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## Organ donation in the United Kingdom

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# ORGAN DONATION IN THE UNITED KINGDOM: From opting in to opting out

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*On Wednesday 20<sup>th</sup> May 2020 England joined Wales in moving to an opt out system of organ donation from an opt in system in the United Kingdom. This article will discuss organ donation in the United Kingdom, considering the need for and supply of organs for donation. It will examine the various types of system that exist for the supply of organs for donation and the legislation that exists in the United Kingdom governing organ donation and why the law in England has changed. It will outline the system that exists in each of the four countries of the United Kingdom and any expected changes to the laws in those countries.*

**Keywords: Organ donation; opting in; opting out; transplantation; legislative change; Max and Keira's law**

## Introduction

This article is concerned with organ donation and transplantation in the four countries of the United Kingdom and the laws that surround this; in particular it is concerned with the law relating to the donation of organs after the donor's death.

Although this article is concerned with and discusses law around organ donation it will not discuss ethical considerations of organ donation and transplantation as a treatment, that is whether it should be undertaken or not, neither will it discuss the law in relation to death or brain stem death or aspects of determination of death or brain stem death.

In order to provide an account of the recent legislative change in England and those that are proposed for Scotland, as well as considering the legal positions in Wales and Northern Ireland, this article will provide an overview of organ donation, organ transplants, a consideration of the statistics of organ donation and transplant, as well as the main ways in which organs can be procured, donated or received.

## Organ donation and transplantation – definitions and history

A few definitions of terms that will be used throughout this article:

- Organ donation refers to one person allowing an organ to be removed from their body, either whilst they are alive or after their death, and used medically or scientifically for the benefit of others.
- Transplantation refers to taking an organ or tissue from one person and placing it in the body of another person. For the purposes of this article it is not referring to moving tissue from the healthy part of a person's body and placing it in an unhealthy part of the same person's body.

If one puts aside blood transfusion, which strictly speaking would be tissue transplantation and not organ, which was first performed in 1818 then organ transplantation is younger than the National Health Service. The National Health Service was established in 1948 and the first organ transplant was performed in 1954 in Boston, United States of America. The first organ to be transplanted was the kidney. The first liver transplant was performed in 1963, again in the United States of America in Colorado. The first heart transplant was performed in 1967 in South Africa. More recently, it was in 2010 that the first full face transplant worldwide was performed in Spain.

In the United Kingdom, the first kidney transplant was performed in 1965, the first heart transplant was in 1968, with the first liver transplant also being in 1968. In 1983 the first worldwide combined heart and lung transplant was performed in England.

Alongside the innovations which supported the developments in transplantation have been developments in organ donation. Concentrating on the United Kingdom, it was 1971 which saw the introduction of the donor card and 1994 when the NHS Organ Donor Register was first set up.

Information in this section was obtained from the NHS Blood and Transplant website available at <https://www.organdonation.nhs.uk/>

### **Organ donation and transplantation statistics**

Transplantation has advanced considerably since its introduction in the 1950s and 60s. There have been advances in the techniques and procedures, as well as in the drugs and regimens used to prevent rejection of the transplanted organ by the recipient's body. As may be expected, the number of transplants has increased as has the types of organs that can be transplanted. The list of organs that can now be transplanted includes:

- Colon
- Cornea
- Heart
- Kidney

- Liver
- Lung
- Pancreas
- Spleen
- Stomach
- And various combinations of these

*Donation and transplant statistics*

According to the NHS Blood and Transplant, which is an executive non-departmental body of the Department of Health and Social Care, that was established in 2005 to oversee and regulate the process of transplantation, during the year 1<sup>st</sup> April 2018 to 31<sup>st</sup> March 2019 there were 6,077 individuals actively on the transplant lists waiting for a transplant and a further 3,222 who had been temporarily suspended from the transplant lists as at March 2019, meaning that 9,399 individuals were in need of a transplant. During the same time period 400 individuals had died whilst waiting for a transplant and another 777 had been removed from the transplant lists because of deteriorating health and were expected to die (NHS Blood and Transplant 2019 p. 2).

Whilst NHS Blood and Transplant notes that the number of individuals waiting for an organ transplant was a 1% increase on the previous year, it also notes that there was a decrease in the number of transplants performed. This varies from a 3% reduction in kidney transplants to a 20% reduction in lung or heart-lung transplants compared to the 2017-18 year (NHS Blood and Transplant 2019 p. 2).

