

**Empowering BAME groups  
to take the lead on  
promoting  
organ donation  
Andi Ttofa (NHSBT)**

# What I'll cover

- Current situation in terms of donation rates and attitudes
- Why the messenger is important
- Current community-led activities
- Looking ahead

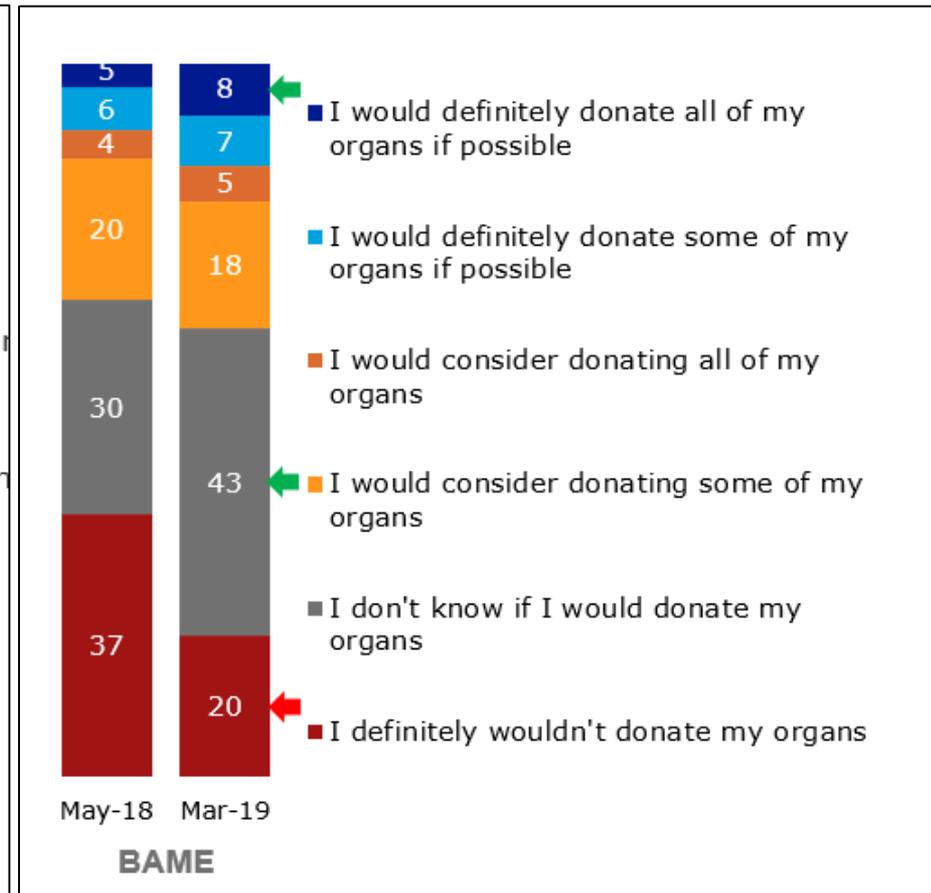
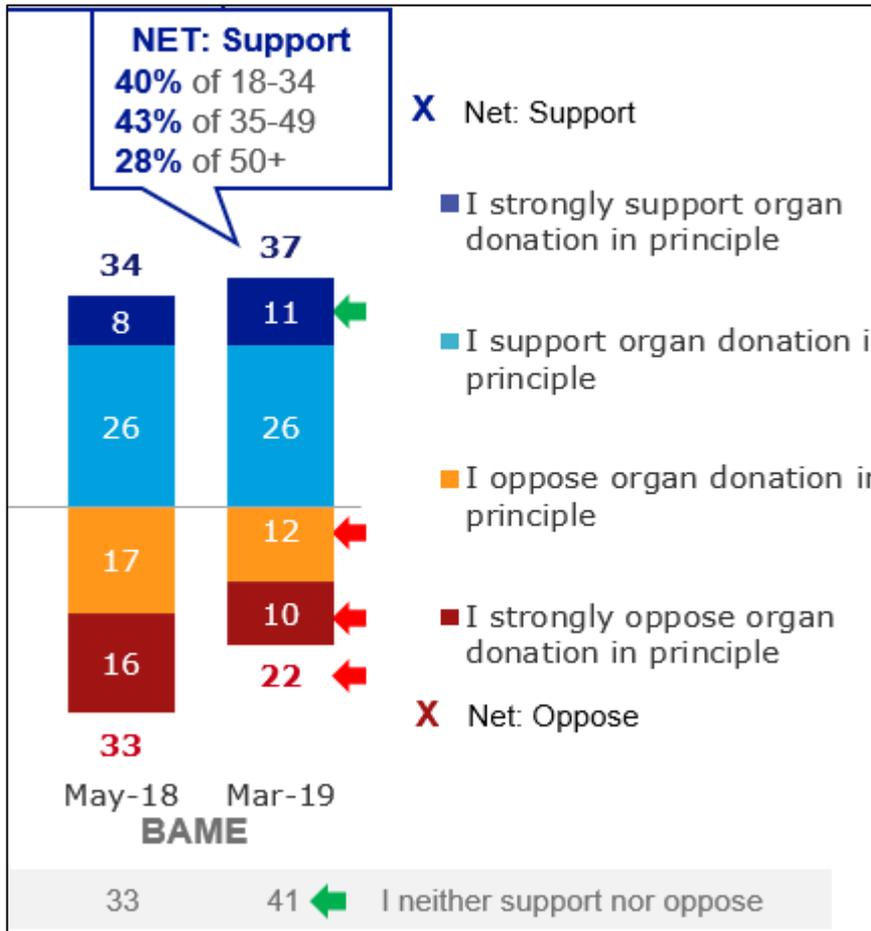
# Where are we now?

