Real-time monitoring of Multiple Sclerosis care guidelines with clinical endpoints and computer-supported PROs: The Swedish MS registry

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Context
The Swedish Neuroregistries (NEUROreg) is a national quality of care registry and a decision support tool where information on patients with 8 groups of diseases within the field of neurology is collected. The part-registry for Multiple Sclerosis (MSreg) is the most developed and covers over 80% of the prevalent MS patient populations. All neurology units in Sweden use NEUROreg/MSreg by its web-based interface.

The Swedish National Board of Health Welfare (Socialstyrelsen) is currently in the process of establishing National Guidelines for MS. In this work information from the MSreg has been instrumental. More importantly, once guidelines have been established, the MSreg will be used for monitoring the extent to which the guidelines are met by units, counties and regions within Sweden. This will be done by assessing quality indicators, i.e. statistics from the MSreg.

Problem
How can the MSreg provide MS care units and decision makers with relevant, reliable and patient relevant information on the quality of care and fulfilment of the coming national MS guidelines in a timely and robust fashion?

Assessment of problem and analysis of its causes
The Swedish Board of Health and Welfare (Socialstyrelsen) develops National Guidelines for MS by a standardized methodology which has as its starting point the identification of a large number of matching “conditions” and “interventions” pairs. Such pairs are then scrutinized from an evidence point of view as well as for a cost-benefit point of view. Pairs are then ranked and indicators chosen to muse in the monitoring of fulfilment of the guidelines.

Intervention
The MSreg is engaged in the work in three different ways. First, it has provided statistics to describe the current practices in MS care, thus defining the problem. Second, it will be adapted to provide indicator statistics. This may include a change in what data to collect, but more typically, to develop out-data functions of the MSreg to enable easy access to statistics. Third, the MSreg will develop an updated format and collection service for patient reported outcomes.

Strategy for change
There is a close collaboration between the project managers at the Board, its experts and the MSreg. Detailed statistics, most importantly on the use of disease modifying treatment (DMT) for MS has already been obtained and submitted for analysis including a cost-benefit approach to be used once guidelines are in place. We are in the process of jointly defining specific indicators for the various guideline elements.

A more ambitious component is the development of improved patient reported outcomes (PROs) by developing and item-bank based computer-assisted questionnaire to be distributed via the patient portal of SMSreg, to which patients log securely in from home.

Measurement of improvement
The MSreg has a unique, versatile and robust out-data function called the Visualization and Analysis Platform (VAP) (with a public component that can be visited on www.neuroreg.se). The VAP is the key element to the process of adapting new indicators and of improving already implemented ones.

Assessing guideline fulfilment with the MSreg is likely to provide a good coverage of the target population.

Providing a modern questionnaire PRO format based on modern test theory is likely to provide measurements with a high degree of validity as well as reliability.

Effects of changes
The project is in progress, and the first deliverable will be base-line information during the first half of 2016 for comparison prospectively with later statistics.

Lessons learnt
So far, we believe that the properties of the VAP will enable the development of indicators with a high degree of acceptance and therefore usefulness due to high coverage.

Messages for others
A clinical MS reg can reach a high degree of acceptance as an internet-based decision support tool and achieve high coverage even in a voluntary situation. We hope to show that a well-designed out-patient functionality can assist in fulfilling treatment guidelines based on physician and patient reported parameters.

Involvement of patients, care or family members in the project
NEUROreg and MSreg both have patient representatives both in the respective boards as well as engaged in the development of new functionalities. In the development of new PROs patient participation is of course vital. We believe, that PROs will become increasingly important as outcome measures. The MSreg Patient Portal is designed with the hope of patients becoming increasingly important active partners in the health care process.

Conflict of interests
The development of the NEUROreg and MSreg is based on federal support only. The current efforts are likewise based on public funding only. In other research projects, JH has been a recipient of unrestricted research grants from Biogen Idec, Merck Serono, Genzyme and Novartis and served on advisory boards or as a speaker for the same companies as well as for Sanofi and Teva. LS, EH and HE do not declare any conflicts of interest.

Ethics Approval
NEUROreg and MSreg are quality registers and as such are not subjected to ethical review.