Transplantation (Authorisation of Removal of Organs etc.) Scotland Bill

General Medical Council

Thank you for the opportunity to submit our views on the Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill. To put this reply in context I will briefly outline the role of the General Medical Council (GMC). We are an independent organisation that helps to protect patients and improve medical education and practice across the UK.

- We decide which doctors are qualified to work here and we oversee UK medical education and training.
- We set the standards that doctors need to follow, and make sure that they continue to meet these standards throughout their careers.
- We take action to prevent a doctor from putting the safety of patients, or the public’s confidence in doctors, at risk.

Every patient should receive a high standard of care. Our role is to help achieve that by working closely with doctors, their employers and patients, to make sure that the trust patients have in their doctors is fully justified.

In October 2014 we submitted a response to Anne McTaggart MSP, outlining our position regarding the Draft Bill. In commenting, our aim was (and remains) to ensure that any obligations the Bill might impose on doctors will not be inconsistent with the standards we set for doctors’ professional practice. I should highlight, however, that our guidance for doctors reflects the laws of all four countries of the UK, and as with any new piece of legislation we would seek counsels’ advice on whether we would need to update our guidance if it were introduced.

We consider questions two and three and four to be within our remit to provide a response, and for consistency have reiterated those parts of our response to Anne McTaggart MSP which we believe to be relevant to this call for evidence.

**Question 2: Do you support the proposal of appointing a proxy. Please provide an explanation for your answer.**

We understand this proposal to be consistent with the law relating to consent and the patient’s ability to appoint a proxy to make decisions about their care. The proposals are also consistent with our guidance to doctors on the appointment of a legal proxy as set out in paragraphs 15 and 16 of Treatment and care towards the end of life: good practice in decision making.

However, our guidance advises on the decision making model that applies when a patient who has appointed a legal proxy is still alive, and so focusses on what would be of overall benefit to the patient. In the context on continuing treatment on a patient after a decision has been made that is of no benefit to them (for example while making arrangements to assemble the transplant team), we think there may be a potential conflict with the principles underlying
the Adults with Incapacity (Scotland) Act 2000, which requires decisions for those without capacity to be based on the 'benefit' to the patient.

Our guidance relating to consent and a patient’s capacity to make decisions about their care takes into account the legal position across the UK. However our guidance supports the role of people close to the patient in this regard. The relevant guidance is Consent: patients and doctors making decisions together (paragraphs 22, 48 and 76)

22. You should accommodate a patient’s wishes if they want another person, such as a relative, partner, friend, carer or advocate, to be involved in discussions or to help them make decisions. In these circumstances, you should follow the guidance in paragraphs 7-21.

23. By law you must get written consent for certain treatments, such as fertility treatment and organ donation. You must follow the laws and codes of practice that govern these situations.

76. You must also consider... the views of people close to the patient on the patient’s preferences, feelings, beliefs and values, and whether they consider the proposed treatment to be in the patient’s best interests.

In Treatment and care towards the end of life: good practice in decision making (paragraphs 17-21, 54 and 81-82) we recognise the significant role that those close to the patient can play in their care and the importance of obtaining their views on the patients preferences, feelings, beliefs and values.

17. The people close to a patient can play a significant role in ensuring that the patient receives high-quality care as they near the end of life, in both community and hospital settings. Many parents, other close relatives and partners, as well as paid and unpaid carers, will be involved in discussing issues with a patient, enabling them to make choices, supporting them to communicate their wishes, or participating directly in the treatment and care. In some cases, they may have been granted legal power by the patient, or the court, to make healthcare decisions when the patient lacks capacity to make their own choices.

18. It is important that you and other members of the healthcare team acknowledge the role and responsibilities of people close to the patient. You should make sure, as far as possible, that their needs for support are met and their feelings respected, although the focus of care must remain on the patient.

19. Those close to a patient may want or need information about the patient’s diagnosis and about the likely progression of the condition or disease, in order to help them provide care and recognise and respond to changes in the patient’s condition. If a patient has capacity to make decisions, you should check that
they agree to you sharing this information. If a patient lacks capacity to make a decision about sharing information, it is reasonable to assume that, unless they indicate otherwise, they would want those closest to them to be kept informed of relevant information about their general condition and prognosis. (There is more guidance in our booklet on Confidentiality.) You should check whether a patient has nominated someone close to them to be kept informed and consulted about their treatment.

20. When providing information, you must do your best to explain clinical issues in a way the person can understand, and approach difficult or potentially distressing issues about the patient’s prognosis and care with tact and sensitivity. (See paragraphs 33-36 on addressing emotional difficulties and possible sources of support.)

21. When discussing the issues with people who do not have legal authority to make decisions on behalf of a patient who lacks capacity, you should make it clear that their role is to advise the healthcare team about the patient’s known or likely wishes, preferences, feelings, beliefs and values. You must not give them the impression they are being asked to make the decision.

54. Depending on the patient’s circumstances, it may also be appropriate to create opportunities for them to talk about what they want to happen after they die. Some patients will want to discuss their wishes in relation to the handling of their body, and their beliefs or values about organ or tissue donation.

**Question 3: Do you have any comments on the role of “authorised investigating persons” as provided for in the Bill?**

As with the previous question, our guidance Consent: patients and doctors making decisions together is the most relevant. Paragraphs 81-82 state that:

81. If a patient is close to death and their views cannot be determined, you should be prepared to explore with those close to them whether they had expressed any views about organ or tissue donation, if donation is likely to be a possibility.

82. You should follow any national procedures for identifying organ donors and, in appropriate cases, for notifying the local transplant coordinator. You must take account of the requirements in relevant legislation and in any supporting codes of practice, in any discussion that you have with the patient or those close to them. You should make clear that any decision about whether the patient would be a suitable candidate for donation would be made by the transplant coordinator or team, and not by you and the team providing the treatment.
**Question 4: Is there anything in the Bill you would change? If yes, please provide more details**

In our response to Anne McTaggart MSP, we said that in considering the implications for equality, it may be helpful to think about whether and how information about donation and transplantation can reach all members of our society. If it doesn’t do so, those already disadvantaged in the healthcare system (those with poor literacy, people with no functional use of English, people with learning difficulties etc.), and likely to experience further inequality. We would therefore question whether the Bill as it is written addresses this point, and encourage amendments at Stage 2 which would seek to do so.

We also commented that we would be interested in understanding how the proposals aim to inform the public and patients about their right to opt out. We therefore welcome section 1 subsection 2 setting out the publicity campaign and the period for patients to register their opt-out prior to the introduction of the new procedures. We would urge that the length and scope of this campaign is sufficient to support patients, doctors and other health professionals adapt to the new procedures.

**Other comments**

In our response to Anne McTaggart MSP, we indicated the proposal that only adults (and not children) should be automatically opted was consistent with our guidance [Consent: patients and doctors making decisions together](#) and [0-18 years: guidance for all doctors](#) which were developed taking account of UK law.

**General Medical Council**