

FINAL REPORT of **Living Transplant INITIATIVE.**

Increasing living kidney donations among some BAME communities.



THIS INITIATIVE IS MANAGED BY THE NBTA AND FUNDED BY NHS BLOOD AND TRANSPLANT

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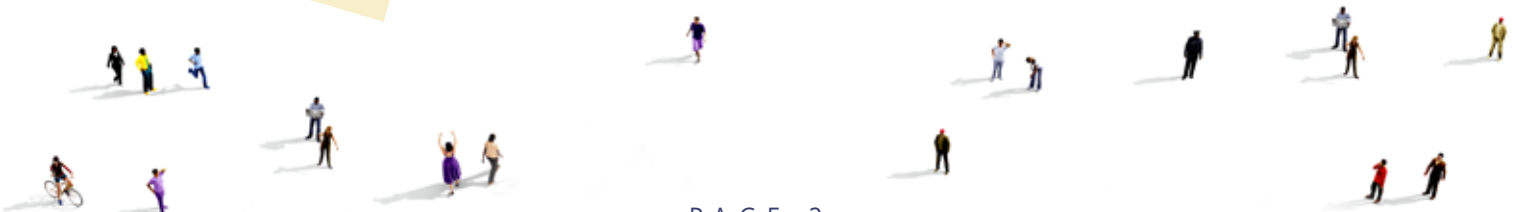
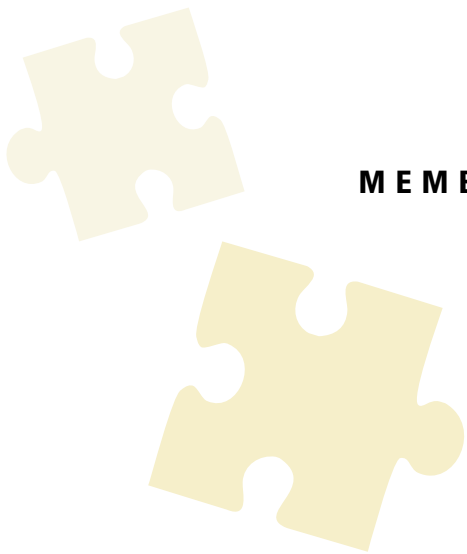
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FOREWORD.

Foreword by : **Kirit Modi** - Chair, LTI Steering Group, NBTA and
Lisa Burnapp - Clinical Lead for Living Donation, NHSBT.

We are delighted to share this important report with you. The Living Transplant Initiative (LTI) was established in 2016 by NHS Blood and Transplant (NHSBT), who commissioned NBTA (National Black, Asian, Mixed Race and Minority Ethnic (BAME) Transplant Alliance) to deliver a pilot scheme for two main reasons: firstly because little work on increasing organ donation within BAME communities had taken place in the UK and secondly because the number of living kidney transplants were plateauing. The pilot was extended and came to an end on 31st March 2019.

Our approach was to enable BAME community groups to undertake work in their communities focusing on living donor kidney transplantation by working closely with their local transplant centres and their referring hospitals. There was a rigorous process for applying for funding which was overseen by a dedicated Steering Group.

Ambitious targets were set for each phase of the LTI. Individual projects were supported and monitored by members of the Steering Group. Overall, the numbers of BAME people expressing an interest in living donation, after receiving detailed information about the process, exceeded expectations. However, the number of people who went on to be assessed as potential living donors and those who actually donated was low. In the current year (2019/20), a continuation to the LTI has been established by NHSBT with a focus on encouraging more people to be assessed and then proceed to donating living kidneys. The LTI was very successful in producing new faith-based resources (videos and leaflets) about living donor kidney transplantation aimed at specific BAME communities. These are now available for

everyone to use at this link: <https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/download-digital-materials/>

One of the legacies of the LTI is that this model of funding BAME community groups to undertake targeted work on organ donation after death in their communities has been adopted by the Health Departments in England and Wales through the Community Investment Scheme (CIS). The CIS is now in its second year; it supported twenty five projects in its first year and a similar number in the second year.

The partnership between NHSBT and NBTA has worked very well and a great deal of mutual respect has been established. The two organisations are currently working together on the development of the “post 2020” UK strategy for organ donation and transplantation to ensure that the needs of the BAME communities are fully reflected in the new strategy.

We are most grateful to everyone involved in the LTI; all project leaders and their teams, many living donor coordinators and nephrologists who have supported local projects, numerous BAME and faith-group volunteers, living donors and recipients who have shared their stories, NHSBT staff and all members of the LTI Steering Group.

Living donor kidney transplantation transforms lives and is an important part of organ donation in the UK. As England and Scotland join Wales in moving to deemed consent in 2020, it is crucial that the profile of living donation is maintained and its contribution to patients waiting for a transplant is not forgotten.



OVERVIEW OF THE LIVING TRANSPLANT INITIATIVE.

1. This innovative initiative was established by NHS Blood and Transplant NHSBT and National Black, Asian, mixed race and Minority Ethnic Groups Transplant Alliance (NBTA) in 2016.

Analysis of BAME organ donors in the UK show that there are more BAME living kidney donors compared to BAME deceased Donors. In 2016/17, there were 143 living kidney donors from BAME background compared with 90 deceased donors. While there had been considerable effort to increase deceased BAME donors, there had been little work done to increase living kidney donation among BAME groups.

Secondly, the overall number of living kidney donors in the UK had 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.

It was important that we take action to explore how BAME living kidney donors could help increase the overall number of living kidney donors.

2. Following discussions between NHSBT and NBTA, NHSBT commissioned NBTA to manage the Living Transplant Initiative, as a pilot, from September 2016 to

March 2018. Following the outcome from the pilot, the LTI was extended to March 2019.

3. An Interim LTI report was published in 2018. In the second phase of the LTI, invitations to bid for funding were invited in the same way as in the first phase. The key difference was that bidders were encouraged to work within their communities in different parts

of the country rather than limit their work to specific geographical areas. The Steering Group decided to allocate funding to seven bidders; four of these were larger projects and three smaller projects dependent on the amount of funding allocated to each project.

THE FOUR LARGER PROJECTS WERE.

BAPS Swaminarayan Sanstha, Hindu Mandir at Neasden, focussing on the Hindu community led by Prof Sejal Saglani.

Vanik Council UK, focussing on the Jain community led by Manharbhai Mehta.

Afro-Caribbean Leukemia Trust (ACLT), focussing on the black community led by Orin Lewis. OBE.

South Asian Health Action (SAHA) focussing on the Hindu and Sikh communities around Leicester, led by Kirit Mistry.



THE THREE SMALLER PROJECTS WERE.

Guy's and St Thomas's Hospital NHS Foundation Trust.

Gift Of Living Donation (GOLD) : Focussing on the black community in North London, led by Lisa Silas & Dela Idowu.

St James Hospital, LEEDS : Focussing on the Muslim community.


Queen Elizabeth Hospital BIRMINGHAM : Focussing on the BAME communities.

4. THE STEERING GROUP.

All members of the Steering Group established in the first phase were invited to continue and they all readily agreed to do so, with one change. Lisa Burnapp took over from Karen Quinn at the request of NHSBT. The strong Steering Group had a huge influence on the work done, in offering support and monitoring progress. A list of the Steering Group members is set out in the Appendix. The Steering Group continued to meet via

tele conferences every two months. Administration support was provided by Tracey Bignall from the Race Equality Foundation (REF) and a contract between NBTA and the REF was agreed for this support. Formal contracts were agreed with the seven projects in the second phase.

5. WHAT TOOK PLACE.



The key features in each of the four big projects were to produce and use appropriate resources on living donor kidney transplantation targeted at the specific community, arrange community events to discuss living kidney 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. All four projects built on the experience from the first phase and extended their reach into the targeted communities to a wide geographical area.

