

## Presumed consent to organ donation and the family overrule

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Many proponents of organ donation support a move to a system of presumed consent where people will no longer have to opt in to organ donation.<sup>1</sup> The assumption is that this change, which recently took place in Wales,<sup>2</sup> will lead to an increase in donation rates, while still allowing those who do not want to donate to opt out. However, the family overrule, where families prevent donation from a registered organ donor, also poses problems under “opt-out” presumed or deemed consent systems. Evidence suggests that, while the move to presumed consent often increases overall support for donation within a society, family overrules still prevent donation in many cases. Why is this?

The main distinction between the overrule in an opt-in system and the overrule in an opt-out system is that in the former, the family is contradicting a recorded wish of a patient, while in the latter, the family is contradicting presumed or deemed consent. The first difficulty is that, despite widespread media campaigns like that in Wales, it remains possible that consent is presumed for people who did not know that they had to opt out if they did not want to donate. If a patient had not discussed donation wishes with his or her family, the family might reasonably have concerns about whether their relative wanted to donate. In opt-in systems, families can be shown the patient’s entry on the donor register, which thus constitutes evidence regarding their intentions. In presumed consent jurisdictions, where patients only have to register if they object to donation, there will be no such evidence. This means that it might be more difficult to prevent a family overrule – and indeed, there might be stronger grounds for allowing an overrule than in an opt-in jurisdiction where there is recorded evidence of a wish to donate.

This issue becomes more nuanced in jurisdictions like Wales where opting in is not required but remains an option. If someone records an intention to donate in a country where there is no need to do so because consent will be presumed, this actually constitutes stronger evidence of a wish to donate than a presumed consent or an opt-in in a country where there is no presumed consent system. The person who opts in when it is not strictly necessary has gone the extra mile, and the family overrule would be even less acceptable than usual in such a situation because

there is evidence of a strong wish to donate. Whether or not it was necessary to register will depend on whether the person opted in before or after the presumed consent legislation was introduced; if it was before, it does provide more weight than presumed consent, but not quite as much as if it was after the new legislation, where the extra effort has extra evidentiary value.

The verdict on each of these different scenarios will also be affected by whether a potential donor has also discussed donation with his or her family. If he has not, the above conclusions apply; if he has, the family should hopefully know one way or the other what the patient wanted, and will support that wish. In situations where the family’s testimony regarding donor intentions contradicts presumed consent or a recorded wish in a presumed consent, the chronology of evidence must be carefully discussed as in opt-in jurisdictions.<sup>3</sup>

Another important point to bear in mind is that not all so-called “overrules” are actually overrules. In approximately 10% of cases in the UK prior to the introduction of informed consent in Wales, the family was not really overruling consent but is actually providing new evidence of refusal.<sup>3</sup> This category is likely to increase in size in Wales and other presumed consent jurisdictions, for the reasons discussed above; if consent is presumed rather than recorded, there will be substantially greater scope for family evidence to overrule presumed consent (assuming, of course, that the patient did not record a wish to donate despite it being unnecessary). The Human Tissue Authority guidance on donation in Wales following the introduction of the new legislation states that, in cases where consent is to be deemed: “When information is provided by a relative or friend of long standing that the person did not want to be an organ donor, this must satisfy a reasonable person that the person would not have given consent.”<sup>4</sup> Furthermore,

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it also provides for “overrule” of a registered *refusal* to donate: “If the recorded decision was not to be an organ donor then this can be communicated to the family. If the family state that the person had changed their mind and wanted to donate their organs, they must provide the SNOD with the evidence they believe proves the person did make a decision to be an organ donor and that this decision supersedes their recorded decision not to donate.”<sup>5</sup> This essentially permits families to reverse a recorded refusal if the patient had more recently expressed a wish to donate (and is thus not really an overrule of what the patient wanted). Though the HTA guidelines concern only Wales, the point should also apply in opt-in parts of the UK. If a family can provide new evidence of consent despite a recorded instance of refusal in a country where refusal is necessary, it should logically be possible for a family to do the same when someone has registered a refusal where it is not necessary to do so.

In a similar vein, around 30% of so-called “overrules” are not genuine overrules or new evidence of refusal, but grounds for reassessing whether donation is still in the patient’s best interests.<sup>3</sup> For example, in an opt-in scenario, a person could have consented to donation without any understanding of what is involved in donation, including potentially pre-mortem measures, donation after circulatory death, and prolonged family distress. These factors are even more important when consent is being presumed. If the patient has recorded a wish to donate, then there is clear evidence that the person wanted to donate, even if it might not be in their best interests because of such factors. But where consent is entirely presumed, it is more likely that donation will not be in the patient’s best interests, as it may be unclear whether the person was one of the few “missed” by the education campaign if he or she did not discuss donation intentions with family members.

Finally, around 50% of recorded overrules in the UK are genuine overrules. Although the introduction of a presumed consent system has implications for new evidence of refusal and assessment of best interests, this last category is unaffected by the change. This is because genuine overrules are based on what the family wants rather than what the patient wanted.<sup>3</sup> It is true that families might feel that their feelings should carry more weight under a presumed consent system in the absence of an opt-in, but the

change in consent system does not affect the ethical status of claims such as “donation is against my religion” or “the patient has suffered enough.”<sup>6</sup>

Over 10% of registered donors who find themselves in a position to donate have donation overruled by their family. It should therefore come as no surprise that families are likely to attempt to overrule a consent that is merely presumed. People who want to donate should continue to opt-in to donation, even if they live in an area with presumed consent – and they should also talk to their families about their wishes. Presumed consent has some potential advantages, but it is no panacea, particularly in terms of the family overrule.

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