OBJECTIVES: SMA is a rare, hereditary, autosomal recessive neuromuscular disorder that is in its most severe forms impacts infants and young children. Capturing health utilities in infants and young children is often challenging and unavailing in clinical trial settings since most Qol or utilities instruments are not designed for such age groups. However, the development of cost effectiveness models, required in managed care reimbursement, necessitates utility generation in this population. The objective of this work is to develop health utilities for infants and young children with SMA utilizing different methodologies. METHODS: Three methodologies were undertaken to develop health utilities for input into CE models for nusinersen, the first approved therapy for treatment of SMA. A cross-sectional study of individuals with SMA in select European countries collected parent-proxy assessed Qol using the EQ-5D-3L. A case vignette study assessed physician and parent-proxy assessed utilities in the nusinersen economic models. Lastly, the CHERISH trial PegQol data was mapped to EQ-5D using a published algorithm. RESULTS: The three methodologies showed differences in health utilities and response formats. The cross-sectional study parent-proxy Qol assessment did not provide sufficient detail on patient health to determine with any amount of certainty an individual’s state of health based on the model health states. Physicians on average differentiated between Qol in different health states in a manner consistent with disease severity, and generally ranked Qol lower than observed by parents. Parent-proxy assessments of Qol in the nusinersen CHERISH trial showed little difference between lower and higher motor function health states, and in general parents rated Qol high, which is consistent with studies in other paediatric diseases. CONCLUSIONS: Our findings show that different methodologies yield distinct and sometimes equivocal results with parents rating Qol higher than physicians in individuals with SMA.

PND49
PATIENT PREFERENCES FOR INTERFERON-BETA IN IRAN: A DISCRETE CHOICE EXPERIMENT
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OBJECTIVES: Multiple sclerosis (MS) is a chronic, progressive, and common disease affecting the central nervous system in young adults. Interferon-beta is one of the most widely used medicines to reduce the disease progression. Given the variety of drugs in this category, we aimed to identify the preferences of patients for IFN-β that play an important role in policymaking in this area. METHODS: Discrete choice experiment method was used in the present study to identify and prioritize the nature of interest for MS patients and increase the probability of the use of IFN-β in their treatment. Questionnaires were given to 358 patients in Isfahan-Iran, who were asked to choose between the two treatment choices in each scenario. RESULTS: The results of the logit model showed that the changes in the efficacy leads to the most changes in the patient utility. Changes in side effects and ease of injection have been placed in the next rankings. CONCLUSIONS: Considering the drug attributes considered more desirable by patients can lead to greater medication adherence and possibly better treatment outcomes. Also, pharmaceutical companies, the health ministry, the Food and Drug Administration, insurance organizations, and neurologists can benefit from this information in production and importation, policymaking, and prescription.

PND50
PATIENTS’ INFORMATION SOURCES AND NEEDS IN MULTIPLE SCLEROSIS: THE INFOSEEK-MS QUESTIONNAIRE
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OBJECTIVES: Patients with multiple sclerosis (MS) are increasingly demanding access to reliable information regarding disease symptoms and management. High-quality information is a key factor in patient empowerment and shared decision-making. This research aimed to develop a self-administered questionnaire to characterize the information needs and preferred sources of information for MS patients in Spain. METHODS: A panel of experts (a neuropsychologist, a neurologist, a nurse, two research managers, a patient organization representative, and a psychometrist) was responsible for the proposal and agreement of all items contents and wording. After literature review for content extraction and thorough conceptual discussion, a 17-item version of the Infoseek-MS questionnaire was proposed. The instrument was pilot-tested in 15 MS patients (McDonald 2010 criteria) in order to assess feasibility, content validity, face validity, and item wording (including wording of items and response formats). RESULTS: The questionnaire was well accepted and most items were easy to understand. Mean response time was 14.4 ± 7.93min. The most frequently selected sources of information were the likelihood to read it (79%), either via mobile or desktop (78%), the most frequently reported types of information sought included healthy lifestyles (84.6%), sharing experiences with other MS patients (69.2%), and receiving information about treatments (61.5%). Neurologists and nurses were the most trusted source of information by the group overall. Physiotherapists and nurses were the most frequently consulted professionals on a monthly basis. Several items were revised after getting all the responses and comments from patients. CONCLUSIONS: The initial stage of content selection, item wording and response formats). The results of the logit model showed that the changes in the efficacy leads to the most changes in the patient utility. Changes in side effects and ease of injection have been placed in the next rankings. CONCLUSIONS: Considering the drug attributes considered more desirable by patients can lead to greater medication adherence and possibly better treatment outcomes. Also, pharmaceutical companies, the health ministry, the Food and Drug Administration, insurance organizations, and neurologists can benefit from this information in production and importation, policymaking, and prescription.

