

# The Black community and organ donation. What about it?

## Introduction

Recently, I was having a conversation with a barber in Cheetham Hill about my charity work and organ donation campaign. I was caught off guard when he asked me a question about what is lacking in Nigeria and Africa as a whole regarding organ donation. This conversation made me realise that organ donation is a mystery for many people from Nigeria and Africa generally.

Nobody in the African and/or Caribbean community talks about their ill-health. It's a taboo subject. Before my health problems began, I never would have thought that I would be the one travelling around the UK, speaking to small and large crowds about organ donation. Sometimes I compare my life now to Saul in the Bible, who persecuted the disciples but later became a convert himself. It takes me back to how my own journey started.

## My story

In 2008, I was pregnant, unfortunately, I had a miscarriage at 22 weeks, which deteriorated to septicaemia, multiple organ failure, two cardiac arrests and I was in a coma for two weeks. When I came out of the coma, I had lost some function in my kidneys and had to go on dialysis. I was on dialysis for a short while, then my kidney function improved.

In 2010, I unfortunately suffered another miscarriage - again at 22 weeks. My lungs collapsed and I had to be placed in a medically-induced coma to save my life. When I woke up, my kidneys were badly damaged and I had to begin dialysis treatment immediately. I have done all types of dialysis and today, I can say that I'm a "professional kidney patient". My whole family - 7 siblings and my parents, including my friend, Onyebuchi Odiaka - came forward to try and donate a kidney, but none was a match. It was a harrowing experience.

I was a recipient of an kidney transplant in 2018. A selfless mother who agreed to organ donation gave me a second chance at life. Since then, I have been campaigning and raising awareness about organ donation, kidney disease, blood donation and health inequalities. I understand that there is a lot of opposition to organ donation, and sometimes I can see where people are coming from when they express their concerns. However, I believe that it is important to understand the law and the rules governing organ donation so that we can make informed decisions.

The *Ekeremadu* case has highlighted the complex issues surrounding organ donation and the Black community. This case has made Nigerians especially, question their assumptions and beliefs about organ donation and perhaps, forced us to consider the perspectives of others. We need to have a conversation about what we think about organ donation and how it can help the UK - African community.

## The case of *Ekeremadu* and organ donation

Nigeria has a law in place that is similar to the organ donation principles in the United Kingdom, called the National Health Act (NHA) (NHA 2014, s48-57). The NHA also forbids donors from being compensated for their organs. However, we know that this law is disregarded, as evidenced by the *Ekeremadu* situation.

In 2019, I was interviewed by a TV station in Lagos about my journey with kidney disease. Just before the interview, the crew went out onto the street to interview ordinary people. The responses were not too surprising, but I guess our white counterparts would be shocked. One response that struck me was from a young woman who was asked if she would donate

her organ to her father if he needed it. She said, "Do you know how old I am? I'm 23 years old. I'm too young to be thinking about that!" My father has lived his life. No, I can't." The aversion to organ donation is more prevalent in the UK's black community, even among highly educated members. This is likely due to a lack of understanding of the UK's organ donation law. Many people do not want to talk about organ donation or become an organ donor or find out about the rules before opting out of the register.

The *Ekeremadu* case is a landmark case for accessing organ donation in the UK from Nigeria, it is the first of its kind. This case has set a legal precedent for organ donation, which means that people should take note and learn from it in order to understand what is required to access organ donation in the UK. The first step to take if you wish to access organ donation in the UK is to find out what the rules are and how they could affect you or your loved ones. You can do this by researching the topic online, contacting MANSAG or other healthcare professionals, or contacting a local organ donation charity or organisation in the UK.

### **The organ donation law. What does it mean?**

Deceased Donation and Living Donation are the two ways to donate organs. High blood pressure and diabetes are the most common causes of kidney disease. Many African people have these diseases because of poor lifestyle choices, which creates a need for transplant.

3 in 10 (31%) of people waiting for transplant across the UK are from Black and Asian communities or backgrounds. Over 35% of people waiting for a kidney are Black or Asian.

Unfortunately, the figures for Black kidney patients waiting for transplants compared to their white counterparts were abysmal, (*and still are*). People and charities campaigned for a law to ensure that people's lives could be saved and, as a result, the organ donation law came into effect on 20 May 2020.

The new law that was introduced is also known as Max and Keira's Law, the Opt-Out Law, and the official name, Organ Donation Law. The decision to become an organ donor is now available to more people and this has the potential to save many lives. The law encourages people to make their decision about organ donation and to share their wishes with their families. This will leave no doubt in their loved ones' minds about what they want to happen after they die.

Many people are still unaware of this law and what it could mean for them, while others may have heard of it but don't know the specifics.

As of May 20th, 2020, all adults over 18 in England who have not specifically chosen to opt-out of organ donation will be automatically considered to have given their consent to donate their organs upon death. This new system, known as 'opt-out', is designed to increase the number of organ donors in the country except the adults are in the excluded group.

