

ANNUAL REPORT 2007

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 4.704 mill. inhabitants (July 2007) and 19 counties with populations ranging from 72500 to 553000. Each county, except one, has a central renal unit and some have additional unit(s) 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 2007, 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 2007

During 2007 a total of 530 new patients (in 2006: 466) entered renal replacement therapy (RRT), i.e. 112.7 per mill. inhabitants.

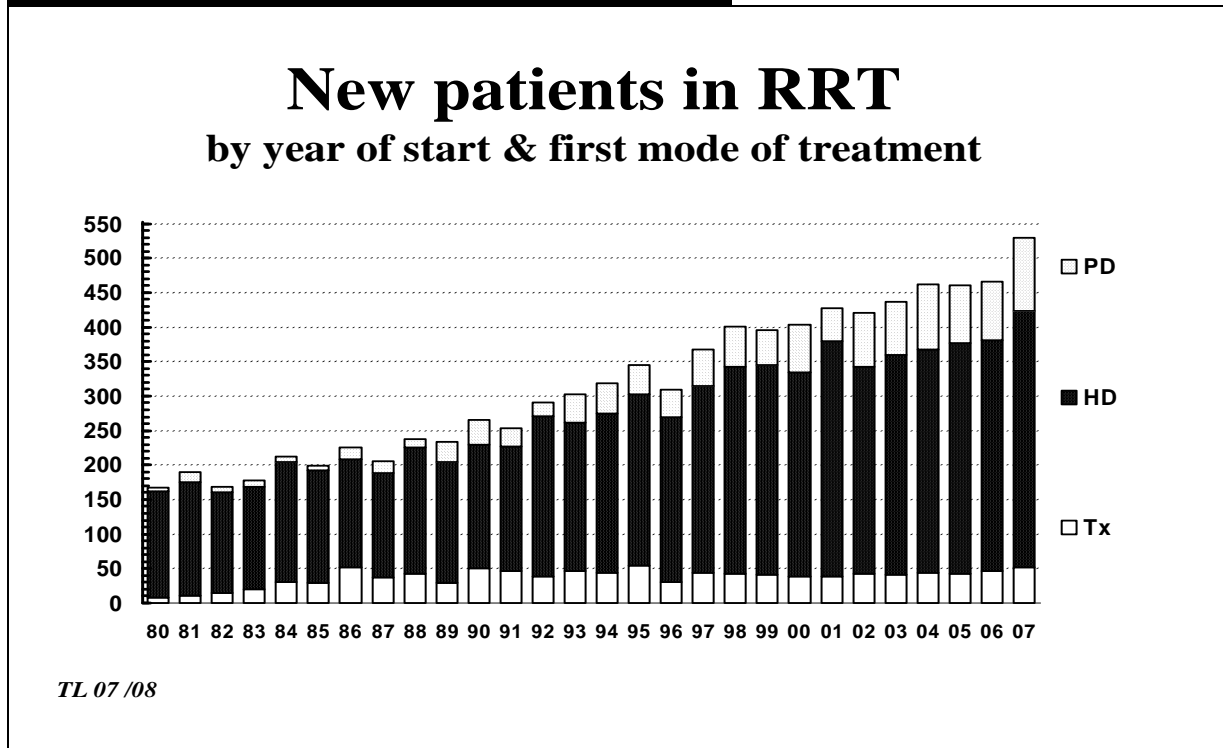
A majority of 66.4 % were males and 33.6 % females. Median age at start was 66.1 years, mean 63.2 years, ranging from 1.5 to 93 years.

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

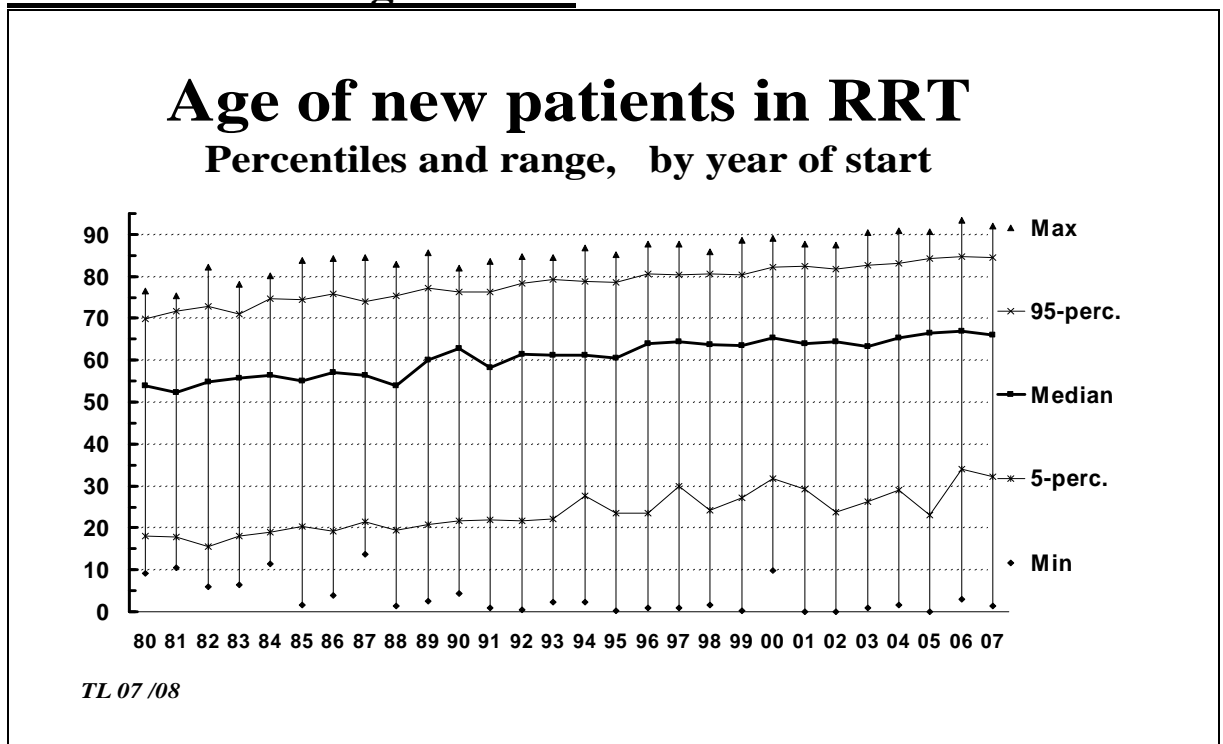
	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75+	Total	in %
HD	1	4	8	26	45	77	99	111	371	70.0
PD	1	6	4	6	14	16	23	37	107	20.2
TX	1	1	11	6	9	19	5	0	52	9.8
Total	3	11	23	38	68	112	127	148	530	100
in %	0.6	2.1	4.3	7.2	12.8	21.1	24.0	27.9	100	

