

INTERIM REPORT of **LIVING TRANSPLANT INITIATIVE.**

Increasing living kidney donations among some BAME communities.



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INTERIM REPORT OF THE LIVING TRANSPLANT INITIATIVE (LTI).

Increasing living kidney donors among
BAME communities in the UK.

LTI is managed by NBTA and funded by NHSBT.



INTRODUCTION.

1. This innovative initiative was developed by NHSBT and NBTA because of the following two reasons.

Analysis of BAME (Black, Asian, Mixed Race and Minority Ethnic) kidney donors show that more BAME patients receive a kidney from a living kidney donor compared to deceased kidney donors. In 2016/17, there were 143 living kidney donors from BAME background compared to 90 deceased donors. However, there had been little work done to increase living kidney donation among BAME groups.

The overall number of living kidney donors in the UK has been going down for the last three years. In 2013/14 there were 1148 living donors; in 2016/17 there were 1043; a reduction of 95 donors. Figures for 2017/18 will be published later on this year. It was important that we take action to increase the number of living kidney donors to help reverse this trend.

2. Following discussions between NHSBT and NBTA, NHSBT commissioned NBTA to manage the Living Transplant Initiative in September 2016 as a pilot. The overall funding available was £90k to be spent by March 2018. A copy of the funding proposal is included in Appendix 1.

3. NBTA had to work quickly to put together a plan of action. It was decided to use all the funding to support local projects which involved targeted communities in specific geographical areas with significant population from the specific BAME community. A LTI Steering Group was set

up by NBTA to manage the initiative. A national advertisement to invite bids to undertake this work was published and a very good response from eleven bidders was received. The Steering Group decided to allocate funding to five bidders which were:

BAPS, Hindu Mandir at Neasden, focusing on the Hindu community in North West London, led by Prof Sejal Saglani.


Vanik Council UK, focusing on the Jain community in North West London, led by Manharbhai Mehta.

ACLT, focusing on the black community in South London, led by Orin Lewis.

Warwick University, focusing on the Hindu and Sikh communities around Leicester, led by Professor Caroline Meyer.

GOLD, focusing on the black community in North London, led by Dela Idowu.

4. The NBTA established a strong Steering Group to manage the initiative. It consisted of individuals with extensive experience of working with BAME communities, health professionals (two nephrologists and three nurses as well a senior representative from NHSBT). Everyone gave up their time on a voluntary basis. A list of the Steering Group members is set out in Appendix 2. The role of the Steering Group was both to support the individual projects and regularly monitor progress. The Steering Group met via tele conferences; initially it had a number of meetings in a short period and then met every two months.



The **Steering Group** worked hard, without any formal support, for three months, and from January 2017, administration support was provided by the Race Equality Foundation (REF). Because NBTA was an informal association at that time, the contract for providing administrative support was between NHSBT and the REF and this was funded separately by NHSBT. Formal contracts were agreed with the five successful bidders in January 2017 and work started in February 2017.

5. What took place and key outcomes.

The key features in each of the five projects were to produce appropriate resources on living kidney donation targeted at the specific community, arrange community events to discuss living donation and provide individual support to those showing an interest in living donation. Each project was encouraged to establish a local project planning group. Working in partnership with the local hospital was essential and, overall, this worked well. Strong partnerships were established with Hammersmith Hospital with Dr Marina Loucaïdu, consultant nephrologist, and Harvinder Dulku, living transplant coordinator and with Mr Bimbi Fernando, consultant surgeon at the Royal Free Hospital by the BAPS and the Vanik Council projects. **In addition Dr.M.K.Phanish (Consultant Nephrologist and Senior Research Fellow Renal Unit St Helier Hospital), Dr Joyce Popoola (Consultant nephrologist at St George's Hospital) and Dr Elizabeth Cording at St George's Hospital** supported the ACLT project. Unfortunately, GOLD was unable to continue with the project after the summer of 2017 because of unforeseen circumstances.

6. The following resources were produced. Most of them are available freely from the NBTA web-site: <http://www.nbta-uk.org.uk/living-transplant-initiative/>, and the NHSBT's hub for living donation : <http://www.nhsbt.nhs.uk/get-involved/promoting-donation-hub/download-digital-materials/black-asian-and-minority-ethnic-living-organ-donors/> The rest will be added soon.

BAPS: leaflet and video on living donation aimed at the Hindu community.

Vanik Council UK: leaflet and video on living donation aimed at the Jain community.


ACLT: leaflet and video on living donation aimed at the Black community.

Warwick University: a video on living donation will be available by the end of June 2018.



7. In NHSBT's funding proposal to NBTA, three measurable outcomes were identified for the LTI, which NBTA aimed to achieve through the pilot projects (see Appendix 1).

40 BAME individuals to express an interest in living kidney donation. The four projects found 151 individuals who did so.



25 BAME individuals to start the assessment process as potential living kidney donors. The four projects found 13 individuals to do so.

10 BAME individuals to become living kidney donors. The four projects found 3 individuals who did so.

The individual outcomes from three of the projects, compared to their targets, are included in the reports from the project leaders below. Unfortunately, it has not been possible to include the report from the Warwick project because it does not finish until the end of June 2018.

It is clear from the large numbers of individuals who expressed an interest in living donation after engaging in the community organised events/ publicity, that many people are willing to donate a live kidney to their loved ones, and would do so if and when this situation arose.

Only those who currently have someone waiting for a kidney transplant at present, or those interested in non-directed altruistic donation, would get assessed and then may go on to become a living donor.

8. What went well.

The contribution of the Steering Group was crucial to the overall success. Members of the Steering Group gave advice and support, attended and contributed to community events, and through sensitive but rigorous monitoring, kept the projects to time scales and budget, as far as possible.

While each project received funding to undertake the activities they had planned, there was a huge amount of work done within projects on a

voluntary basis. It would not have been possible to achieve the outcomes without this impressive voluntary contribution by many individuals from the communities.

