ACHIEVING COMPREHENSIVE COORDINATION IN ORGAN DONATION THROUGHOUT THE EUROPEAN UNION
Spanish Results

Beatriz Domínguez-Gil
Organización Nacional de Trasplantes

http://www.accord-ja.eu
ACCORD - Joint Action co-funded by the European Commission, coordinated by Organización Nacional de Trasplantes (ONT)

**Aim**

ACCORD intends to strengthen the full potential of Member States in the field of organ donation and transplantation, improving the cooperation between them and contributing to the effective implementation of the *EU Directive 2010/53/EU* and the *Action Plan on Organ Donation and Transplantation (2009-2015): Strengthened Cooperation between MS.*
The consortium

Bulgaria: BEAT
Croatia: MOHSW
Cyprus: Ministry of Health
Czech Republic: KST
Estonia: TUH
France: ABM
Germany: DSO
Greece: HTO
Hungary: HNBTS
Ireland: HSE
Italy: ISS-CNT
Latvia: PSCUH
Lithuania: NTB
Malta: MHEC
Norway: HDIR
Poland: Poltransplant
Portugal: IPST
Romania: ANT
Slovenia: Slovenija Transplant
Slovak Republic: NTO
Spain: ONT
The Netherlands: DTF
United Kingdom: NHSBT

ASSOCIATED PARTNERS (23)
The consortium

European Organ Exchange Organizations
- Eurotransplant
- Scandiatransplant

Professional Associations
- European Hospital and Healthcare Federation (HOPE)
- European Society of Intensive Care Medicine (ESICM)
- European Donation and Transplant Coordination Organisation (EDTCO)

Other
- Organisation des Établissements de Soins (Belgium)
- Hospital Clínic Barcelona (Spain)
- Ghent University Hospital (Belgium)
1. Improve MS information systems on living organ donation through the provision of recommendations on the design and management of structured registries and through setting down a model for supranational data sharing (PanEuropean registry of registries)

2. Facilitate the cooperation between critical care professionals and donor transplant coordinators, to optimize the realization of the process of donation from the deceased

3. Implement practical collaborations between EU countries for the transfer of knowledge, expertise or tools in specific areas related to the Directive 2010/53/EU and the Action Plan on Organ Donation and Transplantation (2009-2015), based on comprehensive and specifically prepared protocols
Aim and Objectives of ACCORD WP 5

Coordination: NHSBT

To strengthen the cooperation between critical care professionals and donor transplant coordinators to optimize the development of the process of donation after brain death.

- To describe the usual end-of-life care pathways applied to patients who die as a result of a devastating brain injury in Europe – observational study (Phase 1)

- To apply a rapid improvement methodology (PDSA) to support modifications in end-of-life management that preserve the possibility of donation – intervention study (Phase 2)
Practices at the end-of-life and organ donation

Subanalysis of Spanish data
Patients & methods I

- Transnational, multicenter, observational study

- Prospective review of clinical charts of patients dead as a result of a devastating brain injury (possible donors) in any unit of the hospital, aged ≤ 80 years

- Identification of cases:
  - Daily or quasi-daily review of diagnoses of patients dead in the hospital - ICD -10
  - Review of clinical chart disregarding cases not dead as a result of a devastating brain injury

- Period: 1/3/2013-31/8/2013 – 6 months

- All consecutive cases up to 50
Patients and methods II

Diagram:

Q1 & Q2 General Qs...

