

Comment

## The new data access rules in Ecuador present an opportunity for medical research in Latin America

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### Abstract

Ecuador's public health platform provides a chance to advance medical research throughout Latin America. The authors propose that the Economic Commission for Latin America and the Caribbean (ECLAC) look at Ecuador's public health data collection and presentation system as a successful example for the region.

### To the Editor,

Scientists and citizens can access public information and take action under Right to Information (RTI) laws in several nations. As a result, Goal 16.10 of the Sustainable Development Goals of the United Nation's 2030 Agenda includes the right to access information, underlying its importance in promoting constructive change and a brighter future for all. The capacity to get medical information is critical in combating emerging diseases such as COVID-19 in countries with inadequate public health resources. This is especially true in Latin America, where biomedical and epidemiological research is hampered by unstructured data presentation [1]. Even worse, some countries have preferential requirements like in Peru, where scientific teams must include a Peruvian investigator with ties to a public institution. In other circumstances, data applicants are required to submit a research idea for assessment and approval before being granted access to the data. This behavior is undoubtedly conditioned and does not promote free access to knowledge.

We embarked on a research project on acute lymphocytic leukemia (ALL) in Andean countries, and faced all of these challenges. To conduct statistical and epidemiological analysis, we searched the Ecuadorian INEC (National Institutes of Statistics and Census) and obtained a database of ALL (ICD-91 code, WHO) cases from the previous ten years, organized by age groups, place of residence, province/county, and gender. Obtaining the same statistics in Bolivia, Peru, and Colombia was not easy task. The Colombian National Administrative Department of Statistics (DANE) prohibits the downloading of a list of pediatric and adult patient's deaths from ALL, broken down by gender and place, without management's consent. In the case of Peru, employment as a researcher in one of the country state's institutions is necessary. Although institutions like the National Institute of Statistics and Informatics of Peru (INEI) and the National Computer System of Deaths (SINADEF) issue free and easily available information bulletins on ALL diagnosis, ALL-related deaths are unfortunately not documented. In Bolivia, the Faculty of Medicine of the Universidad Mayor de San Andrés [2] reports the number of ALL cases identified in adult and pediatric patients using the ICD-91 code, gender and major cities, however the Bolivian National Institute of Census Statistics does not. Consequently, even if these data are generated, the statistical government agency does not make them available to the general public.

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To account for differences in epidemiological research in a globalized environment, one of the most essential challenges for biomedical scientists is assessing discrepancies and gaps in clinical information collection and compilation across low-income Latin American and Western countries. The Economic Commission for Latin America and the Caribbean [3] is a UN regional commission entrusted with monitoring and reviewing the 2030 Agenda's implementation. ECLAC sponsors the Forum of Latin American and Caribbean Countries on Sustainable Development every year, and the Statistical Conference of the Americas is one of its affiliates. Overarching non-limiting guidelines for data access and the cooperation between the National Institute of Statistics and the Ministry of Public Health of the Ecuadorian government have made statistical information easily accessible. Based on this editorial comment, we recommend that ECLAC and its related organizations investigate the Ecuadorian public health data collection and presentation system as a successful model. In this regard, the ECLAC might encourage member countries to improve the availability of health data in Latin America, drawing on the Ecuadorian example, if they believe it is necessary.

**Author contributions** XGL performed the formal information search, EFM and XGL contributed to conceptualization, SB contributed to the draft, MG, AG, and SB contributed to the writing of the manuscript.

**Data availability** No datasets were generated or analysed during the current study.

## Declarations

**Competing interests** The authors declare no competing interests.

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