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Differential impact of opt-in, opt-out policies on deceased organ donation rates: a mixed conceptual and empirical study

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ABSTRACT

Objectives To increase postmortem organ donation rates, several countries are adopting an opt-out (presumed consent) policy, meaning that individuals are deemed donors unless they expressly refused so. Although opt-out countries tend to have higher donation rates, there is no conclusive evidence that this is caused by the policy itself. The main objective of this study is to better assess the direct impact of consent policy defaults per se on deceased organ recovery rates when considering the role of the family in the decision-making process. This study does not take into account any indirect effects of defaults, such as potential psychological and behavioural effects on individuals and their relatives.

Design Based on previous work regarding consent policies, we created a conceptual model of the decision-making process for deceased organ recovery that included any scenario that could be directly influenced by opt-in or opt-out policies. We then applied this model to internationally published data of the consent process to determine how frequently policy defaults could apply.

Main outcome measures We measure the direct impact that opt-in and opt-out policies have per se on deceased organ recovery.

Results Our analysis shows that opt-in and opt-out have strictly identical outcomes in eight out of nine situations. They only differ when neither the deceased nor the family have expressed a preference and defaults therefore apply. The direct impact of consent policy defaults is typically circumscribed to a range of 0%–5% of all opportunities for organ recovery. Our study also shows that the intervention of the family improves organ retrieval under opt-in but hinders it under opt-out.

Conclusions This study may warn policy makers that, by emphasising the need to introduce presumed consent to increase organ recovery rates, they might be overestimating the influence of the default and underestimating the power granted to families.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ We used a mixed methods approach combining conceptual analysis and empirical data to estimate the potential impact of consent policies in a novel manner.
- ⇒ We compared the result of the decision-making process under opt-in and opt-out in nine different situations determined by the preferences of the deceased, the preferences of the family and the default.
- ⇒ We obtained data from 21 countries in the 5 continents.
- ⇒ The study considers only the direct effect of opt-out on organ retrieval rates, but not its potential indirect effects, such as psychological and behavioural effects.
- ⇒ The main limitation of the study is the heterogeneity of sources, sample sizes and time periods for the data collected.

INTRODUCTION

There is an international trend to move from explicit consent (opt-in) to presumed consent (opt-out) policies for deceased organ retrieval: Chile (2010), Finland (2010), Greece (2013), Uruguay (2013), Wales (2015), Colombia (2016), Iceland (2019), the Netherlands (2020), England (2020), Scotland (2021), the province of Nova Scotia in Canada (2021) and Switzerland (2022) have implemented opt-out policies in recent years. Australia, Denmark, Germany, Israel, Romania and several states in the USA have been discussing this as well.[1]

Some studies suggest that presumed consent laws contribute to increased organ donor rates,[2–7] while others dispute this claim.[8–13] Research reviews within this field point out an association between presumed consent legislation and higher organ recovery rates, but they also warn against the assumption that the introduction of presumed consent legislation per se is its sole cause.[14–17] International evidence tends to show that opt-out systems can be effective as part of a wider package of measures, but the body of evidence that opt-out legislation in isolation causes increases in organ donation rates lacks robustness and is sparse.[18] Consent policies may, in fact, be just one factor among many, with infrastructure or organisational changes producing greater gains than legislative change alone.[19 20] The role families are allowed to play in the process of organ retrieval decision-making may be another factor tempering the effectiveness of presumed consent policies.[9 21–23]

To measure the potential impact of legislative change *by itself*, in isolation of other measures, it is important to distinguish between consent policies' direct and indirect effects. Opt-out policies can be conceived as behavioural nudges: non-coercive means aimed at fostering specific behaviours to promote beneficial outcomes.[24 25] By setting organ donation as the default and taking advantage of people's tendency to prefer the status quo (ie, their propensity to stick with the current state of affairs or choose default options), opt-out policies aim to foster higher rates of organ donors. The underlying assumption for moving towards opt-out is that the default would almost automatically turn those who are undecided or unconcerned about organ donation into actual donors.[26 27] This is what we call a direct effect of the consent policy.

Changing the legal default donor status from non-donor under opt-in to donor under opt-out can have multiple indirect or secondary effects. For example, it may enable the initiation of organ preservation measures before ascertaining the deceased's preferences or obtaining the authorisation of the family. This could explain the higher prevalence of uncontrolled donation after circulatory arrest protocols—which require expeditious organ preservation measures—in opt-out countries as compared with opt-in countries.[28 29] Other indirect effects are psychological and behavioural, such as increasing people's awareness and conversations within families about organ donation, influencing the meaning they assign to donating or not donating,[30] altering their registration behaviour,[31 32] fostering professionals to identify and refer potential donors and approach their relatives when the deceased failed to register any preference, and changing the conversation between health professionals and relatives.[6 33] In Wales, an increase in family authorisation rates could be explained by such indirect factors, including increased societal concern about organ scarcity, growing confidence of families in healthcare professionals, and specialist nurses' training and familiarity with the legislation.[34] However, the introduction of opt-out legislation can also have negative effects, such as the lone wolf effect,[35] lower incentives for living donation,[36] heightened reactance arising from perceptions of unwarranted government control,[37] or even backlash, as it occurred in Chile and Brazil.[38 39] In sum, although there is a vast body of empirical literature on the indirect effects of consent policy defaults, overall the available evidence is often conflicting and inconclusive.[15 17]

In this article, we aim to determine the direct effects of consent policies per se, in isolation of other measures and country-specific confounding factors. To do so, we focus on the outcome of the decision-making process as determined solely by the preferences of the deceased, the preferences of the family, and the default. First, we propose a conceptual model showing the differential impact that opt-in and opt-out policies can have per se on organ recovery rates, that is, regardless of the country in which they are implemented. Then, we provide empirical evidence for the model based on comprehensive data from 6 European nations and partial data from 16 other countries worldwide. Finally, based on available data on deceased and family preferences, we estimate how changing the default and role of family, ceteris paribus, can directly affect retrieval rates.

METHODS

The development of the research question and outcome measure was informed by the results of a systematic review on public knowledge and attitudes towards consent policies for organ donation[40] and by a conceptual framework of the role of family in organ retrieval decision-making.[41] The review's results suggested, on the one hand, that people's awareness of the consent model is lower in opt-out countries than in opt-in countries, which raises ethical concerns with regard to the respect of individual autonomy, and, on the other hand, that despite the general tendency in Europe and elsewhere to move from opt-in to opt-out policies, a majority of the public tend to prefer opt-in and mandatory choice to opt-out when two or more options are offered. The framework's results suggested that there is no significant difference between opt-in and opt-out policies when family preferences are considered.

Conceptual model

We used the following conceptual model to assess how consent policies can impact organ retrieval rates. This model allows for an examination of the consent policies per se, regardless of country-specific confounding factors such as organisation and infrastructures, professionals' training, incentives, media campaigns, cultural backgrounds and so on.

First, we broke down consent policies into their core components.[42] As their name suggests, opt-in and opt-out policies are relative to individual preferences. This is the first element to consider. Organs may be retrieved when people expressed their consent as *postmortem* organ donors (opt-in) and they may not be retrieved when people expressed their refusal (opt-out). In some countries, such as Germany and the Netherlands, individuals can also choose to delegate the decision to their relatives or a designated proxy. This introduces family preferences as a second element to consider. Indeed, whether the deceased's organs are recovered or not may eventually depend on the next-of-kin's attitudes towards donation. The third element is the default option set by each policy when no preferences have been expressed whatsoever. In such circumstances, organs can nevertheless be retrieved under opt-out, based on presumed consent, while they cannot be retrieved under opt-in.

The procedures deemed valid to express a preference regarding organ donation are also an important part of consent policies. These procedures may include consent and/or refusal registries, organ donor cards, living wills and other written documents, as well as conversations with relatives. Although some of these procedures can exist in a given country, they may be inconsequential as long as people are unfamiliar with them. For example, in France, the refusal register is by law the main procedure to express a decision, but less than 0.5% of the total population were listed in it by 2017.[43] For the sake of simplicity, considering the diversity and varying degrees of use of these procedures, we decided not to include them in our analysis. In the following analysis, we will consider the preferences of individuals and relatives, and the role they play under each policy, regardless of the means by which these preferences can be expressed in any given country.

Second, based on the aforementioned core components of opt-in and opt-out (individual preferences, family preferences and defaults), we identified all the situations where the retrieval outcome depends on individual and/or family preferences or the lack thereof.[42] When relatives' preferences are *not* taken into account, only three possible situations arise, as the deceased person may have either: (*A*) expressed their consent to donate; (*B*) expressed their refusal to donate or (*C*) failed to express any decision regarding donation, in which case the default applies. When relatives *are* consulted, their own preferences regarding the recovery of organs from their loved ones may be either (*a*) favourable, (*b*) unfavourable or (*c*) unknown. The combination of the preferences of the deceased and those of the family thus creates a total of nine (3×3=9) situations (table 1).

Third, we compared the outcomes of opt-in and opt-out policies in these nine situations. For example, whenever the deceased expressed their willingness to donate (*A*) and the family also expressed their authorisation (*a*), organ recovery is most likely to proceed in either opt-in and opt-out policies. This way, by comparing the two policies in each and every scenario, the identification of the situations producing the same retrieval outcome under both policies and those producing variable outcomes is straightforward. This allowed us to evaluate the relative impact of opt-in and opt-out policies per se, regardless of the country-specific confounding factors where these policies are implemented.

Review of the empirical data available

We sought empirical data to support our conceptual model with real-world national figures.

Eligibility criteria

Openly available data, from peer-reviewed articles or grey literature reports from official sources (governments, transplant organisations), from any country, without language restrictions, published in the last 10–15 years, reporting the expression of preferences or the lack thereof, from either the deceased person or their relatives, in all cases of potential/eligible deceased donors. Studies were eligible when the data reported were detailed enough to determine the relative frequency of the situation where defaults apply according to our conceptual model, that is, when both the deceased's preferences and the family's preferences are unknown (table 1, situation *Cc*). Studies were ineligible when the data for this outcome of interest were not reported or could not be determined using the reported data.

Information sources

We searched the PubMed and Google Scholar databases, and the ResearchGate platform, from August 2020 to February 2021. We also used Google's search engine to find and consult the websites of ministries of health and national transplant organisations, when available. The search for data ended in February 2021, although we continued to examine some reports after that date, especially from Austria and Denmark.

Search strategy

We used the following sequences of English terms to search Google Scholar, PubMed and ResearchGate: *potential donor(s)*, *potential organ donor(s)*, *organ donor audit*, *potential organ donation*, *organ donation activity*, *organ donation referral*, *organ donation statistics*, *organ transplantation statistics*. We also used the corresponding sequences of terms in French and in Spanish (eg, "statistiques don organes", "estadísticas donación de órganos"). In addition, in the case of PubMed, we searched the MeSH terms: "Tissue and Organ Procurement/statistics and numerical data" and "Organ Transplantation/statistics and numerical data" in combination with country names.

Selection process, data extraction and quality assessment

One reviewer screened and collected data from each report. We contacted national officials and researchers to help us locate relevant data from their respective

Table 1 Consent-related situations that affect the retrieval outcome under both opt-in and opt-out policies

		Family preferences		
		(*a*) Favourable	**(*b*) Unfavourable**	**(*c*) Unknown**
Deceased's preferences	(*A*) Consent	Agreement in favour	Conflicting preferences	Deceased's consent
	(*B*) Refusal	Conflicting preferences	Agreement against	Deceased's refusal
	(*C*) Unknown	Family authorisation	Family opposition	Default applies

countries, if any, and also to clarify or confirm the information we had collected. To determine the eligibility of some reports, we used automated translation tools (eg, Google Translate) and solicited help from native colleagues. To ensure accuracy, we contacted representatives of health ministries and national transplant organisations for clarifications or for confirmation of our findings. Evidence for the Netherlands, the UK and Denmark have been double-checked and confirmed through personal communications with the *Nederlandse Transplantatie Stichting*, the National Health Service and the *Dansk Center for Organdonation*, respectively. Evidence for Germany has been checked with the assistance of German researchers on organ donation. In a few instances, when no written source of information was available, we contacted the heads of national transplant organisations and other officials for comments.

Risk of bias

To limit potential bias caused by country-specific characteristics, such as religious and cultural background, population size, income per capita, health expenditure, and organ donation and transplantation systems, our search specifically targeted—but was not restricted to—a broad range of countries with very diverse characteristics from all continents (except Antarctica) and all of the continental subregions devised by the United Nations geoscheme—except for Melanesia, Micronesia and Polinesia because no deceased organ donation has been reported there. This list includes the following 56 countries: Algeria, Argentina, Australia, Austria, Belarus, Belgium, Brazil, Canada, Chile, Colombia, Cuba, Croatia, Czech Republic, Denmark, Ecuador, Egypt, Estonia, Finland, France, Germany, Greece, Hong Kong, Hungary, Iceland, India, Iran, Ireland, Israel, Italy, Japan, Kazakhstan, Kenya, Lithuania, Malaysia, Mexico, the Netherlands, New Zealand, Nigeria, the Philippines, Poland, Portugal, Romania, Saudi Arabia, Singapore, Slovenia, South Africa, South Korea, Spain, Sweden, Switzerland, Thailand, Türkiye, the UK (in general) and Wales (in particular), the USA and Uruguay. The countries in this list represent more than two-thirds of the 70+ countries having reported any deceased organ donation activity to either the WHO's Global Observatory on Donation and Transplantation (GODT) or to the International Registry in Organ Donation and Transplantation (IRODaT).

More detailed information about the sources and methods is available in online supplemental file.

Patient and public involvement

No patient involved.

RESULTS

Model results

The three core components of consent policies that influence the outcome of the decision-making process (organ retrieval or non-retrieval) are: (1) the deceased's expressed preferences, if any; (2) the next-of-kin's preferences, if any and (3) the default option set by each policy.

Table 2 Outcome (organ retrieval vs non-retrieval) from organ recovery decision-making based on the deceased's decision and the model of consent

Deceased's decision	Consent	Refusal	Unknown
Opt-in	✓	✗	✗
Opt-out	✓	✗	✓

When family preferences are *not* taken into account, a side-by-side comparison of opt-in and opt-out policies shows that they have identical retrieval outcomes in two out of three situations, that is, whenever the deceased had either consented or refused organ donation (table 2). These two policies only differ in one situation: when the deceased person failed to express any decision and the default therefore applies. In this situation, the absence of an explicit consent precludes organ retrieval under opt-in while the absence of an explicit refusal allows it under opt-out.

When *both* the individual and the family preferences are taken into account, a side-by-side comparison of opt-in and opt-out policies shows these policies having rigorously identical outcomes in eight situations out of nine (table 3). The sole situation when these policies make a difference is when their defaults apply, that is, when the preferences of both the deceased and their family remain unknown to the medical team.

According to this conceptual model, when comparing the outcomes of each situation in the tables above, the differential impact of opt-in and opt-out policies is entirely determined by the default, which only applies when preferences have *not* been expressed. This does not exclude the existence of a differential impact of consent policies based on indirect effects, such as the meaning assigned to the act of donating or not donating, people's registration behaviour, or family authorisation rates. But whether and to what extent these indirect effects can increase organ recovery rates may depend on contingent factors that vary from country to country or population to population, including religious and cultural backgrounds, public attitudes towards the donation and transplantation system, health professionals' training and so on.

Empirical evidence

We obtained relevant empirical data from 21 countries in the 5 continents. Considering the diversity of sources and varying quality of the data, we classified the evidence obtained in two tiers: confirmatory evidence and additional supporting evidence. *Confirmatory evidence* includes comprehensive statistics from either government backed official reports or retrospective studies. *Additional supporting evidence* includes partial statistics from official reports and retrospective studies.

