Introduction / Background

MS patient registries with longitudinally collected data are increasingly important as a base for research and quality assurance of MS care. However, a common limitation of such registries is the insufficient ability to extract meaningful data, thus rendering registries' role to archiving tools, usable only by a small number of researchers.

Objectives

We set out to design and implement a Visualization and Analysis Platform (VAP) connected to the Swedish MS Registry (SMSreg) to allow all users the monitoring of their local data and results of care in comparison to national data, including immediate statistical analysis of their local data and results of care in comparison to MS Registry (SMSreg) to allow all users the monitoring of patients, adequate DMD treatment), assurance (access to MS care, effective investigation and monitoring of MS patients, adequate DMD treatment), descriptive statistics), clinical follow-up, quality assurance (access to MS care, effective investigation and monitoring of patients, adequate DMD treatment), annual reports, patients’ reported outcomes and some analyses of research character, e.g. survival analysis. A user interface with reactive programming was implemented to control the appearance of interactive graphs and tables, and to explore the changes in outcome measures.

Methods

The VAP is built in the SQL and R language using a large collection of R-libraries including a new and powerful web framework Shiny (© RStudio, Inc.). The platform is based on predefined types of analyses such as flexible tabular presentations, cross-sectional and longitudinal comparisons, linear models, comparisons between domains (spider diagrams) and advanced statistical analyses (e.g. locally weighted fitting to experimental data, survival analysis). A user interface with reactive programming was implemented to control the appearance of interactive graphs and tables, and to explore the changes in outcome measures.

Results

A web-based platform for live visualization and interactive statistical analysis of data was developed and linked to SMSreg containing ca. 15,000 patients and 85,000 registered neurological visits. Operations are intuitively controlled via a flexible user interface, supported by different graphical selection tools. Automatic reports are functionally divided into sub-groups, customized for users' needs and access rights. They contain various types of analyses: SMSreg's content (quantity and density of data, descriptive statistics), clinical follow-up, quality assurance (access to MS care, effective investigation and monitoring of patients, adequate DMD treatment), annual reports, patients’ reported outcomes and some analyses of research character, e.g. survival analysis of drugs. Selected reports are open for the public on national, regional and county levels.

Conclusions

The VAP offers a range of visualization and analysis options for graphical and table-form report applications in real-time on SMSreg’s data. It fills a need of providing data back to clinicians, patients and researchers, motivating registration and increasing the quality and density of data.

Conflict of interests

The Swedish MS Registry has received support from Socialstyrelsen – The National Board of Health and Welfare. LS, EH and HE do not declare any conflicts of interests. JH has received unrestricted research grants or honoraria for lectures or advisory boards from BiogenIdec, Merck-Serono, Novartis, Bayer-Schering, Teva and Sanofi-Aventis. His MS research is funded by the Vetenskapsrådet – Swedish Research Council.

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