Annual report 2015

Founded 1969 by the Nordic Council

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Introduction

The year of 2015 was a landmark year in the history of Scandiatransplant. The old user interface was finally closed for user access and replaced with the new YASWA user interface. The number of donors and transplantations were the same as 2014, which was the highest level ever. The working group on revising the articles of Scandiatransplant was very effective and came up with a suggestion to be presented to the Council of Representatives in 2016. Finally a suggestion for the responsibility and ownership of data was put forward for the Nordic Health authorities to be worked on in the time to come.

Organisation

Scandiatransplant is the Organ Exchange Organisation (OEO) of the five Nordic countries: Iceland, Norway, Sweden, Finland, and Denmark. It is an association and the members are the 10 hospitals performing organ transplantation in these countries. According to the current articles the objectives of the association is to:

- to operate as an intermediary in the exchange of human organs and tissue for use by the Association's members in connection with transplantation,
- to develop European cooperation on organ donation and transplantation through maintenance of contacts with other European organ exchange organisations,
- to maintain dialogue with the health authorities in the Nordic countries concerning organ donation and transplantation,
- to operate a database on organ donation and transplantation and communicate optimum information from the database to the Association's members,
- to contribute to promoting the provision of human organs and tissue for use by the Association's members in connection with transplantation,
- to support scientific activities in accordance with the above-mentioned objectives subject to the guidelines laid down by the Council of Representatives.

The members elect Representatives to the Council, which is the association’s supreme authority. It approves the members of the board, which represent all the countries, and is responsible for the day to day operations of the association. Suggestions for the activity and allocation rules are brought forward to the board from a number groups and committees.

During 2015 the council had 39 representatives. The Chairman of the Board was Krister Höckerstedt, Finland and the Board members were Lars Wennberg, Sweden; Helena Isoniemi, Finland; Pål-Dag Line, Norway; Finn Gustafsson, Denmark; and Magrét Andésdóttir, Iceland.

The Scandiatransplant Office is located at Aarhus University Hospital, Denmark. The primary task of the office is to maintain and develop the IT-system holding data on all patients enlisted for organ transplantation in the Nordic countries. It is accessible 24/7 for all health personnel at the member hospital performing organ retrieval and transplantation ensuring correct allocation of organs. In addition to this primary task the Scandiatransplant Office takes care many other tasks such as running follow-up registries, educate and support users, arrange meetings for council, board, groups and committees, comply with demands from owners, researchers, authorities and the public, and participate in meetings with local health competent authorities, EU-commission and EU projects.

At the end of 2015 the staff consisted of 8 people, 6 full-time, the Secretary and the Medical Director, are working part-time. The office's student programmer in the last years, Tito Phiri, achieved his bachelor degree in computer software science and was employed as full time programmer at the Office.

The total expenses were kept within the budget (5 mill. DKK – 700.000 EUR). The expenses in Scandiatransplant are payed by the member hospitals.

Activities in the organisation in 2015

December 10th, 2015 access to the database through the old user interface (SSH) was closed down. This went surprisingly well and shortly afterwards the whole Scandiatransplant IT-system running on physical Solaris servers, with an outdated operating system, were moved to modern virtual servers[1] with updated software greatly enhancing security, stability and performance. This is a landmark in the work that has been going on for years in creating a new modern user friendly, secure and stable IT-system. This work has through the years mainly be done by our programmer Bo Hedemark Pedersen, who deserves credit for this achievement. Credit should also go the three other programmers we hired lately and especially to Ilse Weinreich and Frank Pedersen for assisting the programmers in the

[1] Traditional servers are physical machines that run one operating system, a virtual host is an operating system running on a seemingly physical machine, virtualized by a host operating system (that again could be a virtual machine - but often isn't) that usually contains multiple separate "software containers", each of which runs its own operating system. These software containers are the virtual servers. Each of these isolated virtual machines believes that it is a separate physical computer and behaves accordingly.

designing and testing the new interface. The IT-system has become known by its preliminary name YASWA (Yet Another Scandiatransplant Web Application). Reactions from the users have been positive.

The Working Group for revision of the Articles of the Association Scandiatransplant (WGA) has been working effectively during 2015. Overall outline of the suggestions were presented for Council of Representatives at the annual meeting in May 2015 in Stockholm. The suggested revisions have been worked out together with a lawyer and are ready for presentation and will hopefully be adopted by the Council in 2016.

A new model for the responsibility of data has been suggested. At this time the data responsible authority for the data in Scandiatransplant is Central Region Denmark. It is suggested, that the Hospitals are responsible for their data. This is a way ensure the legality of the data according to all countries. An agreement on data handling will have to be signed between Scandiatransplant and each member Hospital. This has been presented to the Nordic Health Authorities and we will continue to work with them along this model. Another developing joint venture with these authorities is the way to register and report SAE/AE, which could be through the Scandiatransplant IT-system.

Scandiatransplant has participated in the 2 yearly meetings of the competent authorities and the EU-commission on matters of organ transplantation. The main reason has been to balance the participation of Scandiatransplant in the EU projects. The Office has adopted a policy of trying to have at least one person from the Office present at every meeting in the Groups in Scandiatransplant to ensure continuity and updated information on decisions and wishes from the users. The Office has also put resources into education and guidance in relation to the new IT-system.

Transplantation and organ procurement activity

The year 2015 has been a good year for organ transplantation in the five Nordic countries with still an increase in the number of utilized donors to the highest level yet. In this report we have chosen to present some key figures and compare some of them with data from 2006 and onwards showing the last ten year period.

First we looked at the total number of transplanted organs and compared with the number of patients on the waiting list at the end of the year. Although 2015 was the year with most utilized donors, the demand has also increased so that at the end of 2015, there was also the highest number of patients on the waiting list.

In 2015 the number of utilized donors was the highest in the 10-year period for the whole Scandiatransplant area and for all Nordic countries except Norway in actual numbers and PMP (per million population). Iceland increased the donor rate to 36,5 PMP.

Then we present data for the different organs and finally we have taken a closer look at paediatric transplantations within Scandiatransplant.

Further presentation of Scandiatransplant data is available in the annual slideshow:

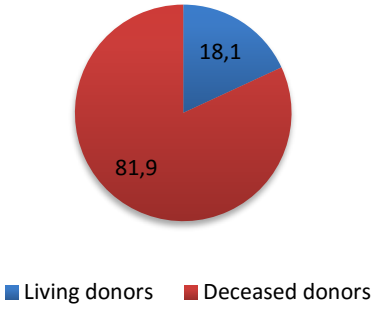
http://www.scandiatransplant.org/resources/dias2015_2.pdf

In relation with the statistics presented please keep in mind that data subjects to change based on future data submission and/or correction

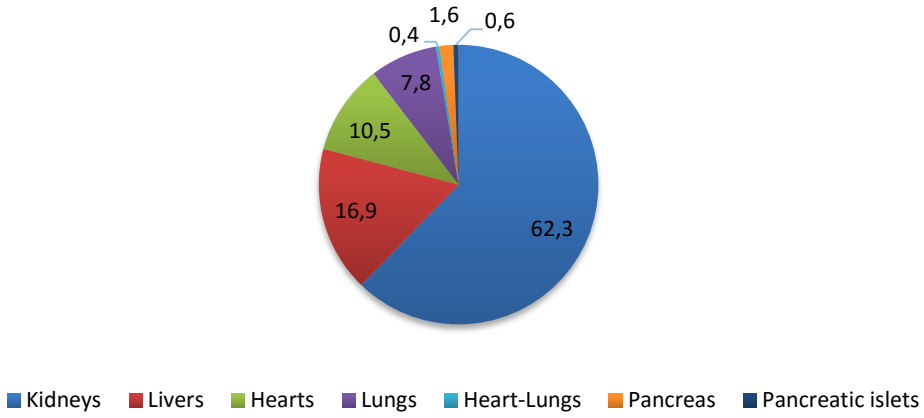
Total number of transplantations registrations in Scandiatransplant

As of **January 1, 2016,** the total number of transplantation registrations in the Scandiatransplant database were **30078**[2]

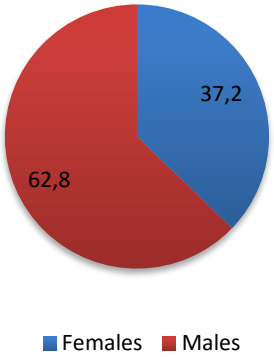
Precentage of registrations divided on donor types



