

NHSBT BOARD MEETING 29 September 2016

ORGAN DONATION AMBASSADOR PROGRAMME

1. Status - Public

2. Executive Summary

The Taking Organ Transplantation to 2020 (TOT2020) strategy commits to 'Develop a community volunteer scheme to support Trust/Health Board donation committees to promote the benefits of donation in local communities, particularly amongst groups with little tradition of organ donation'. This commitment currently sits in year 4 of the strategic plan and a proposal to implement an Organ Donation Ambassador Programme positioned within Organ Donation and Transplantation (ODT) was approved by the March 2016 meeting of the ODT Senior Management Team (SMT). Planning has commenced for implementation in 2017.

3. Action Requested

The Board is asked to:

- Note ODT's plan to establish an Ambassador programme to meet the strategic commitment to a volunteer scheme as set out in TOT2020.
- Note the progress made thus far in the planning of the Ambassador programme and the implementation timescales.
- Agree the recommendation that a Non-Executive Director of NHSBT be appointed as formal sponsor of the Ambassador Programme.

4. Purpose of the paper

The purpose of this paper is to set out the planned programme and update the Board on the progress made since approval was given at the ODT SMT meeting of March 2016. This paper seeks to provide assurance to the Board that work to design, socialise and implement the programme is progressing and that the planned outcome will meet the strategic commitments as set out the in TOT2020 Strategy. The paper further requests that the Board agree that the Ambassador Programme be formally sponsored by a Non-Executive Director.

5. Background

5.1. There is currently no formal volunteer programme in ODT. Any efforts to involve donor families or organ recipients are locally based and ODT has

no oversight of them, no part in training them and no ability to coordinate their efforts. Unfortunately potential volunteers have had to be turned away from NHSBT because there is no process in place to harness their enthusiasm, capture their experiences or support their engagement within their communities. Meanwhile all requests for speakers must be met by Specialist Nurses, who need to focus on their donor co-ordination role to reach the targets set in TOT2020. Regrettably due to the increasing demands on the Specialist Nurses not all requests for speakers can be met under the current arrangements.

- 5.2. The proposal paper supported by the ODT SMT used the learning from the Ambassador programmes of 4 Organ Procurement Organisations in the USA and Canada and outlined the options for the structure and use of an Ambassador Programme in the UK and the benefits that such a programme could bring.
- 5.3. The proposal recommended that ODT seek to design and implement an Organ Donation Ambassador Programme to involve those interested in raising the profile and understanding of organ donation among UK citizens. It would be led by a specialist Ambassador Coordinator who would provide expert leadership and training to optimise the benefits of volunteers.
- 5.4. The financial costs for the programme have been estimated based upon international experience and can be supported from within the existing Organ Donation and Nursing funding envelope.

6. Programme Benefits

- 6.1. A key indicator of the success of this programme is the ability to meet obligations and requests to promote organ donation without placing extra pressure on nursing staff.
- 6.2. Requests for speakers / attendance at events will be directed to the Programme Co-ordinator rather than the Regional / Team Manager. This will subsequently move the activity away from the nursing workforce (unless a clinical speaker is required) freeing up valuable time to facilitate organ donation and hospital development during a period when a continual improvement in donation numbers is required.
- 6.3. The programme offers the potential to further influence how Organ Donation is messaged within the community. At present a number of Donor families and Recipients create Foundations / Charities to promote Organ Donation. These individuals and groups carry out work in their communities but ODT has little ability to share materials, educate or influence how Organ Donation is talked about by these groups. If some of that enthusiasm could be brought under the umbrella of an ODT programme the potential to influence would be considerably greater. The lack of a formal programme leads potential volunteers to either engage with these Charities or walk away and not engage at all.
- 6.4. The potential benefits will be measured in terms of Ambassadors increasing the reach of the Organ Donation message, in particular through using the programme to train and support Ambassadors from communities with little or no tradition of organ donation to go into those communities to initiate donation conversations.

6.5. Any risk that Ambassadors may not display the values, behaviours or standards expected by NHSBT will be mitigated by providing a training programme, tailored to the individual Ambassadors needs to ensure they are effective. They will also be supported by the Programme Coordinator, the Communications / Marketing Teams and ODT Senior leaders to ensure the work undertaken is appropriate. Each Ambassador will sign a code of conduct ensuring agreed standards and those not meeting the required standard will no longer be asked to attend events.

