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ORIGINAL ARTICLE

# The European Renal Association – European Dialysis and Transplant Association (ERA-EDTA) Registry Annual Report 2016: a summary

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# **ABSTRACT**

Background. This article summarizes the ERA-EDTA Registry's 2016 Annual Report, by describing the epidemiology of renal replacement therapy (RRT) for end-stage renal disease (ESRD) in 2016 within 36 countries.

Methods. In 2017 and 2018, the ERA-EDTA Registry received data on patients undergoing RRT for ESRD in 2016 from 52 national or regional renal registries. In all, 32 registries provided individual patient data and 20 provided aggregated data. The incidence and prevalence of RRT and the survival probabilities of these patients were determined.

Results. In 2016, the incidence of RRT for ESRD was 121 per million population (pmp), ranging from 29 pmp in Ukraine to 251 pmp in Greece. Almost two-thirds of patients were men, over half were aged ≥65 years and almost a quarter had diabetes mellitus as their primary renal diagnosis. Treatment modality at the start of RRT was haemodialysis for 84% of patients. On 31 December 2016, the prevalence of RRT was 823 pmp, ranging from 188 pmp in Ukraine to 1906 pmp in Portugal. In 2016, the transplant rate was 32 pmp, varying from 3 pmp in Ukraine to 94 pmp in the Spanish region of Catalonia. For patients commencing RRT during 2007-11, the 5-year unadjusted patient survival probability on all RRT modalities combined was 50.5%. For 2016, the incidence and prevalence of RRT were higher among men (187) and 1381 pmp) than women (101 and 827 pmp), and men had a higher rate of kidney transplantation (59 pmp) compared with women (33 pmp). For patients starting dialysis and for patients receiving a kidney transplant during 2007-11, the adjusted patient survival probabilities appeared to be higher for women than for men.

Keywords: dialysis, end-stage renal disease, epidemiology, kidney transplantation, survival analysis

# INTRODUCTION

The European Renal Association - European Dialysis and Transplant Association (ERA-EDTA) Registry's Annual Report describes the epidemiology of renal replacement therapy (RRT) for end-stage renal disease (ESRD) within Europe and countries bordering the Mediterranean Sea, based on the data collected via national and regional renal registries [1]. The summary of the ERA-EDTA Registry Annual Report, which is published on an annual basis, is intended to provide an overview of the current status of RRT for ESRD in Europe [2-4]. In 2017 and 2018, data for the year 2016 were received from 52 national or regional renal registries in 36 countries covering a general population of 686.9 million people. When leaving out Israel and Tunisia, the remaining countries cover a general population of 677.3 million people, representing 80.5% of the 2016 European general population, which was similar to 2015 (80.3%). A total of 32 national or regional renal registries from 17 countries provided individual patient data, whereas 20 countries or regions provided aggregated data (see Appendix A1). Compared to the 2015 ERA-EDTA Registry Annual Report, there were no differences in country participation.

This summary presents the 2016 incidence and prevalence of RRT, kidney transplantation activity, and the patient and graft survival. A description of the methods used to analyse the data, along with the full results, can be found in the ERA-EDTA Registry 2016 Annual Report [1].

On the occasion of the 2018 global focus on kidneys and women's health, this year's annual report contains additional analyses on sex comparisons, a summary of which is also presented in this article.

#### **RESULTS**

#### Incidence of RRT

In 2016, 83311 individuals commenced RRT for ESRD, which equated to an overall unadjusted incidence of 121 per million population (pmp; Table 1). The unadjusted incidence was highest in Greece (251 pmp), Czech Republic (243 pmp) and Portugal (236 pmp), whereas it was lowest in Ukraine (29 pmp) and Russia (59 pmp; Table 1 and Figures 1 and 2). Of the patients commencing RRT, 62% were men, 52% were aged ≥65 years and 23% had diabetes mellitus (DM) as their primary renal diagnosis (Figure 3). The median age of the patients commencing RRT in all countries and regions combined was 65.8 years, ranging from 51.0 years in Ukraine to 73.8 years in the Dutch-speaking part of Belgium (Table 1). The majority of patients started RRT with haemodialysis (HD; 84%), while 12% of patients started with peritoneal dialysis (PD) and 4% received a pre-emptive kidney transplant (Figure 4). However, the initial treatment modality varied considerably between age groups, as the proportion of patients receiving either PD or a pre-emptive transplant decreased with increasing age. Furthermore, patients with a primary renal diagnosis of DM were less likely to receive a pre-emptive kidney transplant compared with non-diabetic patients (2% versus 6%). Of the incident patients receiving RRT at Day 91 after the start of treatment, the majority (82%) were receiving HD, 13% were receiving PD and 5% were living with a kidney transplant (Figure 5). In the first 90 days of treatment, the percentage of patients receiving HD decreased, and this was particularly evident in the younger age groups.

# Prevalence of RRT

On 31 December 2016, 564638 individuals were receiving RRT for ESRD (Table 2), corresponding to an overall unadjusted

prevalence of 823 pmp. Again, there was considerable variation between countries, with the highest unadjusted prevalence seen in Portugal (1906 pmp) and the Spanish regions of Catalonia (1399 pmp) and Valencia (1388 pmp; Table 2 and Figures 6 and 7). The unadjusted prevalence of RRT was considerably lower in Ukraine (188 pmp) and Belarus (289 pmp). The top five countries with the highest prevalence of RRT have remained the same since 2014. Of the prevalent patients, 60% were men, 42% were aged ≥65 years and 17% had DM as their primary renal diagnosis (Figure 8). The median age of prevalent patients receiving RRT in all countries and regions combined was 62.4 years, ranging from 50.7 years in Albania to 68.0 years in Israel (Table 2). The majority of prevalent patients (58%) were receiving HD, 37% of patients were living with a kidney transplant and only 5% were receiving PD (Figure 9). Once again the modality of RRT varied considerably between age groups as the proportion of patients with a kidney transplant decreased with increasing age. For those aged 20-44 years, 66% were living with a kidney transplant, whereas this was only 42% for patients aged 65-74 years. Prevalent patients with a primary renal diagnosis of DM were much less likely to be living with a kidney transplant compared with the patients without DM (28% versus

#### Kidney transplantation

In 2016, 22 046 kidney transplantations were performed, which equated to an overall unadjusted transplant rate of 32 pmp (Figure 10). Again there was considerable variation between countries/regions with unadjusted kidney transplant rates well over 70 pmp in several Spanish regions, and very low unadjusted kidney transplant rates in Ukraine (3 pmp) and Macedonia (3 pmp). Overall, the unadjusted deceased donor kidney transplant rate was more than twice that of the unadjusted living donor transplant rate (22 pmp versus 9 pmp; 70% versus 30%; Figure 11). The highest unadjusted rates of deceased donor kidney transplants were seen in some Spanish regions (>70 pmp; Figure 12), whereas the highest unadjusted rate of living donor transplants was seen in Northern Ireland (38 pmp), the Netherlands (33 pmp) and Turkey (33 pmp; Figure 12).

# Survival of patients receiving RRT

For patients commencing RRT in the period 2007-11, the 5-year unadjusted patient survival probability for all RRT modalities combined was 50.5% [95% confidence interval (CI) 50.4-50.6]. For patients commencing RRT with dialysis between 2007 and 2011, the 5-year unadjusted patient survival probability was 42.1% (95% CI 42.0-42.3). Adjusted analyses for patient survival on HD and PD revealed higher survival probabilities in the first 3 years for patients receiving PD (Figure 13). For those with a kidney transplant, 5-year adjusted patient and graft survival were higher for living donor transplants compared with deceased donor transplants: 94.6% (95% CI 94.1-95.1) versus 91.9% (95% CI 91.6-92.3) for patient survival and 86.7% (95% CI 85.9-87.4) versus 80.9% (95% CI 80.4-81.4) for graft survival. See Table 3 for a description of the adjustments made and the countries/regions included in these analyses.

