

# Informed Consent Versus Presumed Consent The Role of the Family in Organ Donations

Philippe Février\* and Sebastien Gay<sup>†‡</sup>

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## Abstract

Two types of legislation underlie cadaveric organ donations: presumed consent (PC) and informed consent (IC). In informed consent countries, people are only donors when deceased if they registered to do so while alive. Conversely, in presumed consent countries, anybody is a potential donor when deceased. People have thus to register if they do not want to donate their body. PC has always been perceived as the “best” system for society in terms of organ donations whereas IC is supposed to be more ethical. However, in both systems, the family has a say, especially for the deceased who did not sign anything while alive. Taking the family decision into account, we show that the previous results may be reversed. The difference between both systems resides in the way an individual can commit to his/her will, eventually against the opinion of his/her family. IC can dominate PC in terms of organ donations whereas PC can be a more ethical system. In the general case, two opposite effects are at stake and the result depends on the extent to which people stay in the default situation. We discuss several causes of inactions (death taboo, procrastination, anticipated regret,...) and their impact on both the individual and the family.

**Keywords:** Informed Consent, Presumed Consent, Organ Donation, Procrastination.

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\*Department of Economics, University of Chicago, 1126 E. 59th Street, Chicago, IL 60637, USA., Email: fevrier@ensae.fr.

<sup>†</sup>Department of Economics, University of Chicago, 1126 E. 59th Street, Chicago, IL 60637, USA., Email: sgay@uchicago.edu.

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# 1 Introduction

The increasing gap between supply and demand for organ donations has raised doubt about a quick solution to the shortage of organs. Cadaveric donations have been increasing slightly over the years and the importance of the legislation has been seen as the main reason why some countries have higher rates of donation (Abadie and Gay (2004); Gimbel and al. (2003)). There are two main types of legislation: presumed consent and informed consent. In informed consent countries, also known as opt-in countries, people are only donors when deceased if they registered to do so while alive. Conversely, in presumed consent countries, also called opt-out countries, anybody is potentially a donor. People have to register if they do not want to donate their body.

In the last few years the debate on organ donations has focused on legislation.<sup>1</sup> Spital (1996) and Mustarah (1998) have pointed out that switching to a presumed consent law would increase the rate of organ donations, due to the higher observed rate of donation in presumed consent countries (see figure 1<sup>2</sup>). The idea behind this result is that the presumed consent system benefits from the organs of donors that did not declare any preference for donation while living. Johnson and Goldstein (2003) suggest that a switch to a presumed consent legislation in the United States would increase donations by some additional thousands of donors per year.<sup>3</sup> However, the fact that someone does not register not to donate his/her body does not mean that he/she agrees to be a donor. The society may thus take the organs of someone “against” his/her will in the presumed consent system. Because of this ethical and moral problem, the informed consent legislation may be seen as better (Kennedy and Grubb (2000), National Health and Medical Research Council (1997)).

These two points of view have been clearly expressed by the British Parliament when studying in January 2004 “The Organ Donation (Presumed Consent and Safeguards) Bill” proposed by Parliamentarian Siobhain Mc-

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<sup>1</sup>Another debate concerns the use of monetary incentives to increase the supply of organs (Cohen, 1989; Becker, 1997; Becker and Elias, 2003).

<sup>2</sup>The informed consent curve was derived from the donation rates of the following seven countries: Australia, Denmark, England, Germany, The Netherlands, USA and Switzerland. The presumed consent curve was derived from the donation rates of the following seven countries: Austria, Belgium, France, Italy, Poland, Portugal and Spain.

<sup>3</sup>The default legislation is known in economics to play an important role (see Thaler (2004) for an application to savings).

Donagh. This bill was intended to switch from the actual IC system to the PC system. On one hand, Dr. Michael Wilks, Chairman of the British Medical Association's Ethics Committee argues in favor of the presumed consent system to increase the number of organ donations: "We must increase the number of donors available and we believe that a system of presumed consent with safeguards, will do this." On the other hand, Health Minister Rosie Winterton ruled out the Bill because of ethical problems of the presumed consent system and said that "full consent must be obtained to use human organs and tissue."

Actually because full consent of the deceased is sometimes difficult to achieve, his/her family has a say in the decision of organ donations in both systems. Doctors systematically ask the family before removing organs from the deceased (May et al. (2000)). In case of refusal, the organs will not be taken. Under the British Human Tissue Bill, voted in January 2004 after the debate on the presumed consent system, doctors would no longer be legally able to keep organs from dead patients without the full consent of their families.

