## ODTI Organ Donation and Transplant Ireland

**ANNUAL REPORT 2015** 



Organ Donation and Transplant Ireland has been delegated the regulatory functions assigned to the Health Service Executive (HSE) in Statutory Instrument (SI) 325 (2012), European Union (Quality and Safety of Human Organs Intended for Transplantation) Regulations 2012. This annual report has been produced in compliance with part 5, SI 325 (2012):

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.

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### **Director's Statement**

## Our message is simple, organ donation saves lives

Thanks to the generosity of 81 families donating the organs of their loved ones and 33 people donating their kidney to a family member, 266 people have received the gift of life through transplant surgery in 2015.

This report outlines the activities of Organ Donation and Transplant Ireland in 2015, including the rates of organ donation and transplantation in Ireland in 2015.

We also present the findings of a survey of public attitudes to organ donation. It is encouraging to see that 85% of the population are in support of organ donation.

In 2015 Organ Donation and Transplant Ireland (ODTI) has progressed developments to improve organ donation and transplantation rates for Ireland. Outcomes for transplant recipients in Ireland continue to rank amongst the best in Europe, as presented in this report.

Investment has been made in enhancing the national organ procurement service and in implementing new regulations for quality and safety. Key organ donation personnel were also employed for the first time in 2015 in each of the hospital groups around the country.

ODTI has also provided financial support to the Irish Kidney Association to enable organ donor awareness campaigns.

Significant achievements have included the completion at the Mater Misericordiae University Hospital (MMUH) of the first ever combined heart and lung transplant in Ireland as well as the first innovative new lung transplant procedure using exvivo lung perfusion - the first such operation of its kind in the country.

Living kidney donation plays a vital role in transplantation. Once again we have seen a strong year for living kidney donors. The new National Organ Procurement Service has worked in cooperation with the key organ donation personnel to raise awareness and provide training in best practices for organ donation. As a result of the work of these teams, more families are now considering the real possibility of organ donation of their loved one's organs, an increase of 35% on the previous year.

The need for organ transplants continues to increase. There were 648 patients waiting for an organ transplant at the end of 2015. At the end of 2015, there were 2,015 people in Ireland on renal dialysis for which the only treatment option for many is kidney transplant. This figure has doubled since 2003.

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 Intensive Care Units (ICUs) in the organ donating hospitals across Ireland who have worked closely, cooperatively and professionally with the transplant centres and ODTI. I finally would like to acknowledge the National Organ Procurement Service and the National Organ Donation and Transplantation Advisory Group for their dedication commitment and direction in 2015.

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

Professor Jim Egan Director

# Organ Donation and Transplantation Services in Ireland

Organ Donation and Transplant Ireland (ODTI) is the national office responsible for planning and setting direction for organ donation and transplant services in Ireland. ODTI is dedicated to saving and improving lives by improving organ donation rates in Ireland. The ODTI office is responsible for:

- Planning and setting direction to meet the future needs of organ donation and transplantation for Ireland.
- Providing the best possible outcomes for the Irish population with the best use of resources.
- Compliance with and implementation of assigned functions in the Directive on standards of quality and safety of human organs intended for transplantation (Directive 2010/52/EC) and Statutory Instrument (S.I) No. 325 of 2012, i.e. ensure;
  - Production of a framework for quality and safety is established to cover all stages of organ donation and transplant of organs.
  - Reporting systems for adverse events related to the quality and safety of organs for organ donation and transplantation.
  - Data collection for publication annually in relation to organ donation and transplantation activities.
  - Appropriate organ exchange agreements and arrangements are in place between member states.
  - Ensuring living donor register is kept in accordance with data protection legislation.

ODTI is governed by the HSE and is informed by the National Organ Donation and Transplant Advisory Group, which provides recommendations and sets direction for the office.

Organ donation in Ireland is currently based on a voluntary donation system (opt in) and occurs in 33 intensive care units throughout Ireland. Specialist Organ Donation Personnel are now working in hospital groups throughout the country. They provide training, education, support and advice to ICU staff, they will ensure good practices are in place and that relevant staff have the skills and training when meeting with a donor family.

The National Organ Procurement Service at ODTI is available 24 hours a day 365 days a year to coordinate organ donation between donating hospitals and transplant recipient centres.

Organ transplantation takes place in three national transplant centres. Beaumont hospital the national centre for kidney transplantation and living kidney organ donation. Under its auspices, paediatric kidney transplants take place in Temple Street University Hospital. Mater Misericordiae University Hospital provides heart and lung transplantation. St Vincent's University Hospital provides liver and pancreas transplantation. Children are referred to the UK for heart, lung and liver transplants.

The three transplant centres have developed independently of each other and 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.

## Overview of Developments in 2015

#### **Service Developments**

#### National Organ Procurement Service (NOPS)

An independent review of transplant structures in Ireland identified the need to establish an independent, neutral national organ procurement service. In 2015, the national organ procurement nurse manager and four coordinators were recruited, appointed and trained. A safe and successful transition of the service to ODTI occurred on 21st April 2015. The NOPS has a particular emphasis on protecting the interests of donating families throughout the donation process. Discussions commence earlier with families, allowing for the introduction of health and lifestyle questionnaires. These questions have been introduced to ensure optimisation and quality of organs for transplantation. The discussion also gives families time to learn about and reflect on the option of organ donation before consenting to organ donation.

