

THE NORDIC LIVER TRANSPLANT REGISTRY ANNUAL REPORT 2002

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April 2003

Nordic liver transplant registry - 2002

As of December 31, 2002 the registry comprised data on 2612 patients of whom 2204 had received a first liver allograft. The registry comprises complete data on all patients listed for liver transplantation during the period 1990-2002; 2390 patients. The remaining 222 patients received a liver allograft prior to 1990, waiting list data are not available for these patients.

Transplantation activity 2002

A total of 215 patients were listed for a first liver transplantation in 2002. Of these, 159 received a first liver allograft. Twelve of the 225 patients died while being active on the waiting list. Thirteen were permanently withdrawn from the waiting list without receiving a liver allograft. Forty-three patients were active on the waiting list as of December 31st, a slightly higher number as compared to the previous year.

The total number of patients receiving a first liver allograft during 2002 was 190 (39 patients were listed prior to January 1, 2002), an additional 23 retransplants (21 second, 1 fourth and 1 fifth) were performed.

During 2002 primary sclerosing cholangitis (n=35) followed by alcoholic liver cirrhosis (n=30) and fulminant hepatic failure (n=24) were the most frequent indications for being listed for a liver transplantation.

The number of older recipients (above 60 years of age) receiving a first liver allograft decreased as compared to previous years (24 in 2002 as compared to 40 and 29 in 2001 and 2000 respectively).

Median and mean waiting times (electively listed patients) have increased to 52 and 89 days respectively. Median waiting time for blood type 0 recipients in 2002 was 80 days and did not increase from 2001. The number of deaths on the waiting list is unchanged. A total of 14 patients died while waiting for a liver allograft during 2002.

Donor age has increased steadily during the nineties, but has been stable for the last 3 years with a mean donor age of 43 years in 2002.

Survival rates following liver transplantation are still increasing and for the last 3-year period the 1-year patient survival is above 85%. Survival data strongly depends on patient selection. As this most probably differs between the various centres, comparison between the five participating centres is not performed.

Maintenance of the registry

Most centres are as of today relatively up-to-date as concerns the completeness of data. Data on number of patients, dates of transplantation, diagnosis and status dead/alive are mostly complete.

The results presented in this report are based on the data in the registry as of March 10, 2003.

Acknowledgements - financial support

The maintenance of the software has been performed by ScandiTransplant. We greatly acknowledge the help and support from Niels Grønnet, Melvin Madsen, Christian Mondrup and Frank Pedersen in Aarhus. Without their help and support it would not have been possible to maintain the registry. Without the day-to-day assistance we have received from Christian Mondrup and Frank Pedersen it would not have been possible to tie up a large number of loose ends and develop the registry further.

Transplant nurses and transplant coordinators at the individual centres have made an enormous effort in updating and maintaining the registry. The existence of the registry depends completely on their work and dedication.

The registry received partial financial support from Roche, Fujisawa and Novartis during 2002. This support has been of great help. All financial support has been given without any obligations and the registry has no commitments to any pharmaceutical company.

Organisation and data ownership

It should be emphasised that the registry (software) is the property of ScandiTransplant while the data in the registry is 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. The contact person for each centre is listed below:

Copenhagen	Preben Kirkegaard
Gothenburg	Styrbjörn Friman
Helsinki	Krister Höckerstedt
Oslo	Inge Bjørn Brekke
Stockholm	Bo-Göran Ericzon

This complete report is distributed to a limited number of persons at each centre, further copies can be delivered on request. A preliminary report has been sent to the contact persons for comments.

Oslo April 2003

Kristian Bjørø

NB

Patients listed and receiving liver allografts in Uppsala prior to 2000 are recorded as Stockholm-patients.

ACTIVITY 2002

Activity during 2002 – total number of transplantations, first transplantations, retransplantations, deaths on waiting list and permanent withdrawals – irrespective of time of listing.

	Total tx	First liver tx			ReTx	DEA	PW
		CDT	LDT Living related	LDT Domino			
Copenhagen	40	31	1		8	0	4
Gothenburg	53	39	2	1	11	3	4
Helsinki	47	44			3	2	1
Oslo	25	25			0	5	3
Stockholm	44	39	2	2	1	4	1
Uppsala	4	4			0	0	1
Total	213	182	5	3	23	14*	14

* one patient died while waiting for a retransplantation

DEA - dead while active on waiting list

PW - permanently withdrawn

CDT - cadaveric donor transplants

LDT - living donor transplants (includes domino liver)

Active - active on waiting list as of Dec.31. 2002

Total number of patients accepted on liver tx waiting list (1. acceptance): 225

Outcome of patients *listed* during 2002:

	total	DEA	PW	CDT	LDT	Active
Copenhagen	30	3	2	22	0	3
Gothenburg	57	3	4	42	2	6
Helsinki	51	0	6	37	0	8
Oslo	41	4	1	26	1	9
Stockholm	43	1	1	25	3	13
Uppsala	3		1	1		1
Total 2002	225	11	15	153	6	40

Diagnoses of patients accepted on waiting list 1996-2002 (1. acceptance):

	2002	2001	2000	1999	1998	1997	1996
Acute hepatic failure [@]	24	43	24	28	26	28	19
Primary sclerosing cholangitis	35	36	38	27	25	32	25
Malignant diseases	19	20	18	21	23	10	7
Primary biliary cirrhosis	13	10	16	20	17	17	16
Hepatitis C cirrhosis	23	14	20	20	20	11	10
Alcoholic cirrhosis	30	27	25	18	30	23	15
Metabolic diseases	9	9	11	16	16	5	6
Biliary atresia	11	11	11	11	10	4	7
Autoimmune cirrhosis*	13	7	7	9	3	4	11
Cryptogenic cirrhosis	6	6	8	8	3	7	7
Hepatitis B cirrhosis*	7	8	6	7	6	7	3
Budd Chiari syndrome*	2	6	0	3	5	2	6
Other cholestatic diseases	0	5	2	2	7	6	8
Other	23	23	14	23	11	20	24
Total	215	225	202	213	202	176	164

*Patients with autoimmune hepatitis, HBV and Budd Chiari may be recorded as acute hepatic failure if listed as urgent, the figures given for these diagnoses in this table exclude patients listed as acute hepatic failure.

