Challenges of missing specific disease codes – Estimating incidence and prevalence of primary immunoglobulin A nephropathy (IgAN) using health insurance claims data

EPH52

Timotheus Stremel[1], Matthias Roll[2], Dr. Amadeus Gladbach[2], Isabella Selinger[2], Dr. Thomas Hardt[2], Helena Himmelhaus[1], Dr. Christian Jacob[1], Julia Theil[1], Prof. Dr. med. Jürgen Floege[3]

[1]Xcenda GmbH, part of Cencora Inc., Hannover, Germany; [2]CSL Vifor, Munich, Germany; [3]Universitätsklinikum Aachen, Aachen, Germany

Background

- Claims data from Statutory Health Insurers (SHI) are a valuable resource: they provide extensive and diverse information on patient demographics, diagnoses, treatments and healthcare utilization, making them indispensable for public health research. Hence, they are commonly used to estimate disease epidemiology.
- Accurate diseases identification in claims data relies on the use of diagnostic, pharmaceutical and procedural codes, which are standardized to ensure consistency and reliability in documenting patient health information.
- However, coding practices can be inconsistent and specific diagnosis codes are not always available in health insurance datasets. As a result, physicians may rely on alternative or related codes which pose a challenge for the estimation of accurate epidemiological measures as it can lead to under- or overestimation.
- German SHI datasets include the ICD-10-GM catalogue. However, the catalogue is not always sufficiently detailed when it comes to coding rare disease or the severity of diseases. Consequently, identifying rare medical conditions such as immunoglobulin A nephropathy (IgAN) is challenging.
- IgAN, a rare kidney disease characterized by persistent hematuria, proteinuria, and arterial hypertension, has an unpredictable progression – ranging from mild, long-term symptoms to rapid kidney failure, ultimately leading to terminal renal disease.[1,2]

Objectives

- This study presents an approach how to overcome these challenges to generate epidemiological data for IgAN in Germany.

Methods

Study design

- A large German claims database was used to estimate the 2022 incidence and prevalence of IgAN using two coding algorithms.
- A subset of the Institute for Applied Health Research Berlin (InGef) database, the InGef research database, was used for the analysis.
- The overall database contains anonymized claims data from over 50 health insurance funds, covering around 9 million people.
- The research subset of around 4 million people represents ~ 5% of the German population and ~ 6% of the SHI population as of 2022.
- It accurately reflects the age, gender, geographic representation, morbidity, mortality and drug use of the German population.

Study population

- The described study population was identified in a period from 01.01.2020 to 31.12.2022.
- Two coding algorithms were defined as lower bound (LB) and upper bound (UB), which can be considered as ranges (see Figure 1).
- The LB included specific ICD-10-GM codes (N00.3, N02.3, N06.3) used to confirm IgAN via biopsy.
- In contrast, the UB expanded to codes potentially used to record IgAN or related symptoms identified in a market research study preceding this work (N00.3, N02.3, N02.5, N02.7, N02.8, N02.9, N06.3, N06.8).
- Patients with codes for diseases different from IgAN and comorbidities of secondary IgAN were excluded.
- Incident patients required a documented kidney biopsy around the time of diagnosis.

Figure 1: Patient selection and respective patient counts

Results

Patient population

Prevalence

- Per 100,000 individuals in Germany, the study identified a prevalent population of IgAN-patients ranging from 4.8 (LB) to 38.2 (UB).
- Approximately 73% of the LB were male (see Figure 2), with an average age of 53 years (see Figure 3).
- In the UB, around 57% were male and average age was 59 years.
- In the age distribution of the LB, the largest group consists of individuals aged 50-59 years (see Figure 4).
- The age distribution in the UB does not reveal any particularly large group. The three largest age groups, which are about the same size, are people aged 50-59, 60-69 and 70-79, each with about 20% (see Figure 4).

Incidence

- Incidence rates in 2022 varied from 0.2 to 0.6 per 100,000 individuals.
- About 86% (LB) and 83% (UB) were male and mean age was 36 (LB) and 44 (UB) years.

