



Nederlandse Vereniging
voor Neurologie

gelre ziekenhuizen

Dutch MS Registry

Kitty Harrison, M-ANP, MSCN, Tergooi hospital Blaricum

Emmy Eggink-Bekman, RN, MSCN, Gelre hospital Zutphen

The Netherlands

<https://www.landelijkekwaliteitsregistratie.nl/over-ons>

<https://www.sivz.nl/>

<https://euroqol.org/>



Nederlandse Vereniging
voor Neurologie

gelre ziekenhuizen

Disclosures

Kitty Harrison, M-ANP, MSCN, Tergooi hospital Blaricum

- Relations with Bayer, Biogen, Genzyme, Merck, Mylan, Novartis, Roche

Emmy Eggink-Bekman, RN, MSCN, Gelre hospital Zutphen

- Relations with Bayer, Biogen, Genzyme, Merck, Mylan, Novartis, Roche

Dutch MS Registry

Emmy Eggink, Gelre ziekenhuizen; Kitty Harrison, Tergooi ziekenhuis ; Nynke Kalkers, OLVG ; Joep Killestein, AmsterdamUMC; Brigit de Jong, AmsterdamUMC; Robert van den Bos, MSVN; Stephan Frequin, Antonius ziekenhuis ; Elske Hoitsma, Alrijne ziekenhuis ; Jolijn Kragt, Reinier de Graaf ziekenhuis; Beatrijs Wokke, Erasmus MC; Minse de Bos Kuil , MSVN; Casper van Munster, Amphia ziekenhuis; Janet de Beukelaar, Albert Schweitzer ziekenhuis,; Jeroen van Eijk, Jeroen Bosch ziekenhuis; Marcel van de Wielen, NVN

Background:

Due to the complexity of Multiple Sclerosis (MS) there is no standard treatment available. The Dutch registry of MS is a registration of data on the Dutch population of people with Multiple Sclerosis, which has been set up to measure, improve and justify the quality of care. This registry records the characteristics of the patient and the care provided in terms of actions on the one hand and results on the other. It also contains data reported by patients. By recording the care itself and the most important results in comparable situations (based on previously agreed variables), meaningful connections and comparisons can be made, making it possible to improve care. These treatment data can be compared at local level. Each center can compare their data with the national benchmark. Neurologists, MS nurses and other care providers involved in the care of MS patients participate in this registry. In addition to MS neurologists and MS nurses, representatives from the patient association were also involved in the development of this MS registry

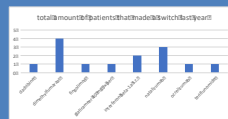
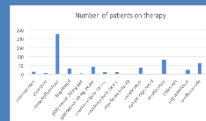
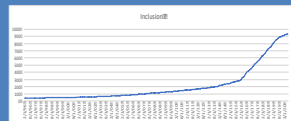
Target:

Mapping, monitoring and improve the continuing care of patients with multiple sclerosis. Gain insight into the effects, side effects and reasons for switching of existing treatments.

Method:

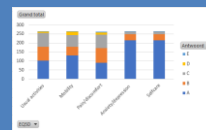
The registry includes patients diagnosed with MS in the Netherlands from January 1, 2016. Various medications and their effects are recorded in this registry. Data are collected on the course of treatment, additional research that has been carried out to make the diagnostic procedures. Data are collected on the course of treatment, diagnostic procedures, treatment by MS nurses, the use and adherence of medication, follow-up of medication, side effects, reasons for switching and the use of rehabilitation. These treatment data can be compared at local level. Each center can compare their data with the national benchmark. Patients complete questionnaires (EQ5-D, supplemented with social status and work and income). This results in Patient Reported Outcome Measures and Patient Reported Experience Measures.

Results:



Labels	A	B	C	D	E	Grand total
Usual activities	102	78	75	8	2	265
Mobility	132	47	64	21	1	265
Pain/discomfort	90	82	75	12	5	264
Anxiety/depression	214	34	15	1	1	265
Selfcare	214	34	15	1	1	265
Grand total	752	275	244	43	10	1324

EQ5D



Conclusion:

The Dutch MS registry provides a valuable insights on both the physical and mental functioning as the treatment strategies on individual level, per hospital and national level. By collecting this information, we gain a better understanding of the quality of care. This registry can therefore contribute to a better treatment for patients with multiple sclerosis.



