Nefrovisie

Nefrodata annual report 2023

Includes data until December 31st 2022

Nefrovisie

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 Nefrodata Annual Report 2023. Nefrodata is the Dutch renal registry. All dialysis centres in the Netherlands provide data to Nefrodata. Recently the name of the registry changed from Renine into Nefrodata. The coverage rate of Nefrodata is 96% for the prevalent patients and 92% for incident patients. Data on renal transplantations are provided by the ‘Nederlandse Transplantatie Stichting’ (NTS).

Shortly after the start of the Covid-19 pandemic in spring 2020 it was decided to collect data on Covid-19 events in the dialysis population. The registration was later on expanded with data on vaccinations. Data was collected until December 2022. This registration has been proven very useful in managing the challenges brought about by the pandemic.

Several measures are being taken to ensure a high quality of the data. Dialysis centres checked and approved their data until December 31st 2022. Nefrovisie performs data verification visits of the dialysis centres at 3-year intervals.

Data from Nefrodata 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 the insight into renal care. Data from Nefrodata is interactively available at www.nefrodata.nl. In this report, we provide additional analyses of the data up to 2022.

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 2022

In this chapter, an overview is provided of the prevalent and incident renal replacement therapy populations in 2022. 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 2022. Reference date for prevalence: December 31st 2022*

	N	%	Change from 2021
Prevalence*			
Renal replacement therapy	18,214		+1%
Dialysis	6,183	34%	-2%
Renal transplant	12,031	66%	+3%
Incidence*			
Renal replacement therapy	1,895		-2%
Dialysis	1,625	86%	-3%
Renal transplant	270	14%	+6%

*253 prevalent dialysis patients and 132 incident RRT patients did not provide consent for their data to be included in Nefrodata. The coverage in 2022 was 96% and 92% respectively.

Table 2.2. Characteristics prevalent dialysis patients (December 31st 2022), N=6,183

	N	%
Sex, male	3,726	60%
Age (yrs), mean (SD)	67 (15)	
Dialysis modality		
Haemodialysis	5,222	84%
Peritoneal dialysis	961	16%
Primary kidney disease		
Glomerulonephritis/sclerosis	724	12%
Pyelonephritis	280	5%
Polycystic kidney disease	321	5%
Hypertension	1,086	18%
Renal vascular disease	479	8%
Diabetes type 1	164	3%
Diabetes type 2	1,140	18%
Miscellaneous	1,234	20%
Unknown	755	12%
Time on RRT (yrs), median (Q1-Q3)	2.7 (1.1-5.9)	
Time on dialysis (yrs), median (Q1-Q3)	2.3 (1.0-4.5)	
History renal transplantation	753	12%
First chronic dialysis episode	5,418	88%

Table 2.3. Characteristics prevalent transplant patients (December 31st 2022), N=12,031

		%
Sex, male	7.339	61%
Age (yrs), mean (SD)	58 (15)	
Living donor	6,501	54%
Post-mortem donor	5,521	46%
Transplant number		
First	10,371	86%
Second	1,380	11%
Third or higher	280	2%
No dialysis history	3,346	28%
Primary kidney disease		
Glomerulonephritis/sclerosis	2,269	19%
Pyelonephritis	785	7%
Polycystic kidney disease	1,267	11%
Hypertension	1,120	9%
Renal vascular disease	330	3%
Diabetes type 1	497	4%
Diabetes type 2	583	5%
Miscellaneous	3,121	26%
Unknown	2,059	17%
Time on RRT (yrs), median (Q1-Q3)	11.1 (5.9-19.4)	
Years with current transplant, median (Q1-Q3)	8.3 (4.0-14.9)	

Table 2.4. Characteristics of incident RRT patients in 2022 with start modality dialysis (N=1,625)

		%
Sex, male	1,050	65%
Age (yrs), mean (SD)	64 (15)	
Modality at start RRT, at day 1		
Haemodialysis	1,275	78%
Peritoneal dialysis	350	22%
Primary kidney disease*		
Glomerulonephritis/sclerosis	177	11%
Pyelonephritis	65	4%
Polycystic kidney disease	85	5%
Hypertension	274	17%
Renal vascular disease	73	4%
Diabetes type 1	32	2%
Diabetes type 2	312	19%
Miscellaneous	387	24%
Unknown	220	14%

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

Table 2.5. Characteristics of incident RRT patients in 2022 with pre-emptive transplantation as initial therapy (N=270)

		%
Sex, male	171	63%
Age (yrs), mean (SD)	52 (16)	
Post-mortem donor	32	12%
Living donor	238	88%

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3 Renal replacement therapy: prevalence and incidence

On December 31st, 2022 18,214 prevalent patients on renal replacement therapy (RRT) were registered in Nefrodata (Figure 3.1). This equals 1,023 patients per million of the total population in the Netherlands (Figure 3.2 (left y-axis)). RRT includes both dialysis treatment and renal transplantations. RRT prevalence showed a steady increase over time, but in recent years the prevalence per million population stabilized. Incidence, i.e. the number of new patients per calendar year, remained more or less stable over the last years. In 2022, 1,895 patients started RRT (=incidence), which equals 106 patients per million population. Men are overrepresented in both the prevalent and incident RRT populations, with respectively 61% and 64% of the populations being male.

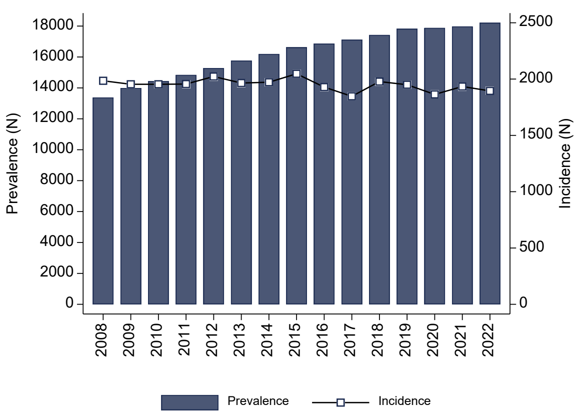


Figure 3.1. Prevalence and incidence of renal replacement therapy.

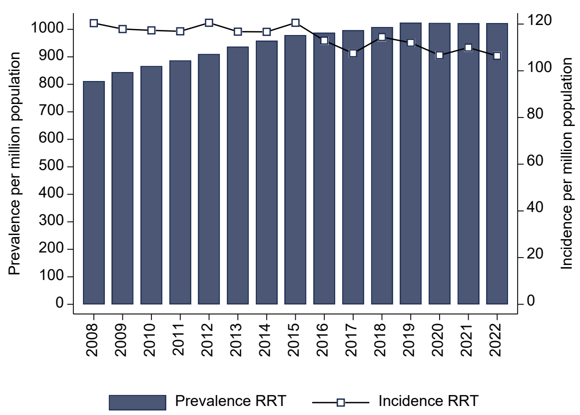


Figure 3.2. Prevalence and incidence of renal replacement therapy per million population.

The proportion of elderly patients in the prevalent RRT population increased over time (Figure 3.3). On December 31st, 2022, 46% of patients on renal replacement therapy were 65 years or older and 20% were 75 years or older. A decade ago (2012) this was 40% and 18% respectively. The mean age of the prevalent RRT population increased from 59 years (SD=16) to 61 years (SD=15) 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. However, prevalence per million population in patients 75 years and older decreased over the last years (Figure 3.4).

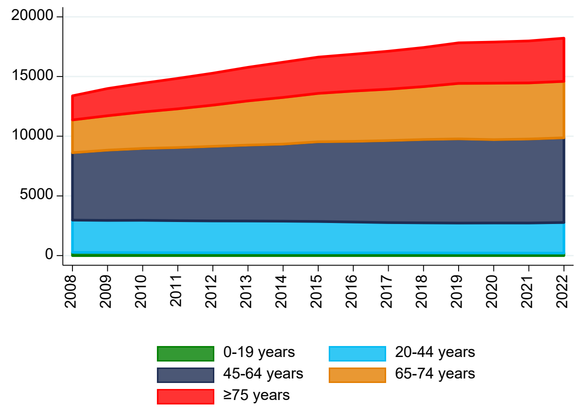


Figure 3.3. Prevalence of renal replacement therapy by age categories.

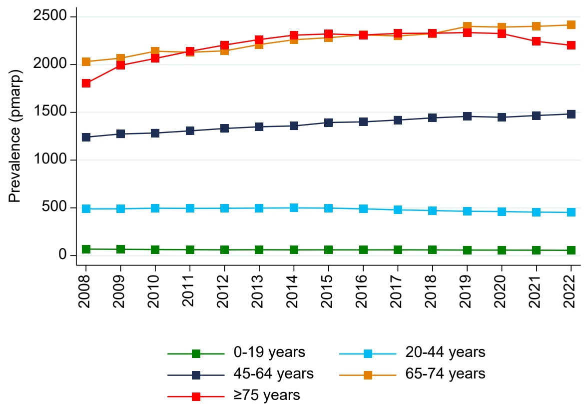


Figure 3.4. Prevalence of renal replacement therapy by age categories expressed per million age related population.

Most of the RRT patients, i.e. 66%, 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 39% in patients in patients 75 years and older. However, the absolute number of patients 75 years and older with a renal transplant is steadily growing (Figure 3.5).

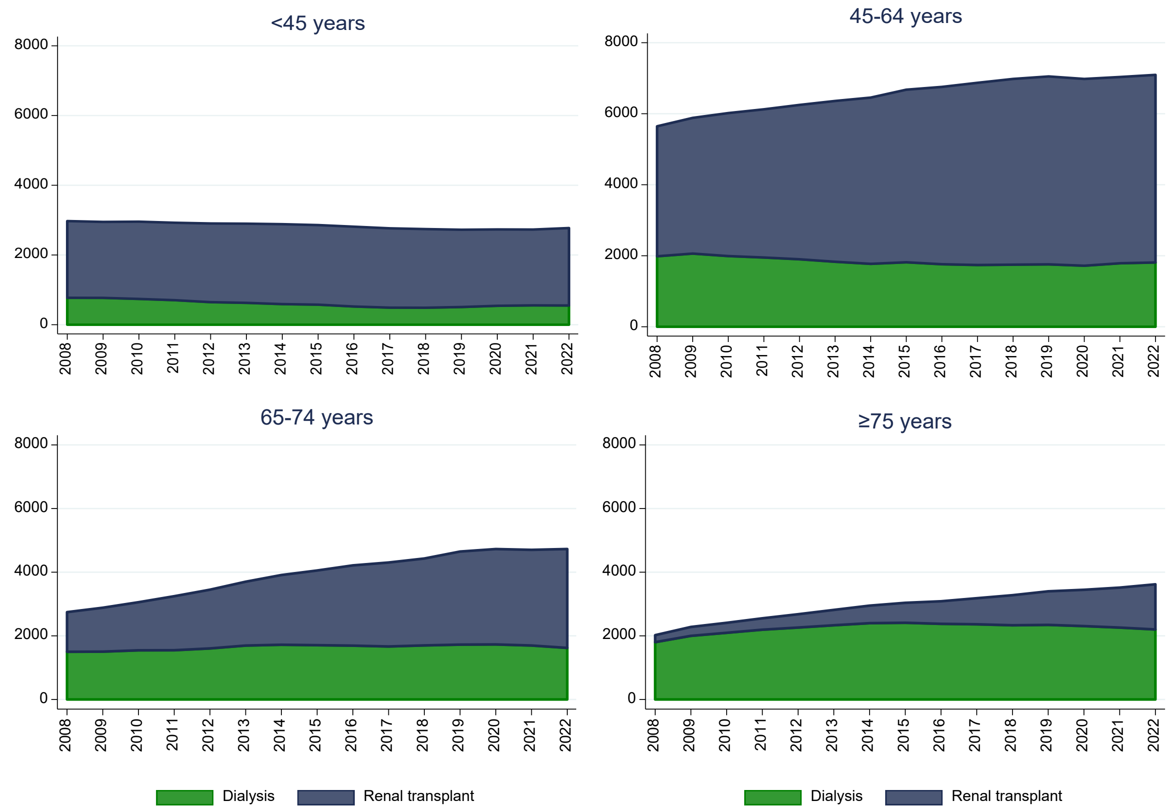


Figure 3.5. Prevalence of dialysis and renal transplants stratified by age categories

The increase in patient numbers in this age category was the highest. December 31st 2022, more than 1,400 patients in this age category were living with a renal transplant, which equals more than three times the number of patients in 2012.

