



ENDING  
THE  
SILENT  
CRISIS

A REVIEW INTO **BLACK,  
ASIAN, MIXED RACE AND  
MINORITY ETHNIC (BAME)**  
BLOOD, STEM CELL AND  
ORGAN DONATION

FINAL REPORT  
JUNE 2018

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# INTRODUCTION

## EXECUTIVE SUMMARY

This report looks into blood, stem cell and organ donation within Black, Asian, Mixed Race and Minority Ethnic (BAME) communities in England. It combines research into the context and current thought around BAME donation with key findings from the public consultation.

Over several years the number of eligible donors has fallen while BAME patients in need of blood, stem cells and organs has risen. The situation has reached a point of extremity that some have called a 'silent crisis'. A wide range of factors have contributed to this, which are discussed in the report.

Clarifying the ways that local, national and international organisations work together is crucial to solving this crisis, but also important is changing the hearts and minds of individuals in BAME communities. The recommendations included at the end of this report break down practical ways of effecting this.

The most significant recommendations are:

- An overarching strategy that sets out collaboration between local, national and international organisations is essential.
- Good practice models must be funded and supported in more areas with communities in need.
- Creating a culture of normality around donation is crucial to raising donor rates. Engagement through national and local media has a vital role to play in achieving this.
- Investing in young members of BAME communities, for example by integrating donation within formal education, will make a huge difference to future donation rates.
- A dedicated review into faith and organ donation within BAME communities would deliver invaluable insights and is highly recommended.
- Further research is recommended into the opinions of young members of BAME communities and the specific experiences that individuals encounter when they become donors.

## ABOUT THE PANEL

The review into blood, stem cell and organ donation within Black, Asian, Mixed Race and Minority Ethnic (BAME) communities has been overseen by a panel of Labour MPs including Sharon Hodgson MP, Shadow Health Minister and Mark Tami MP, Chair of the All-Party Parliamentary Group on Stem Cell Transplantation. It was chaired by Eleanor Smith MP.

## ABOUT THE AUTHORS

Eleanor Smith MP commissioned the Sheffield Street Company to carry out this review.

The Sheffield Street Company is an agency specialising in helping not-for-profit organisations shape their policies, campaigns and communications to achieve sustainable change. They have carried out the review in conjunction with key stakeholders and a panel of MPs who agreed the final set of recommendations based on the evidence collected.



**Eleanor Smith MP, Chair of the review into BAME blood, stem cell and organ donation**

“I am proud to have lead this review into donation in the Black, Asian, Mixed Race and Ethnic Minority communities. In blood alone it is estimated that we will need 27,000 new donors in 2018/19 from BAME communities just to keep up with the growing demand.

I've heard from community organisations, medical professionals, charities and donors themselves about the silent crisis BAME communities are facing. This issue needs to be a national priority as this injustice and unfairness can go on no longer. I'm calling on the Government, NHS bodies, communities and individuals to do more by not only highlighting the scale of the problem, but implementing the review's recommendations immediately so that we can start saving more lives.”



# ABOUT THE REVIEW

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In February 2018 Eleanor Smith MP launched a review into blood, stem cell and organ donation within Black, Asian, Mixed Race and Minority Ethnic (BAME) communities in England<sup>1</sup>. With the support of Shadow Secretary of State of Health, the review's aim was to understand the causes behind, and develop strategic solutions to, the disproportionately low number of BAME individuals who donate their blood, stem cells and organs.

**This report sets out the context and current thought around BAME donation, summarises key findings from the public consultation and makes recommendations to improve donation and save lives on a national scale.**

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## PROCESS

The review went through the following stages:

1. Background research, including scale of the issue and barriers;
2. Stakeholder collaboration, to grow knowledge and understanding;
3. Distillation of key findings and development of recommendations.

## RESEARCH METHODS

- **Background research.** Literature on donation, reports by major organisations, studies from key academics and topics in relevant journals.
- **Open call for written evidence.** Evidence invited from organisations, professionals and individuals who have experience of issues around donation in BAME communities. The review received 24 in-depth submissions from sources including public bodies, national charities, local charities, academics and medical experts.
- **Stakeholder collaboration.** Contributions from over 30 organisations, including grassroots groups and national charities. In-person interviews with key stakeholders such as researchers and NHS Blood and Transplant (NHSBT). Key stakeholders brought together in person to analyse evidence, assess findings and workshop ideas.
- **Oral evidence.** Selection of stakeholders questioned by the panel of MPs, and responses incorporated into final recommendations.
- **Review and publication.** All findings and research distilled into this report with a set of recommendations for improving donation rates across BAME communities in England.

## THEMES

This report is divided into four themes. The findings detailed in each theme have been distilled predominantly from the written submissions and the stakeholder workshop. Instances in which other sources provide significant supporting information (such as Freedom of Information requests, figures that have been interpreted from data, further reading or research recommended in the written submissions), have been noted.

## CONTEXT

In 2017/18, several initiatives made progress in tackling the issues affecting blood, stem cell and organ donation in England. These developments have often not been specific to BAME communities, but have helped to remove some structural barriers and open doors.

