Nefrovisie
Richtlijnen · Registratie · Visitatie

RENINE annual report 2022

Includes data until December 31st 2021

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)

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Contents

1 Introduction

We are pleased to present the Renine Annual Report 2022. Renine is the Dutch registry on chronic renal replacement therapy. All dialysis centres in the Netherlands provide data to Renine. The coverage ratio of Renine is 96% for the prevalent patients and 92% for incident patients. Data on renal transplantations are provided by the 'Nederlandse Transplantatie Stichting' (NTS).

Several measures are being taken to ensure a high quality of the data. Dialysis centres checked and approved their data until December 31st 2021. 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 increase 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 2021.

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

Dr. Marc ten Dam, CEO Nefrovisie

2 Renal replacement therapy: key figures of 2021

In this chapter, an overview is provided of the prevalent and incident renal replacement therapy populations in 2021. Further details and trends over time are presented in the following chapters.

Table 2.1. Number of prevalent and incident patients that received renal replacement therapy (RRT) in 2021. Reference date for prevalence: December 31st 2021*

	N	%	Change from 2020
Prevalence*			
Renal replacement therapy	18,106		+1%
Dialysis	6,248	35%	0%
Renal transplant	11,858	65%	+2%
Incidence*			
Renal replacement therapy	1,900		+2%
Dialysis	1,646	87%	0%
Renal transplant	254	13%	+17%

*256 prevalent dialysis patients and 139 incident RRT patients did not provide consent for their data to be included in Renine. The coverage in 2021 was 96% and 92% respectively.

Table 2.2. Characteristics prevalent dialysis patients (December 31st 2021), N=6,248

	N	%
Sex, male	3,761	60%
Age (yrs), mean (SD)	67 (15)	
Dialysis modality		
Haemodialysis	5,262	84%
Peritoneal dialysis	986	16%
Primary kidney disease		
Glomerulonephritis/sclerosis	713	11%
Pyelonephritis	279	5%
Polycystic kidney disease	319	5%
Hypertension	1,095	18%
Renal vascular disease	598	10%
Diabetes type 1	175	3%
Diabetes type 2	1,152	18%
Miscellaneous	1,190	19%
Unknown	727	12%
Time on RRT (yrs), median (Q1-Q3)	2.7 (1.1-6.0)	
Time on dialysis (yrs), median (Q1-Q3)	2.3 (1.0-4.5)	
History renal transplantation	739	12%
First chronic dialysis episode	5,469	88%

Table 2.3. Characteristics prevalent transplant patients (December 31st 2021), N=11,858

		%
Sex, male	7,186	61%
Age (yrs), mean (SD)	58 (15)	
Living donor	6,349	54%
Post-mortem donor	5,509	46%
Transplant number		
First	10,201	86%
Second	1,374	12%
Third or higher	283	2%
No dialysis history	3,220	27%
Primary kidney disease		
Glomerulonephritis/sclerosis	2,219	19%
Pyelonephritis	793	7%
Polycystic kidney disease	1,223	10%
Hypertension	1,088	9%
Renal vascular disease	339	3%
Diabetes type 1	474	4%
Diabetes type 2	565	5%
Miscellaneous	2,612	22%
Unknown	2.545	21%
Time on RRT (yrs), median (Q1-Q3)	11.0 (5.8-19.2)	
Years with current transplant, median (Q1-Q3)	8.1 (3.9-14.6)	

Table 2.4. Characteristics of incident RRT patients in 2021 with start modality dialysis (N=1,646)

		%
Sex, male	1,061	64%
Age (yrs), mean (SD)	63 (15)	
Modality at start RRT, at day 1		
Haemodialysis	1,301	79%
Peritoneal dialysis	345	21%
Primary kidney disease*		
Glomerulonephritis/sclerosis	186	11%
Pyelonephritis	53	3%
Polycystic kidney disease	76	5%
Hypertension	286	17%
Renal vascular disease	97	6%
Diabetes type 1	51	3%
Diabetes type 2	327	20%
Miscellaneous	367	22%
Unknown	203	12%

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

Table 2.5. Characteristics of incident RRT patients in 2021 pre-emptive transplantations (N=254)

		%
Sex, male	151	59%
Age (yrs), mean (SD)	52 (17)	
Post-mortem donor	30	12%
Living donor	224	88%

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3 Renal replacement therapy: prevalence and incidence

On December 31st, 2021 18,106 prevalent patients on renal replacement therapy (RRT) were registered in Renine (Figure 3.1). This equals 1,029 patients per million of the total population in the Netherlands (Figure 3.2 (left y-axis)). 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 years. In 2021, 1,900 patients started RRT (=incidence), which equals 108 patients per million population. Men are overrepresented in both the prevalent and incident RRT populations, with respectively 60% and 64% of the populations being male.

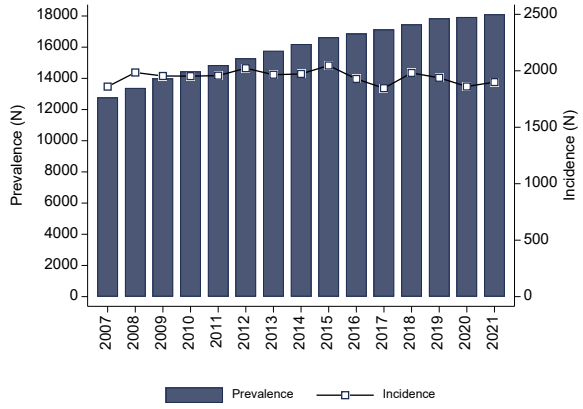

Figure 3.1. Prevalence and incidence of renal replacement therapy.

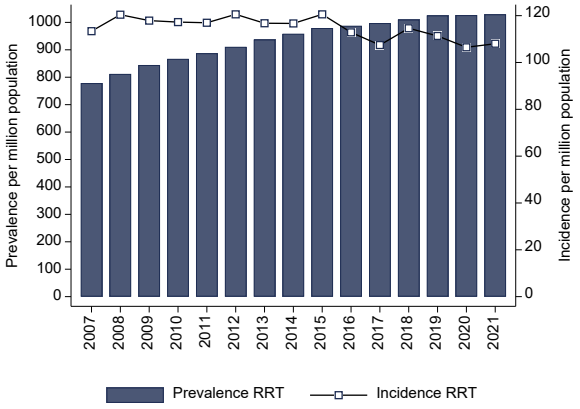

Figure 3.2. Prevalence and incidence of renal replacement therapy per million population.

The proportion of elderly patients in the prevalent RRT population is steadily increasing (Figure 3.3). On December 31st, 2021, 46% of patients on renal replacement therapy were 65 years or older and 20% were 75 years or older. A decade ago (2011) this was 39% 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 still increasing for the age category 65-74 years. For the first time, a slight decrease is observed for patients 75 years and older (Figure 3.4).

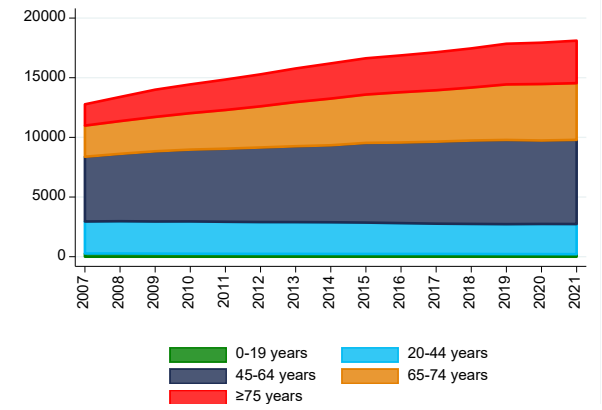

Figure 3.3. Prevalence of renal replacement therapy by age categories.

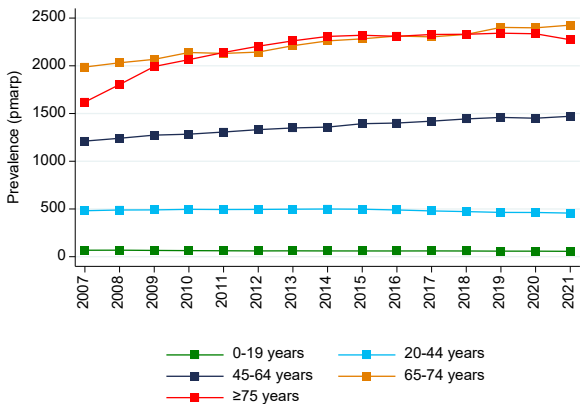

Figure 3.4. Prevalence of renal replacement therapy by age categories expressed per million age related population.

Most of the RRT patients, i.e. 65%, are patients living with a renal transplant. The proportion of transplant patients decreases gradually with increasing age. In RRT patients younger than 45 years, 80% are living with a transplant against 37% in patients in patients 75 years and older. However, the absolute number of patients 75 years and older is steadily growing (Figure 3.5). On December 31st 2021, more than 1,300 patients in this age category were living with a renal transplant, an increase of 270% compared to 2011.

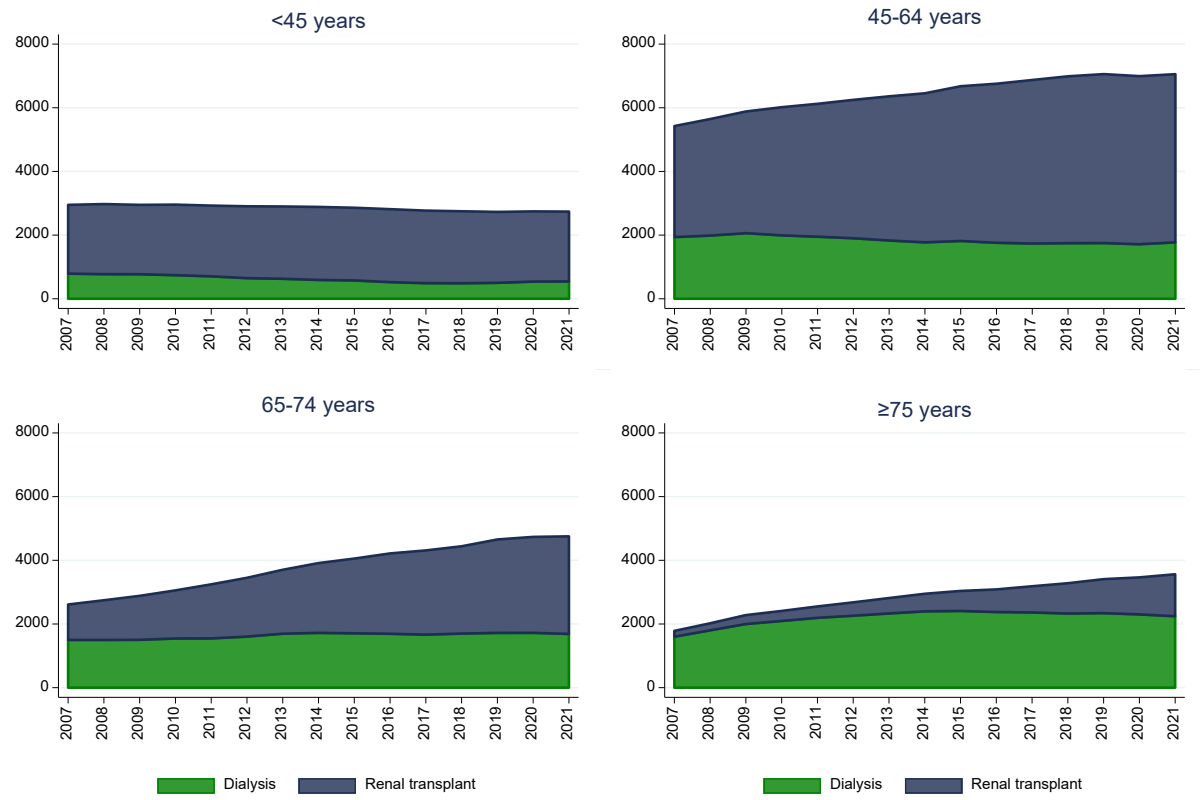

Figure 3.5. Prevalence of dialysis and renal transplants stratified by age categories

Time trends in incidence of RRT, absolute numbers and expressed per million age-related population, are shown stratified for age categories in Figures 3.6 and 3.7 respectively.

