SOCIAL INNOVATION IN HEALTH INITIATIVE

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CENTRE FOR THE DEVELOPMENT OF SCIENTIFIC RESEARCH

CONTINENT	Latin America
COUNTRY	Paraguay
HEALTH FOCUS	Neglected Tropical Diseases, Chagas Disease
AREAS OF INTEREST	Health research, Indigenous peoples, Community mobilization
HEALTH SYSTEM FOCUS	Service delivery

CENTRE FOR THE DEVELOPMENT OF SCIENTIFIC RESEARCH (CEDIC), PARAGUAY

A community-centred research approach inviting inclusive participation of all stakeholders to develop new context-specific solutions to address Chagas disease in the Chaco region of Paraguay.

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This case study forms part of the Social Innovation in Health Initiative Case Collection.

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CONTENTS

ABBREVIATIONS

CEDIC	Centre for the Development of Scientific Research [*Centro para el Desarrollo de la Investigación Cientifica*]
CONACYT	National Research Council for Science and Technology [*Consejo Nacional de Ciencia y Technología*]
MERCOSUR	Southern Common Market [*Mercado Común del Sur*]
NGO	Non-governmental organization
PAHO	Pan American Health Organization
PRONII	National Incentive Program for Researchers [*Programa Nacional de Inventivo a los Investigadores*]
Temha	Studies Workshop for Habitat Improvement [*Taller de Estudios para la Mejora del Habitat*]
SENEPA	Ministry of Public Health and Social Wellbeing responsible of infectious disease control [*Servicio Nacional de Control de Vectores*]
US$	United States Dollar

CASE INTRODUCTION

The Centre for the Development of Scientific Research (CEDIC) is a nongovernmental organization in Paraguay that adopts a community-centred research approach, inviting inclusive participation of all stakeholders to develop new context-specific solutions to address Chagas disease in the Chaco region. Chagas disease is a potentially life-threatening illness affecting between six and seven million people worldwide. It is responsible for 21 000 deaths annually (World Health Organization, 2016). In Paraguay, Chagas disease is endemic to the Gran Chaco region. The Chaco is a vast semi-arid geographic area in western Paraguay. Although sparsely populated, it is home to 115 944 indigenous persons or 2% of the population (Technical Planning Secretariat for Economic and Social Development, 2015). According to the Paraguayan 2012 census, 455 of the country's 711 indigenous communities do not have health facilities of any kind, and where they do exist, the services are often insufficient. The constrained health care service provision poses a major challenge for preventing and managing Chagas disease.

CEDIC recognized the need for a community-owned approach to tackle Chagas disease. An inclusive co-design process allows for the development of an integrated pipeline of innovative product and process solutions. CEDIC draws from its rigorous research experience and its established relationships with local stakeholders such as universities, local municipalities and the national government. Together with its collaborators, CEDIC operates as a "Living Lab", applying principles of co-design and user-centred research. By building relationships with various stakeholders and applying for international grants to finance its projects, CEDIC has been encouraging research and enabling collaboration between institutions and local communities. Although primarily funded through research grants, CEDIC is considering ways to diversify funding and become more sustainable.

This case study illustrates that communities can define new research priorities for academics. They can also actively participate in designing new interventions in response to these priorities in collaboration with experts and academics. By engaging and involving community members it increases their ownership of the implemented interventions in the community. The way CEDIC operates provides an example of how the role of research can extend beyond the generation of new knowledge. Instead, research can also provide an opportunity to mobilize a broader, cross-sectoral group of experts and community members to help solve challenges faced by marginalized communities.

