

Community Investment Scheme

Workshop 1: An introduction to the scheme

Date: 6 November 2020

Housekeeping & introductions

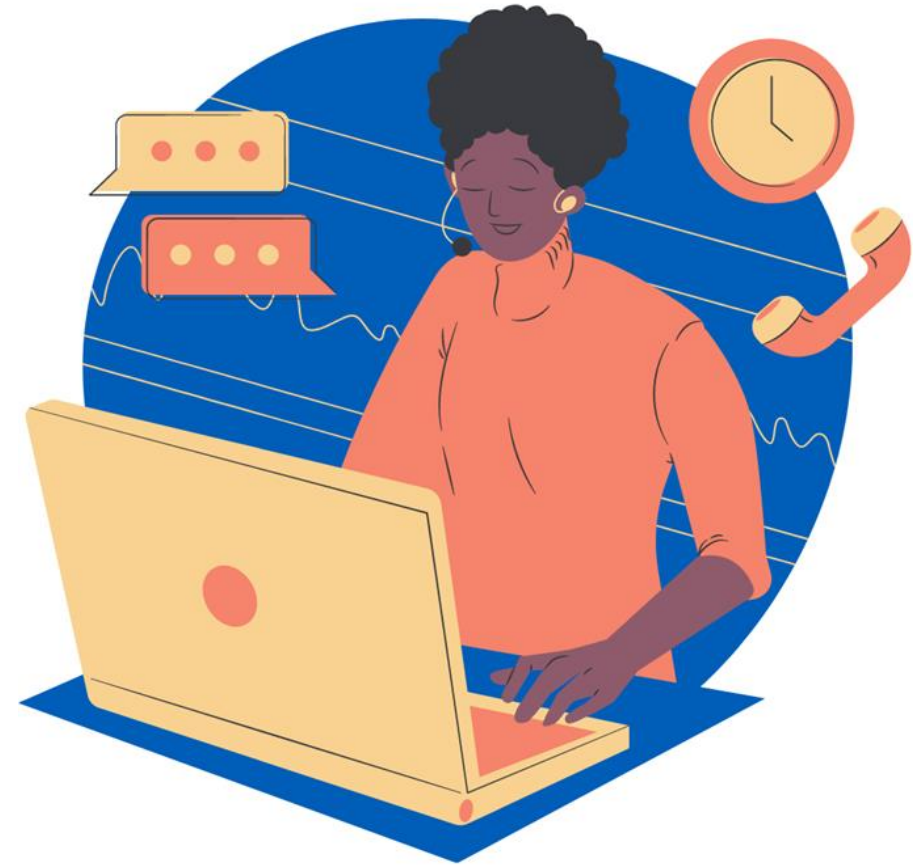
- Please keep yourselves on **mute**. This helps us avoid background noise.
- Please submit any questions through the **chat feature**. Any we don't cover will be answered in the wrap email.
- This slide deck, along with any resources, will be emailed out after the event.



| Agenda | |
|---|---------|
| Aims for this session | 5 mins |
| Introduction: The community investment scheme | 5 mins |
| Context – organ and blood donation in Black, Asian, mixed heritage and minority communities | 30 mins |
| Real life stories & expert speakers | 5 mins |
| Hear from current projects – Bradford College | 5 mins |
| Hear from current projects – Caribbean & African Health Network | 5 mins |
| Community engagement leads | 10 mins |
| Q&A | 25 mins |

Aims for this session

- To know more about why the scheme exists and what it aims to do
- To understand the challenges and current context around blood and organ donation
- To learn about the importance of using real life stories and expert speakers
- To learn from previous funding rounds
- To learn from current projects



Introduction: The community investment scheme

- What does the scheme aim to do?
- How is it different this year?
 - Inclusion of blood donation
 - Higher bands available
 - Community Engagement Leads
 - COVID contingency planning
 - Key KPIs
- Who should apply?
- What are the timescales?
- What kind of projects are NHS Blood and Transplant looking for?



Context



- COVID-19 lockdowns
- People from Black, Asian and minority ethnic backgrounds are being disproportionately affected by COVID-19 and are more likely to be key workers
- Misinformation around organ donation law change leading to opt outs from diverse communities.
- Black communities less likely to view government policies in a positive light or trust government messages
- Brexit effect
- Black Lives Matter/USA election
- People from Black communities are less likely to agree that:
 - the government is putting in the right measures
 - less likely to think they are getting the information they need
 - less likely to think the can be trusted.



Clinical need in diverse communities – organ donation

- Clinical need is higher for people from Black, Asian, mixed heritage and minority ethnic backgrounds.
- This is because people from these backgrounds are more likely to live with conditions that make them more likely to need a transplant.
- Best match comes from someone from the same ethnic background, but people from these communities are less likely to donate.



Organ donation in Black, Asian and ethnic minority communities

One donor can
save or
transform up
to **nine lives** by
donating organs

So much has been achieved...



