

HEALTH AND SPORT COMMITTEE

HUMAN TISSUE (AUTHORISATION) (SCOTLAND) BILL

SUBMISSION FROM THE ROYAL COLLEGE OF NURSING IN SCOTLAND

Background

Earlier this year, the Royal College of Nursing (RCN) issued a position statement on consent for organ and tissue donation after death. It reads:

“The Royal College of Nursing supports an opt-out system of consent for organ and tissue donations after death, where there is evidence that certain safeguards, supports and resources are in place.”

The RCN reached this position after it surveyed its members in early 2018. More than 7,700 members completed the survey. 71% of RCN members were broadly in favour of an opt-out system of consent for organ and tissue donation (rating between 7 and 10 on a scale of 0-10 from opt-in to opt-out). The majority support for an opt-out system was reflected across all four countries of the UK: Wales (75%); England (69%); Scotland (71%), and Northern Ireland (73%).

Whilst the majority opinion on an opt-out system for consent was clear, the survey also highlighted the work still to be done among nursing staff and the public to increase the rate of organ and tissue donation, irrespective of the system of consent.

- Only 25% of RCN members felt they could speak with confidence about organ donation with patients and their families.
- Only 22% of RCN members felt they could speak with confidence about tissue donation with patients and their families.
- Only 10% of members felt that patients tend to have thought much about donating their organs and tissues after death.

Safeguards, supports and resources

Safeguards or conditions attached to any opt-out system had a significant impact on levels of support for an opt-out among RCN members.

- In Wales, all of the safeguards attached to the opt-out already in place were overwhelmingly rated as important.
- Among members elsewhere, when presented with a list of possible safeguards, they:
 - Overwhelmingly reinforced the views of those favouring an opt-out;

- Moved a significant number of those favouring an opt-in towards support for an opt-out, and
- Resulted in those with no fixed view being more likely to move towards favouring an opt-out than an opt-in.

Following the consultation with members, the safeguards, supports and resources the RCN would expect to accompany any opt-out system are set out in the bullet points below:

- Sufficient resources are made available to define and support the additional infrastructure and capacity required to increase the rate of successful donations, including increased and sustainable investment in the number of Specialist Nurses in Organ Donation (SNODs), before any opt-out system is introduced.

The RCN appreciates the difficulty of estimating costs associated with increased organ donation rates as a result of this legislation. The assumptions around the sufficiency of existing indicative funding – including funding to NHS boards who bear the costs of actual transplantation and life-long support for those who have received donor organ or tissues - must be assessed regularly over the 10 year course of the evaluation. In addition, we note the additional staff funding for NHS Blood and Transplant (NHSBT), but again would urge that the evaluation ensures an ongoing assessment of funding for SNODs and Special Requesters. The aspirations of this Bill to support increased donations should not be hampered by lack of resource or predicated on delivery by an over-stretched workforce. We note here the importance of the Health and Care (Staffing) Bill also under consideration by the committee.

The RCN understands the need to manage resources appropriately for families and NHS organisations in the complex and sensitive process of authorisation, donation and transplantation and has supported the development of the nursing role of Specialist Requester in other parts of the UK. SNODs are under significant pressure to staff rotas over wide areas of Scotland and we appreciate that the Special Requester role is an attempt to alleviate this. However, the RCN is clear that the process of inquiry and authorisation does require a nurse (whether a SNOD or Special Requester) with the appropriate, high-level clinical and communication skills to guide families through each stage of this process and ensure they are accurately informed and fully engaged. The individual nurse will also be required to make important and sensitive judgements on whether or not the donation can proceed when authorisation is deemed. The RCN understands why some practical elements of inquiry may be appropriately delegated but is

concerned that the wording of 16J could allow delegation by health boards without clear parameters. This should be considered further.

We would want to see the competencies and skills of nursing taking on Special Requester roles in Scotland articulated clearly to MSPs during the passage of the Bill. This should be reflected in statutory guidance.

Finally, we have a concern that the duty to inquire is placed on individual nurses (as a “health worker”) rather than on organisations. Given the complex inquiries which will be required under this legislation, when time is clearly of the essence, the RCN is concerned that individual staff will not be sufficiently protected when difficult judgements must be made quickly. The Bill should not have the unintended consequence of prompting defensive practice. We would wish to see the decision to make the duty individual, rather than organisational, explored in detail in the committee stages of the Bill.

- An evaluation is commissioned to assess the medium-to-long-term impact of any opt-out system on the rate of successful donations. Any opt-out system is reviewed on the basis of this evidence.

