Nefrovisie
Richtlijnen · Registratie · Visitatie

RENINE annual report 2021

Includes data until December 31st 2020

Nefrovisie
Richtlijnen · Registratie · Visitatie

Dutch Federation for Nephrology

Zicht op nierzorg

In cooperation with the Registration Division (Sectie Registratie) of the Dutch Federation for Nephrology (NFN; Nederlandse Federatie voor Nefrologie)

Nefrovisie
Postbus 830
3500 AV Utrecht
www.nefrovisie.nl
info@nefrovisie.nl

Suggested citation: Renine Registry Annual Report 2021. Nefrovisie, Utrecht, the Netherlands 2021.

Contents

1 Introduction

We are pleased to present the Renine Annual Report 2021. Renine is the Dutch registry on chronic renal replacement therapy. Chronic replacement therapy is defined as either a renal transplant or dialysis for at least 28 days. All dialysis centres in the Netherlands provide data to Renine. Data on renal transplantations are provided by the 'Nederlandse Transplantatie Stichting' (NTS). The coverage ratio of Renine is 96% of the prevalent patients and 94% for incident dialysis patients.

Several measures are being taken to ensure a high quality of the data. Data up to December 31st, 2020 was checked and approved by the dialysis centres. Nefrovisie performs data verification visits of the dialysis centres at 3-year intervals.

Data from Renine enables accurate monitoring of the quality of care of renal replacement therapy in the Netherlands. Together with stakeholders we continuously work on the improvement of the reporting of the data to advance transparency of renal care. Data from Renine is interactively available at www.nefrodata.nl. In this report, we provide additional analyses of the data up to 2020.

In March 2020 Nefrovisie started collecting data on the occurrence and outcomes of Covid-19 in the dialysis population. These data are reported in Chapter 3 of this report. Nefrovisie contributed to an analysis of the impact of the Covid-19 pandemic on non-Covid-19 related care performed by the SKR (Samenwerkende Kwaliteitsregistraties). The full report is available at www.skr-zorg.nl.

The Board of Nefrovisie thanks all participating dialysis centres and the NTS for the excellent cooperation.

Marc ten Dam, CEO Nefrovisie

2 Renal replacement therapy: key figures of 2020

Table 2.1. Number of prevalent and incident renal replacement therapy (RRT) patients registered in Renine in 2020. Reference date for prevalence: December 31st 2020*

	N	%	Change from 2019
Prevalence*			
Renal replacement therapy	18,071		+1%
Dialysis	6,261	35%	-0.8%
Renal transplant	11,810	65%	+2%
Incidence*			
Renal replacement therapy	1,844		-5%
Dialysis	1,627	88%	-2%
Renal transplant	217	12%	-20%

*241 prevalent dialysis patients and 97 incident RRT patients did not provide consent for their data to be included in Renine. The coverage in 2020 was 96% and 94% respectively.

Table 2.2. Characteristics prevalent dialysis patients (December 31st 2020), N=6,261.

Men	3,762	60%
Women	2,499	40%
Age (yrs), mean (SD)	67 (15)	
Haemodialysis	5,260	84%
Peritoneal dialysis	1,001	16%
Primary kidney disease		
Glomerulonephritis/sclerosis	684	11%
Pyelonephritis	281	4%
Polycystic kidney disease	311	5%
Hypertension	1,053	17%
Renal vascular disease	704	11%
Diabetes type 1	171	3%
Diabetes type 2	1,166	19%
Miscellaneous	1,142	18%
Unknown	749	12%
Time on RRT (yrs), mean (SD)	4.9 (6.3)	
History renal transplantation	741	12%

Table 2.3. Characteristics prevalent transplant patients (December 31st 2020), N=11,810

Men	7,161	61%
Women	4,649	39%
Age (yrs), mean (SD)	57 (15)	
Living donor	6,220	53%
Post-mortem donor	5,590	47%
Transplant number		
First	10,171	86%
Second	1,359	12%
Third or higher	280	2%
No dialysis history	3,090	26%
Primary kidney disease		
Glomerulonephritis/sclerosis	2,251	19%
Pyelonephritis	814	7%
Polycystic kidney disease	1,250	11%
Hypertension	1,088	9%
Renal vascular disease	348	3%
Diabetes type 1	486	4%
Diabetes type 2	587	5%
Miscellaneous	2,645	22%
Unknown	2,341	20%
Time on RRT (yrs), mean (SD)	13 (10)	

Table 2.4. Characteristics of incident RRT patients in 2020 with start modality dialysis (N=1,627)

Men	1,053	65%
Women	574	35%
Age (yrs), mean (SD)	65 (15)	
Modality at start RRT, at day 1		
Haemodialysis	1,285	79%
Peritoneal dialysis	342	21%
Primary kidney disease*		
Glomerulonephritis/sclerosis	167	10%
Pyelonephritis	46	3%
Polycystic kidney disease	77	5%
Hypertension	266	16%
Renal vascular disease	171	11%
Diabetes type 1	49	3%
Diabetes type 2	326	20%
Miscellaneous	302	19%
Unknown	223	14%

*The percentages do not add up to 100% due to rounding.

Table 2.5. Characteristics of incident RRT patients in 2020 pre-emptive transplantations (N=217)

Men	127	59%
Women	90	41%
Age (yrs), mean (SD)	52 (15)	
Post-mortem donor	35	16%
Living donor	182	84%

.

3 Covid-19 in the dialysis population

Shortly after the presentation of the first Covid-19 cases in the Netherlands in February 2020, it was decided to expand the registration with data on Covid-19 in the dialysis population. The following items were collected: date of diagnosis, confirmation by a test, outcomes (hospitalisations, ICU admissions, and death due to the Covid-19 infection). The first Covid-19 case in the dialysis population presented itself on March 2nd, 2020. In this chapter, we present the incidence of Covid-19 and outcomes over the year 2020.

During the year a total of 615 Covid-19 cases were registered in Renine (Table 3.1). Practically all cases (98%) were confirmed by a positive test. Almost half of the patients had to be admitted to the hospital. The percentage admitted to the ICU was however low (4%). In the general Dutch population 21% of all patients admitted to the hospital were also admitted to the ICU[1], in dialysis patients this was only 8%. This difference is likely due to the high degree of frailty in the dialysis population which might have been a contraindication for ICU admission. The frailty of the population is also reflected by the high mortality rates after the Covid-19 diagnosis, i.e. 22% of the cases died due to Covid-19. Overall 28-days mortality was slightly higher, i.e. 25%.

Table 3.1. Characteristics of dialysis patients diagnosed with Covid-19 in 2020 (N=615)

	N	%
Confirmed by positive test	604	98%
Hospital admission	301	49%
Intensive care admission	25	4%
Death due to Covid-19	134	22%
Overall 28-days mortality	154	25%

In 2020 incidence of Covid-19 in the dialysis population was double the incidence observed in the general population, i.e. 98 cases per 1,000 persons compared to 47 cases per 1,000 persons[2]. Especially during the first wave incidence in dialysis patients was high (28 versus 3 cases per 1,000 persons), likely mainly due to a higher frequency of testing than in the general population. However, also during the second half of 2020 when availability and application of testing among the general population has increased, incidence remained relatively high in the dialysis (70 versus 45 cases per 1,000 persons). The absolute number of new cases both in Renine and in the general population is shown in Figure 3.1.

[1] Based on data published by NICE (open data).
[2] RIVM open data.

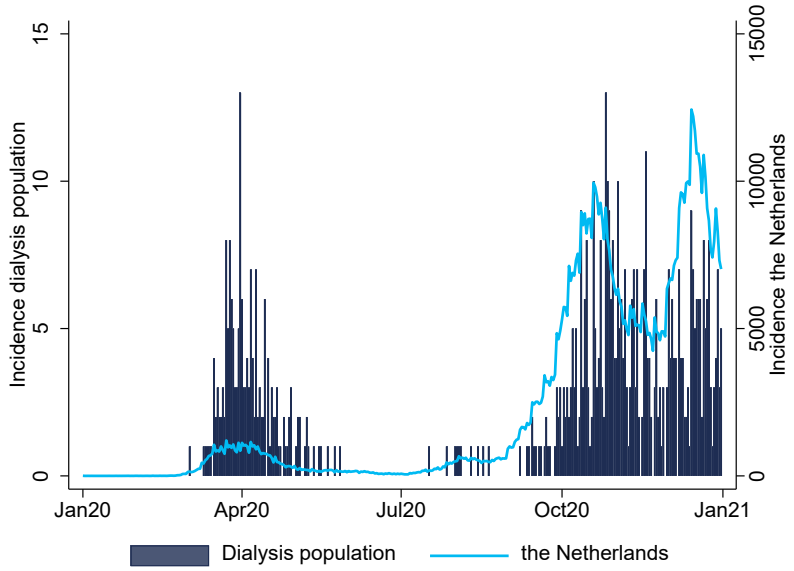

Figure 3.1. Incidence Covid-19 in dialysis patients and in the general Dutch population in 2020.

Table 3.2. shows the characteristics of patients diagnosed with Covid-19 in 2020 in comparison to the overall prevalent dialysis population at midyear (reference date July 1st, 2020). The percentage treated with peritoneal dialysis was lower in Covid-19 patients. This might however also be partly due to a higher frequency of testing in in-centre haemodialysis patients. Furthermore, the Covid-19 population had more often diabetes as primary kidney disease than the overall dialysis population.

Table 3.2. Characteristics Covid-19 patients in 2020 compared to the prevalent dialysis population.

	Covid-19 patients (N=615)	Prevalent dialysis patients (N=6,338)*	P-value**
Modality, peritoneal dialysis	11%	15%	<0.01
Dialysis vintage			0.28
< 2 yrs	43%	46%	
2-5 yrs	33%	32%	
>5 yrs	24%	21%	
Sex, male	61%	60%	0.54
Age			0.38
< 45 yrs	7%	8%	
45-64 yrs	27%	28%	
65-74 yrs	26%	27%	
≥75 yrs	40%	37%	
Primary kidney disease			<0.001
Glomerulonephritis/sclerosis	9%	11%	
Diabetes	30%	21%	
Hypertension/renal vascular	25%	28%	
Other	36%	40%	

*For prevalent dialysis patients July 1st was used as reference date. For characteristics of the Covid-19 patients the date of the Covid-19 diagnosis was used.

**P-values are based on Chi-square tests.

Several characteristics were associated with 28-days mortality. Both univariate, as well as multivariate analyses, are shown in Table 3.3. Male sex, longer dialysis vintage, and older age increased risk for mortality. These associations remained in the multivariate model. Prognosis improved during the second wave. However, this might also be influenced by differences in testing practices leading to the diagnosis of less severe cases. Differences in testing and registry practices might also be responsible for the observed higher mortality risk in peritoneal dialysis patients compared to haemodialysis patients. Glomerulonephritis/sclerosis and hypertension/renal vascular disease were associated with unfavourable outcome. In contrast to findings in the general population, diabetes was not associated with mortality after Covid-19 diagnosis. This finding is in line with the ERACODA study in which diabetes also did not appear to be associated with mortality.[1]

Table 3.3. Association between patient characteristics and mortality at day 28 after Covid-19 diagnosis. Results are presented as odds-ratio (95%-confidence intervals).

	Crude	Multivariate model
Sex, male (ref female)	1.9 (1.3-2.9)	2.1 (1.3-3.2)
Time period (ref Mar-Jun)		
July-December	0.6 (0.4-0.9)	0.7 (0.5-1.1)
Dialysis vintage		
<2 yrs (ref)	1	1
2-5 yrs	1.7 (1.1-2.6)	1.7 (1.1-2.7)
>5 yrs	1.8 (1.1-2.9)	1.7 (1.0-2.9)
Age category		
<65 yrs (ref)	1	1
65-74 yrs	2.6 (1.5-4.4)	2.9 (1.6-5.1)
≥75 yrs	3.6 (2.2-5.8)	3.3 (2.0-5.6)
Modality, PD (ref HD)	1.8 (1.0-3.1)	2.5 (1.4-4.5)
Primary kidney disease		
Other (ref)	1	1
Glomerulonephritis/sclerosis	2.0 (1.0-3.8)	2.3 (1.1-4.6)
Diabetes	1.1 (0.6-1.7)	1.0 (0.6-1.7)
Hypertension/renal vascular	2.4 (1.5-3.8)	1.8 (1.1-3.0)

1 Hilbrands LB et al. COVID-19-related mortality in kidney transplant and dialysis patients: results of the ERACODA collaboration. Nephrol Dial Transplant 2020; 35(11):1973-1983.

Figure 3.2. shows the regional distribution of Covid-19 cases in the dialysis population separately by two time periods, before and after July 1st, 2020. During the first phase, the incidence was highest in Noord-Brabant (5.1%), followed by Limburg (3.7%) and Utrecht (3.3%). During the second half of 2020, the highest incidence was seen for Flevoland (12.1%) and Zuid-Holland (10.3%).

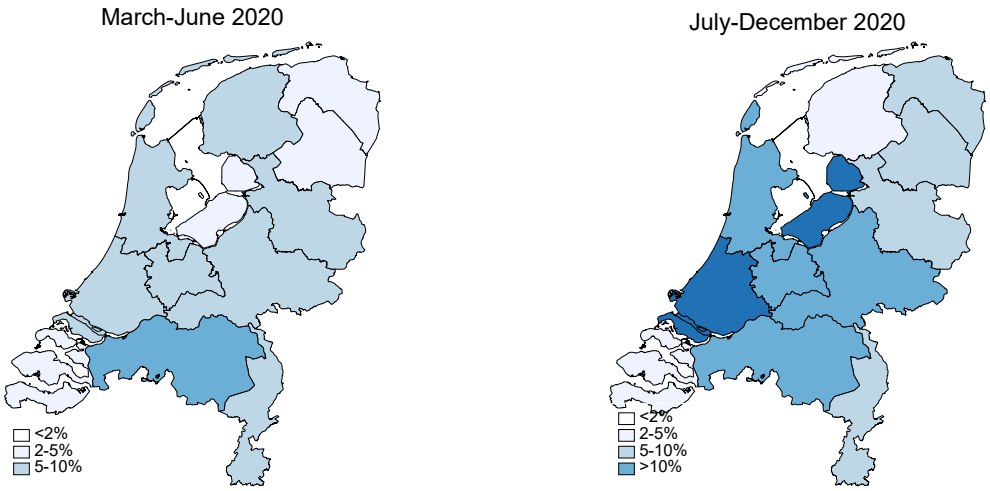

Figure 3.2 Regional incidence of Covid-19 during 2020 (before and after July 1st). Incidence is expressed as percentage of the prevalent dialysis population (reference date July 1st).

