

($p < 0.05$; $p < 0.01$). **CONCLUSIONS:** The Spanish version of the MSTCQ questionnaire is a feasible, reliable and valid tool for the evaluation of satisfaction with the injection device in the treatment of MS.

PND44

ELICITING PATIENTS' PREFERENCES FOR EPILEPSY DIAGNOSTICS: A DISCRETE CHOICE EXPERIMENT

Wijnen BFM¹, de Kinderen RJA¹, Colon AJ², Dirksen CD³, Essers BAB⁴, Hilgsmann M¹, Leijten FFS⁵, Ossenblok PPW², Evers SM¹

¹Maastricht University, Maastricht, The Netherlands, ²Epilepsy Centre Kempenhaeghe, Heeze, The Netherlands, ³Clinical Epidemiology and Medical Technology Assessment, Maastricht University Medical Centre, CAPHRI, Maastricht University, Maastricht, The Netherlands, ⁴Clinical and Medical Technology Assessment, Maastricht University Medical Centre, CAPHRI, Maastricht University, Maastricht, The Netherlands, ⁵Brain Center Rudolf Magnus, University Medical Centre Utrecht, Utrecht, The Netherlands

OBJECTIVES: Diagnosing epilepsy is a lengthy and burdensome process for patients and their family. Although the need for a more patient-centered approach in clinical practice is widely acknowledged, empirical evidence regarding patient preferences for diagnostic modalities in epilepsy is missing. The objectives of this study are 1) to identify to what extent important attributes of diagnostic procedures in epilepsy affect preferences for a procedure; 2) to determine the relative importance of these attributes; and 3) to calculate overall utility scores for routine electroencephalography (EEG) and magnetoencephalography (MEG) registrations. **METHODS:** A discrete choice experiment was performed to determine patients' preferences, which involved presentation of pair-wise choice tasks regarding hypothetical scenarios. Scenarios varied along six attributes: "Way of measuring brain activity"; "Duration"; "Freedom of movement"; "Travel time"; "Type of additional examination"; and "Chance of additional examination". Choice tasks were constructed using a statistically efficient design and the questionnaire contained 15 unique unlabeled choice tasks. Mixed multinomial logistic regression was used to estimate patients' preferences. **RESULTS:** A total of 289 questionnaires were included in the analysis. McFadden's pseudo R^2 showed a model fit of 0.28 and all attributes were statistically significant. Heterogeneity in preferences was present for all attributes. "Freedom of movement" and "Chance of additional examination" were perceived as the most important attributes. Overall utility scores marginally differ between MEG and routine EEG. **CONCLUSIONS:** Our study suggests that the identified attributes are important in determining patients' preference for epilepsy diagnostics. It can be concluded that MEG is not necessarily more patient-friendly than a routine EEG in primary diagnostics and, regarding additional diagnostics, patients have a strong preference for long-term 24h EEG over EEG after sleep deprivation. Furthermore, barring substantial heterogeneity within the parameters in mind, our study suggests that it is important to take individual preferences into account in clinical decision-making.

PND45

QUALITY OF LIFE OUTCOMES IN MULTIPLE SCLEROSIS: A REVIEW OF THE LITERATURE

Rouse M, McKenna S, Twiss J, Graham JE, Wilburn J
Galen Research Ltd., Manchester, UK

OBJECTIVES: Multiple sclerosis (MS) is a chronic neurodegenerative disease affecting the central nervous system. There are a variety of symptoms and activity limitations associated with MS including mobility problems, muscle spasticity, fatigue and mental health problems. In order to gain an accurate insight into the impact of MS on patients it is important for accurate patient-reported outcome (PRO) instruments to be applied. The purpose of this review was to evaluate the available MS-specific PRO measures. **METHODS:** The online literature databases PubMed, Psychinfo and Web of Science were used for the search. The search identified all studies that used a PRO measure in the study design and was restricted to publications from the last fifteen years. Only measures used in at least three clinical trial studies were included. The measures identified were evaluated in terms of; source of items, item reduction methods, unidimensionality, practicality, responsiveness, reliability, internal consistency and face, content and construct validity. **RESULTS:** The search yielded 2317 articles, of which 1066 were duplicates and removed. The review of the remaining articles identified six measures that met the review criteria: MSIS-29, LMSQoL, MSQoL-54, HAQUAMS, MSQLI and PRIMUS. In addition, the MUSIQoL was reviewed because of recent development activity. Most of the measures exhibited some weaknesses. Only the PRIMUS performed well on all the review criteria. It was the only measure to apply a clear theoretical framework and meet the strict measurement requirements of the Rasch model. **CONCLUSIONS:** The PRIMUS is recommended for use in clinical trials. The review suggests that many clinical trials are using PROs that have not benefitted from the use of Item Response Theory and modern psychometric approaches.

PND46

PATIENT-CENTERED OUTCOMES IN UPPER LIMB SPASTICITY: RESULTS FROM A LARGE INTERNATIONAL COHORT STUDY (ULIS-2)

Balcaitene J¹, Kurth H², Fheodoroff K³, Jacinto J⁴, Turner-Stokes L⁵

¹IPSEN Pharma, Boulogne-Billancourt, France, ²IPSEN Pharma, Boulogne Billancourt, France, ³Gaittal-Klinik, Hermagor, Austria, ⁴Serviço de Reabilitação de adultos 3, Alcoitão, Portugal, ⁵King's College London, London, UK

Muscle spasticity following stroke may interfere with motor and activity performance, cause pain, and lead to secondary complications. Goals of spasticity management include improving function (active and passive) and body image, and facilitating concomitant treatments. The efficacy of BoNT-A in upper limb spasticity (ULS) patients focusing on reduction of muscle tone and pain is well established. However, there are no specific ULS patient-reported outcome measures (PROs) available. As patients with ULS are highly heterogeneous, there is a need to develop measures to capture realistic, patient-specific treatment goals. **OBJECTIVES:** To assess effectiveness of BoNTA on ULS considering patient-specific experience. **METHODS:**

A prospective multinational, multicenter (84 centers in 22 countries), observational, post-marketing, longitudinal study (ULIS-2), investigating routine use of BoNT-A for treating post-stroke ULS. Primary outcome: achievement of the patient's primary goal for treatment using Goal Attainment Scaling (GAS). Goals were set together by physicians and patients/caregivers. Patients were able to rate goals for importance. Secondary outcome: global assessment of benefits by both physician and patients/caregiver. **RESULTS:** Among the 456 adults with post-stroke ULS presenting for treatment with BoNT-A, the most commonly selected primary treatment goals were passive function (132 (28.9%)), active function (104 (22.8%)), pain (61 (13.4%)), and impairment (105 (23%)). Patients rated 404/456 primary goals (88.6%) as "important" (395/456 (86.6%) as "very" or "moderately" important), indicating high patient involvement in goal-setting. Overall, 363 (79.6%) (95% CI 75.6% to 83.2%) patients achieved (or overachieved) their primary goal. GAS T-scores were strongly correlated with rating of global benefit and other standard measures (correlations of 0.38 and 0.63, respectively; $p < 0.001$). **CONCLUSIONS:** Patient-centered goal setting and evaluation using GAS to calculate changes of health-related status is a feasible way to capture changes in ULS patient experience. GAS as primary outcome measure in ULIS-2 is a step closer to a PRO in ULS patients.

PND47

PATIENT PREFERENCES AND PRIORITIES FOR ANTI-EPILEPTIC DRUG TREATMENT

Faragher EA¹, Marson A², Jacoby A³, Ring A³, Williamson P³, Hughes DA¹

¹Bangor University, Bangor, UK, ²Walton Centre for Neurology and Neurosurgery Foundation Trust, Liverpool, UK, ³University of Liverpool, Liverpool, UK

OBJECTIVES: Clinical trials in epilepsy may not routinely prioritise patient-oriented outcomes that consider the harms of treatments in addition to their benefits. To date, no systematic empirical research has been undertaken to assess the views of people with epilepsy about treatment outcomes. The aim was to identify which outcomes of drug treatment are considered important to three groups of adults with epilepsy: (i) recently diagnosed, (ii) established diagnosis, (iii) women of childbearing age. **METHODS:** Semi-structured individual interviews containing ranking exercise were used to explore views and interpretations of benefits, harms, and potential life-impacts of anti-epileptic drug treatments ($n=41$); the feasibility of these findings were evaluated in focus groups of health care professionals responsible for prescribing anti-epileptic drugs ($n=8$). Outcomes ranked 1-4 were scored 4-1. For each group, scores were summed and divided by the number of participants. **RESULTS:** Ten recently diagnosed men (mean age 45.9), 13 established (mean age 39.3, 92% male), and 18 women of childbearing age (mean age 34.5) participated. Reduction in seizure frequency was the most highly ranked outcome of drug treatment across all three subgroups (women of childbearing age [score]=2.5, recent=2.4, established=2.23). Adults recently diagnosed were most concerned about feelings of aggression (1.6), depression (1.0) and ability to work (0.9). Adults with established epilepsy were most concerned with ability to work (1.15) negative impacts on relationships (1.0), memory problems (0.69), and social-life (0.69). Women of childbearing age were concerned about memory (1.22), reduced independence (0.78), feeling in control (0.56) and foetal abnormality (0.5). Clinicians considered life-impacts (eg work, relationships, independence) as consequences of benefits and harms of treatment. **CONCLUSIONS:** The importance of remission from seizure was consistent. However, patients' rankings of unfavourable outcomes of drug-treatment varied by subgroup. Selection of outcome measures in clinical trials in epilepsy must consider relevant patient-oriented outcomes which differ by population.

PND48

EVALUATING FATIGUE IN FIBROMYALGIA: DEVELOPMENT AND VALIDATION OF THE DAILY DIARY OF FATIGUE SYMPTOMS IN FIBROMYALGIA (DFS-FIBRO)

Burbridge C¹, Symonds T¹, Humphrey L², Arbuckle R², Hirsch I³, Whelan L¹

¹Pfizer Ltd., Surrey, UK, ²Adelphi Values, Bollington, UK, ³Astra Zeneca, Cheshire, UK

OBJECTIVES: Despite being recognised as an important symptom in Fibromyalgia (FM), existing measures of fatigue are unlikely to meet regulatory standards for clinical trial endpoints. We therefore describe the development and validation of a new, electronically administered patient reported outcome (ePRO) measure of fatigue in FM - the Daily Diary of Fatigue Symptoms-Fibromyalgia (DFS-Fibro). This was developed in accordance with the FDA regulatory guidance and ISPOR good practice recommendations for the development and validation of PROs. **METHODS:** Initial item generation was based on concept elicitation interviews with 40 FM patients (from the US, Germany and France), and clinical relevance of the findings was confirmed by expert clinician review. The draft tool was pilot tested with 20 FM patients for 5-9 days, followed by cognitive debriefing interviews. A methodology study with 145 FM patients then followed, providing data to conduct the psychometric validation of the measure. Both the qualitative and quantitative findings were used to finalise the DFS-Fibro. **RESULTS:** Twenty-three items were generated from concept elicitation interviews, including items focussed on the physical and cognitive impacts of fatigue as well as fatigue 'symptom' items. Some minor wording revisions were made following pilot testing and cognitive debriefing, but none were deleted. All patients found the measure easy to understand and use. Initial psychometric analyses supported removing items previously identified as candidates for deletion in the qualitative work, resulting in a 5-item measure focussed on the core symptom of FM fatigue. The psychometric analyses were then repeated on the final 5-item measure, which had very high internal consistency ($\alpha = 0.99$), strong test-retest reliability ($r > 0.84$), and met a priori criteria for convergent and known groups validity. **CONCLUSIONS:** The DFS-Fibro development followed accepted guidelines and demonstrates strong psychometric properties and content validity as a measure of the symptom of fatigue in FM.

PND49

EVALUATING PATIENT ADHERENCE RATES TO APPROVED DISEASE MODIFYING THERAPIES (DMT) FOR RELAPSING-REMITTING MS (RRMS): OPERATIONAL SETUP FOR A MULTI-COUNTRY, MULTI-CENTER STUDY

Apecechea de Scheffer M, Faber S, Potthoff P, Eichmann F
Kantar Health Germany, Munich, Germany