

## New primary renal diagnosis codes for the ERA-EDTA

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### Abstract

The European Renal Association-European Dialysis and Transplant Association (ERA-EDTA) Registry has produced a new set of primary renal diagnosis (PRD) codes that are intended for use by affiliated registries. It is designed specifically for use in renal centres and registries but is aligned with international coding standards supported by the WHO (International Classification of Diseases) and the International Health Terminology Standards Development Organization (SNOMED Clinical Terms). It is available as supplementary material to this paper and free on the internet for non-commercial, clinical, quality improvement and research use, and by agreement with the ERA-EDTA Registry for use by commercial organizations. Conversion between the old and the new PRD codes is possible. The new codes are very flexible and will be actively managed to keep them up-to-date and to ensure that renal medicine can remain at the forefront of the electronic revolution in medicine, epidemiology research and the use of decision support systems to improve the care of patients.

**Keywords:** codes; ERA-EDTA; ICD; PRD; SNOMED CT

### Introduction

Accurate reporting of basic epidemiology data underpins the practice of medicine, health care planning and social policy.

The European Dialysis and Transplant Association (EDTA) has promoted epidemiology research since its formation in 1963. The EDTA Registry was established in 1964. At that time it published a list of diagnoses that led to end-stage renal failure (ESRF) [1]. This was called the primary renal diagnosis (PRD) list. In 1983, the EDTA changed its name to the European Renal Association-European Dialysis and Transplant Association (ERA-EDTA) and the EDTA Registry became the ERA-EDTA Registry.

Patients who started renal replacement therapy (RRT) for ESRF in countries affiliated to the ERA-EDTA (and formerly the EDTA) were registered by their renal centres and were followed up annually. Initially, this was done by returning a paper form to the Registry office where a computer database was updated. The ERA-EDTA thus established a voluntary comprehensive, longitudinal, international registry many years before other medical specialties and often reported more detailed information than was available even to national authorities including incidence, prevalence, diagnosis, treatment modality and survival.

The adoption of a set of standard diagnostic terms improves communication and supports data analysis. Unfortunately, it can also coerce users, impose unreasonable constraints and provide a false sense of accuracy. Code sets must be designed and used carefully with these benefits and limitations in mind. It must be possible to record events in free text in the primary medical record in order to preserve details and context

and to allow previously unrecognized entities to emerge.

In 2000, the ERA-EDTA Registry office, which at that point was based in London, was reorganized and returned to Amsterdam [1, 2]. The responsibility for patient registration and follow-up was devolved on national and regional renal registries, which collected the data from renal centres, undertook initial validation and sent them in an agreed, secure electronic format to the ERA-EDTA Registry. These data files were sometimes augmented with specially collected data and were used to produce annual reports on incidence, prevalence, treatment methods and survival and scientific papers. They demonstrate the continuing value of good-quality long-term observational studies [3–6]. However, deficiencies imposed by the limited options for recording the PRDs caused frustration [7]. This paper describes the development and publication of a new list of PRD codes that adheres to international standards and will extend their use and reliability. In line with the Strengthening the Reporting of Observational Studies in Epidemiology recommendations for reporting observational studies [8], we provide background on the choices made during the development process.

## The problem

The ERA-EDTA Registry Committee recognized that after having served well for nearly 40 years, the old PRD codes were incomplete and inflexible. The terms lacked definitions, used the word ‘other’ without qualification and because there were no guidelines, the PRDs were applied inconsistently between and even within countries. It was not possible to indicate the accuracy of the code used and there was no formal mechanism for adding new codes or retiring redundant ones.

In the 1960s, when the PRDs were introduced, computers were not widely used in clinical practice, and at that time, it was important that the list could be printed on a single sheet of paper.

Initially, there was very limited quality assurance and data validation, and it was clear that while attempting to convey the limited but useful insights they had about patients, some nephrologists were coding with spurious accuracy (e.g. a PRD of Immunoglobulin A (IgA) nephropathy based purely on clinical presentation). The PRD assigned may have reported the clinical diagnosis but it was sometimes inadequate for secondary uses and epidemiological analysis. There was widespread variation in the use of some codes and it was difficult to find the appropriate codes for some patients, particularly those with systemic vasculitis, where understanding and classification have changed greatly since the PRD list was first agreed. Over the decades, other new diseases have been described that did not fit into existing categories. These problems could not be fixed simply by extending the old PRD list and it was therefore decided that a completely new list of PRD terms and a new philosophy for maintaining it would be produced.