[@]NB The term *acute hepatic failure* is only applied for patients who were listed for a highly urgent liver transplantation, i.e. it does not include patients with "acute on chronic liver failure".

Duration of time on waiting list, patients receiving 1. liver allograft 1996-2002 (excluding urgent listings)

	2002	2001	2000	1999	1998	1997	1996
median (days)	52	42	43	30	21	23	27
mean (days)	89	85	75	55	53	63	64

Annual total number of liver transplantations, 1996-2002

	2002	2001	2000	1999	1998	1997	1996
Tx no 1	190	192	169	164	175	161	141
Tx no 2	21	15	19	16	28	17	20
Tx no 3	0	2	3	3	1	0	5
Tx no 4	1	0	0	0	0	0	2
Tx no 5	1	0	0	0	0	0	0
	213	209	191	183	204	178	168

Number of liver transplantations per centre, 1996-2002

	1.liver transplantations						Retransplantations*					
	2002	2001	2000	1999	1998	1997	2002	2001	2000	1999	1998	1997
Copenhagen	32	26	20	26	37	37	8	6	4	5	6	1
Gothenburg	42	50	40	41	54	46	11	4	8	5	5	2
Helsinki	44	37	28	28	33	23	3	1	3	2	6	5
Oslo	25	32	25	23	19	16	0	5	5	5	6	2
Stockholm	43	46	56	46	41	39	1	1	2	1	6	5
Uppsala	4	1										
Total	190	192	169	164	175	161	23	17	22	18	29	15

* includes all retransplants - second, third and fourth

Retransplantation rates 1990-2002

Comprises data on patients receiving a 1. liver allograft during 1990-2002. The percentage of patients receiving a second allograft will depend strongly on the patient population – e.g. diagnosis, number of small children – but also on donor characteristics – e.g. donor age, cold ischemic time.

	1. LTX	2.LTX	%- 2.LTX
Copenhagen	366	49	13.4%
Gothenburg	492	50	10.1%
Helsinki	372	30	8.1%
Oslo	246	29	11.8%
Stockholm	486	34	7.0%

Diagnoses of patients receiving a first liver transplant 1996-2002

	2002	2001	2000	1999	1998	1997	1996
Primary sclerosing cholangitis	31	37	28	21	24	31	25
Acute hepatic failure	17	33	16	20	18	24	15
Hepatitis C cirrhosis	22	10	16	17	17	11	5
Primary biliary cirrhosis	8	10	18	16	16	14	13
Metabolic diseases	9	9	11	14	15	6	6
Alcoholic cirrhosis	29	21	21	13	28	21	14
Malignant diseases	15	15	17	12	19	9	5
Autoimmune cirrhosis*	10	5	6	10	1	5	9
Biliary atresia	6	11	7	9	8	3	9
Hepatitis B cirrhosis	8	4	6	7	5	5	4
Cryptogenic cirrhosis	5	5	9	4	4	9	6
Budd Chiari syndrome*	4	5	0	3	5	6	6
Other cholestatic diseases	2	4	0	1	6	9	9
Other	22	23	14	17	7	8	19
Total	190	192	169	164	175	161	141

*Patients with Budd Chiari syndrome, autoimmune hepatitis and HBV may be recorded as acute hepatic failure if listed as urgent, the figures given for Budd Chiari in this table exclude patients listed as acute hepatic failure

Age distribution of patients receiving a first liver transplant in 1996-2002 (age at transplantation)

age - year	2002	2001	2000	1999	1998	1997	1996
<1	5	10	2	7	6	2	4
1-2	0	1	4	2	2	6	3
2-10	7	5	2	10	8	4	6
11-20	8	6	5	7	4	8	4
21-30	16	19	19	7	6	12	12
31-40	24	21	14	18	23	17	14
41-50	44	40	50	38	48	44	33
51-60	63	50	56	50	53	42	47
>60	23	40	26	23	23	24	18

**Recipient age – centrewise 1996-2002 (7-year period)*
(first liver allografts)**

	Mean age	Median age	Per cent of recipients being > 60 years
Copenhagen	46.4	50.7	10%
Gothenburg	49.3	51.2	21%
Helsinki	46.4	49.1	14%
Oslo	44.5	46.1	8%
Stockholm	45.8	48.9	16%

*excluding patients <5 years of age

**Total number of young children receiving a liver allograft (1996-2002)
(first liver allografts)**

	No of recipients < 5 years	Per cent recipients being < 5 years
Copenhagen	10	5%
Gothenburg	15	5%
Helsinki	11	5%
Oslo	23	14%
Stockholm	16	6%

**Donor age* (years) – centrewise (1996-2002)
(first liver allografts)**

	Mean	Median	Per cent donors being > 60 years
Copenhagen	41.3	45	9%
Gothenburg	44.9	47	13%
Helsinki	39.1	42	4%
Oslo	38.3	42	7%
Stockholm	44.3	49	21%