The NHS Blood and Transplant 2018/19 report estimates that there were 600,00 deaths in the United Kingdom, of which 290,00 occurred in hospital. Of this number 6,991 were identified as being potential donors and 5,815 as eligible donors, that is individuals with no medical contraindications to organ donation. Although there were 3,245 donor requests, the number of donors with valid consent was 2,279 and this resulted in 1,600 actual donors (NHS Blood and Transplant 2019 p. 6). In addition to deceased donors there were a further 1,039 living donors (NHS Blood and Transplant 2019 p. 13).

This resulted in a total of 3,491 transplants being performed during the year 1<sup>st</sup> April 2018 to 31<sup>st</sup> March 2019, and 4,298 organs transplanted (NHS Blood and Transplant 2019 p. 6).

What these statistics mean is that there are more individuals waiting for an organ transplant than there are organs available to be transplanted. As Woodcock & Wheeler (2010) state 'there has always been a tragic supply and demand gap in organ transplant practice' (at page 282). This is why there have been calls for changes in the way that organs for transplant can be legally increased.

The ways in which organs can be obtained and donated is discussed in the next section.

### **The supply of organs for transplant: unethical, unlawful, both, or lawful**

This section considers ways in which organs can be obtained, or procured, for transplantation. Some of these methods of procurement can be considered to be unethical, others unlawful, some both unethical and unlawful, whilst others are considered to be lawful. For some methods of organ procurement it can be a matter of geography that means what could be seen as unlawful is in fact lawful; whilst for other methods of organ procurement they are inherently unethical and unlawful, as will be explored below.

#### *Unethical and unlawful means of obtaining organs for transplantation*

There could be a myriad ways of obtaining organs for transplantation if you weren't too concerned about the niceties of the law. Obtaining organs for transplantation seems to be a staple of the horror film genre with many films, such as *Taken heart* (2017), *Hansel e Greta* (1999) and *Train* (2008), suggesting that human organ trafficking is a major way of obtaining organs for those that have the money to pay for them.

What is most chilling about these films is that they are not based on pure fantasy. There is truth in the underlying premise of the films: the black market that operates to supply organs for transplantation through trafficking or through paying individuals for their organs.

In 2005 Kishore wrote about the 'recent exposure of an international racket in organ trafficking, extending from Brazil to South Africa' (at page 362). The situation is so widespread in some parts of the world that in 2008 an international summit *Transplant Tourism and Organ Trafficking* was held to outline the ethical principles on which organs should be obtained for transplantation (*International Summit on Transplant Tourism and Organ Trafficking 2008*).

In 2012 the National Health Service website news section reported that in several countries kidneys for transplant can be purchased for as much as £128,000, with the 'donor' being paid as little as £2,500 (National Health Service 2012). Although categorising the individual who has sold their kidney as a donor may seem to be a definition too far as most often these are vulnerable people who are being exploited.

The National Health Service website news report estimated that worldwide the number of transplants that involve organs that have been purchased or obtained through trafficking is thought to be in the region of 10,000 annually (National Health Service 2012).

Thankfully the United Kingdom has criminalised payment for the supply of organs intended for transplantation for profit, and also the trafficking of individuals for the procurement of their organs to be used in transplantation. The full title of the Human Organ Transplants Act 1989, which was repealed by the Human Tissue Act 2004, was 'An Act to prohibit commercial dealings in human organs intended for transplanting; to restrict the transplanting of such organs between persons who are not genetically related; and for supplementary purposes connected with those matters'. It made clear that receiving or making payment was a criminal offence, as was trying to initiate or arrange such a transaction (section 1).

The Human Tissue Act 2004, which repealed and replaced the Human Organ Transplants Act 1989, still has a provision which provides for the 'prohibition of commercial dealings in human material for transplantation' (section 32).

Another method of obtaining organs for transplantation, which is considered unethical although is not unlawful as it has been sanctioned by the state involved, is though the removal of organs from executed prisoners. It is deemed to be unethical because it is considered that prisoners cannot provide a valid consent for their organs to be used after their death due to the lack of freedoms within the prison system they are held in (Cooper 2020).

#### *Lawful means of obtaining organs for transplantation*

Having considered the unlawful and unethical means of procuring organs for transplantation, it is now time to move on to the lawful procurement of organs in the United Kingdom. Put simply, there are two main ways in which an individual can legally donate their organs, either when they are alive or after their death.

#### Live donors

Taking live donors first, let's dismiss one method of procuring organs for transplantation that is lawful in some countries but not in the United Kingdom: that of payment for organ donation.

