



Improving Maternal Health Status in Indigenous Communities of Panama: Community-Based Participatory Research and Interventions Among the *Ngäbe-Buglé* People of Panama

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36.1 Introduction

Indigenous communities perform poorly in global health indicators, when compared to other populations. Reports from the World Health Organization (WHO) indicate that indigenous groups have higher rates of maternal and child mortality, lower access to health services, and more people living under extreme poverty conditions and as a result have a shorter lifespan (Rosenstock et al. 2013; Zhao et al. 2013). This common scenario occurs in Panama, where indigenous groups have limited access to basic health services, health education, and clean drinkable water. A complex combination of social, demographic, and educational factors impacts their health status (Contraloría Nacional de la República 2000; Ministerio de Economía y Finanzas 2003). Collaborative efforts guided by the academic community, government and non-governmental organizations (NGOs), and community members resulted in a community-based educational intervention aiming to improve health literacy in the *Comarca Ngäbe-Buglé* (*Comarca* is the equivalent to an autonomous indigenous reservation in Panama). Figure 36.1 illustrates the geographical location of the *Comarca Ngäbe-Buglé*.

Starting in 2010, and funded through the Panamanian National Secretariat of Science, Technology, and Innovation (SENACYT), a public health educational intervention in the *Ngäbe-Buglé* region, following participatory processes, identified that health educators yearned for culturally appropriate materials. This project aimed to develop these materials using evidence-based references and also involving community members in the process (Fig. 36.2). The project followed social marketing and

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Fig. 36.1 Map of Panama highlighting the *Comarca Ngäbe-Buglé* (red shading)

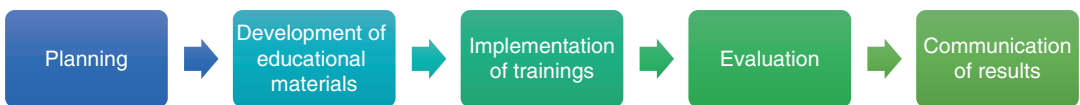


Fig. 36.2 The project phases

community-based participatory research processes (Lefebvre and Rochlin 1997) to develop the health education intervention that includes training of health promoters and development of educational materials. The intervention had four phases: (1) planning, design, and selection of *Promotores* (local community health promoters); (2) formative research; (3) development of culturally appropriate material; (3) training and implementation; and (4) evaluation and sustainability. This chapter describes each of these four phases, barriers for its implementation, and the lessons learned focusing on the pregnancy and reproductive health aspects of the project.

36.2 The Ngäbe-Buglé People

Panama is a small country, located in Central America, with an estimated population of four million people, 13% of which are indigenous. There are eight indigenous groups in Panama that include the *Guna*, *Ngäbe* (previously known as *Guaymí*), *Buglé*, *Teribe/Naso*, *Bokotá*, *Emberá*, *Wounaan*, and *Bri Bri*. These indigenous groups are dispersed throughout the country, but the majority lives in indigenous reservations called *Comarcas*. The *Comarcas* are autonomous indigenous reservations with distinct geopolitical borders, local governments, and political authorities and national representation at the Panamanian national legislative congress (Fig. 36.3).

The *Ngäbe* and the *Buglé* people live in the *Comarca Ngäbe-Buglé*, merging into one mixed group with similar languages and residing in the northwestern side of the country, close to the Costa Rican border. The Ngäbe-Buglé used to be known as *Guamí* by Panamanians. However, during the 1990s as the *Comarca* became a more distinct organizational culture, the indigenous groups requested to be known as the Ngäbe-Buglé. Historic records show that indigenous groups lived in the region since the 1500s, making them one of the oldest indigenous groups in America. These groups share cultural aspects, diet, and traditional medicine (Fig. 36.3).

The *Comarca Ngäbe-Buglé*, which encompasses three Panamanian provinces—Veraguas, Chiriquí, and Bocas del Toro—is a mountainous region occupying 2700 square miles, and it is divided into nine districts (Kankintú, Kusapín, Jirondai, Calovébora, Besikó, Mironó, Nule Düima, Müna, Nürüm). The total population of the *Comarca Ngäbe-Buglé* is approximately 203,185 people, although some reports count greater than 280,000 residents. Life expectancy in the *Comarca* is 69.6 years, significantly lower than the country average of 77.8 years. The fertility rate is 98.3 per 1000 women, which is 30 times greater than the fertility rate of 2.33 in 2016 for rest of Panama (Index Mundi 2016). The main causes of death include malnutrition, diarrhea, and pneumonia. Maternal and child deaths are also observed, mostly due to lack of access to prenatal care and proper health services. The poverty index in the *Comarca* is above 90%, with the Ngäbe-Buglé living in extreme levels of poverty. Main sources of income include small-scale sustainable agriculture, handcraft sales, informal work, and government subsidies. Most males work on coffee farms (*fincas*), where they migrate during cropping



Fig. 36.3 Ngäbe-Buglé women dressed in their typical attire, the enagua

Fig. 36.4 A typical *Ngäbe-Buglé* household in the *Comarca*



seasons. The families tend to migrate together, making it difficult for healthcare delivery and follow-up. Figure 36.4 shows a typical *Ngäbe-Buglé* household in the *Comarca*.

36.3 Planning the Intervention

The *Comarca Ngäbe-Buglé* is located 400 km from the capital of Panama City, Panama. Because the distance, cost of travel, and difficult terrain are major barriers for implementation of health interventions, thus, detailed planning preceded the implementation phase of the project. Planning processes involved hiring of qualified staff, identification of key partners, definition of the overall scope of the project, determining the costs and potential barriers of implementation, and communication of results (Keyonzo et al. 2015; Wright et al. 2015; Kaur et al. 2013). Each of these steps is described in Table 36.1.

36.4 Development of Educational Materials

Health education consists of a continuous iterative process and a combination of learning techniques to improve health in the population. It must be a continuous process because new information is available constantly. However, evidence-based materials for health education at the community level are scarce, especially for indigenous populations of Panama. Our goal was to develop culturally and linguistically appropriate educational materials for the *Ngäbe-Buglé* population. One of the first steps was to organize a community advisory board (CAB), represented by local leaders, traditional doctors, and community health promoters. The CAB identified the health topics, the intervention format, the type of material to be developed, and the trainer profile. The CAB assisted the research team in guiding the process iteratively and to maintain the cultural appropriateness of the project (see Fig. 36.5).

Table 36.1 Sample processes included in the planning phase

Process	Description
Hiring qualified staff	Multidisciplinary projects are complex interventions by design. Therefore, hiring adequate staff is the first step. The project started with a limited staff that included a team leader, educational advisor, a medical advisor, a project coordinator, a community liaison, and administrative staff (e.g., accountings, auditors)
Identification of key partners	Selected partners included health education specialists from the Ministry of Health, community organizations, academic partners, and local <i>Promotores</i> . A community advisory board (CAB) guided the process
Scope of the project	Objectives of the intervention included development of culturally appropriate educational materials, implementation of a “train-the-trainer” educational intervention for community <i>Promotores</i> , and implementation of community-based training by <i>Promotores</i>
Costs of the project	The project had a budget of approximately USD \$400,000 and a duration of 2 years. These costs included staff salary; frequent travel to the community; design and production of educational materials; implementation of train-the-trainer intervention; follow-up trainings at the community level; data analysis; and communication of results in newspapers, scientific journals, conferences, and policy-makers’ meetings
Identification of barriers	This is a unique intervention for the country, and it had multiple barriers at every stage of the project, from sociocultural complications (e.g., closing of roads due to demonstrations), unexpected expenses (e.g., price surges in airline tickets, transportation stipends for community speakers), and extensive iterative processes to develop educational materials in constant consultation with community members and the CAB
Communication of results	Selected channels for communication of results included local and international conferences, press releases, social media, and presentations to community partners

**Fig. 36.5** The community advisory board (CAB) and research team members

Fig. 36.6 Cover of the lay midwife section of culturally appropriate flipchart



Our team conducted four semi-structured focus groups onsite with community members to analyze in great depth their health priorities. Focus group participants identified target populations consisting of men and women, aged 18–54, including every district of the *Comarca Ngäbe-Buglé*. Participants decided that their health priorities were (1) hygiene, (2) nutrition, (3) environment, (4) role of the lay midwife in the community, (5) healthy pregnancy, and (6) domestic violence.

Through the CAB and focus groups, the participants identified the use of flipcharts as an ideal way of reaching the community with health messages (Fig. 36.6). Based on these priorities, our team selected the Hesperian Health Guide's¹ *Where There is No Doctor (Donde no hay doctor)* to provide a scientific baseline (Conant and Fadem 2008; Klein et al. 2013; Werner and Bower 2010; Werner et al. 2010). Identification of relevant information using text guided the selection of messages. Each of these messages was later matched with local pictures to capture the participant's attention and improve their understanding of the material. Afterwards, these messages and pictures were mounted in a flipchart as a method to deliver these messages. These messages underwent a thorough iterative process to validate their cultural and language adequacy. The process had both an internal phase (with team members) and an external phase (with community members) and was executed during a 24-month period.

