



Blood and Transplant

Organ Donation and Transplantation data for Black, Asian and Minority Ethnic (BAME) communities

**Report for 2019/2020
(1 April 2015 - 31 March 2020)**



PREFACE

This report has been produced by Statistics and Clinical Studies, NHS Blood and Transplant.

This report provides information related to organ donation and transplantation within the white and Black, Asian and Minority Ethnic (BAME) communities in the UK. It is published as a supplementary report of the *Organ Donation and Transplantation Activity Report 2019/20*. In this report BAME is defined as Black, Asian, and Minority Ethnic (used to refer to members of non-white communities in the UK).

Data analysed include registrations on the NHS Organ Donor Register (ODR), deceased and living organ donors, transplant recipients, patients and deaths on the transplant lists and waiting times to transplant. Trends in relation to potential organ donors, including donation consent/authorisation rates¹, are also reported. **The categories currently used to collect data on ethnicity are not consistent between these data sources, and the information is provided in as much detail as available data permit.**

The information reported is from the last 5 financial years, unless otherwise stated. One, three and five year post-registration outcomes have been reported from 1 April 2014 to 31 March 2015. Median waiting times include all patients joining the list in a given time period, which varies by organ, and the earliest time period was from 1 April 2007.

Median waiting times are determined by using Kaplan-Meier survival estimates of time from joining the list to allow the inclusion of patients not transplanted (as censored waiting times) and thus provide meaningful estimates. However, it should be noted that none of these waiting times are risk-adjusted for other potentially influential factors (e.g. blood group), and thus should be interpreted with a degree of caution.

Ethnicity of people registering on the ODR is only captured when a registration is made and is not linked to the main ODR and any subsequent updates (removal of duplicates and notifications of death). For this reason, ethnicity can only be reported on data that include duplicates and people who have subsequently died. The updated number of registrations as reported elsewhere is also provided for completeness.

Organ donors, transplant recipients and transplant waiting list data capture does not allow for a detailed breakdown of ethnicity. Overall <1% of recipients and donors did not have ethnicity recorded and where numbers are small ethnicities have been grouped. **This report only includes donors and recipients where ethnicity is reported on 17 June 2020.**

The COVID-19 pandemic has led to unprecedented challenges for UK transplantation. Concerns about the ability to care for transplant recipients, lack of access to resource because it is being used for patients in the pandemic, and the risk versus benefit for immunosuppressed transplant recipients, have resulted in a major reduction in the number of organ transplants undertaken.

Waiting list figures at 31 March 2020 do not accurately reflect the need for an organ transplant due to the COVID-19 pandemic. Different practices have been established across the UK and across organ groups with regards to waiting list management. Due to this, a snapshot of the waiting list at 29 February 2020 has been used to better reflect activity near the end of the 2019-2020 financial year.

Acknowledgement

NHS Blood and Transplant would like to thank all those in the donation and transplantation communities responsible for providing data to the UK Transplant Registry and the Potential Donor Audit, without whom this report would not be possible. Thanks also go to NHS Blood and Transplant staff responsible for data entry and accuracy and completeness of the data.

¹ The consent/authorisation rate is the percentage of eligible donor families or appointed/nominated representatives approached for formal organ donation discussion where consent/authorisation was ascertained.

FOREWORD

Transplantation is truly a lifesaving act, but it would not be possible without the generosity of organ donors and their family's willingness to say 'yes' to donation. It's also thanks to the hard work, co-ordination and determination of all the medical teams also involved in the process, that lives are saved through organ transplants every day.

Until February 2020, we were confident that we would once again see a UK record number of organ donors and transplants. Then the global COVID-19 pandemic hit in March and the impact was felt across the whole of the NHS and in every aspect of UK society, hitting those from black, Asian and minority ethnic backgrounds particularly hard.

In March 2020 we witnessed a sharp reduction in organ donation and transplant activity with a decline in deceased donors as well as the number of transplants from all ethnicities. Donations were reduced as patients who were positive for COVID-19 were unable to donate, but also transplant activity was scaled back due to concerns for safety and the risk of waiting patients being immunosuppressed in the midst of a pandemic. By the end of the year, there was a fall in the overall number of deceased organ donors - 1,580 compared to 1,600 last year.

Despite this, the number of BAME deceased organ donors has increased by 67% over the last 5 years, from 67 in 2015/16 to 112 in 2019/20, representing 7% of all deceased organ donors. Significantly, there were more black deceased donors (30) last year than ever before, showing the successful hard work and dedication of those working in the black communities raising awareness and highlighting the importance of organ donation in saving lives. Last year also saw 142 people from BAME communities becoming living donors, donating a kidney or part of their liver to someone in need. BAME living donors have continued to be significantly higher than BAME deceased donors and constituted 14% of all living donors; with 84 Asian living donors, the same as last year. This reflects the work done within the Asian communities in promoting living donation.

By 29th February 2020, there were 1,909 BAME people on the overall active organ transplant list, this is an increase of 4% from 31 March 2016 and represents 32% of the waiting list. However, it's encouraging to see the waiting lists for kidney transplants continue to decline. In September 2019, there was a change in the way deceased donor kidneys were allocated to patients for transplant. The update to the deceased donor Kidney Offering Scheme made it fairer for those who find it hard to get a match, such as patients from a BAME background, or those who have been waiting for several years.

These patients are given a certain level of priority to help close the gap in the length of time people wait for a transplant. 40% of all deceased donor kidney transplants performed between September 2019 and February 2020 were in black, Asian and minority ethnic patients compared with 33% in the same period the previous year. This percentage uplift will potentially generate much needed hope for the many BAME patients in need of the gift of life given by a matching transplant.

In the UK there is a high proportion of people from black, Asian and minority ethnic backgrounds developing high blood pressure, diabetes and certain forms of hepatitis making them more likely to need a transplant at some point in their lives. Getting the right tissue type and blood match is vital for the most successful transplant and the best match often comes from someone with the same ethnicity.

In 2019/20, Asian people represented 3% of total deceased donors, 14% of transplants from deceased donors and 18% of the transplant waiting list; while black people represented 2% of deceased donors, 9% of transplants from deceased donors and 10% of the transplant waiting list.

This shows the continued imbalance between the need for transplants in our black and Asian communities and the availability of suitable organs with the right blood and tissue type. Although at the moment, only around half as many families from these communities' support donation compared to families from a white background, it's reassuring to see the numbers of BAME people becoming more engaged and agreeing to organ donation. This can be seen by the increase in

people registering their ethnicity when opting-in to the NHS Organ Donor Register. In 2015/16, 5.8% of people from BAME communities who registered their ethnicity opted-in to the ODR and in 2019/20 that rose to 7.8%. Though this is immensely encouraging, we need more people from our BAME communities to be prepared to donate in life or after death.

There is significant over-representation in the number of opt-outs from BAME communities. In particular, 52% of these opt-outs were made by Asian people, mostly of Pakistani origin (30%), followed by white people (26%) and black people (17%). Despite the increase in people choosing to opt-in to organ donation, there is still much work to do to debunk the myths, fears and taboos surrounding organ donation when it comes to the whole process, and whether it is supported within certain faiths and cultures. Not knowing what their relative wanted or believing that organ donation goes against their religious beliefs or culture are the main reasons given by BAME families for saying no to donation when approached by specialist nurses, meaning opportunities for lifesaving transplants are still being missed because families are reluctant to discuss the topic of organ donation.

Now the law has changed in England, and Scotland to follow next year, it is more important than ever to ensure the right information is given to people at the right time to help them make the decision that's right for them and their family. It's important to know that with the new law around organ donation, families still do have a say in whether or not donation goes ahead. Families will still be consulted by Specialist Nurses, and people's faith, beliefs and culture will always continue to be respected.