- 1. Launch of the 'opt-out' consultation.** Led by the Department of Health and Social Care, this public consultation was launched to take the temperature regarding the introduction of an 'opt-out' donation system. This would mean that unless a person has registered or expressed a decision not to donate their organs after their death, they would be regarded as having no objection to it. The consultation specifically asked how a new system might affect groups depending on age, disability, race or faith.
- 2. Commitments from Conservative Party leadership.** At their Conference in 2017 the Conservative Party set out that the Government intended to respond to the need for more donors by 'shifting the balance of presumption in favour of organ donation'<sup>2</sup>. This has been affirmed by the Parliamentary Under-Secretary (Department of Health and Social Care) who has stated that they "remain committed" to tackling the problems around BAME donation rates as a Ministerial Priority<sup>3</sup>.
- 3. Private Members' Bill.** Geoffrey Robinson, MP for Coventry North West, introduced the Organ Donation (Deemed Consent) Private Members' Bill for a second reading in February 2018. The Bill was given its Second Reading with complete consensus from all sides of the House. If passed, the Bill would enable individuals in England to withhold consent for organ donation, transplantation and connected purposes once the opt-in presumption is introduced. This gained support from mainstream media attention through a campaign from the Daily Mirror and other national media outlets<sup>4</sup>.
- 4. Introduction of the opt-out system in Wales.** Wales launched its 'soft' opt-out system in December 2015. The Impact Evaluation Report published by the Welsh government in November 2017 concluded that more time was needed to assess the full impact of the change. It is significant, however, that support for the system is high<sup>5</sup> and only 6% of the Welsh population have actively chosen to opt out<sup>6</sup>.
- 5. Press and public awareness.** In September 2017 there was a high volume of press coverage when pop star Selena Gomez revealed she had undergone a secret transplant, receiving a kidney from a friend, Francia Raisa. Also in September 2017, the media focused on Jemima Layzell, a 13-year-old voluntary donor whose organs helped eight people, including five children<sup>7</sup>.
- 6. Changes in medical guidelines.** Due to changes in NICE guidelines on how to treat and manage patients with sickle cell disease there is now a rapidly increasing demand for BAME blood donors. This means that over 27,000 more BAME donors are needed to meet growing levels of demand<sup>8</sup>.
- 7. Utilising stem cells from cord blood.** As of 2017 there were six hospitals where NHS cord blood banks collected from. Their job involves asking expectant mums to donate their umbilical cord blood – which would usually be thrown away – for use in stem cell transplants. These are often used when a patient doesn't have a match from an adult donor, such as if the patient is from an ethnic minority background, because the young cells are more adaptable to different genetic types<sup>9</sup>. This isn't available widespread across the country and more could be invested into this area.

Although these developments show welcome progress, there has been an absence of any specific mention about the critical situation in BAME communities from across the board.



# BACKGROUND

This section sets out the background to the report and the context within which it sits.

## CURRENT SITUATION

The problem of insufficient blood, stem cell and organ donation is fundamentally one of supply and demand. BAME people are disproportionately affected by this as they are subject to a higher demand and shorter supply than other groups<sup>10</sup>.

The high demand is partly related to BAME groups being particularly vulnerable to illnesses that lead to organ failure<sup>11</sup>. Meanwhile with regard to stem cell donation, the relatively short supply relates to the diverse genetic heritage that BAME individuals are likely to have<sup>12</sup>. These factors (although different for the different types of donation) make it harder to find a BAME patient and donor who are genetically similar than for a White Northern European.

The incremental development of this situation and lack of a specific perpetrator has led to it being called a 'silent crisis'<sup>13</sup>.

## BLOOD DONATION

Fewer than 5% of donors who gave blood in the last year were from BAME communities<sup>14</sup>, although the BAME group makes up around 14% of the total UK population<sup>15</sup>. Currently, only 1% of people who give blood in England are Black<sup>16</sup>.

- The most common blood diseases that affect BAME communities are thalassaemia (primarily the South Asian/Mediterranean communities) and sickle cell disease (primarily the Black community).
  - Approximately 1,000 people in UK have thalassaemia<sup>17</sup>.
  - Between 13,000 and 15,000 people in the UK have sickle cell disease<sup>18</sup>.
- NHS Blood and Transplant (NHSBT) has reported that at least 250,000 new blood donors overall need to be found in 2018/19<sup>19</sup>.
  - Due to changes in medical guidelines to treat patients with sickle cell disease, 10,000 new Black African Caribbean donors with the Ro blood subtype and 17,000 new donors with the O-negative blood type (the universal blood used in emergencies when the Ro subtype is not available) need to be found in 2018/19.

## STEM CELL DONATION

- Only 61% of BAME patients in need of a stem cell transplant find a suitably matched donor, compared to 96% of White Northern European patients<sup>20</sup>.
- BAME donors make up 15% of the stem cell register<sup>21</sup>. Black donors make up 1.2% of potential donors on the British Bone Marrow Registry<sup>22</sup>.
- The chance of a BAME patient finding the best possible match is 20%, whereas the chance of a White Northern European patient finding the best possible match is 69%<sup>23</sup>.

## ORGAN DONATION

### Deceased organ donation

*Organ donation from these individuals happens when they have been pronounced dead, either from circulatory death (DCD) or brain death (DBD), and when the consent of their next of kin has been given.*

- In 2016/17, the NHS organ donor register contained about 23.6 million opt-in donors<sup>24</sup>.
- In the UK, of the 1,413 people who donated their organs after they died<sup>25</sup>, 29 were Asian, 22 were Black and 14 were Mixed Race<sup>26</sup>.
- In 2016/17, 457 people died waiting for a donor<sup>27</sup>. 85 of these were BAME<sup>28</sup>.