1. INNOVATION PROFILE AT A GLANCE

Organization Details

Organization name	Centre for the Development of Scientific Research (CEDIC)
Founding year	2006
Main founders' names	Antonieta Rojas de Arias; Celeste Vega Gomez, Miriam Soledad Rolón, Laboratorio Diaz Gill and Fundación Moises Bertoni
Founder nationality	Paraguayan
Current head of organization	María Celeste Vega Gomez (Executive Director)
Organizational structure	Nongovernmental organization
Size	10 to 20 people, depending on collaborations

Innovation Value

Value proposition	A community-centred research approach ("Living Lab"), inviting inclusive participation of all stakeholders to develop new context-specific solutions to address Chagas disease in the Chaco region.
Beneficiaries	Members from three indigenous communities in the Chaco region
Key components	• Collaborative community-centred research and development • Community-owned solutions to Chagas Disease

Operational Details

Main income streams	Donor and public grants
Annual expenditure	US$ 800 000 (2015)

Scale and Transferability

Scope of operations	Asuncion and Chaco region, Paraguay
Local engagement	Partnerships with the local municipality; the technical branch of the Ministry of Public Health and Social Wellbeing responsible of infectious disease control (SENEPA); the National Council of Science and Technology (CONACYT); and local universities
Scalability	The "Living Labs" research approach is replicable to any context or health situation but is dependent on the willingness of the local community to engage in the process.
Sustainability	• Diversifying income streams beyond grant funding, and allowing for revenue from product sales • Partnerships and voluntary support extends the organization's capacity and reach • Sharing technical expertise and knowledge gained on projects in support of other countries' efforts to combat Chagas disease

2. CHALLENGES

Chagas disease, also known as American trypanosomiasis, is a potentially life-threatening illness affecting between six and seven million people worldwide. It is responsible for 21 000 deaths annually (World Health Organization, 2016). Chagas disease is endemic in areas of Latin America. The disease results from an infection by a parasite called Trypanosoma cruzi *(T.cruzi).* The parasite is carried by an insect vector, the triatomine bug, otherwise called "kissing bugs". Humans are infected when they come into contact with the faeces or urine of these blood-feeding bugs (World Health Organization, 2016). Paraguay has the third highest prevalence of individuals infected in Latin America (World Health Organization, 2015).

Traditionally, Chagas disease control programmes are comprised of two separate strategies: 1) vector control informed by surveillance efforts that detects the triatomine bugs in walls or roof cracks of poorly-constructed homes, followed by insecticide spraying (World Health Organization, 2016); and 2) a disease control programme that diagnoses the disease in affected people and provides medical care to the chronically ill (Gurevitz et al., 2013). Available data from Columbia gives an indication as to the annual cost of medical care for patients affected by Chagas (US$ 267 million) and insecticide spraying vector control (US$ 5 million) (World Health Organization, 2016).

In Paraguay, Chagas disease is endemic to the Gran Chaco region. The Chaco is a vast semi-arid geographic area in western Paraguay. Although sparsely populated, it is home to 115 944 indigenous persons or 2% of the population (Technical Planning Secretariat for Economic and Social Development, 2015). Indigenous people of the Chaco are affected by a lack of security of their rights to their land and resources; a lack of access to justice; racism and discrimination; and widespread poverty (United Nations Human Rights Council, 2015). *"Every year there is a national emergency declared because of drought and flooding in the indigenous communities. This is not an emergency anymore. It's a chronic problem that needs a lasting solution."* (Founder, CEDIC)

A systemic approach to control Chagas disease does not yet exist in the Chaco region. Infestations of triatomine bugs are reported in nearly 30% of the homes in selected communities (Rojas de Arias et al., 2012). The epidemiological situation of Chagas in the Paraguayan Chaco is *"intimately linked to the socio-economic and cultural realities of the indigenous people"* (Founder, CEDIC) and any effort to address the former needs to consider the latter.

According to the Paraguayan 2012 census, 455 of the country's 711 indigenous communities do not have health facilities of any kind. Although 573 communities do receive some services from a family health unit, the nature of those services is often insufficient. The constraints in health care service provision pose a major challenge in preventing and managing Chagas Disease (United Nations Human Rights Council, 2015).

3. INNOVATION IN INTERVENTION AND IMPLEMENTATION

CEDIC, a not-for-profit, nongovernmental organization research centre, was established in 2006 by Dr Antonieta Rojas de Arias. CEDIC is a research institution that has adopted a different approach to developing and testing new solutions in response to local needs. The centre provides training in health and environmental research to undergraduate students. It also serves as a home for Paraguayan researchers returning to the country following their studies abroad. Researchers can develop their own investigations in response to the needs of indigenous communities. CEDIC shows that it is possible to

involve communities throughout the implementation and evaluation process.