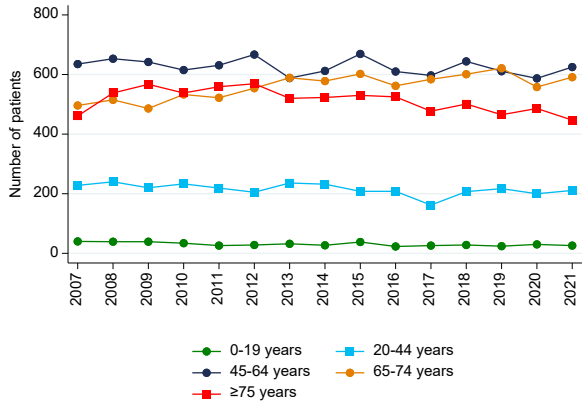

Figure 3.6. Incidence of renal replacement therapy stratified for age categories

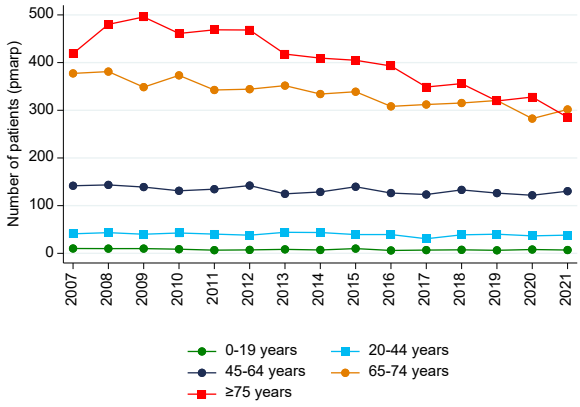

Figure 3.7. Incidence of renal replacement therapy per million age related population stratified for age categories.

The incidence of RRT per million age-related population is steadily decreasing over time in the 75 years and older population, with an incidence of 285 RRT patients per million age-related population in 2021. The highest incidence in this age category was observed in 2009, i.e. 496 per million age-related population. Possible reasons for this decrease (-43%) are improvement in chronic kidney disease care, higher mortality before the start of RRT due to comorbidities, or more frequent choice for conservative treatment.

Most incident RRT patients start RRT treatment by means of haemodialysis. In 2021, the distribution over the start modalities was 68% haemodialysis, 18% peritoneal dialysis, and 13% pre-emptive transplantations. Figure 3.8 shows time trends in modalities at the start of RRT for age categories. Pre-emptive transplantations are most common in young patients.

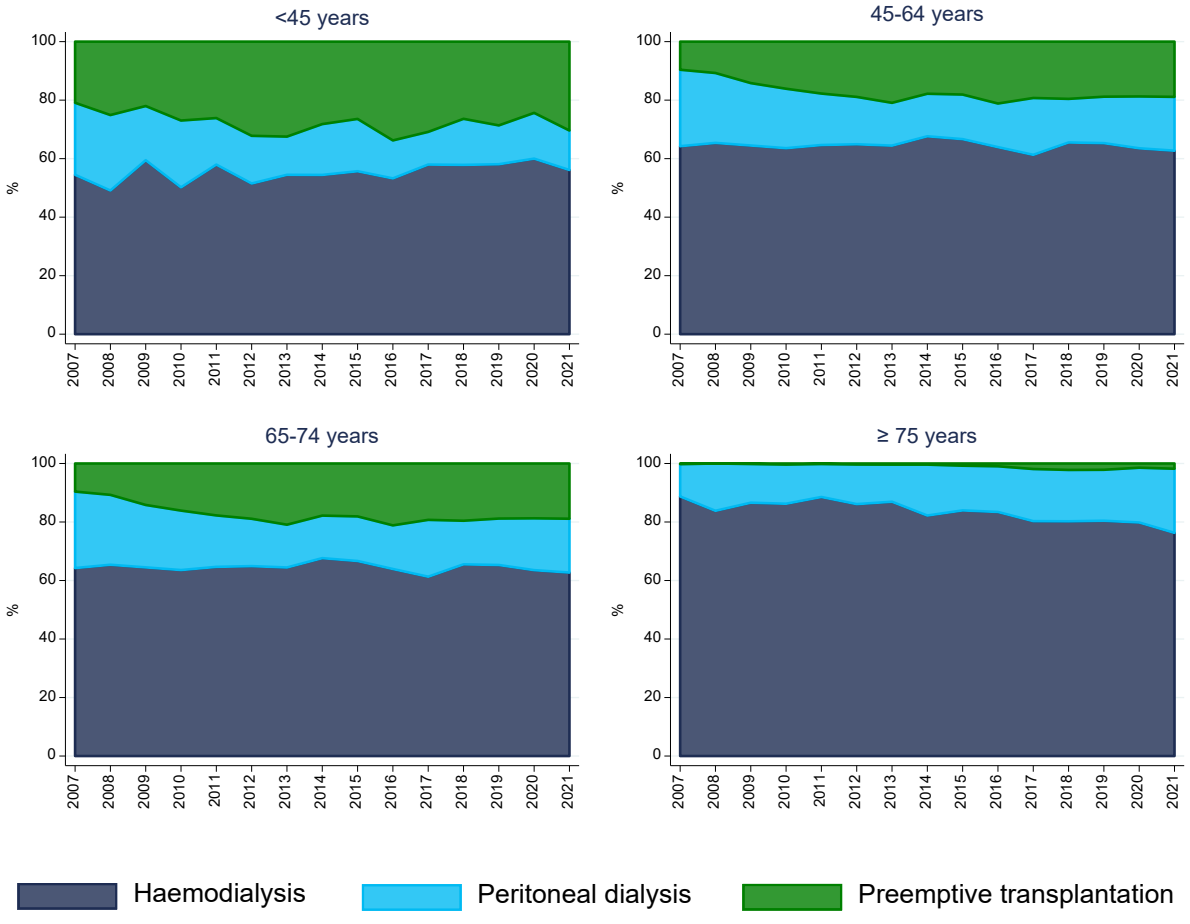

Figure 3.8. Distribution of start modalities in incident RRT patients over time stratified for age categories.

4 Survival on renal replacement therapy

In 2021, 1,184 dialysis patients died. Compared to 2020 this is a decrease of 7%. However, in that year Covid-19 had a clear impact on mortality in dialysis patients. Compared to 2019, the absolute number of deaths was 7% higher in 2021. The mean age at death was 73.9 years. In 2019 and 2020, this was respectively 74.6 and 74.1 years.

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 (Figures 4.1 and 4.2), i.e. in 2021, 28% of all deaths on dialysis were in this category (N=326). Death due to Covid-19 was registered in 8% of all deaths in dialysis patients in 2021. In 2020, this was 10%. Covid-19 thus still had a clear impact on mortality in the dialysis population.

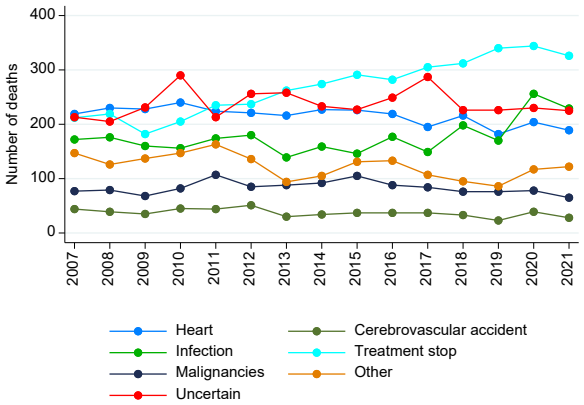

Figure 4.1. Causes of death over time.

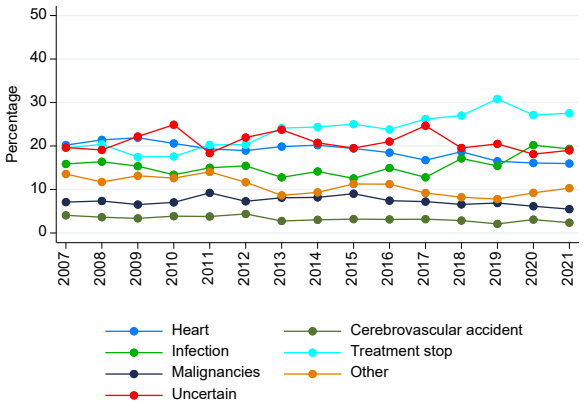

Figure 4.2. Causes of death as percentages over time.

Figures 4.3 and 4.4 show the causes of death in 2021 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.

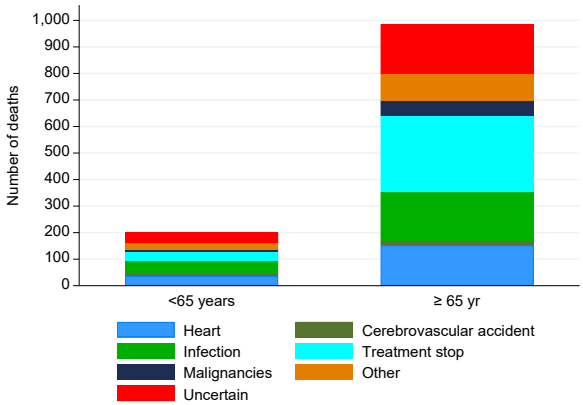

Figure 4.3. Number of deaths in 2021 in patients on dialysis younger and older than 65 years.

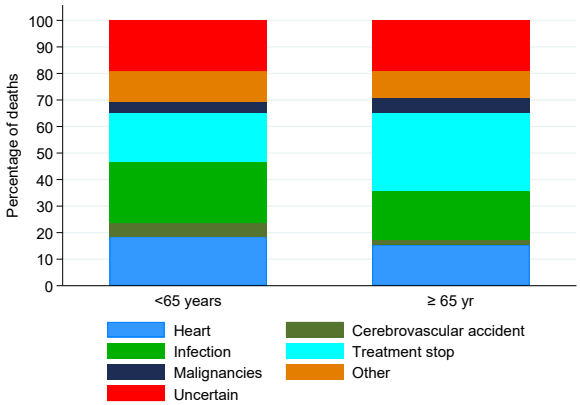

Figure 4.4. Causes of death in 2021 in patients on dialysis younger and older than 65 years as percentage.

Crude survival probabilities of incident dialysis patients are shown in Table 4.1 for two cohorts. Results are shown both with and without censoring for renal transplantation. In the censored analysis, follow-up ends in the case of a renal transplant.

Table 4.1. Survival probabilities for incident dialysis patients, presented as percentage (95% CI).

	1-year survival		3-year survival	
Age at start	**Cohort 2012-2016**	**Cohort 2017-2020**	**Cohort 2012-2016**	**Cohort 2017-2018**
<45 yrs	98 (97-99)	98 (96-99)	95 (93-96)	93 (89-95)
45-64 yrs	91 (90-92)	93 (92-94)	79 (77-80)	78 (76-81)
≥65 yrs	82 (81-83)	84 (83-85)	55 (54-56)	55 (53-57)
Transplantation as censoring event				
Age at start	**Cohort 2012-2016**	**Cohort 2017-2020**	**Cohort 2012-2016**	**Cohort 2017-2018**
<45 yrs	98 (97-99)	97 (96-99)	92 (90-95)	90 (84-93)
45-64 yrs	91 (90-92)	93 (92-94)	75 (73-77)	75 (71-78)
≥65 yrs	82 (81-83)	84 (82-85)	53 (52-55)	53 (50-55)

Figures 4.5 and 4.6 show the one-year and three-year survival of incident dialysis patients over the years, separately for patients younger and older than 65 years of age. In these analyses, the follow-up time was not censored for renal transplantation. Three-year survival improved over time in patients younger than 65 years. This trend is not seen in the older patients, no improvements were seen during the last decade.

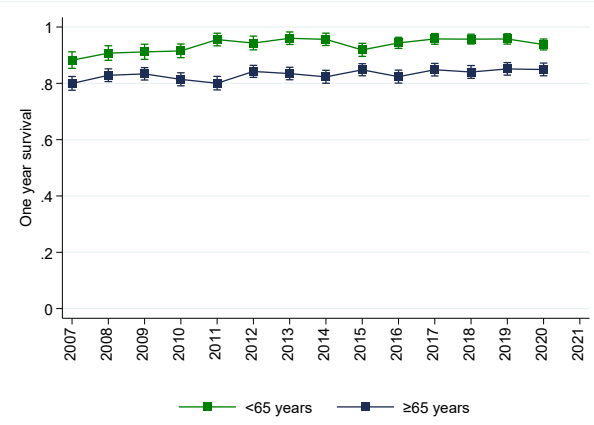

Figure 4.5. One-year survival of incident dialysis patients over the years for patients younger and older than 65 years. The estimates were adjusted for age (within the age category) and sex.

