ANNUAL REPORT 2014

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 5.138 mill. inhabitants (July 2014) 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 2014, 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 2014

During 2014 a total of 521 new patients (in 2013: 512) entered renal replacement therapy (RRT), i.e. 100.8 per mill. inhabitants.

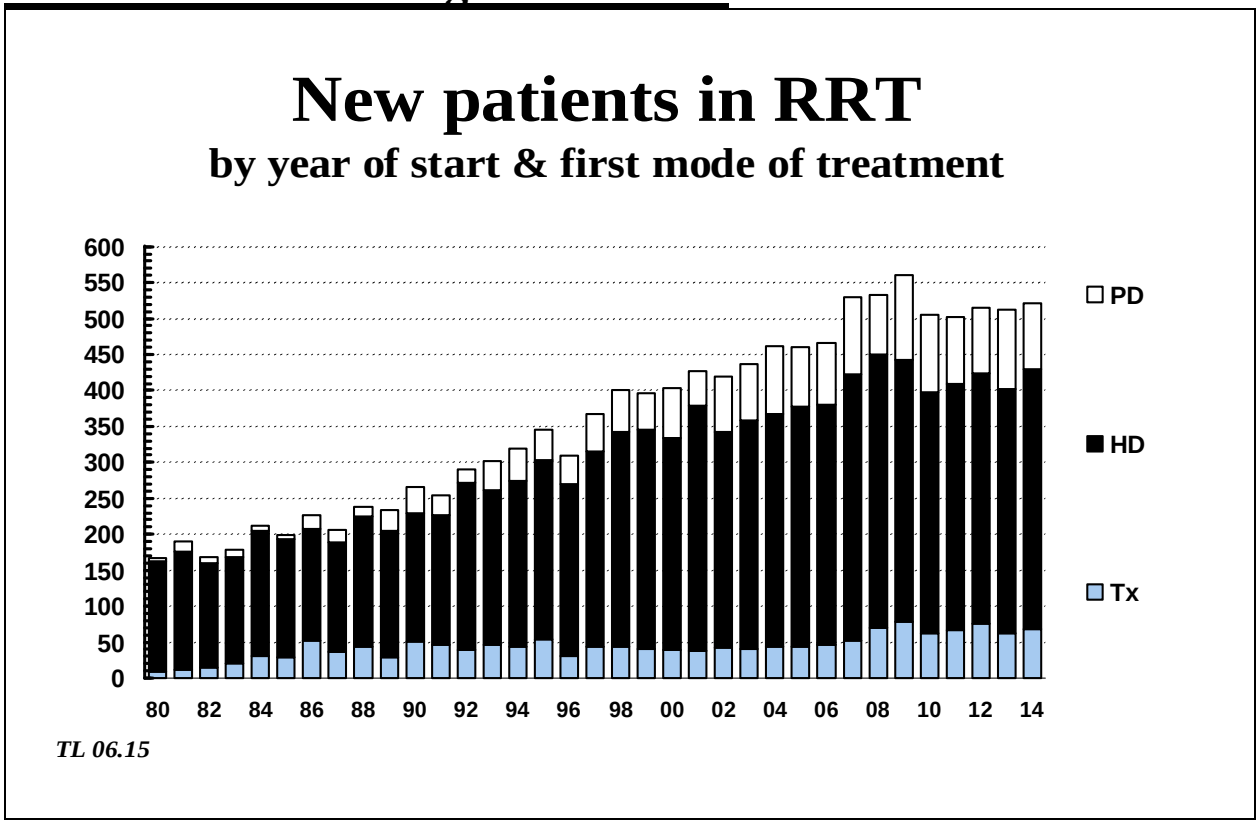
A majority of 362 (69.5 %) were males and 159 (30.5 %) females. Median age at start was 66.2 years, mean 62.3 years, ranging from 0.5 to 90.5 years.

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

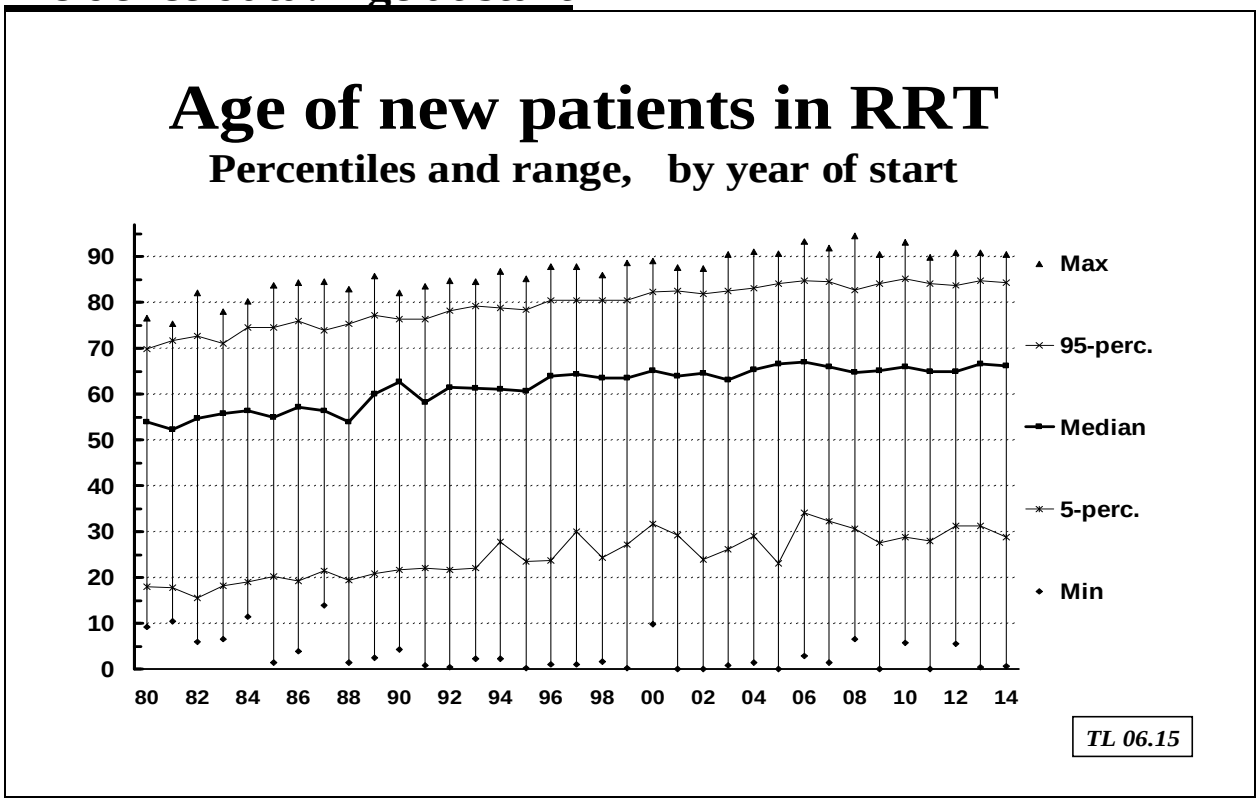
	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total	in %
HD	2	5	12	28	45	60	92	101	16	361	69.3
PD	2	2	4	8	12	16	22	23	3	92	17.7
TX	5	3	5	7	17	13	17	1	0	68	13.1
Total	9	10	21	43	74	89	131	125	19	521	100
in %	1.7	1.9	4.0	8.3	14.2	17.1	25.1	24.0	3.6	100	

