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Beyond the ticked box: organ donation decision-making under different registration systems

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ABSTRACT

Objective: To explore how people experience organ donation decision-making under the conditions of an opt-in, opt-out or noobjection registration system.

Design: A between-subjects experimental 3 × 2 design (registration system x preselection). Participants (N = 1312) were presented with a description of one of the three registration systems and went through a mock donor registration process. In half of the conditions, the default option of the system was visualized by a ticked box. After, participants answered questions about their perceived autonomy and perceived effective decision-making.

Main outcome measurements: Perceived autonomy, perceived decision effectiveness and registration choice.

Results: The preselected box did not impact any of the outcomes. Participants had higher perceived autonomy under the conditions of an opt-in system. There were no differences in effective decision-making across conditions. Registration choices did differ across conditions and educational levels. In the opt-in system, participants more often made an active decision. Lowereducated participants were more likely to choose to do nothing, while higher-educated people more often made an active decision, especially in the no-objection system.

Conclusion: Where the opt-out system potentially leads to the highest number of donors, the opt-in system seems better in terms of preserving people's autonomy and motivating people to make an active decision.

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KEYWORDS

Defaults; autonomy; effective decision-making; no-objection system; registration choices

Introduction

The universal shortage of organs that are available for transplantation remains a public health challenge. While the majority of people are willing to donate their organs when they die, or at least have a positive attitude towards donation, many of them fail to take the necessary steps to actually register a decision (Feeley, 2007; Figueroa et al., 2013). The

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implementation of an opt-out donor registration system is a commonly suggested strategy to tackle this issue. A default option is used in such a system, meaning that people automatically become an organ donor unless they register otherwise. Countries with an opt-out system, as opposed to an opt-in system in which people have to give explicit consent for organ donation, usually have higher donation rates (Johnson & Goldstein, 2003). This partly has to do with the fact that people often choose the preset option when being presented with a default. There are numerous other examples where default options influence people's decision-making in that way, such as living will completion (Kressel et al., 2007), healthcare flexible spending accounts (Schweitzer et al., 1996), using generics in a pharmacist setting (Blumenthal-Barby & Burroughs, 2012), and HIV screening in health care (Hanssens, 2007).

Presenting people with a default is basically a change in the choice environment to stimulate a certain choice; also called a nudge. Nudges can be important to bridge the intention behavior gap between what people want to do and what they actually do (Sheeran, 2002). People generally prefer to stick to the status quo in terms of behavior, rather than doing something different or involving in an effortful choice (Voyer, 2015). People tend to go with the flow because it is simply the most convenient option requiring the least or even no efforts (e.g., cognitively, practically). For instance, when registering a different decision regarding organ donation than the default, this usually involves the decision-making itself, but also completing a registration form and sending it. Finally, not choosing the default option could lead to people being uncomfortable with their decision, because defaults imply that there is a norm with regard to this default.

Potential issues when using organ donation defaults

Defaults can make people choose the desired behavior, which could result in more registered organ donors. However, the choice itself cannot be regarded as the only outcome, because, especially in the context of healthcare, decisions are often value-laden and can therefore not be right or wrong (O'Connor, 1995). People could be hesitant to opt out for many reasons, including the fear to being regarded as ungenerous, selfish, and uncaring (Jacob, 2006). While nudges might steer the majority of the people towards a behavior that aligns with their intentions, they sometimes lead to people making choices that are inconsistent with their actual preferences (Bovens, 2009). Nudges that benefit the society at large, might therefore be at the expense of some. So, while defaults can be useful, they are also criticized as they make it more difficult to ensure that everyone makes a decision that reflects their wishes. This does not make nudges unjustifiable, but it is important to know what and how large this expense exactly is.

