

Minister for Public Health and Sport
Joe FitzPatrick MSP



Scottish Government
Riaghaltas na h-Alba
gov.scot

T: 0300 244 4000
E: scottish.ministers@gov.scot

Lewis Macdonald MSP
Convener
Health and Sport Committee

By E-mail: HealthandSport@parliament.scot

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Dear Lewis

I am writing in response to the Health and Sport Committee's Stage 1 Report on the Human Tissue (Authorisation) (Scotland) Bill.

I am grateful to the Committee for its careful consideration and support for the general principles of the Bill. The Committee has raised a number of important points in the Report, and made a number of recommendations and I am pleased to be able to set out the response on behalf of the Government in the Annex to this letter.

As the Committee heard in evidence, introducing an opt-out system on its own is not likely to increase donation. Organ and tissue donation and transplantation are part of a complex system and no single measure will radically increase donation rates. Over the last decade improvement has been driven through the actions and measures identified in the 2008 *UK Organ Donation Taskforce Report* and *A Donation and Transplantation Plan for Scotland, 2013-2020*, details of which are included in the Annex. This has resulted in significant improvements in awareness and support for donation; improvements to infrastructure; increased deceased donor numbers; and significantly increased transplant numbers and decreased numbers of people waiting for a transplant in Scotland. The Scottish Government intends to build on this and expects to develop a plan for further action beyond 2020. Moving to a soft opt-out system delivered via the Bill will add to the measures which are already in place, along with those which are likely to be delivered through the post-2020 plan.

I would also be grateful if you would convey to the Committee that I am keen to continue to engage with Members who have an interest in making any further improvements to this legislation. In the meantime, I look forward to hearing Members' further views on the Bill during the Stage 1 debate on 26 February.

JOE FITZPATRICK

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St Andrew's House, Regent Road, Edinburgh EH1 3DG
www.gov.scot

HUMAN TISSUE (AUTHORISATION) (SCOTLAND) BILL

Scottish Government response to the Health and Sport Committee Stage 1 Report.

INCREASE IN DONATION RATES?

We acknowledge the need for absolute clarity in this Bill. It is essential individuals feel able to make an informed choice about organ donation whether by opting-in, opting-out or understanding the implications of deemed authorisation. We support the proposed approach to introduce presumed consent alongside retention of opt-in.

We recognise some groups have concerns about the potential impact on donation rates should people consider their rights as individuals are affected. Overall, we do not expect this to become a significant problem although we recommend the Scottish Government take steps to monitor public attitudes after a period of time of perhaps five years after the Act comes into force.

The Committee received evidence to suggest that the link between an increase in donation rates and presumed consent in Wales is inconclusive. Like Wales, we consider a longer period of time to evaluate the impact of the Act is required. It is not possible to make direct comparisons between Scotland and Spain due to the cultural differences and different health care models.

We note the creation of the trauma centres across Scotland and we seek confirmation each has the capacity to support the aims of this Bill.

We further recommend the Scottish Government reviews the infrastructure across the country for organ donation.

SCOTTISH GOVERNMENT RESPONSE:

The Scottish Government shares the Committee's view regarding the need for clarity in the Bill and it may be helpful to clarify initially that the Bill, in line with the approach taken in the Human Tissue (Scotland) Act 2006, enables 'authorisation' to be given, rather than 'consent', and for that authorisation to be potentially 'deemed'. It is also important to note that the Bill also applies to tissue, as well as organs.

The Bill provides a clear framework to establish whether donation is authorised, taking into account the information provided under the duty to inquire provisions. The Bill enables people to make clear decisions and the safeguards contained within the Bill, including the duty to inquire, work to support those individual choices. The Scottish Government welcomes the Committee's support of the proposed approach for the introduction of deemed authorisation alongside retaining the ability to expressly authorise donation. We consider that the continued ability to opt in is an important element of the system to enable people continue to make a express decision in favour of donation if they wish. It may be detrimental to remove this option, resulting in 'opting out' of donation as the only express action available, which could be damaging to public support for donation.