## Possible solutions

A Registry Coding and Definitions Working Group was established to develop a new list of Primary Renal Diagnoses and to report to the ERA-EDTA Registry Committee as part of the QEst European Studies (QUality) initiative [9]. The brief was: ‘to improve and standardize the definitions, terminology and coding used by renal registries in Europe to describe primary renal diagnoses’.

The first task was to review the existing codes and to seek the views of the national and regional registries affiliated to the ERA-EDTA. That was done by a questionnaire and discussion at meetings of registries during ERA-EDTA congresses. It was apparent that there were many very different, well-considered and deeply held views. Some countries had also modified the code set by expanding some sections.

A similar problem has been clearly reviewed by Agar *et al.* [10] in a paper on the terminology of chronic maintenance haemodialysis. They point out that the meaning of terms varies from one geographical region to another and that many publications prompt the reader to ask ‘What exactly did they mean?’ They offer suggestions for improving the situation but realistically warn that changes will not always be welcomed, particularly by those who use terms that have been rejected. In the development of the new PRD codes, we faced the same problem. The key point is that to be of full use in later epidemiology and clinical studies, the contextual information or ‘meta data’ which supports the PRD and other clinical data must be recorded at the same time as the diagnosis and inextricably linked.

In their response to our questionnaire and in subsequent discussions, renal registries expressed a huge range of sometimes irreconcilable views concerning the new PRD terms. It became apparent that many registries and national authorities were already committed to using the International Classification of Diseases (ICD)-10 or the SNOMED Clinical Terms (SNOMED CT). The latter nomenclature offers enormous benefits and is fully maintained by the International Health Terminology Standards Development Organization (IHTSDO), a not-for-profit multinational association.

The main suggestions from Registries are summarized in the following list, which retains the telegraphic style of the questionnaire responses:

- (i) simply retain the existing PRD list without modification because it has served well and is understood,
- (ii) adopt ICD-10 without modifications,
- (iii) adopt SNOMED CT without modifications,
- (iv) create a new list to be maintained entirely by the ERA-EDTA Registry,
- (v) create a new list to be maintained by the ERA-EDTA Registry and keep it aligned with other international coding schemes,
- (vi) include all aspects of a PRD in a single line of text that does not require further qualification,

- (vii) be usable by ordinary clinicians for routine work with little additional training and produce data for registry use, decision support and evidence-based practice as an automatic byproduct from an electronic medical record,
- (viii) acknowledge the uncertainties in clinical practice,
- (ix) be acceptable to the ERA-EDTA Registry and affiliated registries and if possible compatible with other international registries,
- (x) incorporate or map to the existing ERA-EDTA PRD codes,
- (xi) be consistent with emerging medical standards, e.g. SNOMED CT and ICD-11,
- (xii) be comprehensive and rigorous enough to support primary and international epidemiology research, quality improvement, service planning, teaching and funding,
- (xiii) have working definitions,
- (xiv) be flexible so that redundant codes can be retired and new codes added while maintaining good version control,
- (xv) allow continuing research by combining records using the old and new PRDs and
- (xvi) include more renal disorders and remove the restriction to diseases that result in ESRF and the need for RRT

It was clear that a ready-made solution was not available. We adopted plan 5 and attempted to satisfy criteria and suggestions 6–16.

### Materials and methods

The working group corresponded mostly by email and made extensive use of teleconferencing with a shared virtual PC desktop on which we could display the work being discussed and which any member could control and edit. The philosophy was discussed with the registries affiliated to the ERA-EDTA, the IHTSDO and the WHO ICD-11 renal group. An initial set of new PRDs was produced from a list drafted by one of us (G.V.R.), by reviewing the records produced over a 25-year period on a comprehensive electronic patient record system in a large university renal centre (K.S.), by summarizing text books and reviews (C.R.V.T.) and by suggestions from all members of the working group.

