Annual Report - 2024

For the Norwegian Renal Registry (Norsk Nyreregister)

Introduction

During 2024 the registry continued working to improve the new MRS-platform that was launch in January 2024. This new digital platform replaced the old paper-form reporting, and all local centers are now reporting annual data to the registry electronically. The new platform also gives each center local access to all registered data on their own patients. In this local registry the centers themselves can make center-specific analyses.

In this report we have made some layout changes, moving many of the figures to the new homepage of the registry: https://nyreregister.no. There you will find both a PowerPoint presentation with a wide variety of incidence-, prevalence- and survival figures and one with all the results of the quality indicators of the registry. They are free to be used by everyone if the registry is credited when used in presentations. If you do not find the figure that you was looking for, it is still possible to contact the registry or your local center contact to ask for other analyses.

Analyses on the different quality indicators have been adjusted to better differentiate between results in patients with the goal of optimized treatment and those that are treated with a more symptom-relieving goal. In 2026 we will also finally be able to collect PROM-data directly from the patient via the MRS solution.

The registry has a good coverage for both transplanted patients and patients receiving dialysis. We were afraid that with the new MRS-platform and the electronic consent solution we would get some challenges to get all patients that start on dialysis registered, but so far this seems to be only a marginal challenge. We hope that this will continue and that the local centers continue to register all patients continuously and in a timely manner, so we continue to always have a good overview of the population. Last year the registry performed a coverage analysis in cooperation with NPR. Results showed a coverage in the high 70% range. This year we have finalized a similar analysis on the population of CKD5 patients not (yet) on kidney replacement therapy. The results show a low coverage of about only 50%. There are several reasons for this, and the registry will focus on activates that help increasing this coverage. The main strength of our registry has always been a near total overview of the Norwegian “kidney population”. The new MRS-platform makes it easier for those who register to keep track of the full history of the patients, and we hope this will help in increasing the coverage of CKD5 patient in the future.

With regards to the dialysis population, we continue to see a slow but steady increase in home treatment. For Norway as a whole, we are still a few percentage points below the target of 30%, but with a high inter-center variation. Some centers are well above the 30%-target showing that it is possible to achieve this target.

Considering kidney biopsies, the number of kidney biopsies is further increasing over time. The coverage in 2024 was 79%.

History and organization of the 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 (dialysis >3 months).

The current "version" of NRR is a merge in 2016 of the Norwegian Nephrology Registry and the Norwegian Renal Biopsy Registry 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 kidney replacement therapy (KRT) had been collected within The Renal Association since 1980 in a less formalized manner, and the transplant center had stored data on transplanted patients since the late sixties. Further, Norwegian kidney 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 have contributed 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 data available for research. In 2012, the registry was acknowledged as one of the national quality registries. 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 about 13,000 non-neoplastic kidney biopsies. Together with the 6,000 non-neoplastic kidney biopsies collected in the new registry, the total amount of biopsies is about 19,000.

In 2025 the registry received approval to incorporate the Norwegian Registry of Living Kidney Donors into the Norwegian Renal Registry. From 2026 the reporting of follow-up data on living donors will therefore be via the MRS-solution.

National organization and policy

Norway had 5.550 mill. inhabitants (December 2023). Each county has at least one central renal unit and some central units have satellite units run in close collaboration. There is only one transplant center (two during 1963-82). Pre-transplant work-up, as well as post-transplant follow-up beyond 2 months, is handled by the county-centers. County boarders do not always coincide with the area that the different kidney units cover, and this report presents data based on county boarders as well as divided in RHF and HF levels, whenever appropriate.

During 2017 Finnmark was separated from Tromsø and in March 2022 Lovisenberg started to treat patients with severe renal disease. In March 2024 Kongsberg was separated from Drammen. So now there are 28 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 m^2 that is verified after three months. The first date when eGFR <15 mL/min/1.73 m^2 is the CKD5 start date (updated definition!). Progression to the need of kidney replacement therapy (dialysis, transplantation), changes between dialysis modality (PD, "center HD", "home HD"), transfer between centers or immigration/emigration, graft loss and deaths are reported on a continuous basis. For 2024, annual data from the visit closest to December 31st 2024 was to be reported, even if it was in 2025. The overall report rate by the finalization of this report was 95% for the forms requested.

Transplantation has always been considered the kidney replacement treatment of choice, if possible, and preferably with a living related donor. Since 1984, also unrelated living donors have been used. Acceptance criteria for transplantation have been wide and 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 90%. Transplanted patients are crosschecked continuously against the transplantation lists at OUS-Rikshospitalet and annual crosschecks against each of the 28 centers lists of dialysis patients are performed per December 31st each year. For patients in kidney replacement therapy the individual coverage is close to 100%. CKD5 patients not treated with kidney replacement therapy have been included in the registry since 2016. Based on the recent coverage analysis (against Norwegian Patient Registry) over the period 2019-2023 the coverage is only 50%. A coverage analysis of non-neoplastic kidney biopsies for the period 2019-2022 has been performed (against Norwegian Patient Registry). The average coverage in the period was 77%. At regular intervals, reporting of deaths to the registry is checked against the Norwegian National Registry (NO: Folkeregisteret).

NRR is one of the national medical quality registries (https://www.kvalitetsregistre.no/registeroversikt). NRR has identified over 20 quality indicators to cover all relevant subgroups of patients in the registry. The quality indicators are reported annually (https://www.kvalitetsregistre.no/register/nyre/norsk-nyreregister). An updated version of the quality indicators is always available at the homepage of the registry (https://nyreregister.no/om-registeret/).

Biopsy section

Incidence biopsy

During 2024, 642 non-neoplastic kidney biopsies with relevant clinical data were registered in the Norwegian renal registry (**Table 1**). 560 were primary biopsies. In total, 621 biopsies had complete pathology data. For hospital level details, see **Figure 1** where blue bars indicate the number of biopsies registered in 2024, and orange line indicates the number of biopsies registered in 2023.

Table 1. *Number of kidney biopsies per regional health authority in the last 9 years. Neoplastic and transplant biopsies are not included.*

	2016	2017	2018	2019	2020	2021	2022	2023	2024
Helse Sør-Øst	303	326	355	360	400	389	338	442	369
Helse Vest	126	136	137	114	119	104	111	114	140
Helse Midt	73	58	79	60	79	79	82	99	72
Helse Nord	48	50	55	54	50	49	46	51	61
Total	**550**	**570**	**626**	**588**	**648**	**621**	**577**	**706**	**642**

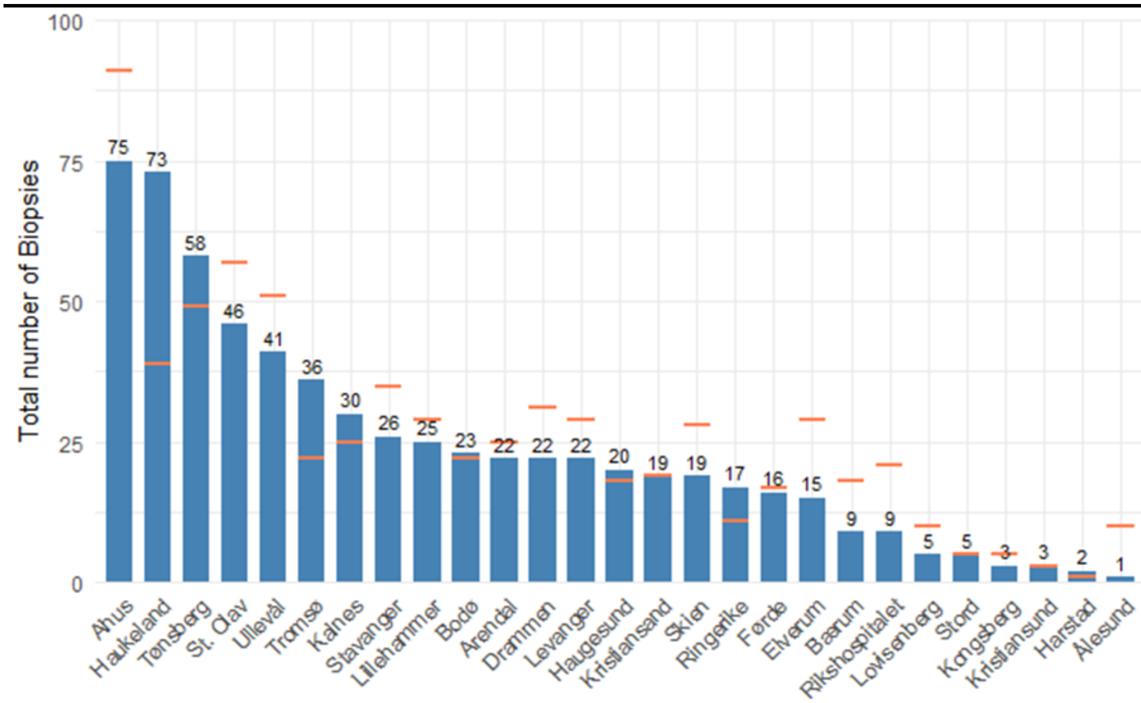

Figure 1. *Total number of kidney biopsies reported to the Norwegian Renal Registry per hospital in 2024 (blue bars), compared to 2023 (orange lines).*

Age: How old were the biopsy patients?

The mean age at kidney biopsy in 2024 was 53.5 years (range 3-91 years, **Table 2**), which is slightly higher compared to the mean age at kidney biopsy in 2023 (51.9, 2-89). The highest mean age at kidney biopsy was reported in Helse Nord (56.5), while the lowest mean age at biopsy was reported in Helse Midt-Norge (47.7).

Of all kidney biopsies reported to the registry in 2024, 25 biopsies (4 %) were performed in patients under the age of 18. The majority of pediatric biopsies (n=12) were performed at Haukeland Hospital in Helse Vest. The percentage of kidney biopsies performed in patients above 80 years of age was 5.3% (34 biopsies), compared to 4% in 2023. Of these were 20 biopsied in Helse Sør-Øst. For hospital level details, see **Figure 2** where the mean age for all hospitals are presented.

Table 2. *Mean age at kidney biopsy, per regional health authority in 2024.*

	Total N=642	Helse Sør-Øst N=369	Helse Vest N=140	Helse Midt N=72	Helse Nord N=61
Mean age in years	**53.5**	54.6	52.1	47.7	56.5
Range	**(3-91)**	(6-91)	(3-89)	(12-81)	(17-83)
<18 years	**25 (4%)**	9	12	3	1
>80 years	**34 (5.3%)**	20	9	2	3

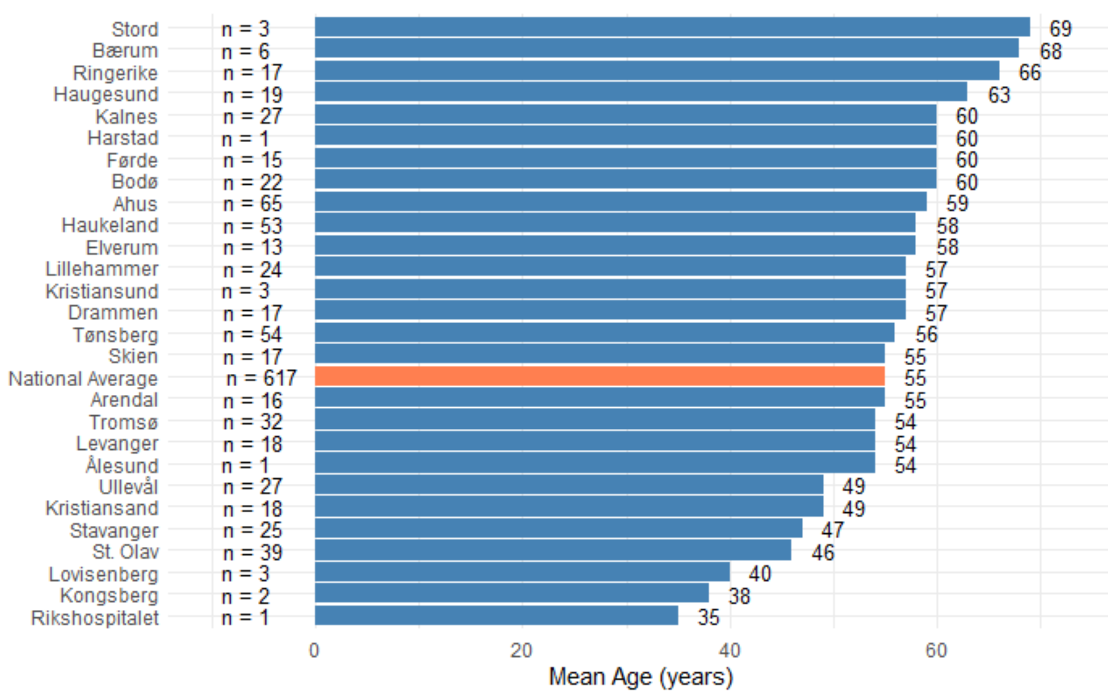

Figure 2. *Mean age in years for patients over 18 years of age at primary kidney biopsy, per hospital in 2024.*

Characteristics of primary biopsy patients by hospital: Serum-Creatinine, Albuminuria and chronic changes (quality indicator)

Serum creatinine

The national average serum-creatinine was 136 µmol/l in 2024, but with big variations between hospitals (**Figure 3**). The median creatinine levels has remained relatively stable around 140 µmol/l from 2016 to 2024 (**Figure 4**).

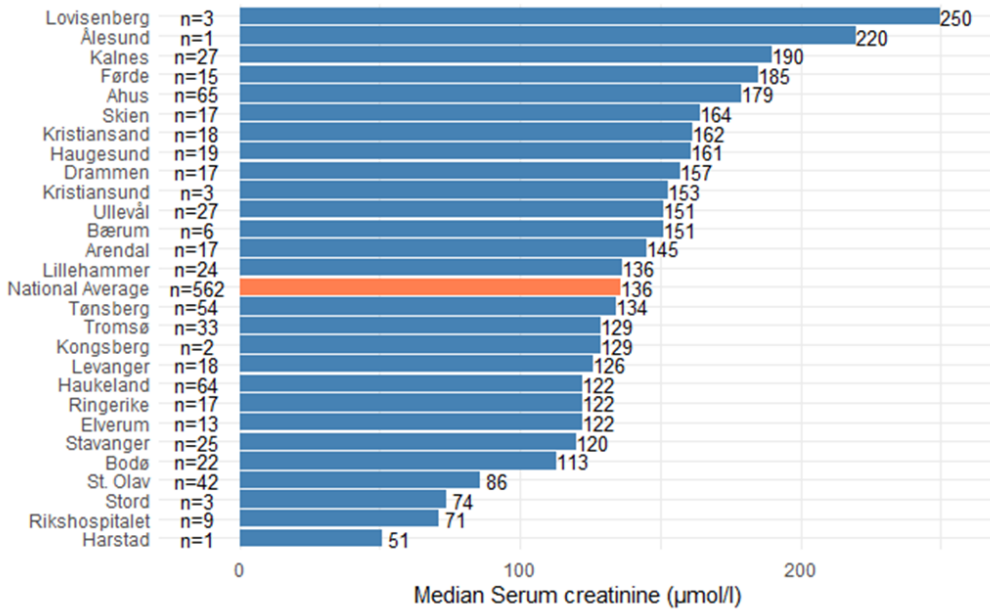

Figure 3. Median serum creatinine (µmol/l) at the time of primary kidney biopsy, per hospital in 2024.

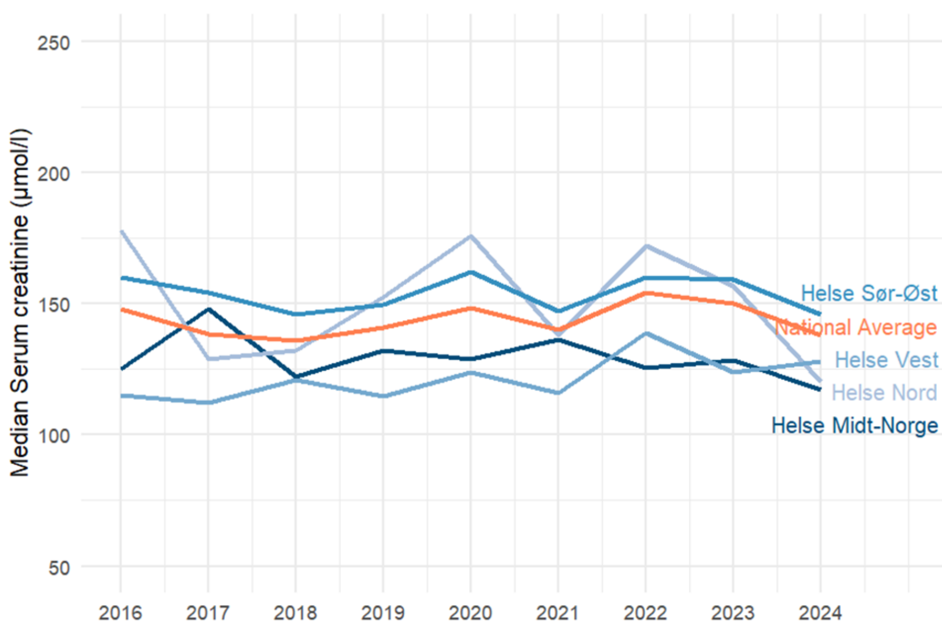

Figure 4. *Median Serum creatinine (µmol/l) at the time of primary kidney biopsy, from 2016 to 2024 according to regional health authority.*

Albuminuria

The national average albuminuria was 63 mg/mmol creatinine in 2024, but with big variations between hospitals (**Figure 5**). It has remained relatively stable around 75 mg/mmol creatinine from 2016 to 2024 (**Figure 6**).

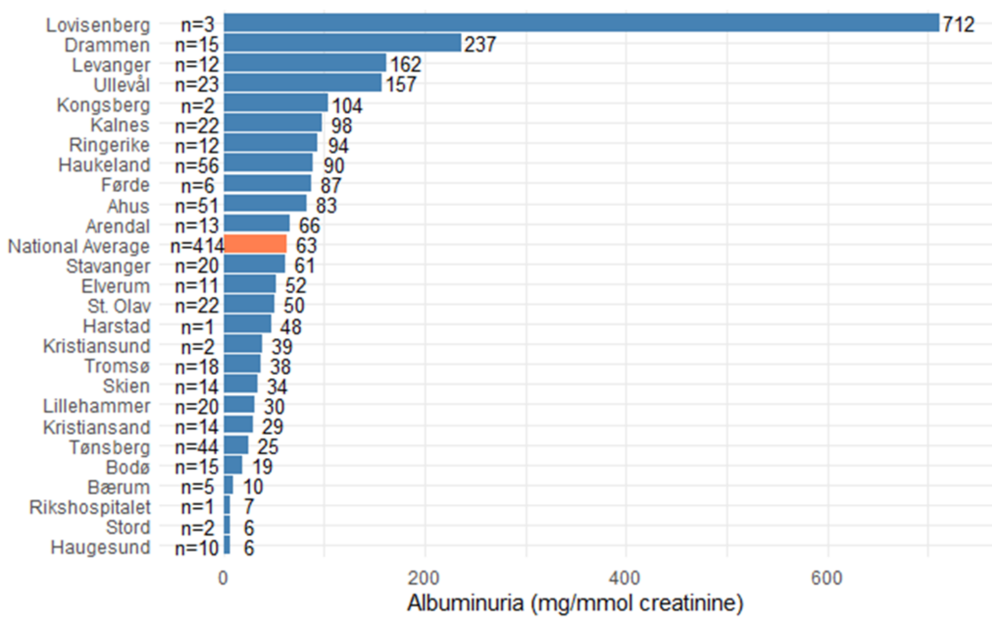

Figure 5. *Median albuminuria (mg/mmol creatinine) at the time of* *primary* *kidney biopsy, per hospital in 2024.*

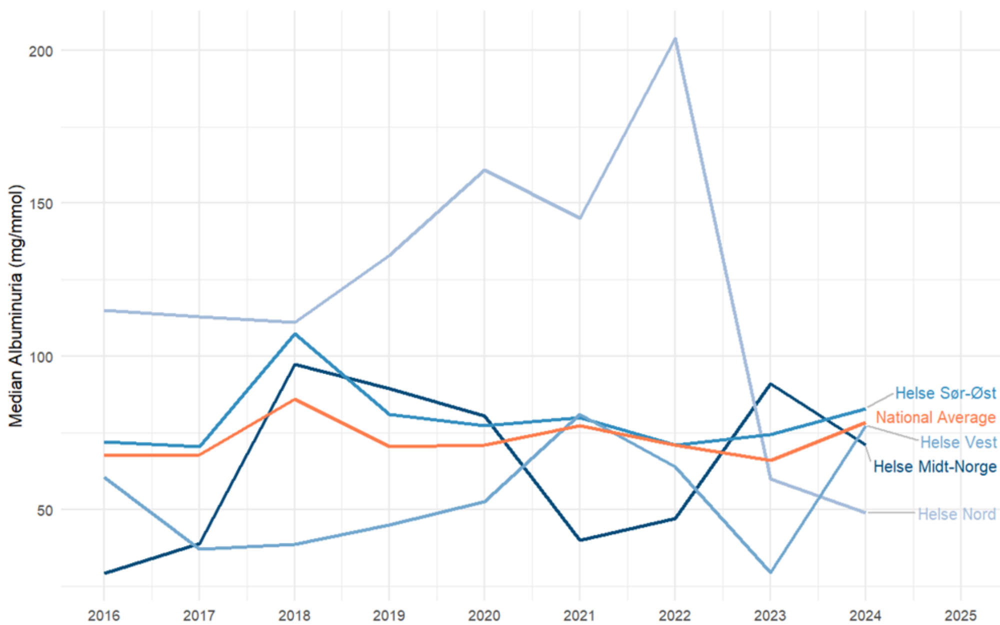

Figure 6. *Median albuminuria (mg/mmol creatinine) at the time of* *primary* *kidney biopsy from 2016 to 2024 according to regional health authority.*

Proportion of primary biopsies with moderate to severe chronic changes (quality indicator)

Chronic kidney changes are persistent and irreversible. A high proportion of such changes indicates an increased risk of kidney function loss and suggests limited potential for treatment response. Early diagnosis is therefore important – before chronic, irreversible damage occurs.

