

ODTI

# Organ Donation and Transplant Ireland

ANNUAL REPORT 2014



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Organ Donation and Transplant Ireland has been delegated the regulatory functions assigned to the HSE in Statutory Instrument 325, European Union (Quality and Safety of Human Organs Intended for Transplantation) Regulations 2012.

Statutory Instrument (SI) 325 (2012) Part 5

*Reporting obligations of HSE*

25.

(1) The HSE shall—

- (a) keep a record of the activities of procurement organisations and transplantation centres, including aggregated numbers of living and deceased donors, and the types and quantities of organs procured and transplanted, or otherwise disposed of in accordance with European Union and national provisions on the protection of personal data and statistical confidentiality,
- (b) draw up and make publicly accessible an annual report on activities referred to in subparagraph (a), and
- (c) establish and maintain an updated record of procurement organisations and transplantation centres.

(2) The HSE shall, upon the request of the Commission or another Member State, provide information on the record of procurement. organisations and transplantation centres.

# Message from the Director

This report outlines the main activities of ODTI in 2014, and plans and goals for 2015.

Thanks to the generosity of 63 families donating the organs of their relatives, 211 people received the gift of life. In addition 40 people have generously donated their kidney to a family member. Meanwhile outcomes for transplant recipients in Ireland rank amongst the best in Europe.

Living kidney donation plays a vital role in transplantation. We have once again seen a record year in the number of living kidney donors. 2014 was a significant year as the Living Donor Reimbursement Policy was introduced by the Minister of Health, Leo Varadkar.

However, the need for organ transplants is increasing. There were 636 patients waiting for an organ transplant at the end of 2014.

Following receipt of much needed funding in 2014, ODTI are in the process of enhancing structures related to organ donation with the support of HSE senior management, the Minister of Health and Department of Health. We have recruited 5 new procurement coordinators and 6 nurse leads across the country. Also six Intensive Care Unit (ICU) Consultants are to be appointed.

I would like to acknowledge the contribution of the three transplant centres in Ireland. Without exception, each transplant centre has provided a complete and responsive service for the Irish public. I would also like to particularly acknowledge the ICUs in the organ donating hospitals across Ireland who have worked closely, cooperatively and professionally with the transplant centres and ODTI. I would like to acknowledge my own team in ODTI and the National Organ Donation and Transplantation Advisory Group for their dedication, commitment and direction in 2014.

Most importantly, I acknowledge the courage and generosity of families that have donated their loved one's organs.

**Professor Jim Egan**  
**Director**  
**Organ Donation and Transplant Ireland**



# Report from the ODTI

Organ Donation and Transplant Ireland (formerly the National Organ Donation and Transplantation Office) was established in 2011. It acts under legislation SI 325 (2012) as the delegated body for the HSE, to establish quality standards and protocols for the entire solid organ donation/transplantation process and to comply with the EU Commission's 10 point action plan in relation to organ donation and transplantation.

The ODTI was initiated to provide governance, integration and leadership for organ donation and transplant in Ireland. The office is responsible for:

- The development, coordination and management of a strategic framework for organ donation and transplant.
- Informing the continual development of services and ensuring best use of resources.
- Facilitating an integrated team approach to organ donation and transplant services within Ireland.

The Directive on standards of quality and safety of human organs intended for transplantation was signed into Irish legislation in 2012 and assigns the following responsibilities to the ODTI:

- Ensure that a framework for quality and safety is established to cover all stages of organ donation and transplant of organs
- Ensure that reporting systems are in place for adverse events related to the quality and safety of organs for organ donation and transplantation
- Ensure data collection for publication annually in relation to organ donation and transplantation activities
- Ensure appropriate organ exchange agreements and arrangements are in place between member states
- Ensure that a living donor register is kept in accordance with data protection legislation

## National Organ Donation and Transplantation Advisory Group

The National Organ Donation and Transplant Advisory Group provides recommendations and sets direction for ODTI.

# Overview of 2014

## Service Planning

ODTI received funding in the 2014 HSE Service Plan for the development of Organ Donation and Transplant services in Ireland. The funding facilitates the implementation of an infrastructure of dedicated expertise at local and national level to strengthen service provision and to support services to develop quality systems for the traceability of organs from organ donation right through to transplantation and outcomes.

ODTI recruited the Quality Management team and the National Organ Procurement Service team in 2014. Recruitment commenced on a national network of Organ Donation Nurse Managers.

Funding was assigned for the implementation of the Living Kidney Donor Reimbursement Scheme. A policy document was developed in conjunction with the Department of Health and Beaumont Hospital and was signed by Minister Leo Varadkar, TD in November 2014. The reimbursement scheme allows for living donors to claim loss of earnings and out of pocket expenses directly due to the living donation, up to a maximum limit set in the policy.

Organ donation awareness is an essential part of ensuring that a sustainable transplant programme can survive and thrive. It is only because of the generosity of the Irish public that patients can receive the life saving treatment of an organ transplant. The Irish Kidney Association has a long experience of organ donation awareness, was given funding by the ODTI to deliver specific organ donation awareness initiatives in 2014.

A working group on public awareness was established in ODTI in 2014. Since then the group agreed to carry out a survey on public attitudes and awareness of organ donation, the results of which are expected to be available in 2015.

## Quality and Safety Framework

The ODTI, in conjunction with the Health Products Regulatory Authority (HPRA), published in 2014 A Framework for Quality and Safety of Human Organs Intended for Transplantation to cover all stages of the chain from donation to transplantation or disposal; in compliance with Part 3, Regulation 12, of S.I. No 325 of 2012 and the rules laid down in the European Directive on the Quality and Safety of Organs intended for transplantation (2010/53/EU).

The framework for quality and safety provides for, and includes details on, the roles and responsibilities regarding the adoption and implementation of operating procedures for:

- a) The verification of donor identity;
- b) The verification of the details of the donor's or the donor family's consent;
- c) The verification of the completion of the organ and donor characterisation in accordance with Regulation 15 and the Annex to the Directive;
- d) The procurement, preservation, packaging and labelling of organs in accordance with Regulations 13, 14 and 16;
- e) The transportation of organs in accordance with Regulation 16;
- f) Ensuring traceability, in accordance with Regulation 18, guaranteeing compliance with the European Union and national provisions on the protection of personal data and confidentiality;



- g) The accurate, rapid and verifiable reporting of serious adverse reactions and events in accordance with Regulation 19;
- h) The management of serious adverse reactions and events in accordance with Regulation 19.

The Framework is used by the HPRA in association with other relevant guidance for authorisation of transplant centres and procurement organisations. The three transplant centres in Ireland were assessed in 2014. Authorisation action plans have been developed between the HPRA and each transplant centre to complete the authorisation programme in 2015.

### **Adverse Reaction/Events (SAR/E)**

The ODTI and the Health Product Regulatory Authority (HPRA) have joint responsibility to receive serious adverse events in relation to organ donation and transplantation. All SAR/Es are reviewed by the NODTAG and advice is issued as appropriate to the relevant locations. The purpose of the reporting system is to learn and improve from the experience of the adverse events. In all cases they are dealt with appropriately at location and at national level, where relevant, and the learning is shared within the relevant organisations.

### **Service Performance**

ODTI continues reporting on organ donation and transplant activities on a regular basis. This includes gathering and reporting on activities as requested by parliamentary questions, public representations, media queries, European Commission, international bodies and other areas of the health services looking for information. The office, in partnership with the procurement service and transplant centres, functions as the source for information for any European data that has been collected.

### **Organ Donation Infrastructure**

ODTI has collaborated with hospitals around the country to implement organ donation structures, commencing with Organ Donation Nurse Managers and Intensive Care Consultants with a special interest in Organ Donation.

### **National Organ Procurement Service Transition Programme**

The National Organ Procurement Service (NOPS) transition programme began with the recruitment of a NOPS Nurse Manager in October 2014. The NOPS Nurse Manager spent a week in an established Nurse Procurement Centre in the UK shadowing the staff and witnessing the Health and Lifestyle questionnaire in practice. Following on from this a network has been built up with the Centre for future training needs. The team expanded with the commencement of four other NOPS Coordinators in January 2015.

### **Meetings And Collaboration with Stakeholders**

The office has worked closely and collaborated with the HSE, regulatory bodies, the Department of Health, stakeholders and patient organisations to advance and promote organ donation and transplantation in Ireland. The office led and participated in meetings with the Department of Health, the HPRA, patient organisations, transplant centres, NHS Blood & Transplant other national health services in 2014. Representatives from the office attended European Regulatory and Clinical meetings and met with relevant personnel in other European Union Member States.

# Donation and Transplant Programmes

## Organ Donation and Retrieval in Ireland

Organ donation in Ireland is based on a voluntary donation system (opt in) and occurs in 33 intensive care units throughout Ireland.

The three transplant centres, which have developed independently of each other, have different requirements in relation to organ donation. Each transplant centre has its own organ retrieval team, which provides 24/7 service and which travels nationwide to retrieve organs.

## National Organ Procurement Service (NOPS)

The renal transplant coordinators based in Beaumont Hospital have provided procurement (donor) coordination services for liver, lung and heart transplantation as well as their own original primary function of coordinating renal and pancreas transplantation. The coordinators have delivered a 24 hour on-call service for the three transplant centres and deal with all organ donor referrals. Furthermore they have provided a valuable link between donor families and the recipients, culminating in the organisation of, with the Irish Kidney Association, an Annual Service of Remembrance and Thanksgiving for organ donors, their families and recipients.

A process began with regard to transferring NOPS to ODTI in the final quarter of 2014.

## National Kidney and Pancreatic Transplant Service (NKPTS)

The National Renal & Pancreatic Transplant Service is the longest established and largest transplant programme in Ireland and is based in Beaumont Hospital. The first Kidney Transplant was performed in Jervis Street Hospital in January 1964 and by the end of 2014 over 4500 renal transplants have taken place. There are approximately 2300 recipients alive with functioning kidney transplants. Pancreas transplantation was established in 1992, and since then over 130 simultaneous pancreas and kidney transplants have been performed on patients with diabetes mellitus. The NKPTS also runs the Living Kidney Donor Programme and to date over 200 renal transplants have taken place because of living donation.

Prior to 2003 any child requiring a kidney transplant had to attend Beaumont Hospital. However, for the past 10 years the Transplant team from Beaumont Hospital have been working with their paediatric colleagues to provide the paediatric renal transplantation service within the Children's University Hospital, Temple Street and to date over 100 transplants have taken place there.

2014 also saw the retirement of Mr. David Hickey following a long distinguished career dedicated to organ transplantation.

### **National Liver Transplant Service**

The liver transplant programme has been running in St. Vincent's University Hospital since 1993. By the end of 2014, 889 liver transplants have been performed, with outcomes very much in keeping with the best results achieved in UK and European centres.

The continued success of the liver transplant programme and the comprehensive multidisciplinary approach to liver disease, which is employed in St Vincent's University Hospital, has resulted in an increased rate of referral of patients for consideration for liver transplantation. Liver Transplantation is carried out for a wide variety of indications including both acute liver failure and chronic liver disease.

### **The National Heart and Lung Transplant Service**

The National Heart Transplant Service has been in place since 1985 and is based at the Mater Misericordiae University Hospital (MMUH). To date over 300 heart transplants have been performed. The Lung Transplant programme is also located at the MMUH and has been in place since 2005 and since then the programme has grown incrementally. In 2006 the first double lung transplant was undertaken and in 2007 the first lung transplant for a cystic fibrosis patient occurred. The 100th Lung Transplant took place in the summer of 2014, and marked with a Thanksgiving Service in October.

### **Paediatric Liver, Heart and Lung Transplants**

The paediatric liver and heart transplantation is managed via Our Lady's Hospital, Crumlin, and the paediatric lung programme is managed via the Children's University Hospital, Temple St. Due to the small numbers involved, the transplants take place in UK hospitals that are centres of excellence for paediatric transplantation.

# Activity in 2014

Ireland continues to do well in comparison with other countries in the EU, ranking in the top 50% for organ donation.

While the number of donors decreased in 2014 (63 compared to 86 in 2013), the utilisation of organs per donor was higher at 3.4 : 1 (3.0 : 1 in 2013).

Kidney transplantation is the most common form of renal replacement therapy in Ireland, with 55% of patients being treated with a transplant while 45% are on some form of dialysis.

In 2014, there were a record number of paediatric kidney transplants (n=20), resulting in an all time low of just sixteen children remaining on dialysis.

Furthermore the kidney living donor programme continues to expand achieving 40 living donations in 2014, the highest number to date. For further information on the kidney transplant programme see <http://www.beaumont.ie/media/BeaumontHospitalKidneyTransplantReport2013%5B1%5D1.pdf>

While the number of liver transplants was lower than the previous year, the percentage of transplants from donations was higher (up by 6%).

Heart transplants were up 64% from 2013, the highest this millennium.

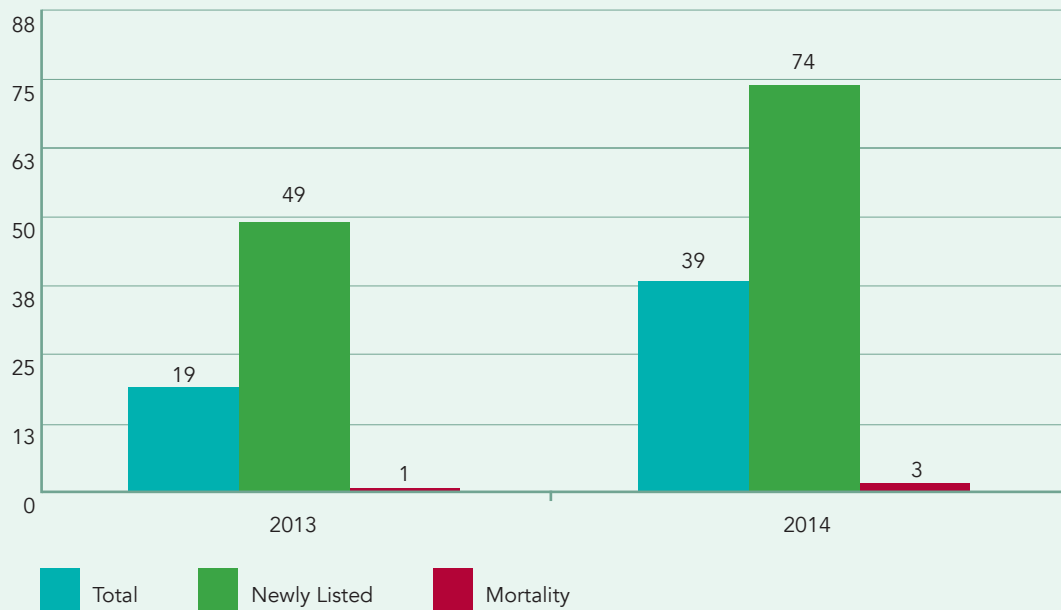
The high number of lung transplants (n=31) continued in 2014, with Ireland having the third highest rate of lung transplantations in Europe.

