

# The Chagas Clinical Research Platform: An innovative and collaborative R&D network model for Chagas disease

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## Background

Chagas disease, caused by *Trypanosoma cruzi*, is endemic in 21 Latin American countries and according to the WHO, approximately 5.7 million people are infected in the region, 30% of whom will develop a chronic heart condition. Also, more than 10,000 deaths are estimated to occur annually from the disease. Chagas is the leading parasitic killer of the Americas and causes the highest disease burden of any parasitic disease in the Western hemisphere. Global migration has resulted in the worldwide spread of infected and diseased individuals. Vector and blood transfusion transmission in Latin America has been reduced, however, further attention must be given to diagnosis and treatment, currently estimated to be below 1%.



## The Chagas Clinical Research Platform

Since 2009, the Chagas Clinical Research Platform (CCRP) has been a collaborative network that brings together researchers, patients, government representatives, international organizations and drug producers involved with Chagas Disease. It was officially launched by DNDi and its partners during the XXV Annual Meeting of Applied Research in Chagas Disease and XII Annual Meeting of Applied Research in Leishmaniasis in Uberaba, Brazil, in the centenary year of the discovery of Chagas disease. It aims to support the

The CCRP aims to:

- Strengthen capacity
- Expand community participation
- Facilitate clinical research
- Improve evaluation and delivery of new treatments across the region

development of new tools, promote capacity building and ensure access to diagnosis and treatment. As an open forum for debate and consensus building, the CCRP is a patient-centered tool independent from public/private interests for the identification of research priorities, standardization/optimization of interventions and collaborations. The model addresses the needs for open cooperation and data sharing, highlighting efficient use of resources, avoidance of duplication and expansion of existing knowledge and initiatives

The CCRP has over 342 members from 23 endemic and non-endemic countries



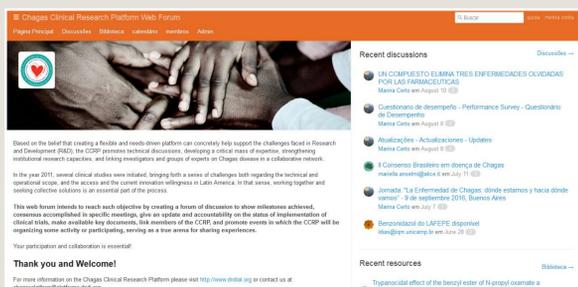
More than 90 institutions from different backgrounds are part of the network

## Objectives

This case study assesses the contributions and the initial impact of the CCRP as a collaborative model to strengthen neglected disease innovation and access.

## Methodology

Bibliographical and documental sources from its events, web-forum, interviews and surveys were reviewed. Quantitative/qualitative analyses show CCRP's recent growth and consolidation.



The CCRP web forum, launched in 2011, has hosted over 490 discussions between more than 340 members.

## Results

With a total of 324 members from >90 institutions and 23 countries, CCRP membership grew 26.4% from Q4-2014 to Q2-2016, with about 40% coming from non-endemic countries. 1,038 web-forum contributions were made in 2015, mainly from Argentina, Brazil and Spain, increasing 45% from 2014. In the same period, the CCRP has contributed to organizing 12 expert and technical meetings that were held in Mexico, Argentina, Bolivia, and Spain. It trained 517 people and was operational for trials in two sites in Bolivia and another one in Buenos Aires, Argentina for the drug-drug interaction study with benznidazole.

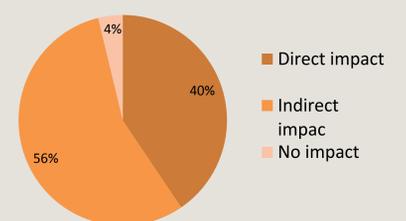
Six newsletters were issued and at least three highly cited articles published with guidelines for the determination of activity of novel *T. cruzi* drugs, as several studies were implemented with the standardized methodology developed in CCRP discussions.



Six Newsletters were published by the CCRP since 2011

In 2016, the Chagas Platform Performance Survey was carried out with the members of the CCRP, receiving very positive feedback. In this survey, it was possible to access the profiles of the Platform's most active members. Preliminary results have shown that most of the members represent R&D institutions (38.1%), while National Health Programs (21.4%), educational institutions (19%) and NGOs (15.5%) are also numerous. Although most of the CCRP researchers are currently working on clinical projects (50%), many are also dedicating themselves to access issues (19.2%).

### CCRP impact on it's members' work or their organization's performance



57.7% of the survey answers stated that members had started a cooperative partnership that led to a specific project, thanks to CCRP activities. In addition, 96.3% of the replies stated that the CCRP had an effect on their work or in their organization's performance, providing an indirect or direct impact on their activities.



A workshop held in 2016 during the VII Chagas Platform Annual Meeting in Rio de Janeiro, Brazil. Previous meetings were held in Argentina, Mexico, Bolivia and Brazil.

## Conclusion

The series of projects, capacity building initiatives and broad scope of networks demonstrate the CCRP's initial effectiveness as an innovative model with potential application for other disease settings. Thus, we see the role of CCRP and other platforms in the optimization of R&D efforts beyond the biomedical approach in an inclusive model, strengthening capabilities of different actors, including patient groups.