7. Programme Initiation

- 7.1. We expect to appoint the Ambassador coordinator in early 2017. The job description and person specification have drawn on international and UK experience in volunteer co-ordination. The postholder will provide leadership to the programme, design the ambassadors training packages and liaise with internal and external partners.
- 7.2. Potential synergies have been considered and contact has been made with the Blood Donation volunteer programme and further calls are planned to ensure any learning and synergies can be utilised in planning the ODT programme. Meetings are being sought with the NHS Volunteer Network and the Queen's Volunteer programmes to ensure the programme incorporates best practice in volunteer management across large geographical areas.
- 7.3. International learning indicates that Ambassadors who have a direct connection to Organ Donation and Transplantation either as a Donor Family member or a Recipient are more likely to commit to the programme long term, and more importantly are more impactful as Ambassadors. Their personal stories reach audiences in a way which interested third parties cannot and the feedback from Ambassadors themselves was that the personal connection was a key to audience engagement and encouraging support for organ donation, especially in communities with little history of organ donation. Therefore the UK programme would seek to fulfil speaking engagements from within these groups. Other supporters of organ donation who for altruistic reasons wish to be involved would be very welcome and will be fully included in the programme.
- 7.4. Ambassador recruitment would be via several routes. Specialist Nurses Organ Donation/Requesters who spend time with donor families will be asked to note any indication that they would be seeking to support donation as a means of commemorating their loved one. These will be picked up within the Donor Records Department and passed to the Ambassador Coordinator for follow up. In the USA, Donor Recognition Ceremonies have been effective recruitment grounds for volunteers and the Annual St John Award events offers an ideal opportunity to socialise the potential for becoming an Ambassador with families and the aim would be that, initially at the larger ceremonies and eventually all events, there would be a programme representative available for families to speak to.

- 7.5. Recipients would need to be reached via their Transplant coordinators and the Ambassador coordinator will work to create a pack to be disseminated through local Transplant coordinators to patients. The programme will offer many opportunities for Recipients to tell their personal stories and, the chance to receive training, learn to speak in public and build their self confidence. For many recipients their illness will have prevented any opportunity to work and the programme would offer a valuable bridge between unemployment and the workplace. The opportunity for the Ambassador coordinator to act as a referee on future job applications has been highly attractive in other programmes and will be offered here.
- 7.6. The introduction of an organ donation Ambassador programme requires sensitive and appropriate socialisation with internal and external colleagues and partners. The Ambassador Programme proposal approved by the ODT SMT was shared with the membership of the TOT2020 Stakeholder Group who considered the proposal and supported its implementation. The committee has been assured that further updates will be taken back to future meetings to ensure they remain fully appraised of developments.
- 7.7. The introduction of the Ambassador Programme was also shared with the members of the ODT Sustainable Funding Committee with representatives from the four UK Health Departments, at their meeting in July 2016. The concept was considered favourably by those present. There have also been meetings with key external stakeholders to ensure they understand and support the programme.
- 7.8. The Ambassador co-ordinator will take a lead in promoting the benefits and uses for the programme. The co-ordinator will work with Hospital based Organ Donation Committees, Clinical Leads for Organ Donation and Recipient Coordinators to ensure that recruitment of Ambassadors is maximised. While the coordinator will provide the day to day leadership of the programme international learning makes clear that the involvement and commitment of senior leaders is vital to the success of any programme.
- 7.9. Non-Executive Director sponsorship would be a clear message about the importance that NHSBT places upon Ambassadors and that their efforts are noted and appreciated at the highest levels within the organisation. Ambassadors feel strongly that their time, effort and work should be valued and makes them a part of the wider organisational team. The attendance of senior leaders at their events, opportunities to join telecons with leaders and the feeling that everyone was 'one big team' were highly prized and the sponsorship of a Non-Executive Director will be a fundamental part of building that into the UK programme.
- 7.10. The Ambassador Programme will be presented at the ODT Congress 2016 which will offer a valuable opportunity to promote the programme and its potential benefits to the attendees who are among key opinion formers in the donation and transplantation community. The aim would be both to outline the expectations of the programme and allow for 2 way dialogue around the best uses for Ambassadors and where delegates envisage a programme would have the most beneficial impact.

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- 7.11. The target for year 1 is the recruitment of 100 volunteers to act as Organ Donation Ambassadors with ongoing recruitment through years 2-5 which, based on international experience, could be expected to yield a volunteer base of around 500 by year 5 end.
- 7.12.Initially it is anticipated that events would be supported in a small number of regions before rolling out. However potential Ambassador will not be turned away and those not in the first regions will be advised that they will be contacted in due course when their region comes into the programme. In this period of roll out Ambassadors will receive regular communications from the Coordinator and all Ambassadors will be invited to an annual or bi-annual Ambassador Congress which will offer training, updates on Organ Donation, the opportunity to meet and socialise and opportunities to meet senior leaders. These activities will support Ambassadors as the roll out brings activity to their areas.

8. Summary

The development of an Organ Donor Ambassador programme will give donor family members and transplant recipients the opportunity to spread our important message in a more consistent and co-ordinated way using their passion and real life experience. It will reduce the pressure on Specialist Nurses and allow them to focus on their core role and it will make sure NHSBT can meet the appetite for community engagement which already exists. Ambassadors will be supported by a volunteer co-ordinator on a daily basis but can also expect support from the senior team in ODT.

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