

International Journal of Population Data Science

Journal Website: www.ijpds.org



From CIDACS Experience to a National Data Strategy for Population Health Sciences and Public Health Purposes: A Brazilian Case

Bethania Almeida¹, Pablo Ramos¹, Roberto Carreiro¹, Juliana Prata de Faria¹, Robespierre Pita², and Mauricio Barreto¹

¹CIDACS/FIOCRUZ, Salvador, Brazil

²CIDACS/FIOCRUZ, Salvador, Brazil; Computer Science Department/Federal University of Bahia, Salvador, Brazil

The integration of administrative data for population-based studies and research faces many challenges, e.g., integrity, quality, privacy, security, and availability of this data. The governance of integrated administrative data for research purposes is context-dependent and involves the articulation of methodological, technical, ethical, legal, and social issues. Brazil, the largest country in Latin America, has an estimated population size of approximately 213 million inhabitants. Despite the country's diverse array of national information systems to support public administration, among them health data from the universal health system, the Sistema Único de Saúde (SUS), these systems are presented and made available in an isolated manner. Present and discuss CIDACS' approach to provide requirements and recommendations for a national health data policy for scientific research and studies

aimed at producing knowledge to support evidence-based public health in Brazil. Reporting experience on a collaboration between the Center for Data and Knowledge Integration for Health (CIDACS/Fiocruz Bahia) and the Information Technology Department of the Unified Health System (DATASUS) to situate proposed strategies to support requirements and recommendations for safe and secure access to, linkage and analysis of existing health data produced by the SUS. Results and Considerations We delineate an approach encompassing a literature review on technical, ethical, legal, and societal issues related to health data usage and reuse for scientific and public health research purposes, articulated with the mapping and analysis of the national and international regulatory landscape, legal consultancy, technical visits, as well as interviews and workshops with data stakeholders.