Precentage of registrations divided on organ type



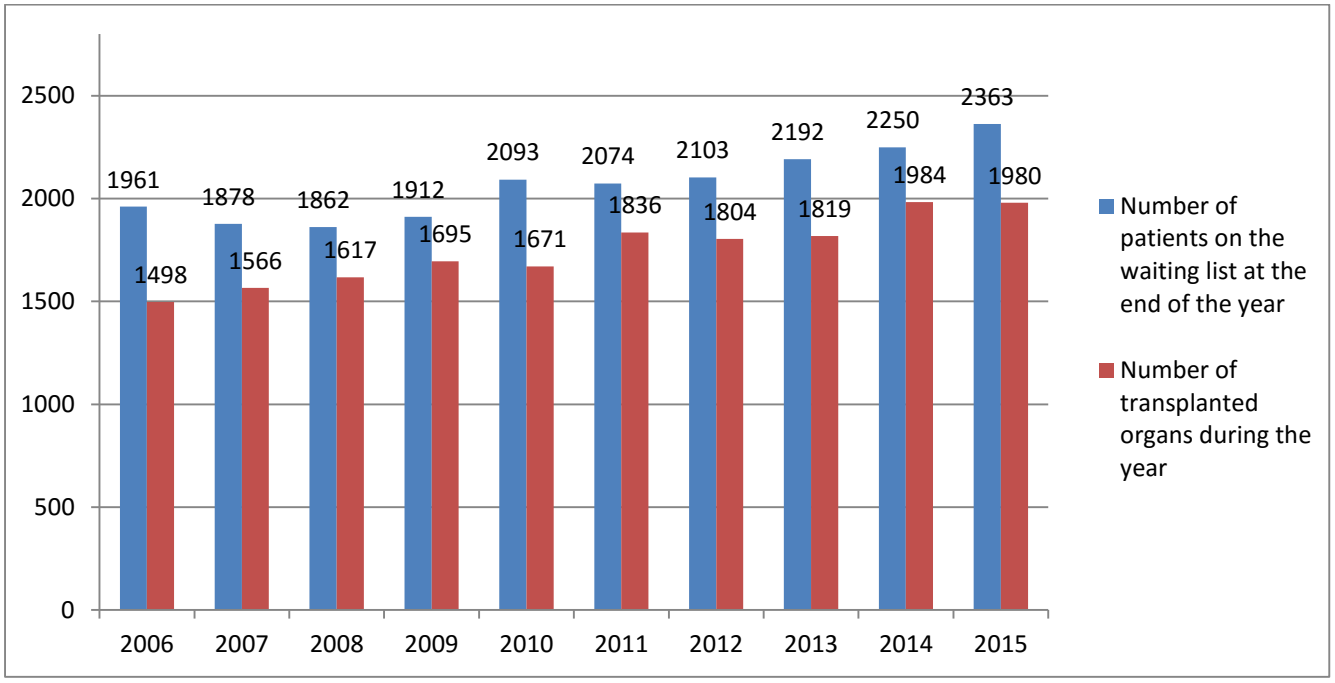
Precentage of transplantations divided on gender



[2] The database contains information on kidney transplantations performed after year 1995, registrations on all other organ types are historical

Total organs transplanted and waiting patients[3] within Scandiatransplant

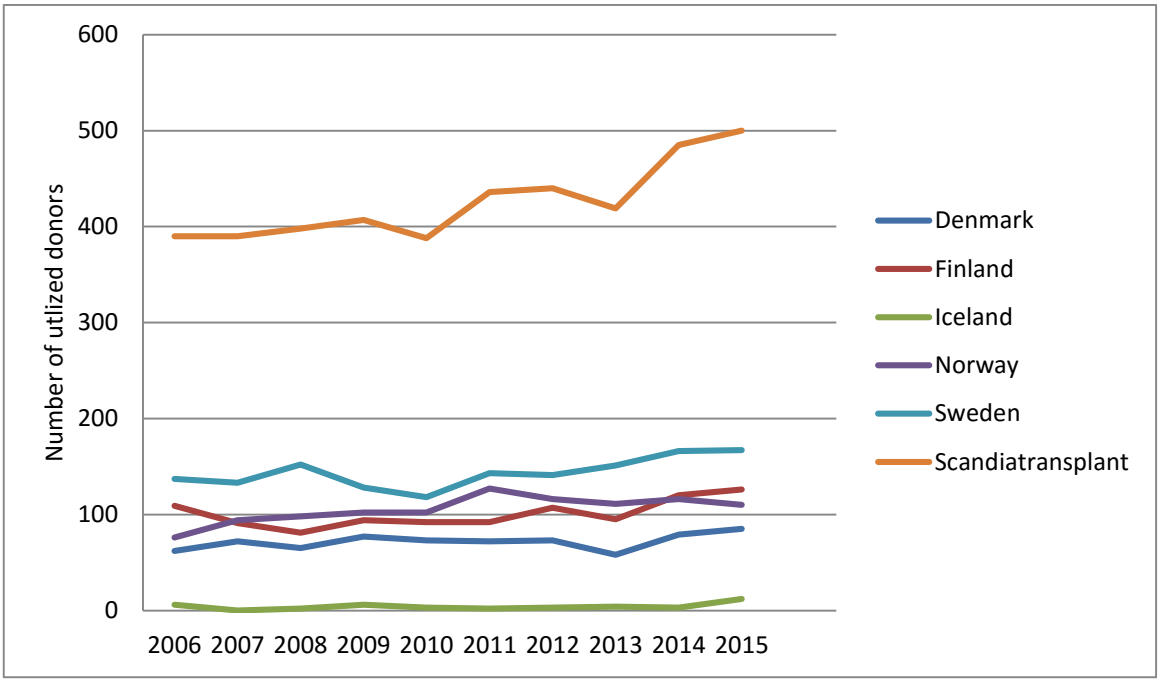
Year	Number of waiting patients	Number of transplanted organs
2006	1961	1498
2007	1878	1566
2008	1862	1617
2009	1912	1695
2010	2093	1671
2011	2074	1836
2012	2103	1804
2013	2192	1819
2014	2250	1984
2015	2363	1980



[3] Including transplantation and waiting list figures for kidney, heart, liver, lung and pancreas. In the figure 'Transplanted organs', each organ is counted is separately in combined organ transplantations.

Utilized deceased donors[4] in numbers in Scandiatransplant

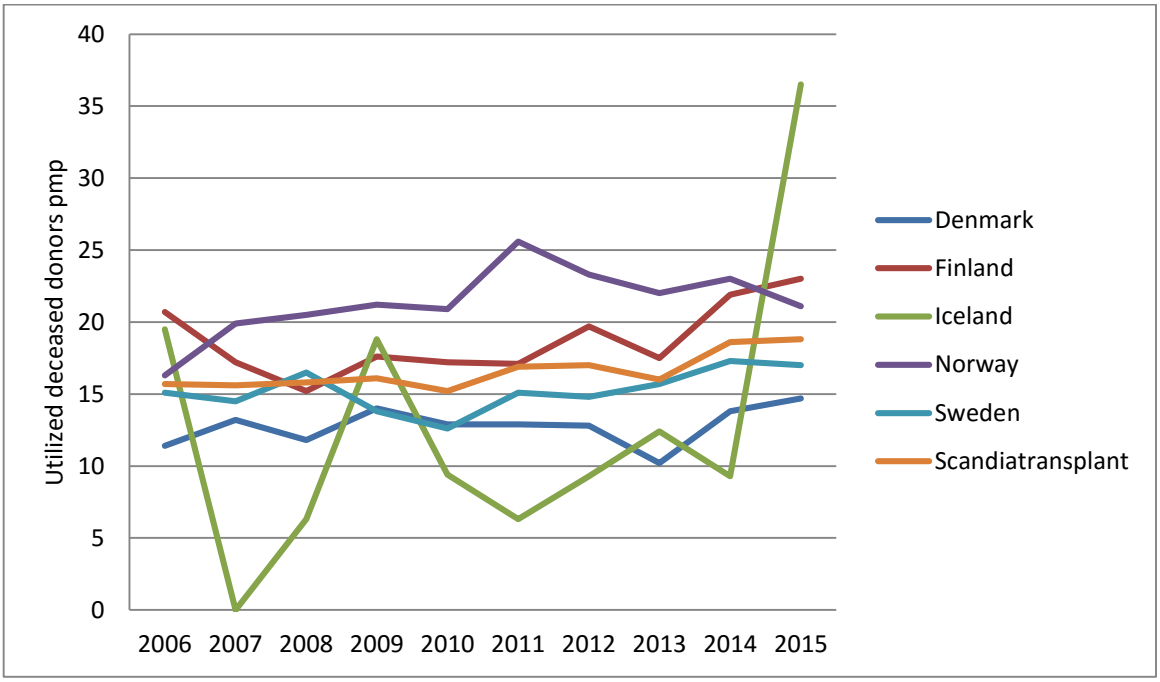
Year	Denmark	Finland	Iceland	Norway	Sweden	Scandiatransplant
2006	62	109	6	76	137	390
2007	72	91	0	94	133	390
2008	65	81	2	98	152	398
2009	77	94	6	102	128	407
2010	73	92	3	102	118	388
2011	72	92	2	127	143	436
2012	73	107	3	116	141	440
2013	58	95	4	111	151	419
2014	79	120	3	116	166	485
2015	85	126	12	110	167	500



[4]Definition of utilized donor: An actual donor from whom at least one solid organ was transplanted. http://www.scandiatransplant.org/news/News_ticker_1_ver_2.pdf