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. 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 265 RRT patients per million age-related population in 2022. The highest incidence in this age category was observed in 2009, i.e. 496 per million age-related population. Possible reasons for this decrease (-47%) are improvement in chronic kidney disease care, higher mortality before the start of RRT due to comorbidities, or more frequent choice for conservative treatment. Incidence per million age related population in patients with age 75 years and older decreased by 24% over the last 15 years.

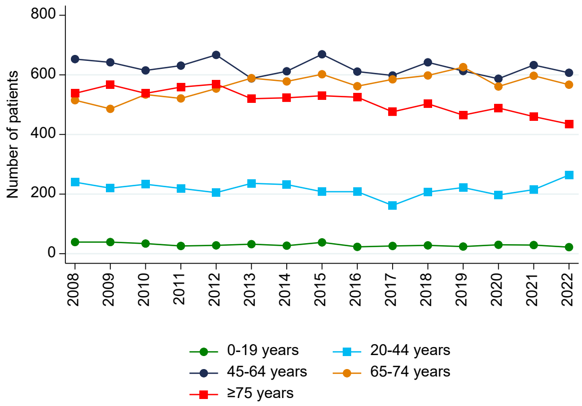


Figure 3.6. Incidence of renal replacement therapy stratified for age categories.

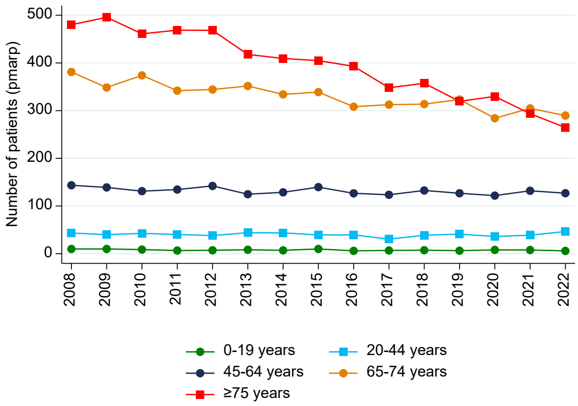


Figure 3.7. Incidence of renal replacement therapy per million age related population stratified for age categories.

Most incident RRT patients start RRT treatment by means of haemodialysis. In 2022, the distribution over the start modalities was 67% haemodialysis, 18% peritoneal dialysis, and 14% 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.

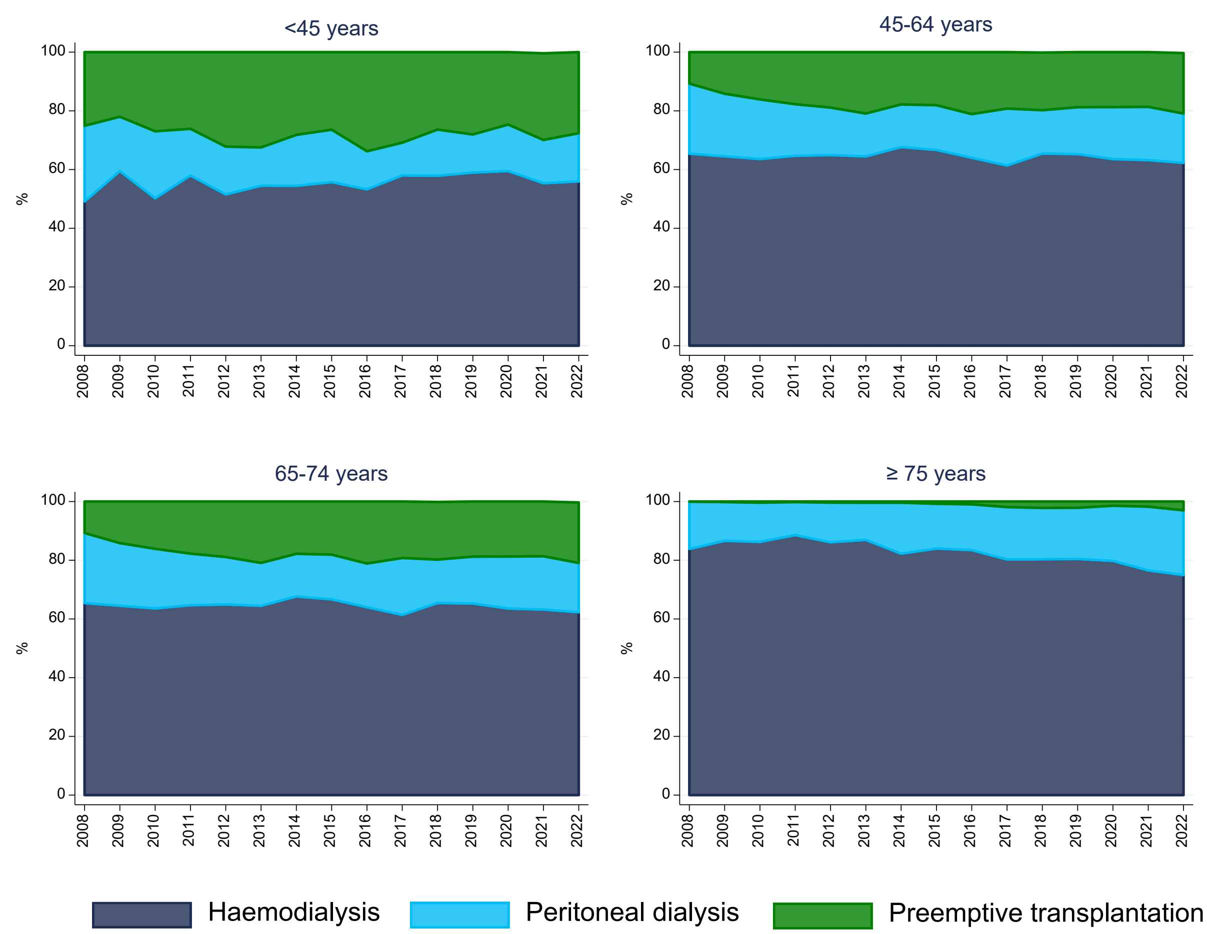


Figure 3.8. Distribution of start modalities in incident RRT patients over time stratified for age categories.

4 Survival on renal replacement therapy

In 2022, 1,217 dialysis patients died. Compared to 2021 this is an increase of 2%. The mean age at death was 74.2 years. In 2020 and 2021, this was respectively 74.1 and 73.8 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 2022, 29% of all deaths on dialysis were in this category (N=354). Covid-19 was no longer a major cause of death in dialysis patients in 2022, with 3% of all deaths registered to be due to Covid-19. In 2020 and 2021 this was 10% and 8% respectively.

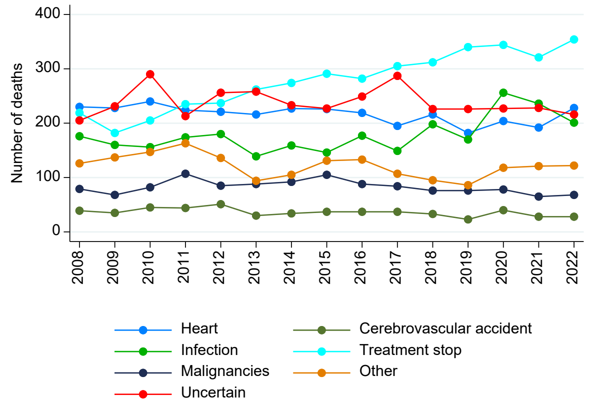


Figure 4.1. Causes of death over time.

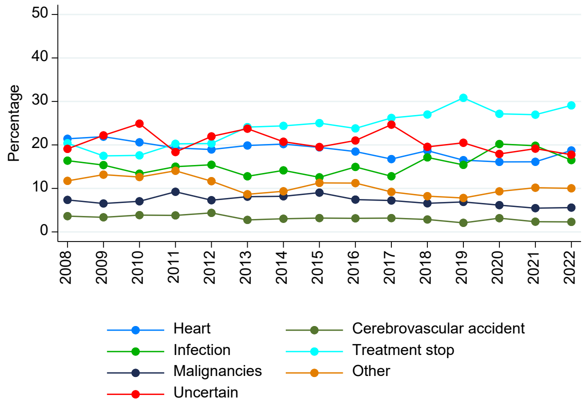


Figure 4.2. Causes of death as percentages over time.

Figures 4.3 and 4.4 show the causes of death in 2022 for dialysis patients in age categories. ‘Treatment stop’ is most common in the oldest age category.

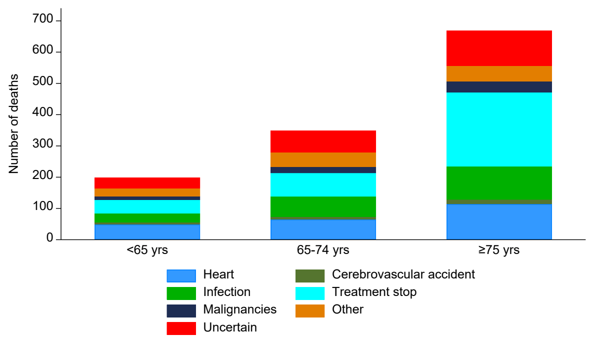


Figure 4.3. Number of deaths in 2022 in patients on dialysis in age categories.

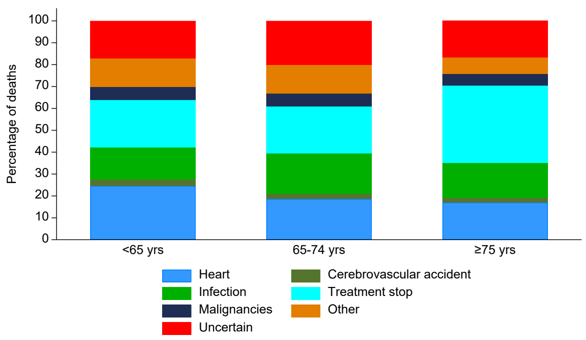


Figure 4.4. Causes of death in 2022 in patients on dialysis in age categories.

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 2013-2017**	**Cohort 2018-2021**	**Cohort 2013-2017**	**Cohort 2018-2019**
<45 yrs	98 (97-99)	97 (95-98)	94 (92-96)	92 (88-94)
45-64 yrs	92 (91-93)	93 (92-94)	79 (77-81)	78 (76-81)
65-74 yrs	85 (83-86)	86 (85-88)	62 (60-64)	62 (59-65)
≥75 yrs	79 (78-81)	82 (80-83)	48 (46-50)	48 (45-51)
Transplantation as censoring event				
Age at start	**Cohort 2013-2017**	**Cohort 2018-2021**	**Cohort 2013-2017**	**Cohort 2018-2019**
<45 yrs	98 (97-99)	97 (95-98)	92 (88-94)	88 (83-92)
45-64 yrs	92 (91-93)	93 (92-94)	75 (73-77)	75 (72-78)
65-74 yrs	85 (83-86)	86 (84-87)	58 (56-60)	59 (55-62)
≥75 yrs	79 (77-81)	82 (80-83)	47 (46-50)	48 (45-51)

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.