The Scottish Government similarly recognises the importance of monitoring public attitudes following the introduction of the opt-out system and can confirm that we intend to do so. As well as informing the ongoing development of public information, as the soft opt-out system becomes familiar to the public monitoring public attitudes will also form part of the longer term monitoring and evaluation arrangements being put in place.

The Policy Memorandum which accompanied the Bill set out some key objectives to be included in a long term impact evaluation of the legislation over a 10 year period. The rationale for this timescale is due to the small numbers involved in deceased donation making it difficult to make a robust assessment of the impact on specific aspects of the system. It also takes into account the experience in Wales. However, as part of the overall evaluation of the legislation it is the intention to produce intermediate information approximately 5 years after introduction on aspects such as public attitudes and awareness. It is envisaged that the Scottish Donation and Transplant Group, as part of their ongoing role, will monitor the progress and impact on donation and transplantation, as they do with any new initiative.

The Committee has also recommended the Scottish Government reviews the infrastructure around organ donation. The Scottish Government is committed to supporting measures, including in relation to infrastructure, to increase donation and transplantation which are set out in *A Donation and Transplantation Plan for Scotland 2013-20*.

This is an on-going commitment and as part of the plan we expect to develop for increasing organ and tissue donation and transplantation in Scotland from 2020 onwards, we will discuss with stakeholders whether there are further initiatives which should be progressed to improve the infrastructure for organ and tissue donation.

The Scottish Government also funds the Scottish Intensive Care Society Audit Group which aims to help drive improvement in the quality of care that is delivered to critically ill patients in Scotland. The audits and reports provide the information which enable NHS Boards to implement appropriate local solutions, including capacity in Intensive Care Units to meet the needs of patients who need to be cared for in that setting, including those who might become donors.

The Committee has requested confirmation that trauma centres have the capacity to support the aims of the Bill. The Scottish Trauma Network (STN), which began implementation in 2017, comprises an inclusive network of hospitals, which will include four Major Trauma Centres (MTCs), and integrated network infrastructure with the aim of improving care for the most severely injured patients and to ensure that they have the best chance of a speedy recovery from their injuries.

The main focus of the network is “saving lives, giving life back” and, while the care provided is at a critical point in a patient’s journey, donation may not be directly relevant. As well as introducing 4 MTCs, a network of Trauma Units and Local Emergency Hospitals will ensure the patient receives the right level of care. The Scottish Government will continue to work with NHS Boards to ensure that anyone who is not expected to survive, but could be a potential organ or tissue donor is identified, receives the appropriate support in a critical care unit and, if donation is feasible, that they are referred to either NHS Blood and Transplant or the Scottish National Blood Transfusion Service and the family is approached about donation.

RIGHTS OF THE FAMILY AND THEIR CONSENT

We note the vital role of the SNODs in supporting families throughout the organ donation process and the approach taken to ascertain the final wishes of the deceased.

We recommend a review of the authorisation process in Scotland to ensure each and every question is of clinical importance. As organ donation is a UK wide framework, we recognise this requires joint collaboration with England, Wales and Northern Ireland. It is imperative this review involves patients and families who have authorised the donation of an organ.

We support the views of Dr Cole that in practical terms it would not ultimately be possible for the medical profession to proceed with donation against the wishes expressed by patient relatives.

We also recommend investigating the use of an online medical system similar to Canada, which could be used to assist the authorisation process.

SCOTTISH GOVERNMENT RESPONSE:

The Scottish Government similarly recognises that the role of Specialist Nurses for Organ Donation (SNODs) and Tissue Donor Coordinators (TDCs) is important in supporting families throughout the process. The sensitive and supportive approach from these specialist staff, which is a real strength of the current system, will continue under the new system. Families will continue to have an important role in the donation process under the proposed system in communicating their loved one's views about donation for transplantation and also by providing the important travel, medical and personal history information about their loved one, to ensure the safety of transplantation. They will also continue to be able to authorise donation in certain circumstances, including for children and adults in excepted categories; for purposes other than transplantation and potentially for donation of excepted body parts where authorisation is deemed. Families will continue to be able to provide authorisation only where they have no knowledge that the potential donor would have been unwilling to donate.