The three small projects were led by hospitals, with GOLD working in partnership with, Guy's and St Thomas's Hospital GSST. They had limited time and budget to develop their projects.

Individual reports from six of the projects are set out in this report and provide details of what they did. Unfortunately, the Birmingham Hospital project was not able to continue with its work because they felt that they could not meet the requirements of the monitoring arrangements which the Steering Group had put in place.



6. DID WE ACHIEVE OUR TARGETS?

The agreement between NHSBT and NBTA included three measurable outcomes for the Living Transplant Initiative in each of the phases, all related to people from BAME background. These are set out below, together with what was achieved in each of the phases.

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 living 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 altruistic donation, would get assessed and then may go on to become a living donor. However, it is also evident that getting those who express an interest in becoming living kidney donors to take the next step by starting the assessment process is more difficult.

PHASE 1.

Number of individuals to express an interest in living kidney donation.

Phase 1 : Target 40 - Achieved 151

Number of individuals who start the assessment process as potential living kidney donors.

Phase 1 : Target 25 - Achieved 13

Number of individuals who donate a living kidney donors.

Phase 1 : Target 10 - Achieved 3

THE THREE KEY TARGETS FOR PHASE 2 WERE:

Number of people indicating an interest in living donation.

150 Target 150 - Achieved 174

Number of people who are referred for assessment as potential donors.

Target 25 - Achieved 1

Number of people donating a living kidney.

Target 10 - Achieved 0



cont:

7. WHAT WENT WELL.

The importance of community groups working with communities they know well was the most significant aspect of this initiative and it worked very well in most cases.

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 timescales 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 generally excellent, and good working relationships were established between some of the project leaders and hospital staff.

The development of specific resources (videos and leaflets) on living donor kidney transplantation aimed at specific communities was very important and these resources were used well. They are now available to use free of charge by anyone and included on the NHSBT hub on living donation.

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

8. FINANCIAL MATTERS.

This financial report is produced by the Race Equality Foundation on behalf of NHSBT and NBTA. NHSBT funded NBTA to manage the LTI programme and towards the operation of NBTA. The fund was £90,000

for the first phase (December 2016 - 31 March 2018) and £75,000 (1 April 2018 - 31 March 2019).



YEAR ONE.

Five projects were funded in the first year:

ACLT	£ 24,000
BAPS	£ 12,750
GSTT/GOLD	£ 20,000
Vanik Council	£ 10,000
Warwick University	£ 23,250
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Total allocated	£ 90,000

During this year, GOLD withdrew from the programme which resulted in a £14,880 underspend.

This underspend allowed additional funding to be granted to the remaining three organisations to undertake supplementary activities. The funding allocated is as follows:

ACLT	£ 1,400
BAPS	£ 3,250
Vanik Council	£ 3,000

OTHER EXPENDITURE.

Interim LTI programme report	£ 750
Meeting and operational costs	£1,611
Application for CIO status	£ 590
Total project allocation	£ 82,770
Other expenditure	£ 2,951
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Total expenditure in year one	£ 85,721

With the exception of Warwick University, all the funded projects spent their allocated budget within the financial year timeline. It was agreed that Warwick would carry over the unspent funds to finalise activities on their project. The LTI programme had an overall underspend of £4,279 in the first phase. This was used for various activities including registering of NBTA as a charitable incorporated organisation, website maintenance, organisational banner and operational costs.



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SECOND PHASE.

Seven projects were funded in phase 2:

ACLT	£ 15,000
BAPS	£ 12,500
Vanik Council	£ 20,000
SAHA	£ 12,000
Leeds Teaching Hospitals Trust	£ 2,260
Guy and St Thomas' NHS Foundation Trust / GOLD	£ 2,800
Queen Elizabeth Hospital Birmingham	£ 2,860
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Total allocated	£ 67,420

OTHER EXPENDITURE.

LTI Programme report	£ 2,000
NBTA bank account	£ 1,000
Secretariat costs	£ 2,500
Meeting costs and operational activities	£ 2,080
Total project allocation	£ 67,420
Other expenditure	£ 7,580
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Total expenditure in year two	£ 75,000

Four projects: ACLT; BAPS; Vanik Council; and Guy's and St Thomas' Hospital NHS Foundation Trust used the entire allocated budget for their projects. However, three projects were underspent because they did not carry out certain activities within the time frame.



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The other two projects, SAHA and Leeds Teaching Hospitals Trust had the following underspend:

Leeds Teaching Hospitals Trust	£ 668.49
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SAHA	£ 4540.00
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Queen Elizabeth Hospital Birmingham did not continue with the project and had not spend any of the £ 2860.00 funding allocated.

The total under spends for phase 2 was £ 8068.49.

FINANCIAL MANAGEMENT.

The LTI fund was managed by the Race Equality Foundation who were the Secretariat for NBTA. This involved overview of all the LTI fund and budgets for each project. A financial monitoring process was set up involving an online excel finance form for completion which would show any variance on spend each quarter.

All projects completed quarterly expenditure reports that were reconciled which then fed into a quarterly reporting system to NHSBT for the overall fund. Quarterly progress and expenditure reports were reviewed by the LTI steering group.

There were some difficulties experienced. The delay by some projects in returning the expenditure monitoring forms would mean that the quarterly payment date were not met. Some organisations disseminated responsibilities for project activities internally and, this impacted on communication with the Secretariat. Communication was only meant to be between the Project Lead and the Secretariat but having more people involved sometimes caused confusion and delayed action. Not all the projects completed the reports on time which impacted on the release of funds for the next quarter.

Whilst, it may have been in retrospect worth amending the reporting forms to reflect the smaller grants and shorter time frame, the reports did capture expenditure that was necessary. Overall the monitoring process worked well. It enabled a clear view each quarter of how the projects were progressing and alerted the Secretariat to any financial issues throughout the programme.

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.



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This means that we need well organised community groups with proven record to undertake this work.

The arrangements for administrative support provided through the REF worked better in the second phase because NBTA obtained its Charitable Incorporation Organisation status and was able to arrange a direct contract with the REF for their support.

10. NEXT STAGES.

The Steering Group carefully considered how we should build on the overall success of the LTI. NBTA is delighted that NHSBT has adopted the LTI model and has now established a NHSBT led LTI. The focus is on how we can get those interested in becoming living kidney donors can be encouraged to move to the next stage. The NHSBT led LTI started in April 2019 and there are five projects across the country which are participating in this work.

11. Links to key documents related to the LTI are set out below.

The links on the NHSBT website where the resources are that have been produced in the LTI (as well as the individual links within the reports) at

<https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/download-digital-materials/#living>

Also link to the general NHSBT living donation materials at:

<https://www.organdonation.nhs.uk/become-a-living-donor/>

For latest statistics and activity reports : <https://www.odt.nhs.uk/statistics-and-reports/>

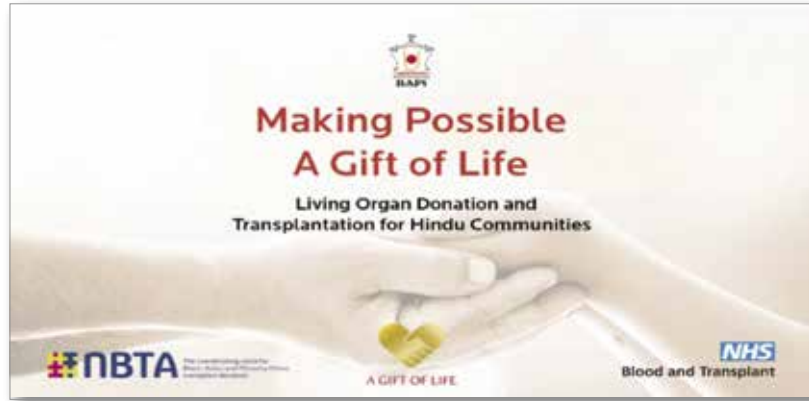
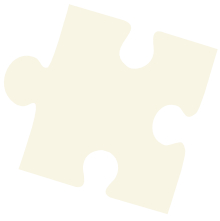
LTI published an Interim report after the first phase and it is available at:

<https://nhsbt.dbe.blob.core.windows.net/umbraco-assets/1837/interim-report-of-living-transplant-initiative.pdf>

12. 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. This model has been used by NHSBT to establish a Community Investment Scheme (CIS.) aimed at increasing BAME organ donors after death and 25 projects are participating in the first year of the CIS. Meanwhile, the NHSBT led LTI continues and NBTA is delighted to support NHSBT in this work during 2019/20.

