4. Case studies of the 15 finalists

4.1. ¡Pasa la voz!

Project	¡Pasa la voz!: spread the word and raise awareness about Chagas disease with and among the stakeholders with the aim of improving access to diagnosis and treatment
Organisation	Fundación Privada Instituto de Salud Global Barcelona (ISGlobal) and Global Chagas Disease Coalition
Research location	Barcelona, Spain
Cooperation partners	International Health Service – "Clínic" Hospital, Barcelona and several Bolivian associations in Barcelona
Team	Five researchers, three field coordinators and one communication manager
Funding sources	Agència Catalana de Cooperació al Desenvolupament (ACCD), Chagas Initiative (ISGlobal), Global Chagas Disease Coalition
Websites	http://www.isglobal.org http://www.coalicionchagas.org/

ORGANISATIONAL BACKGROUND

The research is being carried out by the ISGlobal team and the coordinator of the Global Chagas Disease Coalition. Five researchers from ISGlobal are involved, one of whom coordinates closely with patients at the International Health Service, Hospital Clinic of Barcelona. A campaign designer is also involved and communicates with the project's stakeholders about the project and related events. She is a Chagas patient herself, who is collaborating with the project in the context of her Master's degree in International Health and Cooperation at Universitat Autonoma de Barcelona. The project team collaborates with the Global Chagas Disease Coalition, which coordinates monitoring, evaluation and replication of the methods in other locations.

The project has established a partnership with several Bolivian and Latin American associations in Barcelona, such as *ARBOLAG (La Garriga), La Bayeta Parlante, Cristo Viene, Bolivianos de Corazón (Granollers)* and the *Comité Ejecutivo Cívico Cruceñista en Cataluña*. This partnership has strengthened the project, allowing the design of collaborative and trust-based access to people who may be living with the parasite.

FUNDING

Funding is based on three sources: the Agència Catalana de Cooperació al Desenvolupament (ACCD), Chagas Initiative (ISGlobal) and the Global Chagas Disease Coalition.

PROBLEM BEING ADDRESSED

Chagas Disease is a neglected tropical disease that silently kills thousands each year. In total there are about 6-7 million people living with the parasite, most of whom are poor, both in endemic countries and in places such as Europe. The disease comes from a parasite that lives in houses made of organic material. The parasite can infect many patients without them knowing they are infected. In the early stages, the symptoms of the disease are often not present or may only consist of fever, headaches, or local swelling at the site of the bite. After some eight to twelve weeks the chronic phase begins and about 60-70% of the people infected never have symptoms. For the remaining group, however, the disease can lead to enlarged cardiac ventricles which eventually leads to heart failure. The disease can also have severe digestive complications.

RESEARCH DESIGN AND SOLUTION

ISGlobal has been involved in research and training related to Chagas disease since 2002 and is currently working on an intervention strategy in Bolivia, the country most affected by this forgotten disease. This strategy involves intervention on three levels: measures aimed at providing direct care to patients in order to improve the full cycle of care (prevention, diagnosis, and treatment); training of public health care professionals in the management of Chagas disease; and the development of research protocols through a joint scientific platform.

The main goal is to improve access to diagnosis and treatment by improving awareness of Chagas Disease (CD) with and among affected populations and health professionals.

The specific objectives are:

- To stimulate demand for CD services by implementing Information, Education and Communication (IEC) activities together with patients;
- To understand barriers to accessing CD health services for Bolivian communities living in Barcelona, Spain, and evaluate the effectiveness of IEC practices, through research with and for the community;
- To develop a guide to outreach activities and an "IEC Kit" to be used by other actors;
- To increase knowledge among the community and among health professionals through the Global Chagas Disease Coalition;
- To support the activities of the patient association in promoting to integrated CD care.

The strategy is to implement a pilot IEC project that will improve access to the International Health Service of the "Clínic" Hospital, in Barcelona, Spain, the European country with the largest population affected by CD. Based on the IEC actions, research is conducted on how to approach and inform people and persuade them to take part in diagnosis and treatment. Women play an important role in reaching out to communities. This partipatory approach is essential to gain access to people and persuade them.

Subsequently, and most significantly, the experience of engaging possible patients is studied and focused on demand for CD health services among migrant families. The findings are then developed and communicated in the form of recommendations on ways of improving IEC practices. These practices are shared with other actors in the Global Chagas Disease Coalition.

