

SUBMISSION TO THE GOVERNMENT CONSULTATION ON ORGAN DONATION

MARCH 2018

Question 1

The Government wants to look at different ways for people to register their decision under the new system. This could happen through government processes such as a driving license applications and health setting such as dental surgeries and opticians. Do you think people should have more ways to record a decision about organ and tissue donation?

Yes

The Board of Deputies of British Jews (The Board of Deputies) notes that the underlying premise is of this consultation is of a “new system” of “opt-out”, which is permissive for taking organs without the express consent of the donor and / or their representative(s). However, even under the “old system” the Board of Deputies believes that there should be as many ways as possible to register your decision. Driving licence application prompts are important (presumably there is a so-called “nudge effect” given that road traffic accident victims are often donors.) as are all healthcare settings – such as general practice registration, dental surgeries and opticians.

One route that has not been explored to date is that potential organ donors should be able to register their wishes through community and faith organisations. Religious authorities, places of worship, and religious burial and benevolent societies could all be engaged. The joint 2013 Jewish-Muslim initiative rejected by Government aimed specifically to facilitate this type of approach and is discussed in the response to question 9.

Organ donation affects one of the most personal aspects of life – what will ultimately happen to my body. For Jews respectful handling of our dead is a central obligation. If civil society and faith organisations are given a role in the recording of wishes, it will empower them to have appropriately culturally-sensitive conversations with potential donors, and later if necessary with their families. This is the best way to ensure that potential donors’ wishes are truly carried out. The channels to register a decision such as driving licence applications, while important, are impersonal and may not provide the full engagement necessary to ensure that the potential donor has made an informed decision.

A potential donor’s community can help them make that informed decision. In a more secular setting, the Board of Deputies has noted that the combination of opt-in with prior conversations and discussion led by a Specialist Nurse in Organ Donation (SNOD) provides a remarkable 93% donation rate. A “new system” which provides incentives towards this approach more effectively, rather than any complex switch to “opt-out”, has much to recommend it for faith communities.

Assuming the “new system” is intended to be opt-out (as evidenced by the nature and wording of this consultation, see the answer to question 9), it may operate under deemed or presumed consent entirely. However, it appears that some form of record of one’s personal views will still be required; so all the options noted above should be included. For such a system to ensure that potential donors make informed decisions, the Government presumably intends to deliver considerable additional material because the same vehicles, locations and appropriate information will be needed to inform the public about their opt-out rights. However, the Board of Deputies is concerned that, given that the purpose of such an information campaign (ensuring that individuals know how to opt-out) is

misaligned with the overall goal of a transplant system (maximising donations), adequate resources would not be forthcoming in the medium to long term.

One of the constructive suggestions made to the Board of Deputies in this context is that in the 21st century it should be possible to design a secure App on which one's wishes about organ donation could be recorded. Offering this as a download facility - possibly alongside media subscriptions - to promote opt-in, may achieve not only much wider distribution than any other approach (and thus increase opt-in significantly) but also allow information to be conveyed easily to family, and permit more flexibility for changing views over time. Including a faith sensitive section (as outlined below in the answer to question 9) would be a simple option.

Question 2

There are advantages and disadvantages to including additional information when a person registers their decision on organ donation. On the one hand, potential donors may feel reassured about including information, on the other hand, the process of registering the decision needs to be as simple and straightforward as possible. What do think are the advantages or disadvantages of including personal information on someone's organ donation decision?

The Board of Deputies has reservations about simple "quick fix" approaches to sensitive issues where social, religious and cultural values are involved. There are two ways to understand this question. One way is that the personal information is about organ donation – how the person was informed about the pros and cons, which body parts can be used – all with direct impact on posthumous donation. However, there is a much wider question. How far "personal information" should go is far more complex than a question related to organ donation only. One presumes that for other forms of donation NHS Blood and Transplant have policies about linkage to unified data systems across the NHS, and that the appropriate data protection measures are in place. It would be illogical to creating an entirely separate data set for organ donation records, rather than incorporating additional questions within the existing models.

Question 3

If the new rules come into force we need to make sure that everyone understands how the new system has changed. We would like to know what you think are the best ways of telling people what the changes are, so they can decide what they want to do. How can we make people more aware of the new rules on organ donation?