NBTA is most grateful to everyone involved in the LTI, all BAME community members who have been involved in this work, all members of the Steering Group, all staff in hospitals who have supported the initiative and, of course all community members who have come forward to support living kidney donation.



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

Increasing awareness of Living Organ Donation
in Hindu communities nationally across England.



Report by : Prof Sejal Saglani : ssaglani@yahoo.co.uk

BACKGROUND TO BAPS

In the UK, BAPS Swaminarayan Sanstha is respected as one of the largest and most active Hindu organisations within the Indian diaspora. It is especially known and respected for its community outreach activities and the internationally-acclaimed 'Neasden Temple' (BAPS Shri Swaminarayan Mandir) in London. Our first project to raise awareness about living organ donation among Hindus was based at the temple in Neasden and

the geographical surrounding of North West London. Apart from the mandir in London, BAPS also has smaller mandirs (hari mandirs) in Birmingham, Coventry, Leeds, Leicester, Loughborough, Luton, Manchester (Ashton), Nottingham, Preston, and Wellingborough, as well as a further 24 centres across the UK. All of which are located in regions with a high concentration of Hindus.

OUR KEY OBJECTIVES FOR THIS PROJECT OVER 2 YEARS WERE TO:

1. Design some information resources about Living Organ Donation for Hindus – these included an information leaflet, available in printed format and online, and a short video, available on line and on Youtube.
2. Hold 3 events in London and the Midlands to raise awareness about living organ donation among Hindus and distribute the information resources created.
3. Hold smaller events nationally at a further 5 BAPS centres across the country to raise awareness about living organ donation.
4. Hold smaller follow-up workshops in 3 locations for those interested in finding out more about living organ donation and to encourage them to move forward to be tested.
5. Work with other Hindu organisations at large religious festivals to raise awareness about living organ donation.





PROGRESS AND ACHIEVEMENTS FOR EACH OBJECTIVE:

1. Designing information resources:

We have successfully designed an information leaflet and made a short 10 minute video that provides information about living organ donation and specifically gives the Hindu perspective. We have included stories from Hindu families that have undergone living organ donation (Donors and recipients), also facts from medical experts and opinions from leading Hindu

religious leaders in both the leaflet and video.

Both are available to download on the BAPS Swaminarayan Sanstha web-site and on BAPS Channel YouTube, and we are very happy to share these resources for wider use and for them to be added to the NHSBT online resources.

The link for both is: <http://londonmandir.baps.org/forthcoming-events/living-organ-donation/>

The link for the leaflet is: http://londonmandir.baps.org/images/2017/10/LivingOrganDonation_leaflet.pdf

The direct link for the video on youtube is: <https://www.youtube.com/watch?v=vwAYdVS4ytk>



2. Three large awareness events in London and the Midlands:

We have held 3 awareness events during the 2 year project, each of which included talks and panel discussions with families with living organ donors, recipients and those currently on the transplant list awaiting an organ. In addition, the events included information from medical experts including transplant surgeons and Living Transplant coordinators and nurses. All also included talks from Hindu religious leaders and

aimed to dispel any myths about living organ donation not being aligned to Hindu beliefs. The events were held in the Swaminarayan Mandir Neasden, London (Oct 2017), Birmingham (Sept 2018) and Leicester (Nov 2018). Each event was attended by between 100-200 people. Detailed reports with photos of each event are available on the BAPS web-site at the following links:

<https://www.baps.org/News/2017/Living-Organ-Donation-Conference-12396.aspx> - London

<https://www.baps.org/News/2018/Living-Organ-Donation-Conference-13962.aspx> - Birmingham

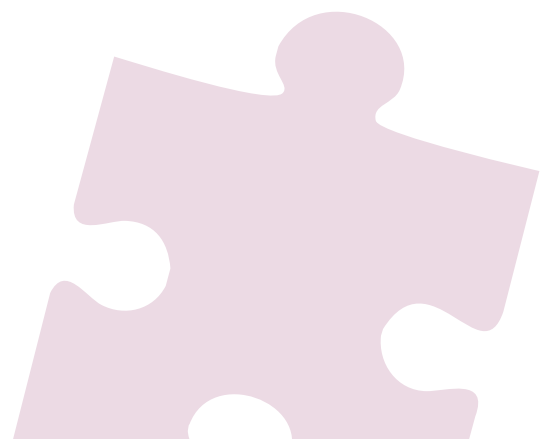
<https://www.baps.org/News/2018/Living-Organ-Donation-Conference-14793.aspx> - Leicester



3. Smaller national awareness events at all national BAPS centres

20-minute awareness seminars will be held at all BAPS centres nationally (36 in total). We had originally only planned to deliver this at an additional 5 centres, but with the support of our Board of Trustees, we have developed a presentation pack which has been sent to all centres. The pack includes powerpoint slides with key factual information, the YouTube video that we have generated to be shown and distribution of our leaflets including information of who can be contacted for those who want to find out more. The lead coordinator for each centre will confirm all dates. We already have dates confirmed for delivery of the seminars in Harrow, South-East London, East London, Coventry, Southend-on-Sea,

Croydon. A member of the project core team will attend and deliver the seminars when possible, if this is not possible, a script has been prepared and we will ensure it is delivered after some brief training. The key will be to deliver the seminar, distribute our leaflets and encourage people to contact us if they want more information.



BELOW IS A TABLE THAT SUMMARISES THE CENTRES THAT HAVE ALREADY HAD A SEMINAR.

MANDIR/CENTRE	LEAFLETS PLANNED	DATE SET	DONE	MEDIA REPORT SUBMITTED?
Chigwell	450	16-Jun	Y	Y
Leicester	800	15-Jun	Y	N
Loughborough	200	09-Jun	Y	N
Luton	200	07-Jul	Y	Y
Preston	150	20-Apr	Y	Y
Wellingborough	200	08-Jun	Y	Y
Cambridge	75	16-Jun	Y	N
London SM Sabha	200	20-Apr	Y	N
London Finchley	400	26-May	Y	Y
London Harrow & Brent	850	18-Apr	Y	N
London South	500	23-Jun	Y	Y
London South East	200	24-May	Y	N
London West	250	18-Jun	Y	Y
Oxford	50	15-Jun	Y	Y
Watford	100	26-Apr	Y	N

There are currently 3 centres that have not had a seminar – Harlow, Manchester and Nottingham – they will all complete the seminar by the end of August.

SUCSESSES:

- We have delivered our aims of generating resources for Hindus about Living organ donation and have held a large number of awareness events nationally where resources have been distributed, both at BAPS centres and in collaboration with other Hindu organisations. We have also generated media coverage during our work. We have planned follow-up events for those who wish to find out more and at least 50 people will attend.

- We presented our work and progress at the House of Commons at a meeting organised by Lord Jitesh Gadhia and attended by Jackie Doyle-Price MP.