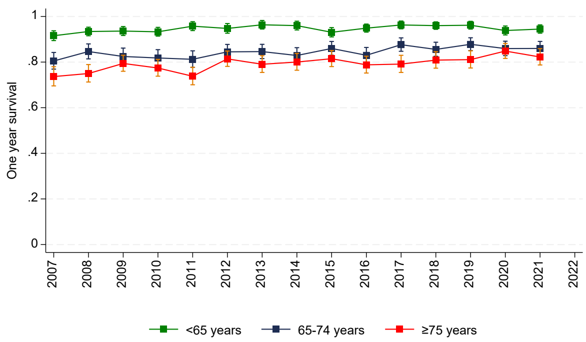


Figure 4.5. One-year survival of incident dialysis patients over the years stratified for age categories. The estimates were adjusted for age (within the age category) and sex.

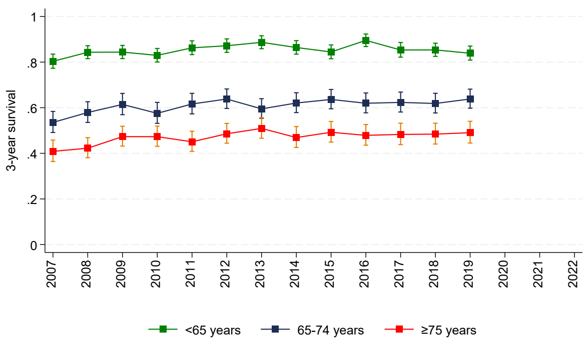


Figure 4.6. Three-year survival of incident dialysis patients over the years stratified for age categories. The estimates were adjusted for age (within the age category) and sex.

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)	97 (94-99)	99 (97-99)	92 (87-96)
45-64 yrs	95 (94-96)	91 (88-92)	93 (91-95)	86 (83-89)
65-74 yrs	93 (90-95)	81 (78-84)	78 (73-83)	69 (64-74)
≥75 yrs	74 (59-84)	76 (65-83)	67 (46-81)	57 (42-70)

Inclusion period: 2015-2019. $ Inclusion period: 2015-2017

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, socioeconomic status (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. Out of 57 centres, 3 centres had a 1-year mortality rate outside of the confidence intervals, 2 above and 1 below. Three centres had a significantly increased 3-year mortality rate and 3 centres had a lower mortality rate than the average over all centres.

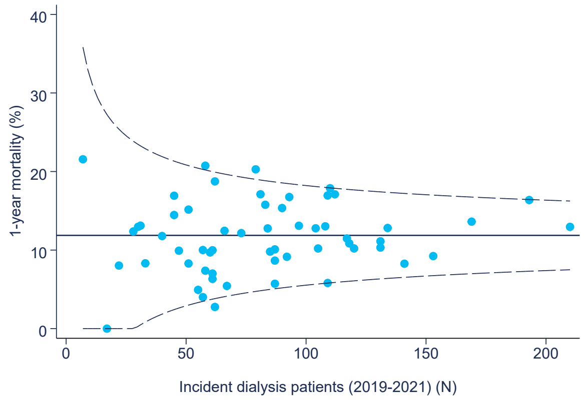


Figure 4.7. Centre variation in 1-year mortality in incident dialysis patients. Inclusion period 2018-2020. Adjustments were made for age, sex, SES, and primary kidney disease categories.

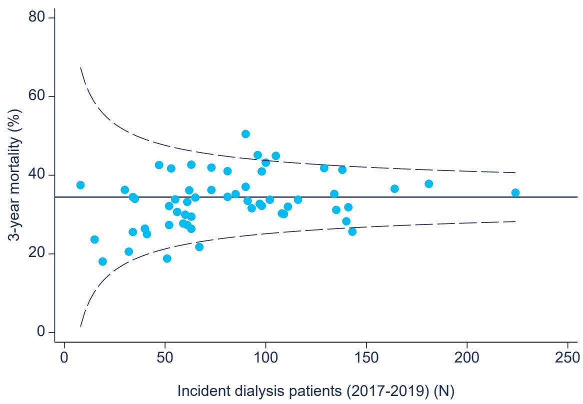


Figure 4.8. Centre variation in 3-year mortality in incident dialysis patients. Inclusion period 2015-2017. Adjustments were made for age, sex, SES, and primary kidney disease categories.

5 Dialysis treatment

Prevalence includes all patients on dialysis treatment, irrespective of their RRT history. On December 31st, 2022, 6,183 patients were on chronic dialysis treatment. In 2022 1,867 patients started chronic dialysis therapy. For the majority of these patients (i.e. N=1,669, 89%) this was their first time on chronic dialysis treatment and 198 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.

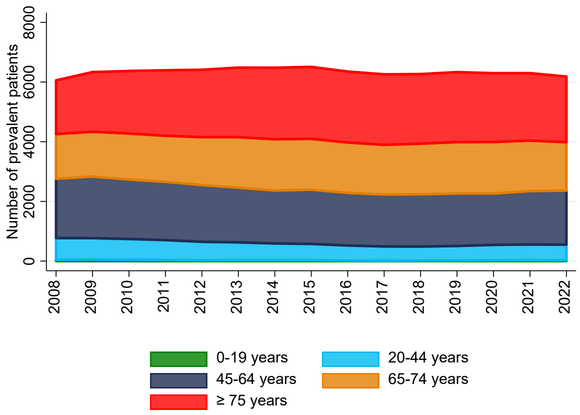


Figure 5.1. Prevalence of dialysis (December 31th) by age categories.

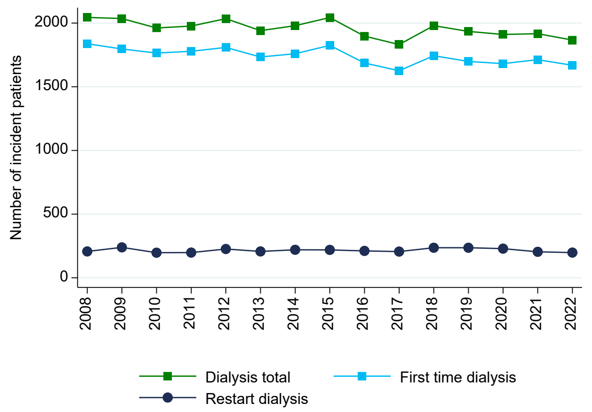
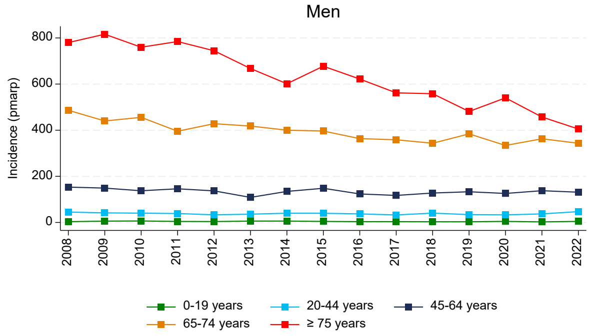


Figure 5.2. Incidence of dialysis. A distinction was made between first time chronic dialysis and patients with a dialysis history restarting chronic dialysis.

The sex-specific incidence of dialysis treatment per million age-related population is shown stratified for sex and age categories in Figures 5.3 and 5.4. Dialysis incidence in the older age categories is substantially higher in men than in women. 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.

In 2022, the incidence in 75-plus men was 2.8 times higher than in 75-plus women (405 versus 144 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]

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



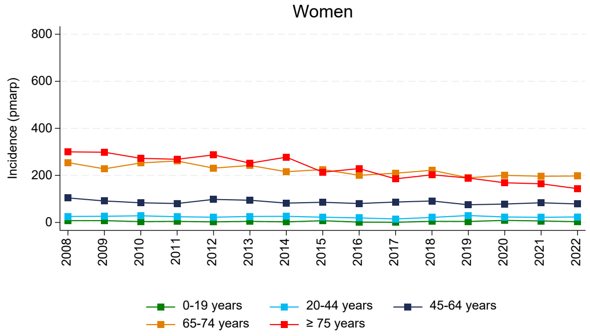


Figure 5.3. Incidence per million age related population of first-time dialysis in men stratified for age categories.

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

In 2022, 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 and the age category 45-64 years, i.e. both 22%. After a period with declining percentages of home dialysis in these age categories, these percentages stabilized in recent years. In contrast, in 75-plus patients an increasing trend in home-based dialysis modalities is observed.

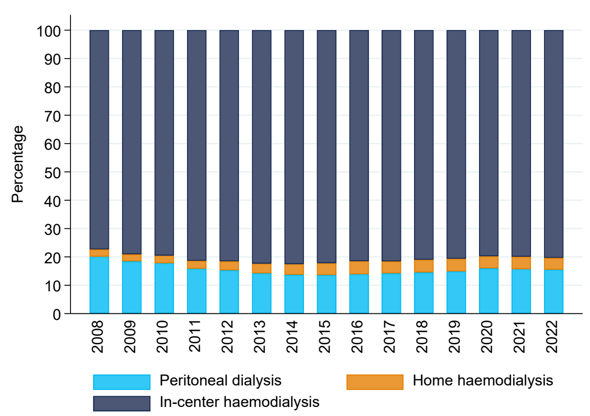


Figure 5.5. Distribution of dialysis modalities in prevalent chronic dialysis patients.

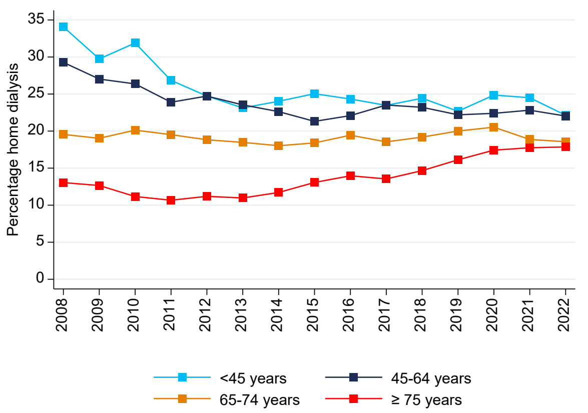


Figure 5.6. Percentage home dialysis in age categories.

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.