Table 3 Outcome (organ retrieval vs non-retrieval) from organ recovery decision-making based on the deceased's decision, family attitudes and the model of consent

Deceased's decision	**Consent**			**Refusal**			**Unknown**		
Family preferences	In favour	**Against**	Unknown	In favour	Against	Unknown	In favour	Against	Unknown
Opt-in	✔	✔ or ✗	✔	✗	✗	✗	✔	✗	✗
Opt-out	✔	✔ or ✗	✔	✗	✗	✗	✔	✗	✔

Check-marks (✔) mean that organs may be retrieved; X marks (✗) mean that organs may not be retrieved. When the deceased had consented, organs will likely be retrieved unless the family objects, this being the case for both policies. If the family is against organ retrieval, the likely outcome under opt-in and opt-out will depend on whether the family is allowed to over-rule (veto) the deceased's consent. When the deceased had refused to donate, organ retrieval is unlikely to proceed under any circumstances (regardless of family preferences or the default rule), as this would be contrary to the ethical principles of organ retrieval and transplantation.[28] Finally, when the deceased had failed to express any preference, there is no difference between opt-in and opt-out whether the family authorises or opposes organ retrieval: in both cases, the expressed preferences of the family will be respected. The only situation where consent policies actually differ in their outcome is when both the preferences of the deceased and those of the family are unknown. Family preferences can be unknown to the medical team in the following circumstances: the deceased had no remaining family or close friends to be consulted, they may have not been contacted in time or may be too emotionally distressed to be consulted about organ recovery, or they could hold conflicting views on the matter.

Confirmatory evidence

We found comprehensive nationwide statistics from official sources in Denmark, Germany, the Netherlands, and the UK, and from peer-reviewed retrospective studies in Sweden and Wales. In addition, we found comprehensive statistics from a retrospective study of all patients who died at one of the largest hospitals in Denmark between 2000–2003 and 2007–2010. Our findings show that, when families intervene, the situation where defaults apply according to our analysis—that is, when both individual and family preferences are unknown—is limited to a range of 0%–4% of all organ retrieval opportunities, based on the available empirical data from these six countries (table 4; see online supplemental file for more detailed information about the data, sources and methodology).

Additional supporting evidence

We found partial statistics from 16 countries regarding the situation where policy defaults apply according to our analysis. In particular, we found nationwide statistics from official sources in Belgium, Chile, Colombia, Ireland, Spain, Sweden and Switzerland. We also found retrospective studies, mostly from a single hospital and varying periods of time, in Australia, Brazil, Finland, France, Hong Kong, South Africa, South Korea, Spain, Türkiye and the USA. In addition, we obtained informal comments and assessments through personal communication with officials from Belgium, Colombia, Denmark, Finland, France, South Korea and Spain. More detailed information about the data, sources and methodology is available in online supplemental file.

Results suggest that the potential differential impact of opt-in and opt-out policies, according to our analysis, is limited to a range of 0%–2% of all retrieval opportunities in six countries (Australia, Chile, Colombia, Finland, South Korea and Spain), to a range of 3%–5% in six countries (Belgium, France, Hong Kong, Switzerland, Türkiye and the USA), and to more than 5% in three countries (Brazil, South Africa and Sweden). These results coming from a wide variety of countries are consistent with those detailed in table 4.

Estimation of potential retrieval rates under different policies in six countries

To better assess the relative impact of the family's intervention in each consent system, all other things being equal, we estimated the potential for organ retrieval in four distinct scenarios (figure 1). On the one hand (left), we considered opt-in and opt-out policies based on the deceased's wishes alone, without any family intervention. On the other hand (right), we considered opt-in and opt-out policies based on both the deceased's and the family's wishes. In other words, for each reviewed country, we estimated the potential for organ retrieval if the policy in place in that country was: (α) opt-in and deceased's wishes alone; (β) opt-out and deceased's wishes alone; (γ) opt-in with family intervention and (δ) opt-out with family intervention (see online supplemental file for more information about the data and methodology).

The estimated potential retrieval rates in these four scenarios, according to our analysis of defaults, suggest that individual consent policies only make a significant difference when family preferences are disregarded. In this case, moving from opt-in to opt-out may dramatically increase the number of potential donors from which organs can be retrieved (left bars). However, when families are allowed to intervene and their own preferences are taken into consideration, then the potential retrieval outcomes under opt-out are just a little higher than under opt-in (right bars). Here, we only consider the direct effects of a change in policy, all other things being equal, and not the indirect effects that a change in policy would most certainly entail.

DISCUSSION

Our analysis of the core components of consent policies (individual preferences, family preferences and defaults)

Table 4 Actual frequency of each scenario among potential organ donor cases when both the deceased's decision and the family's preferences are considered in Denmark, Germany, the Netherlands (NL), Sweden, the UK at large and Wales in particular

Deceased's decision		**Consent (%)**			**Refusal (%)**			**Unknown (%)**		
Family preferences		In favour	Against	Unknown	In favour	Against	Unknown	In favour	Against	Unknown
Denmark	Opt-in N=235*	n/a	n/a	6 †	n/a	n/a	8 †	32	51	3
	n=163‡	n/a§	2	n/a§	n/a	n/a	7 †	61 §	29	1
Germany	Opt-in N=1399¶	n/a	n/a	32 **	n/a	n/a	9 **	42	16	2
NL	Opt-in†† N=1039‡‡	19	3	0	n/a	0	15	16	43	4
Sweden	Opt-out N=1275§§	n/a	0	35 †	n/a	n/a	14 †	36	14	2
UK	Opt-in†† N=1542¶¶	37	2	0–1	n/a	5	0	33	20	0–2
Wales	Opt-out N=182***	49	7	0	n/a	19	0	15	10	0

Each row corresponds to one possible scenario that combines the deceased's decision (consent, refusal, or unknown) and the family's preferences (in favour, against or unknown). The frequency of each scenario is indicated as a proportion of the total number of cases of potential organ donors in each country. For instance, out of 1039 cases of potential organ donors in the Netherlands in 2018, 16% of these cases correspond to the situation where the deceased's decision was unknown and the family authorised the removal of organs, 43% correspond to the situation where the deceased's decision was unknown and family opposed recovering the organs, and 4% correspond to the scenario where both the deceased's and the family's decisions were unknown. These figures show how potential donors cases are distributed among the nine possible scenarios. Because some potential donors do not become effective donors, the official percentages of organ retrieval/non-retrieval in each country may differ slightly from those displayed in this table. See the additional file for further details.

*Potential donors in a single hospital over two periods of 3.5 years each (2000–2003, 2007–2010).[54]

†Detailed family preferences data when the deceased had consented or refused is not available and is reported here as unknown.

‡Potential donors nationwide in 2020.[55]

§In all cases of actual donors, we have not been able to determine the proportion of individuals who had registered their consent, that is, whether organ recovery could proceed based on the deceased's consent (first and third columns) or on family's authorisation (seventh column). All these cases (61%) are reported here as if the deceased's wishes were unknown and the family had authorised, but an unknown proportion of them should appear as cases of consent from the deceased.

¶Potential donors after the determination of death in 2018.[56]

**In Germany, according to DSO officials, when the deceased has expressly consented or refused organ donation, the opinion of the family is almost always known (personal communication). However, as the family is not allowed to authorise or oppose the recovery of organs, and the percentages of families who would support or oppose organ recovery in these circumstances is not available, all these cases are reported as unknown.

††The Netherlands, England and Scotland implemented an opt-out system in 2020.

‡‡Potential donors in 2018.[57]

§§Eligible organ donors from 2009 to 2014.[58]

¶¶Potential donors after brain death (DBD) alone, from 1 April 2018 to 31 March 2019, in the UK at large (including Wales).[59]

***Potential donors from December 2015 to February 2016.[60]

shows that opt-in and opt-out models perform identically in all but one situation, that is, when preferences have not been expressed and therefore defaults apply. It is the frequency of this particular situation that determines the direct impact of consent policies per se, in isolation of other measures and indirect effects, on organ recovery rates.

If only the preferences of the deceased person were taken into account, the opt-out would allow the recovery of organs from all individuals who have expressed no preference, while the opt-in would prevent it. Depending on how often this situation would happen in a given country, switching from opt-in to opt-out could dramatically increase organ recovery rates.

However, there are few countries in the world where only the preferences of the deceased person are considered.[3 21 41 44–46] On the contrary, most opt-in and opt-out countries worldwide allow the family, either de jure or de facto, to make a decision when the deceased had not, and even to overrule the deceased's consent to donate (cf. online supplemental file).[9 41 46]

If both the preferences of the deceased and those of the family are taken into account, then the opt-out enables the recovery of organs when both individual and family preferences are unknown to the medical team. This is obviously a less frequent situation. Based on empirical data, if any of the reviewed opt-in countries decided to adopt an opt-out policy, the application of the default *alone* in

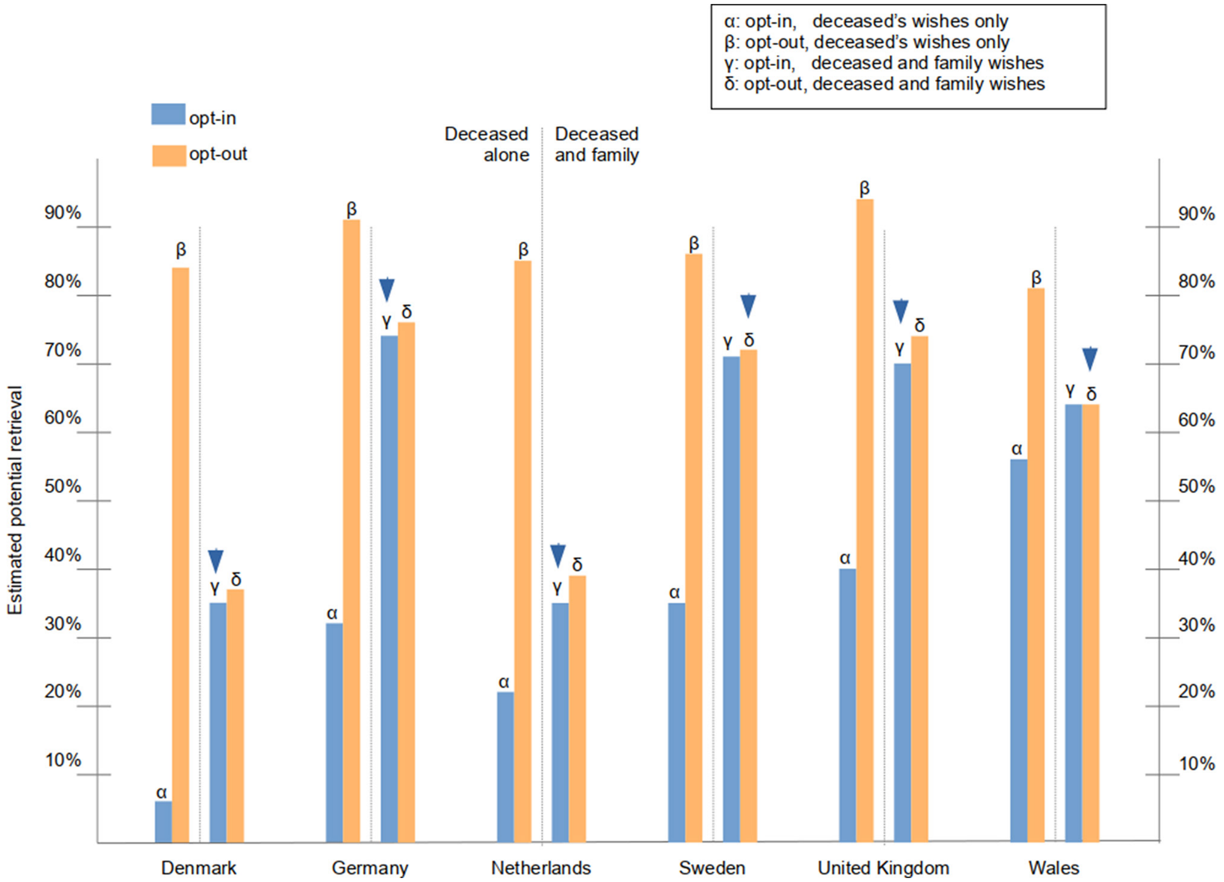

Figure 1 Retrieval rates under four different policies, if only the policy changes, all other things being equal.

this particular situation could, by itself, increase organ recovery by 0%–5%. Conversely, if any of the reviewed opt-out countries decided to adopt an opt-in policy, this legal change *alone* could *by itself* decrease organ recovery by 0%–5%.

However, it appears that some opt-out countries are not taking full advantage of the opportunity provided by presumed consent to retrieve organs without explicit authorisation. In France, Sweden and Türkiye, we found that 'family disagreement' and 'relatives could not be contacted' were mentioned as reasons for non-donation. This means that organs were *not* recovered when both individual and family preferences were unknown to the medical team. Indeed, doctors may feel reluctant to procure organs without any expressed consent or authorisation, even when they are legally allowed to do so. In Belgium, Finland and Spain, officials informed us that, to their knowledge, the situation where the deceased did not express any preference, the family could not be reached or make a decision, and organs were nevertheless procured—according to the law—is very rare. In addition, a review of organ donation laws in the EU pointed out that in Cyprus and Greece organs cannot be legally recovered without the authorisation of the deceased's relatives.[47] Therefore, the direct effect of changing the default alone might be smaller than indicated above because, in practice, the opt-out default is not necessarily implemented to its full potential. That said, changing the default may also cause indirect effects, including on the behaviour of individuals and families, which could increase or decrease organ recovery beyond the figures indicated above, but such effects are beyond the scope of this work.

Previous studies have shown that in most countries, both opt-in and opt-out, families are consulted in order to make a decision on organ donation.[9 46] Furthermore, we have previously shown that, in most countries, the role of the family in organ donation decisions is greater in clinical practice than according to the law.[41] However, we had not been able to assess how common it is for families to be consulted in a given country. A contribution of this article is to provide both qualitative and quantitative insights into how and to what extent family preferences are used in organ donation decisions. On the one hand, we can now state quite confidently that when the deceased did not leave a written record of their preferences, family members are almost always consulted, either as witnesses to the deceased's wishes or to make a decision based on their own preferences. This applies to those countries we have been able to include in this study. However, we lack sufficient data from some opt-out countries where the results might be different, including Argentina, Colombia and Uruguay where recent laws prevent the next-of-kin from opposing organ recovery, as well as Austria, where this has been the case for a long time. In France, although families can no longer legally object to the recovery of organs since 2017 (but can only act as a witness to the deceased's wishes), family objections have not disappeared but rather increased since then, reaching 37% in April 2022 (46% in the Paris region), according to a press release from the Agence de la Biomédecine (dated 15 June). All this affects the direct impact of consent policies per se, because whenever preferences are taken into account, defaults are not applied.

On the other hand, our study shows that the intervention of the family improves organ retrieval under opt-in but hinders it under opt-out (figure 1). Though this may seem counter-intuitive, a plausible explanation for this phenomenon is the following. The intervention of the family increases the proportion of likely organ donors under opt-in policies (figure 1, blue bars) in all examined countries, as family authorisations in absence of the deceased' consent outnumber family oppositions when the deceased had consented. In other words, as a majority of deceased individuals fail to express their preferences before death, a majority of organs could not be retrieved in opt-in countries but for the next-of-kin's authorisation. Meanwhile, family intervention decreases the proportion of likely organ donors under opt-out policies (figure 1, orange bars). Indeed, when the deceased consented or their preferences are unknown, family oppositions prevent the retrieval of organs that would otherwise be retrieved. In other words, the organs of all those who remained silent could be retrieved in opt-out countries if it was not because of opposition from families.

The power of our approach stems from the combination of conceptual analysis with real-world statistics from multiple and diverse countries, allowing us to measure the frequency of that particular situation where opt-in and opt-out policies actually differ in their application. In other words, our study is the first to examine the impact of opt-in and opt-out by focusing on what makes these policies different from each other. To our knowledge, this specific information has never been actively sought nor specifically published before in the scientific literature, and it is seldom reported in official statistics even in countries, such as Spain, with advanced organ donation and transplantation programmes. This makes the data we obtained the best empirical evidence available to date.