The support of health staff from hospitals was excellent, on the whole, and good working relationships were established between some of the project leaders and hospital staff.


The development of specific resources mentioned above took time and considerable effort but we now have excellent resources which can be used nationally to increase living kidney donation.

There were numerous specific challenges faced by each of the projects and most of these were resolved. NBT is most grateful for ongoing support from Lisa Burnapp, NHSBT's Lead Nurse for Living Donation.

9. What did we learn.

This model of working was new and it showed that BAME communities are effectively able to engage with their communities to promote organ donation so long as they receive some funding to do so, are able to get support as needed from local health professionals and have a clearly defined plan of action with clear targets.

The importance of an effective local project planning group for each project was proved through this initiative. It is too risky to rely too much on one individual. This means that we need well organised community groups with proven record to undertake this work.



Three of the projects were community led and one as led by a University. Experience showed that the University led project faced greater bureaucracy and needed more time to complete its work.

The arrangements for administrative support provided through the REF were not straightforward because it was accountable to NHSBT and not to NBTA. NBTA has now obtained Charitable Incorporation Organisation status and it will be possible for it engage directly to arrange administrative support in the future.

10. Next stages.

NBTA requested NHSBT to provide some funding to continue with this initiative for one more year and this has been approved. NBTA has invited the four project leaders to submit a bid for further funding until March 2019 so that they can make better use of the resources which have been developed. Each submission will, of course, have to set targets which will be under the same three headings as set out in paragraph 7 above. While each project will target the same BAME community, there will be no geographical restriction and work can be undertaken anywhere in England.

11. Conclusion.

The LTI has shown that this model of working can be both effective and that a relatively small amount of funding is needed to enable community groups to take the lead. NBTA is most grateful to everyone involved in the LTI, particularly all those, both in hospitals and the community, who have contributed on a voluntary basis. We will, of course, produce a final report after March 2019.

If you have any queries about this Interim report or the LTI, please contact Kirit Modi, Chair of the LTI Steering Group (kiritmodi1@hotmail.com).



MAKING A GIFT OF LIFE THROUGH LIVING KIDNEY DONATION TO YOUR NEAREST AND DEAREST.

Report of the BAPS Swaminarayan Sanstha.
project to promote living organ donation by Hindus.

AIMS AND OBJECTIVES :

It is widely known that the Asian community, including Hindus, have a higher rate of hypertension and diabetes than the indigenous population and this increases the risk of end stage renal failure and need for dialysis and kidney transplant. Organ donation rates in the Hindu community are historically low. BAPS Swaminarayan Sanstha has supported drives to promote organ donation registration to allow donation after death, including a conference held in 2011 at BAPS Shri Swaminarayan Mandir, London (popularly known as the 'Neasden Temple'.

The aim of the current initiative was to raise awareness and educate the Hindu community about living organ donation. Our objectives were to produce educational material including a leaflet and video which expanded on the topic with patient and family stories, opinions from Hindu religious leaders and from medical professionals specialising in renal medicine and transplantation. We aimed

to distribute the resources generated within the community at the Mandir and other local temples and community groups in north-west London. We also aimed to hold a conference at the Neasden Temple to allow a forum for discussion and education on the topic and subsequently work with other local Hindu centres to hold similar awareness events and drives to maximise the reach of the educational message.

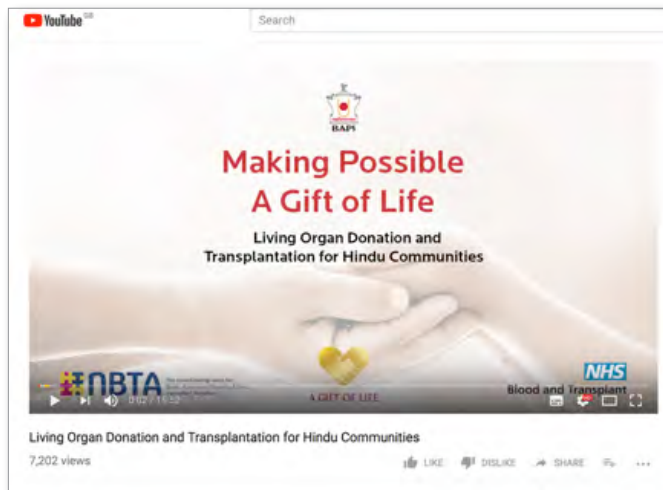
During the project, we aimed to produce a clear, unified message from a religious and medical perspective unreservedly supporting living organ donation within the Hindu community. We hoped that by doing so, patients and their families and friends seeking or offering a kidney transplant would have material and awareness of the process so that more members of the community would come forward to support loved ones and fewer patients would be left on dialysis without a kidney transplant.

ACTIVITIES : 1. Educational Video Production :

Our aim was to produce a high quality video with a clear message in support of living organ donation that could be uploaded to YouTube and shared widely within the community. With the support of a volunteer-based audio-visual team at the temple, we found and filmed interviews with two Hindu families, including the donor and recipient,

about life before and after donation. We also filmed interviews with a consultant renal physician and a consultant transplant surgeon at our local renal centre in Hammersmith Hospital focusing specifically on the medical benefits of living organ transplantation. We filmed Kirit Modi, Honorary President of the National BAME Transplant Alliance





A 16-MINUTE YOUTUBE VIDEO WAS CREATED HIGHLIGHTING:

- The experiences of patients who received or donated a kidney
- Opinions from various Hindu leaders
- Expert views

(NBTA) about the wider landscape of Organ Donation in the Asian community. Furthermore we filmed interviews with Hindu religious leaders and representatives including the spiritual leader of our organisation, His Holiness Mahant Swami Maharaj, the Head Swami at our London Temple, Yogvivekdas Swami, a minister of religion from the ISKCON Krishna Temple in Watford, Nila Madhav Ji and

Governor of the Shri Vallabh Nidhi UK Temple, Ajay Jobanputra.

From hours of filmed material, a concise short video was edited, produced and uploaded onto YouTube as planned. The video was also shared with worshippers within the temple community via e-mail and also with other Hindu organisations and healthcare teams.

ACTIVITIES : 2. Educational leaflet production :

Using the material from interviews during the video production, we created an educational A4 foldable leaflet about living organ donation within the Hindu community. A high quality leaflet was edited and

produced by an expert volunteer from the graphics team at the temple and after finalisation, an electronic form has been uploaded onto our temple website.





Organ Donation Educational Leaflet which included expert information, personal accounts and opinions from Hindu leaders – 35,000 leaflets were printed and distributed during the annual Diwali communications in October 2017

The leaflet was printed and widely distributed to 40,000 Hindus including all attendees at the Temple during the annual Diwali and Hindu New Year celebrations. The leaflet was also shared with local collaborating temples and community groups

and with Hammersmith Hospital for distribution to anyone from a Hindu background who may be seeking culturally sensitive information about living organ donation.

ACTIVITIES : 3. Launch of Project at the Temple in the presence of His Holiness Mahant Swami Maharaj :

We were fortunate that His Holiness Mahant Swami Maharaj was in the UK near the time of the project launch and in his presence during the living organ donation awareness drive was launched including the finished video and leaflet.

An announcement to the gathered devotees was made and an e-mail was sent to all to further increase the impact within our temple community.





ACTIVITIES : 4. Conference on Living Organ Donation : 28 October 2017.

The flagship activity and event of the project was the conference on Saturday 28 October 2017. Prior to the conference, a great deal of effort was invested in planning including sourcing the speakers, audio-visual aids and marketing which included invitation of special guests and publicising the event within our temple and other local temples/community groups as well as media outlets such as ethnic newspaper/radio stations. The event was attended by over 100 people. Guest speakers included a nephrologist, transplant nurse, families that have undergone kidney transplant and a

patient who was currently awaiting a transplant. There was healthy discussion in the question-and-answer session with a panel of speakers as well as during the refreshment break. At the end of the event, other local community group representatives made pledges of further actions to raise awareness of the topic in their own communities.

The event was followed up with a website report with pictures which was emailed out to all attendees at our temple to further raise awareness.

ORGAN DONATION CONFERENCE.

Panel interview with medical experts, patients and representatives of different Hindu faiths.





ACTIVITIES : 5. International Women’s Day Event : 10 March 2018.

One of the key themes for the BAPS annual International Women’s Day celebrations was “Be kind” and explored elements of generosity and selflessness through promoting organ donation. More than 1,000 women of all ages gathered for the conference at BAPS Shri Swaminarayan Mandir, London on Saturday 10 March 2018. The overall need for increased organ donors from the Hindu community was highlighted, and more specifically the prevalence of kidney disease in the Asian community and need for kidney transplants, especially the urgent need for living kidney donors was discussed.

An interview was held with a mother and daughter kidney transplant/recipient pair and a workshop that focussed on kidney disease, signs and symptoms and staying healthy with kidney disease took place.



THE KEYNOTE SPEECH WAS DELIVERED BY MRS MEENA MODI OBE, A FORMER HEADTEACHER IN WATFORD.

She explained her journey to transform Chater Infant School into an “outstanding” Ofsted-rated school. She also shared details of her kidney donation to her husband, and how this act of selflessness positively impacted her wider family. This was echoed by Kanchan Bhagat, who received a kidney from her daughter Swati.



ACTIVITIES : 6. Further work planned :

A number of future activities which have sprouted from the work done so far are still being planned. These include:

- Similar conferences or awareness events at BAPS Swaminarayan Sanstha centres nationally across England
- Working with ISKCON Watford Mandir to hold an awareness stall and event at their major festival of the year
- Working on a similar seminar event with SVNK Sanatan Hindu Mandir on Ealing Road

ACTIVITIES : 7. Management :

The conference drew a large audience of 120 people. One of the greatest successes of the conference was the production of a timetable and speaker list that provided a balance of knowledge sharing and sharing of personal experiences to foster open discussions and reduce anxieties by demystifying the concept of living donation and where this treatment stands within the concept of Hindu religious practice. The interest from the audience was reflected in the large volume of questions raised by the audience during the panel discussions and the sharing of their own personal experiences by many audience members. The energetic and heartfelt sharing of their own experiences, by our patient-speakers generated an atmosphere that fostered greater participation from the audience. This had the effect of producing a large number of enthusiastic pledges from the audience to translate thoughts and words to actions and to raise further awareness within their own friends, family and community circles over the next year.

In reaching out to other local community and religious groups, we were given tremendous

support for both the event and the production of the health-promotional educational materials. Local health and charity groups also agreed to advertise our event and distribute leaflets which allowed this message to reach a far wider audience in this area of London, and beyond. They have formed the core of our early network within the community to widen the platform for this message, and are keen to collaborate further for future awareness drives.

Using multiple media outlets to advertise the event, and multiple media formats to communicate the key messages about living donation in Hindu communities has helped to reach out to as many people as possible through as many routes as possible; something we believe is key to generate support from the younger demographic in our community.

Scheduling an event to ensure successful attendance can be one of the greatest challenges and will always require much consideration. Our conference timing allowed for the greatest availability of speakers and a diversity of attendance in the audience. Encouraging the younger members

of the community to attend, learn and contribute to this event was thoughtfully encouraged by using a number of media and social media channels in our communication of information and advertising of the event. The video was received with enthusiasm at the conference and will form a key part of our online health promotional materials to help reach the younger demographic.

The feedback from the conference audience was that over 90% of the respondents would feel confident or very confident in discussing living donation and would consider donating a kidney to a friend or family member. Nearly 75% of the audience would consider donating to a stranger. Over 97% of respondents would attend a future event to learn more about living donation and promote the message. A comment regarding the availability of translators for audience members to help clearly communicate the message to members of the audience with limited English will be taken on board for our next event, to ensure greater

access to this information and support for all members of the community. Overall, this feedback shows the interest within the community to learn more about living donation, and the effectiveness of such events and educational materials in supporting this goal, to improve living organ donation within the Hindu community.

