ANNUAL REPORT 2010

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: torbjorn.leivestad@rikshospitalet.no

Preface

The Norwegian Renal Registry (Norsk Nefrologiregister) was formally constituted in 1994 as 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 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 4.888 mill. inhabitants (July 2010) and 19 counties with populations ranging from 72500 to 580000. 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 county-centres are responsible for reporting data from day 1 on all patients receiving renal replacement therapy (RRT) for chronic renal failure within their area. 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 2010, 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 2010

During 2010 a total of 505 new patients (in 2009: 561) entered renal replacement therapy (RRT), i.e. 103.3 per mill. inhabitants.

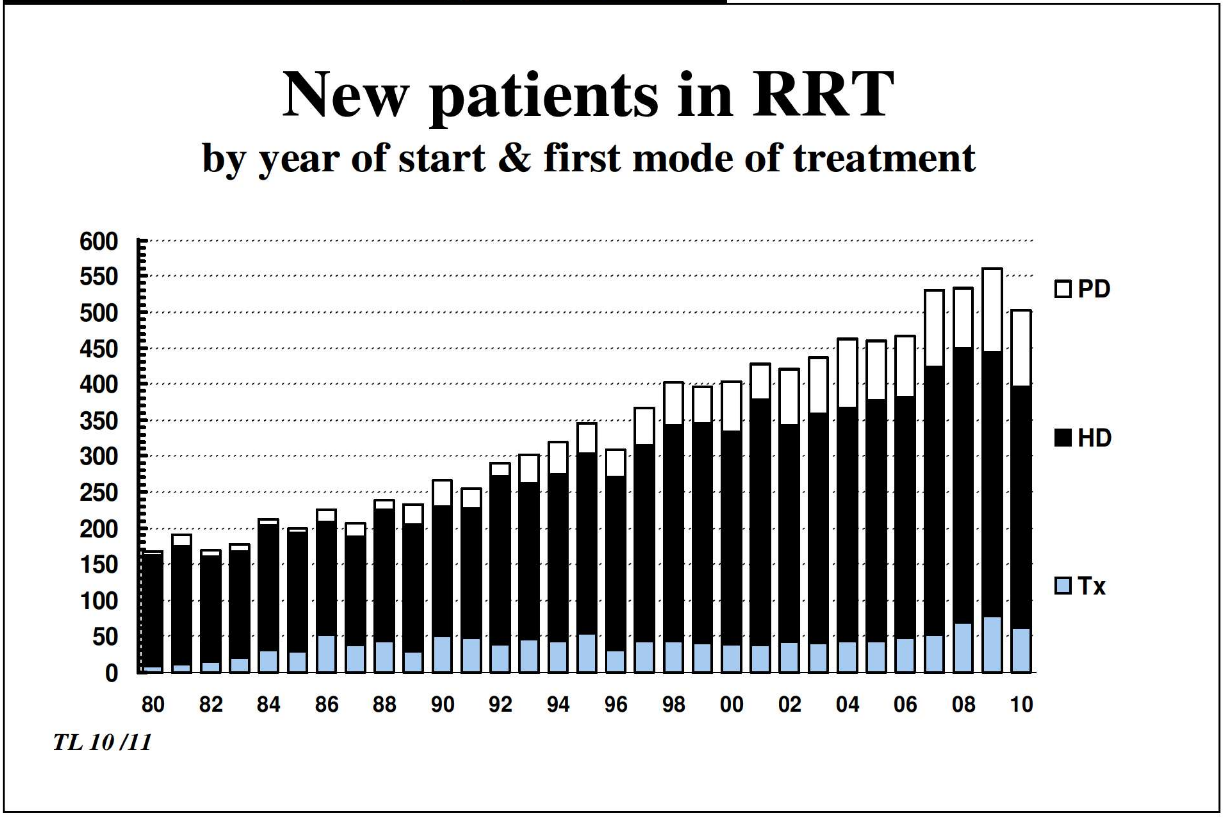
A majority of 339 (67.1 %) were males and 166 (32.9 %) females. Median age at start was 66.0 years, mean 62.4 years, ranging from 5.7 to 93.1 years.

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

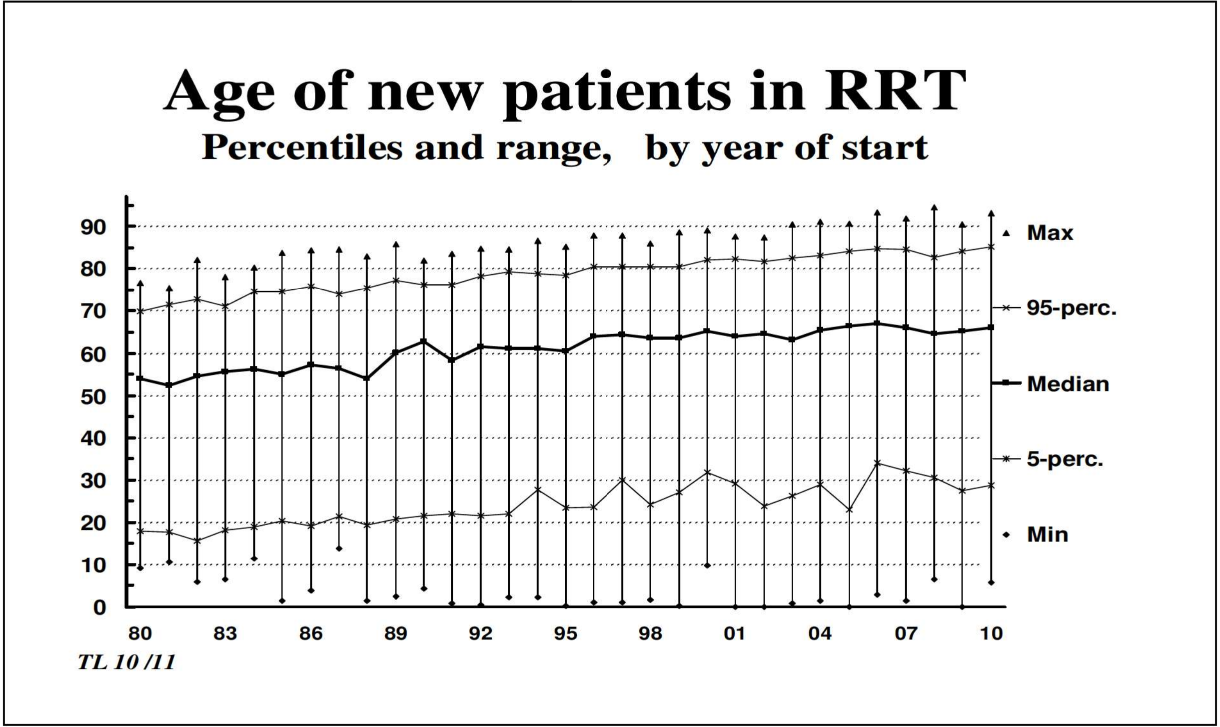
	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total	in %
HD	2	10	12	34	38	50	91	75	24	336	66.5
PD	0	1	2	12	10	18	25	35	4	107	21.2
TX	2	4	6	10	12	14	13	1	0	62	12.3
Total	4	15	20	56	60	82	129	111	28	505	100
in %	0.8	3.0	4.0	11.1	11.9	16.2	25.5	22.0	5.5	100	

At start of treatment, 329 (65 %) were considered by their nephrologist to be a potential candidate for transplantation, while 176 (35 %) were accepted for life-long dialysis (the latter constituting 42 % of those starting with HD and 34 % of those starting PD).
Among patients starting dialysis in 2010, 78 % had been under control by the renal unit for at least four months, while 22 % were previously unknown.

Incidence data: Changes 1980-2010



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 2009 at age 3 days. Four children below 15 years started RRT in 2010; 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	1990-94	1995-99	2000-04	2005-09	2010
Glomerulonephritis	35%	31%	24%	18%	18%	15%
Pyelo/interstitial nephr.	16%	11%	11%	11%	9%	7%
Polycystic diseases	10%	9%	9%	9%	8%	7%
Diabetic nephropathy	13%	12%	11%	15%	16%	17%
Amyloidosis	6%	6%	4%	3%	2%	2%
Vascular/hypertensive	7%	18%	25%	29%	31%	38%
Immune/systemic	5%	4%	5%	4%	4%	4%
Kidney tumour	1%	1%	1%	1%	2%	3%
Myelomatosis	2%	2%	2%	3%	3%	1%
Other defined	4%	4%	3%	4%	4%	3%
Unknown	3%	3%	4%	4%	4%	3%
N:	2019	1418	1817	2149	2556	505

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 10-15% per year. Until 1995 sub-classification was not reliably registered. In 2010, 35 were registered as having Type I and 52 as Type II diabetes, 67 patients with other types of primary renal disease were recorded as having diabetes as a co-morbid factor (one was Type I and 66 Type II), thus 31% of new patients were diabetics.
The time from onset of diabetes to start of RRT differed considerably. For the 35 with Type I diabetes the mean time was 32.5 years, for the 52 with Type II diabetic nephropathy the mean time was 16.4 years. Type II diabetics judged to have a primary renal disease other than diabetic nephropathy in mean had 12.5 years of pre-RRT diabetes duration.

Cardiovascular disease is often present at start of RRT. Coronary heart disease was reported in 143 (28%), one had a previous heart transplant. Left ventricular hypertrophy was reported in 152 (30%). Cerebrovascular disease was reported in 68 (13%) and peripheral atherosclerotic disease in 86 patients (17%).

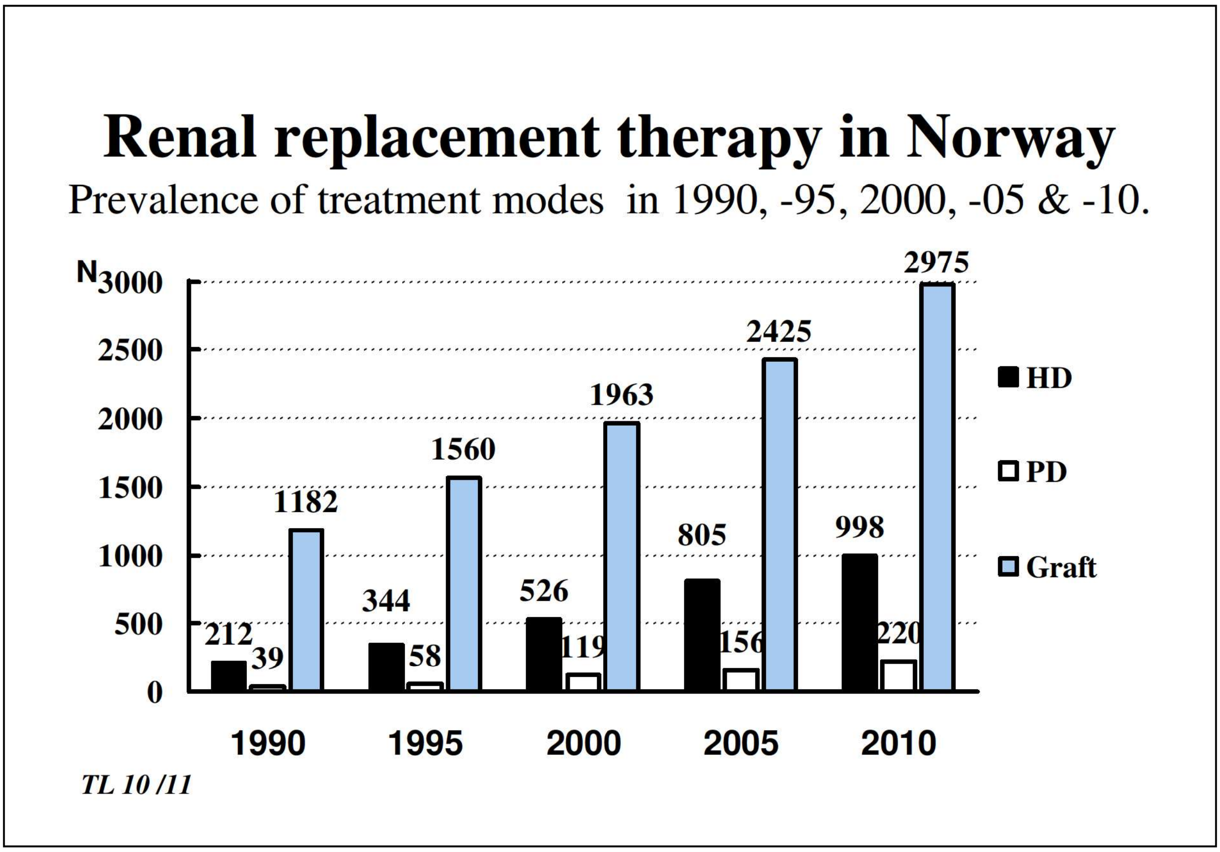
Prevalence data: Status by 31.dec. 2010.