Q3: Intubated and Ventilated

Q4: Clinical condition consistent with brain death

Q5: Brain death tested

Q6: Brain death confirmed

Q7: Donation after Circulatory Death considered

Q8: Potential Donor referred to the DTC

Q9: Family approached considered

Q9.2: Who approached family

Q10: Did donation occur
Hospitals participating in ACCORD

67 hospitals / 15 MS

<table>
<thead>
<tr>
<th>Country</th>
<th>Number of audited hospitals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Croatia</td>
<td>2</td>
</tr>
<tr>
<td>Estonia</td>
<td>2</td>
</tr>
<tr>
<td>France</td>
<td>2</td>
</tr>
<tr>
<td>Germany</td>
<td>2</td>
</tr>
<tr>
<td>Greece</td>
<td>2</td>
</tr>
<tr>
<td>Hungary</td>
<td>2</td>
</tr>
<tr>
<td>Ireland</td>
<td>2</td>
</tr>
<tr>
<td>Italy</td>
<td>4</td>
</tr>
<tr>
<td>Latvia</td>
<td>2</td>
</tr>
<tr>
<td>Lithuania</td>
<td>2</td>
</tr>
<tr>
<td>Portugal</td>
<td>3</td>
</tr>
<tr>
<td>Slovenia</td>
<td>2</td>
</tr>
<tr>
<td>Spain</td>
<td>17</td>
</tr>
<tr>
<td>The Netherlands</td>
<td>4</td>
</tr>
<tr>
<td>UK</td>
<td>19</td>
</tr>
<tr>
<td>Total</td>
<td>67</td>
</tr>
<tr>
<td>Region</td>
<td>Hospital Name</td>
</tr>
<tr>
<td>--------------------</td>
<td>-------------------------------------------------------</td>
</tr>
<tr>
<td>ANDALUCÍA</td>
<td>Hospital Univ. Carlos Haya - Málaga</td>
</tr>
<tr>
<td>CANTABRIA</td>
<td>Hospital Univ. Marqués de Valdecilla- Santander</td>
</tr>
<tr>
<td>CASTILLA Y LEÓN</td>
<td>Complejo Asistencial de Ávila - Ávila</td>
</tr>
<tr>
<td></td>
<td>Complejo Asistencial Univ. De Burgos - Burgos</td>
</tr>
<tr>
<td></td>
<td>Complejo Asistencial Univ. de León - León</td>
</tr>
<tr>
<td></td>
<td>Complejo Hospitalario de Salamanca - Salamanca</td>
</tr>
<tr>
<td></td>
<td>Hospital General de Segovia - Segovia</td>
</tr>
<tr>
<td></td>
<td>Hospital Clínico Universitario - Valladolid</td>
</tr>
<tr>
<td></td>
<td>Hospital Río Hortega - Valladolid</td>
</tr>
<tr>
<td></td>
<td>Hospital Virgen de la Concha - Zamora</td>
</tr>
<tr>
<td>CASTILLA LA MANCHA</td>
<td>Complejo Hospitalario La Mancha Centro – Alcázar de San Juan</td>
</tr>
<tr>
<td></td>
<td>Hospital General Univ. de Ciudad Real – Ciudad Real</td>
</tr>
<tr>
<td>CATALUÑA</td>
<td>Hospital General de la Vall d'Hebrón - Barcelona</td>
</tr>
<tr>
<td>GALICIA</td>
<td>Hospital Univ. de Lugo - Lugo</td>
</tr>
<tr>
<td>PAÍS VASCO</td>
<td>Hospital Santiago Apóstol - Vitoria</td>
</tr>
<tr>
<td></td>
<td>Hospital de Cruces - Bilbao</td>
</tr>
<tr>
<td></td>
<td>Donostia Ospitalea – San Sebastian</td>
</tr>
</tbody>
</table>

Spanish hospitals participating in ACCORD

Thanks to all
### Possible donors: demographics & clinical data

During 6 months, 413 possible donors were identified

<table>
<thead>
<tr>
<th>AGE (years)</th>
<th>0-17</th>
<th>18-34</th>
<th>35-49</th>
<th>50-59</th>
<th>60-69</th>
<th>70+</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>11 (3%)</td>
<td>17 (4%)</td>
<td>42 (10%)</td>
<td>48 (12%)</td>
<td>100 (24%)</td>
<td>195 (47%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>GENDER (%)</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>269 (65%)</td>
<td>144 (35%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>MAIN CAUSE OF DEATH (%)</th>
<th>Cerebrovascular Accidents</th>
<th>Trauma</th>
<th>Cerebral damage other</th>
<th>Cerebral Neoplasm</th>
<th>Infections</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>253 (61%)</td>
<td>61 (15%)</td>
<td>54 (13%)</td>
<td>36 (9%)</td>
<td>9 (2%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TIME FROM BRAIN INJURY TO DEATH (days)</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4-6</th>
<th>7-9</th>
<th>10+</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>17 (4%)</td>
<td>115 (28%)</td>
<td>70 (17%)</td>
<td>52 (13%)</td>
<td>56 (14%)</td>
<td>44 (11%)</td>
<td>59 (14%)</td>
</tr>
</tbody>
</table>

62%
Statement best describing the care of the patient during final illness

A. Full active treatment on CCU until Brain Death (n=158)
B. Full active treatment on CCU until unexpected cardiac arrest (n=27)
C. Admitted to CCU to incorporate organ donation into end-of-life care (n=32)
D. Full active treatment on CCU until the decision to withdraw life sustaining treatment (n=99)
E. Not admitted/Admitted to CCU but subsequently discharged (n=97)

Controlled DCD? 24.0%
Losses? 23.5%

N=413
The pathway of Donation after Brain Death

N=101 NOT INTUBATED

- Not of overall benefit to the patient, due to the severity of the acute event (51%)
- Not appropriate (35%)
- Not needed (9%)
- Other (3%)

62% Medically unsuitable

BENEFIT OF THE PATIENT ONLY CONSIDERED FROM A MEDICAL PERSPECTIVE BY SOME PHYSICIANS

Percentage of losses at each step of the process, over cases remaining from the previous step
The pathway of Donation after Brain Death

Percentage of losses at each step of the process, over cases remaining from the previous step.
The pathway of Donation after Brain Death

- Medical Unsuitability (58%)
- Cardiac arrest/hemodynamic instability (42%)

Percentage of losses at each step of the process, over cases remaining from the previous step.
The pathway of Donation after Brain Death

Percentage of losses at each step of the process, over cases remaining from the previous step

- N=24 FAMILY NOT APPROACHED
  - Medical unsuitability (92%)
  - Unable to contact the family (4%)
  - Other (4%)

N=413
The pathway of Donation after Brain Death

Percentage of losses at each step of the process, over cases remaining from the previous step.

- Audited patients: 450
- Intubated: 400
- BSD suspected: 37%
- BSD tests performed: 8%
- BSD confirmed: 0%
- Patient referred: 0%
- Family approached: 13%
- Consent: 20%
- Donation: 4%

% Donation: 125/413 = 30% vs 322/1670 = 19% entire cohort
Possible donors not admitted at the ICU

413 Possible donors

97 Not admitted at the ICU (23%)

33 Medically suitable (34%)

3 Intubated – 2 dead in ≤ 3 days
30 Not intubated – 18 dead in ≤ 3 days

28 Possible donors not admitted in the ICU and medically suitable were never referred to the DTC
Possible donors admitted at the ICU to incorporate donation to end-of-life care

- 413 Possible donors
- 32 Admitted to incorporate donation (referred to the DTC) (8%)
- 28 Brain Death (88%)
- 25 Family approached (89%)
- 18 Actual Donation (72%)

14% Actual donors during the study period
413 Possible donors

99 Dead following WLST (24%)

97 DCD not considered (98%)

47 Medically suitable (48%)

25% Possible donors dead following WLST could be potential controlled DCD

25 aged ≤ 70 years (53%)
Critical assessment of Spanish results

**STRENGTHS**

- The process of DBD is optimized starting at the point when a clinical condition consistent with brain death is identified.

- The admission of possible donors at the ICU to incorporate donation at the end-of-life contributes to 14% of the overall actual donation activity.

**WEAKNESSES - OPPORTUNITIES**

- There is a great opportunity for improvement outside the ICU, based on the cooperation with extra-ICU and inclusive of strategies for the routine and early referral of possible donors to the ICU/DTC and the consideration of elective ventilation.