At start of treatment, 314 (59.2 %) were considered by their nephrologist to be a potential candidate for transplantation, while 216 (40.8 %) were accepted for life-long dialysis (constituting 49 % of those starting with HD and 33 % of those starting PD). Among patients starting dialysis in 2007, 73 % had been under control by the renal unit for at least four months, while 27 % 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. Three children below 15 years started RRT in 2007; 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	2005-06	2007
Glomerulonephritis	35%	31%	24%	18%	19%	16%
Pyelo/interstitial nephr.	16%	11%	11%	11%	8%	9%
Polycystic diseases	10%	9%	9%	9%	8%	9%
Diabetic nephropathy	13%	12%	11%	15%	15%	14%
Amyloidosis	6%	6%	4%	3%	2%	2%
Vascular/hypertensive	7%	18%	25%	29%	31%	33%
Immune/systemic	5%	4%	5%	4%	4%	4%
Kidney tumour	1%	1%	1%	1%	2%	1%
Myelomatosis	2%	2%	2%	3%	3%	4%
Other defined	4%	4%	3%	4%	4%	5%
Unknown	3%	3%	4%	4%	5%	4%
N:	2019	1418	1817	2149	926	530

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.

Diabetic nephropathy has contributed 10-15% per year. Until 1995 sub-classification was not reliably registered. In 2007, 29 were registered as having Type I and 43 as Type II diabetes. In addition, 66 patients with other types of primary renal disease were recorded as having diabetes as a co-morbid factor (one was Type I and 65 Type II), thus 26% of new patients were diabetics.

The time from onset of diabetes to start of RRT differed considerably. For the 29 with Type I diabetes the mean time was 33.1 years, for the 43 with Type II diabetic nephropathy the mean time was 15.5 years. Type II diabetics judged to have a primary renal disease other than diabetic nephropathy in mean had 10.1 years of pre-RRT diabetes duration.

Cardiovascular disease is often present at start of RRT. Coronary heart disease was reported in 166 (31%); another one had a previous heart transplant. Left ventricular hypertrophy was reported in 136 (26%). Cerebrovascular disease was reported in 66 (12%) and peripheral atherosclerotic disease in 100 patients (19%).

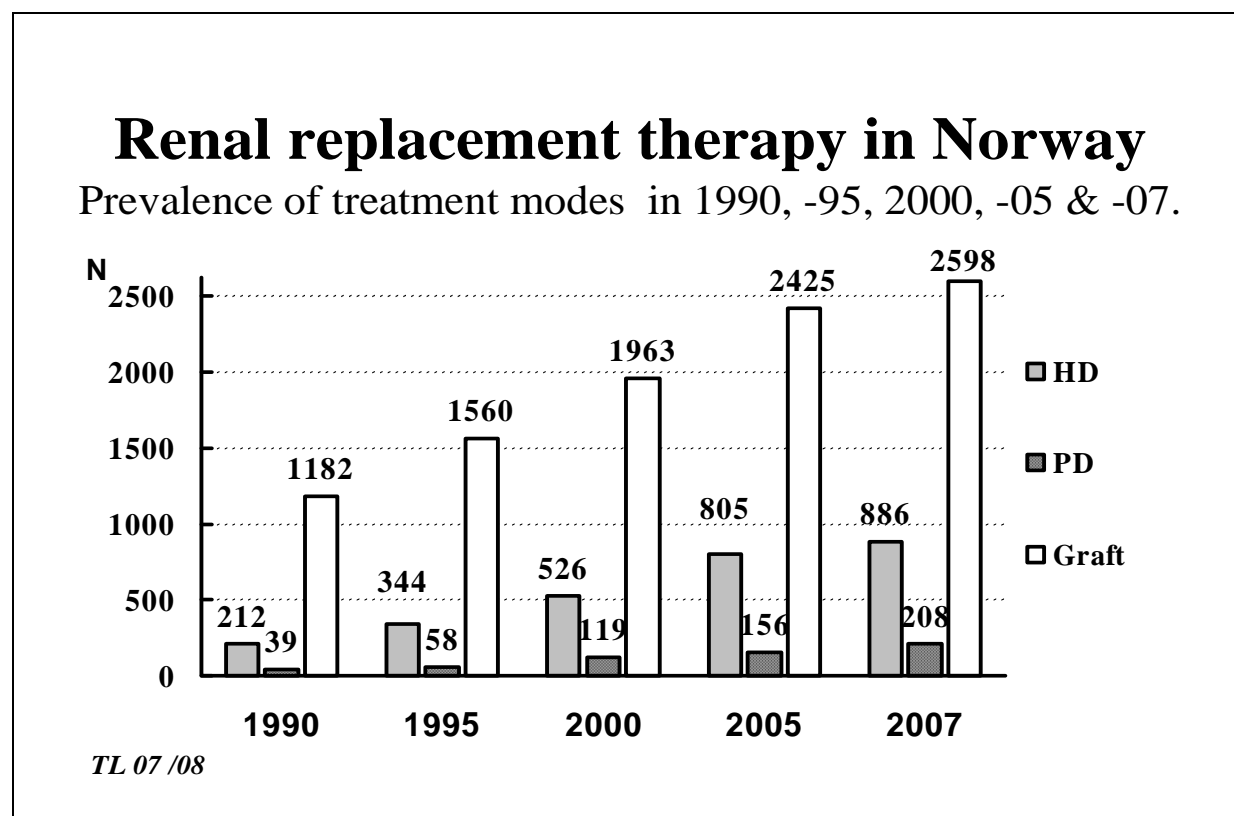
Prevalence data: Status by 31.dec. 2007.

