ANNUAL REPORT 2015

The
Norwegian Renal Registry

(Norsk Nefrologiregister)

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 5.189 mill. inhabitants (July 2015) and 19 counties with populations ranging from 75.500 to 640.300. 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 2015, 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 2015

During 2015 a total of 514 new patients (in 2014: 521) entered renal replacement therapy (RRT), i.e. 100.0 per mill. inhabitants.

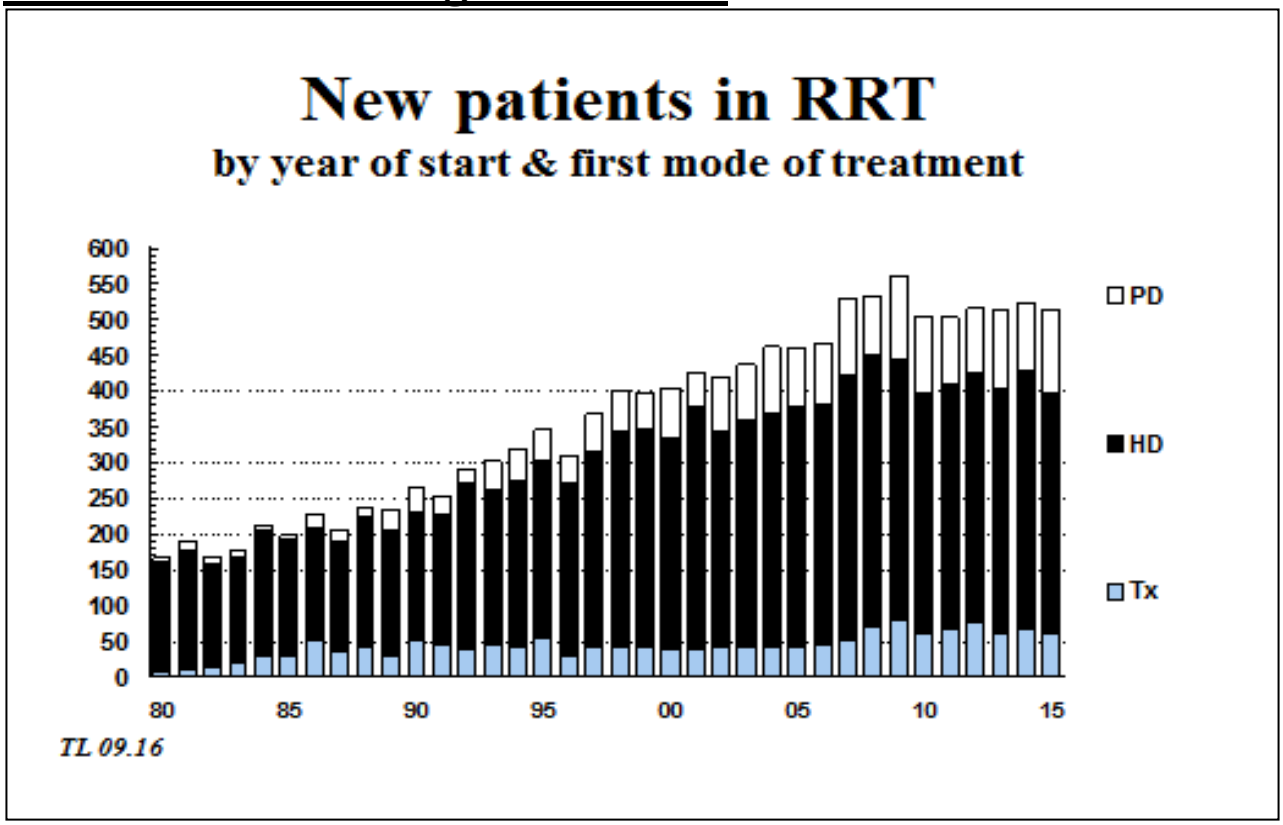
A majority of 341 (66.3 %) were males and 173 (33.7 %) females. Median age at start was 66.9 years, mean 62.8 years, ranging from three days to 90.4 years.

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

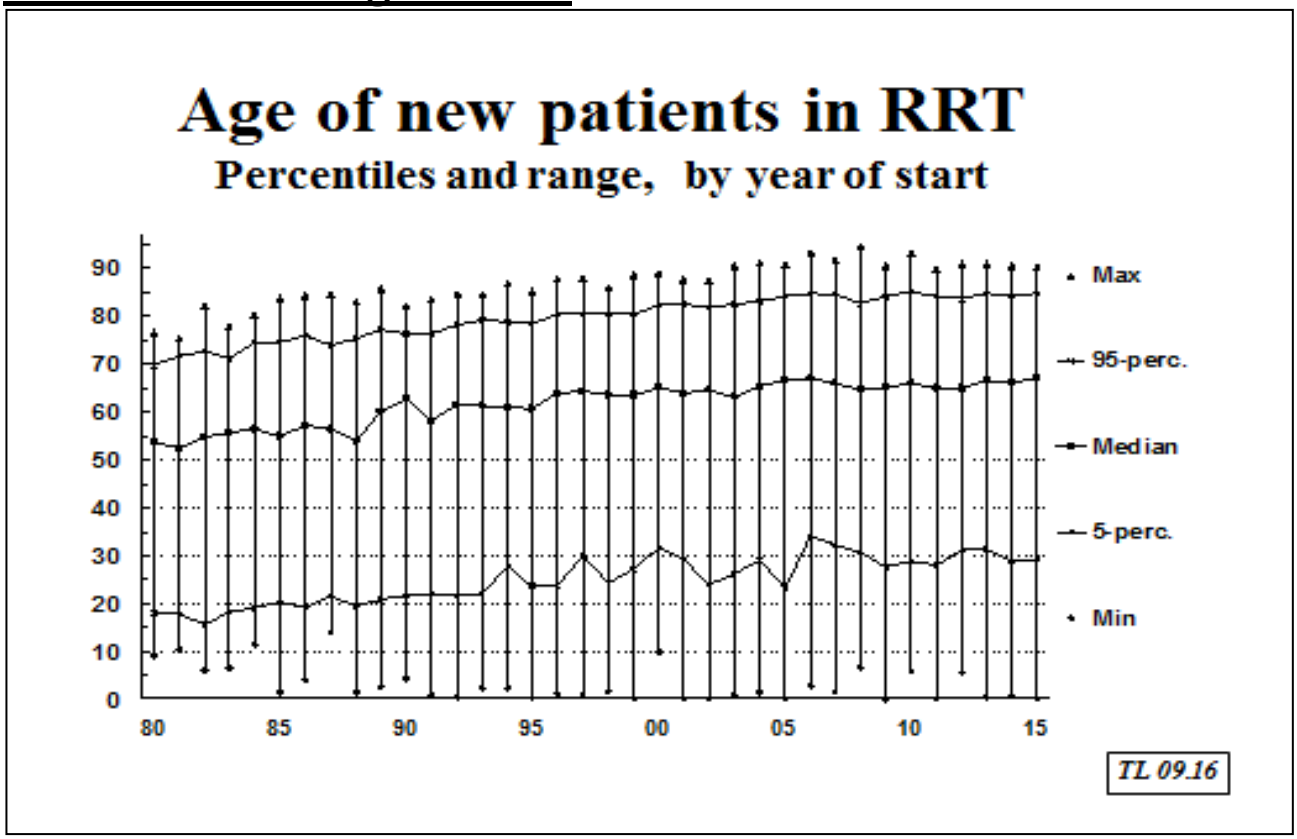
	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total	in %
HD	1	5	13	21	44	57	100	84	14	339	66.0
PD	4	3	3	11	11	21	25	32	6	116	22.6
TX	6	2	4	7	9	15	15	1	0	59	11.5
Total	11	10	20	39	64	93	140	117	20	514	100
in %	2.1	1.9	3.9	7.6	12.5	18.1	27.2	22.8	3.9	100	