4 Renal replacement therapy: prevalence and incidence

On December 31st, 2020 18,071 prevalent patients on renal replacement therapy (RRT) were registered in Renine (Figure 4.1). This equals 1,034 patients per million of the total population in the Netherlands (Figure 4.2). RRT prevalence shows a steady increase over time. Incidence, i.e. the number of new patients per calendar year, remained more or less stable over the last decade. In 2020 incidence of RRT was 1,844 patients, which equals 106 patients per million population. Compared to 2019 this is a decrease of 5%. Both prevalence and incidence of RRT are higher in men than in women. On December 31st, 2020 60% of prevalent RRT patients were male. Of the patients starting RRT in 2020 64% was male.

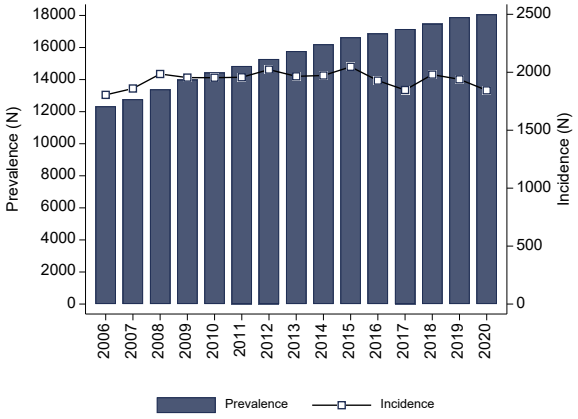

Figure 4.1. Prevalence and incidence of renal replacement therapy.

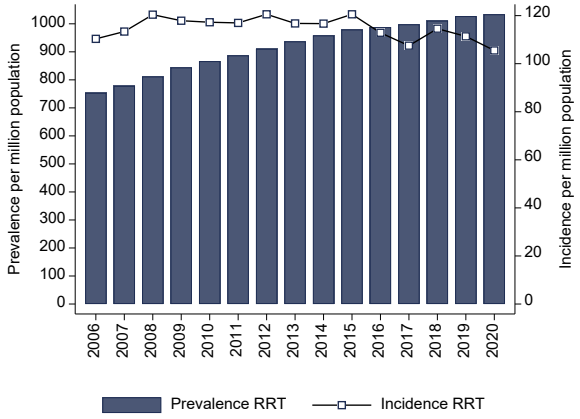

Figure 4.2. Prevalence and incidence of renal replacement therapy per million population.

The proportion of elderly patients in the prevalent RRT population is steadily increasing (Figure 4.3). On December 31st, 2020 46% of patients on renal replacement therapy were 65 years or older and 19% were 75 years or older. A decade ago (2010) this was 38% and 17% respectively. The mean age of the prevalent RRT population increased from 58 years (SD=16) to 61 years (SD=16) during this period.
The number of prevalent RRT patients per million of the age-related population is increasing in age categories above 65 years of age (Figure 4.4).

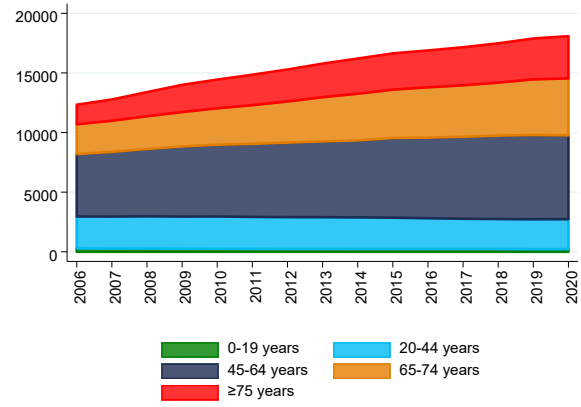

Figure 4.3 Prevalence of renal replacement therapy by age categories.

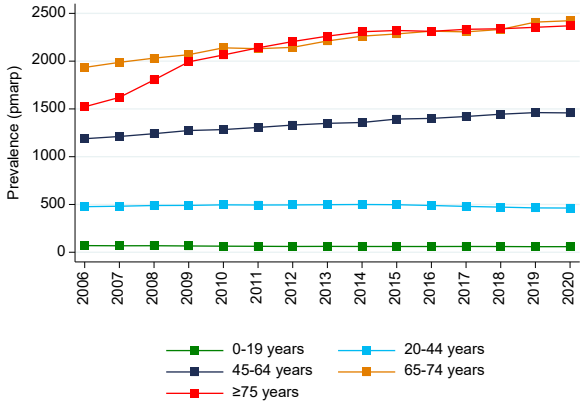

Figure 4.4.Prevalence of renal replacement therapy by age categories expressed per million age related population.

Most of the RRT patients, i.e. 65%, are patients living with a renal transplant. The proportion of transplant patients ranges from 35% in patients ≥75 years to 80% in patients younger than 45 years (Figure 4.5). However, numbers are increasing over the years in older patients. In 2010 only 13% of the RRT patients in the oldest age category were having a transplant.

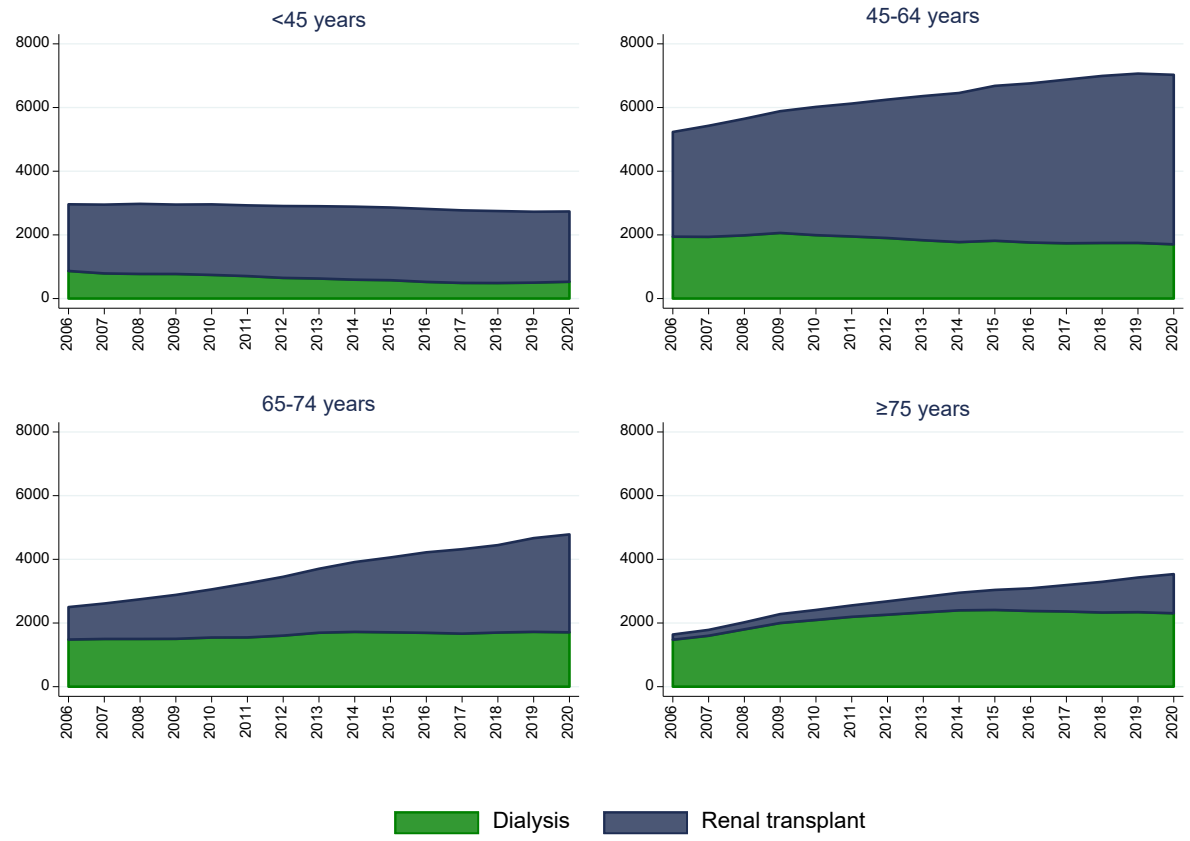

Figure 4.5.Prevalence of dialysis and renal transplants stratified by age categories.

Time trends in incidence of RRT in absolute numbers and expressed per million age-related population are shown stratified for age categories in Figures 4.6 and 4.7 respectively. Incidence per million age-related population shows a downwards trend for the 75 years and older category. In 2020 321 incident RRT patients per million age-related population were registered for this age category. In 2009 this was at its highest at 496 per million age-related population. Possible reasons for this decrease (-34%) are improvement in chronic kidney disease care, higher mortality before the start of RRT due to comorbidities, or more frequent choice for conservative treatment

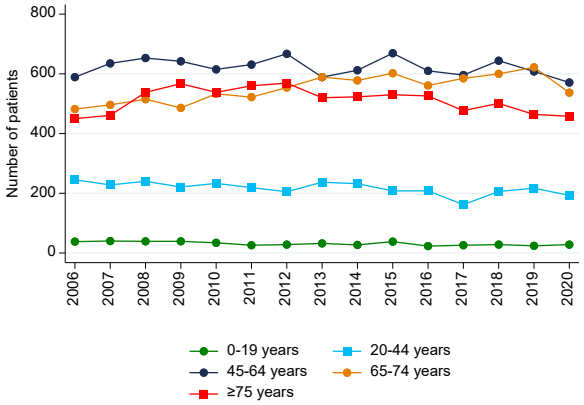

Figure 4.6 Incidence of renal replacement therapy stratified for age categories.

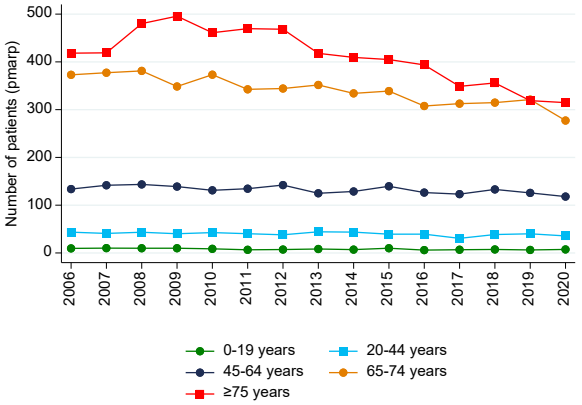

Figure 4.7 Incidence of renal replacement therapy per million age related population stratified for age categories.

Most incident RRT patients start RRT treatment by means of haemodialysis. In 2020 the distribution over the start modalities was 70% haemodialysis, 19% peritoneal dialysis, and 12% pre-emptive transplantations. The percentage of pre-emptive transplantations was slightly lower in 2020 than in 2019, which is likely caused by the Covid-19 pandemic. The impact of the Covid-19 pandemic on renal transplantations is further described in Chapter 8. Figure 4.8 shows time trends in modalities at the start RRT for age categories. Pre-emptive transplantations are most common in young patients.

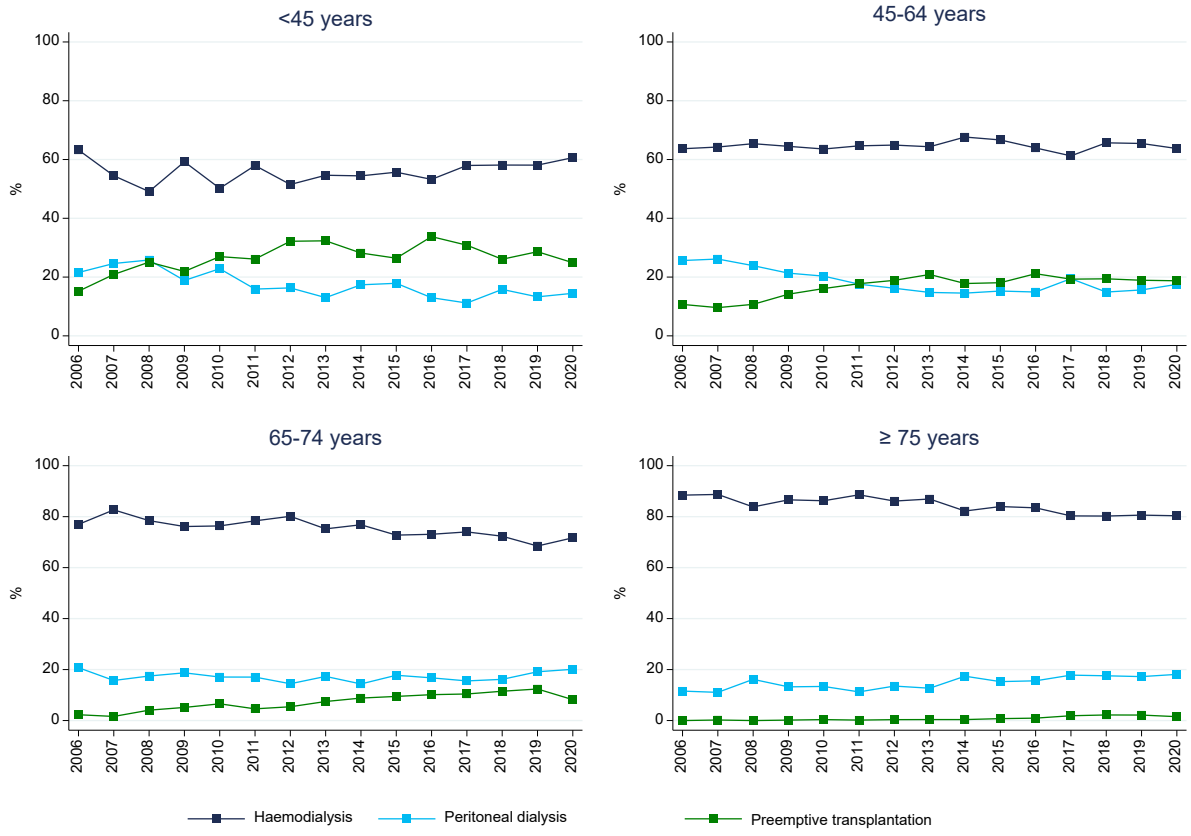

Figure 4.8 Distribution of start modalities in incident RRT patients over time stratified for age categories.

The overall incidence of RRT was 5% lower in 2020 than in 2019. To estimate whether the Covid-19 pandemic had an impact on RRT incidence the incidence over 2020 was compared to the mean over the preceding two years (Figure 4.9). To limit short time fluctuations moving averages over three weeks were calculated. During the first wave of the Covid-19 pandemic, fewer patients started RRT compared to the two preceding years and the decline was most apparent for the age category 65 years and older. In this category, the drop was 27% compared to 18% for the younger patients. Throughout 2020 a partial catch-up was observed.

