

Multiple Sclerosis Care Units; a state of the art early investigation

The MS Care Unit survey ([mscu-ecf-2021](#)) aims at mapping the access to specialist MS treatment across the world. It was launched by the European Charcot Foundation in collaboration with Multi-Act¹ Project, in the context of the Multidisciplinary MS Care Unit Project with the purpose of establishing a more even access to expert treatment for people with MS in multidisciplinary MS clinics.

The survey runs on the Multi-act Digital Toolbox² administered by the Italian Foundation of Multiple Sclerosis. The MSCU Survey which is still running, collected 147 submissions, so far.

Many thanks to whom participated to survey and we welcome any further contribution of other centres to have not yet reply to the survey to enrich the present analysis that will translate in a peer review publication.

The next paragraphs want to return a first analysis on the nature of the answers received by the survey, to contextualize the reading of the data that will be provided in the second part of the article.

Survey distribution:

- *Country*

The survey was distributed worldwide via emails. The invitation was circulated by the European Charcot Foundation.

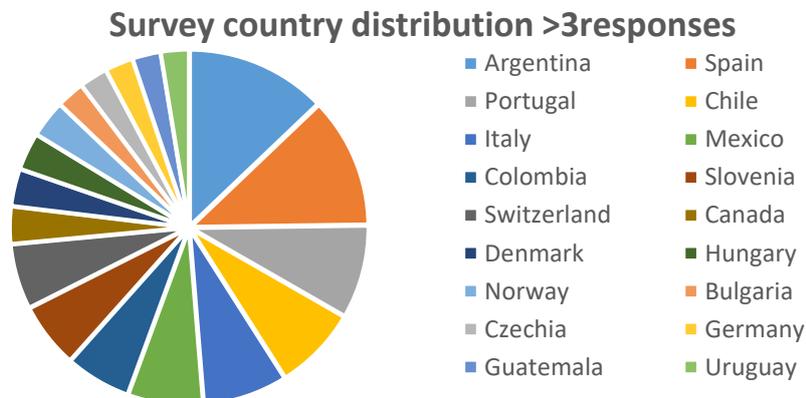


Figure 1 Submission by country (>3 submissions)

The pie chart above shows the global nature of the contribution. Feedbacks were sent by a total of 38 different countries, the graph shows those where the number of submissions were greater or equal to 3.

- *Type of organization*

With respect to the type of organizations and their dimensions, the highest rate of responses belong to hospitals; we will observe proportional majority in the following analysis.

¹ Multi-Act project has received funding from the European Union's Horizon 2020 Research and Innovation Programme under the Grant Agreement No. 787570

² <https://toolbox.multiact.eu/>

In fact, the feedbacks from Hospitals represents the 58% of the total sample. Following, Universities (22%) are the second type of organization here represented.

It shall be noted thou, that the dimensions of the organizations mapped by the survey range from very small entities (<500 MS patients attended in one year) to large (2000-3500) and very large (>3500) bodies.

Below it is provided the distribution of hospitals dimension as reference.

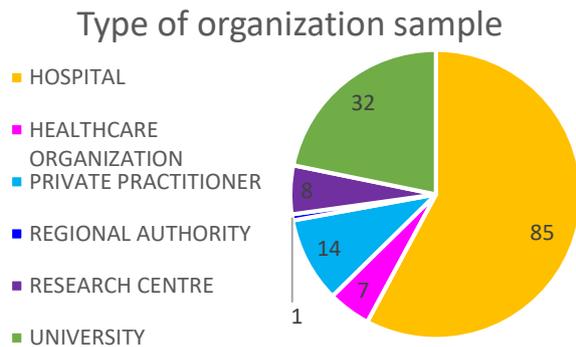


Figure 2 Type of organization responses.

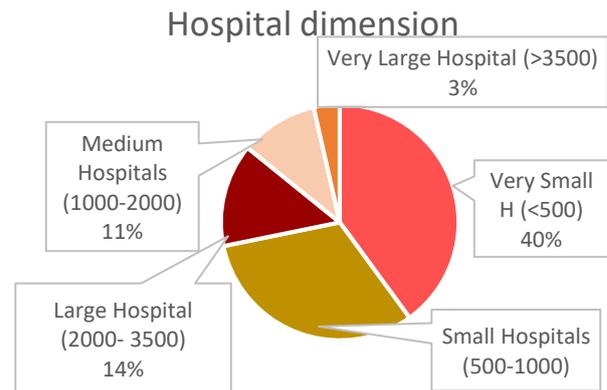


Figure 3 Hospital by size

Survey results:

As reported by Sorensen 2019³, “A multidisciplinary MS Care Unit approach can be defined as the presence of a group of different specialists, who work together and with the MS neurologists and nurses with a formalized diagnostic workup procedure, protocols for initiation and follow-up of DMTs and management of complications.”.

