The Nordic Liver Transplant Registry

Annual report 2006

Responsible contact persons:

Copenhagen; Preben Kirkegaard
Gothenburg; Styrbjörn Friman
Helsinki; Krister Höckerstedt
Oslo; Aksel Foss
Stockholm; Bo-Göran Ericzon
Uppsala; Frans Duraj

Report prepared by:

Tom Hemming Karlsen, Oslo

tom.hemming.karlsen@rikshospitalet.no

1. Source of data

Numbers and graphs in the present report are based on data extracted from the Nordic Liver Transplant Registry (NLTR) on 17th of April 2007. Prior to this export, data were subjected to quality control in terms of presentation of complete data as well as key numbers for 2006 to all transplantation centres (14th of February) with subsequent correction of errors noted by responsible contact persons.

2. Data content NLTR 2006

Up to the 31st of December 2006, data from a total of 3705 patients had been entered to the NLTR. The registry comprises data from all transplantation centres in Denmark, Sweden, Norway and Finland from 1982-2006. For the 219 patients receiving a liver allograft prior to 1990, no waiting list data are available. Among the patients receiving a liver allograft from 1994-2006, a total of 8.1% were listed as "highly urgent" (median waiting list time 2 days).

3. Transplantation activity 2006

The total number of patients who underwent first liver transplantation in 2006 was 249 (Figure 1). In addition, 29 re-transplantations were performed. The total number of 278 liver transplantations is the highest ever (Table 1).

Figure 1.
Number of patients receiving first liver allograft 1982-2006.

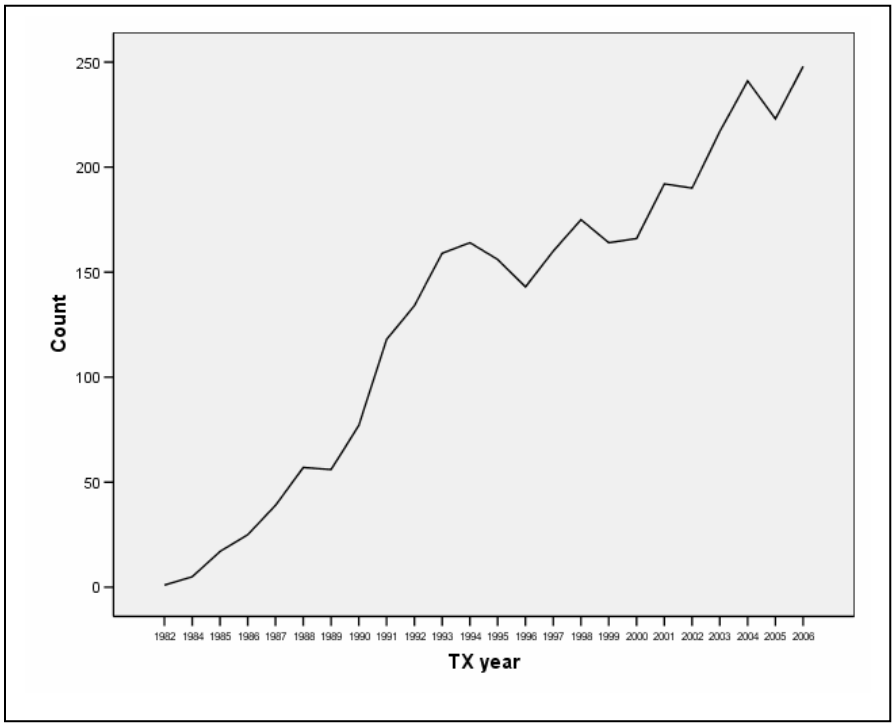


Table 1. *Annual numbers of liver transplantations (TX) 2000-2006.*

	2000	2001	2002	2003	2004	2005	**2006**
First TX	166	194	190	217	241	224	**249**
Second TX	22	15	22	25	23	29	**23**
Third TX	4	2	0	5	7	2	**6**
Fourth TX	0	0	0	1	2	0	**0**
Fifth TX	0	0	1	0	0	0	**0**
Sixth TX	0	0	1	0	0	0	**0**
Total TX	192	211	214	248	273	255	**278**

Table 2. *Liver transplantations performed per centre 2000-2006. There is a marked increase in transplantation activity in Helsinki and Oslo from 2005 to 2006.*

	Number of first liver transplantations							***Number of re-transplantations***						
	2000	2001	2002	2003	2004	2005	**2006**	2000	2001	2002	2003	2004	2005	**2006**
Copenhagen	20	26	32	36	37	36	**32**	4	6	8	3	6	4	**4**
Gothenburg	39	52	41	62	59	53	**52**	10	4	12	7	11	14	**8**
Helsinki	28	37	44	40	46	39	**49**	3	1	3	3	4	3	**4**
Oslo	25	32	25	31	43	32	**52**	5	5	0	8	4	7	**10**
Stockholm	54	46	44	41	45	56	**56**	4	1	1	9	7	4	**3**
Uppsala	0	1	4	7	11	7	**8**	0	0	0	1	0	0	**0**
Total TX	166	194	190	217	241	223	249	26	17	24	31	32	32	29

4. The waiting list 2006

In 2006, a total of 333 patients were entered to the liver transplantation waiting list (288 registered for first liver transplantation, 45 for re-transplantations, 32 listed as highly urgent). A total of 321 patients were withdrawn from the waiting list (Table 3). The number of deaths on the waiting list is not increasing (18 patients in 2006 versus 18 patients in 2005). The number of patients permanently withdrawn from the waiting list is not increasing (25 patients in 2006 versus 28 patients in 2005).

Table 3. *Patients withdrawn from the waiting list in 2006 classified by outcome.*

Deceased donor	***Living donor***	***Domino***	***Dead***	***Permanent withdrawal***
268	6	4	18	25

Patients receiving their first liver allograft in 2006 waited a median of 42 days (excluding patients listed as “highly urgent”). Non-systematic fluctuations are evident in the waiting times for the years 2000-2006 (Table 4).

Table 4. *Median time on waiting list (days) for patients receiving first liver allograft.*

	2000	***2001***	***2002***	***2003***	***2004***	***2005***	***2006***
All blood types	43	40	55	38	41	41	42
Blood type A	39	33	28	27	34	38	27
Blood type 0	76	56	104	74	71	60	105

There are marked differences in waiting times between the different centres in 2006 (Table 5), with some trends notable when 5-year periods are considered (Figure 2).

