



## **Government Consultation on Organ Donation (Department of Health and Social Care) March 2018**

### **Our Background**

1. Muslim Women's Network UK (MWN UK) is a national Muslim women's organisation in Britain ([www.mwnuk.co.uk](http://www.mwnuk.co.uk)). We are a small national charity (no. 1155092) that works to improve the social justice and equality for Muslim women and girls. Our membership also includes women of other faiths or of no faith and men who support our work. We find out about the experiences of Muslim women and girls through research and helpline enquiries. We identify policy and practice gaps and use this information to inform decision makers in government as well as informing our community campaigns at a grassroots level.
2. We also develop resources and train women so they are better aware of their rights. We have a separate website for our national helpline ([www.mwnhelpline.co.uk](http://www.mwnhelpline.co.uk)) that provides advice and support on a range of issues some of which include: domestic abuse, forced marriage, honour based violence, sexual abuse, female genital mutilation, divorce, discrimination and mental health etc.
3. The impact of our work is particularly felt in reducing the vulnerability of Muslim women and girls, reducing the prejudice they face, and giving them greater access to rights and services – all of which allow them to contribute to society like any other citizen. We are also creating a critical mass of voices to influence change with more women being confident to challenge discriminatory practices within their communities and in society and to influence policy makers.

### **Introduction**

4. To save more lives, the government plans to change organ donation laws in England so that everyone will be a donor unless they explicitly register an objection and opt out. As this new rule will affect every Muslim woman as well, we felt it was important we ensure that the views of Muslim women were also heard on how this new rule should be implemented. Muslim women are also likely to also play a key role in decisions taken after family member passes away.

5. To help with our response we consulted 25 Muslim women who were in their 20s, 30s and 40s. An overview of their responses to the questions in the government consultation is provided in the following paragraphs, which were submitted online.

**Do you think people should have more ways to record a decision about organ and tissue donation? Would it be sufficient to record your decision onto the NHS Organ Donor Register online/on the phone? Or do you think it should be made easier to record the decision at other services such as at the GP. If so, why?**

6. Most respondents wanted multiple ways to be able to record their decision whether to 'opt out' of donating or to even record they consent even though this would not be necessary. Many felt it was important to record their agreement especially as they did not want health professionals to assume that just because they had not opted out that meant all of their tissues and organs could be taken. For example, some women indicated that they are only happy to donate certain organs and tissues.
7. The most popular method to record their organ donation decisions was through the GP. However, the younger women tended to prefer recording their decisions online. Concerns about identification were raised for decisions being taken online and via the telephone. The respondents were worried whether sufficient measures would be in place to verify identity to prevent others from making decisions on their behalf or even changing their decisions. They wanted opting out to be made easy as possible.
8. People who are illiterate or whose first language is not English may not fully understand the issue and therefore may not be making informed decisions. Any methods used to record decisions should also be inclusive and ensure everyone understands their decisions.

**When registering the decision on organ donation, you can also record additional information. What do you think are the advantages or disadvantages of including personal information on someone's organ donation decision?**

9. Although participants acknowledged advantages of recording additional information, most were concerned about their privacy and with whom this additional information would be shared given that NHS is slowly being privatised. For example, one Muslim woman said '*you never know where your information will end up.*' Some specific concerns about breaches of confidentiality were also raised such as insurance companies and lawyers being able to access these additional personal details.
10. Other disadvantages listed included: not being able to receive an organ due to lifestyle choices and also not receiving an organ due to discrimination if the donor's family became aware of the recipient's race or religion. Some were worried about donor families and recipients finding out too much information about each other. The fact that information of donors and recipients is not shared without consent was not well known and so the public should be educated regarding this with perhaps a 'Frequently Asked Questions' section on the opt-out register. Questions were asked about information becoming out of date including

decisions taken on opting out or not. Time intervals should therefore be determined on how often people are reminded to update their information.

11. Some benefits of recording additional information that were mentioned include:

- Donor families having access to some information on the recipient to ease suffering after having lost a loved one
- To more easily match donors and recipients
- To identify if a person would be a suitable donor or not due to medications they may be taking or their lifestyles
- Information on reasons to opt out or even record why they wish to donate can be useful for educational public campaigns

**If the new rules come into force we need to make sure that everyone understands how the system has changed. What do you think are the best ways of telling people what the changes are, so they can decide what they want to do?**

12. All of the respondents felt it was important to have a national campaign to raise awareness of the new rules through a combination of methods that included: TV / radio adverts (including BME media), billboards, media articles, leaflets, booklets, posters (especially in GP / dental surgeries and hospitals), letters to every household. Additional suggestions included providing free information packs and posters to community centres and faith institutions e.g. mosques. It was also considered important to provide information in different languages and formats (e.g. for those with hearing impairments or reading difficulties). Social media promotion was also considered essential and the younger women did not just want this limited to Facebook or Twitter but also Instagram, which is especially popular with teenagers.