### Living organ donation

*These donors elect to give an organ while they are still alive.*

- In 2016/17, 42% (1,043) of the UK's organ donors were living donors<sup>29</sup>.
- Of all UK living kidney and liver donors in this year, 79 were Asian, 17 were Black, 5 were Mixed Race<sup>30</sup>.
- NHSBT reports say that over a third of those on the waiting list for a kidney are from BAME communities<sup>31</sup>, while BAME people wait on average a year longer for a kidney transplant than their White counterparts<sup>32</sup>.

## ACKNOWLEDGED BARRIERS

There is a great deal of existing research into the barriers that prevent people from donating. These cross cultures, socio-economic groups, religious doctrines and donation types. The following three barriers are generally recognised:

1. Lack of knowledge or awareness<sup>33</sup>
2. Religious permissibility<sup>34</sup>
3. Lack of trust in medical institutions<sup>35</sup>

### LACK OF KNOWLEDGE OR AWARENESS

Lack of information and appropriate exposure (i.e. that is culturally sensitive) to information surrounding donation is a barrier. For example, research about organ donation conducted by Optimisa Research in 2014 stated that 85% of BAME participants said the subject had simply never come up compared with 44% of the general population sample in a previous study<sup>36</sup>.

### RELIGIOUS PERMISSIBILITY

Although none of the major religions object to organ donation in principle, there are varying schools of thought, and perceived or assumed religious barriers to organ donation do exist<sup>37</sup>. Even when there is high-level religious support, efforts often see limited results due to how they are publicised and disseminated - such as the 1995 Fatwa permitting organ donation issued by the Muslim Law Council<sup>38</sup>.

### LACK OF TRUST IN MEDICAL INSTITUTIONS

Literature suggests there is a mistrust of medical institutions within some BAME groups and a fear of medical exploitation along class and ethnic lines<sup>39</sup>. A combination of factors, such as historical medical exploitations<sup>40</sup>, current institutional barriers in the NHS workforce and leadership<sup>40</sup> and greater demand for organs than supply of them, may go some way to explaining this.



# THE ROLE OF LOCAL, NATIONAL AND INTERNATIONAL

“There is a non-practical approach by NHSBT and Department of Health towards raising awareness and changing attitudes and behaviour within Black and other Ethnic Minority communities. The continuous usage of financially compensated 3rd party agencies and external non-ethnic parties in working within Black communities has not resulted in significant increases in consenting donors. This is because of aforementioned bodies not understanding and appreciating these communities in relation to their history, culture, demographics, social nuances, etc.”

AFRICAN CARIBBEAN LEUKAEMIA TRUST (ACLT)

“While increasing BAME stem cell donation within the UK is incredibly important, this approach alone will not be enough to meet the needs of BAME patients who require a stem cell transplant. The majority (60%) of UK patients already receive stem cell transplants from international donors<sup>42</sup>, something made possible by our volunteer couriers, but to give BAME patients the best chance of survival more needs to be done to develop and grow stem cell donor registers in regions such as Africa and South Asia.”

ANTHONY NOLAN

## SUMMARY

### 1. The role of national and local

- A culture shift around donation is crucial. To create this, local and national organisations need to work together cohesively.
- The roles of BAME-focused local and national organisations should be delineated in an overarching and long-term strategy, which should have a collaborative, rather than top-down, approach.
- Funding, resources and support infrastructure must be provided for, and easily accessible by, small organisations.
- Both local and national organisations must expand their activity beyond London, to tap into the pool of BAME communities in cities across the UK.

### 2. The role of national and international

- The Government must provide funding and support for projects that work with international donor banks, such as stem cell registries and cord blood banks.
- Alliances with international health organisations must be expanded to share best practice worldwide.
- It is important to be sensitive to perceptions around Mixed Race ethnicities and the BAME acronym, as this will inform how the links between donation, race and ethnicity are seen.

### 1. The role of national and local

- The rate of donor recruitment by BAME grassroots and community organisations is high. In this context, 'grassroots' organisations is taken to mean those that originate from a BAME group due to a certain need, and 'community' organisations to mean those that relate to, and work closely with, members of BAME communities. Both can be assumed to be local.
- Grassroots and community organisations' knowledge of respective target audiences, and their dissociation from governmental institutions, generate higher levels of trust from BAME groups. This allows them to reach under-represented communities more effectively.
- These organisations are small by their nature, and do not have the resource to scale upwards. In order to deliver sustainable change, they need to be empowered with funding, strategic direction and support infrastructure in place is key to empowering them and delivering sustainable change. NHSBT, meanwhile, is currently the only platform that can affect certain processes on a nationwide scale, such as research, collation and dissemination.
- There is little activity involving national bodies and grassroots or community organisations outside of London. The effects of this London-centric view show themselves in the disproportionately high number of living donors recruited in London compared to the rest of the UK<sup>43</sup>. There are pockets of good practice, for example in Birmingham, but the potential of these to be expanded has not been utilised. National bodies must spread resources much more widely to see BAME donations rise as a whole across England.
- Defining roles and responsibilities for local and national organisations is an essential first step in facilitating cohesive collaboration. This is essential to creating a strategic culture shift.
- These roles should be developed as part of an overarching and long-term national strategy which has a collaborative, rather than top-down, approach. This strategy should leave operational responsibility and decision-making to BAME grassroots and community organisations, as opposed to a directive approach from national organisations. It should be well-funded and resourced, without being politically partisan.