#### Expected remaining lifetime

There is still a substantial difference in the expected remaining lifetime between the general population and those receiving dialysis (Figure 14). Patients aged 20-44 years receiving dialysis

Table 1. Incidence of RRT in 2016 at Day 1, by country/region, for all primary renal diseases combined and DM types 1 and 2, as count (n) and unadjusted rate pmp, and the mean and median age at the start of RRT

Country/region  Albania	General population covered by the registry in thousands						Incidence of RRT in 2016, at Day 1						
Albania		All (n)	All (pmp)	Mean age (years)	Median age (years)	DM (n)	DM (pmp)						
Albailla	2860	252	88	52.6	52.2	50	17						
Austria	8700	1155	133	64.4	67.3	305	35						
Belarus	8172	504	62	53.0	54.0	92	11						
Belgium, Dutch-speaking <sup>a</sup>	6509	1214	187	71.0	73.8	256	39						
Belgium, French-speaking <sup>a</sup>	4822	906	188	67.3	69.3	202	42						
Bosnia and Herzegovina	3531	397	112	62.2	63.9	131	37						
Bulgaria	7102	1109	156			309	44						
Croatia	3755	675	180	64.9	66.0	181	48						
Cyprus	857	165	193	66.7	69.0	47	55						
Czech Republic <sup>b</sup>	10 262	2496	243										
- Denmark	5784	740	128	63.3	67.4	192	33						
Estonia	1316	112	85	59.7	61.6	19	14						
Finland	5495	560	102	60.9	63.8	189	34						
France	66 860	11 033	165	67.9	70.6	2566	38						
Georgia	3720	754	203	60.4	61.9	187	50						
Greece	10 776	2702	251	70.8	73.6	710	66						
Iceland	335	30	89	61.7	65.1	5	15						
Israel	8545	1612	189	65.1	68.0	805	94						
Italy (6 of 20 regions)	20 921	3023	144	68.8	71.8	522	25						
Latvia	1560	171	110	60.3	63.0	26	17						
Lithuania	2888	310	107	61.8	62.5	52	18						
Macedonia	2022	332	164	63.7	65.0	84	42						
Norway	5235	556	106	63.1	66.5	88	17						
Poland <sup>b</sup>	38 362	5716	149			2098	55						
Portugal	10 358	2446	236			757	73						
Romania	19 505	3454	177	62.4	64.5	356	18						
Russia <sup>b</sup>	143 869	8521	59	54.3	57.0	1491	10						
Serbia <sup>c</sup>	7058	618	88	62.0	64.6	139	20						
Slovakia <sup>b</sup>	5435	835	154	64.6	66.0	316	58						
Spain (All regions)	46 558	6600	142	63.0	67.5	1610	35						
Spain, Andalusia	8406	1133	135	63.5	66.0	294	35						
Spain, Aragon	1317	165	125	63.5	67.3	39	30						
Spain, Asturias	1041	188	181	64.8	66.6	41	39						
Spain, Basque country	2166	284	131	63.4	65.4	57	26						
Spain, Cantabria <sup>a</sup>	582	59	101	63.1	67.7	12	21						
Spain, Castile and León <sup>a</sup>	2445	308	126	68.1	71.3	85	35						
Spain, Castile-La Mancha <sup>a</sup>	2045	287	140	66.1	69.1	67	33						
Spain, Catalonia	7523	1260	167	65.9	68.7	261	35						
Spain, Extremadura	1088	120	110	65.6	66.6	34	31						
Spain, Galicia	2715	399	147	66.0	68.7	102	38						
Spain, Community of Madrid	6467	870	135	64.9	67.7	227	35						
Spain, Region of Murcia	1465	202	138	63.3	65.3	47	32						
Spain, Navarre <sup>a</sup>	639	82	128	64.7	67.2	21	33						
Spain, Valencian region	4960	858	173	65.8	68.9	178	36						
Sweden	9923	1204	121	64.0	67.9	324	33						
Switzerland	8373	844	101	63.8	66.6	181	22						
The Netherlands	16 349	1906	117	64.2	67.4	368	23						
Tunisia, Sfax region <sup>b</sup>	1213	193	159	60.5	63.0	62	51						
Turkey <sup>d</sup>	79 815	11 169	140	23.0	-3.0	787	10						
UK, England <sup>a,e</sup>	55 268	6454	117	62.3	64.4	1618	29						
UK, Northern Ireland <sup>a</sup>	1862	225	121	62.8	66.4	55	30						
UK, Scotland	5405	571	106	59.2	61.6	55 171	32						
UK, Wales <sup>a</sup>	3113	371	119	64.9	66.5	92	30						
Ukraine	42 590	1246	29	49.7	51.0	303	30 7						
All countries	687 084	83 311	121	63.1	65.8	17 757	29						

When cells are left empty, the data are unavailable and could not be used for the calculation of the summary data.

<sup>&</sup>lt;sup>a</sup>Patients <20 years of age are not reported. The true incidence counts are, therefore, slightly higher than the counts reported here.

 $<sup>{}^{\</sup>rm b}{\rm Data}$  on incidence include dialysis patients only.

 $<sup>^{</sup>m c}$ The incidence is underestimated by  $\sim$ 29% due to centres not submitting complete data for 2016.

<sup>&</sup>lt;sup>d</sup>Data on incidence of primary renal disease (DM) is based on 2078 dialysis patients (18.6% of total).

 $<sup>^{</sup>m e}$ The incidence is underestimated by  $\sim$ 2% due to a small number of centres not submitting complete data for 2016.

DM, diabetes mellitus as primary renal disease.

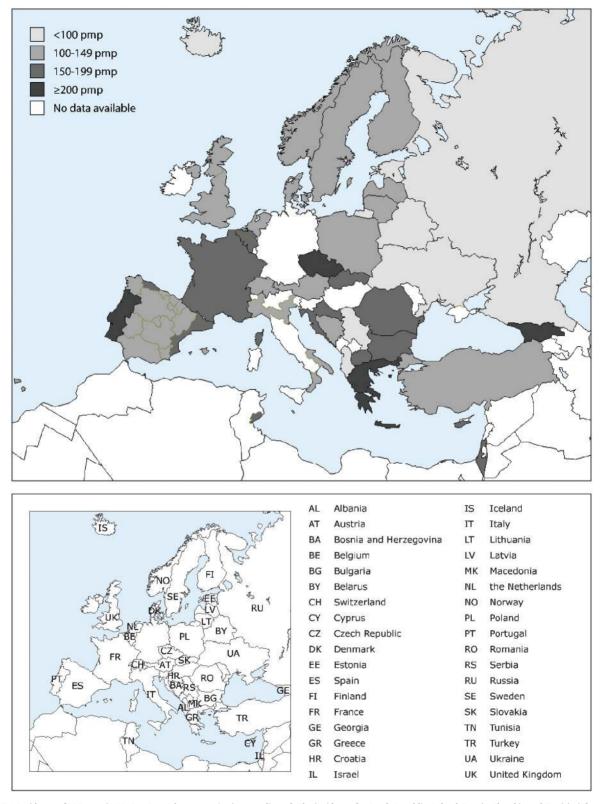


FIGURE 1: Incidence of RRT pmp in 2016, at Day 1, by country/region, unadjusted. The incidence for Czech Republic, Poland, Russia, Slovakia and Tunisia (Sfax region) only includes patients receiving dialysis. For Serbia and England (UK), the incidence is underestimated by, respectively,  $\sim$ 26% and  $\sim$ 2% (see Table 1).

