

ANNUAL REPORT 2011

The Norwegian Renal Registry

(Norsk Nefrologiregister)

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

Correspondence to:
Dr.med Torbjørn Leivestad
Renal Unit, OUS-Rikshospitalet, Box 4950 Nydalen, N-0424 Oslo, Norway.
Tel: 47- 23 07 36 62.
E-mail: tleivest@ous-hf.no

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.

During the recent years a process of transition from a pure epidemiological registry into a quality-oriented registry has been initiated. Some results from this have appeared in the latest annual reports. With the present way of collecting and processing quality data, they cannot be collected in time to be included in the annual report. Selected data will be included in the next report; others will be theme for quality-seminars and special reports.

National organisation and policy

Norway has 4.953 mill. inhabitants (July 2011) and 19 counties with populations ranging from 73500 to 607000. 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 1963-83). Pre-transplant work-up, as well as post-transplant follow-up beyond 3 months, is handled by the county-centres.

The centres, at present 24, are responsible for reporting data from day 1 on all patients receiving renal replacement therapy (RRT) for chronic renal failure within their area.

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 2011, 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 2011

During 2011 a total of 503 new patients (in 2010: 505) entered renal replacement therapy (RRT), i.e. 101.4 per mill. inhabitants.

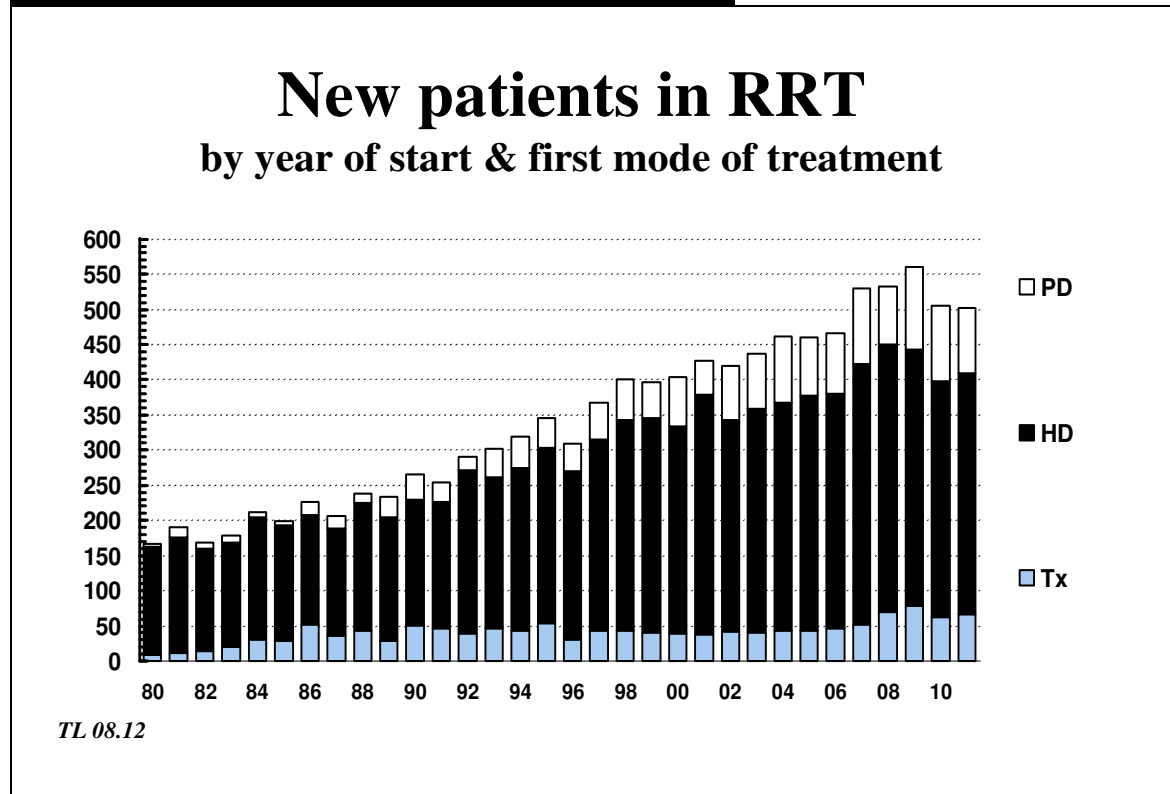
A majority of 354 (70.4 %) were males and 149 (29.6 %) females. Median age at start was 65.0 years, mean 61.9 years, ranging from two days to 89.9 years.