Future work to reach our targets of seeing people through the process of being assessed for living donation:

We will be holding a small focus group of the people that have expressed an interest in finding out more about living organ donation. This will be in collaboration with the transplant nurse co-ordinator at Hammersmith Hospital, Harvinder Dhulku. We hope to achieve our aim of seeing 3-5 people through the process by the end of 2018.

In relation to the three key targets we had set, the outcomes were as follows.

Number of people expressing interest in living donation after the Conference: Target 6, Achieved 20

Number being assessed for living donation: Target 4, Achieved 0

Number of living kidney donors: Target 2, Achieved 0.





SUMMARY :

Our project to date has been successful in raising awareness about living organ donation and the need for donors in the Hindu community, in London and the South-East. The key messages have included:

- Living organ donation is in keeping with Hindu beliefs and the act of 'seva' – selfless service
- Encouraging open discussion with family or friends that may be on dialysis about living donation
- Living donors will only be accepted after thorough medical assessments and if they are fit enough
- Medical assessments of donors continue for the rest of their life

We have also achieved widespread media coverage, including a 30-minute chat show that has been

broadcast on our project and has focussed on the topic living organ donation for South Asians. Our YouTube video has been seen by another reporter who wishes to raise the topic in America and has asked permission to use our footage for her report.

We now aim to raise equal awareness nationally for Hindus by having at least eight smaller and focussed awareness at our centres in England, including the Midlands and North of England.

We will also continue to work with two other Hindu community groups in London to distribute the message in 2018.

Our attention will also turn to having small focus groups to ensure those who are interested in finding out more are given the opportunity for more detailed discussion and may consider assessment to be living transplant donors.

VANIK COUNCIL (UK) - LIVING ORGAN DONATION

"Give a Gift" Final Report
2017 - 2018



1. AIMS AND OBJECTIVES.

So many Hindus and Jains suffer from high blood pressure and diabetes, the chances of developing kidney failure in our community is high.

The drop in the number of living kidney donations and transplants over the last two years is becoming a major concern.

Within the Jain community, organ donation, particularly with kidneys is on the decrease. Statistics provided by NHS Blood and Transplant in their 2015/16 report indicate that there were 5189 patients waiting for a kidney transplant in the UK and 944 (18%) were from Asian background. There were only 98 organ donors from the Asian community; 71 were live donors and 27 were donors after death and the numbers of donors are going down. Overall, patients from Asian background have to wait longer for a donor after death compared to white patients, if they are lucky enough to get a transplant. Overall, 3 patients die every day while waiting for an organ transplant in the UK.

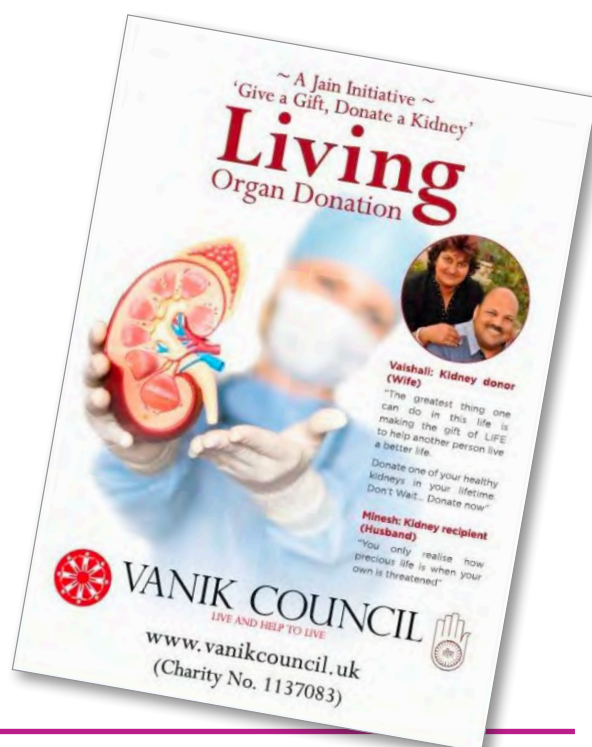
In view of the above, the main aim of our project was to make Jains aware of the need to donate an organ with emphasis on individuals within our community to come forward.

The Jain/Hindu community, in general, has been reluctant to come forward or openly discuss matters relating to organ donation. Our aim at inception has been to help our community come out of this shell thus help individuals and their families to better understand and endeavour to remove the

fear that currently appears to exist. Our community will, as a result, be better informed and we hope this project will provide sufficient information to allow them to come forward, discuss amongst friends and families and consider donating a kidney.

As part of this project, Vanik Council set out some specific targets and it was our aim to meet these targets, namely –

- People seeking information or expressing an interest in living donation be 10.
- Of the above, possibility of people going ahead for assessment be 5 to 6.
- People found suitable for living donation could be between 1 to 2.





2. ACTIVITIES UNDERTAKEN.

- At the start of the project we were keen to produce a leaflet that provided our community with answers to key questions on living organ donation. As part of producing the leaflet, we carried out research on the internet, speaking to individuals within our community and seeking advice from professionals and Jain leaders. Following gathering of information, we down selected questions to those which we thought would be useful to our community. These now appear on the Leaflet that we have designed. The leaflet on completion was circulated to all community members on our data base (2000 plus families) and we further distributed the printed copies of the leaflets to those attending events organised by our affiliated organisations and at the events we arranged. The leaflets on completion was uploaded to the Vanik Council website and was also provided to NBTA and NHSBT for uploading onto their websites for wider awareness.

