When are bereaved family members approached for consent to organ donation? Commentary from 10 European member states.

Nichon E. Jansen, PhD[1]

Maryon McDonald, PhD[2]

Bernadette J.J.M. Haase-Kromwijk, MSc[1]

Magi Sque PhD[3]

Tracy Long-Sutehall T PhD[4]

[1] Dutch Transplant Foundation, Leiden, the Netherlands

[2] Department of Social Anthropology, University of Cambridge, UK

[3]Faculty of Education, Health and Wellbeing University of Wolverhampton and The Royal Wolverhampton Hospitals NHS Trust, Wolverhampton, UK

[4]Faculty of Health Sciences, University of Southampton, UK

Corresponding Author
Nichon E. Jansen
Senior researcher,
Dutch Transplant Foundation
P.O. Box 2304
2301 CH Leiden
The Netherlands
Tel: +31-71-5795701
Fax: +31-71-5766728
E-mail: n.jansen@transplantatiestichting.nl

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Abstract

Background - To scope the timing of the approach to bereaved family members and request for organ donation in DBD and DCD potential donors, in 10 European member states. Are there changes in established practice regarding when family members are asked to consider organ donation?

Methods – Representatives from 10 member states responded to a survey seeking information about: how death is diagnosed in the DBD and DCD potential donor; the legal consent system and law on organ donation; the existence of national or local protocols specifying when to approach relatives; and practices around the first moment of discussing organ donation and the formal request.

Results – Findings suggest that the historic practice of decoupling the confirmation of death discussion and the request for organ donation in the potential DBD situation is becoming more 'flexible' or is changing to one in which a discussion about the potential of organ donation is taking place before confirmation of death.

Conclusions – Decisions about the moment of asking may benefit from being embedded within local practices of 'end of life' care. Establishing donation as a usual part of end of life care would mean that the moment of asking would become a step in the dying trajectory, facilitating the fulfilment of wishes regarding post-death use of organs for transplantation.

Introduction

The ‘Deceased Donation Working Group’ is one of 7 within the European discussion platform known as ’Ethical, Legal and Psychosocial Aspects of Organ Transplantation’ (ELPAT). ELPAT acts as the official, advisory committee of the European Society for Organ Transplantation (ESOT) and aims to integrate and structure this field of science by bringing together professionals from varied backgrounds across more than 25 European countries. Recent discussions within the Deceased Donation Working Group have focussed on the timing of the moment of asking [1] for organ donation - and how the introduction of Donation after Circulatory Death (DCD) might potentially be impacting on the established practice whereby the request for organ donation *follows* the confirmation of brain or brain stem death.

Diagnosis of death across Europe

Legislation or guidance specifying the criteria that are both necessary and sufficient to diagnose death, and the clinical tests and standards that physicians must use to establish that the criteria have been fulfilled, has been in existence since at least the late 1960s [2]. Despite modification and amendment over subsequent decades each country delivering an organ donation service will have clinical criteria in place to guide the diagnosis of death in the potential organ donor. In all European countries except the UK, the criteria that must be fulfilled are that of a whole brain death formulation, which requires that all clinical functions of the brain (cerebral hemispheres, diencephalon, and brainstem) must have ceased[*]. In the UK, the criteria that must be fulfilled are laid out in a brainstem death formulation [3]. Both diagnoses of death require the irreversible loss of the capacity to breathe, combined with the irreversible loss of the capacity for consciousness.

Donation after Circulatory Death

Until roughly the mid-1960s, the widely accepted definition of death was based on cardio respiratory criteria. With the development of whole brain and brainstem death criteria for diagnosing death, and the beginnings of organ donation programmes, the brain dead donor became the sole source of organs for transplantation due to the superior quality of the organs retrieved and the fact that only brain dead donors could donate hearts [4]. Therefore the trajectory of dying that led to deceased organ donation was via a diagnosis of death based on neurological criteria, now referred to as Donation after Brain Death (DBD). However, since the beginning of the 1980s, there has been a growing interest in the potential of retrieving organs from individuals diagnosed dead via circulatory (previously ‘cardio-respiratory’) criteria, now referred to as Donation after Circulatory Death, (DCD). This was stimulated by a persistent shortfall in organs for use in transplant operations [5]. The modified

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[*] Confirmed by auxiliary tests as per country guidelines.