When debating the impact of the legislation, previous studies (Johnson and Goldstein (2003), Mustarah (1998), Spital (1996)) never take into account the role of the family. The aim of this paper is on the contrary to understand the impact of the family decision on cadaveric organ donations. Taking the opinion of the family into account, we find that, surprisingly, the informed consent system may be preferable to the presumed consent one in terms of organ donations. On the contrary, the informed consent system may be less preferable when looking at the respect of the deceased's will. The idea behind this result is that both systems are equivalent when the deceased does not take any decision while alive. In both systems, the final decision is the family's. The difference resides in the way an individual can commit his/her will, eventually against the opinion of his/her family. In informed consent countries, he/she can register to donate his/her organs. He/she can thus take a binding commitment with respect to donation. On the contrary, in presumed consent countries, he/she can only register not to donate his/her organs. He/she can only take a binding commitment in favor of non donation. This commitment effect pleads in favor of the informed consent system as far as the number of organ donations is concerned. This commitment effect also explains why presumed consent countries create donor cards when the family is involved in the decision process. It allows individuals to commit to give their organs, which is positive for both ethics and organ donations.

However the default legislation may play a key role, as the family decision is also intrinsically influenced by the default. In that case, two opposite effects play against each other. The dominant effect hinges on the reason why people do not to take any stance on organ donations. Several causes of inactions can explain why the individual stays in the default situation. On one hand, doctors stress the importance of death taboo: people do not want to think about their death and what will or would happen to their body when deceased. On the other hand, the economic literature has shown the importance of procrastination, anticipated regret and loss aversion that can partially explain why an individual does not take any decision regarding organ donations. The family, contrary to the individual, has to decide once and for all in a short amount of time and cannot postpone such a decision. Ignorance, procrastination and death taboo thus appear to be less relevant for the family. However, the family has a difficult decision to take and faces anticipated regret. It is thus possible that the family is influenced by the default situation and procrastinates in the sense that they do not want to take such an unpleasant decision.

The paper is organized as follows: section 2 develops a model for presumed consent (PC) and informed consent (IC) without the family and section 3 develops a model that takes into account the influence of the family. The issues of death taboo and procrastination are addressed in section 4. Section 5 concludes.

## 2 IC and PC without the family

Let first consider a model of organ donations without taking into account the decision of the family. We will suppose that an individual has a utility  $u_d$  if he/she donates his/her organs and a utility  $u_k$  if he/she decides to keep his/her organs. We note  $v = u_d - u_k$  the difference between these utilities. If  $v > 0$ , he/she wants to donate his/her organs, whereas if  $v < 0$  he/she wants to keep them.

Figure 2 describes the two models. In the IC case, he/she keeps by default his/her organs but can take the decision to donate them. Let  $c$  be the cost of donating his/her organs. Similarly, in the PC case, he/she donates by default his/her organs, but can take the decision to keep them by paying a cost  $c$ .

In most countries, obtaining registration to donate or not organs is as simple as sending a letter, an email or make a free phone call. As a consequence, the cost  $c$  in the model is not a standard cost. It reflects the

tendency to procrastination that people may have (Akerlof (1991), Madrian and Shea (2001), Thaler and Benartzi (2004)). It may also represent the cost doctors usually refer to. It is the moral cost individuals have to face when thinking about their death and what will happen to their body (National Health and Medical Research Council (1997)).

**Proposition 1.** *There are more organ donations in PC systems than in IC systems.*

**Proof:** In the PC case, the individual will take the decision to keep his/her organs if and only if  $v < -c$ . In the IC system, the individual will take the decision to give his/her organs iff  $c < v$ . Consequently, if  $c < v$ , he/she donates his/her organs under both rules. If  $-c < v < c$ , he/she donates his/her organs under the PC rule but keeps them in the IC case. If  $v < -c$ , he/she keeps his/her organs under both rules. The PC system thus dominates the IC one.  $\square$

Proposition 1 shows that in order to maximize the number of organs, society wants to adopt the PC system. The difference between the two systems comes from the fraction of people who would stay in the default system whatever the rule is. In a PC system, these individuals give their organs whereas they will keep them under the IC system.

It is also interesting to note that these people are the ones who do not have a clear preference about the issue of organ donations. If giving his/her organs is important for an individual, it is more likely that  $v$  would be greater than the cost and this individual will register in an IC system to give his/her organs.