BACKGROUND

- Due to the complexity of Multiple Sclerosis (MS) there is no standard treatment available.
- The Dutch MS registry is a registration of data on the Dutch population of people with Multiple Sclerosis, which has been set up to measure, improve and justify the quality of care.
- In addition to MS neurologists and MS nurses, representatives from the patient association were also involved in the development of this MS registry.





Background II **gelre**ziekenhuizen

- This Dutch MS registry is recording the characteristics of the patient and the care provided in terms of actions on the one hand and results on the other.
- It contains patient reported outcomes by use of EQ5D. By recording the care itself and the most important results in comparable situations (based on previously agreed variables), meaningful connections and comparisons can be made, making it possible to improve care.
- Neurologists, MS nurses and other care providers involved in the care of MS patients participate in this registry.
- These treatment data can be compared at local level. Each center can compare their data with the national benchmark.





Target

- Mapping, monitoring and improve the continuing care of patients with multiple sclerosis.
- Gain insight into the effects, side effects and reasons for switching of existing treatments.





Methods



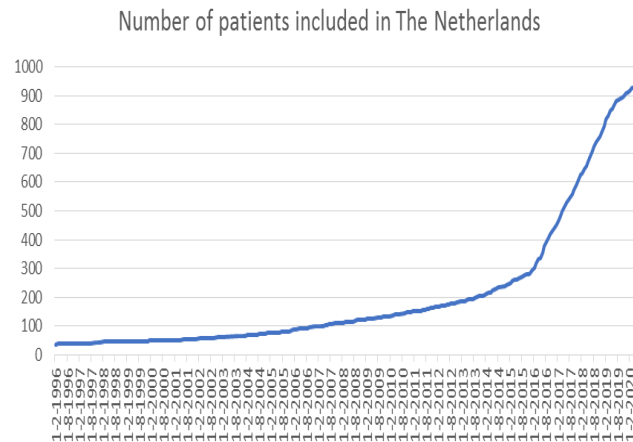
- The Dutch MS registry includes patients diagnosed with MS in the Netherlands from January 1, 2016.
- Various medications and their effects are recorded in this registry.
- Data are collected on the course of treatment, diagnostic procedures, treatment by MS nurses, the use and adherence of medication, follow-up of medication, side effects, reasons for switching and the use of rehabilitation.
- Patients complete questionnaires (EQ5-D, supplemented with social status and work and income). This results in Patient Reported Outcome Measures and Patient Reported Experience Measures.



