

ANNUAL REPORT 2017

The Norwegian Renal Registry

(Norsk Nyreregister)

This report will also be available on:
<http://www.nephro.no/registry.html>

Registry Chairperson: Anna V. Reisæter (areisate@ous-hf.no)
Director of Registry: Anders Åsberg (aaasbe@ous-hf.no)

Adress: Norsk Nyreregister, ATX-Nyreseksjonen, OUS Rikshospitalet, Pb. 4950 Nydalen,
0424 Oslo, Norway.

History and Organisation of Norwegian Renal Registry (NRR)

The Norwegian Renal Registry is an epidemiology quality registry for patients with severe renal disease. Inclusion in the registry is based on written informed consent and patients are followed for their entire life course. Patients in whom a diagnostic kidney biopsy is obtained or who have developed chronic kidney disease stadium 5 (CKD5) are included in the registry. Acute kidney failure patients are not included in the registry unless they develop chronic kidney failure.

The current version of NRR is a merge of the Norwegian Nephrology Registry and the Norwegian Renal Biopsy Registry in 2016 and consists of two sections; Section for dialysis and transplantation (at Oslo University Hospital) and Section of kidney biopsy (at Haukeland University Hospital). In the merge all historic data from the Norwegian Nephrology Registry was continued, while historic data from the Norwegian Renal Biopsy Registry was not eligible for transfer into the new registry. The historic biopsy data is however still available for analyses.

The Norwegian Nephrology Registry was formally constituted in 1994 as a collaboration between The Norwegian Renal Association (Norsk Nyremedisinsk Forening) and Oslo University Hospital-Rikshospitalet, with the latter as the formal owner. National data on renal replacement therapy (RRT) had been collected within The Renal Association since 1980 in a less formalised manner, and the transplant centre had stored data on transplanted patients since the late sixties. Further, Norwegian renal units had reported to the ERA-EDTA-registry since the late sixties. Since the mid-90ies, a process of transition from a pure epidemiological registry into a quality-oriented registry has progressed.

Norwegian Renal Biopsy Registry was established in 1988. It has been run by the Renal unit at Haukeland University Hospital. Both, nephrologists and pathologists contributed with data related to non-neoplastic kidney biopsies. The aim of the registry was, first of all, to provide a platform for development of expertise and improvement of quality, second to have a material available for research. In 2012, the registry was acknowledged a national quality registry. From 2012, the registry has been building a digital slide archive of kidney biopsies. In 2015, the registry had collected clinical and pathological data of 13000 non-neoplastic kidney biopsies.

National organisation and policy

Norway had 5.278 mill. inhabitants (July 2017) and 19 counties with populations ranging from 76,228 to 669,060 inhabitants. Each county has a central renal unit and some have two, further some have satellite units run in close contact with the central unit. There is only one transplant centre (two during 1963-82). Pre-transplant work-up, as well as post-transplant follow-up beyond 3 months, is handled by the county-centres. County boarders does not always coincide with the area that the different renal units cover and this report present data based on county boarders as well as divided in RHF and HF levels, whenever appropriate.

During 2017 Finnmark was separated from Tromsø, so now there are 26 centers responsible for reporting data to NRR, and they all do. Each center is responsible to report all patients from whom a diagnostic kidney biopsy is taken and all patients established in CKD5 on a continuous basis (eGFR < 15 ml/min/1.73 m² for more than 2 months. Progression to need of renal replacement therapy (dialysis, transplantation), changes between dialysis modality (PD, center HD, "home HD"), transfer between centers or immigration/emigration, graft loss and deaths is reported on a continuously basis. During 2017, data from the last visit before December 31st 2017 was to be reported for all CKD5 patients, either if they were not treated

with renal replacement therapy or if they received dialysis or had a functioning renal graft. The overall report rate by the finalization of this report was 97.2%.

Transplantation has always been considered the renal replacement treatment of choice, if possible, with a living related donor. Since 1984, also unrelated donors have been used. Acceptance criteria for transplantation have been wide, strict age limits have not been applied. Over time, an increasing number of non-transplantable patients have also been offered life-long dialysis.

Individual coverage of the registry for the entire cohort is estimated to be at least 95%. Transplanted patients are crosschecked continuously against the transplantation lists at OUS-Rikshospitalet and annual crosschecks against each of the 26 centers lists of dialysis patients are performed per December 31st each year. For patients in renal replacement therapy the individual coverage is close to 100% (5 alive without consent in 2017). CKD5 patients not treated with renal replacement therapy have only been included in the registry since 2016 and the coverage is still suboptimal. Based on prevalence data from the literature a conservative estimate of coverage of this group is at least 58%. A coverage analysis of non-neoplastic kidney biopsies has been performed in 2014 and 2015. The coverage was dropping from 89% in 2014 to 71% in 2015 because of a change in the reporting procedure. At regular intervals, reporting of deaths to the registry is checked against the Norwegian National Registry (NO: *Folkeregisteret*).

NRR is one of 53 national medicine quality registries and include 22 quality indicators that are reported annually (<https://www.kvalitetsregistre.no/registers/norsk-nyreregister>). These data are in addition included in the present report. A list of all quality indicators can be found here: <http://www.nephro.no/nnr.html>.

Incidence data 2017

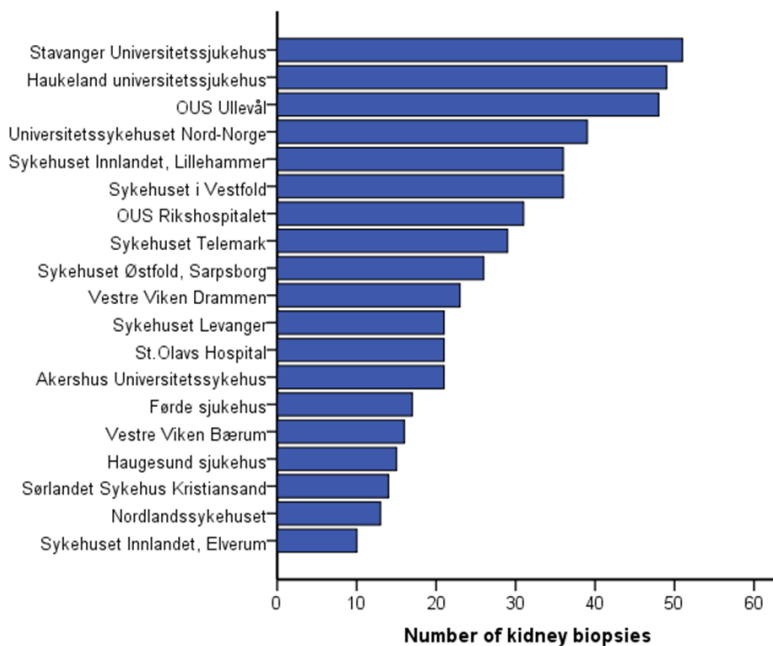
During 2017 a diagnostic kidney biopsy was performed in 545 patients, 289 were reported as new patients established in CKD5 and 579 patients started renal replacement therapy (i.e. 100.0 per mill. inhabitants).

Biopsy

Number of kindey biopsies per regional health authority

	2015	2016	2017
South-Eastern Norway Regional Health Authority	320	297	305
Western Norway Regional Health Authority	172	126	134
Central Norway Regional Health Authority	64	62	54
Northern Norway Regional Health Authority	40	47	52

Number of kidney biopsies per hospital in 2017



This figure shows the number of kidney biopsies performed per hospital in 2017. Hospitals which performed less than 10 kidney biopsies in 2017 are excluded from the analysis.

Average age at kidney biopsy in 2017 per Regional Health Authority

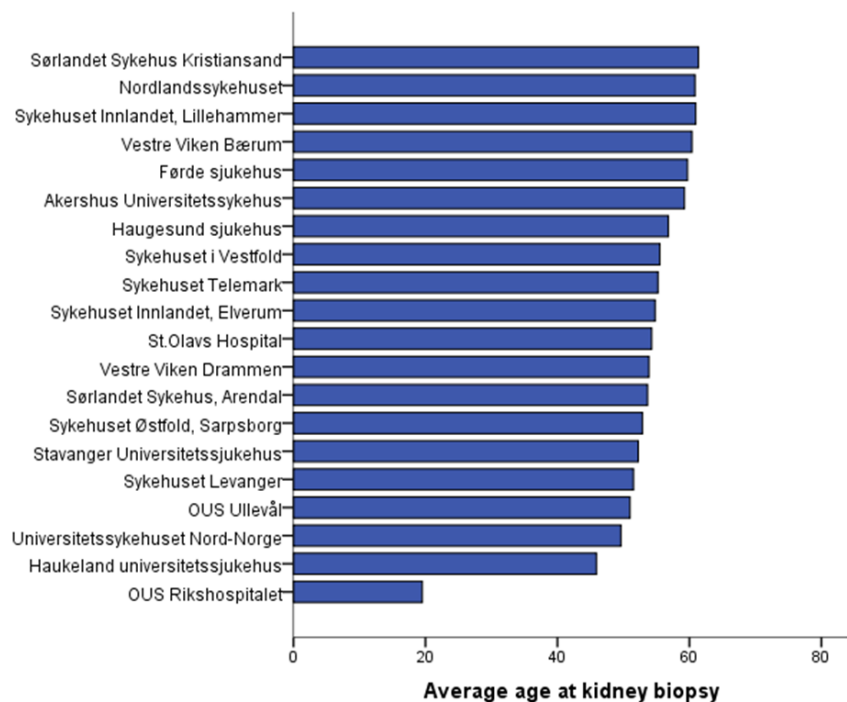
	South-Eastern Norway N=305	Western Norway N=134	Central Norway N=54	Northern Norway N=52	Total N=545
Mean age (\pm SD)	52.2 \pm 20.2	51.7 \pm 17.4	54.0 \pm 18.7	52.4 \pm 19.6	52.3 \pm 19.3

The national mean age at kidney biopsy in 2017 was 52.2 (\pm 19.3) years, unchanged from 2016. The maximum difference in mean age at kidney biopsy between the Norwegian health regions was 7.7 years in 2016, whereas the difference in mean age in 2017 was 2.3 years. The lowest mean age at kidney biopsy was reported in Western Norway, whereas the highest mean age at kidney biopsy was reported in Central Norway, unchanged from 2016.

In 2017, 5.5% of all reported native kidney biopsies were performed in individuals aged 17 years old or younger. 93% of kidney biopsies performed in individuals younger than 18 years old were performed at a university hospital; Oslo University Hospital Rikshospitalet 76.7 %, Haukeland University Hospital 6.7 %, Oslo University Hospital Ullevål 3.3 %. Vestre Viken Bærum hospital performed 3.3 % of all kidney biopsies in patients younger than 18 years old, as did Ålesund hospital.

In 2017 2.9 % of all kidney biopsies were performed in patients above 80 years of age, most octogenarians were biopsied in hospitals located in the South-Eastern Regional Health Authority.

Average age at kidney biopsy per hospital in 2017

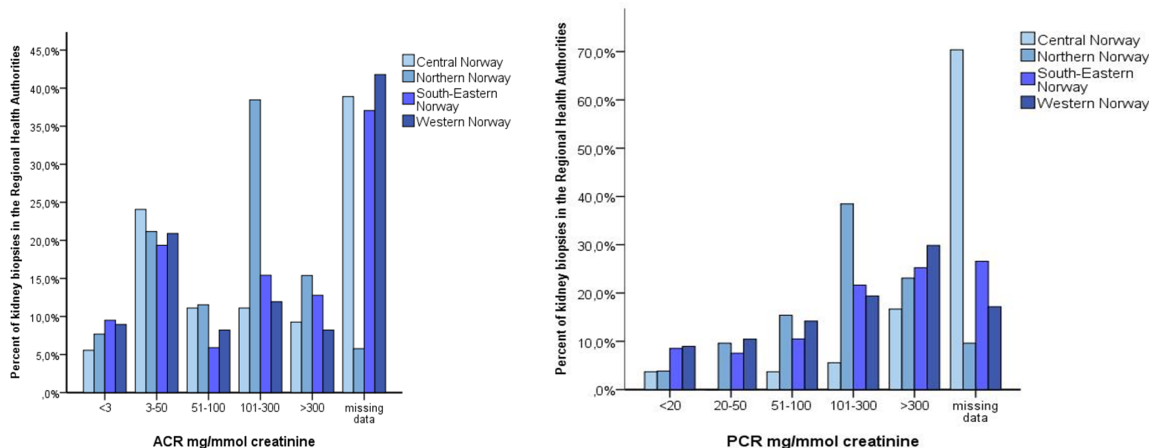


Reported clinical indications for kidney biopsy, number (%) of kidney biopsies in the Regional Health Authorities

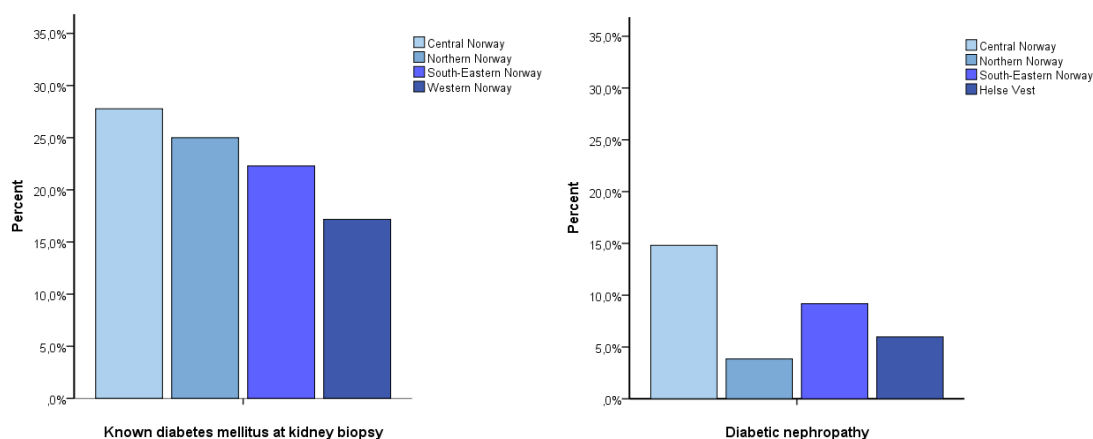
	South-Eastern Norway N(%)	Western Norway N(%)	Central Norway N(%)	Northern Norway N(%)	Total N(%)
Nephrotic syndrom	38 (12.5 %)	35 (26.1 %)	7 (13.0 %)	11 (21.2 %)	91 (16.7 %)
Nephritic syndrom	39 (12.8 %)	28 (20.9 %)	15 (27.8 %)	10 (19.2 %)	92 (16.9 %)
Acute kidney failure	75 (24.6 %)	27 (20.1 %)	13 (24.1 %)	15 (28.8 %)	130 (23.9 %)
Chronic kidney failure	106 (34.8 %)	31 (23.1 %)	17 (31.5 %)	12 (23.1 %)	166 (30.5 %)
Proteinuria	155 (50.8 %)	75 (56.0 %)	26 (48.1 %)	32 (61.5 %)	288 (52.8 %)
Haematuria	90 (29.5 %)	56 (41.8 %)	30 (55.6 %)	25 (48.1 %)	201 (36.9 %)
Other	12 (3.9 %)	6 (4.5 %)	2 (3.7 %)	1 (1.9 %)	21 (3.9 %)

It is possible to report more than one clinical indication for kidney biopsy. As a result the total number of clinical indication may exceed the total number of kidney biopsies performed in 2017. Some regional differences in clinical indication for biopsy are apparent, nephrotic syndrome is more frequently reported by hospitals in the Western and Northern Regional Health Authorities as compared to the rest of Norway. The same trend was observed in 2016.

Urin albumin to creatinine ratio and protein to kreatinine ratio (mg/mmol creatinine) at the time of kidney biopsy in the different Regional Health Authorities



Diabetes mellitus and diabetic nephropathy



Diabetes mellitus (type 1 or 2) is more frequently reported by hospitals in the Central and Northern Regional Health Authorities, as compared to hospitals in the other parts of Norway. Even though about 25 % of patients were reported to have diabetes mellitus (type 1 or 2) by hospitals in the Central Regional Health Authority, less than 5 % of these patients were diagnosed with diabetic nephropathy.