#### Appointment of Group Clinical Leads and Nurse Managers in Organ Donation

ODTI has coordinated the development of 5 Intensive Care Consultants and 6 Nurse Managers in Organ Donation for the Hospital groups, and all were appointed in 2015. Already a 35% increase in activity has been observed. These key organ donation personnel will be working to foster a strong culture of organ donation, optimise conversion rates and champion educational strategies and training programmes that promote organ donation to health care professionals in ICUs across each hospital group.

#### Authorisation by Health Products Regulatory Authority (HPRA) of the procurement and transplant services in Ireland in 2015

New regulations for the quality and safety of organs which serve to protect the organ recipients have now been put in place in each transplant and procurement centre in Ireland. The Framework for Quality and Safety of Human Organs Intended for

Transplantation is used by the HPRA in association with other relevant guidance for legal authorisation of transplant centres and procurement organisations. The Framework provides for, and includes details on, the roles and responsibilities regarding the adoption and implementation of procedures, compliant with quality and safety requirements. All three transplant centres - Mater Misericordiae University Hospital, St Vincent's University Hospital and Beaumont Hospital, along with the National Organ Procurement Service, ODTI, achieved authorisation in 2015. Recognition should also be given to other services that are key to the quality and safety of organ donations and transplants, i.e., National Histocompatibility and Immunogenetics Service for Solid Organ Transplantation (NHISSOT) and the National Virus Reference Laboratory.

#### Living Donor Reimbursement Scheme

A Living Donor Reimbursement policy was developed in conjunction with the Department of Health, ODTI 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. In its first year of operation (2015), the scheme was availed of by 31 living donors.

#### **Advisory Support Activity**

ODTI has worked closely with stakeholders to provide a solution for the ongoing provision of a pancreatic transplant service for Ireland and this has been put in place in St Vincent's University Hospital for 2016.

#### Links with Northern Ireland

ODTI has established links with Northern Ireland Transplant service and aims to strengthen collaboration.

#### **Service Performance**

#### Annual publication of activity

ODTI commenced regular reporting of activities in its first annual report for 2013. ODTI continues reporting on organ donation and transplant activities. This includes gathering and reporting on activities as requested by parliamentary questions, public representations, media queries, European Commission and 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 Audit**

ODTI is working closely with National Office for Clinical Audit (NOCA) and the Intensive Care Society of Ireland (ICSI) to develop an audit tool for organ donation.

### **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 and Transplant and other health services in 2015. Representatives from the office attended European regulatory and clinical meetings and met with relevant personnel in other jurisdictions.

#### **Organ Donor Awareness**

A working group on Public Awareness has been established in ODTI. A new funding structure for organ donation awareness campaigns was developed in partnership with the Irish Kidney Association in 2015. In February 2015, IPSOS MRBI was commissioned on behalf of ODTI to conduct a research study that would provide evidence of the levels of public support for organ donation in Ireland. The survey was undertaken in partnership with patient advocate organisations and results are published in Part 2.

#### **Key Findings**

- More than 8 in 10 people stated that they would be willing to donate their own organs or donate the organs of a close family member (85%). However, only half (50%) of respondents have discussed organ donation with their family.
- The majority of the general public stated that they were well informed about organ donation. Of those who stated they were not informed (26%), nearly half indicated they would not donate their own organs.
- The majority of the general public are happy to receive an organ (92%).
- One third of the general population currently carry an organ donor card.
- The general public is most likely to source information on the internet followed by a medical practitioner when looking for further information on organ donation.
- The statement "one organ donor can save 5 lives" was considered the most effective media communication by 83% of respondents.
- Just over half agreed that family should have the final say in what happens to your organs, of which just 45% of these had actually discussed organ donation with their family.

#### PART 1

## Activity in 2015

In 2015 a total of 266 people received a life saving organ transplant in Ireland. Compared to 2014 this represents overall increases in kidney (deceased and living donor combined), lung and liver transplants. Overall, the number of organ transplants in Ireland for 2015 was the third highest on record.

The number of deceased donors increased in 2015 to 81 - up from the low of 63 in 2014. The increase in 2015 was assisted by the introduction of the national organ procurement service and key organ donation personnel.

The number of kidney transplants from deceased donors has increased to 120 in 2015, despite a reduced number of available transplant surgeons. The number of living donors was at 33 compared to a record of 40 in 2014.

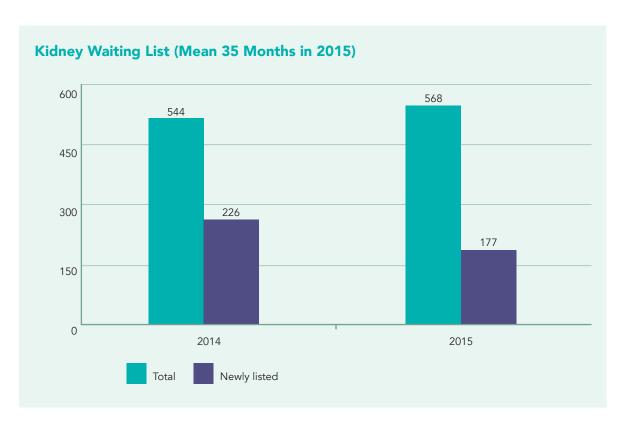
The number of liver transplants carried out was 61 - up from 44 in 2014 and the second highest figure on record (64 in 2009).