Utilized deceased donors pmp[5] in Scandiatransplant

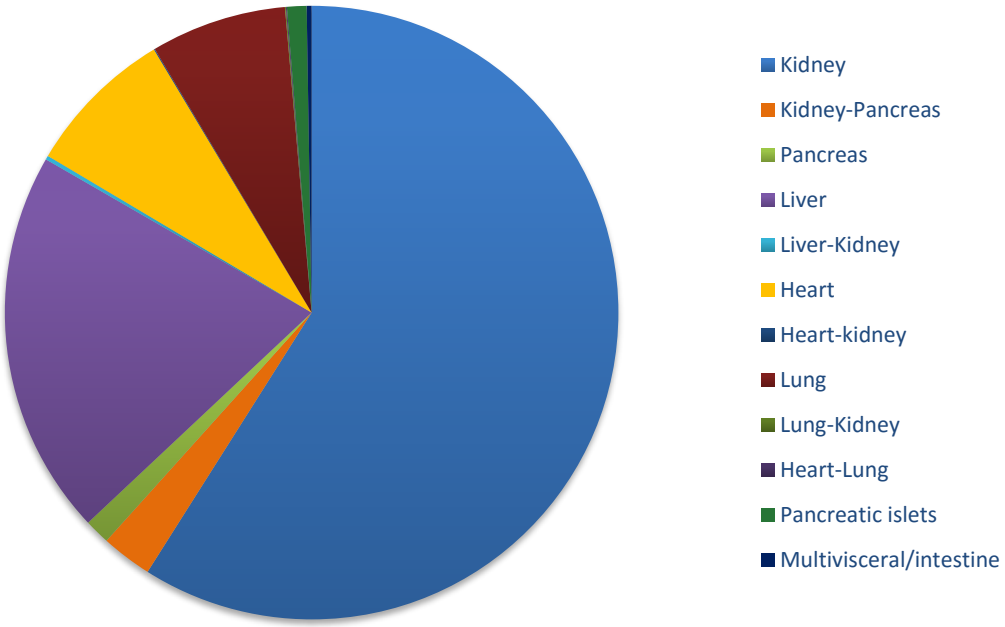
Year	Denmark	Finland	Iceland	Norway	Sweden	Scandiatransplant
2006	11,4	20,7	19,5	16,3	15,1	15,7
2007	13,2	17,2	0	19,9	14,5	15,6
2008	11,8	15,2	6,3	20,5	16,5	15,8
2009	14,0	17,6	18,8	21,2	13,8	16,1
2010	12,9	17,2	9,4	20,9	12,6	15,2
2011	12,9	17,1	6,3	25,6	15,1	16,9
2012	12,8	19,7	9,3	23,3	14,8	17,0
2013	10,2	17,5	12,4	22,0	15,7	16,0
2014	13,8	21,9	9,3	23,0	17,3	18,6
2015	14,7	23,0	36,5	21,1	17,0	18,8



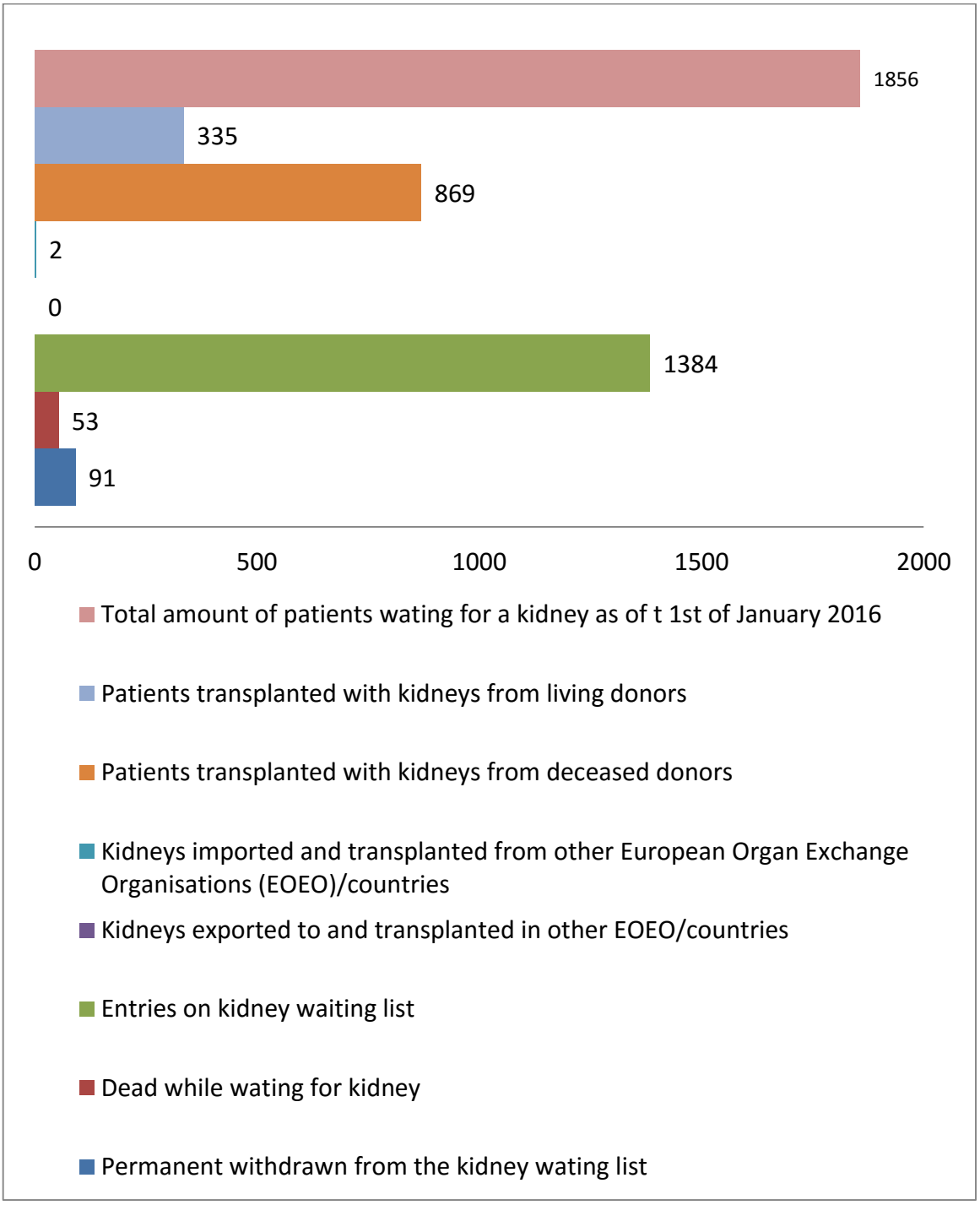
[5] pmp: per million population

Transplanted patients in Scandiatransplant 2015

Organ(s) transplanted	Number of transplantations
Kidney	1146
Kidney-Pancreas	52
Pancreas	26
Liver	395
Liver-Kidney	4
Heart	153
Heart-Kidney	1
Lung	139
Lung-Kidney	1
Heart-Lung	1
Pancreatic islets	20
Multivisceral/intestine	5
Total transplanted patients	**1943**

