

The Need for Open-access, Structured Data in Endocrine Research

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ABSTRACT

Data sharing has become a 'hot topic' for university librarians, faculty, and research centers, with particular focus within biomedical science, to prevent duplication of effort, promote scientific integrity, and permit the creation of new data sets when data from multiple sources are combined. However, access to and sharing of scientific data require substantial effort and investment to define specifications and generate requisite resources. Studies from well-designed and well-conducted medical registries can provide a real-world view of clinical practice, patient outcomes, safety, and may strengthen evidence-based decision making processes.

At present, if cardiovascular data management has been sufficiently documented with data exchange in all clinical research, clinical registry, and patient care environments, including all electronic health records. It is nevertheless still necessary to create a database for endocrinology, particularly in light of new medical research that have blurred the concept of endocrinology as a discipline of basic science. The aim of this paper is to conceive datasets in endocrinology research and facilitate the exchange of data across studies and to promote interoperability between different research centers.



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1. Main Text

Over the recent years, the large volume of clinical research data associated with advances in medical informatics has resulted in a significant reorganization of healthcare through information technology. In this respect, the concept of open science has emerged according to which scientific research data is made available to all – professionals and non-professionals. Open science started with the advent of the academic journal and when the scientific society began to feel the need to share their knowledge with other groups and thus be

able to cooperate. In particular, open access to the scientific literature means the removal of barriers from accessing scholarly work and has become a 'hot topic' for university librarians, faculty, and research centers with focus on biomedical science. Now the integration of computational technologies into biomedical science has catalyzed the development of several experimental platforms that can stage and disseminate data in a readily accessible form to researchers focusing on a specific disease.^{1,2} In view of these current demands related to the new technological context,

in which even the biomedical science is moving, more efficient access to and sharing of research data can have considerable benefits for public health issues and worldwide disease prevention and control. Open-access data sustains scientific research, promotes different types of analysis, makes possible testing of new or alternative hypotheses, and finally permits the creation of new data sets when data from multiple sources are combined.

Nevertheless, relatively little attention has been paid to data exchange both in the clinical and patient care domain. Actually, clinical research studies are still frequently conducted locally, as well as clinical information used in patient care which is also supervised locally with distinct and inconsistent data systems. Furthermore, information available from health-services data about the practice and outcomes of new procedures is still limited which delays and challenges healthcare funding bodies in making a decision whether new procedures should be implemented.

In this context, the necessity emerges to create medical registries that collect data from multicentre studies, essential to foster improvements in technology, facilitate the refinement of patient selection and enhance the quality of patient care and outcomes, as well as the efficient use of resources in medical practice through current and new options. Despite their key role in medical research and their potential effects in improving health care, clinical registries face several problems related to missing data and poor data quality, lack of guidelines for data collection, and the absence of precise definitions for data details.³ However, the adoption of open-source electronic health record systems by medical centres has created significant potential for the re-use of clinical data. Trends in biomedical research indicate a need for data platforms that can stage and disseminate data to researchers with a particular focus on genomic, imaging, and other complex data types.

In particular, experimental data sharing in the biomedical science will increase the transparency of the scientific process. Today, it is a challenge and an opportunity for the biomedical community but will probably become a demand in the near future. Primarily, it is necessary in order to prevent duplication of effort, to promote scientific integrity, and to facilitate scientific advancements.⁴ Access to data in the real world requires centralized repositories, while the access to these resources requires common data formats. Although research institutions, academic and funding

authorities all agree that the scientific data produced from public- and charity-funded research should be shared and accessible, access to and sharing of scientific data require substantial effort and investment to define specifications to support them.

In this respect, national policies and research centres play a crucial role in promoting and supporting data accessibility since they provide the required resources, establish rules for data management and regulate the protection of privacy.⁵ The latter is of great importance in the context of open access; indeed, questions on how to use and disseminate data from human beings through open data and biomedical research have long been considered. Intellectual property is another important issue in supporting data sharing, especially when funding for research comes from the industry. Others are the role of providing informed consent, particularly for the management, and the future archiving of medical data. With regard to the use of data access and sharing in public research, taking into consideration the potential constraints, it is important to fully exploit the possibilities of global digital networks and to capture their benefits to the global community not only at institutional and national level but also internationally.

At present, even though the cardiovascular data management has been well documented in literature,^{6,7} there is still a need to create a database for endocrinology which allows to relate different pathologies and endocrine system. This necessity arises from the results of medical research in the past several decades that have blurred the concept of endocrinology as a discipline of basic science. In fact, although general principles remain unchanged over time, the medical science is, by definition, forever mutable and endocrinology, in particular, is moving on very rapidly. New technologies have dramatically changed molecular genetics applied to the endocrine system (molecular endocrinology) and overall the language of new biology has strongly permeated endocrinology.⁸

First, Starling in the Croonian lecture⁹ believed that chemical (endocrine), neurological and immune mechanisms were three separate control systems of the body. The concept of three separate control systems began to decay almost immediately with the separation between the endocrine and neural systems thanks to the pioneering studies of Henry Dale, Otto Loewi, Walter Cannon, and Ernst and Berta Scharer¹⁰ who have formulated a unified neuroendocrine control system. At present, the idea of three independent systems of

communication among cells has been replaced by recognition of a complex, interacting and integrated control network involving immune, neural and chemical messengers. In addition, the profound changes in endocrinology in the past years are largely due to the application of the advances in other fields as chemistry, physics, cell and molecular biology, genetics, immunology, neuroscience and cybernetics, so that hormones are now discovered, synthesized, measured and studied in new ways. It is also appropriate to consider the impact that endocrinology has had on other divisions of biomedical science; in fact endocrine science continues to be one of the most dynamic branches of biomedical discipline and endocrinology is the most quantitative of the clinical area.

From this perspective, we often speak about cardiovascular endocrinology, neuroendocrinology, immune-endocrinology, nephro-endocrinology, gastrointestinal-endocrinology, etc. From these premises, it is not surprising that the progress of knowledge in the endocrine area must be grounded on the integrated availability of information previously confined to different disciplines. In fact, the complexity of the endocrine signal bases its pivotal role in maintaining organ-specific and systemic homeostasis by generating a suitable cross-talk of cells to ultimately produce normal growth, development and adaptation of the organism to stress. Hence the need to generate, also in the endocrinological field, medical registries to prevent the lack of harmonization between the clinical and research workflows and to create a global biomedical community no longer limited to national registries of pathology. These platforms for developing biomedical datasets will include investigation of the mechanisms of endocrine dysfunctions, therapeutic interventions, clinical trials, development of new technologies and outcomes, and health services research. Some fields already have data-sharing practices. However, as it was mentioned above there is little information in the context of endocrinology; therefore, the aim of the editorial is to conceive datasets in endocrinology research to facilitate the exchange of data across studies and to promote interoperability between different research centres.

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