Table 5. *Median time on waiting list (days) for patients receiving first liver allograft in 2006.*

	Copenhagen	***Gothenburg***	***Helsinki***	***Oslo***	***Stockholm***	***Uppsala***
All blood types	47	41	32	27	63	74
Blood type A	33	21	17	18	49	55
Blood type 0	238	137	37	101	104	277

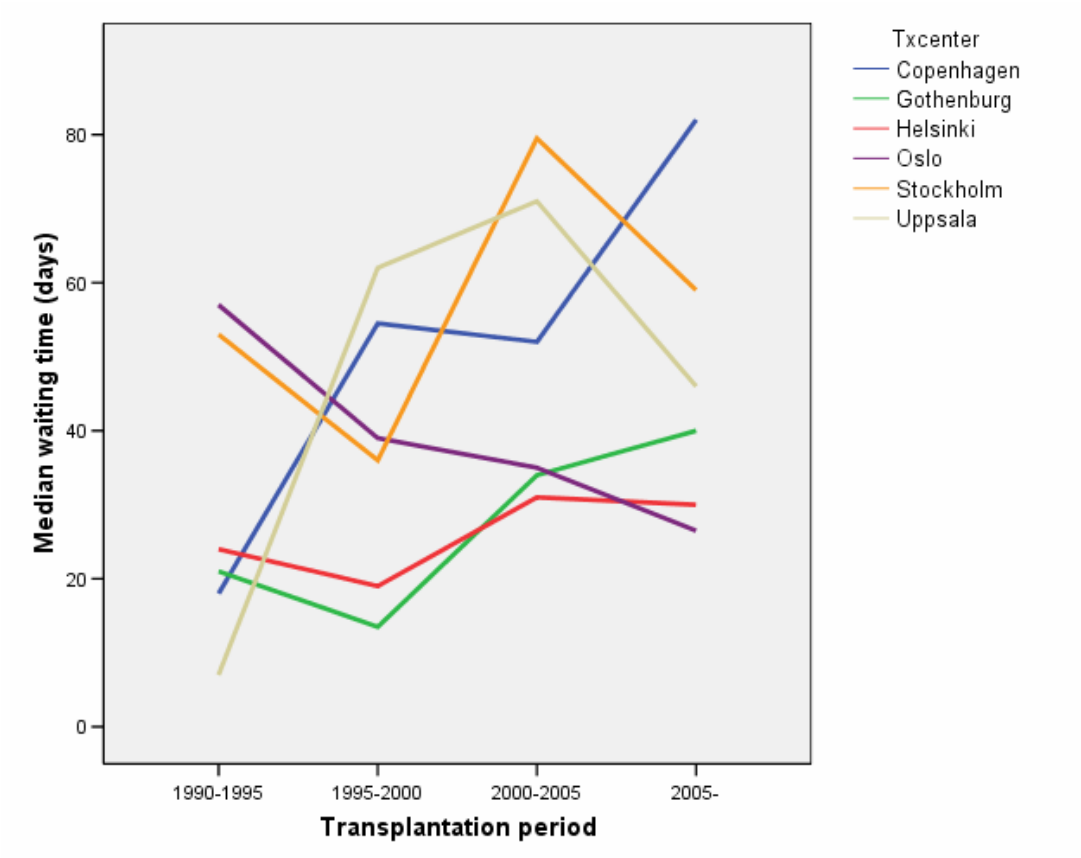


Figure 2. *Waiting time for first liver transplantation per 5-year period.*

5. Age of recipient and donor

The median age at first liver transplantation in 2006 was 50 years as compared with 51 years in 2005. Looking at 5-year intervals, recipient age is increasing at some centres, whereas stable at other (Figure 3).

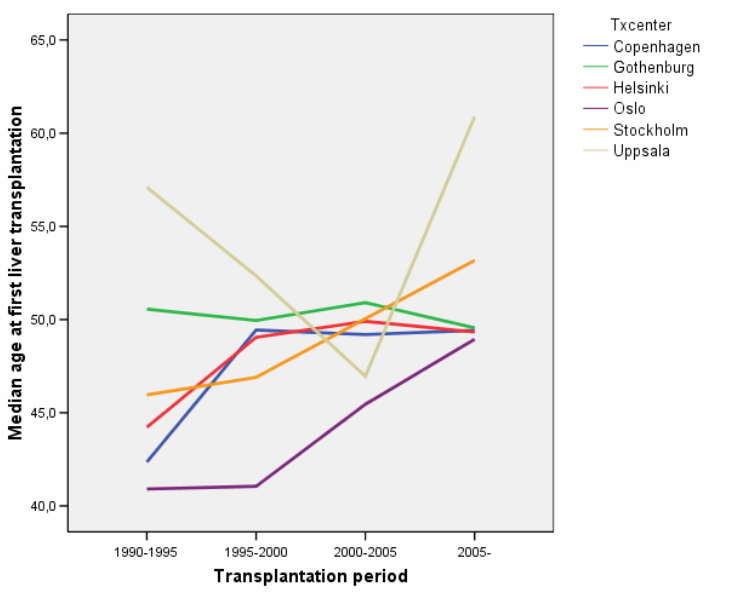


Figure 3. *Recipient age per 5-year period.*

The median donor age was 51 in 2006 as compared with 50 in 2005. Looking at 5 years intervals, the median donor age is steadily increasing at all centres (Figure 4).

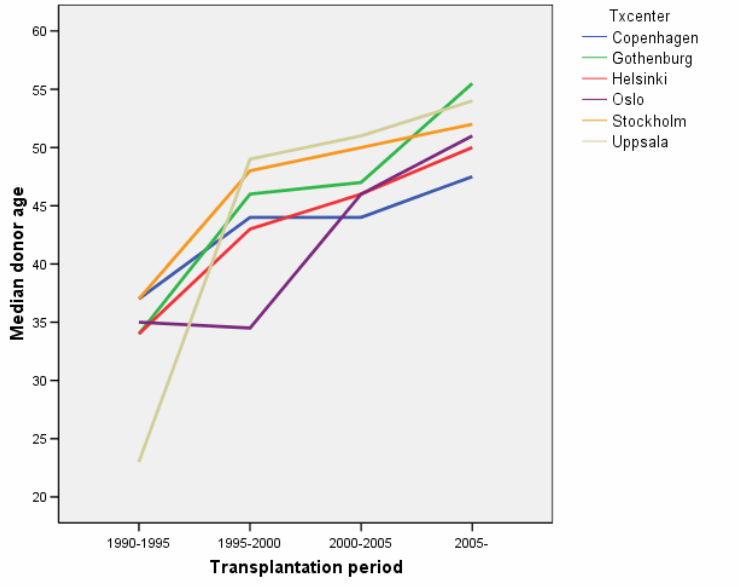


Figure 4. *Donor age per 5-year period.*

The fraction of first allograft recipients above 60 years of age increased from 1995-2000, but now seems rather stable (Figure 5). The fraction of children <5 years of age at first liver transplantation show no particular trend (Figure 5).