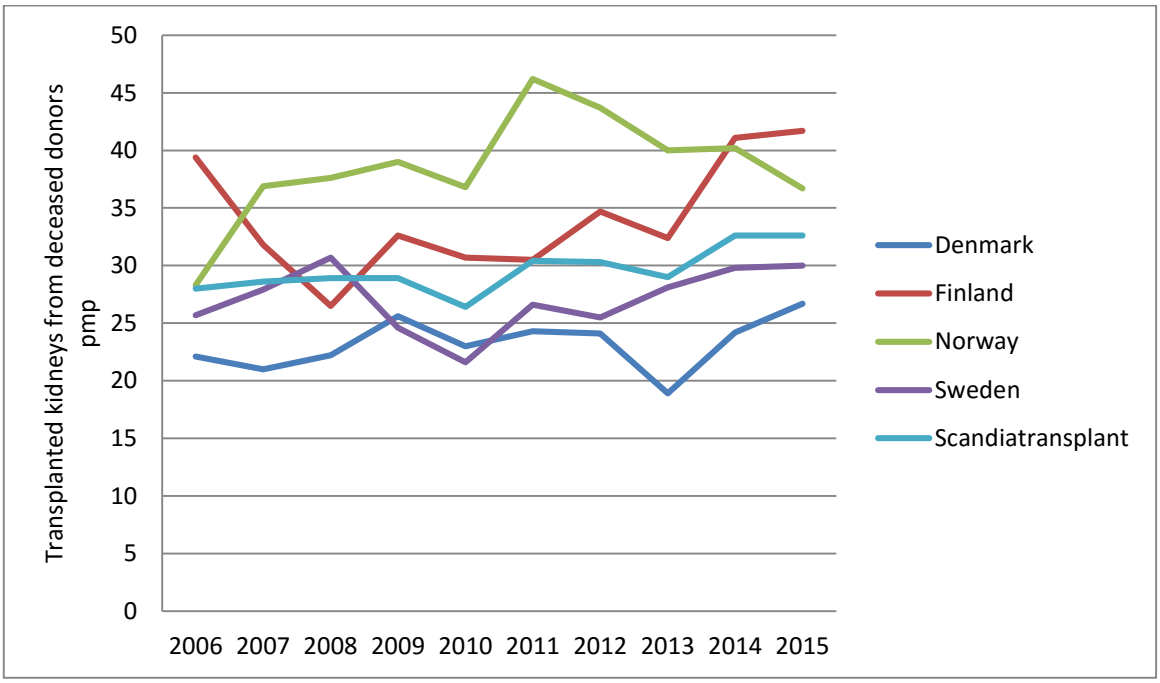


Kidneys 2015



Transplanted kidneys pmp[6] from deceased donors per year

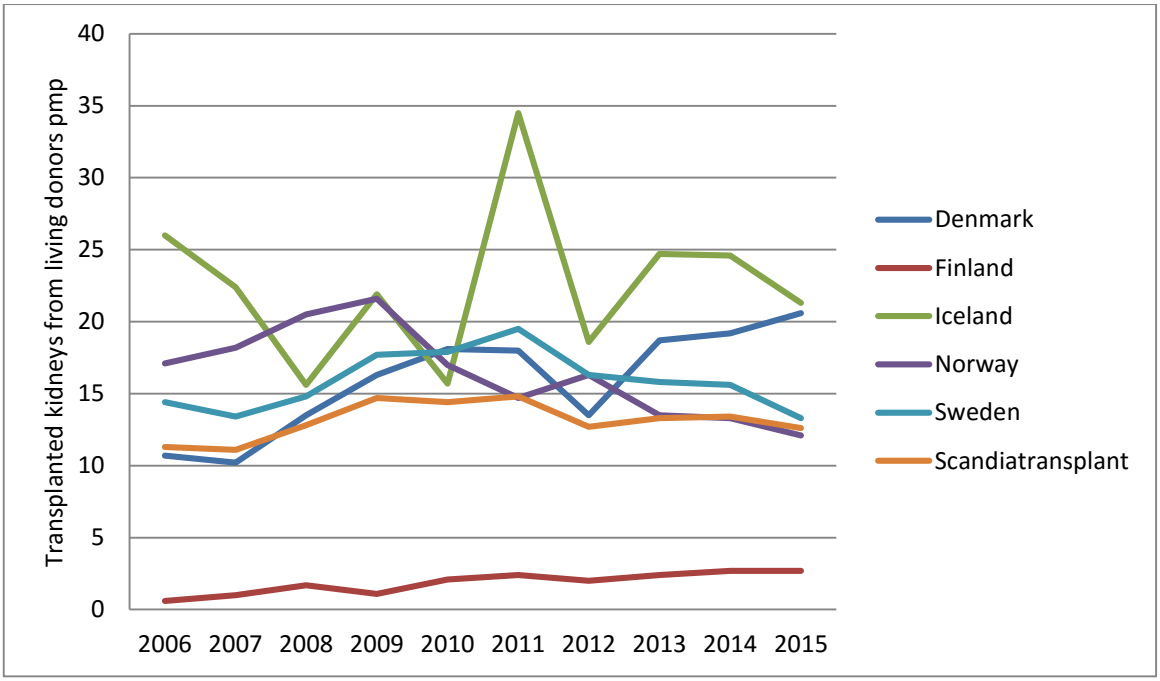
Year	Denmark	Finland	Norway	Sweden	Scandiatransplant
2006	22,1	39,4	28,3	25,7	28,0
2007	21,0	31,8	36,9	27,9	28,6
2008	22,2	26,5	37,6	30,7	28,9
2009	25,6	32,6	39,0	24,6	28,9
2010	23,0	30,7	36,8	21,6	26,4
2011	24,3	30,5	46,2	26,6	30,4
2012	24,1	34,7	43,7	25,5	30,3
2013	18,9	32,4	40,0	28,1	29
2014	24,2	41,1	40,2	29,8	32,6
2015	26,7	41,7	36,7	30,0	32,6



[6] pmp: per million population

Transplanted kidneys pmp[7] from living donors per year

Year	Denmark	Finland	Iceland	Norway	Sweden	Scandiatransplant
2006	10,7	0,6	26,0	17,1	14,4	11,3
2007	10,2	1,0	22,4	18,2	13,4	11,1
2008	13,5	1,7	15,6	20,5	14,8	12,8
2009	16,3	1,1	21,9	21,6	17,7	14,7
2010	18,1	2,1	15,7	17,0	17,9	14,4
2011	18,0	2,4	34,5	14,7	19,5	14,8
2012	13,5	2,0	18,6	16,3	16,3	12,7
2013	18,7	2,4	24,7	13,5	15,8	13,3
2014	19,2	2,7	24,6	13,3	15,6	13,4
2015	20,6	2,7	21,3	12,1	13,3	12,6

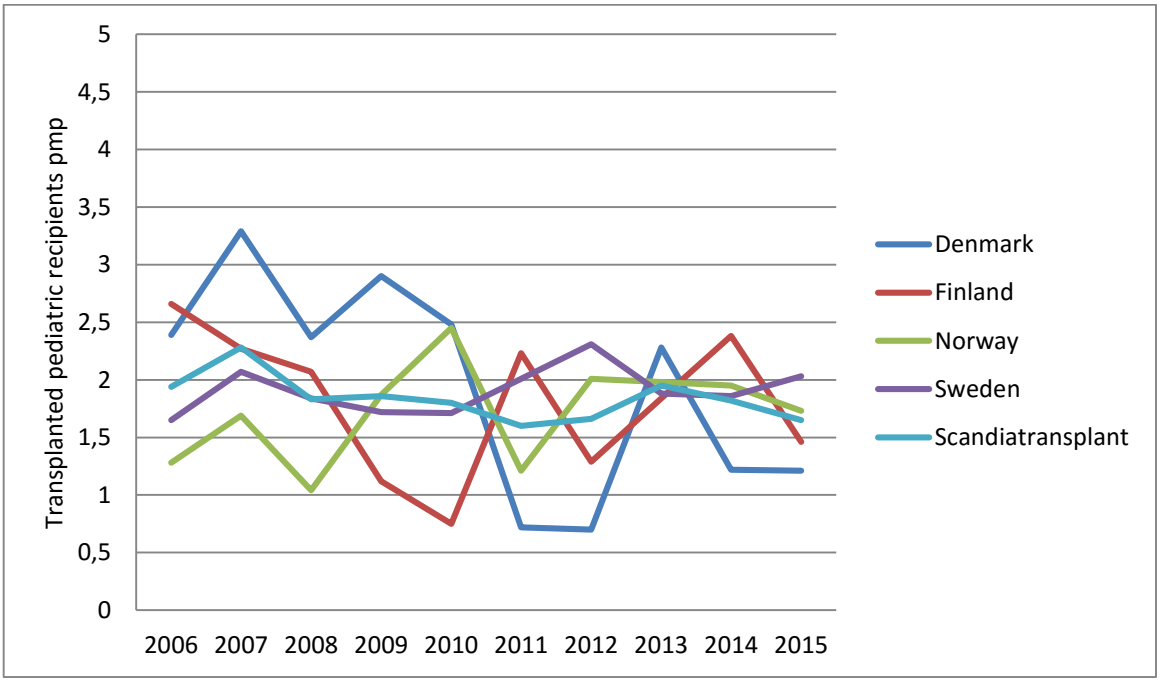


[7] pmp: per million population

Transplanted kidneys to pediatric[8] patients per year (numbers and PMP)

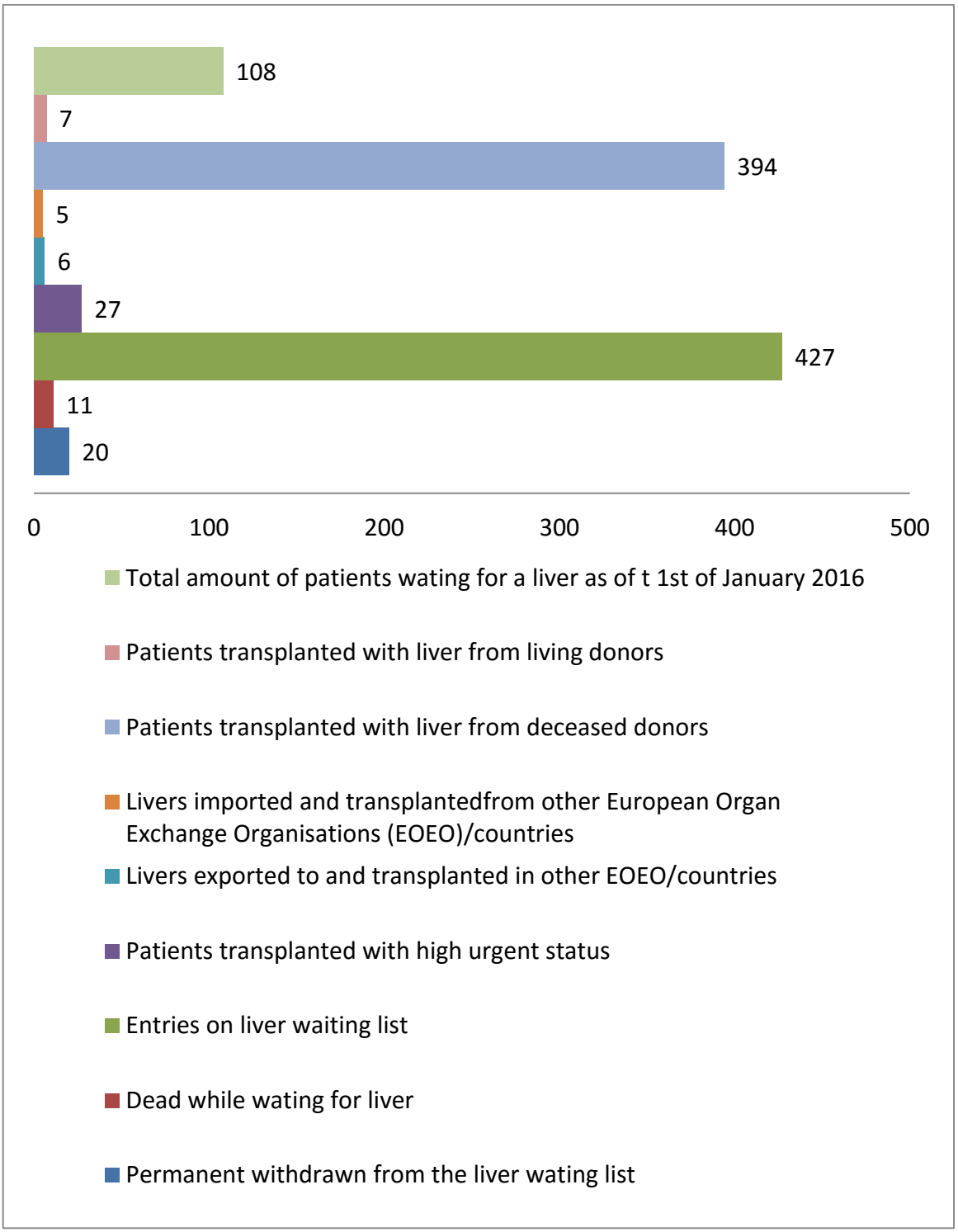
Year	Denmark	Finland	Norway	Sweden	Scandiatransplant
2006	13	14	6	15	48
2007	18	12	8	19	57
2008	13	11	5	17	46
2009	16	6	9	16	47
2010	14	4	12	16	46
2011	4	12	6	19	41
2012	4	7	10	22	43
2013	13	10	10	18	51
2014	7	13	10	18	48
2015	7	8	9	20	44

