ANNUAL REPORT 2008

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 collaboration between The Norwegian Renal Association (Norsk Nyremedisinsk Forening) and Rikshospitalet University Hospital, 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 4.769 mill. inhabitants (July 2008) and 19 counties with populations ranging from 72500 to 569000. 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 2008, 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 2008

During 2008 a total of 533 new patients (in 2007: 531) entered renal replacement therapy (RRT), i.e. 111.8 per mill. inhabitants.

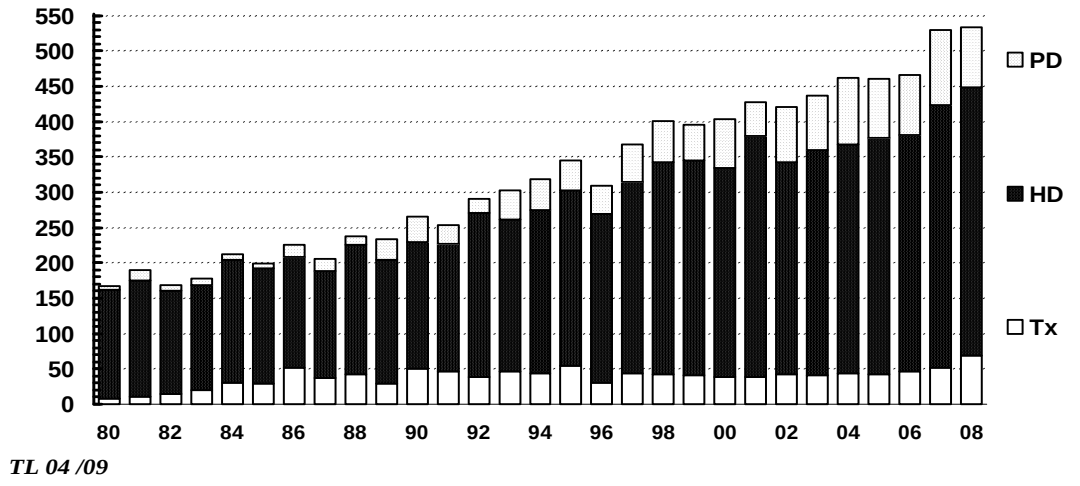
A majority of 361 (67.7 %) were males and 172 (32.3 %) females. Median age at start was 64.8 years, mean 62.5 years, ranging from 6.5 to 94.6 years.

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

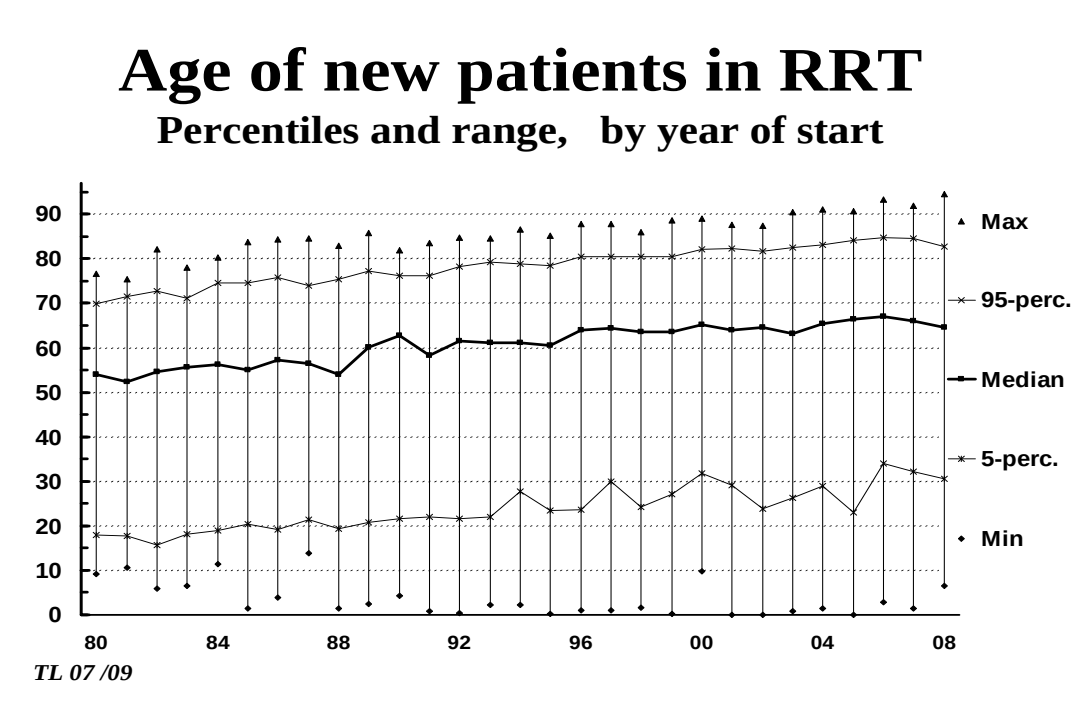
	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total	in %
HD	3	5	12	24	47	84	96	98	12	381	71.5
PD	1	0	4	10	8	14	20	23	3	83	15.6
TX	2	5	8	6	14	22	10	2	0	69	12.9
Total	6	10	24	40	69	120	126	123	15	533	100
in %	1.1	1.9	4.5	7.5	12.9	22.5	23.6	23.1	2.8	100	

At start of treatment, 344 (64.5 %) were considered by their nephrologist to be a potential candidate for transplantation, while 189 (35.5 %) were accepted for life-long dialysis (the latter constituting 43 % of those starting with HD and 31 % of those starting PD).
Among patients starting dialysis in 2008, 70.5 % had been under control by the renal unit for at least four months, while 29.5 % were previously unknown.

