ANNUAL REPORT 2004

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 can not be collected in time to be included in the annual report. They will instead be the theme for yearly quality-seminars and for special reports.

National organisation and policy

Norway has 4.589 mill. inhabitants (July 2004) and 19 counties with populations ranging from 73000 to 525000. 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 spouse 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 2004, 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 2004

During 2004 a total of 459 new patients (in 2003: 436) entered renal replacement therapy (RRT), i.e. 100.0 per mill. inhabitants.

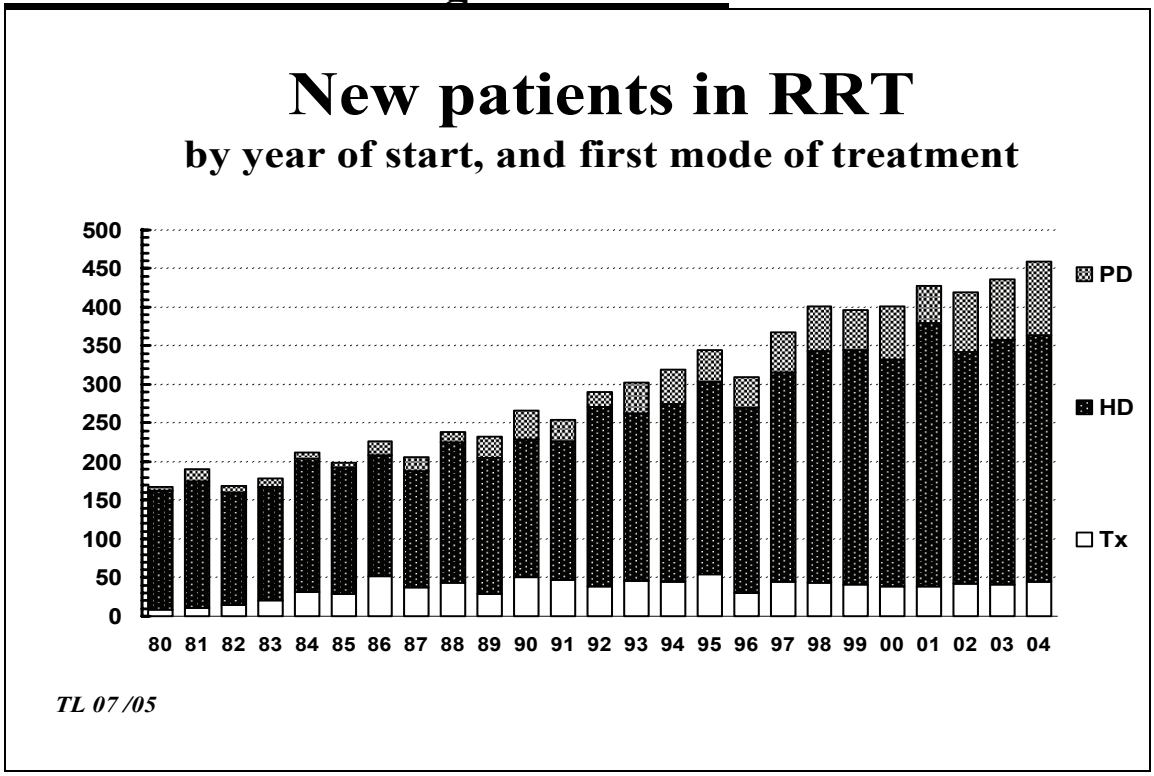
A majority of 65.8% were males and 34.2% females. Median age at start was 65.4 years, mean 62.3 years, ranging from 1.5 to 90 years.

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	15	21	34	65	75	105	320	69.7
PD	0	4	5	8	11	19	19	29	95	20.7
TX	4	3	5	8	9	10	4	1	44	9.6
Total	5	11	25	37	54	94	98	135	459	100
in %	1.1	2.4	5.4	8.1	11.8	20.5	21.4	29.4	100	

At start of treatment, 286 (62.3%) were considered by their nephrologist to be a potential candidate for transplantation, while 173 (37.7%) were accepted for life-long dialysis (constituting 43% of those starting with HD and 38% of those starting PD).
Among patients starting dialysis in 2004, 23% were previously unknown to the renal unit when they presented with terminal renal failure, 53% were known and started RRT as planned, while 24% were known but had a hastened RRT-start.

Incidence data: Changes 1980-2004



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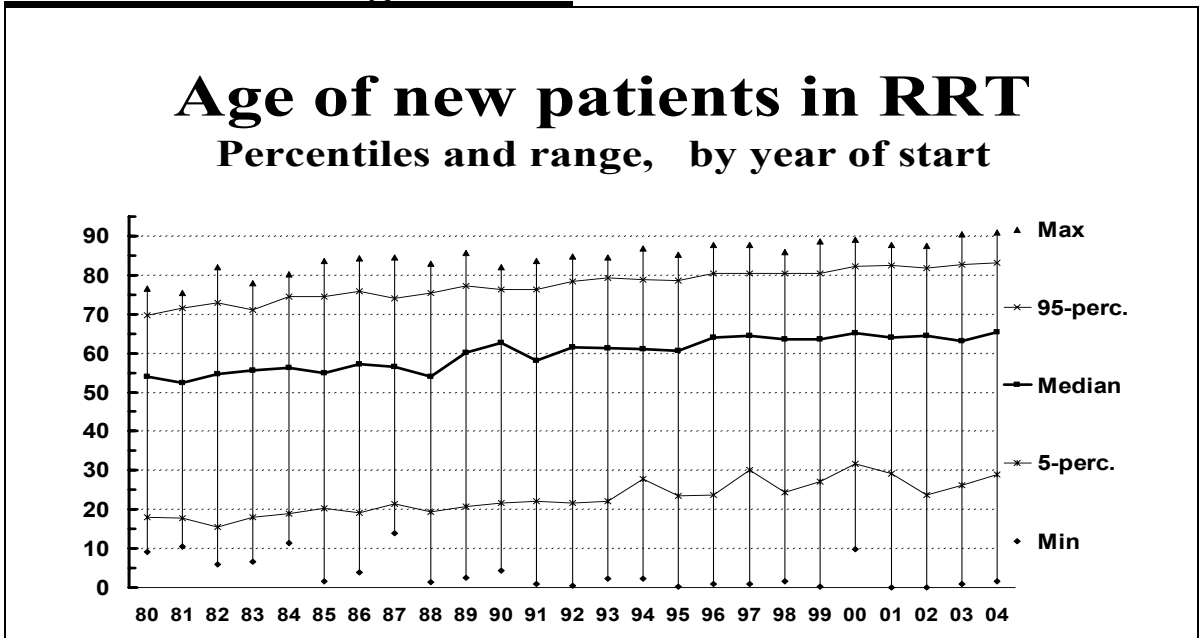
Incidence data: Age at start



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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 2002 at age 13 days. The number of children below 15 years has not changed during the period - it has ranged from two to ten per year.

Incidence data: Primary renal disease

	1980-84	1985-89	1990-94	1995-99	2000-03	2004
Glomerulonephritis	34%	36%	31%	24%	18%	16%
Pyelo/interstitial nephr.	16%	14%	11%	12%	11%	11%
Polycystic diseases	10%	9%	9%	9%	9%	8%
Diabetic nephropathy	13%	12%	12%	11%	14%	17%
Amyloidosis	7%	6%	6%	4%	3%	2%
Vascular/hypertensive	5%	8%	18%	24%	28%	29%
Immune/systemic	4%	5%	4%	6%	4%	3%
Kidney tumour	1%	1%	1%	1%	1%	2%
Myelomatosis	3%	2%	1%	2%	3%	4%
Other defined	4%	4%	4%	3%	4%	2%
Unknown	3%	3%	3%	4%	4%	5%
N:	912	1106	1419	1817	1687	459

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 2004, 37 were registered as having Type I and 42 as Type II diabetes. In addition 37 patients with other types of primary renal disease were recorded having diabetes as a co-morbid factor (two were Type I and 35 Type II), thus 25% of new patients were diabetics.
The time from onset of diabetes to start of RRT differed considerably. For the 37 with Type I diabetes the mean time was 30.9 years, for the 42 with Type II diabetic nephropathy the mean time was 18.0 years. Type II diabetics judged to have a primary renal disease other than diabetic nephropathy in mean had 9.8 years of diabetes duration.

Cardiovascular disease is often present at start of RRT. Symptomatic heart disease was reported in 149 (32%); one out of these had a previous heart transplant. Cerebrovascular disease was reported in 42 (9%) and peripheral arteriosclerotic disease in 88 patients (19%).

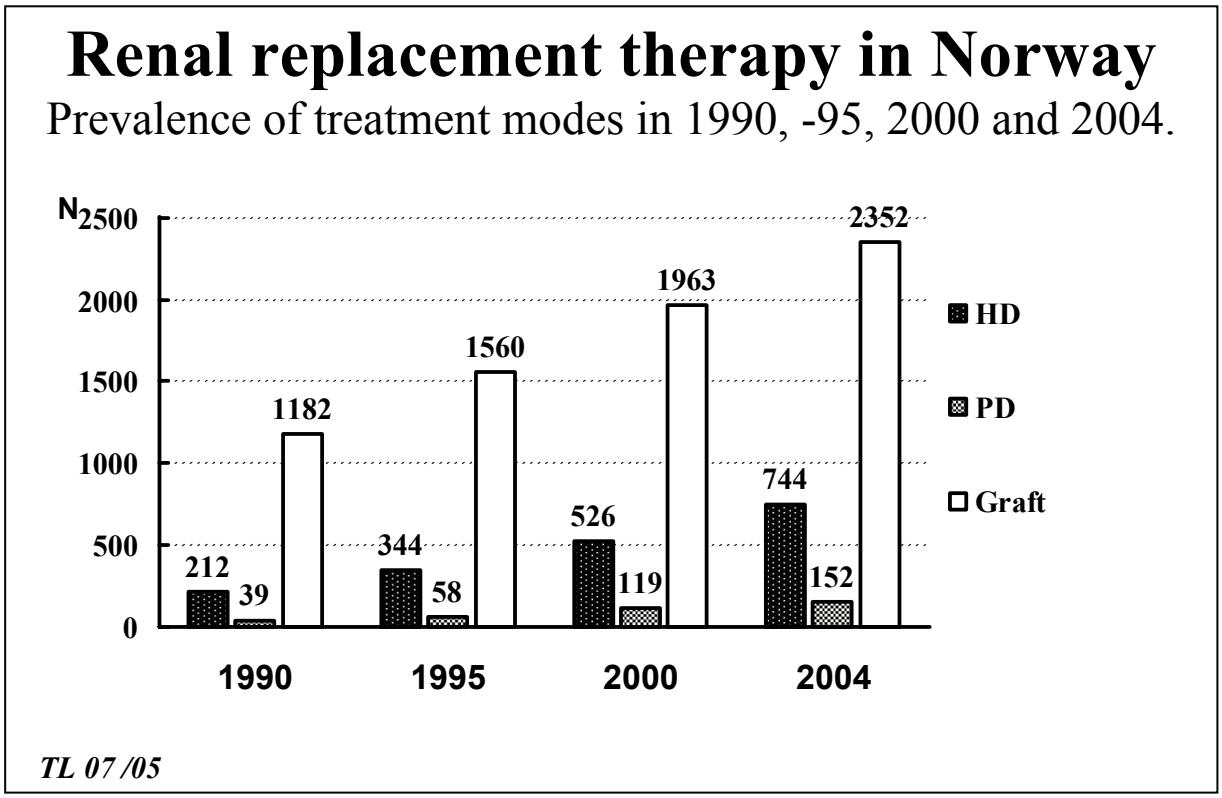
Prevalence data: Status by 31.dec. 2004.