At start of treatment, 304 (59 %) were considered by their nephrologist to be a potential candidate for transplantation, while 210 (41 %) were accepted for life-long dialysis (the latter constituting 50% of those starting with HD and 35 % of those starting PD).
Among the 455 patients starting dialysis in 2015, 80 % had been under control by the renal unit for at least four months, while 20 % were previously unknown and counted as "late referrals".

Incidence data: Changes 1980-2015



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. Eleven children below 15 years started RRT in 2015.

Incidence data: Primary renal disease

	1980-89	1990-99	2000-04	2005-09	2010-14	2015
Glomerulonephritis	35%	27%	18%	18%	16%	12%
Pyelo/interstitial nephr.	15%	11%	11%	10%	9%	9%
Polycystic diseases	10%	9%	9%	8%	8%	10%
Diabetic nephropathy	13%	11%	15%	16%	17%	18%
Amyloidosis	6%	5%	3%	2%	2%	3%
Vascular/hypertensive	7%	21%	28%	31%	35%	32%
Immune/systemic	5%	5%	4%	4%	4%	6%
Kidney tumour	1%	1%	1%	2%	1%	2%
Myelomatosis	2%	2%	3%	3%	1%	2%
Other defined	4%	4%	3%	4%	4%	5%
Unknown	3%	3%	4%	4%	3%	2%
N:	2018	3234	2149	2556	2571	514

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 seems again to increase, caused by chronic infections in i.v.-drug abusers.

Diabetic nephropathy has contributed 10-18 % per year. In 2015, 23 out of these were registered as having Type I and 67 as Type II diabetes, 66 patients with other types of primary renal disease were recorded as having diabetes as a co-morbid factor (3 Type I and 63 Type II), thus 32 % of new patients were diabetics.
The time from onset of diabetes to start of RRT differed considerably. For the 23 with Type I diabetes the mean time was 33 years, for the 67 with Type II diabetic nephropathy the mean time was 17 years. The 63 Type II diabetics judged to have a primary renal disease other than diabetic nephropathy, most often hypertensive, in mean had 12 years of pre-RRT diabetes duration.

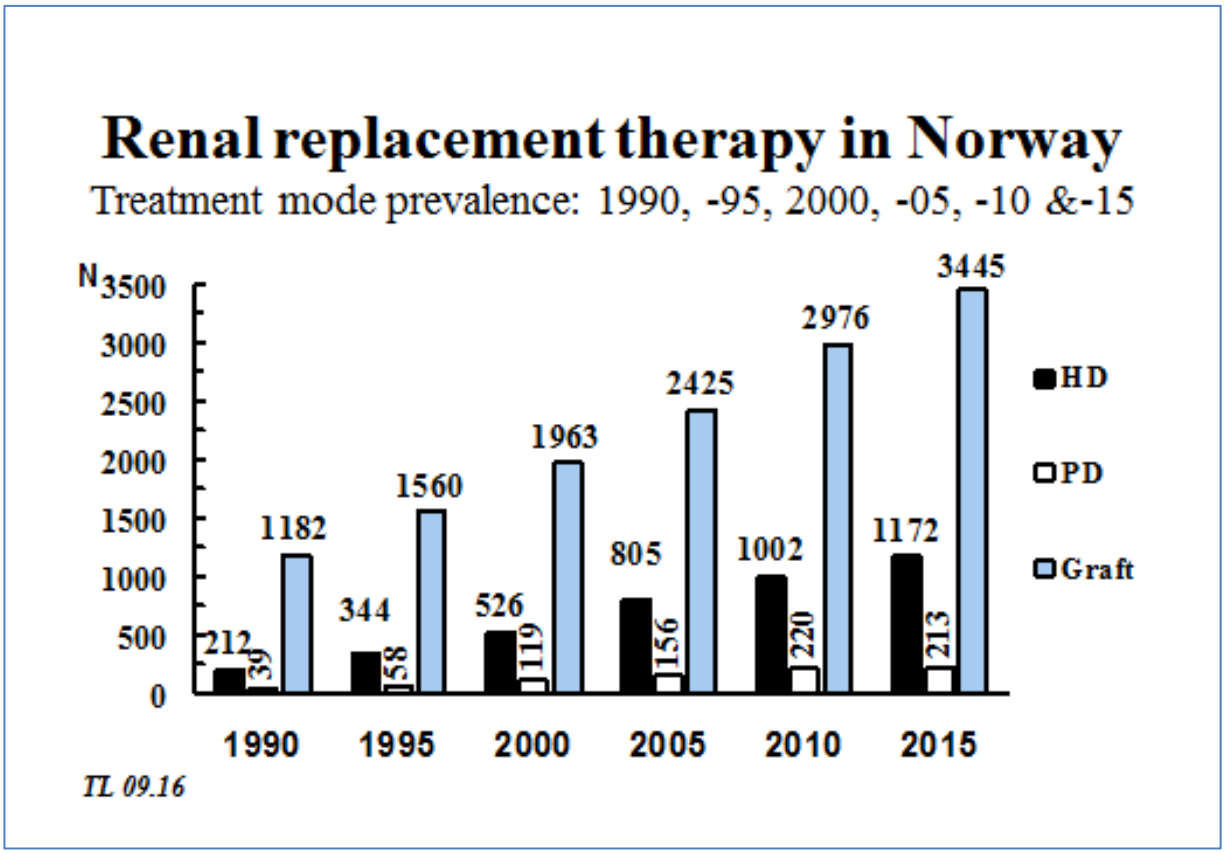
Cardiovascular disease is often present at start of RRT. Coronary heart disease was reported in 134 (26%), two had a previous heart-tx. and 92 (18%) had anamnestic heart failure. Echo-verified left ventricular hypertrophy was reported in 107 (20%). Cerebrovascular disease was reported in 60 (12%) and peripheral atherosclerotic disease in 79 patients (15%) while 48 (9%) had chronic obstructive lung disease.

