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 Kestig, 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 15 million EUR (Tacrolimus, 2005-2012). It took from 1 (matinib) to 19 years (Glatteracite) to be launched in Slovakia after orphan designation. Top 20 orphan drugs had average DOT 472 EUR or less and their market DOT 43% of 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: These 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 rationing mechanism that incentivizes innovation and improvements of companies of 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.

PSY110 EFFECT OF EXCLUDING NON-PATIENT BENEFITS AS AN ELEMENT ON ACGM NEWBORN SCREENING (NBS) RECOMMENDATIONS
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OBJECTIVES: In 2006 the American College of Medical Genetics (ACMG) developed a stakeholder survey to take 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 the list of conditions that were determined for High Priority Screening (High Priority Screening or Primary) and Secondary Targets or Not Recommended. Among these attributes was a controversial one - non-patient benefits (NPP). Such attributes have historically not been considered during newborn screening recommendations because of concern over the reservation of these incentives for industry. If the exclusion of this attribute would affect recommendations.
METHODS: The ACGM report provided scores for individual attribute survey responses. We deleted the attribute score for NPB (0 to 100 points) and restored 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 the 10, 67% did change EPA and, of those, 3 (30%) changed final category (in all cases from Core to ST). Of the 29 recommended Core conditions, there would be a 10 percent reduction in 12 cases. The EPA decreased in 4 cases. Total 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 ACGM 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.

PSY111 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 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 2012 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 EOPYYF if it is not available at the hospital pharmacy and in the second case through a public sector organization (GTEF). All cases are characterized by excessive 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 among 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 costs changes in 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.

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 costs of patients with NB at diagnosis, and during follow up and with the most common being stimulant laxatives (20%), omnicef laxatives (15%) and stool softeners (7%). 63% of patients reported discussing OIC with a health care provider, 3% reported a visit to the emergency room and 2.0% reported being hospitalised due to their OIC. During a 6-month time period 9% of employed patients reported missing an average of 4.6 hours per week due to adverse constipation and 32% reported impaired work while working due to constipation. CONCLUSIONS: The cumulative impact of OIC on work office and the negative impact on work-related activities for OIC may be substantial.

PSY113 DATABASE ANALYSIS ON PATIENTS USING IMMUNOLOGICAL DRUGS IN A BRAZILIAN PRIVATE HEALTH CARE PLAN: A REAL WORLD DATA ANALYSIS
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OBJECTIVES: Patients’ profile undergoing intravenous immunological 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%), 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 treated, golimumab and abatacept were the most commonly prescribed drugs (23%), whereas 48.7% of total were receiving the third immunobiological drug and 35.9% were receiving it for the second time. 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.