Demographics of paediatric renal replacement therapy in Europe: 2007 annual report of the ESPN/ERA-EDTA registry

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The ESPN/ERA-EDTA registry

Few data are available regarding the epidemiology of end-stage renal disease (ESRD) in children. The European Society of Paediatric Nephrology (ESPN), in collaboration with the European Renal Association–European Dialysis and Transplant Association (ERA-EDTA), has recently established a meta-registry of European paediatric patient registries [1]. Thirty European countries reported individual patient data with information on date of birth, gender, start date renal replacement therapy (RRT), treatment modality at the start, changes in treatment, and important events such as

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death and transfer out of registry. Here we provide the first demographic information obtained by the ESPN/ERA-EDTA registry, relating to the calendar year 2007, including data from 28 countries.

Hungary provided data for 86%, and Russia for 50% of the population; the demographic figures from these countries were extrapolated accordingly. As Italy only provided information on those starting on dialysis, this country was omitted from the calculation of the transplantation-specific incidence and prevalence. As the majority of countries (Belarus, Croatia, Czech Republic, Estonia, FYR of Macedonia, Hungary, Italy, Latvia, Lithuania, Montenegro, Poland, Portugal, Russia, Serbia, Slovakia, Slovenia, and the United Kingdom) collected information mainly from paediatric centres, information on individuals 15–17 years could be incomplete. In order to provide a valid comparison between countries, reporting has therefore been restricted to patients younger than 15 years of age.

Incidence was defined as the number of new patients starting RRT in 2007, and the point prevalence was given by the total number of patients on RRT on 31 December 2007 [2]. Both incidence and prevalence were expressed in absolute numbers and per million age-related population (pmarp). Furthermore, to allow calculations of the number of children on RRT based on population data, results were also expressed per million total population, including adults (pmtp).

### Incidence of paediatric RRT across Europe

In 2007, the overall incidence rate of RRT among children under the age of 15 was 6.5 pmarp, which was 1.0 pmtp. The median reported incidence by region/country was 6.5 pmarp (interquartile range 3.7–7.8). The incidence was highest in adolescence (8.0 pmarp; age group 10–14 years), lowest in mid-childhood (4.6 pmarp), and intermediate (6.7 pmarp) in children younger than 5 years of age. RRT incidence was almost 50% higher in males (7.5 pmarp) than in females (5.4 pmarp). The modality-specific incidences were 2.8 pmarp for peritoneal dialysis, 2.4 pmarp for haemodialysis, 1.0 pmarp for pre-emptive transplantation and unknown for 0.3 pmarp (Table 1).

### Prevalence of paediatric RRT across Europe

The overall point prevalence of paediatric RRT on 31 December 2007 was 33.6 pmarp, which was 5.4 pmtp. The median prevalence across countries and regions was 31.1 pmarp, with an interquartile range of 24.5 to 41.6 pmarp. Prevalence increased more than threefold from the infant to

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**Table 1** Incidence of paediatric patients accepted for renal replacement therapy (RRT) in 2007 and general population characteristics of countries contributing 2007 data to the European Society for Paediatric Nephrology/European Renal Association—European Dialysis and Transplant Association (ESPN/ERA-EDTA) registry

| Country | RRT patients | General population |
|---------|--------------|---------------------|
|         | 0–14 years   | 0–14 years          |
|         | Count pmarp  | Count               |
| Austria | 10           | 7.7                 | 1,296,776 |
| Belarus | 10           | 7.0                 | 1,421,557 |
| Croatia | 2            | 2.9                 | 686,967  |
| Czech Republic | 9 | 6.1               | 1,478,219 |
| Denmark | 5            | 4.9                 | 1,025,793 |
| Estonia | 0            | 0.0                 | 199,223  |
| Finland | 11           | 12.3                | 897,885  |
| France | 77           | 6.5                 | 11,767,559 |
| FYR of Macedonia | 3 | 7.9              | 381,868  |
| Greece | 13           | 8.1                 | 1,598,665 |
| Hungary | 3           | 2.3                 | 1,306,516 |
| Iceland | 1            | 15.2                | 65,633   |
| Italy | 35           | 4.2                 | 8,350,585 |
| Latvia | 1            | 3.2                 | 315,386  |
| Lithuania | 3 | 5.7              | 527,561  |
| Montenegro | 0 | 0                | 123,048 |
| The Netherlands | 22 | 7.5        | 2,947,170 |
| Norway | 3            | 3.3                 | 906,655  |
| Poland | 41           | 6.9                 | 5,961,618 |
| Portugal | 16 | 9.8             | 1,633,245 |
| Romania | 8           | 2.4                 | 3,298,815 |
| Russia | 81           | 7.8                 | 10,426,340 |
| Serbia | 5            | 4.4                 | 1,142,760 |
| Slovakia | 4           | 4.6                 | 860,833  |
| Slovenia | 2          | 7.1                 | 281,081  |
| Spain, Andalusia | 10 | 7.6             | 1,316,682 |
| Spain, Aragon | 2           | 11.7                | 170,569  |
| Spain, Basque | 1          | 3.7                 | 271,786  |
| Spain, Catalonia | 4 | 3.8             | 1,046,915 |
| Spain, Valencia | 7 | 9.9             | 707,577  |
| Sweden | 11           | 7.1                 | 1,545,660 |
| United Kingdom | 83 | 7.7          | 10,721,100 |
| Total | 483          | 6.5                 | 74,682,067 |