There are examples of collaborative projects and independent charity-led initiatives that have worked well:

#### KIDNEY RESEARCH UK

Kidney Research UK has worked in a collaborative manner with national statutory organisations such as the Department of Health and Social Care, the Scottish Government and NHSBT. Supported by their funding Kidney Research UK managed and delivered projects that engage directly with BAME communities by deploying 'Peer Educators', passionate and dedicated volunteers from the target communities, who are trained and supported through an accredited training programme.

#### BEING AFRICAN CARIBBEAN

This campaign, a partnership between the African Caribbean Leukaemia Trust (ACLT) and Anthony Nolan, aimed to increase awareness of stem cell donation, increase understanding of the need for African Caribbean donors to sign-up to the register and, ultimately, help find a donor for every African Caribbean person who needs a stem cell transplant.

#### HITHER GREEN BAPTIST CHURCH DRIVES

In December 2017 a coalition of grassroots organisations, led by Sicklekan Sickle Cell Foundation, ran a drive that received over 70 blood donations from BAME individuals in one day, more than double the previous record of 30. Every organisation had worked closely with members who either had sickle cell disease or had benefited from receiving blood, meaning that their promotional insights were acute. Content creators were asked to develop messages tailored to their demographic without shying away from the reason that blood donations were needed; local influencers from the community were invited on the day along with singers, performers and social media influencers, whose active involvement and passion inspired their followers. This drive was followed by one in March 2018, another collaborative effort that broke even more records.

Findings suggests the following methods of establishing cohesion and mutual support between local and national organisations would be successful:

- **Provision of resources and information.** Raising awareness requires accurate and accessible resources - both financial and non-financial. This is essential as small organisations have found it challenging to have nuanced conversations without clear, consistent and appropriate resources. Resources include relevant, up to date, culturally-specific statistics and materials such as sign-up forms.
  - **Knowledge sharing.** Putting organisations in touch with each other strategically would allow them to share information and areas of expertise.
  - **A formal commissioning process.** A commissioning process owned by NHSBT could facilitate funding and collaborations. This would build trust with BAME grassroots and community organisations and charities, addressing the perception that support is on an ad hoc basis. In addition to being more transparent, direct commissioning would be more efficient and cost effective.
  - **Co-produce messages and work together to deliver.** The message or the framing might be accurate but its effectiveness is dependent on the messenger and mode of delivery. Due to their integration in local communities, BAME grassroots and community organisations are best placed to judge the types of approach that will work best for which topics. Creating and delivering these messages in collaboration with large organisations would merge their expertise with the resource of national organisations.
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## 2. The role of national and international

- There is scope for the Government to increase funding for projects that work with donor banks in countries with high BAME populations, and support relationships between national and international organisations. For example, supporting international stem cell registries and cord blood banks would raise the chance of matching donors. Meanwhile, supporting alliances between donation bodies and organisations such as the World Marrow Donor Association (WMDA) would promote shared insight and contribute to raising survival rates.
- NHSBT does not routinely export blood or tissue products other than stem cells, and it only shares small numbers of organs with other EU countries. It is part, however, of a number of international bodies - including the Alliance of Blood Operators, the European Blood Alliance and organisations such as the Uganda Blood Transfusion Service and Uganda UK Health Alliance. Further expanding these alliances would contribute to sharing best practice internationally.
- With regards to organ donation, NHSBT is making positive changes: an additional £1.2 million per year has been invested in behaviour change activities in England, following the publication of their 2013 report 'UK Strategy: Taking Organ Transplantation to 2020'. However, according to information provided under the Freedom of Information act the budget is divided by activity rather than audience, and no funding is ring-fenced<sup>44</sup>. Consistent funding to support these specific groups must be built in to strategies as a proactive measure.
- Mixed Race is the UK's fastest growing ethnic minority group. In the context of increasing global migration, it is important to be sensitive to perceptions around Mixed Race ethnicities and the BAME acronym. The ways in which individuals self-define and see others inform how donation is viewed by the general public, especially the links between donation and race (a social construct) and ethnicity (genetic heritage).



# NORMALISATION

“The key component here is who is delivering the message. Me as a Black person hearing from someone that is White why I need to give blood won't resonate with me because I don't feel connected or compelled to hear your message, now if this message was delivered by someone who looks like me with key hard hitting facts such as I could die if I don't get your blood, or ten minutes of your time could possibly save my life. These are messages that are bound to spark people into action.”

SICKLEKAN SICKLE CELL FOUNDATION

“To reduce fragmentation and enable a seamless donor care pathway, the health service must train its staff and nurses to interact with donors in ways that are most effective in engendering repeat donation behaviour (or “repeat business”). Cultural competency and communication skills training should form a part of that. A donor-centric approach will require a significant culture shift within NHSBT and the wider health service.”

