Nefrovisie
Richtlijnen · Registratie · Visitatie

RENINE annual report 2019

Nefrovisie
Richtlijnen · Registratie · Visitatie

Dutch Federation for Nephrology

Zicht op nierzorg

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Contents

1. Introduction

We are pleased to present the Renine Annual Report 2019. Renine is the Dutch registry on chronic renal replacement therapy. Chronic renal replacement therapy 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 renal transplantations, date of transplantation and type of transplantation are provided by the 'Nederlandse Transplantatie Stichting' (NTS). The coverage ratio of Renine is 96% of the prevalent patients and 93% for incident patients.

A number of measures are being taken to ensure a high quality of the data. Data up to December 31st 2019 was checked and approved by the dialyses centres. Nefrovisie performs data verification visits of the dialysis centres at 3-year intervals.

Data from Renine enables accurate monitoring of the quality of care of renal replacement therapy in the Netherlands. Together with stakeholders we continuously work on the improvement of the reporting of the data to advance transparency of renal care. Data from Renine is interactively available at www.nefrodata.nl. In this report we provide additional analyses of the data up to 2019.

New in this report is information on Patient Reported Outcome Measures (PROMs) in the dialysis population. This includes a quality of life questionnaire (SF-12) and a disease specific symptoms questionnaire (DSI). For 2019 over 1500 PROMs are available originating from 48 centres and the number of participating centres is growing. Nefrovisie facilitates the use of PROMs in clinical care, and so far the experiences show that this has added value. The analyses on PROMs will be expanded over the coming years.

We plan to expand the registry to earlier phases of chronic kidney disease. The coming year pilots will be performed for the CKD3-5 population. To limit the registration burden to a minimum we will focus on data collection from the electronic patient databases.

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

Marc ten Dam, CEO Nefrovisie

2. Renal replacement therapy: key figures of 2019

Table 1. Characteristics of prevalent renal replacement therapy patients registered in Renine on December 31th 2019 (N=17,933).*

Modality	**N**	**%**
Haemodialysis	5,362	30
Peritoneal dialysis	931	5
Transplant	11,640	65
Sex	**N men**	**% men**
Dialysis patients	3,795	60%
Transplant patients	7,062	61%
Primary kidney disease	**N**	**%****
Glomerulonephritis/sclerosis	2924	16
Pyelonephritis	1119	6
Polycystic kidney disease	1554	9
Hypertension	2125	12
Renal vascular disease	1090	6
Diabetes type 1	653	4
Diabetes type 2	1732	10
Miscellaneous	3760	21
Unknown	2967	17
Age (year)	**Mean (SD)**	
Dialysis patients	67 (15)	
Transplant patients	57 (15)	
Duration renal replacement therapy (year)	**Mean (SD)**	
Dialysis patients	4.9 (6.4)	
Transplant patients	13.0 (9.7)	

*268 prevalent RRT patients (not included in this table) did not provide consent for their data to be included in Renine. The coverage in 2019 was 96%. ** The percentages do not add up to 100% due to rounding.

Table 2. Characteristics of incident renal replacement therapy patients registered in Renine in 2019 (N=1922)*.

Modality at start RRT, at day 1	**N**	**%**
Haemodialysis	1,328	69
Peritoneal dialysis	323	17
Transplant	271	14
Sex	**N men**	**% men**
Dialysis patients	1054	64
Transplant patients	159	59
Primary kidney disease	**N**	**%****
Glomerulonephritis/sclerosis	193	10
Pyelonephritis	60	3
Polycystic kidney disease	96	5
Hypertension	270	14
Renal vascular disease	209	11
Diabetes type 1	62	3
Diabetes type 2	289	15
Miscellaneous	425	22
Unknown	318	17
Age (year)	**Mean (SD)**	
Dialysis patients	65 (15)	
Transplant patients	54 (16)	

* 132 incident RRT patients (not included in this table) did not provide consent for their data to be included in Renine (6%) **The percentages do not add up to 100% due to rounding.

3. Renal replacement therapy: prevalence and incidence

On December 31st 2019 17,933 prevalent patients on renal replacement therapy (RRT) were registered in Renine (Figure 3.1). This equals 1,030 patients per million of the total population in the Netherlands (Figure 3.2). RRT prevalence shows a steady increase over time. Incidence, i.e. the number of new patients per calendar year, remained more or less stable over the last decade. In 2019 incidence of RRT was 1,922 patients, which equals 110 patients per million population. Both prevalence and incidence of RRT are higher in men than in women. On December 31st 2019 60% of prevalent RRT patients were male. Of the patients starting RRT in 2019 63% was male.

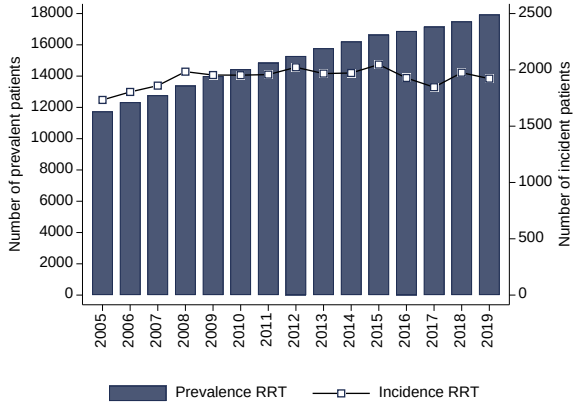


Figure 3.1. Prevalence and incidence of renal replacement therapy.

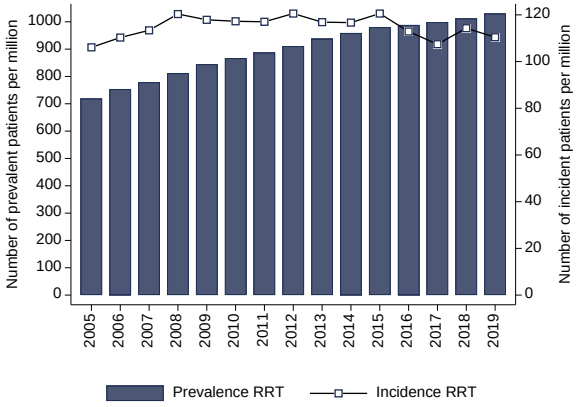


Figure 3.2. Prevalence and incidence of renal replacement therapy expressed per million population.

The proportion of elderly patients in the prevalent RRT population is steadily increasing (Figure 3.3). On December 31st 2019 45% of patients on renal replacement therapy were 65 years or older and 19% were 75 years or older. A decade ago (2009) this was 37% and 16% respectively. Mean age of the prevalent RRT population increased from 58 years (SD=16) to 61 years (SD=16) during this period.
The number of prevalent patients relative to the size of the age related population is increasing in all age categories above 45 years of age (Figure 3.4).

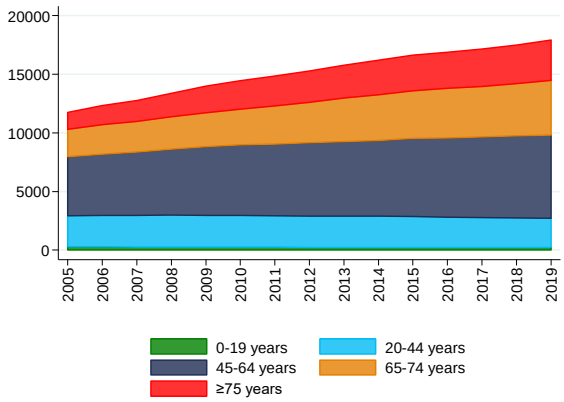


Figure 3.3 Prevalence of renal replacement therapy by age categories.

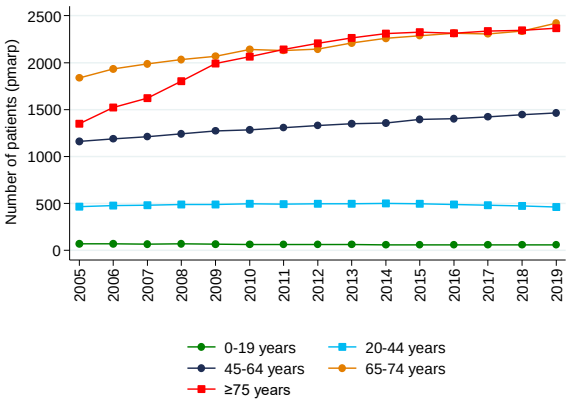


Figure 3.4.Prevalence of renal replacement therapy by age categories expressed per million age related population

Figure 3.5 shows the distribution of dialysis patients and patients living with a functioning renal transplant over time stratified for different age categories.

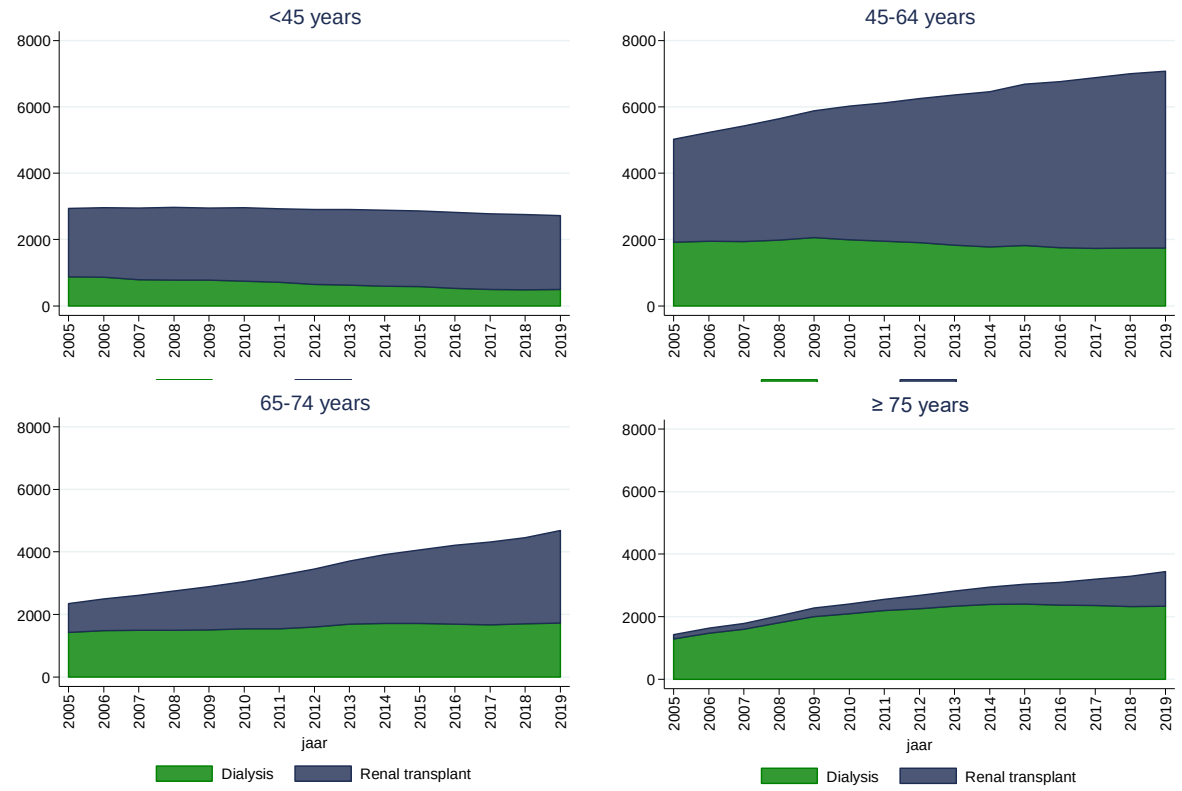


Figure 3.5.Prevalence of dialysis and renal transplants stratified by age categories.