By the end of 2004, 3248 patients in Norway received renal replacement therapy, i.e. 707.7 per million inhabitants. This represents an increase of 209 patients or 6.8 % since 2003.
Gender: 63.9% males and 36.1% females.

Median age by the end of the year was 57.1 years, mean 56.0 years and range 1.6-92.2 years.

Tabulated by last mode of treatment, and age by end of 2004:

	< 15	15-24	25-34	35-44	45-54	55-64	65-74	75+	Total	in %
HD	1	13	31	53	80	150	158	258	744	22.9
PD	0	3	5	10	19	32	25	58	152	4.7
TX	39	70	215	395	502	608	375	148	2352	72.4
Total	40	86	251	458	601	790	558	464	3248	100
In %	1.2	2.6	7.7	14.1	18.5	24.3	17.2	14.3	100	



Death in RRT in 2004:

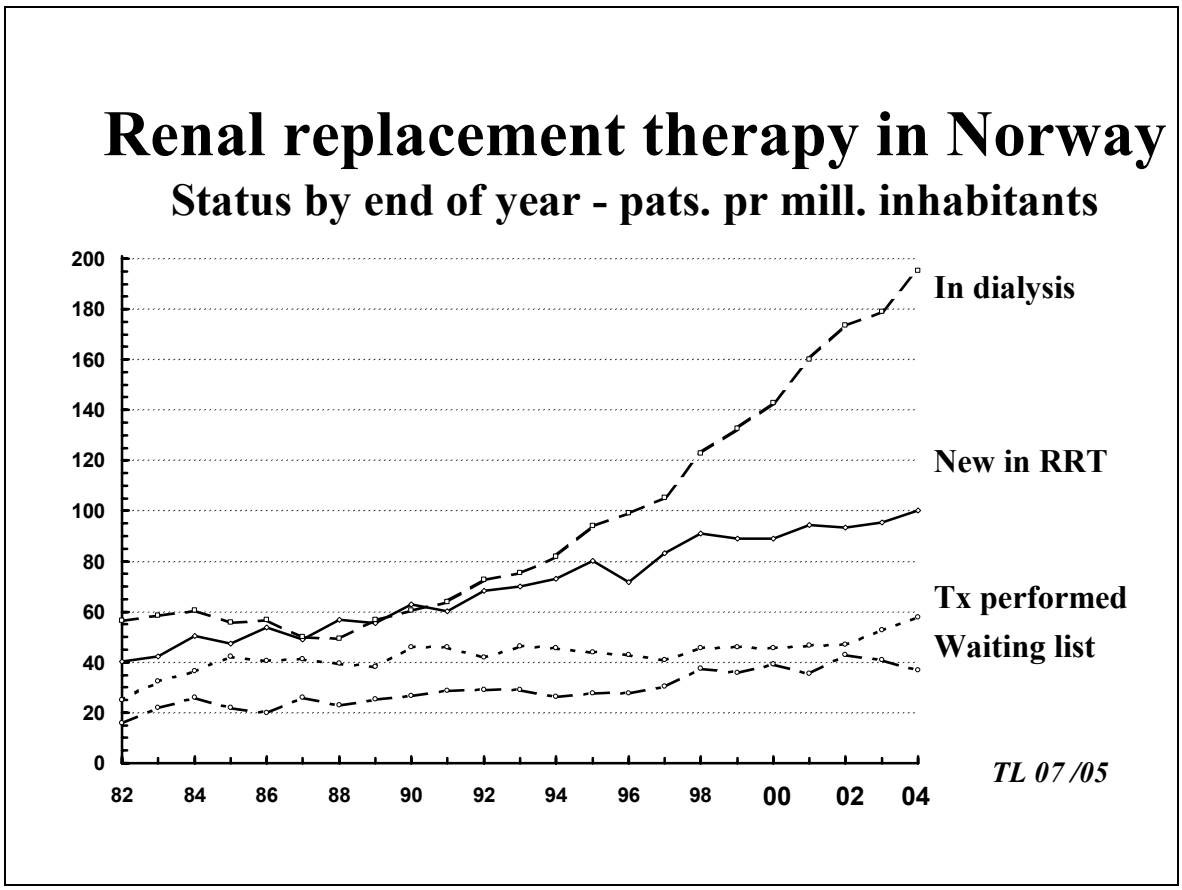
A total of 254 patients in renal replacement therapy died during 2004, i.e. 7.3 % out of the 3498 persons at risk. Among these, 70% were males and 30% females. Median age at death was 74 years, mean 71.1 years, and the range 19-91 years. Median time from start of RRT until death was 30.8 months, with a range spanning from 12 days to 27.3 years.
The final mode of treatment was HD for 165 patients and PD for 23, while 66 died with a more or less well-functioning graft. One died within two months after graft loss; thus 67 deaths were termed 'TX-related'. Treatment was terminated and followed by death in 28 patients, two of those because the patient refused further treatment.
As in previous years, cardiac (33%) complications were the most frequent causes of death, followed by infections (22%), malignant tumours (10%), and vascular complications (9%).

Transplantation and waiting lists:

A total of 265 renal transplants were performed at Rikshospitalet University Hospital in 2004, i.e. 57.7 per million inhabitants. In 95 (35.8%) the graft came from a living donor (LD), 30 of those were biologically unrelated to the recipient (21 were spouses). Among the LD-graft recipients 26 out of 89 first graft recipients were grafted pre-emptively, 3 of 6 re-graft recipients did not receive dialysis. 170 patients received a cadaveric donor graft (CD), 18 out of the 140 first graft recipients were pre-emptively transplanted (13 %), while four out of 30 had a re-graft without entering dialysis. There were 229 first grafts (89 LD and 140 CD), 29

were second grafts (5 LD, 24 CD), and 7 third grafts (1 LD, 7 CD). Simultaneous kidney + pancreas transplantation was performed in 8. Among patients with a functioning kidney graft five received one or more doses of isolated Langerhans Islet cells and one received a whole pancreas ("dyssynchroneous").

