RENINE annual report 2017

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Nefrovisie
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Dutch Federation for Nephrology

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Zicht op nierzorg

Contents

1 Introduction

Renine is the Dutch registry which contains data of patients on chronic renal replacement therapy (RRT). This is defined as either a renal transplant or dialysis for a period of at least 28 days. All dialysis centres in the Netherlands provide data to Renine. Data on patients with a transplant are provided by the 'Nederlandse Transplantatie Stichting' (NTS). Renine is an important tool to monitor parameters related to quality of care of renal replacement therapy in the Netherlands. Together with stakeholders we want to improve the reporting of the data to advance transparency of renal care.

In this report we focus on age and sex differences of incident treatment modalities and whether treatment modality changed in the first year. Also one and three years survival for incident dialysis patients is shown for the first time. More than 70% availability could be achieved for registration of clinical variables in 2017. This is an important increase, since only 48% of these variables were registered in 2016.

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

Marc Hemmelder, CEO Nefrovisie

2 Renal replacement therapy: key figures of 2017

Table 1. Characteristics of prevalent renal replacement therapy patients registered in Renine on December 31th 2017 (N=17,531).*

Modality	**N**	**%**
Haemodialysis	5356	31
Peritoneal dialysis	870	5
Transplant	11305	64
Sex	**% men**	
Dialysis patients	61	
Transplant patients	60	
Primary kidney disease	**N**	**%****
Glomerulonephritis/sclerosis	2915	17
Pyelonephritis	1181	7
Polycystic kidney disease	1555	9
Hypertension	2028	12
Renal vascular disease	1067	6
Diabetes type 1	657	4
Diabetes type 2	1649	9
Other	3517	20
Unknown	2962	17
Age (year)	**Mean (SD)**	
Dialysis patients	67.6 (14.6)	
Transplant patients	56.3 (15.0)	
Duration renal replacement therapy (year)	**Mean (SD)**	
Dialysis patients	4.9 (6.3)	
Transplant patients	12,8 (9.6)	

*218 prevalent RRT patients did not provide consent for their data to be included in Renine. The coverage in 2017 was 97%. ** The percentages do not add up to 100% due to rounding.

Table 2. Characteristics of incident renal replacement therapy patients registered in Renine in 2017 (N=1829)*.

Modality at start RRT, at day 1	**N**	**%**
Haemodialysis	1294	71
Peritoneal dialysis	308	17
Transplant	227	12
Sex	**% men**	
Dialysis patients	64	
Transplant patients	59	
Primary kidney disease	**N**	**%****
Glomerulonephritis/sclerosis	157	9
Pyelonephritis	66	4
Polycystic kidney disease	97	5
Hypertension	257	14
Renal vascular disease	207	11
Diabetes type 1	52	3
Diabetes type 2	303	17
Other	368	20
Unknown	322	18
Age (year)	**Mean (SD)**	
Dialysis patients	65.7 (14.0)	
Transplant patients	52.4 (17.2)	

*113 incident RRT patients did not provide consent for their data to be included in Renine (5,8%) **The percentages do not add up to 100% due to rounding.

3 Renal replacement therapy: incidence and prevalence

Over the last decades the number of prevalent patients on renal replacement therapy (RRT) steadily increased and this increase sustained in 2017 (Figure 3.1.). On December 31th 2017 17,531 prevalent RRT patients were registered in Renine. This equals 1,020 patients per million population (pmp) of the Netherlands (Figure 3.2.).

However, incidence of new patients on renal replacement therapy (incidence) has been declining since 2015. In 2017 1,829 new RRT patients were registered in Renine. This equals 106 patients per million population, a drop of 6% compared to 2016.

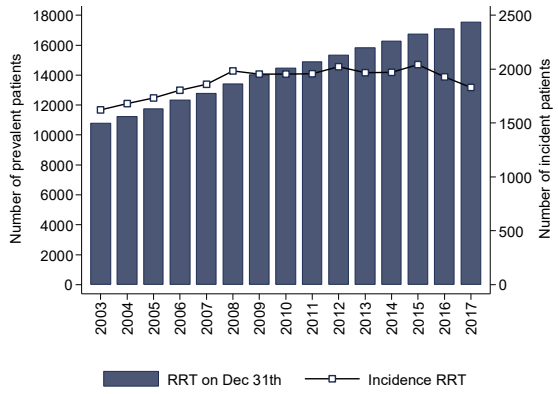


Figure 3.1. Prevalence and incidence of renal replacement therapy.

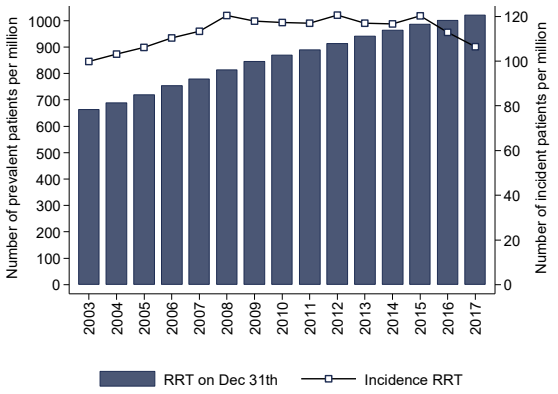


Figure 3.2. Prevalence and incidence of renal replacement therapy expressed per million population.

More men than women are being treated with RRT. On December 31th 2017 the percentage men was 60%. Concerning incident patients, 63% was male. Figure 3.3 and 3.4.show prevalence and incidence over the years separately for men and women.

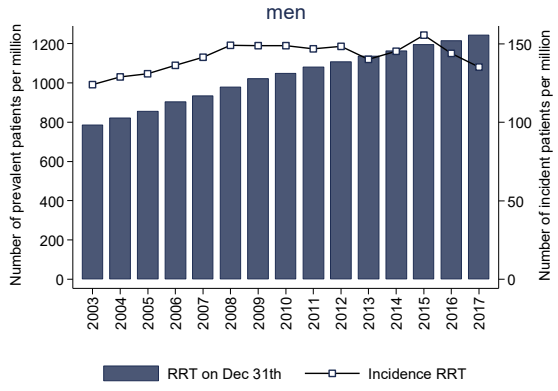


Figure 3.3. Prevalence and incidence of renal replacement therapy in men.

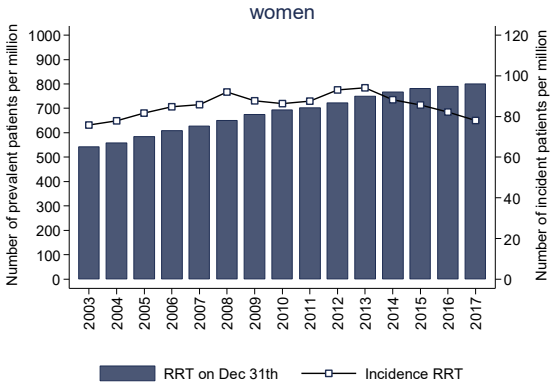


Figure 3.4. Prevalence and incidence of renal replacement therapy in women.

On December 31th 2017 45% of the prevalent RRT patients was 65 years or older and 19% was 75 years or older. These percentages have slowly changed over the years. In 2012 these percentages were 40% and 16% respectively. In 2017, 58% of the incident patients was 65 years or older.

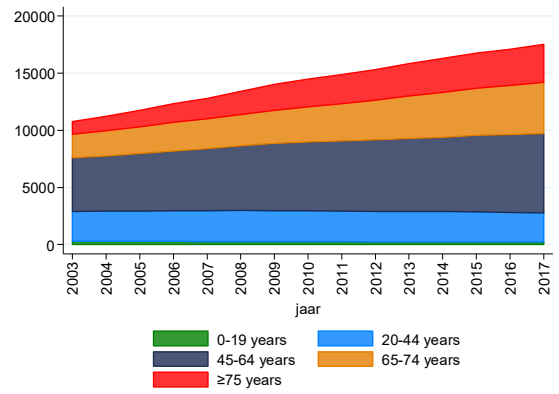


Figure 3.5. Prevalence of renal replacement therapy by age categories.

Figures 3.6 and 3.7 show RRT incidence stratified for age categories. Although the absolute number of patients in the two highest age categories remains stable, when expressed per million of the age related population a decrease in incidence is observed. This decrease is most prominent in the patients 75 years and older.

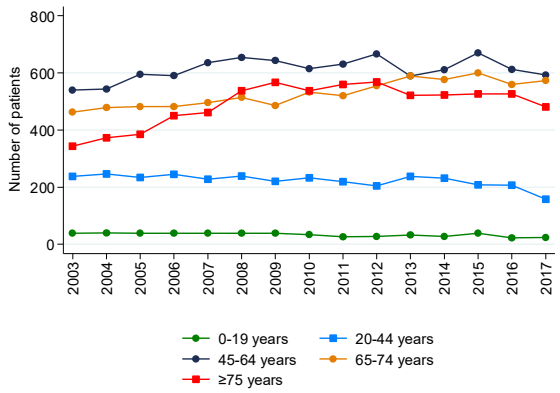


Figure 3.6. Incidence of renal replacement therapy stratified for age categories.

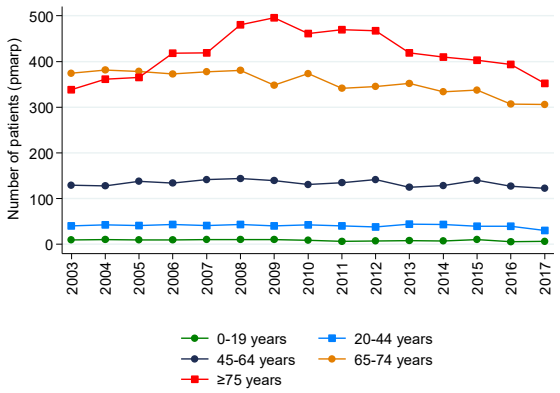


Figure 3.7. Incidence of renal replacement therapy expressed per million age related population stratified for age categories.