Time trends in incidence of RRT in absolute numbers and relative to the size of the population are shown stratified for age categories in Figures 3.6 and 3.7 respectively. Relative incidence shows a clear downwards trend for the population of 75 years and older. In 2019 317 incident RRT patients per million age-related population were registered for this age category. In 2009 this was 496 per million.

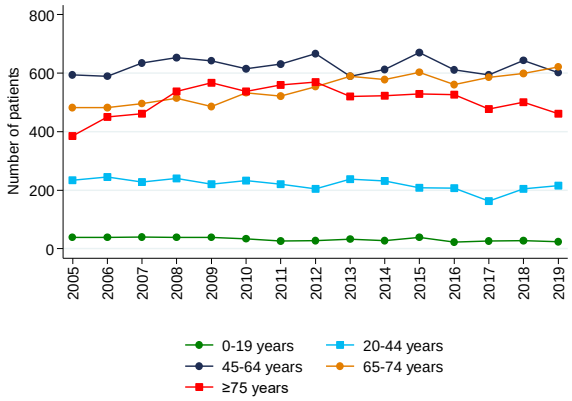


Figure 3.6. Incidence of renal replacement therapy stratified for age categories.

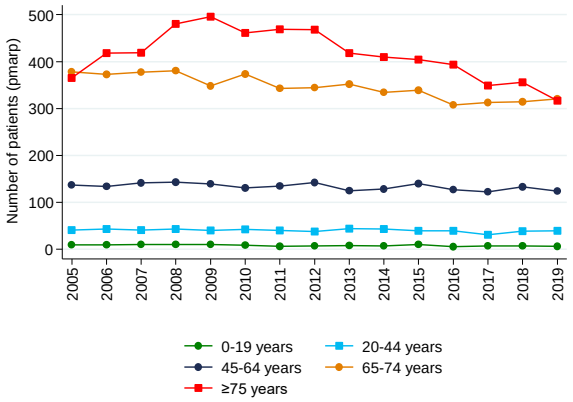


Figure 3.7. Incidence of renal replacement therapy expressed per million age related population stratified for age categories.

Most incident RRT patients start treatment by means of haemodialysis. In 2019 the distribution over the start modalities was 68% haemodialysis, 17% peritoneal dialysis and 14% pre-emptive transplantation. In Figure 3.8 the time trends of the different start modalities are shown stratified by age categories.

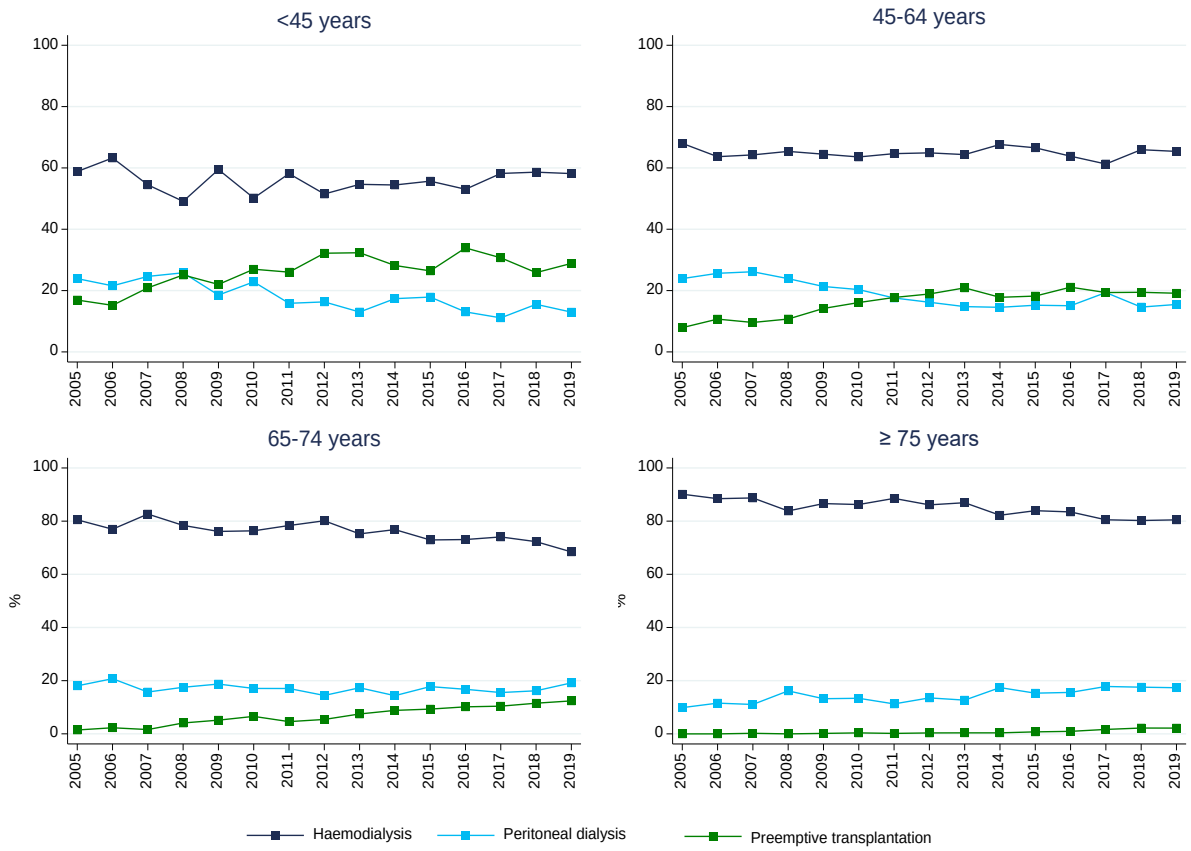
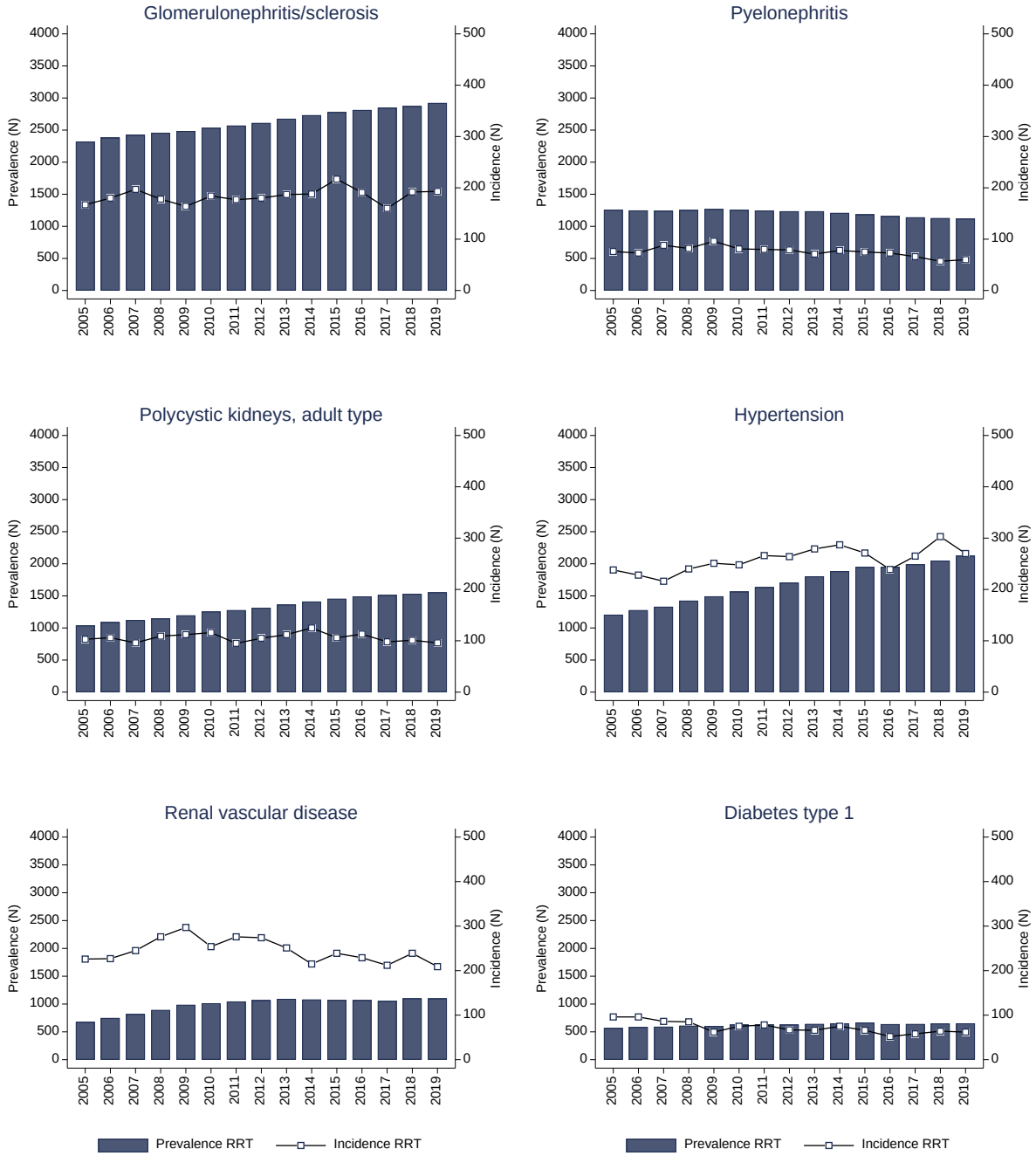


Figure 3.8. Distribution of start modalities in incident RRT patients over time stratified for age categories.

Figure 3.9 shows time trends in prevalence and incidence for different primary kidney disease categories. The most common PRD category is the category “miscellaneous”, for 2019 21% of the prevalent patients and 20% of incident RRT patients fell in this category. Within this PRD category “Other identified renal disorders” was the prominent indicated PRD.



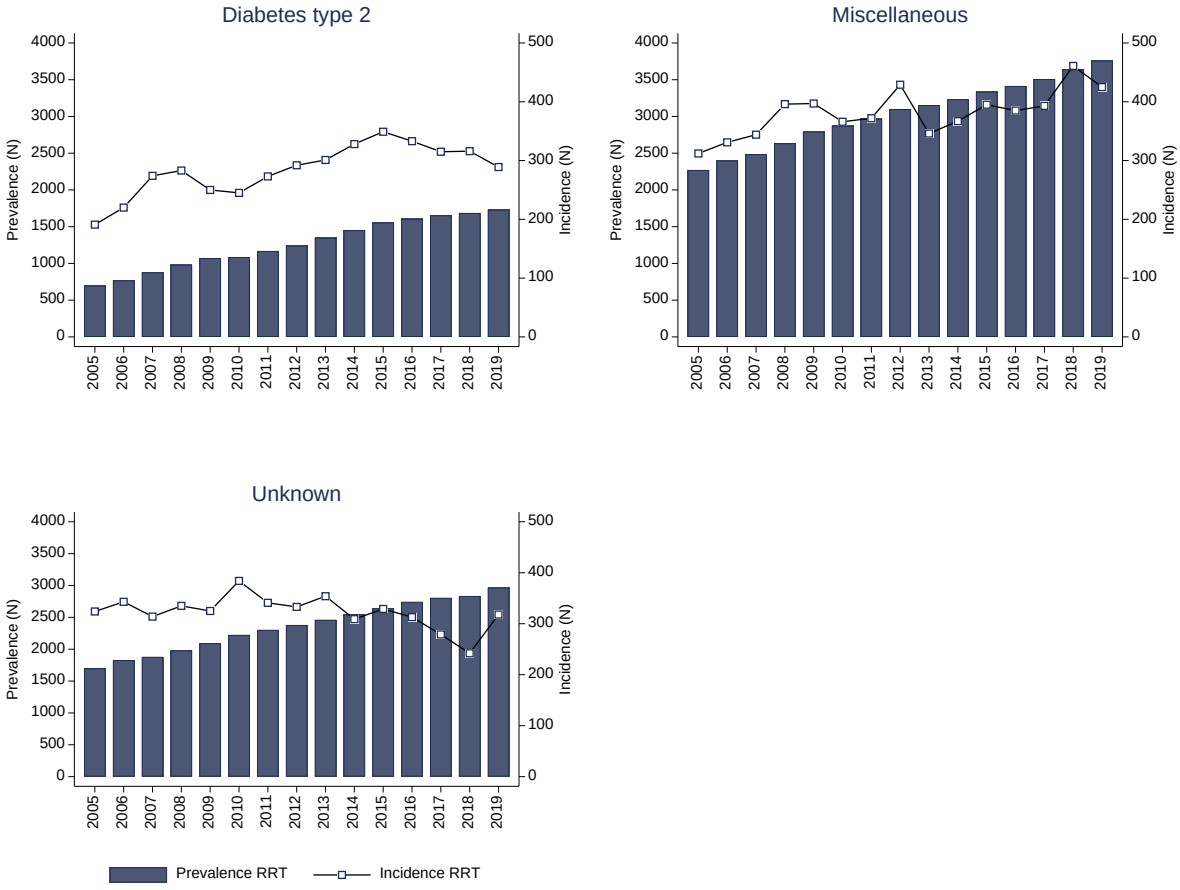


Figure 3.9. Incidence and prevalence of renal replacement therapy stratified for primary kidney disease categories.

4. Dialysis treatment

Over recent years the number of patients treated with chronic dialysis remained rather constant (Figure 4.1). Prevalence includes all patients on dialysis treatment, irrespective of their RRT history. On December 31st 2019, 6,293 patients were on chronic dialysis treatment. Of these patients 37% were 75 years or older.

In 2019 1,906 patients started chronic dialysis therapy. The majority of these patients (i.e. 88%) started chronic dialysis treatment for the first time and 235 patients (12%) restarted dialysis treatment, for example after a graft failure. For the remaining of this chapter incidence of dialysis only includes first-time start of chronic dialysis treatment.

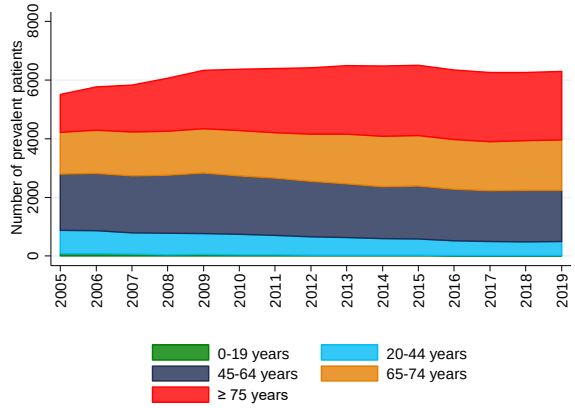


Figure 4.1. Prevalence of dialysis (December 31th) by age categories.

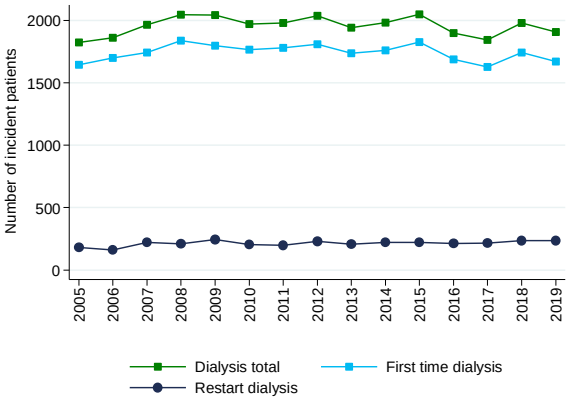


Figure 4.2. Incidence of dialysis per year. A distinction was made between patients receiving chronic dialysis for the first time and patients with dialysis treatment in the past restarting dialysis treatment.

The sex specific incidence of dialysis treatment per million population shows different time trends for men than for women (Figures 4.3 and 4.4). In men, in 2009 a peak was observed for the age category ≥75 years with a steady decrease afterwards. Incidence in women is lower and more constant over time.

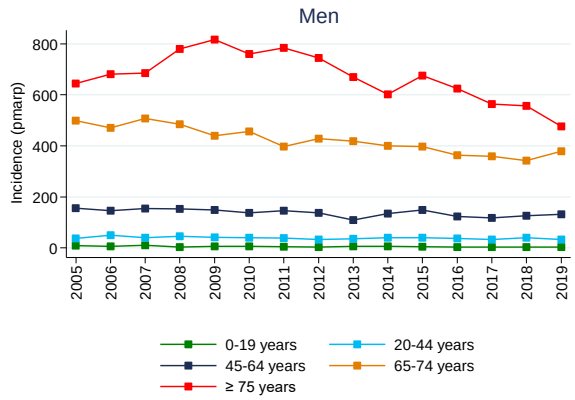


Figure 4.3. Incidence per million age related population of first-time dialysis stratified for age categories in men

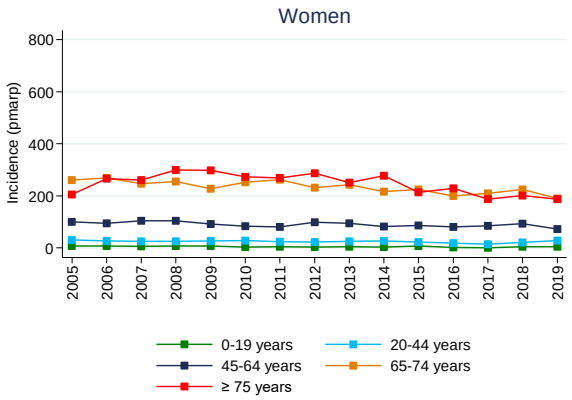


Figure 4.4. Incidence per million age related population of first-time dialysis stratified for age categories in women.

Haemodialysis remains the most performed dialysis modality. In 2019, 15% of prevalent dialysis patients were treated with peritoneal dialysis (Figure 4.5), whereas 20% of the new dialysis patients started with peritoneal dialysis (Figure 4.6). These percentages were more or less stable over recent years.

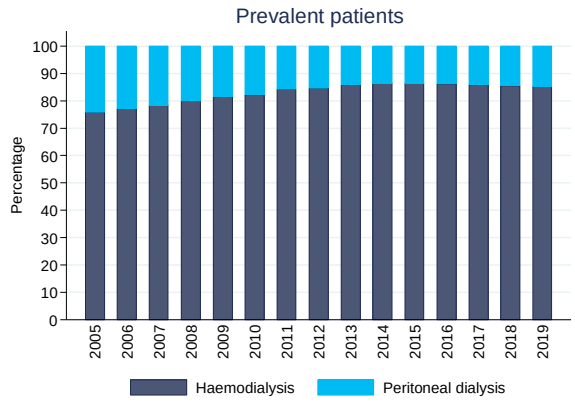


Figure 4.5. Distribution of haemodialysis and peritoneal dialysis in prevalent chronic dialysis patients. (Date: December 31th of each year).

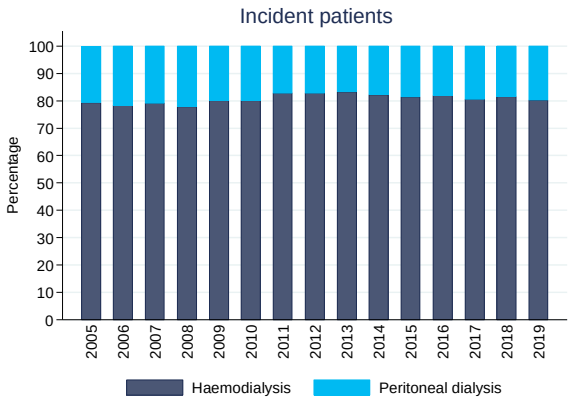


Figure 4.6. Distribution of haemodialysis and peritoneal dialysis in incident chronic dialysis patients per year.

Figures 4.7 shows percentages of chronic dialysis in different age categories that are being treated with home-based dialysis modalities, i.e. peritoneal dialysis and home haemodialysis. Over time decreases in peritoneal dialysis were observed for younger patients. Although this seems to stabilize in recent years. A small proportion of dialysis patients is treated with home haemodialysis. On December 31st 2019 287 patients were registered on this modality, which equals 5% of all dialysis patients. In older patients the percentage treated with home haemodialysis is on the rise.

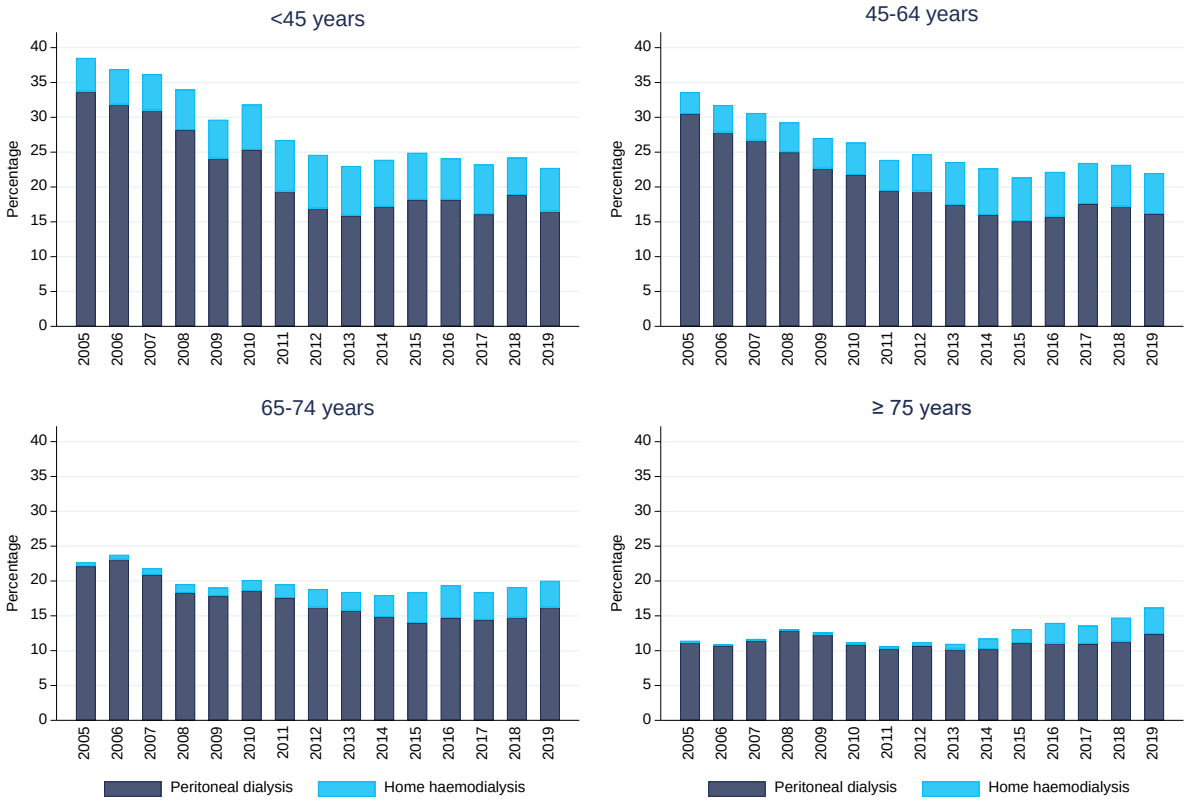


Figure 4.7. Percentages of prevalent dialysis patients treated with home-based dialysis modalities

The proportion of patients treated with home dialysis (home haemodialysis or peritoneal dialysis) shows substantial variation among centres (Figure 4.8). In this analysis we looked at treatment modality 3 months after start of chronic dialysis treatment to account for the time needed to prepare for home (haemo-)dialysis. To account for differences in case-mix between dialysis centres adjustments were made for age, sex, socioeconomic status (SES), and categories of primary kidney disease).). See Appendix A for an explanation on funnel plots.

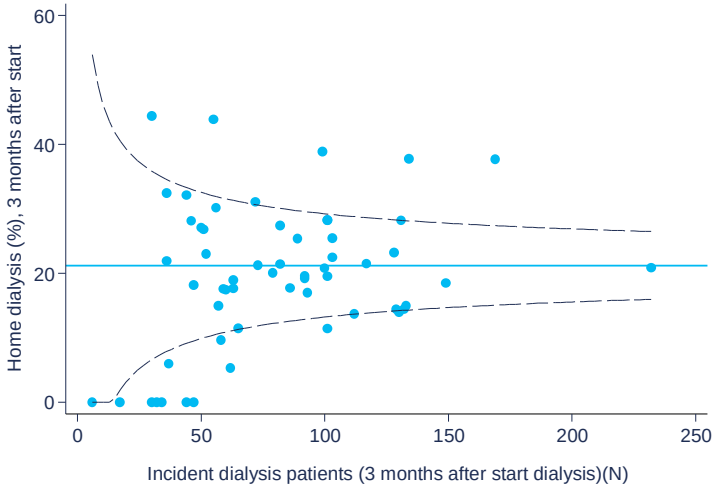


Figure 4.8. Center variation in percentage home dialysis three months after start dialysis. Home dialysis includes peritoneal dialysis and home haemodialysis. Data is adjusted for age, sex, SES, and primary kidney disease categories.

Figures 4.9 and 4.10 show the status of patients one and three year after the start of haemodialysis and peritoneal dialysis as first dialysis modality respectively. Mortality was higher and transplantation rates were lower in haemodialysis compared to peritoneal dialysis. This is possibly due to differences in case-mix. During the first year of treatment more patients switched from peritoneal to haemodialysis than vice versa. This trend is also observed after three years of follow-up. Of the patients who started haemodialysis in 2018 72% were still on haemodialysis treatment one year later, 4% switched to peritoneal dialysis, 6% received a transplant and 18% died. In peritoneal dialysis the percentages that switched to either haemodialysis or received a transplant were somewhat higher, i.e. 15% switched to haemodialysis and 9% had a functioning renal transplant one year after they started peritoneal dialysis. After start of peritoneal dialysis, mortality was 10% in the first year.

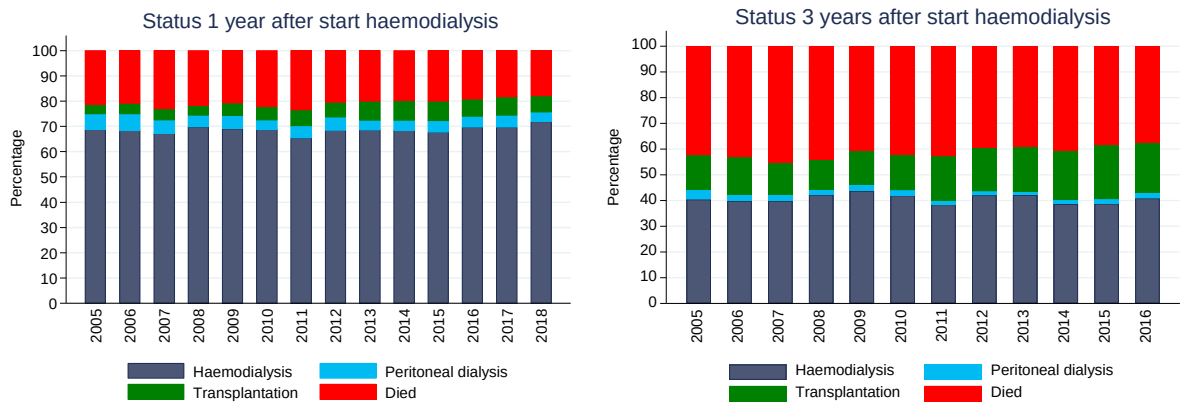


Figure 4.9. Status one and 3 year after start HD as percentage. The year represents the year in which HD was started.

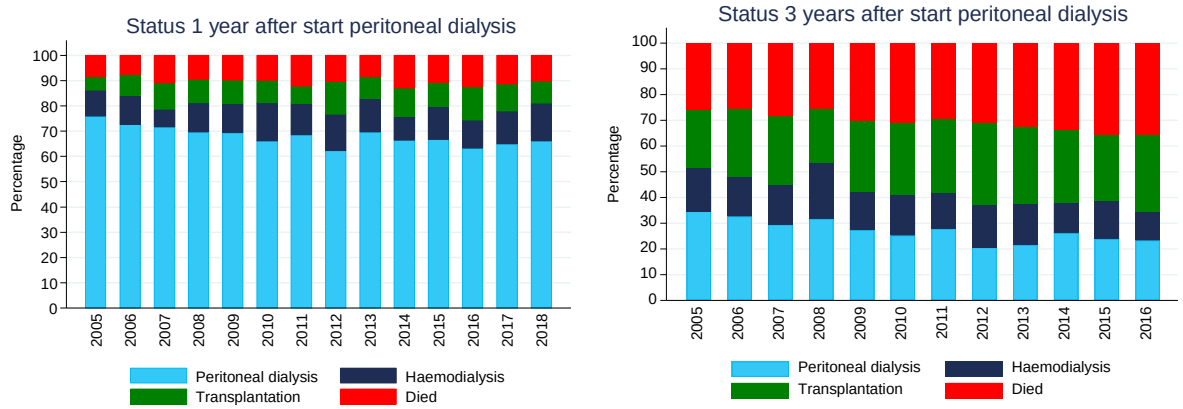


Figure 4.10. Status one and 3 year after start PD as percentage. The year represents the year in which HD was started.

Figures 4.11 and 4.12 show centre variation in the percentages switches between modalities during the first year on dialysis in funnel plots. To account for differences in case-mix between dialysis centres adjustments were made for age, sex, socioeconomic status, and categories of primary kidney disease. In these analyses modality at three months after start of dialysis was taken as initial modality. Only patients still on dialysis after one year were included.

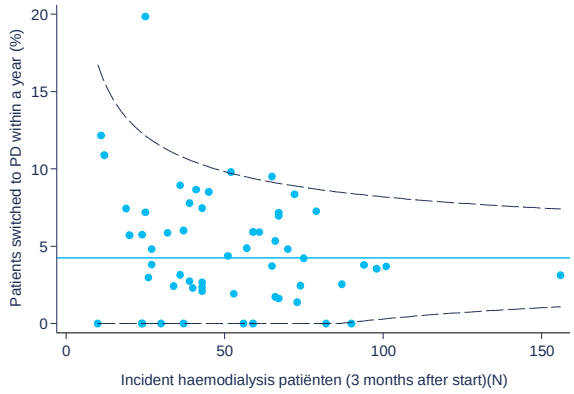


Figure 4.11. Centre variation in switches from HD to PD. Patients were included if on HD 3 months after start dialysis and still on dialysis after one year. Adjustments were performed for age, sex, SES, and primary kidney disease categories.

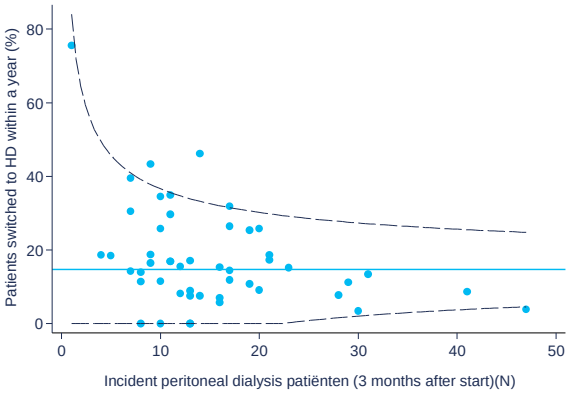


Figure 4.12. Centre variation in switches from PD to HD. Patients were included if on PD 3 months after start dialysis and still on dialysis after one year. Adjustments were performed for age, sex, SES and primary kidney disease categories.

5. PROMS in dialysis patients

Registry of patient-reported outcome measures (PROMs) in Renine started in 2018. The PROMs consist of two questionnaires; the 12-item short form (SF-12) health survey to assess health-related quality of life and the Dialysis Symptom Index (DSI) to assess symptom burden. In 2019 1,570 PROMs assessments from 1,327 unique patients were registered in Renine. This equals 21% of the prevalent dialysis population.

A small subsample of the patients filled out multiple PROMs throughout the year. The maximum number of available PROMs per person was 4 (N=5). In Table 5.1 patient characteristics of patients with at least one available questionnaire in 2019 are reported. Characteristics of the total prevalent dialysis population in the participating centres are also shown for comparison. Haemodialysis patients are overrepresented in the patients with PROMs available and also have a shorter dialysis vintage compared to the overall prevalent dialysis population.

Table 5.1. Characteristics of dialysis patients with at least one PROMs measurement available in 2019 in comparison to the overall dialysis population in the centres participating in the PROMS collection.

	PROMS available*	Total (participating centres**)
N	1,327	5,003
Age (yrs)	67 (14)	68 (14)
Age categories		
<45 yrs	8%	7%
45-64 yrs	29%	28%
65-74 yrs	30%	27%
≥75 yrs	34%	37%
Socio-economic status		
Low	47%	54%
Intermediate	31%	27%
High	22%	19%
Dialysis vintage (yrs)	2.0 (0.6-4.7)	2.5 (1.1-5.1)
History transplantation	12%	11%
Male (%)	61%	59%
Haemodialysis (%)	89%	85%

* Patient characteristics were determined at the date of the first available questionnaire for a patient.
** Only includes dialysis patients in centres participating in PROMs data collection. Reference date is July 1st 2019.

Information on the exact number of invitations to patients to fill out the PROMs is lacking. Therefore, it is not possible to validly estimate response rates.

Figures 5.1 and 5.2 show the distributions of both the physical and mental scores of the SF-12 questionnaire. The means physical component score is 36 (SD=10). Scores on the mental component were higher with a mean value of 48 (SD=10). The distribution of the mental component score is somewhat skewed. The median value was 51. Women scored slightly lower than men on the physical component score (34 versus 37, P<0.001). For the mental scores no differences were observed. Patients of 65 years and older scored lower on the physical component (35 versus 37, P<0.001) than the younger patients. However, they scored higher on the mental score (49 versus 47, P<0.001).

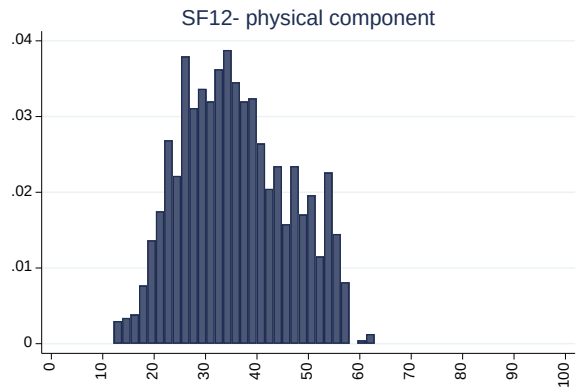


Figure 5.1. Distribution of scores of the physical component of the SF-12.

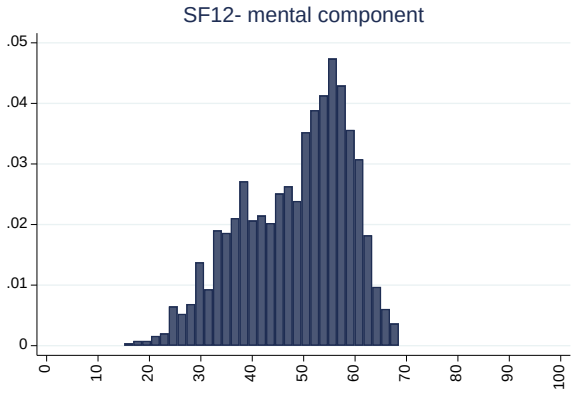


Figure 5.2. Distribution of scores of the mental component of the SF-12.

Patients experienced on average 10.7 out of 30 symptoms (SD=6.4). Figure 5.4. shows the distribution of the number of symptoms that patients registered to experience. Women reported slightly more symptoms than men (11.2 versus 10.4, P=0.01). No differences in number of experienced symptoms were observed for patients younger and older than 65 years.

In the following tables the 10 most frequently reported symptoms and the most burdensome symptoms are reported separately for men and women. More women than men experience tiredness, dry skin and muscle cramps. In men sexual problems are reported to be most burdensome.

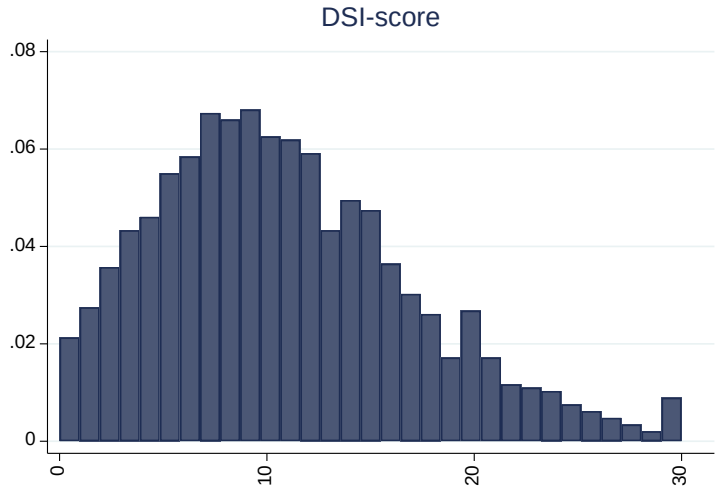


Figure 5.3. Distribution of the number of experienced symptoms (DSI).

Table 5.2. Top 10 most frequent symptoms separately for men and women

Men		Women	
Feeling tired/lack of energy	73%	Feeling tired/lack of energy	77%
Dry skin	52%	Dry skin	68%
Trouble staying asleep	51%	Muscle cramps	56%
Muscle cramps	51%	Trouble staying asleep	52%
Itching	49%	Dry mouth	50%
Dry mouth	45%	Bone or joint pain	49%
Shortness of breath	44%	Itching	47%
Trouble falling asleep	43%	Trouble falling asleep	44%
Bone or joint pain	41%	Coughing	43%
Decreased interest in sex	41%	Restless legs	43%

Table 5.3. Top 10 most burdensome symptoms

Men	Mean score	Women	Mean score
Difficulty becoming sexually aroused	3.27	Trouble falling asleep	3.24
Decreased interest in sex	3.14	Difficulty becoming sexually aroused	3.19
Trouble falling asleep	3.07	Trouble staying asleep	3.17
Feeling tired/lack of energy	3.06	Feeling tired/lack of energy	3.13
Trouble staying asleep	3.06	Bone or joint pain	3.13
Itching	3.01	Decreased interest in sex	3.05
Bone or joint pain	2.95	Dry skin	3.04
Dry skin	2.89	Numbness or tingling in feet	3.02
Restless legs	2.87	Restless legs	3.01
Numbness or tingling in feet	2.83	Itching	2.91

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

6. Survival on renal replacement therapy

In 2019 1,387 patients died on renal replacement therapy. The majority of deaths (n=1,103) were in patients on dialysis therapy.

Crude survival estimates for incident dialysis patients are shown in Table 6.1. Results are shown both with and without censoring for a renal transplant. Slightly improved estimates were observed for patients starting dialysis in the period 2015-2018 compared to patients who started in the time period 2010-2014.

Table 6.1. Survival probabilities for incident dialysis patients presented as % (95% CI).

	1-year survival		3-year survival	
Age at start	**Cohort 2010-2014**	**Cohort 2015-2018**	**Cohort 2010-2014**	**Cohort 2015-2018**
<45 yrs	98 (97-99)	98 (97-99)	95 (94-96)	96 (94-97)
45-64 yrs	93 (92-93)	94 (93-95)	81 (80-83)	83 (81-85)
>65 yrs	81 (80-82)	84 (82-85)	55 (54-57)	58 (56-60)
Transplantation as censoring event				
Age at start	**Cohort 2010-2014**	**Cohort 2015-2018**	**Cohort 2010-2014**	**Cohort 2015-2018**
<45 yrs	98 (96-98)	97 (95-98)	91 (88-93)	93 (89-96)
45-64 yrs	91 (89-92)	93 (92-94)	73 (71-75)	76 (73-78)
>65 yrs	80 (79-81)	82 (81-83)	52 (51-54)	53 (51-55)

Survival probabilities after a first kidney transplantation are presented in table 6.2. Survival after a transplantation from a living donor is higher than after a transplantation from a deceased donor.

Table 6.2. Survival probabilities after first kidney transplantation presented as % (95% CI).

	3-year survival		5-year survival	
Age at transplant	**Living**	**Post mortal**	**Living**	**Post mortal**
<45 yrs	99 (98-99)	96 (93-97)	98 (96-99)	94 (91-96)
45-64 yrs	96 (95-97)	91 (89-93)	92 (90-94)	85 (83-88)
>65 yrs	90 (87-93)	81 (78-83)	77 (73-81)	67 (63-70)

Inclusion period: 2012-2018.

In Figures 6.1 and 6.2 centre variation is shown for 1-year and 3-year mortality in incident dialysis patients. The data was adjusted for age, sex, SES, and primary kidney disease categories. However, other important factors affecting prognosis such as comorbidities are not available. Results should therefore be interpreted with caution.

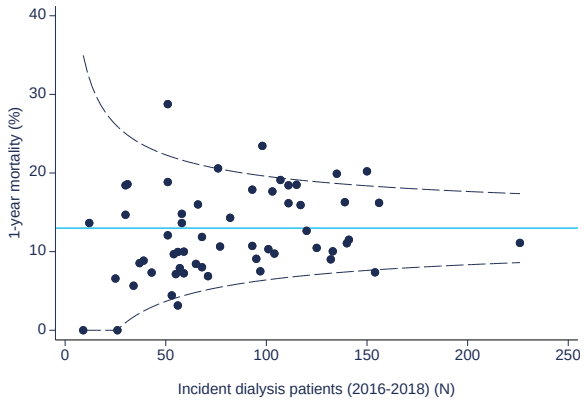


Figure 6.1. Centre variation in 1-year mortality in incident patients. Inclusion period 2015-2017. Adjustments were performed for age, sex, SES, and primary kidney disease categories

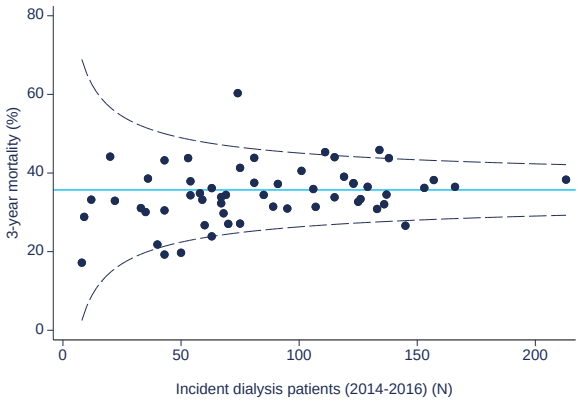


Figure 6.2. Centre variation in 3-year mortality in incident dialysis patients. Inclusion period 2013-2015. Adjustments were performed for age, sex, SES, and primary kidney disease categories

Figure 6.3 shows the cumulative incidence of death and receiving a kidney transplant for incident dialysis patients by primary kidney disease categories. Patients with glomerulonephritis or cystic disease have the highest chances of receiving a kidney transplant in the 5-year period after they started dialysis. Mortality is lower for these patients than for the other PRD categories.