As part of the process under the current legislation, SNODs and TDCs will ask the family about their loved one's views about donation and are trained to work with families to encourage them to support their loved one's wishes. The Bill reflects this process, section 23 requires certain health workers to undertake a number of inquiries, including to inquire into the views of the potential donor in relation to donation and the carrying out of pre-death procedures to ensure that donation and pre-death procedures do not progress against the wishes of the potential donor.

The Bill sets out a clear framework to establish whether donation is authorised, taking into account the information provided under the duty to inquire provisions. It may be helpful to confirm that the Bill does not require authorisation from families for authorisation to be deemed, but families will be able to provide information about any objection to donation that their loved one held. The Scottish Government notes that the Committee supports the view expressed by individuals working in the system that for practical reasons it would not be possible to proceed with donation against the wishes of the family.

The Committee has recommended a review of the authorisation process to ensure every question is of clinical importance. Donation and transplantation is necessarily a lengthy process given the complexities and risks involved. For families it occurs following a tragic event and at a time of great sorrow. When developing the Bill provisions the Scottish Government has been very mindful of these circumstances and has worked closely with NHS Blood and Transplant (NHSBT)

and Scottish National Blood Transfusion Service (SNBTS) to try to mirror the processes undertaken where it is necessary to reflect this in legislation so that any impact on current practice around authorisation is minimised. The development of practice is informed by the feedback received from donor families who are able to complete a service evaluation form.

The authorisation process, which the Bill provides for, is vital to ensure that proceeding with deceased donation is lawful and to provide clarity about what organs or tissue have been authorised for donation and for what purpose(s). As the Committee has noted, this is separate from the safety aspect of the process, of which the Medical and Social History (MASH) questionnaire is an important part to ensure that transplantation is safe and successful.

It is for NHSBT and SNBTS to determine what questions should be included in the MASH questionnaire and to ensure they are of clinical importance. This assessment is based on the requirements of the Human Tissue Authority (HTA) to ensure compliance with regulations to ensure the safety of organ and tissue transplantation. Advice is also provided by the Advisory Committee on the Safety of Blood, Tissues and Organs (SaBTO), which includes lay and patient representatives, and from other professional groups and bodies.

It would not be appropriate for the Scottish Government to seek to influence this as such decisions need to be taken by those with appropriate clinical expertise and the HTA as regulator, but the Scottish Government will be writing to both organisations to draw their attention to the Committee's recommendation.

The Committee has also recommended investigating the use of an online medical records system. Medical records are accessed as part of the donation process in order to inform the risk assessment of organs and tissue for transplantation. However, medical records will not contain all the information which is required to inform the risk assessment, for example travel and social history and any health problems which have not been reported and investigated. This is why the MASH questionnaire is used to provide supplementary information, not contained in medical records, to enable a full risk assessment to be carried out.

Even if this information were to be added to medical records, including by potential donors during their lifetime, there would be no guarantee that it would be complete and contain all the information required, or that it would be up to date. Families would still need to be asked to confirm the position, provide further detail and the most up to date information. For these reasons our view is that access to records, via an online system or otherwise, may always provide only part of the information needed in relation to organ and tissue donation and will continue to need to be supplemented by information from families.

PRE-DEATH PROCEDURES

We recognise the careful steps taken to inform and involve families in pre-death procedures and we accept the proposals in this Bill. We recommend the procedures be reviewed in 5 years.

SCOTTISH GOVERNMENT RESPONSE:

The Scottish Government welcomes the Committee's acceptance of the proposals in the Bill and can confirm that the intention is to keep the procedures under review with key stakeholders and the Scottish Donation and Transplant Group. It may be helpful to clarify that the UK Donation Ethics Committee ceased to be in operation from April 2016. The procedures will be set out in regulations following consultation, and will be kept under review e.g. whether any changes to the lists of Type A and Type B procedures should be made in future.

We also share the Committee's recognition of the care taken to inform and involve families in pre-death procedures. The Committee highlighted the involvement of families in tests carried out to diagnose death by neurological criteria (or "brain-stem death"). These tests are separate to the pre-death procedures covered in the Bill which are carried out to help facilitate successful transplantation where a person is expected to die following circulatory death. Families will continue to be involved in end of life care, and the donation process including providing information about their loved one's views about pre-death procedures. The Bill also includes a duty on Scottish Ministers to raise awareness about pre-death procedures so more generally people will be aware of these procedures, and therefore what may be involved as part of the donation process.