By the end of 2007, 3692 patients in Norway received renal replacement therapy, i.e. 784.8 per million inhabitants. This represents an increase of 182 patients or 5.2 % since 2006. Gender: 64.2% males and 35.8% females.

Median age by the end of the year was 58.9 years, mean 57.4 years and range 2-94.2 years.

Tabulated by last mode of treatment, and age by end of 2007:

	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total	in %
HD	1	11	35	66	93	169	185	253	73	886	24.0
PD	0	4	8	16	24	34	46	65	11	208	5.6
TX	41	72	183	431	543	700	454	163	11	2598	70.4
Total	42	87	226	513	660	903	685	481	95	3692	100
In %	1.1	2.4	6.1	13.9	17.9	24.5	18.5	13.0	2.6	100	

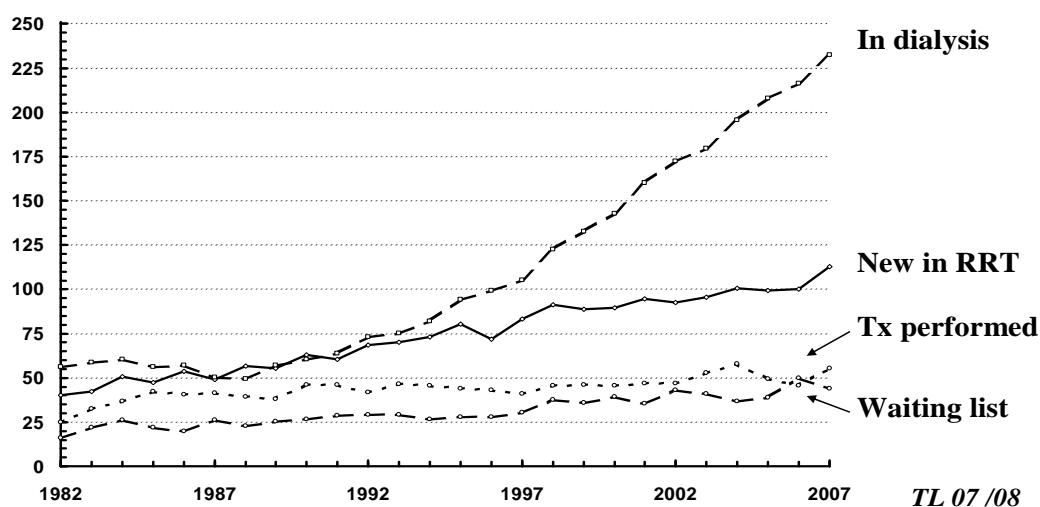


Transplantation and waiting lists:

A total of 260 renal transplants were performed at Rikshospitalet University Hospital in 2007, i.e. 55.3 per million inhabitants. In 86 (37%) the graft came from a living donor (LD), 22 of those were biologically unrelated to the recipient (13 were spouses). Among the LD-graft recipients 31 out of 76 first graft recipients were grafted pre-emptively, three out of 10 re-graft recipients did not receive dialysis. 174 patients received a deceased donor (DD) graft, 22 out of the 151 first graft recipients were pre-emptively transplanted (15%), while three out of 23 had a re-graft without entering dialysis. There were 227 first grafts (76 LD and 151 DD), 27 were second grafts (8 LD, 19 DD), three third grafts (1 LD, 2 DD), and three fourth grafts (1LD, 2 DD). Simultaneous kidney + pancreas transplantation was performed in 14. Among patients with a functioning kidney graft three 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 151 first DD-graft recipients in 2007 ranged from 15 to 82 years, with a mean age of 55 y. Out of these, 29% were above the age of 65 and 4% were 75 or older. The 78 recipients of a first LD-graft were from 1 to 73 years, mean 46.7 y. Re-graft recipients (n=33) were from 20 to 59 years, mean 39.8 y.

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



By end 2007, 206 patients (43.8 per mill.) were on the active waiting list for a DD renal graft. This represented a reduction of 26 patients (11%) since 2006. Among those waiting by Dec.31, median time on the list was 10 months. 32 % had waited less than 6 months, 56 % less than one year and 20 % more than two years. The 174 recipients given a DD-graft in 2007 had a median waiting time of 12 months and a maximum of 80 months at the time of grafting.

Among the 1094 patients in dialysis treatment by Dec.31, 560 (51.2 %) were for various reasons not considered candidates for a new renal graft.

Quality measures in RRT.