Incident rates may vary over the years due to random variation because of small numbers

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A Assuming 86% coverage of general population for Hungary and 50% coverage for Russia
B Pre-emptive transplantation not included
C Only patients from paediatric centres included
### Table 2
Prevalence of paediatric patients on renal replacement therapy (RRT) on 31 December 2007. Prevalent counts and prevalence per million age-related population by age and gender in countries contributing 2007 data to the European Society for Paediatric Nephrology/European Renal Association—European Dialysis and Transplant Association (ESPN/ERA-EDTA) data registry

| Country             | Total (years) RRT patients | Age groups (years) | Gender (years) | Treatment modality\(d\) (years) |
|---------------------|-----------------------------|-------------------|----------------|---------------------------------|
|                     |                             | 0–14              | 0–4            | 5–9               | 10–14           | 0–14 | 0–14 | 0–14 | 0–14 | 0–14 | 0–14 |
|                     |                             | Count             | pmarp          | pmarp            | pmarp           | pmarp | pmarp | pmarp | pmarp | pmarp | pmarp |
| Austria             | 54                          | 41.6              | 17.5           | 50.3             | 54.3            | 49.6  | 33.3  | 2.3   | 3.9   | 35.5  |
| Belarus             | 19                          | 13.3              | 8.7            | 17.6             | 13.4            | 13.6  | 12.9  | 2.8   | 9.8   | 0.7   |
| Croatia             | 19                          | 27.7              | 14.6           | 17.5             | 47.4            | 31.2  | 23.9  | 2.9   | 11.6  | 13.1  |
| Czech Republic      | 33                          | 22.3              | 19.8           | 15.5             | 30.7            | 21.1  | 23.6  | 1.4   | 8.8   | 12.2  |
| Denmark             | 38                          | 37.0              | 15.2           | 38.4             | 56.0            | 45.7  | 28.0  | 3.9   | 1.9   | 31.2  |
| Estonia             | 2                           | 10.0              | 0.0            | 16.2             | 14.8            | 9.8   | 10.3  | 0     | 10.0  | 0     |
| Finland             | 83                          | 92.4              | 79.3           | 93.8             | 103.0           | 102.5 | 81.9  | 1.1   | 10.0  | 81.3  |
| France              | 401                         | 34.1              | 15.5           | 29.3             | 57.9            | 41.7  | 26.1  | 5.0   | 2.3   | 26.4  |
| FYR of Macedonia    | 7                           | 18.3              | 0.0            | 16.1             | 34.6            | 25.4  | 10.8  | 0     | 18.3  | 0     |
| Greece              | 46                          | 28.8              | 9.3            | 33.1             | 43.9            | 34.0  | 23.2  | 5.6   | 10.0  | 13.1  |
| Hungary\(a\)       | 37                          | 28.3              | 7.2            | 21.7             | 52.5            | 38.8  | 17.3  | 1.5   | 3.1   | 23.7  |
| Iceland             | 2                           | 30.5              | 0.0            | 94.1             | 0.0             | 0.0   | 62.1  | 0     | 0     | 30.5  |
| Italy\(b\)         | 247                         | 29.6              | 18.2           | 31.8             | 38.7            | 33.8  | 25.1  | 2.6   | 7.7   | na    |
| Latvia\(c\)        | 2                           | 6.3               | 0.0            | 10.5             | 8.9             | 6.2   | 6.5   | 0     | 6.3   | 0     |
| Lithuania           | 17                          | 32.2              | 19.7           | 23.8             | 48.2            | 44.4  | 19.4  | 11.4  | 9.5   | 11.4  |
| Montenegro          | 1                           | 8.1               | 0.0            | 24.7             | 0.0             | 15.7  | 0.0   | 0     | 0     | 8.1   |
| The Netherlands     | 131                         | 44.4              | 18.8           | 45.6             | 68.2            | 52.4  | 36.1  | 7.8   | 6.4   | 30.2  |
| Norway              | 42                          | 46.3              | 24.0           | 39.9             | 73.2            | 56.0  | 36.2  | 1.1   | 0     | 45.2  |
| Poland              | 230                         | 38.6              | 22.7           | 38.7             | 51.2            | 45.2  | 29.3  | 6.5   | 18.6  | 12.4  |
| Portugal\(d\)      | 64                          | 39.2              | 22.1           | 45.5             | 49.9            | 47.7  | 30.2  | 1.2   | 19.6  | 18.4  |
| Romania             | 35                          | 10.6              | 1.9            | 7.3              | 21.9            | 8.9   | 12.4  | 5.8   | 4.2   | 0.6   |
| Russia\(a\)        | 168                         | 16.1              | 5.5            | 14.0             | 29.1            | 16.3  | 15.9  | 5.5   | 3.7   | 6.6   |
| Serbia              | 28                          | 24.5              | 5.4            | 27.4             | 39.5            | 32.4  | 16.2  | 6.1   | 1.8   | 16.6  |
| Slovakia            | 23                          | 26.7              | 7.6            | 25.8             | 43.1            | 27.2  | 26.2  | 4.6   | 11.6  | 10.5  |
| Slovenia            | 6                           | 21.3              | 10.9           | 33.0             | 20.4            | 27.7  | 14.6  | 7.1   | 10.7  | 3.6   |
| Spain, Andalusia    | 41                          | 31.1              | 6.8            | 25.7             | 60.4            | 33.9  | 28.2  | 1.5   | 2.3   | 27.3  |
| Spain, Aragon       | 6                           | 35.2              | 34.0           | 17.9             | 53.8            | 45.6  | 24.2  | 0     | 0     | 35.2  |
| Spain, Basque       | 26                          | 95.7              | 20.0           | 134.0            | 145.5           | 100.3 | 90.8  | 3.7   | 7.4   | 84.6  |
| Spain, Catalonia    | 48                          | 45.8              | 31.0           | 46.9             | 62.7            | 55.6  | 35.4  | 5.7   | 1.9   | 38.2  |
| Spain, Valencia     | 29                          | 41.0              | 32.8           | 34.6             | 55.9            | 54.9  | 26.2  | 7.1   | 4.2   | 29.7  |
| Sweden              | 75                          | 48.5              | 30.8           | 44.5             | 68.5            | 55.5  | 41.2  | 1.3   | 5.2   | 42.1  |
| United Kingdom      | 552                         | 51.5              | 23.1           | 46.7             | 83.4            | 60.8  | 41.1  | 6.8   | 11.8  | 24.0  |
| Total               | 2512                        | 33.6              | 16.4           | 32.2             | 51.5            | 39.2  | 27.5  | 4.8   | 7.4   | 20.1e |

