

A regional fight against Chagas disease: lessons learned from a successful collaborative partnership

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ABSTRACT

Objective. To identify the intangible elements that characterize the successful effort to fight Chagas disease in the Americas, determine how they contributed to the overall success of the partnership, and learn lessons from the experience that could be applied to other programs. **Methods.** This study was based on the Partnership Assessment Tool (PAT) developed by the Nuffield Institute for Health ("the Institute") at the University of Leeds (London). The PAT draws heavily on scientific literature and the extensive experience of sociologists and health experts working for the Institute. The Pan American Health Organization (PAHO) modified the tool slightly to adapt it to its needs and provide a general structure for the study. The six key principles of the PAT framework were applied in the design of the research questionnaires.

Results. The findings show that a successful collaboration requires a clear objective; a good-quality pool of data; and comprehensive qualitative and quantitative knowledge of the problem, its dimensions, and its impact. The collaboration was elaborated from a common idea and a shared, quantified plan based on data gathered by independent scientists plus a strategy with explicit milestones. The clarity of purpose allowed for an improved synergy of efforts and made it possible to resolve differences in opinions and approaches.

Conclusions. PAHO's experience with effective collaborations such as the joint initiative to fight Chagas disease provides a rich knowledge base for analysis of the advantages, limitations, and paradigms of community involvement, collaborative practices, and partnerships.

Key words

Chagas disease; international cooperation; neglected diseases; communicable diseases; Americas.

Working in isolation becomes increasingly difficult when faced with global health challenges. Therefore, governments, academia, and the private sector must work together if they wish to meet these challenges. Achieving success requires building and maintaining the capacity to implement technical solutions globally and in an integrated manner.

performance. A successful experience can also reveal best practices that can be duplicated in future endeavors.

The data gathered can prove useful in assessing progress made in different collaborative efforts. Assessing these collaborations can help illustrate the added value and achievements resulting from a common commitment. A key element contributing to the success of partnership programs is the effectiveness of the partnership as a "project" in its own right. Therefore, studies of partnership programs should include examination of the partnership itself as a key factor

The Pan American Health Organization (PAHO) has developed a rich knowledge base for the field of international collaborative efforts on public health initiatives through its exposure to different models of effective collaboration among various countries and stakeholders. These experiences provide an excellent opportunity to explore the advantages, limitations, and paradigms of community involvement and collaborative practices. While there is no set formula for success, lessons learned from past experiences are often instrumental for understanding and improving future

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that affects success in achieving program and/or project outcomes. This should include consideration of the intangible human factors that are crucial for reaching participants' goals. It is therefore vital to understand all aspects of a positive collaborative partnership. This article briefly examines the epidemiological characteristics of Chagas and some of the progress achieved through collaborative efforts to fight the disease in the Americas, with a particular focus on the intangible aspects that contributed to the success of the partnership.

Chagas disease is part of the group of diseases known as "neglected" (or "diseases of poverty") that have multiple socioeconomic and environmental determinants outside the purview of the health sector. Chagas is a communicable disease with a tropical parasitic characteristic and is caused by the flagellate protozoan Trypanosoma cruzi. Human infection with T. cruzi protozoa is currently endemic in 21 countries in Latin America (1–4). In the mid-1980s, it was estimated that 90–100 million people in the Americas were at risk of contracting Chagas disease (5), and by the 1990s, 30 million were infected (1, 6).

The most common way for humans and animals to become infected with Chagas disease is through vector-borne transmission. The insect vectors, known as "triatomine bugs," are blood-sucking insects that become infected by biting an infected animal or human. Once infected, the bugs transmit T. cruzi parasites through their feces. Humans can also become infected by consuming uncooked food contaminated with feces from the infected bugs; congenital transmission; blood transfusions; organ transplants; and accidental laboratory exposure (4). T. cruzi infection, which is often asymptomatic, has been detected in the blood of untreated individuals decades after the original contraction of the disease and thus can be easily transmitted to someone else through blood transfusions and organ transplants (1). The fact that the infection remains in the bloodstream for so long also allows for its spread across countries worldwide through immigration.

