

Cystic Fibrosis a fight we must win

Cystic Fibrosis Trust Response to the Scottish Government Consultation for Proposed Organ and Tissue Donation (Scotland) Bill

The Cystic Fibrosis Trust has produced a dedicated programme of work with NHS Blood and Transplant and other organisations to develop a national standard for transplant services. In addition the Cystic Fibrosis Trust will continue to fund research into ensuring more organs are available for transplant, such as the reconditioning of lungs.

Whilst formulating our programme the Cystic Fibrosis Trust consulted with the cystic fibrosis community, including people with cystic fibrosis, families of people with cystic fibrosis and physicians within the cystic fibrosis and transplant fields. This response reflects their views and concerns regarding the proposed changes in the organ donation system.

About the Cystic Fibrosis Trust

The Cystic Fibrosis Trust was founded in 1964 and is the UK's only national charity working to fund research into a cure and effective treatments for cystic fibrosis and to ensure appropriate clinical care and support for people with cystic fibrosis. It aims to ensure that people with cystic fibrosis receive the best possible care and support in all aspects of their lives, and provides information, advice and support to anyone affected by cystic fibrosis.

Whilst new treatments and better management of care are helping people with cystic fibrosis live longer, many will reach a point at which receiving lung transplant is their only option to prolong life significantly.

The Cystic Fibrosis Trust supports all efforts to ensure that all those with cystic fibrosis as suitable for a lungs transplant receive one.

Our Response

Consultation questions

1. The overarching purpose of my proposal is to move from the current opt-in system to a soft opt-out system of organ donation. Do you support this move? Please indicate “yes/no/undecided” and explain the reasons for your response.

Yes. The Cystic Fibrosis Trust believes a legislated system of consent will heighten the national debate around transplantation and encourage people to discuss organ donation with their friends and families while they are still alive.

The Cystic Fibrosis Trust have kept up with the progress of the Human Transplantation Act in Wales which from 2015 introduces a system where consent to organ donation after death is deemed to be given in the absence of express consent.

2. How essential is it to change the law (from an opt-in to a soft opt-out system) in order to achieve the intended benefits (increased transplant rates, reduced waiting lists)? Are there other (non-legislative) measures that could achieve similar outcomes without the need for legislation?

One in three young people with cystic fibrosis on the lung transplant waiting list will die before receiving a lung transplant.

We welcome the change in legislation but it is essential it is done alongside a number of other measures in order to improve the rates of organ donation. It is generally accepted that the UK’s inability to convert potential donors into actual donors in a significant number of cases contributes to the shortfall, so the on-going work must be supported and investment in Organ Donation co-ordinators, Specialist Nurses and Clinical Leads sustained. We believe we cannot afford for a change in the consent system to distract attention away from the need to improve the systems and infrastructure around organ donation in the UK.

Please refer to our Hope for More Report here:

www.cysticfibrosis.org.uk/media/443623/PAFF9%20Transplant%20report%20-%20online.pdf

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.

No. Although the UK continues to have one of the highest rates of family refusal to organ donation in the Western world we are of the opinion that limiting the role of the family in legislation could cause a negative backlash appearing as a top down approach which would detract from the clearer aims of the Bill. There is a great deal more to do to shift opinion among the general public and in society at large. Having “the chat” with family must be encouraged so that each person’s wishes are known. Families will then have no doubt that

they are honouring their loved ones' intentions when agreeing to donate and of their role in the organ donation process.

4. Do you think an 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. An adult should be able to appoint a proxy in the event of incapacity and that both parties know and understand the decisions they enter into. A suggestion may be to have a third person agree to the decision.

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.

Undecided. We have no justification to oppose or amend this clause however we feel more information and evidence is required by us to make a more informed decision around this proposal.

6. Do you agree the age limit for an adult should be set at 16 years old? Please indicate "yes/no/undecided" and explain the reasons for your response. If you answered no, what would you consider a more appropriate age?

Undecided. We have no justification to oppose or amend this clause however we feel more information and evidence is required by us to make a more informed decision around this proposal.

7. Do you agree the soft opt-out system should apply to people who have been resident in Scotland for a minimum period of 1 year prior to their death? Please indicate "yes/no/undecided" and explain the reasons for your response.

Yes. We have no justification to oppose or amend this clause.

