# ANNUAL REPORT 2013

# The
# Norwegian Renal Registry

# (Norsk Nefrologiregister)

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

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# Preface

The Norwegian Renal Registry (Norsk Nefrologiregister) was formally constituted in 1994 as a collaboration between The Norwegian Renal Association (Norsk Nyremedisinsk Forening) and Oslo University Hospital-Rikshospitalet, with the latter as the formal owner. National data on renal replacement therapy (RRT) had been collected within The Renal Association since 1980 in a less formalised manner, and the transplant centre had stored data on transplanted patients since the late sixties. Further, Norwegian renal units had reported to the ERA-EDTA-registry since the late sixties.

Since the mid-90ies, a process of transition from a pure epidemiological registry into a quality-oriented registry has progressed. With the present way of collecting and processing quality data, they cannot be collected in time to be included in the annual report, but selected data may be included in the next years report; others will be theme for quality-seminars and special reports.

## National organisation and policy

Norway has 5.078 mill. inhabitants (July 2013) and 19 counties with populations ranging from 74.800 to 629.300. Each county, except one, has a central renal unit and some have two, further some have satellite units run in close contact with the central unit. There is only one transplant centre (two during 1963-82). Pre-transplant work-up, as well as post-transplant follow-up beyond 3 months, is handled by the county-centres.

The centres, at present 25, are responsible for reporting data from day 1 on all patients receiving renal replacement therapy (RRT) for chronic renal failure within their area. Based on annual cross-checks, reporting is considered to be complete. Treatment of acute renal failure is not reported unless the failure turns out to be irreversible, in which case the whole treatment period is included. Minor changes of treatment modality, e.g. from HD to HDF or between CAPD and APD, are not reported. Similarly, temporary changes to HD for PD-patients are not reported. At intervals, cross-checking for unreported deaths is performed against official census data.

Transplantation has always been considered the 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.

Incidence and prevalence calculations in this report are based on the national population data from July 2013, although this in some instances may be slightly misleading since population changes have not been uniform in all counties during the period.

# Incidence figures for 2013

During 2013 a total of 512 new patients (in 2012: 515) entered renal replacement therapy (RRT), i.e. 100.8 per mill. inhabitants.

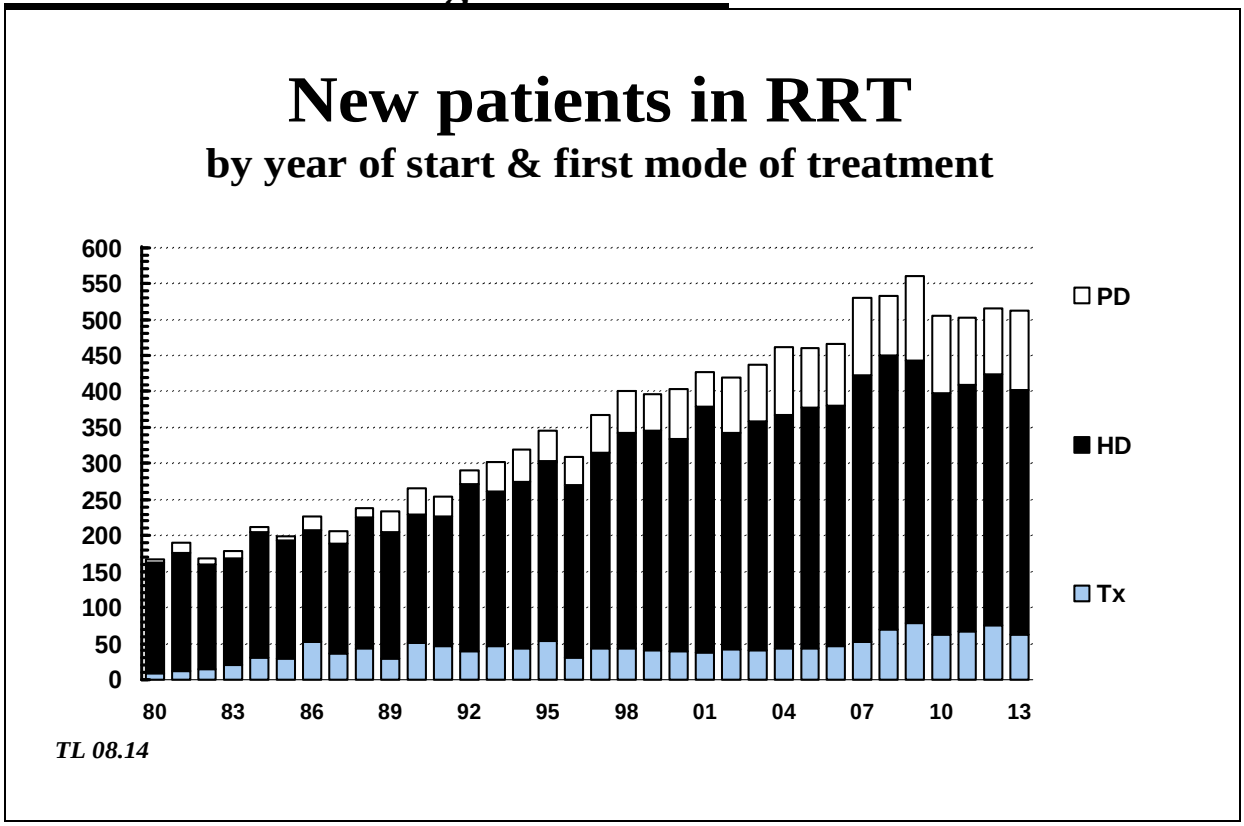
A majority of 345 (67.4 %) were males and 167 (32.6 %) females. Median age at start was 66.5 years, mean 63.3 years, ranging from 0.4 to 90.9 years.

Tabulated by first mode of treatment, and age at start of treatment:

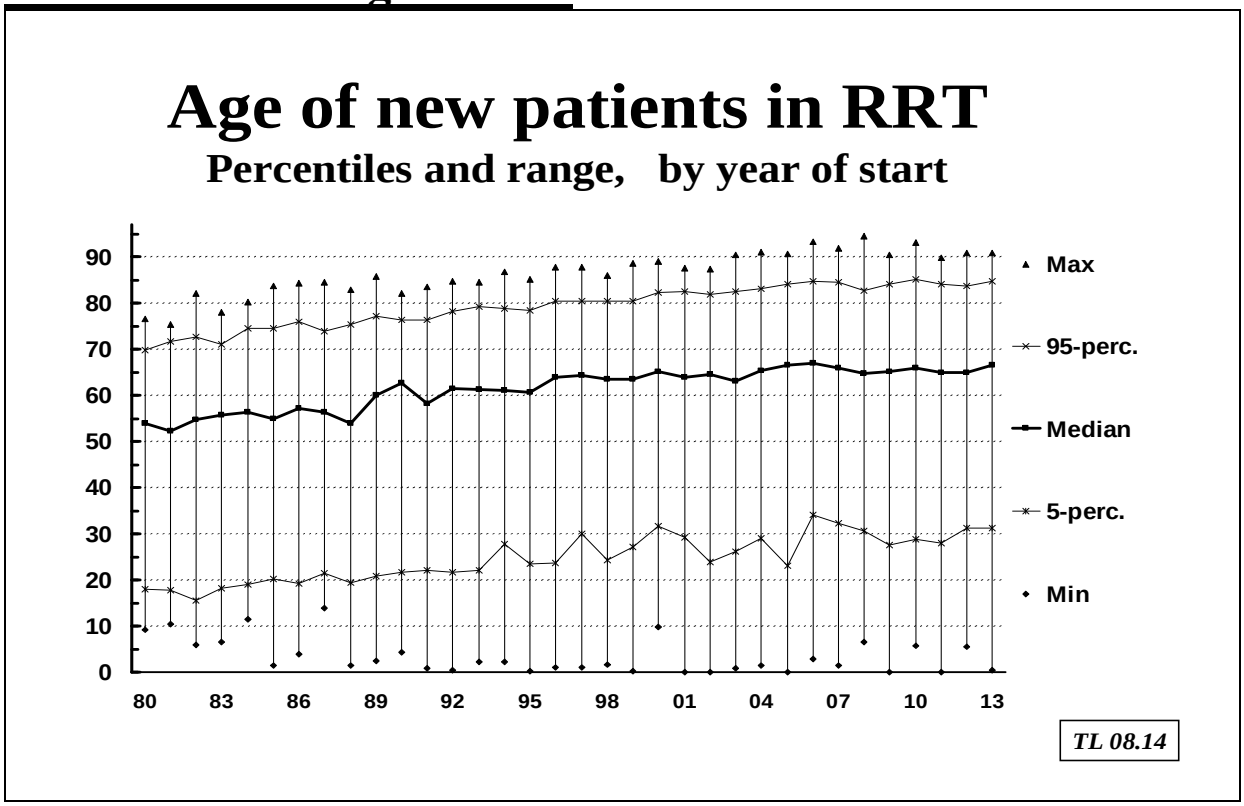
| | < 15 | 15-24 | 25-34 | 35-44 | 45-54 | 55-64 | 65-74 | 75-84 | 85+ | Total | in % |
|---|---|---|---|---|---|---|---|---|---|---|---|
| HD | 1 | 5 | 16 | 25 | 42 | 56 | 93 | 82 | 19 | 339 | 66.2 |
| PD | 1 | 1 | 3 | 9 | 9 | 18 | 34 | 29 | 6 | 110 | 21.5 |
| TX | 2 | 1 | 4 | 11 | 11 | 17 | 15 | 2 | 0 | 63 | 12.3 |
| Total | 4 | 7 | 23 | 45 | 62 | 91 | 142 | 113 | 25 | 512 | 100 |
| in % | 0.8 | 1.4 | 4.5 | 8.8 | 12.1 | 17.8 | 27.7 | 22.1 | 4.9 | 100 | |

At start of treatment, 305 (60 %) were considered by their nephrologist to be a potential candidate for transplantation, while 207 (40 %) were accepted for life-long dialysis (the latter constituting 49 % of those starting with HD and 37 % of those starting PD).
Among the 449 patients starting dialysis in 2013, 79 % had been under control by the renal unit for at least four months, while 21 % were previously unknown.

## Incidence data: Changes 1980-2013




## Incidence data: Age at start



Since registration started in 1980 there has been a continuous shift in patient age. Both the maximum and the median age at start of RRT have increased. Also the 5-percentile and 95-percentile values (i.e. including the majority of patients) have increased with a similar number of years. But also smaller children have been accepted; the youngest ever started PD in 2011 at age two days. Four children below 15 years started RRT in 2013; after the peak number of 12 in 2005 we seem to be back to the previous range; between two and ten per year.

# Incidence data: Primary renal disease

| | 1980-89 | 1990-99 | 2000-04 | 2005-09 | 2010-12 | 2013 |
|---|---|---|---|---|---|---|
| Glomerulonephritis | 35% | 27% | 18% | 18% | 16% | 16% |
| Pyelo/interstitial nephr. | 15% | 11% | 11% | 10% | 9% | 11% |
| Polycystic diseases | 10% | 9% | 9% | 8% | 9% | 7% |
| Diabetic nephropathy | 13% | 11% | 15% | 16% | 16% | 19% |
| Amyloidosis | 6% | 5% | 3% | 2% | 2% | 1% |
| Vascular/hypertensive | 7% | 21% | 28% | 31% | 36% | 34% |
| Immune/systemic | 5% | 5% | 4% | 4% | 4% | 4% |
| Kidney tumour | 1% | 1% | 1% | 2% | 1% | 1% |
| Myelomatosis | 2% | 2% | 3% | 3% | 2% | 1% |
| Other defined | 4% | 4% | 3% | 4% | 3% | 3% |
| Unknown | 3% | 3% | 4% | 4% | 3% | 3% |
| N: | 2018 | 3234 | 2149 | 2556 | 1533 | 512 |

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. Amyloidosis also seems reduced over time.

**Diabetic nephropathy** has contributed 10-17 % per year. In 2013, 28 were registered as having Type I and 68 as Type II diabetes, 79 patients with other types of primary renal disease were recorded as having diabetes as a co-morbid factor (2 Type I and 77 Type II), thus 34 % of new patients were diabetics.
The time from onset of diabetes to start of RRT differed considerably. For the 28 with Type I diabetes the mean time was 29.6 years, for the 68 with Type II diabetic nephropathy the mean time was 18.9 years. Type II diabetics judged to have a primary renal disease other than diabetic nephropathy, most often hypertensive, in mean had 12.3 years of pre-RRT diabetes duration.

**Cardiovascular disease** is often present at start of RRT. Coronary heart disease was reported in 147 (29%), 80 (16%) had anamnestic heart failure. Echo-verified left ventricular hypertrophy was reported in 113 (22%). Cerebrovascular disease was reported in 87 (17%) and peripheral atherosclerotic disease in 75 patients (15%) while 51 (10%) had chronic obstructive lung disease.

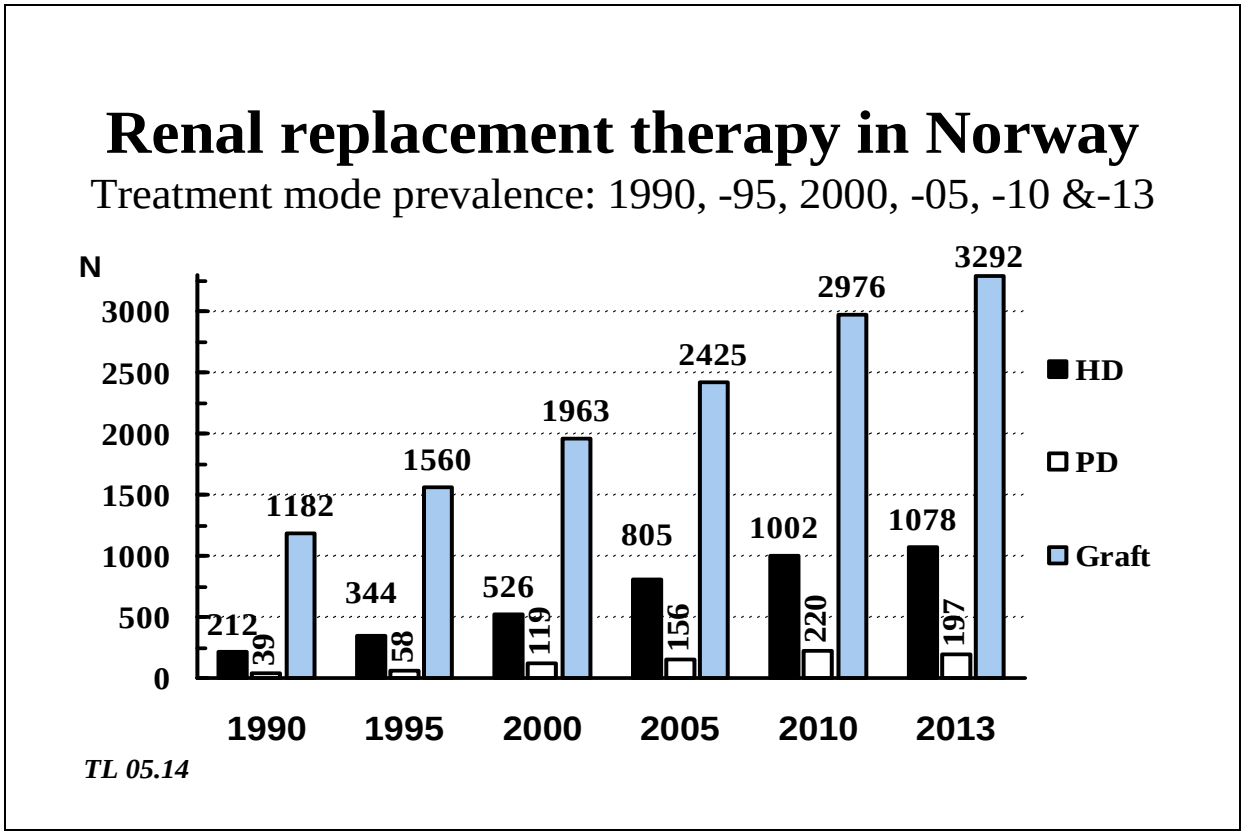
# Prevalence data: Status by 31.Dec. 2013.

