

ORIGINAL ARTICLE

## The ERA Registry Annual Report 2020: a summary

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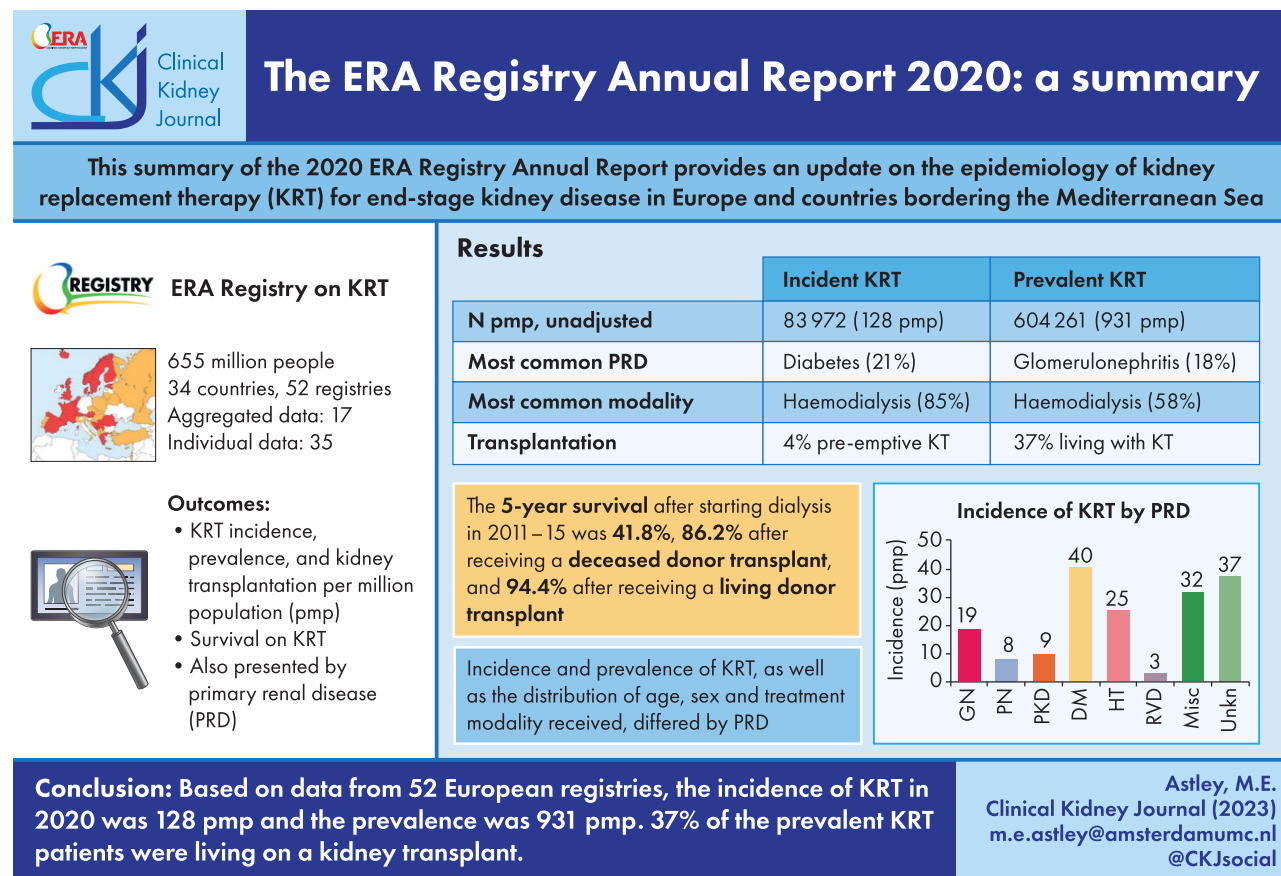
## ABSTRACT

**Background.** The European Renal Association (ERA) Registry collects data on kidney replacement therapy (KRT) in patients with ESKD. This paper is a summary of the ERA Registry Annual Report 2020, also including comparisons among primary renal disease (PRD) groups.

**Methods.** Data were collected from 52 national and regional registries from 34 European countries and countries bordering the Mediterranean Sea: 35 registries from 18 countries providing individual level data and 17 registries from 17 countries providing aggregated data. Using this data, KRT incidence and prevalence, kidney transplantation rates, expected remaining lifetimes and survival probabilities were calculated.

**Results.** A general population of 654.9 million people was covered by the ERA Registry in 2020. The overall incidence of KRT was 128 per million population (p.m.p.). In incident KRT patients, 54% were older than 65 years, 63% were men and the most common PRD was diabetes mellitus (21%). Regarding initial treatment modality in incident patients, 85% received haemodialysis (HD), 11% received peritoneal dialysis (PD) and 4% received a pre-emptive kidney transplant. On 31 December 2020, the prevalence of KRT was 931 p.m.p. In prevalent patients, 45% were older than 65 years, 60% were men and glomerulonephritis was the most common PRD (18%). Of these patients, 58% were on HD, 5% on PD and 37% were living with a kidney transplant. The overall kidney transplantation rate in 2020 was 28 p.m.p., with a majority of kidney grafts from deceased donors (71%). The unadjusted 5-year survival, based on incident dialysis patient from 2011–15, was 41.8%. For patients having received a deceased donor transplant, the unadjusted 5-year survival probability was 86.2% and for patients having received a living donor transplant it was 94.4%. When comparing data by PRD group, differences were found regarding the distribution of age groups, sex and treatment modality received.

## GRAPHICAL ABSTRACT



**Keywords:** dialysis, epidemiology, ESKD, kidney transplantation, patient survival



## INTRODUCTION

The European Renal Association (ERA) Registry Annual Report 2020 [1] (Supplementary data) provides updates on the epidemiology of kidney replacement therapy (KRT) for end-stage kidney disease (ESKD) in Europe and countries bordering the Mediterranean Sea. This paper will provide a summary of these data. Individual or aggregated data were provided by 52 national or regional registries from 34 countries. Thirty-five registries from 18 countries provided individual level data, the remaining registries provided aggregated data. The general population covered by the participating registries was 654.9 million people, 76.8% of the total European population. This article will present data on the incidence and prevalence of KRT, and kidney transplantation rates in 2020. Additionally, patient and graft survival using data from 2011–18 will be presented. For the first time we will also present comparisons across primary renal disease (PRD) groups.

Information on methods used for analysis are described in the ERA Registry Annual Report 2020.

## RESULTS

## KRT incidence

Out of a population of 654.9 million patients, 83 972 patients with ESKD initiated KRT. This corresponds to a KRT incidence rate of 128 per million population (p.m.p.) or about 1 per 7800 Europeans (Table 1). This was slightly lower compared with the KRT incidence rate in 2019 (132 p.m.p.). The lowest unadjusted incidence was 1 per 17 500 inhabitants in Estonia (57 p.m.p.) and the highest unadjusted incidence was 1 per 3670 inhabitants in Cyprus (273 p.m.p., Table 1 and Figs 1 and 2). When adjusted to age and sex using the distribution of the EU28 population [2], the overall adjusted incidence of KRT for the available 46 countries/regions was 138 p.m.p. (Fig. 2). Adjusted incidence ranged from 1 per 17 300 inhabitants in Estonia (58 p.m.p.) to 1 per 3410 inhabitants in Israel (293 p.m.p., Fig. 2). The overall median age at KRT initiation was 65.6 years and spanned a range of 62.6 years old in Lithuania to 74.2 years in Greece (Table 1). In countries providing individual data, 58% of patients starting KRT were aged over 65 years (Fig. 3). This was slightly lower in countries providing

**Table 1: Summary data on the unadjusted incidence of KRT in 2020 on Day 1, by country or region, the mean and median age at the start of KRT, and the incidence of KRT of patients with DM as PRD.**

Country/region	General population covered by the registry in thousands	Incidence of KRT in 2020, at Day 1					
		All (n)	All (p.m.p.)	Mean age (years)	Median age (years)	DM (n)	DM (p.m.p.)
Albania	2818	368	131	62.5	65.0	84	30
Austria <sup>a</sup>	8901	1085	122	65.0	68.6	272	31
Belarus <sup>b</sup>	9380	696	74			145	15
Belgium, Dutch-speaking <sup>c</sup>	6654	1156	174	71.0	73.5	236	35
Belgium, French-speaking <sup>c</sup>	4890	944	193	67.6	69.6	208	43
Bosnia and Herzegovina	3531	408	116	63.0	65.0	107	30
Croatia <sup>d</sup>	3441	376	109	69.1	71.0	105	31
Cyprus	888	242	273	70.0	72.0	101	114
Czech Republic <sup>d</sup>	10 488	2230	213				
Denmark	5888	707	120	64.3	67.1	193	33
Estonia	1330	76	57	60.2	63.4	18	14
Finland	5530	522	94	61.0	64.6	175	32
France	67 488	10 696	158	67.5	70.5	2486	37
Greece	10 699	2749	257	71.5	74.2	659	62
Hungary	9672	1923	199	63.7		527	54
Iceland	366	38	104	65.3	72.2	5	14
Israel	9215	1797	195	67.0	69.2	804	87
Italy (8 of 20 regions)	21 471	3405	159	68.6	71.5	520	24
Kosovo	1688	214	127	61.1	64.0	68	40
Lithuania	2794	242	87	60.8	62.6	39	14
Montenegro <sup>c</sup>	621	75	121	61.3	63.0	14	23
North Macedonia	2069	381	184	63.9	66.0	96	46
Norway	5379	543	101	62.3	65.9	90	17
Poland	38 354	4781	125			1484	39
Portugal <sup>e</sup>	10 298	2361	229			773	75
Romania	18 302	2990	163	62.2	64.6	378	21
Russia <sup>d</sup>	143 248	12 103	84			2900	20
Serbia	6209	474	76	60.3	63.1	138	22
Slovakia <sup>d</sup>	4324	540	125	64.4	66.0	163	38
Spain (All)	47 451	6643	140	63.8	68.3	1668	35
Spain, Andalusia	8490	1185	140	64.4	67.7	316	37
Spain, Aragon	1331	182	137	64.5	68.2	46	35
Spain, Asturias	1016	170	167	67.1	69.6	50	49
Spain, Basque country	2188	288	132	65.4	69.3	73	33
Spain, Canary Islands	2241	382	170	64.0	66.5	126	56
Spain, Cantabria <sup>c</sup>	583	73	125	65.4	67.0	21	36
Spain, Castile and León <sup>c</sup>	2395	285	119	69.0	70.9	70	29
Spain, Castile-La Mancha <sup>c</sup>	2047	215	105	65.1	66.2	62	30
Spain, Catalonia	7780	1336	172	66.8	70.4	255	33
Spain, Community of Madrid	6780	745	110	64.5	68.3	195	29
Spain, Extremadura	1064	150	141	65.9	66.7	48	45
Spain, Galicia	2700	393	146	67.5	69.6	109	40
Spain, La Rioja	316	33	104	68.2	69.2	6	19
Spain, Murcia	1511	212	140	65.0	66.9	49	32
Spain, Navarre <sup>c</sup>	657	70	107	63.4	68.7	26	40
Spain, Valencian region	5057	773	153	66.5	70.3	177	35
Sweden	10 353	1137	110	64.0	68.5	281	27
Switzerland	8638	846	98	65.2	68.9	159	18
the Netherlands	16 395	1861	114	63.9	67.7	389	24
Turkey <sup>f</sup>	83 614	11 596	139			707	45
UK, England	56 550	6097	108	61.0	63.5	1618	29
UK, Northern Ireland	1896	206	109	60.1	64.0	39	21
UK, Scotland	5466	542	99	60.0	63.0	161	29
UK, Wales	3170	356	112	61.5	65.4	92	29
All countries	654 932	83 972	128	65.1	65.6	18 068	31

DM = diabetes mellitus as PRD.

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

<sup>a</sup>The incidence is underestimated by approximately 1% due to one HD centre not submitting data.<sup>b</sup>Patients younger than 18 years of age are not reported.<sup>c</sup>Patients younger than 20 years of age are not reported: the true incidence counts are therefore slightly higher than the counts reported here.<sup>d</sup>Data include dialysis patients only.<sup>e</sup>Data on PRD are available for dialysis patients only (99.1% of total N = 2361).<sup>f</sup>Data on the incidence of PRD (DM) is based on 2180 dialysis patients (18.8% of total).