Next, people could be faced with high barriers in case they want to opt-out. Nudges are defined as being easily avoidable, but that is often not the case (Barton & Grüne-Yanoff, 2015). There are several steps in opting-out, that might not seem too difficult, but could be problematic for many people. First, they have to be aware of the policy and, second, they should have the knowledge and capabilities to opt-out (Blumenthal-Barby & Burroughs, 2012). This is especially an issue when it comes to

people with vulnerabilities (e.g., lower educational levels or low literacy). It is known that people with lower levels of education less often look for information about organ donation on the Internet, talk less about organ donation with others and are less acquainted with media coverage on this topic (Cox, 2005). These people might therefore struggle even more with understanding what they have to do and understanding what making a choice (or not making one) actually means.

Autonomy

Autonomy is another commonly raised issue when it comes to using defaults (in organ donation). Advocates of an opt-out system usually argue that people's autonomy is not violated in such system. The rationale being that in defaults, options generally do not change and therefore the freedom of choice should not change. However, previous studies suggest otherwise and show that nudges can in fact undermine people's autonomy (Arvanitis et al., 2019). This is an ethical concern and it could also influence the success of an opt-out system in terms of donors, as frustration about the unmet need for autonomy could even lead to reactance (e.g., registering as non-donor as a form of protest) (Van Petegem et al., 2015). The first aim of this study, therefore, is to explore what organ donation defaults do to people's feeling of autonomy satisfaction and frustration about unmet needs. We hypothesize that even though the freedom of choice does not change, people perceive a lower feeling of autonomy when presented with an opt-out system and have higher levels of frustration about unmet needs.

Effective decision-making

In the end, it is questionable to what extent people are able to make an effective decision when presented with a default. According to O'Connor, effective decisionmaking is defined as the extent to which a person agrees that their decision was informed, consistent with personal values, acted upon and to which extent that person is satisfied with that decision (O'Connor, 1995). Difficulties in decision-making are found more often when people feel uninformed about options, feel pressured to select a certain option, or when they are not ready or skilled for decision-making (O'Connor et al., 2003).

While these feelings apply to decision-making (about organ donation) in general, these could be even more relevant and affected when there is an opt-out default. This could partly be due to the fact that people tend to reject a default when it regards a decision with a high degree of moral sensitivity (Sunstein, 2016). People generally feel that active choosing is better when the outcome of a default could be morally troubling (to them). The effectiveness of decision-making could therefore be lower in an opt-out system compared to an opt-in system, which would be an undesirable side effect. However, this could as well be the other way around, as the default option in an opt-in system (meaning you will not be registered, which in turn often means that your organs will not be transplanted) could also be morally troubling, as patients could die. The second aim of this study, therefore, is to gain insight into the

effectiveness of decision-making under different defaults. It is expected that people's decision-making is less effective when being presented with an opt-out system.

A third – more explorative – aim concerns the possible association between satisfaction and frustration of the need for autonomy and effective decision-making. As the basic psychological needs of the Self-Determination Theory (of which autonomy is one) facilitate the natural tendency of people to internalize values and regulations of their social groups (Deci & Ryan, 2000), satisfaction of these needs could possibly increase effective decision-making. As very little is known about satisfied needs and decision-making in general, this will be done in a more explorative fashion. We would expect that a lower autonomy satisfaction and higher levels of frustration about unmet needs, is associated with lower levels of effective decision-making regarding organ donation.

New Dutch organ donation law

Differences between opt-in and opt-out systems regarding organ donation have been studied before. In the Netherlands, where the current study is carried out, a new kind of system will be introduced in July 2020; the so-called no-objection system. Within the no-objection system, every unregistered citizen in the Netherlands will receive a letter asking them to make a decision about organ donation. They could choose to become an organ donor, to become a non-donor or to leave the decision to next of kin (same options as the current opt-in system). When they fail to respond, they receive a reminder six weeks later. When still no decision is made, they will automatically be registered in the donor registry with a no-objection registration.

In case someone with this no-objection registration dies, the medical professional will tell the family that this person has not registered an objection against organ donation (which is different from being registered as a donor) and will then ask them for consent to transplant the organs. The family members always have the final say in this. This is not very different from the current opt-in policy, in which family members are also asked for consent when no donor record in available.