By the end of 2010, 4193 patients in Norway received renal replacement therapy, i.e. 857,8 per million inhabitants. This represents an increase of 119 patients or 3 % since 2009. Gender: 65.0 % males and 35.0 % females. Eight patients were on home-HD (six in 2009).

Median age by the end of the year was 60.3 years, mean 58.2 years and range 1.2 - 93.2 years.

Tabulated by last mode of treatment, and age by end of 2010:

	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total	in %
HD	0	12	35	61	118	177	245	268	82	998	23.8
PD	2	2	3	19	20	37	50	70	17	220	5.2
TX	34	88	179	462	608	775	606	209	14	2975	71.0
Total	36	102	217	542	746	989	901	547	113	4193	100
In %	0.9	2.4	5.2	12.9	17.8	23.6	21.5	13.0	2.7	100	

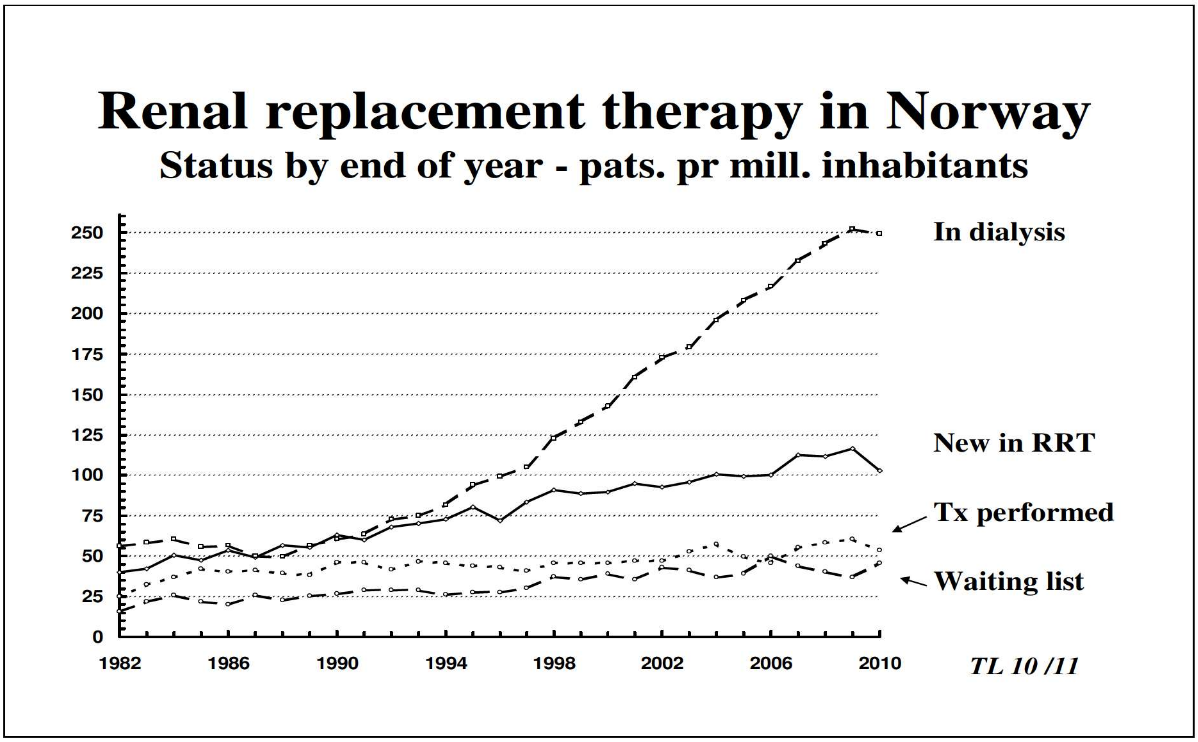

Renal replacement therapy in Norway

Prevalence of treatment modes in 1990, -95, 2000, -05 & -10.

Transplantation and waiting lists:

A total of 263 renal transplants were performed at Rikshospitalet University Hospital in 2010, i.e. 53.8 per million inhabitants. In 83 (31.6%) the graft came from a living donor (LD), 27 of those were biologically unrelated to the recipient (21 were spouses). Among the LD-graft recipients 31 out of 74 first graft recipients were grafted pre-emptively, 3 out of 9 re-graft recipients did not receive dialysis. 180 patients received a deceased donor (DD) graft, 31 out of the 153 first graft recipients were pre-emptively transplanted (20 %), while 8 out of 27 had a re-graft without entering dialysis. There were 227 first grafts (74 LD and 153 DD), 31 were second grafts (6 LD, 25 DD), five third grafts (3 LD, 2 DD). Simultaneous kidney + pancreas transplantation was performed in 14.