Tubular atrophy is a hallmark of chronic kidney disease. Moderate to severe tubular atrophy often means that the biopsy was taken late in the disease process either because the patient presented late or the diagnostic pathway was delayed.

The national **quality indicator** "Number of primary kidney biopsies with moderate to severe chronic changes" expects that less than 30% of biopsies from one centre should show moderate or severe tubular atrophy. This reflects whether patients are being examined early in the course of their kidney disease. The quality indicator is calculated by dividing the number of biopsies showing moderate or severe tubular atrophy by the total number of biopsies at the centre. Some patients have multiple kidney biopsies. For the calculation, only the first biopsy taken from a patient is used.

Figure 7 highlights two issues: First, some nephrology units show a high number of cases with moderate to severe tubular atrophy. This may reflect late patient presentation or differing biopsy indications among these units. Second, data interpretation for some nephrology units (e.g. Levanger and St. Olavs Hospital) is limited because reports from the associated pathology department had many missing/incomplete data for this indicator (figure 18-21).

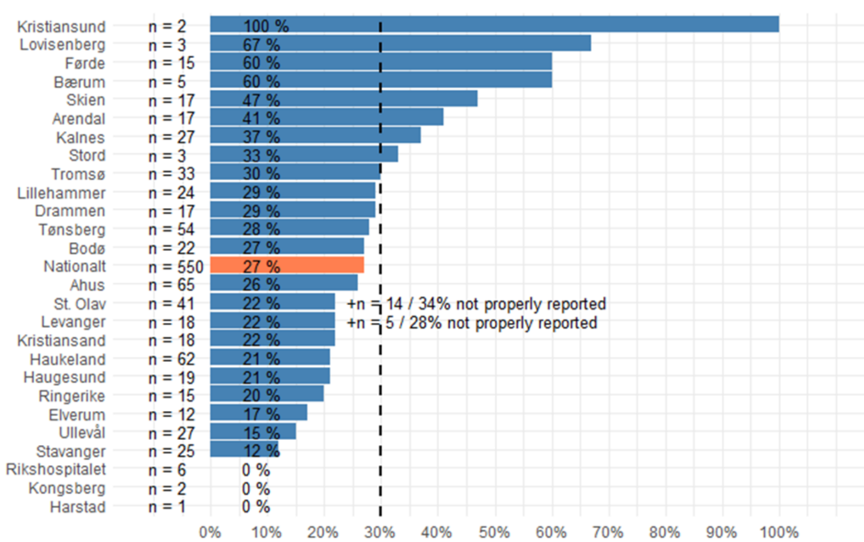

Figure 7. *Percent kidney biopsies with moderate to severe tubular atrophy and percent of biopsies without proper registration of tubular atrophy per hospital in 2024. The vertical black dotted line indicates quality indicator goal (<30%).*

Serious complications (quality indicator)

In most kidney biopsies, no procedure-related complications occurred: Of 642 kidney biopsies reported to the registry in 2024, 91.3% were reported without complications **(Figure 8/Tables 3**).

A serious complication is defined as the need for blood transfusion, and/or the need for interventions. Minor, self-limiting bleeding is not considered a serious complication.

In 2024, serious complications were reported in 1.2% of all 642 kidney biopsies (**Table 3**). This corresponds to 8 serious complications (transfusion or intervention) in 6 different patients. This is below the target of 2%, and a slight decrease compared to the previous year. These biopsies with serious complications, were performed at six different hospitals, and there was considerable variation in patient age (54–91 years). All biopsies in which serious complications occurred were performed by a radiologist using an 18G biopsy needle, with between one and three passes taken. It should be noted that the small numbers result in large percentage variations in the calculations.

A positive development is a significant decrease in missing reports on complications — from 6.2–11.8% in the years 2018–2023 to only 1.6% in 2024 **(Figure 8/Table 3)**. The reduction is attributed to the new electronic reporting system (MRS), in which the fields concerning complications are mandatory.

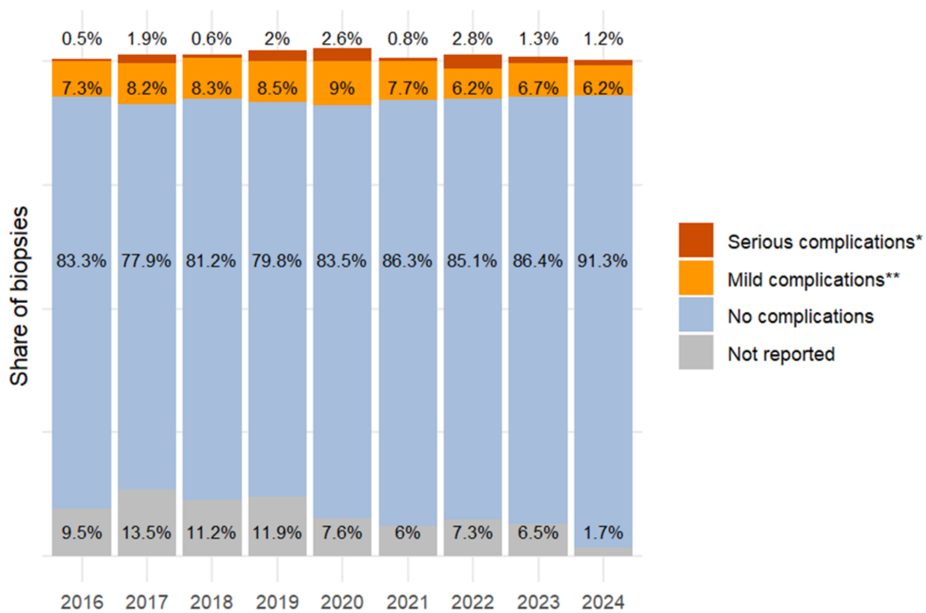

Figure 8. *Percentage of serious procedure related complications, no complications and not reported complications from 2018 to 2024.*
* Transfusion and/or intervention.
**Macroscopic hematuria and/or other complications, such as hematoma without the need for transfusion, which are reported to the registry as a comment in free text.
The total percentage may exceed 100% because more than 1 complication may be reported per biopsy.

Table 3. *Reported complications per regional health authority in 2024.*

	National total (N=642)		Helse Sør-Øst (N=369)		Helse Vest (N=140)		Helse Midt (N=72)		Helse Nord (N=61)	
	n	**(%)**	**n**	**(%)**	**n**	**(%)**	**n**	**(%)**	**n**	**(%)**
No complications reported	586	(91.3 %)	336	(91.1 %)	131	(93.6 %)	66	(91.7 %)	53	(86.9 %)
Serious complications*	8	(1.2 %)	6	(1.6 %)	0	(0 %)	0	(0 %)	2	(3.3 %)
Transfusion	6	(0.3 %)	5	(1.4%)	0	(0 %)	0	(2.0 %)	1	(1.6 %)
Intervention	2	(0.4 %)	1	(0.3 %)	0	(0 %)	0	(0 %)	1	(1.6 %)
Macroscopic Hematuria	13	(2 %)	9	(2.4 %)	0	(0 %)	3	(4.2 %)	1	(1.6 %)
Other**	21	(4.2 %)	15	(4.1 %)	8	(5.7 %)	0	(0 %)	4	(6.6 %)
Not reported	11	(1.7 %)	5	(1.4 %)	1	(0.7 %)	3	(4.2 %)	3	(3.3 %)

The total number of complications may exceed the total number of reported biopsies as it is possible to report more than one complication per biopsy.

* Transfusion and/or intervention.

**Other complications, such as hematoma without the need for transfusion, are described as a comment in free text.

Procedure-related parameters per regional health authority from 2016 to 2024

In Helse Midt-Norge, Helse Nord and Helse Sør-Øst almost all biopsies are performed by radiologists (**Figure 9**). In Helse-Vest the proportion of biopsies performed by radiologists has increased from 2016 to 2024, reaching 50% of biopsies performed by radiologists. At Haukeland and Stavanger the majority of kidney biopsies are performed by nephrologists and in Førde, Haugesund and Stord the majority is performed by radiologists (**Figure 9b**).

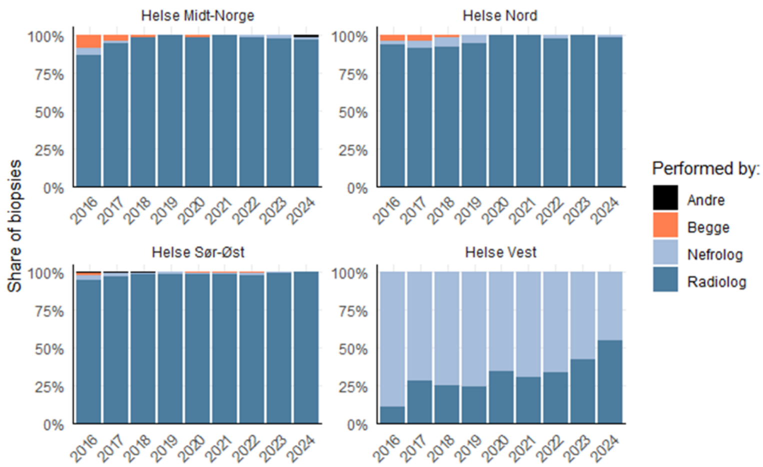

Figure 9. *Proportion (%) of biopsies performed by radiologist, nephrologist, both and other from 2016 to 2024, according to regional health care authority*

Figure 9b. *Proportion (%) of biopsies performed by radiologist and nephrologist, from 2016 to 2024, by hospital in Helse-Vest.*

16 G is the most used biopsy needle diameter in Helse Midt-Norge, Helse Nord and Helse Vest (**Figure 10**). In Helse Sør-Øst 18 G is used for the majority of kidney biopsies. The proportions have been relatively stable from 2016 to 2024.

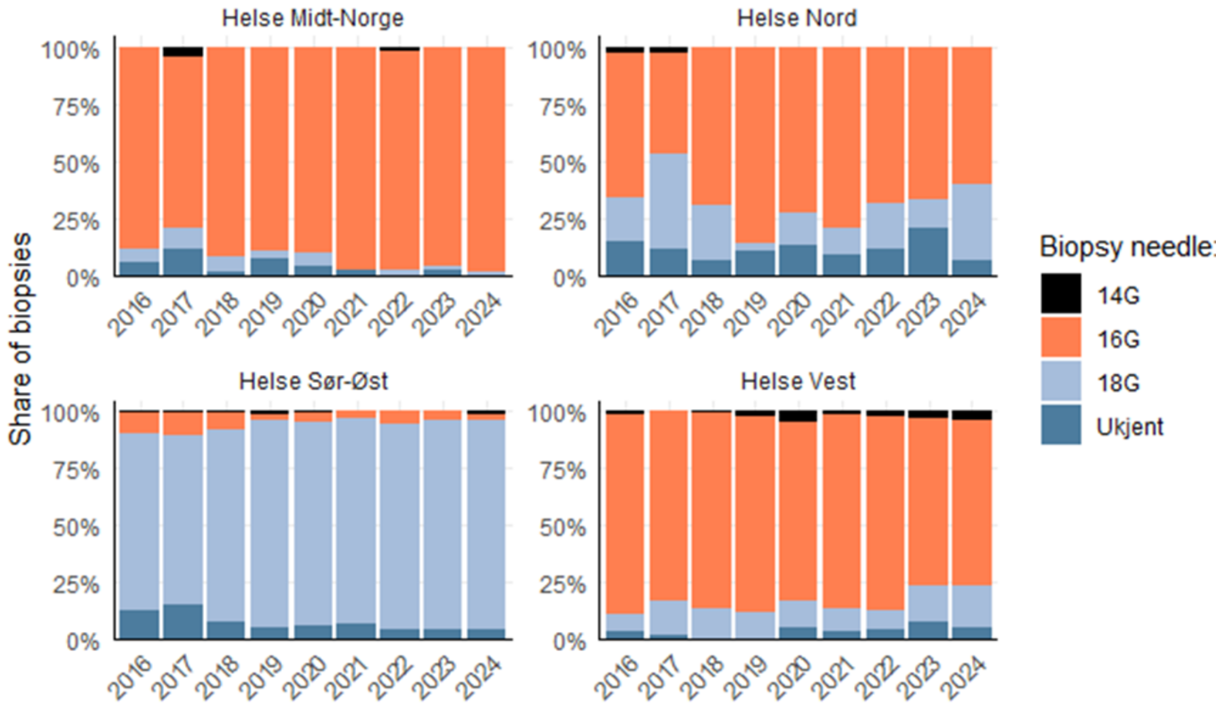

Figure 10. *Proportion (%) of kidney biopsies performed with different biopsy needle size (14G, 16G, 18G) from 2016 to 2024, according to regional health care authority.*

Regarding the number of passes per kidney biopsies - 2 and 3 number of passes is the most common in Helse Midt-Norge, Helse Nord and Helse Sør-Øst (**Figure 11**). In Helse-Vest the majority of kidney biopsies are performed with 2 passes, but 1 is also common. The proportions have been relative stable over time. In Helse-Vest, approximately 50% of kidney biopsies are performed by nephrologists, who often use a single-pass technique. At Haukeland, however, radiologists are advised to perform at least two passes when conducting kidney biopsies. This difference in practice may help explain the observed distribution in the number of passes across Helse-Vest.

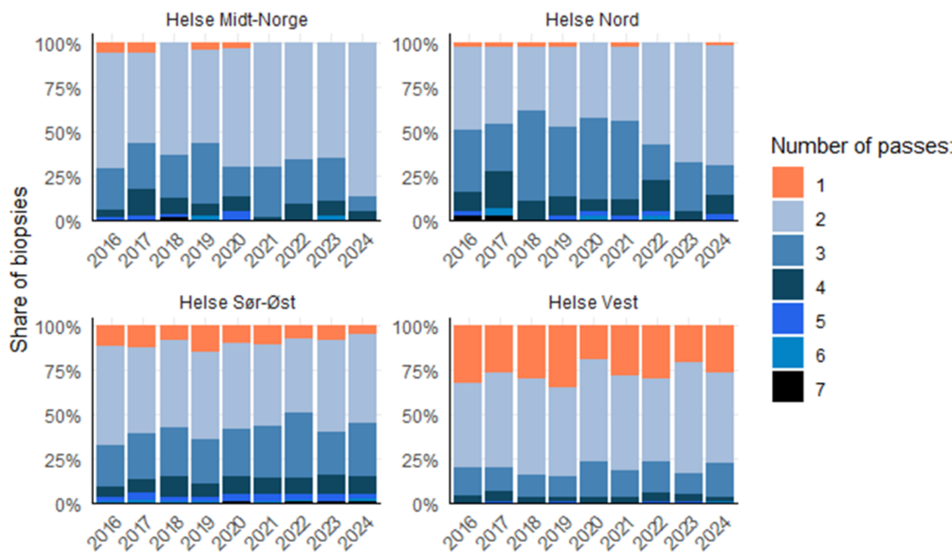

Figure 11. *Proportion (%) of kidney biopsy procedures by number of passes (1–7) from 2016 to 2024, according to regional health care authority.*

Most kidney biopsy patients are "inpatients" in all regional health care authorities (**Figure 12**). In Helse Sør-Øst the proportion of inpatient kidney biopsies has slightly decreased from 2018 to 2024, and increased Helse Vest.

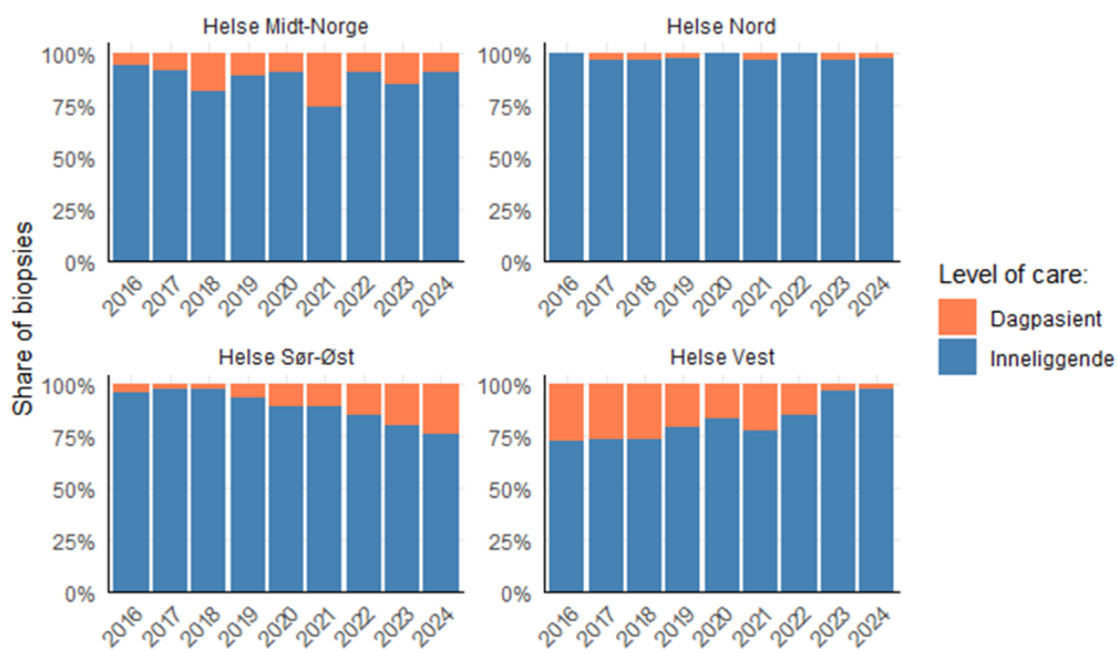

Figure 12. *Level of care: Kidney biopsies taken in inpatient and outpatient care.*

Kidney biopsies with 10 or more glomeruli (quality indicator)

The kidneys have three compartments that may be affected by disease: glomeruli, tubules/interstitial tissue, vasculature. A kidney biopsy is often necessary to determine which compartment(s) are compromised, and which kidney disease explains the clinical picture. Each kidney contains normally about 1 million glomeruli, which are capillary convolutes that continuously filter the blood, producing pre-urine. Numerous diseases can affect the glomeruli. It is important to realize, that a glomerular disease may not affect all glomeruli and that the affected glomerulus might only show changes in a part of the glomerulus. In addition, early and late stages of a disease may be observed in different glomeruli at the same time in one biopsy.

Therefore, to detect and evaluate changes, the kidney biopsy must contain sufficient material: for a reliable diagnosis, at least 10 glomeruli should be present in the biopsy material prepared for light microscopy. This requirement defines the national **quality indicator** “Percentage of kidney biopsies with 10 or more glomeruli”. At least 90% of biopsies taken at one nephrology centre should meet this standard.

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 paraffin embedded material prepared for light microscopy. Four of the hospitals reported 10 or more glomeruli in 90% or more of the kidney biopsies (**Figure 13**), thus fulfilling the national quality indicator. The average number of glomeruli per kidney biopsy shows a slight increase on a national basis from 2016 to 2024 (**Figure 14**).