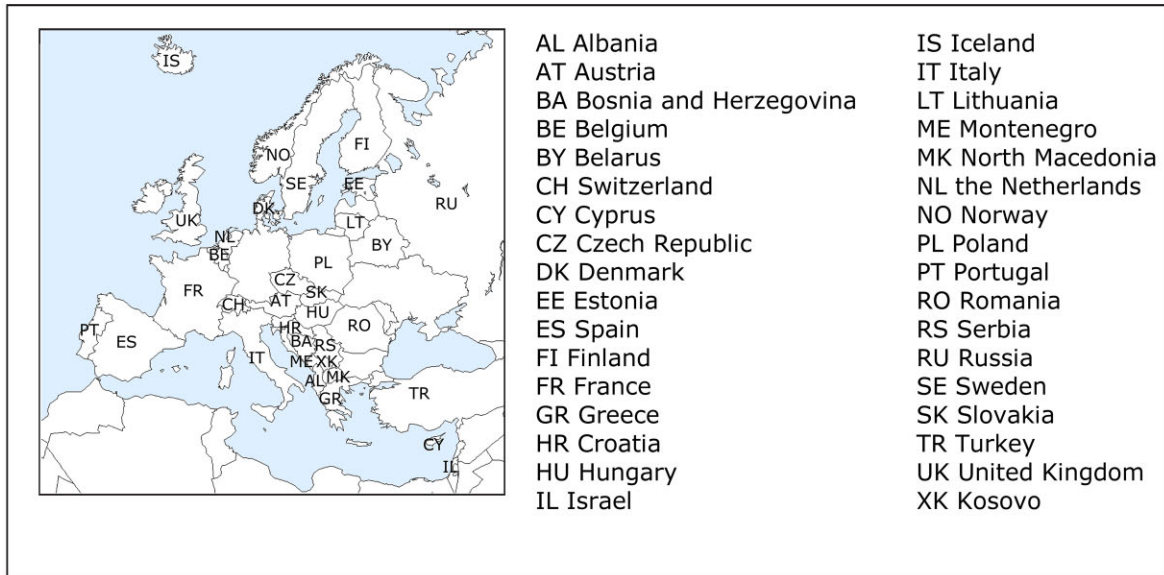
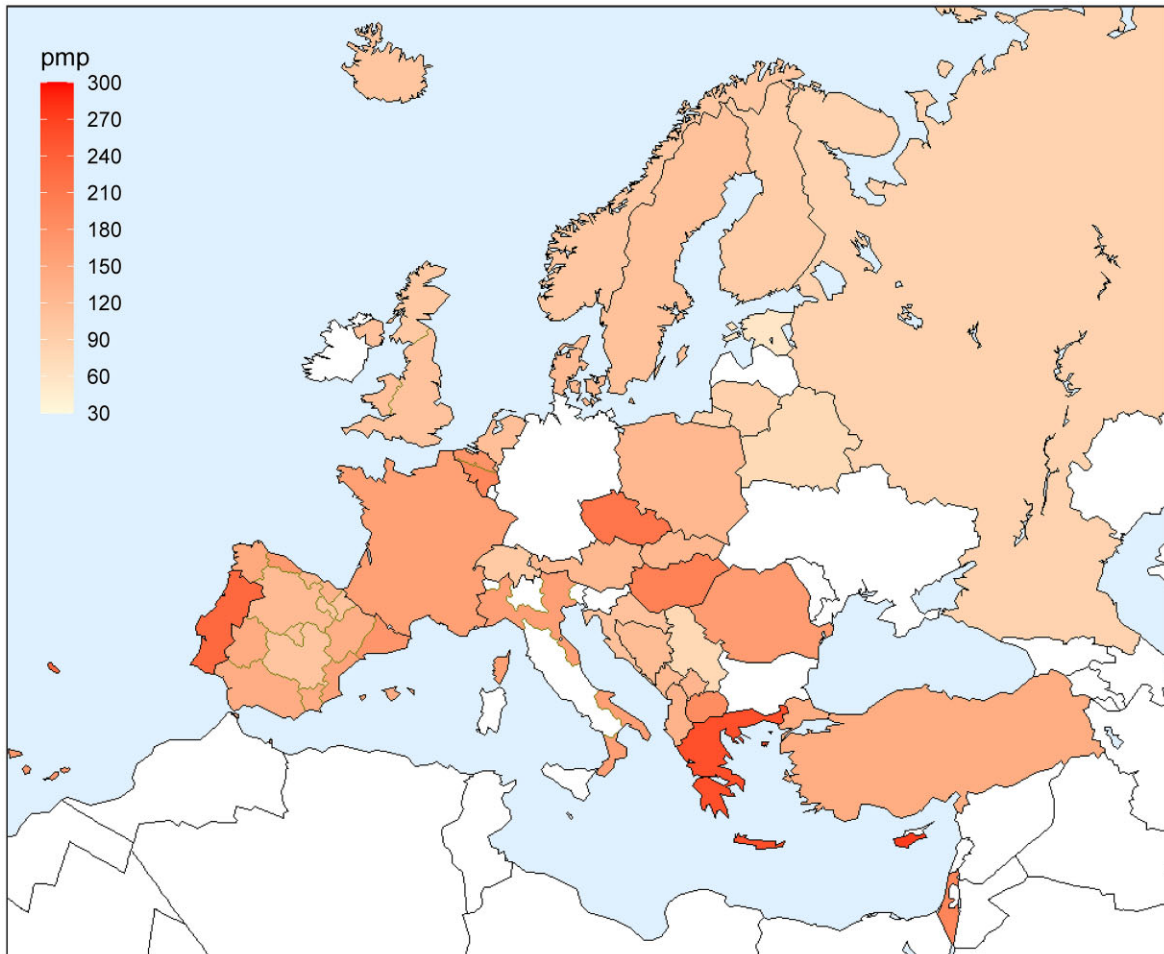
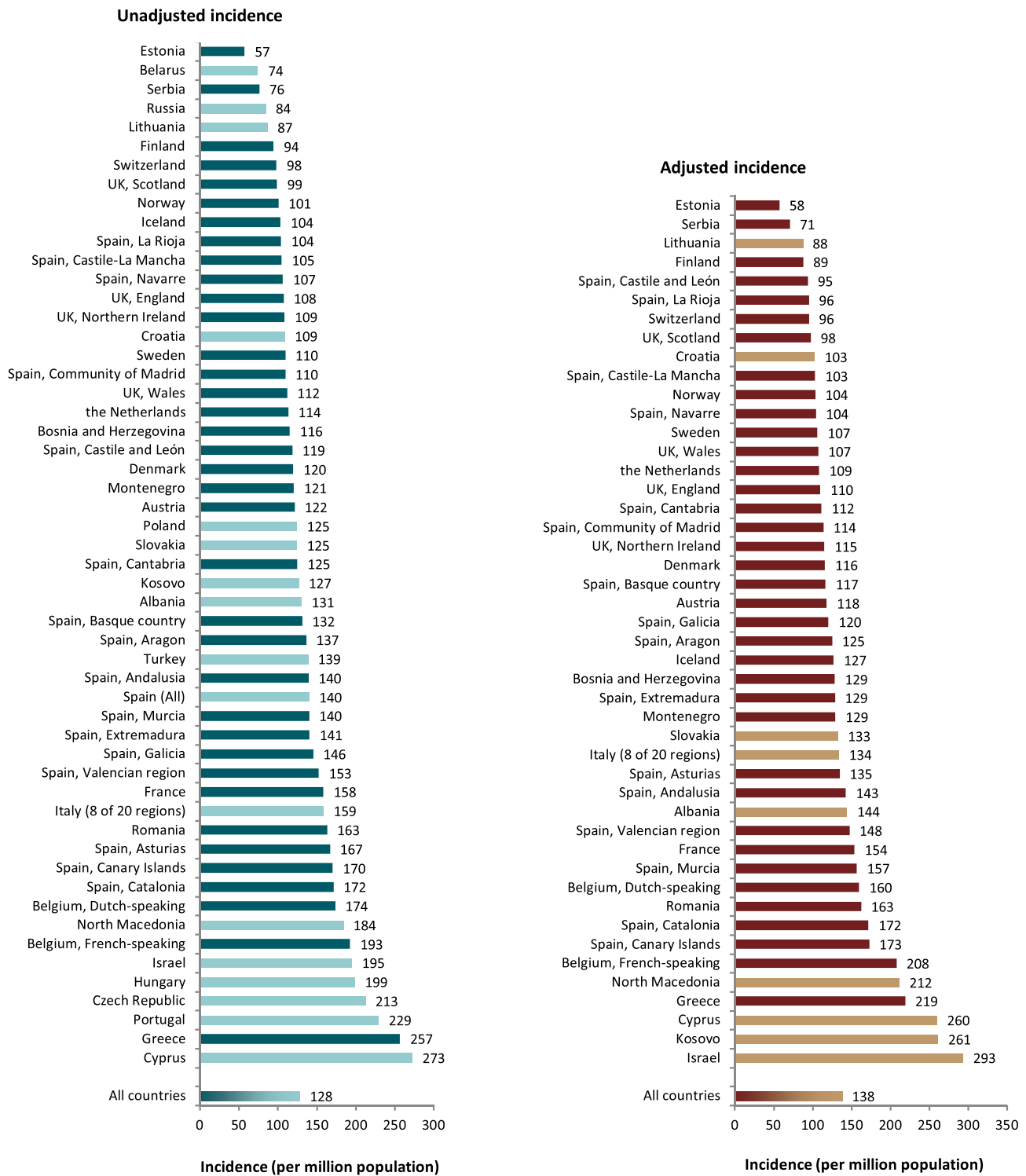


Figure 1: Incidence of KRT in 2020 on Day 1 by country or region, unadjusted.



**Figure 2:** Incidence of KRT in 2020 on Day 1 by country or region, unadjusted (left panel) and adjusted (right panel). Registries providing individual patient data are shown as dark bars, and registries providing aggregated data as light bars. See Appendix 1 for a list of countries and regions providing individual patient data or aggregated data. Adjustment of the incidence was performed by standardizing the incidence to the age and sex distribution of the EU28 population.

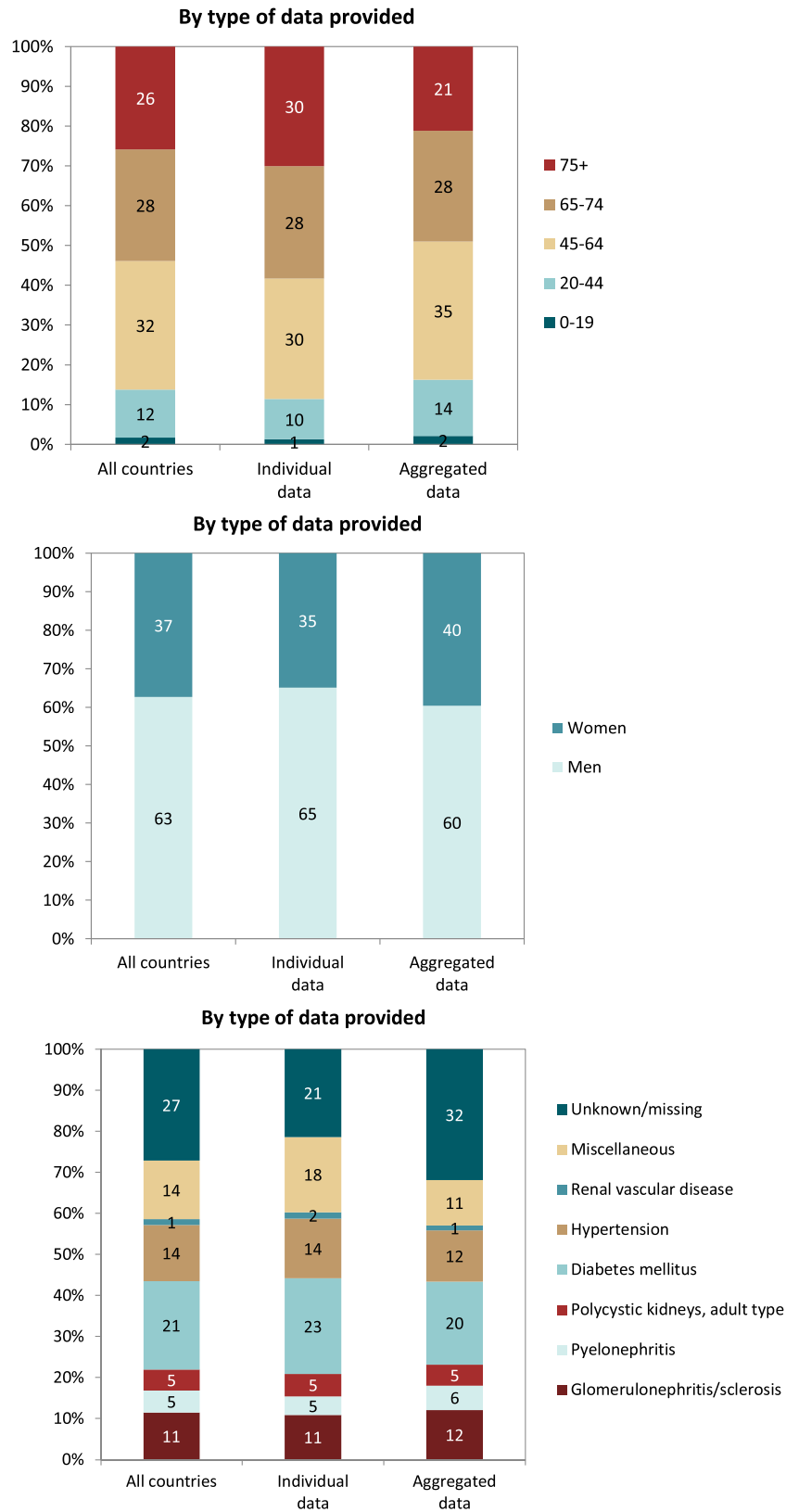


Figure 3: Distribution of (A) age, (B) sex and (C) PRD by type of data provided for incident patients accepted for KRT in 2020, on Day 1, unadjusted.