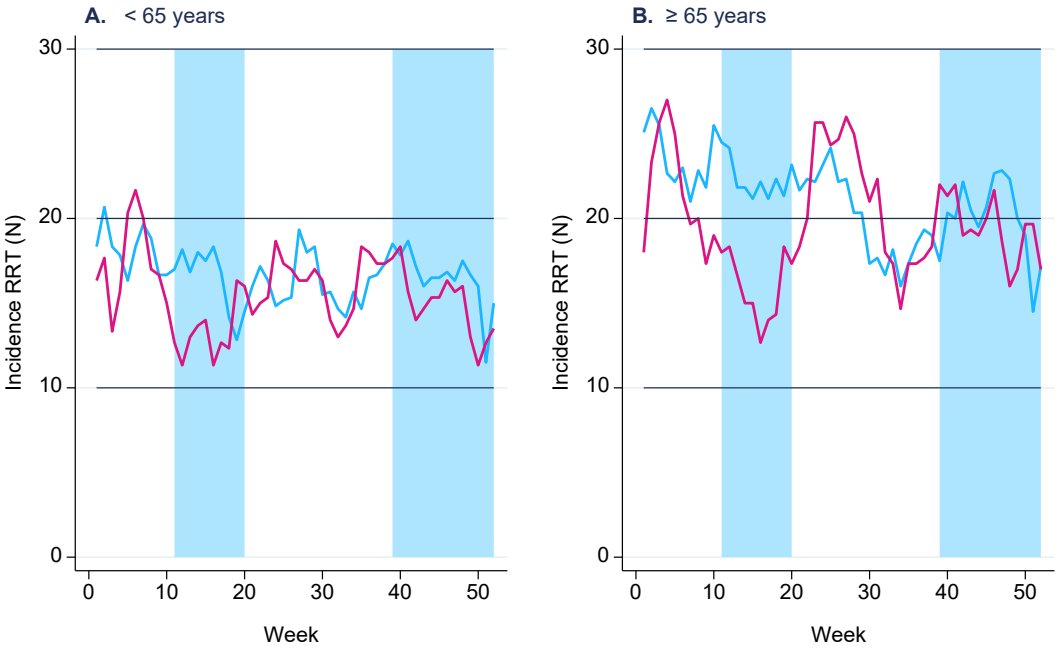

Figure 4.9 Incidence of RRT in 2020 compared to the mean of 2018-2019 (3-week moving averages).

5 Dialysis treatment

Over recent years the number of patients treated with chronic dialysis remained fairly constant (Figure 5.1). Prevalence includes all patients on dialysis treatment, irrespective of their RRT history. On December 31st, 2020, 6,261 patients were on chronic dialysis treatment. Of these patients, 37% were 75 years or older.

In 2020 1,894 patients started chronic dialysis therapy. For the majority of these patients (i.e. N=1,664, 88%) this was their first time on chronic dialysis treatment and 230 patients (12%) restarted dialysis treatment, for example after a graft failure. For the remaining of this chapter incidence of dialysis only includes the first-time start of chronic dialysis treatment.

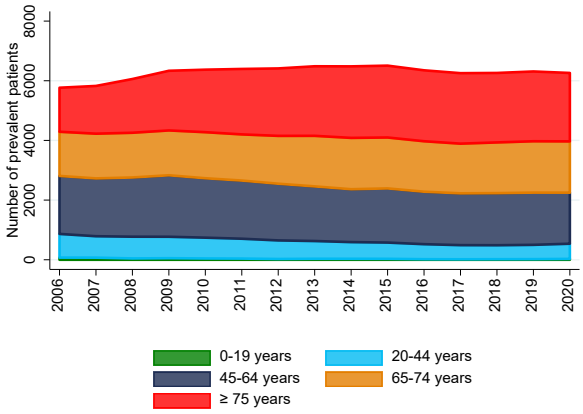

Figure 5.1. Prevalence of dialysis (December 31th) by age categories.

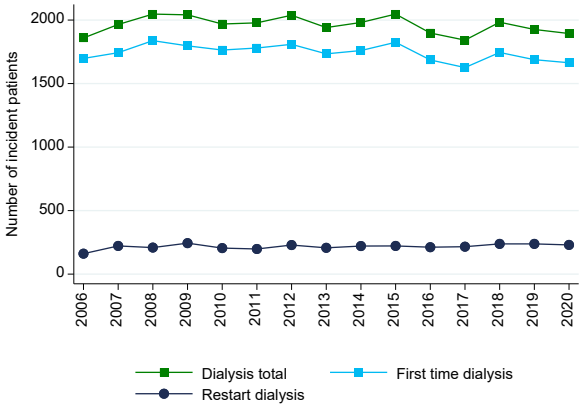

Figure 5.2. Incidence of dialysis per year. A distinction was made between patients receiving chronic dialysis for the first time and patients with dialysis treatment in the past restarting dialysis treatment.

The incidence of first-time dialysis was slightly lower in 2020 compared to 2019 (-1.4%). However, during the first Covid-19 wave the number of incident dialysis patients of 65 years and older was considerably lower (-24%) compared to the same time interval of the previous two years (Figure 5.3). It appears that during the first Covid-19 wave start of dialysis was postponed for some weeks. Whether this has a detrimental effect on the prognosis of these patients will have to be monitored in the coming years.

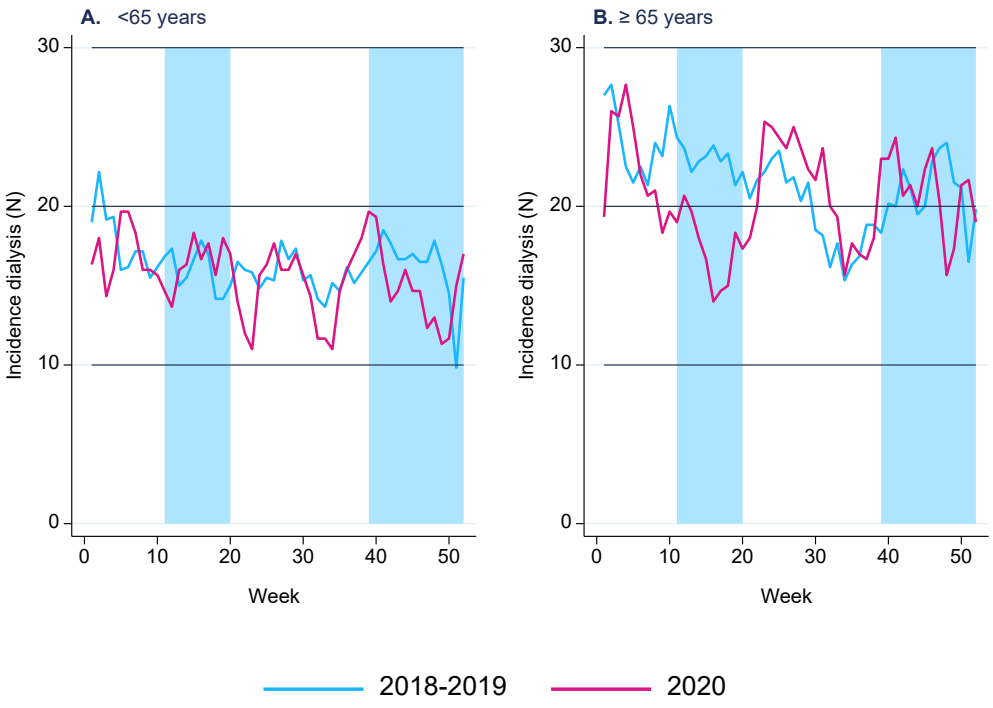

Figure 5.3. Incidence of dialysis treatment in 2020 compared to the mean of 2018-2019 (3-week moving averages).

The sex-specific incidence of dialysis treatment per million population shows different time trends for men than for women (Figures 5.4 and 5.5). In men, in 2009 a peak was observed for the age category ≥75 years followed by a decreasing trend. This downward trend might be due to a stronger focus on conservative therapy in recent years or might be the effect of improved prevention. It remains unclear why this trend is not observed in women. The overall incidence in women is lower and more constant over time.

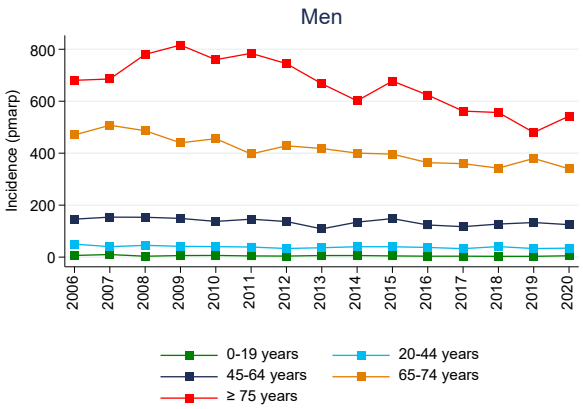

Figure 5.4. Incidence per million age related population of first-time dialysis stratified for age categories in men

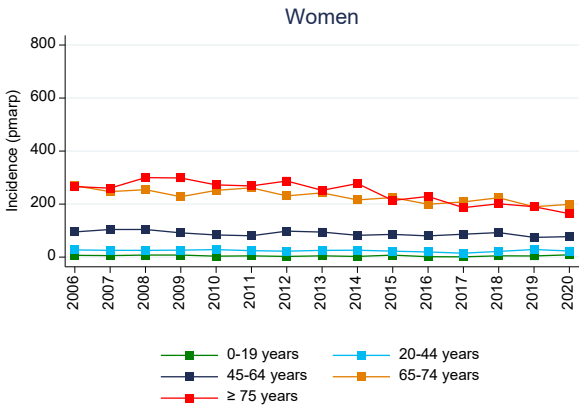

Figure 5.5. Incidence per million age related population of first-time dialysis stratified for age categories in women.

In-centre haemodialysis is the most common dialysis modality. In 2020 the distribution of the prevalent dialysis population was 80% in-centre haemodialysis, 16% peritoneal dialysis, and 4% home haemodialysis (Figure 5.6). The number of peritoneal dialysis patients was in 2020 7% higher than in 2019 (1.001 versus 938 patients). In 2020 21% of the incident dialysis patients started with peritoneal dialysis (Figure 5.7). This percentage slightly increased over time. Due to the necessity of a training period home haemodialysis as the first modality is not possible and therefore not included in Figure 5.7.

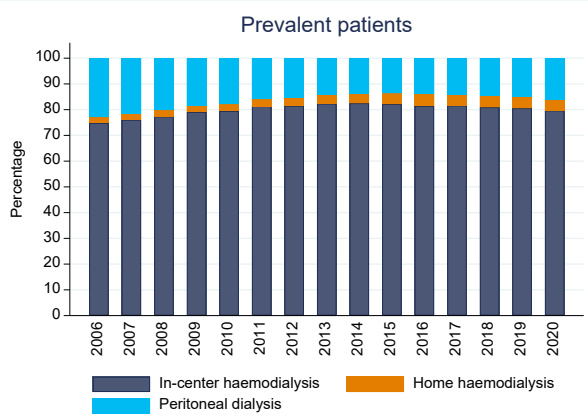

Figure 5.6. Distribution of in-center haemodialysis, home haemodialysis and peritoneal dialysis in prevalent chronic dialysis patients.

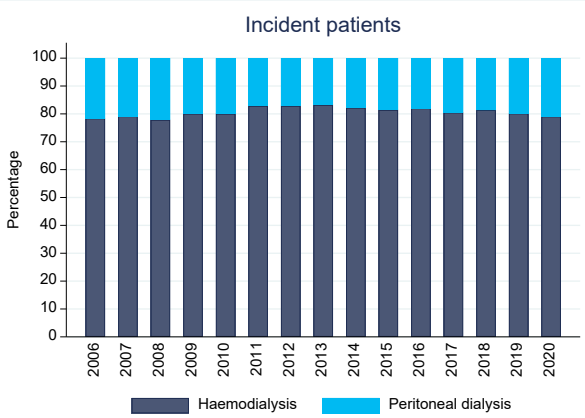

Figure 5.7. Distribution of haemodialysis and peritoneal dialysis in incident chronic dialysis patients per year.

Patients treated with home-based dialysis modalities (i.e. PD or home haemodialysis) are younger than in-centre haemodialysis patients. In 2020 the difference in mean age was 2.8 years. Aging of the populations is observed for both groups, but stronger for the home-based treatment group. Figure 5.9 also shows increases over time in home-based dialysis modalities for older patients.

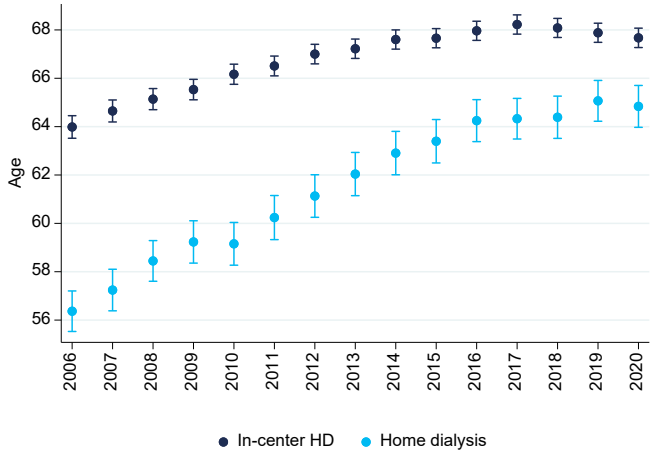

Figure 5.8. Mean age of in-center haemodialysis and home dialysis patients. Results are presented with 95%-confidence intervals.

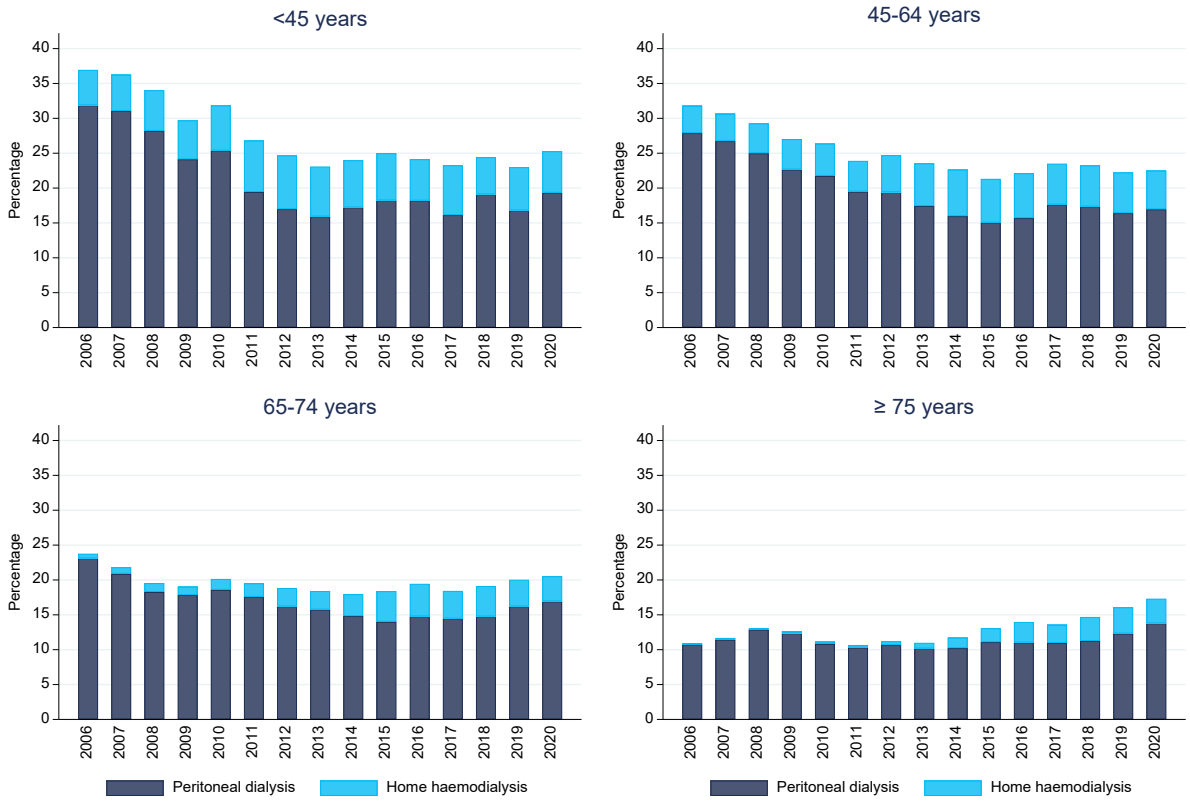

Figure 5.9. Percentages of prevalent dialysis patients treated with home-based dialysis modalities.

