The NephroQUEST project is nearing completion. Since 2007 the project partners have worked together to produce deliverables that are vital for the future of renal registries in Europe and for their potential for international comparisons and scientific collaboration. The magic word within NephroQUEST is standardization. The project’s first and crucial step forward was to finalize and approve of a list of standardized clinical performance indicators to be collected by renal registries. That list was based on fundamental input by the four QUEST clinical working groups, whereas additional input from countries was used for further decision making. Thereafter, this list was adapted by paediatric nephrologists involved in the ESPN/ERA-EDTA Registry to make it suitable for data collection on renal replacement therapy (RRT) in children.

Along the same lines the NephroQUEST partners are in the process of standardizing data extraction, using Health Level 7 (HL7) version 3, an international standard for the exchange, management and integration of electronic healthcare information. As a preparation these partners produced documents on aspects like the legal context of data collection, data safety and current standards for secure data transfer and capture of data at renal centres. Currently, during the project’s final stage, in 5 pilot centres across Europe experience is being acquired with this uniform structure for data extraction from electronic patient data management systems. In this perspective it is of note that this NephroQUEST effort is being complemented by the development of a new coding system for primary renal disease (PRD) by the QUEST Coding & Definitions Working Group. This new PRD coding system was first presented during the World Congress of Nephrology in 2009. Recently, the PRD codes in the new system have been mapped to SNOMED and ICD which will increase the system’s value for use in clinical practice.

For new and developing renal registries the co-funding within NephroQUEST has been fundamental. Six national registries and the European ESPN/ERA-EDTA Registry have been quite successful in increasing their coverage with respect to numbers of centres, patients and countries. All of them have included NephroQUEST clinical performance indicators in their data sets; some have already included such indicators in scientific publications, others will start collecting such data in 2011 after receiving approval to do so from their Ministries of Health.

Finally, state-of-the-art methods are being developed in projects on data quality, techniques for reporting of registry data and quality improvement programmes based on registry data. The researchers involved in the latter project have conducted a systematic review on the implementation of best practice to improve RRT care. Together with surveys among registry representatives and national experts in quality improvement this may outline the possibilities of and provide recommendations for using registry data for ‘quality improvement of RRT care’, which is the aim of NephroQUEST.

A summary of the project results will be presented in the NephroQUEST symposium.

NephroQUEST project results – the basis for the further development of renal registries

From Kitty Jager, NephroQUEST Project Manager and Carmine Zoccali, former ERA-EDTA Registry Chairman

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This newsletter arises from the NephroQUEST project, which has received funding from the European Union, in the framework of the Public Health Programme (project no: 2006114).

This year Turkish nephrology is celebrating the 40th anniversary of the establishment of the Turkish Society of Nephrology (TSN). The TSN Registry of renal replacement therapy (RRT) was set up in 1990 and has been one of TSN’s main activities.

Two decades ago, when the registry started, there were only a couple of dialysis centres in a few large cities. Initially, just aggregated data were collected, but five years later individual patient data collection was added. Until 2007, when TSN joined NephroQUEST, the data set included the ERA-EDTA Registry core data set plus data on comorbidity. Because of the rapidly increasing number of centres and patients, individual data collection included only a portion of the centres and therefore we mainly focused on increasing the collection of aggregated data. By 2008 the coverage of collection of these aggregated data had increased to 99% of 760 centres.

Until 2006 all data were collected on paper forms, but from that year we started to collect data via data entry into a web-based database. In 2007 we joined NephroQUEST and during the 3 years that have passed from that date, paper forms have been eliminated totally. Now all centres are accustomed to enter their data via internet. During this period we further developed our infrastructure. The website that serves as an interface between the centres and the TSN includes two roads to data entry; (1) entry of aggregated data which we intend to continue for a few years, until individual data collection becomes the routine way for all centres, and (2) individual data entry.

TSN decided to adopt data collection of both the core and the extended NephroQUEST datasets and our registry’s database was built in full concordance with the NephroQUEST’s standard operating procedures for the capture of data in renal centres. At this moment we are waiting for the Turkish Ministry of Health to give TSN permission to indeed collect these NephroQUEST datasets via the web. As soon as we have obtained this we will open the website for centres to enter these individual data. As in our country there are more than 60 thousand RRT patients that are being cared for in 900 dialysis centres, we set our target at initially covering 25-30% of the centres that include the 40-50% of the patients.

By September 2010, we will publish the 20th annual report of our registry. This year’s report will include the results of aggregated data corresponding to 2009. It will also include an analysis of the individual patient data of the 1995-2005 cohort including a survival analysis adjusted for standard correction factors, so that it can be compared with patient survival in other countries participating in the ERA-EDTA Registry.

The contribution of NephroQUEST to the Turkish Registry of Renal Replacement Therapy

From Oktay Özdemir – Data manager, on behalf of Turkish Registry of RRT

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Being one of the NephroQUEST partners gave a boost to our action plan:

- We transformed our way of data collection from paper forms to a web-based database,
- We extended the dataset from a basic one including just the ERA-EDTA data set plus comorbidities to the NephroQUEST core and extended data sets, including many variables related with the quality of care,
- We increased our focus on the analysis of existing individual patients, including survival analysis.

There is, however, still work to be done and we hope that, the TSN registry of RRT will be in full compliance with ERA-EDTA Registry data collection by 2011.

Oktay Özdemir

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