*donor age is missing in approximately 3-5% of cases

Retransplantations according to diagnosis – 1990-2002

	NO. OF 1. LIVER TX	NO. OF 2. LIVER TX	TIME FROM 1. TO 2. LTX		% OF 2. LTX WITHIN 3 WEEKS
			Mean	Median	
Acute hepatic failure	255	36 (14%)	453	137	39%
Alcoholic cirrhosis	214	10 (5%)	910	767	10%
Autoimmune cirrhosis	77	7 (9%)	59	14	57%
Biliary atresia	97	16 (16%)	366	14	63%
Hepatocellular carcinoma	98	6 (6%)	313	105	67%
Hepatitis C cirrhosis	120	12 (10%)	133	81	17%
Primary biliary cirrhosis	236	20 (9%)	500	178	20%
Prim. scler.cholangitis	292	31 (11%)	525	137	13%

Distribution of some of the major diagnoses (patients receiving a 1.liver allograft) – centerwise – 1995-2002

	Copenhagen	Gothenburg	Helsinki	Oslo	Stockholm
AHF	33	24	59	14	29
ALCI	60	51	24	14	21
AUCI	7	21	6	9	12
BIAT	14	12	8	18	18
BCDI	4	6	8	5	5
CRCI/OCCI	23	22	16	12	10
MEDI	11	11	6	9	46
PBCI	17	29	38	17	21
PCYS	8	8	0	2	0
PHCC	10	33	3	12	45
PHCB	4	20	0	4	14
SCCH	23	55	39	43	58
HCCA	2	12	16	2	35
SECA		8		1	
OTCA	4	10	5	2	3

- AHF - acute hepatic failure
- ALCI - alcoholic cirrhosis
- AUCI - autoimmune hepatitis-cirrhosis
- BCDI - Budd Chiari (only chronic cases)
- BIAT - biliary atresia
- CRCI/OCCI – cryptogenic cirrhosis and cirrhosis other causes
- MEDI - metabolic diseases
- PBCI - primary biliary cirrhosis
- PCYS - polycystic liver disease
- PHCC - HCV cirrhosis
- PHCB - HBV cirrhosis
- SCCH – primary sclerosing cholangitis
- HCCA - hepatocellular carcinoma
- OTCA - all other cancers including cholangiocarcinoma, other primary hepatic cancers and secondary cancers

Activity 1982-2002

A total of 2204 first liver transplantations and 236 retransplantations have been performed since 1982, the distribution among the centres is given below.

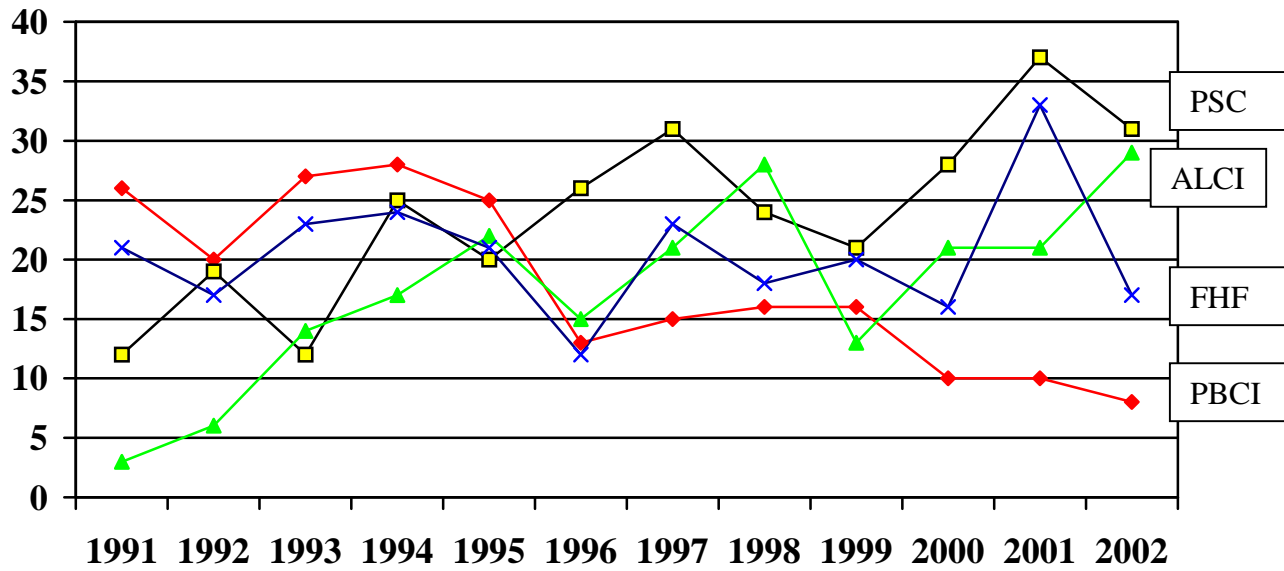
Survival curves for the total material, for different time periods and for major diagnostic groups are given. In addition survival curves for a limited number of diagnoses – primary sclerosing cholangitis, primary biliary cirrhosis, HCV and HBV are presented. The survival curves comprise data for all patients who have received a liver allograft as of March 1. 2002

	1.liver transplants	Retransplants α	Total number
Helsinki	417	46	463
Stockholm	564	51	615*
Gothenburg	567	67	634
Copenhagen	372	56	428
Oslo	279	36	315
Uppsala	23*	2*	25
Aarhus	20	3	23
total	2204	259	2463