ACTION ON BLOOD

## SUMMARY

- Creating a culture in which donation is normalised requires a shift in culture and perception. This could be achieved through framing within a more positive public health campaign
- Focusing attention on the donor and their family, as opposed to the patient, could be done by national media and culturally-specific media campaigns.
- The most effective way way of raising awareness is from within BAME communities themselves, but organisations doing this must be supported by relevant, up to date, culturally-specific statistics and resources.

## IN-DEPTH FINDINGS FROM RESEARCH AND OPEN CALL FOR WRITTEN EVIDENCE

- Creating a culture in which being a donor is normal, and in which donors are recognised, is key to increasing their numbers across all communities.
- The power of mainstream media in shifting perceptions of donation is acknowledged across the board: by academic literature, organisations spreading awareness and donors themselves. Examples of this have included storylines in national TV programmes such as Coronation Street, and targeted and culturally-specific media campaigns such as those using Punjab radio.
- Although it would be oversimplistic to rely on mass media alone, messages delivered in a familiar setting can benefit those in a ‘pre-contemplation’ stage or those with negative attitudes towards organ donation<sup>45</sup>. This would contribute to opening up and normalising the conversation in the context of donation not being on the radar in many households<sup>46</sup>.

- Findings have also suggested that visibility of donation within organisations like workplaces and businesses can create a culture of acceptance. By setting aside volunteering days for staff to take, companies could encourage donation and altruism amongst their employees. Likewise, one study has found that raising exposure to donation through primary care interventions (even with simple promotional materials in GPs' surgeries) could raise registration numbers and family consent levels<sup>47</sup>.
- Focusing attention on the donor and their family, as opposed to the patient, has produced demonstrable change in other countries. In Spain, a world leader in organ donation<sup>48</sup>, the local and regional press features a deceased donor or their family every 6-8 weeks. The UK has the right infrastructure to emulate this approach. All hospitals have an Organ Donation Committee (ODC), which could engage with local and regional media to develop a greater understanding of organ donation and transplantation. Local donor families, who are comfortable with sharing their story, could be supported by the ODC to engage with the media.
- In recent years there has been significant work done by NHSBT to raise awareness about donor shortages within BAME communities. However the findings suggests that the most effective way of delivering this message is from within BAME grassroots communities themselves. For example, Kidney Research UK's Peer Educator project, which recruits volunteers from target BAME communities and trains them in raising awareness within that community, has seen registration numbers rise around many targets. National bodies, such as NHSBT, have an important supporting role to play here, ensuring that relevant, up to date, culturally-specific statistics and resources are easily accessible for these programmes and individuals.
- The findings also suggests that more needs to be done to allow existing donors to feel valued. Researching the 'donor journey' would deepen NHSBT's understanding of pressure points and allow targeted support to be offered at key times, ensuring higher retention of donors. Examples might include hospital Donor Committees sending donors a thank you card, a text to say how many lives their donation has saved, or an email tracking their donation.
- Public health campaigns raise awareness, which is essential for improving donation rates, but they can sometimes be undermined by inappropriate use of tone, messaging or approach. There is a feeling that they are imposed on BAME grassroots and community organisations as top-down a method of disseminating information. More needs to be done to ensure that these organisations help craft public health campaigns, and that their input is sought out at conceptual and creative stages, rather than being tokenistic. For example, a BAME steering committee could advise on, monitor and co-produce campaigns.



# YOUNG PEOPLE AND EDUCATION

“We have had particular success working with schools, colleges and universities across the UK. We have found the key to be focusing on establishments/areas with a high percentage of BAME students, without necessarily needing to tailor our messages to suit a BAME audience.”

ANTHONY NOLAN

“In February 2018 we presented at the first ‘community summit’ in Southwark, jointly with NHS Blood and Transplant, to seek to engage further with the local communities within the borough and take the education programme to the next level. As a result, we are now focusing our attentions upon the 75 primary schools in the London borough of Southwark, not least because the borough’s demographic is predominantly (60%+) BAME, under 30 years of age and we are in the process of starting a pilot in 10 primary schools.”

TEAM MARGOT

## SUMMARY

- Educating children and young people through formal education and community outreach initiatives contributes to both short-term and long-term goals.
- More should be done to integrate information about donation into the formal curriculum.
- Encouraging organic conversation through popular culture and culturally relevant celebrities would be powerful ways of engaging young audiences.

## IN-DEPTH FINDINGS FROM RESEARCH AND OPEN CALL FOR WRITTEN EVIDENCE

- Organisations that work with schools and young people have found great success raising awareness and recruiting potential future donors. Not only is this a means of creating long-term sustainable donations, but it also provides young people with reliable information, giving them myth-busting tools that are often vitally needed in BAME communities. Well-informed young people are also more likely to carry facts home to their families, increasing the chance of reaching older generations.
- Although some resources for schools exist, there is no national requirement to use them. Their effectiveness therefore relies on the initiative of individual teachers, and their ability to proactively integrate this information in the curriculum.
- More should be done by the Department for Education, supported by the Department of Health and Social Care, to integrate information about donation into the formal curriculum. OFSTED guidance must

incorporate explicit reference to the issue, and the Department for Education must ensure school governors are aware of this.

