Supplementary File 2

Except good to excellent psychometric properties, the selection of outcome measures depended also on patient involvement during their development, patient acceptability of the tools or recommendations from relevant governmental organisations or MS Societies. The MusiQol was developed using individual semistructured interviews of 1992 PwMS in five countries, followed by qualitative content analysis. The MS-EDGE Outcome Measure Task Force reviewed and recommended the MusiQol for use in PwMS[1]. Similarly, both the German long and short versions of the Resilience Scale are based on face-to-face interviews of 2031 people. The GSE was exposed to repeated validation studies in thousands of participants where excellent validity and reliability were confirmed. A study explored the validity of the HADS in PwMS using interviews by an interviewer who was blind to the HADS scores [2]. The acceptability of the German HADS to various patient populations was tested and confirmed [3]. The UK National Institute for Health and Care Excellence (NICE) 2018 Guidelines for MS[4] recommended the HADS anxiety subscale as a sensitive and specific anxiety screening tool, based on a review[5]. The NFI-MS was developed through a two-stage process in 635 PwMS; quantitative validation and qualitative interviews with patients. The NFI-MS was reviewed and recommended by the MS International Federation (MSIF)[6].

References

- Potter K, Cohen ET, Allen DD, et al. Outcome measures for individuals with multiple sclerosis: recommendations from the American Physical Therapy Association neurology section task force. Phys Ther 2014;94(5):593-608 doi: 10.2522/ptj.20130149[published Online First: Epub Date]|.
- Watson TM, Ford E, Worthington E, et al. Validation of Mood Measures for People with Multiple Sclerosis. Int J MS Care 2014;16:105–09
- Herrmann C. International experiences with the Hospital Anxiety and Depression Scale--a review of validation data and clinical results. Journal of psychosomatic research 1997;42(1):17-41
- Surveillance of Multiple sclerosis in adults: management (NICE guideline CG186). Secondary Surveillance of Multiple sclerosis in adults: management (NICE guideline CG186) 2018.

https://www.nice.org.uk/guidance/CG186/documents/surveillance-reviewproposal.

- Litster B, Fiest KM, Patten SB, et al. Screening Tools for Anxiety in People with Multiple Sclerosis: A Systematic Review. Int J MS Care 2016;18(6):273-81 doi: 10.7224/1537-2073.2016-004[published Online First: Epub Date]].
- 6. MSIF. Fatigue and MS. MS in focus 2012;1:1-28