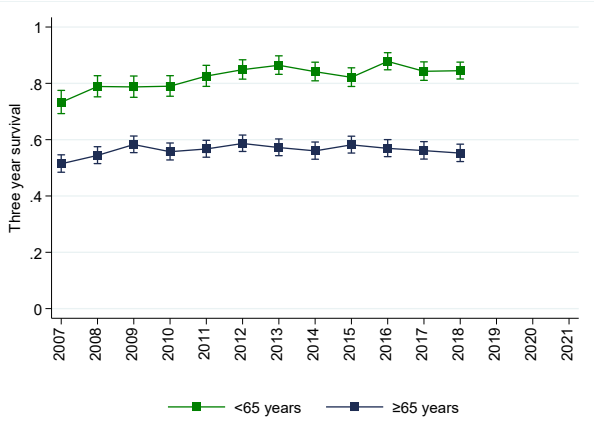

Figure 4.6. Three-year survival of incident dialysis patients over the years for patients younger and older than 65 years. The estimates were adjusted for age (within the age category) and sex.

Survival probabilities after first kidney transplantation are presented in table 4.2. 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 4.2. Survival probabilities after first kidney transplantation presented as percentage (95% CI).

	3-year survival[#]		5-year survival[$]	
Age at transplant	**Living**	**Post-mortem**	**Living**	**Post-mortem**
<45 yrs	99 (97-99)	96 (93-98)	97 (95-99)	92 (87-95)
45-64 yrs	96 (94-97)	91 (89-92)	93 (90-94)	86 (83-89)
≥65 yrs	91 (88-93)	81 (78-83)	78 (72-82)	67 (62-72)

Inclusion period: 2014-2018. $ Inclusion period: 2014-2016

In Figures 4.7 and 4.8 centre variation is shown for 1-year and 3-year mortality in incident dialysis patients. See Appendix A for an explanation of funnel plots. 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.

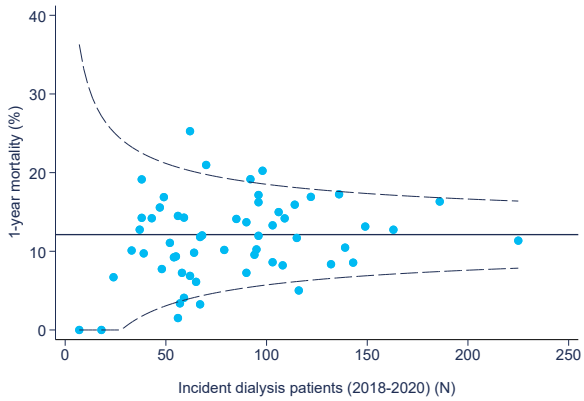

Figure 4.7. Centre variation in 1-year mortality in incident dialysis patients. Inclusion period 2018-2020. Adjustments were made for age, sex, SES, and primary kidney disease categories.

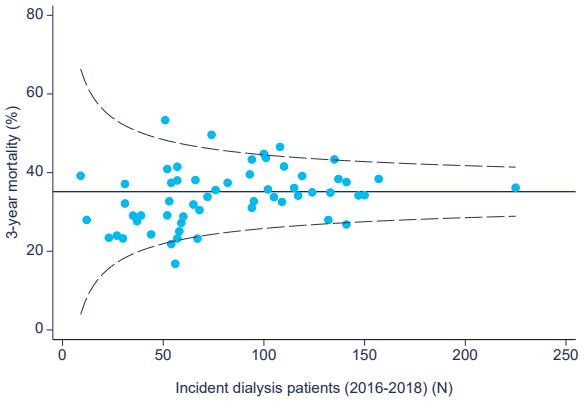

Figure 4.8. Centre variation in 3-year mortality in incident dialysis patients. Inclusion period 2015-2017. Adjustments were made for age, sex, SES, and primary kidney disease categories.

5 Dialysis treatment

Over recent years, the number of patients treated with chronic dialysis remained constant (Figure 5.1). Prevalence includes all patients on dialysis treatment, irrespective of their RRT history. On December 31st, 2021, 6,248 patients were on chronic dialysis treatment. Of these patients, 36% were 75 years or older.

In 2021 1,882 patients started chronic dialysis therapy. For the majority of these patients (i.e. N=1,679, 89%) this was their first time on chronic dialysis treatment and 203 patients (11%) 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.

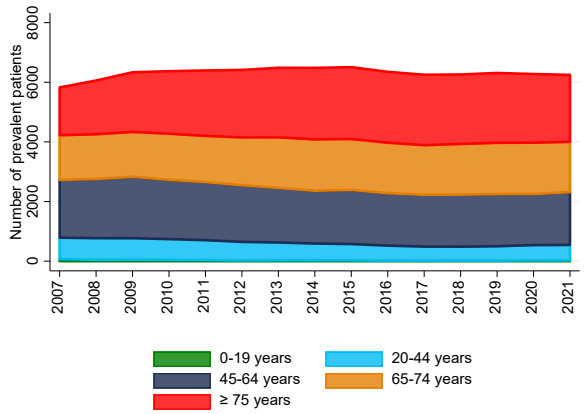

Figure 5.1. Prevalence of dialysis (December 31th) by age categories.

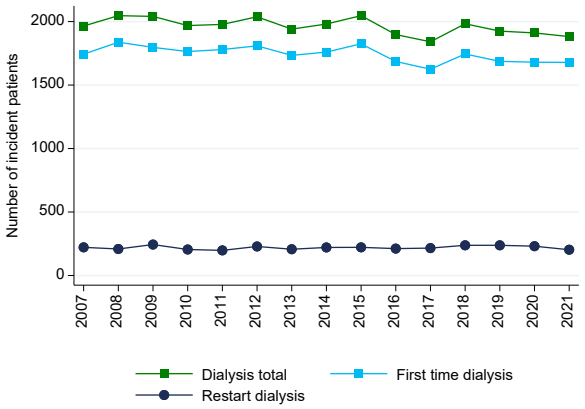

Figure 5.2. Incidence of dialysis. A distinction was made between first time chronic dialysis and patients with a dialysis history restarting chronic dialysis.

The sex-specific incidence of dialysis treatment per million population shows different time trends for men than for women (Figures 5.3 and 5.4). 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 care for chronic kidney disease.

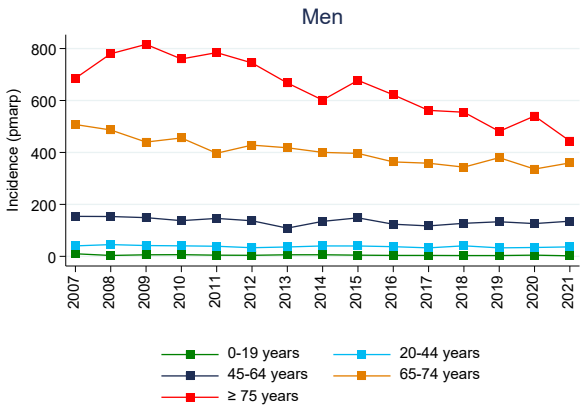

Figure 5.3. Incidence per million age related population of first-time dialysis in men stratified for age categories.

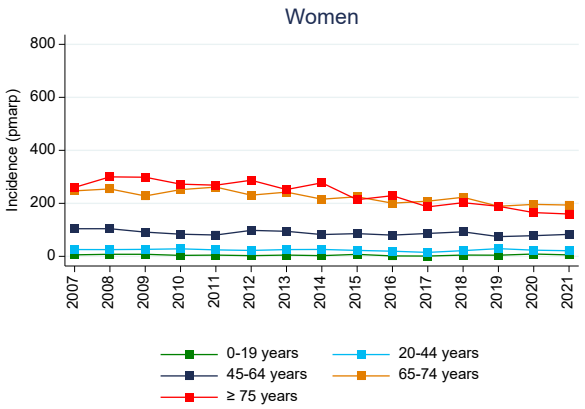

Figure 5.4. Incidence per million age related population of first-time dialysis in women stratified for age categories.

Dialysis incidence in the older age categories is substantially higher in men than in women. In 2021, the incidence in 75-plus men was 2.8 times higher than in 75-plus women (444 versus 160 patients per million population). The reasons for these distinct differences remain unclear and need further investigation. This might partly be due to a higher prevalence of cardiovascular diseases in men. It has also been suggested that elderly women are more likely to choose conservative therapy than men are.[1]

In 2021, the distribution of the prevalent dialysis population was 80% in-centre haemodialysis, 16% peritoneal dialysis, and 4% home haemodialysis (Figure 5.5). The percentage home-based treatments, i.e. peritoneal dialysis or home haemodialysis, was the highest for patients younger than 45 years, i.e. 24%. After a period with declining percentages of home dialysis in this age category as well as in the age category 45-64 years, these percentages stabilized in recent years. In contrast, in 75-plus patients an increasing trend in home-based dialysis modalities is observed.

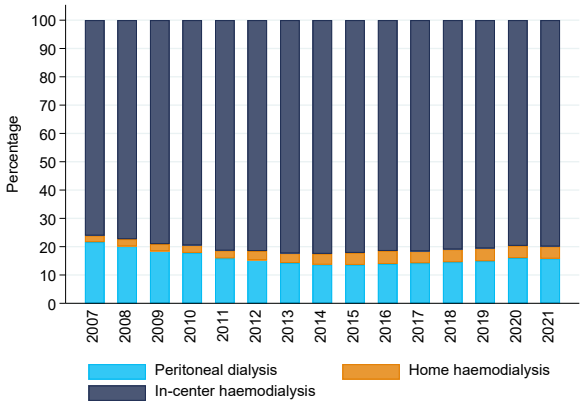

Figure 5.5. Distribution of dialysis modalities in prevalent chronic dialysis patients.

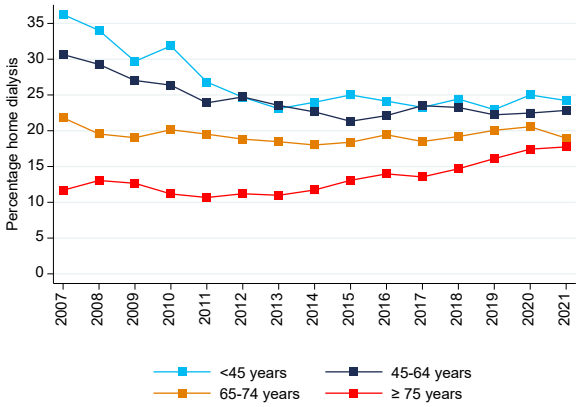

Figure 5.6. Percentage home dialysis in age categories.

Figure 5.7 shows the absolute number of patients treated with different dialysis modalities in age categories over time. Most patients treated with home-based dialysis modalities are in the age categories 45-64 years and 75-plus.

1 Carrero JJ, Hecking M, Chesnaye NC, Jager KJ. Sex and gender disparities in the epidemiology and outcomes of chronic kidney disease. Nature Reviews 2018;14:151-164

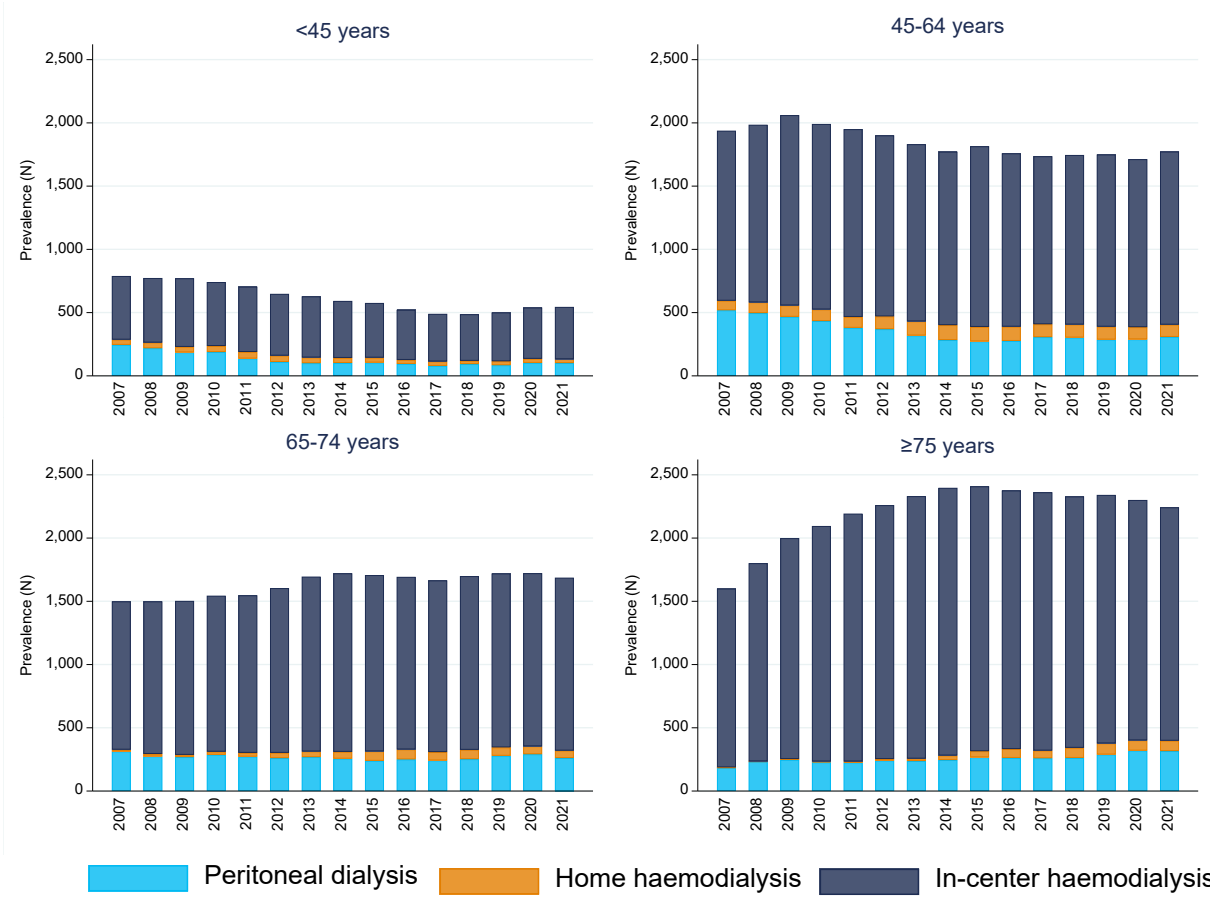

Figure 5.7. Distribution of dialysis modalities in prevalent chronic dialysis patients, stratified for age categories.