The excluded group are, people under 18, people who have lived in England for less than 12 months before their death or are not living here voluntarily, people who lack the capacity to understand change.

Adults covered by the change in law, will still have a choice whether they want to be an organ donor and their families will be involved before organ donation goes ahead.

Whatever decision people make, they should make their choice or decision known to their family and closest friends.

## Number of people on the transplant list/comparison with other ethnic communities/white communities

NHS Blood and Transplant's Annual Report on Ethnicity Differences in Organ Donation and Transplantation was published on 12<sup>th</sup> January 2023, it showed that more needs to be done this year to save more lives. Examining the statistics, in 2021-22, *people of Asian heritage represented 3% of deceased donors but 15% of deceased donor transplants and 18% of the transplant waiting list; while those of Black heritage represented 2% of deceased donors but 9% of deceased donor transplants and 10% of the waiting list... – [NHSBT report](#)*

However, it seems the figures remain the same as 2020-21.

It goes on to say, "In total, 1,072 patients of Black or Asian heritage were able to receive an organ transplant from either a deceased or living donor in 2021-22." (We don't have the exact breakdown for these figures). Nonetheless, it is less than pre-covid figures of 1,150 in 2019-20. "*The number of deceased donors of Black or Asian heritage, increased by 31% (from 84 in 2020/21 to 110 in 2021/22). While 125 ethnic minority living donors generously gave the gift of life to another in 2021-22. This is an increase of 61% from the previous year which saw just 62 donors.*" – *NHSBT report*<sup>1</sup>

		2017/18		2018/19		2019/20		2020/21		2021/22	
		N	%	N	%	N	%	N	%	N	%
White	British	19,704	6.9	20,736	18.6	161,410	23.0	274,165	65.8	133,549	61.9
	Irish	322	0.1	315	0.3	1,857	0.3	3,327	0.8	1,839	0.9
	Other	2,916	1.0	2,422	2.2	16,740	2.4	25,202	6.0	20,693	9.6
	<b>Total</b>	<b>22,942</b>	<b>8.0</b>	<b>23,473</b>	<b>21.0</b>	<b>180,007</b>	<b>25.7</b>	<b>302,694</b>	<b>72.6</b>	<b>156,081</b>	<b>72.4</b>
Asian	Indian	39,327	13.7	7,720	6.9	46,090	6.6	13,094	3.1	8,239	3.8
	Pakistani	105,791	36.8	31,968	28.6	207,420	29.6	32,717	7.9	12,595	5.8
	Bangladeshi	50,782	17.7	17,221	15.4	78,960	11.3	12,160	2.9	4,115	1.9
	Other	10,554	3.7	3,471	3.1	31,140	4.4	10,002	2.4	6,191	2.9
<b>Total</b>	<b>206,454</b>	<b>71.8</b>	<b>60,380</b>	<b>54.1</b>	<b>363,610</b>	<b>51.9</b>	<b>67,973</b>	<b>16.3</b>	<b>31,140</b>	<b>14.4</b>	
Black	Caribbean	21,269	7.4	9,333	8.4	38,930	5.6	9,560	2.3	2,938	1.4
	African	19,903	6.9	10,888	9.7	71,392	10.2	14,541	3.5	6,485	3.0
	Other	3,459	1.2	1,591	1.4	8,654	1.2	2,607	0.6	3,593	1.7
	<b>Total</b>	<b>44,631</b>	<b>15.5</b>	<b>21,812</b>	<b>19.5</b>	<b>118,976</b>	<b>17.0</b>	<b>26,708</b>	<b>6.4</b>	<b>13,016</b>	<b>6.0</b>
Mixed	White/Black Caribbean	1,954	0.7	928	0.8	6,159	0.9	2,784	0.7	1,327	0.6
	White/Black African	788	0.3	437	0.4	2,632	0.4	1,146	0.3	944	0.4
	White/Asian	1,819	0.6	634	0.6	3,900	0.6	1,955	0.5	1,078	0.5
	Other	3,160	1.1	1,264	1.1	7,883	1.1	3,498	0.8	2,012	0.9
<b>Total</b>	<b>7,721</b>	<b>2.7</b>	<b>3,263</b>	<b>2.9</b>	<b>20,574</b>	<b>2.9</b>	<b>9,383</b>	<b>2.3</b>	<b>5,361</b>	<b>2.5</b>	
Chinese	304	0.1	295	0.3	1,256	0.2	2,413	0.6	5,644	2.6	
Other	5,510	1.9	2,476	2.2	16,486	2.4	7,539	1.8	4,412	2.0	
Total reported	287,562	100.0	111,699	100.0	700,909	100.0	416,710	100.0	215,654	100.0	
Not reported	22,659	7.3	12,626	10.2	153,191	17.9	85,757	17.1	54,699	20.2	
<b>TOTAL OPT-OUT REGISTRATIONS (incl. known duplicates/deaths)</b>	<b>310,221</b>		<b>124,325</b>		<b>854,100</b>		<b>502,467</b>		<b>270,353</b>		
<b>TOTAL OPT-OUT REGISTRATIONS (excl. known duplicates/deaths)</b>	<b>303,362</b>		<b>122,019</b>		<b>821,701</b>		<b>483,684</b>		<b>269,347</b>		