Like other neglected diseases, Chagas disease mainly affects the poor and can often be embedded at the community level in a web of transmission of infectious diseases, along with chronic malnutrition, and thus can contribute to

trapping families in a cycle of poverty. Prevention and control of diseases of poverty such as Chagas therefore require an intersectoral and multi-disease approach, with special emphasis on preventing disease spread at the community level.

By the 1990s, virtually all of the 21 endemic countries in the region (1, 2) had academic institutions that contributed to the recognition of Chagas disease as a public health problem. Those academic centers, many of which were located in the Southern Cone subregion (Argentina, Brazil, Chile, Paraguay, and Uruguay), stimulated the establishment and implementation of national Chagas disease programs.³ In July 1991, a meeting attended by health ministers from the Southern Cone countries, held in Brazil, resulted in the Southern Cone Initiative to Control/Eliminate Chagas Disease (Iniciativa del Cono Sur para controlar y eliminar la enfermedad de Chagas, INCOSUR). Subsequently, various collaborative efforts against Chagas disease were developed in other subregions of the Americas, including Central America, the Amazon, and the Andes (3, 6, 7), resulting in three more subregional initiatives.⁴ Any overlap across the various collaborations was identified as a potential forum for information exchange among participating scientists.

The various collaborations led to the development of one comprehensive joint initiative that maintains subregional profiles, with PAHO as secretariat, to prepare programs for the Americas subregions with one common action plan for the elimination of Chagas disease through the control of domestic infestation and transfusion (4). This initiative focused on three main goals: 1) interrupting household vector transmission of T. cruzi through integrated control programs with objectives specifically designed for the epidemiological situation in each country or subregion; 2) helping to stop the transfusion of T. cruzi; and 3) supporting any effective measures proposed by member countries in the areas of diagnosis, surveillance, and clinical management of Chagas disease (6, 7). The initiative focused on each country's conditions, national plans, and mechanisms for technical cooperation with other countries in the region.

There are substantial differences in eco-biological diversity, biogeography, epidemiology, socioeconomics, and sociocultural situations, as well as in the vectors that transmit *T. cruzi*, and the degrees of development and continuity of disease surveillance and control, across the countries participating in the Chagas initiative. At present, PAHO's integrated program for management of the disease is headquartered in Uruguay (7). Its principal goal is to carry out technical cooperation activities in countries where Chagas disease is endemic.

The disease always posed a serious obstacle for socioeconomic development and quality of life in the region, placing an especially heavy burden on endemic countries. However, significant improvements have occurred as a result of various initiatives on Chagas disease that have been conducted in the Americas. The best indicator for measuring the disease's impact or burden on the development of the region is disabilityadjusted life years (DALYs).5 In 1990, the burden of Chagas disease in Latin America was 2.7 million DALYs lost (8). By 2001, this number had dropped to 586 000 DALYs lost (8). This remarkable change also implies a drastic corresponding decrease in the loss of human capital at both the country and household level. As shown in Table 1 (1),

Entities such as the European Community Latin American Network for Research on the Biology and Control of Triatominae (ECLAT), and the Chagas Disease Intervention Activities–European Community (CDIA/EC) also played important roles. The Latin American Network for Vector Control (Red Latinoamericana de Control de Vectores, RELCOV) is another network that has primarily dealt with the training of personnel and the standardization of techniques to monitor vector resistance to insecticides.

Two of them-the Initiative of the Andean Countries to Control Vectoral and Transfusional Transmission of Chagas Disease (Iniciativa de los Países Andinos de Control de la Transmisión Vectorial y Transfusional de la Enfermedad de Chagas, IPA) and the Initiative of Central American Countries for the Interruption of Vectoral and Transfusional Transmission and Medical Care of Chagas Disease (Iniciativa de los Países de América Central para el Control de la Transmisión Vectorial, Transfusional y la Atención Médica de la Enfermedad de Chagas, IPCA)—were launched in 1997 with similar structures. The IPA originated within the framework of the Andean Health Organization (Organismo Andino de Salud)/Convenio Hipólito Unanue (ORAS/ CONHU) with collaboration among Colombia, Ecuador, Peru, and Venezuela. In 2013, the IPCA incorporated as IPCAM to represent its original member countries plus Mexico. For more information see PAHO's website on subregional initiatives on Chagas (http://www.paho.org/hq/index. php?option=com content&view=article&id=6138 &Itemid=4218&lang=pt).