Incidence data: Changes 1980-2007



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 2005 at age 13 days. Six children below 15 years started RRT in 2008; 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	2005-07	2008
Glomerulonephritis	35%	31%	24%	18%	18%	20%
Pyelo/interstitial nephr.	16%	11%	11%	11%	8%	11%
Polycystic diseases	10%	9%	9%	9%	8%	7%
Diabetic nephropathy	13%	12%	11%	15%	14%	18%
Amyloidosis	6%	6%	4%	3%	2%	1%
Vascular/hypertensive	7%	18%	25%	29%	32%	27%
Immune/systemic	5%	4%	5%	4%	4%	4%
Kidney tumour	1%	1%	1%	1%	1%	3%
Myelomatosis	2%	2%	2%	3%	3%	2%
Other defined	4%	4%	3%	4%	4%	4%
Unknown	3%	3%	4%	4%	4%	4%
N:	2019	1418	1817	2149	1459	533

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 2008, 34 were registered as having Type I and 62 as Type II diabetes, further one had secondary DM. In addition, 79 patients with other types of primary renal disease were recorded as having diabetes as a co-morbid factor (one was Type I and 78 Type II), thus 33% of new patients were diabetics.
The time from onset of diabetes to start of RRT differed considerably. For the 34 with Type I diabetes the mean time was 33.8 years, for the 62 with Type II diabetic nephropathy the mean time was 17.9 years. Type II diabetics judged to have a primary renal disease other than diabetic nephropathy in mean had 9.6 years of pre-RRT diabetes duration.

Cardiovascular disease is often present at start of RRT. Coronary heart disease was reported in 171 (32%); another four had a previous heart transplant. Left ventricular hypertrophy was reported in 135 (25%). Cerebrovascular disease was reported in 75 (14%) and peripheral atherosclerotic disease in 104 patients (20%).

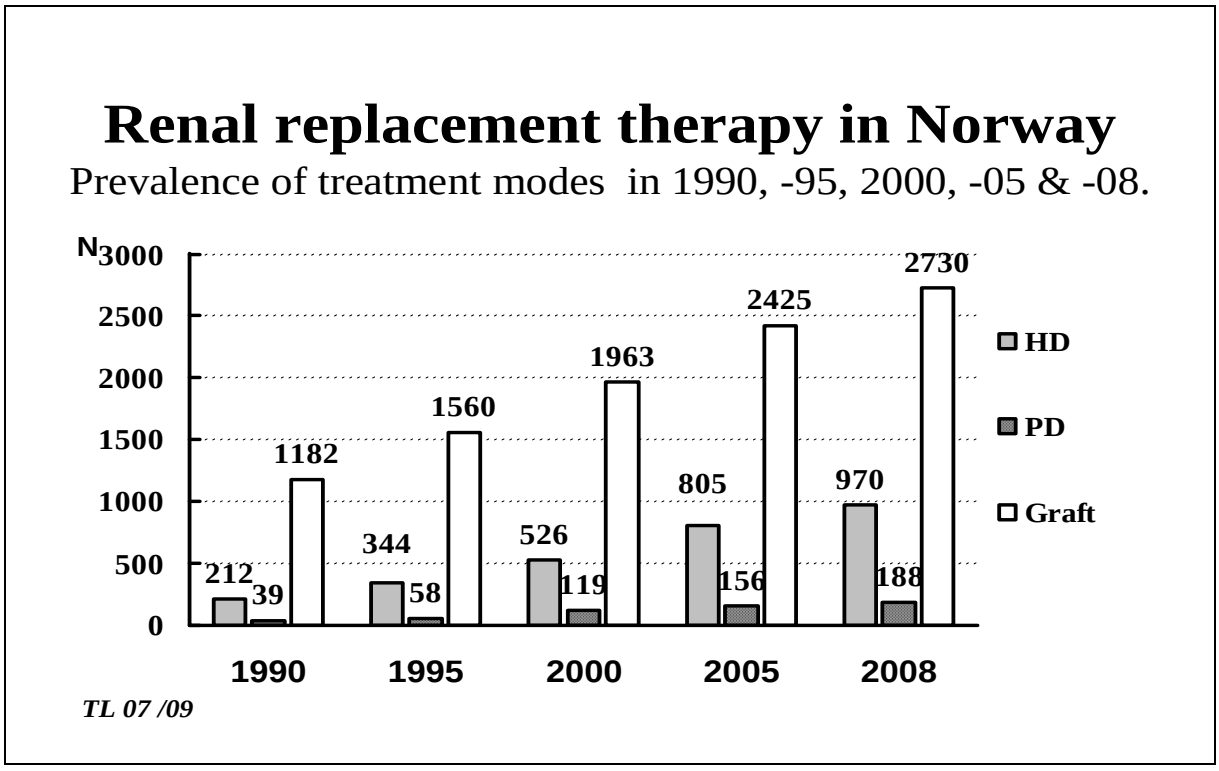
Prevalence data: Status by 31.dec. 2008.

By the end of 2007, 3888 patients in Norway received renal replacement therapy, i.e. 815.3 per million inhabitants. This represents an increase of 196 patients or 5.3 % since 2007. Gender: 64.7% males and 35.3% females.

Median age by the end of the year was 59.5 years, mean 57.8 years and range 3-95.2 years.