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

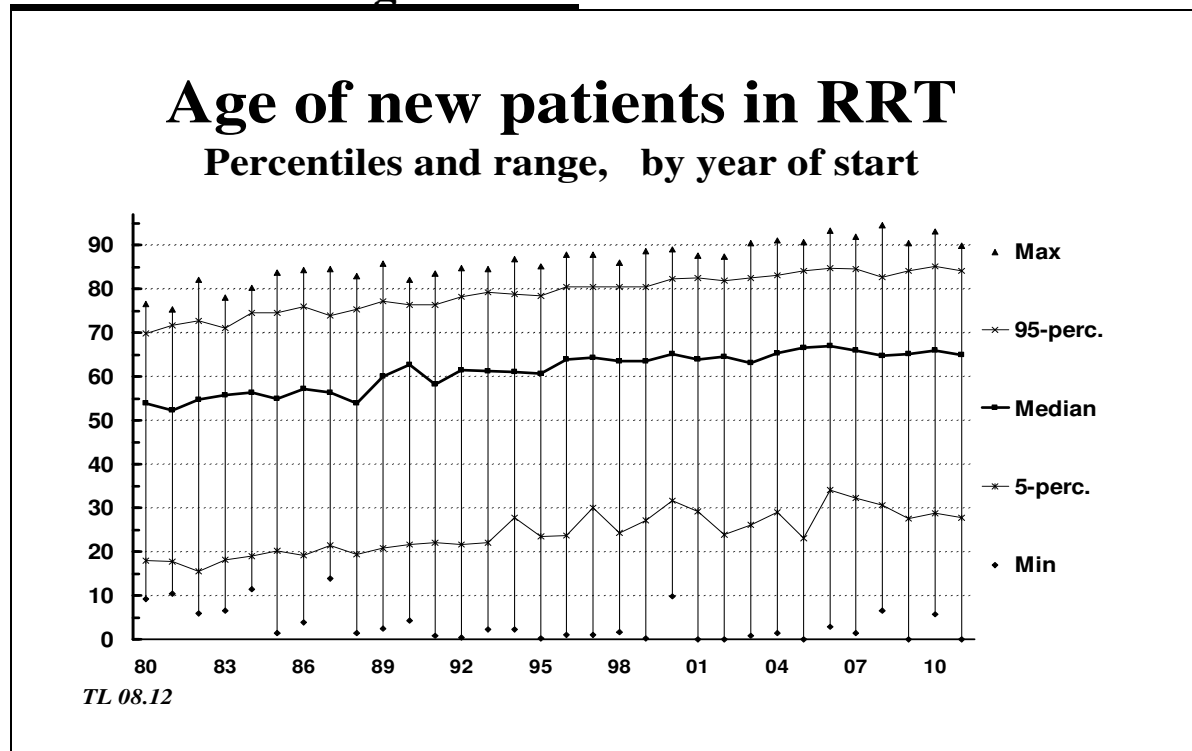
	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total	in %
HD	5	7	13	27	38	74	81	84	13	342	68.0
PD	4	0	2	5	8	20	22	27	6	94	18.7
TX	1	2	6	17	7	17	12	5	0	67	13.3
Total	10	9	21	49	53	111	115	116	19	503	100
in %	2.0	1.8	4.2	9.7	10.5	22.1	22.9	23.1	3.8	100	

At start of treatment, 312 (62 %) were considered by their nephrologist to be a potential candidate for transplantation, while 191 (38 %) were accepted for life-long dialysis (the latter constituting 45 % of those starting with HD and 38 % of those starting PD). Among patients starting dialysis in 2011, 73 % had been under control by the renal unit for at least four months, while 27 % were previously unknown.

Incidence data: Changes 1980-2011



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. Ten children below 15 years started RRT in 2011; 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	2011
Glomerulonephritis	35%	27%	18%	18%	16%	17%
Pyelo/interstitial nephr.	15%	11%	11%	10%	7%	11%
Polycystic diseases	10%	9%	9%	8%	7%	7%
Diabetic nephropathy	13%	11%	15%	16%	17%	14%
Amyloidosis	6%	5%	3%	2%	2%	2%
Vascular/hypertensive	7%	21%	28%	31%	39%	39%
Immune/systemic	5%	5%	4%	4%	4%	3%
Kidney tumour	1%	1%	1%	2%	3%	1%
Myelomatosis	2%	2%	3%	3%	1%	1%
Other defined	4%	4%	3%	4%	4%	3%
Unknown	3%	3%	4%	4%	3%	3%
N:	2018	3234	2149	2556	509	503

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. Until 1995 sub-classification was not reliably registered. In 2011, 20 were registered as having Type I and 52 as Type II diabetes, 71 patients with other types of primary renal disease were recorded as having diabetes as a co-morbid factor (two were Type I and 69 Type II), thus 28 % of new patients were diabetics.

The time from onset of diabetes to start of RRT differed considerably. For the 20 with Type I diabetes the mean time was 37.1 years, for the 52 with Type II diabetic nephropathy the mean time was 17.7 years. Type II diabetics judged to have a primary renal disease other than diabetic nephropathy in mean had 11.5 years of pre-RRT diabetes duration.

Cardiovascular disease is often present at start of RRT. Coronary heart disease was reported in 153 (30%), one had a previous heart transplant. Echo-verified left ventricular hypertrophy was reported in 97 (19%). Cerebrovascular disease was reported in 53 (11%) and peripheral atherosclerotic disease in 101 patients (20%).

