

Having a taboo conversation

Thursday 13th May 2021

Community Investment Scheme Cohort Three

Housekeeping

- 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 up email.
- Please note, this workshop will be recorded.
- This slide deck, along with any resources, will be emailed out after the event and added to our [new CIS webpage](#).



Agenda

- **12.00 – 12.05** Welcome and Objectives – *Charlotte Silver, Senior Marketing and Campaigns Officer – Organ Donation Marketing*
- **12.05 – 12.25** Organ Donation – *Angie Ditchfield, Diversity Lead Nurse-ODT, Specialist Nurse Organ Donation*
- **12.25 – 12.35** Blood donation – *Colin Anderson, Community & Engagement Lead*
- **12.35 – 12.45** Guest speaker – *Abiola Okubanjo, Action On Blood.*
- **12.45- 13.00** Q&A and Next Steps - *Charlotte Silver, Senior Marketing and Campaigns Officer – Organ Donation Marketing*

Objectives

1. To understand the most common myths and misconceptions when it comes to blood and organ donation
2. To feel equipped at addressing myths and misconception around both blood and organ donation when speaking to people in your community
3. To hear how Action On Blood successfully addressed Myths and Misconceptions in their project work and what they learnt along the way.

Why talk about Organ donation?

- UK is one of the largest multi cultural societies
- We are all living longer
- Impacts on society
- Impacts on NHS
- Impacts on organ donation & transplantation



Why is it so important?

- On average, patients from black and Asian communities will wait six months longer for a kidney transplant than a white patient, due to the lack of suitable organs
- Organs from people from the same ethnic background are more likely to be a close match and give the best chance of a positive outcome.
- Although more than half a million people die each year across the UK, only around 1 in 100 die in circumstances where their organs can be donated, so every donor is precious.
- We need to help reduce these inequalities



Specialist Nurses Organ Donation Training

- Award winning professional development team
- 5-6 months intensive training
- Bespoke communication skills
- Cultural/Religious/Belief's training & resources
- A variety of resources are available



Faith/beliefs

- Faith/ Beliefs Declaration introduced in December 2018 on Organ Donor Register
- Supported by revised faith pages on the website and faith-specific organ donation cards

Faith/beliefs

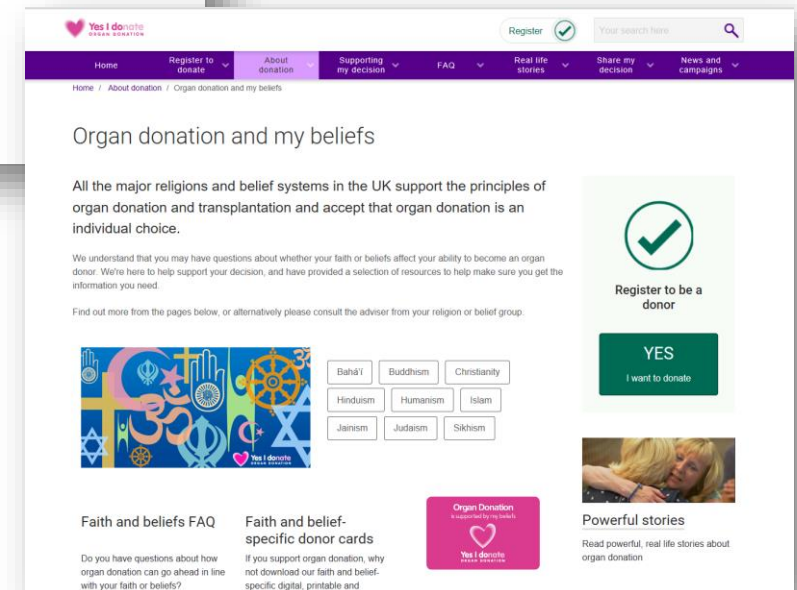
I would like NHS staff to speak to my family and anyone else appropriate about how organ donation can go ahead in line with my faith or beliefs.