Tabulated by last mode of treatment, and age by end of 2008:

	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total	in %
HD	3	11	22	64	104	200	224	266	76	970	24.9
PD	1	1	5	21	15	30	46	59	11	189	4.9
TX	35	76	197	435	554	738	501	181	12	2729	70.2
Total	39	88	224	521	673	968	771	506	99	3888	100
In %	1.0	2.3	5.8	13.4	17.3	24.9	19.8	13.0	2.5	100	

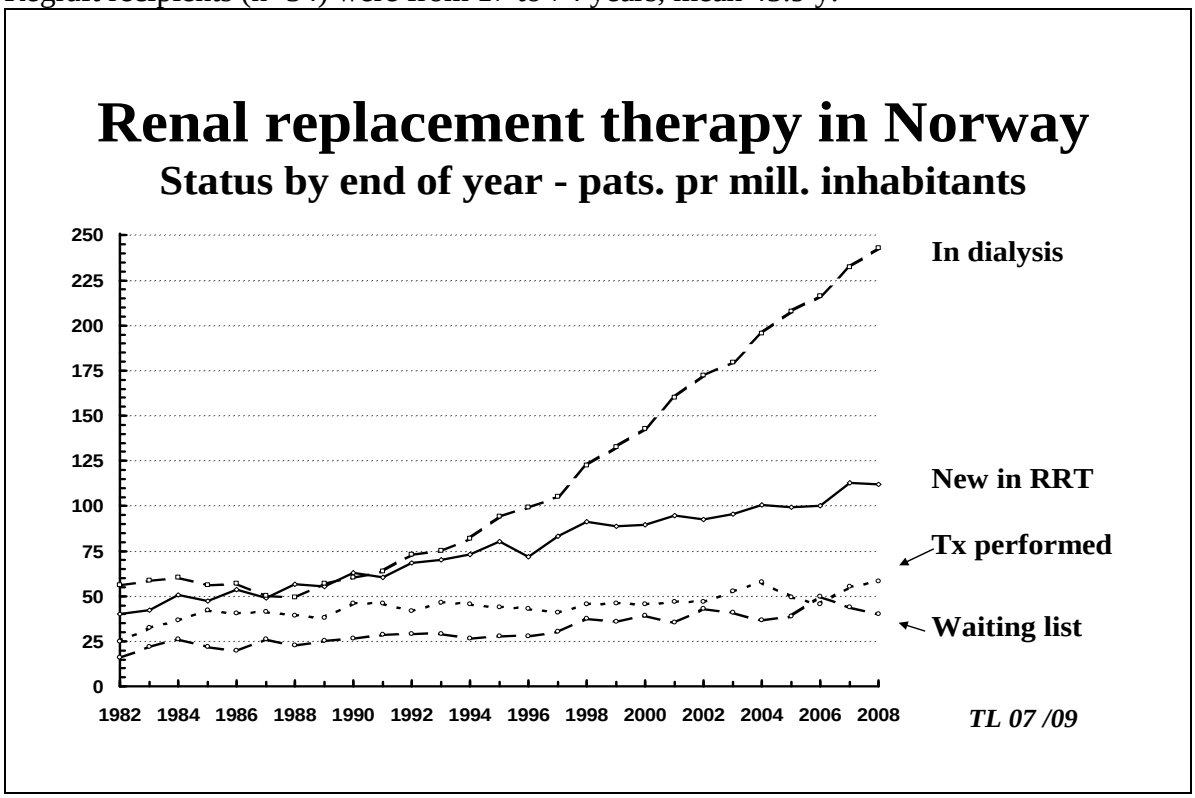


Transplantation and waiting lists:

A total of 278 renal transplants were performed at Rikshospitalet University Hospital in 2008, i.e. 58.3 per million inhabitants. In 98 (35%) the graft came from a living donor (LD), 24 of those were biologically unrelated to the recipient (17 were spouses). Among the LD-graft recipients 35 out of 75 first graft recipients were grafted pre-emptively, seven out of 23 re-graft recipients did not receive dialysis. 180 patients received a deceased donor (DD) graft, 37 out of the 149 first graft recipients were pre-emptively transplanted (25 %), while two out of 31 had a re-graft without entering dialysis. There were 224 first grafts (75 LD and 149 DD), 48 were second grafts (19 LD, 29 DD), six third grafts (4 LD, 2 DD). Simultaneous kidney + pancreas transplantation was performed in nine. Among patients with a functioning kidney graft four received one or more doses of isolated Langerhans Islet cells.

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 149 first DD-graft recipients in 2008 ranged from 22

to 82 years, with a mean age of 55 y. Out of these, 26 % were above the age of 65 and 6 % were 75 or older. The 75 recipients of a first LD-graft were from 6 to 74 years, mean 46.7 y. Regraft recipients (n=54) were from 17 to 74 years, mean 45.9 y.



By end 2008, 192 patients (40.3 per mill.) were on the active waiting list for a DD renal graft. This represented a reduction of 14 patients (7 %) since 2007. Among those waiting by Dec.31, median time on the list was 8.3 months. 42 % had waited less than 6 months, 68 % less than one year and 14 % more than two years. The 180 recipients given a DD-graft in 2008 had a median waiting time of 12 months and a maximum of 46 months at the time of grafting.
Among the 1159 patients in dialysis treatment by Dec.31, 616 (53.1 %) were for various reasons not considered candidates for a new renal graft.