8. If you answered no to the above how long, if any, should this period of residency last before they become subject to the soft opt-out system? Would this residency need to be for a continuous period?

9. Do you think 6 months is a long enough period to run a campaign prior to change over?

No. There needs to be a period of educational campaigns before the change-over, which should be at least a year, to 24 months. The educational campaigns should concentrate on educating the Scottish public of what the new Bill and ultimately the law will mean.

A national debate needs to take place on organ donation and transplantation so that the profile of the issue is increased, and the general public has a better understanding of the realities of transplantation. Many people currently sign up to the Organ Donor Register, but do not discuss it with their family which leaves the family a painful decision at the hardest

possible moment. It is only when donating your organs after death becomes usual, not unusual, that we will be on the road to giving people on the waiting list real hope. The Cystic Fibrosis Trust agrees that we need to change culture of organ donation so relatives know patients' wishes.

We would also support the Public Health Minister being an advocate of organ donation so that this type of discussion continues to heighten the debate at Parliament level.

We need to observe and learn the lessons from the Welsh Government process of implementing the Human Transplantation (Wales) Act 2013 and once the Act comes into effect.

10. What is your assessment of the likely financial implications (if any) of the proposed Bill to you or your organisation? What (if any) other significant financial implications are likely to arise?

No.

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?

No. This Bill should work to improve equality of access to organs.

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

The Cystic Fibrosis Trust supports the Scottish Government proposals to legislate for a soft opt-out system of organ donation in Scotland, but we are aware that legislation alone will not be enough to significantly improve transplantation rates.

We hope that such a change in legislation will lead to a UK wide re-appraisal of the current situation, and a much needed discussion of organ transplantation, ultimately leading to increased donation rates across the whole of the UK.

We also believe there needs to be consideration of those accepting organs; ensuring that individuals requiring a transplant are receiving adequate psychological support throughout the whole transplant process. This includes pre transplant, waiting for transplant and post-transplant. We believe that this will help post-transplant health status as individuals can be supported effectively and are able to explore issues surrounding transplant as well as end of life issues if the transplant does not come in time. This psychological support may be extended to family and friends, who often become carers of those requiring a transplant.

How to respond

You are invited to respond to this consultation by answering the questions in the consultation and by adding any other comments that you consider appropriate.

Responses should be submitted by 5pm 25 September 2014 and sent to:

Anne McTaggart MSP,

M1.11,

Scottish Parliament,

Edinburgh, EH99 1SP.

Tel: 0131 348 6211

E-mail: anne.mctaggart.msp@scottish.parliament.uk

Please indicate whether you are a private individual or an organisation.

Respondents are also encouraged to begin their submission with short paragraph outlining briefly who they are, and who they represent (which may include, for example, an explanation of how the view expressed was consulted on with their members).

To help inform debate on the matters covered by this consultation and in the interests of openness, please be aware that the normal practice is to make responses public – by posting them on my website www.annemctaggart.co.uk. I am also obliged to provide copies of all responses to the Scottish Parliament's Information Centre (SPICe), which may then make them available to MSPs or staff on request.

Therefore, if you wish your response, or any part of it, to be treated as **anonymous**, please state this clearly along with the reasons for this. If I accept the reasons, I will publish it as “anonymous response”, and only the anonymised version will be provided to SPICe. If I do not accept the

reasons, I will let you know and give you the option of withdrawing it or submitting it on the normal attributable basis. If your response is accepted as anonymous, it is your responsibility to ensure that the content does not allow you to be identified.

If you wish your response, or any part of it, to be treated as **confidential**, please state this clearly and give reasons. If I accept the reasons, I will not publish it (or publish only the non-confidential parts). However, I would still be obliged to provide a full copy of the response to the Parliament's Non-Government Bills Unit, and a redacted copy to SPICe when lodging my final proposal. As the Parliament is subject to the Freedom of Information (Scotland) Act (FOISA), it is possible that requests may be made to see your response (or the confidential parts of it) and the Parliament may be legally obliged to release that information. Further details of the FOISA are provided below.

NGBU may be responsible for summarising and analysing the results of this consultation and will normally aim to reflect the general content of any confidential response in that summary, but in such a way as to preserve the confidentiality involved. You should also note that members of the committee which considers the proposal and subsequent Bill may have access to the full text of your response even if it has not been published in full.