That being said, the data reported here are indicative rather than representative, meaning that the aggregated data provide a general estimate of the frequency of the situation where the default option is applicable, but individual figures should be treated with caution. Indeed, these figures were extracted from a wide variety of sources with significant differences in their definitions, samples, methods and dates. As a consequence, two reports from the same country may give different results, as is the case for some of those we have examined (eg, Denmark). In addition, the type of information we were looking for is not usually reported by healthcare professionals, nor is it usually compiled in statistics or, when compiled, publicly available or, when available, usable for this study's purpose. Thus, we were unable to find relevant data sources in many countries and, where we did, the data provided was often incomplete, inaccurate or difficult to extract. For example, reports often detail the reasons why organs could not be retrieved, including 'lack of consent', but are usually ambiguous about whether this refers to the expressed refusal of the deceased, the expressed opposition of relatives, both or, conversely, the absence of expressed consent or authorisation. In contrast, it is much rarer to find useful information for cases where organs have been retrieved, apart from the occasional vague mention of consent. For these reasons, we were unable to include data from numerous reports. The best available results are those reported in table 4. For the rest of the data available, in view of the above limitations, we have opted to provide only ranges of values rather than specific figures for each country. We hope that this study will serve to alert clinicians and authorities to the need to collect more comprehensive and detailed data on the organ donation preferences of the deceased and their families.

Our study focuses specifically on the direct effects of consent policies, as defined in the introduction. It does not take into account indirect or secondary effects of policy defaults or the effects of other factors and measures that may accompany or follow legal changes. Our conclusions should be interpreted within this scope.

Our results may warn contemporary organ retrieval policy makers that, by emphasising the need to introduce presumed consent, they might be overestimating the direct influence of policy defaults, and underestimating the power granted to families in expressing their preferences and making decisions about organ donation. Improving infrastructures, coordination and training, communication to the public and modifiable factors influencing family authorisation might prove more effective for increasing organ retrieval rates than moving from opt-in to opt-out.

One way around families' capacity to overrule both explicit and presumed consent would be to lessen the authority families currently have in the decision over donation.[48] The USA amended its Uniform Anatomical Gift Act in 2006 to restrict the family's authority to veto the deceased's first-person authorisation (opt-in). Belgium amended its law (opt-out) in 2007 by removing the option for the family to oppose organ procurement. Other countries, including Uruguay (2013), Colombia (2016), France (2017) and Argentina (2018) changed their opt-out laws to prevent relatives from opposing organ recovery both when the deceased had expressed no preference (presumed consent) and when the deceased wished to become a donor (explicit consent).

The effectiveness of such restrictive measures remains to be assessed. Their governance quality should also be assessed, although we may lack proper data to do so.[49] Recent systematic reviews have raised concerns by suggesting that the population in opt-out countries tend to be less aware of their consent system than in opt-in countries[40] and that a majority of the public supports the involvement of the family in organ recovery decision-making and, in particular, their role as surrogate when the deceased has expressed no preference.[50 51 50 51] This adds to the ongoing ethical debates over the family veto[52] and opt-out policies acceptability.[53]

This figure uses the available data on deceased's and family's preferences in six countries to estimate how changing the default and the family's role, all other things being equal, may affect retrieval rates. For each country, four possible situations are considered, from left to right: (α) opt-in and deceased's preferences only; (β) opt-out and deceased's preferences only; (γ) opt-in and both deceased's and family preferences; (δ) opt-out and both deceased's and family preferences. Data for this figure results from adding the percentages of the scenarios shown in table 4 (Denmark, Germany, the Netherlands, Sweden, the UK and Wales). For each country, the situation that is actually in place in the country is signalled by an arrow. Changing the policy in place in any given country would almost certainly cause some indirect effects that we are not taking into consideration here because we do not know the nature, the sign and the intensity of such effects in this particular country.

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REFERENCES

1 Glazier A, Mone T. Success of Opt-In organ donation policy in the United States. *JAMA* 2019;322:719.
2 Abadie A, Gay S. The impact of presumed consent legislation on cadaveric organ donation: a cross-country study. *J Health Econ* 2006;25:599–620.
3 Horvat LD, Cuerden MS, Kim SJ, *et al*. Informing the debate: rates of kidney transplantation in nations with presumed consent. *Ann Intern Med* 2010;153:641–9.
4 Bendorf A, Pussell BA, Kelly PJ, *et al*. Socioeconomic, demographic and policy comparisons of living and deceased kidney transplantation rates across 53 countries. *Nephrology* 2013;18:633–40.
5 Shepherd L, O'Carroll RE, Ferguson E. An international comparison of deceased and living organ donation/transplant rates in opt-in and opt-out systems: a panel study. *BMC Med* 2014;12:131.
6 Ugur ZB. Does presumed consent save lives? Evidence from Europe. *Health Econ* 2015;24:1560–72.
7 Ahmad MU, Hanna A, Mohamed A-Z, *et al*. A systematic review of Opt-out versus Opt-in consent on deceased organ donation and transplantation (2006-2016). *World J Surg* 2019;43:3161–71.
8 Coppen R, Friele RD, Gevers SKM, *et al*. The impact of donor policies in Europe: a steady increase, but not everywhere. *BMC Health Serv Res* 2008;8:235.
9 Bilgel F. The impact of presumed consent laws and institutions on deceased organ donation. *Eur J Health Econ* 2012;13:29–38.
10 Boyarsky BJ, Hall EC, Deshpande NA, *et al*. Potential limitations of presumed consent legislation. *Transplantation* 2012;93:136–40.
11 Arshad A, Anderson B, Sharif A. Comparison of organ donation and transplantation rates between opt-out and opt-in systems. *Kidney Int* 2019;95:1453–60.
12 Matesanz R, Domínguez-Gil B. Opt-out legislations: the mysterious viability of the false. *Kidney Int* 2019;95:1301–3.
13 Vela RJ, Pruszynski J, Mone T, *et al*. Differences in organ donation and transplantation in states within the United States and in European countries: is there a benefit to Opting out? *Transplant Proc* 2021;53:2801–6.
14 Rithalia A, McDaid C, Suekarran S, *et al*. Impact of presumed consent for organ donation on donation rates: a systematic review. *BMJ* 2009;338:a3162.
15 Steffel M, Williams EF, Tannenbaum D. Does changing defaults save lives? effects of presumed consent organ donation policies. *Behavioral Sciences and Policy* 2019;5:69–88.
16 Saab S, Saggi SS, Akbar M, *et al*. Presumed consent: a potential tool for countries experiencing an organ donation crisis. *Dig Dis Sci* 2019;64:1346–55.
17 Etheredge HR. Assessing global organ donation policies: Opt-In vs Opt-Out. *Risk Manag Healthc Policy* 2021;14:1985–98.
18 Niven J, Chalmers N. *Opt out organ donation: a rapid evidence review*. Edinburgh: Scottish Government, 2018.
19 Willis BH, Quigley M. Opt-out organ donation: on evidence and public policy. *J R Soc Med* 2014;107:56–60.
20 Matesanz R, Domínguez-Gil B, Coll E, *et al*. How Spain reached 40 deceased organ donors per million population. *Am J Transplant* 2017;17:1447–54.
21 Coppen R, Friele RD, Gevers SKM, *et al*. Imagining the impact of different consent systems on organ donation: the decisions of next of kin. *Death Stud* 2010;34:835–47.

22 Costa-Font J, Rudisill C, Salcher-Konrad M. 'Relative Consent' or 'Presumed Consent'? Organ donation attitudes and behaviour. *Eur J Health Econ* 2021;22:5–16. doi:10.1007/s10198-020-01214-8
23 Bea S. Opt-out policy and the organ shortage problem: critical insights and practical considerations. *Transplant Rev* 2021;35:100589.
24 Thaler RH, Sunstein CR. *Nudge: improving decisions about health, wealth, and happiness*. New Haven: Yale University Press, 2008.
25 Beraldo S, Karpus J. Nudging to donate organs: do what you like or like what we do? *Med Health Care Philos* 2021;24:329–40.
26 Johnson EJ, Goldstein D. Do defaults save lives? *Science* 2003;302.
27 MacKay D, Robinson A. The ethics of organ donor registration policies: Nudges and respect for autonomy. *Am J Bioeth* 2016;16:3–12.
28 Rodríguez-Arias D, Ortega-Deballon I, Smith MJ, *et al*. Casting light and doubt on uncontrolled DCDD protocols. *Hastings Cent Rep* 2013;43:27–30.
29 Lomero M, Gardiner D, Coll E, *et al*. Donation after circulatory death today: an updated overview of the European landscape. *Transpl Int* 2020;33:76–88.
30 Davidai S, Gilovich T, Ross LD. The meaning of default options for potential organ donors. *Proc Natl Acad Sci U S A* 2012;109:15201–5.
31 van Dalen HP, Henkens K. Comparing the effects of defaults in organ donation systems. *Soc Sci Med* 2014;106:137–42.
32 Steenaart E, Crutzen R, de Vries NK. Beyond the ticked box: organ donation decision-making under different registration systems. *Psychol Health* 2021;36:511–28.
33 Albertsen A. Deemed consent: assessing the new opt-out approach to organ procurement in Wales. *J Med Ethics* 2018;44:314–8.
34 Madden S, Collett D, Walton P, *et al*. The effect on consent rates for deceased organ donation in Wales after the introduction of an opt-out system. *Anaesthesia* 2020;75:1146–52. doi:10.1111/anae.15055
35 Ferguson E, Shichman R, Tan JHW, . When lone wolf Defectors undermine the power of the Opt-Out default. *Sci Rep* 2020;10:8973.
36 Golsteyn BHH, Verhagen AMC. Deceased by default: consent systems and organ-patient mortality. *PLoS One* 2021;16:e0247719.
37 Miller J, Currie S, McGregor LM, *et al*. 'It's like being conscripted, one volunteer is better than 10 pressed men': a qualitative study into the views of people who plan to opt-out of organ donation. *Br J Health Psychol* 2020;25:257–74. doi:10.1111/bjhp.12406
38 Csillag C. Brazil abolishes "presumed consent" in organ donation. *Lancet* 1998;352:1367.
39 Zúñiga-Fajuri A. Increasing organ donation by presumed consent and allocation priority: Chile. *Bull World Health Organ* 2015;93:199–202.
40 Molina-Pérez A, Rodríguez-Arias D, Delgado-Rodríguez J, *et al*. Public knowledge and attitudes towards consent policies for organ donation in Europe. A systematic review. *Transplant Rev* 2019;33:1–8.
41 Delgado J, Molina-Pérez A, Shaw D, *et al*. The role of the family in deceased organ procurement: a guide for clinicians and policymakers. *Transplantation* 2019;103:e112–8.
42 Molina-Pérez A, Delgado J, Rodríguez-Arias D. Defining Consent: Autonomy and the Role of the Family. In: Hansen SL, Schicktanz S, eds. *Ethical challenges of organ transplantation: current debates and international perspectives*. Transcript Verlag, 2021: 43–64.
43 Touraine J-L. Mission 'flash' relative aux conditions de prélèvement d'organes et du refus de tels prélèvements, 2017. Paris: : Assemblée Nationale. Available: https://www2.assemblee-nationale.fr/static/15/commissions/CAffSoc/Mission_flash_don_organes_communication_rapporteur_20171220.pdf [Accessed 9 Jan 2021].
44 Bagheri A. Organ transplantation laws in Asian countries: a comparative study. *Transplant Proc* 2005;37:4159–62.
45 Rithalia A, McDaid C, Suekarran S, *et al*. A systematic review of presumed consent systems for deceased organ donation. *Health Technol Assess* 2009;13:1–95.
46 Rosenblum AM, Horvat LD, Siminoff LA, *et al*. The authority of next-of-kin in explicit and presumed consent systems for deceased organ donation: an analysis of 54 nations. *Nephrol Dial Transplant* 2012;27:2533–46.
47 Morla-González M, Moya-Guillem C, Delgado J, *et al*. European and comparative law study regarding family's role in deceased organ procurement. *Revista General de Derecho Público Comparado* 2021;29 https://www.iustel.com//v2/revistas/detalle_revista.asp?id_noticia=423928&popup=
48 Shaw D, Georgieva D, Haase B, *et al*. Family over rules? an ethical analysis of allowing families to Overrule donation intentions. *Transplantation* 2017;101:482–7.
49 Rodríguez-Arias D, Molina-Pérez A, Hannikainen IR, *et al*. Governance quality indicators for organ procurement policies. *PLoS One* 2021;16:e0252686.
50 Molina-Pérez A, Delgado J, Frunza M, *et al*. Should the family have a role in deceased organ donation decision-making? A systematic review of public knowledge and attitudes towards organ procurement policies in Europe. *Transplant Rev* 2022;36:100673. doi:10.1016/j.tre.2021.100673
51 Díaz-Cobacho G, Cruz-Piqueras M, Delgado J, *et al*. Public perception of organ donation and transplantation policies in southern Spain. *Transplant Proc* 2022;54:567–74. doi:10.1016/j.transproceed.2022.02.007
52 Albertsen A. Against the family veto in organ procurement: why the wishes of the dead should prevail when the living and the deceased disagree on organ donation. *Bioethics* 2020;34:272–80.
53 Qurashi GM. Opt-out paradigms for deceased organ donation are ethically incoherent. *J Med Ethics* 2021. doi:10.1136/medethics-2021-107630. [Epub ahead of print: 11 Sep 2021].
54 Thybo KH, Eskesen V. The most important reason for lack of organ donation is family refusal. *Dan Med J* 2013;60:A4585.
55 National Klinisk Kvalitetsdatabase. *Årsrapport Organdonations-databasen*. 2021. Dansk Center for Organdonation, 2020.
56 DSO. *Jahresbericht Organspende und transplantation in Deutschland 2018*. Frankfurt/Main: Deutsche Stiftung Organtransplantation, 2019.
57 Nederlandse Transplantatie Stichting. Jaarverslagen, 2019. Available: https://www.transplantatiestichting.nl/bestel-en-download/jaarverslagen [Accessed 21 Mar 2019].
58 Nolin T, Mårdh C, Karlström G, *et al*. Identifying opportunities to increase organ donation after brain death. An observational study in Sweden 2009-2014. *Acta Anaesthesiol Scand* 2017;61:73–82.
59 NHS. Transplant activity report. NHS organ donation, 2019. Available: /helping-you-to-decide/about-organ-donation/statistics-about-organ-donation/transplant-activity-report/ [Accessed 6 Aug 2020].
60 Noyes J, McLaughlin L, Morgan K, *et al*. Short-Term impact of introducing a soft opt-out organ donation system in Wales: before and after study. *BMJ Open* 2019;9:e025159.

Differential impact of opt-in, opt-out policies on deceased organ donation rates: a mixed conceptual and empirical study

Supplementary information

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Contents

1. Differential impact of opt-in, opt-out policies when only the deceased´s preferences are considered

A 2012 review of 27 nations where organ donation registries exist showed that only 141 million people out of 719 million (20%) were registered worldwide [1]. In Europe, among 16 nations with registries, only 27 million people out of 272 million (10%) had registered a decision in favour or against donation [1]. As regards organ donor cards, a 2006 survey of 25 EU member states reflected a similar average: only 12% of European citizens were card holders [2]. A further survey of 27 EU member states in 2009 showed that 40% of Europeans had raised the issue of organ donation and transplantation with their family, compared to 59% who had never broached the subject [3].

