# ANNUAL REPORT 2020

# The
# Norwegian Renal Registry

# (Norsk Nyreregister)

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

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# Table of Contents

# History and Organization 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 (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 renal replacement therapy (RRT) 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 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 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 3,000 non-neoplastic kidney biopsies collected in the new registry the total amount of biopsies is about 16,000.

## National organization and policy

Norway had 5.372 mill. inhabitants (July 2020) and 12 counties with populations ranging from 243,311 to 1,241,165 inhabitants. Each county has a central renal unit and some have more, further some have satellite units run in close contact with the central unit. 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 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 $m^2$ 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 2020, data from the last visit before December 31$^{st}$ 2020 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 96.4%.

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 83%. 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 31$^{st}$ each year. For patients in renal replacement therapy the individual coverage is close to 100% (currently 24 patients (0.44%) alive without consent). CKD5 patients not treated with renal replacement therapy have only been included in the registry since 2016 and the coverage is improving for each year. Based on prevalence data from the literature it is expected that there is between 550-600 prevalent CKD5 patients not on RRT in Norway. For 2020 this results in an estimated coverage of about 85%. However, considering that some Norwegian centers have reported many patients and some none, this coverage estimate is probably too high. Scaling the prevalence for the top five reporting centers give an anticipated national coverage of about 56%. A coverage analysis of non-neoplastic kidney biopsies is performed 3 to 4 times per year since 2020. The last coverage was 78%. At regular intervals, reporting of deaths to the registry is checked against the Norwegian National Registry (NO: *Folkeregisteret*).

NRR is one of 51 national medicine quality registries (https://www.kvalitetsregistre.no/registeroversikt). NNR has identified 22 quality indicators in order to cover all relevant subgroups of patients in the registry. The quality indicators 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: https://www.nephro.no/nnr.html.

# Incidence data 2020

During 2020, a diagnostic kidney biopsy, and relevant clinical data, was available from 612 patients. Also, 294 new patients with CKD5, not previously established in renal replacement therapy, were reported and 537 patients started renal replacement therapy (i.e. 100.0 per mill. inhabitants).

## Biopsy

**Table 1. Number of kidney biopsies per regional health authority**

| | 2015 | 2016 | 2017 | 2018 | 2019 | 2020 |
|---|---|---|---|---|---|---|
| **Helse Sør-Øst** | 320 | 297 | 305 | 353 | 346 | 372 |
| **Helse Vest** | 172 | 126 | 134 | 137 | 113 | 115 |
| **Helse Midt** | 64 | 62 | 54 | 78 | 60 | 77 |
| **Helse Nord** | 40 | 47 | 52 | 54 | 54 | 48 |
| **Total** | **596** | **532** | **545** | **622** | **573** | **612** |

Helse Sør-Øst: South-Eastern Norway Regional Health Authority
Helse Vest: Western Norway Regional Health Authority
Helse Midt: Central Norway Regional Health Authority
Helse Nord: Northern Norway Regional Health Authority

*This does not include neoplastic or transplant biopsies.*

**Figure 1. Number of native kidney biopsies per hospital in 2020**

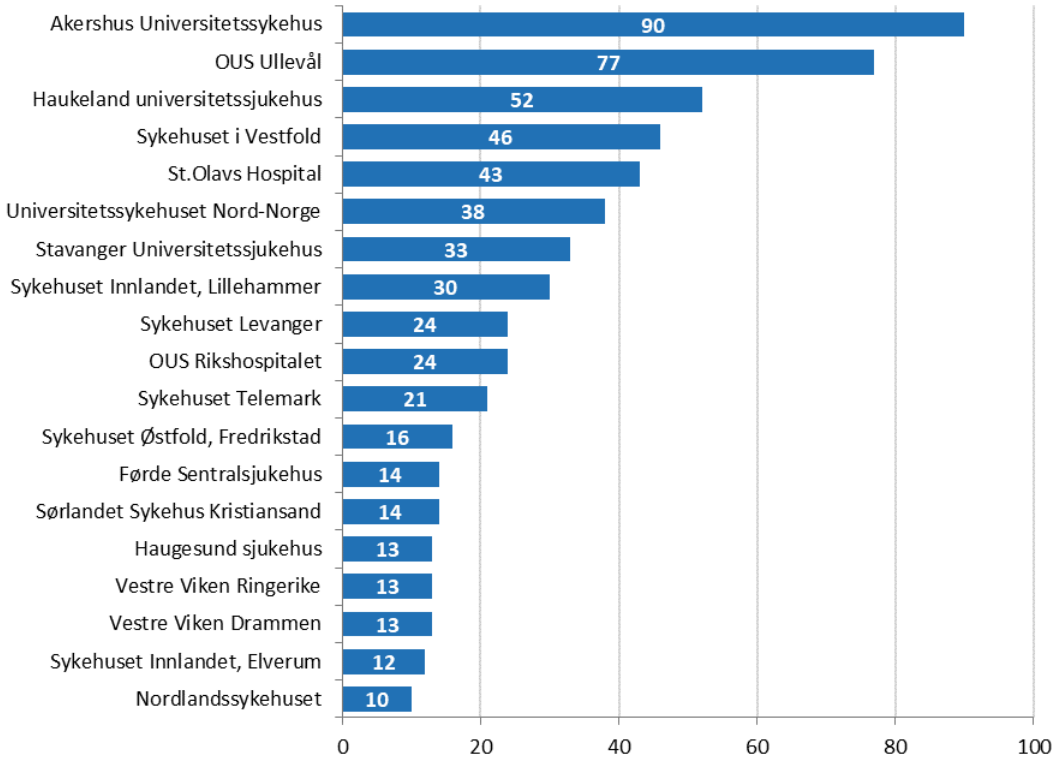



Figure 1 shows the number of kidney biopsies performed per hospital in 2020. Seven hospitals were excluded from the analysis, as they reported less than ten native kidney biopsies in 2020.

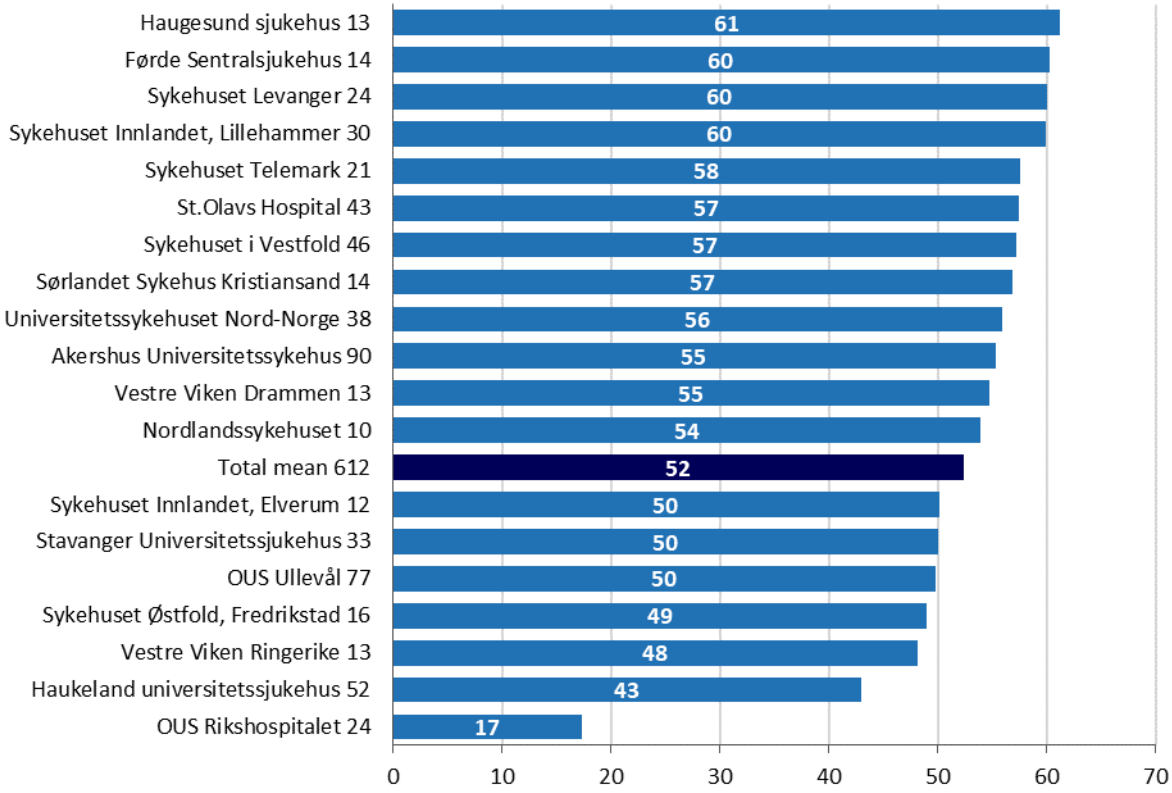
**Table 2. Mean age at kidney biopsy, per Regional Health Authority**

| | Helse Sør-Øst N=372 | Helse Vest N=115 | Helse Midt N=77 | Helse Nord N=48 | Total N=612 |
|---|---|---|---|---|---|
| **Mean age in years (±SD)** | 51.7 (±19.9) | 49.6 (±20.7) | 58.4 (±16.5) | 55.4 (±19.6) | 52.4 (±19.8) |

Mean age at kidney biopsy in 2020 was 52.4 (±19.8) years (table 2), which is comparable to mean age at kidney biopsy the last two years. The highest mean age at kidney biopsy was reported in Central Norway (Helse Midt) (58.4 years), while the lowest mean age at biopsy was reported in Western Norway (Helse Vest) (49.6 years).

The percentage of kidney biopsies performed in the pediatric age range remained similar to previous years; 5.6 % of all kidney biopsies reported were performed in patients under the age of 18 years old. The majority of these biopsies was performed at OUS Rikshospitalet (58.8 %) in Helse Sør-Øst. 67.6 % of all native kidney biopsies in the pediatric age range were performed in Helse Sør-Øst. 5.1 % of all kidney biopsies were performed in patients above 80 years of age, which is slightly higher compared to previous years (3.7 % in 2019). Most of the octogenerians were biopsied in Helse Sør-Øst (48.4 %

**Figure 2. Average age at kidney biopsy, per hospital and total in 2020**




*Seven hospitals were excluded from the analysis, as they reported less than ten native kidney biopsies in 2020.*

**Table 3. Reported clinical indications for kidney biopsy, number (%) of kidney biopsies in the Regional Health Authorities**

| | Helse Sør-Øst | | Helse Vest | | Helse Midt | | Helse Nord | | Total | |
|---|---|---|---|---|---|---|---|---|---|---|
| | N | (%) | N | (%) | N | (%) | N | (%) | N | (%) |
| **Nephrotic syndrome** | 67 | 18,0 % | 19 | 16,5 % | 11 | 14,3 % | 11 | 22,9 % | 108 | 17,6 % |
| **Nephritic syndrome** | 46 | 12,4 % | 20 | 17,4 % | 8 | 10,4 % | 8 | 16,7 % | 82 | 13,4 % |
| **Acute kidney failure** | 119 | 32,0 % | 34 | 29,6 % | 17 | 22,1 % | 16 | 33,3 % | 186 | 30,4 % |
| **Chronic kidney failure** | 118 | 31,7 % | 20 | 17,4 % | 25 | 32,5 % | 15 | 31,3 % | 178 | 29,1 % |
| **Proteinuria** | 154 | 41,4 % | 61 | 53,0 % | 34 | 44,2 % | 22 | 45,8 % | 271 | 44,3 % |
| **Hematuria** | 92 | 24,7 % | 47 | 40,9 % | 28 | 36,4 % | 12 | 25,0 % | 179 | 29,2 % |
| **Other** | 4 | 1,1 % | 0 | 0,0 % | 1 | 1,3 % | 0 | 0,0 % | 5 | 0,8 % |

It is possible to report more than one clinical indication for biopsy. As a result, the total number of clinical indications exceeds the total number of reported kidney biopsies for 2020. Some regional differences are apparent. Nephritic syndrome was more frequently reported in Western and Northern Norway when compared to the rest of the country, but the difference is less pronounced than in 2019. An increase in chronic kidney failure as an indication for kidney biopsy was reported in all the Regional Health Authorities, except in Western Norway, as compared to 2019. In total, acute kidney failure as an indication for kidney biopsy was more frequently reported when compared to 2019 (30,4% vs 20,4%).

**Figure 3. Proteinuria and albuminuria (mg/mmol creatinine) at the time of kidney biopsy in the different Regional Health Authorities**

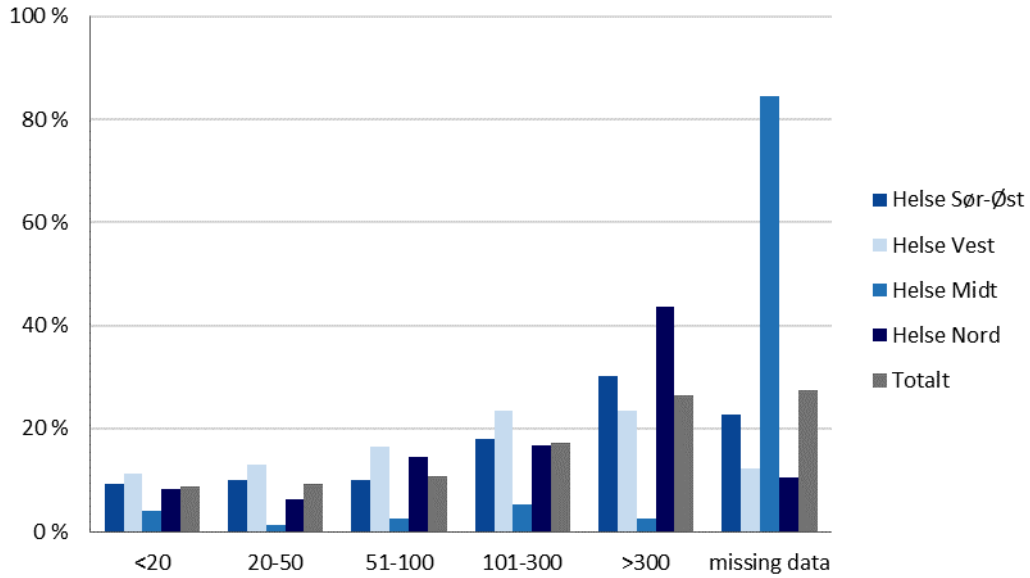


**Figure 4. Albuminuria (mg/mmol creatinine) at the time of kidney biopsy in the different Regional Health Authorities**

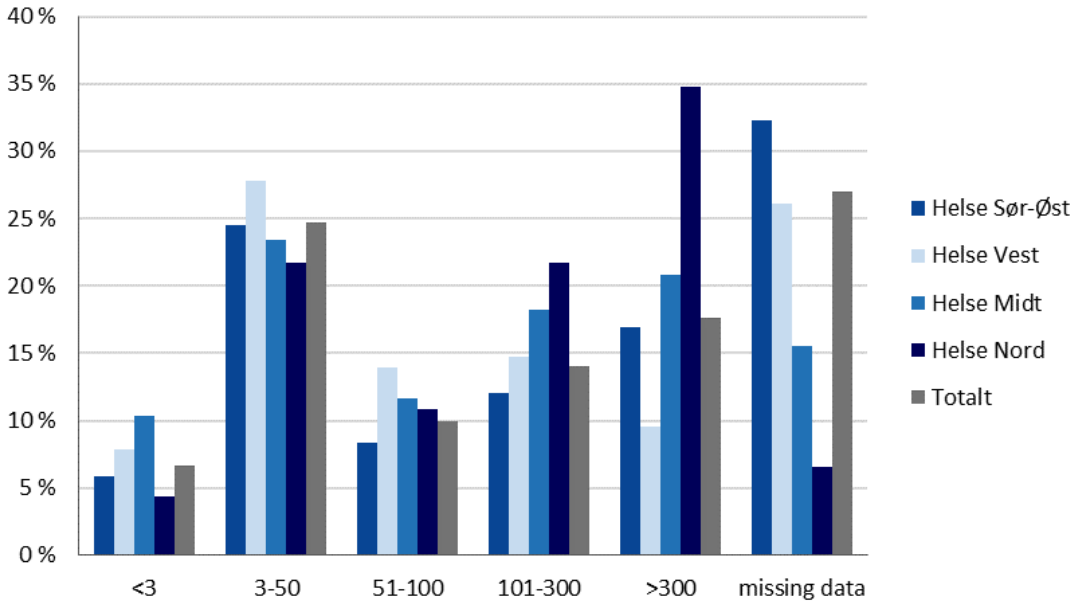



**Figure 5. Serum creatinine (µmol/liter) at the time of kidney biopsy, per Regional Health Authority**

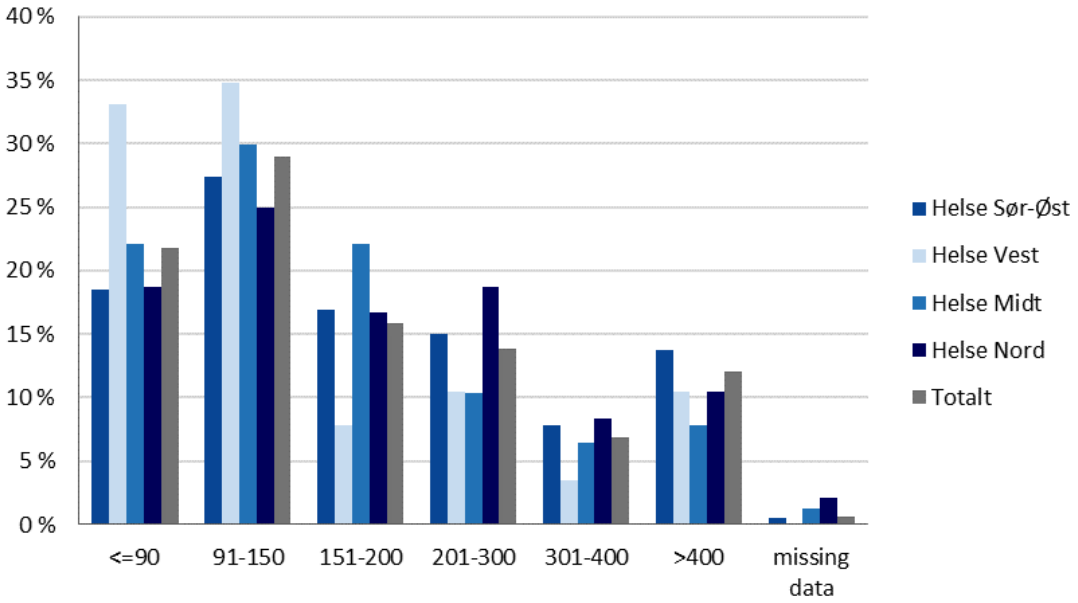
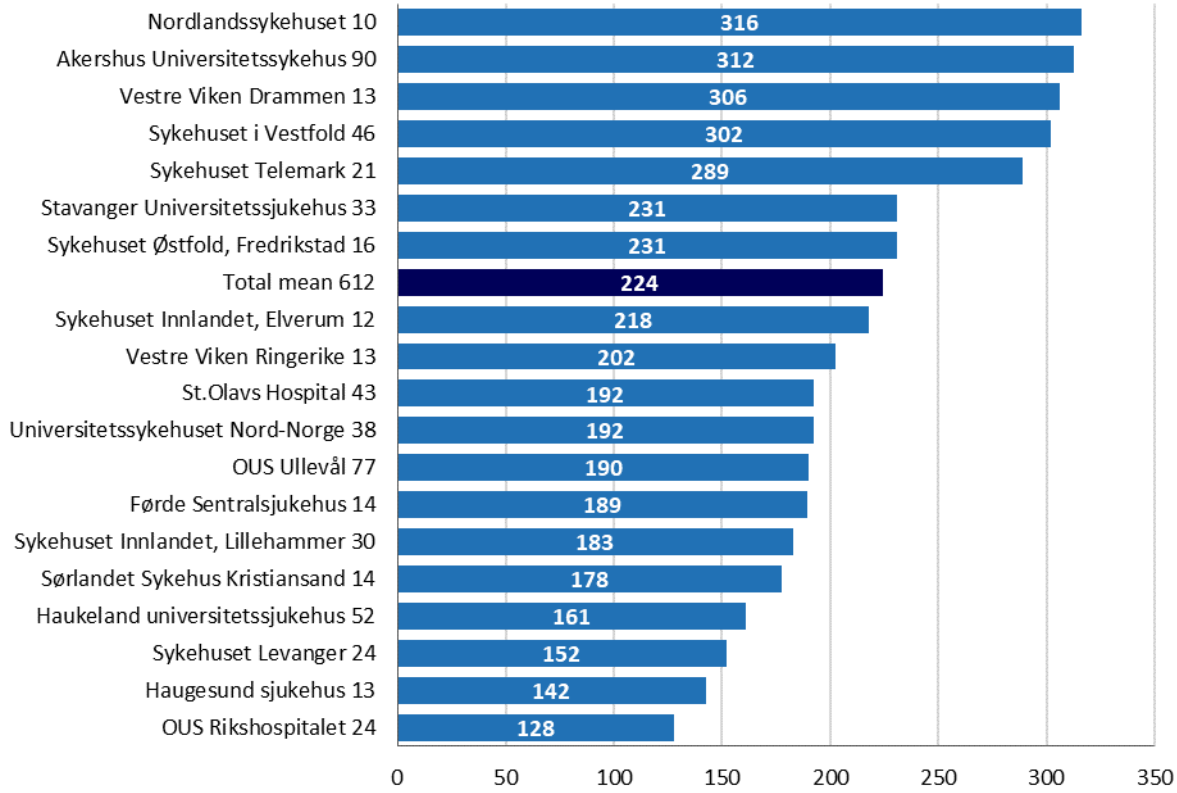


**Figure 6. Mean serum creatinine at the time of kidney biopsy, per hospital**




*Seven hospitals were excluded from the analysis, as they reported less than ten native kidney biopsies in 2020.*

**Table 4. Quality indicators for division of kidney biopsy**

| Quality indicator | Target | What does it indicate? |
|---|---|---|
| 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 if patients are investigated in a timely fashion |

## Serious complications

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.

**Table 5. Percentage of procedure related complications**

| | 2016 | 2017 | 2018 | 2019 | 2020 |
|---|---|---|---|---|---|
| Serious complications | 0,6 % | 2,0 % | 0,6 % | 2,1 % | 2,8 % |
| No complications | 82,9 % | 78,3 % | 81,0 % | 79,6 % | 83,0 % |
| Not reported | 9,1 % | 13,0 % | 9,8 % | 11,8 % | 7,7 % |

Most kidney biopsies are reported without procedure related complications. In 2020, seventeen serious complications were reported in eleven biopsies from eight different hospitals.

However, 7.7 % of all biopsies are reported with missing data regarding this very important quality indicator. It is important to strive for more complete reporting of serious procedure related complications, as changes in the number of serious complications may impact local and/or national guidelines for kidney biopsies and patient care. Complications can be reported to the registry after the initial clinical data report has been submitted, if necessary.

**Table 6. Reported complications in 2020 per Regional Health Authority**

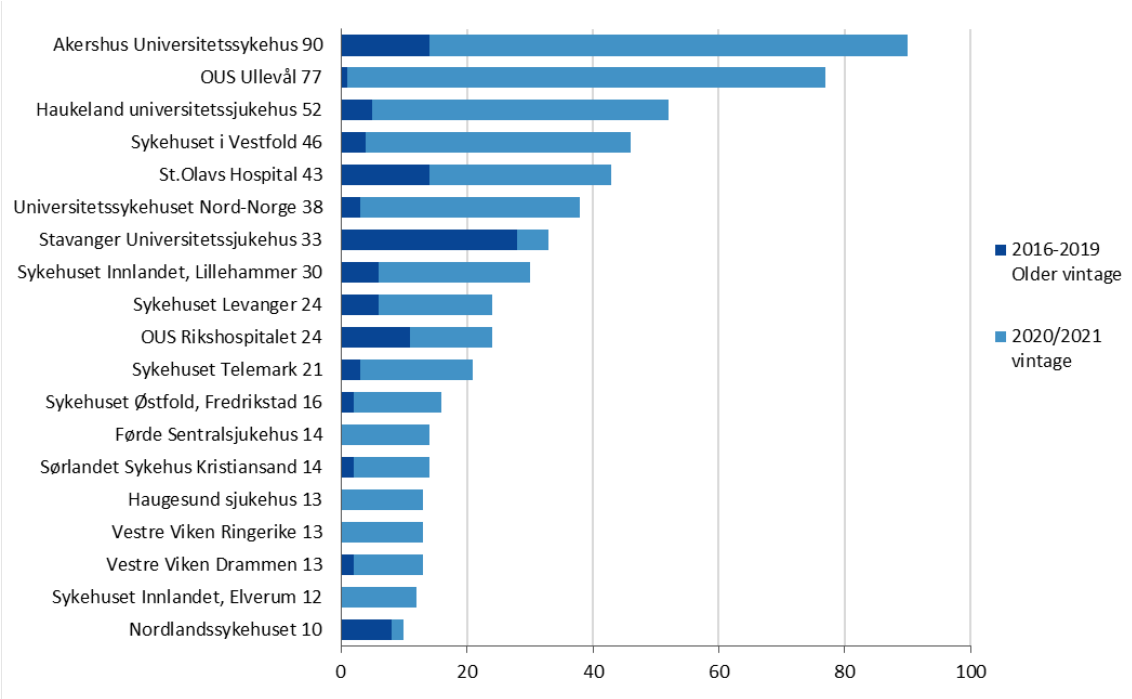
| | Helse Sør-Øst (N=372) | | Helse Vest (N=115) | | Helse Midt (N=77) | | Helse Nord (N=48) | | Totalt (N=612) | |
|---|---|---|---|---|---|---|---|---|---|---|
| | n | (%) | n | (%) | n | (%) | n | (%) | n | (%) |
| None | 307 | (82,5%) | 98 | (85,2 %) | 67 | (87,0 %) | 36 | (75,0 %) | 508 | (83,0 %) |
| Transfusion | 9 | (2,4 %) | 1 | (0,9 %) | 1 | (1,3 %) | 0 | (0,0 %) | 11 | (1,8 %) |
| Intervention | 4 | (1,1 %) | 1 | (0,9 %) | 1 | (1,3 %) | 0 | (0,0 %) | 6 | (1,0 %) |
| Other | 33 | (8,9 %) | 2 | (1,7 %) | 3 | (3,9 %) | 4 | (8,3 %) | 42 | (6,9 %) |
| Hematuria | 9 | (2,4 %) | 2 | (1,7 %) | 2 | (2,6 %) | 2 | (4,2 %) | 15 | (2,5 %) |
| Missing data | 25 | (6,7 %) | 12 | (10,4 %) | 4 | (5,2 %) | 6 | (12,5 %) | 47 | (7,7 %) |

It is possible to report more than one complication per procedure. Clinical data were reported for 612 kidney biopsies in 2020, and 83.0 % were reported without complications. Seventeen (2.8 %) serious complications from eleven different patients were reported to the registry in 2020; eleven blood transfusions and six intervention. There is great variation in the patient's age. Eight out of eleven patients had systolic blood pressure below 150 mmHg at the time of biopsy. Nine of the biopsies were performed with biopsy needle 18G, two with biopsy needle 16G, none with biopsy needle 14G. Fourty-two "other" complications were reported, most of which were related to subcapsular hematomas not requiring further action.

## Table 7. Procedure-related parameters

| | Helse Sør-Øst (N=372) | | Helse Vest (N=115) | | Helse Midt (N=77) | | Helse Nord (N=48) | | Totalt (N=612) | |
|---|---|---|---|---|---|---|---|---|---|---|
| | n | (%) | n | (%) | n | (%) | n | (%) | n | (%) |
| **Biopsy performed by** | | | | | | | | | | |
| Nephrologist | 4 | (1,1 %) | 71 | (61,7 %) | 0 | (0,0 %) | 0 | (0,0 %) | 75 | (12,3 %) |
| Radiologist | 359 | (96,5 %) | 34 | (29,6 %) | 75 | (97,4 %) | 46 | (95,8 %) | 514 | (84,0 %) |
| Other | 1 | (0,3 %) | 0 | (0,0 %) | 1 | (1,3 %) | 0 | (0,0 %) | 2 | (0,3 %) |
| Not reported | 8 | (2,2 %) | 10 | (8,7 %) | 1 | (1,3 %) | 2 | (4,2 %) | 21 | (3,4 %) |
| **Biopsy needle** | | | | | | | | | | |
| 14G | 0 | (0,0 %) | 5 | (4,3 %) | 0 | (0,0 %) | 0 | (0,0 %) | 5 | (0,8 %) |
| 16G | 14 | (3,8 %) | 86 | (74,8 %) | 65 | (84,4 %) | 34 | (70,8 %) | 199 | (32,5 %) |
| 18G | 326 | (87,6 %) | 14 | (12,2 %) | 4 | (5,2 %) | 5 | (10,4 %) | 349 | (57,0 %) |
| Unknown | 20 | (5,4 %) | 5 | (4,3 %) | 3 | (3,9 %) | 6 | (12,5 %) | 34 | (5,6 %) |
| Not reported | 12 | (3,2 %) | 5 | (4,3 %) | 5 | (6,5 %) | 3 | (6,3 %) | 25 | (4,1 %) |
| **No. of passes** | | | | | | | | | | |
| 1 | 34 | (9,1 %) | 19 | (16,5 %) | 2 | (2,6 %) | 0 | (0,0 %) | 55 | (9,0 %) |
| 2 | 168 | (45,2 %) | 58 | (50,4 %) | 44 | (57,1 %) | 18 | (37,5 %) | 288 | (47,1 %) |
| 3 | 96 | (25,8 %) | 21 | (18,3 %) | 11 | (14,3 %) | 20 | (41,7 %) | 148 | (24,2 %) |
| 4 or more | 53 | (14,2 %) | 3 | (2,6 %) | 9 | (11,7 %) | 5 | (10,4 %) | 70 | (11,4 %) |
| Not reported | 21 | (5,6 %) | 14 | (12,2 %) | 11 | (14,3 %) | 5 | (10,4 %) | 51 | (8,3 %) |
| **Level of care** | | | | | | | | | | |
| Out-patient | 33 | (8,9 %) | 12 | (10,4 %) | 5 | (6,5 %) | 0 | (0,0 %) | 50 | (8,2 %) |
| In-patient | 264 | (71,0 %) | 57 | (49,6 %) | 48 | (62,3 %) | 31 | (64,6 %) | 400 | (65,4 %) |
| Not reported | 75 | (20,2 %) | 46 | (40,0 %) | 24 | (31,2 %) | 17 | (35,4 %) | 162 | (26,5 %) |

## Figure 7. Number of clinical forms and vintage, per hospital in 2020



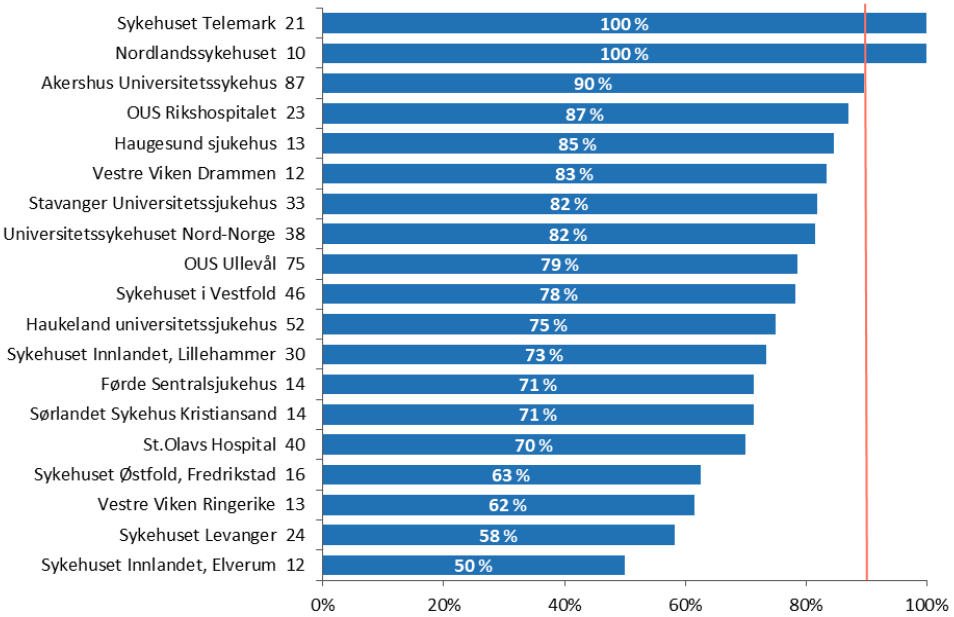

*Seven hospitals were excluded from the analysis, as they reported less than ten native kidney biopsies in 2020.*

The variables included on the clinical form used by the clinician to report kidney biopsies to the registry change over time. Of the 612 clinical forms reporting kidney biopsies for 2020 received by June 2021, 18 % were older vintage. Updated forms can be downloaded or printed from www.nephro.no.