In 2017 1,294 patients started RRT with haemodialysis which is 71% of incident RRT patients. Over the years this percentage has remained stable (Figure 3.8). However, an increase is observed in preemptive transplantations as first treatment modality accompanied with a decrease in peritoneal dialysis as first treatment. These trends are observed both in men as well as in women. In 2017 227 patients (17%) started RRT by means of a renal transplant and 308 (17%) patients started peritoneal dialysis as first treatment.

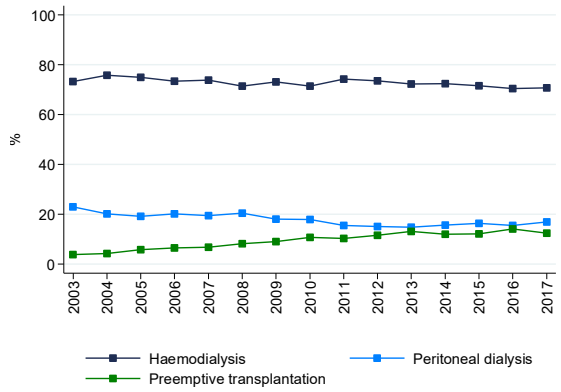


Figure 3.7. Distribution of start modalities in incident RRT patients over time.

The proportion patients starting RRT on haemodialysis increases with age. In young patients (<45 years) this is 59% compared to 81% in patients ≥75 years. In young patients preemptive transplantations are more common than peritoneal dialysis as first treatment modality (Figure 3.8).

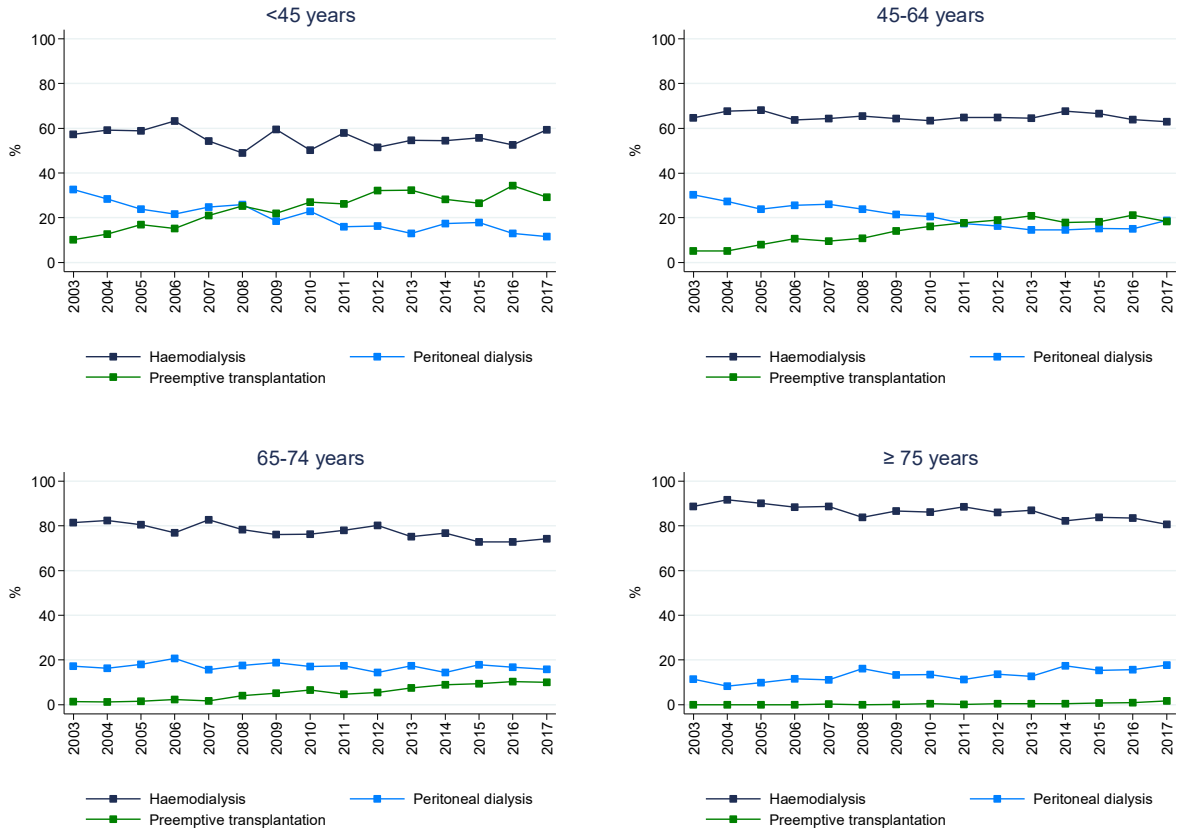
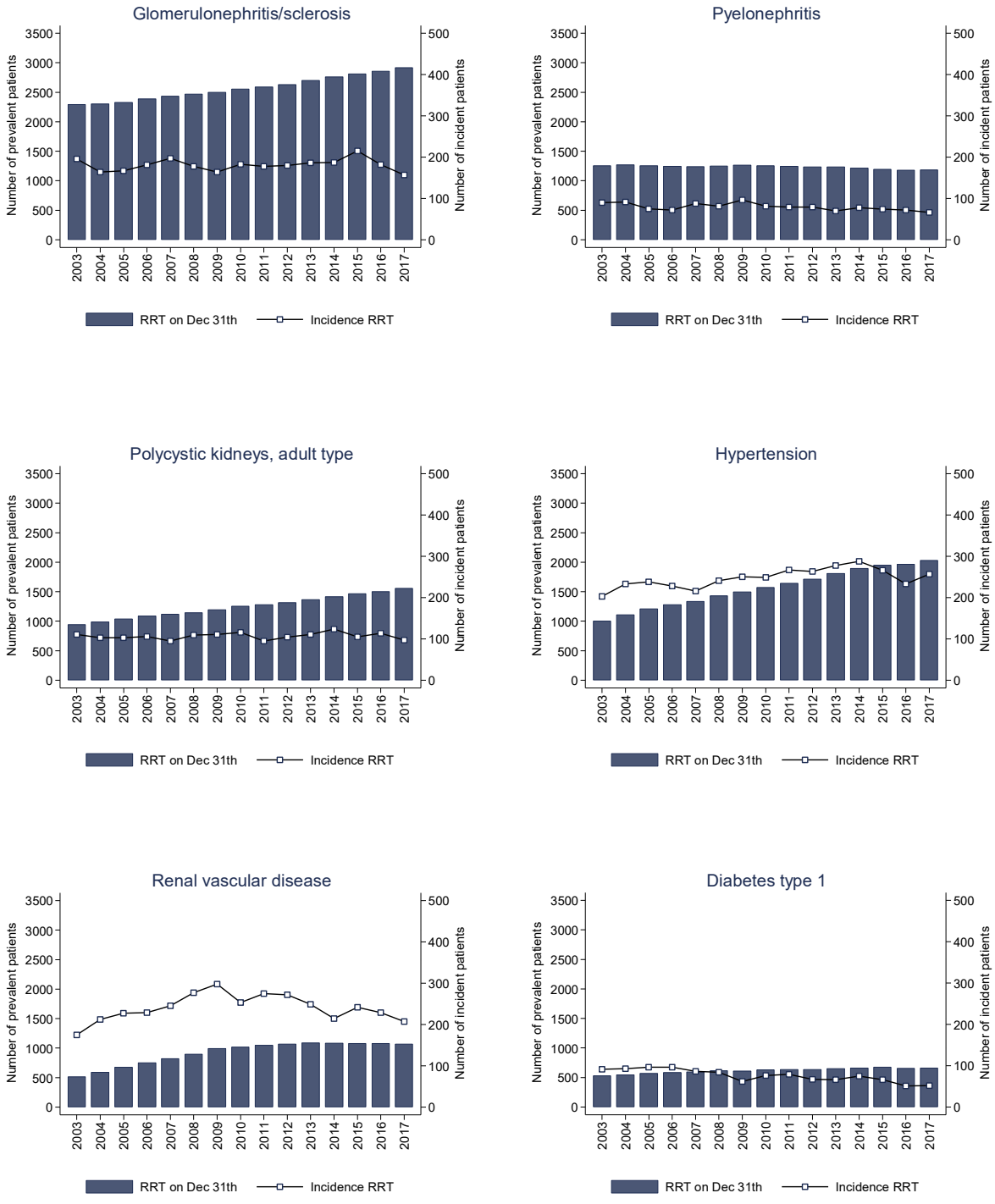


Figure 3.8. Distribution of start modalities in incident RRT patients over time stratified for age categories.

Figure 3.9 shows incidence and prevalence of renal replacement therapy stratified for primary kidney disease categories. Incidences show downwards trends for glomerulonephritis/sclerosis, renal vascular disease and diabetes type 2. The latter might indicate that preventive actions are effective.



