

## **Scope for the Community Investment Scheme to positively engage black, Asian, mixed race and minority ethnic and faith/belief communities in organ donation.**

Following on from the previous black, Asian and minority ethnic (BAME) Community Investment Scheme funding call in September 2018, NHS Blood and Transplant is calling for applications for funding from community and faith/belief-based organisations to positively engage diverse communities in organ donation across England and Wales.

We are looking for applications that will deliver projects to reach black, Asian, mixed race and minority ethnic communities and/or engage people around their faith/beliefs. We are committed to building support for organ donation among BAME and faith/belief communities. Trusted organisations with a footprint in those communities can be very effective at doing this due to their specialist knowledge, understanding and standing in the community.

During the first year of the Community Investment Scheme 2018-19, over 20 organisations delivered community-led projects, organising a wide range of activities to engage and support their community around organ donation. Examples from last year include:

- A project to work with young black people in North London, mobilising young ambassadors to go out into the community to engage other young people around organ donation. The Royal Free used spoken word as a creative way to engage young people in organ donation.
- Community-led events in the Jain community
- Collaborative efforts between three Sikh organisations to deliver events at Gurdwaras and community Melas, attended by donor family members, patients waiting for a transplant and specialists in the field
- The development of content around organ donation for inclusion in an app aimed at the Muslim community
- Engagement activities within the Muslim community attended by scholars and imams to further understanding of the Islamic perspective on organ donation and transplantation, as well as expanding understanding of the clinical need among the south Asian community

You can download a list and summary of the funded projects from the [Community Investment Scheme page on the NHS Blood and Transplant website](#).

We hope that this funding call will again attract a high number of applications.

While projects could be delivered face to face or digitally, applicants will need to be able to demonstrate how they will make a difference. As well as face-to-face project ideas, we are particularly interested in innovative ideas or projects that use technology to drive awareness, understanding and behaviour change.

It is important that all applicants set out how their plans will build on or complement previous activity carried out by themselves or other organisations in the target community or communities.

Please note, there are a range of existing materials that exist on the NHS Organ Donation You Tube channel and website as well as materials in development to explain the change in

the law in England in different languages. So please think about and outline how you would use existing resources where applicable/appropriate.

All applications should provide clear information about the number of people you expect to engage through your project and how you will evaluate the impact of this engagement.

As the organ donation law will be changing in England from spring 2020, programmes running in England will need to demonstrate how they will help contribute to awareness and understanding of the new opt out system so people understand their choices and make and share their donation decision. They should also address myths and barriers and increase support for organ donation among the target audience(s) of their project.

In Wales, as an opt out system came into effect in December 2015, programmes should focus on increasing understanding and support for organ donation among their target audiences so more people from these communities commit to become organ donors. This includes ensuring projects normalise donation and address myths and barriers.

### **Specific considerations for projects focussed on engaging the Muslim community**

Any applications focussed on the Muslim community should demonstrate:

- how they will work with Islamic faith leaders and diverse Muslim communities to increase understanding about organ donation and the need for donors from a BAME background
- how they will work with Islamic faith leaders, patients and donors who are supportive of organ donation to broaden the discussion about the humanitarian and social benefits of organ donation
- how they will increase awareness of the law change around organ donation in England, an opt-out system (also known as 'deemed consent').

Applicants should make use of existing NHSBT materials and videos that show the faith perspectives and real-life impact of donation and transplantation.

Since 2013, NHS Blood and Transplant has been engaging with Islamic scholars, imams, chaplains and umbrella organisations through its Transplantation in Islam project. A fatwa (religious edict) was published in June 2019 by Mufti Mohammed Zubair Butt, adding to the dialogue and discussion around organ donation and Islam and support from the Muslim community is needed to help disseminate this fatwa and to hold discussions within their community.