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 453 patients starting dialysis in 2014, 77 % had been under control by the renal unit for at least four months, while 23 % were previously unknown and counted as “late referrals”.

Incidence data: Changes 1980-2014



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. Nine children below 15 years started RRT in 2014; 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	2010-13	2014
Glomerulonephritis	35%	27%	18%	18%	16%	16%
Pyelo/interstitial nephr.	15%	11%	11%	10%	9%	9%
Polycystic diseases	10%	9%	9%	8%	8%	7%
Diabetic nephropathy	13%	11%	15%	16%	17%	17%
Amyloidosis	6%	5%	3%	2%	2%	3%
Vascular/hypertensive	7%	21%	28%	31%	35%	33%
Immune/systemic	5%	5%	4%	4%	4%	3%
Kidney tumour	1%	1%	1%	2%	1%	1%
Myelomatosis	2%	2%	3%	3%	1%	2%
Other defined	4%	4%	3%	4%	3%	6%
Unknown	3%	3%	4%	4%	3%	3%
N:	2018	3234	2149	2556	2047	521

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 10-17 % per year. In 2014, 29 out of these were registered as having Type I and 59 as Type II diabetes, 79 patients with other types of primary renal disease were recorded as having diabetes as a co-morbid factor (1 Type I and 78 Type II), thus 32 % 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 31 years, for the 68 with Type II diabetic nephropathy the mean time was 20 years. 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.

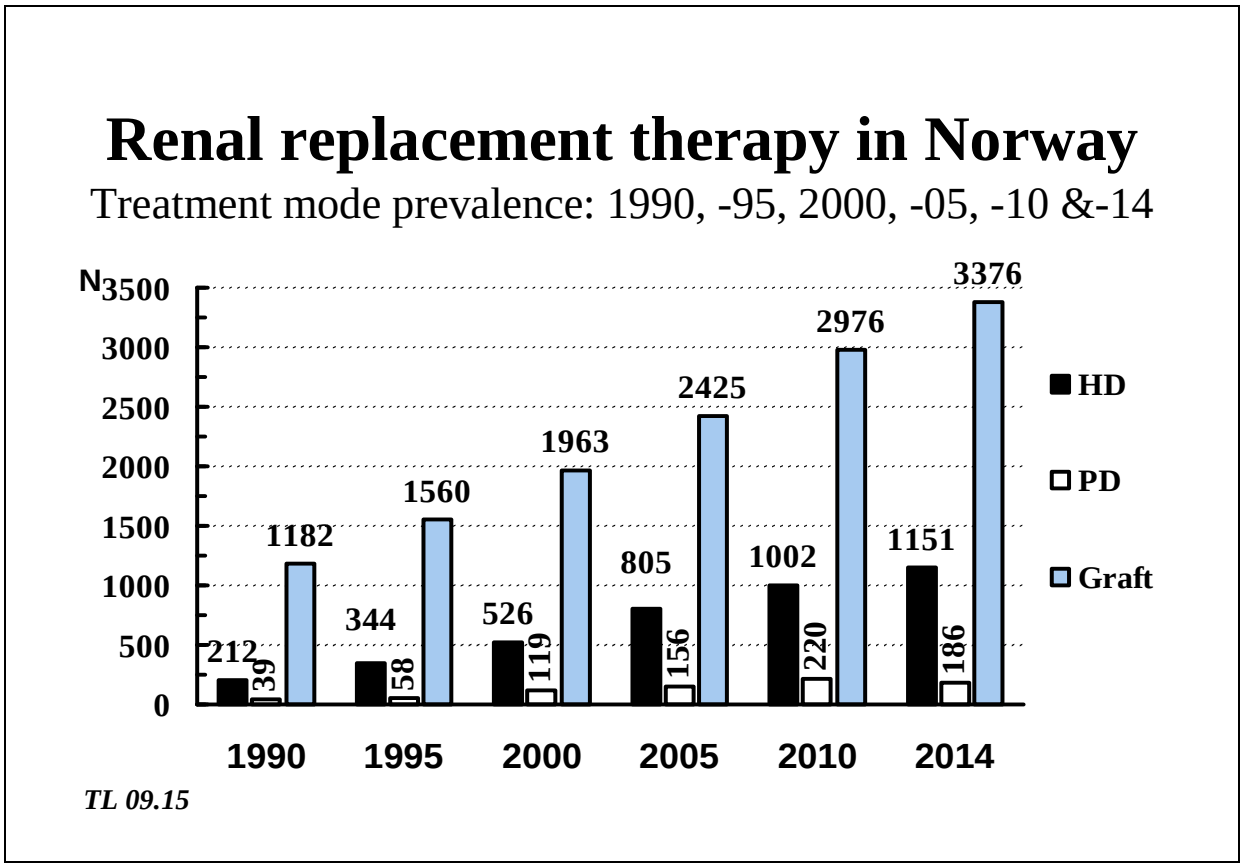
Cardiovascular disease is often present at start of RRT. Coronary heart disease was reported in 144 (28%), one had a previous heart-tx. and 91 (18%) had anamnestic heart failure. Echo-verified left ventricular hypertrophy was reported in 111 (21%). Cerebrovascular disease was reported in 85 (16%) and peripheral atherosclerotic disease in 99 patients (19%) while 66 (13%) had chronic obstructive lung disease.

