

What's new at the ERA-EDTA Registry?

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INTRODUCTION

The registry of the European Renal Association – European Dialysis and Transplant Association (ERA-EDTA) made a fresh start in the year 2000. After the restructuring of the data collection and the creation of a new database it began collaboration with 6 national renal registries¹. Currently 29 registries from 12 countries send their individual patient data to the Registry on an annual basis². Another 19 registries from 19 countries, one of which is Portugal, provide the Registry with aggregate data. These data are used to produce the Registry Annual Report which presents information on incidence, prevalence and survival on RRT across Europe².

The database with individual patient data includes the treatment histories of almost half a million patients on dialysis or living with a functioning graft. Those data that comprise a limited data set including some demographics, primary renal disease, treatment modality and time of death, have enabled basic epidemiological research to be performed and the preparation of papers for nephrology journals. They have also made it possible to embark on collaborative studies with colleagues from the registries of Australia and New Zealand (ANZ-DATA), Canada (CORR) and other registries³⁻⁶.

QUALITY EUROPEAN STUDIES (QUEST) AND NEPHROQUEST

The Registry has extended its scope over time. Three years ago it launched the QUEST initiative⁷. The

reasons for this were manifold. It was felt that renal registry data had been used for clinical, epidemiological, economic and outcome studies at the national and international level and that their data have proved very useful in planning treatment facilities and in providing information on patient outcomes, but that nowadays many stakeholders, patients, health authorities and physicians, across Europe and the EU in particular, are demanding information on the quality of RRT care. That issue is of fundamental importance, because it is widely felt that the huge health expenditures that European countries make in RRT demand verification that treatments are delivered according to high standards. The need for such information has already been acknowledged by a few registries in Europe which started to extend their data sets a few years ago. Under the umbrella of the ERA-EDTA this initiative has now been boosted by QUality European STudies (QUEST), which joined forces with a large number of national and regional renal registries and the ERA-EDTA Registry. The aim of QUEST is to improve RRT patient outcomes by making available information that can be used to improve the quality of RRT care. One part of QUEST comprises the setting up of a network of European researchers. Clinical experts from many European countries have been invited to participate in four 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). As a result two collaborative studies are running in the area of anaemia⁸⁻⁹ and two others in dialysis adequacy, with studies in

the two remaining areas in preparation. The other part of QUEST deals with the collection of clinical performance indicators to obtain information on the quality of care. The data collection process itself poses a huge problem here, with some countries still making use of paper forms or other labour intensive methods. Another problem is the lack of standardisation of methods to determine the variables to be collected.

As any attempt to solve these problems is a costly undertaking, it was decided to apply for a grant under the Public Health Programme of the European Commission. The application was successful and last autumn a consortium of 27 organisations from 17 countries, including renal registries, national and European societies for nephrology, an ICT institute, a dialysis company and a quality improvement institute launched the NephroQUEST project. While the QUEST clinical working groups produced a draft list of standardised clinical performance indicators including a priority for data collection, under the NephroQUEST project this list has been finalised using the input from national registry committees and boards of the national societies of nephrology. The next step is to make it into a standard document for renal registries use.

Given the additional working burden for centres and the fear of incomplete data returns, many registries have long hesitated to extend their data collection. After all, the data collection in most European countries is still voluntary and not linked to the reimbursement of RRT. It was the QUEST data extraction group (chair: R. Kramer – Austria) that took action to try to solve this problem. The enormous variety of electronic patient management systems used in dialysis centres across Europe has led this group to take a standardised approach to this matter also. The group adopted the 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. A uniform infrastructure for data extraction from electronic patient data management systems using HL7 will be further developed under the NephroQUEST project. We expect it to take at least a few years before such a system becomes a reality.

The standardisation of both clinical performance indicators and data extraction has also made it necessary to take a fresh look at the different 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) which is currently working on the extension and definitions of the coding system for primary renal disease and the definitions of co-morbidity and treatment modalities.

■ OTHER PROJECTS

One of the aims of the Registry is to stimulate high-quality nephrology research in Europe. For this reason the Registry started an ERA-EDTA CME ‘Introductory course in Epidemiology’. That this educational activity meets a need has been proven by the warm reception given to these eight courses that have educated more than 200 nephrologists and nephrology researchers in Europe, and the two subsequent sessions given at the invitation of the South-American and the Greek Societies of Nephrology. Their success has also led to an educational ‘ABC in Epidemiology’ series that is now being published in *Kidney International*¹⁰.

A recent separate initiative, but housed in the same department and very closely collaborating with the ERA-EDTA Registry, is the Registry of the European Society for Paediatric Nephrology (ESPN). In addition to the data on paediatric patients that have already been collected by the ERA-EDTA Registry the ESPN Registry will collect additional data from a number of European countries with the aim of performing collaborative studies in children on RRT.

■ BREAKING NEW GROUND

In conclusion, we are confident that the ERA-EDTA Registry is here to stay and play an important role in the European renal registries network. It has taken the lead in trying to solve a number of problems in data collection for research, audit and benchmarking. In addition, it works towards stimulating collaboration in international research, convinced that this will add additional value to a number of studies and, finally, it lends its professional epidemiological expertise to help improve the quality of nephrology research in Europe.

We believe that a registry serving the European Nephrologist community should maintain a proactive attitude and pave the way for systematic collection of new data in areas where prevention and treatment of renal diseases will be vitally important in the foreseeable future. In this respect chronic kidney disease (CKD) is increasingly recognised as a major public health problem. In Europe several surveys on CKD have now been completed and these studies indicate that CKD is of major relevance to public health. Importantly, CKD is now well defined and the CKD staging proposed by Levey *et al.*, is almost universally accepted¹¹. CKD is a dangerous clinical condition for two reasons. Firstly as renal impairment may be a prelude to the development of end stage renal diseases (ESRD), *i.e.* the disease stage where dialysis and transplantation are needed, and secondly as it amplifies the risk of cardiovascular complications. We believe that establishing a European Registry focusing on stage 4 CKD is now a priority. Creating stage 4 CKD registries is formally recommended by Kidney Disease Initiative Global Outcome (KDIGO) experts¹¹. We believe that the ERA-EDTA Registry should move in this direction and stimulate national societies to create renal registries collecting data at a pre-dialysis stage. This is not an easy task but we will strive to facilitate the process and to set the stage for the creation of a stage 4 CKD ERA-EDTA Registry based on national and regional registries of this kind.

The challenge posed by the high prevalence of CKD at a population level is enormous. Renal registries should provide the nephrology community with solid documentation, enabling nephrologists to inform public health authorities of the urgency of the problem. The ERA-EDTA Registry will make a major effort to advance renal epidemiology and to serve patients and renal physicians alike in fighting CKD epidemics.

Conflict of interest statement. None declared.

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