GRAND CHALLENGE BEING ADDRESSED

¡Pasa la Voz! aims to break the cycle of negligence caused by the fact that Chagas Disease can lie dormant for decades. This is often the result of a lack of political willingness, and the profile of affected populations, who are predominantly marginalised and lack a political voice. CD is a hidden public health crisis needing attention. Some 6-7 million people live with the parasite, with a global financial cost exceeding $7 billion annually, while less than 1% of CD infected people receive treatment. We need effective IEC practices to stimulate demand and activate political willingness. Not only is treating patients a matter of basic human rights, it is also a public health responsibility and a cost-effective, wise investment. Treating women during their child-bearing years stops transmission to newborns. Women are key to changing the future of CD, as it is unacceptable for children to be born and live with CD in the modern world.

Evidence-based research shows that treating chronic patients is possible, and there is reported evidence of benefits of treatment among different population groups. Medical evidence, however, is not enough, since many public health professionals and clinical care communities are unaware of the treatment options or reluctant to implement them. Furthermore, people at risk of being infected do not look for information or for comprehensive care. This is mainly because the disease is associated with poor living conditions. Having the infection shows that people are poor or have lived in poor housing conditions, so it will adversely affect their social position. Stigmatisation and fear may also play a role in the lack of active demand. Even if IEC practices are considered as a key part of Integral Care Programs, these often lack the effectiveness to bring about changes. Furthermore, having the disease is not always uncomfortable during the chronic phase, while the treatment requires adapting the way people live their lives and also comes with side-effects, so they do not acknowledge the benefits of treating CD.

RESPONSIBLE RESEARCH AND INNOVATION

This project incorporates key stakeholders from the beginning until the evaluation stage, ensuring their participation in working groups and encouraging them to make an active contribution. Key stakeholders in the pilot project are migrant populations, patients and patient associations, as well as health professionals. Women are involved as change agents in spreading the word about CD. Through training and distribution of IEC kits, women will lead IEC practices across their communities.

A participatory approach helps to thoroughly investigate social and economic determinants which prevent access to health services. The research follows a detailed approach on how to target audiences, identify groups and communities to communicate with and make detailed lists of who is informed, interviewed and diagnosed and followed up. To motivate people to take part in the diagnosis, social networks are engaged to help to support them through the process. Women are important in supporting and accommodating the process. The researchers take part in social events at churches, Bolivian community and sporting events to communicate about CD and the options for diagnosis and treatment. Another key element of engagement and non-formal science education will be the activities with and for patient´s associations, aiming to empower and accompany them in advocacy and communication activities.

A political willingness to address the disease is crucial. It helps to involve patients more so that they can be diagnosed and treated. Collaboration therefore takes place with stakeholders such as key decision-makers, the scientific community, key actors working on CD and the general public who will be target audiences and/or will disseminate awareness activities. By integrating different stakeholders the team addresses the gender balance, responsibility, ownership and recognition and brings about the added value for the community.

To reach out to wider audiences and the political landscape, the research team draws on the Global Coalition and the pilot activities, led by a coordinator, ensure excellent internal communication: including the working groups, calling for participation and preparing minutes to update all key stakeholders. In the framework of the pilot project, health staff in clinical services both in Spain and Bolivia ensure regular and informed communication with patients. In addition, the team promotes communication among the group of identified women who will be spreading the word in their communities. Finally workshops and training courses also form part of the communication plan.

External communication, in a spirit of open and transparent science, will be led by the Global Coalition and ISGlobal. The website is a hub where CD-related information and resources to develop effective IEC practices will be available for any actor. Dissemination will be furthered by a newsletter and through twitter and Facebook accounts. All relevant information including both an IEC kit and an IEC set of recommendations will be available for download. The methodology, implementation and evaluation of the project are fully accessible to other research teams, associations, or other stakeholders willing to do the same in their own contexts.

EVALUATION AND DISSEMINATION

The team at IS Global involved in research on CD constitutes a small group within IS Global but is well embedded in the community where the research is taking place. The main coordinator María Jesús Pinazo Delgado is Bolivian and conducted research on similar topics before joining IS Global and this project. The team is well connected to a hospital, has several communication and event organisers and has established a network of coordinators to obtain access to the Bolivian community.

The project team has published three articles and twelve book contributions since 2010 within the area of Medical and epidemiological publications. The articles were published in international journals such as *Acta Tropica* and the *Journal of Gastroenterology and Hepatology*. In the area of Sociological research, four reports and a book contribution were presented. Several of these publications specifically target governments in Spain and Bolivia. The impact on civil society is relatively large, partly due to its focus on communication about CD. Also within the policy landscape, the research is actively disseminating its findings. The project team was recently contacted by Raíses Andinas, a Latin American association which has fifty members and could reach 300 Bolivian citizens living in Zaragoza, Spain. Contact was made through whatsapp videos and they will have access to Chagas disease diagnostics. Public health practitioners in Zaragoza are not as aware of the disease as they are in Barcelona.