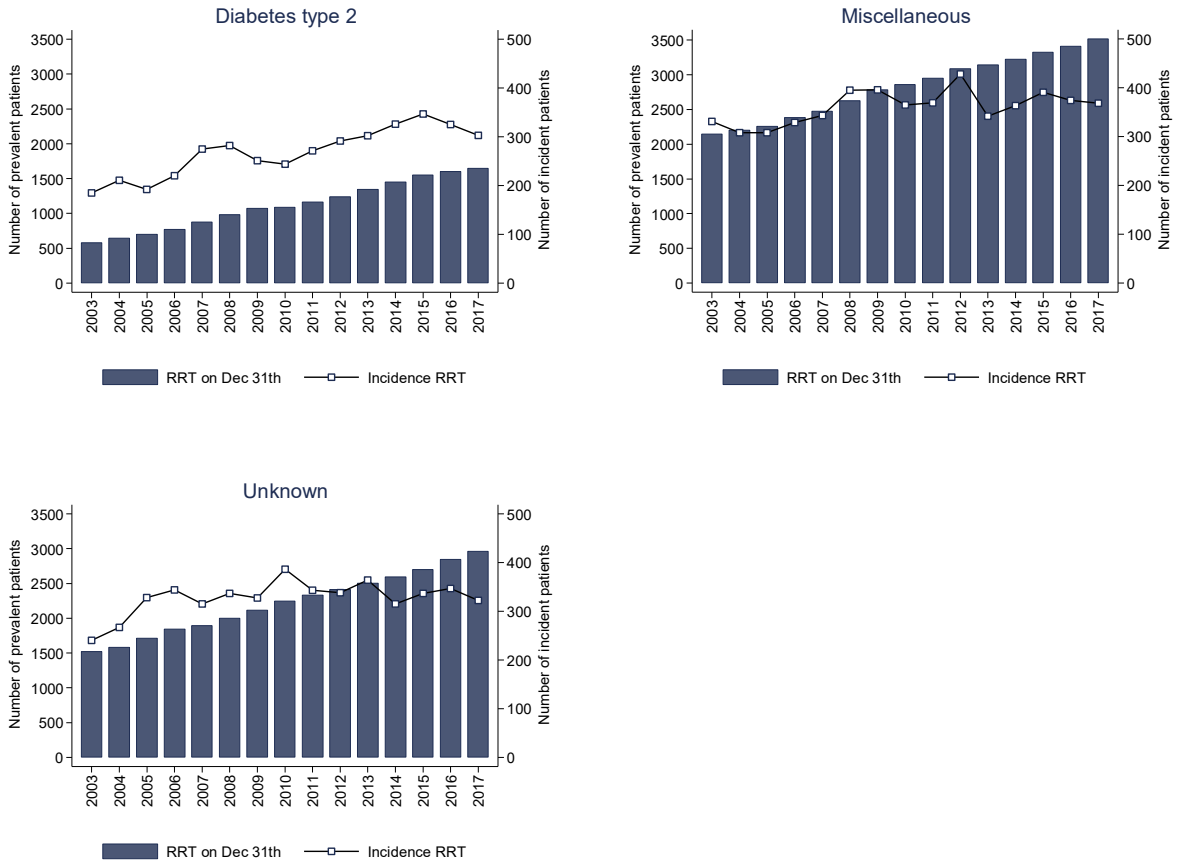


Figure 3.9. Incidence and prevalence of renal replacement therapy stratified for primary kidney disease categories.

4 Dialysis treatment: incidence and prevalence

In recent years the incidence of dialysis has decreased. In 2017 1,834 patients started chronic dialysis which is 3% lower than in 2016. The majority of these patients received dialysis treatment for the first time. In 2017 209 patients with a history of dialysis restarted chronic dialysis treatment. Further on in this chapter incidence of dialysis only includes first-time dialysis treatment ever. Dialysis incidence however does include patients with a previous renal transplant. Prevalence includes all patients on dialysis treatment, irrespective of RRT history. Overall prevalence of dialysis is also slightly decreasing (Figure 4.2.). On December 31th 2017 6,226 patients were on dialysis, a decrease of 2% compared to 2016.The age distribution of dialysis patients has changed substantially over time with increasing numbers of elderly patients. In 2017 38% of all dialysis patients were 75 years or older.

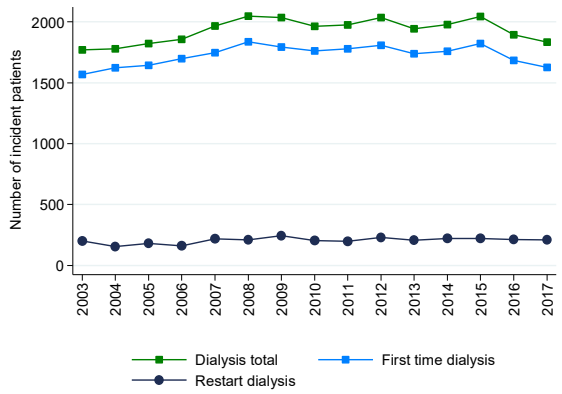


Figure 4.1. Incidence of dialysis per year. A distinction was made between patients receiving chronic dialysis for the first time and patients with dialysis treatment in the past restarting dialysis treatment.

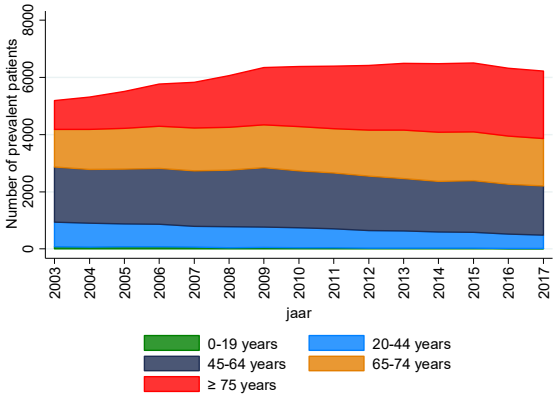


Figure 4.2. Prevalence of dialysis on December 31th by age categories.

Figure 4.3 and figure 4.4. show incidence of first-time dialysis stratified for age categories (absolute numbers and expressed per million age related population respectively). We observe a steady decrease in new patients in the age category 20-44 years. Compared to ten years ago the absolute number of new patients in this age category has dropped by 33%. Expressed per million age related population the decrease was 30%. Absolute numbers of new patients in the older age categories remained rather stable in recent years. However, if we take into account the higher number of elderly in the general population by expressing incidence by million age related population, the decrease in incidence in patients aged 75 years and above is most evident. Compared to 2009 the incidence per million age related population dropped by 30%.

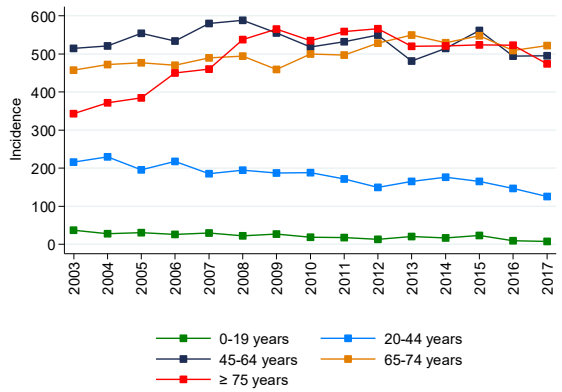


Figure 4.3. Incidence of first-time dialysis (absolute numbers) over time stratified for age categories.

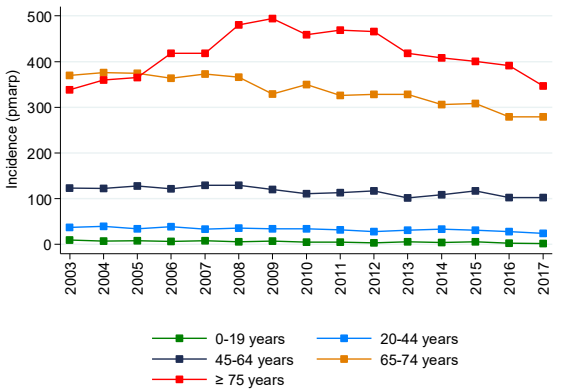


Figure 4.4. Incidence per million age related population of first-time dialysis stratified for age categories.

5 Dialysis modalities

Haemodialysis remains the most frequently applied dialysis modality. The proportion patients treated with peritoneal dialysis dropped until 2010 but remained stable afterwards. In 2017 this percentage was 16%. The percentage incident dialysis patients starting dialysis treatment with peritoneal dialysis is slightly higher, i.e. 19%.

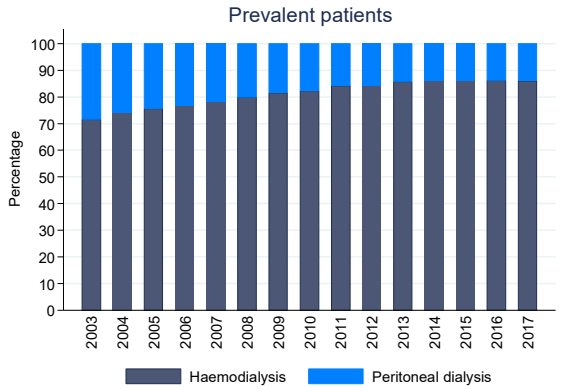


Figure 5.1. Distribution of haemodialysis and peritoneal dialysis in prevalent chronic dialysis patients. (Date: December 31th of each year).

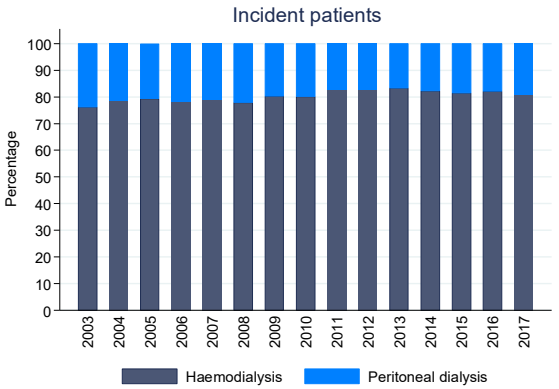


Figure 5.2. Distribution of haemodialysis and peritoneal dialysis in incident chronic dialysis patients per year.

Figures 5.3 and 5.4. show the absolute number of prevalent and incident patients on peritoneal dialysis stratified for age categories. In comparison to a decade ago, the number of elderly (≥75 years) increased substantially. In 2017 311 patients started dialysis with peritoneal dialysis and of these 85 were 75 years or older (27%).

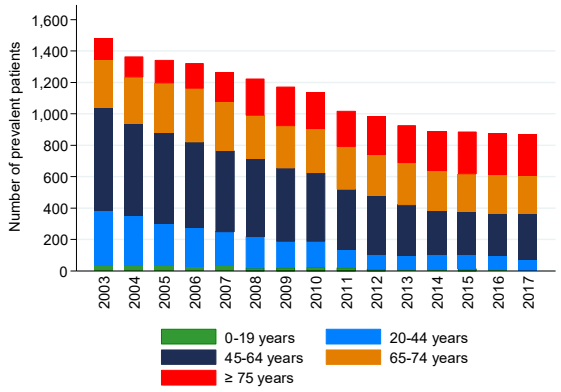


Figure 5.3. Number of prevalent peritoneal dialysis patients in age categories (December 31th).