PND51
OBSTAINING TRADITIONAL & COMPLEMENTARY MEDICINE (T&CM) USE TO THE HEALTH CARE PROVIDERS: A QUALITATIVE STUDY AMONG THALASSEMIAS PATIENTS IN MALAYSIA
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OBJECTIVES: This study was carried out to discover the true thalassaemia patients have in disclosing their use of Traditional and Complementary Medicine (T&CM) to their health care providers. METHODS: Twenty-one patients with thalassaemia were recruited from the Thalassemia Society of Kedah, Malaysia from July to October 2019. The semi-structured interviews were audio-taped, transcribed verbatim and translated into English. RESULTS: Thematic analysis identified four themes from the interview analysis: the fear of the termination of provided treatment by the health care provider, the convenience of T&CM, the influence of T&CM use and the decision to disclose or not to disclose to the health care provider. The patients’ reasons for not disclosing T&CM use were more related to their trust in the health care provider. CONCLUSIONS: Future research will be insightful once thalassaemia patients have in disclosing their use of Traditional and Complementary Medicine (T&CM) to their health care providers.

PND52
REAL WORLD CHARACTERISTICS AND PERCEIVED EFFICACY OF PEGINTERFERON BETA-1A COMPARED WITH OTHER PLATFORM INJECTABLE THERAPIES AMONG MS PATIENTS: EVIDENCE FROM FIVE EUROPEAN COUNTRIES
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OBJECTIVES: Describe the demographic and disease characteristics of peginterferon beta-1a users in a real world, observational setting, and compared them with a means to improve quality of life of multiple sclerosis (MS) patients treated with peginterferon beta-1a versus other platform injectable therapies (IFN interferon beta-1a, SC interferon beta-1a, interferon beta-1b, glatiramer acetate) in five European countries. METHODS: In this retrospective study, cross-sectional data from 2014 to 2016 were obtained from Adelphi MS Disease Specific Program (III, IV, V). MS patients who received peginterferon beta-1a or other platform injectable therapies were identified. Descriptive analysis was conducted to examine patient characteristics, treatment patterns and patient reported outcomes. RESULTS: Sixty-five peginterferon beta-1a patients and 3,908 patients treated with other platform injectable therapies were identified and compared. MS patients on peginterferon beta-1a were slightly younger with a mean (SD) age of 36 (10.5) years vs. 38 (10.9) years (p = 0.05), respectively, and had a lower mean (SD) Expanded Disability Status Scale (EDSS) score of 1.7 (2.1) vs. 2.5 (1.5) (p = 0.0007), respectively. Sixty-five percent of identified patients considered efficacy “the most important reason in choosing treatment with peginterferon beta-1a patients were less likely to be treatment naive (58% vs. 80%, p < 0.0001). Compared with patients on other platform injectable therapies, patients on peginterferon beta-1a were less likely to report “lack of efficacy” as a current treatment issue, more likely to report a convenient administration profile and to have “less disruption to a patient’s life.” CONCLUSIONS: The average peginterferon beta-1a patient appears younger and with lower disability as compared to patients treated with other platform injectable therapies. Of patients receiving platform injectable therapy, efficacy is the most important reason for treatment choice, and identified patients rate peginterferon beta-1a as more convenient than other platform injectable therapies. Further research will be insightful once peginterferon beta-1a has been on market for a longer duration.

PND53
CONCEPTUAL MODEL AND INSTRUMENT REVIEW IN MULTIPLE SCLEROSIS
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OBJECTIVES: The objectives were to a) develop a preliminary conceptual model based on qualitative research in patients with multiple sclerosis (MS) and b) identify and evaluate commonly patient reported outcome measures (PROMs) in MS to improve quality of life (e.g., EuroQol Group, EQ-5D, and United States, United States (U.S.) Department of Health and Human Services, Office of Disease Prevention and Health Promotion, National Institute of Standards and Technology (NIST), and European Medicines Agency (EMA) labeling claims. METHODS: PubMed was searched to identify recent (since 2010) qualitative research studies in patients with MS as well as relevant PROMs (measures that are recommended for a selected subset of PROMs) was compared against the recommendations contained in the FDA PRO guidance. RESULTS: The PubMed search identified 3 qualitative studies focusing on key symptoms and impacts experienced by patients with MS. The three symptoms being fatigue, pain and walking, the other aspects such as stiffness, spasm, and difficulty walking, and balance problems. Based on these results, a preliminary conceptual model was developed displaying the relationship between the disease process, present factors, aggravating symptoms reported by patients, and the impact of MS. Nine PROMs were identified from the searches and live most