The number of Black, Asian and minority ethnic deceased organ donors has increased by **67%** over the last 5 years



There has been an increase in **black deceased donors**, highlighting the hard work and dedication from the black community

But there's still work to be done

Black, Asian and minority ethnic patients are **over-represented** on the transplant waiting list. 3 in 10 people waiting are from a Black, Asian or minority ethnic background.

Black and Asian patients **wait longer** on average due to a shortage of organ donors, with Black patients waiting around 900 days and Asian patients waiting 736 days in comparison with 573 days for white patients

BAME families are **less likely** than white families to consent to organ donation when a relative dies (42.3% compared to 71.0%) as of 2019/20

Willingness to donate organs among Black and Asian adults in England

Willingness to donate own organs (%)

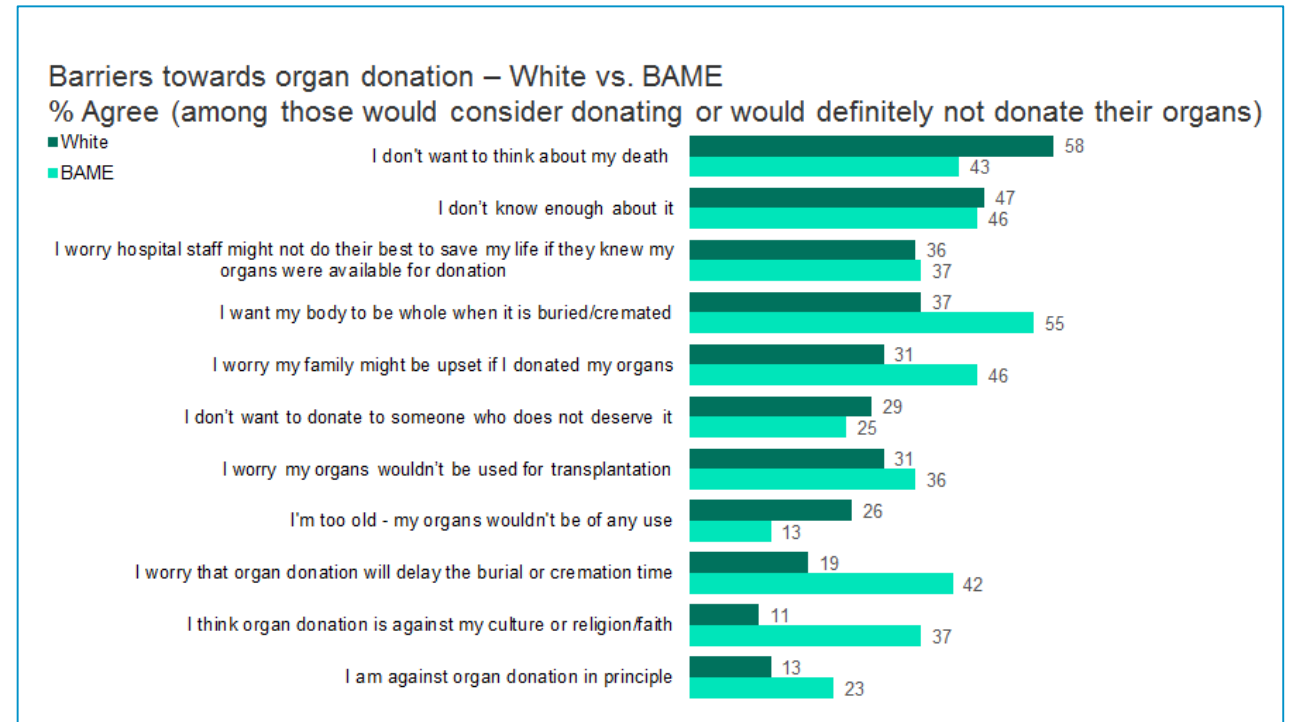
| Metric/Subgroup | W1 Aug 2015 | W5 Nov 2017 | W6 Oct 2018 | W7 Jun 2019 | W8 Nov 2019 | W9 Jun 2020 |
|--|----------------|----------------|----------------|----------------|----------------|----------------|
| DEFINITELY WOULD or WOULD CONSIDER donating SOME OR ALL organs (NET) | | | | | | |
| White | 82% | 82% | 84% | 82% | 83% | 82% |
| BAME | 64% | 69% | 68% | 66% | 62% | 61% |

Please note that due to sample size, fluctuation of up to 9 percentage points cannot be considered statistically significant

Barriers to organ donation amongst Black, Asian and ethnic minority groups in England

Key concerns

- More concerned than white population about the body being whole when buried or cremated (55% compared to 37%)
- Worries around upsetting family more prevalent than in white population (46% compared to 31%)
- Concerns around delaying burial/cremation (42%)
- Belief that organ donation is against religion/faith (37%)
- More likely to be against organ donation in principle (23%)



Motivations for organ donation amongst Black and Asian and ethnic minority groups in England

Motivations for donating organs after death – White vs. BAME

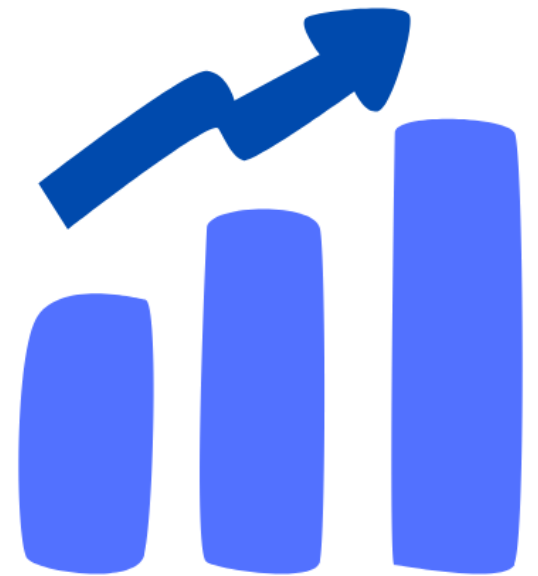
% Agree (among those would consider or would definitely donate their organs)



Key motivators

- Share many of the key motivations of the white population
- More motivated by "donating would help my community" (77% compared to 66% of white population)
- Personal experience among family/friends is greater motivation than for the white population (37% compared to 20% of white population)
- Less likely to be motivated by idea that organs will go to waste

Any questions around organ donation data?



Blood donation: our purpose

To **save and improve**
even more lives through
blood donation

To ensure there are
sufficient numbers of the
right type of donors to **meet**
patient need.



Background: recruiting Black blood donors

- The NHS provides a ground-breaking service. Since 2017, the NHS has changed the way it treats sickle cell patients. It now provides regular transfusions to patients with sickle cell to help avoid sickle cell patients going into crisis. We are not aware of any other health service that provides this.
- Regular blood transfusions mean that people with sickle cell can enjoy a more normal life. Subtypes are important when someone has regular transfusions as they need blood that ethnically matches their own as closely as possible.
- Many people with sickle cell have a rare blood type call 'Ro'. People of Black heritage are ten-times more likely to have the Ro subtype.
- We need more Black donors because of the rise in demand for Ro to help treat sickle cell patients.



The Ro subtype

- The Ro subtype is a variation of the Rh positive blood type. You might have it if you have O positive, A positive, B positive or AB positive blood.
- The Ro subtype is particularly important for two reasons:
 - demand is increasing by 10-15% each year
 - only 2% of regular donors have the Ro subtype
- So there's a gap between the number of donations we collect, and the amount of Ro blood hospitals need.



| Saving lives | | | |
|---|--|--|---|
| Self | Community | Pro-social | Family |
| <ul style="list-style-type: none">• Feel positive• Experimentation• Self-achievement• Medical curiosity• Pay in for future• Time out | <ul style="list-style-type: none">• My responsibility• Social approval/go along with others• Feeling part of something | <ul style="list-style-type: none">• Help others• Greater good• Charity alternative | <ul style="list-style-type: none">• Keeping up the family tradition• Recipient payback• Protection for family |

- In order to feel motivated to donate blood, people need to care about those who will receive it and feel good about saving lives
- Motivations for people from Black, Asian and minority ethnic backgrounds are similar, however additional motivations include helping someone from their own community and having ‘special blood’. There are differences in altruism (i.e. giving to strangers) and lower levels of trust, but they do have high levels of trust for NHS and NHSBT
- Male motivations - less sensitive to emotional appeals – motivated by feeling better about themselves (impure altruism), sense of duty, non-monetary incentives and impact on body and rewards
- Blood group specific comms focused on the need / purpose of their blood group rather than individuals saving lives (i.e. rare / can be given to anyone)