\(HD\) haemodialysis, \(PD\) peritoneal dialysis, \(Tx\) transplantation
\(a\) Assuming 86% coverage of the general population for Hungary, 50% for Russia
\(b\) Pre-emptive transplantation not included
\(c\) Only patients from paediatric centres included
\(d\) Patients with unknown treatment modalities excluded
\(e\) Patients from Italy excluded
the adolescent age group. More than half of the patients had a functioning kidney allograft (20.1 pmarp), whereas 7.4 patients pmarp were on peritoneal dialysis and 4.8 on haemodialysis. Treatment modality was unknown in 1.4 patients pmarp (Table 2).

Conclusions

The data contributed by 32 registries from 28 European countries by the end of 2007 allowed us to calculate current demographic figures for paediatric RRT across the continent. Both incidence and prevalence of RRT are about 20 times lower in children compared with adults [3]. In comparison to the last demographic report of the former EDTA registry 14 years ago [4], we found nearly threefold higher incidence and prevalence of RRT among children aged younger than 15 years. This difference is likely to be due to the critical underreporting to the previous registry based on questionnaire collection from individual centres. However, it may in some part also reflect a recent achievement of RRT programmes for all children in many countries and an increasing acceptance and survival of infants and children with multiple comorbidities in paediatric RRT programmes, resulting in a truly increased incidence and prevalence of RRT. Nevertheless, information extracted from the report on paediatric RRT of the current ERA-EDTA registry [5], which comprised data collected in 2000 from 11 western European countries, showed that children younger than 15 years had a very similar incidence and slightly higher prevalence compared with data presented in this report.

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Conflict of interest  None

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