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Databases and Registries in Medicine

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The last three decades the use of databases and registries in the field of medicine has created, along with the use of personal computers and the internet, a major revolution in the way of learning and practicing medicine and surgery.

If I had been asked to write this article a few decades ago, I would have to spend enormous time and effort just to find the relevant information from books, abstracts, and published articles. I had to go to the hospital or the university library, to search at 'subject indexes', to find the volumes of the medical journals containing the required articles, ask the librarian to photocopy them or apply for the articles and wait a few days to get them.

The whole above procedure is now replaced by just clicking at my computer's keyboard from my office and searching in the local library's databases, as well as in huge international databases such as the Medline. Indeed enormous saving of time, money, and effort and major improvement in fast and complete access to the required information.

What is a database? A medical database is an organized collection of data from patients and/or diseases, tables, diagnostic views, operative procedures, complications, queries, treatment policies etc. The data is typically organized in a way that supports the processes of retrieving information and provides several reports. Additionally, a database application is a computer program whose primary purpose is entering and retrieving information from a computerized database. Early examples of database applications were accounting systems and airline reservations systems, developed in the 50s. In the 90s, it became more common to build database applications with a Web interface. Rather than developing custom software to run on a user's PC, the user would use the same Web browser program for every application. A database application with a Web interface had the advantage that it could be used on devices of different sizes, with different hardware, and with different operating systems.

Therefore, a characteristic of modern database applications is that they facilitate simultaneous updates and queries from multiple users. This progress allows the use of national and international databases from users from different cities, countries, or even continents.

What is a registry? A registry is a collection of information about individuals, usually focused around a specific diagnosis or condition. Many registries collect information about people who have a specific disease or condition, while others seek participants of varying health status who may be willing to participate in research about a particular disease. A registry may be personal, institutional, national, or international and can be sponsored by a government agency, nonprofit organization, health care facility, or private company.

Registries focused on specific diseases or conditions collect information that individuals provide about themselves on a voluntary basis. There are several legal questions about distribution of information, data ownership, and anonymity of the patient's health information.

Usually, a registry has a governing committee that makes decisions about how the data can be used or shared and a specially trained coordinator, regarding information security requirements, is responsible for respecting the strict privacy requirements set by law. As a general rule, data and reports may be shared with the participants and their families, and approved healthcare professionals and researchers. Personal identifying information is kept absolutely private.

The use of personal, Institutional, National and International databases and registries provided very powerful tools in revolutionizing modern medical education, research, and clinical practice and has enormous implications in the objectively appraisal of each surgeon's practice, as well as in improving patient's safety and management (1).

An example of the latest implementation of those tools, is the experience gained from the Center of Excellence

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program of the international federation for surgery of obesity (IFSO), administered by the European Accreditation Council for bariatric surgery (EAC-BS). Surgeons, through the internet, are entering data of their patients undergoing bariatric operations, in an international bariatric registry (IBAR). Demographic characteristics, co-morbidities prevalence, operative details, complications, outcome of surgery, long term follow-up data including weight loss and resolution of obesity co-morbidities are entered in the IBAR. Numerous reports are provided by the registry concerning each surgeon's results, each hospital's results and accumulated results from all participating surgeons and centers from Europe, Middle East and Africa. This allows each surgeon to compare the results of his own practice with the results of all surgeons that are participating in the Center of Excellence program and have an objective indicator of his abilities to provide safe and effective patients' management.

Another important clinical implication is the ability of a database to combine patient data from the region's major hospital and clinics and to enable the doctors to intervene quickly in emergency cases by retrieving critical information. In addition, this function may improve care by enabling much faster exchange of clinical data between regional or national centers and this is an amazing step forward.

In the field of medical education for students, doctors, and patients, the use of databases and registries created a number of important implications. The easy access of students and doctors to the wealth of information has improved the distribution of knowledge and help in more advanced educational programs. Tutors, on the other hand, are now able to follow the annual progress of their students and accordingly modify and improve the educational curricula. Additionally, registries are utilized to provide education, information, and genetic counseling services to patients, families, and health professionals and contribute to both clinical and basic science studies of many diseases such as the colon and breast cancer (2).

No need to emphasize the importance and features provided by these two tools in the field of clinical and basic research. Collection and analysis of data would have been more difficult and time-consuming without the help of databases and registries.

Registries can provide healthcare professionals and researchers with first-hand information about people with certain conditions, both individually and as a group, and over time, to increase our understanding of that condition. Other registries invite people to sign up to be contacted about participating in clinical research. These ask very basic questions about health history that would help determine whether someone is possibly eligible to join a research study. Doctor's participation in a registry is likely to increase his knowledge about a specific condition, improve treatment, and allow to design better studies on a particular condition, including the development and testing of new treatments (2, 3).

It is therefore highly advisable for surgeons to maintain their own database and join national and international registries. Although this may usually have a little cost charged by the administrator of the registry, the money spent is worthy taking into account the easy access to important professional information and the time saving (1).

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