vectors/index.html

Appendix 2

Synthetic Estimation

Synthetic estimation can be used to identify how many potential cases there may be by using available data (such as from the United States Census) and current country-level prevalence numbers (https://amandairish.github.io/chagas_maps/). An example of this is included below, using Massachusetts data at the state level, as Massachusetts is a relatively small state. However, Census data is available at a more micro level if this feels more accurate. While this methodology is not necessarily precise, it can be a very useful tool when there are no baseline data available or in communities where there has been little to no testing thus far. A downloadable, pre-populated excel spreadsheet that guides you through the process is available on our website: www.bu.edu/chagas/.

If the results of the synthetic estimation indicate you may have potential Chagas cases in your community, you should strongly consider implementing a screening program. If synthetic estimation is out of your scope or too complex for the needs of your community, you could begin screening anyone from an endemic area, with the understanding that you may not find any cases. However, knowing that Chagas is not a concern among your patients can also be valuable.

Figure 2. Synthetic Estimation Example Using State-Level Data for Massachusetts

A. Country of Origin	B. Population based on Census data	C. Home Country Prevalence based on WHO report	D. Potential Cases of Chagas Disease (BxC)
HISPANIC OR LATINO			
Total population	6,547,629		
Hispanic or Latino (of any race)	627,654		
Not Hispanic or Latino	5,919,975		
HISPANIC OR LATINO BY TYPE			
Hispanic or Latino (of any race)	627,654		
Mexican	38,379	1.03	395
Puerto Rican	266,125	NA	NA
Cuban	11,306	NA	NA
Dominican (Dominican Republic)	103,292	NA	NA
			NA
Central American (excludes	96,958		
Costa Rican	2951	0.53	16
Guatemalan	32,812	1.98	651
Honduran	12,533	3.05	383
Nicaraguan	1,722	1.14	20
Panamanian	2,436	0.01	0
Salvadoran	43,400	3.37	1,463
Other Central American	1,104	NA	NA
South American	54,398	NA	NA
Argentinean	4,022	4.13	166
Bolivian	1,401	6.75	95
Chilean	3,045	0.99	30
Colombian	23,843	0.96	229
Ecuadorian	7,592	1.74	132
Paraguayan	380	2.54	10
Peruvian	7,360	0.69	51
Uruguayan	2317	0.66	15
Venezuelan	3,982	1.16	46
Other South American	456	NA	NA
Other Hispanic or Latino	57,196	NA	NA
Spaniard	6,829	NA	NA
Spanish	6,309	NA	NA
Spanish American	397	NA	NA
All other Hispanic or Latino	43,661	NA	NA
		TOTAL	3,306

Appendix 3

Laboratory Procedures Guide

It will be beneficial to arrange an early meeting with your laboratory director in charge of microbiology and/or send-out tests to address the following points.

1. Laboratory personnel will need to be trained on the storage and send-out procedures for serology samples (if not done already).
2. If you will be performing initial serology testing on site, ensure that staff training has been completed and that you have a consistent way to track your samples.
3. If you are sending samples out to a third party for serology testing (i.e. Quest Diagnostics, ARUP, Mayo Clinic, etc.), be sure that they know when to expect samples, how many samples, and how often. You will want to ensure that there is adequate freezer storage space to store samples before sending them in batches.[2]
4. Initial screening tests will require confirmatory testing. This is often done at CDC but generally requires that your state lab is aware (and/or that the sample goes through the state lab first). Have your laboratory team address this question with the state lab, designate a method to send your samples to your state lab, if applicable (e.g., a courier). Consider whether you need to create a schedule for bringing samples to the state lab.[3]
5. If you are sending your samples directly to the CDC, ensure that the laboratory staff is familiar with the required paperwork and process for sending samples. In general, this requires storing the samples 4 degrees Celsius. Additional information on this process can be found at: https://www.cdc.gov/laboratory/specimen-submission/detail.html?CDCTestCode=CDC-10458
6. Once the CDC has results, ensure that you are familiar with how results will be received. This may be by faxed to the laboratory or to the State lab. Discuss how the results will be entered into the EMR.

Additional Tips/Troubleshooting:

1. In most cases, it will be beneficial to have two aliquots; one can be retained and sent to CDC if the initial test is positive.
2. Certain Laboratory Information System (LIS) software options have more streamlined ways to track and share test results. If your LIS does not have a cataloging system, we recommend creating a laboratory freezer space which is designated for CDC test samples. This will make it easier to manage the samples and ensure that specimens are sent as needed.

Appendix 4

Common Terms in Spanish Related to Chagas

Triatomine bugs, the vector that transmits *T. cruzi*, are commonly referred to by many different names. These are also referred to as kissing bugs. A few of them that your patient may be familiar with are as follows:

Chinche
El bicho besador
La chinche besucona
Chinchorro
Vinchuca
Chipo
Chirimacha

Other Common Terms in Spanish:

Anemia:
La anemia

Anorexia
La anorexia

Blood draw:
La extracción de sangre
La muestra de sangre

Blood test:
La prueba de sangre

Body aches:
Los dolores corporales

Chagas disease:
El mal de Chagas
La enfermedad de Chagas

Constipation
El estreñimiento

Diarrhea
La diarrea

Difficulty breathing:
La dificultad para respirar

Death:
La muerte

Dysphagia
La disfagia

Echocardiogram (echo):
El ecocardiograma

Edema
El edema

Electrocardiogram (EKG):
El electrocardiograma

Fatigue
La fatiga

Fever:
El fiebre

Headache
El dolor de cabeza

Heart disease:
Los problemas en el corazón
La caCcrdiomiopatía

Intestinal problems:
Los problemas intestinales

Lightheadedness:
El aturdimiento

Low birth weight:
El bajo peso al nacer

Nausea
La nausea

Orthopnea
La ortopnea

Palpitations:
Las palpitaciones
Las palpitaciones cardíacas

Pregnancy/ pregnant
El embarazo
Embarazado

Premature birth:
El nacimiento prematura

Rash
El sarpullido
La erupción

Severe disease:
La enfermedad severa

Shortness of breath:
La falta de aliento

Stroke:
El derrame cerebral

Swollen/inflamed liver:
La inflamación del hígado

Swollen/inflamed spleen:
La inflamación del bazo

Symptoms:
Los síntomas

Vomiting
Vomitando
El vómito