

Northern Ireland

The Health Committee Clerk, Room 419, Parliament Buildings, Belfast, BT4 3XX

committee.health organdonationbill@niassembly.gov.uk

16 September 2021

Dear Sir/Madam

Re: Organ and Tissue Donation (Deemed Consent) Bill

BMA Northern Ireland welcomes the opportunity to respond to this consultation on deemed consent for organ and tissue donation.

The BMA is a professional association and trade union representing and negotiating on behalf of all doctors and medical students in the UK. It is a leading voice advocating for outstanding health care and a healthy population. It is an association providing members with excellent individual services and support throughout their lives.

General comments

BMA Northern Ireland strongly supports the principle of a deemed consent system for organ donation in Northern Ireland and has actively campaigned for this change for more than two decades. We believe that, when properly introduced and with sufficient publicity, this will increase donation rates as well as respecting the wishes and autonomy of those who donate. Moreover, and importantly, over a period of time an opt-out system will lead to a change in the overall philosophy within society so that donation is seen as a positive and natural thing to do when someone dies.

National director (Northern Ireland): Claire Armstrong Chief executive officer: Tom Grinyer

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We support the approach that has been taken in the Bill, very closely following the approach taken in England. We offer some comments and suggestions below for consideration.

Clause 1(4) – "excepted adult"

The Bill applies to adults who have lived in Northern Ireland for at least 12 months, and who die in Northern Ireland. Similar legislation in Wales, England and Scotland applies to those who live and die in each of those jurisdictions. Given that organ donation is organised, and organs are allocated, on a UK-wide basis, it would be good to consider whether there is any way of 'joining up' the various pieces of legislation in some way.

The current Bill will set the legal framework for removal and transplantation of organs in Northern Ireland. We would welcome exploration of whether this Bill could be amended to permit those who have lived in Wales, England or Scotland for 12 months (and would be covered by deemed consent if they died in their home nation) to also be covered by deemed consent if they die in Northern Ireland.

If this is not possible, or considered appropriate, this could be the subject of future discussion on a UK-wide basis, to ensure that an individual who lives (and dies) in any part of the UK that is covered by a deemed consent system, could have their consent deemed. This would ensure that those who want to donate organs after their death, and so are happy for their consent to be deemed, can have that wish respected irrespective of where in the UK they die.

Clause 1 (4) – "permitted material"

We support the proposal in the Bill that Regulations should specify which organs and tissues are covered by the legislation (and thus by deemed consent), rather than the approach in the rest of the UK whereby regulations specify the organs and tissues that are excluded. This provides clear information to the public about the scope of the legislation, allowing them to make informed decisions about their wishes.

Clause 1 (7) – duty to promote transplantation

We welcome the inclusion of a specific duty on the Minister to inform the public, at least once a year, about the effect of this legislation and to inform people about how they can record their wishes about transplantation or appoint someone to make those decisions for them. It is essential that this message is repeated at regular intervals, to inform those who move to the area, or reach the age of 18 in the future, and as a reminder to those who are covered by the deemed consent system, in case they wish to change their decision.

In the explanatory and financial memorandum, it is mentioned that:

"Over half a million people die each year in the UK, but only around 5,000 of those die in circumstances that mean that their organs could be considered for transplantation."

This is a very important fact that many members of the public are unaware of. It is important that, in any educational/promotional material that is provided about the new



legislation, it is made clear that, whilst we expect deemed consent to increase the number of organs available for donation, this will not 'solve' the problem of organ shortage. Northern Ireland has a very active and successful programme for living donation; it is important that this is not harmed due to a perception that once deemed consent is in place, this will no longer be needed.

• Clause 1(7) – the Act's effectiveness in promoting transplantation

The Human Transplantation (Wales) Act 2013 includes a provision stating that:

"The Welsh Ministers must - ...

(d) ensure that the resources available to Local Health Boards include the specialist skills and competencies required for the purposes of this Act"

We would very much welcome a similar duty on Ministers in Northern Ireland, to ensure that sufficient resources – both financial and staff- are made available to ensure the potential benefits of the legislation can be realised.

We are very optimistic that the changes proposed will, over time, increase the consent rate for donation and lead to an increase in organ donation in Northern Ireland. In order for this to be realised, however, the infrastructure must be sufficiently robust to ensure that donation can proceed whenever consent is in place. This means that, at the same time as introducing the legislation, steps must be taken to ensure that the necessary staff (including transplant surgeons) and resources are in place to make sure that these additional organs translate into more transplants, so that the ability to save and transform lives is maximised.

If it is not possible to amend the Bill to make this a legal duty, we would very much welcome a clear, public, commitment from Ministers that the necessary resources will be provided to ensure that no organs available for donation in Northern Ireland will be lost due to resource constraints within the system.

Once again, we would like to thank the department for the opportunity to respond to this important consultation. Should you have any questions in relation to it, please contact Judith Cross, head of policy and committee services, in the first instance via jcross@bma.org.uk

Yours sincerely

Dr Tom Black Chair

BMA NI Council

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