3.1. COLLABORATIVE COMMUNITY-CENTRED RESEARCH AND DEVELOPMENT

Early on, CEDIC recognized the need for a community-owned approach to tackling Chagas disease. An inclusive co-design process allows for the development of an integrated pipeline of innovative product and process solutions. CEDIC draws from its rigorous research experience and its established relationships with local stakeholders such as universities, local municipalities and the national government. Together with its collaborators, CEDIC operates as a "Living Lab", applying principles of co-design and user-centred research. When wanting to pursue a new research question, CEDIC approaches it by applying the following steps (Rojas de Arias et al., 2014):

1. Identify the stakeholder community affected by the challenge and gain their perceptions of the challenge;
2. Foster relationships with the stakeholder community using participatory methods that deepen understanding and ownership of the challenge;
3. Develop a community-owned project proposal engaging stakeholders from academia, public administration and private industry; and
4. Co-design a new solution to address this challenge. Action-research cycles are applied to study the effectiveness of the solution during implementation and make iterations along the way.

CEDIC draws on a range of different disciplines in its work including: epidemiology, public health, engineering, and social sciences. CEDIC also has laboratory facilities equipped with the latest technologies to develop pharmaceutical products.

3.2. COMMUNITY SOLUTIONS ADDRESSING CHAGAS DISEASE

Model brick homes to reduce vector infestation

Overcrowding and a lack of quality housing are pressing social and health issues expressed by the indigenous communities of the Chaco. Low quality housing makes vector control for Chagas disease difficult as the triatomine bugs live in the wooden walls or roof cracks of poorly constructed homes (Rojas de Arias et al., 2012).

Through the Living Lab approach, CEDIC seeks solutions that can address the lack of housing and reduce the risk of triatomine bug infestation. In collaboration with a social enterprise called Temha (the Studies Workshop for Habitat Improvement) a new building technique was developed. This technique allows for homes to be built from mud, using very little water, and only 5% cement.

Temha's architect taught the building technique to the local communities so that they could use it to build their own houses.

Construction of the houses engaged different stakeholders. A university laboratory tested local soil samples to find deposits appropriate for brick making and established that the bricks could sustain mechanical stress. A local business provided construction tools, and the local government provided communities with meals and transport. The communities decided to turn the first buildings into health posts and a school. It is envisaged that this project will affect over 200 families in the Chaco region.

Surveillance system to enhance vector detection

Continuous surveillance efforts are important to detect the vector (triatomine bugs) responsible for spreading Chagas disease. Once the vector is detected, insecticide spraying can be done to eliminate it.

Communities identified a lack of good surveillance in the Chaco. Different approaches, such as community training and awareness, support surveillance efforts but several challenges undermine vector control. These challenges include the diverse languages and cultures of different groups living in the Chaco; migration and vast distances between communities; quick re-infestation of homes with the triatomine bugs following insecticide spraying as a result of the wooden walls.

CEDIC, in collaboration with computer scientists in the National University of Asuncion, has developed an innovative trap with infrared sensors and pheromones that attracts the triatomines (Rojas de Arias et al., 2012). The infrared detector, powered by solar cells, aims to notify the researchers in real-time of the presence of triatomines by communicating with a central reporting hub. The initial laboratory results are promising with significant "visits" from the triatomines. CEDIC is developing the final adjustments for pheromone release to attract the triatomines. It hopes to launch the field assay of this product in the local communities later this year.

Educational games for community awareness

CEDIC identified the need to raise awareness of Chagas disease amongst community members of all ages. To teach children about Chagas disease, CEDIC partnered with the graphic design department at the American University in Asuncion. An undergraduate student competition was established to encourage the development of different educational games to teach children about the basics about Chagas prevention.

The effectiveness and engagement of these games were tested with school children and Chagas disease experts by means of focus groups. Four board games and stories were funded by the Pan America Health Organization (PAHO) and rolled out across schools in the Chaco and the rest of the country.

