

## DEPARTMENT OF HEALTH PUBLIC CONSULTATION



# PROMOTING HUMAN ORGAN DONATION AND TRANSPLANTATION IN NORTHERN IRELAND

Key information and policy background

11 December 2017

## ORGAN DONATION - KEY INFORMATION

- Organ donation is where a person, living or dead, donates their organs and tissue for transplant. A transplant can be life-saving, or improve the health and quality of life for patients suffering from chronic illness, and their families and carers, whilst also bringing great comfort to donors' families.
- One person's decision to donate their organs is a gift that can save and improve the lives of up to nine other people.
- Living donations can include: a kidney, part of the liver and some tissue.
- Donations after death can include kidneys, heart, liver, lungs, pancreas, small bowel, corneas and tissue.
- In Northern Ireland, your organs and tissue will only be used if you
  have given prior consent (e.g. by having joined the Organ Donor
  Register or ODR), or if a close friend or relative does so on your
  behalf after your death, which is made easier when they know what
  your wishes were.
- The health service can also benefit through the reduced cost of treating patients, whose health has been improved through this altruistic act, by releasing resources to provide treatments for patients suffering from other ill-health conditions.
- Further information about organ donation in Northern Ireland is available at: https://www.organdonationni.info
- The NHS Organ Donation Website contains further information including links to the Organ Donor Register: https://www.organdonation.nhs.uk/
- Further information is available in Appendix 1

### **ORGAN DONATION - KEY FIGURES**

- In Northern Ireland 770,000 people have signed the Organ Donor Register (ODR), accounting for 42% of the population. This has increased steadily from 30% in 2013 at the launch of the strategy Taking Organ Donation to 2020.
- At present, around 200 people in Northern Ireland are on the transplant waiting list, and every year around 14 people in Northern Ireland die waiting for an organ transplant.
- The majority of people living in Northern Ireland are in favour of organ donation, and most would accept a donated organ if they needed one, however much fewer have stated their wishes either by joining the ODR or by talking with family and friends.
- Only a small number of us (approx. 1%) will die in circumstances where organ donation is clinically possible. It is therefore important that when these circumstances do arise, the opportunity to help others is not lost.
- In 2016/17, the consent rate for donation to proceed in Northern Ireland was 64%, compared to UK average of 63%. The 2020 Strategy target is 80%.
- In 2016/17, Northern Ireland had 22.7 deceased donors per million of its population (pmp), compared to the UK average of 21.6 pmp (making the UK the world's 12<sup>th</sup> leading nation). The five leading countries were: Spain (43.4pmp), Croatia, (38.6 pmp), Portugal (32.6 pmp), Belgium (31.6 pmp) and France (27.5 pmp).
- In 2016/17 Northern Ireland had 42.2 living donors pmp compared to the UK average of 16.1 pmp. The five leading countries were: Turkey (45.4 pmp), South Korea (38.4 pmp), Netherlands (33.9 pmp), Saudi Arabia (27.3 pmp) and Israel (27.0 pmp).

## **Policy Background**

### **Legislative Context**

The Health (Miscellaneous Provisions) Act (Northern Ireland) 2016 Part 4 Human Transplantation Section 15 provides a duty to promote transplantation requiring that:

- (1) The Department must—
  - (a) promote transplantation, and
  - (b) provide information and increase awareness about transplantation and the donation for transplantation of parts of the human body.
- (2) The duty under subsection (1) includes in particular a duty to promote a campaign informing the public at least once a year.

Following a detailed examination of all aspects of soft opt-out systems the Northern Ireland Assembly decided in 2016 not to proceed with specific legislation to introduce a soft opt-out system as a possible means of increasing levels of organ donation in Northern Ireland. However, the Assembly in recognition of the importance of promoting organ donation, passed the above legislation, which places a statutory duty on the Department to promote transplantation and increase awareness about transplantation and the donation of human organs.

The Department will therefore use this new statutory power to achieve higher rates of donation to be delivered throughout the consent journey under the current legal framework.

The Act also requires the Department to lay before the Assembly an annual report about transplantation in that year. The report must include every five years: the opinion of the Department as to whether this Act has been effective in promoting transplantation, and; any recommendations the Department considers appropriate for amending the law so as to further promote transplantation. This statutory provision therefore enables the Assembly to review the policy at appropriate intervals.

#### **Strategic Context**

The Department is a signatory, along with the English, Welsh and Scottish Health Departments, to NHS Blood and Transplant's (NHSBT) UK strategy *Taking Organ Donation to 2020*<sup>1</sup>, which calls for a revolution in attitudes to consent to donation, and advocates a sustained and well-coordinated programme of communication activities to promote organ donation across all parts of the UK.

<sup>&</sup>lt;sup>1</sup> http://www.nhsbt.nhs.uk/to2020/

#### **Policy Aim**

The Department's overall aim in implementing the new statutory duty is to build upon the principles of the *2020* strategy by promoting positive, cultural, long term change to 2020 and beyond, through an approach that is tailored to meet the needs of the Northern Ireland population. It is hoped that this will help to consistently secure authorisation to proceed with donation in 80% of potential cases; which in turn will consolidate and improve Northern Ireland's standing amongst the world's best performing regions and countries. In 2016/17, Northern Ireland had 22.7 deceased donors per million of population (pmp), and a world-leading 42.2 living donors pmp.