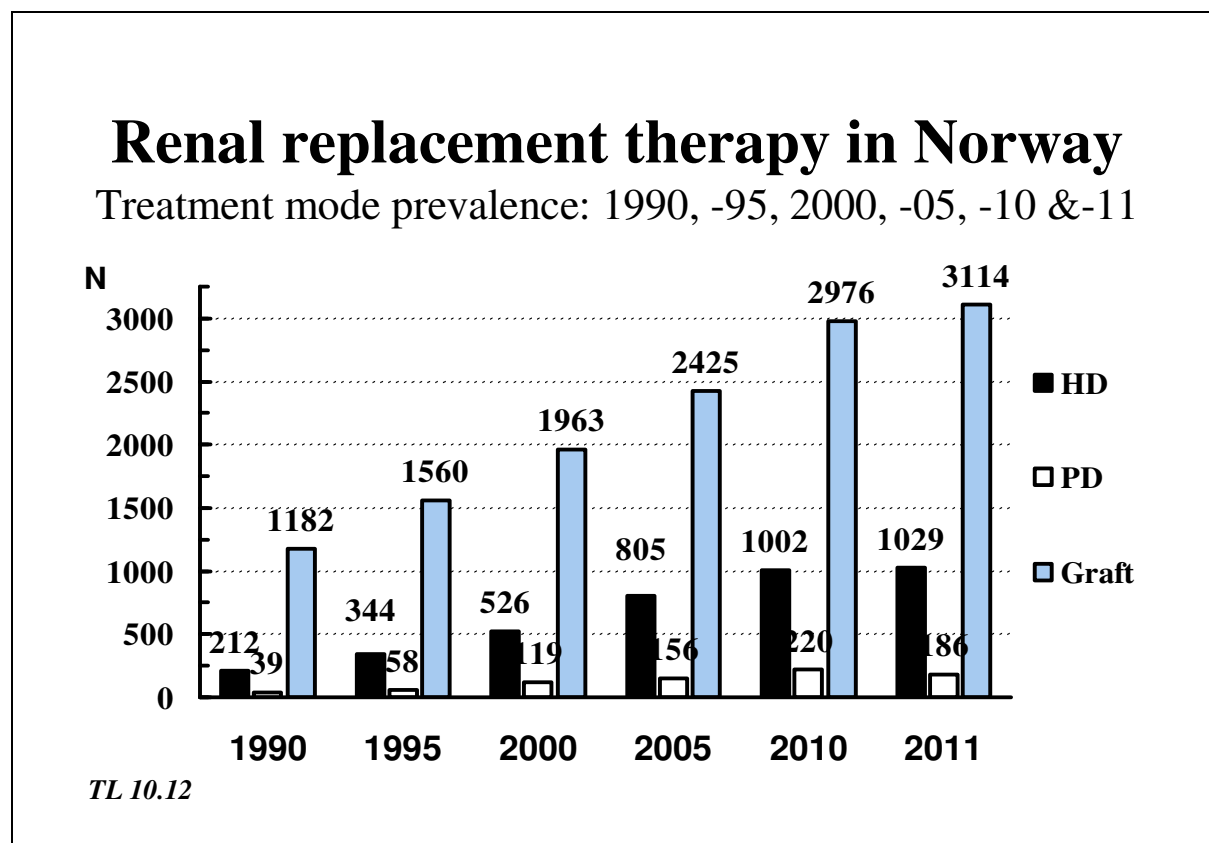
Prevalence data: Status by 31.dec. 2011.

By the end of 2011, 4329 patients in Norway received renal replacement therapy, i.e. 874.0 per million inhabitants. This represents an increase of 131 patients or 3 % since 2010. Gender: 65.0 % males and 35.0 % females. Seven patients were on home-HD (8 in 2010).

Median age by the end of the year was 60.4 years, mean 58.3 years and range 0.2 - 94.2 years.

Tabulated by last mode of treatment, and age by end of 2011:

	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total	in %
HD	3	9	41	64	116	191	263	271	71	1029	23.8
PD	5	0	2	7	16	38	34	70	14	186	4.3
TX	33	87	188	476	620	803	654	238	15	3114	71.9
Total	41	96	231	547	752	1032	951	579	100	4329	100
In %	0.9	2.2	5.3	12.6	17.4	23.8	22.0	13.4	2.3	100	

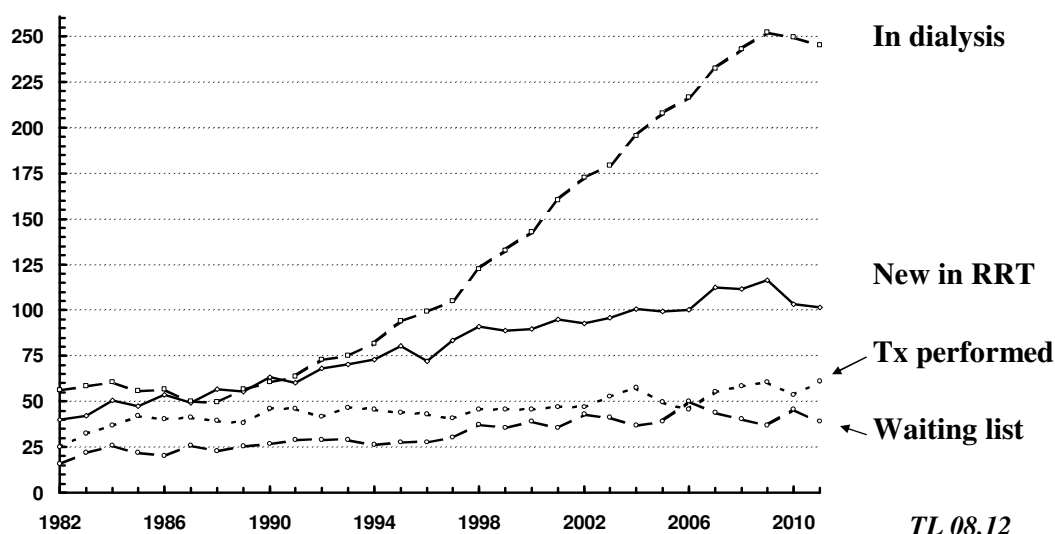


Transplantation and waiting lists:

An all time high total of 302 renal transplants were performed at Oslo University Hospital Rikshospitalet in 2011, i.e. 61.0 per million inhabitants. In 73 (24.2%) the graft came from a living donor (LD), 18 of those were biologically unrelated to the recipient (16 were spouses). Among the LD-graft recipients 28 out of 61 first graft recipients were grafted pre-emptively, 7 out of 12 re-graft recipients did not receive dialysis. 229 patients received a deceased donor (DD) graft, 40 out of the 200 first graft recipients were pre-emptively transplanted (20 %), while 3 out of 29 had a re-graft without entering dialysis. There were 227 first grafts (61 LD and 200 DD), 35 were second grafts (10 LD, 25 DD), six third grafts (2 LD, 4 DD). Simultaneous kidney + pancreas transplantation was performed in 16.

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 200 first DD-graft recipients in 2011 ranged from 18 to 82 years, with a mean age of 57 y. Out of these, 34 % were above the age of 65 and 8 % were 75 or older. The 61 recipients of a first LD-graft were from 1 to 72 years, mean 42 y. Re-graft recipients (n=41) were from 15 to 73 years, mean 48 y.

