

"Function Watch" – a real time, graphical composite representation of MS patients' health status, as a decision support tool in daily clinical practice

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Background

Longitudinally collected clinical data of MS patients have an increasing importance for quality assurance of MS care. However electronic healthcare records have limited ability to extract meaningful quantitative data and compare it with matching reference groups. They function largely as archiving tools rather than support tools used in daily clinical practice.

A clinical support tool used to present patients data in an easy way and comparing it with the results of a matching reference groups is truly demanded.

Objectives

Primarily to design and implement a tool assembling a composite graphic, based on a set of 12 standardized, nationally collected measurements of patient's functions.

Secondarily to facilitate a real-time comparisons of individual patient's results with a matching reference group of patients from the Swedish MS registry (SMSreg), applying a flexible matching criteria adapted to each individual patient.

The tool had to be connected to the SMSreg allowing a direct visualization of data during patient's visit to a neurologist (Fig.3). Additionally, quality control of the test results was to be employed, and quality of matching a reference group checked.

Method

A *Function Watch* is built in SQL and R language, using a collection of R libraries. Minimum and maximum values of each test were scaled from 0 to 100%. It could be a negative or a positive value but the least possible performance (min) of each test was assigned to 0%, and the best (max) performance available to 100%. As such, tests of various types became quick and easy to compare visually.

Matching procedure involves five variables identifying a patient: gender, age, disease duration (DD), clinical course and treatment strategy. Matching for sex, age and treatment is a simple, direct process. Age matching is based on a patient age ±5 years interval. However in order to find a proper time interval to match an individual patient's DD, the distribution of all DDs for different age groups is analyzed and IQRs for corresponding age groups evaluated (Fig.1) in real time.

The IQRs of DD, calculated for different age groups, define individual DD time interval for a patient being at a particular age which is further used in matching procedure. Then the individual patient's age ± 5 years and patient's DD $\pm IQR/2$ years (Fig.2) are used together with the other three matching variables to constitute a complete reference group from all the MS patients in the SMSreg. Matching can be applied on the whole country data or on a county level if needed for local comparisons.

Only data of function tests of matching patients, which are not older than 2 years, are taken into account in all evaluations.

Fig.1 The distribution of disease duration for different age groups:A Box-Whisker plot displays individually calculated IQRs of disease duration for 10 years age-intervals. These IQRs further define the width of disease duration's interval for matching the individual patient's DD at a particular age with DD data from SMSreg.

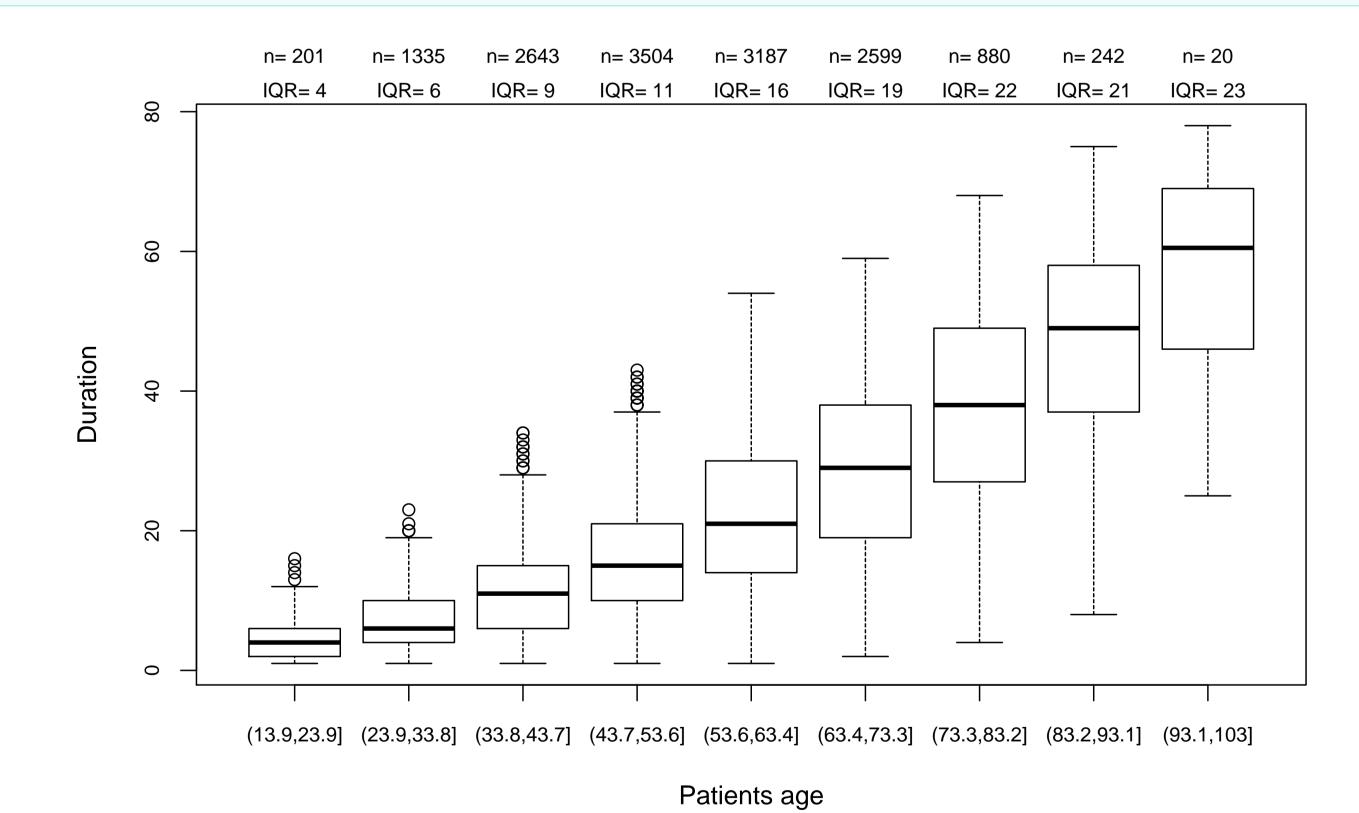
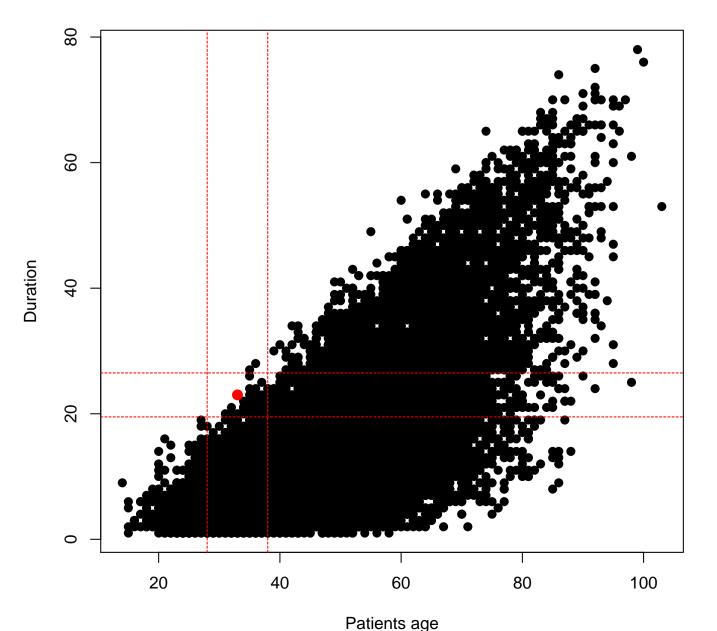


Fig.2 Matching procedure for age and disease duration:Figure shows how matching procedure for age an DD works. It presents "age interval" i.e. patient age ±5 years and a corresponding interval for DD, evaluated as described in Methods and shown on Fig.1, over a scatterplot of patients from SMSreg. Two patients

having different age and disease durations are presented as red dots, lines represent individually fitted intervals for age and DD.



Area inside a rectangle defines a matching subgroup from SMSreg.

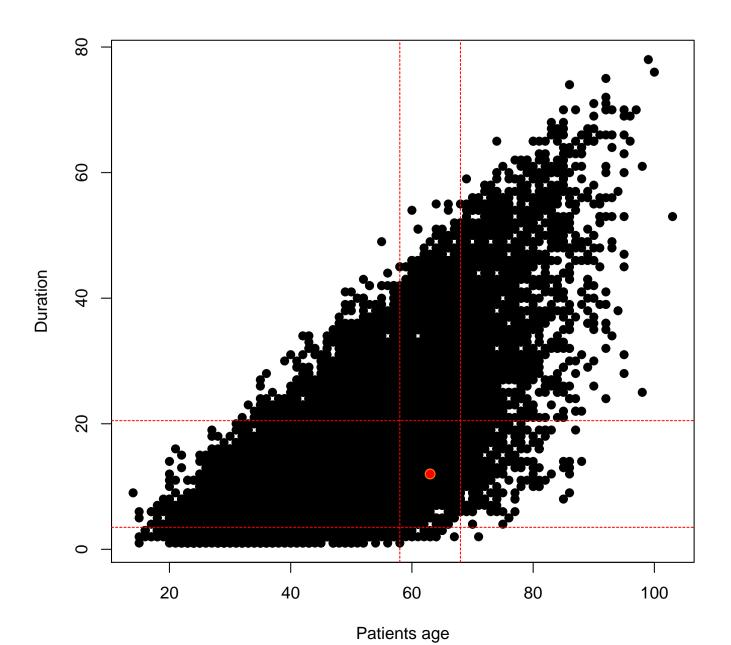


Fig.3 Function Watch:

A *Function Watch* visualizes current medical results of a selected patient in comparison with a matching reference group of patients. A screen dump from a SMSreg's user interface illustrates a *Function Watch* as it is implemented in the system. A neurologist can also easily see the most recent data of the patent and get suggestions of what problems should be addressed during the visit.



Fig.4 Examples of *Function Watch* representing two pairs of similar patients performing better and worse: Individual patient's values (red and gold dots) located peripherally represent better performance than the reference group of matched patients from the SMSreg (blue area), whereas points positioned inside the area, denote worse performance.

A represents a pair of young, treated RRMS patients with a short DD. B depicts a pair of treated RRMS patients in a middle age with a long DD. One can immediately see that the patients on the left side of the figure perform better than the matched reference patients (blue area). Parients who perform worse are depicted on the right side of the figure.



Results

Individual patient's data are automatically retrieved from the SMSreg. Last registered results of 12 relevant tests are selected and expressed as a fraction of a defined 100%. Such normalized values are plotted on a spider diagram.

By flexible matching a group of MS patients exhibiting similar characteristics according to the selected patient's gender, age, disease duration, clinical course and treatment strategy are taken from a pool of 16,500 patients and 100,000 neurological visits already registered in SMSreg.

Mean and median values for each of 12 tests are then evaluated for the matching group of MS patients. These values are scaled according to the procedure described in Methods and plotted on the same spider diagram as an area, defining the results of a matching reference group (Fig.3). Individual patient's values located peripherally represent better performance than the reference group, whereas points positioned inside the area, denote worse performance (Fig.4). The time since each measurement was registered is shown for quality assurance. Mean either median values can be selected for visualization in a *Function Watch*.

Selection of matching variables can be changed by the user and adjusted to her/his own needs, dependently on how big reference group is needed or how good matching is required. For patients with an untypical disease course, a doctor can always choose a more conservative or more liberal matching procedure to get an idea about reference values.

The *Function Watch* is implemented in the web interface of SMSreg. It is used in daily clinical work with MS patients throughout Sweden.

Conclusions

A *Function Watch* representing 12 scores is a handy tool for immediate feedback, clearly displaying if a patient performs better or worse than a mean/median patient from a matching reference group of MS patients with a similar gender, age, disease duration, clinical course and treatment strategy. It gives a direct suggestion to the neurologist whether treatment outcome is acceptable and what problems should be addressed during the visit.

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 Idec, Merck Serono, Novartis, Sanofi and Teva.







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