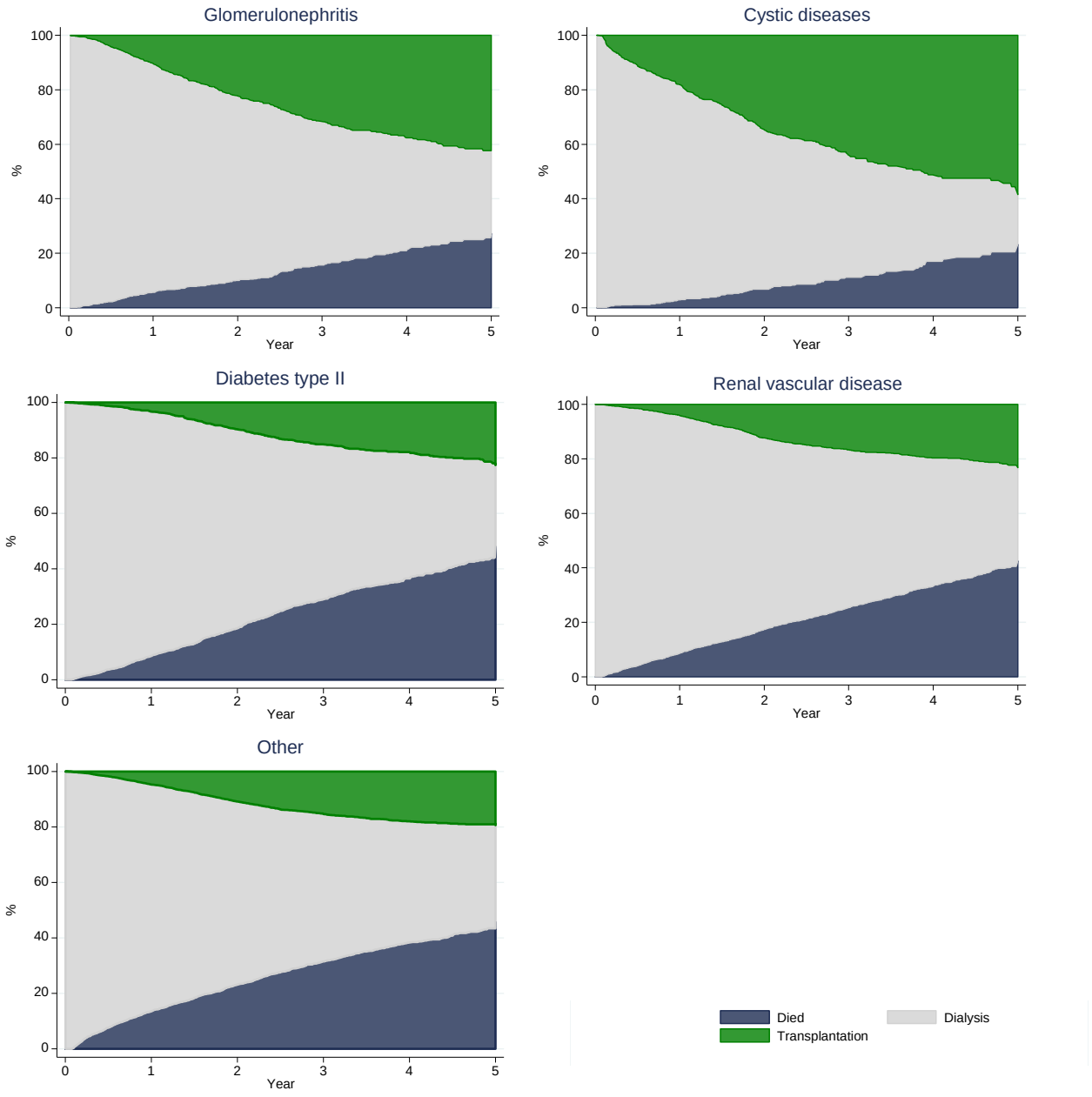


Figure 6.3. Survival and transplantations in incident dialysis patients stratified for primary kidney disease categories. Inclusion period 2012-2018. Competing risk analyses were performed (Fine and Gray method). Adjustment was done using fixed values of age and sex

Causes of death were coded according to the ERA-EDTA coding system and grouped according to the categorization as applied by the UKRR (Appendix C). 'Treatment stop' is the most common cause of death in dialysis patients (Figure 6.4 and 6.5), i.e.in 2019 31% off all deaths on dialysis were in this category (N=345). 'Treatment stop' is more common in elderly patients (Figure 6.6 and 6.7).

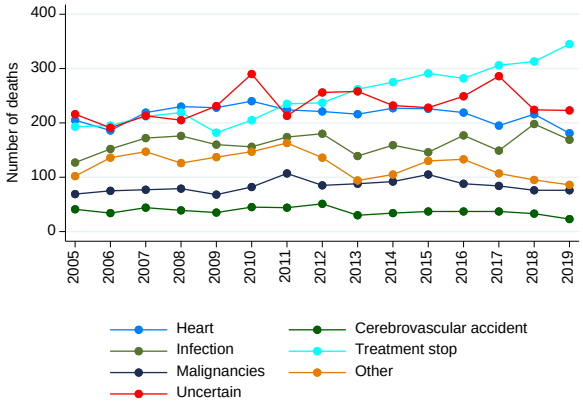


Figure 6.4. Causes of death over time

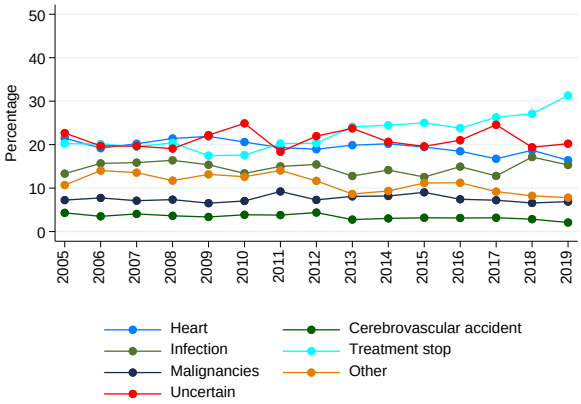


Figure 6.5. Causes of death expressed as percentages of total number over time

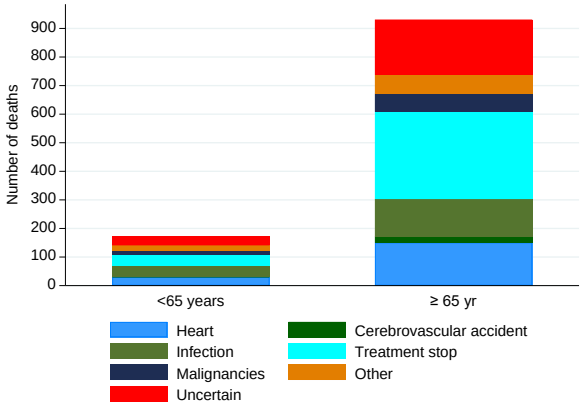


Figure 6.6. Number of deaths in 2019 in patients on dialysis younger and older than 65 years.

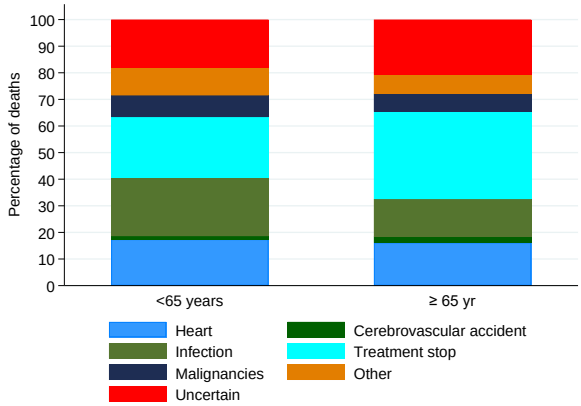


Figure 6.7. Causes of death in 2019 in patients on dialysis younger and older than 65 years as percentage

7. Renal transplantations

The number of prevalent patients living with a functional renal transplant shows a steady increase over time (Figure 7.1). On December 31th 2019 11,640 prevalent patients were registered in Renine, which is 65% of all patients on renal replacement therapy. The increase is mostly because of an increase in patients numbers with renal transplants from living donors. In 2019 52% of the prevalent transplant patients were living with a transplant from a living donor (Figure 7.2).

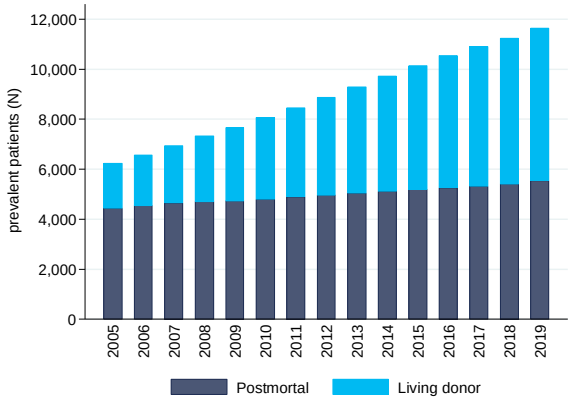


Figure 7.1. Number of prevalent transplant patients according to donor type

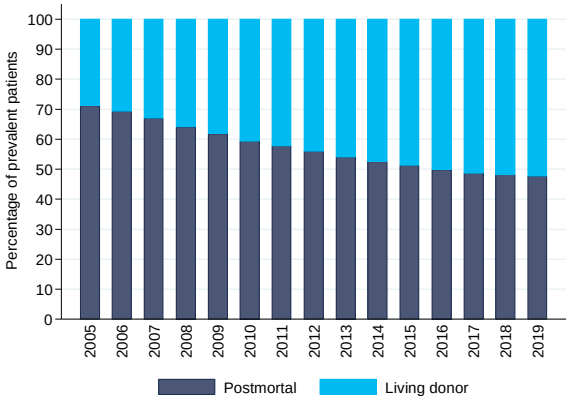


Figure 7.2. Percentage of prevalent transplant patients according to donor type

The prevalent transplant population consist of a growing proportion elderly patients (Figure 7.3). Elderly patients more often have a transplant from a post mortal donor compared to the younger patients (Figure 7.4).

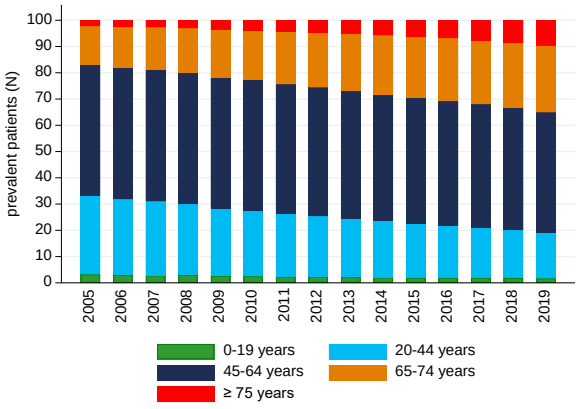


Figure 7.3. Prevalent transplant patients stratified for age categories

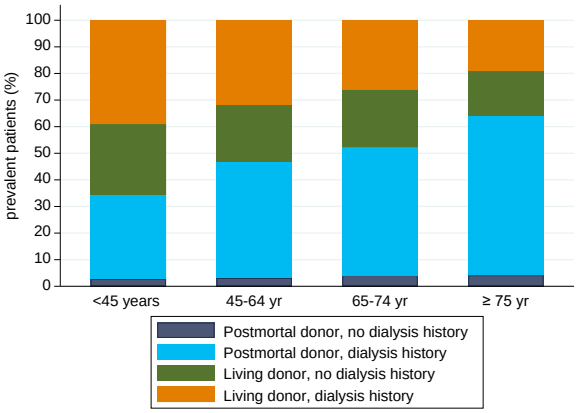


Figure 7.4. Distribution of renal transplant types in age categories in prevalent patients in the year 2019

Over time an increase in pre-emptive transplantations is observed (Figure 7.5). In 2019 271 pre-emptive transplantations were registered in Renine which is 29% of all transplantations. The number of renal transplantations following dialysis treatment shows a slight downwards trend. In Figure 7.6 transplantations are grouped into four categories based on donor type and whether or not the patient had a dialysis history.