## Percentage of kidney biopsies with 10 or more glomeruli

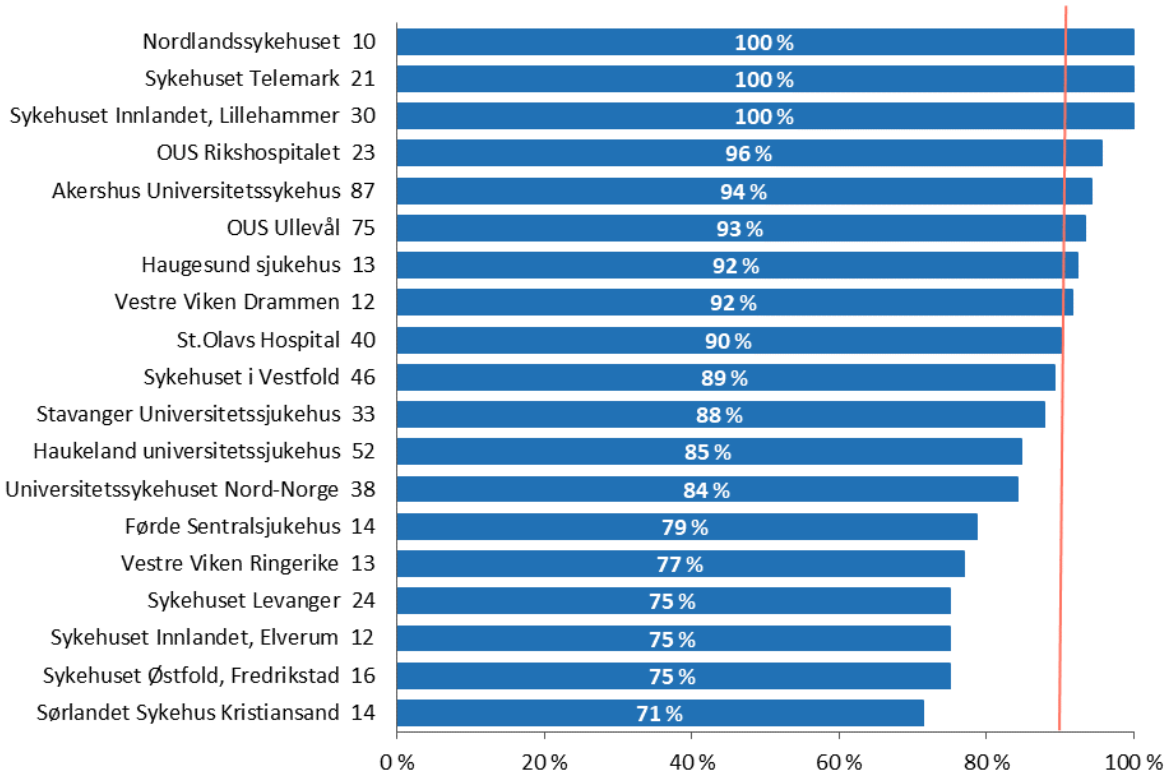
The kidneys consist of three compartments, which may be attacked by disease: the glomeruli, the tubules/interstitial tissue and the vasculature. A kidney biopsy is often necessary in order to investigate which compartment or compartments of the kidney are affected by disease and which kidney disease is responsible for the clinical picture observed. The normal kidney contains about 1 million glomeruli, which continuously filter the blood, producing pre-urine. Numerous diseases can affect the glomeruli. Here it is important to realize, that a disease may not affect all glomeruli and that the affected glomeruli 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, in order to detect changes and to be able to 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 number is the basis for the definition of the national quality indiciator "Number of glomeruli per biopsy": **At least 90% of biopsies taken at one nephrology center should contain 10 or more glomeruli.** 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. Three of 19 hospitals reported 10 or more glomeruli in 90% or more of the kidney biopsies (figure 8). The national average number of glomeruli in 2020 is 17.2 per kidney biopsy.

**Figure 8. Percent biopsies with 10 or more glomeruli by hospital in 2020**




*The number behind the hospital name is the number of non-neoplastic kidney biopsies per year. The calculation is based on the number of glomeruli in the paraffin embedded biopsy tissue. Only hospitals with 10 or more non-neoplastic kidney biopsies are shown. Red line indicates quality indicator goal*

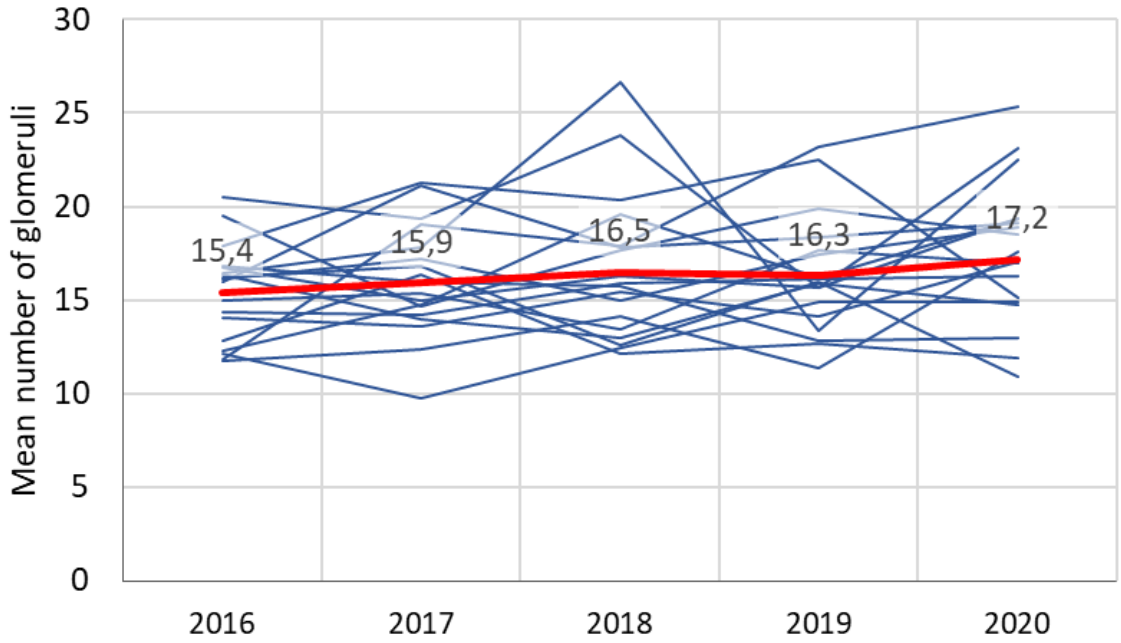
**Figure 9. Percent biopsies with 10 or more glomeruli by hospital in 2020 based on all material from a kidney biopsy**




*The number behind the hospital name is the number of non-neoplastic kidney biopsies per year. The calculation is based on the number of glomeruli both in the paraffin embedded biopsy tissue, the frozen tissue for immunofluorescence (only few departments) and the tissue processed to electron microscopy. Only hospitals with 10 or more non-neoplastic kidney biopsies are shown. Red line indicates quality indicator goal.*

Figure 8 shows the number of glomeruli in paraffin embedded material prepared for light microscopy. An alternative assessment of the number of glomeruli is the inclusion of all material from a kidney biopsy, taking in also material prepared for electron microscopy and immunofluorescence (figure 9). If applying this assessment method, nine hospitals achieved 10 or more glomeruli per biopsy in 90% of cases

**Figure 10. Mean number of glomeruli from 2016 – 2020.**




*Mean number of glomeruli from 2016 – 2020.* Blue lines represent the hospitals and the red line represent the mean number of glomeruli of all biopsies taken.

Figure 10 shows the trend of mean number of glomeruli over time from 2016 to 2020. Overall, there is a positive trend with a slight increase in the number of glomeruli per kidney biopsy.

## Number of primary kidney biopsies with moderate to severe chronic changes

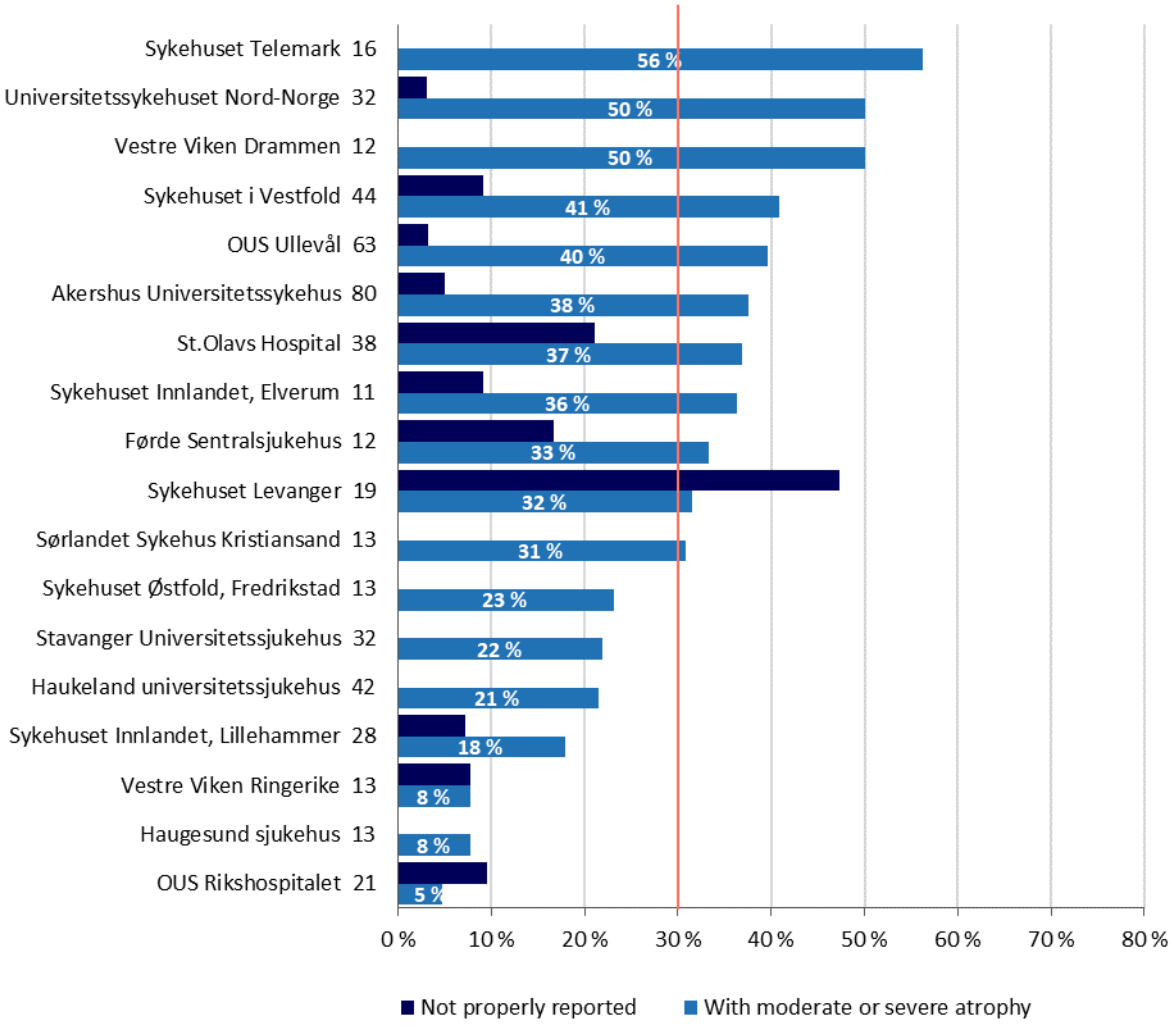
Chronic changes in the kidney are persistent and irreversible. A high proportion of chronic changes in the biopsy indicates a high risk of loss of kidney function. A high proportion of chronic changes may also indicate that treatment cannot achieve stabilization or improvement in kidney function. It is therefore important to diagnose kidney disease early on in the disease process, before the disease manifestations result in chronic, irreversible changes.

Tubular atrophy is a hallmark of chronic kidney changes. Moderate to pronounced tubular atrophy indicates that the biopsy was taken late in the course of the disease implying that the patient was late in seeing a doctor or that the investigation process was not optimal.

The proportion of biopsies with moderate or severe tubular atrophy is calculated by dividing the number of biopsies showing moderate or pronounced tubular atrophy by the total number of biopsies at the center. Some patients have multiple kidney biopsies. For the calculation, only the first biopsy taken from a patient is used.

The national quality indicator “Grade of chronic changes” expects that less than 30% of biopsies from one center should have moderate of severe tubular atrophy.

**Figure 11. Percent biopsies with moderate or severe tubular atrophy and biopsies without proper registration of tubular atrophy by hospital in 2020.**




*Light blue bars represent percent biopsies with moderate or severe tubular atrophy by hospital. Dark blue bars represent percent biopsies without proper registration of tubular atrophy by hospital. The number behind the hospital name is the number of primary non-neoplastic kidney biopsies per year. Only hospitals with 10 or more non-neoplastic kidney biopsies are shown. Red line indicates quality indicator goal.*

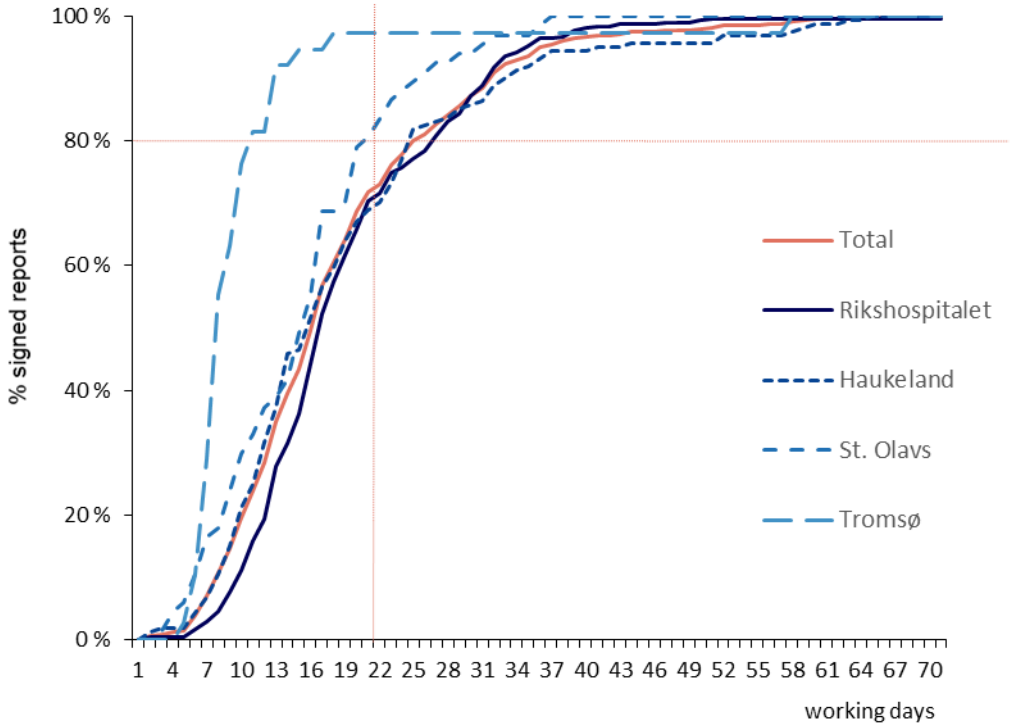
Figure 11 shows two important aspects related to chronic changes in kidney biopsies. First, about half of the hospitals do show a significant number of biopsies with moderate or severe tubular atrophy. Second, some of the pathology reports do not show a proper registration of tubular atrophy. Tubular atrophy is either mentioned in the report, but not semiquantitatively assessed, or tubular atrophy is not mentioned at all. In the latter case it is uncertain if tubular atrophy is absent, or if the data has been missed. In the light of these findings, low percentage of biopsies with moderate or severe tubular atrophy in hospitals with a high percentage of not properly registered tubular atrophy should be considered with caution.

## Turnaround time pathology departments

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 in particular is 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 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 after electron microscopy.

Two pathology departments met the quality standard of a final diagnostic report in 80 % of the cases within 21 working days (one month) (figure 12).

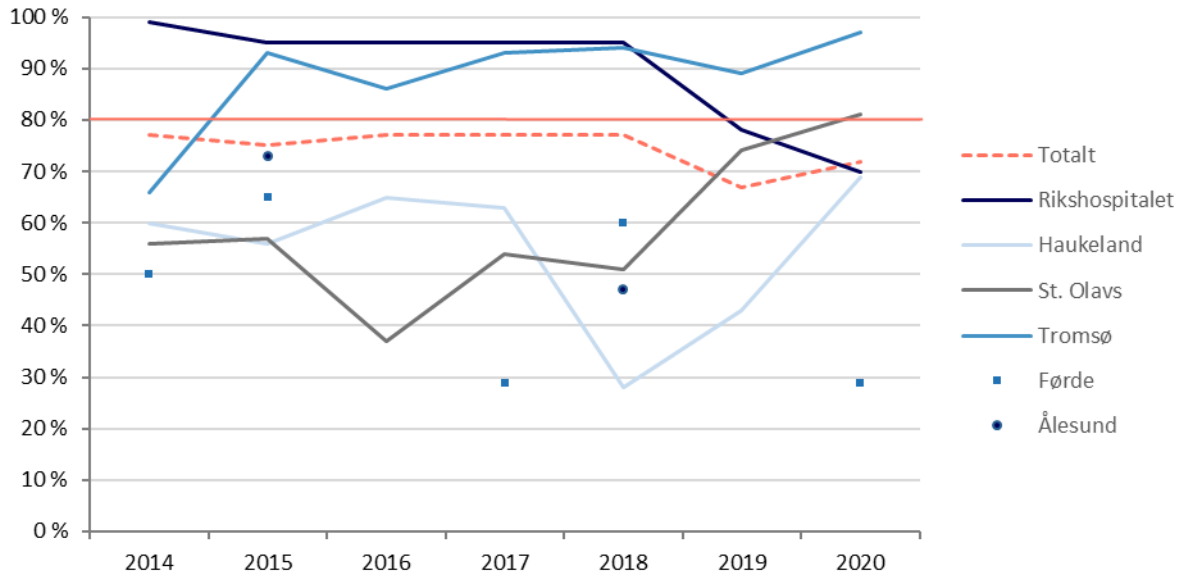
**Figure 12. Percent kidney biopsies finally reported within 21 working days, total and by pathology department in 2020.**




*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.*

Looking at turnaround times with a long-term perspective, there is a slightly negative trend for all pathology departments taken together (figure 13). Generally, the goal of having reported 80% of biopsies within 21 working days is not achieved in the period 2014 – 2020. Times vary both between and within pathology departments. Some pathology departments have either constantly good turn-around times or show a positive trend in the last years, whereas there is a negative trend the last 2 years for one pathology department.

**Figure 13. Percent kidney biopsies finally reported within 21 working days, total and by pathology department from 2014 – 2020.**




*The solid red line indicates the quality indicator goal. Some of the percentages for Førde and Ålesund are not included due to small number of kidney biopsies.*

The turnaround time does not seem to be correlated with the number of biopsies per pathology department when comparing results from figure 5 and 6 with the number of biopsies per pathology department (table 8). Factors such as staffing and various routines at the pathology departments

probably affect turnaround times.

**Table 8. Number of kidney biopsies per department 2014 – 2020.**

| | 2014 | 2015 | 2016 | 2017 | 2018 | 2019 | 2020 |
|---|---|---|---|---|---|---|---|
| **Rikshospitalet** | 277 | 255 | 243 | 223 | 279 | 252 | 314 |
| **Haukeland** | 219 | 234 | 186 | 197 | 191 | 186 | 161 |
| **St. Olavs** | 78 | 53 | 57 | 39 | 53 | 50 | 67 |
| **Tromsø** | 32 | 27 | 35 | 27 | 36 | 47 | 38 |
| **Førde** | 12 | 17 | 6 | 17 | 10 | 5 | 14 |
| **Ålesund** | 9 | 15 | 5 | 8 | 15 | 5 | 7 |
| **Totalt** | 627 | 601 | 532 | 511 | 584 | 545 | 601 |

One confounding factor is the percentage of electron microscopic (EM) investigations carried out by pathology departments (table 9). Three pathology departments show a constant high percentage of EM investigations whereas the fourth department shows a lower rate. As an EM investigation takes time, a lower rate of EM investigations will reduce the turnaround time.

**Table 9. Percentage of electron microscopic investigations per pathology department per year.**

| | 2016 | 2017 | 2018 | 2019 | 2020 | 2021 |
|---|---|---|---|---|---|---|
| **Rikshospitalet** | 94 | 94 | 96 | 94 | 95 | 97 |
| **Haukeland** | 90 | 89 | 83 | 92 | 88 | 80 |
| **St. Olavs** | 71 | 70 | 88 | 76 | 73 | 63 |
| **Tromsø** | 100 | 100 | 97 | 94 | 89 | 100 |

In conclusion, the results show that there is an overall potential for improvement in terms of turn-around time for most of the pathology departments reporting kidney biopsies. Follow-up examinations should look at the causes for both positive and negative trends.

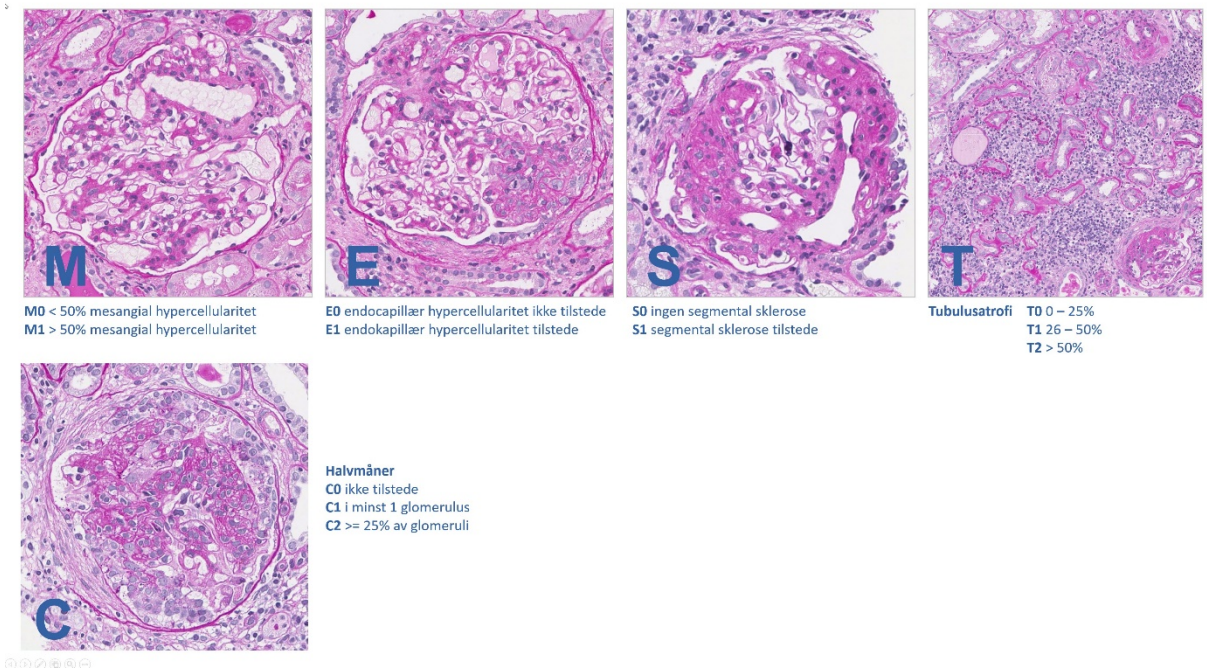
## Oxford classification of IgA nephropathy

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 (Figure …):

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

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

**Figure 14**: Morphologic changes included in the MEST score /Oxford classification of IgA nephropathy




The Oxford classification gives information on how «active» and/or "chronic" an IgA nephropathy is. The higher the M (mesangial hypercellularity), E (endocapillary

hypercellularity) and C (crescents) scores are, the more active the disease process is. Segmental sclerosis (S) and tubular atrophy (T) scores give information on chronic, irreversible changes.

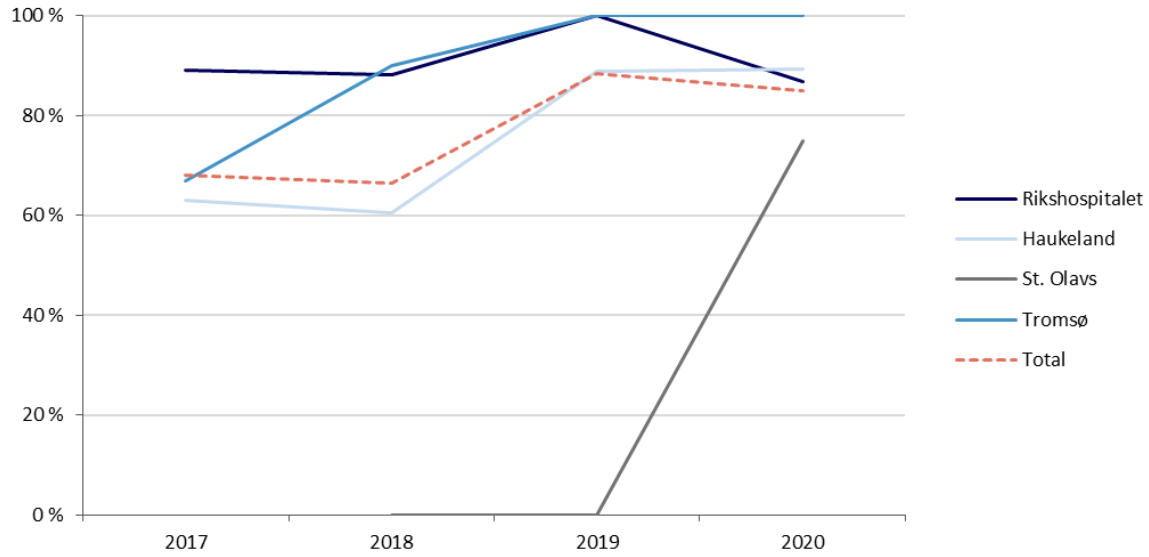
The scoring model is of value in the clinical setting, and Norwegian pathologists have therefore started scoring IgA nephropathies according to this model. The registry has investigated to which degree pathology departments have implemented the Oxford classification of IgA nephropathy (Table 10). In 2020, four of six pathology departments have implemented the scoring system to varying degrees. 3 of 4 pathology departments show high reporting rates whereas the remaining department shows a slightly lower reporting rate. In cases with less than 8 glomeruli scoring according to the Oxford classification is not recommended. Thus, a 100% reporting rate is not expected.

**Table 10. Total number of kidney biopsies and number of IgA nephropathies with Oxford classification, per pathology department in 2020.**
The total number of kidney biopsies is based on reported biopsy forms (N=602).

| Pathology department | No. Of kidney biopsies | No. of IgA nephropathies | % IgA nephropathies | No. of reports with Oxford classification | % reports with Oxford classification |
|---|---|---|---|---|---|
| Rikshospitalet | 314 | 53 | 17 % | 46 | **87 %** |
| Haukeland | 162 | 28 | 17 % | 25 | **89 %** |
| Førde | 14 | 1 | 7 % | 0 | **0 %** |
| Ålesund | 7 | 2 | 29 % | 0 | **0 %** |
| St. Olavs | 67 | 12 | 18 % | 9 | **75 %** |
| Tromsø | 38 | 11 | 29 % | 11 | **100 %** |
| Total | 602 | 107 | 18 % | 91 | **85 %** |

As figure 14 shows, the rate of reports that include the Oxford classification has steadily increased over the years. The rate seems to be stabilizing at a high level.

**Figure 15. Percentages IgA biopsies with Oxford classification per pathology department in 2017 - 2020**




*Only pathology departments with five or more biopsies diagnosed with IgA is included in the table.*

If we look at the distribution of the individual scores by department, different patterns become visible (table 11). To give an example: the rate of biopsies with endocapillary hypercellularity (E1) differs considerably between departments. While one hospital scores E1 in only 4% of its biopsies, the score E1 is given in about 50% of the biopsies in two other hospitals.

**Table 11. Oxford classification MEST in 2020.**

| Category | M | | E | | S | | T | | | C | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Score** | **0** | **1** | **0** | **1** | **0** | **1** | **0** | **1** | **2** | **0** | **1** | **2** |
| Rikshospitalet | 65 % | 35 % | 96 % | 4 % | 22 % | 78 % | 72 % | 17 % | 11 % | 67 % | 28 % | 4 % |
| Haukeland | 36 % | 64 % | 76 % | 24 % | 24 % | 76 % | 44 % | 48 % | 8 % | 44 % | 52 % | 4 % |
| St. Olavs | 33 % | 67 % | 44 % | 56 % | 33 % | 67 % | 33 % | 56 % | 11 % | 89 % | 11 % | 0 % |
| Tromsø | 36 % | 55 % | 36 % | 55 % | 73 % | 27 % | 18 % | 55 % | 27 % | 64 % | 27 % | 0 % |
| **Total** | **51 %** | **48 %** | **78 %** | **21 %** | **30 %** | **70 %** | **54 %** | **34 %** | **12 %** | **63 %** | **33 %** | **3 %** |

Table 11 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

## Table 12. Overview over diagnoses by pathology departments in 2020.

| | All | Rikshospitalet | Haukeland | St. Olavs | Tromsø | Førde | Ålesund |
|---|---|---|---|---|---|---|---|
| Minimal change nephropathy | 32 | 17 | 11 | 1 | 3 | 0 | 0 |
| FSGS[1] primary | 14 | 4 | 6 | 2 | 2 | 0 | 0 |
| FSGS secondary | 5 | 3 | 2 | 0 | 0 | 0 | 0 |
| Membranous GN[2] | 30 | 21 | 4 | 2 | 3 | 0 | 0 |
| IgA nephropathy | 107 | 53 | 28 | 12 | 11 | 1 | 2 |
| Mesangioprol. GN without IgA | 10 | 6 | 3 | 0 | 0 | 1 | 0 |
| Endokapillary prol. GN | 4 | 2 | 2 | 0 | 0 | 0 | 0 |
| Membranoproliferativd GN | 15 | 9 | 2 | 1 | 2 | 1 | 0 |
| ANCA associated GN | 46 | 17 | 20 | 6 | 3 | 0 | 0 |
| Anti-GBM nephritis | 3 | 1 | 1 | 0 | 1 | 0 | 0 |
| GN with crescents not ANCA | 5 | 2 | 1 | 2 | 0 | 0 | 0 |
| HSP[3] | 3 | 1 | 1 | 1 | 0 | 0 | 0 |
| Lupus nephritis - I | 1 | 1 | 0 | 0 | 0 | 0 | 0 |
| Lupus nephritis - II | 4 | 4 | 0 | 0 | 0 | 0 | 0 |
| Lupus nephritis - III | 3 | 2 | 1 | 0 | 0 | 0 | 0 |
| Lupus nephritis - IV | 7 | 2 | 4 | 1 | 0 | 0 | 0 |
| Lupus nephritis - V | 2 | 0 | 1 | 1 | 0 | 0 | 0 |
| Lupus nephritis - VI | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Lupus nephritis - not classified | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Diffuse proliferative GN | 1 | 1 | 0 | 0 | 0 | 0 | 0 |
| Dense deposit disease | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Fibrillary glomerulopathy | 3 | 1 | 1 | 1 | 0 | 0 | 0 |
| Immunotactoid GP[4] | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Cryoglobulinemia | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Pre-eclampsia-ass. GN | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Sclerosing GN | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| GN unclassified | 7 | 1 | 3 | 1 | 1 | 1 | 0 |
| Alport syndrome | 4 | 4 | 0 | 0 | 0 | 0 | 0 |
| Thin basement membrane GP | 11 | 5 | 2 | 2 | 2 | 0 | 0 |
| Fabry's disease | 8 | 3 | 5 | 0 | 0 | 0 | 0 |
| Other hereditary diseases | 1 | 1 | 0 | 0 | 0 | 0 | 0 |
| Diabetic nephropathy | 42 | 27 | 9 | 5 | 1 | 0 | 0 |
| Benign nephrosclerosis | 39 | 22 | 10 | 4 | 1 | 1 | 1 |
| Malign nephrosclerosis | 4 | 4 | 0 | 0 | 0 | 0 | 0 |
| Cholesterolemboli | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Vasculitis other | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| TMA[5] | 5 | 3 | 1 | 0 | 1 | 0 | 0 |
| TMA - atypical HUS[6] | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Scleroderma | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Amyloidosis not classified | 2 | 0 | 1 | 1 | 0 | 0 | 0 |
| Amyloidosis - AA | 9 | 8 | 0 | 0 | 1 | 0 | 0 |
| Amyloidosis - AL | 13 | 5 | 4 | 2 | 2 | 0 | 0 |
| Amyloidosis other | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Myeloma kidney | 10 | 6 | 3 | 1 | 0 | 0 | 0 |
| Ig[7] deposition disease | 2 | 1 | 0 | 0 | 0 | 0 | 1 |
| ATN[8] | 12 | 10 | 1 | 1 | 0 | 0 | 0 |
| Acute interstitial nephritis | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Tubulointerstitial nephritis | 48 | 26 | 10 | 5 | 2 | 4 | 1 |
| Granulomatous TIN[9] / Sarc. | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| TIN - drug associated | 2 | 0 | 2 | 0 | 0 | 0 | 0 |
| Lithium nephropathy | 2 | 2 | 0 | 0 | 0 | 0 | 0 |
| Phosphate nephropathy | 1 | 0 | 0 | 1 | 0 | 0 | 0 |
| Oxalate nephropathy | 3 | 2 | 0 | 0 | 0 | 1 | 0 |
| TIN with uveitis | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| TIN aminoglycosides ass. | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| TIN autoimmune disease ass. | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| TIN cisplatin ass. | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| TIN hantavirus infection | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Calcineurin inhibitor toxicity | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Normal | 21 | 9 | 5 | 6 | 0 | 1 | 0 |
| Uncharacteristic atrophy | 26 | 16 | 2 | 5 | 0 | 1 | 2 |
| End stage kidney | 2 | 2 | 0 | 0 | 0 | 0 | 0 |
| No code - free text | 9 | 2 | 5 | 1 | 1 | 0 | 0 |
| Not representative | 24 | 8 | 11 | 2 | 1 | 2 | 0 |
| | | | 21 | | | | |
| All | 602 | 314 | 162 | 67 | 38 | 14 | 7 |

## 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 are male (71.3%) and median age at time of entering CKD5 stage was 70.4 years (mean 67.1 years), ranging from 6.1 to 96.3 years. Patients had been known at the nephrology unit in 88% of the cases and a total of 80% were considered as RRT candidates and 11% were definitely not candidates for RRT treatment (9% unsure/missing status). The main reason for not being RRT candidate was comorbidity. A selection of clinical chemistry values and drugs used by patients entering the CKD5 stage in 2020 are shown in **Table 13**.

**Table 13. Status at first time reported as CKD5 (without RRT) in 2020**

| | **Total (n:329)** |
|---|---|
| eGFR (CKD-EPI, mean) [mL/min/1.73m$^2$] | 12 |
| eGFR (CKD-EPI) - % <15 mL/min/1.73m$^2$ | 95% |
| Creatinine (mean) [µmol/L] | 418 |
| Albumin (mean) [g/L] | 39 |
| Haemoglobin (mean) [g/dL] | 11.2 |
| Haemoglobin - % with <10 g/dL | 19 % |
| Proteinuria (ACR>3 and/or PCR>15) | 89 % |
| ESA use | 29 % |
| Active D vitamin use | 51 % |
| Statin use | 63 % |
| Not on antihypertensive drugs | 4 % |
| Using ACEi/ARB | 44 % |
| Using ≥3 antihypertensive drugs | 55 % |

Hypertension was the main cause of renal failure, still continuing to decrease in relation to other causes, with 39% of the patients having this as their main diagnosis. Diabetes was the primary diagnosis in 16% of the patients. Including diabetes as comorbidity, a total of 35% patients was diabetic (93% Type II diabetes mellitus) and they had had the diagnosis for a median of 17 years at time of entering the CKD5 stage.

For patients starting RRT during 2020 the median (range) time in the CKD5 stage was 12.7 (0 to 129) months. During 2020, 67 patients in this stage died, 46% of these were considered candidates for RRT when entering the CKD5 stage.