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 153 first DD-graft recipients in 2010 ranged from 15 to 81 years, with a mean age of 57 y. Out of these, 33 % were above the age of 65 and 4 % were 75 or older. The 74 recipients of a first LD-graft were from 1 to 74 years, mean 44 y. Regraft recipients (n=36) were from 8 to 73 years, mean 47 y.



By end 2010, 224 patients (45.8 per mill.) were on the active waiting list for a DD renal graft. This represented an increase of 45 patients (25 %) since 2009. Among those waiting by Dec.31, median time on the list was 7.5 months. 42 % had waited less than 6 months, 67 % less than one year and only 12 % more than two years. The 180 recipients given a DD-graft in 2010 had a median waiting time of 7 months and a maximum of 79 months at the time of grafting.

Among the 1217 patients in dialysis treatment by Dec.31, 613 (50.4 %) were for various reasons not considered candidates for a new renal graft.

Quality measures in RRT.

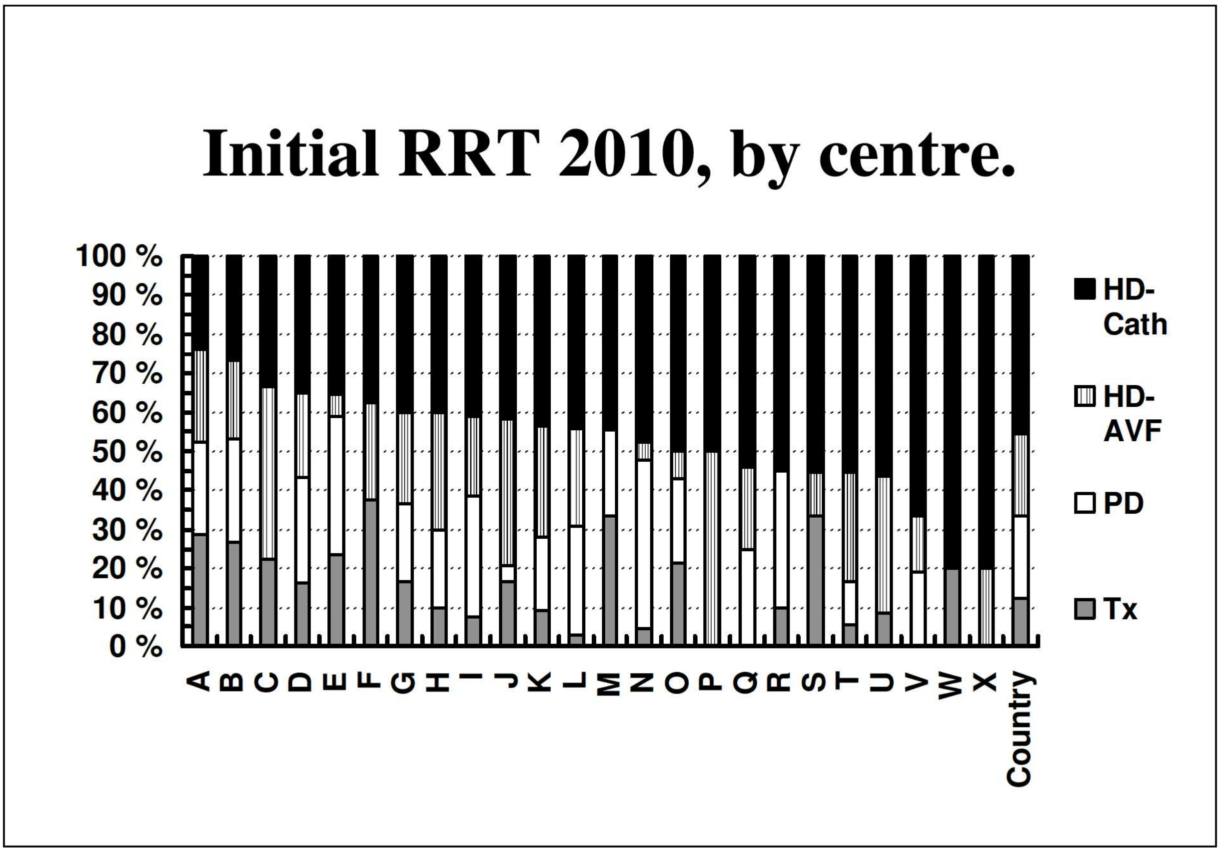
A: New patients in 2010 – status at start of RRT.

A total of 505 patients started RRT in 2010. Among the 336 starting haemodialysis, the access was via catheter in 231 patients (69%), while 31% had AV-fistula (104) or graft (1) as access.

Status at start of RRT	Total (n:505)	HD (n:336)	PD (n:107)	Tx (n:62)
Creatinine (mean)	622 mmol/l	651	599	506
GFR (mean), by MDRD formula	9.4 ml/min	9.1	8.7	11.8
Albumin, mean	36 g/L	35	38	42
Haemoglobin, mean	10.6 g/dL	10.3	10.9	12.0
Haemoglobin - % <11 g/dL	60 %	70 %	53 %	19 %
ESA use	59 %	55 %	72 %	53 %
Active D vitamin use	60 %	55 %	65 %	79 %
Statin use	57 %	54 %	63 %	63 %
Not on antihypertensive drugs	10 %	14 %	3 %	5 %
Using >2 antihypertensive drugs	53 %	51 %	60 %	55 %

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, 83 % 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 ranged by the proportion starting with catheter (same centre coding will be used also in following figures).



B: Prevalent RRT patients by end of 2009

Once a year, the registry collects data on a set of treatment details and quality measures for all patients in RRT. Data collection for the treatment year 2010 is not yet completed; selected data will be part of the next annual report.