The number of organs is not however the only criterium to evaluate both systems. For ethical and moral reasons, society may also want to choose a system that respects the “will” of individuals. Most religions think that organ donation is morally acceptable only if the donor has given his/her explicit consent.

**Proposition 2.** *None of the two systems respects the will of the people who do not register.*

**Proof:** In the PC case, if  $-c < v < 0$ , the individual gives his/her organs whereas he/she would like not to. In the IC case, if  $0 < v < c$ , the individual does not give his/her organs whereas he/she would like to.  $\square$

Proposition 2 shows that it is difficult to choose a system that respects the will of people when not expressed! Under PC rules, society may take

the organs of some people against their “will”. Under IC rules, society may not take the organs of some individuals that would like to give them.

The results of the two propositions above are the ones on which the debate between PC and IC hinges. A recent example of such a debate occurred in January 2004 when the British Parliament studied “The Organ Donation (Presumed Consent and Safeguards) Bill”. The advocates of the PC system argue that it increases the number of organ donations, which is beneficial to society because of the shortage of organs. The proponents of the IC system use ethical reasons for arguing that it is unacceptable to take the organs of a person if he/she does not explicitly agree.<sup>4</sup>

### 3 IC and PC with the family

Under the PC system (respectively the IC system) we cannot distinguish an individual that has not thought about organ donations when alive or has procrastinated ( $-c < v < c$ ) and whose will is unknown, from an individual that really want to (resp. not to) donate his/her organs ( $c < v$  (resp.  $v < -c$ )). For that matter, in almost all countries, doctors ask for the family decision before taking someone’s organs. Doctors always follow the will of the family, even if in PC countries, they could legally take the organs (May et al. (2000)). It is thus necessary, when comparing both systems, to include the decision of the family.

We will suppose that the family has a utility  $u_d^f$  if they donate the organs of the deceased and a utility  $u_k^f$  if not. We will denote by  $v^f = u_d^f - u_k^f$  the difference and we suppose that  $v$  and  $v^f$  are common knowledge. We finally suppose in this part that there is no cost to the family to take its decision.

Figure 3 represents the game with the family. In both models, if the individual decides to register, the family has no choice but to respect his/her decision. If, on the contrary, the individual stays in the “default” situation, the family takes the final decision.<sup>5</sup>

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<sup>4</sup>They however “forget” to mention that the IC system does not either respect the “will” of some people that would like to donate their organs.

<sup>5</sup>This model is conformed for example to the decision process in the Netherlands (IC) and in Belgium (PC). In most countries however, in both systems, the family can decide not to respect the will of the deceased, even if he/she registered when alive. This event is however rare. One can extend the model to let the family decide even when the deceased had registered. If the family has a huge cost to change the decision of the deceased when expressed, the conclusions will be very similar to the simpler model presented here.

**Proposition 3.** *If the family has the same preferences as the individual, both systems are equivalent.*

*If the family can have different preferences, there are more organ donations in the IC system than in the PC system.*

**Proof:** If  $v^f = v$ , the equilibrium in both systems is the same. The individual stays in the “default” situation and the family takes the good decision in the end.

If preferences can be different, the analysis changes. In a PC system, the individual registers if and only if  $v < -c$  and  $v^f > 0$  i.e. iff he/she does not really want to give his/her organs but the family wants to. In a IC system, the individual registers if and only if  $v > c$  and  $v^f < 0$  i.e. iff he/she really wants to give his/her organs but the family does not want to. As a consequence both systems are equivalent in all the situations except if  $(v < -c, v^f > 0)$  and  $(v > c, v^f < 0)$  where the individual will donate his/her organs in the IC system but not in the PC system.  $\square$

The first result is quite intuitive. If the family and the individual always agree, individuals do not register and let the family take the good decision when deceased.

This is however not what we observe as people do register in both systems<sup>6</sup>. Many reasons can explain that the value of the family differs from the value of the individual. The family can have their own preferences and choose their decision by taking into account both their preferences and the preferences of the individual. Doctors also complain about people not speaking enough about this issue when alive and that the family has no idea of the stance of the individual on organ donations (Rocheleau (2001)). In that case, one can suppose that the family takes their decision using their own valuation. The difference between the individual will and the family’s opinion is a real concern. Recently, the British Parliament passed a Bill on that subject and UK Transplant chief executive Sue Sutherland said: “The Human Tissue Bill reinforces the importance of consent for donation but makes it explicit that it is the wishes of the individual that should prevail. Many people have found it difficult to accept that relatives can overturn those wishes and this Bill deals with those concerns”.