Renal replacement therapy in Norway Status by end of year - pats. pr mill. inhabitants



By end 2011, 193 patients (39.0 per mill.) were on the active waiting list for a DD renal graft. This represented a reduction of 31 patients (18 %) since 2010. Among those waiting by Dec.31, median time on the list was 7.0 months. 40 % had waited less than 6 months, 68 % less than one year and only 11 % more than two years. The 229 recipients given a DD-graft in 2011 had a median waiting time of 8 months and a maximum of 107 months at the time of grafting.

Among the 1215 patients in dialysis treatment by Dec.31, 652 (53.7 %) were for various reasons not considered candidates for a new renal graft.

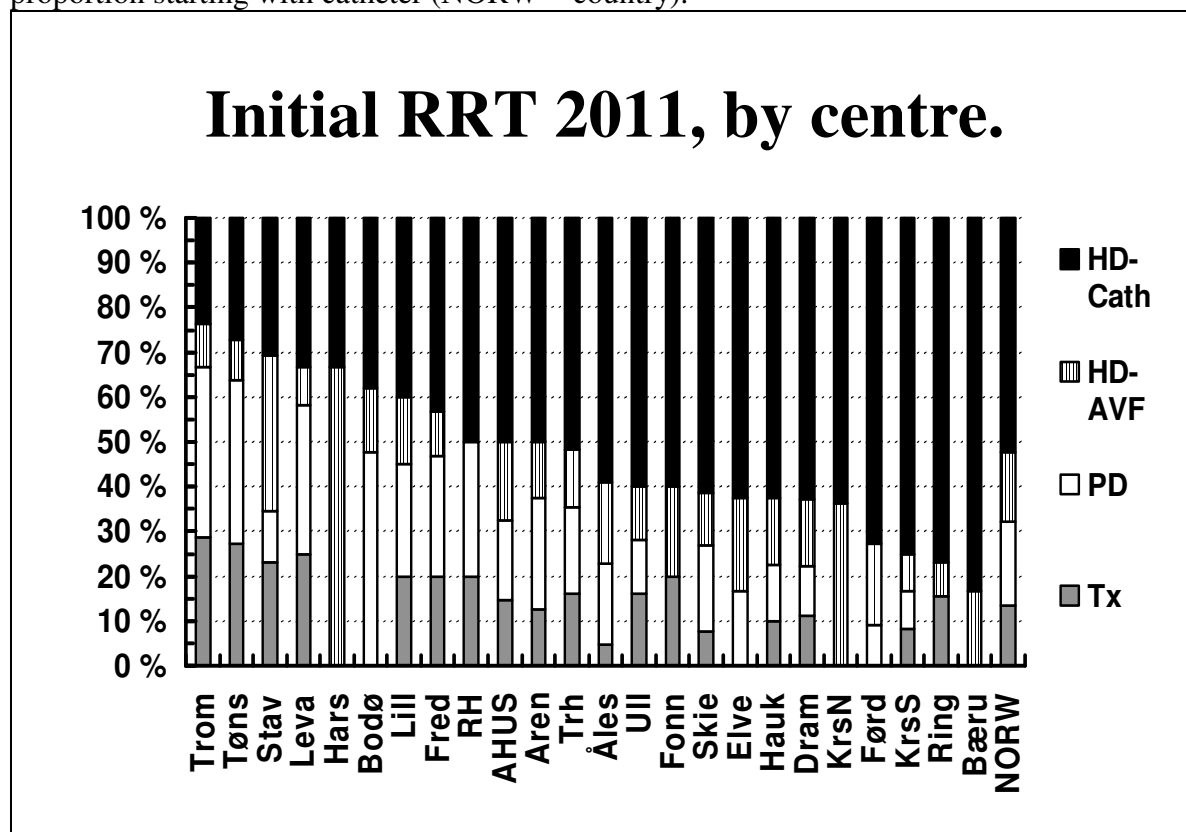
New patients in 2011 – status at start of RRT.

A total of 502 patients started RRT in 2011. Among the 341 starting haemodialysis, the access was via catheter in 264 patients (77%), while 23% had AV-fistula (76) or graft (2) as access.

Status at start of RRT	Total (n:503)	HD (n:342)	PD (n:94)	Tx (n:67)
Creatinine (mean)	618 μ mol/l	669	540	467
eGFR (mean), (excl. children)	9.6	8.8	10.2	12.7
Albumin (mean)	36 g/L	34	38	42
Haemoglobin (mean)	10.5 g/dL	10.2	11.0	11.6
Haemoglobin - % <11 g/dL	62 %	70 %	54 %	34 %
ESA use	48 %	47 %	60 %	34 %
Active D vitamin use	62 %	56 %	82 %	69 %
Statin use	55%	52 %	67 %	55 %
Not on antihypertensive drugs	12 %	14 %	7 %	8 %
Using >2 antihypertensive drugs	55 %	53 %	72 %	43 %

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, 81 % had haemoglobin <11 g/dL.

While pre-emptive transplantation is considered the best initial RRT, HD by catheter may be considered the poorest alternative. In the following figure, individual centres are ranked by the proportion starting with catheter (NORW = country).



Patient survival on RRT:

Patient survival as of July 2012 has been calculated by actuarial method for all patients starting RRT in Norway since 1980; the period since 2000 was divided into two 6-year blocks. The observed one-, five-, and ten-year survival rates, from first day of RRT, are given in the following tables. Further, the time until half of the patients have died (“half-life”) has been noted, or extrapolated based on a semi-logarithmic survival curve plot (marked by *).

