What do you think are the key strengths and weaknesses of the proposals to introduce ‘deemed authorisation’ for those who have not made their wishes on organ donation known?

CARE for Scotland is opposed to the proposed ‘deemed authorisation’ scheme both for ethical reasons and on grounds of practicality. These issues are interconnected as the practical failure of implementation of presumed consent or ‘deemed authorisation’ is often linked to the fact that people respond negatively to the state claiming a right over their bodies.

Ethical Considerations

Our primary ethical concern is that the proposal disrespects the personhood of people by considering their bodies to be commodities which the state can acquire without prior consent having been obtained from the individual involved. This runs contrary to the Christian understanding of the human person as being created in the image of God. Human beings possess a measure of autonomy and freedom which cannot be disregarded without our being treated in a degrading, impersonal and dehumanising manner.

The problem with ‘deemed authorisation’ is that it creates a system that treats human beings with a degree of automation and bypasses their personhood. It is good that people choose to donate their organs – this should be encouraged. However, if we introduce an arrangement which results in the taking of people’s organs after death – without direct and honouring engagement with their personhood prior to death – we cannot guarantee that the organs are given freely and with consent and, therefore, the donor’s personhood is potentially disrespected. A new framework and understanding of humanity and our relationship to state power is introduced that will alter the way in which our culture views people generally and not just in relation to organ availability. It promotes a utilitarian ethic in which the state makes a claim to ownership of the bodies of human beings and seeks to use them for the purpose it deems appropriate without the explicit consent of the individual concerned and/or his/her immediate relatives.
Additionally, there are a number of more generic ethical concerns. First, there is a danger that a system of ‘deemed authorisation’ could undermine organ donation as an entirely altruistic gift. In 2008, the Organ Donation Task Force (ODTF) reported that representatives from the Donor Family Network highlight the importance of the gift relationship. They were concerned that a system of ‘deemed authorisation’, however weak, would promote conflict between families and clinical staff, conflict that would rapidly degrade the trust that was vital to decision making. Moreover, recipients and their families are concerned also that donation should always be a genuine gift. The importance of this ‘gift’ aspect is acknowledged by the Scottish Government which states in the Bill’s Policy Memorandum:

“The willingness of donor families to think of other people and the gift of donation at such times makes their generosity all the more special.”  

Second, the concept of ‘deemed authorisation’ is a misnomer. In practice, no authorisation can be assumed to have been given by the donor and his/her family. In some cases the individual concerned may have consented but did not, for any number of reasons, register this view while still alive. However, it is also very likely under the proposed system that organs will be removed from individuals who would not have consented to their removal. For some, this prospect will be of real concern.

Third, the proposed system has the potential to be abused in order to meet the state’s perceptions of the ‘greater good’ whilst the autonomy and discretion of the individual may be violated. For example, there is a danger that in cases where life sustaining treatment is withdrawn of clinical decisions being influenced, in part, by organ transplantation considerations (e.g. the timing of decisions to withdraw treatment). Concerns exist also in relation to those jurisdictions where euthanasia has been legalised in which lack of explicit consent is a common feature and organ donation is practiced in relation to euthanised patients. The temptation for clinicians to be unduly influenced by a combination of financial pressures and pressure to meet transplantation demand should not be overlooked. If we are not extremely careful, a commoditised view of the human person could lead to a policy

3 Studies have shown that between 32% and 45% of euthanasia deaths in Belgium are without explicit request or consent. In Belgium, organ donation guidelines have been introduced to apply in cases of euthanasia.
of euthanasia without consent for people with severe neurological conditions who are likely to cost the NHS considerable sums in ongoing care with their organs being harvested for transplantation purposes.

**International Experience**

We are not convinced by the international evidence that the introduction of this system will lead to an increase in organ donation. The debate has been confused because Spain is often claimed to utilise an opt-out system. However, that the country does not in practice utilise such a system. While it may have been legislated for in Spain, there is in practice no way to opt-out as there is no opt-out register. Spain in practice uses an opt-in model and it is the world leader in terms of deceased organ donation. The most successful country in the world, therefore, in terms of organ donation is using an opt-in system in practice. Other strongly performing countries in terms of organ donation, such as the USA, also use an opt-in system.

International experience shows that some countries with ‘deemed authorisation’ or presumed consent systems have seen a decline in organ donation. In 2012, Chile moved from a system of informed consent to one of presumed consent. The organ donation figure fell from 8.6 donors per million in 2012 to 5.6 donors per million in 2013. Columbia is another country which operates a presumed consent system which has seen falling organ donation levels in recent years, falling from 12.3 per million in 2010 to 6.8 per million in 2013. Within Europe, Luxembourg, Slovakia and Sweden have all experienced a fall in the level of organ donation over recent years despite operating systems of presumed consent. In those states which have adopted an opt-out system and where levels of organ donation have increased there remains a question as to whether this was caused solely by the introduction of the presumed consent system or by other factors.

It is worth noting that a host of countries which operate opt-out systems have lower levels of organ donation than Scotland. In the year 2013/2014, Scotland’s rate was around 20 donors per million. This was higher than Finland, Latvia, Sweden, Hungary, Poland, Slovakia, Luxembourg, Israel, Greece and Cyprus which all operate opt-out systems. This suggests that there are a number of factors which impact on the level of organ donation within a state. Among these is obtaining the consent of patients and families, but other factors such as training of medical professionals and the availability of specialist health care staff are of equal or greater importance.