When taking into account the family decision, we surprisingly find the opposite of the usual claim. The IC system leads to more organ donations

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<sup>6</sup>In 2003 for example, about 37% of the Dutch population have made a registration to donate their organs (The Netherlands is an IC country.).

than the PC system, because the argument of the model without the family does not apply anymore. When an individual does not want to think about his/her death or procrastinates ( $-c < v < c$ ), he/she lets his/her family decide for him/her. Both systems are thus equivalent for these agents. However, the fact that the family can take the decision for the individual, even when he/she has clear preferences concerning organ donations ( $v < -c$  or  $v > c$ ), has a perverse effect when the family and the individual disagree. Registering is a protection against the family and has a value of commitment. In the IC system, the individual can register and commit to give his/her organs. In the PC system, on the contrary, the individual can only register to commit to keep his/her organs. This commitment effect explains why the IC system potentially leads to more organ donations.

Interestingly, most of the countries seem aware of this commitment problem and offer the possibility to register as a donor in the PC system. Kluge (1997), for example, asserts that the shortage of organ donations would decrease if the donor card is used as a proof of donation to bypass some families reluctant to donating. This donor card only exists to try to protect the individual against his/her family.<sup>7</sup>

**Corollary 1.** *Introducing a donor card in the PC system helps an individual to give his/her organs when the family does not agree.*

*There are still more donations in the IC system than in the PC system with donor cards.*

One can argue that both systems are quite equivalent because an individual can commit him/herself by writing a note saying that he/she does or does not want to give his/her organs. Nonetheless this note will presumably be in the possession of the family and this supposes that the family would respect the will of the deceased. It is more difficult to credibly commit with a note than by going through an official process. To restore the equivalence between the two systems, one would like to allow an individual to have a non-donor card in the IC system. Generally this is not the case.

The commitment problem faced by the agents when the family has a say leads to another surprising result when looking at ethical and moral reasons.

**Proposition 4.** *If the family has the same preferences as the individual, both systems respect the will of all agents.*

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<sup>7</sup>Austria has a very strict PC system where the decision of the family is never taken into account. In this country, no donor card exists.



*If the family can have different preferences, none of the two systems respects entirely the will of the people. The PC system with donor cards is however more conform to the will of the individuals than the IC system.*

**Proof:** If the family and the individuals have the same preferences, it is clear that both systems respect the will of the deceased.

Suppose now that the family can have different preferences. When  $-c < v < c$ , the individual does not register and lets the family decide for him/her. If the family does not have the same preferences, his/her will may not be respected in both systems.

If  $v < -c$  and  $v^f > 0$ , the individual does not want to give his/her organs but the family does. In the PC system, he/she can register to keep his/her organs, whereas in the IC system, he/she can not commit not to give his/her organs. In that sense, the PC system is better than the IC system.

Finally, if  $v > c$  and  $v^f < 0$ , the individual wants to give his/her organs but the family does not. In the IC system, he/she can register to give his/her organs, whereas in the PC system, he/she can not commit to give his/her organs. This is not true with a donor card.

In conclusion, both the PC and the IC system do not respect the will of individuals, but the PC system with a donor card is better than the IC system.  $\square$

This result is surprising for several reasons.

First, introducing the family seems worse in terms of ethical and moral reasons than not asking for their decision as soon as some disagreements exist between the family and the deceased. The will of individuals, who have clear preferences towards organ donations, is not respected anymore because of the commitment problem they face when disagreeing with their families.

Second, the proponents of the IC system are usually deeply concerned with taking the organs of someone against his/her will. Our result proves that, actually, this event will happen more frequently in an IC system than in a PC system and will strictly affect people who would have taken a binding decision not to donate their organ donations if they had this opportunity. Here, however, the family, and not society, is responsible for not implementing the choice of the deceased. People usually consider that this is not as ethically and morally unacceptable as when society decides.

Third, introducing a donor card is very important on ethical and moral grounds as it allows to respect the will of the deceased. May et al. (2000) argue that, even if the family does not consent to donation, respecting the

documented wishes of a deceased to donate is not only morally permissible, but morally required. Chouchau and Draper (2003) also argue about the superiority of the PC system with a donor card when it comes to the respect of the will of people.