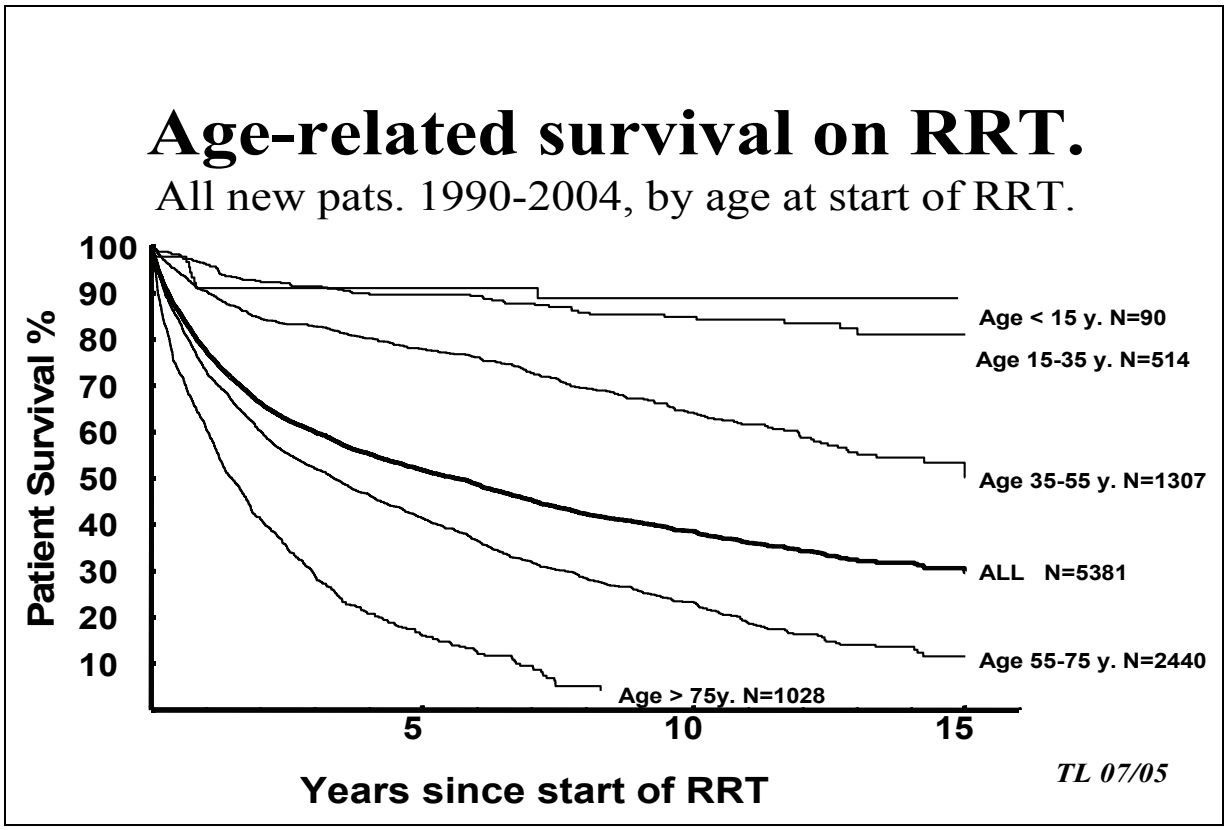
In principle, transplantation is offered to all patients considered to profit from it, with no strict upper or lower age limit. The age of the 140 first cadaveric graft recipients in 2004 ranged from 1.5 to 78 years, with a mean age of 55.8 y. Out of these, 28 % were above the age of 65 and 8 % were 75 or older. The 89 recipients of a first living donor graft were from 2 to 73 years, mean 41.7 y. Regraft recipients (n=36) were from 11 to 81 years, mean 46.6 y.



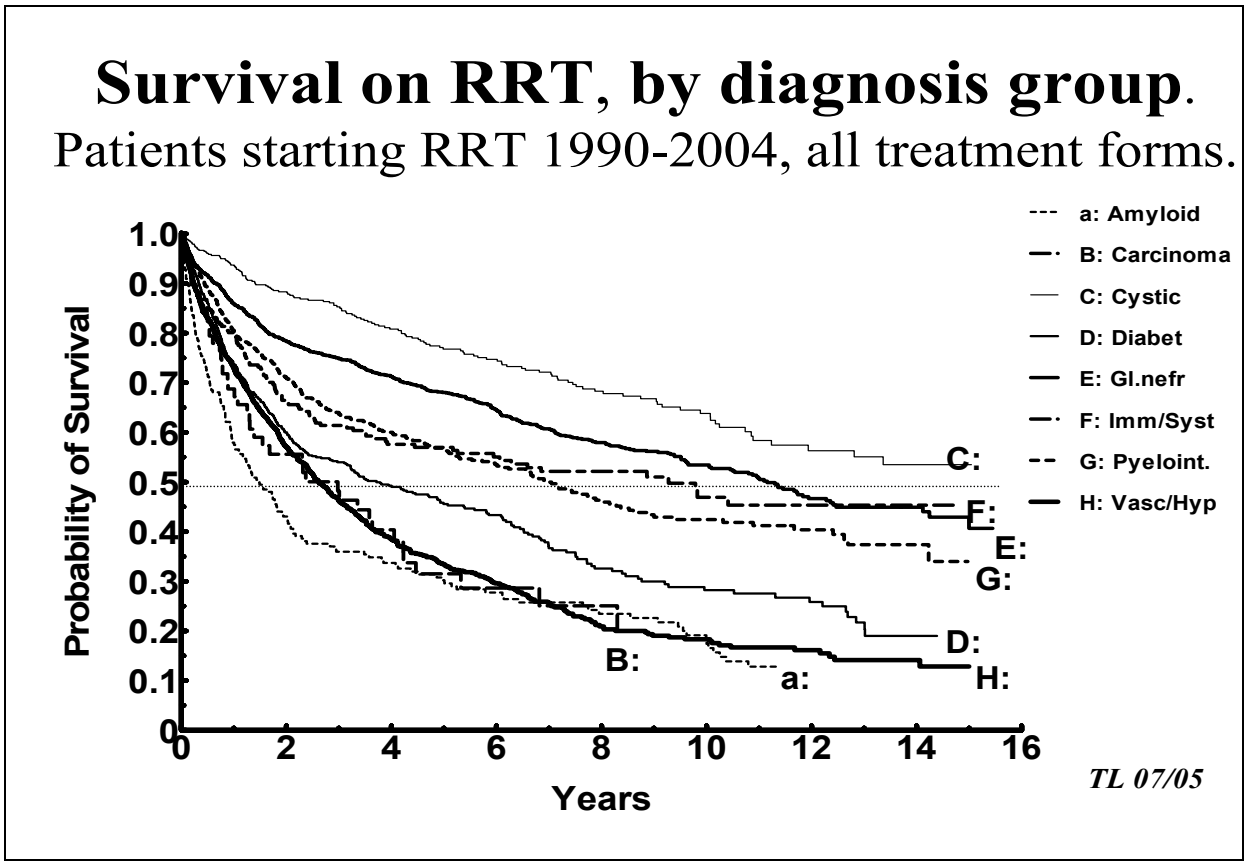
By end 2004, 169 patients (36.8 per mill.) were on the active waiting list for a CD renal graft. This represented a reduction of 18 patients (10%) since 2003. Among those waiting by Dec.31, median time on the list was 8 months. 41 % had waited less than 6 months, 64 % less than one year and only 6 % more than two years. The 170 recipients given a CD-graft in 2004 had a median waiting time of 8 months and a maximum of 68 months at the time of grafting. Among the 896 patients in dialysis treatment by Dec.31, 449 (50.1 %) were for various reasons not considered candidates for a new renal graft.

