

2019

European Kidney Forum

Organ Donation and
Transplantation in Europe

Are We Meeting the Needs of Patients?

A POLICY ROUNDTABLE

Hosted by the MEP Group for Kidney Health Tuesday, 25 June 2019
16:30 – 18:30 followed by a networking dinner
Renaissance Brussels Hotel - Rue du Parnasse 19, 1050 Bruxelles, Belgium



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Panel discussion: Towards improved organ donation and transplantation in Europe



Wim Van Biesen

Moderator



Raymond Vanholder

EKHA Chairman



Robert van der Wolk

Speaker, Coach and Author



Stefaan Van der Spiegel

Team Leader 'Substances of human origin', DG SANTE, European Commission



Elisabeth Coll

Medical Director, National Transplant Organisation in Spain



Uwe Heemann

Professor of Nephrology, Hospital of the Technical University of Munich



Gabriel C. Oniscu

ESOT Secretary



Stela Živčić-Čosić

Representative of the Ministry of Health of Croatia

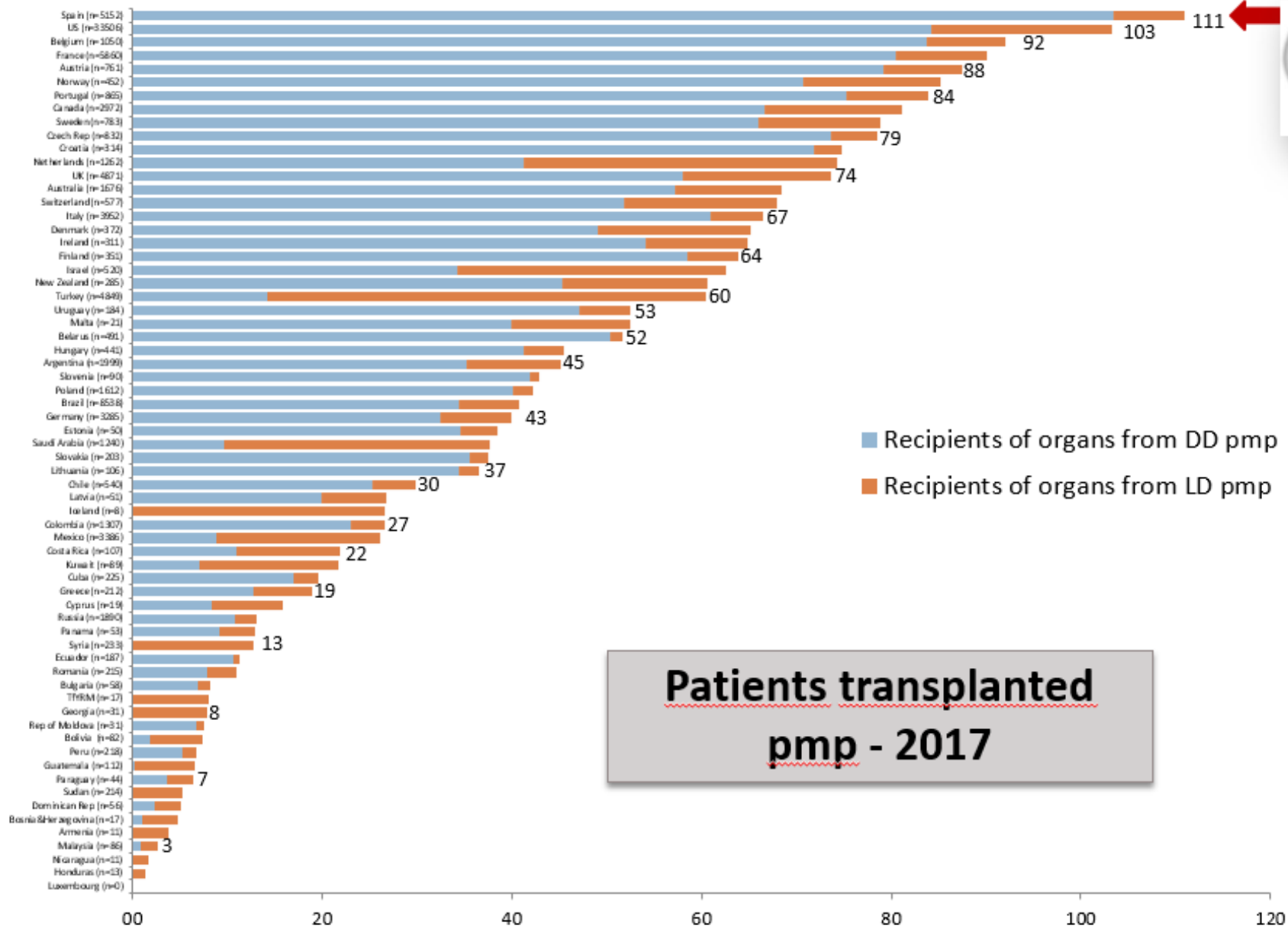
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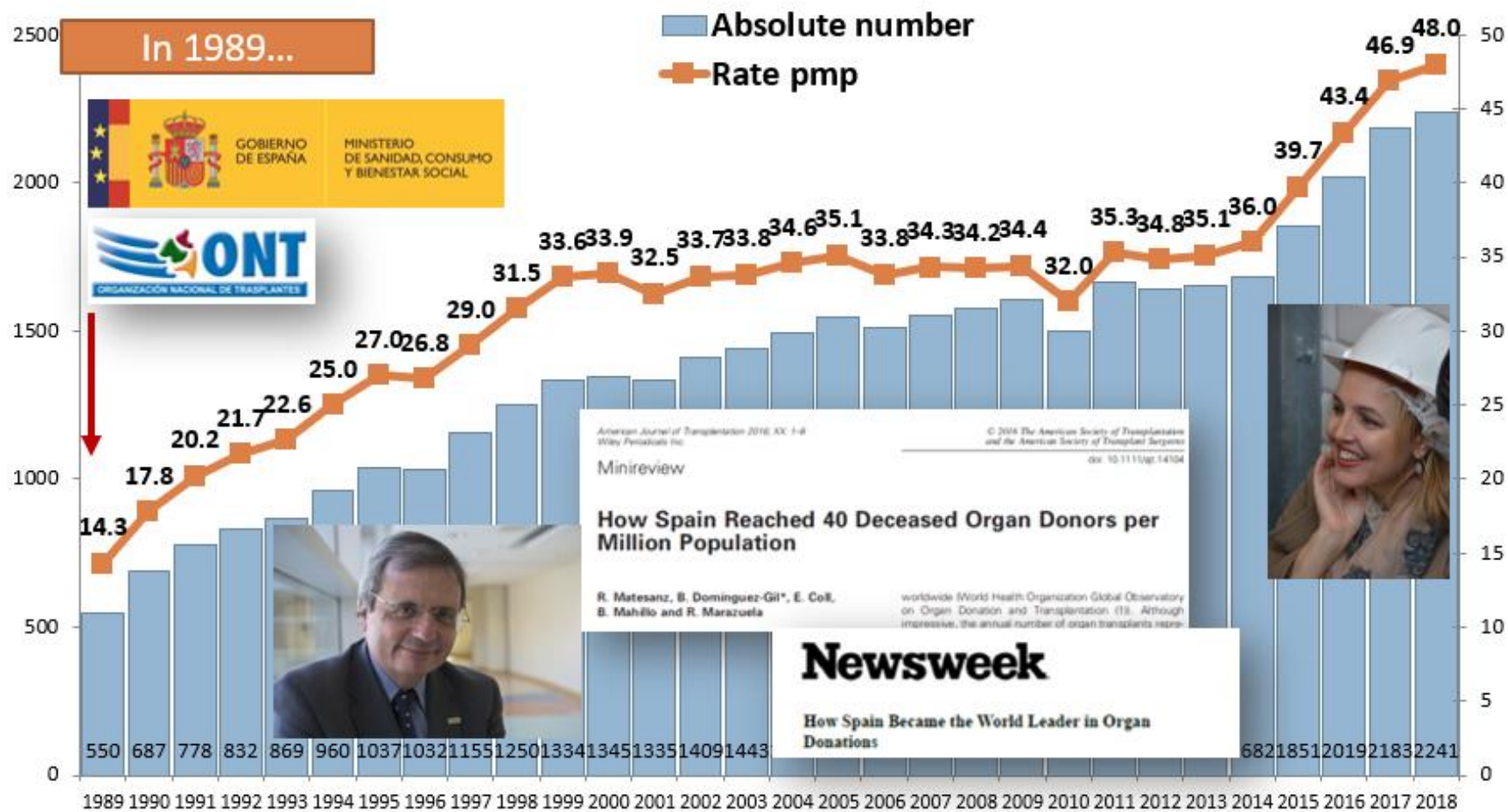
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Actual Deceased Organ Donors in Spain. 1989-2018



