several sources of real world data available to researchers. METHODS: We compare and contrast the pros and cons of data available from administrative (payment) databases, electronic medical record (EMR) databases, and surveys. RESULTS: Administrative claims databases provide fully-integrated, all-encounter patient data on diagnoses, procedures, and payments. However, data quality varies depending upon whether particular fields are required for provider payment. Data on lab and test values are typically lacking. Prescriptions that are written, but not filled by the patient, are usually not captured. Medical record data overlap, to a certain extent, with administrative data. While information on payments for services may not be included, detailed information on test results and lab values are usually captured in the EMR. Data are included on written prescriptions, but the researcher will not know whether the prescription was filled by the patient. Depending upon the clinical system covered, only some encounters (e.g., ambulatory care in the outpatient setting) may be available. Both administrative and EMR data hold the potential to provide rich patient information that is not subject to recall or social desirability biases that often affect survey data. However, information on satisfaction with care, quality of life, activities of daily living, and many other metrics, may only be captured with survey data. CONCLUSIONS: Several sources of rich, longitudinal patient data are available to provide real world evidence on drug effectiveness and cost. In some cases, data may be combined to overcome limitations of a single source. With care, data may be found that will produce generalizable findings for the population of interest.

PM34 ROUTINE DATA IN HTA: RECORD LINKAGE IN AUSTRIAS GAP-DRG DATABASE
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OBJECTIVES: Gathering data tends to be an expensive and time consuming task. During the IFEDH research project different methods for using routine data on models in HTA were discussed, improved and developed. Connecting a rich dataset from Austria inpatient sector lacking patient identifiers and (kind of) personalized but sparse records from the outpatient sector provided by different social security institutions is the objective of this project. A detailed description of the setup and usage of the results were presented at the SHIP Conference 2011 in St. Andrews (http://www.scot-ship.ac.uk/conference-2011) and the International Data Linkage Conference 2012 in Perth (http://www.datalinkage2012.com.au). METHODS: Documentation of prior processing and information of the provided data were not fully available. Furthermore, conditions of data quality and the presence of possible duplicates result in technical and contextual challenges. After preprocessing, data quality assessment and other preparations, a deterministic record linkage approach was developed using a combination of the open and freely available statistical environment R and PostgreSQL database. Based on dynamically created SQL statements and extensive logging, the linkage process can be enhanced easily if new knowledge about the input data gets available. RESULTS: The resulting linked dataset provides high quality and immediately available information. Additionally the deterministic linkage process can be examined and understood by its users. Therefore linkage and data errors are identified easily and feedback can be used to enhance the overall result. These experiences also lay the foundation for more advanced linkage methods and further improvements. CONCLUSIONS: After the long and challenging way from the first data import to a functioning data collection, all functions can be used in different projects with low costs and users confidence.

PM35 PREVALENCE OF RARE DISEASES – A SPECIAL CHALLENGE FOR BENEFIT ASSESSMENT AND HEALTH ECONOMICS
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OBJECTIVES: With introduction of AMNOG legislation, the pharmaceutical companies must submit a dossier when launching new drugs. The dossier must include an estimate of number of patients to be treated. This is particularly challenging in case of rare diseases, as shown with transthyretin-type familial amyloid polyneuropathy (TTR-FAP). METHODS: Several sources were used for a comprehensive gathering of information. Apart from systematic literature research, incidence data was searched by internet research and within patient registries. Since current therapy of choice is liver transplantation, the German Organ Transplantation Foundation was consulted regarding frequency of liver transplantation in connection with TTR-FAP. Assuming all patients are immediately placed on a waiting list after diagnosis, the number of annually performed surgeries was equaled with the incidence of the TTR-FAP. Results of this research were compared to billing data of a national statutory health insurance. RESULTS: Given its European prevalence of approx. 1/1,100,000, TTR-FAP is an ultra-orphan-disease. For endemic regions approx. 1/1,100,000, TTR-FAP is an ultra-orphan-disease. For endemic regions, prevalence estimates are improved with the addition of different sources of real world data available to researchers. METHODS: We compare