Year	Denmark	Finland	Norway	Sweden	Scandiatransplant
2006	2,39	2,66	1,28	1,65	1,94
2007	3,29	2,27	1,69	2,07	2,28
2008	2,37	2,07	1,04	1,84	1,83
2009	2,90	1,12	1,87	1,72	1,86
2010	2,48	0,75	2,45	1,71	1,80
2011	0,72	2,23	1,21	2,01	1,60
2012	0,70	1,29	2,01	2,31	1,66
2013	2,28	1,84	1,98	1,88	1,95
2014	1,22	2,38	1,95	1,86	1,82
2015	1,21	1,46	1,73	2,03	1,65



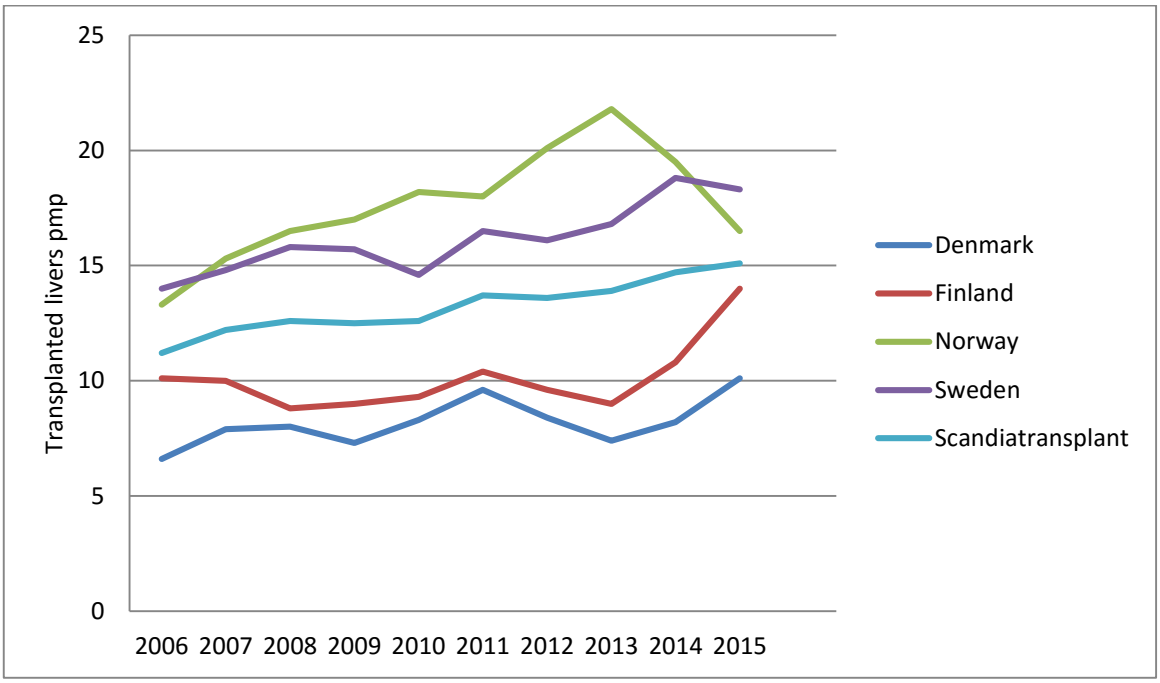
[8] Pediatric recipients < 18 years

Livers 2015


108
7
394
5
6
27
427
11
20
0
100
200
300
400
500
Total amount of patients wating for a liver as of t 1st of January 2016
Patients transplanted with liver from living donors
Patients transplanted with liver from deceased donors
Livers imported and transplantedfrom other European Organ Exchange Organisations (EOEO)/countries
Livers exported to and transplanted in other EOEO/countries
Patients transplanted with high urgent status
Entries on liver waiting list
Dead while wating for liver
Permanent withdrawn from the liver wating list

Transplanted livers (Deceased and living donors) pmp[9] per year

Year	Denmark	Finland	Norway	Sweden	Scandiatransplant
2006	6,6	10,1	13,3	14,0	11,2
2007	7,9	10,0	15,3	14,8	12,2
2008	8,0	8,8	16,5	15,8	12,6
2009	7,3	9,0	17,0	15,7	12,5
2010	8,3	9,3	18,2	14,6	12,6
2011	9,6	10,4	18,0	16,5	13,7
2012	8,4	9,6	20,1	16,1	13,6
2013	7,4	9,0	21,8	16,8	13,9
2014	8,2	10,8	19,5	18,8	14,7
2015	10,1	14,0	16,5	18,3	15,1

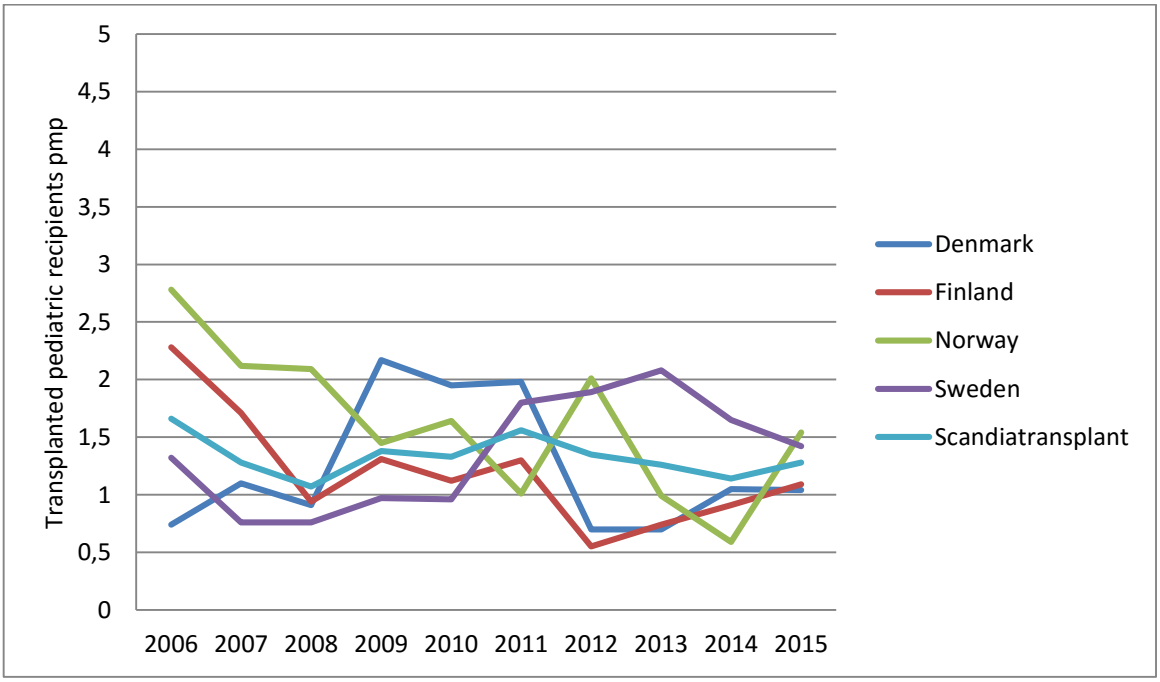


[9] pmp: per million population

Transplanted livers to pediatric[10] patients per year (number and pmp)