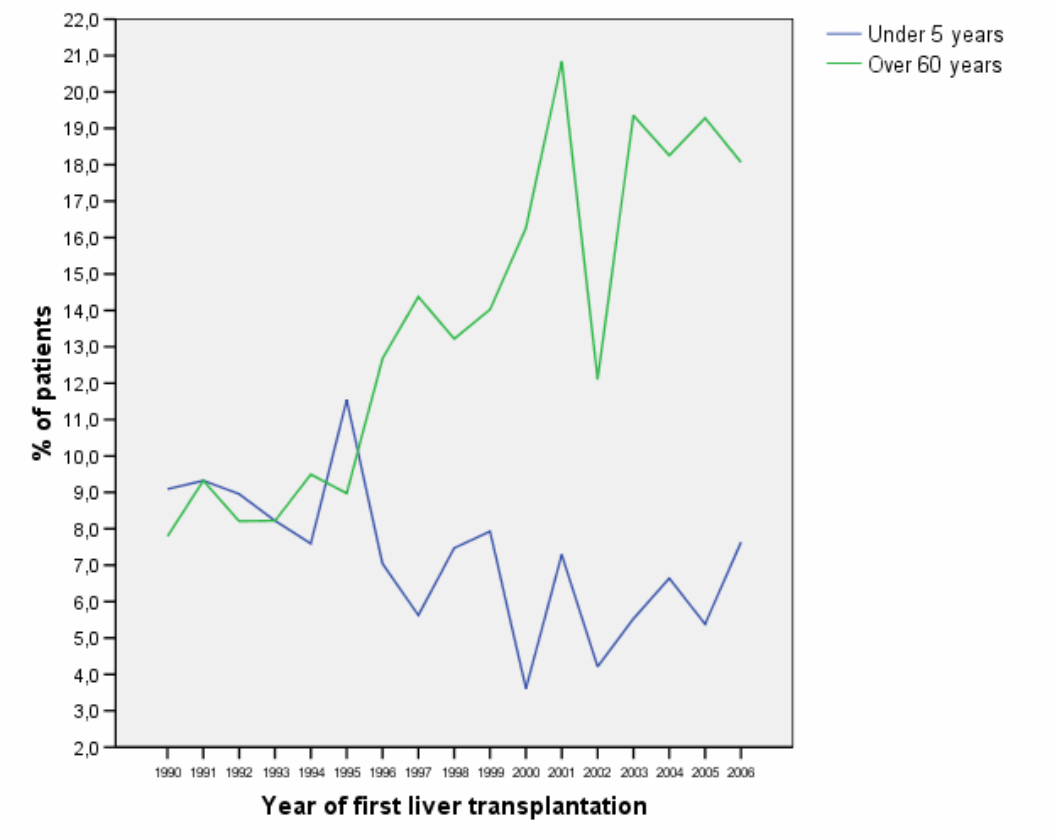


Figure 5. *Fraction of patients <5 and >60 years at first liver transplantation.*

There are only minor differences in donor and recipient age, and the fraction of old (>60 years) or very young (<5 years) recipients between the centres in 2006 (Table 6). There are marked differences in the fraction of old (>60 years) or very young (<5 years) recipients between the different transplantation centres (Table 6).

Table 6. *Age at first liver transplantation for donor and recipient (years) along with fraction of recipients <5 and >60 years.*

	Median donor age	*Median recipient age*	*% above 60 years (n)*	*% below 5 years (n)*
Copenhagen	42	48	15.6 (5)	6.3 (2)
Gothenburg	57	52	25.0 (13)	3.8 (2)
Helsinki	51	49	10.2 (5)	12.2 (6)
Oslo	51	49	19.2 (10)	9.6 (5)
Stockholm	51	52	14.3 (8)	7.1 (4)
Uppsala	42	60	50 (4)	0 (0)

6. Diagnoses

Primary sclerosing cholangitis (PSC) is still the leading diagnosis among patients listed for the first liver transplantation in the Nordic countries in 2006 (Table 7), closely followed by alcoholic liver cirrhosis, post-hepatitis C cirrhosis, malignant diseases (e.g. hepatocellular carcinoma) and primary biliary cirrhosis (PBC). The number of patients with post-hepatitis C cirrhosis, alcoholic liver cirrhosis and malignant liver diseases has increased markedly over the last 10 years (Table 7).

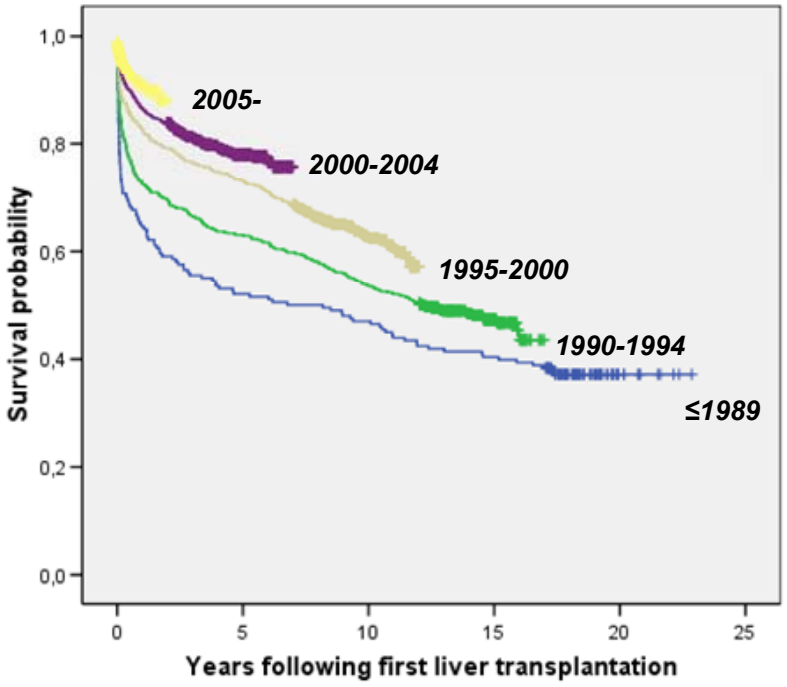
Table 7. *Diagnoses of patients accepted on the waiting list 1996-2006 (first allograft).*

	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
PSC	26	31	24	21	28	37	32	37	42	36	33
Alcoholic liver cirrhosis	15	21	28	13	21	21	29	24	25	26	30
Post-hepatitis C cirrhosis	4	11	17	18	15	11	22	23	26	23	29
Malignant disease	10	12	20	12	17	15	15	20	27	20	29
Acute liver failure	12	23	18	20	16	32	15	26	21	15	28
PBC	13	15	16	16	18	11	8	17	18	15	23
Other liver diseases (grouped)	18	13	14	13	11	21	17	20	20	18	22
Biliary atresia	10	5	8	8	6	12	6	9	10	11	12
Cryptogenic cirrhosis	7	9	4	5	9	7	7	10	8	9	11
Autoimmune cirrhosis	9	5	1	10	6	4	10	7	12	12	8
Metabolic liver disease	7	6	15	15	11	9	10	9	14	20	8
Budd-Chiari	6	1	5	3	0	5	4	1	2	2	5
Post-hepatitis B cirrhosis	4	5	5	8	6	4	8	5	11	5	5
Diagnosis missing	0	0	0	1	0	1	7	8	4	11	5

7. Patient survival

When looking at 5-years intervals, patient survival (defined as time from the first liver transplantation until death) has constantly improved and is still improving (Figure 6). The 1-year survival rate for patients receiving a liver allograft in 2005 was 90%.

Figure 6. *Kaplan-Meier patient survival curves per 5-years period.*



The one year survival rate for patients receiving their first liver allograft >60 years of age in 2005 was 83% and the long term survival probability for this patient group is constantly improving when 5-year intervals are considered (Figure 7).