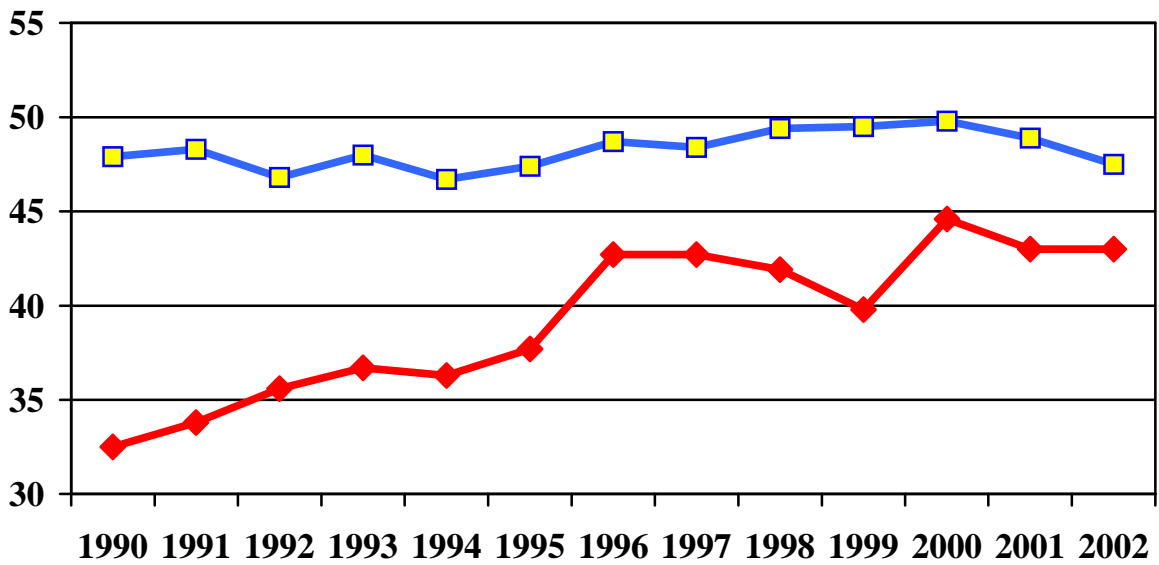
α Includes both 2nd, 3rd, 4th and 5th transplantations

*18 of the 1.liver transplants and both retransplants were performed during the period 1994-1998, these transplants are also included in the Stockholm figures

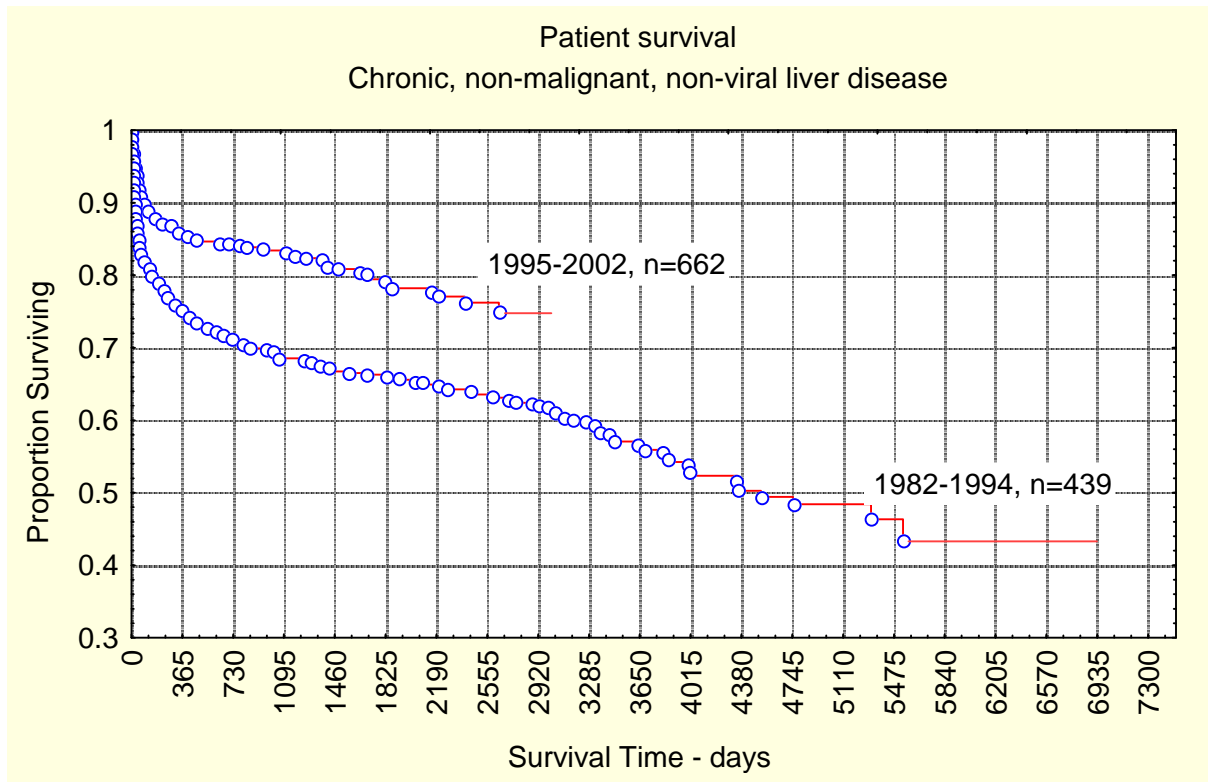
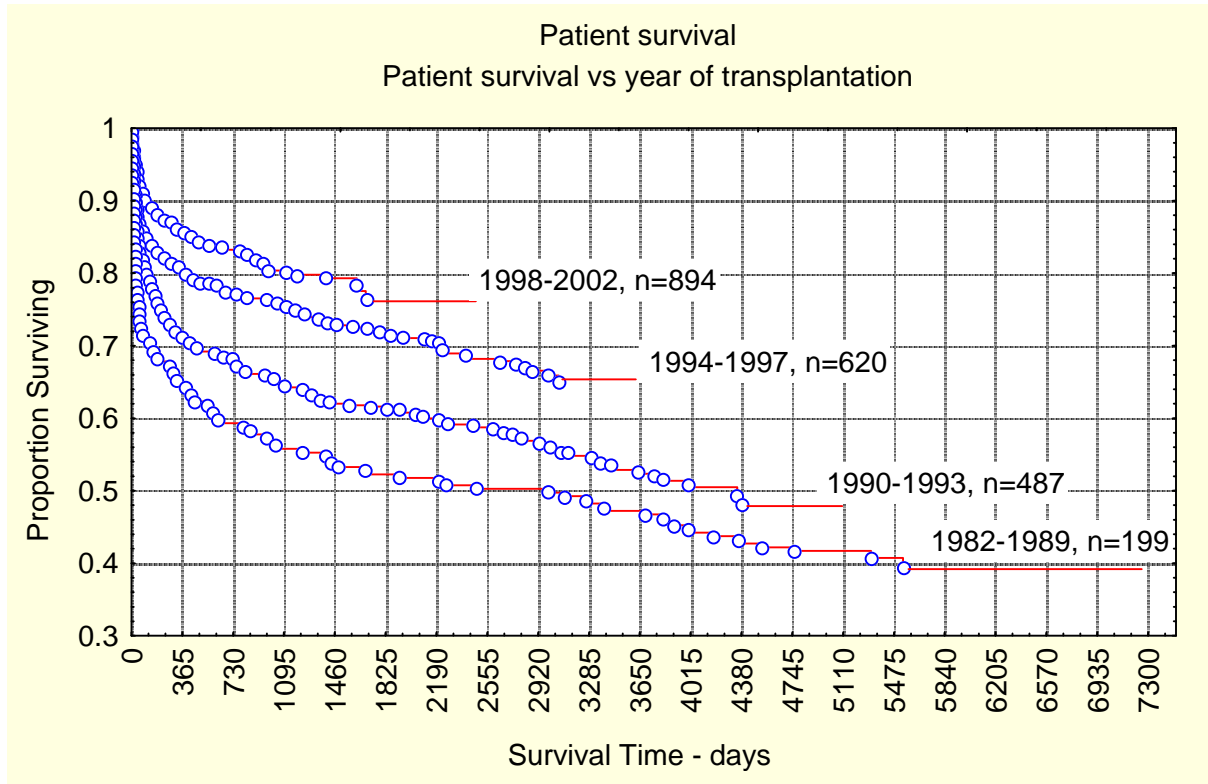
Annual number of first liver transplantations according to diagnosis (PSC-primary sclerosing cholangitis, FHF-acute hepatic failure, ALCI-alcoholic cirrhosis, PBC-primary biliary cirrhosis)