The RCN acknowledges that the Financial Memorandum to the Bill sets out funding for full evaluation and, given the learning in Wales in evaluating after just two years, we accept the need to set evaluation in a longer-time scale. We would be keen to see the Scottish Parliament take a clear role in monitoring the implementation and impact of this Bill, if passed. We are also interested to hear what action could be taken if any new legislation were to have a negative effect, over the timeframe of the evaluation, on successful donation rates.

- The Scottish Government starts a public awareness campaign no less than a year before any change to an opt-out system, and then sustains that campaign. There are multiple, accessible routes for every adult to opt-out of donating, at any time, if they so choose.

The RCN is pleased to see additional funding committed to a public campaign, with a commitment to begin activity a year before commencement. It appears that there will be different routes to formal opt-out, however we would note that the explanation of these is not always very clear in the documents accompanying the Bill. We would expect to see plain English translation of these options to inform the public in the run up to commencement, and continuing thereafter.

- The Scottish Government starts an awareness and education programme for all health care professionals, tailored to the needs of specific groups, no less than a year before any change to an opt-out system, and then sustains that programme. Clear and up-to-date

guidance on the operation of any opt-out scheme is available to all health care staff.

The additional funding allocated to NHSBT, with a particular focus on those directly involved in the transplantation process, is a positive step. However, the sums involved will not, we would anticipate, fund the level of education and support requested by our members.

Nursing staff employed across sectors will need to be able to answer questions from the public about the impact of the changes factually and correctly. In addition, ensuring that family and friends are aware of an individual's wishes, so that these can be shared authoritatively during the authorisation process, requires early and open conversations, which many people will find difficult. Nursing staff working across all settings, including GP surgeries, care homes, community teams and general wards, could support authorisation rates by having the confidence to raise the issue of donation at any stage of a person's life. With only a quarter of RCN members feeling confident to discuss organ and tissue donation with patients and families, greater investment in education of the wider clinical workforce is key to the success of this and other interventions to increase donation rates. Additional funding is required to develop resources and guidance in partnership with clinicians, including nursing. We appreciate that NHSBT may not be the appropriate organisation to lead this wider programme, and this may sit more appropriately with the Scottish Government.

- Trained health professionals must discuss the expressed wishes of the deceased person with the person's family, where contactable, before any donation proceeds. If a family does not want a donation to go ahead it will not be forced.

The RCN acknowledges that Bill sets out the process for "healthcare workers" to take all reasonable steps to inquire with family and others as to the last known wishes of the person on donation (see concerns raised above). Guidance must make absolutely clear to practitioners the parameters of any new duty to inquire and support them to make difficult judgements – for example where family members may not be able to express clearly the wishes of their loved ones where no decision has been recorded, or where disputes arise between different family members. In practice, the RCN is clear that our nursing members should not be in a position of forcing a donation to take place in the face of significant opposition from loved ones. We understand that this is how the opt-out in Wales is, in effect, managed.

- The opt-out system is limited to adults only. Consent for donations from children and young people should continue to be addressed by existing opt-in/parental consent arrangements.

We acknowledge that the Bill, in line with the RCN position, does not intend to extend deemed authorisation to children and young people. In terms of changes which are included in the Bill to authorisation for children and young people, this goes beyond the extent of the RCN member consultation and resulting position. However, as with many of our comments, we note that the language used to explain the changes in the Bill is not user-friendly. It will be imperative that formal guidance and public communication on these issues is absolutely clear. Any person with parental responsibility dealing with the death of a child, and any nurse supporting them, must have information available in the simplest form.

- Adults who have never had the capacity to consent would not be included in the opt-out scheme. The scheme must also make clear how adults who lost the capacity to consent for a period before death would be excluded from the opt-out.

The RCN is content that the Bill addresses this point. The detailed guidance for SNODs and Special Requesters, however, will be key if they are to make appropriate judgement on this point during the authorisation process.

- The opt-out scheme is limited to organs and tissue donated for transplant. Adults must still opt-in to donate organs and tissue for research and other purposes.
- Any opt-out scheme makes clear which organs and tissues are included.

The RCN is content that the Scottish Bill is in line with both these safeguards in the RCN position. However, the explanations provided are not always clear and will require plain English communications to the public.

- Any opt-out scheme should have clear residency criteria included to ensure that temporary residents are not presumed to have given consent.

The RCN is content that intent of the legislation is in line with this safeguard in the RCN position. Guidance must make clear to RCN members what steps are reasonable to ascertain compliance with r