Quality indicators for division of kidney biopsy

Patientgroup	Quality indicator	Indicator	What does it indicate?
Kidney biopsy	Percentage of serious Complications	<2 %	Procedure related safety
	Percentage of kidney biopsies with 10 or more glomeruli	90 %	Procedure related quality
	Number (%) of kidney biopsies with a final diagnosis within 1 month	80 %	Indicates quality related to structure in the investigative process
	Number of primary kidney biopsies with moderate to severe chronic changes	< 30%	Indicates whether patients are investigated in a timely fashion

Number (%) of kidney biopsies with 10 or more glomeruli

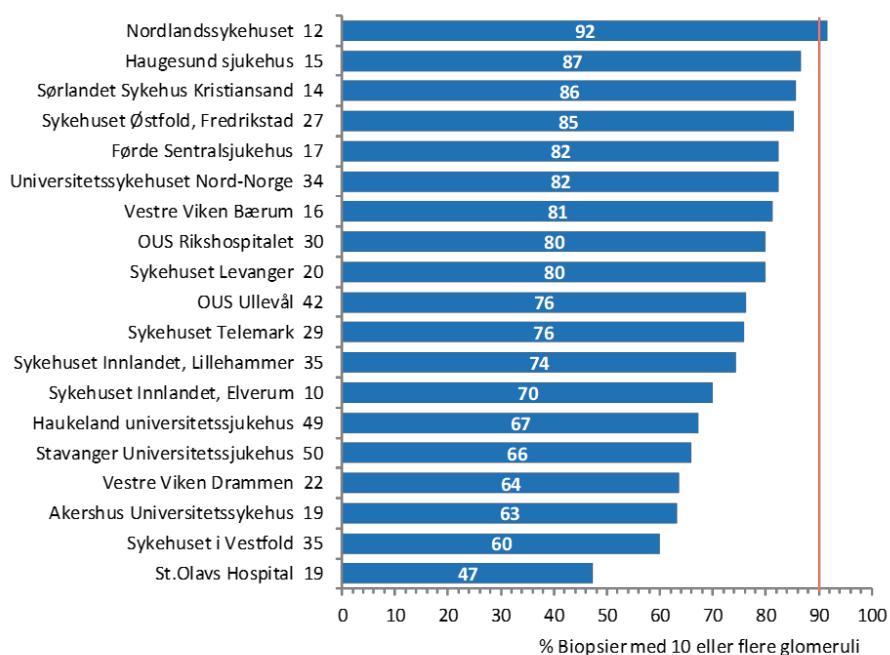
The kidneys consist of three compartments which may be attacked by disease: the glomeruli, the tubuli/interstitial tissue and the vasculature. A kidney biopsy is often necessary in order to investigate which compartment or compartments of the kidney are affected by disease and which kidney disease is responsible for the clinical picture observed.

The normal kidney contains about 1 million glomeruli which continuously filter the blood, producing pre-urine. The glomeruli can be affected by several different disease processes, and sufficient material in the kidney biopsy is necessary in order to be able to make an accurate diagnosis. A disease process may not affect all glomeruli, and different stages of disease process may be observed in different glomeruli. The number of affected glomeruli, and the degree of affliction may impact the clinician's decisionmaking process.

The number of glomeruli in a kidney biopsy may be obtained by different methods. The most common approach is to count the number of glomeruli in the material prepared for light microscopy. For a reliable diagnosis, at least 10 glomeruli should be present in the biopsy material prepared for light microscopy.

The national average number of glomeruli in 2017 is 15,9 per kidney biopsy, however only one hospital reported 10 or more glomeruli in 90% of kidney biopsies.

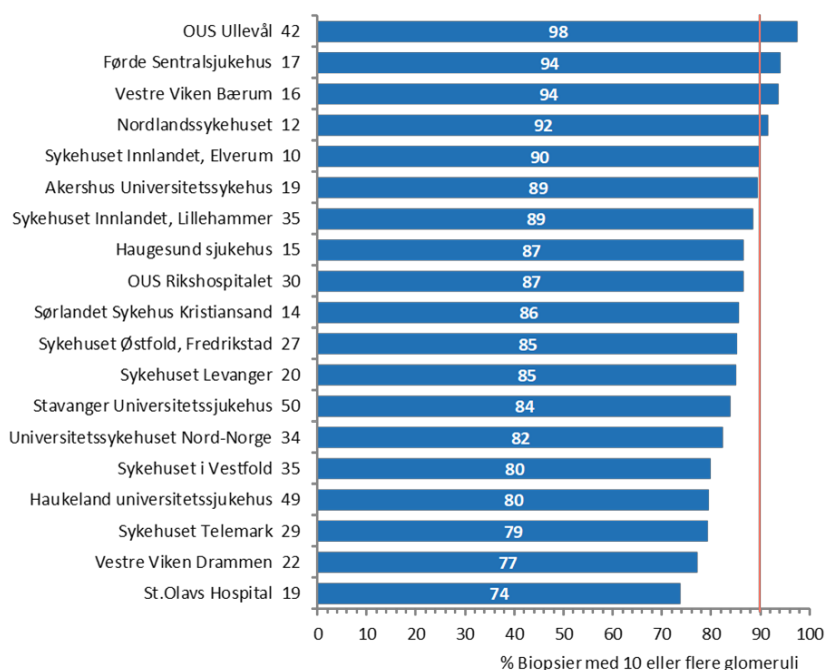
Percent of kidney biopsies with 10 or more glomeruli in paraffin embedded material, per hospital



This figure shows the number of glomeruli in paraffin embedded material prepared for light microscopy. Only hospitals which performed 10 or more kidney biopsies are included in the analysis.

An alternative assessment of the number of glomeruli is the inclusion of all material from a kidney biopsy, taking in also material prepared for electronmicroscopy and immunofluorescence. If applying this assessment method, still only 5 of the 19 hospitals achieved 10 or more glomeruli per biopsy in 90% of cases.

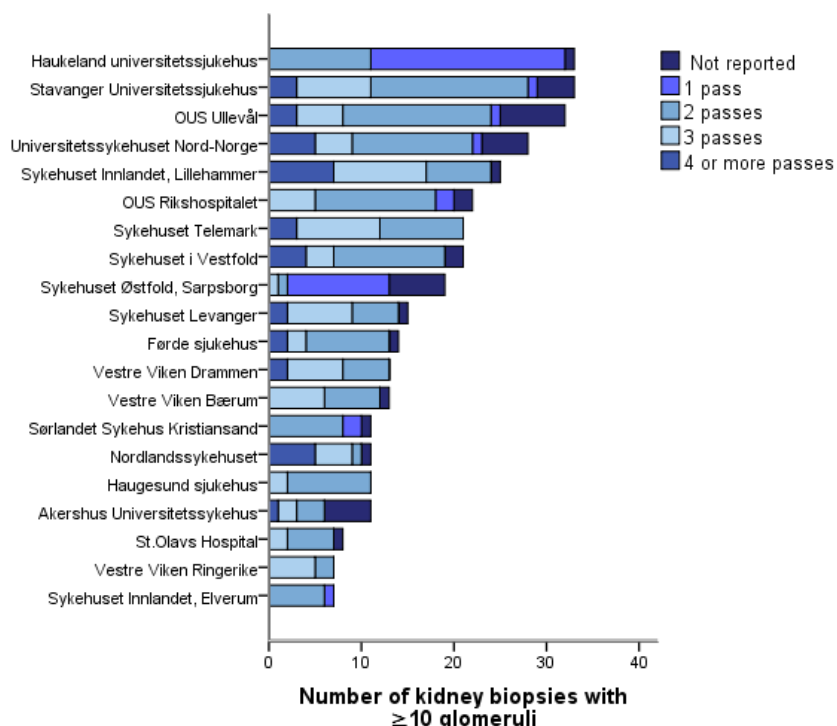
Percent of kidney biopsies with 10 or more glomeruli in all available material, per hospital



This figure shows the number of available glomeruli in paraffin embedded material, EPON embedded material for electron microscopy and frozen material prepared for immunofluorescence. Only hospitals with 10 or more kidney biopsies are included in the analysis.

In order to secure enough material for adequate diagnostic evaluation, more than one tissue cylinder per procedure may be required.

Number of kidney biopsies with ≥10 glomeruli and number of passes with the biopsy needle



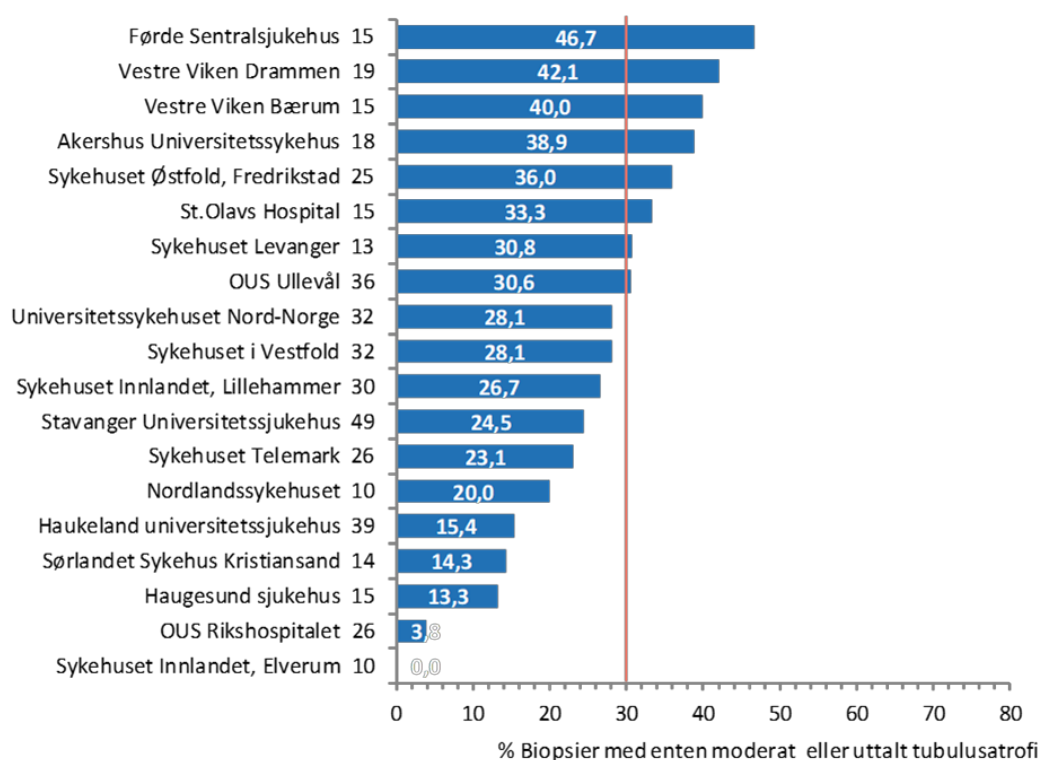
This figure shows the number of kidney biopsies with ≥10 glomeruli per hospital, and how many passes with the biopsy needle were made in order to obtain sufficient material in the 328 biopsies with reported data on number of passes with the biopsy needle and number of glomeruli in the sample.

Proportion of kidney biopsies with moderate to severe chronic changes

Chronic changes in the renal tissue are persistent and irreversible. A high proportion of chronic changes in the biopsy may indicate a future risk of loss of kidney function, and low potential for stabilisation or recovery of kidney function with medical intervention.

It is important to diagnose kidney disease early on in the disease process, before the disease manifestations result in chronic, irreversible changes. Both tubular atrophy and glomerulosclerosis are good marks of chronic changes in the kidneys.

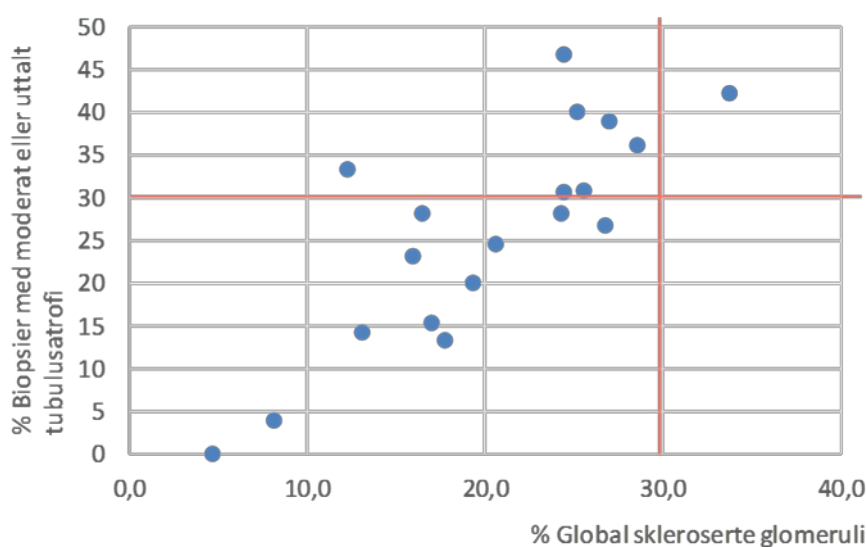
Primary kidney biopsies (%) with moderate to severe tubular atrophy



Tubular atrophy is a form of irreversible change within the kidney. Only hospitals which performed 10 or more kidney biopsies in 2017 are included in the analysis.

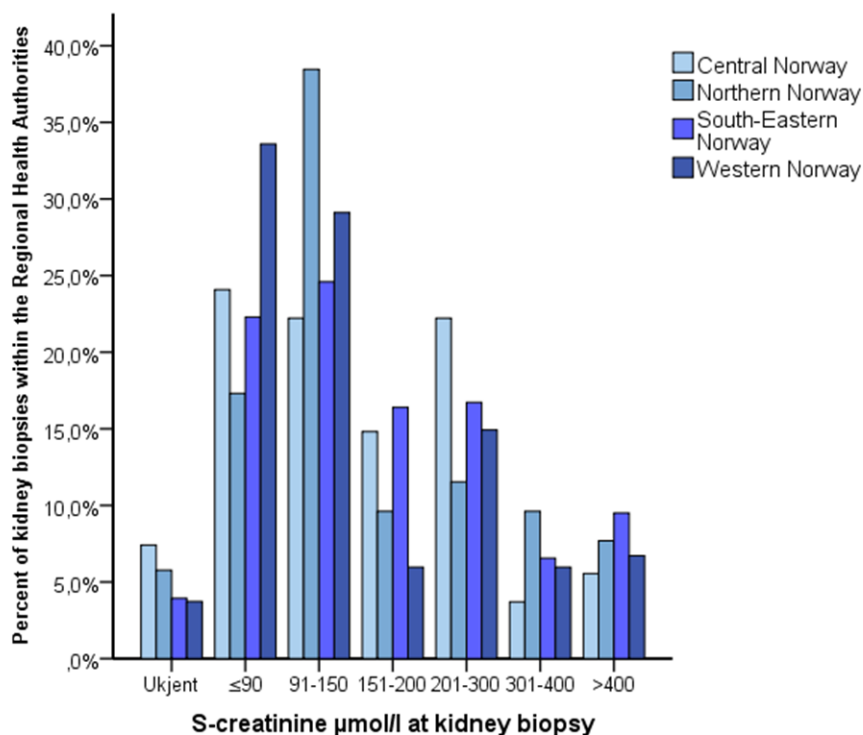
The graph shows a wide variation of proportion of biopsies with moderate to severe chronic changes between hospitals. Further investigation is needed to elucidate the reason for this variation.

Correlation between global glomerulosclerosis (%) and moderate to severe tubular atrophy (%) per hospital



The analysis includes only primary kidney biopsies, re-biopsies are excluded from the analysis. The figure shows that tubular atrophy might be a more sensitive parameter to evaluate atrophic changes as compared to global glomerulosclerosis. Many kidney biopsies show a greater degree of tubular atrophy than glomerulosclerosis.