The sum of years of potential life lost due to premature mortality and years of productive life lost due to disability.

TABLE 1. Epidemiological changes in Chagas disease, Americas region, 1990–2006

Parameter	1990	2000	2006
Annual incidence	700 000	200 000	41 200
Deaths per year	> 45 000	21 000	12 500
Prevalence (in millions)	30	18	15
Population at risk (in millions)	100	40	28
Distribution (number of countries)	21	21	21

Source: (1), reprinted with permission from the publisher.

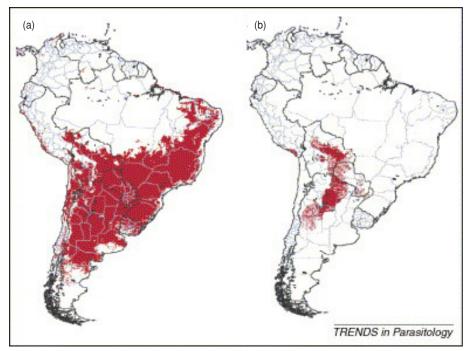
the epidemiological changes have been particularly striking. The program for the fight against Chagas boasts significant achievements, with the population at risk decreasing from 100 million to 28 million over a period of 16 years (1). According to a study conducted after the publication of Table 1, the prevalence of Chagas disease actually dropped from 30 million to 8 million between 1990 and 2006 (2), 7 million less than the estimated 15 million indicated in Table 1 (1).

The effort against Chagas has also been highly cost-effective. From 1991 to 2001, the combined investment of participating governments was estimated at slightly more than US\$ 320 million (8), with direct benefits from savings in medical costs alone of about US\$ 53 million per year (9). While implementing

programs to prevent and control Chagas disease does incur costs, they must be weighed against the costs of postponing these types of measures, which are often substantial.

Figure 1 (5) shows two estimated distributions for *Triatoma infestans* in South America for the year 2006: 6 278 081 km² (if there had been no control interventions) and 913 485 km² (the actual distribution with the control interventions). These estimates are based on geographic information system (GIS) reports from the Intergovernmental Commission for the Southern Cone Initiative. The difference in the two distributions is the estimated measure of disease spread (85%) prevented by the Chagas control intervention that was begun prior to 2006.

FIGURE 1. Maximum estimated distribution of *Triatoma infestans* if there had been no control interventions (a) versus estimated actual distribution with the control interventions (b), based on geographic information system (GIS) reports, South America, 2006^{a,b}



a Source: (5), reprinted with permission from the publisher.

One of the primary objectives of the joint Chagas initiative was to provide expertise on transfusion control and to stimulate an immediate review of the problem in different countries. Activities supporting these objectives included technical workshops; expert visits; updating of epidemiological data; sharing of techniques, references, and reagents; and the establishment of reference laboratories in each endemic country. In addition, almost all of the endemic countries of the Americas now have legislation regulating the screening of blood for transfusion, although the issue of transfusion remains a global concern (1, 9).

The study reported here aimed to identify the intangible elements that characterize this successful effort to fight Chagas disease in the Americas, determine how they contributed to the overall success of the partnership, and learn lessons from the experience that could be applied to other programs.