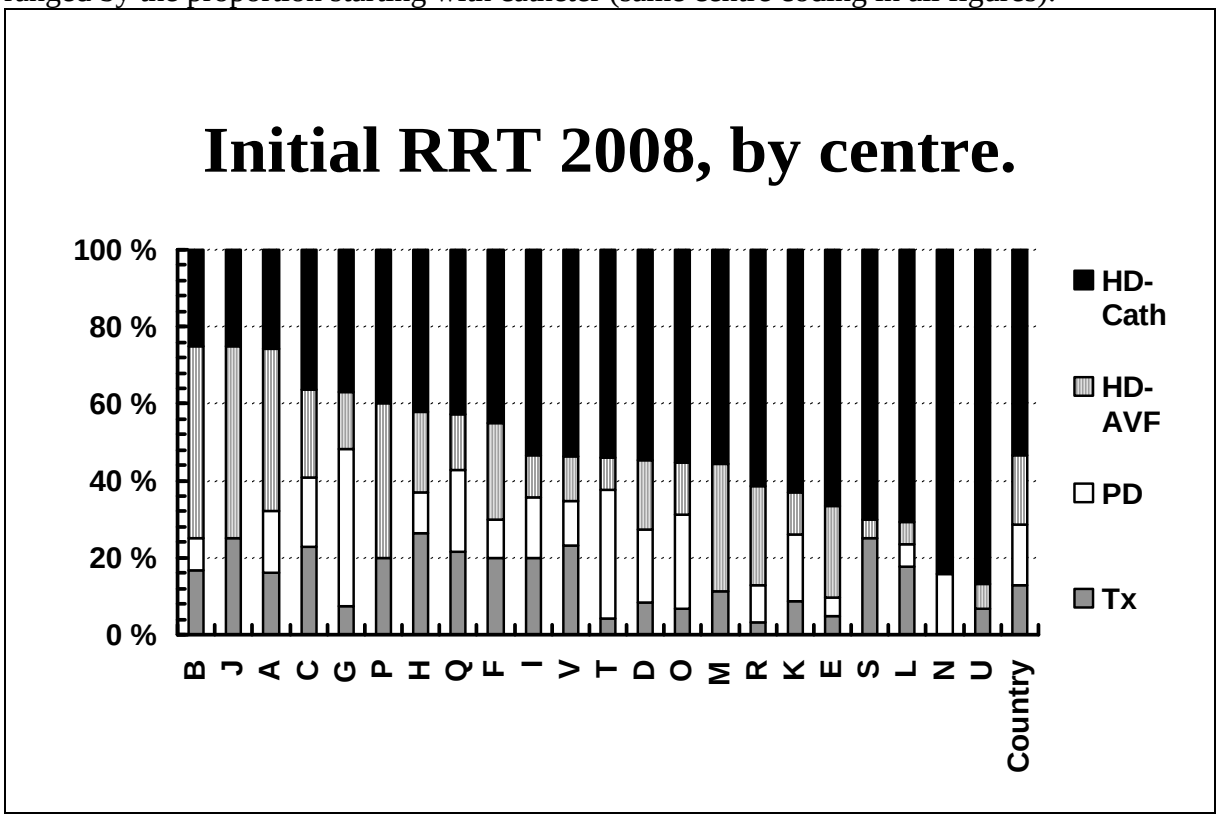
Quality measures in RRT.

A: New patients in 2008 – status at start of RRT.

A total of 533 patients started RRT in 2008. Among the 381 starting haemodialysis, the access was via catheter in 285 patients (75%), while 25% had AV-fistula (93) or graft (3) as access.

Status at start of RRT	Total (n:533)	HD (n:381)	PD (n:83)	Tx (n:69)
Creatinine (mean)	612 mmol/l	633	601	510
GFR (mean), by MDRD formula	9.4 ml/min	9.2	8.9	11.2
Albumin, mean	36 g/L	35	39	43
Haemoglobin, mean	10.8 g/dL	10.4	11.3	12.1
Haemoglobin - % <11 g/dL	56 %	66 %	37 %	20 %
ESA use	58 %	58 %	66 %	48 %
Active D vitamin use	60 %	55 %	63 %	83 %
Statin use	57 %	55 %	60 %	62 %
Not on antihypertensive drugs	12 %	13 %	7 %	7 %
Using >2 antihypertensive drugs	77 %	76 %	82 %	77 %

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. Pre-emptive transplantation is considered the best initial RRT, while HD by catheter is considered the poorest alternative. In the following figure, individual centres are shown, ranged by the proportion starting with catheter (same centre coding in all figures).



B: Prevalent RRT patients by end of 2007

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 2008 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.2007, the return was 100%. Similarly, data were requested for all patients with a functioning graft except those transplanted during September to December 2007. The return rate was above 99%.

