

February 2018



CLINKS  
RESPONSE

# Clinks response to the consultation on introducing 'opt-out' consent for organ and tissue donation in England

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## About Clinks

Clinks is the national infrastructure organisation supporting voluntary sector organisations working in the criminal justice system (CJS). Our aim is to ensure the sector and those with whom it works are informed and engaged in order to transform the lives of people in the criminal justice system and their communities. We do this by providing specialist information and support, with a particular focus on smaller voluntary sector organisations, to inform them about changes in policy and commissioning, to help them build effective partnerships and provide innovative services that respond directly to the needs of their users. We are a membership organisation with over 500 members, working in prisons and community settings, including the voluntary sector's largest providers as well as its smallest. Our wider national network reaches 4,000 voluntary sector contacts. Overall, through our weekly e-bulletin Light Lunch and our social media activity, we have a network of over 15,000 contacts. These include individuals and agencies with an interest in the CJS and the role of the voluntary sector in rehabilitation and resettlement. For more information see [www.clinks.org](http://www.clinks.org)

## About this response

The government plans to change the existing organ donation system to an 'opt-out' system. Under the current system people, who want to donate their organs 'opt in' or agree to donate after their death by signing up as a donor on the NHS Organ Donor Register and telling their family their decision. If the person had not recorded a decision to donate then NHS staff provide information to their family to help them to reach a decision about whether organ donation should go ahead. The proposed new system would be an 'opt out' system, meaning unless people had registered to opt out of donating their organs, they will be assumed to have consented. The aim of the consultation was to establish what more could be done in England to ensure that public support for organ donation is supported both within the legal system and in the NHS and that a person's decision to donate is supported whenever possible.

We responded to an online questionnaire, and have reproduced our answers in this document. We have only included the questions which we gave written answers to. Our response to this consultation focuses on the potential impact of the proposed changes to consent for organ and tissue donation on people in the CJS and their families, and has been informed by feedback collected from Clinks members.

You can read more about the consultation on the government website- see end notes<sup>1</sup>.

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## **Making it easy for a decision to be known under 'opt-out' consent**

### **3.1 Recording a decision about organ and tissue donation**

#### **Q1. Do you think people should have more ways to record a decision about organ and tissue donation?**

- Yes – there should be more ways to record a decision, including when people are doing other things, such as registering with a GP

Under the proposed new system of 'opt-out' consent, it will be vital to encourage as many people as possible to register their decision, to ensure people's wishes are fully taken into account and avoid unknowing donation. The process to do so must be as easy and accessible as possible.

People in contact with the criminal justice system experience significant health and social inequalities. Many experience multiple and complex needs, and often have ineffective contact with health and other statutory services. Allowing people to record a decision regarding organ donation in other healthcare settings must be approached in a sensitive manner, to ensure this does not become an additional barrier to people registering with health services, or deter them from accessing healthcare.

It may be more appropriate to offer the opportunity to record a decision as part of an ongoing care planning process, rather than at the initial point of registration with a health service. However, the process should not require people to go through a third party to register, and must be designed so that their decision remains confidential.

People in prison face additional barriers to recording a decision. Access to online services is extremely limited in prisons, where most people have no access to the internet, and only restricted access to approved sites through central prison facilities such as the prison library. Access to phone calls is also limited due to both the high cost of calls, and for the majority of prisons which do not have in-cell telephony, lack of time and privacy when using phones on the wings. (Mobile phones are banned in all prisons in England). In addition, healthcare services in prisons often have long waiting lists and access to appointments is difficult, making it impractical to rely on contact with health services as a means for people to record their decision.

One solution to this could be to train peer supporters in prisons to initiate discussions around organ donation and support people to record their decision (although as noted above, the registration process itself must be kept independent and confidential). Many prisons operate existing peer support schemes, for example, 'buddy' schemes to provide care to prisoners with social care needs; peer healthcare reps; and similar initiatives. For prisons where in-cell telephony is available, the phone number for recording a decision with the NHS Organ Donor Register should also be added to the Freephone list to allow people in these prisons to call without incurring a charge.

### **3.3 Potential recording of additional information on a decision**

#### **Q2. What do you think are the advantages or disadvantages of including personal information on someone's organ donation decision?**

As noted above, to ensure as many people as possible are encouraged to record their decision on organ donation, the process to do so will need to be as simple as possible. People in contact with the criminal justice system may be reluctant to divulge additional personal information, due to their situation or a lack of trust in statutory services. Asking for additional details may therefore deter people from registering their decision. A person's faith and beliefs may also change over time, meaning that if this information was held on the organ donation register, it could become out of date before the person's death, creating uncertainty about their decision to opt in or out.