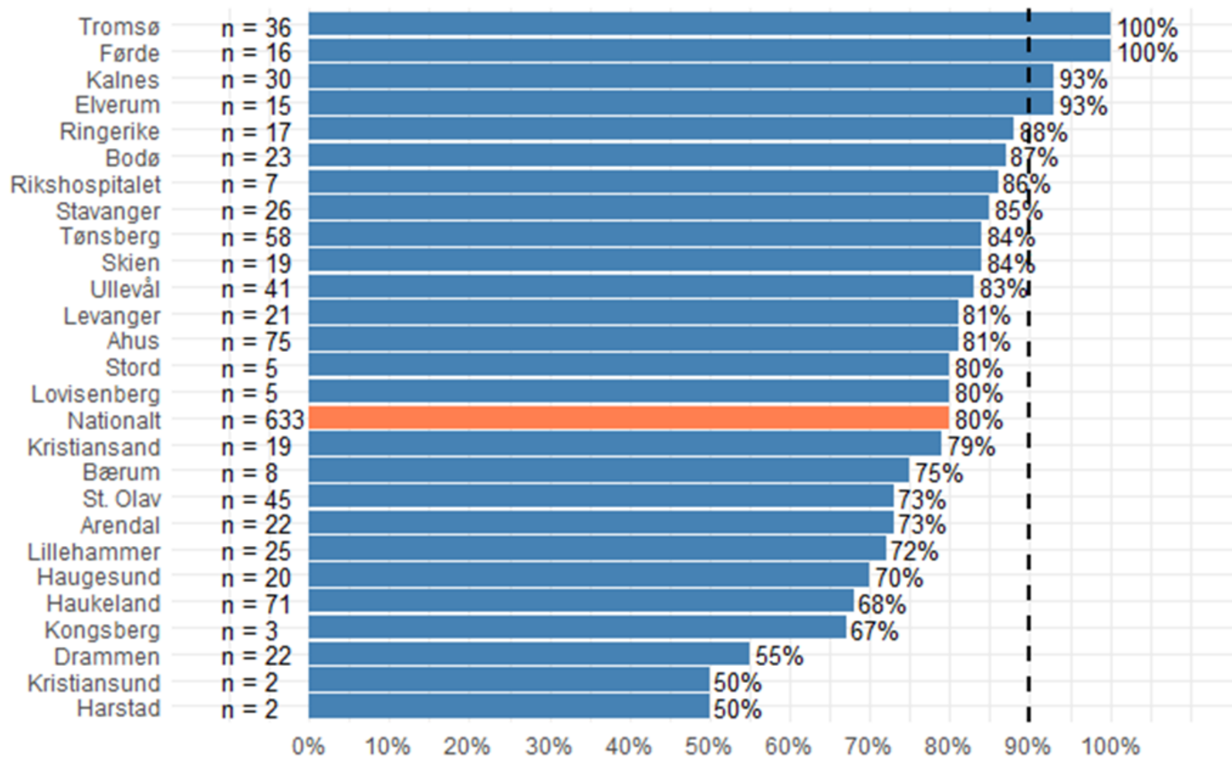

Figure 13. *Percentage of kidney biopsies with 10 or more glomeruli, in paraffin-embedded material in total and per hospital in 2024. The calculation is based on the number of glomeruli in the paraffin embedded biopsy tissue. The vertical dotted black line indicates quality indicator goal.*

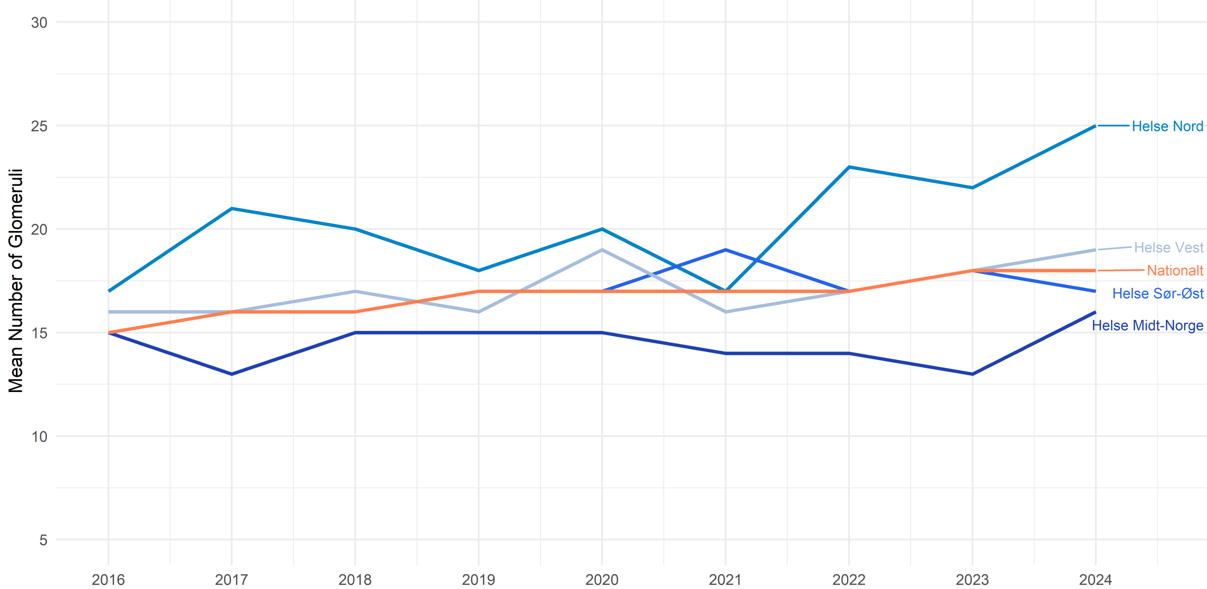

Figure 14. *Mean number of glomeruli from 2016 to 2024 per regional health authority and nationally.*

Pathology

Number of biopsies per pathology department, percentage of biopsies examined by electron microscopy, turnaround time, and occurrence of pathology diagnosis in 2024.

Number of biopsies per pathology department and % electron microscopy investigated biopsies

The number of non-neoplastic kidney biopsies per pathology department shows some year-to-year variation. In 2024, both Rikshospitalet (RHH) and St. Olavs Hospital reported fewer biopsies compared to 2023 (**Figure 15**). However, 2023 represented the peak year for kidney biopsies in Norway (**Table 1**), which likely explains the subsequent decline. Overall, the long-term trend indicates a gradual increase in biopsy numbers across most departments.

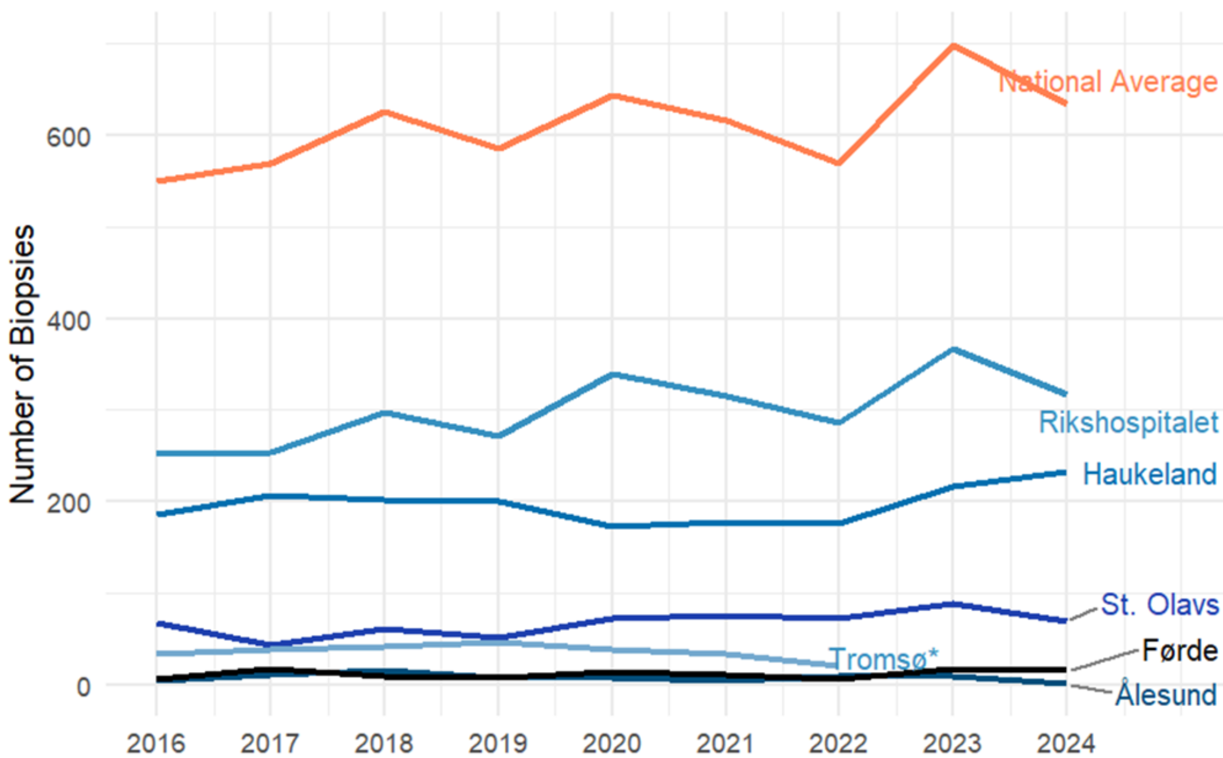

Figure 15. *Number of kidney biopsies per pathology department 2016 – 2024.*
** Starting in 2023, biopsies from Tromsø have been reported by the pathology department of Haukeland University Hospital.*

In kidney biopsy diagnostics, electron microscopy complements light microscopy. Instead of light the electron microscope uses electron beams that pass through a very thin section of tissue. These electron beams light up on a fluorescent screen which results in a black and white image of tissue structures - an examination also known as ultrastructural examination. Electron microscopy provides much higher magnification than light microscopy which is essential for detecting subtle tissue changes in certain kidney diseases. To prepare sections thin enough for this technique, a part of the kidney biopsy is specially fixed and embedded in a hard plastic material (EPON).

The proportion of biopsies subjected to electron microscopic examination is shown in **Figure 16**. Overall, a high percentage of kidney biopsies undergoes electron microscopy reflecting its established role in diagnostic work-up. In previous years, St. Olavs Hospital did not consistently follow this practice, although the department has conducted a substantial number of ultrastructural assessments.

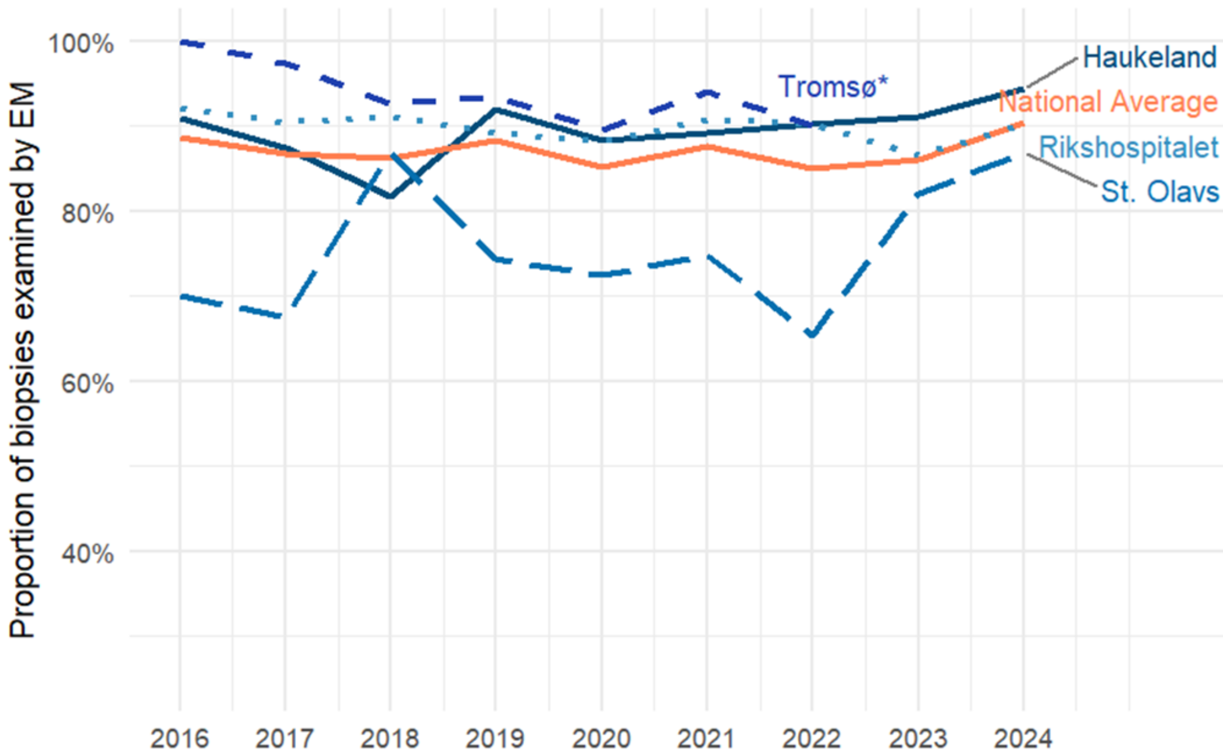

Figure 16. *Proportion (%) of biopsies subjected to electron microscopic examination per pathology department from 2016 to 2024.*
** Starting in 2023, biopsies from Tromsø have been reported by the pathology department of Haukeland University Hospital. EM: electron microscope.*

Turnaround time in pathology departments (quality indicator)

The turnaround time is the time interval from the registration of a kidney biopsy in the pathology department until the nephropathologist has signed the final report including the electron microscopic investigation. This time interval is a **quality indicator**, as the clinician will base treatment choices on the final pathology diagnosis. Delays in reporting may cause delays in treatment and consequently impact patient outcomes negatively. The electron microscopy examination is labour-intensive and time-consuming, and a kidney biopsy is therefore often reported in stages. Kidney biopsies from severely ill patients are usually communicated orally by the pathologist to the clinician by telephone as soon as the biopsy is read for the first time by light microscopy. This oral report is followed by a preliminary written report, which may or may not include immunopathology findings. The final pathology report is usually signed after electron microscopy.

In 2024, only the pathology department at St. Olavs Hospital met the quality target of issuing 80% of final reports within 21 working days (**Figure 17**). At Rikshospitalet (RHH), it took 31 working days to reach 80% of completed reports, at Haukeland University Hospital (HUS) 28 working days, which corresponds closely to the national average of 29 working days.

Whereas the proportion of biopsies reported within 21 working days decrease further for HUS, both RHH and St. Olavs showed an increase in the proportion of biopsies reported within 21 working days compared with 2023 (**Figure 18**). As a result, St. Olavs reached the quality standard of providing a final diagnostic report for at least 80% of cases within 21 working days (approximately one month). Consequently, the national average has levelled off, marking the first time since 2020 that it has not continued to decline.

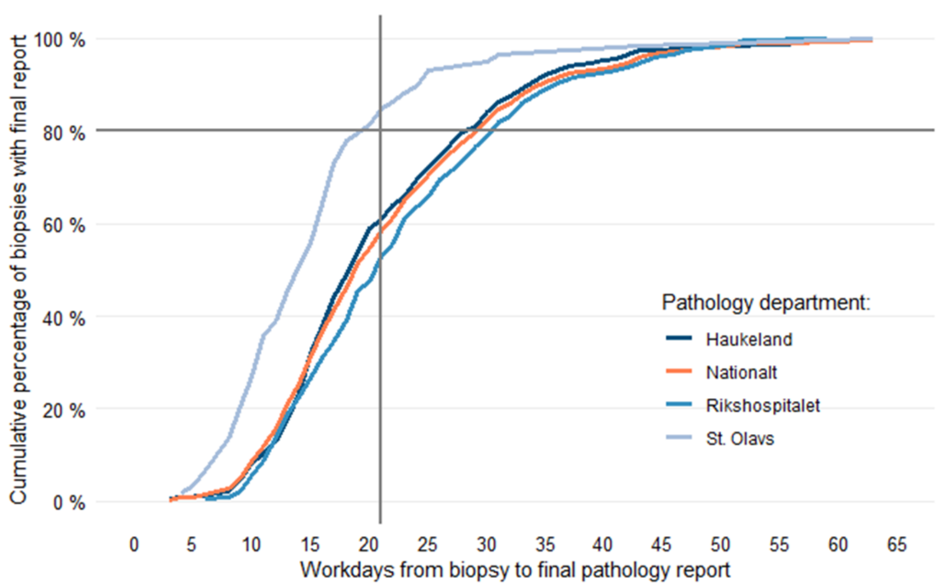

Figure 17. *Percent kidney biopsies finally reported in relation to working days, total and by pathology department in 2024. Lines placed in the upper left quadrant indicate that the pathology department has reached the quality criterion of having reported 80% of biopsies within 21 working days. The slope of the individual curves indicates how quickly biopsies are answered: the steeper the faster. The pathology departments in Førde and Ålesund are excluded due to small number of cases.*

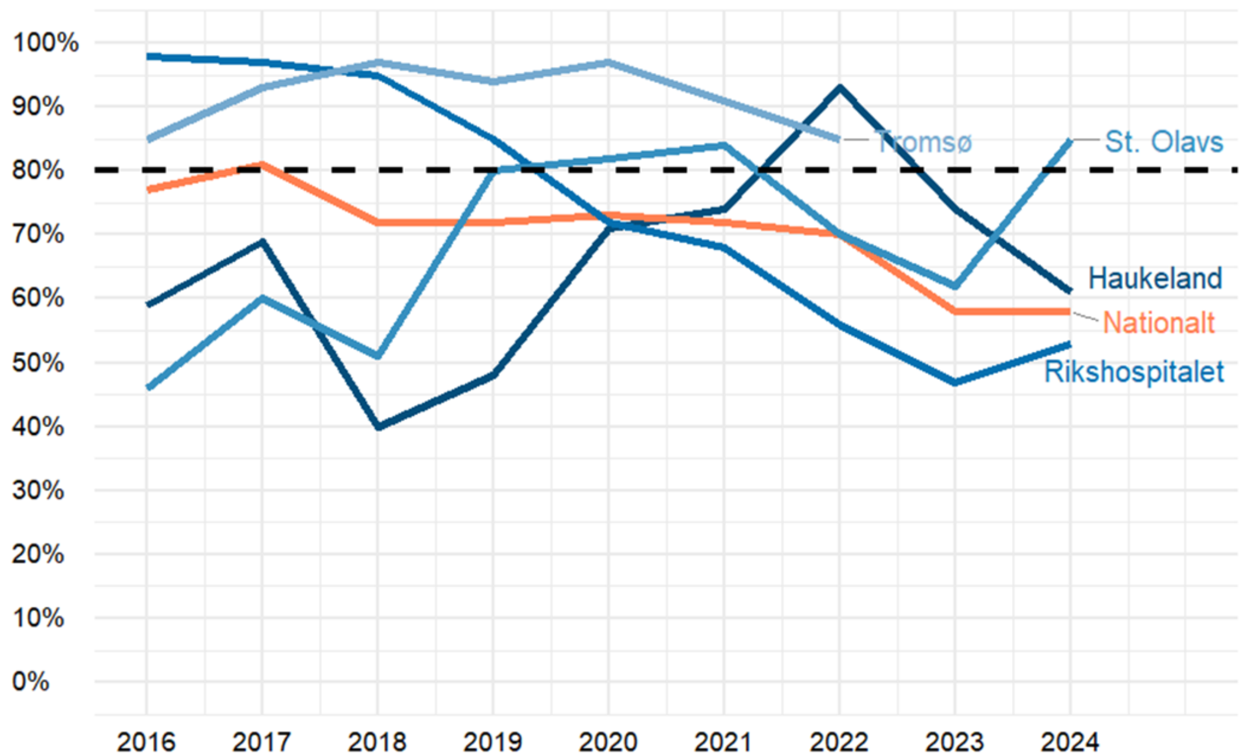

Figure 18. *Percentage of kidney biopsies finally reported within 21 working days, by pathology department from 2016 to 2024 (Quality indicator). Black dashed line indicates quality indicator goal at 80%.*
**The pathology department in Tromsø has not been recording kidney biopsies in 2023. Biopsies from Tromsø are currently reported by the pathology department of Haukeland University Hospital. The pathology departments in Førde and Ålesund are excluded due to small number of cases.*

Pathology diagnosis

The registry is using 2 coding systems: The ERA Coding system for Primary Renal Diseases (PRD)[1] and various versions of the proprietary coding system the registry is using since 1988. The table is based on the proprietary coding system of the registry. The current version still does not contain all possible pathology diagnoses as indicated by 16 cases in the category “no code - free text”.

Table 4. *overview over pathology diagnoses in Norway and per pathology department in 2024. Individual numbers are not shown for the departments in Førde and Ålesund because of low number of cases. The 15 biopsies from Førde pathology department and the one biopsy belonging to Ålesund pathology department is included in the total number.*
1: Focal and segmental glomerulosclerosis, 2: Glomerulonephritis, 3: Henoch Schönlein's purpura, 4: Glomerulopathy, 5: Thrombotic microangiopathy, 6: Hemolytic uremic syndrome , 7: Immunoglobin, 8: Acute tubular necrosis, 9: Tubulointerstitial nephritis, RH: Rikshospitalet, HUS: Haukeland University Hospital

Diagnosis	Total	HUS	RHH	St. Olavs
Glomerular disease:				
Minimal change nephropathy	31	7	19	5
FSGS primary	12	6	3	1
FSGS secondary	9	4	3	2
Membranous GN	33	13	15	5
IgA nephropathy	128	48	64	16
Mesangioprol. GN without IgA	5	1	4	0
Endocap. prol. GN	5	5	0	0
Membranoproliferative GN	12	7	3	2
ANCA associated GN	52	25	22	5
Anti-GBM nephritis	3	2	0	0
GN with crescents - not ANCA	9	3	5	0
IgA vasculitis	4	2	2	0
Lupus nephritis - I	1	0	1	0
Lupus nephritis - II	7	3	2	2
Lupus nephritis - III	3	2	1	0
Lupus nephritis - IV	11	3	5	1
Lupus nephritis - V	1	1	0	0
Lupus nephritis - VI	1	0	1	0
Dense deposit disease	2	0	2	0
Fibrillary glomerulopathy	2	0	1	1
Immunotactoid glomerulopathy	1	0	1	0
Cryoglobulinemia	2	1	1	0
Idiopathic nodular glomerulosclerosis	1	1	0	0
GN unclassified	16	5	11	0

Hereditary diseases:				
Alport disease	4	1	1	1
Thin basement membrane disease	14	1	12	1
Fabry disease	3	3	0	0
Metabolic disease and related disorders:				
Diabetic nephropathy	42	9	24	7
Benign nephrosclerosis	49	9	36	4
Vascular disease:				
Vasculitis other	2	2	0	0
TMA	6	4	2	0
Diseases related to monoclonal gammopathy and myeloma:				
Amyloidosis - AA	5	1	4	0
Amyloidosis - AL	13	8	4	0
Amyloidosis not classified	3	0	3	0
Myeloma kidney	1	0	0	0
Ig deposition disease	1	1	0	0
Tubulointerstitial diseases:				
ATN	17	0	13	4
Tubulointerstitial nephritis	34	15	16	2
Granulomatous TIN/Sarc.	6	2	2	2
TIN drug-associated	11	6	3	0
Lithium nephropathy	3	1	2	0
TIN with uveitis	1	1	0	0
Calcineurin inhibitor toxicity	1	1	0	0
IgG4 related TIN	1	1	0	0
Other:				
Normal	10	4	4	2
Uncharacteristic atrophy	21	9	8	3
No code - free text	9	3	5	1
Not representative	11	5	5	1
Donor biopsy	1	1	0	0
Total	**642**	**317**	**233**	**69**

C3 glomerulopathy

There are rare kidney diseases that are not included in any coding system, as well as kidney diseases that have emerged in recent years and are therefore not yet covered by an established coding system. In the Norwegian Renal Registry, such diseases are assigned the code “no code available – free text.” This placeholder helps us identify conditions for which the coding system should be expanded.