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Basic principles of the Spanish Model on organ donation & transplantation



- ✓ ADEQUATE LEGAL & TECHNICAL BACKGROUND
- ✓ DONOR COORDINATION NETWORK
- ✓ SPECIAL PROFILE OF DONOR COORDINATOR
- ✓ DONOR COORDINATORS INSIDE THE HOSPITALS
- ✓ CENTRAL OFFICE (ONT) AS A SUPPORT AGENCY
- ✓ CONTINUOUS POTENTIAL DONOR AUDIT
- ✓ GREAT EFFORT IN PROFESSIONAL TRAINING
- ✓ HOSPITAL REIMBURSEMENT
- ✓ CONTINUOUS ATTENTION TO THE MASS MEDIA

PLASTICITY/INNOVATION
INVOLVEMENT PROFESSIONAL SOCIETIES



Matesanz R, et al. Transpl Int 2011;24:333-43

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Situation in Germany

Uwe Heemann

Abteilung für Nephrologie

Klinikum rechts der Isar

Technische Universität München



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Problems for Post-Mortem Donation in Germany

- **Lack of nurses reduces ICU capacity**
- **ICU capacity insufficient for standard care**
- **Competition between standard care and donors on ICU**
- **No dedicated financing of ICU beds for donation**

- **Historical reasons for reluctancy of acceptance of brain death concept in the population**



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Solutions

- **Financing of 1 ICU bed in all major hospitals for donation only (under the guidance of the transplant coordinator)**
- **European legislation for brain death and donation**



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Challenges and opportunities



- Variation in clinical practice
- Inequity in access
- Variations in outcome
- Lack of benchmarking
- Variation in access to all aspects of donation
- Share best practice
- Equity in access
- European registry allowing benchmarking
- Increase LD
- Promote DCD and DBD donation



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- Dogma
- Practice

Challenge

- Guidelines
- Share best practice
- Benchmarking

- Practice
- Behaviour
- Knowledge
- Perception

Change

- Guidelines
- Share best practice
- Education
- Access to European experts



Engage

- Public
- Patients
- Political establishment
- Stakeholders
- Lobby and campaign
- Influence transplant policy

Empower

- Patients
- Professionals
- Engage dialogue
- Produce the evidence

Connect

- Professionals network
- Guidelines
- Research
- ESOT hub
- Educational activities
- European data



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ON BEHALF OF THE MINISTRY OF HEALTH,
INSTITUTE FOR TRANSPLANTATION AND BIOMEDICINE

CROATIA
Stela Živčić-Ćosić

European Kidney Forum, Brussels, 25th June 2019

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CROATIAN MODEL - KEY ELEMENTS

- ✓ **Governing capacities (Ministry of Health)**
 - national leader
 - regulatory framework (presumed consent)
 - training, education, funding
 - international organ exchange and collaboration
(ET: organ allocation criteria, transparency, rules)
 - monitoring of donor hospital performance
- ✓ **Hospital-based capacities for organ donation**
 - clinical leader
 - pathway for the deceased organ donor standardized
 - training, education, trust, enthusiasm
- ✓ **Society**
 - altruistic donation, culture and public trust