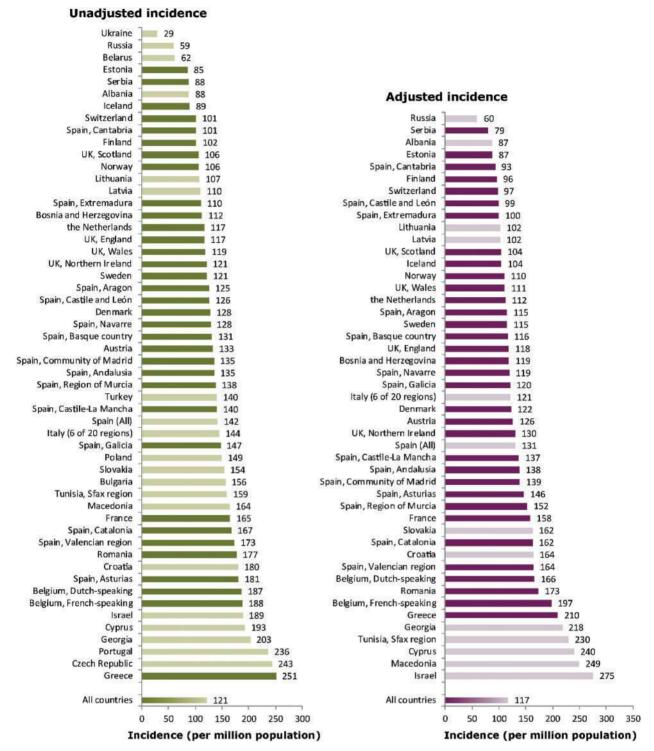
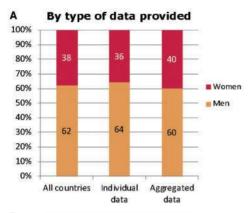
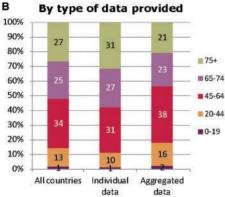


FIGURE 2: Unadjusted (left panel) and adjusted (right panel) incidence of RRT pmp in 2016, at Day 1, by country/region. Registries providing individual patient data are shown as dark bars, and registries providing aggregated data as light bars. Adjustment of incidence was performed by standardizing the rates to the age and gender distribution of the EU27 population [5]. The incidence for Czech Republic, Poland, Russia, Slovakia and Tunisia (Sfax region) only includes patients receiving dialysis. For Serbia and England (UK), the incidence is underestimated by, respectively,  $\sim$ 26% and  $\sim$ 2% (see Table 1).





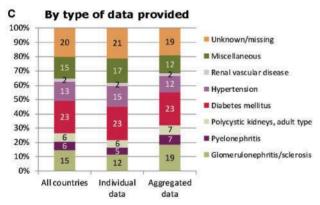
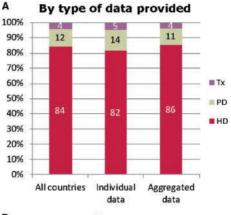
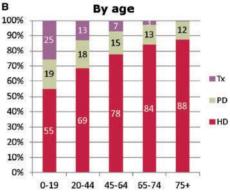


FIGURE 3: (A) Sex, (B) age and (C) primary renal disease distribution by type of data provided for incident patients accepted for RRT in 2016, at Day 1. See Appendix A1 for a list of countries and regions supplying individual patient data or aggregated data

are expected to live only one-third of the expected remaining lifetime of the age-matched general population, which is about 33 years less. The prospect is even worse for patients aged 45-64 years, as they are expected to live only a quarter as long as their age-matched counterparts in the general population (~21 years less). Patients living with a kidney transplant fare better than those receiving dialysis. However, the life expectancy of the transplant recipients aged 20–44 years is still  $\sim$ 30% less than that of the age-matched general population ( $\sim$ 15 years less). Thus, as the age of the transplant recipient increases, the relative difference in the expected remaining lifetime from that of the age-matched general population also increases although the absolute difference decreases.





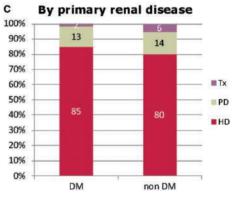
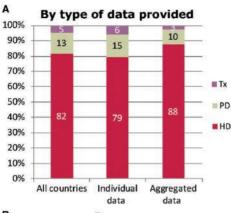


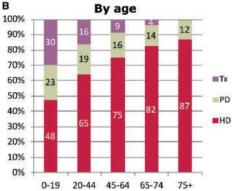
FIGURE 4: Treatment modality distribution, at Day 1, by (A) type of data provided (B) age and (C) primary renal diagnosis (DM and non-DM) for incident patients accepted for RRT in 2016. Parts (B) and (C) are only based on the data from registries providing individual patient data. See Appendix A1 for a list of countries and regions supplying individual patient data or aggregated data. Tx, kidney transplant.

# Sex comparisons

Figures 15-31 showing comparisons of the sexes are based on the data from 32 national or regional renal registries from 17 countries that provided individual patient data, representing 33.8% of the 2016 European general population.

In 2016, 26446 men and 14820 women commenced RRT resulting in a higher unadjusted incidence among men (187 pmp) than women (101 pmp). This was the case for all age groups, with the incidence in men aged  $\geq$ 75 years (807 pmp) being 2.7 times that of women aged ≥75 years (300 pmp; Figure 15). In men and women commencing RRT, the distribution of the age groups was very similar (Figure 16). About 36% of patients commencing RRT were female, decreasing from around





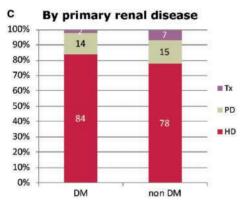


FIGURE 5: Treatment modality distribution, at Day 91, by (A) type of data provided, (B) age and (C) primary renal diagnosis (DM and non-DM) for incident patients accepted for RRT in 2016. Parts (B) and (C) are only based on the data from registries providing individual patient data. See Appendix A1 for a list of countries and regions supplying individual patient data or aggregated data. Tx, kidney transplant.

39% of patients <45 years at the start of RRT to about 36% of patients aged ≥45 years (Figure 17).

Diabetes was the most frequent primary renal disease in both men and women starting RRT (Figure 18). The incidence of men starting RRT for ESRD due to glomerulonephritis/sclerosis (23 pmp) and hypertension (29 pmp) was more than double that of their female counterparts (10 and 13 pmp, respectively), while the incidence of polycystic kidney disease in men (9 pmp) was only about 30% higher than in women (7 pmp). When viewed by sex, the distribution of the primary renal disease was similar. Of the men commencing RRT, 16% had hypertension and 12% had glomerulonephritis/sclerosis, and for women this was 13 and 10%, respectively (Figure 19).

The incidence of all treatment modalities was higher among men than women (Figure 20). Of the men and women initiating RRT in 2016, the majority started with HD (82 and 81%, respectively; Figure 21). Although more men (8 pmp) than women (5 pmp) received a pre-emptive transplant, the percentage of patients starting RRT with a pre-emptive transplant was similar among men (4%) and women (5%).

On 31 December 2016, 195 810 men and 121 755 women were receiving RRT for ESRD, resulting in a higher prevalence of RRT among men (1381 pmp) than women (827 pmp), which was the case for all age groups (Figure 22). In men, the highest prevalence was found in the group aged ≥75 years, whereas in women the highest prevalence was found in the group aged 65-74 years. The age distribution of patients receiving RRT was similar for both sexes, with most patients in the 45- to 64-year age group (39%; Figure 23). The percentage of women within the different age groups varied between 37% among patients aged 65-74 years and 40% among patients aged 0-19 years (Figure 24). The prevalence of men on RRT with glomerulonephritis/sclerosis and hypertension (301 and 167 pmp) was more than twice that of women (140 and 75 pmp; Figure 25). For men receiving RRT, the most frequent primary renal disease was glomerulonephritis/sclerosis (22%), while for women their most frequent primary renal disease category was 'miscellaneous' (Figure 26, Appendix 2). For both men and women, the majority of patients were receiving HD (668 and 399 pmp), and slightly fewer men and women were living with a kidney transplant (642 and 382 pmp, respectively; Figure 27). The distribution of treatment modalities was similar across the sexes (Figure 28).