These figures may have improved over time with variable intensity across countries and procedures. For instance, accrued registrations slightly improved in the Netherlands from 40% in 2010 [1] to 49% in January 2020 [4]. In Germany, the total number of donor-card holders rose from 9% in 2006 [2] to 36% in 2019 [5], and family discussions from 44% in 2009 [3] to 47% in 2019 [5]. Overall, 56% of German citizens had made a decision in 2019, but only 47% had documented and/or communicated it to someone [5]. In the UK, accrued registrations went from 37% in 2009 [3] to 38% in 2019 [6]. In Belgium, the total number of registered citizens increased from 300,000 in 2010 [3] to 550,000 in 2018 [7], which still represents less than 5% of the population. In Italy, cumulative registrations doubled from 1.2 million in 2010 [1] to 2.5 million in 2019 [8], which is nearly 4% of the population. In France, the refusal register is by law the main procedure to express a decision, yet only 300,000 people –less than 0.5% of the total population– were listed in the register by 2017 [9,10].

2. Classification of the role of the family in opt-in, opt-out countries

Table 1. Classification of the role of the family in opt-in, opt-out countries according to Delgado and colleagues (2019) fourfold level of involvement[11]. Depending on each country's policy, the family may have either no role at all in the decision-making process (L0), act as a mere witness to the deceased's wishes, without any capacity to make a decision (L1), act as a surrogate decision-maker when the deceased had not expressed any preference (L2), or have full decisional capacity, including the capacity to overrule the deceased's explicit wishes (L3). Delgado and colleagues differentiate the family's involvement according to the law and in clinical practice. The other two sources are not specific enough about this difference. A previous and slightly different version of this table has been published elsewhere[12].

		Role of the family				
Consent policy		**L0 No role**	**L1 Witness**	**L2 Surrogate**	**L3 Full decisional capacity**	**Source**
opt-in	**law**			CA, DE, NL[a], UK[b], USA	IN	[11]
	practice			DE	CA, IN, NL[a], UK[b], USA	
				NL, RO, UK, USA	AU, BR, CA, CH, CU, DE, DK, EE, IE, IL, IN, IS, JP, KR, KW, LT, MT, MX, MY, NZ, PH, SA, TH, VE, ZA	[13]
		CA			AU, CH, DE, DK, IE, IL, NL, NZ, UK, USA	[14]
opt-out	**law**	AR, AT, PT[c], UY	BE[d], CL, ES, FR, SG	SE	JP	[11]
	practice			BE, SE, SG	AT, CL, ES, JP, NO, PT	
				BE, FI, SG, SE	AM, AT, BY, CL, CO, CR, CZ, EC, ES, FR, HR, IT, LU, NO, PL, PY, RU, SI, SK, TN, TR	[13]
		AT, CZ, LU		GR, PT, SK	BE, ES, FI, FR, HR, HU, IT, NO, RO, SE, SI	[14]

AM: Armenia; AR: Argentina; AT: Austria; AU: Australia; BE: Belgium; BR: Brazil; BY: Belarus; CA: Canada; CH: Switzerland; CL: Chile; CO: Colombia; CR: Costa Rica; CU: Cuba; CZ: Czech Republic; DE: Germany; DK: Denmark; EC: Ecuador; EE: Estonia; ES: Spain; FI: Finland, FR: France; HR: Croatia; HU: Hungary; IE: Ireland; IL: Israel; IN: India; IS: Iceland; IT: Italy; JP: Japan; KR: South Korea; KW: Kuwait; LT: Lithuania; LU: Luxemburg; MT: Malta; MX: Mexico; MY: Malaysia; NL: The Netherlands; NO: Norway; NZ: New Zealand; PH: Philippines; PL: Poland; PT: Portugal; PY: Paraguay; RO: Romania; RU: Russia; SA: Saudi Arabia; SE: Sweden; SG: Singapore; SI: Slovenia; SK: Slovakia; TH: Thailand; TN: Tunisia; TR: Türkiye; UK: United Kingdom (Wales excepted); USA: United States of America; UY: Uruguay; VE: Venezuela; ZA: South Africa.

a. The Netherlands has enacted an opt-out policy by July 2020.

b. England and Scotland have implemented opt-out policies by May 2020, and Wales by December 2015.

c. The role of the family in Portugal according to the law was not initially included in Delgado et al. (2019).

d. The role of the family in Belgium according to the law was wrongly classified as *L2: surrogate* in Delgado et al. (2019).

3. Family oppositions

Table 2. ***Family oppositions to organ retrieval in 2016***

Europe			America			Other countries		
Country	Oppositions (N° of interviews)	Rate (%)	Country	Oppositions (N° of interviews)	Rate (%)	Country	Oppositions (N° of interviews)	Rate (%)
Austria	80 (294)	27	Argentina	434 (1,177)	37	Australia	428 (1,074)	40
Belgium	51 (402)	13	Brazil	2,561 (5,921)	43	Israel	52 (137)	38
Croatia	20 (186)	11	Chile	139 (272)	51	Malaysia	168 (227)	74
Germany	217 (1,399)[a]	16	Colombia	286 (714)	40	Saudi Arabia	230 (333)	69
Hungary	16 (242)	7	Cuba	12 (161)	8	South Korea	884 (1393)[b]	63
Ireland	36 (72)	50	Dominican Republic	40 (72)	56	Türkiye	1,425 (1,988)	72
Italy	807 (2,488)	32	Uruguay	2 (96)	2	TOTAL	3,187 (5,152)	62
Lithuania	26 (103)	25	TOTAL	3,474 (8,413)	41			
Poland	71 (677)	11						
Romania	57 (352)	16						
Slovakia	11 (112)	10						
Slovenia	13 (55)	24						
Spain	372 (2,391)	16						
UK	1,172 (3,145)	37						
TOTAL	2,949 (11,918)	25						

Data shows the raw numbers of family oppositions versus total interviews (requests) conducted Only countries where more than 50 interviews were conducted are reported here. Source: EDQM, Newsletter Transplant 2017.

[a] *Source for Germany: [15].*

[b] *Source for South Korea: [16]*.

4. Differential impact of opt-in, opt-out policies when both the deceased's and family preferences are considered

To determine the frequency of each of the nine possible scenarios when both the deceased's and family preferences are considered (see Table 3 of the main article), it is necessary to get very detailed data. We conducted a non-systematic search on Pubmed, Google Scholar, and ResearchGate using the following keywords in three languages (English, Spanish, French): potential donor(s), potential organ donor(s), organ donor audit, potential organ donation, organ donation activity, organ donation referral, organ donation statistics, organ transplantation statistics, and the MeSH terms "Tissue and Organ Procurement/statistics and numerical data" and "Organ Transplantation/statistics and numerical data". We also searched directly into the websites of several national transplant organisations, when available.

We specifically but not exclusively sought data from the following list of 56 countries including most of the statistical sub-regions as defined by the United Nations geoscheme: Algeria, Argentina, Australia, Austria, Belarus, Belgium, Brazil, Canada, Chile, Colombia, Cuba, Croatia, Czech Republic, Denmark, Ecuador, Egypt, Estonia, Finland, France, Germany, Greece, Hong Kong, Hungary, Iceland, India, Iran, Ireland, Israel, Italy, Japan, Kazakhstan, Kenya, Lithuania, Malaysia, Mexico, the Netherlands, New Zealand, Nigeria, the Philippines, Poland, Portugal, Romania, Saudi Arabia, Singapore, Slovenia, South Africa, South Korea, Spain, Sweden, Switzerland, Thailand, Türkiye, the United Kingdom (in general) and Wales (in particular), the United States, and Uruguay. These 56 countries account for more than two thirds of the 70+ countries having reported some activity in deceased organ donation in recent years to the Global Observatory on Donation and Transplantation database (coordinated by the World Health Organization and the Spanish Transplant Organization) or to the International Registry in Organ Donation and Transplantation (IRODaT.org).

We contacted scholars and officials from the following countries to request data or clarifications:

Table 3: Data requests by email (personal information has been anonymised for privacy reasons)

Country	Contact person/institution	Date of data request	Answer received
Argentina	INCUCAI (Instituto Nacional Central Único Coordinador de Ablación e Implante)	18/12/2020	Yes
Australia	DonateLife, Organ and Tissue Authority	28/01/2021	No
Austria	Individual 1, Tyrolean Private University; Individual 2, Medical University Innsbruck	14/01/2021	Yes
Belgium	Individual 3, University of Antwerp	14/01/2021	Yes
Colombia	Coordinación Red Nacional de Donación y Trasplantes, INS (Instituto Nacional de Salud)	02/01/2021	Yes
Denmark	Individual 4, University of Copenhagen	08/01/2121	Yes
Denmark	Individual 5, Danish Center for Organ Donation	28/01/2021	Yes
Finland	Findata – Health and Social Data Permit Authority	04/01/2021	Yes
Finland	Individual 6, Helsinki University Hospital	04/01/2021	Yes
France	Agence de la Biomédecine	04/01/2021	Yes
Germany	Individual 7, University of Bremen	01/08/2020	Yes
Germany	Individual 8, DSO (Deutsche Stiftung Organtransplantation)	13/08/2020	Yes
Hungary	Organ Coordination Office	04/01/2021	No
India	Individual 9, NOTTO (National Organ & Tissue Transplant Organisation)	04/01/2021	No
Israel	ADI, National Transplant Center	14/01/2021	No
Israel	Individual 10, The Van Leer Jerusalem Institute	29/01/2021	Yes
Kenya	Ministry of Health	15/01/2021	No
Lithuania	National Transplant Bureau under the Ministry of Health	23/01/2021	No
Malaysia	Individual 11, National Transplant Resource Center, Kuala Lumpur Hospital	19/01/2021	Yes
The Netherlands	Individual 12, NTS (Nederlandse Transplantatie Stichting)	26/02/2020	Yes
Philippines	National Kidney and Transplant Institute	15/01/2021	No
Poland	Poltransplant	28/01/2021	No
South Korea	Individual 13, Korean Organ Donation Agency	22/01/2021	Yes

South Korea	Individual 14, Ewha Womans University	22/01/2021	No
Spain	Individual 15, ONT (Organización Nacional de Trasplantes)	17/08/2020	Yes
Sweden	Socialstyrelsen (National Board of Health and Welfare)	13/12/2021	Yes
Thailand	Organ Donation Center, Thai Red Cross Society	24/01/2021	No
United Kingdom	NHS (National Health Service)	27/02/2020	Yes
Uruguay	INDT (Instituto Nacional de Donación y Trasplante de Células, Tejidos y Órganos)	02/01/2021	No

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In the following, scenario *Cc* refers to the particular situation where both the deceased's preferences and the family's preferences are unknown to the medical team. Family preferences can remain unknown under several circumstances, including: (a) the deceased had no living relatives or close friends to be asked; (b) relatives could not be contacted in time; (c) relatives were too distressed to be asked or to make a decision regarding donation; (d) relatives held conflicting views and could not reach a common decision.

In opt-out countries, organs can legally be recovered when both individual and family preferences are unknown (scenario *Cc*). Therefore, these cases should be reported among the cases where organ recovery did happen. However, this is not necessarily what occurs in all opt-out countries. In Cyprus and Greece, the law requires an authorisation from the family to proceed with organ procurement when the deceased's wishes are unknown (which means that, according to our definition, these two countries should not be considered opt-out countries, as it is usually the case, but opt-in countries; see [17]). In Spain, although organ retrieval under scenario *Cc* is legally permissible, guidelines of good clinical practice require an authorisation from the family. In general, doctors may feel reluctant to procure organs without any expressed consent or authorisation, even when they are legally allowed to do so. As a result, in some countries, such as Türkiye, the fact that the family could not be contacted is considered a reason for non donation. Therefore, to identify cases of scenario *Cc*, we must look among the cases where organ recovery did happen, as well as among those where it did not happen.

However, as shown below, it is much more common to find detailed data on the later. Indeed, in those cases where organs are retrieved, many reports do not specify whether consent was obtained from the deceased, or from the family, or both, or neither. To compensate for this lack of written data, we contacted national transplant organisations' representatives or other officials who, on the one hand, confirmed that these data are not recorded and, on the other hand, informed us (personal communication) that the situation where the deceased didn't express any preference, the family could not be reached, and organs were nevertheless procured—according to the law—is very rare. This assessment is corroborated by data from those opt-out countries where more detailed information is available, including Sweden and Wales.

Eventually, we found partial data regarding scenario *Cc* (when both the deceased's preferences and the family's preferences are unknown) in Australia, Austria, Brazil, Belgium, Chile, Colombia, Denmark, Finland, France, Hong Kong, Ireland, South Africa, South Korea, Spain, Switzerland, Sweden, Türkiye, and the USA. We also found more comprehensive data that allowed us to determine the frequency of each scenario in Denmark, Germany, the Netherlands, Sweden, the UK (in general) and Wales (in particular). All datasets used in this study were publicly available prior to the initiation of the study. All data sources are cited below. This includes all relevant data sources whose results we mention in the article, as well as some of the data sources we deemed potentially relevant but could not use eventually. The following is a description of how and why data could or could not be extracted from these data sources.

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Argentina (opt-out) implemented in August 2018 a law to limit the family's capacity to oppose organ procurement. Official data shows that, between the first and second semester of 2018, family opposition dropped from 43% to 22% and organ donors increased from 279 to 422 [18]. Meanwhile, organ donors increased from an average of 13,1 organ donors per million people (ppm) in the 5-year period (2013-2017) before the law was implemented, to 15,75 ppm in 2018 and a record 19,65 ppm in 2019 [19]. Despite contacting with officials at INCUCAI (the national agency of organ donation and transplantation), we were unable to determine the frequency of scenario *Cc*.

In **Australia** (opt-in), among a cohort of 116 patients admitted at the ICU for "potential organ donation" at The Alfred Hospital, Melbourne, from 2007 to 2016, organ donation could not be discussed with the family in only one case [20]. In all other cases, the family could make a decision. This means that scenario Cc occurred in 1% of cases in that cohort during a 10-year period.

In **Austria** (opt-out), the family is not legally allowed to make a decision and can only inform the medical team about the deceased's oral refusal, if any. In 2020, there were 1,036 possible donors, out of which 682 were excluded for medical reasons (including 342 brain death criteria not fully met) and 40 patients had expressed refusal (35 orally, 5 written)[21]. Then, out of 314 remaining potential donors, 83 were excluded for medical reasons, 10 patients had refused (orally), and 6 excluded for other reasons. Then, out of 215 eligible donors, 20 patients had refused (19 orally, 1 written), 1 suffered circulatory failure and 2 did not become actual donors for other reasons. The total number of actual donors was 192, with 70 patients excluded because of their expressed refusal at different stages of the process, and 844 excluded for other reasons unrelated to consent/refusal. If we sum actual donors with non-donors because of refusal, we obtain 192+70=262 potential donors (with no medical or other issues unrelated to consent/refusal). If we consider only the potential donors after brain death was determined and the refusals after that stage, then we have 192+30=222 eligible donors. Therefore, if we assume that all organ procurements were based on presumed consent (deceased's preferences unknown to the medical team), we can fill the following table:

AUSTRIA (hard opt-out)	Deceased's wishes		
	Consent	Refusal	Unknown
N=262 potential donors	n/a	27% (N=70)	73% (N=192)
N=222 eligible donors	n/a	14% (N=30)	86% (N=192)

We know that 192 individuals had not expressed their refusal and therefore became actual donors, but there is no information about how many of them really wanted (would have consented) to be donors. This is problematic because it makes us unable to assess the direct impact of the default. According to these figures, if Austria had had an opt-in policy, no organs at all (0%, N=0) would have been procured in 2020, which is very unlikely. It is more reasonable to suppose that some of these 192 potential donors in the last column actually wanted to be donors and may have even expressed their wish to their relatives (or registered their consent, had there been a registry of donors). If this is the case, then these willing donors should appear in the first column, not in the last. However, as their wishes are not recorded, we cannot differentiate the "consent" situation from the "unknown" situation. Therefore, unfortunately, we cannot determine the differential impact of the opt-in and opt-out defaults based on these figures. It is somewhere between 0% and 73% (or 0-86%) but this is too vague to be useful.