Along with the above-mentioned criterion, the article proposes a set of minimum requirements that define a MS Care Unit.

Our analysis started from the concept that a MS Care Unit is a body which; at first includes the three professional figures identified above: neurologist, nurse and physiotherapist.

In addition to this, a MS Care unit does keep a record of a Multiple Sclerosis registry and it collects Patient Reported Outcome (PRO) along with the standard clinic data.

Last, despite the following feature is not listed as MS Care Unit priority, the present report considered relevant the measurement of the Patient Satisfaction level as measurement as Patient reported dimension indicator according to Multi-Act definition.

³ Soelberg Sorensen P, Giovannoni G, Montalban X, Thalheim C, Zaratin P, Comi G. The Multiple Sclerosis Care Unit. *Mult Scler.* 2019 Apr;25(5):627-636. doi: 10.1177/1352458518807082. Epub 2018 Oct 23. PMID: 30351211; PMCID: PMC6439947.

Methodology:

In order to determine compliance of organization mapped MSCU gold standard criteria, the 147 submissions were filtered to cross-check the satisfaction of all the benchmarks selected.

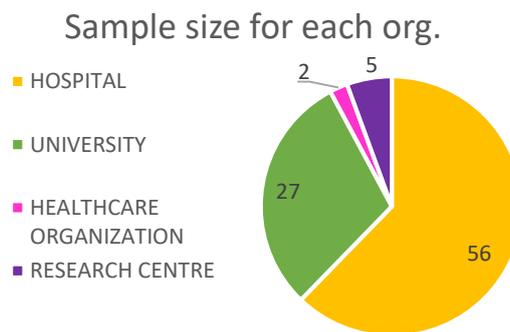
Fourteen bundles of data were submitted by Private practitioners. Despite the data referring to these professionals provide important insight on the care standard for Multiple Sclerosis patients, their data do not fulfil the purpose criteria of the current report.

Each benchmark was reviewed, if relevant, to possibly draw statistics on the performance on each.

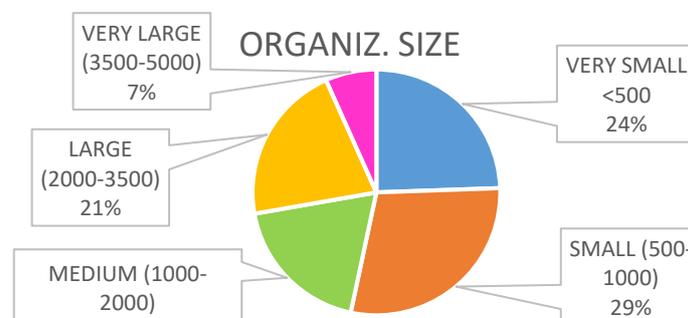
- *Presence of 3 core professionals*

The presence of all three professional figures of neurologist, nurse and physiotherapist has been here considered as first parameter to identify those entities, which potentially meet MCSU gold standards. In fact, the presence of these healthcare professionals is the first example of multidisciplinary management of the MS disease.

We have identified 90 bodies whose staff counts the presence of these figures. As expected, the greatest sample is represented again by hospitals, but the corresponding percentage (62%) mirrors the one regarding participation.



The size of the body , again measured with respect to MS cases treated in a year, is apparently having an influence, showing that there is only approximately 50%(of total submittent) of small and very small entities covering all the recommended professional figures, while for larger institutions, the proportion reaches above the 75%; e.g: 19 large org. have core professionals over the 22 large org. submitting the survey.



It shall also be noted that, among the non-compliant organization, the most neglected professional figure show to be the physiotherapist. In fact, 31 bodies were excluded from the MSCU gold standard selection due to the lack of dedicated physiologists.

- *Registry of Multiple Sclerosis*

The second parameter for the selection regards the availability and maintenance of Registry of Multiple Sclerosis. Those registries keep records of patients' data such as number of patient identification, date of birth, sex, date of diagnosis and date of exacerbations (relapses) and other diagnosis and diagnostic procedures used in the patient. Registries often collect information regarding clinical assessment, hospital admissions and treatments.

Among the 133 institutions monitored by the survey, the majority (113) report the existence of a register. However, the level of details can vary from one entity to another and there is often fragmentation in data collection and data analysis. Nonetheless, the quality of these databases and registries is essential and again depends on the MS centre organization.

For the purpose of this paper, we decided to include all the organization provided with a MS register, considered as basic requirement, conscious that further investigations on one side, and standardization efforts on the other, are recommended.

- *Patient reported outcome*

A *PRO* is defined as information about the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else⁴. Recent data suggest that patients' self-reported symptoms and health status are associated with the use of medical services (e.g., emergency room visits and hospitalizations), costs, outpatient medication compliance, and survival^{5,6}. The process of patient self-reporting itself can improve symptom management, quality of life, communication, and satisfaction with care⁷.

Hence, the present report maps, as best performing MSCU, those using Patient reported Outcomes in their daily evaluation. PROs are increasingly considered a standard approach to add aside to the other measures. This trend can be observed within our case.

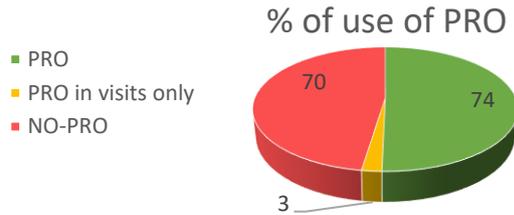
⁴ U.S. Food and Drug Administration. Guidance for Industry. Patient-reported outcome measures: use in medical development to support labeling claims. December 2009.

<http://www.fda.gov/downloads/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/UCM193282.pdf>.

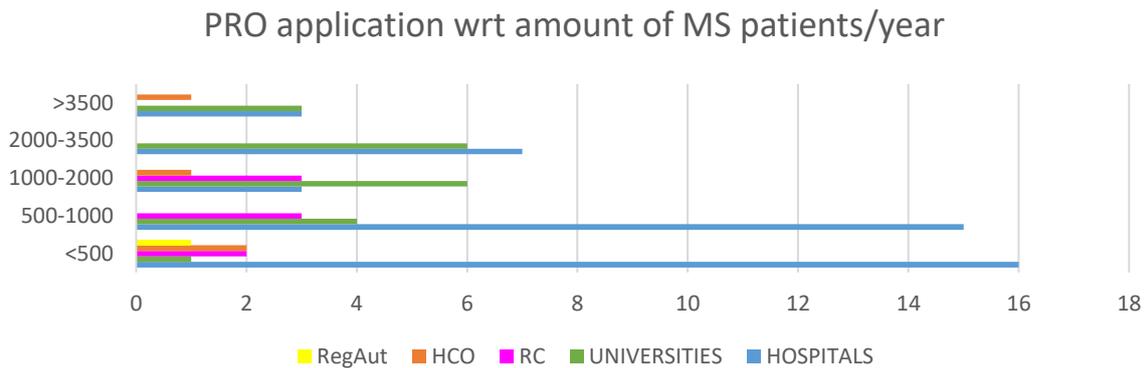
⁵ P.L. Harrison, J.E. Pope, C.R. Coberley, E.Y. Rula Evaluation of the relationship between individual well-being and future health care utilization and cost, *Popul Health Manag*, 15 (2012), pp. 325-330

⁶ C.C. Gotay, C.T. Kawamoto, A. Bottomley, F. Efficace The prognostic significance of patient-reported outcomes in cancer clinical trials, *J Clin Oncol*, 26 (2008), pp. 1355-1363

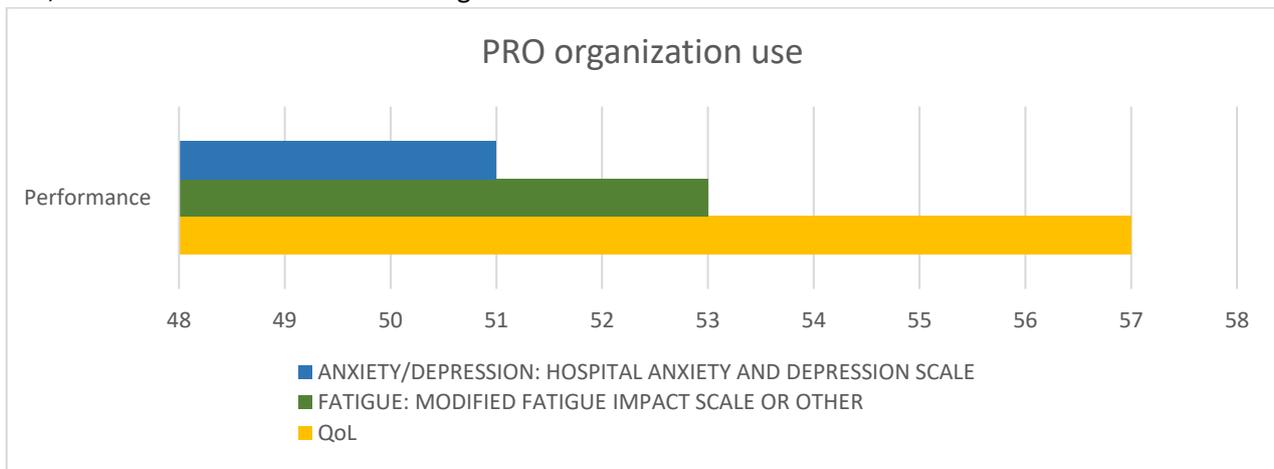
⁷ E. Basch, J. Spertus, R. Adams Dudley, A. Wu, C. Chuahan, P. Cohen, M. L.Smith, N.Black, A. Crawford, K. Christensen, K. Blake, C. Goertz, Methods for Developing Patient-Reported Outcome-Based Performance Measures (PRO-PMs), *Value in Health*, Volume 18, Issue 4, 2015, <https://doi.org/10.1016/j.jval.2015.02.018>



More than half of the participant institutions keep record the patient reported dimension. The following bar graph provides an overview of the use of PRO according to both type and dimension of the unit.



Also, it was observed that the following PRO are the most used:



The other PRO in use listed by the survey were: MSIS, CESD, NfL;AQ4A and BICAMS.

- *Measurement of satisfaction level*

The last parameter to consider regards the indicators of processes and clinical results of the mscu/year.

The survey listed the following parameters as indicator of performance:

- number of treatments administered in the day hospital/outpatient clinic. (oral or iv)
- number of treated exacerbations (relapses)
- number of severe adverse events
- use of disability progression, expanded disability status scale (edss)
- assessment of degree of satisfaction of users

- administrative data
- presence of cost accountability

In line with the MULTI-ACT master scorecard, the present analysis give relevance to the assessment of degree of satisfaction of users, as a potential values base health care indicator.

Patient satisfaction shows to be a relevant parameter in most cases; in fact 71 institutions declare to evaluate user satisfaction. On the contrary, 62 entities do not.

Notably, around 71% (52/71) of tracking-satisfaction organizations also make use of the PRO. Out of the not-tracking-satisfaction organizations, a 60% does neither record PRO (37/62).

Results and next steps

From the above process, we have identified 30 organization that are compliant with all the above criteria.

They are spread across variegated countries;

- 9 pertain to northern European countries,
- 10 to southern Mediterranean countries
- 5 are present in the south American continent
- 4 in the eastern Europe
- 1 in Africa
- 1 in Middle East

They belong to the Hospital or university type. Best performances do not seem to have a direct relation to the dimension (case treated) of the institution.

All these institutions are very well positioned to be compliant to the MS care units gold standards and these are potentially eligible to test the impact of the establishment of multidisciplinary MS Care Units on multidimensional indicators .

- *Next steps*

The present analysis shall be considered preliminary.

A greater number of submission and feedback would allow a deeper understanding of the MSCU field and could potentially provide us information and details for their contestant improvement.

For this reason, the recommendation is to keep the inspection as a lively tool and the current report as a stepping-stone to foster future works.

In addition, the completion of the survey can be the initial phase of a process preparatory to the understanding of the compliance status regarding MSCU gold standard of the different bodies participating in healthcare. It could also lead to the development of research project to assess the costs/benefits of starting up MSCU and the validation of values base health care indicators to apply to those organizations participating in the survey.