

# SCRUTINY REVIEW OF PUBLICITY RE. ORGAN DONATION

# To: Health & Social Care Scrutiny Panel

Date of meeting: 12<sup>th</sup> December, 2017

Notes of: Committee Administrator

# **BRIEFING NOTE**

## Background

- 1. Following a Pendle wide invitation to put forward topics for this year's scrutiny work programme, a local resident asked if more could be done to encourage people to become involved in the organ donation process.
- 2. The following (unsubstantiated) statement was submitted in support of the request -

'Every year 64,000 people in the UK have end stage renal failure. South Asian and African Caribbean people are more likely to develop renal failure. Asian people with diabetes are 10 times more likely to develop with it. Diabetes is the single largest cause followed by poor blood pressure control. Approx 5 ½ thousand are awaiting transplant with only 1 in 3 being done before dying. With the large ethnic population in our locality and poor response from this area, do we and the CCG need to do more.'

3. Panel members agreed to include this item in their 2017/18 work programme for a light touch review.

#### **Current position**

- 4. The NHS Blood and Transplant Service manage the NHS Organ Donor Register and National Transplant Register.
- 5. Although in 2016/17 they were able to facilitate more transplants than ever before, there is still more that needs to be done. This is demonstrated by the following statistics, accurate at the time of writing –

- Over 6,000 people are needed to give blood every day to meet the needs of patients in England.
- To do this, 200,000 new donors need to be attracted each year to replace those who can no longer donate for health or other reasons.
- Less than 3% of people actively give blood.
- Across the UK, there are around 6,500 people in need of an organ transplant. This includes around 150 children and teenagers.
- Since April of this year, 2,377 people have received a transplant.
- On average three people die every day across the UK in need of an organ transplant, due to a shortage of donors.
- More than a third (34%) of patients waiting for a kidney are Black, Asian or Minority Ethnic (BAME). However only 6 out of every 100 people who have signed up to the NHS Organ Donor Register have stated that their ethnicity is from BAME communities.
- BAME patients therefore wait significantly longer for a kidney transplant than white patients due to lack of suitable organs.
- Last year (2016/17) 89 families declined to donate despite knowing that their loved one was on the NHS Organ Donor Register.
- Only 47% of families agree to donation going ahead if they are unaware of their loved one's decision to be a donor. This rises to almost 91% when the decision to be an organ donor is known.

# Facts you may not know

- Most donated organs and tissue come from people who have died. However, you can also become a living donor by choosing to donate a kidney; part of your liver; or some types of tissue during your lifetime.
- You can register your decision to donate on the NHS Organ Donor Register at any age.
- Having an illness or long-term condition doesn't prevent you from registering as an organ and tissue donor.
- Signing up only takes about 2 minutes and can be done easily online.
- You can choose which organs/tissue you do or do not want to donate. Those that can be donated are lungs; heart; liver; small bowel; kidneys; pancreas; cornea; tendons; valves; skin; veins; and bones.
- Organ donation is done anonymously with a donor's organs going to patients who are well matched.
- You do not need to carry an Organ Donor Card for your organs to be donated.
- Being on the NHS Organ Donor Register or carrying a Donor Card is not enough to allow you to become a donor. If you die in circumstances where you could become a donor your family will be asked for consent and their decision will be abided by. If your family doesn't know your decision they may not support it, therefore it is important to talk about your wishes.
- If you donate your organs after you die you could save and improve the lives of up to nine people, and help even more if you donate tissue.
- Only around 5000 people across the UK each year die in circumstances where they could donate their organs.
- People from Black and Asian communities have a higher incidence of conditions such as diabetes and certain forms of hepatitis, making them more likely to need a transplant.
- All the major religions of the UK support the idea of organ donation.

## Local position

- 6. As at 31<sup>st</sup> March 2017, the number of people in Lancashire on the NHS Organ Donor Register was 521,225.
- 7. Of these 25,021 were from Pendle (4.8%).
- 8. The statistics throughout this report demonstrate that there is a shortage of people on the Organ Donor Register.
- 9. They also highlight that there is a need for more BAME donors.
- 10. This is particularly relevant to the population of Pendle, which largely comprises of White and Pakistani ethnicities.
- 11. According to the Pendle Profile 2015, 77.2% of people in Pendle are of White British ethnicity. 17.1% of the Pendle population are Pakistani.

#### How can we help?

- 12. The focus of this Panel's review is to establish if there are any ways in which the Council can help promote organ donation.
- 13. At present, information on organ donation is primarily provided by the NHS. Its Blood and Transplant website <u>www.nhsbt.nhs.uk</u> provides considerable information on the work that they do.
- 14. However, they are keen to make partnerships with other organisations to help them reach more people.
- 15. Partners can reach new audiences and help keep blood donation at the forefront of people's minds. They can also help change perceptions of organ donation and encourage people to register and talk about their decision with their families.
- 16. Current partnerships include Boots; DVLA; Facebook; the Women's Institute; and a number of councils, including Manchester City Council.
- 17. Help can still be provided without an official partnership. The NHS Blood and Transplant website provides access to promotional materials for individuals and organisations to use. Examples include -
  - Leaflets in various languages
  - Social media graphics
  - Posters
  - Supportive signature for use on emails
  - Header for a website page
- 18. NHS Blood and Transplant also welcome assistance in helping educate young people about organ and tissue donation.

- 19. They have developed a portfolio of teaching resources, aimed at students aged between 11 and 16 and it is hoped that this could be incorporated into lesson planning.
- 20. They have also partnered with Team Margot to develop the Giving to Help Others education programme to engage primary school children; teachers; parents; and carers.
- 21. The Team Margot Foundation is an established campaigning organisation dedicated to raising awareness about the need for more potential bone marrow/stem cell donors.

## **The Way Forward**

- 22. The information provided in this report illustrates that potentially, there are ways in which the Council can help in the promotion of organ donation.
- 23. The Panel is asked to consider what, if any, action it wishes to take.

References:

NHS Blood and Transplant website - <u>www.nhsbt.nhs.uk</u> Pendle Profile 2015 - <u>http://www.pendle.gov.uk/downloads/file/8643/pendle\_profile\_2015</u>

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