36.4.1 Internal Phase

The purpose of the internal phase was to develop short messages based upon evidence-based sources, match them with pictures, and convert them into digital slides for easy management. Also, based on CAB feedback, our team decided that using flipcharts would be the best method to deliver community health training (McKay et al. 2015; Chi et al. 2014; Caniza et al. 2007). This phase of the process lasted 6 weeks.

¹Hesperian is a nonprofit organization that works on health education since the 1970s. Since then, the organization has published more than 50 books in 20 different languages on health training, health education, community empowerment, international health, and women's health. For more information visit

36.4.2 External Phase

The goal of the external phase was to field test the materials with community members, a form of pretesting. Our team traveled to several *Ngäbe-Buglé* communities, seeking representation throughout the *Comarca*, to discuss educational materials with community members and *Promotores* using participatory processes. The participative processes included several focus groups to evaluate texts and images. Our team collected perceptions and recommendations to tailor the educational materials (Reed et al. 2014; Bryan et al. 2014; Revere et al. 2014).

During this phase, *Promotores* also shared their concerns about the weather and the long walking distances that were required to travel to communicate these messages. Their proposed solution was to use waterproof flipcharts with detachable pages and a comfortable bag to carry the material. This was an unexpected feedback for the team, only obtained through participatory processes.

36.5 Implementation

The implementation phase of the project included the *train-the-trainer* aspect of the intervention for *Promotores* and a 6-month follow-up period to measure the reach of the project.

36.5.1 Training the Trainers

A *train-the-trainers* intervention is based on a basic premise—the transfer of knowledge from experienced trainers to less, or naïve, trainers who, in turn, train their peers or implement an educational intervention. If successful, the trainees gain additional skills, become experienced trainers, and continue the training process (Sarli 2016; Pearce et al. 2012; Murphy et al. 2008; Mintjes et al. 2001).

Prior to the initial training, extensive logistics planning was undertaken to ensure maximum participation from the selected *Promotores*:

- Identification of speakers (trainers)
- Development of the training agenda
- Development of educational materials (slides, practices)
- Transportation stipends
- Adequate lodging and meals
- Centrally located meeting area that could accommodate the group

Experienced trainers prepared a comprehensive agenda that included material from the flipchart, physical language, effective teaching methods, community-gathering techniques, practice skits, reporting of results, and evaluation. The training period used a hands-on approach to identify weaknesses while delivering the community trainings and empowering participants with teaching tips to overcome possible issues in the field.

A total of 78 *Promotores*—consisting of lay midwives, traditional medicinal doctors, and community health promoters—participated in the training and received a training kit that included a 75-page sturdy and waterproof flipchart, a bag, and evaluation report forms. The training the *Promotores* received lasted 3 days at a time. At the end of their training, the *Promotores* signed a contract agreeing to reach a minimum of 20 people in their own community. Each *Promotor* prepared a training agenda (e.g., a document describing the communities, proposed dates for trainings, and topics to be discussed)

and made commitments to deliver ten community trainings and submit a monthly report to the project team members (see Fig. 36.7).

36.5.2 Follow-up

At the end of their training, *Promotores* were highly motivated and ready to deliver training to their communities. The implementing team randomly selected some communities along the *Comarca* and visited these communities bi-weekly. The purpose of the follow-up was to evaluate *Promotores* in the field, while delivering the educational intervention, to provide support to the community members, and to evaluate difficulties while delivering the trainings (Fig. 36.8). This phase lasted 6 months.



Fig. 36.7 Training the Trainers



Fig. 36.8 Follow-up of training in the field in the *Comarca*

Table 36.2 Baseline, process, and result evaluation

	Baseline evaluation	Process evaluation	Result evaluation
Purpose	To identify feasibility of the intervention and understand needs from the community member's perspective	To assess completion of activities of the project	To describe the overall result of the project and measure if objectives were completed
Moment of implementation	Beginning of the project	Entire duration of the train-the-trainers intervention	End of project
Method of implementation	Semi-structured focus groups and interviews of key stakeholders	Observational using predesigned forms	Intention measurements Knowledge evaluations Report forms
Results	<i>Gathering preference:</i> 67% of community trainings included individuals or small groups <i>Target population:</i> 81% of the lectures are oriented to adults, women less than 33%, children and adolescents 44% <i>Health priorities:</i> personal hygiene (78%), food-related (41%), environment (44%)	<i>Number of trainings:</i> 3 (2 days each session) <i>Number of people trained:</i> 78 <i>Topics:</i> role of the community promoter, use of flipchart, delivering reports	<i>People trained:</i> 6876 people during the project (an additional 12,460 people were trained after a 1-year follow-up) <i>Number of community trainings:</i> 651 trainings in every district of the indigenous reservation

36.6 Evaluation

Measuring impact of any intervention is a difficult task, even for experienced teams. For this project, the team developed an extensive evaluation process that included a baseline evaluation (needs assessment), process evaluation (program monitoring), and a result evaluation (Waqa et al. 2013; Rawat et al. 2013; Crawford and Garrard 2013). Table 36.2 describes briefly each of these evaluation processes.