Prevalence data: Status by 31.Dec. 2014.

By the end of 2014, 4713 patients in Norway received renal replacement therapy, i.e. 917.3 per million inhabitants. This represents an increase of 146 patients or 3.3 % since 2013.
Fourteen patients were on home-HD (same number as in 2013).
Median age by the end of the year was 61.0 years, mean 59.1 years and range 1.0 - 96 years.
Gender: 65.3 % males and 34.7 % females.

Tabulated by last mode of treatment and age by end of 2014:

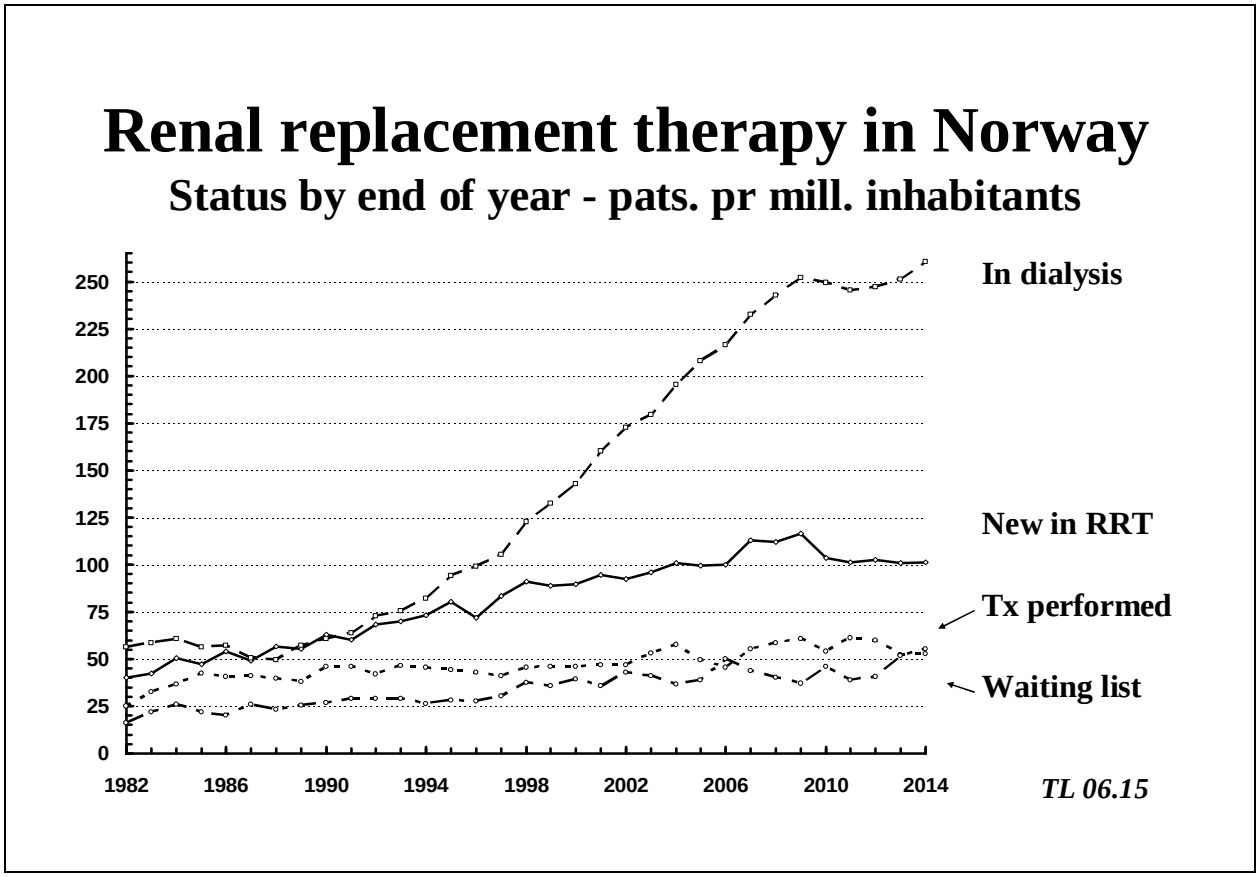
	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total	in %
HD	1	11	44	91	138	186	286	285	109	1151	24.4
PD	1	2	3	12	18	28	47	61	14	186	3.9
TX	44	79	197	434	692	824	796	295	15	3376	71.6
Total	46	92	244	537	848	1038	1129	641	138	4713	100
In %	1.0	2.0	5.2	11.4	18.0	22.0	24.0	13.6	2.9	100	



Transplantation and waiting lists:

A total of 270 renal transplants were performed at Oslo University Hospital Rikshospitalet in 2014, i.e. 52.6 per million inhabitants. In 68 (25%) the graft came from a living donor (LD), 19 of those were biologically unrelated to the recipient (16 were spouses). Among the LD-graft recipients 28 out of 58 first graft recipients were grafted pre-emptively, 6 out of 10 re-graft recipients did not receive dialysis. 202 patients received a deceased donor (DD) graft, 39 out of the 169 first graft recipients were pre-emptively transplanted (23 %), while 3 out of 33 had a re-graft without entering dialysis. There were 227 first grafts (58 LD and 169 DD), 36 were second grafts (6 LD, 30 DD), six third grafts (3 LD and 3 DD) and one fourth graft (LD).
Simultaneous kidney + pancreas (SPK) transplantation was performed in 13, in addition, four 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 169 first-DD-graft recipients in 2014 ranged from 9 to 80 years, with a mean age of 57 y. Out of these, 33 % were above the age of 65 and 7 % were 75 or older. The 58 recipients of a first LD-graft were from 1 to 74 years, mean 44 y. Regraft recipients (n=43) were from 23 to 71 years, mean 51 y.