Status data were requested for all dialysis patients who had been on RRT for at least one month by 31.Dec.2009. One centre failed to report dialysis data, thus the return rate was only 96.1%. Similarly, data were requested for all patients with a functioning graft except those transplanted during September to December 2009. The return rate was 97.6 %.

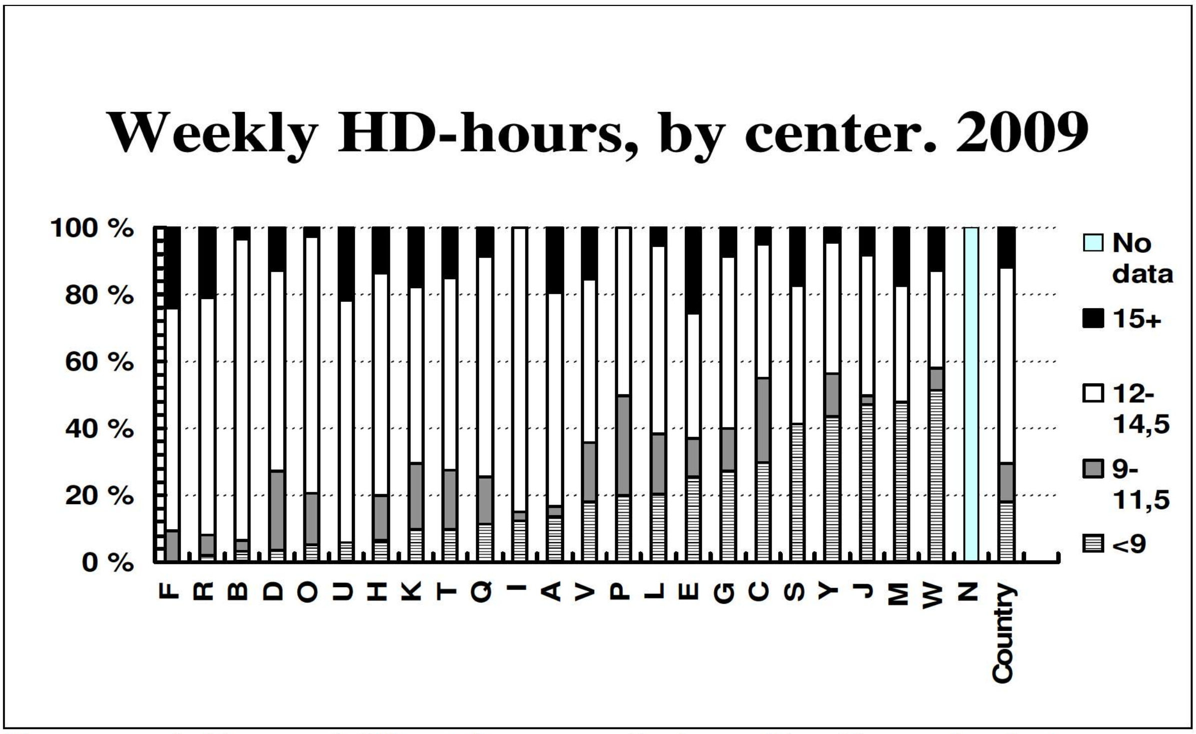
“Dialysis dose”:

Due to a lack of standardisation, the registry has not been able to collect reliable data on given dialysis dose in the form of Kt/V or URR (Urea reduction rate). The number of HD-sessions pr. week, as well as the number of weekly HD treatment hours, is collected. The published European Best Practice Guidelines indicates that: “The standard HD dose should be delivered as 3x4 h. Even if the standards of adequacy such as dose expressed as eKt/V are reached, a minimum time of 3x4 h/week is desirable.” Further, according to the DOPPS report 2006:”On average, each 30-minute increase on haemodialysis (HD) was associated with a 7% lower RR of mortality.”

During 2008 concern was raised by the registry that as much as 23% of HD-patients received less than three sessions pr week, at one centre this applied to 71% of their patients. By end of 2009, these figures have been somewhat improved, to 19% and 48% respectively. One might expect that centres with the longest travel distances would have the highest proportion of patients receiving few HD-sessions. This is clearly not the case.

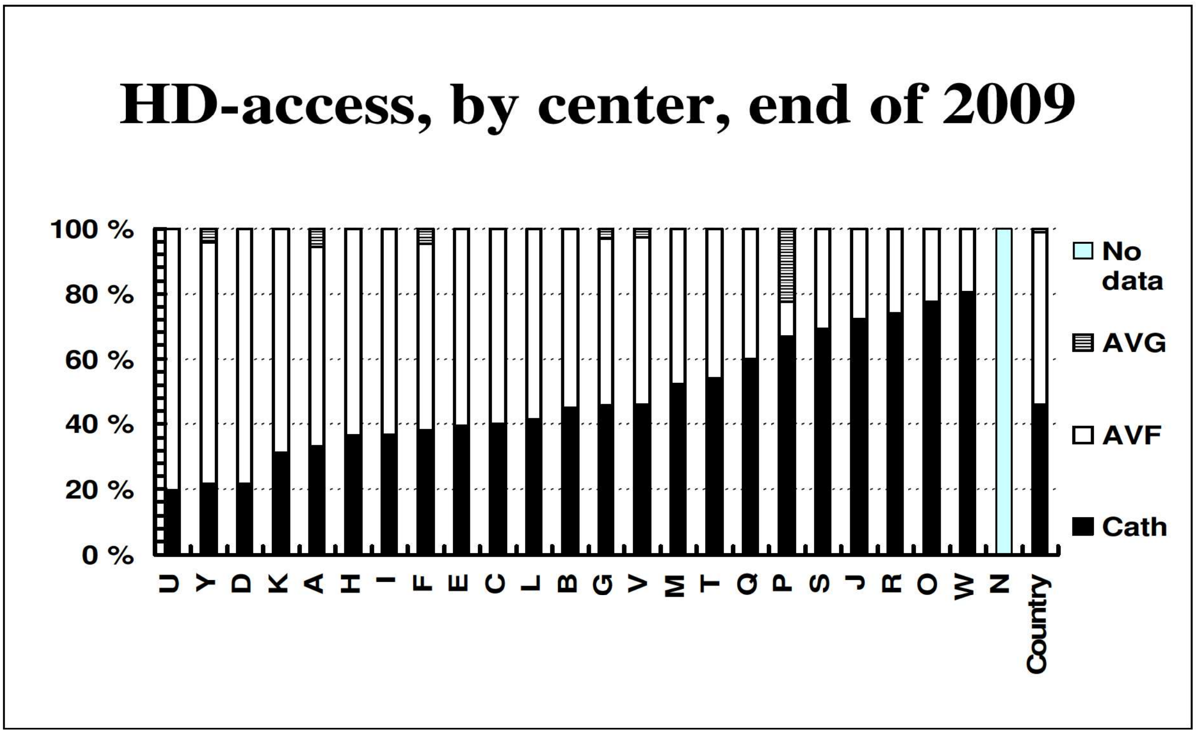
Ten percent of patients received more than three HD sessions, in two centres this was the case for more than 25% of their HD-patients.