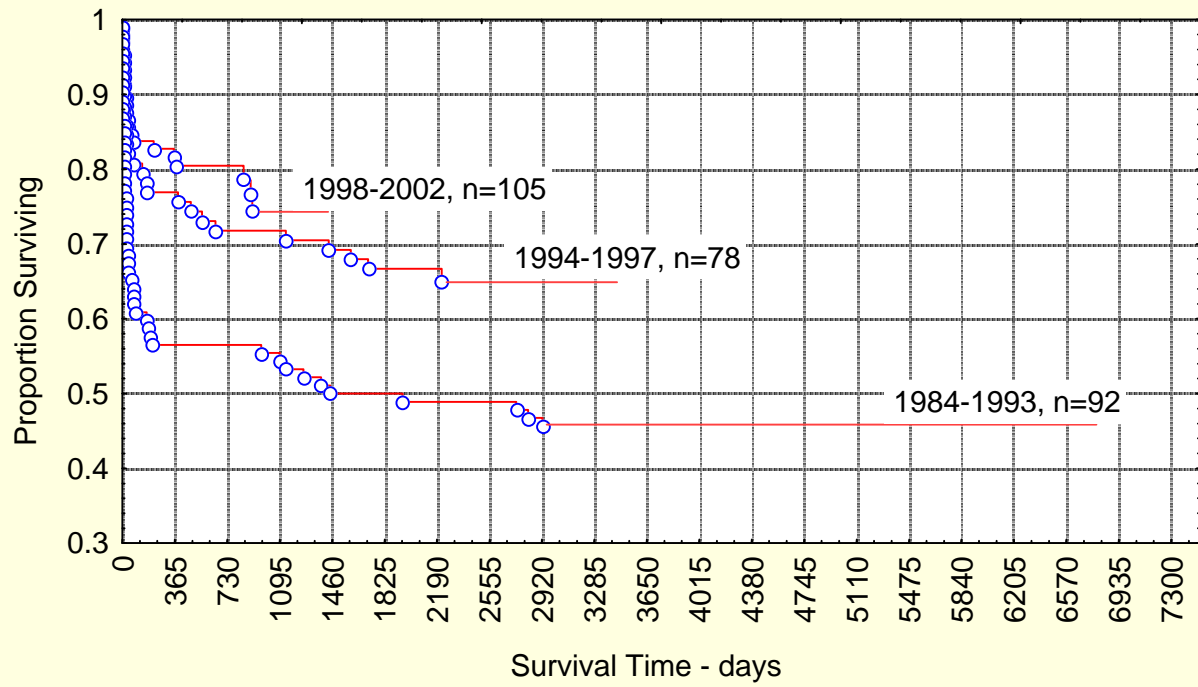
Mean donor (red - lower) and recipient age (blue - upper) during 1990-2001