In **Belgium** (opt-out), there were 712 potential organ donors in 2019 and the reasons for non-procurement were: 38,3% medical contraindications, 12,6% family refusal, 1,3% registered refusal, 0,4% objection by the coroner, and 4,4% because of "other/unknown" reasons [22]. If we exclude all cases of medical contraindications, there were 439 potential donors in 2019, out of which 31 (7%) were not retrieved because of "other/unknown" reasons. However, these cases may or may not correspond to scenario Cc. Therefore, cases of scenario Cc may be as low as 0% or as high as 4% or 7% of cases, depending on the definition of potential donor. When searching further information, we were told by a Belgian representative in the European Committee on Organ Transplantation that "The situation where the potential donor had failed to make a decision and the preferences of the family regarding donation are also unknown, is extremely rare. If the family cannot be reached after trying for a long time, the opt out will be performed. For Belgium I know maybe of 2 cases in my whole career where this happened. If the potential donor had failed to make a decision and the family can be reached, we only contact the family members in the first degree. If they are disagreeing among themselves, we leave them some time and then re-contact them. If there is still disagreement, we will not proceed with the organ removal" (Personal communication). Therefore, although the number and ratio of cases of scenario Cc is not known, available data indicates that these cases are likely very rare and that, in any case, they were below 4-7% in 2019.

In **Brazil** (opt-in), a retrospective study in a single hospital between January 2008 and December 2010 found 1346 deaths, with 41 notifications of brain death, 21 notifications of cardiac death (out of 1305 cardiac death), and a total of 1284 non-notifications, out of which 49 cases were not notified because of "patients without identification" and 11 cases because of "missed family" [23]. This means that scenario Cc would represent 49+11 out of 1346 cases, that is 4.3%. However, it is not clear to us that all deaths reported here are cases of potential donors. A different study of 47 records of family refusal from a hospital in the state of Parana reports 5 cases of family disagreement [24]. However, the number of potential donors in this study is not mentioned. Another retrospective study in an area of Brazil's Northest between Nov. 2015 and Jan. 2017 found 150 brain dead potential donors and 74 cases of family refusal, out of which 17 because of the deceased's refusal in life and 15 because of familiar disagreement [25]. If we consider these cases of familiar disagreement as instances of unknown wishes, instead of instances of family refusal, then scenario Cc would have occurred in 10% of cases in that area.

In **Chile** (opt-in in 2008), the 2008 annual report of the now extinct Transplant Corporation (Corporación del Trasplante) indicates that, out of 303 potential donors, the family could not be contacted in two occasions and the deceased had no family in one occasion [26]. This means that scenario Cc occurred in 1% of total cases in 2008.

In **Colombia** (opt-out), presumed consent for organ donation has been implemented in 1988 and the family was allowed to authorised or oppose donation. This law was amended in 2016 so that the family is no longer allowed to intervene (to authorise or to oppose) since 2017. However, the number of family authorisations, oppositions, and cases of presumed consent were recorded up to (and including) 2017 (see Table below). Since 2018, the occurrences of family acceptance and refusal are no longer recorded in official statistics because the 2016 law does not allow the family to intervene in the decision (Coordinación Red Nacional de Donación y Trasplantes: personal communication on January 19th, 2021). The table below shows that during the four years before the new law was enacted, presumed consent was anecdotal (0% to 1%) and rose to 4% in 2017 (data source: [27]).

Table 4: Organ donation statistics in Colombia up to 2017

Year	2013	2014	2015	2016	2017	Total
Eligible donors	621	662	823	715	755	3576
Family opposition	229	254	325	286	203	1297
Family authorisation	392	408	493	428	521	2242
Presumed consent	1	1	5	1	31	39
Total donors	393	409	498	429	474	2203

Source: Colombia's Instituto Nacional de Salud [25].

In **Denmark** (opt-in), see below.

In **Finland** (opt-out), presumed consent has been implemented in 2010 and the family is not legally allowed to oppose organ donation. However, in practice, organs are never procured against the wishes of the family (National transplant coordinator, Hospital University of Helsinki: personal communication). Data from a single hospital study between 2005 and 2015 identified 83 potential organ donors with no case corresponding to scenario *Cc* [28]. Finland's national transplant coordinator confirmed to us that it is extremely rare that the family cannot be contacted and this situation may have happened only once in several decades (personal communication). This means that the frequency of scenario Cc is nearly 0%.

In **France** (opt-out), a law to limit the family's capacity to oppose organ donation has been implemented on January 1st, 2017. Since that date, the family cannot legally oppose organ donation but only act as a witness of the deceased's wishes (when the deceased did not register their refusal). Official data shows that, in the 3-year period before (2014-2016) and after (2017-2019) the law was implemented, oppositions (either by the deceased or the family) dropped by 2,2% from 32,5% to 30,3%, and organ donors increased by 2,2% from 48% to 50.2% of all brain dead patients [29]. According to a Parliament's internal report in December 2017, relatives still opposed organ donation *de facto*, although this was not allowed *de jure*, either by claiming (wrongfully) that the deceased was unwilling to donate while alive, or by expressing fierce or even violent [sic] objections to the medical team [10]. In the latter case, this is officially reported as "because of the context, organ procurement was not possible" ("en raison du contexte, le prélèvement n'a pas été possible") which is a new category created in 2017. Official records for 2019 report that, out of 3,471 brain dead individuals, there were 1,729 procurements, 683 non-procurements for reasons unrelated to refusal/opposition (mostly medical contraindications), and 1,059 non-procurements because of oppositions classified as "opposition from the legal representative" (N=50), "because of the context,…" (N=491), and "deceased's refusal" (N=518) (source: Agence de la biomédecine, https://rams.agence-biomedecine.fr/le-prelevement-dorganes-en-vue-de-greffe, "Prélèvement sur donneur décédé en état de mort encéphalique", Tableau P2 & P7). There is no direct indication of situations that would correspond to scenario *Cc* and we were unable to determine or estimate the frequency of that scenario from official data. A representative of the Agence de la Biomédecine confirmed to us that there is no official data available and that only transplant coordinators may know from their own personal experience the frequency of scenario Cc (personal communication). Nonetheless, we managed to find two studies from a single harvesting centre that mention family disagreement: 3 cases out of 227 potential organ donors between Jan. 2010 and Dec. 2011 and 22 out of 426 between Jan. 2012 and Dec. 2015, respectively 1% and 5%, although they do not mention if a decision was made eventually by the family [30,31]. These two studies were conducted by the same authors, in the same centre, with the same methodology, during consecutive periods. Therefore, by combining their results, we have 3+22=25 cases out of 227+426=653 potential donors: 3.8%.

In **Hong Kong** (opt-in), a study of all family members of potential donors after cardiac death approached by the local eye bank staff members from January 2008 to December 2014 identified 1,740 cases, out of which 1,099 refused corneal donation and 79 of them because of "lack of consensus in the family" [32]. Since only families approached are included, this means that scenario Cc occurred in at least 4.5% of cases. Another retrospective study conducted in 2014 at Queen Elizabeth Hospital, the largest regional acute hospital in HK, reported 21 eligible donors after brain death and families were approached in all cases, which means that scenario Cc did not happen [33].

In **Iceland** (opt-out), a study of all brain dead patients in two hospitals from Jan. 2003 to Dec. 2016 mentions 125 potential donors and 99 eligible donors, with 64 cases of family consent, 21 cases of family refusal, and 15 cases of permission not requested, among which 11 cases where the reason for not requesting permission for donation could not be determined [34]. If all these cases were instances of scenario Cc (which we actually don't know), this scenario would be limited to 11% or less of all eligible donors.

In **India** (opt-in), data from a single hospital reported 61 potential donors after brainstem death, out of which "based on their previous interaction with the patients' family members, the treating team did not feel it appropriate to counsel four patients' family members for deceased organ donation" [35]. However, it is not clear whether the medical team did not approach the family because of their emotional distress or because they were likely to refuse.

In **Iran** (opt-in), a study of the causes of family refusal in 2009-2010 (73 out of 125 brain dead patients) mentions 3 cases as "other" [36]. If these were all cases of scenario Cc (which we don't know), this scenario would be limited to 4% or less.

In the **Republic of Ireland** (opt-in), data from a potential donor audit shows that, between September 2007 and August 2008, among 138 potential donors, when the deceased had not expressed any preference, the family preferences remained unknown in four cases, namely, because the next-of-kin was not traceable in time, the family was too distressed, there was a language barrier, and one unspecified reason [37,38]. This means that scenario Cc occurred in 3% of all potential donor cases during that period.

In **South Africa** (opt-in), data from the Groote Schuur Hospital, Cape Town, over a 10-year period (2007-2016), indicates that, among 861 patients referred for donation, the identity of the patient was unknown or their family could not be contacted successfully in 72 cases [39]. This means that scenario Cc occurred in 8.4% of all cases in that hospital during that period.

In **South Korea** (opt-in), data from a retrospective survey (2014-2019) shows that, among 9,587 potential brain death cases suitable for organ donation, 536 did not proceed because of disagreements between family members, which represents less than 6% of the total [40]. This is consistent with a second study (2013-2018) indicating that out of 6,987 medically available potential brain deaths, 441 (6.3%) were initially consented by next of kin but refused by other family members [16]. However, the first survey cited provides no detailed information (it is just a conference abstract) and the second survey cited shows contradictions: Table 2 indicates 105 cases of initial consent by next-of-kin but refusal by other family members (in 2018), while Fig. 1 indicates 100+5 cases mentioning respectively “Refused by medical staff” and “No family member for consent”, in addition to 11 cases of “cancel consent”. A third study using data from the same period (2013-2018) indicates 100 cases mentioning “Refused to meet medical staff” and 3 cases of “donation withdrawal” (in 2018) [41]. In addition, while the second study mentions that, out of 884 cases of donation refusal in 2018, 655 families refused the interview itself when approached [16], the third study mentions 88 cases of donation refusal in 2018 and 100 additional cases of families that “refused to meet medical staff” [41]. In Korea, the authorisation of the family is mandatory for organ donation, and refusal to meet the medical staff may be considered a way to oppose organ donation. With regard to family disagreement, this may or may not be understood as a situation of unknown family wishes because some family members initially accept organ donation and that decision is eventually overruled by other family members, so that the final decision of the family is a refusal. We contacted the author of the second study, who is the president of the Korea Organ Donation Agency, for clarification. Based on all this, we consider that the only clear cases of unknown family wishes are those where no next-of-kin is available to make a decision. This corresponds to 30 cases out of 1,833 medically available potential donors in 2018, that is 1.6% [16].

In **Spain** (opt-out), the data on outcomes from potential donors recorded by the National Transplant Organization (ONT) is not detailed enough to ascertain the relative frequency of all nine scenarios or of scenario *Cc*. A study of 1,844 brain dead patients from 42 ICUs mentions 7 cases of patient’s refusal during lifetime, 244 cases of family opposition, and no causes of loss of donors that can correspond to scenario Cc beside 14 cases classified as “other” [42]. If all these 14 “other” cases were instances of scenario Cc, this scenario would occur in less than 1% of potential donor cases. Another study at a high-volume, tertiary hospital with one of the highest proportions of DCD in the country mentions that, out of 621 donor-eligible individuals from 2008 to 2017, 5 were lost owing to the absence of a decision-making family member [43]. These cases corresponds to the definition of scenario Cc and represent less than 1% of eligible donors. ONT statistics relative to donation after brain death show that, in 2018, there were 1,607 organ donors, 313 cases of family refusals, and 5 cases in which the family could not be contacted [44]. This means that the frequency of scenario Cc is nearly 0%. ONT authorities confirmed to us that scenario Cc is extremely rare (personal communication).

In **Sweden** (opt-out), official data from the National Board of Health and Welfare (Socialstyrelsen) shows that, in 2020, out of 882 patients who met the criteria for a potential donor, 863 were identified in one way or another in the medical record, 181 became actual donors, and consent-related reasons for non-nonation include: 38 written refusals, 35 oral refusals (communicated by close relatives), 1 family veto, and 20 cases of unknown willingness to donate where close relatives could not be notified [45]. This means that scenario Cc occurred in 20 / 275 = 7 % of all potential donor cases in 2020. For more complete data, see below.

In **Switzerland** (opt-in; changed to opt-out in 2022), data from Swisstransplant shows that, between September 2011 and August 2012, among 216 potential donors, when the deceased failed to express any preference, the next-of-kin could not be contacted in six cases, and the family could not make a decision in one case [46–48]. This means that scenario Cc occurred in 3% of all potential donor cases during that period.

In **Türkiye** (opt-out), a study of all adult and paediatric patients diagnosed with brain death between January 2001 and December 2016 in a tertiary reference university hospital with 73 ICU beds shows that, out of 303 patients with brain death, the patients’ relatives could not be interviewed (no reason mentioned) in 5 occasions [49]. If we suppose that these families could not be contacted, the frequency of scenario Cc would be 2%. Data from another single hospital study between 2008 and 2019 mentions that, out of 82 brain dead potential donors, 3 cases of families who refused to communicate for the donation process [50]. This corresponds to 3.7%.

In the **United States of America**, a retrospective analysis of all referrals during a 4-year period (2004-2007) to an Organ Procurement Organization (OPO) in South and Central Texas mentions that 44 families of the 827 potential organ donors referred to that OPO were divided on the decision [51]. No indication is given on whether the deceased had expressed their willingness to donate. This means that scenario Cc occured in 5% or less of all potential donor cases referred to that OPO during that period. In the USA at large, a review of hospital medical records of deaths occurring in the ICU from 1997 through 1999 in 36 OPOs indicates that “in 3 percent of the cases, organs were not donated for other reasons, such as restrictions imposed by the medical examiner, the occurrence of cardiac arrest in the patient, precluding organ recovery, or the lack of a family member who could give consent.” [52]. A study of donation decisions of 420 families in Ohio and Pennsylvania identified 26 cases of family disagreement [53].

Table 5. ***Estimated frequency of scenario Cc in several countries.***

Consent model	**Country**	**Period**	**Potential/eligible donors**[a]	**Cases of scenario Cc (%)**
Opt-in	Australia	2007-2016	116[c]	1 (1)
	Brazil	2016	150[c]	15 (10)
	Chile[b]	2008	303	3 (1)
	Hong Kong	2008-2014	1740	79 (5)
	Rep. of Ireland	2007-2008	138	4 (3)
	South Africa	2007-2016	861[c]	72 (8)
	South Korea	2018	1,833	30 (2)
	Switzerland	2011-2012	216	7 (3)
	USA	1997-98 2004-07 n/a (~2005)	n/a 827 420	n/a (3) 44 (5) 26 (6)
Opt-out	Belgium	2019	712	n/a (0-7)
	Colombia	2013-2017	3,576	39 (1)
	Finland	2005-2015	83	0 (0)
	France	2010-2015	653[c]	25 (4)
	Spain	2018	1925	5 (0)
	Sweden	2020	275	20 (7)
	Türkiye	2001-2016 2008-2019	303[c] 82[c]	5 (2) 3 (4)

[a] The definition of a potential donor varies between countries.

[b] Chile had an opt-in system in 2008 and switched to opt-out in 2010.

[c] Data from a single hospital or a single organ procurement organization.

In addition, we were able to extract the detailed information required for filling the table from six countries: Denmark, Germany, the Netherlands, the United Kingdom, Wales, and Sweden. German colleagues helped us interpreting documentation written in German. Then, we contacted the respective national transplantation organisations by email to confirm our results. We received confirmation from the Nederlandse Transplantatie Stichting (Netherlands) and the NHS Blood and Transplant (UK). The DSO (Germany) answered our email but did not provide either confirmation or refutation of our results.