# Numbers on Waiting List (31st Dec 2014)

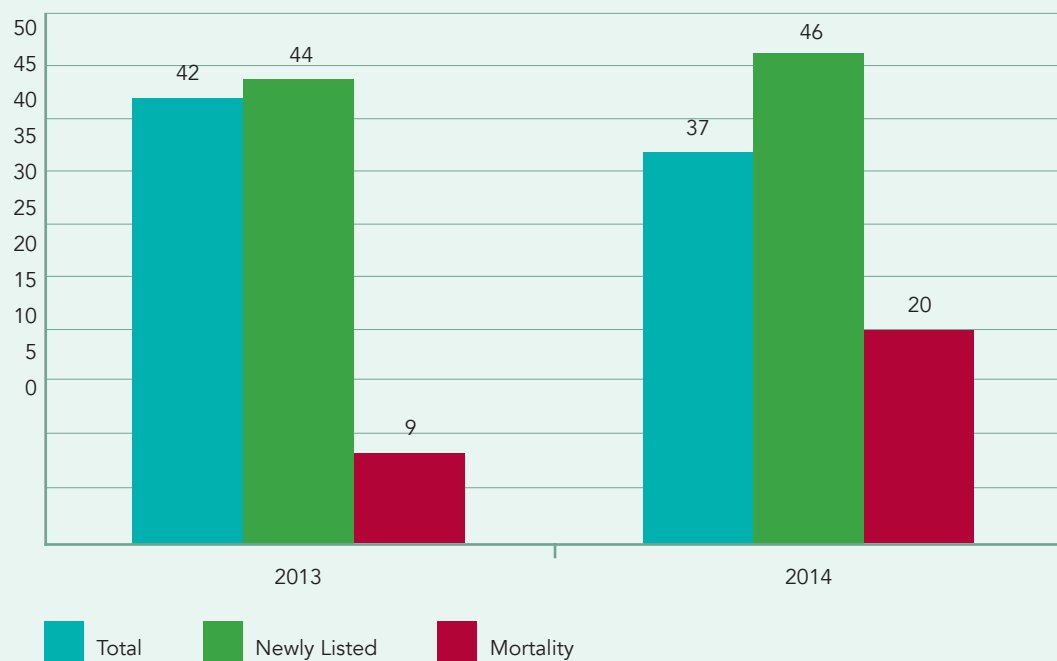
## Kidney Waiting List (Median time 31 Months in 2014)



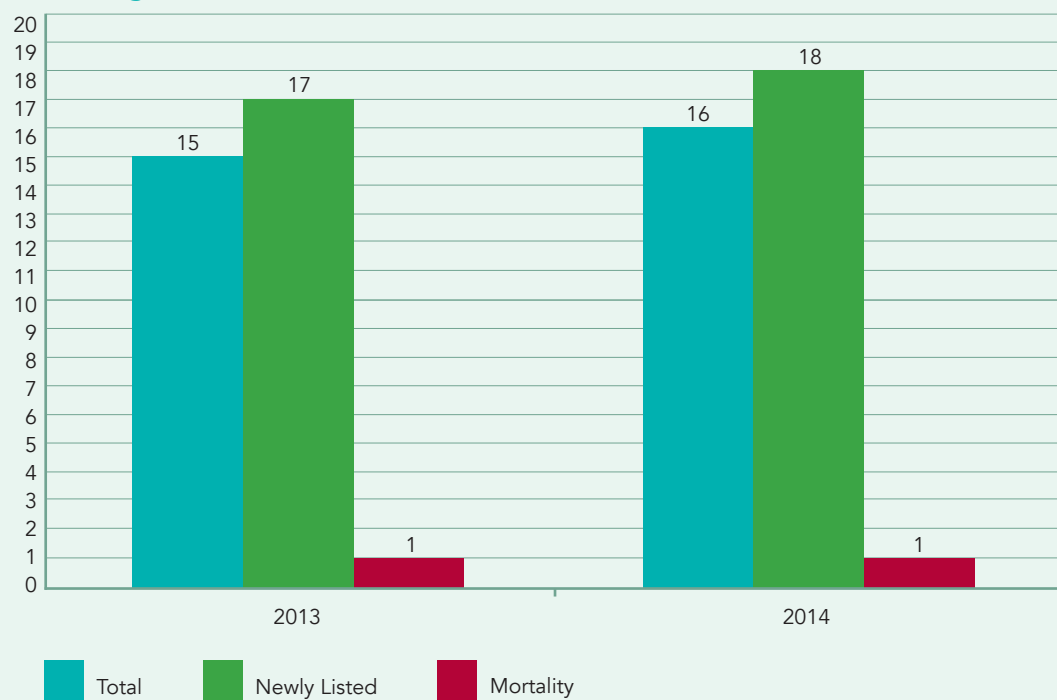
## Liver Waiting List (Median time 5 Months in 2014)



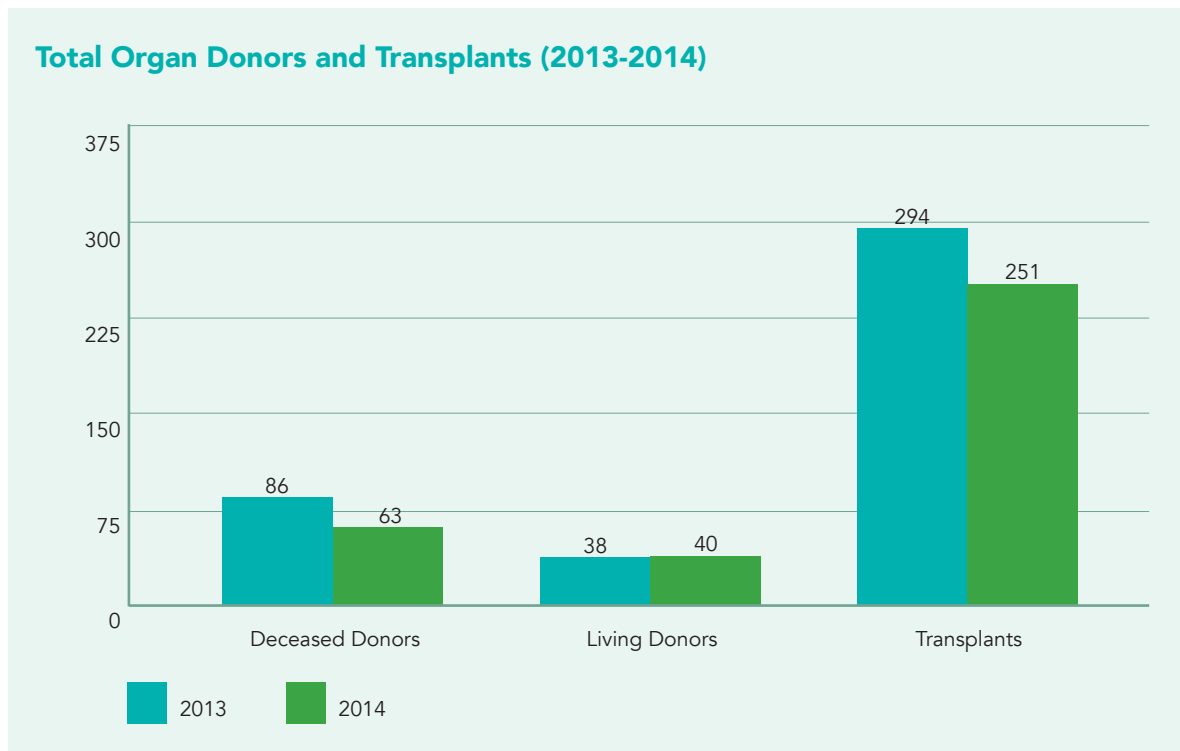
### Lung Waiting List (Median time 4.5 Months in 2014)