In 2016, 8355 kidney transplantations were performed in men, and 4827 in women, equating to transplant rates of 59 and 33 pmp, respectively (Figure 29). For men, 22% of the transplants came from living donors, and for women 24% (Figure 30).

For patients commencing RRT with dialysis in the period 2007-11, for both HD and PD, the adjusted patient survival probabilities were higher for women than for men (Figure 31). For both men and women receiving a kidney transplant in the period 2007-11, the adjusted patient survival was higher with a living donor transplant compared with a deceased donor transplant, and this difference was more prominent in men than in women.

# **AFFILIATED REGISTRIES**

Albanian Renal Registry (M. Barbullushi, A. Idrizi and E. Bolleku Likaj); Austrian Dialysis and Transplant Registry [OEDTR] (R. Kramar); Belarus Renal Registry (K.S. Komissarov, K.S. Kamisarau and A.V. Kalachyk); Dutch-speaking Belgian Society of Nephrology [NBVN] (M. Couttenye, F. Schroven and J. De Meester); French-speaking Belgian Society of Nephrology [GNFB] (JM. des Grottes and F. Collart); Renal Registry Bosnia and Herzegovina (H. Resić, Z. Stipancic and N. Petkovic); Bulgaria (E.S. Vazelov and I. Velinova); Croatian Registry of renal replacement therapy [CRRRT] (I. Bubić and M. Knotek); Cyprus Renal Registry (K. Ioannou and all of the renal units providing data); Czech Republic: Registry of Dialysis Patients [RDP] (I. Rychlík, J. Potucek, and F. Lopot); Danish Nephrology Registry [DNS] (J.G. Heaf); Estonian Society of Nephrology (Ü. Pechter, K. Lilienthal and M. Rosenberg); Finnish Registry for Kidney Diseases (P. Finne, A. Pylsy and P.H. Groop); France: The Epidemiology and Information Network in Nephrology [REIN] (M. Lassalle and C. Couchoud); Georgian Renal Registry (N. Kantaria and Dialysis Nephrology and Transplantation Union of Georgia); Hellenic Renal Registry (N. Afentakis); Icelandic ESRD Registry (R.

Table 2. Prevalence of RRT on 31 December 2016, by country/region, for all primary renal diseases combined and DM types 1 and 2, as count (n) and unadjusted rate pmp, and the mean and median age on 31 December 2016

	General population covered by	Prevalent patients on RRT in 2016						
Country/region	the registry in thousands	All (n)	All (pmp)	Mean age (years)	Median age (years)	DM (n)	DM (pmp)	
Albania	2860	1450	507	49.6	50.7	230	80	
Austria	8700	9397	1080	61.2	62.7	1848	212	
Belarus	8172	2360	289	51.6	53.0	295	36	
Belgium, Dutch-speaking <sup>a</sup>	6509	8257	1269	66.1	67.9	1426	219	
Belgium, French-speaking <sup>a</sup>	4822	6317	1310	64.9	66.5	1109	230	
Bosnia and Herzegovina	3531	2679	759	59.7	61.7	548	155	
Bulgaria	7102	4333	610					
Croatia	3755	3908	1041	65.7	67.0	710	189	
Cyprus	857							
Czech Republic	10 262	11 265	1098					
Denmark	5784	5433	939	58.8	60.4	929	161	
Estonia	1316	919	698	57.9	58.6	168	128	
Finland	5495	4861	885	59.2	61.5	1231	224	
France	66 860	85 471	1278	62.8	64.6	13 833	207	
Georgia	3720	2652	713	60.1	61.2	539	145	
Greece	10 776	13 841	1284	64.6	66.8	2637	245	
Iceland	335	224	668	54.9	56.3	26	78	
Israel <sup>b</sup>	8545	6566	768	66.0	68.0	3035	355	
Italy (6 of 20 regions)	20 921	24 035	1149	62.0	64.1	2654	127	
Latvia	1560	1038	665	56.3	57.0	98	63	
Lithuania	2888	2193	759					
Macedonia	2022	1665	823	58.6	60.0	273	135	
Norway	5235	4974	950	59.4	61.5	654	125	
Poland	38 362	31 144	812			6132	160	
Portugal	10 358	19 738	1906	66.9	67.9	3435	332	
Romania <sup>c</sup>	19 505	20 445	1048	61.2	63.0	2051	105	
Russia	1 43 869	44 544	310	55.5	57.0	5340	37	
Serbia <sup>d</sup>	7058	3833	543	59.5	62.0	640	91	
Slovakia <sup>b</sup>	5435	3370	620	63.8	66.0	1140	210	
Spain (All regions)	46 558	57 433	1234	60.0	63.2	9031	194	
Spain, Andalusia	8406	10 019	1192	60.5	61.9	1548	184	
Spain, Aragon	1317	1588	1205	62.9	64.0	274	208	
Spain, Asturias	1041	1325	1273	63.0	63.5	215	207	
Spain, Basque country	2166	2704	1249	62.0	63.8	304	140	
Spain, Cantabria <sup>a</sup>	582	686	1179	62.6	64.0	91	156	
Spain, Castile and León <sup>a</sup>	2445	2858	1169	64.8	65.8	505	207	
Spain, Castile-La Mancha <sup>a</sup>	2045	2357	1153	62.5	63.3	373	182	
Spain, Catalonia	7523	10 523	1399	63.0	64.8	1499	199	
Spain, Community of Madrid	6467	7450	1152	61.9	63.2	1323	205	
Spain, Extremadura	1088	1263	1161	62.0	62.3	191	176	
Spain, Galicia	2715	3619	1333	62.5	64.0	598	220	
Spain, Navarre <sup>a</sup>	639	837	1310	62.5	64.0	128	200	
Spain, Region of Murcia	1465	1949	1331	62.1	63.3	274	187	
Spain, Valencian region	4960	6883	1388	63.3	65.2	933	188	
Sweden	9923	9718	979	59.9	62.0	1742	176	
Switzerland <sup>e</sup>	8373	7503	896	62.1	63.9	1159	138	
The Netherlands	16 349	17 117	1047	60.5	62.4	2229	136	
Tunisia, Sfax region <sup>b</sup>	1213	946	780	58.2	59.0	200	165	
Turkey <sup>f</sup>	79 815	74 475	933			2719	34	
UK, England <sup>a,g</sup>	55 268	52 641	952	58.8	59.2	8884	161	
UK, Northern Ireland <sup>a</sup>	1862	1784	958	58.7	58.4	280	150	
UK, Scotland	5405	5028	930	56.8	57.7	826	153	
UK, Wales <sup>a</sup>	3113	3062	984	59.5	60.3	503	162	
Ukraine	42 590	8019	188	49.5	51.0	1280	30	
All countries	687 084	564 638	823	60.6	62.4	79834	134	

When cells are left empty, the data are unavailable and could not be used for the calculation of the summary data.

<sup>&</sup>lt;sup>a</sup>Patients <20 years of age are not reported. The true prevalent counts are therefore slightly higher than the counts reported here.

 $<sup>^{\</sup>mathrm{b}}\mathrm{Data}$  on prevalence include dialysis patients only.

 $<sup>^{\</sup>circ}$ The prevalence is underestimated by  $\sim$ 3% due to an estimated 30% under-reporting of patients living with a functioning graft.

 $<sup>^{</sup>m d}$ The prevalence is underestimated by  $\sim$ 29% due to centres not submitting complete data for 2016.