As for the weekly treatment time, 30 % received less than 12 hours/week. There was a marked centre variation, from 8 and up to 56 % received less than the recommended number of hours, somewhat improved each year since 2007. If the DOPPS-data apply also to a Norwegian haemodialysis population, less than optimal patient survival is to be expected.



There are probably several different factors contributing to this widespread under-treatment, as compared to the guidelines. Patients may oppose to spending more hours in dialysis than they feel necessary. Locally, there may also be a lack of resources. Nevertheless, the data still give reasons for concern.

HD-access: 53 % of prevalent HD patients had a functioning AV-fistula; additionally 1 % had a graft, while the remaining 46 % were dialysed via catheter. The methods of access varied considerably between the various centres, as shown below (same codes as above):



The widespread use of catheter-access may have negative consequences. There have been several reports demonstrating increased mortality related to catheter use, both in mortality from infections and all-cause mortality. Several centres seem to need to revise their policy in this respect.

Anaemia control: Among prevalent dialysis patients, 32 % had an Hgb level below the recommended range of 11-12 g/L, while 36 % were above. ESA was used by 91 %, including most patients with Hgb > 12. In general, transplanted patients had higher Hgb; only 8 % of them were using ESA.

	< 9 g/L	9-11 g/L	11-12 g/L	12-13 g/L	13-15 g/L	> 15 g/L
HD	3 %	30 %	33 %	23 %	10 %	0.5 %
PD	3 %	24 %	29 %	29 %	14 %	2 %
Tx	0.4 %	8 %	15 %	21 %	42 %	14 %

Comparing the dialysis centres, the best one had 60% of their dialysis patients within the range 11-12 g/L; the poorest had only 19% within that range.

Blood pressure control: A majority of patients use antihypertensive medication; only 20 % of dialysis patients and 17 % of patients with functioning graft do not. Among dialysis patients, 21 % use 3 or more antihypertensive drugs; this is also the case in 16 % of the transplanted.

	BP ≤ 130/80	BP 131-140/81-90	BP > 140 and/or > 90
Dialysis patients	52 %	4 %	45 %
Transplanted patients	69 %	10 %	22 %

Also here a considerable variance between centres could be seen. In the best performing dialysis centre 81% of patients had BP 130/80 or lower, while others only obtained such control in 22%. The fraction of well controlled Tx-patients varied between 81% and 59 %.

Phosphate control: 82 % of dialysis patients were reported to use phosphate binders, 20% using calcium-containing, 40 % using calcium-free and 22% using a combination of the two. Serum phosphate was 1.8 mmol/L or below in 67%; the control was better among those not using binders. It also seemed that control was poorest among those given the combination.

Death in RRT:

A total of 367 patients in renal replacement therapy died during 2010, i.e. 8.0 % out of the 4577 persons at risk. Among these, 65% were males and 35% females. Median age at death was 75 years, mean 73 years, and the range 13-96 years. Median time from start of RRT until death was 38 months, with a range spanning from one week to 37 years.

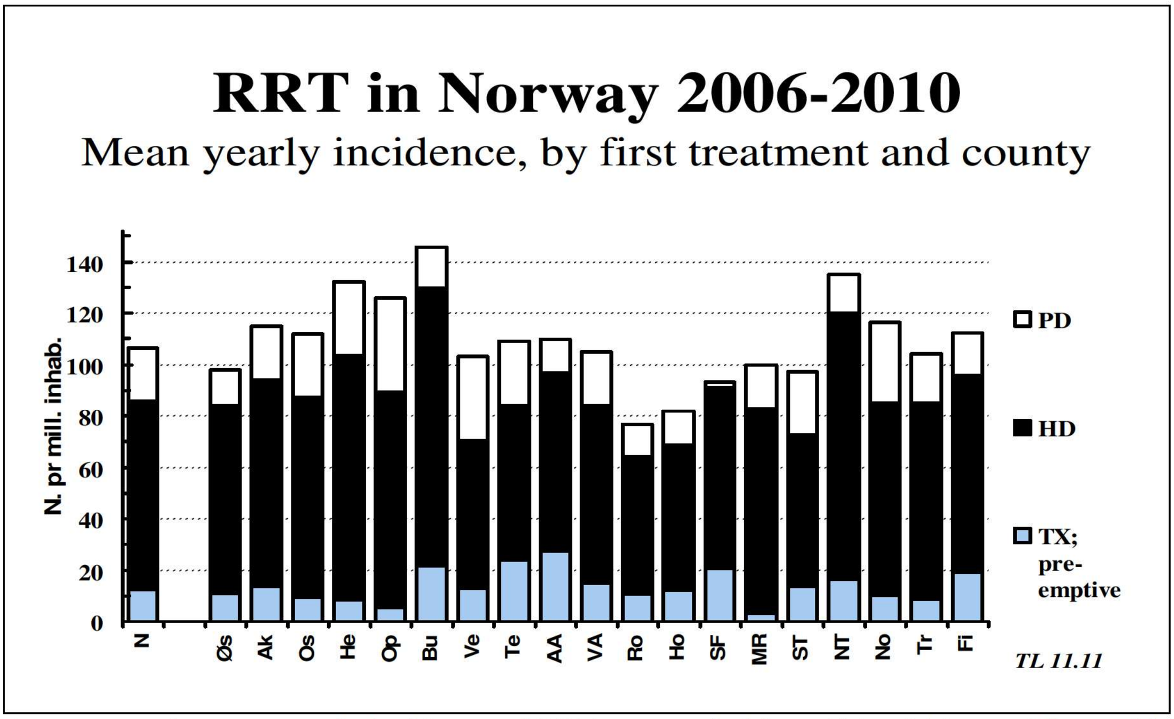
The final mode of treatment was HD for 238 patients and PD for 39, while 90 died with a more or less well-functioning graft, two of these refused further treatment when the graft failed. Dialysis treatment was terminated and followed by death in 54 patients; in 12 of those the patient refused further treatment.

