

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 selected outcome parameters using predefined graphical and table-form template reports.

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 subgroups, 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.













Visualization and Analysis Platform in the Swedish National MS Registry for Real-Time Data Feedback

Leszek Stawiarz¹, Eva Hagel^{1,2}, Håkan Eriksson³, Jan Hillert¹, Swedish MS Registry ¹Department of Clinical Neuroscience (CNS) and ²Department of Learning, Informatics, Management and Ethics (LIME), Karolinska Institutet, Stockholm; ³Carmona AB, Halmstad, Sweden

Fig. 4 An example from Clinical Research "Locally weighted fitting to experimental data": Fig. 1 User interface of Visualization and Analysis Platform (VAP) Using modern fitting methods as LOESS or GEM it is possible to follow actual changes of various outcome measures without any previous knowledge about the shape of the function. **VAP** Visualization and Analyses Platform in the Swedish MS Registry for real-time feedback to health care personal, patients and Antal observationer: 858 researchers The VAP system is built on predefined analysis types that are controlled through an intuitive graphical user interface. Automatic reports are grouped into several categories offering different types of analyses, tailored for users' needs. Separata linjer för kvinnor/m **Clinical research** Annual Reports Other Analysis of results from •Diagrams defined Behandlingsaktivitet functional tests in annual reports Pågående visualising current •Survival analysis of drugs Behandlade (ITT) status of MS care Hospital activity reports Aldrig behandlande (inga registrerade behandlinga) in Sweden and •Patient reported major indicators Visa linjär regressior outcomes used for Visa LOESS longitudinal LOESS viktning (Locally weighted fitting monitoring of MS (based on current SMSreg's data) 🔜 📥 Spara som PD Antal månader från deb **Fig. 2** Patient Overview: Spider diagram visualizes current medical results of a selected Fig. 5 An example from Quality Assurance "MS clinical course": patient in comparison to a matching reference group estimated on the basis of SMSreg data. Diagram presents the distribution of MS clinical course by selected confounding variables. 'Nytt besök 📝 Rehab 싎 Besöksblankett 🤬 Rapportera fel/ändring 🧟 Sök patient 📎 Lägg till diagnos 🍚 PER-registreringar 🏡 Min sida Graf Tabel versikt - MS MSSS-matris Väli kriterier för jämförelse: kdomsduration 🖉 Redigera basd Aktuell ålder: MS Duration: 2år 10m 19d Behandling: Pågåen SDMT (1.1 år PATIENT DATA MSSS: 2.44 50% MSFC: 0.0852 2012-10-23 1år 10m 4d MSIS-29-FYS: 1.0 2013-01-29 1år 6m 26d)atum för diagnos MSIS-29-PSYK: 1 1år 10m 4d RR - Skovvis förlöpande M SDMT: 55 FSMC (- ar) gående behandling FSS: 2.22 EQ5D: 0.848 25% rbetsförmåg amtliga patienter 1år 6m 19d Tysabri - 300 mg/ - 1/månad SF36-1:3 REFERENSGR Inkludera saknade värden (för kvalitetsko FSS (1.1 ar) SF36.1 (0.9 år) Intal n=524 dministrativ niv 📥 Spara till PDF eferensgrupp matchad på (ön: TRUE örlopp: TRUE Juration: TRUE Behandling: TRUE 🔶 Referensaru Patient: Max 2 år gammal referensdata: TRU Fig. 3 An example from Open Comparisons "Do we treat the adequate patients": Conclusions Diagram presents coverage analysis for RRMS patients with disease duration ≤15 years, treated The VAP offers a range of visualization and analysis options for graphical and table-form reports with DMD-drugs registered in SMSreg (RR15), versus estimated (prevalent) number of patients applied in real-time on SMSreg's data. It fills a need of providing data back to clinicians, patients suitable for treatment with the same clinical characteristics. Grey bars indicate the same treated and researchers, motivating registration and increasing the quality and density of data. RR15 groups vs. actually registered and suitable for treatment patients in SMSreg. Andelen RR-patienter, med MS-duration ≤ 15 år, som behandlas Jppföljningsår (t.o.m. sista december) Västerbotten (20) Östergötland (316) **Conflict of interests** Blekinge (9: Jämtland (84 The Swedish MS Registry has received support from Socialstyrelsen – The National Board of Health and Welfare. Alla patienter Värmland (185) LS, EH and HE do not declare any conflicts of interests. tockholms län (1367) Skåne (669) Ila patienter JH has received unrestricted research grants or honoraria for lectures or advisory boards from BiogenIdec, Merck-Serono, Novartis, Västra Götaland (90: Bayer-Schering, Teva and Sanofi-Aventis. His MS research is funded by the Vetenskapsrådet – Swedish Research Council. Endast kvinnliga patienter RIKET (5449) Endast manliga patienter Södermanland (146 Dalarna (182) Örebro län (139 Kronoberg (97 Gävleborg (148 Corresponding author: /ästmanland (12: Kalmar län (105 Leszek Stawiarz Västernorrland (10 Svenska neuroregister Swedish Neuro Registry Development Coordinator lönköpings län (163 Karolinska Institutet **Multipel Skleros** Gotland (29 Department of Clinical Neuroscience (CNS) Halland (12) Widerströmska huset, Tomtebodavägen 18A ppsala län (* Norrbotten (106 171 77 Stockholm, Sweden leszek.stawiarz@ki.se http://www.neuroreg.se http://carmona.se tel: +46 8 524 845 00 tel: +46 35 187 250 tel: +46 765 562 503 No. of DMD-treated / No. of estimated pat. suitable for DMD-treatment 📕 No. of DMD-treated / No. of registered pat. suitable for DMD-treatment