### **3.4 Public awareness**

#### **Q3. How can we make people more aware of the new rules on organ donation?**

Any awareness campaign must be co-produced with people from a range of different backgrounds and communities, and fully take into account the diversity of communication, language and other needs of all those who will be affected by the change. People in contact with the CJS, and their families, often come from disadvantaged communities which are disproportionately affected by digital exclusion, poor literacy, and high levels of social and economic inequalities.

A specific targeted campaign will be needed to reach people in prison. People serving longer sentences, including the growing number of older prisoners, may remain in prison throughout the duration of the proposed awareness campaign and until after the legislation comes into effect. As those in prison are unable to access mainstream communications such as social media, they would be excluded from generic awareness-raising campaigns. The many voluntary sector organisations working in prisons; peer support schemes (as noted above); and prison-based media, such as National Prison Radio and Inside Time, would be effective partners in delivering a targeted campaign.

This would also need to take into account the fact that many people in prison have low literacy, communication or learning difficulties: Up to one quarter of the prison population are understood to have difficulties in communicating and/or processing new or complex information; and more than three times as many men and women in prison have a learning disability compared to the general population<sup>2</sup>. Over half (57%) of people entering prison in 2011 were assessed as having literacy skills expected of an 11 year old – more than three times higher than in the general adult population (15%)<sup>3</sup>.

Facilitating positive conversations about organ donation with people in prison can also have a community dividend<sup>4</sup>, as people return to their communities after release and may continue these conversations with friends and family. BAME individuals are also disproportionately represented at all stages of the CJS; meaning that increasing awareness and support for organ donation among people in prison could support the need to increase availability of donated organs from minority ethnic groups.

## **4. Changing to an opt-out system of consent**

### **4.5 Family members making the final decision regarding organ donation**

#### **Q6. 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?**

- Other (please give details)

When a person who dies while in prison has not opted-out, family members should be given the final decision wherever possible. Families bereaved while someone is in prison have described feeling as though "the person's sentence never ends", as their loved one never returns having entered prison. This distress could be compounded if the person's organs are donated without them being consulted or the person's decision being explained.

However, equally it should not be assumed that simply because a person is in prison they cannot, or would not want to, donate their organs or tissue. In some instances, the opportunity to donate organs after a person dies in prison is seen by the individual and their family as an important way of bringing something positive from their situation.

#### **Q7. 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?**

- Sometimes – there are some circumstances where someone's family should be able to make a different decision

#### **Can you explain more about why you think this?**

Where a person has recorded a decision about organ donation, the majority of organisations and service users who Clinks spoke to felt that families should respect their deceased relative's decision. It is important to note that if the person has made, or changed, this decision while in custody, family members may be unaware that this has happened.

Maintaining contact with their families can be difficult for people in prison, due to the limited time available for visits or phone calls, and the stress of the situation. Many people may not wish, or find it appropriate, to discuss organ donation with family members while in prison. This means it will be important to ensure that family members are aware of and understand the person's decision in order to minimise any distress.

### **4.8 Exceptions and safeguards in a new system**

#### **Q8. Which of the following should not be included in the proposed new rules about organ donation?**

We agreed all the groups outlined below should not be included in the new proposals.

- children under 18 years old
- people who lack capacity



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- visitors to England
- people living in England for less than 12 months (for example, students from overseas, armed forces personnel)

**Are there any other groups you think should not be included? Please say why you think this.**

None.



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**Clinks supports, represents and campaigns for the voluntary sector working with offenders. Clinks aims to ensure the sector and all those with whom they work, are informed and engaged in order to transform the lives of offenders.**

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## End notes

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1. <https://www.gov.uk/government/consultations/introducing-opt-out-consent-for-organ-and-tissue-donation-in-england>
2. Revolving Doors Agency, 2016 - Rebalancing Act – Online: <http://www.revolving-doors.org.uk/file/2050/download?token=m-t2NRKC> (last accessed 20.02.2018)
3. Prison Reform Trust, 2017 – Bromley Briefings Prison Factfile Autumn 2017 – Online: <http://www.prisonreformtrust.org.uk/Portals/0/Documents/Bromley%20Briefings/Autumn%202017%20factfile.pdf> (last accessed 20.02.2018)
4. Revolving Doors Agency, 2016 – ibid