ACHIEVING COMPREHENSIVE COORDINATION IN ORGAN DONATION THROUGHOUT THE EUROPEAN UNION

Spanish Results

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Organización Nacional de Trasplantes

http://www.accord-ja.eu

ACCORD AIM

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.*

Accord

Achieving Comprehensive Coordination in Organ Donation

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)

COLABORATING PARTNERS (10)

Other

Organisation des Établissments de Soins (Belgium)
Hospital Clínic Barcelona (Spain)
Ghent University Hospital (Belgium)

ACCORD Objectives

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 <u>any unit</u> of the hospital, <u>aged ≤ 80 years</u>**
- **Identification of cases:**
  - Daily or cuasi-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
- **Períod: 1/3/2013-31/8/2013 – 6 months**
- **All consecutive cases up to 50**

Patients and methods II

- 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 approched considered
- Q9.2: Who approched family
- Q10: Did donation occur
- STOP

Hospitals participating in ACCORD

67 hospitals / 15 MS

Country	Number of audited hospitals
Croatia	2
Estonia	2
France	2
Germany	2
Greece	2
Hungary	2
Ireland	2
Italy	4
Latvia	2
Lithuania	2
Portugal	3
Slovenia	2
Spain	17
The Netherlands	4
UK	19
Total	67

Spanish hospitals participating in ACCORD

ANDALUCÍA	Hospital Univ. Carlos Haya - Málaga	Miguel Lebrón
CANTABRIA	Hospital Univ. Marqués de Valdecilla- Santander	Eduardo Miñambres
CASTILLA Y LEÓN	Complejo Asistencial de Ávila - Ávila	Antonio Isusi
	Complejo Asistencial Univ. De Burgos - Burgos	Mª Amor Hernando
	Complejo Asistencial Univ. de León - León	Carlos Fernández-Renedo
	Complejo Hospitalario de Salamanca - Salamanca	Alvaro García Miguel
	Hospital General de Segovia - Segovia	Santiago Macías
	Hospital Clínico Universitario - Valladolid	Pablo Ucio
	Hospital Río Hortega - Valladolid	Pedro Enríquez
	Hospital Virgen de la Concha - Zamora	Ana Caballero
CASTILLA LA MANCHA	Complejo Hospitalario La Mancha Centro – Alcázar de San Juan	Carmen Martín
	Hospital General Univ. de Ciudad Real – Ciudad Real	MªSol Martínez Mingallón
CATALUÑA	Hospital General de la Vall d'Hebrón - Barcelona	Teresa Pont
GALICIA	Hospital Univ. de Lugo - Lugo	Jose Mª Sánchez Andrade
PAÍS VASCO	Hospital Santiago Apóstol - Vitoria	Esther Corral
	Hospital de Cruces - Bilbao	Kepa Esnaloa
	Donostia Ospitalea – San Sebastian	Lucía Elosegui

Thanks to all

Possible donors: demographics & clinical data

During 6 months, 413 possible donors were identified

AGE (years)	0-17	11 (3%)
	18-34	17 (4%)
	35-49	42 (10%)
	50-59	48 (12%)
	60-69	100 (24%)
	70+	**195 (47%)**
GENDER (%)	Male	**269 (65%)**
	Female	144 (35%)
MAIN CAUSE OF DEATH (%)	Cerebrovascular Accidents	**253 (61%)**
	Trauma	61 (15%)
	Cerebral damage other	54 (13%)
	Cerebral Neoplasm	36 (9%)
	Infections	9 (2%)
TIME FROM BRAIN INJURY TO DEATH (days)	0	17 (4%)
	1	115 (28%)
	2	70 (17%)
	3	52 (13%)
	4-6	56 (14%)
	7-9	44 (11%)
	10+	59 (14%)

62%

Statement best describing the care of the patient during final illness

%	Value
A. Full active treatment on CCU until Brain Death (n=158)	38,3
B. Full active treatment on CCU until unexpected cardiac arrest (n=27)	6,5
C. Admitted to CCU to incorporate organ donation into end-of-life care (n=32)	7,7
D. Full active treatment on CCU until the decision to withdraw life sustaining treatment (n=99)	24,0
E. Not admitted /Admitted to CCU but subsequently discharged (n=97)	23,5

N=413

Controlled DCD?