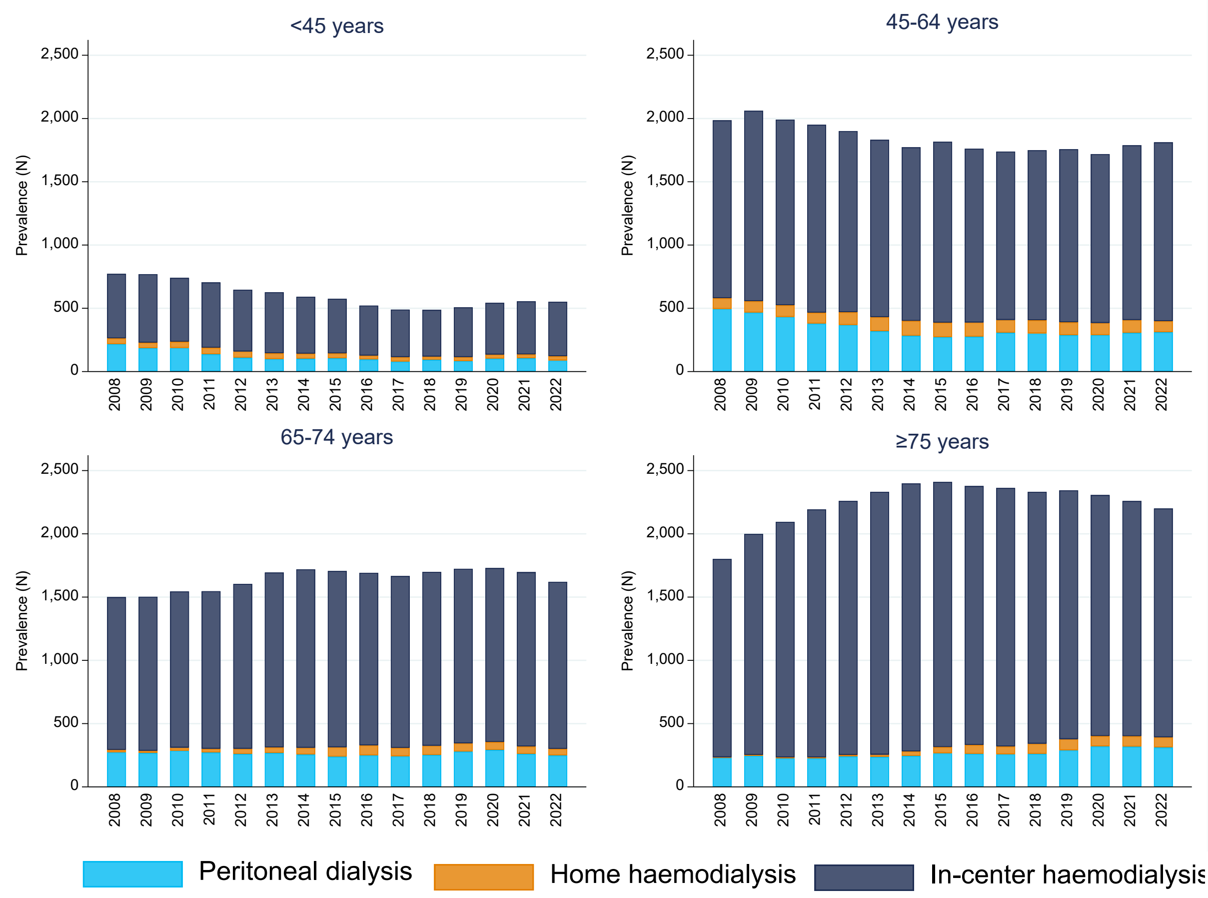


Figure 5.7. Distribution of dialysis modalities in prevalent chronic dialysis patients, stratified for age categories.

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 2022, the age difference was 2.1 years (67.0 versus 64.9 years). Up to 2017, both dialysis populations aged. However, form 2017 onwards the mean age of in-centre haemodialysis patients decreased, whilst mean age of home dialysis patients remained stable (Figure 5.8).

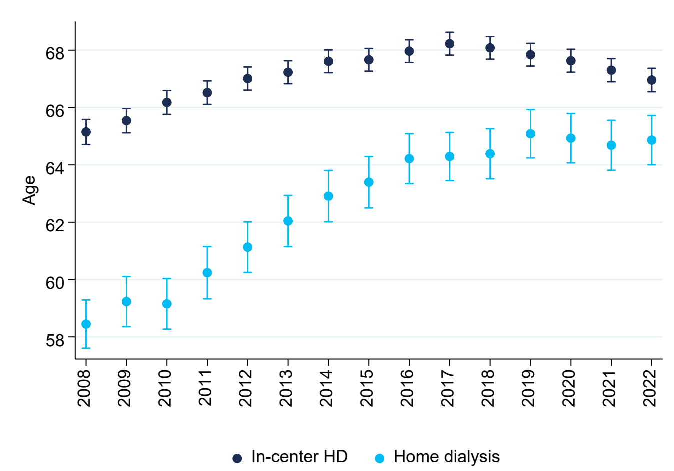


Figure 5.8. Mean age of prevalent in-center haemodialysis and home dialysis patients. Results are shown with 95%-confidence intervals.

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 just over 200 patients in 2022. 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.

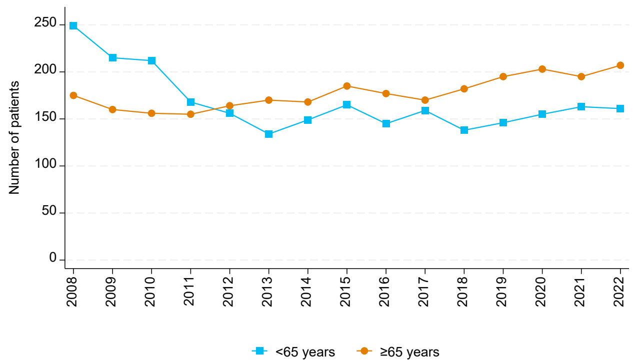


Figure 5.9. Home dialysis at 3 months after dialysis onset in patients younger and older than 65 years.

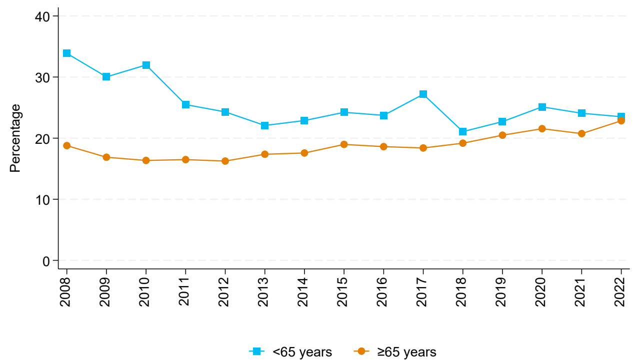


Figure 5.10. Percentage home dialysis at 3 months after dialysis onset in patients younger and older than 65 years.

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. Out of 57 centres, at 9 centres the percentage of home dialysis patients is significantly lower than average, suggesting that there might be room for improvement in facilitating home dialysis. However, more insight in the underlying reasons for the lower uptake of home dialysis in some centres is needed before firm conclusions can be drawn.

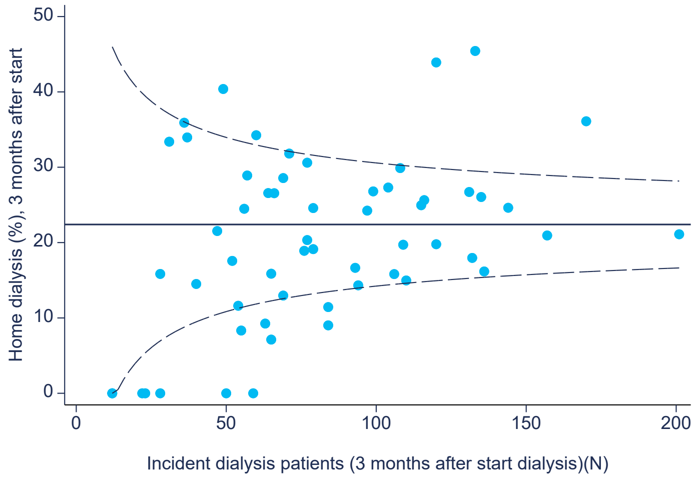
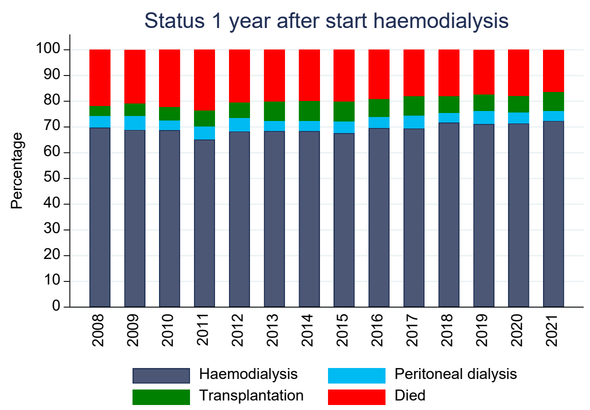


Figure 5.11. Center variation in percentage home dialysis three months after start dialysis. Home dialysis includes peritoneal dialysis and home haemodialysis. Data is adjusted for age, sex, SES, and primary kidney disease categories. Inclusion period 2020-2022.

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.



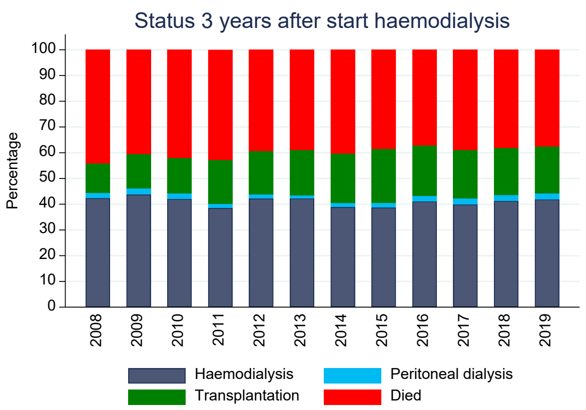


Figure 5.12. Status 1 and 3 years after start HD as percentage. The year represents the year in which HD was started.

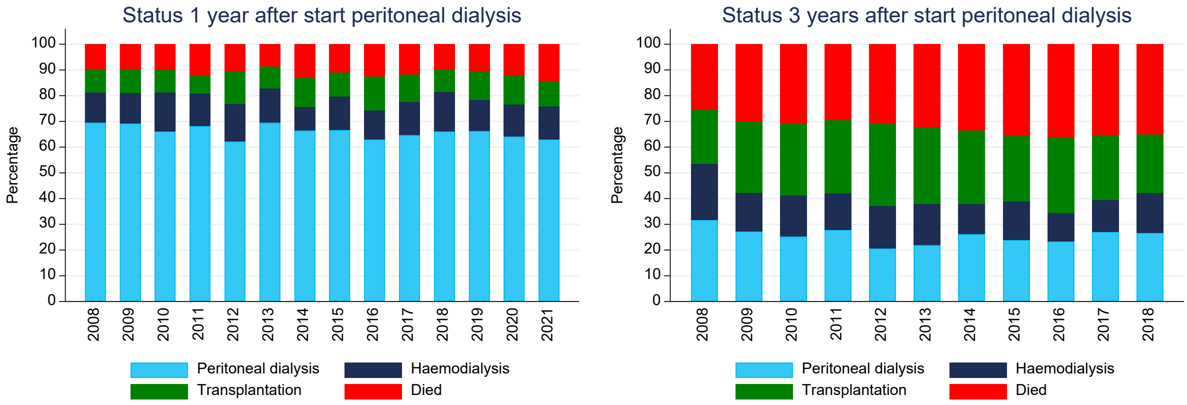


Figure 5.13. Status 1 and 3 years after start PD as percentage. The year represents the year in which PD was started.

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 2021, 72% were still on haemodialysis treatment one year later, 4% switched to peritoneal dialysis, 7% received a transplant and 16% 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 10% had a functioning renal transplant one year after they started peritoneal dialysis. After the start of peritoneal dialysis, mortality was 14% in the first year.

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.

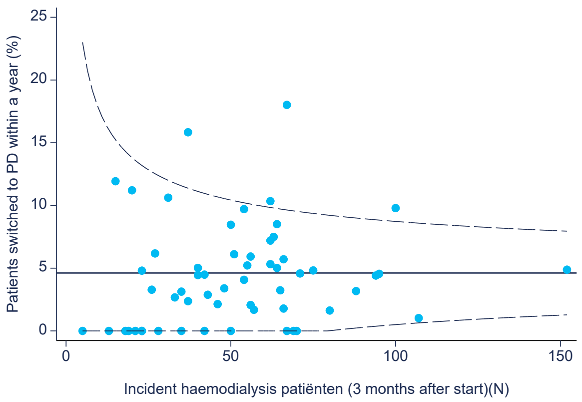


Figure 5.14. Centre variation in switches from HD to PD. Patients were included if on HD 3 months after start dialysis and still on dialysis after 1 year. Adjustments were made for age, sex, SES, and primary kidney disease categories.

