There are several approaches and methods for identifying ND, ranging from the very detailed and deep ascertainment of the pathology in an individual, to a brief and broad standard assessment emphasizing individual functioning (Launer 2011). These measurements not only differ in their validity and reliability, but may also lead to different estimates of the prevalence and incidence of ND. The purpose of the research being conducted determines the assessment approach. If the aim is to better understand the etiology of ND, to identify risk factors, and to predict who will suffer from the disease based on individual's specific characteristics, then a deep phenotyping based on neuropsychological tests, biomarkers, and MRT and PET scans is necessary. If, however, the aim is to determine the prevalence and incidence of the disease for the purposes of general health planning and related activities, a broad approach is sufficient (Launer 2011). As detailed phenotyping is cost-intensive, usually only a limited number of individuals are enrolled in these studies. Thus, the estimates suffer from large standard errors and are imprecise, particularly at older ages. The broad approach to assessing NDs permits the inclusion of large numbers of people, sometimes even the total population, and provides a better understanding of the occurrence of the disease; it cannot, however, provide information about etiology.

In Germany, claims data from the German statutory health insurance system constitute a secondary data source that contains information about the assessment of ND. These data document reimbursements of medical doctors by public health insurers. The data cover the total population insured under the statutory health insurance system, who represent 86% of the total German population; or they stem from a particular health insurer. The data include all insured individuals, regardless of whether they received any medical treatment in a given quarter. Information about diagnosis and treatment is available at the individual level, and can be followed longitudinally based on an anonymized personal identification number. The data are not restricted to people who live in the community, as they also include people who live in institutions.

These claims data do, however, have some important limitations. Unlike for population-based epidemiologic and clinical research, there is no connection to the research question at the time of data collection. There are no clinical data on, for example, the severity of the disease; and the validity of diagnoses is not fully given. Furthermore, routine data are subject to legal changes and to international changes in the data-handling procedures of the health insurers. Therefore, an internal validation of the diagnoses is required. At present, there are no options for validating claims data externally, except for comparing the estimated prevalence and incidence with results from other national and international studies. Following the latter approach, German health insurance claims data have been proven to be a suitable source for epidemiologic research, especially for providing a general picture of the occurrence of dementia (Ziegler & Doblhammer 2009; Ziegler 2011; Doblhammer et al. 2012). The following figures compare prevalence and incidence rates based on claims data from health insurers with results from international studies.

Gabriele Doblhammer, Anne Fink
Fig. 1: Comparison of the prevalence of dementia from different studies. Source: Ziegler 2011, Doblhammer et al. 2012, NeuroDiseaseMonitor.

[Graph showing the prevalence of dementia in different age groups (65-69, 70-74) across various studies such as Bickel, Lopes & B, EuroCoDe, Hofmann, Frattigioni, Jorm 1981, Ziegler 20.]

http://www.dzne.de/forschung/forschungsbereiche/populationsforschung/neurodiseasemonitor/health-claims-data.html?print=1
References


Fig. 2: Comparison of incidence rates of dementia from different studies. Source: Ziegler 2011, Doblhammer et al. 2012, NeuroDiseaseMonitor.