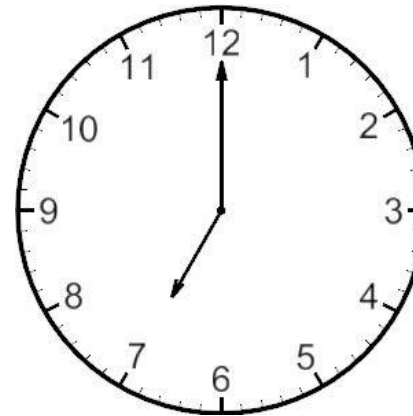
Yes - this is applicable to me

No - this is not applicable to me

Prefer not to say

Record whether you want our specialist nurses to discuss your faith or beliefs with your family when they approach them about organ donation.





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Leave them certain  Organ Donor

How to handle concerns / myths / misconceptions



- 1 – Pay attention to what is being said – really listen to what is being said. You may wish to ask open questions to explore the concern more
- 2 – Withhold judgment – try and remain neutral
- 3 – It can sometimes be frustrating to hear what you know isn't true – be patient and hear their thoughts, and seek to understand why they feel like this or where this information arose from
- 4 – Open body language, maintain eye contact to show interest
- 5 - Re state what they have said to ensure you have understood..... ' so am I right in thinking you believe organ donation will delay your funeral'
- 6 – Further questioning can help. Reassure at this point with the facts – 'well I see why that may be a concern for you. What it may help you to know is that the funeral will not be delayed – let me explain a little more about what actually happens.....'

‘I am too old to be a donor’

People can donate their organs into their 80s and the specialist nurse will assess the patient's suitability to be an organ donor at the point of referral. There will be a number of factors taken into consideration at that time such as current situation, travel history, medical history, social history and also the current function of the organs

Common Myths & Misconceptions

‘No one will want my organs I’ve got too much wrong with me’

It is important to let people know that they are assessed at the point of referral and this is only after the decision has been made that they are at the end of life. The organs are assessed for suitability depending on several factors as mentioned previously and the current function. There are so many people waiting for life saving transplants that more marginal organs need to be considered.

Common Myths & Misconceptions

‘Organ donation will disfigure my body’

Donating your organs does mean that there is the need for an operation. The operation is like any other operation and carried out by highly experienced transplant surgeons. It's a dignified delicate operation and the surgeons pay extra care, everyone involved recognises the importance of the operation and that someone is giving a life to another human. Afterwards the person is cared for in the same way and the operation site is dressed the same. We explain all of this to the family prior to the operation.

Common Myths & Misconceptions

‘It will delay the funeral’

We recognise that some families need the body to be released immediately and will work with the hospital and doctors to obtain the death certificate as quickly as we possibly can. There are instances when this isn't possible and it's out of our control, such as if the coroner is involved. We also support the families wishes as much as we can and will liaise with the burial organisation if needed to ensure the body is collected as soon as the operation is complete.

Common Myths & Misconceptions

‘The doctors won’t try their best to save me if they know I want to be a donor’

The doctors who care for patients are completely separate from NHSBT. They are employed by the hospital and the Specialist nurses work for NHSBT and are guests in their hospitals helping to support end of life care. The doctors will try absolutely everything to save a person’s life but sometimes they just cannot and only after they have tried everything and have no other choice and the patient is end of their life do the specialist nurses become involved.

Common Myths & Misconceptions

‘I won’t be treated with dignity or respect?’

The gift of organ donation is the most selfless act anyone can do, and everyone involved has the upmost respect. All patients are treated with complete dignity and respect, and this is engrained in us all as professionals.

Common Myths & Misconceptions

‘My religion does not allow organ donation’!!

We have worked with so many respected religious leaders over the years and many fully support organ donation. People have many questions around religion/faith and organ donation, and it is important to understand the facts and discuss these with your religious leaders. We have lots of guidance around this and we recognise that there are many different schools of thought and so we continue to work closely with religious leaders.

Common Myths & Misconceptions

Anyone can be an organ donor after they have died??

You have to die in specific circumstances to become an organ donor. You have to die in a critical care environment such as ITU or A&E and be on a life support machine at the end of your life.

1 % of the population die in circumstances that mean they can become organ donors.

Many people think that anyone can donate their organs at the time of their death and this is not true as you can see. This means that only a very small amount of people can go onto to save other peoples lives.