The mean age of patients treated with home-based dialysis modalities (i.e. PD or home haemodialysis) is lower than that of in-centre haemodialysis patients. In 2021, the age difference was 2.5 years. Up to 2017, both dialysis populations aged. However, in recent years the mean age in the dialysis population decreased (Figure 5.8).

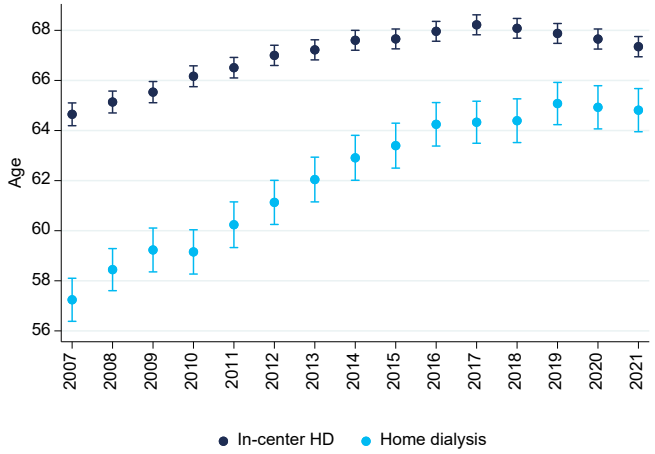

Figure 5.8. Mean age of prevalent in-center haemodialysis and home dialysis patients. Results are shown with 95%-confidence intervals.

In Figure 5.9 home dialysis utilization is shown for incident dialysis patients. To allow for a training period, dialysis modality was determined three months after patients started dialysis treatment. Over the years, the number of patients aged 65 years and older increased to almost 200 patients in 2021. For patients younger than 65 years, numbers were stable over the last decade, following a period of declining numbers (up to 2013). The same numbers are shown as percentage home dialysis of total dialysis in Figure 5.10.

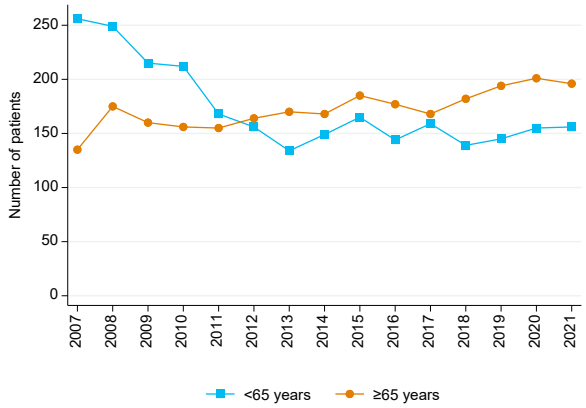

Figure 5.9. Home dialysis at 3 months after dialysis onset in patients younger and older than 65 years.

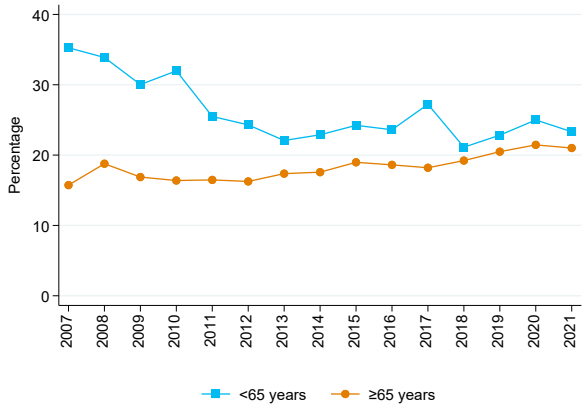

Figure 5.10. Percentage home dialysis at 3 months after dialysis onset in patients younger and older than 65 years.

The proportion of incident dialysis patients treated with home dialysis (home haemodialysis or peritoneal dialysis) shows substantial variation among centres (Figure 5.11). Also in this analysis, the outcome is treatment modality 3 months after the start of chronic dialysis treatment. Data from three calendar years (2019-2021) were combined because of low patient numbers per centre.

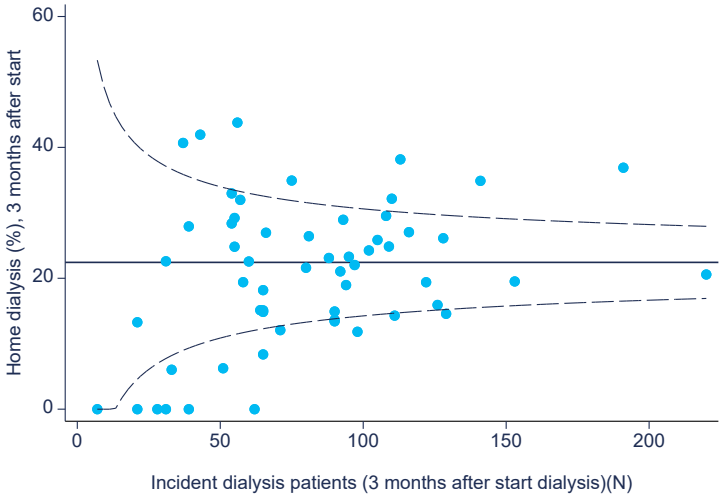

Figure 5.11. Center variation in percentage home dialysis three months after start dialysis. Home dialysis includes peritoneal dialysis and home haemodialysis. Data is adjusted for age, sex, SES, and primary kidney disease categories. Inclusion period 2019-2021.

Figures 5.12 and 5.13 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 most likely 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 2020, 71% 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. 13% switched to haemodialysis and 12% had a functioning renal transplant one year after they started peritoneal dialysis. After the start of peritoneal dialysis, mortality was 12% in the first year.

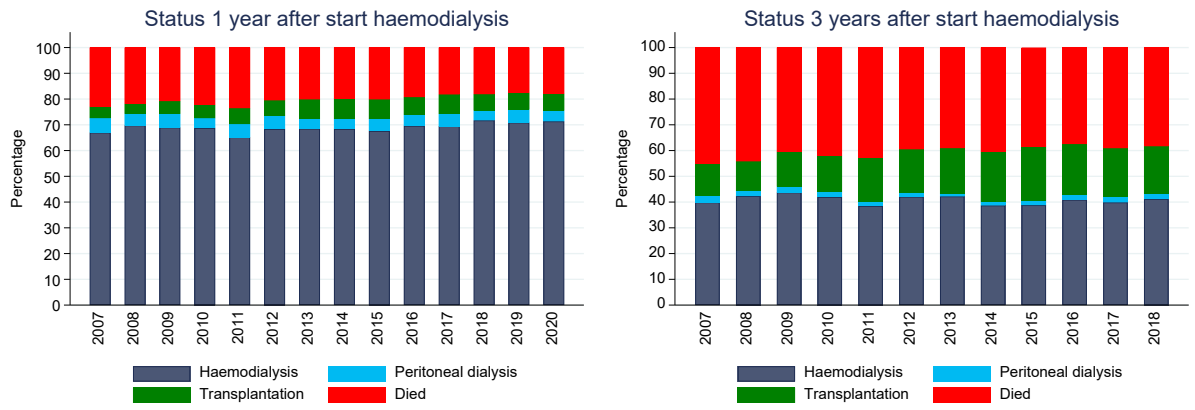

Figure 5.12. Status 1 and 3 years after start HD as percentage. The year represents the year in which HD was started.

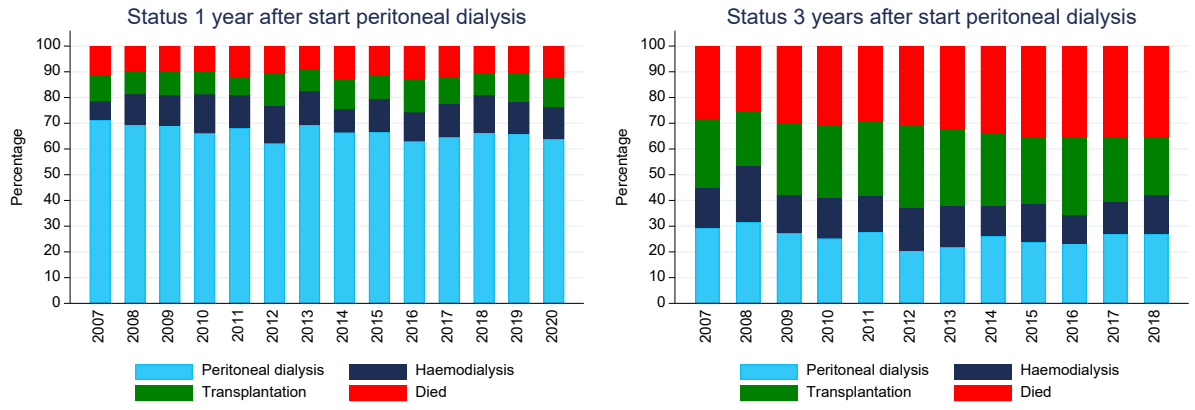

Figure 5.13. Status 1 and 3 years after start PD as percentage. The year represents the year in which PD was started.

Figures 5.14 and 5.15 show centre variation in the percentage switches between modalities during the first year of dialysis in funnel plots. 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.

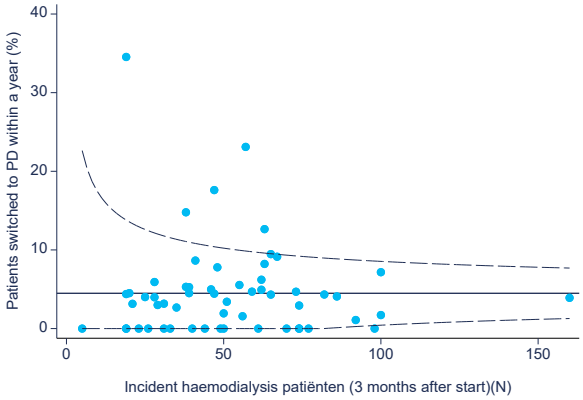

Figure 5.14. Centre variation in switches from HD to PD. Patients were included if on HD 3 months after start dialysis and still on dialysis after 1 year. Adjustments were made for age, sex, SES, and primary kidney disease categories.

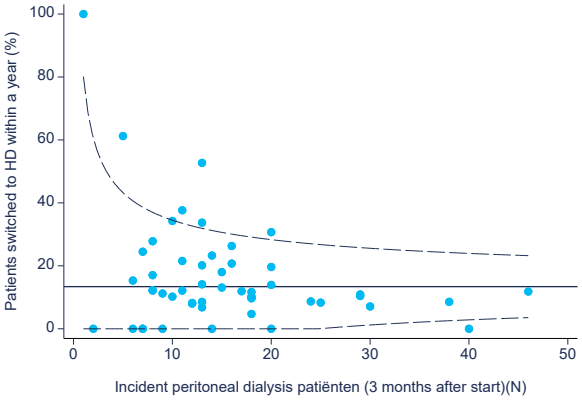

Figure 5.15. Centre variation in switches from PD to HD. Patients were included if on PD 3 months after start dialysis and still on dialysis after 1 year. Adjustments were made for age, sex, SES, and primary kidney disease categories.