 $<sup>^{\</sup>rm e} {\rm The~prevalence~is~underestimated~by~} \sim \! 6\%~{\rm due~to~an~estimated~} 11\%~{\rm under-reporting~of~patients~living~with~a~functioning~graft}.$ 

Data on the prevalence of primary renal disease (DM) is based on 8043 dialysis patients (10.8% of total)

 $<sup>^</sup>g$ The prevalence is underestimated by  $\sim$ 1% due to a small number of centres not submitting complete data for 2016.

DM, diabetes mellitus as primary renal disease.

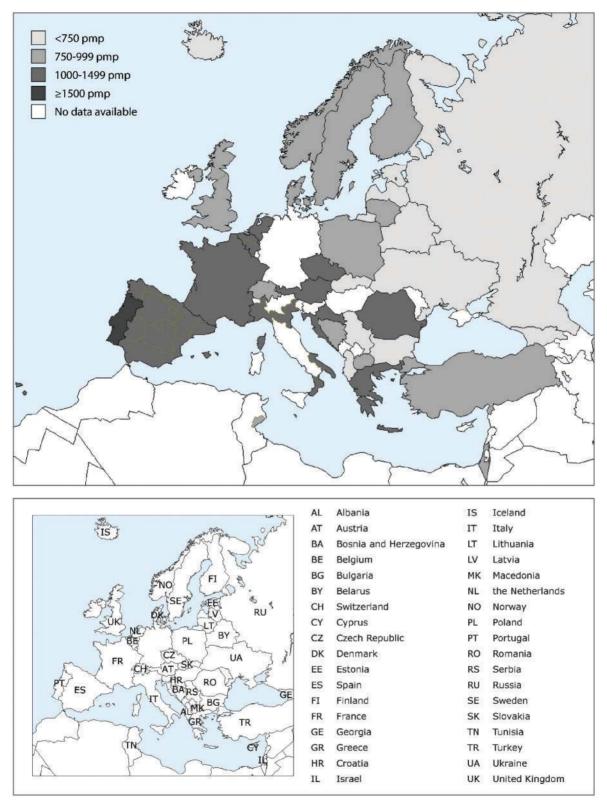


FIGURE 6: Prevalence of RRT pmp on 31 December 2016 by country/region. The prevalence for Israel only includes patients receiving dialysis. For Romania, Serbia, Switzerland and England (UK), the prevalence is underestimated by, respectively,  $\sim$ 30,  $\sim$ 29,  $\sim$ 6 and  $\sim$ 1% (see Table 2).

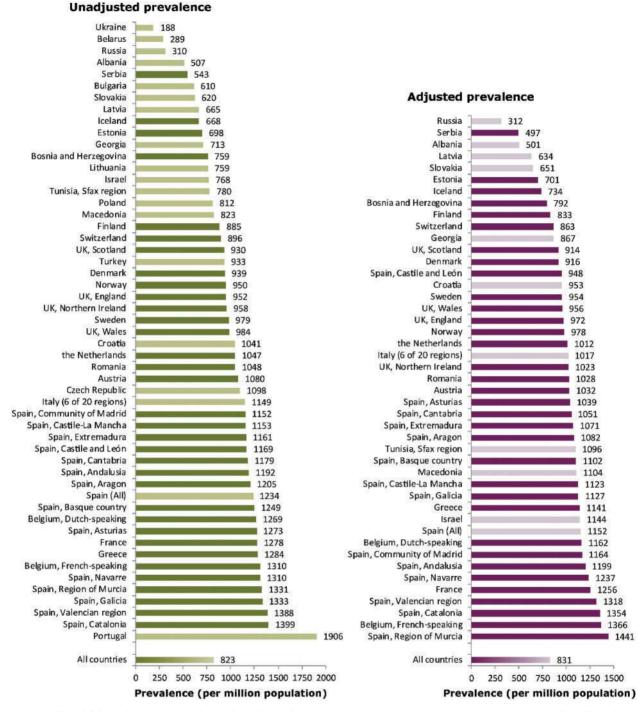
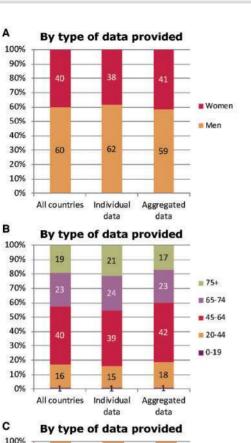


FIGURE 7: Unadjusted (left panel) and adjusted (right panel) prevalence of RRT pmp on 31 December 2016 by country/region. Registries providing individual patient data are shown as dark bars, and registries providing aggregated data as light bars. Adjustment of the prevalence was performed by standardizing the prevalence to the age and gender distribution of the EU27 population [5]. The prevalence for Israel only includes patients receiving dialysis. For Romania, Serbia, Switzerland and England (UK), the prevalence is underestimated by, respectively,  $\sim$ 30,  $\sim$ 29,  $\sim$ 6 and  $\sim$ 1% (see Table 2).



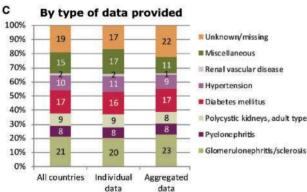


FIGURE 8: (A) Sex, (B) age and (C) primary renal disease distribution by type of data provided for prevalent patients on RRT on 31 December 2016. See Appendix A1 for a list of countries and regions supplying individual patient data or aggregated data

Palsson); Israel National Registry of Renal Replacement Therapy (R. Dichtiar, T. Shohat and E. Golan); Italian Registry of Dialysis and Transplantation [RIDT] (A. Limido, M. Nordio and M. Postorino); Latvian Renal Registry (H. Cernevskis, V. Kuzema and A. Silda); Lithuanian Renal Registry (I.A. Bumblyte, V. Vainauskas and E. Žiginskienė); Macedonian Renal Registry (M. Nedelkovska, N. Dimitriova and O. Stojceva-Taneva); Norwegian Renal Registry (T. Leivestad, A.V. Reisæter and A. Åsberg); Polish Renal Registry (G. Korejwo, A. Debska-Ślizień and R. Gellert); Portuguese Renal Registry (F. Macário and A. Ferreira); Romanian Renal Registry [RRR] (G. Mircescu, L. Garneata and E. Podgoreanu); Russian Renal Registry (N. Tomilina, A. Andrusev and H. Zakharova); Renal Registry in Serbia (N. Maksimovic, R. Naumovic, all of the Serbian renal units, and the Serbian Society of Nephrology); Slovakian Renal Registry (V. Spustová, I. Lajdová and M. Karolyova); Spanish RRT

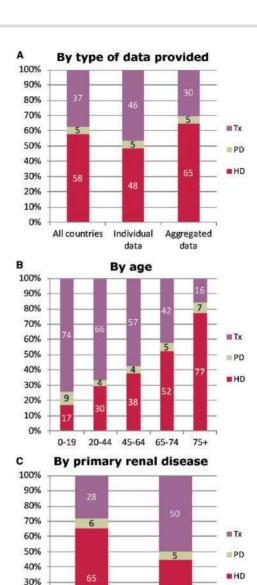


FIGURE 9: Treatment modality distribution by (A) type of data provided (B) age and (C) primary renal diagnosis (DM and non-DM) for prevalent patients on RRT on 31 December 2016. Parts (B) and (C) are only based on the data from registries providing individual patient data. See Appendix A1 for a list of countries and regions supplying individual patient data or aggregated data. Tx, kidney transplant.