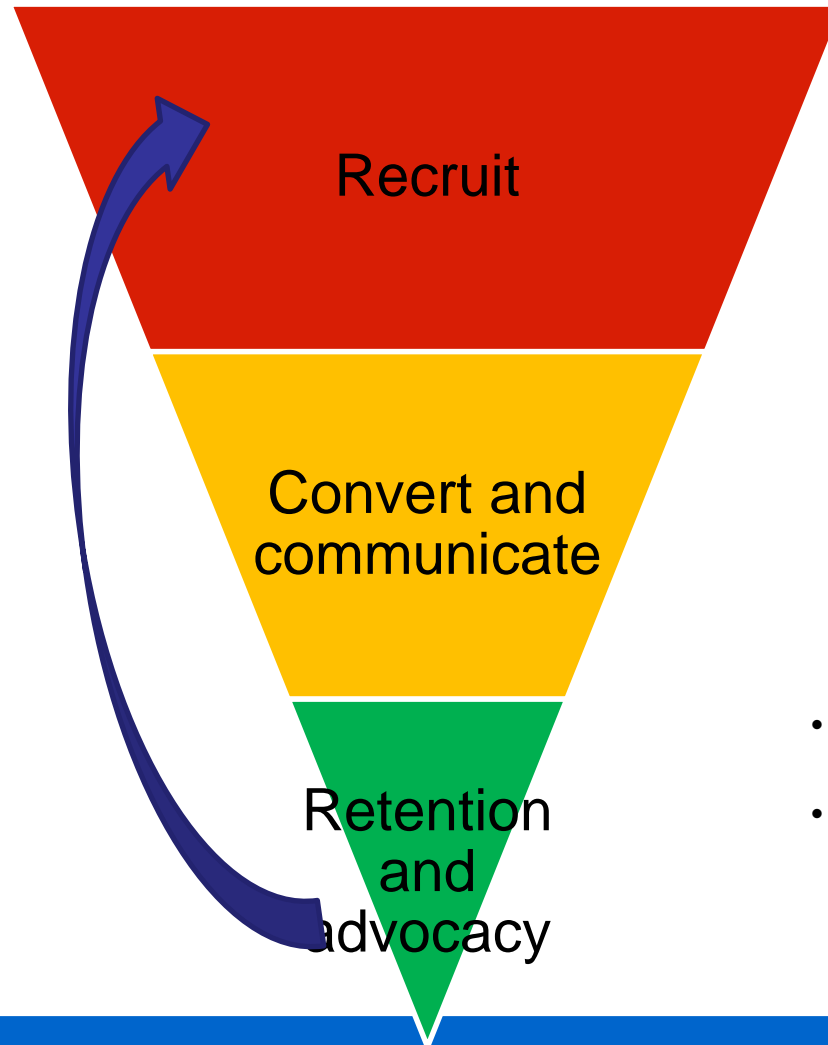
| | Personal | Process |
|-------------------|---|---|
| General | <ul style="list-style-type: none"> • Time • Health • Lifestyle (e.g. tattoos) • Travel • Belief there is enough blood (cultural / lack of appointments / lack of stock appeals) • Not that important | <ul style="list-style-type: none"> • Appointment availability or wait times • Locations • Cancelled appointments |
| Black communities | <ul style="list-style-type: none"> • Trust in the state • Awareness of need • Much more likely to believe they are not eligible to donate and that their blood is not needed • Less aware of NHSBT or the difference between NHSBT and the NHS • Unaware of the process to donate or where to donate | <ul style="list-style-type: none"> • Deferral process • Local appointments |
| Men | <ul style="list-style-type: none"> • Fear of feeling weak • Health concerns • Time | |

Myths and Misconceptions

| Myth and Misconception Generic Theme | Sub-Categories |
|--|---|
| MM-1: Poor Hygiene/Fear of Infection: The hygiene of donor centre and causal role of needles used to result in infection | <p>(1) Generic Fear of Infection: A generalized belief that donating blood is unsafe and can lead to infection with no stated mechanisms</p> <p>(2) Genetic Lack of Hygienic Environment: A generalized belief that the donor centre environment are unclean and unsterile. Which may lead to infection</p> <p>(3) Needles as the Cause: A clear belief that needles used are unclean and cause infection in donors</p> |
| MM-2: Unsafe Storage and Use of Blood: How blood is stored and tested and where blood goes | <p>(1) Process Contamination and Detection: this is the belief that after blood is taken the blood can be contaminated afterward or is not screened properly.</p> <p>(2) Product Destination: Who receives the blood, is it sold and what is it used for.</p> |
| MM-3: Eligibility to Donate: This focuses on a belief that Black community members are not actually eligible to donate or will be deferred for long periods of time due to travel | <p>(1) Just not Eligible: This is the belief that Black people are not eligible to donate blood at all.</p> <p>(2) Permanent or Very Long Deferral: The beliefs that the deferral for travel to Africa is either permanent or that the deferral person is longer than it is.</p> <p>(3) Generalization from Other Countries: This is the belief that is you are deferred in one country this will apply to the UK.</p> <p>(4) Sufficient blood to Donate: The belief that the person does not have enough blood to be able to donate blood.</p> |
| MM-4: BME Blood not Used, Wanted or Accepted. This reflects a misconception that blood from Black people is not wanted or accepted by others and if taken not used. | <p>(1) This reflects a misconception that blood from Black people is not wanted or accepted by others and if taken not used</p> |
| MM-5: Negative Health Effects: This is the belief that the act of blood donation leads to detrimental health effects. | <p>(1) Generic Negative Health Effects: In general the belief that donating blood can be bad for your health</p> <p>(2) Loss of Blood: The specific belief that it is the loss of blood per se. that is the cause of believed negative health effects.</p> |
| MM-6: Disclosure of blood donor's identity: The belief that donors detail will not be held safely | <p>(1) The belief that donors detail will not be held safely</p> |

Approach

- Build awareness of need from the black community and provide education – from corporate, trusted channels and voices
- Capitalise on seasonal peaks
- Targeted campaign addressing barriers
- Ensure there is sufficient appointments for black prospective donors but communicate they might need to wait
- Communicate it is safe to do so through NHSBT and trusted sources
- Encourage donors and stakeholders to normalise and share feel good factor - encouraging advocacy
- Review cancellation communications / provide additional reasoning to avoid fake news



Key messages

- 'The NHS needs more black donors. Be ready to save lives when your NHS needs you. Join the blood donor community. Register today.'
- 'Book an appointment for the future'
- 'The NHS needs black donors.'
- 'To make donating even safer for you and our staff we've introduced extra safety measures.'
- 'Thank you for keep donating blood stocks good. You have helped the NHS.'
- 'Dealing with COVID-19 has resulted in some challenges to our usual service. This has meant some last-minute changes for donors and we are sorry to have cancelled a number of appointments.'

