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Does default organ donation registration compromise autonomous choice?

Public responses to a new donor registration system

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Abstract

Objective: Defaults have been shown to substantially increase the number of organ donor registrations. However, it is unclear whether defaults violate personal autonomy of the people being registered. The implementation of a new Donor Act in the Netherlands, providing people with the opportunity for active registration before being defaulted, allowed for examining to what extent default registration affects personal autonomy and associated concepts.

Methods: In an online survey among a representative sample ($N = 1259$), four groups were compared regarding autonomy, decision making competence, decision satisfaction, and being pressured to register as a donor: people (1) who had registered their status prior to the Donor Act, (2) who had not yet received an invitation for default registration, (3) who had received an invitation and then registered their choice, and (4) who had received an invitation but took no action and were defaulted into being registered as a donor.

Results: We find that groups did not differ on measures of autonomy, decision making competence or decision satisfaction, except for people who had received an invitation but took no action and reported significantly lower levels of autonomy, decision making competence, and decision satisfaction as compared to the other three groups. Participants who received a letter of invitation reported to experience more pressure than participants who had already registered themselves prior to the introduction of the new Donor Act.

Conclusion: We conclude that default organ registration does not compromise autonomy except for a minority of people who pass the opportunity to register themselves.

Key words: organ donation, default effect, autonomy, nudging, field experiment

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In 2019, 67 people in the Netherlands died waiting for a kidney transplant, and another 112 got off the waiting list for a kidney as their condition got too bad to still receive a transplant (Dutch Kidney Foundation, 2019). In comparison to other European countries, the Netherlands has a low number of organ donors (Ploeg, Berger, Abdo, & Reinders, 2017). About two decades ago, Johnson and Goldstein brought attention to the big gap in donor registration percentages between countries, which could not be explained by factors like religion, education levels and other differences between populations (Johnson & Goldstein, 2003). Rather, whether or not countries employed defaults with people having to actively opt out instead of opt in to promote registration as a donor played a major part in explaining the difference between countries.

Defaults are part of a group of behavior change techniques called ‘nudges’. Nudges were introduced by Thaler and Sunstein (2008) as an umbrella term for strategies that speak to people’s non-reflective decisions to promote desirable choices. Nudges have been defined as ‘any aspect of the choice architecture that alters people’s behavior in a predictable way, without forbidding any options or significantly changing their economic incentives’ (Thaler & Sunstein, 2008, p.6). Default nudges specifically are expected to affect behavior through various mechanisms that relate to non-reflective decision making, including inertia (Madrian & Shea, 2001), loss aversion (Baron & Ritov, 1994), status quo bias (Suri, Sheppes, Schwartz, & Gross, 2013), and suggesting a norm or recommendation (McKenzie, Liersch, & Finkelstein, 2006).

Defaults have been frequently used and found to be effective across various domains of public policy that involve personal choices, including the uptake of green energy arrangements (Liebe, Gewinner, & Diekmann, 2021) and donating to charities (Goswami & Urminsky, 2016). It is therefore not surprising that Johnson and Goldstein found that in countries where an opt-out donor registration arrangement is in place, more citizens are registered as donors than in countries where citizens have to take action themselves to be registered as a donor (an opt-in arrangement) (Johnson & Goldstein, 2003). The Netherlands, with its low number people registered as potential organ donors, unsurprisingly, employed the less effective opt-in format.

Acknowledging the problematic low number of organ donor registrations and the potential effectiveness of an opt-out format as opposed to the opt-in format to increase donor registrations, the Netherlands introduced the new Donor Act in 2020, changing donor registration into to an opt-out system (New Donor Act, 2021). While this change was expected to be highly effective in increasing the number of registered donors, it was, however, not uncontroversial (NOS, 2018). In particular, concerns were voiced regarding the ethical aspects of the government manipulating such a highly personal and impactful choice. It was also suggested that the new opt-out format could negatively impact individuals' experience of autonomy (we will use the term 'autonomy' to refer to the personal experience of autonomy) (Pennings, 2002). These ethical concerns, and concerns regarding autonomy specifically, are not unique for the case of organ donation or for the Netherlands but are central in heated debate in the broader literature on nudging as well as a frequent barrier to implementation of nudges in practice (Vugts, Van den Hoven, De Vet, & Verwij, 2020; De Ridder, Kroese, & Van Gestel, 2021).