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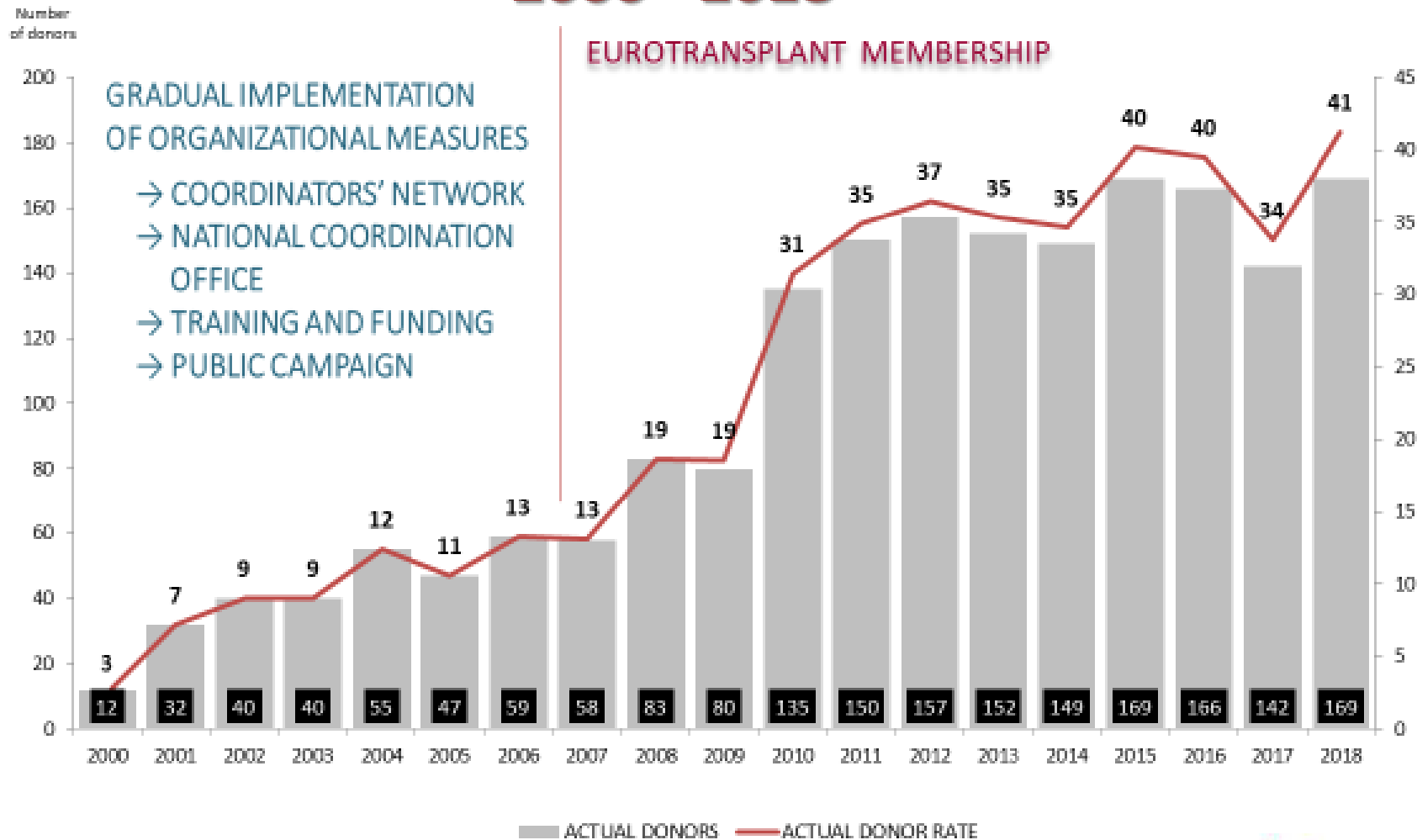
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CROATIAN ACTUAL ORGAN DONOR RATE 2000 - 2018



Source: Ministry of Health



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Propelling Deceased Donation

T R U S T

Public

- **Trust**

Professionals

- **Competence**
- **Confidence**
- **Capacities**

Health Authority

- **Policies**
- **Coordination**
- **Monitoring**

Education and Training

Country driven and local-reality adapted approach to the organ donation pathway through learning alliances



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We all speak Donor

The Croatian Organ Donation and Transplantation Program has been comprehensively based on the **highest quality** and **safety standards** and **ethical principles** that both positively reflect Croatian professional health care standards and Croatian social values.



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FOCUS POINTS



■ Prevention of graft loss:

- Progressive failure
- Fibrosis
- Rejection

■ Prevention of conditions leading to fatal outcomes:

- Cancer
- Diabetes mellitus
- Cardio-vascular disease
- Infections



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FOCUS POINTS

- **Prevention of graft loss:**
 - Progressive failure
 - Fibrosis
 - Rejection
- **Prevention of conditions leading to fatal outcomes:**
 - Cancer
 - Diabetes mellitus
 - Cardio-vascular disease
 - Infections
- **Transition to dialysis**



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TOOLS



- **Action via:**
 - EU and from there top to bottom to the national level
 - National stakeholder societies
 - Thematic Network Partners
 - National competent authorities
- **Enforcing the generation of:**
 - Registries including complications and long-term outcomes
 - Evidence-based recommendations
- **Facilitating research projects on transplantation and their financial support**



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EU Action Plan on Organ Donation and Transplantation (2009-2015)

Stefaan Van der Spiegel, MD, MBA
Substances of Human Origin (SoHO)

European Commission
DG Health and Food Safety (SANTE)