Losses?

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

N=413

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

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

The pathway of Donation after Brain Death

Audited patients
450
400
350
300
250
200
150
100
50
0
24%
37%
6%
0%
0%
13%
20%
4%
Audited patients
Intubated
BSD suspected
BSD tests performed
BSD confirmed
Patient referred
Family approached
Consent
Donation

N=24 FAMILY NOT APPROACHED

- Medical unsuitability(92%)
- Unable to contact the family (4%)
- Other (4%)

N=413

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

Possible donors not admitted at the ICU

413 Posible 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

Controlled DCD

413 Possible donors

99 Dead following WLST (24%)

97 DCD not considered (98%)

47 Medically suitable (48%)

25 aged ≤ 70 years (53%)

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

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

Training in the PDSA methodology

ACCORD WP5: Sesión Formativa en PDSA

Fecha: 21 de Noviembre de 2013
Sede: Organización Nacional de Trasplantes. C/ Sinesio Delgado 6, pabellón 3. 28029 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

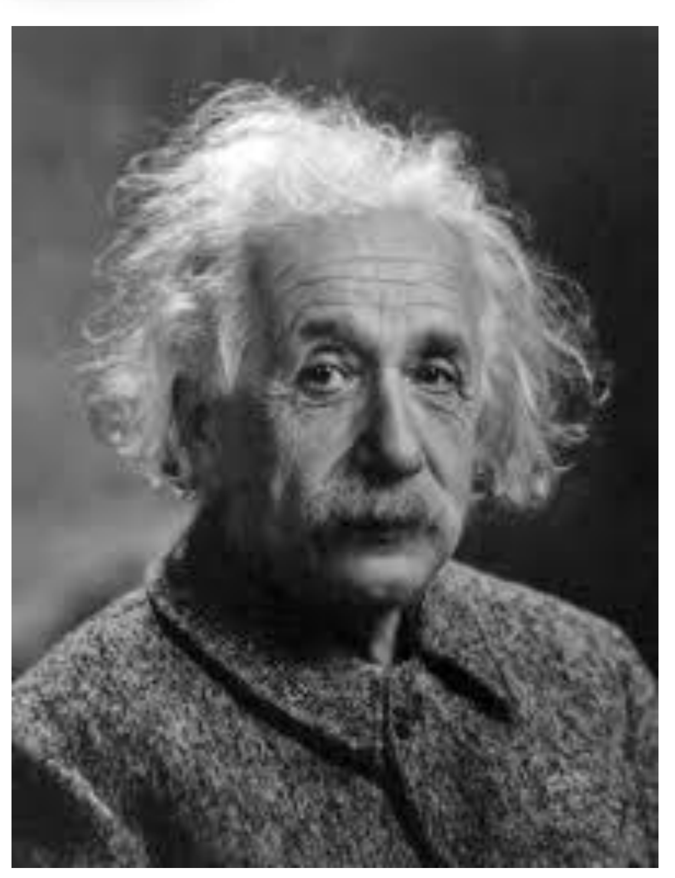
11:00 h – 14:00 h: PRIMERA PARTE

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**



"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

Model for Improvement

What are we trying to accomplish?

How will we know that a change is an improvement?

