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A review of a standards-based set of information security practices applied in Data Linkage Centers

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Objectives

This research aimed to study regulatory and operational aspects related to information security, especially confidentiality, in organizations that systematically carry out record linkage.

Approach

We searched international experiences of data linkage units from the literature and from the catalog of International Population Data Linkage Network (IPDLN) members. In addition, we surveyed technical standards of the International Association for Standardization (ISO) on health informatics.

Results

We studied organizations in Australia, Canada, UK and the United States. Six standards were selected for deep analysis. In the end, we organized a set of 75 practices relating to information security in data linkage units, grouped by 5 dimensions: infrastructure and operations; record linkage model; relationship with managers; relationship with researchers and relationship with the society. The linkage process must be described in a sufficiently clear and didactic way, so that ordinary citizens are able to understand that the privacy of their health information is protected. In addition to a transparent work process, the data linkage center must also make their privacy policies available. The Australian and Canadian experiences with ethic review committees that include social participation and awareness of media and explanations to the public are a good source of inspiration. Regarding safety, the institutions responsible for health databases should apply security controls in their information systems to consider the rules on consent to perform record linkage.

Ideally, all institutions should seek full compliance with the controls recommended in the technical safety standards. However, the scarcity of resources (human, financial and technical) lead to the prioritization of the implementation of these security controls. The criteria for this prioritization can be given by feasibility analysis (cost / time impact, benefits), providing an orderly road map for the adoption of these measures.

Conclusion

The practices systematized in this study can be used in order to check current information security conditions of data linkage centers and as guidelines for further improvements. This will certainly bring more confidence in the data linkage center process and, at least, help researchers, managers and society move forward toward the same objective of better public health.

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