After the working group had produced the initial list of new PRDs, it was reviewed by registries affiliated to the ERA-EDTA, the ERA-EDTA QUEST initiative, recognized experts and by international renal registries. We have also followed the advice from coding experts that we should avoid terms that included the concept of 'other'. This is of sufficient importance that a short note is appropriate here. The old PRDs made extensive use of the term 'other' to describe things that did not fit anywhere else. This is the common strategy adopted by classification systems that are attempting to achieve complete coverage. The concept of 'other' is used in two distinct ways: for residual categories where the code could be more accurate but the correct term cannot be found, e.g. 'Not Elsewhere Classified (NEC)', 'due to other cause' and 'other specified type', and secondly for cases where more detailed information is not available, e.g. 'Not Otherwise Specified (NOS)' and 'cause not specified'.

These are often referred to as the 'NOS and NEC codes'. They are designed to be used in classification systems rather than as part of a true coded terminology system for clinical diagnosis. Although they are intended to allow the best possible choice from a limited data set, they have unfortunately been used inconsistently. While 'NOS and NEC' codes allow quick data entry, they often render data less useful for analysis.

Even with good version control, it is often not clear what alternatives were available when a 'NOS' code was used, and therefore, it was unclear what it might include or exclude. Furthermore, ambiguity is introduced when new codes are added because the domain deferred to 'other' changes every time the code set is altered.

Modern medical terminology systems try to avoid this problem by capturing clinical information at the level of detail appropriate for clinical practice and by allowing new codes to be added in an easy but controlled way. The approach now favoured is to provide high-level (also called 'generic', 'less granular' or 'super concept') terms like 'glomerulonephritis', 'familial nephropathy' and 'chronic renal failure (CRF)' and to use these super concepts in four distinct settings:

- (i) where a sound diagnosis of a well-described condition has been made but an appropriate code cannot be found in the code set being used,
- (ii) where the user thinks that a new disorder or syndrome has been recognized,
- (iii) where a patient is still being investigated and the final diagnosis has not yet been determined but where a general diagnosis can be made and
- (iv) where a user, for a particular purpose, does not need or want to work with a very accurate code.

It is possible, for example, to enter and store Goodpasture's syndrome and to report it simply as a glomerulopathy or even just as a renal disease if only a summary report is required. The internal relationships that underpin SNOMED-CT link Goodpasture's to lung diseases, vasculitis and autoimmune diseases. This allows complex analysis of huge databases and enables appropriate literature to be linked to individual patient records for optimal clinical practice and decision support. Care must be taken when generating detailed (granular) terms from a diagnosis that was initially saved at a generic (less granular) level but the utility of automatically providing all the available attributes of a diagnostic term is obvious.

### The new PRD list

The 2012 ERA-EDTA PRD codes are published as Supplementary material to this paper. In addition, they are freely available in a spreadsheet and in a searchable web browser on the ERA-EDTA Registry website at [www.era-edta-reg.org](http://www.era-edta-reg.org).

As requested by the national registries, the 273 new PRD terms not only include all the common and many rare nephropathies that result in ESRF, but also many other kidney conditions which do not usually cause advanced chronic kidney disease (CKD).

In the list, each new PRD term has been assigned a unique number, which serves only to identify it and to help electronic communication. We came to the conclusion that a single hierarchy of codes would be impossible. For example, it would be equally logical to include familial IgA nephropathy in a 'familial' category or in a 'glomerulonephritis' category. The many complex ways in which lists of diagnoses can be searched, sorted and examined are already well handled in SNOMED CT and these tools will be available when the new PRD terms are accessed on a modern computer browser. A default sorting order decided by the working group is included so that if required, the list can be viewed in a standard order. This default order has no particular significance and users can rearrange the list and use any convenient software tools to search, sort and manipulate it. If required, printed copies can be used. Suggestions for addition or inactivation of terms should be sent to the ERA-EDTA Registry office at [erareg@amc.uva.nl](mailto:erareg@amc.uva.nl).

Further details about the codes and their attributes are given in 'Notes for Users' which are published with the codes. An unusual feature of the PRDs is the inclusion of the term 'histologically proven' and 'no histology' even for some PRDs, which should not reasonably be used without histological evidence. These terms are used to satisfy the requirement to provide detail, as a measure of the certainty of the diagnosis and to say everything in a single line of text. We provide PRDs that contain the words 'no histology' for diagnoses that clearly require histological proof (eg 'IgA nephropathy - no histology'). It is clear from Registry records that PRDs which describe the histological appearance of a kidney biopsy are frequently used even when histological evidence is not available and an alternative less granular PRD would be more suitable. We do not condone this practice. We hope that nephrologists who wish to record such a diagnosis will use the PRD which contains the words 'no histology' so that if required they can be analysed separately from the similar PRD which contains the words 'histologically proven'. We hope that it will henceforth be possible to distinguish an honest guess from a firm diagnosis using gold standard criteria, and we recognize that as new and accurate non-histological diagnostic techniques (e.g. genetic tests) are developed, additional codes will be needed to include and specifically exclude these options. For Registry purposes, only one PRD code can be assigned to a patient.