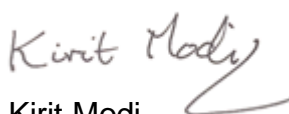
Working together with partners, stakeholders, community groups and the NHS to provide education, faith and cultural engagement is more important than ever before. We are committed to continuing with community projects and campaigns that highlight the need for more diversity in organ donation and to address the stark underrepresentation of BAME people who become organ donors or have opted-in via the NHS Organ Donor Register. NHSBT has been working in partnership with National BAME Transplant Alliance (NBTA) on two important initiatives for a few years to empower BAME community groups to take the lead in promoting organ donation within specific communities; the Living Transplant Initiative and the Community Investment Scheme. Both are now established and are successful.

We know from regular attitudinal research carried out by NHS Blood and Transplant that in July 2020, 64% of BAME respondents who wanted to donate, said they would be happy to donate all of their organs, and for patients in need that is very reassuring. This figure had risen from 51% from the same survey in November 2019. We hope to build on this insight which has set us on the right path for a further increase in numbers and a transformation of willingness into reality in the years to come.

We, individually and collectively, remain firmly committed to working with all those with a passion for promoting the benefits of organ donation within our black, Asian and minority ethnic communities and working together to narrow the gap between those from BAME communities on the waiting list and the number of BAME people who go on to donate.



Millie Banerjee
Chair of NHSBT



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Hon. President of
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SUMMARY

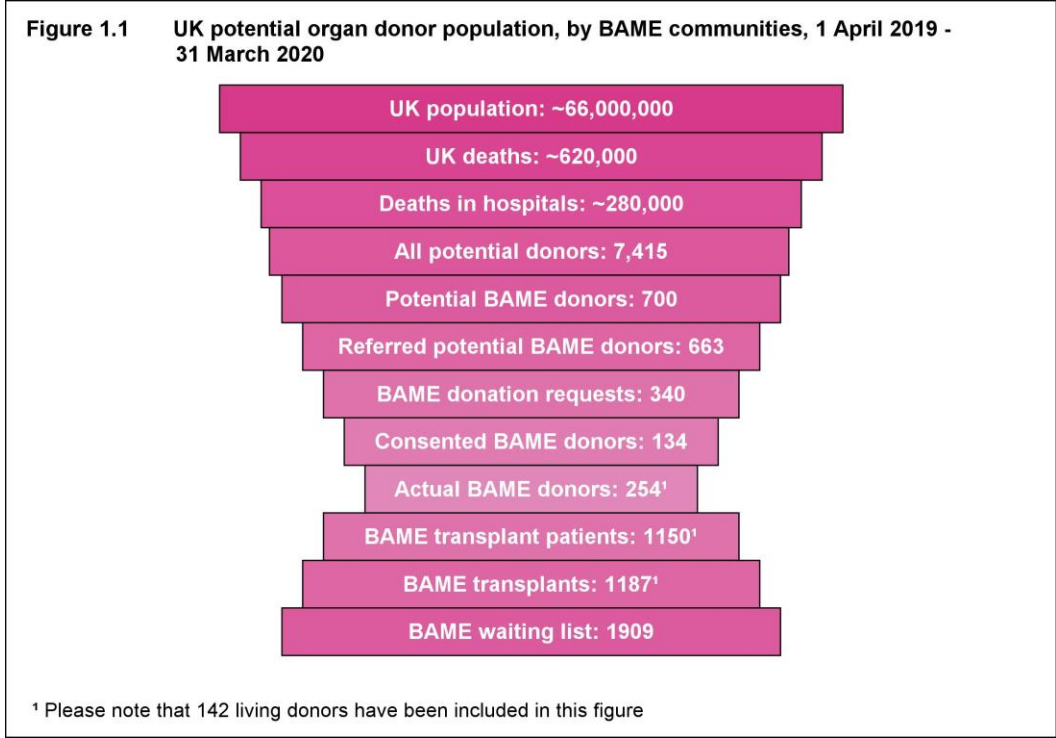
1 SUMMARY

Organ Donor Register

- There has been a small increase in the proportion of opt-in registrations from BAME communities added to the Organ Donor Register (ODR) over the past 5 years; 5.9% of opt-ins with ethnicity reported in 2015/16 and 7.8% in 2019/20.
- All minority groups were under-represented in ODR opt-in registrations; BAME represent 7.8% of opt-in registrations compared with 14.0% of the BAME population for England and Wales. However, there continues to be some variation in the proportion of opt in from different BAME community groups.
- Relative to the English and Welsh population, there is over-representation in 700,909 opt-outs with ethnicity reported, for all but white and Chinese people. In particular, 52% of these opt-outs were made by Asian people, mostly of Pakistani origin (30%), followed by white people (26%) and black people (17%).
- The number of ODR opt-in registrations with ethnicity reported has fallen – from 33% in 2018/19 to 25% last year. In 2019/20, the proportion of ODR opt-out registrations with ethnicity reported was 82%, compared to 90% in 2018/19.

Potential organ donors

- Referral rates to specialist nurses of potential white and BAME organ donors are comparable ranging from: 99-100% for donors after brain death (DBD) last year and 92-93% for donors after circulatory death (DCD).
- Family consent/authorisation is much lower for BAME eligible donors (42% DBD, 43% DCD) than for white eligible donors (77% DBD, 66% DCD). Overall (DBD and DCD combined), consent rates were 42% for BAME and 71% for white potential donors last year, similar to the previous year.

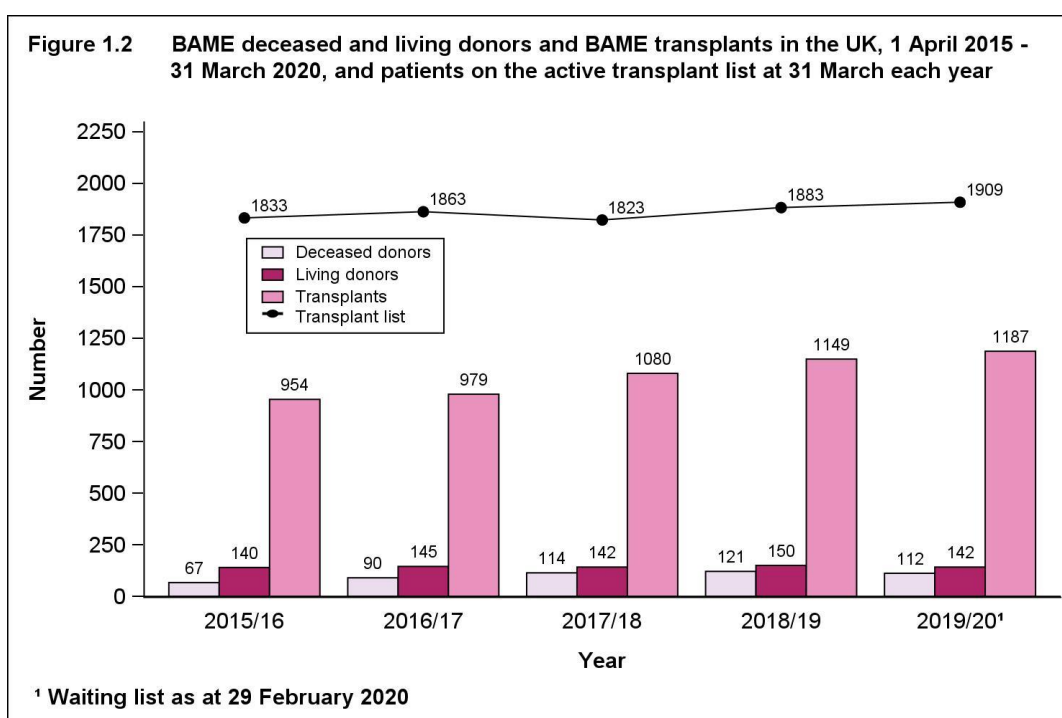


- The main reasons BAME families gave for declining consent/authorisation for organ donation was that they felt it was against their religious/cultural beliefs or they were unsure whether the patient would have agreed to donation. Survey results of BAME communities shows that not knowing enough about organ donation is also a major barrier to organ donation. NHSBT and the National BAME Transplant Alliance (NBTA) have been working in partnership over a number of years to address these barriers. The Community Investment Scheme and the Living Transplant Initiative are now well-established programmes which empower BAME community groups to promote organ donation in targeted groups.