- In order to raise awareness directly with our community, we arranged a number of events through which we could promote living organ donation. In total we arranged and held four events . During these events, we invited a GP Living Donor Coordinator, kidney surgeon/consultant, Dietician (targeted to vegetarians), NBTA Honorary President and community leaders. These events were also attended by Donors and Recipients, people who have been through this process who gave an insight on what they have had to consider; the decisions they have had to make including the impact that their kidney problems have had to on their lives. The

presentations/stories were followed with a Question and Answer session. In addition to these events we also delivered relevant talks at events organised by some of our affiliated associations.

- Following the events that were organised , we arranged further follow-up sessions for those members who wanted more information. Senior LDCs were invited to explain the process and answer their questions.

- As part of this project, we also produced a Video for whoever was interested in donating a kidney. Our expectation was that this could be used by friends, families to generally promote living organ donation within our community. The final videos that we produced included members from NBTA/ Vanik Council who provided a brief summary of the project, medical professionals who provided details on Living organ donation, interviews with recipients and donors who have been through this process and Jain leaders who gave an insight from a religious perspective. These videos were provided to NBTA and NHSBT for uploading it onto their websites. We have also uploaded it onto the Vanik Council website. In total two videos were produced, one which is around 22 minutes and a shortened version, about 5 mins.



3. MANAGEMENT.

Throughout the Project, regular meetings were held to plan, review, monitor and track progress of activities that we had undertaken.

- **Leaflet** – The generation of the leaflet required considerable effort to ensure answers to key questions were provided. This involved research on the internet, reviewing of material that existed, interviewing people and obtaining approval for the accuracy of the leaflet.

- **Events** – Arrangements of events to Promote Living Organ Donation on a large scale takes a lot of organisation including promotion to attract large numbers from our community. This is non-trivial and took considerable effort and time from many



individuals. Planning the event including identifying and gathering key speakers who could provide the information takes considerable time and effort to arrange. In order to plan these events, numerous meetings and discussions took place prior to the events.

- **Video** – Numerous meetings were held to discuss the content of the video. As part of the video plans to interview key speakers, recipients and Donors has to be coordinated with interviews being convened at convenient times for the participants. Following completion of the video, considerable time was spent on editing the content to ensure maximum effectiveness.



4. BUDGET.

We were allocated a total of £13,000, a 14.5% of the overall NHSBT funding of £90,000 however Vanik Council also contributed to this project as the funds allocated were insufficient to fulfil our aims

and objectives. Organisation of events on a large scale takes considerable time, effort and cost to hire venues to hold the capacity we were targeting is expensive.



5. WHAT WORKED WELL.

- Participation of community members to events that we organised. For one of the events that we organised, more than 250 people attended.
- Awareness of the project through circulation of the leaflet to over 2000 families
- We set our targets appropriate to the Jain community in NW London.
- Participation of key medical professionals at our events.
- Participation of Donors and Recipients including heart-warming stories at our events.
- Excellent Question and Answers sessions from community members at events.
- Completion of feedback forms with positive results.
- Positive interest in community members expressing an interest in living donation
- Positive feedback on event organisation of events.



6. EVALUATION.

Target Detail.	Targets Set by Vanik Council.	Our achievement.
People seeking information or expressing an interest in living donation.	10	96
People assessed for living donation.	5	4
People, after assessment, being suitable for living donation.	1 to 2	These 2 people have made living donation during the project period



7. THE MAIN CHALLENGES.

- Attracting community members has been difficult, however with great determination, we exceeded our expectations.
- Video – producing the video has consumed a lot of time and effort. In particular interviewing all involved in the video took a lot of preparation.
- Event arrangements and preparation has taken a lot longer than envisaged.
- Schedule of events has had to be carefully organised to ensure maximum effectiveness.
- Invitations to key speakers and confirmation to attend events was time consuming.
- Leaflet generation consumed a lot more time to ensure accuracy and also for it to be useful for the future.



8. CONCLUSION.

In summary, Vanik Council exceeded expectations on a number of fronts –

- Attendees at events exceeded expectations
- Target exceeded by over twice the objective set.
- Number of people who came forward for being assessed.
- Most impressive is that as a result of our promotion two members donated their kidneys following the start of this project.
- Finally, Vanik Council is keen to promote living donation amongst Jains living in other parts of the country and would be pleased to continue with this project, subject to funding to support our work.

BLACK LIVES DO MATTER: CHANGING ATTITUDES ABOUT LIVING ORGAN DONATION WITHIN THE BLACK COMMUNITY.

Evaluation: Executive summary: May 2018

Message from CEO of the African Caribbean Leukaemia Trust (ACLT)

“The Black community is experiencing a silent crisis and urgent action needs to be taken to prevent the dramatic decline in donor numbers. In the year 2016-17, only 24% of Black people in need received a kidney. This left 76% who didn't which equates to over 600 people still on the waiting list.

The scale of this problem is staggering. If you're Black and need a kidney, you'll be waiting nearly a

year longer to receive it than if you'd been white. Our silent crisis needs to not be silent anymore: we need investment and increased national priority from the Government and the NHS. A game-changer needs to happen soon: if action is not taken and awareness not raised, the current trend will continue. In other words, the future looks bleak for our community.”

Orin Lewis, CEO African Caribbean Leukaemia Trust (ACLT).

METHODOLOGY.

The research methods for this project included statistical analysis, a robust literature review and original qualitative methods to gather the information needed to establish how living organ donation could be increased in the BAME community. The report's recommendations are founded on evidence from:

- A statistical analysis of NHS England data on BAME blood and transplant donation.
- A literature review to obtain a comprehensive understanding of what research exists on the subject matter and to provide a foundation for the project's further research.

- Unstructured interviews were carried out with key staff members from the African Caribbean Leukaemia Trust to provide expertise on the subject-matter
- Structured interviews with a sample of African Caribbeans in South London were used in a scoping exercise to take into account public perceptions on the subject-matter in a quick and convenient way.
- In-depth interviews with organ donors and recipients to obtain detailed perspectives on the subject-matter.





CURRENT SCALE OF BAME ORGAN DONATION.