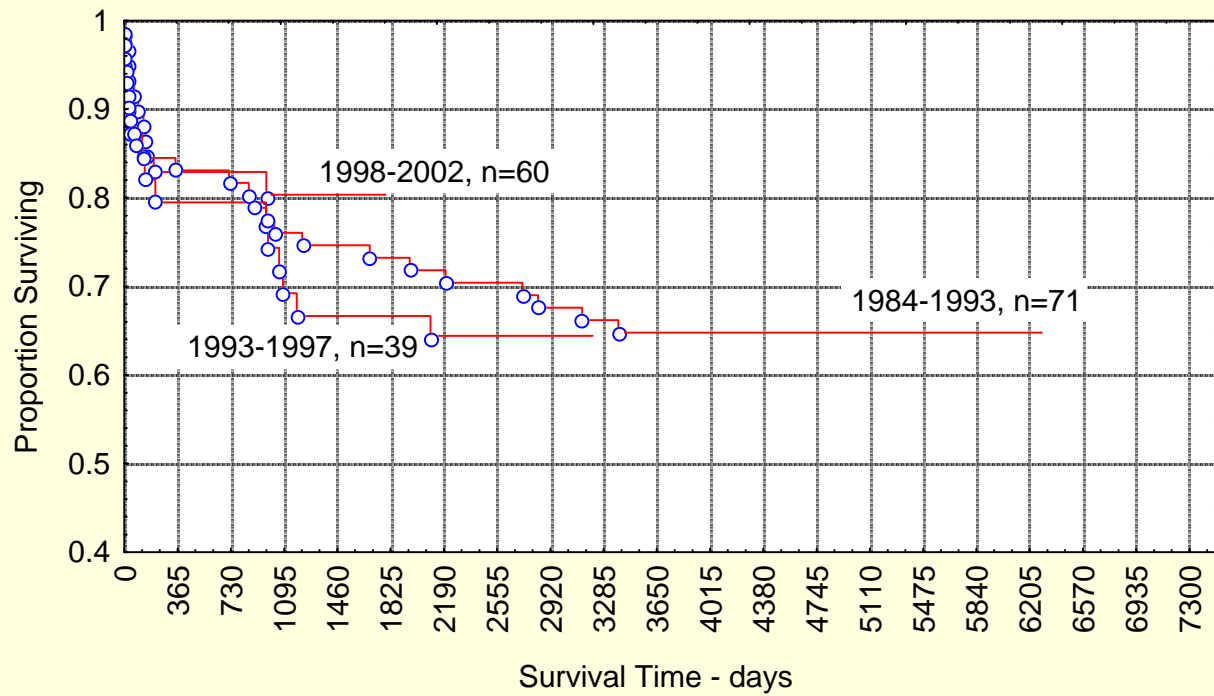
Survival curves



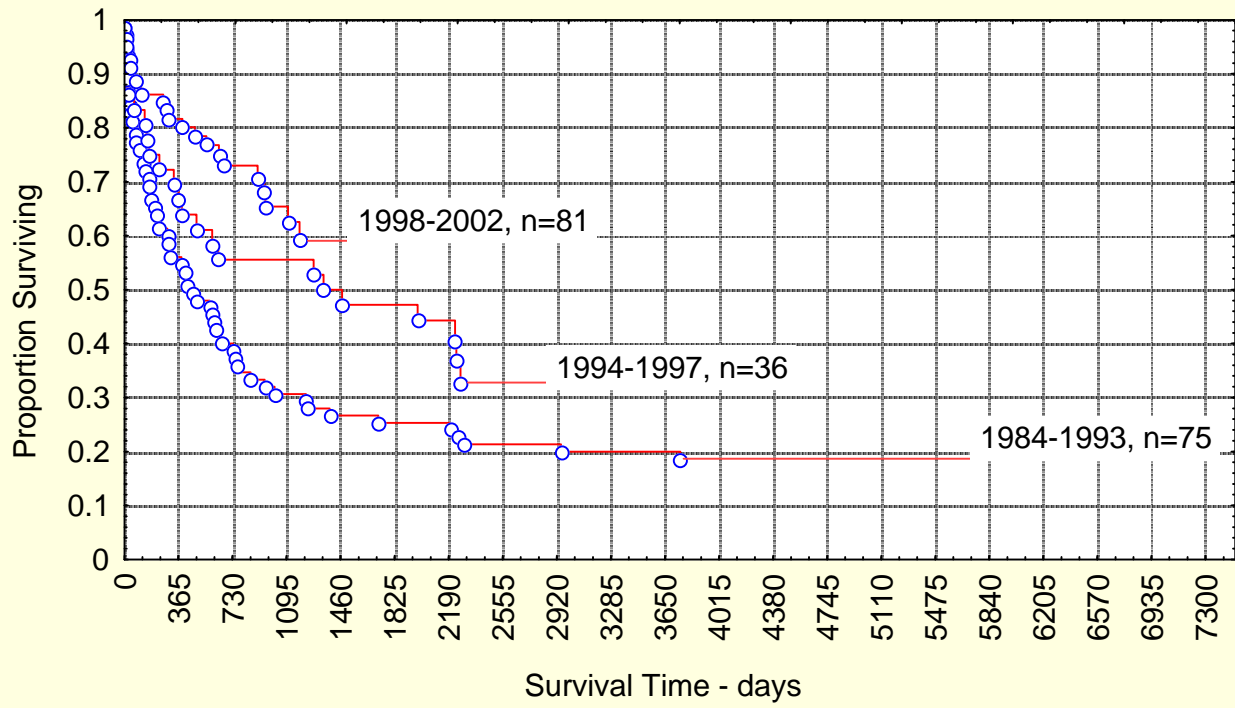
Patient survival
Fulminant hepatic failure