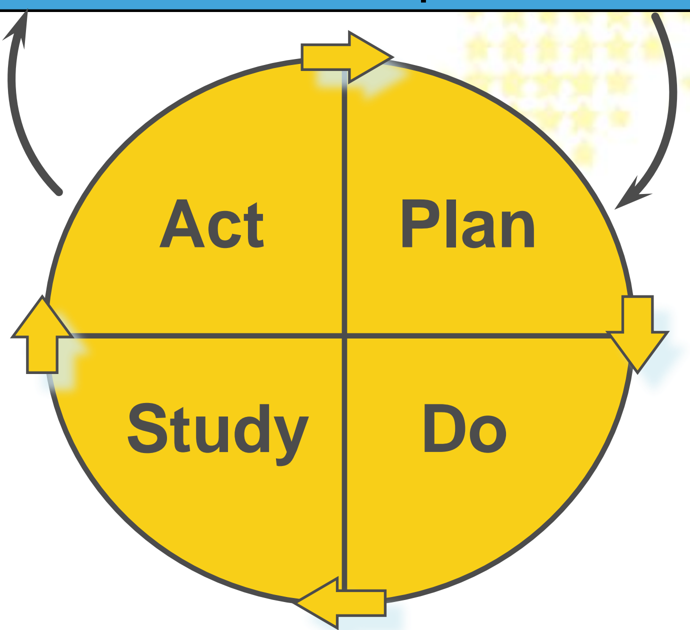
What change can we make that will result in improvement?

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?

Langley G, Moen R, Nolan K, Nolan T, Norman C, Provost L, (2009), *The Improvement Guide: a practical approach to enhancing organizational performance (2nd ed)*, Josses Bass Publishers, San Francisco

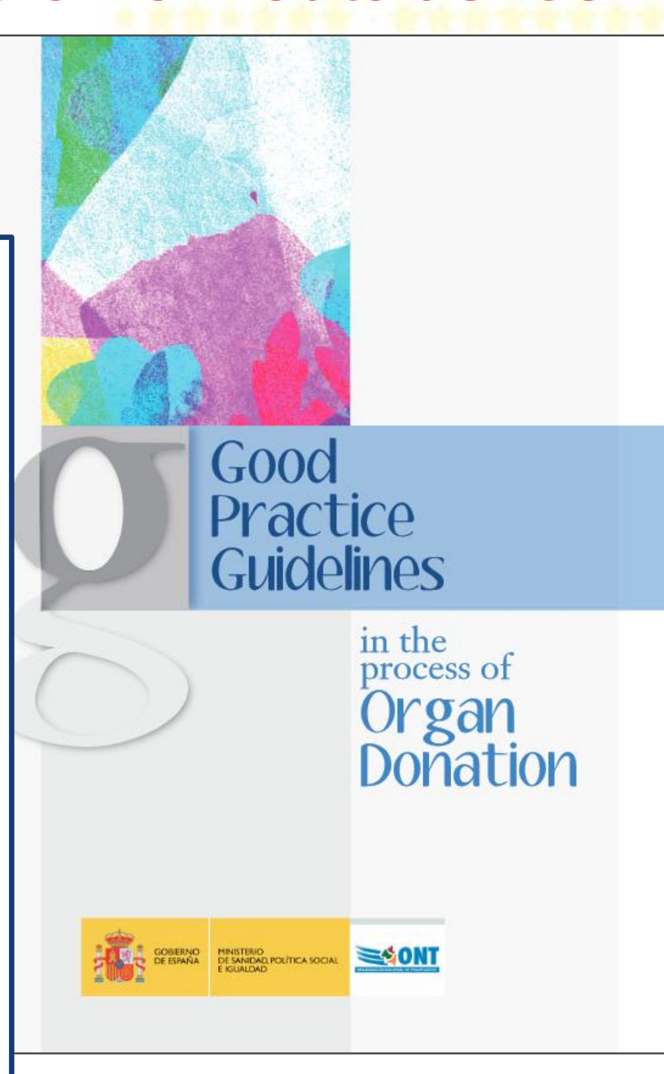


Challenge yourself

Interventions to increase referral of possible donors from outside ICU

EMERGENCY DEPARTMENT
NEUROLOGY
INTERNAL MEDICINE

- **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 responsiblity in the process of donation after death (Transplant Committee).



http://www.ont.es/publicaciones/Documents

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).