2014/15	2018/19
6.3% of new ODR registrations were ethnicity given were BAME	7.1% of new ODR registrations were ethnicity given were BAME
BAME consent rate = 36%	BAME consent rate = 41.7%
BAME waiting list = 1957 (28.6% of list)	BAME waiting list = 1883 (31.4% of list)
80 deceased donors (6.2% of deceased donors)	121 deceased donors (7.6% of deceased donors)
159 BAME living donors (14.6% of living donors)	149 living donors (14.3% of living donors)
892 BAME organ transplants (20.3% of all transplants)	1,148 BAME organ transplants (23.2% of all transplants)



# Current attitudes

- Two waves of face to face surveys – black and Asian people living in England (c 1000 participants)

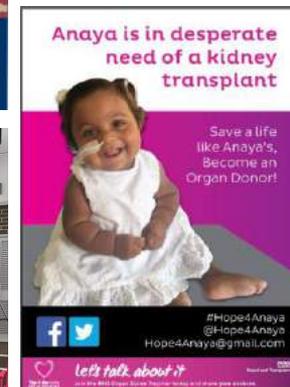


# Driving behaviour change

- We want more people from black, Asian, mixed race and minority ethnic communities to donate their organs
- Influences on behaviour:
  - Personal factors
  - Social influence (peer to peer, testimony, authoritative voices)
  - Environmental factors
- Importance of the messenger to overcoming barriers

# Current community approach

- Grants to organisations (Living Transplant Initiative and Community Investment scheme)
- Work with the Muslim community coordinated by Amjid Ali on behalf of NHS Blood and Transplant
- Development of the ambassador programme
- Motivated individuals eg Anaya's family
- Working with faith bodies to ensure information we have available is accurate and reflects stance



# Living Transplant Initiative

<b>Year 1 (2016/17)</b>	<b>£90k</b>	<b>Mostly faith based community events and developing educational resources</b>
Year 2 (2018/19)	£75k + 10k NBTA admin/transition funds	Mostly faith based community events and developing educational resources
Year 3 (commissioned by NHSBT) – 2019/20	£100k	<p>5 projects funded each focusing on interventions to encourage engagement with interested donors and convert them to actual donors or people who enter an assessment pathway.</p> <p>Projects are all collaborative between community/patient groups and clinical teams and build on learning from last LTI</p>

# Funding of deceased organ donation community initiatives

- Introduction of BAME Community Investment Scheme
- 25 short term organ donation awareness-raising projects funded Oct 2018-June 2019
- C£140,000
- We granted funding to:
  - 2 national projects
  - 9 projects in the North
  - 6 projects in the London area
  - 7 projects in the Midlands
  - 1 project in the South West region
  - 2 Christian projects
  - 4 Hindu projects
  - 1 Jain project
  - 8 Multi-faith projects
  - 7 Muslim projects
  - 3 Sikh projects
  - 1 Swahili community

# Second funding call

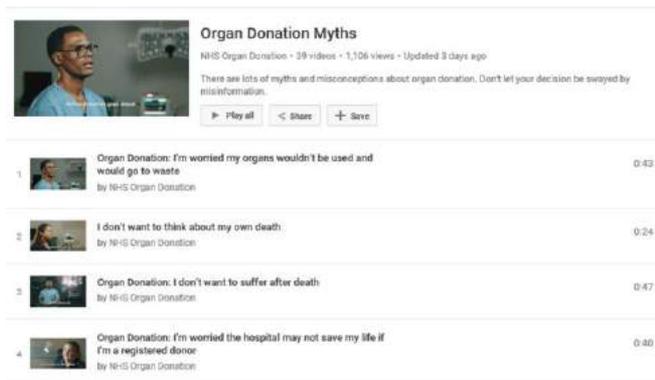
- Need to both communicate law change and break down barriers towards donation
- 60 applications
- 25/26 successfully met criteria for funding
- Total value c£200,000
- Mixture of ethnic and faith-led programmes, including content on a faith app and theatre led approach
- First project funded by NHSBT focusing on Chinese community

# NHS Blood and Transplant's role



Blood and Transplant

- Providing easy access to messages, stats, evaluation codes and materials to support events etc
- Storytelling development
- Materials in a range of languages
- Support and advice
- National media buying to target gen pop and BAME audiences
- Ensuring BAME elements in national PR stories and activities
- Ongoing engagement with faith and BAME organisations



# Looking ahead to the next 5 years

- We want to see ongoing improvement in BAME consent rates
- Ongoing development of grant models across blood and organs – using insight to understand where the gaps are
- Effective evaluation metrics for grant holders to capture and report on
- Research to understand what activities are driving change in BAME communities and in which demographics / communities we are seeing change
- Gain understanding of mixed race communities
- Ongoing commitment and funding of activity – we can't ignore the fact that opt outs much higher among BAME than white people

# What would success look like

- If the strategy is working, we would expect to see:
  - Greater awareness of the need to donate
  - Greater visibility of BAME donors and their stories
  - Changing attitudes and beliefs about donation (e.g. that it is common for BAME people to donate)
  - More positive word of mouth
  - More registrations
  - More people donating and higher consent rates
  - Narrowing of the gaps in waiting times

**Change is going to take time,  
focus, investment and  
collaboration**