6 Clinical data dialysis patients

Clinical variables including laboratory measurements, details of dialysis treatment, and vascular access data of dialysis patients are 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. However, for 2021 overall completeness of clinical data slightly decreased. For 9% of the dialysis patients, no clinical data were available in 2021. In 2020, this was 6%. For 2021 completeness of the data was 87% for phosphate levels (Figure 6.1) in dialysis patients and 90% for vascular access in haemodialysis patients (Figure 6.2).

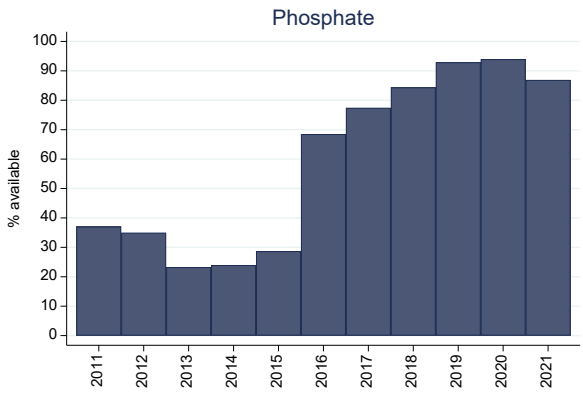

Figure 6.1. Availability of phosphate measurements per year expressed as percentage of the total number of potential measurements.

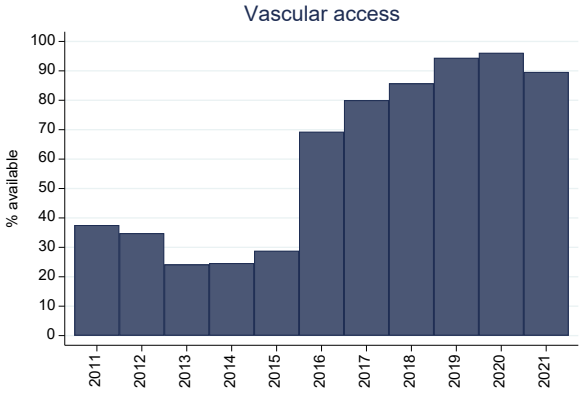

Figure 6.2. Availability of vascular access data per year expressed as percentage of the total number of potential measurements.

Figures 6.3 and 6.4 show mean haemoglobin and ferritin levels over time for dialysis patients younger and older than 65 years.

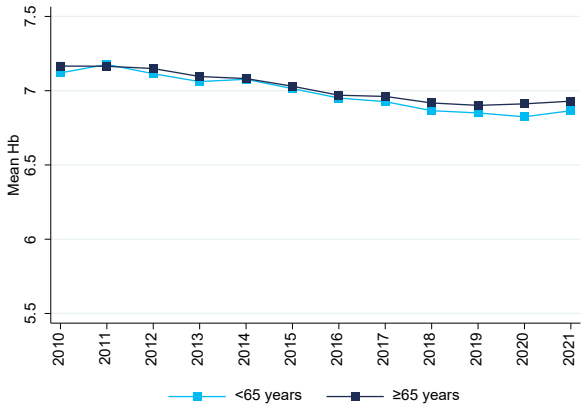

Figure 6.3. Mean hemoglobin levels per year in age categories.

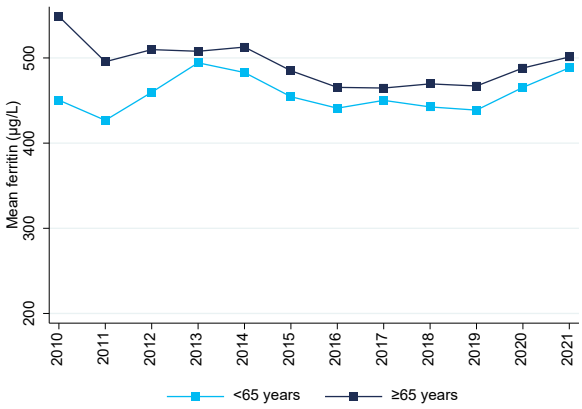

Figure 6.4. Mean ferritin levels per year in age categories.

Mean haemoglobin levels decreased over the years. 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 6.5 shows mean phosphate levels over time for dialysis patients in four age categories. Mean phosphate is higher for younger age categories and trends towards higher phosphate levels are observed over time. In 2021, 78% of the phosphate levels were below 1.8 mmol/L for 75-plus patients, whilst these percentages were lower for younger patients (Figure 6.6). In about 40% of the patients younger than 65 year, phosphate levels lower than 1.8 mmol/L were achieved. Differences in nutritional status and (adherence to) treatment might contribute to these observed differences.

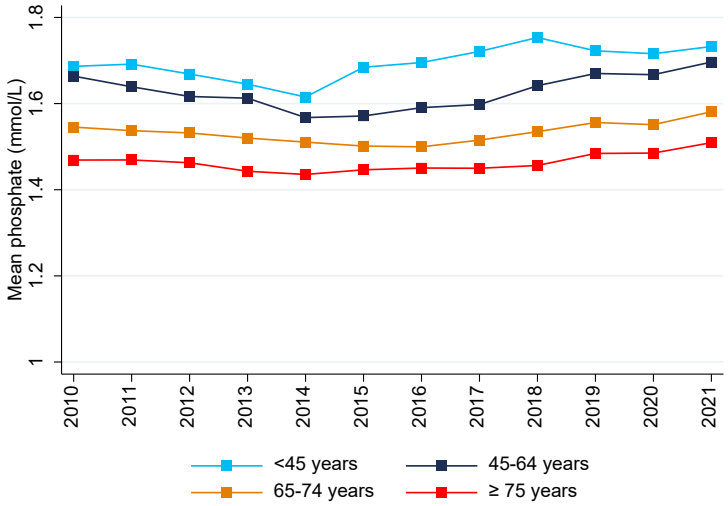

Figure 6.5. Mean phosphate levels per year in age categories.

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 6.6 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.

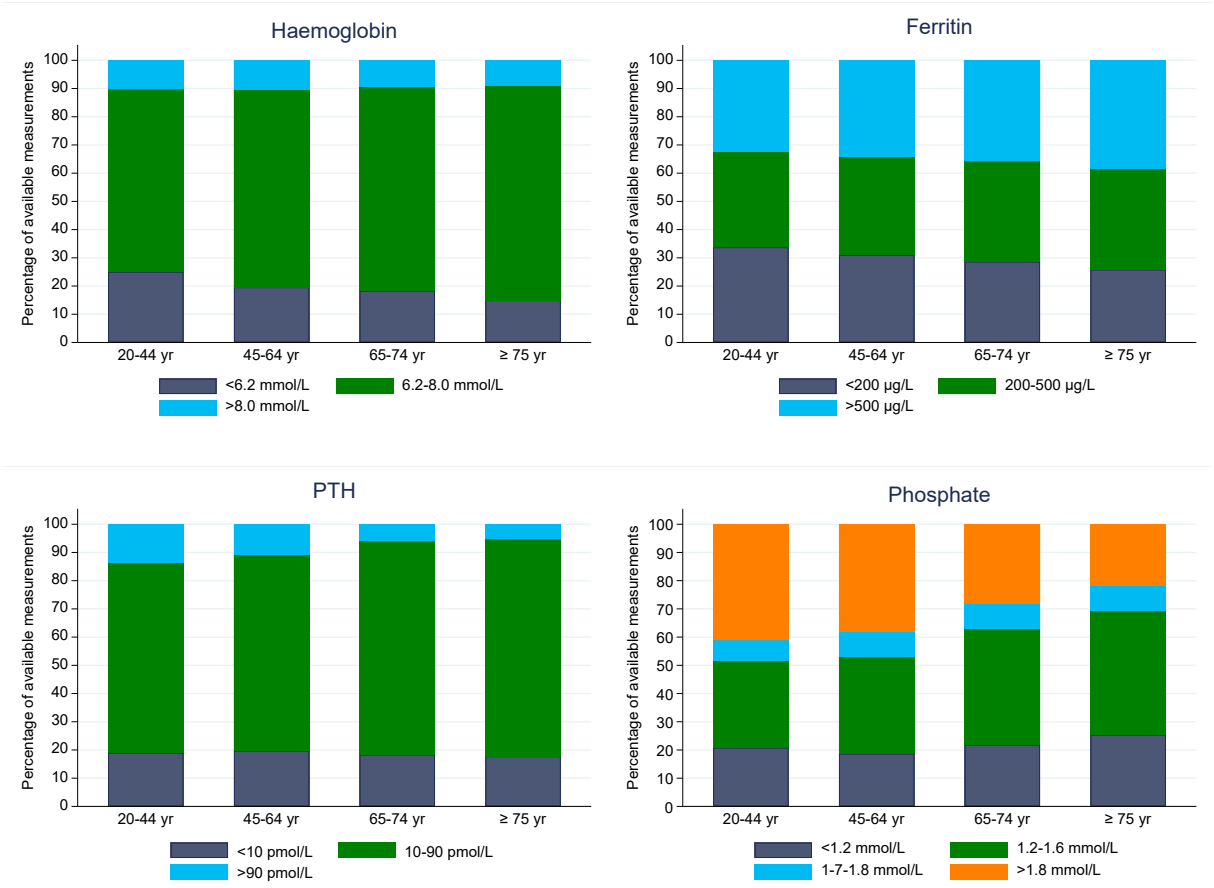

Figure 6.6. Categories of clinical variables stratified for age categories.

Substantial variation in mean values was observed across different centres as is shown in the funnel plots (Figure 6.5).

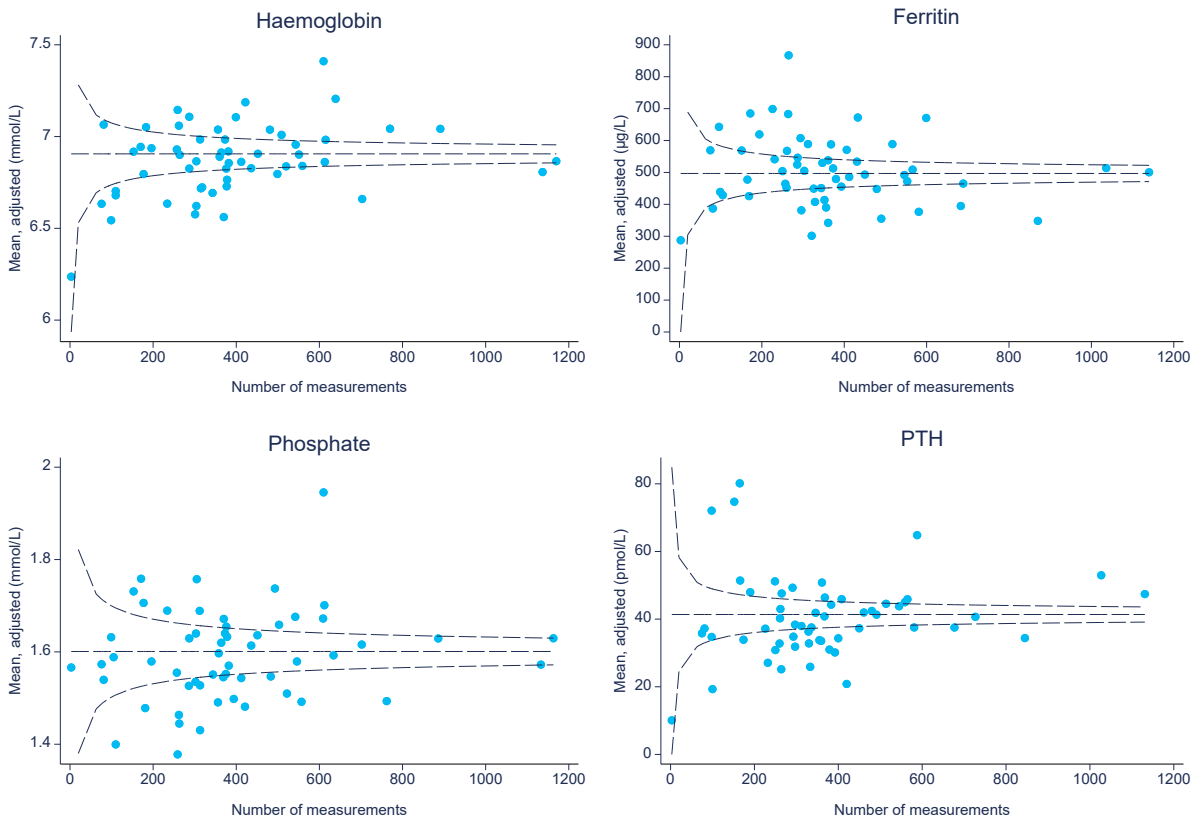

Figure 6.7. Funnel plots showing centre variation of mean values of clinical variables in 2021. The funnels were adjusted for differences in case-mix (age, gender, SES, and primary kidney disease categories).