## CKD5 in RRT (Dialysis or Transplantation)

A majority of the patients are male (67.8 %) and median age at start of RRT was 66.0 years mean 62.2 years), ranging from 1.9 to 89.8 years. At time of start of dialysis 40 % were assessed by the treating physician to be a Tx-candidate. Of the patients starting hemodialysis and that had been know at the treating center for at least 4 months 40 % started dialysis using an AV-fistula as blood access, a stable level the last 10 years. A selection of clinical chemistry values and drugs used in patients starting RRT in 2020 are shown in **Table 14**.

**Table 14. Status at start of RRT in 2020**

| | **Total (n:537)** | **HD (n:338)** | **PD (n:145)** | **Preempt. Tx (n:54)** |
|---|---|---|---|---|
| Age (mean) [years] | 62.2 | 62.6 | 65.5 | 52.1 |
| Male sex | 68% | 67% | 71% | 67% |
| Creatinine (mean) [µmol/L] | 661 | 692 | 641 | 475 |
| Albumin (mean) [g/L] | 38 | 35 | 43 | 43 |
| Hemoglobin (mean) [g/dL] | 10.0 | 9.7 | 10.5 | 10.7 |
| Hemoglobin - % <10 g/dL | 51 % | 59 % | 34 % | 48 % |
| ESA use | 53 % | 53 % | 61 % | 31 % |
| Active D vitamin use | 62 % | 61 % | 67 % | 56 % |
| Statin use | 54 % | 54 % | 61 % | 33 % |
| Not on antihypertensive drugs | 8 % | 9 % | 3 % | 15 % |
| Using ACEi/ARB | 36 % | 37 % | 33 % | 41 % |
| Using ≥3 antihypert. drugs | 53 % | 53 % | 62 % | 24 % |

As might be anticipated, pre-emptively transplanted patients had a somewhat lower serum creatinine, thus higher renal function, and a higher hemoglobin than those starting dialysis. Control over hemoglobin levels in preemptive transplants is suddenly worse than previous years. Overall, the percentage of patients with a level below 10 g/dL increased from 16%, a stable level for many years, to 48% in 2020. Also, among patients known less than four months there was an increase, from 63% in 2019 to 73 % in 2020.
The use of statins in patients receiving a preemptive transplant continued on a decreasing trend; from 60% in 2016 to 41% in 2019 and now 33% in 2020.

In Figure 16 to 19 below the annual incidence of new patients in RRT by first treatment modality, age and if they are considered as Tx-candidates by the local treating physician is presented.

**Figure 16:**

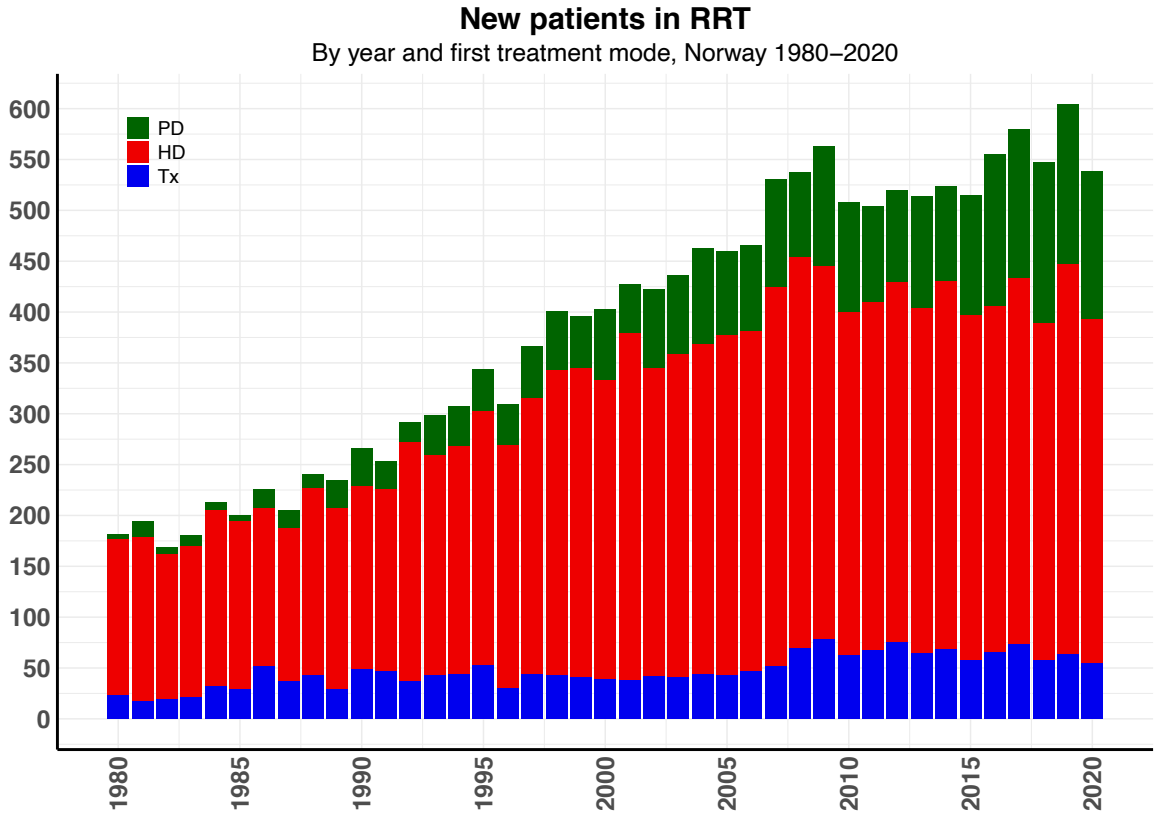



**Figure 17:**

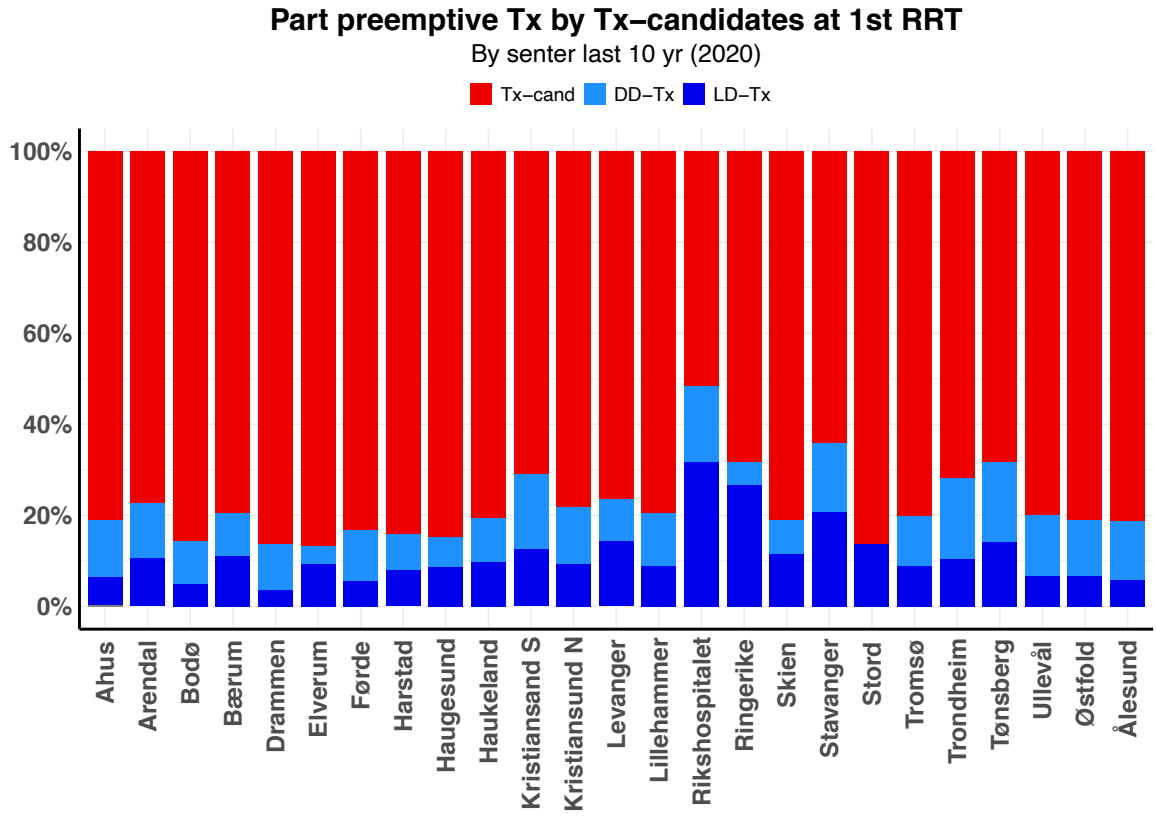


**Figure 18:**

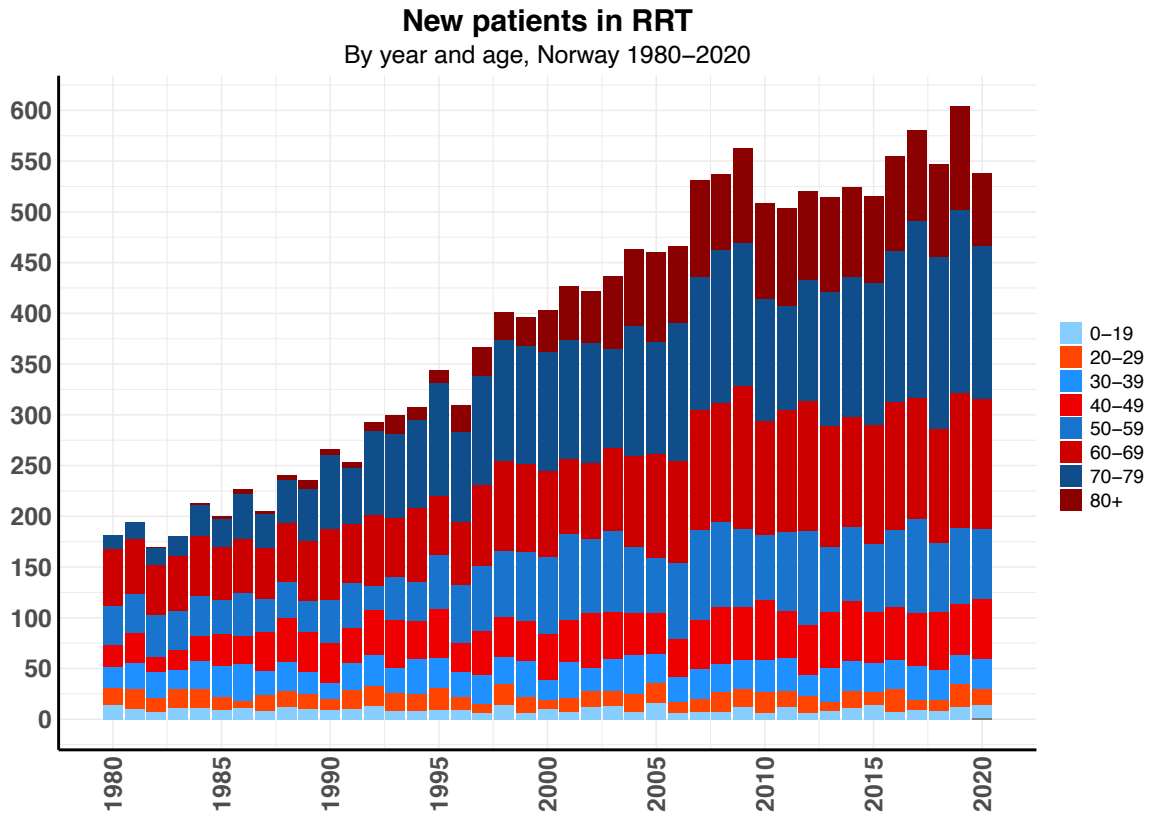
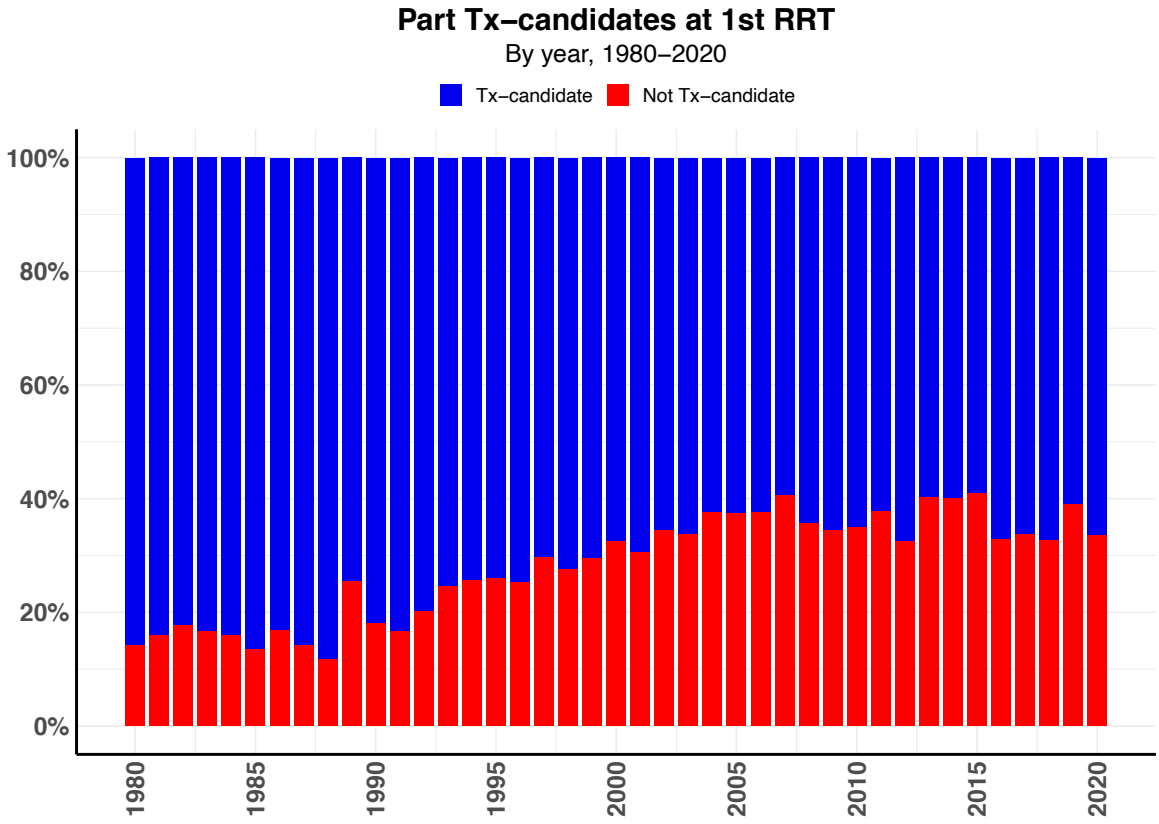



**Figure 19:**



Since registration started in 1980 there has been a continuous shift in patient age. (Figure 20) 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, younger children have been accepted; the youngest ever started PD in 2011 at age two days. Ten children below 16 years started RRT in 2020; transplantation (n=4), HD (n=3) and PD (n=3).

**Figure 20:**

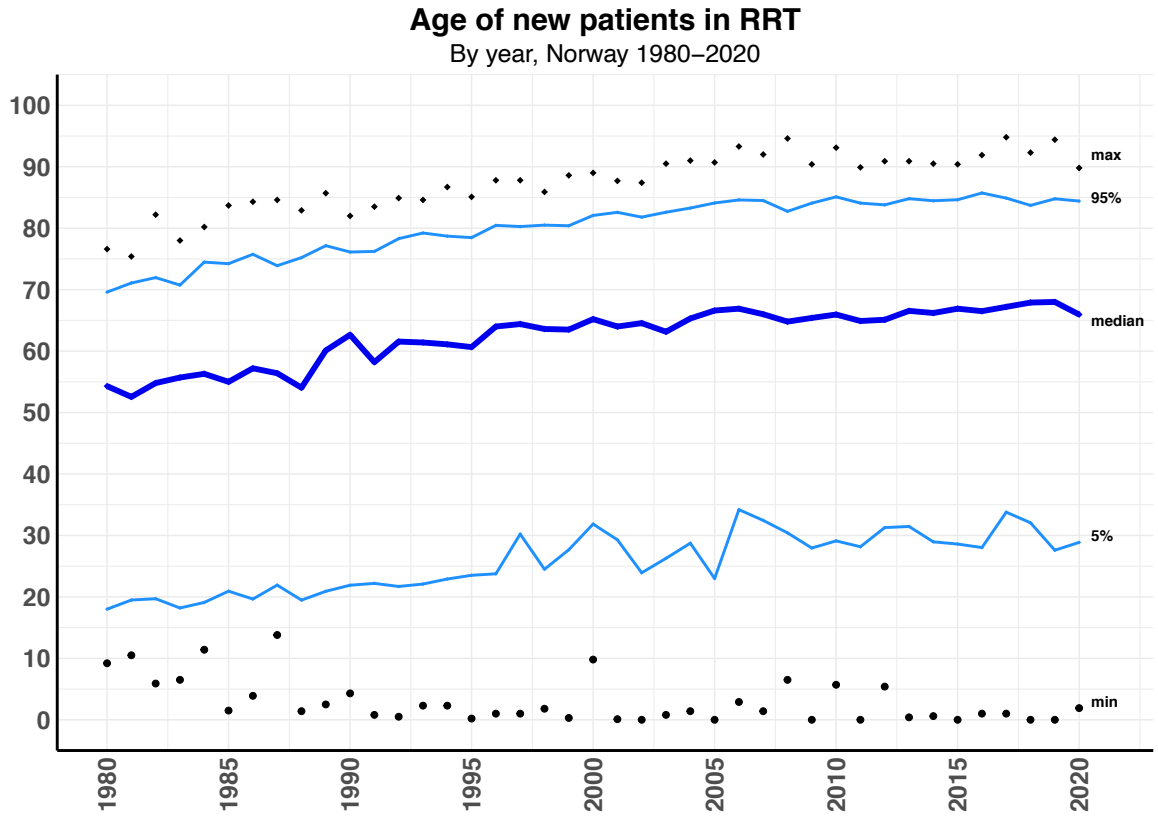



**Table 15. Primary renal disease at start of RRT**

| | 1980-89 | 1990-99 | 2000-04 | 2005-09 | 2010-14 | 2015-19 | *2020* |
|---|---|---|---|---|---|---|---|
| Glomerulonephritis | 35% | 27% | 18% | 18% | 16% | 15% | *18%* |
| Pyelo/interstitial nephr. | 15% | 11% | 11% | 10% | 9% | 8% | *7%* |
| Polycystic diseases | 10% | 9% | 9% | 8% | 7% | 9% | *9%* |
| Diabetic nephropathy | 13% | 11% | 15% | 16% | 17% | 17% | *17%* |
| Amyloidosis | 6% | 5% | 3% | 2% | 3% | 2% | *2%* |
| Vascular/hypertensive | 7% | 21% | 28% | 31% | 32% | 32% | *32%* |
| Immune/systemic | 5% | 5% | 4% | 4% | 4% | 4% | *4%* |
| Kidney tumor | 1% | 1% | 1% | 2% | 1% | 1% | *1%* |
| Myelomatosis | 2% | 2% | 3% | 3% | 2% | 2% | *1%* |
| Other defined | 4% | 4% | 3% | 4% | 7% | 7% | *7%* |
| Unknown | 3% | 3% | 4% | 4% | 2% | 3% | *2%* |
| N: | 2018 | 3234 | 2151 | 2557 | 2570 | 2801 | *537* |

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** has stabilized on a higher levels as primary diagnosis cause for renal disease the last decade. In 2020, 26% of these were registered as having Type I diabetes mellitus. Including also patients with other primary diagnoses of renal disease a total of 183 patients were recorded as having diabetes mellitus at start of RRT (15% Type I), thus 34 % 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 35 years, while for the patients with Type II diabetic nephropathy the median time was 17 years.

**Cardiovascular disease** is often present at start of RRT. Coronary heart disease was reported in 25% and 18% had anamnestic heart failure. Echo-verified left ventricular hypertrophy was reported in 25%. Cerebrovascular disease was reported in 12% and peripheral atherosclerotic disease in 10% while 12% had chronic obstructive lung disease.

## Prevalence data CKD5 by December 31st 2020.

The national coverage of CKD5 patients not in RRT is in the range of 56% to 85%. The registry is currently performing a coverage analysis in cooperation with the Norwegian Patient Registry (NPR). The reported data on CKD5 patients not in RRT should hence be interpreted with caution.

There were 515 CKD5 patients in the registry that did not receive renal replacement therapy by the end of 2020 (507 in 2019). The median length of stay in this category, before being initiated in RRT during 2020 was 13 months, ranging from 0 to 129 months. In total 351 (58%) of those starting RRT during 2020 had not been included in the registry before RRT start; 62% of those starting in HD, 50% of those starting in PD and also 51%of those being preemptively transplanted. This underlines that there is a significant underreporting of patients to the registry when they enter in CKD5.

## Prevalence data RRT by December 31st 2020.

By the end of 2020, 5,450 patients in Norway received renal replacement therapy, i.e. 1,014.5 per million inhabitants. This represents an increase of 94 patients or 1.8 % since 2019, similar as the year before.

Median age by the end of the year was 62.2 years, mean 60.2 years and range 2.5 to 98.4 years. Gender: 64.3 % males.

**Table 16. Age distribution in prevalent patients by December 31st 2020**

| | Total (n:5,450) | HD (n:1,347) | PD (n:415) | Tx (n:3,688) |
|---|---|---|---|---|
| Age (mean) [years] | 62.2 | 65.7 | 66.3 | 57.4 |
| Age (median) [years] | 60.2 | 68.5 | 70.2 | 59.2 |
| Age (minimum) [years] | 2.5 | 6.3 | 2.5 | 2.5 |
| Age (maximum) [years] | 98.4 | 95.4 | 90.5 | 98.4 |

Figures 21 and 22 show prevalence per treatment modality, development over time and by center in 2020

**Figure 21:**

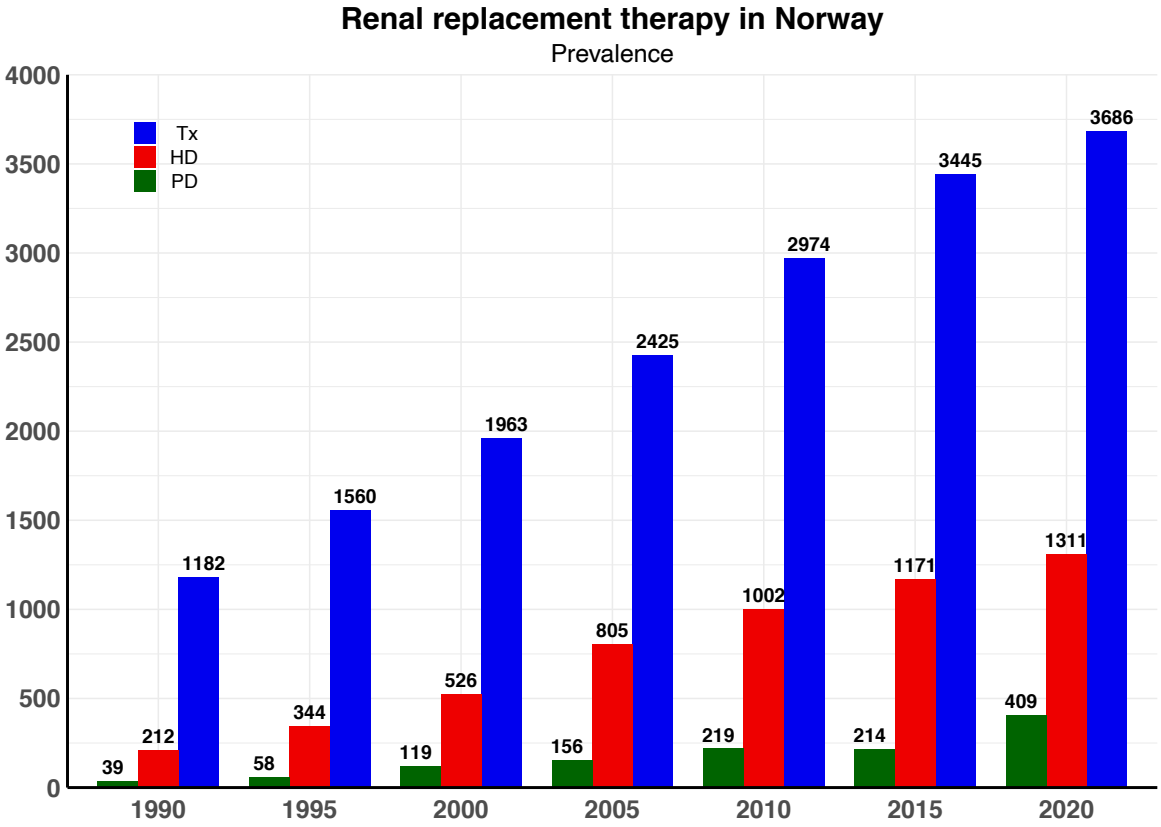
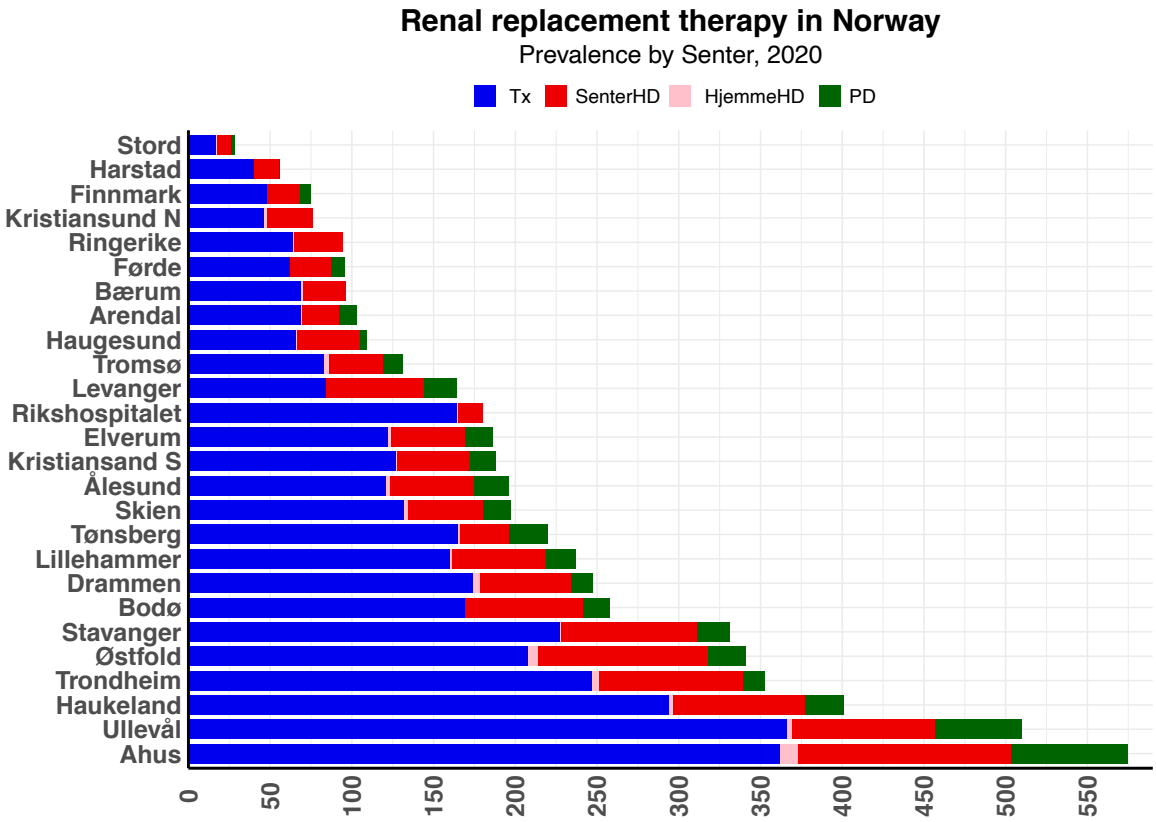


**Figure 22:**




## New annual variables in the registry:

In case of patients not using AV-fistula as blood access when starting RRT as a Hemodialysis patient, information about the reason for not having an AV-fistula was collected in the 2020 annual data. This information was also prospectively assessed for new patients in 2021 as part of a quality project.

## Transplantations and patients listed for transplantation:

A total of 240 renal transplants were performed in Norway in 2020, i.e. 44.7 per million inhabitants, 17% were retransplantations. Preemptive transplantation was performed in 22% of all first transplantations in 2020. The144 non-preemptive, first transplant recipients had been in dialysis for a median of 1.9 years (mean 2.4 years), ranging from 8 days to 11.5 years. 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 5 patients and simultaneous liver and kidney transplantation in 4 patients and simultaneous kidney and lung in one patient.

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 111 first-DD-graft recipients in 2020 ranged from 13 to 80 years, with a median age of 58 years. Out of these, 34% were above the age of 65 and 5 % were 75 or older. The 29 recipients of a first LD-graft were from 2.5 to 73 years, with a median age of 38 years. Regraft recipients, LD and DD (n=41), were from 33 to 68 years, median 53 years.

The list of patients actively waiting for a kidney transplant at entry into 2020 consisted of 364 patients and at the end of 2020 it has increased to 410 patients. Including those temporarily not on the list, the total number of patients waiting for a kidney in 2020 is 535, an increase from 505 by end of 2019 (459 end of 2017).

### Fun-facts Transplantation:

The oldest kidney transplant recipient ever was 84.1 year at time of transplantation (youngest 9.5 months). In total 967 recipients have been transplanted at an age older than 70 years, 43 older than 80 years. The oldest kidney transplant recipient became 93.8 years and the now living oldest recipient is 91.8 years. In total 13 patients have become older than 90 years (2 now living) and 589 reached an age over 80 years (157 now living).

The longest graft survival is 51.3 years, and still functioning. In total 46 (26 still working) grafts have functioned in a new body for over 40 years. The oldest transplanted kidney ever is 109.7 years and it is still working. In total 12 (5 still working) transplanted kidneys have reached a total age of over 100 years and 90 (42) over 90 years. As a comparison, in total 18 person in Norway have reached an age of over 110 years (none still living).

