

S.O.S.MS PROJECT

STANDARD OUTCOME SET MULTIPLE SCLEROSIS

WHY?

Currently, there is a lack of insight in patient-relevant outcomes of MS care. Developing an internationally accepted standard outcome set for Multiple Sclerosis (MS) is essential to advance knowledge and expertise on treatment of MS. The standard outcome set can be used to measure, analyze, (inter)nationally benchmark and improve outcomes for MS patients globally.

WHAT?

In the development of the S.O.S.MS, the whole chain of care delivery will be considered and patient-relevant outcomes will be selected based on multidisciplinary involvement. The S.O.S.MS will include both clinical outcomes as well as symptoms, daily functioning and quality of life. The end product of the S.O.S.MS project will consist of two documents:

- a) Complete reference guide of the standard outcome set and its definitions, measurement time points, instruments and risk factors
- b) Scientific publication: participants of the S.O.S.MS expert panel will be offered co-authorship of the publication

HOW?

± 4 Delphi consensus meetings with a multidisciplinary group of leading international MS-experts (S.O.S.MS Expert panel)

- Consensus on medical condition and treatment options
- Validation of long list of outcome measures and case-mix variables
- Consensus on short list of outcome measures
- Validation of short list of case-mix variables and consensus final standard outcome set.

WILL YOU JOIN THE S.O.S.MS EXPERT PANEL?

We invite various MS-experts to participate in the Delphi consensus meetings:

- MS Neurologists
- MS Nurses
- Physiotherapists
- Patient representatives

WHEN?

The 4 Delphi consensus meetings will take place once a month in September, October, November and December 2019.

- Participation in Delphi consensus meetings (video): ± 4 x 1,5 hour
- Preparation time before each meeting: 4 x 0.5 hour

JOIN US NOW!

S.O.S.MS PROJECT

STANDARD OUTCOME SET MULTIPLE SCLEROSIS

WHO INITIATED THIS PROJECT?

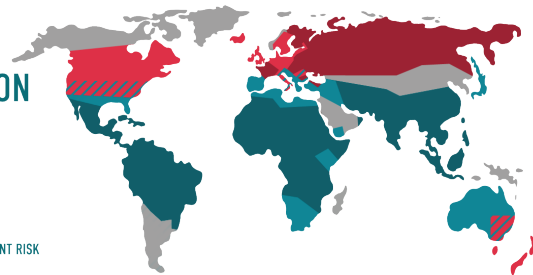
The S.O.S.MS project was initiated by St. Antonius Hospital (Nieuwegein/Utrecht, the Netherlands) which is part of the Santeon hospital group. Santeon is a strategic partner of ICHOM and has been very active in the development and implementation of standard outcome sets and VBHC.

IQ healthcare is a research department connected to the academic hospital Radboudumc in Nijmegen, The Netherlands. IQ healthcare also has a long track record in developing, implementing and evaluating outcome indicators in healthcare.

S.O.S.MS EXPERT PANEL

The multidisciplinary international S.O.S.MS Expert panel will consist of leading MS experts from all 'high risk' areas in the world.

GLOBAL DISTRIBUTION OF MS



JOIN THE S.O.S.MS PROJECT!

Do you want to participate in the S.O.S.MS Expert panel?
Or do you have any questions regarding the S.O.S.MS project? Please feel free to contact Kirsten Daniels (researcher) via k.daniels@antoniusziekenhuis.nl

Examples of outcome sets developed by St. Antonius Hospital:

- Verberne, W. R., Das-Gupta, Z., ... & Bos, W.J.W. (2019). Development of an International Standard Set of Value-Based Outcome Measures for Patients With Chronic Kidney Disease: A Report of the International Consortium for Health Outcomes Measurement (ICHOM) CKD Working Group. *American Journal of Kidney Diseases*, 73(3), 372-384.
- Daeter, E. J., Timmermans, M. J., ... & van der Nat, P.B. (2018). Defining and Measuring a Standard Set of Patient-Relevant Outcomes in Coronary Artery Disease. *The American journal of cardiology*, 121(12), 1477-1488.
- Kampstra, N. A., Grutters, J. C., ... & van der Nat, P.B. (2019). First patient-centred set of outcomes for pulmonary sarcoidosis: a multicentre initiative. *BMJ Open Respiratory Research*, 6(1), e000394.

This project was funded by Roche Nederland B.V.

IQ Scientific Institute for
Quality of Healthcare

ST ANTONIUS
een santeon ziekenhuis