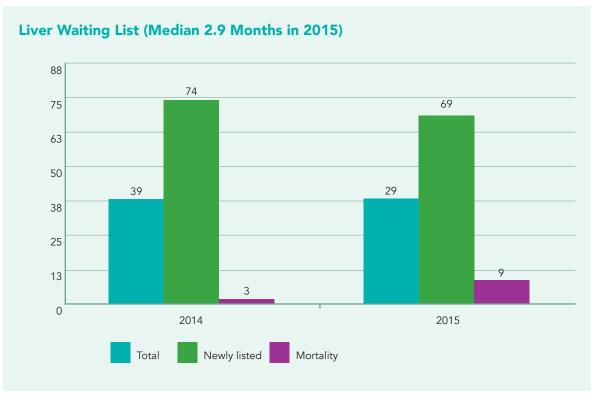
A new record was set for lung transplants in Ireland in 2015, at 36, and is one of highest rates in Europe. In addition, the first combined heart / lung transplant took place in Ireland. The Mater Misericordiae University Hospital also performed an innovative new lung transplant procedure using ex-vivo lung perfusion which allows the lungs to be successfully reconditioned for transplant - the first such operation of its kind in the country. The new technique greatly enhances the potential lung donor pool.

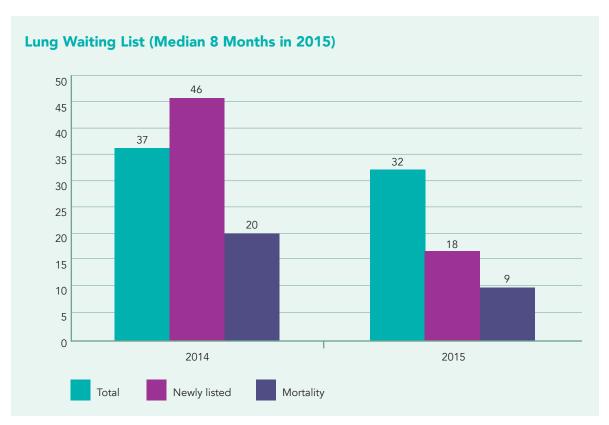
Meanwhile, the number of heart transplants at 16 was the second highest on record, just behind 2014's figure of 18.

Pancreas transplant has relocated to St Vincent's University Hospital and a team are in place to deliver the transplant programme.

## Numbers on Waiting Lists End December 2015

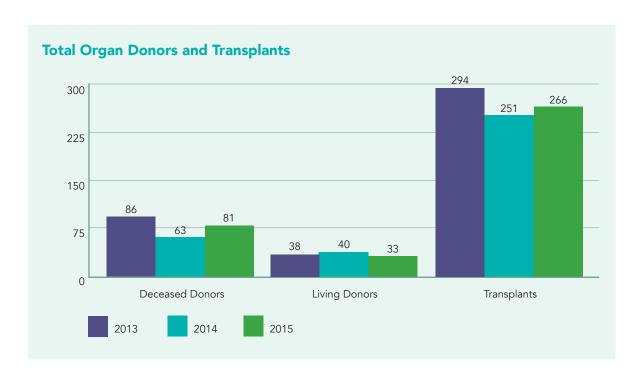








## **Organ Donation**

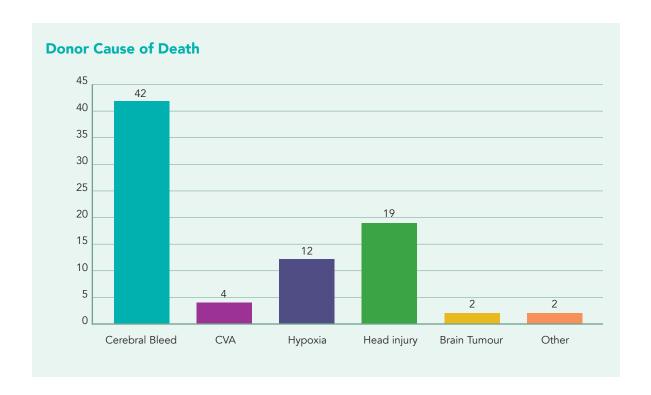


	2014	2015
Ratio of donors to transplants	1:4	1 : 3.3

#### **Organ Donation and Transplant Summary 2011 - 2015**

Organ Donation and Transplant 2011 - 2015								
		2011	2012	2013	2014	2015	5 year total	5 year average
Transplantation	Kidney	165	131	147	112	120	675	135
From	Liver	61	50	55	44	61	271	54
Deceased	Lungs	8	14	32	31	36	121	24
	Heart	6	10	11	18	16	61	12
	Pancreas	8	1	11	6	0	26	5
Sub-total		248	206	256	211	233	1154	231
Living Kidney Transplants		27	32	38	40	33	170	34
Living and Deceased Kidney Transplants		192	163	185	152	153	845	169
Total Organ Transplants		275	238	294	251	266	1324	265

#### **Donor Statistics 2015**



#### **Donor Figures Per Hospital Group**

Dublin North East						
2011	2012	2013	2014	2015		
29	20	28	21	27		

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

Dublin Midlands						
2011	2012	2013	2014	2015		
14	12	11	9	11		

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

Dublin East					
2011	2012	2013	2014	2015	
14	19	11	8	3	

<sup>\*</sup>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						
2011	2012	2013	2014	2015		
20	15	20	12	20		

<sup>\*</sup>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						
2011	2012	2013	2014	2015		
9	7	10	5	13		