C3 glomerulopathy is one such disease. The term was introduced in 2010[1]. C3 glomerulopathies represent a group of glomerular disorders characterized by dominant C3 deposition with an absence or near absence of immunoglobulin deposits. Some of these conditions have a genetic basis. The category includes two entities: Dense Deposit Disease (DDD) and C3 glomerulonephritis (C3GN). While DDD has a very distinctive morphology, with thick electron-dense bands in the lamina densa of the basement membrane, C3GN is morphologically more heterogeneous. A membranoproliferative pattern is often seen, but other glomerular reaction patterns are also possible.

We have long had a code for Dense Deposit Disease, but there is no specific code for C3 glomerulonephritis, and its frequency in the registry remains uncertain. The obvious consequence is that such a code should be included in our coding system. As we have used the comment field for free-text notes, typically mentioning the diagnosis or suspected diagnosis in cases of membranoproliferative glomerulonephritis and in all cases coded as “no code available – free text, it is still possible to calculate a rough estimate of the incidence of C3 glomerulopathy. Therefore, to estimate how often we diagnose C3 glomerulopathy, we reviewed the number of cases from 2016 onward, including:

- All biopsies diagnosed as Dense Deposit Disease
- All biopsies diagnosed as membranoproliferative glomerulonephritis where C3 glomerulopathy was considered in the comment field
- All biopsies coded as “no code available – free text” where C3 glomerulopathy was considered in the comment field

Table 5 on the following page shows the number of possible C3 glomerulopathy cases per year. Incidence was calculated per 1 million inhabitants, assuming a registry coverage of 80%.

[1] Fakhouri F, Frémeaux-Bacchi V, Noël LH, Cook HT, Pickering MC. C3 glomerulopathy: a new classification. Nat Rev Nephrol. 2010 Aug;6(8):494-9.

Table 5. *Number of biopsies with the diagnosis Dense Deposit Disease and number of biopsies where C3 glomerulonephritis was considered as possible diagnosis.*

Year	C3 glomerulonephritis	Dense deposit Disease	Population	Incidence per 1000000
2016	5	1	5258317	1,43
2017	3	2	5295619	1,18
2018	5	0	5328212	1,17
2019	2	0	5367580	0,47
2020	0	0	5391369	0,00
2021	0	0	5425270	0,00
2022	0	0	5488984	0,00
2023	1	1	5550203	0,45
2024	0	2	5594340	0,45

The estimated incidence aligns with figures reported in the literature for some years (e.g., 2016–2018), while in other years it is slightly lower (2019, 2023, and 2024)[2]. Notably, the diagnosis was not recorded in the years 2020–2022.

Missing/incomplete data

Pathology

Based on the results of the quality indicator “Number of primary kidney biopsies with moderate to severe chronic changes” we reviewed missing or incomplete data related to chronic tubulointerstitial and vascular changes. Since the pathology report is the only source of pathology data for the registry, a complete and standardized report is essential for accurate documentation of chronic changes. International guidelines specify what information should be included in these reports[3]. In addition, the Norwegian dataset “Datasett ikke-neoplastisk nyrebiopsi” is available on the homepage of “Den norske patologforening” for reference[4]. Grading the severity of tubulointerstitial and vascular changes is consistently recommended by all guidelines for pathology reporting.

Figures 19-22 presents an overview over missing or incomplete data per pathology department from 2016 to 2024. Missing data refers to the complete absence of information about the parameter in the pathology report. Incomplete data means that some information is provided, but not all details required for the parameter, for example “areas of tubular atrophy” is mentioned but not graded. One possible reason for the higher proportion of missing or incomplete data in reports from St. Olavs Hospital is the use of

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[2] Medjeral-Thomas NR, O'Shaughnessy MM, O'Regan JA, Traynor C, Flanagan M, Wong L, Teoh CW, Awan A, Waldron M, Cairns T, O'Kelly P, Dorman AM, Pickering MC, Conlon PJ, Cook HT. C3 glomerulopathy: clinicopathologic features and predictors of outcome. Clin J Am Soc Nephrol. 2014 Jan;9(1):46-53.

[3] Chang, A., Gibson, I. W., Cohen, A. H., Weening, J. W., Jennette, J. C., & Fogo, A. B. (2012). A position paper on standardizing the nonneoplastic kidney biopsy report. Hum. Pathol, 43(8), 1192-1196.

[4] https://www.legeforeningen.no/foreningsledd/fagmed/den-norske-patologforening/faggrupper/nyrepatologi-ikke-neoplastisk/

free-text descriptions of findings, whereas the other pathology departments use either structured data or preformatted text building blocks in their reports.

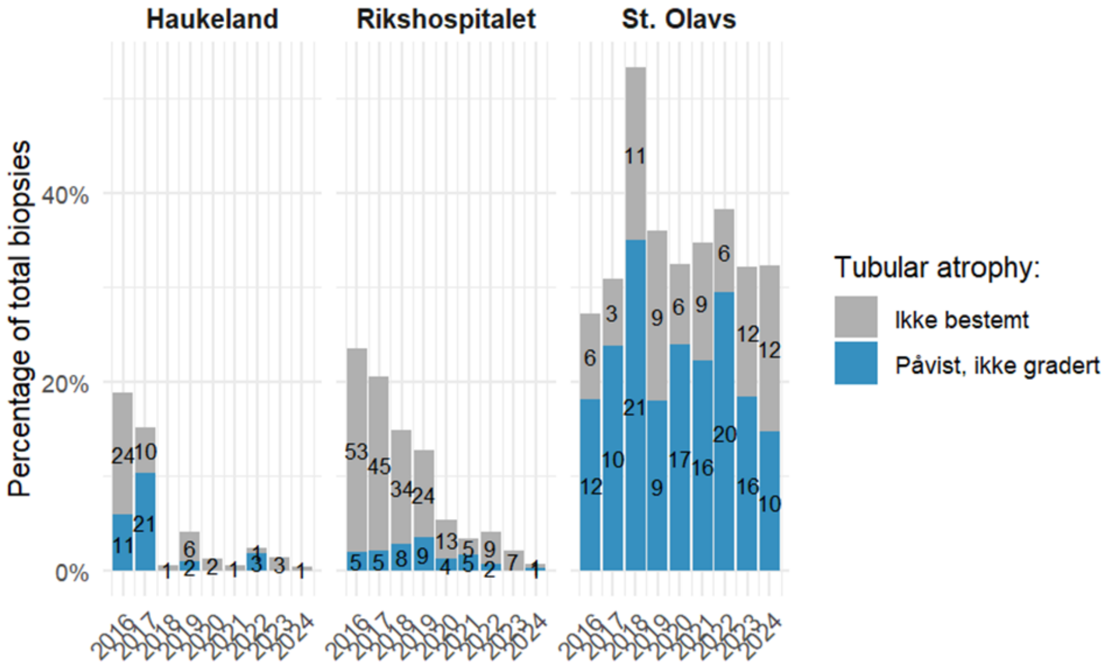

Figure 19. ***Missing data: Tubular atrophy:*** *the proportions (%) of missing/incomplete information in the pathology reports from each pathology department regarding tubular atrophy from 2016 to 2024.*

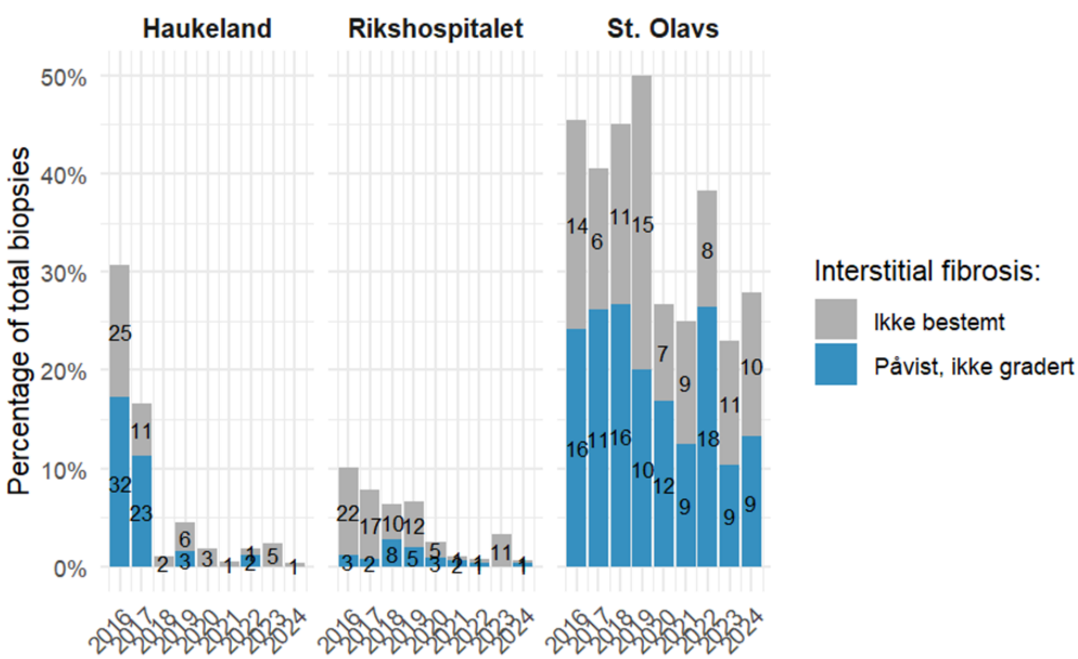

Figure 20. ***Missing data: Interstitial fibrosis:*** *the proportion (%) of missing/incomplete information in the pathology reports from each pathology department regarding interstitial fibrosis from 2016 to 2024.*

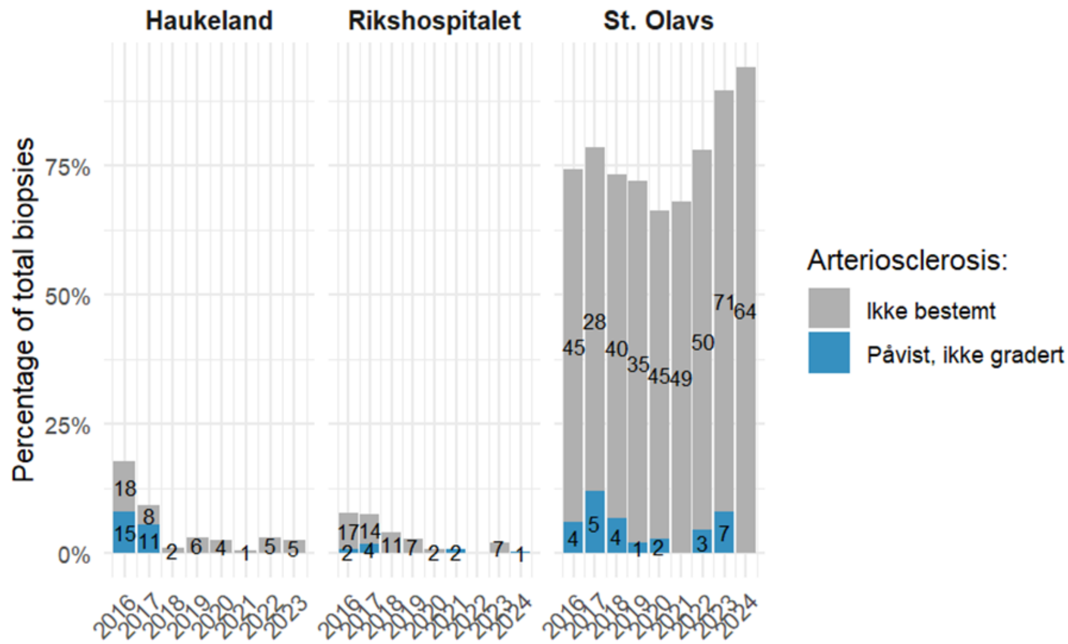

Figure 21. ***Missing data: Arteriosclerosis:*** *the proportion (%) of missing/incomplete information in the pathology reports from each pathology department regarding* ***arteriosclerosis*** *from 2016 to 2024.*

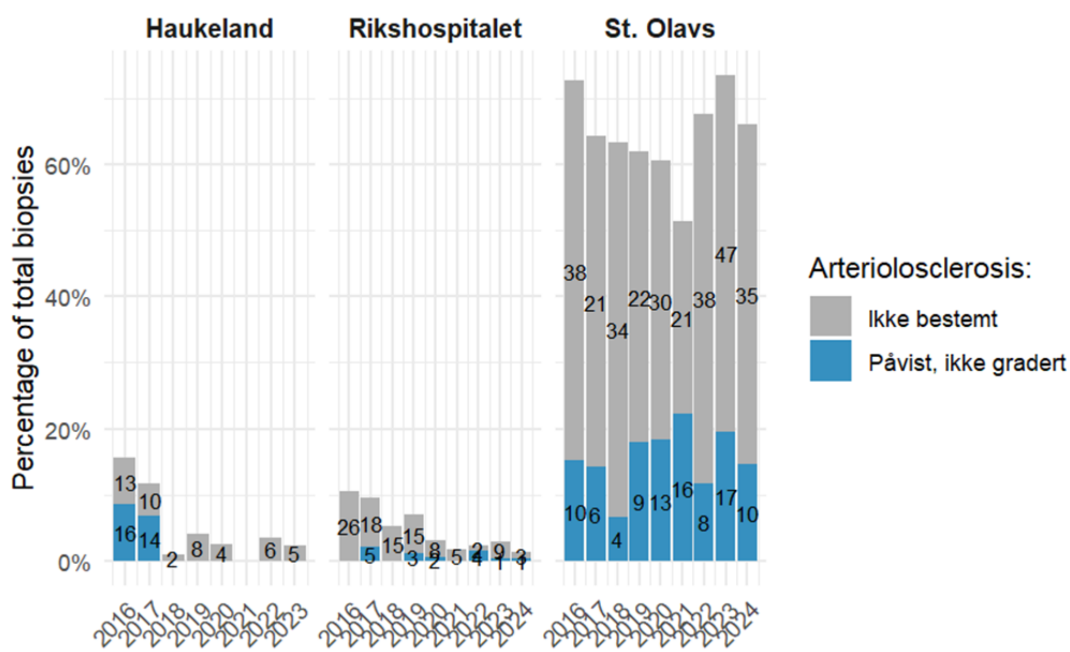

Figure 22. Missing data: ***Interstitial fibrosis:*** *the proportion (%) of missing/incomplete information in the pathology reports from each pathology department regarding* ***arteriolosclerosis*** *from 2016 to 2024.*

Serum creatinine

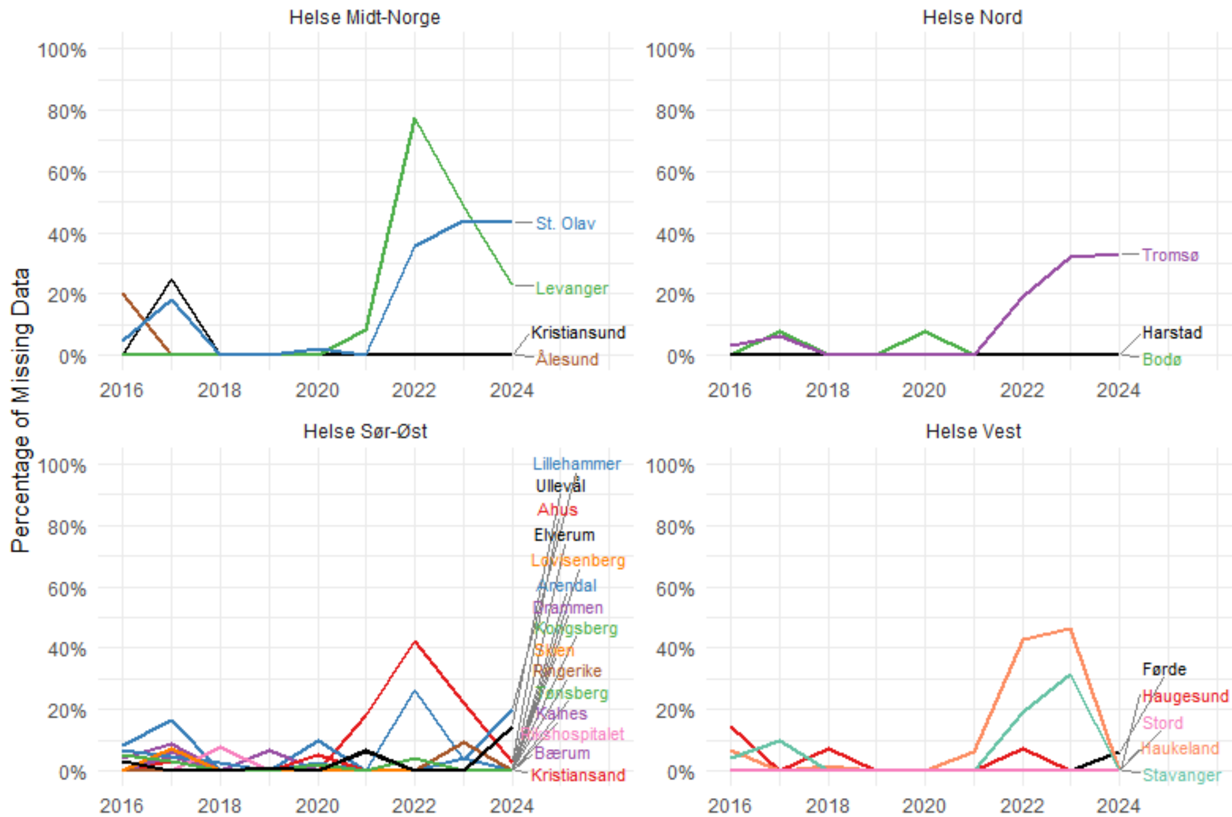

Figure 23. Missing data: *serum creatinine:* *Percentage of missing data for serum creatinine (µmol/l) at the time of kidney biopsy in different Regional Health Regions from 2016 to 2024.*

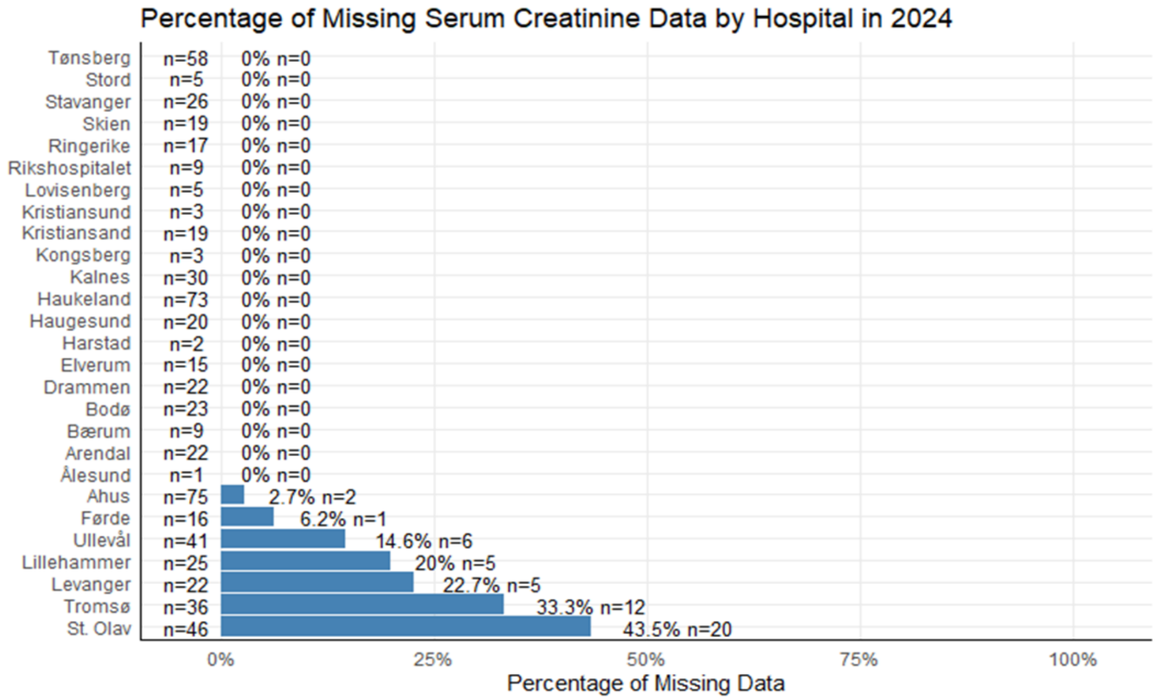

Figure 24. Missing data: *serum creatinine:* *Percentage of missing data for serum creatinine (µmol/l).*

