BMA

Northern Ireland

Evidence to the HSSPS committee on the Human Transplantation Bill

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Introduction

1. BMA Northern Ireland is both a Professional Association and a Trade Union which represents the medical profession in Northern Ireland across all Branches of Practice and our mission is, 'we *look after doctors so they can look after you.'*

2. BMA has 169,000 members worldwide, and 75% of doctors and medical students are members in Northern Ireland.

3. BMA Northern Ireland welcomes this Private Members Bill, on human transplantation as we have a long history supporting the introduction of an opt-out system for organ donation. Organ transplantation is an area that has seen amazing medical advances, however in order to capitalise on these advances more needs to be done in order to increase the availability of organs for transplantation.

4. BMA has published, *'Building on Progress: Where next for organ donation policy in the UK*[1]*,'* and whilst this report celebrates the success to date, we also highlight the fact that people are still dying unnecessarily due to the lack of available organs. BMA Northern Ireland believes that an opt-out system with safeguards would increase the donation rate. Under this system people would have the right to opt-out and choose not to donate their organs. The built in safeguards that we believe should form part of the Bill would ensure that the family is always consulted and asked about any unregistered objection to ensure that the deceased individual's wishes are respected.

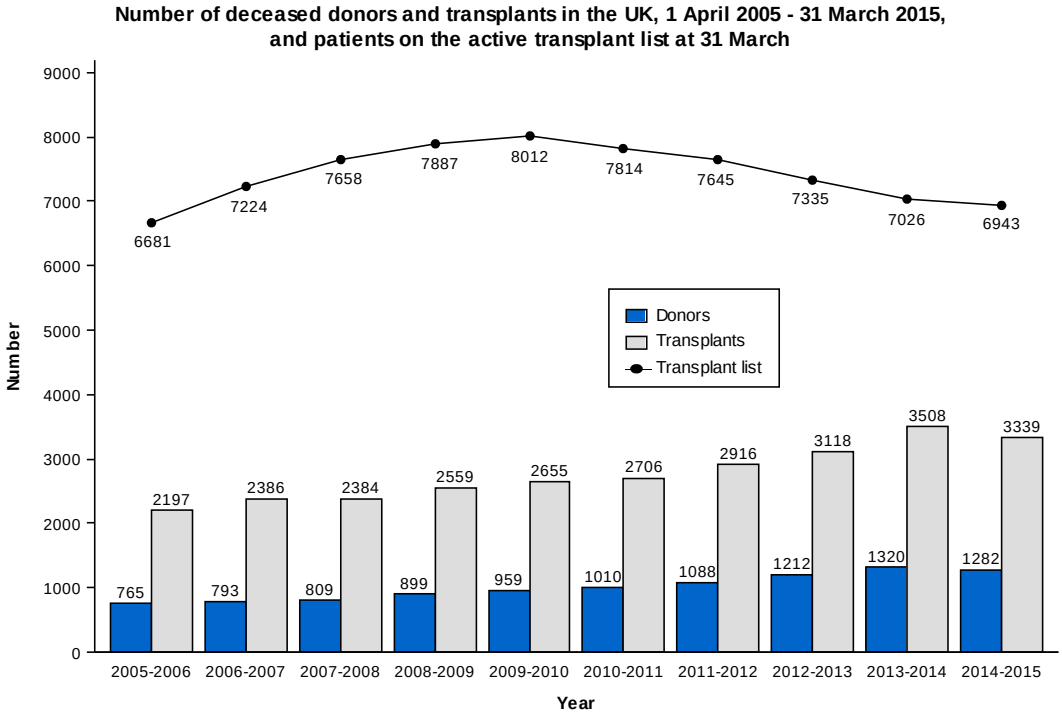
5. In essence BMA Northern Ireland believes that under an opt-out system, individuals have exactly the same choice as under an opt-in system – to donate or not to donate.

[1] BMA (2012) *Building on Progress: Where next for organ donation policy in the UK*. BMA, London. http://bma.org.uk/working-for-change/improving-and-protecting-health/organ-donation

Individuals are given information about the new system and can easily opt out of donation if that is their wish.

Donation rates and trends

6. For more than a decade, significant attention has been given to addressing the increasing gap between the number of organs available and the number of people requiring a transplant. The following chart shows that there has been a slight decrease in the number of transplants and donors from 2013-14 and the transplants list has also seen a slight decrease across the UK.



Source: Transplant activity in the UK, 2014-2015, NHS Blood and Transplant

Graph reproduced with kind permission of the NHS Blood and Transplant

7. Whilst there has been increases in the number of donors over the last 10 years, there have also been changes to the characteristic of donors[2]:

    - 33% of deceased donors were aged 60 years and over in 2014-15 compared with 17% in 2005-06
    - The proportion of clinically obese donors has increased from 16% to 26% in deceased donors in the last 10 years
    - The number of all deceased donors after a trauma death has fallen from 16% to 8% over the same period.

8. This shift in the profile of donors may have an adverse impact on the quality of the organs and the subsequent transplant outcome for the patient/recipient.