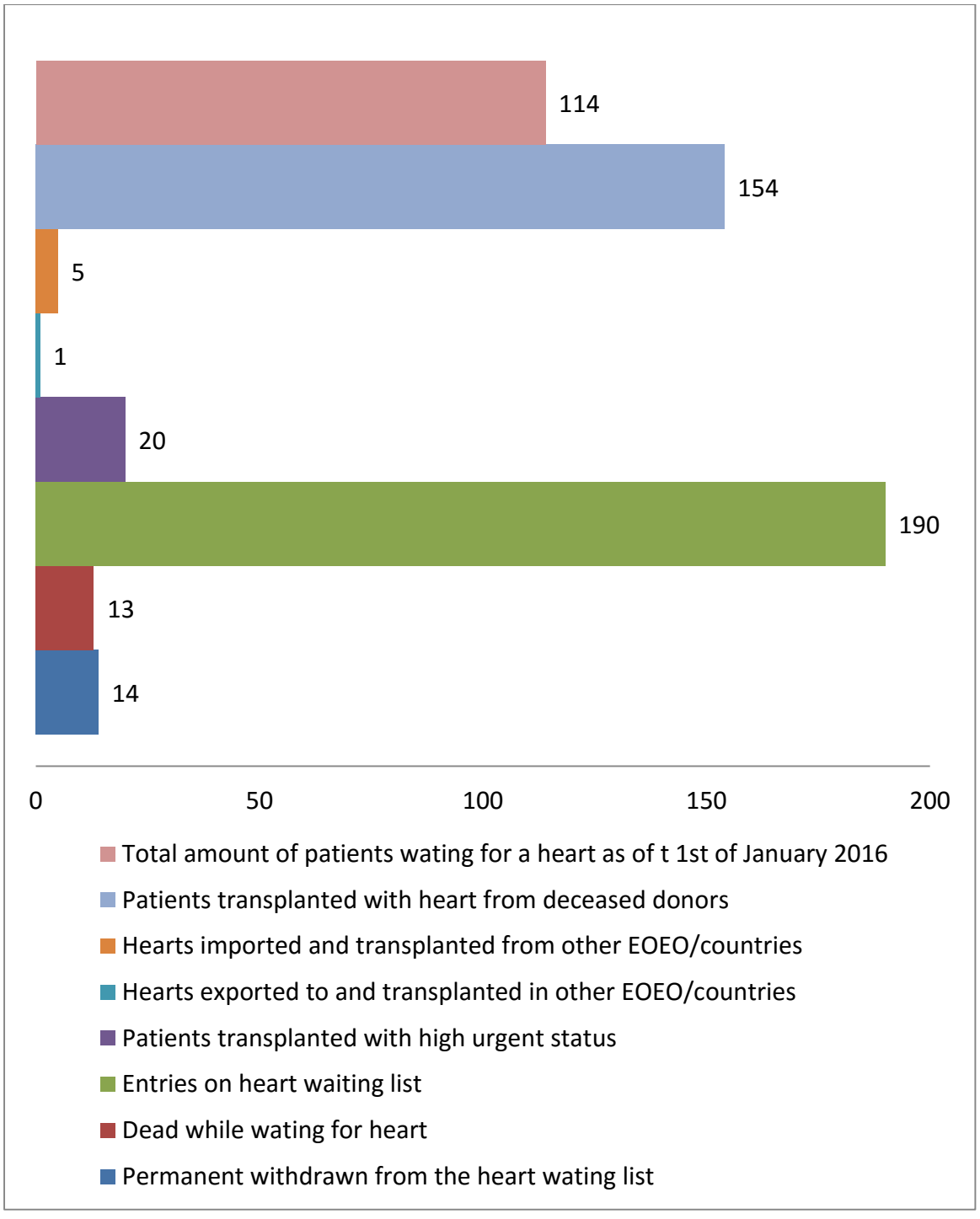
Year	Denmark	Finland	Norway	Sweden	Scandiatransplant
2006	4	12	13	12	41
2007	6	9	10	7	32
2008	5	5	10	7	27
2009	12	7	7	9	35
2010	11	6	8	9	34
2011	11	7	5	17	40
2012	4	3	10	18	35
2013	4	4	5	20	33
2014	6	5	3	16	30
2015	6	6	8	14	34

Year	Denmark	Finland	Norway	Sweden	Scandiatransplant
2006	0,74	2,28	2,78	1,32	1,66
2007	1,10	1,71	2,12	0,76	1,28
2008	0,91	0,94	2,09	0,76	1,07
2009	2,17	1,31	1,45	0,97	1,38
2010	1,95	1,12	1,64	0,96	1,33
2011	1,98	1,30	1,01	1,80	1,56
2012	0,70	0,55	2,01	1,89	1,35
2013	0,70	0,74	0,99	2,08	1,26
2014	1,05	0,91	0,59	1,65	1,14
2015	1,04	1,09	1,54	1,42	1,28



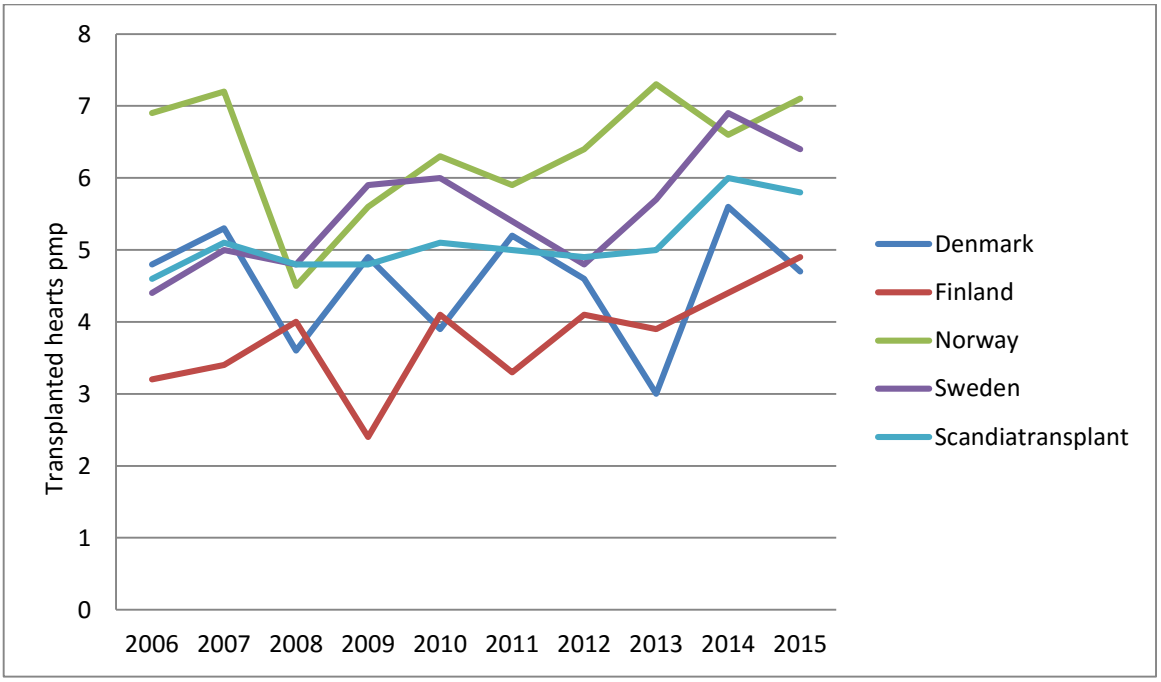
[10] Pediatric recipients < 18 years

Hearts 2015


114
154
5
1
20
190
13
14
0
50
100
150
200
Total amount of patients wating for a heart as of t 1st of January 2016
Patients transplanted with heart from deceased donors
Hearts imported and transplanted from other EOEO/countries
Hearts exported to and transplanted in other EOEO/countries
Patients transplanted with high urgent status
Entries on heart waiting list
Dead while wating for heart
Permanent withdrawn from the heart wating list

Transplanted hearts pmp[11] per year

Year	Denmark	Finland	Norway	Sweden	Scandiatransplant
2006	4,8	3,2	6,9	4,4	4,6
2007	5,3	3,4	7,2	5,0	5,1
2008	3,6	4,0	4,5	4,8	4,8
2009	4,9	2,4	5,6	5,9	4,8
2010	3,9	4,1	6,3	6,0	5,1
2011	5,2	3,3	5,9	5,4	5,0
2012	4,6	4,1	6,4	4,8	4,9
2013	3,0	3,9	7,3	5,7	5,0
2014	5,6	4,4	6,6	6,9	6,0
2015	4,7	4,9	7,1	6,4	5,8

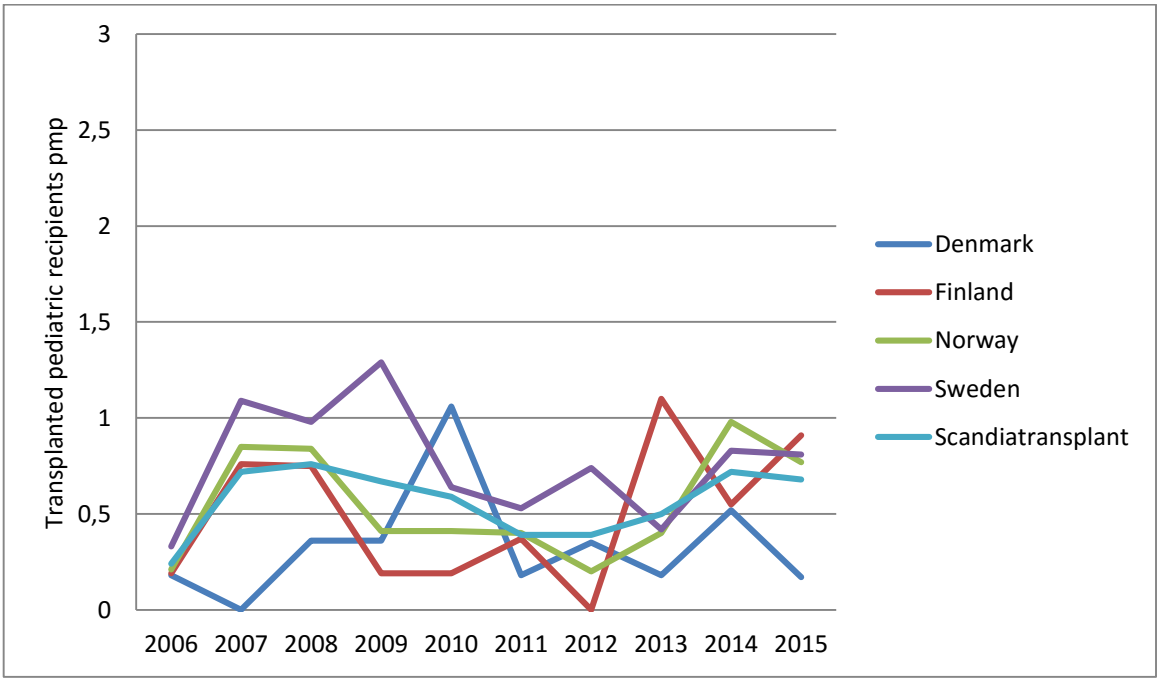


[11] pmp: per million population

Transplanted hearts to pediatric[12] patients per year (number and pmp)