non DM

DM

20%

10%

National Registry at ONT, Spanish Regional Registries and Spanish Society of Nephrology (SEN) and the regional registries of Andalusia [SICATA] [P. Castro de la Nuez (on behalf of all users of SICATA)], Aragon (F. Arribas Monzón, J.M. Abad Diez and J.I. Sanchez Miret), Asturias (R. Alonso de la Torre, J.R. Quirós and RERCA Working Group), Basque country [UNIPAR] (Á. Magaz, J. Aranzabal, M. Rodrigo and I. Moina), Cantabria (J.C. Ruiz San Millán, O. Garcia Ruiz and C. Piñera Haces), Castile and León (M.A. Palencia García), Castile-La Mancha (G. Gutiérrez Ávila and I. Moreno Alía), Catalonia [RMRC] (E. Arcos, J. Comas and J. Tort), Extremadura (J.M. Ramos Aceitero and M.A. García Bazaga), Galicia (E. Bouzas-Caamaño), Community of Madrid (M.I. Aparicio de Madre), Renal Registry of the Region of Murcia (C. Santiuste de Pablos and I. Marín Sánchez), Navarre (M.F. Slon

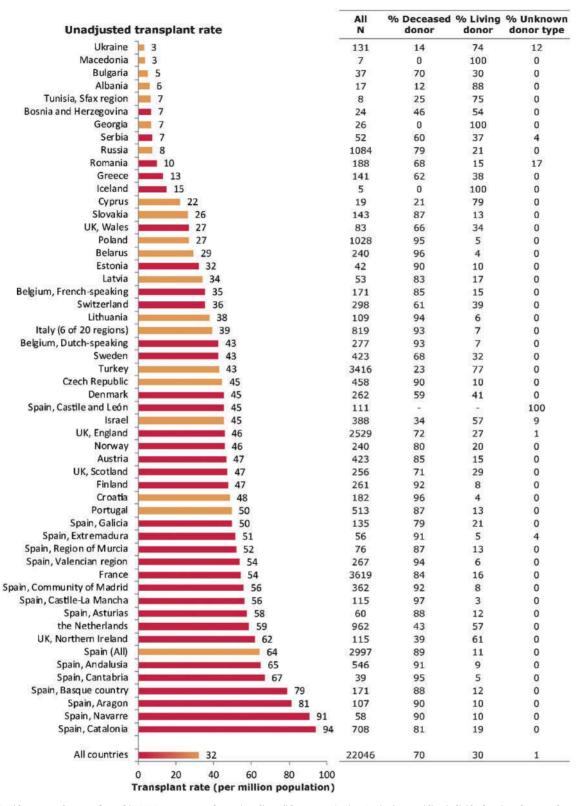


FIGURE 10: Kidney transplants performed in 2016, as counts and pmp (unadjusted) by country/region. Registries providing individual patient data are shown as dark bars, and registries providing aggregated data as light bars. Data based on patients aged ≥20 years in Dutch-speaking Belgium, French-speaking Belgium, the Spanish regions of Cantabria, Castile and León, Castile-La Mancha and Navarre and UK: England, Northern Ireland and Wales. The total count for Austria is based on residents  $and non-residents. For Romania, Serbia, Switzerland \ and England \ (UK), the overall kidney \ transplant \ rate is underestimated \ by, \ respectively, \ \sim 30, \ \sim 36, \ \sim 6 \ and \ \sim 7\%.$ 

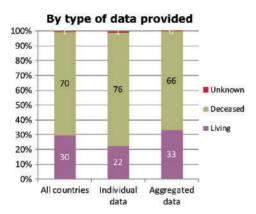


FIGURE 11: Donor-type distribution for kidney transplants performed in 2016, by type of data provided. See Appendix A1 for a list of countries and regions sup plying individual patient data or aggregated data.

Roblero, J. Manrique Escola and J. Arteaga Coloma) and the Valencian region [REMRENAL] (M. Ferrer Alamar, N. Fuster Camarena and J. Pérez Penadés); Swedish Renal Registry [SNR] (K.G. Prütz, M. Stendahl, M. Evans, S. Schön, T. Lundgren and M. Segelmark); Swiss Dialysis Registry (P. Ambühl and R. Winzeler); Dutch Renal Registry [RENINE] (L. Heuveling, S. Vogelaar and M. Hemmelder); Tunisia, Sfax region (F. Jarraya and D. Zalila); Registry of the Nephrology, Dialysis and Transplantation in Turkey [TSNNR] (G. Süleymanlar, N. Seyahi and K. Ates); Ukrainian Renal Data System [URDS] (M. Kolesnyk, S. Nikolaenko and O. Razvazhaieva); United Kingdom Renal Registry [UKRR] (all the staff of the UK Renal Registry and of the renal units submitting data); Scottish Renal Registry [SRR] (all of the Scottish renal units).

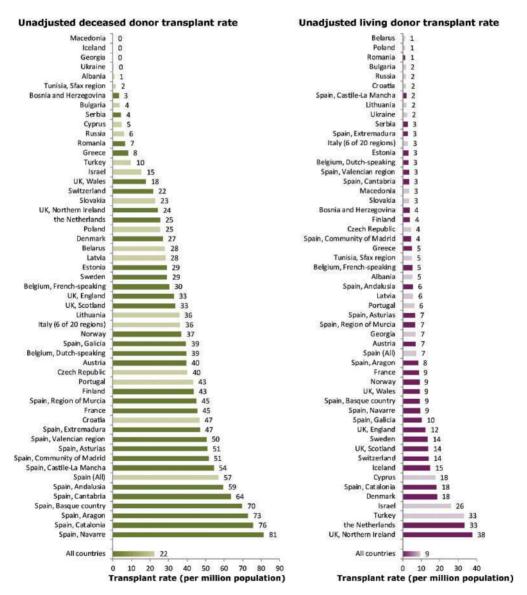


FIGURE 12: Deceased donor (left panel) and living donor (right panel) kidney transplants performed in 2016 pmp, by country/region, unadjusted. Registries providing individual patient data are shown as dark bars, and registries providing aggregated data as light bars. Data based on patients aged  $\geq$ 20 years in Dutch-speaking Belgium, French-speaking Belgium, the Spanish regions of Cantabria, Castile and León, Castile-La Mancha and Navarre and UK: England, Northern Ireland and Wales. The total count for Austria is based on residents and non-residents. For Romania, Switzerland and England (UK), the kidney transplant rate is underestimated by, respectively,  $\sim$ 30,  $\sim$ 6 and  $\sim$ 7%. For Serbia, the transplant rate is underestimated by  $\sim$ 29% for deceased donor transplants and by  $\sim$ 39% for living donor transplants.

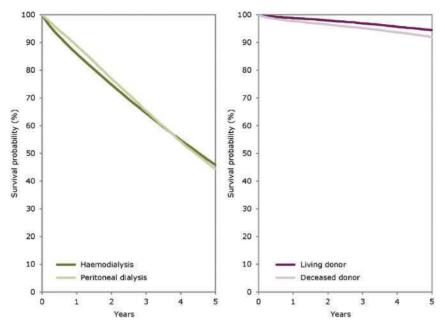


FIGURE 13: Patient survival of patients starting HD and PD between 2007 and 2011 from Day 91 (left panel) and patients receiving a first kidney transplant from a living or deceased donor between 2007 and 2011 (right panel). Survival on dialysis was censored for transplantation, and adjusted using fixed values for age (67 years), gender (63% men) and primary renal disease (24% DM, 19% hypertension/renal vascular disease, 11% glomerulonephritis and 46% other causes). Survival after kidney transplantation was adjusted using fixed values for age (50 years), gender (63% men) and primary renal disease (14% DM, 10% hypertension/renal vascular disease, 23% glomerulonephritis and 53% other causes). These figures are based on the data from the following registries providing individual patient data: Austria, Belgium (Dutchspeaking), Belgium (French-speaking), Denmark, Finland, France, Greece, Iceland, Norway, Spain (Andalusia), Spain (Aragon), Spain (Asturias), Spain (Basque country), Spain (Cantabria), Spain (Castile and León), Spain (Castile-La Mancha), Spain (Catalonia), Spain (Extremadura), Spain (Galicia), Spain (Community of Madrid), Spain (Valencian region), Sweden, the Netherlands and the UK (all countries).