<https://www.easterneye.biz/leaders-encouraged-to-raise-organ-Donor-registration-awareness-in-uk/>



MEDIA COVERAGE :

Radio XL (1296 AM) Evening Gujarati Programme with Himat Chauhan - 5 minute talk given about living organ donation (11/09/2018). Examples of recent coverage are below and coverage in our first year was presented in the previous report.



LIMITATIONS :

The hardest part of the project has been to achieve the target of encouraging those who want to know more about living donation to be assessed and progress towards donating. However, we feel certain that at least two families do have donors who want to find out more and are willing to be assessed, they will attend the workshops arranged in May 2018. They have become aware of this as a possibility as a result of our work.

Another factor that has diverted the focus from living donation to donation after death is the legislation for deemed consent that has been passed in the last year, during the second year of our project and the introduction of the faith specific Donor cards. We have

been actively involved in the work of the "JHOD" group, the Jain and Hindu Organ Donation Group, and generating resources and information for Hindus about deemed consent and donation after death.

This has taken much of our capacity and volunteer time and so it has been difficult to arrange the follow-up events within the timeline of the project by March 2019. However, the follow-up events have been planned and will be delivered at all centres by June 2019 at the latest.

FUTURE PLANS :

Our focus for organ donation awareness for the next year to 18 months will be to provide clear messages for all Hindus about the process of deemed consent. What the legislation means and what, if anything, needs to be done from a practical point of view by Hindus. We are generating resources and information that clarify the deemed consent process in collaboration with JHOD and NHSBT and we believe the time is now right to focus on increasing awareness about donation after death in order to ensure people are not given the wrong

messages and fully understand that it remains aligned with the Hindu Faith.

The resources remain easily available online and we have a generic email address that people can write to if they want to find out more about living organ donation for Hindus. We also remain very happy to collaborate with other organisations raising awareness about living donation in Hindus.





VANIK COUNCIL(UK)

LIVING ORGAN DONATION - "GIVE A GIFT".

Final Report 2017-2019.

Report by : Mr Manhar Mehta: manhar.mehta@vanikcouncil.uk

1. ACTIVITIES UNDERTAKEN.

The following tasks were undertaken –

LEAFLET : a leaflet was designed and produced to help othe joint community answer key questions on living organ donation. Following completion of the leaflet, it 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.

DIET LEAFLET : Vanik Council also published a leaflet titled 'Guidance on reducing Potassium (K) content for Gujarati vegetarian diet' - The leaflet was distributed at events that we held and is also published on our website.

CONFERENCES : In order to raise awareness directly with our community, we arranged a number of conferences through which we could promote living organ donation. During 2017-2018 we held four events and in 2018-2019, we held conferences in Manchester, Leicester, Crawley and in North West London. During these events, we invited a GPs, Living Donor Coordinator, kidney surgeon/consultant, Dietician (targeted to vegetarians), NBTA Honorary President and community leaders. The presentations/stories from Donors/recipients were followed with a Question and Answer session.

FOLLOW-UP : Following events that were held, we arranged follow-up sessions for those members

who wanted more information. Senior Living Donor Coordinators (LDCs) were invited to explain the process and answer their questions.

VIDEOS : 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. At events held during 2018-2019, the videos were also shown to those who attended.



LIVING ORGAN DONATION SHORT



LIVING ORGAN DONATION LONG



2. MANAGEMENT.

Throughout the Project, regular meetings were held to plan, review, monitor and track progress of activities that we had undertaken. Considerable effort from volunteers within Vanik Council and affiliated organisations ensured the success of both projects.

- **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.

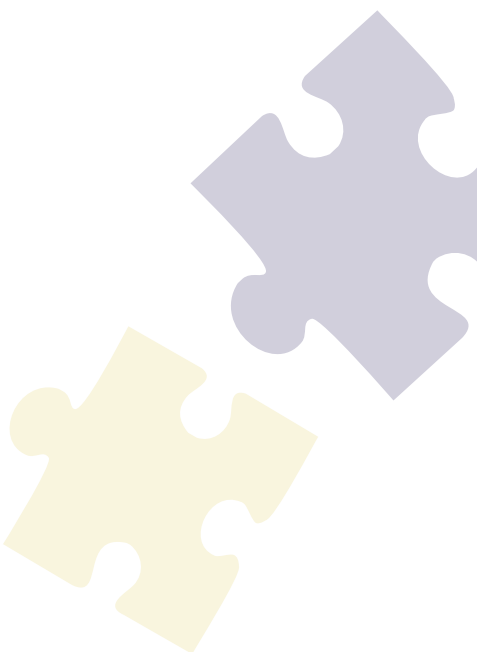
- **COORDINATION.**

Organising events away from London needed considerable effort particularly with monitoring and continued guidance to ensure success. There were a number of challenges that had to be overcome particularly with arrangements of speakers and scheduling of the day's itinerary.





3. 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
 - 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.
 - Three kidney donations from living donors due to our campaign.
 - Positive feedback from those who attended the conferences
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4. EVALUATION.

Considerable effort and time was devoted by Vanik Council executive committee members, Volunteers, Medical professionals, Donors , Recipients and many others.

In terms of finance, the amount of budget that we spent far exceeded the budget that was allocated, however

the results from the promotion and interest shown from our community has made this a very worthwhile project to be involved with.

Mr Kirit Modi has been instrumental in providing us guidance and support through both projects. Vanik Council is indebted for this continued support.



5. 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.
- Attendance at follow-up sessions was poor
- Individuals who showed an interest in donating at the conferences, failed to pursue.
- Difficulties in coordinating with affiliated organisations where executives from Vanik Council are not based.

6. SUMMARY OF CONFERENCES.

	Venue	Date	Attendance	Expressing Interest
2017-2018	Navant Vadil Mandal	May-17	160	No Forms
	Navnat Vadil Kenra	Jun-17	190	26
	Follow Up Sattavisgam	Aug-17	15	N/A
	Navnat Centre	Oct-17	250	50
	Follow Up Sattavisgam	Dec-17	10	N/A
	Follow Up Sattavisgam	Feb-18	35	N/A
	Sattavisgam	Mar-18	100	20
	Total 2017-2018		760	96
2018-2019	Manchester	Oct-18	160	124
	London	Feb-19	106	39
	Crawley	Mar-19	150	26
	Leicester	Mar-19	150	34
		Total 2018-2019		566
	Total 2017-2019		1326	319

		Target	Actual
2017-2018	Number of People Interested	10	96
	Number of People Assessed	5 to 6	4
	Number of People Suitable	1 or 2	2
	Number of Live Donation	2
2018-2019	Number of People Interested	45	138
	Number of People Assessed	7	5
	Number of People Suitable	2 or 3	1
	Number of Live Donation	1
	People offering live donation but recipients waiting for results of assessments	4



7. CONCLUSION.

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

- Attendees at events exceeded expectations
 - Good response in completion of feedback forms.
 - Number of people who came forward to being assessed.
 - As a result of the promotion, remarkably three members of our community donated their kidneys.
 - During 2018-2019, we found at least one person at every event who as a result of our promotion had come forward to donate an organ, however, could not continue due to issues with the assessment
-



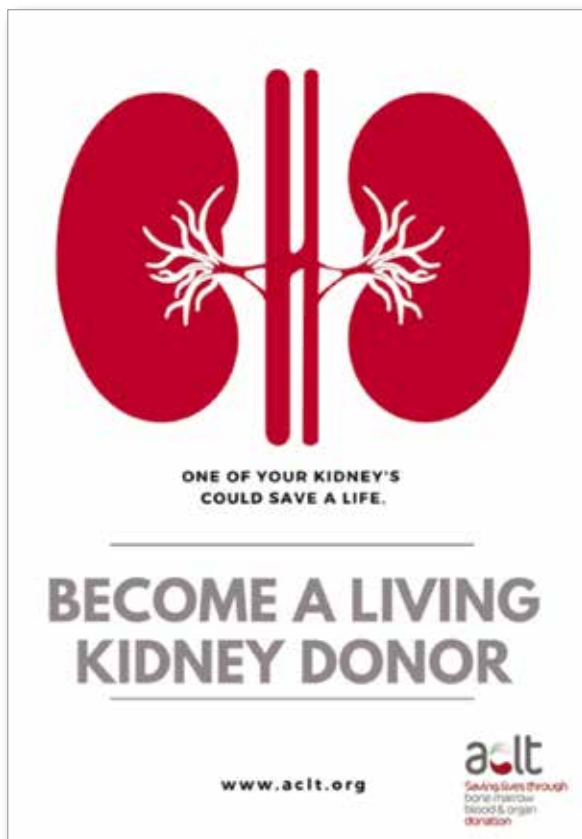


HOW TO INCREASE LIVING ORGAN DONATION WITHIN AFRICAN CARIBBEAN COMMUNITIES.