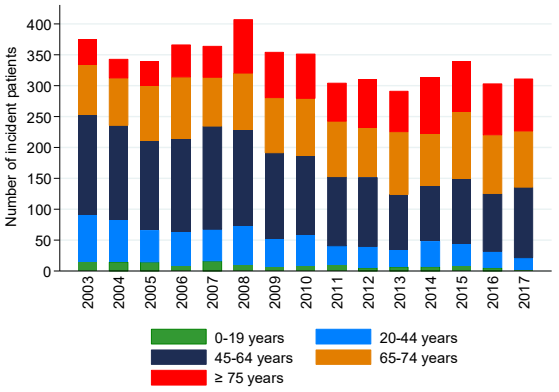


Figure 5.4. Number of incident peritoneal dialysis patients per year in age categories

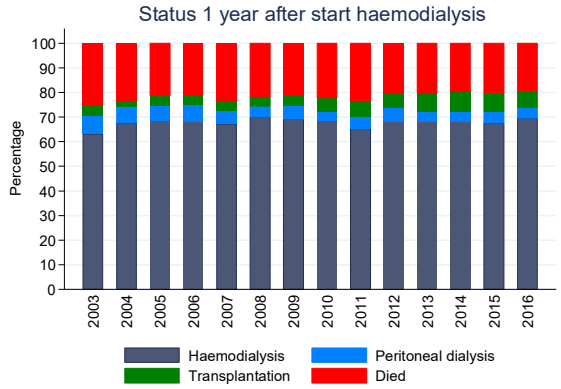


Figure 5.5. Status one year after start HD as percentage. The year represent the year in which HD was started.

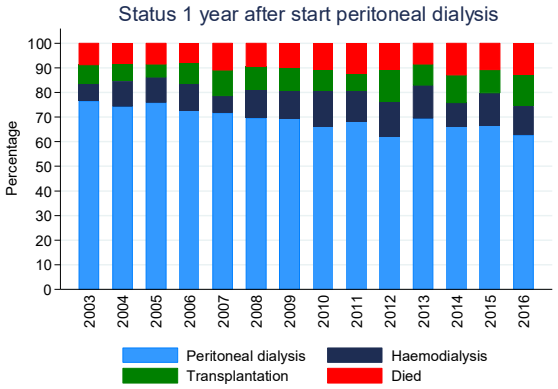


Figure 5.6. Status one year after start PD as percentage. The year represent the year in which PD was started

Figure 5.5. and 5.6. show the status of patients one year after the start of haemodialysis or peritoneal dialysis as first dialysis modality. Patients starting dialysis in 2017 are not included in this analysis as one year follow-up is not yet available for all of these patients. In haemodialysis patients, mortality is higher and transplantation rate is lower compared to peritoneal dialysis, possibly due to differences in case-mix. More patients switch from peritoneal to haemodialysis in the first year than vice versa. Of the patients starting haemodialysis in 2016 after 1 year 70% of these were still treated with haemodialysis, 4% switched to peritoneal dialysis, 7% received a transplant and 19% died. In peritoneal dialysis the percentages that switched to either haemodialysis or received a transplant were somewhat higher, i.e. 12% switched to haemodialysis and 13% of these patients had a functioning transplant one year after they started peritoneal dialysis. After start of peritoneal dialysis, mortality was 12% in one year.

Figure 5.7 and 5.8 show centre variation in the percentages switches between modalities during the first year in funnel plots. In these analyses modality at three months after start of dialysis was taken as initial modality. Only patients still on dialysis after one year were included.

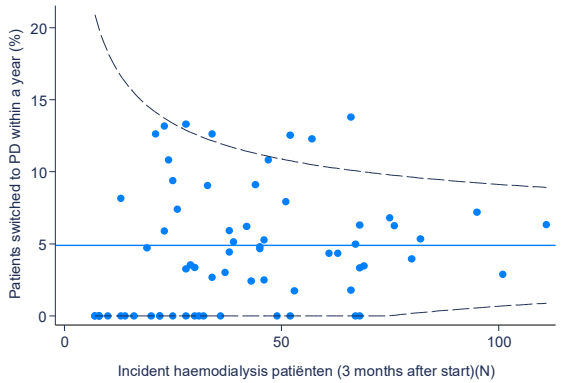


Figure 5.7. Centre variation in switches from HD to PD. Patients were included if on PD 3 months after start dialysis and still on dialysis after one year. Adjustments were performed for age, sex and primary kidney disease categories.

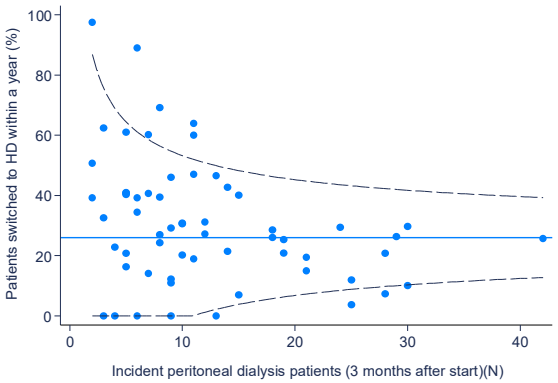


Figure 5.8. Centre variation in switches from PD to HD. Patients were included if on HD 3 months after start dialysis and still on dialysis after one year. Adjustments were performed for age, sex and primary kidney disease categories.

6 Home dialysis

Home dialysis includes both home haemodialysis and peritoneal dialysis. On December 31th 2017 1,134 patients were on home dialysis, which is 18% of the overall dialysis population (Figure 6.1 and 6.2). The majority of these patients was treated with peritoneal dialysis. In recent years the proportion of patients on home dialysis stabilized.

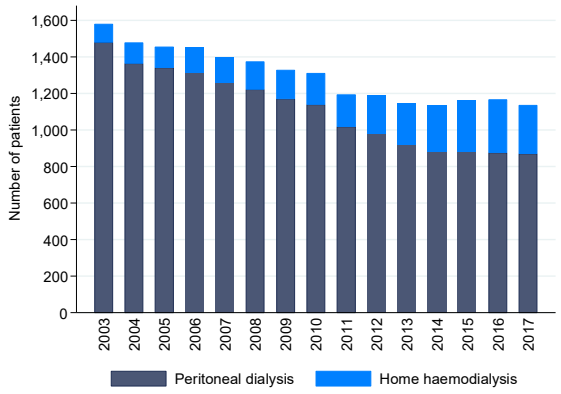


Figure 6.1. Number of prevalent home dialysis patients (peritoneal dialysis and home haemodialysis) at December 31th of each year.

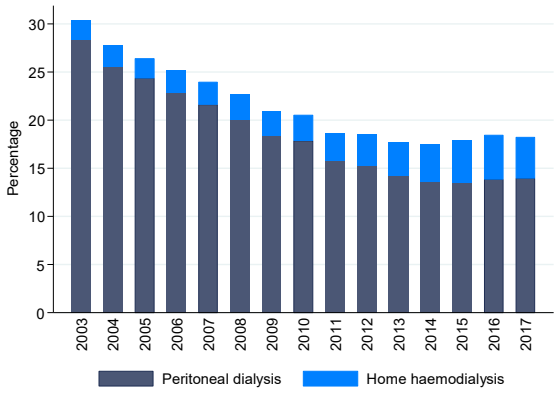


Figure 6.2. Home dialysis (peritoneal dialysis and home haemodialysis) as percentage of total dialysis in prevalent patients.

In 2017 64 patients started home haemodialysis for the first time (figure 6.3). Compared to 2016 this is a drop of 35%. Age at which patients start home haemodialysis initially showed an increase over time. However, during the last two years median age at start was somewhat lower. In 2017 this was 62 years.

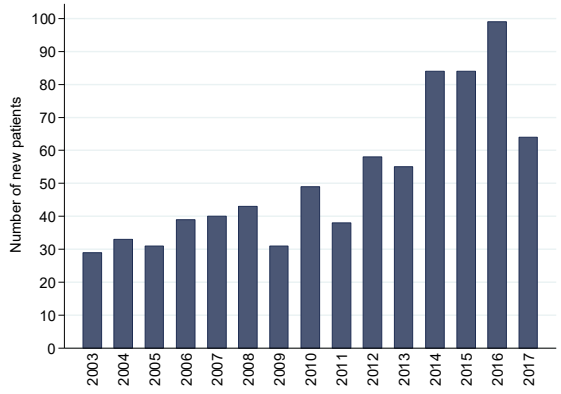


Figure 6.3. Number of patients starting home haemodialysis.

Figure 6.4. Median age of patients starting home haemodialysis. The bars represent the 5-95th percentiles

Figure 6.5. shows home dialysis in different age categories as percentages of total dialysis. These figures show in adult patients stabilization of this percentage over the last few years. In the youngest age category the percentages are decreasing over time. However, this is a very small group.