Maastricht classification identifies four categories of patients who could be potential donors after confirmation of circulatory death [5; 6] (Table 1), and the circumstances of death leading to DCD. Currently, DCD category III is not widespread within European donation programmes, with only three countries having high DCD category III activity: Belgium, the Netherlands and the United Kingdom [5]. France and Spain only implement donation from Maastricht category I and II patients [7]. However, DCD programmes account for increasing numbers of the deceased donor pool in those countries that offer this route to donation. In 2012, DCD accounted for 50% of the deceased donor pool in The Netherlands [7, 8] and in the UK, DCD donors accounted for 40% of the deceased donor pool in the period 2011-2012 [9].

Table 1. Modified Maastricht categories of potential DCD [NHB] donors I - IV [Kootstra et al 1995]

Category	Description	Explanation	Type of DCD	Countries carrying out
I	Dead on arrival at the hospital	The patient is declared dead at the scene of the accident/injury and is transferred to the hospital for organ donation.	Uncontrolled	Spain
II	Unsuccessful resuscitation	The patient is in the hospital or brought into the Emergency Room, while being resuscitated. When efforts for CPR have turned out to be ineffective DCD donation is an option.	Uncontrolled	Spain
III	Awaiting cardiac arrest	A patient with a very poor prognosis, for whom ongoing treatment is agreed to be futile, and who is deemed to be likely to die shortly after support is withdrawn: for example, patients with severe brain damage, but not fulfilling all the brain(stem) death criteria.	Controlled	The Netherlands UK
IV	Cardiac arrest whilst brain (stem) dead	The patient has been confirmed brain (stem) dead (by testing), and somewhere in the process before organ procurement starts, the patient suffers an unexpected cardiac arrest that does not respond to CPR.	Controlled	The Netherlands UK

There are differences in how death is diagnosed and when it is confirmed, depending on whether the patient is a potential DBD or DCD donor. Of necessity, there is also a difference in the content of discussions with family members about the potential for organ donation - and a difference in the timing of a formal request.

The timing of the request for donation

The issue of 'when' family members should be asked about organ donation first appears in the literature in the late 1980s, with authors proposing that family members needed time to accept that death had occurred before they were presented with the option of organ donation [10-12]. The timing of the approach was reported as being a critical factor in the consent process [13] and influential in family grieving [14]. During this period of research activity, Garrison and colleagues [13] introduced a new concept to the timing debate - that of decoupling. They report that allowing a ‘temporal separation’ between the explanation of death, or the certainty of family acceptance of death, and the request for donation yielded a higher consent rate than when the death discussion and request were completed at the same time [13].

More recent work has linked the timing of the donation request to family member’s agreement or disagreement to donation [15], and studies reporting factors that influence family members’ decision-making have included the timing of the request [16-19]. A systematic review carried out by Simpkins et al in 2009 [20] indicated that the timing of the request for organ and tissue donation was one of the main modifiable factors (others are listed) associated with consent or refusal for organ donation by relatives. This underlined the significance of the timing of the approach.

Perhaps as a result of this early empirical work and reinforcement from later work, the formal request to the family for their consent[†] in DBD donation has usually come *after* the confirmation of death by country-specific testing of brain function[‡]. This is not the situation in DCD donation where the discussion with family members regarding the potential for organ donation is reported to follow on from a discussion about the futility of on-going treatment and the intention of the ICU team to withdraw life sustaining treatment. This difference in the timing of approach is necessary as seeking consent *after* circulatory death has been confirmed would mean that organs would not be available for donation purposes due to extended periods of warm ischemia.

However, anecdotal evidence from practice and empirical work from The Netherlands [4; 21] suggests that the practice of discussing donation with relatives *prior* to the certified death of the potential DBD donor has become increasingly common, thereby undermining the concept of decoupling. Since research [4; 21] suggests that this may be impacting on consent rates, and yet may not be an obvious change in historic practice, the Deceased Donation Working Group decided to try and scope current practice about the moment of asking for DBD and DCD donation across member states. This paper reports the results from that scoping exercise.

