

bursement status and availability of top 20 orphan drugs in Slovakia from 2005 till 2012. Data were obtained from government sources. **RESULTS:** We considered orphan drugs list (Cote and Keating, 2012) that exceeded 1 billion \$ sales in 2008 (globally) and compared molecules' availability in Slovakia. Same molecules are among best selling 20 orphan drugs in Slovakia, with highest sale of 95 million EUR (Bevacizumab, 2005-2012) compared to lowest sale of 19 million EUR (Tacrolimus, 2005-2012). It took from 1 (Imatinib) to 19 years (Glatiramer acetate) to be launched in Slovakia after orphan designation. Top 20 orphan drugs had average DOT 472 EUR compared to total pharma market DOT average 0,43 EUR. From selected orphan drugs 60% had full (100%) reimbursement status and 40% were fully covered by hospital budgets. Only 4 of them were launched in Slovakia since 2005 (included), 16 of them were launched from 1990 till 2004. Prices ranged from 330 EUR to 5800 EUR (ex-factory, one package, 2012). **CONCLUSIONS:** There are highly valuable incentives for industry to invest in to development of orphan drugs in EU. Current context of economic constraints in EU however justifies the need to pay close attention to the rationale of maintaining such incentives in the context of potential return on investments of companies offering high priced drugs. Top 20 orphan drugs in Slovakia have prices high above average and also full reimbursement status. We expect more restrictive drug policy measures in this field.

PSY109

EFFECT OF EXCLUDING NON-PATIENT BENEFITS AS AN ELEMENT ON ACMG NEWBORN SCREENING (NBS) RECOMMENDATIONS

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OBJECTIVES: In 2006 the American College of Medical Genetics (ACMG) developed a stakeholder survey to make recommendations for 84 rare conditions to be considered for mandatory newborn screening (NBS). Scores of 19 different surveyed attributes for each condition were totaled. These scores determined an entry point to an algorithm (EPA) that determined final recommendations (Core conditions, Secondary Targets or Not Recommended). Among these attributes was a controversial one - non-patient benefits (NPB). Such attributes have historically not been considered in mandatory screening recommendations. This analysis examines how the exclusion of this attribute would affect recommendations. **METHODS:** The ACMG report provided scores for individual attribute survey responses. We deleted the attribute score for NPB (0 to 100 points) and rescored the totals for each condition. We then assessed whether score changes were sufficient to alter the EPA and whether a different EPA would result in changes to the recommendations. **RESULTS:** Six conditions had missing data. Of the 78 remaining, there were 15 conditions (19%) whose initial total scores were capable of changing by enough in this exercise (maximum 100 point reduction) to change the EPA. Of those, 10 (67%) did change EPA and, of those, 3 (30%) changed final category (in all cases from Core to ST). Of the initial 29 recommended Core conditions, there would be a 10 percent reduction to 26 and an increase in Secondary Targets from 25 to 28. **CONCLUSIONS:** Including screening benefits to non-patients (family or society) is controversial and has not been standard in the past. We have shown that in the ACMG recommendations, had no changes been made to the algorithm consequent to dropping non-patient benefits from consideration, 3 conditions would have changed from a Core recommendation for screening to only a Secondary Target.

PSY110

ACCESS TO ORPHAN DRUGS IN GREECE DURING ECONOMIC CRISIS

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OBJECTIVES: Orphan Drugs (ODs) are medicinal products intended for diagnosis, prevention or treatment of rare diseases. Access to ODs is crucial for patients' health and quality of life. The aim of this study was to identify current problems and future challenges of patients' access to ODs in Greece. **METHODS:** A qualitative study took place between December 2013 and January 2014. Data were retrieved through semi-structured interviews with six representatives of key stakeholders in Greece and policy documents identified through web searches using keywords "orphan drugs" and "rare diseases" in Greek. Web-based documents and transcribed interviews were content analyzed. **RESULTS:** Delays in pricing and reimbursement of ODs in the Greek pharmaceutical market, budget cuts in hospitals and absence of patient registries constitute according to the analysis the greatest barriers in patients' access to ODs. There are two main channels through which the patient can have access to an OD and it depends whether it is licensed in Greece or not. In the first case the patient can take the drug through the hospital or the pharmacy of EOPYY if it is not available at the hospital pharmacy and in the second case through a public sector organization (IFET). All cases are characterized by extensive bureaucracy and involvement of up to three organizations in order to receive the approval, a procedure creating delays in patients' access and risking their health. Also, the absence of a well-described procedure and lack of cooperation between the organizations and committees create further delays. **CONCLUSIONS:** Ensuring patients' access to ODs in Greece is challenging especially during the economic crisis. Financial constraints and continuous legislative changes in the health system and the pharmaceutical market constitute important barriers to patients' access. There is a need to describe, organize and communicate the pathway of patients' access to ODs.

PSY111

SELF REPORTED HEALTH CARE RESOURCE USE AND INDIRECT ECONOMIC BURDEN OF OPIOID INDUCED CONSTIPATION (OIC)

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OBJECTIVES: To describe the health care resource utilization associated with the diagnosis, treatment, and general management of opioid-induced constipation (OIC)

and events attributed to OIC including the negative impact on job-related activities. **METHODS:** A prospective longitudinal study conducted in the United States (US), Canada (CN), UK (UK), and Germany (GE) of patients with OIC who have been on opioid therapy for at least four weeks was conducted. OIC related medical history and health care resource use was collected from participants self report. The number of hours missed from work and the extent to which the work productivity and regular daily activities were affected was collected using the WPAI-SHP. **RESULTS:** A total of 489 eligible participants (US: 238; CN: 38; GE: 115; UK: 98). Back pain (77%) and joint pain (52%) were the most common pain diagnosis with an average duration of chronic pain and opioid medication use of 10 and 6 years respectively. 27% of participants were currently employed. 18% of participants used at least one prescription laxative; 70% reported using at least one over-the-counter (OTC) laxative with the most common being stimulant laxatives (20%), osmotic laxatives (15%) and stool softeners (7%). 63% of participants reported discussing OIC with a health care provider, 3.0% reported a visit to the emergency room and 2.0% reported being admitted to a hospital because of their OIC during a 6-month time period. 9% of employed participants reported missing an average of 4.6 hours per week because of problems associated with constipation and 32% reported impairment while working due to constipation. **CONCLUSIONS:** The cumulative impact of OTC use, physician office visits and the negative impact on work-related activities for OIC may be substantial.

PSY112

HEALTH CARE UTILISATION AND SELECTED EXPENDITURES ASSOCIATED WITH NEUROBLASTOMA IN ENGLAND

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OBJECTIVES: Neuroblastoma (NB) is a rare cancer of childhood, with nearly 90% of cases diagnosed by age 5 (ACS 2013). Our objective was to report the utilisation and cost of hospital services related to patients who have a diagnosis of NB and High Risk NB (HRNB) reported in an England dataset from a Clinical Commissioning Group (CCG) perspective. **METHODS:** We used an England dataset covering hospital events (April 2010 - September 2013). Patients were included if they were under age 18 and had a hospital event with a primary or secondary diagnosis coded as International Classification of Disease 10th Edition (ICD10) C749. Newly diagnosed patients were identified if they had no hospital events in the first 4 months of the study period. From this newly diagnosed cohort we identified a HRNB cohort (bone marrow transplant) that included patients who had a high risk procedure that did not occur in the last 12 months of the study period. Cost and utilisation is reported from hospital admissions, emergency department visits, and outpatient attendances. **RESULTS:** We observed 336 patients as newly diagnosed and an additional 33 patients were identified as HRNB. Newly diagnosed population inpatient admits were 12 per patient, compared with 22 per patient for the HRNB population. Total costs associated with the 336 newly diagnosed patients were £24.3m. Total costs associated with the 33 HRNB patients were £4.3m. Costs per HRNB patient (£130,303) were almost double the costs per newly diagnosed patient (£72,321). The average length of stay was 6 days for both sets of patients. **CONCLUSIONS:** To our knowledge this is the first retrospective analysis of NB cost and utilisation using encounter data from England. While it does not capture the entire costs to the England health care system, it indicates the level of resource intensity and cost at the CCG level.

PSY113

DATABASE ANALYSIS ON PATIENTS USING IMMUNOBIOLOGICAL DRUGS IN A BRAZILIAN PRIVATE HEALTH CARE PLAN: A REAL WORLD DATA ANALYSIS

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OBJECTIVES: Patients' profile undergoing intravenous immunobiological treatment is very limited. This study aimed to describe this information from the perspective of a Brazilian health plan, located in Fortaleza. **METHODS:** This was a cross sectional study with data obtained from the HMO database as presented by Reis H et al at ISPOR 18th Annual Meeting. Eligible criteria for data analysis were patients being treated for rheumatoid arthritis (RA), ankylosing spondylitis (AS), psoriatic arthritis (PsA) or Crohn's disease (CD) who have received at least one dose of immunobiological drug between March/2012 and October/2013. Data was stratified by indication (RA, AS, PsA and CD), patient weight and treatment profile (naïve versus non-naïve patients). **RESULTS:** A total of 118 patients had been analyzed, with an average age of 51 years, and 66.9% (n = 79) of them being women. RA (n = 53,44,9%) and AS (n = 49,41,5%) were the most prevalent diseases being treated, followed by PsA (n = 13,11%) and CD (n = 3,2, 5%). The average weight of patients varied according to the disease being treated: 67 kg for RA and CD, and 70 kg for AS and PsA. It was observed that 65.5% patients were naïve to immunobiological drug, of which 73% initiated treatment with an anti-TNFa, being infliximab the most commonly prescribed one (85.2%). As for patients who had already been previously treated, golimumab and abatacept were the most commonly prescribed drugs (23%), whereas 48.7% out of total were receiving the third immunobiological drug and 35.9% were receiving the second one. **CONCLUSIONS:** The knowledge of patients profile and treatment information is the basis for any planning strategy in an HMO. Associated with costs, this data is crucial in supporting HMO board decisions on best treatment alternatives and so optimize the provided care.

PSY114

MULTI-CRITERIA DECISION ANALYSIS FOR REIMBURSING ORPHAN DRUGS: A DUTCH DEMONSTRATION STUDY USING THE ANALYTIC HIERARCHY PROCESS METHOD

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