

## 31 October 2016

## **Guidance for submitting a bid to increase living transplants**

- All those interested in submitting a bid to NBTA to increase living transplants among Black, Asian and Minority Ethnic (BAME) communities are requested to carefully consider this guidance. NHS Blood and Transplant (NHSBT) have commissioned NBTA to manage the delivery on the Living Transplant Initiative and a copy of the commissioning document is attached.
- 2. Why is there a focus on living transplants? There are two main reasons. Firstly, limited promotion of living transplants (mainly kidneys) among BAME communities has been undertaken so far and secondly, figures over the last two years indicate that the number of living transplants among these communities has decreased.

#### 3. What is NBTA?

The National BAME Transplant Alliance (NBTA) consists of those passionate about promoting organ, stem cell and blood donation among BAME communities in the UK. Its members are individuals and organisations including charities, religious establishments, medical experts, academics and are supported by NHSBT and the Department of Health (England). It is the national voice of those from BAME backgrounds interested in increasing donations among BAME communities. It encourages, supports and promotes local and national initiatives. Further details are available at <a href="https://www.nbta-uk.org.uk">www.nbta-uk.org.uk</a>.

4. How will NBTA manage the delivery of the Living Transplant Initiative (LTI)? Firstly, NBTA has set up a LTI Steering Group to lead on this initiative on behalf of NBTA. Secondly, the Steering Group is now inviting any organisation interested in submitting a bid to undertake a project to support the LTI to do so. There is a pro-forma to complete which is attached. The first phase of the bidding process takes place from 31 October 2016 and subject to the availability of funds, it is anticipated that a second phase will be announced in 2017.



- 5. What are the priority geographical areas and communities?
  There are four priority geographical areas and BAME communities associated with each as follows.
  - North West London: Hindu and Jain communities
  - West London: Sikh communities
  - North London boroughs of Brent, Haringey, Enfield and Hackney & South London boroughs of Lambeth, Lewisham and Croydon: African and African-Caribbean communities
  - Leicester: Hindu and Sikh communities

There are three reasons for identifying these areas and communities.

- Analysis provided by NHSBT in its commissioning document on the largest number of BAME patients on the kidney waiting list.
- There are two other NHSBT projects on living transplantation taking place in the West Midlands and the South London borough of Southwark and it was important not to duplicate efforts.
- Finally, analysis from the Organ Donor Register was used to identify BAME communities which tend to be generally more positive about organ donation.

However, the Steering Group will consider bids from any part of the country and targeting any BAME community, if there are sufficient funds available.

- 6. What outcomes are expected from individual bids?
  There are three key outcomes which are listed in the NHSBT commissioning document, namely
  - 40 people from BAME background seeking information or expressing an interest in living donation
  - 25 people from BAME background being assessed for living donation
  - 10 people from BAME background, after assessment, being suitable for living donation.



A number of barriers to living transplantation have been identified in the literature and six barriers are mentioned in NHSBT's commissioning document. All bidders are encouraged to submit projects which address some of these barriers. The six barriers are:

- Recipients' reluctance to initiate the conversation about living donation and transplantation.
- A lack of skills on how to identify and approach potential donors
- Concerns for the donor e.g. process being too difficult, financial cost, guilt, effect on other family members.
- Lack of knowledge about the donor process, surgical outcome, risks and impact on future health
- Insufficient culturally sensitive resources.
- Access to clinic/hospital –based education only.

## 7. What is the timescale for bidding?

Following this announcement for seeking submissions, all bids should be made by 5 December 2016, using the pro-forma. The Steering Group will announce decisions on the submissions by 15 December 2016 with the aim that projects can commence in early 2017. It is anticipated that this first round of submissions will be followed by a second round in 2017, depending on the availability of the funding.

#### 8. How will the submissions be assessed?

The Steering Group will be looking for understanding of the BAME environment and organ donation. In addition, projects should be well structured so that they are likely to hit the milestone targets.

The following ten criteria will be used to assess submissions:

- a) The extent to which the bid contributes to the three key outcomes set by NHSBT and the six barriers, see paragraph 6.
- b) The appropriateness of the bid in targeting at least one of the four geographical and at least one of the specified communities.
- c) Evidence of previous experience of working in the targeted geographical area.



- d) Evidence of previous experience of working with the specified communities.
- e) Evidence of successful experience of promoting organ donation and transplantation within BAME communities.
- f) Evidence of clear plans on how local community organisations, community members and kidney patients on the transplant waiting list from the specified communities will be involved in delivering the project.
- g) Evidence of experience of working with staff in local hospitals.
- h) Experience of managing budgets.
- i) Experience of writing regular monitoring reports.
- j) Ability to listen to constructive advice and make changes needed to deliver the agreed outcomes.