### Heart Waiting List (Median time 2.6 Months in 2014)

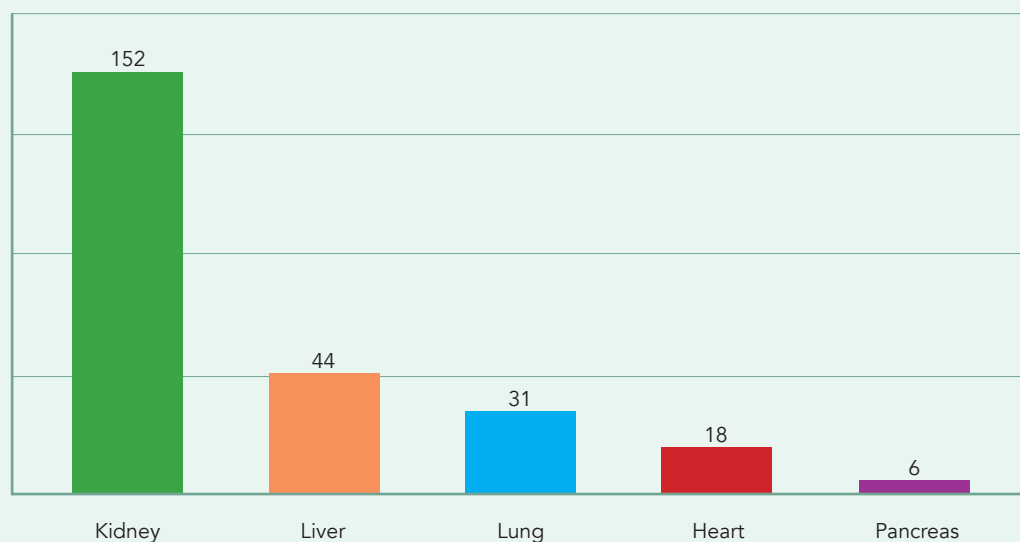


# Organ Donation



	2013	2014
<b>Ratio of transplants to donors</b>	3.0 : 1	3.4 : 1

## Organs Transplanted (2014)



## Transplant Summary 2010 - 2014

Organ Transplant 2010 - 2014								
		2010	2011	2012	2013	2014	5 year total	5 year average
Transplantation From Deceased	Kidney	98	165	131	147	112	653	131
	Liver	38	61	50	55	44	248	50
	Lungs	4	8	14	32	31	89	18
	Heart	3	6	10	11	18	48	10
	Pancreas	8	8	1	11	6	34	7
<b>Sub-total</b>		<b>151</b>	<b>248</b>	<b>206</b>	<b>256</b>	<b>211</b>	<b>1072</b>	<b>214</b>
Living Kidney Transplants		23	27	32	38	40	160	32
Living and Deceased Kidney Transplants		121	192	163	185	152	813	163
<b>Total Organ Transplants</b>		<b>174</b>	<b>275</b>	<b>238</b>	<b>294</b>	<b>251</b>	<b>1232</b>	<b>248</b>



## Donor Figures Per Hospital Group (2010-2014)

Dublin North East				
2010	2011	2012	2013	2014
19	29	20	28	21

\*Beaumont Hospital; Our Lady of Lourdes Hospital, Drogheda; Connolly Hospital; Cavan General Hospital; Rotunda Hospital; Louth County Hospital; Monaghan Hospital.

Dublin Midlands				
2010	2011	2012	2013	2014
6	14	12	11	9

\*St James's Hospital; Tallaght Hospital; Midlands Regional Hospital, Tullamore General Hospital; Naas General Hospital; Midlands Regional Hospital, Portlaoise General Hospital.

Dublin East				
2010	2011	2012	2013	2014
11	14	19	11	8

\*Mater Misericordiae University Hospital; St Vincent's University Hospital; Midland Regional Hospital, Mullingar; St Luke's General Hospital, Kilkenny; Wexford General Hospital; Our Lady's Hospital Navan; St Columcille's Hospital; St Michael's Hospital Dun Laoghaire.

South/South West				
2010	2011	2012	2013	2014
11	20	15	20	12

\*Bantry General Hospital; Cork University Hospital; Cork University Maternity Hospital; Kerry General Hospital; Mallow General Hospital; Mercy University Hospital; South Infirmary Victoria University Hospital; South Tipperary General Hospital; Waterford Regional Hospital.

West/North West				
2010	2011	2012	2013	2014
8	9	7	10	5

\*University Hospital Galway; Merlin Park University Hospital; Sligo Regional Hospital; Letterkenny General Hospital; Mayo General Hospital; Portiuncula Hospital; Roscommon County Hospital.

Midwest Group				
2010	2011	2012	2013	2014
2	4	4	4	4

\*Mid-Western Regional Hospital, Limerick; Ennis General Hospital; Nenagh General Hospital; St John's Hospital Limerick.

Acute Paediatric Dublin				
2010	2011	2012	2013	2014
1	1	1	2	4

\*Our Lady's Children's Hospital, Crumlin; Children's University Hospital, Temple Street; National Children's Hospital, Tallaght

Others				
2010	2011	2012	2013	2014
0	2	0	0	0

Mater Private Hospital; Bon Secours Hospital, Cork; Blackrock Clinic.