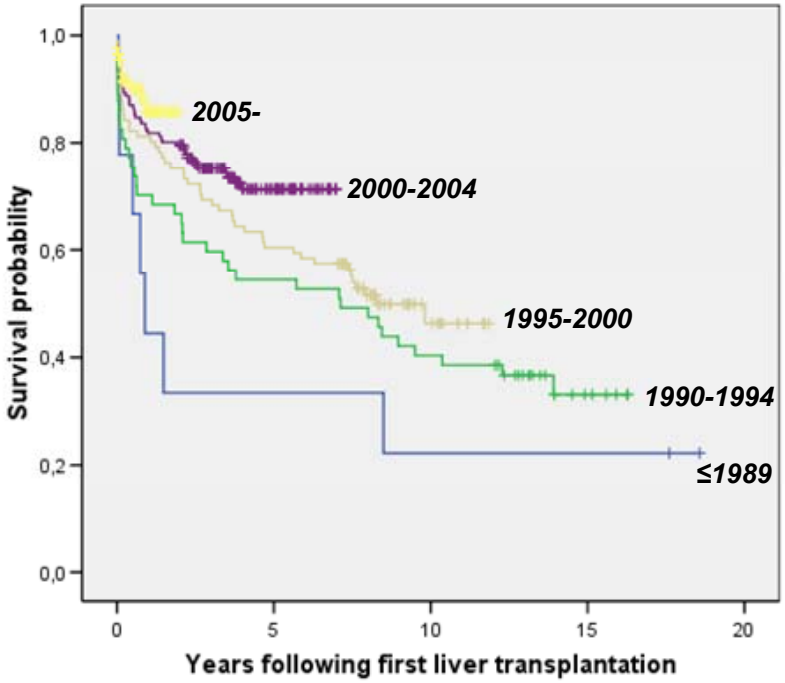


Figure 7. *Kaplan-Meier patient survival curves for patients over 60 years per 5-years period.*

There are distinct differences in patient survival rates according to diagnosis. Inferior long term survival is notable for patients receiving a liver allograft on the basis of malignant disease, hepatitis C cirrhosis and acute liver failure (Table 8).

Table 8. *Patient survival rates (1 year and 5 years) according to diagnosis and period of transplantation (2005 and the entire period 2000-2006). Age at first liver transplantation as well as re-transplantation rate for the same period is given for each diagnosis.*

	2005	2000-2006		2000-2006	2000-2006
	% (1 year survival)	% (1 year survival)	% (5 years survival)	Median age (years)	Re-TX rate
Acute liver failure	66.7	79.6	73.6	43	12.3%
Alcoholic liver cirrhosis	88.5	89.9	78.3	55	6.3%
Biliary atresia	81.8	83.0	79.2	1	9.1%
Budd-Chiari	100	89.5	89.5	40	5.3%
Cryptogenic cirrhosis	88.9	88.4	88.4	52	1.6%
Malignant disease	80.0	80.3	59.2	55	7.0%
Metabolic liver disease	100	92.5	89.7	47	3.7%
Post-hepatitis C cirrhosis	95.0	80.3	64.0	53	7.4%
Post-hepatitis B cirrhosis	100	100	91.8	50	6.8%
PBC	86.7	92.0	83.4	57	5.5%
PSC	97.2	91.9	85.6	45	8.6%

8. Maintenance of the registry

Most centres are relatively up to date with data entry, and waiting list/transplantation status and survival data for all patients are now complete for 2006. Quality control of existing data and ensuring completeness of remaining parameters is a continuous priority. Coordination and responsibility regarding data content has been transferred from Bjørn Brandsæter to Tom Hemming Karlsen at Rikshospitalet in Oslo from 2007 onwards. Kristian Bjøro at Rikshospitalet in Oslo remains the senior supervisor for this work.

In collaboration with Frank Pedersen and Christian Mondrup at Scandiatransplant a four stage revision of the existing data structure of the NLTR is in process:

1) Suggestions for changes in the existing registration forms were discussed via e-mail involving contact persons at all transplantation centres in the period 16.11.06-12.12.06. Main aims were to simplify the existing forms, add necessary aspects and remove/update obsolete objects while preserving present layout. Kristian Bjøro and Tom Hemming Karlsen discussed limitations/prospects of the revisions with Frank Pedersen at Scandiatransplant in Aarhus 12.02.07.

2) The revised forms were conclusively discussed in Helsinki 13.03.07. Main aims were to preserve a core of "hard data" (e.g. survival, diagnoses etc.) in the NLTR, add aspects for follow-up (for which incomplete data exists as of today) and ensure compatibility with the European Liver Transplant Registry. This strategy resulted in new forms (see Appendix) likely to ensure the future of the NLTR as a basis for collaboration between the Nordic liver transplantation centres, not least scientifically in terms of the increased sample-size/statistical power. Detailed data not available in the NLTR will be maintained in local registries (e.g. the HUSLTR from Helsinki).

3) Implementation of the revised forms (software) started at Scandiatransplant April 2007. In parallel, work was initiated in Helsinki to enable future data transfer between the HUSLTR and the NLTR.

4) Use of the new forms at the individual transplantation centres will be initiated as soon as the software is updated. A particular challenge is the logistics of ensuring complete follow-up data for the patients (Form C).

10. Acknowledgements - financial support

The maintenance of the software has been performed by Scandiatransplant. We are extremely grateful for the help and support from Frank Pedersen and Christian Mondrup in Aarhus. Without their assistance it would not have been possible to maintain the registry. Transplant nurses and transplant coordinators at the individual centres have also made an enormous effort in updating and maintaining the registry. The existence of the registry depends completely on their work and dedication. Because of the organizational changes, the registry only applied for partial financial support from Roche in 2006.

11. Organisation and data ownership

It should be emphasised that the registry (software) is the property of Scandiatransplant, while the data in the registry are the property of the Nordic Liver Transplantation Group. Utilisation of data should be censored by the latter. The data presented here should not be used without permission from the Nordic Liver Transplantation Group.

12. Publications based on the NLTR 1990-2006

Full length articles:

1. Keiding S, Ericzon BG, Eriksson S, Flatmark A, Hockerstedt K, Isoniemi H, Karlberg I, Keiding N, Olsson R, Samela K, Schrumpf E. Survival after liver transplantation of patients with primary biliary cirrhosis in the Nordic countries. Comparison with expected survival in another series of transplantations and in an international trial of medical treatment. Scand J Gastroenterol 1990; 25:11-8
2. Hockerstedt K, Ericzon BG, Eriksson LS, Flatmark A, Isoniemi H, Karlberg I, Keiding N, Keiding S, Olsson R, Samela K. Survival after liver transplantation for primary biliary cirrhosis: use of prognostic indices for comparison with medical treatment. Transpl Proc 1990; 22:1499-500

