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Dear Ms McTaggart MSP

Thank you for the opportunity to respond to your consultation on changing the system of organ and tissue donation registration from an opt-in system to a soft-opt out system. I have been asked to respond on behalf of the General Medical Council (GMC).

The GMC is the independent regulator for doctors in the UK. Our purpose is to protect, promote and maintain the health and safety of the public by ensuring proper standards in the practice of medicine. We do this by:

- keeping up-to-date UK registers of qualified doctors
- fostering good medical practice in the UK
- promoting high standards of medical education in the UK
- dealing firmly and fairly with doctors practising in the UK whose fitness to practise is in doubt.

Our role includes advising all doctors across the UK on the standards of professional conduct expected of them. Doctors must be familiar with and follow our guidance, set out in *Good medical practice* and our explanatory guidance\* and be willing and able to justify any departure from that guidance. Serious or persistent failure to follow the guidance will put a doctor's registration at risk.

In commenting on the proposed draft legislation, our aim is to ensure that any obligations it might impose on doctors will not be inconsistent with the standards we set for doctors' professional practice.

We haven't commented on consultation questions 1, 2, 6, 7, 8, 9 and 10 as they fall outside our remit. Our response to the remaining questions is as follows.

\* All our ethical guidance is available on our website at: <http://www.gmc-uk.org/guidance/index.asp>

### **Question 3**

***I believe the role of the family should be limited to being consulted on whether they are aware of any (unregistered) objection by the deceased rather than asking for their consent. Do you agree? Please indicate 'yes/no/undecided' and explain the reasons for your response.***

This is consistent with our guidance relating to consent and a patient's capacity to make decisions about their care which 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.*

*48. 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<sup>18</sup>*

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 their 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.

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 potential organ donors and, in appropriate cases, for notifying the local transplant coordinator.<sup>xiv</sup> You must take account of the requirements in relevant legislation<sup>xv</sup> and in any supporting codes of practice<sup>xvi</sup>, in any discussions 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 treatment.

#### **Question 4**

**Do you think that the individual should be able to appoint a proxy to make the final decision regarding transplantation on their behalf? Please indicate 'yes/no/undecided' and explain the reasons for your response.**

Yes, we understand this to be consistent with the law relating to consent and the patient's ability to appoint a proxy to make decisions about their care. Your proposals are 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 focuses on what would be of overall benefit to the patient. In the context of continuing treatment on a patient after a decision has been made that it 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.

### **Question 5**

***My proposal is that only adults should be automatically opted –in to be a donor. Younger persons would have to register to be a donor, by themselves or with parental consent as they currently do. This approach is I believe the best way to safeguard children and young people. Do you agree? Please indicate 'yes/no/undecided' and explain the reasons for your response.***

Yes, this is 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. However, I would highlight our advice at [paragraphs 25-26 of 0-18 years: guidance for all doctors](#).

*25. The capacity to consent depends more on young people's ability to understand and weigh up options than on age. When assessing a young person's capacity to consent, you should bear in mind that:*

*a. at 16 a young person can be presumed to have the capacity to consent ([see paragraphs 30 to 33](#))*

*b. a young person under 16 may have the capacity to consent, depending on their maturity and ability to understand what is involved.<sup>6</sup>*

*26. It is important that you assess maturity and understanding on an individual basis and with regard to the complexity and importance of the decision to be made. You should remember that a young person who has the capacity to consent to straightforward, relatively risk-free treatment may not necessarily have the capacity to consent to complex treatment involving high risks or serious consequences.\* The capacity to consent can also be affected by their physical and emotional development and by changes in their health and treatment.*

### ***Question 11***

***Is the proposed bill likely to have any substantial positive or negative implications for equality? If it is likely to have a substantial negative implication, how might this be minimised or avoided?***

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.), are likely to experience further inequality.

### ***Question 12***

***Do you have any other comments on or suggestions relevant to the proposal?***

Our comments focus on potential impact that legislation might have on the ability of doctors to fulfil their professional obligations and also on the relationship between doctors and patients. This professional relationship is premised on respecting the autonomy of the patient and their individual responsibility for decision-making.

A system of presumed consent which relies on a person's silence may be perceived to create a risk that the person is held to have consented when in fact they have not. We would therefore be interested in understanding how the proposals aim to inform the public and patients about their right to opt out.

We hope that these comments are helpful. We would be happy to discuss further. Please contact Nilla Varsani on 020 7189 5202.

Yours sincerely

**Judith Hulf**

**Director of Education and Standards**

**General Medical Council**