Opponents of nudges argue that nudges may have a negative effect on autonomy because they take advantage of automatic thinking and thus circumvent deliberate decision

making (Hansen, & Jespersen, 2013). Nudges also have been criticized because their presence and influence is often undetected or underestimated by the decision maker (Bovens, 2009; Schmidt & Engelen, 2020). However, these claims are mostly based on abstract ethical notions about decision making. A strong empirical basis to support claims about these unfavorable effects of nudging on autonomy is lacking. In fact, to date the few studies that have empirically investigated the effect of defaults on autonomy showed no or only marginally negative effects in hypothetical scenarios (Michaelson, Johansson, & Hedesström, 2021; Wachner, Adriaanse, & De Ridder, 2020a; Wachner, Adriaanse, & De Ridder, 2021), also in case of organ donation (Steenart, Crutzen, & De Vries, 2021). However, results from hypothetical studies may be very different compared to when people are actually confronted with a default nudge in real life (Wachner et al., 2021; Wachner, Adriaanse, & De Ridder, 2020b). Studies that employed real-life decisions thus far have only investigated decisions with very low stakes, such as being defaulted into choosing a 5 min longer version of a questionnaire (Wachner et al., 2021). Clearly, these findings cannot be extrapolated to the complex context of decision to register oneself as an organ donor. Whether changing from an opt-in to an opt-out arrangement when registering for organ donation negatively impacts individuals' autonomy thus remains an open question. With the present research, we employ the transformation of the Dutch organ donation registration system to conduct a quasi-experimental study aimed at addressing this important issue.

The stepped-wedged introduction of the new Donor Act in the Netherlands provides a unique opportunity to investigate the effects of a default nudge on autonomy in real life. The Donor Act was implemented in the Netherlands in June 2020 by sending a letter to all citizens who had, by that time, not yet recorded their choice (either or not in favor of registration as a donor) in the Dutch organ donation registry, urging them to register their choice. Should they not register their choice (to be a donor, to not be a donor, to let a specific

person decide, or to let relatives decide), they received a second letter, and should they not register their choice within the next six weeks upon receiving the second letter, they would be registered as a donor (under the label ‘no objection to organ donation’) in the Donor Register by default.

Crucially, the timing of receiving the first letter was dependent on the province of residence, which means that at the time of data collection for this study (Spring 2021), individuals in some provinces were still waiting to receive their first letter, some had just received the second letter, and for others the six-week waiting period after receipt of the second letter had already passed. As a result, we could compare individuals who would not be subjected to a nudge as they were already registered before the introduction of the Donor Act, to the target population consisting of people who were in expectation of an invitation to register by default or already received at least one letter of invitation. Moreover, the province-based timing of implementation of the Donor Act allowed for the opportunity to compare within the nudge condition individuals who had already actively registered their choice upon receiving the letter to individuals who were inactively being defaulted into being registered as an organ donor.

In order to examine whether default registration as an organ donor poses a threat to autonomy, we thus created different groups that allowed for comparing autonomy in people who already registered their choice before the implementation of the new default registration (Group 1), people who did not already register their choice and were still waiting to be invited to register (Group 2), people who were invited to register and either actively responded by registering (Group 3) or did not respond to this invitation (Group 4). We did so by asking about 1200 participants about their registration status and their experience of autonomy upon making a decision. We also assessed participants’ experience of competence in making the decision and satisfaction with their decision as these constructs are closely

related to autonomy (Michaelsen et al., 2021). Finally, we asked all participants to what extent they experienced pressure to make a decision as this has been found to be associated with autonomy (Wachner et al., 2020a). For ethical reasons, we did not directly ask participants what choice they registered but focused on their experience of autonomy when making this decision.