Material and Methods

Initial discussions about this potential change in practice took place during the annual meeting of the Deceased Donation Working Group in November 2011. Members of the group based in: Spain, Sweden, The Netherlands, and the United Kingdom, who were working in intensive care medicine, health/social sciences, and clinical

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[†] Or authority (Scotland)

[‡] This may not be the case if family members, recognising the futility of the situation, and knowing the wishes of the deceased regarding donation, raise the issue with health care professionals before testing has commenced.

practice, developed brief commentaries about current practices in the timing of approaches to family members asking them to consider donation in both DBD and DCD donation. These initial commentaries (four countries) together with findings from a literature review seeking to identify the legislative frameworks and consent systems underpinning organ donation programmes across Europe, were used to develop a brief, factual questionnaire comprising 15 questions. The questions covered: how death is diagnosed in the DBD and DCD potential donor; the legal consent system and law on organ donation; the existence of national or local protocols specifying when to approach relatives; and the practice of the first moment of discussing organ donation. This questionnaire was completed by the members who had prepared commentaries, and the initial findings from four countries were discussed at the deceased donation working group in November 2012. Following these discussions, a decision was taken to try and canvass a broader picture of current practice and so the questionnaire was e-mailed to contacts in 15 further countries (Table 2).

Table 2. Overview of countries contacted and response or no response to the questionnaire

Response to questionnaire	Croatia. Estonia. Germany. Norway (2). Poland, Switzerland	6 (40%)
No response	Austria, Belgium, Czech republic, Denmark, Finland ,France, Hungary, Italy, Turkey	9 (60%)

Results

Recruitment

Fifteen country contacts were approached and asked to complete the questionnaire. This yielded seven responses from six countries, a response rate of 40%. To preserve the anonymity of the contacts, only their clinical disciplines are listed. Participants included seven medical practitioners (Intensivists/transplant coordinators (doctor or nurse)/MD).

Responses from these six countries were combined with the responses from the initial four (n=10) and all are reported here.

Question 1. How is death diagnosed in the case of a potential DBD or heart-beating donor (by brain stem death, whole brain death (including EEG and apnoea test), or otherwise))?

Death confirmation in the potential DBD donor is based on the whole brain formulation in all responding countries other than the UK (where brain stem death criteria apply) and Estonia where both sets of criteria are used (depending on the time line). The use of auxiliary tests for checks varies by country with, for example, The

Netherlands requiring an EEG and apnoea test as mandatory, while in Sweden an EEG is not performed (see Table 3).

Question 2. Is DCD donation or donation after circulatory death (non-heart-beating donation) implemented in your country/hospital?

Four countries reported implementing donation after circulatory death: Spain (mainly category I and II), Switzerland (category I, II and III), The Netherlands and the UK (category II, III and IV) (Table 3).

Table 3. Response to Question 1 and 2.

	Death diagnoses in DBD donors	**Donation after circulatory death implemented?**
Croatia	Whole brain death is diagnosed, including apnoea test and some of the following ancillary tests : electroencephalogram (EEG), transcranial doppler (TCD), angiography, gamagraphy.	No
Estonia	Both brainstem death (brain death protocol: 12 hours; 72 hours in certain cases) and whole brain death is diagnosed (brain death protocol: 6 hours, including ancillary tests, usually either EEG or TCD). The apnoea test is performed in every case. The method of diagnosing brain death can depend on the feasibility of ancillary tests.	No
Germany	Whole brain death is diagnosed, including appropriate additional ancillary tests such as: EEG, , BAEP (early acoustically evoked potentials) / somatosensorisch evoked potentials (SEP), detection of cerebral circulation arrest (TCD, perfusion scintigraphy), cerebral angiography.	No
Norway	Whole brain death is diagnosed, confirmed by cerebral angiography/arcography for all donors (mandatory). Before this test is performed, the law requires a full brain stem reflex test with apnoea test.	No
Poland	Whole brain death including apnoea test. EEG is not mandatory, but in some cases we have to use instrumental tests.	No
Spain	Whole brain death is diagnosed, including TCD, EEG, gamma-grafie and apnoea test.	Yes, for potential DCD donor Maastricht category I and II. In small numbers for category III
Sweden	Whole brain death is diagnosed but without EEG.	Not
Switzerland	Whole brain death is diagnosed, including appropriate additional ancillary tests such as: EEG, computed tomography angiography (CTA), TCD, intra-arterial digital subtraction angiography (IA-DSA), magnetic resonance imaging and angiography.	Yes, category I, II and III, but only in very small numbers
The Netherlands	Whole brain death is diagnosed, including EEG and apnoea test as mandatory tests (or TCD, CTA if applicable)	Yes, category II, III and IV, but only high numbers on category III
UK	Brainstem death is diagnosed with no confirmatory tests needed (UK is the only country in Europe that uses these criteria).	Yes, category II, III and IV, but high numbers only for category III