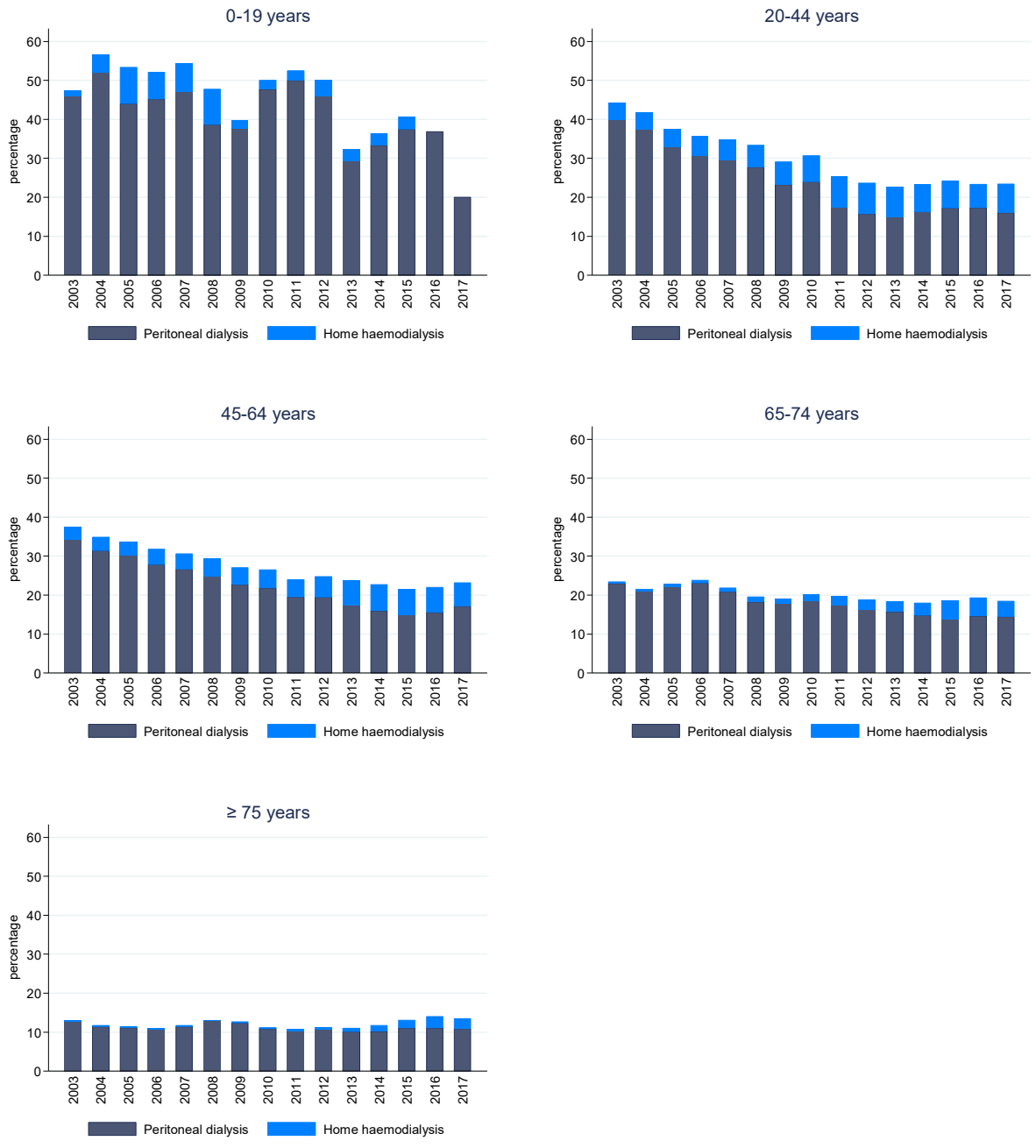


Figure 6.5. Home dialysis (peritoneal dialysis and home haemodialysis) as percentage of total dialysis in prevalent patients stratified for age categories.

The proportion of patients treated with home dialysis shows substantial variation among centres. In Figure 6.6. a funnel plot shows the percentage of home dialysis in incident patients at three months after start of dialysis. The plot is adjusted for case-mix (age, sex, and primary kidney disease).

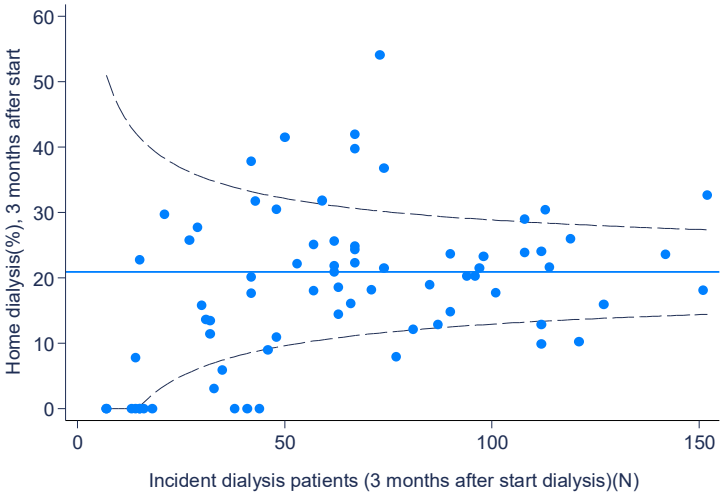


Figure 6.6. Funnel plot showing centre variation in percentage home dialysis at three months after start dialysis. Home dialysis includes peritoneal dialysis and home haemodialysis. Data is adjusted for age, sex, and primary kidney disease categories.

7 Mortality on dialysis

In 2017 1,314 patients died on renal replacement therapy. The majority of the deaths (n=1,141) were patients on dialysis therapy. In Figure 7.1. patterns of 5-year mortality is shown stratified for modality and age below or above 65 years. In these analyses transplantation is regarded a competing event. Mortality is comparable for haemodialysis and peritoneal dialysis in patients younger than 65 years. Transplantations however are more common in patients starting on peritoneal dialysis. As expected, mortality is much higher in patients of 65 years and older. Also in this older age category patients with peritoneal dialysis more often receive a transplant.

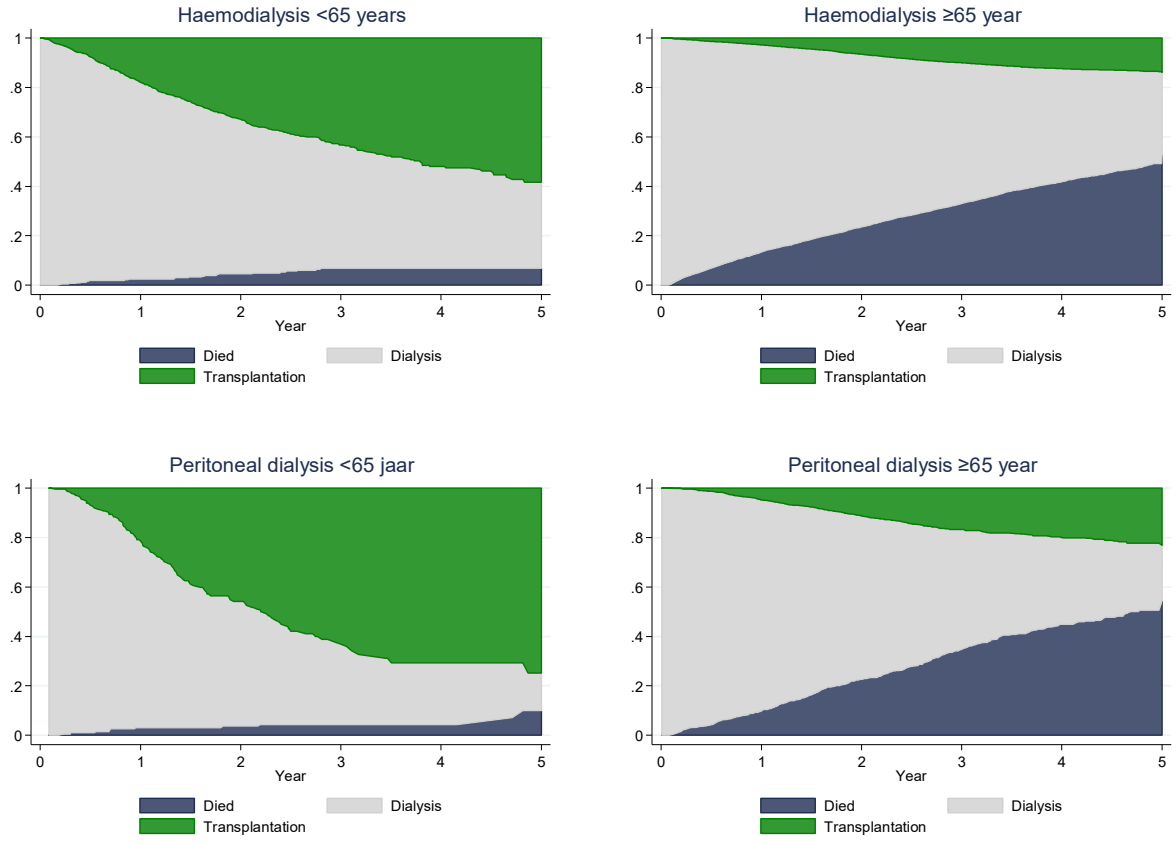


Figure 7.1. Survival and transplantations in incident haemodialysis and peritoneal dialysis patients younger and older than 65 years. Inclusion period 2011-2017. Competing risk analyses were performed (Fine and Gray method). Adjustment was done using fixed values of age, sex and primary kidney disease categories.

In Figure 7.2. and 7.3. centre variation among centres are shown for 1-year and 3-year mortality in incident dialysis patients. Variation is considerable and 5 centres have a 1-year mortality higher than the 95%-confidence interval. The data was adjusted for age, sex and primary kidney disease categories. However, other important factors influencing prognosis such as comorbidities are not available. Results should, therefore, be interpreted with caution.

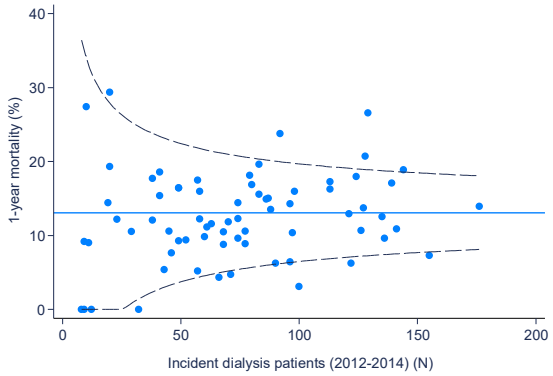


Figure 7.2. Centre variation in 1-year mortality in incident patients. Inclusion period 2014-2016. Adjustments were performed for age, sex and primary kidney disease categories

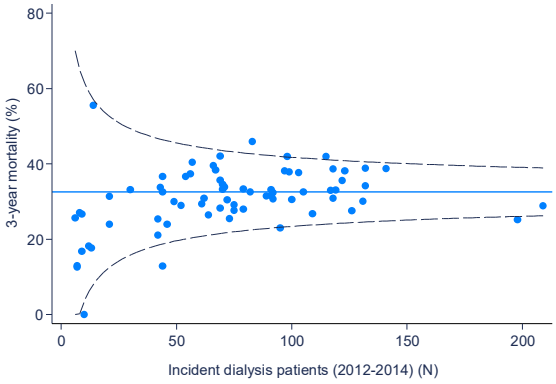


Figure 7.3. Centre variation in 3-year mortality in incident dialysis patients. Inclusion period 2012-2014. Adjustments were performed for age, sex and primary kidney disease categories

Causes of death were coded according to the ERA-EDTA coding system and categorized according to the categorization as applied by the UKRR (Appendix C). In Figure 7.2 and 7.3. absolute and relative numbers of causes of death are shown for patients who died on dialysis therapy. As in previous years 'treatment stop' is the most dominant cause of death. In Figure 7.4 causes of death of patients on dialysis is shown stratified for age below or above 65 years. 'Treatment stop' is more common in elderly patients, whilst cerebrovascular accidents and malignancies are less often recorded as cause of death.