- Responses suggest that engaging younger audiences through informal avenues to open up organic conversations would be powerful. This might be done through engaging the conversation through popular culture and gaining endorsements from culturally relevant celebrities and role models.
- This strategy and its content should be informed by organisations who already work with schools effectively, such as grassroots charity Team Margot. It should also be informed by groups that can advise on framing and messaging to maximise their impact, such as advocate support group Unsickle My Cells.
- There are fewer entrenched preconceptions among young people than older groups, and they are more likely to become repeat donors due to their age. Directing efforts towards this group could therefore offer a large outcome for a relatively small input. Focusing more resources on exploring the barriers and motivations young people experience towards donation, as well as related projects like age-targeted drives, would be beneficial.

#### THE HERO PROJECT FROM ANTHONY NOLAN AND NHSBT

The Hero Project is an education programme that teaches 16 to 18 year olds about the importance of donating stem cells, blood and organs. Trained volunteers deliver inspirational sessions to students across the UK, explaining how they could save a life. This takes 30 to 50 minutes, usually during assembly time or other curriculum slots such as PSHE lessons. They then offer the school or college the opportunity to hold a recruitment event, which gives young people the chance to join the Anthony Nolan stem cell donor register. Of the potential donors recruited through events in London in 2018, 62% are from BAME backgrounds.

#### THE POWER OF ONE PROJECT BY TEAM MARGOT

Team Margot's work with the London City Hall Education and Youth Team's Peer Outreach Workers (POWs) has been extremely helpful in terms of spreading awareness, both over the course of the last 18 months and on an ongoing basis. Having met Team Margot, the POWs embraced the cause and have themselves signed up as potential bone marrow donors and donors of other kinds too. Individually, they are, in their own time and in their own way, helping to spread awareness and encourage people within their own communities to join the bone marrow register.

The support, involvement and advocacy of the POWs is significant because they are themselves from a wide variety of BAME communities. This work culminated in an event on 30 October 2017, which heralded the launch of a photographic exhibition entitled 'The Power of One'. The exhibition remained on display at City Hall for five weeks and led to extensive media coverage.



# RACE, CULTURE AND RELIGION

“Having seen various programmes and interviews, it is clear that there is no consistent message or mechanism to disseminate information to the BAME community. There is little collaborative working between charities, Government or government departments on this subject. With this in mind, the Foundation would be willing to set up a stem cell and donation group and invite other charities and institutions, and government departments to work together so that a national campaign could be introduced with a uniform message tailored to BAME community about the lack of donors and the need for this community in particular.”

UK STEM CELL FOUNDATION

“The way in which organ donation is promoted may not take sufficiently into consideration cultural and/or religious values and beliefs in BAME communities. It is very important that this is addressed if the Government introduces opt out, otherwise there could be a lot of confusion and negative feeling amongst BAME communities, which could ultimately mean that donation rates remain relatively low. NHSBT should consult particularly carefully on this matter and should be very careful to explain any changes properly.”

KIDNEY CARE UK

## SUMMARY

- BAME communities should not be seen as one homogenous group.
- Understanding the historic mistrust in the NHS and government felt by some BAME groups is key to overcoming it.
- NHS staff should be trained to a higher level on different cultural viewpoints.
- It is important to be aware of, and respect, the viewpoints of religious scholars and their communities.

## IN-DEPTH FINDINGS FROM RESEARCH AND OPEN CALL FOR WRITTEN EVIDENCE

- Recognising the cultural and ethnic heterogeneity of groups that fall within 'BAME' is crucial. BAME communities should not be seen as one homogenous group, and nor should mixed-race people, who face their own specific and growing challenges: there are many nuances in race, religion and culture which need to be understood to engage these communities.
- Recognising the role of race in perceptions of the NHS is likewise crucial. Within some BAME communities there is an historic mistrust in the NHS and government as institutions, which acts as a barrier to meaningful engagement. It is only through understanding why, from an historic perspective, certain BAME communities associate the NHS with injustice, that we can overcome it. The gap between communities and institutions

can be bridged by acknowledging this and proactively working to rebuild trust.

