Gac Sanit. 2026;40(S4):222

Gaceta Sanitaria

https://www.gacetasanitaria.org

248 - FROM FRAGMENTATION TO AN IDEAL STATE: MAPPING CVD DATA IN EUROPE. A JACARDI CONTEXT ANALYSIS

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Resumen

Background/Objectives: Cardiovascular diseases (CVD) remain a major source of morbidity and mortality in Europe, highlighting the need for high-quality, accessible, and interoperable data to inform evidence-based policy. This study assessed the legal, infrastructural, and operational frameworks for CVD data collection, quality, access, and sharing to identify gaps and guide progress toward an Ideal State (IS) of data governance.

Methods: A specific survey was distributed to National Focal Points for Health in 32 European countries and complemented with qualitative input from JACARDI (Joint Action on Cardiovascular Diseases and Diabetes) pilot projects. The questionnaire was developed following a multi-step methodology, including the definition of a CVD Data IS. Information was analysed across key domains - legal and strategic framework, funding, intersectoral approach, service delivery, and capacity - using descriptive analyses, with results presented through tables and maps.

Results: A total of 20 NFPH and 41 JACARDI pilot projects contributed data, enabling a comprehensive assessment of current CVD data governance and the identification of gaps towards an IS. Marked heterogeneity was observed in the organization, management, and integration of CVD-related health data across Member States. Some countries reported comprehensive legal frameworks and registries, while others reported a lack of specific legislation or cohesive strategies. Several key enablers for future data integration were identified, notably the widespread adoption of national electronic health record systems (68.6% of the countries) and the use of unique patient identifiers (73.7%). In contrast, several key barriers were identified, including the inconsistent implementation of standardized data models (30.0%), extract-transform-load (ETL) processes (44.4%), and common terminologies (55.0%), which continues to hamper cross-border interoperability and research potential.

Conclusions/Recommendations: By identifying key gaps in the current landscape, this project outlines a roadmap toward the IS for CVD data in Europe. Current health data infrastructures remain fragmented, with limited interoperable systems linking administrative, clinical, and socioeconomic data. Inconsistent implementation of standardized data models further hampers progress. Member States should use these findings to transition from fragmented registries to integrated, automated systems.

Funding: JACARDI Joint Action (Grant Agreement n. 101126953).