While the new no-objection system is seen as a form of a (soft) opt-out system, it has many similarities to an opt-in system as well (e.g., family members are asked for consent when no active decision was made). In other words, it is a compromise between an opt-in and an opt-out system. By implementing this system, policy makers hope to increase the donor rates, while preserving people's freedom of choice. Little is known about the decisions that people might make under the conditions of this system and if these are different from a hard opt-out system and the currently used opt-in system. A fourth aim is therefore to explore what choices people make under these different systems.

As the no-objection system is a new system, we can also predict what the effects of this will be on how people make a decision about organ donation. After years of political discussion, the general public is also not unanimously positive about the law change. Within one day after the acceptance of this new law in the Dutch parliament in 2018, 30,000 people decided to register as a non-donor and over 6,000 people changed their current registration into a hard 'no' (NOS, 2018). This could be due to

many people rejecting the idea of something being presumed in general, especially when it comes to such a sensitive topic. So, while policy makers see the no-objection system as a compromise, this might not be the perception of Dutch citizens. Next to comparing a traditional opt-in and opt-out system in terms of feelings of autonomy satisfaction and frustration and effective decision-making, it would therefore be interesting to also compare these systems to the new Dutch system as well. It is said that people's autonomy will be preserved in this new system, but it is unknown how this holds up against a traditional opt-in or opt-out system. Is this really an optimum balance between the opt-in and opt-out system? Or does it lead to more frustration and confusion in the end?

Finally, it is important to realize that in the context of organ donation, defaults are implied without actually being visible to the public. When they fill out a registration form, whether this is on paper or online, there is not an actual ticked box present. There are examples of studies about organ donation defaults, in which a ticked box is used to represent the default (Moseley & Stoker, 2015). The impact of the physical presence of this ticked box compared to only explaining what the default option is, is unknown. Therefore, different systems will be included in this study both with and without a preselected box. In other words, with and without visualizing the default within that system.

Materials and methods

A between-subjects experimental design, in which participants were presented with a description of either an opt-in system, an opt-out system or a no-objection system, with either the default option visually being ticked or not. So, in total there were six conditions, varying in two factors (3 \times 2; system x preselection). The study was preregistered on Open Science Framework (OSF) (https://osf.io/mngxc) on February 17, 2020.

Participants

A representative sample of the Dutch population above the age of 18 was recruited to participate in the study. The sample included people from different regions, sexes, age categories and educational levels. They were recruited through the Flycatcher panel. Flycatcher is a consumer panel, which started in 2000 as a spin-off of Maastricht University. This panel complies with strict quality requirements for research and submits itself to audits by an independent auditing committee. These requirements were laid down in the ISO 20252 standard for market research and opinion polls and ISO 26362 for research panels. As information and data constitute the core of their business, they have also obtained ISO 27001 certification, the internationally recognized standard for information security. Flycatcher makes use of a reward system, in which participants receive points when filling out a questionnaire, which they can later use to get a voucher or donate the money to charity. As the questionnaire is short, they will receive a small number of points.

A sample size calculation was done using G*Power 3.1 (Faul et al., 2009). A total of 1290 participants was required, based on a small effect size (Cohen's f: 0.1), a power of .8 and an alpha of .05. As participants were randomly assigned to one of six conditions, each condition should consist of approximately 215 participants.

Ethics approval

This study was approved by the ethics committee of the Faculty of Health, Medicine and Life Sciences on February 14, 2020 (reference number: FHML-REC/2020/013).

Procedure

People voluntarily register as panel members and sign a generic informed consent when they register. They get invited to participate in research over e-mail on a regular basis. They get an e-mail when new questionnaires are available for them. They always have the choice whether they would like to participate or not. The participants in the current study also received an email. They were randomly assigned to a condition when they agreed to participate. When the total number of participants was achieved, the questionnaire was closed and could not be completed anymore by panel members.