"This includes a rise in the number of people of Black or Asian heritage. As of 31st March 2021, there were 1237 people from ethnic minority backgrounds listed for transplants and by the 31st March 2022 this had risen to **1967**."

One of the reasons why organ donation rates are lower for potential donors from ethnic minority backgrounds is because families often do not give their consent. Last year, overall consent rates were only 40% for ethnic minority donors, compared to 71% for white potential donors. This is similar to the rates from the previous year.

<sup>1</sup> NHSBT report - <https://www.odt.nhs.uk/statistics-and-reports/annual-report-on-ethnicity-differences/>

I was shocked to learn that “Approximately 80% of transplants in people from ethnic minority backgrounds are from white donors.” – [NHSBT report](#)

If we want to increase organ donation rates from all potential donors, we need to work on getting more families to support it. This could involve educational campaigns to raise awareness about the importance of organ donation and how it can save lives, especially living donation, which is the gold standard.

The tables below is a comparison of the number of people signing up to the register and those opting out. Take special note of the African figures.

Table of opt-out registrations – African – NHSBT report

Table 2.1 Ethnicity of all ODR opt-in registrations by year of registration <sup>1</sup> , 1 April 2017 - 31 March 2022											
		2017/18		2018/19		2019/20		2020/21		2021/22	
		N	%	N	%	N	%	N	%	N	%
White	British	381,028	85.1	400,442	85.5	268,290	83.9	174,513	81.2	231,273	77.6
	Irish	9,929	2.2	11,645	2.5	8,384	2.6	3,845	1.8	4,890	1.6
	Other	23,681	5.3	23,123	4.9	18,033	5.6	16,983	7.9	31,229	10.5
	<b>Total</b>	<b>414,638</b>	<b>92.6</b>	<b>435,210</b>	<b>92.9</b>	<b>294,707</b>	<b>92.2</b>	<b>195,341</b>	<b>90.9</b>	<b>267,392</b>	<b>89.7</b>
Asian	Indian	8,726	1.9	9,495	2	6,957	2.2	5,146	2.4	8,643	2.9
	Pakistani	1,635	0.4	1,546	0.3	1,259	0.4	929	0.4	1,276	0.4
	Bangladeshi	464	0.1	430	0.1	348	0.1	306	0.1	398	0.1
	Other	4,096	0.9	3,965	0.8	3,167	1	2,800	1.3	4,499	1.5
	<b>Total</b>	<b>14,921</b>	<b>3.3</b>	<b>15,436</b>	<b>3.3</b>	<b>11,731</b>	<b>3.7</b>	<b>9,181</b>	<b>4.3</b>	<b>14,816</b>	<b>5.0</b>
Black	Caribbean	1,890	0.4	1,888	0.4	1,439	0.5	874	0.4	1,105	0.4
	African	2,387	0.5	2,325	0.5	1,730	0.5	1,360	0.6	1,729	0.6
	Other	307	0.1	331	0.1	273	0.1	334	0.2	821	0.3
	<b>Total</b>	<b>4,584</b>	<b>1.0</b>	<b>4,544</b>	<b>1</b>	<b>3,442</b>	<b>1.1</b>	<b>2,568</b>	<b>1.2</b>	<b>3,655</b>	<b>1.2</b>
Mixed	White/Black African	964	0.2	967	0.2	777	0.2	710	0.3	990	0.3
	White/Black Caribbean	2,635	0.6	2,803	0.6	1,980	0.6	1,328	0.6	1,776	0.6
	White/Asian	2,771	0.6	2,768	0.6	2,054	0.6	1,529	0.7	2,177	0.7
	Other	2,501	0.6	2,590	0.6	2,030	0.6	1,699	0.8	2,562	0.9
	<b>Total</b>	<b>8,871</b>	<b>2.0</b>	<b>9,128</b>	<b>1.9</b>	<b>6,841</b>	<b>2.1</b>	<b>5,266</b>	<b>2.5</b>	<b>7,505</b>	<b>2.5</b>
Chinese	1,513	0.3	1,391	0.3	1,056	0.3	866	0.4	2,333	0.8	
Other	3,134	0.7	2,721	0.6	1,921	0.6	1,702	0.8	2,306	0.8	
Total reported		447,661	100.0	468,430	100	319,698	100	214,924	100.0	298,007	100.0
Not reported		872,308	66.1	941,998	66.8	975,177	75.3	846,998	79.8	932,117	75.8
<b>TOTAL OPT-IN REGISTRATIONS (incl. known duplicates/deaths)</b>		<b>1,319,969</b>		<b>1,410,428</b>		<b>1,294,875</b>		<b>1,061,922</b>		<b>1,230,124</b>	
<b>TOTAL OPT-IN REGISTRATIONS (excl. known duplicates/deaths)</b>		<b>1,024,664</b>		<b>1,230,560</b>		<b>1,039,485</b>		<b>827,777</b>		<b>1,027,724</b>	