Organ donors, transplant recipients and transplant waiting list

Overview

- The number of BAME deceased organ donors has increased by 67% over the last 5 years: from 67 in 2015/16 to 112 in 2019/20, representing 7% of all deceased organ donors. There were more black deceased donors (30) last year, than ever before (20 in 2018/19).
- The number of BAME living donors has remained at approx. 140-150 per year, representing 14% of all living organ donors. Last year, there were fewer white living donors whereas black (26) and Asian (84) living donors remained stable.
- The number of transplants in BAME people has increased by 24% over the last 5 years, representing 25% of all transplants with 1187 transplants in BAME people last year.
- There were 1909 BAME people on the active organ transplant list at 29 February 2020, up 3% from 31 March 2016 and representing 32% of the waiting list. Of these, 18% were Asian and 10% were black people.



- In 2019/20, Asian people represented 3% of deceased donors (DD), 14% of DD transplants and 18% of the transplant waiting list; black people represented 2% of DD, 9% of DD transplants and 10% of the list, similar to the previous year.
- In 2019/20, Asian people represented 8% of living donors (LD) and 10% of LD transplants; black people represented 3% of LD and 4% of LD transplants, similar to the previous year.
- One year after being listed for a transplant (all organs), 41% (N=1717) of white and 28% (N=316) of BAME people have been transplanted. Five years after listing, 74% (N=3085) of white and 72% (N=829) of BAME people have been transplanted, while 9% (N=386) of white and 7% (N=84) of BAME people have died on the list.
- Median waiting times to transplant show that, generally, white patients wait less time than BAME patients, with the exception of patients waiting for an adult liver, pancreas or non-urgent heart. Black patients often wait the longest (**Table 4.3**).
- The majority of transplant donors (deceased and living) are white across all recipient ethnic groups: approx. 80% of transplants in Asian, black and Chinese/East Asian and mixed-race people are from white donors.

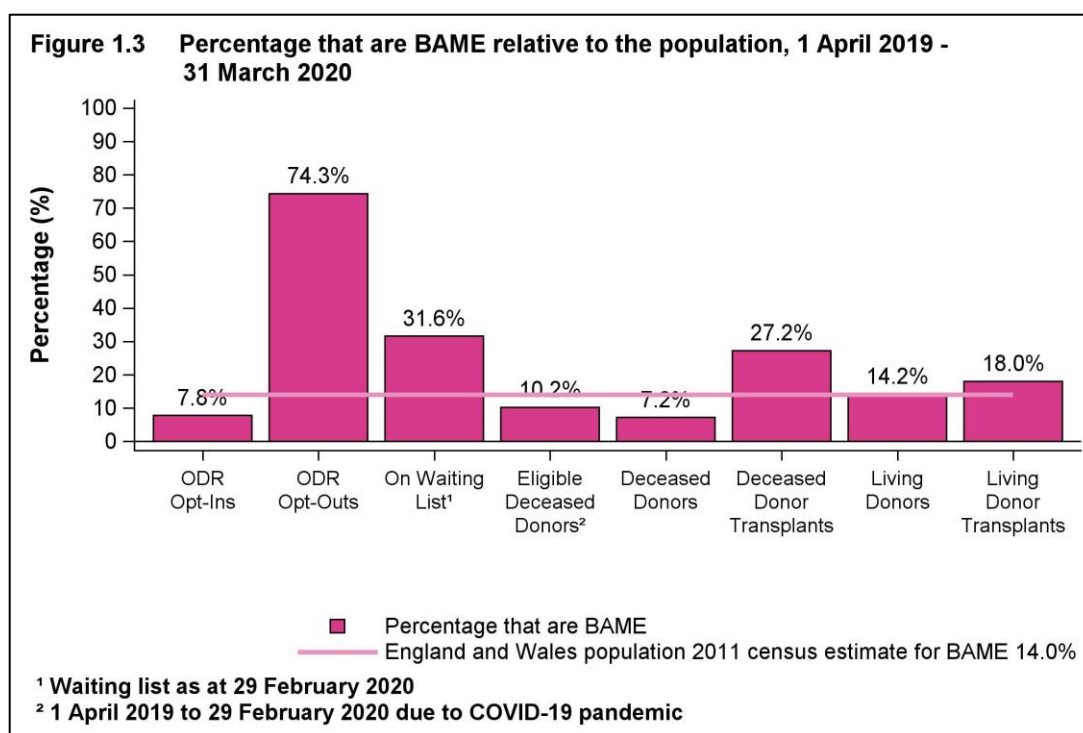
Kidney

- One year after being listed for a kidney transplant, 31% of white and 20% of BAME people have received a transplant. Five years after listing, 75% of white and 72% of BAME people have been transplanted while 7% of white and 6% of BAME people have died on the list.
- There has been an overall decline in waiting times for all ethnicities, although black patients are waiting almost a year longer for a transplant than white patients (median waits are 900 days for black, 736 days for Asian, 743 days for other BAME and 573 days for white people). Over time, it is predicted that the differences in the waiting times across ethnic groups will be reduced with the introduction of a new kidney offering scheme in 2019.
- In 2019/20, Asian people represented 3% of deceased kidney donors (DD), 17% of DD kidney transplants and 20% of the transplant waiting list; black people represented 2% of kidney DD, 13% of DD transplants and 12% of the list.
- There were more deceased donor kidney transplants in black patients than ever before (312 transplants). In comparison to the previous year, the number of deceased donor kidney transplants in Asian patients has decreased from 433 to 419 transplants.
- The majority of kidney transplants from DD are from white donors across all recipient ethnic groups: approx. 90% of transplants in Asian, black and Chinese/East Asian and mixed-race people are from white donors.
- 64% of Asian and 49% of black kidney transplant recipients receive a kidney from a living donor of the same ethnicity. This was not the case for Chinese/East Asian or mixed-raced ethnicities who mostly received a living kidney donor from a white person.

Other organs

- One year after listing for transplant:
 - **Pancreas and pancreas/kidney:** 31% of white and 39% of BAME patients have received a transplant, while 5% and 4% have died on the list, respectively.
 - **Liver:** 65% of white and 71% of BAME patients have received a transplant, while 7% and 6% have died on the list, respectively.
 - **Cardiothoracic:** 48% of white and 38% of BAME patients have received a transplant, while 16% and 21% have died on the list, respectively.
- In 2020, Asian people represented:
 - **Pancreas and pancreas/kidney:** 3% of donors, 5% of transplants and 9% of the transplant list.
 - **Liver:** 3% of donors, 8% of transplants and 11% of the transplant list
 - **Cardiothoracic:** 4% of donors, 9% of transplants and 8% of the transplant list
- In 2020, black people represented:
 - **Pancreas and pancreas/kidney:** 2% of donors, 9% of transplants and 3% of the transplant list.
 - **Liver:** 2% of donors, 3% of transplants and 3% of the transplant list
 - **Cardiothoracic:** 3% of donors, 1% of transplants and 5% of the transplant list

Figure 1.3 shows an over-representation of BAME relative to the population of England and Wales for ODR opt-outs, those on the waiting list, deceased donor transplants and to a lesser extent living donor transplants. The proportion of living donors is similar to the proportion of the population. BAME communities are under-represented in deceased donors as well as eligible deceased donors and those registering on the opt-in ODR. In comparison to the previous year, there has been a slight drop in the proportion of BAME ODR opt-outs from 79% to 74% and a small increase in deceased donor transplants from 25% to 27% in 2019/20.