Key groups



Organ donation

Applications are welcome from all ethnic minority communities, but work is particularly vital in these groups

- South Asian inc. Indian, Bangladeshi, Pakistani
- Black African and Caribbean
- Young people aged 16-24



Blood donation

- Black African and Caribbean

Your work within the wider NHSBT context

- Work with the media (mass media and faith/community media)
- TV advertising starting early November RE law change
- Out of home
- Q4 campaign – new campaign will focus on the role of the family (organs) / Ethnicity matters (blood)
- BuzzFeed / Channel 4 partnerships
- Key calendar moments: NBW, ODW, SCAM etc
- Hyper local activity
- Improving the donor journey



BuzzFeed



Real life stories & expert speakers



- Ambassador programme – organ donation
 - No geographical/travel limits with digital work
 - Be clear in your ask: use the ambassador request form
 - Contact via ambassadors.ODT@nhsbt.nhs.uk
- Advisors/judges, clinicians and SNODs
 - Advisors/judges score projects and support project leads in delivery
 - Clinicians and SNODs can reassure audiences from a professional medical perspective
 - Listed in a directory – will be uploaded to the site
 - Contact via community.funding@nhsbt.nhs.uk
- Volunteer speakers for blood
 - Contact via community.funding@nhsbt.nhs.uk

Key Learnings from Years 1&2

Key learnings

- SMART objectives and focus on evaluation
- Collaboration
- Flexibility – COVID contingency
- Use your advisor
- Young people are key changemakers
- Real life stories
- Use of healthcare professionals
- Engaging faith leaders as messengers
- Bespoke materials or content
- Relationships with community and regional media



Hear from current projects





Precious Life Savers

Raising Awareness of Organ Donation in Greater Manchester and Recruiting Caribbean & African Donors to the NHS Organ Donation Register



Lead | Educate | Support | Advocate | Enhance

Vision

To end health inequalities for Caribbean and African people in a generation

Mission

To lead strategic engagement on behalf of the Caribbean and African community so that Black people and organisations are empowered to improve and sustain holistic health and wellbeing!