INTRODUCTORY OUTCOME AND QUALITY OF LIFE INSTRUMENTS DATABASE (PROQOLID): EVOLUTION OF CONTENT, STRUCTURE, AND FUNCTIONALITIES (2002-2012)
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OBJECTIVES: PROQOLID was developed in 2002 to provide all those involved in health care evaluation with a comprehensive and unique source of information on Patient-Reported Outcome (PRO) and Health-Related Quality of Life (HRQL) measures. The aim of this study is to review the evolution of content, structure, and functionalities of PROQOLID since 2002. METHODS: The archives of PROQOLID were searched to retrieve the database just before its launch and to compare its content and structure as it was in April 2012. RESULTS: The first database, then known as QOLID, was retrieved. It included 313 instruments (24 generic and 114 specific), with an increase of almost 40 instruments each year (up by 401 in 10 years). Instruments specific to nervous system diseases are the most frequent (141), reflecting the evolution in the field (e.g., 76.7% of the neurological products authorized by the EMA have been approved since 2003). The database displayed for each instrument has been enriched with the addition of translatable questionnaires. Thus, we provide a database of descriptive information, content validity documentation, measurement properties, references, and websites. In January 2005 the database was renamed PROQOLID to reflect the wider use of the term PRO. In April 2012, a new Google application was created that allows users to perform searches with keywords. Currently, only 5% of users will have more information about instruments distributed by MAPI Research Trust. CONCLUSIONS: In just over 10 years, the PROQOLID database has considerably evolved in content and structure, and offers a range of information and services adapted to the evolution of the field.

PM36 DIRECT IDENTIFICATION OF PAYER PERCEPTIONS THROUGH RETROSPECTIVE ANALYSIS OF INTERVIEW WRITE-UPS
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OBJECTIVES: As part of conducting projects IMSCC performs >5000 payer interviews p.a. Interview analysis is typically focused on insights directly related to research objectives. However, often respondents provide perceptions/ unprompted insights unrelated to research objectives, which have never been analysed before. The objective was to test whether information obtained from unprompted payer responses in interview write-ups can be identified and analysed, to develop insights of payer perceptions of pharma and their impact on payer decisions. METHODS: We selected 100 projects performed 2008-2011 including double blinded interviews with national/regional payers/advisors, advising in English in the IMSCC project database. Interviews were screened for quotes reflecting perceptions of pharma unrelated to the research objective. Only unprompted expressions were extracted and buzz-words created that allowed compression into a single word/phrase. Buzz-words were valued and categorized into perception clusters. RESULTS: A total of 614 specific quotes, 53% unprompted, were mapped separately. Respondents’ function and geography were interlinked with the information. PERCEPTIONS: We identified 543 interviews including 900 quotes with unprompted expressions of perceptions in 1900 buzz-words. Distribution of unprompted expressions of perceptions in interviews was equal between national/regional payers, but 80% of quotes came from regional payers. Top5 EU accounted for majority of quotes. Company specific and industry perceptions were evenly split. Data allows a variety of perception analysis: national vs. regional payer, pharma vs. company, company perceptions of national vs. regional payers. Perception clusters identify the cause of perceptions. Analysis of the impact of perception on payer decisions is feasible, based on 5% of overall quotes. CONCLUSIONS: The data allows a structured analysis of unprompted expressions of payer perceptions in retrospective research. Database processing is ongoing to derive in the future statistically significant answers related to the impact of perception on decisions and what these perceptions are based upon.

PM38 ESTIMATION OF A MARKOV CHAIN FOR CROHN’S DISEASE AND CLASSIFICATION OF PATIENTS INTO DISEASE PHENOTYPES, IN EIGHT COUNTRIES USING INDIVIDUAL LONGITUDINAL DATA AGGREGATED OVER TIME
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