- Approximately 11% of the UK population is from BAME backgrounds, yet approximately 34% of the kidney waiting list is people from BAME backgrounds meaning they are three times over-represented.
- In 2016, the waiting list for kidney transplants was made up of 34% BAME people but of all the transplants, only 28% were BAME recipients.
- Not only is the number of Black people affected by kidney failure disproportionately high but the number of Black donors is critically low as well: in 2016-17, only 17 Black people were living kidney donors, the lowest number in five years.
- In 2016-17, Black patients who need a transplant had to wait one year longer for a kidney than white patients.

Across the UK, around 5000 people are in need of a kidney and in 2016-17, 250 died waiting for one.

FINDINGS : MOTIVATIONS FOR DONATION:

- Having a connection to kidney failure
- If there is no immediate connection to kidney failure, then imagining it could be someone they care about through hearing about case studies
- Viewing organ donation as opportunity to make a difference and an addition to previous altruistic acts such as having donated blood and volunteering
- Being informed and viewing donation as a rational response to a problem which disproportionately affects Black people.
- Hearing hopeful stories through inter-personal engagement and knowing that peers and people from the same faith or cultural group have been both donors and recipients

FINDINGS : BARRIERS TO DONATION:

- Doubts about donation within the family often causes the biggest barriers but most potential altruistic donors will not be swayed by this but instead by the facts and evidence.
- Lack of information and awareness about need, especially the racial inequality.
- Lack of information around procedure and risk
- Perception that donation is incompatible with faith or culture
- Scepticism and lack of trust in the NHS.

RECOMMENDATIONS TO INCREASE LIVING KIDNEY DONATION.

1. **EVOKE AND INSPIRE** through personal stories and case studies that people can relate to. Reinforce characteristics in potential altruistic donors such as being generous and self-assured

2. **INFORM AND EDUCATE** by disseminating facts that are both digestible, easy to pass on but not patronising or judgmental. Ensuring information demonstrates tangible outcomes that result from actions and relate this specifically to African-Caribbean's.

3. **DISCUSS AND DEBATE** through the facilitation of organic conversations in a social and community setting. Utilise community leaders to start conversations and build on common values of reciprocity and support.

4. **SUPPORT AND GUIDE** to ensure support is available at every stage of a potential donor's journey. Ensure that the relevant professionals are available and knowledgeable

THE PLAN.

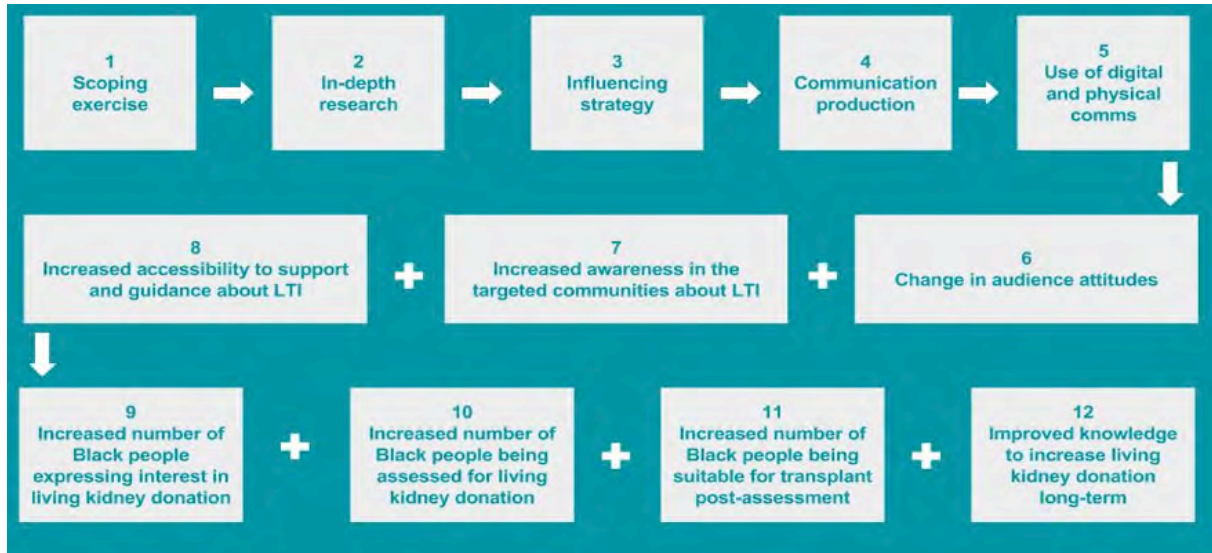
We turned the NBTA's targets (20 black people seeking information or expressing an interest in living donation; 12 black people being assessed for living donations; and 5 black people after assessment, being suitable for living donation) and ACLT's bid (entitled Black Lives Do Matter:

Changing attitudes about Living Organ Donation within the Black Community) into a strategy and action plan.



GOAL, AIMS AND OBJECTIVE.

Overview: a step-by-step project journey.



Numbers 6-8 correlates with the project objectives and numbers 9-12 correspond with the project aims.

We worked with the ACLT using a co-production approach, an important and effective way of working with communities and grassroots organisations. It meant we worked with them

and other stakeholders such as the donors, taking their views into account at all stages of the project planning and delivery.

ACTIVITIES.

1. Scoping exercise : structured interviews with a sample of African Caribbeans in South London were used in a scoping exercise to take into account public perceptions on the subject-matter in a quick and convenient way.

2. In-depth research:

a. An analysis of NHS England data on BAME blood and transplant donation.

b. A literature review to obtain a comprehensive

understanding of what research exists on the subject matter and to provide a foundation for the project's further research.

c. Unstructured interviews were carried out with key staff members from the ACLT to provide expertise on the subject-matter

d. In-depth interviews with organ donors and recipients to obtain detailed perspectives on the subject-matter.