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

Midwest Group					
2011	2012	2013	2014	2015	
4	4	4	4	4	

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

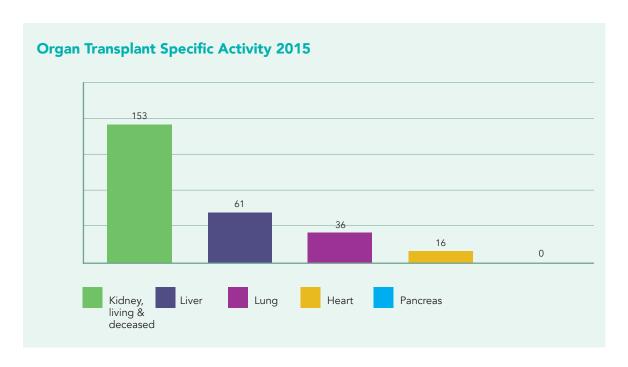
Acute Paediatric Dublin					
2011	2012	2013	2014	2015	
1	1	2	1	3	

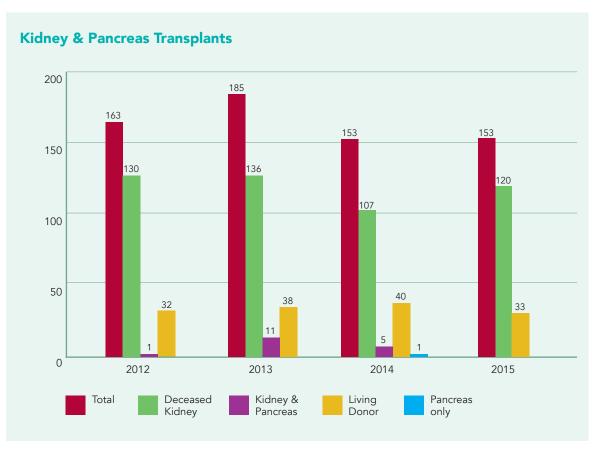
<sup>\*</sup>Our Lady's Children's Hospital, Crumlin; Children's University Hospital, Temple Street; National Children's Hospital, Tallaght (Mater Private Hospital; Bon Secours Hospital, Cork; Blackrock Clinic).

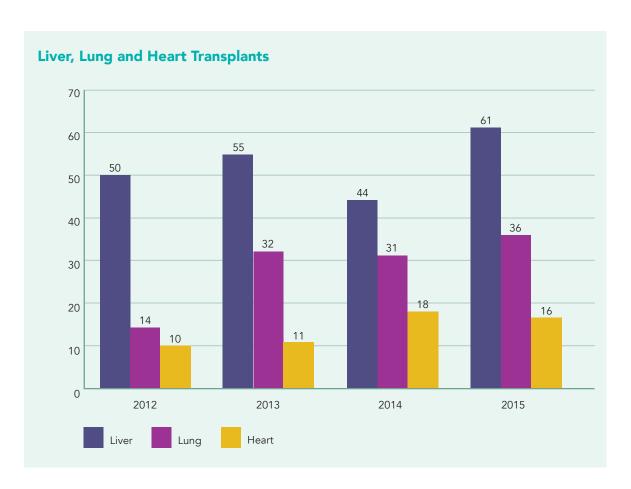
National Overall Total						
2011	2012	2013	2014	2015		
93	78	86	63	81		

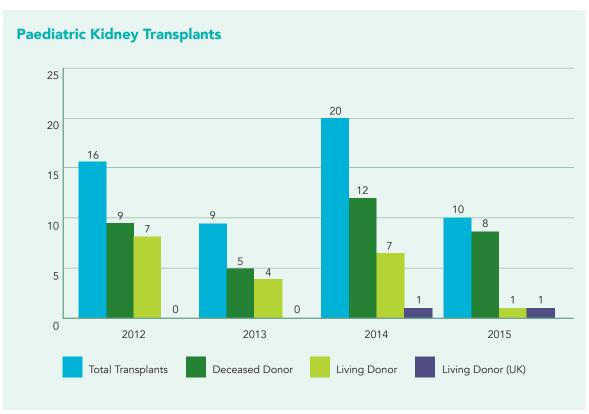
Donations Per Million Of Population						
2011	2012	2013	2014	2015		
20.6	17.3	19	14	17.6		