Applicants can find out more about this and other existing fatawa at:

<https://www.organdonation.nhs.uk/helping-you-to-decide/your-faith-and-beliefs/islam/> and

Applicants can watch some existing videos at:

<https://www.youtube.com/playlist?list=PLjl4wHu2TagPtfYFYgym-5C0QoPJMAita>

### **Specific considerations for projects focussing on black Caribbean or black African communities**

We are particularly interested in receiving applications for projects that will engage black Caribbean and black African communities. The reason for this is that:

- Only a small number of the project applications and successful bids last year were for projects focussed on these communities

- Only 0.9% of those who gave us their ethnicity when registering as an organ donor in 2017/18 told us they were of black African or black Caribbean heritage
- The average waiting time for black patients waiting for a kidney transplant is longer than for both Asian and white patients due to a shortage of donors from the black community

### Specific considerations for projects focussing on Hindu and Jain communities

If your proposed project focusses on the Hindu and Jain communities, you can obtain support from the Jain and Hindu Organ Donation (JHOD) Steering Group. Details can be found on the [Community Investment Scheme page on the NHS Blood and Transplant website](#).

### Projects to reach young people

We are particularly interested in receiving applications that will engage young black, Asian, mixed race and minority ethnic communities, between the ages of 16-24. We're interested in seeing interesting and innovative project ideas that will engage this age group. There are a number of reasons for this:

- We received a very small number of applications last year for projects focussed on younger audiences and we want to see this grow with phase 2 funding.
- The opt out system will affect people from age 18 in England. Teenagers and young adults will not have had the same opportunity to see/hear information about organ donation as older generations over the course of their lifetime
- Current awareness levels around the law change are lower for this age group than for older age groups
- Young people can be seen as change makers and are considered more likely to trigger conversations with older generations about organ donation

### Why the BAME community investment scheme is needed

Around 6,000 people are waiting for an organ transplant across the UK. In 2017/18, over 400 people died across the UK waiting for an organ transplant, and 1 in 5 of these were from a black, Asian or minority ethnic background.

While consent rates among black, Asian and minority ethnic communities for donation after death have been slowly increasing over the last decade, families from these communities are far less likely to support donation going ahead than white families.

The lower levels of support and shortage of organ donors from these communities matters because people from black and Asian communities are more likely to develop high blood pressure, diabetes and certain forms of hepatitis than white people. This makes them more likely to need a transplant.

35% of patients waiting for a kidney are from black, Asian and minority ethnic communities.

Although many black and Asian patients are able to receive a transplant from a white donor, for many the best match will come from a donor from the same ethnic background. Unfortunately, donation rates from these communities are a lot lower than for white people.

By increasing the number of black and Asian deceased organ donors and living organ donors each year, we will narrow the waiting time gap and save and improve the lives of more black and Asian patients.

More donors from black, Asian and minority ethnic groups are urgently needed to address an increase in patients from the same communities dying whilst waiting for an organ transplant.

We know that the proportion of people from black, Asian and minority ethnic communities who have registered a decision to donate is lower than for white people across the UK. Also, of those in the last 12 months who have given their ethnicity when registering and told us they are BAME, the vast majority have recorded an opt out decision. Much of this 'opt out' registration activity has been in response to incorrect information circulating.

While it is everybody's choice whether or not they want to donate, we want to ensure that people base their donation decision on the facts. We also want to ensure that people discuss their decision with those closest to them so their loved ones know what they want to happen. We know that faith or beliefs are important considerations for some people when making their choice regarding organ donation, so initiatives that reassure people around the acceptability of organ donation in the context of their faith or beliefs are important.

### **How big is the Community Investment Scheme?**

NHS Blood and Transplant's Community Investment Scheme for organ donation will cover projects in England and / or Wales.

NHS Blood and Transplant's total estimated investment is likely to be in the region of £200,000 for projects in England and £20,000 for projects in Wales. This is a flexible budget and could increase/decrease based on the quality of applications put forward and the number meeting the funding criteria.

Organisations looking to apply for funds to cover projects in both countries can either put in separate applications or one application to cover both countries. But it is important that the organisation applying has a community footprint in the regions the application covers and can state the proportion of work that will take place in each country.