1: Survival by epoch:

Year of start	N	Mean age	1 year	5 years	10 years	“Half-life”
1980-89	2018	51.7 y.	75.0 %	50.3 %	36.5 %	61 months
1990-99	3234	57.9 y.	75.6 %	49.7 %	36.1 %	59 months
2000-05	2609	61.2 y.	80.5 %	50.7 %	35.6 %	62 months
2006-11	3107	62.8 y.	84.3 %	51.2 %		61 months

2: Survival by diagnosis group – for patients starting RRT in 2000-2011:

	N	Mean age	1 year	5 years	8 years	“Half-life”
Glomerulonephritis	1021	54.3 y.	90.8 %	74.5 %	65.2 %	* 14.0 years
Pyelo/interstit. neph.	558	61.1 y.	84.8 %	55.7 %	43.9 %	67 months
Polycystic diseases	463	57.0 y.	94.9 %	80.1 %	69.6 %	* 15.5 years
Diabetic nephropathy	887	58.4 y.	83.7 %	49.8 %	38.7 %	60 months
Amyloidosis	125	59.6 y.	61.5 %	24.7 %	17.2 %	19 months
Vascular/hypertensive	1782	71.3 y.	78.6 %	34.8 %	22.2 %	39 months
Immunol./systemic	228	55.6 y.	80.9 %	54.5 %	50.4 %	95 months
Kidney tumour	93	67.1 y.	70.7 %	34.3 %	29.0 %	34 months

3: Survival by initial evaluation and subsequent transplantation:

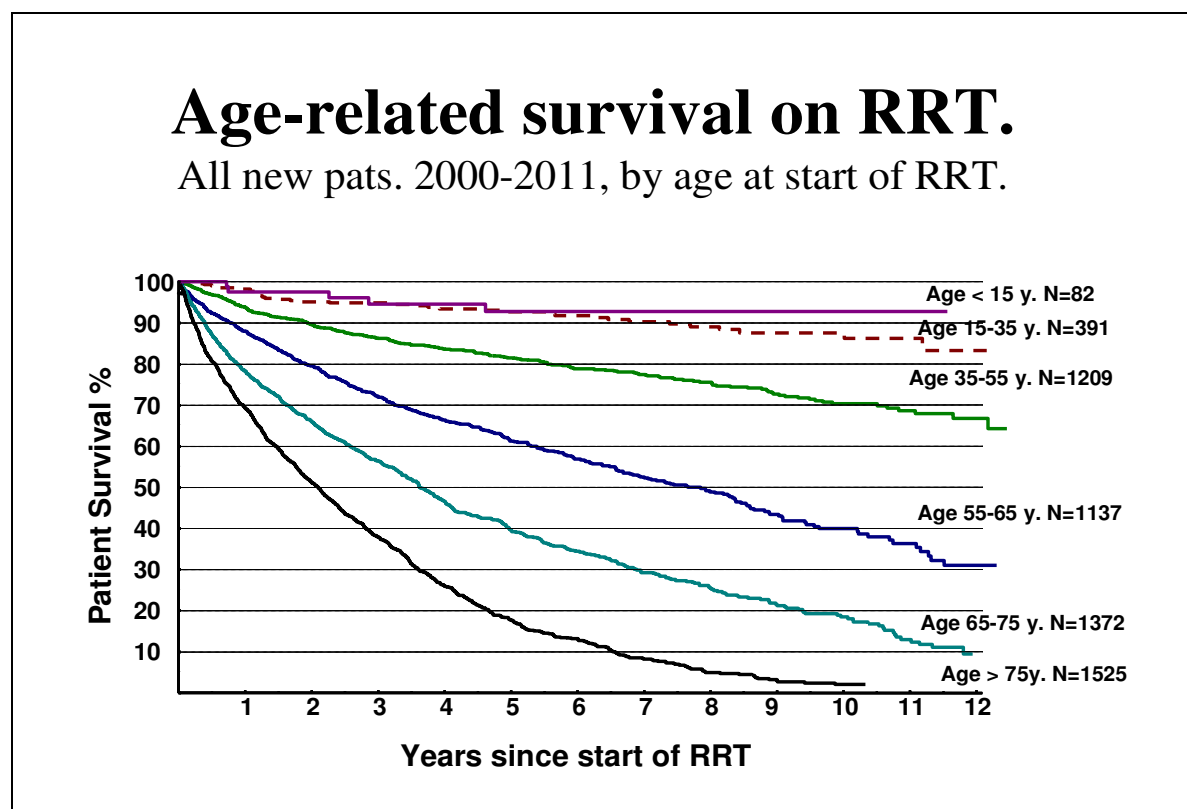
For patients starting treatment during 2000-11, both patient evaluation and treatment protocols have been relatively stable. We have compared the survival rates of those initially evaluated not to be transplant candidates with the potential candidates, and further divided the latter group according to whether they have actually received a graft (by July 2012) or not:

	N	Mean age	1 year	5 years	8 years	“Half-life”
Not Tx-candidate	2044	75.0 y.	63.4 %	14.4 %	5.8 %	21 months
Potential Tx-candidate	3672	54.9 y.	91.0 %	68.7 %	57.8 %	* 10.5 years
Tx-candidate, no Tx.	1271	62.9 y.	76.9 %	22.9 %	7.2 %	31 months
Tx-candidate, transplanted	2401	50.6 y.	98.3 %	88.5 %	79.6 %	* 21 years

As appears, patients not evaluated to be transplant candidates are generally older. Among the potential candidates, the likelihood to actually be grafted is higher in the younger group. We therefore repeated the calculation separately for those above and those below 65 years of age at start of RRT:

Tx-cand.	Tx.	Group	N	Mean age	1 year	5 years	8 years	“Half-life”
No		> 65 y.	1756	78.2 y.	63.9 %	13.2 %	4.2 %	20 months
Yes	No	> 65 y.	650	72.5 y.	76.5 %	20.3 %	4.6 %	32 months
Yes	Yes	> 65 y.	491	70.5 y.	97.5 %	71.7 %	55.3 %	106 months
No		< 65 y.	288	55.3 y.	63.6 %	24.1 %	15.5 %	23 months
Yes	No	< 65 y.	621	59.9 y.	78.2 %	26.2 %	9.9 %	30 months
Yes	Yes	< 65 y.	1910	45.5 y.	98.5 %	91.9 %	85.3 %	* 35 years

Patients not considered being transplant candidates at RRT-start have a limited survival, with little difference whether above or below 65 years. The younger group probably includes more patients with severe complicating conditions. Patients considered potential candidates, but not transplanted will represent a negatively selected group. This group will mainly include those not transplanted due to early death of the patient or where complicating conditions are discovered or develop during RRT. With the high transplantation activity in Norway, a valid evaluation of survival in dialysis for “standard” RRT patients is not possible.



Death in RRT:

A total of 365 patients in renal replacement therapy died during 2011, i.e. 8 % out of the 4700 persons at risk. Among these, 63 % were males and 37 % females. Median age at death was 76 years, mean 73 years, and the range 15-91 years. Median time from start of RRT until death was 42 months, with a range spanning from 9 days to 35 years.

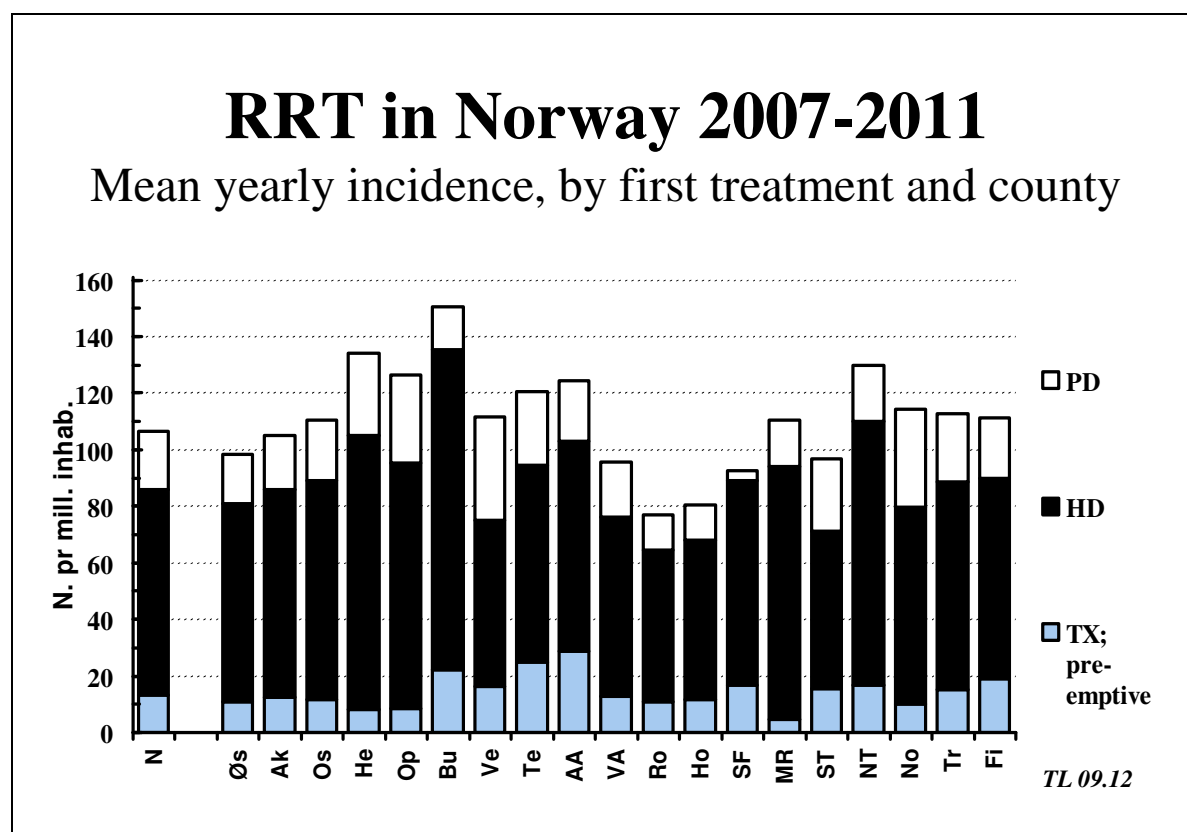
The final mode of treatment was HD for 220 patients and PD for 46, while 99 died with a more or less well-functioning graft. Six patients died within two months after graft loss, thus 105 deaths were termed “Tx-related”. Dialysis treatment was terminated and followed by death in 46 patients; in 16 of those the patient refused further treatment.

Cardiac complications (32%) were the most frequent causes of death, followed by infections (23 %), and malignant tumours (18 %).

Regional differences within Norway.

Incidence:

During all the years since data collection was started, the number of patients reported has differed substantially between centres, also after correction for population size. Further the first mode of treatment (HD, PD or pre-emptive transplant) for new patients differs considerably. In the following figure, patients were grouped by county of domicile at RRT-start and the incidences were calculated as a yearly mean for the five-year period 2007-2011:



As appears, the mean yearly incidence of RRT-start varied from 77 to 150 pr. million, with Rogaland having the lowest and Buskerud 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.