**Figure 4:** Distribution of treatment modality by (A) type of data provided, (B) age, (C) sex and (D) PRD (DM and non-DM) for incident patients accepted for KRT in 2020, on Day 1, unadjusted. Panels (B), (C) and (D) are only based on the data from registries providing individual patient data. See Appendix 1 for a list of countries and regions providing individual patient data or aggregated data. Abbreviations: Tx: transplant.





Figure 5: Distribution of treatment modality by (A) type of data provided, (B) age, (C) sex and (D) PRD (DM and non-DM) for incident patients accepted for KRT in 2020, on Day 91, unadjusted. Panels (B), (C) and (D) are only based on the data from registries providing individual patient data. See Appendix 1 for a list of countries and regions providing individual patient data or aggregated data. Abbreviations: Tx: transplant.

Table 2: Summary data on the unadjusted prevalence of KRT in 2020 on 31 December 2020, by country or region with the mean and median age at 31 December 2020, and the prevalence of KRT of patients with DM as PRD.

Country/region	General population covered by the registry in thousands	Prevalent patients on KRT in 2020					
		All (n)	All (p.m.p.)	Mean age (years)	Median age (years)	DM (n)	DM (p.m.p.)
Albania	2818	1664	591	52.2	51.0	356	126
Austria <sup>a</sup>	8901	9181	1031	62.4	63.8	1728	194
Belarus <sup>b</sup>	9380	3881	414			514	55
Belgium, Dutch-speaking <sup>c</sup>	6654	8571	1288	66.5	68.4	1389	209
Belgium, French-speaking <sup>c</sup>	4890	6663	1363	65.5	67.0	1186	243
Bosnia and Herzegovina	3531	2547	721	59.9	61.4	478	135
Croatia <sup>d</sup>	3441	2028	589	66.4	69.0	510	148
Cyprus	888						
Czech Republic	10 488	11 287	1076				
Denmark	5888	5685	966	59.3	60.8	962	163
Estonia	1330	1049	789	59.0	60.0	200	150
Finland	5530	5303	959	60.1	62.5	1323	239
France	67 488	92 864	1376	63.4	65.6	15 361	228
Greece	10 699	15 169	1418	65.9	68.0	2815	263
Hungary	9672	9651	998				
Iceland	366	302	824	58.5	59.7	33	90
Israel <sup>d</sup>	9215	6916	751	67.4	69.3	3254	353
Italy (8 of 20 regions)	21 471	28 127	1310	63.1	65.0	2930	136
Kosovo	1688	784	465	60.2	62.0	231	137
Lithuania	2794	2417	865				
Montenegro <sup>c</sup>	621	241	388	58.2	61.5	35	56
North Macedonia	2069	1762	852	59.8	61.0	312	151
Norway	5379	5464	1016	60.2	62.3	757	141
Poland <sup>d</sup>	38 354	19 647	512			5449	142
Portugal	10 298	20 713	2011	67.7		3684	358
Romania	18 302	22 074	1206	63.4	65.3	2104	115
Russia	143 248	61 164	427			11 102	78
Serbia	6209	5516	888	60.7	63.0	976	157
Slovakia <sup>d</sup>	4324	3105	718	64.0	66.0	928	215
Spain (All)	47 451	64 621	1362	60.4	63.7	10 560	223
Spain, Andalusia	8490	11 053	1302	61.4	62.7	1848	218
Spain, Aragon	1331	1872	1407	65.0	66.7	328	246
Spain, Asturias	1016	1477	1454	64.6	66.2	272	268
Spain, Basque country	2188	2783	1272	62.4	64.5	356	163
Spain, Canary Islands	2241	3409	1521	62.5	63.6	921	411
Spain, Cantabria <sup>c</sup>	583	680	1166	63.7	65.3	111	190
Spain, Castile and León <sup>c</sup>	2395	3187	1331	66.0	67.0	547	228
Spain, Castile-La Mancha <sup>c</sup>	2047	2462	1203	63.7	64.3	424	207
Spain, Catalonia	7780	11 593	1490	63.5	65.3	1628	209
Spain, Community of Madrid	6780	7753	1144	62.2	63.7	1338	197
Spain, Extremadura	1064	1384	1301	63.1	63.7	226	212
Spain, Galicia	2700	3951	1463	63.7	64.8	669	248
Spain, La Rioja	316	383	1212	62.7	63.7	48	152
Spain, Murcia	1511	2165	1433	63.0	63.8	334	221
Spain, Navarre <sup>c</sup>	657	904	1376	63.7	65.7	149	227
Spain, Valencian region	5057	7470	1477	64.1	66.0	1127	223
Sweden	10 353	10 332	998	60.3	62.5	1784	172
Switzerland	8638	8528	987	62.8	64.7	1269	147
the Netherlands	16 744	17 931	1071	61.2	63.2	2393	143
Turkey <sup>e</sup>	83 614	83 350	997			2638	347
UK, England	56 550	54 971	972	58.3	59.5	9908	175
UK, Northern Ireland	1896	2032	1072	58.3	59.2	298	157
UK, Scotland	5466	5421	992	57.3	59.0	940	172
UK, Wales	3170	3300	1041	58.6	59.9	599	189
All countries	649 818	604 261	931	60.7	59.3	89 006	159

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

<sup>a</sup>The prevalence is underestimated by approximately 1% due to one HD centre not submitting data.

<sup>b</sup>Patients younger than 18 years of age are not reported.

<sup>c</sup>Patients younger than 20 years of age are not reported. The true prevalent counts are therefore slightly higher than the counts reported here.

<sup>d</sup>Data on prevalence include dialysis patients only.

<sup>e</sup>Data on the prevalence of PRD (DM) is based on 7585 dialysis patients (9.1% of total).

DM = diabetes mellitus as PRD.

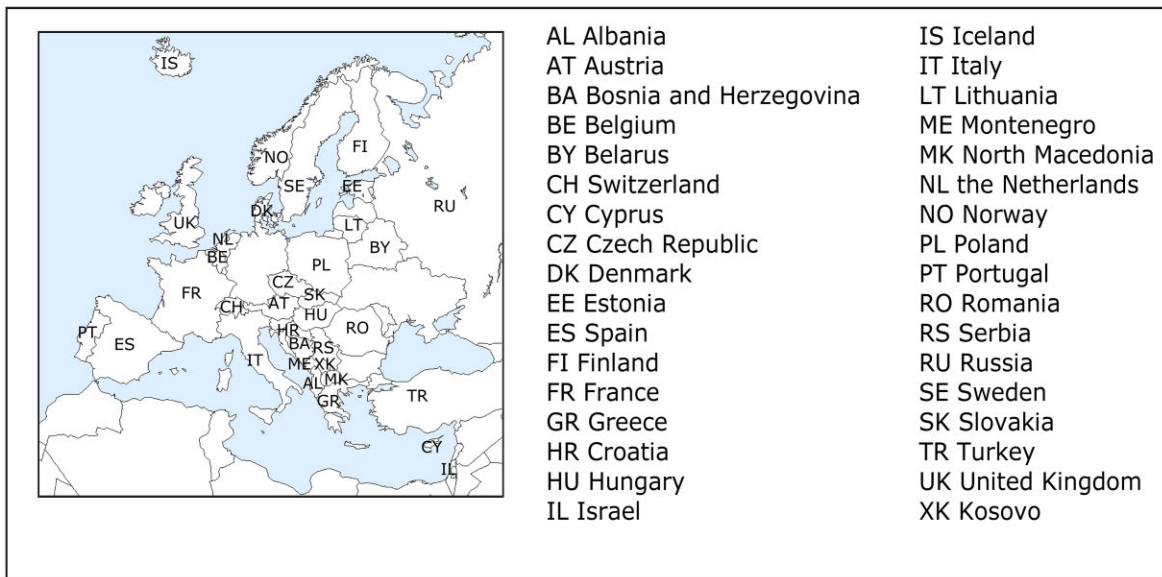
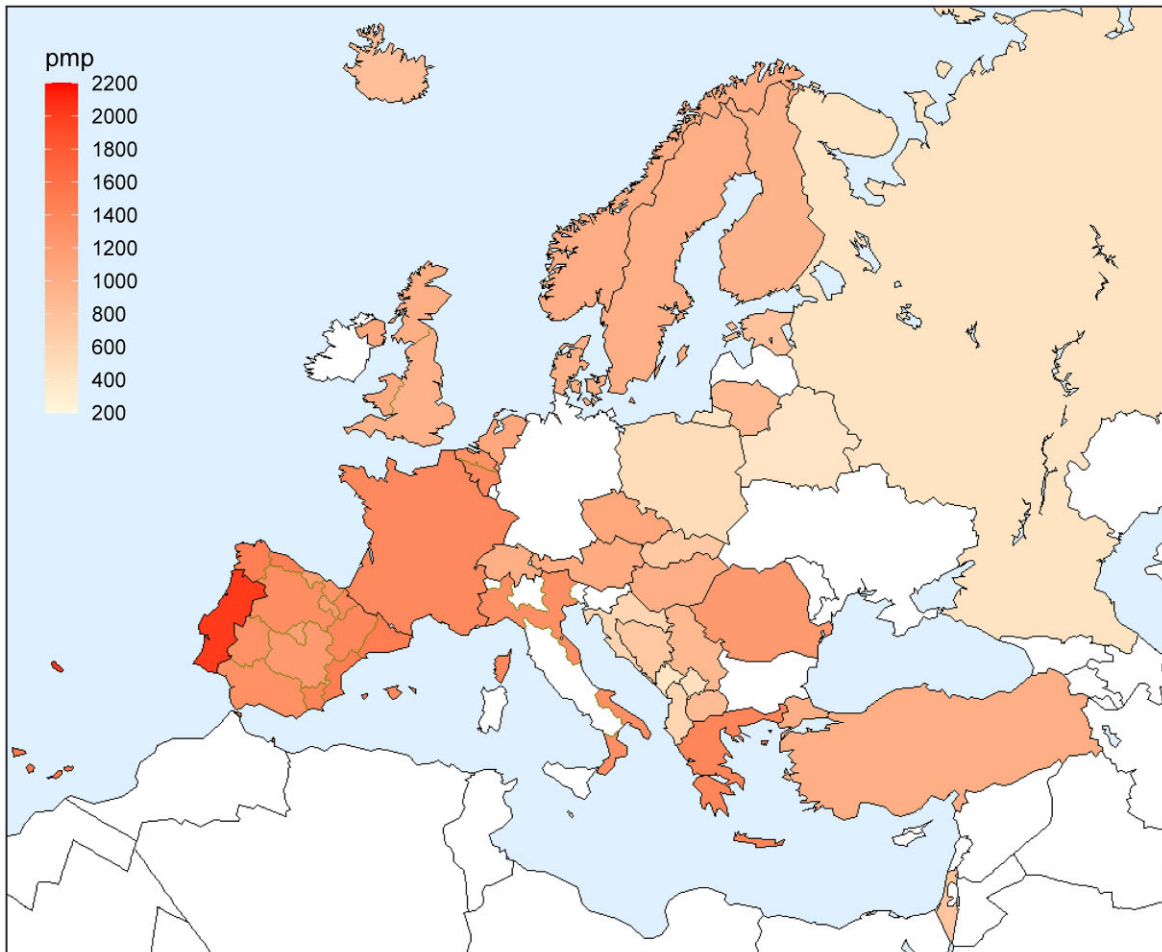


Figure 6: Prevalence of KRT on 31 December 2020 by country or region, unadjusted.