Other community solutions

Indigenous communities in the Chaco expressed an urgent need for access to clean water for consumption and agriculture. Ceramic water filters and drought-resistant irrigation clay pitchers, both previously developed by Temha, were distributed to the communities through a financially enabling partnership by CEDIC. The water filters remove 99% of impurities from the water. The irrigation pitcher, when planted with a suitable crop, uses 80% less water. The communities were taught how to manufacture the water filters so that they are able to produce these on their own when the necessary infrastructure (oven and clay) becomes available.

4. ORGANIZATION AND PEOPLE

CEDIC's founder is Dr Antonieta Rojas de Arias, supported by co-founders Dr Maria Celeste Vega Gomez, Dr Miriam Rolón, Laboratorio Diaz Gill and Fundación Moisés Bertoni. Originally trained as a biologist, Dr Rojas de Arias started studying Chagas disease transmission in Paraguay during her PhD in the United Kingdom. She has worked in various institutions in Brazil and Paraguay and was a technical consultant to PAHO. She was also the technical coordinator for the Paraguayan Ministry of Public Health Vector Control Programme. She has strong relationships with her colleagues at the Ministry of Health, in particular with the National Program for Chagas Control of the Health and Social Welfare.

After founding CEDIC in 2006, Dr Rojas de Arias served as its Executive Director for five years. This administrative function now rotates between the three principal investigators and founders every five years. Currently, Dr Maria Celeste Vega Gomez spends 80% of her time in the role of Executive Director. Dr Gomez, a microbiologist and parasitologist, also specialized in Chagas disease during her PhD.

CEDIC operates without formal employees. Instead, the three principal researchers (Dr Antonieta Rojas de Arias, Dr Maria Celeste Gomez and Dr Miriam Rolón) employ technicians through research grants and supervise students who work on a voluntary basis.

CEDIC operates through strong partnerships with other organizations and institutions. CEDIC has collaborated with Temha, a local social enterprise on the housing and water filtration projects. CEDIC also holds a memorandum of understanding with

collaborating universities (Autonomous University of Asunción, American University and National University of Asunción) and with the local municipality of Teniente Irala Fernández where the fieldwork with three communities in the Chaco is currently being undertaken.

Lastly, CEDIC maintains a very close working relationship with the National Ministry of Health and the local municipality. The technical branch director of the Ministry of Health notes the relationship to be *"an organic relationship, working together and learning from each other."* (Technical Branch Director, Ministry of Health)

5. COST CONSIDERATIONS

In 2011, The Government of Paraguay established the National Incentive Program for Researchers (PRONII), encouraging scientific research in national universities. Prior to this, the country had limited research programmes beyond a few private and public activities.

By building relationships with various stakeholders and applying for international grants to finance its projects, CEDIC has been encouraging research and enabling collaboration between institutions. Dr Rojas de Arias advised the government during discussions on the establishment of CONACYT (the National Research Council for Science and Technology) in 2008, which now offers the main incentives through PRONII for in-country research and graduate education. The three principal investigators in CEDIC apply independently to CONACYT and to international grant agencies. To date, CEDIC has received grant funding from International Development Research Centre (IDRC), the World Health Organization (WHO) and other international funding bodies. During the first seven years of operation, CEDIC's laboratory infrastructure was supported through Diaz Gill Medical Laboratories' Social Responsibility Programme. This support helped consolidate CEDIC's mission and vision. The Moises Bertoni Foundation, a Paraguayan not-for-profit organization that specializes in sustainable development in the country, has supported CEDIC in the financial administration of its grants since 2006 (although CEDIC is now taking over this aspect). The Moises Bertoni Foundation has also been instrumental in securing CEDIC's current offices and laboratory in Asuncion. It covered CEDIC's rental fees for a period of time but recently announced it would donate the whole plot of land and associated buildings to the centre.