National Overall Total				
2010	2011	2012	2013	2014
58	93	78	86	63

Donors Per Million of Population				
2010	2011	2012	2013	2014
12.8	20.6	17.3	19	14

## European Deceased Organ Donor Rates 2013

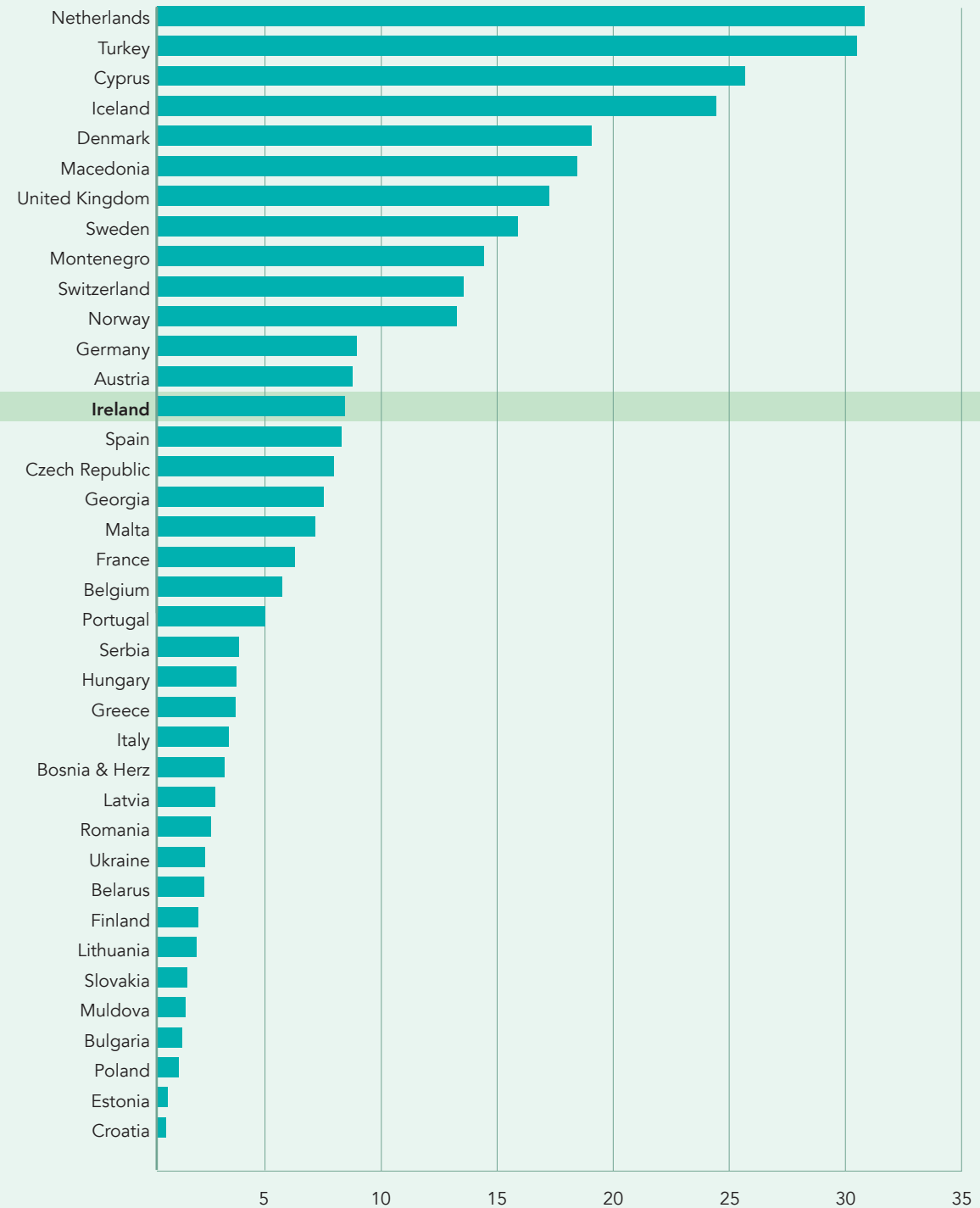
per million of population



from Irish Kidney Association Report October 2014

## European Living Kidney Donors Rates 2013

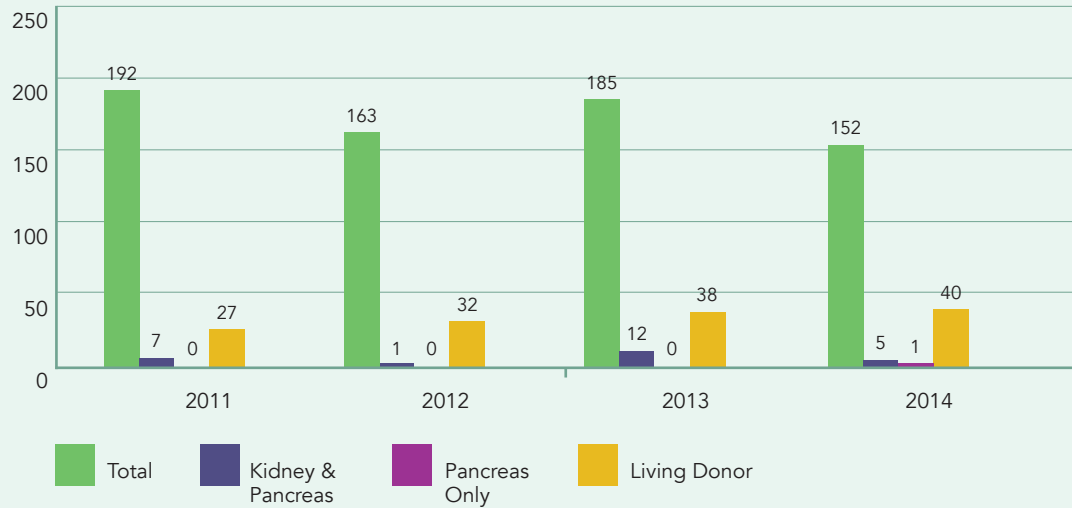
per million of population



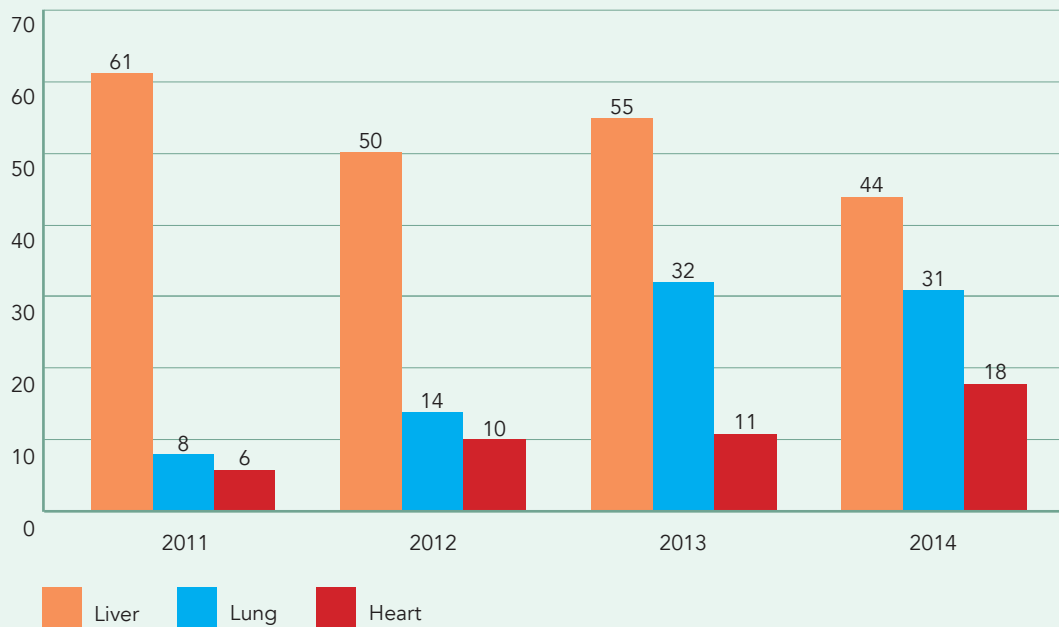
from Irish Kidney Association Report October 2014