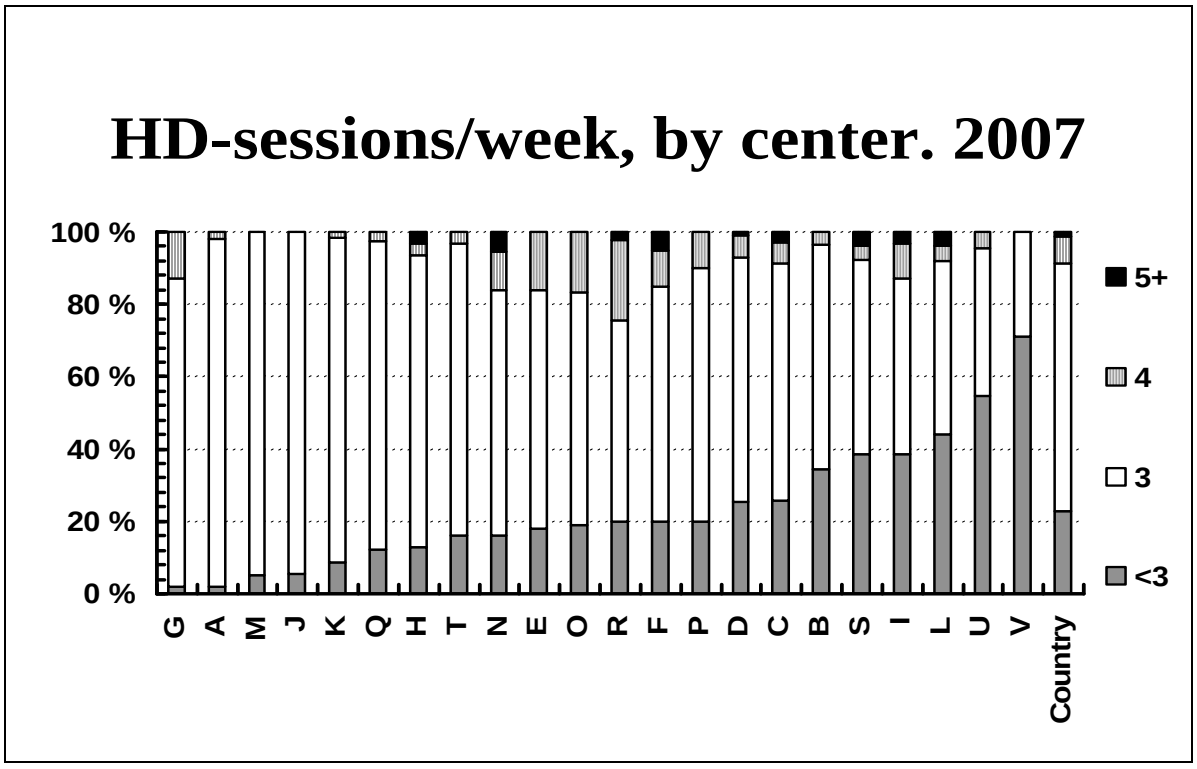
"Dialysis dose":

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). But the registry collects data on the number of HD-sessions pr. week as well as the number of weekly HD treatment hours. 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."

As illustrated below (next page), 23% of the prevalent HD-patients received less than the three weekly sessions, at one centre this applied to 71% of their HD patients. 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.

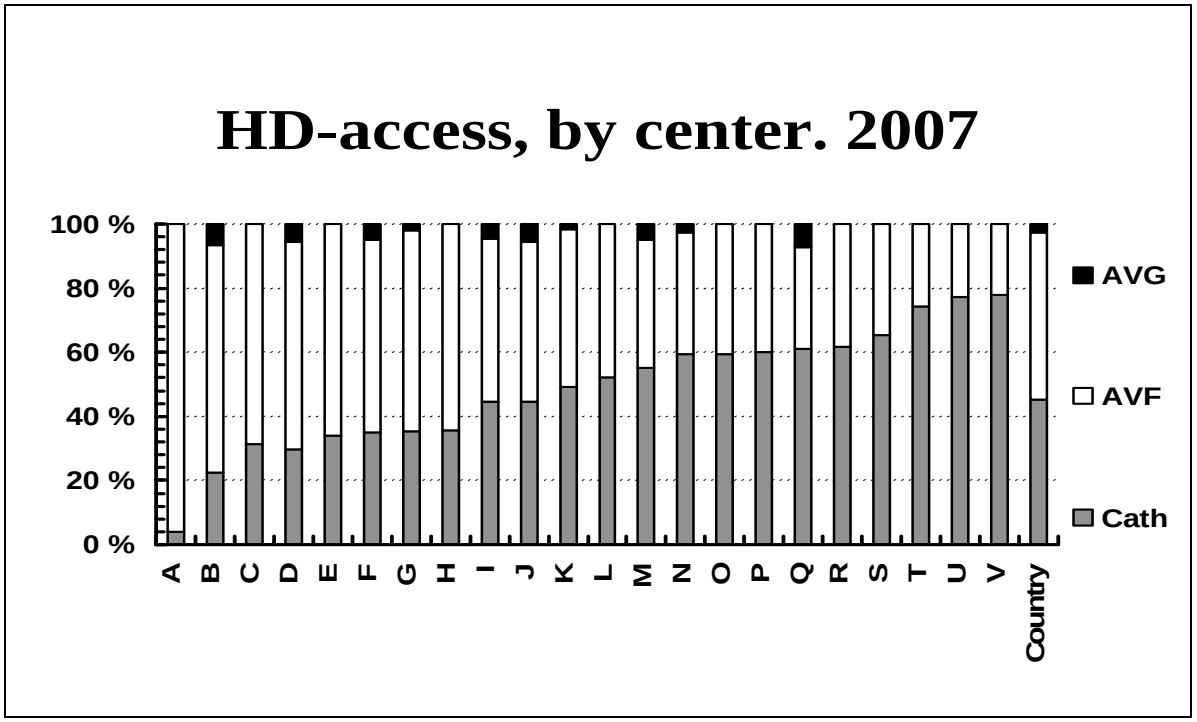
Nine percent of patients received more than three HD sessions, in one centre this was the case for 24 % of their HD-patients.

As for the weekly treatment time, 34 % received less than 12 hours/week. Again, there was a marked centre variation, from 5 and up to 77 % received less than the recommended number of hours. 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 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 coding 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, 25 % were below the target Hgb level of 11 g/L. while 16 % were above the proposed upper limit of 13 g/L. ESA was used by 90 %, 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 %	25 %	31 %	25 %	17 %	0.5 %
PD	2 %	14 %	27 %	39 %	19 %	0.5 %
Tx	0.3 %	6 %	14 %	20 %	44 %	15 %

Comparing the dialysis centres, the best one had 85% of their dialysis patients within the range 11-13 g/L; the poorest had 40% within that range.

Blood pressure control: A majority of patients use antihypertensive medication; only 21 % of dialysis patients and 18 % of patients with functioning graft do not. Among dialysis patients, 19 % 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 %	44 %
Transplanted patients	66 %	11 %	23 %

Also here a considerable variance between centres could be seen. In the best performing dialysis centre 80% of patients had BP 130/80 or lower, while others only obtained such control in 25%. The fraction of well controlled Tx-patients varied between 83 and 52 %.

Phosphate control: 85 % of dialysis patients were reported to use phosphate binders, 27% using calcium-containing, 35 % using calcium-free and 23% using a combination of the two. Serum phosphate was below 1.8 mmol/L in 61 %; 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 330 patients in renal replacement therapy died during 2008, i.e. 7.8 % out of the 4225 persons at risk. Among these, 67% were males and 33% females. Median age at death was 75 years, mean 72 years, and the range 15-92 years. Median time from start of RRT until death was 33 months, with a range spanning from nine days to 39 years.

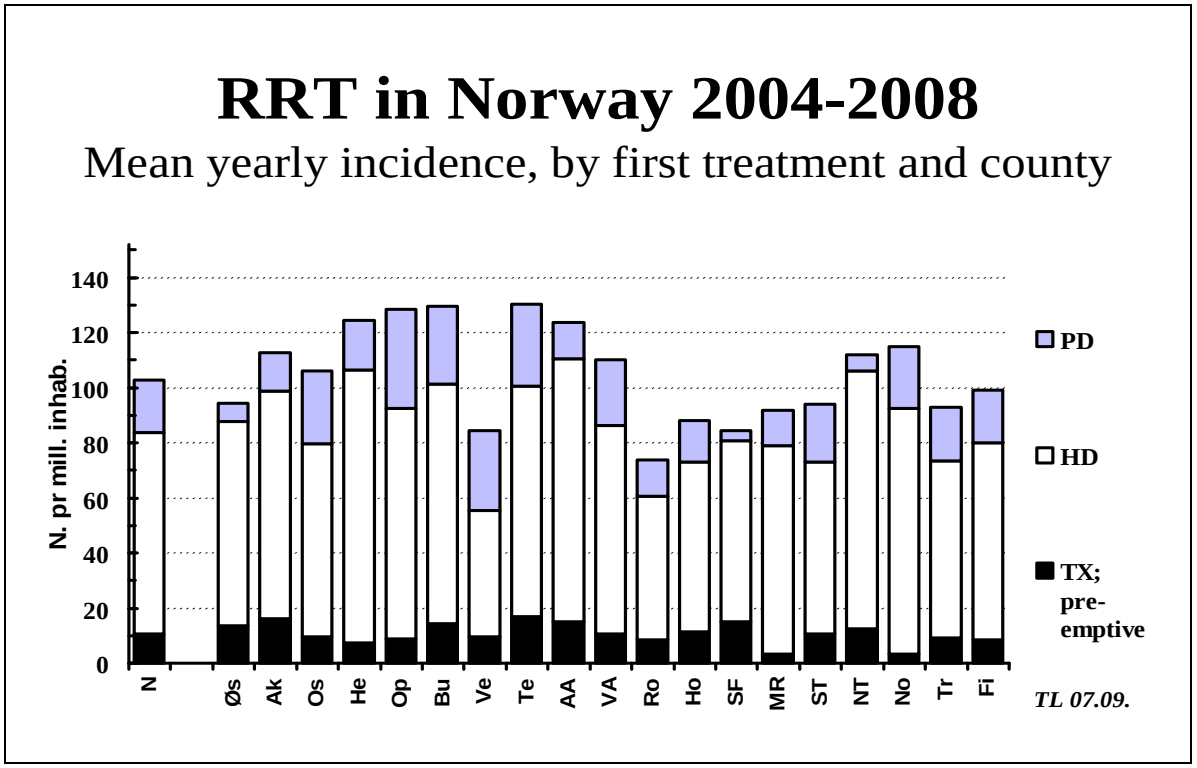
The final mode of treatment was HD for 201 patients and PD for 48, while 81 died with a more or less well-functioning graft. Six died within two months after graft loss; thus 87 deaths were termed 'TX-related'. Dialysis treatment was terminated and followed by death in 49 patients; in 15 of those the patient refused further treatment.

Cardiac complications and infections were the most frequent causes of death (both 26 %), followed by malignant tumours (14 %), and vascular complications (13 %).

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 2004-2008:



As appears, the mean yearly incidence of RRT-start varied from 71 to 131 pr. million, with Rogaland having the lowest and Telemark 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.

