Transplantation (Authorisation of Removal of Organs etc.) Scotland Bill
NHS Greater Glasgow and Clyde

1. Do you support the Bill?

Overall, yes if the underlying aim is of ensuring that all available organs and tissues that are suitable for clinical transplantation are made use of however the way the Bill is trying to go about achieving this does raise concerns.

As you will be aware, since the Bill was first drafted there have been changes to the UK ODR so that all (including Scottish) people can now formally register a wish NOT to donate, so that requirement of the Bill is no longer required.

2. Do you think the Bill (if enacted) would achieve its aim of increasing the number of organs and tissue made available for transplantation in Scotland? Please provide an explanation for your answer.

Overall, it is likely that the Bill if enacted would increase the number of organs made available, as it would increase the proportion of the population for whom a clear statement of the wishes of the potential donor had been stated and recorded. In view of the high proportion who in principle support organ donation this should result in more individuals being recorded in the Organ Donor Register. It should be noted, that the major overall barrier to maximising deceased donor numbers in Scotland is ICU capacity and practice but the current rate limiting step is non-consent of actual potential donors. This Bill has the potential to make a strong statement that Scotland is a pro-donation/pro-transplantation society and that donation is the expected norm – whilst providing a well publicised means for those who disagree to ensure their wishes are respected. That would empower SNOD’s to obtain authorisation in a greater number of cases.

The NHSGGC Organ Donation Committee view is that it would be wise to await the outcome/results of the change to an opt-out system in Wales.

3. Do you support the proposal of appointing a proxy? Please provide an explanation for your answer.

The concept of a proxy was not supported. We think it unwise that a proxy should be appointed without he/she being aware of the proposal, not least since ideally the proxy should have had the opportunity to discuss donation with the potential donor. We are concerned by the proposal to have as many as three proxies, as this potentially complicates the demanding process of gaining authorisation within the required often short time-frame rather than expediting it.

We think therefore that proxies would potentially introduce unnecessary complexity – given that now all can register a wish to either donate or not to donate. It is unclear what a proxy would add to this (particularly as they may not even be aware of the fact that they may be a proxy) – proxies can only be appointed in writing so if someone is going to the trouble of formally
appointing a proxy they may, arguably, be as well formally registering their wish to donate or otherwise.

4. **Do you have any comments on the role of “authorised investigating persons” as provided for in the Bill?**

This role appears identical to the current role of SNOD’s. It would be helpful therefore to clarify that SNODS would continue to be the “**authorised investigating persons (AIPs)**”. Any other course of action would be impractical given the decades of experience this group of specialists has developed.

The Bill gives no detail as to which profession they will come from, what training they will be given in order to discharge their duties – as we state above, the role seems identical to the role the SNODs and TCS currently already play as regards ensuring that donation only goes ahead as long as it is legal to do so – AIPs will be required to be available 24/7 – we are unclear whether we would be able to appoint sufficient numbers to make this a viable role. It is acknowledged that the Bill implies they will be required in addition to the SNODs/TCDs.

Presumed consent would remove the need to gain authorisation from the next of kin and while at first glance this should lead to an increase in organs/tissues available we believe we still need the Next of Kin (NOK) to be fully engaged to ensure the SAFETY of what is retrieved as they are the main source of information, re medical, behavioural and lifestyle details. Further, going ahead in the face of a NOK objection is likely to lead to public outcry which would potentially have a significant negative effect on donation numbers. Waiting to see how Wales get on is sensible. Further there is no detail as to what a “reasonable time” would be for an AIP to either contact subsequent proxies or to take a decision to proceed with retrieval through authorisation by operation of law – leaving it open to interpretation and legal challenge which may well have a detrimental effect on donation overall – as “reasonable time” is likely to be very subjective it could lead to situations where the AIP has decided to proceed before proxies/NOK come back with evidence of objection to donation.

5. **Is there anything in the Bill you would change? If yes, please provide more details.**

While the goal of the Bill is to maximise the number of available organs and while the wishes of the potential donor should be paramount, we nevertheless do not believe that it is reasonable to take organs from an individual even on the Register when the immediate family object. Organ donation occurs at times of major emotional distress for relatives. While the expressed wish of the donor should be brought to the attention of the family and persuasion attempted it is the family who will ultimately have to deal with the consequences of donation against their wishes. The notion therefore that this legislation may lead to removal of organs in the context of an active family objection is not likely and which no person with real experience of organ donation could give credible concern. Safety of recipients is paramount for
professionals involved in transplantation and organ donation and without cooperation from NOK, the necessary safety protocols cannot be enacted making donation contraindicated. Cooperation from the next of kin is and always will be a sine qua non – even though it has not been legally necessary for nearly a decade.

So while we would be keen to ensure that the NOK did not overturn potential donor’s wishes, it is equally important to ensure safety of organs/tissues donated so we would need the NOK on board. A better way is to maybe raise public awareness and introduce a target for clinicians that donation is considered at each and every death and ensure they are given the resources in order to make this viable.

The Bill also makes provision only for a one off 6 month publicity campaign, which seems rather a short period of time. Also the public will be deemed to be ordinarily resident in Scotland after 6 months (would include all students), how will we ensure that all teenagers coming of age and all new migrants are aware of this and its implications for them. There is a need to have a way of continuing publicity.

In Section 7 of the Bill “Rule if order of acts unclear” where it is uncertain which of authorisation, appointment of a proxy or registering an objection came last then the adult will be deemed to have done none. That implies that donation through authorisation by law would be allowed implying that the objection will always be ignored!

In point 62 in the explanatory notes document the Bill seems to imply that for adults with incapacity a welfare attorney cannot either appoint a proxy or object to donation. This implies that in adults with incapacity authorisation by operation of law will always be possible irrespective of the opinion of those who knew them best.

NHSGGC fully supports increasing the number of organ/tissue donors but this Bill causes concern – as mentioned we think the way forward is to raise awareness and provide resource/target to clinical staff to ensure that donation is considered at each and every death.

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