

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Org)15 - Royal College of Nursing

Royal College of Nursing

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17 January 2013

Mark Drakeford AM
Chair of the Health and Social Care Committee
National Assembly for Wales
Cardiff Bay
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Dear Mr Drakeford AM,

Thank you very much for your letter of the 6th December 2012 inviting the response of the Royal College of Nursing (RCN) to your Inquiry into the general principles of the Human Transplantation (Wales) Bill.

On 24th July 2009 the RCN Council was asked to consider our position on organ donation. At this meeting Council agreed to support the retention of the current opt-in system and closely monitor progress against the Organ Donation Taskforce Report recommendations up to 2013. RCN Council would then be asked to consider if there was a need to change the RCN's position in light of the progress against the Organ Donation Taskforce recommendations. **Therefore, the RCN does NOT at present favour a legislative change to an opt-out system for organ or tissue donation.**

The RCN continues to support NHS Blood and Transplant's strategy of 'changing public behaviour with regard to organ donation' and 'maximising conversion of

potential donors into actual donors' by means other than adoption of an opt-out approach to consent. The further views expressed below on the Bill and Draft Explanatory Memorandum should be understood in this context.

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Residency

One of our significant concerns is that the arrangements and tests for establishing residency are clear enough to deal with cross-border challenges. There is not sufficient detail in the Draft Explanatory Memorandum on safeguards that need to be in place to deal with issues arising from diverse cultural models of residency.

For example, given the significance placed in the proposals on residency, the Explanatory Memorandum should acknowledge the importance of, and anticipate strategies for, specific engagement with the gypsy and traveller community.

Communication and Education

We are also concerned about the effectiveness of any public awareness campaign to adequately explain this change in the law. The need for a greater level of public understanding about organ donation is widely acknowledged, and the RCN regards it as essential that relevant education should begin at an early age. It may also be useful to undertake a survey of public knowledge before and after any campaign to evaluate which sections of the population may need further activity and which methods were acceptable and effective. In addition to the Welsh Government's commitment given to specific consultation with BME groups, the Explanatory Memorandum must indicate what strategies will be pursued to ensure optimal public understanding in communities communicating in languages other than Welsh or English. Strategies suggested by the RCN are employing health care professionals, link workers and interpreters/ advocates from minority ethnic groups, checking a patient's understanding of what has been said to them, and ensuring that information has been translated appropriately in a culturally sensitive way, and educating health care professionals on the health beliefs of different cultural communities.

The communication plan will also need to target health professionals to explain the impact on their individual areas of practice. It must also be clear how the new system will impact on students resident in Wales and how this will be communicated to them.

If a new system were to come into operation in Wales, a pressing concern of the Royal College of Nursing would be the need for training and education for nursing

staff. Nurses and health care support workers are the largest staff group in the NHS and the most likely to be in direct daily contact with patients and families. Specific resources must be developed and targeted at this group.

We are also aware that the majority of Local Health Boards are currently operating a suspension of training for nursing staff as a financial savings measure.

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Chief Executives and Nurse Directors must be supported with a specific ministerial authorisation to implement the training and education necessary to implement the significant process of change proposed.

Nurses can be the first clinicians to broach this difficult subject with relatives of potential donors. When patients become critically ill and consideration is being given to whether they will be suitable for organ donation, nurses play a central role in the assessment to establish their suitability, and a key component of the role of the nurse is to endeavour to ensure that end-of-life care conforms to what are known to be, or can be reasonably assumed to be, the expectations of the patient. In our 2009 consultation, some concerns were expressed by our members that public trust in nurses' ability to fulfil this role could be undermined by adoption of an opt-out system of donor registration. The thought was that a perception of a conflict of interests might arise, whereby the nurse's role in caring for the dying patient might be regarded as secondary to the nurse's role in facilitating retrieval of organs for transplantation. To minimise the possibility of such a misconception of the role of the nurse, and to improve public understanding of organ donation, the RCN strongly encourages the Welsh Government to make explicit the principle that organ and tissue donation should be integrated into the culture of best practice in end-of-life care. The RCN believes that this will have a substantially beneficial impact on donation rates.