**Figure 23:**

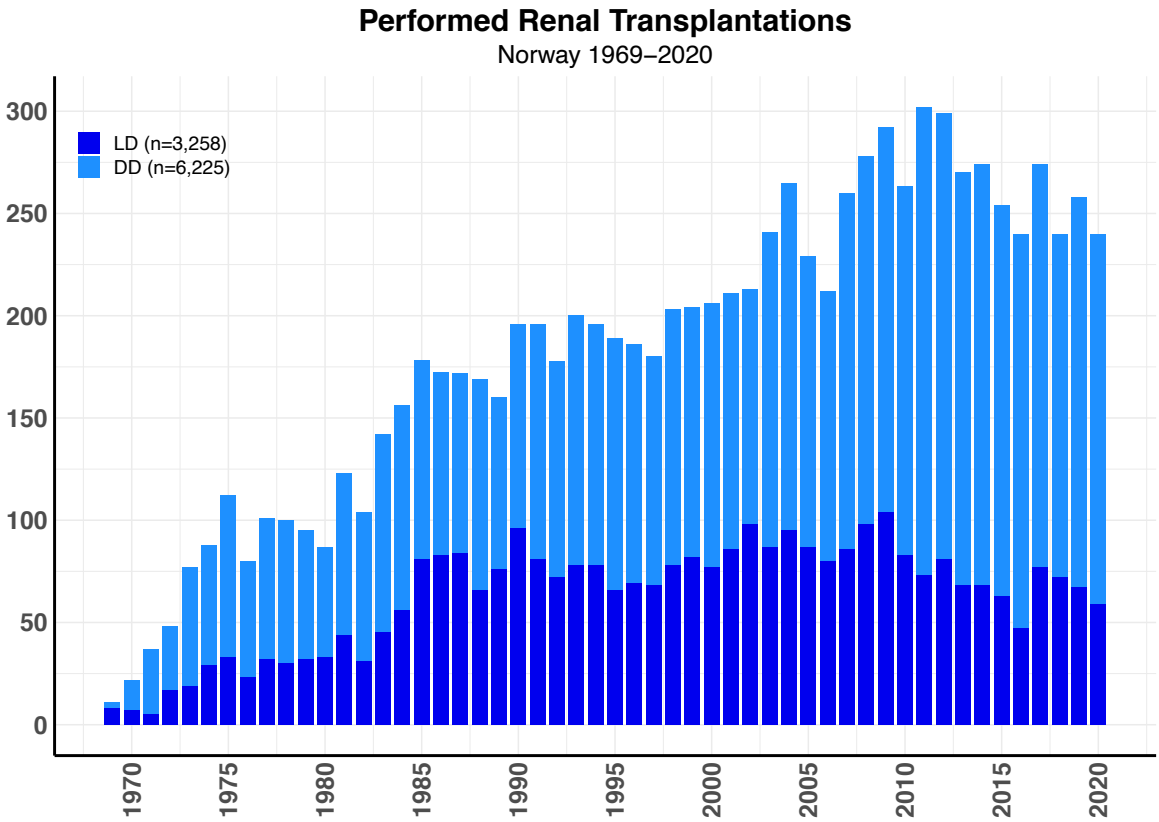



**Figure 24:**

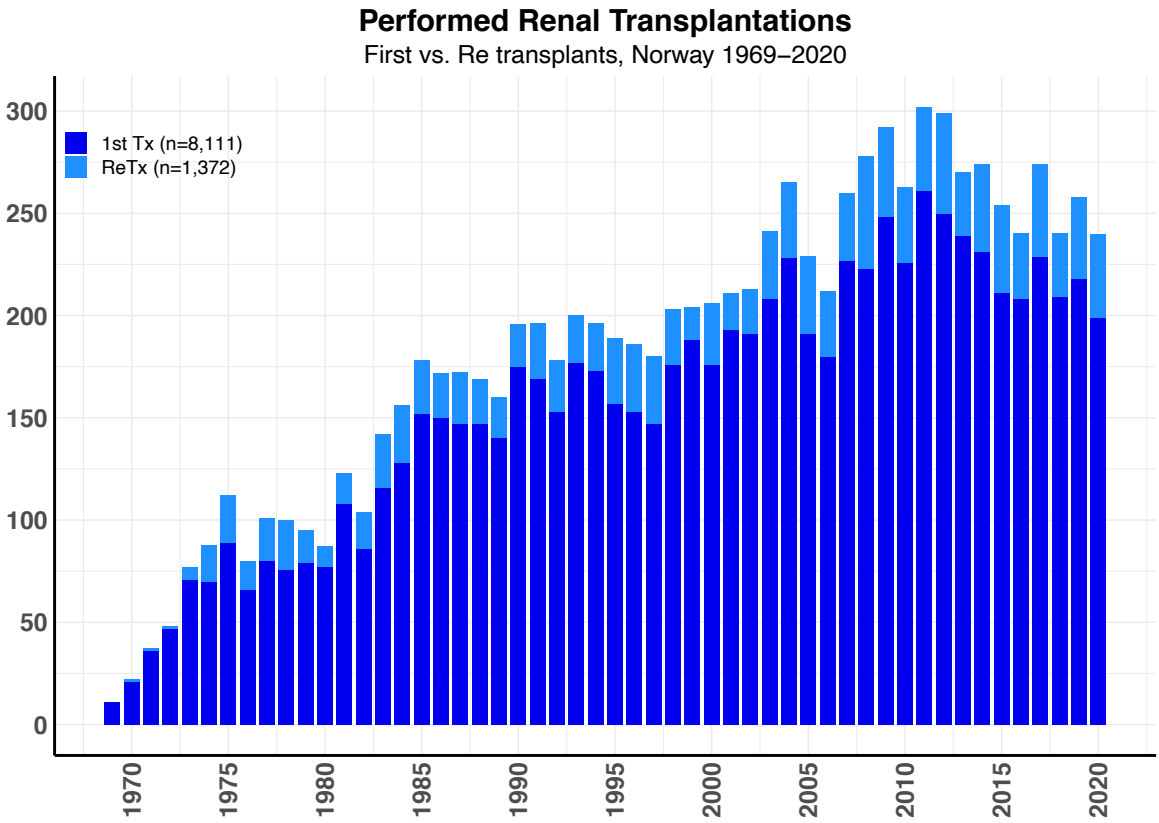


**Figure 25:**

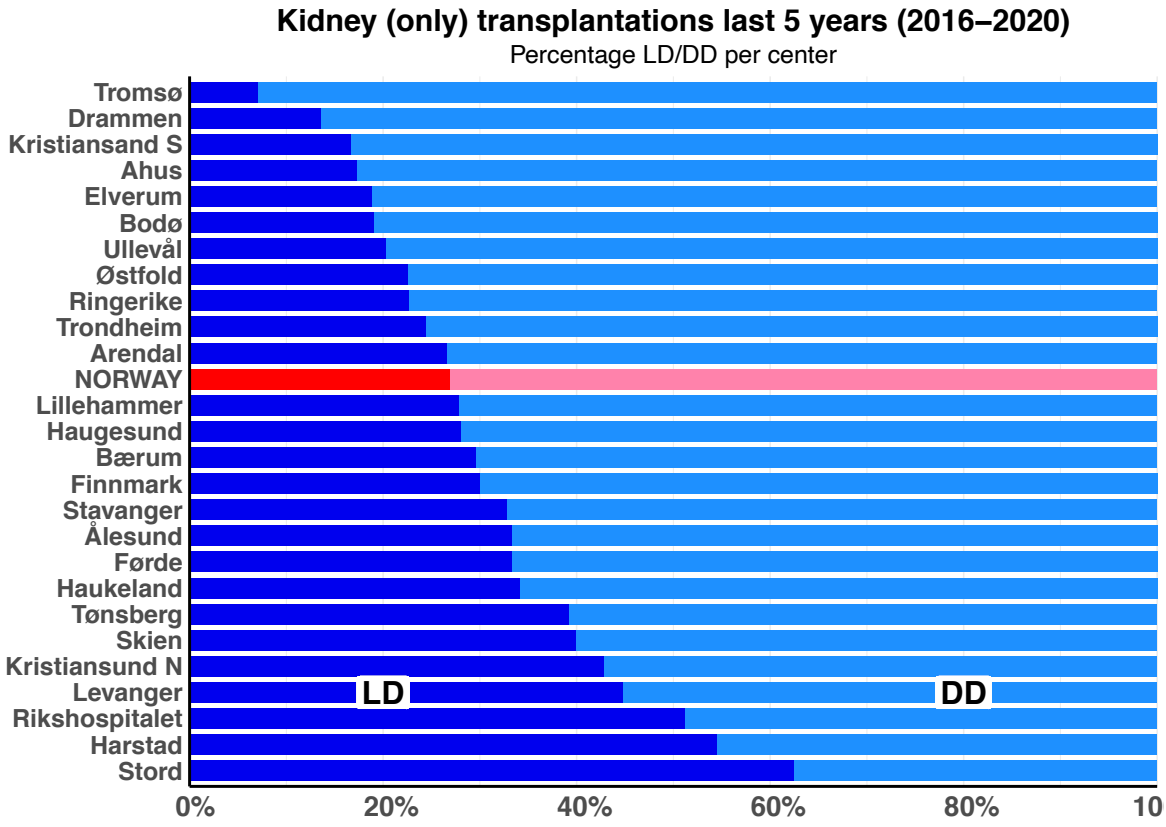



**Figure 26:**

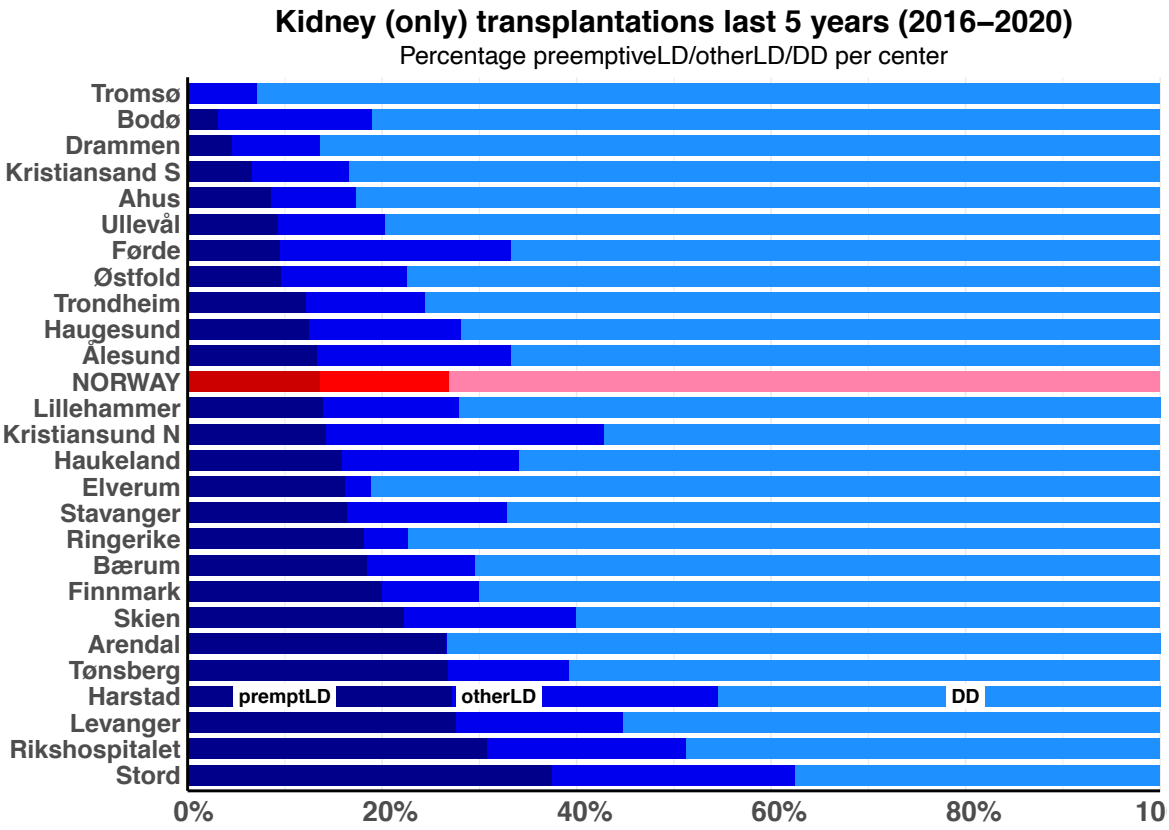


**Figure 27:**

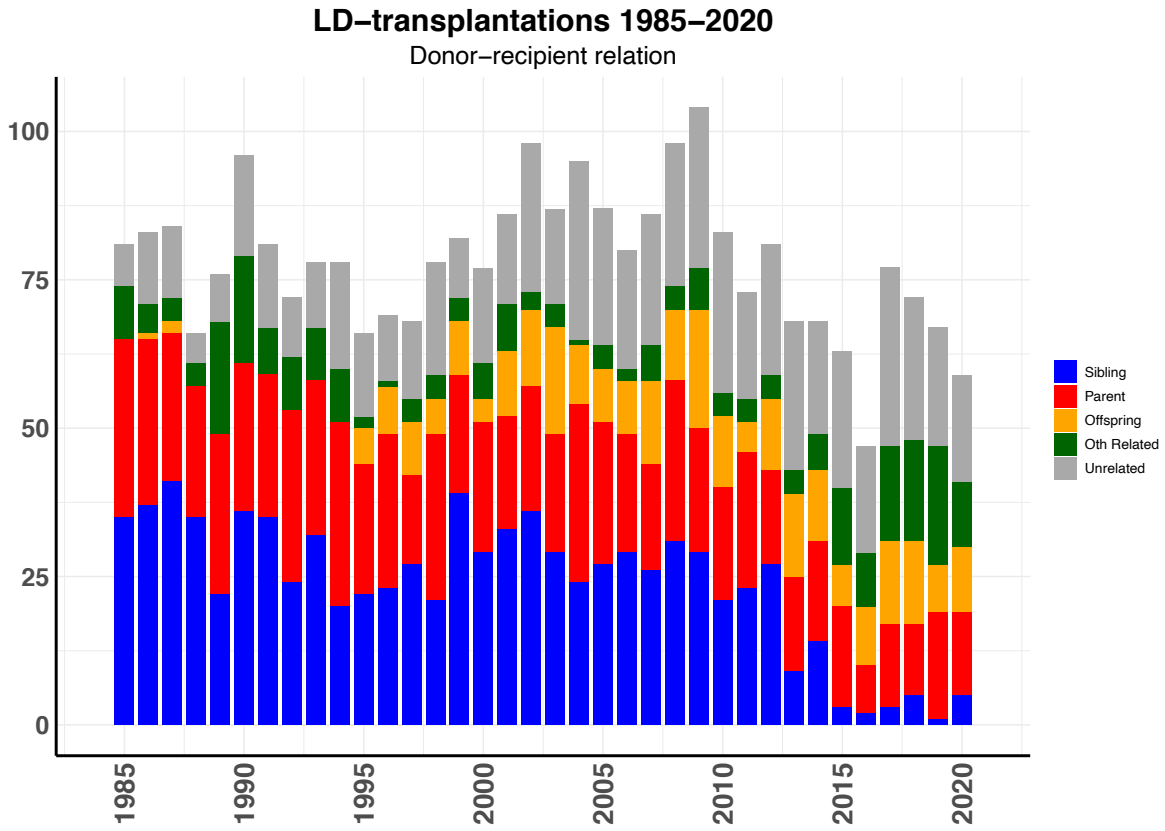
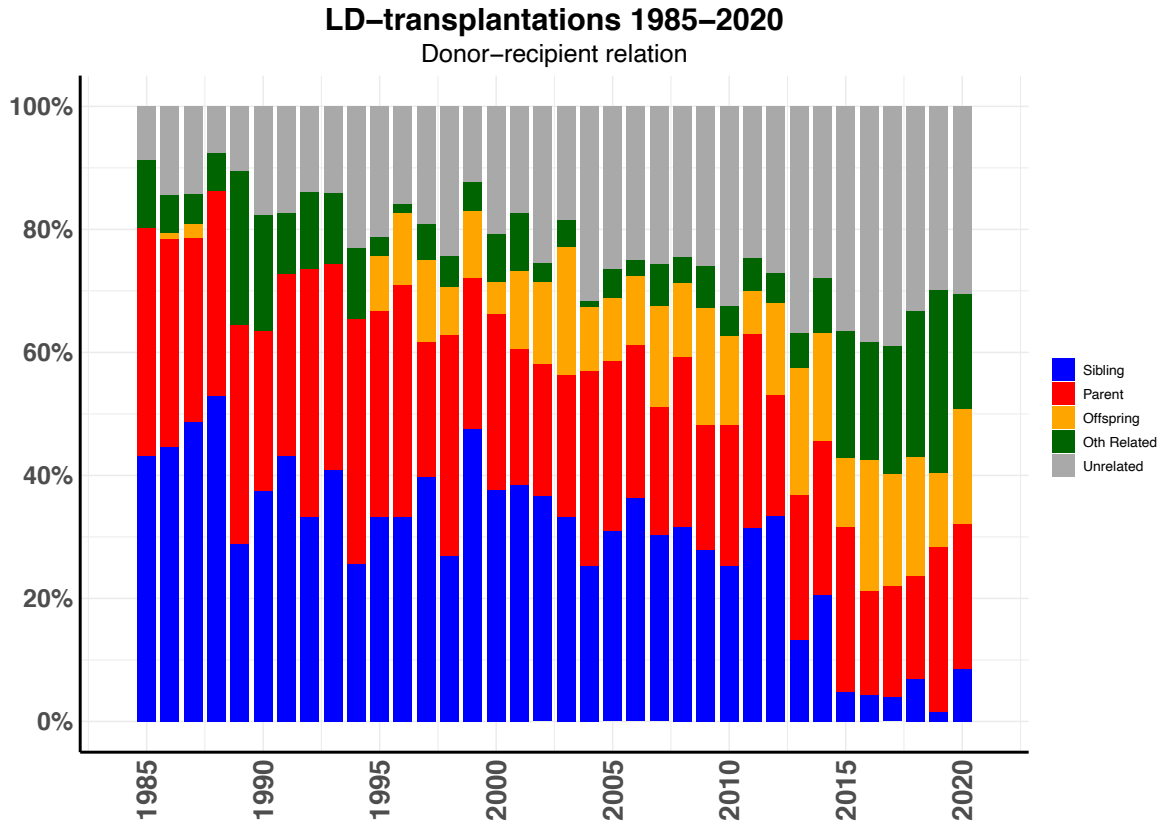
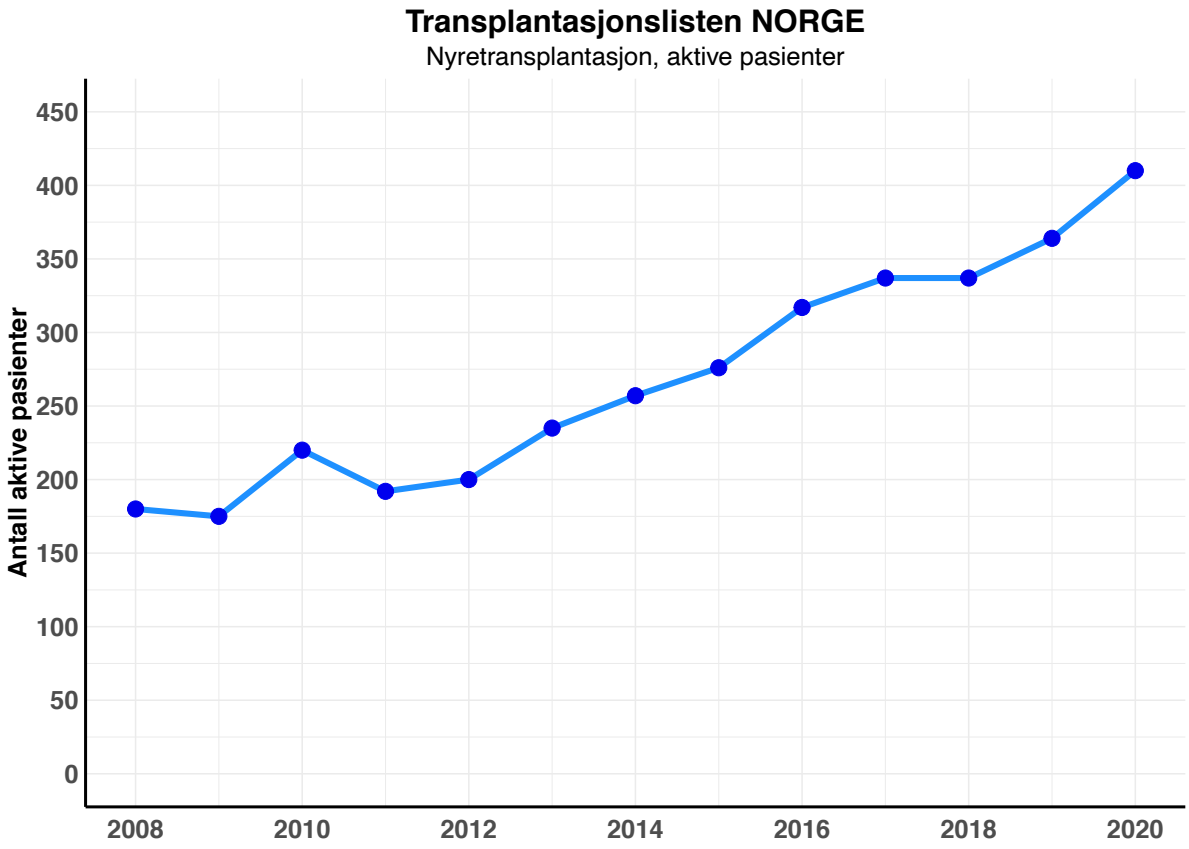



**Figure 28:**



By end 2020, 410 patients (76.3 per mill.) were on the active waiting list for a DD renal graft, a 13 % increase from 2019. Among those waiting by December 31st, median time on the list was 13 months for a first transplant, 49 % had waited less than one year and 23 % more than two years. The 184 recipients transplanted with a DD-graft in 2020 had a median waiting time of 13 months for a first transplant and 17 months for a retransplant and a maximum of 51 months at the time of grafting.

**Figure 29:**



# Patient and graft survival:

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

**Figure 30:**

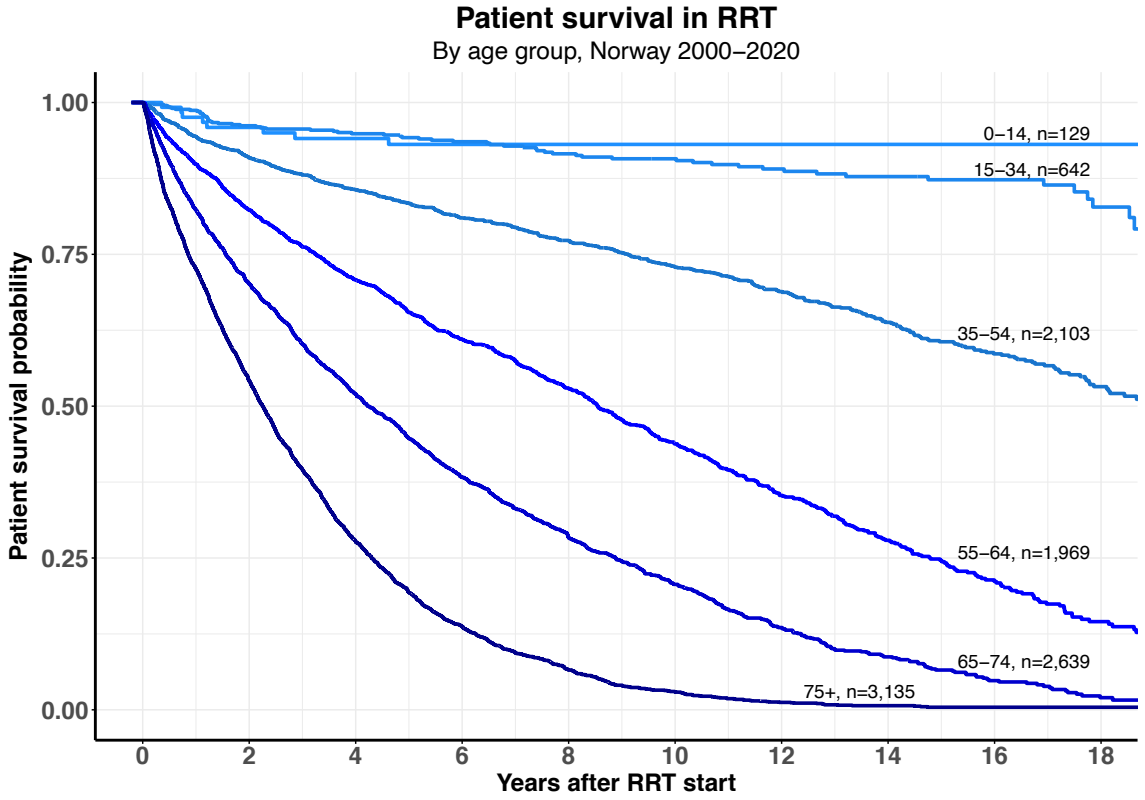



**Figure 31:**

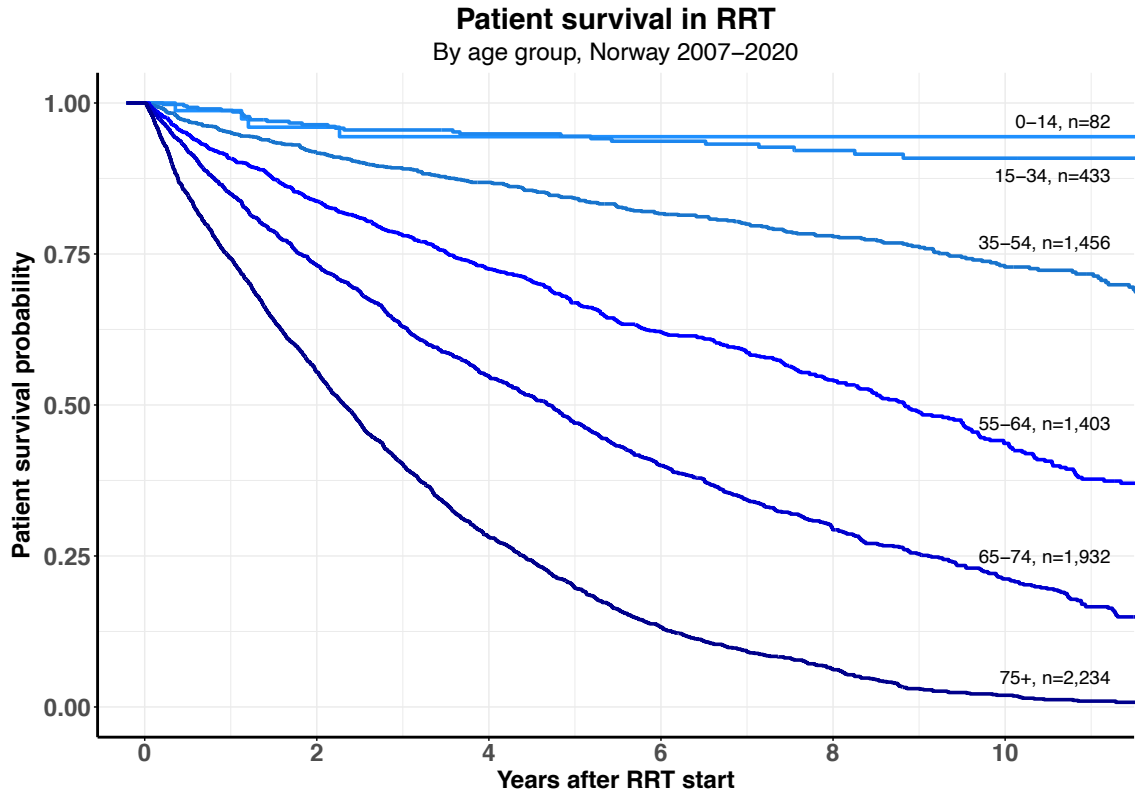


**Figure 32:**

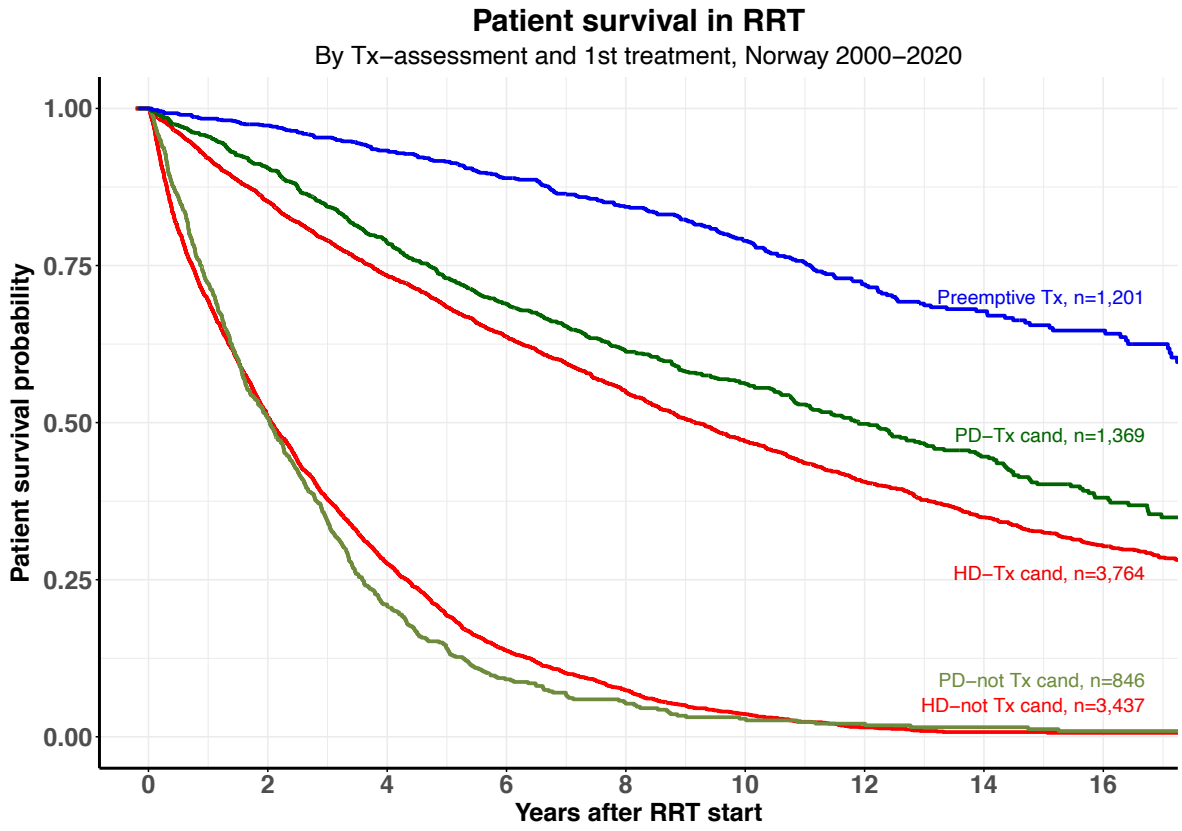
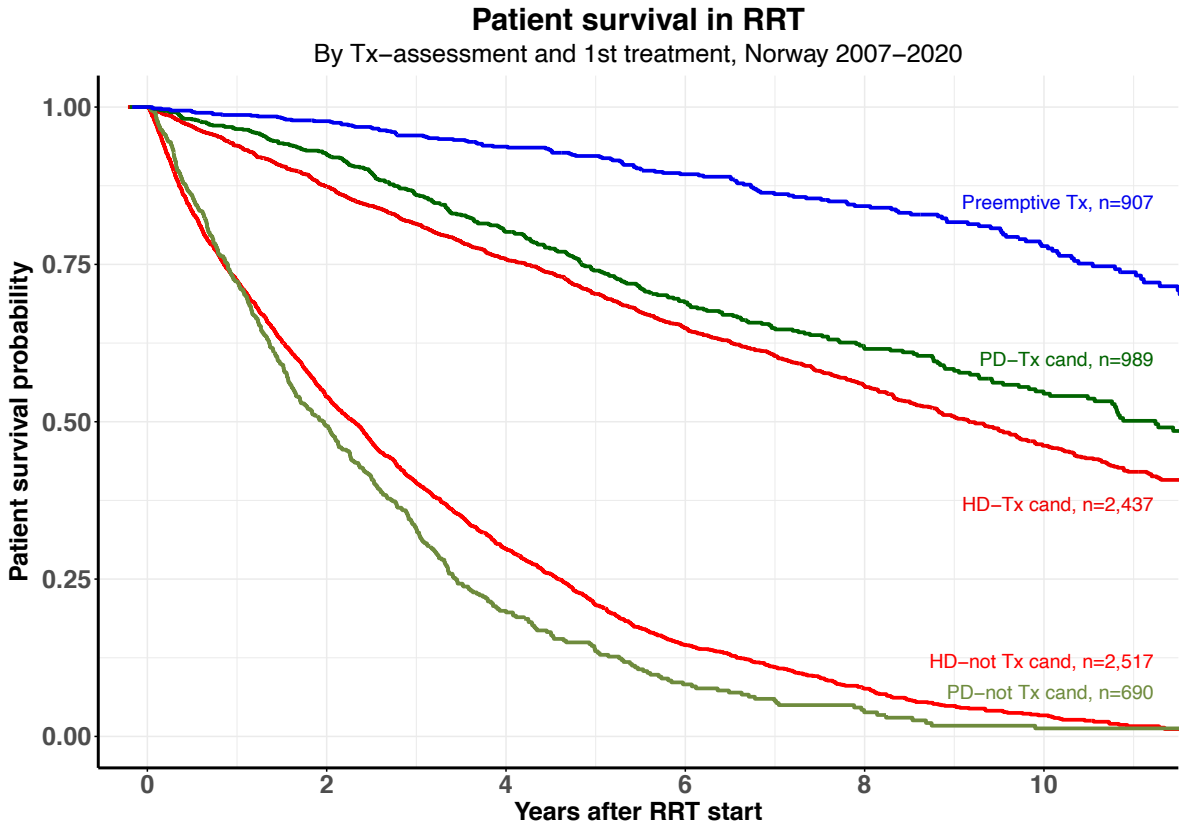



**Figure 33:**



A new analysis in this year's annual report the 2-year patient survival of patients in renal replacement therapy has been included. The data, both un- and age adjusted, are shown in **Figure 34** for each health region separately. The trends are presented using 1-year overlapping, 4-year bins since the year 2000.

## Figure 34:

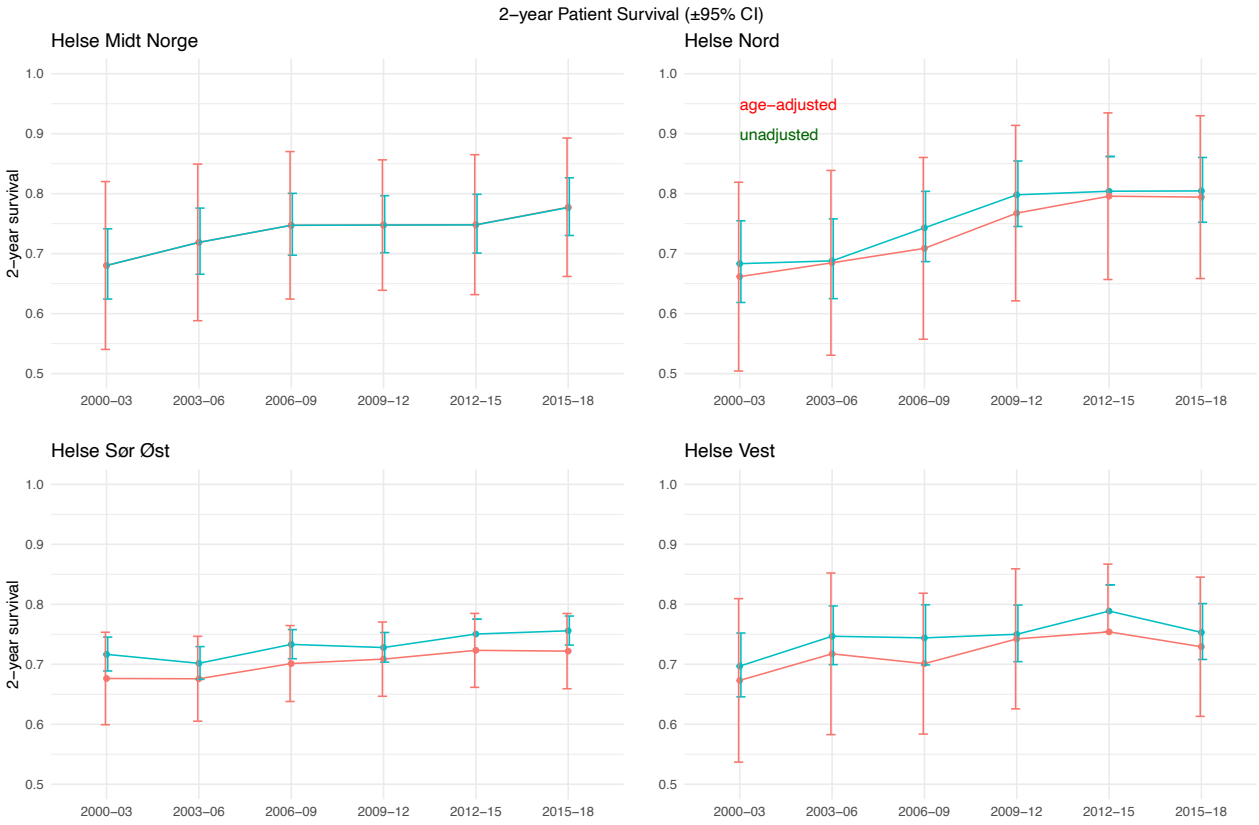


**Figure 35:**

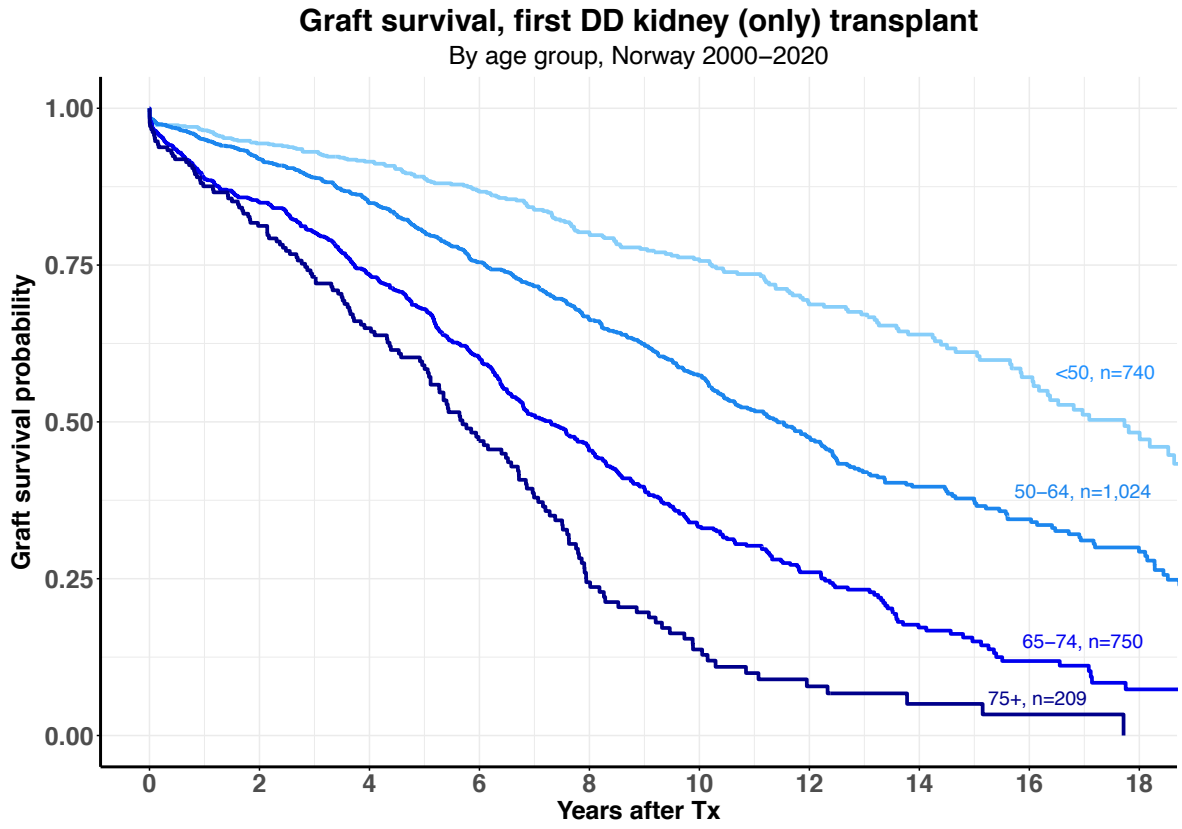



**Figure 36:**

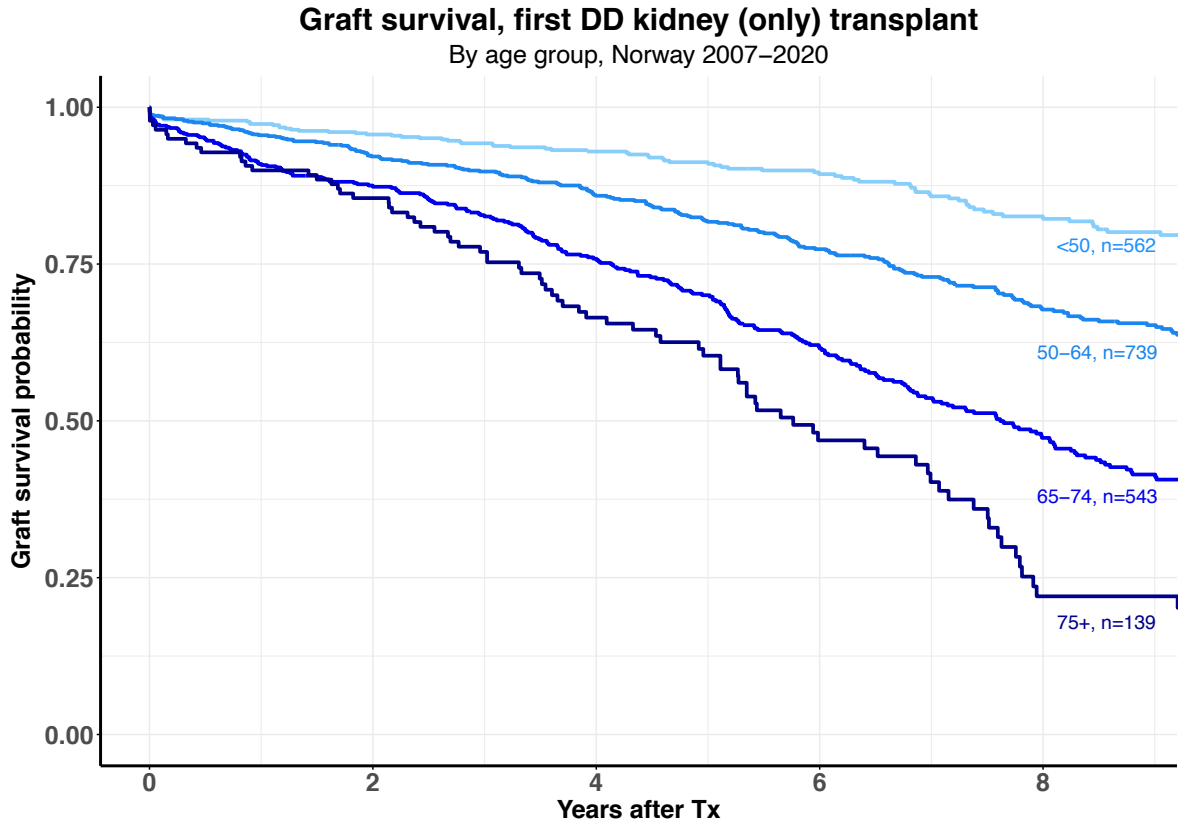


**Figure 37:**

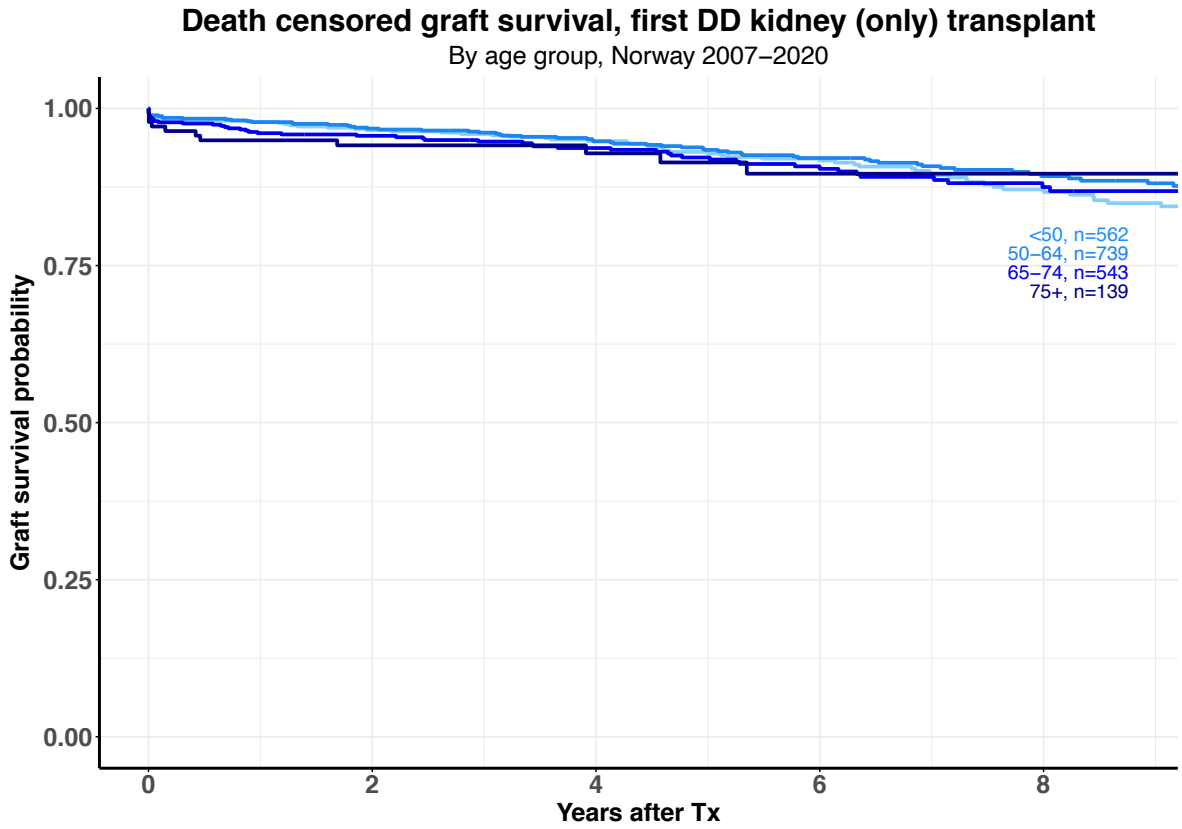



**Figure 38:**

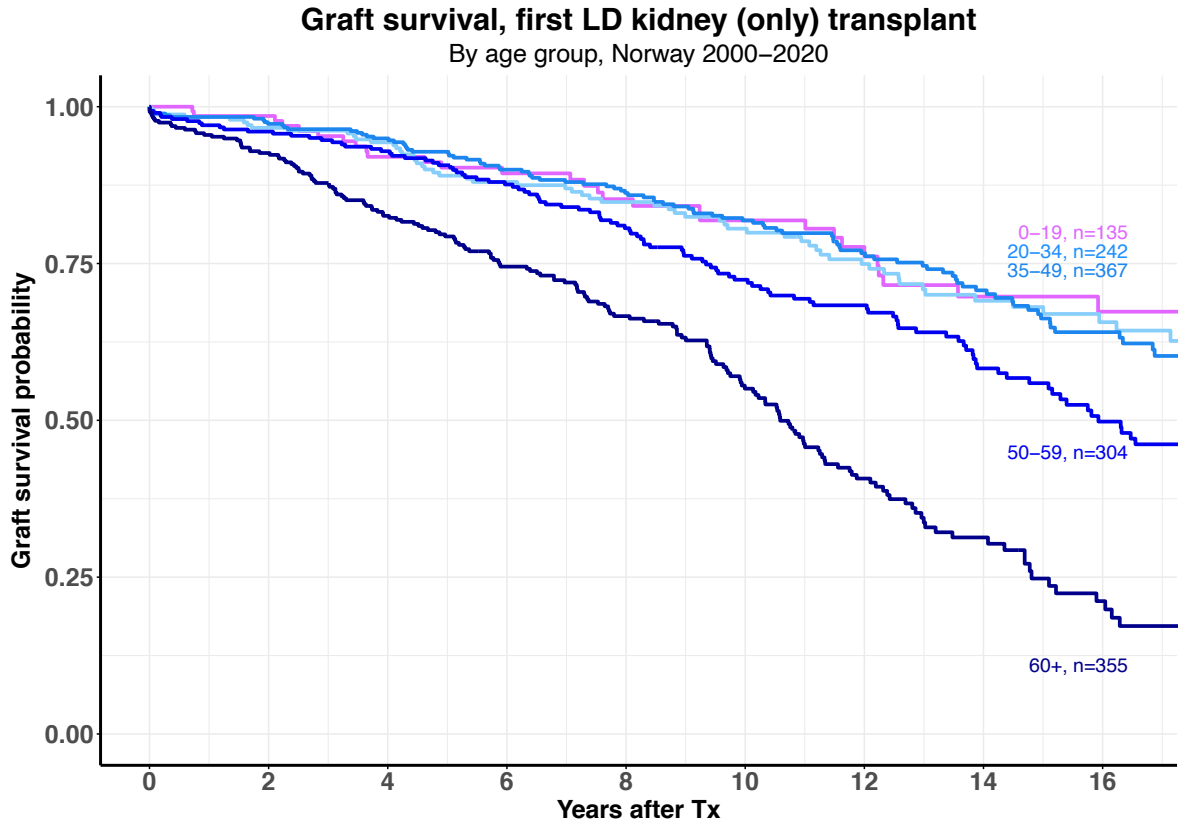


**Figure 39:**

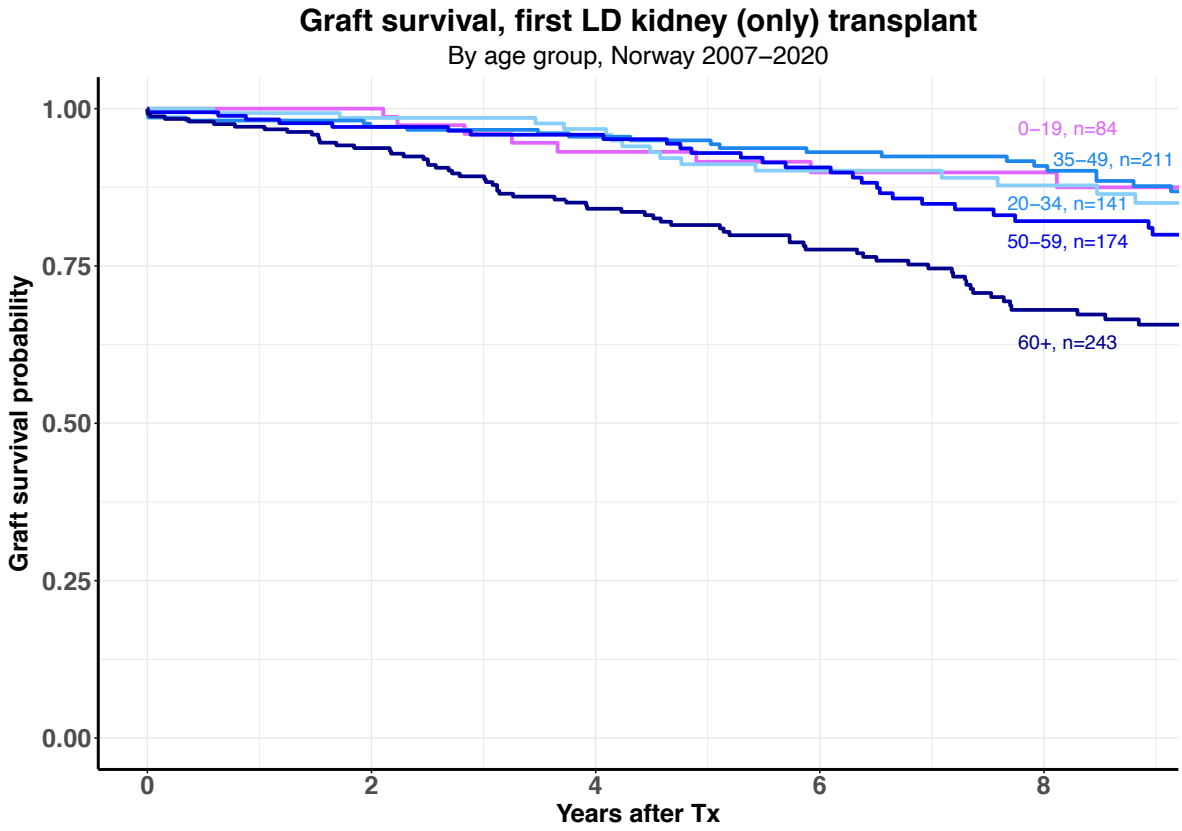



**Figure 40:**

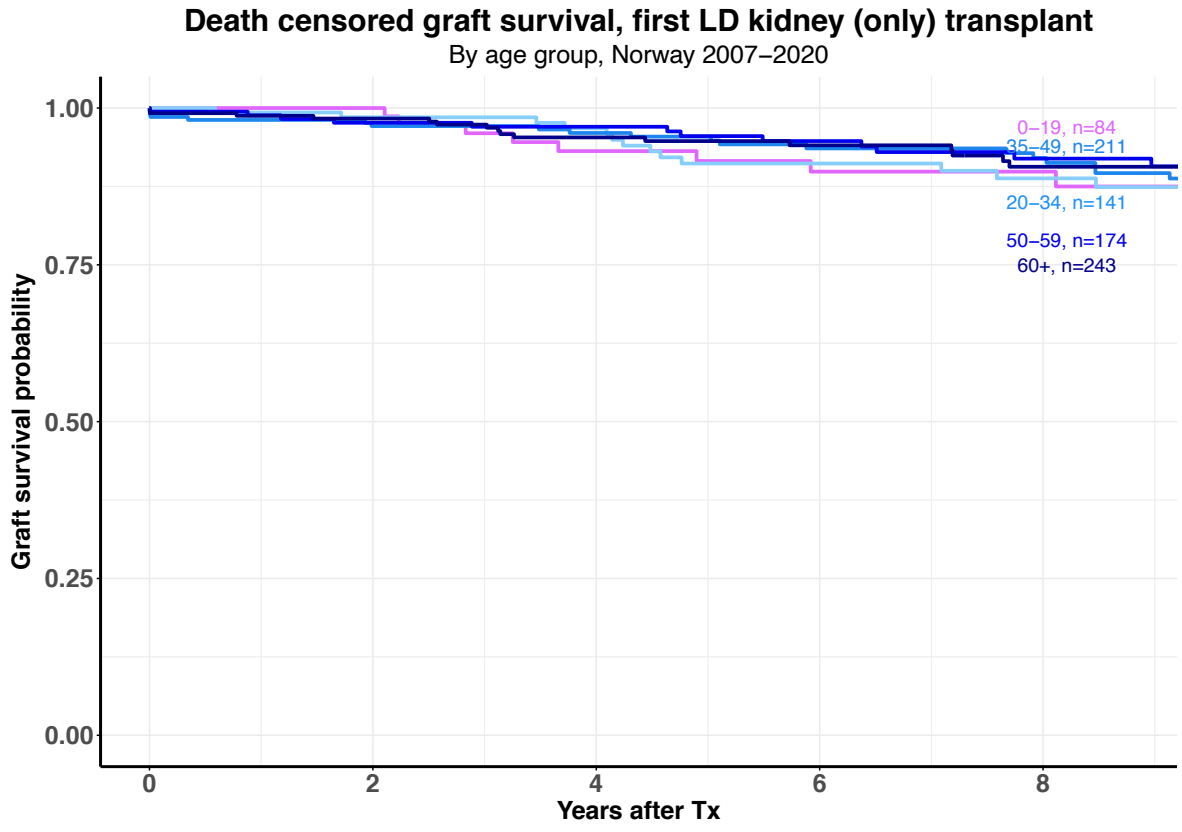


**Figure 41:**

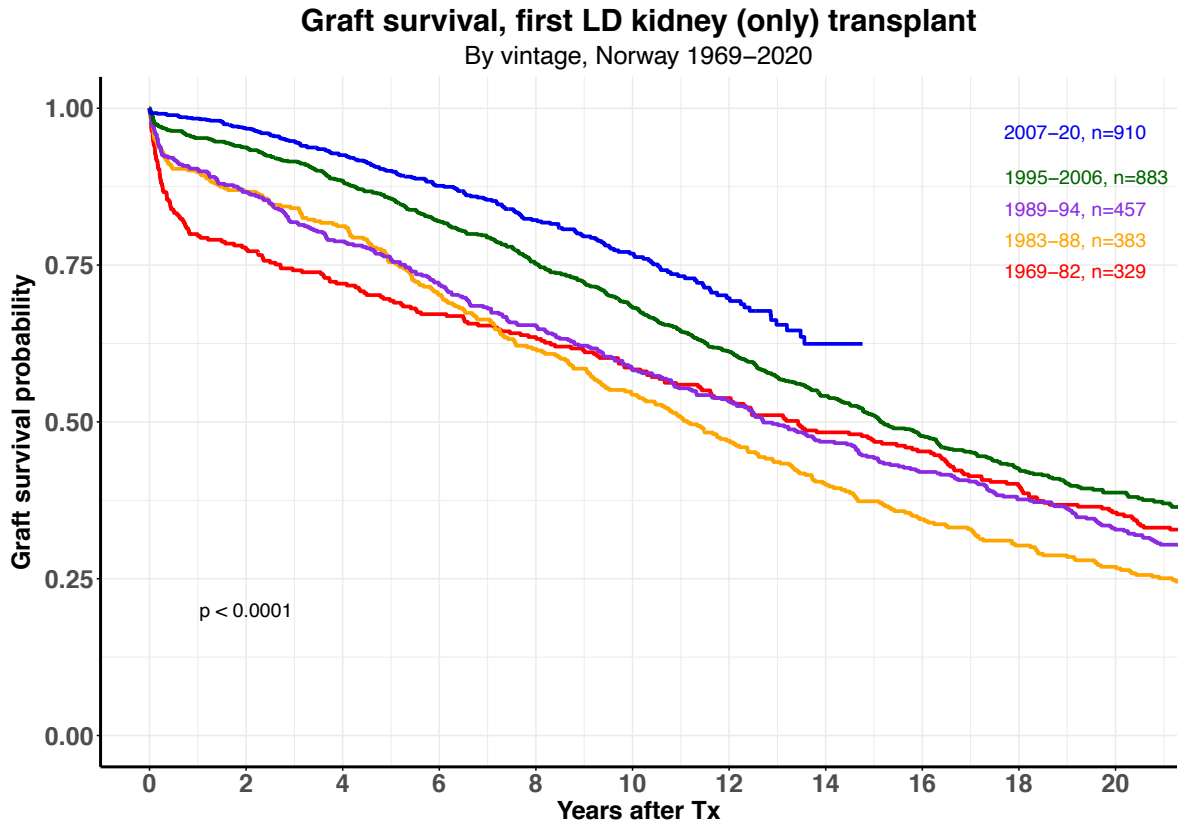



**Figure 42:**

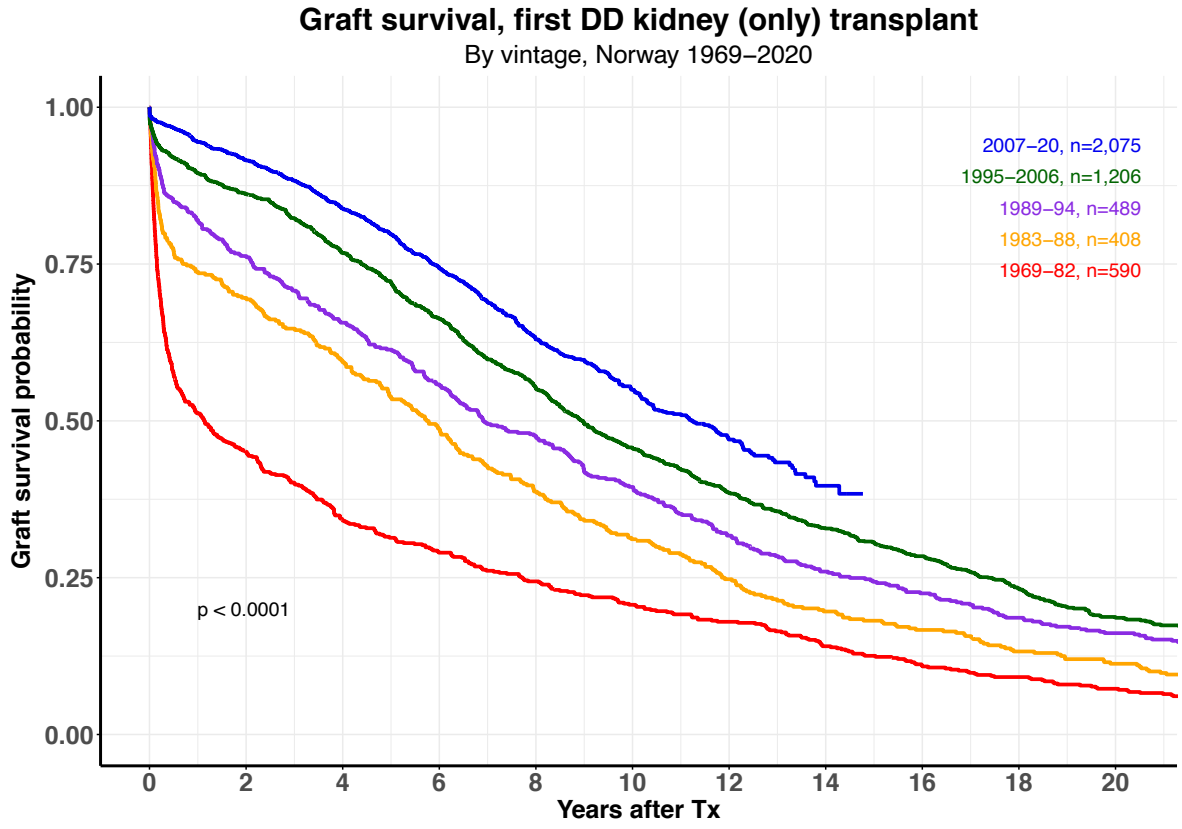
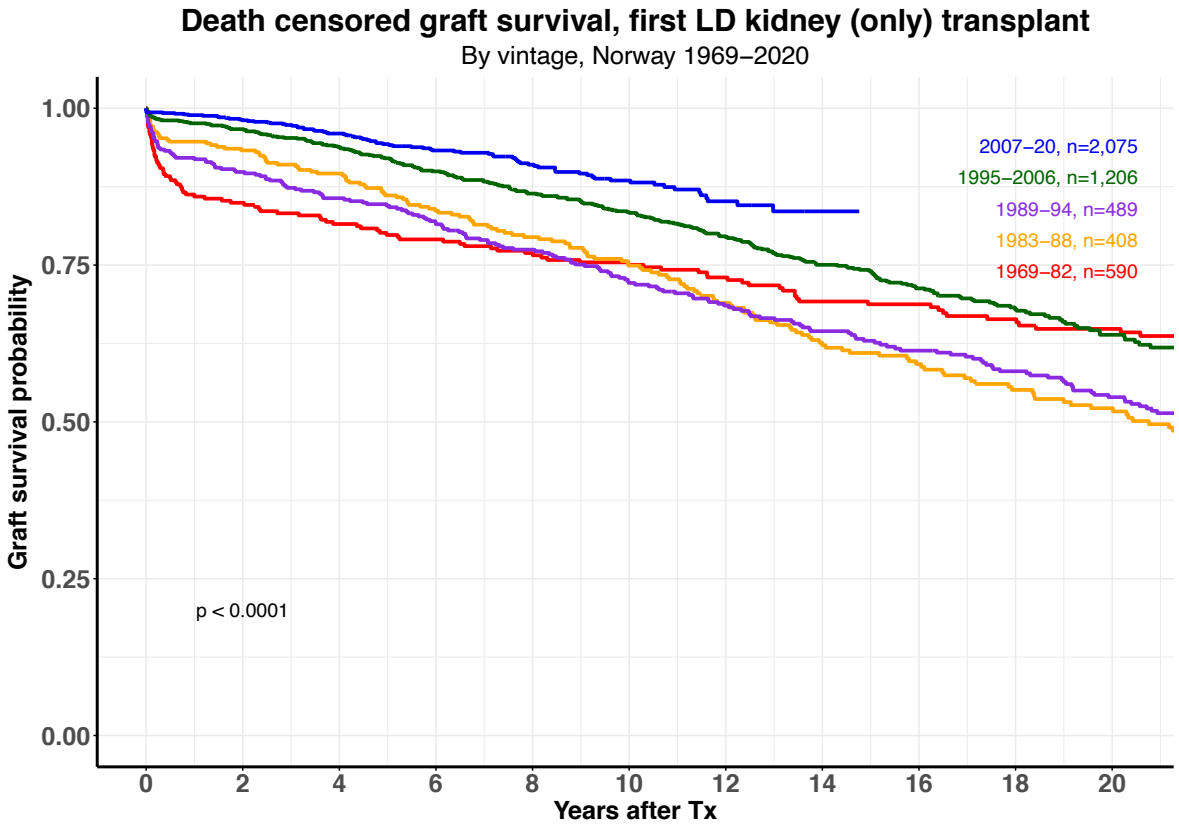


**Figure 43:**

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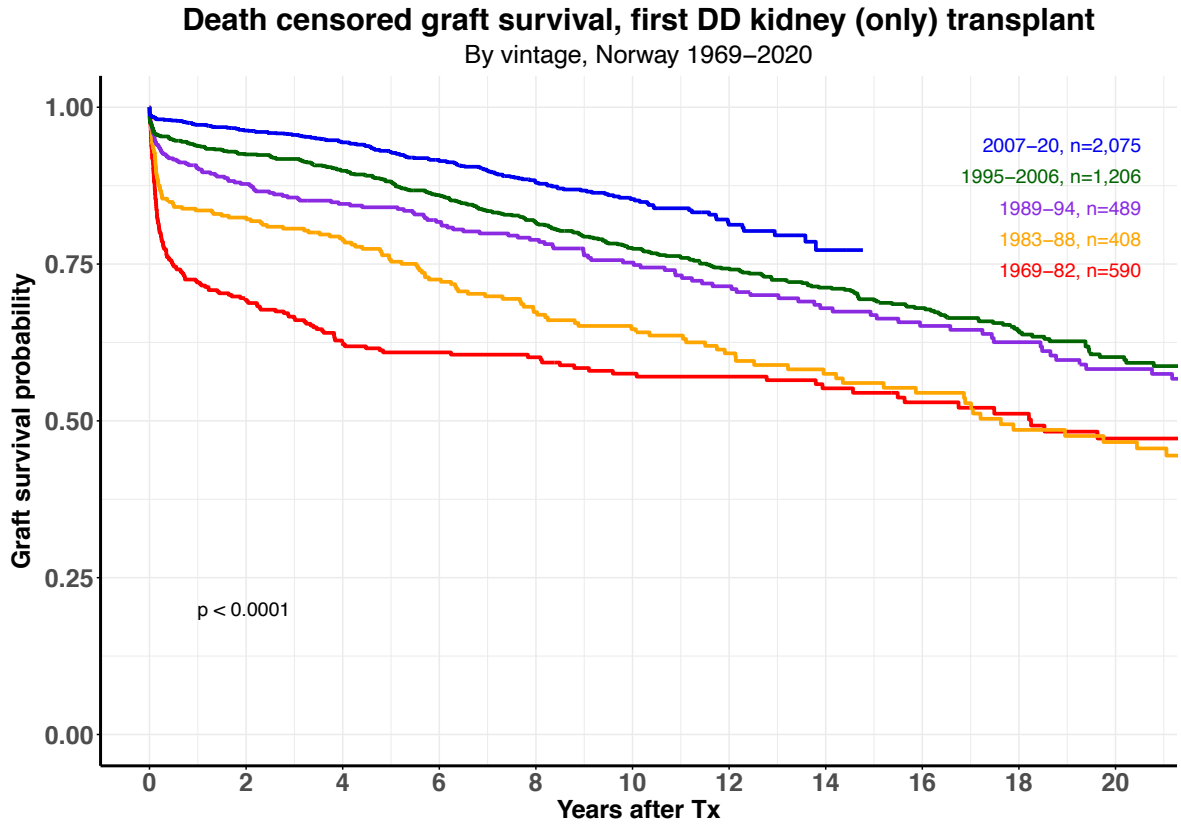


**Figure 45:**

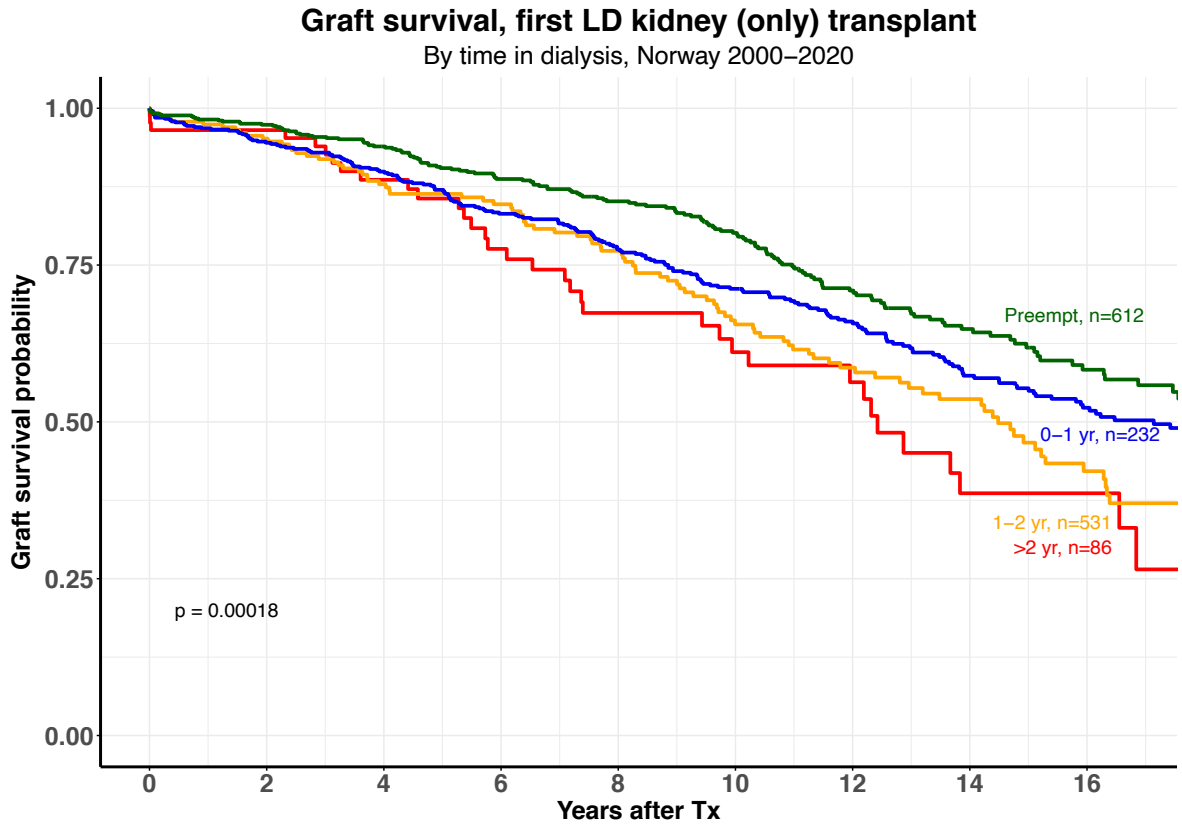
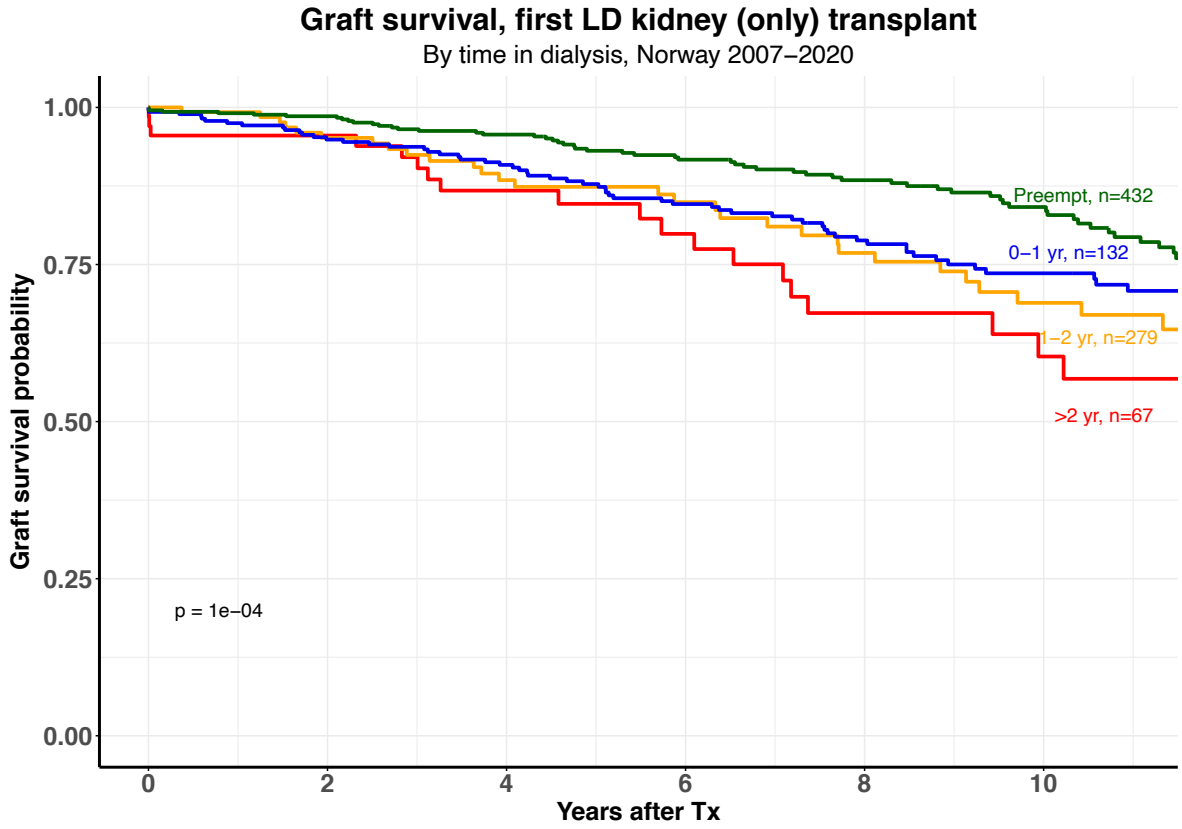



**Figure 46:**



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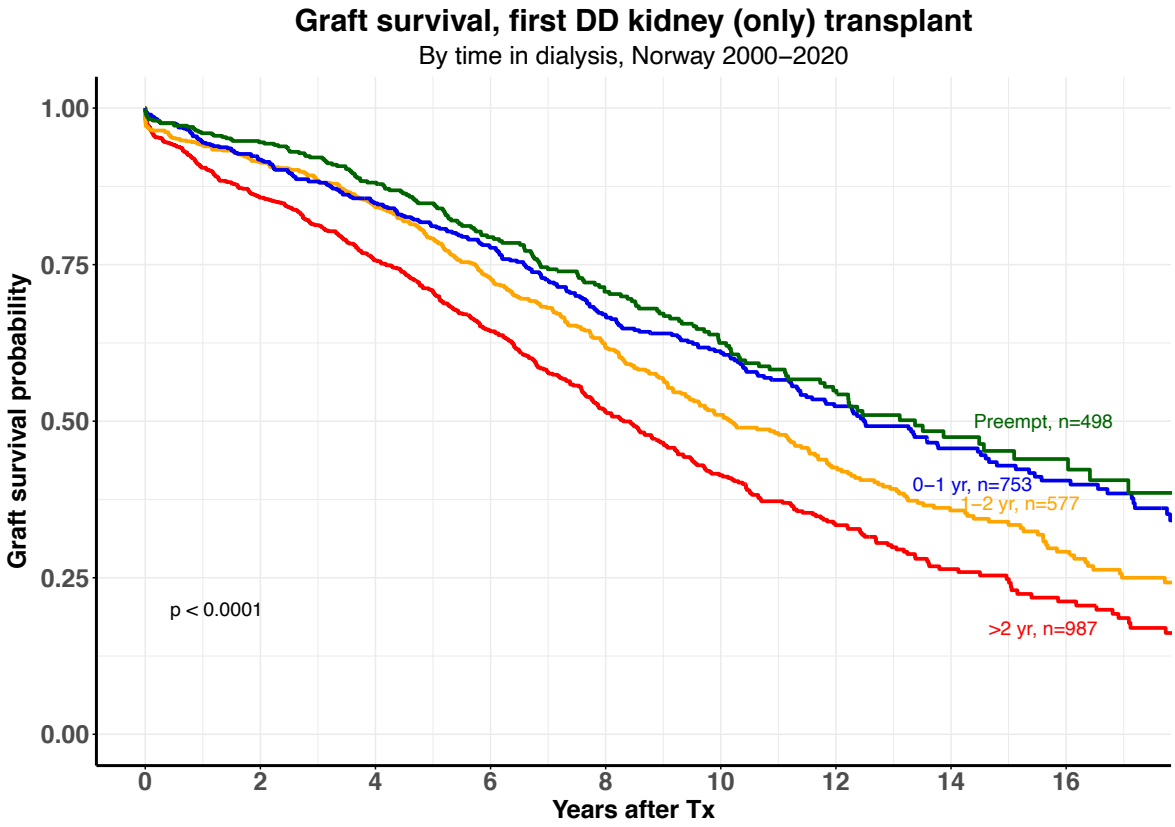



**Figure 48:**

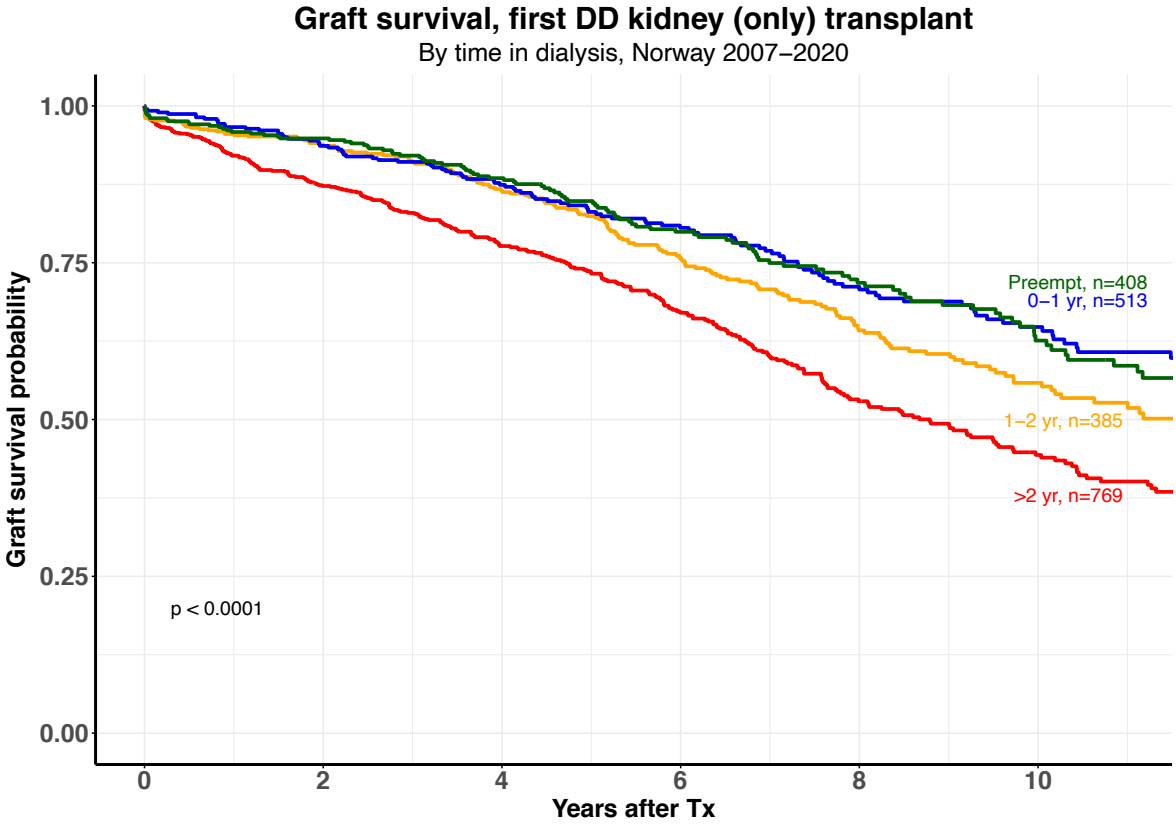


**Figure 49:**

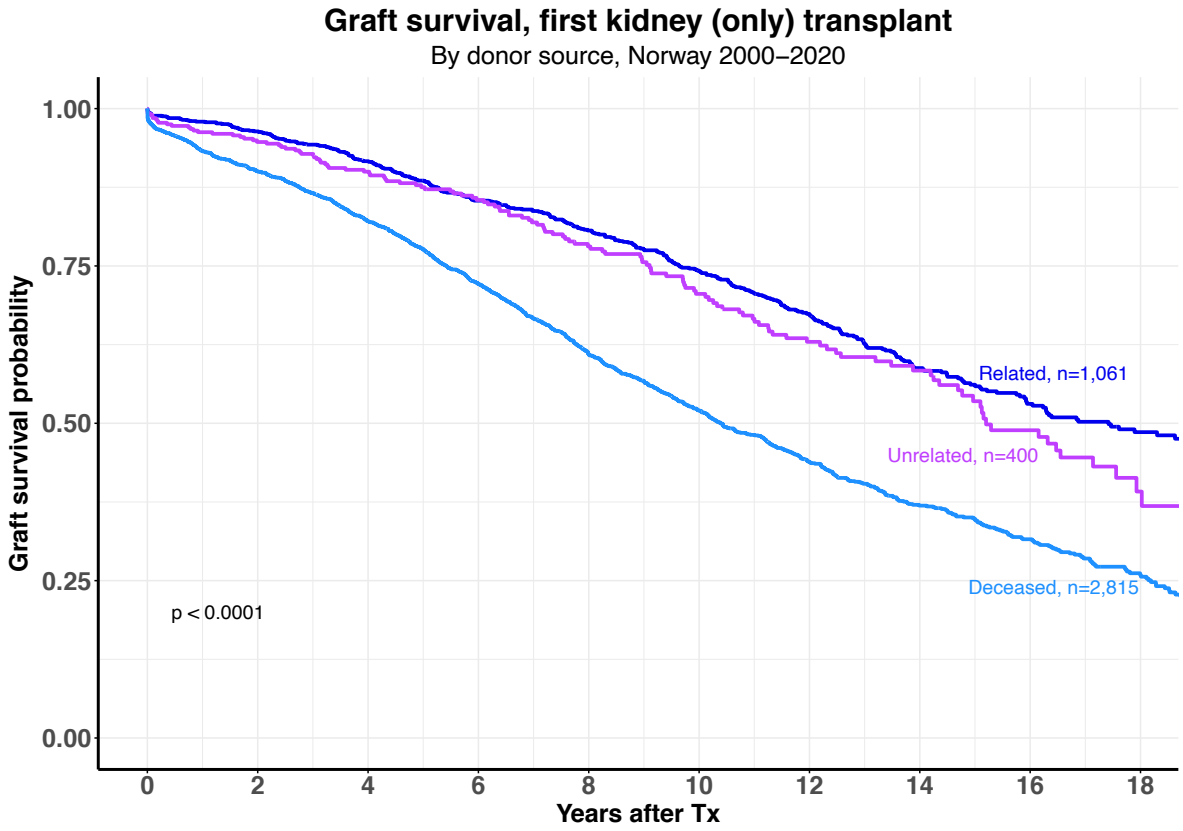
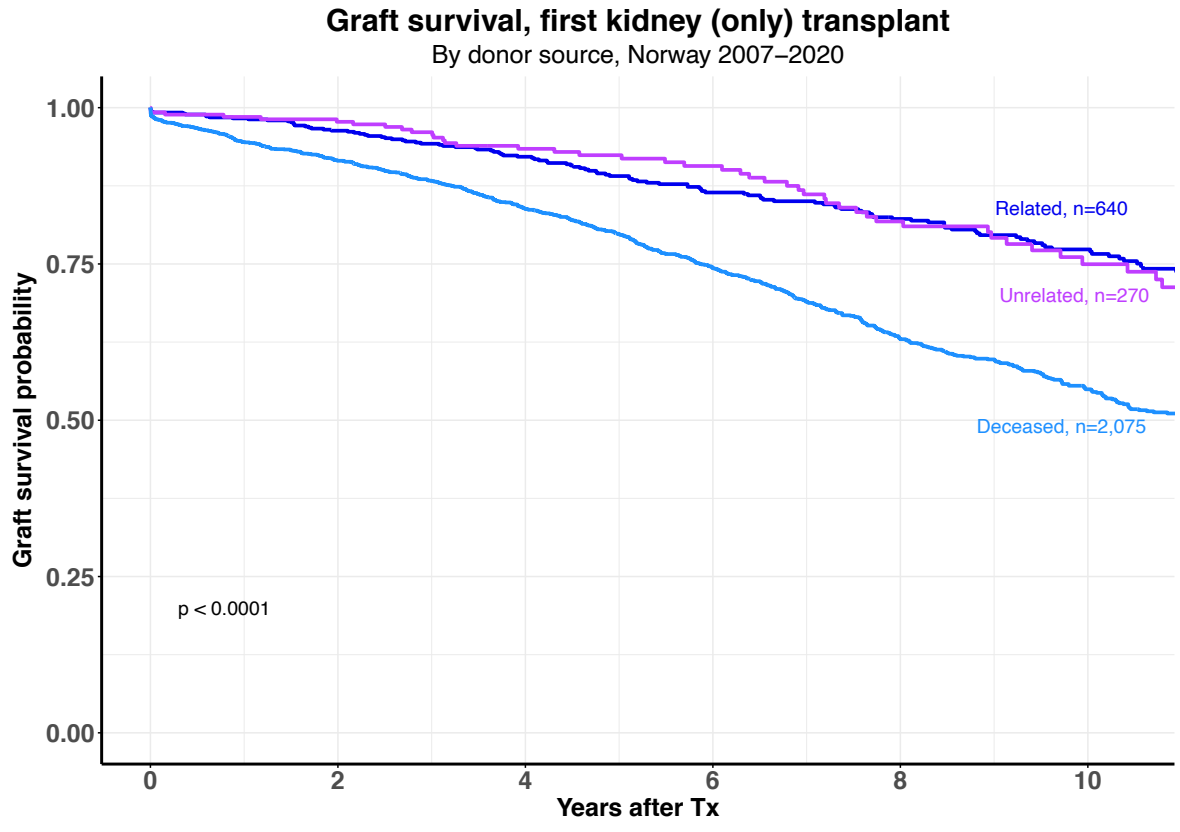



**Figure 50:**



## Death in CKD5:

A total of 582 patients in CKD5 died during 2020, 63 of these patients had never started RRT (48% being RRT candidates), 253 of patients were in active dialysis (of which 25 were previously transplanted) and 143 transplanted. Dialysis treatment was terminated and followed by death in 57 patients.

Median age at death was 77 years (mean 75 years), ranging from 29 to 96 years. Median time from start of RRT until death was 5.4 years (mean 8.6 years), ranging from 1 day to 52 years.

Infections (19%, of which 8 (1.4%) were death due to COVID-19) and cardiac complications (21%) were the most frequent causes of death, followed malignant tumors (13%).

## Quality indicators:

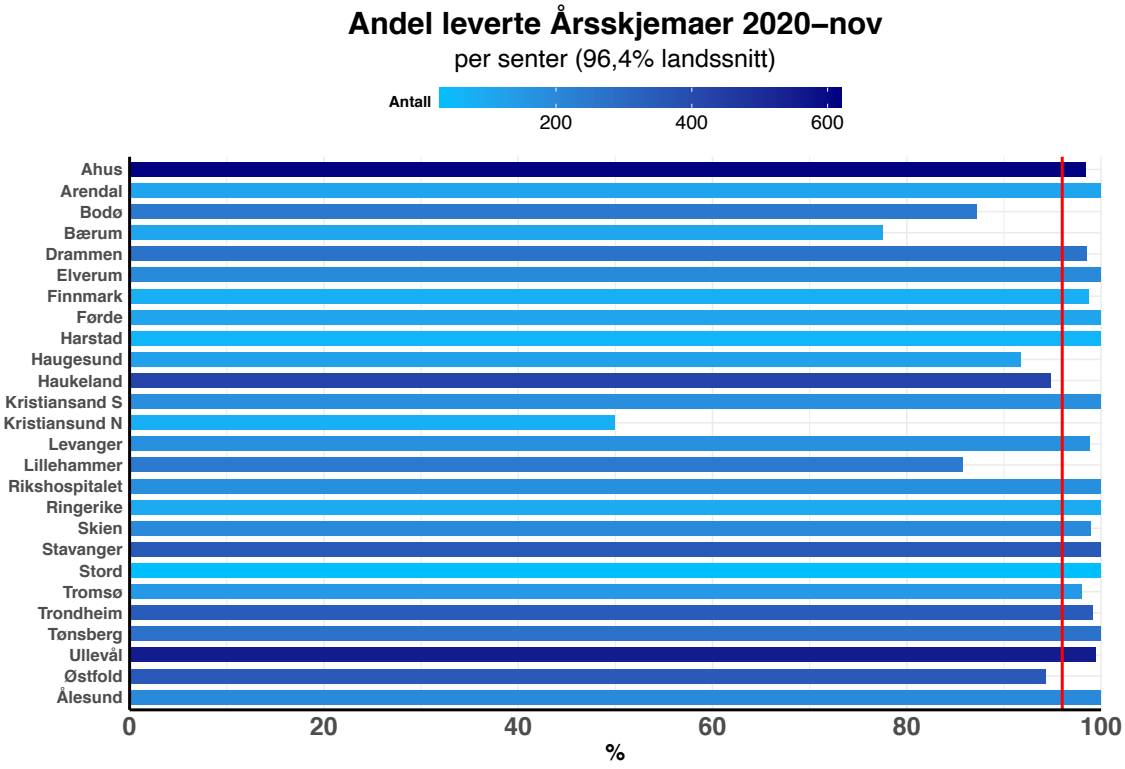
The registry has implemented 22 quality indicators (see appendix) that will be followed year by year to assure the quality of the treatment the patients included in the registry is subjected to. These data are presented interactively at this site (https://www.kvalitetsregistre.no/registers/464/resultater) and the national quality indicator of part in home dialysis is presented three times per year here (https://www.helsedirektoratet.no/statistikk/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 was implemented in 2017 to correct this. These data are hence only presented for the last three years in this report. 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. The approximate acute rejection rate the first year after transplantation is in the range of 10% to 13%.

Data on part of the patients on the waiting list for a kidney transplant that has been in dialysis for more than 2 years (first kidney transplant only, excluding immunized patients, counting also time during temporary withdrawals) is not relevant to present on a center level. In 2020 the part increased from 28% in 2019 to 30%.

In the figures below the red line indicate the target percentage, the black line the national average and shading in color the relative number of patients at respective center.

**Figure 51:**

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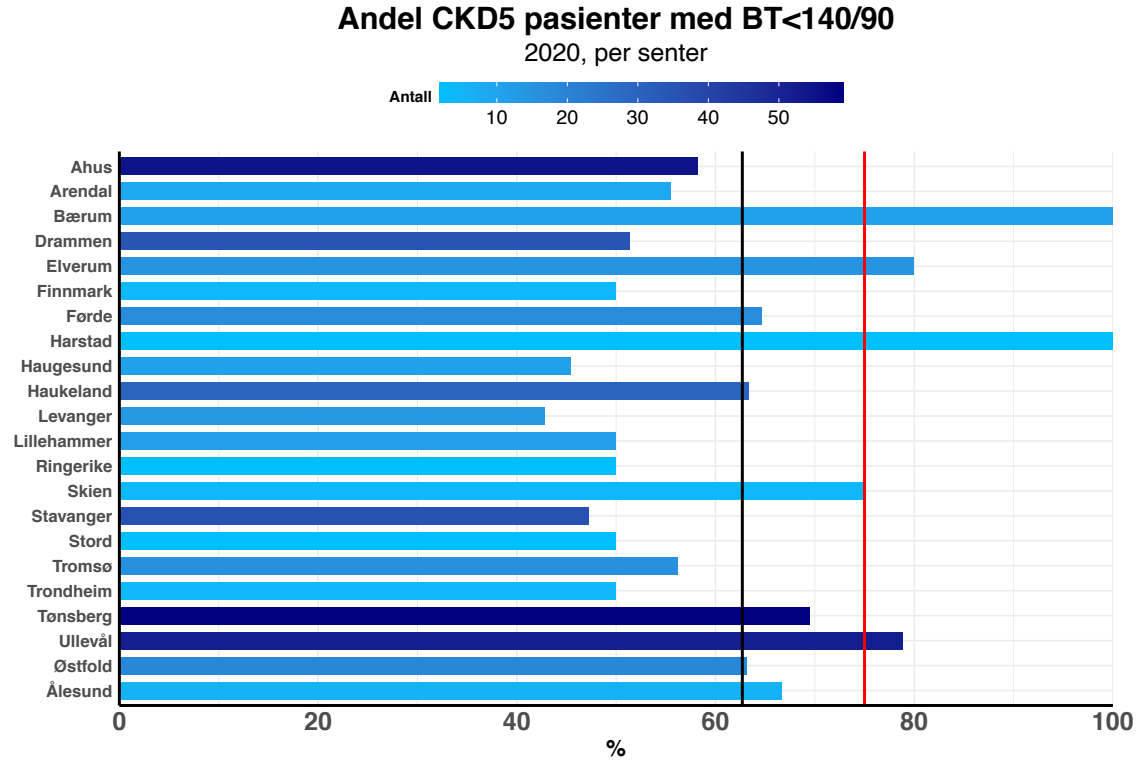


**Figure 53:**

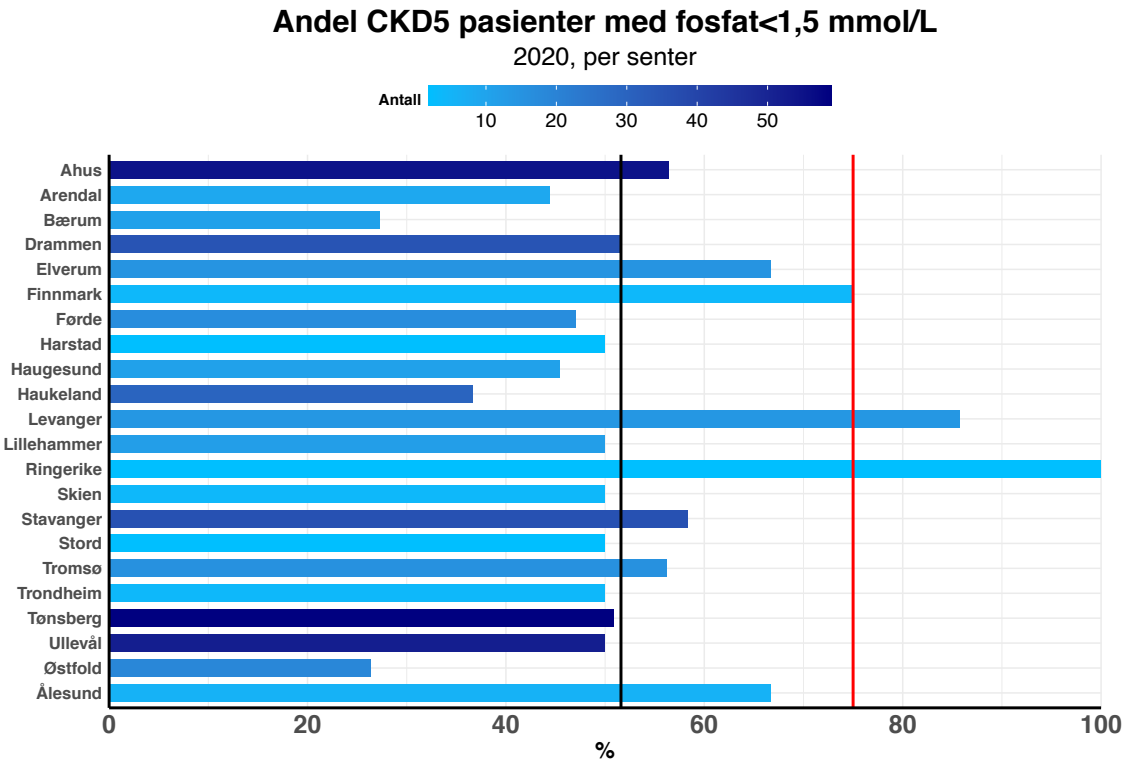



**Figure 54:**

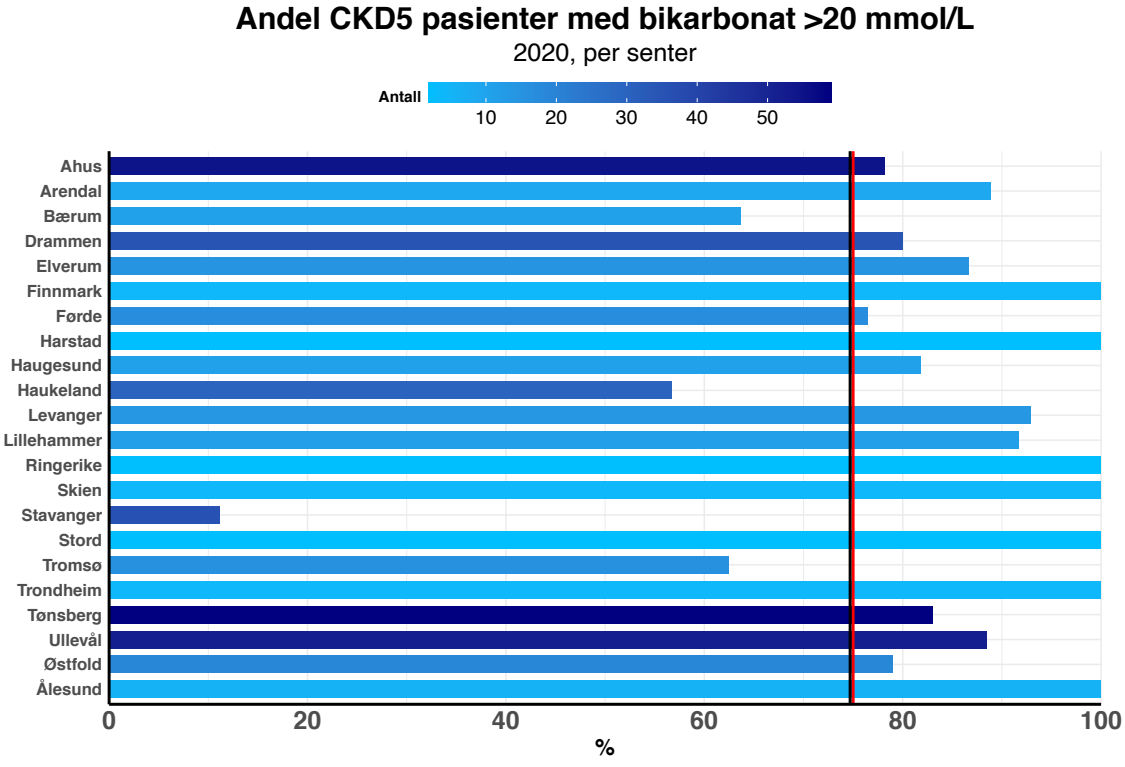


**Figure 55:**

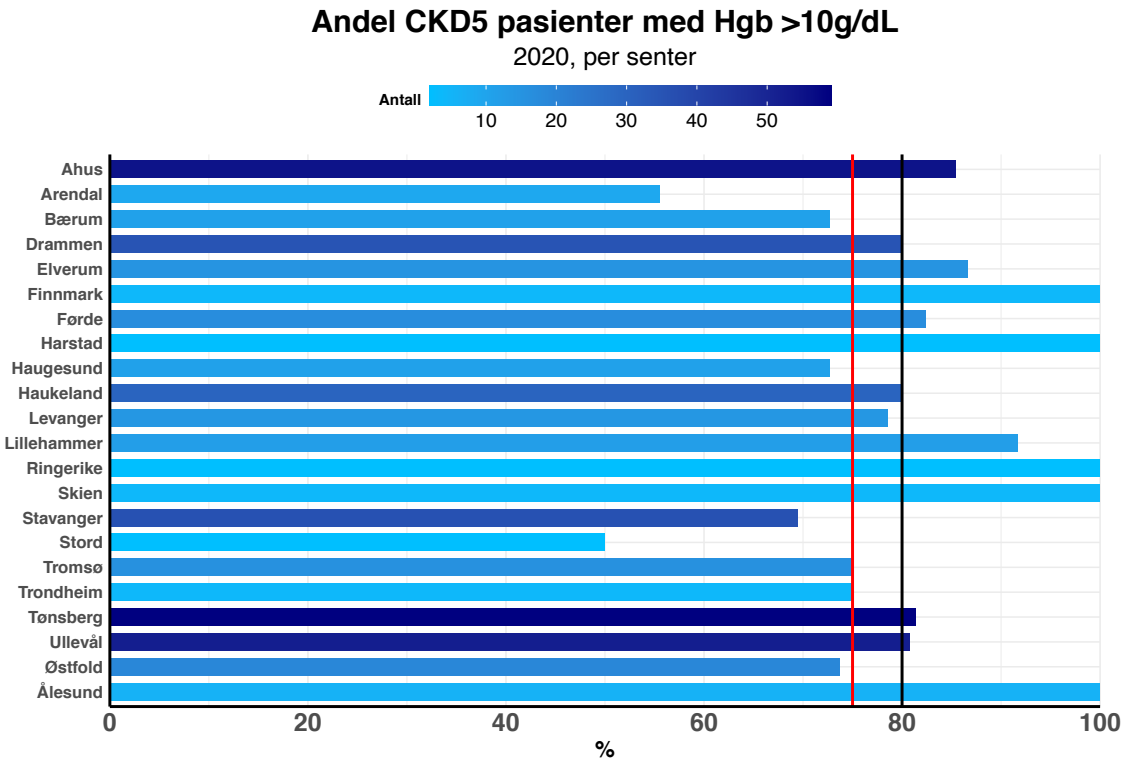



**Figure 56:**

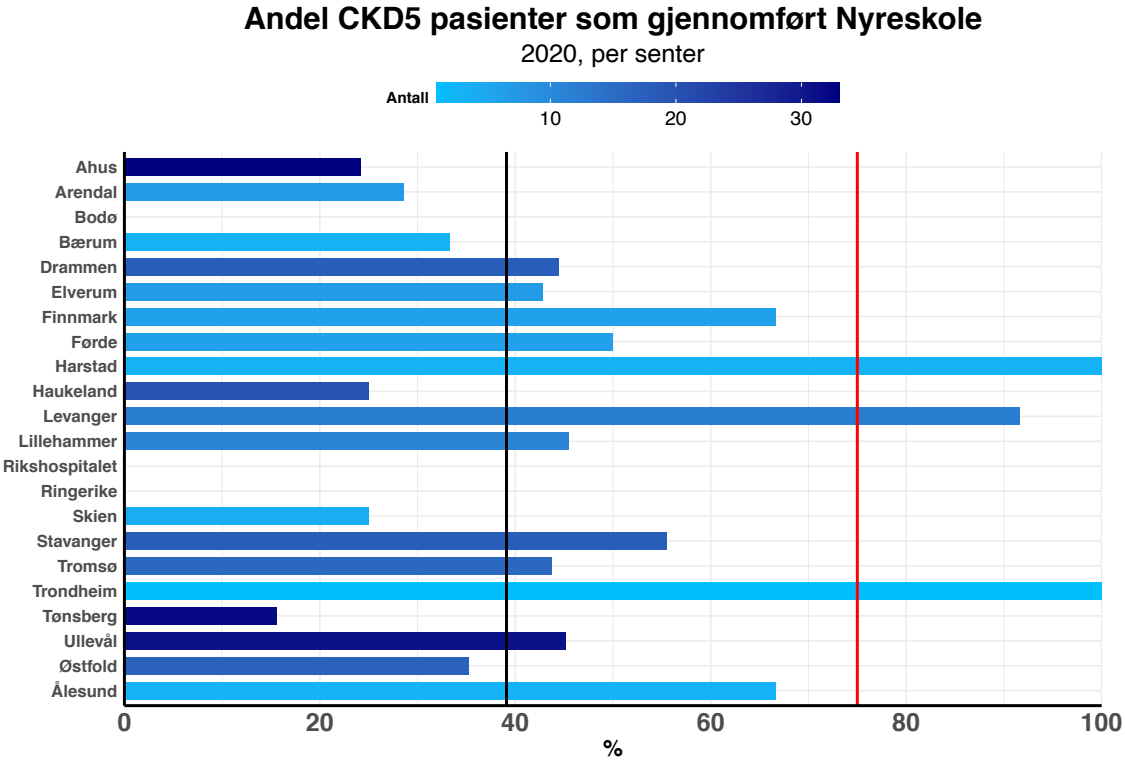


**Figure 57:**

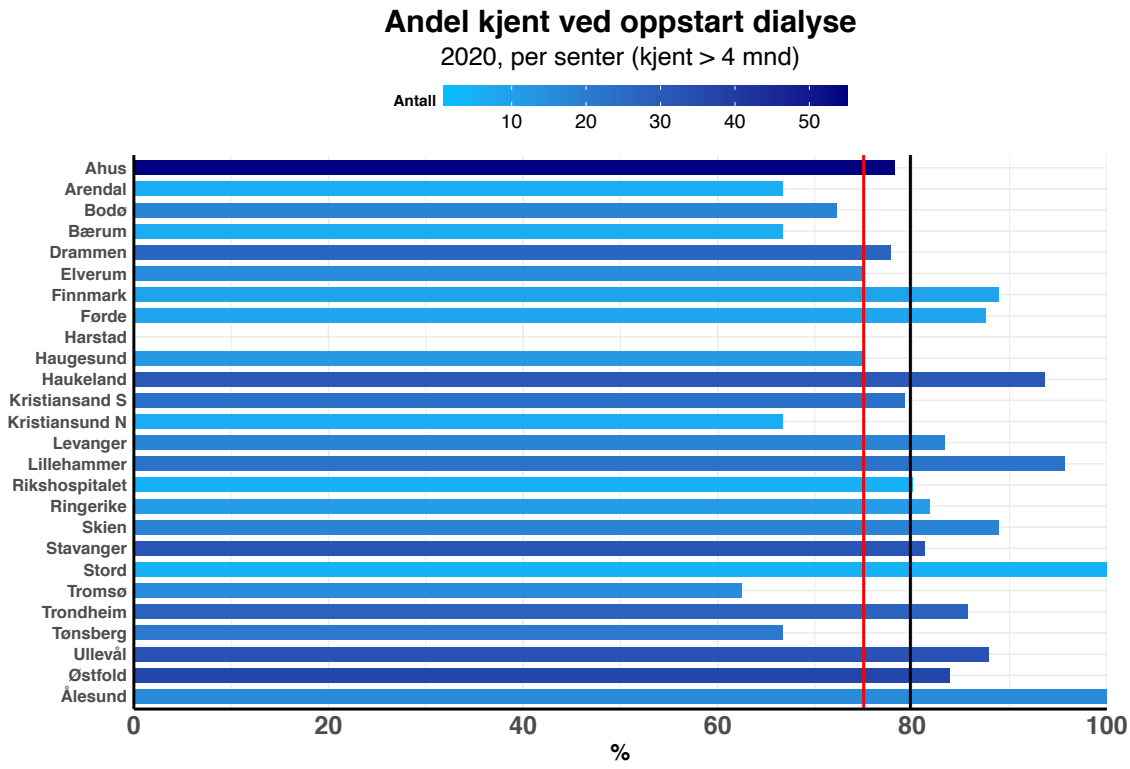
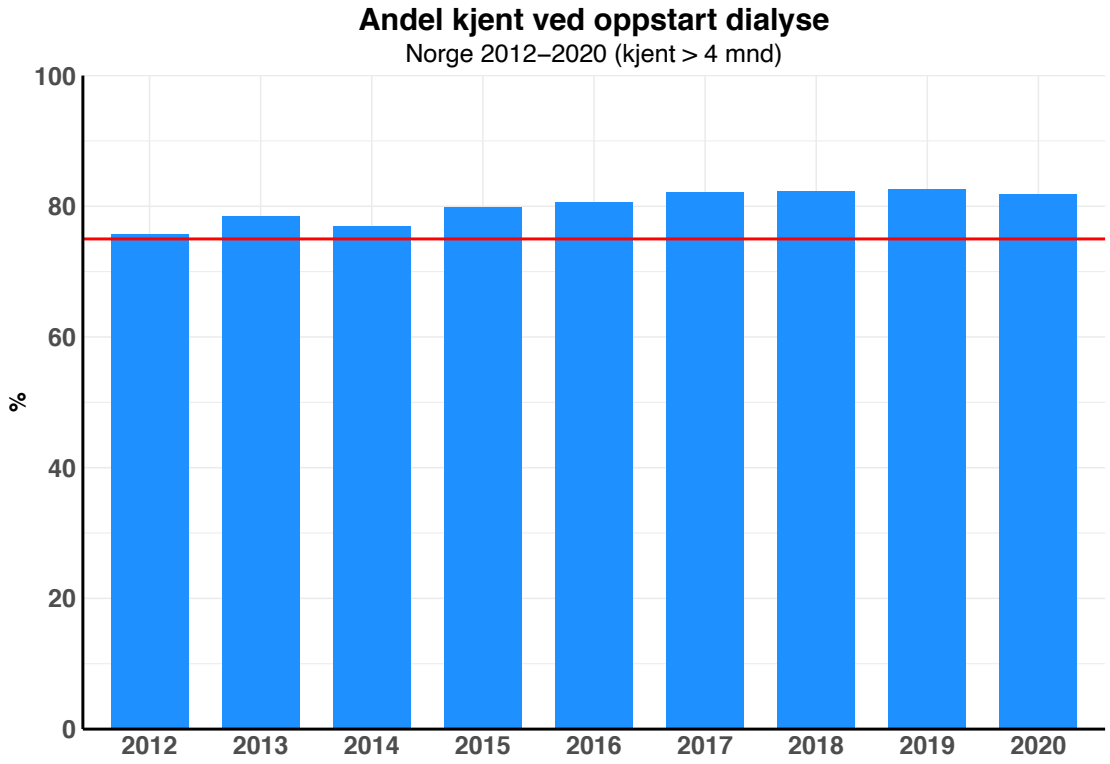



