

Validation of ICD-11 (Beta) in the field of Nephrology - Final report for the ICD-11 Beta Field Test in Germany

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Introduction

Nephrology as a specialty of internal medicine and pediatrics focuses on the study of normal kidney function and kidney problems including the preservation of kidney health. The different aspects of treatment include diet, medication and renal replacement therapy, i.e. dialysis and kidney transplantation. Systemic conditions that affect the kidneys (such as diabetes and autoimmune disease) and systemic problems that occur as a result of kidney problems (such as renal osteodystrophy and hypertension) are also part of this discipline. Examples include acquired conditions such as systemic vasculitides (e.g. ANCA vasculitis) and autoimmune diseases (e.g., lupus), as well as congenital or genetic conditions such as polycystic kidney disease.

The classification system for recording, analysis, interpretation and comparison of mortality and morbidity data in the field of nephrology is the International Classification of Diseases (ICD). Therefore, the classification must be able to translate the nomenclature of nephrological diagnoses of diseases and other health problems into an alphanumeric code which allows the data to be stored, retrieved and analyzed.

The ICD has evolved over the past 150 years to become the international standard diagnostic classification and can be used for analysis of general health situations of population groups, monitoring the incidence and prevalence of diseases, and other health problems in relation to other variables, such as the characteristics and circumstances of the individuals affected. It is also suitable for studies of financial aspects, such as billing issues or resource allocation. Users of the ICD include physicians, nurses, other health care providers, researchers, health information management professionals, coders, health information technology workers, analysts, policymakers, insurers, patient organizations, and many more.

The ICD is primarily designed for the classification of diseases and injuries. However, not every problem or reason for getting into contact with health services can be categorized in this way. Consequently, the ICD includes a wide variety of signs, symptoms, abnormal findings, complaints and social factors that represent the content from health-related records (see section on morbidity). The ICD can therefore be used to classify data recorded under headings such as “Diseases”, “External causes of morbidity and mortality”, “Factors that influence the state of health and lead to the use of the health care system”, “Injuries, poisoning and certain other consequences of external causes” and “Pregnancy, childbirth and postpartum”.

A specific disease entity that is of particular importance for nephrology, or that occurs frequently in nephrology, should have its own category. Otherwise, categories are assigned to groups of separate but related conditions.

In this field test, the complete range of diseases in the field of nephrology is examined with regard to their ability to be coded using ICD-11 (current beta version). Clinical applicability should be evaluated through targeted encoding of typical clinical constellations of nephrology patients (reference coding in ICD-10-GM and coding in the beta version of ICD-11). The aim was to identify not only problem areas in ICD-11, but also the appearance of known problem areas in the ICD-10 (-GM), in order to assess the development of ICD-11.

In this field test the following questions regarding the appropriateness, completeness and coverage of needs for coding of different aspects of nephrology should be answered:

- Are the concepts (entities) of the foundation or classes of the ICD-11 MMS (Draft for Quality Assurance) scientifically equivalent to the state of medicine?
- Can all disease entities be assigned in the ICD-11 or are there missing entries?
- How is the practicability assessed for the investigated case (eg, inpatient treatment and imaging in the DRG system, epidemiology, etc.)? Will all aspects of nephrology be covered in ICD-11?

Material and methods

The work was coordinated by the DRG Office of the DGfN (German Society of Nephrology). The project was subdivided into two phases:

At the beginning of the project, a detailed schedule was created. 58 medical reports from four hospitals, as well as seven real-world cases of nephrological situations in pregnancy were collected and anonymized, resulting in a total of 65 cases. These cases were coded by coding assistants specialized in the field of nephrology. The selected descriptive approach focuses on the appearance of frequent and typical situations with a qualitative assessment. The statistical assessment is therefore mainly descriptive.

The terminology belonging to the field of nephrology and the concepts for diseases, syndromes, as well as general health problems, symptoms, abnormal findings, complaints, social circumstances or external causes of injuries were firstly collected to ensure a comprehensive data base. The ICD-11 coding in this first phase was done with mapping to the ICD-10, and the ICD-FiT coding tool of the WHO was used.

5 raters performed the basic work of participating in studies as classification users. They registered with the ICD-FiT-system on invitation and by completing the participant form. After that, he/she should access his/her own web page, check for assigned cases in field trial studies, fill in the related forms, and also complete the final evaluation form after completing all cases of a study.

Results

The results for the different phases of the investigation are presented below.

Line Coding

A collection of terminology was created from textbooks of nephrology (U. Kuhlmann et al.: Nephrologie, 6th edition, published by Thieme 2015 and R. Johnson et al.: Comprehensive Clinical Nephrology, , 5th edition, published by Elsevier 2015) as well as other documents, including the DRG Coding Guide for nephrology. This consisted of a total of 909 terms after compilation from the various sources and consolidation. This collection of foundations and entities was assigned to the various categories of the ICD. A classification of the concepts from a nephrological point of view also was made. This list of entities was coded in the ICD-11 by use of the ICD-FiT-Tool. The results are summarized below and are also available as detailed tables with all raw data.

Table 1: Nephrological Line-Foundation

Nephrological Categories	Lines (n)
Congenital malformations, deformities and chromosomal anomalies	52
Diseases	463
External causes of morbidity and mortality	6
Factors that influence the state of health and lead to the use of the health care system	4
Injuries, poisoning and certain other consequences of external causes	23
Pregnancy, childbirth and postpartum	358
Unknown	3
Total	909

Table 2: Categorization using ICD-categories

Category ICD	Lines (n)
Acid-base & Electrolyte disturbances	117
Acute Renal Failure	38
Chronic Renal Failure	115
Congenital kidney disease	1
Dialysis associated	52
Diseases, other	126
General nephrologically relevant pathological findings	59
Glomerular Kidney Disease	66
Hypertension	44
Infection of the urogenital system	22
Interstitial kidney disease	69

Category ICD	Lines (n)
Obstructive nephropathy	42
Systemic Diseases	108
Transplantation	48
Unknown	2
Total	909

The assignment of the concepts to the different categories shows that all aspects are covered, the collection was considered as complete. Subsequently, after coding the terms, an assessment was made as to how securely the coding was. Three categories were defined:

- one, possibly several, codes can be assigned to the term
- no code was found
- a code was found, but the assignment appears questionable.

The following Table summarizes these results and the individual assessments can be found in the appendix.

Table 3: Certainty of Coding in the different categories of ICD

Category (ICD)	Code can be identified	No Code could be identified	Questionable	Overall
Congenital malformations, deformities and chromosomal anomalies	41	11	0	52
Diseases	349	93	21	463
External causes of morbidity and mortality	3	1	2	6
Factors that influence the state of health and lead to the use of the health care system	3	1	0	4
Injuries, poisoning and certain other consequences of external causes	14	7	2	23
Pregnancy, childbirth and postpartum	216	121	21	358
Unknown	2	1	0	3
Total	628	235	46	909

Regarding the different categories of the ICD-system, 75,4% (n= 349) of the lines in the category "Diseases" can be assigned to a code, in 20,1% (n= 93) no code was found and in 4,5% (n= 21) it was questionable. The proportion of lines without a code or questionable codes was bigger in the category "Pregnancy, childbirth and postpartum" with 39,7% (n= 121).

A corresponding assessment of the security in the coding was made by means of the nephrological categories (Table 4).

Table 4: Certainty of Coding in the different categories of Nephrology

Category in Nephrology (alphabetical order)	Code can be identified	No Code identified	Questionable, insecure	Over all
Acid-base & Electrolyte disturbances	88	26	3	117
Acute Renal Failure	27	7	4	38
Chronic Renal Failure	70	41	4	115
Congenital kidney disease		1	0	1
Dialysis associated	25	25	2	52
Diseases, other	101	13	12	126
General nephrologically relevant pathological findings	45	11	3	59
Glomerular Kidney Disease	44	15	7	66
Hypertension	27	15	2	44
Infection of the urogenital system	18	2	2	22
Interstitial kidney disease	49	20	0	69
Obstructive nephropathy	24	16	2	42
Systemic Diseases	82	25	1	108
Transplantation	26	18	4	48
Unknown	2	0	0	1
Total	628	235	46	909

The level of certainty is highest in the category for Infection of the urogenital system (81,8%), Diseases, other (80,2%), general nephrologically relevant pathological findings (76,3%), , Systemic Diseases (75,9%) and Acid-base & Electrolyte disturbances (75,2%).

Result of Case Coding

The 65 cases were coded using the ICD-FiT-Tool, results are presented below in an overview. The detailed results can be found in the appendix.

Table 5: Overview of cases and raters

Case Title	Rater 002	Rater 003	Rater 004	Rater 005	Rater 006	Over all
Acute Renal Failure			2	2		4
Amyloidosis			1			1
ANCA-Vasculitis			1			1
Autosomal Dominant Polycystic Disease (AD PKD)		1	1	1	1	4
Cardio-renal Syndrome			1			1
Chronic Renal Disease			1			1
Chronic Renal Failure with Cystic Renal			1			1