By the end of 2013, 4567 patients in Norway received renal replacement therapy, i.e. 899.4 per million inhabitants. This represents an increase of 113 patients or 2.5 % since 2012.
Gender: 65.2 % males and 34.8 % females. Fourteen patients were on home-HD (11 in 2012).

Median age by the end of the year was 60.7 years, mean 58.9 years and range 0.5 - 96 years.

Tabulated by last mode of treatment and age by end of 2013:

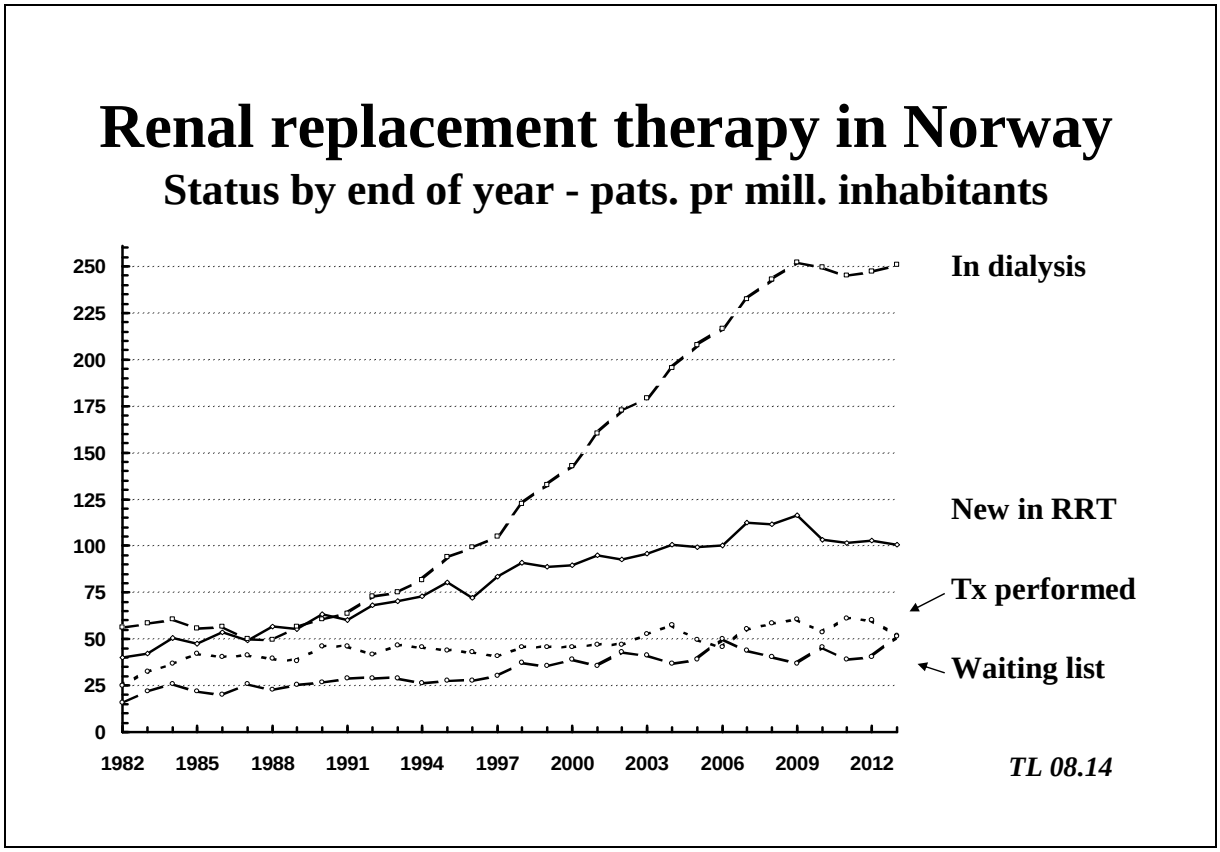
| | < 15 | 15-24 | 25-34 | 35-44 | 45-54 | 55-64 | 65-74 | 75-84 | 85+ | Total | in % |
|---|---|---|---|---|---|---|---|---|---|---|---|
| HD | 0 | 10 | 44 | 86 | 116 | 189 | 275 | 257 | 101 | 1078 | 23.6 |
| PD | 1 | 1 | 4 | 9 | 17 | 33 | 39 | 80 | 13 | 197 | 4.3 |
| TX | 40 | 78 | 194 | 445 | 672 | 824 | 759 | 268 | 12 | 3292 | 72.1 |
| Total | 41 | 89 | 242 | 540 | 805 | 1047 | 1073 | 605 | 126 | 4567 | 100 |
| In % | 0.9 | 1.9 | 5.3 | 11.8 | 17.6 | 22.9 | 23.5 | 13.2 | 2.8 | 100 | |




## Transplantation and waiting lists:

A total of 264 renal transplants were performed at Oslo University Hospital Rikshospitalet in 2013, i.e. 52 per million inhabitants. In 68 (26%) the graft came from a living donor (LD), 25 of those were biologically unrelated to the recipient (17 were spouses). Among the LD-graft recipients 27 out of 64 first graft recipients were grafted pre-emptively, 2 out of 4 re-graft recipients did not receive dialysis. 196 patients received a deceased donor (DD) graft, 40 out of the 170 first graft recipients were pre-emptively transplanted (24 %), while 9 out of 26 had a re-graft without entering dialysis. There were 234 first grafts (64 LD and 170 DD), 26 were second grafts (4 LD, 22 DD), three third grafts (all DD) and one fifth graft (DD).
Simultaneous kidney + pancreas (SPK) transplantation was performed in 14, further two patients with a functioning renal graft received a dys-synchrone pancreas graft. In addition, five Danish recipients received SPK in Oslo (not included in the above calculations).