Results (Continued)

Figure 2: Gender distribution in 2022

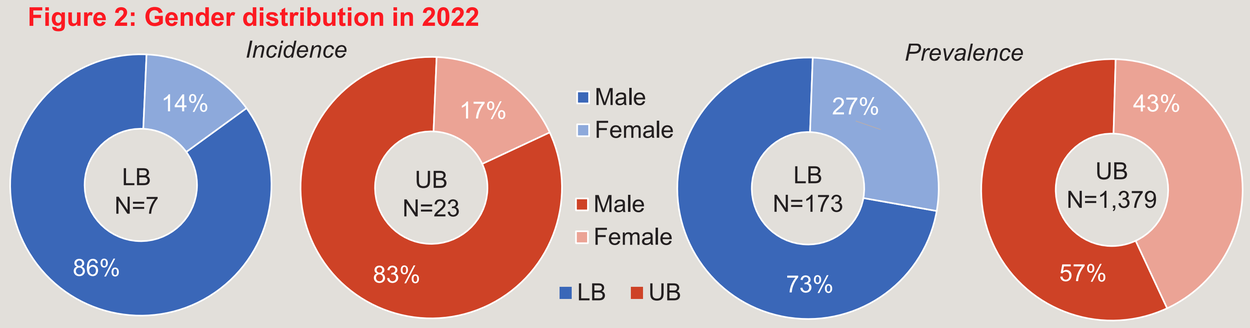


Figure 3: Mean age (in years) in 2022

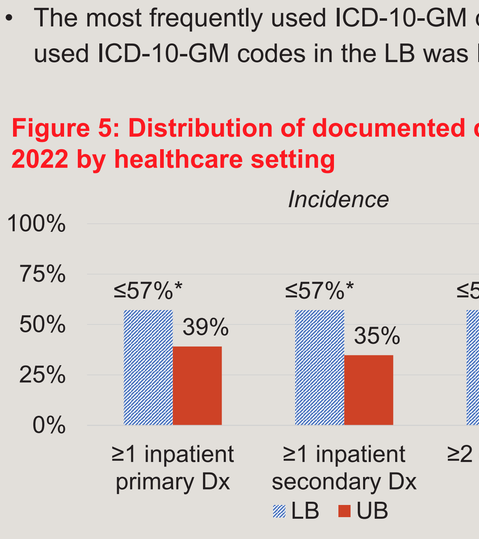
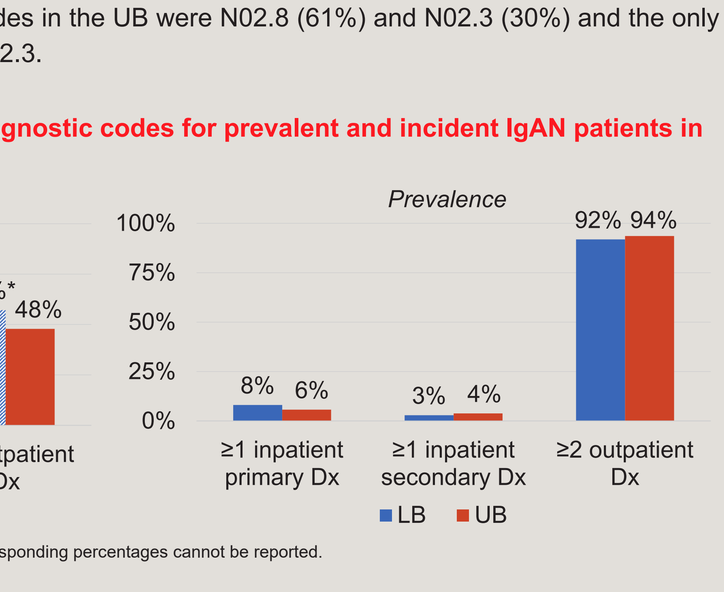