Denmark

Source: Thybo KH, Eskesen V. The most important reason for lack of organ donation is family refusal. Dan Med J. 2013;60: A4585. [54]

A retrospective study of all patients who died at Rigshopsitalet between 2000-2003 and 2007-2010 shows that, out of a total of 284 potential donors during these two periods, 25 (12+13) were eventually not converted into actual donors because of contraindications, 23 (12+11) because donation was not considered, and 2 (1+1) because of forensic examination. If we exclude these 49 cases of non-donation that are unrelated to consent, the number of potential donors is 235.

The number of effective donors is 90 (42+48). Among them, 15 (5+10) had registered their willingness to donate, and in the remaining 75 cases, authorisation was given by the next-of-kin (scenario Ca).

The number of non-donors is 167 (98+69). Among them, the deceased had refused donation in 18 (15+3) cases, and the next-of-kin opposed it in 120 (67+53) cases. In addition, there are 6 (4+2) cases signalled as “no next of kin”.

This is consistent with but higher than nationwide data from the Dansk Center for Organ Donation for the period 2014-2018, with 9 cases where both the wishes of the deceased and those of the family were unknown because relatives could not be found (personal communication). The annual average of potential donors in this period was 260, which means a total of approximately 1300 (personal communication). Therefore, the frequency of scenario Cc in Denmark for that period was less than 1%.

Denmark has an opt-in system where the family can make a decision when the deceased had not, but cannot legally overrule (veto) the deceased’s consent. Therefore, we can consider that all 120 cases of family opposition correspond to scenario *Cb*. When the deceased had made a decision, the preferences of the family are not considered and remain unknown to us. Therefore, the 15 cases of deceased’s consent correspond to scenario *Ac* and the 18 cases of deceased’s refusal correspond to scenario *Bc*.

Table 6

N=235 potential donors			**Family preferences**		
			(a) favorable	**(b) unfavorable**	**(c) unknown**
			31.9% (N=75)	*51% (N=120)*	*16.6% (N=39)*
Deceased’s decision	**(A) consent**	*6.4% (N=15)*	*n/a*	*n/a*	*6.4% (N=15)*
	(B) refusal	*7.7% (N=18)*	—	*n/a*	*7.7% (N=18)*
	(C) unknown preferences	*85.5% (N=201)*	*31.9% (N=75)*	*51% (N=120)*	*2.6% (N=6)*

In addition, a study of all patients who died in Aalborg University Hospital in 2012 shows that 47 patients died in ICU and 32 where identified as potential donors, out of which “3 patients died without having their relatives confronted by ICU staff about organ donation” but no mention is made of the reasons why relatives were not approached, and all other families either authorised (12) or refused (17) organ procurement [55]. Depending on whether or not we consider these three cases as instances of scenario *Cc*, the frequency of scenario *Cc* would be either 0% or 10%.

Denmark

Source: [National report] Årsrapport Organdonations-databasen 2020. Dansk Center for Organdonation 2021.[56], pages 28-29.

In 2020, there were 285 potential donors (before brain death was determined), out of which 179 were excluded for the following reasons:

- 11 patients had refused
- 4 patients had consented but their relatives opposed
- 45 patients' wishes unknown, relatives opposed
- 2 patients' wishes unknown, relatives not found
- 2 police banned donation
- 86 medical reasons (62+9+11+2)
- 31 explanation not given

Then, out of 106 brain dead potential donors, 5 were excluded for medical reasons, and 2 cases of patient's wishes unknown and relatives opposed. Eventually, there were 99 actual donors.

If we exclude from the total of potential donors those who were excluded for reasons unrelated to consent/refusal, we obtain 163 potential donors (99 actual donors + 64 non-donors).

We have the required information concerning all cases of non-donors, including the 2 cases where the deceased's wishes are unknown and the family could not be contacted (scenario *Cc*), but we lack information about the cases where organ procurement could proceed. In particular, we lack information about the number of potential donors who had registered their consent. (Page 37 provides information about registration, but we failed to make sense of it in relation to the above information.) In other words, we ignore the proportion of cases where organ procurement could proceed based on the deceased's consent (with or without family support, which is not required by law) or based on family authorisation (when the deceased had failed to express any preference). Therefore, we are unable to determine how the 99 actual donors should be distributed in the table below, i.e. how many correspond respectively to the cells (in grey) *Aa*, *Ac*, and *Ca*.

Table 7

N=163 potential donors			**Family preferences**		
			(a) **favorable** *%* *(N=)*	**(b)** **unfavorable** *%* *(N=)*	**(c)** **unknown** *%* *(N=)*
Deceased's decision	**(A) consent**	*%* *(N=)*	*n/a*	*2.5%* *(N=4)*	*n/a*
	(B) refusal	*%* *(N=)*	—	*n/a*	*6.7%* *(N=11)*
	(C) unknown preferences	*%* *(N=)*	*60.7%* *(N=99)*	*28.8%* *(N=47)*	*1.2%* *(N=2)*

Germany

Source: Deutsche Stiftung Organtransplantation (DSO), Jahresbericht organspende und transplantation in deutschland 2018 [15], pages 52 and following:

Fig. 18, p. 52, shows a total of 2,811 donation-related contacts to the DSO before the determination of total brain failure, out of which 1,395 were excluded at this stage and, among those not excluded, 955 became actual donors and 461 did not.

Fig. 21, p. 54, shows that among those 1,395 exclusions, 498 deceased individuals had previously refused to be organ donors (likely through their donor-card). In addition, there are 30 cases where the conversation with relatives was deemed unreasonable, or there was no consent from the authorized persons, or opposition from the prosecutor.

Fig. 22, p. 56, shows that, after the determination of brain death, the total number of potential donors was 1,416, among which there were eventually:

- 955 effective donors
- 340 non-donors because of the deceased’s refusal or family opposition
- 99 non-donors for medical reasons
- 22 non-donors for other reasons (including family interview deemed unreasonable or lack of authorisation from the prosecutor/judge)

Fig. 25, p. 58, shows that the number of decisions made about organ retrieval are divided into 1,037 authorisations and 340 oppositions, totalling 1,377. Decisions are distributed as follows:

- ➔ Authorisations (N=1,037):
    - ☞ Presumed willingness to donate: 45,5% (N=472)
    - ☞ Oral consent: 25.4% (N=263)
    - ☞ Written consent: 17.6% (N=182)
    - ☞ Relatives: 11.6% (N=120)
- ➔ Oppositions (N=340)
    - ☞ Presumed willingness not to donate: 31.2% (N=106)
    - ☞ Oral refusal: 32.1% (N=109)
    - ☞ Written refusal: 4.1% (N=14)
    - ☞ Relatives: 32.6% (N=111)

The number of favourable decisions (1,037) is higher than the number of actual donors (955), which means that there were 1,037 - 955 = 82 cases where organs were not actually removed despite authorisation. Thus, among 99 non-donors for medical reasons, there were 82 cases with a favourable decision and 17 cases with no decision being made either in favour or against. In addition, there were 22 cases of non-donors for other reasons, including family interviews deemed unreasonable and lack of relatives to ask for organ retrieval. This gives us 17 + 22 = 39 cases without a decision. This number corresponds to the difference between the total number of potential donors after brain-death and the number of cases with a decision: 1,416 - 1,377 = 39.

- ➔ No decision (N=39)
    - ☞ 17 excluded for medical contraindications
    - ☞ 22 excluded for other reasons (including family interviews deemed unreasonable, no relatives to consult, no authorisation from the prosecutor)

Germany has an “extended consent” policy, which means that it operates an opt-in policy wherein individuals are encouraged to document their wishes on a donor-card (as there is no register) or inform their relatives. When the deceased had not expressed their wishes in written or oral form, relatives are asked to make a decision based on the presumed wills of the deceased. Only if this presumed will of the deceased cannot be determined do the relatives decide according to their own ideas. This corresponds to the distribution of cases of authorisations and oppositions shown above. In the following, we are going to suppose that the deceased´s expressed decision is sufficient (to proceed or not to proceed with organ removal) and that said decision cannot be overruled by the family. This implies that, whenever the deceased had expressed a decision, the preferences of the family are not taken into account. Hence, when the deceased had expressed a decision, family preferences will be considered as unknown.

Now, we can try to figure out the distribution of cases in our scenarios.

- There are 263 cases of oral consent and 182 cases of written consent, totalling 445 cases of expressed willingness to donate by the deceased. As family preferences are considered unknown, these cases correspond to scenario Ac.
- There are 109 cases of oral refusal and 14 cases of written refusal by the deceased, totalling 123 cases. Again, as family preferences are considered unknown, these cases correspond to scenario Bc.
- There are 472 cases of presumed willingness to donate and 120 cases of relatives' authorisation based on their own preferences, totalling 592. In both circumstances, the deceased's wishes are unknown, thus corresponding to scenario Ca.
- There are 106 cases of presumed willingness not to donate and 111 cases of relatives' oppositions based on their own preferences, totalling 217. In both circumstances, the deceased's wishes are unknown, thus corresponding to scenario Cb.
- There are 22 cases with no decision being made for non-medical reasons.
- There are 17 cases with no decision being made for medical reasons. In these cases, we are going to suppose that *because of medical contraindications* that excluded these individuals as potential donors, the family interview did not take place.

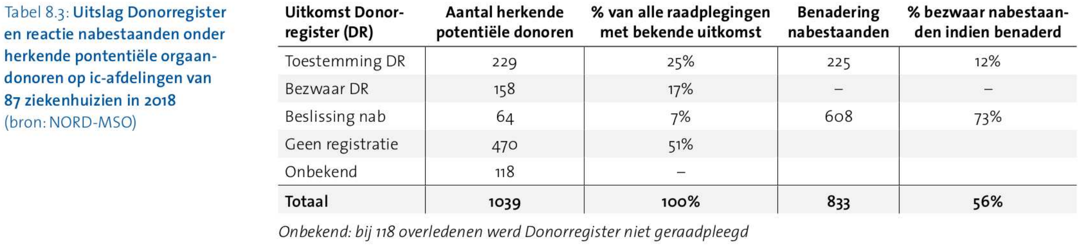
If we exclude these 17 cases of medical contraindications (before families could be asked), we end up with 1,037 (decisions in favour) + 340 (decisions against) + 22 (without any decision) = 1,399 total cases.

Table 8

N=1,399 potential donors			**Family preferences**		
			(a) favorable	**(b) unfavorable**	**(c) unknown**
			42.3% (N=592)	*15.5% (N=217)*	*42.2% (N=590)*
Deceased's decision	**(A) consent**	31.8% (N=445)	*0% (N=0)*	*0% (N=0)*	*31.8% (N=445)*
	(B) refusal	8,8% (N=123)	—	*0% (N=0)*	*8.8% (N=123)*
	(C) unknown preferences	59.4% (N=831)	*42.3% (N=592)*	*15.5% (N=217)*	*1.6% (N=22)*

The Netherlands

Source: Nederlandse Transplantatie Stichting (NTS), Jaarverslag 2018 [57], Table 8.3, page 100



Tabel 8.3: **Uitslag Donorregister en reactie nabestaanden onder herkende pontentiële orgaandonoren op ic-afdelingen van 87 ziekenhuizen in 2018**
(bron: NORD-MSO)

Uitkomst Donorregister (DR)	Aantal herkende potentiële donoren	% van alle raadplegingen met bekende uitkomst	Benadering nabestaanden	% bezwaar nabestaanden indien benaderd
Toestemming DR	229	25%	225	12%
Bezwaar DR	158	17%	–	–
Beslissing nab	64	7%	608	73%
Geen registratie	470	51%		
Onbekend	118	–		
Totaal	**1039**	**100%**	**833**	**56%**

Onbekend: bij 118 overledenen werd Donorregister niet geraadpleegd

Out of 1,039 (100%) potential organ donors, 229 (22%) had consented, 158 (15%) had refused, and 652 (63%) had unknown wishes, among which 64 (6%) had left the decision to their relatives, 471 (45%) were not registered, and in 118 (11%) cases the register was not consulted.

The family was consulted on 833 occasions, both when the deceased had consented (225/833) and when his/her wishes were not known (608/833). The family was not consulted on 206 occasions, either because the deceased had already registered a refusal (158/206) or for other undisclosed reasons (48/206).

In the case of registered consent by the deceased, the family authorized organ retrieval on 198 occasions and opposed a veto on 27 occasions. In the case of unknown preferences from the deceased, the family authorized organ retrieval on 164 occasions and opposed it on 444 occasions.

Table 9

			Family preferences		
N=1,039 potential donors			**(a)** **favorable**	**(b)** **unfavorable**	**(c)** **unknown** **(family not consulted)**
			35% *(N=362)*	*45%* *(N=471)*	*20%* *(N=206)*
Deceased	**(A) consent** (registered)	22% (N=229)	*19%* *(N=198)*	*3%* *(N=27)*	*0%* *(N=4)*
	(B) refusal (registered)	15% (N=158)	—	*0%* *(N=0)*	*15%* *(N=158)*
	(C) unknown preferences*	63% (N=652)	*16%* *(N=164)*	*43%* *(N=444)*	*4%* *(N=44)*

* Decision left to relatives 6% (N=64); Deceased Unregistered 45% (N=471); Register not consulted 11% (N=118)

Sweden

Source: Nolin, T., Mårdh, C., Karlström, G., & Walther, S. M. (2017). Identifying opportunities to increase organ donation after brain death. An observational study in Sweden 2009–2014. Acta Anaesthesiologica Scandinavica, 61(1), 73–82. https://doi.org/10.1111/aas.12831 [58]

A prospective observational study of all ICU death in Sweden (from Jan. 1, 2009 to Dec. 31, 2014) found 1,575 confirmed potential donors, 240 of which had contraindications to organ donation. Therefore, there was a total of 1,275 eligible organ donors during that 6 years period. Among those 1,275 eligible donors, organ procurement did not proceed because:

- the deceased had expressed their refusal to donation in 176 cases;
- when the deceased's decision was unknown, the family opposed organ recovery in 175 cases;
- when the deceased's decision was unknown, the family could not express a decision in 20 cases (they could not be informed: N=9; they disagreed with one another: N=11).

The resulting 904 eligible donors had either expressed their individual consent or their family authorised recovery:

- the deceased had expressed their consent to donation in 449 cases;
- when the deceased's decision was unknown, the family authorised organ recovery in 455 cases;

Among these 904 eligible donors, the next-of-kin eventually expressed their opposition in 2 additional cases. From the article's description, it seems that these 2 family oppositions should be retracted from the 449 cases where the deceased had consented. Organ recovery was not carried out in 50 additional cases for other reasons (new medical contraindication, no recipient, circulatory collapse, etc.). Eventually, organ recovery was carried out in 852 cases (actual organ donors) out of 904.

During the 6 years period examined, the deceased's preferences and the family's preferences were both unknown (Cc) in 20 cases. Organ recovery did not proceed in these cases. Therefore, during six years (2009-2014), no organs were recovered based on presumed consent. All organs were recovered based on either the deceased's consent or family authorisation.

Table 10

			Family preferences		
N=1,275 eligible donors			**(a) favorable**	**(b) unfavorable**	**(c) unknown (family not consulted)**
			n/a	*n/a*	*50% (N=643)*
Deceased's decision	**(A) consent**	35% (N=449)	*n/a*	*0% (N=2)*	*35% (N=447)*
	(B) refusal	n/a	—	*n/a*	*14% (N=176)*
	(C) unknown preferences	51% (N=650)	*36% (N=455)*	*14% (N=175)*	*2% (N=20)*

* Family not informed (N=9); Disagreement among family members (N=11).

The United Kingdom

Sources:

- NHS Transplant Activity Report, Potential Donor Audit (1 April 2018 - 31 March 2019) [6].
- NHS Potential Donor Audit (standalone version) (1 April 2018 - 31 March 2019) [59].
- Further clarifications from NHS's ODT Statistical Enquiries (personal communication).

