

NHSBT BOARD

28th September 2017

Response to recommendation made in the recent study: Family attitudes, actions, decisions and experiences following implementation of deemed consent and the Human Transplantation Act (Wales) 2013'

1. Status – Public

2. Executive Summary

This paper summarises the response from NHS Blood and Transplant (NHSBT), to the recommendations made following a two-year study led by Bangor University. The study was designed to explore the impact of the Human Transplantation Act (Wales) 2013 on donor family attitudes, actions, decisions and experiences.

3. Action Requested

- The Board is asked to consider and comment on NHSBT's proposed response.

4. Background

This was a two-year (01.10. 2015-21.9.2017) co-productive study led by Bangor University and funded by Health and Care Research Wales. Partners included NHS Blood and Transplant (NHS BT) and Welsh Government. High Patient and Public involvement of over 50 people/organisations received acclaim, especially for involving third sector organisations representing black, Asian and minority ethnic communities.

Data were collected on all of the 205 approaches to relatives of potential organ donor patients between 01.01.15-31.05.17 (18 months) in Wales. Sixty-two in-depth interviews with 78 family members of 58 patients who were potential/actual organ donors, Two focus groups or individual interviews with 23 NHSBT professionals were also carried out. Following the analysis of the research results six recommendations were made.

5. Recommendations

1) Future Media Campaigns

The Welsh Government's communications team will respond to this recommendation as the responsible organisation however the learning has been noted by NHSBT in planning future NHSBT lead campaigns.

2) Achieving target 2020 consent rates

The Welsh Government will respond to recommendations that fall within their remit in further strengthening the Act. NHSBT will review the consent training for the SN-ODs alongside the finding to ensure consistency in the use of the language of the Act and ensure practice reflects the Act as intended.

3) Specialist Requesters

NHSBT are planning to implement the Specialist Requester role in South Wales within the 2017/18 fiscal year. Whilst the Specialist Requester role is now being rolled out as a business as usual activity, NHSBT will continue to monitor the impact of the role and consent rates as part of routine performance monitoring and management.

4) Health systems issues that impact on consent rates

NHSBT is working to reduce the time of the donation process. It is recognised that the time taken from patient referral to transplantation has increased and a comprehensive action plan with a series of initiatives is in place to address this.

As part of the Taking Organ Transplantation to 2020 Strategy NHSBT will continue to ensure that organ donation becomes a routine end of life care choice offered to all families who find themselves in the situation where donation is an option.

The Welsh Government will consider the recommendations to improve hospital facilities and the perceived quality of NHS care.

5) NHSBT processes

NHSBT will continue to monitor, evaluate and research all outcomes of legislative change to learn how best to improve the service we provide.

6) Bereavement and Follow up care

As part of the aftercare provided to the families of organ donors NHSBT will continue to signpost families to established specialist bereavement support. We will particularly consider how bereavement support can be signposted for families that choose not to donate as these reported the greatest difficulties.

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