

POSTER SESSION III

HEALTH CARE USE & POLICY STUDIES – Consumer Role in Health Care

ORPHAN DRUGS: DOES SOCIETY VALUE RARITY?

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OBJECTIVES: A general societal preference for prioritizing treatment of rare diseases over common ones could provide a justification for accepting higher cost-effectiveness thresholds for orphan drugs. We attempt to determine whether such a preference exists. **METHODS:** We surveyed a random sample of 1547 Norwegians aged 40–67. Respondents chose between funding treatment for a rare versus common disease and completed a person trade-off (PTO) exercise between the diseases for each of two scenarios: 1) identical per person costs, and 2) higher costs for the rare disease. Diseases were described identically with the exception of prevalence. Respondents were randomized to either no information or different amounts of information about disease severity (severe vs. moderate) and expected benefits of treatment (high vs. low). All respondents rated five statements concerning equity attitudes on a Likert-scale. **RESULTS:** A total of 68% of respondents agreed completely with the statement “rare disease patients should have equal right to treatment regardless of costs.” Faced with trade-offs, 11.3% of respondents favored treating the rare disease, 24.9% the common disease and 64.8% expressed indifference. When the rare disease entailed a higher opportunity cost, results were 7.4%, 45.3% and 47.3%, respectively. Framing (“extra funding” vs. “replace patients”) and amount of information about severity and treatment effectiveness had a small impact on preferences. **CONCLUSIONS:** Although there is strong support for general statements expressing a desire for equal treatment rights for rare disease patients, that support evaporates when individuals are faced with opportunity costs.

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THE HTA PUZZLE: VALUES, PRIORITIES, TECHNOLOGY AFFORDABILITY, AND PATIENT AND COMMUNITY PREFERENCES. HOW CAN WE MAKE IT LL FIT TOGETHER?

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OBJECTIVES: This research considers how mature health technology assessment (HTA) systems incorporate patient and community preferences and priorities into decision-making processes. This presentation examines the policy rationale for increased patient and community involvement, as well as providing case studies to illustrate different approaches to community focused HTA practices. Effective options for patient and community engagement will also be covered. **METHODS:** Qualitative semi-structured interviews with key stakeholders in six developed countries: Australia, Canada, England, France, Germany, and Scotland. A literature review was also undertaken to assess current HTA systems across the six countries. **RESULTS:** There was significant variation across countries in terms of implementation, organization, and prioritization. This study revealed two different, but parallel, considerations that are important in HTAs: The ‘consumer perspective’ offers insight into variations in health outcomes of technologies being assessed, as well as providing detail beyond what is captured by QALY assessments in relation to community values, preferences, and priorities. Secondly, the ‘community perspective’ takes a broader societal approach to examine values, access, use, affordability of new technologies. **CONCLUSIONS:** An understanding of these two ‘HTA puzzle pieces’ is required for the establishment of governance and participation processes that will enable well defined consumer and community roles in HTA, and will lead to more systematic approaches to the integration of patient perspectives. Findings from this research suggest there is a strong need to consider a wider perspective of patient engagement in health policy and delivery, of which HTA is but one part.

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THE VALUE OF PATIENT PERSPECTIVES IN THE DRUG DEVELOPMENT LIFECYCLE

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OBJECTIVES: Research was undertaken to determine the impact and value of soliciting patient viewpoints at key stages within the drug development lifecycle. **METHODS:** Interviews were held with representatives from the biopharmaceutical, regulatory and pricing and reimbursement sectors to identify the value and impact attributed to patient perspectives. Additionally, surveys of European patient organizations and patients with airways disease provided insight into their attempts to influence treatment decisions, which could affect market uptake. **RESULTS:** Industry engagement with patients was often reactive and linked to the identification of factors which may impact on the success of a product. Earlier consultation may help the biopharmaceutical industry to optimise product development or assist key go/no-go decisions. Whilst there is a harmonised regulatory process that engages patient organizations through the European Medicines Agency, patient viewpoints or quality of life data seldom influence access or pricing and reimbursement decisions in the main European markets. Numerous examples were cited where this has led to political lobbying and emotive decision making and a more transparent process involving patients may help

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to ensure decisions are based on clinical and cost-effectiveness. Involving patients in the drug development lifecycle has the potential to improve health outcomes and reduce health expenditure associated with poor management, often related to non-compliance. The earlier patients are involved, the greater the potential to avert or minimise factors that could affect commercial success and return on investment. **CONCLUSIONS:** For the biopharmaceutical industry, the value of patient perspectives lies as part of a risk-mitigation strategy to provide greater insight and control over factors that affect market success. For regulators and payers, the value lies in the potential to improve health outcomes and reduce health care budgets.