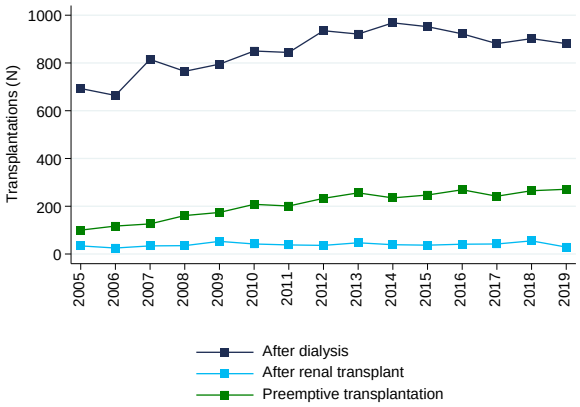


Figure 7.5. Transplantations according to preceding therapy.

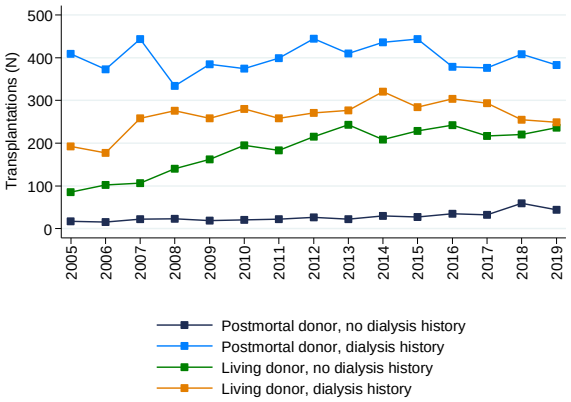


Figure 7.6. Number of different types of renal transplantations over time

Substantial variation between centre variation exists regarding the proportion of incident patients starting RRT therapy by means of a pre-emptive renal transplant (Figure 7.7). Figure 7.8 shows centre variation in the percentage of prevalent dialysis patients that received a renal transplant in 2019. In these analyses patients were included aged 18-75 years. The analyses were adjusted for age, sex, SES, and primary kidney disease categories.

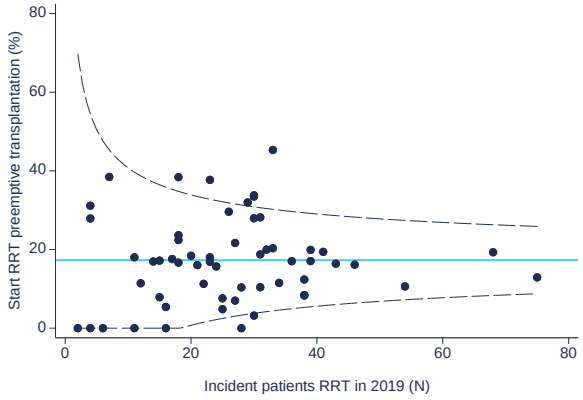


Figure 7.7. Centre variation in percentage pre-emptive transplantations in incident RRT patients in 2019. Adjustments were performed for age, sex, SES, and primary kidney disease categories.

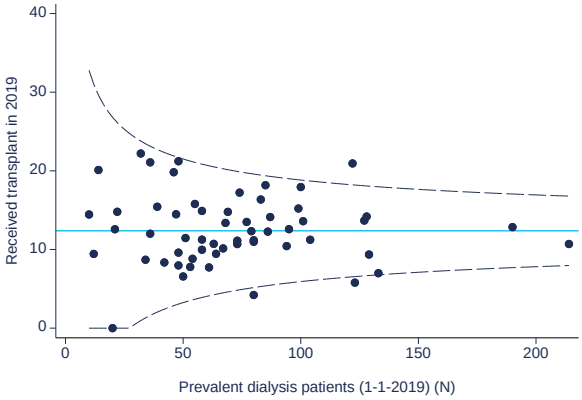


Figure 7.8. Centre variation in percentage of prevalent dialysis patients on January 1st that received a transplant in 2019. Adjustments were performed for age, sex, SES, and primary kidney disease categories.

Figure 7.9 shows the number of months patients were treated with dialysis separately for recipients of post mortal and living donor renal transplants. Time on dialysis shows a steep downwards trend for the post mortal transplantations.

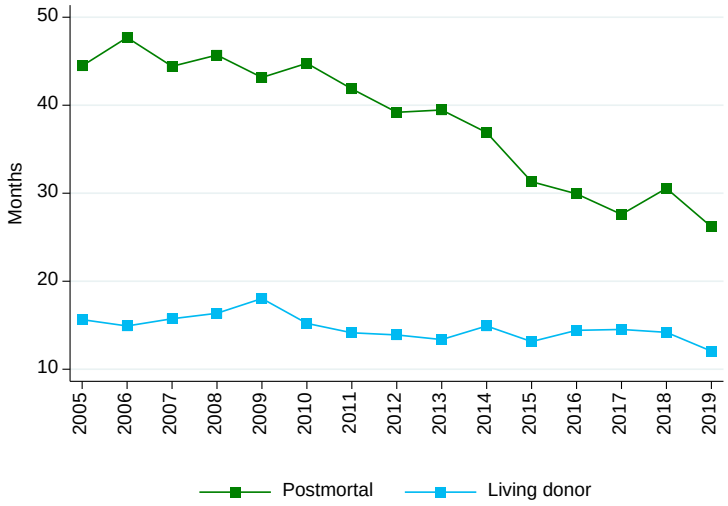


Figure 7.9. Time on dialysis in months in recipients of post-mortal and living donor renal transplants

8. Clinical data dialysis patients

Clinical variables such as laboratory measurements, details of dialysis treatment and vascular access data of dialysis patients are being registered four times per year. Since 2016 registration of clinical variables is a mandatory component of the Renine registry. This resulted in a steep increase in availability of data in that year. For 2019 completeness of the data was 90% for phosphate levels (Figure 8.1) in dialysis patients and 91% for vascular access in haemodialysis patients (Figure 8.2). Over the years completeness of clinical data is increasing. In 2016 for 27% of the dialysis patients no clinical data was available. This percentage decreased to 6% in 2019.

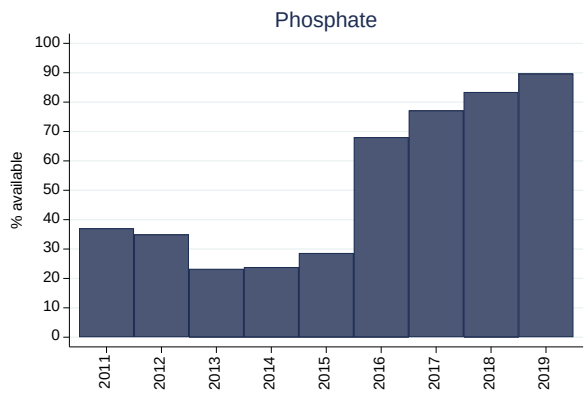


Figure 8.1. Availability of phosphate measurements per year expressed as percentage of the total number of potential measurements.

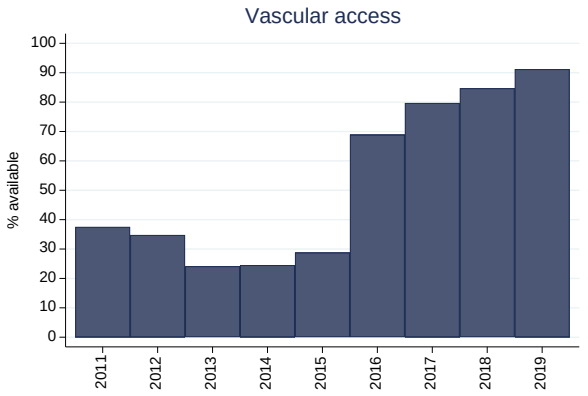


Figure 8.2. Availability of vascular access data per year as percentage of the total number of potential measurements

Figure 8.3. shows categories of clinical indicators stratified for age categories. Boundaries of the categories were chosen arbitrarily as clinical guidelines do not provide clear cut-off values. For phosphate substantial variation across age categories is observed. Substantial variation in observed mean values was observed across different centres as is shown in the funnel plots (Figure 8.4). Adjustments were performed for differences in case-mix (age, sex, SES, and primary kidney disease categories.