The proportion of patients treated with home dialysis (home haemodialysis or peritoneal dialysis) shows substantial variation among centres (Figure 5.10). In this analysis, the outcome is treatment modality 3 months after the start of chronic dialysis treatment. This was chosen to account for the time needed to prepare for home (haemo-)dialysis. Data of three calendar years were combined because of low patient numbers per centre. To account for differences in case-mix between dialysis centres adjustments were made for age, sex, socioeconomic status (SES), and categories of primary kidney disease. See Appendix A for an explanation of funnel plots.

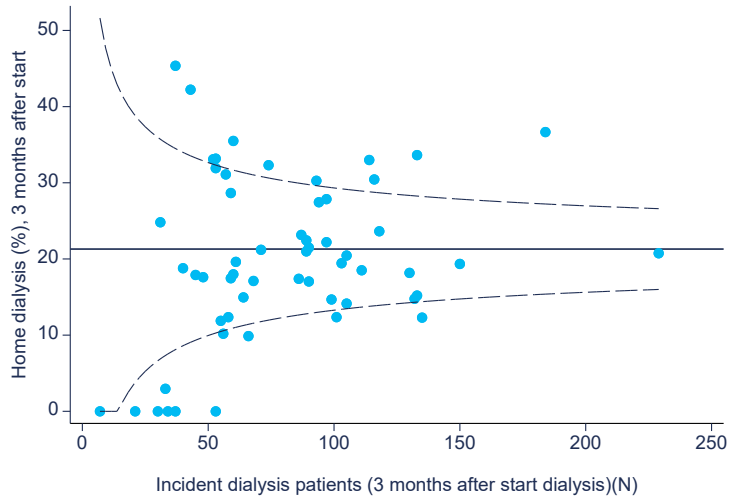

Figure 5.10. Center variation in percentage home dialysis three months after start dialysis. Home dialysis includes peritoneal dialysis and home haemodialysis. Data is adjusted for age, sex, SES, and primary kidney disease categories. Inclusion period 2018-2020.

Figures 5.11 and 5.12 show the status of patients one and three years after the start of haemodialysis and peritoneal dialysis as the first dialysis modality respectively. Mortality was higher and transplantation rates were lower in haemodialysis compared to peritoneal dialysis. This is possibly due to differences in case-mix. During the first year of treatment, more patients switched from peritoneal to haemodialysis than vice versa. This trend is also observed after three years of follow-up. Of the patients who started haemodialysis in 2019 72% were still on haemodialysis treatment one year later, 4% switched to peritoneal dialysis, 6% received a transplant and 18% died. In peritoneal dialysis the percentages that switched to either haemodialysis or received a transplant were somewhat higher, i.e. 15% switched to haemodialysis and 9% had a functioning renal transplant one year after they started peritoneal dialysis. After the start of peritoneal dialysis, mortality was 10% in the first year.

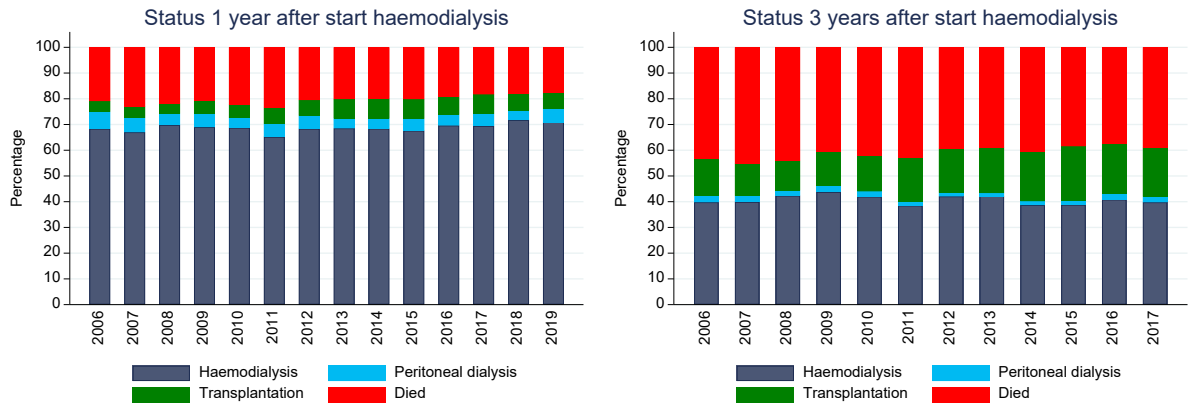

Figure 5.11 Status one and 3 year after start HD as percentage. The year represents the year in which HD was started.

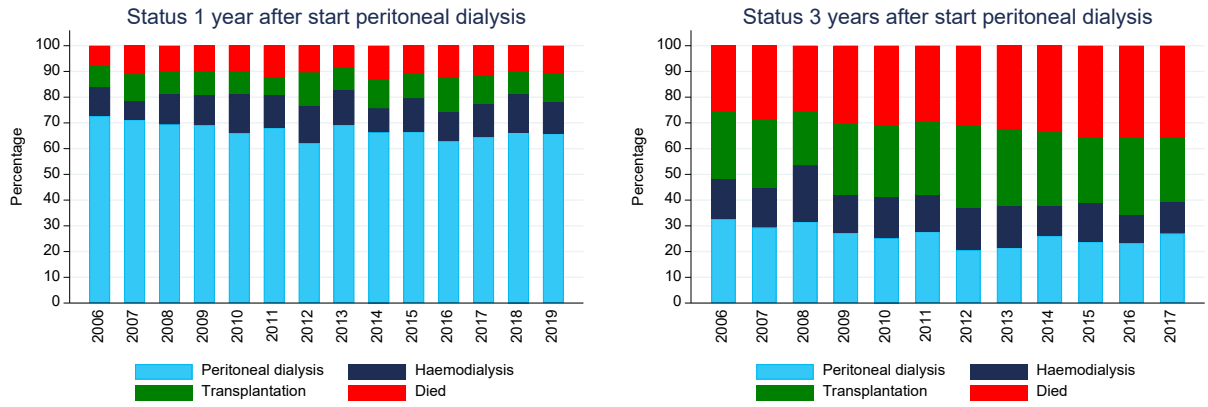

Figure 5.12 Status one and 3 year after start PD as percentage. The year represents the year in which PD was started.

Figures 5.13 and 5.14 show centre variation in the percentages switches between modalities during the first year on dialysis in funnel plots. To account for differences in case-mix between dialysis centres adjustments were made for age, sex, socioeconomic status, and categories of primary kidney disease. In these analyses modality at three months after the start of dialysis was taken as the initial modality. Only patients still on dialysis after one year were included.

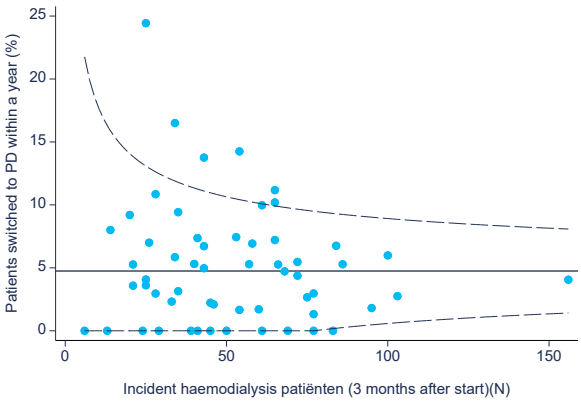

Figure 5.13. Centre variations in switches from HD to PD. Patients were included if on HD 3 months after start dialysis and still on dialysis after one year. Adjustments were made for age, sex, SES, and primary kidney disease categories.

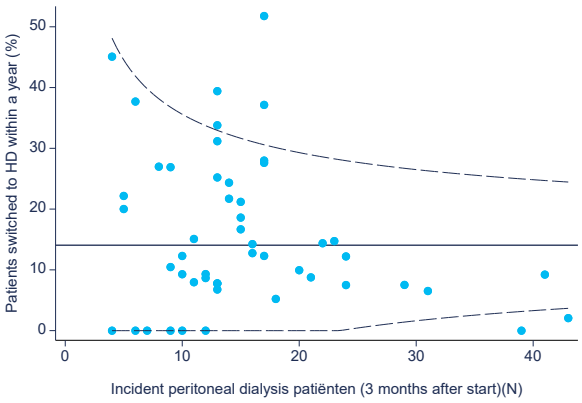

Figure 5.14. Centre variations in switches from PD to HD. Patients were included if on PD 3 months after start dialysis and still on dialysis after one year. Adjustments were made for age, sex, SES, and primary kidney disease categories.

6 PROMs in dialysis patients

The registry of patient-reported outcome measures (PROMs) in Renine started in 2018. The PROMs consists of two questionnaires; the 12-item short-form (SF-12) health survey to assess health-related quality of life and the Dialysis Symptom Index (DSI) to assess symptom burden. In 2020 2,192 dialysis patients, which equals 35% of the prevalent dialysis population, filled out at least one PROM. A small subsample of the patients filled out PROMs on more than one occasion throughout the year. The maximum number of available PROMs per person was 4 (N=5).

Over time participation is increasing. Figure 6.1 shows the available measurements per month and cumulative over time. Figure 6.2 shows the cumulative number of centres participating in PROMs data collection. Some centres only participated within the context of scientific studies linked to Renine (i.e. Domestico). At the end of 2020 in total 54 out of 59 centres (=92%) participated in PROMs and data was available for 3,002 dialysis patients (i.e. at least one measurement). The majority (i.e. 59%) filled out the PROMs on a single occasion. However, the number of patients with measurements at multiple time points is increasing. At the end of 2020 1,237 patients had at least 2 measurements.

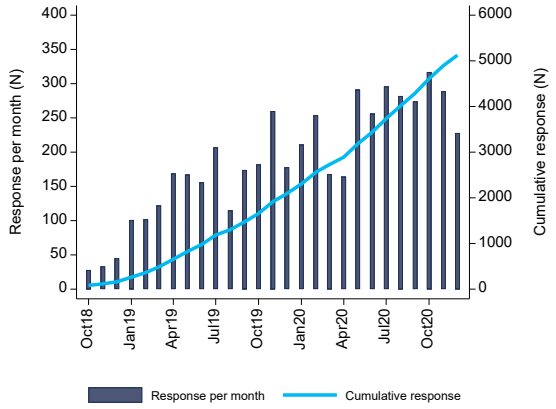

Figure 6.1 PROMs response per month and cumulative over time.

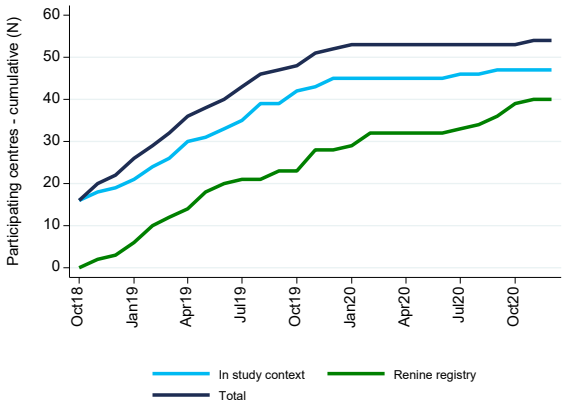

Figure 6.2 Cumulative number of participating centres over time.

Characteristics of dialysis patients with at least one available questionnaire in 2020 are shown in Table 6.1. Characteristics of the total prevalent dialysis population are presented for comparison. Haemodialysis patients are slightly overrepresented in the patients with PROMs available. Other characteristics are comparable.

Table 6.1. Characteristics of dialysis patients with at least one PROMs measurement available in 2020 in comparison to the overall dialysis population in the centres participating in the PROMS collection.

	PROMS available*	Prevalent dialysis population**
N	2,192	6,338
Age (yrs), mean (SD)	68 (14)	67 (15)
Age categories		
<45 yrs	7%	8%
45-64 yrs	26%	28%
65-74 yrs	31%	27%
≥75 yrs	36%	37%
Socio-economic status		
Low	49%	51%
Intermediate	31%	28%
High	21%	21%
Dialysis vintage (yrs), median (Q1-Q3)	1.5 (0.5-3.7)	2.2 (1.0-4.5)
History transplantation	10%	12%
Male	61%	60%
Haemodialysis	87%	85%

* Patient characteristics were determined at the date of the first available questionnaire for a patient.
** Reference date is July 1st 2020.

Figure 6.3 shows the distributions of both the physical and mental scores of the SF-12 questionnaire. The reference lines display the mean values in the general Dutch population.[1] The mean physical component score is 36 (SD=10), which is substantially lower than in the general Dutch population (mean score of 50). Scores on the mental component were higher with a mean value of 48 (SD=10). In the general Dutch population a mean score of 51 is observed. The distribution of the mental component score in the dialysis population is somewhat skewed. The median value was 51. Women scored slightly lower than men on the physical component score (34 versus 37, P<0.001). For the mental scores, no differences were observed. Patients 65 years and older scored lower on the physical component (35 versus 38, P<0.001) than the younger patients. However, they scored higher on the mental score (49 versus 47, P<0.001).

