



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.

Fig. 1 User interface of Visualization and Analysis Platform (VAP)



VAP Visualization and Analyses Platform in the Swedish MS Registry for real-time feedback to health care personal, patients and 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.

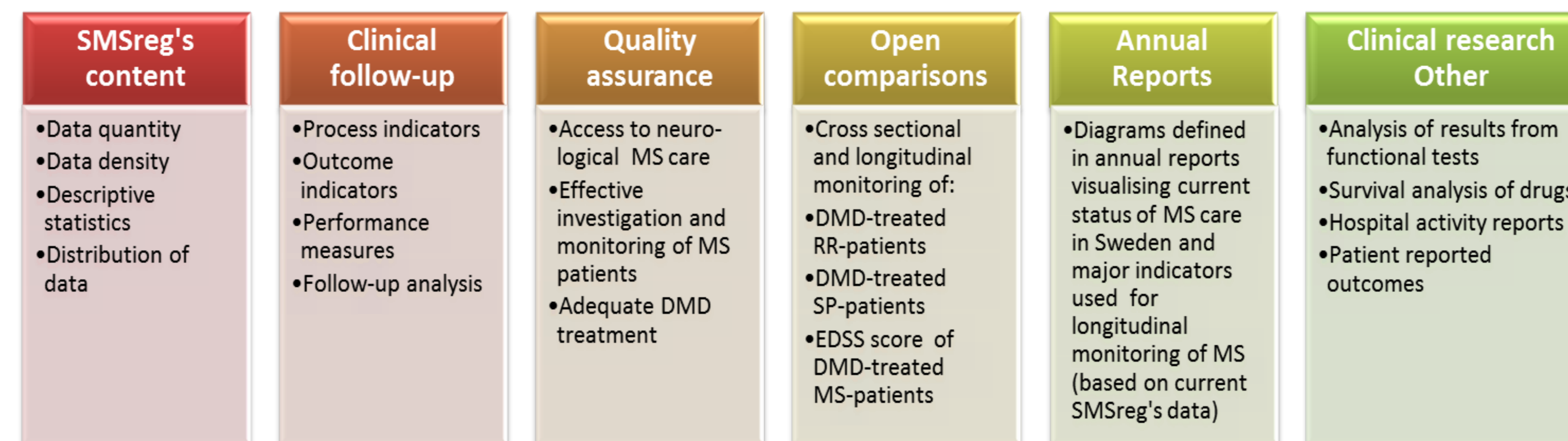
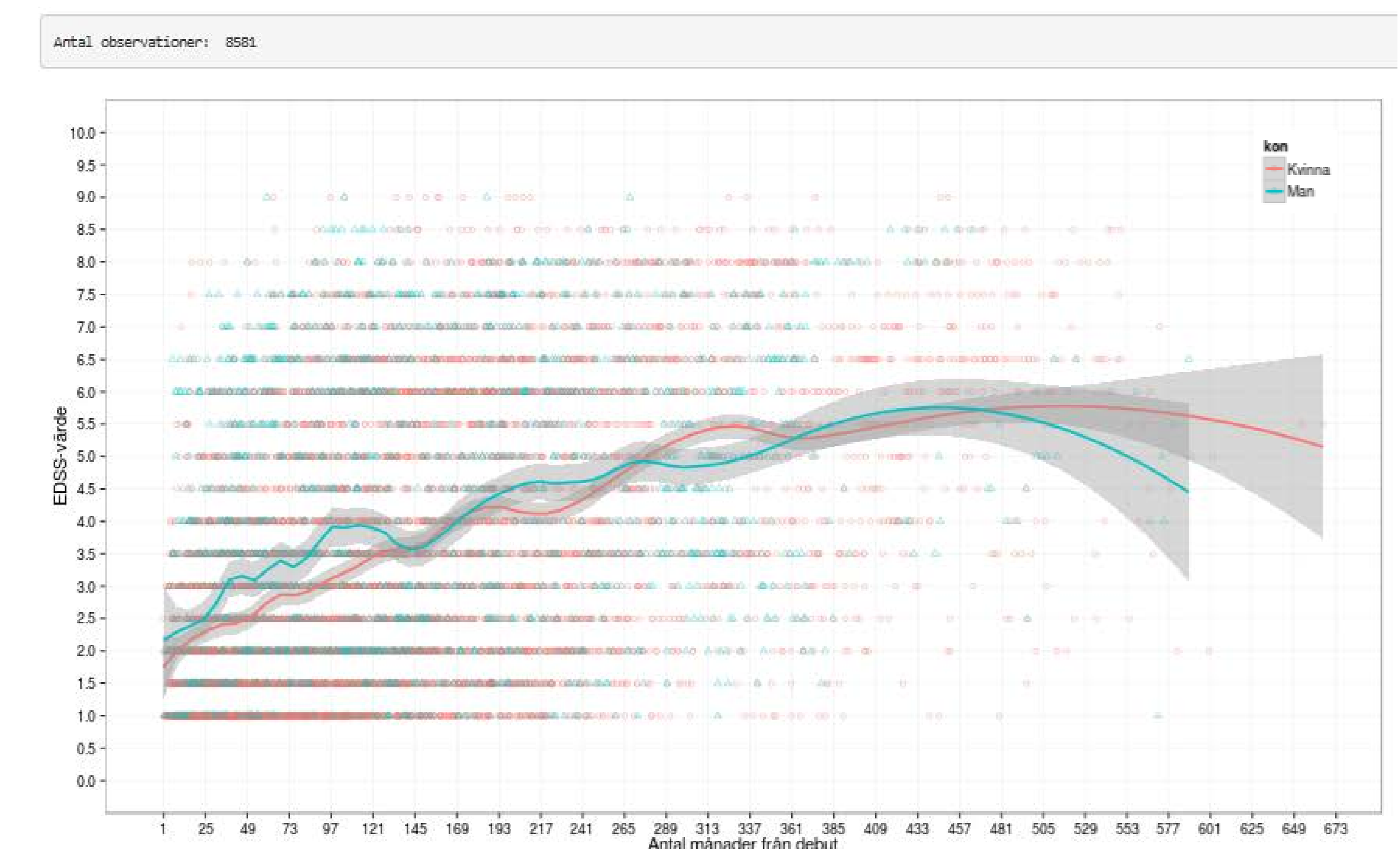
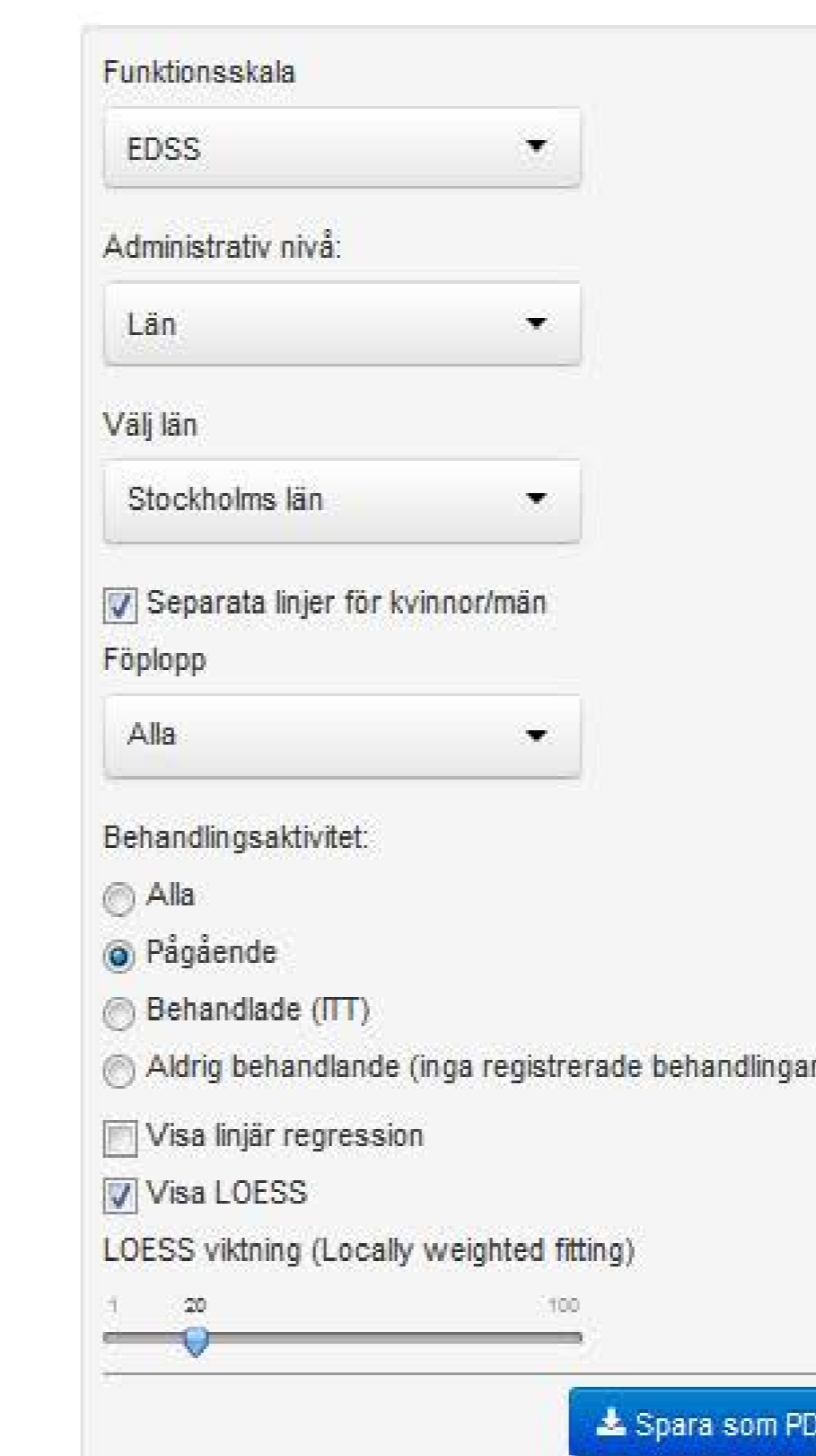