Nurses have consistently highlighted the benefits of an open and honest process in encouraging donation, as well as increased support for relatives at the end of life. It is understandable that the needs of recipients of organs are usually emphasised in discussion about donation ethics and policy. However, the RCN suggests that it is equally important for willing potential donors that a culture should continue to evolve in which donation is recognised as an important element of person-centred end-of-life care. Effective communication and recording the individual's preferences and wishes enables both the individual and their carers to become empowered. Such a culture would also enable those close to the dying person to understand that their role in facilitating a loved one's donation is not a threat to the interests of the patient, but

rather enables them to ensure that the wishes of the patient are as far as possible realised.

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Individual Clinician Concerns

The RCN 2009 member consultation also revealed that some nurses might have concerns specific to involvement in donation processes in an opt-out system. These concerns were relevant to wider consideration of the possibility of an individual's 'conscientious objection' to participation in organ retrieval and transplantation. Sometimes, individual healthcare professionals perceive the grounds for such an objection to be based on religious or cultural origins. Regardless of an individual's specific reasons for wishing to be excluded from facilitating donation and transplant, it is an important matter of policy that such 'conscientious objections' (whether enduring, modifiable or perceived) should be anticipated, and that adequate guidance for the management of such eventualities should be provided for. It is essential that clinicians' duty of care in such circumstances is clearly defined in such guidance.

For example, in what circumstances and for what reasons can a clinician elect to withdraw from donation and transplant procedures? What processes should be recommended for individuals and clinical services to reflect on and learn from such incidents in order to improve services on subsequent occasions? In particular, what strategies for training and education should be provided for staff to ensure that any personal decision taken to withdraw from donation is as far as possible based on informed choices. We understand that in some cases individuals who have taken a decision to withdraw have been asked to find a replacement member of staff and procedures should be put in place within the organisations involved to prevent such a situation.

As part of their professional registration with the Nursing and Midwifery Council (NMC), all nurses in the UK are personally accountable for their actions and omissions in their practice, and must always be able to justify their decisions. Failure to comply with their code of conduct may bring their fitness to practise into question and endanger their registration. The NMC code sets out clear standards of conduct, performance and ethics for nurses. We would urge the Welsh Government to consult with the NMC on any of the systems and processes that it establishes in the future.

Additional Resources

The RCN acknowledges the detailed discussion in the Draft Explanatory Memorandum of the anticipated resource implications of adopting a 'soft' opt-out system, but wishes to state its concerns about the need to provide adequate resources to implement any strategy to improve rates of donation.

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Healthcare professionals and the public need to be assured at all stages that the Welsh Government's encouragement of the population to be more supportive of organ donation and transplant is matched by appropriate financial commitment on the part of government.

To conclude, the RCN wishes to strongly emphasise that introduction of any new system or approach to organ donation requires corresponding investment in public education and expansion of infrastructure. Identifying larger numbers of willing donors is only valuable if the supporting infrastructure is able to cope with the additional workload.

Kind regards

Yours sincerely

TINA DONNELLY
DIRECTOR, RCN WALES

ABOUT THE ROYAL COLLEGE OF NURSING (RCN)

The RCN is the world's largest professional union of nurses, representing over 400,000 nurses, midwives, health visitors and nursing students, including over 23,000 members in Wales. The majority of RCN members work in the NHS with around a quarter working in the independent sector. The RCN works locally, nationally and internationally to promote standards of care and the interests of patients and nurses, and of nursing as a profession. The RCN is a UK-wide organisation, with its own National Boards for Wales, Scotland and Northern Ireland. The RCN is a major contributor to nursing practice, standards of care, and public policy as it affects health and nursing.

The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies.