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ERA-EDTA Registry

New Medical Coding System for Kidney Disease

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The European Renal Association-European Dialysis and Transplant Association (ERA-EDTA) and the International Health Terminology Standards Development Organisation (IHTSDO) announced today that the ERA-EDTA Registry has published a new and comprehensive list of codes for kidney disorders. The ERA-EDTA Registry records dialysis and kidney transplant patients in Europe for public health and research purposes. The newly developed coding system replaces the former one which was almost forty years old and which, according to current medical and coding standards, was incomplete and inflexible.

Nephrologists in Europe will be able to use the new coding scheme to record kidney disorders accurately in their patient's electronic medical records and in their national renal registries which are affiliated to the ERA-EDTA Registry. The coded information will also be useful in applications developed for medical decision support. The national renal registries will use the data for improving the quality of care for patients, for teaching and for research. Including 273 different codes, the new system provides far more detail than the former one, making it possible to assign specific codes to the many patients who are suffering from a rare disease and to those who need dialysis or a kidney transplant. This will allow case-finding of patients with rare diseases and development of international research projects aiming to improve of quality of care.

Another important advantage of the new coding system is that it maps the ERA-EDTA Registry codes for kidney disease to related terms in well established international coding standards like ICD-10 and SNOMED - Clinical Terms (SNOMED CT). The ERA-EDTA Registry Coding & Definitions Working Group, who developed the new coding system, has sought direct collaboration with IHTSDO for mapping to SNOMED CT terms. Dr. Keith Simpson, Chair of the Coding & Definitions Working Group, feels that this mapping to international coding standards was a key condition to ensure the use of these codes in daily medical practice where disease codes are applied for many different purposes.

IHTSDO has provided free use of the SNOMED CT terms and codes in the new ERA-EDTA Registry coding system for kidney disease. The two organisations will collaborate to ensure that the new ERA-EDTA Registry codes for kidney disease and the associated SNOMED CT are managed jointly. The new coding system, a sophisticated search tool, user notes and the associated SNOMED CT, ICD-10 and old ERA-EDTA Registry codes are freely available at www.era-edta-reg.org.

For further questions, please contact our press offices: press@era-edta.org or media@ihtsdo.org

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About the ERA-EDTA Registry and the ERA-EDTA

The ERA-EDTA Registry collects and processes data from the national and regional renal registries in Europe and countries bordering the Mediterranean Sea with the purpose of performing scientific research and reporting statistics on kidney disease in Europe. In particular, the Registry studies disease patterns, treatment and patient outcomes in the various member countries. With the help of experts the Registry has taken a leading role in the development and adaptation of ERA-EDTA coding systems for use in registries. Registry results are summarised in annual registry reports, presentations at the ERA-EDTA congresses and articles in medical journals.

The Registry is housed in the Department of Medical Informatics at the Academic Medical Center, Amsterdam, The Netherlands, and is funded by the ERA-EDTA. For more information please visit www.era-edta-reg.org

With more than 6,600 members, the ERA-EDTA ("European Renal Association – European Dialysis and Transplant Association") is one of the biggest nephrology associations worldwide and one of the most important and prestigious European Medical Associations. It supports basic and clinical research in the fields of clinical nephrology, dialysis, renal transplantation and related subjects. The ERA-EDTA supports a number of studies as well as research groups and has founded a special "Fellowship Programme" for young investigators as well as grant programmes. Besides, it has established various research networks and different working groups to promote the collaboration of nephrologists with other medical disciplines (e.g. cardiology, immunology). Furthermore, a "European Renal Best Practice" (ERBP) advisory board has been established by the ERA-EDTA to draw up and publish guidelines and position statements.

Another important goal of the ERA-EDTA is education: Several series of CME-courses as well as the annual congress offer an attractive scientific programme to cover the need of continuous medical education for doctors working in the fields of nephrology, dialysis and transplantation. The association's journals, NDT (Nephrology, Dialysis, Transplantation) and CKJ (Clinical Kidney Journal), are currently the leading nephrology journals in Europe. For more information please visit www.era-edta.org.

About IHTSDO and SNOMED CT

The IHTSDO (International Health Terminology Standards Development Organisation) and its members seek to improve the health of humankind by fostering the development and use of suitable standardized clinical terminologies, notably SNOMED CT, in order to support the safe, accurate and effective exchange of health information. IHTSDO's governance structure allows members to control and guide the development of SNOMED CT, to ensure it meets both their joint needs and the specific needs of their individual countries. SNOMED Clinical Terms, or SNOMED CT, is a standardized terminology that can be used as the foundation for electronic health records and other applications. SNOMED CT is the most comprehensive, multilingual clinical terminology in the world. It enables safe and effective communication, retrieval and use of meaningful health information. The terminology is in use in more than 50 countries around the world. SNOMED CT was originally created by the College of American Pathologists by combining SNOMED RT and a computer-based nomenclature and classification known as Clinical Terms Version 3, formerly known as Read Codes Version 3. For more information please visit www.ihtsdo.org

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