### **Who can apply?**

The scheme is open to organisations. This could include registered charities, limited companies, charitable incorporated organisations, community interest companies, or unincorporated groups.

Bidding organisations will be required to provide details of their organisation in the application form. If you are planning to work with partner organisations, this should be outlined in the application too.

### **Who cannot apply?**

An individual cannot apply on their own behalf as all financial grants will need to be made to organisations.

If an individual has an idea and wants to put in an application, they would need to align with an organisation that is willing to put in the application on their behalf, take responsibility for funding, project delivery and reporting.

Any organisation that is not a registered charity or organisation with its own bank account will not be able to receive funding. Therefore, if an organisation is in this situation and wants

to put in a bid, they would need to align with a partner organisation that is willing to take responsibility for the application, funding, project delivery and reporting.

We are not looking for applications from marketing, PR or advertising agencies, research bodies or market research organisations.

The grant scheme is designed to support projects that engage with and inform black, Asian, mixed race or minority ethnic or faith/belief communities. We are not looking to fund research projects.

### **How much money can bidders apply for?**

Applicants can apply for one of two options; funds up to £2,499 or funds between £2,500 - £10,000. The application and judging process for each level of funding will be different.

Please note that your budget outline should be inclusive of unrecoverable VAT.

Bidders can apply for a project of up to £2,499 and a project of £2,500 to £10,000 if they so wish. Please only put in applications for both funding levels if you could complete both projects in the timeframe you have specified, if both were to be successfully funded. Also ensure the applications are sufficiently different to avoid duplicate funding

Bidders can apply for projects for delivery across one of the following three timescales:

- projects up to the end of June 2020
- projects up to the end of October 2020
- projects up to the end of March 2021

Organisations applying for funds should make clear if they are applying for money from any other sources and should think carefully about the areas that they are requesting funding for, as these grants are funded by taxpayers. For example, we could not pay fees to artists/influencers or celebrities to endorse organ donation or fund international travel. Any travel costs for people to attend events etc would need to be standard class travel.

If applicants intend to use monies received from a successful bid to employ a post or contribute towards staffing costs, NHS Blood and Transplant will not undertake any employment liability for these posts. All liability remains with the applying organisation.

### **What type of donation should the projects cover?**

The focus of the proposed projects needs to be on promoting organ donation after death.

### **When does the work need to be carried out?**

All projects will need to be completed by either the end June 2020, by the end of October 2020 or by end March 2021. We would like to see all applicants lay out the timeframes of their proposed project in the application form.

### **Important considerations around the timing of projects in England (see section on Wales for Welsh considerations)**

The opt out system in England will be coming into effect in spring 2020.

## Blood and Transplant

Projects funded through this BAME Community Investment Scheme taking place in England have an important role to play in helping people understand that the law is changing and ensuring they are aware of the choices available to them prior to the law change. The activity delivered by organisations on the Government's behalf will be an important channel to deliver information about organ donation and the change in the law through trusted messengers.

Much of this community-led activity will be happening within the context of a national campaign to communicate the change in the law. This campaign, called 'Pass It On', aims to ensure that there are high levels of awareness around the law change and that people record and share their donation decision.

<https://www.organdonation.nhs.uk/get-involved/organ-donation-campaigns/>

We want people to:

- understand the positive and lifesaving nature of organ donation and to decide whether they want to **pass on** their organs to save lives
- Make and share their donation decision and **pass it on** to those closest to them
- Help **pass on** the campaign message to others, making them aware of the law change and helping them access the information they need to make their own donation decision.

For applicants in England, please note the following options for project lengths and end points. You may like to:

- deliver a short-term project up to and shortly after the law change in England comes into effect to ensure that people in your community are aware that the law is changing, that they understand their choices and that they are aware of the facts around organ donation and make the decision that is right for them. These projects can run **up to the end of June 2020**
- run a project over a twelve-month period, **up to the end of October 2020**, which includes activity to inform people about the change in the law and the choices available to them prior to spring 2020
- plan and deliver a longer-term project **up to the end of March 2021**. These projects also need to include activity to inform people about the change in the law and choices available to them prior to spring 2020.