Participants were first asked to read a short, neutral description of one of the three registration systems. A timer prohibited participants to continue to the questions for 15 seconds, to give them time to read the text. Participants were then asked to make a decision about their organs under this system (I do nothing/I actively register as a donor/I actively register as a non-donor). This was a hypothetical decision, not an actual registration – a so-called vignette study. The default option in every system was 'not making a decision', however, with different consequences depending on the system. In three conditions, the box of the default option was already ticked to visualize the default explicitly (see Figure 1). Participants always had the freedom to make any choice they wanted. After, they answered questions related to their feelings of ASF and EDM. Demographic information was obtained from their accounts, which they are asked to update yearly.

Data collection took place in the first week of March 2020, four months before the actual implementation of the law change in the Netherlands. During this week a reminder was sent to participants who did not respond yet. We received the data with regard to the measured variables specified below as well as demographic information of the people who participated. The data we received is non-traceable. The data file and syntax can be found on https://osf.io/kt76z/. These efforts are taken to maximize scrutiny, foster accurate replication, and facilitate future data syntheses (e.g., meta-analyses) (Peters et al., 2012).

Measurements

The online questionnaire assessed people's registration decision, autonomy satisfaction and frustration (ASF) and effective decision-making (EDM). The questionnaire was pilot tested (n = 22) among employees of Maastricht University after which slight changes

No-objection system with default option preselected	No-objection system without default option preselected
What would be your choice when a 'no-objection' system would be used?	What would be your choice when a 'no-objection' system would be used?
You only make this choice for this questionnaire; it will not be recorded as an actual registration!	You only make this choice for this questionnaire; it will not be recorded as an actual registration!
 ✓ I do nothing and will be recorded in the donor register with a 'no-objection' registration ☐ I actively register as a donor ☐ I actively register as a non-donor 	☐ I do nothing and will be recorded in the donor register with a 'no-objection' registration☐ I actively register as a donor☐ I actively register as a non-donor
Please tick the box of your choice	Please tick the box of your choice

Figure 1. Example of the no-objection system with and without the preselected default option.

were made in the formulation of the introduction text and questions. Demographic information was obtained from participants' accounts, which is updated yearly.

Demographics

Sex (male/female), age (in categories), and level of education (low/medium/high) were included as demographic variables.

Registration decision

Hypothetical decision based on the registration system they were randomly assigned to (I do nothing/I actively register as a donor/I actively register as a non-donor). So, regardless of the registration system, people always had the option to actively register a 'yes' or 'no' next to the default option of that system.

ASF

ASF are part of the Basic Psychological Need Satisfaction and Frustration Scale (BPNSNF). This scale includes not only the degree to which needs are satisfied, but also the degree of need frustration. The latter is included as the absence of needs does not necessarily imply frustration. The most applicable BPNSNF scale for this particular study was the vignette/situation version, as the participants were being presented with one of three organ donation registration systems. The Dutch version of this scale was used. The short version of this scale was chosen for this study, which consists of 4 questions instead of 8 (two on autonomy satisfaction and two on frustration) (Van Petegem et al., 2017). The autonomy frustration items were reversed, after which a mean score of ASF was computed (ω =.83).

EDM

EDM is one of the three subscales of the Decisional Conflict Scale (DCS) (O'Connor, 1995). EDM concerns questions related to the feeling that the choice is informed, values-based, likely to be implemented and expressing satisfaction with the choice. This subscale includes 4 statements to be answered on a 5-point-likert scale. These statements were translated to Dutch. A mean score of EDM was computed (ω =.91).