**If the law changes, would this affect your decision about organ donation? For example, it would make no difference, you are more likely to become an organ donor after your death, or you are more likely to want to opt-out of being an organ donor after your death?**

13. Mixed responses were received on whether people wanted to donate or not. Respondents fell into three categories of roughly equal in size:

- Those who were happy to be an organ donor - These respondents had already decided to become a donor but had not necessarily taken any action to formalise the decision. They found the new law changes positive and helpful. Some even said they knew of family members, friends or people in Muslim communities who had benefited from an organ donation. They said if we are willing to accept organs then we should be willing to donate them too.

- Those who were unsure – These respondents did not know how they felt about organ donation as they had not thought about it previously or did not have sufficient knowledge about the issue, which included different religious perspectives. Many of these respondents were unsure what the Islamic view was on the issue and whether their faith allowed it.
- Those who did not want to donate – These respondents said they would definitely 'opt out' and most did not explain why. However, some did provide reasons, which included: believing it was against their faith while others said that they would 'opt out' until they were able to make a more informed decision. Some expressed a willingness to be a donor in their youth but did not want to be a donor when older e.g. *'I don't want to be 'cut open' when I am really old.'* A couple of women said they did not mind being live donors to family or friends such as donating a kidney but did not like the thought of being 'cut open' after they had deceased.

**A person's faith or background can play an important part in deciding whether to be an organ donor. Do you think this change could have a negative impact on people from some religious groups or ethnic backgrounds? Please explain why you think this and what could be done about these concerns.**

14. The vast majority of respondents were not clear about what the Islamic perspective was on organ donation. In fact they stated that religious scholars have opposing views with some being against organ donation because it amounts to the mutilation of the body after death while others were in agreement with organ donation because it resulted in saving human life. They questioned which religious scholars they should believe and would prefer a joint statement and consensus amongst scholars in the UK to clarify the matter. In fact, many wanted honesty from scholars and wanted them to state with their positions that there is no black and white definitive answer on the issue and their opinions are human interpretations of what they think. It was considered important not to be misled by faith leaders.
15. For the women who feel it is against their beliefs to donate organs and tissue they were worried that if they had intended to opt out but had not done so before their death, their families would be traumatised if their organs were taken. Some acknowledged that even opinions varied with families on whether organ donation is allowed or not in Islam. It is therefore important to ensure people who want to consent still record this consent (and the reasons why) even if though they don't need to so families cannot dispute their decisions afterwards.
16. A number of the women, especially those who supported organ donation, questioned whether people who are not willing to be a donor themselves (e.g. have opted out) should have the right to accept and want an organ donation if they required it. They went further and were critical of those who did not want to donate organs believing it is against their faith (e.g. due to bodies being mutilated) but at the same time felt their faith allowed them to be a recipient even though someone else's body would have been cut open for them to receive the organ or tissue. Further debate and discussion is required on this ethical dilemma and whether such decisions can be used to prioritise recipients. These are important discussions given that of those on the waiting list for an organ transplant,

approximately 30% are black and Asian. However, only about 6% of donors are from these backgrounds.

**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?**

17. The majority of respondents (75%) felt that families should be able to overrule the decision (especially for children) to block organ donation even if the deceased person had not opted out. Many felt that just because someone had not opted out, it did not necessarily indicate they were willing to donate e.g. not gotten around to opting out, may have still been deciding, may not have indicated which organs or tissue they were willing to donate or may have changed their mind on organ donation and had not yet recorded their decision by opting out.

18. Some of the women suggested a five-year period where families could overrule the deceased's wishes. This could be reviewed in the future. This period could be used to assess the opt-out system's impact on families of the deceased.

**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 about your views.**

19. All of the respondents were in full agreement that if the deceased had clearly indicated they wanted to donate, their reasons for donating and that decision had been recorded, then family members should not be able to change this decision. It is therefore important to ensure that during awareness raising it is important to highlight the importance of both opting out but also recording consent to organ donation. Such decisions should be updated at regular time intervals, which also need to be determined.

**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 don't usually live in England. It means they would still need to 'opt-in' to be an organ donor when they were alive. Which of the following should not be included in the proposed new rules about organ donation?**

20. The vast majority of the Muslim women we consulted agree that the following categories of people e.g. children under 18, people who lack capacity, visitors to England and people living in England for less than 12 months, should not be included in the new rules.

**On Behalf of Muslim Women's Network UK  
Shaista Gohir OBE  
Chair  
6<sup>th</sup> March 2018**