CONCLUSIONS: Resource utilization and costs associated with migraine increased with greater headache frequency. Treatments that reduce headache frequency have the potential to have a positive economic impact by reducing costs associated with migraine care.

PND3

UTILIZING A PAPER STANDARD GAMBLE INSTRUMENT TO ASSESS HEALTH UTILITY IN PATIENTS WITH HEMOPHILIA B
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OBJECTIVES: To conduct a pilot study examining the validity and reliability of a paper-based standard gamble (PSG) instrument and to administer the validated PSG among persons with hemophilia B enrolled in the Hemophilia Utilization Group Study (HUGS-Vb).

METHODS: Fifteen pharmacy students were enrolled in this pilot. We presented a hypothetical scenario describing a patient with severe hemophilia to each participant, followed by three tests: (1) Standard Gamble (SG) using the probability wheel, (2) PSG and (3) Visual Analog Scale (VAS), each administered in random order. PSG was re-administered after two weeks to assess test-retest reliability. The validated PSG was subsequently administered to participants enrolled in HUGS-Vb, a prospective, multicenter study collecting utilization and other data associated with hemophilia B in the United States. Participants or their parent(s) completed a demographic questionnaire, the PSG and the EQ-5D. A PSG was administered in each of four QALY domains using the 5-level anchor (0 = death, 5 = perfect health) and the EQ-5D was scored dichotomously.

RESULTS: Mean age was 21.8 years (range 2-61). Mean PSG and VAS scores were 0.91 ± 0.13 and test-retest ICC was 0.85 (95% CI: 0.63-0.94; p = 0.0001). Of 71 HUGS-Vb participants, 52 (74%) were adults; 38 (54%) had severe hemophilia. Mean age was 21.8 years (range 2-61). Mean PSG and VAS scores were 0.91 ± 0.13 and test-retest ICC was 0.85 (95% CI: 0.63-0.94; p = 0.0001). Of 71 HUGS-Vb participants, 52 (74%) were adults; 38 (54%) had severe hemophilia.

CONCLUSIONS: A paper-based standard gamble instrument may be a valid, reliable alternative to SG for measuring health utility in hemophilia patients.

PND4

MAPPING THE INSOMNIA SEVERITY INDEX (ISI) TO THE EQ-5D UTILITIES
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OBJECTIVES: To map the Insomnia Severity Index (ISI) to the EQ-5D utilities.

METHODS: A cross-sectional, online survey was conducted among adult US residents with self-reported sleep problems. Respondents provided demographic, comorbidity, and sleep-related information, and completed the ISI and the EQ-5D. The ISI, a seven-item instrument measuring perceived insomnia severity. Each ISI item is scored from 0-4 with minimum total score of 0 (no insomnia) and a maximum of 28 (most severe insomnia). Respondents can be classified into four ISI categories (0-7, no clinically significant insomnia, 8-14 subthreshold insomnia, 15-21 mild insomnia, 22-28 severe insomnia). Each ISI item was used to map the seven ISI items (Model 1), the ISI summary scores (Model 2), and the four ISI clinical categories (Model 3) onto EQ-5D utilities. Predictions were estimated using 50/50 split sample validation. Model fits were assessed using mean squared error (MSE) and distributional quality of predicted values. RESULTS: Respondents (n=2,842) were predominantly middle-aged, female, Caucasian, with a ≥1 comorbidity. Mean sleep duration was 7.8 h (range 2-61). Mean PSG and VAS scores were 0.91 ± 0.13 and test-retest ICC was 0.85 (95% CI: 0.63-0.94; p = 0.0001). Of 71 HUGS-Vb participants, 52 (74%) were adults; 38 (54%) had severe hemophilia.

CONCLUSIONS: A paper-based standard gamble instrument may be a valid, reliable alternative to SG for measuring health utility in hemophilia patients.

PND5

CREATION OF A WEB-BASED MULTIPLE SCLEROSIS PATIENT-REPORTED OUTCOMES RESEARCH PROGRAM
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OBJECTIVES: To create and implement a secure web-based research program that collects and tracks validated patient-reported outcomes (PROs) for multiple sclerosis (MS) and shares outcomes with healthcare providers (HCPs).

METHODS: My MS Health program can be accessed through a HIPAA secure website, www.mymyshealth.org. A pilot study to evaluate the My MS Health program has been IRB-approved. Assessment of inclusion/exclusion criteria, enrollment, and informed consent with an electronic signature occurs through this secure web-site. Enrolled patients are prompted to complete a series of nine validated PRO surveys that measure MS specific symptom status, functional status, and quality-of-life, and results are immediately available. Patients may elect to give their HCPC access to their real-time PRO results electronically. Aggregate data analysis can also be performed on the PRO data.