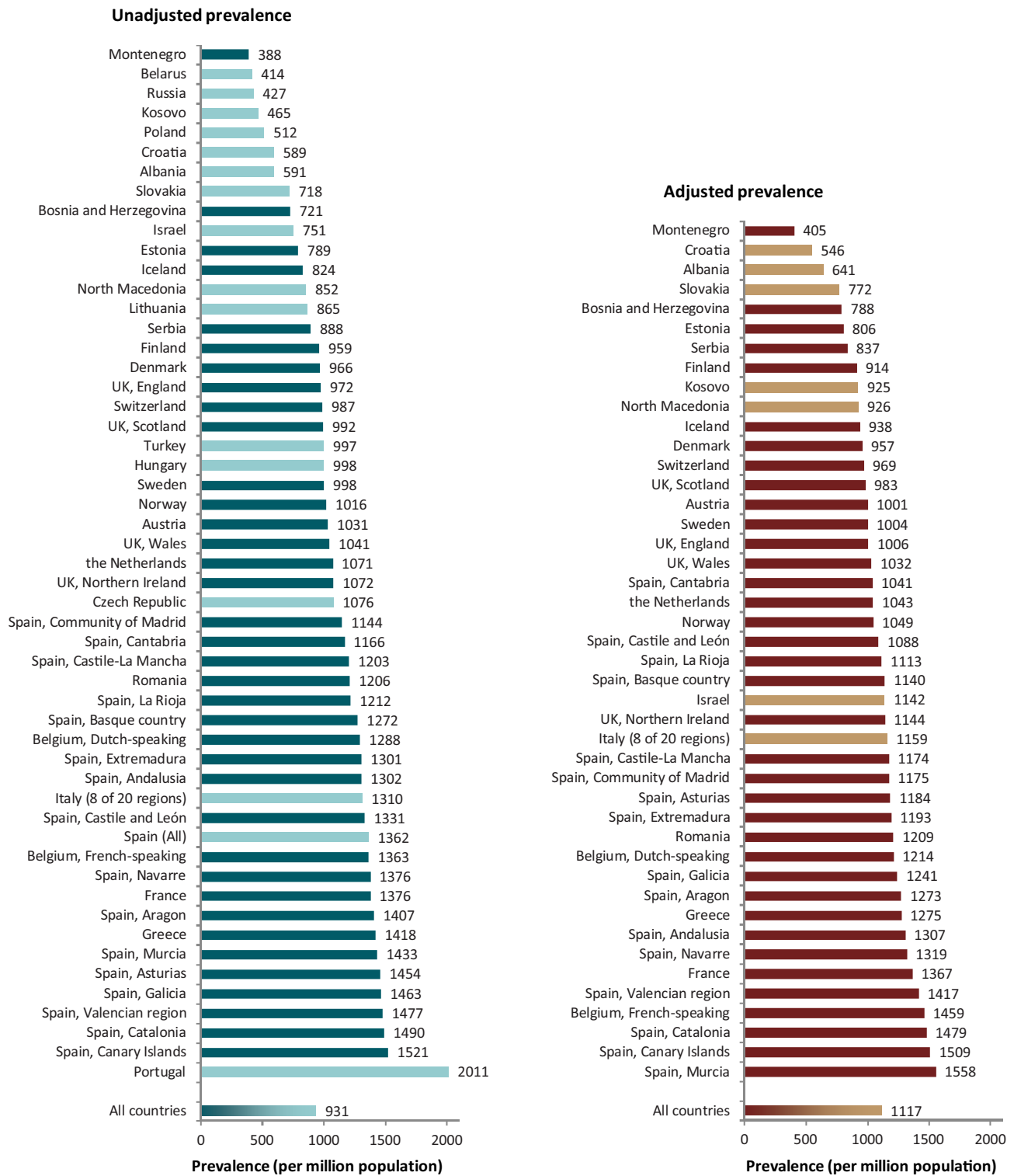


Figure 7: Prevalence of KRT on 31 December 2020 by country/region, unadjusted (left panel) and adjusted (right panel).

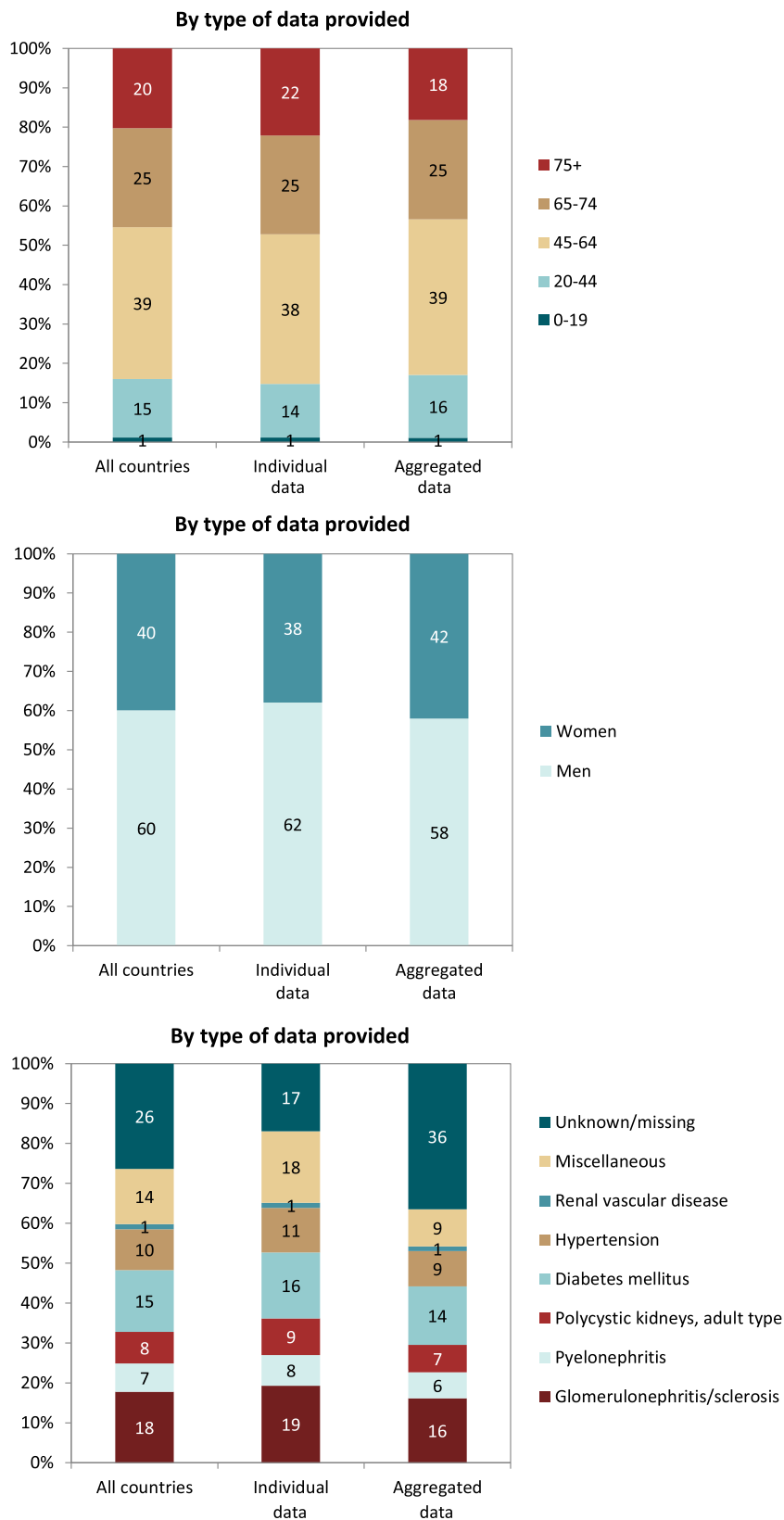


Figure 8: Distribution of (A) age, (B) sex and (C) PRD by type of data provided for prevalent patients on KRT on 31 December 2020, unadjusted.

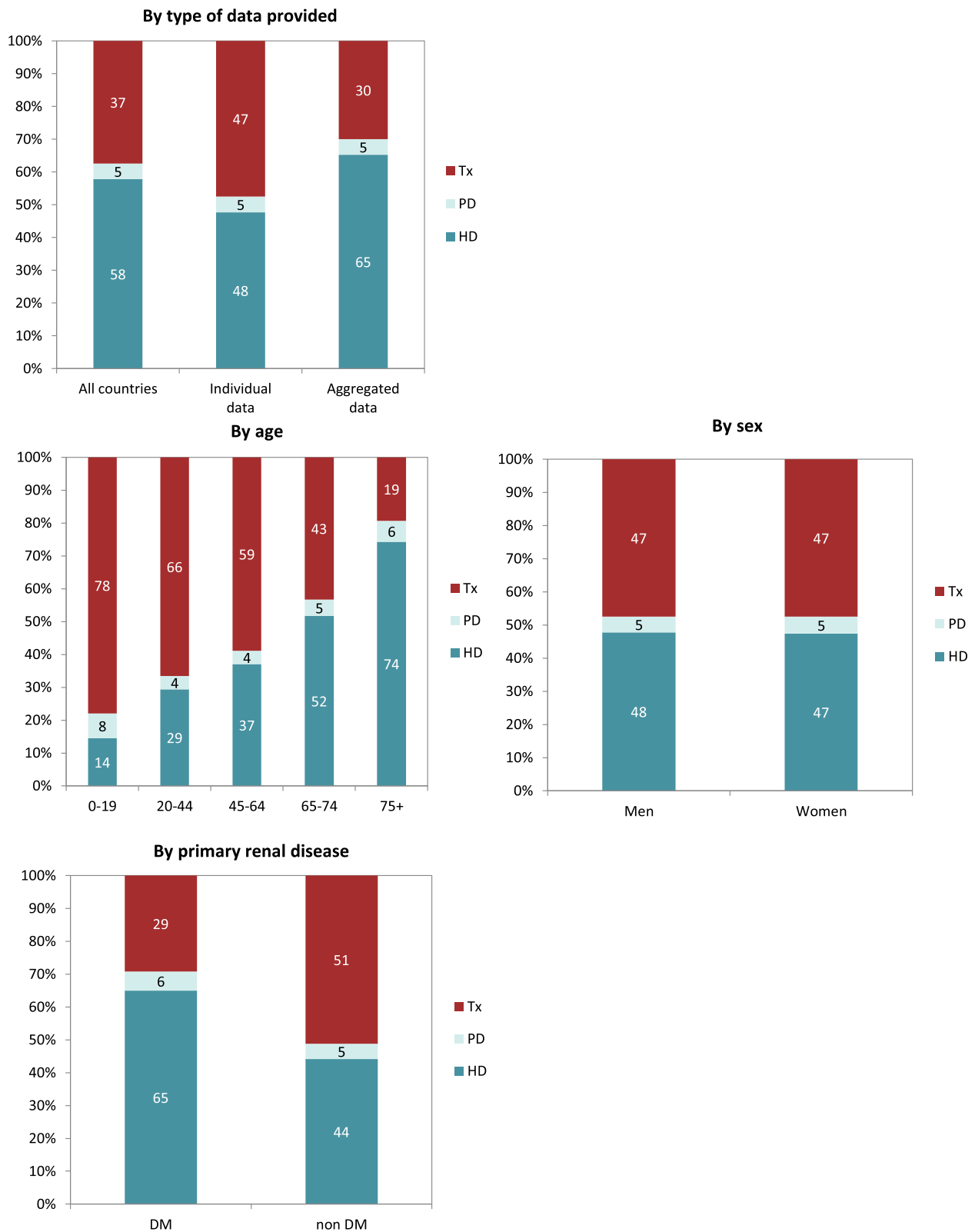


Figure 9: Distribution of treatment modality by (A) type of data provided, (B) age, (C) sex and (D) PRD (DM and non-DM) for prevalent patients on KRT on 31 December 2020, unadjusted. Panels (B), (C) and (D) are only based on the data from registries providing individual patient data. See Appendix 1 for a list of countries and regions providing individual patient data or aggregated data. Abbreviations: Tx: transplant.