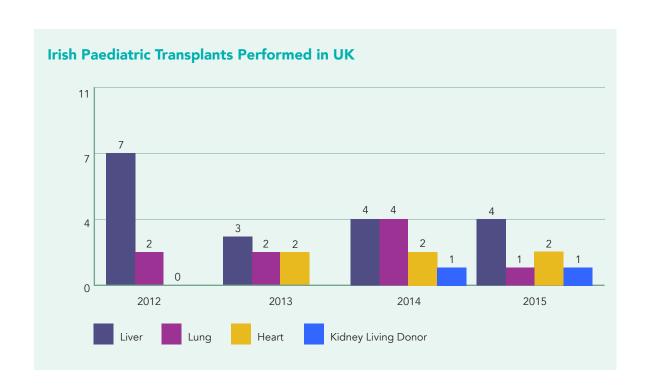
### **Transplantation in 2015**



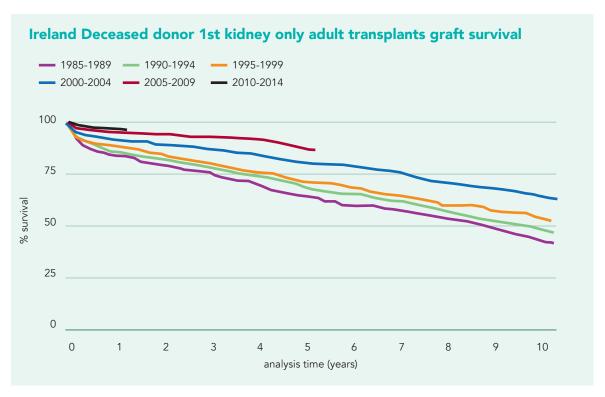




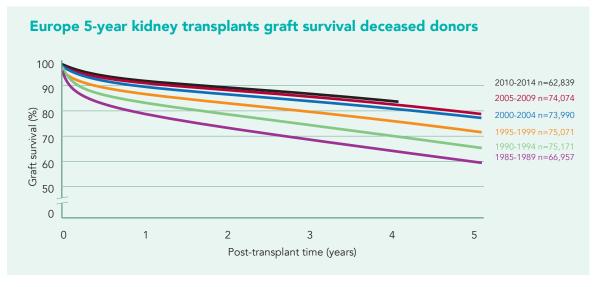




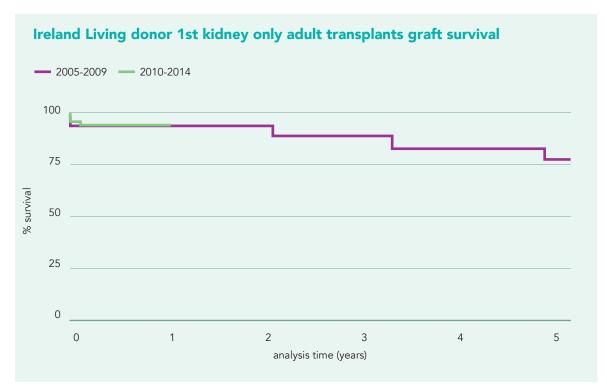
#### **Survival Rates**



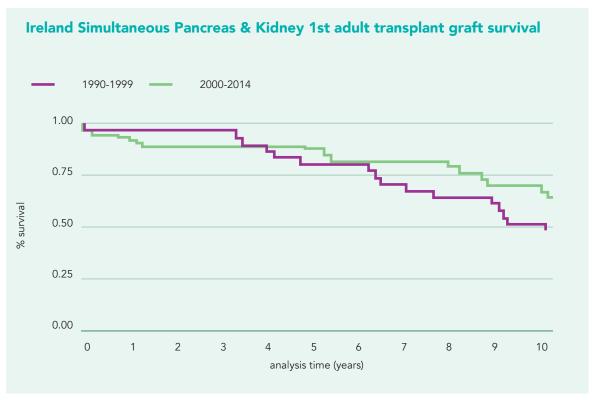
Source: National Renal Transplant Programme, Beaumount Hospital



Source: CTS Collaborative Study



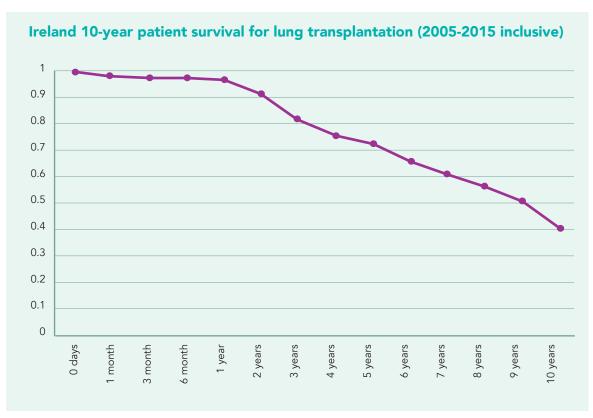
Source: National Renal Transplant Programme, Beaumount Hospital



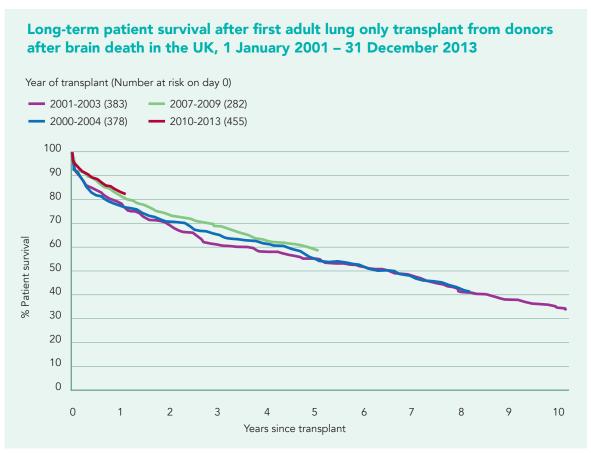
Source: National Renal Transplant Programme, Beaumount Hospital



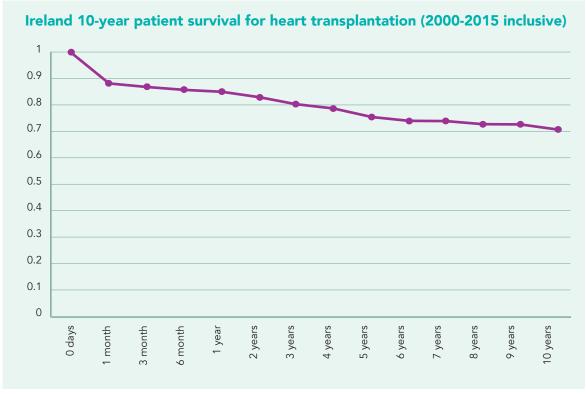
Source: National Renal Transplant Programme, Beaumount Hospital



Source: National Heart Lung Transplant Programme, Mater Misericordiae University Hospital



Source: NHSBT Organ Donation and Transplant Activity Report 2014/2015



Source: National Heart Lung Transplant Programme, Mater Misericordiae University Hospital



Source: NHSBT Organ Donation and Transplant Activity Report 2014/2015

## **Expectations for 2016**

#### **Planned Deliverables**

Transplant	Activity Expected 2016	
Living donor		
Kidney	40	
Deceased donor		
Kidney	144	
Liver	65	
Lung	35	
Heart	15	
Pancreas	1	

#### **Priorities**

In 2016 ODTI will continue to 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.