Question 3. What kind of legal consent system do you have, opting-in (explicit consent) or opting-out (presumed consent)?

Six countries have opt out systems in place (Croatia, Estonia, Norway, Poland, Spain, Sweden), and four countries have opting in systems where individuals can register their views about what organs or tissues they wish to donate after their death (Table 4).

Question 4. Do you have a law on organ donation and, if so, is it explicit concerning the timing of the approach to the family for organ donation (before or after death)?

Nine out of the 10 responding countries have a specific law underpinning and guiding the process of organ donation (Poland does not), and eight out of the ten have local guidance, recommendations or protocols in place (Poland and Estonia do not) (Table 4). The Netherlands is the only country where the law stipulates that a formal request for organ donation can only take place after death is confirmed.

Question 5. Do you have a ***national*** *protocol or national guidelines on organ donation and, if so, is this document explicit concerning the timing of the approach to the family for organ donation (before or after death)?*

Of the six countries that provided detailed feedback, two countries (Croatia and The Netherlands) report national protocols that legislate when to request donation. Two countries, Norway and the UK, cite protocols that state when an approach should be made, and one country, Switzerland, cites national guidelines[§] indicating when the approach should be made (Table 4).

[§] It is important to note that guidelines are not mandatory.

Table 4. Response to Question 3, 4 and 5.

	Q3 Legal consent system	**Q4 Law on organ donation**	**Q5 National protocol or guidelines explicit concerning timing of the approach to relatives?**
Croatia	Opting-out	Transplant law	National protocol in which states that organs can be retrieved only from a dead person, which actually means we talk to family after death of the patient.
Estonia	Opting-out	Handling and Transplantation of Cells, Tissues and Organs Act	No national protocol
Germany	Opting-in	Transplant law	National guidelines, formally the result of any request is only binding when death had been certified and consent still exists.
Norway	Opting-out	Transplant law	National protocol says family approach should be done when all clinical signs indicate the total destruction of the brain. Some hospitals use cerebral echo Doppler or CT angiography for correct timing. In case of family refusal there is no need for cerebral angiography before withdrawal of treatment.
Poland	Opting-out	No	No
Spain	Opting-out	Transplant law	Good practices guide
Sweden	Opting-out	Transplant law	Recommendations
Switzerland	Opting-in	Transplant law	National guidelines, but their use is not mandatory. It's explained to ask the family once brain death is determined.
The Netherlands	Opting-in	Dutch organ and tissue act	National protocol for organ and tissue donation is explicit; only ask consent after death (conform with the law on donation).
UK	Opting-in	Human Tissue Act	Management protocol description documents indicate that family member should be approached after a diagnosis of death (DBD and DCD) has been made.

Question 6. Do you have ***local*** *protocols on organ donation and, if so, are they explicit concerning the timing of the approach to the family for organ donation (before or after death)?*

Only three countries indicate that they have local protocols/guidelines: Spain, Sweden and the UK (Table 5), however they are not explicit concerning the timing of the approach to the relatives.

Question 7. In general, when is the first discussion on organ donation with relatives?

Reponses indicate variation in practice. Four countries (Poland, Spain, Switzerland, Croatia) report the first discussion taking place after the first or second sets of tests, or after confirmation of death. Four countries (Germany, Sweden, The Netherlands, UK) report that the request is made before death is confirmed by testing as part of either an end of life care discussion, or withdrawal of treatment discussion. Estonia and Norway report that the timing of the first discussion varies, and in Norway it is linked to family members raising the issue of organ donation themselves (Table 5).

Question 8. When is an organ donation request made to the relatives: is this before or after death?