Table 3. The survival probabilities at 1, 2 and 5 years by treatment modality and cohort, from Day 1 of the start of RRT/dialysis, or from the day of kidney transplantation

		Survival probabilities as percentage (95% CI)								
		Cohort: 2007–11	Cohort: 2010–14							
Survival type	1 year	2 years	5 years	1 year	2 years					
Patient survival on F	RRT									
Unadjusted	83.6 (83.4-83.7)	73.2 (73.1-73.4)	50.5 (50.4-50.6)	84.6 (84.4-84.7)	74.6 (74.5-74.8)					
Adjusted <sup>a</sup>	86.3 (86.1–86.4)	76.6 (76.4–76.9)	51.7 (51.5–52.0)	87.1 (86.9–87.3)	77.9 (77.7–78.1)					
Patient survival on d	lialysis	,	, ,	, ,	, ,					
Unadjusted	82.5 (82.4–82.7)	70.8 (70.6-71.0)	42.1 (42.0-42.3)	83.5 (83.3-83.6)	72.1 (71.9-72.2)					
Adjusted <sup>a</sup>	84.7 (84.5–84.9)	74.0 (73.7–74.2)	45.5 (45.2–45.8)	85.9 (85.7–86.0)	75.6 (75.4–75.8)					
Patient survival afte	r first kidney transplantati	on (deceased donor)								
Unadjusted	96.3 (96.1–96.5)	94.4 (94.1-94.6)	87.7 (87.3-88.0)	96.3 (96.1-96.5)	94.3 (94.0-94.5)					
Adjusted <sup>b</sup>	97.7 (97.5–97.9)	96.4 (96.2–96.6)	91.9 (91.6–92.3)	97.9 (97.8–98.1)	96.7 (96.5–96.9)					
Graft survival after f	irst kidney transplantatior	(deceased donor)								
Unadjusted	91.1 (90.7-91.4)	88.2 (87.9-88.5)	78.7 (78.3-79.1)	91.0 (90.8-91.3)	88.0 (87.7-88.3)					
Adjusted <sup>b</sup>	92.1 (91.8–92.4)	89.6 (89.2–89.9)	80.9 (80.4–81.4)	92.6 (92.3–92.9)	90.0 (89.7–90.4)					
Patient survival afte	r first kidney transplantati	on (living donor)								
Unadjusted	98.7 (98.4–98.9)	97.8 (97.4–98.0)	94.1 (93.6-94.5)	99.1 (98.9-99.2)	98.1 (97.9-98.4)					
Adjusted <sup>b</sup>	98.8 (98.6–99.1)	98.0 (97.7–98.3)	94.6 (94.1–95.1)	99.2 (99.1–99.4)	98.5 (98.2–98.7)					
Graft survival after f	irst kidney transplantatior	ı (living donor)								
Unadjusted	95.9 (95.5–96.3)	94.1 (93.6-94.5)	87.5 (86.9-88.0)	96.8 (96.5-97.1)	95.1 (94.7-95.4)					
Adjusted <sup>b</sup>	95.6 (95.2–96.1)	93.7 (93.2–94.2)	86.7 (85.9–87.4)	96.6 (96.3–97.0)	94.8 (94.4–95.2)					

This is based on the data from the following renal registries providing individual patient data: Austria, Belgium (Dutch-speaking), Belgium (French-speaking), Denmark, Finland, France, Greece, Iceland, Norway, Spain (Andalusia), Spain (Aragon), Spain (Asturias), Spain (Basque country), Spain (Cantabria), Spain (Castile and León), Spain (Castile-La Mancha), Spain (Catalonia), Spain (Extremadura), Spain (Galicia), Spain (Community of Madrid), Spain (Valencian region), Sweden, the Netherlands and the UK (all countries)

a Analyses were adjusted using fixed values: age (67 years), gender (63% men) and primary renal disease (24% DM, 19% hypertension/renal vascular disease, 11% glomerulonephritis and 46% other causes)

bAnalyses were adjusted using fixed values: age (50 years), gender (63% men) and primary renal disease (14% DM, 10% hypertension/renal vascular disease, 23% glomerulonephritis and 53% other causes)

# Expected remaining lifetimes of the general population and of prevalent dialysis and transplant patients

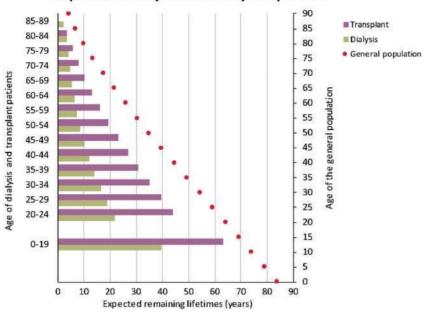


FIGURE 14: Expected remaining lifetimes of the general population (cohort 2012–16), and of prevalent dialysis and kidney transplant patients (cohort 2012–16), by age and gender. This figure is based on data from the following registries providing individual patient data: Austria, Belgium (Dutch-speaking), Belgium (French-speaking), Denmark, Finland, France, Greece, Iceland, Norway, Spain (Andalusia), Spain (Aragon), Spain (Asturias), Spain (Basque Country), Spain (Cantabria), Spain (Castile and León), Spain (Castile-La Mancha), Spain (Catalonia), Spain (Extremadura), Spain (Galicia), Spain (Community of Madrid), Spain (Valencian region), Sweden, the Netherlands and the UK (all countries)

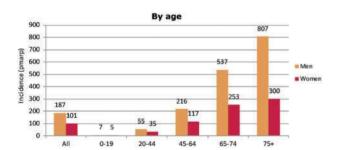


FIGURE 15: Incidence of RRT per million age-related population (pmarp) in 2016, at Day 1, by age and sex. Figure is only based on the data from registries providing individual patient data (see Appendix A1).

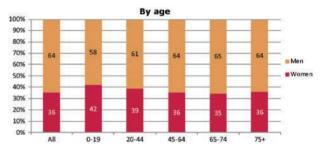


FIGURE 17: Sex distribution by age for incident patients accepted for RRT in 2016, at Day 1. Figure is only based on the data from registries providing individual patient data (see Appendix A1).

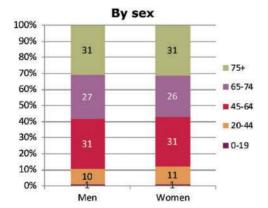


FIGURE 16: Age distribution by sex for incident patients accepted for RRT in 2016, at Day 1. Figure is only based on the data from registries providing individual patient data (see Appendix A1).

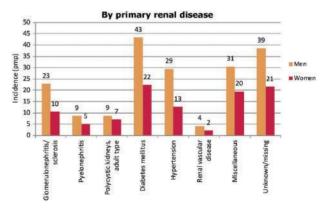


FIGURE 18: Incidence of RRT pmp in 2016, at Day 1, by primary renal disease and sex. Figure is only based on the data from registries providing individual patient data (see Appendix A1).

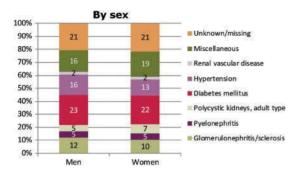


FIGURE 19: Primary renal disease distribution by sex for incident patients accepted for RRT in 2016, at Day 1. Figure is only based on the data from registries providing individual patient data (see Appendix A1).

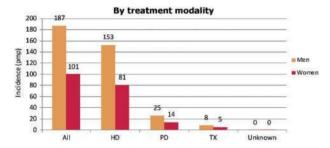


FIGURE 20: Incidence of RRT pmp in 2016, at Day 1, by treatment modality and sex. Figure is only based on the data from registries providing individual patient data (see Appendix A1)

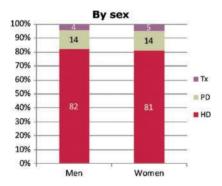


FIGURE 21: Treatment modality distribution by sex for incident patients accepted for RRT in 2016, at Day 1. Figure is only based on the data from registries providing individual patient data (see Appendix A1). Tx, kidney transplant.