Albuminuria

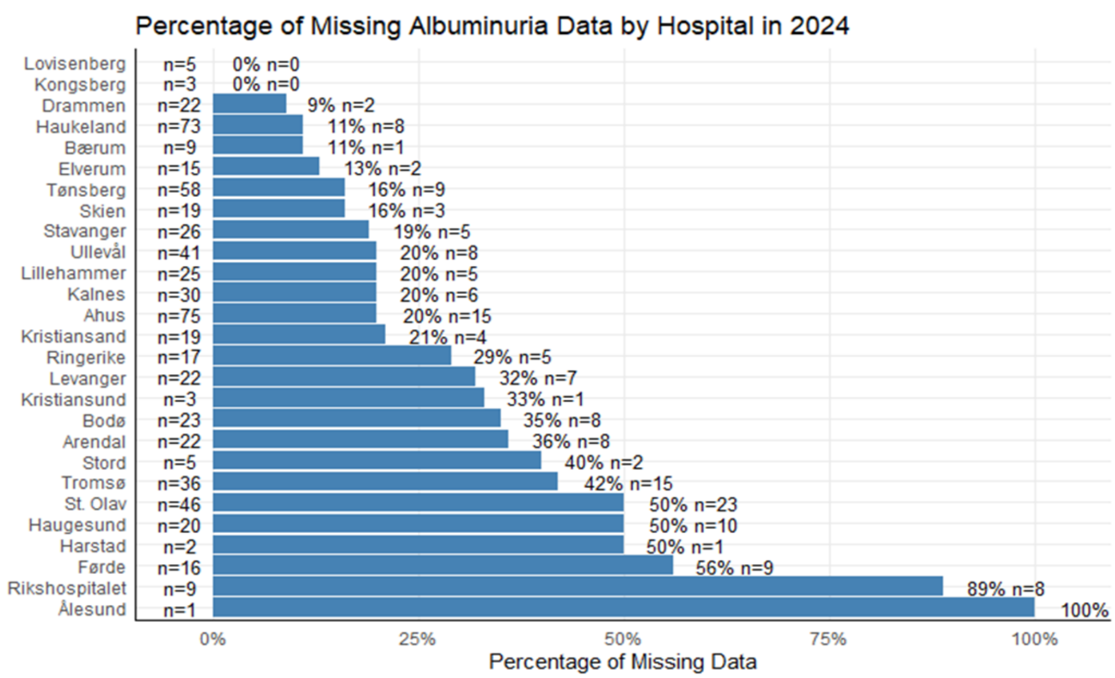

Figure 25. Missing data: *albuminuria:* *Percentage of missing data for albuminuria (mg/mmol creatinine) at the time of kidney biopsy in different Regional Health Regions from 2016 to 2024.*

Coverage for kidney biopsies in the Norwegian Renal Registry

The national target for patient coverage in a national registry, is at least 80% over the past two years. A high coverage ensures that the registered data and according analyses are complete and representative. In the case of kidney biopsies, a high coverage in the Norwegian renal registry is also important to identify differences and gaps in patient data and kidney biopsy procedures throughout the country. In the case of this analysis, the absolute number of kidney biopsies taken in Norway in 2024 was obtained by the pathology departments, from which we obtain the amount of non-neoplastic biopsies taken per year. In 2024, the national coverage of kidney biopsies in the NNR was 79% (number of biopsies registered: 642, divided by number of biopsies reported by pathology department: 812 (**Figure 26**). This means 21 % of biopsies were not registered into this national registry in 2024. Three hospitals (Ullevål, Haugesund and Stavanger reach practically 100% coverage, and four hospitals (Førde, Arendal, Haukeland and Kristiansand) reach more than 90% coverage (**Figure 26**). The coverage of kidney biopsies for each reporting hospital from 2020 to 2024 according to health region is presented in **Figure 27**. The coverage within the hospitals varies from year to year, but some hospitals have consistently high coverage (Stavanger, Ullevål), but other hospitals have greater variations, and some have had a stable low coverage (Kristiansund, Rikshospitalet).

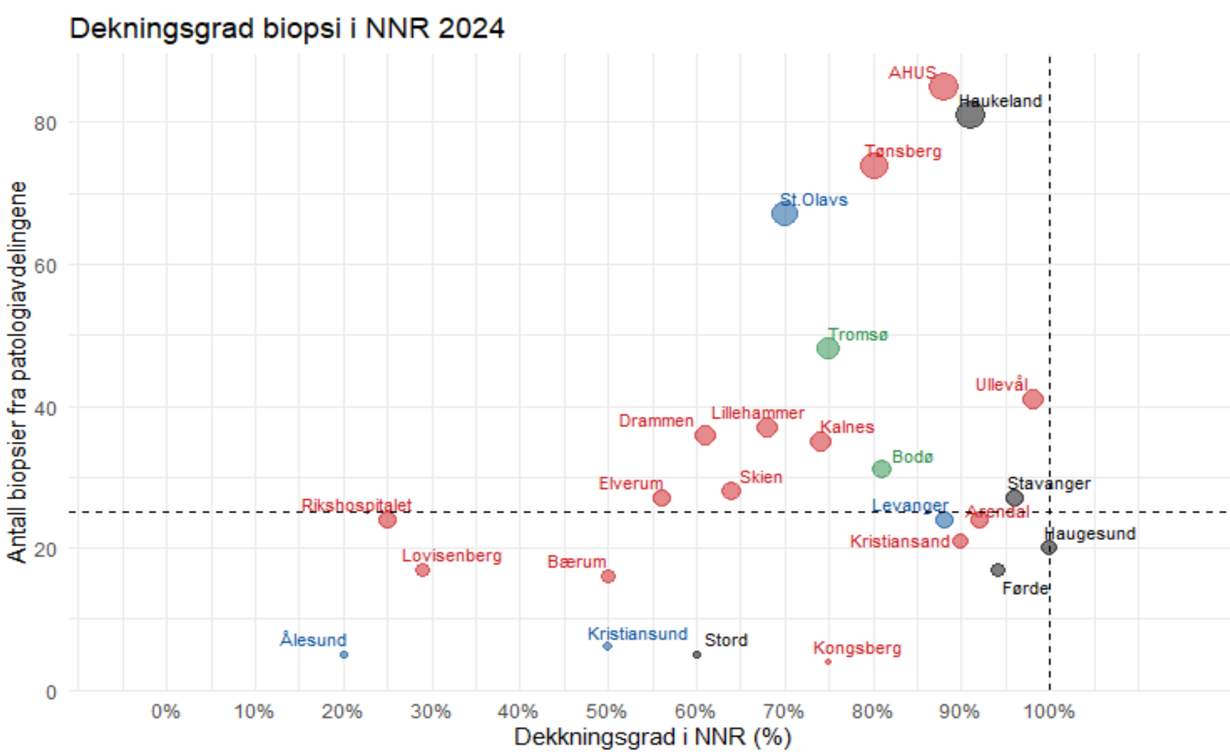

Figure 26. *Coverage of kidney biopsies (x-axis) according to number of biopsies taken per hospital.*

norsk nyreregister

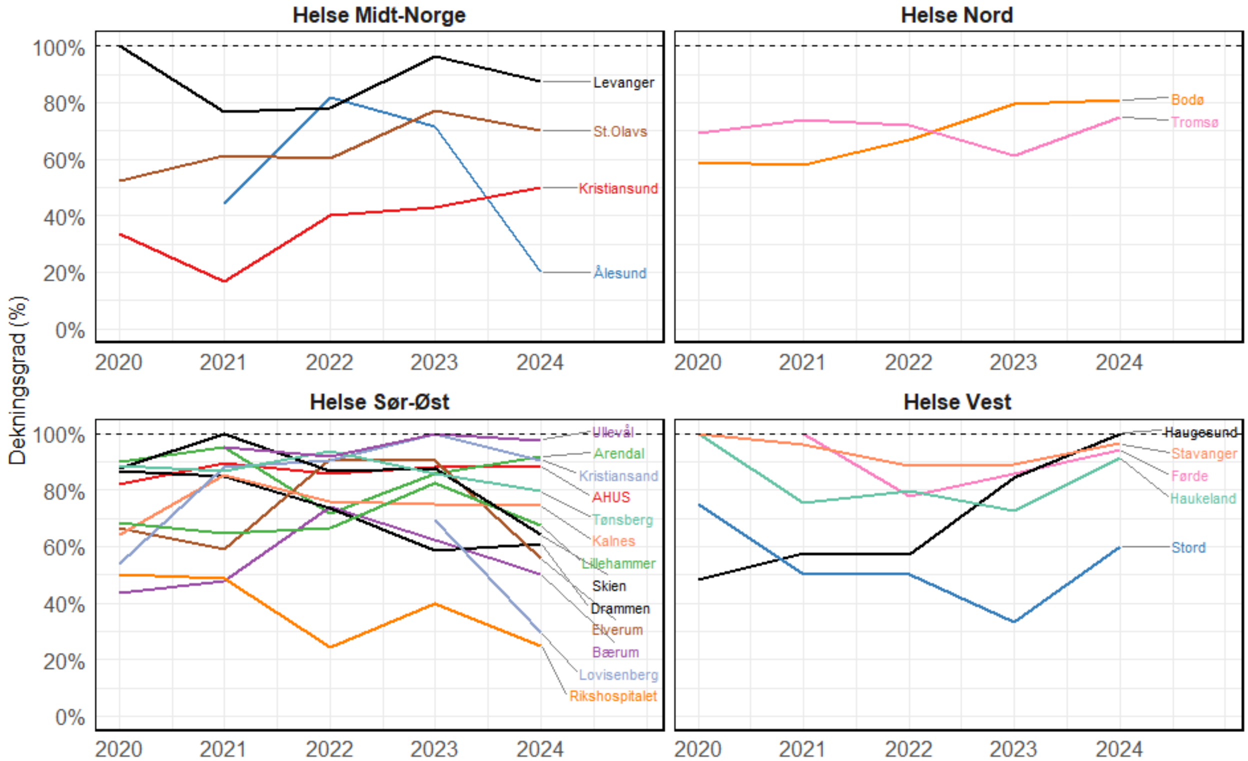

Figure 27. *Coverage of kidney biopsies per year according to health region.*

Incidence CKD5 not in KRT

New patients with CKD5, not treated with KRT, that is reported to the registry have remained relatively stable at about 320 patients per year over the last years but this year almost 400 CKD5 patients have been registered. Most patients are male (71%), with median (range) age of entering the CKD5 stage being 70 (19-93) years old and a mean BMI of 27.0 kg/m^2. Patients were known at the nephrology unit in 91% of cases, and 83% were candidates for KRT at the time of entering in CKD5. The percentage of patients who are not candidates for KRT at entry in the registry is fluctuating, have been relatively stable just below 10%; from 9% in 2021, 8% in 2022, 5% in 2023 and up to 8% in 2024. The main reason for not being a transplant candidate was comorbidity. Type II diabetes is prevalent in the CKD5 population; from 33% in 2021, 28% in 2022, 29% in 2023 increasing slightly to 34% in 2024.

Selected clinical chemistry values and demographic variables are available in **Table 6** below

Table 6: Status at first time reported as CKD5 (without KRT) in the report year

Variable	Value
Number of patients	398
eGFR (CKD-EPI 2021, mean) [mL/min/1.73m^2])	11
eGFR (CKD-EPI 2021 - % <15 mL/min/1.73m^2)	96%
Creatinine (mean) [µmol/L]	428
Albumin (mean) [g/dL]	38
Haemoglobin (mean) [g/dL]	11.1
Haemoglobin - % with <10 g/dL)	21%
Proteinuria (ACR>3 and/or PCR>15)	99%
ESA use	30%
Active use of vitamin D	52%
Statin use	69%
Not on antihypertensive drugs	7%
Using ACEi or ARB	64%
Using ≥3 antihypertensive drug	60%
Using bicarbonate	58%

Starting in 2023, we report reasons for CKD5 over time using the grouping provided by the ERA. The reason for CKD5 over time is provided in **Table 7**.

Table 7: Reason for CKD5 over time

Reason	2020	2021	2022	2023	2024
Glomerular disease	20%	9%	8%	7%	27%
Tubulointerstitial disease	16%	4%	7%	4%	25%
Familial / hereditary nephropathies	17%	6%	9%	32%	24%
Hypertension / Renal vascular disease	23%	68%	24%	43%	12%
Diabetes Mellitus	10%	10%	47%	7%	7%
Miscellaneous renal disorders	8%	2%	4%	5%	4%
Other systemic diseases affecting the kidney	6%	1%	2%	1%	1%

While the percentage of patients entering CKD5 using three or more hypertensive drugs has remained steady around 60% in previous years; 60% in 2021 and 57% in 2022, it decreased sharply to 50% in 2023 but has returned to 60% in 2024.

However, the percentage of patients using ACE-inhibitors or ARB has increased sharply when compared to previous years, from 52% in 2021, 48% in 2022, 45% in 2023 and now 64% in 2024.

For patients starting KRT during 2024, the median (range) time in the CKD5 stage was 13 months (0-113). The median time in CKD5 prior to KRT has been relatively stable over the last five years 11.5 (2019), 12.6 (2020), 12.8 (2021), 13.1 (2022), 11.7 (2023) and now 13.1 (2024) months, with a similar trend for the mean.

Incidence of CKD5 in KRT (dialysis or transplantation)

The total number of new patients in KRT has been stable over the last three years, with 551 patients in 2020, 530 in 2021, 540 in 2022, 558 in 2023 and now, slightly reduced to 514 in 2024. It seems that the breaking of the 600 level in 2019 was an exception.

Most patients are male (71%) and median age at start of KRT was 66 years (mean 62 years), ranging from 0 to 91 years. At start of dialysis 43% were assessed by the treating physician to be a transplant candidate (and additionally 18% possible candidates). Of the patients starting hemodialysis, and that had been known at the treating center for at least 4 months, 66% started dialysis using the “optimal” blood access for respective patient, slightly down from 78% in 2023. A selection of clinical chemistry values and drugs used in patients starting KRT in 2024 are shown in **Table 8**.

Table 8: Status at start of KRT in the report year

	Total	HD	PD	Preempt. Tx
Number of patients	514	289	169	56
eGFR (CKD-EPI 2021, mean) [mL/min/1.73m^2])	8	7	7	12
eGFR (CKD-EPI 2021 - % <15 mL/min/1.73m^2)	97%	98%	99%	88%
Creatinine (mean) [µmol/L]	674	711	668	500
Albumin (mean) [g/dL]	35	34	36	43
Haemoglobin (mean) [g/dL]	10.1	9.8	10.3	11
Haemoglobin - % with <10 g/dL)	46%	57%	37%	20%
Proteinuria (ACR>3 and/or PCR>15)	95%	92%	99%	100%
ESA use	49%	51%	51%	34%
HIF use	10%	8%	16%	3%
Active use of vitamin D	63%	62%	63%	71%
Statin use	66%	60%	76%	62%
Not on antihypertensive drugs	7%	10%	3%	5%
Using ACEi or ARB	54%	51%	54%	66%
Using ≥3 antihypertensive drug	60%	61%	65%	42%
Using bicarbonate	60%	56%	65%	62%

The major changes from the years before are, increased number of patients using blood pressure lowering drugs, also more patients using more than two drugs. In addition, use of ESA has decreased, mainly in preemptive transplanted patients (19%-points), from last year. Surprisingly, this is not explained by an increased use of HIF in the same population and warrants further investigation.

In the following figures we present the annual incidence of new patients in KRT by first treatment modality (**Figure 28**), age (**Figure 29**), if they are considered as candidates for transplantation by the local treating physician (**Figure 30**), age at start KRT (**Figure 31**) and primary renal disease (**Figure 32**).