# Transplantation (2011-2014)

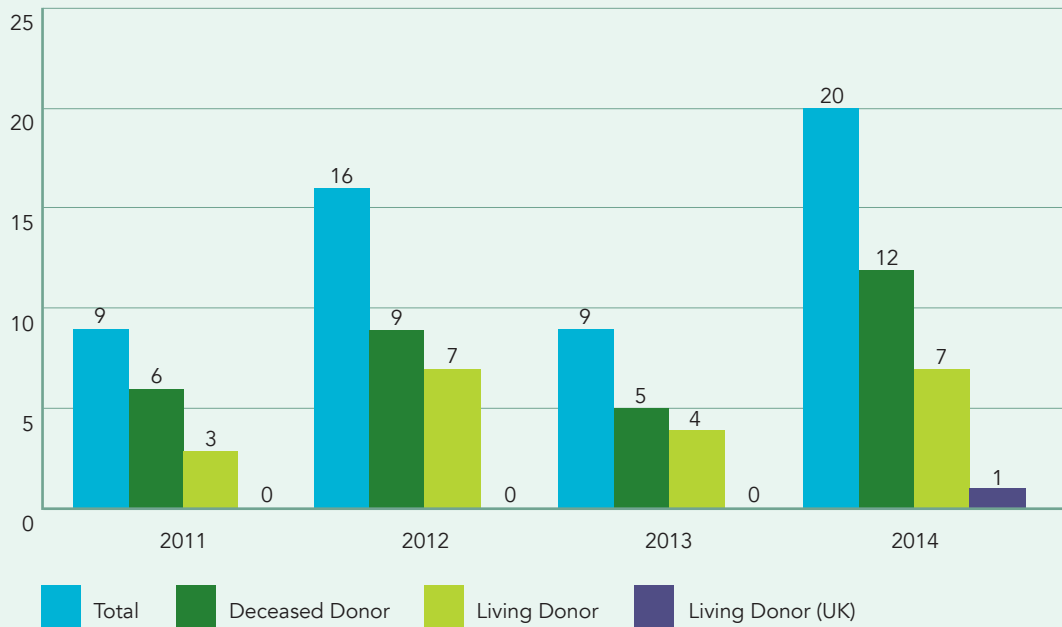
## Kidney & Pancreas Transplants



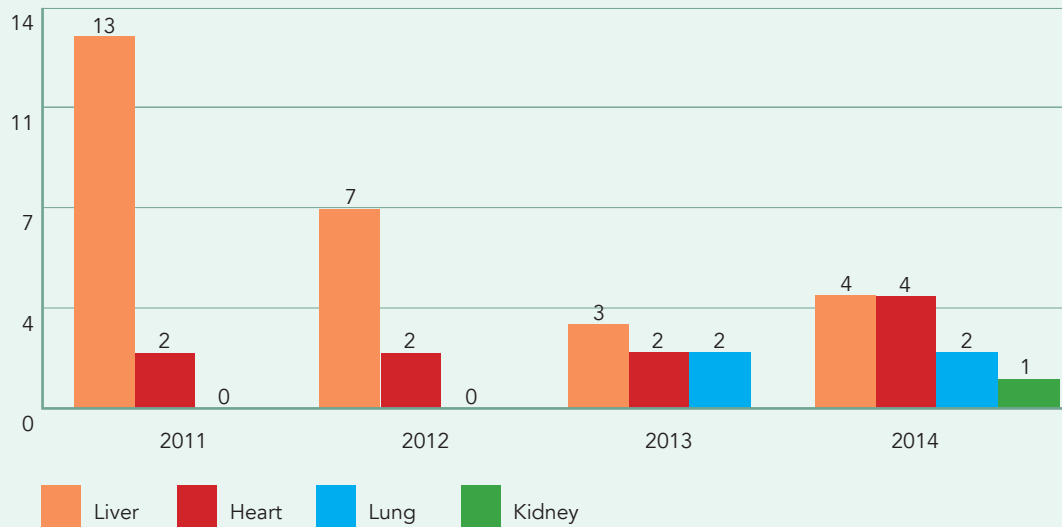
## Liver, Heart and Lung Transplants



## Paediatric Kidney Transplants

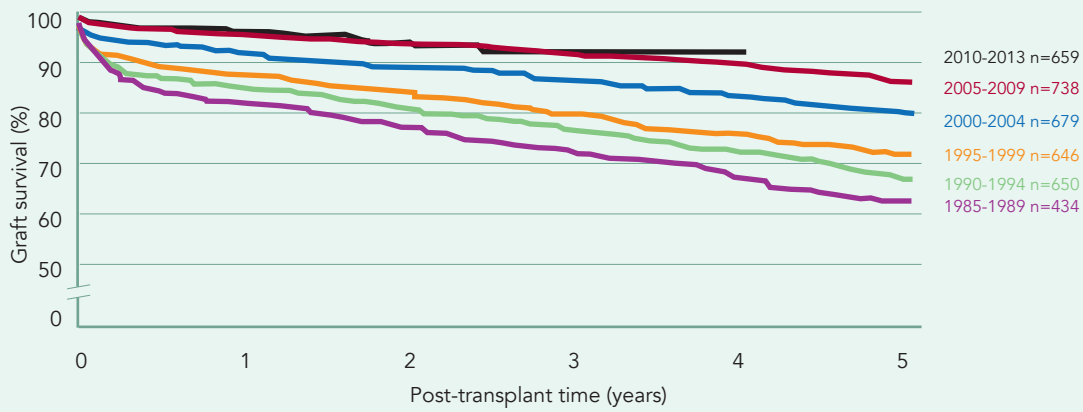


## Irish Paediatric Transplants Performed in UK

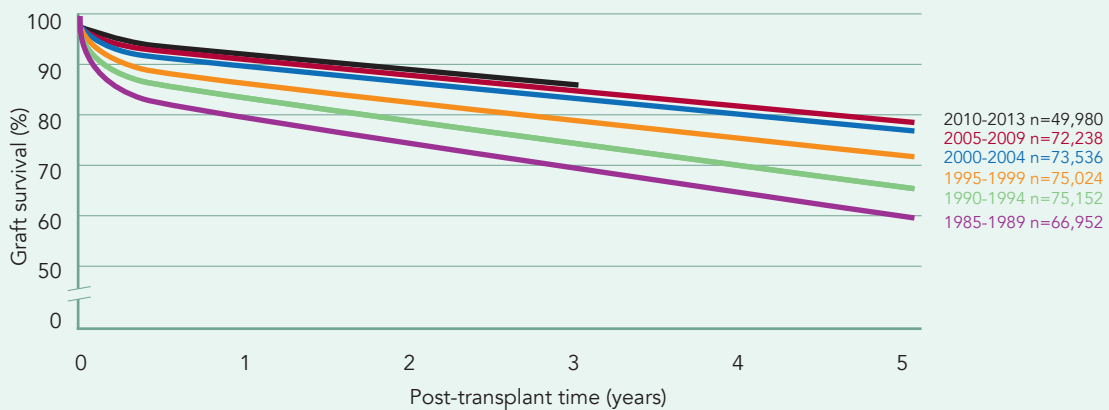


# Survival Rate

## Irish 5 Year Kidney Transplant Survival

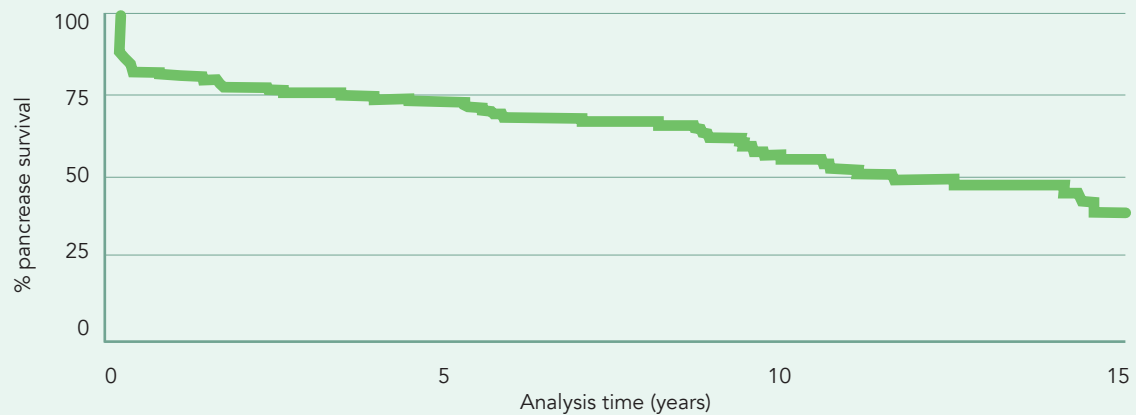


## European 5 Year Kidney Transplant Survival

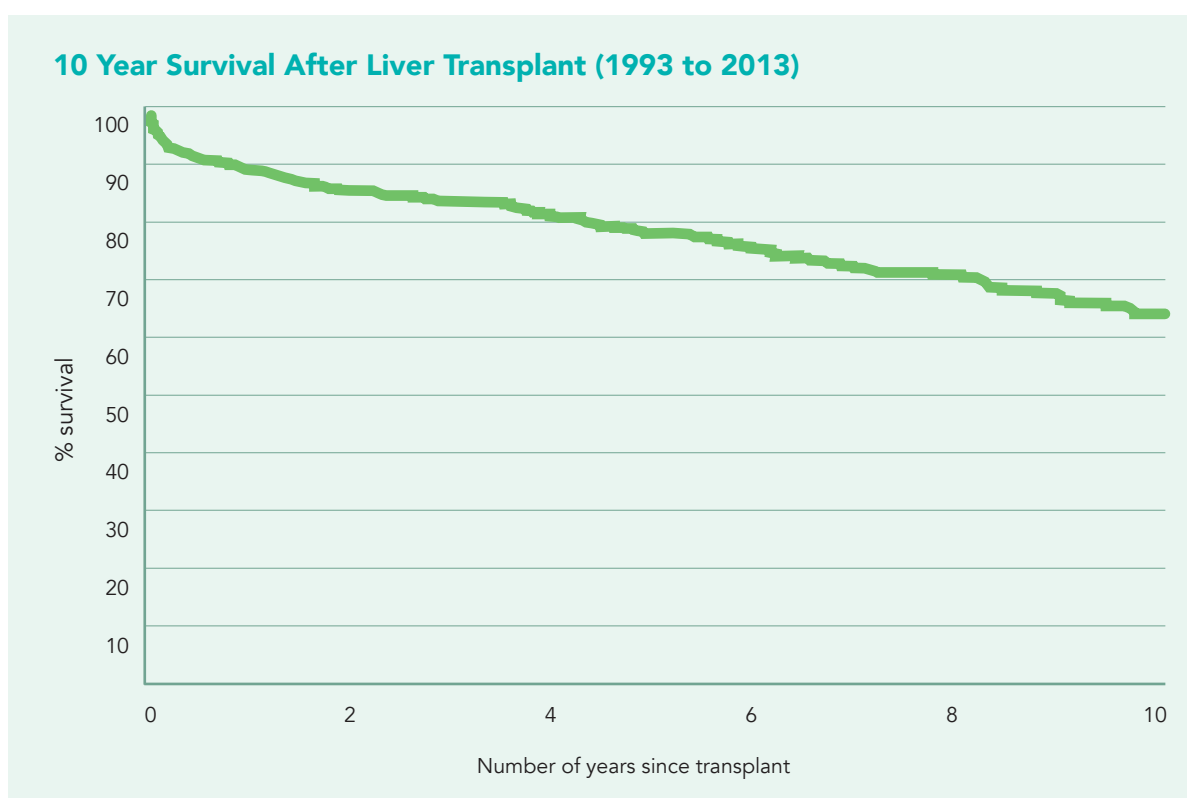