ACLT Evaluation Report: Executive summary April 2019

Report by : **Mr Orin Lewis OBE** :orin@aclt.org

This evaluation report is a simple but robust way to measure ACLT's contribution to the NBTA's Living Transplant Initiative (LTI): through a targeted approach. ACLT's target are black communities in London and South East, Birmingham, Manchester.



OUR GOAL

To increase the number of living kidney transplants in targeted black communities.

OUR AIMS

1. Increased number of black people expressing interest in living kidney donation.
2. Increased number of black people being assessed for living kidney donation.
3. Increased number of black people being suitable for transplant for transplant post-assessment .
4. Improved knowledge to increase living kidney donation long-term.

OUR OBJECTIVES

1. To influence a change in audience perception on living kidney donation.
2. To increase awareness in the targeted community about LTI.
3. To increase accessibility to support and guidance about LTI



WHAT WE DID

WHAT WORKED WELL

Creation of Influencing Strategy based upon Research findings of types of potential Donors.

Creation of influencing strategy based upon research findings of types of potential donors. Our team of volunteers set about the best way to approach the black community with a more expansive qualitative research of attitudes to living organ donation. This was a combination of controlled /uncontrolled vox pops at key high populated cultural events.

Creation of Communications Plan to roll out Awareness activities.

We learnt and updated the findings from last year's plan to fine tune our Social Media and Mainstream TV Media messaging for more Deceased and Living Donors.

Bringing volunteers, patients & Donors to meet 1 to 1 to learn & share.

We held a series of informal get together meetings between key volunteers and 1 Donor and 2 patients at the ACLT office and an awareness event.

Rolling out planned registration drives incorporating living Donor messaging.

We delivered a selected series of summer drives incorporating the Living Donation messaging as part of the overall Giving the Gift of Life ACLT process.

Linking interested people with a Living Donor Coordinator to start assessment.

We assisted and signposted all of the 60 interested individuals via our Interested Register website portal via our template email communication protocol.

ACLT attendance at black History Month cultural, social, religious, artistic, sports, theatrical, comedic, etc. events to deliver talks, video showings

We delivered numerous Living Donation talks at various events before, during and after musical and cultural events. We have also utilised Patients (Lonyo Ongele and Naomi Adams) and Living Donors at Registration drives & 1st GLA event to spread messaging and awareness about Living donation utilising our reprinted existing LTI leaflet "Donating your spare kidney ..."

ACLT Gift of Life Fundraising Ball

We successfully delivered extensive messaging via News Media TV, Radio & Print.

Gaining Advice from Project Planning Group

We communicated via telephone & email with Physicians at St Georges and St Helier (Dr Phanish, Dr Cording & Dr Popoola). I have also had 2 face to face meetings with Dr Joyce Popoola (to clarify our definitions and findings) after the 2 GLA events.



WHAT WE LEARNT :

Through analysing the responses from the ACLT, the public, ‘suspected altruistic’ and previous organ Donors we are able to note the following themes which are helpful in identifying the barriers and motivations to altruistic donation:

- 1.** Having a connection to kidney failure is hugely important to motivating somewhat reluctant people who have never considered donation.
- 2.** Family is a strong pull factor to donation and this is backed up by empathy. If it is not an immediate family member who needs an organ then someone with strong empathy will be able to put themselves in others shoes.
- 3.** Religion could play a factor in both motivation and a barrier to doing it. Even if people don’t immediately class themselves as religious the need to have these influences in their life.
- 4.** Doubts within the family often causes the biggest barriers but most altruistic will not be swayed by this but instead the facts and evidence.
- 5.** Scepticism of the NHS could play a huge barrier but if the potential Donor is able to see the NHS in practice they are likely to have more faith and trust.
- 6.** Importance of a personal story and interpersonal engagement was a strong theme because people respond to emotions more than statistics.

GRANT RECEIVED £15,000

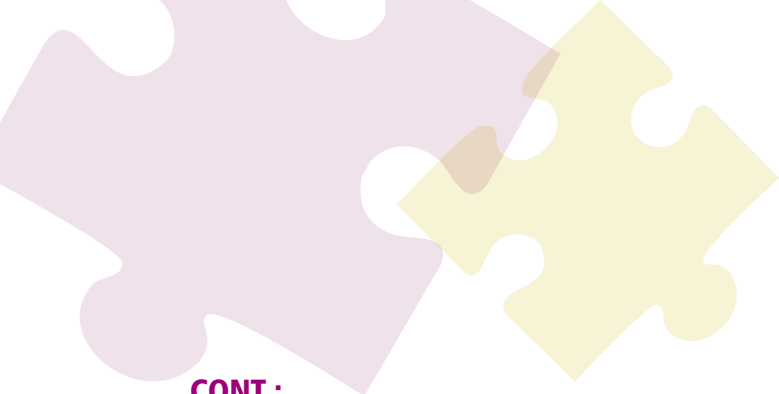
ACTUAL EXPENDITURE £15,000

WHAT WE ACHIEVED: THE SPACE BELOW IDENTIFIES KEY SUCCESSES OVER THE LIFETIME OF THE PROJECT.

Our Evaluation findings have enabled ACLT to identify why some black people (against all expectations) want to become Altruistic Organ Donors and what are the key triggers that motivate them. In correlation to the findings from the previous project we found that black people (in general) would respond more to general awareness and small nudges than insistent calls to action.

This will have to be taken into account during the next 12 months’ worth of Deemed Consent messaging and promotion, etc. Also our findings highlighted that a dual purpose Organ donation messaging communications strategy enables individuals to cherry pick their preference on either Deceased or Living

donation, because of the realisation that there are actually 2 distinct but similar ways to save a life. Therefore the altruistic choices allows (which at the moment doesn’t seem obvious) the individual more freedom of thinking in picking their preferred singular or dual way of registering to donate. This in turn resulted in more traffic activity on our Website, social media communications and Interested Register. The ACLT Gift of Life Fundraising Ball generated substantial News Media and black public interest in all forms of donation including Living, due to the multiple features surrounding the 10 year anniversary of the



CONT :

passing of Multiple Organ failure patient, Daniel De-Gale. There followed numerous News Media TV interviews and programmes including London Tonight, Charity Cheats with our dual purpose Organ donation messaging being disseminated on TV and Social Media, etc.

awareness about Living donation. This saw a spike via our Interested Register website portal where individuals have completed a form to directly request information about becoming a Donor and contacting a Transplant Centre and Co-ordinator. We also completed the Ashley Avorgah patient video & digital poster.