When ethical and moral reasons are debated, it seems that politicians, doctors, and religious people, all agree that the right thing to do is to respect the will of the deceased. However, this may be questionable. A standard hypothesis in economics is that the utility of dead people is zero. As a consequence, the only utility that should matter is the family's. In such a case, none of the legislations is ethically and morally perfect. The "best" system would be a system in which the individual has no say and in which the family has all the power to take a decision regarding organ donations. It is hard enough that a family member passed away. Perhaps, the family should not have also to bear on top of that the fact that they must respect the will of the deceased if his/her decision is painful for them. In a sense, most countries maximize the utility of the living by giving them the final decision. Still, to reach that goal, the commitment effect that exists in both system should be eliminated.

## 4 Procrastination and death taboo

The previous models (with and without family) are two extreme cases of a more general model where the family is also affected by the default situation. If the family bears a cost  $c_f$  of not staying in the default situation, the model without family (section 2) corresponds to  $c_f = +\infty$  whereas the model with family (section 3) corresponds to  $c_f = 0$ . In the general case, the effects derived in the extreme cases are both at stake. Two opposite forces are actually conflicting and each one could potentially be dominant. Figure 4 represents the equilibrium in the general case. Both systems are equivalent except in three regions. In the middle region, taking a decision is too costly for both the individual and the family. The choice directly comes from the default situation. In such a case, the PC system dominates the IC system. In the two other regions, the individual and the family want to make a decision, but disagree. The commitment effect is central here and the IC system dominates the PC system. The total effect is ambiguous and depends on the values  $v$  and  $v^f$  and on the costs  $c$  and  $c^f$ . The choice of an "optimal" system in a given country should thus depend on the behavior of people regarding their death or the death of a relative.

Let first consider the situation of an individual. The blind acceptance of the default by agents, also called status quo, has been pointed out to be central even when strong reasons for change exist. Loss aversion, anticipated regret and ignorance (Kahneman and Tversky (1979); Kahneman, Knetsch and Thaler (1991); Laibson (1998); Samuelson and Zeckhauser (1988)) are among the explanations that causes inaction. Related to this point is the issue of procrastination. Strictly speaking, procrastination is to keep delaying something that must be done, often because it is unpleasant. Procrastination has been studied in economics in order to better understand inadequate savings or organizational failures (Akerlof 1991). In our model, the lack of registrations can be interpreted as procrastination, hence creating an important cost to the individual to register. Recent papers have emphasized the importance of procrastination in a default system: Choi et al. (2003) and Thaler and Benartzi (2004) show that default options have a remarkable impact on household 'choices' in term of savings, for opting out of a default is costly and people's tendency to procrastinate. Madrian and Shea (2001) also study the effect of the default system on savings. They found that 86% of the employees hired after the implementation of an automatic participation rule stay in the default savings plan designed by the company. On the opposite, only half of the employees hired before the automatic enrollment take part in the plan. In the organ donation process, procrastination can be modelled by an important cost for the individual who wants to delay his decision.

The other explanation expressed by doctors to understand why people do not register is death taboo (National Health and Medical Research Council (1997)). Unfortunately, it is difficult to have an objective measure of death taboo. A good proxy can be the willingness of people to let the family know or not about their post mortem decisions. In Quebec<sup>8</sup> for instance, only 50% of the population writes a testament. In 4 cases out of 5 this testament is registered by a notary. Moreover these testaments usually deal with the succession but very few people let specific instructions regarding their funeral. These figures underline the importance of death taboo. People do not like to think about their death and to what will happen to their body once deceased. This argument also emphasizes that the cost for the individual may be important.<sup>9</sup>

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<sup>8</sup>These figures were given to us by the Chambre des Notaires du Quebec.

<sup>9</sup>This cost may vary by individual. The richer, the older and the more educated an individual is, the more likely s/he is to write a testament and therefore to think ahead about their death.

The family, contrary to the individual, has no choice but to think about the situation and take a decision quickly after the death of their relative. They have to decide once and for all in a short amount of time and cannot postpone this decision. Ignorance, procrastination and death taboo thus appear to be less relevant for the family which is expected to have a smaller cost  $c^f$  than the cost  $c$  to the individual. Nevertheless, this cost may not be zero. The family has a difficult decision to take and faces anticipated regret. It is thus possible that the family procrastinates in the sense that they do not want to take such an unpleasant decision. Moreover, in PC countries, by refusing to donate the organs, the family “kills” someone who should have lived under the strict application of the law. Such a decision, under the pressure of medical doctors, may be hard to take. In IC countries, on the contrary, members of the family have the law on their side when deciding not to give organs. If such effects are at stake, the cost for the family may not be negligible.