Two examples of common clinical situations with the old PRD terms which might have been used and the new PRDs which are now available will illustrate the utility of the new list.

#### Example 1

An adult patient presents with a vasculitic rash and a rising serum creatinine. Haematuria and proteinuria are present. Tests for Anti-Neutrophil Cytoplasmic Antibody (ANCA) are strongly positive. Kidney biopsy is technically impossible because of obesity. A clinical diagnosis of microscopic polyangiitis is made, and the patient responds well to immunosuppressive treatment.

With the old classification, the patient might have been allocated one of the following codes:

- 00 Chronic renal failure; aetiology uncertain,
- 10 Glomerulonephritis; histologically NOT examined,
- 74 Wegener's granulomatosis,
- 89 Multi-system disease—other and
- 99 Other identified renal disorders.

With the new codes, we will probably use either:

- 1396 Systemic vasculitis—ANCA positive—no histology or
- 1401 Granulomatosis with polyangiitis - no histology

#### Example 2

A 60-year-old patient with morbid obesity is referred with an estimated glomerular filtration rate of 28 mL/min/1.73 m<sup>2</sup>. The patient has had diabetes mellitus (DM) for 10 years

and has been treated with insulin for the last 18 months. There is a past medical history of hypertension, myocardial infarction, transient ischaemic attacks and intermittent claudication. Dipstick urinalysis is negative. Urine albumin:creatinine ratio is 7 µg/mmol.

With the old PRD classification, the patient might have been allocated one of the following PRD codes:

- 00 Chronic renal failure; aetiology uncertain,
- 72 Renal vascular disease due to hypertension,
- 80 Diabetes glomerulosclerosis or diabetic nephropathy—Type I,
- 81 Diabetes glomerulosclerosis or diabetic nephropathy—Type II.

We know from previous Registry analyses that many patients with Type 2 diabetes are incorrectly coded as Type 1. There is also marked variation in the use of codes for diabetic glomerulosclerosis, suggesting that clinicians may have chosen these codes without considering the possibility of alternative aetiologies for kidney disease in patients with diabetes mellitus.

The new classification gives additional guidance on the choice of the code in this situation. For instance, the code '2337 Diabetic nephropathy in Type II diabetes—no histology' includes the guidance:

- (i) A diagnosis of Type II diabetes mellitus must have been made.
- (ii) For a diagnosis of diabetic nephropathy, proteinuria must have been documented at some point in the patient's history.
- (iii) A PRD of diabetic nephropathy is not mandatory in the presence of DM with proteinuria and alternative diagnoses can be considered.
- (iv) In the absence of renal histology, the differential diagnosis will include 'Chronic kidney disease (CKD) / chronic renal failure (CRF) - aetiology uncertain/unknown - no histology', ischaemic nephropathy, renovascular disease and atheroembolic renal disease.
- (v) Distinguish from: Inherited/genetic diabetes mellitus Type II.

In addition, newly described nephropathies have been added to the PRD coding system, e.g.

- 2274 Nephropathy related to HIV—no histology,
- 2288 Nephropathy related to HIV—histologically proven.

Finally, many rare diagnoses were omitted from the old PRD list but are now included, e.g.

- 1074 Denys-Drash syndrome,
- 2929 Dent disease and
- 2938 Lowe syndrome (oculocerebrorenal syndrome).

When a definitive test has not been used, there will always be uncertainty, but the new PRD codes allow both

a clinical diagnosis to be recorded faithfully. At the same time, by noting the absence of a definitive test, we can also convey the degree of uncertainty. Where appropriate, patient records can be grouped according to the degree of accuracy and certainty required for a particular analysis and research teams can decide whether to examine a small number of patients with accurate diagnoses or larger numbers with phenotypic similarities. Cohorts can be combined if required and nothing is lost by using the more granular coding scheme apart from the slight additional effort of choosing the best diagnostic term from a larger list. With computer aids, the extra effort is trivial although we must recognize that we now have more diagnostic options than we can commit to memory.