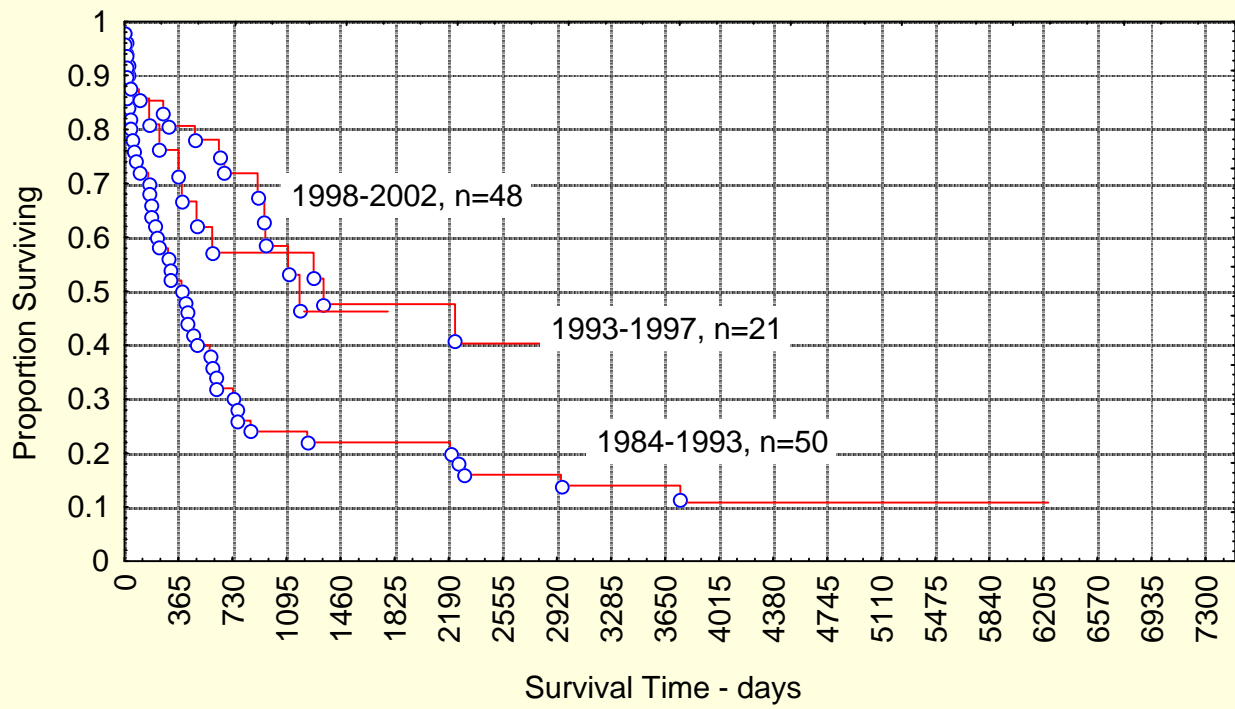
Patient survival
Metabolic diseases



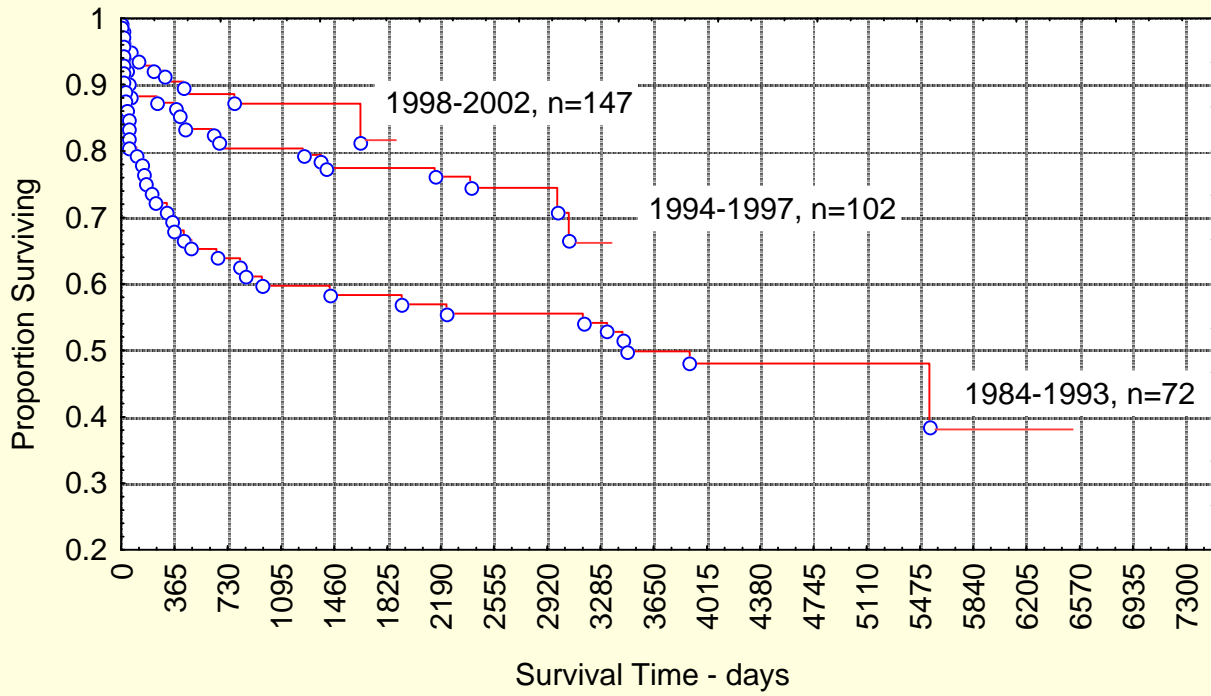
Patient survival
Malignant liver disease