From Collaborative Transplant Study Heidelberg Germany

## 15 Year Survival for Pancreas Transplants



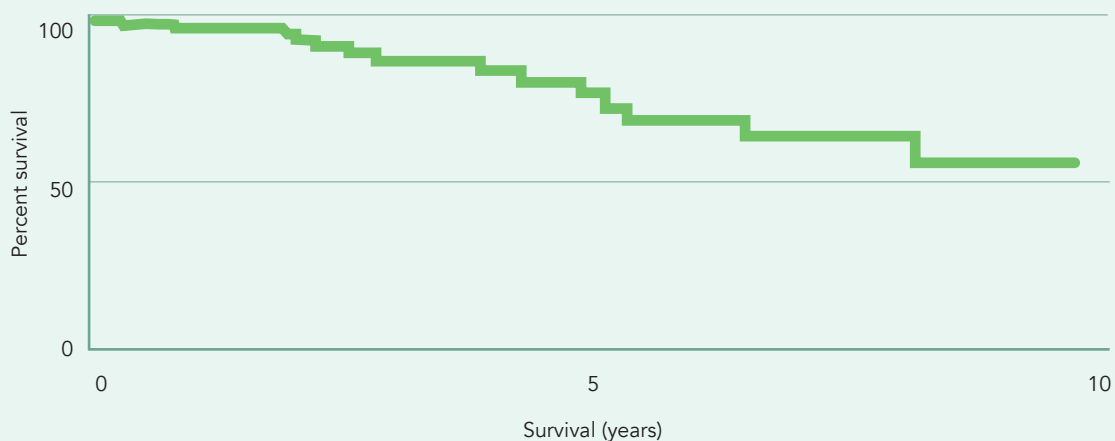
	1 year	5 year	10 year
<b>Kidney Transplant Deceased Donor Survival</b>	<b>96%</b>	<b>87%</b>	<b>65%</b>
*UK Kidney Transplant Deceased Donor Survival	94%	85%	72%
<b>Pancreas Transplant Deceased Donor Survival</b>	<b>80%</b>	<b>72%</b>	<b>54%</b>
*UK Pancreas Transplant Deceased Donor Survival	84%	76%	N/A
<b>Kidney Transplant Living Donor Survival</b>	<b>95%</b>	<b>87%</b>	<b>N/A</b>
*UK Kidney Transplant Living Donor Survival	97%	91%	77%