For all of the options above, you will need to be able to demonstrate that you can deliver activity prior to the change in the law and how you will ensure people in your community are engaged and motivated to make their organ donation decision.

### Important considerations around projects in Wales

The opt out system came into effect in Wales in December 2015 and there are now generally high levels of awareness around the opt out system. However, there is still a lot of work to do to engage black, Asian, mixed race and minority ethnic communities living in Wales. We are looking for project ideas that help normalise donation and address myths and barriers among the black, Asian, mixed race, minority ethnic and faith/belief communities.

In a survey of black and Asian adults living in Wales carried out earlier this year, half of the 221 people surveyed told us they neither support or oppose organ donation, and 50% told us they didn't know whether they would donate their organs. Only a small number of respondents had ever had a conversation about organ donation.

### Support for applications



To support bidders with their funding applications for the new Community Investment Scheme, NHS Blood and Transplant will be holding a free workshop.

Date: Wednesday 7 August  
Time: 10am (for a 10.30am start) – 2pm  
Venue: Holiday Inn Bloomsbury, Coram St, Bloomsbury, London WC1N 1HT

This will also be a good opportunity for organisations to hear more about the type of projects carried out in the first year of the grant scheme, find out more about the national context and see if they want to collaborate and put in joint applications with other organisations.

It is not essential to attend the workshop to put in an application for funding. All information provided within the workshop will be made available on the website afterwards.

To reserve a place, please email [community.funding@nhsbt.nhs.uk](mailto:community.funding@nhsbt.nhs.uk)

## **How applications will be assessed**

The criteria for awarding the funds is based on:

- how the activity will make a positive impact
- how the activity will raise awareness of the law change in England (for projects in England and for projects covering both England and Wales)
- understanding of the audience, local community and issues
- experience of previous activity for organ donation or a similar subject
- ability to evaluate the impact of the proposed activity
- value for money

Additional considerations will be; geographic and community spread; future planning and the ability to adapt.

There are different judging criteria for projects in England/ England and Wales and Wales only projects.

- Judging criteria for projects in England or England and Wales
- Judging criteria for projects being delivered exclusively in Wales

Details of these criteria can be viewed and downloaded from the [Community Investment Scheme page on the NHS Blood and Transplant website](#).

## **Judging process and panel**

The judging panel is comprised of key stakeholders in the organ donation and transplant community. These are likely to include a family/patient with first-hand experience of organ donation; members of the marketing and communications team at NHS Blood and Transplant; the lead diversity nurse for Organ Donation; clinicians and nurses involved in organ donation and transplantation; a representative from the Department of Health and Social Care; a representative from the Welsh Government, a representative from the National BAME Transplant Alliance, the NHS Blood and Transplant BAME Marketing Manager, the chair of the Stakeholder 2020 group. The judging panel and steering group for this round of funding is still being finalised.

Members of the judging panel are being vetted for potential conflicts of interest and will not provide scores for any applications where they have a personal conflict of interest.

For any applications where the judging panel feel that further clarification from the applicant is needed before they can make a final decision, clarification questions will be asked. These questions will be asked after the judges have convened to review the applications and discussed their scores and comments on applications.

### **Notification of awards**

We hope to notify applicants of funding decisions during October 2019. However, if we are awaiting clarification before being able to make a decision, some decisions may be delayed.

### **Release of funding**

Successful applicants will be expected to sign a Memorandum of Understanding prior to the release of funding. Depending on the size and length of the projects, the funds may be released by NHS Blood and Transplant on a phased basis, with funds for activity being carried out in 2019/20 provided in 2019/20, and with remaining funds being paid after April 2020. The phasing will be confirmed with each organisation being funded for the work.

### **Financial scrutiny**

The funded organisation will be required to maintain records of expenditure and NHS Blood and Transplant reserves the right to have its auditors investigate that the funded activity has/is being done.

NHS Blood and Transplant reserves the right to ask for and receive funds to be returned in the case that the agreed activity has not been undertaken (partially or at all).