Statistical analyses

Data were analyzed using SPSS version 25. Descriptive analyses were done for all variables. As skipping questions was not allowed in the online questionnaire, there were no missing values. Two-way analyses of variance (ANOVA) were performed, to test for the main effects of registration system (opt-in versus opt-out versus no-objection) and preselection (yes versus no), and their interaction, on ASF and EDM. Both the interaction and the main effect of preselection were not statistically significant (p-value > .05) for both ASF and EDM (see Results for more details). Post hoc Tukey HSD tests were used to specify between which registration systems the differences occurred. In order to identify whether an association exists between ASF and EDM, a bivariate analysis (i.e. correlation coefficient) was used. Additional analyses were done to gain insight in the choices people made under the different registration systems, to be able to make a prediction of the effects of the Dutch law change in terms of registration behavior. Descriptive analyses were used to explore these differences. Next, these descriptive statistics were stratified by educational level, to gain insight in differences in the choices people make with different educational levels, as differences in (understanding) registration systems could result in different choices.

Results

The sample in this study included 1312 participants, randomized over 6 conditions (ranging from 216 to 222 participants per condition). Fifty percent was male, and the

Table 1. Descriptive information study sample.

Total sample	N = 1312
Sex (male)	50.0%
Age	49.8 ± 17.2
18-24	9.0%
25-29	8.0%
30-34	7.5%
35-39	7.4%
40-44	7.2%
45-49	8.2%
50-54	9.0%
55-59	9.8%
60-64	9.5%
65+	24.5%
Level of education	
Low	26.5%
Medium	42.9%
High	30.6%

 $\label{eq:decomposition} \mbox{Data presented as mean} \pm \mbox{standard deviation for continuous variables and percentages for categorical variables}.$

Table 2. Mean scores on ASF and EDM per condition.

	- to T	Opt-in	ci.	Opt-out	tuo tao	No-objection	acito do N	Preselection x registration system	ion x system	Preselection	uc	Registration system	ion
	l Ola	(bleset)		(besaid)	Options	(besset)	NO-ODJECTION	Partial η^2	Ф	Partial η^2 p		Partial η^2	۵
z	1312	216	217	219	222	217	221						
ASF	3.60 ± 1.00	3.84 ± 0.85	3.81 ± 0.88	3.35 ± 1.09	3.54 ± 1.03	3.54 ± 1.07	3.50 ± 1.00	.003	.15	000.	.45	0.027	<.001
EDM	4.18 ± 0.82	4.17 ± 0.89	4.14 ± 0.82	4.22 ± 0.85	4.16 ± 0.84	4.24 ± 0.75	4.17 ± 0.79	000	.95	.001	.19	.001	99:

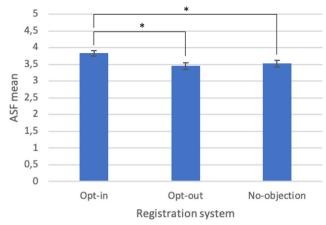


Figure 2. Mean (with 95% CI) ASF for different registration systems. Two-way ANOVA, asterisks indicate significant differences between registration systems

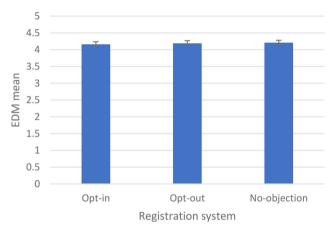


Figure 3. Mean (with 95% CI) EDM for different registration systems. Two-way ANOVA

mean age was 49.8 (SD = 17.2). A representative distribution was found in terms of educational level. See *Table 1 for detailed information*.

Table 2 shows the mean scores on ASF and EDM per condition. No significant interactions were found between registration system and preselection for ASF (F=1.90, p=.15). Also, the effect of preselection was not significant (F=0.57, p=.45), indicating that the presence of a ticked box does not affect people's ASF. The two-way ANOVA did reveal significant differences in ASF for different registration systems (F=18.11, p<.001). A Tukey HSD test showed that an opt-in system is associated with a higher ASF score compared to an opt-out system or a no-objection system (p<.001) but the opt-out system and no-objection system did not differ significantly (p=.52) (Figure 2).