3. Hockerstedt K, Isoniemi H, Ericzon BG, Broome U, Friman S, Persson H, Bergan A, Schrumpf E, Kirkegaard P, Hjortrup A. Is a 3-day waiting list appropriate for patients with acute liver failure? Transpl Proc 1994;26:1786-7
4. Bjøro K, Friman S, Höckerstedt K, Kirkegaard P, Keiding S, Schrumpf E, Olausson M, Oksanen A, Isoniemi H, Hjortrup A, Bergan A, Ericzon BG. Liver transplantation in the Nordic countries, 1982-1998: Changes of indications and improving results. Scand J Gastroenterol 1999;34:714-722
5. Bjøro K, Höckerstedt K, Ericzon BG, Friman S, Hjortrup A, Keiding S, Schrumpf E, Duraj F, Olausson M, Mäkisalo H, Bergan A, Kirkegard P. Liver transplantation in patients over 60 years of age. Transpl Int 2000; 13, 165-170
6. Bjøro K, Kirkegaard P, Ericzon BG, Friman S, Schrumpf E, Isoniemi H, Herlenius G, Olausson M, Rasmussen A, Foss A, Höckerstedt K. Is a 3-day limit for highly urgent liver transplantation for fulminant hepatic failure appropriate – or is the diagnosis in some cases incorrect? Transpl Proceed 2001;33:2511-3
7. Ericzon BG, Bjøro K, Höckerstedt K, Hansen B, Olausson M, Isoniemi H, Kirkegaard P, Broome U, Foss A, Friman S. Time to request AB0-identity when transplanting for fulminant hepatic failure? Transpl Proc 2001;33:3466-7
8. Leidenius M, Broome U, Ericzon B-E, Friman S, Olausson M, Schrumpf E, Höckerstedt K. Hepatobiliary carcinoma in primary sclerosing cholangitis: a case control study. J Hepatol 2001; 34: 792-8.
9. Olausson M, Mjornstedt L, Backman L, Lindner P, Olsson R, Krantz M, Karlsen KL, Stenqvist O, Henriksson BA, Friman S. Liver transplantation--from experiment to routine care. Experiences from the first 500 liver transplantations in Gothenburg. Lakartidningen 2001;98:4556-62
10. Brandsæter B , K Höckerstedt, BG Ericzon, S Friman, P Kirkegaard, H Isoniemi, Foss A, Olausson M, Hansen B, Bjøro K: Outcome following listing for liver transplantation due to fulminant hepatic failure in the Nordic countries. Liver Transplantation 2002;8:1055-62
11. Bjøro K, Ericzon BG, Kirkegaard P, Höckerstedt K, Söderdahl G, Olausson M, Foss A, Schmidt LE, Brandsæter B, Friman S. Liver transplantation for fulminant hepatic failure: impact of donor-recipient ABO-matching on the outcome. Transplantation 2003; 75:347-53
12. Brandsæter Bjørn, Broomé Ulrika, Isoniemi Helena, Friman Styrbjörn, Hansen Bent, Schrumpf Erik, Oksanen Antti, Ericzon Bo-Göran, Höckerstedt Krister, Mäkisalo Heikki, Olsson Rolf, Olausson Michael, Kirkegaard Preben, Bjøro Kristian. Liver transplantation for primary sclerosing cholangitis in the Nordic countries: outcome after acceptance to the waiting list. Liver Transpl. 2003;9:961-9.
13. Brandsaeter B, Friman S, Broome U, Isoniemi H, Olausson M, Backman L, Hansen B, Schrumpf E, Oksanen A, Ericzon BG, Hockerstedt K, Makisalo H, Kirkegaard P, Bjoro K.Outcome following liver transplantation for primary sclerosing cholangitis in the Nordic countries. Scand J Gastroenterol. 2003;38:1176-83.
14. Brandsaeter B, Isoniemi H, Broome U, Olausson M, Backman L, Hansen B, Schrumpf E, Oksanen A, Ericzon BG, Hockerstedt K, Makisalo H, Kirkegaard P, Friman S, Bjoro K. Liver transplantation for primary sclerosing cholangitis; predictors and consequences of hepatobiliary malignancy. J Hepatol. 2004;40:815-822.

15. Bjøro K, Schrumpf E. Liver transplantation for primary sclerosing cholangitis. J Hepatol. 2004;40:570-7.
16. Brandsaeter B, Isoniemi H, Broomé U, Olauson M, Bäckmann L, Hansen B, Oksanen A, Ericzon BG, Höckerestedt K, Mäkisalo H, Kirkegaard P, Frimann S, Bjøro K, Schrumpf E (Nordic Liver Transplantation Group). Chemopreventive effect of ursodeoxycholicacid in primary sclerosing cholangitis? Falk Symposium 141. Bile Acid Biology and its Therapeutic Implications. XVIII International Bile Acid Meeting (page 242-249).
17. Melum E, Schrumpf E, Bjøro K. Liver TX for hepatitis C cirrhosis in a low prevalence population: risk factors and status at evaluation. Scand J Gastroenterol. 2006;41:592-6.
18. Bjøro K, Brandsaeter B, Foss A, Schrumpf E. Liver transplantation in primary sclerosing cholangitis. Semin Liver Dis. 2006;26:69-79.

Abstracts:

16. Bjøro K, Keiding S, Ericzon BG, Friman S, Olausson M, Kirkegaard P, Hjortrup A, Höckerstedt K, Isoniemi H, Bergan A, Schrumpf E. The Nordic liver transplant registry. Organisation and outcome of 1160 patients accepted for liver transplantation 1990-1996. Scandinavian Congres for Organ transplantation, Oslo 1997, abstract
17. Bjøro K, Keiding S, Ericzon BG, Friman S, Olausson M, Kirkegaard P, Hjortrup A, Höckerstedt K, Isoniemi H, Bergan A, Schrumpf E. Indication for liver transplantation in the Nordic countries during 1982-1996. Scandinavian Congress for Organ transplantation, Oslo 1997, abstract
18. Bjøro K, Olsson R, Broome U, Höckerstedt K, Schrumpf E, Kirkegaard P, Isoniemi H, Ericzon BG, Olausson M, Hansen B, Bergan A, Friman S. Liver transplantation for primary sclerosing cholangitis (PSC). 9th Congress of the European Society for Organ transplantation, Oslo 1999, abstract no 52
19. Höckerstedt K, Ericzon BG, Bjøro K, Friman S, Hjortrup A, Keiding S, Schrumpf E, Duraj F, Olausson M, Mäkisalo H, Bergan A, Kirkegaard P. Liver transplantation in patients above 60 years of age. 9th Congress of the European Society for Organ transplantation, Oslo 1999, abstract no 1177
20. Bjøro K, Keiding S, Friman S, Ericzon BG, Kirkegaard P, Schrumpf E, Olausson M, Broome U, Isoniemi H, Hansen B, Bergan A, Höckerstedt K. Outcome of patients listed for liver transplantation in the Nordic countries 1990-1998. 9th Congress of the European Society for Organ transplantation, Oslo 1999, abstract no 1178
21. Bjøro K, Kirkegaard P, Ericzon BG, Schrumpf E, Isoniemi H, Söderdahl G, Olausson M, Hansen B, Foss A, Höckerstedt K. Liver transplatnation for fulminant hepatic failure in the Nordic countries 1990-1999. XVII International Congress of the Transplantation Society, Rome 2000, abstract no 783
22. Bjøro K, Kirkegaard P, Ericzon BG, Friman S, Schrumpf E, Isoniemi H, Herlenius G, Olausson M, Rasmussen A, Foss A, Höckerstedt K. Is a 3-day limit for highly urgent liver transplantation for fulminent hepatic failure appropriate - or is the diagnosis in some cases incorrect. Scandinavian Congress for organ transplantation, Helsinki 2000, abstract
23. Foss A, Höckerstedt K, Ericzon BG, Friman S, Kirkegaard P, Bergan A, Mäkisalo H, Söderdahl G, Olausson M, Hansen B, Bjøro K. Improved outcome after liver