Given the expected structure of the costs (high cost for the individual and smaller cost for the family), one crucial element is the distribution of the preferences  $(v, v^f)$ . If the individual and the family have well correlated preferences, the PC system may be a better one. As already mentioned, this is not necessarily the case. Because of the death taboo, the family often has no idea of the will of the deceased. This absence of communication on organ donations can lead to more disagreements between the choice of both the individual and the family. For these reasons, when death taboo is an important issue, it gives some arguments for a country towards choosing the IC system. Furthermore, the family is known to be much more reluctant than the deceased to tackling the issue of organ donations.<sup>10</sup> It is thus possible that in a PC country, an important number of people would like to give their organs but cannot commit themselves against their family,<sup>11</sup> which leads to the conclusion that the IC system could be better in terms of organ donations.

Our results show that the comparison between both systems is more complicated than usually thought and give an argument in favor of the IC system in terms of organ donations. It would be interesting to have data by

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<sup>10</sup>Verzijden and Schothorst (2003) for example state that 86% of the Dutch population would donate their organs. However, for the 63% of them that did not register, the family refuses in 80% of the cases to give the deceased’s organs.

<sup>11</sup>In theory, we have seen that this problem could be solved by a donor card. Countries however do not have a registry for people who ask for a donor card. Having a donor card is less binding for the family than registering to give his/her organs.

country to estimate precisely what the different effects are in each country.<sup>12</sup> This will require to have data on the decision of both the individual and the family that countries have just begun to collect.

## 5 Conclusion

The introduction of the family in the process of decision for organ donation can reverse the intuitive comparison between presumed consent and informed consent legislations. Registering to be a donor in informed consent countries is a credible commitment against his/her family in favor of donation, whereas registering in a presumed consent country is a commitment not to donate. This commitment effect can lead to the superiority of the IC system in terms of organ donations. Another consequence of that effect is the introduction of donor cards in PC countries to prevent families from refusing donation if the deceased was willing to donate his/her body. When looking at ethical and moral reasons, our results show the superiority of a PC system with a donor card to respect people's will.

The default situation may still play an important role and, in general, two opposite effects are in the balance. The result depends on the extent to which people stay in the default situation. We discussed several causes of inactions (death taboo, procrastination, anticipated regret...) and their impact on both the individual and the family.

Ronald Davis, Editor of the British Medical Journal, writes in his editorial in 1999, "Both the American and the British medical associations are looking at ways of increasing organ donation, including presumed consent. While the ethics of presumed consent continue to be debated, policymakers can and should move forward with mandated choice, which has the potential to narrow, if not eliminate, the gap between organ supply and demand." (Davis (1999)). Our results show that the arguments on which the debate between PC and IC systems are based may not be as accurate as expected when the family decision is taken into account.

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<sup>12</sup>Empirical studies that estimate the effect of the legislation on organ donations (Abadie and Gay (2004), Gimbel and al. (2003)) use cross countries data. They usually find that PC countries have higher rates of donation than IC countries.

