

Spotlight on: Population-based cancer registries

In June 2018, Dr. Nelli Saraí Padilla, from the [Asociación Hondureña de Lucha Contra el Cáncer \(AHL\)](#), visited the [Registro Poblacional de Cáncer de Cali \(RPCC\)](#) in Cali, Colombia to broaden her knowledge on population-based cancer registries.



AHL is a non-profit cancer prevention and treatment centre in Honduras that provides education and early detection programmes, housing for patients and support groups. Nelli works as a doctor in their [Centro de Cáncer “Emma Romero de Callejas”](#) which

provides treatment and care through radiation therapy, an outpatient clinic for chemotherapy and holistic treatment plans, and is committed to providing services to low income communities.

As the only cancer centre in Honduras with statistical data on cancer, AHL provides data and reports used to plan national public health programmes. Nelli was awarded a [grant](#), sponsored by the [Prevent Cancer Foundation \(PCF\)](#), to visit the Cali Registry to learn how to establish a high quality population-based cancer registry in Honduras and how to improve data collection and analysis for hospital registries. The RPCC was established in 1962 and represents one of the strongest and longest-running population-based [cancer registries in Latin America](#), making it an ideal place to learn how to establish cancer registries. Cali, Colombia is also a [C/Can 2025 Key Learning City](#).

Particularly, the goals of Nelli’s visit were the following:

1. Learn to establish a functional and high quality population-based cancer registry.
2. Apply new methods and practices to improve the collection and quality of data in the existing hospital registry that she coordinates.

The project was initiated following the [Leadership in Action meeting in Mexico](#) in 2017, where the topic of cancer registries featured prominently, including a presentation by Dr. Luis Eduardo Bravo, the director of Cali Cancer Registry.

Ultimately, this visit was intended to create strong synergies between AHL and RPCC, and lay the foundation for a Honduran registry. Establishing the Honduras population-based cancer registry is integral to ensuring quality prevention programmes, as AHL is involved both in its own prevention campaigns and in informing those of the Honduras Ministry of Health. She also hoped to grow her skills in research methods so that AHL would be able to carry out rigorous studies on cancer survivorship in the future.

The visit

During Nelli’s visit she met with both management and operational staff from Cali’s registry, and as a result she:

- Learned about the functions of the registry, its history and its areas of coverage through interviews
- Gained technical knowledge of specific systems, including RPCC’s programme [VIGICANCER](#), a real-time surveillance system that assess childhood cancer survival rates
- Was introduced to various methods of ensuring the quality of registry data through data cleaning systems and software (such as [Link Plus](#), [IARC Tools](#) and [SISCAN](#))
- Was exposed to various international frameworks to help conceptualise the Honduras registry in a global context, such as the [European Network of Cancer Registries \(ENCR\)](#) guidelines and [Planning and Developing Population-Based Cancer Registration in Low- and Middle-Income Settings](#) framework
- Was provided with a procedure manual on hospital registries that she will share with AHL and their partners in the establishment of the Honduras cancer registry.

Nelli's visit highlighted **the importance of creating a strong city-wide network, including clinics, public and private hospitals, and laboratories in order to collect cases**, as Cali has. She also learned that



ensuring the cancer registry's information and data are publically accessible is an integral best practice that should be replicated by the Honduras registry. Consulting on difficult cases with partners in the city-wide network, and following-up with patients to update their records were also important suggestions.

In addition to shadowing RPCC, she met with a separate institution to observe how they collect, code, type, and review cases for the Cali registry.

Moving forward

Nelli's visit was an example of how countries in Latin America can share their knowledge to advance cancer control initiatives. In the short term, she has learned how to improve AHL's hospital registry system by automating the verification of cases, and creating formal procedures. **Improving the AHL hospital registry will have far-reaching benefits for the prevention of cancer in Honduras, as their data is used by media, researchers and prevention campaigns throughout the country.**



Nelli states that, **"The long-term project would be to serve as a body that formulates recommendations for the establishment of a population registry, an important tool to know in depth the epidemiological behaviour of cancer in a given geographical area."** In future, the knowledge gained through Nelli's visit will inform the creation of a strong population-based cancer registry in Honduras that incorporates regional best practices and gathers quality data.

AHL and RPCC have since established an important relationship that will continue after this visit. Connecting an established registry with a nascent one could be beneficial for the entire Latin American region. This new collaboration can foster future learning and disseminate best practices to an even wider network, perhaps even encouraging other countries in the region to create their own population-based cancer registries.



"In the future, if we are to establish our population-based cancer registry, there will be openness and accessibility to technical advice from the Cali Registry"

Registries are one of the best sources of cancer data, and their establishment is a significant step in creating national policy around cancer prevention and treatment. It is also an essential step for Latin American countries, where only a few countries have registries, and those that do have limited coverage and poor quality data. Nelli believes that **"it is important to ensure the quality of the data, because statistical data are frequently used to formulate important projects for the benefit of patients that are aimed at prevention, diagnosis and treatment of cancer. These are important pillars of the mission of our institution."**

Nelli's visit connects with [Treatment for All's](#) effort to improve access to cancer services, with emphasis on data.

Learn more about the [Cali Population-based Cancer Registry](#), some of the work done by [AHL](#), and the [importance of cancer registries](#). Learn more about UICC regional capacity building programmes [here](#).