Patient survival on RRT.

Patient survival by end of June 2005 was calculated by Kaplan-Meier method, censoring only for date of emigration. Patients starting RRT after 1.Jan.1990 have been grouped according to age at start of RRT, by primary renal disease, or by the initial evaluation of potential transplantability as given by the reporting nephrologist. Further, survival by 5-year epoch of RRT-start for the whole material was calculated and a Cox-analysis was performed.



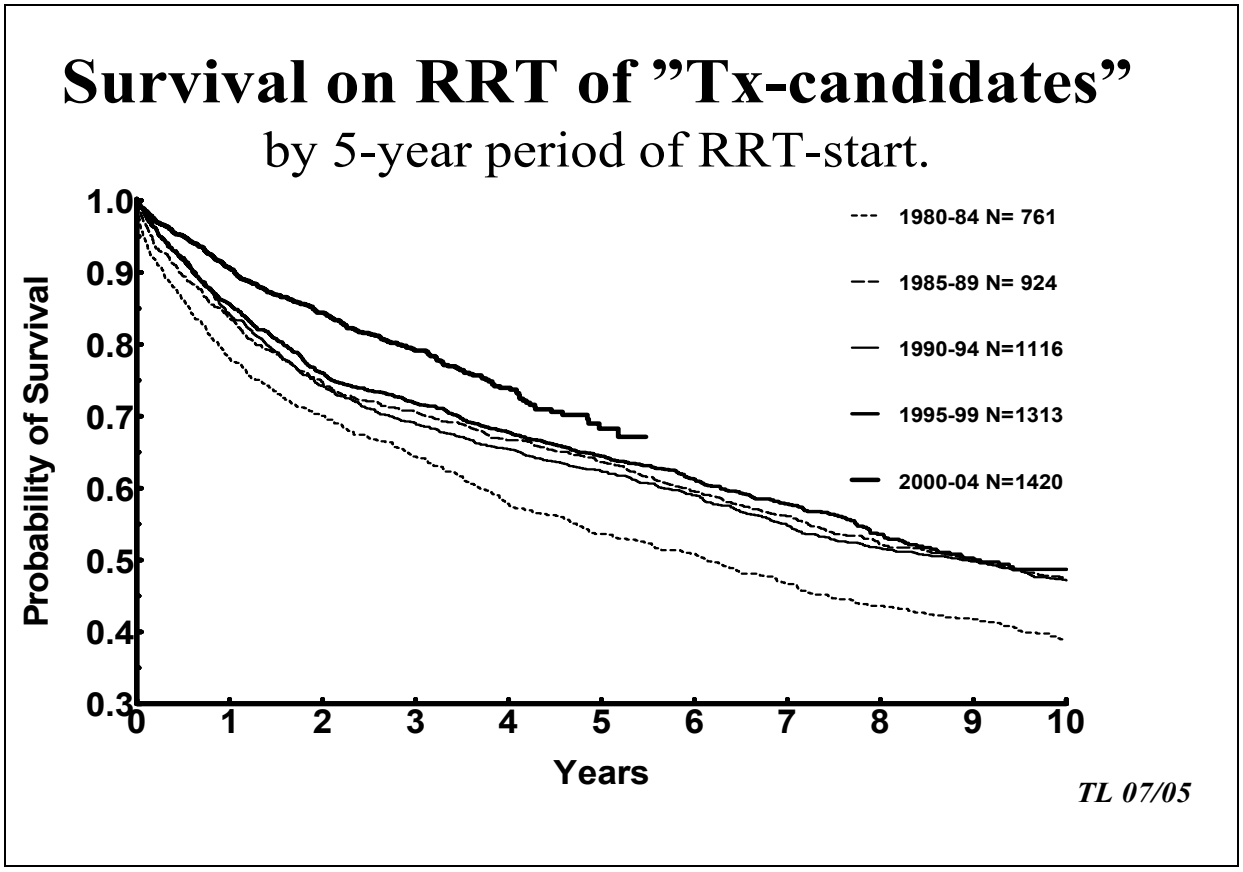
As expected, the survival on RRT decreases with increasing patient age. In the youngest group, all were considered transplant candidates and 94% have been transplanted, in the 75+ group, 21% were considered candidates and only 27% of these have received a graft.