Prevalence data: Status by 31.Dec. 2015.

By the end of 2015, 4829 patients in Norway received renal replacement therapy, i.e. 930.5 per million inhabitants. This represents an increase of 116 patients or 2.5 % since 2014.
Seventeen patients were on home-HD (14 in 2014).
Median age by the end of the year was 61.3 years, mean 59.3 years and range 0.25 to 96.9 years.
Gender: 65.1 % males and 34.9 % females.

Tabulated by last mode of treatment and age by end of 2015:

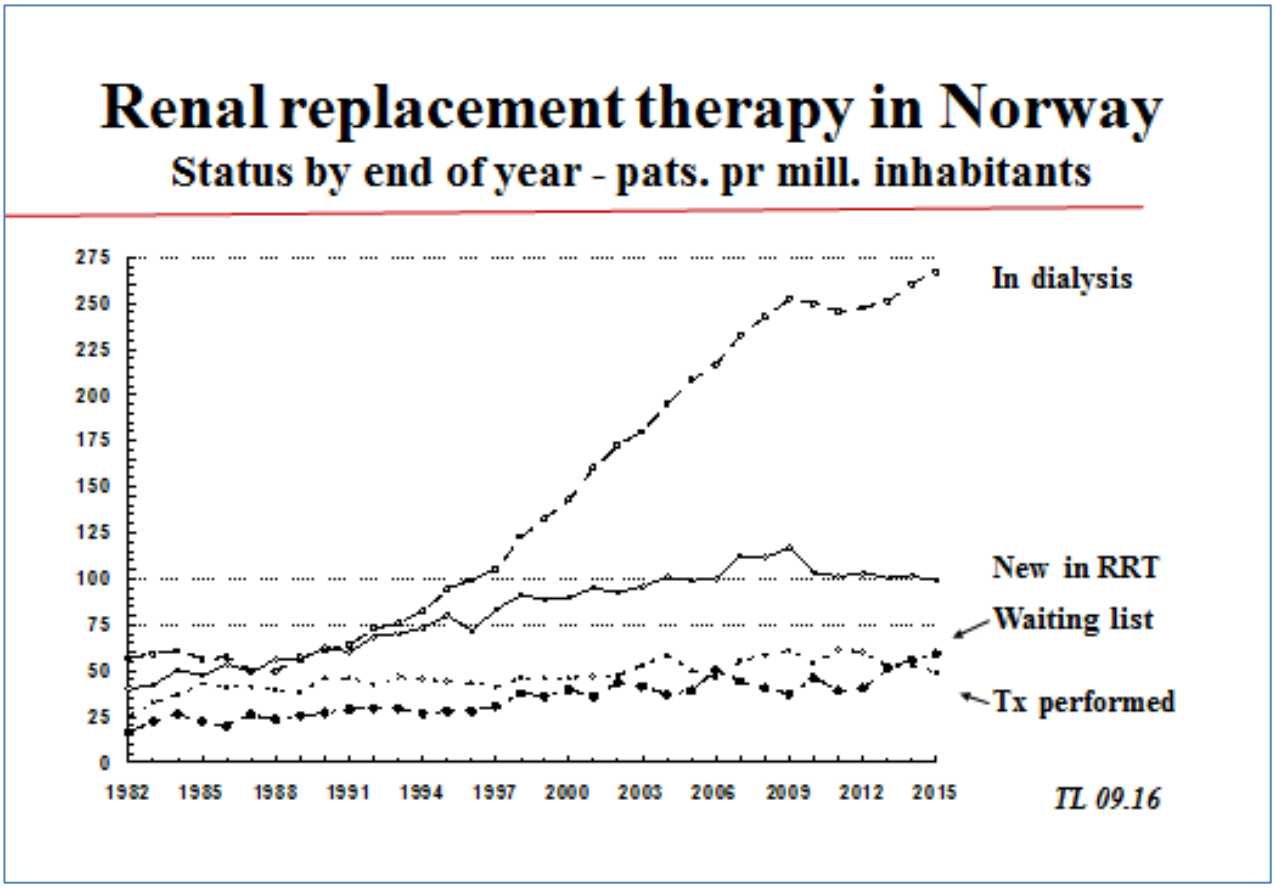
	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total	in %
HD	1	11	48	81	143	191	304	287	106	1172	24.3
PD	4	3	6	11	22	32	53	63	19	213	4.4
TX	49	76	202	428	700	846	809	320	15	3445	71.3
Total	54	90	256	520	865	1069	1166	670	140	4830	100
In %	1.1	1.9	5.3	10.8	17.9	22.1	24.1	13.9	2.9	100	



Transplantation and waiting lists:

A total of 253 renal transplants were performed at Oslo University Hospital Rikshospitalet in 2015, i.e. 48.8 per million inhabitants. In 63 (25%) the graft came from a living donor (LD), 17 of those were biologically unrelated to the recipient (12 were spouses). Among the LD-graft recipients 24 out of 47 first graft recipients were grafted pre-emptively, 5 out of 16 re-graft recipients did not receive dialysis. 190 patients received a deceased donor (DD) graft, 33 out of the 163 first graft recipients were pre-emptively transplanted (20 %), while 3 out of 27 had a re-graft without entering dialysis. There were 210 first grafts (47 LD and 163 DD), 36 were second grafts (15 LD, 21 DD), seven third grafts (1 LD and 6 DD).
Simultaneous kidney + pancreas (SPK) transplantation was performed in 10, in addition, one Danish recipient 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 163 first-DD-graft recipients in 2015 ranged from 1 to 83 years, with a mean age of 55 y. Out of these, 33 % were above the age of 65 and 7 % were 75 or older. The 47 recipients of a first LD-graft were from 3 to 74 years, mean 43 y. Regraft recipients (n=43) were from 15 to 72 years, mean 47 y.