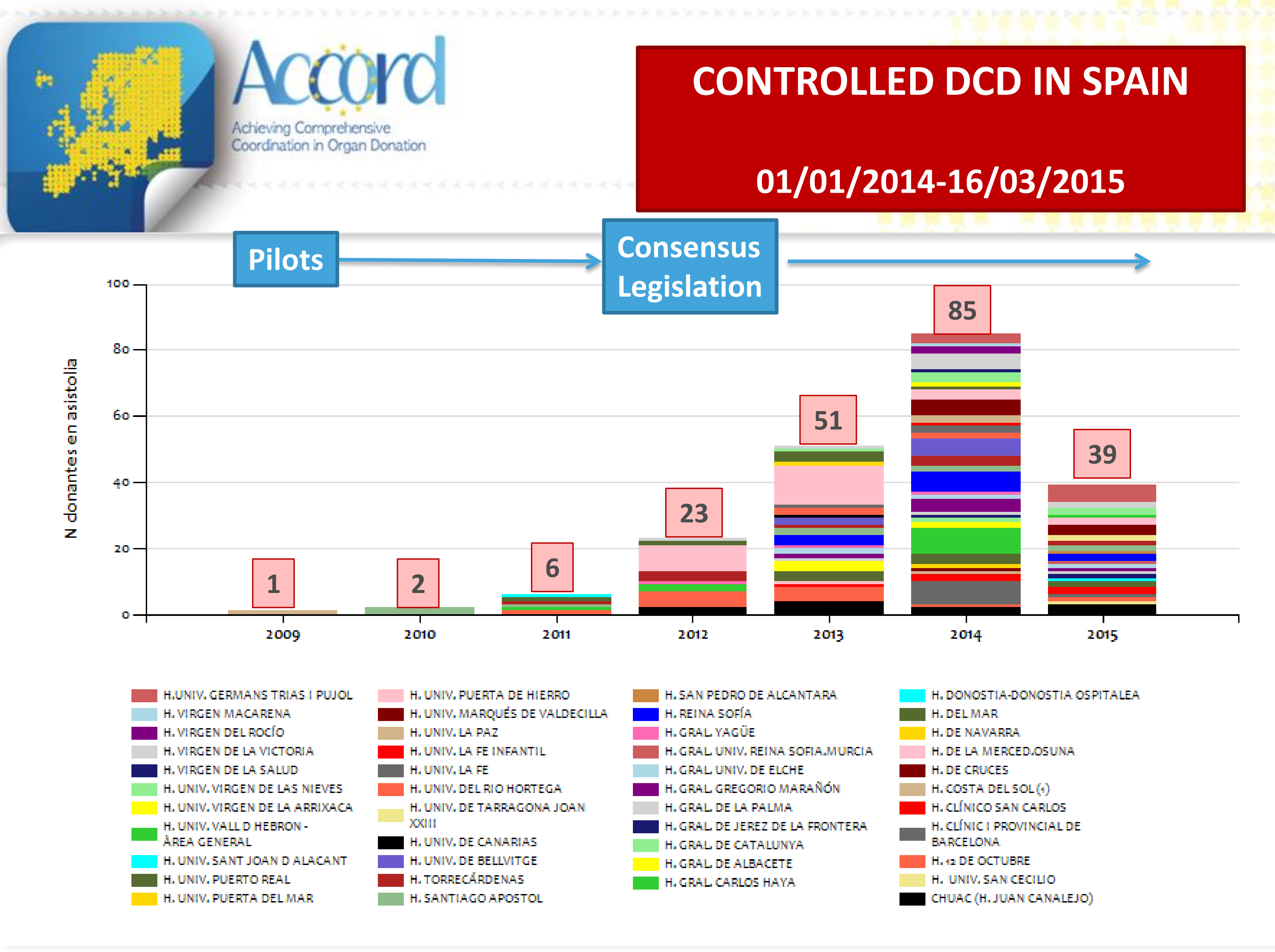
Results: 1st versus 2nd phase Hospital Vall d´Hebrón

N (%)	Phase 1 (n:51 – 6 months)	Phase 2 (n: 42 – 4.5 months)
Admitted to ICU to incorporate donation	1 (2%)	5 (12%)
Referred to the DTC	39 (78%)	37 (90%)
Dead intubated	35 (69%)	30 (73%)
Condition consistent with brain death over intubated	23 (66%)	26 (86%)
Consent declined	5 (24%)	1 (10%)
Actual donors	13 (26%)	19 (46%)