Methods

Ethics Statement

Ethical approval for the study was obtained from Ethics Committee of the Faculty of Social and Behavioural Sciences of Utrecht University, filed under number 21-0079.

Participants

Participants were recruited via a Dutch online panel agency (Flycatcher.eu). Informed consent was obtained from all individual participants included in the study and all data were collected in accordance with the Helsinki declaration. Out of the 1897 panel members who were invited, 1185 completed the survey. The sample is representative of the Dutch adult population in terms of gender, age, education, and region (see Supplementary Materials for details).

[insert Figure 1]

Procedure

After giving informed consent, participants were asked six questions regarding their donor registration status in order to assign them to one of four groups (see Figure 1). Next, they were shown a brief description of their current registration status based on their answers and were then asked to fill out questionnaires on autonomy, decision making competence, decision satisfaction, and pressure to register as a donor. Finally, participants were debriefed

and thanked for their participation. They were also provided with links to check on their current donor registration status.

Materials

All questionnaires can be found in the Supplementary Materials.

Registration status. This routed questionnaire comprised four questions (see Figure 1). A total of 16 participants who answered ‘no’ to all questions and therefore fell into the categories of ‘will definitely not actively register as a donor’ ($N = 6$), ‘will definitely actively register as a donor’ ($N = 9$), or ‘not sure whether or not to register’ ($N = 1$) were excluded from all analyses as the sample sizes, even when summed into one group, were too small for a meaningful examination.

Autonomy. Autonomy was measured with nine items (e.g., ‘I felt free to choose what I wanted’) on a 5 point scale, ranging from 1 = “totally disagree” to 5 = “totally agree” (Vugts, Van den Hoven, De Vet, & Verweij, 2019). Items were presented in randomized order for each participant.

Decision Making Competence. Competence was measured with six items (e.g., ‘I was pretty skilled at making this decision’) on a 5 point scale, ranging from 1 = “totally disagree” to 5 = “totally agree” (Wachner et al., 2020a). Items were presented in a randomized order for each participant.

Decision Satisfaction. Decision Satisfaction was measured with a slightly adjusted questionnaire (Sainfort & Booske, 2000) comprising five items (e.g., ‘My choice is the right one for my situation’) on a 5 point scale, ranging from 1 = “totally disagree” to 5 = “totally agree”. Items were presented in a randomized order for each participant.

Pressure to register as a donor. Participants indicated on a slider from 0 to 100 how much pressure they experienced to make a decision about donor registration.

Demographic data. Data on participants' gender, age, level of education, and region were provided by the panel agency.

Results

Descriptives

Based on their responses to the registration status questionnaire, participants were categorized into the four aforementioned groups. Table 1 provides an overview of the sample size, gender composition and age for each group. A table with means and standard deviations, as well as correlations of a broader set of demographics can be found in the Supplementary Materials.

[insert Table 1]

Autonomy, Decision Making Competence and Decision Satisfaction

The pattern of results (see Table 2) reveals that participants in all groups reported on average relatively high levels of autonomy, with mean scores well above the neutral midpoint of the scale for all conditions. The same holds for mean scores on decision making competence and decision satisfaction. A MANOVA with autonomy, decision making competence and satisfaction as the dependent variables, and group as the independent variable was conducted to test the differences between the four groups. This yielded a significant multivariate effect, Wilk's $\Lambda = .801$, $F(9, 2806) = 29.7$, $p < .001$, $\eta^2 = 0.067$. The univariate effects were also significant: Group significantly predicted autonomy $F(3, 1155) = 75.6$, $p < .001$, decision making competence $F(3, 1155) = 68.1$, $p < .001$, and decision satisfaction $F(3, 1155) = 68.1$, $p < .001$.

