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Journalists Workshop ORGAN DONATION AND TRANSPLANTATION

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Health and Consumers

ORGAN DONATION AND TRANSPLANTATION FACTS & FIGURES - BEST PRACTICES

PATIENTS ON WAITING LISTS

Totally over 61,500 patients were on a waiting list in the European Union at the end of 2011:

- over 42,000 patients on the kidney waiting lists
- over 10,000 on the liver waiting lists
- around 4,000 on the heart waiting lists
- around 2,300 on the lung waiting lists...

The number of patients dying on waiting lists was estimated to 5,500 for the European Union in 2011.

Remarks:

- **The management of waiting lists** is a national competence (which can partially be delegated to and co-managed with a "European Organ Exchange Organisation"). It includes the definition of criteria to place patients on the list or exclude patients from a waiting list. The lists are generally specific to the types of organ and transplant needed (kidney, liver, lung, heart, pancreas, small bowel, combined transplants...) and might also be specific for children (paediatric transplants).
- If no transplant programme is available or if it is only starting in a country, patients might not (yet) be placed on waiting lists, i.e. the existence or length of waiting lists also reflects the possibilities to be transplanted, whereas the absence or shortness of a waiting list does not mean that there is no need for transplants.

DONATION RATES IN 2011⁽¹⁾

| DECEASED DONATION RATES (per million of population, pmp) | | | | | |
|--|----------------|---------------|--------------|--|--|
| MaximumSpain + 35,3Croatia + 33,6Belgium + 30,1 | | | | | |
| Minimum | Bulgaria 🔿 0,5 | Romania 🔿 3,6 | Cyprus 🔿 5,5 | | |

LIVING KIDNEY DONATIONS (pmp)

| Maximum | The Netherlands → 26,3 | Sweden 🔿 19,6 | Denmark & Cyprus 🔿 17,9 & 17,3 | | | |
|---|------------------------|---------------|--------------------------------|--|--|--|
| Minimum | Lithuania 🔿 0,9 | Poland → 1,0 | Bulgaria → 1,2 | | | |
| (Luxembourg and Slovenia: no kidney transplants from living donors) | | | | | | |

(Luxembourg and Slovenia: no kidney transplants from living donor

LIVING DONATION REPRESENTS GLOBALLY AT EU LEVEL

2,855 transplantations (kidney + liver) in 2009

3,852 transplantations (kidney + liver) in 2010

4,100 transplantations (kidney + liver) in 2011 (4,196 with Croatia, Iceland, Norway)

20,6 % of kidney transplants in 2011 (19,8 % in 2010, 18,7% in 2009)

3,5 % of liver transplant activity in 2011 (3,6 % in 2010, 3,1% in 2009)

EUROPEAN ORGAN EXCHANGES ORGANISATIONS

| | 6 EU Member States (BENELUX, DE, AT, SI) + Croatia + HU (preliminary phase) | | |
|---------------------|--|--|--|
| EUROTRANSPLANT (ET) | exchange 20% of all organs transplanted each year | | |
| | around 3,300 organs (2,100 deceased donors) | | |
| | only 2% of organs leave or enter the ET area | | |
| | 3 EU Member States (SE, FI, DK) + Norway and Iceland | | |
| SCANDIATRANSPLANT | between 10 % (Kidney) and 27% (Heart) of organs were exchanged between members | | |

EXAMPLES OF BILATERAL AGREEMENTS ON ORGAN EXCHANGES

| ITALY AND MALTA 2008-2010 → 20 organs (kidney, heart, liver, split liver) from Malta were transplanted in Italy |
|--|
|--|

TRANSPLANT DONOR COORDINATORS

The combination of an efficient system for organ donor identification, detection and procurement has been identified as one of the keys to increasing deceased donation. In particular, the presence of a key donation person at hospital level (transplant donor coordinator), whose main responsibility is to develop a proactive donor detection programme, is the most important step towards optimising organ donation and improving donor detection rates.

The appointment of transplant donor coordinators in Spain increased donation rates from 14 donors pmp in 1989 to 33 to 35 donors pmp in just a few years.

All Member States already employ transplant donor coordinators or plan to do so.