For 2015/2016, CEDIC's projects have run on three grants that the investigators secured from the CONACYT: a grant worth US$ 200 000 for surveillance research; and two grants worth US$ 189 000 each for laboratory-based projects on Leishmaniasis and Chagas disease. CEDIC has also secured a regional grant worth US$ 464 000 from MERCOSUR, South America's leading trading block, to use for equipment and laboratory infrastructure. CEDIC currently applies for funding on a monthly basis with the longest of its grants having lasted for three years. While CEDIC is keen to maintain its status as an independent not-for-profit research institution, it is seeking to achieve financial sustainability by commercialising its products, some of which they believe would attract significant pharmaceutical interest in the region.

6. OUTPUTS AND OUTCOMES

6.1. IMPACT ON HEALTH CARE DELIVERY

CEDIC has yet to quantify the impact of its work in the Chaco. Its impact on the socioeconomic welfare and health outcomes of the communities; the incidence of Chagas and the infestation rate of triatomines cannot be fully measured due to difficulties in obtaining reliable baseline data and

determining confounding variables. The National Program for Chagas Control of the Ministry of Health, however, reported a decline in the infestation rate in homes in affected communities from 30% to 12%. In some areas, infestation has remained unreported since CEDIC started working.

To better document its own impact, CEDIC has been working on a household survey tool for the in which communities it works. CEDIC's household survey aims to collect enough data to establish a baseline measure of the economic, health, social and cultural context of the communities, against which all the effects of interventions can be compared. This survey, in collaboration with the National University of Asuncion, was designed using the Open Data Kit (ODK). ODK is a free and open-source tool that allows survey data to be collected and managed using an electronic tablet or mobile phone, even in the absence of internet connectivity. Collecting data at household level electronically removes cumbersome paper forms and costly data entering processes. Utilization of this electronic survey tool is a first in the country. Government agencies have already expressed interest in collaborating with CEDIC to expand its use in other regions.

In the absence of quantitative impact measures, CEDIC has been able to document its impact of its work qualitatively:

Affordable housing

As compared to government budgeted costs of US$ 15 000 per building, the cost of CEDIC's model brick homes cost US$ 5 000. In addition, community participation and related skills development has resulted in some members finding new employment opportunities.

Community development

In Karandillas, a community most affected by drought, a newly built school is making education more accessible. Previously, children had to walk 6 km to the nearest school. In addition, the clay water filters currently housed in schools are providing safe drinking water to the children, and the irrigation pitchers have allowed a small school vegetable garden to thrive. Children are learning relevant agricultural practices, and mothers are incorporating leafy greens into their children's lunches.

Academic engagement

A PhD student working with CEDIC will be assessing the impact of the educational games on health outcomes. A short discussion with the community leader where the games were made available revealed that the children understood the basics of prevention and could relate this to their parents. However, without a separate effort to reach the parents, the community leader thought that the information could be lost.

6.2. COMMUNITY AND BENEFICIARIES

Community members spoke positively of their experiences with CEDIC. Community leaders expressed their satisfaction with CEDIC's approach and were pleased that CEDIC continues to understand their needs and to work on more projects. *"We like working with them, they are the only ones that keep coming back [and helping us]."* (Community Leader) Community members are engaged in the work done by CEDIC and willing to voice their opinions. A vegetable garden (watered by the clay irrigation pitchers) was initially placed in the centre of the community. Community members quickly expressed that they would prefer the garden to be inside the school grounds for children to engage with. School children have now taken responsibility for maintaining the garden while acquiring basic agricultural skills. The teacher explained that moving the garden in the school grounds was important in generating ownership of the project from the community. Seeing these results, surrounding communities have asked to start a similar garden or have already started one, and they hope to plant enough produce to sell.

Students engaging with CEDIC are grateful for the training and practical exposure they have received. A computer scientist working on the surveillance platform was proud to be involved and appreciated the opportunities it brought for future graduate research.

6.3. ORGANIZATIONAL MILESTONES

CEDIC is proud of its achievements in research outputs and partnerships established. CEDIC has established academic collaborations with local and international partners. To date, 45 peer-reviewed articles have been published by CEDIC and its researchers have participated in over 30 scientific meetings. CEDIC has a growing number of PhD students and frequently hosts academic visitors.