Tukey HSD post-hoc tests revealed significant differences between all groups on all variables $ps < .026$ (for details see Supplemental Materials). As shown in Table 2, among the target population for the default nudge (those who were not yet registered on June 1st 2020, Groups 2-4), participants who were exposed to the nudge and actively registered (Group 3), reported on average higher levels of autonomy, $M = 3.95$, $SD = 0.54$, compared to participants who had not yet received a letter of invitation to register (Group 2), $M = 3.62$, $SD = 0.66$, and participants who had received a letter but did not respond to this letter (Group 4), $M = 3.28$, $SD = 0.66$. The latter group of participants, those who let the deadline pass, reported the lowest level of autonomy of all groups. In contrast, participants who had responded positively to the invitation letter by indicating their preferred choice (Group 3) had near to similar levels of autonomy as participants who had indicated their choice prior to the introduction of the new Donor Act (Group 1), $M = 4.20$, $SD = 0.50$. A similar pattern was observed for the dependent measures competence for making a decision and satisfaction with the decision (see Table 2).

[insert Table 2]

Pressure

An ANOVA was conducted to test whether the groups differed in the pressure they experienced to make a decision about donor registration. The effect of group was significant $F(3, 1155) = 24.41$, $p < .001$. A Tukey HSD post-hoc test revealed significant differences between Group 1 and all other groups (all $ps < .026$), indicating that all participants who received the letter (Groups 3 and 4) or who were waiting to receive the letter (Group 2) experienced more pressure compared to the participants who had already registered (Group

1). No other comparisons were significant. See Table 3 for means and differences between the groups on pressure.

[insert Table 3]

Discussion

The aim of the current study was to investigate how the newly implemented Donor Act in the Netherlands that employs a default to promote donor registration affects personal autonomy and related concepts. To that end, we asked participants about their registration status, exposure to the default nudge (receipt of the letter) and their response to this nudge (active registration or not) on their experience of autonomy, decision making competence, satisfaction with their decision, and experienced pressure to make a decision. The results show that individuals who had registered their choice before the new Donor Act was implemented reported the highest levels of autonomy. This is not surprising, as they made their own decision, even before being urged to do so by invitation and as a result were not confronted with the new default arrangement. The most noticeable result is the low experience of autonomy in individuals who received an invitation to register and let the deadline pass without taking the opportunity for actively registering either or not as a donor (Group 4).

Compared to the group of individuals who had not been exposed to the nudge because they were still awaiting an invitation letter (Group 2), the low levels of autonomy in people who did not respond to the nudge (Group 4) could be interpreted as evidence that there is a negative relationship between exposure to a default nudge and autonomy. However, people who responded to the nudge by actively registering upon receiving the letter (Group 3) were

also confronted with the new default, but actually reported higher levels of autonomy than people who did not respond (Group 4) and even higher than people who had not yet received the letter of invitation (Group 2). In fact, the people who did respond to the invitation to register came close to the high level of autonomy of people who had already registered before implementation of the default arrangement (Group 1). Based on this pattern of results with marked differences in autonomy and related concepts between groups, we argue that the most striking finding of this study is the observation that it is not the nudge itself that affects autonomy but rather the response to the nudge, i.e., whether invitees take the opportunity to either or not register themselves (in whatever way).

One could argue that people who did not actively register upon being invited to do so may not want to exercise autonomy because they did not want to be confronted with the difficult question of organ donation or did not want to be personally responsible for this decision. If this would be the case, a lower level of experienced autonomy would not be necessarily negative. However, the pattern of results for decision making competence and satisfaction with one's choice mimicked the findings on autonomy. This suggests that lower autonomy was experienced negatively to the extent that people were less satisfied with their decision and also felt less competent to make this decision. Our findings on how much pressure people experienced to make a decision about registration reveal that the nudge (invitation letter for default registration) resulted in a higher experience of pressure regardless of how people responded to the invitation. This implicates that the differential pattern of autonomy (and decision making competence and satisfaction) between groups who received the letter is not a reflection how much pressure they experienced (Wachner et al, 2021).