Case Title	Rater 002	Rater 003	Rater 004	Rater 005	Rater 006	Over all
Disease						
Clostridium infection			1	1		2
COPD			1			1
Diabetes mellitus		1	1		1	3
Diverticulitis, Chronic renal failure			1			1
Gitelman Disease				1		1
Global Decompensation		1			1	2
Goodpasture Syndrome			1			1
HELLP Syndrome			1	1		2
Hypertensive Crisis			2	1		3
IgA-Nephritis			1	1		2
IgA-Vasculitis		1			1	2
Lupus	1	1	1	1	1	5
Membranous GN			2			2
Mesangio-prol. GN			1			1
Nephritis			1			1
Nephrotic Syndrome			1			1
Norovirus			1			1
Poly-Angiitis		1			1	2
Post-partial Renal Failure			1			1
Preeclampsia			1	1		2
Progressive Renal Disease		1	1		1	3
Purpura schoenlein-Henoch		1			1	2
Pyelonephritis			1	1		2
Rapid progressive GN			2	1		3
Renal Artery Stenosis		1	1		1	3
Sarcoidosis				1		1
Sectio Preeclampsia			1	1		2
Sepsis		1	1	1	1	4
Shunt Complication				1	1	2
Systemic Lupus Erythematodes			2			2
Wegener Disease			1			1
Total	1	10	36	16	11	74

The raters made a judgement whether difficulties in performing the coding were encountered or not. In only 7 cases difficulties were seen.

Table 6: Overview of cases with difficulties in coding

Case Title	No difficulty encountered	Yes	(Empty)	Overall
Acute Renal Failure	4			4
Amyloidosis	1			1
ANCA-Vasculitis	1			1
Autosomal Dominant Polycystic Disease (AD PKD)	4			4
Cardio-renal Syndrome	1			1
Chronic Renal Disease	1			1
Chronic Renal Failure with Cystic Renal Disease	1			1
Clostridium infection	1	1		2
COPD	1			1
Diabetes mellitus	2		1	3
Diverticulitis, Chronic renal failure		1		1
Gitelman Disease	1			1
Global Decompensation	2			2
Goodpasture Syndrome	1			1
HELLP Syndrome	2			2
Hypertensive Crisis	3			3
IgA-Nephritis	2			2
IgA-Vasculitis	2			2
Lupus	3	2		5
Membranous GN	1	1		2
Mesangio-prol. GN	1			1
Nephritis	1			1
Nephrotic Syndrome	1			1
Norovirus	1			1
Poly-Angiitis	2			2
Post-partial Renal Failure	1			1
Preeclampsia	2			2
Progressive Renal Disease	3			3
Purpura schoenlein-Henoch	1		1	2
Pyelonephitis	2			2
Rapid progressive GN	3			3
Renal Artery Stenosis	3			3
Sarcoidosis	1			1
Sectio Preeclampsia	2			2
Sepsis	3	1		4
Shunt Complication	1	1		2
Systemic Lupus Erythematodes	2			2
Wegener Disease	1			1
Total	65	7	2	74

Conclusion

In summary, on behalf of the German Society of Nephrology, we assessed the ICD-11 as follows: The concepts (entities) of the Foundation and the classes of the ICD-11-MMS (Draft for Quality Assurance) generally correspond to the state of medicine from a scientific point of view. However, the illustration of the disease group of glomerulonephritis does not correspond to the current status. This may reduce the acceptance of the products by clinically active physicians. Nothing essential is missing, but the systematics of the ICD-11 is not easy to understand. This may also be due to the nature of the classification and the differences to medical terminology. It is understandable, however, that the classification cannot follow the frequently changing clinical classifications. Some participants in the study were somewhat confused by the fact that some diagnoses can be mapped with different coding options. For example, IgA nephritis can be documented by different codes.

Individual diagnoses such as the occlusion of a shunt in hemodialysis patients or peritonitis in peritoneal dialysis patients or infections of an atrial catheter were not found at all.

The study participants could not find any differences to the ICD-10 in terms of the availability of individual codes. However, the systematics are fundamentally different. This has an impact on the need for training. This applies in particular to countries where the ICD-10 is deeply rooted (such as Germany, which has been using the DRG system since 2003).

The suitability for practical use is assessed in such a way that the coding effort could be significantly higher, since the most frequently occurring new codes have to be newly learned. This is much easier with ICD-10. In the ICD-11, unlike the ICD-10, each code must be searched for individually. The unspecific code is selected first in the coding tool, so that you still have to search for it. Our coding time for each discharge letter was between 15 - 20 minutes, which is well above the current values. Very few diagnoses appear to be transferable 1:1 from ICD-10 to ICD-11. This will lead to conflicts. Some participants remarked that despite the training, it seemed unclear what logic was behind the codes. The question arose as to why some codes start with letters and others with numbers? Even if there are reasons for this, it is difficult for clinically active colleagues to communicate this.

However, the evaluation of the ICD-11 based on "line coding" showed greater difficulties. It was not possible to achieve an assignment of the existing terms of 100% or even nearly 100%. This is particularly true for particular disease entities such as the glomerulo-nephritis. Similar problems will be expected in many areas of nephrology, especially if classifications and concepts will change. In this context, it is important to emphasize that the classifications for acute and chronic rejections of transplanted kidneys as well as acute renal failure or other areas are updated on a regular base and quite frequently. A "mechanism" could be helpful here, which would allow the rapid introduction of new findings and concepts in the existing system of classification.