The Board of Deputies has played an active role in encouraging organ donation from members of the Jewish community in general, and has participated in many of the interfaith initiatives run by NHS Blood and Transplant. Notably the question refers to "the new rules" when these new rules are not provided, making this difficult to answer. Some of the issues about communication are discussed in response to question 1 above.

Notably, the Jewish community has within it a charity (Sue Harris Trust) which carries out "spit test" - based tissue typing, and stores the resultant information on a register of potential donors for bone marrow transplantation. As a result, there is much ongoing positive experience and expertise within the Jewish community about increasing transplantation awareness, which could be an asset in future plans. However, there would be a clash in culture if there is indeed a switch to opt-out: the Jewish community bone marrow registry is based very firmly upon opt-in.

The Board of Deputies concerned that, whatever the undoubted good intentions at design stage of an information campaign around an opt-out and / or presumed consent system, it will inevitably fall short. Under an opt-out system, the moral obligation to ensure citizens are making fully-informed decisions and the overriding systemic goal of maximising organ donations are misaligned, creating downward pressure on resources in financially difficult times. This has to be seen in perspective in

the current strains on public finances in general, and NHS spending in particular. There must be a likely probability that an information campaign and SNOD provision might not be adequately resourced. There was no cost benefit health economic analytic comparison made between the current system, and an enhanced opt-in system (involving more support from faith and cultural groups) – i.e. whether enhanced opt-in would be a less costly change than shifting to opt-out.

Based upon the Jewish community experience with strategies to increase immunisation uptake, the Board of Deputies suggests that public authorities need to be fully incentivised to generate a properly funded public information campaign that engages with its target audience. Otherwise the issue gets sidelined by other priorities. The Board of Deputies' view is that there remain opportunities for organ donation campaigns to link up with the full range of civil society organisations, such as places of worship and burial societies, in disseminating information about organ donation as part of their commitment to health improvements. Organ donor families and recipients themselves, and SNODs, as well as civil society organisations, have an important role to play as disseminators of information and recruiters of potential donors.

Question 4

If the law changes, would this affect your decision about organ donation?

Yes

It is unclear how this question should be answered by an organisation. There are several potential interpretations. For example, a decision in favour of accepting that one might be willing to permit deceased organ donation may be followed by a decision to opt-out to ensure that my family are properly engaged in the way that one would want; but my family might (mis)interpret that to mean that I really do not intend to donate.

It is also difficult to define how “law change” itself influences personal decisions. Some vulnerable people may want to opt-out, but may fear that they may be stigmatised as a result; and others may have the opposite anxiety and fear that their treatment at times of ill health will be affected adversely by the “need for their organs”. This highlights even further that law change cannot be a substitute for culturally sensitive programmes of education and awareness.

Question 5

A person's faith or background can play an important part in deciding whether or not to be an organ donor. If the law changes, people would be considered willing to be an organ donor unless they have opted out. Do you think this change could have a negative impact on people from some religious or ethnic backgrounds?

Yes

To understand the Board of Deputies' response to this question, some background about the organisation itself is necessary. It is the cross-communal organisation that exists to promote and defend the religious and civil liberties of all British Jewry. Deputies are elected every three years. The Board of Deputies provides a unique means through which British Jews can be represented and heard. Some parts of the Jewish community do not participate in the Board's electoral and representational process, but wherever possible there is consultation and discussion with them about submissions to public bodies where there is a perception that there is a community of interest.

The Board of Deputies recognises that there are some areas, particularly in the medical field, where a wide range of views may be expressed within the community. Decisions are made by the individual (or the individual family) – even if that decision is to consult with and accept the view of a religious authority. Therefore, when making submissions on these topics, the Board of Deputies seeks to put

forward a position which allows all Jews to practice Jewish traditions and customs, including when there is diversity in the understanding of those traditions. The Board of Deputies is not a religious authority, does not give rulings about interpretation of Jewish law (known as “halacha” / “halachic law”) and ethics, and does not have any formal jurisdiction status. However, the Board of Deputies has had a long standing and consistent role in advocating and defending religious freedom for all Jews.