- NHSBT has invested in a lead diversity nurse, BAME specialist nurse lead and a volunteer manager<sup>49</sup>. This is promising as long as it is not a replacement for empowering the existing grassroots organisations and making collaborative decisions at all levels. This current situation was seen as exclusionary and top-down by many of those submitting evidence.
- Awareness campaigns focusing on specific BAME groups can be powerful, but targeting age groups in areas with high BAME populations - as opposed to ethnicities or religions - could produce results with more longevity.
- Responses suggest that learnings could be taken from other countries. For example in Barcelona, where there is a wide range of ethnic and religious communities, hospitals regularly invite local faith leaders to learn about the work of the hospital, the workings of intensive care units and about organ donation and transplantation in general. They do this at low-stress times, which allows leaders to feel more at ease with the process as a whole; consequently, if families do require religious support at the time of donation, the hospital has pre-established relationships with local faith leaders that it can call upon. Spain's rate of deceased donors last year was 47 per million population (pmp); the UK equivalent was 32. The UK's infrastructure would support a move to Barcelona's approach: it would be possible for hospitals' Organ Donation Committees to engage with local faith leaders and deepen their understanding.
- There is a lack of ethnic diversity in the staffing of this area of the NHS. Specialist nurses for organ donation (SNODs) who looking after BAME patients are typically not BAME themselves. In America, some hospitals support the use of in-house 'race-specific' requesters<sup>51</sup>, who can discuss organ donation with families, ensuring a level of empathy and cultural understanding from the beginning of their relationship. Responses suggest that recruiting more BAME staff would have a positive impact on donation rates, as well as other areas.
- NHS staff directly involved in blood, stem cell and organ donation should be trained to a higher level on different cultural viewpoints (for example on death and donation), as suggested in the 2016 DonaTE study<sup>52</sup>. The lack of knowledge and cultural sensitivity has previously acted as a barrier to donation. Cultural competence training would equip staff to understand different perspectives, have useful and informative conversations, and ensure that stereotypes about race and ethnicity are not being fuelled by inaccurate information such as donor ineligibility due to country of origin.
- Conversations regarding religion and donation are nuanced. It is crucial that outreach attempts respect the pace of religious scholars and their communities, or risk alienating them completely. It may also be important to actively research the spectrum of viewpoints in order to target them efficiently. One model divides attitudes into three segments: cynics, 'interested but cautious' and 'interested but uninformed'. It suggests that the second and third are more beneficial to target. In the Islamic community, the cynics "feel organ donation is a serious breach of their faith" and "feel that Islam strictly prohibits organ donation". The 'interested but uninformed' individuals, meanwhile, "would like to participate but [do] not know enough about the process" and "feel it is important to participate but need clarification from the Shariah scholars", and the interested but cautious segment wants to participate but "is worried about Shariah rulings" and feels "it is important to participate" but fears "the Islamic consequences"<sup>53</sup>.
- The number and complexity of such issues within faith communities, their sensitivity and the inherent barriers they raise, suggest that a separate review could be desirable.



# RECOMMENDATIONS

If we accept the status quo, the number of preventable deaths in England's BAME population will rise. For a nation with a proud history of embracing and supporting diversity, allowing that to happen is unthinkable. The NHS's consultation on opt-out organ donation, despite being so clearly in the public eye, doesn't go nearly far enough to resolve the specific crisis in BAME communities. To gloss over it is tantamount to discrimination.

There are therefore a number of recommendations that must urgently be implemented.

## TO GOVERNMENT

- Department of Health and Social Care must create overarching and long-term strategy foregrounding a collaborative, rather than top-down, approach to improve BAME donation rates. Key elements of the strategy to include:
  - Creation in collaboration and consultation with, BAME grassroots and community organisations
  - Clearly-defined roles and responsibilities for different types of organisations, with strategies for working together cohesively
  - Engagement plans for reaching out to national media, culturally-specific media, local media and culturally-relevant influencers
  - Strategy to support BAME grassroots and community organisations in exploring new ways of targeting BAME communities, such as targeting age groups in areas with high BAME populations
  - Working with partners to evaluate and increase the evidence base for these interventions;
  - Steps for improving access to research and resources, as well as the facilitation of knowledge-sharing between organisations
  - Time-specific and measurable targets
- Department of Health and Social Care must commission a separate, dedicated and nuanced review of barriers to organ, blood and stem cell donation specifically within BAME faith communities.
- Department of Health and Social Care must provide grants to support research into specific barriers and motivations affecting BAME donation rates.
- Department of Health and Social Care must provide resource to allow cultural competence training to be developed and rolled out to the NHS workforce directly involved in blood, stem cell and organ donation.
- Department of Health and Social Care must fund further research into the effect of exposure to donation through primary care interventions.
- Department of Health and Social Care must ensure ring-fenced funding is available for NHSBT to support grassroots and community organisations to engage BAME communities in donation.
- The Department of Health and Social Care must provide support for projects that work with international donor banks, and expand its alliances with international health organisations to ensure best practice is shared.

#### TO DEPARTMENT FOR EDUCATION

- Department of Education, supported by Department of Health and Social Care, to integrate information about donation into the formal curriculum. Local Education Authorities, OFSTED and boards of governors all have an explicit role in ensuring this is effectively implemented.

#### TO NHS BLOOD AND TRANSPLANT (NHSBT) AND NHS ENGLAND

- NHSBT must set up a formal commissioning process to facilitate collaborations between organisations as well as provide funding for donor recruitment initiatives based on evidence suggesting that community networking approaches are successful<sup>54</sup>.
- With the input of a committee formed from relevant BAME grassroots and community organisations, NHSBT must co-produce messaging for, and collaborate on delivering, public health campaigns.
- NHSBT must undertake further research into:
  - The specific experiences of individuals who become donors, including points at which support is needed to prevent drop-outs (the 'donor journey');
  - The barriers and motivations of young BAME people around donation
  - Successful awareness practices from other countries
- NHS Trusts to ensure donor committees in hospitals are working with local media and community groups to publicise donors and their families.

#### TO PARLIAMENTARIANS

- Parliamentarians must set up an APPG on BAME donation, to ensure there is cross party support for overseeing improvements in this area.
- Party leadership must encourage MPs and local councillors to lead by example and donate, during engagement weeks like Organ Donation Week.
- Parliamentarians to lead by example by becoming ambassadors for donation, promoting it both in their constituencies and personally.

#### TO COMMUNITIES, BUSINESSES AND INDIVIDUALS

- Businesses must ensure they offer volunteering days to encourage staff to donate, as part of corporate social responsibility programmes.
- Businesses, communities, schools and MPs must engage in Organ Donation Week and call upon others to do the same.
- Members of BAME communities must consider volunteering with organisations that work within BAME communities to help raise awareness about donation.
- Individuals must consider the benefits of making a blood, stem cell or organ donation, and, if they can, make one.