The present findings have important implications for debates about whether and how nudges affect autonomy as well as whether and how nudges should be implemented in public policy. First, our findings inform current debates regarding the ethics of nudging and suggest

that nudges may have a double advantage as they both lead to an increase in donor registrations while at the same time preserving autonomy, decision making competence, and satisfaction with one's decision. It should be noted, however, that about 30% of invitees did not register their choice upon being invited to do so. This inertia in response to the default may eventually help to increase the number of donor registrations but comes at a cost for experienced autonomy, decision making competence and decision satisfaction for individuals who did not take the opportunity to express their choice. Future research is required to investigate in more detail the characteristics of this group, as these might be individuals who are already more vulnerable and lack resources to respond to the invitation to register proactively (Keizer, Tiemeijer, & Bovens, 2019). This implies that it is crucial to design default nudges in such a way that it increases the odds of active registration while at the same time maintaining or enhancing individual autonomy by, for example, encouraging them to take action themselves.

The present findings also inform the broader literature on nudging as they suggest that it is important to distinguish not only between a no nudge (control) and a nudge (experimental) condition, but also to differentiate between responses to a nudge when examining the psychological downstream consequences of nudges. Had we lumped together people who either or not responded to the nudge (Groups 3 and 4) as a nudge condition and compared them to people who had not been nudged (Group 2), we would have concluded that nudges do not affect autonomy. The present analyses in which we differentiate between whether or not people responded to the nudge show that effects are markedly different for these two groups. Finally, it is worth pointing out that in fact the majority of people who received the letter did actively register (111 out of 163 or about 70%) but not all of them did, which indicates that inertia, loss aversion and status quo bias may be less important

mechanisms in explaining the effects of defaults. Rather, these findings suggest that implicit recommendation may drive default effectiveness (McKenzie, et al., 2006).

Several limitations should be noted. First, an important observation in the current study is that roughly 80% of the participants reported to have already been registered before the new default arrangement was put into effect. This is more than expected, as only about 50% of the Dutch population older than 18 was registered in the Netherlands at the time of conducting our study (Organ Donor Registry, 2021) and our sample was found to be representative of the general population in terms of gender, age, and education. A possible explanation for the discrepancy is that participants were able to choose whether or not to participate in our study, possibly leading to a bias where people who avoid thinking about organ donation and did not register may have been less willing to participate in the study. Second, it is important to point out that results refer to registration of a choice in the donor register which can range from either or not being registered as a donor or let relatives decide later on. We interpret the pattern of results based on whether people actively registered their choice, but this is at least partly confounded with donor status (all participants in group 2 were not registered as a donor whereas all participants in group 4 were registered as a donor). A final limitation relates to the quasi-experimental design of the study, precluding definite conclusions about the causal effect of the default arrangement on the experience of autonomy, decision satisfaction, and decision making competence.

Conclusion

In conclusion, our findings show that autonomy, decision satisfaction, and decision making competence after being nudged by default to register as a donor is also associated with the response to the nudge and not simply the result of mere nudge exposure. People who take the opportunity to register their donor status in response to a default nudge report higher levels of autonomy, decision making competence and satisfaction with their decision than

people who ignore the nudge and end up being registered as a donor at the cost of lower experienced autonomy.

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Table 1

Means and standard deviations of background information per group and total.

Variable	Group 1	Group 2	Group 3	Group 4	Total
N	929	67	111	52	1159
Gender	50.6% female	47.8% female	45.9% female	42.3% female	49.6% female
Age	33.8 (17.3)	37.7 (17.8)	35.1 (17.6)	31.1 (17.7)	34.0 (17.4)

Table 2

Means with standard errors for autonomy, decision making competence, and decision satisfaction, for all groups.

Table 3

Means with standard errors for pressure for all groups.

Figure 1

Flowchart of the routed questionnaire on registration status.