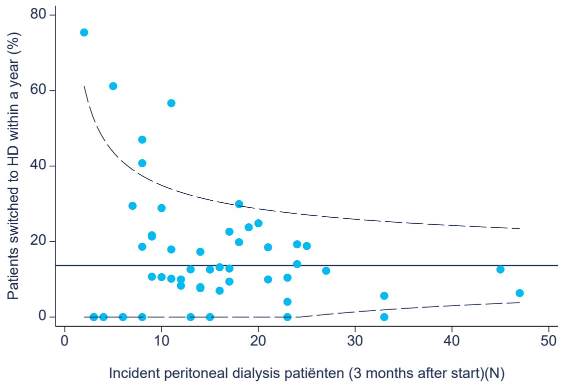


Figure 5.15. Centre variation in switches from PD to HD. Patients were included if on PD 3 months after start dialysis and still on dialysis after 1 year. Adjustments were made for age, sex, SES, and primary kidney disease categories.

6 Clinical data dialysis patients

Clinical variables, such as laboratory measurements, dialysis treatment specifics, and vascular access data for dialysis patients are recorded quarterly. A significant improvement in data completeness was observed after making registration of clinical data mandatory in 2016. Completeness is stable since 2019. In 2022, clinical data was completely lacking for 8% of the dialysis patients. For 2022 completeness of the data was 91% for phosphate levels (Figure 6.1) in dialysis patients and 94% for vascular access in haemodialysis patients (Figure 6.2).

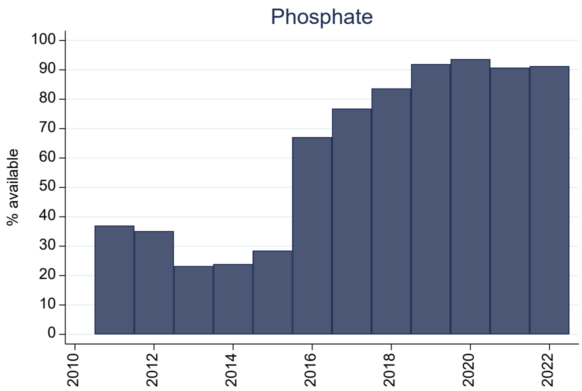


Figure 6.1. Availability of phosphate measurements per year expressed as percentage of the total number of potential measurements.

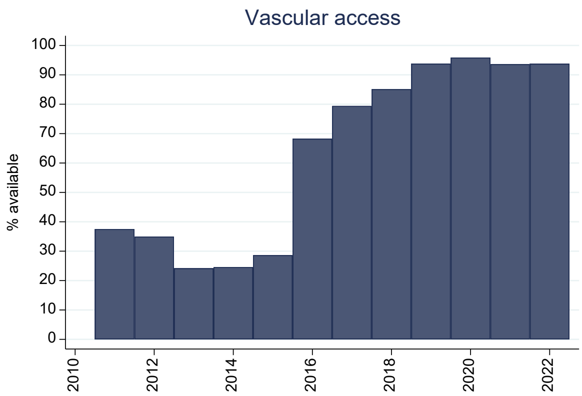


Figure 6.2. Availability of vascular access data per year expressed as percentage of the total number of potential measurements.

Figures 6.3 and 6.4 show mean haemoglobin and ferritin levels over time for dialysis patients younger and older than 65 years. 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. Since 2019, mean ferritin levels increased. This is likely an effect of the PIVOTAL trial[2], based on which the target values for ferritin increased.

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 2019;380(5):447-458.

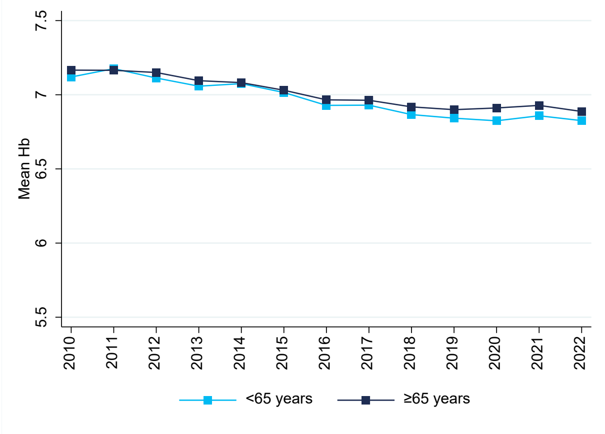


Figure 6.3. Mean hemoglobin levels per year in age categories.

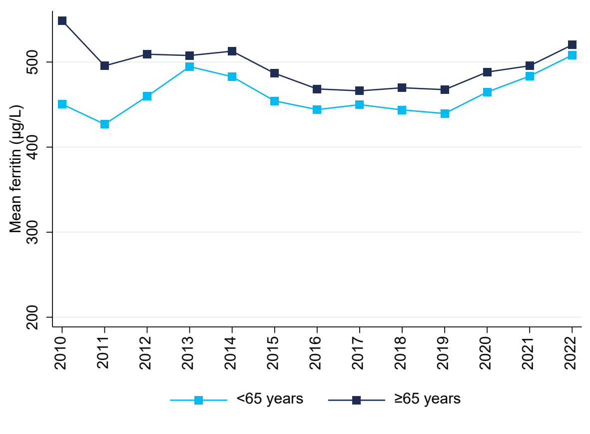


Figure 6.4. Mean ferritin levels per year in age categories.

Figure 6.5 shows mean phosphate levels over time for dialysis patients in four age categories. Trends towards a higher phosphate level over time are observed. Mean phosphate is higher for younger age categories, despite the potential benefit of achieving target levels might be greater for younger patients. In 2022, in 78% of the 75-plus patients the phosphate levels were below 1.80 mmol/L. In only 61% of the patients younger than 65 year, phosphate levels lower than 1.80 mmol/L were achieved (Figure 6.7). Differences in nutritional status and (adherence to) treatment might contribute to these observed differences. Also increased trends in PTH levels were observed over time (Figure 6.6.).

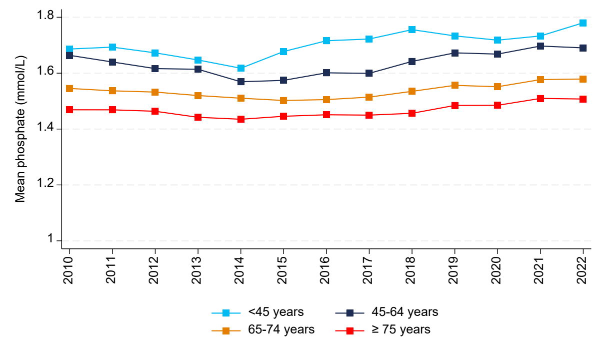


Figure 6.5. Mean phosphate levels per year in age categories.

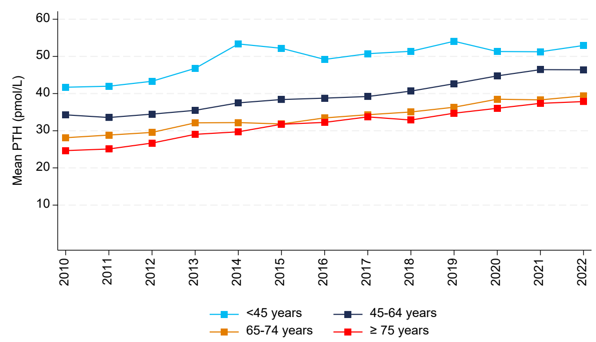


Figure 6.6. Mean PTH levels per year in age categories.

Figure 6.7. 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.

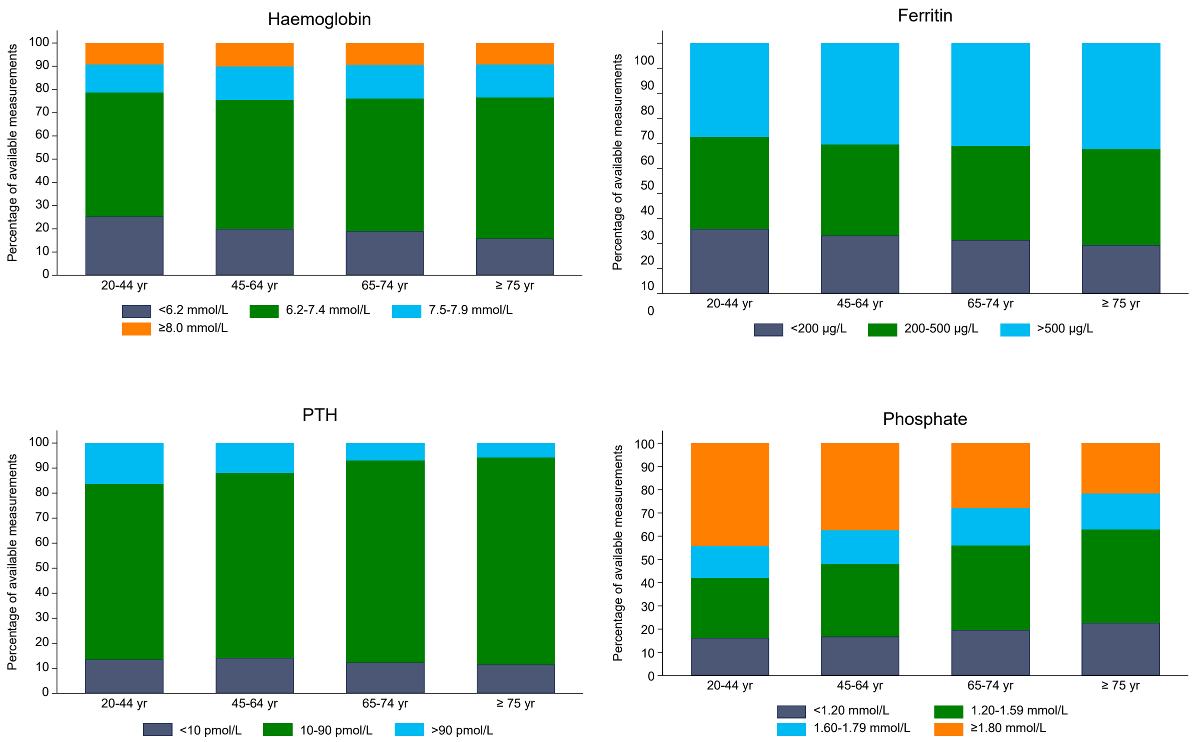


Figure 6.7. Categories of clinical variables stratified for age categories.

Substantial variation in mean values was observed across different centres as is shown in the funnel plots (Figure 6.8). This variation gives rise to further analysis whether this is due to a difference in guideline adherence.

