

Board Meeting in Public Tuesday 30th September 2025

Title of Paper	Patient Story - NHSBT Community Grants Programme and Sabia Rehman, Cornea Transplant Recipient, Organ Donation Lead, British Islamic Medical Association (BIMA) & Muslim Chaplain, Sheffield Teaching Hospitals			&	Agenda No.	2.1
Nature of Paper	□ Official Sensitive					
Author(s)	Sabia Rehman – Organ Donation Lead, British Islamic Medical Association (BIMA) & Muslim Chaplain, Sheffield Teaching Hospitals Umar Malik – Community Grants Manager, NHSBT					
Lead Executive	Mark Chambers, Director Donor Experience Denise Thiruchelvam, Chief Nursing Officer					
Non-Executive Director Sponsor	-					
Presenter at Meeting	Sabia Rehman – Organ Donation Lead, British Islamic Medical Association (BIMA) & Muslim Chaplain, Sheffield Teaching Hospitals Umar Malik – Community Grants Manager, NHSBT					
Presented for (tick all that applies)	☐ Approv		⊠Inforn □Upda			
Executive Summary	(max 300 w	ord count)				
This board story introd lead at the British Islan Sabia shares her pers work with BIMA to rais	mic Medical onal journey	Association (BIMA as a cornea trans	A) who are a fu splant recipient	unded partner t and how it ha	·. as inspired her a	-
Previously Consider	ed by					
N/A						
Recommendation	The Board is asked to note the contents of this paper.					
Risk(s) identified (Lin	nk to Board	Assurance Fram	ework Risks)			
No risks associated w P-04 – Donor numbers P-01 – Donor and pati	s and Divers ient safety	ity, P-06 – Clinica	l outcomes an	d Health Ineq	ualities	
Strategic Objective(s	s) this paper	relates to: [Click	on all that app	oly]		
⊠Collaborate with partners ☐ Modernise our operations						
•		☐Invest in people ☐Grow and dive	e and culture rsify our donor		⊠Drive innovatio	on



Community Grants Programme and the British Islamic Medical Association

The Community Grants Programme¹ (CGP) is part of our commitment to building support for blood, organ and living kidney donation amongst Black, Asian, mixed heritage and minority ethnic communities. In line with our key strategic priority to grow and diversify our donor base², the programme aims to address the shortage of Black blood donors, whose blood is used to treat conditions like sickle cell, and the shortage of ethnically matched organs for those waiting for a transplant in all Black, Asian, mixed heritage and minority ethnic communities.

Since 2019, the programme - originally launched as the 'Community Investment Scheme' with support from the National BAME Transplant Alliance (NBTA) - has funded community and faith-based organisations to drive awareness, understanding, and behaviour change. Trusted local organisations are uniquely positioned to achieve these goals and overcome the unique motivations and barriers to donation due to their deep-rooted community connections and specialist knowledge³.

In 2023, the Community Investment Scheme merged with the Living Transplant Initiative, which focused on grants for living kidney donation, to form the Community Grants Programme. In its first year, the programme delivered over 417 community-led events, produced multiple engaging resources and pieces of content⁴, and reached over 12 million people through a range of activations at the hearts of communities. We evaluate Community Grants Programme activity through measuring reach, engagement and registrations whilst recognising the programme's focus on long-term behaviour change. The current cohort funds 51 organisations⁵ in a two-year programme aiming to deepen our commitment and maximise impact through partnerships, investing £600,000 per year to support blood, deceased organ, and living kidney donations across diverse ethnic and faith communities.

Through the Community Grants Programme, we look to empower grassroots organisations to engage, educate and recruit more donors. Working with trusted and authentic voices in the community to deliver these messages and building trust in these communities is vital to making a real change for those whose lives will be improved or saved by donation.

The British Islamic Medical Association (BIMA⁶) is one such partner that NHSBT work with to advance organ donation awareness in Muslim communities. BIMA is a UK-wide umbrella body representing over 8,000 healthcare professionals and students nationwide. Through our collaboration, BIMA has empowered Muslim communities with impactful health education initiatives, equipping individuals with the knowledge and tools to make informed decisions. By working with community organisations, expert religious leaders, and healthcare providers nationally, BIMA has delivered a range of events, literature, scholarly engagement, and an organ donation film⁷ produced as part of a previous funding round.

¹ Community Grants Programme - NHS Blood and Transplant

² Our strategy - NHS Blood and Transplant

³ Factors influencing COVID-19 vaccine uptake among minority ethnic groups, 17 December 2020 - GOV.UK 'To overcome these barriers, multilingual, non-stigmatising communications should be produced and shared, including vaccine offers and endorsements from trusted sources to increase awareness and understanding and to address different religious and cultural concerns.'

⁴ <u>Cianna's Smile docudrama: Life in Your Blood - YouTube</u> – *An example of an engaging docudrama produced by a partner.*

⁵ About the programme - NHS Blood and Transplant - Full list of 2024-26 funded projects

⁶ British Islamic Medical Association (BIMA)

⁷ organ donation film – produced by BIMA as part of the Programme



A key focus of BIMA's upcoming work is the revival of the religious edict or *fatwa* produced by Mufti Mohammed Zubair Butt with NHSBT in 2019⁸, coordinated and spearheaded by the late Amjid Ali. Islamic scholars and imams play a critical role in providing guidance to members of the Muslim community on organ donation and this fatwa provided clear guidance to help Muslims to make informed decisions around organ donation. Due to the sudden passing of Amjid Ali, the important community socialisation stage of the fatwa never materialised. BIMA will look to continue Mr Ali's essential work and engage senior scholars and expert imams nationally, facilitating roundtables to enable discussion and endorsement. This scholarly engagement is essential in shaping attitudes and fostering acceptance within communities. Without the input of senior faith leaders, community-level initiatives alone will not drive the necessary change. To sustain progress in organ donation awareness and acceptance, it is essential to invest in these leaders and build long-term strategic relationships with a national, co-ordinated approach to compliment the invaluable localised efforts of BIMA. We are committed to building on this critical work in partnership with BIMA, where leaders with lived experience like Sabia, play a key role in driving progress.