Lead | Educate | Support | Advocate | Enhance

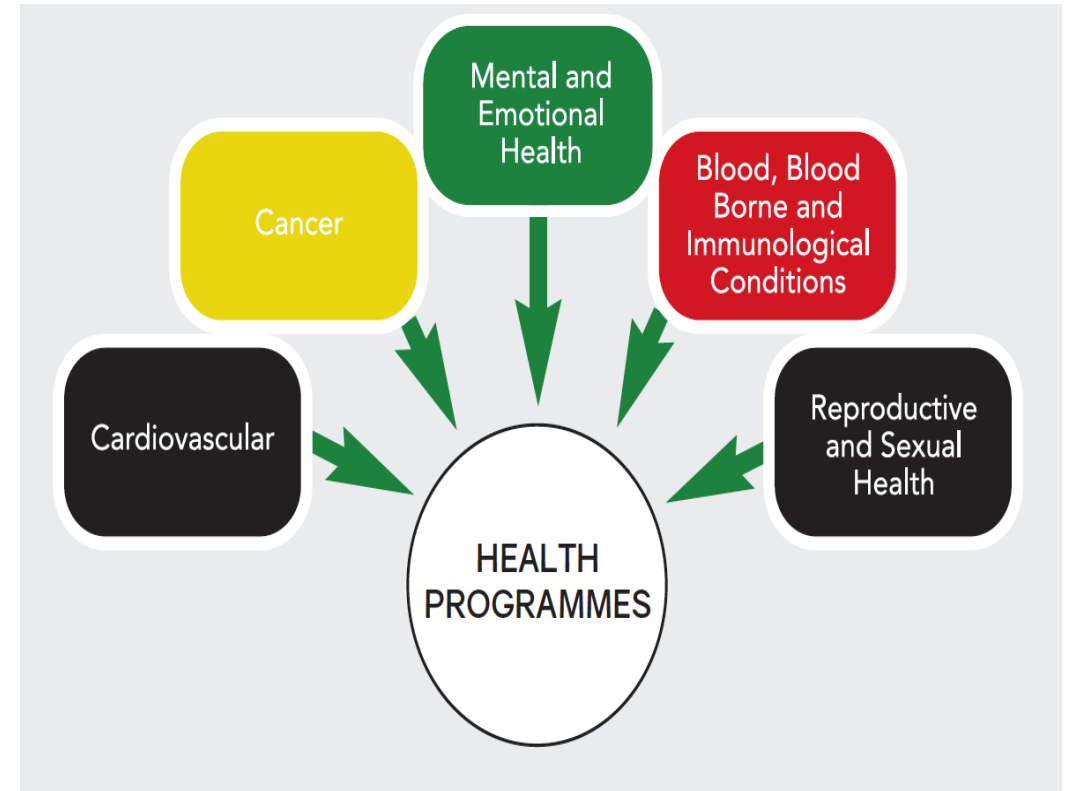
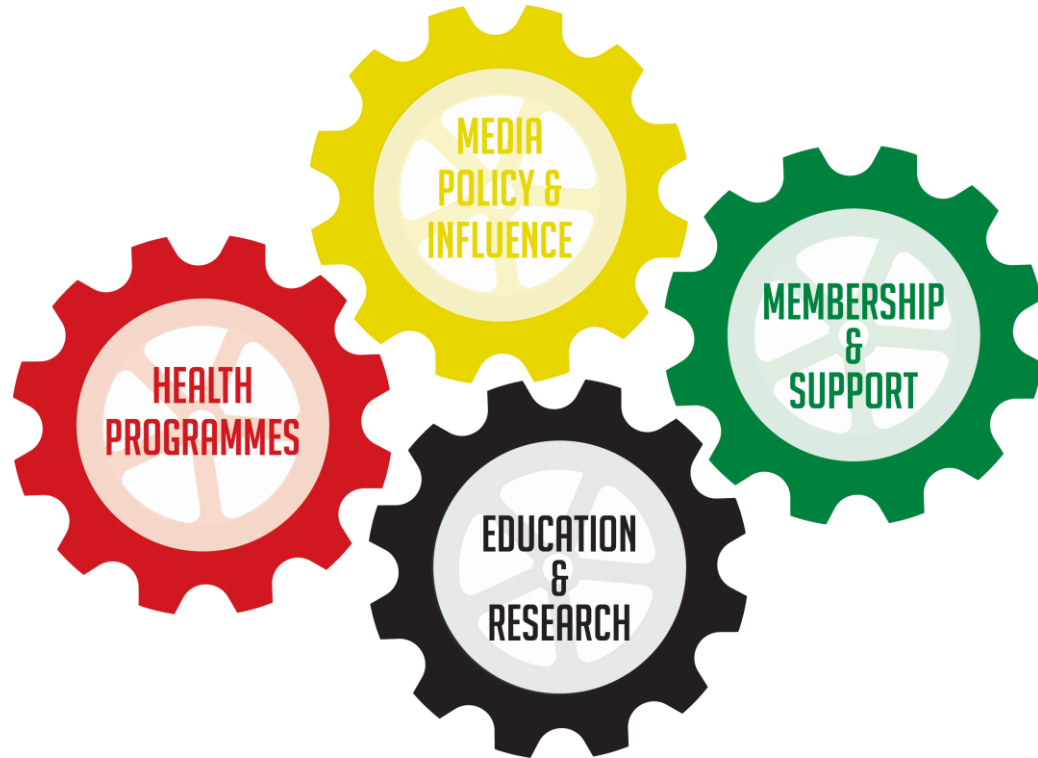
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Our Strategy



Precious Life Savers project

CAHN  **NHS**
Caribbean & African Health Network Greater Manchester Blood and Transplant

Precious Life Savers

Organ Donation Awareness & Recruitment Project

Around 600 black people are waiting for an organ transplant across the UK

More than 2300 people from the black community are alive today thanks to organ donors

Last year, sadly 31 patients from black backgrounds died waiting for a transplant

Sign up today to the NHS Organ Donation Register
www.organdonation.nhs.uk/preciouslifesavers

CAHN  **NHS**
Caribbean & African Health Network Greater Manchester Blood and Transplant

Sauveurs de Vie Irremplaçables

Projet de sensibilisation et de recrutement pour les dons d'organes

Environ 600 personnes noires attendent une greffe d'organe à travers le Royaume-Uni.

Plus de 2300 personnes de la communauté noire sont aujourd'hui en vie grâce aux donateurs d'organes

L'année dernière, 31 patients de milieux noirs sont malheureusement décédés en attente d'une greffe.

Inscrivez-vous dès aujourd'hui au registre des dons d'organes du NHS
www.organdonation.nhs.uk/preciouslifesavers

The law around Organ Donation changed in England in spring 2020

Let's talk about it



Local Church Leaders supporting Organ Donation as an act of love and giving!

Email: organdonation@cahn.org.uk Contact: 07575 579377
Spread the word #PreciousLifeSavers #PassItOn #ShareYourWishes
Visit www.cahn.org.uk/organ-donation for further information.

La loi sur le don d'organes en Angleterre a changé au printemps 2020.

Parlons-en



Les dirigeants des églises locales soutiennent le don d'organes comme un acte d'amour et de don.