Against this background, concerning organ donation, there is strong consensus across the UK Jewish community – and most other Jewish communities that have addressed the issue - in favour of the principle of organ donation. The concept of a life-saving opportunity arising out of the death of your loved one is paramount, taking precedence over other prohibitions such as the need to respect the body as in life, to bury the body intact, and not to exploit the deceased person’s body for benefit.

There is less theoretical consensus, and some diversity of opinion, about the opt-in / opt-out question. Some Jews would say that opt-out, but with consultation safeguards and SNODs is satisfactory. Others would regard opt-out – but not opt-in – as an infringement of religious freedom, interfering with the rights of the Jewish family and community to handle the deceased’s body according to their traditions. One of these is to save life wherever possible, which would certainly permit, if not indeed obligate, organ donation. To balance this, the Board of Deputies is perhaps more aware than other parts of the community of how deeply felt considerations of handling of the body after death can become at the time when a family is confronted with the death situation. It is this element of respect for the deceased body, and for rapid responsiveness, that underpins the widespread cross-communal distress caused by the recent controversy relating to the attitude of the Inner London Coroner, which is being heard in the High Court.

There is diversity within the UK Jewish community about the secondary issue of definition of death. This question has been tackled by several rabbinical authorities. It is a question that has only arisen since the 1960s. Some authorities recognise only cardiorespiratory death, while others accept brain stem death. Recently the Israeli Chief Rabbinate has accepted brain stem death criteria both in general and for organ donation.

A contrasting view is that, if one rejects brain stem death but it is accepted by the wider society, then this may lead to organ donation taking place when the deceased person, and their family, would consider the donor to be still alive. The Board of Deputies is not qualified to express a position on this definition. However, the Board of Deputies expects that opt-out systems, where the authorities are perceived to be more “in control”, are likely to face a serious loss of trust from communities who follow the cardiorespiratory definition of death, and as a consequence it may lead to more Jews opting out. The Board of Deputies notes that the National Institute for Clinical Excellence (NICE) recognises both definitions of death and provides alternative guidelines for each. Thus NICE acknowledges that both views are acceptable in society, and this may affect the type of donated organs that can be used, but not the principle of donation.

During the early part of the present century the Board of Deputies was involved not only in developing materials to publicise the donor registry on behalf of the Jewish community but also in responding to the Government consultations which led to the Human Tissue Act 2004. This followed on the unauthorised retention of hearts in Bristol and of multiple organs at Alder Hey Hospital. It was clear to Board of Deputies representatives that the intent of the 2004 Act was to give families greater control over the bodies of their loved ones. The Jewish community welcomed this legislation, and this possible move to an opt-out system jars with its intent. The prospect is that under an opt-out system there will be less room for family discretion, representing a backward step, conceptually treating dying patients and their families as subjects to whom things are done, rather than as citizens who are fully involved in extremely personal matters.

At that time the Board was also engaged the processes of learning lessons in the aftermath of two other controversies. One of these led to a major UK report (Isaacs Report 2004) which centred on autopsy and organ (brain) retention from a Jewish man. The other was about the use of anatomical remains from Holocaust victims in medical facilities in Europe. In both these examples the outcome was that Jewish human rights and related religious freedoms were respected. In a prevailing opt-out system it is unclear and uncertain that this would have happened.

The Board of Deputies also has concerns about the issue of consent in an opt-out system. Current concepts of consent in medicine, too, are linked to the medical abuses of the Holocaust period. These concepts continue to resonate in other fields, and influence legislation. For example, as part of the UK Government's General Data Protection Regulations, "consent" can only be said to be given by an individual if that consent is "freely given, specific, informed and an unambiguous indication of the individual's wishes." This, presumably, is to ensure that vulnerable members of society are protected. The Government appears to be proposing a higher threshold for ensuring such people do not receive unwanted sales calls, than for situations where it is in theory possible that their organs can be taken against their will or the wishes of their family.