We also worked closely with the London Assembly in in the planning, designing and filming (dual branding) of the joint London Assembly/ACLT Celebrity video featuring an ex-Organ patient (Lonyo Engele) and ACLT Celebrities about the need for more BAME Organ Donors for the 18th March GLA event. Also, the ACLT talk at this event was well received by the attendees and disseminated via Social Media channels.

In the background we have been communicated to on a semi regular basis without any coercion or peer pressure) by many people who have started their Living Donation journey via our Interested Register website portal and the individual who has been assessed and who has now passed all of their stages in readiness to donate in September 2019 onwards.

This in turn resulted in the ACLT being successful in gaining access to large black audiences directly via our own ACLT driven events, Social Media and News Media coverage plus attending external events where many individuals have shown keen interest in the option of Living Donation as against or alongside Deceased. The process was helped by the involvement of Patients (Naomi Adams) and Living Donors at Registration drives and GLA events to spread messaging and



TARGET

WHAT WE ACHIEVED

45 Seeking information

60 people have shown a direct interest by filling in our online Interested Register form, with others choosing to become deceased Donors.

6 Assessed for donation

1 was assessed at final stage for donation at Guys (hopefully 2-3 more during the next 4 months and 2 more within the next 6-9 months).

3 Suitable to continue to donation

1 Individual (above) has now passed all tests & is being put into the Pool in April 2019, in order to donate in July 2019 (2 others from the above category are in the early stages of communicating with a Transplant Co-ordinator).



LIVING KIDNEY TRANSPLANT REPORT.

South Asian Health Action.

Report by : Mr Kirit Mistry: kiritmistry2@gmail.com

A partnership between academics (University of Warwick), health care professionals (University Hospitals at Leicester and St. James's University Hospital at Leeds), a community group/ charity (South Asian Health Action) and community members (expert patients, carers and general public).

OUR AIMS AND OBJECTIVES.

- To improve awareness of living kidney donation in BAME communities and increase overall number of living kidney transplantation in line with 2020 vision.
- To develop a culturally appropriate video on living kidney donation, based on evidence generated via focus group exercises and subsequent thematic analysis
- To explore and develop case studies of living kidney donation and use these for peer education
- To train expert patients as community ambassadors to facilitate discussions around living kidney donation
- To facilitate one to one interaction by community ambassadors in clinics and people's home (as part of prospective study at NHS Trust)
- To engage with the Hindu and Sikh communities via relevant events in temple /Gurdwara and community organisations (in both Leicester and Leeds).
- To engage Hindu and Sikh Council UK to further engage with the Hindu and Sikh Communities and to develop a long-term partnership.
- To engage into partnership with the media (both social and traditional media) to promote message regarding living kidney donation.

FIRST YEAR.

The first year of the project was focused around an academic approach. We developed a protocol based on our literature review, obtained university ethics and conducted three focus groups to explore themes around facilitators and barrier to living kidney donation.



SECOND YEAR.



The second year focused on the delivery of large community events at Leicester and Leeds. This was led by the South Asian Health Action (SAHA) charity. Three community events were designed to engage with the South Asian community and raise awareness about Living Kidney Donation within these communities according to culturally sensitive needs. We recognised that due to cultural differences, traditions (and often myths) it can be difficult to engage with South Asian communities.



Thus, it was vital that for the events organised, we invited guest speakers who were from a South Asian background and therefore understood the challenges faced with engaging our community. We used a similar structure and itinerary for all three events, which consists of; first-hand accounts of living

kidney donation, medically accurate and informative presentations, and free food as an incentive.

The three events were; Celebrate Diwali with Real Heroes - Living kidney Donors' Event- 28th November 2018 (Leeds), 'Living Kidney Donation – Hindu Religion and Personal Perspectives' 24th February 2019 (Leicester), Living Kidney Transplant for Sikh Communities in Leicestershire, on 17th March 2019 at Guru Tegh Bahadur Gurdwara, Sikh Temple. Following these events, a follow up information session on How to Become a Living Kidney Donor on the 19th March 2019.





EVENT	DATE	ATTENDANCE	EXPRESSING INTEREST FOR FURTHER INFORMATION
Celebrate Diwali with Real Heroes - Living kidney Donors' Event- (Leeds)	28th November 2018	200	14
'Living Kidney Donation – Hindu Religion and Personal Perspectives' (Leicester)	24th February 2019	150	33
Living Kidney Transplant for Sikh Communities in Leicestershire, at Guru Tegh Bahadur Guradwara (Leicester)	17th March 2019	26	3

SUCSESSES:

- **Dissemination and sharing of outcomes** of focus group research at the National British Transplant Congress 2018
- **Engagement of communities** at Leicester and Leeds was a success by collaborating with community / faith leaders and through social media and word of mouth promotion.
- **The community ambassadors and volunteers** tireless, selfless hard work was key to our work. The community ambassadors were the bridge between the community and the charity, encouraging others to examine their views, traditions, and dispel myths which were influence by religion/community surrounding Living Kidney Donation.
- **Feedback** from the Living Transplant Initiative steering group and shared learning from other projects helped us to develop the evaluation form (to comply with GDPR rules) and prepare a follow-up

plan. The evaluation forms have allowed our team to obtain feedback from the attendees in order to inform adaptations for future events to better suit participants' needs.

- **Mainstream and social media engagement** – BBC, ITV both local and national level engagement was achieved. This media coverage was beneficial and influential, encouraging more people to attend our events or seek us out for further information.





LIMITATIONS:

- **The rather complex bureaucracy** regarding contract and approvals at the University of Warwick was a stumbling block and it took a while to get the momentum in the first year.
- **Workforce**, loss of a key person in video team in between the project meant further contract issues and identifying private team to edit and complete the video
- **Need for number of ethical amendments** during the first phase and then prolong delay in NHS ethical application.
- **Return of funds** back due to missing second deadline in the first phase meant we were not able to complete Hindi/Gujarati Video (though recordings are ready)
- **Prospective NHS study** at Leicester, not started due to multiple delay and expiry of end-date on ethical application. A further amendment to seek extension is in process
- **Failed engagement** Hindu Council and Sikh Council UK: Both councils were unable to engage with us on these events.
- Developing **community ambassador role at Leeds** did not happen due to time constraints and difficulties around how they could be governed under Leeds Trust governance as the registered volunteers are not allowed community work.

ACHIEVEMENTS:

- **We improved awareness** of living kidney donation among BAME communities (Hindu and Sikh mainly) and increased the overall number of living kidney transplantation we are aware of a number of living kidney transplants which have taken place due to the engagement of our community ambassadors who work on the renal unit as volunteers
- **We developed and validated a culturally appropriate video** on living kidney donation by the users using focus group exercises and thematic analysis (<http://www.nbta-uk.org.uk/living-transplant-initiative/>).
- **We established and trained community ambassadors** to facilitate discussions around living kidney donation.
- **We delivered three successful community events** with large number of attendances.
- **We recruited number of BAME communities to Organ Donation Register (ODR)**, the numbers are not available from central team and as a by-product of events educated communities around Opt-Out system.
- **We developed a partnership with the media** (both social and traditional media) to promote information about living kidney donation, despite lack of engagement with local newspaper



WHAT WE LEARNT:

Our key learnings were around challenges with process and working in partnership. Although these LTI schemes were focused on community intervention but we took a research approach governed by sound ethical approval and academic university.

As a result, the proposal and work conducted required several ethical amendments and bureaucracy did lead to several delays. Furthermore, contracting with partners (as this was a collaborative approach with number of institutes) was a long and difficult process due to legal and finance department processes.

As a result of this and the delay, we were not able to undertake a prospective study to evaluate the impact and value in a clinical setting. Activities to achieve this are now well under way. It is evident that there is a need for culturally appropriate events to engage with and inform the community. It is apparent that

we must consider the needs, traditions and beliefs of the different communities and faith groups within the community. This makes a difference to whether these communities actively engage and that individual in those communities take a step further towards becoming a living kidney Donor.