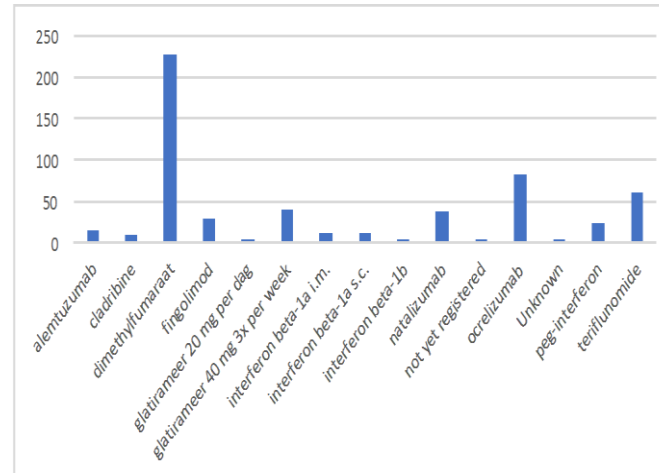
Results



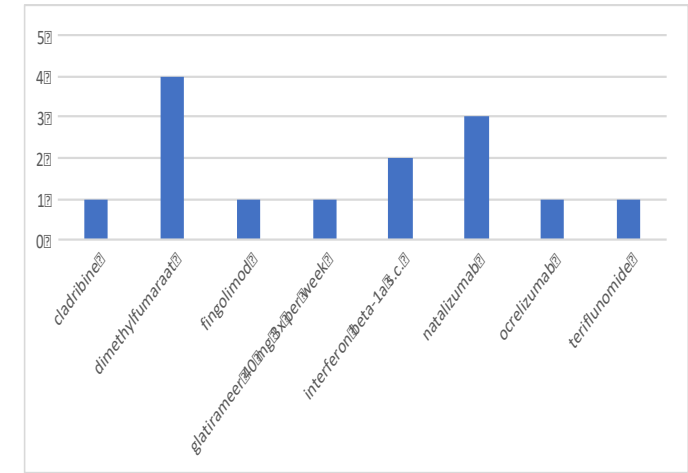
- The pilot for the registry started 2017 in 10 hospitals.
- During 2018 and 2019 it has been rolled out in most hospitals in the Netherlands. August 2020 almost all clinics participate.



The Netherlands has approximately 17.000 people with MS



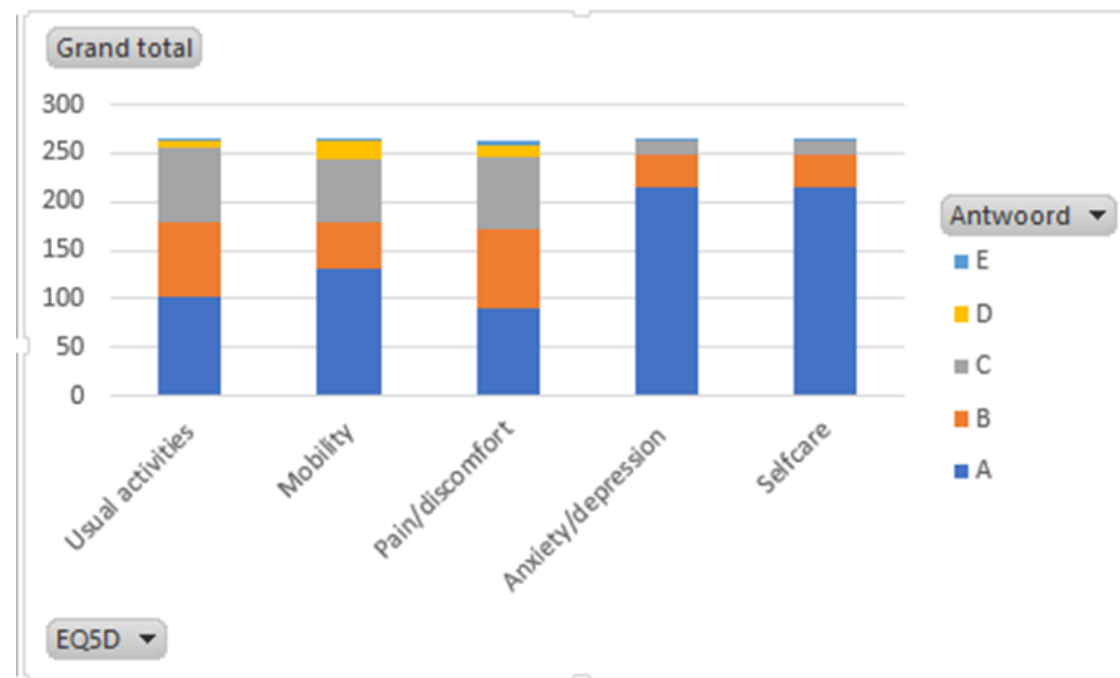
Number of patients on therapy



Total amount of patients that recently made a switch to...



Suffer from MS complaints in scale A (No problems) – E (Extreme problems)	A	B	C	D	E	Grand total
Usual activities	102	78	75	8	2	265
Mobility	132	47	64	21	1	265
Pain or discomfort	90	82	75	12	5	264
Anxiety/Depression	214	34	15	1	1	265
Selfcare	214	34	15	1	1	265
Grand total	752	275	244	43	10	1324



A: no problems

B: slight problems

C: moderate problems

D: severe problems

E: extreme problems





Conclusion



- The Dutch MS registry provides a valuable insights on both the physical and mental functioning as the treatment strategies on individual level, per hospital and national level.
- By collecting this information, we gain a better understanding of the quality of care. This registry can therefore contribute to a better treatment for patients with multiple sclerosis.