36.7 Communication of Results

To be sustainable over time, community health education must be firmly anchored in the health system. If leaders successfully guide and promote effective health practices, the health status of the indigenous population should improve. Effective communication of results is as important as using a thorough implementation process and analysis of results.

Selected channels of communication included meeting with health authorities, community organizations, public health conferences in Panama and the United States, scientific journals, radio shows, newspaper publications, and social media. Each of these targeted a different population and improved communication of the results.

36.8 Application of Training to Maternal Health Among the Ngäbe-Buglé

As mentioned before, the CAB and community members selected six main health topic areas: hygiene, nutrition, healthy environments, prenatal care, the role of the lay midwife in the community, and domestic violence. Most of these topics are consistently related to disease burden and mortality rates, mainly pregnancy issues in poor rural settings. Women and

children in the *Comarca Ngäbe-Buglé* tend to present the most disease burden. The Ministry of Social Development and the National Institute of Women in Panama had been working toward reaching the millennium development goals (MDGs) and sustainable development goals of the United Nations (<https://www.un.org/sustainabledevelopment/sustainable-development-goals/>) of decreasing maternal and child mortality among indigenous groups in Panama, where maternal and child mortality occurred at higher rates than in the rest of the country.

The educational intervention presented in this chapter is part of the initiative of the Panamanian government, coupled with the research team from the University of South Florida Panama Program at the City of Knowledge in Panama, to provide relevant health information to the largest indigenous group in the country. The health topics identified by the community reflect the needs of reproductive-aged indigenous women during pregnancy. Also, the community members identified the need to gain access to better health services for prenatal care, delivery, and postnatal care of these women. The evaluation and improvement of health service delivery are beyond the scope of this project; however, information on prenatal care, proper nutrition during pregnancy, working with lay midwives in the community, domestic violence, and environmental health all relate to pregnancy outcomes in the *Comarca*. For example, cases of domestic violence tend to increase during pregnancy. Thus, incorporating the health topics into maternal health was a main objective of the project (Figs. 36.9 and 36.10).



Comer Bien

- Comer Bien durante el embarazo para:
- Ayudar a crecer bien al bebé
- Tener huesos y dientes fuertes

Fig. 36.9 Flipchart sections explaining the importance of nutrition (*comer bien*) during pregnancy and what constitutes a healthy pregnancy (*embarazada sana*)

Fig. 36.10 Flipchart sections explaining the importance of nutrition (comer bien) during pregnancy and what constitutes a healthy pregnancy (embarazada sana)

Embarazada Sana

- La embarazada debe tener buen estado de salud
- Tiene piel sana
- Se siente con energía
- Se mueve con fácil
- Piensa y habla con claridad
- Está contenta
- Proyecta seguridad



Conclusions

Creating a community advisory board (CAB) and incorporating the community into the decision-making, implementation, educational, and evaluation processes proved to be important techniques to follow when working in international community settings with indigenous groups. Several important conclusions can be drawn from this process. It was clearly that empowerment of community participants occurred. When the project was first initiated, the *Promotores* were timid and quiet; by the end of the project, the same group of *Promotores* were outspoken and handled the health information expertly.

The community members are specialists on their own community needs and identified health topics that the research team had not considered incorporating into this training project. Domestic violence was one of such topics selected by participants as an important problem. Although the research team had been well aware of the issues of domestic violence occurring in the communities of *Comarca Ngäbe-Buglé* (Calvo et al. 2014), this topic had not been expected to be identified in the participatory process. Nonetheless, during iterations, the domestic violence issues sparked much reaction and acceptance by community members, despite the associated stigma.

Finally, community participation resulted in the acceptance of the project. Community members eagerly participated in focus group discussions, shared their insights, accepted information, took ownership of the project, and continued the sustainability of the project after it was finalized. The initial goal of community participation was to have the participation of 800 community members. This proved to be unexpectedly conservative—through outreach and participatory processes, over 6000 community members were reached during the active phase of the project. Once the project finalized, the *Promotores* continued performing outreach and education, reaching over 12,000 people upon last report. Based upon our results, we can conclude that working closely with community members, gaining their trust, respecting their cultural beliefs, and including them in the process provide positive outcomes when working with indigenous groups in international settings.

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