Figure 4: Distribution of age groups in 2022



Diagnostic codes

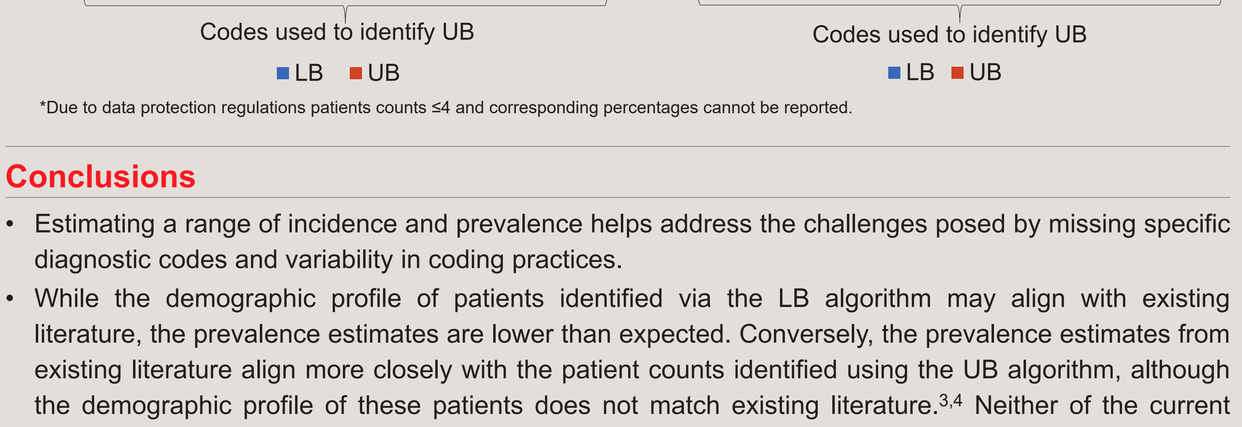
Prevalence

- More than 90% of cases identified in both the LB and UB received their IgAN codes during outpatient care (see Figure 5).
- In the UB, a high proportion of codes were nonspecific, with N02.8 and N02.9 accounting for 38% and 49% of cases, respectively. Of the three codes included in the LB, code N02.3 was the most frequently used (78%) (see Figure 6).

Incidence

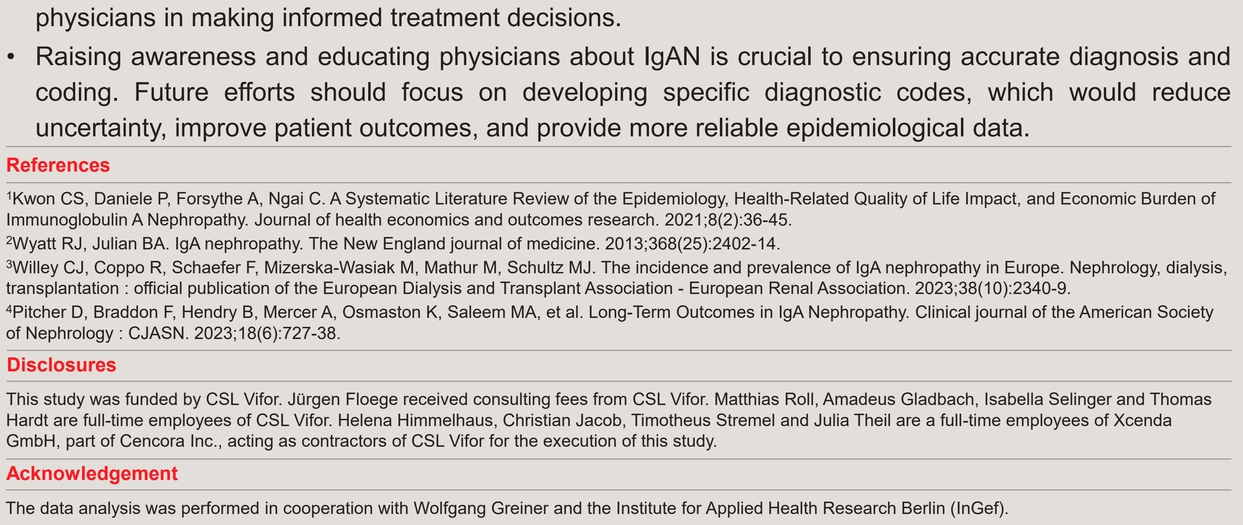
- In the UB, around 74% (39%+35%) of cases received inpatient codes, and 48% received outpatient codes.
- The most frequently used ICD-10-GM codes in the UB were N02.8 (61%) and N02.3 (30%) and the only used ICD-10-GM codes in the LB was N02.3.

Figure 5: Distribution of documented diagnostic codes for prevalent and incident IgAN patients in 2022 by healthcare setting



*Due to data protection regulations patients counts ≤4 and corresponding percentages cannot be reported.

Figure 6: Distribution of documented diagnostic codes for prevalent and incident IgAN patients in 2022 by 4-digit ICD-10-GM code



*Due to data protection regulations patients counts ≤4 and corresponding percentages cannot be reported.

Conclusions

- Estimating a range of incidence and prevalence helps address the challenges posed by missing specific diagnostic codes and variability in coding practices.
- While the demographic profile of patients identified via the LB algorithm may align with existing literature, the prevalence estimates are lower than expected. Conversely, the prevalence estimates from existing literature align more closely with the patient counts identified using the UB algorithm, although the demographic profile of these patients does not match existing literature.[3,4] Neither of the current approaches provides a fully accurate picture, and the true values likely lie somewhere in between.
- More precise coding would significantly enhance the accuracy of epidemiological studies and assist physicians in making informed treatment decisions.
- Raising awareness and educating physicians about IgAN is crucial to ensuring accurate diagnosis and coding. Future efforts should focus on developing specific diagnostic codes, which would reduce uncertainty, improve patient outcomes, and provide more reliable epidemiological data.

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Disclosures

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