Please note that submissions which meet a significant majority of the criteria set out above will also be considered by the Steering Group.

- 9. Who are the members of the Steering Group? The Steering Group members were approved by the full NBTA committee on 4 October 2016. They are:
  - Ms Tracey Bignall, Senior Policy & Practice Officer, Race Equality Foundation
  - Dr Sunil Daga, Consultant Nephrologist (Leeds Hospital), NBTA member.
  - Mr Orin Lewis OBE, Co-chair of NBTA and Chief Executive of ACLT (African Caribbean Leukaemia Trust)
  - Mr Kirit Mistry, Co-chair of NBTA, Community Link-organ donation (Derby and Leicester Hospitals)
  - Mr Kirit Modi, Honorary President of NBTA, Life Vice President, NKF and Chair of Steering Group
  - Dr. Adnan Sharif (Consultant Nephrologist), Secretary of Doctors Against Forced Organ Harvesting, Steering Committee member of Give A Kidney Charity, Member of NBTA.

Karen Quinn, NHSBT Assistant Director UK Commissioning, will join the Steering Group during the process of assessing all submissions.



The Steering Group will seek advice and support from co-opted members, as needed.

10. What are the terms of reference of the Steering Group? The terms of reference are as follows:

- a) To provide effective leadership in delivering the outcomes set by NHSBT in their commissioning paper.
- b) To report three monthly on progress and challenges to full NBTA meetings.
- c) To be responsible for producing and submitting three monthly monitoring reports to NHSBT.
- d) To make sound arrangements for seeking project bids for the Initiative and to determine successful bids based on a transparent basis.
- e) To receive monitoring reports from successful project organisations and to support them, as appropriate.
- f) To confirm the distribution of phased funding to successful project organisations.
- g) To identify good practice emerging from the Initiative and to advise NBTA and NHSBT on how it can be promoted nationally.
- h) All members of the Steering Group must declare any conflict of interest at the earliest opportunity to other members of the Group.
- i) If a member of the Steering Group belongs to an organisation which has submitted a bid, then that member of the Steering Group will not be involved in assessing their bid at any stage. In addition, that member will not be involved in assessing any bid which covers the same geographical area and the same BAME community.

## 11. How much funding will be allocated to successful bids?

The overall budget for this Initiative is up to £90k until 31 March 2018. It is up to individual organisations to determine the level of funding they are seeking. However, the Steering Group will do all it can to ensure that that there are successful submissions covering all four geographical area all the targeted communities. Submissions can cover more than one geographical area or more than one targeted community.



- 12. What type of outcomes will there be to the submissions? There will be three broad types of outcomes:
  - (a) One outcome could be full approval for the submission
  - (b) A second could be rejection of the submission
  - (c) A third outcome could be one which approves the submission but with conditions. In this case, organisations will be required to meet the conditions and these may include scaling down the funding requested in the submission.

All submissions should provide a realistic breakdown of the funding needed as well as details of phasing of the payments over the project period.

13. Will organisations be interviewed once they have made submissions?

It is anticipated that there will either be interviews or phone conversations between members of the Steering Group and lead members of the organisations which have made the submission before any final decisions are made. A simple contract between the Secretariat of NBTA (which will be the host organisation) and the successful organisations will be signed by both sides. The decision of the Steering Group will be final.

- 14. Who will make the phased payments?
  The agreed phased payments will be made by the Secretariat of NBTA.
  Organisations will be expected to provide invoices directly to the Secretariat.
- 15. What will be the arrangements for publicising individual project?

  The successful organisation will be encouraged to publicise the project as appropriate and publicity by the organisations should normally include clear statements indicating that the project is part of the Living Transplant Initiative managed by NBTA and that NHSBT has provided the funding for the project. Also, NBTA's logo should be normally be used in any publicity although clearly may will not be possible in using the social media. Any use of NHSBT logo needs to be agreed in advance with NHSBT on <a href="mailto:brand.communications@nhsbt.nhs.uk">brand.communications@nhsbt.nhs.uk</a>. Any reference to NHSBT needs to be agreed with NHSBT on <a href="mailto:externalaffairs@nhsbt.nhs.uk">externalaffairs@nhsbt.nhs.uk</a>. If there are any



queries related to this aspect, then organisations should contact Kirit Modi, in the first instance.

# 16. Where can I get further information?

Organisations considering making a submission are requested to contact Kirit Modi (<a href="mailto:kiritmodi1@hotmail.com">kiritmodi1@hotmail.com</a>) for any queries or further information, in the first instance.