Cardiac complications (32%) and vascular complications (25%) were the most frequent causes of death, followed by infections (12 %), and malignant tumours (12 %).

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 2006-2010:



As appears, the mean yearly incidence of RRT-start varied from 77 to 146 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.

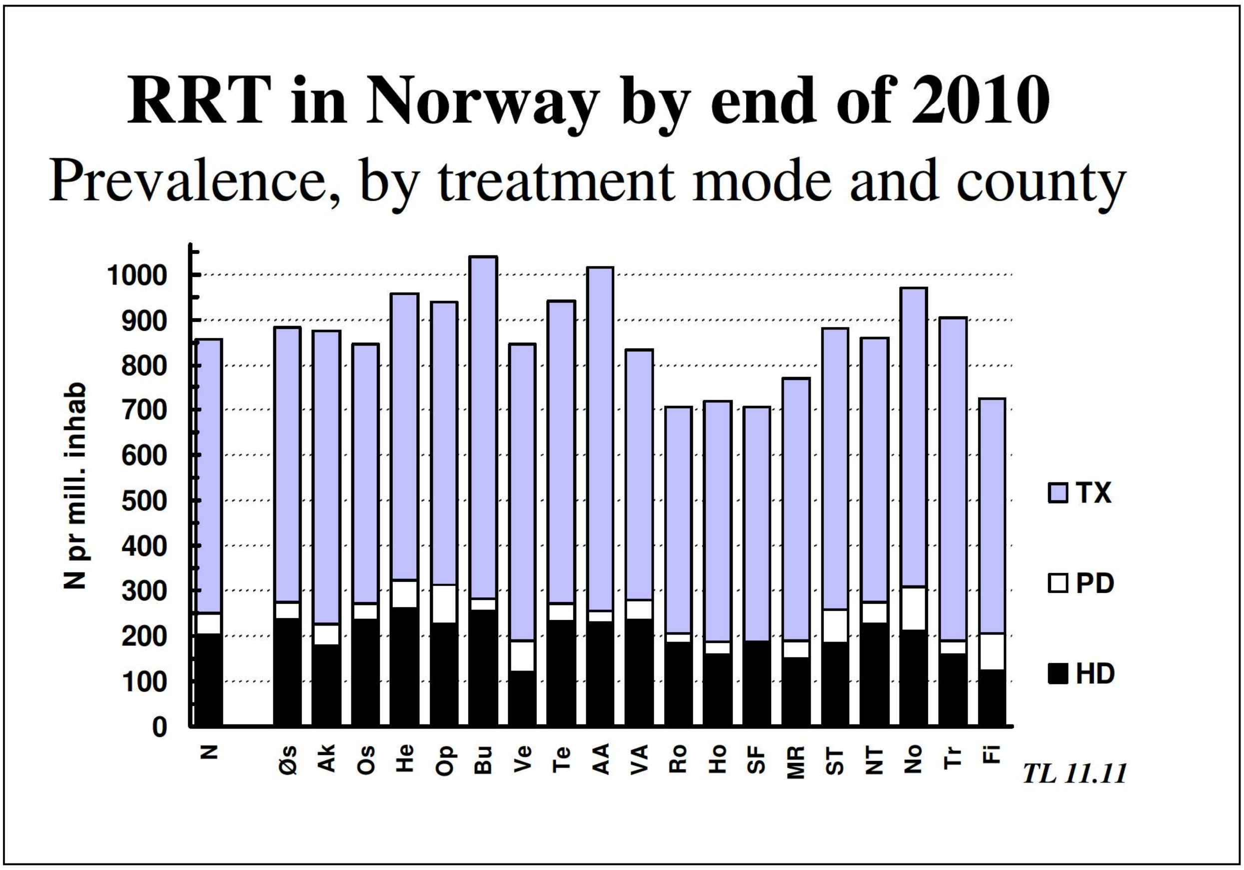
There is national consensus that pre-emptive transplantation is preferable. Looking solely at 2010-data (i.e. not the figure above), this was achieved in 12% of all. In the individual counties the numbers are small, but this figure ranged from 0% to 38% (Sogn og Fjordane). Efforts are also done to increase the use of PD. Still in some counties PD is rarely used, in others up to 44% of new patients in 2010 had this as first treatment mode. 66% received HD as first treatment mode, in the counties this ranged from 41% to 80%.

The proportion of the new dialysis patients in 2010 who started RRT without having been known by the renal unit for at least 4 months was 25 %, with wide variations between centres; from 15% and up to 50%. 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 seems 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 2010 mean age of new patients in the different counties ranged from 55 to 71 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 66% to 79% of the total RRT-population. The dialysis prevalence ranges from 186 to 319 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.