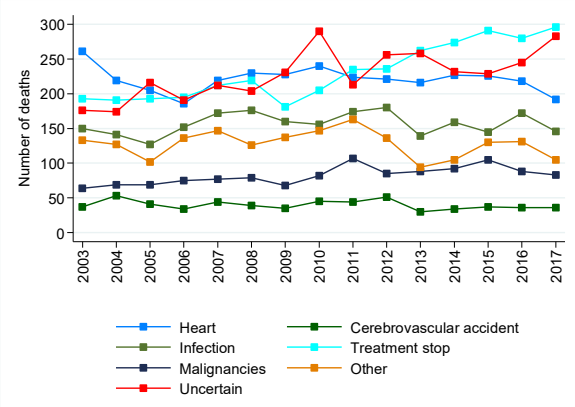


Figure 7.2. Causes of death over time.

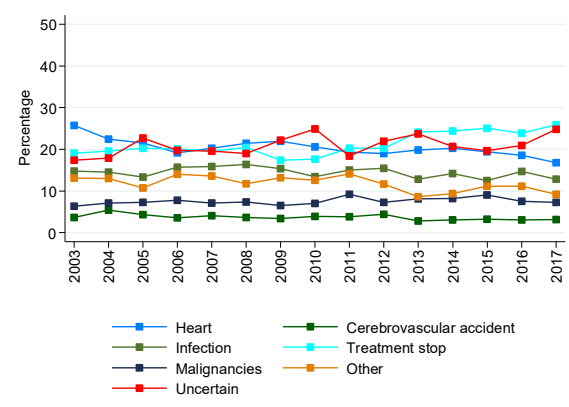


Figure 7.3. Causes of death expressed as percentage of total over time.

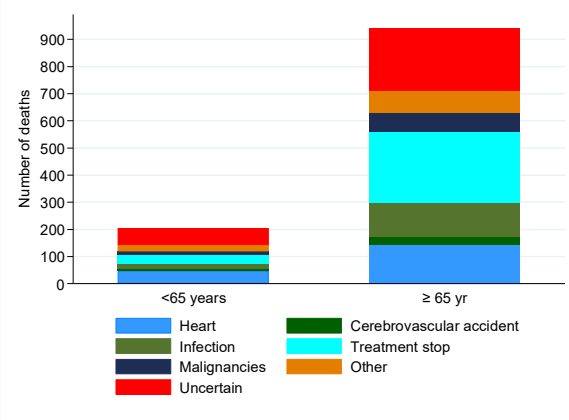


Figure 7.4. Absolute numbers of causes of death in 2017 stratified for dialysis patients below or above 65 years.

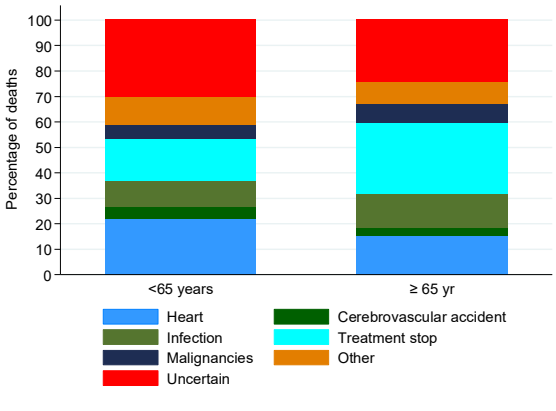


Figure 7.5. Causes of death in 2017 stratified for dialysis patients below or above 65 years expressed as percentages of total.

8 Renal transplantations

On December 31th 2017 11,305 prevalent patients living with a renal transplant were registered in Renine. Figure 8.1. and 8.2. show time trend of prevalence of renal transplantation separately for patients with and without a history of dialysis. The proportion of patients with a renal transplant without previous dialysis increased substantially over time. In 2017 this reached 23% of the patients. Figures 8.3 and 8.4 show the same data for prevalent patients with a post-mortal or living donor kidney. The percentage patients living with a renal transplant from a living donor showed a steep increase over time and this percentage reached 51% in 2017. In 2017 904 new renal transplants were registered in Renine. Of these 764 were first transplants and 140 (15%) were re-transplantations. Of the transplantations performed in 2017, 26% was in patients without previous treatment by dialysis. In 56% of the transplantations were performed with a living donor kidney.

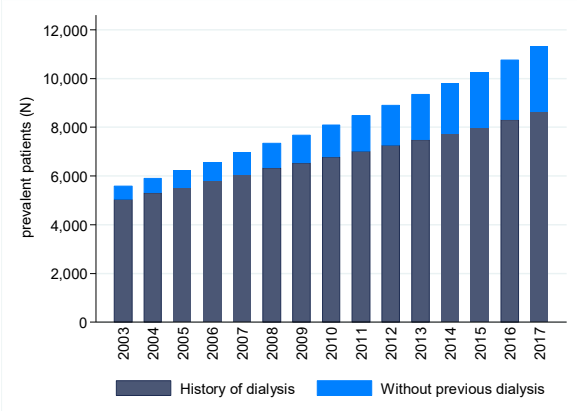


Figure 8.1. Number of prevalent transplant patients stratified for dialysis history.

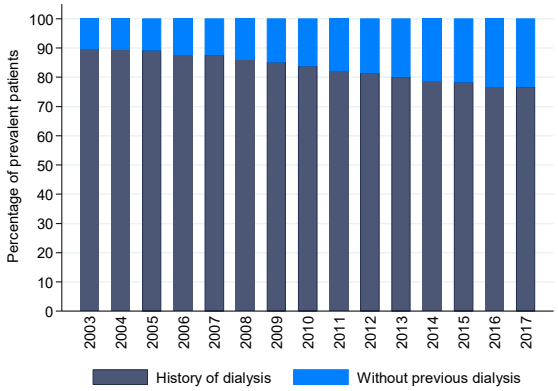


Figure 8.2. Percentage of prevalent transplant patients with and without a history of dialysis.

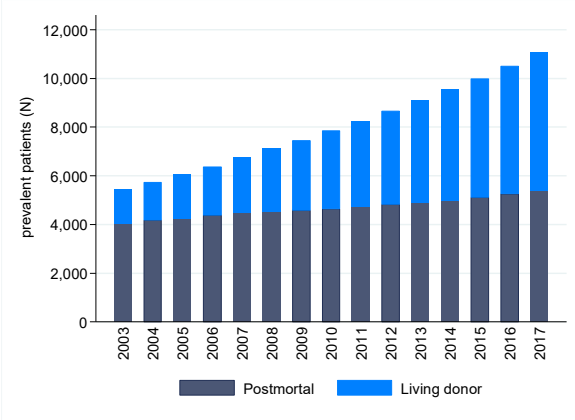


Figure 8.3. Number of prevalent transplant patients according to donor type.

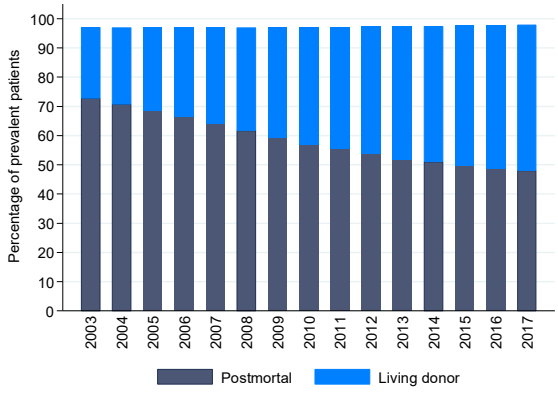


Figure 8.4. Distribution of prevalent transplant patients according to donor type.

In Figure 8.5. the prevalence is categorized into four transplant types based on the combination living/post-mortal donor and dialysis history of the patient. The incidence is shown in Figure 8.7. The distribution over these categories differs across age categories (Figures 8.7 and 8.8). In young patients (i.e. <45 years) transplantations with living-donor kidneys before chronic dialysis treatment became necessary are most common.

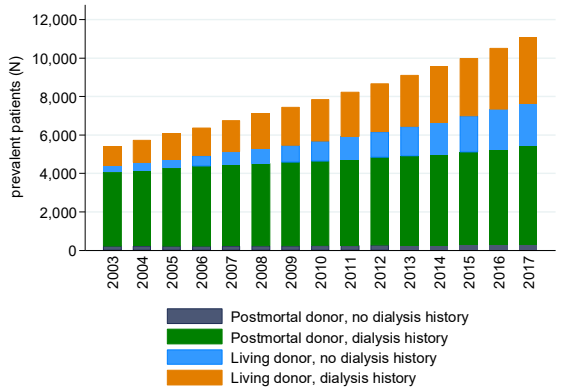


Figure 8.5. Number of prevalent dialysis patients according to type of transplant.

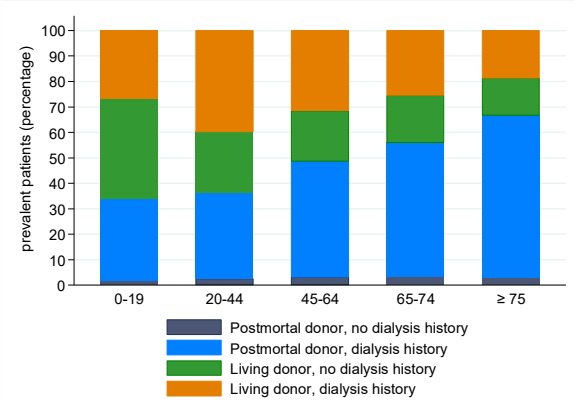


Figure 8.6. Distribution of transplant types in age categories in transplant patients (December 31th 2017).