Common Myths & Misconceptions

If you want to donate doctors won't try to save you??

Specialist nurses only become involved AFTER the doctors have tried to save the life and are at the point when they have decided the person cannot survive and are at the end of life. The specialist nurses are then informed as part of end-of-life care decision making and only at this point do we check the ODR and see if the person is able to become an organ donor and only then will we offer this amazing end of life choice to the family.

The specialist nurses do not work for the hospitals and only work alongside the doctors and nurses to ensure everyone gets exceptional end of life care and everyone is offered the choice to donate their loved one's organs to prevent another person from dying.

Common Myths & Misconceptions

Only patients who are confirmed dead using neurological criteria can be donors??

There are two types of donation, donation after Death confirmed using neurological criteria and donation after circulatory death, when the heart has stopped beating.

Donation after death is confirmed using neurological criteria is the most common type of donation which most people have heard of and we used to call this brain stem death. This happens to Patients who have suffered an injury to their brain which has led to the irreversible loss of the capacity for consciousness and the irreversible loss of the capacity to breath. These functions are important part of the brain which makes us all human beings, a series of tests are carried out using neurological criteria which diagnosis and confirms death and the person can no longer function as a human being.

DCD donation is different by which the doctors have tried all treatment and can no longer make the person better and they make the difficult decision to stop the treatment as it is no longer benefiting the patient and won't cure them. After this decision has been made the specialist nurses ensure the patient can donate then offer this to the family. If the family agree to donation, then the specialist nurses work hard to ensure that the best possible match is found for the organs once they have been found then a specialist team of surgeon come to the hospital to perform the dignified operation. Once they are at the hospital the treatment is stopped and once the patient's heart has stopped then they are then moved to theatre for the operation. The family can stay with the patient right up until they have to go to the theatre.

Common Myths & Misconceptions

You need to be on the NHS Organ Donor Register to donate in England??

If a patient has registered onto the ODR then the specialist nurse will work with the family to ensure that they support the patients wishes to donate. The family are spoken to about the patient decision out of respect for them at the difficult time. They then work together to gain information about the patients history and ensure their last wish is fulfilled.

If a patient is not registered onto the ODR the specialist nurse will still speak to the family following end of life decisions to establish their thoughts about donation and they will be asked to make a decision at this time. The specialist nurses will support them through making this decision ensuring they have all the correct information and that they have time to consider their decision. All families are offered this choice.

Common Myths & Misconceptions

Families always honour a relative's decision to donate??

Each year over 90 families go against their loved one's end of life wishes.

We always discuss their decision and try to understand why they would override their loved one's decision. Sometimes it is due to misconceptions and the specialist nurses can make sure the families have accurate information. Families still do disregard their loved one's decision and go with their own decision not to donate and help others.

Common Myths & Misconceptions

If you donate you can't have an open casket funeral??

Organ donation is a precious gift of life, and the patient is treated with the upmost dignity and respect. The highly skilled surgeons who attend to perform the operation are part of a national team of experts and the whole team involved in organ donation recognise that this person is doing the most amazing thing possible by agreeing to give the gift of life to others. The operation is respectful dignified, and the patient is treated with care and compassion.

Care compassion dignity and respect is entrenched in our training and so we all work together in this way recognising this amazing occasion. There is an incision, but it is cared for the same as if the patient was alive and is dressed the same. The appearance of the patient does not change and if in an open casket the incision will be dressed and covered.

Thank you

Blood Myths and Misconceptions (1)

Not Covid-19 safe/Poor Hygiene/Fear of Infection: The hygiene of donor centre and causal use of needles resulting in infection

- 1. Generic Fear of Infection:** A generalized belief that donating blood is unsafe and can lead to infection with no stated mechanisms
- 2. Generic Lack of Hygienic Environment:** A generalized belief that the donor centre environment are unclean and unsterile. Which may lead to infection
- 3. Needles as the Cause:** A clear belief that needles used are unclean and cause infection in donors

Blood Myths and Misconceptions (2)

Unsafe Storage and Use of Blood: How blood is stored and tested and where blood goes

1. **Process Contamination and Detection:** this is the belief that after blood is taken it can be contaminated later or is not screened properly.
2. **Secret Testing:** Additional DNA testing and for things like drugs.
3. **Product Destination:** Who receives the blood, is it sold and what is it used for.