By end 2014, 285 patients (55.5 per mill.) were on the active waiting list for a DD renal graft. This represented an increase of 23 patients (9 %) since 2013. Among those waiting by Dec.31, median time on the list was 8 months. 35 % had waited less than 6 months, 71 % less than one year and only 5 % more than two years. The 202 recipients given a DD-graft in 2014 had a median waiting time of 13 months and a maximum of 53 months at the time of grafting.
Among the 1338 patients in dialysis treatment by Dec.31, 704 (52.6 %) were for various reasons not considered candidates for a (new) renal graft.

New patients in 2014 – status at start of RRT.

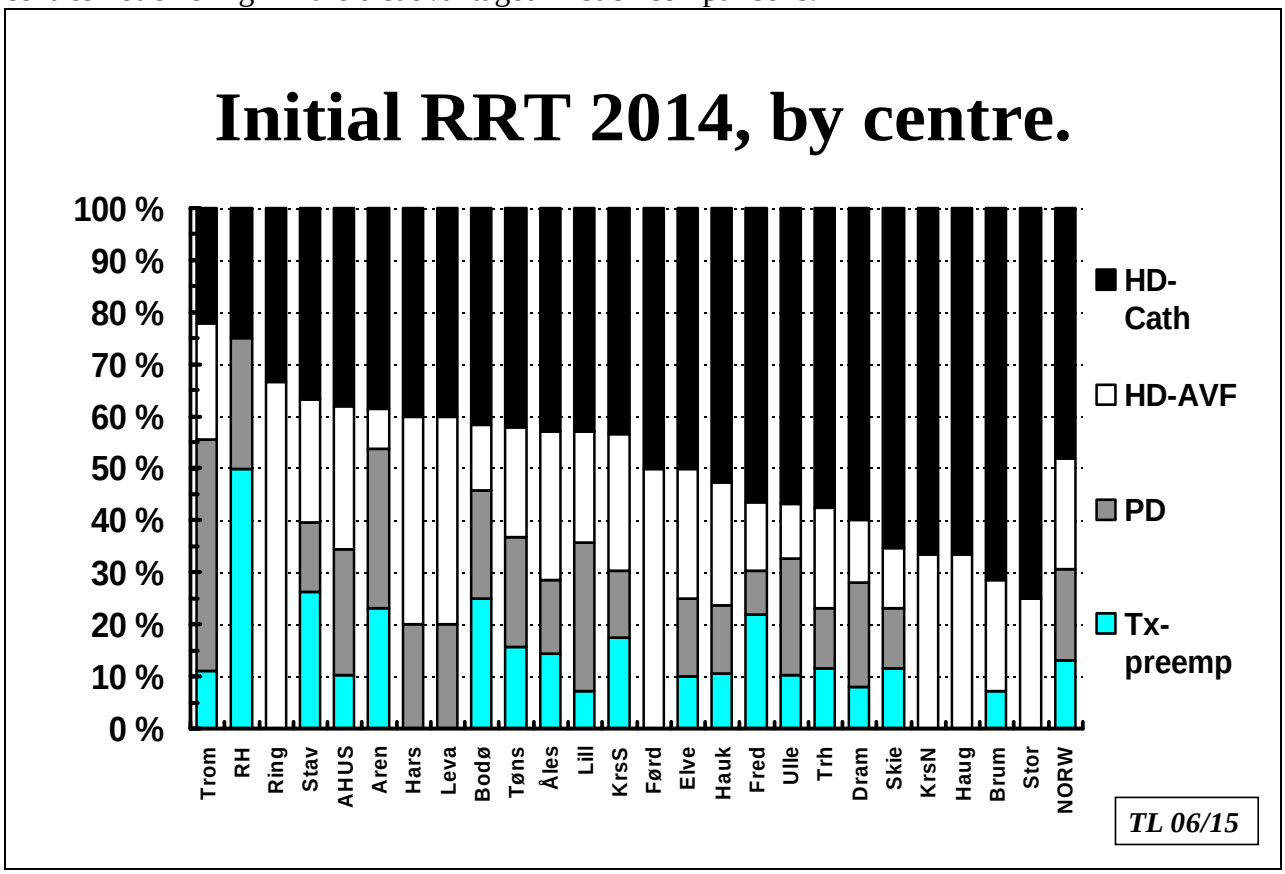
A total of 521 patients started RRT in 2014. Among the 361 starting haemodialysis, the access was via catheter in 250 patients (69 %), while 111 had AV-fistula or graft (31 %) as access.

Status at start of RRT	Total (n:521)	HD (n:361)	PD (n:92)	Tx (n:68)
Creatinine (mean)	635 µmol/l	666	618	492
eGFR (mean), (excl. children)	10.1	9.1	11.8	13.0
Albumin (mean)	36 g/L	34	37	43
Haemoglobin (mean)	10.3 g/dL	10.1	10.3	11.9
Haemoglobin - % <11 g/dL	67 %	74 %	68 %	29 %
ESA use	45 %	44 %	55 %	32 %
Active D vitamin use	62 %	58 %	70 %	69 %
Statin use	55 %	56 %	54 %	50 %
Not on antihypertensive drugs	10 %	12 %	7 %	9 %
Using >2 antihypertensive drugs	51 %	48 %	63 %	54 %