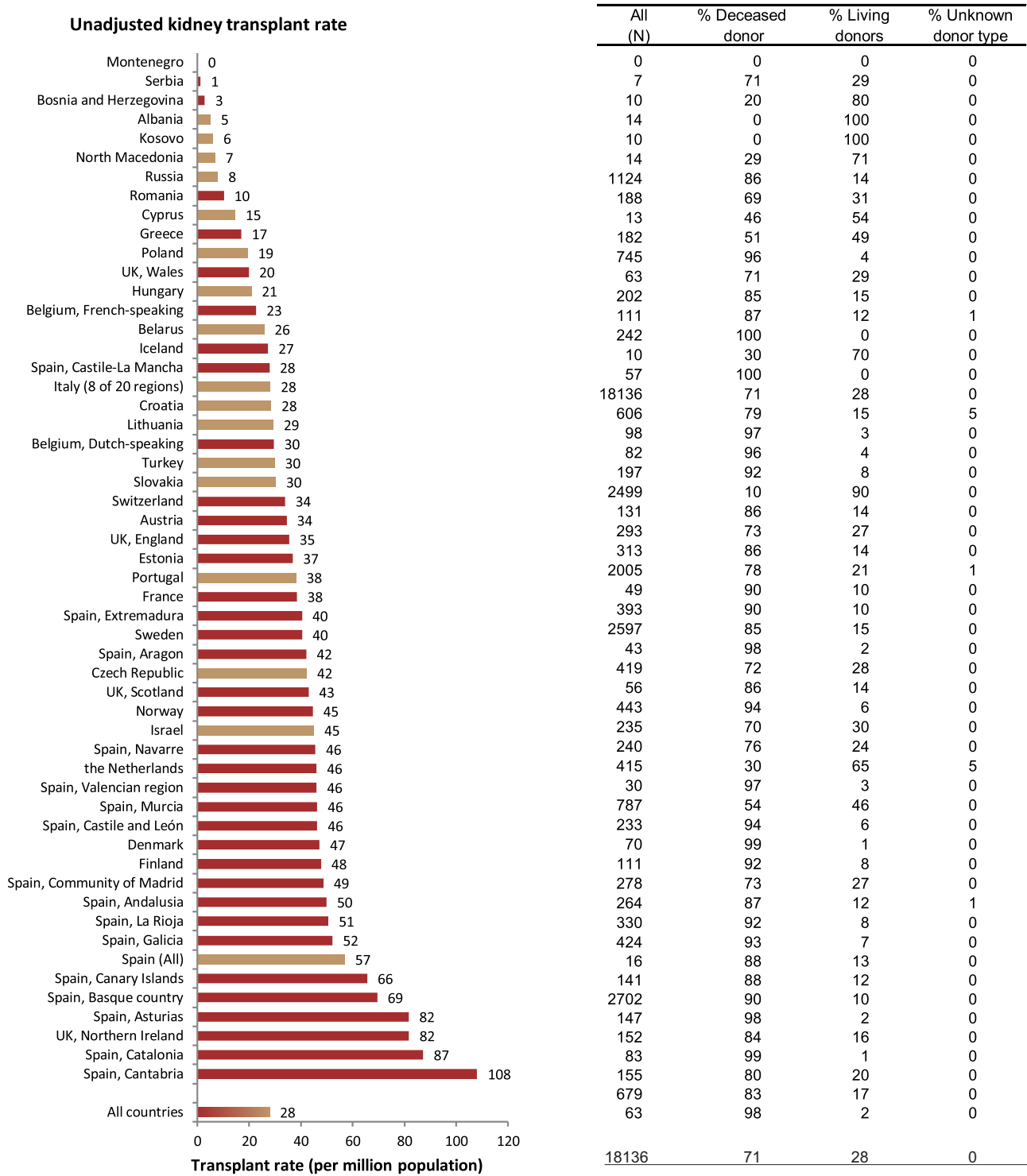


Figure 10: Kidney transplantations performed in 2020 by country or region, unadjusted. Registries providing individual patient data are shown as red bars, and registries providing aggregated data as orange bars.

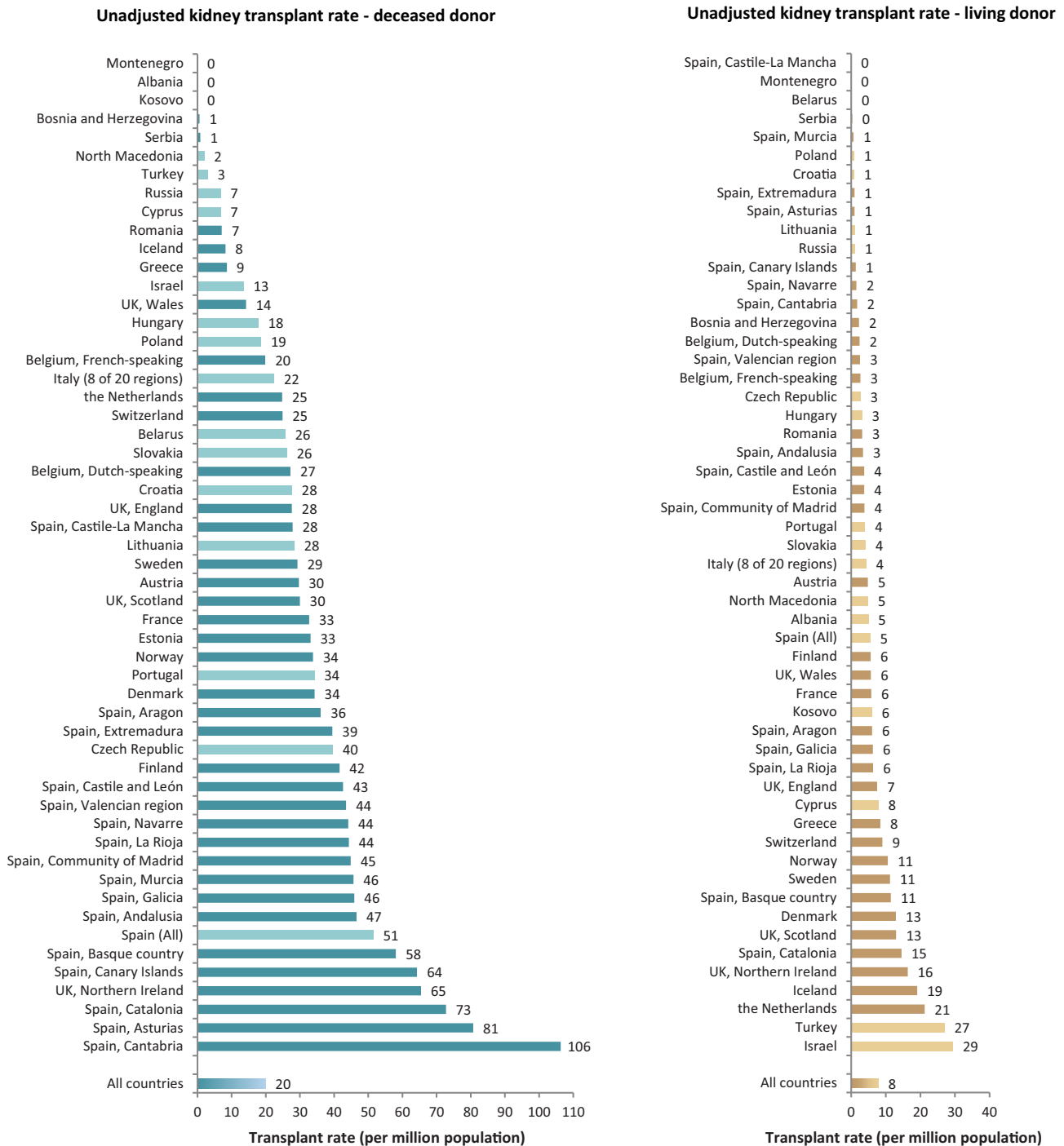


Figure 11: Kidney transplantations performed in 2020 for deceased donor (left panel) and living donor (right panel) transplantations, unadjusted. Registries providing individual patient data are shown as dark bars, and registries providing aggregated data as light bars.

aggregated data, where 49% of patients starting KRT were aged over 65 years old (Fig. 3). The overall KRT incidence for men was 1 per 6275 (159.3 p.m.p.), and for females 1 per 11 200 (89.0 p.m.p.). This differed between countries providing individual data (men: 180.4 p.m.p., women: 93.0 p.m.p.) and countries providing aggregated data (men: 141.3 p.m.p., women: 84.6 p.m.p.). On average, 63% of patients initiating KRT were men (Fig. 3), and this was 65% for countries providing individual data and 60% for countries providing aggregated data (Fig. 3). The overall unadjusted incidence of KRT for ESKD due to diabetes mellitus (DM) was

31 p.m.p. and ranged from 14 p.m.p. in Estonia to 114 p.m.p. in Cyprus (Table 1). The most common known PRDs for patients initiating KRT were DM (21%) and hypertension (HT, 14%, Fig. 3). PRD cause was unknown/missing for 27% and categorized as miscellaneous for 14% of incident patients (Fig. 3). Most patients initiating KRT received haemodialysis (HD, 85%), followed by peritoneal dialysis (PD, 11%) and pre-emptive kidney transplant (4%, Fig. 4). In registries providing individual level data, the proportion of pre-emptive kidney transplants were highest in patients under 20 years old (21%, Fig. 4). Patients aged over 75 most



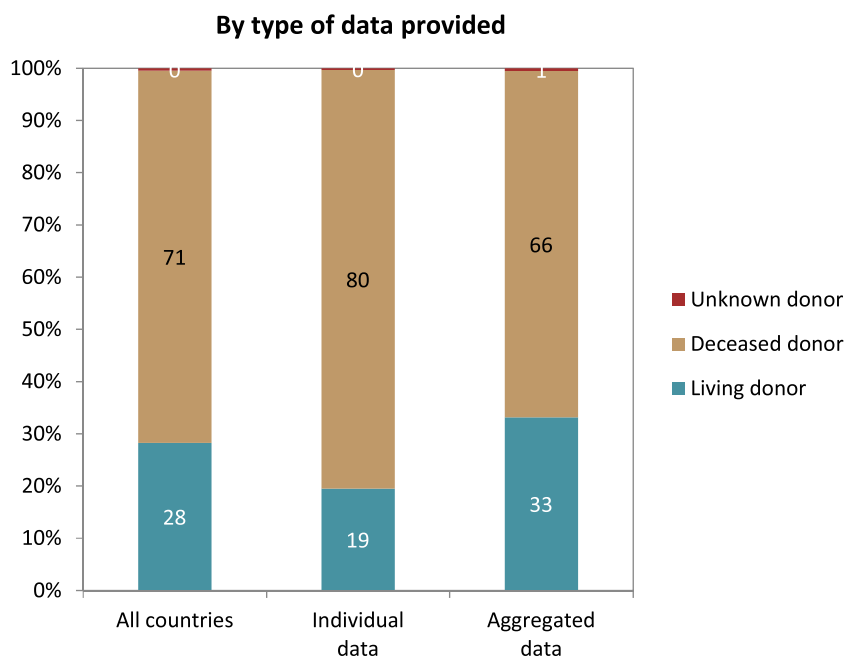


Figure 12: Distribution of donor type by type of data provided for kidney transplantations performed in 2020, unadjusted.

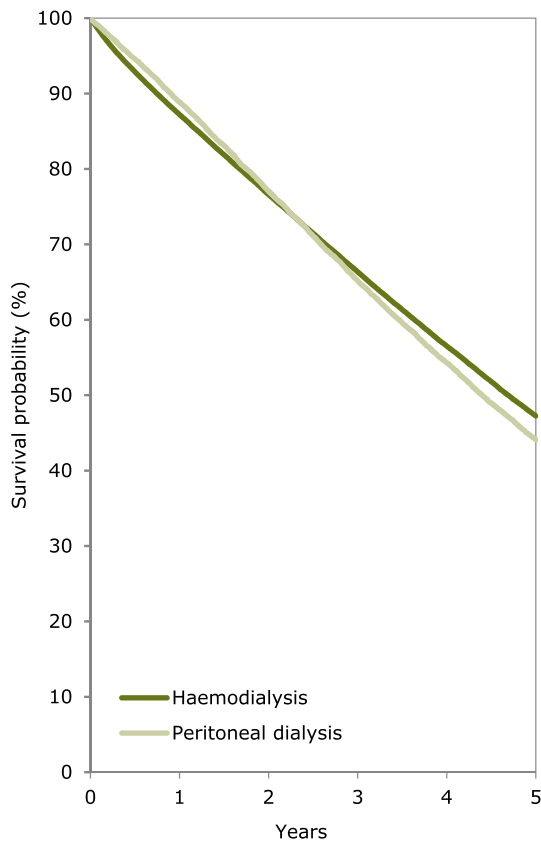
Table 3: One-, 2- and 5-year survival probabilities by treatment modality and cohort, from Day 1 of the start of KRT, dialysis, or from the day of first kidney transplantation.