Fig. 4 An example from Clinical Research “Locally weighted fitting to experimental data”: Using modern fitting methods as LOESS or GEM it is possible to follow actual changes of various outcome measures without any previous knowledge about the shape of the function.



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.

Fig. 2 Patient Overview: Spider diagram visualizes current medical results of a selected patient in comparison to a matching reference group estimated on the basis of SMSreg data.

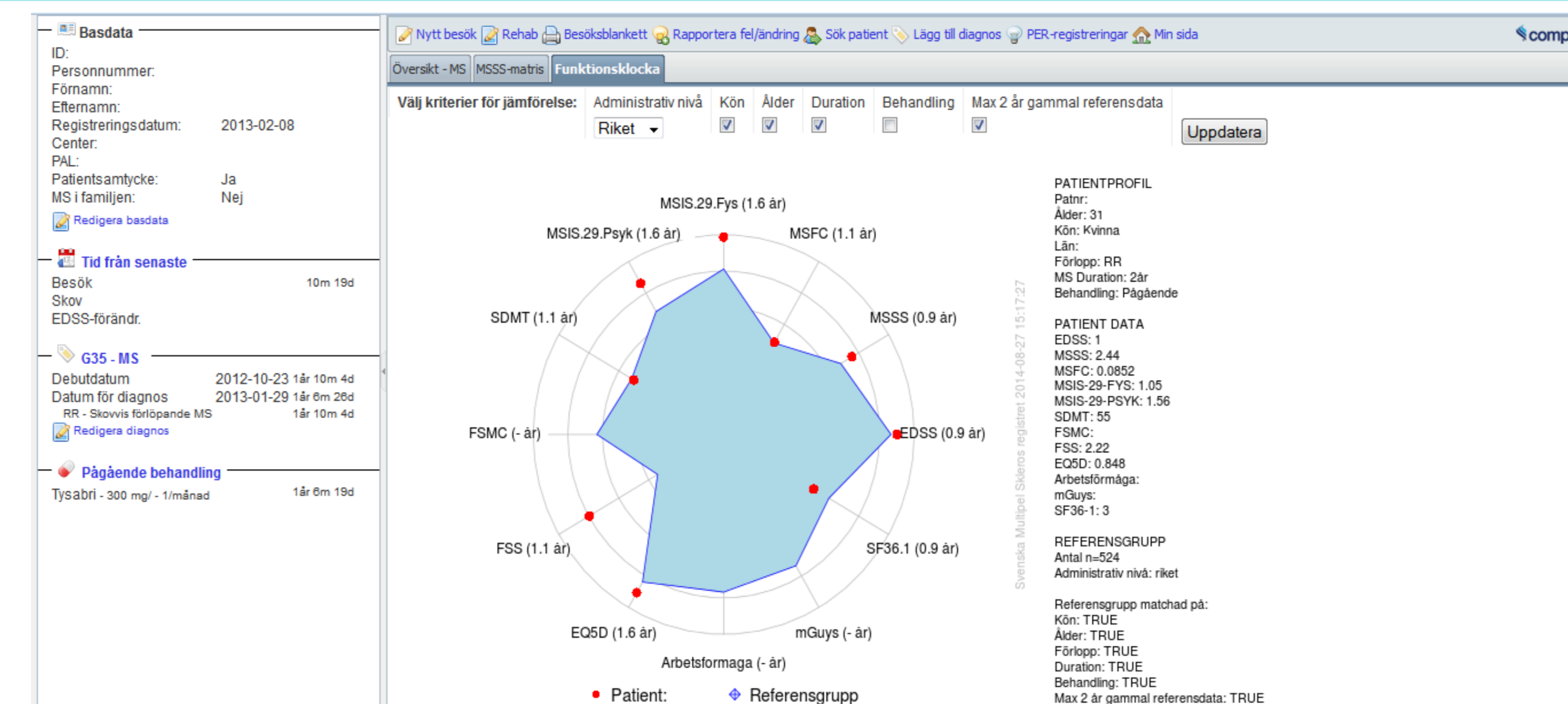
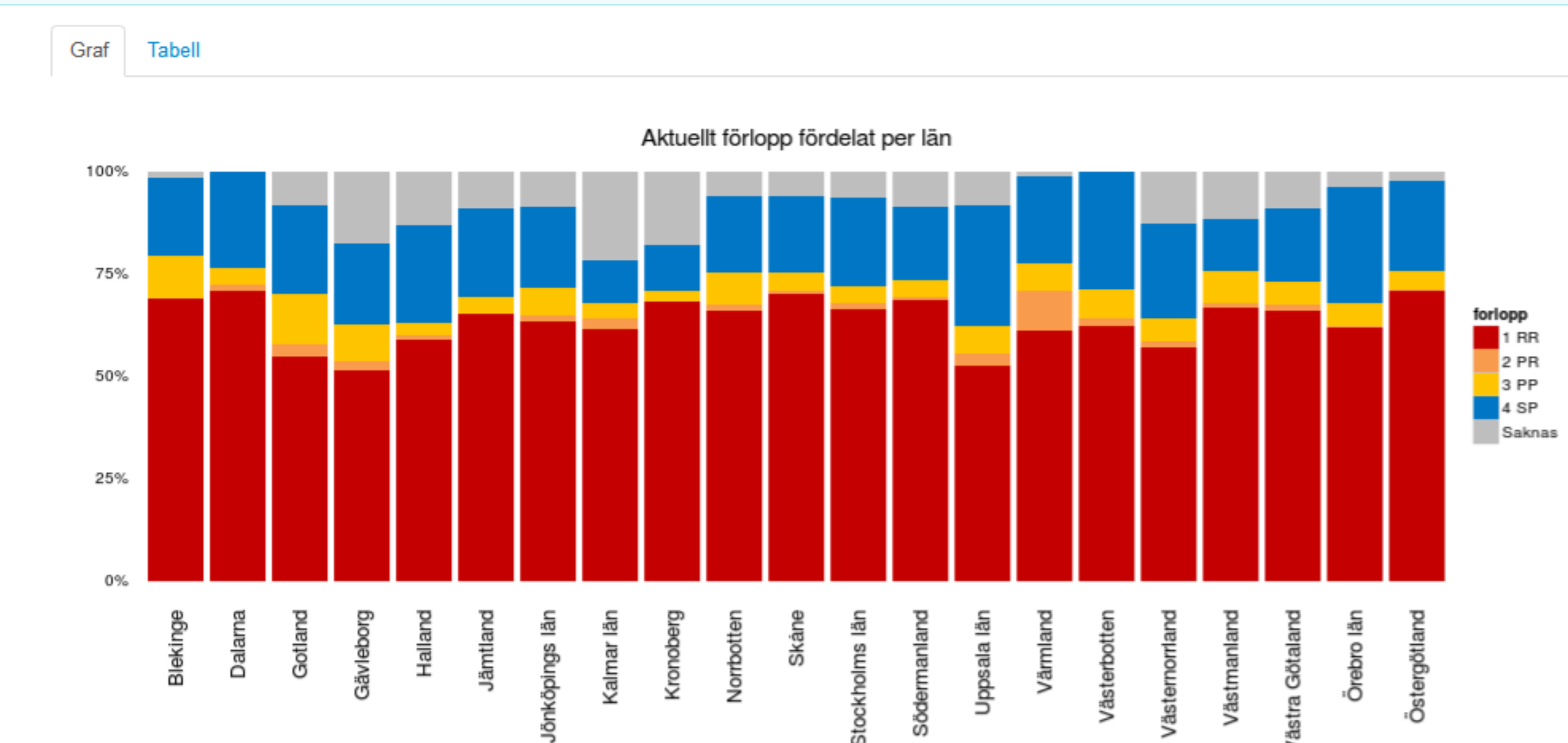
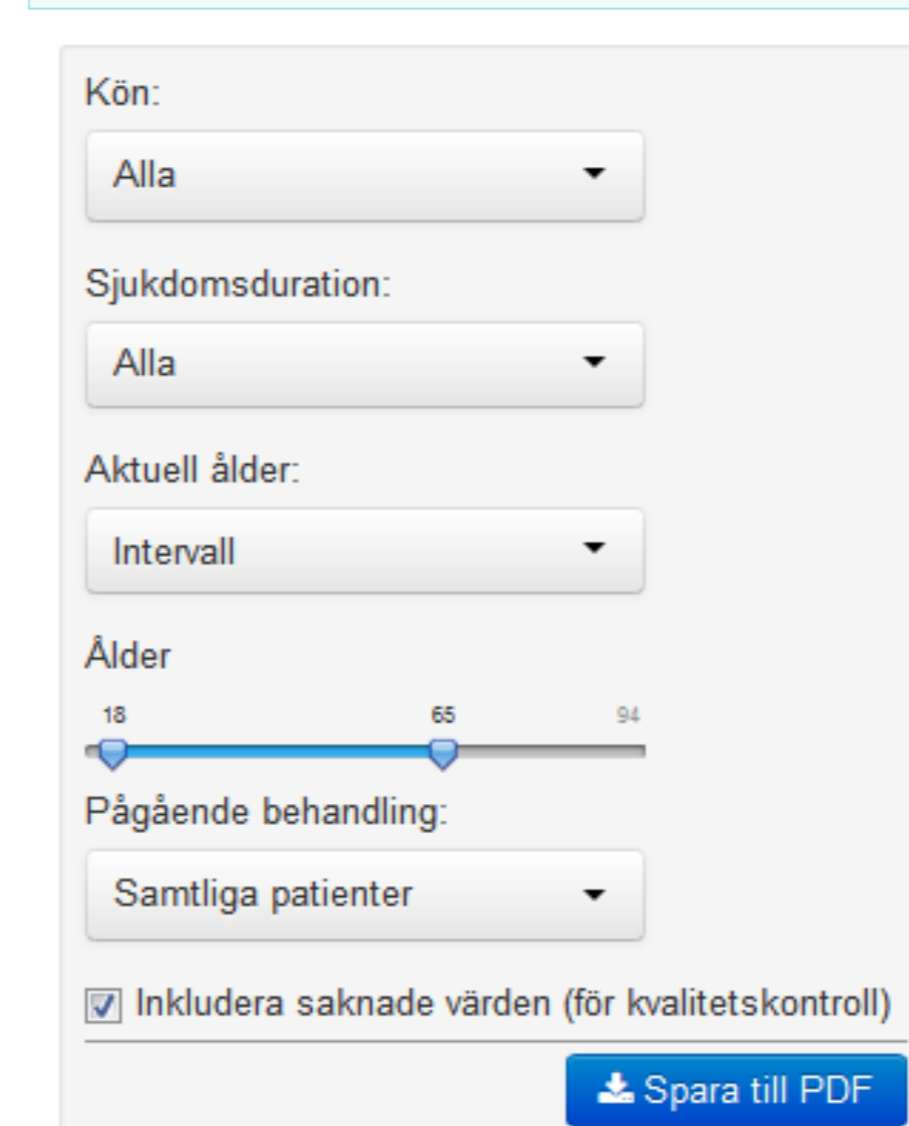