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- Amelia Chong: Policy and Public Affairs Manager, Anthony Nolan
- Kye Gbangbola: Chairman, Sickle Cell Society
- Nigel Gordon: PR and Communications Officer, DKMS
- Neerja Jain: Health Equalities Project Manager, Kidney Research UK
- Joyce Kabochi: Member, Kevin Kararwa Leukaemia Trust
- Balvinder Kaur: Project Manager, Sikh Community and Youth Services
- Veronica Kararwa: Co-founder, Kevin Kararwa Leukaemia Trust
- Orin Lewis OBE: Co-Founder & Chief Executive, African Caribbean Leukaemia Trust (ACLT)
- Fiona Loud: Policy Director, Kidney Care UK
- Julie Macharia: Volunteer, Kevin Kararwa Leukaemia Trust
- Yaser Martini: Co-Founder, Team Margot
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- NHS Blood and Transplant
- Professor Brendon Noble: Chief Scientific Officer, the UK Stem Cell Foundation
- Abiola Okubanjo: Director, Action On Blood
- Faiza Peeran: MSc candidate, Imperial College London
- Dr Gurch Randhawa: Professor of Diversity in Public Health and Director, Institute for Health Research, University of Bedfordshire
- Kehind Salami: Founder and Director, Sicklekan Sickle Cell Foundation
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- Hannah Wanjik: Volunteer, Kevin Kararwa Leukaemia Trust

**FACE-TO-FACE AND PHONE INTERVIEWS (IN ALPHABETICAL ORDER BY SURNAME):**

- Amjid Ali: Project Lead, Transplantation within the framework of Shariah, NHS Blood and Transplant (NHSBT)
- Leonie Austin: Director of Marketing and Communications, NHS Blood and Transplant (NHSBT)
- Amelia Chong: Policy and Public Affairs Manager, Anthony Nolan
- Wayne Lawley: Head of Corporate Communications, NHS Blood and Transplant (NHSBT)
- Dr Majid Mukadam, Transplant (Retrieval) Surgeon, Heart and Lung Transplant Unit, Queen Elizabeth Hospital Birmingham
- Dr Gurch Randhawa: Professor of Diversity in Public Health and Director, Institute for Health Research, University of Bedfordshire
- Geoffrey Robinson, MP for Coventry North West: Sponsor of the Organ Donation (Deemed Consent) Bill 2017-19 (Private Members' Bill)
- Sarah Rogers: Regional Register Development Manager (London), Anthony Nolan
- Mark Tami, MP for Alyn and Deeside: Chair of All Party Parliamentary Group on Stem Cell Transplantation

## ORAL EVIDENCE SESSION

### Panel of MPs:

- Sharon Hodgson, MP Washington and Sunderland West: Shadow Minister for Public Health
- Eleanor Smith, MP for Wolverhampton South West: Chair of the Review into Black, Asian, Mixed Race and Minority Ethnic (BAME) Blood, Stem Cell and Organ Donation
- Mark Tami, MP for Alyn and Deeside: Chair of All Party Parliamentary Group on Stem Cell Transplantation

### Witnesses:

- Richard Davidson: Director of Engagement, Anthony Nolan
- Beverley De-Gale OBE: Director of Operations, the African Caribbean Leukaemia Trust (ACLT)
- Neerja Jain: Health Improvement Project Manager, Kidney Research UK
- Orin Lewis OBE: Chief Executive and Co-Founder, the African Caribbean Leukaemia Trust (ACLT)
- Dr Gurch Randhawa: Professor of Diversity in Public Health and Director, Institute for Health Research, University of Bedfordshire
- Ian Trenholm: Chief Executive, NHS Blood and Transplant

## STAKEHOLDER WORKSHOP ATTENDEES

- Emmanuel Amuah: Founder, We Are Not The Same (WANTS) Sickle Cell Group
- Simon Butler: Head of Policy and Public Affairs, Anthony Nolan
- Beverley De-Gale OBE: Director of Operations, African Caribbean Leukaemia Trust (ACLT)
- Orin Lewis OBE: Co-Founder and Chief Executive, the African Caribbean Leukaemia Trust (ACLT)
- Neerja Jain: Health Improvement Project Manager, Kidney Research UK
- Dr Gurch Randhawa: Professor of Diversity in Public Health and Director, Institute for Health Research, University of Bedfordshire
- Yaser Martini: Co-Founder, Team Margot
- Kehind Salami: Founder and Director, Sicklean Sickle Cell Foundation
- Dr Shuja Shafi: Secretary General, the Muslim Council of Britain
- Chanel Taylor: Founder, Unsickle My Cells

# ENDNOTES

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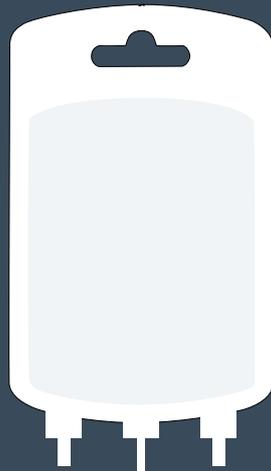
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