Recommended requisites for a hospital to embark on controlled DCD

Optimized DBD
Agreed upon and fully implemented protocols for **WLST & terminal extubation – independent ethics committee approval**
Established registry of brain death cases and WLST
Local protocol on controlled DCD – independent ethics committee approval
Training of all professionals involved
Education– informative session for the entire hospital on the programme
Required authorization – institutional support

2012 Spanish National Consensus Document for DCD. Available at: http://www.ont.es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CONTROLLED DCD IN SPAIN
01/01/2014-16/03/2015
Pilots
Consensus Legislation
N donantes en asistolia
100
80
60
40
20
0
1
2
6
23
51
85
39
2009
2010
2011
2012
2013
2014
2015
H.UNIV. GERMANS TRIAS I PUJOL
H. VIRGEN MACARENA
H. VIRGEN DEL ROCÍO
H. VIRGEN DE LA VICTORIA
H. VIRGEN DE LA SALUD
H. UNIV. VIRGEN DE LAS NIEVES
H. UNIV. VIRGEN DE LA ARRIXACA
H. UNIV. VALL D HEBRON - ÀREA GENERAL
H. UNIV. SANT JOAN D ALACANT
H. UNIV. PUERTO REAL
H. UNIV. PUERTA DEL MAR
H. UNIV. PUERTA DE HIERRO
H. UNIV. MARQUÉS DE VALDECILLA
H. UNIV. LA PAZ
H. UNIV. LA FE INFANTIL
H. UNIV. LA FE
H. UNIV. DEL RIO HORTEGA
H. UNIV. DE TARRAGONA JOAN XXIII
H. UNIV. DE CANARIAS
H. UNIV. DE BELLVITGE
H. TORRECÁRDENAS
H. SANTIAGO APOSTOL
H. SAN PEDRO DE ALCANTARA
H. REINA SOFÍA
H. GRAL. YAGÜE
H. GRAL. UNIV. REINA SOFIA.MURCIA
H. GRAL. UNIV. DE ELCHE
H. GRAL. GREGORIO MARAÑÓN
H. GRAL. DE LA PALMA
H. GRAL. DE JEREZ DE LA FRONTERA
H. GRAL. DE CATALUNYA
H. GRAL. DE ALBACETE
H. GRAL. CARLOS HAYA
H. DONOSTIA-DONOSTIA OSPITALEA
H. DEL MAR
H. DE NAVARRA
H. DE LA MERCED.OSUNA
H. DE CRUCES
H. COSTA DEL SOL (+)
H. CLÍNICO SAN CARLOS
H. CLÍNIC I PROVINCIAL DE BARCELONA
H. 12 DE OCTUBRE
H. UNIV. SAN CECILIO
CHUAC (H. JUAN CANALEJO)

Team work

Conclusions

- **Potential donor audits should be continuosly 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 <u>way of thinking and acting</u>.**
- ACCORD has been extended to the entire Spanish network of procurement hospitals **- ACCORD Spain (71 hospitals).**

Accord

Achieving Comprehensive Coordination in Organ Donation

Thanks

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

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Coordination in Organ Donation