Blood Myths and Misconceptions (3)

Eligibility to Donate: Belief that Black community members are not eligible to donate or will be turned away/deferred for long periods of time due to travel

1. **Just not Eligible:** This is the belief that people from African or the Caribbean are not eligible to donate blood at all.
2. **Permanent or Very Long Deferral:** The beliefs that the deferral for travel to Africa is either permanent or that the deferral period is longer than it is. Confusion around being Sickle trait/carrier.
3. **Generalisation from Other Countries:** This is the belief that if you are deferred in one country this will apply to the UK. Also you only give when another member of family/relative require one.
4. **Sufficient blood to Donate:** The belief that the person does not have enough blood to be able to donate blood. Beliefs surrounding Iron/Hb levels – if tested once to be low then can not donate.

Blood Myths and Misconceptions (4)

BAME Blood not Used, Wanted or Accepted. Cannot get appointments

1. **NHS Pretence around Recipients:** This reflects a misconception that blood from Black people is not wanted or accepted by others and if taken not used.
2. **Discarded Blood:** Previously parts of blood from Black people were discarded as “Tropical area blood” due to lack of testing for malaria.
3. **No Appointment Slots:** When booking online no slots available for months therefore they must have enough blood.

Blood Myths and Misconceptions (5)

Negative Health Effects: This is the belief that the act of blood donation leads to detrimental health effects.

1. **Generic Negative Health Effects:** In general, the belief that donating blood can be bad for your health.
2. **Loss of Blood:** The specific belief that it is the loss of blood per se thus reducing your life vitality. That is the cause of believed negative health effects.

Blood Myths and Misconceptions (6)

Disclosure of blood donor's identity: The belief that donor's detail will not be held safely

1. **Trust in The System:** The belief that donor's detail will not be held safely.
2. **Sharing of personal Information:** The belief that this is part of a conspiracy to gather personal and pass it on to other authorities and 3rd parties who are monitoring everyone.

Guest speaker - Abiola Okubanjo, Action On Blood

Thursday 13th May 2021

Community Investment Scheme Cohort Three

ABIOLA OKUBANJO - 13TH MAY 2021

TABOO CONVERSATIONS

HAIR2DEBATE
MY FAREWELL HANDBOOK
CARE WORKER CONVERSATIONS



KEY POINTS

Introduction to projects

Tackling taboo subjects

The conversation itself

Challenges & flexibility

Most proud of..





TACKLING TABOO SUBJECTS

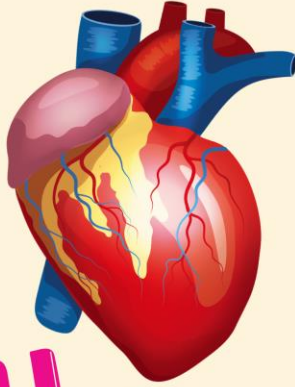




THE CONVERSATION ITSELF



**Ask us how
the new organ
donation law
affects **YOU****



**What has changed?
Why has the law changed?
Is anyone excluded?
Who needs the organs?
Does this affect black people?
Do black people donate?
Do I still have a choice?
How do I make my wishes known?**



CHALLENGES & FLEXIBILITY



**ACTION
ON
BLOOD**

GUIDANCE ON HOMEMADE CLOTH FACE MASKS



Sources: Public Health England: COVID-19 - guidance on home care provision;
Centers for Disease Control & Prevention (CDC) - Coronavirus Disease 2019

ADVICE ON HOMEMADE CLOTH FACE MASKS FOR CARE WORKERS

Provision of care and support in people's homes is a high priority service. To tackle the coronavirus pandemic, Public Health England says that the government is working hard to ensure that care workers have access to personal protective equipment (PPE) where necessary.



"There will be free issue of PPE to support adult social care providers (residential care and domiciliary care) to comply with the updated advice on use of PPE to support management of symptomatic patients presenting in these settings.