In this analysis, for obvious reasons, the Board of Deputies has emphasised the issues of concern to the Jewish community. There are also many shared interests with other communities. From the Sikh community we have been told that cultural factors are as relevant to organ donation consent as religious ones. We are aware of very similar discussions about organ donation within the Catholic communities. We have worked together with the Muslim community, and they have shared our concerns about the less affluent and more vulnerable amongst our coreligionists. The data that 6.4% of donors are from BAME groups; but that 22% of recipients and 30% of the waiting list are from these groups is disturbing and it is unclear how an opt-out system will have an impact on this.

If there is an increase in organ donation as a result of an opt-out system, it might come from those individuals who struggle to make an informed decision without support and without a strong social network. In short, it will be the socially isolated, especially among the elderly, those with low levels of education and poor English speakers who will ultimately donate without giving true consent. The Jewish population itself includes many such individuals.

Thus, in summary, there is a combination of religious, ethnic and cultural reasons why an opt-out system is likely to be viewed with misgivings within parts of the UK Jewish community. The current system could be enhanced and improved, and made to work more effectively, but overall it is far more inkeeping with Jewish traditions of respect for the dead body and support for the bereaved family.

Question 6:

If someone is going to die and it is possible for them to donate their organs, medical staff always talk to their family or a long-standing friend to find out if they wanted to be a donor.

In many cases, families find it easier to support organ donation if they know that was what their loved one wanted. If the law changes, and someone has died and they have not opted out of organ donation, should their family be able to make the final decision?

For the reasons noted above, the Board of Deputies' view is that the family play the key role and should always be consulted. Furthermore, as noted previously, the handling of the end of life period, death and bereavement is when the Jewish family will often want to practice structures of observance more rigorously than they do in other areas. There is evidence that it is in fact fears about how the deceased's body is handled during the organ donation process, different from Jewish practice, that impacts at present on opt-in decisions. The Jewish family's mourning and bereavement processes are important not only as ritual but also as part of their maintenance of mental health during a stressful

life event. Any infringement on family autonomy in such situations could have a very detrimental effect on coping with loss.

Question 7

Do you think someone's family should be able to decide if their organs are donated, if it is different to the decision they made when they were alive? Can you explain more why you think this?

Sometimes. There are some circumstances where someone's family should be able to make a different decision. There may be conflicts – for example, an expressed wish to be cared for and die at home rather than in a high technology setting that is not immediately compatible with an expressed wish to donate organs; an objection to the method being used to determine death despite a desire to donate; and a concern by family members about coercion, or about deficiencies in care and handling, which may increase their distress and lead to refusal.

This question demonstrates the crux of the problem with an opt-out organ donation system: Donation should be the outcome of conversations: between a person and family / health care professionals during life; between medical professionals; possibly between a potential donor and their family and religious guides; and between other combinations of these participants. If the conversations have taken place, then the dilemma the question addresses should not arise and opt-in incentivises such conversations when the overriding goal is maximising donations. An opt-out system creates an active disincentive to have such conversations. The family might interpret that the public authority wishing to see an increase in organ donation has a vested interest. With a subject as sensitive as this, it is almost impossible to generate blanket rules that will ensure that every individual's rights are protected, but this does not mean that the attempt should be abandoned.

Question 8

The government thinks there are some people who should not be included in the new rules. This is either because they are too young, they're not able to make a decision about organ donation, or they do not usually live in England. It means they would still need to 'opt-in' to be an organ donor when they are alive. Which of the following should not be included in the proposed new rules about organ donation?

Children under 18 years old – yes

People who lack the capacity, which means they are not able to make the decision - yes

Visitors to England - yes

People living in England for less than 12 months (for example students or people in the armed forces). – yes

[Note that these exclusions relate to exemption from opt-out, but do not necessarily preclude a conversation about possible opt-in]

Are there any other groups you think should be included? Please say why?

The vulnerable groups in the community noted in the answer to question 5 need to be considered; but it is almost impossible to define categorical definitions for such individuals resembling “those under the age of 18” under an opt-out system.

Question 9

Please tell us about any opinions or evidence you have about opting out of organ donations

The consultation

The poorly structured nature of this consultation, worded on the assumption that there will be a change in the system, is unlike all the previous consultations on the subject to which the Board of Deputies has responded. This is not a faith issue: not only the Board of Deputies but also the Nuffield Council

for Bioethics offered a dialogue on what the format might be to express our concerns most efficiently. This offer was rejected.