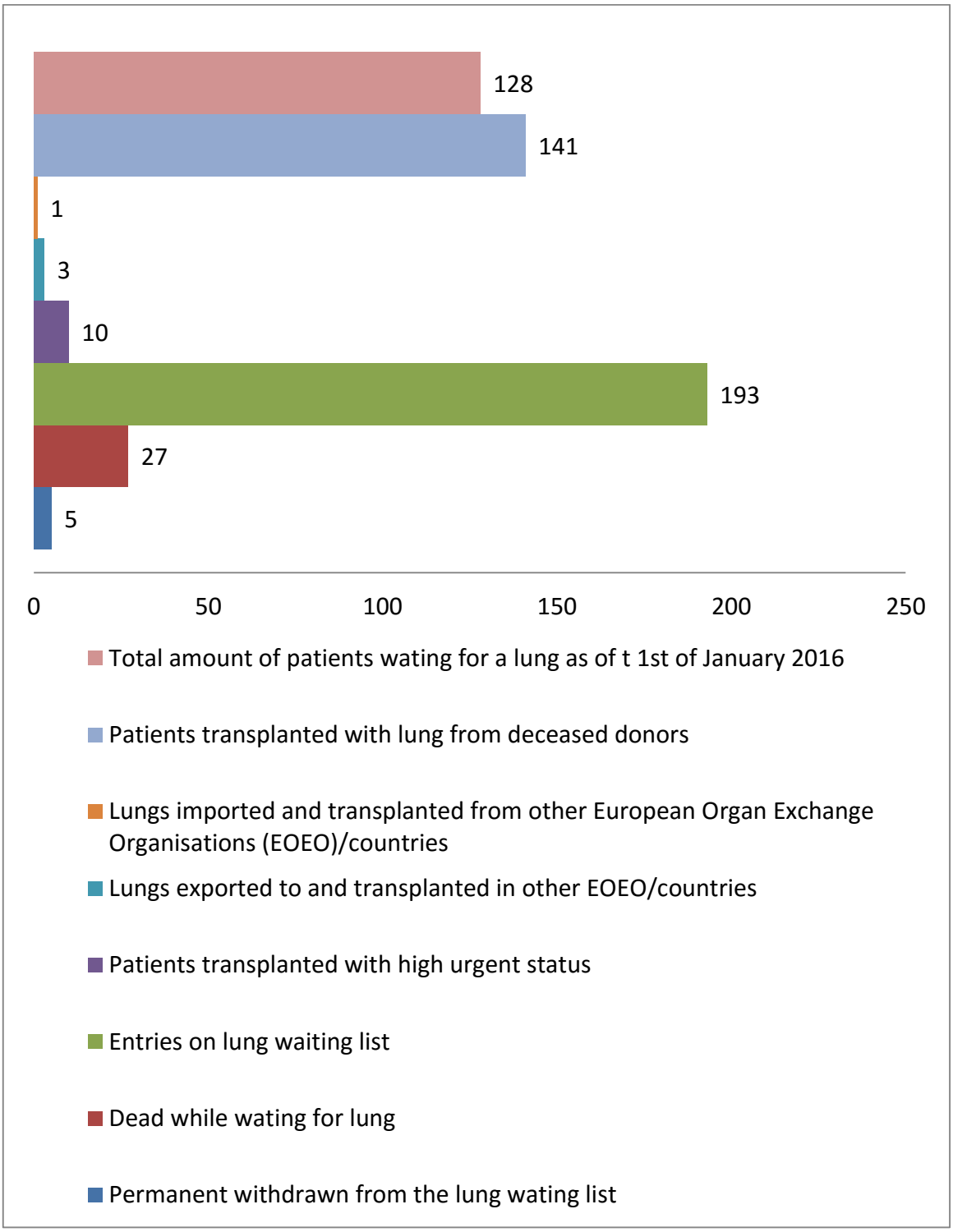
Year	Denmark	Finland	Norway	Sweden	Scandiatransplant
2006	1	1	1	3	6
2007	0	4	4	10	18
2008	2	4	4	9	19
2009	2	1	2	12	17
2010	6	1	2	6	15
2011	1	2	2	5	10
2012	2	0	1	7	10
2013	1	6	2	4	13
2014	3	3	5	8	19
2015	1	5	4	8	18

Year	Denmark	Finland	Norway	Sweden	Scandiatransplant
2006	0,18	0,19	0,21	0,33	0,24
2007	0	0,76	0,85	1,09	0,72
2008	0,36	0,75	0,84	0,98	0,76
2009	0,36	0,19	0,41	1,29	0,67
2010	1,06	0,19	0,41	0,64	0,59
2011	0,18	0,37	0,40	0,53	0,39
2012	0,35	0	0,20	0,74	0,39
2013	0,18	1,10	0,40	0,42	0,50
2014	0,52	0,55	0,98	0,83	0,72
2015	0,17	0,91	0,77	0,81	0,68



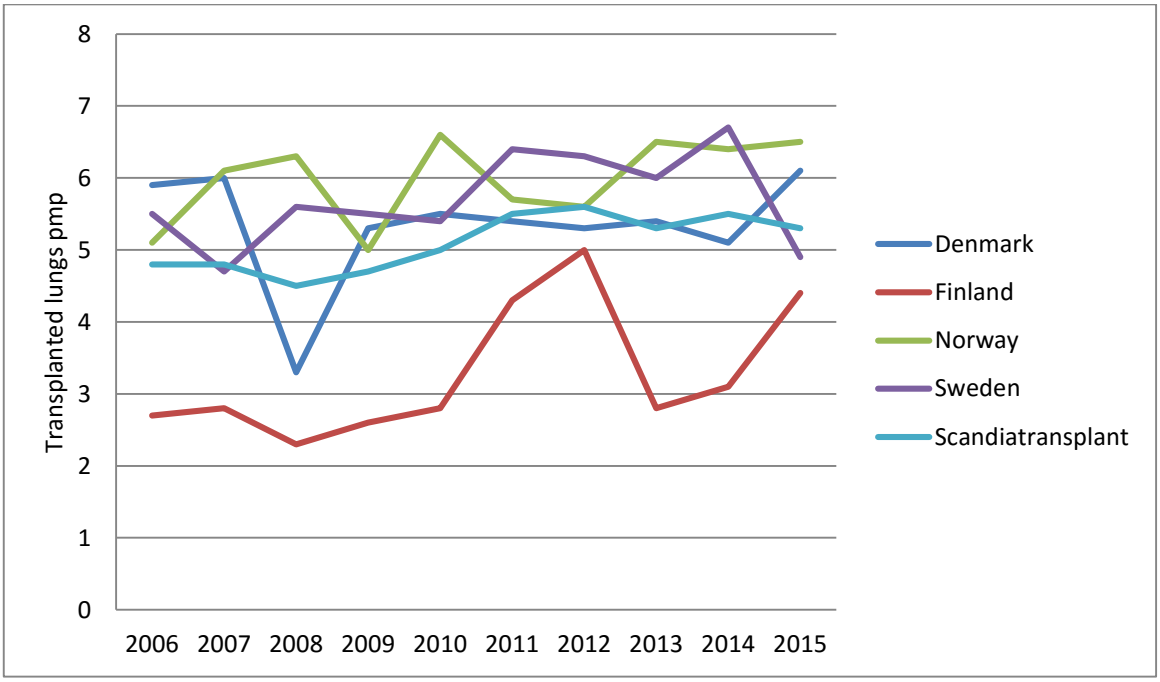
[12] Pediatric recipients < 18 years

Lungs 2015


128
141
1
3
10
193
27
5
0
50
100
150
200
250
Total amount of patients wating for a lung as of t 1st of January 2016
Patients transplanted with lung from deceased donors
Lungs imported and transplanted from other European Organ Exchange Organisations (EOEO)/countries
Lungs exported to and transplanted in other EOEO/countries
Patients transplanted with high urgent status
Entries on lung waiting list
Dead while wating for lung
Permanent withdrawn from the lung wating list

Transplanted lungs (Double, single and heart-lung) pmp[13] per year

Year	Denmark	Finland	Norway	Sweden	Scandiatransplant
2006	5,9	2,7	5,1	5,5	4,8
2007	6,0	2,8	6,1	4,7	4,8
2008	3,3	2,3	6,3	5,6	4,5
2009	5,3	2,6	5,0	5,5	4,7
2010	5,5	2,8	6,6	5,4	5,0
2011	5,4	4,3	5,7	6,4	5,5
2012	5,3	5,0	5,6	6,3	5,6
2013	5,4	2,8	6,5	6,0	5,3
2014	5,1	3,1	6,4	6,7	5,5
2015	6,1	4,4	6,5	4,9	5,3