Where neither the care worker nor the individual receiving care and support is symptomatic, then no PPE is required above and beyond normal good hygiene practices."



The Centers for Disease Control & Prevention (CDC) "advises the use of simple cloth face coverings to slow the spread of the virus and help people who may have the virus and do not know it from transmitting it to others". So care workers - like the general public - can wear cloth face masks as an additional, voluntary public health measure.



Fashioned from household items or made at home from common materials, homemade, reusable cloth masks are an alternative to government-issued PPE that should be reserved for frontline workers most at risk.

CAUTION!

Please note that cloth face coverings are NOT as effective as surgical masks or N-95 respirators. They should NOT be used by people treating COVID-19 patients in hospitals or supporting them in the community.

They should not be placed on young children under age 2, anyone who has trouble breathing, or is unconscious, incapacitated or otherwise unable to remove the mask without assistance.

Wearing a cloth face mask isn't a substitute for physical distancing (aka social distancing) and other preventative measures. You'll still need to try to stay at least 2 metres away from others, wash your hands often, and clean high-touch surfaces frequently.

USING YOUR REUSEABLE CLOTH FACE MASK



Sources: Public health England: COVID-19 - guidance on home care provision;
Centers for Disease Control & Prevention (CDC) - Coronavirus Disease 2019

CLOTH FACE MASKS SHOULD

- fit snugly but comfortably against the side of the face
- be secured with ties or ear loops
- include multiple layers of fabric
- allow for breathing without restriction
- be able to be laundered and machine dried without damage or change to shape



HOW TO USE YOUR REUSEABLE CLOTH FACE MASK

Plan to use your mask when going out into the community, especially if you're going to be around other people.



- Before you go out in your mask, make sure that it:
- is properly secured using ear loops or ties
 - has a snug yet comfortable fit

Try to avoid touching your mask while you're wearing it. If you must touch or adjust your mask while you have it on, be sure to wash your hands immediately afterwards.

TO REMOVE YOUR MASK

- make sure you have clean hands
- remove the mask using the loops or ties. Don't touch the front
- avoid touching your mouth, nose, or eyes during removal
- thoroughly wash your hands after you've taken your mask off



TO CARE FOR YOUR MASK

It's important to clean your cloth face mask after each use. Not only is there a small chance you could get some contamination on the outside of the mask when you're outdoors but... it probably won't smell too good by the end of the day!



You don't need any special equipment or antibacterial laundry soap. Using your washing machine or washing by hand with clean, hot, soapy water should suffice. You can even wash your mask along with your clothes.

After washing, dry your mask in your dryer on high heat. If you don't have a dryer, you can hang your mask up to dry. This final step eradicates any remaining pathogens on the mask.



MOST PROUD OF...





ABIOLA OKUBANJO

ACTION ON BLOOD

www.actiononblood.org

actiononblood.org



You**Tube**





Resources

We have a number of helpful resources available which can support your work and discussions in this area.

- Our [Get the facts](#) webpage explores the truth behind some common misconceptions about organ donation after death
- Visit our YouTube site for [videos addressing common Organ Donation Myths](#), please share these on your social channels within your community.
- We have a wide variety of educational and informative videos on our NHS Give Blood YouTube channels, one of our most recent videos looks to [Debunk Safety on Session](#) when donating blood and is well worth a watch and a share.

Next steps

1. Dates for your diary:

- Thursday 3rd June 2021 – Engaging the media lunchtime session
- Thursday 24th June 2021 – Making the most of social media lunchtime session

Dial in details are in the Sway calendar.

2. Monitoring Form

Please complete the first **monitoring form** that was sent out on the 6th May for all activity during April and send back to the Community Funding inbox as soon as possible - community.funding@nhsbt.nhs.uk

3. Ask for help

Consider booking a lunchtime drop-in sessions 12 -1 on a Tuesday or Thursday if you have any questions whether it be help on ordering leaflets, guidance on using your tracked link or request for statistics to support your project. You can join via your phone or using Microsoft Teams on a laptop, tablet or computer. To book a slot please email - community.funding@nhsbt.nhs.uk

Thank You For Attending

Any questions please contact us:
community.funding@nhsbt.nhs.uk