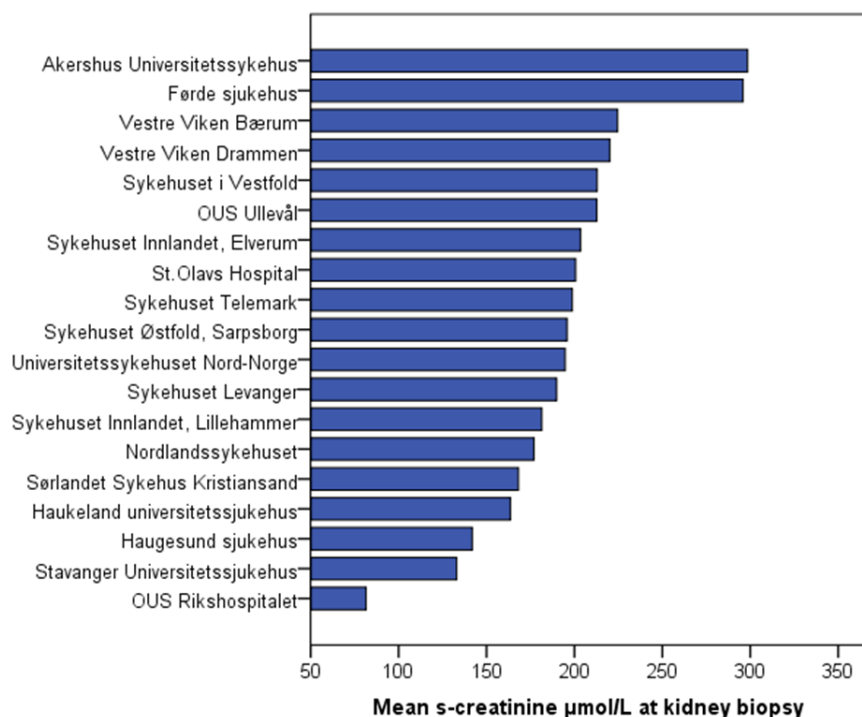
Serum creatinine (6 groups) at kidney biopsy, per Regional Health Authority



Serum creatinine increases as kidney function declines. The disease process by which kidney function is lost has often started some time prior to the increase in serum creatinine. In performing a kidney biopsy in a timely fashion, prior to development of moderate to severe chronic changes, more therapeutic gains may be made by the patients and treating nephrologists. Serum creatinine is reported at the time of kidney biopsy, the registry is planning on collecting follow-up data for select groups of patients in the future.

As in 2016, most kidney biopsies are performed in patients aged 18 years or above when serum creatinine exceeds 200 $\mu\text{mol/L}$. The number of reported kidney biopsies fall as serum creatinine exceeds 300 $\mu\text{mol/L}$. More kidney biopsies performed in patients with s-creatinine > 400 $\mu\text{mol/L}$ were reported by the hospitals in the South-Eastern Regional Health Authority (10.4 %) as compared to 5.9-7.9% in the other Regional Health Authorities.

Mean s-creatinine $\mu\text{mol/L}$ at kidney biopsy, per hospital



The university hospitals performed the majority of the kidney biopsies in the paediatric age range in 2017, and the lower mean s-creatinine reported from these centers is likely reflect the lower muscle mass in the paediatric age group.

Serious procedure related complications; blood transfusion and/or intervention

	2015	2016	2017
No complications	74 %	82.9 %	78.3 %
Missing data	16.9 %	9.1 %	13.0 %

Reported complications in 2017 per Regional Health Authority

	South-Eastern Norway N(%)	Western Norway N(%)	Central Norway N(%)	Northern Norway N(%)	Total N(%)
None	241 (79 %)	107 (79.9 %)	39 (72.2 %)	40 (76.9 %)	427 (78.3 %)
Transfusion	5 (1.6 %)	3 (2.2 %)	2 (3.7 %)	0 (0 %)	10 (1.8 %)
Intervention	1 (0.3 %)	0 (0 %)	0 (0 %)	0 (0 %)	1 (0.2 %)
Other	19 (6.2 %)	5 (3.7 %)	3 (5.6 %)	2 (3.8 %)	29 (5.3 %)
Haematuria	11 (3.6 %)	1 (0.7 %)	3 (5.6 %)	0 (0 %)	15 (2.8 %)
Missing data	34 (11.1 %)	20 (14.9 %)	7 (13.0 %)	10 (19.2 %)	71 (13.0 %)

It is possible to report more than one complication per procedure. Total number of kidney biopsies performed in 2017 with available clinical data n= 545.

Eleven serious complications were reported in 545 kidney biopsies in 2017 (2,0%). The median age for patients who experienced serious complications was 62.9 (28-82) years.

Serious adverse events were reported for 6 males and 5 females, median serum creatinine at was 288 $\mu\text{mol/L}$ (range 31-756). No obvious relation to the number of passes with the biopsy needle was found, 45.5% of the biopsies were performed with 1-2 passes, 27.3 % were performed with 3-4 passes and the number of passes with the biopsy needle was not reported in 18.2 % of the cases. Furthermore, no single diagnosis was associated with a higher risk of procedure related adverse events, 7 different clinical diagnoses were reported.

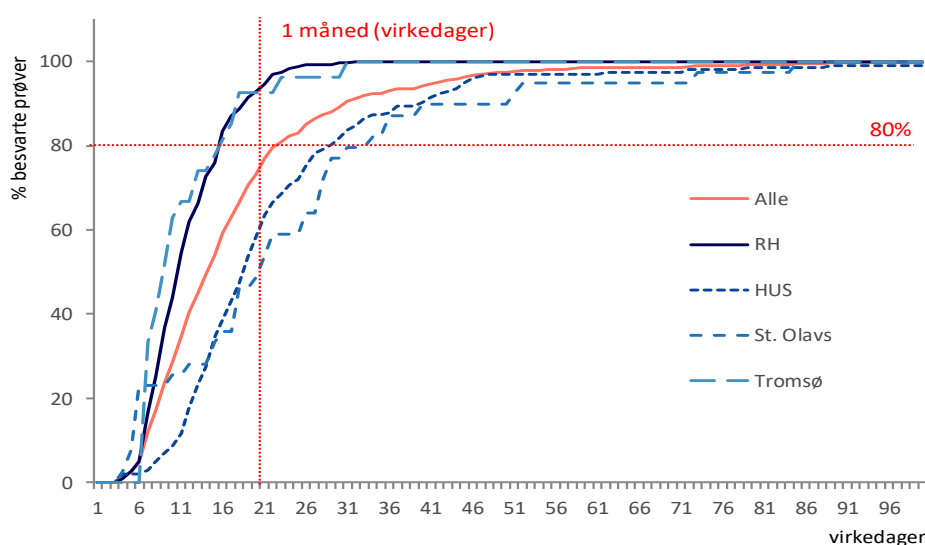
As the number of serious adverse events is low, small changes in absolute numbers may result in large changes in the percentage of biopsy related complications from year to year. Data accumulated over a five-year period will likely give a more accurate representation of the risk of serious adverse events related to kidney biopsy. As data from the Norwegian Kidney Biopsy Registry cannot be incorporated into the new division of Kidney Biopsy, reporting on five-year data is not yet possible.

Proportion of kidney biopsies signed off by the department of pathology within one month

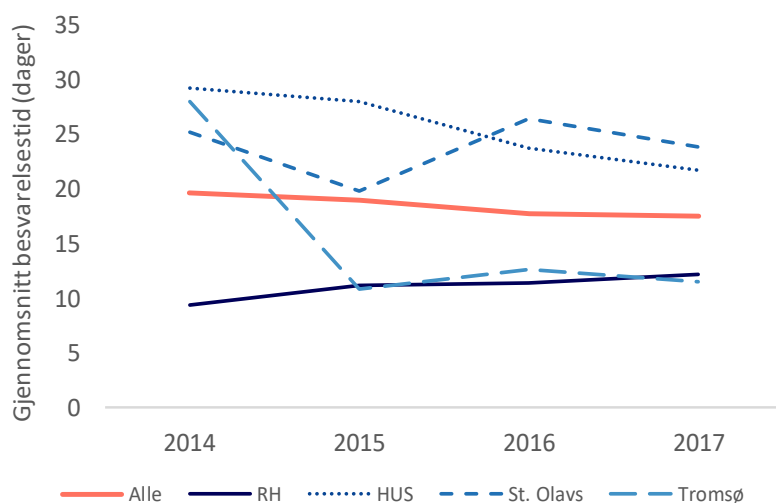
The time interval from a kidney biopsy is registrerd with the pathology department until the nephropathologist has signed off the final report including the electron microscopic investigation is a quality indicator, as the clinician will base treatment choices on the final pathology diagnosis. Delays in reporting on the kidney biopsy may cause delay in treatment of the kidney disease, and consequently impact patient outcomes negatively.

The electron microscopy examination in particular is time-consuming, and a kidney biopsy is therefore often reported on in stages. Kidney biopsies from severely ill patients are usually reported on by the pathologist to the clinician by telephone as soon as the biopsy is prepared for light microscopy. This oral report is followed by a preliminary written report, which may or may not include immunohistochemistry. The final pathology report is signed off after electron microscopy.

Percentage of kidney biopsies reported on within 1 month (21 workdays) in 2017



Average time to final pathology report, by department of pathology, since 2014



Only 2 pathology departments met the quality standard of a final diagnostic report within 1 month. Over the years there has been a slightly positive overall trend towards shorter reporting time.

Procedure related parameters

As in 2016, kidney biopsies are mainly performed by radiologist, with the exception of hospitals within the Western Regional Health Authority. Some centers have a nephrologist assess the tissue cylinder in the stereomicroscope to ensure adequate quality before the biopsy is transported to the department of pathology. The kidney biopsy is more likely to be performed as an in-hospital procedure, some centers in the Western Regional Health Authority regularly perform kidney biopsies as an out-patient procedure. More than one third of kidney biopsies are reported to the registry without sufficient information as to level of care at the time of biopsy.

	South-Eastern Norway N (%)	Western Norway N (%)	Central Norway N (%)	Northern Norway N (%)	Total N (%)
Biopsy performed by					
Nephrologist	8 (2.6 %)	91 (67.9 %)	1 (1.9 %)	2 (3.8 %)	102 (18.7 %)
Radiologist	276 (90.5 %)	34 (25.4 %)	46 (85.2 %)	45 (86.5 %)	401 (73.6 %)
Both	1 (0.3 %)	0 (0 %)	2 (3.7 %)	2 (3.8 %)	5 (0.9 %)
Unknown	20 (6.6 %)	9 (6.7 %)	5 (9.3 %)	3 (5.8 %)	37 (6.8 %)
Biopsy needle					
14G	1 (0.3 %)	0 (0 %)	2 (3.7 %)	1 (1.9 %)	4 (0.7 %)
16G	28 (9.2 %)	111 (82.8 %)	38 (70.4 %)	21 (40.4 %)	198 (36.3 %)
18G	221 (72.5 %)	18 (13.4 %)	4 (7.4 %)	19 (36.5 %)	262 (48.1 %)
Unknown	55 (18 %)	5 (3.7 %)	10 (18.5 %)	11 (21.2 %)	81 (14.9 %)
No. of passes					
1	33 (10.8 %)	33 (24.6 %)	2 (3.7 %)	1 (1.9 %)	69 (12.7 %)
2	131 (43.0 %)	66 (49.3 %)	25 (46.3 %)	19 (36.5 %)	241 (44.2 %)

3	72 (23.6 %)	17 (12.7 %)	13 (24.1 %)	13 (25.0 %)	115 (21.1 %)
4 or more	34 (11.1 %)	8 (6.0 %)	8 (14.8 %)	13 (25.0 %)	63 (11.6 %)
Unknown	35 (11.5 %)	10 (7.5 %)	6 (11.1 %)	6 (11.5 %)	57 (10.5 %)
Level of care					
Out-patient	4 (1.3 %)	19 (14.2 %)	3 (5.6 %)	1 (1.9 %)	27 (5.0 %)
In-patient	213 (69.8 %)	52 (38.8 %)	32 (59.3 %)	33 (63.5 %)	330 (60,6 %)
Unknown	88 (28.9 %)	63 (47.0 %)	19 (35.2 %)	18 (34.6 %)	188 (34,5 %)

Oxford classification of IgA nephropathy

The Oxford classification of IgA nephropathy, the so-called MEST score, was introduced in 2009. Four morphologic features of prognostic and partly predictive value are scored:

- Mesangial hypercellularity (M)
- Endocapillary hypercellularity (E)
- Segmental sclerosis (S)
- Tubular atrophy (T)

Crescents (C) were added to the model in 2016.

The scoring model is of value in the clinical setting, and Norwegian pathologists have therefore started scoring IgA nephropathies according to this model. The registry has investigated to which degree pathology departments have implemented the Oxford classification of IgA nephropathy. In 2017, three of six pathology departments have implemented the scoring system to varying degrees.

Total number of kidney biopsies and number of IgA nephropathies with Oxford classification, per pathology department

Pathology department	No. of kidney biopsies	No. of IgA nephropathies	% IgA nephropathy	No. of biopsies with Oxford classification	% IgA biopsies with Oxford classification
Rikshospitalet	224	35	16	31	89
Haukeland universitetssjukehus	200	49	25	31	63
Førde sjukehus	17	1	6	0	0
Ålesund sjukehus	8	2	25	0	0
St. Olavs Hospital	40	4	10	0	0
UNN Tromsø	34	6	18	4	67
Total	523	97	19	66	68

The total number of kidney biopsies is based on reported pathology forms (N=523). The Oxford classification gives information on how «active» an IgA nephropathy is. The higher the M (mesangial hypercellularity) and E (endocapillary hypercellularity) scores are, the more active the disease process is. Segmental sclerosis (S) and tubular atrophy (T) scores give information on chronic, irreversible changes.

Oxford Classification MEST score in 2017

Category	M		E		S			T		
Score	0	1	0	1	0	1	2	0	1	2
% all	58	42	74	26	32	68	0	62	26	12
RH	58	42	90	10	48	52	0	58	19	23
HUS	58	42	61	39	19	81	0	74	26	0
UNN	50	50	50	50	0	100	0	0	75	25

RH: Oslo University Hospital, Rikshospitalet. HUS: Haukeland University Hospital. UNN: Tromsø University Hospital.

The table above shows the MEST scores from the different pathology departments. Many of the biopsies show chronic changes (S1, T1-2), and the chronic changes are often pronounced (T2). Active changes (M1, E1) are less frequent.

There is some variability between the different pathology departments. There are different explanations for this variability. It might simply be due to small numbers of IgA nephropathies scored with the MEST score. Over time, the numbers will increase and results become more reliable. Other explanations could be actual differences in the severity of IgA nephritis or local differences in how the MEST score is applied.

CKD5 not in RRT

The age and sex distribution of CKD5 patients not treated with RRT is as expected in relation to the RRT population that has been followed in Norway for many years. A majority of patients were male (65.7%) and median age at time of entering CKD5 stage was 69.6 years (mean 66.3 years), ranging from 0.8 to 92.4 years. Patients had been known at the nephrology unit in 90% of the cases and a total of 84% were considered as RRT candidates and 7% were definitely not candidates for RRT treatment (9% unsure status). The main reason for not being RRT candidate was comorbidity, followed by patient/family wish not to start RRT.

Hypertension was the main cause of renal failure with 37% of the patients having this as their main diagnosis. Diabetes was the primary diagnosis in 19% of the patients, including diabetes as comorbidity a total of 34% patients was diabetic (90% Type II diabetes mellitus). Median time with a diabetes diagnosis before entering the CKD5 stage was 19 years.

Proteinuria (ACR>3 and/or PCR>15) was present in 89% of the patients at time of entering CKD5.

Status at start of CKD5 (without RRT)

	Total (n:289)
Creatinine (mean) [$\mu\text{mol/L}$]	395
Albumin (mean) [g/L]	38
Haemoglobin (mean) [g/dL]	11.4
Haemoglobin - % <10 g/dL	18 %
ESA use	27 %
Active D vitamin use	61 %
Statin use	63 %
Not on antihypertensive drugs	7 %
Using ACEi/ARB	50 %
Using >2 antihypertensive drugs	53 %

CKD5 in RRT (Dialysis or Transplantation)

A majority of the patients were male (67.1 %) and median age at start of RRT was 67.0 years (mean 63.5 years), ranging from 1.0 to 94.8 years. At time of start of RRT 63 % were assessed by the treating physician to be a Tx-candidate. Of the patients starting haemodialysis and that had been known at the treating center for at least 4 months 39 % started dialysis using an AV-fistula as blood access.