Despite what was said above about it being unethical and/or unlawful for people to procure organs through payment, in some countries, not those of the United Kingdom, it is lawful for payment to be made to individuals who donate an organ, usually a kidney. For instance, such a system operates in Iran where the system is regulated and those who act as intermediaries do not receive payment (Associated Press 2016). The regulated system in Iran is markedly different to the black market system of payment for organs discussed above, which is considered to be unethical and unlawful and which by its nature is unregulated and exploitative. Iran's method of procuring organs for transplantation by

allowing payment to be made to the donor is said to have 'helped effectively eliminate the country's kidney transplant waiting list since 1999' (Associated Press 2016).

In the United Kingdom there are two ways in which a live donor may donate their organs, usually a kidney or a part of a liver. There are various terms used to describe the two ways of live donation and some of these, such as altruistic, can be said to be value laden and so the terms used in this article will be directed and non-directed (U.S. Department of Health & Human Services 2015).

A directed organ donation is one where the donor states who the donation is for. This is usually a situation such as where a parent donates a kidney for their child, or a wife for their husband, or a sister to her brother. Usually, a donation from a deceased individual would be allocated to the person highest on the transplant waiting list who is the best match for the organ. Indeed, such organs are accepted on the grounds that there is no limitation on how the organ is allocated. However, where the donor is a living person a limitation is allowed on the basis that without the limitation that the organ is being donated for a specific named individual the organ would not be donated and therefore not available for transplantation.

A directed organ donation may also be one where the donated organ does not go to an individual known by the donor but instead goes to a third individual and in exchange someone on behalf of that recipient donates an organ to an individual in need known by the first donor. For example, A wishes to donate an organ to their sister B but is not a match. Instead they donate an organ to C and D who wishes to donate an organ to their husband C but is not a match donates their organ to B. A and D have both donated organ and the people they wish to receive organs (who they would have directed their organs for if they could), B & C, both receive an organ. They are usually referred to as paired or pooled donations and can involve several pairs of donors and recipients.

A non-directed organ donation is one where the donor does not specify that the organ has to be transplanted into a specified individual but rather makes an organ donation without knowing who the organ is intended for and without trying to influence who will receive it. A non-directed organ donation is similar to the donation by the deceased donor in that it will be allocated to the person most in need on the transplant list and who is a match for the organ. No payment is made to the donor of a non-direction organ donation in the United Kingdom. Although provision is made within the legalisation of the United Kingdom for living donors, wherever directed or non-directed, to be allowed to receive reimbursement of expenses.

The National Health Service in England states that

NHS England will reimburse living donors in order to ensure that the financial impact on the living donor is cost neutral [and that] The principle of

reimbursement is founded on the premise that there should be no financial incentive or disincentive in becoming a living donor (NHS England 2018)

The main expenses that can be claimed for are loss of earnings and travel and accommodation expenses as a direct result of the donation. All claims for expenses must be made to a specific organisation on specified forms and evidence of the expense being claimed is needed. No payment is made in the United Kingdom for the actual act of donation itself.

#### Deceased donors

There are two main systems for the donation of organs from deceased donors: opt in and opt out.

The opt in system is one that many people in the United Kingdom will be familiar with as a result of the various organ donor campaigns run to increase organ donation rates by increasing public awareness of how to donate.

Under an opt in system an individual has to register their wish for their organs to be used after their death. Different countries operate their opt in systems in different ways meaning that the result of registering on an organ donor register has different effects. In some countries once someone has registered on an organ donor register their relatives have no say in what happens after that person's death. In other countries if a relative objects to organs being donated from a deceased relative this is respected even if the relative has registered their desire to be an organ donor.

The opt in system can be criticised for the fact that it actively requires someone to do something, opting in or registering their wishes for organ donation, and this may be offset by inertia and/or a tendency to put it off until tomorrow. As a consequence some countries, such as the United Kingdom, also operate a system whereby the relatives of deceased individuals who have not opted in are asked whether their relatives organs can be donated. The relative is asked if the deceased individual has expressed a preference either for or against donation way; if there is no reason why the organ should not be donated, if the deceased individual had expressed opposition to donation for instance, the relative is asked for their consent for the donation to proceed.

Countries currently operating an opt in system include Germany, Ireland, the United States of America and, as we shall see, some parts of the United Kingdom.

The opt out system is, as may be expected, the opposite of the opt in system. In the opt out system an individual is presumed to consent to their organs being donated after their death unless they explicitly remove themselves from the donor register or register their objections



to their organs being sued after their death, depending on the actual system in place in the country they reside: because of this the opt out system is sometimes called a presumed consent or deemed consent model of organ donation.

