



NephroQUEST

From Carmine Zoccali, ERA-EDTA Registry Chairman



Carmine Zoccali

Even though this is a problematic, restructuring phase for most medical registries, thanks to the efforts of dedicated nephrologists and epidemiologists, renal registries in Europe receive increasing attention for the extension and the quality of information they collect. Apart from epidemiologic research, renal registries were initially used for planning the needs for treatment of ESRD and for gathering basic information on patient outcomes. Today there is an increasing demand by patients and health authorities alike for closer monitoring RRT. In some European countries reimbursement or certification already depends on quality assurance defined on the basis of validated indicators.

To respond to the demand for a better quality of renal care, in 2003 the ERA-EDTA registry committee envisaged a new initiative aimed at making available information that can be used in quality improvement programs. In essence this initiative aimed at accelerating the evolution of renal registries towards high quality clinical data-bases that may be used as quality control instruments. Thanks to the enduring commitment of the ERA-EDTA Registry, the national registry representatives, QUEST working groups, and to the support of

national societies, this initiative was translated into a project successfully submitted to the European commission. NephroQUEST is now a dream that becomes reality. This will soon provide European nephrologists with a benchmarking system useful for establishing regional and local quality improvement initiatives.

The positive attitude of national registries that embarked in this endeavour is a warranty that that this common effort will be successful and set the basis for new achievements of the European renal registries community.

NephroQUEST Progress Report 2008

From Kitty Jager, NephroQUEST Project Manager, Ronald Cornet, NephroQUEST IT Manager and Carmine Zoccali, ERA-EDTA Registry Chairman

Last autumn a consortium of 27 organisations from 17 countries, including renal registries, national and European societies for nephrology, including ERA-EDTA, an ICT institute, a dialysis company and a quality improvement institute launched NephroQUEST, a project



Kitty Jager

funded under the Public Health Programme of the European Commission.

Last November the consortium set down to finalize a draft list of standardised clinical performance indicators that had been prepared by the QUEST clinical working groups on anaemia (chair F. Locatelli - Italy), calcium-phosphate metabolism (chair J. Cannata-Andia - Spain), cardiovascular risk (chair C. Wanner - Germany) and dialysis adequacy (chair J. Kooman - The Netherlands). Prior to the meeting the registries had collected further input from national registry committees and the boards of their national societies that was used for further decision-making.

The next step will be to make this list into a standards document.

Given the additional working burden for renal centres and the fear of incomplete data returns, many registries have long hesitated to extend their data collection. The QUEST

NephroQUEST Associated partners

- ERA-EDTA (United Kingdom)
- Academisch Medisch Centrum (The Netherlands)
- Agence de la biomédecine (France)
- Ceská Nefrologická Společnost (Czech Republic)
- Consiglio Nazionale delle Ricerche - Istituto di Biomedicina (CNR-IBIM) (Italy)
- Groupement des Néphrologues Francophones de Belgique (Belgium)
- Klinični Center Ljubljana (Slovenia)
- Nederlandstalige Belgische Vereniging voor Nefrologie (Belgium)
- Renal Association, UK Renal Registry (United Kingdom)
- RENINE (The Netherlands)
- Spitalul Clinic de Nefrologie "Dr Carol Davila" (Romania)
- Szpital Kliniczny Nr 1 Akademickie Centrum Kliniczne AMG (Poland)
- Tartu Ülikool (Estonia)
- Türk Nefroloji Denerjisi (Turkey)
- Universität zu Köln - QiN (Germany)

NephroQUEST Collaborating partners

- Eesti Nefroloogide Selts (Estonia)
- Fresenius Medical Care Deutschland (Germany)
- Hans Mak Instituut (The Netherlands)
- Ministry of Health and Welfare, General Hospital of Athens (Greece)
- Nederlandse Federatie voor Nefrologie (The Netherlands)
- Società Italiana di Nefrologia (Italy)
- Societatea Romana de Nefrologie (Romania)
- Société Suisse de Néphrologie (Switzerland)
- Stichting Nationaal ICT Instituut in de Zorg (The Netherlands)
- Suomen munuaistautirekisteri (Finland)
- Svensk Njurmedicinsk Förening (Sweden)

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News on the QUEST Coding and Definitions Working Group From Keith Simpson, Working Group Chair and Paul van Dijk, ERA-EDTA Registry medical informatician



Keith Simpson

The standardization of clinical performance indicators and data retrieval routines have made it necessary to have a fresh look at the ERA-EDTA coding systems and definitions used by renal registries. The QUEST Coding and Definitions working group is currently working on the coding system for the causes of renal disease, the definition of treatment modalities and it is producing a list describing the comorbid illnesses. According to the response on a sur-

vey some years ago the national and regional registries felt that the existing primary renal disease (PRD) coding system lacks detail and cannot be mapped to other international codes. This resulted in many misclassified patients and common use of the code "00/ chronic renal failure; aetiology uncertain". Secondly, the system was said to fail to capture important features of many conditions. It is however easy to use. A new coding system should be compatible with the existing ERA-EDTA PRD codes.

At the meeting of national registries at the Stockholm Congress, the working group will present a completely revised system. It is simple, comprehensive, expandable and will map to other coding systems while remaining easy to use.

For the first time the terms used have been defined. The coding group has avoided the temptation to write a textbook. The definitions will guide the nephrologists in the selection of the most appropriate diagnosis code when they have completed their in-

vestigations but should not be used to guide those investigations. A key feature of the system is the ability to state when the diagnosis has been confirmed by a renal biopsy while allowing an alternative code when patients present with classical clinical features in the absence of a biopsy.

The system mentions only key diagnostic features, which allows the selection of the correct code. It does not mention other non-discriminating features even where these are very common (e.g. the presence of proteinuria in biopsy proven glomerulonephritis).

National and regional registries will be asked for their comments and the working group will then discuss the codes with international registries, expert groups on specific diseases and coding organizations (e.g. Snomed).

We hope that the QUEST groups and the ERA-EDTA Registry Committee will accept the new coding system by the end of 2008 and that thereafter it will be quickly and widely adopted.

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data extraction group (chair R. Kramar - Austria) adopted Health Level 7 (HL7) version 3, an international standard for the exchange, management and integration of electronic healthcare information, to be instrumental in the data extraction process from electronic patient management information systems. A uniform infrastructure for data extraction will be developed. Together with other partners QiN (Germany) produced a report on data safety aspects and standards for secure data transfer.

The standardization of indicators and data extraction have also made it necessary to take a fresh look at the different ERA-EDTA coding systems and the definitions for variables used

by renal registries. This task has been taken up by the QUEST coding and definitions working group (chair K. Simpson - United Kingdom). Their work is described in more detail in another contribution to this Newsletter.

Finally, in a report for the Public Health Executive Agency the new registries in the project defined their 'starting points' as of 2007 as well as their ambitions for the year 2010. To assist these registries in their efforts the ERA-EDTA Registry organized a number of educational activities.

After attending the Introductory Course on Epidemiology participants joined three more registry course days in the AMC in Amsterdam. Lec-

tures and hands-on-sessions on data quality, benchmarking, database software, data processing practice and reporting, standards and terminology systems were alternated with presentations by Reinhard Kramar (Austrian Renal Registry) and David Ansell (UK Renal Registry) who are well-known and much respected for their registry work.

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