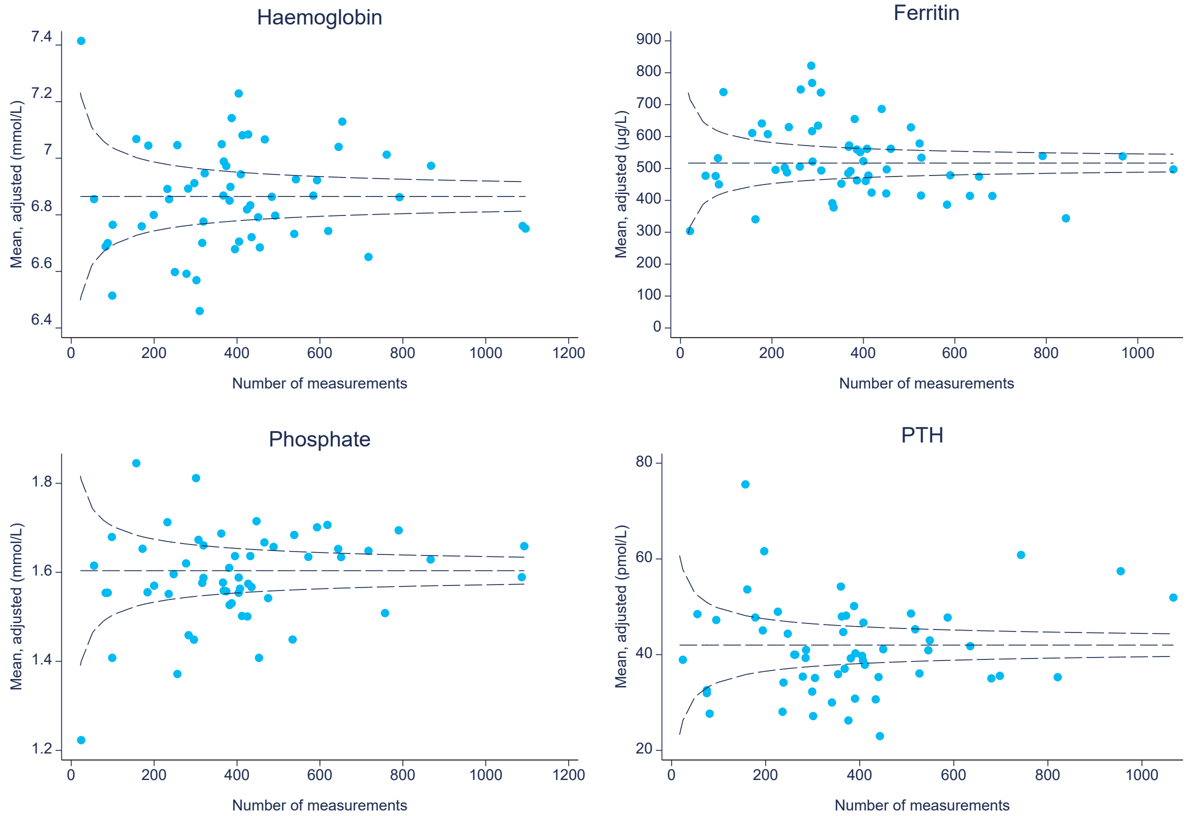


Figure 6.8. Funnel plots showing centre variation of mean values of clinical variables in 2022. The funnels were adjusted for differences in case-mix (age, gender, SES, and primary kidney disease categories).

An AV-fistula is the most common type of vascular access in prevalent haemodialysis patients. Dialysis via catheter is more common in patients younger than 45 years (34%) than in the older groups (24%) (Figure 6.9). In incident patients, a catheter is more common than in prevalent patients in all age groups (Figure 6.10).

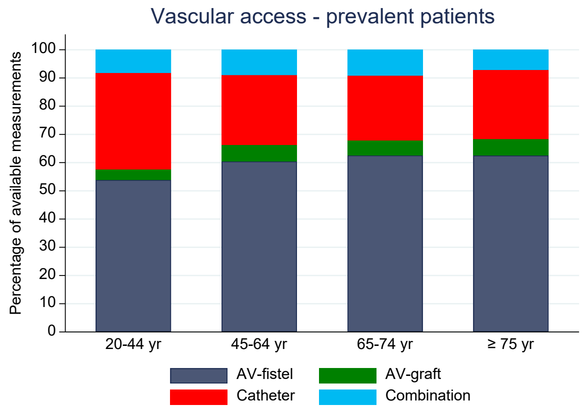


Figure 6.9. Percentages of vascular access categories in prevalent haemodialysis patients in 2022.

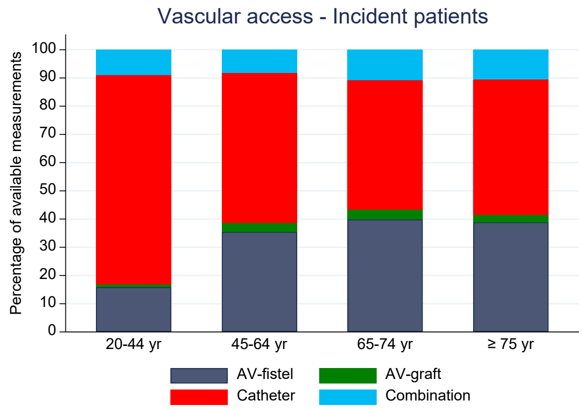


Figure 6.10. Percentages of vascular access categories in incident haemodialysis patients in 2022.

Over time a downwards trend is observed in the use of AV-fistels and an increase in catheters in both prevalent and incident haemodialysis patients (Figures 6.11 and 6.12).

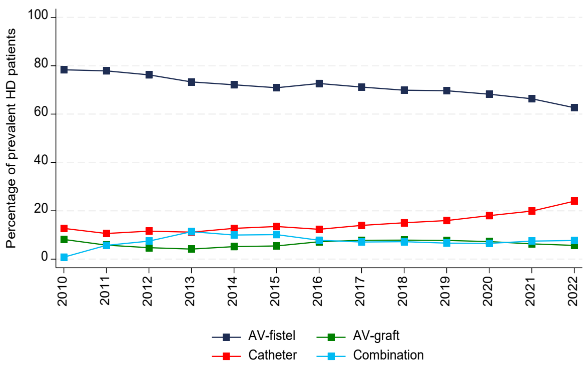


Figure 6.11. Percentages of vascular access categories in prevalent haemodialysis over time.

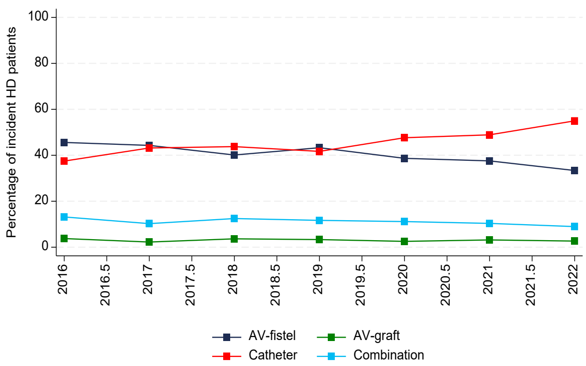
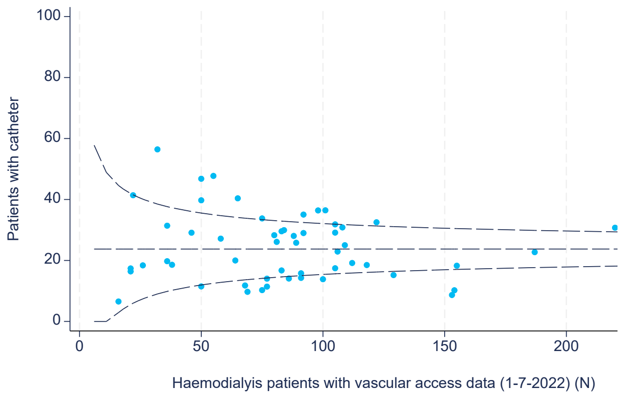


Figure 6.12. Percentages of vascular access categories in incident haemodialysis patients over time.

Figures 6.13 and 6.14 show the centre variation in the percentages of patients with a central venous catheter for prevalent and incident haemodialysis patients respectively.



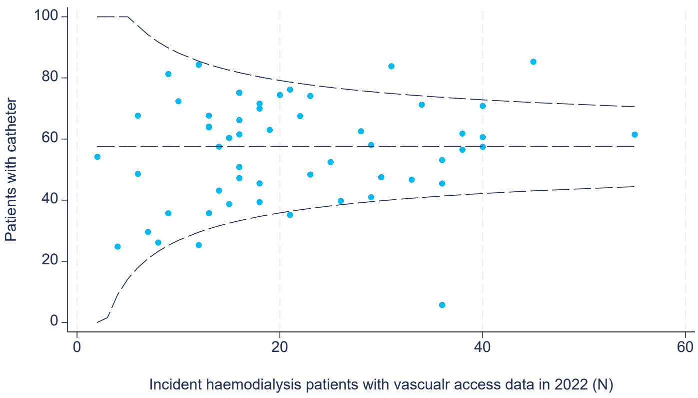


Figure 6.12. Centre variation in catheter use in prevalent haemodialysis patients. Adjustments were performed for age, sex, SES, and primary kidney disease categories.

Figure 6.13. 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 Nefrodata 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 2022, 2,825 dialysis patients, which equals 46% of the prevalent dialysis population, filled out at least one PROM. The majority (78%) filled out PROMs once during the year, for 16% (N=460) of these patients two PROMs were available in 2022. Figure 7.1 shows both the number of patients with at least 1, 2 or 3 PROMs measurements available over time. At the end of 2022, 56 out of 59 centres (=95%) participated in PROMs.

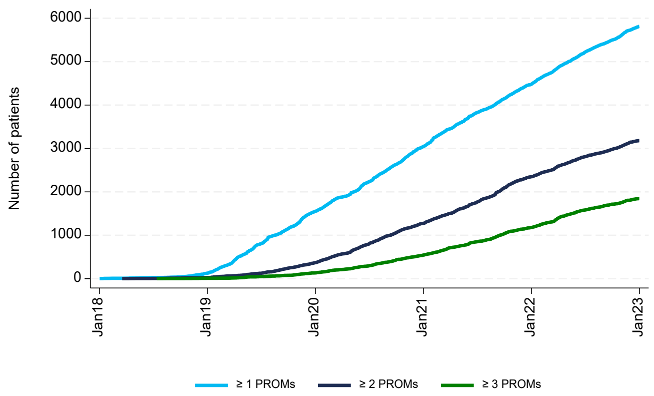


Figure 7.1. Number of patients with PROMs data available (cumulative).

The characteristics of the dialysis patients with PROMs data in 2022 are shown in Table 7.1. For comparison, characteristics of the general prevalent dialysis population are also shown. This shows that the population with PROMs data available is representative sample of the overall population.

Table 7.1. Characteristics of dialysis patients with at least one PROMs measurement available in 2022 in comparison to the overall dialysis population (reference date 01-07-2022).

	PROMS available*	Prevalent dialysis population**
N	2825	6416
Male	61%	60%
Haemodialysis	86%	84%
Age (yrs), mean (SD)	68 (13)	67 (15)
Age categories		
<45 yrs	6%	9%
45-64 yrs	28%	28%
65-74 yrs	29%	28%
≥75 yrs	36%	36%
Socio-economic status, mean (SD)	-0.04 (0.25)	-0.05 (0.25)
Dialysis vintage (yrs), median (Q1-Q3)	1.8 (0.7-3.5)	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 2022.

Figure 7.2 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 (49). The mean mental component score was 47 (SD=11). In the general Dutch population, the mean score is 50. The distribution of the mental component score in the dialysis population is skewed. The median value was 49. Women scored lower than men on the physical component score (34 versus 47 in men, P<0.001). For the mental scores, no differences were observed between the sexes.

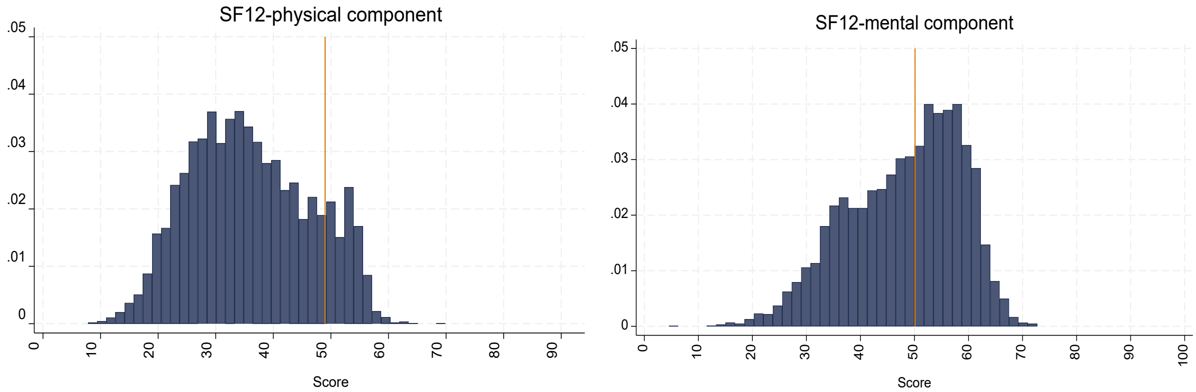


Figure 7.2. Distribution of SF-12 scores. The reference lines indicate mean scores in the general Dutch population.