At the end of March 2019, there had been 1,635 potential DBD organ donors (i.e. with no medical contraindications at this stage), and 1,493 requests for authorisation conveyed to their families. The overall consent/authorisation rate was 72.5% (1,082 authorisations over 1,493 family requests):

- When the patient's decision (by any method) was known: 566 consents over 595 requests = 95.13%;
    - 29 families overruled their loved one's known decision (by any method) to be an organ donor.
    - When the patient's decision on ODR and known: 488 consents over 516 requests;
    - Therefore: when the patient's decision was known by other means: 566-488=78 consents over 595-516=79 requests
- When the patient had not expressed a decision or the patient's ODR status was not known: 516 consents over 898 requests = 57.46%
    - However, among the 411 family oppositions, the reason was that the patient previously expressed a wish not to donate on 82 occasions (Table 13.10). Hence, these are 82 cases of known refusal, and unknown ODR status is 898-82=816.

These figures are reported in Table 10:

Table 11

Decision		Family		
		Authorisation	Opposition	Total requests
Consent	ODR	488	28	595 (39.85%)
	Other means	78	1	
Refusal		—	82	82 (5.49%)
Unknown		516	300	816 (54.66%)
Total		1,082	411	1,493

The reasons given to explain why the family was not formally approached provide further important details:

a)	Patient’s general medical condition	N=45
b)	Coroner / Procurator Fiscal refused permission	N=28
c)	Other	N=25
d)	Other medical reason	N=17
e)	Family stated that they would not support donation before they were formally approached	N=9
f)	Family untraceable	N=6
g)	Family considered too upset to approach	N=5
h)	Patient had previously expressed a wish not to donate	N=4
i)	Not considered as a potential donor / organ donation not considered	N=3
	TOTAL	N=142

Reasons *a*, *b*, *d*, and *i* mean that the corresponding cases were not real opportunities for organ recovery (the deceased was not a potential donor for medical reasons or for other causes unrelated to individual or family preferences). Therefore, these cases should be removed from the total number of opportunities for organ recovery (potential DBD donors): 1635-45-28-17-3=1542.

Reason *e* means that there are 9 cases where the family was unfavorable (column b) and the deceased’s wishes are undisclosed. These cases should be added to the Family opposition/deceased’s unknown situation: 300+9=309.

This leaves reasons *c*, *f*, *g* and *h* totalling 40 cases (instead of 142) that belong to the column of unknown family preferences. Reason *h* means that in 4 out of these 40 cases the deceased had registered their refusal and the family preferences are unknown (because they were not approached), which corresponds to situation *Bc* (refusal-unknown).

In the rest of cases, N=36 (2.3%), we ignore whether the deceased had consented (by any means), refused (orally), or failed to express any preferences. Therefore, the relative frequency of the Cc situation is necessarily between 0% and 2.3%.

If the two variables (deceased’s and family preferences) are independent, the proportion of individuals who failed to express any preference while alive should be the same regardless of whether or not their family were formally approached after their death. If true, then 55% of those 36 individuals (whose families were not approached) failed to express any preference. This means that the relative frequency of the Cc situation is more likely around 1.3% (N=20).

Table 12

			Family preferences		
N=1542 potential DBD donors			**(a) favorable**	**(b) unfavorable**	**(c) unknown (family not consulted)**
			70.2% *(N=1,082)*	*27.2%* *(N=411+9)*	*2.6%* *(N=40)*
Deceased	**(A) consent** (by any means*)	38.6-39.5% (N=595-609)	*36.7%* *(N=566)*	*1.9%* *(N=29)*	*0-0.9%* *(N=0-14)*
	(B) refusal (oral)	5.6-5.7% (N=86-88)	—	*5.3%* *(N=82)*	*0.3-0.4%* *(N=4-6)*
	(C) unknown preferences (ODR status)	53.5-55.8% (N=825-861)	*33.4%* *(N=516)*	*20.0%* *(N=309)*	*0-2.3%* *(N=0-36)*

*ODR status (488 authorisations over 516 family approaches) or other means (78 authorisations over 79 family approaches)

Wales

Sources:

— [60] Noyes J, McLaughlin L, Morgan K, et al. Short-term impact of introducing a soft opt-out organ donation system in Wales: before and after study. BMJ Open 2019;9:e025159. doi:10.1136/bmjopen-2018-025159

— [6] NHS, Potential Donor Audit (1 April 2017 - 31 March 2018).

During the 15-month period following the implementation of the opt-out (so called “deemed consent”) system, out of 182 deceased adults, 102 had expressed their decision to donate (56%), 34 had expressed their decision to opt-out (18.7%), and 46 had not expressed any preference (25.3%).[1] In all cases, the family was consulted and had the opportunity to either support (123/182) or overrule (13/182) the deceased’s decision[1], and to support (28/182) or oppose (18/182) the recovery of organs when the deceased’s had not expressed any preference (deemed consent).[1] In the UK at large, which includes both opt-in and opt-out systems, circumstances where the family is either untraceable, considered too upset to approach, or divided over the decision were rare (1,6 percent of all eligible donors) between 2017-18.[2] Under those circumstances, organ recovery did not proceed, even in the presence of an explicit consent from the deceased (in opt-in systems) or a deemed consent (in opt-out systems).[2] Wales opt-out default (scenario Cc) was never applied [1].

Table 13

				Family	
N=182 potential donors			**(a) authorises**	**(b) opposes**	**(c) unknown preferences (family not consulted)**
			64% (N=117)	*36% (N=65)*	*0% (N=0)*
Deceased	**(A) consent**	56% (N=102)	*49% (N=89)*	*7% (N=13)*	*0% (N=0)*
	(B) refusal	19% (N=34)	—	*19% (N=34)*	*0% (N=0)*
	(C) unknown preferences	25% (N=46)	*15% (N=28)*	*10% (N=18)*	*0% (N=0)*

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[1] We assume that family opposition only applies to the deceased’s decision.

The United States of America

Source: “National Survey of Organ Donation Attitudes and Practices”, U.S. Department of Health and Human Services, 2019. [Online: https://www.organdonor.gov/sites/default/files/about-dot/files/nsodap-organ-donation-survey-2019.pdf]

The full tables of responses can be found at: https://www.organdonor.gov/sites/default/files/about-dot/files/nsodap-full-response-tables.xlsx

We found some data regarding consent and refusal by the deceased an their family. For instance, data from a study on all eligible death from 2008 to 2013 indicates that, among 52,571 eligible donors, authorisation for donation was based on registration in a donor registry in 7,562 cases (14%), and it was obtained from family or next-of-kin (with or without prior registration in a donor registry) in 30,870 cases (59%) [61]. See also [51,52]. However, we couldn’t find detailed enough actual data from the US to fill the scenarios table.

Instead, we will consider an hypothetical situation based on stated attitudes towards donation, under the assumption that these attitudes reflect actual behaviour, even though we know that this not necessarily the case. For that reason, we do not include the US in Table 3 of the manuscript.

A US national survey of public attitudes on a sample of 10.000 individuals found half (49,9%) of respondents had signed up as donors (N=4,990). Of those who were not signed up as donors (46.2%, N=4,620), half said they wished to donate their organs after death (50.3%, N=2,324), less than half said they wished not to donate (46.7%, N=2,158), and 3% (N=139) didn’t answer. Among those who signed up as donors, 68.9% (N=2,438) discussed their wish with a family member, and 27.2% didn’t discuss it. Among those who wished not to donate, 23.5% (N=507) discussed their wish not to donate with their family while 59.6% didn’t discuss it. We don’t know about family discussions of those who wished to be donors but didn’t sign up. However, to the question “Has any member of your family told you about his or her wish to donate or not to donate his or her organs after death?”, 45,6% answered “yes” and 54,4% answered “no”. Considering that this question includes both willingness and unwillingness to donate, and considering that individuals tend to have more than one family member, we will suppose that among those who wished to donate but didn’t sign up (N=2,324), only 30% (N=697) discussed their wish with their family.

Therefore, regarding the deceased’s preferences:

- Known consent to donate: 5,687
    - Signed up as donors: 4,990
    - Didn’t sign up but discussed it with family: 697
- Known refusal to donate: 507
    - Discussed it with family: 507
- Unknown wishes: 3,806
    - Didn’t answer about their wishes: 139
    - All those who didn’t sign up nor discussed their wishes: 3,667

About willingness to donate family member’s organs: 88,3% would donate a family member’ organs if their wishes to donate were know and 11,7% would not; while 68,8% say they would donate a family member’s organs if their wishes were unknown and 31,2% would not. These responses allow us to fill the table:

- Deceased’s known consent and family authorisation: 88,3% of 5,687 = 5,022
- Deceased’s known consent and family opposition: 11,7% of 5,687 = 665
- Deceased’s known consent and unknown family decision: 5,687-5,022-665=0
    - However, we can’t rule out the possibility that the deceased had no family, that the family could not be contacted on time, or that they didn’t agree between each other.

- Deceased’s unknown wishes and family authorisation: 68,8% of 3,806 = 2,619
- Deceased’s unknown wishes and family opposition: 31,2% of 3,806 = 1,187
- Deceased’s unknown wishes and family unknown wishes: 3,806-2,619-1187=0
- Decesead’s known refusal and family authorisation: although some family members would consider overruling their loved one refusal (11% according to Sellers et al. 2018), this option is currently not allowed by consent systems. For that reason, we will consider it as nil. Anyway, there is no data in this survey about that option.
- Deceased’s known refusal and family opposition: no data available
- Deceased’s known refusal and family unknown wishes: all individual refusal cases = 507

Table 14

			Family		
N=10,000 respondents			**(a)** **authorises**	**(b)** **opposes**	**(c)** **unknown preferences**
Deceased	**(A) consent**	57% (N=5,687)	*50%* *(N=5,022)*	*7%* *(N=665)*	*0*
	(B) refusal	5% (N=507)	—	*n/a*	*5%* *(N=507)*
	(C) unknown preferences	38% (N=3,806)	*26%* *(N=2,619)*	*12%* *(N=1,187)*	*0*

Our result for scenario Ab (7%) is consistent with a survey of all 58 Organ Procurement Organizations (OPO) in the US that estimated that the frequency of family objecting to organ donation in cases of registered donors was <10% [62]. However, following the First Person Authorization policy, most OPOs would ignore the family opposition and proceed to organ donation anyway: “Over the past 5 years, 65% of OPOs have participated in procuring organs even when the next-of-kin and the deceased have differing opinions regarding organ donation [and the remaining 35% of OPOs have not participated in organ procurement from a registered organ donor in the setting of family objection]. Nearly 80% of OPOs reported that this situation occurred one to five times, whereas the remaining 20% reported more than five occasions during that period.” [62]. Therefore, the figure of 7% in scenario Ab may correspond to family oppositions but not to actual outcomes (organs not being procured in that circumstance).

To include the US in figure 1 as an hypothesis, we need to tweak the figures from attitudes to reflect more realistic data about actual outcomes. This is the likelihood of procuring organs in different scenarios according to the OPOs survey [62]:

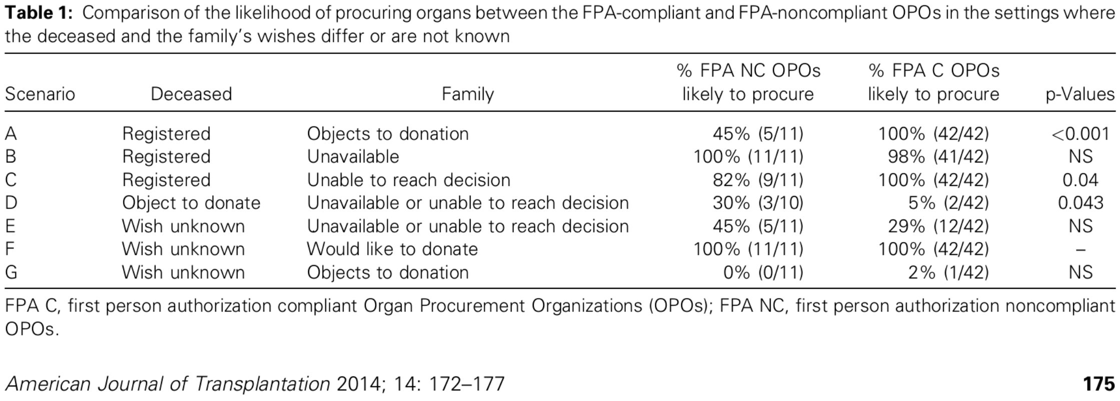

Table 1: Comparison of the likelihood of procuring organs between the FPA-compliant and FPA-noncompliant OPOs in the settings where the deceased and the family's wishes differ or are not known

Scenario	Deceased	Family	% FPA NC OPOs likely to procure	% FPA C OPOs likely to procure	p-Values
A	Registered	Objects to donation	45% (5/11)	100% (42/42)	<0.001
B	Registered	Unavailable	100% (11/11)	98% (41/42)	NS
C	Registered	Unable to reach decision	82% (9/11)	100% (42/42)	0.04
D	Object to donate	Unavailable or unable to reach decision	30% (3/10)	5% (2/42)	0.043
E	Wish unknown	Unavailable or unable to reach decision	45% (5/11)	29% (12/42)	NS
F	Wish unknown	Would like to donate	100% (11/11)	100% (42/42)	–
G	Wish unknown	Objects to donation	0% (0/11)	2% (1/42)	NS

FPA C, first person authorization compliant Organ Procurement Organizations (OPOs); FPA NC, first person authorization noncompliant OPOs.

American Journal of Transplantation 2014; 14: 172–177 **175**

Likelihood of procuring organs in these scenarios is:

A (Ab): 47 OPOs (5+42) out of 53 /(11+42) = 88,6%

B (Ac): 52 out of 53 = 98,1%

C (Ac): 51 out of 53 = 96,2%

D (Bc): 5 out of 52 = 9,6% (sic! This means that OPOs may procure organs despite the deceased's refusal and without an authorization from the family)

E (Cc): 17 out of 53 = 32,1%

F (Ca): 53 out of 53 = 100%

G (Cb): 1 out of 53 = 1,9%

In addition, we will consider that unknown family wishes in scenarios Ac and Cc are 2% (N=200) each. These figures are retracted proportionally from the other scenarios:

Table 15

			Family		
N=10,000 respondents			**(a)** **authorises**	**(b)** **opposes**	**(c)** **unknown preferences**
Deceased	**(A) consent**	57% (N=5,687)	*48%* *(N=4,845)*	*6%* *(N=642)*	*2%* *(N=200)*
	(B) refusal	5% (N=507)	—	*n/a*	*5%* *(N=507)*
	(C) unknown preferences	38% (N=3,806)	*24%* *(N=2,481)*	*11%* *(N=1,125)*	*2%* *(N=200)*

Therefore, the likelihood of procuring organs in the current system (opt-in) and considering the family wishes is:

— When the deceased's consent is known (Aa: 4,845; Ab: 642*88,6%=569; Ac: 200*96,2%=192): 5,606

— When the deceased's refusal is known (Bc: 507*9,6%=49): 49

— When the deceased's wishes are unknown (Ca: 2,481*100%=2,481; Cb: 1,125*1,9%=21; Cc: 200*32,1%=64): 2,566

— Total: 8,221 out of 10,000 = 82%

If in the current system (opt-in) the family wishes were ignored:

— When the deceased's consent is known: 5,687

— When the deceased's refusal is known: 0

— When the deceased's wishes are unknown: 0

— Total: 5,687 out of 10,000 = 57%

If in an opt-out system and the family wishes were considered (as they are now): same as in opt-in but adding the 200 cases of scenario Cc. Total: 8,221+200=8,421 –> 84%

If in an opt-out system and the family wishes were ignored:

— When the deceased's consent is known: 5,687

— When the deceased's refusal is known: 0

— When the deceased's wishes are unknown: 3,806

— Total: 9,493 out of 10,000 = 95%

Table 16: Data used to draw Fig. 1 of the article

	Deceased's wishes alone		Deceased's and family wishes	
Country	Opt-in	Opt-out	Opt-in	Opt-out
Denmark	6	84	35	37
Germany	32	91	74	76
The Netherlands	22	85	35	39
Sweden	35	86	71	72
United Kingdom	40	94	70	74
Wales	56	81	64	64
United States	57	95	82	84

Table 16bis

	Opt-in			Opt-out		
Country	Deceased alone	Deceased + family	Variation	Deceased alone	Deceased + family	Variation
Denmark	6	35	29	84	37	-47
Germany	32	74	42	91	76	-25
The Netherlands	22	35	13	85	39	-46
Sweden	35	71	36	86	72	-14
United Kingdom	40	70	30	94	74	-20
Wales	56	64	8	81	64	-17
United States	57	82	25	95	84	-11

5. References:

1. Rosenblum AM, Li AH-T, Roels L, Stewart B, Prakash V, Beitel J, et al. Worldwide variability in deceased organ donation registries. Transpl Int. 2012;25: 801–811. doi:10.1111/j.1432-2277.2012.01472.x

2. European Commission. Special Eurobarometer 66.2: Health in the European Union. European Commission; 2007. Available: https://ec.europa.eu/health/ph_publication/eb_health_en.pdf

3. European Commission. Special Eurobarometer 333a: Organ donation and transplantation. Brussels; 2010.

4. CBS. Nearly half of Dutch population included in Donor Register. In: Statistics Netherlands [Internet]. 17 Jun 2020 [cited 6 Aug 2020]. Available: https://www.cbs.nl/en-gb/news/2020/25/nearly-half-of-dutch-population-included-in-donor-register

5. Caille-Brillet A-L, Zimmering R, Thaiss HM. Bericht zur Repräsentativstudie 2018 „Wissen, Einstellung und Verhalten der Allgemeinbevölkerung zur Organ- und Gewebespende“. Köln: BZgA-Forschungsbericht; 2019.