- The absence of controlled DCD programmes is an important limitation to increase the availability of organs for transplantation.
Applying the PDSA methodology

Experience in Spain
ACCORD WP5: Sesión Formativa en PDSA

Fecha: 21 de Noviembre de 2013
Sede: Organización Nacional de Trasplantes. C/ Sinesio Delgado 6, pabellón 3.
28020 Madrid.

Objetivos de la jornada:
- Adquirir conocimientos en los principios y la implementación de la metodología Plan, Do, Study, Act (PDSA), para desarrollar y conseguir mejoras en el proceso de la donación.
- Hacer una primera aproximación a los planes de mejora a nivel de cada uno de los hospitales participantes, en base a los puntos débiles identificados en el proceso, según los datos recopilados en la primera fase del proyecto ACCORD.
- Los asistentes a esta jornada podrán trasladar esta formación al resto de miembros de sus equipos de coordinación y a otros profesionales sanitarios implicados en el proceso de donación en sus respectivos hospitales, con el fin de analizar el proceso en equipo y acordar el plan definitivo y las intervenciones de mejora.

AGENDA

11:00 h – 14:00 h: PRIMERA PARTE

1. Bienvenida

2. Introducción y análisis de cuestionarios

3. Herramientas y técnicas de mejora
   a. Principios de mejora
   b. Definición del problema
   c. Modelo de mejora: objetivos y medida

4. Modelo de mejora: intercambio de ideas y planificación,
   a. Desarrollo, prueba y medida de las ideas de mejora
   b. Sostenibilidad

5. Fase del proyecto: Próximos pasos

14:00 – 14:45 h DESCANSO – COMIDA

14:45 h – 17:30 h: SEGUNDA PARTE

6. Diseño del plan de mejora

Training in the PDSA methodology
“If I had one hour to save the world, I would spend 55 minutes defining the problem and only 5 minutes finding the solution.”

Albert Einstein
What are we trying to accomplish?

How will we know that a change is an improvement?

What change can we make that will result in improvement?

Understanding the problem. Knowing what you’re trying to do - clear and desirable aims and objectives

Measuring processes and outcomes

What have others done? What idea do we have? What can we learn as we go along?

Challenge yourself
Interventions to increase referral of possible donors from outside ICU

- **Proactive follow-up of patients with a devastating brain injury** – admission department-ICD, neuroimages, etc. –discussion of cases with physicians in charge.

- **Protocols for the routine and early referral of possible donors to ICU/DTC** when no therapeutic intervention is considered appropriate – incorporation of donation as an option at the end-of-life.

- **Supporting material and training sessions.**

- **Appointment of professionals at extra-ICU units** with responsibility in the process of donation after death (Transplant Committee).
Summary of interventions
Hospital Vall D´Hebrón

- Monitoring compliance with pre-existing protocol for routine and early referral of possible donors to identify losses outside the ICU - all hospital deaths were reviewed daily.
- Feed-back by the treating physician, in case of non-compliance with the protocol. Non-compliance and reasons registered.
- Training and informative sessions on the routine and early referral protocol in all relevant areas.
- Ongoing development of general hospital recommendations regarding end-of-life care inclusive of the option to donate (involving hospital Ethics Committee).
### Results: 1\textsuperscript{st} versus 2\textsuperscript{nd} phase

Hospital Vall d’Hebrón

<table>
<thead>
<tr>
<th>N (%)</th>
<th>Phase 1 (n: 51 – 6 months)</th>
<th>Phase 2 (n: 42 – 4.5 months)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admitted to ICU to incorporate donation</td>
<td>1 (2%)</td>
<td>5 (12%)</td>
</tr>
<tr>
<td>Referred to the DTC</td>
<td>39 (78%)</td>
<td>37 (90%)</td>
</tr>
<tr>
<td>Dead intubated</td>
<td>35 (69%)</td>
<td>30 (73%)</td>
</tr>
<tr>
<td>Condition consistent with brain death over intubated</td>
<td>23 (66%)</td>
<td>26 (86%)</td>
</tr>
<tr>
<td>Consent declined</td>
<td>5 (24%)</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>Actual donors</td>
<td>13 (26%)</td>
<td>19 (46%)</td>
</tr>
</tbody>
</table>
**Recommended requisites for a hospital to embark on controlled DCD**