Lower scores on the physical component were seen with increasing age (Table 7.2). However, an opposite trend is observed for the mental score.

Table 7.2. SF-12 scores for age categories (mean (SD)).

	PCS	MCS
<65 yrs	38 (10)*	45 (11)*
65-74 yrs	36 (10)	48 (11)*
≥75 yrs	35 (11)	49 (11)*

* Significantly different from other age categories (P<0.05).

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

Dialysis patients experienced on average 10.8 out of 30 symptoms (SD=6.1). Women reported slightly more symptoms than men (11.6 versus 10.3, P<0.001). Younger patients (<65 years) reported more symptoms than patients in the older age categories (65-74 year: 10.5 and 75 plus years: 10.6).

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. No apparent differences were observed for different age categories (data not shown).

Table 7.3. Top 10 most frequent and most burdensome symptoms

Most frequent symptoms	%	Most burdensome symptoms	Mean score#
Feeling tired/lack of energy	77%	Difficulty becoming sexually aroused	3,24
Dry skin	61%	Decreased interest in sex	3,01
Itching	53%	Trouble falling asleep	3,01
Muscle cramps	53%	Feeling tired/lack of energy	3,00
Trouble staying asleep	53%	Trouble staying asleep	3,00
Dry mouth	45%	Bone or joint pain	2,93
Bone or joint pain	44%	Dry skin	2,82
Trouble falling asleep	43%	Numbness or tingling in feet	2,80
Restless legs	41%	Itching	2,80
worry	40%	Restless legs	2,78

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

8 Covid-19 and vaccinations in the dialysis population

Shortly after the start of the Covid-19 pandemic, in spring 2020, it was decided to start collecting data on the incidence and outcomes of Covid-19 in dialysis patients. Later, this was expanded with vaccination data. Fortunately, at this stage, Covid-19 has much less of an impact on the dialysis population. The most important reason being the availability of effective vaccines and because less severe variants of the virus became dominant. These developments led to the decision to stop the Covid-19 registration in dialysis patients by the end of 2022. Overall, 2,830 Covid-19 events were registered in Nefrodata and 258 patients died due to Covid-19. In Figure 8.1 shows the course of the pandemic in the dialysis population.

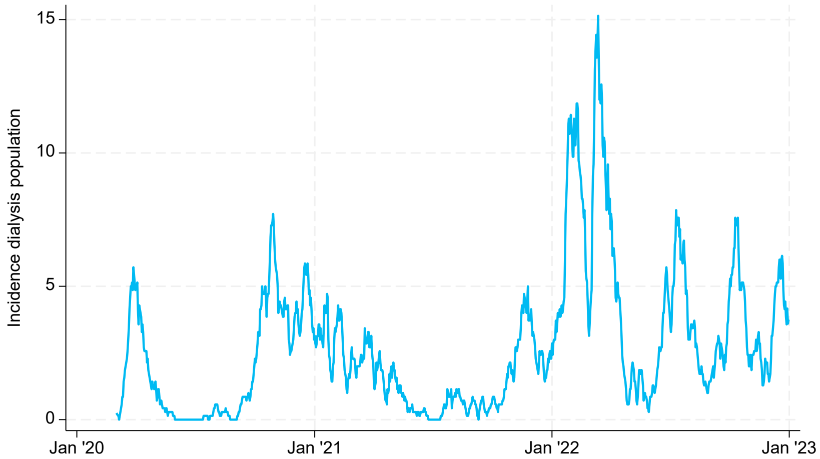


Figure 8.1. Covid-19 incidence in the dialysis population during the Covid-19 pandemic. Incidences are shown as 7-day moving averages.

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 – July '22**	**Aug '22 – Dec '22**
	N (%)	N (%)	N (%)	N (%)	N (%)
Incident cases	172	728	218	1207	505
Hospital admission	102 (59%)	323 (44%)	92 (42%)	171 (14%)	71 (14%)
Intensive care admission	5 (3%)	33 (5%)	16 (7%)	5 (0%)	4 (0%)
Death due to Covid-19	49 (28%)	139 (19%)	37 (17%)	28 (2%)	5 (1%)
Overall 28-days mortality	55 (32%)	157 (22%)	44 (20%)	63 (5%)	21 (4%)

In Table 8.2 characteristics of patients diagnosed with Covid-19 in 2022 (N=1,684) are shown in comparison with characteristics of the overall prevalent dialysis population. Peritoneal dialysis was underrepresented in the Covid-19 population. 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.

Table 8.2. Characteristics Covid-19 patients in 2022 compared to the prevalent dialysis population (31-12-2022)

	Covid-19 patients (N=1684)	Prevalent dialysis patients (N=6,183)	P-value*
Modality, peritoneal dialysis	75 (4%)	1,020 (16%)	<0.001
Dialysis vintage			0.27
< 2 yrs	795 (47%)	2,849 (46%)	
2-5 yrs	566 (34%)	2,037 (33%)	
>5 yrs	323 (19%)	1,297 (21%)	
Sex, male	1054 (63%)	3,726 (60%)	0.09
Age			0.49
< 45 yrs	145 (9%)	551 (9%)	
45-64 yrs	467 (28%)	1,811 (29%)	
65-74 yrs	443 (26%)	1,621 (26%)	
≥75 yrs	629 (37%)	2,200 (36%)	
Primary kidney disease			0.08
Glomerulonephritis/sclerosis	176 10%)	724 (12%)	
Diabetes	400 (24%)	1,304 (21%)	
Hypertension/renal vascular	409 (24%)	1,565 (25%)	
Other	699 (42%)	2,590 (42%)	

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

In Table 8.3 the vaccination status of the prevalent dialysis population (reference date December 31st 2022) is shown. Vaccination status is unknown for 42% of the dialysis patients. Based on the population with known vaccination status, the vaccination rate was 92% on December 31st 2022. Most patients received the vaccine of Moderna.

Table 8.3. Vaccination status of the prevalent dialysis population on December 31st 2022

	Vaccinated#		Not vaccinated		Status unknown	
	N	%	N	%	N	%
Number of dialysis patients	3.307	54%	278	5%	2.578	42%
Vaccine type						
BioNTech-Pfizer	942	28%				
Moderna	2.002	61%				
AstraZeneca or Jansen	101	3%				
Unknown	262	8%				

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 2022

	Vaccination rate
Total dialysis population	92%
Age categories	
<65 yrs	88%
65-74 yrs	94%
>= 75 yrs	95%
Men	93%
Women	91%
Haemodialysis	92%
Peritoneal dialysis	94%
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 vaccination was available and severe variants of the Covid-19 virus were still dominant. During this period, 217 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. The same data is provided in Table 8.6 for the period December 2021 until December 2022. During this period less severe variants of the virus (Omicron) became dominant.

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

	Vaccinated* N=124 (57%)	Not vaccinated N=32 (15%)	Vaccination status unknown N=61 (28%)	P-value**
Hospital admission	39 (31%)	18 (56%)	35 (57%)	0.001
Intensive care admission	9 (7%)	3 (9%)	4 (7%)	-
Death due to Covid-19	13 (10%)	7 (22%)	17 (28%)	0.009
Overall 28-days mortality	16 (13%)	8 (25%)	20 (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.

Table 8.6. Outcomes of Covid-19 during December 2021 – December 2022, stratified for vaccination status at time of the Covid-19 infection

	Vaccinated* N=1,039 (68%)	Not vaccinated N=98 (6%)	Vaccination status unknown N=402 (26%)	P-value**
Hospital admission	134 (13%)	38 (39%)	50 (12%)	0.001
Intensive care admission	5 (0%)	2 (2%)	2 (0%)	-
Death due to Covid-19	16 (2%)	7 (7%)	9 (2%)	0.001
Overall 28-days mortality	45 (5%)	11 (12%)	19 (5%)	0.014

*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 also performed for 2 different periods, before and after Omicron became dominant (Table 8.7 and 8.8). The population consisted of prevalent dialysis patients on the reference date with known vaccination status. These patients were followed for Covid-19 infections and detrimental Covid-19 outcomes. 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. The protection provided by vaccination was stronger in the pre-Omicron period.

Table 8.7. Hazard ratios (95%-confidence intervals) for vaccinated# dialysis patients compared to not vaccinated patients. (Reference date May 1st 2021)

	Number of events	HR crude	HR adjusted##
Covid-19 diagnosis	145	0.36 (0.24-0.55)	0.36 (0.23-0.55)
Hospital admission due to Covid-19	54	0.24 (0.13-0.44)	0.24 (0.13-0.44)
Intensive care admission due to Covid-19	12	0.25 (0.07-0.93)	0.27 (0.07-1.02)
Death due to Covid-19	18	0.13 (0.05-0.34)	0.13 (0.05-0.33)
All –cause mortality	369	0.81 (0.57-1.15)	0.71 (0.50-1.01)

Dialysis patients who received at least one dose on the reference data. Follow-up ended at 31-12-2-21.

Adjusted for age, sex and socio-economic status (3 categories).

Table 8.8. Hazard ratios (95%-confidence intervals) for vaccinated[#] dialysis patients compared to not vaccinated patients. (Reference date December 1st 2021)

	Number of events	HR crude	HR adjusted[##]
Covid-19 diagnosis	1060	0.81 (0.66-1.01)	0.81 (0.65-1.00)
Hospital admission due to Covid-19	163	0.26 (0.18-0.37)	0.24 (0.16-0.35)
Intensive care admission due to Covid-19	7	0.20 (0.04-1.02)	0.17 (0.03-0.90)
Death due to Covid-19	23	0.18 (0.07-0.44)	0.14 (0.06-0.34)
All –cause mortality	846	0.94 (0.73-1.20)	0.82 (0.64-1.13)

Dialysis patients who received at least one dose on the reference data.

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 2022, 12,031 prevalent transplant patients were registered in Nefrodata, which equals 66% of all patients on renal replacement therapy. The majority of the patients (54%) have a transplant from living donors (Figure 9.2).

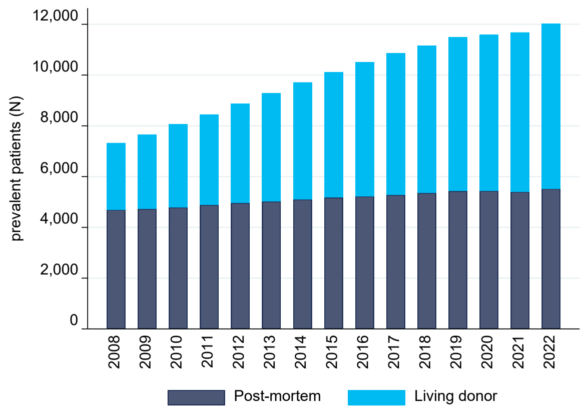


Figure 9.1. Number of prevalent patients according to donor type.

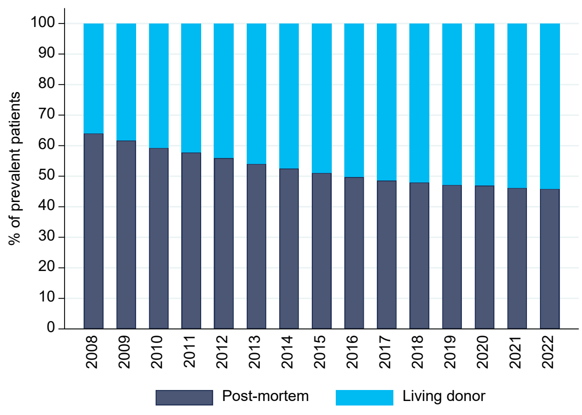


Figure 9.2. Percentage of prevalent transplant patients according to donor type.