The health and wellbeing of the patient remains the priority. The Bill clearly sets out the circumstances in which the procedures may be undertaken, including that the procedures may not be carried out prematurely, reflecting current good practice and the high standard of care provided to people who may become donors.

POST-TRANSPLANT CARE

We applaud the actions taken to ensure families feel valued and appreciated following the organ donation process. We recommend this continues even if there is an increase in the number of organs and tissues donated.

We recommend the support given to families is included in the evaluation of the Bill, five years from the date of implementation of the Act.

SCOTTISH GOVERNMENT RESPONSE:

The Scottish Government recognises the role of the family in the gift of donation and the selfless decision families make to support the process. **The Scottish Government accepts the Committee's recommendation that the support given to families is included in the evaluation of the Bill, five years from the date of implementation of the Act.** Whilst recognition and support for donor families is primarily a matter for NHSBT and SNBTS, it is the intention to continue these actions in future, such as the annual donor recognition service including the presentation of St John's medals, the ongoing upkeep of the organ and tissue donor memorial and the Loveseat at the Kelvingrove museum, memorial services and the work carried out by NHSBT and SNBTS to write to donor families to keep them informed about the outcome of the donation process.

The support given to families can be taken into account in the evaluation of this legislation, although the main focus of the evaluation will be on the effectiveness of the legislation, the procedures and training which have been put in place and what impact there has been on donation and transplantation.

MENTAL HEALTH

Having heard first-hand evidence suggesting there is a gap in mental health funding relating to pre and post-transplant care, there should be no difference in the approach between those donating blood stem cell or bone marrow and those making donations under this Bill. We recommend the Scottish Government improves the services available for patients on the transplant waiting list, recipients of organ donation and families who have authorised the donation of an organ from a relative.

SCOTTISH GOVERNMENT RESPONSE:

NHS National Services Scotland's National Services Division (NSD) is responsible for commissioning transplantation services including elements of psychological support in the pre- and immediate post-transplant phases. The provision of psychological support across all nationally-commissioned specialist services, including both organ transplantation and paediatric stem cell transplantation, is currently being reviewed by NSD to ensure appropriate provision is in place. The Scottish Government understands that the review will be completed later this year.

Current levels of psychological support for those waiting for and who have recently received an organ transplant are very similar to those for people waiting for or who have recently received a stem cell or bone marrow transplant. It should be clarified that there is no specific mental health support provided to stem cell or bone marrow donors (as opposed to recipients) as there is not considered to be a clinical need for such support.

As part of the plan the Scottish Government expects to develop for donation and transplantation from 2020 onwards, we intend to look at post-transplant aftercare being provided by NHS Boards and whether there are appropriate ways this could be improved, with increased equity of support across Scotland. As part of this, we plan to consider ongoing provision of mental health support as well as ensuring each patient's physical health is appropriately supported.

Psychological support is one element of the wider package of care which includes support and signposting from non-psychological staff, and support from third sector organisations, for example peer support delivered through charities supporting those with issues such as renal failure or heart disease. Broader work is also ongoing to try to improve the utilisation of organs so that the number of potential recipients who are stood down for transplants is reduced.

In terms of support for donor families, bereaved families can be directed to their GP or Cruse Bereavement Care Scotland where appropriate. However, that support is with regards to bereavement – not donation, which is broadly seen as a positive part of the bereavement process. As the Committee has acknowledged, families receive broader recognition and support following donation as noted above.

AWARENESS RAISING

We welcome a high profile public information campaign for at least 12 months before commencement of the system but suggest the Scottish Government Reviews the engagement strategy in Wales following the implementation of the Human Transplantation (Wales) Act 2013. We recommend reviewing their methods of reaching new residents to the country, different demographics, various cultural backgrounds and ethnic minority groups to ensure the law is upheld and maintained with public awareness at the highest level.

Following the strategy applied in Wales, we also recommend undertaking outreach sessions with minority groups in order to explain the implications of the Bill with regards to deemed authorisation (presumed consent).

In relation to engaging with children specifically, we welcome the work undertaken by the Anthony Nolan Trust and their collaboration with Fire and Rescue Service (SFRS). SFRS volunteers have delivered presentations and events in secondary schools and colleges, raising awareness of blood cancers and the stem cell donor register. This has increased the number of donors available to save the lives of others, including children. We recommend a collaboration with the Anthony Nolan Trust and Fire and Rescue Service (SFRS), adding organ donation to their programme in secondary schools and colleges. An umbrella of information covering blood cancers, stem cell donation and organ donation could raise awareness but also utilise resources in Scotland. The secondary school and college curriculum should include equal information on the three options available; how to opt-in, how to opt-out and the meaning of deemed authorisation. This programme should begin 12 months prior to the implementation of the Act and be sustained to ensure universal coverage.

We also recommend utilising social media platforms to engage with children before they reach the age of consent and continuing the campaign for future years to include application for a driving licence and entrance to University (UCAS).

SCOTTISH GOVERNMENT RESPONSE:

The Scottish Government accepts the Committee's recommendation to review the engagement strategy undertaken in Wales. In developing public information for organ and tissue donation a review of the Welsh public awareness campaign is to be undertaken. In addition, we are in contact with colleagues in NHSBT which is developing campaign information for the proposed introduction of an opt-out system in England, on behalf of the UK Government, to access their research and to keep updated on their campaign development. Learning from both countries will be considered to ensure that public information in Scotland is based on the best evidence available.

In addition, evidence already gathered from previous campaigns about awareness and attitudes towards organ donation in Scotland will be utilised and new research commissioned to fill any gaps in understanding. Evaluation of the most recent donation campaign also incorporated a number of questions to assess current awareness levels about the proposed change to a soft opt-out system. As is practice with all Scottish Government public information campaigns, key messages and graphics will be tested on sample groups of the public to gauge understanding and impact.

The Scottish Government also accepts the Committee's recommendation to undertake outreach sessions with minority groups. As part of the consultation on proposals to increase donation and transplantation meetings and focus groups where held with representatives of faith groups, learning disabled people, and young people, including those who are care experienced. There was broad agreement from all these groups of the importance of reaching minority groups in as many different ways as possible and also providing accessible information in a range of formats.

The Equality Impact Assessment which accompanies the Bill highlights the importance of the awareness raising activities reaching a wide range of people including hard to reach groups and those with specific needs. For example, the impact assessment acknowledged the need for awareness raising materials to take account of the needs of people who don't speak English, or speak little English, by providing information in different languages. Information will also be produced in different formats including easy read and British Sign Language (BSL), so that people can make informed decisions. The Scottish Government will work with a range of organisations to ensure that as many methods of raising awareness as possible are developed and that information provided meets the needs of different groups.

On-going awareness raising work regarding donation and also future awareness raising specifically regarding the soft opt-out system will be important in explaining what choices people will have and also in helping to increase understanding and support for donation more broadly. Given the lower donation rates amongst ethnic minority groups it is important that current work continues to promote awareness and support for donation within ethnic minority communities and that this takes account of the change to the new system and seeks to allay concerns that communities may have. As part of ongoing outreach initiatives on organ and tissue donation the Scottish Government works with Kidney Research UK which trains volunteers from ethnic minority communities to become peer educators to increase awareness of kidney disease and organ donation. This work, along with that of those within the donation workforce with specific responsibility with regards to ethnic minority communities, will continue and will be important in promoting understanding and awareness of the change to an opt-out system. We have had early discussions with the peer educator network lead, and the NHS Clinical Lead for Black Asian and Minority Ethnic (BAME) donation and plan to undertake further work to engage with these communities. This will build on the ongoing work to raise awareness about donation.

NHSBT already produces leaflets which explain the organ donation system and how it relates to the different faiths. These are produced in collaboration with faith groups. As well as this, the work carried out amongst ethnic minority communities is done primarily through faith networks. We will continue to use our links with these networks to raise awareness about the new system. Additionally, in our engagement with faith groups we have made contacts to help disseminate factual information about the move to an opt-out system.

The Committee has recommended a number of initiatives regarding raising awareness amongst young people. The Scottish Government recognises the importance that, as part of broader awareness raising activities, awareness is raised about the new system amongst young people specifically as they approach the age from which authorisation may be deemed, so they are aware of its implications for them.

The Scottish Government has proposed direct mailings for young people approaching the age boundary to inform them of their choices, we are currently exploring ways of achieving this and costing for this is included in the Financial Memorandum. This was identified as one of the preferred methods of communication by focus groups of young people who were considering the proposals for a soft opt-out system and how best to communicate with young people about this. It is also a method utilised to inform those attaining the age boundary in Wales.

The focus groups with young people have helped to identify which methods of communication are preferred and will feed into the overall awareness raising strategy. The Scottish Government is aware that the Welsh Government raised awareness amongst students newly resident in Wales through UCAS and would be happy to consider a similar approach to reach university and college students as part of our broader awareness raising work.

The application for a DVLA driving licence includes the option to opt in to donation and the intention is for this to remain available under the new system. It is only possible to opt in via the DVLA as there is some inevitable time-lag in processing registrations between third parties and the ODR and it is imperative that opt-out decisions are recorded promptly.

As part of the tools to raise awareness amongst children and young people about donation generally and about the soft opt-out system, the Scottish Government intends to update its internationally recognised teaching resource pack which covers all aspects of organ and tissue donation. It is aimed at pupils from age 12, when they are able to record donation decisions. It does not seek to influence decision making by children and young people, rather to present them with information so that they can make an informed choice about donation if they wish.

Separately to this, the Scottish Government works in partnership with Anthony Nolan to raise awareness of its stem cell register amongst young people aged 16 and above, including in schools and colleges. The Scottish Fire and Rescue Service (SFRS)/Anthony Nolan presentations to schools, delivered by SFRS, already raise awareness of organ and tissue donation. The intention is to continue to do this and SFRS colleagues are happy to assist in raising awareness of the new system. We are discussing with SFRS how this may be done. However, it would be more appropriate for this to be a supplementary, rather than the only, means of raising awareness amongst children and young people in schools.

Firstly, the SFRS/Anthony Nolan sessions are aimed at young people from age 16 as this is the age from which a young person can join their stem cell register. However it will be important to raise awareness of organ and tissue donation and the soft opt-out system among children and young people from when they are able to record a decision, at age 12, and particularly in advance of them reaching the age of 16 when deemed authorisation would apply if they were to die in circumstances where they could become a deceased donor.

Secondly, the requirements of the Human Tissue (Authorisation) (Scotland) Bill are fairly complex. Therefore, whilst SFRS/Anthony Nolan Partnership can give an overview of the deemed authorisation system and signpost young people to sources of further information, it is not something that could be added on briefly to a presentation primarily about living stem cell donation and it's unlikely to be possible to cover both topics fully. There is also a risk of causing confusion between the two topics.

Thirdly, the SFRS/Anthony Nolan presentations do not cover all Scottish schools, whereas the resource pack is sent to all secondary schools. The Scottish Government considers that the combined sources of information from the resource pack, SFRS/Anthony Nolan presentations, the letter to each 15 year old, as well as broader awareness raising would maximise awareness raising amongst young people across the country.

Therefore, the Scottish Government considers that the main method of schools-based communication with children and young people about the soft opt-out system should continue to be via the teaching resource pack. The pack will be updated to reflect the change to the new system, including what choices children and young people will be able to make and what the implications will be from age 16. However, as the Committee suggests, we will aim to use other opportunities, such as SFRS/Anthony Nolan presentations to reinforce awareness raising.

ADULTS WITH INCAPACITY

We are content with the provisions in the Bill relating to adults with incapacity.

SCOTTISH GOVERNMENT RESPONSE:

The Scottish Government notes that the Committee is content with the Bill's provisions relating to adults with incapacity. The Bill recognises that a person who lacks capacity to understand deemed authorisation cannot reasonably be expected to have made a choice in favour of donation by not opting out. People will be affected in different ways; some with conditions that cause intermittent incapacity before capacity is lost completely, others with lifelong incapacity. The reason for the incapacity is not relevant for the Bill, only whether or not there has been a lack of capacity over a significant period of time.

In the absence of the adult opting in or out, the nearest relative can authorise donation provided that the person was not unwilling to donate. In addition, the provisions also recognise the requirements and principles of the United Nations Convention on the Rights of Persons with Disabilities, the Mental Health (Care and Treatment) (Scotland) Act 2003 and the Adults with Incapacity (Scotland) Act 2000 by requiring the nearest relative to also have regard to the past wishes and feelings of the potential donor which are relevant to donation, as far as they are known. This allows for circumstances where a person may have had a view on donation, but subsequently lost capacity (unless the person had previously actively opted in or out of donation, in which case the previous recorded decision would still apply as under the current legislation).

The Bill provides that a potential donor falls within this excepted category only where the lack of capacity has existed over a significant period of time. The Bill is not prescriptive as to what a significant period is as it is likely to vary from case to case, but it should be long enough so as to mean that the potential donor cannot have been reasonably considered to have had an understanding of the opt-out system. The provisions are flexible to allow interpretation in each individual case and to allow the SNOD or TDC to enquire into medical records and have discussion with the clinical team and the family.

OVERALL CONCLUSIONS

The Committee supports the general principles of this Bill.

We have received evidence to suggest this Bill alone will not achieve an increase in donation rates. We consider an ongoing, targeted engagement strategy which encourages greater awareness of the benefits and requirements of organ donation, is required. The role of the specialist nurses and the way in which they communicate with relatives prior to donation is also key to the success of this Bill.

We have endeavoured to raise constructive suggestions throughout this report and seek further detail and information to strengthen the Bill. We look forward to receipt of the Scottish Government's response to the issues we have raised.

SCOTTISH GOVERNMENT RESPONSE:

The Scottish Government welcomes the Committee's support for the general principles of the Bill. The Scottish Government similarly recognises that there is little firm evidence that opt-out legislation in isolation causes increases in donation. However, there is encouraging evidence that, as part of a package of measures, it can lead to increases.

Work has been ongoing in Scotland and across the UK to deliver a package of measures to improve donation and transplantation over the last decade. The 2008 UK Organ Donation Taskforce report considered the introduction of an opt-out system but prioritised improvements in infrastructure. The report identified barriers to donation around donor identification and referral; donor co-ordination; and organ retrieval arrangements. It made a number of recommendations which have contributed towards the progress which has been seen since. These include:

- Establishment of a UK-wide organ donation organisation (NHSBT)
- Establishment of a network of Clinical Leads for Organ Donation
- Establishment of NHS Organ Donation Committees in NHS boards
- Improvements in data monitoring
- Establishment of an electronic organ offering system
- Establishment of a UK-wide network of retrieval teams
- Training for clinical staff likely to be caring for potential donors

Building on the UK Taskforce report, *A Donation and Transplantation Plan for Scotland, 2013-2020* provided the basis for the Scottish Government, in partnership with NHSBT, SNBTS and others, to deliver further improvements to the system of organ and tissue donation and transplantation in Scotland. The plan identifies five priorities the Government wishes to deliver: increasing the number of people who have made their wishes about organ donation known; increasing the availability of organs; making every donation count; ensuring NHS Scotland supports donation and transplantation; and ensuring the public in Scotland is informed and engaged about donation and transplantation. Its actions include:

- Dedicated regional manager for Scotland to manage the Specialist Nurses for Organ Donation and to take forward key initiatives to help increase donation.
- High profile publicity campaigns to encourage people to join the Organ Donor Register
- Internationally recognised schools educational resource pack to increase awareness of organ and tissue donation from age 12

- Working with Kidney Research UK which trains volunteers from black, Asian and minority ethnic communities to become peer educators to increase awareness of kidney disease and organ donation

Taken together these programmes of work have delivered significant improvements in donation and transplantation. The introduction of a soft opt-out system of organ and tissue donation will contribute further to this work and to the progress already made. The Scottish Government intends to build further on this and expects to develop a Plan for further action beyond 2020, which will incorporate elements of the Committee's recommendations.