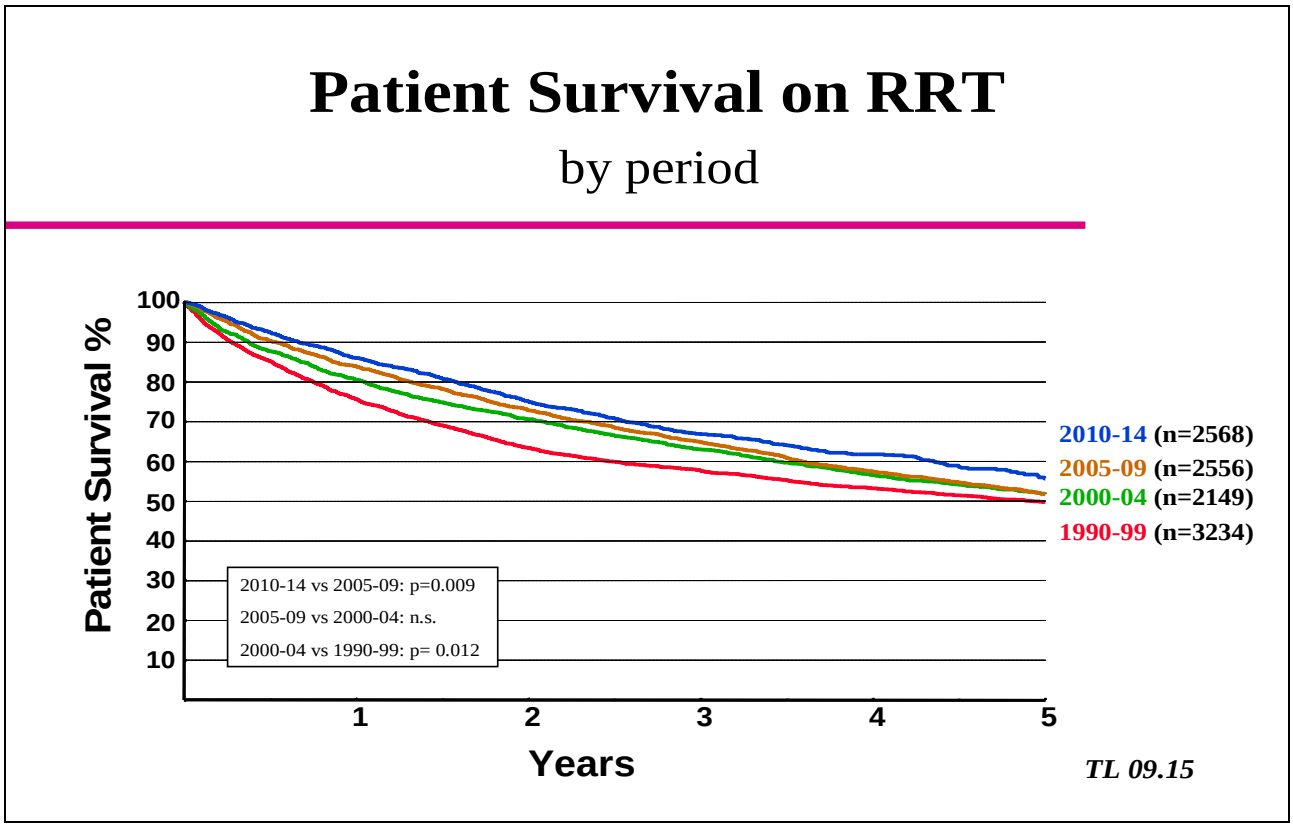
As might be anticipated, pre-emptively transplanted patients had a somewhat lower serum creatinine, thus higher GFR, and a higher haemoglobin and albumin than those starting dialysis. Among patients known less than four months, 82 % had haemoglobin <11 g/dL.

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 by 5-year period:

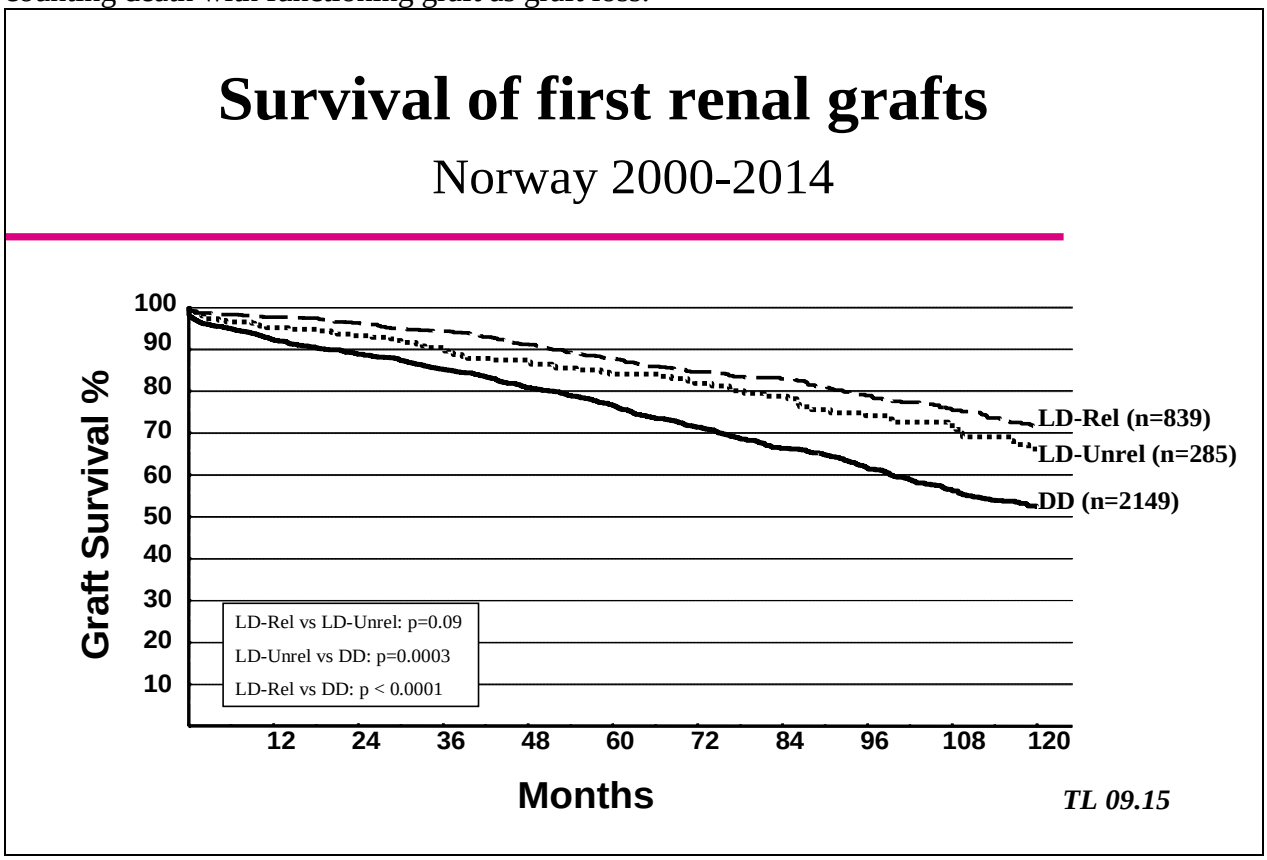


For the period 2000-14 a Cox regression analysis was performed, using age, gender, initial evaluation (“dialysis only” vs. “potential tx-candidate”) and late referral as covariates. While

gender did not influence survival rate, odds ratio was 1.01 (95% CI 1.008-1.012, p < 0.0001) per year, 1.058 (95% CI 1.029-1.088, p <0.0001) for late referral and 1.961 (95% CI 1.847-2.082, p <0.0001) for not being considered a probable candidate for transplantation at start of RRT.