ORGAN DONOR REGISTER

2 Organ Donor Register (ODR)

Ethnicity of people registering on the ODR is only captured as a registration is made and is not linked to the main ODR and any subsequent updates (removal of duplicates and notifications of death). For this reason, ethnicity can only be reported on data that include duplicates and people who have subsequently died. The updated number of registrations as reported elsewhere is also provided for completeness. It should also be noted that considerable work has been undertaken in 2019 to consolidate duplicate registrations on the Organ Donor Register that arise as a result of people re-registering for various reasons and through different routes, etc. Thus, numbers of registrations and people on the ODR may not match previous reports.

The primary sources of opt-in ODR registrations in 2019/20 were the Driver and Vehicle Licensing (57%), online registrations (20%), GP registrations (19%), Boots Advantage card (3%) and Other (1%).

Most sources of opt-in registration provided by NHSBT's partners do not have an option to record or report ethnicity. Even when the option is available, it is not possible to tell how many people choose not to provide the information when registering via these routes. Consequently, only 25% of people registering on the ODR in 2019/20 have their ethnicity recorded.

Table 2.1 shows the number of opt-in registrations per year by ethnicity from 1 April 2015 to 31 March 2020. In 2019/20, 92% of registrations with ethnicity recorded were from white people, 4% from Asian, 1% from black, 0.3% from Chinese, 2% from mixed race and 1% from other ethnic groups.

On 1st December 2015, Wales introduced legislation for an opt-out approach to organ donation and this was implemented in England on 20th May 2020, albeit with slight differences to the legislation. Opt-out registrations were first recorded on the ODR in June 2015. In order to have complete data across each financial year, **Table 2.2** shows the number of opt-out registrations per year by ethnicity from 1 April 2016 to 31 March 2020. Most opt-out registrations are entered online and as a result have a higher proportion of people reporting their ethnicity (82% in 2019/20). In the last year, there has been a large increase in the number of opt-out registrations, although the proportional breakdown by ethnicity has remained similar to 2018/19. In 2019/20, the majority of opt-out registrations were among Asian people (52%), mostly of Pakistani origin (30%), followed by white people (26%) and black people (17%).

Table 2.1 Ethnicity of all ODR opt-in registrations by year of registration¹, 1 April 2015 - 31 March 2020

		2015/16		2016/17		2017/18		2018/19		2019/20	
		N	%	N	%	N	%	N	%	N	%
White	British	395,204	86.9	301,917	84.9	381,028	85.1	400,442	85.5	268,290	83.9
	Irish	12,209	2.7	9,502	2.7	9,929	2.2	11,645	2.5	8,384	2.6
	Other	20,923	4.6	20,140	5.7	23,681	5.3	23,123	4.9	18,033	5.6
	Total	428,336	94.2	331,559	93.2	414,638	92.6	435,210	92.9	294,707	92.2
Asian	Indian	7,150	1.6	6,443	1.8	8,726	1.9	9,495	2.0	6,957	2.2
	Pakistani	1,242	0.3	1,362	0.4	1,635	0.4	1,546	0.3	1,259	0.4
	Bangladeshi	339	<0.1	328	0.1	464	0.1	430	0.1	348	0.1
	Other	2,898	0.6	2,992	0.8	4,096	0.9	3,965	0.8	3,167	1.0
	Total	11,629	2.6	11,125	3.1	14,921	3.3	15,436	3.3	11,731	3.7
Black	Caribbean	1,655	0.4	1,458	0.4	1,890	0.4	1,888	0.4	1,439	0.5
	African	1,725	0.4	1,617	0.5	2,387	0.5	2,325	0.5	1,730	0.5
	Other	246	<0.1	248	0.1	307	0.1	331	0.1	273	0.1
	Total	3,626	0.8	3,323	0.9	4,584	1.0	4,544	1.0	3,442	1.1
Mixed	White/Black African	853	0.2	707	0.2	964	0.2	967	0.2	777	0.2
	White/Black Caribbean	2,339	0.5	2,041	0.6	2,635	0.6	2,803	0.6	1,980	0.6
	White/Asian	2,429	0.5	2,086	0.6	2,771	0.6	2,768	0.6	2,054	0.6
	Other	2,010	0.4	1,812	0.5	2,501	0.6	2,590	0.6	2,030	0.6
	Total	7,631	1.7	6,646	1.9	8,871	2.0	9,128	1.9	6,841	2.1
Chinese		1,207	0.3	1,114	0.3	1,513	0.3	1,391	0.3	1,056	0.3
Other		2,142	0.5	1,985	0.6	3,134	0.7	2,721	0.6	1,921	0.6
Total reported		454,571	100.0	355,752	100.0	447,661	100.0	468,430	100.0	319,698	100.0
Not reported		921,336	67.0	1,004,320	73.8	872,308	66.1	941,998	66.8	975,177	75.3
TOTAL OPT-IN REGISTRATIONS (incl. known duplicates/deaths)		1,375,907		1,360,072		1,319,969		1,410,428		1,294,875	
TOTAL OPT-IN REGISTRATIONS (excl. known duplicates/deaths)		1,014,142		925,794		1,024,664		1,230,560		1,039,485	

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

Table 2.2 Ethnicity of all ODR opt-out registrations by year of registration, 1 April 2016 - 31 March 2020

		2016/17		2017/18		2018/19		2019/20	
		N	%	N	%	N	%	N	%
White	British	17,004	74.2	19,704	6.9	20,736	18.6	161,410	23.0
	Irish	199	0.9	322	0.1	315	0.3	1,857	0.3
	Other	1,161	5.1	2,916	1.0	2,422	2.2	16,740	2.4
	Total	18,364	80.2	22,942	8.0	23,473	21.0	180,007	25.7
Asian	Indian	585	2.6	39,327	13.7	7,720	6.9	46,090	6.6
	Pakistani	1,018	4.4	105,791	36.8	31,968	28.6	207,420	29.6
	Bangladeshi	371	1.6	50,782	17.7	17,221	15.4	78,960	11.3
	Other	519	2.3	10,554	3.7	3,471	3.1	31,140	4.4
	Total	2,493	10.9	206,454	71.8	60,380	54.1	363,610	51.9
Black	Caribbean	357	1.6	21,269	7.4	9,333	8.4	38,930	5.6
	African	739	3.2	19,903	6.9	10,888	9.7	71,392	10.2
	Other	82	0.4	3,459	1.2	1,591	1.4	8,654	1.2
	Total	1,178	5.1	44,631	15.5	21,812	19.5	118,976	17.0
Mixed	White/Black Caribbean	84	0.4	1,954	0.7	928	0.8	6,159	0.9
	White/Black African	65	0.3	788	0.3	437	0.4	2,632	0.4
	White/Asian	74	0.3	1,819	0.6	634	0.6	3,900	0.6
	Other	110	0.5	3,160	1.1	1,264	1.1	7,883	1.1
	Total	333	1.5	7,721	2.7	3,263	2.9	20,574	2.9
Chinese		162	0.7	304	0.1	295	0.3	1,256	0.2
Other		375	1.6	5,510	1.9	2,476	2.2	16,486	2.4
Total reported		22,905	100.0	287,562	100.0	111,699	100.0	700,909	100.0
Not reported		2,407	9.5	22,659	7.3	12,626	10.2	153,191	17.9
TOTAL OPT-OUT REGISTRATIONS (incl. known duplicates/deaths)		25,312		310,221		124,325		854,100	
TOTAL OPT-OUT REGISTRATIONS (excl. known duplicates/deaths)		25,201		303,362		122,019		821,701	

Given the lack of opt-in registrations for which ethnicity is recorded, it is not meaningful to compare absolute numbers of people registering each year. However, looking at proportions of those with ethnicity reported is meaningful. If it is assumed that the proportions are representative of all ODR opt-in and opt-out registrations, it is possible to see differences relative to the population of the England and Wales (Appendix, **Table I**).

