

Fifty years of ERA-EDTA Registry—a registry in transition

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In 1964 the ERA-EDTA Registry was started as one of the first renal registries in the world. This meeting report describes how this European registry has developed over the 50 years of its existence. Where the first report presented patient numbers, nowadays the Registry acts as a platform for collaborative renal research in Europe. In addition, it provides training in epidemiology methods to nephrologists and other renal researchers.

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THE BIRTH OF A RENAL REGISTRY

In 1964, just 1 year after the birth of the European Dialysis and Transplant Association (EDTA), Dr Willem Drukker, a Dutch nephrologist who worked at the Wilhelmina Hospital in Amsterdam, decided to start a European registry including data on dialysis patients. By that time dialysis was still an experimental therapy that was provided to a very restricted number of patients with end-stage renal disease. In the spirit of friendship European nephrologists worked together to report the outcomes of this relatively new therapy. This first report of this new registry contained 271 patients starting hemodialysis and 6 peritoneal dialysis patients (Figure 1) with a mortality in the next year that was as high as 40–50%.¹

In the early seventies the Registry moved to Germany. Professor Gurland got the job of Registry Chair because he

Report on regular dialysis treatment in Europe

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Questionnaires were sent to all members of the EDTA by the end of July. The number of questions was limited to facilitate replies. The figures which are presented, may give an overall picture of what is going on in Europe in the field of regular dialysis treatment and may offer a general impression on methods, techniques and results. The results however of the questionnaire cannot be subjected to scientific or statistical analysis. We really hope that the rough results of this questionnaire may point the way for future more exact and complete information from all European centers, which may be subjected to more scientific and statistical analysis.

Replacement of terminal renal failure by intermittent dialysis was started for the first time in Europe in 1948 by Alwall in Lund (Sweden) and the second chronic program was begun 12 years later by Von Kresz on 17th December 1960 in West-Berlin.

In 41 of the 44 centers that replied, 1 or more patients received regular dialysis treatment. Altogether 271 patients were admitted to regular haemodialysis treatment. By August 1965 the total number of survivors was 160, that is 59% (Table I). Only 6 patients underwent intermittent peritoneal dialysis as a substitute for terminal renal failure; 5 of them only for less than 6 months. At the time of reporting they were all alive.

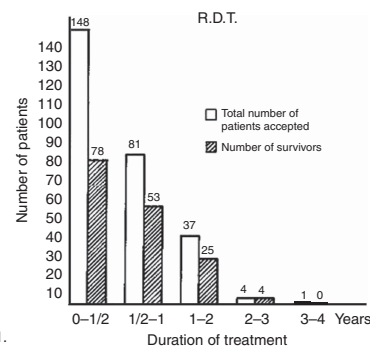


Fig. 1.

In Figure 1, survival data of the haemodialysis patients are presented: of 148 patients under

Figure 1 | First EDTA Registry report.¹

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had been critical of the Registry work at that time. He proposed to bring together the data on dialysis and transplant patients and to organize them in one computer database with complete and dated treatment sequences of patients on renal replacement therapy—before that time they had been kept apart. Second, he introduced more rigorous scientific methods. For the calculation of mortality, he suggested to use ‘patient year at risk’ and ‘innovative’ life table methods instead of the percentage of deaths, which had been used before. Fritz Port therefore later called him the midwife of renal epidemiology, an epidemiology specialty that has come to flourish over the past few decades.

In 1976 Hans Gurland and Tony Wing, the new Registry Chair in London, drove the Registry from Munich to London in a Volkswagen. Years later Tony Wing related upon this transport of the European Registry’s paper filing system that was only 1.5 m long and 0.5 m in height. When the Registry was housed in St Thomas’ Hospital in London in the 1980s, it served as a center of excellence. A high number of publications were coming out and a high number of visitors came from all over the world, eager to adopt the methods of the European Registry. Only one e-mail to people working with the Registry at that time immediately provided a number of examples on how useful the European Renal Association (ERA)-EDTA Registry had been to the development of their own national registry work in the United States and Canada.

After this successful period, in the early 1990s problems started to occur. The Registry could not handle the high number of data returns from the rapidly growing number of dialysis centers in Europe that by that time had increased to around 4000. The data quality decreased and there were problems with the database as the Registry was unable to keep up with the developments in information technology and database systems. For these and other reasons, the ERA-EDTA Council looked for a different place to house the Registry.

RETURN TO AMSTERDAM

In 2000, through efforts made by Sandy Davison and Douglas Briggs, the Registry therefore returned to Amsterdam and is now housed in the Academic Medical Center. Instead of collecting data from renal centers, the new Registry took a different policy by choosing to collect data from national and regional registries.² As a consequence the data quality very much improved, but unfortunately at the same time the coverage of Europe decreased as not all countries had renal registries. Nevertheless, this new environment inspired the confidence of the ERA-EDTA Council as it was academic, while the people working on the Registry were well-versed in information technology and had the renal epidemiology and biostatistical skills needed. The first report of this new ERA-EDTA Registry was published soon thereafter.³

Since then it has continued to collect a core data set including demographical variables, the primary renal disease, the treatment history and date and cause of death of all dialysis, and transplant patients through the affiliated

registries. On the basis of these data, it publishes a biostatistical annual report and a number of scientific papers each year.

To facilitate contacts and collaborations with European nephrology researchers, Registry Chair Carmine Zoccali proposed to organize introductory courses in epidemiology. From the first course in 2004 there has been a huge interest for these courses from nephrologists all over Europe and even from Latin America. Each time there were 30–35 participants to teach them epidemiology at an introductory level making ample use of nephrology examples. In April 2014 the 25th edition of the course was organized in Amsterdam. The course has served as a basis for the writing of a number of epidemiology papers including article series in *Kidney International*, *Nephrology Dialysis Transplantation*, and *Nephron Clinical Practice*.⁴ Since 3 years, this course program has been supplemented with research methods training for future junior reviewers of *Nephrology Dialysis Transplantation*. As a result the Registry now has an active role in the educational activities of ERA-EDTA.

Other research activities consist of special studies making use of additional data collections. They cover a wide variation of subjects, for example, pre-dialysis research in the EQUAL study;⁵ the development of registry methodology including new ERA-EDTA coding systems in collaboration with the International Health Terminology Standards Development Organization;⁶ non-medical factors affecting patient outcomes in the EVEREST study;^{7–9} and a focus on rare diseases and events.¹⁰ Most are performed under the umbrella of the so-called ERA-EDTA QUality European STudies (QUEST) initiative, which has aimed to create a collaborative European renal research network. This network now includes many renal centers in virtually all European countries. The set-up of an affiliated European Society for Paediatric Nephrology/European Renal Association—European Dialysis and Transplant Association(ERA-EDTA) pediatric renal registry in 2007¹¹ has further strengthened the research collaboration with the pediatric nephrology community and has provided a substantial boost to pediatric renal epidemiology work.

Combining research and education, the authors of this report have set up an ‘ERA-EDTA Clinical Epidemiology Learning and Research Centre’ to host visiting researchers at Academic Medical Center and to provide them with data, information, and training on the job of data analyses. In the past 5 years, this center hosted over 20 visiting researchers for short- or long-term visits.

Finally, ERA-EDTA Registry activities have recently been complemented by EURO DOPPS, a research collaboration between Arbor Research and ERA-EDTA, that provides the Registry with access to the European DOPPS data. This is another new and exciting activity that will further extend the collaborative research network that was started through the QUEST initiative. The idea behind the current ERA-EDTA Registry is that by working together we can make most of the nephrology data available.

DISCLOSURE

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REFERENCES

1. Alberts C, Drukker W. Report on regular dialysis in Europe. *Proc Eur Dial Transplant Assoc* 1965; **2**: 82–87.
2. Briggs JD. The ERA-EDTA Registry returns to Amsterdam. *Nephrol Dial Transplant* 2000; **15**: 1326–1327.
3. van Dijk PC, Jager KJ, de Charro F *et al*. Renal replacement therapy in Europe: the results of a collaborative effort by the ERA-EDTA registry and six national or regional registries. *Nephrol Dial Transplant* 2001; **16**: 1120–1129.
4. Zoccali C. General and clinical epidemiology at square two: a new educational series for the renal physician. *Kidney Int* 2007; **72**: 411.
5. Jager KJ, Ocak G, Drechsler C *et al*. The EQUAL study: a European study in chronic kidney disease stage 4 patients. *Nephrol Dial Transplant* 2012; **27** (Suppl 3): iii27–iii31.
6. Venkat-Raman G, Tomson CR, Gao Y *et al*. New primary renal diagnosis codes for the ERA-EDTA. *Nephrol Dial Transplant* 2012; **27**: 4414–4419.
7. Caskey FJ, Kramer A, Elliott RF *et al*. Global variation in renal replacement therapy for end-stage renal disease. *Nephrol Dial Transplant* 2011; **26**: 2604–2610.
8. Kramer A, Stel VS, Caskey FJ *et al*. Exploring the association between macroeconomic indicators and dialysis mortality. *Clin J Am Soc Nephrol* 2012; **7**: 1655–1663.
9. van de Luitgaarden MW, Jager KJ, Stel VS *et al*. Global differences in dialysis modality mix: the role of patient characteristics, macroeconomics and renal service indicators. *Nephrol Dial Transplant* 2013; **28**: 1264–1275.
10. Wühl E, van Stralen KJ, Wanner C *et al*. Renal replacement therapy for rare diseases affecting the kidney: an analysis of the ERA-EDTA Registry. *Nephrol Dial Transplant* 2014; **29**(Suppl 4): iv1–iv8.
11. Tizard EJ, Verrina E, van Stralen KJ *et al*. Progress with the European Society for Paediatric Nephrology (ESPN)/ERA-EDTA Registry for children with established renal failure (ERF). *Nephrol Dial Transplant* 2009; **24**: 2615–2617.