The Working group on Deceased donation under the EU Action Plan on Organ donation and Transplantation has developed and finalised in 2011, for national Competent Authorities and experts in the field, a Manual on how to set up a system for Transplant donor coordination.

TRANSPLANT (TX) DONOR COORDINATORS

| SPANISH REFORMS (including appointment of tx coordinators) | donation rates increased 130% (10 years) | | |
|--|--|--|--|
| GREECE (introduction of transplant coordinators) | 132% increase in tx rates ('01 and '05) | | |
| ITALIAN REGION OF TUSCANY (introduction of Spanish Model) | doubled donation rate in 1 year | | |

IMPROVEMENT OF LIFE AND ADDITIONAL LIFE YEARS

| «QUALITY ADJUSTED LIFE YEARS» (QALYS) AND LIFE YEARS | | | | | |
|--|---|--|--|--|--|
| MORTALITY RATES waiting for a heart, liver or lung | range from 15 to 30% | | | | |
| LIFETIME SURVIVAL RATES | | | | | |
| patients undergoing dialysis treatment | 10 years | | | | |
| kidney transplantation patients | 20 years | | | | |
| kidney transplants | 93% survival rate in one year following transplantation (tx) | | | | |
| | LIVER tx has the highest QALY gain (11.5); | | | | |
| "QUALITY ADJUSTED LIFE YEARS" (QALYS) GAINED | HEART tx has 6.8 QALY gain | | | | |
| | LUNG tx has 5.2 QALY gain | | | | |
| COST EFFICIENCY - LIVING DONATION | Annual savings in haemodialysis post kidney transplantation ~70% => -17,000£/y/patient (UK DoH, 2010) | | | | |

¹ **The quality-adjusted life year (QALY)** is a measure of disease burden, including both the quality and the quantity of life lived. The QALY model requires utility independent, risk neutral and constant proportional tradeoff behaviour. The QALY is based on the number of years of life that would be added by the intervention. Each year in perfect health is assigned the value of 1.0 down to a value of 0.0 for death. If the extra years would not be lived in full health, for example if the patient would lose a limb, or be blind or have to use a wheelchair, then the extra life-years are given a value between 0 and 1 to account for this. FROM THE TRANSPLANT NEWSLETTER (COUNCIL OF EUROPE – ONT)⁽¹⁾

EUROPEAN UNION DATA (2009/2010/2011 DATA)

| YEAR | TOTAL NUMBER OF DECEASED ORGAN DONORS | KIDNEY (% living donors) | Liver (% living donors) | Heart | Lung | Pancreas | Small bowel | | |
|------|--|--------------------------------------|-----------------------------------|-------|------|----------|----------------|--|--|
| | from which organs were 'utilised' | Number of transplants per organ-type | | | | | | | |
| 2009 | 9152 | 17886 (18,7%) | 6687 (3,1%) | 2090 | 1418 | 779 | n.a. | | |
| 2010 | 9206 | 18246 (19,8%) | 6655 (3,6%) | 1984 | 1505 | 769 | 50 | | |
| 2011 | 9604 | 18712 (20,6%) | 7006 (3,5%) | 1980 | 1677 | 859 | 56 | | |

→ a constant evolution in the number of **deceased donors**

→ also an increased importance in the number of **living donors**

→ an overall progression in the total annual number of transplants

DONATION AND TRANSPLANTATION NUMBERS PER COUNTRY (2011 DATA) (TX = TRANSPLANTS)