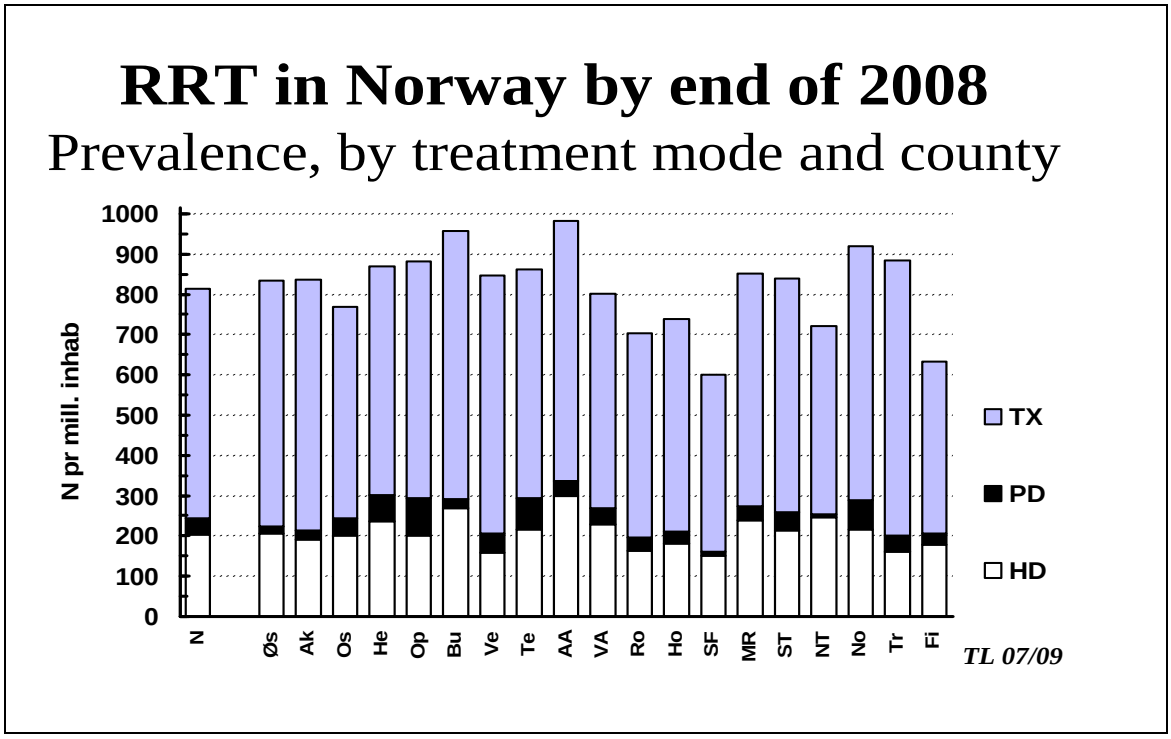
Although there is national consensus that pre-emptive transplantation is preferable, this was only achieved in 10 %; in the individual counties this figure ranged from 3 % (Nordland) to 18 % (Sogn og Fjordane).
In some counties PD is rarely used, in others up to 34 % of new patients have this as first treatment mode. 71 % received HD as first treatment mode, in the counties this ranged from 54 % to 84 %.

The proportion of the new patients in 2008 who started dialysis without having been known by the renal unit for at least 4 months was 30 %, with wide variations between centres; from none in one centre and up to 63 % at highest. 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; thus in most counties it seems to be need for improved co-operation within 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 2008 mean age of new patients in the different counties ranged from 52 to 69 years. The huge variation in age-specific incidence between counties was latest shown 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 77% of the total RRT-population. The dialysis prevalence ranges from 160 to 336 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.



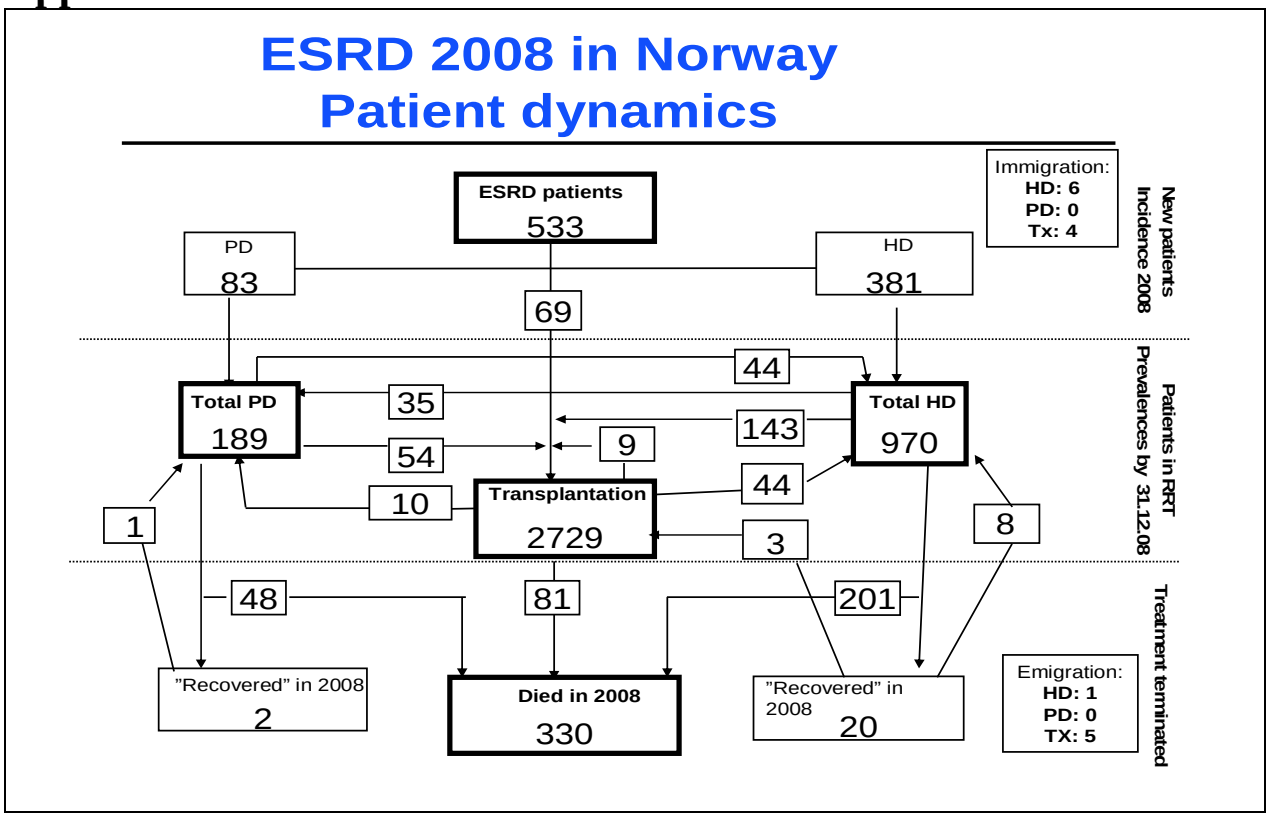
Concluding remarks:

It may seem that the incidence of RRT tends to stabilize also in Norway, similarly, but somewhat delayed, to other European countries (see Kramer A & al in Nephrol Dial Transpl 2009, in press). With an increased survival rate (as demonstrated in the 2004-report), a markedly increased prevalence of RRT-patients can nevertheless be expected over the coming years. Marked county differences may also indicate that in some areas there may still be under-treatment. If so, we can still expect a further increase in national incidence. The year 2008 gave a new high transplantation rate. Yet the dialysis population grew with 6 % from 2007. Even with an officially declared aim of doubling the donation rate, it is not obvious that the supply of organs for transplantation will rise further. The number of patients in dialysis will probably still rise and will constitute an increasing proportion of the RRT-population. Unless home-based treatment (i.e. CAPD and home-HD) is radically expanded, the capacity of the hospital HD-units will need to be further increased.

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.

Report completed 16.10.2009
Torbjørn Leivestad M.D. Ph.D.

Appendix:



Centre	Satellittes	New pat. in RRT 2008				Pat. in RRT pr 1/1.2009				Dialyses etc. 2008			Died 2008		
		HD/HDF	PD	Pre-emptive	Total	HD/HDF	PD	Graft	Total	HD sessions	Pl.exch.	Other	Dial.pat	Tx-pat.	Not Tx-candidate
Tromsø	4	14	2	4	20	30	8	120	158	4402	85	0	11	2	22
Harstad		4	0	1	5	9	0	38	47	1507	0	0	3	1	6
Bodø	8	20	7	2	29	48	17	123	188	7827	17	212	13	3	42
Levanger	3	9	1	2	12	32	1	58	91	4625	0	0	7	1	20
Trondheim	4	14	11	2	27	63	13	183	259	9575	195	225	12	7	47
Kristiansund	1	2	0	0	2	23	0	20	43	3673	0	0	1	0	16
Ålesund	1	25	3	1	29	34	9	110	153	4789	26	0	10	1	31
Førde	2	6	0	2	8	17	1	45	63	3202	14	45	4	3	13
Bergen	1	29	7	9	45	72	14	227	313	10361	301	62	14	5	44
Stord/Hauges	1	8	0	1	9	28	5	63	96	3596	30	45	4	4	17
Stavanger		21	5	5	31	52	9	173	234	8082	43	50	9	4	30
Kristiansand	1	8	3	3	14	40	8	93	141	6188	53	0	12	0	29
Arendal		13	1	3	17	30	3	63	96	3695	0	40	10	1	20
Skien	2	12	2	5	19	36	13	97	146	5497	16	96	9	5	24
Tønsberg		13	4	5	22	36	11	137	184	5360	127	47	12	7	31
Hønefoss	1	14	0	1	15	28	0	38	66	3734	0	0	7	0	17
Drammen	1	17	3	6	26	45	6	126	177	5561	31	0	10	4	18
Lillehammer	2	16	3	0	19	38	19	105	162	6383	8	0	19	7	21
Elverum	1	15	8	1	24	40	11	92	143	5350	0	24	7	5	22
Fredrikstad	1	19	1	1	21	55	5	165	225	8871	25	0	11	8	27
AHUS		34	8	4	46	69	13	169	251	10069	0	0	20	4	41
Aker		10	0	0	10	14	0	22	36	1841	0	0	6	0	11
Ullevål		43	14	6	63	97	23	256	376	13805	95	0	27	14	48
RH		15	0	5	20	34	0	206	240	5053	292	46	5	1	19
SUM		***381***	***83***	***69***	***533***	***970***	***189***	***2729***	***3888***	***143046***	*1358*	*892*	***243***	***87***	***616***
- Pr. mill inh.		*79,9*	*17,4*	*14,5*	*111,8*	*203,4*	*39,6*	*572,2*	*815,3*	*ie.+ 8,5%*					*129,2*
% of total		*71,5*	*15,6*	*12,9*	*100,0*	*24,9*	*4,9*	*70,2*	*100,0*	*fra 2007*					*53,1*