Patient survival on RRT depends on many factors, including the primary renal disease. In general, patients with cystic diseases (EDTA 40-49) have the best survival (94% at one year),

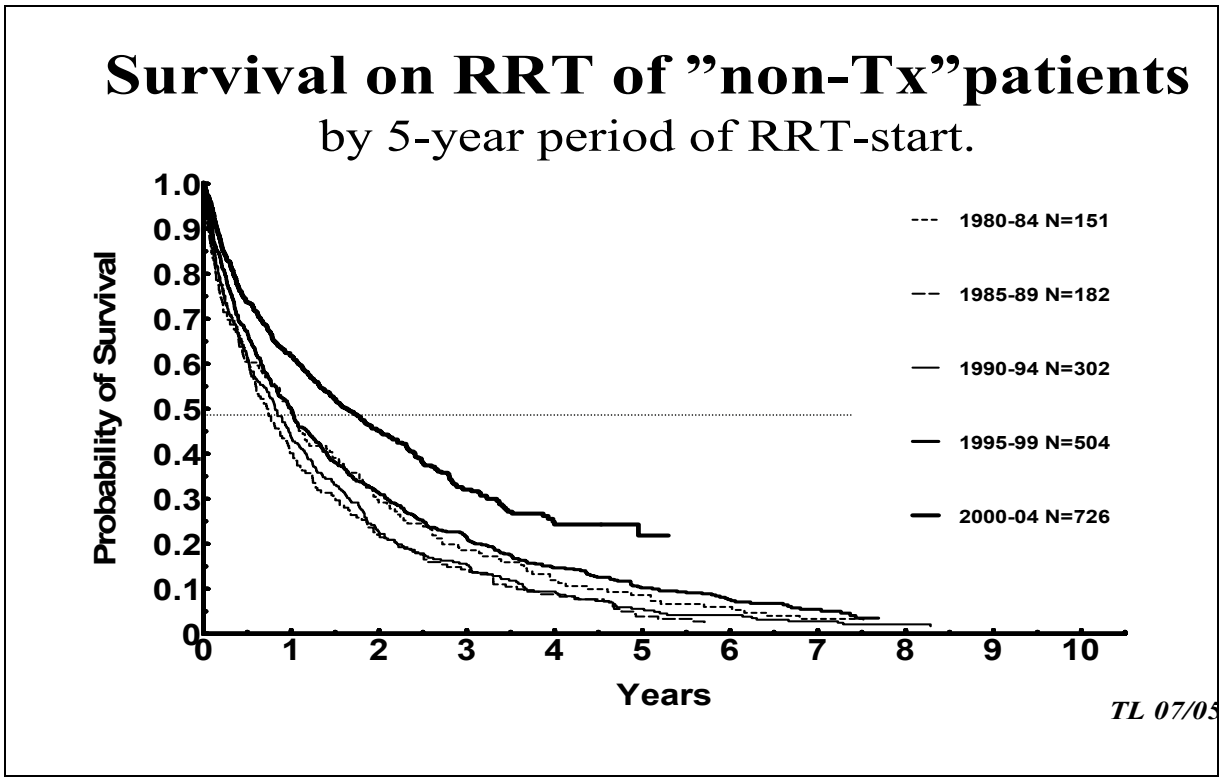
while patients with amyloid (58%) or renal carcinoma do worse (69%). Even poorer survival, 42% at one year, was seen in myeloma patients.

Since the start of registration in 1980 there have been major changes in immunosuppressive therapy, leading to markedly improved graft survival. Over time, an increasing proportion of non-transplantable patients have received RRT. To assess whether patient survival has improved over time, we studied the potential transplantation candidates (70% have actually been transplanted) and the non-transplantables (of whom 3% have been grafted) separately.



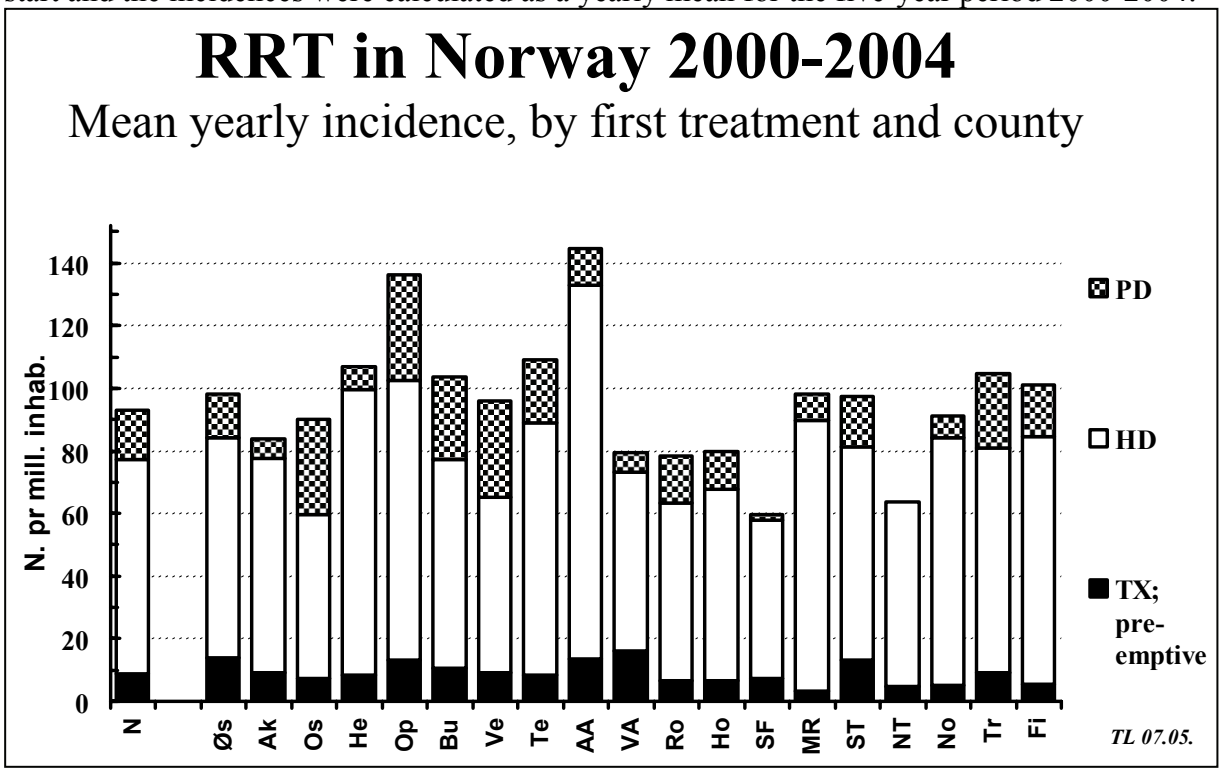
The patient survival among those initially evaluated to be potential candidates for renal transplantation improved markedly from 1980-84 to 1985-89, which probably was a consequence of CsA-based immunosuppression from January 1983. Over the following 5-year periods there was no further improvement until the 2000-04 period. While the observed two-year survival in the 1995-99 cohort was 76%, the corresponding figure for the 2000-04 cohort was 84%. The reasons for this improvement are not clear, but may be related to further improvements in immunosuppression, or better treatment of anaemia, hypertension and lipids.