Possible donors not referred to the Donor Transplant Coordinator

413 Possible donors

115 Not referred to the DTC (28%)

45 Medically suitable (39%)

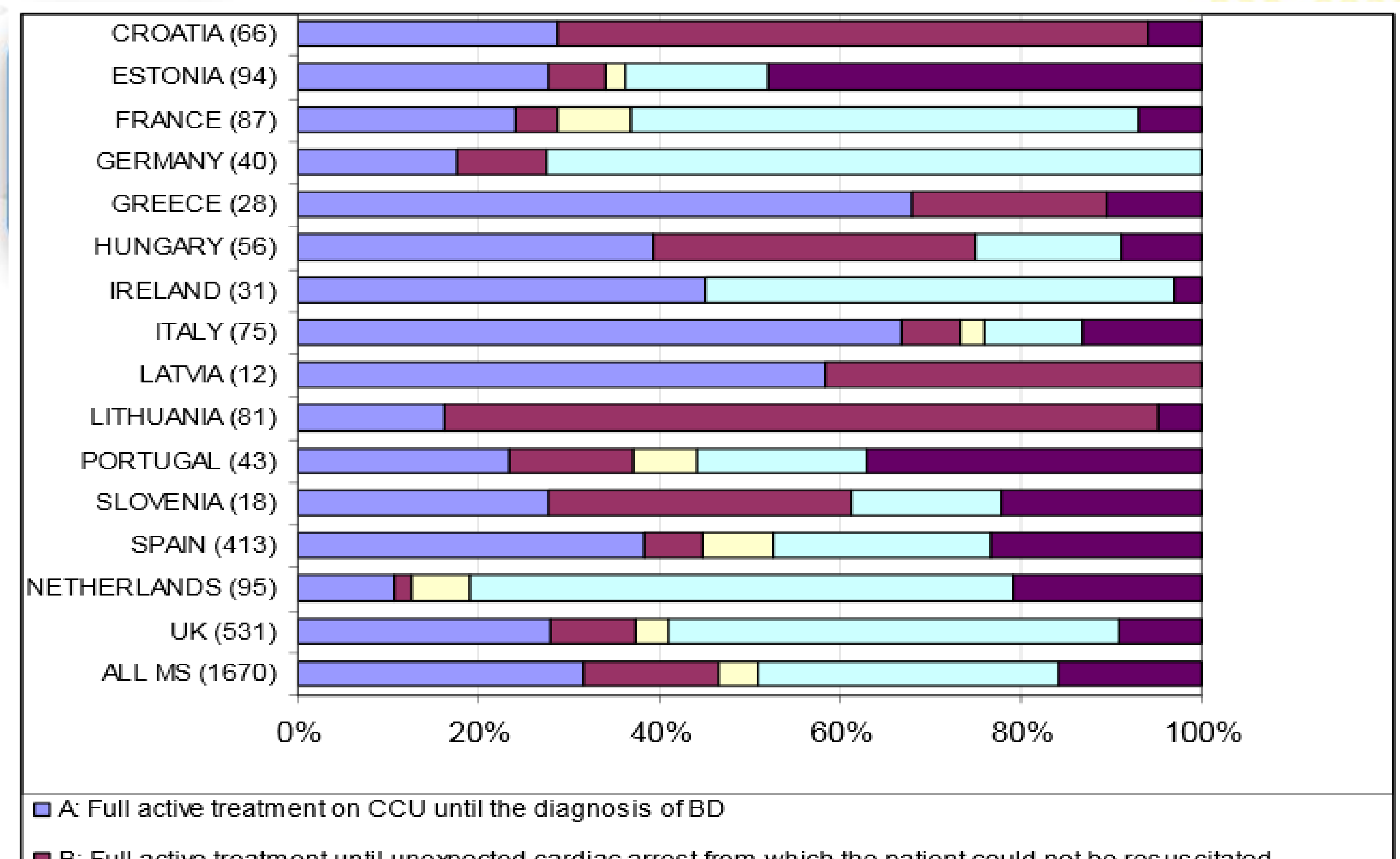
15 Intubated – 7 dead in ≤ 3 days
30 Not intubated – 18 dead in ≤ 3 days

Unit where death occurred

- Ward– 20
- Emergency room– 8
- Stroke Unit– 6
- ICU adults– 7
- ICU neurosurgery- 1
- Other - 3