By end 2015, 304 patients (58.6 per mill.) were on the active waiting list for a DD renal graft. This represented an increase of 19 patients (7 %) since 2014. Among those waiting by Dec.31, median time on the list was 9 months. 30 % had waited less than 6 months, 60 % less than one year and only 10 % more than two years. The 190 recipients given a DD-graft in 2015 had a median waiting time of 15 months and a maximum of 61 months at the time of grafting.
Among the 1385 patients in dialysis treatment by Dec.31, 732 (52.9 %) were for various reasons not considered candidates for a (new) renal graft.

New patients in 2015 – status at start of RRT.

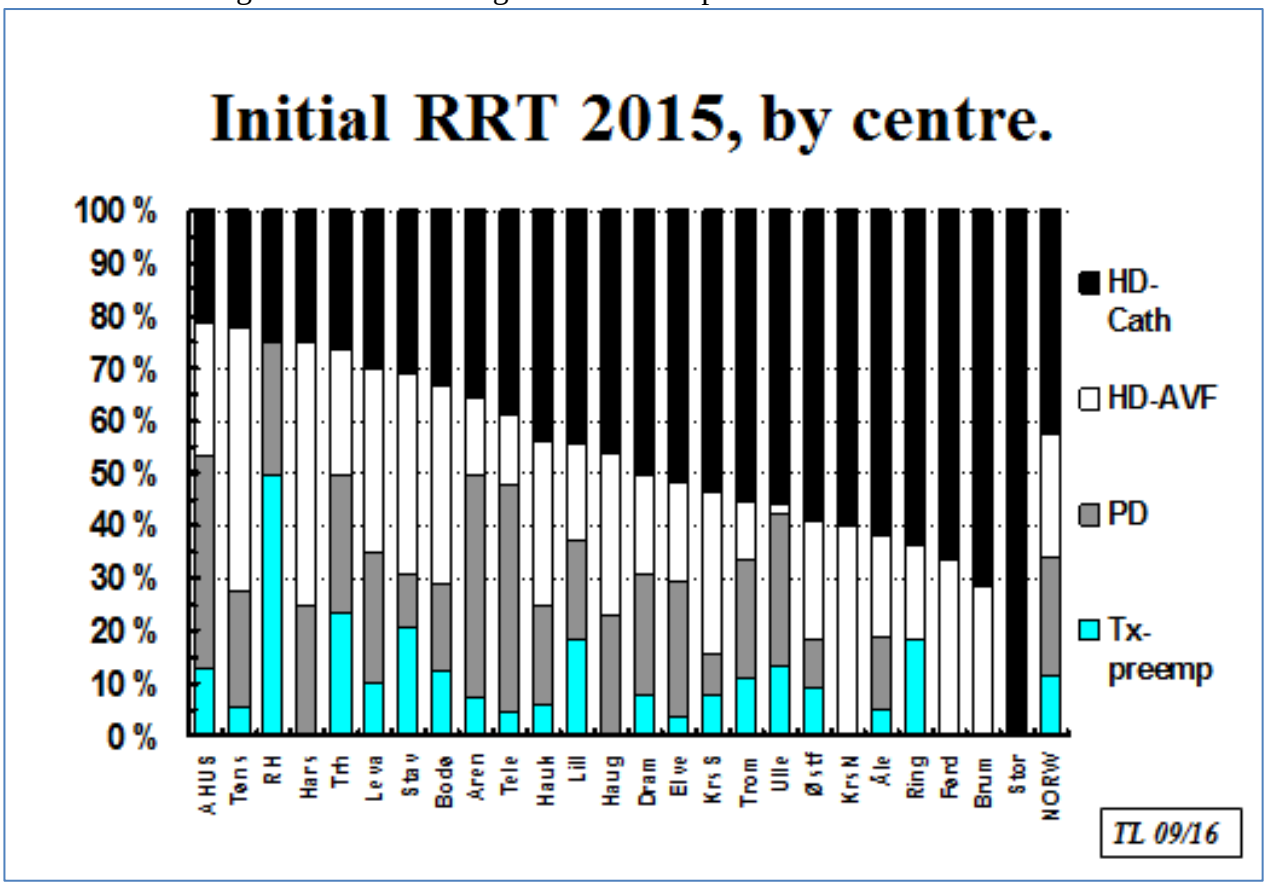
A total of 514 patients started RRT in 2015. Among the 339 starting haemodialysis, the access was via catheter in 219 patients (65 %), while 120 had AV-fistula or graft (35 %) as access.

Status at start of RRT	Total (n:514)	HD (n:339)	PD (n:116)	Tx (n:59)
Creatinine (mean)	639 µmol/l	684	585	480
eGFR (mean), (excl. children)	8.8	8.4	8.9	11.4
Albumin (mean)	35 g/L	33	37	43
Haemoglobin (mean)	10.2 g/dL	9.8	10.6	11.6
Haemoglobin - % <11 g/dL	71 %	77 %	64 %	45 %
ESA use	50 %	48 %	61 %	40 %
Active D vitamin use	62 %	58 %	71 %	66 %
Statin use	50 %	51 %	49 %	43 %
Not on antihypertensive drugs	11 %	11 %	4 %	19 %
Using >2 antihypertensive drugs	55 %	55 %	64 %	35 %

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.