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 6.8). In incident patients, a catheter is more common (Figure 6.9).

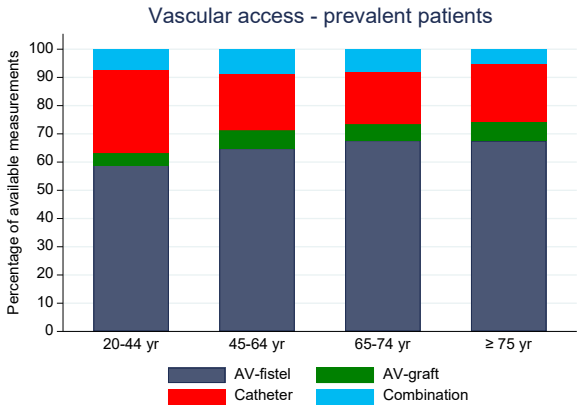

Figure 6.8. Percentages of vascular access categories in prevalent haemodialysis patients in 2021.

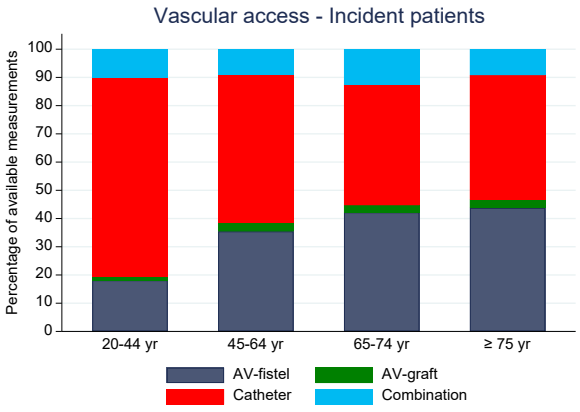

Figure 6.9. Percentages of vascular access categories in incident haemodialysis patients in 2021.

Figures 6.10 and 6.11 show the centre variation in the percentages of patients with a central venous catheter for prevalent and incident haemodialysis patients respectively.

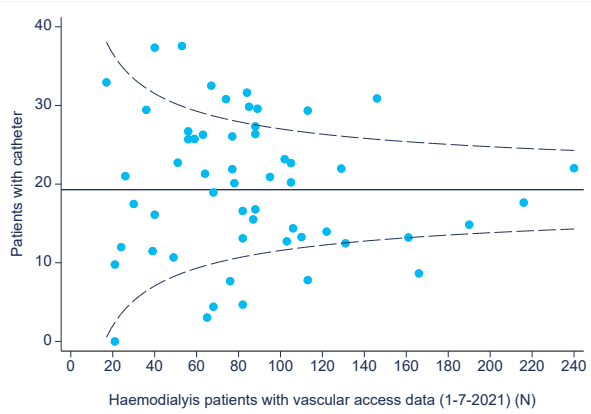

Figure 6.10. Centre variation in catheter use in prevalent haemodialysis patients. Adjustments were performed for age, sex, SES, and primary kidney disease categories.

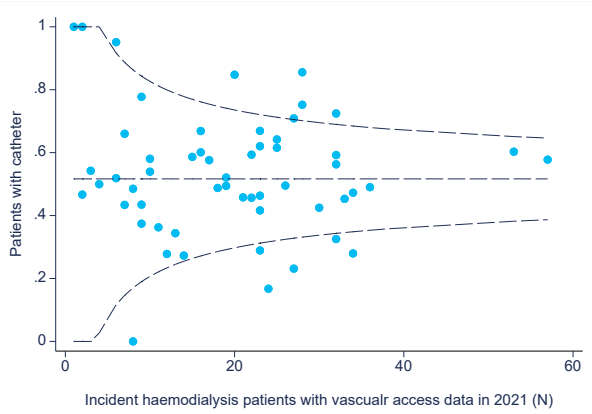

Figure 6.11. Centre variation in catheter use in incident haemodialysis patients. Adjustments were performed for age, sex, SES, and primary kidney disease categories.

7 PROMs in dialysis patients

The registry of patient-reported outcome measures (PROMs) in Renine started in 2018. The PROMs consist 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 2021, 2,746 dialysis patients, which equals 44% of the prevalent dialysis population, filled out at least one PROM. The majority (69%) filled out PROMs once during the year, for 24% (N=662) of these patients two PROMs were available in 2021.

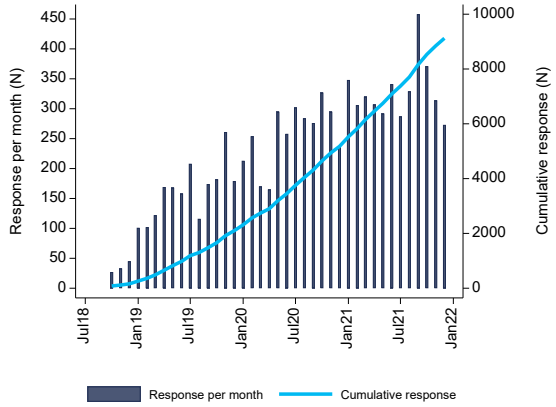

Figure 7.1. PROMs response per month and cumulative over time.

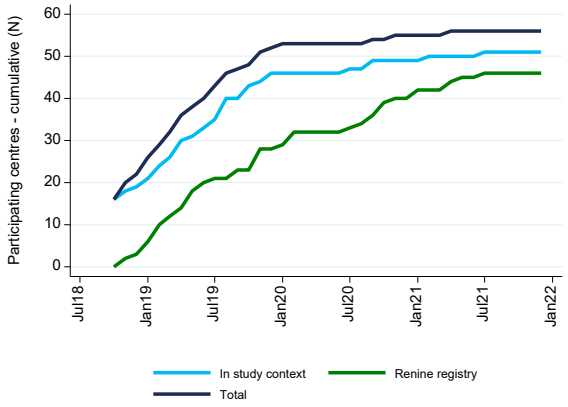

Figure 7.2. Cumulative number of participating centers over time.

Over time, participation is increasing. Figure 7.1 shows both the available measurements per month and cumulative over time. Figure 7.2 shows the cumulative number of centres participating in PROMs data collection. Some centres only participated within the context of scientific studies linked to Renine. At the end of 2021, 56 out of 59 centres (=95%) participated in PROMs and data was available for almost 4,500 dialysis patients (i.e. at least one measurement). More than half of these patients (52%) filled out PROMs on at least two occasions. In 2021, PROMs data was available for 2,746 patients. The characteristics of these patients are shown in Table 7.1. For comparison, characteristics of the general prevalent dialysis population are also shown.

Table 7.1. Characteristics of dialysis patients with at least one PROMs measurement available in 2021 in comparison to the overall dialysis population (reference data 01-07-2021).

	PROMS available*	Prevalent dialysis population**
N	2,746	6,403
Male	61%	60%
Haemodialysis	85%	84%
Age (yrs), mean (SD)	68 (13)	67 (15)
Age categories		
<45 yrs	7%	9%
45-64 yrs	27%	28%
65-74 yrs	31%	28%
≥75 yrs	35%	36%
Socio-economic status		
Low	48%	50%
Intermediate	30%	29%
High	22%	21%
Dialysis vintage (yrs), median (Q1-Q3)	1.6 (0.5-3.5)	2.2 (0.9-4.4)
History transplantation	10%	12%

* Patient characteristics were determined at the date of the first available questionnaire for a patient.

** Reference date is July 1st 2021.

Figure 7.3 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=11), which is substantially lower than in the general Dutch population (mean score of 50). The mean mental component score was 48 (SD=11). In the general Dutch population, the mean score is 51. The distribution of the mental component score in the dialysis population is somewhat skewed. The median value was 49. 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 (48 versus 46, P<0.001).

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

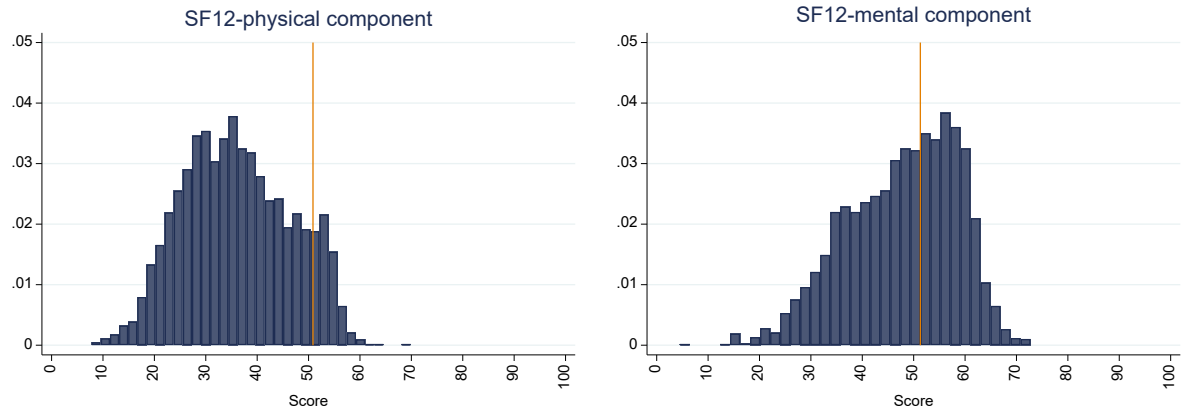

Figure 7.3. Distribution of SF-12 scores. The reference lines indicate mean scores in the general Dutch population.

Dialysis patients experienced on average 10.8 out of 30 symptoms (SD=6.3). Women reported slightly more symptoms than men (11.6 versus 10.3, P<0.001). Younger patients (<65 years) report more symptoms than patients 65 years and older (11.1 vs 10.6, P=0.04).

In the following table, the 10 most frequently reported symptoms and the most burdensome symptoms are reported. Feeling tired/lack of energy and having dry skin are the most common symptoms. Sexual dysfunction and sleeping problems impose a high burden on patients.

Table 7.2. Top 10 most frequent and most burdensome symptoms

Most frequent symptoms	%	Most burdensome symptoms	Mean score#
Feeling tired/lack of energy	76%	Difficulty becoming sexually aroused	3.21
Dry skin	60%	Trouble falling asleep	3.08
Muscle cramps	53%	Feeling tired/lack of energy	3.07
Trouble staying asleep	52%	Trouble staying asleep	3.07
Itching	51%	Decreased interest in sex	3.02
Dry mouth	44%	Bone or joint pain	2.98
Trouble falling asleep	43%	Dry skin	2.86
Bone or joint pain	43%	Restless legs	2.84
Restless legs	41%	Itching	2.84
Shortness of breath	40%	Numbness or tingling in feet	2.81

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

8 Covid-19 and vaccinations in the dialysis population

Up to December 2021, 1,186 Covid-19 events were registered in Renine. Figure 8.1 shows the course of the pandemic in the dialysis population and in the general Dutch population. For both populations, the daily incidence of Covid-19 is expressed per 100,000 persons. For the dialysis population, 7-day moving averages are shown because of the much smaller size of the population. Compared to the general population, Covid-19 incidence was very high in the dialysis population during the first wave of the pandemic (March 2020 to July 2020). However, this can be explained by more frequent testing in the dialysis population. At this stage, Covid-19 tests were not yet widely available among the general population. Up until the first months of 2021, the incidence remained higher in the dialysis population than in the general population.

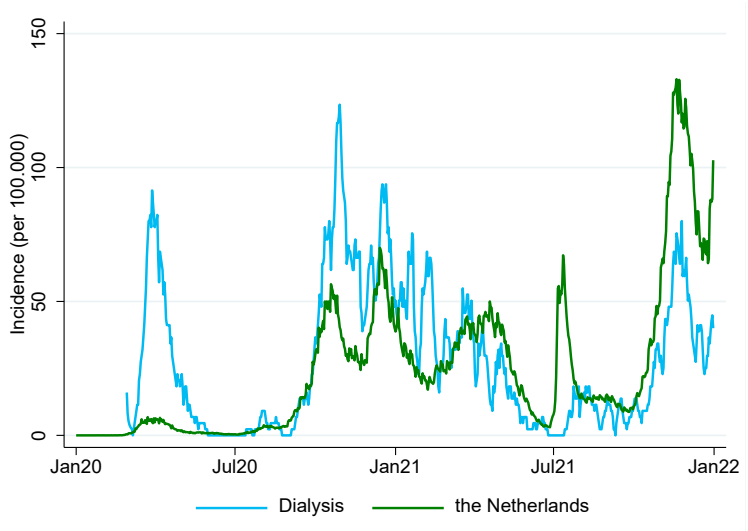

Figure 8.1. Covid-19 incidence in the dialysis population and in the Netherlands. Incidence is shown per 100,000 persons. For the dialysis population 7-day moving averages are shown.