MATERIALS AND METHODS

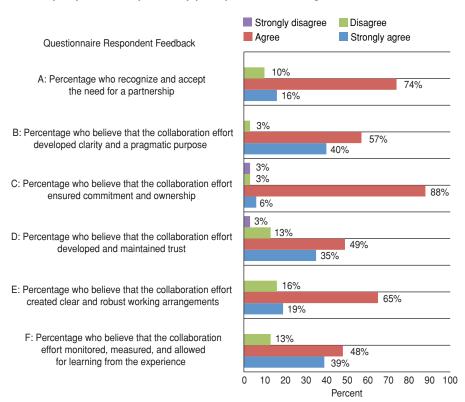
The instrument used for the study was the University of Leeds Nuffield Institute for Health ("the Institute") Partnership Assessment Tool (PAT) (10), which draws on an extensive program of research on partnerships carried out by the Institute and on work undertaken in public health and social work.⁶ The purpose of the PAT is to acquire partners' perspectives in order to gain an understanding of the building blocks of a successful partnership. PAHO revised and adapted the PAT to tailor it to the specific needs of this study.⁷ The adapted tool served as the basis for the study questionnaire and the structured interviews administered by PAHO to assess collaborative efforts to fight Chagas disease. The tool is based on six "partnership principles" that research and fieldwork have shown help form the building blocks for successful partnerships (Figure 2). Principles A and B relate to the "shared vision"; principles C and D relate to "internalization";

^b GIS reports were from the Intergovernmental Commission for the Southern Cone Initiative.

The Strategic Partnering Taskforce at the Office of the Deputy Prime Minister of the United Kingdom commissioned the University of Leeds Nuffield Institute for Health (London) to develop a mechanism to appraise partnerships.

Opinions from different partners were reviewed and analyzed, and the required remedial actions were planned. A database was created for future use in tracking the development of the partnership.

FIGURE 2. Elements that characterized a successful collaboration to fight Chagas disease, based on survey responses from partnership participants, Americas region, 2010



and principles E and F relate to "governance." The PAT was modified by PAHO to 1) rate the relative importance of each principle, 2) rank the principles in terms of their importance in collaborative efforts, and 3) compare those rankings to the rankings of the same six principles by the participants. At the end of the survey participants were asked to provide their opinions on four other aspects related to satisfaction with and clarity of the partnership.

The study comprised four stages: 1) preparation; 2) assessment; 3) analysis and feedback; and 4) action-planning, using the study findings. In the preparation stage, PAHO adapted the PAT to the context of the study, prepared the questionnaires, and approved the use of the test for structured interviews. The questionnaires were then distributed and tested as a pilot. In the assessment stage, PAHO distributed the PAT to a total of 54 partners.⁸ In the analysis and feedback stage, PAHO compared the individual re-

sponses to the scores provided by the PAT and arranged a workshop meeting so that participants could collectively discuss the underlying principles and specific questions. In the final stage (action-planning), PAHO utilized feedback from the overall assessment of the collaborative process to develop and design future steps.

RESULTS

Figure 2 shows the intangible elements that characterized the successful collaboration to fight Chagas disease, based on survey responses from partnership participants.

DISCUSSION

Lessons learned from the partnership

According to the survey respondents and those who participated in the structured interviews, the following intangible elements are the building blocks of a successful partnership:

Recognition of the need for a partnership. Partnership in the fight against Chagas disease was based on a strong history of collaboration among local scientists that permitted the development of a shared understanding of the need to combine efforts toward a common goal. All of the survey respondents interviewed agreed that the countries involved in the partnership were prepared, politically as well as operationally, to embark on a collaborative effort. The joint Chagas disease initiative was reported by respondents as a clear example of a group of scientists who were able to shape political commitment at the national and international level. Hence, a common underlying rationale triggered the creation of the original nucleus of collaboration. All partners shared the mutual belief that an international agreement would favor the continuity of national policies for disease control and that cooperation among nations would reduce the risk of accidental cross-border transmission of the vectors or of infected blood products. Governments and scientists were aware that they could not meet all of their objectives alone and based exclusively on existing national expertise.

