

HUMAN TISSUE AUTHORITY: DRAFT CODE OF PRACTICE: CODE F: DONATION OF SOLID ORGANS AND TISSUE DONATION



Response from Humanists UK, September 2019

ABOUT HUMANISTS UK

At Humanists UK, we want a tolerant world where rational thinking and kindness prevail. We work to support lasting change for a better society, championing ideas for the one life we have. Our work helps people be happier and more fulfilled, and by bringing non-religious people together we help them develop their own views and an understanding of the world around them. Founded in 1896, we are trusted to promote humanism by over 85,000 members and supporters and over 100 members of the All Party Parliamentary Humanist Group. Through our ceremonies, pastoral support, education services, and campaigning work, we advance free thinking and freedom of choice so everyone can live in a fair and equal society.

1. Are you responding as a professional/on behalf of an organisation, or as a member of the public?

I am responding on behalf of an organisation

2. If you agree to be contacted further regarding your feedback, please provide your contact details below

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3. Is the Code of Practice clear?

No

4. If no, which part(s) are difficult to understand?

Overall, we are supportive of the change to an opt-out donation system across England, and believe that the Human Tissue Authority's (HTA) Code of Practice (the Code) gives a thorough grounding in the practical applications of the Organ Donation (Deemed Consent) Act. However, we have concerns about the clarity of sections on conditions on consent for organ transplant (para 24-26), the role of the family (para 53-56), and the lack of inclusive language and equal consideration of non-religious beliefs in the section covering 'faith and beliefs' (para 57-70). Therefore, we would like to recommend changes to the text in order to make the code fully inclusive of all religion and belief groups including the non-religious. We do this in response to questions 6, 10, and 12.

5. Are the examples in the Code of Practice helpful to practitioners?

No



6. If no, please tell us why.

Most of the examples given are helpful and illustrative of when consent can be deemed or not, and when the decision to go ahead with donation can be altered by new information. However, there are two areas where we believe that the examples given could be improved.

Firstly, the examples given in paragraph 24 of the type of prohibited restrictions on the recipient of donated organs are not clear. This list states that the nine characteristics protected under the Equality Act 2010 are included, but then lists some but not all of them separately. There seems no logical reason to do this, and it causes confusion by giving the impression that a restriction, for example, on the grounds of gender or race, which are listed separately, is more important than sexual orientation or sex, which are not, when legally all characteristics are afforded equal protection in law. Moreover, the language used in the Code should reflect that used in equality legislation. Therefore, 'religion' should be listed as 'religion or belief' to indicate that it applies not only to religious beliefs, but also to certain protected philosophical beliefs. It also lists race, colour, and national origin as separate characteristics when by law the latter two are part of the definition of race. It also conflates 'national and social origins', the first part being an aspect of race that is protected by law and the second referring to social class which is not defined in law. This should be separated out into 'national and ethnic origins' to reflect the Equality Act protections and 'social origins' be added as a separate and additional item in the list.

Secondly, as detailed fully in question 18, we believe that the Code could benefit from additional practical examples of how SNODs can access the suitability of the information given by families about the intentions of the deceased.

7. Does the Code of Practice make clear in which situations consent may be deemed?

Yes

8. If no, please tell us why.

N/A

9. Role of the Family (paragraphs 48-54): Is the role of the family clear within the Code of Practice?

No

10. If no, please tell us why.

We are concerned that the Code, as proposed, does not clarify whether donation in practice can go ahead if there is consent from the deceased, but an objection from the family. In paragraph 53 the Code makes it clear that a family has no legal right to object to donation where appropriate consent is in place, yet other parts of the Code state that although established consent means a donation can take place, it does not mandate that it will proceed.



During stakeholder meetings with the HTA and representatives from religion and belief groups, it was stated that donations would be unlikely to go ahead even in cases where the deceased's consent was clear and not deemed. This amounts to a *de facto* power of veto from family members, if not a *de jure* one. This was a contentious issue for many religion and belief groups and highlighted concerns that the balance has not been struck correctly between the rights of family members to observe their religion or belief with regards to their deceased family members, and the individual's right to determination over their organs. The Code does not come to a satisfactory resolution for practitioners about how to resolve a conflict beyond discussing the matter 'sensitively' with families, and if and how to proceed with a donation if the family raise objections. The fact that the family does not have a legal right to override the donor's decision, which is the case under both opt-in and opt-out systems, does not offer practical assistance to proceeding in such circumstances. We are keen to see the Code address this issue directly as it was raised on a number of occasions by stakeholders in religion or belief groups.

11. Faith and cultural considerations (paragraphs 55-64): Are considerations around faith and culture captured appropriately within the Code of Practice?

No.

12. If no, please tell us why.

We recommend that the language used in the Code should at all times be equally inclusive of the non-religious and that the best way in which to achieve this is to reflect the language used in the Equality Act (i.e. 'religion or belief' rather than 'faith').

The recent British Social Attitudes survey, the most comprehensive poll of the beliefs and social views of the UK population, reports that over half (52%) of the population identify as non-religious.¹ Importantly, it shows that about a third of people describe themselves as 'very or extremely non-religious'. The Code should recognise that many of these people will have seriously and sincerely held non-religious beliefs and values which may inform their attitudes to organ donation. The language of the code should reflect this.

In the current proposed Code the term 'faith' is being used as a proxy for religious beliefs. This is inappropriate and lacks clarity. Firstly, the term 'faith' is inappropriate as it is an exclusive term and at times within this Code is used without clarification or implication that the term should also include non-religious donors, non-religious practices or observances, or accredited pastoral carers in hospital teams who provide the equivalent of religious chaplaincy. Secondly, the term 'faith' lacks clarity as it is not legally defined and is not always understood to mean religious beliefs. For example, the word 'faith' is used secularly to describe a confidence in a belief or opinion that does not relate to that person's religious or cultural background. The Code's language should not assume that only religious people have faith.