A: New patients in 2007 – status at start of RRT.

A total of 530 patients started RRT in 2007. Among the 371 starting haemodialysis, the access was via catheter in 278 patients (75%), while 25% had AV-fistula as access.

Status at start of RRT	Total (n:530)	HD (n:371)	PD (n:107)	Tx (n:52)
Creatinine (mean)	659 mmol/l	697	590	536
GFR (mean), by MDRD formula	8.8 ml/min	8.4	9.1	11.3
Albumin, mean	35 g/L	34	37	43
Haemoglobin, mean	10.9 g/dL	10.5	11.4	12.2
Haemoglobin - % <11 g/dL	53 %	62 %	36 %	19 %
ESA use	60 %	56 %	70 %	64 %
Active D vitamin use	61 %	53 %	80 %	79 %
Statin use	51 %	49 %	55 %	52 %
Not on antihypertensive drugs	11 %	12 %	8 %	6 %
Using >2 antihypertensive drugs	54%	53 %	57 %	56 %

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.

B: Prevalent RRT patients by end of 2006

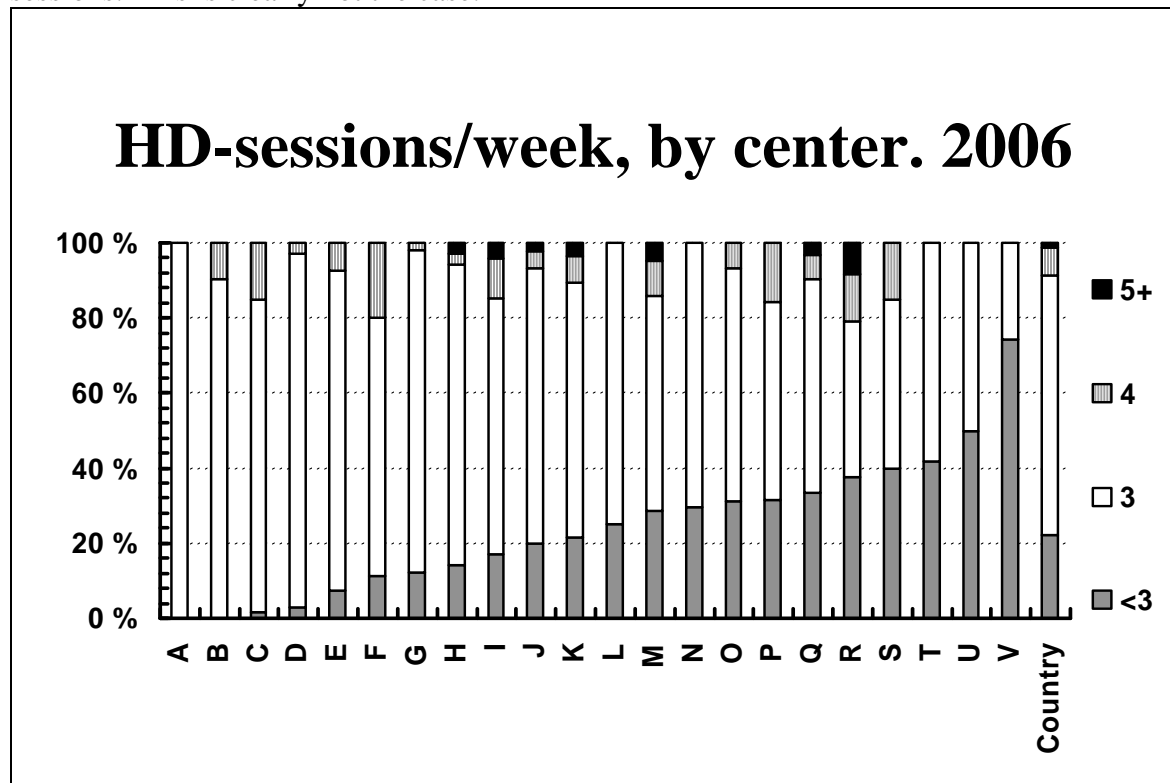
Once a year, the registry collects data on a set of treatment details and quality measures for all patients in RRT. Data collection for the treatment year 2007 is not yet completed; selected data will be part of the next annual report.

Status data were requested for all dialysis patients who had been on RRT for at least one month by 31.Dec.2006, the return was 100%. Similarly, data were requested for all patients with a functioning graft except those transplanted during September to December 2005. 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.”

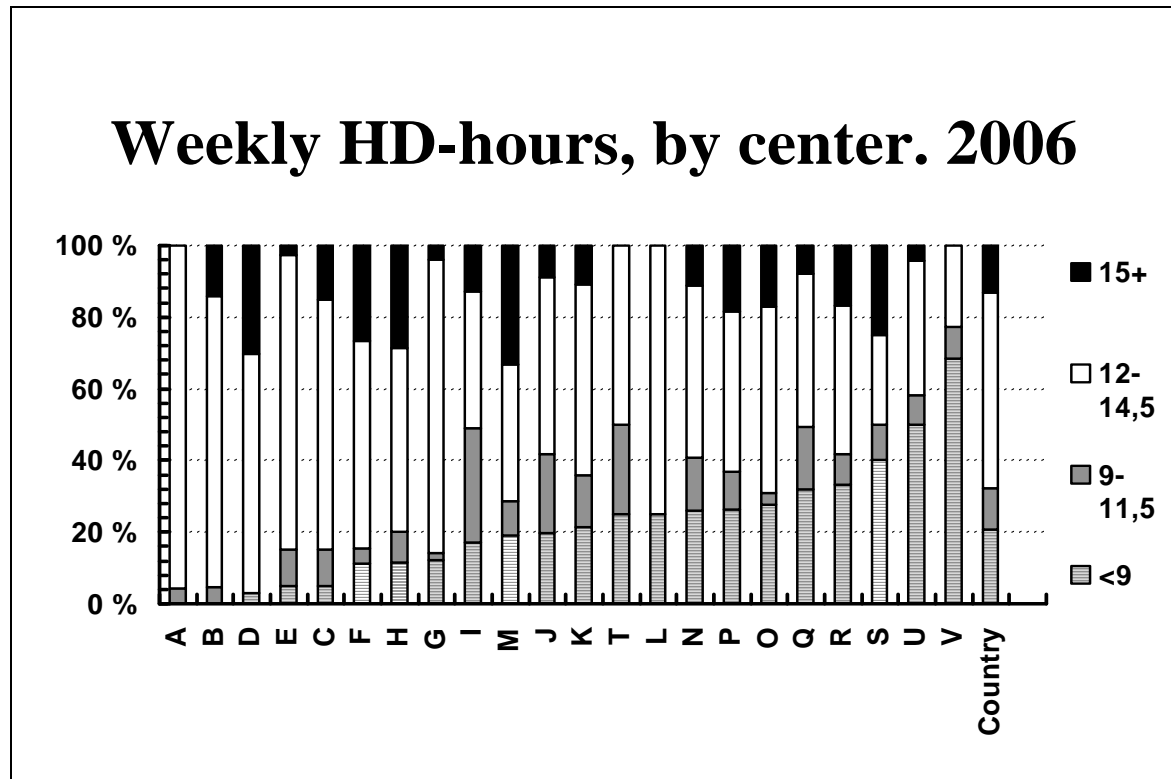
As illustrated below, 22% of the prevalent HD-patients received less than the three weekly sessions, at one centre this applied to 75% of their HD patients. Each centre is given a code that has been made known to the leaders of all centres. One might expect that centres with the longest travel distances 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 two centres this was the case for 20 % of their HD-patients.

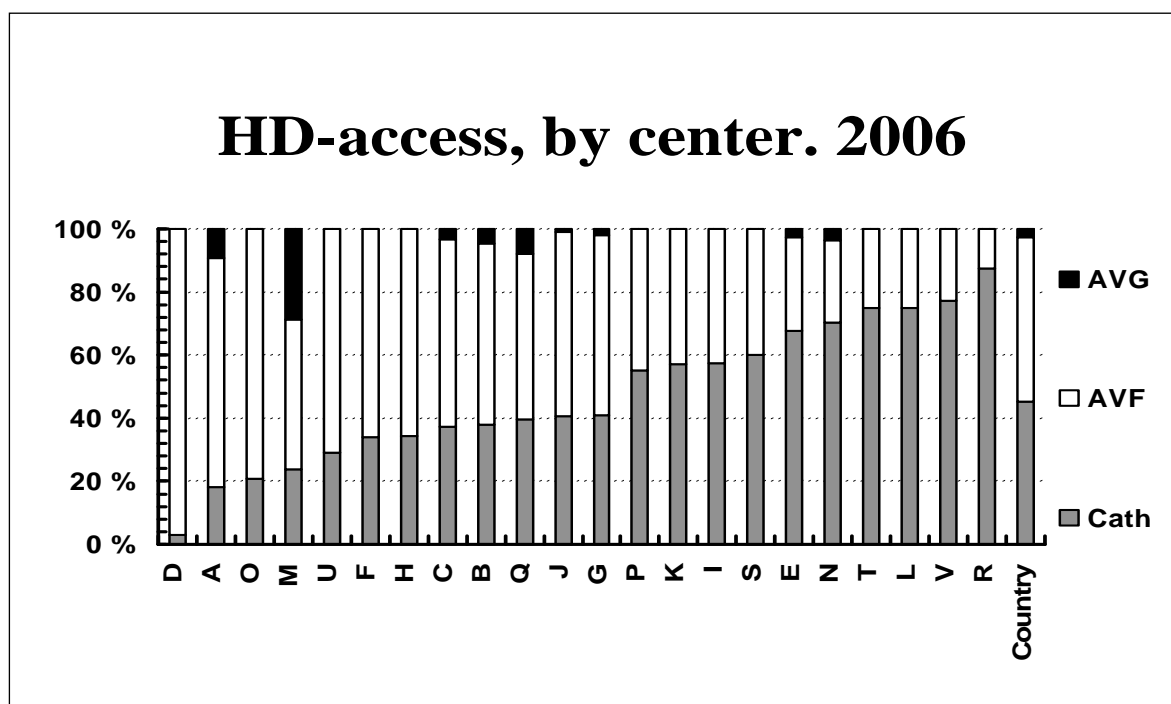
As for the weekly treatment time, 32 % received less than 12 hours/week. Again, there was a marked centre variation, from four and up to 77 % received less than the recommended number of hours. If the DOPPS-data apply also to a Norwegian haemodialysis population, less than optimal patient survival is to be expected. But with the small HD population in

Norway as a whole, and even more so because the individual centres are small, reliable estimates of effects of treatment time on survival in the different Norwegian centres can hardly be made.



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: 52 % of prevalent HD patients had a functioning AV-fistula; additionally 3 % had a graft, while the remaining 45 % 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 also 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.

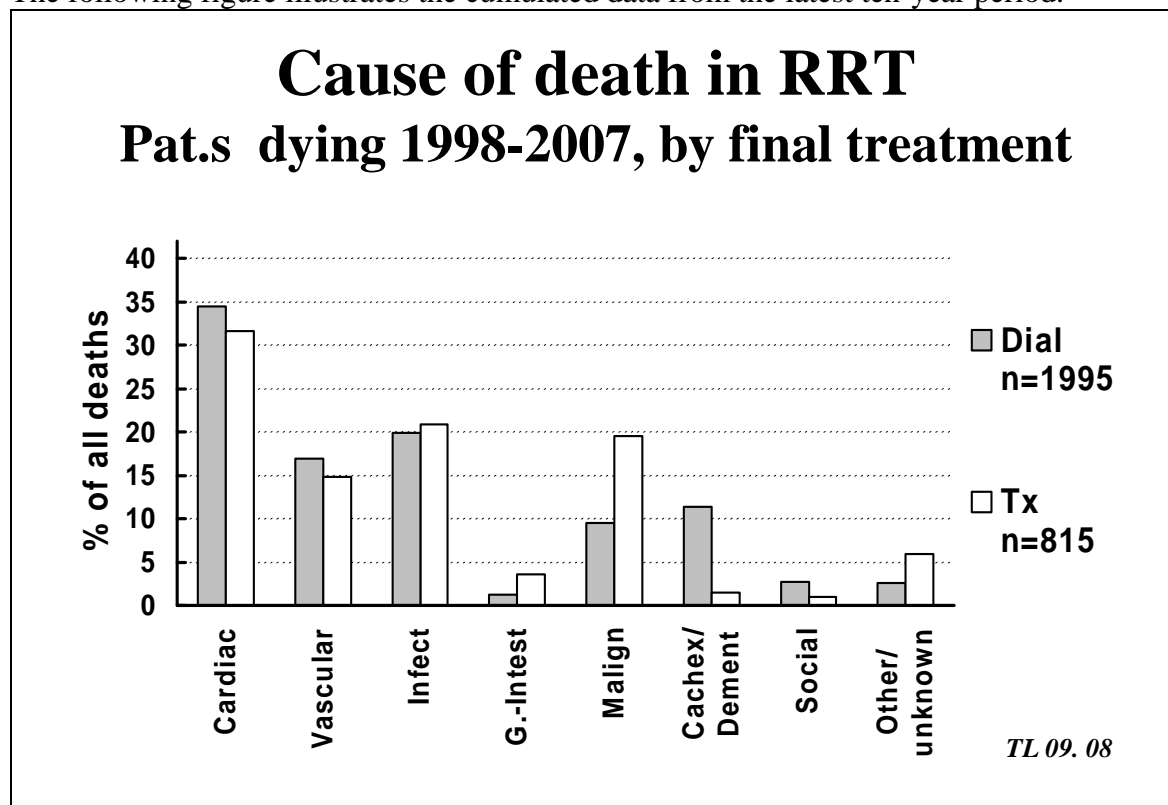
Death in RRT:

A total of 345 patients in renal replacement therapy died during 2007, i.e. 8.5 % out of the 4037 persons at risk. Among these, 68% were males and 32% females. Median age at death was 74.5 years, mean 71.9 years, and the range 27-94 years. Median time from start of RRT until death was 37 months, with a range spanning from two weeks to 37 years.

The final mode of treatment was HD for 213 patients and PD for 36, while 96 died with a more or less well-functioning graft. Two died within two months after graft loss; thus 98 deaths were termed 'TX-related'. Dialysis treatment was terminated and followed by death in 36 patients; in seven of those the patient refused further treatment.

As in previous years, cardiac (29%) complications were the most frequent causes of death, followed by infections (25%), vascular complications (17%), and malignant tumours (12%).

The following figure illustrates the cumulated data from the latest ten-year period.



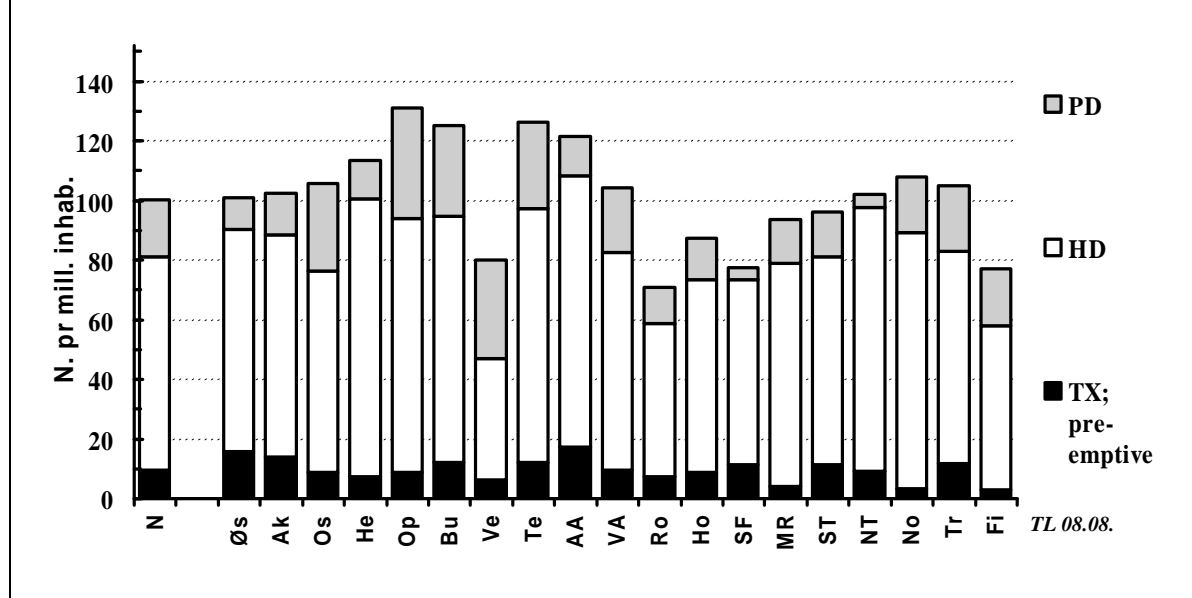
Regional differences within Norway.

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 2003-2007:

RRT in Norway 2003-2007

Mean yearly incidence, by first treatment and county



As appears, the mean yearly incidence of RRT-start varied from 71 to 131 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.

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 16 % (Østfold).

In some counties PD is rarely used, in others up to 41 % of new patients have this as first treatment mode. 71 % received HD as first treatment mode, in the counties this ranged from 51 % to 86 %.

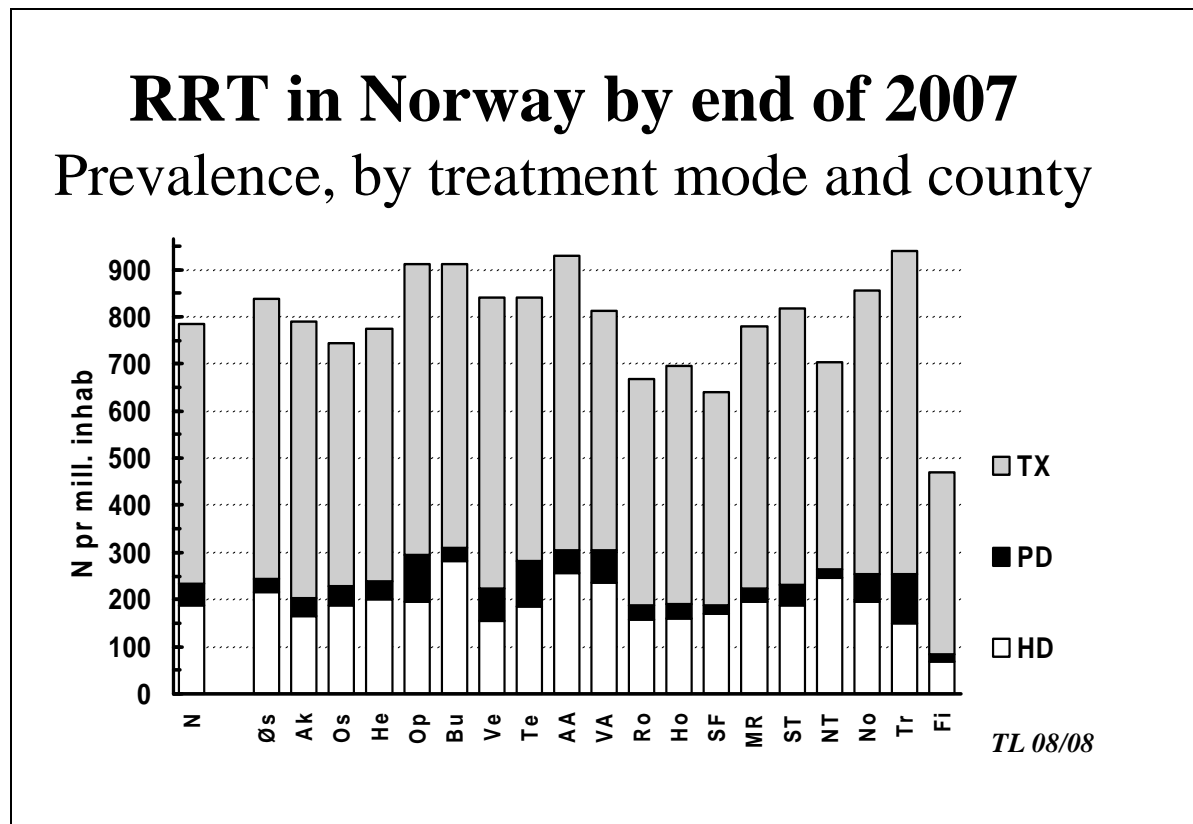
The proportion of the new patients in 2007 who started dialysis without having been known by the renal unit for at least 4 months was 27 %, with wide variations between centres; from 8% in one centre and up to 53 % at highest. In the majority of these cases the diagnosis would imply that renal failure has developed gradually over years. Over the 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 2007 mean age of new patients in the different counties ranged from 58 to 73 years, comparable to 2006, and with less variation than in 2005. 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 61% to 77% of the total RRT-population. The dialysis prevalence ranges from 83 to 309 per mill. inhabitants in the

counties, indicating considerable differences in workloads and costs. In some counties, two out of three dialysis patients are not considered candidates for a new graft, in others this applies to 25-30 %. But counties with high dialysis prevalence do not necessarily have a high prevalence of 'non-transplantable' patients.



Concluding remarks:

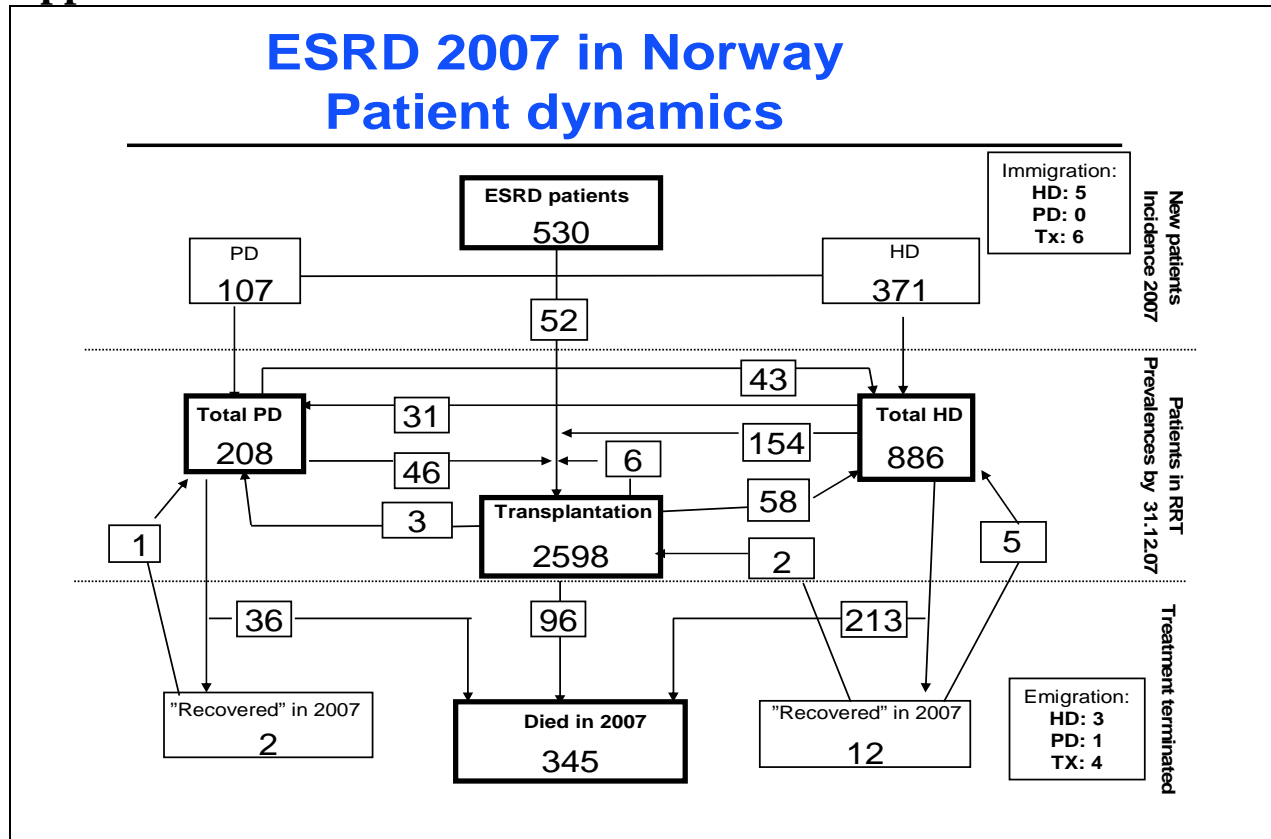
While the incidence of chronic renal failure over some years seemed to have levelled off, 2007 again showed an increase. With an increased survival rate (see the 2004-report), a markedly increased prevalence of RRT-patients can nevertheless be expected over the coming years. Marked county differences 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 2007 also gave a high transplantation rate, second only to the top-year of 2004. Yet the dialysis population grew with 15 %. 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 22.09.2008
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Appendix:

ESRD 2007 in Norway Patient dynamics



Centre	Satellites	New pat. in RRT 2007				Pat. in RRT pr 1/1.2008				Dialyses etc. 2007			Died 2007		Not Tx-candidate
		HD/HDF	PD	Pre-emptive	Total	HD/HDF	PD	Graft	Total	HD sessions	Pl.exch.	Other	Dial.pat	Tx-pat.	
Tromsø	4	13	5	3	21	21	16	116	153	4405	25	0	17	6	19
Harstad		8	0	0	8	10	0	36	46	1586	0	0	1	3	6
Bodø	7	10	5	1	16	43	13	120	176	5993	25	155	8	6	23
Levanger	3	17	2	1	20	31	3	52	86	3569	15	0	10	2	20
Trondheim	4	18	5	3	26	56	13	181	250	9560	320	317	11	7	45
Ålesund	2	15	2	0	17	47	7	127	181	7951	16	0	13	4	37
Førde	2	6	1	2	9	18	2	42	62	3003	14	45	7	0	12
Bergen	1	21	6	5	32	64	13	210	287	10247	159	64	20	9	45
Stord/Hauges.	1	8	2	1	11	23	8	66	97	2923	5	23	4	1	18
Stavanger		19	6	2	27	51	6	156	213	7100	26	51	2	7	30
Kristiansand	1	16	10	2	28	41	11	87	139	6518	12	0	17	4	38
Arendal		7	2	1	10	25	5	62	92	3666	0	31	2	3	18
Skien	1	10	6	4	20	31	16	95	142	5465	26	92	13	6	24
Tønsberg		16	9	1	26	37	14	130	181	4833	92	33	7	7	21
Hønefoss	1	12	0	0	12	23	0	34	57	2300	0	0	2	1	14
Drammen	1	21	9	3	33	46	8	109	163	5106	27	0	16	4	15
Lillehammer	2	23	7	2	32	42	19	104	165	6041	29	0	18	7	32
Elverum	1	16	1	2	19	32	5	91	128	4895	39	25	9	2	22
Fredrikstad	1	20	2	3	25	57	7	157	221	8414	34	0	10	4	21
AHUS		30	5	5	40	59	12	152	223	8690	0	0	14	6	40
Ullevål		49	22	10	81	102	30	260	392	14911	102	0	36	6	45
RH		16	0	1	17	27	0	211	238	4655	328	50	10	3	15
SUM		371	107	52	530	886	208	2598	3692	131831	1294	886	247	98	560
- Pr. mill inh.		78,9	22,7	11,1	112,7	188,3	44,2	552,2	784,8	ie. + 6,1 %					119,0
% of total		70,0	20,2	9,8	100,0	24,0	5,6	70,4	100,0	from -07					51,2