Although there was lot of enthusiasm and interest at the end of the event, we did not see people taking next steps towards coming forward for work-up to move along living kidney donation. This needs to be the focus for the next line of work, including both research and a clinical survey.





REPORT FROM GUY'S & ST THOMAS TRUST & GIFT OF LIVING DONATION.

Report by : Ms Lisa Silas: Lisa.Silas@gstt.nhs.uk
and Ms Dela Idowu: info@giftoflivingdonation.co.uk

"A Peer Volunteer Home Education Programme to Engage African and Caribbean Patients and Their Families in Living Donor Kidney Transplantation".

Our Objectives:

Despite an increase in living donation education and awareness, the disparities in living Donor kidney transplantation (LDKT) for African and Caribbean patients with End Stage Renal failure still very much exists. Our objective was to consolidate learning from an initial pilot of the Acceptance, Choice and Empowerment (ACE) LDKT Pilot Project funded by NHSBT and embed the principles of a peer volunteer home- based education programme model in conjunction with clinic- based education for black patients attending Guy's Hospital (GSTT).

By using Peer Educator Volunteers (PEV) rather than healthcare professionals, the goal was to test the efficacy of a scalable model that could be used in any transplant or referring centre to provide culturally appropriate information, support decision making and improve access to LDKT for patients and their families. By engaging with patients and their families in the home environment, the primary aim was to improve awareness and access to LDKT. The 'at home' element of the intervention offered, a more relaxed environment, easier access to family and friends, the opportunity to discuss barriers to LDKT, to provide information and to build trust. We also aimed to identify any unique characteristics that would encourage better engagement with patients from lower socio-economic groups.

What We Did:

The lead PEV met with the dialysis unit managers and pre dialysis nursing lead and explained to principles and the aims of the project to them. Posters and leaflets with details of the project were distributed and displayed in the dialysis units and the outpatient clinic areas.

The lead PE and peer volunteers conducted visits to four dialysis units during the morning, afternoon and twilight dialysis sessions on Monday and Tuesday.

65 black patients were identified across the units. Of those patients, those who were active on the national deceased Donor transplant waiting list (n= 53) were approached. The purpose of engaging patients at the units was too explore their perceptions and attitudes towards living kidney donation.

During each talk volunteers introduced themselves and gave a brief background into the initiative, why they were there and what they hoped to achieve. Patients were also given an information leaflet about home visits. Each talk with patients lasted 10 minutes.



CONT:

They were asked:

- Were they interested in living donation?
- Had they had the conversation about living donation with friends and family?
- Had someone offered to be their living donor?
- Had they previously had a transplant?
- Ethnic origin, age, faith
- Number of years on dialysis
- Would they benefit from a home visit?

TABLE.

Baseline of social demographics and clinical characteristics on 53 patients at Camberwell, Borough, Forest Hill, New Cross Gate dialysis units active on the transplant list who participated in the initiative.

SOCIAL DEMOGRAPHICS	NUMBER
Women	25
Men	40
African	38
Caribbean	23
Mean age group	40-70
Patients who had family/ spouse aboard	9
Patients who classified themselves as Christian	60
Patients who classified themselves as Muslim	1
Patients who classified themselves with having no faith	4
CLINICAL CHARACTERISTICS:	
Average length of time on dialysis(years)	3
Prior kidney transplant 1. Living 2. Deceased	1(4) 2.(11)
Percentage of patients interested in living donation	92%
Percentage of patients who had the conversation of living donation	75%
Patients who had a negative response from family members.	50%
Patients who refused living donation	6
Patients over 60 who preferred dialysis	8



CONT :

Follow up:

A follow up call was made to all patients two weeks after the initial engagement at the unit. In total, the Peer Educator Volunteers (PEVs) made over 50 follow up calls which gave them the opportunity to provide ongoing support to patients. Voice messages and text messages were left for patients that the volunteers were not able to talk with directly

Home visits:

Out of the 50 follow up calls, three home visits were realised. Home visits involved a 90 minute

interactive session with the patient, family members and 2 volunteers. The session included a discussion about further background to the initiative, volunteers sharing their personal stories of LDKT, patient and family discussion and questions followed by a break, then a short DVD about LDKT and a follow up plan.

As a result of the home visits, 2 family members showed a keen interest in coming forward as potential kidney Donors, but are yet to contact the living Donor coordinators.

WHAT WORKED WELL?

- Effective collaboration between the peer volunteers, advanced kidney care clinic nurses, living Donor coordinators, dialysis managers and nurses.
- There was a strong belief and commitment on their behalf to support the LTI.
- The opportunity for peer volunteers to visit four of Guy's hospital dialysis units and engage directly with

patients enabled Guy's and GOLD to hear first-hand some of the difficulties patients were facing in finding a living Donor.

- The information and data gathered will allow Guy's Hospital and GOLD to develop a strategy that will offer better support for black patients.

WHAT DID NOT WORK WELL?

Peer Educator engagement:

Despite having a large pool of PEVs on the original ACE pilot, there was a lower uptake of PEVs on this project. This was largely due to the long recruitment process at GSTT which discouraged many people from volunteering and also due to the time that had elapsed since the original training.

Time constraints:

Several of the patients needed more time to approach

family members and the six months' time constraints of the study did not allow us the opportunity to pursue these patients. Our original project proposal was for one year.

Continuity:

The PEVs noticed that during their follow up calls, patients who had previously been willing during the face to face visits to talk with their family now seemed reluctant to do so.



CONT :

What we learnt:

The project was evaluated by the healthcare professionals, PEVs, patients, friends, and family members. This was carried out through questionnaires, and group meetings.

From health care professionals (HCP) :

All those involved felt the project was good value for money and an effective intervention with the potential to make a positive impact on access to LDKT for BME patients. Strong leadership from the PE Lead (Dela Idowu) the nursing team and the PEC for the volunteer network was considered key to the success. HCPs felt that they could commit to their current level of time and involvement but would not have the time or human resources to coordinate all the different aspects of the programme, including the volunteer network once the project ended. Having established the home visits, it was agreed that more time was needed to consolidate learning and evaluate the impact of home-based interventions and to follow up on some of the patients who wanted more time to approach friends and relatives.

From patients and family members:

80 % of patients wanted earlier engagement and support from peer volunteers from the same ethnic background who had experience of living donation to increase and boost their levels of confidence. This holistic approach makes it easier to have the conversation about living donation with their friends and families.

Quote from a family member:

“health decisions are often strongly supported by family members and this form of engagement which involves support from people from their own community is imperative if they are to make informed decisions about living donation”.

Budget matters:

The funding assumptions were based upon the time that the PEs would require to re-engage and develop the expertise of the network, support home visits and deliver the responsibilities detailed above, as well as travel and subsistence costs to support the volunteer network. The project was delivered within budget. However, we were originally offered half the funding for the project from our local Kidney Patients Association on the basis that we matched the funding from an external source. Having received the agreement for half the funding from the NBTA LTI, the GSTT KPA were unable to commit to the funding we had hoped for as we were not able to satisfy the requirement that the project would provide “the specific evidence that GSTT requires to commit funding to a BAME strategy for living donation”. Our original proposal to the KPA was for one year, so we were able to carry out the project for 6 months using the money received from the NBTA LTI within the required time frames.



DOING THE RIGHT THING PROJECT: LEEDS HOSPITAL.

Report by : **Dr Brendan Clarke: Brendan.clarke@nhs.net**

Our objectives:

The aim of our project was to increase awareness of live kidney donation in the South-Asian Community in Yorkshire (mainly targeting the South-Asian Muslim Community).