Survival type	Survival probabilities as percentage (95% CI)				
	Cohort: 2011–15			Cohort: 2014–18	
	1 year	2 years	5 years	1 year	2 years
<b>Patient survival on KRT</b>					
Unadjusted	84.8 (84.6–85.0)	74.8 (74.6–75.1)	51.8 (51.6–52.0)	85.5 (85.4–85.7)	75.6 (75.4–75.8)
Adjusted <sup>a</sup>	87.6 (87.4–87.7)	78.5 (78.3–78.7)	53.9 (53.6–54.2)	88.1 (88.0–88.3)	79.0 (78.8–79.2)
<b>Patient survival on dialysis</b>					
Unadjusted	83.7 (83.5–83.9)	72.2 (72.0–72.5)	41.8 (41.5–42.1)	84.5 (84.3–84.6)	72.9 (72.7–73.1)
Adjusted <sup>a</sup>	85.9 (85.8–86.1)	75.6 (75.4–75.8)	46.8 (46.5–47.1)	86.8 (86.7–87.0)	76.6 (76.4–76.8)
<b>Patient survival after a first kidney transplantation (deceased donor)</b>					
Unadjusted	96.2 (96.0–96.4)	94.1 (93.8–94.3)	86.2 (85.8–86.5)	96.3 (96.2–96.5)	94.1 (93.9–94.3)
Adjusted <sup>b</sup>	98.0 (97.9–98.1)	96.8 (96.7–97.0)	92.1 (91.9–92.4)	98.1 (97.9–98.2)	96.8 (96.7–97.0)
<b>Graft survival after a first kidney transplantation (deceased donor)</b>					
Unadjusted	91.0 (90.7–91.3)	87.9 (87.5–88.2)	77.3 (76.9–77.7)	91.3 (91.0–91.6)	88.0 (87.7–88.4)
Adjusted <sup>b</sup>	92.9 (92.6–93.1)	90.3 (90.0–90.6)	81.3 (80.9–81.8)	93.1 (92.8–93.3)	90.4 (90.1–90.7)
<b>Patient survival after a first kidney transplantation (living donor)</b>					
Unadjusted	99.0 (98.8–99.1)	98.1 (97.8–98.3)	94.4 (94.0–94.8)	98.9 (98.7–99.0)	98.0 (97.8–98.3)
Adjusted <sup>b</sup>	99.1 (98.9–99.3)	98.3 (98.1–98.5)	95.0 (94.6–95.4)	99.1 (98.9–99.2)	98.4 (98.1–98.6)
<b>Graft survival after a first kidney transplantation (living donor)</b>					
Unadjusted	96.6 (96.3–97.0)	94.9 (94.5–95.3)	88.1 (87.5–88.7)	96.7 (96.3–97.0)	95.2 (94.8–95.5)
Adjusted <sup>b</sup>	96.4 (96.0–96.7)	94.5 (94.1–95.0)	87.3 (86.6–87.9)	96.5 (96.1–96.8)	94.9 (94.5–95.3)

<sup>a</sup>Analyses were adjusted using fixed values: age (67 years), sex (63% men) and PRD (24% DM, 19% HT/RVD, 11% GN and 46% other causes)

<sup>b</sup>Analyses were adjusted using fixed values: age (50 years), sex (63% men) and PRD (14% DM, 10% HT/RVD, 23% GN and 53% other causes)

This table is based on data from the following registries providing individual patient data: Austria, Belgium (Dutch-speaking), Belgium (French-speaking), Bosnia and Herzegovina, Denmark, Estonia, 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 (Community of Madrid), Spain (Extremadura), Spain (Galicia), Spain (Murcia), Spain (Valencian Region), Sweden, the Netherlands, the UK (England/Northern Ireland/Wales) and the UK (Scotland).

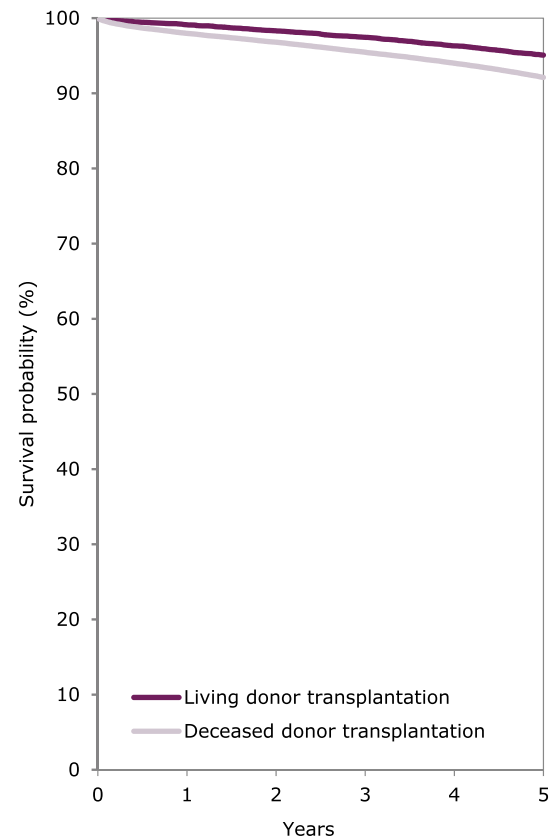


**Figure 13:** Patient survival by modality, either HD or PD, in incident dialysis patients from Day 91. Survival was adjusted using fixed values for age (67 years), sex (63% men) and PRD (24% diabetes mellitus, 19% hypertension/renal vascular disease, 11% glomerulonephritis and 46% other causes). This figure is based on patients starting dialysis between 2011 and 2015 from the following registries providing individual patient data: Austria, Belgium (Dutch-speaking), Belgium (French-speaking), Bosnia and Herzegovina, Denmark, Estonia, 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 (Community of Madrid), Spain (Extremadura), Spain (Galicia), Spain (Murcia), Spain (Valencian Region), Sweden, the Netherlands, the UK (England/Northern Ireland/Wales) and the UK (Scotland).

commonly started with HD (88%) while in patients under 19 years old this was much less common (52%). KRT modality did not differ by sex (Fig. 4). Patients with DM as PRD had slightly fewer pre-emptive kidney transplants (2%) compared with non-DM patients (5%). HD as first treatment modality was higher in patients with DM than non-DM (86% compared with 81%), but PD was similar in DM and non-DM patients (13% compared with 14%, Fig. 4). At Day 91, 82% of incident KRT patients were on HD, 14% on PD and 4% living with a kidney transplant (Fig. 5).

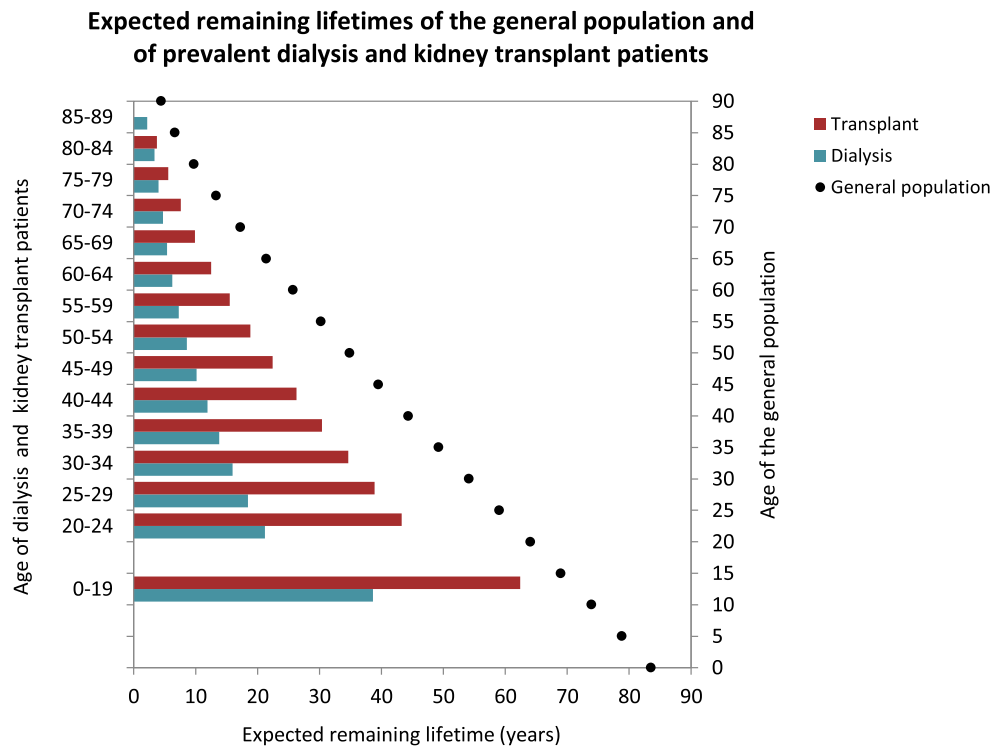
### KRT prevalence

A total of 604 261 patients with ESKD were receiving KRT on 31 December 2020. This corresponds to an unadjusted KRT prevalence of around 1 per 1070 Europeans (931 p.m.p., Table 2), which is slightly higher than in 2019 (893 p.m.p.). The unadjusted prevalence of KRT ranged from 1 per 2580 inhabitants (388 p.m.p.) in Montenegro to 1 per 497 inhabitants (2011 p.m.p.) in Portugal (Table 2 and Figs 6 and 7). When adjusted to age and sex using

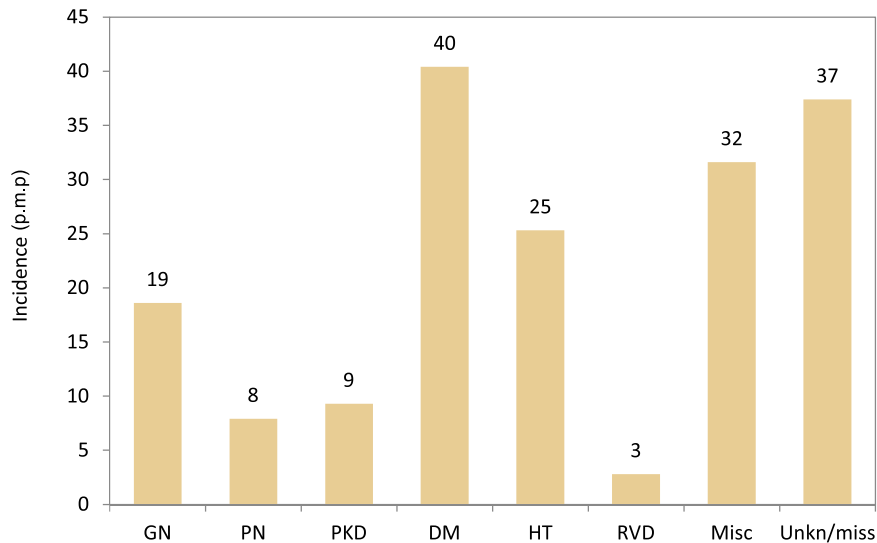


**Figure 14:** Patient survival in kidney transplant recipients by donor type, either deceased or living donors, from day of transplantation. Survival was adjusted using fixed values for age (50 years), sex (63% men) and PRD (14% diabetes mellitus, 10% hypertension/renal vascular disease, 23% glomerulonephritis and 53% other causes). This figure is based on patients receiving a kidney transplant between 2011 and 2015 from the following registries providing individual patient data: Austria, Belgium (Dutch-speaking), Belgium (French-speaking), Bosnia and Herzegovina, Denmark, Estonia, 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 (Community of Madrid), Spain (Extremadura), Spain (Galicia), Spain (Murcia), Spain (Valencian Region), Sweden, the Netherlands, the UK (England/Northern Ireland/Wales) and the UK (Scotland).

the distribution of the EU28 population, the overall prevalence of KRT for the available 44 countries/regions was 1 per 895 Europeans (1117 p.m.p., Fig. 7). Adjusted prevalence ranged from 1 per 2470 inhabitants (405 p.m.p.) in Montenegro to 1 per 642 (1558 p.m.p.) in the Murcia region (Spain) (Fig. 7). The median age for patients on KRT was 59.3 years old, ranging from 51.0 years in Albania to 69.3 in Israel, although this latter country only included dialysis patients (Table 2). A majority of prevalent patients were aged over 45 years (84%, Fig. 8). The overall prevalence of KRT among men was 1 per 882 (1133.5 p.m.p.) and among women 1 per 1405 (711.9 p.m.p.). For countries providing individual data this was 1482.5 p.m.p. for men and 873.9 p.m.p. for women, and for countries providing aggregated data it was 880.9 p.m.p. for men and 589.2 p.m.p. for women. Overall, 60% of all prevalent patients were men (Fig. 8). The prevalence of patients with DM as PRD was 159 p.m.p., ranging from 55 p.m.p. in Belarus to 411 p.m.p. in the Canary Islands region (Spain) (Table 2). The most common PRD was glomerulonephritis/sclerosis (18%), followed by DM (15%) and HT (10%, Fig. 8). Twenty-six percent of PRD



**Figure 15:** Expected remaining lifetime, in years, of the general population (cohort 2016–20) and of prevalent dialysis and kidney transplant patients (cohort 2016–20) by age. This figure is based on data from the following registries providing individual patient data: Austria, Belgium (Dutch-speaking), Belgium (French-speaking), Bosnia and Herzegovina, Denmark, Estonia, 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 (Community of Madrid), Spain (Extremadura), Spain (Galicia), Spain (Murcia), Spain (Valencian Region), Sweden, the Netherlands, the UK (England/Northern Ireland/Wales) and the UK (Scotland).