### **Evaluation of projects**

All organisations receiving funding will be expected to evaluate their project in line with the Government Communication Service's Evaluation Model. This means being able to outline

- what you have done (inputs)
- outputs in terms of what has been delivered (numbers of people reached etc)
- outtakes in terms of any measures around attitudes or engagement levels, or measurement of people's stated intention to act
- outcomes – number of decisions recorded etc

<https://gcs.civilservice.gov.uk/guidance/evaluation/tools-and-resources>

You can find an example of the final evaluation form used in the first year of the grant scheme here: <https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/16473/190712-cis-year-2-final-evaluation-report-template.docx>

You can read some tips on measuring an organ donation campaign here:

<https://www.nhsbt.nhs.uk/get-involved/promoting-donation-hub/tips-and-guidance/measuring-your-organ-donation-campaign/>

Organisations will be required to provide quarterly reports (depending on the length and size of the project) and a final evaluation report.



Final evaluation reports will need to be provided to NHS Blood and Transplant within 8 weeks of completing the project (the end date set out in their application)

### **Information on organ donation**

You can find a wealth of information about organ donation on our website [www.organdonation.nhs.uk](http://www.organdonation.nhs.uk)

For example:

<https://www.organdonation.nhs.uk/about-donation/what-is-organ-donation/>

<https://www.organdonation.nhs.uk/about-donation/what-can-i-donate/>

Information about the change in the law in England

<https://www.organdonation.nhs.uk/uk-laws/organ-donation-law-in-england/>

Information about the Pass it On Campaign in England

<https://www.organdonation.nhs.uk/get-involved/organ-donation-campaigns/>

You can also find information in our Promoting Donation Hub.

<https://www.nhsbt.nhs.uk/get-involved/promoting-donation-hub/>

You can also find information on our YouTube Channel:

<https://www.youtube.com/user/nhsorgandonation>

### **Information on the need for organs from people in BAME communities**

There is information on our website about organ donation and faith/ethnicity, and also a number of statistical reports relating to BAME communities, organ donation and transplantation.

For example:

Ethnicity

<https://www.organdonation.nhs.uk/about-donation/organ-donation-and-ethnicity/>

Faith and beliefs

<https://www.organdonation.nhs.uk/helping-you-to-decide/your-faith-and-beliefs/>

Statistical reports

<https://www.organdonation.nhs.uk/supporting-my-decision/statistics-about-organ-donation/>

<https://nhsbt.dbe.blob.core.windows.net/umbraco-assets/1849/bame-organ-donation-and-transplantation-data-2017-18.pdf>

### **Important information on working with celebrities and influencers**

Engaging celebrities, VIPs and influencers can be a fantastic way of amplifying the vital work that you do, but involving highly influential people with that work also presents a unique set of risks and challenges. Please ensure you that you read our celebrity and VIP safeguarding

guidelines, which can be found on the [Community Investment Scheme page on the NHS Blood and Transplant website](#).

All applicants will need to acknowledge in the relevant section of the application form that they have read, understood and commit to follow these guidelines.

### **What is GDPR?**

General Data Protection Regulation (GDPR), agreed upon by the European Parliament and Council in April 2016, and replaced the Data Protection Directive 95/46/etc in Spring 2018. It is the primary law regulating how companies protect EU citizens' personal data and refers to collection, usage, storage, and destruction of that data.

<https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/>

### **Further questions**

If you have any further questions about the scheme, please send them to [community.funding@nhsbt.nhs.uk](mailto:community.funding@nhsbt.nhs.uk) and we will respond as soon as we can.

You can also contact:

- Emma Dixon: Senior Campaigns and Marketing Officer 07384915736
- Hazel Preece: Senior Campaigns and Marketing Officer 07711447569
- Emma Avery: Senior Campaigns and Marketing Officer 07823 351 838 (works Wednesdays and Thursdays)
- Andrea Ttofa: Head of Organ Donation Marketing 07889 304 143

Please note that we cannot review applications in advance of submission.