In 2017, 904 renal transplantations were registered in Renine. This number is lower than the number reported by the NTS (N=956). We will explore, in cooperation with the NTS, the reasons for these deviation in numbers. Over the years, more living donor transplantations in patients without a history of dialysis treatment have been performed (Figure 8.7.). In young patients the majority of transplantations in 2016 were with living donor kidneys (Figure 8.8).

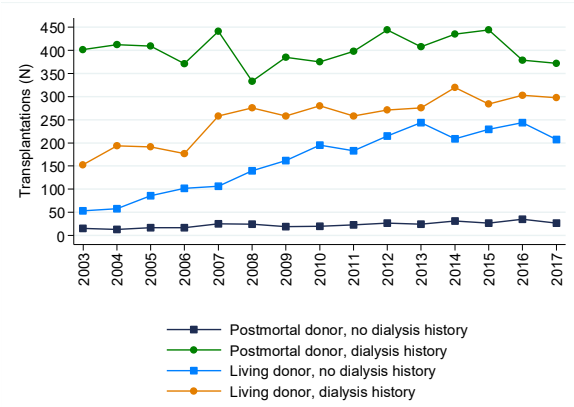


Figure 8.7. Number of different types of renal transplantations over time.

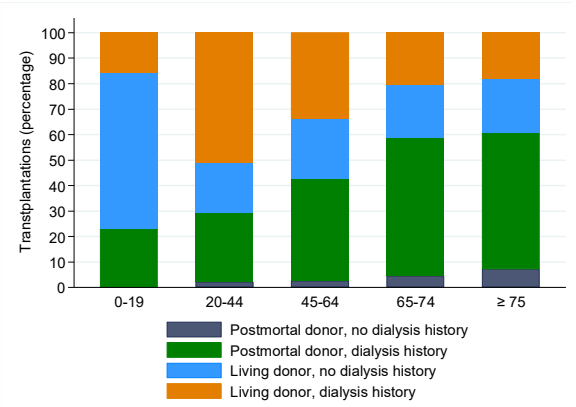


Figure 8.8. Distribution of different types of renal transplantations in age categories in the year 2017.

Substantial variation exists between centres regarding the proportion of incident RRT patients starting therapy by means of a pre-emptive renal transplant (Figure 8.9.). Figure 8.10 shows centre variation in the percentage prevalent patients transplanted in 2017. In these analyses patients included were aged 18-75 years. The analyses were adjusted for age, sex and primary kidney disease categories.

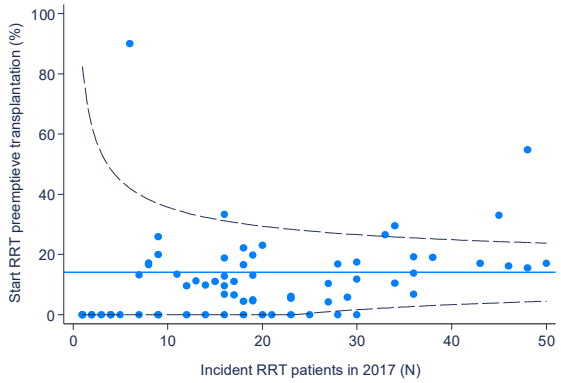


Figure 8.9. Centre variation in percentage pre-emptive transplantation in incident RRT patients Adjustments were performed for age, sex and primary kidney disease categories

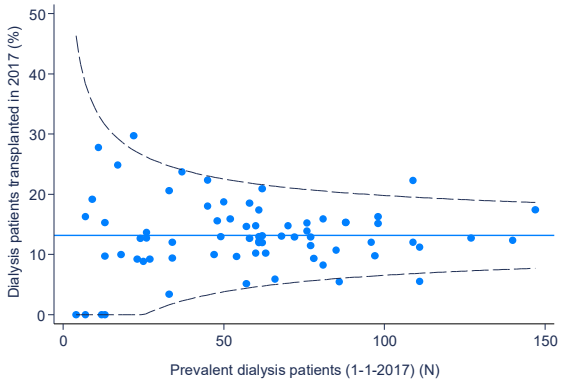


Figure 8.10. Centre variation in percentage of prevalent patients on January 1 that received a transplant in 2017. Adjustments were performed for age, sex, primary kidney disease categories and dialysis vintage.

9 Clinical variables

Since 2016 registration of clinical variables is a mandatory component of the Renine registry. This resulted in a steep increase in availability of data in that year. This increase continued in 2017 as is illustrated in Figure 9.1. and 9.2. for phosphate levels (in all dialysis patients) and vascular access (in haemodialysis patients). More than 70% availability was achieved in 2017. Centres are requested to provide individual patient data four times per calendar year. Availability is expressed against the number of expected measurements based on the number of prevalent patients at the four reference dates per year.

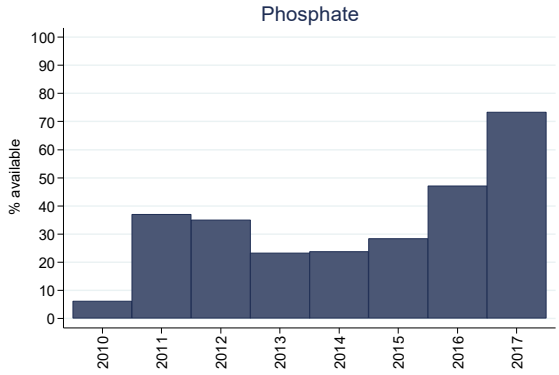


Figure 9.1. Availability of phosphate measurements per year expressed as percentage of the total number of potential measurements.

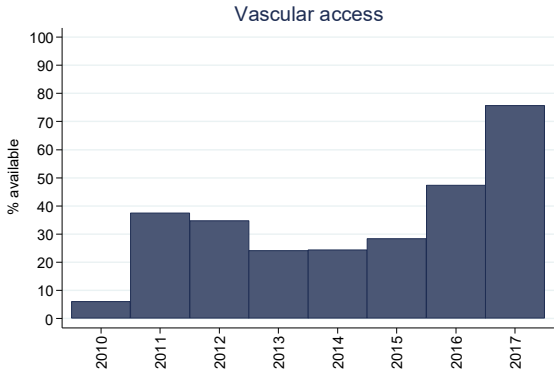


Figure 9.2. Availability of vascular access data per year as percentage of the total number of potential measurements.

Figure 9.3. shows categories of clinical indicators stratified for age categories. Substantial variation in observed mean values is observed across different centres as is shown in the funnel plots (Figure 9.4.). Adjustments were performed for differences in case-mix (age, sex, and primary kidney disease categories).