<sup>1</sup> Most sources of registration onto the ODR provided by NHSBT's partners do not have an option to record or report ethnicity

Table for opt-ins – African

## Why it is important to donate

Donating an organ as a live donor (kidney or liver) is not only better for the recipient, but also for the donor. Research has shown that organs donated by live donors last, on average, 25 years while organs donated by deceased donors last, on average, 15 years. Additionally, it is better if the donation comes from someone from the same ethnic background as the recipient - transplant success rates are significantly higher in these cases.

The importance of donation is often underestimated because people don't realise how it can directly impact them until it's too late. We need to campaign and raise awareness about organ donation in our community so that we can save lives.

**Table 4.6 Number of donors, transplants and waiting list patients in the UK, by ethnicity and financial year, 1 April 2017 - 31 March 2022**

Ethnicity	2017/18		2018/19		Financial year 2019/20		2020/21		2021/22	
	N	%	N	%	N	%	N	%	N	%
<b>Deceased donors</b>										
White	1441	92.7	1468	92.4	1454	92.8	1061	92.7	1253	91.9
Asian	37	2.4	56	3.5	40	2.6	32	2.8	43	3.2
Black	25	1.6	20	1.3	30	1.9	18	1.6	24	1.8
Mixed	24	1.5	9	0.6	12	0.8	8	0.7	20	1.5
Other	28	1.8	36	2.3	30	1.9	26	2.2	23	1.7
<b>Deceased donor transplants</b>										
White	3094	77.4	2939	75.2	2701	72.8	2222	76.5	2412	72
Asian	506	12.7	513	13.1	518	14	379	13.1	517	15.4
Black	255	6.4	305	7.8	347	9.4	209	7.2	288	8.6
Mixed	19	0.5	7	0.2	15	0.4	8	0.3	21	0.6
Other	122	3.1	146	3.7	130	3.5	85	2.9	112	3.4
<b>Waiting list</b>										
White	4126	69.4	4102	68.5	3776	67.4	2952	70.5	4159	67.9
Asian	958	16.1	1006	16.8	1003	17.9	725	17.3	1079	17.6
Black	614	10.3	629	10.5	591	10.5	376	9	628	10.3
Mixed	22	0.4	31	0.5	30	0.5	25	0.6	36	0.6
Other	229	3.8	216	3.7	202	3.6	111	2.6	224	3.6
<b>Living donors</b>										
White	922	86.7	896	85.7	896	84.9	388	86.2	776	86.1
Asian	75	7	84	8	89	8.4	36	8	70	7.8
Black	17	1.6	25	2.4	30	2.8	8	1.8	25	2.8
Mixed	5	0.5	7	0.7	4	0.4	3	0.7	4	0.4
Other	45	4.2	34	3.3	36	3.4	15	3.3	26	2.9
<b>Living donor transplants</b>										
White	869	82.9	852	82.6	845	81.3	359	80.9	735	82.3
Asian	94	9	90	8.7	99	9.5	45	10.1	86	9.6
Black	25	2.4	30	2.9	43	4.1	16	3.6	33	3.7
Mixed	9	0.9	8	0.8	3	0.3	5	1.1	10	1.1
Other	51	4.9	51	5	49	4.7	19	4.3	29	3.2

Unknown ethnicity was excluded

**Table 4.7** summarises all deceased donor transplants by country of residence, ethnicity of recipient and organ transplanted in 2021/22. Patients in Wales, Scotland and Northern Ireland requiring transplants that are not undertaken in that country are referred to another UK country (usually England) for transplantation. If the patient's address was unknown the country of transplant was used instead. Few ethnic minority deceased donor transplant recipients live in Northern Ireland, Scotland or Wales.

Snapshot of year on year statistics – courtesy NHSBT

## How can you become a living donor?

If anyone is interested in becoming a living donor, they can contact their local hospital's Living Donation Team or the National Health Service Blood and Transplant by calling 0300 123 23 23. Alternatively, they can also reach out to WSH BME Kidney Network by calling 0300 102 159 or 07862 348 994 and we will support you through the process. Interested individuals can also sign up to the register here: <https://bit.ly/3gUwFoW>