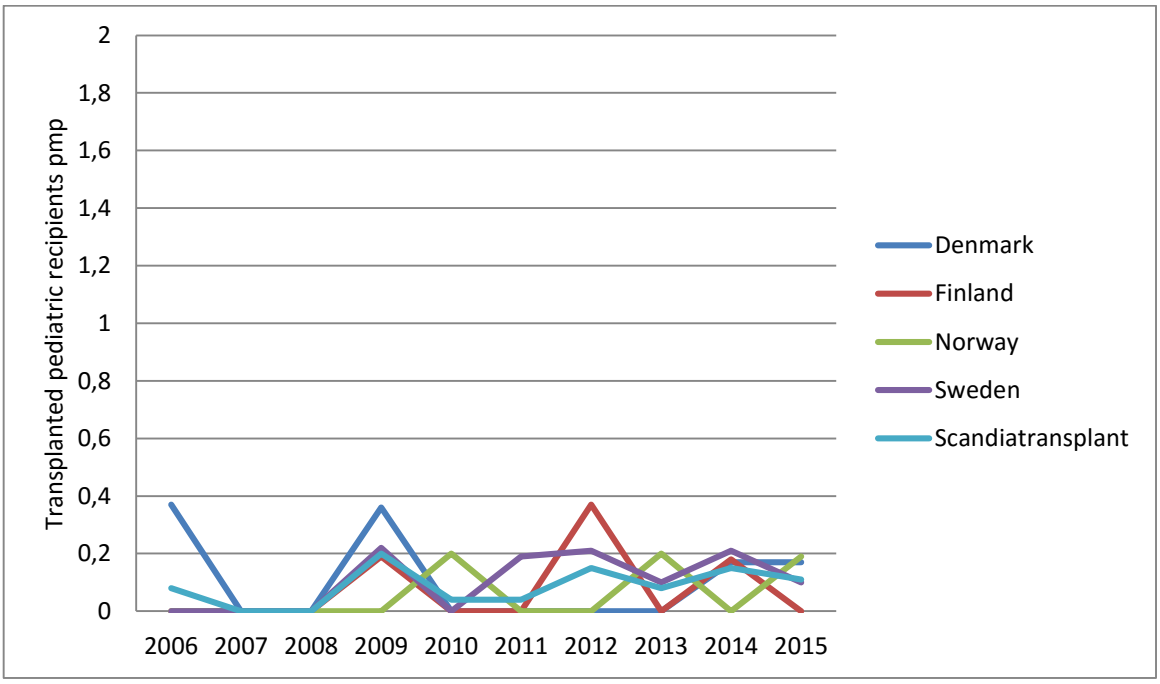


[13] pmp: per million population

Transplanted lungs to pediatric[14] patients per year (numbers and pmp)

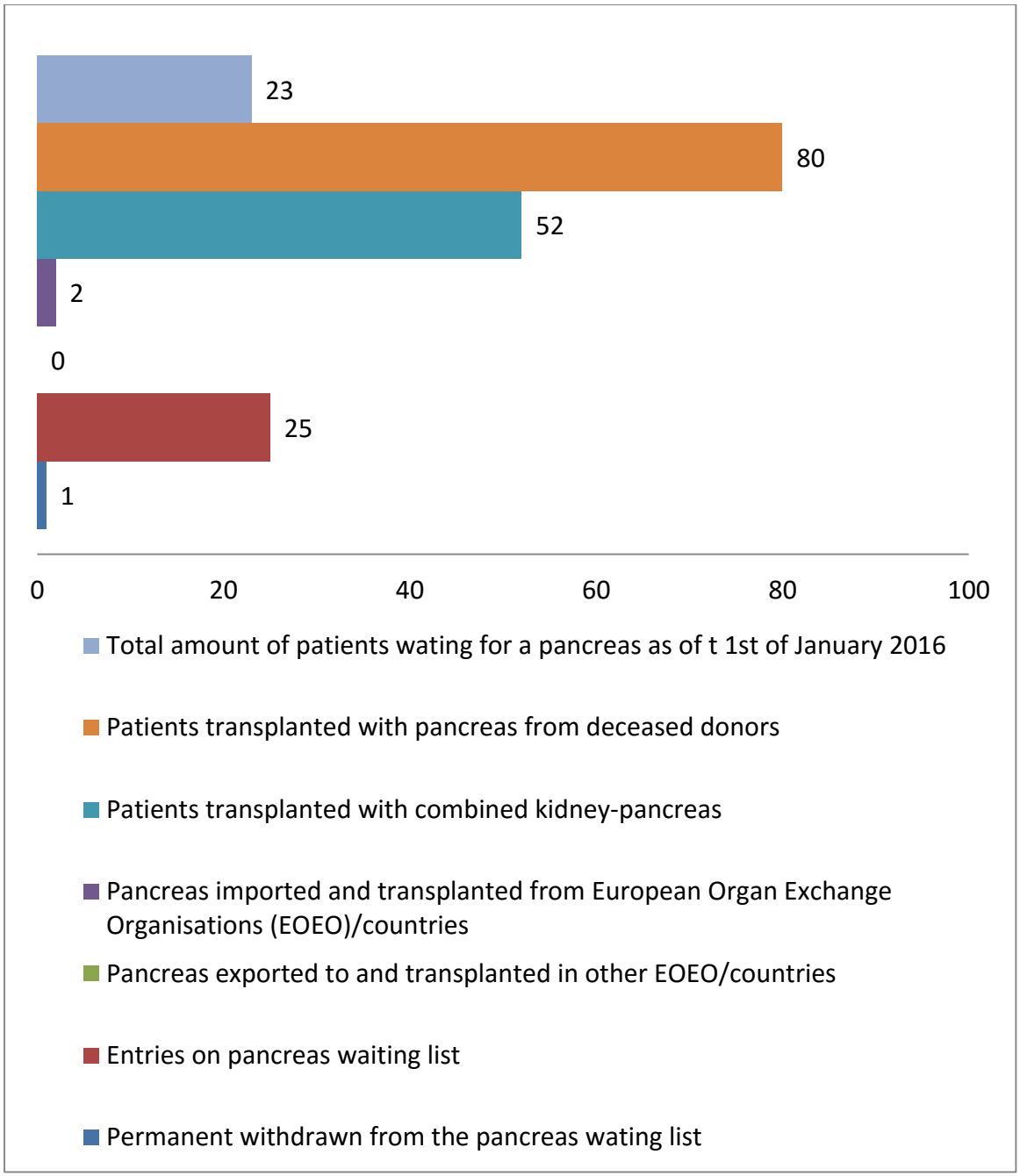
Year	Denmark	Finland	Norway	Sweden	Scandiatransplant
2006	2	0	0	0	2
2007	0	0	0	0	0
2008	0	0	0	0	0
2009	2	1	0	2	5
2010	0	0	1	0	1
2011	0	0	0	1	1
2012	0	2	0	2	4
2013	0	0	1	1	2
2014	1	1	0	2	4
2015	1	0	1	1	3

Year	Denmark	Finland	Norway	Sweden	Scandiatransplant
2006	0,37	0	0	0	0,08
2007	0	0	0	0	0
2008	0	0	0	0	0
2009	0,36	0,19	0	0,22	0,20
2010	0	0	0,20	0	0,04
2011	0	0	0	0,19	0,04
2012	0	0,37	0	0,21	0,15
2013	0	0	0,20	0,10	0,08
2014	0,17	0,18	0	0,21	0,15
2015	0,17	0	0,19	0,10	0,11



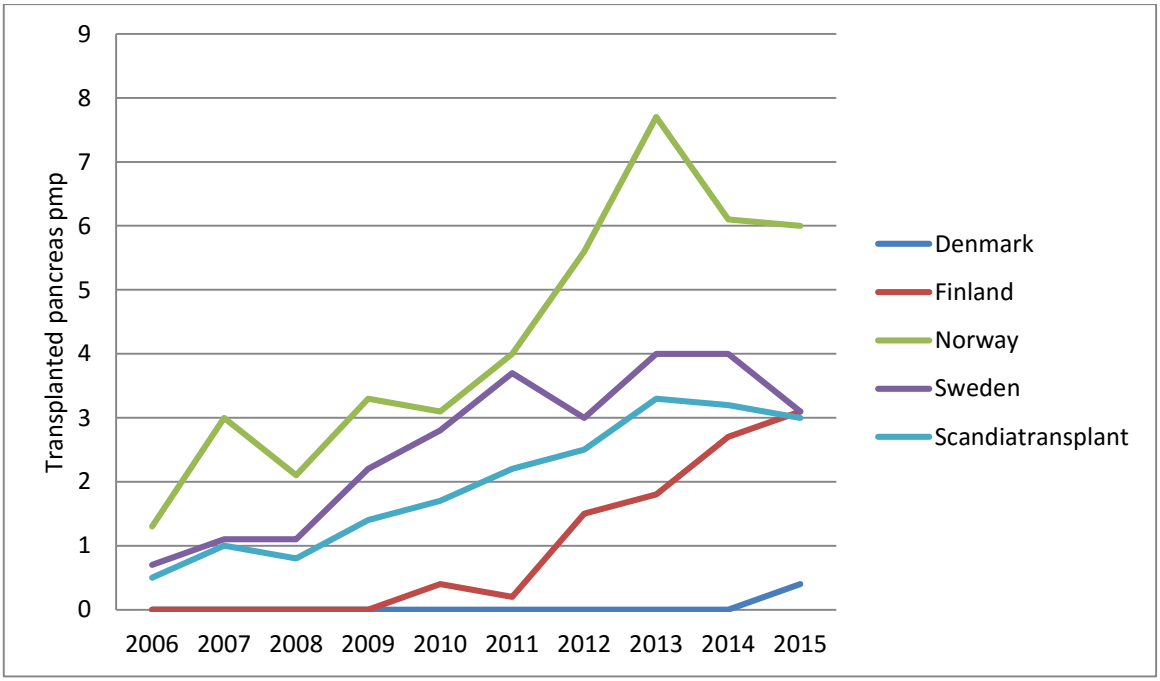
[14] Pediatric recipients < 18 years

Pancreas 2015



Transplanted pancreas pmp[15] per year

Year	Denmark	Finland	Norway	Sweden	Scandiatransplant
2006	0	0	1,3	0,7	0,5
2007	0	0	3,0	1,1	1,0
2008	0	0	2,1	1,1	0,8
2009	0	0	3,3	2,2	1,4
2010	0	0,4	3,1	2,8	1,7
2011	0	0,2	4,0	3,7	2,2
2012	0	1,5	5,6	3,0	2,5
2013	0	1,8	7,7	4,0	3,3
2014	0	2,7	6,1	4,0	3,2
2015	0,4	3,1	6,0	3,1	3,0



[15] pmp: per million population

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(Chairman)	(Medical Director)	(Clinical Data Manager)