RESULTS: Preliminary results indicate My MS Health is an efficient and user-friendly technology platform that patients will continue to use. Future evaluations will assess the impact of using the program on patient and HCP communication.

PND6

INTERNAL LOCUS OF CONTROL AND TREATMENT SATISFACTION WITH NATALIZUMAB
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OBJECTIVES: To assess the relationship between internal locus of control (LOC) and treatment satisfaction in MS patients after 1 year of natalizumab treatment.

METHODS: MS patients completed the Treatment Satisfaction Questionnaire for Medication (TSQM) prior to natalizumab initiation (BL) and after the 12th natalizumab infusion. Effectiveness, Convenience and Global Satisfaction subscale scores ranged from 0 to 100. Higher scores indicate better satisfaction. TSQM was assessed at BL and after the 12th infusion using the ILOC subscale of the Multidimensional Health Locus of Control questionnaire. Subscale scores range from 6 to 36; higher scores indicate greater ILOC. Correlation analysis and regression models evaluated the relationship between ILOC and satisfaction. A 3% improvement after 12 infusions, controlling for BL patient characteristics. RESULTS: A total of 333 patients (mean age 46.8 ± 10.4 years and median of 9 years since MS diagnosis) completed all assessments. BL and 12th ILOC was correlated with BL and 12th Global Satisfaction (r = 0.13, p = 0.0247 and r = 0.27, p < 0.0001, respectively) and Effectiveness (r = 0.11, p = 0.0001 and r = 0.29, p < 0.0001, respectively). 12th ILOC was correlated with 12th ILOC with a Codec (p = 0.12, p = 0.0373). Regression model results showed that, after controlling for covariates, higher ILOC predicted greater global satisfaction (p = 0.003), effectiveness (p = 0.001) and convenience (p = 0.017) with natalizumab after 12 infusions. Patients with MS with stronger internal beliefs about having control over their own health have higher satisfaction with natalizumab treatment after 12 infusions. Interventions supporting and reinforcing patients’ health beliefs may have a positive impact on overall treatment satisfaction resulting in improved treatment adherence.

PND7

INVESTIGATION OF THE PSYCHOMETRIC PROPERTIES OF THE SHORT PARKINSON’S EVALUATION SCALE/SCALES FOR OUTCOMES IN PARKINSON’S DISEASE (SPES/SCOPA)
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OBJECTIVES: The Short Parkinson’s Evaluation Scale/Scales for Outcomes in Parkinson’s disease (SPES/SCOPA) is a valid and reliable clinical tool to assess motor impairment measurement. The SPES/SCOPA also had exhibited good psychometrics, including evidence of construct validity with the Unified Parkinson’s Disease Rating Scale (UPDRS). This study aimed to further investigate the reliability and validity of the SPES/SCOPA motor clinical examination, as relatively little research in the US has been done so. METHODS: The BRAVURA study was designed to investigate order effects associated with the UPDRS motor examination at 2 centers in the US. Patients, stratified by center and previous Hoehn and Yahr (H&Y) stage, were randomly assigned to 1 of 2 UPDRS item sequences. All scale evaluations occurred during a single clinic visit. In addition to the 8-item SPES/SCOPA motor clinical examination and the 14-item UPDRS motor examination, scales included current H&Y stage and patient- and physician-rated Schwab and England Activities of Daily Living (ADL). Data were analyzed using Cronbach’s alpha and Spearman’s correlation. RESULTS: Construct data were available for 112 patients (mean time from diagnosis to 1.05 years). The SPES/SCOPA demonstrated good internal reliability (alpha = 0.79). Construct validity was supported with the SPES/SCOPA correlating 0.76 with the UPDRS. Furthermore, the SPES/SCOPA correlated 0.47 with current H&Y stage and −0.39, −0.45 with patient- and physician-rated ADL, respectively. CONCLUSIONS: In this US sample of PD patients with varied disease severity, the SPES/SCOPA exhibited strong psychometric properties, providing evidence of construct validity with the current standard of motor impairment measurement. The SPES/SCOPA also had good internal consistency and correlated with 3 broad evaluations of disease disability in a similar fashion to the UPDRS.

PND8

THE HIDDEN TOLL OF CAREGIVER BURDEN IN MULTIPLE SCLEROSIS
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OBJECTIVES: The hidden toll of caregiver burden in MS has been understudied. The survey was just right, and 91% felt the website was easy to use (4.5 ± 1.05). In addition, 92% reported that they likely continue participating in the program (4.0 ± 1.11) and 78% reported they would likely recommend My MS Health to others (3.8 ± 1.48).

CONCLUSIONS: Preliminary results indicate My MS Health is an efficient and user-friendly technology platform that patients will continue to use. Future evaluations will assess the impact of using the program on patient and HCP communication.

PND9

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