For EDM, the interaction between registration system and preselection was also not significant (F = 0.06, p=.95). There were also no significant differences in EDM for the different registration systems (F = 0.42, p=.66) or preselection (F = 1.70, p=.19) (Figure

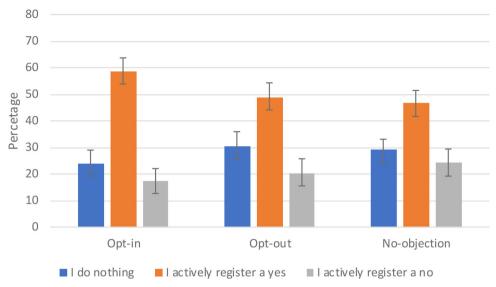


Figure 4. Percentage (with 95% CI) of registration choices under different registration systems.

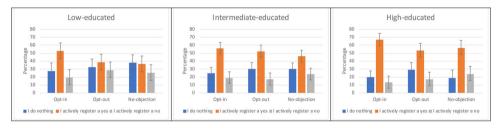


Figure 5. Differences in percentage (with 95% CI) of registration choices under different registration systems between different educational levels.

3). This suggests that different registration systems and the presence of the ticked box both do not influence people's EDM.

A medium-sized correlation was found between ASF and EDM (r=.34; 95%CI = [0.29-0.39]).

When looking at the registration choices people would make under the different registration systems, the potential effect of the enforcement of the no-objection law in the Netherlands becomes visible. Figure 4 shows the descriptive statistics of the choices that were made (including confidence intervals). It appears that people make very similar choices when being presented with an opt-out and a no-objection system (Table S1). Compared to the opt-in system, which is currently used in the Netherlands, the new no-objection system could potentially lead to less active registrations (70.8% versus 76.0%) and active yeses (46.6% versus 58.7%). The proportion of people choosing to actively register a 'no' is highest in the no-objection system (24.2% versus 20.4% in opt-out and 17.3% in opt-in).¹

Another interesting observation concerns the high percentage of participants who choose to actively register a yes or no under the conditions of the current opt-in system (76%). This is much higher than the actual registration rate in the Netherlands (42%) (Centraal Bureau voor de Statistiek, 2019), showing the intention-behavior gap between registration intentions/willingness and actual registration behavior.

Stratifying these percentages by level of education reveals clear differences between these subgroups in terms of the decisions that are made (Table S2, Figure 5). Regardless of the registration systems they were presented with, these groups make different registration choices. Low-educated people (Figure 5; left) in general choose more often for a passive registration (doing nothing) (33.0% versus 28.4% in intermediate-educated and 22.9% in high-educated). People with a high educational level (Figure 5; right) more often choose to actively register a decision (yes or no) compared to lower educational levels (77.1% versus 71.6% in intermediate-educated and 66.9% in low-educated). The pattern for intermediate-educated people (Figure 5; middle) is quite comparable to the higher-educated group, but they less often choose an active ves (42.2% in intermediate-educated versus 59.1% in high-educated).

When looking more closely at the different registration systems, the largest differences between groups are found in the no-objection system. The majority of the loweducated group (Figure 5; left) chooses for a passive registration (doing nothing) (38.1% versus 36.4% active yeses and 25.4% active noes), while in the high-educated group this choice is made least often (19.2% versus 56.8% active yeses and 24.0% active noes). The intermediate-educated group (Figure 5; middle) is in between the low and high-educated group (30.3% chooses to do nothing).

Discussion

The current study aimed to gain insight in how different organ donation registration systems are related to ASF and EDM, whether ASF and EDM are correlated and what choices people make in the end. Further, half of the conditions included a preselected box to research the implicit or explicit presence of a default. Next to a traditional optin and opt-out system, the new Dutch no-objection system was included in this study. ASF was found to be higher when people were presented with an opt-in system compared to the other registration systems. The difference was small but significant. In terms of EDM, no significant differences were found. ASF and EDM showed to have a medium-sized correlation.

