

Data Collection and Data Sharing – the Holy Grail of Transfusion Medicine and Modern Bioscience

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To collect, to structure, and to share data has become a key issue for modern civilization to assure technological and social prosperity. Tools for data collection and sharing have become the basis for the progress in technology and the high level of inter-institutional standardization that we rely on in our institutions today. Databases are part of the driving forces for new achievements; data collection and data exchange in health and science serve for the benefit of both individual patients and the community.

Two groundbreaking events can be seen that stand at the beginning of this development:

First, the successful launch of Sputnik I by the communistic USSR in 1957. This was perceived as a socio-cultural shock in the western world, and all of a sudden the assumed superiority in technology and science of the Western world was put into question [1]. Subsequently, deficiencies in the education and training of people in the USA as well as in Europe were brought forward; among them the missing exchange of information on hot topics in science and technology between peers were perceived as major hurdle for technological advancement. The National Defense Education Act (NDEA) passed by the Congress of the USA aimed to provide the country with defense-oriented personnel trained in mathematics and computer science [2]. In Europe major efforts were made to establish general accessibility of basic and advanced education. Governments allocated substantial financial resources to build up new structures and push forward general as well as specific training of young people. The lack of scientifically trained people was recognized as a major weakness of western society in defense against the assumed communistic threat.

Secondly, the invention of the Internet was pivotal for the further development of western culture and science. In 1973/1974 Vint Cerf and Bob Kahn improved the primary APRA (Advanced Project Agency) network of the US Defense Department by generalizable communication protocols

such as TCP/IP to connect various computer networks establishing the first version of Internet [3]. Following the design of the World Wide Web by Tim Bernes-Lee at CERN, the US National Science Foundation decided to commercialize the Internet in 1990. The major break-through of the Internet occurred in 1993 when graphic browsers such as ‘Mosaic’ became available free of charge. Internet and the World Wide Web finally opened the highway for unrestricted exchange of information between unlimited numbers of data repositories.

All today’s research and technology, including the many activities in live sciences, are based on the efficient exchange of data between various sources. This issue of TRANSFUSION MEDICINE AND HEMOTHERAPY presents some of the relevant data repositories pertinent to the transfusion medicine community. It is the purpose of this issue to introduce readers into content, applicability, and use of various databases providing online information to the transfusion specialist. We are aware that this assembly of databases represents only a very limited collection of the available resources. Interested readers are being referred to other more comprehensive collections of databases. Among others, the ‘2014 NAR Database Summary Paper Category List’ [4] and the collection of ‘Databases on Medicine and Molecular Biology’ [5] provide online access to more than 2,000 databases covering medicine and molecular biology. These sites may be useful to navigate interested readers to the most suitable database covering the respective research question the user may have.

The contribution by Hustinx [6] for this special issue of TRANSFUSION MEDICINE AND HEMOTHERAPY describes the initiative of Regional Blood Transfusion Service in Berne, Switzerland, to establish a registry of active donors with rare blood group phenotypes who are recruited in German-speaking Europe. The registry is run under the auspices of the German Society for Transfusion Medicine and Immunohematology (Deutsche Gesellschaft für Transfusionsmedizin und Immun-

hämatologie; DGTI) and will soon be completed by a lot of new genotypes identified at Regional Blood Transfusion Service in Zurich using mass spectrometry-based genotyping [7]. Flickinger [8] gives an overview on the American Rare Donor Program which covers 82 member facilities in the USA and contains more than 59,000 active rare donors. Taken together, these two registries represent comprehensive repositories to organize freshly donated rare blood for patients in need. The article by Patnaik et al. [9] entitled ‘BGMUT (Blood Group antigen MUTation) database of allelic variants of genes encoding human blood group antigens’ introduces into the most complete collection of variations of blood group antigens. The database is hosted by the National Center of Biomedical Information (NCBI), and its access is free of charge. The utility of the database for transfusion medicine specialists is eloquently described. Takeshita et al. [10] review the Allele Frequency Net Database (AFND) with focus on HLA, KIR, and otherwise rare alleles as well as cytokines polymorphisms.

AFND represents an indispensable data repository for transplantation and transfusion medicine as well as for anthropology. Instructions how to submit data to the database as well as how to search for suitable donor population for organ donation in case of highly sensitized patient are given. ‘The Rhesus Site’ by Wagner and Flegel [11] introduces into the most complex human blood group system. Besides access to the ever growing list of newly discovered Rhesus alleles, it also contains a section providing information on the immunogenic potential of various Rhesus D alleles. This data collection may help to decide on the clinical validity of variant Rhesus D alleles. Finally, the topic-oriented guide by Metzendorf et al. [12] for using the most popular literature databases for biomedical sciences closes this selection of biomedical databases in transfusion medicine.

We hope that readers will welcome the databases selected, and hopefully they will be well served by the tips and hints for their use as given in the respective manuscripts.

References

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