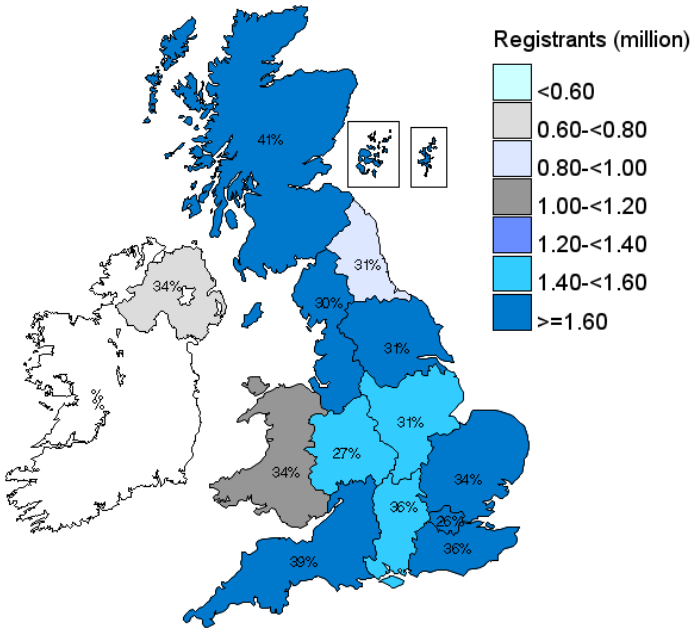
9. There are 162 patients on the transplant waiting list and there were 86 organ transplants in the first two quarters of 2015-16.[3]

10. It is important to note that only 43% of the deceased donors in 2014/15 were on the ODR (Organ Donation Register).

11. There are 647,237 people in Northern Ireland on the ODR representing 34% of the population as the following chart shows:

[2] NHS (2015) *Organ Donation and Transplantation: Activity Report 2014/15.* London: DoH
[3] https://nhsbtdbe.blob.core.windows.net/umbraco-assets/1069/northern_ireland.pdf, assessed 2 Dec 15

Proportion of population registered on the NHS Organ Donor Register by 31 March 2015, by Strategic Health Authority



Source: Transplant activity in the UK, 2014-2015, NHS Blood and Transplant

Graph reproduced with kind permission of the NHS Blood and Transplant

Public opinion on organ donation

12. Public opinion is crucial to the success of an opt-out system and BMA Northern Ireland believes there should be a well-resourced, consistent and persistent publicity campaign to enable a more informed public debate. There is a high level of support within Northern Ireland for change.

13. The Public Health Agency in 2013 undertook a representative sample survey of the public to determine their attitudes towards organ donation. The main points from the survey were[4]:
    - 84% supported the idea of organ donation
    - Awareness of the ODR is low at 36% with the lowest level of awareness found amongst younger and older age groups
    - Of those who did not sign the ODR, 35% said they did not want to donate and 31% said they had not thought about it
    - 78% agreed that it was important to discuss their donation wishes with family and friends, however only 38% had done so
    - 57% of GPs said they would be willing to record organ donation wishes on patient records.

14. The survey also found that knowledge about organ donation was also low but 78% of respondents said they would be willing to accept an organ if they needed one. There was also low (29%) awareness of the current debates around opt-in/opt-out systems.

15. The Human Transplantation (Wales) Act 2013 was implemented in December 2015 and adopts the opt-out system, having had an ongoing public awareness campaign. There have been repeated public surveys in Wales to assess awareness and support for the new legislation. Figures from June 2015 show 64% support for the new law, with 20% undecided or needing more information and 17% opposed.

16. Therefore, it is vital that education and awareness campaigns run parallel to the introduction of any new legislation.

Clause by clause comment and recommendations

[4] PHA (2013) *Organ Donation: public attitudes and stakeholder engagement in Northern Ireland 2013.* Belfast. PHA

Living donation

17. Before commenting on the clauses of the Bill, BMA Northern Ireland is concerned that the Bill includes transplantation from living donors. The Human Transplantation (Wales) Act applies only to removing 'from the body of a deceased person' any relevant material and we believe the same should apply in Northern Ireland.

18. We believe that living donation is best left as it is, under the auspices of the Human Tissue Authority which approves all living organ donation and has the appropriate safeguards in place.

19. We will provide additional comment on Clause 8 deemed consent: activities involving material from living adults who lack capacity to consent, later in this paper.

Clause 1: Duty to promote transplantation

20. BMA Northern Ireland has long advocated for the introduction of an-opt out system of organ donation with safeguards and a role for the family for those over the age of 16 and as such strongly supports the general thrust of Clause 1.

21. We believe that an extensive high profile publicity campaign is needed to ensure all members of society are aware of the forthcoming changes and to encourage them to consider their own wishes about donation and to make their wishes known.

22. BMA Northern Ireland is of the view that having donation as the default positon over time, changes the philosophy within society making organ donation the norm.

23. In relation to **Clause 1 (c)** and the role of family in 'affirming deemed consent', our comments in relation to **Clause 4 (2)** will be relevant and can be read across.