**Figure 58:**



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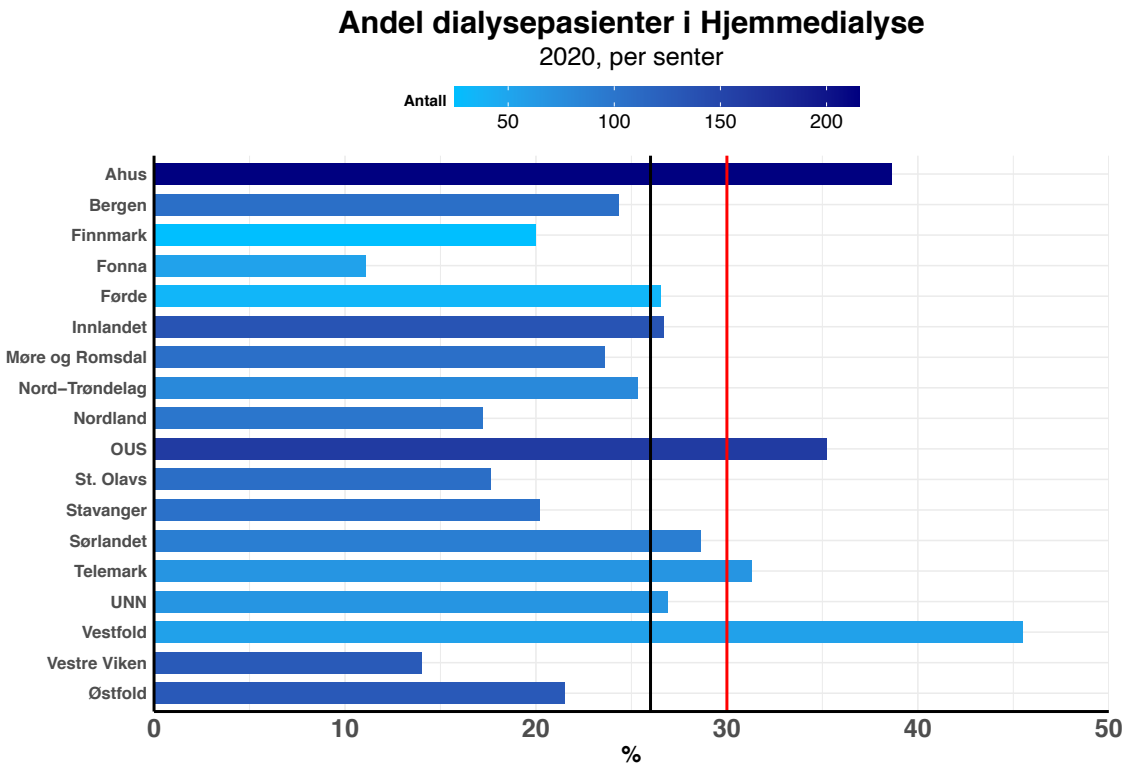


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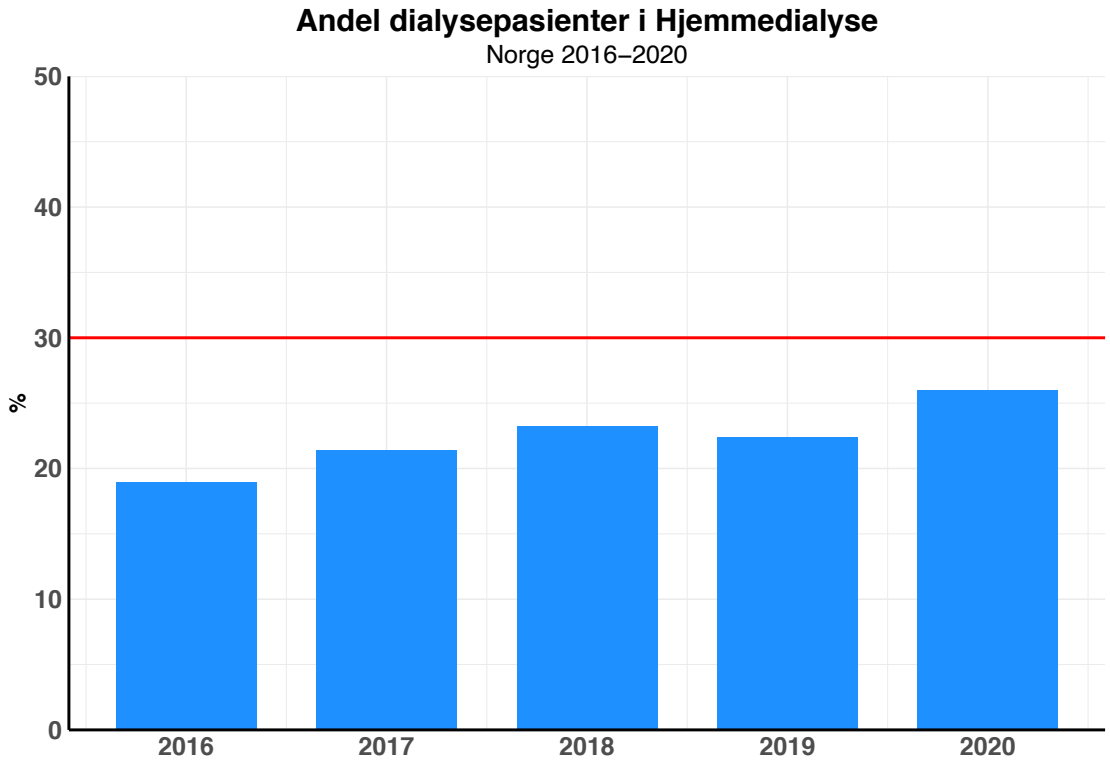


**Figure 61:**

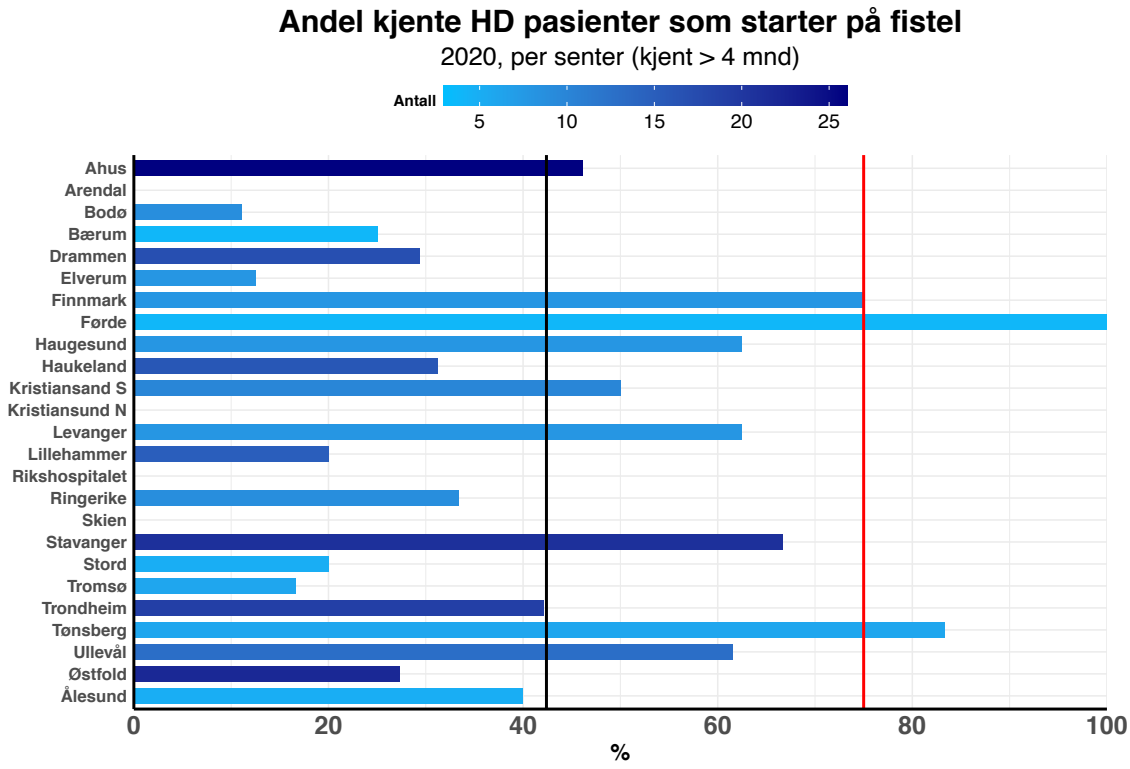



**Figure 62:**

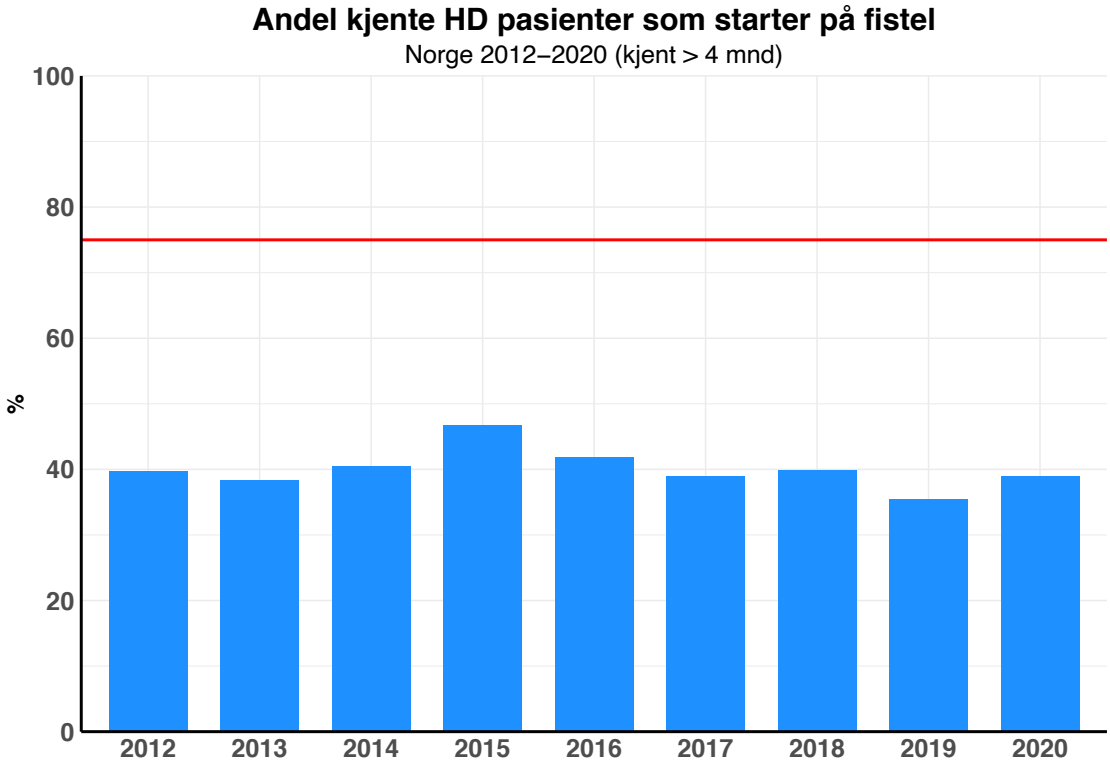


**Figure 63:**

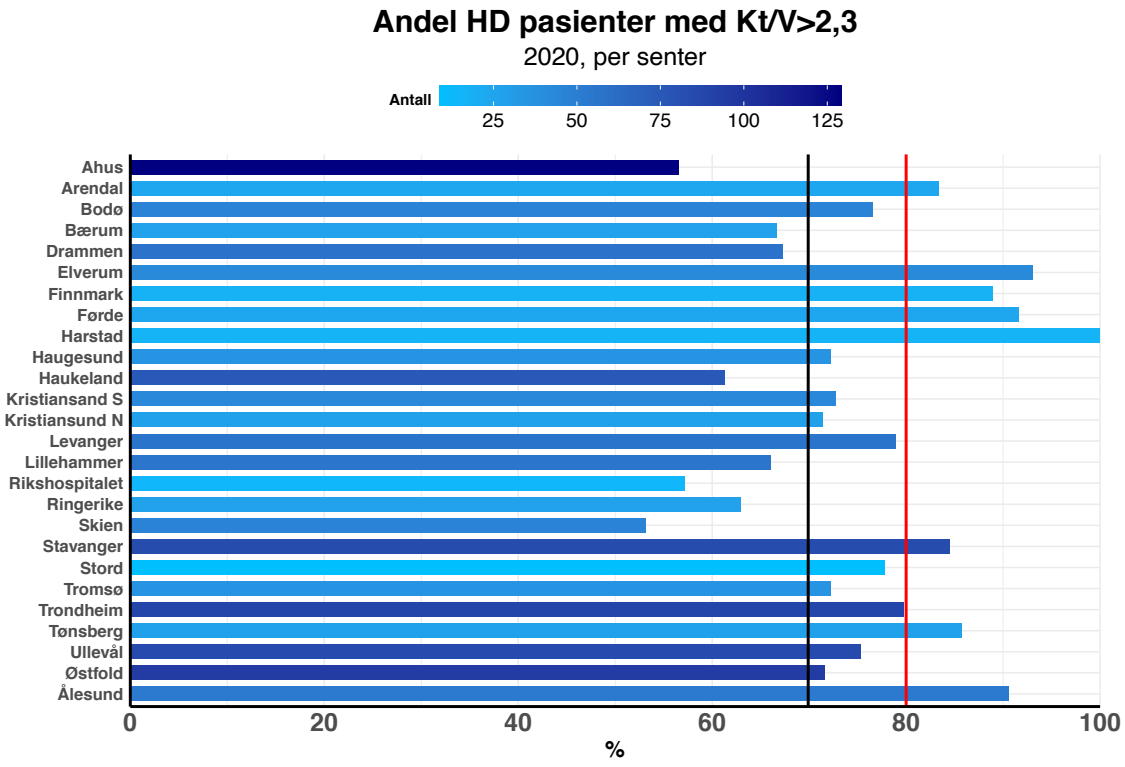
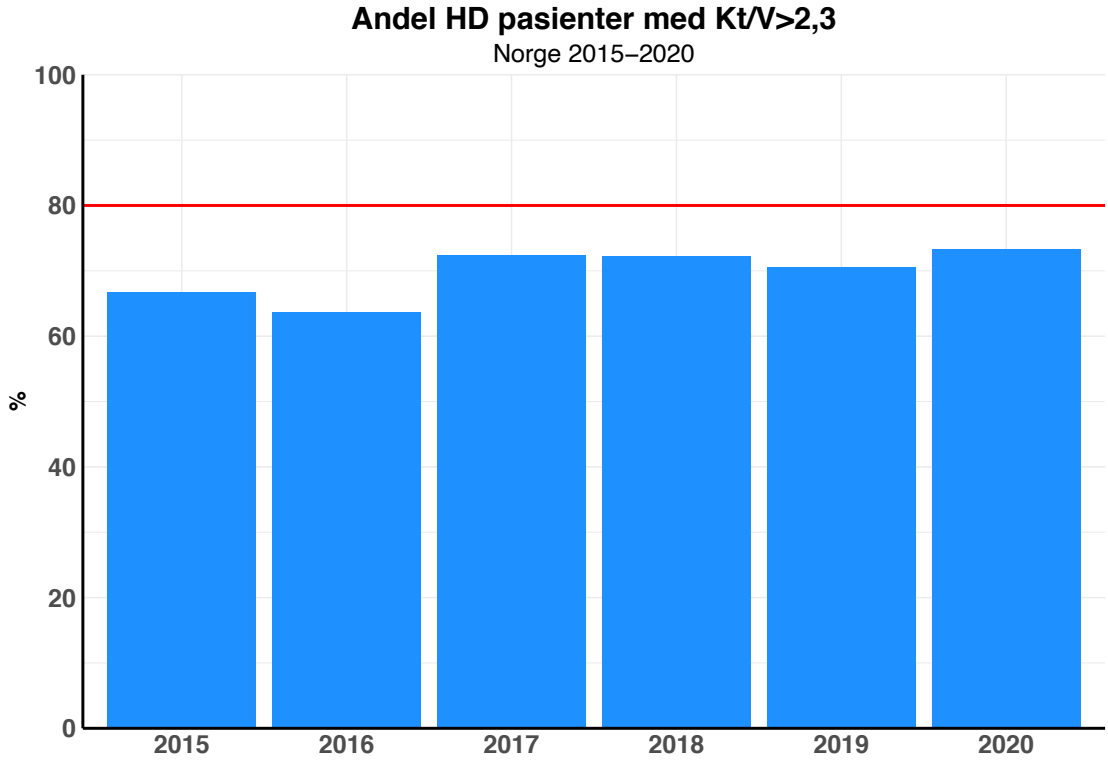



**Figure 64:**



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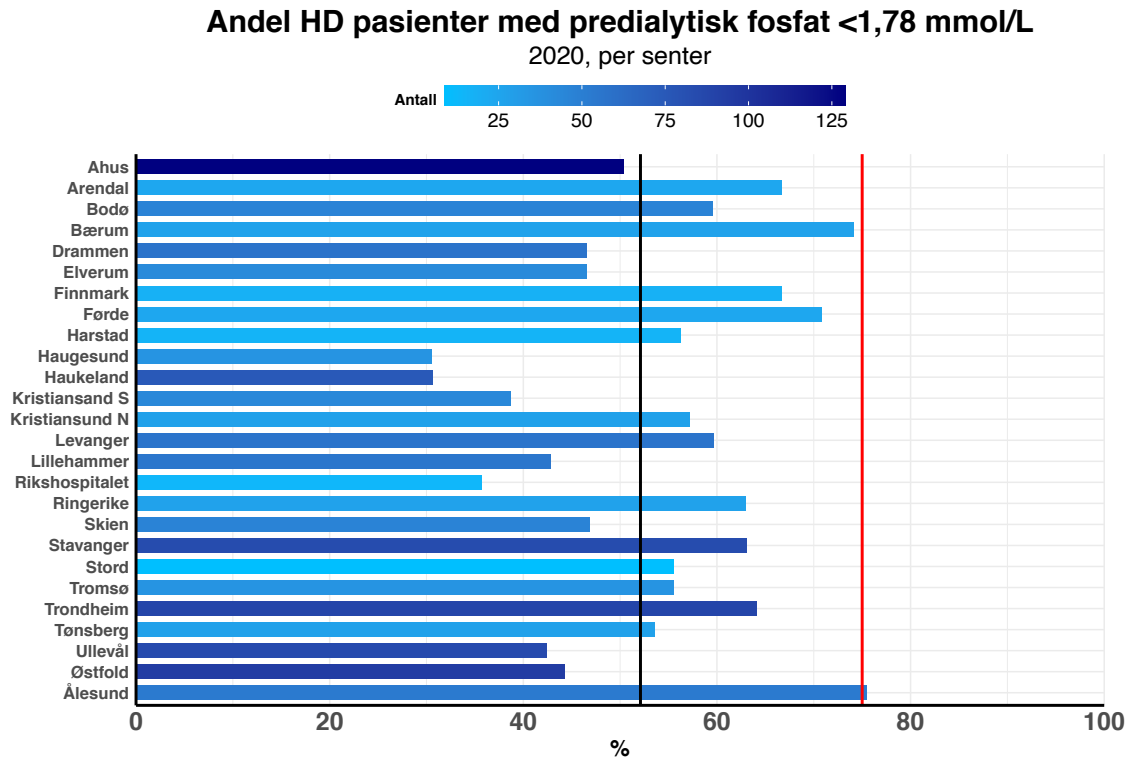
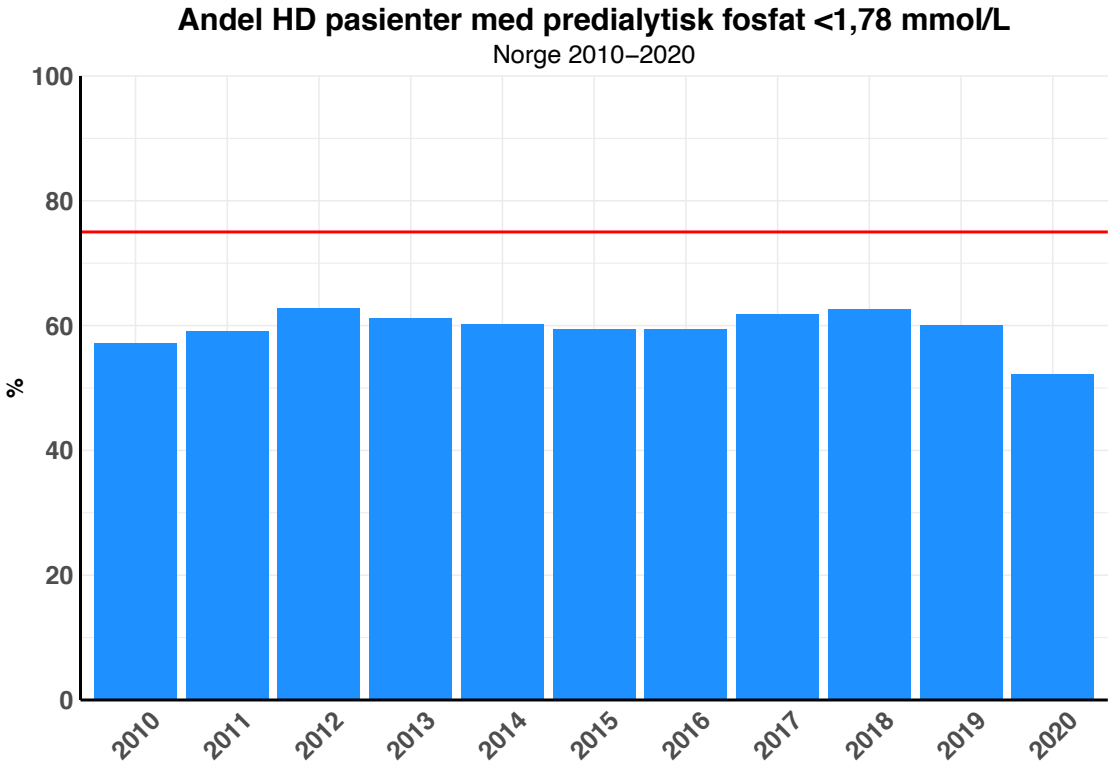



**Figure 66:**



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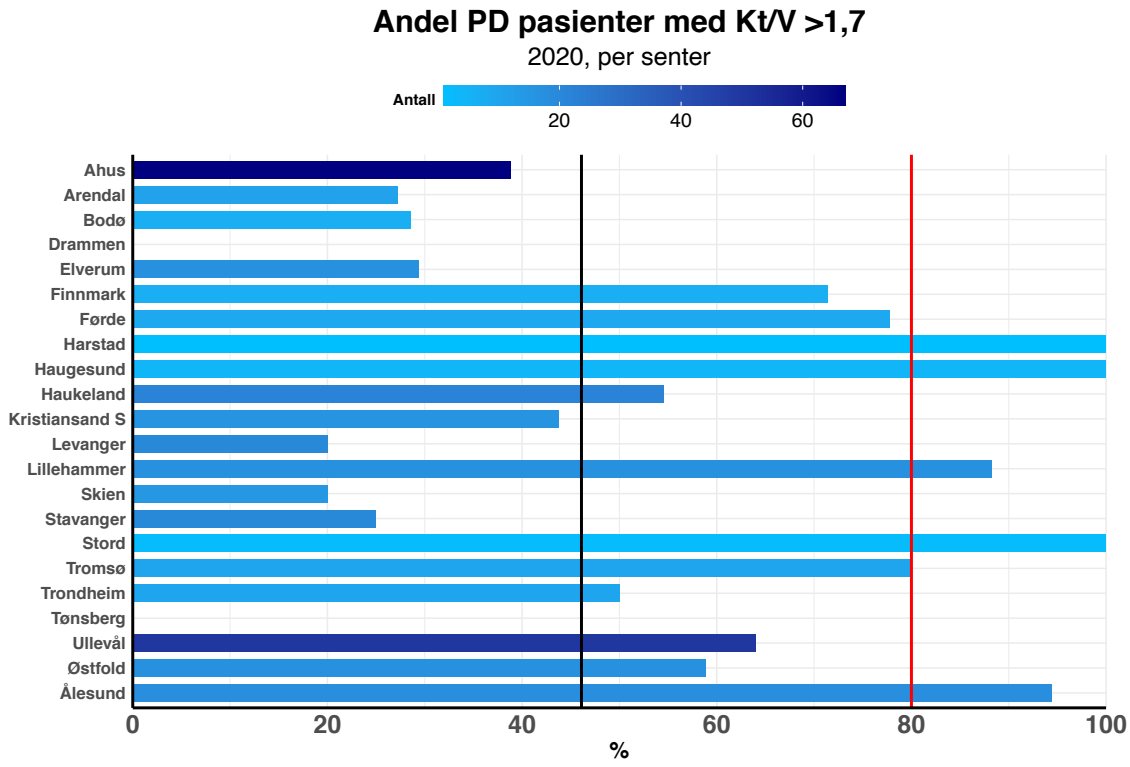


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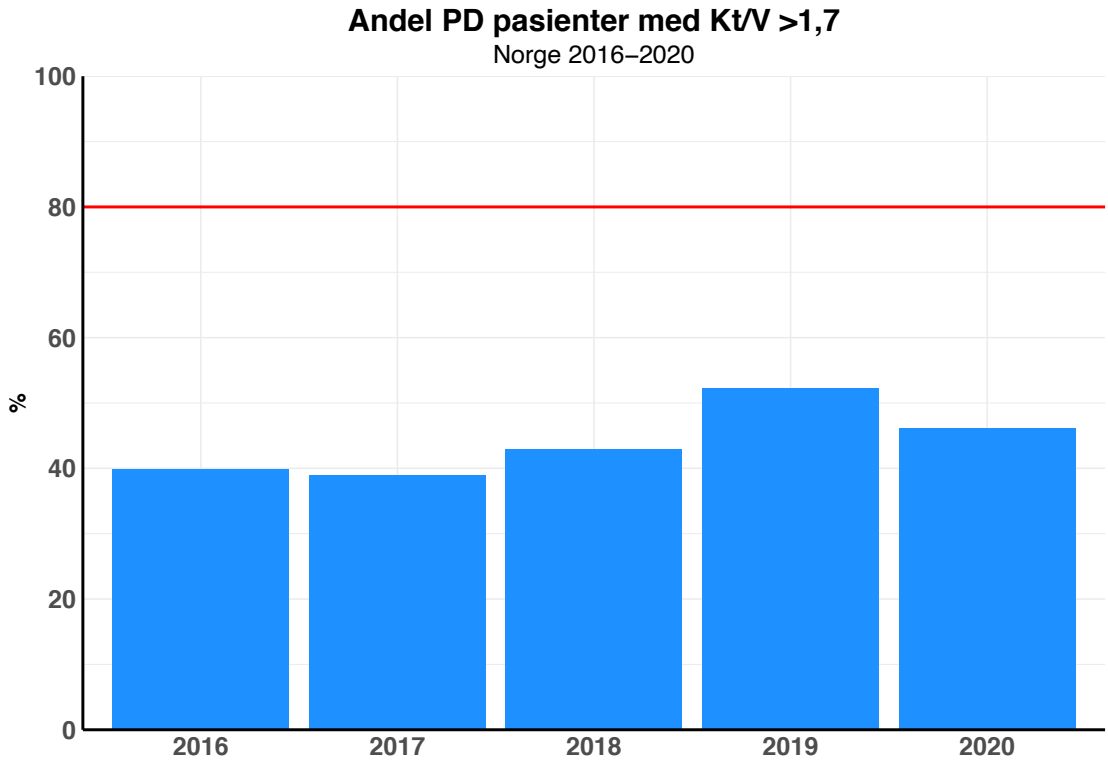

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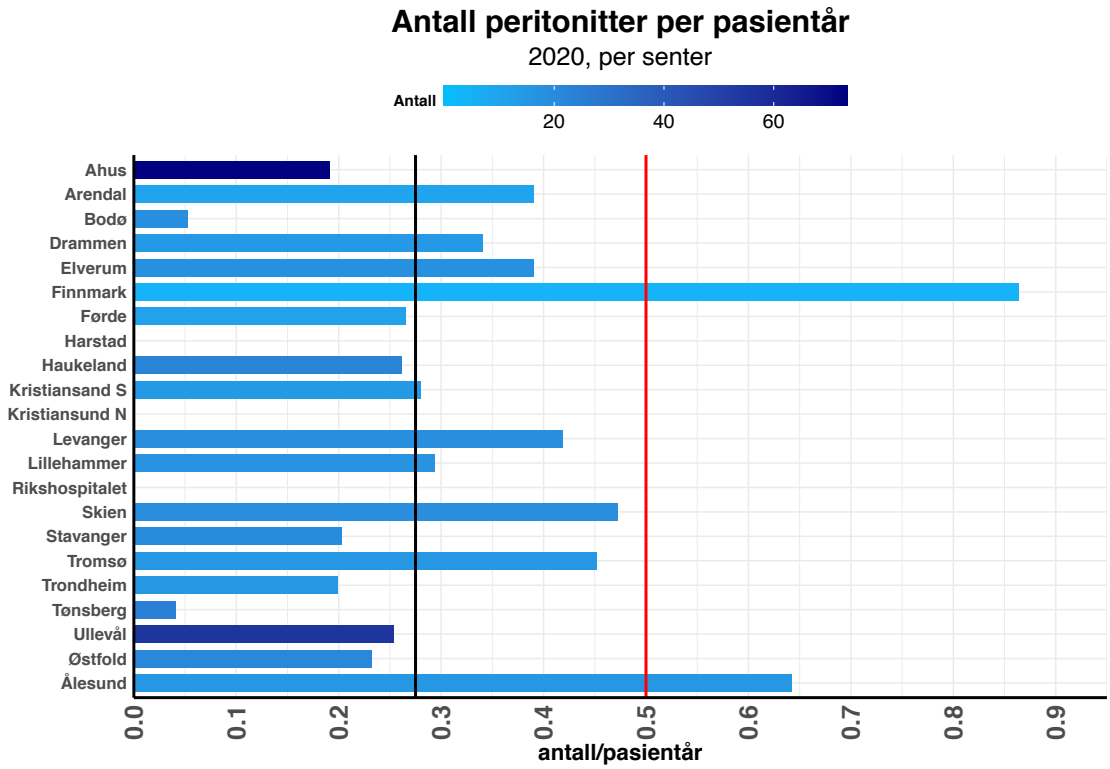


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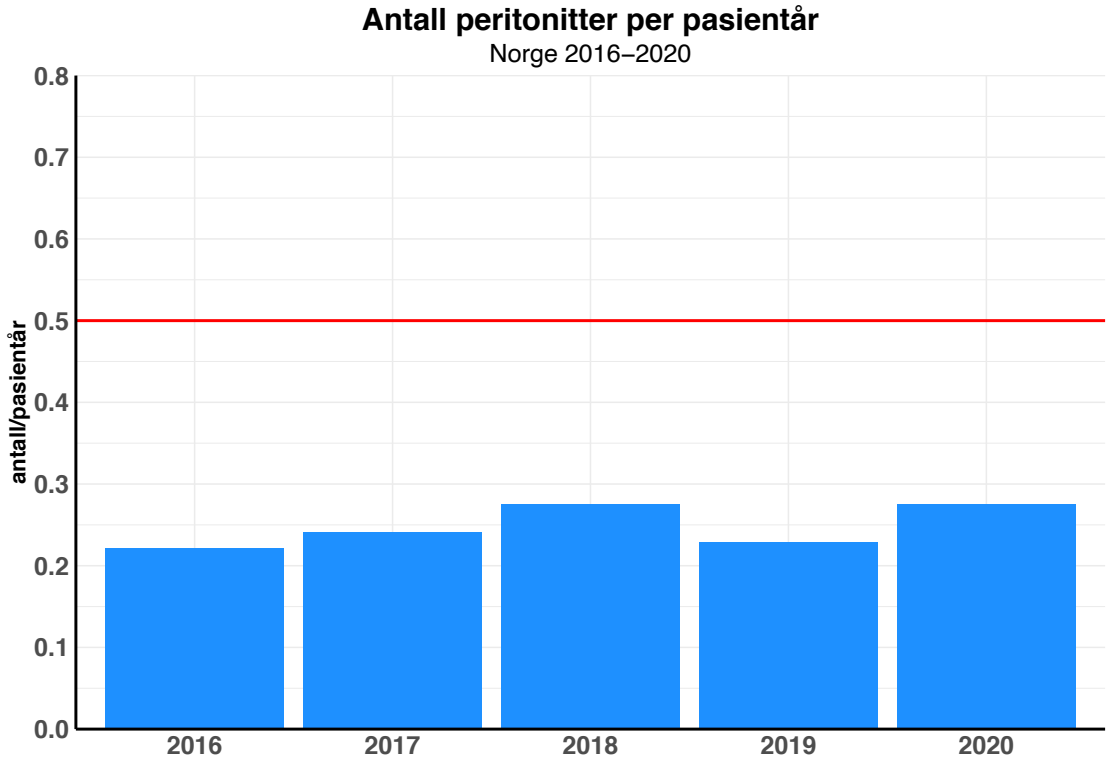

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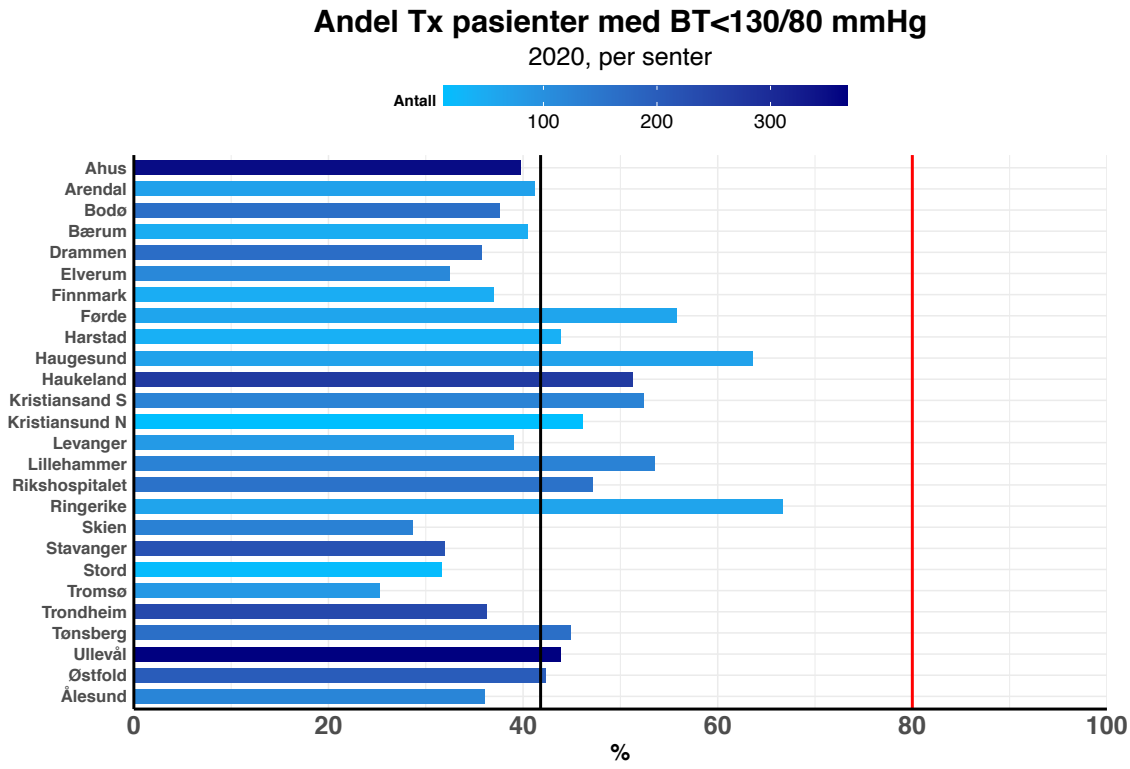


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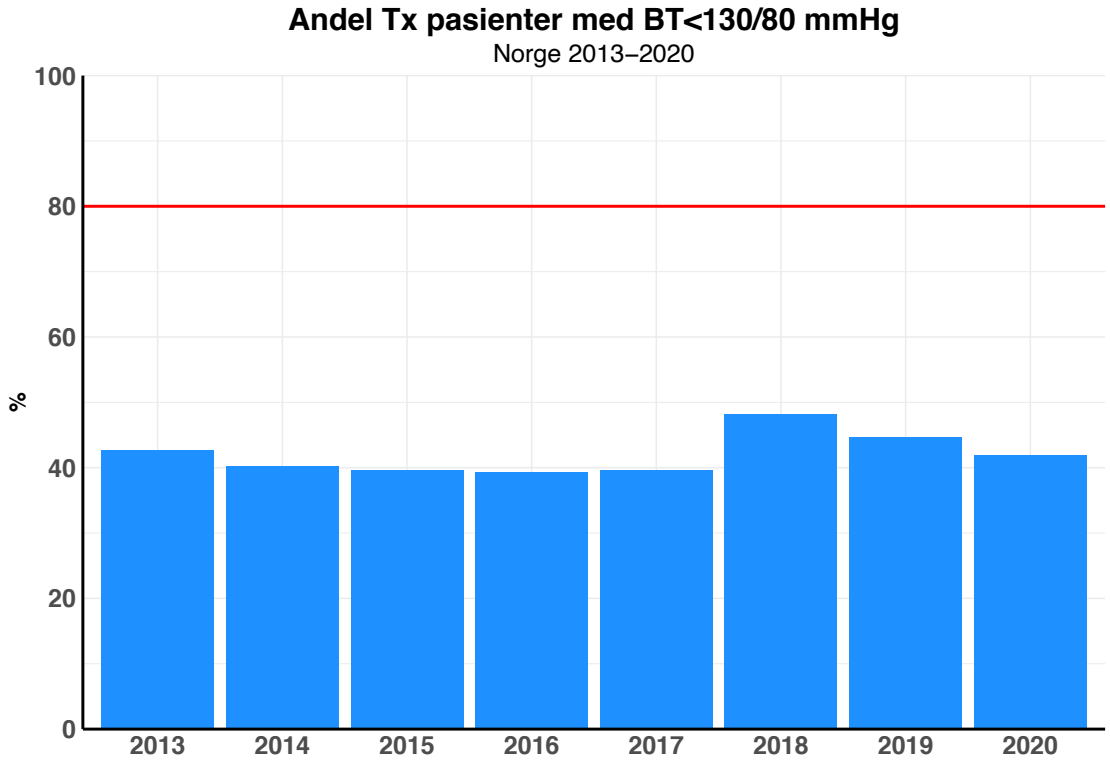

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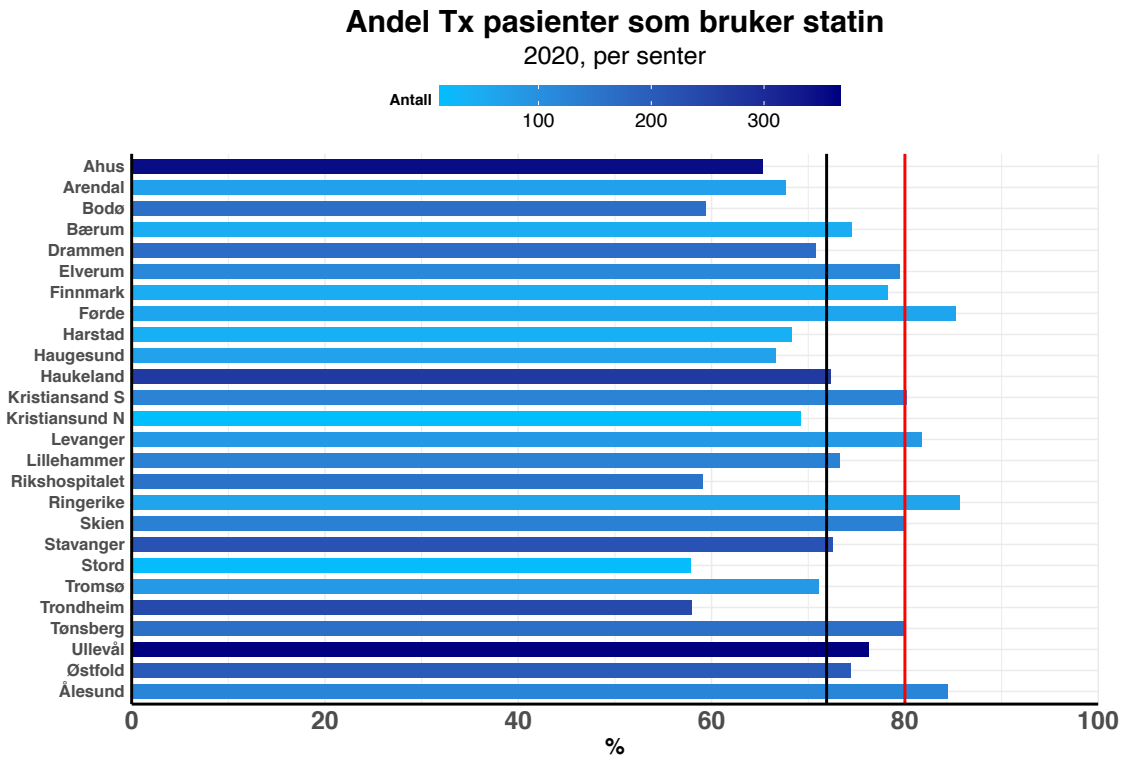


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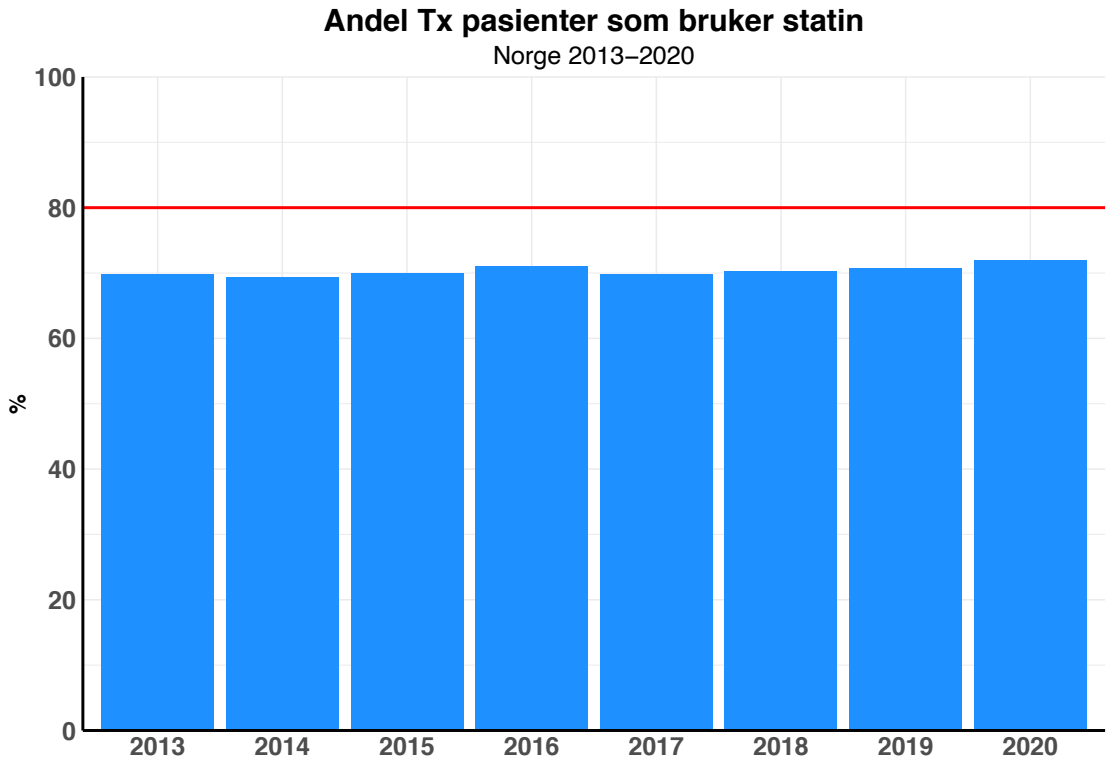

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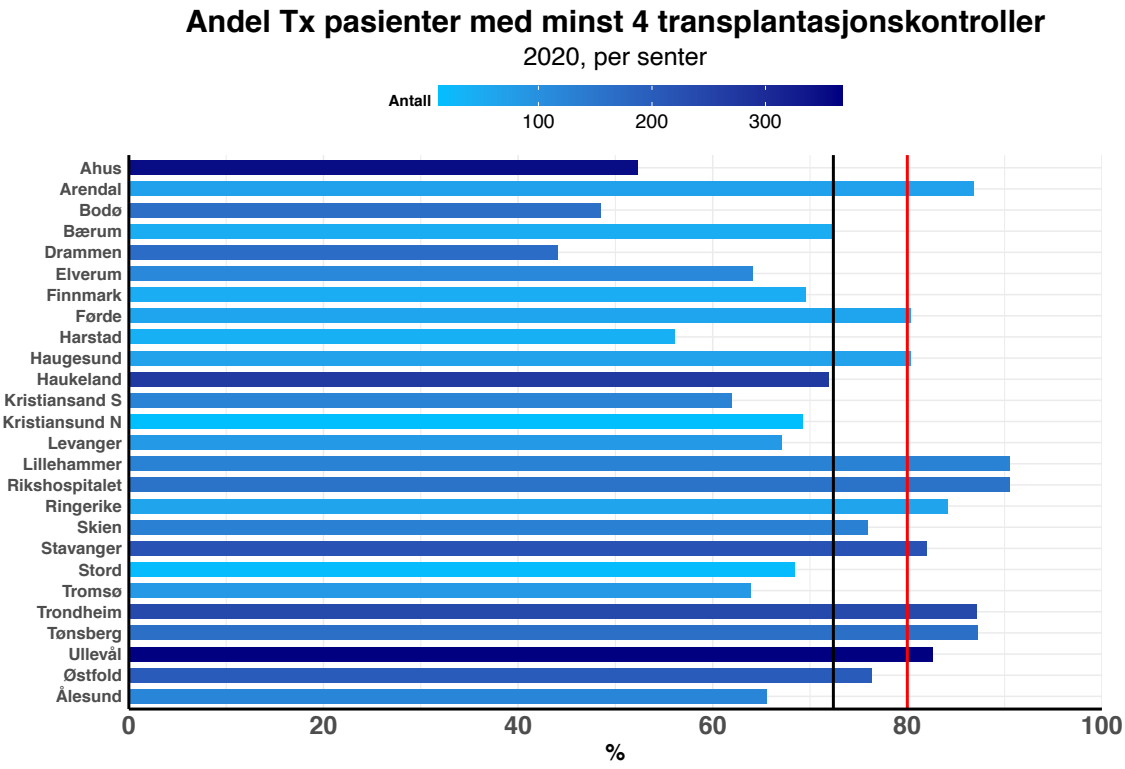


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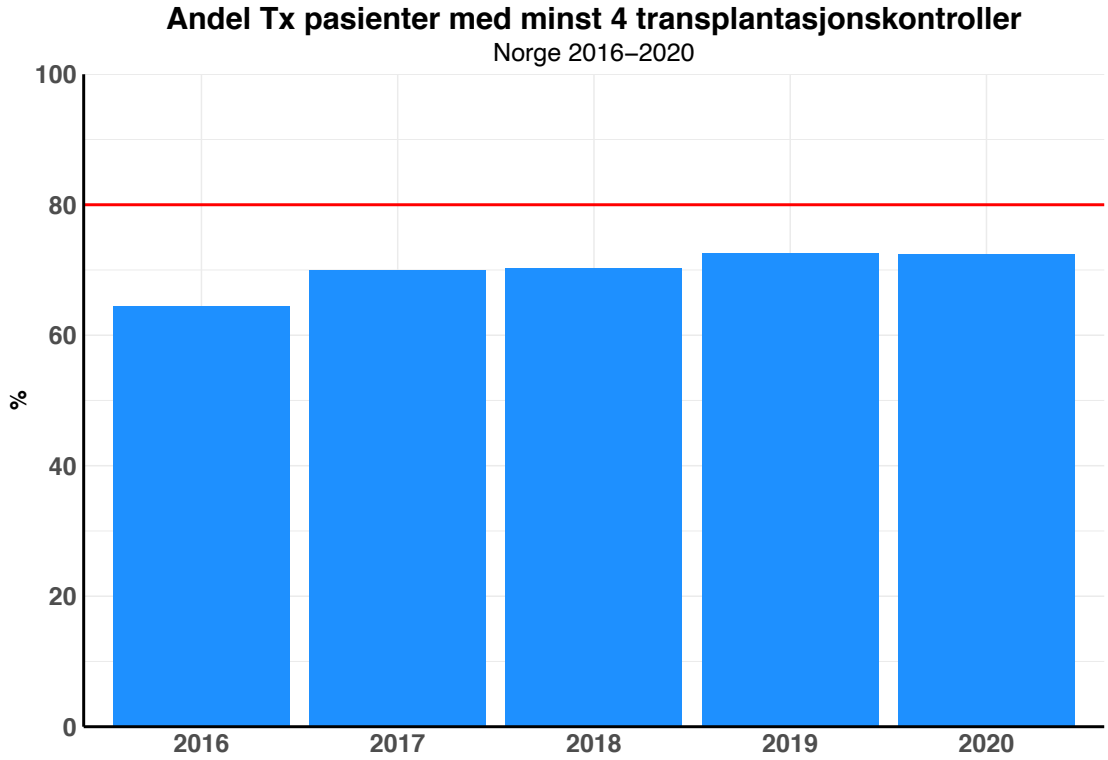
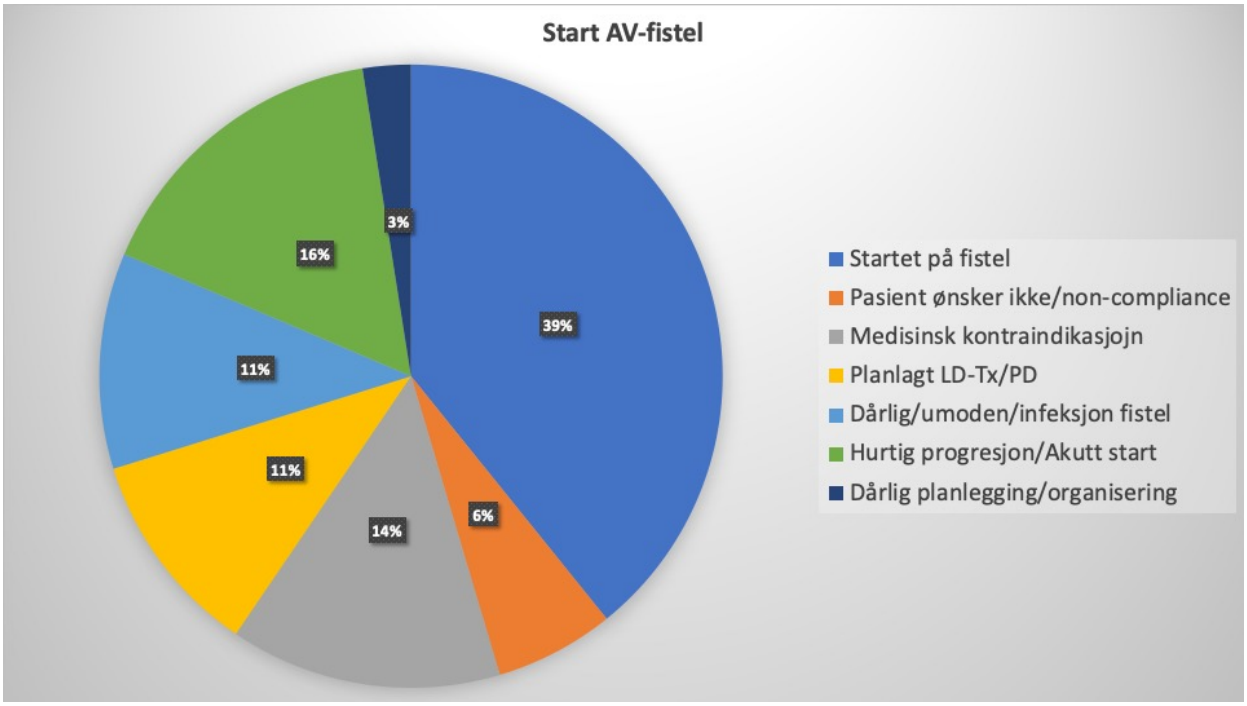


# Quality projects

## Reasons for not starting HD with AV-fistula as blood access:

One of the quality indicators for the registry is part of new patients (known at the nephrology unit for more than 4 months) starting HD with AV-fistula as blood access. The target achievement has been low over many years and in 2020 it was just over 40% reaching this target. The goal for the registry is to have 75% of the patients using an AV-fistula when starting HD. Maybe this is not realistic? So, in 2020 a quality project was initiated to collect reasons for not starting with AV-fistula. Data collection has been continued in 2021 and here we present data on 429 patients fulfilling the above-mentioned criteria for being included in the calculation of this quality indicator. In total 168 (39.2%) of the patients did start on AV-fistula. There is missing information of reason for 114 patients (26.6%). In **Figure 77** below the patients without information is disregarded, assuming that the percentage of different reasons for not starting using an AV-fistula is represented by those with reasons provided.

**Figure 77.** Percentage of different reasons for not starting HD using AV-fistula as blood access in the period 2020 to fall 2021. Total number of patients in the period is 429, for114 (26.6%) of patients not starting on an AV-fistula there is missing information about reason.

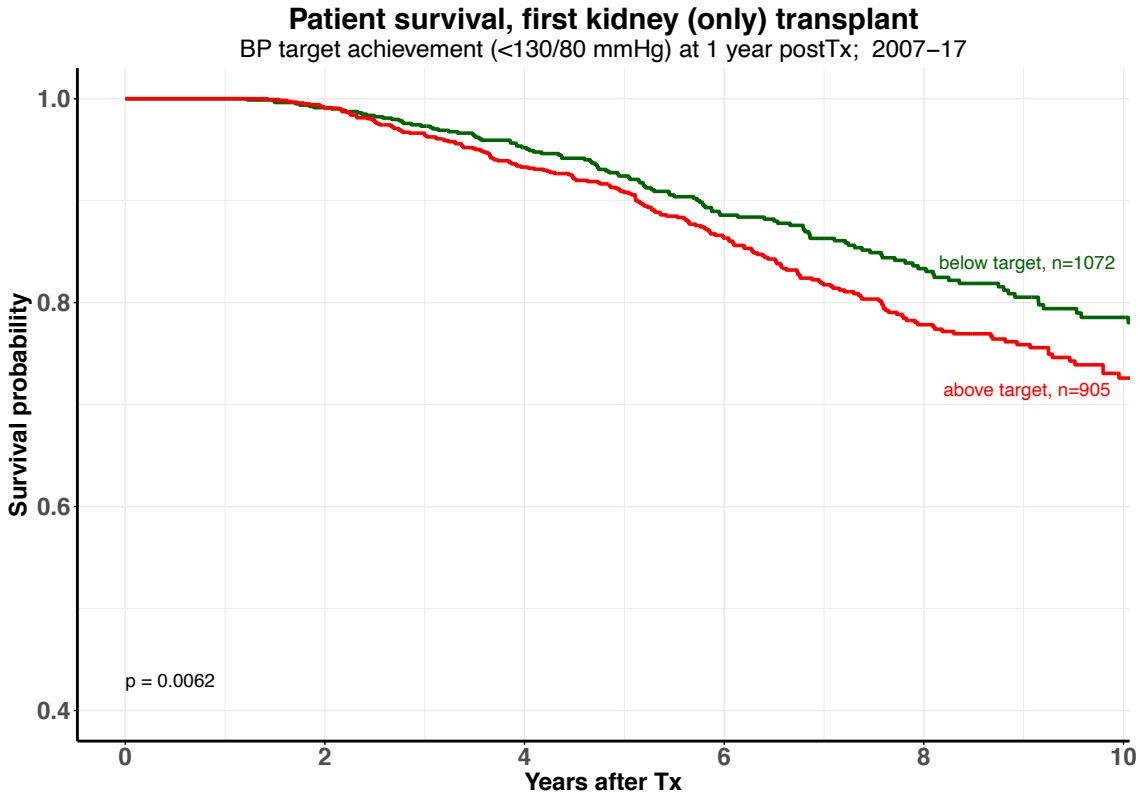



From these results it seems unrealistic to get 75% of patients starting on AV-fistula. The second to fourth reason listed in the figure, in total 31% of the total is not supposed to be started on AV-fistula. A part of the patients covered by reason five and six is probably possible to get started on AV-fistula with some relevant interventions but it is difficult to state an exact number. Assuming that 25% of the at least are possible AV-fistula starters the target level for this quality indicator should probably be more in the range of 50%.

## Blood pressure in kidney transplant recipients:

The registry performed a survey in relation to capture of the 2018 annual data from kidney transplant recipients in order to collect more information about the low target achievement of the quality indicator of part of patients with a blood pressure below 130/80 mmHg. The results of the project is published [Onsøien MO et al. Transplant Direct. 2021; 7(4): e688] and it was a hope that increased awareness would result in more patients reaching the target in the coming years as there was an increase in 2018. Unfortunately, it does not look like this is enough as the target achievement decrease both in 2019 and in 2020 and is still in the 40% range. Blood pressure treatment is a risk factor (**Figure 78**) that affects patient survival that to a high degree is possible to influence in most patients by optimized treatment. We will continue working with this topic and for the annual data capture in 2021 the blood pressure measurement method will be included. There is also a study on home-monitoring of blood pressure in the planning and it will most probably start in 2022, after a pause due to COVID-19.

**Figure 78**. Patient survival probability by blood pressure target achievement and in the era of modern immunosuppressive therapy in Norwegian renal replacement recipients.



## COVID-19 in patients on renal replacement therapy

In 2020 the registry started to collect data on renal replacement patients with COVID-19. The registry also reported data to the European collaboration initiative ERACODA, coordinated by ERA-EDTA. In cooperation with researchers at OUS-Rikshospitalet and all the local contact persons at the 26 nephrology units in Norway a national screening of SARS-CoV-2 IgG antibodies was also initiated, inviting all kidney transplant recipients in the registry, to see how many of the patients that had been infected with the virus, also covering subclinical infections. In 2021 this national screening was extended to also investigate immunological response to the SARS-CoV-2 vaccines, in both dialysis and kidney transplant patients, which was rolled out during the first quarter of 2021,

By the end of 2020 had 70 patients (1.3%) been registered with COVID-19; 35 patients in dialysis (2.0%) of which 12 later died due to COVID-19 and 35 kidney transplant recipients (0.9%) of which 7 later died due to COVID-19. In the national screening of SARS CoV-2 antibodies we received samples from over 60% of all kidney transplants in relation to the first COVID-19 wave and a total of 16 patients were identified with positive SARS CoV-2 IgG antibodies. From these data and international publications, it is clear that patients on renal replacement treatment is a high-risk population with a high death rate when infected and that most of the patients have been very careful during the pandemic and managed to not become infected.

# Concluding remarks:

The incidence of patients in CKD5 is still increasing. Patients starting RRT is steadily being older by the year. When interpreting the incidence rate, it should however 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. A coverage analysis on the 2019 data underway in cooperation with the Norwegian Patient Registry (NPR). The prevalence is still 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 in order to meet the demand. Recently a new source of deceased donor organs has been approved in Norway, the so called cDCD. It is still too early to evaluate what impact this will have on the number of available organs.

The quality projected performed in 2019 (2018 annual data), focusing on blood pressure treatment in transplanted patients, revealed a certain potential for reaching a higher level of goal achievement. Based on these results the 80% goal was kept. Unfortunately, this year's data do not indicate any improvement of target achievement so additional initiative is needed to increase the number of patients researching the target blood pressure.

This year the focus has been on why only a low number of patients starting on hemodialysis utilize AV-fistula as blood access. The results of a survey indicate that the target level should be lowered. This will be addressed by the "Fagråd" during 2022.

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 2020 a total of 11 international peer reviewed papers, but no 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"). The registry has also been active in keeping track of all RRT patients developing CVOID-19. These data show a high death rate from COVID-19 in RRT patients but that RRT patients in Norway seem to have adopted a behavior to avoid infection.

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 GREATLY acknowledged!

*Report completed 25.11.2021*

# Appendix:

| | | New patients in RRT 2020 | | | | Patients in RRT by 31.12.2020 | | | | | Dialyses etc. 2020 | | | Died 2020 | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 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 | 33 | 21 | 7 | 61 | 130 | 11 | 72 | 362 | 575 | **23,166** | 0 | 0 | 33 | 18 | 119 |
| Arendal | | 5 | 1 | 1 | 7 | 23 | 0 | 11 | 69 | 103 | **3,451** | 0 | 41 | 6 | 4 | 27 |
| Bergen | 2 | 18 | 13 | 4 | 35 | 81 | 2 | 24 | 294 | 401 | **12,694** | 25 | 50 | 15 | 8 | 44 |
| Bodø | 8 | 13 | 5 | 2 | 20 | 72 | 0 | 17 | 169 | 258 | **13,600** | 9 | 0 | 17 | 8 | 45 |
| Bærum | | 6 | | 3 | 9 | 26 | 1 | | 69 | 96 | **4,570** | 0 | 0 | 8 | 1 | 22 |
| Drammen | 1 | 25 | 4 | 2 | 31 | 56 | 4 | 13 | 174 | 247 | **8,071** | 17 | 0 | 14 | 11 | 11 |
| Elverum | | 12 | 4 | 0 | 16 | 45 | 2 | 17 | 122 | 186 | **7,368** | 0 | 21 | 11 | 7 | 36 |
| Finnmark | 5 | 9 | | 0 | 9 | 20 | 0 | 7 | 48 | 75 | **3,020** | 0 | 0 | 4 | 1 | 13 |
| Førde | 2 | 5 | 3 | 0 | 8 | 25 | 0 | 9 | 62 | 96 | **4,288** | 0 | 0 | 6 | 1 | 18 |
| Harstad | | 1 | | 1 | 2 | 15 | 0 | 1 | 40 | 56 | **2,375** | 0 | 0 | 1 | 3 | 5 |
| Haugesund | 2 | 11 | 1 | 1 | 13 | 39 | 0 | 4 | 66 | 109 | **5,235** | 22 | 23 | 7 | 5 | 22 |
| Hønefoss | 1 | 11 | | 0 | 11 | 30 | 0 | | 64 | 94 | **4,024** | 0 | 0 | 4 | 3 | 17 |
| Kristiansand S | 1 | 14 | 10 | 0 | 24 | 45 | 0 | 16 | 127 | 188 | **6,900** | 20 | 0 | 13 | 3 | 44 |
| Kristiansund N | 1 | 6 | | 0 | 6 | 28 | 2 | 0 | 46 | 76 | **4,817** | 0 | 0 | 4 | 0 | 18 |
| Levanger | 6 | 10 | 8 | 3 | 21 | 60 | 0 | 20 | 84 | 164 | **10,359** | 5 | 109 | 11 | 3 | 60 |
| Lillehammer | 3 | 16 | 7 | 1 | 24 | 58 | 1 | 18 | 160 | 237 | **8,200** | 16 | 0 | 13 | 5 | 46 |
| Rikshospitalet | | 5 | | 1 | 6 | 15 | 1 | | 166 | 182 | **3,551** | 143 | 85 | 1 | 8 | 6 |
| Stavanger | | 26 | 6 | 3 | 35 | 83 | 1 | 20 | 227 | 331 | **12,525** | 22 | 21 | 14 | 9 | 56 |
| Stord | | 5 | | 1 | 6 | 9 | 0 | 2 | 17 | 28 | **1,246** | 0 | 0 | 4 | 1 | 6 |
| Telemark | 4 | 11 | 7 | 2 | 20 | 46 | 2 | 17 | 132 | 197 | **7,656** | 1 | 0 | 14 | 5 | 44 |
| Tromsø | 3 | 11 | 5 | 0 | 16 | 33 | 3 | 12 | 83 | 131 | **7,040** | 0 | 0 | 14 | 6 | 22 |
| Trondheim | 4 | 23 | 5 | 4 | 32 | 88 | 4 | 14 | 247 | 353 | **15,240** | 118 | 255 | 18 | 7 | 61 |
| Tønsberg | | 13 | 7 | 1 | 21 | 30 | 1 | 24 | 165 | 220 | **5,306** | 14 | 74 | 8 | 3 | 35 |
| Ullevål | | 16 | 17 | 9 | 42 | 88 | 3 | 53 | 366 | 510 | **15,424** | 34 | 0 | 25 | 11 | 73 |
| Østfold | 2 | 29 | 9 | 4 | 42 | 104 | 6 | 23 | 208 | 341 | **16,045** | 23 | 0 | 13 | 10 | 68 |
| Ålesund | 1 | 5 | 11 | 4 | 20 | 52 | 2 | 21 | 121 | 196 | **8,812** | 66 | 0 | 7 | 9 | 49 |
| ***SUM*** | ***47*** | ***339*** | ***144*** | ***54*** | ***537*** | ***1,301*** | ***46*** | ***415*** | ***3,688*** | ***5,450*** | ***214,983*** | ***535*** | ***679*** | ***285*** | ***150*** | ***967*** |
| *# Pr. mill innb.* | | *63.1* | *26.8* | *10.1* | *100.0* | *242.2* | *8.6* | *77.3* | *686.5* | *1014.5* | | | | | | *180.0* |
| *% of total* | | *63.1* | *26.8* | *10.1* | *100,0* | *23.9* | *0.8* | *7.6* | *67.7* | *100,0* | | | | | | *17.7* |

## 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. |
| | | | |

27-11-2017

| 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 transplantasjons kontroller 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≥80%) | < 10% | Mål på om behandlingstilbudet er godt nok |
| | Biopsipåvist akutt rejeksjon 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) |
| | | | |