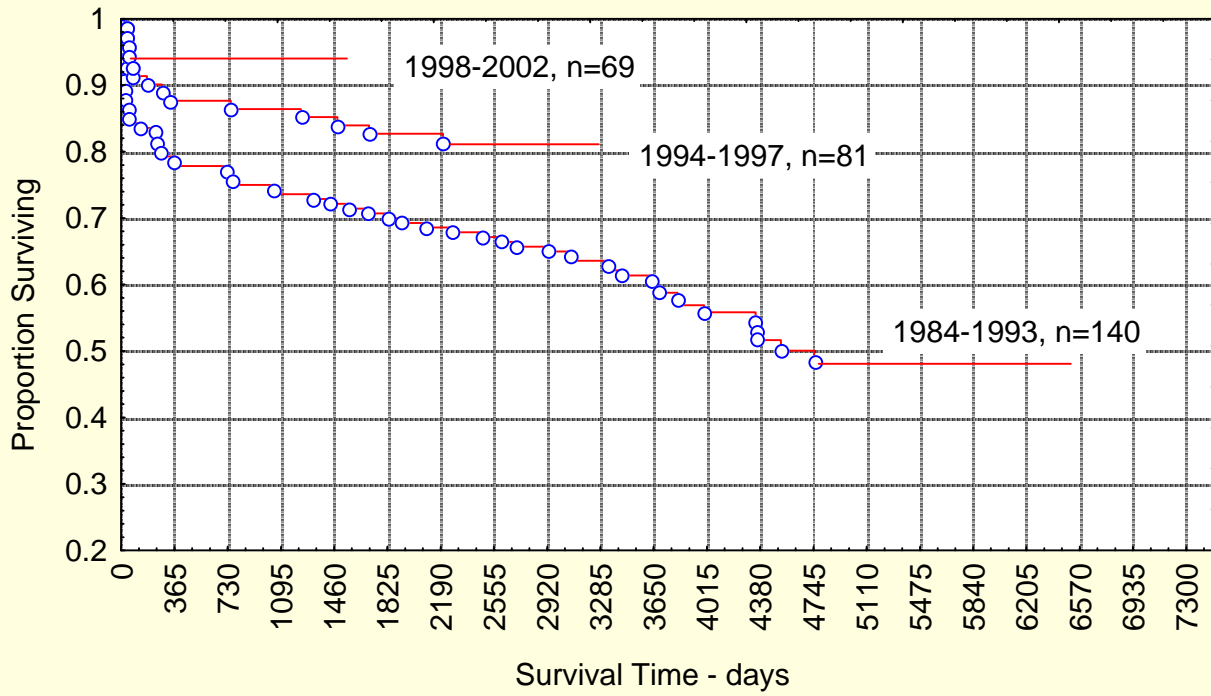
Patient survival
Hepatocellular carcinoma



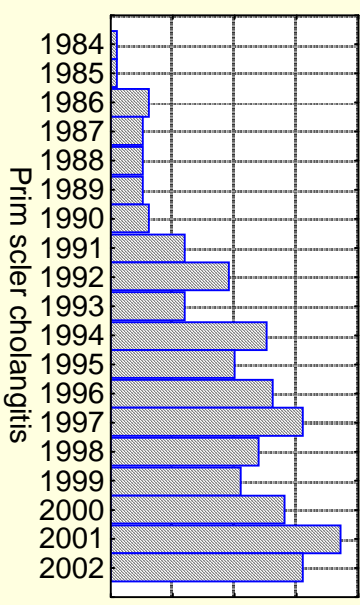
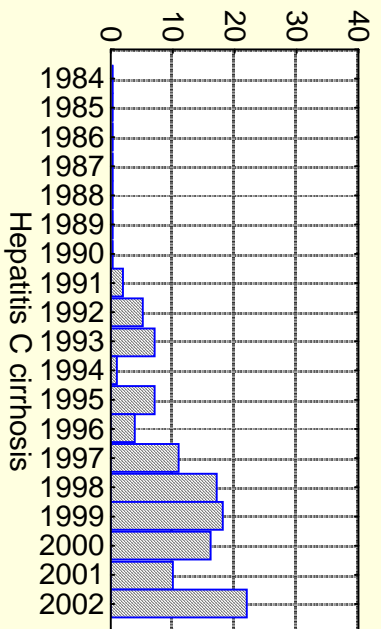
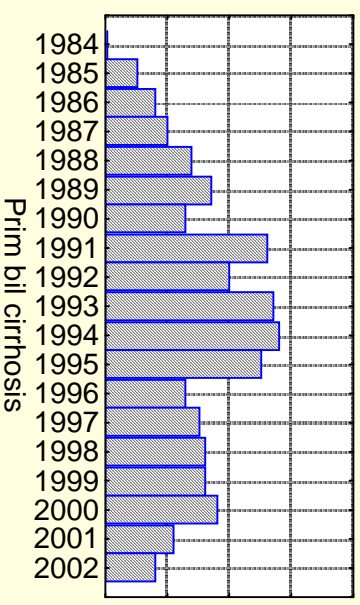
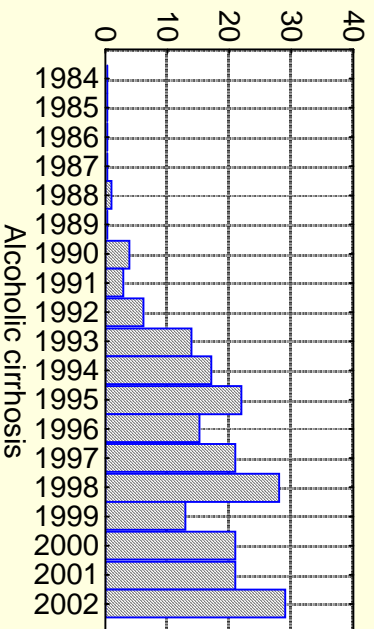
Patient survival
Primary sclerosing cholangitis



Patient survival
Primary biliary cirrhosis



Annual number of liver transplantations according to diagnosis



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