PHP4

POST HEALTH CARE REFORM PERCEPTIONS IN THE US: CONSUMER PULSE SURVEY

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OBJECTIVES: In March 2010, President Barak Obama signed the Patient Protection and Affordable Care Act (PPACA), which radically changed the health care landscape in the United States. We carried out a survey to gauge consumers’ opinion about the U.S. health care system after the PPACA was signed into the U.S. law. **METHODS:** We commissioned Harris Interactive to conduct a nationally representative telephone survey of 1,019 adults from the U.S. between May 21–24. Respondents were questioned on their current insurance coverage status, their knowledge about the PPACA, and their perception of the reform. Data were weighted to be representative of the total U.S. adult population in terms of age, sex, geographic region and race. The survey has a sampling error of $\pm 3\%$ at 95% confidence level. **RESULTS:** 84% of all adults surveyed have an health insurance; 96% of adults 65 years old and above have health insurance. Overall, while 36% of all adults surveyed think they will be “better off” as a result of the reform; 43% think they will become “worse off”. 61% of respondents said they are “very knowledgeable” or “somewhat knowledgeable” about the PPACA; 54% of adults surveyed who rated themselves as “very knowledgeable” think they will be “worse off” as a result of the bill. Adults surveyed anticipate an increase in tax (76%), hospital and physician prices (65%), health insurance cost (65%) and cost of medications (54%). **CONCLUSIONS:** According to the survey, while the majority of consumers are satisfied with their current health care coverage, many have concerns about potential changes from PPACA. Concerns include health insurance coverage, access to quality health care and potential cost increase. In addition, the majority of consumers said that they are at least somewhat knowledgeable about PPACA.

HEALTH CARE USE & POLICY STUDIES – Diagnosis Related Group

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PATIENT DISCHARGE FROM INTENSIVE CARE UNITS WITHIN AND BETWEEN HOSPITALS IN HUNGARY

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OBJECTIVES: In our earlier study we found that measured by the number of cases (patients), the market share of intensive therapy was analyzed in Hungary and was found between 0.84% and 1.80% during a 14-year period (1995–2008). The discharge of patient not needing intensive therapy is obligated. The aim of the study was to analyze patient discharge. **METHODS:** Data were derived from the National Health Insurance Fund Administration. The two types of patient discharge were analyzed during a 9-year period, the discharges from intensive care unit within the same hospital and between different hospitals from 2000 to 2008. **RESULTS:** Compared to the total discharges the within and between hospitals discharges changed between 70.6% (2000) and 77.3% (2005) during the 9 years (2000–2008). Within hospital discharge started from 65.2% (2000) and the highest value was 73.0% (2006). Between hospitals discharged changed between 2.9% (2006) and 5.4% (2000). The sum of the two types discharge steadily increased from 70.6% (2000) to 77.3% (2005) in the first 6 years and after a linear descending it finished on 74.7% in 2008. Within hospital discharge increased from 65.2% (2000) to 73.0% (2006) and decrease to 69.6% until 2008. Between hospitals discharges decreased from 5.4% (2000) to 4.3% (2001), but it were steady from 2002 to 2005 (4.5%–4.8%). In 2006 a sudden decrease happened to 2.9% and after it the values were 3.3%–3.2% in the last 2 years. The mean of the within hospital discharges were 70.5% while the between hospitals discharges were 4.2%. **CONCLUSIONS:** In Hungary between 2000 and 2008 the discharges of the patients from the intensive care units to other hospital departments were 70.5%. The majority (94.38%) of the discharged patients was treated in the same hospital and only a minor proportion (5.62%) were moved to other hospitals.