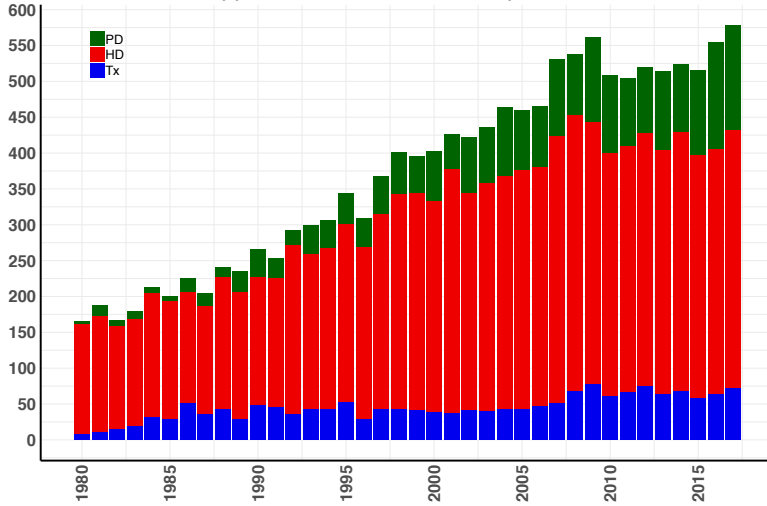
Status at start of RRT

	Total (n:579)	HD (n:360)	PD (n:146)	Preempt. Tx (n:73)
Creatinine (mean) [$\mu\text{mol/L}$]	622	645	630	490
Albumin (mean) [g/L]	36	34	37	42
Haemoglobin (mean) [g/dL]	10.3	9.9	10.7	11.1
Haemoglobin - % <10 g/dL	43 %	53 %	34 %	12 %
ESA use	50 %	56 %	48 %	26 %
Active D vitamin use	65 %	63 %	69 %	68 %
Statin use	56 %	53 %	69 %	52 %
Not on antihypertensive drugs	12 %	12 %	5 %	22 %
Using ACEi/ARB	32 %	30 %	35 %	27 %
Using >2 antihypertensive drugs	50 %	51 %	54 %	41 %

As might be anticipated, pre-emptively transplanted patients had a somewhat lower serum creatinine, thus higher GFR, and a higher haemoglobin and albumin than those starting dialysis. Among patients known less than four months, 71 % had haemoglobin <11 g/dL.

New patients in RRT

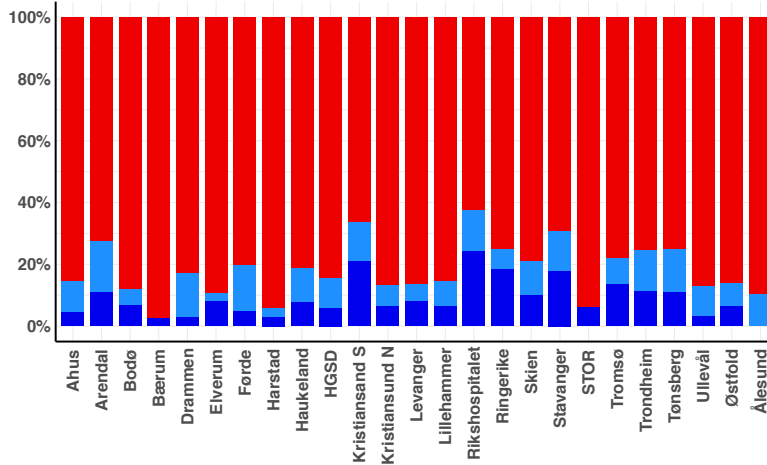
By year and first treatment mode, Norway 1980–2017



Part preemptive Tx by Tx-candidates at 1st RRT

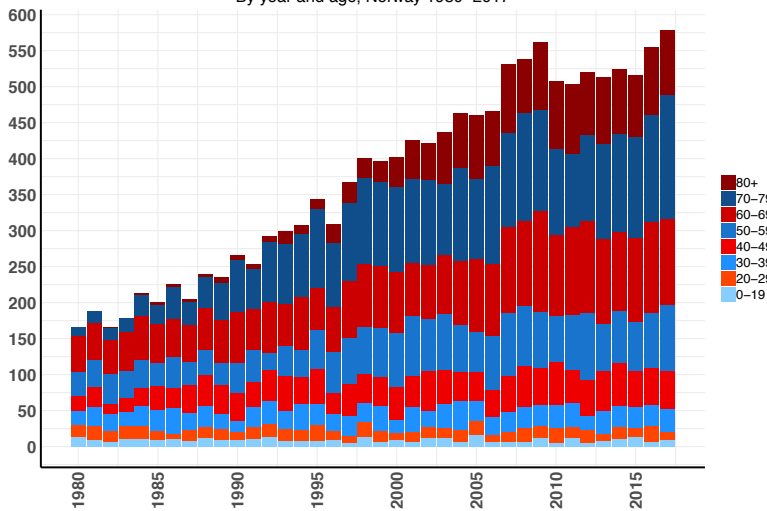
By senter last 10 yr, 2008–2017

Tx-cand DD-Tx LD-Tx



New patients in RRT

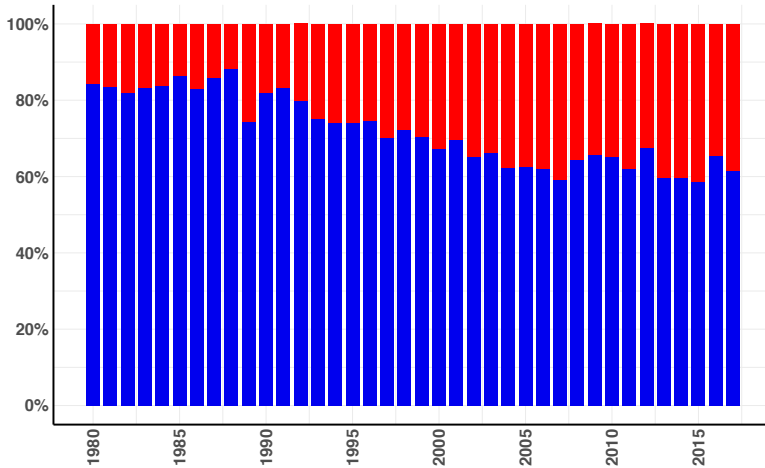
By year and age, Norway 1980–2017



Part Tx-candidates at 1st RRT

By year, 1980-2017

Not Tx-candidate Tx-candidate

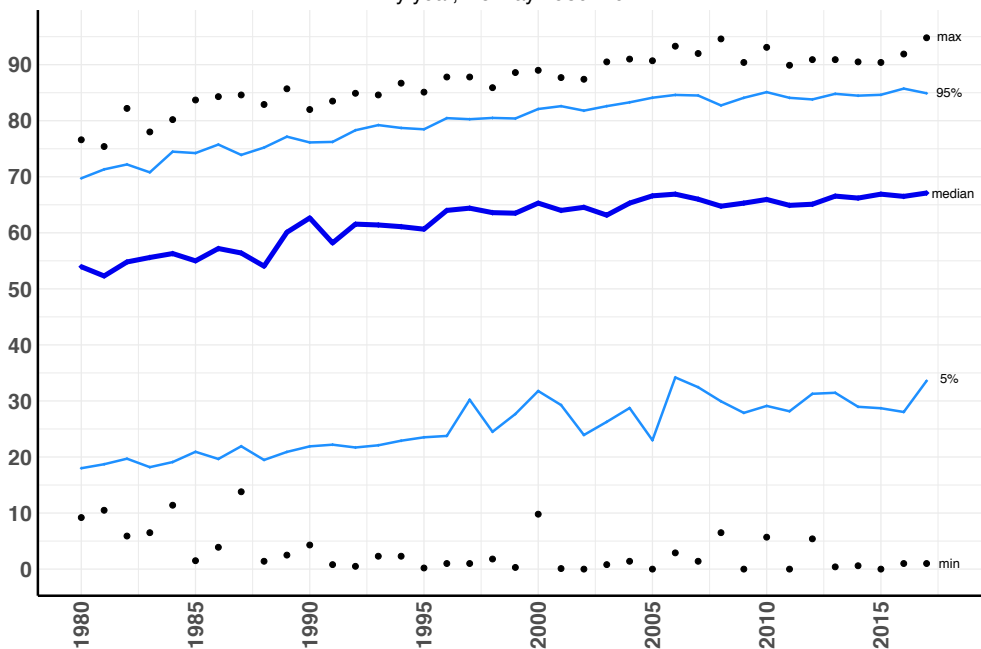


Since registration started in 1980 there has been a continuous shift in patient age. Both the maximum and the median age at start of RRT have increased. Also the 5-percentile and 95-percentile values (i.e. including the majority of patients) have increased with a similar number of years. But also smaller children have been accepted; the youngest ever started PD in 2011 at age two days. Seven children below 16 years started RRT in 2017.

Primary renal disease at start of RRT

Age of new patients in RRT

By year, Norway 1980-2017



	1980-89	1990-99	2000-04	2005-09	2010-14	2017
Glomerulonephritis	35%	27%	18%	18%	16%	13%
Pyelo/interstitial nephr.	15%	11%	11%	10%	9%	9%
Polycystic diseases	10%	9%	9%	8%	8%	9%
Diabetic nephropathy	13%	11%	15%	16%	17%	18%
Amyloidosis	6%	5%	3%	2%	2%	2%
Vascular/hypertensive	7%	21%	28%	31%	35%	28%
Immune/systemic	5%	5%	4%	4%	4%	8%
Kidney tumour	1%	1%	1%	2%	1%	2%
Myelomatosis	2%	2%	3%	3%	1%	1%
Other defined	4%	4%	3%	4%	4%	5%
Unknown	3%	3%	4%	4%	3%	5%
N:	2018	3234	2149	2556	2571	579

The main change over time has been an increase of vascular/hypertensive nephropathy and a relative reduction of glomerulonephritis. Whether this only reflects changed coding practice or a true shift is not known.

Diabetic nephropathy shows a tendency to increase as primary diagnosis cause for renal disease. In 2017, 30% of these were registered as having Type I diabetes mellitus. Including also patients with other primary diagnoses of renal disease a total of 194 patients were recorded as having diabetes mellitus at start of RRT (17% Type I), thus 33 % of new patients in RRT were diabetics.

The time from onset of diabetes to start of RRT differed considerably. For the patients with Type I diabetes the median time was 33 years, while for the patients with Type II diabetic nephropathy the median time was 16 years.

Cardiovascular disease is often present at start of RRT. Coronary heart disease was reported in 29% and 19% had anamnestic heart failure. Echo-verified left ventricular hypertrophy was reported in 28%. Cerebrovascular disease was reported in 14% and peripheral atherosclerotic disease in 16% while 11% had chronic obstructive lung disease.

[Number of biopsies with a given diagnosis by December 31st 2017.](#)

By the end of 2017 1089 diagnoses are registered, both related to primary biopsies and follow-up biopsies.

Minimal change nephropathy	35
Focal and segmental glomerulosclerosis primary	26
Focal and segmental glomerulosclerosis secondary	16
IgA nephropathy	176
Mesangioproliferative glomerulonephritis without IgA	9
Lupus nephritis	37
Endocapillary proliferative glomerulonephritis	10
Membranous nephropathy	38
Membranoproliferative glomerulonephritis	21
Anti-GBM nephritis	6
ANCA associated glomerulonephritis	88
Glomerulonephritis with necrosis/crescents idiopathic	9

Sclerosing glomerulonephritis	2
Henoch Schönlein purpura	23
Vasculitis	2
Thrombotic microangiopathy	14
Scleroderma	2
Malignant nephrosclerosis	5
Benign nephrosclerosis	101
Diabetic nephropathy	91
Amyloidosis	45
Myeloma kidney	7
Fibrillary glomerulonephritis	7
Immunotacotid glomerulonephritis	0
Preeclampsia associated glomerulopathy	1
Hereditary nephropathy, others	6
Fabry disease	13
Alport disease	15
Thin basement membrane disease	25
Tubulointerstitial nephritis	83
Acute tubular necrosis	24
Calcineurin inhibitor toxicity	3
Sarcoidosis	1
End stage kidney	2
Other glomerular / kidney disease unclassified	25
Normal or slight unspecific changes	36
Not representative	29
Uncharacteristic atrophy changes	28
Monoclonal immunoglobulin deposition disease	0
Dense deposit disease	3
Diffuse proliferative glomerulonephritis	1
Cryoglobulinemia	0
Cholesterol emboli	3
No code available	21

Prevalence data CKD5 by December 31st 2017.

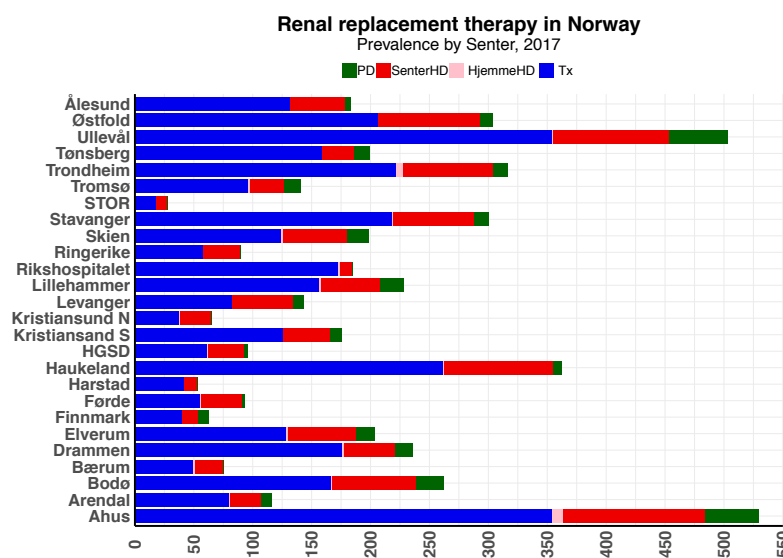
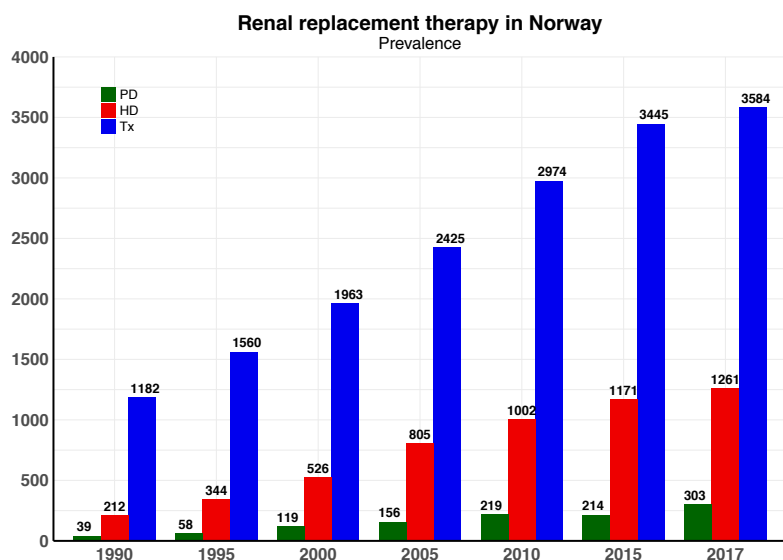
The data on CKD5 patients not in RRT is not complete as the register started to collect these data in 2016. The “best guess” is that the coverage of these patients is just below 60%. The reported data on CKD5 patients not in RRT should hence be interpreted with caution.

There were 319 CKD5 patients in the registry that did not receive renal replacement therapy by the end of 2017. The median length of stay in this category, before being initiated in RRT during 2017 was 10 months in the 158 patients where this had been registered, ranging from 0 to 128 months.

Prevalence data RRT by December 31st 2017.

By the end of 2017, 5,148 patients in Norway received renal replacement therapy, i.e. 975 per million inhabitants. This represents an increase of 179 patients or 3.6 % since 2016.

Median age by the end of the year was 62.0 years, mean 59.9 years and range 2.5 to 96.4 years. Gender: 64.8 % males.

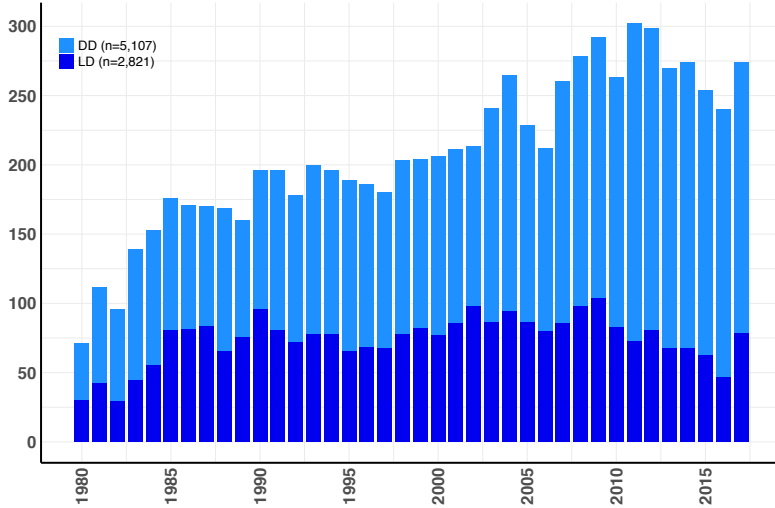


Transplantations and waiting list:

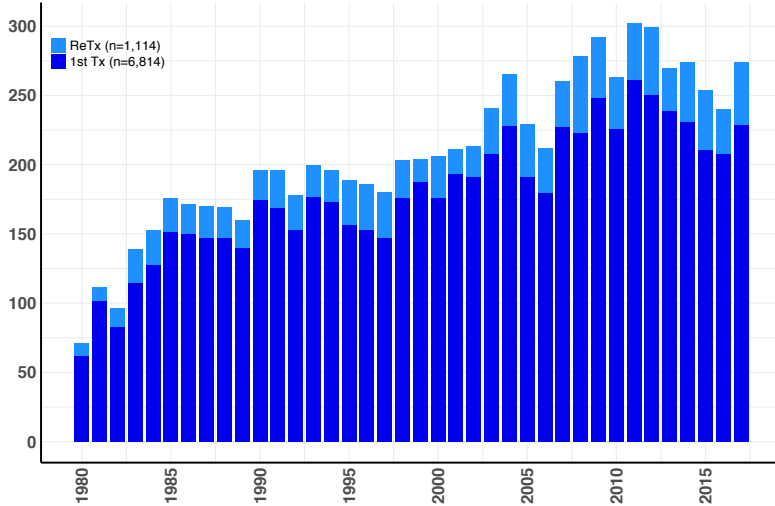
A total of 274 renal transplants were performed in Norway in 2017, i.e. 51.9 per million inhabitants, 16% were retransplantations. Distribution of transplantations with deceased and living donors, relation between recipient and donor etc is presented in the figures below. Simultaneous pancreas and kidney (SPK) transplantation was performed in 11 patients.

In principle, transplantation is offered to all patients considered to profit from it, with no strict upper or lower age limit. The age of the 160 first-DD-graft recipients in 2017 ranged from 14 to 80 years, with a median age of 57 years. Out of these, 33% were above the age of 65 and 11 % were 75 or older. The 69 recipients of a first LD-graft were from 2 to 75 years, with a median age of 50 years. Re-graft recipients (n=45) were from 14 to 75 years, median 56 years.

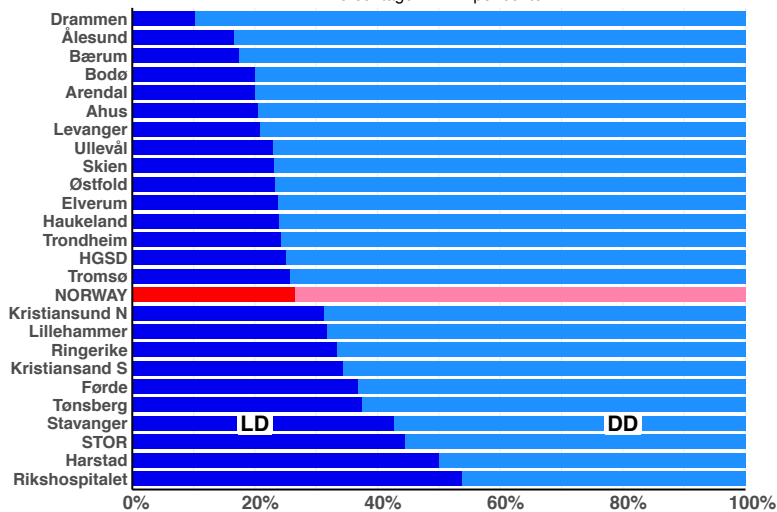
Performed Renal Transplantations
Norway 1980–2017



Performed Renal Transplantations
First vs. Re transplants, Norway 1980–2017

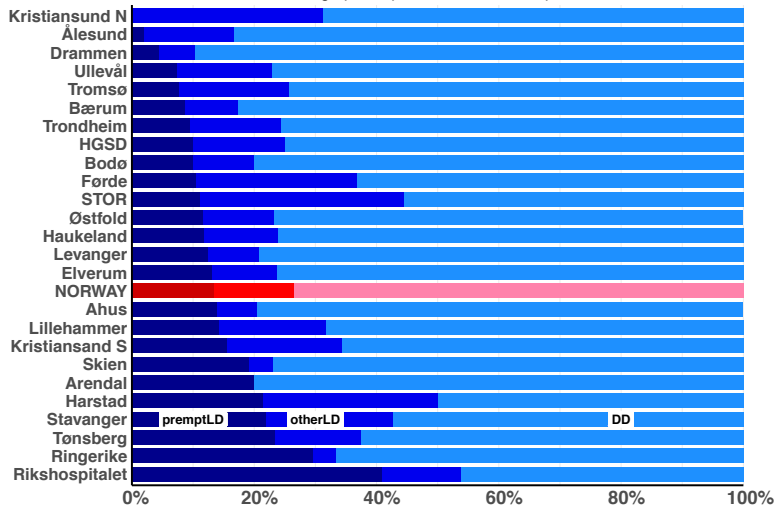


Kidney (only) transplantations 2013–2017
Percentage LD/DD per center



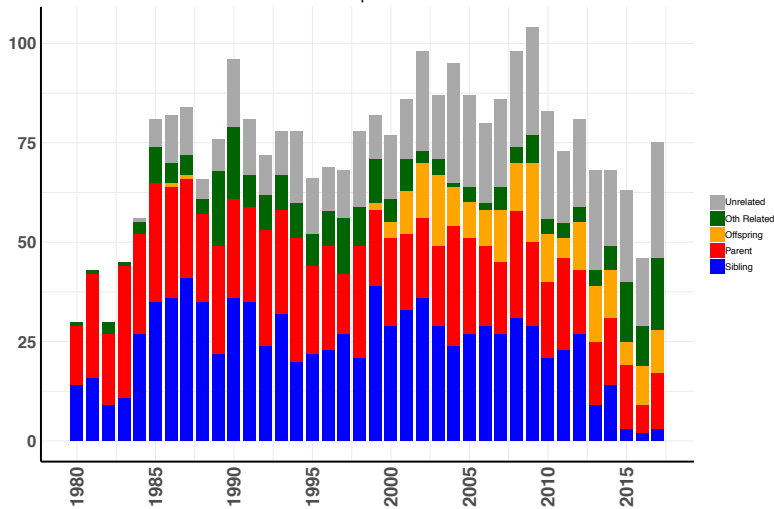
Kidney (only) transplantations 2013–2017

Percentage preemptiveLD/otherLD/DD per center



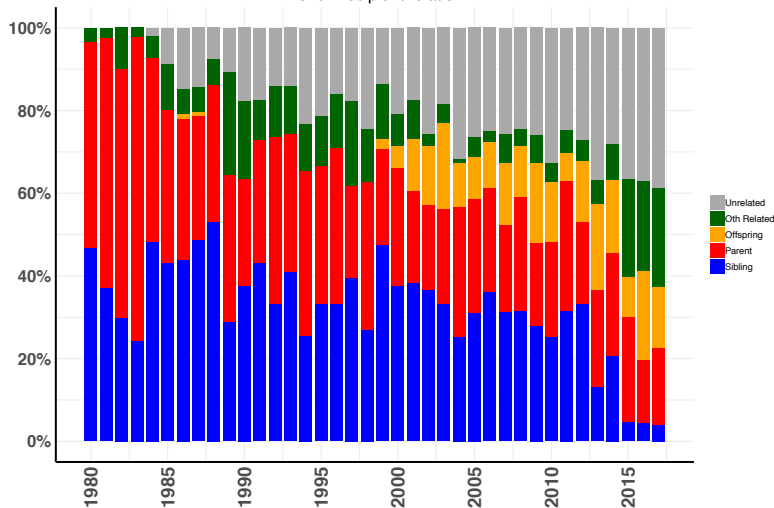
LD-transplantations 1980–2017

Donor–recipient relation



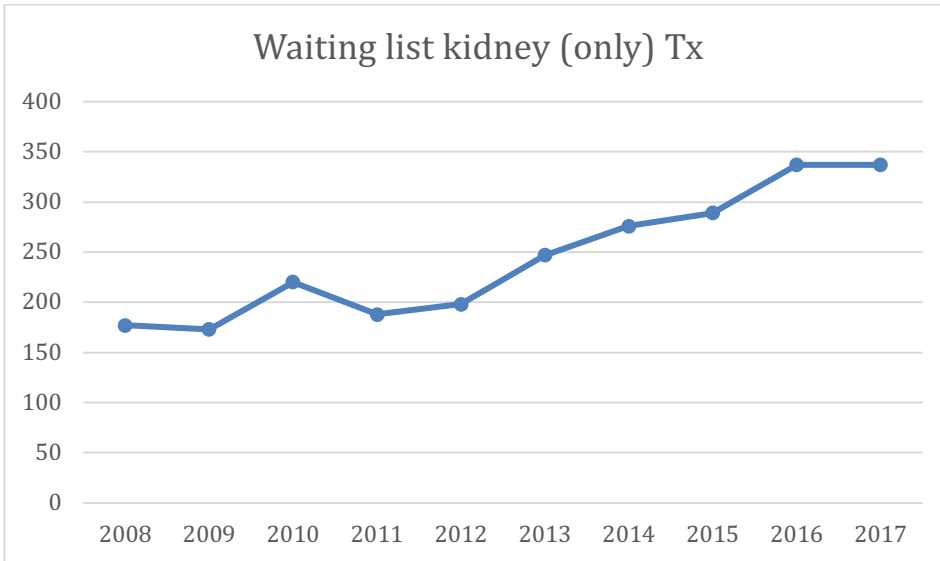
LD-transplantations 1980–2017

Donor–recipient relation



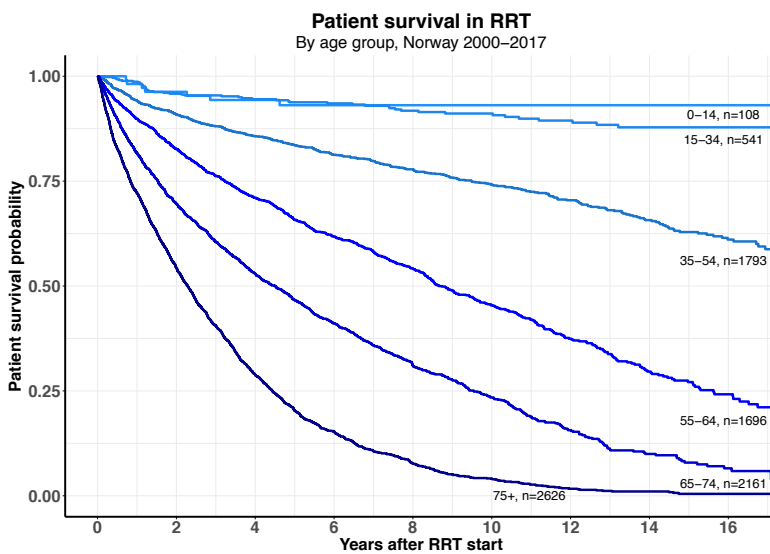
By end 2017, 337 patients (63.8 per mill.) were on the active waiting list for a DD renal graft, similar as in 2016. Among those waiting by December 31st, median time on the list was 9 months for a first transplant. 60 % had waited less than one year and 15 % more than two years. The 197 recipients transplanted with a DD-graft in 2017 had a median waiting time of

13 months for a first transplant and 14 months for a retransplant and a maximum of 79 months at the time of grafting.

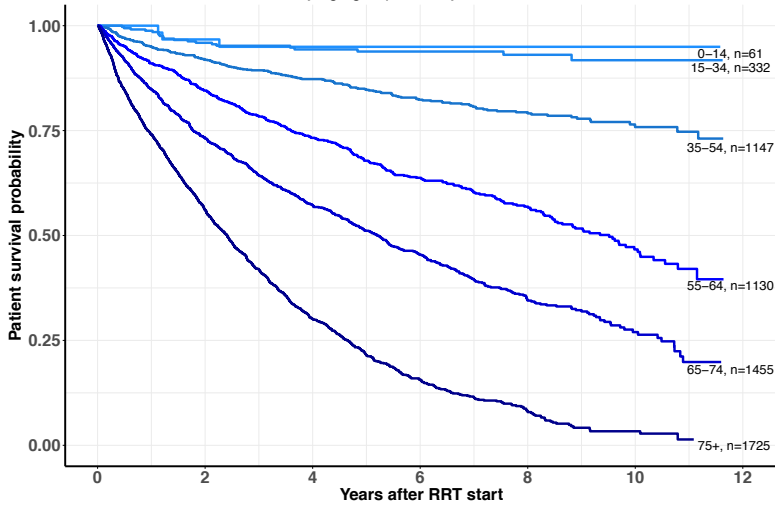


Patient and graft survival :

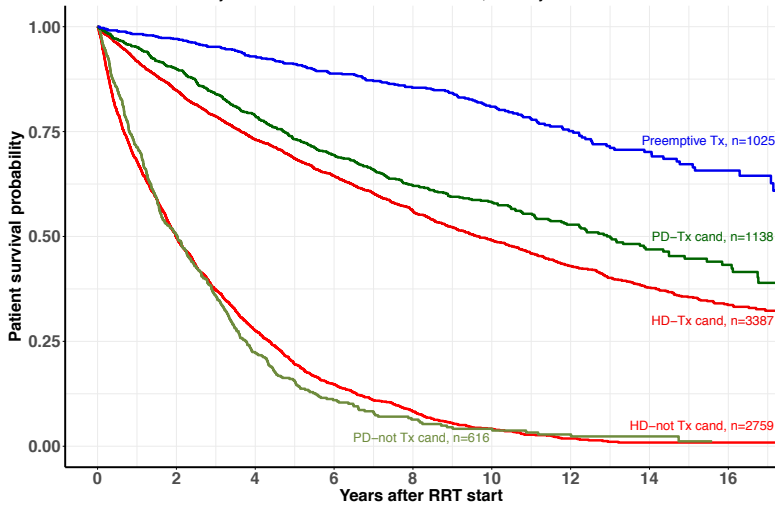
Below different Kaplan-Meier analyses on graft (not death censored) and patient survival are presented, crude plot only. Changes in baseline characteristics should be taken into consideration, for example that median age when starting RRT is increasing by the year.



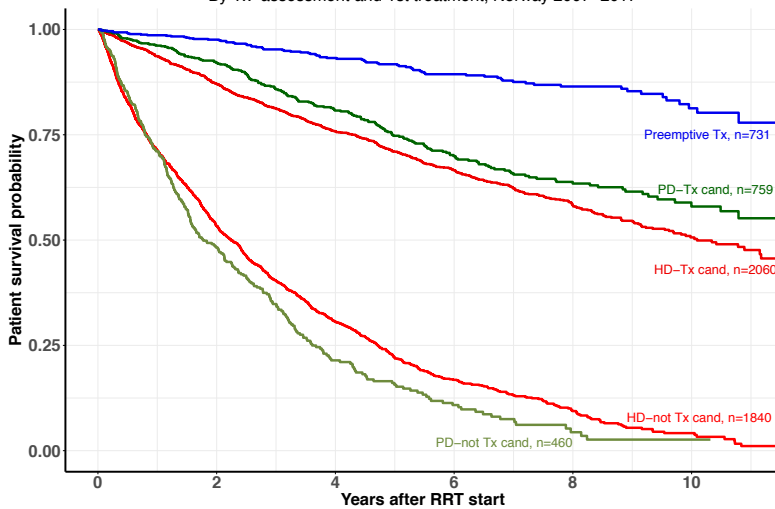
Patient survival in RRT
By age group, Norway 2007–2017



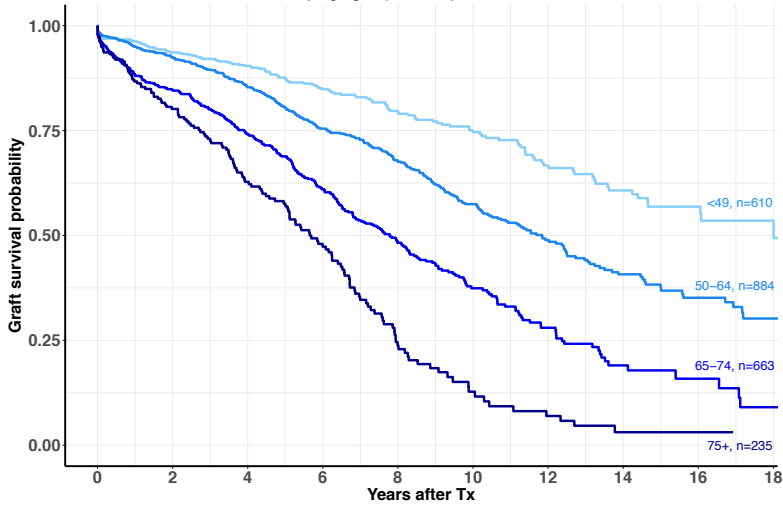
Patient survival in RRT
By Tx-assessment and 1st treatment, Norway 2000–2017



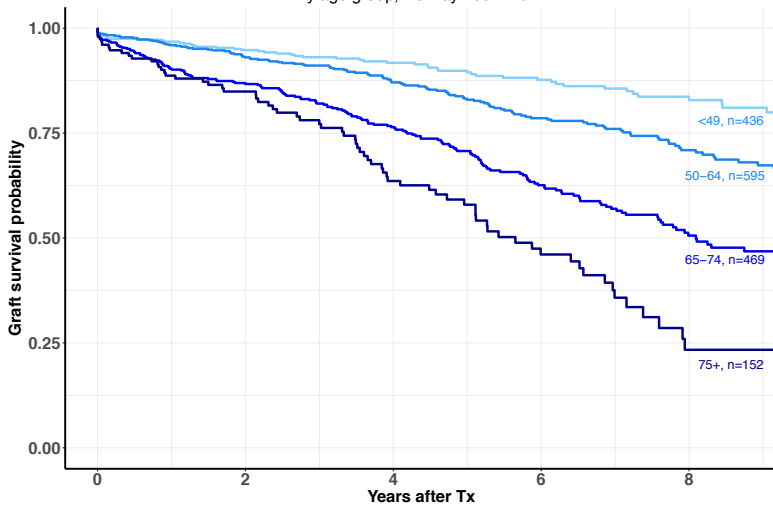
Patient survival in RRT
By Tx-assessment and 1st treatment, Norway 2007–2017



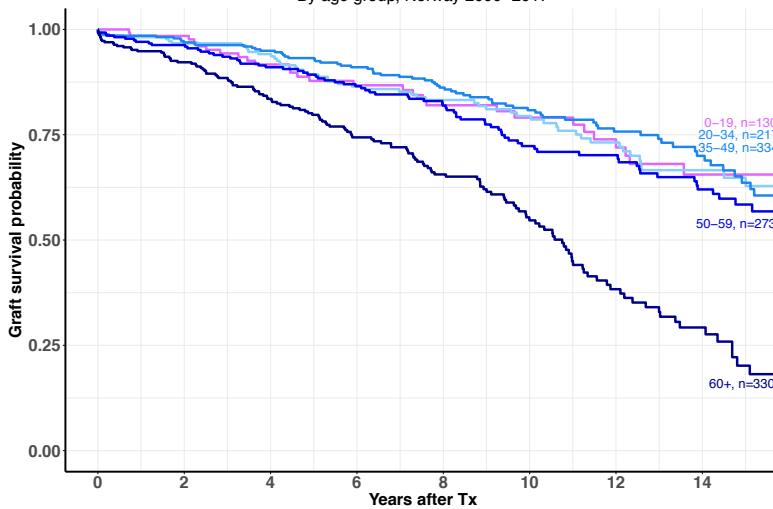
Graft survival, first DD kidney (only) transplant
By age group, Norway 2000–2017



Graft survival, first DD kidney (only) transplant
By age group, Norway 2007–2017

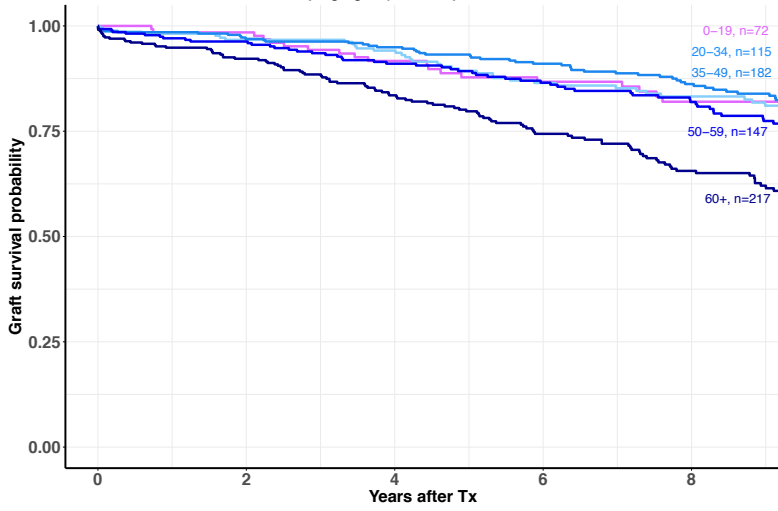


Graft survival, first LD kidney (only) transplant
By age group, Norway 2000–2017



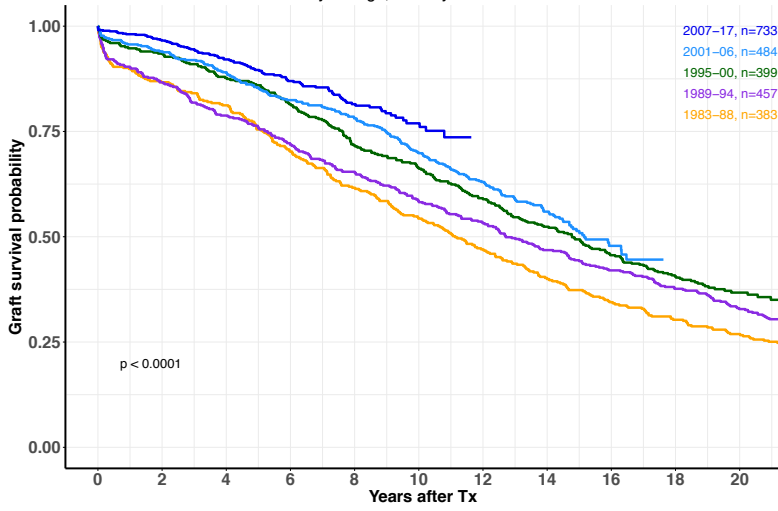
Graft survival, first LD kidney (only) transplant

By age group, Norway 2007–2017



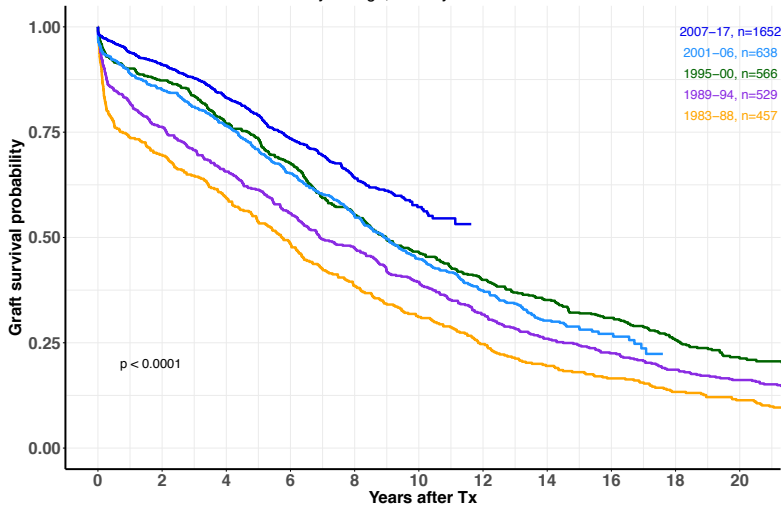
Graft survival, first LD kidney (only) transplant

By vintage, Norway 1983–2017



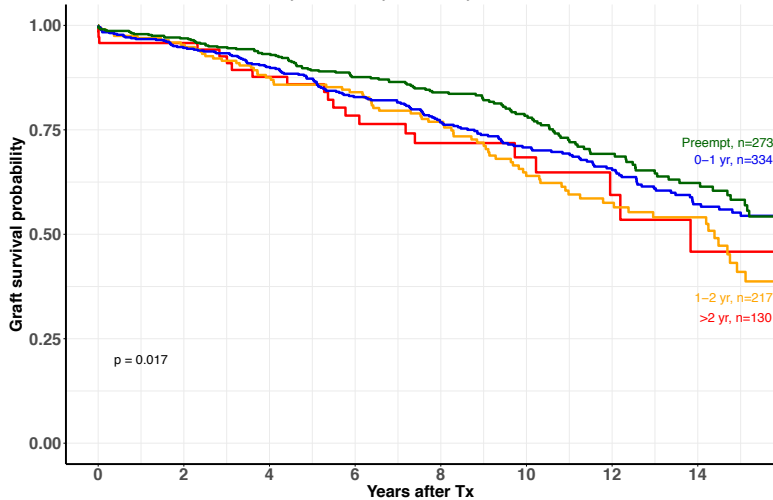
Graft survival, first DD kidney (only) transplant

By vintage, Norway 1983–2017



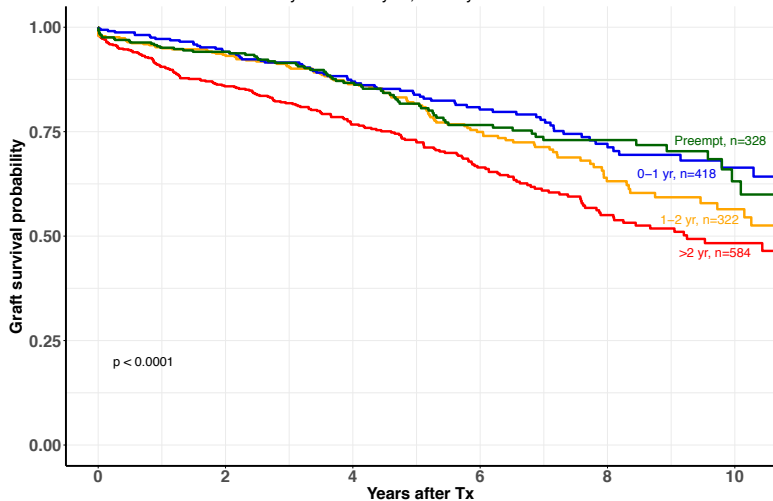
Graft survival, first LD kidney (only) transplant

By time in dialysis, Norway 2000–2017



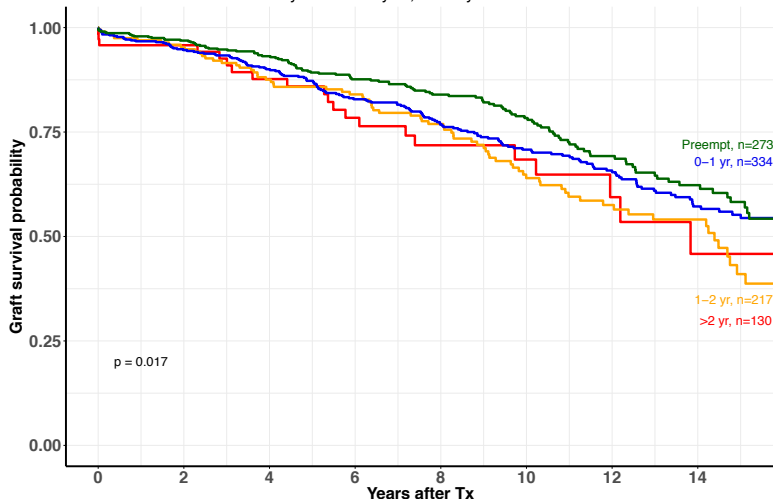
Graft survival, first DD kidney (only) transplant

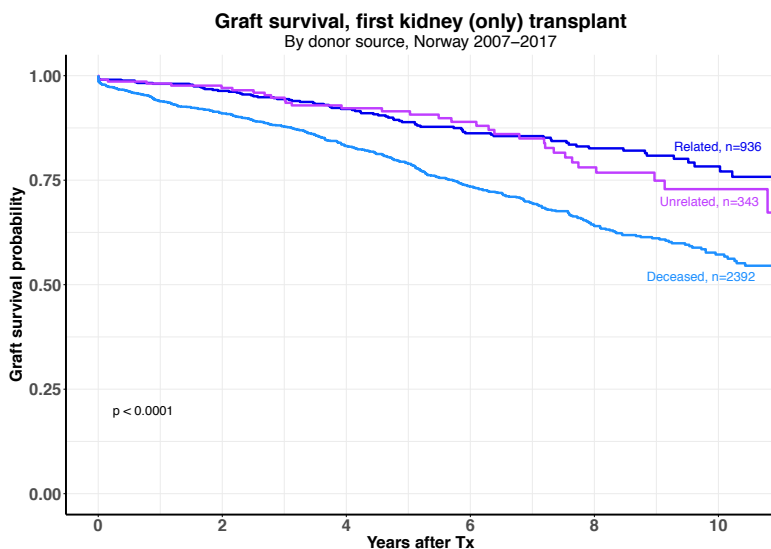
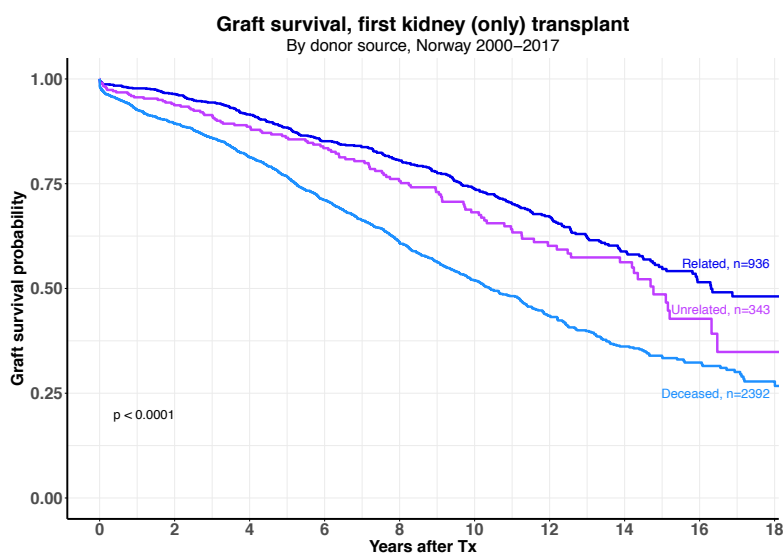
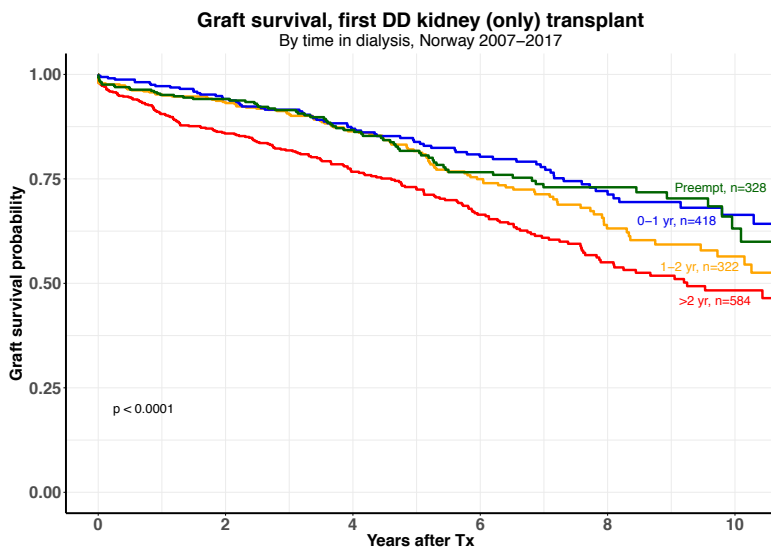
By time in dialysis, Norway 2007–2017



Graft survival, first LD kidney (only) transplant

By time in dialysis, Norway 2000–2017





Death in CKD5:

A total of 424 patients in CKD5 died during 2017, 31 of patients had never started RRT, 193 of patients were in active dialysis and 109 transplanted. Dialysis treatment was terminated and followed by death in 75 patients.

Median age at death was 76 years (mean 74 years), ranging from 32 to 94 years. Median time from start of RRT until death was 4.5 years (mean 7.7 years), ranging from 4 days to 48 years.

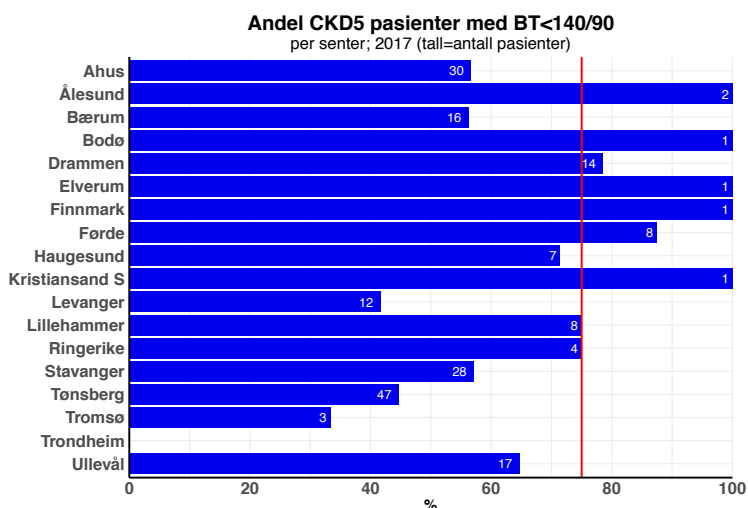
Cardiac complications (29%) were the most frequent causes of death, followed by malignant tumours (21%) and infections (20%).

Quality indicators:

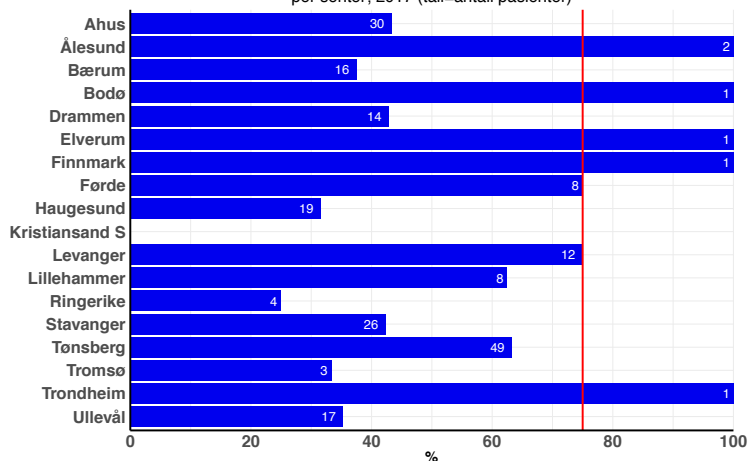
The registry have implemented 22 quality indicators (see appendix) that will be followed year by year to assure the quality of the treatment the patients included in the registry is subjected to. These data are presented interactively at this site (<https://www.kvalitetsregistre.no/registers/464/resultater>) and the quality indicator of part in home dialysis is presented three times per year here (<https://helsenorge.no/Kvalitetsindikatorer/behandling-av-sykdom-og-overlevelse/andel-dialysepasienter-som-har-hjemmedialyse>). Only a short summary of the results is presented as figures in this report for completeness.

The registration of all cases of peritonitis during the year has not been complete and a change in collection procedure has been implemented to correct this. These data is hence not presented in this report. Also data on acute rejections are not possible to extract from the database where these are registered at OUS-Rikshospitalet why complete data is not available and this indication is not presented in the present report.

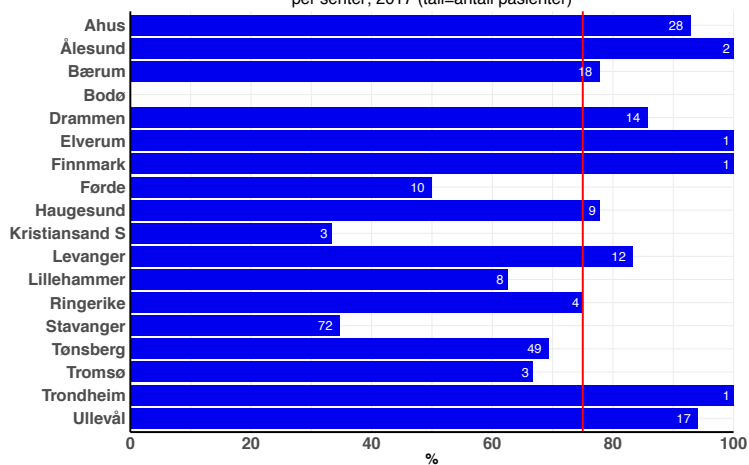
Data on part of the patients on the waiting list for a kidney transplant that has been in dialysis for more than 2 years is not relevant to present on a center level. In 2017 the part had been reduced to 10% from 16% in 2016.



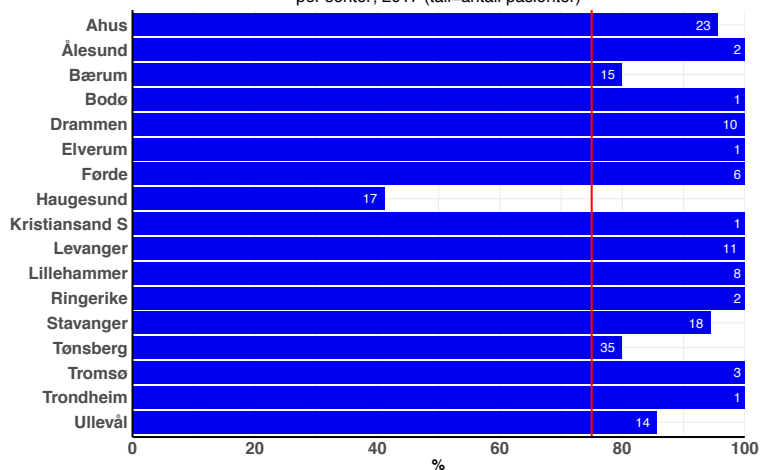
Andel CKD5 pasienter med fosfat <1,5 mmol/L
per senter; 2017 (tall=antall pasienter)



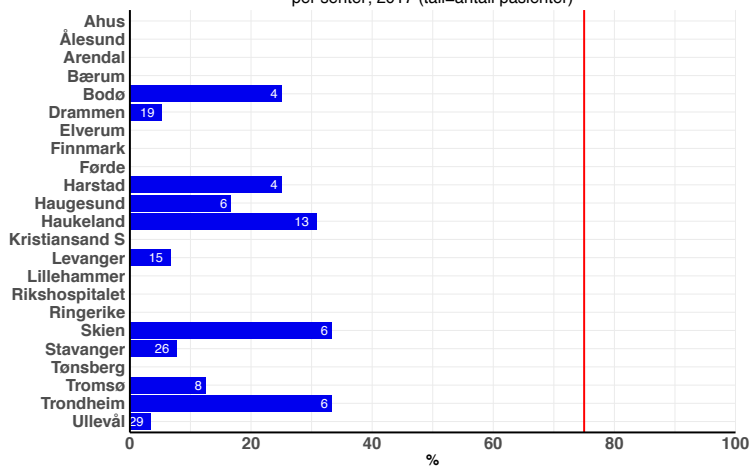
Andel CKD5 pasienter med bikarbonat >20 mmol/L
per senter; 2017 (tall=antall pasienter)



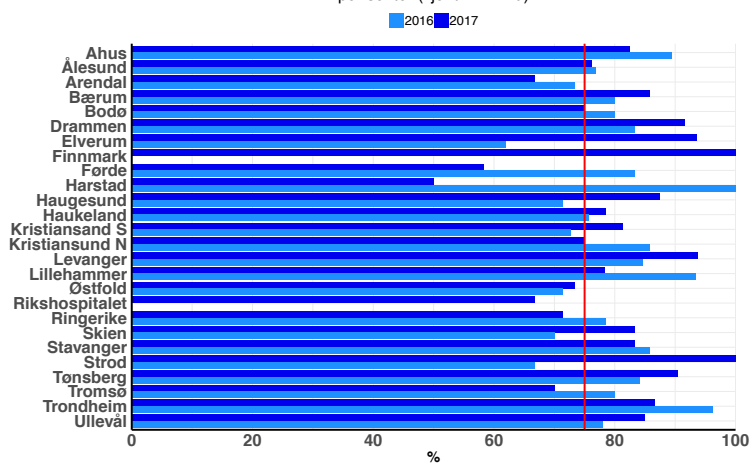
Andel CKD5 pasienter med Hgb >10g/dL
per senter; 2017 (tall=antall pasienter)



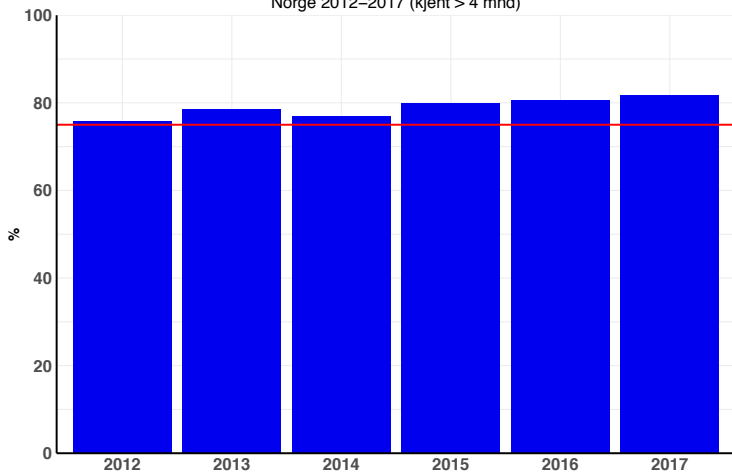
Andel CKD5 pasienter som gjennomført Nyreskole
per senter; 2017 (tall=antall pasienter)



Andel kjent ved oppstart dialyse
per senter (kjent > 4 mnd)

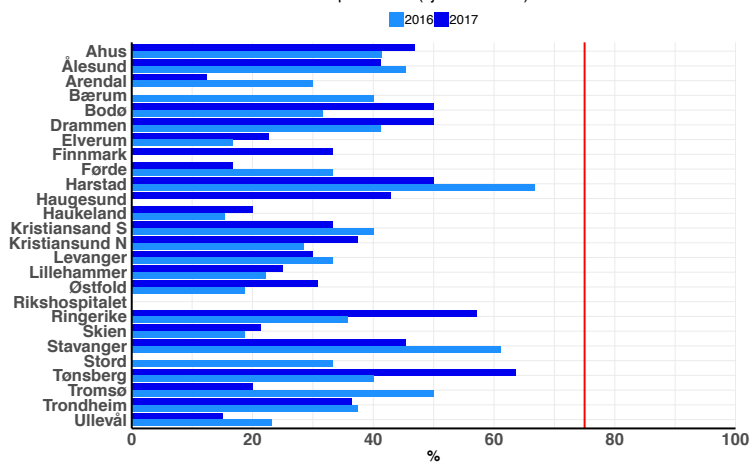


Andel kjent ved oppstart dialyse
Norge 2012–2017 (kjent > 4 mnd)



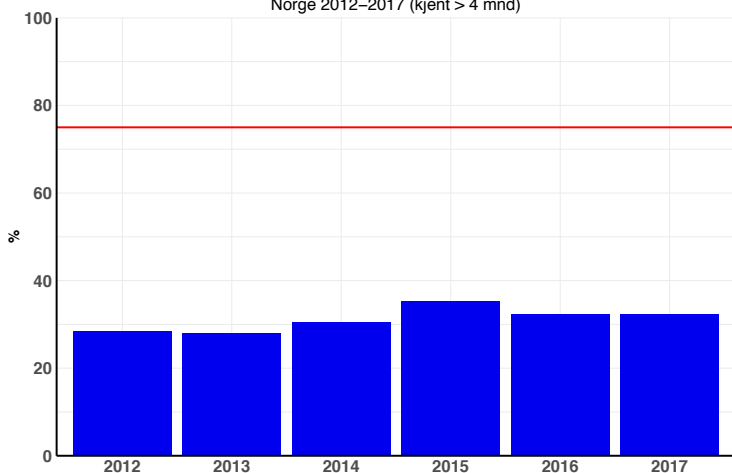
Andel kjente HD pasienter som starter på fistel

per senter (kjent > 4 mnd)



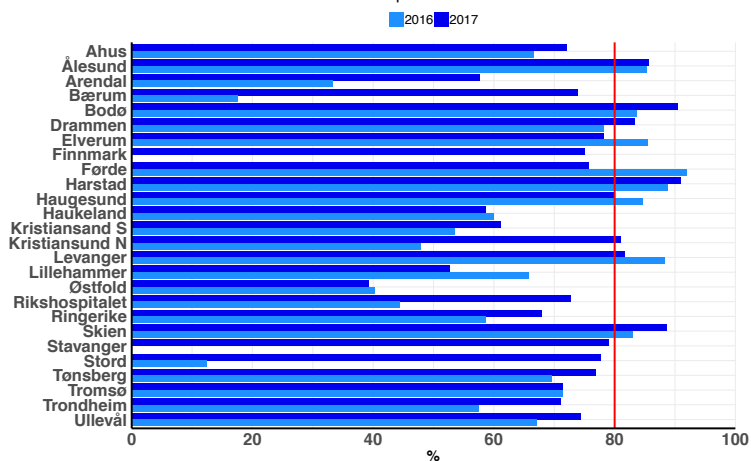
Andel kjente HD pasienter som starter på fistel

Norge 2012-2017 (kjent > 4 mnd)



Andel HD pasienter med Kt/V > 2,3

per senter



Andel HD pasienter med Kt/V>2,3

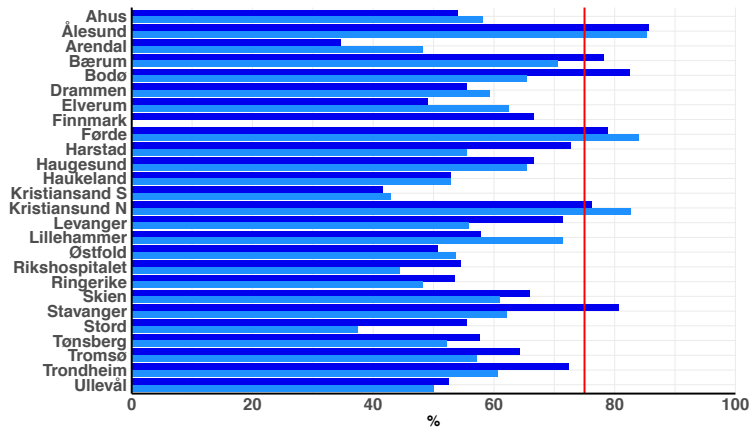
Norge 2015-2017



Andel HD pasienter med predialytisk fosfat <1,78 mmol/L

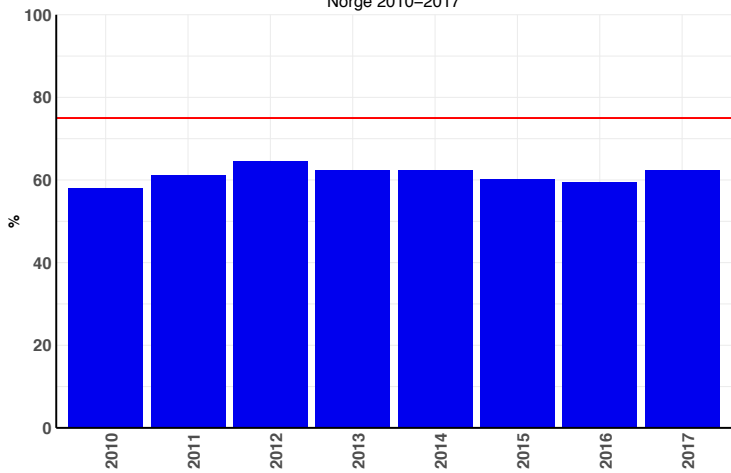
per senter

2016 2017

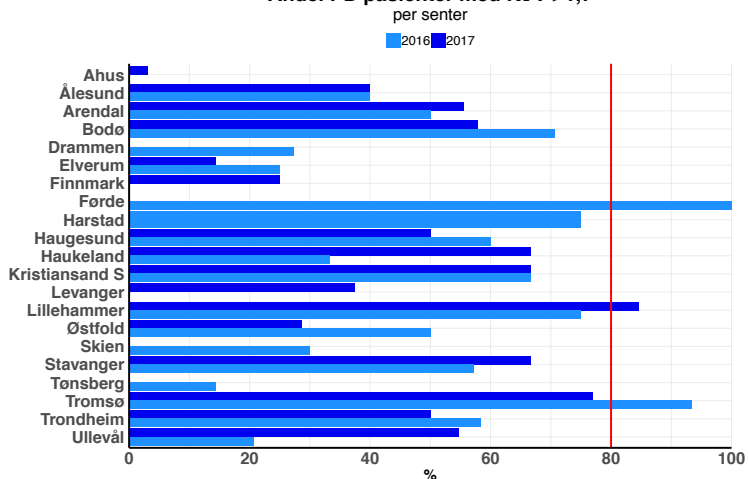


Andel HD pasienter med predialytisk fosfat <1,78 mmol/L

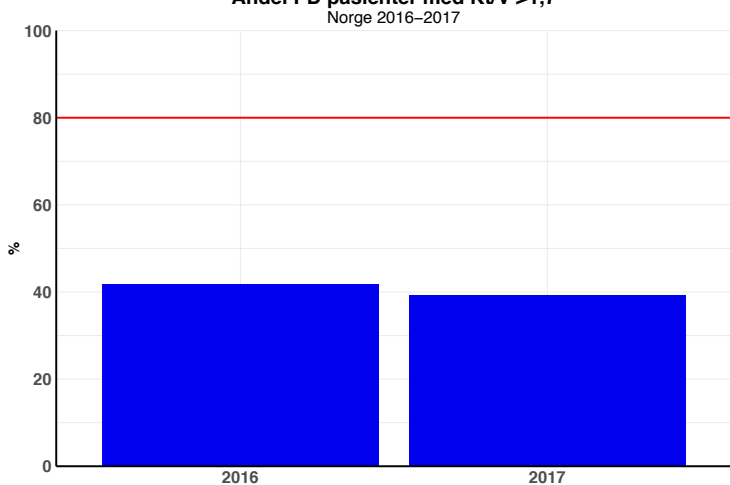
Norge 2010-2017



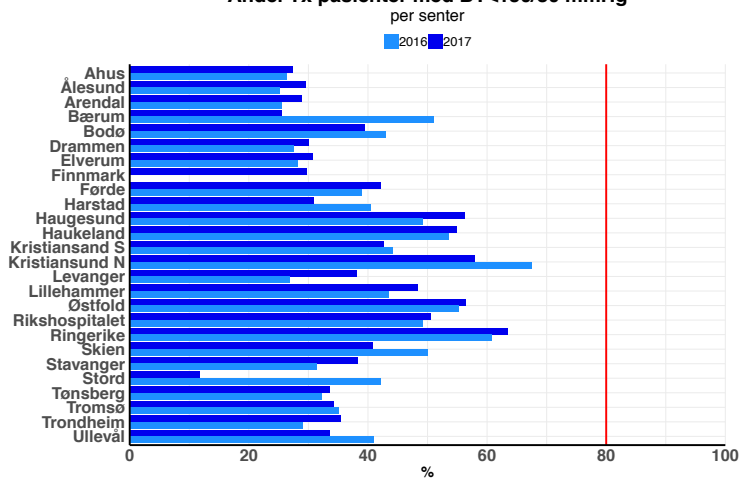
Andel PD pasienter med Kt/V >1,7



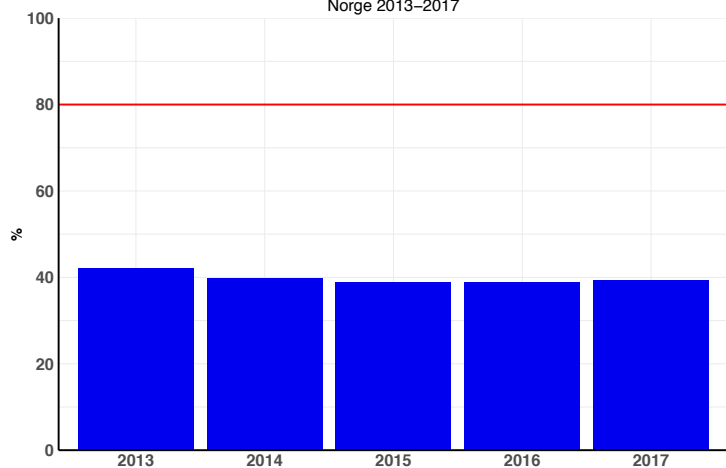
Andel PD pasienter med Kt/V >1,7



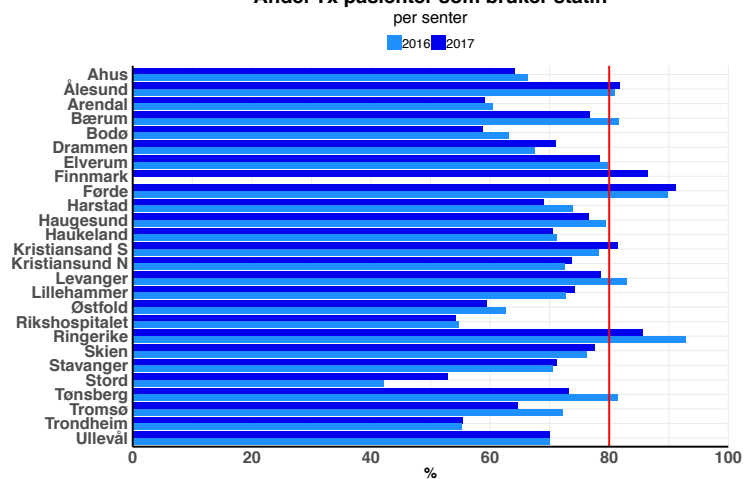
Andel Tx pasienter med BT < 130/80 mmHg



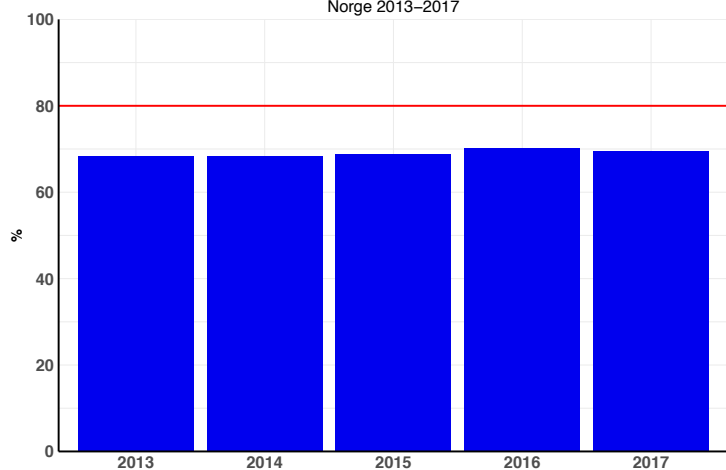
Andel Tx pasienter med BT<130/80 mmHg
Norge 2013–2017



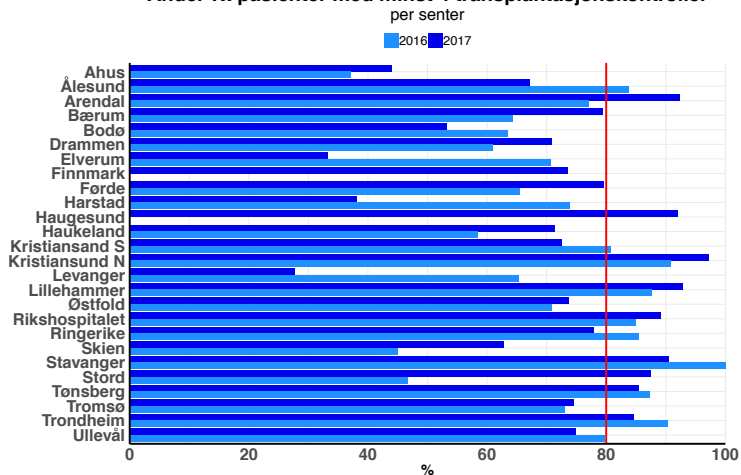
Andel Tx pasienter som bruker statin
per senter



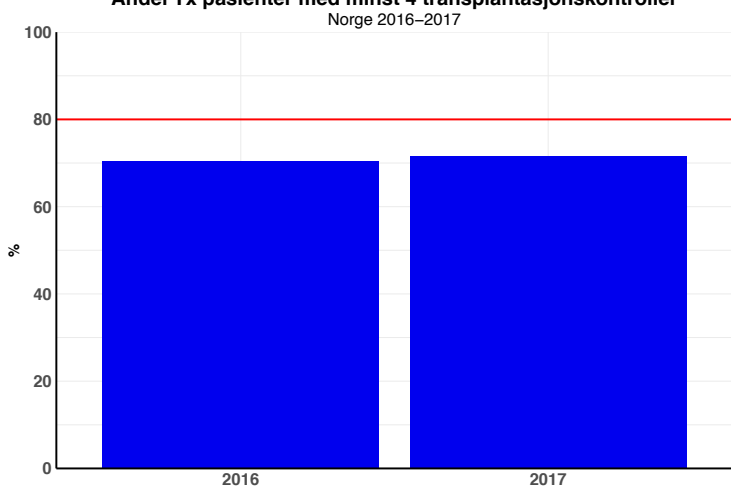
Andel Tx pasienter som bruker statin
Norge 2013–2017



Andel Tx pasienter med minst 4 transplantasjonskontroller



Andel Tx pasienter med minst 4 transplantasjonskontroller



Concluding remarks:

The incidence of patients in CKD5 still shows an increasing trend and patients starting RRT is steadily being older by the year. When interpreting the incidence rate, it should be kept in mind that the true incidence first will be known when the coverage of CKD5 patients not in RRT reaches a higher level. The prevalence is also increasing, majorly driven by an increased survival in RRT. Despite the increased age in patients starting RRT the survival is increasing

A worrying trend is the increasing waiting list for kidney transplantation. Action has been taken to increase the number of living donors with a good result, but there is still need of more available organ for transplantation.

During the analysis of the 22 quality variables in the registry two areas where further investigation of underlying reasons are needed; i) blood pressure treatment in transplant patients and ii) blood access used when starting patients in haemodialysis.

Registry data are also regularly used by Norwegian nephrologists as basis for scientific papers, congress presentations and PhD-thesis. A list of publications is published on www.nephro.no along with the annual reports. During 2017 a total of 31 international peer reviewed papers and five PhD-theses have been more or less based upon data from the registry.

Data delivered to the ERA-EDTA Registry in Amsterdam are included in its reports and publications; some data are also forwarded to the USRDS-reports (the chapter of "International Comparisons")

Regardless of status, the cooperation with all Norwegian nephrologists and nephropathologists, demanding their steady efforts to keep the registry updated, has always been, and will always be, a prerequisite for keeping a complete and reliable registry. All hard work over the entire country is acknowledged!

Report completed 13.12.2018

Appendix:

	Satellitres	New pat in RRT 2017				Pat. in RRT by 31.12.2017					Dialyses etc. 2017			Died 2017		Not tx-cand.
		HD/HDF	PD	Pre-emptive	Total	HD/HDF	HjemmeHD	PD	Graft	Total	HD sessions	Pl.exch.	Other	Dial.pat	Tx-pat	
AHUS		32	25	8	65	120	10	45	354	529	20,108	0	0	22	11	86
Arendal		8	1	2	11	26	1	9	80	116	4,139	0	121	8	4	23
Bergen	4	25	3	2	30	92	1	7	262	362	13,844	91	47	10	14	50
Bodø	8	14	10	1	25	72	0	23	167	262	10,421	32	0	9	3	57
Bærum		7		3	10	24	1	0	50	75	3,815	0	0	4		19
Drammen	1	14	10	3	27	43	2	15	176	236	7,330	49	26	16	4	14
Elverum	1	22	9	2	33	58	1	16	129	204	8,543	0	40	15	1	45
Finnmark	3	3	2		5	14	0	9	40	63	1,938	0	0			13
Førde	2	12		1	13	35	0	2	56	93	5,160	5	0	4	1	28
Harstad		2		1	3	11	0	0	42	53	1,460	0	0	5		5
Haugesund	2	7	1	2	10	31	0	3	62	96	4,364	6	28	8	2	18
Hønefoss	1	9	7	2	18	32	0	0	58	90	4,545	0	0	7	2	18
Kristiansand S	1	8			8	40	0	10	126	176	6,721	20	0	10	4	34
Kristiansund N	1	10	6	2	18	27	0	0	38	65	3,409	0	0	5		14
Levanger	6	28	9	5	42	51	0	9	83	143	8,742	0	76	11	3	27
Lillehammer	3	3		5	8	50	1	20	157	228	6,813	34	0	15	3	40
Rikshospitalet		7		3	10	11	1	0	173	185	2,776	283	67		5	4
Stavanger		14	10	2	26	69	0	12	219	300	10,960	13	44	15	6	54
Stord		22	2	6	30	10	0	0	18	28	1,435	0	0	1	2	6
Telemark	3	2			2	54	2	18	124	198	8,782	70	0	8	4	45
Tromsø	3	15	5	1	21	29	2	14	96	141	5,749	18	0	14	5	25
Trondheim	4	22	8	2	32	76	6	12	222	316	13,071	131	541	17	8	57
Tønsberg		11	10	7	28	27	0	13	159	199	4,542	62	53	11	7	20
Ullevål		20	20	7	47	98	1	50	354	503	16,938	37		30	12	75
Østfold	2	26	4	6	36	86	0	11	207	304	13,744	35	0	13	5	44
Ålesund	1	17	4		21	46	0	5	132	183	6,868	96	0	10	4	28
SUM		360	146	73	579	1,232	29	303	3,584	5,148	196,217	982	1,043	268	110	849
# Pr. mill innb.		68.2	27.7	13.8	109.7	233.4	5.5	57.4	679.0	975.4						160.9
% of total		62.2	25.2	12.6	100,0	23.9	0.6	5.9	69.6	100,0						16.5

27-11-2017

Norsk Nyreregister -- Kvalitetsmål

Pasientgruppe	Kvalitetsmål	Måltall	Hva måler det?
Biopsi	Andel med alvorlige komplikasjoner i forbindelse med biopsitaking (definert som blodtransfusjon eller intervensjon)	<2%	Måler sikkerhet ved biopsitaking
	Andel biopsier med ≥ 10 glomeruli	90%	Måler kvalitet på selve biopsitakingen
	Andel biopsier endeligbesvart fra patologiavdelingene innen 1 mnd	80%	Måler rutiner og struktur i utredningsapparatet
	Andel primære biopsier med moderate til uttalte kroniske forandringer i biopsien	<30%	Mål på om pasientene utredes tidlig nok i forløpet av sin nyresykdom
CKD5	Andel med blodtrykk under 140/90 mmHg	75 %	Mål på om guidelines og anbefalinger følges
	Andel med fosfat < 1,5 mmol/L	75 %	Mål på om guidelines og anbefalinger følges
	Andel med bikarbonat > 20 mmol/L	75 %	Mål på om guidelines og anbefalinger følges
	Andel med Hgb > 10 g/dL (10-12 hvis ESA)	75 %	Mål på om guidelines og anbefalinger følges
	Gjennomført "Nyreskole" ved start i CKD5 (hvis kjent av nefrolog > 4 mnd.)	75 %	Fange opp at behandlingen for hver enkelt pasient tilpasse den enkelte pasient og er planlagt i god tid.

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Pasientgruppe	Kvalitetsmål	Måltall	Hva måler det?
Dialyse (felles)	Andel kjent >4 mnd før dialyseoppstart	75 %	Fanges pasientene opp av avdelingen? Henvisningspraksis, ressurser og opplæring av primærhelsetjeneste og kollegaer
	Andel i hjemmedialyse (hjemmeHD + PD)	30%	Mål på om individualisert behandling etterstrebes i stort nok omfang
Hemodialyse	Andel med ukentlig Kt/V >2,3 (inkludert restfunksjon)	80 %	Mål på bevissthet og kvalitet av dialysebehandlingen
	Andel pasienter, kjent > 4 mndr, som starter HD på fistel	75 %	Er det en plan for når og hvordan pasientene skal starte? Interne prosedyrer for å planlegge dialyseoppstart
	Andel med predialytisk fosfat < 1,78 mmol/L	75 %	Mål på fokus og behandling av metabolske forstyrrelser og komplikasjoner
Peritonealdialyse	Andel med ukentlig Kt/V >1,7 (inkludert restfunksjon)	80 %?	Mål på bevissthet og kvalitet av dialysebehandlingen
	Antall peritonitter per år	≤ 0.5 /pas.år	Mål på at behandlingen blir utført på tilfredsstillende måte
Transplantasjon	Andel med blodtrykk under 130/80 mmHg	80%	Mål på om guidelines og anbefalinger følges
	Andel som bruker statin	80%	Mål på om guidelines og anbefalinger følges
	Andel med ≥ 4 transplantasjonskontroller per år	80%	Mål på om pasientene blir tatt hånd om på en god nok måte
	Antall aktivt på Tx-venteliste med dialysetid > 2 år (unntatt PRA \geq 80%)	< 10%	Mål på om behandlingstilbudet er godt nok
	Biopsipåvist akutt reaksjon første år etter transplantasjon	< 20%	Overordnende mål på om behandlingen er godt nok tilpasset pasientene
	Graftoverlevelse	vs. ScandiTx	Sammenligner overordnede kvalitet på behandlingen i forhold til land som er naturlig å sammenligne med (Norden)