Supplementary Materials

Means, standard deviations, and correlations of all variables with confidence intervals

Variable	<i>M</i>	<i>SD</i>	1	2	3	4	5
1. Autonomy	4.10	0.57					
2. Satisfaction	4.16	0.68	.68** [.64, .71]				
3. Competence	3.96	0.63	.67** [.64, .70]	.75** [.72, .77]			
4. Sex	0.50	0.50	.13** [.07, .18]	.00 [-.06, .06]	.00 [-.05, .06]		
5. Education	2.03	0.76	.14** [.08, .19]	.03 [-.02, .09]	.04 [-.02, .09]	.16** [.11, .22]	
6. Age	34.04	17.39	-.10** [-.16, -.04]	.03 [-.02, .09]	.07* [.01, .13]	-.33** [-.38, -.28]	-.39** [-.44, -.34]

Note. *M* and *SD* are used to represent mean and standard deviation, respectively. Values in square brackets indicate the 95% confidence interval for each correlation. The confidence interval is a plausible range of population correlations that could have caused the sample correlation (Cumming, 2014). Level of education is represented on a three point scale.* indicates $p < .05$. ** indicates $p < .01$.

Autonomy within and between groups.

	Group 1	Group 2	Group 3	Group 4
Group 1	$M = 4.20, SD = 0.50$			
Group 2	$p < .001, d = 1.13$	$M = 3.62, SD = 0.66$		
Group 3	$p < .001, d = 0.50$	$p < .001, d = 0.56$	$M = 3.95, SD = 0.54$	
Group 4	$p < .001, d = 1.81$	$p = .003, d = 0.52$	$p < .001, d = 1.15$	$M = 3.28, SD = 0.66$

Note. M and SD on autonomy for all four groups. As well as p values from a Tukey HSD post-hoc test with group as the independent, and autonomy as the dependent variable, and Cohen's d values.

Satisfaction within and between groups.

	Group 1	Group 2	Group 3	Group 4
Group 1	$M = 4.27, SD = 0.61$			
Group 2	$p < .001, d = 1.05$	$M = 3.62, SD = 0.74$		
Group 3	$p < .001, d = 0.60$	$p = .026, d = 0.38$	$M = 3.90, SD = 0.64$	
Group 4	$p < .001, d = 1.60$	$p = .016, d = 0.44$	$p < .001, d = 0.89$	$M = 3.28, SD = 0.81$

Note. M and SD on satisfaction for all four groups. As well as p values from a Tukey HSD post-hoc test with group as the independent, and satisfaction as the dependent variable, and Cohen's d values.

Representativeness of the sample as compared to the Dutch population.

Gender	Sample	Population
Men	50%	49%
Women	50%	51%
Age		
18-24	9%	11%
25-29	9%	8%
30-34	7%	8%
35-39	7%	8%
40-44	7%	7%
45-49	8%	9%
50-54	10%	9%
55-59	9%	9%
60-64	9%	8%
65 and older	25%	23%
Education		
Low	27%	28%
Medium	42%	52%

High	30%	30%
Province		
Drenthe	2%	3%
Flevoland	2%	2%
Friesland	4%	4%
Gelderland	13%	12%
Groningen	3%	3%
Limburg	7%	7%
Noord-Brabant	16%	15%
Noord-Holland	17%	17%
Overijssel	7%	7%
Utrecht	8%	8%
Zeeland	3%	2%
Zuid-Holland	21%	21%

Questionnaires

Questions with an asterisk (*) are reverse coded. All items were answered on a 5 point scale, ranging from 1 = completely disagree to 5 = completely agree.

Autonomy Questionnaire

I felt like I had a choice.

I felt free to choose what I wanted.

*The circumstances influenced my decision.**

I had my own reasons to make my decision.

I deliberated this decision.

I thought about it before I made my decision.

This decision is typical for me.

This decision fits what I find important.

This decision says something about me.

Satisfaction Questionnaire

My decision is sound.

I am comfortable with my decision.

My decision is the right one for my situation.

I am satisfied with my decision.

*It was difficult to make a choice.**

Competence Questionnaire

I think I am pretty good at making these kinds of decisions.

I think I did pretty well at making this decision, compared to other people.

After making this decision, I feel competent.

I am satisfied with my performance at this decision.

I was pretty skilled at making this decision.

*This was an activity that I couldn't do very well.**