Sabia Rehman - Corneal transplantation9

I was just 16 years old when I walked into an optician's office for what I believed would be a routine eye test. I had been experiencing some blurriness in my right eye for a while, but I never thought it was anything serious. It was only when the optician examined my eyes that I realised just how weak my vision was. He found a scratch on the surface of my eye and noticed a significant change in its shape. Concerned, he referred me to the hospital.

A few months later, I met with a specialist who diagnosed me with keratoconus¹⁰. At the time, the term meant nothing to me. I naively assumed I would just need a stronger prescription for glasses. But as the doctor explained, I learned that my condition was progressive and that glasses would not be enough. I needed rigid gas permeable contact lenses to improve my vision and slow down the deterioration. The doctor asked if anyone in my family had the condition since it is often hereditary. At the time, I was the only one. Later, however, more members of my family were diagnosed.

When my first lens was fitted, I was stunned. I could see clearly for the first time in what felt like forever. I hadn't realised how much of the world I had been missing until that moment. Over the years, adjustments had to be made, and eventually, I needed a lens for my left eye as well. But as time passed, my right eye started rejecting the lens. It became unbearable, causing me excruciating pain, constant scratches, and relentless discomfort.

This was during my university years, a time when I was immersed in theological studies. But my vision was failing me. I struggled to read my books, the pain making it nearly impossible to focus. Eventually, my specialist recommended surgery. I was devastated. The thought of pausing my education for an entire year weighed heavily on me, but I had no choice. I turned to my family, and together, we realised that I would need a corneal transplant.

The thought of receiving an organ donation unsettled me. I wasn't sure where I stood Islamically. I sought guidance from two scholars, both of whom assured me that organ donation was permissible. I felt a deep sense of relief but also an overwhelming guilt. Someone had passed away, and their gift was now giving me a second chance at sight. I prayed endlessly for my donor, for their soul, and for their family who had made the difficult but generous decision to donate.

⁸ <u>Islam - NHS Organ Donation</u> – religious edict/fatwa

⁹ [1] section-10-cornea-activity.pdf – NHSBT Cornea activity. Last year there was an increase of 9% in the total number of corneas retrieved to NHSBT Eye Banks (5,152) and the number of corneal transplants increased by 11% to 4,165.

¹⁰ Keratoconus - Moorfields Eye Hospital



The surgery itself was an experience I will never forget. I woke up in agonising pain, feeling as if I had been hit over the head with a sledgehammer. As I lay in the hospital bed, I reflected on the enormity of what had just happened. I carried a piece of someone else with me, a stranger whose kindness had changed my life forever. I wondered who they were, what kind of life they had lived, and if their family knew just how grateful I was.

Life moved forward, and I adapted. One year later, I rejoined university and proudly graduated in 2003. My left eye, aided by a lens, carried most of my vision, while my right eye remained difficult to manage. Despite numerous attempts, no lens ever seemed to fit well enough to provide stable vision. Over time, my right eye became increasingly painful, and eventually, ten years after my first transplant, I had to undergo another. This time, I was prepared. The procedure was still daunting, but I had learned to lean into gratitude rather than fear.

Throughout all these years, one thing stood out to me, no medical professional had ever spoken to me about the profound gift I had received. No one had encouraged me to reflect on the incredible generosity of my donor's family. This thought stayed with me, buried deep in my heart, until I could no longer ignore it.

I realised that I couldn't just be grateful in silence, I needed to act. My experience opened my eyes to the urgent need for awareness, particularly in the Muslim community, where organ donation is often misunderstood. Too many people are hesitant, uncertain about its permissibility, and unaware of the life changing impact it can have. I knew I had to do something.

Since then, I have dedicated myself to raising awareness about organ donation, particularly within the BAME and Muslim communities¹¹. I have engaged with scholars, encouraging conversations about its importance and helping to bridge the gap between faith and medical necessity.

Because of my donor, I have been able to see my children grow, to witness the beauty of the world, and to live a life full of meaning. Their selfless gift has allowed me to flourish in ways I never imagined from my career to my social and voluntary work. I owe them everything. And in their honour, I will continue advocating for organ donation, ensuring that others in my community understand its significance and the incredible blessings it can bring.

To my donor, wherever they may be, and to their family who made the courageous decision to give the gift of sight, I am forever grateful. The kindness they had shown not only changed my life but continues to touch the lives of those I share this message with.

^{11 [1]} <u>Version 9.4 SAS System Output</u> – NHSBT Annual Report on Ethnicity Differences in Organ Donation and Transplantation, 2023/24.

⁻ A five year high on the number of patients of Black, Asian and minority ethnic backgrounds receiving an organ transplant.

⁻ Ethnic minority groups make up 33% of the transplant waiting list.