In Table 8.1 the number of Covid-19 events in dialysis patients and the outcomes after an event are shown separately for different periods. During the first wave, the fatality was very high, about a third of all patients diagnosed with Covid-19 died within 28 days after the diagnosis. However, also in the later stages of the pandemic, severe outcomes of Covid-19 remained common. Only after the Omicron variant became dominant (December 2021), a substantial drop in hospital admissions and fatalities was observed.

Table 8.1. Incidence and outcomes of Covid-19 in 2020 and 2021 in dialysis patients

	Before July '20	July '20 – April '21	May '21 – Nov '21	Dec '21
	N (%)	N (%)	N (%)	N (%)
Incident cases	171	726	216	73
Hospital admission	101 (59%)	322 (44%)	91 (42%)	21 (29%)
Intensive care admission	5 (3%)	33 (5%)	15 (7%)	0 (0%)
Death due to Covid-19	49 (29%)	136 (19%)	36 (17%)	5 (7%)
Overall 28-days mortality	55 (32%)	157 (22%)	43 (20%)	11 (15%)

In Table 8.2 characteristics of patients diagnosed with Covid-19 in 2021 (N=579) are shown in comparison with characteristics of the overall prevalent dialysis population. Patients diagnosed with Covid-19 had a lower socioeconomic status than the overall dialysis population. In addition, diabetes as a primary kidney disease was more common in Covid-19 patients, whilst peritoneal dialysis was underrepresented. Peritoneal dialysis is a home-based treatment, which makes self-isolation easier. The low number of peritoneal dialysis patients might however also be due to less accurate registration of Covid-19 events, and especially relatively mild Covid-19 infections might have been missed. The high Covid-19 fatality rate in peritoneal dialysis patients supports this; in 2021, 31% of the peritoneal dialysis patients with Covid-19 died due to Covid-19 compared to 15% of the haemodialysis patients. It is however also possible that the high Covid-19 fatality rate that we observed is a true effect. In the ERACODA database, also a higher mortality risk was observed for peritoneal dialysis patients[1].

Table 8.2. Characteristics Covid-19 patients in 2021 compared to the prevalent dialysis population (01-07-2021)

	Covid-19 patients (N=579)	Prevalent dialysis patients (N=6,403)	P-value*
Modality, peritoneal dialysis	49 (8%)	1,020 (16%)	<0.001
Dialysis vintage			0.24
< 2 yrs	257 (44%)	2,981 (47%)	
2-5 yrs	182 (31%)	2,065 (32%)	
>5 yrs	140 (24%)	1,357 (21%)	
Sex, male	333 (58%)	3,837 (60%)	0.26
Age			0.24
< 45 yrs	55 (10%)	563 (9%)	
45-64 yrs	148 (26%)	1,783 (28%)	
65-74 yrs	147 (25%)	1,761 (28%)	
≥75 yrs	229 (40%)	2,296 (36%)	
Socioeconomic status*			0.03
Low	323 (56%)	3,201 (50%)	
Middle	152 (26%)	1,811 (29%)	
High	103 (18%)	1,338 (21%)	
Primary kidney disease			0.01
Glomerulonephritis/sclerosis	48 (8%)	722 (11%)	
Diabetes	157 (27%)	1,378 (22%)	
Hypertension/renal vascular	156 (27%)	1,741 (27%)	
Other	218 (38%)	2,562 (40%)	

*P-value for difference between groups in distribution, tested with Chi-square.

[1] Abrahams AC, Noordzij M, Goffin E, et al. Outcomes of COVID-19 in peritoneal dialysis patients: A report by the European Renal Association COVID-19 database. Perit Dial Int. 2023;43(1):23-36.

Because of the observed high risk for detrimental outcomes, dialysis patients were given priority in the vaccination program. Most dialysis patients received their first dose of the vaccine before April 2021. The vaccination program for dialysis patients included an extra dose during the last quarter of 2021. Figure 8.2 provides an overview of the cumulative numbers of Covid-19 vaccinations as registered in Renine. The dialysis centres provided the first and second doses to their patients. However, the third dose was not provided by the dialysis centres but by the municipal health service (GGD), resulting in a less accurate registration.

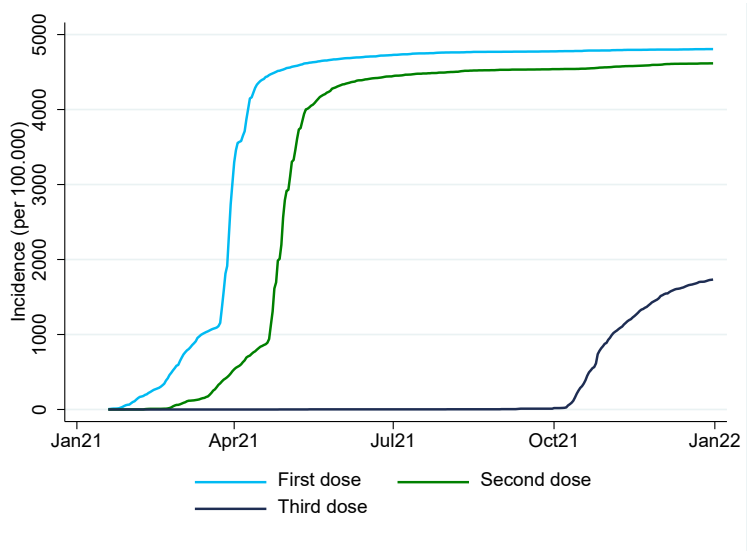

Figure 8.2. Covid-19 incidence in the dialysis population and in the Netherlands. Incidence is shown per 100,000 persons. For the dialysis population 7-day moving averages are shown.

In Table 8.3 the vaccination status of the prevalent dialysis population (reference date December 31st 2021) is shown. Vaccination status is unknown for 30% of the dialysis patients. Based on the population with known vaccination status, the vaccination rate was 93% on December 31st 2021. Most patients received the vaccine of Moderna.

Table 8.3. Vaccination status of the prevalent dialysis population on December 31st 2021

	Vaccinated#		Not vaccinated		Status unknown	
	N	%	N	%	N	%
Number of dialysis patients	4,074	65%	329	5%	1,845	30%
Vaccine type						
BioNTech-Pfizer	1,076					
Moderna	2,617					
AstraZeneca or Jansen	98					
Unknown	283					

Received at least the first dose of the vaccine.

Vaccination rates are slightly lower in younger patients and in patients with a low socioeconomic status (Table 8.4).

Table 8.4. Vaccination rate. Reference data December 31th 2021

	Vaccination rate
Total dialysis population	93%
Age categories	
<65 yrs	90%
65-74 yrs	94%
>= 75 yrs	94%
Men	93%
Women	91%
Haemodialysis	93%
Peritoneal dialysis	93%
Socioeconomic status	
Low	90%
Middle	95%
High	94%

Table 8.5 shows the outcomes of Covid-19 infections according to vaccination status in the period May 2021-November 2021. During this period, 215 Covid-19 events were registered. In the vaccinated patients, outcomes were less severe than in unvaccinated patients or in the group with unknown vaccination status. Events in December 2021 were excluded from this analysis because of the emergence of the less severe Omicron variant.

Table 8.5. Outcomes of Covid-19 during May-November 2021, stratified for vaccination status at time of the Covid-19 infection

	Vaccinated* N=125 (58%)	Not vaccinated N=32 (15%)	Vaccination status unknown N=58 (27%)	P-value**
Hospital admission	41 (33%)	18 (56%)	32 (55%)	0.004
Intensive care admission	9 (7%)	3 (9%)	3 (5%)	-
Death due to Covid-19	13 (10%)	7 (22%)	16 (28%)	0.01
Overall 28-days mortality	16 (13%)	8 (25%)	19 (33%)	0.005

*Date of first dose of the vaccine was ≥14 days before Covid-19 diagnosis.

**Differences between groups were tested with Chi-square. Intensive care admissions were not tested for significance because of the low numbers.

Survival analysis was performed in the prevalent dialysis population on May 1st of 2021. These patients were followed for Covid-19 infections and detrimental Covid-19 outcomes until November 2021. Dialysis patients who received at least one vaccine dose had a lower risk to get Covid-19 than unvaccinated patients did. This protection remained after adjusting for age, sex and socio-economic status. In addition, vaccination gave strong protection against hospital admissions and death due to Covid-19. Overall mortality was also lower after vaccination.

Table 8.6. Hazard ratios (95%-confidence intervals) for vaccinated[#] dialysis patients compared to not vaccinated patients.

	Number of events	HR crude	HR adjusted[##]
Covid-19 diagnosis	147	0.36 (0.24-0.54)	0.35 (0.23-0.54)
Hospital admission due to Covid-19	57	0.25 (0.14-0.46)	0.25 (0.13-0.46)
Intensive care admission due to Covid-19	12	0.24 (0.07-0.90)	0.26 (0.07-0.98)
Death due to Covid-19	18	0.13 (0.05-0.33)	0.12 (0.05-0.32)
All –cause mortality	366	0.78 (0.55-1.10)	0.68 (0.48-0.97)

Dialysis patients who received at least one dose on the reference data. Follow-up ended at November 30th 2021.
Adjusted for age, sex and socio-economic status (3 categories).

9 Renal transplantations

The number of prevalent patients living with a functional renal transplant shows a steady increase over time (Figure 9.1). On December 31st 2021, 11,858 prevalent transplant patients were registered in Renine, which equals 65% of all patients on renal replacement therapy. The majority of the patients (54%) have a transplant from living donors (Figure 9.2).

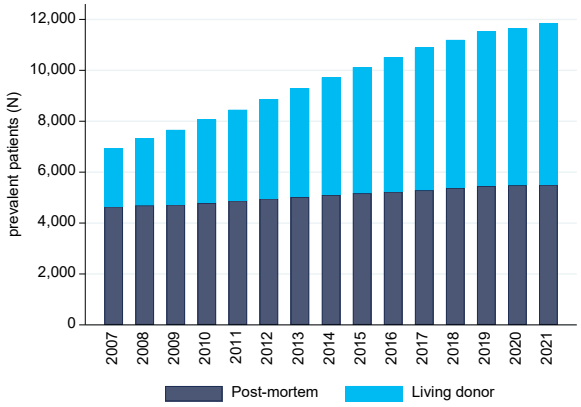

Figure 9.1. Number of prevalent patients according to donor type.

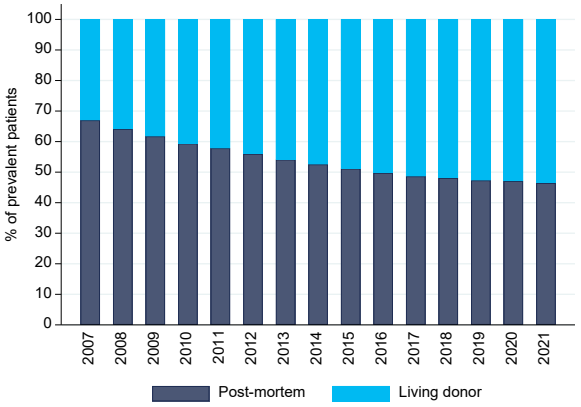

Figure 9.2. Percentage of prevalent transplant patients according to donor type.

The prevalent transplant population consists of a growing proportion of elderly patients (Figure 9.3). Elderly patients more often have a transplant from a post-mortem donor compared to younger patients (Figure 9.4).