*European Kidney Forum
Organ Donation and Transplantation
25 June 2019*



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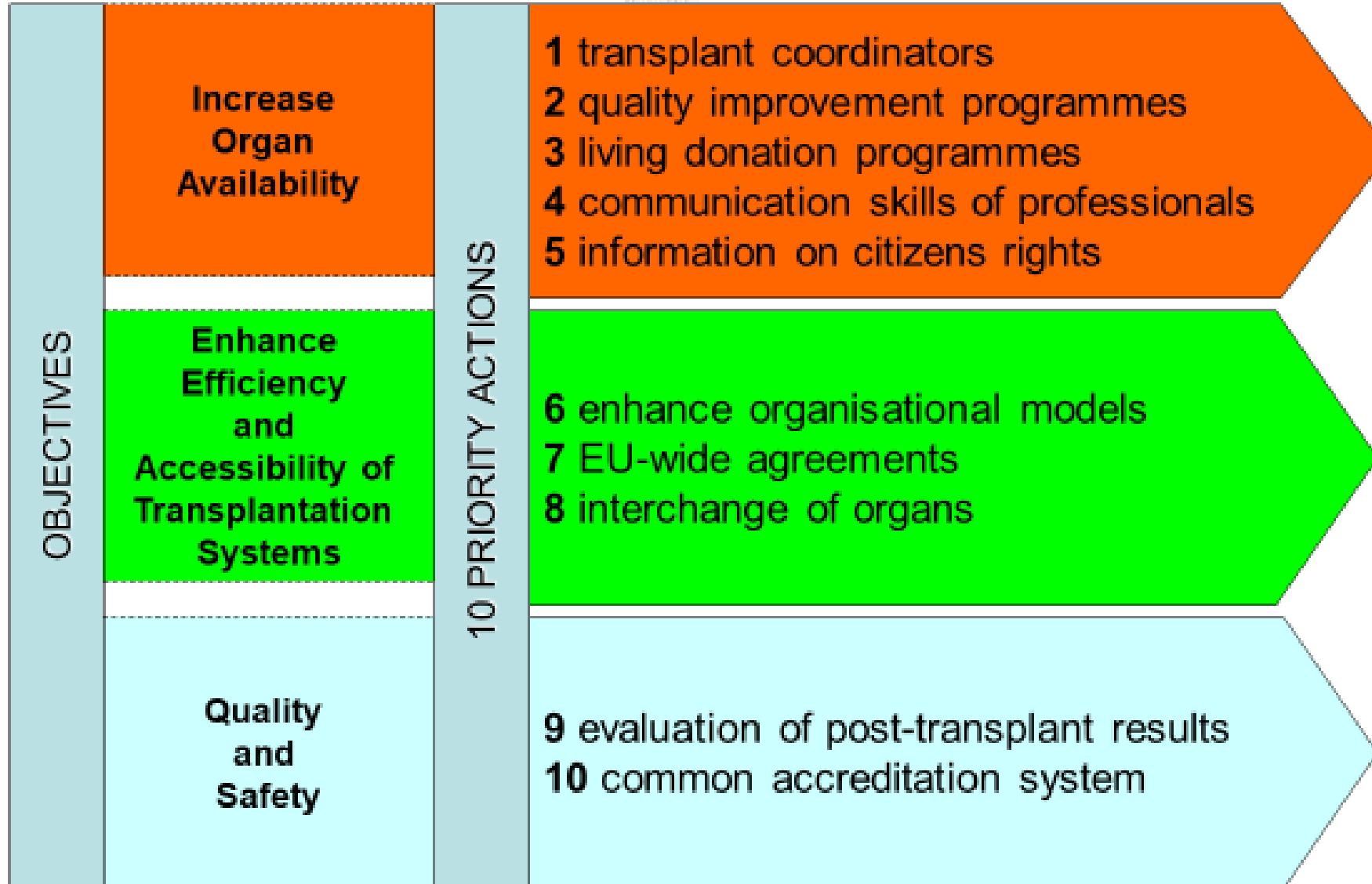
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10 Priority Actions



