

**NHSBT Board Meeting**  
May 2020

**Organ Donation Consent Legislation and Public Awareness Campaign - Update**

**1. Status – Official**

**2. Executive Summary**

Following the successful progression of the secondary legislation through Parliament, Max and Keira's Law went live on the 20<sup>th</sup> May. During the debate of the secondary legislation regarding exempted materials, Lord Bethell made a number of positive commitments regarding ongoing awareness campaigns and effective resourcing for organ donation and transplantation, including the use of affordable novel technologies.

We plan to adopt a phased approach to implementing the legislation change, so that training and awareness raising can be undertaken as soon as teams are ready, rather than wait for the COVID-19 national crisis to pass. This approach has been shared with the DHSC and the HTA and means that we will be able to realise the benefits of the legislation as soon as possible. The key elements are:

- **Operational** – All engagement roadshows were cancelled, to allow clinicians to focus on the COVID-19 response. Plans are in place to provide online awareness briefing sessions in the coming weeks for the tissue and organ donation and transplantation clinical community.
- **Training** – 95% of the SNOD workforce has had training on the new legislation and the conversation with families. Plans are in place to refresh on previously delivered content and complete the remaining training – including the Human Tissue Authority Codes of Practice – as soon as the specialist nurses are back from providing front line support.
- **Communications** – Research conducted in April shows that awareness of the law change has dipped slightly to 58% from 62% in January (2019/20 target is 60%). Radio advertising communicating that the law is changing recommenced from Thursday 7 May.

Despite the COVID-19 pandemic, the organ donation service has continued and every opportunity to support a life-saving transplant has been explored. Although in recent weeks the number donors per day has been far below usual levels, we are beginning to see signs of recovery in some regions.

### **3. Action Requested**

- **Note the revised plans for implementation of Max and Keira's Law, which seek to realise the benefits of the new legislation as quickly as possible.**
- **Support the recommendation to complete the training and implementation on a phased approach across the country as soon as teams have entered the recovery phase from COVID-19.**
- **Note the revised plans for communicating the law change.**

### **4. Purpose of the paper**

This paper outlines the key progress made and planned actions for ensuring we meet our commitments regarding the change in legislation across the country and describes the adaptations made to our approach in response to the COVID-19 pandemic.

### **5. Communication**

- 5.1 April advertising tracking research shows that awareness of the law change amongst adults has dipped slightly to 58%, down from a high of 62% in January and below the 60% target for 2019/20. Awareness amongst BAME groups has dipped to 41% from 48%. Although the indications are not positive, this is not a statistically significant drop due to the smaller sample size. We did not meet our 60% target for BAME groups in 2019/20 and this remains a key focus for the year ahead. Most of the communications campaign was paused towards the end of March as it was vital that people heard the COVID-19 campaign messages to protect the NHS and help save lives. This will have impacted on awareness amongst adults in England.
- 5.2 Radio advertising recommenced from Thursday 7th May including channels with good reach to key BAME populations. This will be supported by proactive media activity and search marketing to ensure that people can find information on the law change when they search online. We are also updating our wide network of partners and stakeholders and encouraging them to help communicate the change in the law, which will help to provide additional reach to BAME and faith and beliefs communities.
- 5.3 The 'Pass It On' strapline has been removed from creative assets where possible, as it does not feel appropriate during a pandemic. However, the core creative remains the same.
- 5.4 Advertising will continue after the law has changed, throughout June, to reinforce the message that the law has changed, encourage people to find out more, and reassure that people will continue to have a choice about whether to become an organ donor after the law change.
- 5.5 Planning is underway for a high profile burst of activity later in the financial year, to meet awareness and behavioural targets for 2020/21. This is in place of activity that was deferred from April and May, due to the outbreak of COVID-19.

## **6. Legislation**

6.1 England – The Secondary legislation was debated in the Lords and Commons on 18<sup>th</sup> and 19<sup>th</sup> May 2020 respectively. The go-live date remained 20<sup>th</sup> May 2020.

6.2 Given the challenges arising from the NHS responding to the COVID-19 pandemic and social distancing, the Department of Health and Social Care have confirmed that it is unlikely that transplants will proceed under deemed consent. We have received feedback from clinical and faith colleagues, that they have found this reassuring.

6.3 During the debates of the secondary legislation, the Government acknowledged that deemed consent may not come into practice straight away, due to COVID-19 and the need to ensure that transplants go ahead when it is safe and training for returning specialist nurses has been completed. They also committed to:

- Resuming and then maintaining marketing activity, including a focus on BAME groups.
- Putting in place measures to reduce health inequalities for BAME people.
- Ensuring that there are enough nurses, who are given the right training, to support the anticipated increase in donors.
- Making sure that the NHS has the resources to carry out additional transplants, including using affordable novel technologies.

6.4 Scotland - The Scottish Government confirmed that the launch of their legislation is deferred from Autumn 2020 to March 2021. All legislation and implementation activity has been paused.

6.5 Wales - The Welsh Government has now closed the consultation on the revisions to excluded material, which seeks to align with other UK legislation's exclusions. An NHSBT response to the proposals has been submitted.

## **7. Operational and Training considerations.**

7.1 Before the pandemic, all the specialist nurses have been trained in the principles of the legislation. 75% of the nurses received face to face training in the practical changes to the family conversation. Due to COVID-19 restrictions, 20% received training in the conversation via Zoom and the training planned regarding the HTA Code of Practice was postponed due to nurses returning to the front line. Completing the training will be prioritised alongside recovery plans for the regional teams.

7.2 Plans are being finalised to accommodate both a national and regional approach for the reboot of training and engagement activities, so that the full benefits of the legislation are realised as soon as possible. All training and engagement activities have been adapted to be delivered via Zoom, rather than face to face, so we comply with ongoing social distancing.

- 7.3 The Potential Donor Audit (PDA) development has been paused and will be rolled out later in the year, when we have the capacity to finalise the work and deliver training to the teams. Whilst this is not ideal, there is a system in place already for recording and monitoring deemed consent which can be utilised until such time as the PDA work is completed.
- 7.4 The effects of COVID-19 on organ donation and transplantation activity makes it difficult to establish a fair baseline for monitoring the impact of the legislation. We are liaising with the London School of Hygiene and Tropical Medicine as well as our colleagues in our Department of Statistics and Clinical Studies and the DHSC, to agree the best approach for evaluating and monitoring the impact of Max and Keira's Law.
- 7.5 Work to amend the faith declaration on the Organ Donor Register was completed and wording agreed with the Office of the Chief Rabbi. The project has been paused until it is appropriate to share the changes with the wider faith / belief community. It can then quickly be implemented.
- 7.6 It is established practice in OTDT that donation conversation training covers scenarios where face-to-face is not possible. This was the exception to practice but moving forwards the use of digital technology will feature more prominently in training and in the clinical setting.

## **8. Risks and Issues**

The main risks associated with the opt out implementation programme are:

- Max and Keira's law going live during a pandemic might attract negative media attention that may cause long-term reputational damage for both the organ and tissue donation programme and NHSBT. We are managing this risk through communicating with internal and external stakeholders.
- The clinical community are concerned that implementation of the legislation will distract attention from managing the COVID-19 crisis in hospitals. The risk mitigations agreed with the DHSC and the HTA are:
  - In situations where a decision is recorded on the NHS Organ Donor Register, then deemed consent would not apply as the patient has already given their consent.
  - Where there isn't a recorded or known decision, we will support families to make a decision on behalf of the patient.

## **9. COVID-19 Recovery**

- 9.1 The impact of COVID-19 on organ donation and transplantation has been significant. During the response phase NHSBT has taken a system leadership role, to both support and where appropriate co-ordinate the organ donation and transplant community in their response to the pandemic.
- 9.2 A programme of work is being established to ensure we recover safely, effectively and stronger from this crisis. This programme will support the recommencement of operational service and incorporate the OTDT change / transformation initiatives with the aim to move forward in the recovery phase

rather than back to the pre COVID-19 position. The programme will also balance the priorities of responsiveness to any new emergencies with the operational and clinical recovery whilst working through the backlog of planned work.

- 9.3 Ways of working within OTDT, NHSBT and the wider NHS have changed during the pandemic. Consideration is being given to those changes and where the change has been effective it will be maintained. The programme will also actively look out into the wider NHS to take advantage of emerging opportunities from their response to, and recovery from, the pandemic in order to further improve service delivery for donors and patients.

## **10. Conclusion**

The challenges arising from the COVID-19 pandemic have impeded the delivery of plans to implement Max and Keira's Law. We have strategies in place which enable us to promptly complete the training and ensure awareness for teams as soon as they are available. This means that we will be able to quickly realise the full benefits of Max and Keira's Law and save more lives through the gift of organ donation.

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