- Support the provision of a 'soft opt out' donation system
- Implement initiatives to improve levels of organ donation and transplantation in Ireland
- Increase public awareness of organ donation through collaborative initiatives with patient advocate bodies and organ donation personnel
- Publication of information regarding organ donation and transplant activity
- Provide ring fenced facilities for National Transplant Programmes in the respective acute hospital environments
- Develop policies and standards in relation to organ donation and transplant
- 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 services for Northern Ireland

#### PART 2

## Public Attitudes to Organ Donation



#### **Background & Objectives**



- In February 2015, Ipsos MRBI were commissioned on behalf of Organ Donation and Transplant Ireland, the Irish Donor Network and the Irish Kidney Association to conduct a research study that would provide evidence of the levels of public support for organ donation in Ireland.
- The objectives of the research were as follows:
  - Discover levels of support for organ donation in Ireland, disaggregated along demographic factors including gender, age, social/educational background and national origin.
  - Benchmark results with previous surveys.
  - Evaluate responses to core public awareness messages.
  - Employ the results as a benchmark for future research and the on-going effectiveness of the organ donation public awareness programme.
- The survey questionnaire was designed in consultation, and utilised a number of the Eurobarometer 2009 organ donation questions for comparison purposes (please note that the Eurobarometer 2009 survey utilised a face-to-face methodology).

Ipsos MRBI

Ipsos

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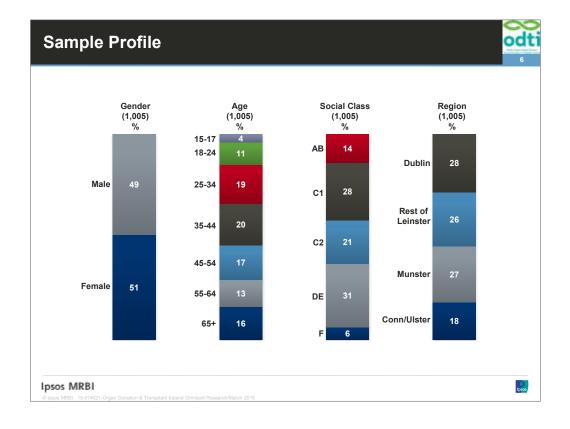
#### **Research Methodology**



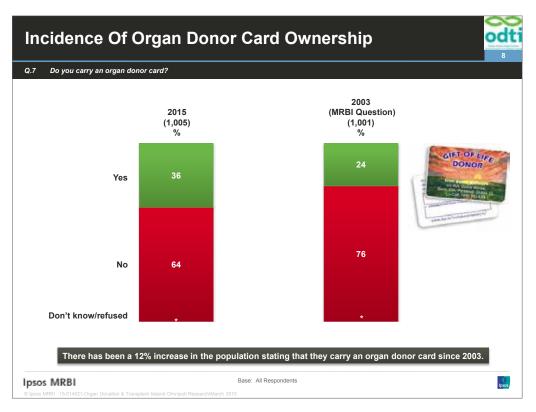
- This research was carried out on Omnipoll, Ipsos MRBI's telephone omnibus service.
- Omnipoll interviews a fresh nationally representative sample of 1,000 adults aged 15+ every three weeks.
- The sample used is RDD (random digit dialling) to ensure that both listed and unlisted phone numbers have the same probability of being contacted. Interviews are conducted with people via their landline and mobile phone.
- At analysis stage the data is weighted in line with the known profile of the population according to the latest CSO estimates. The sample size achieved on Omnipoll is robust at 1,000 respondents, giving a low margin of error (of +/-3) at an overall level.
- Fieldwork for this research was conducted from 2<sup>nd</sup> 16<sup>th</sup> March, 2015.

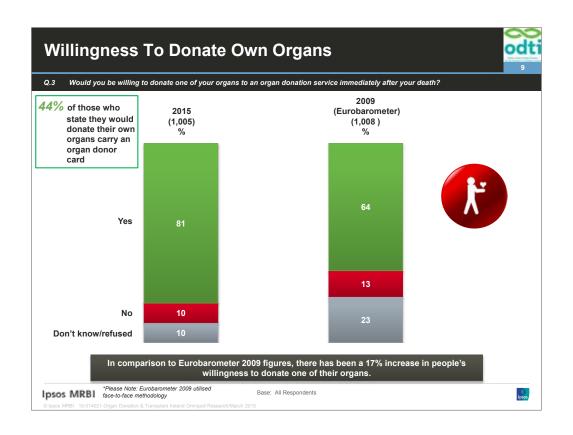
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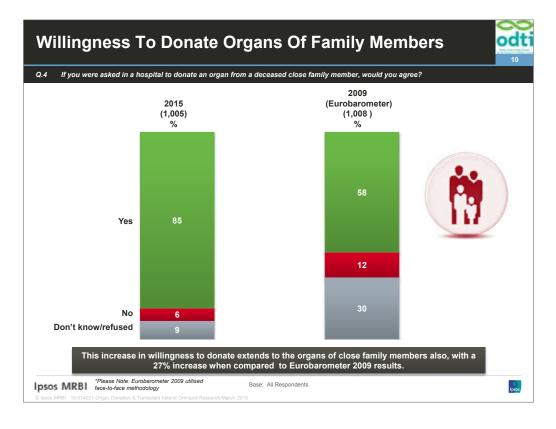
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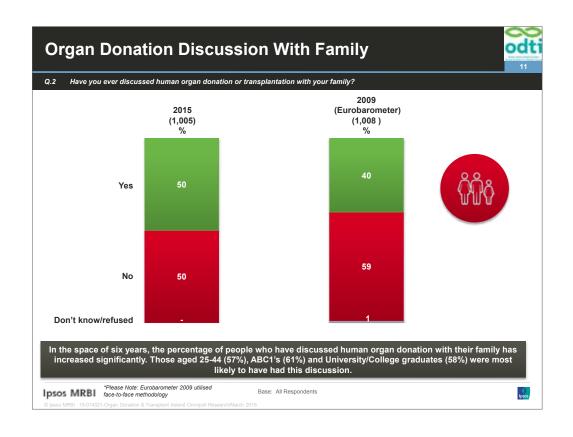


