hospitals were collected. Double bootstrap data envelopment analysis was utilized to assess the technical efficiency of the centres where an input-oriented variable return to scale model was adopted. Bootstrap truncated regression was later conducted to identify the factors affecting the performance levels. ***Results:*** The average bias-corrected technical efficiency score was found to be 0.62 (SD=0.15). 13.3% thalassaemia treatment centres demonstrated good efficiency scores (0.8-1.0). Presence of multidiscipline specialized treatment team is found to positively influence the efficiency levels. In contrary, having longer operating hours did not improve the performance levels. ***Conclusions:*** This study provides primary baseline performance benchmark for public hospitals with thalassaemia treatment centres in Malaysia. The findings could also provide vital insights for policymakers and service managers for better resource allocation to ensure optimal healthcare delivery to thalassaemia patients in Malaysia.

Systemic Disorders/Conditions - Patient-Centered Research

PSY42
PATIENTS' AND HAEMATOLOGISTS' PREFERENCES ON IMMUNE THROMBOCYTOPENIA (ITP) TREATMENT ALTERNATIVES: A CONJOINT ANALYSIS

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Introduction: ITP treatments seek to reverse and prevent bleeding by maintaining a safe platelet count. Several treatment options exist but differences on probability of response or relapses and on safety profiles may impair adherence and affect the clinical benefit. ***Objectives:*** To assess haematologists' and patients' preferences for several attributes of ITP treatment alternatives. ***Methods:*** A cross-sectional study was conducted using conjoint analysis to determine the relative value for each attribute. A sample of 25 haematologists and 50 patients with ITP previously treated was aimed. Preference assessment included 16 hypothetical ITP treatment alternatives created using orthogonal design. Participants ranked treatment profiles from 1 (the most acceptable) to 16 (the least acceptable). Treatment attributes included: route and frequency of administration, clinical efficacy (treatment duration, response and relapses) and safety. ***Results:*** Preliminary results of the preferences of 22 haematologists and 32 patients who completed the study so far are presented. Both, the haematologists and ITP patients placed the greatest relative importance on the *route and frequency of administration* attribute (46.15% and 46.73%, respectively) followed by safety (28.51% and 29.62%, respectively) and efficacy (25.34% and 23.65%, respectively). For both populations, haematologists and ITP patients, the highest utility value was achieved by the *oral, daily* level within the attribute *route and frequency of administration*. Results revealed differences with regard to the efficacy utility values between both groups. ITP patient's utility values showed higher preferences for *long-term treatments with low probability of relapses* (0,54) while haematologists gave higher utility values to *short-term treatments with probability of relapses* (0,26). ***Conclusions:*** Patients' and haematologists' treatment preferences were mainly driven by the route and frequency of administration. Understanding which treatment characteristics are meaningful for patients may help haematologist to identify the best treatment alternative for their patients in the clinical practice setting.

PSY43
HEALTH STATE UTILITIES ASSOCIATED WITH SICKLE CELL DISEASE AND ITS TREATMENT: LITERATURE REVIEW

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Objectives: Sickle cell disease (SCD) typically requires lifelong comprehensive care and is associated with early mortality. The only available potentially curative therapy is allogeneic hematopoietic stem cell transplant with a matched sibling donor, recommended only for younger patients and limited by donor availability. As new treatments are introduced, cost-utility analyses (CUA) are required to understand their value. To conduct CUAs, appropriate and robust health state utility estimates are required. The purpose of this study was to review utilities representing SCD and its treatments. ***Methods:*** Two PubMed literature searches were conducted: (1) publications mentioning SCD and utilities or related terms; (2) publications on cost-utility analyses of treatments for SCD so that reference sections could be searched for additional sources. Abstracts were reviewed, and potentially relevant articles were obtained to assess eligibility. Information extracted from each eligible article included study type, utility assessment methods, sample characteristics, health states represented by utilities, and limitations. ***Results:*** The two searches yielded 124 and 24 abstracts, respectively. Eight of these references were relevant to SCD utilities. Three presented EQ-5D values for SCD. However, applicability of these values in CUAs is questionable because the populations had specific treatment characteristics that may not be generalizable to most patients. Also, the extent to which this generic instrument captures the burden of SCD and its treatment options is unknown. Two other references included CUAs based on estimates provided by two or three physicians, rather than utilities from patients or a preference-based task. Another two CUAs used utilities representing treatment approaches instead of SCD. The final article was a literature review with no additional primary sources of utilities. ***Conclusions:*** Utilities representing SCD are limited. Given the prevalence of this condition, utility values are needed to represent various aspects of the disease state in economic models examining the value of new treatments.

PSY44
ECONOMIC BURDEN OF MYALGIC ENCEPHALOMYELITIS/ CHRONIC FATIGUE SYNDROME (ME/CFS) TO PATIENTS: COMPARATIVE STUDY

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Objectives: Research is performed in framework of COST (European Cooperation in Science and Technology) Action 15111 EUROMENE (European Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Research Network) to investigate the opportunities for evaluation of economic impact of ME/CFS to patients. ***Methods:*** To achieve the objectives of this research, a study based on patient-reported survey has been carried out in Latvia, Italy and the United Kingdom (UK). The survey included questions concerning the socio-economic consequences of the disease, particularly regarding the health care costs. For data processing and analysis, the methods of economic analysis and statistical analysis are embraced. ***Results:*** In Latvia the survey has been launched with coverage of 100 patients (with dominance income of €500 per household member monthly). The results show that 1% of respondents spend more than €100 as an out-pocket payment for medicines and health care services monthly, 1.8% spend €51-100 for medicines, health care services and food supplements monthly, 17.2% spend €21-50, and 80% of respondents spend until €20 monthly to reduce the ME/CFS consequences. The study performed in Italy with 87 participants suffered by ME/CFS found that 23% were unemployed and 55% had an income less than €15.000 annually. Patients spend average €210 monthly on medication and therapy. A study conducted in the UK covered 262 patients with ME/CFS and healthy controls. The analysis shows marked lower economic well-being of people with ME/CFS in comparison with healthy controls. Average adjusted income for participants with CFS/ME was £12.242, but for healthy controls - £23.126. Considering the prevalence of ME/CFS in the UK population, the total cost of illness was estimated at £1.713 million per year. ***Conclusions:*** The patient-reported outcomes is a significant tool to collect the data for evaluation of socio-economic impact of ME/CFS, but for comparative studies the purchasing power parities should be taken into account.

PSY45
PATIENT-REPORTED OUTCOMES USED IN CLINICAL TRIALS OF SYSTEMIC LUPUS ERYTHEMATOSUS: A REVIEW OF SUITABILITY FOR FDA LABELLING CLAIMS

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Objectives: This review sought to identify patient-reported outcome (PRO) instruments that have been used in clinical trials of systemic lupus erythematosus (SLE) and examine their suitability for FDA labelling claims, based on proximity of the concept they measure to symptoms of SLE and evidence of content validity in SLE patients. ***Methods:*** A search was conducted on clinicaltrials.gov to identify PROs used as primary and/or secondary endpoints in SLE clinical trials. A literature review of identified PROs was then conducted, examining their structure, the concept they measure and evidence of content validity as per FDA standards, including involvement of SLE patients in instrument development. ***Results:*** 49 different PRO instruments, used across 129 trials, were identified. The majority (39) measured multi-dimensional constructs or distal concepts of disease, including health-related quality of life (HRQOL), impacts on mental function (depression, anxiety, stress, anger), cognition, physical activity, sleep, social functioning and work performance, as well as self-management/efficacy, coping strategies and global impression of change. 10 identified PROs measured proximal concepts/symptoms of disease, namely fatigue and pain. Out of all 49 instruments that were identified, only 4 PROs, all HRQOL instruments, were SLE-specific and three of those, the LupusQoL, LupusPro and SLEQOL, had satisfactory evidence of content validity. A further review of these three instruments revealed that only LupusQOL contained domains that measure well-defined and proximal concepts/symptoms of disease, namely pain and fatigue. ***Conclusions:*** Despite a considerable number of PROs that have been used in SLE clinical trials, only three instruments had satisfactory evidence of content validity in SLE patients in line with FDA standards. Only one of these instruments, the LupusOOL, contains domains measuring proximal concepts/symptoms of disease (pain and fatigue) that could be considered suitable for inclusion in endpoint models in SLE drug development with intended PRO-based labelling claims in the US.

PSY46
WORK PRODUCTIVITY LOSS IN PATIENTS WITH INFLAMMATORY ARTHRITIS

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Objectives: Limited data exist of work productivity loss in patients with Rheumatoid Arthritis (RA), Psoreatic Arthritis (PsA) and Spondyloarthritis (axSpA). The objective of this research was to assess productivity loss and absenteeism in patients with RA, PsA and axSpA. ***Methods:*** The study was designed as a cross-sectional study aimed to collect patient-reported outcomes from patients with RA, PsA and axSpA in Denmark via a nurse administered questionnaires and patient journals. Patients ≥18 years with RA, PsA or axSpA were consecutively recruited for the study over a 6-month period via routine visits to outpatient rheumatology clinics. Descriptive statistics were analyzed using SAS. ***Results:*** Of 488 respondents, 62% were women and mean age was 53.5 years (RA:57.4; PsA:52.6; axSpA:43.6). Average time since diagnosis was 11-15 years, however, for PsA and axSpA most patients answered 6-10 and 0-5 years, respectively. 280 (57%) answered that they had a job and completed the WPAI questionnaire (RA: 149 (51%); PsA: 48 (56%); axSpA: 83 (75%)). Average work hours was 31.9 in the last week (RA:31.2; PsA:33; axSpA:32.4). Average missed work hours were 4.3 in the last 7 days ((RA:4.0; PsA:4.2; axSpA:4.8), of which 32% was missed due to their inflammatory arthritis (RA:30%; PsA:38%; axSpA:32%). Mean absenteeism was highest for patients with PsA (mean=6.8; SD=17.7) followed by patients with axSpA (mean=5.4; SD=15.1) and with RA (mean=3.4; SD=12.2). Mean productivity loss was 20.5 (SD=23.8) for patients with RA, 27.6 (SD=25.8) for PsA and 26.3 (SD=25.8) for axSpA. ***Conclusions:*** We found that patients with PsA or axSpA miss more hours of work compared with patients with RA and when they are at work they have a higher absenteeism/lower productivity. This even though that both the group of patients with PsA and the axSpA were younger and had lived less time with their diagnosed disease compared with the group with RA.

PSY47
PATIENT-REPORTED OUTCOMES IN CHINESE ADULT RHEUMATOID ARTHRITIS PATIENTS: A SYSTEMATIC REVIEW AND META-ANALYSIS

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Objectives: To summarize the results of patient-reported outcome (PRO) and related instruments adopted in recent publications among Chinese adult rheumatoid arthritis (RA) patients. ***Methods:*** Articles published between 2016 to 2018 were systematically searched. Studies reported PRO results for Chinese adult RA patients separately were included. PRO measures were classified into health domains according to prior publications and European League Against Rheumatism (EULAR) outcome library. Meta-analysis was applied to pool the PROs using Stata 15.0 (StataCorp). ***Results:*** A total of 167 articles with 28,775 subjects of interests were included. In total, 103 PRO instruments were reported. The most commonly assessed health domains were pain (41.9%), physical function (40.1%) and morning stiffness (32.3%), while pain visual analogue scale (VAS) (36.5%), morning stiffness duration (MSD) (32.3%) and health assessment questionnaire (HAQ) (28.1%) were the most popular instruments. The mean (95%CI) pain VAS scores (0-10) at baseline, week 4, 8 and 12 were 5.7 (5.1-6.3), 3.6 (2.5-4.7), 3.7 (3.1-4.4) and 3.2 (2.2-4.2). The mean MSD (mins) was 93.6 (95%CI: 80.8-106.5) at baseline, and reduced to 42.0 and 42.3 at week 12 and 24, respectively. For HAQ (0-3), the mean (95% CI) values were 1.5 (1.0-2.1), 0.9 (0.6-1.3) and 0.4 (0.2-0.5) at baseline, week 12 and 24. Additionally, the mean (95%CI) patient global assessment VAS (0-10) scores were 6.0 (5.5-6.6) and 2.9 (2.3-3.6) at baseline and week 12. Fatigue VAS (0-10) was averagely 4.9 (95%CI: 3.9-5.9) at baseline. I^2 statistics for combined estimates above were > 90%. ***Conclusions:*** The health domains and PRO instruments were reported consistently to the recommendation. However, there were high heterogeneity among the PROs. Chinese RA patients were not satisfied on their health status at baseline, although improvements were shown after treatments. Further studies are needed to understand disease burden and explore effective ways to improve PROs among Chinese RA patients.

PSY48
DO CLINICAL AND DEMOGRAPHIC CHARACTERISTICS AFFECT PATIENT PREFERENCE HETEROGENEITY FOR PSORIASIS TREATMENTS? RESULTS FROM A DISCRETE-CHOICE EXPERIMENT IN A MULTICOUNTRY STUDY

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Objectives: Several therapeutic options exist for the treatment of plaque psoriasis and different patients may prefer different treatments. This study aimed to elicit patients' preferences for psoriasis treatments and to test whether patients with different characteristics have systematically different preferences. ***Methods:*** A discrete-choice experiment (DCE) was employed to elicit preferences of patients with plaque psoriasis in multiple countries. The survey instrument included a series of choice questions between three hypothetical treatments, each characterized by varying levels of six attributes: mode and frequency of application, time to reach clinically meaningful results, reduction in psoriasis lesions, reduction in itching, risk of moderate-to-severe side effects, and frequency and duration of the appearance of side effect. Random parameters logit was used to model the data. Results were compared across multiple subgroups defined by country, comorbidities, location of psoriasis plaques, body surface area, age, and marital status using a Wald test for systematic differences in preferences between subgroup. ***Results:*** The survey was completed by 1,123 respondents in Canada, France, Spain, Italy, and the United Kingdom (UK). On average, respondents preferred weekly tablets to other modes of administration. Preference for attributes with naturally ordered levels were ordered as expected (e.g. higher efficacy and lower side effects were preferred). In addition, we found significant differences between male and female ($P<0.001$), respondents from Italy or France compared to the UK ($P<0.001$), respondents with body surface area between 3% and 10% compared to less than 3% ($P=0.004$), as well as respondents with concomitant genital or nail psoriasis or psoriatic arthritis ($P<0.001$). There was no evidence of systematic differences between respondents with and without psoriasis on the face or in other subgroups considered. ***Conclusions:*** We identified systematic differences in preferences across multiple subgroups indicating that determining the appropriate psoriasis treatment may be informed by patient characteristics and their preferences.

PSY49
THE JOURNEY OF THALASSAEMIA PATIENT IN SEEKING TREATMENT IN MALAYSIAN HEALTHCARE

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Objectives: Thalassaemia patients in Malaysia largely seeks treatment in public healthcare facilities which are heavily funded by the government. This study aims to explore the journey of transfusion-dependent thalassaemia patients in seeking treatment in Malaysian public hospitals. ***Methods:*** A qualitative study using semi-structured interviews were conducted between July- September 2018 in five states in Malaysia to map the journey of thalassaemia patients in seeking treatment. Adult thalassaemia patients and caretakers of pediatric thalassaemia patients were recruited in seven public hospitals. Interviews were recorded with patients' written consent. Audio recordings were transcribed by different investigators and transcriptions were compared to ensure validity. Contents were then analysed to map patients' experiences to seek treatment. ***Results:*** A total of 23 participants were interviewed. All participants reported satisfactory access to initial diagnosis and treatment in public healthcare. 82.9% participants reported to having multiple visits to hospitals in a month for blood tests and transfusions causing loss of productivity and financial strain. Participants from rural areas reported difficulty having to take several modes of public transportation to reach the hospitals. Overcrowding in public hospitals put further strain in patients' adversity. ***Conclusions:*** This study reveals vital insight of patient's challenges in getting treatment in public hospitals. The findings suggest some correctional measures must be taken by service provider to ensure optimal healthcare delivery to thalassaemia patients in Malaysia.

PSY50
PATIENT PREFERENCES FOR PATIENT-CENTERED HEALTHCARE IN THE TREATMENT OF HEMOPHILIA: A BEST-WORST SCALING CASE 3

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Objectives: Hemophilia is a rare bleeding disorder which requires a complex diagnosis and management. The objective of this study was to assess patient preferences for alternative treatments, treatment-related benefits and risks in the therapy of hemophilia A. ***Methods:*** A literature search and pre-test interviews were conducted to determine the most relevant attributes in terms of effects, risks, and administration of a hemophilia A treatment. A Best-Worst Scaling (BWS) Case 3 approach with four attributes was applied: bleeding frequency per year, type of application, risk of thromboembolic events, development of inhibitors. The BWS was conducted between October 2018 and May 2019 using a fractional factorial design. Each respondent answered 13 choice tasks, including one dominant task, comparing three different treatment profiles. Data was analyzed using random-parameters logit models. ***Results:*** The preliminary analysis included N=49 patients (98.0% male). "Bleeding frequency per year" (Level Difference (LD): 7.833) and "development of inhibitors" (LD: 6.369) had the greatest impact on respondents' decisions. Patients disliked being at risk of inhibitor development more than being at risk of thromboembolic events (LD: 2.399). The type of application, either intravenous or subcutaneous, was of less importance (LD: 1.405). There was a significant preference variation for all attributes. All coefficients proved to be significantly different from zero at the level $p \leq 0.01$. ***Conclusions:*** This study identifies and weights key decision-making criteria for optimal management of hemophilia A from the perspective of patients. Patients value low frequency of bleeding per year and low risk of development of inhibitors higher than remaining attribute levels in the decision context of the study. An increase of risk and frequency would significantly decrease the impact on choice decisions. The application does not seem to influence the choice decision very much compared to the other attributes. Regarding preference heterogeneity, further analysis is needed to identify subgroups among patients and their characteristics.