Clarity and pragmatism of purpose. According to the study participants, scientists working to combat Chagas had substantial knowledge of the problem in the region and the initiative had a welldefined objective since its inception. Although there was a lamentable tendency to underestimate the real socioeconomic cost of Chagas disease, partners were clear on a broad set of shared understandings, as well as more specific aims and objectives. With this initial clarity and pragmatism, it was easier to unite efforts and to encourage commitment from others. Having a pragmatic purpose included considering whether the partners had sufficient common ground to work together. Partners understood that collaborations are hard to shape without a clear conceptual basis and prospects of producing results that merit the efforts expended. Expectations can often be unclear or unrealistic or may lack the needed supporting evidence. According to the study participants, clarity of scope of the joint Chagas initiative allowed for synergistic efforts and made it possible to resolve differences of opinion and highlight progress toward a common goal.

Commitment and ownership. Partnerships, especially among senior-level

A total of 23 structured interviews were conducted and 31 questionnaires distributed among a strategically selected group of health care managers and academics. Those who could not participate in the structured interviews completed the questionnaire instead.

officials, were strengthened by broad commitment to and ownership of their operations. According to one respondent, an important factor in the initiative's success was "the willingness of the partners to give up certain specific interests or institutional ambitions for the benefit of overall collaboration." The general sense of commitment to collaborative efforts was encouraged due to the high level of respect toward each country's approach and strategy. This point was illustrated by another respondent who said that "everyone could see that the operations were carried out with full respect of national programs, incorporating their choices and not replacing

The first and foremost indicator of this feeling of ownership among the partners was the substantial amount of funding pledged by the participating countries. Funds for the various initiatives essentially came from investments made by the countries, with each one principally financing its own national activities and retaining complete autonomy for program implementation. Municipalities reported different experiences, most likely due to contextual variations such as whether they were urban or rural. Decentralization allowed the general population to play an active role in initiative activities, and this was the foundation of many substantial accomplishments.

Building and maintaining trust. According to the study participants, trust was a cohesive element that underpinned successful partnership. In general, while respondents tended to give higher priority to the principles connected to the more concrete measures, trust-though elusive-was considered crucial to the undertaking of any common effort. Respondents reported that periodic meetings fostered feelings of solidarity within an international community jointly tackling a common problem, further motivated the partners, and provided a shared sense of trust in the partnership. An important element, according to the respondents, was involving credible participants with a wide range of contacts. These persons were often central to bringing together individuals and institutions that would not have considered working together otherwise and creating consensus on decision-making. Some countries' political decisions were heavily influenced by the

results that other countries presented in open discussion forums, exchanges with other initiatives, and meetings. Trust was also triggered by the inclusion and strong commitment of technicians and scientists, from different countries, conducting the bulk of the sessions while at the same time maintaining genuine independence. In turn, the decisions made by national governments to give priority to Chagas control efforts translated into additional resources, greater institutional participation, and expanded activities.

Clarity of partnership arrangements. Respondents reported that all collaborative efforts needed effective control mechanisms that enhanced mutual trust. However, these mechanisms had to be carefully balanced in terms of time and bureaucratic requirements. Otherwise, there was a risk that excessive bureaucracy would create frustration among the partners, diminishing their enthusiasm for and commitment to the partnership. Some respondents mentioned the need to increase the centralization of information and improve the use of the Internet for information exchange. In the interviews, the respondents indicated that the creation of "subregional initiatives"—with all their mechanisms for linkages among partners and exchanges among participants from different sectors—was responsible for much of the progress in the fight against the disease. Holding an annual meeting on applied research on Chagas encouraged connections between academics and colleagues in other sectors and from different countries. Such events often led to the establishment of formal control programs in certain countries and allowed for program operators' self-identification as a community. Respondents said that they perceived the "time factor"—the length of time that a partner was part of the collaborative effort—as a crucial aspect of this principle and that rapid turnover of staff did not allow for the establishment of lasting human relations. Similarly, when there was no expectation of ongoing involvement, the individuals' commitment to joint actions was reduced.