Courriel: organdonation@cahn.org.uk téléphone: 07575 579377
Faites Passer le mot #Des sauveurs de vie précieux # Répandez le message # Partagez vos souhaits
Visitez www.cahn.org.uk/organ-donation pour plus d'information

Precious Life Savers

Promotion Organ Donation as an act of

- **Love – John 15:13**

‘Greater love has no man than this: that a man lay down his life for his friends’

- **Grace – Matthew 10:8**

‘... Freely you have received; freely give’

- **Giving – Acts 20:35**

‘... It is more blessed to give than to receive’

Cultural & Religious Barriers

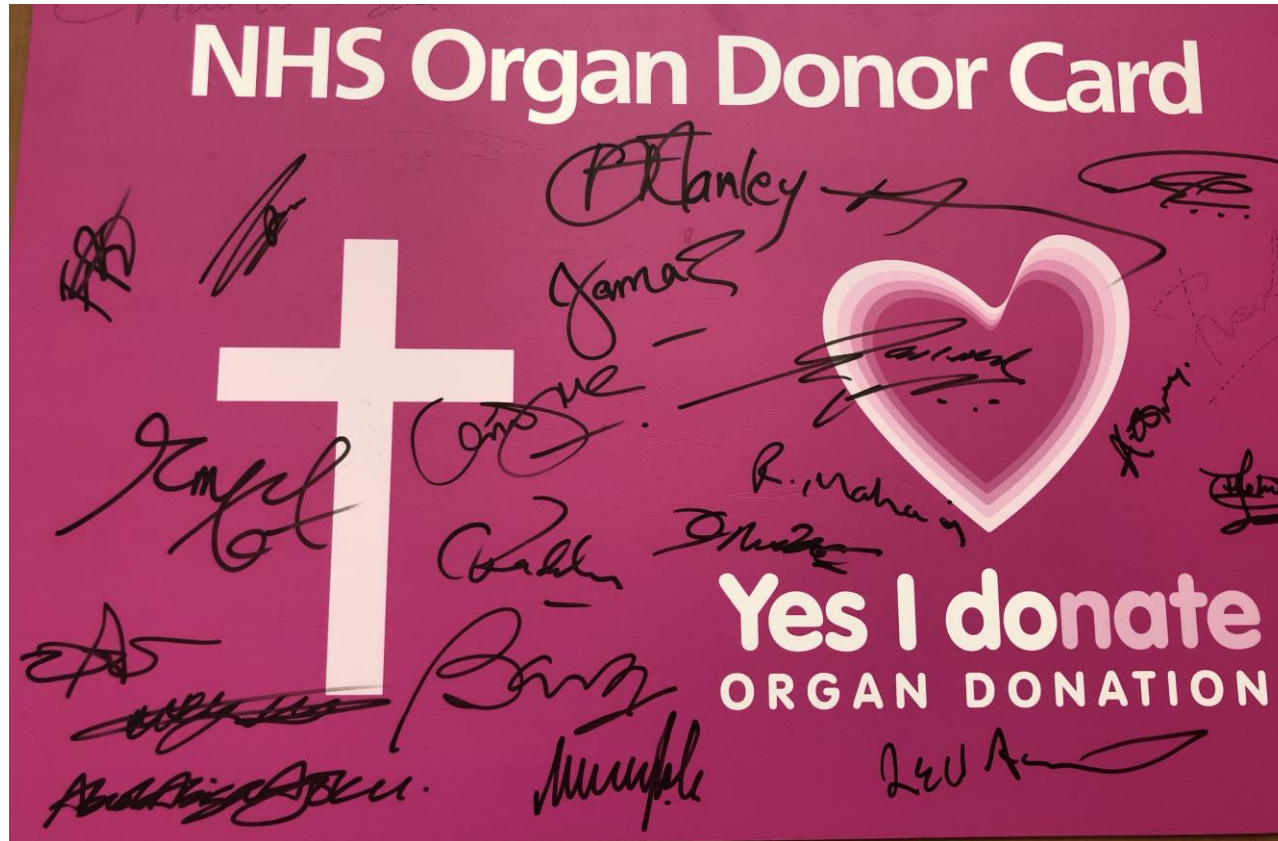
- Cultural & Religious Concerns due to backgrounds
- Resurrection – ‘I want to go to heaven with everything’
- Blurred lines – faith & culture
- Knowledge of post-transplantation appearance

Pastors & Church Leaders Workshop – Manchester and London



Pastors & Church Leaders Commitment

Greater Manchester



Sign up now –

**[www.organdonation.nhs.uk
/preciouslifesavers](http://www.organdonation.nhs.uk/preciouslifesavers)**



For further information:

www.cahn.org.uk/organdonation

Facebook – Cahn Greater manchester

Twitter: @cahn_gm

Email: organdonation@cahn.org.uk

Telephone: 07853 556591

Community Engagement Leads

What is the Community Engagement Leads pilot?

It is an adapted version of a place base approach to health inequality.

