

## Quantitative study - other

# Competing wishes of next-of-kin versus the deceased when it comes to organ donation consent

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**Commentary on:** Shepherd L, O'Carroll RE, Ferguson E. Assessing the factors that influence the donation of a deceased family member's organs in an opt-out system for organ donation. *Soc Sci Med*. 2023 Jan;317:115 545. doi: 10.1016/j.socscimed.2022.115545. Epub 2022 Nov 17.

## Implications for practice and research

- ▶ Next-of-kin approval for organ donation is based on knowledge of the deceased's wishes but mediated by anticipated regret and their own attitude.
- ▶ Targeted research exploring next-of-kin approval in organ donation settings, including behaviour change interventions, is required.

## Context

Countries have either opt-in or opt-out legislation to support organ donation. With opt-out systems, presumed or deemed consent occurs when an individual has made no explicit decision either way. While many believe deemed consent facilitates more organ donation, differences in actual organ donation rates are negligible.<sup>1</sup> This could be due to the requirement for next-of-kin approval within both organ donation systems and how next-of-kin attitudes impact on decisions. This was explored by Shepherd and colleagues in their study.<sup>2</sup>

## Methods

The investigators recruited 848 participants living in Wales, with random online allocation to one of three experimental conditions to represent the deceased: opted in, opted out or deemed consent. Next-of-kin approval was the dependent variable; uncertainty and anticipated regret were the mediating variables; and negative affective attitudes and perceived benefits were the potential moderating variables. Analyses of variance were used to assess the effect of the deceased's registration status on next-of-kin approval of donation, uncertainty and anticipated regret.

## Findings

Participants in the three different condition groups had similar demographics and attributes. As expected, the deceased's organ donor status (ie, opted in, opted out or deemed consent) had a significant effect on next-of-kin decision making. Next-of-kin approval was lower with opt-out compared with opt-in or deemed consent. In deemed consent conditions, the deceased's organ donor status had an indirect effect on

next-of-kin approval via anticipated regret (when compared with opt-out). Finally, the indirect effects of the deceased's organ donor status on next-of-kin approval via anticipated regret varied by next-of-kin negative affective attitudes but not perceived benefits.

## Commentary

The study from Shepherd and colleagues shines a light on a complex area of decision making: seeking approval for deceased organ donor consent from the next-of-kin. This is termed 'soft' consent and is an established principle in most organ donor systems, regardless of opt-in versus opt-out legislation. While decision making may be easier for next-of-kins when an implicit decision has been made by their loved one during life, this can still be overruled. In the context of deemed consent, the assumption that the deceased would have been happy to donate has a lot of uncertainty. The work from Shepherd and colleagues demonstrates how next-of-kin beliefs and attitudes, predominantly negative rather than positive, will impact on approval for organ donation.

By default, seeking next-of-kin approval for deceased organ donation occurs in an exceptionally upsetting and distressing time: the death of a loved one. From a behavioural science perspective, decision making in this stressful setting can be impacted by different stressors: information overload, time pressure, complexity and uncertainty.<sup>3</sup> All of these are present in organ donor discussions and could influence consent rates. Despite repeated public health initiatives to raise awareness of organ donation among the general population, we have failed to target the key decision makers in this situation: the next-of-kin.

If we accept that underlying cognitive obstacles may impact on decision making for organ donation in stressful situations, interventions to target and overcome these hurdles would be beneficial. One suggestion has been to design interventions embedded with the concept of nudge theory, where next-of-kin decision making is influenced by encouraging positive reinforcement and indirect suggestion to overcome underlying cognitive biases.<sup>4</sup> However, stakeholder engagement to allay concerns over such a strategy as a form of coercion will need attenuating.<sup>5</sup> In addition, under-represented communities may have negative attitudes to the concept of nudging and require clear framing.<sup>6</sup> Targeting negative affective attitudes is important, but how we successfully achieve this remains unclear. The work from Shepherd and colleagues shines a light on an important area that warrants further research.

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