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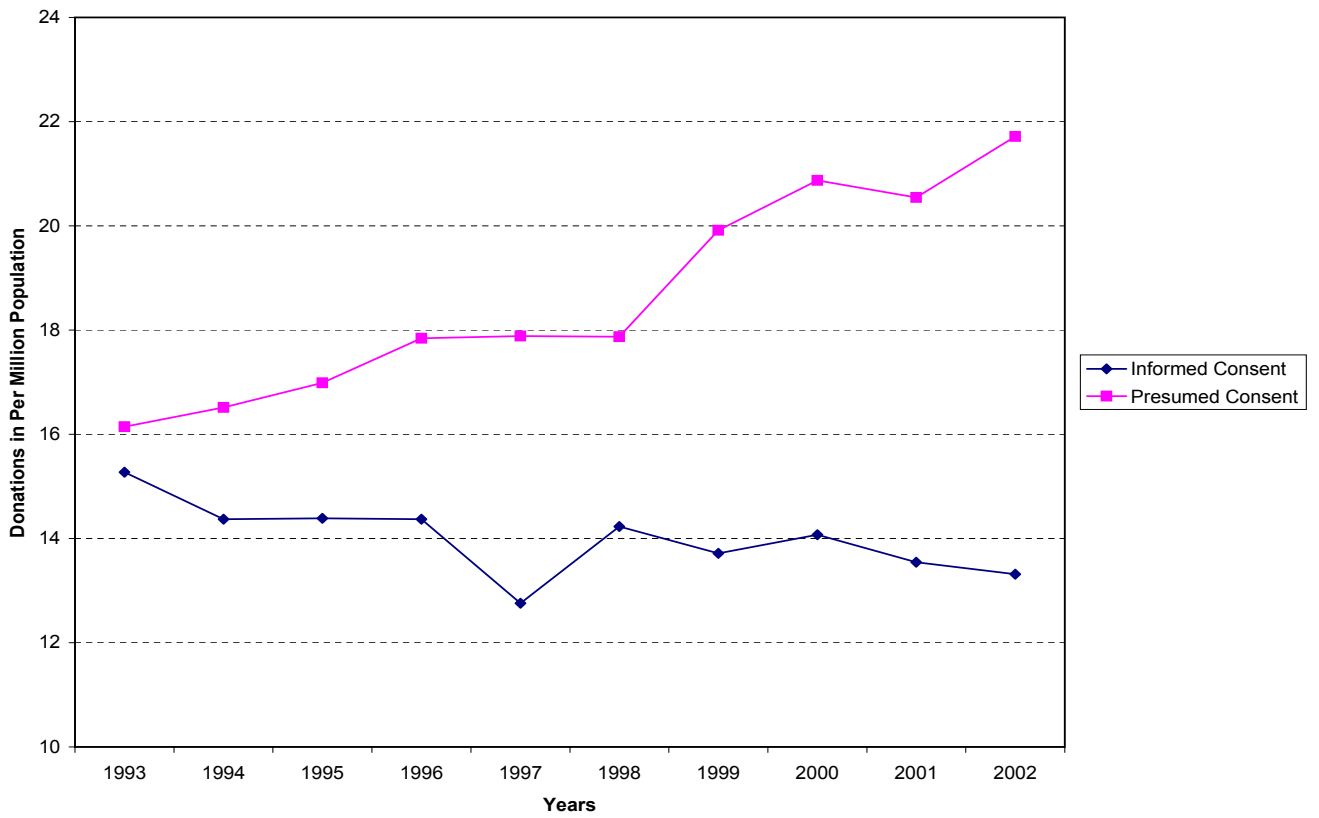


Figure 1: Average Organ Donations By Type of Legislations Over the Years 1993-2002