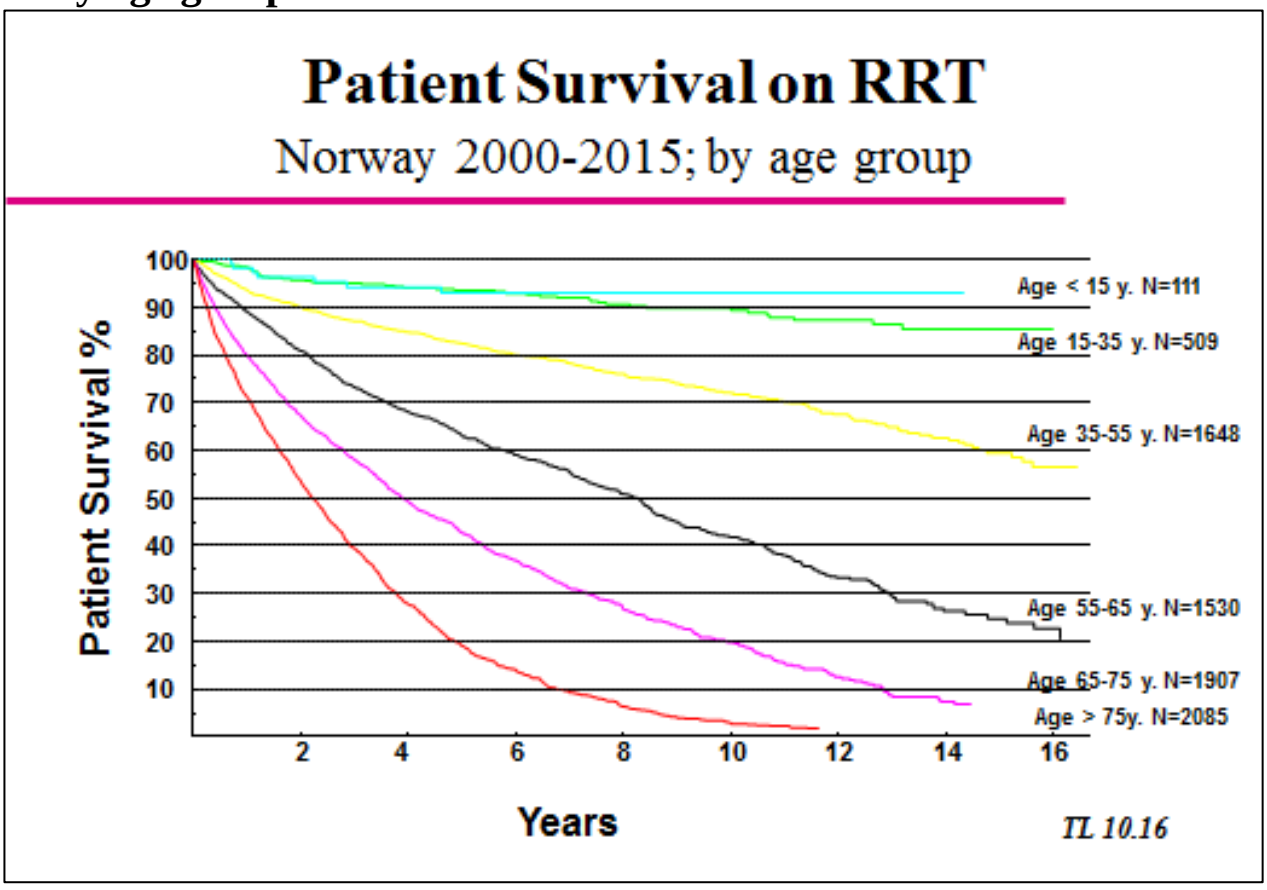
While pre-emptive transplantation is considered the best initial RRT, HD by catheter may be seen as the poorest alternative. In the following figure, individual centres are ranged by the proportion

starting with catheter (NORW = country) from “best” to “poorest”. Admittedly, small centres and centres not offering PD are disadvantaged in such comparisons.



Patient survival :

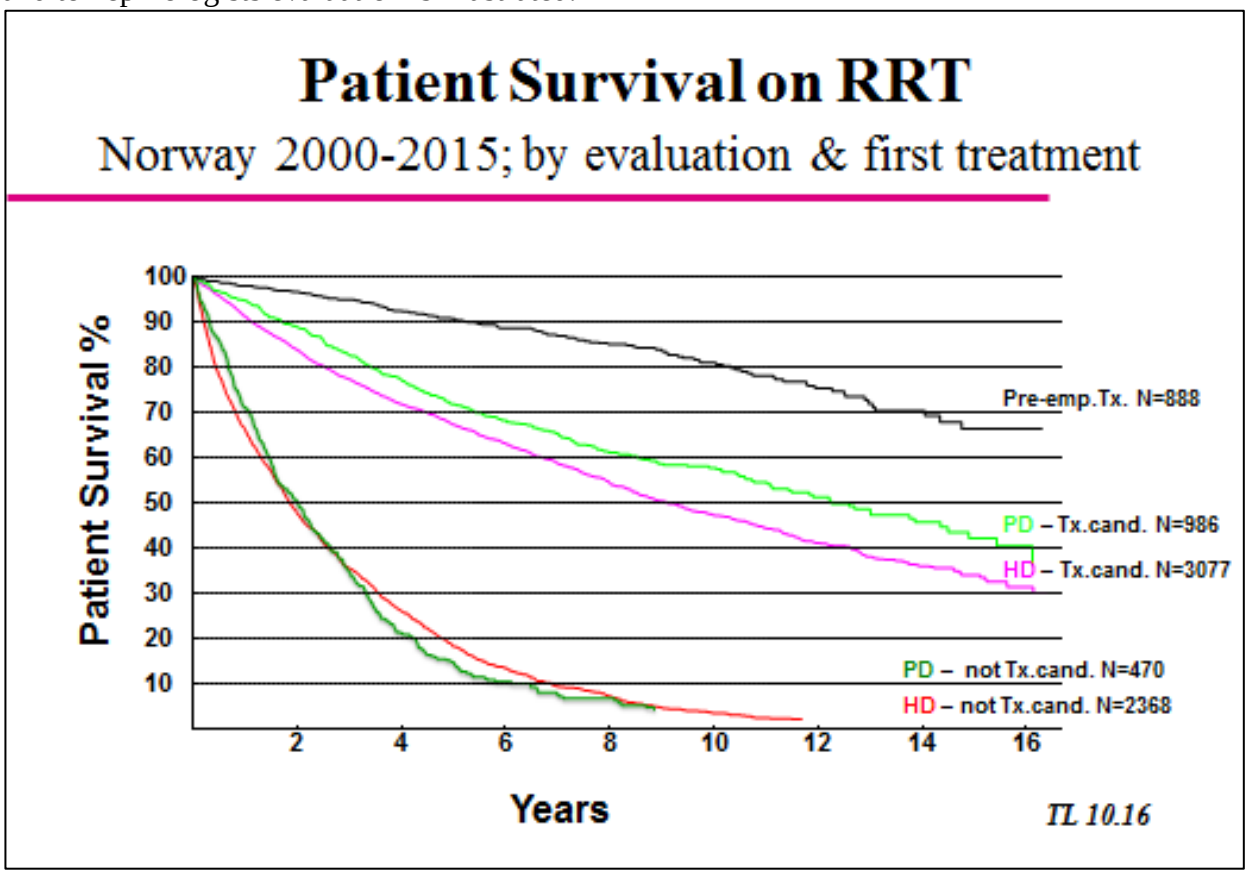
a: By age group:



A Kaplan-Meier plot comparing survival on RRT according to the age groupings used in the tables for all patients starting during 2000-2015 confirms a marked effect of age at start. Except for the two youngest groups (<15y. vs. 15-25y.) having a comparable survival rate, all other curves differ significantly from each other (Mantel-Haenszel p< 0.0001).
The adult groups had similar calculated GFR at start and a similar rate of late referrals. The proportion with diabetes was 14% in the 15-35 group, 31-33% in the groups from 35 to 75 years and somewhat lower (25%) in the oldest group. The proportion having cardiac or vascular comorbidities at start was zero in the paediatric group, but increased significantly with increasing age, up to 66% among those >75y. While all children had been evaluated by their nephrologist as potential candidates for transplantation, this was the case for only 18% in the 75+ group.

b: By first treatment mode & initial evaluation:

For all patients starting RRT, the reporting nephrologist gives an evaluation whether the patient could be considered a potential candidate for future transplantation, or was expected to have life-long dialysis. In this Kaplan-Meier plot, the survival on RRT according to initial treatment mode and to nephrologists evaluation is illustrated.



The preemptively transplanted patients are younger, have higher GFR, lower rate of diabetes and cardiac or vascular comorbidities, and as expected have a significantly better survival rate.

Patients evaluated as potential tx-candidates as expected had much higher survival rate than those not considered candidates. Among those considered potential candidates, those starting with PD had significantly better survival than those starting with HD. The PD and HD groups did not differ in age, GFR at start, or proportion with diabetes, but the HD-group had significantly higher proportion with cardiovascular comorbidities, previous malignancies and late referrals.

In patients not considered tx-candidates, the survival rate for the HD- and PD-groups was comparable. The PD-group were significantly older, however the HD-group had higher proportions with previous malignancy diagnosis and late referrals.

A Cox regression analysis on all patients starting dialysis in the period was performed, using age, late referral, diabetes, previous malignancy, cardiac-, cerebrovascular-, and peripheral vascular

comorbidity and HD vs PD as covariates. The analysis showed all these factors were highly associated with a reduced survival rate. For HD vs PD the Odds Ratio was 1.33 (95% CI 1.043-1.232) with p=0.003, for late referral OR=1.364 (1.276-1.459), p<0.0001..

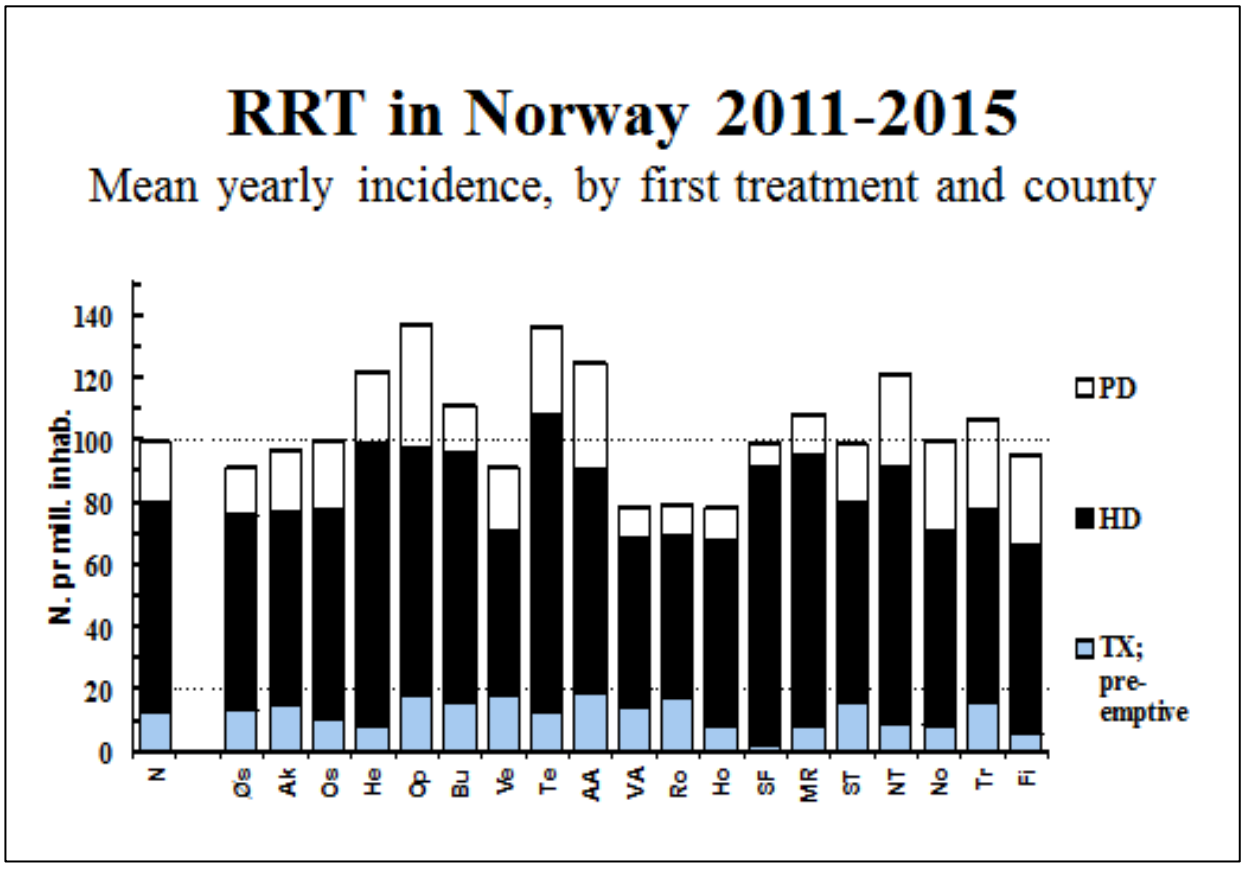
Death in RRT:

A total of 393 patients in renal replacement therapy died during 2015, i.e. 7.5% out of the 5243 persons at risk. Among these, 68% were males and 32% females. Median age at death was 76 years, mean 74 years, and the range 4-93 years. Median time from start of RRT until death was 41 months, with a range spanning from 10 days to 36 years.
The final mode of treatment was HD for 249 patients and PD for 44, while 100 died with a more or less well-functioning graft. Four patients died within two moths after graft loss, thus 104 deaths were termed "Tx-related". Dialysis treatment was terminated and followed by death in 38 patients; in 13 of those the patient had decided to refuse further treatment.
Cardiac complications (33%) were the most frequent causes of death, followed by infections (30%), and malignant tumours (13%).