Some countries utilising an opt out system of organ donation give a veto to family members, such as Spain and Wales. This is sometimes known as the soft opt out system and means that even if someone was in favour of organ donation, if their relatives do not want the deceased person's organs to be donated then these wishes will be respected and the organs will not be used for transplantation.

Other countries operate what is known as the hard opt out system and the presumption is absolute: so, unless the deceased individual registered an objection to their organs being used, they will be removed for transplantation even if the family were to object.

Countries option opt out systems of organ donation include Austria, Brazil, Bulgaria, England since May 2020, France, Luxembourg, Spain, Sweden and Wales since 2015.

The opt out or presumed consent system of organ donation is said to increase the number of organs being available for transplantation and this is the reason that many countries change to an opt out system. Zúñiga-Fajuri notes that

there is evidence that supports the association between presumed consent and increased donation rates and that countries with opt-out laws have rates 25 to 30% higher than those in countries requiring explicit consent (2015 at page 199).

#### Incentive schemes

In addition to opt in and opt out systems of organ donation, some countries have introduced incentive schemes for potential donors.

Singapore introduced such a scheme in 1987 when it

passed the Human Organ Transplant Act, which applies the priority rule with an opt-out system. If a person objects to donating their organs upon death, they give up priority for receiving an organ should they need one in future (Zúñiga-Fajuri 2015 at page 199).

Whilst the Singapore incentive scheme is aimed at increasing the number of organs from deceased donors, Israel has adopted a different form incentive approach to organ donation amongst live and deceased donors.

In January 2010, the Organ Transplant Act 2008 came into effect in Israel, which governs organ donation and allocation. The new law introduced a priority point system to motivate individuals to donate their organs. This

system rewards those who are willing to donate an organ with preferential status as a recipient. A person can gain priority points by signing a donor card, making a non-directed/ non-specified organ donation during their lifetime, or being a first-degree relative signing a donor card or consenting to procurement of organs after death (Zúñiga-Fajuri 2015 at page 199).

### **Current legal position of organ donation in the United Kingdom**

Having considered the various aspects of organ donation and transplantation this section will discuss the legal position governing organ donation in each of the 4 countries of the United Kingdom.

#### *England*

Until 20<sup>th</sup> May 2020 England was operating an opt in system of organ donation but on that day it joined Wales in moving to an opt out system of organ donation with the coming into force of the Organ Donation (Deemed Consent) Act 2019.

You may see the opt out system in England referred to as 'Max and Keira's' law. It is named after two children Keira Ball aged 9 who had her organs donated after her death and Max Johnson aged 9 who received Keira's heart. Max Johnson's family campaigned for the law to be changed to allow for the move to the opt out system.

#### *Northern Ireland*

Northern Ireland currently operates an opt in system of organ donation and currently there are no plans to change from this system.

#### *Scotland*

Scotland currently operates an opt in system of organ donation. It is expected that Scotland will move to an opt out system in early 2021 with the passage into law of the Human Tissue (Authorisation) (Scotland) Act 2019 in July 2019.

#### *Wales*

Wales operates an opt out system of organ donation and was the first country in the United Kingdom to do so when the Human Transplantation (Wales) Act 2013 came into effect in December 2015.

#### *Soft opt out systems*

The opt out system in England and Wales is a soft opt out system and Scotland is expected to also move to a soft opt out system when it changes in 2021.

Although the opt out system operating in the United Kingdom, albeit regulated and legislated differently in each of the countries that utilise it, affects everyone there are certain groups of individuals within each of the legislative provisions who are deemed to be excluded from the provisions.

These excluded individuals include:

- Those who for a significant period before their death lacked the capacity to understand the effect of opting out;
- Those under 18;
- Those who have not lived in the country in which they died for at least 12 months prior to their death.

For these groups express consent will be required from the relevant relative of the deceased person, and in the case of a child this will be the parent(s).

### Conclusion

Organ donation for transplantation is shrouded by both ethical and legal issues and difficulties. Several systems to regulate the procurement of organs operate through the world, but most are based on versions of the opt in or opt out system. There is evidence that the opt out system results in higher numbers of organs becoming available for donation. As a consequence, many countries that have operated an opt in system are moving to an opt out system. In the United Kingdom, both Wales and, more recently, England have moved from opt in to opt out systems and Scotland is expected to follow next year.

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