transplantation for fulminant hepatic failure during 1990 to 1999. Scandinavian Congress for organ transplantation, Helsinki 2000, abstract
24. Brandsæter B, Höckerstedt K, Hansen B, Ericzon BG, Bjøro K, Olausson M, Isoniemi H, Kirkegaard P, Söderdahl G, Foss A, Friman S. Fulminant hepatic failure – outcome after listing for highly urgent liver transplantation – impact of AB0 blood type. 36th Annual meeting European Association for the Study of Liver Diseases, Prague 2001, abstract no 1423
25. Bjøro K, Höckerstedt K, Friman S, Kirkegaard BG, Ericzon BG. Outcome after listing for highly urgent liver transplantation – impact of AB0 blood type. Joint Meeting of International Liver Transplantation Society and European Liver Transplantation Association. Berlin 2001, abstract no 91
26. Ericzon BG, Bjøro K, Höckerstedt K, Hansen B, Olausson M, Isoniemi H, Kirkegaard P, Söderdaghl G, Foss A, Friman S. Time to request AB0-identity when transplanting for fulminant hepatic failure? Transpl Odysse, Istanbul, August 2001
27. Brandsæter B. Outcome of liver transplantation for primary sclerosing cholangitis in the Nordic countries. Second European Transplant Fellow Workshop. Zürich, 2001;30.11-01.12.
28. Brandsæter B, Friman S, Ericzon BG, Höckerstedt K, Kirkegaard P, Olausson, Broome U, Isoniemi H, Hansen B, Schrumpf E, Bjøro K. Outcome following listing for liver transplantation in primary sclerosing cholangitis. European Assoc for the Study of Liver Disease, Madrid, April 2002
29. Brandsæter B, Broomé, Isoniemi He, Friman S, Hansen B, Schrumpf E, Oksanen A, Ericzon, B, Höckerstedt K, Mäkisalo H, Olsson R, Olausson Ml, Kirkegaard P, Bjøro K Primary sclerosing cholangitis in the Nordic countries – survival after liver transplantation. The XXIV Nordic Meeting of Gastroenterology, Aarhus May 2002
30. K Bjoro, K Höckerstedt, S Friman, BG Ericzon, L Schmidt, B Brandsæter, H Isoniemi, M Olausson, G Söderdahl, A Foss, P Kirkegaard. Fulminant hepatic failure – outcome following liver transplantation. The XXIV Nordic Meeting of Gastroenterology, Aarhus May 2002.
31. Brandsæter B, Broomé U, Isoniemi H, Friman S, Schrumpf E, Oksanen A, Ericzon BG, Höckerstedt K, Mäkisalo H, Olsson R, Olausson Michael, Kirkegaard P, Hansen B, Bjøro K. Hepatobiliary malignancies in patients with primary sclerosing cholangitis accepted on the Nordic liver transplantation waiting list. The XXV Nordic Meeting of Gastroenterology, June 11-14, 2003. Helsinki, Finland.
32. Brandsæter B, Isoniemi H, Broomé U, Olausson M, Bäckman L, Hansen B, Oksanen A, Ericzon BG, Höckerstedt K, Mäkisalo H, Kirkegaard P, Friman S, Bjøro K, Schrumpf E. Chemopreventive effect of URSO in PSC? The XVIII International Bile acid meeting. Falk symposium no 141. June 18-19, 2004. Stockholm Sweden.
33. E Melum, S Friman, H Gjertsen, H Isoniemi, P Kirkegaard, L Bäckman, M Olausson, U Broomé , F Duraj, K Bjøro, BG Ericzon. Liver transplantation for HCV cirrhosis in the Nordic countries, a rising indication in a low prevalence area. The XXXVII Nordic Meeting of Gastroenterology, May 3-5, 2006. Västerås, Sweden
34. L Bäckman, E Melum, S Friman, H Gjertsen, H Isoniemi, P Kirkegaard, M Olausson, U Broomé , F Duraj, K Bjøro, BG Ericzon. Liver transplantation for HCV cirrhosis in the Nordic countries, a rising indication in a low prevalence area. The XXII congress of The Scandinavian Transplantation Society, May 10-12, 2006, Göteborg, Sweden.

Appendix

REGISTRATION FORM
THE NORDIC LIVER TRANSPLANT REGISTRY

FORM A ACCEPTANCE

Social security number_____
Surname_____ First name_____
Weight_____ kg
Height _____ cm
A1A2B0 blood group _____

Date of acceptance ____ ____ ____ (d m y)

Diagnosis first liver transplantation (see list of diagnoses page 1):

Primary diagnosis _____

Secondary diagnoses _____

Diagnosis re-transplantation (see list of diagnoses page 2):

Retransplantation diagnosis _____

Previous malignancy ____ (N/Y)
- Type: _____ (lymphoproliferative [LPD] or other)
- Year: _____

Events (at <u>any time</u> up to acceptance):		***Events at acceptance on waiting list (within +/- 2 weeks):***	
Encephalopathy	____ (N/1-4)	In hospital	_____ (N/Y) (except control)
Variceal bleeding	____ (N/Y)		
Ascites	____ (N/Y)	Ventilator	_____ (N/Y)

REGISTRATION FORM
THE NORDIC LIVER TRANSPLANT REGISTRY

FORM A cont.

At acceptance on waiting list (within +/- 2 weeks for non-acute patients, within a few days for acute patients)

Biochemistry:			Alternate unit
Hemoglobin	_____	g/100ml	_____ mmol/l
Thrombocytes	_____	10^9/l	
INR	_____		
ALAT	_____	U/l	_____ microkat/l
ASAT	_____	U/l	_____ microkat/l
Albumin	_____	g/l	_____ micromol/l
Bilirubin	_____	µmol/l	
Creatinine	_____	µmol/l	
Urea	_____	mmol/l	
Hemodialysis	_____	(N/Y)	(for MELD/PELD)

Serology:	
Anti CMV IgG	___ (+/-/ND)
Hepatitis Bs antibody	___ (+/-/ND)
Hepatitis Bc antibody	___ (+/-/ND)
Hepatitis Bs antigen	___ (+/-/ND)
Hepatitis Be antigen	___ (+/-/ND)
Hepatitis B DNA PCR	___ (+/-/ND)
Hepatitis C antibody	___ (+/-/ND)
Hepatitis C RNA PCR	___ (+/-/ND)
Anti HIV antibodies	___ (+/-/ND)
EBV IgG	___ (+/-/ND)
Hepatitis C genotype	___

Alfa-1-foetoprotein	_____	µ/L
CA19-9	_____	U/mL
CEA	_____	ng/ml

REGISTRATION FORM
THE NORDIC LIVER TRANSPLANT REGISTRY

FORM B TRANSPLANTATION

Scandiatransplant no. _____ Social security number _____
Surname _____ First name _____
Weight _____ kg Height _____ cm (only if age < 18 years)

Transplantation date ____ ____ ____ (d m y)

Simultaneous transplantations (state "Y" only if performed):

