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 based on written prescriptions, but the research data don’t 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 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.

PRM34 ROUTINE DATA IN HTA: RECORD LINKAGE IN AUSTRIAN GAP-DRG DATABASE
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OBJECTIVES: Gathering data tends to be an expensive and time consuming task. During the IFEDH (International Federation of the Evaluation of Medical Health Care) project different survey methods were used for obtaining data. Data on models in HTA were discussed, improved and developed. Connecting a rich dataset from Austrian inpatient sector lacking patient identifiers and (kind of) personalized but sparse records from the outpatient sector provided by different social security institutions that are part 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 and also questionable data quality and the presence of possible duplicates result in technical and contextual challenges. After prepossessing, 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, adequate information can now be used in different projects with low costs and users confidence.

PRM35 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-rare-disease. For endemic regions (Sweden, Portugal) the disease is well captured. For Germany, comparable published data is available. 5 national treatment centers were identified that document their patients in various registers, reflecting an incidence of about 7 surgeries per year. According to the German Organ Transplantation Foundation, in average 6 new TTR-FAP patients per annum were added to the waiting list, confirming the estimate of the incidence derived from registries. Domino transplantation is usual in TTR-FAP with an average of 6.5 domino transplantations p.a. – validating the estimate of an incidence of 6 – 7 patients per year. Billing data reflects an estimated prevalence between 0.6 and 1.4/100,000. CONCLUSIONS: Data on the prevalence of rare diseases frequently is not available or very unreliable. Different sources produce strongly varying results due to several reasons. This must be taken into account when assessing the number of patients in the value dossiers for new drugs.

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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 (HRQoL) measures. Methods for deriving information on satisfaction, setting) may be available. Both administrative and EMR data hold the potential to provide rich 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.