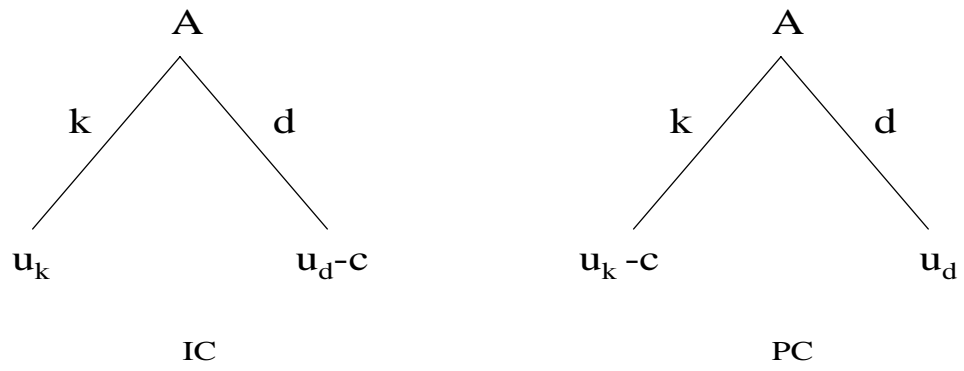


Figure 2: Informed Consent and Presumed Consent without the family's decision

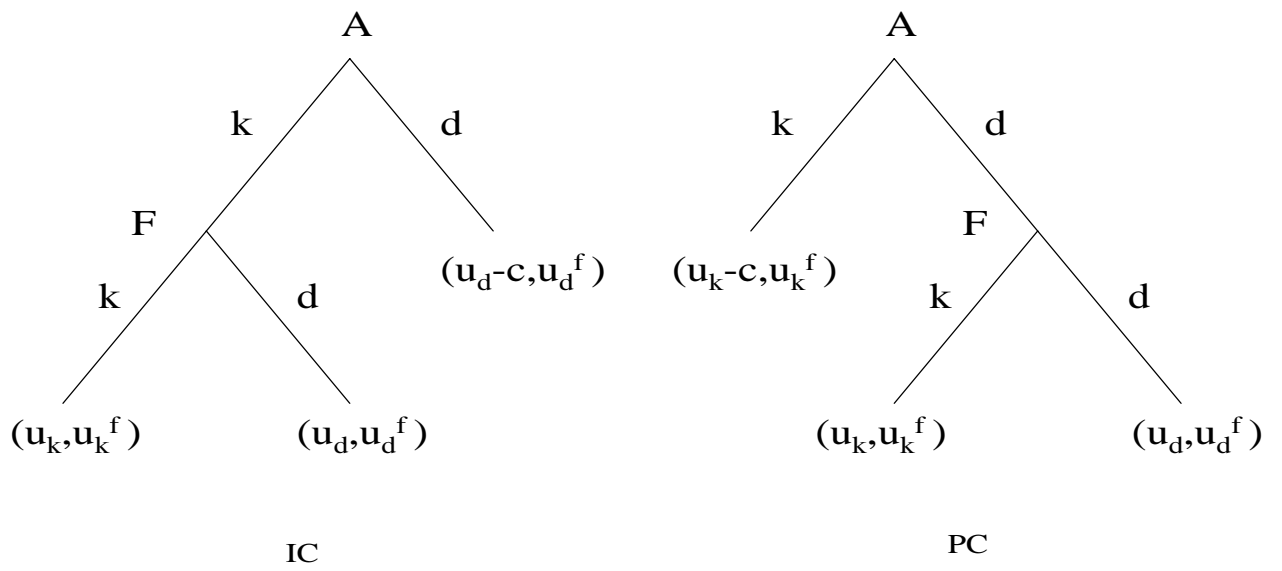


Figure 3: Informed Consent and Presumed Consent with the family's decision

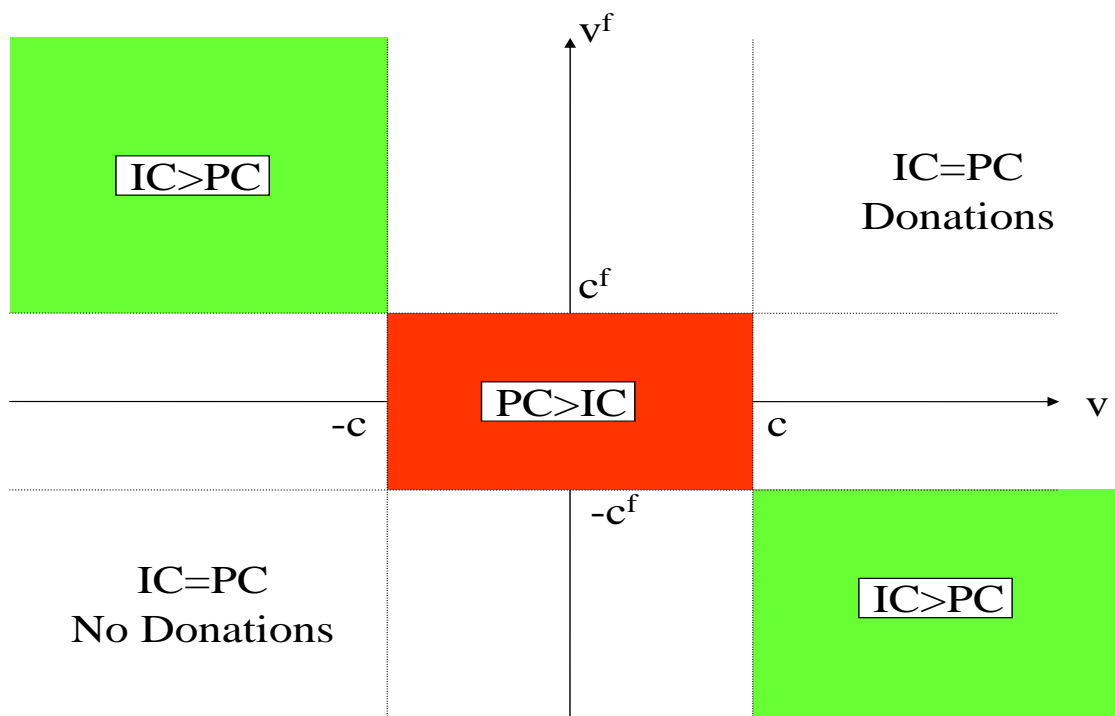


Figure 4: Comparison of both systems in the general case with family