- We focus on one ethnicity within one geographical area to focus our work.

Through this pilot we hope to

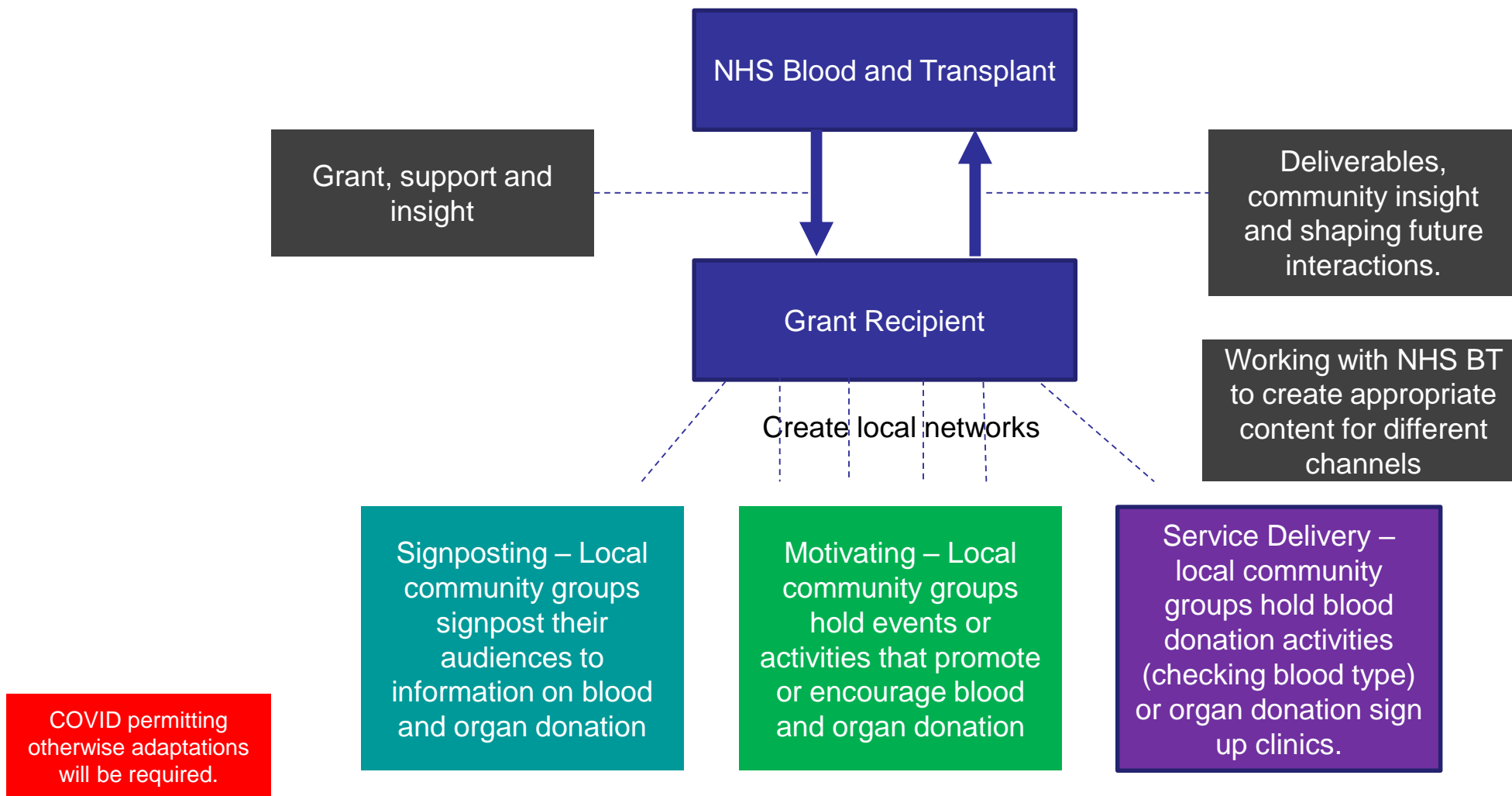
Focus activity

Gain insights
about culturally
appropriate
content

Understand more
about the barriers
and motivations
to donating

Develop an
understanding
about what
works.

Community Engagement Leads Framework



Grant Recipient
selected
(Grant administration
process begins)

Phase 1 – Creating Baseline

This is where the grantee will map the local area for partners. NHS BT will provide the local insight that it has. A document will be created that demonstrates the current picture in terms of relationships and activities.

Phase 2 - Agreeing the activity plan and the deliverables.

In this phase we will look to agree the deliverables with grantees. We will also explore the available content that we have, its level of appropriateness and methods of dissemination.

Phase 3 – Delivery of activity

In this phase the organisation will deliver the activity and provide regular updates to NHS BT.

Phase 4 -End point assessment

This final stage will map the change that has taken place within the area. It will also serve as an evaluation to document the journey and learning that has taken place in this process

Timeframe – Feb 2021 to October 2021

Q&A