Only three counties- Croatia, Poland and Switzerland - stipulated that the request for organ donation came after death had been confirmed by testing. In other countries practice varied (Table 5).

Table 5. Response to Question 6, 7 and 8.

Country	**Q6 Local protocols on organ donation explicit in timing approach relatives?**	**Q7 When is first discussion of organ donation?**	**Q8 Donation request before or after death?**
Croatia	No local protocols	After death	After death is confirmed by testing
Estonia	No local protocols	Depending on various factors.	It's the choice of the ICU doctor, usually right after brain death is confirmed, but there are many variations.
Germany	No local protocols	Most people introduce the end of life care and the need to start brain death diagnostics, which means prolongation of therapy until death has been certified.	This can be before or after death is confirmed. The physician can give communication a turn to the point that relatives ask "what are you going to do after brain death certified", you have to give a true answer…
Norway	No local protocols	Big differences between hospitals and situations. Also relatives often ask quite early whether organ donation would be an option.	There is no formal difference between first discussion and the actual request.
Poland	No local protocols	It depends on many things, but it's usually after first session of brain death tests.	After death is confirmed by testing.
Spain	Protocols and recommendation but not on timing approach	In the normal process it's after brain death diagnosis, but there are different scenarios at end of life.	Usually after death, but we can introduce the topic in the emergency department and request intubation and admission to the ICU only for donation.
Sweden	Protocols and recommendation, but no detailed instruction	Today earlier approach, when discussing the meaningfulness of continuing intensive care.	If possible after death, but see Q 7 about timing.
Switzerland	No local protocols	In general after brain death, it may happen that the family asks the question before.	After death [is confirmed by testing] for DBD donor and before death in the case of potential DCD donors.
The Netherlands	No local protocols	Nearly always before death of the potential donor.	Before death is confirmed by testing in potential DBD donors. For potential DCD donors it is before death, but after treatment is futile
UK	Local guidelines exist, but not on timing approach.	Before brainstem death (BSD) testing, but when a discussion about futility has taken place.	Before the 1st BSD test or immediately after the 1st set. But there appears to be variability. For potential DCD donors it's before death, but after treatment is futile.

Question 9. Are there differences in practice in the moment of asking for organ donation between cases of potential heart-beating donors and those of potential non-heart-beating donors Maastricht category III (if applicable)?

In those countries where DCD category III donation is practised - Switzerland, The Netherlands and the UK - the discussion about donation takes place before death has occurred (Table 6).

Question 10. Have there been changes in practice in the moment of asking for organ donation during the last 5 years? If so, please explain what exactly has changed and the reasons why.

Four countries report that there have been no changes in practice over the past 5 years. Those who indicate changes in the moment of asking, and provide their reasoning for it cite: limited resources, e.g. ICU beds and the changing profile of the potential organ donor as factors (Spain and Germany); and testing only being carried out if donation is to proceed (UK) (Table 6).

Table 6. Response to Question 9 and 10.

	Q9 Differences in practice in moment of asking between potential DBD or DCD category III donors?	**Q10 Changes in practice in timing to approach relatives during the last 5 years?**
Croatia	Not applicable	No
Estonia	Not applicable	No
Germany	Not applicable	Some people say that more often during the introduction of end of life care, the communication drifts to donation. Secondly, many hospitals in my state have problems of intensive care medicine resources. If no consent to organ donation exists, live care therapy is limited and the patient dies.
Norway	Not applicable	No
Poland	Not applicable	No
Spain	Not applicable	Yes, due to the type of organ donors (old and multi-morbidity) and the application of vital support limitation and constraint of ICU resources, recently we ask for donation before brain death in specific cases. We are trying to “fish” patients suitable for organ donation in the A&E, in case there are no treatment options. We ask relatives about “intention to donate”, if they are pro-donation, the patient is admitted to the ICU as a potential donor. If the family does not agree, we transfer the patient to a regular ward.
Sweden	Not applicable	With an increasing knowledge and also though it is mandatory to be honest about why care is continued after futility, there is today a change in the moment of asking.
Switzerland	Yes, in case of DCD the family is approached before treatment withdrawal.	Yes, in the past, a lot of physicians asked the family for donation before death. This could be changed with the national guidelines and the training courses, in which it is explained to ask the family after the brain death diagnosis is performed.
The Netherlands	In former days in DBD donors relatives were approached after BD, but nowadays it’s before all BD tests are performed. So too in potential DBD as for DCD donors relatives are approached before death is certified.	Yes, more and more relatives are approached for DBD donation before brain death is certified. Ten years ago, only in a few cases relatives were approached before brain death was formally diagnosed. Nowadays it is the other way round.
UK	Main difference is that for DCD the discussion must be before death has occurred.	No evidence that there have been significant changes, although it would appear that BSD testing is only done in some places *if* the family wants to donate.

Question 11. Is there a national Donor Register in your country? If so, what are the options it offers for the registration of your preferences for donation?

Registration of an individual's decision regarding organ and tissue donation is facilitated by a national Donor Register in five countries, with four using donor cards to register wishes, and one country requiring a digital signature to be listed with other health information (Table 7).

Question 12. When is it permitted by law to consult the Donor Register: is this before or after the death of the potential organ donor?

Four countries report legislative boundaries as to when the Donor Register can be consulted (Croatia, Poland, Sweden and The Netherlands), with consultation only being allowed: after death is confirmed by testing (Croatia and Sweden), during testing (Poland), when death is expected within 12 hrs (The Netherlands). In the UK and Estonia, consultation of the register can take place at any time (Table 7).

Question 13. What is the role of the family in the decision-making process: (i) do they need to give consent for donation (even when consent is presumed) and (ii) are they allowed to veto the decision made by the potential donor in the register or on a donor card?

In The Netherlands and Switzerland, if the deceased has consented to donation via registration, family members are informed of this decision and their consent is not needed for donation to proceed. In Norway, family members are asked to confirm that the deceased would not have objected to donation. In all other countries, family members are asked for consent to donation. In all 10 countries, family members can veto the decision of the deceased to become an organ donor (Table 7).

Table 7. Response to Question 11, 12 and 13.

	Q11 Is there a national Donor Register, if so, what are the options?	Q12 When is it permitted to consult the Donor Register?	Q13 What is the role of family in the decision-making process?
Croatia	Yes, citizens who do not wish to donate sign the form which is then deposited in the Register of the Ministry of Health.	After death.	Family need to give consent only for minors and citizens in guardianship. But if they oppose donation we follow their decision.
Estonia	It is possible to express consent by digital signature through health information system, but unfortunately no enquiries are made.	That is not regulated by law.	The family gives consent for donation, even though the law states presumed consent. By law: other persons shall not prohibit the removal of cells, tissues or organs, if the deceased person had consented during their lifetime.
Germany	No, since 1-11-2012 every person of16 years or older should get a donor card from the health insurance, which may be signed voluntarily without further registration.	Not applicable	The next of kin should respect the assumed wishes of the deceased (written or oral).
Norway	No, but you can fill in a donor card (you have to indicate name and phone number of next of kin whom you inform about your post mortem will.)	Not applicable	Relatives have to confirm that the potential donor would not have any objection to organ donation. Families may veto the donors known will.
Poland	Yes, it only offers the possibility of saying that you don't want to be a donor.	During brain death diagnosis.	Relatives are allowed to veto.
Spain	No, only donor card.	Not applicable	Although we have presumed consent, the family is always asked.
Sweden	Yes, you can sign to consent (including research, education purposes) and there are possibilities to exclude organs or tissues you do not want to donate.	After the declaration of death.	Information to next of kin is mandatory in Swedish law (presumed consent), when the will is unknown the next of kin shall interpret the wish of the deceased. If unknown, there is possibility to veto.
Switzerland	No, only a donor card.	No applicable	The law gives priority to the donor's consent. So if there is a donor card, we just have to inform the family. In practice: even when the donor card says 'yes' and the family is opposed, the process will be stopped.
The Netherlands	Yes, with four options: - Consent (you can exclude one or more organs or tissues) - Objection - Decision by relatives - Decision by specific person (by name)	Before death, according to the law when death is expected within approximately 12 hours.	When consent is registered the relatives will be informed about donation and not requested. Legally, no consent is needed.
UK	Yes, you can say yes to all organs and tissues or specify them.	There is no law on consulting, it can be accessed at any time. Some hospitals check the status of all patients admitted to ICU, others won't allow until treatment becomes futile.	Yes, we still need an agreement from the family, even if the donor was on the register and had recorded a 'yes'. Family can veto the recorded wishes of the deceased.

Question 14. Amongst the medical profession or more widely, is the idea that 'donation is a right' strong in your country?

Only one country responded unequivocally in the positive to this question (Croatia), with the rest indicating that the option of donation *as a right* is not generally supported among the medical professions in their country (Table 8).

Question 15. Are there other cultural differences framing, encouraging or inhibiting the practice, including the timing, of requesting organ donation from relatives?

Only one country responded positively to this question (Germany), but did not offer any details of what cultural differences might be in evidence (Table 8)[**].

Table 8. Response to Question 14 and 15

	Q14 Amongst medical professionals or more widely, is the idea that 'donation is a right' strong in your country?	**Q15 Are there other cultural differences framing, encouraging or inhibiting the practice of requesting?**
Croatia	Absolutely.	No
Estonia	Amongst medical professionals this idea is not strong, but still positively supported. More widely this idea is not strong, because of no public awareness campaigns, people are not well informed about donation and transplantation in general.	There are no cultural differences that influence the donation request.
Germany	Most people do not think this way as they feel uncomfortable about donation, they are afraid to harm donor relatives.	Yes
Norway	No information.	No
Poland	Yes.	No
Spain	No, although donation is a patient's right by law, not all doctors respect this option. Young doctors are accepting this right, and offering donation is a doctor's obligation. We try to define donation as a high quality care in patients' end-of-life care.	Cultural differences include both written and unwritten codes of communication. The way in which death is experienced and its cultural representations are varied. Doctors need to discover and interpret these keys in communication in order to achieve consensus in end-of-life care decision making and organ donation.
Sweden	Partly	In principle no.
Switzerland	Unfortunately not. According to the federal office for public health, the option to make your own decision is "the right", whatever you decide.	We have very high refusal rates, more in German part then in Italian or French part. The biggest problem is that donors are not detected, or even do not reach the ICU, and die on a general ward.
The Netherlands	No, that is not a strong idea in our country.	No
UK	According to our view it is 50/50. Some medical professionals believe very strongly that it is a right, but others do not give it much thought.	There has been a lack of focus on what the barriers are. It is not only the family saying 'no'. A lack of a cohesive system of: assessment of potential donors, testing, approach, coordination with transplant services, etc., all have a role in the low levels of donation.

[**] It is well-known, and well established in the literature, however, that historical reasons still play a large part in Germany in both local perceptions and national policy concerning the use of body parts. The reunification of East and West Germany only served to inject new concerns, and new caution, in matters concerning bodies, science and the state. Hogle, L. 1999 *Recovering the Nation's Body. Cultural Memory, Medicine, and the Politics of Redemption.* Rutgers University Press.

Discussion

We now have more pieces in the European jigsaw (1). Our group discussion and small, fact-finding questionnaire is informative in providing a picture of empirical practice - rather than of the ideal or of the written guidance - and suggests support for reported changes in established practice regarding when family members are asked to consider organ donation. The limitations of this study are acknowledged in that: this investigation was a small-scale exploratory scoping exercise, the number of respondents in each country was limited to one in most instances and therefore findings are not claimed to be representative, and the survey tool was not subjected to validation; however, the findings are of interest and require further investigation.

This investigation has identified that there are specific drivers that appear to be underpinning changes to the moment of asking – such as the use of extended donor criteria organs from elderly donors and the locality in which discussions take place. In Spain, with elderly donors providing a lower number of organs for transplantation and a reported shortage of ICU beds, such potential donors are no longer admitted to intensive care units for a diagnosis of brain death. As indicated in the quotation below, discussions with family members are increasingly taking place in the Accident and Emergency (A&E) Department as a means of determining what the next step will be. Only those patients considered to be suitable for organ donation, and where families agree, will be moved into the ICU to undergo testing to confirm death (22).

Furthermore, comments from in-country contacts in Sweden, Switzerland and Germany indicate that the approach for organ donation is being made during discussions of whether or not to continue intensive care treatment. If donation is not agreed to by family members, testing to confirm death does not take place. This change suggests that the requirement for confirmation that death has occurred is perceived to be necessary only when organ donation is to proceed, but not, as suggested in previous research, as part of facilitating consent or of the grieving process [10 – 12].

Comments from The Netherlands point to another potential driver, the time and cost of an EEG assistant and neurologist to perform the mandatory EEG, and that of an anaesthetist/Intensivist performing the apnoea test. Therefore ascertaining the wishes of the family concerning donation early on will facilitate these services being put in place if the family agree to donation, and avoids the need if the family declines. As all but one of the countries contacted require that auxiliary testing be carried out when diagnosing neurological death, these costs may play a more important role in moving the moment of asking earlier in the previously established temporal sequencing of i) confirming the neurological death of the potential donor, and ii) the request for organ donation.

Reported changes to the moment of asking in the UK and the Netherlands may be related to practice linked to DCD category III donation, where donation must be requested *before* the cessation of the heartbeat of the patient and *after* an infaust prognosis (or decision about the futility of treatment). This practice of linking the futility discussion and the donation discussion may be being applied in the case of DBD donors – since, as indicated above, if the patient does not go on to full DBD, organs can still be donated via a DCD procedure. However, in countries where DCD donation is not implemented (Estonia, Sweden, Germany, Poland, Croatia and Norway) contacts report changes in practice or comment that there are variations in practice across the country, thereby suggesting that it is not the introduction or practice of DCD programmes that is stimulating the practice of introducing the topic of organ donation before confirmation of neurological death in the DBD donor[††], but that this change may be linked to pragmatic decisions about the use of increasingly limited resources in situations where a family may decline organ donation.

So, we have gathered some, if admittedly limited, evidence that the moment of asking for organ donation is occurring earlier in the trajectory of dying in the DBD donor. Respondents suggest that the request for organ donation is being made either *before* any brainstem tests are carried out, as a means of deciding whether they will be carried out, or *after* the first set of brainstem tests have been performed, but *before* auxiliary testing, as a means of planning end of life care.

More robust evidence is provided by de Groot et al [4], who completed a retrospective chart review of all brain dead donors in one University's hospital intensive care unit in The Netherlands between 1987 and 2009. One of the aims of this study was to determine whether the timing of discussing organ donation with relatives of patients who were diagnosed with a catastrophic brain injury had changed over time. Results indicated that between 1987 and 1998, of the 228 cases reviewed, 87% fitted the scenario of first discussion *after* determination of absence of all brainstem reflexes and confirmation of whole brain death by EEG and apnoea test, whereas between 1999 – 2009, this practice happened in only 18% of cases. So more recently, between 1999 – 2009, the usual practice was to instigate the first discussion after testing for brain stem reflexes but before confirmation of whole brain death by auxiliary testing in 58% of cases; and in 24% of cases, the first discussion took place after a discussion of catastrophic brain injury, but before brainstem and auxiliary testing.

In their discussion of the reasons for this change, de Groot et al [4] propose the following explanations: the introduction of a donor register facilitating knowledge regarding the potential donors' views in relation to organ

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[††] Only Croatia reported that the topic of organ donation would not be raised until after brain death is diagnosed.

donation; the introduction of a DCD programme into the hospital in which the study was conducted, with the requirement for physicians to discuss withdrawal of life support in patients with brain injury but who were not brain dead; and the pressure on ICU beds stimulating consideration of the futility of on-going treatment. We see here the indication of factors similar to the ones that our own survey has suggested as potentially impacting on the timing of the moment of asking.

Whilst it may be argued that moving the moment of asking families about organ donation may be a pragmatic decision, it is important that the impact of no longer decoupling the determination of death and the request for organ donation be considered in relation to family refusal rates: de Groot and colleagues propose that the 'high' (sic) on-going refusal rates in The Netherlands may be associated with the change in timing of the moment of asking.

Conclusion

The importance of the timing of the moment of asking requires further research that takes into consideration the issues and contexts of different countries in the light of current practice and policy. Decisions about the moment of asking may also benefit from being embedded within local practices of care, including explicit 'end of life' care initiatives, instead of being viewed only as a way of achieving organ donation. Establishing donation as a usual part of end of life care would mean that the moment of asking would become a step in the dying trajectory, a usual part of end of life care planning, facilitating the fulfilment of wishes regarding post-death use of organs for transplantation.

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