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 2011-2015:



As appears, the mean annual incidence of RRT-start varied from 78 to 137 pr. million, with Hordaland having the lowest and Oppland the highest mean incidence. With the rather small

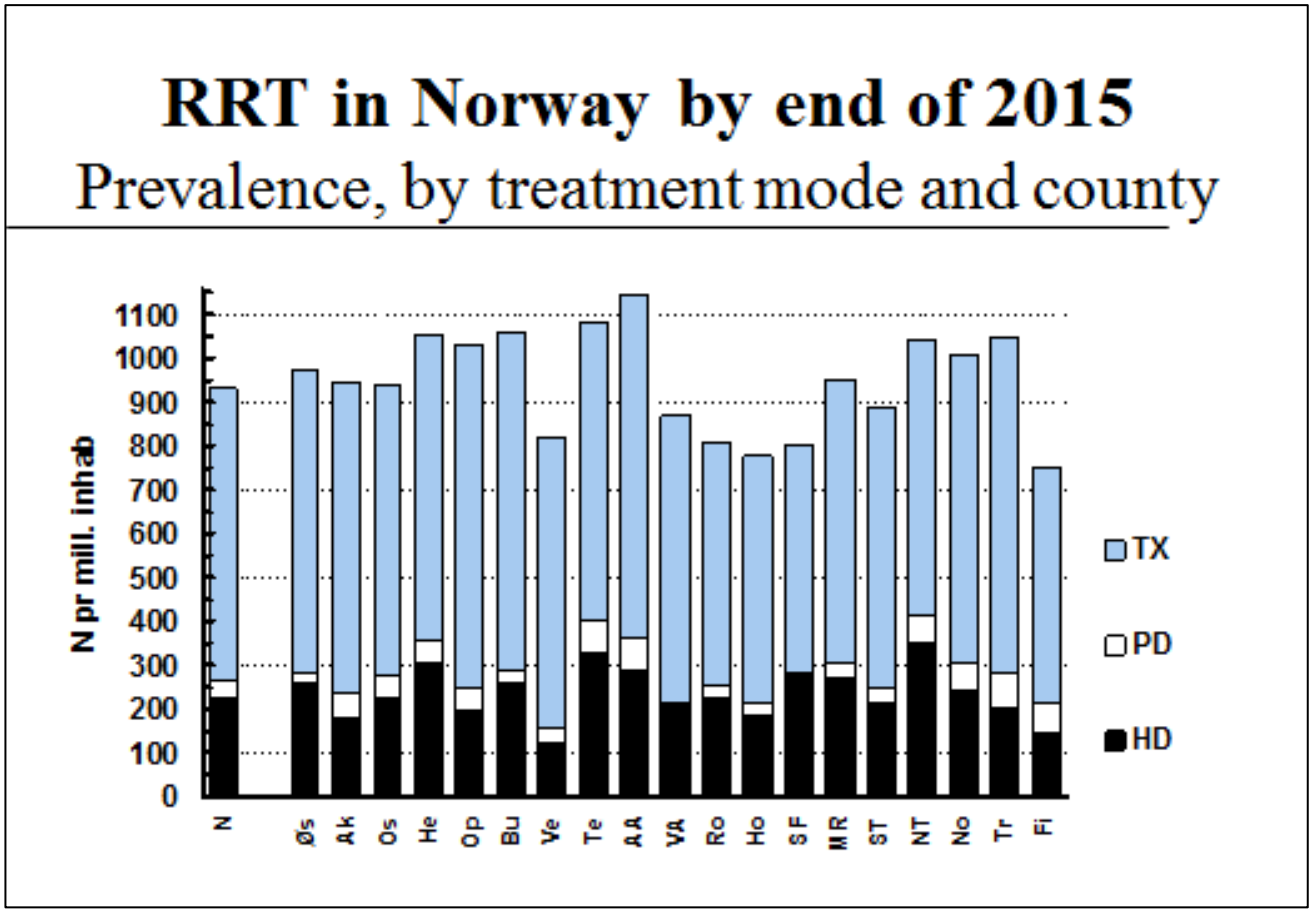
population in most counties, figures may be expected to change from year to year, but over years there has been a lower incidence in the west-coast counties. Analysis of county-wise age groupings, diagnosis groupings, differences in acceptance for permanent dialysis, or late referral rates, has failed to explain the marked variations in incidence.

There is national consensus that pre-emptive transplantation is preferable. Looking solely at 2015-data (see Appendix), this was achieved in only 11 % of all. In the individual counties the numbers are small, but this figure ranged from 0 % to 23 % (Sør-Trøndelag).
Efforts are also done to increase the use of PD. Still in some counties PD is rarely used, in others up to 44 % (Telemark) of new patients in 2015 had this as first treatment mode. 66% received HD as first treatment mode, in the counties this ranged from 51 % to 100 %.

The proportion of the new dialysis patients in 2015 who started RRT without having been known by the renal unit for at least 4 months was 20 %, with wide variations between centres; from 0 % and up to 39 %. 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 it still seems 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 60% to 81% of the total RRT-population. The dialysis prevalence ranges from 156 to 412 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 2015 figures confirm that the incidence of RRT in Norway is levelling off, in line with that seen in other European countries. The transplantation rate in 2015 was a little lower than that of previous years; still the transplant population increased by 2.0 %, while the dialysis population increased by 3.4 % compared to end of 2014, and the number of recorded HD-sessions increased by 3.6 %. Due to improving survival rate in dialysis and transplantation, further increased prevalence of RRT-patients can be expected over the coming years.

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, during 2015 a total of 13 papers and two 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").