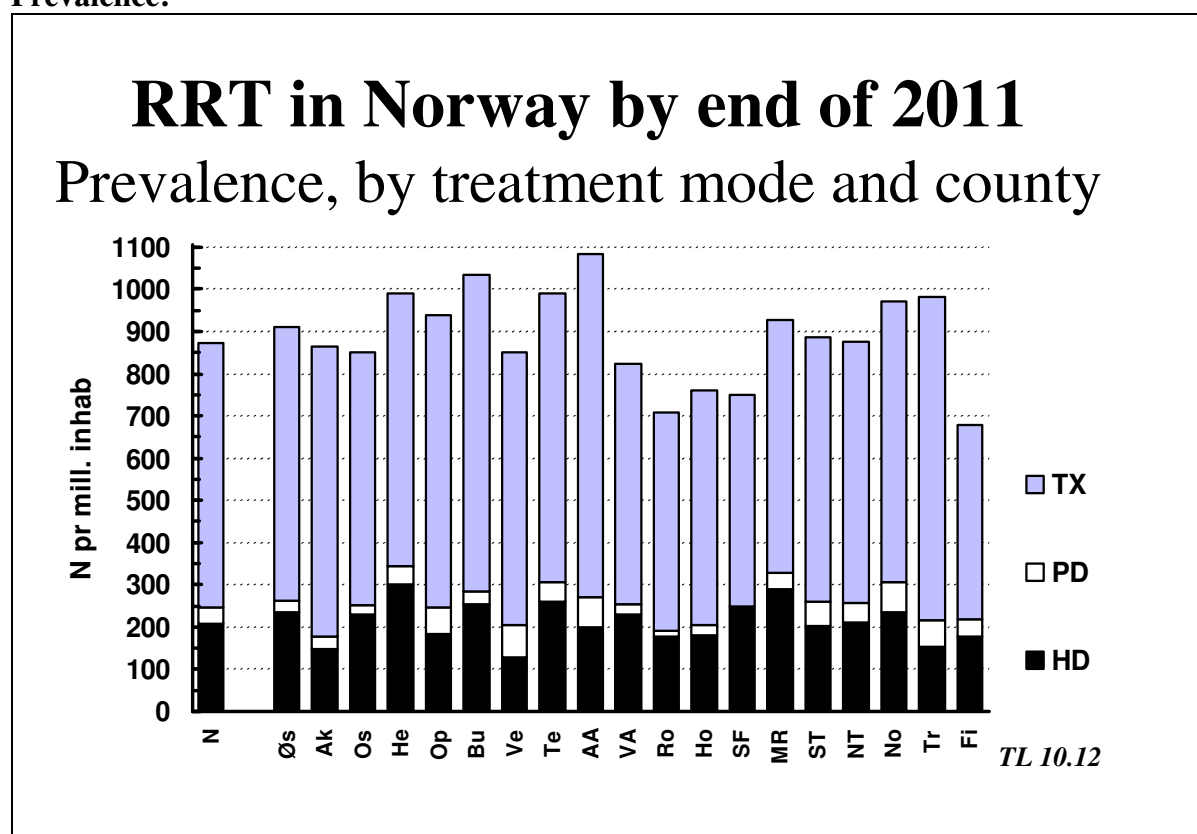
There is national consensus that pre-emptive transplantation is preferable. Looking solely at 2011-data (i.e. not the figure above), this was achieved in 14 % of all. In the individual counties the numbers are small, but this figure ranged from 0% to 29 % (Troms).

Efforts are also done to increase the use of PD. Still in some counties PD is rarely used, in others up to 44 % (Nordland) of new patients in 2011 had this as first treatment mode. 68% received HD as first treatment mode, in the counties this ranged from 38 % to 100 %.

The proportion of the new dialysis patients in 2011 who started RRT without having been known by the renal unit for at least 4 months was 27 %, with wide variations between centres; from 0 % and up to 55 %. 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 early referrals.

We have previously reported marked centerwise differences in the age distribution of incident patients. In 2011 mean age of new patients in the different counties ranged from 48 to 73 years. The huge variation in age-specific incidence between counties has previously been shown (latest in the 2004 report).

Prevalence:



Again, the data demonstrate great differences between the counties. In all counties the majority of patients have a functioning graft, constituting from 65% to 80% of the total RRT-population. The dialysis prevalence ranges from 178 to 344 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 2011 figures seem to confirm that the incidence of RRT in Norway is levelling off, in line with that seen in other European countries (Kramer A & al, Nephrol Dial Transpl 2009; 24: 3557-3566). This year also gave a high transplantation rate, thus the dialysis population stayed stable. Due to improving survival rate in dialysis and transplantation, further increased prevalence of RRT-patients can be expected over the coming years.

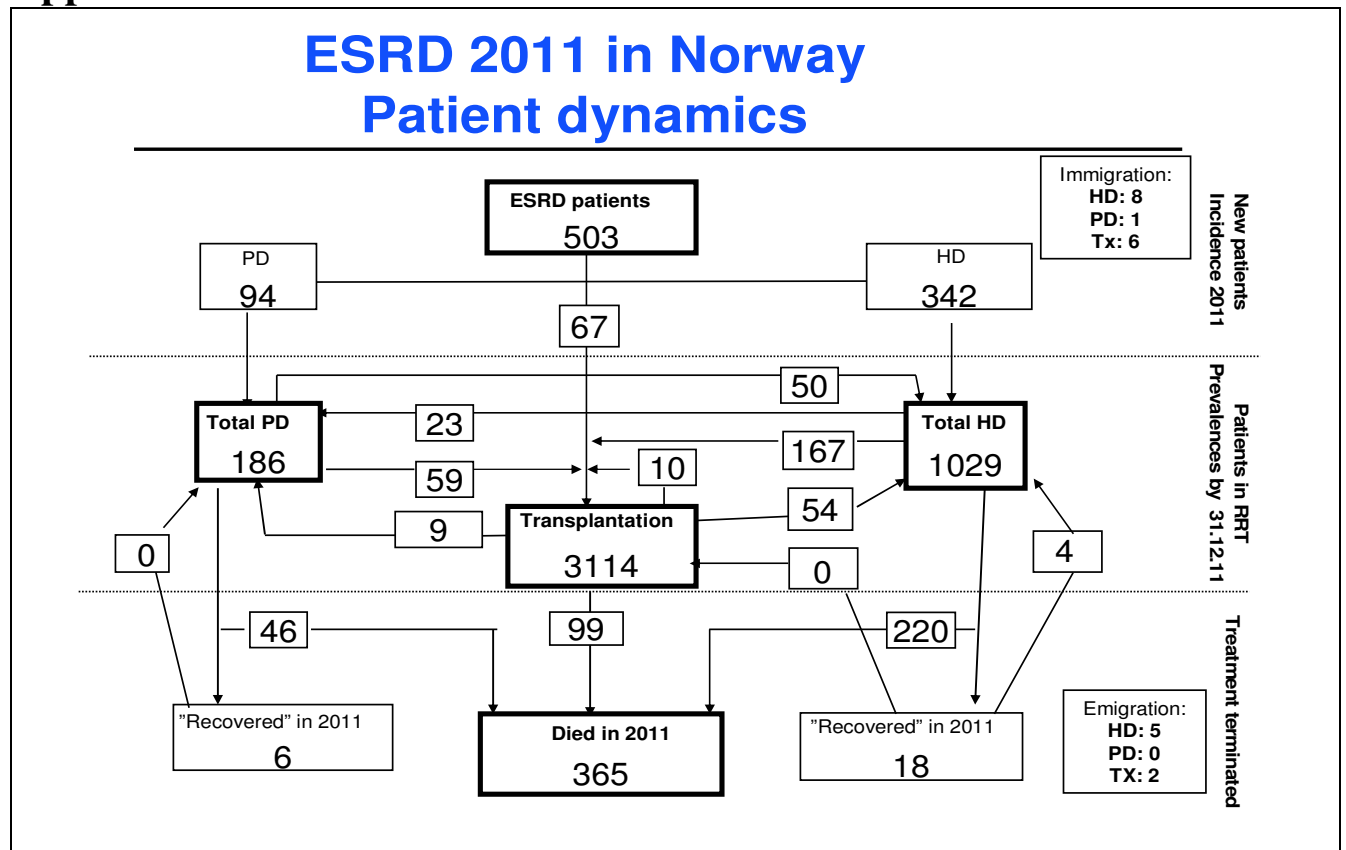
Comparing our data on the quality of RRT with updated international guidelines, it seems that there still is room for quality improvement. Registry data will over the coming years be used for comparisons between the centres to a greater extent than has been the case. Hopefully, the registry can in this 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 spring 2012 been presented on www.nephro.no along with the annual reports, and will be regularly updated. 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 individual) is under way. An application for status as a National Medical Quality Registry is under evaluation 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 19.10.2012
Torbjørn Leivestad M.D. Ph.D.*

Appendix:



	New pat in RRT 2011					Pat. in RRT by 1/1.2012				Dialyses etc. 2011			Died 2011		Not tx-cand.
	Satellites	HD/HDF	PD	Pre-empive	Total	HD/HDF	PD	Graft	Total	HD sessions	Pl.exch.	Other	Dial.pat	Tx-pat	
Tromsø	6	8	8	6	21	35	13	136	184	6222	128	0	5	7	31
Harstad		6	0	0	6	8	0	36	44	937	0	0	1	1	3
Bodø	7	11	10	0	21	51	17	134	202	8806	121	182	13	6	43
Levanger	5	5	4	3	12	28	6	79	113	4539	36	36	7	2	16
Trondheim	4	20	6	5	31	62	17	204	283	9966	155	363	17	7	57
Kristiansund N	1	11	0	0	11	25	0	23	48	3463	0	0	7	1	15
Ålesund	1	17	4	1	22	49	10	117	176	5966	163	0	5	3	33
Førde	2	10	1	0	11	27	0	51	78	3790	0	50	4	2	18
Bergen	2	31	5	4	40	77	11	248	336	11337	63	83	14	5	58
Stord/Hauges.	2	4	0	1	5	29	1	72	102	4778	12	52	6	4	17
Stavanger		17	3	6	26	60	6	177	243	9291	23	45	9	10	33
Kristiansand S	1	10	1	1	12	40	5	109	154	6950	12	0	9	1	31
Arendal		10	4	2	16	22	7	84	113	3229	11	44	6	2	16
Skien	3	19	5	2	26	44	8	118	170	6912	3	57	11	1	33
Tønsberg		8	8	6	22	29	16	144	189	4199	91	48	15	7	18
Hønefoss	1	11	0	2	13	29	0	48	77	3990	0	0	11	3	15
Drammen	1	21	3	3	27	42	13	154	209	5919	40	0	18	3	21
Bærum		12	0	0	12	28	0	9	37	4078	0	0	8	0	14
Lillehammer	2	11	5	4	20	36	12	130	178	5560	10	0	13	6	34
Elverum	1	20	4	0	24	50	7	109	166	6911	0	51	11	6	31
Fredrikstad	2	16	8	6	30	64	8	180	252	10827	13	0	12	6	29
AHUS		23	6	5	34	82	14	254	350	11880	0	0	25	8	37
Ullevål	1	36	6	8	50	95	14	292	401	18615	48	0	30	12	43
RH		5	3	2	10	17	1	206	224	4027	185	211	3	2	6
SUM		342	94	67	503	1029	186	3114	4329	162192	1114	1222	260	105	652
# Pr. mill inh.		69,0	19,0	13,5	101,6	207,8	37,6	628,7	874,0	ie.+ 6,0 %					131,6
% of total		68,0	18,7	13,3	100,0	23,8	4,3	71,9	100,0	From2010					53,7