<table>
<thead>
<tr>
<th><strong>Optimized DBD</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Agreed upon and fully implemented protocols for <strong>WLST &amp; terminal extubation</strong> – independent ethics committee approval</td>
</tr>
<tr>
<td><strong>Established registry of brain death cases and WLST</strong></td>
</tr>
<tr>
<td><strong>Local protocol on controlled DCD</strong> – independent ethics committee approval</td>
</tr>
<tr>
<td><strong>Training</strong> of all professionals involved</td>
</tr>
<tr>
<td><strong>Education</strong> – informative session for the entire hospital on the programme</td>
</tr>
<tr>
<td><strong>Required authorization</strong> – institutional support</td>
</tr>
</tbody>
</table>

*2012 Spanish National Consensus Document for DCD. Available at: [http://www.ont.es](http://www.ont.es)*
Team work
Conclusions

- Potential donor audits should be continuously adapted to capture the areas for improvement in deceased donation within a given jurisdiction – focus on units extra-ICU and potential for controlled DCD mandatory in the Spanish reality.
- **PDSA** - methodology for a systematic approach to analysing opportunities for improvement and testing small scale interventions –**useful in deceased donation.**
- **Continuous improvement should become a way of thinking and acting.**
- ACCORD has been extended to the entire Spanish network of procurement hospitals - **ACCORD Spain (71 hospitals).**
ACCORD

Associated partners

ACCORD Collaborating partners

ACCORD WP5 leaders - NHSBT

Clinical Reference Group – Miguel Lebrón, Eduardo Miñambres & Teresa Pont

Participating hospitals throughout Europe

ONT personnel

http://www.accord-ja.eu
Possible donors not referred to the Donor Transplant Coordinator

413 Possible donors

115 Not referred to the DTC (28%)

45 Medically suitable (39%)

15 Intubated – 7 dead in ≤ 3 days
30 Not intubated – 18 dead in ≤ 3 days

Unit where death occurred
- Ward – 20
- Emergency room – 8
- Stroke Unit – 6
- ICU adults – 7
- ICU neurosurgery – 1
- Other – 3
Practices at the end-of-life and organ donation

A comparison of Spanish results with other countries
A: Full active treatment on CCU until the diagnosis of BD
B: Full active treatment until unexpected cardiac arrest from which the patient could not be resuscitated
C: Admitted to CCU to incorporate organ donation into end-of-life care
D: Full active treatment on CCU until the decision of withdrawal or limiting life sustaining therapy was made, with an expected final cardiac arrest
E: Not admitted, or admitted to CCU but subsequently discharged
The process of Donation after Brain Death
Spain versus UK

N=413

N=531
The process of Donation after Circulatory Death: Spain versus UK

**Spain, DCD pathway**
- Donation rate: 0%

**UK, DCD pathway**
- Donation rate: 10%

*Graphs showing the process of donation after circulatory death in Spain and UK, with N=413 and N=531 respectively.*
### Work Plan

**HORIZONTAL WORK PACKAGES**

<table>
<thead>
<tr>
<th></th>
<th>Coordination</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Dissemination</td>
</tr>
<tr>
<td>3</td>
<td>Evaluation</td>
</tr>
</tbody>
</table>

**CORE WORK PACKAGES**

<table>
<thead>
<tr>
<th></th>
<th>Living donor registries</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>ICU and DTC collaboration</td>
</tr>
<tr>
<td>6</td>
<td>Twinning on organ donation and transplantation</td>
</tr>
</tbody>
</table>
Unit/Ward where death was confirmed

28% outside the ICU

N=413