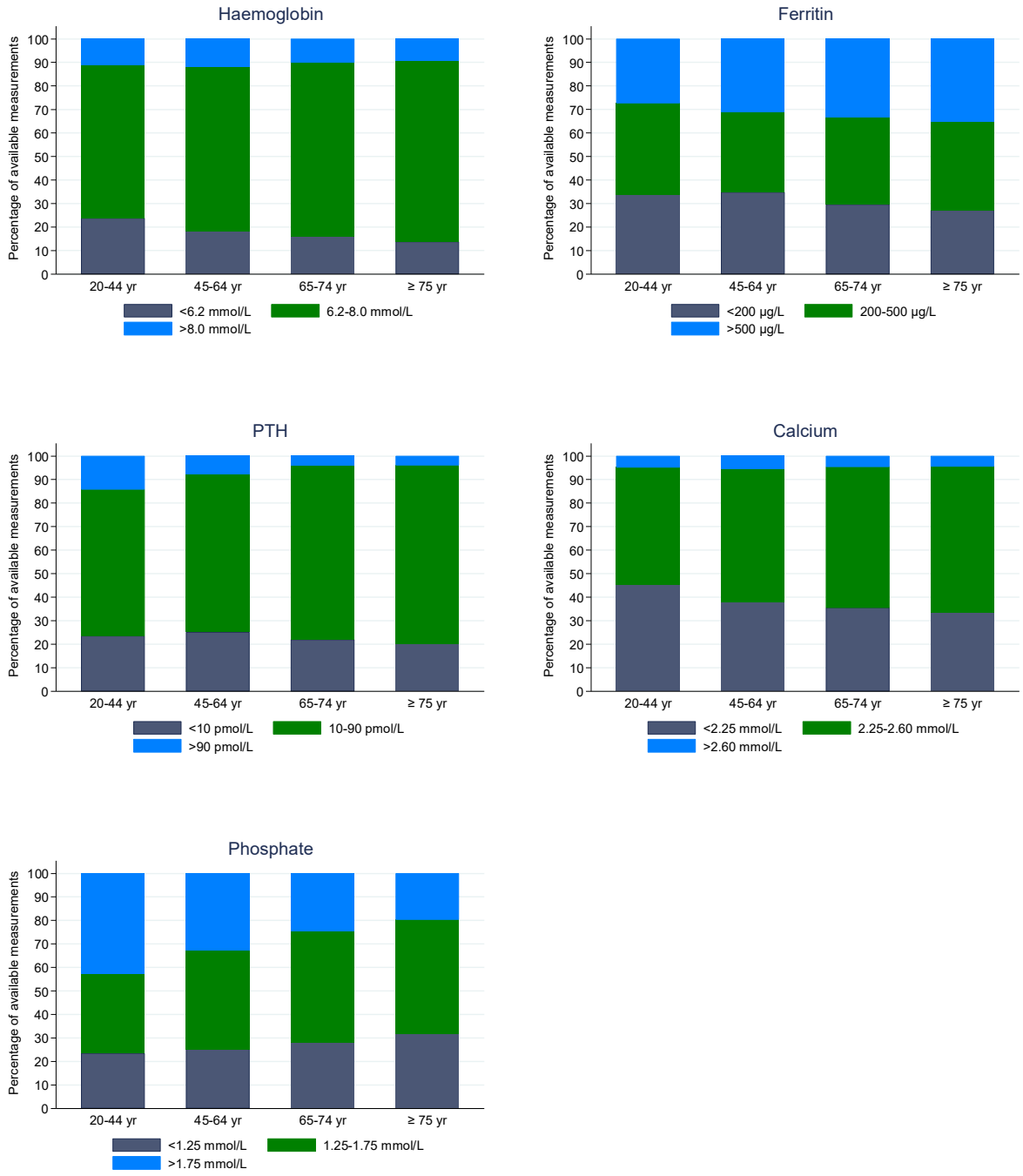


Figure 9.3. Categories of clinical variables stratified for age categories

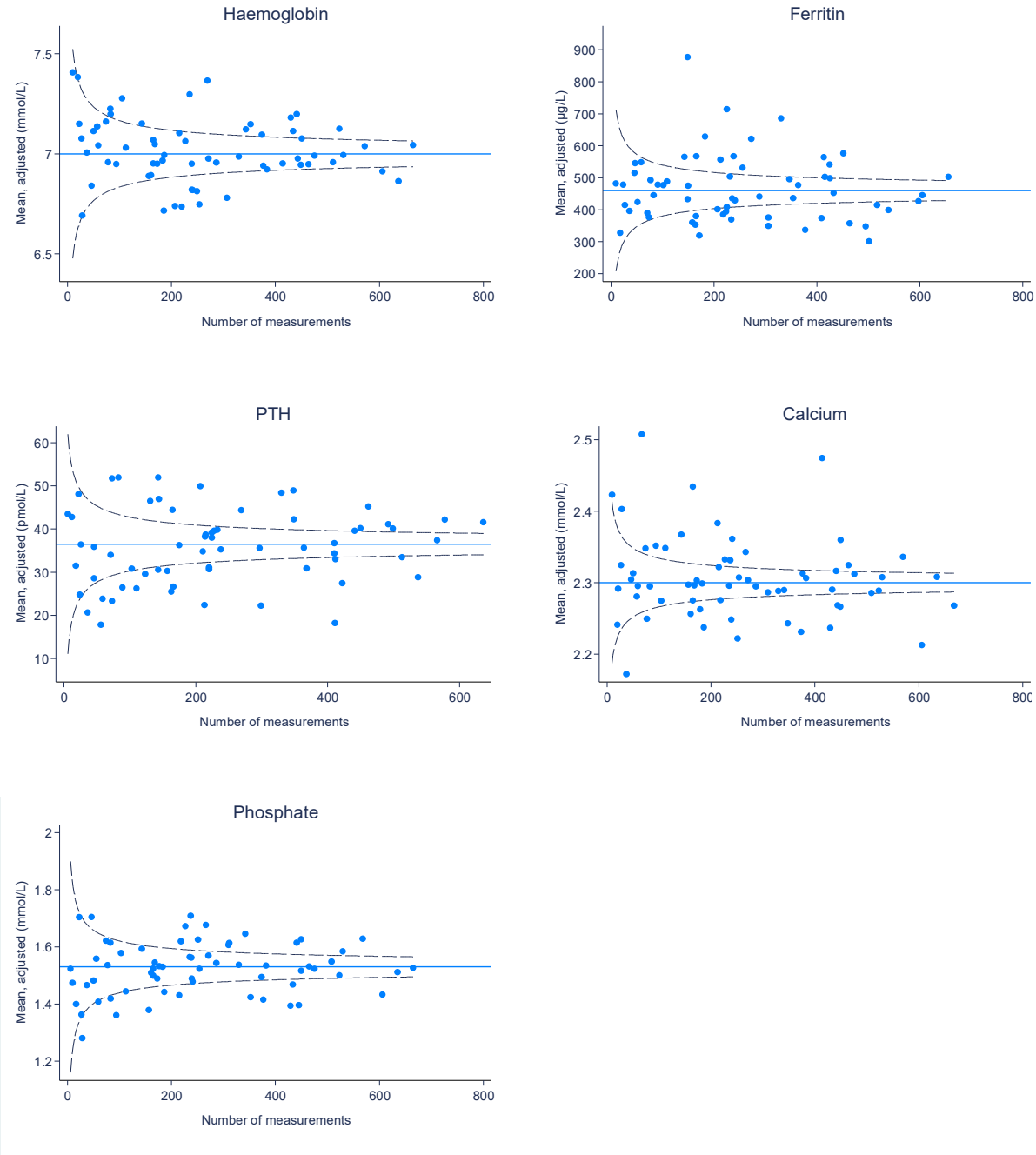


Figure 9.4. Funnel plots showing centre variation of mean values of clinical variables. The funnels were adjusted for differences in case-mix (age, gender and primary kidney disease categories).

In prevalent haemodialysis patients an AV-fistula is the most common vascular access type. The percentage patients with a central venous catheter is lowest in the age category 75 years and older. In Figures 9.6 and 9.7. centre variation in the percentages patients with a central venous catheter is shown for prevalent and incident haemodialysis patients respectively.

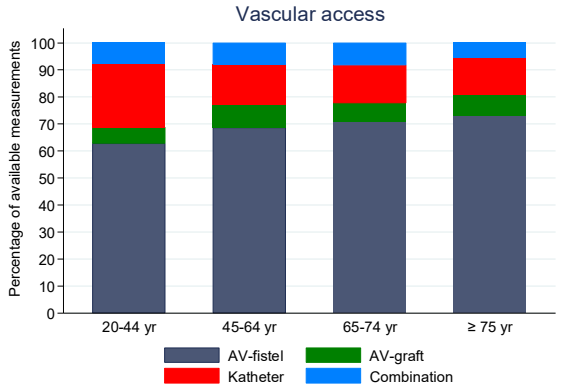


Figure 9.5. Distribution of vascular access categories in prevalent haemodialysis patients stratified for age categories.

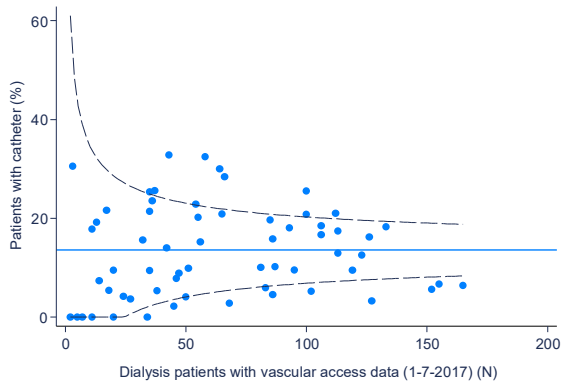


Figure 9.6. Centre variation in catheter use in prevalent haemodialysis patients. Adjustments were performed for age, sex and primary kidney disease categories

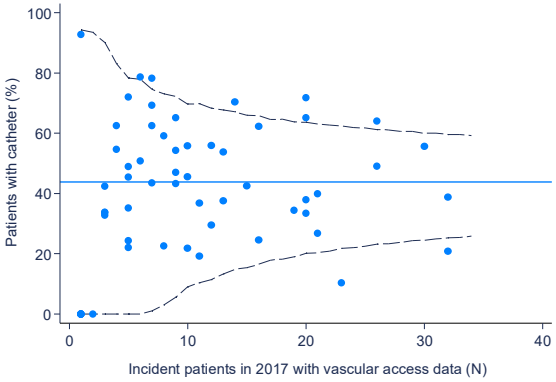


Figure 9.7. Centre variation in catheter use in incident patients. Adjustments were performed for age, sex and primary kidney disease categories.

10 Conclusions

This annual report concerning renal replacement therapy in the Netherlands in 2017 shows a decrease in incident RRT patients, whereas the prevalence of RRT patients still has increased due to renal transplantation. Incident declines are observed over all therapies, i.e. haemodialysis, peritoneal dialysis and kidney transplantation. From a few additional analyses, we think that this decline is not fully due to the new European GDPR directive and the ensuing refusals to be included in the Renine registry. The actual cause of this decline, however, cannot be derived from the registry. Possibly, they are intended consequences of preventive strategies in chronic kidney disease that started in 2009 (LTA Chronic Kidney Disease) and the increased attention for conservative therapy in elderly patients with CKD 5.
The proportion of patients on home dialysis remained stable. It is important that the decline of previous years does not continue, but, however, all efforts to stimulate home dialysis have not resulted in an increase in the number of prevalent home dialysis patients in 2017.

In the present report, we have tried to provide more insight in variation among dialysis centres. These appear to be present in the proportion of home dialysis patients, the proportion of patients starting RRT with an pre-emptive kidney transplant and the proportion of patients using a central-venous catheter for haemodialysis access. It is important to evaluate further practices of those centres that appear to have results outside the confidence intervals: from these centres it can be learned what success factors and fail factors are with respect to these outcomes. Furthermore, in the upcoming annual reports, analyses addressing variation among institutions will be elaborated in more detail, especially since visitation of dialysis centres in the Netherlands appears to move into a more outcome oriented approach.

Appendix A Methods and definitions

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

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

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

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

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

Survival analysis
Cumulative incidence curves were plotted using the Fine and Gray method for competing events. Subject were censored in case of recovery of renal function, loss to follow-up or end of follow-up time (December 31th 2017). Survival was analyzed from day 1 of chronic dialysis treatment. The cumulative incidence curves were adjusted for fixed values of age (50 years for the age category <65 years and 70 years for the age category ≥65 years), sex (63% men) and primary kidney disease categories (24% Diabetes; 19% Hypertension/renal vascular disease; 11% Glomerulonephritis; 46% Other causes).

Funnel plots
Centre variations in the year 2017 are presented by funnel plots. In these plots a centre-specific mean or percentage is plotted against a variable indicating centre size. For binary and continuous outcomes 95%-confidence intervals were plotted based on the binomial and normal distribution respectively. Funnels are plotted around the average estimate over all centres. Any centres which fall outside the 95%-confidence intervals of the funnels are significantly different from the average. The funnel shape of the limits reflects the fact that for smaller centres a greater observed difference from the average is required for it to be statistically significantly different. To account for differences in case-mix a number of adjustments were performed. For binary outcomes a logistic model with age, sex, 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-EDTA 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)

Category	ERA-EDTA code	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
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

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

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

Category	ERA-EDTA code	Cause of death
	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