7. SUSTAINABILITY AND SCALABILITY

The collaborative, community-centred research approach adopted by CEDIC is replicable and scalable to any context or health issue. This approach is based on a set of key foundational principles such as community-engagement, inclusive stakeholder co-creation and action-research. Its application in the Chaco region of Paraguay has supported the development of context-appropriate solutions owned and supported by indigenous communities.

For CEDIC as an independent research institution, several considerations are noteworthy for its sustainability and scalability:

Revenue streams

CEDIC's dependence on research grant funding does pose limitations for the organization in terms of pursuing longer term community engagement projects and retaining and training students or technicians. CEDIC would like to diversify its income streams and explore the possibility of generating revenue by commercialising some of the products developed.

Partnerships

Partnerships and voluntary support have been important to CEDIC's operations and have provided opportunities to scale the products developed. Through its collaboration with Temha, an ambitious rollout of its water filters is planned. The hope is that this will create economic opportunities for the indigenous peoples of the Chaco, who have been taught how to make the clay water filters.

Technical expertise

CEDIC anticipates that its expertise in controlling Chagas disease could be in high demand outside of the Chaco and that it could share their technical knowledge. Some governments encountering challenges in Chagas disease control have already contacted CEDIC to see what lessons can be learnt from its work.

8. KEY LESSONS

8.1. IMPLEMENTATION LESSONS

Getting started

Open communication and flexible problem-solving were central to CEDIC's initial growth. CEDIC engaged local stakeholders and remains open to adapting, expanding and revising projects and timelines while respecting the socio-cultural situation of the indigenous communities. CEDIC's founder invests in frequent and prolonged visits to the Chaco region to establish trust with the leaders and understand the needs of the communities.

Maintaining efforts

CEDIC has established multidisciplinary research collaborations with universities. CEDIC invests time to engage with students and researchers on the evolving challenges experienced by communities in the Chaco. Its open communication and inclusivity has attracted

international visiting researchers, interested PhD students, invitations to a variety of international and national meetings.

Overcoming challenges

CEDIC frequently consults with local communities and their leaders to avoid disputes or disagreements. In response to regular political changes and relatively inexperienced administration of funds for scientific research, the founder prioritises regular meetings with both local and national governments to familiarise them with CEDIC's work. The founder's close relationship with the local municipality has allowed CEDIC to gain insight into other NGOs' work and to work with them effectively.

8.2. PERSONAL LESSONS

The story of CEDIC is a reflection of strong, committed leadership. CEDIC's founder, Antonieta Rojas de Arias has dedicated over 23 years of her career to the study of Chagas disease. She now champions the cause of marginalized and neglected indigenous communities and frequently travels internationally to raise awareness.

Dr Rojas de Arias takes a systems-thinking approach to the control and elimination of Chagas Disease. She emphasises the need to "respect the Vinchuca (triatomes) as part of the ecosystem" in order to create a solution. She brings great passion to her work at CEDIC and her engagements with collaborators. She believes that three values have helped her in her work: being honest in her relationship with stakeholders; being a "doer" and "living by what you think". For Dr Rojas de Arias it is important to engage locally with government as well as internationally. The severity of the situation in the Chaco requires increased awareness and attention globally.

At the heart of Dr Rojas de Arias's research is a deep respect for the community. She seeks not to impose new solutions upon them, but rather to develop solutions based on their perception of the challenges. Over the years, Dr Rojas de Arias has developed an understanding of the cultural norms of the indigenous communities in which CEDIC works. She also wants to make sure that CEDIC pays close attention to any negative effects that its work may have on the communities.

CASE INSIGHTS

1. Communities can define new research priorities requiring attention by academics. They can also actively participate in designing new interventions in response to these priorities in collaboration with experts and academics. By engaging and involving community members it increases their ownership of the implemented interventions in the community.

2. The role of research extends beyond the generation of new knowledge. It provides an opportunity to mobilize a broader, cross-sectoral group of experts and community members to help solve challenges faced by marginalized communities.

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