1 Data from CBS. Available from www.opendata.cbs.nl.

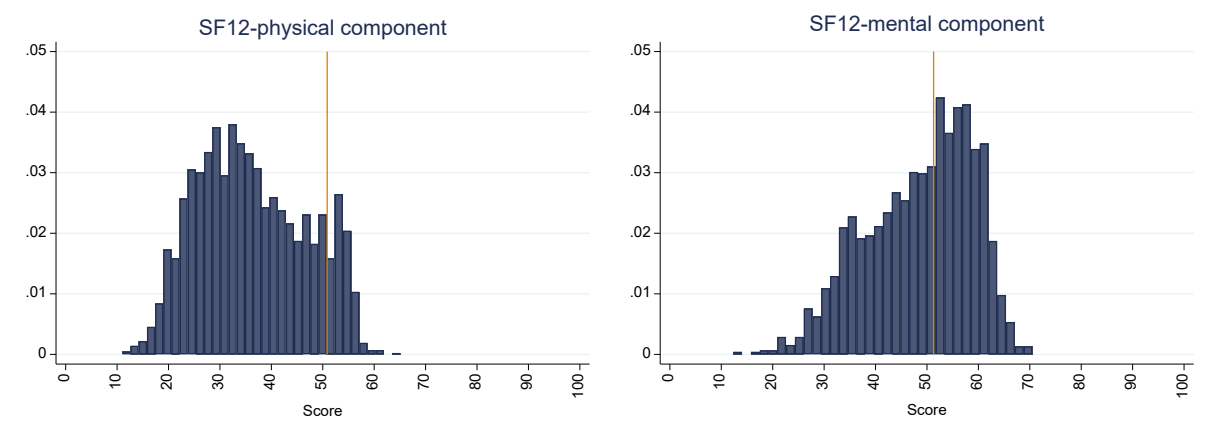

Figure 6.3. Distribution of SF-12 scores. The reference lines indicate mean scores in the general Dutch population.

Dialysis patients experienced on average 10.7 out of 30 symptoms (SD=6.2). Figure 6.4. shows the distribution of the number of symptoms experienced by patients. Women reported slightly more symptoms than men (11.4 versus 10.3, P<0.001). Younger patients (<65 years) report more symptoms than patients 65 years and older (11.2 vs 10.5, P=0.01).

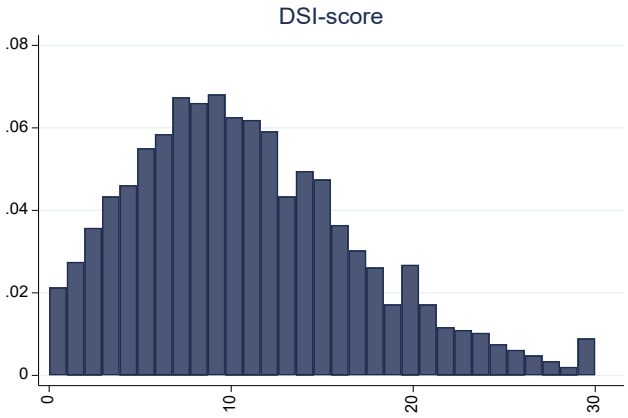

Figure 6.4. Distribution of the number of experienced symptoms (DSI).

In the following tables, the 10 most frequently reported symptoms and the most burdensome symptoms are reported separately for men and women. More women than men experience tiredness and dry skin. Sexual dysfunction, sleeping problems, and tiredness/lack of energy impose the highest burden on patients.

Table 6.2. Top 10 most frequent symptoms separately for men and women

Men		Women	
Feeling tired/lack of energy	71%	Feeling tired/lack of energy	80%
Dry skin	53%	Dry skin	68%
Muscle cramps	53%	Muscle cramps	56%
Itching	52%	Trouble staying asleep	54%
Trouble staying asleep	52%	Dry mouth	50%
Decreased interest in sex	43%	Itching	49%
Difficulty becoming sexually aroused	42%	Bone or joint pain	48%
Dry mouth	42%	Trouble falling asleep	48%
Trouble falling asleep	41%	Worrying	44%
Restless legs	40%	Feeling sad	43%

Table 6.3. Top 10 most burdensome symptoms

Men	Mean score*	Women	Mean score*
Difficulty becoming sexually aroused	3.22	Difficulty becoming sexually aroused	3.15
Decreased interest in sex	3.03	Feeling tired/lack of energy	3.06
Trouble falling asleep	2.97	Decreased interest in sex	3.05
Trouble staying asleep	2.96	Trouble staying asleep	3.05
Feeling tired/lack of energy	2.96	Bone or joint pain	3.04
Bone or joint pain	2.93	Trouble falling asleep	2.98
Itching	2.81	Dry skin	2.98
Restless legs	2.81	Itching	2.92
Numbness or tingling in feet	2.80	Numbness or tingling in feet	2.81
Worrying	2.79	Restless legs	2.79

Burden score (1-5) reported when the symptom was present.

7 Survival on renal replacement therapy

In 2020 1,270 dialysis patients died. The absolute number of deaths in dialysis patients was 15% higher in 2020 compared to 2019. The mean age at death was 74,1 years. In 2018 and 2019 this was respectively 74,8 and 74,6 years. As described in Chapter 3, Covid-19 had a high fatality rate in dialysis patients. About 25% of registered Covid-19 patients died within 28 days after diagnosis. In 2020, 13% of deaths in dialysis patients involved patients diagnosed with Covid-19. Covid-19 thus had a clear impact on mortality in the dialysis population.

Figure 7.1 shows the pattern of deaths over the year in 2020 compared to the mean over 2018-2019 stratified for age (<65 and ≥65 years). The first and second waves of the Covid-19 pandemic are indicated by the blue areas. During the first wave, a steep increase in mortality was seen for patients 65 years and older, followed by a period with normal to low mortality. During the second wave, the numbers increased again. Excess mortality over 2020 was 7%. The absolute numbers were much lower in patients <65 years. However, excess mortality was 25% compared to 2018-2019 in this age category. In relative terms, the impact of the Covid-19 pandemic was thus larger in the younger patients.

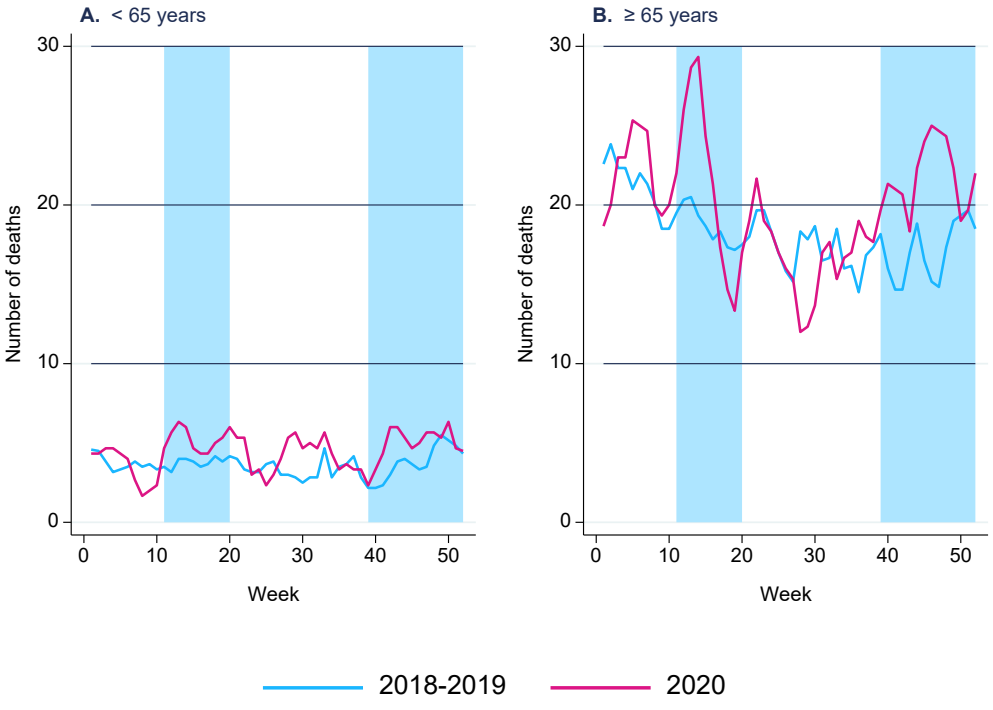

Figure 7.1. Deaths on dialysis treatment in 2020 compared to the mean of 2018-2019 (3-week moving averages) The light blue areas indicate the first and second Covid-19 waves.

Causes of death were coded according to the ERA-coding system and grouped according to the categorization as applied by the UKRR (Appendix C). 'Treatment stop' is the most common cause of death in dialysis patients (Figure 7.2 and 7.3), i.e. in 2020 31% of all deaths on dialysis were in this category (N=345). The increase in "infection" as the cause of death reflects the impact of Covid-19. In 2020 20% of all deaths in dialysis patients fell into this category compared to 15% in 2019. In 47% of these events, it concerned a Covid-19 patient.

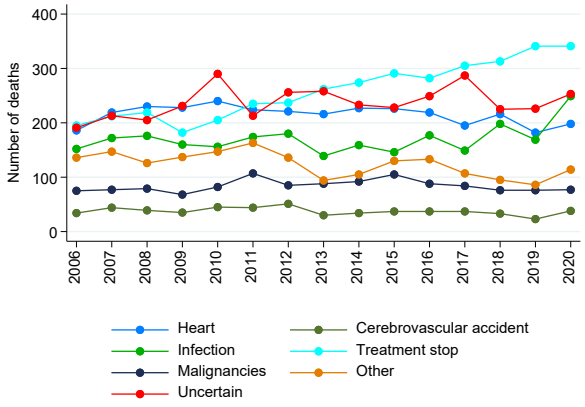

Figure 7.2 Causes of death over time.

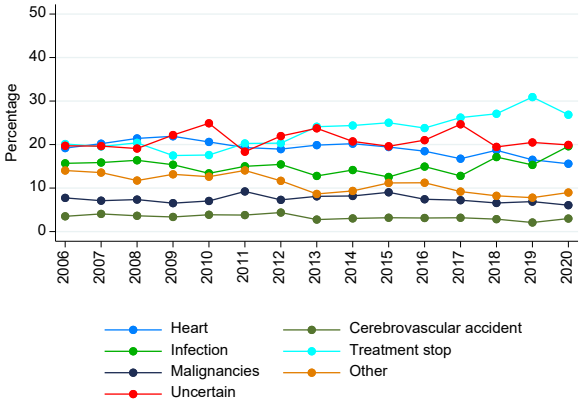

Figure 7.3. Causes of death expressed as percentages of total number over time.

Figures 7.4 and 7.5 show the causes of death in 2020 for dialysis patients younger and older than 65 years of age. The most apparent difference is the higher percentage of 'Treatment stop' in older patients.

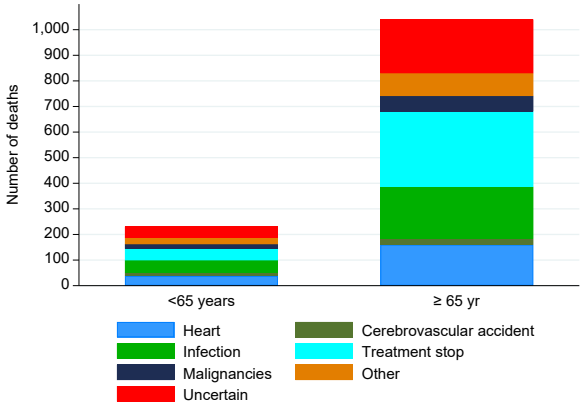

Figure 7.4. Number of deaths in 2020 in patients on dialysis younger and older than 65 years.

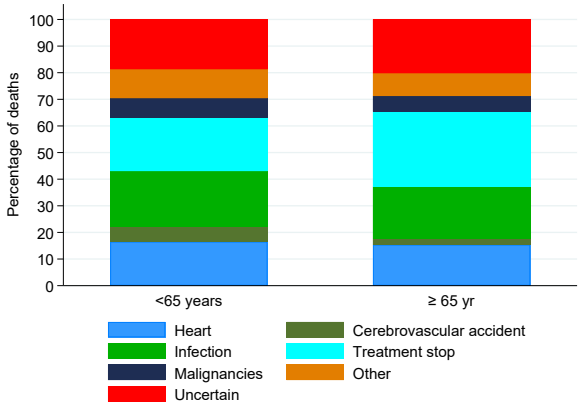

Figure 7.5. Causes of death in 2020 in patients on dialysis younger and older than 65 years as percentage.

Crude survival estimates for incident dialysis patients are shown in Table 7.1 for two cohorts. Results are shown both with and without censoring for renal transplantation. Slightly improved estimates were observed for patients starting dialysis in the period 2016-2019 compared to patients who started in the period 2011-2015.

Table 7.1. Survival probabilities for incident dialysis patients presented as % (95% CI).

	1-year survival		3-year survival	
Age at start	**Cohort 2011-2015**	**Cohort 2016-2019**	**Cohort 2011-2015**	**Cohort 2016-2019**
<45 yrs	98 (97-99)	98 (96-99)	94 (92-96)	95 (92-96)
45-64 yrs	91 (90-92)	94 (93-95)	77 (76-79)	79 (77-81)
≥65 yrs	81 (80-82)	83 (81-84)	55 (53-56)	55 (53-57)
Transplantation as censoring event				
Age at start	**Cohort 2011-2015**	**Cohort 2016-2019**	**Cohort 2011-2015**	**Cohort 2016-2019**
<45 yrs	98 (96-99)	98 (96-99)	92 (89-94)	92 (88-95)
45-64 yrs	90 (89-91)	94 (93-95)	73 (71-75)	76 (73-78)
≥65 yrs	81 (80-82)	82 (81-84)	53 (51-54)	53 (51-54)

Patients with a history of transplantation are excluded.

Survival probabilities after a first kidney transplantation are presented in table 7.2. Survival after transplantation from a living donor is higher than after transplantation from a deceased donor. This might however partially be explained by differences in case-mix.

Table 7.2. Survival probabilities after first kidney transplantation presented as % (95% CI).

	3-year survival		5-year survival	
Age at transplant	**Living**	**Post-mortem**	**Living**	**Post-mortem**
<45 yrs	99 (98-99)	96 (94-98)	98 (97-99)	93 (90-96)
45-64 yrs	96 (95-97)	91 (89-93)	92 (91-94)	85 (82-87
≥65 yrs	91 (88-93)	81 (79-84)	79 (75-83)	67 (63-71)

Inclusion period: 2013-2019.

In Figures 7.6 and 7.7 centre variation is shown for 1-year and 3-year mortality in incident dialysis patients. The data was adjusted for age, sex, SES, and primary kidney disease categories. However, other important factors affecting prognosis such as comorbidities are not available. Results should therefore be interpreted with caution.

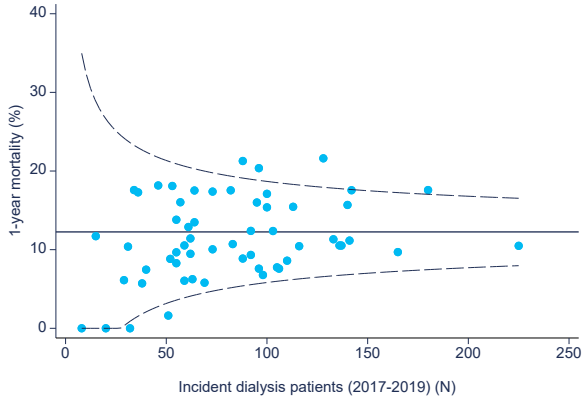

Figure 7.6. Centre variation in 1-year mortality in incident patients. Inclusion period 2017-2019. Adjustments were performed for age, sex, SES, and primary kidney disease categories.