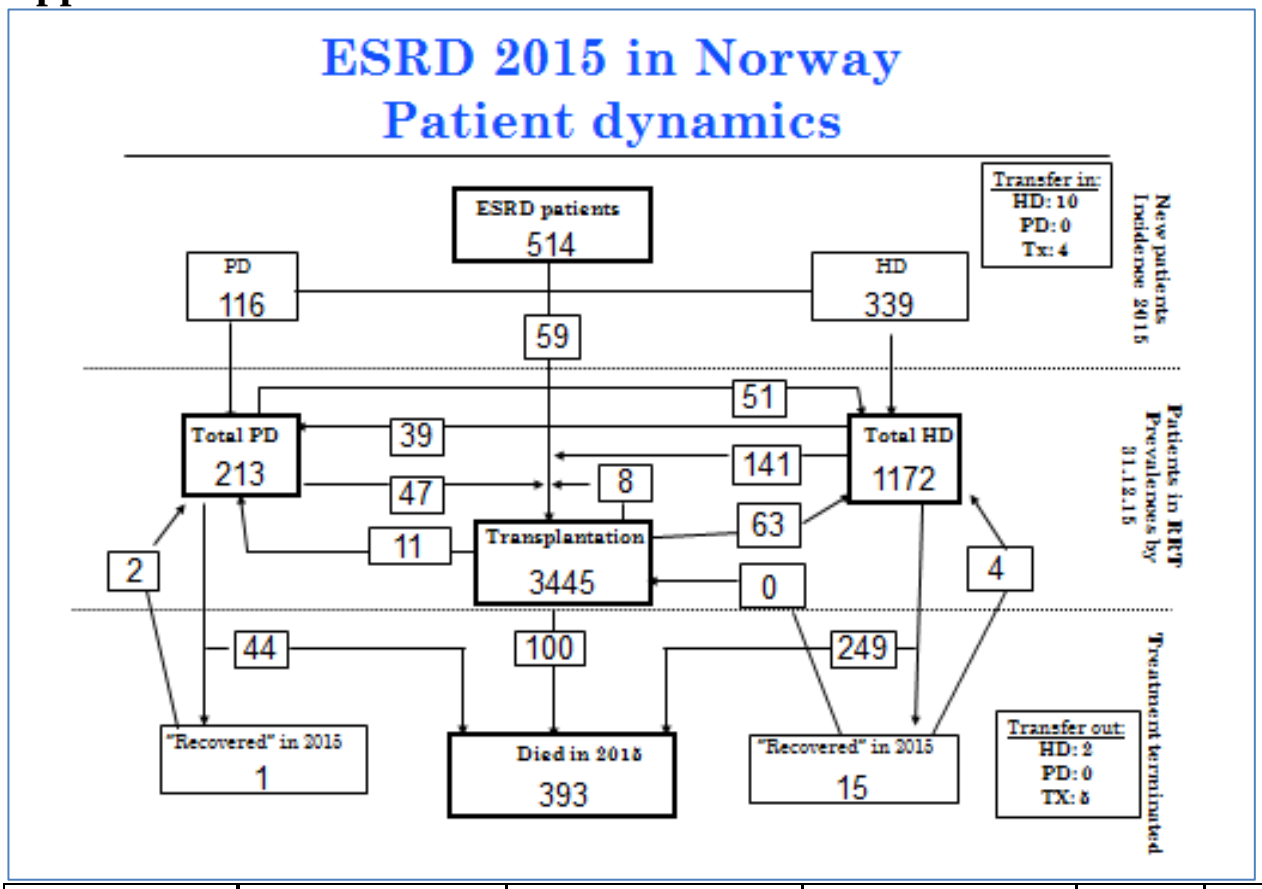
The registry has received status as a National Medical Quality Registry by the proper National authorities. Consequently, as of 01.01.2016 the RRT-registry has been merged with the Norwegian Renal Biopsy Registry into "Norsk Nyreregister" (The Norwegian Renal Registry). Thus, this annual report will be the last annual report in the present format from the old "Norsk Nefrologiregister".

Regardless of status, the cooperation with all Norwegian nephrologists, 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.

The author will take this opportunity to thank all collaborating colleagues for their cooperation through all these years, making the registry to what it has become.

Report completed 18.10.2016
Torbjørn Leivestad M.D. Ph.D.

Appendix:



		New pat in RRT 2015				Pat. in RRT by 1/1.2016				Dialyses etc. 2015			Died 2015		
	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	8	12	4	2	18	34	16	134	184	**6345**	18	6	11	5	27
Harstad		3	1	0	4	14	3	47	64	**2065**	0	0	1	3	7
Bodø	8	17	4	3	24	54	14	153	221	**8635**	12	78	11	6	34
Levanger	7	13	5	2	20	50	8	82	140	**7595**	0	58	9	3	37
Trondheim	4	17	9	8	34	68	10	219	297	**10515**	144	749	15	7	50
Kristiansund N	1	5	0	0	5	29	0	30	59	**3960**	0	0	8	1	18
Ålesund	1	17	3	1	21	43	7	131	181	**6924**	64	0	7	6	35
Førde	2	6	0	0	6	30	0	54	84	**5349**	5	49	10	2	21
Bergen	4	24	6	2	32	81	12	269	362	**12756**	80	138	26	6	40
Stord		3	0	0	3	9	0	23	32	**1355**	0	0	3	2	5
Haugesund	2	10	3	0	13	35	6	49	90	**4923**	8	52	5	0	20
Stavanger		27	4	8	39	75	8	214	297	**10981**	13	48	11	5	40
Kristiansand S	1	11	1	1	13	42	2	128	172	**6911**	12	0	15	3	31
Arendal		7	6	1	14	30	8	81	119	**3874**	0	78	7	3	26
Telemark	3	12	10	1	23	54	13	117	184	**10285**	20	49	13	3	33
Tønsberg		13	4	1	18	27	8	155	190	**4730**	67	138	14	6	16
Hønefoss	1	9	0	2	11	24	0	57	81	**4096**	0	0	9	1	10
Drammen	1	18	6	2	26	50	12	165	227	**7540**	80	40	16	6	14
Bærum		7	0	0	7	30	0	34	64	**3880**	0	0	5	1	15
Lillehammer	3	17	5	5	27	42	10	147	199	**5519**	19	0	15	4	32
Elverum	1	19	7	1	27	53	9	118	180	**7253**	0	96	13	1	31
Østfold	2	18	2	2	22	75	6	199	280	**11160**	39	0	11	7	41
AHUS		22	19	6	47	110	35	325	470	**17455**	0	0	19	12	77
Ullevål		30	15	7	52	103	25	339	467	**16970**	64	0	33	6	67
RH		2	2	4	8	10	1	175	186	**3132**	148	117	2	5	5
SUM		***339***	***116***	***59***	***514***	***1172***	***213***	***3445***	***4830***	***184208***	*793*	*1696*	***289***	***104***	***732***
# Pr. mill innb.		*65,3*	*22,4*	*11,4*	*99,0*	*225,8*	*41,0*	*663,8*	*930,7*	*ie. +3,6 %*					*141,1*
% of total		*66,0*	*22,6*	*11,5*	*100,0*	*24,3*	*4,4*	*71,3*	*100,0*	*fra 2014*					*52,9*