HemoRec – Improving the Quality of Life of Hemophilia Patients

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Medicine is an information intensive sector, where patient’s treatment is determined by the availability of a large amount of diagnostic knowledge. Nowadays we can hardly imagine processing of such a huge amount of data and extraction of relevant hypothesis or knowledge, which could be used e.g. later for the treatment of other patients, without proper ICT infrastructure. This poster presents HemoRec – international project involving the web based information system with the same name, designed to capture, handle and analyze data regarding patients mainly with hemophilia and other coagulation disorders. HemoRec is currently focused on treatment centers in five central European countries (Czech Republic, Hungary, Poland, Slovakia and Slovenia) and the ultimate goal of this project is to improve (medical) care of hemophilia patients and to improve quality of life of patients by providing physicians with the possibility to create new hypothesis or to evaluate existing ones on the data regarding patients from different countries.

HemoRec information system has been developed as a patient data management tool to be used in the clinical environment. It enables comprehensive, structured, and standardized data collection to facilitate everyday working procedures in hemophilia treatment centers, and to provide a basis for advanced clinical research. HemoRec system is a web based application, which was designed mainly for the internet environment, however it can be used also as a standalone application with the possibility of batch synchronization of the data. Most of the this information system was coded using ASP.NET technology. One of the key issues when developing and using medical information systems is the security. HemoRec system respects all the standards and current legislative in the areas of security and personal data privacy.

The HemoRec system is a data driven application, which means that the content of the application is defined by metadata stored in the database. Almost every aspect of system is driven by the metadata. Metadata enables us to provide to the users various customization features, which can be used for the modification of system’s behavior according to the needs of various users or treatment centers. Because HemoRec was designed to be used in several countries it is a multilingual system. It can be easily localized to various languages and users can choose, which language they prefer (their native one usually).

When users collect and enter data to the information system they would also usually like to perform some data analysis tasks using the collected data. Therefore HemoRec provides to the users possibilities of basic data analysis, overview of data characteristics and possibilities to export data to other formats for the data analysis performed in software packages developed by third parties. Analytical and export tools in HemoRec include standard charts – available in both graphical and tabular form, reports, advanced tables and standard tables. The system also includes an effective, secure, and easy to use tool called MyHemoRec, which can be used by patients themselves to share bleeding and infusion data directly with their healthcare provider.

The HemoRec information system itself is currently fully functional and we are starting to register treatment centers, which would like to participate in this project. These centers will be responsible for the entering data to the system and they will be available to use results of the data analysis performed on the basis of these data in the future. More information about the project can be found on the web page http://www.hemorec.com.

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