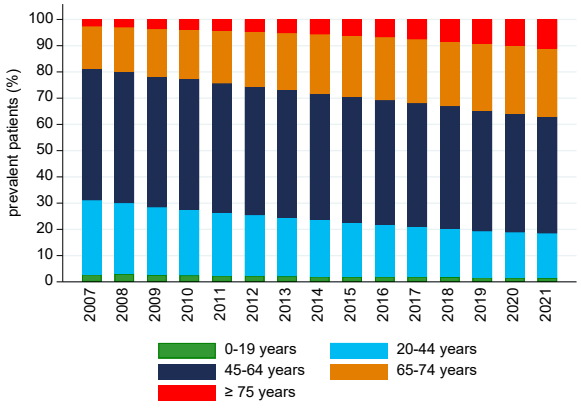

Figure 9.3. Prevalent transplant patients stratified for age categories

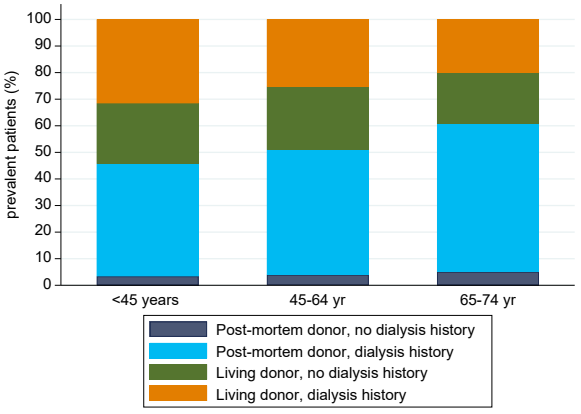

Figure 9.4. Distribution of renal transplant types in age categories in prevalent patients in 2021.

In 2021, 874 renal transplants were registered, an increase of 11% compared to 2020. The number of transplants in 2020 was however lower than usual due to the Covid-19 pandemic. Compared to 2019 the total number of transplantations dropped by 4%. In 2021, 29% of renal transplants were pre-emptive. The increase in the number of pre-emptive transplants has stagnated (Figure 9.5). In Figure 9.6, transplantations are grouped into four categories, based on donor type and whether or not the patient had a dialysis history. Compared to five years ago, the number of living donor transplantations in patients with a dialysis history is substantially lower (-32%), whilst living donor transplantations in patients without previous dialysis remained constant (-3%).

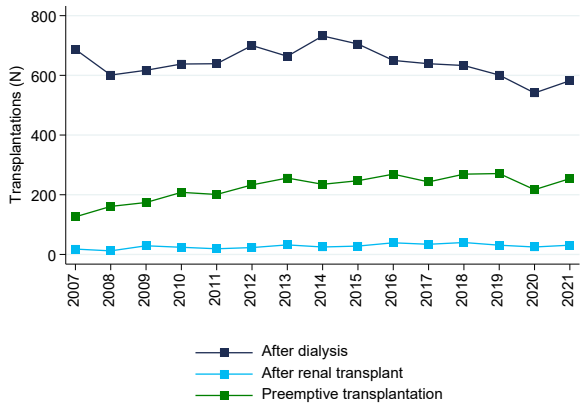

Figure 9.5. Transplantations according to preceding therapy.

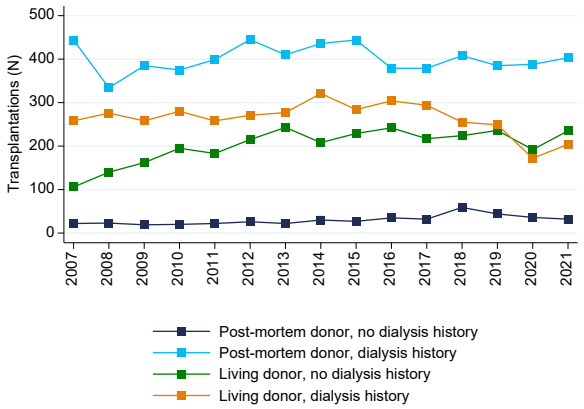

Figure 9.6. Number of different types of renal transplantations over time.

Most of the transplantations, living and post-mortem combined, are in the age category 45-64 years. The numbers are low but increasing in 75-plus patients. In 2021, 41 transplantations in this age category were registered (Figure 9.7).

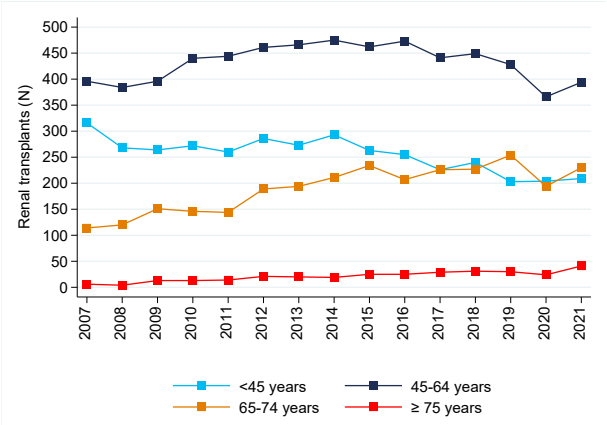

Figure 9.7. Number of renal transplantations by age categories.

Substantial variation between centres exists in the proportion of incident patients starting RRT therapy by means of a pre-emptive renal transplant (Figure 9.8). Figure 9.9 shows centre variation in the percentage of prevalent dialysis patients that received a renal transplant in 2021. In these analyses, patients aged 18-75 years were included.

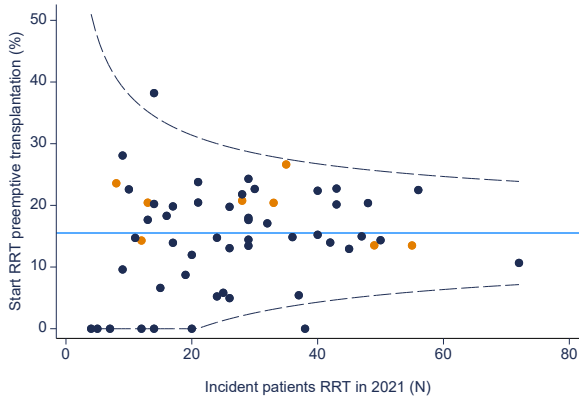

Figure 9.8. Centre variation in percentage pre-emptive transplantations in incident RRT patients in 2021. Adjustments were performed for age, sex, SES, and primary kidney disease categories. The academic medical centers are marked in orange.

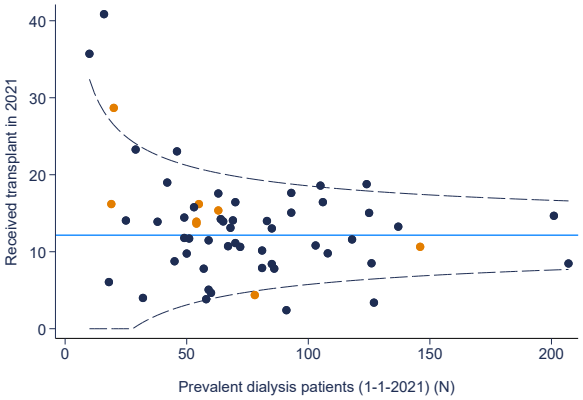

Figure 9.9. Centre variation in percentage of prevalent dialysis patients on January 1st that received a transplant in 2021. Adjustments were performed for age, sex, SES, and primary kidney disease categories. The academic medical centers are marked in orange.

Figure 9.10 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 downward trend for post-mortem transplantations. The median time is no longer decreasing for post-mortem transplants.

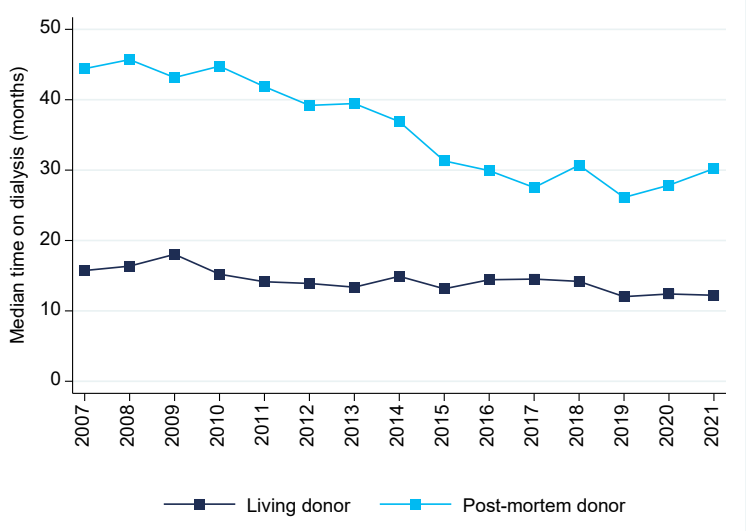

Figure 9.10. Time on dialysis in months in recipients of post-mortem and living donor renal transplants.

10 Conclusions

More than 18,000 patients in the Netherlands are on renal replacement therapy and this number is steadily growing. This increase is the result of a growing population of renal transplantation patients, whilst the number of dialysis patients remains stable at around 6,000 patients.

In 2020, the impact of the Covid-19 pandemic was severe. Especially during the first wave, the number of transplantations dropped dramatically and high Covid-19 fatality rates for dialysis patients were observed. The situation improved substantially in 2021, most importantly because vaccines became available early in the year. The vaccination rate is high in the dialysis population and the vaccines turned out to substantially protect dialysis patients against infection and severe outcomes. In 2021, the number of renal transplantations returned to normal. Despite these positive developments, the impact of Covid-19 was still substantial in 2021 and the vaccination programme remains crucial. It should be further investigated whether Covid-19 is more severe in peritoneal dialysis patients or whether the observed association is biased by differences in the registration of events.

The incidence of renal replacement therapy steadily decreased over the years for the oldest age category, i.e. 75-plus. In 2021, we also observed (for the first time) a slight decrease in the prevalence of renal replacement therapy for this age category. The number of renal transplants in 75-plus patients is still low but does show an increasing trend. Also in the age category 65-74 years, an upward trend in renal transplantations is observed. Another important positive development is that the time on dialysis preceding a renal transplant decreased over the years.

The proportion of dialysis patients treated with a home-based dialysis modality, i.e. peritoneal dialysis or home haemodialysis, is stable at around 20%. However, the percentage in prevalent 75-plus patients is increasing and in this age group also an increase in incidence is seen.

Mean haemoglobin levels decreased over the years, probably due to lower targets recommended in the national guideline of 2015. The increase in mean ferritin level over time might reflect a higher target level following publication of the results of the PIVOTAL trial[1,]

Phosphate levels are relatively well controlled in older dialysis patients. The percentage of phosphate measurements below 1.8 mmol/L is substantially higher than in younger patients. Differences in nutritional status and (adherence to) treatment might contribute to these observed differences. In addition, substantial centre variation in mean phosphate levels exists, which should be further explored.

1 Macdougall et al. Intravenous iron in patients undergoing maintenance hemodialysis. N Eng J Med 380;5:447-458.

Appendix A Methods and definitions

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. The coverage ratio in 2021 was 96% for the prevalent patients and 92% for incident patients. Data on renal transplantations are provided by the 'Nederlandse Transplantatie Stichting' (NTS).

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
Survival was analysed from day 1 of chronic dialysis treatment or a renal transplant. Subjects were censored in case of recovery of renal function, loss to follow-up or end of follow-up time (December 31th 2020). In some analyses follow-up time was additionally censored at a renal transplantation. Kaplan-Meier estimates were used for unadjusted survival estimates. Cox-regression analysis was used to apply adjustments for case-mix.

Funnel plots
Funnel plots present centre variations. 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
	79	Renal vascular disease-classified
Diabetes, type 1	80	Type I Diabetes Mellitus

Category	ERA code	Primary renal disease
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
	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

Category	ERA code	Primary renal disease
	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
	68	Malignant disease: lymphoproliferative disorders except those of 66
Other	12	Hyperkalaemia
	13	Haemorrhagic pericarditis
	17	Hypokalaemia
	21	Pulmonary embolus

Category	ERA code	Cause of death
	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)
	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

S. van den Berg, representative V&VN

Prof. dr. S.P. Berger, internist-nephrologist, representative LONT

Prof. dr. W.J. Bos, internist-nephrologist

Dr. M. van Buren, internist-nephrologist

Dr. M.A.G.J. ten Dam, internist-nephrologist, Executive director Nefrovisie

Dr. B. van Dam, internist-nephrologist, representative Guidelines Division NFN

Prof. dr. F.W. Dekker, epidemiologist LUMC

Dr. H. van Hamersvelt, internist-nephrologist, representative Guidelines Division NFN

J. Hart, representative V&VN

Prof. dr. M.H. Hemmelder, internist-nephrologist, chair “Sectie Registratie” NFN

Dr. M. Ho-dac, director of the Dutch Kidney Patient Association

Dr. T. Hoekstra, Nefrovisie

Drs. L. Heuveling, Nefrovisie

Dr. H. de Jong, pediatric nephrologist

W. Konijn, representative of the Dutch Kidney Patient Association

Dr. W. Michels, internist-nephrologist

Dr. V.S. Stel, epidemiologist, ERA-registry

Dr. A. de Vries, internist-nephrologist, representative LONT