The population of England and Wales broken down by ethnicity is reported using the census data from the Office for National Statistics (ONS) and the most recent census was 2011.

Table 2.3 shows data on percentage of the ODR opt-in registrations in 2015/16 and 2019/20 as well as ODR opt-out registrations in 2019/20 against the percentage of the general population for England and Wales. In 2015/16, 5.9% of ODR registrations of known ethnicity were BAME which has increased to 7.8% in 2019/20. It is estimated that 14.0% of the population for England and Wales is BAME, reflecting an under-representation of BAME communities on the ODR opt-in and an over-representation on the ODR opt-out.

Table 2.3 BAME registrations on the ODR vs the population for England and Wales

Ethnicity	2015/16 % of the ODR opt-in registrations¹	2019/20 % of the ODR opt-in registrations¹	2019/20 % of the ODR opt-out registrations¹	2011 % of the population²
Asian-Indian	1.6	2.2	6.6	2.5
Asian-Pakistani	0.3	0.4	29.6	2.0
Asian-Bangladeshi	0.0	0.1	11.3	0.8
Asian-Other	0.6	1.0	4.4	1.5
<i>Asian-Total</i>	<i>2.6</i>	<i>3.7</i>	<i>51.9</i>	<i>6.8</i>
Black-African	0.4	0.5	10.2	1.8
Black-Caribbean	0.4	0.5	5.6	1.1
Black-Other	0.0	0.1	1.2	0.5
<i>Black-Total</i>	<i>0.8</i>	<i>1.1</i>	<i>17.0</i>	<i>3.3</i>
Chinese	0.3	0.3	0.2	0.7
Mixed race	1.7	2.1	2.9	2.2
Other ethnicity	0.5	0.6	2.4	1.0
Total BAME	5.9	7.8	74.3	14.0

¹ Where ethnicity is reported

² Source - Office of National Statistics

Note some rounding effects

POTENTIAL ORGAN DONORS

3 Potential organ donors

Due to the impact of the COVID-19 pandemic the Potential Donor Audit is currently incomplete for March 2020, therefore 2019-2020 activity presented in this section, includes 11 months of data from 1 April 2019 – 29 February 2020. Data presented on previous financial years include 12 months of data.

NHS Blood and Transplant (NHSBT) capture information about potential organ donors through the Potential Donor Audit (PDA). This audit is of all patient deaths in UK Intensive Care Units and emergency departments, excluding deaths on wards and any patients over 80 years of age. The PDA provides information about the organ donation process and identifies potential barriers to organ donation. All data shown in this section use the following definitions:

Patients for whom **neurological death is suspected** meet all of the following criteria: Apnoea, coma from known aetiology and unresponsive, ventilated, fixed pupils. However, cases for which cardiac arrest occurred despite resuscitation, brainstem reflexes returned, and neonates - less than 2 months post term are excluded.

Eligible donors after brain death (DBD) are defined as patients for whom death was confirmed following neurological tests and who had no absolute medical contraindications to solid organ donation.

Eligible donors after circulatory death (DCD) are defined as patients who had treatment withdrawn and death was anticipated within 4 hours, with no absolute medical contraindications to solid organ donation.

The neurological death testing rate is the proportion of patients in whom neurological death was suspected who were tested (DBD donor process only).

The referral rate is the percentage of patients for whom neurological death was suspected, or imminent death was anticipated, that were discussed with the Specialist Nurse - Organ Donation (SN-OD).

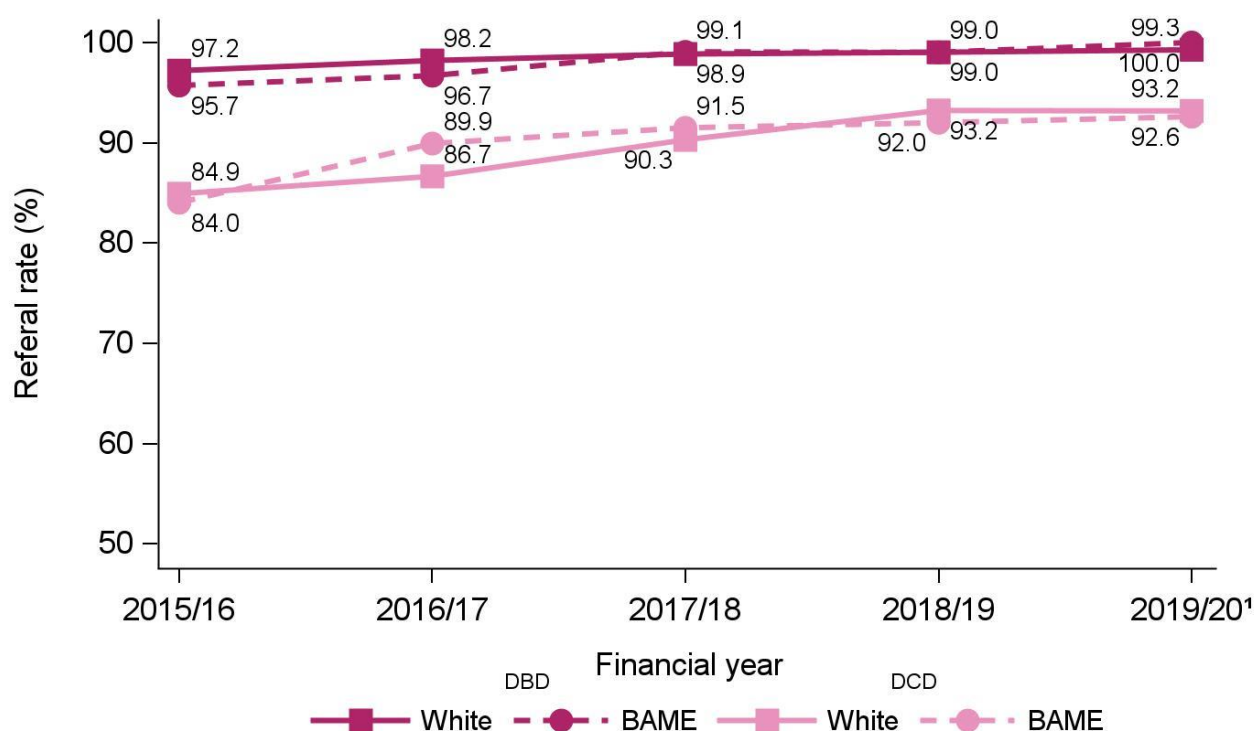
The consent/authorisation rate is the percentage of eligible donor families or nominated/appointed representatives approached for formal organ donation discussion where consent/authorisation was ascertained.

Tables II and III in the Appendix show more detailed data by BAME communities from both the DBD and DCD organ donation processes, respectively. The data in these tables are used to produce some of the figures in this chapter.

The neurological death testing rate for white and BAME potential DBD donors has been fairly constant over the past 5 years. Rates of neurological death testing for white and BAME potential donors were the same in 2019/20 (88%).

Figure 3.1 presents the DBD and DCD referral rates for white and BAME communities. Since 2015/16, there has been an increase in the referral of BAME potential DCD donors to a SN-OD from 84% to 93% in 2019/20. A similar rise has occurred for potential white DCD donors. In the last year, referral rates for BAME and white potential DBD donors were 100% and 99%, respectively.