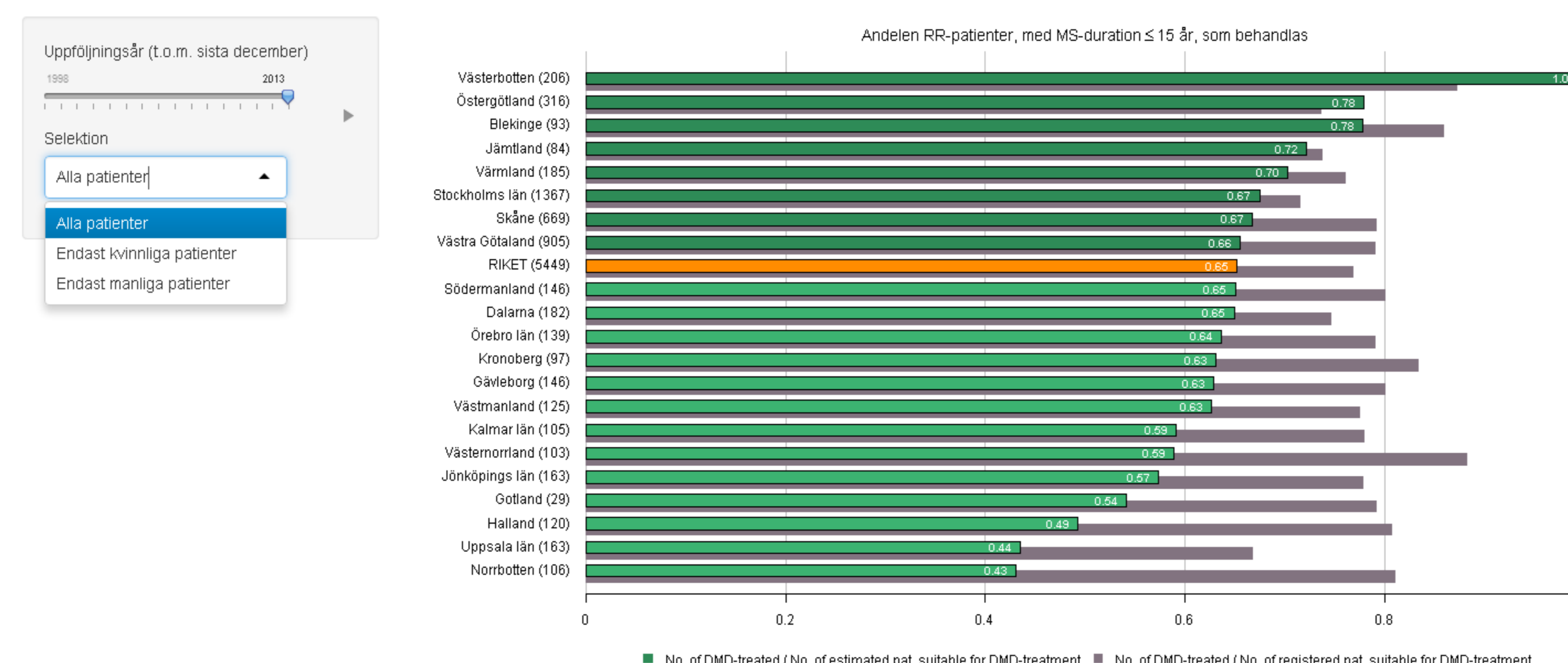
Fig. 5 An example from Quality Assurance “MS clinical course”: Diagram presents the distribution of MS clinical course by selected confounding variables.



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.

Fig. 3 An example from Open Comparisons “Do we treat the adequate patients”: Diagram presents coverage analysis for RRMS patients with disease duration ≤15 years, treated with DMD-drugs registered in SMSreg (RR15), versus estimated (prevalent) number of patients suitable for treatment with the same clinical characteristics. Grey bars indicate the same treated RR15 groups vs. actually registered and suitable for treatment patients in SMSreg.



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 reports applied 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 Biogen/Dec, Merck-Serono, Novartis, Bayer-Schering, Teva and Sanofi-Aventis. His MS research is funded by the *Vetenskapsrådet* – Swedish Research Council.

Corresponding author:

Leszek Stawiarz
Swedish Neuro Registry Development Coordinator
Karolinska Institutet
Department of Clinical Neuroscience (CNS)
Widerströmska huset, Tomtebodavägen 18A
171 77 Stockholm, Sweden
leszek.stawiarz@ki.se
tel: +46 765 562 503



Svenska neuroregister
Multipel Skleros



<http://www.neuroreg.se>
tel: +46 8 524 845 00

<http://carmona.se>
tel: +46 35 187 250