First of all, the preselected box did not impact any of the outcomes, so the three registration systems were compared regardless the preselection. In a real-life organ donation default, the ticked box will usually not be visible, but the default is always there. As organ donation registration is moving from paper-based registration to digital registration, this opens up possibilities for adding a visible default in the form of a ticked box in the registration procedure. In that respect, it was interesting to find out that the visible ticked box was not significantly associated with both ASF and EDM, suggesting that people do not have different decision-making experiences with an implicit default compared to a visible default.

Many articles discuss the ethical considerations around organ donation systems, of which autonomy is an important one (Bester & Gross, 2016; Gill, 2004; MacKay & Robinson, 2016; Taylor, 2006). There is still a debate whether defaults undermine autonomy or not and whether that is important or not. Few studies researched whether people actually perceive different levels of autonomy under different organ donation systems. The current study showed that the perceived autonomy is in fact higher in an opt-in system, compared to the other systems. However, differences are small. During the debates around the new Dutch registration system, preserving people's autonomy appeared to be an important reason not to implement a hard opt-out system. The current study shows that people do not perceive different levels of autonomy when being presented with a hard opt-out system or the no-objection system, which was supposed to preserve people's autonomy better.

In terms of EDM, no differences were found between the different registration systems, which was not in line with our expectations. The validation of the DCS showed that the perceived EDM is associated with being clear about personal values and feeling informed about options, risks and benefits (O'Connor, 1995). The absence of an association between the systems and EDM could be explained by the fact that participants did not receive much information and all information was very similar for all systems. Further, the EDM subscale of the DCS is different than the other subscales at it can only be used after a decision has been made, while the others can also be used during the deliberation (O'Connor, 1995). In the current study, participants had to determine their EDM right after making their decision. In order for EDM to change, people might need more information and more time to process that, to consider the options and to clarify their values.

A medium-sized correlation was found between ASF and EDM. Previous research already showed that people who experienced decisional conflict, reported lower levels of autonomy (and relatedness and competence, i.e. the other basic psychological needs from the Self-Determination Theory) compared to people who did not (Ritchie et al., 2016). This is in line with the correlation that was found in the current study. This suggests that a better satisfaction of the basic psychological needs is associated with less decisional conflict, and thus higher EDM. In that respect, one would have expected significant differences in EDM for the different registration systems in this study, as the levels of autonomy also differed for the different registration systems. However, as the association between ASF and EDM is only of moderate strength and the differences in ASF were also small, these might not have been detected. It is however difficult to draw conclusions on this, as the current study only included one subscale of decisional conflict and one of the basic psychological needs. More research will be needed to understand these associations better.

The choices that people made under the systems were very similar for people presented with an opt-out and no-objection system. In the opt-in system, people more often chose to actively register in general and also chose more often to register an active 'yes'. The no-objection system showed the most active 'no' registrations. While the differences in ASF and EDM were (very) small for the different systems, there were larger differences in registration behavior. The differences between the no-objection and opt-out system were small, but the opt-in system seems to lead to different registration behavior. Where the opt-in system yields the most active yeses, the no-objection system leads to more active noes. This could partly be caused by reactance due to autonomy frustration (Van Petegem et al., 2015). However, the differences in ASF between the different systems are too small to draw conclusions on that.

A previous study suggested that a presumed consent system (opt-out) system and mandated choice system were most effective in increasing the number of registered donors, compared to an explicit consent system (opt-in) (Van Dalen & Henkens, 2014). When strictly looking at potential donors, the opt-out system also seems most effective in the current study, as about 80% chose to do nothing (and thus become a donor) or register an active yes under the conditions of this system. With about 76%, the no-objection system is not far behind, but doing nothing (and thus having a no-objection registration) does not necessarily lead to an extra potential donor. In an opt-out system, a passive registration is in principle the same as an active yes, and thus means an extra potential donor. However, in a no-objection system, family members are still consulted, and their wishes are decisive. The impact of these registrations on the number of transplantations is therefore still difficult to predict.