| COUNTRY | NUMBER OF DECEASED DONORS ⁽²⁾ | DECEASED DONATION | KIDNEY TX FROM DECEASED DONORS (PMP) | KIDNEY TX FROM LIVING DONORS (PMP) | LIVER TX (PMP) | HEART TX (PMP) | LUNG TX (PMP) | | |
|-----------------|--|----------------------------|--|--|-------------------|-------------------|------------------|--|--|
| | DONORS | RATES (PMP) ⁽³⁾ | | donors per million po | opulation = pr | pulation = pmp | | | |
| AUSTRIA | 205 | 24,4 | 42,9 | 6,5 | 15,2 | 6,1 | 14,3 | | |
| BELGIUM | 331 | 30,1 | 43,1 | 3,6 | 27,2 | 6,9 | 10,1 | | |
| BULGARIA | 4 | 0,5 | 1,1 | 1,2 | 0,8 | 0,3 | - | | |
| CYPRUS | 6 | 5,5 | 10,9 | 17,3 | 5,5 | - | - | | |
| CZECH REPUBLIC | 185 | 17,6 | 30,5 | 3,8 | 8,4 | 6,5 | 1,7 | | |
| DENMARK | 73 | 13 | 24,1 | 17,9 | 9,1 | 5,2 | 5,4 | | |
| ESTONIA | 22 | 16,9 | 30,8 | 3,1 | 6,2 | - | 2,3 | | |
| FINLAND | 93 | 17,2 | 17,2 | 2,4 | 10,4 | 3,3 | 4,3 | | |
| FRANCE | 1630 | 25 | 41,1 | 4,6 | 17,9 | 6,3 | 5 | | |
| GERMANY | 1200 | 14,7 | 25,1 | 9,7 | 14,7 | 4,5 | 4,1 | | |
| GREECE | 79 | 6,9 | 12,2 | 4 | 3,7 | 0,5 | - | | |
| HUNGARY | 131 | 13,1 | 20,4 | 4,7 | 4,4 | 1,4 | - | | |
| IRELAND | 93 | 20,7 | 36,7 | 6 | 13,6 | 1,3 | 1,8 | | |
| ITALY | 1325 | 21,8 | 25,3 | 3,5 | 17 | 4,6 | 2 | | |
| LATVIA | 40 | 18,2 | 33,6 | 1,4 | 0,5 | 1,4 | - | | |
| LITHUANIA | 39 | 11,8 | 21,8 | 0,9 | 3,6 | 1,5 | 0,3 | | |
| LUXEMBOURG | 9 | 18 | - | - | - | - | - | | |
| MALTA | 12 | 30 | 30 | 15 | - | 2,5 | - | | |
| THE NETHERLANDS | 227 | 13,6 | 25,1 | 26,3 | 8,1 | 2,6 | 4,1 | | |
| POLAND | 553 | 14,4 | 27 | 1 | 7,8 | 2,1 | 0,4 | | |
| PORTUGAL | 301 | 28,1 | 45,1 | 4,4 | 20,5 | 4,3 | 1,7 | | |
| ROMANIA | 77 | 3,6 | 6,7 | 3,5 | 3 | 0,3 | - | | |
| SLOVAKIA | 69 | 12,5 | 21,1 | 2,4 | 4,5 | 3,5 | - | | |
| SLOVENIA | 31 | 15,5 | 23 | - | 10 | 7 | - | | |
| SPAIN | 1667 | 35,3 | 46,3 | 6,6 | 24,1 | 5 | 4,9 | | |
| SWEDEN | 146 | 15,5 | 26,7 | 19,6 | 16,6 | 5,5 | 6,4 | | |
| UNITED KINGDOM | 1056 | 17 | 27,7 | 16,5 | 12,2 | 2,4 | 3,1 | | |
| CROATIA | 148 | 33,6 | 51,8 | 2 | 28,2 | 8,6 | - | | |
| ICELAND | 2 | 6,7 | - | 36,7 | - | - | - | | |
| NORWAY | 127 | 24,5 | 45,8 | 14,6 | 17,8 | 6 | 5,6 | | |
| TURKEY | | 4,2 | 7 | 32,4 | 12,1 | 1,2 | 0,1 | | |

This table reflects the numbers of transplants taking place in the country mentioned, including patients transplanted via an official bilateral agreement between two countries. For example, there is a bilateral agreement between Spain and Portugal for lung transplantation: Portuguese patients might be transplanted in Spain with Portuguese or Spanish organs, but as the transplantation takes place in Spain, it is counted in Spain.

For numbers on **Pancreas and Small bowel** transplantation, data is available pages 11 and 12 of the 2012 Council of Europe Newsletter: *http://www.edqm.eu/medias/fichiers/newsletter_transplant_vol_17_no_1_sept_2012.pdf*

- (2) Number of actual (procured) deceased organ donors (after brain death and after circulatory death)
- (3) donors per million population = pmp

⁽¹⁾ http://www.ont.es/publicaciones/Paginas/Publicaciones.aspx