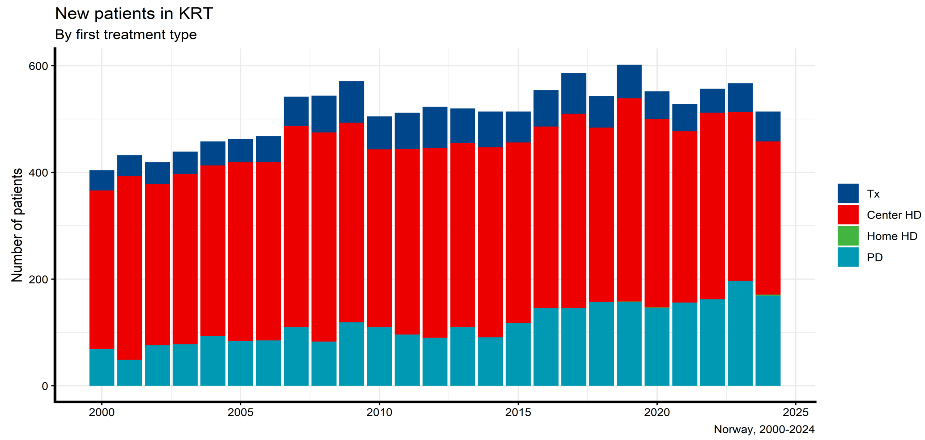

Figure 28: New patients in KRT by treatment modality

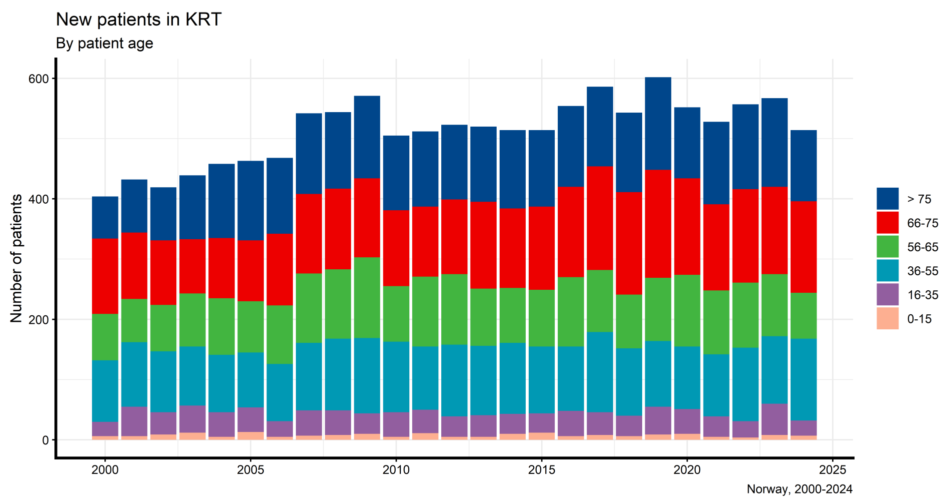

Figure 29: New patients in KRT by age

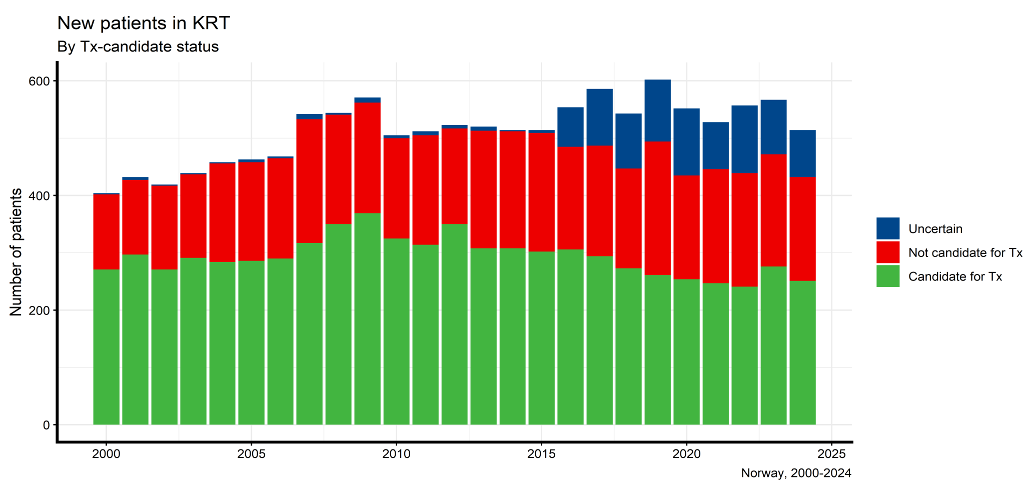

Figure 30: New patients in KRT by Tx-candidacy status

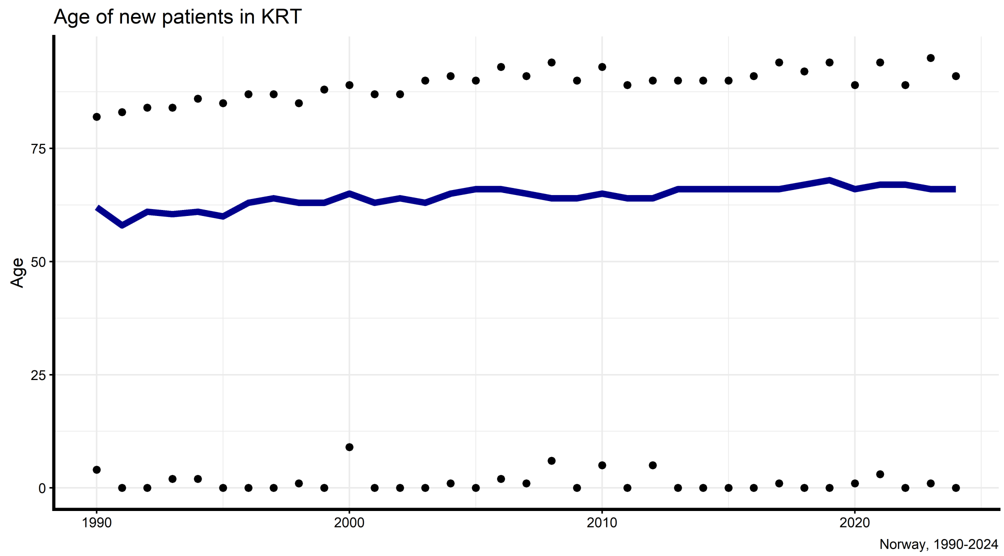

Figure 31: Age of new patients in KRT

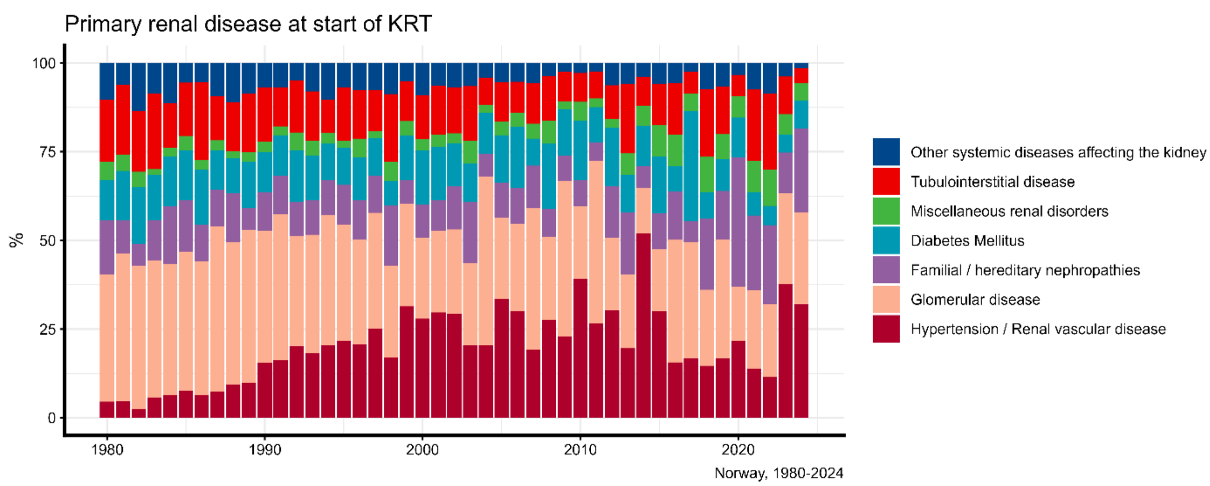

Figure 32: Primary renal disease at start of KRT

Diabetes as primary renal disease has decreased over the years but when counting also patients with other PRD-codes a total of 36% of all patients starting KRT in 2024 had diabetes (of which 19% Type 1 and 81% Type 2)

Prevalence of CKD5

The registry has recently completed a coverage analysis for the period of 2019-2023, in cooperation with the Norwegian Patient Registry (NPR). The national coverage of CKD5 patients not in KRT is generally poor (about 50%, the full analysis is presented later in this report). The reported data on CKD5 patients not in KRT should hence be interpreted with caution.

The reported prevalence of CKD5 not in KRT patients is shown in **Figure 33**.

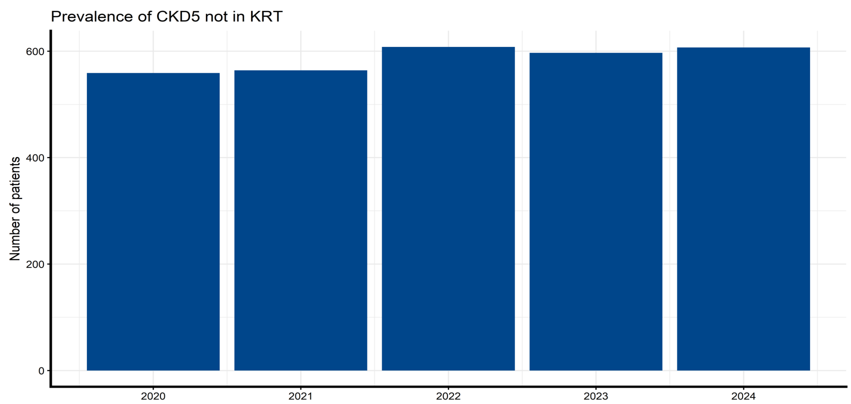

Figure 33: Prevalence of CKD5 not in KRT

As also indicated by **Figure 34**, there is a significant underreporting of patients to the registry when they enter CKD5. We show the proportion of patients starting KTR with and without a previous CKD5 form.

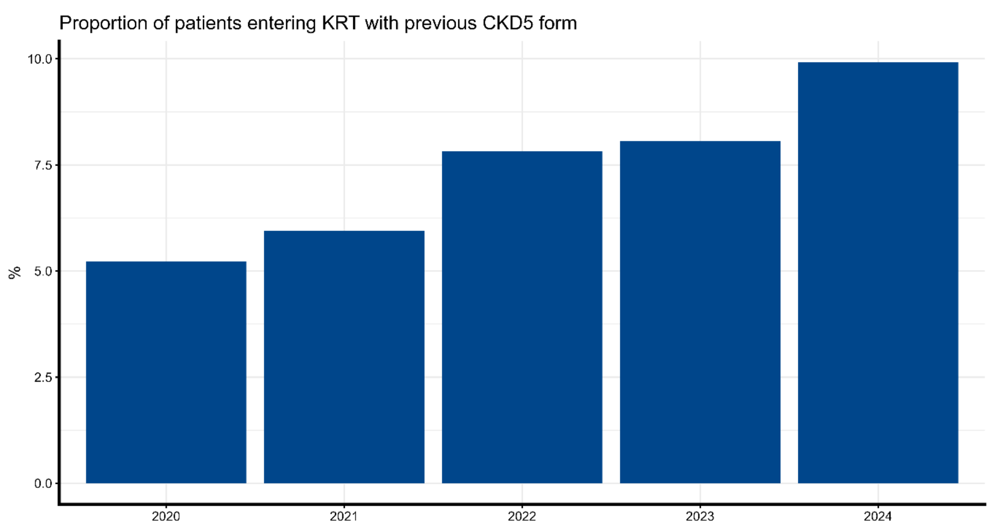

Figure 34: Prevalence of CKD5 not in KRT

Prevalence of KRT

The prevalence of patients requiring KRT seems to have reached a stable level, as shown in **Figure 35**. Since the effect is most apparent in the kidney Transplant group a possible explanation is the high number of kidney transplant recipients that died during the COVID-19 pandemic.

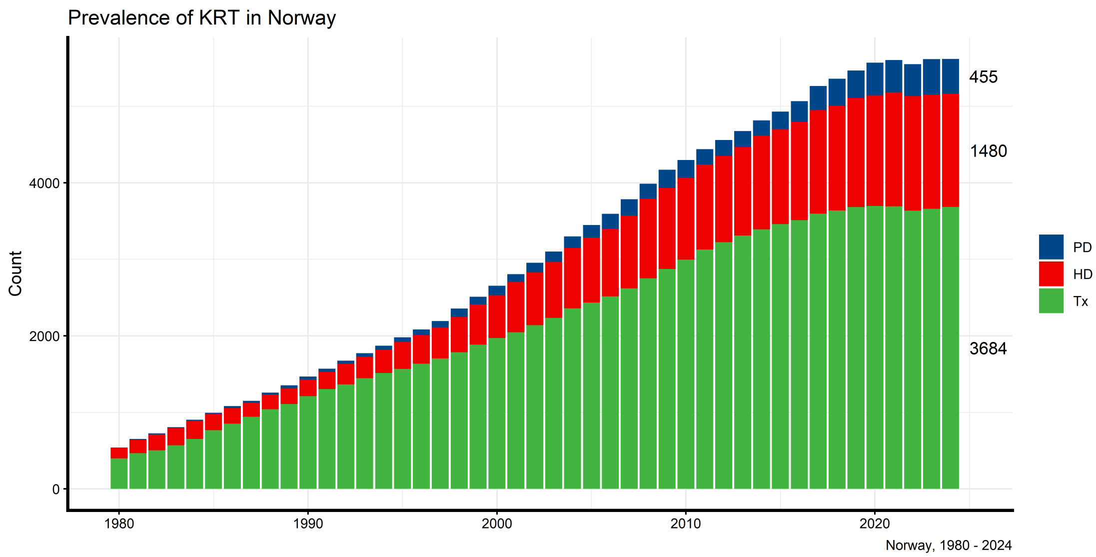

Figure 35: Historic prevalence of KRT

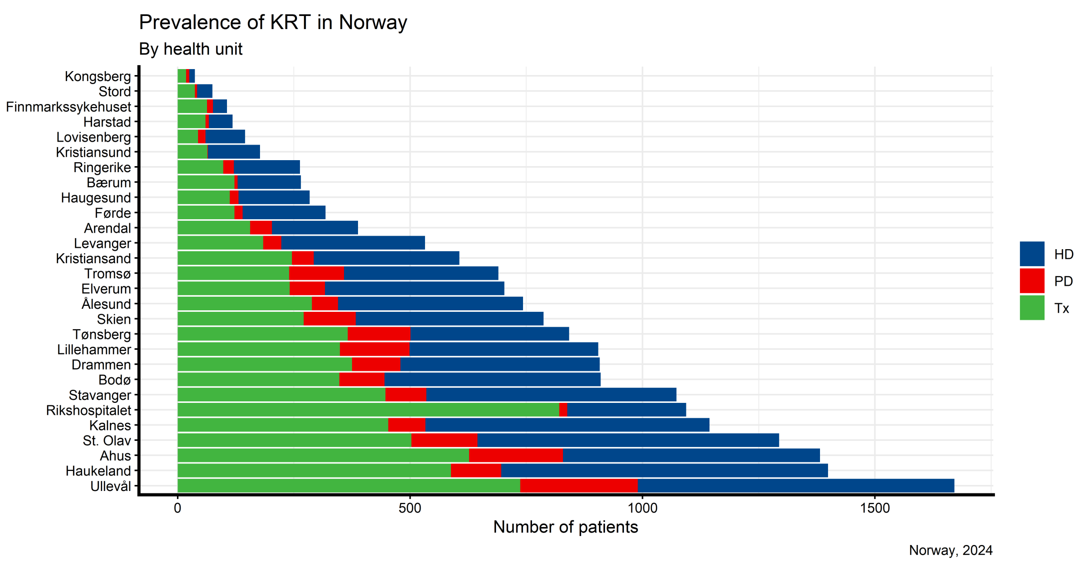

Figure 36: Prevalence of KRT by treatment center

The age distribution of prevalent KRT patients is shown in Table 9 below.

Table 9: Age distribution of prevalent patients in kidney replacement therapy (KRT)

	Total (n:5623)	**HD (n:1483)**	**PD (n:456)**	**Tx (n:3684)**
Age (mean) [years]	60.4	66.1	65.4	57.6
Age (median) [years]	62.4	68.7	69.1	59.3
Age (minimum) [years]	1.1	18.8	13.2	1.1
Age (maximum) [years]	93.8	93.8	91.9	93.3
Male (%)	65%	68%	70%	63%

Kidney transplantation

A total of 257 kidney transplantations were performed in Norway in 2024, i.e. 45.7 per million inhabitants, 36 (13%) were re-transplantations (13% also in 2023) and 73 (28%) were living donor transplants (19% in 2023) (**Figures 37-39**).

Preemptive transplantation was performed in 25% of all first transplantations in 2024 (**Figure 40).** The 165 non-preemptive, first transplant recipients had been in dialysis for a median of 2.1 years (mean 2.6 years), ranging from 60 days to 7.86 years before transplantation.

In principle transplantation is offered to all patients considered to benefit from it, with no strict upper or lower age limit. The age of the 158 first DD-graft recipients in 2024 ranged from 1 to 79 years, with a median age of 59 years. Out of these, 33% were above the age of 65 and 7% were 75 or older. The 63 recipients of a first LD-graft were from 2 to 77 years, with a median age of 45 years.

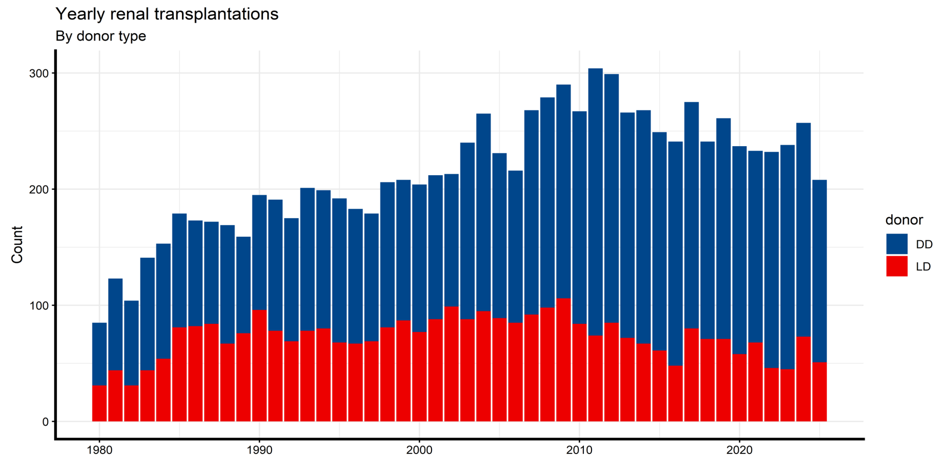

Figure 37: Yearly renal transplantations

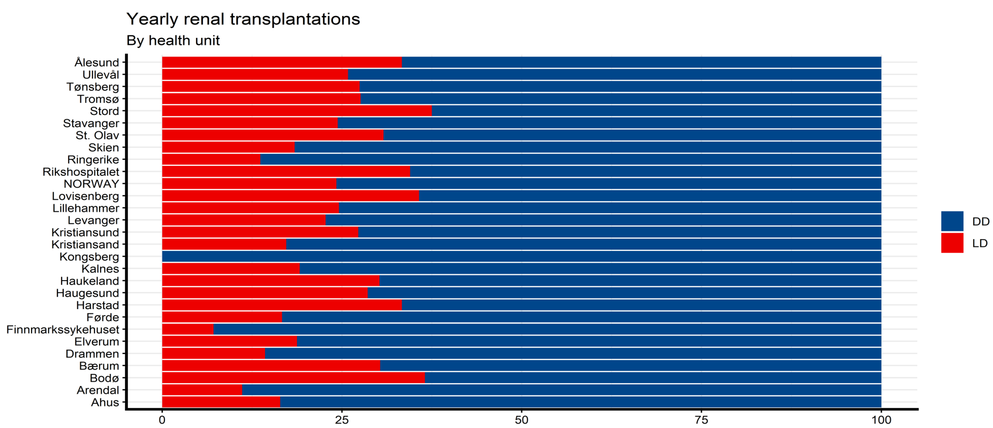

Figure 38: Yearly renal transplantations

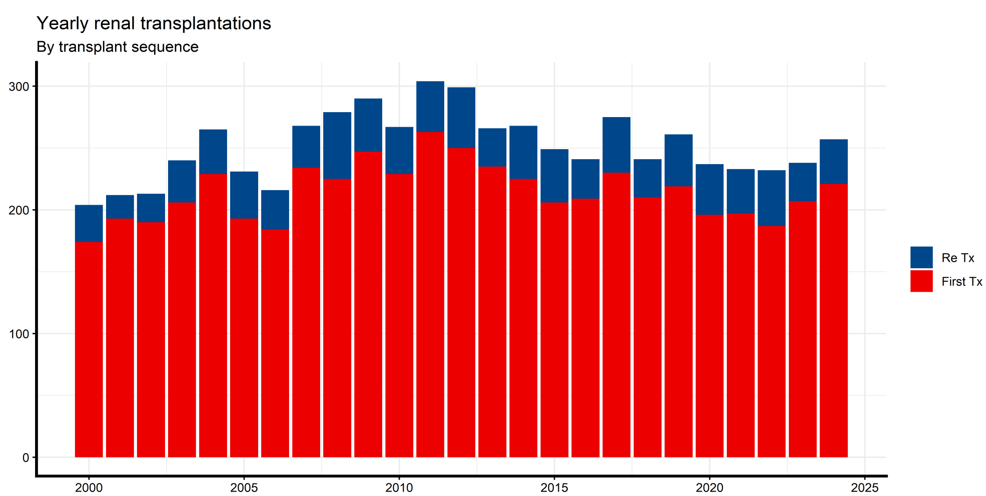

Figure 39: Yearly renal transplantations

The proportion of pre-emptive transplantations are shown in Figure 40.

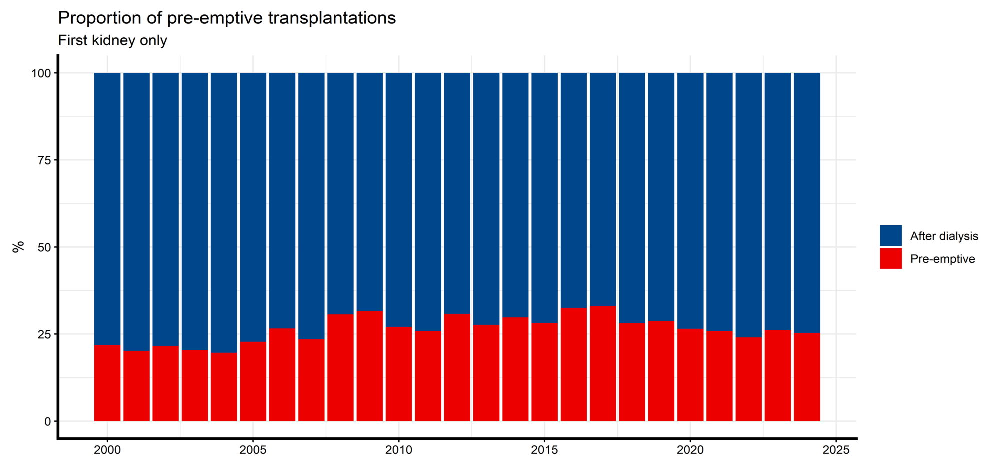

Figure 40: Proportion of pre-emptive transplantations

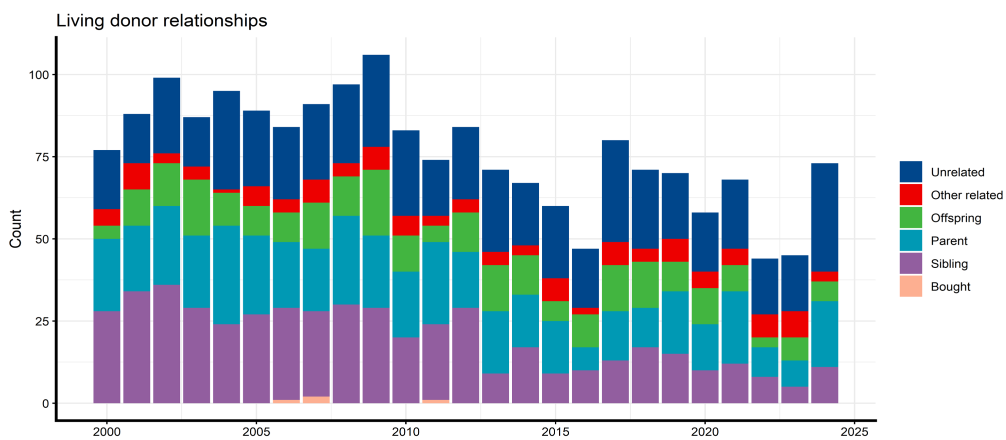

Figure 41: Yearly renal transplantations

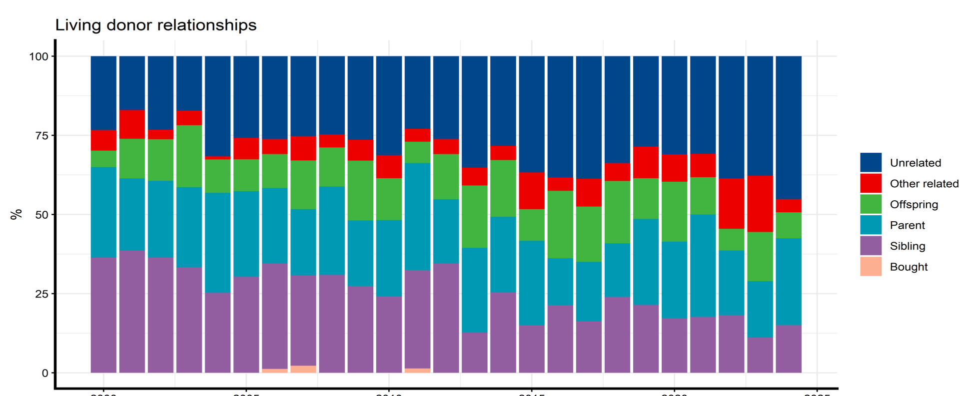

Figure 42: Yearly renal transplantations

Fun-facts kidney transplantation

In the table below, we summarize some fun facts regarding kidney transplantation outcomes in Norway.

Youngest age at transplantation	9.5 months
Oldest age at transplantation	84.1 years
Number of recipients >70 years at transplantation	1,128
Number of recipients >80 years at transplantation	49
Oldest transplant recipient ever	94.9 years (93.3 still living)
Number of recipients reaching at least 90 years of age	23 (5 still living)
Number of recipients reaching at least 80 years of age	785 (193 still living)
Longest kidney graft survival	55.1 years (still working)
Number of kidneys with >40 years in the new body	59 (32 still working)
Oldest transplanted kidney ever	112.2 years
Oldest transplanted kidney still working	106.8 years
Number of transplanted kidneys >100 years	14 (6 still working)
Number of transplanted kidneys >90 years	112 (45 still working)

Immunosuppression

The use of immunosuppressive drugs has changed substantially since 2000, and is visually presented in **Figure 43** and **Figure 44.**

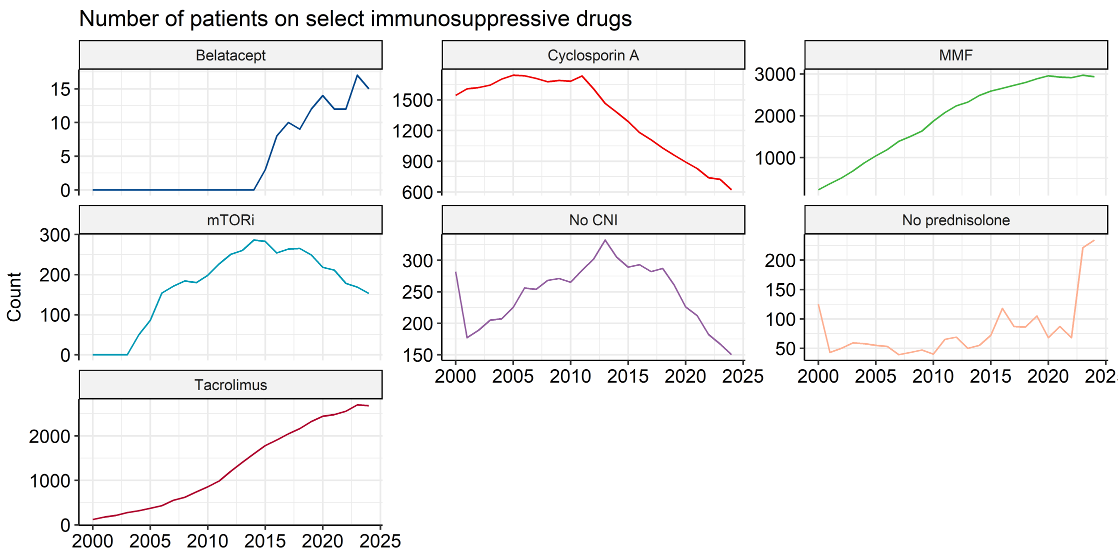

Figure 43: Use of immunosuppressive drugs

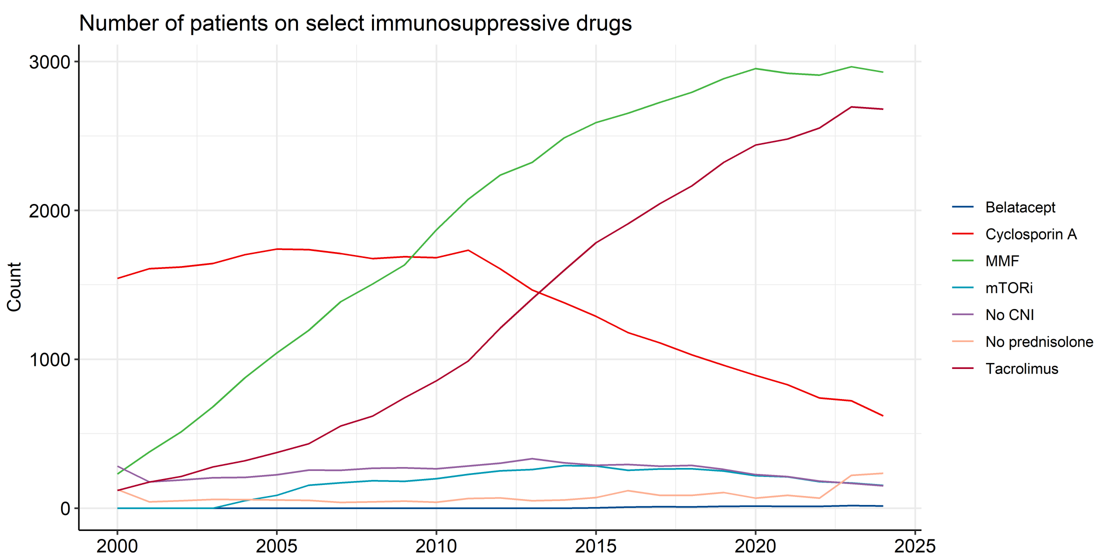

Figure 44: Use of immunosuppressive drugs

Infections are common in patients using immunosuppressive drugs and can be a sign of excessive immunosuppression. The yearly incidence following the introduction of modern immunosuppression in 2007 is shown in Figure 45.

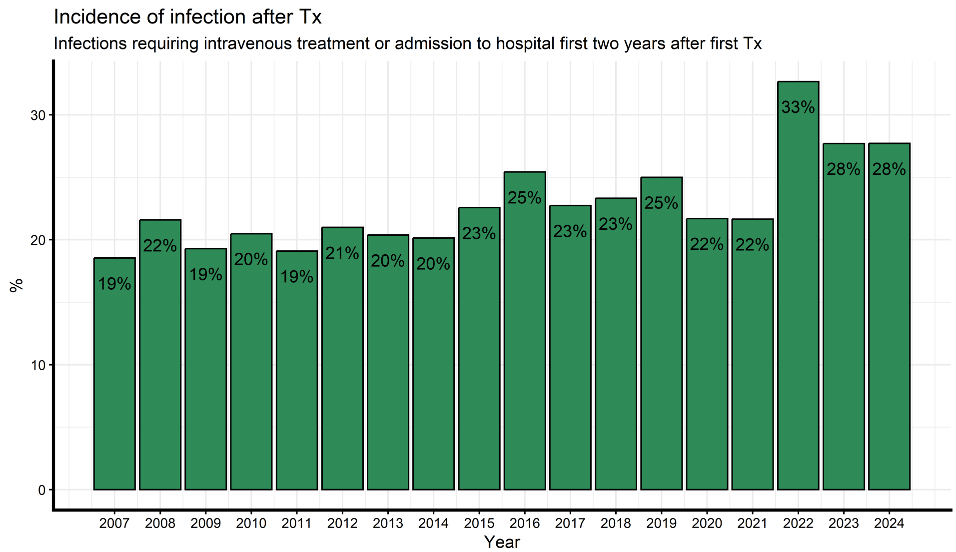

Figure 45: Incidence of infection after transplantation

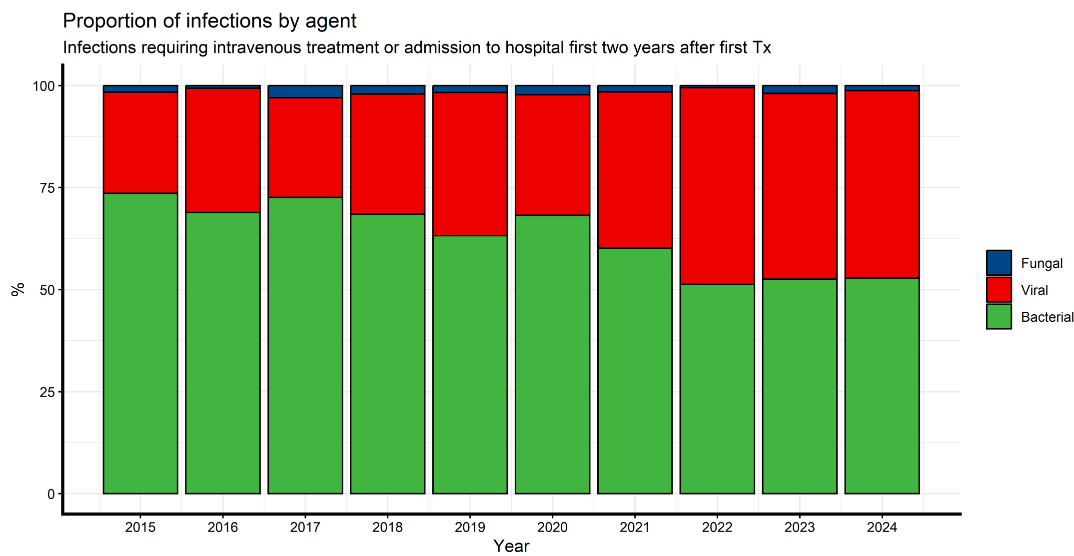

Figure 46: Proportions of infections by infectious agent

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Patients listed for transplantation

The list of patients waiting for a kidney transplant has shown a marked increase over the last decade.

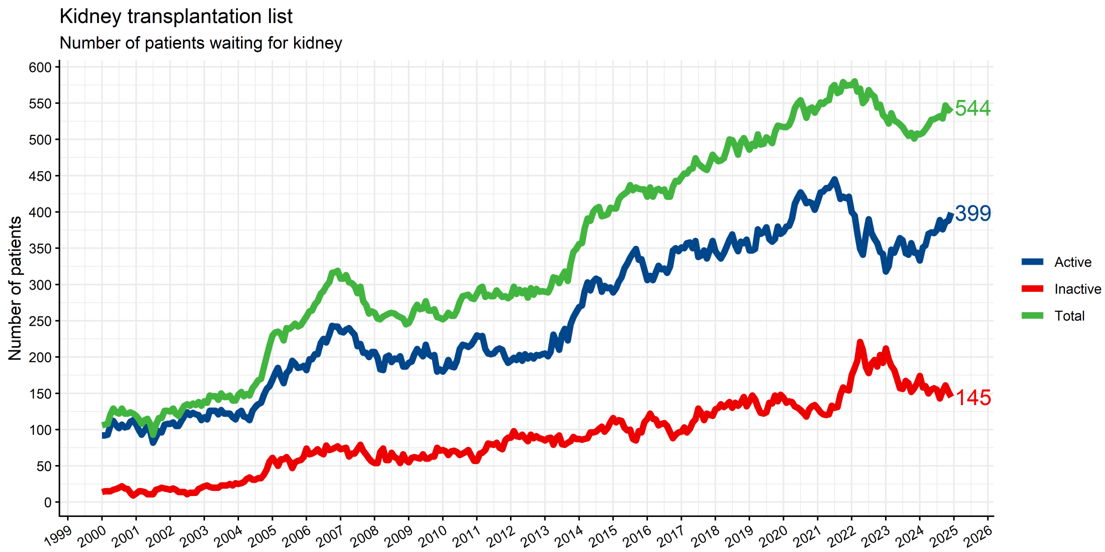

Figure 47: Number of patients waiting for kidney since 2000

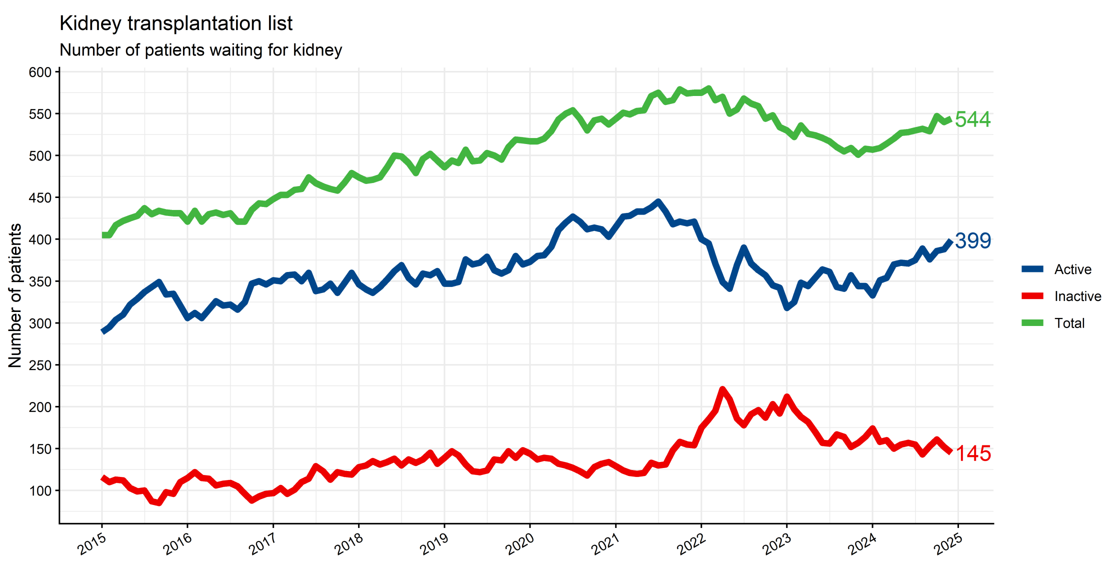

Figure 48: Number of patients waiting for kidney in the last ten years

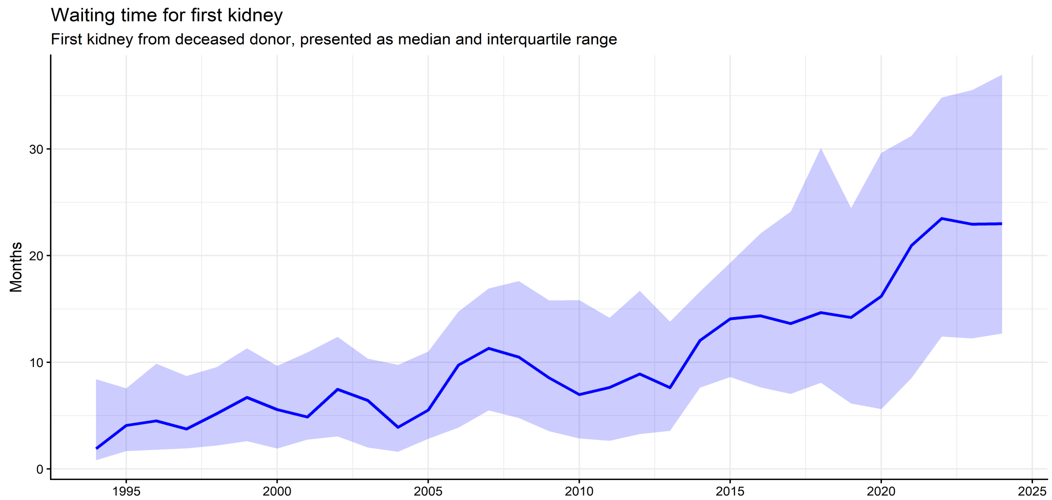

Figure 49: Waiting time for first kidney from deceased donor

Patient and graft survival

Below we present a selection of Kaplan-Meier analyses on patient survival in KRT and graft (not death censored) survival after transplantation, crude plots only. Changes in baseline characteristics and treatment should be taken into consideration, for example that median age when starting KRT is increasing by the year. Additional Kaplan-Meier analyses including patient- and death censored graft survivals can be downloaded from the homepage (https://nyreregister.no/rapporter/).

Patient survival in KRT

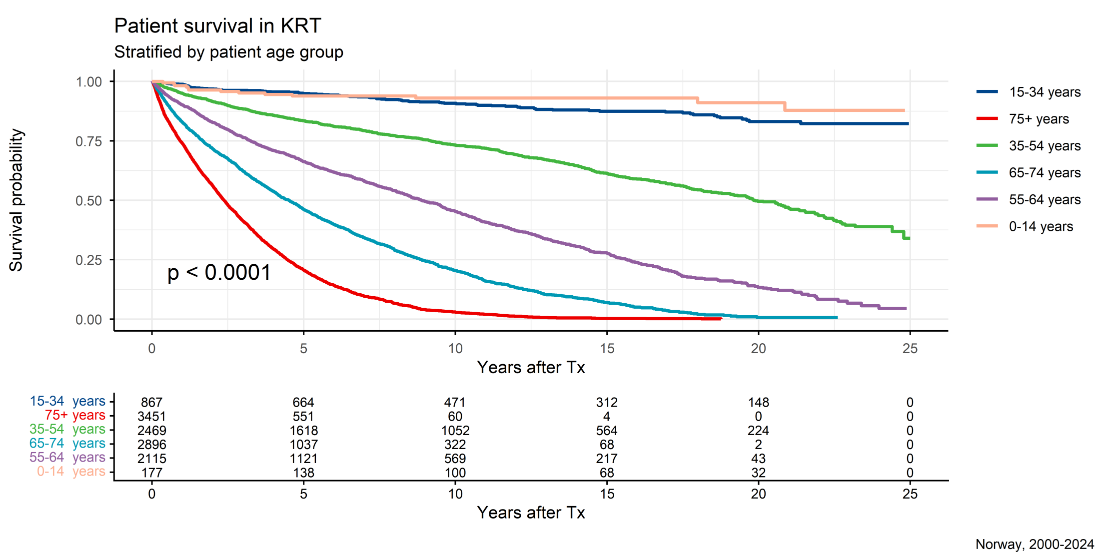

Figure 50: Patient survival in KRT by patient age group.

Graft survival after transplantation

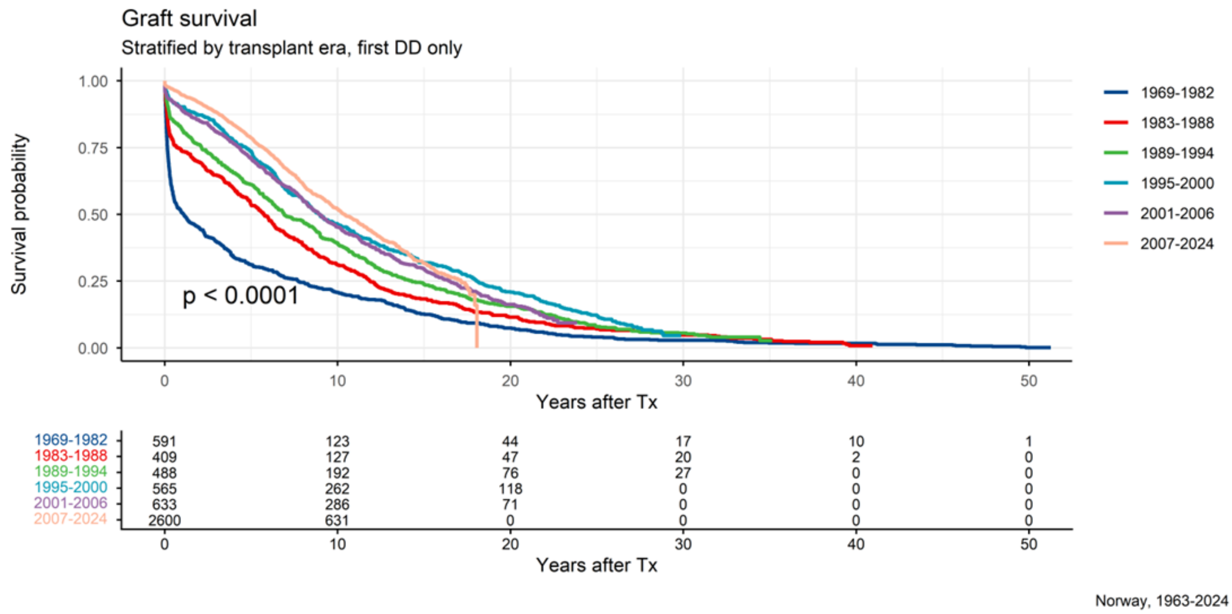

Figure 51: Graft survival in KRT by patient transplant era.

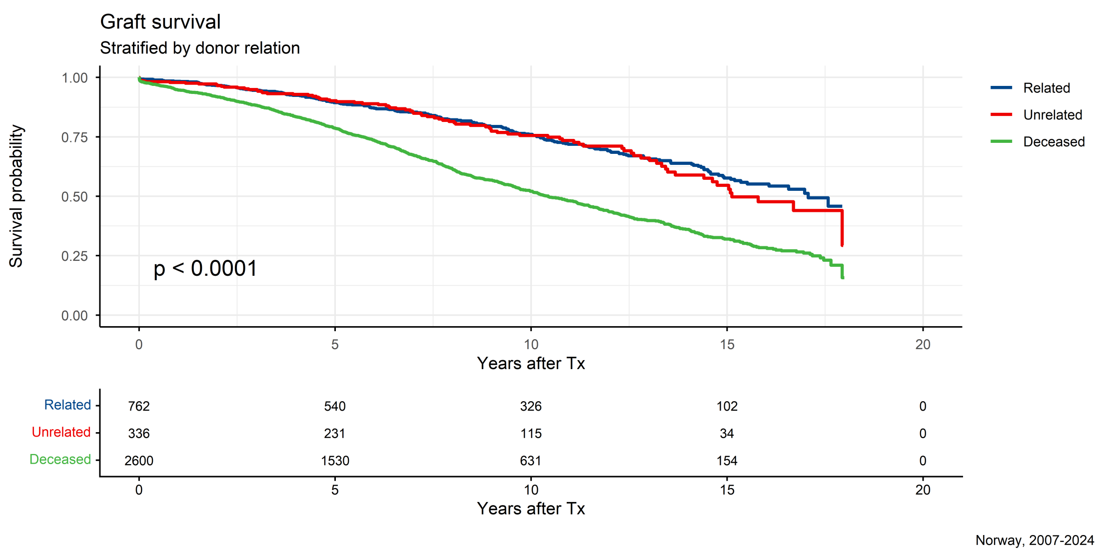

Figure 52: Graft survival in KRT by patient relation.

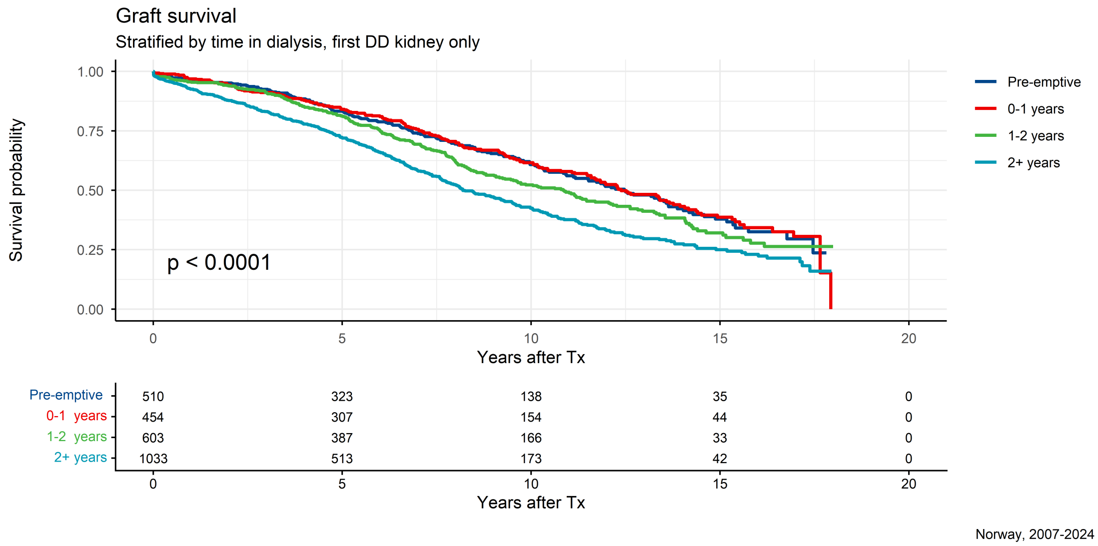

Figure 53: Graft survival in KRT by time in dialysis.

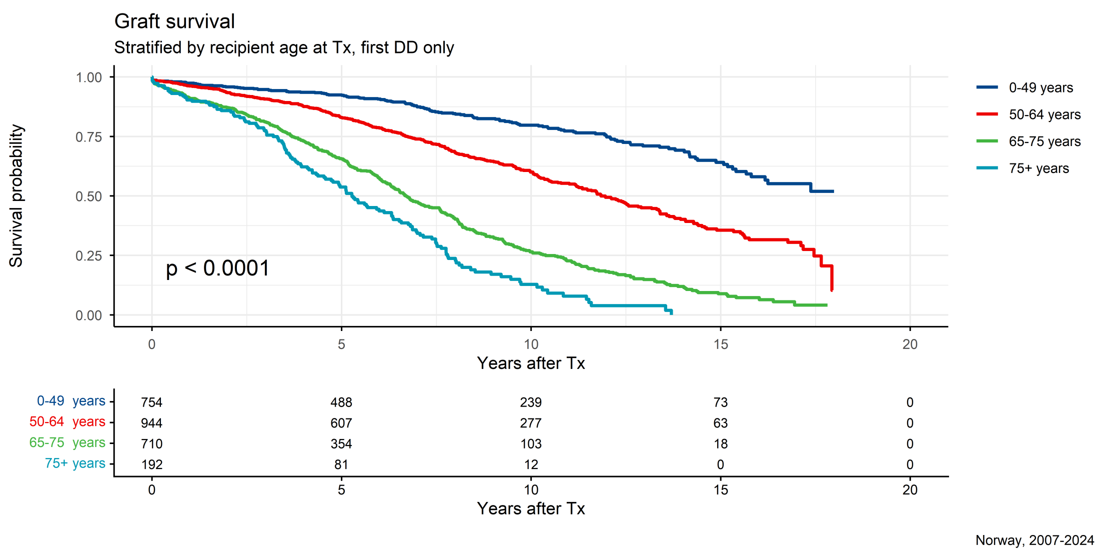

Figure 53: Graft survival in KRT by recipient age.

Death in CKD5 patients

In **Table 10** we show the number of deaths reported to the registry with complete data for the previous five years. Note that deaths that have occurred but have not yet been fully reported to the registry, is not counted. As such, some lag time is expected and could lead to a lower-than-expected number of deaths in the reporting year compared to previous years. As such, the numbers for this year should be considered with some caution.

Table 10: Reported deaths in CKD5 patients

Treatment	2020	2021	2022	2023	2024
CKD5	68	77	58	79	101
Dialysis	283	329	383	345	335
Tx	151	157	223	151	162
Total	**502**	**563**	**664**	**575**	**598**

The cause of death across treatment modalities is shown in Table 11.

Table 11: Reported deaths in CKD5 patients by year and cause of death

Treatment	Cause of death	2020	2021	2022	2023	2024
CKD5	Cardiovascular	32%	38%	26%	27%	23%
CKD5	Complication during KRT	1%	0%	2%	3%	3%
CKD5	Infection	10%	18%	28%	18%	20%
CKD5	Malignancy	19%	10%	7%	14%	7%
CKD5	Other	34%	32%	31%	37%	47%
CKD5	Treatment withdrawal	3%	1%	7%	3%	1%

Treatment	Cause of death	2020	2021	2022	2023	2024
Dialysis	Cardiovascular	34%	37%	31%	30%	31%
Dialysis	Complication during KRT	2%	3%	4%	3%	3%
Dialysis	Infection	24%	20%	20%	21%	19%
Dialysis	Malignancy	9%	8%	10%	9%	8%
Dialysis	Other	25%	28%	31%	29%	31%
Dialysis	Treatment withdrawal	6%	4%	4%	7%	7%

Treatment	Cause of death	2020	2021	2022	2023	2024
Tx	Cardiovascular	28%	15%	16%	24%	16%
Tx	Complication during KRT	0%	1%	0%	2%	1%
Tx	Infection	26%	35%	44%	31%	24%
Tx	Malignancy	25%	23%	18%	18%	22%
Tx	Other	19%	26%	22%	24%	36%
Tx	Treatment withdrawal	2%	0%	0%	1%	2%

CKD5 coverage analysis

In cooperation with the Norwegian Patient Registry (NPR) the registry has performed a coverage analysis for the period of 2019-2023. CKD5 patients (not yet in kidney replacement therapy) was identified in the NPR through the diagnosis code N18.5. The definition of patients with chronic kidney disease stage 5 (CKD5) is that the patient should have had a glomerular filtration rate (GFR) below 15 mL/min/1.73 m^2 (i.e. N18.5) for 3 months (to distinguish them from transient acute kidney failure). The date of start of CKD5 (without kidney replacement therapy) was set to the verification date at least 3 months after the first GFR below 15 mL/min/1.73 m^2. Patients who start kidney replacement therapy (dialysis or kidney transplantation) within this 3-month period was not counted as "CKD5 patients" in the coverage analysis. Results are shown in **Tables 12-14**.

Table 12: Individual coverage rate for NRR

Norway	Both	Only NRR	Only NPR	Total	CCR, NRR (%)	CR, NPR (%)
Pasient	951	682	1544	3177	51,4	78,5
Pasient/År	630	1003	1865	3498	46,7	71,3
Pasient/HF	886	747	1609	3242	50,4	77

Table 13: Individual coverage rate for NRR by year

Year	Both	Only NRR	Only NPR	Total	CR, NRR (%)	CR, NPR (%)
2019	121	237	328	686	52,2	65,5
2020	104	210	369	683	46	69,3
2021	111	201	394	706	44,2	71,5
2022	122	214	366	702	47,9	69,5
2023	126	187	454	767	40,8	75,6
Totalt	584	1049	1911	3544	46,1	70,4

Table 14: Individual coverage rate for NRR by center

Center	Both	Only NRR	Only NPR	Total	CR, NNR (%)	CR, NPR (%)
Akershus universitetssykehus, Nordbyhagen	61	118	232	411	43,6	71,3
Diakonhjemmet sykehus	0	0	3	3	0	100
Finnmarkssykehuset HF	6	17	18	41	56,1	58,5
Helse Bergen, Haukeland	47	72	141	260	45,8	72,3
Helse Fonna, Haugesund	12	24	47	83	43,4	71,1
Helse Fonna, Stord	8	14	9	31	71	54,8
Helse Førde, Førde	26	20	24	70	65,7	71,4
Helse Møre og Romsdal, Kristiansund	1	0	35	36	2,8	100
Helse Møre og Romsdal, Ålesund	3	10	48	61	21,3	83,6
Helse Nord-Trøndelag, Levanger	23	46	39	108	63,9	57,4
Helse Stavanger, Stavanger	49	82	59	190	68,9	56,8
Lovisenberg Diakonale Sykehus	5	26	24	55	56,4	52,7
Nordlandssykehuset, Bodø	5	6	128	139	7,9	95,7
OUS, Rikshospitalet	0	6	29	35	17,1	82,9
OUS, Ullevål	87	122	130	339	61,7	64
St. Olavs hospital, Trondheim	2	6	147	155	5,2	96,1
Sykehuset Innlandet, Divisjon Lillehammer	27	51	104	182	42,9	72
Sykehuset Innlandet, Elverum	21	29	62	112	44,6	74,1
Sykehuset Telemark, Skien	9	18	96	123	22	85,4
Sykehuset i Vestfold, Tønsberg	50	129	76	255	70,2	49,4
Sykehuset Østfold, Kalnes	50	73	146	269	45,7	72,9
Sørlandet sykehus, Arendal	11	25	40	76	47,4	67,1
Sørlandet sykehus, Kristiansand	1	1	49	51	3,9	98
Universitetssykehuset Nord-Norge, Harstad	6	10	14	30	53,3	66,7
Universitetssykehuset Nord-Norge, Tromsø	22	46	60	128	53,1	64,1
Vestre Viken, Bærum	17	26	35	78	55,1	66,7
Vestre Viken, Drammen	33	55	80	168	52,4	67,3
Vestre Viken, Ringerike	2	17	36	55	34,5	69,1
Totalt	584	1049	1911	3544	46,1	70,4

Conclusion: The coverage rate was low for both NPR and NRR. It is the number of patients that are only found in NRR that causes the coverage rate for NPR to be low. The syntax for extracting patients from NPR is probably too strict and needs to be better adapted to clinical reality. It is unlikely that patients who are defined by a kidney specialist as “CKD5 patient” in NRR are wrong. Based on the large variation in coverage rate between centers, it is likely that NRR is missing many patients. There may be a lack of resources at the centers

in addition to ambiguity about the actual definition of CKD5 start date.
In conclusion, the syntax should be further developed in the next analysis of the coverage rate, but the question of whether it is possible to create rules that identify the data basis from NPR arises, as the courses of the patients are complicated and vary.

Quality indicators

The quality indicators continuously undergo evaluation by the “Fagråd” and is adapted to better serve its cause. The version of the quality indicators currently that at any time is in use can be found at the homepage of the registry (https://nyreregister.no/om-registeret/).

The latest analyses of these quality indicators can be downloaded from the registry homepage (https://nyreregister.no/rapporter/).

Quality projects

Method for blood pressure measurement:

The register collects information on blood pressure from all patients each year. As a follow-up to the quality project of blood pressure treatment in kidney transplanted patients, we now also collect the method used for the reported blood pressure. In **Table 15** the methods for blood pressure measurement are reported by treatment modality, CKD5, dialysis and kidney transplants. Home measurement and 24-hour ambulatory are the preferred methods, and the aim is to increase the use of these methods as they better describe the relevant blood pressure for long-term outcomes compared to attended office blood pressure.

Table 15: Percentage of different blood pressure methods used for the reported blood pressure in 2024 annual forms.

	Total (n:5595)	**CKD5 (n:422)**	**DIAL (n:1702)**	**Tx (n:3445)**
Office present	87%	84%	97%	83%
Office alone	5%	6%	1%	7%
24-hour ambulatory	1%	0%	0%	1%
Home measurements	6%	6%	2%	10%
Not measured	0%	1%	0%	0%

Blood access when starting hemodialysis:

In the 2022 annual report this was presented: The register collected information on reasons for not starting hemodialysis with AV-fistula as blood access. The data clearly indicates that the target figure is set too high, as AV fistula is not possible for medical reasons in many patients. In consultation with the renal community, work has continued to adjust the quality indicator to better describe the quality of the health care provided. The target goal attainment of each health unit is shown in **Figure 54**.

As a result of this work, we now collect on the annual form both which blood access is considered best for the individual patient and if this is the blood access used. In 2024, for patients treated with dialysis to prolong life, and not just relieve symptoms, AV-fistula was considered the best choice for 57%, catheter for 41%, and graft for 1%, and 76% of patients were treated with their supposedly best blood access, down from 83% in 2023.

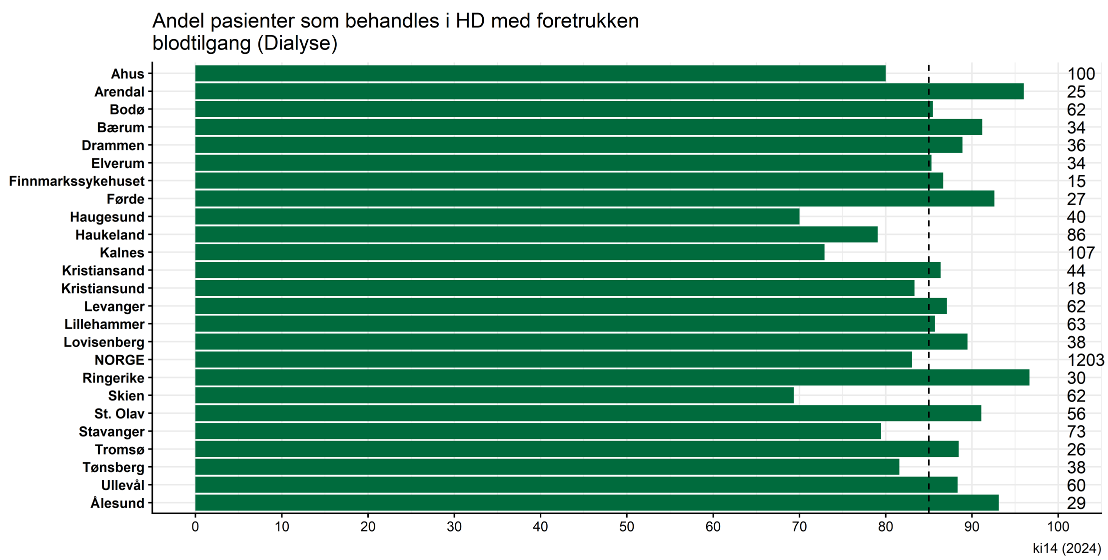

Figure 54: Number of patients in hemodialysis treated with their optimal access.

Scientific production

During the report year 2024, a total of 18 scientific publications (have used data from the registry an in total 5 PhD candidates using data from the registry defended their thesis

Yngvar Haaskjold: Prognostic Models in IgA Nephropathy (Bergen)

Lene Ugilt Pagter Ludvigsen: Epstein-Barr virus infection in kidney transplant recipients – Investigating the clinical relevance and the prospects for prevention of post-transplant lymphoproliferative disorder (Århus)

Kjersti Benedicte Blom: Viral infections in Norwegian kidney transplant recipients: Impact of COVID-19 and CMV (Oslo)

Ingvild Andrea Kindem: Medication adherence and home-monitoring among kidney transplanted adolescents and young adults in Norway (Oslo)

Inga Thorsen: New biomarkers in patients with chronic kidney disease, after kidney transplantation, in kidney donors and in acute myocardial infarction (Stavanger)

Maryam Saeed: Risk of Coronary Heart Disease and End-Stage Renal Disease in Type 1 Diabetes with onset before 15 years of age, 1973-2017 (Oslo)

These, and other scientific productions, are listed on the registry homepage (https://nyreregister.no/publikasjoner/).

Concluding remarks

The registry coverage of patients in CKD5 without KRT is only 50%. Between centers the coverage is however very variable which indicates that it will be possible to achieve a high coverage and as a result of that get reliable data also on this cohort of patients. We will need a high focus on this challenge during the upcoming years!

The transition to the new database (MRS) has been successful and all centers are reporting electronically now. After the implementation of the system there has been some work to finetune its appearance and a more complete system will be available from 2026, also including a PROM module.

The registry has published a new homepage (https://nyreregister.no). During the years as a combined registry (since 2016) intensive work has been made to get relevant quality indicators. They have now been considerable revised, and the new version is available on the homepage of the registry.

Registry data are regularly used by Norwegian nephrologists and other researchers as basis for scientific papers, congress presentations and PhD-theses. A list of publications is published on https://nyreregister.no along with the annual reports. The total number of international peer reviewed publications from the registry are 380, of which 18 were published in 2024. In total 54 PhD-theses, of which five were in 2024, have at least partly been based on data from the registry.

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 the hard work over the entire country is GREATLY acknowledged!

Report completed 4.12.2025

Appendix; center annual KRT numbers

		New patients in KRT 2024				Patients in KRT by 31.12.2024					Dialyses etc. 2024			Died 2024		
	Satellittes	HD/HDF	PD	Pre-emptive	Total	HD/HDF	HjemmeHD	PD	Graft	Total	HD sessions	Pl.exch.	Other	Dial.pat	Tx-pat	Not tx-cand.
AHUS	1	28	22	9	59	107	6	64	352	529	18,393	0	0	38	25	104
Arendal		11	3	0	14	25	0	14	74	113	3,885	0	32	15	3	31
Bodø	9	8	5	3	16	59	1	19	165	244	11,695	6	0	18	8	49
Bærum		9	4	1	14	40	0	6	83	129	5,413	0	0	4	5	33
Drammen		14	8	2	24	36	2	31	158	227	6,360	33	0	7	10	26
Elverum		8	6	2	16	46	4	21	111	182	8,273	0	27	11	9	38
Finnmark	5	3	3	0	6	15	1	3	43	62	2,447	0	0	5	4	9
Førde	2	10	2	0	12	32	0	6	58	96	4,725	0	0	6	8	26
Harstad		1	1	0	2	8	0	2	40	50	1,608	0	0	2	2	6
Haugesund	2	8	1	0	9	47	0	4	55	106	7,160	83	23	7	3	27
Haukeland	3	28	8	4	40	113	2	20	308	443	16,960	89	40	17	12	82
Hønefoss	1	6	3	0	9	31	0	8	62	101	4,018	0	0	12	2	28
Kongsberg		1	3	0	4	11	0	8	14	33	?	0	0	0	6	14
Kristiansand S	1	11	5	2	18	50	0	9	130	189	6,609	24	0	10	6	27
Kristiansund N	1	6	0	0	6	24	0	0	42	66	3,461	0	0	3	3	16
Levanger	5	9	3	0	12	63	5	7	82	157	10,085	7	65	16	3	52
Lillehammer	3	13	11	4	28	65	1	26	155	247	9,655	66	0	21	8	68
Lovisenberg		8	3	2	13	38	0	8	36	82	4,800	0	0	8	0	40
Rikshospitalet		2	1	2	5	7	1	1	136	145	1,962	141	43	2	7	3
St. Olav	5	15	8	6	29	93	4	17	228	342	15,301	79	106	22	12	71
Stavanger		9	4	3	16	76	2	13	237	328	12,205	41	23	13	4	30
Stord		0	1	0	1	10	1	1	25	37	1,779	0	0	1	1	5
Telemark	4	12	16	1	29	63	0	38	125	226	10,231	14	0	18	5	57
Tromsø	3	8	1	0	9	23	3	7	94	127	5,165	38	0	12	1	16
Tønsberg		11	10	1	22	44	1	29	158	232	6,305	111	87	16	6	29
Ullevål		19	20	9	48	78	3	35	370	486	12,409	26	0	16	7	57
Østfold	2	24	13	2	39	113	8	31	213	365	17,608	30	0	28	9	50
Ålesund	1	9	4	3	16	32	0	14	127	173	5,719	76	0	15	3	37
SUM	***48***	***291***	***169***	***56***	***516***	***1,349***	***45***	***442***	***3,681***	***5,517***	***214,231***	***864***	***446***	***343***	***172***	***1,031***
# Pr. mill innb.		*52.0*	*30.2*	*10.0*	*92.2*	*241.2*	*8.0*	*79.0*	*658.0*	*986.2*						*184.3*
% of total		*56.4*	*32.8*	*10.9*	*100,0*	*24.5*	*0.8*	*8.0*	*66.7*	*100,0*						*18.7*