No current coding system in widespread use has full definitions. While desirable, this would be a huge task and would require extensive international and cross-specialty collaboration. In our PRD list, we have made some progress by providing partial definitions that indicate what type of diagnostic information should be used to support each PRD but with the exception of histological evidence, these are not mandatory and we must still rely on the good judgement of individual nephrologists.

Fortuitously, while the work on the PRDs was proceeding, the renal community in the UK was establishing a subset of existing renal SNOMED CT codes and they agreed to incorporate the new ERA-EDTA PRD codes in their list without modification. That work introduced one of the authors (Y.G.), who is an expert in clinical terminology, to the PRD codes. He was co-opted onto the PRD working group and undertook the detailed mapping of the new PRDs to SNOMED CT and ICD-10. Not only did that ensure that the terms favoured by the nephrologists were acceptable to professional terminologists, but it also allowed the new PRDs to be aligned to SNOMED CT with all the subtle semantic links that make it such a powerful tool.

Each new PRD has been linked (often called mapping) to the most appropriate PRD in the old code set and *vice versa*. These translation tables are offered for use where automated conversion of large numbers of records is required. For detailed research work where the historic coding practice is well understood, it may be appropriate to develop alternative mappings or to re-examine individual records to ensure that the correct new PRD has been chosen. They need not be followed slavishly but users are encouraged to publish the mapping tables they use along with their results. Conversion from old to new PRDs may be necessary when historic data are being combined with contemporary data or when historic data with modern data analysis techniques that use SNOMED CT or ICD codes.

In addition to allowing conversion between new and old PRD codes, a powerful feature of the new PRD coding system is that the assignment of an ICD-10 code, a SNOMED CT identifier and where necessary a set of post-coordinated SNOMED CT codes will allow users to access the full power and utility of these modern and internationally supported clinical terminology systems. The most immediate and obvious benefit of a link to SNOMED CT may be the provision of validated

translation into other languages and the possibility of participating in further translation work if required. This makes the codes and their extended uses (e.g. links to literature and semantic links) available to non-English speakers and allows codes to be entered in one language and displayed in another. A single example persuaded the coding group of the utility of this approach. We considered the diagnosis of 'renal vein thrombosis'. Using a SNOMED CT browser and irrespective of the language that is used or whether the fully specified name or a local preferred term is used, the relationship to renal disorders, venous disorders and thrombotic disorders is clear. SNOMED CT uses words with which we are familiar but behind the scenes it preserves the concepts and the true biological meaning via the codes and not simply by looking up the words.

The introduction of SNOMED CT into clinical practice is still at an early stage but its power and potential are obvious and the ERA-EDTA will be able to contribute to it as it develops. The new PRD list also has extensive links to the Online Mendelian Inheritance in Man (OMIM) database, which is a comprehensive medical and scientific resource maintained by US National Library of Medicine and the William H. Welch Medical Library at Johns Hopkins University. The online version was developed by the US National Center for Biotechnology Information.

The ERA-EDTA Registry will accept patient data returns using the new PRDs from its contributing registries from January 2012. It will continue to accept data using the old PRDs for some time and it will announce on its website 2 years before the date on which it will no longer be able to accept the old PRDs.

### Further developing the codes and putting them to use

Future development of the codes will be the responsibility of the ERA-EDTA Registry committee and its coding group. The initial task will be to collaborate with other specialties under the general guidance of IHTSDO to develop codes relevant to the disorders on the boundary with another specialty or affecting more than one organ, e.g. extra-renal vasculitis and amyloidosis. We hope that national registries and renal centres will help us to improve the PRD list by notifying the Registry of any errors, omissions, redundancies, clarifications or new terms that are required. Within the structure of SNOMED CT, there are stable mechanisms for undertaking this work, which allows the codes to evolve while retaining all the information in the existing records.

We believe that we have produced a useful new list of PRDs which satisfies most of the requirements set by renal registries affiliated to the ERA-EDTA and which incorporates most of the suggestions from colleagues who reviewed the work.

The new PRD codes will be maintained by the ERA-EDTA Registry and are aligned with major international coding schemes.

## Supplementary data

The '2012 ERA-EDTA Primary Renal Diagnosis Codes' are available as supplementary data online at <http://ndt.oxfordjournals.org>.

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