**Figure 16:** Incidence of KRT in 2020 on Day 1 by PRD, unadjusted. Abbreviations: Misc: miscellaneous; Unkn/miss: unknown/missing.

causes were unknown/missing and 14% were miscellaneous. A majority of prevalent patients were receiving HD (58%), followed by kidney transplantation (37%) and PD (5%, Fig. 9). Seventy-eight percent of patients under 20 years old were living with a kidney transplant, and this proportion progressively decreased with in-

creasing age groups (Fig. 9). Only 19% of patients over 75 years were living with a kidney transplant and the majority of those over 75 years were receiving HD (74%). Treatment modality for prevalent patients was similar between men and women (Fig. 9). Patients with DM as PRD were less likely to be living with a

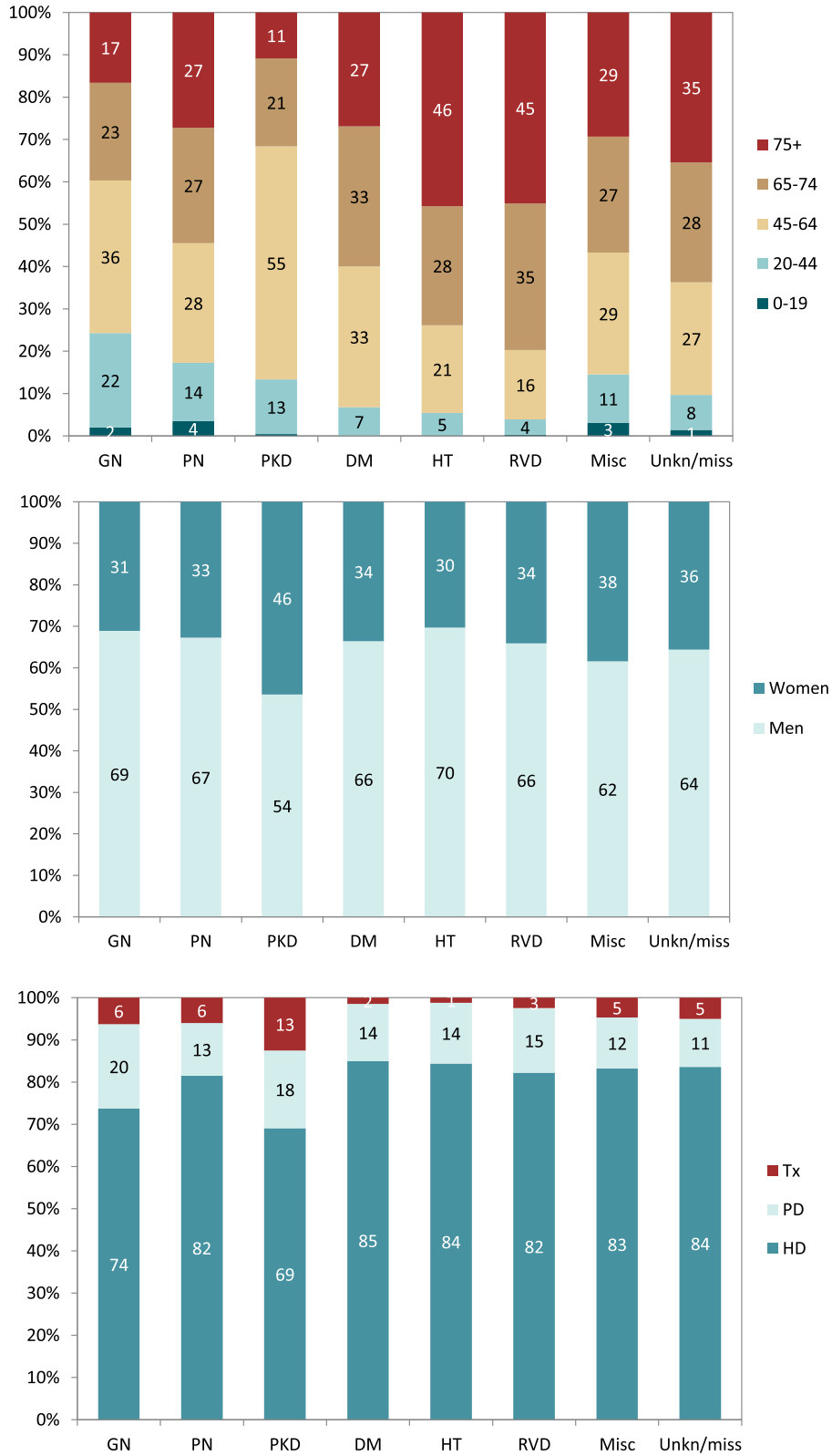
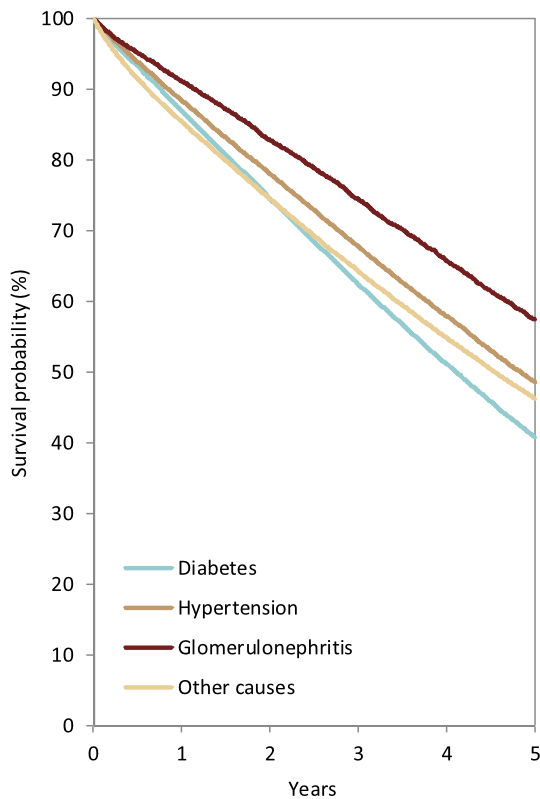


Figure 17: Distribution of (A) age, (B) sex and (C) treatment modality by PRD for incident patients accepted for KRT in 2020, on Day 1, unadjusted. Abbreviations: Misc: miscellaneous; Unkn/miss: unknown/missing; Tx: transplant.



**Figure 18:** Patient survival by PRD in incident dialysis patients from Day 91. Survival was adjusted using fixed values for age (67 years) and sex (63% men). This figure is based on patients starting dialysis between 2011 and 2015 from the following registries providing individual patient data: Austria, Belgium (Dutch-speaking), Belgium (French-speaking), Bosnia and Herzegovina, Denmark, Estonia, 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 (Community of Madrid), Spain (Extremadura), Spain (Galicia), Spain (Murcia), Spain (Valencian Region), Sweden, the Netherlands, the UK (England/Northern Ireland/Wales) and the UK (Scotland).

kidney transplant (29%) compared with those not having DM as PRD (51%) and more likely to be receiving HD (65%) compared with those not having DM as PRD (44%, Fig. 9).

### Kidney transplantation

In 2020, a total of 18 136 kidney transplantations were performed, which corresponds to an unadjusted kidney transplantation rate of 1 per 35 800 Europeans (28 p.m.p., Fig. 10) and is lower than in 2019 (35 p.m.p.). Kidney transplantation rate ranged from 0 p.m.p. in Montenegro to 108 p.m.p. in the Cantabria region (Spain) (Fig. 10). Overall, most kidney transplantations were from deceased donors (71%). Albania and Kosovo had no kidney transplantations from deceased donors while Belarus and the Spanish region of Castile-La Mancha had all kidney grafts from deceased donors. The overall transplantation rate from deceased donors (20 p.m.p.) was more than twice that from living donors (8 p.m.p., Fig. 11). The deceased donor transplantation rate was highest in the Cantabria region (Spain) (106 p.m.p.). Eighty percent of kidney transplants from countries providing individual level data were from deceased donors, which is a larger proportion compared with that within the countries providing aggregated data (66%, Fig. 12). The highest rate of living donor transplantations was in Israel (29 p.m.p., Fig. 11).

### Survival probability of patients receiving KRT

Using data on patients starting KRT during the period 2011–15, the unadjusted 5-year survival probability was 51.8% [95% confidence interval (95% CI) 51.6–52.0, Table 3]. The 5-year unadjusted survival probability for patients receiving a first kidney transplant during the period 2011–15 from either a deceased (86.2%; 95% CI 85.8–86.5) or living donor (94.4%; 95% CI 94.0–94.8) was higher than the survival probability for patients starting dialysis (41.8%; 95% CI 41.5–42.1). Patients initiating dialysis with HD had a slightly higher 5-year adjusted survival probability (47%) than those initiating dialysis with PD (44%) (Fig. 13). In patients that received a kidney transplant, the 5-year survival probability of those having received a deceased donor transplant (92.1%; 95% CI 91.9–92.4) was lower than for those having received a living donor transplant (95.0%; 95% CI 94.6–95.4, Table 3 and Fig. 14). Five-year adjusted graft survival was also lower after deceased donor kidney transplantations (81.3%; 95% CI 80.9–81.8) than after living donor kidney transplantations (87.3%; 95% CI 86.6–87.9, Table 3).

### Expected remaining lifetime

Using data from 2016–20, the expected remaining lifetime of KRT patients was consistently lower than the general population across all age groups (Fig. 15). Patients on dialysis had about a 50% lower expected remaining lifetime compared with patients with a kidney transplant. However, in patients above the age of 70 years the gap in expected remaining lifetime between those on dialysis and those with a transplant became smaller.

### Comparisons by primary renal disease

For the first time, comparisons across PRD groups are presented. Using individual patient-level data from 35 registries from 18 countries in Europe, Figs 16–23 show comparisons across PRD groups. Causes of PRD were grouped into eight categories: glomerulonephritis/sclerosis (GN), pyelonephritis (PN), adult type polycystic kidneys (PKD), DM, HT, renal vascular disease (RVD), miscellaneous causes (Appendix 2) and unknown/missing PRD.

In 2020, DM was the most common PRD in incident KRT patients (40 p.m.p.), followed by HT (25 p.m.p.) and GN (19 p.m.p., Fig. 16). Patients aged over 75 comprised the highest proportion of patients with HT (46%) and RVD (45%, Fig. 17). Patients younger than 45 years old comprised the lowest proportion of incident patients in most PRD groups, except for GN and PKD. The proportion of women was highest in patients with PKD (46%), and in other PRD groups the prevalence of women ranged from 30% to 38% (Fig. 17). Regardless of PRD, HD was the most common form of KRT in incident patients, with the proportion of patients using HD ranging from 69%–85% among the PRD groups (Fig. 17). The proportion of patients receiving a pre-emptive kidney transplant was 2-fold higher for those with PKD (13%) compared with other PRD groups (1% to 6%, Fig. 17). Survival probabilities of incident dialysis patients (Day 91) by PRD group adjusted to age and sex are shown in Fig. 18. After 5 years, the highest 5-year survival probability was found for patients with GN (57%), and the lowest for DM (41%, Fig. 18).

The most common PRDs in prevalent KRT patients on 31 December 2020 were GN (288 p.m.p.), DM (246 p.m.p.) and HT (169 p.m.p., Fig. 19). Prevalent KRT patients under 45 years old comprised 20% of patients with GN and 23% of patients with PN, but a significantly smaller proportion of patients with PKD (5%), DM (7%), HT (6%) and RVD (5%, Fig. 20). Prevalent KRT patients

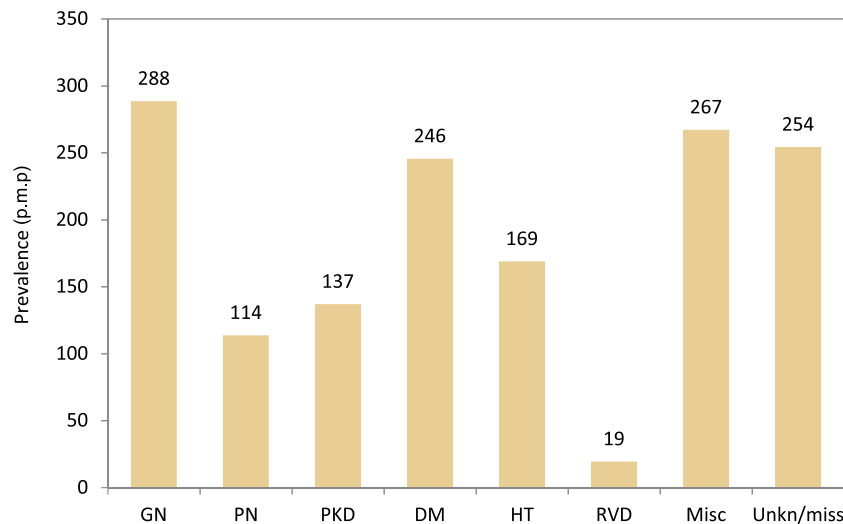


Figure 19: Prevalence of KRT on 31 December 2020 by PRD, unadjusted. Abbreviations: Misc: miscellaneous; Unkn/miss: unknown/missing.

over 75 years old comprised the largest proportion of patients with RVD (43%) or HT (39%). The proportion of women in PRD groups ranged from 32% in patients with HT to 47% in patients with PKD (Fig. 20). Kidney transplantation was the most common KRT for prevalent patients with PKD (67%), GN (62%) and PN (56%, Fig. 20). For the remaining PRD groups, HD was the most common form of KRT for prevalent patients, with the use of HD ranging from 59% to 65% (Fig. 20).

Patients with GN received most of the available kidney transplants (23%, Fig. 21). The percentage of kidney transplants available was lower for patients with DM (14%), PKD (12%), HT (9%) and PN (6%). Only 1% of all kidney transplants was available for patients with RVD. A majority of transplants were from deceased donors regardless of PRD group (76%–91%, Fig. 22). Patients with PN, GN or PKD had the highest proportion of living donor transplantations (22%, 21% and 20%, respectively). Comparatively, patients with DM or HT had about 50% lower proportions of living donor transplants (9% and 12%). Age- and sex-adjusted survival probabilities after first transplantation slightly differed by PRD group (Fig. 23), with DM patients having the lowest survival probability after 5 years (88%).

## AFFILIATED REGISTRIES

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## ERA REGISTRY COMMITTEE MEMBERS

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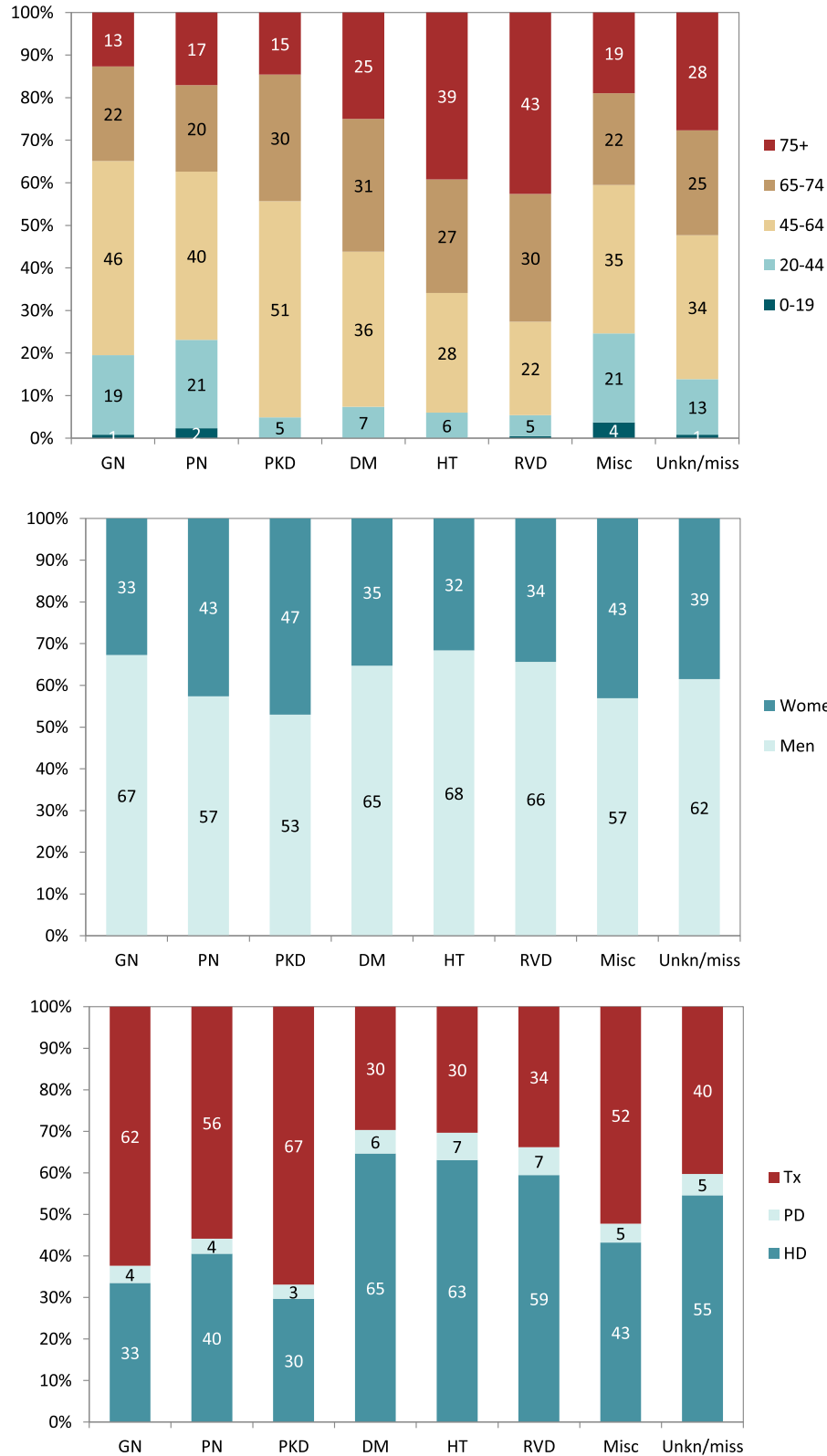


Figure 20: Distribution of (A) age, (B) sex and (C) treatment modality distribution by PRD in prevalent patients on KRT on 31 December 2020, unadjusted. Abbreviations: Misc: miscellaneous; Unkn/miss: unknown/missing; Tx: transplant.

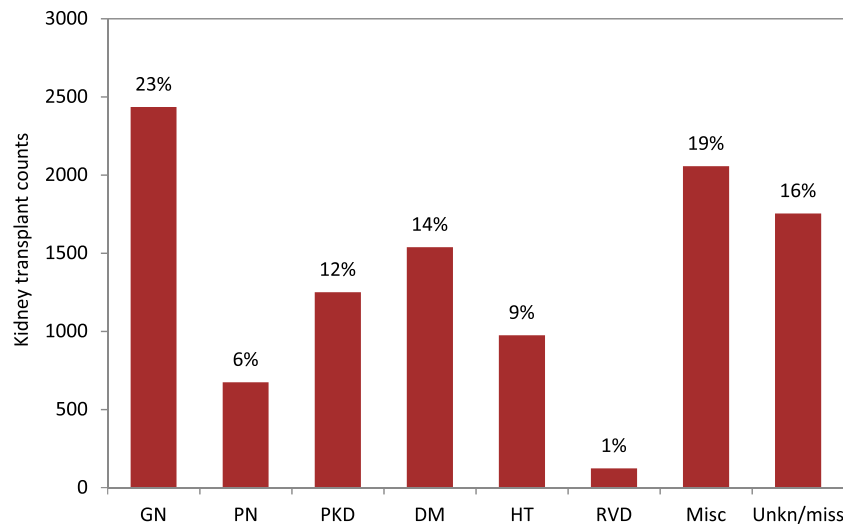


Figure 21: Kidney transplantations in both prevalent and incident KRT patients performed in 2020 by PRD, unadjusted. The percentages in this figure sum up to 100% for all PRD groups together. Abbreviations: Misc: miscellaneous; Unkn/miss: unknown/missing.

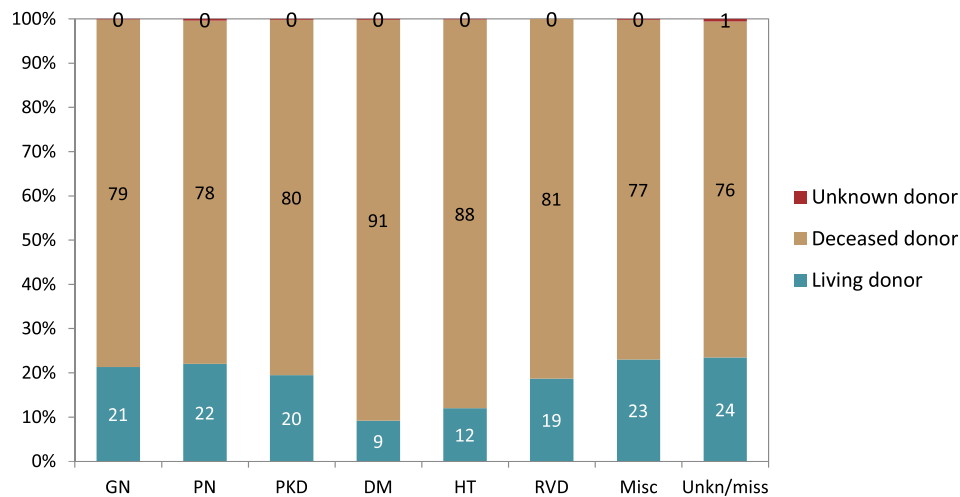


Figure 22: Distribution of donor type by PRD for kidney transplantations performed in 2020, unadjusted. Abbreviations: Misc: miscellaneous; Unkn/miss: unknown/missing.

S. Bakkaloglu, Turkey; P.M. Ferraro, Italy; J. Helve, Finland; J.E. Sánchez-Alvarez, Spain; M. Segelmark, Sweden; S.S. Sørensen, Denmark; E. Vidal, Italy.

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### SUPPLEMENTARY DATA

Supplementary data are available at [ckj](#) online.

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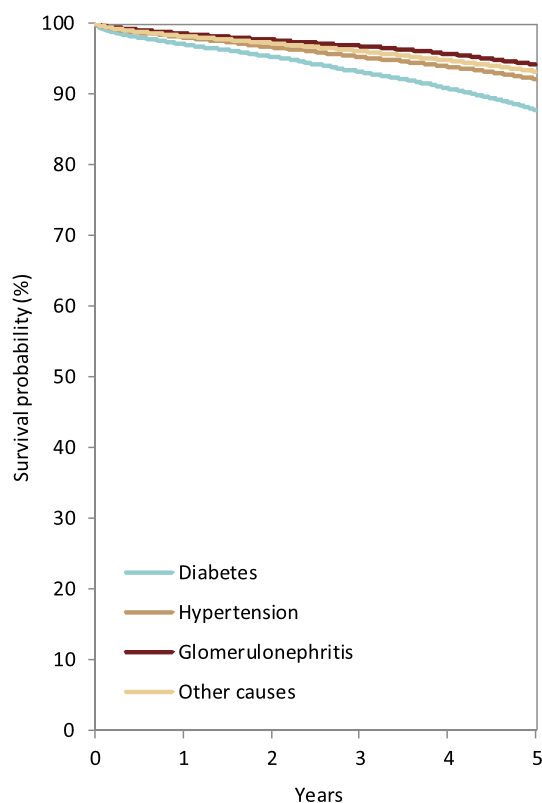
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**Figure 23:** Patient survival by PRD in kidney transplant recipients from day of transplantation. Survival was adjusted using fixed values for age (50 years) and sex (63% men). This figure is based on patients receiving a kidney transplant between 2011 and 2015 from the following registries providing individual patient data: Austria, Belgium (Dutch-speaking), Belgium (French-speaking), Bosnia and Herzegovina, Denmark, Estonia, 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 (Community of Madrid), Spain (Extremadura), Spain (Galicia), Spain (Murcia), Spain (Valencian Region), Sweden, the Netherlands, the UK (England/Northern Ireland/Wales) and the UK (Scotland).

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## CONFLICT OF INTEREST STATEMENT

A.O. is the previous Editor-in-Chief of CKJ.

## DATA AVAILABILITY STATEMENT

The data underlying this article cannot be shared publicly due to privacy laws, such as the General Data Protection Regulation (GDPR).

## APPENDIX 1

### Countries or regions providing individual patient data to the ERA Registry

Austria, Belgium (Dutch-speaking), Belgium (French-speaking), Bosnia and Herzegovina, Denmark, Estonia, Finland, France,

Greece, Iceland, Montenegro, Norway, Romania, Serbia, Spain (Andalusia), Spain (Aragon), Spain (Asturias), Spain (Basque country), Spain (Canary Islands), Spain (Cantabria), Spain (Castile and León), Spain (Castile-La Mancha), Spain (Catalonia), Spain (Community of Madrid), Spain (Extremadura), Spain (Galicia), Spain (La Rioja), Spain (Murcia), Spain (Navarre), Spain (Valencian region), Sweden, Switzerland, the Netherlands, the UK (England/Northern Ireland/Wales) and the UK (Scotland).

### Countries or regions providing aggregated data to the ERA Registry

Albania, Belarus, Croatia, Cyprus, Czech Republic, Hungary, Israel, Italy (8 of 20 regions), Kosovo, Lithuania, North Macedonia, Poland, Portugal, Russia, Slovakia, Spain, Turkey.

### Countries part of the European Union (EU-28) population in 2015 (used as reference population)

Austria, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, the Netherlands, Poland, Portugal, Romania, Slovakia, Slovenia, Spain, Sweden, the UK.

## APPENDIX 2

### Miscellaneous primary renal disease

Nephropathy (interstitial) due to analgesic drugs, nephropathy (interstitial) due to cis-platinum, nephropathy (interstitial) due to cyclosporin A, lead-induced nephropathy (interstitial), drug-induced nephropathy (interstitial) not mentioned above, cystic kidney disease—type unspecified, polycystic kidneys; infantile (recessive), medullary cystic disease; including nephronophthisis, 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 syndrome), renal vascular disease due to polyarteritis, Wegener's granulomatosis, ischaemic renal disease/cholesterol embolism, glomerulonephritis related to liver cirrhosis, cryoglobulinaemic glomerulonephritis, myelomatosis/light chain deposit disease, amyloidosis, lupus erythematosus, Henoch-Schoenlein 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 haemolytic uraemic syndrome), tuberculosis gout, nephrocalcinosis and hypercalcaemic nephropathy, Balkan nephropathy, kidney tumour, traumatic or surgical loss of kidney, other identified renal disorders.

## REFERENCES

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