Achieving this aim lies firstly in encouraging people to want to become donors through increasing their knowledge about the process and about the benefits it can bring, and secondly in increasing the rate of consent to donation given by their next of kin in circumstances where donation is possible. This is more likely to occur when our organ donation wishes are already known through prior discussion, and when families are given the opportunity to receive appropriate advice from healthcare professionals at this difficult time.

In 2016/17, almost four out of ten families, when faced with the decision, did not give their consent for donation to proceed, sometimes against the known wishes of the patient. Understanding and addressing the reasons for their refusal in these difficult circumstances will help us consistently achieve the *2020* strategy target of an 80% consent rate.

#### **Key Underpinning Principle**

The Department is committed to working across the Health and Social Care (HSC) system, the public sector and wider society to promote organ donation in Northern Ireland through a coordinated, tailored and sustained approach to education and awareness, aimed at both members of the public and healthcare professionals. Through this approach, we aspire to see more people benefit from this gift of life by striving to increase the number of organs available for transplantation.

#### How Organ Donation and Transplantation works in Northern Ireland

Organ donation and the allocation of organs for transplantation is managed across Northern Ireland, England, Scotland and Wales by NHS Blood and Transplant (NHSBT).

NHSBT is responsible for managing the ODR, the UK's national transplant waiting list, matching and allocating organs on a UK-wide basis, and retrieving donated organs

and transporting them to the appropriate centre for transplantation. While this means that some organs from donors in Northern Ireland may go to people in other parts of the UK (and occasionally elsewhere in Europe), it also means that people in Northern Ireland can benefit from the opportunity of receiving an organ from elsewhere in the UK and the rest of Europe.

Organs need to be carefully matched to a recipient, taking into account the blood group, age, weight and the tissue type of the donor and potential recipient. This is important to give the best possible chance for a transplant to be successful. If an organ is not a good match with the recipient, there is a risk that it won't function effectively.

### **Becoming an Organ Donor after Death**

People who wish to donate their organs after their death can join the NHS Organ Donor Register (ODR), or simply make their donation wishes known to a close relative or friend. In the event of someone's death, whether they have joined the register or not, it is up to families give final consent for organ donation to take place. Knowing that their relative had signed up to the ODR often helps with that decision. Knowing that during their lifetime they had expressed a wish to become an organ donor is equally important.

However, only a small proportion of people die in circumstances where it is possible for them to be an organ donor, e.g. in an intensive care unit<sup>2</sup>. Only in these limited circumstances will it be possible for healthcare professionals to discuss the person's wishes with their families, or to check whether they have been registered on the ODR. Even then, there may be reasons as to why donation is not possible at that time. This is why it is important for loved ones to know what the wishes of the deceased person were during their lifetime.

In these circumstances the SNOD will check to see if the patient has authorised donation themselves, and commence the sensitive discussion with the patient's family with regard to donation. If donation is to proceed, the clinical team caring for the patient will work with the SNOD, who will ensure all the necessary clinical checks are made. This will include checking that there are suitable recipients for each organ that can be donated.

Throughout this process, the comfort and needs of the donor patient remain paramount and the main focus of the clinical staff in the critical care unit will be on

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<sup>&</sup>lt;sup>2</sup> Taking Organ Transplantation to 2020 2 Taking Organ Transplantation to 2020 – A UK Strategy notes that over half a million people die each year in the UK, but fewer than 5000 people each year die in circumstances or from conditions where they could become donors.

caring for their patient. SNODs also support the donor's family during this difficult time and to answer any questions the family has.

The organs are then retrieved by a completely different team of specialist surgeons who are not otherwise involved in the care of the patient. Organs are always removed with the greatest care and respect. They are then stored in fluid and usually kept cool to help preserve them and transported to whichever hospital or hospitals will carry out the transplant(s). As soon as possible, a separate team of surgeons will then transplant each organ into the patient who is going to receive it.

By ensuring that potential donors are referred to the SNOD service at the appropriate time along the patient's donation journey, and by maximising the number of people who have had an informed discussion about their donation wishes with their families, there is potential to increase the consent rate and thus the amount of actual donors year on year.

#### **Becoming a Living Organ Donor**

It is also possible to be a living donor. This most commonly occurs through kidney donation, when one kidney is removed from a healthy individual and transplanted into another person. In recent years, it has also become possible for people to donate part of their liver.

Living donation is obviously a very major decision, and every person who comes forward undergoes a rigorous assessment. All live donors and recipients are reviewed by an independent assessor who is responsible for making sure there's no pressure or coercion involved, and that all parties understand the risk of complications.

The Organ Donor Register is only for those who wish to donate after death. To be a living donor, people can contact a transplant centre directly.

#### **Further information**

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