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4 [http://www.clinmed.rcpjournal.org/content/14/6/567.full.pdf+html](http://www.clinmed.rcpjournal.org/content/14/6/567.full.pdf+html) and [http://www.bmj.com/content/341/bmj.c4973.long](http://www.bmj.com/content/341/bmj.c4973.long)
Experience in Wales

The Welsh experience in this area needs to be taken into consideration. In the original White Paper introducing their legislation in this area, the Welsh Government stated the aim of the introduction of this policy was “to increase the number of organs available”\(^5\) and claimed that “research suggests that organ donation rates from deceased persons increase by approximately 25% to 30% in countries where an opt-out system applies.”\(^6\)

In Wales, opponents of the proposed change (including CARE) argued that in fact the introduction of an opt-out system did not in and of itself increase the level of organ donation. It was argued that other factors such as the quality of health infrastructure, societal knowledge and the training of specialists played a far greater role with the example of Spain being cited.

Experience in Wales suggests that the expected increase of 25% to 30% in organ donation rates does not automatically materialise following the introduction of the ‘deemed authorisation’ system. In 2013/14 there were 54 deceased donors in Wales and 157 deceased donor transplants occurred. Although by 2018/19 the number of deceased donors had increased to 74, the number of deceased donor transplants had fallen to 137. Moreover, for most of the period (the first four years) after the introduction of their ‘deemed authorisation’ system, there was only a marginal increase in the number of deceased donors (averaging 59.7) and the number of deceased donor transplants varied remarkably from year to year with 128 in 2014/15, 168 in 2015/16 and 135 in 2016/17.\(^7\)

The data from Wales, therefore, presents a mixed and confusing picture. Whether the increase in the number of deceased donors is owing to the introduction of the new system or to other factors is far from clear. Moreover, the fact that the number of deceased donor transplants varies so much from year to year and shows no sign of an overall upward trend, casts doubt on the claimed benefits of introducing a ‘deemed authorisation’ system.

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6 “Proposals for Legislation on Organ and Tissue Donation” p4.

7 [https://nhsbtdbe.blob.core.windows.net/umbraco-assets/1518/wales-quarterly-stats.pdf](https://nhsbtdbe.blob.core.windows.net/umbraco-assets/1518/wales-quarterly-stats.pdf)
The data from Wales should also be compared with data in other parts of the UK to see if there is any perceptible difference as a result of the introduction of the ‘deemed authorisation’ system. The latest statistics released by NHS Blood and Transplant show that the number of deceased donors in Scotland increased from 98 in 2014/15 to 133 in 2016/17 before falling to 102 in 2017/18. The number of deceased donor transplants in Scotland increased steadily over the period from 300 in 2014/15 to 375 in 2017/18. In England the number of deceased donors increased from 1,076 in 2013/14 to 1,358 in 2017/18 and the number of deceased donor transplants increased from 2,834 in 2014/15 to 3,411 in 2017/18. In Northern Ireland the number of deceased donors fell from 48 in 2014/15 to 40 in 2017/18 and the number of deceased donor transplants increased from 79 in 2014/15 to 115 in 2017/18.

### Deceased Organ Donor Transplants 2014/15-2017/18

<table>
<thead>
<tr>
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<th>2014/15</th>
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<tr>
<td>Wales</td>
<td>128</td>
<td>168</td>
<td>135</td>
<td>139</td>
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<tr>
<td>Scotland</td>
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<td>332</td>
<td>348</td>
<td>375</td>
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<tr>
<td>England</td>
<td>2,834</td>
<td>2,931</td>
<td>3,155</td>
<td>3,411</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>79</td>
<td>100</td>
<td>75</td>
<td>115</td>
</tr>
</tbody>
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Source NHS Blood and Transplant

Whilst there has been a variable, but overall downward, trend in the number of deceased donor transplants in Wales over the last four years there have been steady increases in the number of deceased donor transplants of 25% in Scotland, 20% in England and up to 45% in Northern Ireland during the same period. This is important because it suggests that the move in Wales to a ‘deemed authorisation’ system has not significantly improved the number organs being made available for transplant from deceased donors whilst precisely the opposite trend is observable in those jurisdictions which have retained an opt-in system.

One other factor it is salient to consider is the number of individuals who have opted out of being organ donors in Wales. The number of people opting out of the organ donor register (ODR) has risen consistently over the last three years since the presumed consent or

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‘deemed authorisation’ system came into force. By the first quarter of 2018, some 182,764 individuals (6% of the population) had opted out of being organ donors in Wales. The organs of these individuals have been lost from the system whereas previously these individuals may have proven to be suitable donors if their families had agreed to donate organs in the situation where deceased individuals had expressed no preference. In contrast to the Welsh situation, in Scotland 5,943 people (0.11% of the population), in Northern Ireland 545 people (0.03% of the population) and in England 416,287 people (0.9% of the population) have opted out of the ODR.

In Wales, by the first quarter of 2018 only 40% of the population had opted into the organ donor system. This compares to 37% in England, 44% in Northern Ireland and 50% in Scotland. Scotland has been much more successful than other parts of the UK in encouraging people to opt into the ODR. It is unclear, therefore, why the Scottish Government is proposing at this time to introduce a ‘deemed authorisation’ system when it has been making so much progress in increasing the rates of deceased donor transplants and in persuading people to opt into the ODR under the current system and the claimed benefit of the ‘deemed authorisation’ system is unproven.

**Conclusion**

In view of the serious ethical issues raised by the proposed opt-out system of organ and tissue donation and doubts about its practical benefit based on both the Welsh and international experiences, CARE for Scotland suggests that the Scottish Parliament should reject this Bill at Stage 1. More resources should be assigned to recruiting and training specialist health care staff and improving transplant management. Initiatives such as these are much more likely to produce the desired result of increasing the number of organs available for transplant than the introduction of the proposed ‘deemed authorisation’ system. We would be pleased to give oral evidence to the Health and Sport Committee during the Stage 1 process.