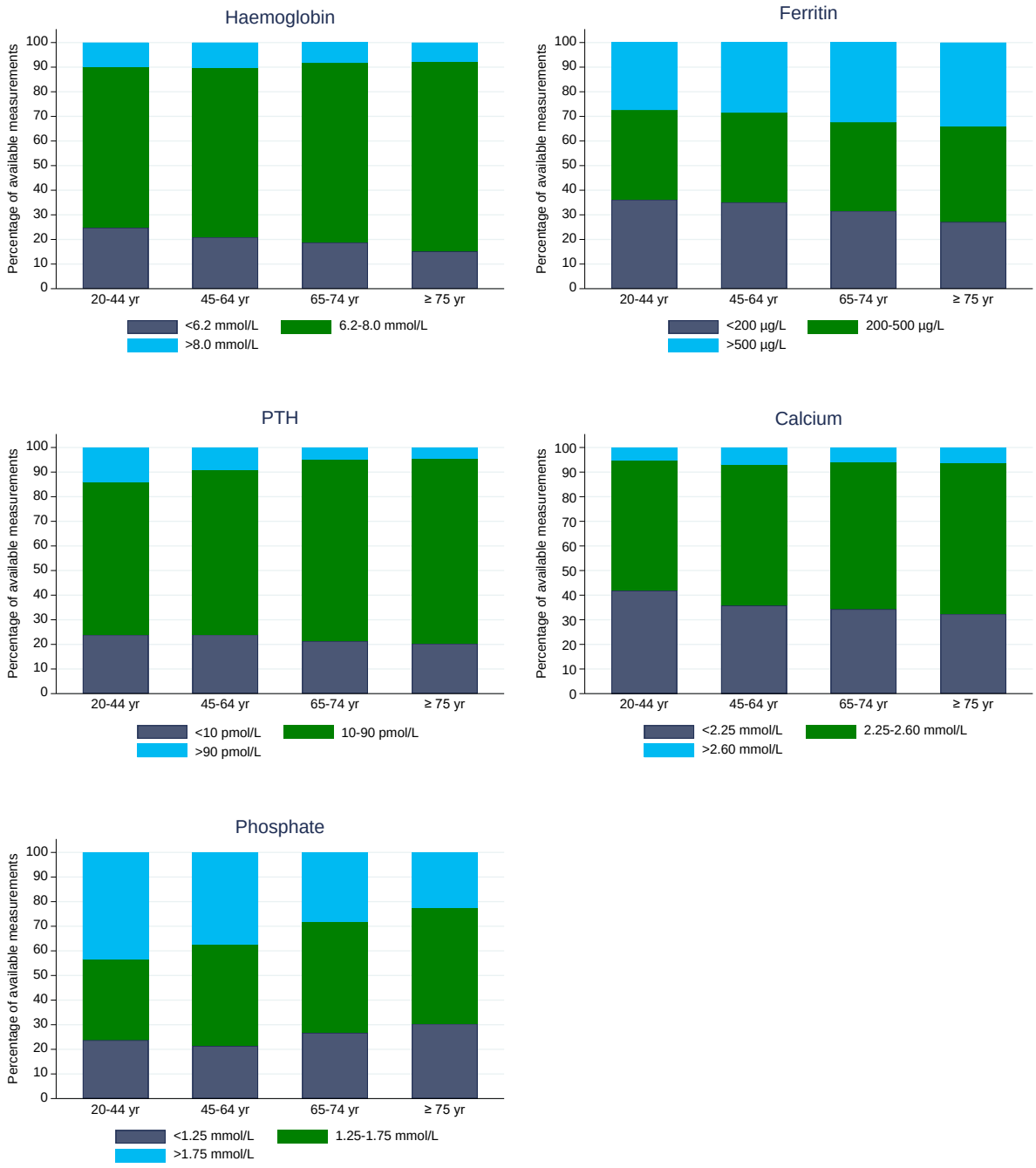


Figure 8.3. Categories of clinical variables stratified for age categories

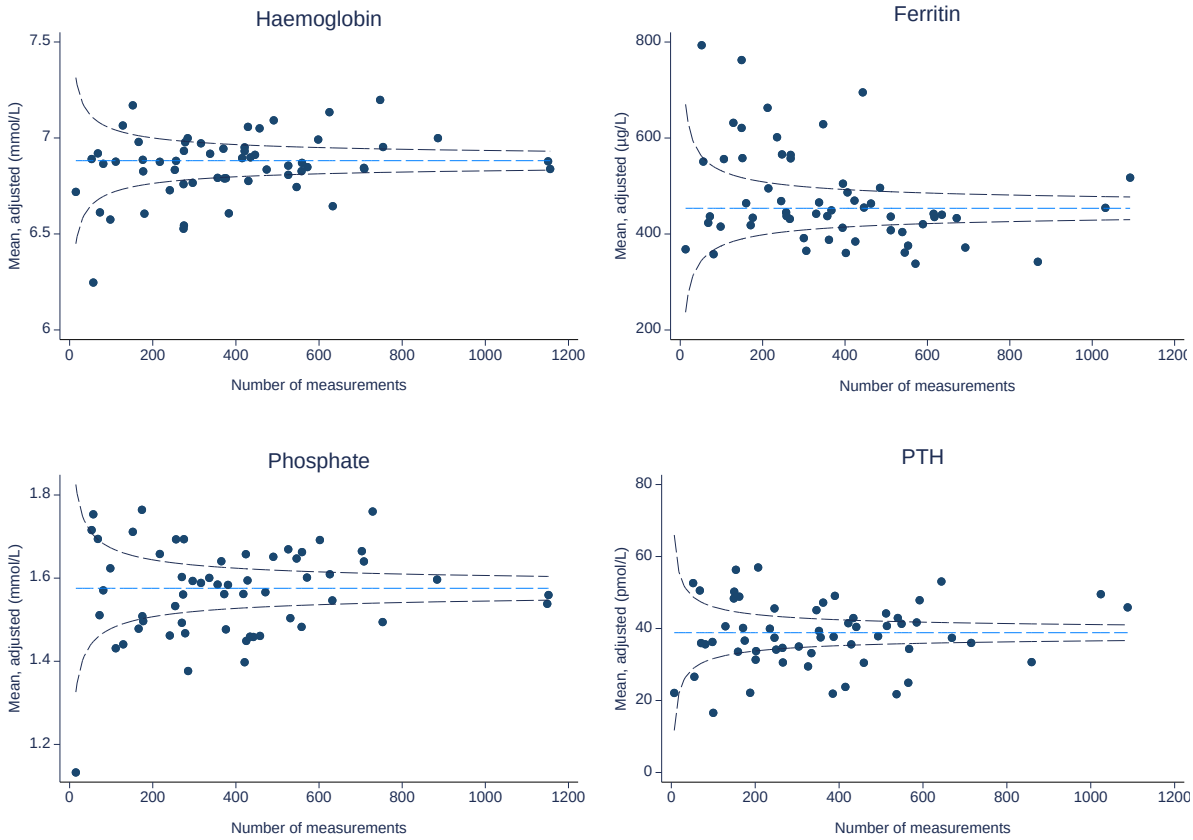


Figure 8.4. Funnel plots showing centre variation of mean values of clinical variables. The funnels were adjusted for differences in case-mix (age, gender, SES, and primary kidney disease categories).

An AV-fistula is the most common type of vascular access in prevalent haemodialysis patients. Dialysis via catheter is less common for older patients (Figure 8.5).

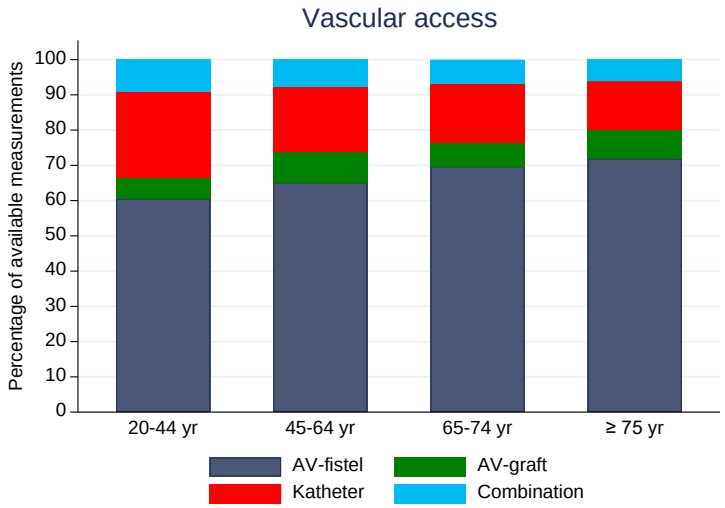


Figure 8.5. Distribution of vascular access categories in prevalent haemodialysis patients in 2019

In Figures 8.6 and 8.7 centre variation in the percentages patients with a central venous catheter is shown for prevalent and incident haemodialysis patients respectively.

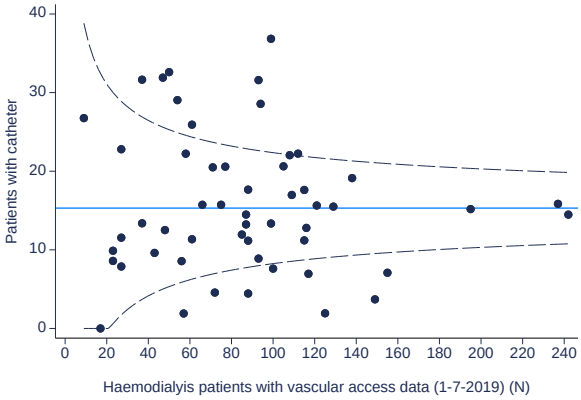


Figure 8.6. Centre variation in catheter use in prevalent haemodialysis patients. Adjustments were performed for age, sex, SES, and primary kidney disease categories.

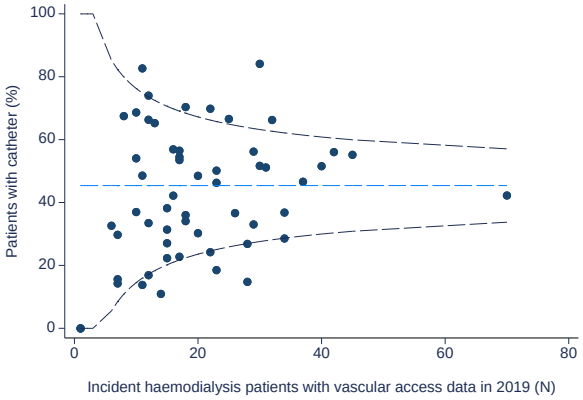


Figure 8.7. Centre variation in catheter use in incident haemodialysis patients. Adjustments were performed for age, sex, SES, and primary kidney disease categories.

9. Conclusions

The number of patients depending on renal replacement therapy shows a steady increase over the years. This increase is mainly accounted for by higher number of patients with a renal transplant. The population of the Netherlands is ageing and this is also reflected in the age distribution of the renal replacement population. It is notable that we observe a decrease in the incidence of dialysis treatment in the age group 65-75 and over 75 years. This might indicate that elderly patients more often avert from dialysis treatment and choose conservative treatment. An alternative explanation is that, due to improvement in chronic kidney disease care, fewer elderly patients reach the stage of renal failure that requires renal replacement. This decrease is mainly observed in male patients, whilst incidence is more stable in women. We do not have a clear explanation for this but this notable finding warrants further investigation.

The percentage of dialysis patients treated with peritoneal dialysis is more or less stable during recent years whilst home haemodialysis is increasing in the elderly patients. This might partly be the effect of a number of initiatives to promote home dialysis. Similar to previous years there is a significant centre variation in percentage of home dialysis.

Among patients with a renal transplant the percentage of those with a living donor is increasing as is the percentage of elderly patients. There is significant centre variation in the percentage of incident kidney transplants in relation to the incident patient on renal replacement therapy. Time on dialysis before post mortal kidney transplantation shows a steep downward trend.

PROMs have only recently been added to Renine and we are pleased to be able to present the first results over the year 2019. More than 1500 questionnaires are filled out in 2019 and a growing number of dialyses centres participate in the data collection. We expect that this will continue to grow in the coming years. A unique feature of the PROMs in Renine is that it is also applicable in clinical practice where it may help to address issues that are burdensome to the patient. The coming years more detailed analyses of the PROMs data will be performed including trajectories over time.

Completeness of clinical data is increasing. Remarkably there is a centre variation in the clinical variables haemoglobin, ferritin, phosphate, and PTH.
For 2019 clinical data was lacking for only 6% of the dialysis population. We aim to further increase data availability by electronic registration from primary data sources in the near future. We will furthermore expand the data collection with so far lacking essential data such as comorbidities and prescribed drugs. This will permit more detailed monitoring of the quality of renal care in the Netherlands. The coming year we will furthermore focus on expanding the registration to earlier stages of chronic kidney disease. Pilots are planned for the coming months.

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. Subjects were censored in case of recovery of renal function, loss to follow-up or end of follow-up time (December 31th 2019). Survival was analysed from day 1 of chronic dialysis treatment. The cumulative incidence curves were adjusted for fixed values of age (50 years for the age category <65 years and 70 years for the age category ≥65 years), sex (63% men) and primary kidney disease categories (24% Diabetes; 19% Hypertension/renal vascular disease; 11% Glomerulonephritis; 46% Other causes).

Funnel plots
Centre variations in the year 2019 are presented by funnel plots. In these plots a centre-specific mean or percentage is plotted against a variable indicating centre size. For binary and continuous outcomes 95%-confidence intervals were plotted based on the binomial and normal distribution respectively. Funnels are plotted around the average estimate over all centres. Any centres which fall outside the 95%-confidence intervals of the funnels are significantly different from the average. The funnel shape of the limits reflects the fact that for smaller centres a greater observed difference from the average is required for it to be statistically significantly different. To account for differences in case-mix a number of adjustments were performed. For binary outcomes a logistic model with age, sex, SES, and primary kidney disease as independent variables was used to derive a probability of the event for every individual patient. These probabilities were summed over the patients within a centre to give an expected number of events (E). A standardized percentage is calculated by multiplying the ratio of observed and expected events (O/E) by the overall percentage over all centres. For continuous outcomes expected outcomes were estimated using linear regression models. An adjusted mean was calculated by adding the difference between the observed and expected mean (O-E) to the overall mean value.

Appendix B Categories of primary kidney disease

Category	ERA-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)
	72	Renal vascular disease due to hypertension (NO primary renal disease)

Category	ERA-EDTA code	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
	74	Wegener’s granulomatosis

Category	ERA-EDTA code	Primary renal disease
	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 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-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