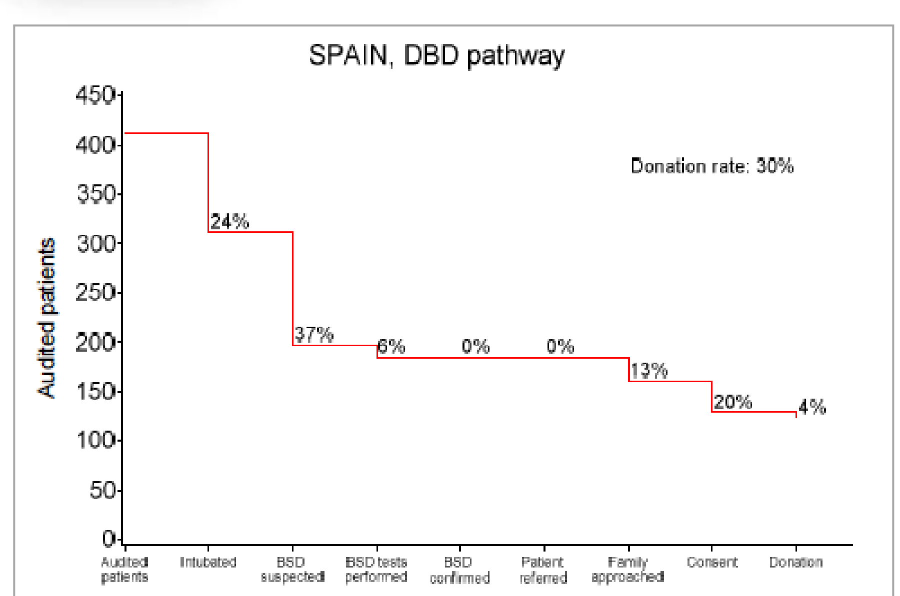
Practices at the end-of-life and organ donation

A comparison of Spanish results with other countries



CROATIA (66)
ESTONIA (94)
FRANCE (87)
GERMANY (40)
GREECE (28)
HUNGARY (56)
IRELAND (31)
ITALY (75)
LATVIA (12)
LITHUANIA (81)
PORTUGAL (43)
SLOVENIA (18)
SPAIN (413)
NETHERLANDS (95)
UK (531)
ALL MS (1670)
0%
20%
40%
60%
80%
100%
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