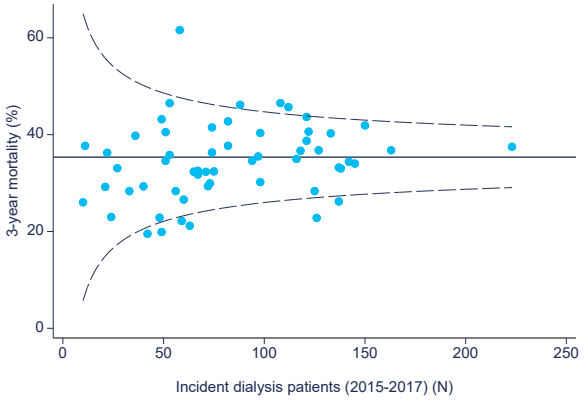

Figure 7.7. Centre variation in 3-year mortality in incident dialysis patients. Inclusion period 2015-2017. Adjustments were performed for age, sex, SES, and primary kidney disease categories.

Figure 7.8 shows the cumulative incidence of death and kidney transplantation for incident dialysis patients by previous transplantation status. The most pronounced difference is the lower probability for a new renal transplant for patients with a transplant history.

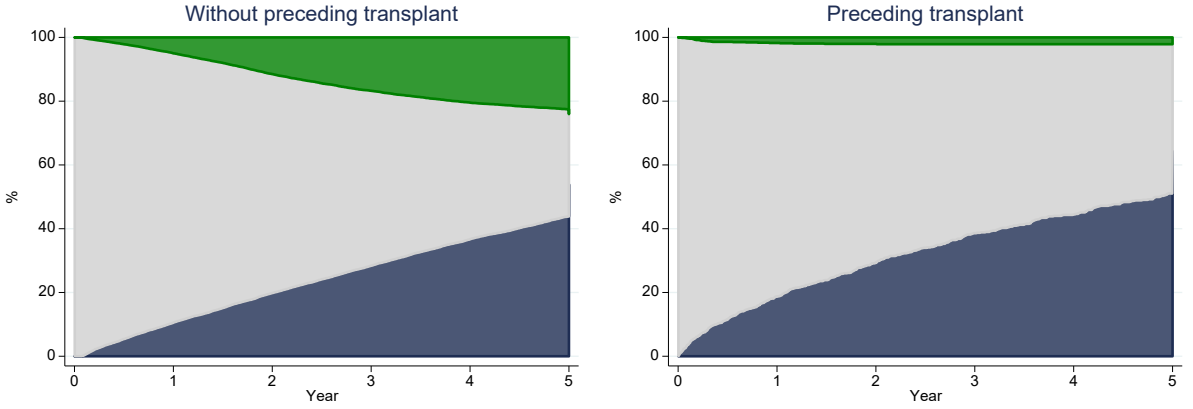

Figure 7.8. Survival and transplantations in incident dialysis patients stratified for history of renal transplantation. Inclusion period 2013-2019. Competing risk analyses were performed (Fine and Gray method). Mortality is shown by the dark blue area renal transplants by the green area. The grey area represents the proportion still on dialysis. Adjustment was done using fixed values of age and sex.

8 Renal transplantations

The number of prevalent patients living with a functional renal transplant shows a steady increase over time (Figure 8.1). On December 31th 2020 11,810 prevalent patients were registered in Renine, which equals 65% of all patients on renal replacement therapy. The majority of the patients (53%) have a transplant from a living donor (Figure 8.2).

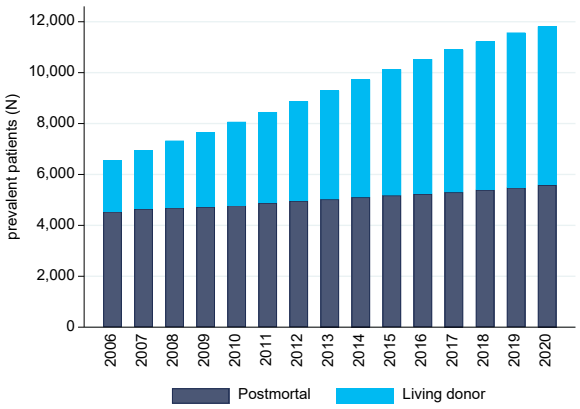

Figure 8.1. Number of prevalent transplant patients according to donor type.

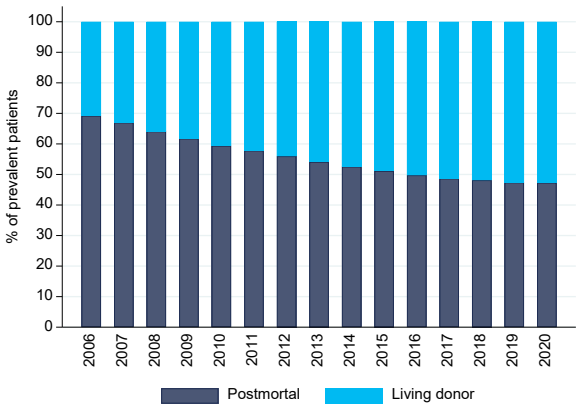

Figure 8.2. Percentage of prevalent transplant patients according to donor type.

The prevalent transplant population consists of a growing proportion of elderly patients (Figure 8.3). Elderly patients more often have a transplant from a post-mortem donor compared to younger patients (Figure 8.4).

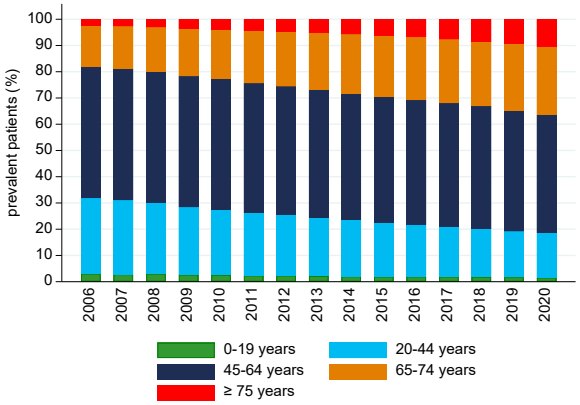

Figure 8.3. Prevalent transplant patients stratified for age categories.

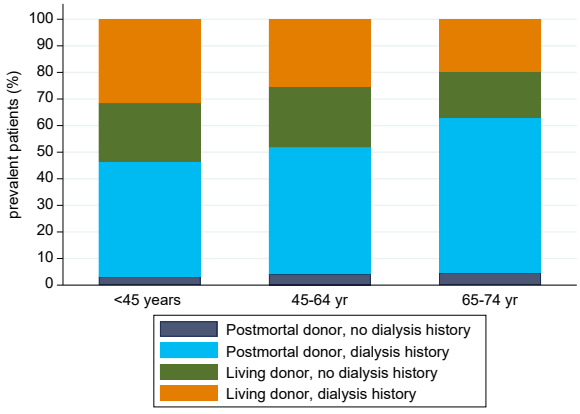

Figure 8.4. Distribution of renal transplant types in age categories in prevalent patients in the year 2020.

In 2020 788 renal transplants were registered, which is considerably lower than in 2019 (i.e. 914 renal transplants). This drop of 14% is likely caused by the Covid-19 pandemic (Figure 8.5.) During the first wave, the renal transplant program was almost completely stopped.

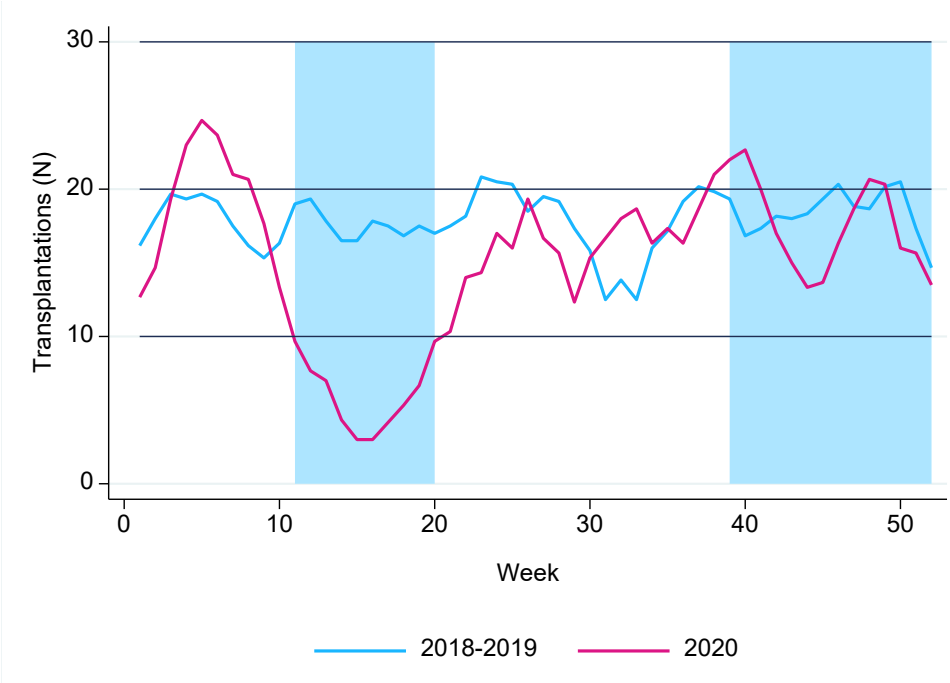

Figure 8.5. Renal transplantations in 2020 compared to the mean of 2018-2019 (3-week moving averages). The light blue areas indicate the first and second Covid-19 waves.

Over time, an increase in pre-emptive transplantations is observed (Figure 8.6). In 2020 271 pre-emptive transplantations were registered in Renine which is 28% of all transplantations. The number of renal transplantations following dialysis treatment shows a slight downward trend. The drop in 2020 represents the above-described impact of Covid-19. In Figure 8.7 transplantations are grouped into four categories based on donor type and whether or not the patient had a dialysis history.

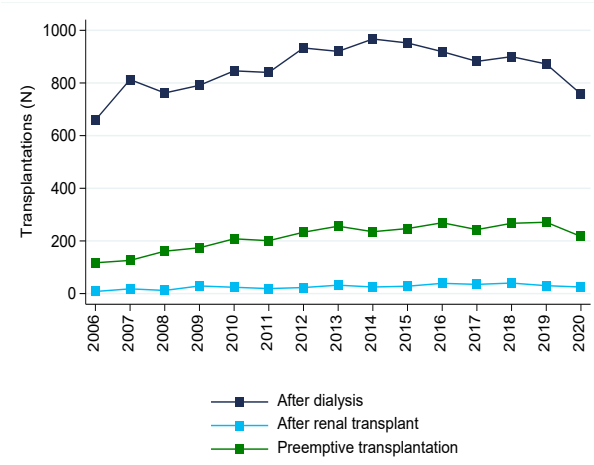

Figure 8.6. Transplantations according to preceding therapy.

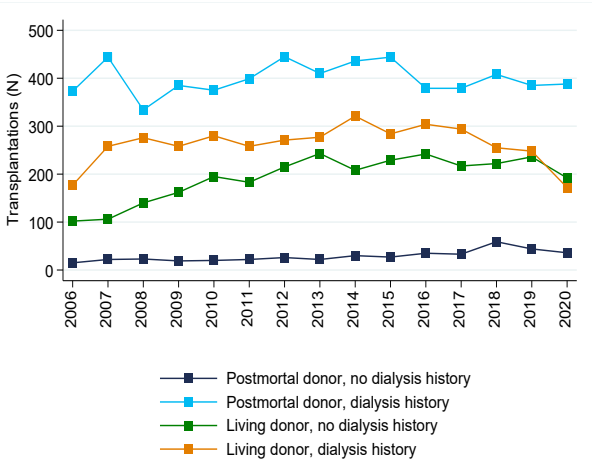

Figure 8.7. Number of different types of renal transplantations over time.

Substantial variation between centre variation exists regarding the proportion of incident patients starting RRT therapy by means of a pre-emptive renal transplant (Figure 8.8). Figure 8.9 shows centre variation in the percentage of prevalent dialysis patients that received a renal transplant in 2020. In these analyses, patients aged 18-75 years were included. The analyses were adjusted for age, sex, SES, and primary kidney disease categories.

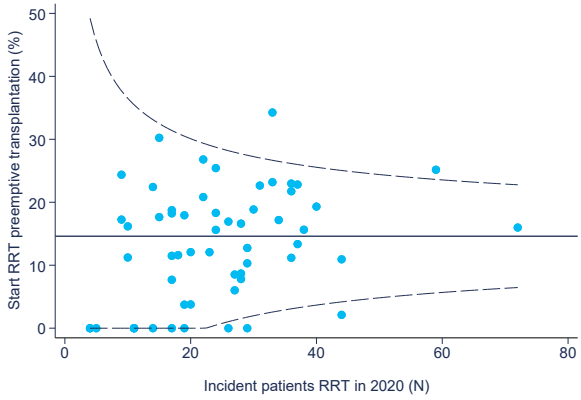

Figure 8.8. Centre variation in percentage pre-emptive transplantations in incident RRT patients in 2020. Adjustments were performed for age, sex, SES, and primary kidney disease categories.

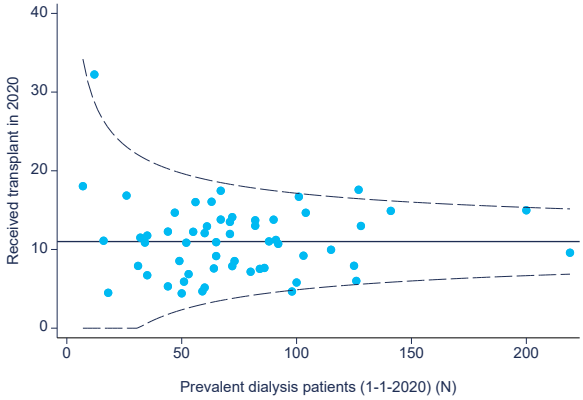

Figure 8.9. Centre variation in percentage of prevalent dialysis patients on January 1st that received a transplant in 2020. Adjustments were performed for age, sex, SES, and primary kidney disease categories.

Figure 8.10 shows the number of months patients were on dialysis treatment at the time of the transplant separately for post-mortem and living donor renal transplants. Until 2017, time on dialysis showed a steep downwards trend for post-mortem transplantations. A slight increase was seen in 2020, potentially caused by the impact of the Covid-19 pandemic on the transplant program.