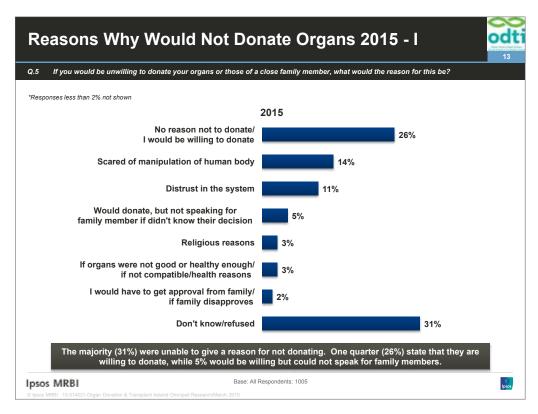


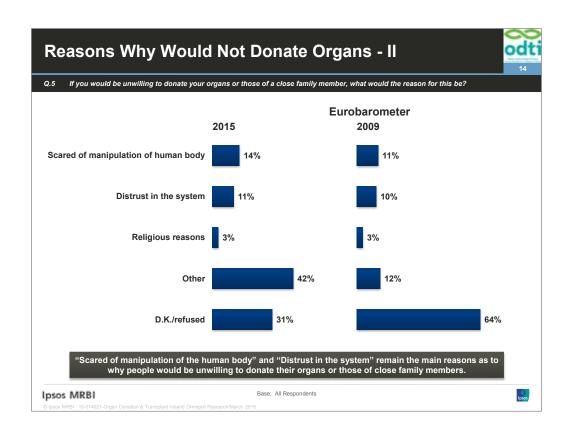


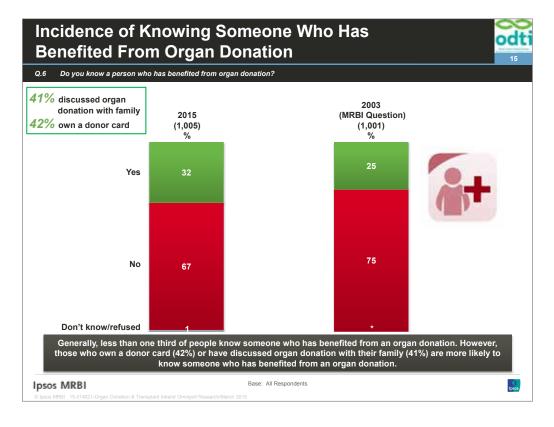


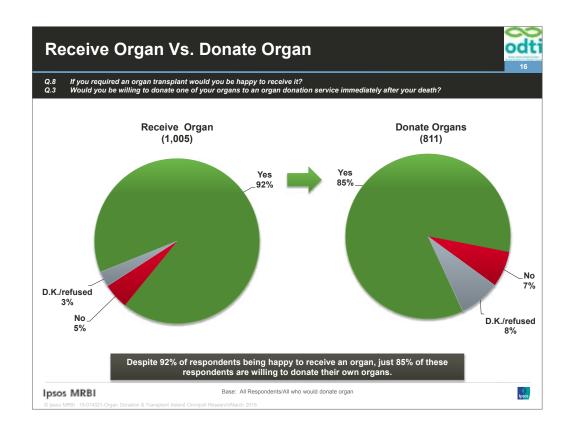


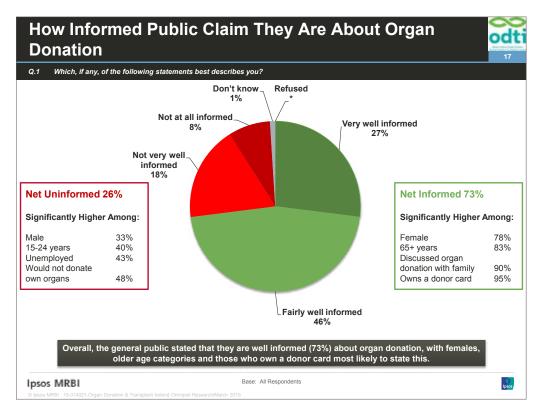


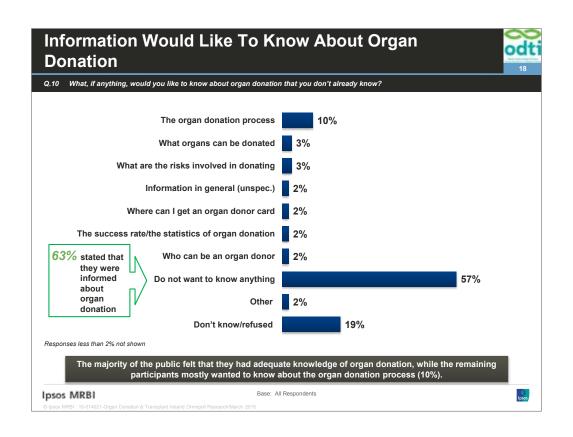


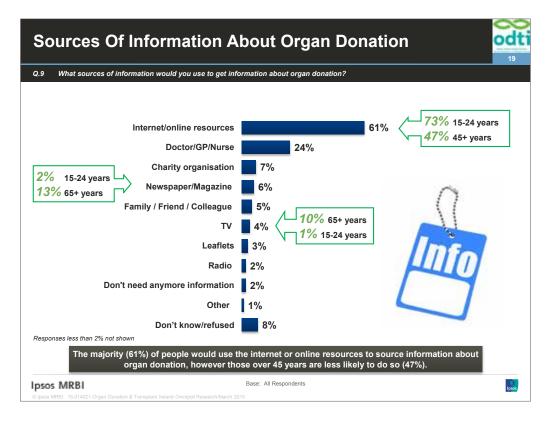


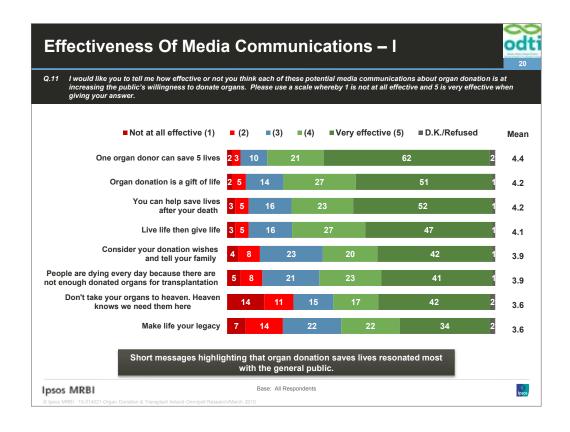


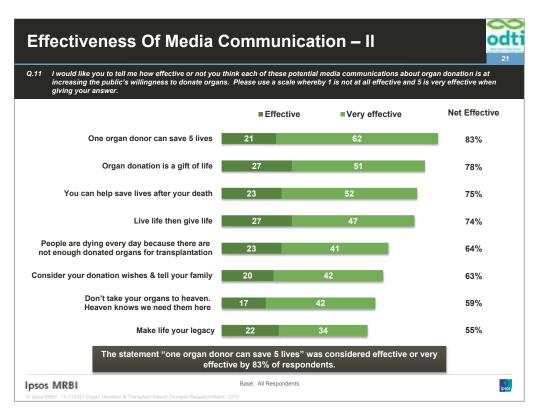


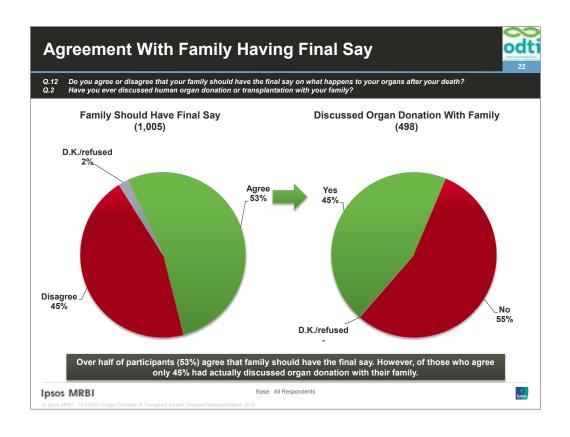


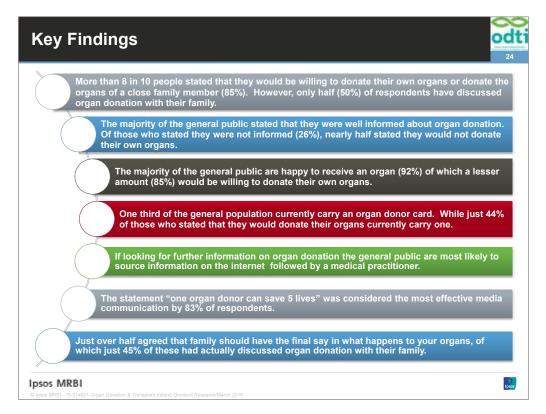












## Acknowledgements

#### 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 2015 the NODTAG met six times and was made up of fifteen 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, retired from NODTAG in June 2015

#### Dr Rory Dwyer

Consultant in Anaesthesia and ICU Medicine

#### Mr Emir Hoti

Consultant Hepatobiliary Liver Transplant Surgeon

#### Dr Diarmaid Houlihan

Consultant Hepatologist

#### Dr Mary Keogan

Consultant Immunologist

#### Ms Ciara Norton

Chief Operations Officer

#### Dr Colman O'Loughlin

Consultant Intensivist

#### Ms Karen Redmond

Specialist Thoracic Lung Transplant Surgeon

#### Mr Mark Murphy

CEO, Irish Kidney Association

#### Ms Angela Fitzgerald

Deputy National Director, Acute Hospital Directorate, HSE

#### Ms Regina Reynolds

National Organ Procurement Service Manager

#### Ms Dilly Little

Consultant Renal Transplant Surgeon, joined NODTAG March 2015

#### Mr Lars Nolke

Consultant Cardiothoracic Surgeon, joined NODTAG March 2015

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  2004/23/EC of the European Community and
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  and testing of human tissues and cells.

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#### **ODTI Organ Donation and Transplant Ireland**

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