RRT in Norway by end of 2010

Prevalence, by treatment mode and county

Concluding remarks:

The 2010 figures may indicate that the incidence of RRT is levelling off, in line with other European countries (Kramer A & al, Nephrol Dial Transpl 2009; 24: 3557-3566). The 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.

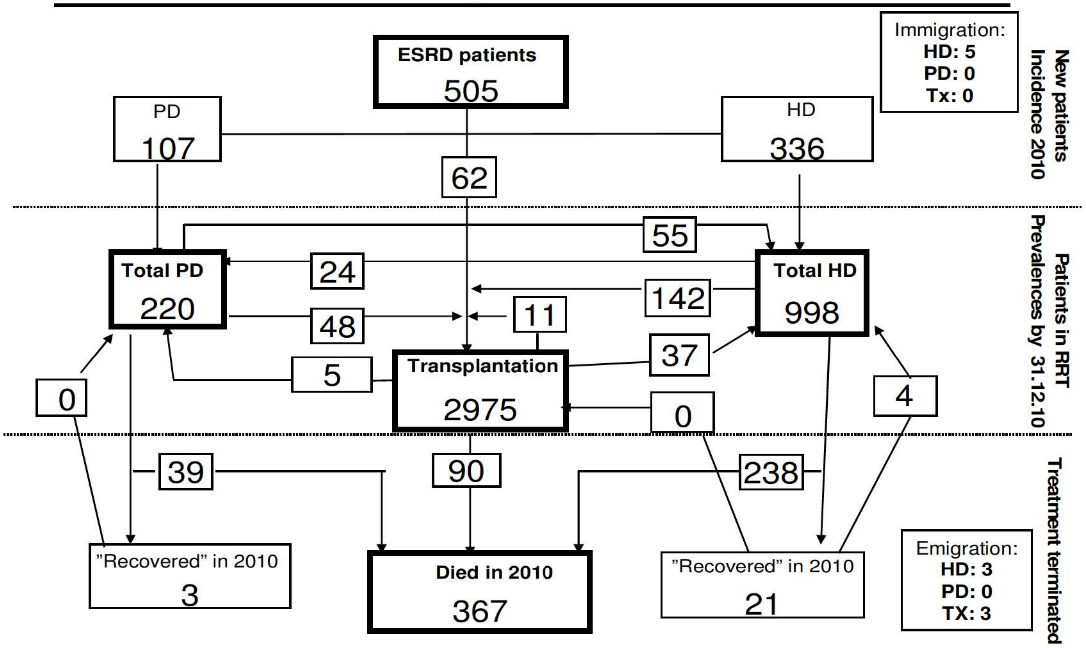
Registry data are also regularly used by Norwegian nephrologists as basis for scientific papers, congress presentations and PhD-thesis. A list of publications will in the future be presented on www.nephro.no along with the annual reports. Data delivered to the ERA-EDTA Registry in Amsterdam are included 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 Renal Unit and a process of making the registry less vulnerable (i.e. dependent on one individual) is under way. Still, 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 21.11.2011
Torbjørn Leivestad M.D. Ph.D.

Appendix:

ESRD 2010 in Norway
Patient dynamics



		New pat in RRT 2010				Pat. in RRT by 1/1.2011				Dialyses etc. 2010			Died 2010		
	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	5	10	5	6	21	35	12	129	176	5394	62	0	15	5	11
Harstad		2	0	0	2	3	0	39	42	1075	0	0	7	0	2
Bodø	7	11	7	2	20	46	22	134	202	8609	25	190	12	2	42
Levanger	5	14	4	2	20	29	6	74	109	4946	59	0	9	1	23
Trondheim	3	21	10	6	37	58	22	199	279	9832	68	392	15	5	49
Kristiansund N	1	7	0	2	9	24	0	21	45	2973	0	0	4	2	14
Ålesund	1	17	4	0	21	38	9	114	161	5474	57	0	13	3	33
Førde	2	5	0	3	8	20	0	53	73	3527	15	51	3	0	13
Bergen	2	19	6	5	30	68	14	232	314	10284	177	68	23	12	43
Stord/Hauges.	1	7	4	4	15	31	2	72	105	5016	11	52	9	1	20
Stavanger		21	0	2	23	57	8	170	235	8864	55	50	17	4	27
Kristiansand S	1	8	3	3	14	41	8	100	149	6758	0	0	5	2	24
Arendal		4	2	3	9	24	3	77	104	3500	4	45	3	3	18
Skien	2	7	6	4	17	39	7	114	160	6803	19	50	13	3	29
Tønsberg		12	10	1	23	29	17	144	190	4544	111	49	20	8	14
Hønefoss	1	12	0	3	15	33	0	47	80	4259	0	0	8	2	22
Drammen	1	19	1	4	24	39	6	151	196	6124	12	0	18	5	27
Bærum		5	0	0	5	25	0	1	26	1665	0	0	4	0	13
Lillehammer	2	18	6	0	24	40	17	119	176	5932	42	0	13	5	30
Elverum	1	17	2	1	20	43	10	104	157	5717	0	49	11	3	26
Fredrikstad	1	23	6	3	32	65	10	168	243	9519	6	0	10	6	32
AHUS		24	12	3	39	76	17	188	281	11172	0	0	19	8	36
Ullevål	1	47	19	2	68	119	30	318	467	17852	47	0	23	9	60
RH		6	0	3	9	16	0	207	223	3178	252	134	3	1	5
SUM		***336***	***107***	***62***	***505***	***998***	***220***	***2975***	***4193***	***153017***	*1022*	*1130*	***277***	***90***	***613***
# Pr. mill inh.		*68,7*	*21,9*	*12,7*	*103,3*	*204,2*	*45,0*	*608,6*	*857,8*	*.+ 2,0 % vs. 2009*					*125,4*
% of total		*66,5*	*21,2*	*12,3*	*100,0*	*23,8*	*5,2*	*71,0*	*100,0*						*50,3*