Monitoring & evaluation and sufficient body of knowledge. Evaluating Chagas activities in the Americas strengthened the commitment and trust among the partners involved. As described above, another element of a successful collaboration was having an adequate body of knowledge on the disease, which made it possible to define and focus attention on the situation in the region, even when official local statistics were not available. This was reinforced by a system of oversight and study carried out by commissions composed of independent experts who stimulated action and provided a solid base of evidence. As one respondent said, "Perhaps one of the greatest achievements of the multinational initiative against Chagas disease is that surveillance and control of the disease and its vectors are currently on the agenda of all the endemic countries." This means that, with adequate data compilation and comparison, it was possible to deal with the existing disease impact and detect potential new transmission outbreaks and other epidemiological trends.

Limitations

The unity of action in the Chagas initiative was always ensured by PAHO's technical guidance and operational role as Secretariat of subregional efforts. The context of implementation of the Chagas program was extremely diversified. Therefore, the main limitation of this research is the fact that the complex nature of the collaboration precluded capturing all of the finer points and nuances that may have influenced the collective social action. To explore this cultural variety further, contextual assessment studies are needed in the future.

Conclusions

PAHO's experience with the Chagas partnership provided an opportunity to explore the advantages, limitations, and paradigms of this type of collaboration, revealing the intangible elements that played a crucial role in its success, according to the perceptions of the initiative stakeholders. These elements included 1) having a clear objective, 2) having a solid base of data, and 3) having comprehensive qualitative and quantitative knowledge of the problem, its dimension, and its impact. Important conditions for successfully integrating the various partners were mutual trust, credibility of the international technicians involved, and respect and consideration for policy decisions made by

their national programs. These intangible aspects, among others identified in the study, were evident due to the qualitative assessment made. These aspects should be taken into consideration in all design and implementation of partnership efforts. They should also continue to be evaluated throughout the life of the

program because, as the results of this study demonstrate, intangible aspects of a partnership are crucial to synergizing efforts and ensuring the successful outcome of a collaboration.

Acknowledgments. This article is dedicated to the memory of the re-

nowned Brazilian public health physician Dr. Antonio Carlos Silveira, whose formidable research and brilliant guidance helped countries in the Americas advance the prevention, control, and treatment of Chagas disease.

Conflicts of interest. None.

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RESUMEN

Lucha regional contra la enfermedad de Chagas: lecciones aprendidas de una alianza colaborativa exitosa *Objetivo*. Establecer los elementos intangibles que caracterizan la exitosa iniciativa para combatir la enfermedad de Chagas en la Región de las Américas, determinar cómo contribuyeron al éxito general de la alianza y extraer enseñanzas de la experiencia que podrían ser aplicadas a otros programas.

Métodos. Este estudio se basó en la Herramienta de Evaluación de Alianzas (PAT, por sus siglas en inglés: *Partnership Assessment Tool*) creada por el Nuffield Institute for Health ("el Instituto") de la Universidad de Leeds (Londres). La PAT utiliza en gran medida la bibliografía científica y la vasta experiencia de los sociólogos y expertos en salud que trabajan para el Instituto. La Organización Panamericana de la Salud (OPS) modificó ligeramente la herramienta para adaptarla a sus necesidades y proporcionar una estructura general para el estudio. En el diseño de los cuestionarios de investigación, se aplicaron los seis principios clave del marco de la PAT.

Resultados. Los resultados indican que una colaboración exitosa requiere un objetivo claro; una base de datos de buena calidad; y un conocimiento exhaustivo cualitativo y cuantitativo del problema, sus dimensiones y su repercusión. La colaboración se elaboró a partir de una idea común y un plan compartido y cuantificado basado en datos recopilados por científicos independientes, junto a una estrategia con hitos explícitos. La claridad de los objetivos permitió una mejor sinergia de las iniciativas e hizo posible la resolución de las diferencias de opiniones y enfoques.

Conclusiones. La experiencia de la OPS en materia de colaboraciones eficaces, como la iniciativa conjunta para combatir la enfermedad de Chagas, proporciona una rica base de conocimientos para analizar las ventajas, las limitaciones y los paradigmas de la participación comunitaria, las prácticas colaborativas y las alianzas.

Palabras clave

Enfermedad de Chagas; cooperación internacional; enfermedades desatendidas; enfermedades transmisibles; Américas.