Clause 4: deemed consent – deceased adults

24. BMA Northern Ireland is aware of the sensitivities around the issue of the role of relatives at this distressing time. However the key issue should be what the deceased person wanted in relation to donation. The family role is to provide information to contribute to that decision, rather than to give consent themselves.

25. Currently, when an individual's views are not known, the relatives are asked for consent. In Northern Ireland around 40% of families are refusing[5]. BMA Northern Ireland believes that the introduction of an opt-out system with the appropriate publicity campaign will encourage more discussion within families so that the views of loved ones are known by family members prior to their death.

26. We are concerned that the use of the word 'affirm' could be seen as family consent which undermines the principle of an opt-out system.

27. It is helpful to consider the process of authorisation for donation in three distinct phases:
    - The register is checked and if the individual has opted out, then families will not be approached and donation will not take place
    - If the individual has not opted out of donation, there will be consultation with those close to the patient to determine whether they are aware of any unregistered objection or have convincing evidence that the individual, despite not opting out, did not want to donate
    - If there is no evidence that the individual would not have wanted to donate, donation may lawfully proceed. There is scope, however not to do so if the clinical team believes that donation is not appropriate (eg. If the family strongly objects and it is evident donation would cause them significant distress).

[5] NHS (2015) *Organ Donation and Transplantation: Activity Report 2014/15.* London: DoH

28. The last point above does not need to be explicitly covered in the legislation as the law is permissive. In other words whilst it gives the legal authority to proceed, it does not require that donation actually takes place.

29. In practice, we do not believe that transplant teams would proceed with donation in the face of strong and sustained opposition from the family – irrespective of the model of consent. The clinical team are aware of the duty they have to the bereaved family and the need not to add to their distress.

30. As outlined above, we realise that family involvement is a sensitive issue but the proposal at **clause 4 (2), Deemed Consent: deceased adults**, we believe could lead to confusion. Relatives should be asked if they are aware of any unregistered objection, but they should not be specifically asked to 'affirm' that the individual wanted to donate.

31. We are recommending that this clause is reworded to read,

> *'deemed consent is only effective if a relative or friend of long standing of the person is not aware of any unregistered objection to that transplantation activity.'*

Clause 5: express consent: excepted adults

32. BMA Northern Ireland has deep reservations in regards to **clause 5 (3) (b)** for adults who lack capacity before death. This is an important issue and has the potential to apply to a significant number of patients.

33. The length of time an individual has lacked capacity before death is irrelevant – the relevant issue is whether they ***had*** capacity for a reasonable period of time since the new system was implemented and therefore had the opportunity to opt-out if they had wished to do so. For example if an individual died 10 years after the opt-out system

came into force and may have lacked capacity for nine years but had capacity for the first years and did not opt out, in our view this should be sufficient for consent to be deemed.

34. Therefore the definition of expected adult should refer to the period for which they have had capacity since the new system came into effect, rather than the period for which they lacked capacity.

Clause 8: activities involving material from living adults who lack capacity to consent

35. The BMA has very serious concerned about any deemed consent system being applied to donation from living individuals. Any procedure carried out on a living individual who lacks capacity must be in the individual's best interests. Living donation from incapacitated adults are made very rarely and only after careful consideration, and usually with the approval of a court. It is not appropriate for this to be part of an opt-out system for organ donation and this clause should be deleted.

Clause 9: Appointed representatives

36. BMA Northern Ireland has always promoted a standard model of opt-out for organ donation whereby, following extensive publicity, and the opportunity to opt-out, donation may lawfully proceed where there is no evidence that the individual objected to donation. This Bill follows the model in Wales, by giving individuals a range of options:
    - Opt in
    - Opt out
    - Nominate someone to make the decision
    - Do nothing and be deemed to have consented

37. We can see the benefit of adopting a similar model to Wales and our only concern is that it may be difficult to convey this more complex model to all members of society. This is not to say it cannot be achieved but that it may be more difficult.

38. There are also some areas of concern about the current proposals for nominating individuals. For example **clause 9 (4),** states that an oral appointment is only valid if made in the presence of at least 2 witnesses present at the same time. This is very subjective and there are no qualifications on who witnesses are or the context in which the oral statement was given. This leaves **clause 9 (12)** potentially unworkable in relation to oral appointments – how are relatives or a clinical team expected to be aware that the person made an oral appointment and to whom?

39. Similar concerns arise in relation to **clause 9 (5) (c)** in that there will be a time delay after the death of an individual and the reading of a will making the issue obsolete.

Clause 18 (1): Supplementary

40. BMA Northern Ireland has always believed that the opt-out system should apply at the age of 16 and not 18 as indicated in the Bill. At 16 there is a presumption that young people are legally competent to make their own important and complex decisions regarding their care and treatment. We see no reason for setting a different age for young people to opt-out of organ donation than for other important decisions.

41. For those under the age of 16, the young person's own consent and/or that of their parents should be obtained.

42. We are therefore recommending that this is changed to age 16.

ENDS
4 December 2015