¹ Humanists UK, *Latest British Social Attitudes survey shows continuing rise of the non-religious* July 2019. <https://humanism.org.uk/2019/07/11/latest-british-social-attitudes-survey-shows-continuing-rise-of-the-non-religious/>



In most cases the term 'faith' should be replaced with 'religion or belief' or just 'beliefs' as appropriate. In addition, the provision of non-religious pastoral carers/leaders should be recognised along with religious leaders/chaplains (para 64 & 66). Training should encompass those with non-religious beliefs as well as those with religious beliefs (para 65).

We also recommend the following changes to the wording of the Code by paragraph number:

24. Replace 'religion' with 'religion or belief'. [Article 14 of the European Convention on Human Rights, the Human Rights Act 1998, and the Equality Act 2010 refer to 'religion or belief' not just 'religion'. The difference is important as it means that those with non-religious worldviews must not be discriminated against.]

33. Replace 'faith and beliefs' with 'religion or beliefs'.

56. After para 56 replace the sub-heading 'Faith and beliefs' with 'Beliefs'

57. Replace 'a decisive' with 'an important'. [As currently written this paragraph implicitly assumes that a person's beliefs are a decisive factor. This is inconsistent with a person-centred approach. It is up to the person to decide if these beliefs should be a decisive factor or not.]

58. First sentence, replace 'faith or belief' with 'religion or belief'. Second sentence, delete 'faith or'.

60. After 'donors' delete 'faith'. After 'support from' replace 'faith' with 'religion or belief'. [It may be appropriate for a SNOD/SR to seek advice from a non-religious pastoral carer or a humanist leader.]

61. Replace 'faith or' with 'their'.

62. Replace 'faith' with 'religion'.

63. Replace 'faith, belief' with 'religious/non-religious belief'

64. First sentence, after 'donor's' replace 'faith' by 'religion'. The remaining paragraph should be replaced with 'Where indicated, SNOD/SRs should facilitate consultation with religious/non-religious leaders to provide counsel or clarification on how donation may proceed. For example, the family may wish to receive advice on appropriate end of life rituals or ensure that any religious obligations are observed should donation take place'. [The proposed wording has the advantage that it includes people with non-religious beliefs. For example, they may want a humanist or civil funeral. This wording also puts more emphasis on giving advice... to families.]

65. Delete 'and religious imperatives' and replace with 'religious and non-religious beliefs'. [As currently written, those with non-religious beliefs are disregarded. The proposed text includes those with non-religious beliefs. It is important that this is followed up in developing training



programmes which will cover the support available to those with non-religious beliefs. The use of the word 'imperatives' is inappropriate (see 57 above)].

66. Replace with 'Hospitals may also have trained faith advisers, chaplains or accredited non-religious pastoral carers who can help facilitate conversations about organ donation between the family and SNOD/SRs'. [As currently written, this only refers to religious people. The proposed wording pays due regard to those with non-religious beliefs. A large proportion of hospitals now have accredited non-religious pastoral carers.]

Page 16 Example. Replace 'faith' with 'belief'.

We are also concerned that the Code does not provide specific guidance on circumstances where the deceased's religion or belief, and consequently view of organ donation, may be different to those of their family and friends and if those come into conflict. This is a particular problem for apostates, people who leave their religion to either convert to another religious belief system or to become non-religious. Such people may not wish to specify that their belief system is important to them in the decision-making process as described in paragraphs 58-61, but also not wish for the views of their former religions to be taken into account through consultation with family members who are still part of that religion. We suggest that an additional sentence is added to paragraph 63 stating 'It should be noted that the religion or beliefs of the deceased may be different to that of the family and the object of the conversation is to establish the intentions and beliefs of the deceased.'

13. Ordinarily resident (paragraphs 129-137): Does the Code of Practice make clear how practitioners will decide whether a person is ordinarily resident in England?

Yes

14. If no, please tell us why.

N/A

15. Information that a person would not have wanted to be donor (paragraphs 148-157): Where deemed consent is a possibility, does the Code of Practice provide sufficient clarity about who can provide information that a person would not have wanted to be a donor?

Yes

16. If no, please tell us why.

N/A

17. Are the steps that the Specialist Nurses for Organ Donation /Specialist Requesters would need to take to assess the information clear?

No

18. If no, please tell us why.

The list of questions laid out in paragraph 156 somewhat help to inform a practitioner of how to



assess the information provided by the family regarding consent in cases where it could be deemed. However, it is not clear in what situations a SNOD could reasonably dismiss such information on the grounds that it is likely to be inaccurate or unsatisfactory. In what is likely to be a highly emotional interaction with a family, there needs to be greater clarity about the criteria by which such information is assessed, especially as the HTA has indicated during stakeholder meetings that donation would be unlikely to take place if there were strong objections from family to deemed consent regardless of the strength of the evidence presented about the deceased wishes. Therefore, it would be useful to include two example scenarios, one where the information would satisfy a reasonable person and one where it would not to clarify this point.

19. Is there any information that should be included in the Code of Practice that is currently missing?

We have had enquiries from our membership regarding procedure under the 2019 Act for those who wish to donate organs after death, but also wish to donate their bodies and tissues for anatomical examination and/or research purposes. From conversations with the HTA, we understood that in practical terms this would not be possible as the two systems operate separately. We recommend that a paragraph be added to the Code for practitioners addressing how to make clear to potential donors how these two systems interact and how they could best express consent in these cases to reflect their wishes.

20. Is there anything you else to which you would like to specifically draw our attention?

No

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