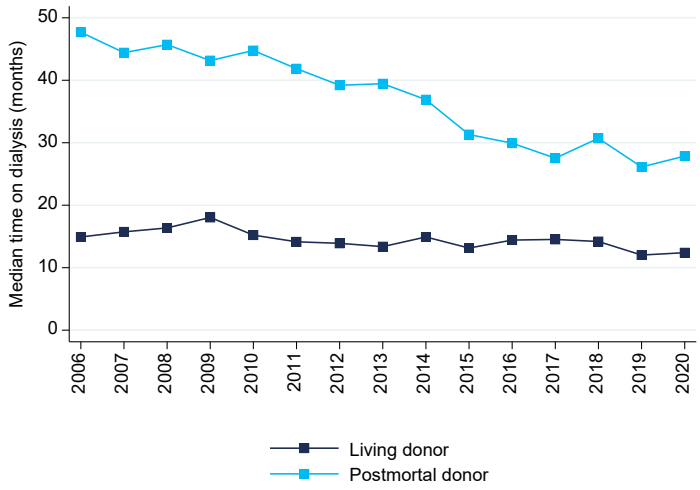

Figure 8.10. Time on dialysis in months in recipients of post-mortem and living donor renal transplants.

9 Clinical data dialysis patients

Clinical variables including laboratory measurements, details of dialysis treatment, and vascular access data of dialysis patients are being registered four times per year. Since 2016 registration of clinical variables is a mandatory component of the Renine registry which resulted in a clear improvement in data completeness. In succeeding years completeness further increased. In 2016 for 27% of the dialysis patients no clinical data were available whilst this percentage decreased to 6% in 2020. For 2020 completeness of the data was 92% for phosphate levels (Figure 9.1) in dialysis patients and 94% for vascular access in haemodialysis patients (Figure 9.2).

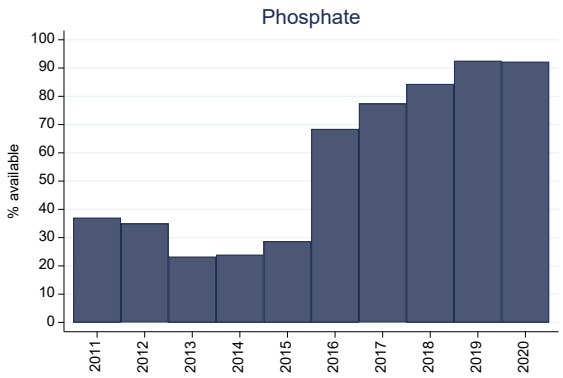

Figure 9.1. Availability of phosphate measurements per year expressed as percentage of the total number of potential measurements.

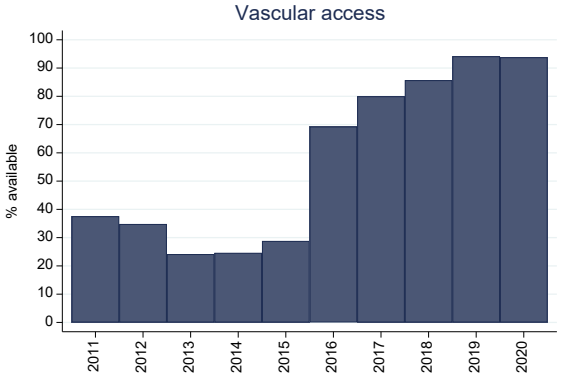

Figure 9.2. Availability of vascular access data per year as percentage of the total number of potential measurements.

Figures 9.3 and 9.4. show mean haemoglobin and ferritin levels over time for dialysis patients younger and older than 65 years.

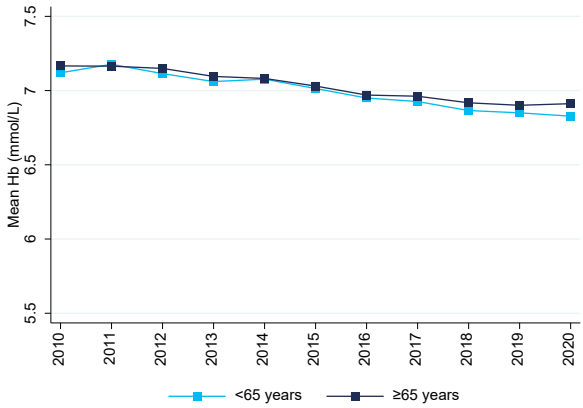

Figure 9.3. Mean hemoglobin levels per year in age categories.

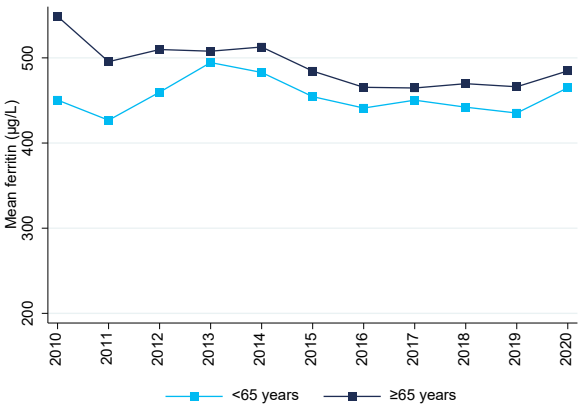

Figure 9.4. Mean ferritin levels per year in age categories.

Mean haemoglobin levels decrease over time. This trend might (partly) be the result of a guideline from 2015[1] in which lower haemoglobin targets are being advised. Based on the PIVOTAL trial[2], target values for ferritin increased. It is too early to see if this has a lasting effect on mean ferritin values in the dialysis population. Figure 9.5 shows mean phosphate levels over time for dialysis patients younger and older than 65 years.

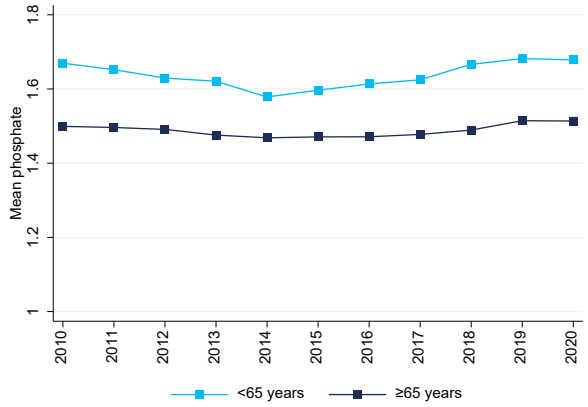

Figure 9.5. Mean phosphate levels per year in age categories.

Figure 9.6. shows categories of clinical factors stratified for age categories. Boundaries of the categories were chosen arbitrarily as clinical guidelines do not provide clear cut-off values. For phosphate substantial variation across age categories, is observed.

1 Richtlijn anemie bij chronische nierziekte, Nederlandse federatie voor Nefrologie, 2015
2 Macdougall et al. Intravenous iron in patients undergoing maintenance hemodialysis. N Eng J Med 380;5:447-458.

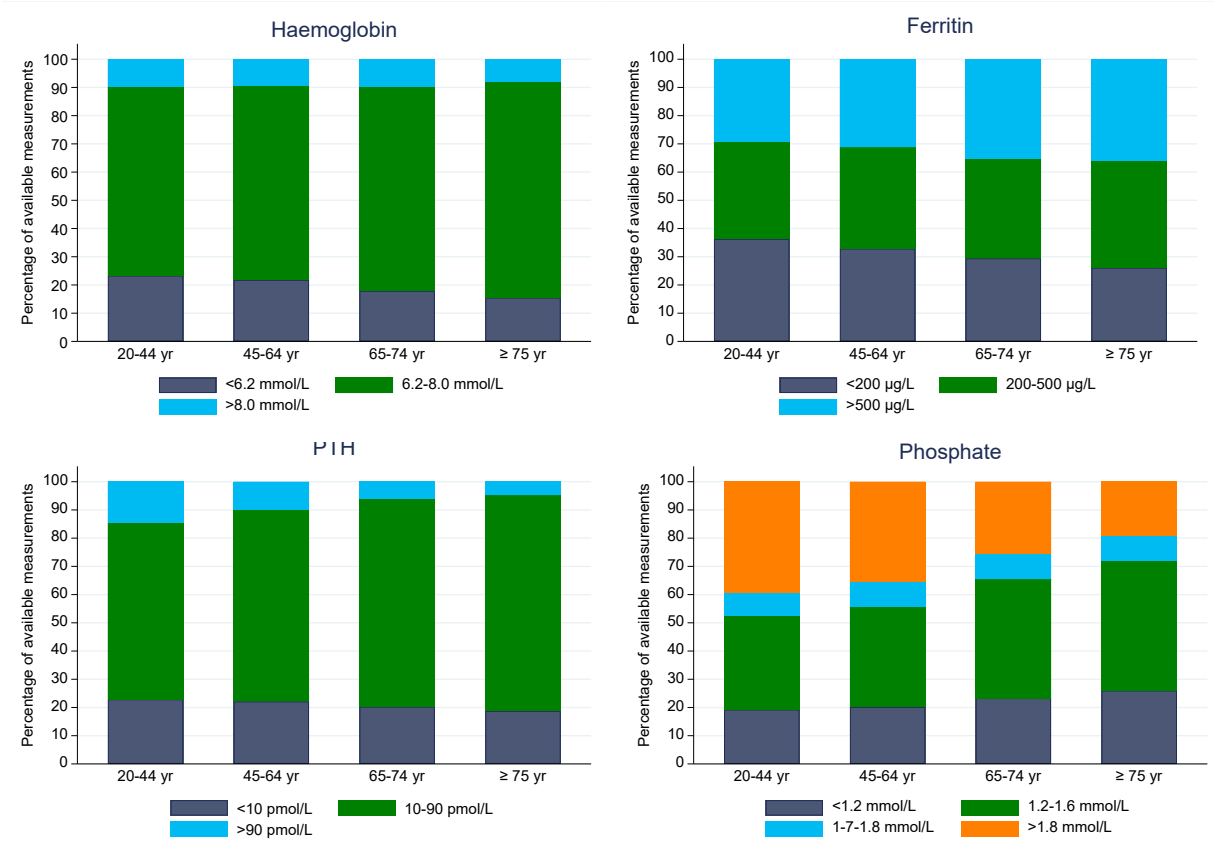

Figure 9.6. Categories of clinical variables stratified for age categories.

Substantial variation in mean values was observed across different centres as is shown in the funnel plots (Figure 9.5). Adjustments were performed for differences in case-mix (age, sex, SES, and primary kidney disease categories.

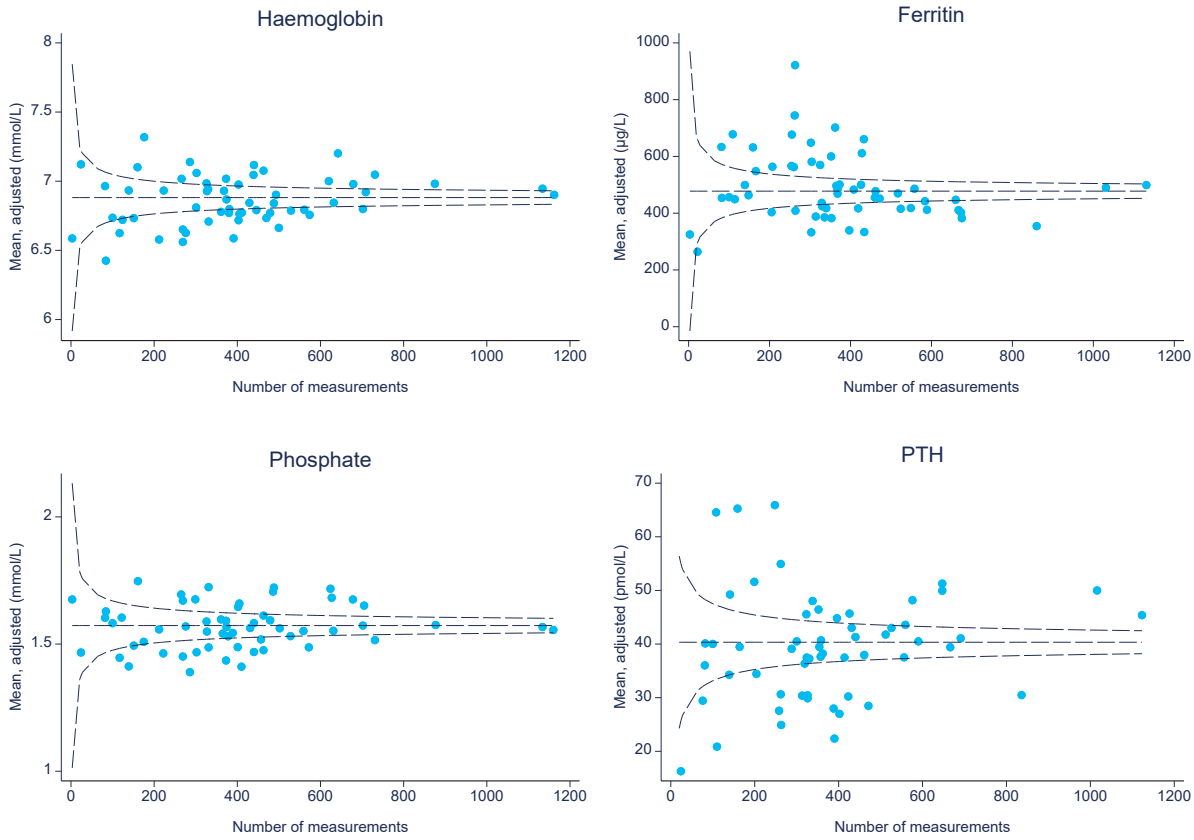

Figure 9.5. Funnel plots showing centre variation of mean values of clinical variables in 2020. The funnels were adjusted for differences in case-mix (age, gender, SES, and primary kidney disease categories).

An AV-fistula is the most common type of vascular access in prevalent haemodialysis patients. Dialysis via catheter is less common for older patients (Figure 9.6).

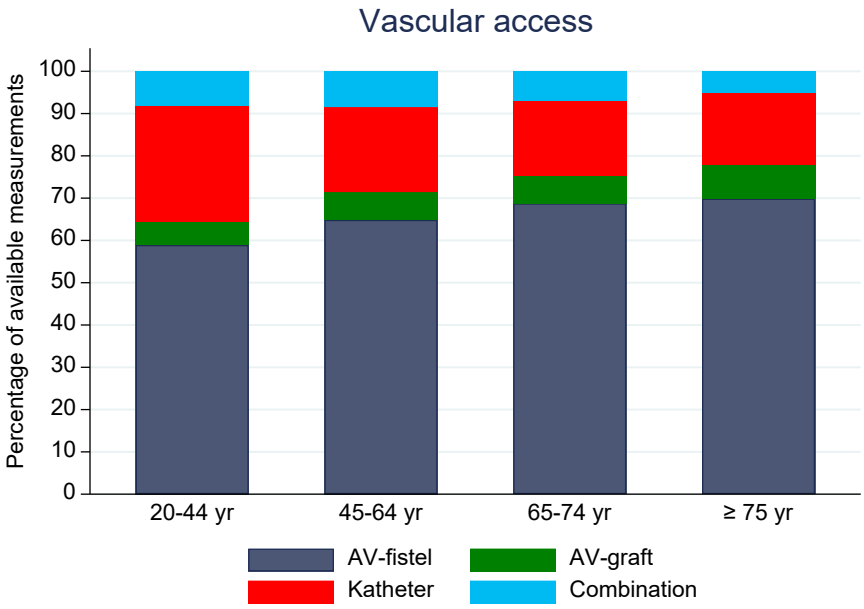

Figure 9.6. Percentages of vascular access categories in prevalent haemodialysis patients in 2020.