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).

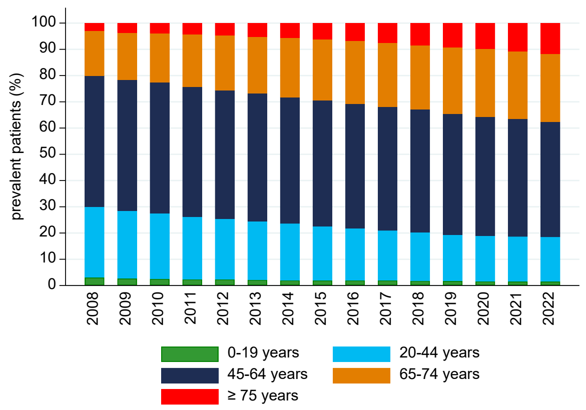


Figure 9.3. Prevalent transplant patients stratified for age categories.

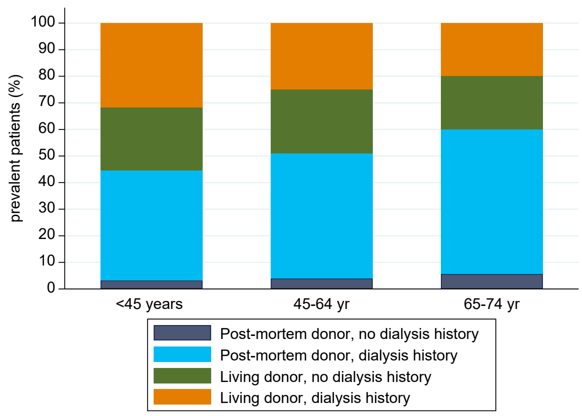


Figure 9.4. Distribution of renal transplant types in age categories in prevalent patients in 2022.

The mean age at which patients received their first renal transplantation increased from 49 years in 2008 to 54 years in 2022 (Figure 9.5).

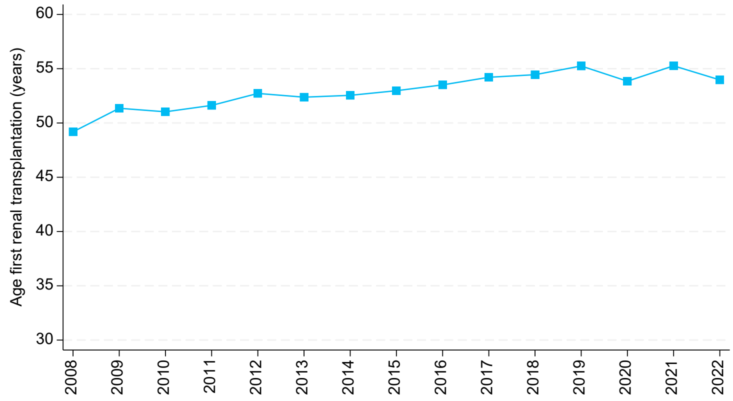


Figure 9.5. Mean age at which patients received their first renal transplant.

In 2022, 958 renal transplants were registered, an increase of 9% compared to 2021. In 2022, 28% of renal transplants were pre-emptive. The increase in the number of pre-emptive transplants has stagnated (Figure 9.6). In Figure 9.7, transplantations are grouped into four categories, based on donor type and whether or not the patient had a dialysis history.

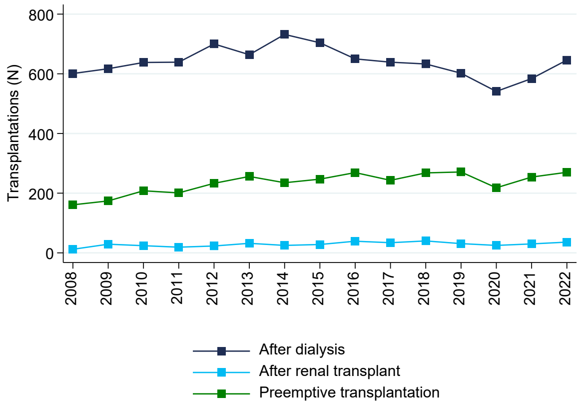


Figure 9.6. Transplantations according to preceding therapy.

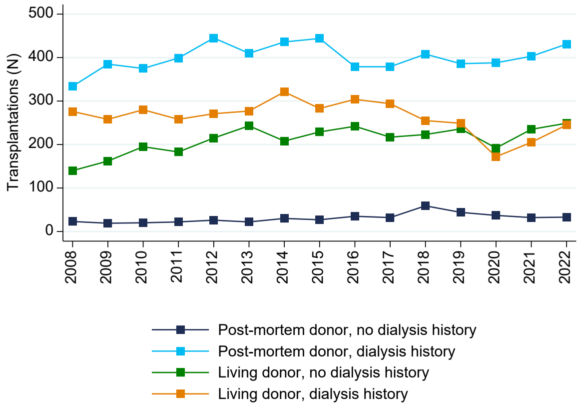


Figure 9.7. Number of different types of renal transplantations over time.

Most of the transplantations, living and post-mortem combined, are in the age category 45-64 years. The numbers are still low in 75-plus patients. In 2022, 35 transplantations in this age category were registered.

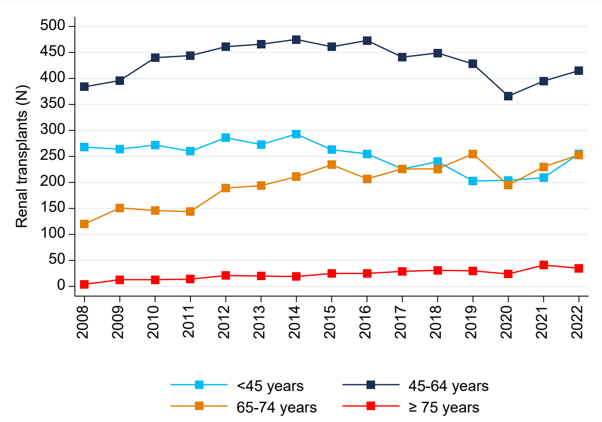


Figure 9.8. Number of renal transplantations by age categories.

Substantial variation between centres exists in the proportion of incident patients starting RRT therapy by means of a pre-emptive renal transplant (Figure 9.9). Figure 9.10 shows centre variation in the percentage of prevalent dialysis patients that received a renal transplant in 2022.

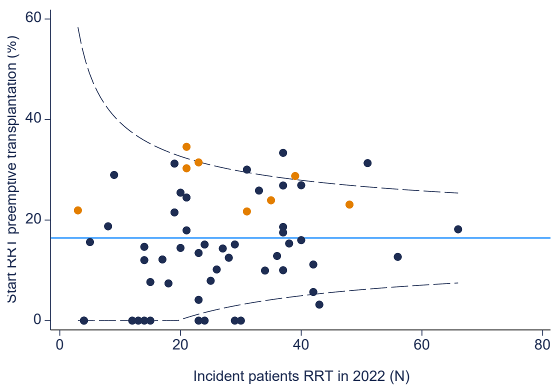


Figure 9.9. Centre variation in percentage pre-emptive transplantations in incident RRT patients in 2022. Adjustments were performed for age, sex, SES, and primary kidney disease categories. The academic medical centers are marked in orange.

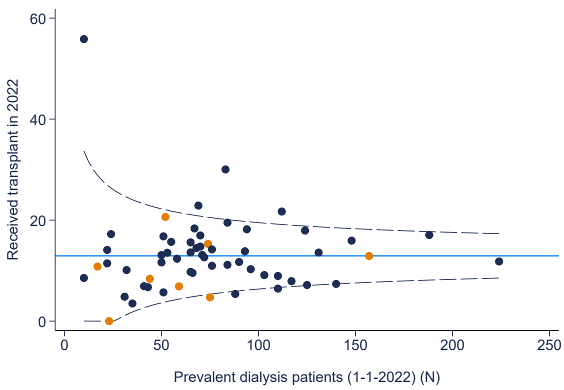


Figure 9.10. Centre variation in percentage of prevalent dialysis patients on January 1st that received a transplant in 2022. Adjustments were performed for age, sex, SES, and primary kidney disease categories. The academic medical centers are marked in orange.

Time on dialysis is decreasing over time, especially for post-mortem transplantations.

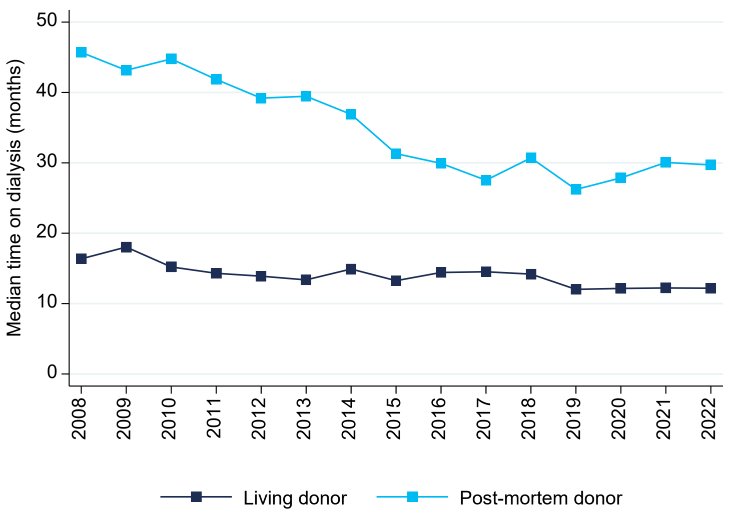


Figure 9.11. Time on dialysis in months in recipients of post-mortem and living donor renal transplants.

10 Conclusions

More than 18,000 patients in the Netherlands are on renal replacement therapy and this number is slowly 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. The incidence of renal replacement therapy is steadily decreasing over the years for older 75-plus patients, which is now also reflected in a lower relative prevalence for this age category.

A remarkable difference in the incidence of dialysis treatment is observed between men and women in the older age categories. In 2022, the incidence of dialysis in 75-plus men was 2.8 times higher than in 75-plus women. 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. 'Treatment stop' is the most common cause of death in dialysis patients, especially in the age category 75 years or older.

After a period with declining percentages of home dialysis in younger patients, these percentages stabilized in recent years. In contrast, in 75-plus patients an increasing trend in home-based dialysis modalities is observed. The observed centre variation in the uptake of home dialysis modalities suggests that there suggesting that there might be room for improvement in facilitating home dialysis. However, more insight in the underlying reasons for the lower uptake of home dialysis in some centres is needed before firm conclusions can be drawn.

Phosphate levels are relatively well controlled in older dialysis patients. The percentage of phosphate measurements below 1.80 mmol/L is substantially higher than in younger patients. Differences in nutritional status and (adherence to) treatment might contribute to these observed differences. In haemodialysis patients a decrease in the uptake of AV-fistels is seen, whilst the use of catheters is on the rise.

Outcomes after a Covid-19 infection were much less severe than in the beginning of the pandemic. Vaccination importantly protected the patients, but also the Omicron variant was less severe. The Covid-19 registration ended December 2022.

The number of prevalent patients living with a functional renal transplant steadily increases over time. Especially in elderly the relative increase is strong. In 2022, 12% of the pre-emptive transplantations were from post-mortem donors. This emphasizes the importance of timely preparation of patients and timely placing patients on the waiting list.

Time on dialysis prior to a post-mortem transplant decreased significantly over the period 2009-2019.

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 Nefrodata. The coverage ratio in 2022 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 2022). 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

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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.W. van Hamersvelt, internist-nephrologist, representative Guidelines Division NFN

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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

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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, chair LONT