From the following figure it appears that the life expectancy for those initially assessed to be non-transplantable did not change much over time, until the latest 5-year period. But from 1995-99 to 2000-04, the one year survival increased from 50% to 62% (50% in the latter period was seen at 1.6 years). Between the same periods, the mean age of the new patients increased from 73.3 to 74.6 years. We have no indications that the acceptance criteria for RRT have been made more rigorous over time, possibly the nephrologists have become more restricted in assessing a patient as a transplantation candidate. However, the similar survival improvement also among transplant candidates seems to indicate that the quality of patient treatment in general has been improved during the later years.



Regional differences within Norway.

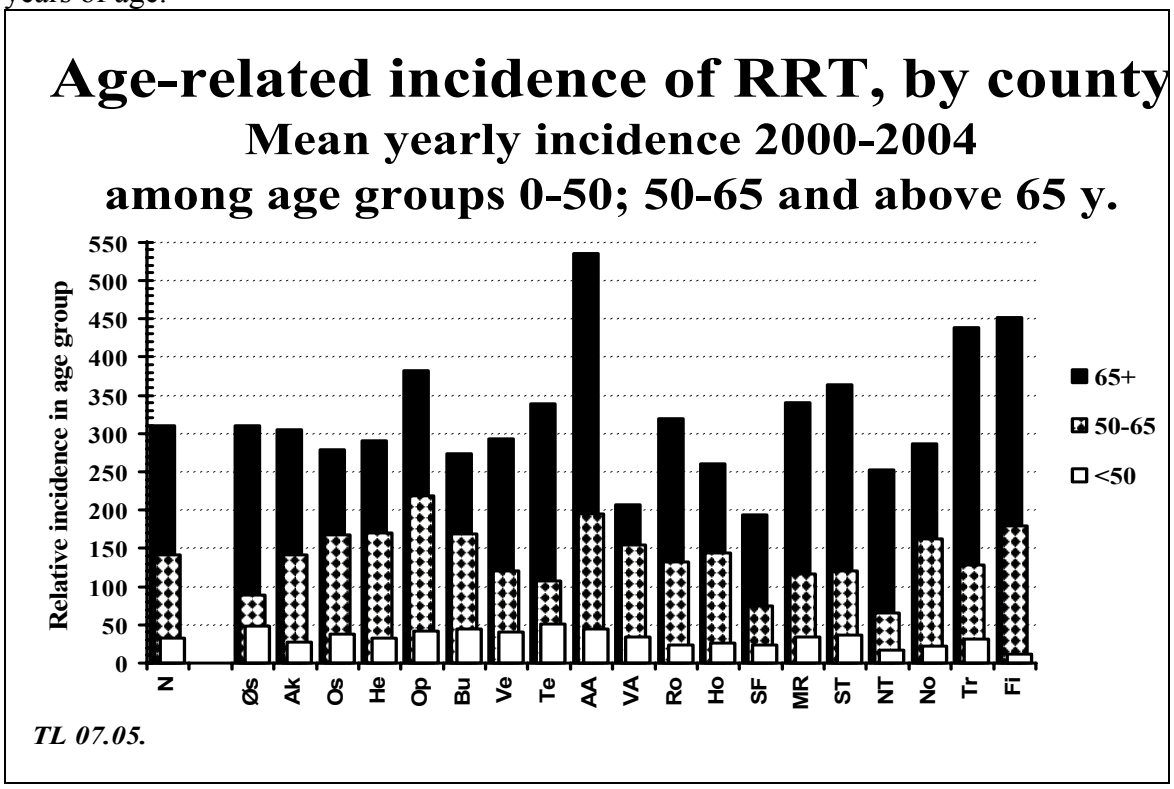
Incidence:
During all the years since data collection was started, the number of patients reported has differed substantially between centres, also after correction for population size. Further the first mode of treatment (HD, PD or pre-emptive transplant) for new patients differs considerably. In the 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 2000-2004:



As appears, the mean yearly incidence of RRT-start varied from 60 to 144 pr. million. Noticeably, the county having the lowest incidence (Sogn og Fjordane) is also known to be where people live the longest and have the lowest general morbidity. Also noteworthy is that Aust-Agder which had the second lowest mean yearly incidence during the 90ies (55/mill) now is in lead with 144.4/mill.
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 % to 20 %.
In some counties PD is rarely used, in others up to 34 % of new patients have this as first treatment mode. 73 % received HD as first treatment mode, in the counties this ranged from 58 % to 93 %.