Heart	___	(Y)
Kidney	___	(Y)
Pancreas	___	(Y)
Small Bowel	___	(Y)
Lung	___	(Y)
Pancreatic islets	___	(Y)
Bone marrow	___	(Y)

At Transplantation:

Encephalopathy	___	(N/1-4)
In hospital	___	(N/Y) (except for control)
Ventilator	___	(N/Y)
Artificial liver supp.	_____	(N/MARS/Prometheus), no. treatments: __

Biochemistry:

			Alternate unit
Hemoglobin	_____	g/100ml	_____ mmol/l
Thrombocytes	_____	10^9/l	
INR	_____		
ALAT	_____	U/l	_____ microkat/l
ASAT	_____	U/l	_____ microkat/l
Albumin	_____	g/l	_____ micromol/l
Bilirubin	_____	µmol/l	
Creatinine	_____	µmol/l	
Urea	_____	mmol/l	
Hemodialysis	_____	(N/Y)	(for MELD/PELD)

Pre-pathology: Liver tumor diagnosed _____ (N/Y)
Post-pathology: Liver tumor diagnosed _____ (N/Y)
Type _____ HCC/CC/other; comment: _____
Number _____
Diameter _____ (mm, largest lesion)
Extrahepatic growth _____ (N/Y)

REGISTRATION FORM
THE NORDIC LIVER TRANSPLANT REGISTRY

FORM B cont.

Donor:

Deceased/living Donor	_____ (CDT/LDT/domino)
Harvesting center	_____
Sex	____ (M/F)
Age	____ years
A1A2BO Blood group	____ (if no A subgroup available, state A)
Weight	____ kg Heigth _____ cm
Perfusion	____ (UW / Custodiol / Celsior / Other: _____)

Donor serology:

Anti CMV IgG	___ (+/-)
Hepatitis Bs antibody	___ (+/-/ND)
Hepatitis Bc antibody	___ (+/-/ND)
Hepatitis Bs antigen	___ (+/-/ND)
Hepatitis Be antigen	___ (+/-/ND)
Hepatitis C antibody	___ (+/-)
EBV IgG	___ (+/-)

Operation:

Whole/partial/split liver	_____ (W/P/S)
Liver segments	_____ (I,II,III,IV...)
Cold ischemia time	_____ hours (whole numbers)
Biliary anastomosis	_____ (Chol-cholstomy, Chol-jejenostomy)
Piggy-back	_____ (N/Y)

Immunosuppression (during first month) – check box:

- ☐ *glucocorticoids (GLU)*
- ☐ *tacrolimus (FK)*
- ☐ *everolimus (EVE)*
- ☐ *sirolimus (SIR)*
- ☐ *cyclosporine A (CSA)*
- ☐ *azathioprine (AZA)*
- ☐ *mycophenolatmofetile (MMF)*
- ☐ *anti-thymocyte globulin (ATG)*
- ☐ *anti-CD3 antibodies (OKT)*
- ☐ *basiliximab (BAS)*
- ☐ *daclizumab (DAC)*
- ☐ *other (OTH)*

REGISTRATION FORM
THE NORDIC LIVER TRANSPLANT REGISTRY

FORM C FOLLOW-UP ADMISSION

(Minimum use: 1, 3, 5, 10, 15, 20, 25, 30 years controls)

Scandiatransplant no. _____ Social security number _____
Surname _____ First name _____
Weight _____ kg Height _____ cm (only if age < 18 years)

Date at follow-up: ____ ____ ____ (d m y)

Biochemistry:			Alternate unit
INR	_____		
Bilirubin	_____	µmol/l	
Albumin	_____	g/l	_____ micromol/l
Creatinine	_____	µmol/l	
Hemodialysis	_____	(N/Y)	(for MELD/PELD)

Immunosuppression (at follow-up) – check box:

- □ *glucocorticoids (GLU)*
- □ *tacrolimus (FK)*
- □ *everolimus (EVE)*
- □ *sirolimus (SIR)*
- □ *cyclosporine A (CSA)*
- □ *azathioprine (AZA)*
- □ *mycophenolatmofetile (MMF)*
- □ *anti-thymocyte globulin (ATG)*
- □ *anti-CD3 antibodies (OKT)*
- □ *basiliximab (BAS)*
- □ *daclizumab (DAC)*
- □ *other (OTH)*

Events (since last control):

Acute rejections (treated) ____ (N/Y), how many: _____
Recurrent disease ____ (N/Y)
Portal vein thrombosis (total) ____ (N/Y or doppler not done - DND)
A. hepatica thrombosis (total) ____ (N/Y or doppler not done - DND)
Biliary strictures (treated) ____ (N/Y)
Liver tumor ____ (N/Y), comment: _____
Extrahepatic malignancy ____ (N/Y), comment: _____
New onset diabetes (insulin) ____ (N/Y)
New onset renal failure ____ (N/Y),
- If yes: medical treatment only (MTO)/dialysis/tx: _____
Transplant other organ ____ (N/Y), comment: _____
Children (numbers) ____ (state for both females and males)

REGISTRATION FORM
THE NORDIC LIVER TRANSPLANT REGISTRY

FORM D DEAD (all patients)

Scandiatransplant no. _____
Social security number _____

Surname _____
First name _____

Date of survival status ____ ____ ____ (d m y)

Survival status _____ (dead/alive)

For dead patients:

Date of death ____ ____ ____ (d m y)

Cause of death (see list of diagnoses page 2):