Survival of first renal grafts since 2000:

Survival of first renal grafts from the period 2000-14 was calculated by Kaplan-Meier method, counting death with functioning graft as graft loss.



As the figure shows, grafts from living donors (LD) do significantly better than deceased donor (DD) grafts. Grafts from related donors tend to do better than grafts from unrelated (mostly spousal) donors, but not significantly so.

However, the groups are not fully comparable. Recipient mean age was 56.5 y. for DD-recipients, 53.2 y. for LD-unrelated and 41.9 y. for LD-related (p<0.001 for all comparisons). Also mean donor age differed, 49.6 y for DD-recipients and 51.0 for LD-unrelated (n.s.), LD-related donors were younger, mean 47.2 y (p<0.001), and DD-recipients had spent longer time on dialysis (mean 18 months vs 7 months (p<0.001).

While little can be done to influence recipient and donor age, efforts to find a potential living donor and efforts to reduce dialysis time (at best to avoid dialysis) and optimal immuno-suppression are considered beneficial for transplantation results. Thus, we performed a Cox regression analysis, including all groups, that confirmed a significant influence (p-value < 0.0001) of age (odds ratio 1.027, 95% CI 1.022-1.032 per year), donor age (odds ratio 1.016, 95% CI 1.012-0.1021 per year), dialysis time (odds ratio 1.336, 95% CI 1.17-1.525 for having >12 months on dialysis). Still, the effect of having a DD-graft had significant effect, odds ratio 1.285 (95% CI 1.102-1.497, p=0.0013) compared to LD-grafts. Around 70% in all groups had received induction therapy with IL2-R-blocker or ATG, this resulted in odds ratio 0.753 (95% CI 0.66-0.859, p<0.0001).

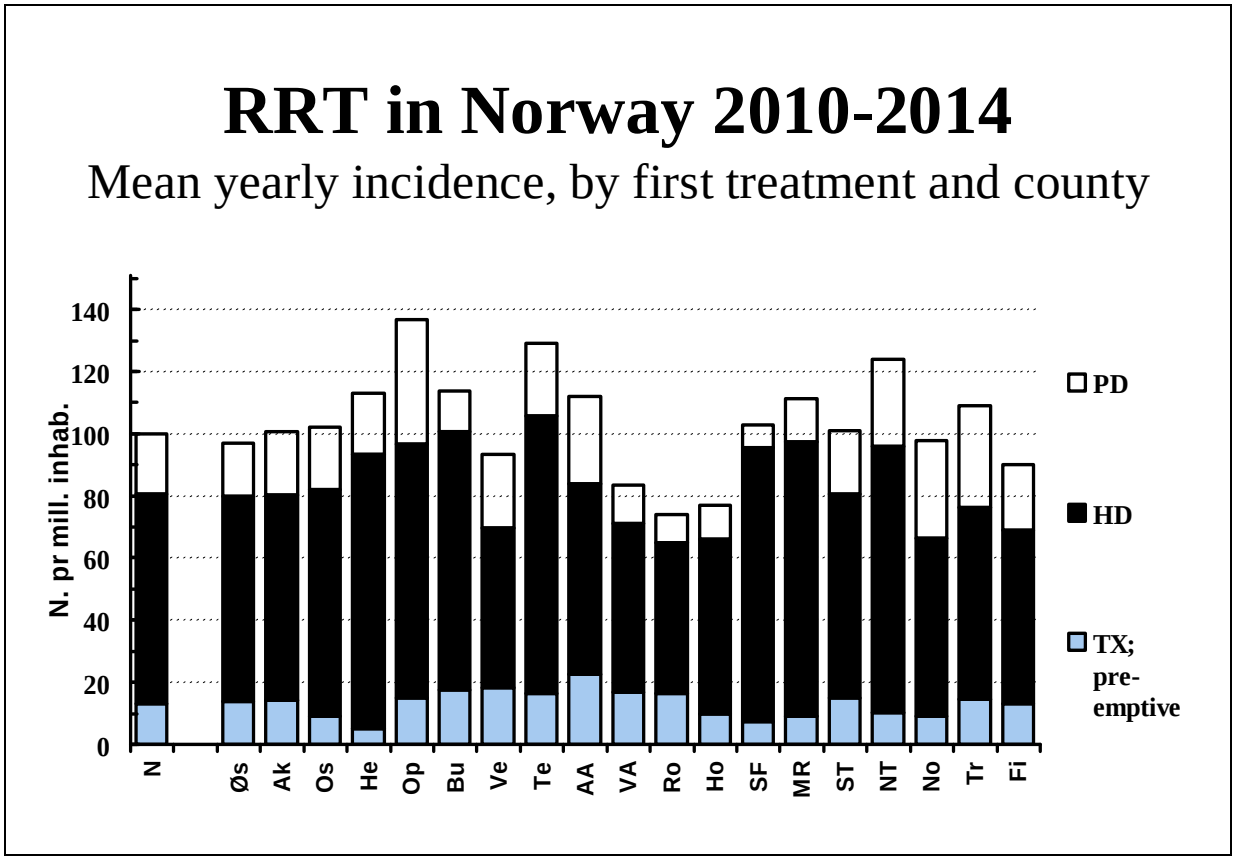
Death in RRT:

A total of 363 patients in renal replacement therapy died during 2014, i.e. 7% out of the 5089 persons at risk. Among these, 70% were males and 30% females. Median age at death was 73 years, mean 72 years, and the range 27-96 years. Median time from start of RRT until death was 55 months, with a range spanning from 20 days to 45 years.
The final mode of treatment was HD for 214 patients and PD for 40, while 109 died with a more or less well-functioning graft. Four patients died within two moths after graft loss, thus 113 deaths were termed “Tx-related”. Dialysis treatment was terminated and followed by death in 34 patients; in 15 of those the patient decided to refuse further treatment.
Cardiac complications (32%) were the most frequent causes of death, followed by infections (27%), 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 2010-2014:



As appears, the mean annual incidence of RRT-start varied from 74 to 137 pr. million, with Rogaland 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

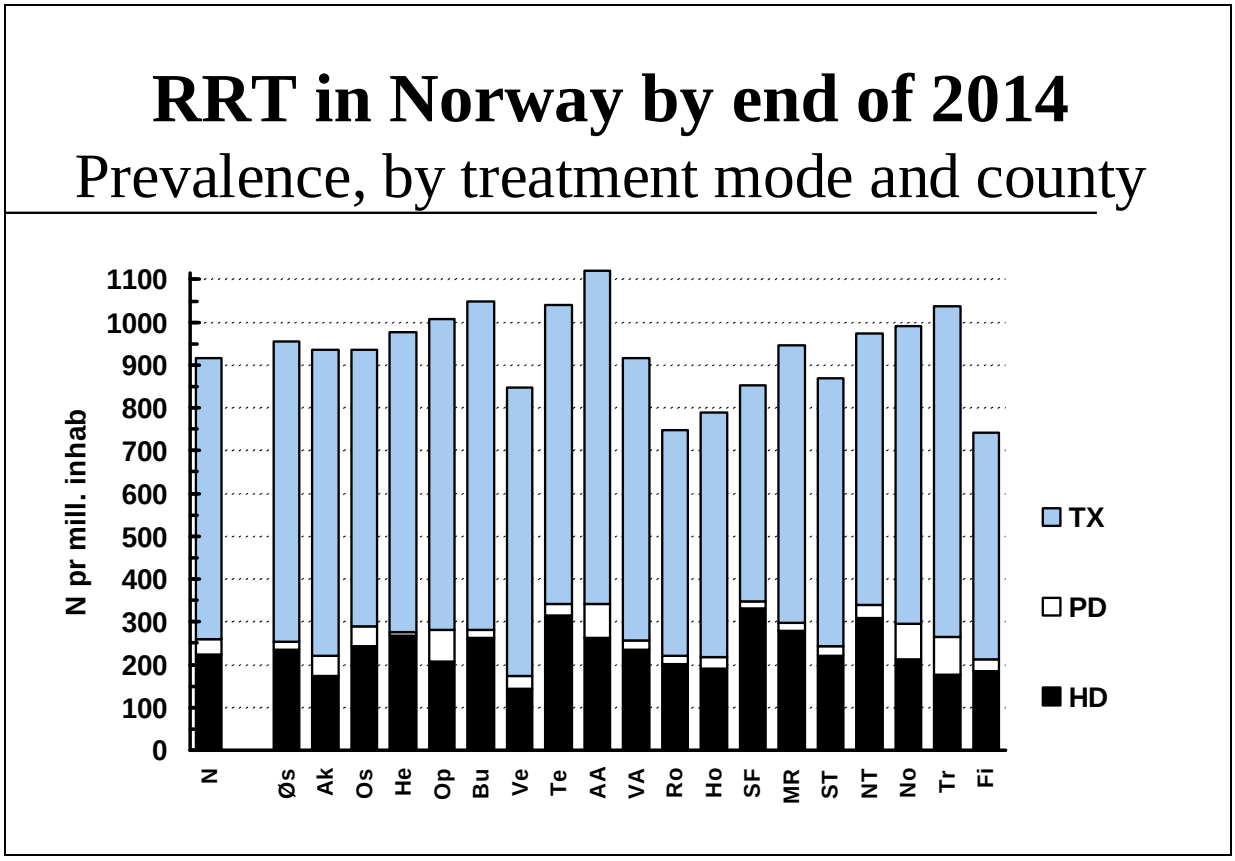
groupings, diagnosis groupings, differences in acceptance for permanent dialysis, or late referral rates, has failed to explain the marked variations in incidence.

There is national consensus that pre-emptive transplantation is preferable. Looking solely at 2014-data (see Appendix), this was achieved in 13 % of all. In the individual counties the numbers are small, but this figure ranged from 0 % to 24 % (Nordland).
Efforts are also done to increase the use of PD. Still in some counties PD is rarely used, in others up to 47 % (Troms) of new patients in 2014 had this as first treatment mode. 69% received HD as first treatment mode, in the counties this ranged from 40 % to 100 %.

The proportion of the new dialysis patients in 2014 who started RRT without having been known by the renal unit for at least 4 months was 23 %, 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 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 59% to 80% of the total RRT-population. The dialysis prevalence ranges from 174 to 347 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.



