

## Special article

# A Spanish version for the new ERA-EDTA coding system for primary renal disease<sup>☆</sup>

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## ABSTRACT

**Background:** The European Renal Association and the European Dialysis and Transplant Association (ERA-EDTA) have issued an English-language new coding system for primary kidney disease (PKD) aimed at solving the problems that were identified in the list of “Primary renal diagnoses” that has been in use for over 40 years.

**Purpose:** In the context of Registro Español de Enfermos Renales (Spanish Registry of Renal Patients [REER]), the need for a translation and adaptation of terms, definitions and notes for the new ERA-EDTA codes was perceived in order to help those who have Spanish as their working language when using such codes.

**Methods:** Bilingual nephrologists contributed a professional translation and were involved in a terminological adaptation process, which included a number of phases to contrast translation outputs. Codes, paragraphs, definitions and diagnostic criteria were reviewed and agreements and disagreements aroused for each term were labelled. Finally, the version that was accepted by a majority of reviewers was agreed.

**Results:** A wide agreement was reached in the first review phase, with only 5 points of discrepancy remaining, which were agreed on in the final phase.

**Conclusions:** Translation and adaptation into Spanish represent an improvement that will help to introduce and use the new coding system for PKD, as it can help reducing the

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time devoted to coding and also the period of adaptation of health workers to the new codes.

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## Adaptación en español del nuevo sistema de codificación de enfermedad renal primaria de la European Renal Association-European Dialysis and Transplant Association (ERA-EDTA)

### R E S U M E N

#### Palabras clave:

Códigos  
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Adaptación

**Antecedentes:** La European Renal Association-European Dialysis and Transplant Association (ERA-EDTA) ha publicado, en lengua inglesa, una nueva lista de códigos de enfermedad renal primaria (ERP), con el fin de solventar los problemas detectados en la «Lista de diagnóstico renal primario» que se venía utilizando desde hacía más de 40 años.

**Objetivos:** En el seno del Registro Español de Enfermos Renales (REER) se consideró conveniente traducir y adaptar los términos, definiciones y notas de los nuevos códigos de la ERA-EDTA para facilitar su uso por parte de quienes usan como lengua de trabajo el español.

**Métodos:** Se realizó un proceso de traducción profesional y adaptación terminológica que contó con la participación de nefrólogos bilingües con varias fases de contraste del resultado de la traducción, en las que se revisaron los códigos, literales, definiciones y criterios diagnósticos y se marcaron los acuerdos y discrepancias surgidos para cada término. Finalmente se acordó la versión aceptada por la mayoría de los revisores.

**Resultados:** El acuerdo en la primera fase de revisión fue amplio, con solo 5 puntos de discrepancia que se acordaron en la fase final.

**Conclusiones:** La traducción y adaptación al español representa una mejora para la introducción y uso del nuevo sistema de codificación de ERP, ya que puede contribuir a reducir el tiempo dedicado a la codificación y también el período de adaptación de los profesionales a los nuevos códigos.

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## Introduction

Disease coding for international use has a long history, and its beginnings date from 1893.<sup>1</sup> Since then, various coding systems have been developed for cause of death, diseases, processes, and clinical acts. The most extensively used is the group of international classifications<sup>2</sup> endorsed by the World Health Organisation, the most notable is the International Classification of Diseases and Related Health Problems (ICD). One of the main reasons of using this type of classification is to be able to compare the status of various diseases both nationally and internationally.

In the field of renal disease, the European Dialysis and Transplant Association (EDTA), at the beginning of its registry activities<sup>3</sup> in 1963, published a list of diagnoses, which was named “primary renal diagnosis (PRD) list”, which served as a guideline when making a diagnosis of primary kidney disease (PKD). After several years of use, and being supported since 1983 by the European Renal Association (ERA) and the EDTA, by means of the ERA-EDTA registry, this PRD list, which was subsequently expanded and modified, turned into a commonly used standard in renal disease registries, for coding of PKD. However, the presence of gaps in the PRD list often caused frustration among the users, because they

had to adapt to a system that did not offer adequate coding options and had a limited guarantee of quality and data validation, as the precision of the coding was not guaranteed. After more than 40 years of use, the ERA-EDTA Registry Committee identified its problems, recognising<sup>4</sup> that the terms in the PRD list were incomplete and inflexible; the list lacked definitions, the term “other/s” was used without a defined criteria, there were no users guidelines, its application was inconsistent both nationally and internationally, it was not possible to indicate how accurate was the code used, and there were no formal mechanisms to add or remove codes. Also, the list had been developed in an era before the use of computers, so it was not adapted for use in that context. Furthermore, the codes did not have correspondence with other classification systems—such as ICD or SNOMED-CT (Systematised Nomenclature of Medicine-Clinical Terms)<sup>5</sup>—which made interoperability between registries very difficult, and limited the possibility of such data being used for epidemiological studies or other additional uses.

It was in these circumstances that the ERA-EDTA expressed the interest in developing and publishing a new PRD code list<sup>4</sup> that would be adjusted to international standards so the use and reliability would be increased, just as been proposed by those renal patient registries that were consulted.

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