Primary cause _____

Secondary causes _____

_____

_____

LIST OF DIAGNOSES
THE NORDIC LIVER TRANSPLANT REGISTRY

Page 1 - diagnoses - first liver transplantation

A1	Acute hepatic failure	Fulminant or subfulminant hepatitis	Virus A
A2	Acute hepatic failure	Fulminant or subfulminant hepatitis	Virus B
A3	Acute hepatic failure	Fulminant or subfulminant hepatitis	Virus C
A4	Acute hepatic failure	Fulminant or subfulminant hepatitis	Virus D
A5	Acute hepatic failure	Fulminant or subfulminant hepatitis	Other known
A6	Acute hepatic failure	Fulminant or subfulminant hepatitis	Other unknown
A7	Acute hepatic failure	Fulminant or subfulminant hepatitis	Paracetamol
A8	Acute hepatic failure	Fulminant or subfulminant	Other drug related
A9	Acute hepatic failure	Fulminant or subfulminant	Toxic (non-drug)
A91	Acute hepatic failure	Fulminant or subfulminant	Heat shock
A10	Acute hepatic failure	Post-operative	
A11	Acute hepatic failure	Post traumatic	
A12	Acute hepatic failure	Other	
A13	Subacute hepatitis	Virus A	
A14	Subacute hepatitis	Virus B	
A15	Subacute hepatitis	Virus C	
A16	Subacute hepatitis	Virus D	
A17	Subacute hepatitis	Other known	
A18	Subacute hepatitis	Other unknown	
A19	Subacute hepatitis	Paracetamol	
A20	Subacute hepatitis	Other drug related	
A21	Subacute hepatitis	Toxic (non-drug)	
B1	Cholestatic disease	Secondary biliary cirrhosis	
B2	Cholestatic disease	Primary biliary cirrhosis	
B3	Cholestatic disease	Primary sclerosing cholangitis	
B4	Cholestatic disease	Others	
C1	Congenital biliary disease	Caroli disease	
C2	Congenital biliary disease	Extrahepatic biliary atresia	
C3	Congenital biliary disease	Congenital biliary fibrosis	
C4	Congenital biliary disease	Choledochal cyst	
C5	Congenital biliary disease	Alagille syndrome	
C6	Congenital biliary disease	Others	
D1	Cirrhosis	Alcoholic	
D2	Cirrhosis	Autoimmune	
D3	Cirrhosis	Virus B	
D4	Cirrhosis	Virus C	
D5	Cirrhosis	Virus BD	
D6	Cirrhosis	Virus BC	
D7	Cirrhosis	Virus BCD	
D71	Cirrhosis	Combined virus C and alcoholic cirrhosis	
D72	Cirrhosis	Combined virus B and alcoholic cirrhosis	
D73	Cirrhosis	Virus E related cirrhosis	
D8	Cirrhosis	Virus Other	
D9	Cirrhosis	Drug related	
D10	Cirrhosis	Other	
D11	Cirrhosis	Unknown cause	
E1	Cancers	Hepatocellular carcinoma and cirrhosis	
E2	Cancers	Hopatocellular carcinoma and non-cirrhotic liver	
E3	Cancers	Hepatocellular carcinoma - Fibrolamellar	
E4	Cancers	Biliary tract carcinoma (Klatskin)	
E5	Cancers	Hepatic cholangiocellular carcinoma	
E6	Cancers	Hepatoblastoma	
E7	Cancers	Epithelioid hemangioendotelioma	
E8	Cancers	Angiosarcoma	
E9	Cancers	Secondary liver tumors - Carcinoid	
E10	Cancers	Secondary liver tumors - Other neuroendocrine	
E11	Cancers	Secondary liver tumors - Colorectal	
E12	Cancers	Secondary liver tumors - GI non colorectal	
E13	Cancers	Secondary liver tumors - Non gastrointestinal	
E14	Cancers	Other liver malignancies	
F1	Metabolic diseases	Wilson	
F2	Metabolic diseases	Haemochromatosis	
F3	Metabolic diseases	Antitrypsin deficiency	
F4	Metabolic diseases	Glycogen storage disease	
F5	Metabolic diseases	Hypercholesterolemia	
F6	Metabolic diseases	Tyrosinemia	
F7	Metabolic diseases	Familial amyloidotic polyneuropathy	
F8	Metabolic diseases	Primary oxaluria	
F9	Metabolic diseases	Protoporphyria	
F91	Metabolic diseases	NASH	
F10	Metabolic diseases	Other Porphyria	
F11	Metabolic diseases	Crigler-Najjar	
F12	Metabolic diseases	Cystic fibrosis	
F13	Metabolic diseases	Byler disease	
F14	Metabolic diseases	Others	
G	Budd-chiari		
H1	Benign liver tumors or polycystic disease	Hepatic adenoma	
H2	Benign liver tumors or polycystic disease	Adenomatosis	
H3	Benign liver tumors or polycystic disease	Hemangioma	
H4	Benign liver tumors or polycystic disease	Focal Nodular Hyperplasia	
H5	Benign liver tumors or polycystic disease	Polycystic disease	
H6	Benign liver tumors or polycystic disease	Nodular regenerative hyperplasia	
H7	Benign liver tumors or polycystic disease	Other benign tumor	
I1	Parasitic disease	Schistosomia	
I2	Parasitic disease	Alveolar echinococcosis	
I3	Parasitic disease	Cystic hydatidosis	
I4	Parasitic disease	Other	
J	Other liver disease		
K	Not available		
L	TPN-induced cholestasis		
M	Hepatopulmonary syndrome		
N	Microangiopathy		
O	Small for size syndrome		

LIST OF DIAGNOSES
THE NORDIC LIVER TRANSPLANT REGISTRY

Page 2 – diagnoses – re-transplantation or death

A1	Intraoperative (death on table)		
B1	Infection	Bacterial infection	
B2	Infection	Viral infection	
B3	Infection	HIV	
B4	Infection	Fungal infection	
B5	Infection	Parasitic infection	
B6	Infection	Other	
C1	Liver complications	Acute rejection	
C2	Liver complications	Chronic rejection	
C3	Liver complications	Arterial thrombosis	
C4	Liver complications	Hepatic vein thrombosis	
C41	Liver complications	Early portal vein thrombosis	
C42	Liver complications	Outflow impairment	
C5	Liver complications	Primary non-function (≤7 days)	
C6	Liver complications	Primary dys-function (>7 days)	
C61	Liver complications	Small for size syndrome	
C7	Liver complications	Anastomotic biliary complication	
C8	Liver complications	Non-anastomotic biliary complication	
C9	Liver complications	Recurrence of original disease	Virus B
C10	Liver complications	Recurrence of original disease	Virus C
C11	Liver complications	Recurrence of original disease	Virus D
C12	Liver complications	Recurrence of original disease	Alcoholic
C13	Liver complications	Recurrence of original disease	PBC
C14	Liver complications	Recurrence of original disease	PSC
C15	Liver complications	Recurrence of original disease	Autoimmune
C16	Liver complications	Recurrence of original disease	Budd-Chiari
C17	Liver complications	Recurrence of original disease	Other
C18	Liver complications	De novo Virus B	
C19	Liver complications	De novo Virus C	
C20	Liver complications	De novo Virus D	
C21	Liver complications	Massive hemorrhagic necrosis	
C22	Liver complications	Other viral hepatitis	
C23	Liver complications	Infection	
C24	Liver complications	Other	
D1	Gastrointestinal complications - GI hemorrhage		
D2	Gastrointestinal complications - Pancreatitis		
D3	Gastrointestinal complications - Visceral perforation		
D4	Gastrointestinal complications - Other		
E1	Cardiovascular complications - Myocardial Infarction		
E2	Cardiovascular complications - Other		
F1	Cerebrovascular complications - Intracranial hemorrhage		
F2	Cerebrovascular complications - Ischaemic stroke		
F3	Cerebrovascular complications - Cerebral oedema		
F4	Cerebrovascular complications - Cerebral infarction		
G1	Tumor	Recurrence of original tumor	
G2	Tumor	Recurrence of previously unrelated tumor	
G3	Tumor	De novo solid organ tumor	
G4	Tumor	Donor transmitted tumor	
G5	Tumor	Lymphoproliferative disease	
H1	Renal failure		
H2	Urinary tract infection		
I1	Pulmonary complications - Embolism		
I2	Pulmonary complications - Infection		
J1	Social complications	Non compliance immunosuppression	
J2	Social complications	Suicide	
J3	Social complications	Trauma	
K1	Bone marrow depression		
L1	Other		
M1	Not available		
N1	Neurological complication		
O1	NLTR pre-transplant specific causes of death	Hepatic: hepatorenal syndrome	
O2		Hepatic: ascending cholangitis	
O3		Hepatic: hepatocellular carcinoma	
O4		Hepatic: cholangiocarcinoma	
O5		Hepatic: metastasis to liver	
O6		Other: extrahepatic malignancy	