

# ANNUAL REPORT 2003 ERA - EDTA REGISTRY

## **Suggested citation**

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# ERA - EDTA REGISTRY ANNUAL REPORT 2003

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## **I INTRODUCTION**

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## **II METHODS**

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## I Introduction

The ERA-EDTA Registry collects data on renal replacement therapy (RRT) via the national and regional renal registries in Europe.

This 2003 annual report includes information based on 55 registries from 27 countries.

Section

A contains data on incidence, prevalence and survival as well as data on expected remaining life times from those 32 national and regional registries from 12 countries whose individual patient data are included in the ERA-EDTA Registry database (shown in red).

Section B relates to 24 national and regional registries from 17 countries providing aggregated

data based on individual patient data, centre questionnaire data or information from health authorities (shown in orange). Their data are not included in the ERA-EDTA Registry database.

These registries complete the tables themselves and return them to the ERA-EDTA Registry office for inclusion in this annual report.

Austria 15 November 2004

Belgium, Dutch-speaking 15 December 2004

Belgium, French-speaking 28 April 2003

Denmark 20 November 2004

Finland 14 January 2005

Greece 15 February 2005

Iceland 22 November 2004

Italy (13 of 20 regions) 4 February 2005

Norway 1 November 2004

Spain, Asturias 18 February 2005

Spain, Basque country 10 March 2005

Spain, Cantabria 14 January 2005

Spain, Castile and Leon 25 February 2005

Spain, Castile-La Mancha 14 January 2005

Spain, Catalonia 5 November 2004

Spain, Valencian region 11 November 2004

Sweden 21 January 2005

The Netherlands 11 November 2004

United Kingdom, England/Wales 4 April 2005

United Kingdom, Scotland 14 February 2005

## **II Methods**

### **Section A**

The tables in this section are based on the analyses of data sets received from national and regional registries collecting individual patient data, which are included in the ERA-EDTA Registry database. Like in 2002, it was not possible for French-speaking Belgium to participate in this report with recent data as they had technical problems at the start of a new web-based computer system. This year the Italian national registry covered 62% of the total population with individual patient data. However, the data of the regions Apulia and Lazio did not fit with the structure of the ERA-EDTA registry database. Therefore, data presented on Italy in this report cover 45% of the total Italian population and are based on 13 of 20 regions, including Abruzzi, Basilicata, Calabria, Emilia-Romagna, Liguria, Marche, Molise, Piedmont, Sardinia, Trentino-Alto Adige, Tuscany, Valle d'Aosta and Veneto. The databases serving as a basis for the analyses were received on the dates shown in the following table.

#### **Registry Date**

Registry data are subject to continuous alteration and improvement. Small differences between ERA-EDTA Registry data and the data presented in the national/regional registry's own annual reports may therefore result from different times of data extraction.

#### **Differences in data collection between collaborating registries and inclusion of their data into the ERA-EDTA Registry database**

In the comparison of data between registries it should be recognized that there may be small differences between registries in definitions and in the collection of their data. The different registries do not for example collect data at the same level of detail, especially with regard to the different subtypes of the treatment modalities. If registries provide information on the residency of their patients, only data on residents in the coverage area of such registries are included into the ERA-EDTA Registry database.

The data present from Belgium (Dutch-speaking), Spain (Asturias), Spain (Cantabria), Spain (Castile and Leon), Spain (Castile-La Mancha), and the United Kingdom (England/Wales) comprise only patients older than 20 years of age. In the UK, inclusion of data on children would add 2 pmp to the overall UK incidence rate and 12 pmp to the UK prevalence. In addition, it should be noted that the prevalence figures produced by the UK Renal Registry are slightly higher than those produced by the ERA-EDTA Registry. This is due to the fact that the UK Renal Registry calculates prevalence rates from the electronic quarterly data returns (which are not part of the ERA-EDTA Registry data set) rather than from the timeline which can be incomplete for some patients.

#### **Incidence and prevalence**

The incidence tables refer to all patients who started RRT for end stage renal disease (ESRD) in 2003 and the prevalence tables to all patients who were alive and on RRT on 31 December 2003. General population data for the year 2003, provided by Eurostat, the national bureaus of statistics or the national or regional registry, served as the population base. The grouping of renal diseases is provided in Appendix 1.

For the adjustment of incidence and prevalence for age and gender we used the age and gender distribution of the European population of 1995 as provided by Eurostat.

#### **Survival analysis**

For the analysis of survival data we used two five-year cohorts:

. 1994-1998 - for the presentation of 90-day (for survival on RRT and on dialysis), one-, two- and five-year survival probabilities. These analyses were based on data from Austria, Belgium (Dutch-speaking), Belgium (French-speaking), Denmark, Finland, Greece, Iceland, Italy (Basilicata), Italy (Calabria), Italy (Emilia-Romagna), Italy (Marche), Italy (Piedmont), Italy (Sardinia), Italy (Veneto), Norway, Spain (Asturias), Spain (Basque country), Spain (Cantabria), Spain (Catalonia), Spain (Valencian region), Sweden, The Netherlands, United Kingdom (England/Wales) and United Kingdom (Scotland).

. 1997-2001 - for the presentation of 90-day (for survival on RRT and on dialysis), one-

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and two-year survival probabilities. These analyses were based on data from Austria, Belgium (Dutch-speaking), Belgium (French-speaking), Denmark, Finland, Greece, Iceland, Italy (Basilicata), Italy (Calabria), Italy (Emilia-Romagna), Italy (Marche), Italy (Piedmont), Italy (Sardinia), Italy (Veneto), Norway, Spain (Asturias), Spain (Basque country), Spain (Cantabria), Spain (Catalonia), Spain (Valencian region), Sweden, The Netherlands, United Kingdom (England/Wales) and United Kingdom (Scotland).

With regard to the inclusion of data, some further comments need to be made. The data were used from the date from which they were available, which in a small number of cases was later than the first cohort year, this being due to the fact that the national or regional registry was established later. Survival was analysed from day 1 and from day 91 onwards for those patients alive and on RRT on those days. All patients had the opportunity to complete the entire follow-up period with the exception of patients starting in the last 90 days of a cohort in a survival analysis from day 91.

For the different types of survival analysis we defined the following events and censoring.

**Survival type Event Censoring**

Patients on renal replacement therapy Death of patient Recovery of renal function

Loss to follow-up

End of follow-up time

Patients on dialysis Death of patient Transplantation

Recovery of renal function

Loss to follow-up

End of follow-up time

First transplant recipients Death of patient Loss to follow-up

End of follow-up time

First graft Death of patient Loss to follow-up

Graft failure End of follow-up time

Survival is presented in tables and figures. As the ERA-EDTA Registry database is still growing with respect to the coverage of European countries, we chose to adjust for fixed values for a number of parameters in our survival analyses. The values used for the survival tables are shown in the following table.

**Survival type Age Gender Renal disease**

Patients on renal replacement therapy 60 years 60% male 20% diabetes mellitus  
17% hypertension/rvd \*

15% glomerulonephritis

48% other cause

Patients on dialysis 60 years 60% male 20% diabetes mellitus

17% hypertension/rvd

15% glomerulonephritis

48% other cause

First transplant recipients 45 years 60% male 10% diabetes mellitus  
(cadaver donor) 8% hypertension/rvd

28% glomerulonephritis

54% other cause

First transplant recipients 45 years 60% male 10% diabetes mellitus  
(living donor) 8% hypertension/rvd

28% glomerulonephritis

54% other cause

First graft (cadaver donor) 45 years 60% male 10% diabetes mellitus  
8% hypertension/rvd

28% glomerulonephritis

54% other cause

First graft (living donor) 45 years 60% male 10% diabetes mellitus

8% hypertension/rvd

28% glomerulonephritis

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54% other cause

\* *rvd: renal vascular disease*

In unadjusted survival analysis the cells in the tables were left blank when there were less than 30 patients in that cell. In the adjusted survival analysis, cells with less than 30 events were left empty. The latter analysis excluded patients for whom age, gender, or primary renal disease was missing.

In the Figures A.5.1 to A.5.3 survival was adjusted for age 60 years and gender 60% male. In addition, Figure A.5.1 was adjusted for renal disease distribution: 20% diabetes mellitus; 17% hypertension/renal vascular disease (rvd); 15% glomerulonephritis and 48% other cause.

For the calculation of expected remaining lifetimes of the patients and the general population we used the same methodology as the USRDS (USRDS 2004 Annual Report). For Europe, the mortality data of the general population of the contributing countries were provided by Eurostat. The size of the contribution of each country to the general population that was used to calculate expected remaining lifetimes was in proportion to the size of the general population covered by its registry.

### **Section B**

These tables relate to countries which provide aggregated data based on individual patient data, centre questionnaire data or information from health authorities. As their data are not included in the ERA-EDTA Registry database, the tables were completed by national and regional registries themselves and sent to the ERA-EDTA Registry for inclusion in this annual report. Data from France are based on 7 of 24 regions, including Auvergne, Bretagne, Champagne-Ardenne, Languedoc-Roussillon, Limousin, Lorraine, and Rhône-Alpes, whereas the data of Spain are based on 14 of 19 regions, including Andalusia, Asturias, Basque country, Canary Islands, Cantabria, Castile and Leon, Castile-La Mancha, Extremadura, Galicia, La Rioja, Navarra, Valencian region, and on the two overseas cities Ceuta and Melilla.

The incidence tables refer to all patients who started RRT for ESRD in 2003 and the prevalence tables to all patients who were alive and on RRT on 31 December 2003. General population data for the year 2003 were provided by the national or regional registries. For the adjustment of incidence and prevalence for age and gender they used the age and gender distribution of the European population of 1995. For the French data it was assumed that patients with a functioning graft with unknown residence lived in the same region where they were followed.