3. Influencing strategy : this document laid out a strategy to achieve the following objectives: to influence NHS England and UK Parliament to prioritise BAME living organ donation; to develop a robust evidence base supporting the call for national action on BAME living organ donation; and to position the ACLT as a key player in the discussions on BAME organ donation. It included practical plans on how to: influence parliament and NHS England; gather information through written parliamentary questions and Freedom of Information Act Requests; stakeholder engagement; changing the position of decision makers through select committees and the National Audit Office; other tactics such as developing cross party support and media activity.

OUTPUTS.

6. Change in audience attitudes : (measured via monitoring social commentary to digital posts etc. and face-to-face interactions on the subjects matter)

7. Increased awareness in the targeted communities about LTI (measured via monitoring the communications distribution and indicators such as website and social media traffic and unique visits).

8. Increased accessibility to support and guidance about LTI (measured via monitoring communication statistic such as “shares” and “likes” and the number of enquiries about LTI.

4. Communication production : We produced both general and targeted communications to fit the different audiences we defined in our research (altruists, health donors and kidney-connected individuals). Our communications strategy corresponded with the influencing strategy and defined specific “calls to action” required to achieve the project aims and objectives. For example, see the website content we created www.aclt.org/organs-living/

5. Use of physical and digital communication: communications (website restructure, social media content, videos, infographics, leaflets and posters) were rolled out across different online platforms and made available for ACLT to use at events.

Regular communication between the ACLT and us including a mid-project evaluation meant both parties could see what was going well and make suggestions to reach the final project outcomes. For example, midway through the project, we were invited to support the ACLT with a funding bid for an extension of the LTI project linked to the existing aims and objectives. The successful funding bid meant that we provided the ACLT with the following extra deliverables: an influencing strategy extension paper, refreshed social media and email content and increase presence of offline communications.

OUTCOMES.

Activity.	How delivered.
The design, production and distribution of new culturally sensitive African and Caribbean flyers, video, posters and literature.	Leaflet and Video content focused on a case study (Nina) was targeted at a key African and Caribbean audience. This was designed, conceived and delivered after a Vox Pop Researched survey amongst Black individuals in South London. We also designed an Infographic webpage with statistically black Living Organ facts and figures highlighting the severity of the present day situation surrounding the low numbers of donors. We also posted new Social Media content:
Attending cultural, social, religious, artistic, sports, theatrical, comedic, etc. events to deliver talks, video showings and distribution of new African/Caribbean Living Donation literature and speaking to black people expressing a real interest in living donation.	We did this also as part of our rolling out planned set of stem cell, blood and organ registration drives incorporating (when appropriate) living donor messaging. This successful activity took place bi-monthly or more throughout the year of the project and resulted in an uplift of interested activity either on a face to face or email enquiry basis.
Face to face meetings with black people expressing a real interest in living donation	Interested individuals spoke to us on either a one to one basis or via email to highlight their strong desire to be assessed for Living donation. We then electronically linked them to the NHSBT Living Organ donation website to start their individual journey.

In the following section we set out the three key targets and the progress we have made.

Our Evaluation findings have enabled the ACLT to clearly identify Organ donation type individuals, and what key triggers motivate the different profiles. Also our Website traffic spikes in unique users, social media activity and Interested Register signups correlated directly, suggesting that our audience would respond more to general awareness and small nudges than insistent calls to action.

Our most popular posts showed more interest in a person (Nina and others) as opposed to statistics. Facebook also revealed women aged 35-44 are key demographic on that platform.

People are expressing interest across platforms and it is consistently positive. This should not be

underestimated because it's a potentially contentious topic.

The number of Interested Register signups has exceeded expectations. This suggests that there is a huge opportunity for helping people to sign up with low commitment, and guiding them through the process.

Comments and feedback from events and other face-to-face interaction have helped to build fuller picture of barriers and motivation to Living Kidney donation.

The ACLT's appearances at events have been very effective at generating signups - as expected!



Living BAME Donor.

“You don’t have to be brave to be a donor. There’s nothing scary about it. If I had a not had one, I’d do it again, in a heartbeat. The recovery time was minimal, I didn’t feel any different to how I was before.”

Nina Greywoode donated her kidney altruistically to someone she didn’t know as she was inspired by her friend not being able to find a suitable donor.

CONCLUSION.

African Caribbean Leukaemia Trust.

ACLT is a 30+ times award winning charity committed to providing hope to patients living with blood cancer and illnesses where a matched donor (stem cell, blood or organ) is required to save a life. Our work is driven by a belief that no one should die waiting for a donor to become available.

Through our work, we improve odds of finding matches by registering potential donors en masse from all ethnicities, with a focus on donors from the African and Caribbean communities. This is due to an extreme shortage of potential African and Caribbean donors.

Contact: info@act.org **web:** www.act.org

Sheffield Street Company.

Sheffield Street Company is a team of determined and passionate individuals with years of campaigning experience. Having worked together on many different projects, our combined skills ensure the campaigns we organise are powerful, well-researched and highly resilient.

We’ve worked with driven campaigners and vulnerable people, lobbied parliament on national policy, organised, trained and mobilised campaigners, conducted and implemented research and run highly successful communications campaigns. But our real strength is understanding unique organisations and facilitating them to shine and create sustainable change.

Contact: info@sheffst.co



OFFER OF SUPPORT TO INCREASE THE NUMBER OF LIVING DONORS FROM THE BLACK AND ASIAN COMMUNITIES.

1. CONTEXT.

The risk of end stage kidney disease (ESKD) in black and Asian and other minority ethnic (BAME) communities is more than three times higher than in the Caucasian population and the number of people waiting for a kidney from BAME populations is disproportionately high, currently comprising 30% of the overall kidney transplant list. In comparison with 882 days for white patients, median waiting time to transplant for adult black recipients is 1134 days and 1070 days for Asian recipients.