6. NHS. Transplant activity report. In: NHS Organ Donation [Internet]. 2019 [cited 6 Aug 2020]. Available: /helping-you-to-decide/about-organ-donation/statistics-about-organ-donation/transplant-activity-report/

7. Service Public Fédéral SP. Don d’organes - Statistiques. In: SPF Santé Publique [Internet]. 2019 [cited 6 Aug 2020]. Available: https://www.health.belgium.be/fr/sante/prenez-soin-de-vous/debut-et-fin-de-vie/don-dorganes/don-dorganes-statistiques

8. Ministero della Salute. Trapianti. In: Trapianti - Sito ufficiale del Centro Nazionale Trapianti [Internet]. 2019 [cited 6 Aug 2020]. Available: http://www.trapianti.salute.gov.it/trapianti/homeCnt.jsp

9. France Info. Greffe : les refus de prélèvement d’organes restent trop nombreux. In: Franceinfo [Internet]. 22 Dec 2017 [cited 6 Aug 2020]. Available: https://www.francetvinfo.fr/sante/soigner/don-d-organes/greffe-les-refus-de-prelevement-d-organes-restent-trop-nombreux_2526989.html

10. Touraine J-L. Mission “flash” relative aux conditions de prélèvement d’organes et du refus de tels prélèvements. Paris: Assemblée Nationale; 2017 Dec. Available: https://www2.assemblee-nationale.fr/static/15/commissions/CAffSoc/Mission_flash_don_organes_communication_rapporteur_20171220.pdf

11. Delgado J, Molina-Pérez A, Shaw D, Rodríguez-Arias D. The Role of the Family in Deceased Organ Procurement. A Guide for Clinicians and Policy Makers. Transplantation. 2019;103: e112–e118. doi:10.1097/TP.0000000000002622

12. Molina-Pérez A, Delgado J, Rodríguez-Arias D. Defining Consent: Autonomy and the Role of the Family. In: Hansen SL, Schicktanz S, editors. Ethical Challenges of Organ Transplantation: Current Debates and International Perspectives. Transcript Verlag; 2021. pp. 43–64.

13. Rosenblum AM, Horvat LD, Siminoff LA, Prakash V, Beitel J, Garg AX. The authority of next-of-kin in explicit and presumed consent systems for deceased organ donation: an analysis of 54 nations. Nephrol Dial Transplant. 2012;27: 2533–2546. doi:10.1093/ndt/gfr619

14. Bilgel F. The impact of presumed consent laws and institutions on deceased organ donation. Eur J Health Econ. 2012;13: 29–38. doi:10.1007/s10198-010-0277-8

15. DSO. Jahresbericht Organspende und Transplantation in Deutschland 2018. Frankfurt/Main: Deutsche Stiftung Organtransplantation; 2019.

16. Cho W-H. Organ donation in Korea in 2018 and an introduction of the Korea national organ donation system. Korean J Transplant. 2019;33: 83. doi:10.4285/jkstn.2019.33.4.83

17. Morla-González M, Moya-Guillem C, Delgado J, Molina-Pérez A. European and comparative law study regarding family's role in deceased organ procurement. Revista General de Derecho Público Comparado. 2021;29.

18. INCUCAI. Procuración y trasplante de órganos, tejidos y células en Argentina. Memoria 2018. 2019.

19. INCUCAI. Procuración y trasplante de órganos, tejidos y células en Argentina. Memoria 2019. 2020.

20. Melville A, Kolt G, Anderson D, Mitropoulos J, Pilcher D. Admission to Intensive Care for Palliative Care or Potential Organ Donation: Demographics, Circumstances, Outcomes, and Resource Use. Critical Care Medicine. 2017;45: e1050–e1059. doi:10.1097/CCM.0000000000002655

21. OBIG-Transplant. Transplant-Jahresbericht 2020. Gesundheit Österreich, Wien; 2021. Available: https://transplant.goeg.at/publikationen

22. SBT. Rapport annuel 2019 - Section belge des coordinateurs de transplantation - SBT. Service Public Fédéral; 2016 Apr.

23. Dell Agnolo CM, de Freitas RA, Toffolo VJO, de Oliveira MLF, de Almeida DF, Carvalho MDB, et al. Causes of Organ Donation Failure in Brazil. Transplantation Proceedings. 2012;44: 2280–2282. doi:10.1016/j.transproceed.2012.07.133

24. Rosário EN do, Pinho LG de, Oselame GB, Neves EB. Recusa familiar diante de um potencial doador de órgãos. Cad saúde colet. 2013;21: 260–266. doi:10.1590/S1414-462X2013000300005

25. Marinho BBO, Santos ATF, Figueredo AS, Cortez LSAB, Viana MCA, Santos GM, et al. Challenges of Organ Donation: Potential Donors for Transplantation in an Area of Brazil's Northeast. Transplantation Proceedings. 2018;50: 698–701. doi:10.1016/j.transproceed.2018.02.055

26. Corporación del Trasplante. Memoria Anual 2008. Corporación del Trasplante, Chile; 2009. Available: https://studylib.es/doc/8240405/memoria-2009---corporaci%C3%B3n-del-trasplante

27. Instituto Nacional de Salud. Informe anual Red de Donación y Trasplantes. Instituto Nacional de Salud, Colombia; Available: https://www.ins.gov.co/Direcciones/RedesSaludPublica/DonacionOrganosYTejidos/Paginas/default.aspx

28. Kämäräinen O-P, Huttunen J, Lindgren A, Lång M, Bendel S, Uusaro A, et al. Identification of potential organ donors after aneurysmal subarachnoid hemorrhage in a population-based neurointensive care in Eastern Finland. Acta Neurochir. 2018;160: 1507–1514. doi:10.1007/s00701-018-3600-2

29. Agence de la biomédecine. Organes - Le prélèvement d'organes en vue de greffe. 2020 [cited 15 Jan 2021]. Available: https://rams.agence-biomedecine.fr/le-prelevement-dorganes-en-vue-de-greffe

30. Le Nobin J, Pruvot F-R, Villers A, Flamand V, Bouye S. Organ donation, reasons for family refusal: A retrospective study in a French organ harvesting center. Progres en Urologie. 2014;24: 282–287. doi:10.1016/j.purol.2013.08.318

31. Hénon F, Le Nobin J, Ouzzane A, Villers A, Strecker G, Bouyé S. Analyse des raisons motivant le refus du don d'organes par les familles de patients en état de mort encéphalique dans un centre régional de prélèvement. Progrès en Urologie. 2016;26: 656–661. doi:10.1016/j.purol.2016.09.050

32. Lee A, Ni MY, Luk ACK, Lau JKP, Lam KSY, Li TK, et al. Trends and Determinants of Familial Consent for Corneal Donation in Chinese: Cornea. 2017;36: 295–299. doi:10.1097/ICO.0000000000001091

33. Cheung C, Pong M, Au Yeung S, Chau K. Factors affecting the deceased organ donation rate in the Chinese community: an audit of hospital medical records in Hong Kong. Hong Kong Med J. 2016 [cited 20 Jun 2021]. doi:10.12809/hkmj164930

34. Palsson TP, Sigvaldason K, Kristjansdottir TE, Thorkelsson T, Blondal AT, Karason S, et al. The potential for organ donation in Iceland: A nationwide study of deaths in intensive care units. Acta Anaesthesiol Scand. 2020;64: 663–669. doi:10.1111/aas.13551

35. Kumar V, Ahlawat R, Gupta AK, Sharma RK, Minz M, Sakhuja V, et al. Potential of organ donation from deceased donors: study from a public sector hospital in India. Transpl Int. 2014;27: 1007–1014. doi:10.1111/tri.12355

36. Dehghani SM, Gholami S, Bahador A, Nikeghbalian S, Eshraghian A, Salahi H, et al. Causes of Organ Donation Refusal in Southern Iran. Transplantation Proceedings. 2011;43: 410–411. doi:10.1016/j.transproceed.2011.01.022

37. Health Service Executive. Audit of Potential Organ Donors, Republic of Ireland. Government of the Republic of Ireland, Health Service Executive; 2009.

38. Hegarty M, O’Neill W, Colreavy F, Dwyer R, Cunningham P, Hanlon M. Potential organ donor audit in Ireland. Ir Med J. 2010;103: 294–296.

39. Du Toit T, Manning K, Thomson D, McCurdie F, Muller E. A 10-year analysis of organ donor referrals to a South African tertiary public sector hospital. S Afr Med J. 2020;110: 132. doi:10.7196/SAMJ.2020.v110i2.14125

40. Yu E, Lee M, Lee E, Chong Y, Jeong Y, Lee J, et al. Causes of Lowered Family Consent Rate for Organ Donation. Transplantation. 2020;104: S275. doi:10.1097/01.tp.0000699876.43588.39

41. Park J, Kim CJ. Recent Decrease in Organ Donation from Brain-Dead Potential Organ Donors in Korea and Possible Causes. J Korean Med Sci. 2020;35: e94. doi:10.3346/jkms.2020.35.e94

42. Escudero D, Valentín MO, Escalante JL, Sanmartín A, Perez-Basterrechea M, de Gea J, et al. Intensive care practices in brain death diagnosis and organ donation. Anaesthesia. 2015;70: 1130–1139. doi:10.1111/anae.13065

43. Viñuela-Prieto JM, Escarpa Falcón MC, Candel FJ, Mateos Rodríguez A, Torres González JI, del Río Gallegos F. Family Refusal to Consent Donation: Retrospective Quantitative Analysis of Its Increasing Tendency and the Associated Factors Over the Last Decade at a Spanish Hospital. Transplantation Proceedings. 2021 [cited 1 Sep 2021]. doi:10.1016/j.transproceed.2021.07.026

44. Organización Nacional de Trasplantes. Programa de Garantía de Calidad del Proceso de Donación. Memoria de Resultados de la Autoevalución. Año 2018. Available: http://www.ont.es/infesp/DocumentosCalidad/Memoria%20PGC_2018%203.pdf

45. Sverige Socialstyrelsen. Organ- och vävnadsdonation i Sverige 2020. 2021.

46. Weiss J, Keel I, Immer FF, Wiegand J, Haberthür C. Swiss Monitoring of Potential Organ Donors (SwissPOD): a prospective 12-month cohort study of all adult ICU deaths in Switzerland. Swiss medical weekly. 2014;144: w14045. doi:10.1111/j.1432-2277.2010.01174.x

47. Weiss J, Coslovsky M, Keel I, Immer FF, Jüni P. Organ Donation in Switzerland - An Analysis of Factors Associated with Consent Rate. PLoS One. 2014;9. doi:10.1371/journal.pone.0106845

48. Immer FF, Comité National du Don d'Organes. Variation in Organ Donation Rates in Switzerland: Prospective Cohort Study of Potential Donors (SwissPOD). Swisstransplant; 2014.

49. Aydin K, Ergan B, Tokur M, Çalişkan T, Gürsoy G, Savran Y, et al. Current Status of Organ Donation in a University Hospital in İzmir: Identifying Obstacles and Possible Future Solutions. Turkish Journal of Intensive Care. 2019;17. doi:10.4274/tybd.galenos.2018.54366

50. Leblebici M. Prevalence and Potential Correlates of Family Refusal to Organ Donation for Brain-Dead Declared Patients: A 12-Year Retrospective Screening Study. Transplantation Proceedings. 2020; S004113452032683X. doi:10.1016/j.transproceed.2020.08.015

51. Brown CVR, Foulkrod KH, Dworaczyk S, Thompson K, Elliot E, Cooper H, et al. Barriers to Obtaining Family Consent for Potential Organ Donors. Journal of Trauma and Acute Care Surgery. 2010;68: 447–451. doi:10.1097/TA.0b013e3181caab8f

52. Sheehy E, Conrad SL, Brigham LE, Luskin R, Weber P, Eakin M, et al. Estimating the Number of Potential Organ Donors in the United States. N Engl J Med. 2003;349: 667–674. doi:10.1056/NEJMsa021271

53. Siminoff L, Mercer MB, Graham G, Burant C. The Reasons Families Donate Organs for Transplantation: Implications for Policy and Practice: The Journal of Trauma: Injury, Infection, and Critical Care. 2007;62: 969–978. doi:10.1097/01.ta.0000205220.24003.51

54. Thybo KH, Eskesen V. The most important reason for lack of organ donation is family refusal. Dan Med J. 2013;60: A4585.

55. Sørensen P, Kousgaard SJ. Barriers toward organ donation in a Danish University Hospital. Acta Anaesthesiol Scand. 2017;61: 322–327. doi:10.1111/aas.12853

56. National Klinisk Kvalitetsdatabase. Årsrapport Organdonations-databasen 2020. Dansk Center for Organdonation; 2021.

57. Nederlandse Transplantatie Stichting. Jaarverslagen. In: Nederlandse Transplantatie Stichting [Internet]. 2019 [cited 21 Mar 2019]. Available: https://www.transplantatiestichting.nl/bestel-en-download/jaarverslagen

58. Nolin T, Mårdh C, Karlström G, Walther SM. Identifying opportunities to increase organ donation after brain death. An observational study in Sweden 2009–2014. Acta Anaesthesiologica Scandinavica. 2017;61: 73–82. doi:https://doi.org/10.1111/aas.12831

59. NHS. Potential Donor Audit Report. NHS Blood and Transplant; 2019. Available: https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/16878/annual-pda-report-2018-19.pdf

60. Noyes J, McLaughlin L, Morgan K, Walton P, Curtis R, Madden S, et al. Short-term impact of introducing a soft opt-out organ donation system in Wales: before and after study. BMJ Open. 2019;9: e025159. doi:10.1136/bmjopen-2018-025159

61. Goldberg DS, French B, Abt PL, Gilroy RK. Increasing the Number of Organ Transplants in the United States by Optimizing Donor Authorization Rates. American Journal of Transplantation. 2015;15: 2117–2125. doi:10.1111/ajt.13362

62. Chon WJ, Josephson MA, Gordon EJ, Becker YT, Witkowski P, Arwindekar DJ, et al. When the Living and the Deceased Cannot Agree on Organ Donation: A Survey of US Organ Procurement Organizations (OPOs). American Journal of Transplantation. 2014;14: 172–177. doi:10.1111/ajt.12519