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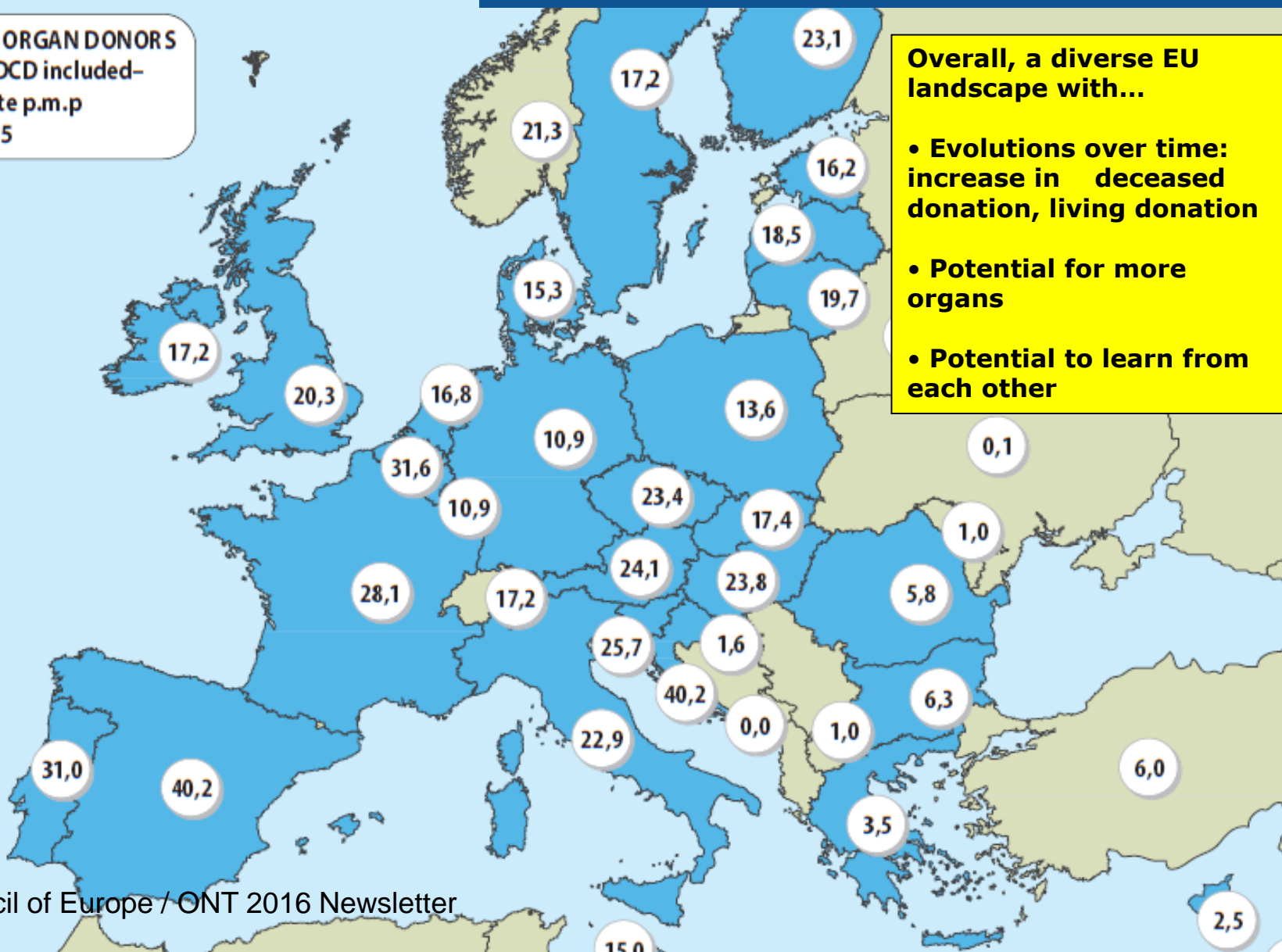
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MEMBER STATE DIFFERENCES DRIVE OPPORTUNITIES

DECEASED DONOR RATES - 2015

ACTUAL DECEASED ORGAN DONORS
-both DBD and DCD included-
Annual Rate p.m.p
2015



Overall, a diverse EU landscape with...

- Evolutions over time: increase in deceased donation, living donation
- Potential for more organs
- Potential to learn from each other



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Source: Council of Europe / ONT 2016 Newsletter

Experience with organ transplantation

- 2,5 years on waiting list
- Incompatible donor kidney
- 2012 kidney and pancreas transplant.
- 2x operation in 24 hours
- 6 weeks recovery
- 9 weeks of decreasing health due to medication overdose
- Total recuperation time: 12 maanden
- Ambassador of the Dutch National Kidney Foundation



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How can patients and the public be empowered to contribute to the gift that is organ donation and transplantation?

- Be conscious that health is fundamental for everything in life
- The secret of living is giving
- #1: organ donation
 - Research
 - Collecting and fundraising
 - Volunteering
- Media coverage
 - Patients share their story in interviews and broadcasts
- Local or Regional Associations
- Public debate



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