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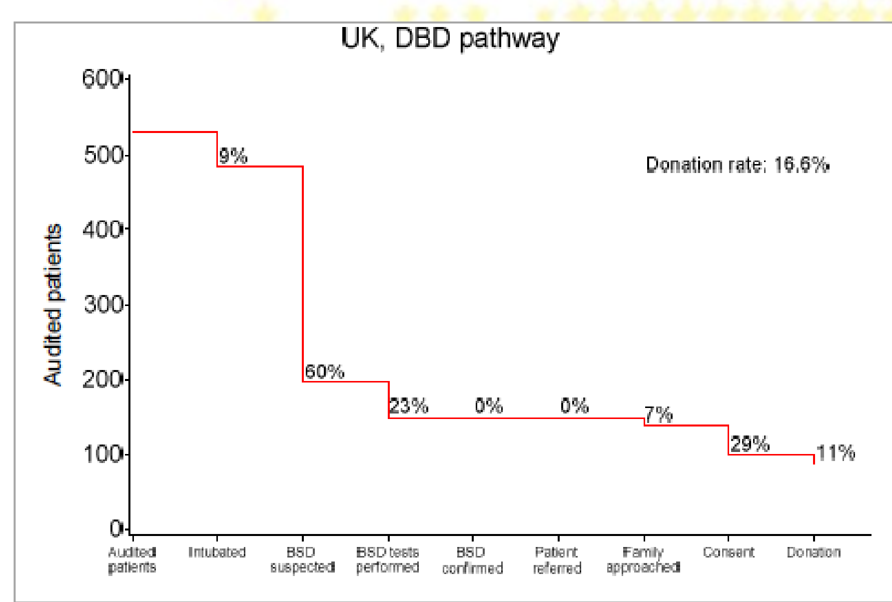
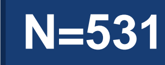
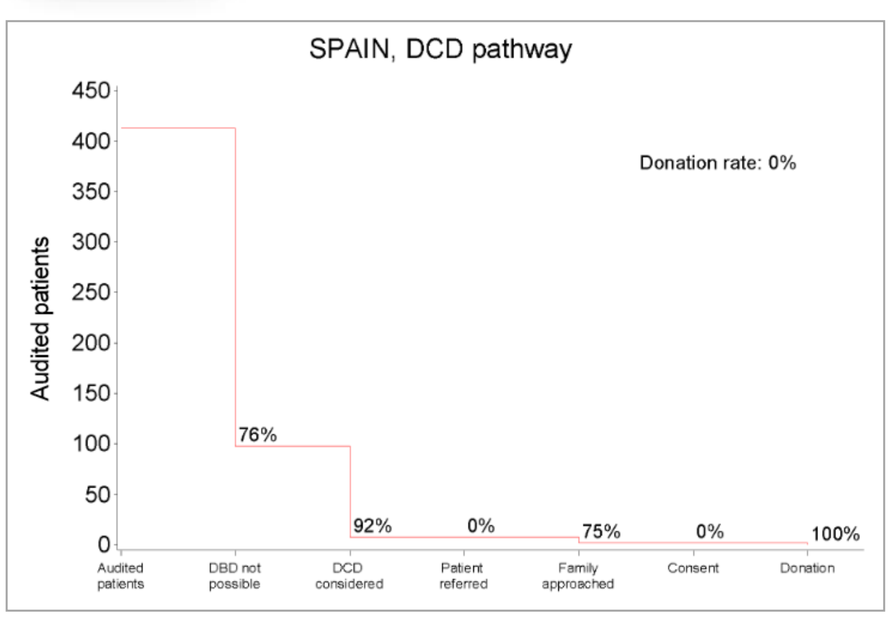
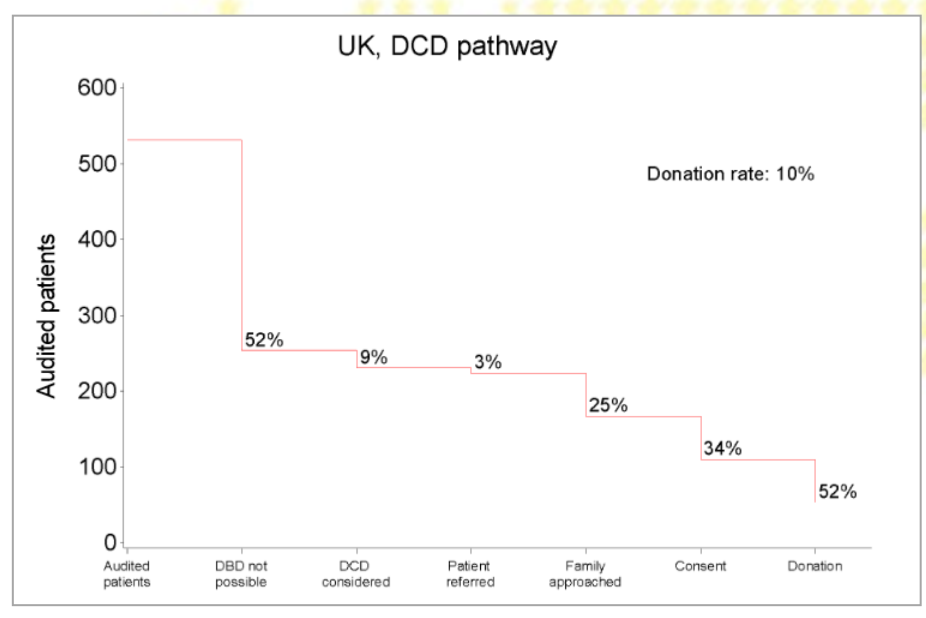




The process of Donation after Circulatory Death Spain *versus* UK





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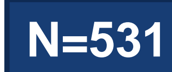

Work Plan

	HORIZONTAL WORK PACKAGES
1	Coordination
2	Dissemination
3	Evaluation

42 m

	CORE WORK PACKAGES
4	Living donor registries
5	ICU and DTC collaboration
6	Twinning on organ donation and transplantation

36 m

Unit/Ward where death was confirmed

N=413

Unit/Ward	%
Adult Intensive Care	55,0
Specialised Neurosurgical Intensive Care	9,7
Paediatric Intensive Care	1,9
Emergency Department	6,8
Medical Ward	18,4
Stroke Unit	2,9
Other	5,3

28 % outside the ICU