NHS National Services Scotland (also known as the Common Services Agency) (“NSS”) is pleased to be involved in responding to the call for evidence on the Transplantation (Authorisation of Removal of Organs etc) (Scotland) Bill. Noted below are each of the posed questions in turn together with NSS’s responses.

1. **Do you support the Bill?**

   The above mentioned Bill aims to introduce a “soft opt-out” system in Scotland as well as provide the Scottish public the ability to appoint a proxy or to register in advance an objection to removal of organs/tissues with the overall aim being to increase the number of organs/tissues available for transplantation.

   While we applaud the underlying aim of ensuring that all available organs and tissues that are suitable for clinical transplantation are made use of we have a number of observations regarding the detail of the Bill.

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.**

   Since the Bill was first drafted and presented there have been changes to the UK wide NHS Organ Donor Register such that all UK residents (including Scottish residents) are now able to register both a wish to donate (opt-in) and also register an objection to donation (opt-out). To this end, as of June 2015, the Scottish public already has the ability to register an objection to donation, so that the Bill is no longer required for this purpose.

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

   The Bill would also make provision for adults resident in Scotland to appoint a proxy. The Bill does not provide detail as to who would be eligible to act as a proxy. Proxies need to be appointed in writing. They can only make a decision about removal of organs/tissue for transplantation purposes; the next of kin would be needed to provide authorisation for non-transplantation purposes (e.g. research, education). Given that at present the Scottish public is already able to register the wish to either donate or to not donate it is unclear what the proxy would add to the decision making process. There is however the likelihood that the need to try and identify and contact one or more proxies may lead to delay to the already complicated process of organ/tissue donation; separating authorisation for transplantation from authorisation for research/education also adds a further layer of complexity to the process. Further the Bill does not go into detail as to who would be responsible for ensuring that the details of proxies are kept up to date to ensure timely contact when/if required.
4. Do you have any comments on the role of “authorised investigating persons” as provided for in the Bill?

The Bill also describes a new role, an “Authorised Investigating Person” (AIP), health professionals whose role would be to ensure that the ability to proceed with organ/tissue retrieval is done lawfully. The Bill does not provide detail as to what profession AIPs would come from and what training will be required in order to fulfil such a role. AIPs would need to be available at all times of day and night if transplantation is to go ahead; it is unclear whether it will be possible to recruit sufficient numbers to such a role to make it viable. Further it is unclear what AIPs would add over what is currently already done by Specialist Nurses – Organ Donation (SNODs) and Tissue Donor Co-ordinators (TDCs) who ensure that organ/tissue retrieval only proceeds if there is no suggestion that the donor had expressed an objection to donation and either had expressed a wish to donate in life, or in the absence of an expressed wish to donate by the potential donor then the next of kin are asked to provide such an authorisation. Indeed it is very likely that introducing AIPs will further complicate the donation process.

Presumed consent i.e. authorisation by operation of law as in the Bill, would remove the need to gain authorisation from the next of kin. While, *prima facie*, this should lead to an increase in the number of organs/tissue available for transplantation, proceeding with organ/tissue donation in the face of next of kin objections to donation is likely to have a negative effect on donation as a whole, both due to the likely negative publicity that may ensue and more importantly due to the fact that the transplantation community is entirely dependent on the next of kin to provide the necessary medical, social and behavioural history of the potential donor to ensure the safety of the donated organs/tissue for future intended recipients. Proceeding with donation in the absence of next of kin support is likely to lead to a decline in the safety of the retrieved organs/tissue.

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 by law, leaving it open to interpretation and legal challenge which may well have a detrimental effect on donation overall. While different clinical situations provide different challenges the absence of a minimum “reasonable time” will make it very subjective and open to challenge particularly if a proxy gets in touch at a later time point or the family get in touch with evidence that the donor had indeed objected to donation after an AIP has taken the decision to proceed with donation.

While it is important to try and minimise occurrences where next of kin overturn the potential donor’s wishes to donate it is equally, if not more, important to ensure that organ and tissue donation continues to take place safely. Next of kin support and involvement remains key for this. Raising awareness and providing teaching to the public on the importance and reasons behind organ and tissue donation may be a more effective way of ensuring that donor numbers increase while at the same time maintaining the safety of all donations.

5. Is there anything in the Bill you would change? If yes, please provide more details.
At present it is unclear whether the Bill is likely to lead to an increase in the number of organs/tissue donated such that there is a significant impact on waiting list numbers. It may be sensible to wait and see the effect that a similar Bill in Wales will have on donor numbers and importantly on the effect this Bill will have on family involvement and support of donation.

The Bill seems to make provision for only a one-off publicity campaign lasting six months only. Further anyone will be considered ordinarily resident in Scotland for the purposes of this Bill and as having had reasonable opportunity to record an objection within a similar time frame. Six months seems a relatively short time for both the publicity campaign and the time interval after which one would be deemed to be ordinarily resident in Scotland (this would include most students). It will be important to ensure that children turning sixteen and new immigrants are informed of the contents of this Bill. To this end there will be the requirement to ensure either continuing publicity about this or to find an alternative way of ensuring that all teenagers and new immigrants are informed in such a way that they understand the implications of the Bill for them.

In section 7 of the Bill “Rule if order of acts unclear”, where it is uncertain which of authorisation, appointment of a proxy or register an objection came last the adult is to be treated as having done none of them which would imply that authorisation by operation of law for donation would be allowed. Given that such a potential donor has registered an objection as some point in time it is unclear why this would be ignored. Proceeding with donation under such circumstances may lead to public outcry.

In Point 62 in the Explanatory Notes document it seems that the Bill, in the case of Adults with Incapacity, would prevent a welfare attorney from either appointing a proxy or objecting to the removal of the adult’s organs. This implies that in the case of all Adults with Incapacity that Authorisation by operation of law would be possible, irrespective of the opinion of those who knew them best.

Aiming to increase the number of organ and tissue donors is indeed very important and to be supported and encouraged. Equally important however is the need to ensure public support of donation and to maintain safety of transplantation. Putting in measures to ensure and facilitate the ability to actively consider organ/tissue donation at each and every death may be more important as that would lead to organ/tissue donation being seen as a normal extension to end of life care. Introducing this as a target for clinical teams and providing them with the resource to allow this to happen will help to identify each and every potential donor. Public awareness and teaching so that the general public starts to expect being approached for donation at the time of death of a loved one may be an alternative way of ensuring donor numbers increase.