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 170 first-DD-graft recipients in 2013 ranged from 7 to 82 years, with a mean age of 57 y. Out of these, 37 % were above the age of 65 and 4 % were 75 or older. The 64 recipients of a first LD-graft were from 1 to 77 years, mean 48 y. Regraft recipients (n=30) were from 8 to 74 years, mean 45 y.




By end 2013, 262 patients (51.6 per mill.) were on the active waiting list for a DD renal graft. This represented an increase of 60 patients (30 %) since 2012. Among those waiting by Dec.31, median time on the list was 6 months. 49 % had waited less than 6 months, 76 % less than one year and only 6 % more than two years. The 196 recipients given a DD-graft in 2013 had a median waiting time of 9 months and a maximum of 36 months at the time of grafting.
Among the 1275 patients in dialysis treatment by Dec.31, 721 (56.5 %) were for various reasons not considered candidates for a (new) renal graft.

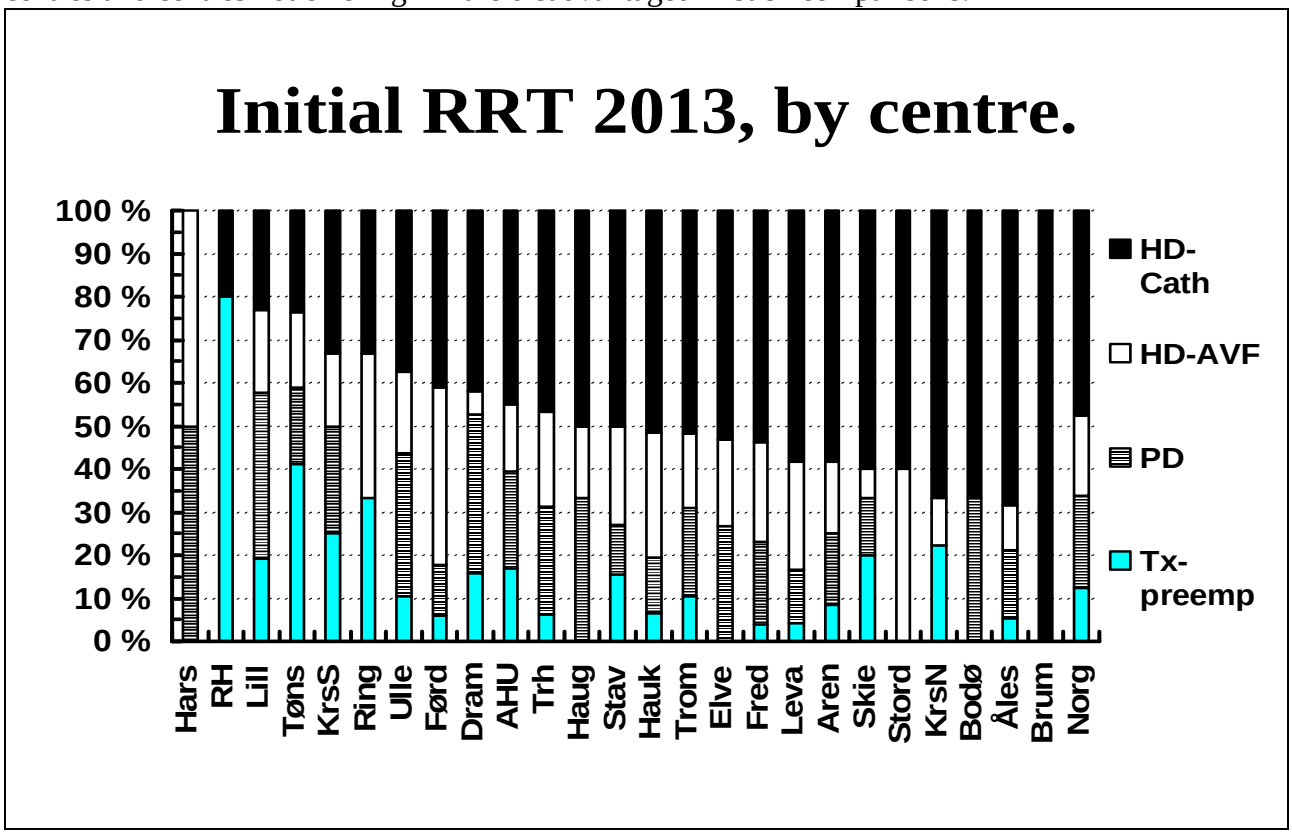
## New patients in 2013 – status at start of RRT.

A total of 512 patients started RRT in 2013. Among the 339 starting haemodialysis, the access was via catheter in 244 patients (72 %), while 95 had AV-fistula (28 %) as access.

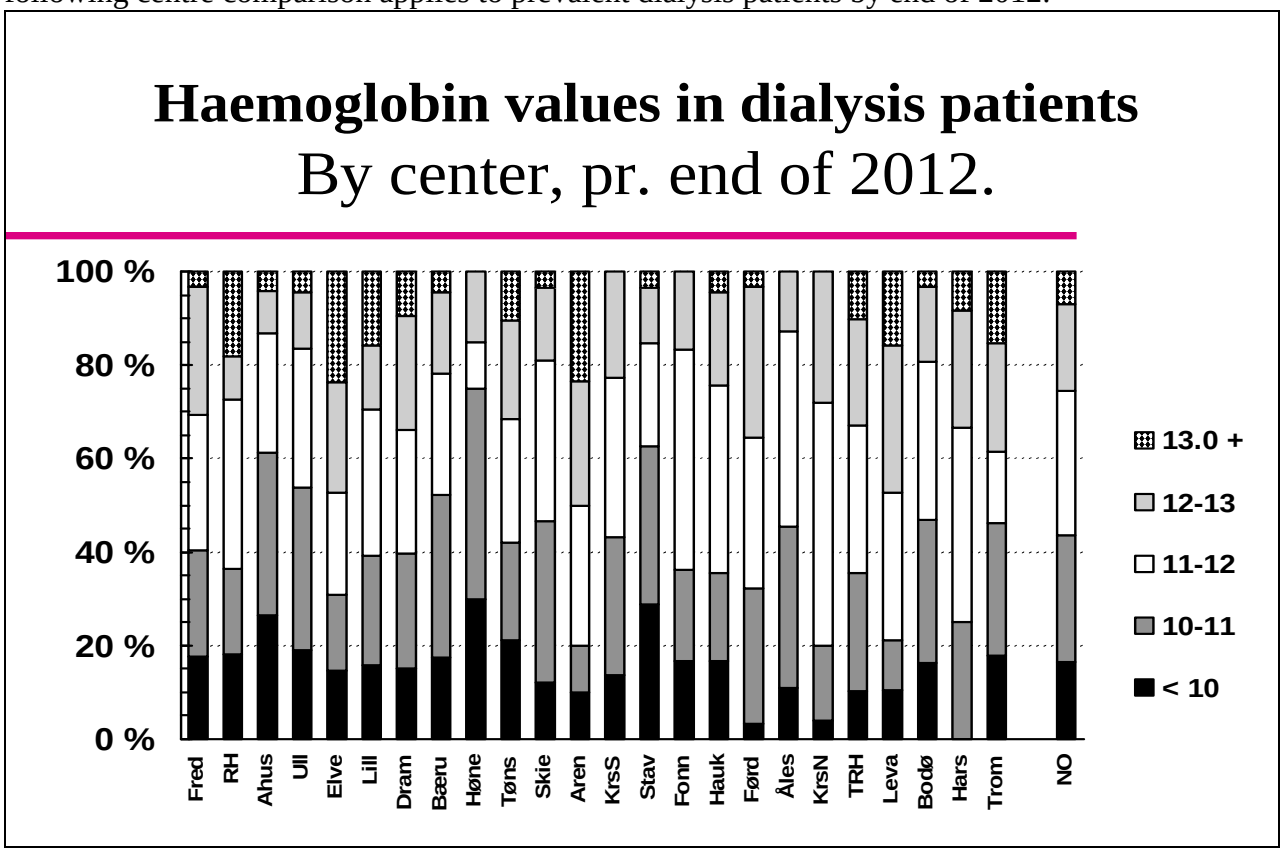
| Status at start of RRT | Total (n:512) | HD (n:339) | PD (n:110) | Tx (n:63) |
|---|---|---|---|---|
| Creatinine (mean) | 629 µmol/l | 662 | 625 | 456 |
| eGFR (mean), (excl. children) | 9.3 | 8.9 | 8.8 | 12.1 |
| Albumin (mean) | 36 g/L | 34 | 38 | 45 |
| Haemoglobin (mean) | 10.5 g/dL | 10.1 | 10.9 | 12.3 |
| Haemoglobin - % <11 g/dL | 61 % | 71 % | 56 % | 14 % |
| ESA use | 49 % | 48 % | 59 % | 35 % |
| Active D vitamin use | 61 % | 57 % | 68 % | 71 % |
| Statin use | 55 % | 52 % | 63 % | 57 % |
| Not on antihypertensive drugs | 11 % | 14 % | 4 % | 6 % |
| Using >2 antihypertensive drugs | 54 % | 50 % | 64 % | 57 % |