We based our approach around three areas; Science, Family and Religion. We aimed to explain the need for donation from the same ethnic community by explaining the science in simple terms how a match between a recipient and Donor are determined.

The family section included topics relating to the Donor i.e. how and why they decide to donate, procedure of donation pre and post donation, and effect on a family as a whole.

Finally the religion part of the work was focused on what the Islamic Sharia law and what the Holy Qur'an says regarding organ donation.

The aim was to provide high-confidence, authoritative information with intention to facilitate the development of a consensus view on the 'right thing' to do in the context of the decision to become a living Donor.

What we did:

We collated data for HLA antigen distribution in the UK Donor population; this was taken from the current NHSBT-ODT dataset. Local recipient data was then collected from wait list active patient records and finally local Donor data was obtained from the laboratory database.

This data indicated that the gap between requirement for kidney transplantation (34% on the Leeds waitlist)

and number of Donors (6%) from black, Asian and Minority Ethnic (BAME) community is large. The rate of living Donor kidney transplantation is also low compared to Caucasians. Due to the ethnic differences in HLA tissue type, patients from BAME community not only have to wait longer time for transplantation but also receive less well matched organs; which may have implications for subsequent transplantation.

The data also identified that recipients from the South-Asian Muslim Community comprised 25% of our wait-listed cohort for deceased Donor renal transplantation; whereas only 0.8% of Donors processed by the centre were of South-Asian Muslim descent. Consequently in 2017 only 1/25 (4%) received kidney from a matched ethnicity Donor. HLA-A and B mismatch grades in this group were poorer than amongst Caucasian recipients (HLA-A 1.2 vs. 1.1 and HLA-B 1.13 vs. 0.98 respectively, p-value = non-significant).

This data provides cause for concern to the local South-Asian Muslim Community. In seeking to address this we decided to put together a presentation that would include the above mentioned topics and opened a holistic dialogue with the community with respect to living Donor transplantation. This involved focus groups, hosting community events, and engaging with local Imams and community leaders.

CONT :

Focus Group:

Our first presentation was with the focus group, this consisted of five people, four out of these five were not from a science background, and therefore it helped us to see if the science part of the presentation would be understood by the general public. This section of the PowerPoint presentation consisted of 4 slides, which were well received and the concept of tissue typing understood to certain degree, there were couple of questions regarding live vs deceased Donor; as in which is the better option and why?

Religion:

This section also consisted of 4 slides, as each slide was slightly different and referred to different parts of Islam, i.e The Qur'an, The Islamic Sharia Council and Islamic view in general, therefore each of these slide led to series of debates which also led to more questions i.e.

- There is a Fatwa (law) in the Sharia Council regarding organ donation. This came about in the year 1995. The question that came about from this statement was: who decreed this law? How did come about? Was the right protocols followed when the law was established?
- What does the Qur'an mean when it says "Whosoever saves a life, it would be as if he saved the life of all mankind." (Chapter 5, vs. 32)
- What is stopping the Muslim community from donating to their loved ones to give them a better life?

Family:


Finally the last section of the presentation was focussed on Family; why decide to donate? How would it help the rest of the family if one member had a better standard of living via organ donation?



First Event:

The first community event was held at a venue in Leeds, again it was well received and the questions arising were such as; according to Islam can a male donate to a female; what will the quality of life be for the Donor after donation? We had a panel of experts that were able to answer these questions.





These were the questions asked:

- What is the best age range for donating?
- Does male/female donation make a difference in Islam?
- Do family members feel a need to donate to a loved one?
- Can donors be adversely affected later in life?
- Do you provide interpreters?
- How many people are on the waiting list that can't find a match?
- How can we give awareness back out to the community (non-English speakers, illiterate)?
- What is the age limit for donating?

Second Event:

The second event was held at a community centre in Bradford. This event was not as successful as the first, as we had a very low turnout. So we decided to use the small group as a workshop and try to address the issues as in why the percentage of live organ donation is low in the Pakistani Muslim community.

What worked well:

Including people from the different sections of transplantation was a good idea as we had an expert from each stage of organ donation and these experts were all readily available to answer any questions that had been raised by the audience.

What did not work well:

Our first attempt to secure a venue did not go to well, we decided to use a primary school as platform to present our presentation, after a few months of going back and forth the school management declined the request on the basis of not coming across as supporting what we were presenting i.e. the religious views regarding organ donation.

It was difficult to get into a local mosque and do a presentation as the Imams did not want the subject discussed because there are different Islamic schools of thought and they did not want to create any controversies.

It was also difficult to find family that had been through live organ donation and willing to come with us to a couple of the workshops and explain what their experiences had been like, and how life had changed for all members of the family.

What we learnt / Conclusions:

The workshop with the focus group lasted two hours, which is what we were aiming for; this included all the debates that were going on around some of the slides. As the science part was well received we have decided not to make any changes to that section. But have decided to follow the science with the family section as the religion section had taken up most of the time and we had to rush through the family part. So the slide on religion will be delivered last.



The family section needed a little more work; to include a slide which explained what the process is for the donor from when they say yes up until donation and post donation.

After presenting to the focus group we changed the layout of the presentation according to feedback we received from the group, we were also able to add and remove certain information from the presentation.

According to the literature that we have researched we have come to the conclusion that there is nothing that says that organ donation is not permissible in Islam, even though some of the scriptures are difficult to understand and there is no definitive proof stating for or against permissibility of organ donation. The problem arises from cultural differences and there is a variation in religious beliefs and practices hence a variation in choice, therefore no one person follows the same belief.

From the interactions with the community we have come to understand that people don't care for the topic because it doesn't affect them in any way, but when something like organ failure occurs within family, these same people don't know who to turn

to for the right information, and take the word of a hierarchy (family elder, Imam or Mufti) and follow them as in what to do in that situation, without understanding the science behind transplantation.

Budget matters:

We did under spend as this project was the first of its kind done by the laboratory; hence we were a little way of overspending at the beginning of the project.

What we achieved:

As a team we designed an informative leaflet that could be used in community centres or at general practitioners surgeries. The PowerPoint presentation also came well together and included information on most frequently asked questions.

What we plan to do next:

It is planned to further develop the science aspect of the presentation and then expand the project across the BAME community in the Yorkshire area.

MEMBERSHIP OF THE LIVING TRANSPLANT INITIATIVE STEERING GROUP.

Kirit Modi (Chair): Hon President NBTA.

Orin Lewis: Co-Chair, NBTA.

Kirit Mistry: Co-Chair, NBTA.

Dr Adnan Sharif: Consultant Nephrologist, Queen Elizabeth Hospital, Birmingham.

Dr Sunil Daga: Consultant Nephrologist, St James University Hospital, Leeds.

Karen Quinn: Assistant Director (Commissioning), NHSBT. (2016 -18)

Angela Ditchfield: Lead BAME Specialist Nurse for Organ Donation, NHSBT.

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.

Lisa Burnapp: Clinical Lead for Living Donation, NHS Blood and Transplant. (2018 -19)

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





HAPPY ENDINGS.



Mum Helen Shaw donated a kidney to her daughter Holly Shaw.



Meena donated a kidney to her husband Kirit.



Swati Bhagat donated a live kidney to her mum, Kanchan Bhaga.



Mum, Rachel Woodings donated a kidney to daughter Sophia Alexandra



Martha donated a kidney through the living kidney sharing scheme so that her husband David could receive a live kidney.



Mum Venessa donated a kidney to her son Jamel.



The coordinating voice for black, Asian, Mixed Race and Ethnic Minority transplant donation.

To contact us email info@nbta.co.uk our web address ; www.nbta-uk.org.uk

Reg Charity no 1177538