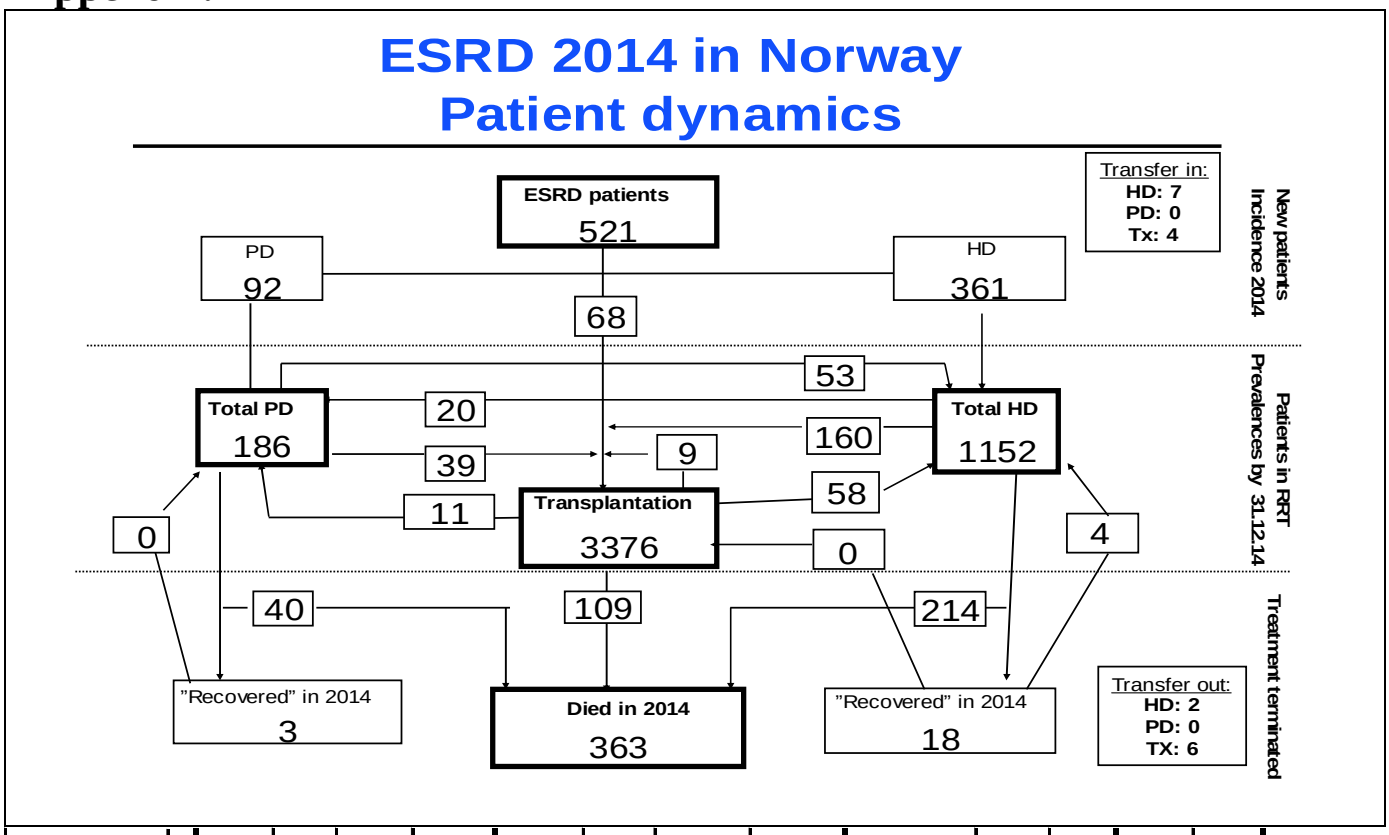
Concluding remarks:

The 2014 figures 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 2014 was comparable to that of previous years; still the transplant population increased by 2.6 %, while the dialysis population increased by 4.8 % compared to end of 2013 and the number of recorded HD-sessions increased by 6.2%. 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, from the list appears that during 2014 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 are also forwarded to the USRDS-reports (chapter of International comparisons).
The registry has received status as a National Medical Quality Registry by the proper National authorities. As a consequence, a process of merging the RRT-registry with the Norwegian Renal Biopsy Registry has been initiated. This may over time also lead to inclusion of patients with less advanced renal insufficiency into the registry.
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 12.10.2015
Torbjørn Leivestad M.D. Ph.D.

Appendix:



	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	7	8	8	2	18	37	14	133	184	**6473**	39	6	10	6	27
Harstad		4	1	0	5	11	3	49	63	**1693**	0	0	1	1	3
Bodø	7	13	5	6	24	46	19	148	213	**8303**	31	107	9	6	40
Levanger	6	8	2	0	10	43	4	81	128	**7486**	3	58	14	3	33
Trondheim	4	20	3	3	26	68	8	213	289	**10767**	229	550	21	6	51
Kristiansund N	1	9	0	0	9	28	0	31	59	**4154**	0	0	5	0	16
Ålesund	1	10	2	2	14	45	4	129	178	**6853**	109	0	8	2	28
Førde	2	8	0	0	8	35	2	52	89	**5354**	7	53	6	3	25
Bergen	4	29	5	4	38	81	13	269	363	**12279**	96	148	19	9	55
Stord	1	4	0	0	4	12	0	22	34	**1800**	0	0	3	0	7
Haugesund	1	3	0	0	3	31	4	50	85	**4319**	14	53	4	0	24
Stavanger		23	5	10	38	66	6	201	273	**10072**	23	50	7	5	46
Kristiansand S	1	16	3	4	23	47	4	127	178	**6777**	11	0	9	3	36
Arendal		6	4	3	13	26	9	80	115	**4140**	0	91	5	4	17
Skien	3	20	3	3	26	54	5	120	179	**8641**	6	47	19	3	36
Tønsberg		12	4	3	19	33	6	156	195	**4622**	83	116	11	3	17
Hønefoss	1	9	0	0	9	29	0	52	81	**3855**	0	0	0	3	15
Drammen	1	18	5	2	25	46	9	166	221	**7076**	11	33	13	5	17
Bærum		13	0	1	14	25	0	31	56	**3747**	0	0	6	2	11
Lillehammer	3	18	8	2	28	41	13	135	189	**6566**	16	0	13	8	33
Elverum	1	15	3	2	20	47	2	120	169	**7420**	0	95	14	4	18
Fredrikstad	2	16	2	5	23	67	5	199	271	**10507**	94	0	9	4	29
AHUS		38	14	6	58	109	32	306	447	**16833**	0	0	19	16	47
Ullevål		39	13	6	58	113	23	327	463	**15041**	33	0	22	16	69
RH		2	2	4	8	11	1	179	191	**3076**	280	314	3	1	4
SUM		***361***	***92***	***68***	***521***	***1151***	***186***	***3376***	***4713***	***177854***	*1085*	*1721*	***250***	***113***	***704***
# Pr. mill innb.		*70,3*	*17,9*	*13,2*	*101,4*	*224,0*	*36,2*	*657,1*	*917,3*	*ie. + 6,2 %*					*137,0*
% of total		*69,3*	*17,7*	*13,1*	*100,0*	*24,4*	*3,9*	*71,6*	*100,0*	*fra 2013*					*52,7*