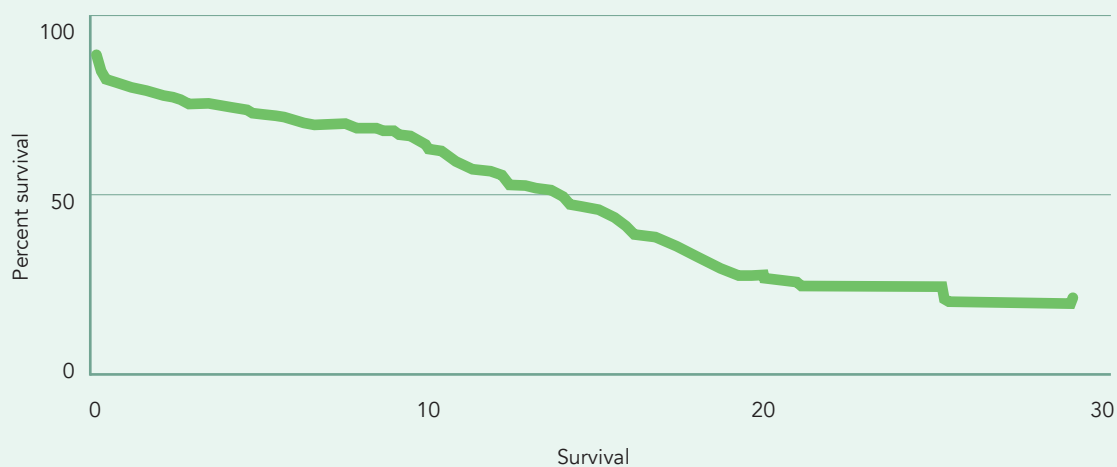
	1 year	5 year	10 year
<b>Liver Transplant Survival</b>	<b>90%</b>	<b>78%</b>	<b>63%</b>
*UK Liver Transplant Survival	93%	80%	62%

\* Figures from NHSBT Organ Donation and Transplant Activity Report 2012/13

### 10 Year Survival after Lung Transplant



### 30 Year Survival after Heart Transplant



	1 year	5 year	10 year
<b>Irish Lung Transplant Survival</b>	<b>97%</b>	<b>77%</b>	<b>56%</b>
*UK Lung Transplant Survival	82%	55%	32%
<b>Irish Heart Transplant Survival</b>	<b>80%</b>	<b>73%</b>	<b>62%</b>
*UK Heart Transplant Survival	81%	78%	59%

\* Figures from NHSBT Organ Donation and Transplant Activity Report 2012/13



# Goals for 2015

## Planned Deliverables

Transplant	Activity Expected 2015
<b>Living donor</b>	
Kidney	40
<b>Deceased donor</b>	
Kidney	160
Liver	51
Lung	30
Heart	15
Pancreas	4

## Priorities

In 2015, ODTI will continue to recruit and train specialist staff in the field of organ donation, procurement and transplantation. We will work closely with health service providers to plan for and improve services. We will also engage with stakeholders in initiatives to increase awareness in organ donation. In 2015, ODTI will establish the National Organ Procurement Service.

- Implement initiatives to improve levels of organ donation and transplantation in Ireland such as appointing an abdominal retrieval team
- Commence National Organ Procurement Service in April 2015
- Increase public awareness of organ donation through public attitude survey, publications and collaborative initiatives
- Publication of information regarding organ donation and transplant activity
- Participate in International programmes
- Recruit, train and develop a national team of experts in organ donation
- Provide ring fenced facilities for National Transplant Programmes in the respective acute hospital environments
- Develop policies and standards in relation to organ donation and transplantation
- Develop an enhanced national database for all organ donation and transplant activity
- Place key performance indicators relating to organ transplantation in the public domain.
- Engage with NHS BT in regard to synergies in providing and accessing services for Northern Ireland.

# Bibliography

- S.I No: 158 of 2006, European Communities (Quality and Safety of Human Tissues and Cells) Regulations 2006.

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- S.I. No: 598 of 2007, European Communities (Human Tissues and Cells Traceability Requirements, Notification of Serious Adverse Reactions and Events and Certain Technical Requirements) Regulations 2007.

---
- S.I. No: 325 of 2012, European Union (Quality and Safety of Human Organs Intended For Transplantation)

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- Directive 2004/23/EC of the European Parliament and of the Council of 31 March 2004 setting standards of quality and safety for the donation, procurement, testing, processing, preservation, storage and distribution of human tissues and cells.

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- Commission Directive 2006/12/EC of 8 February 2006 implementing Directive 2004/23/EC of the European Community and of the Parliament as regards certain technical requirements for the donation, procurement and testing of human tissues and cells.

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- Commission Directive 2006/86/EC of 24 October 2006 implementing Directive 2004/23/EC of the European Community and of the Parliament as regards traceability requirements, notification of serious adverse reactions and events and certain technical requirements for the coding, processing, preservation, storage and distribution of human tissues and cells.

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- Commission Directive 2010/53/EC of 7 July 2010 of the European Parliament and the Council of the European Union on standards of quality and safety of human organs intended for transplantation.

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- ODTI, A Framework for Quality and Safety of Human Organs Intended for Transplantation (2014).

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# Acknowledgements

## **The National Organ Donation and Transplant Advisory Group (NODTAG)**

The NODTAG is the clinical advisory group to the ODTI which provides recommendations and sets direction for the office. In 2014 the NODTAG met six times and was attended by seventeen committee members.

### **Professor Jim Egan**

Director ODTI and Chair NODTAG  
Consultant Respiratory Physician

### **Professor Peter Conlon**

Consultant Nephrologist and Renal Transplant Physician

### **Mr Michael Conroy**

Principal Officer, Department of Health

### **Dr Philip Crowley**

National Director of Quality and Patient Safety

### **Ms Phyllis Cunningham**

Transplant Coordinator

### **Dr Rory Dwyer**

Consultant in Anaesthesia and ICU Medicine

### **Ms Margaret Giffney**

Administrator

### **Mr David Hickey**

Director of Kidney & Pancreas Transplantation & Organ Procurement in Ireland

### **Mr Emir Hoti**

Consultant Hepatobiliary Liver Transplant Surgeon

### **Dr Diarmuid Houlihan**

Consultant Hepatologist

### **Dr Mary Keogan**

Consultant Immunologist

### **Mr James McCarthy**

Consultant Cardiothoracic Transplant Surgeon

### **Ms Ciara Norton**

Chief Operations Officer

### **Dr Colman O'Loughlin**

Consultant Intensivist

### **Ms Karen Redmond**

Specialist Thoracic Lung Transplant Surgeon

## **Three additional members were appointed to the group in 2014:**

### **Mr Mark Murphy**

CEO, Irish Kidney Association

### **Ms Angela Fitzgerald**

Deputy National Director, Acute Hospital Directorate, HSE

### **Ms Regina Reynolds**

Procurement Coordinator Manager

The ODTI would like to acknowledge

**Mr David Hickey** and **Ms Phyllis Cunningham**

who retired from the group in 2014.







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