As might be anticipated, pre-emptively transplanted patients had a somewhat lower serum creatinine, thus higher GFR, and a higher haemoglobin and albumin than those starting dialysis. Among patients known less than four months, 80 % had haemoglobin <11 g/dL.

While pre-emptive transplantation is considered the best initial RRT, HD by catheter may be seen as the poorest alternative. In the following figure, individual centres are ranged by the proportion starting with catheter (Norg = country) from "best" to "poorest". Admittedly, small centres and centres not offering PD are disadvantaged in such comparisons.

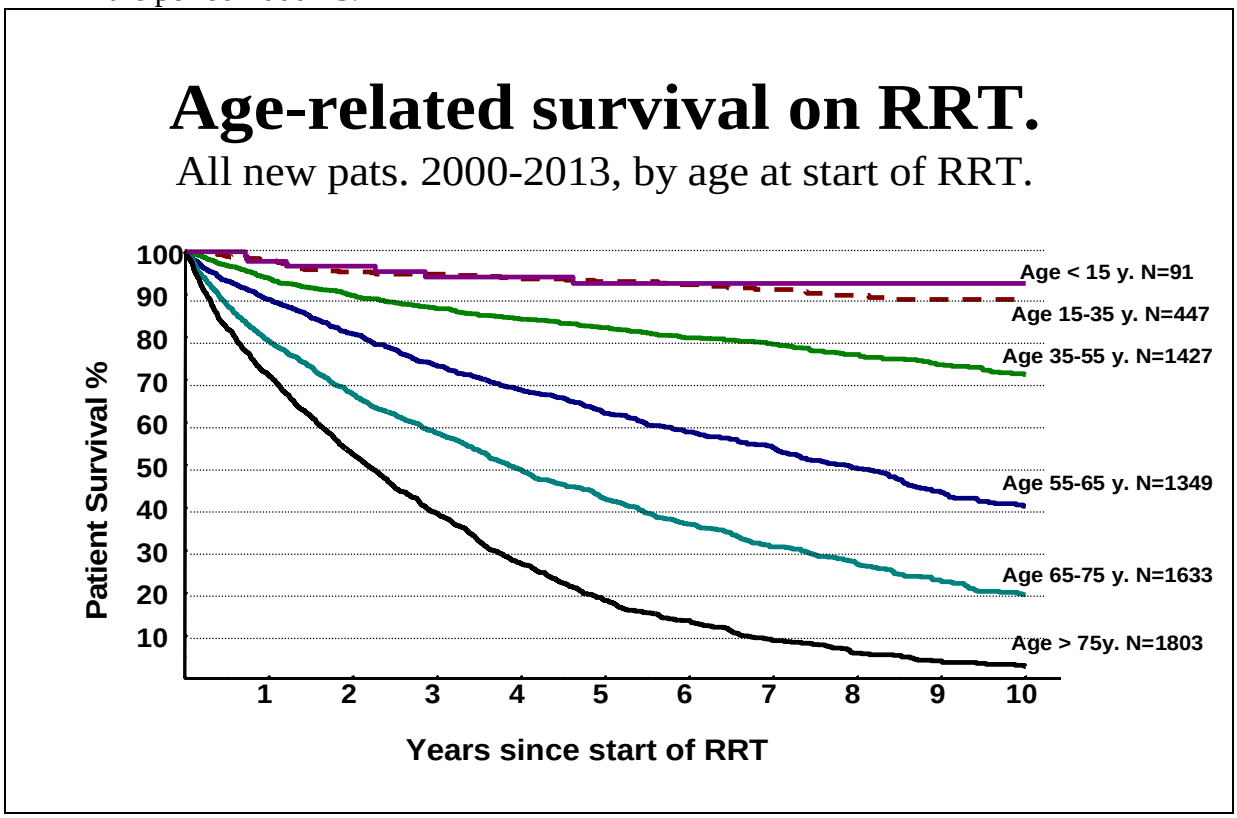



Another measure of treatment quality is the ability to obtain target haemoglobin values; the following centre comparison applies to prevalent dialysis patients by end of 2012:

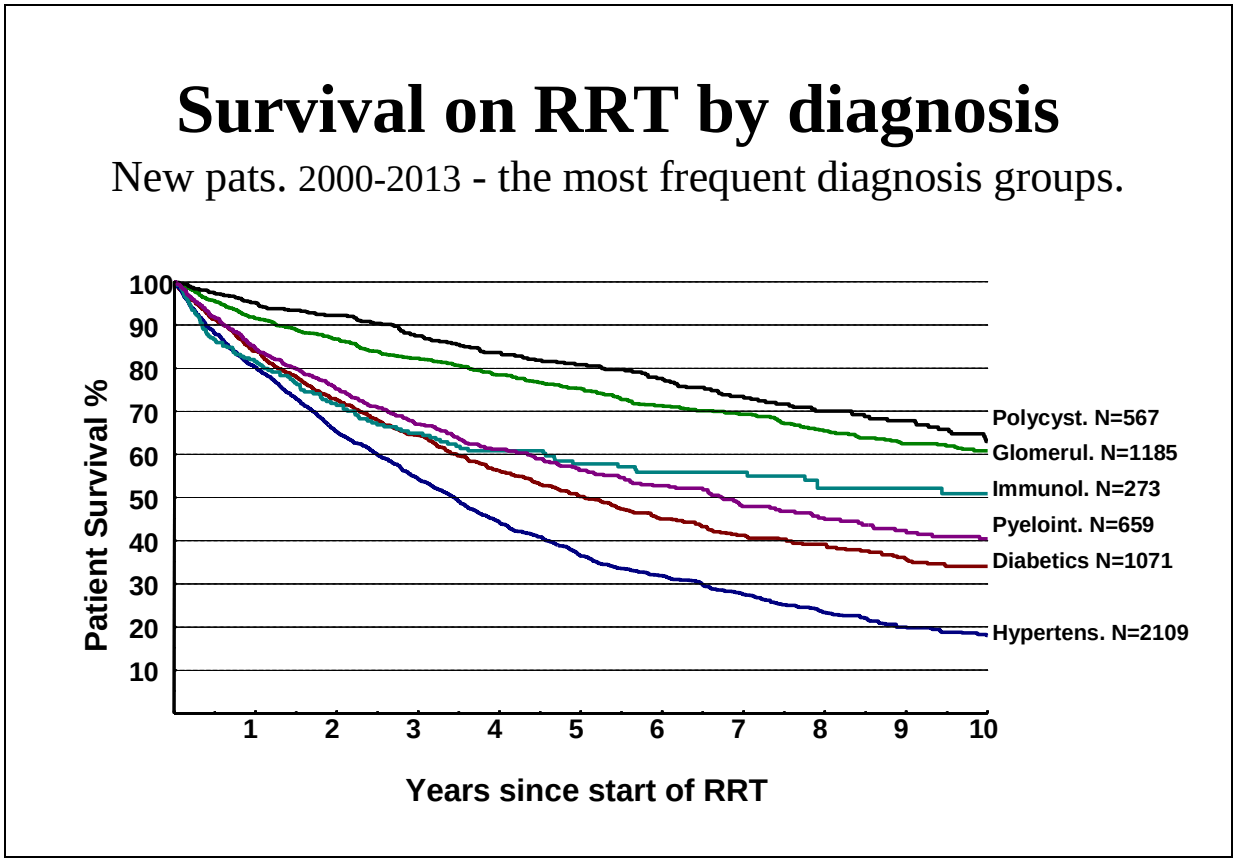


## Patient survival on RRT:

Patient survival by June 2014 was calculated by Kaplan-Meier method for all patients starting RRT in the period 2000-13.




As expected, the survival declined with increasing patient age. Among the youngest, all were considered potential graft recipients and 97% actually had got a graft, in the oldest age group 18% were considered potential recipients by start, but only 5% had received a graft.



Patient survival among those belonging to the most frequent diagnosis groups was also calculated. The vascular/hypertensive group was the oldest (mean 71 y.) and had the lowest proportion of actual graft recipients (55%). The glomerulonephritis group was the youngest (mean 54 y.), while the polycystic group had the highest proportion of graft recipients (85%).

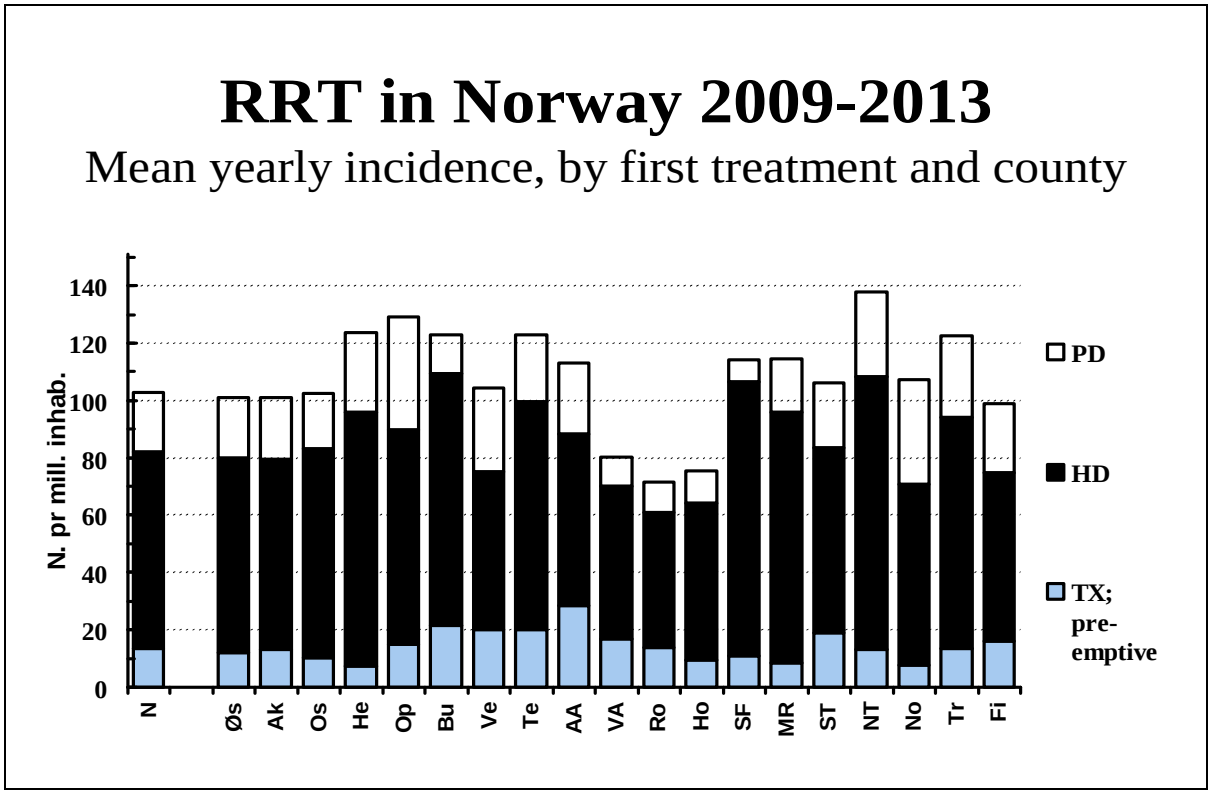
# Death in RRT:

A total of 388 patients in renal replacement therapy died during 2013, i.e. 8% out of the 4966 persons at risk. Among these, 68% were males and 32% females. Median age at death was 74 years, mean 72 years, and the range 8-92 years. Median time from start of RRT until death was 42 months, with a range spanning from 10 days to 39 years.
The final mode of treatment was HD for 220 patients and PD for 55, while 113 died with a more or less well-functioning graft. Four patients died within two moths after graft loss, thus 117 deaths were termed “Tx-related”. Dialysis treatment was terminated and followed by death in 43 patients; in 22 of those the patient decided to refuse further treatment.
Infections (27%) were the most frequent causes of death, followed by cardiac complications (26%), and malignant tumours (17%).

# Regional differences within Norway.

## Incidence:

The 25 Norwegian centres differ in size and their use of the different treatment modes (HD, PD or pre-emptive transplant). Further the number of new RRT-patients varies considerably from year to year. To make up for the annual variations and the overlapping centre coverage, patients were grouped by county of domicile at RRT-start and the incidences were calculated as a yearly mean for the five-year period 2009-2013:




As appears, the mean yearly incidence of RRT-start varied from 72 to 138 pr. million, with Rogaland having the lowest and Nord-Trøndelag the highest mean incidence. With the rather

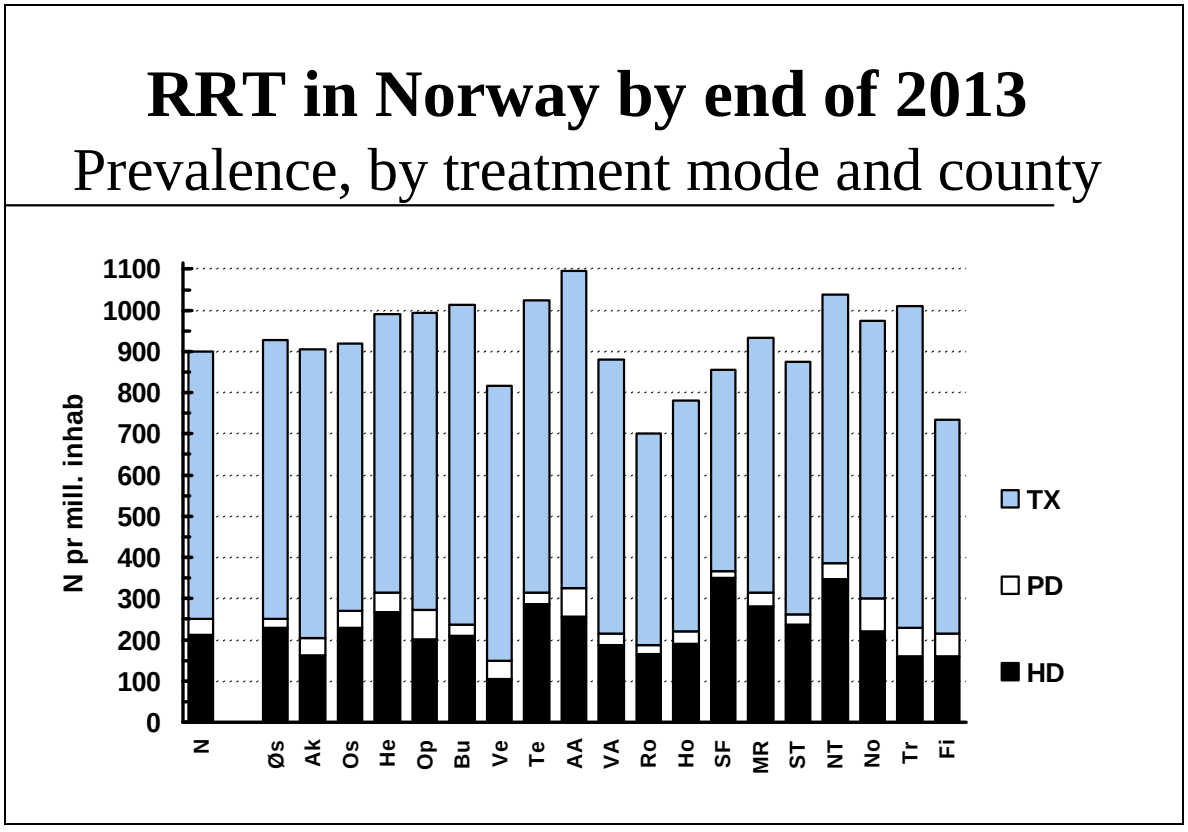
small population in most counties, figures may be expected to change from year to year, but over years there has been a lower incidence in the west-coast counties. A preliminary analysis of county-wise age groupings, diagnosis groupings, differences in acceptance for permanent dialysis, or late referral rates, gave no explanation of the marked variations in incidence.

There is national consensus that pre-emptive transplantation is preferable. Looking solely at 2013-data (see Appendix), this was achieved in 12 % of all. In the individual counties the numbers are small, but this figure ranged from 0 % to 37 % (Vestfold).
Efforts are also done to increase the use of PD. Still in some counties PD is rarely used, in others up to 37 % (Oppland) of new patients in 2013 had this as first treatment mode. 66% received HD as first treatment mode, in the counties this ranged from 42 % to 84 %.

The proportion of the new dialysis patients in 2013 who started RRT without having been known by the renal unit for at least 4 months was 21 %, with wide variations between centres; from 0 % and up to 36 %. In the majority of these cases the diagnosis would imply that renal failure has developed gradually over years. These figures seem not to have improved significantly over the years; thus in most counties there seem to be need for improved co-operation with the primary health service in order to achieve more in-time referrals.

## Prevalence:

Again, the data demonstrate great differences between the counties. In all counties the majority of patients have a functioning graft, constituting from 57% to 82% of the total RRT-population. The dialysis prevalence ranges from 150 to 326 per mill. inhabitants in the counties, indicating considerable differences in workloads and costs. In some counties, three out of four dialysis patients are not considered candidates for a new graft, in others this applies to one out of three. But counties with high dialysis prevalence do not necessarily have a high prevalence of 'non-transplantable' patients.



# Concluding remarks:

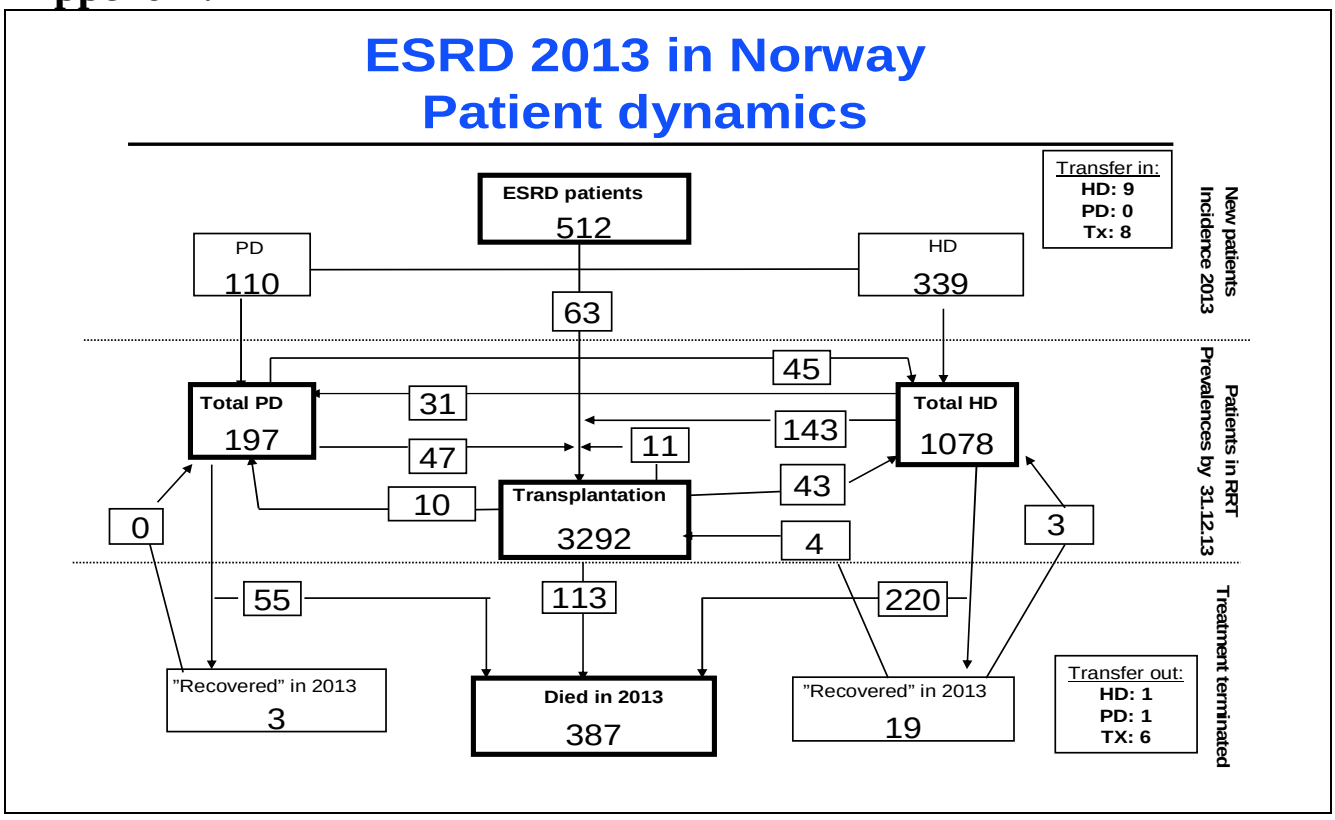
The 2013 figures seem to confirm that the incidence of RRT in Norway is levelling off, in line with that seen in other European countries. The transplantation rate in 2013 was somewhat lower than in the two previous years; still the transplant population increased by 2.7 %, while the dialysis population increased by 2% compared to end of 2012. Due to improving survival rate in dialysis and transplantation, further increased prevalence of RRT-patients can be expected over the coming years.

Comparing our data on the quality of RRT with updated international guidelines, it seems that there still is room for quality improvement. Registry data will over the coming years be used for comparisons between the centres to a greater extent than has been the case. Hopefully, the registry can in this way be an instrument for improved RRT quality and thus benefit the patients who have consented to have their data included in the registry.

Registry data are also regularly used by Norwegian nephrologists as basis for scientific papers, congress presentations and PhD-thesis. A list of publications has since 2012 been presented on www.nephro.no along with the annual reports, from the list appears that during 2013 a total of 11 papers and three 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 are also forwarded to the USRDS-reports (chapter of International comparisons).
From January 2011, the Registry has moved from Institute of Immunology to the Renal Unit (within Department of Transplantation Medicine), and a process of making the registry less vulnerable (i.e. dependent on one single individual) is in progress. The registry has received status as a National Medical Quality Registry by the proper National authorities.
Regardless of status, the cooperation with all Norwegian nephrologists, demanding their steady efforts to keep the registry updated, is a prerequisite for keeping a complete and reliable registry.

*Report completed 01.10.2014*
*Torbjørn Leivestad M.D. Ph.D.*

# Appendix:




| | | New pat in RRT 2013 | | | | Pat. in RRT by 1/1.2014 | | | | Dialyses etc. 2013 | | | Died 2013 | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Satellittes | HD/HDF | PD | Pre-emptive | Total | HD/HDF | PD | Graft | Total | HD sessions | Pl.exch. | Other | Dial.pat | Tx-pat | Not tx-cand. |
| Tromsø | 6 | 20 | 6 | 3 | 29 | 34 | 15 | 135 | 184 | 5618 | 57 | 0 | 14 | 6 | 25 |
| Harstad | | 2 | 2 | 0 | 4 | 8 | 3 | 48 | 59 | 1576 | 0 | 0 | 1 | 3 | 4 |
| Bodø | 6 | 14 | 7 | 0 | 21 | 49 | 16 | 140 | 205 | 8032 | 59 | 122 | 10 | 3 | 43 |
| Levanger | 6 | 20 | 3 | 1 | 24 | 48 | 5 | 83 | 136 | 6233 | 7 | 86 | 3 | 3 | 31 |
| Trondheim | 4 | 22 | 8 | 2 | 32 | 73 | 9 | 207 | 289 | 11049 | 137 | 406 | 20 | 14 | 54 |
| Kristiansund N | 1 | 7 | 0 | 2 | 9 | 28 | 0 | 25 | 53 | 3991 | 0 | 0 | 5 | 2 | 17 |
| Ålesund | 1 | 15 | 3 | 1 | 19 | 44 | 8 | 124 | 176 | 7397 | 122 | 0 | 12 | 3 | 31 |
| Førde | 2 | 14 | 2 | 1 | 17 | 37 | 2 | 50 | 89 | 5409 | 0 | 50 | 9 | 2 | 23 |
| Bergen | 4 | 25 | 4 | 2 | 31 | 76 | 13 | 262 | 351 | 11797 | 46 | 151 | 22 | 6 | 59 |
| Stord | 1 | 5 | 0 | 0 | 5 | 15 | 0 | 19 | 34 | 2435 | 0 | 0 | 2 | 0 | 10 |
| Haugesund | 1 | 8 | 4 | 0 | 12 | 29 | 7 | 47 | 83 | 3772 | 15 | 52 | 1 | 3 | 24 |
| Stavanger | | 19 | 3 | 4 | 26 | 51 | 5 | 192 | 248 | 8683 | 21 | 48 | 18 | 6 | 31 |
| Kristiansand S | 1 | 6 | 3 | 3 | 12 | 36 | 5 | 126 | 167 | 5793 | 15 | 0 | 9 | 2 | 32 |
| Arendal | | 9 | 2 | 1 | 12 | 26 | 8 | 79 | 113 | 3299 | 27 | 77 | 9 | 2 | 17 |
| Skien | 4 | 10 | 2 | 3 | 15 | 49 | 5 | 123 | 177 | 7343 | 7 | 50 | 13 | 3 | 49 |
| Tønsberg | | 7 | 3 | 7 | 17 | 23 | 10 | 155 | 188 | 3958 | 95 | 95 | 10 | 10 | 15 |
| Hønefoss | 1 | 6 | 0 | 3 | 9 | 22 | 0 | 53 | 75 | 3103 | 0 | 0 | 4 | 3 | 11 |
| Drammen | 1 | 9 | 7 | 3 | 19 | 39 | 11 | 162 | 212 | 7117 | 63 | 0 | 10 | 5 | 17 |
| Bærum | | 8 | 0 | 0 | 8 | 21 | 0 | 23 | 44 | 3496 | 0 | 0 | 7 | 1 | 9 |
| Lillehammer | 3 | 11 | 10 | 5 | 26 | 37 | 14 | 131 | 182 | 6013 | 16 | 0 | 20 | 6 | 24 |
| Elverum | 1 | 11 | 4 | 0 | 15 | 49 | 8 | 117 | 174 | 7313 | 0 | 92 | 12 | 2 | 37 |
| Fredrikstad | 2 | 20 | 5 | 1 | 26 | 65 | 5 | 193 | 263 | 9910 | 54 | 0 | 11 | 9 | 31 |
| AHUS | | 43 | 16 | 12 | 71 | 104 | 25 | 289 | 418 | 15409 | 0 | 0 | 27 | 12 | 59 |
| Ullevål | | 27 | 16 | 5 | 48 | 102 | 23 | 322 | 447 | 15514 | 68 | 0 | 20 | 7 | 64 |
| RH | | 1 | 0 | 4 | 5 | 13 | 0 | 187 | 200 | 3176 | 189 | 266 | 2 | 4 | 4 |
| ***SUM*** | | ***339*** | ***110*** | ***63*** | ***512*** | ***1078*** | ***197*** | ***3292*** | ***4567*** | ***167436*** | *998* | *1495* | ***271*** | ***117*** | ***721*** |
| *# Pr. mill innb.* | | *66,8* | *21,7* | *12,4* | *100,8* | *212,3* | *38,8* | *648,3* | *899,4* | *ie. + 1,2 %* | | | | | *142,0* |
| *% of total* | | *66,2* | *21,5* | *12,3* | *100,0* | *23,6* | *4,3* | *72,1* | *100,0* | *fra 2013* | | | | | *56,5* |