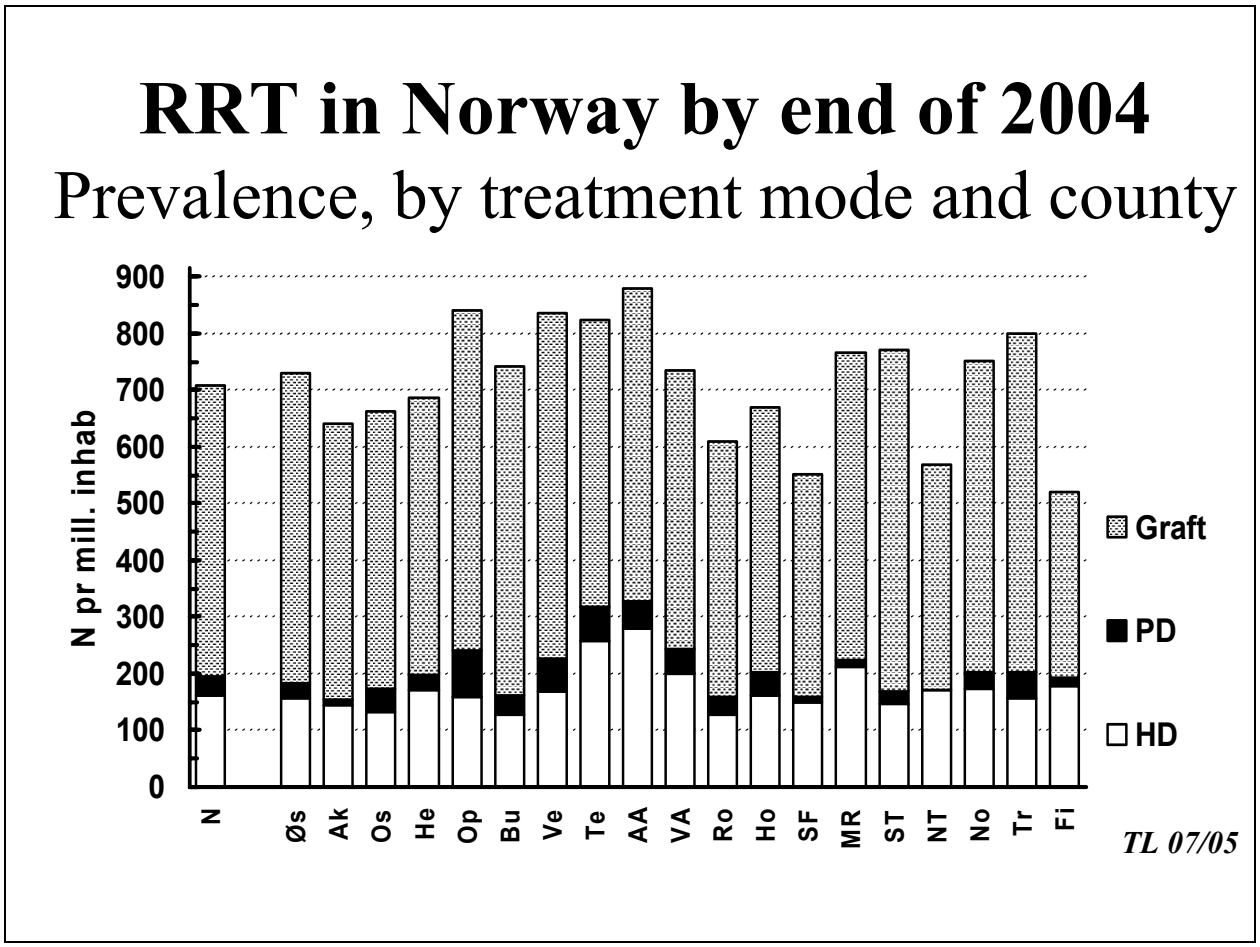
The proportion of the new patients in 2004 who first presented in the renal unit with a terminal renal failure was 23 %, with wide variations between centres – from 0 % in one centre and up to 44 % at highest. In the majority of these cases the diagnosis would imply that renal failure has developed gradually over years. Over the years, these figures seem not to have improved; thus in most counties it seems to be need for improved co-operation within the primary health service in order to achieve early referrals.

We have previously reported marked centerwise differences in the age distribution of incident patients. In 2002 mean age of new patients ranged from 52.3 to 67.6 years. For the five-year period 1998-2002 we have calculated the mean yearly relative take-on rate of patients of patients in three different age populations: less than 50 years; 50-64 years; and those above 65 years of age.



As appears from the figure, the mean RRT-incidence among persons below 50 years does not seem to differ much, though ranging from 19 to 46 pr. mill. inhabitants. In the age group 50-64 years, the RRT-incidence ranges from 81 to 207 pr. mill. (mean 145); while among the population of 65 years and above the incidence ranged from 157 to 484 pr. mill. inhabitants (mean 291). The reasons for such marked geographical differences are not clear.

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 78% of the total RRT-population. The dialysis prevalence ranges from 155 to 329 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:

The incidence of chronic renal failure is still rising, although the increase last year seemed to have levelled off. With the increased survival rates seen in the latest 5-year period, a markedly increased prevalence of RRT-patients can be expected over the coming years. Further, the marked county differences may indicate that we still can expect further increased national incidence. The high transplantation rates achieved in 2002-04 may seem to have retarded the yearly increase in dialysis prevalence somewhat. It is not obvious that the supply of organs for transplantation will rise further; it may even decrease in the future. But in spite of a higher transplantation rate in Norway than in most other countries, the number of patients in dialysis will still rise and they will constitute an increasing proportion of the RRT-population.

Compared to the Swedish RRT-incidence (121 per million in 2003) and prevalence (774 per million), and the Danish figures for 2004 (131 and 753 respectively), Norwegian numbers still

are low. There are no obvious reasons for such a difference between our nations that are so similar in most respects. Therefore, the Norwegian health service needs to prepare for accommodating a significantly increased number of RRT-patients in the coming years.

Report completed 14.09.2005
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Appendix: