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Epidemiologist

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Medical Information scientist

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The EVEREST Study: Explaining variation in RRT through expert opinion secondary data sources and trend analysis

From Fergus J Caskey, Kitty Jager, Robert F Elliott, Vianda Stel and Alison M MacLeod for the EVEREST Study group



Fergus J Caskey

The EVEREST Study is a collaborative study under the umbrella of the QUEST initiative and has been formally endorsed by the ERA-EDTA and the ISN.

The incidence of Renal Replacement Therapy (RRT) shows huge variation across the world. (1) Even amongst economically developed countries there are large differences: around 100 cases per million of the population (pmp) in the UK, Australia, New Zealand and the Netherlands; around 200 pmp in Germany and Greece; over 350 pmp in the US and more than 400 pmp in Taiwan. (1) While rates of hypertension and diabetes in the general population and progression of CKD to established renal failure (ERF) are no doubt important factors this variation (2-4), organisational and financial factors determining the availability of dialysis facilities are also likely to have a direct or indirect effect on patients' pathways onto RRT around the world.

[Read more](#)

The ESPN/ERA-EDTA registry – the new pediatric registry has made a successful start

From Karlijn van Stralen, Enrico Verrina, Jane Tizard and Kitty Jager

Established renal failure in children and young adults is a rare disease. Single country data may be underpowered to show any differences or effects of treatment and therefore cooperation between countries is essential to improve their outcome. Until 2007 data collection on children and young adults on renal replacement therapy (RRT) in Europe was limited to that of the ERA-EDTA Registry and specific data collection from Italy, the UK and Turkey. As the ERA-EDTA Registry does not include paediatric patients from all participating countries, data on children have only been available from a limited part of Europe. For this reason the new ESPN/ERA-EDTA registry started in February 2007. An epidemiologist was appointed to work with the ERA-EDTA registry team and with the two ESPN representatives in the ERA-EDTA registry committee. Forty European countries were contacted via the presidents of national societies or known registry leads and 33 responded favourably to being interested in participating in the future registry. In 2008, 29 paediatric registries (from 25 countries) contributed data to the ESPN/ERA-EDTA registry regarding patients who were on RRT in 2006. In that year 2370 patients under 15 years of age were on RRT in a population covering 81 million children and a total population over 435 million individuals.



Karlijn van Stralen

[Read more](#)

Sample size calculations

From Marlies Noordzij, ERA-EDTA Registry epidemiologist



Marlies Noordzij

The sample size is the number of patients or other experimental units included in a study. Pre-study calculation of the required sample size is warranted in the majority of quantitative studies. Usually, the number of patients in a study is restricted because of ethical, cost, and time considerations. However, if the sample size is too small, one may not be able to detect an important existing effect, whereas samples that are too large may waste time, resources and money. It is therefore important to optimize the sample size.

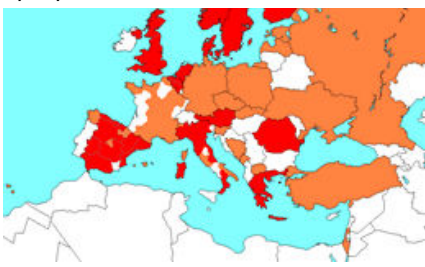
[Read more](#)

Announcements

Starting from January 2009 a new series of 20 articles on epidemiology will be written for *Nephron Clinical Practice*. The papers will discuss a broad variety of epidemiological and biostatistical topics and will be authored by investigators collaborating with the ERA-EDTA Registry located in Reggio Calabria, Italy, and



Leiden and Amsterdam, the Netherlands.



In 2009 the ERA-EDTA Registry will perform an international survey on reasons when to start renal replacement therapy (RRT). With this survey we aim to determine European nephrologists' current opinions about when to start RRT for ESRD in early referred adult patients. Furthermore, we aim to identify which clinical, social, and logistical factors influence this decision and which factors play a role in the decision not to start RRT. At present the questionnaire is being developed in cooperation with Charlie Tomson and David Ansell (UK), Cecile Couchoud (France), Giovanni Cancarini (Italy), Marlies Noordzij, Vianda Stel, and Kitty Jager (The Netherlands). Within a few months many European nephrologists will receive an invitation to participate in the study and we hope they will take a few moments to complete our questionnaire. If you have any questions regarding this study, please contact the study coordinator Moniek van de Luitgaarden: m.w.vandeluitgaarden@amc.uva.nl.

Contributions as of July 1, 2008

registries contributing individual patient data to the ERA-EDTA registry database

registries sending selected aggregated data to be included in the annual report

no registry/no contribution/data not eligible for analysis

Agenda of ERA-EDTA Registry activities:

- March 14-16, 2009 10th [CME Introductory Course on Epidemiology](#), Brussels, Belgium
- April 15-16, 2009 CME Introductory Course on Epidemiology as a pre-congress course of the XV SLANH congress. Mexico-City, Mexico

Forthcoming issues

Newsletter 14, May 2009

WHY BECOME A MEMBER?

ERA-EDTA RENEWAL

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World Congress of Nephrology 2009
 May 22-26, 2009 - Milan, Italy
www.wcn2009.org

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