In London, 72% (n=813) of patients on the kidney transplant list are from BAME communities with 47% (n=381) Black, 44% (n=355) Asian and 9% (n=77) other ME groups. 28% of eligible deceased donors in London are from BAME communities with a range of 11-30% across transplant centres. Outside London, the main transplant centres with a significant number of BAME patients waiting for kidney transplant are: Queen Elizabeth Hospital, Birmingham 51%(n=205), Leicester Royal Infirmary 42% (n=71). Coventry University Hospital 39% (n= 32).

Overall, there is a lower conversion rate of potential living donors to actual donors from BAME communities in comparison with white donors due to predisposing factors such as diabetes mellitus and hypertension. This data is held by individual transplant centres but, experience suggests that only one in every three or four donors from BAME communities may be suitable to proceed to donation following assessment.

Latest statistics confirm that, in comparison with white communities, fewer people from BAME backgrounds:

- Give consent for deceased donation (33% BAME versus 66% white)
- Are aware of the Organ Donor Register (57% BAME versus 74% white)
- Agree that its important to share their decision about organ donation (38% BAME versus 59% white)
- Have had the conversation with family (27% BAME versus 48% white)
- Are aware of the organ donation decision of family members (77% BAME versus 83% white)

In living donor kidney transplantation (LDKT), the number of Black and Asian patients accessing LDKT is substantially lower compared with white patients with only 14% of BAME recipients transplanted directly from a family member or friend in comparison with 86% of white recipients. A number of barriers have been identified in the literature:

- Recipients' reluctance to initiate the conversation about LDKT.
- 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
- BAME donors are significantly under represented in non-directed altruistic kidney donation and engagement from these communities is low. 99%

of non-directed donors are Caucasian but 24% of recipients of these donated kidneys are from BAME communities.

1.1. WORK IN PROGRESS: Pilot Project Acceptance, Choice & Empowerment (ACE) in Living Donor Kidney Transplantation (LDKT).

As part of delivering the Living Donor Kidney Transplantation (LDKT) 2020 Strategy, NHSBT is currently funding and working in collaboration with Kidney Research UK (KRUK) on a 1 year pilot project – ‘Acceptance, Choice & Empowerment (ACE) in Living Donor Kidney Transplantation (LDKT)’ from April 2016 to March 2017. This is the first UK pilot, specifically focused on increasing uptake of LDKT for Black and Asian patients with End Stage Kidney Disease (ESKD) and their families. Two pilot sites are enrolled- West Midlands (Queen Elizabeth Hospital, Birmingham- Asian patients) and South London (Guy’s & St. Thomas’ Foundation Trust, London- African and Caribbean patients).

Evidence suggests that BAME communities are more likely to donate to loved ones within their own communities than to engage with ‘general population’ donation appeals. The project aims to engage with BAME communities using a unique home-based education intervention with Peer Educator volunteers. It combines proven models from the Netherlands (NL), USA and the UK that have been effective in overcoming barriers within BAME family and friend networks to increase uptake of LDKT. ACE LDKT has the potential to offer an innovative, cost-effective, culturally sensitive solution to increasing LDKT in BAME communities.

The measurable outcomes for this project have been chosen so that they are realistic for the short duration of the pilot. As there is little data currently available, the aim is to provide benchmarks for future projects:

- 1) Number of expressions of interest from enrolled patients and their families about living kidney donation
- 2) Number of potential recipients taking up attendance at patient education sessions/events including prospective patients and reengage with ‘lapsed’ individuals/poor attendees
- 3) Number of home visits- uptake and attendance

The pilot project will also deliver:

- A toolkit/template covering governance processes, recruitment and training to inform future projects and roll out to other centres
- A qualitative assessment of the experience and reflections of participants (Individuals, families and friends, Multi-disciplinary team, Peer Educator Volunteers) based on focus groups and questionnaire surveys.





2. PROPOSAL.

NHSBT is making £90,000 available for an 18 month period from 1st November 2016 to increase the number of people from BAME communities who have an opportunity to be transplanted from a living donor. NBTA will

agree which projects to support with the aim of delivering 25 people from the black and asian community who enter the assessment programme for living donation.

3. KEY PERFORMANCE INDICATORS (MEASURABLE OUTCOMES).

There is little existing data in this area to benchmark performance targets and therefore the following are recognised as stretch targets. Within an 18 month project, proposed targets to be achieved are the numbers of donors from

BAME communities:

- Seeking information/expressing an interest: 40
- Assessed for donation – key measurable: 25
- Suitable to continue to donation: 10

4. GOVERNANCE : NBTA to take responsibility for :

- Collectively identifying and agreeing the projects, assessing value for money and likely deliverability and the suitability of outcomes/ key performance indicators against which they will be judged. A transparent decision-making process should ensure the confidence of all wishing to propose projects.
- Presenting the projects to NHSBT for sign off
- Performance managing the projects to deliver the agreed outcomes whilst supporting project leads to deliver
- Reporting progress quarterly to NHSBT
- Ensuring good financial governance is exercised through the body chosen to hold the funding on behalf of NHSBT

Sources:

1. Latest statistics and NHSBT Activity Reports, 2015/16 <http://www.odt.nhs.uk/uk-transplantregistry/annual-activity-report/>
2. ACE LDKT Pilot Project April 2016 to March 2017, NHSBT/KRUK (in progress- full documentation awaiting publication)

MEMBERSHIP OF THE LIVING TRANSPLANT INITIATIVE STEERING GROUP.

Kirit Modi (Chair): Hon President NBTA

Orin Lewis: Co-Chair, NBTA

Kirit Mistry: Co-Chair, NBTA

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Karen Quinn: Assistant Director
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Angela Ditchfield: Lead BAME Specialist Nurse
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Sandra Cruickshank: Living Donor Co-ordinator,
Lister Hospital

Dr Agimol Pradeep: Transplant Recipient Co-
ordinator, Kings College Hospital, London.

Tracey Bignall: Senior Policy and Practice Officer,
Race Equality Foundation.

Further details about members of the Steering Group are available at
<http://www.nbta-uk.org.uk/living-transplant-initiative/steering-group/>