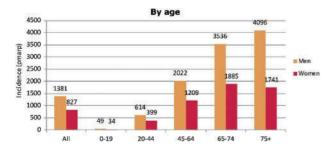


FIGURE 22: Prevalence of RRT pmarp on 31 December 2016, by age and sex. Figure is only based on the data from registries providing individual patient data (see Appendix A1)

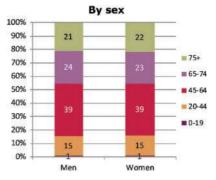


FIGURE 23: Age distribution by sex for prevalent patients on RRT on 31 December 2016. Figure is only based on the data from registries providing individual patient data (see Appendix A1).

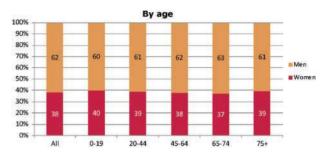


FIGURE 24: Sex distribution by age for prevalent patients on RRT on 31 December 2016. Figure is only based on data from registries providing individual patient data (see Appendix A1).

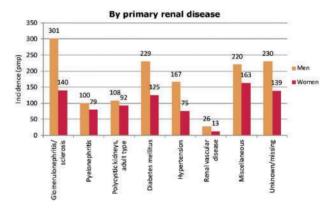


FIGURE 25: Prevalence of RRT pmp on 31 December 2016, by primary renal disease and sex. Figure is only based on data from registries providing individual patient data (see Appendix A1).

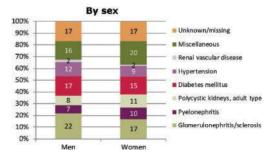


FIGURE 26: Primary renal disease distribution by sex for prevalent patients on RRT on 31 December 2016. Figure is only based on the data from registries providing individual patient data (see Appendix A1).

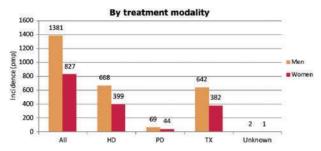


FIGURE 27: Prevalence of RRT pmp on 31 December 2016, by treatment modality and sex. Figure is only based on the data from registries providing individual patient data (see Appendix A1).

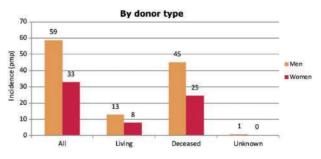


FIGURE 29: Kidney transplants performed pmp in 2016, by donor type and sex. Figure is only based on the data from registries providing individual patient data (see Appendix A1).

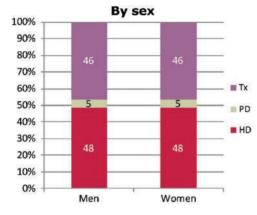


FIGURE 28: Treatment modality distribution by sex for prevalent patients on RRT on 31 December 2016. Figure is only based on the data from registries providing individual patient data (see Appendix A1). Tx, kidney transplant.

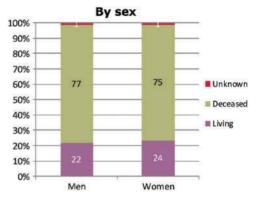


FIGURE 30: Donor-type distribution for kidney transplants performed in 2016, by sex. Figure is only based on the data from registries providing individual patient data (see Appendix A1).

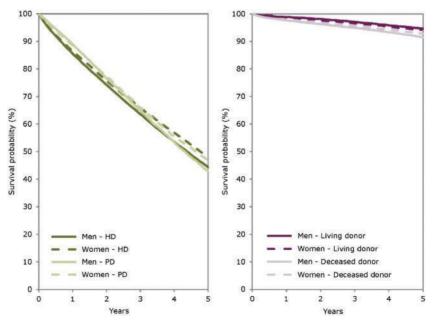


FIGURE 31: Patient survival of men and women starting HD and PD between 2007 and 2011 from Day 91 (left panel) and men and women receiving a first kidney transplant from a living or deceased donor between 2007 and 2011 (right panel). Survival on dialysis was adjusted using fixed values for age (67 years) and primary renal disease (24% diabetes mellitus, 19% hypertension/renal vascular disease, 11% glomerulonephritis and 46% other causes). Survival after kidney transplantation was adjusted using fixed values for age (50 years) and primary renal disease (14% diabetes mellitus, 10% hypertension/renal vascular disease, 23% glomerulonephritis and 53% other causes). These figures are based on the data from the following registries providing individual patient data: Austria, Belgium (Dutch-speaking), Belgium (French-speaking), Denmark, Finland, France, Greece, Iceland, Norway, Spain (Andalusia), Spain (Aragon), Spain (Asturias), Spain (Basque country), Spain (Cantabria), Spain (Castile and León), Spain (Castile-La Mancha), Spain (Catalonia), Spain (Extremadura), Spain (Galicia), Spain (Community of Madrid), Spain (Valencian region), Sweden, the Netherlands and the UK (all countries).

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# CONFLICT OF INTEREST STATEMENT

None declared.

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# APPENDIX A1

Countries or regions providing individual patient data are: Austria, Dutch-speaking Belgium, French-speaking Belgium, Bosnia and Herzegovina, Denmark, Estonia, Finland, France, Greece, Iceland, Norway, Romania, Serbia, the Spanish regions of Andalusia, Aragon, Asturias, Basque country, Cantabria, Castile and León, Castile-La Mancha, Catalonia, Extremadura, Galicia, Community of Madrid, Murcia, Navarre, Valencian region, Sweden, Switzerland, the Netherlands, the UK, England/ Northern Ireland/Wales and UK, Scotland.

Countries or regions providing aggregated data are: Albania, Belarus, Bulgaria, Croatia, Cyprus, Czech Republic, Georgia, Israel, Italy, Latvia, Lithuania, Macedonia, Poland, Portugal, Russia, Slovakia, Spain, Tunisia (Sfax region), Turkey, Ukraine.

# APPENDIX A2

Miscellaneous primary renal diseases: Nephropathy (interstitial) due to analgesic drugs, nephropathy (interstitial) due to cisplatinum, nephropathy (interstitial) due to cyclosporin A, leadinduced nephropathy (interstitial), drug-induced nephropathy (interstitial) not mentioned above, cystic kidney disease type unspecified, polycystic kidneys; infantile (recessive), medullary cystic disease; including nephronophtisis, cystic kidney disease—other specified type, hereditary/familial nephropathy—type unspecified, hereditary nephritis with nerve deafness (Alport's Syndrome), cystinosis, primary oxalosis, Fabry's disease, hereditary nephropathy—other specified type, renal hypoplasia (congenital)—type unspecified, oligomeganephronic hypoplasia, congenital renal dysplasia with or without urinary tract malformation, syndrome of agenesis of abdominal muscles (prune belly), renal vascular disease due to polyarteritis, Wegener's granulomatosis, ischaemic renal disease/cholesterol embolism, glomerulonephritis related to liver cirrhosis, cryoglobulinemic glomerulonephritis, myelomatosis/ light-chain deposit disease, amyloid, lupus erythematosus, Henoch-Schonlein purpura, Goodpasture's Syndrome, systemic sclerosis (scleroderma), haemolytic uraemic syndrome (including Moschcowitz Syndrome), multi-system disease-other (not mentioned above), tubular necrosis (irreversible) or cortical necrosis (different from 88), tuberculosis, gout, nephrocalcinosis and hypercalcaemic nephropathy, Balkan nephropathy, kidney tumour, traumatic or surgical loss of kidney, other identified renal disorders.