An important question for the Dutch context, is what these results mean for the new donor law. This study suggests that there is a possibility that the proportion of active registrations will decrease and the proportion of noes will increase. It is important that people are aware of the law change and understand that actively registering is important. Especially the registration behavior in the low-educated group suggests that this group does not fully understand this. This is in line with a recent report about the evaluation of the organ donation campaign around the new donor law in vulnerable groups (Rolink et al., 2019). This report showed that the current campaign does not provide this group with enough support and that more proactive activities are needed to reach this group better. The current study emphasized the need for better strategies for these groups.

Limitations

Participants made hypothetical choices in this study about their registration behavior and were asked to imagine what that would do to their autonomy and then report on how effective that decision felt for them. In the comments section at the end of the measurements, some participants also mentioned that it was difficult for them to answer the questions, as they already registered in real-life. One should realize that hypothetical choices do not equal their actual registration behavior or their experiences. After the implementation of the no-objection system, further research is recommended to learn more about people's experiences in a real-life setting. Further, this could answer questions relating to changes in people's decision-making behavior over a longer period of time.

The main difference between the results of study and the real-life situation is the amount of effort that is required from people to register an active decision. In this study, participants were presented with information, had to read that information and had to make a decision right after (as part of this study to which they already agreed to participate). This is different compared to the real-life situation, where people receive a letter from the government and can decide for themselves whether they want to open it, whether they want to read it and whether they want to act on the information. In the end, choosing to actively make a decision and to register this requires some effort. One could even say that this study shows the potential of a mandated choice system, as people did not have the opportunity to skip the question.

Showing intentions in a study and performing the actual behavior in real life are two different things (Webb & Sheeran, 2006). There is quite a large intention-behavior gap in organ donation registration behavior (Schütt, 2002). This is also clearly visible when comparing the reported behavior of the opt-in system in this study with the current registration rates (42% actively registered in real-life, versus 76% in this study) (Centraal Bureau voor de Statistiek, 2019). After the implementation of the no-objection system, it is likely that a similar gap is found in terms of active registrations. The possible effects of the no-objection system on people's registration behavior might therefore be more extreme than the results of this study showed (i.e. even fewer active registrations). This further demonstrates the urgency for educational initiatives around the implementation of the law and also in the future to increase these numbers.

Finally, the generalizability of the results of this study to other countries is difficult. Every country has different legal, religious and cultural contexts and beliefs about organ donation (Guy & Aldridge, 2001), which all call for a different approach in terms of legislation. The results of this study might not immediately apply to other countries, but we can still learn from each other. It is important to share experiences and adapt strategies to the context in each country. Research findings like this can help in understanding when systems are successful and could help in choosing the best fit for each country.

Conclusion

Could the no-objection system be regarded as the perfect compromise between the opt-in and opt-out system? This study suggests that it could not. For many outcomes, the no-objection system performs similar to the opt-out system (in terms of ASF, EDM and choices that are made). As family members still play an important role in this noobjection system, the impact of these registrations on the number of transplantations is very difficult to predict.

Which system is best, is difficult to conclude and depends on what is considered 'best.' Where the opt-out system potentially leads to the highest number of donors, the opt-in system seems better in terms of preserving people's autonomy and motivating people to make an active decision. This will continue to be a difficult balance and the context of a country will contribute to the success of a system. It is important to realize that the implementation of any registration system alone will not be enough. Flanking policies are key to support this registration system and contribute to the success. They help to create an environment that is not only effective, but also has the support from the society and is executable in real-life. These policies could include educational initiatives for the public, financing structures, organizational changes in the transplantation process or training for medical professionals.

Declaration of interest statement

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Note

1. Based on a reviewer suggestion we ran a post-hoc analysis to assess the relationship between making an active choice and ASF and EDM. There was no difference in ASF between those who made an active choice versus those that did not (M1 vs M2, t = x, p = x), but those that made an active choice scored higher on EDM (M1 vs M2, t = x, p = x).

Disclosure statement

The authors declare that they have no competing interests.

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Data availability statement

The datasets and materials generated and analyzed during the current study are available in the Open Science Framework repository, https://osf.io/mnqxc.

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