In Figures 9.7 and 9.8 centre variation in the percentages of patients with a central venous catheter is shown for prevalent and incident haemodialysis patients respectively.

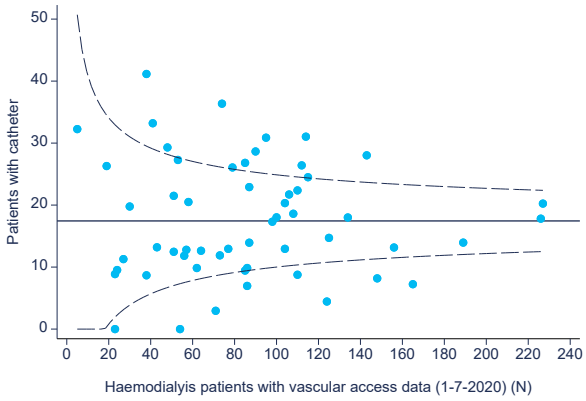

Figure 9.7. Centre variation in catheter use in prevalent haemodialysis patients. Adjustments were performed for age, sex, SES, and primary kidney disease categories.

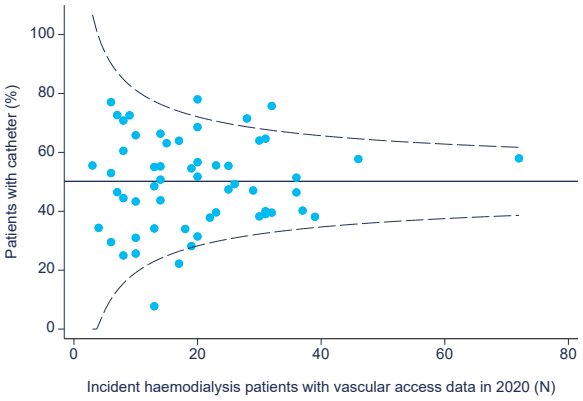

Figure 9.8. Centre variation in catheter use in incident haemodialysis patients. Adjustments were performed for age, sex, SES, and primary kidney disease categories.

10 Conclusions

The covid-19 pandemic had a clear impact on the patient population on renal replacement therapy. Throughout 2020 about 10% of the dialysis patients were confronted with a covid-19 infection. Mortality rates were high in this frail patient population, i.e. in 22% of all cases, the patient died due to covid-19. In absolute numbers, the number of all-cause deaths was highest in patients aged 65 years or older. However, relatively the largest impact on mortality was seen for the younger patients, with 25% more deaths in 2020 compared with the two previous years.

The covid-19 pandemic had furthermore a significant impact on the renal transplantation programs. A smaller effect was observed on the commencement of dialysis treatment. During the first wave, a delayed start of treatment is observed. The long-term effects of the pandemic and the effects of vaccination on the patient population and outcomes will be monitored in the coming years.

Despite the above-mentioned impacts, the patient population remained rather stable. The total number of patients treated with renal replacement therapy increased to over 18,000 patients. The aging of the patient population also continued. However, over the last decade, a decreasing trend in renal replacement therapy incidence is observed in elderly patients. It seems likely that this is at least partly caused by increased uptake of conservative therapy. However, we cannot support this theory by data as conservative therapy is not yet registered in Renine.

The number of patients treated with peritoneal dialysis shows a steady increase over time, with 7% more patients in 2020 than in 2019. The overall prevalence of home haemodialysis slightly decreased. However, for the age category 75 years and older, a substantial increase in home-based dialysis modalities is seen. In 2020 17% of the patients in this age category, i.e. almost 400 patients, were on home dialysis (peritoneal dialysis or home haemodialysis).

We observed an increase in the number of dialysis centres participating in PROMs. In the coming years we will study this in more detail.

Appendix A Methods and definitions

Incidence
An incident population is defined as the population starting renal replacement therapy or a specific treatment modality in a calendar year. Unless otherwise stated this only includes first-time start of renal replacement therapy or a specific dialysis treatment modality.

Prevalence
Prevalence is defined as the population on renal replacement therapy or a specific treatment modality on December 31th of a calendar year.

Per million population (pmp)
The incidence or prevalence pmp is the observed incident or prevalent count divided by the general population in that year and multiplies by one million.

Per million age-related population (pmarp)
The incidence or prevalence pmarp is the observed incident or prevalent count for a specific age group divided by the general population of that age group and multiplied by one million.

Coding
Renal diseases and causes of death were defined according to the ERA coding systems and classified into groups. See Appendix B and C for details.

Survival analysis
Cumulative incidence curves were plotted using the Fine and Gray method for competing events. Subjects were censored in case of recovery of renal function, loss to follow-up or end of follow-up time (December 31th 2020). Survival was analysed from day 1 of chronic dialysis treatment. The cumulative incidence curves were adjusted for fixed values of age (50 years for the age category <65 years and 70 years for the age category ≥65 years), sex (63% men) and primary kidney disease categories (24% Diabetes; 19% Hypertension/renal vascular disease; 11% Glomerulonephritis; 46% Other causes).

Funnel plots
Centre variations in the year 2020 are presented by funnel plots. In these plots a centre-specific mean or percentage is plotted against a variable indicating centre size. For binary and continuous outcomes 95%-confidence intervals were plotted based on the binomial and normal distribution respectively. Funnels are plotted around the average estimate over all centres. Any centres which fall outside the 95%-confidence intervals of the funnels are significantly different from the average. The funnel shape of the limits reflects the fact that for smaller centres a greater observed difference from the average is required for it to be statistically significantly different. To account for differences in case-mix a number of adjustments were performed. For binary outcomes a logistic model with age, sex, SES, and primary kidney disease as independent variables was used to derive a probability of the event for every individual patient. These probabilities were summed over the patients within a centre to give an expected number of events (E). A standardized percentage is calculated by multiplying the ratio of observed and expected events (O/E) by the overall percentage over all centres. For continuous outcomes expected outcomes were estimated using linear regression models. An adjusted mean was calculated by adding the difference between the observed and expected mean (O-E) to the overall mean value.

Appendix B Categories of primary kidney disease

Category	ERA code	Primary renal disease
Glomerulonephritis/sclerosis	10	Glomerulonephritis, histologically NOT examined
	11	Severe nephrotic syndrome with focal sclerosis (paediatric patients only)
	12	IgA nephropathy (proven by immunofluorescence, not code 85)
	13	Dense deposit disease membrano-proliferative GN, type II (proven by immunofluorescence and/or electron microscopy)
	14	Membranous nephropathy
	15	Membrano-proliferative GN, type I (proven by immunofluorescence and/orelectron microscopy - not code 84 or 89)
	16	Rapidly progressive GN without systemic disease (crescentic, histologically confirmed, not coded elsewhere)
	19	Glomerulonephritis, histologically examined
	17	Focal segmental glomerusclerosis with nephrotic syndrome in adults
Pyelonephritis	20	Pyelonephritis/Interstitial nephritis-cause not specified
	21	Pyelonephritis/Interstitial nephritis associated with neurogenic bladder
	22	Pyelonephritis/Interstitial nephritis due to congenital obstructive uropathy with or without vesico-ureteric reflux
	23	Pyelonephritis/Interstitial nephritis due to acquired obstructive uropathy
	24	Pyelonephritis/Interstitial nephritis due to vesico-ureteric reflux without obstruction
	25	Pyelonephritis/Interstitial nephritis due to urolithiasis
	29	Pyelonephritis/Interstitial nephritis due to other cause
Polycystic kidneys, adult type	41	Polycystic kidneys, adult type (dominant)
Hypertension	71	Renal vascular disease due to malignant hypertension (NO primary renal disease)
	72	Renal vascular disease due to hypertension (NO primary renal disease)
Renal vascular disease	70	Renal vascular disease-type unspecified

Category	ERA code	Primary renal disease
	79	Renal vascular disease-classified
Diabetes, type 1	80	Type I Diabetes Mellitus
Diabetes, type 2	81	Type II Diabetes Mellitus
Miscellaneous	30	Tubulo interstitial nephritis (not pyelonephritis)
	31	Nephropathy due to analgesic drugs
	32	Nephropathy due to cis-platinum
	33	Nephropathy due to cyclosporin A
	39	Nephropathy caused by other specific drug
	40	Cystic kidney disease-type unspecified
	42	Polycystic kidneys, infantile (recessive)
	43	Medullary cystic disease, including nephronophthisis
	49	Cystic kidney disease-other specified type
	50	Hereditary/Familial nephropathy-type unspecified
	51	Hereditary nephritis with nerve deafness (Alport's Syndrome)
	52	Cystinosis
	53	Primary oxalosis
	54	Fabry’s disease
	59	Hereditary nephropathy-other
	60	Congenital renal hypoplasia-type unspecified
	61	Oligomeganephronic hypoplasia
	63	Congenital renal dysplasia with or without urinary tract malformation
	66	Syndrome of agenesis of abdominal muscles (Prune Belly Syndrome)
	73	Renal vascular disease due to polyarteritis
	74	Wegener’s granulomatosis
	82	Myelomatosis/light chain deposit disease
	83	Amyloid
	84	Lupus erythematosus

Category	ERA code	Primary renal disease
	85	Henoch-Schoenlein purpura
	86	Goodpasture's Syndrome
	87	Systemic sclerosis (scleroderma)
	88	Haemolytic Uraemic Syndrome including Moschcowitz Syndrome
	89	Multi-system disease-other
	90	Cortical or tubular necrosis
	91	Tuberculosis
	92	Gout
	93	Nephrocalcinosis and hypercalcaemic nephropathy
	94	Balkan nephropathy
	95	Kidney tumour
	96	Traumatic or surgical loss of kidney
	99	Other identified renal disorders
	34	Lead induced interstitial nephropathy
	75	Ischaemic renal disease / cholesterol embolization
	76	Glomerulonephritis related to liver cirrhosis
	78	Cryglobulinaemic glomerulonephritis
Unknown	0	Chronic renal failure, aetiology uncertain

Appendix C Categories of causes of death

Category	ERA code	Cause of death
Heart	11	Myocardial ischaemia and infarction
	14	Other causes of cardiac failure
	15	Cardiac arrest / sudden death; other cause or unknown
	16	Hypertensive cardiac failure
	18	Fluid overload / pulmonary oedema
Cerebrovascular accident	22	Cerebro-vascular accident, other cause or unspecified
Infection	30	Infection
	31	Pulmonary infection (bacterial - not code 73)
	32	Pulmonary infection (viral)
	33	Pulmonary infection (fungal or protozoal; parasitic)
	34	Infections elsewhere except virus hepatitis
	35	Septicaemia
	36	Tuberculosis (lung)
	37	Tuberculosis (elsewhere)
	38	Generalized viral infection
	39	Peritonitis (all causes except for Peritoneal Dialysis)
	100	Peritonitis (bacterial, with peritoneal dialysis)
	101	Peritonitis (fungal, with peritoneal dialysis)
	102	Peritonitis (due to other cause, with peritoneal dialysis)
Treatment stop	51	Patient refused further treatment for ESRF
	54	ESRF treatment withdrawn for medical reasons
	61	Uremia caused by graft failure
	53	ESRF treatment ceased for any other reason
Malignancy	66	Malignant disease, possibly induced by immunosuppressive therapy
	67	Malignant disease: solid tumors except those of 66

Category	ERA code	Cause of death
	68	Malignant disease: lymphoproliferative disorders except those of 66
Other	12	Hyperkalaemia
	13	Haemorrhagic pericarditis
	17	Hypokalaemia
	21	Pulmonary embolus
	23	Gastro-intestinal haemorrhage
	24	Haemorrhage from graft site
	25	Haemorrhage from vascular access or dialysis circuit
	26	Haemorrhage from ruptured vascular aneurysm (not code 22 or 23)
	27	Haemorrhage from surgery (not code 23, 24 or 26)
	28	Other haemorrhage (not codes 23-27)
	29	Mesenteric infarction
	41	Liver disease due to hepatitis B virus
	42	Liver disease due to other viral hepatitis
	43	Liver disease due to drug toxicity
	44	Cirrhosis - not viral
	45	Cystic liver disease
	46	Liver failure - cause unknown
	52	Suicide
	62	Pancreatitis
	63	Bone marrow depression
	64	Cachexia
	69	Dementia
	70	Peritonitis (sclerosing, with peritoneal dialysis)
	71	Perforation of peptic ulcer
	72	Perforation of colon
	73	Chronic obstructive airways disease
	80	Accident (all causes)
	81	Accident related to ESRF treatment (not code 25)

Category	ERA code	Cause of death
	82	Accident unrelated to ESRF treatment
	90	Gastro-intestinal - other
	99	Other identified cause of death
Uncertain	0	Cause of death uncertain / not determined

Appendix D Members ‘Sectie Registratie’ of the Dutch Federation for Nephrology

Prof. dr. F.W. Dekker, epidemiologist
Prof. dr. M.H. Hemmelder, internist-nephrologist, chair Registration Division NFN
Dr. M.A.G.J.ten Dam, Uitvoerend bestuurder Nefrovisie
Dr. H. van Hamersvelt, internist-nephrologist, representative Guidelines Division NFN
Dr. B. van Dam, internist-nephrologist, representative Guidelines Division NFN
Dr. A. de Vries, internist-nephrologist, representative LONT
Prof. dr. S.P. Berger, internist-nephrologist, representative LONT
Dr. V.S. Stel, epidemiologist, ERA-registry
Dr. M. van Buren, internist-nephrologist
Prof. dr. W.J. Bos, internist-nephrologist
Dr. W. Michels, internist-nephrologist
Dr. H. de Jong, pediatric nephrologist
J. Hart, representative V&VN
S. van den Berg, representative V&VN
Dr. M. Ho-dac, director of Dutch Kidney Patient Association
W. Konijn, representative of Dutch Kidney Patient Association
Drs. L. Heuveling, Nefrovisie
Dr. T. Hoekstra, Nefrovisie

Appendix E Publications

Data from Renine is, when conditions are met, available for scientific studies. Requests for data can be made at the website of Nefrovisie (www.nefrovisie.nl/dataverzoek).

In 2021 two studies based on Renine data were published:

- Bonenkamp AE, Hoekstra T, Hemmelder MH, van Eck van der Sluijs A, Abrahams AC, van Ittersum FJ, van Jaarsveld BC. Trends in home dialysis use differ among age categories in past two decades: A Dutch registry study. *Eur J Clin Invest* 2021.

- Van Oevelen M, Abrahams AC, Bos WJW, Hoekstra T, Hemmelder MH, ten Dam M, van Buren M. Dialysis withdrawal in the Netherlands between 2000 and 2019: time trends, risk factors and centre variation. *Nephrol Dial transplant* 2021; 36:2112-2119.

Nefrovisie contributed to the SKR Impact Report 2021. The report is available from www.skr-zorg.nl.