Proposals to enhance organ donation rates

There have been several previous attempts to promote organ donation within faith communities. This is based on the view that, in the UK context, an even more positive public climate for organ donation could be secured with the robust help of faith leaders (including the Chief Rabbi). The aim, as clearly identified in the Taskforce Report of 2008, was (and is) that the opt-in system with SNODs and NHS recognised organ donation consent forms would facilitate the opportunities for many more religious believers to become registered organ donors.

In 2013, prompted by a speech made by the then responsible Under Secretary of State, Prof David Katz and Dr Shuji Shafi, on behalf of the Jewish and Muslim communities respectively, proposed that the following statement should be made accessible via the organ donation register to encourage take up of opt-in:

*"I agree to my name being placed on the organ donation register provided that:
My family is entitled to request advice and support from my religious authorities at any stage in the continuum of my critical illness.*

In the case of my imminent or apparent death, my family will be consulted about my wishes regarding organ donation, and specific provision will be made for them to consult with my religious authorities.

If my family wishes a religious adviser to be present with them during these discussions, and / or during any investigations or procedures which will be performed on my body, then these wishes will be respected by my healthcare attendants. The religious adviser has my explicit permission to be allowed to review any medical records pertaining to my illness and the procedures performed to ascertain the moment of my death.

My family will be entitled to make the final decision as to how my death is confirmed with respect to consideration of organ donation and how my wishes about organ donation are respected"

The Board of Deputies believes that this option should be revisited. It would facilitate wider religious community participation and be helpful to healthcare professionals who are involved in caring for the donor and the bereaved family. Furthermore, it would promote educational exchange between the healthcare professionals and the religious authorities which would be to the advantage of all.

How to achieve increases in organ donation rates

The Board of Deputies would have opted for the consultation to be phrased to allow respondents to describe how they would increase organ donation rates in general, and would then have outlined how Jewish religious and cultural sensitivities might be accommodated, rather than to confine us into comment and possible critique of an undefined opt-out system.

One of the questions raised is the evidence base against which opt-out is proposed. The impact assessment appears to confirm that there is no robust evidence that organ donation rates are increased by opt-out systems. This is consistent with the conclusion of the 2008 Organ Donation Taskforce which explored the issues in detail, and of the 2008 House of Lords Select Committee. Prof Rudge, the then Director of NHS Blood and Transplant, has recently written that opt-out does not increase donation, that it is not a better form of consent and that there are alternatives which the Taskforce proposed and which could continue to be employed (Brit J General Practice, February

2018). The Nuffield Council on Bioethics (December 2018) stated that ‘the case had not been made’ that opt-out systems lead to greater donation rates.

Although the Spanish system is often described as an ‘opt-out system’ this is inaccurate as there is no register for such ‘opt-outs’ to be recorded. The family is always asked for consent, and the family’s wishes are always final. Spanish levels of organ donation increased not in 1979 when opt-out was introduced, but in 1989, when several innovations were introduced, most notably the introduction of transplant co-ordinators in hospitals that engage with families in the process of organ donation. In addition, the Spanish national transplant organisation has worked to create cultural change by, for example, having 24-hour information lines and working with journalists to promote organ donation. These measures would be feasible as part of an opt-in system

In Wales the information thus far is not conclusive. In the first year of the operation of the opt-out system there has been a fall of the number of organ donors from 64 in 2015-16 to 61 in 2016-17. This compares to a rise from 1,364 to 1,413 across the UK during the same period, and a greater than 30% increase in Scotland, under an opt-in system, from 99 to 133.

For 2016/7, Prof Neuberger, the second Director of NHS Blood and Transplant, and his colleagues (BMJ, December 2017) reported that there were 5618 eligible deceased organ donors. 3,144 relatives were approached, and 2,082 gave consent, which resulted in donation from 1,413 of them. The target group about which evidence is required are thus the 2474 eligible donors who were not approached, and the 1,062 who declined. If their details – including faith and cultural issues – could be defined accurately, then there would be much clearer evidence how increased deceased organ donor rates might be achieved, rather than making a drastic shift in how Government views the human body.