Figure 3.1 Referral rates by ethnicity, 1 April 2015 - 29 February 2020



Small number of potential BAME donors per year

¹ 1 April 2019 - 29 February 2020

Figure 3.2 shows the number of eligible DBD donors and eligible DBD donors with consent ascertained over time for white and BAME communities, **Figure 3.3** shows the overall DBD consent/authorisation rates. Similarly, **Figure 3.4** and **Figure 3.5** illustrate the same information for DCD donation, respectively.

Figure 3.2 demonstrates that there was a similar number of BAME eligible DBD donors and a decrease in white eligible DBD donors as well as in white and BAME eligible consented/authorised DBD donors compared to 2018/19. This slight drop in activity is likely due to the reporting of 11-months' worth of data for 2019/20, many SNODs were transferred to ICU's in response to the COVID-19 pandemic. There has been no impact on the overall DBD consent/authorisation rates for white communities and the rate for BAME communities has fallen slightly as shown in **Figure 3.3**.

Whilst there is large pool of eligible DCD donors, many families are not approached for organ donation consent/authorisation due to the DCD screening process which precludes unsuitable donors from solid organ donation. As a result, there are fewer consented/authorised DCD donors as shown in **Figure 3.4**.

Over the last 5 years for BAME communities, there has been an increase in the number of eligible DCD donors and eligible consented/authorised DCD donors which is reflected in the growing DCD consent/authorisation rate. For white people, the number of eligible DCD donors and consented/authorised DCD donors dropped slightly. Overall, the consent/authorisation rate continues to increase over time and is unaffected by the reporting of 11 months of data for 2019/20.

In 2018/19, the proportion of eligible BAME deceased donors was 9.6%, this has increased to 10.2% in the last year.

Figure 3.2 Eligible DBD donors and eligible consented/authorised DBD donors by ethnicity, 1 April 2015 - 29 February 2020

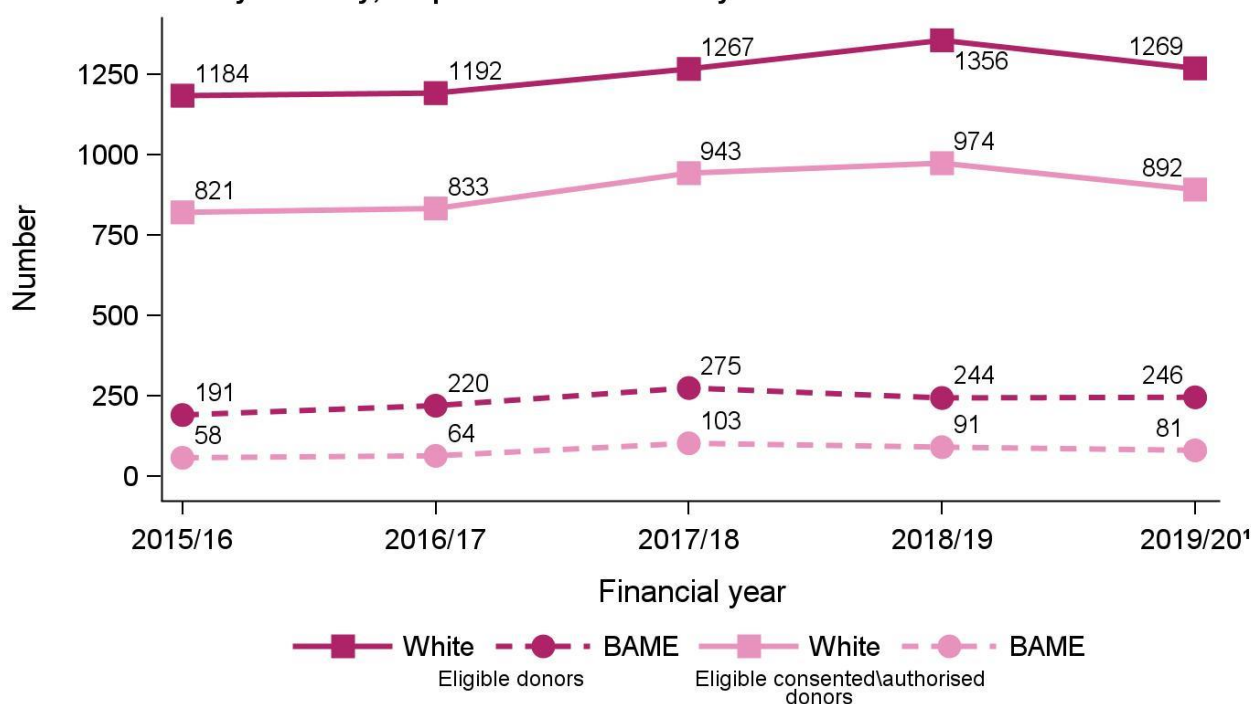
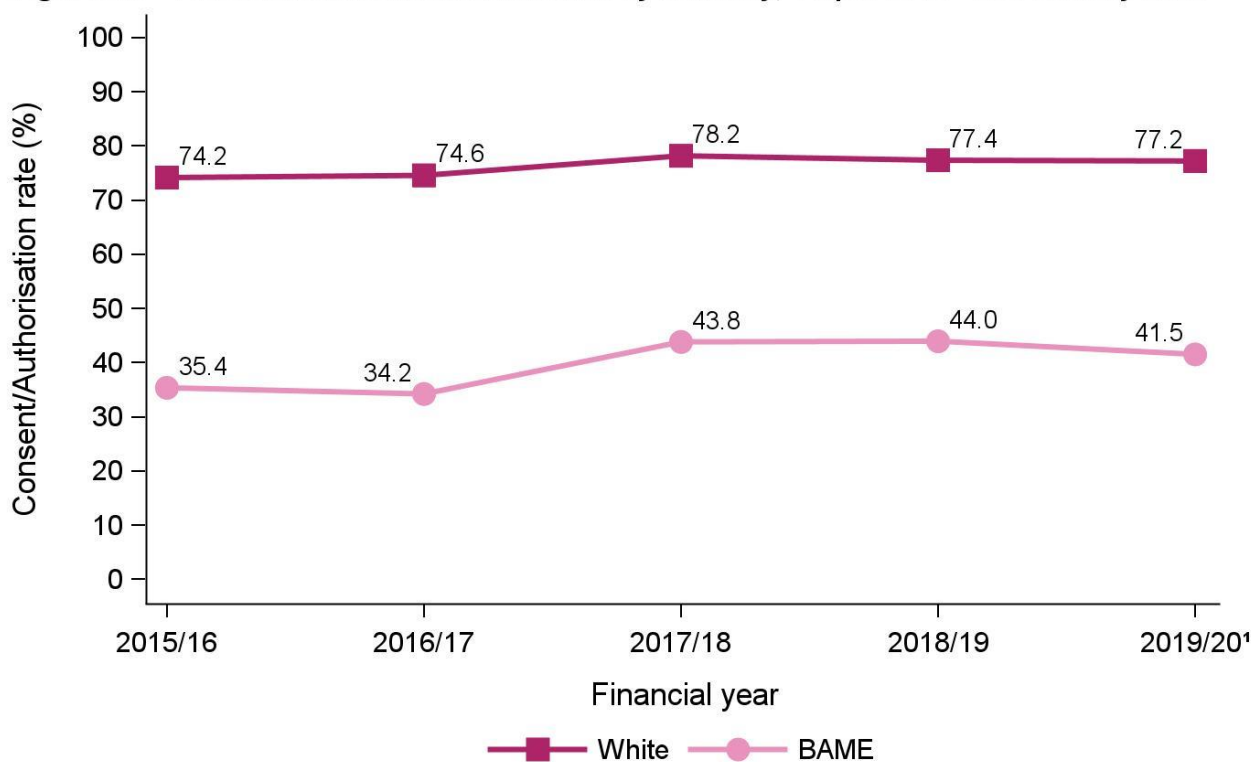
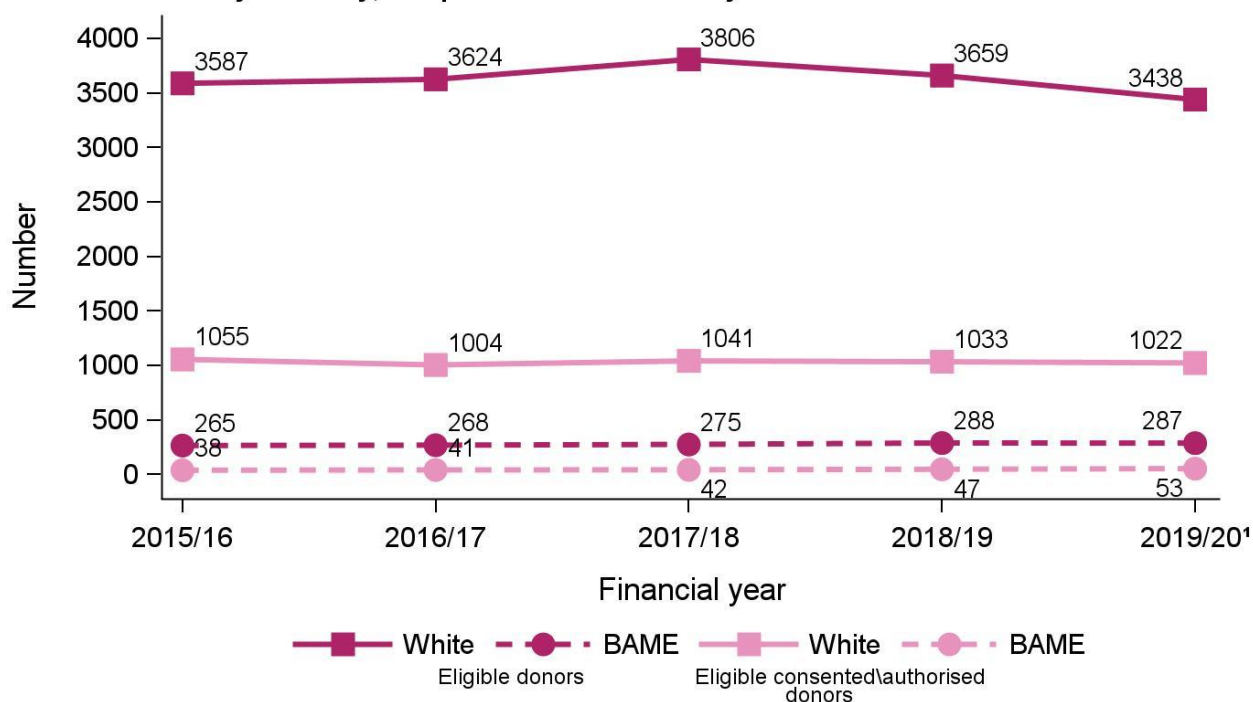


Figure 3.3 DBD consent/authorisation rates by ethnicity, 1 April 2015 - 29 February 2020



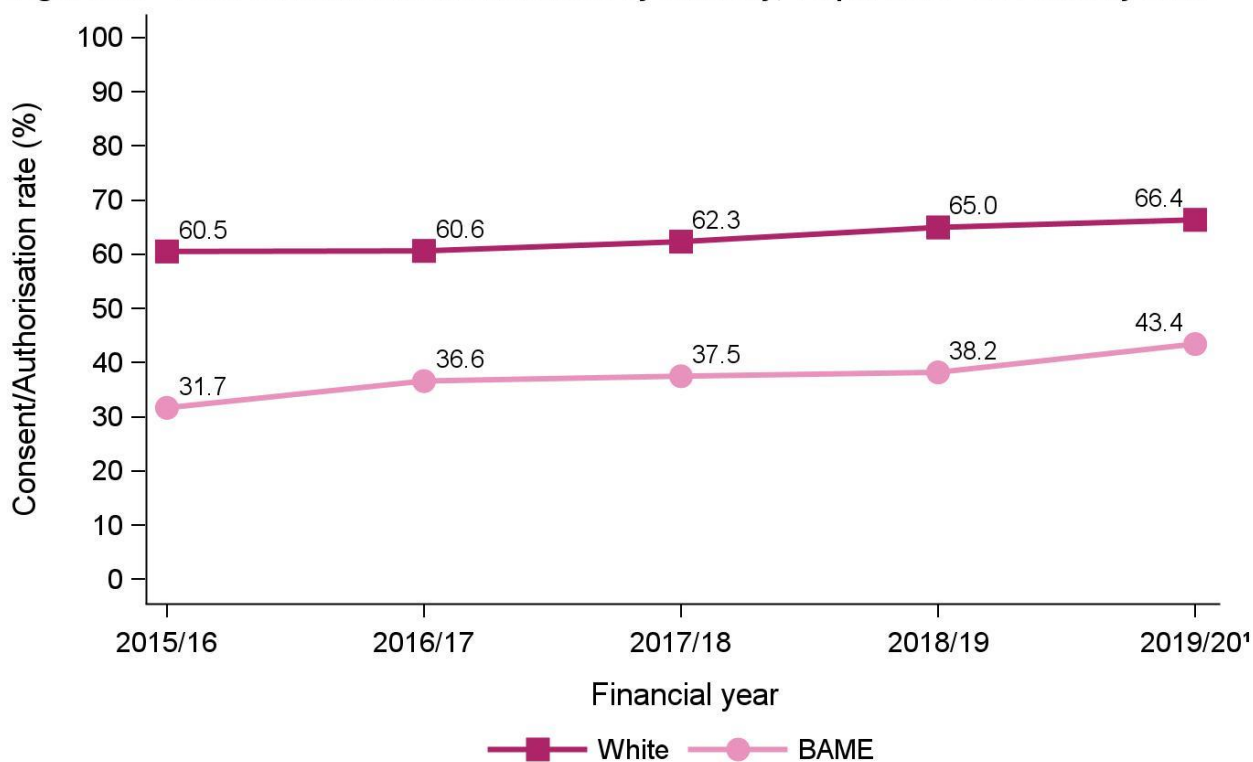
Rates should be interpreted with caution due to small numbers of BAME patients' families approached
¹ 1 April 2019 - 29 February 2020

Figure 3.4 Eligible DCD donors and eligible consented/authorised DCD donors by ethnicity, 1 April 2015 - 29 February 2020



¹ 1 April 2019 - 29 February 2020

Figure 3.5 DCD consent/authorisation rates by ethnicity, 1 April 2015 - 29 February 2020



Rates should be interpreted with caution due to small numbers of BAME patients' families approached

¹ 1 April 2019 - 29 February 2020

Table 3.1 shows the consent/authorisation rates separately for white and BAME patients broken down by the Organ Donation Services Teams (ODSTs) in the UK from 1 April 2015 to 29 February 2020. The data reports on a five-year period due to a small number of eligible BAME donors in some regions.

Table 3.1 DBD and DCD consent/authorisation rates from the Potential Donor Audit by Organ Donation Services Team (ODST) and ethnicity, 1 April 2015 - 29 February 2020							
ODST	Number of eligible DBD donors	Number of eligible DBD donors whose family were approached	DBD consent/authorisation rate (%)	Number of eligible DCD donors	Number of eligible DCD donors whose family were approached	DCD consent/authorisation rate (%)	Overall consent/authorisation rate (%)
White							
Eastern	587	559	76.6	2418	1020	66.7	70.2
London	685	648	72.2	1286	646	63.6	67.9
Midlands	683	621	76.2	2438	1172	60.5	65.9
North West	826	772	76.7	2581	1020	63.7	69.3
Northern	430	412	74.8	1328	507	62.7	68.1
Northern Ireland	255	235	66.4	505	214	57.9	62.4
Scotland	496	457	76.4	1271	683	52.4	62.0
South Central	438	420	81.0	1470	629	63.8	70.6
South East	648	589	75.7	1496	719	66.9	70.9
South Wales	238	227	81.5	751	329	65.7	72.1
South West	432	394	82.7	980	526	64.3	72.2
Yorkshire	550	510	76.9	1590	734	63.9	69.2
Total	6268	5844	76.4	18114	8199	62.9	68.5
BAME							
Eastern	91	77	40.3	136	70	41.4	40.8
London	501	439	41.2	456	202	41.6	41.3
Midlands	164	125	34.4	279	92	27.2	31.3
North West	102	86	31.4	104	41	24.4	29.1
Northern	13	13	61.5	26	10	50.0	56.5
Northern Ireland	6	4	50.0	7	5	60.0	55.6
Scotland	23	17	29.4	24	11	18.2	25.0
South Central	50	42	54.8	78	43	41.9	48.2
South East	147	125	45.6	136	60	36.7	42.7
South Wales	9	8	75.0	17	6	66.7	71.4
South West	13	10	60.0	28	14	50.0	54.2
Yorkshire	57	42	19.0	92	35	34.3	26.0
Total	1176	988	40.2	1383	589	37.5	39.2

Families of BAME eligible donors' consent/authorise organ donation at a rate of 40% for DBD donation and 38% for DCD donation compared with families of white eligible donors' whom consent/authorise organ donation at a rate of 76% for DBD donation and 63% for DCD donation from 1 April 2015 to 29 February 2020.

Table 3.2 shows the consent/authorisation rates for families approached for organ donation by ethnicity and financial year for the same time period. Overall, there has been a small increase in consent/authorisation rates for white people from 66% to 71% and a slightly bigger increase for BAME communities from 34% to 42%.

Table 3.2 Consent/authorisation (Con/auth) rates for families approached (app) for organ donation by ethnicity and financial year, 1 April 2015 - 29 February 2020										
Ethnicity	2015/16		2016/17		Financial year 2017/18		2018/19		2019/20¹	
	App	Con/auth rate %	App	Con/auth rate %	App	Con/auth rate %	App	Con/auth rate %	App	Con/auth rate %
White	2850	65.8	2773	66.2	2876	69.0	2849	70.4	2695	71.0
Asian	148	29.7	145	26.9	155	38.1	166	39.8	151	35.8
Black	81	29.6	93	36.6	97	34.0	90	32.2	93	39.8
Chinese/East Asian	10	30.0	18	22.2	24	29.2	18	50.0	20	50.0
Mixed	16	43.8	21	81.0	29	79.3	17	64.7	17	47.1
Other	29	62.1	22	50.0	42	54.8	39	59.0	36	69.4
BAME	284	33.8	299	35.1	347	41.8	330	41.8	317	42.3
¹ 1 April 2019 to 29 February 2020										

Table 3.3 shows the reasons given by a family when declining consent/authorisation for organ donation, by ethnicity, from 1 April 2015 to 29 February 2020. The main reasons BAME families gave for refusing consent/authorisation for organ donation was that they felt it was against their religious/cultural beliefs or they were unsure whether the patient would have agreed to donation. It is important to note that the most fitting reason following family discussion is chosen from a list by the attending/facilitating SNOD. Survey results of BAME communities shows that not knowing enough about organ donation is also a major barrier to organ donation. NHSBT and the National BAME Transplant Alliance (NBTA) have been working in partnership over a number of years to address these barriers. The Community Investment Scheme and the Living Transplant Initiative are now well-established programmes which empower BAME community groups to promote organ donation in targeted groups.

Table 3.3 Reasons for family refusal to give consent/authorisation for organ donation by ethnicity, 1 April 2015 - 29 February 2020												
Consent/authorisation refusal reason	Potential donor ethnicity											
	White		Asian		Black		Chinese/ East Asian		Mixed		Other	
	N	%	N	%	N	%	N	%	N	%	N	%
Patient previously expressed a wish not to donate	1056	23.9	63	12.5	53	17.8	4	7.0	6	17.6	8	11.8
Family were not sure whether the patient would have agreed to donation	720	16.3	55	10.9	44	14.8	11	19.3	8	23.5	11	16.2
Family felt the length of time for donation process was too long	615	13.9	11	2.2	7	2.4	3	5.3	3	8.8	2	2.9
Family did not want surgery to the body	427	9.6	46	9.1	17	5.7	6	10.5	3	8.8	7	10.3
Family felt the patient had suffered enough	358	8.1	18	3.6	11	3.7	1	1.8	3	8.8		
Other	342	7.7	30	6.0	22	7.4	1	1.8	3	8.8	10	14.7
Family were divided over the decision	203	4.6	23	4.6	16	5.4			2	5.9	2	2.9
Family felt the body needs to be buried whole (unrelated to religious or cultural reasons)	185	4.2	28	5.6	26	8.8	5	8.8	2	5.9	6	8.8
Strong refusal - probing not appropriate	176	4.0	23	4.6	14	4.7	1	1.8	1	2.9	1	1.5
Family did not believe in donation	142	3.2	32	6.4	18	6.1	5	8.8	2	5.9	3	4.4
Family wanted to stay with the patient after death	62	1.4	4	0.8	1	0.3	1	1.8				
Family concerned that organs may not be transplanted	62	1.4	4	0.8								
Family felt it was against their religious/cultural beliefs	43	1.0	157	31.2	57	19.2	19	33.3	1	2.9	17	25.0
Family had difficulty understanding/accepting neurological testing	14	0.3	2	0.4	4	1.3						
Family concerned that other people may disapprove/be offended	8	0.2	4	0.8	3	1.0						
Families concerned about organ allocation	6	0.1			3	1.0						
Family concerned donation may delay the funeral	5	0.1	3	0.6							1	1.5
Patients treatment may be or has been limited to facilitate organ donation	1	0.0			1	0.3						
Total	4425	100.0	503	100.0	297	100.0	57	100.0	34	100.0	68	100.0

ORGAN DONORS, TRANSPLANT RECIPIENTS AND TRANSPLANT WAITING LIST

4.1 Overview

This section contains data on all organ donors (living and deceased), transplants and patients on the transplant waiting list over time. Further information is also included on post-registration outcomes, median waiting times to transplant and donor to recipient ethnicities.

Figure 4.1 shows BAME deceased and living donors, all BAME transplants and those patients on the active transplant list as at 31 March every financial year (with the exception of this year) from 1 April 2015 to 31 March 2020. Many patients became suspended from the active transplant list as transplant centres reacted to the COVID-19 pandemic in March 2020, thus 29 February 2020 is used as a more representative date for the number of patients on the active transplant list at year end this year.

The number of BAME transplant recipients has increased year on year, while the number of BAME patients on the transplant list has grown at a smaller rate over this time. Each year there are consistently more BAME living donors than BAME deceased donors. In 2019/20, there were 1187 deceased and living donor transplants for BAME patients, 142 living BAME donors, 112 deceased BAME donors whilst 1909 BAME patients were waiting for a transplant. Although in the last year, there was an increase in transplants for BAME recipients, it is likely that the suspension of elective surgeries as a result to COVID-19 had a slight impact on these figures. This is also shown by a reduction in the number of living and deceased donors.

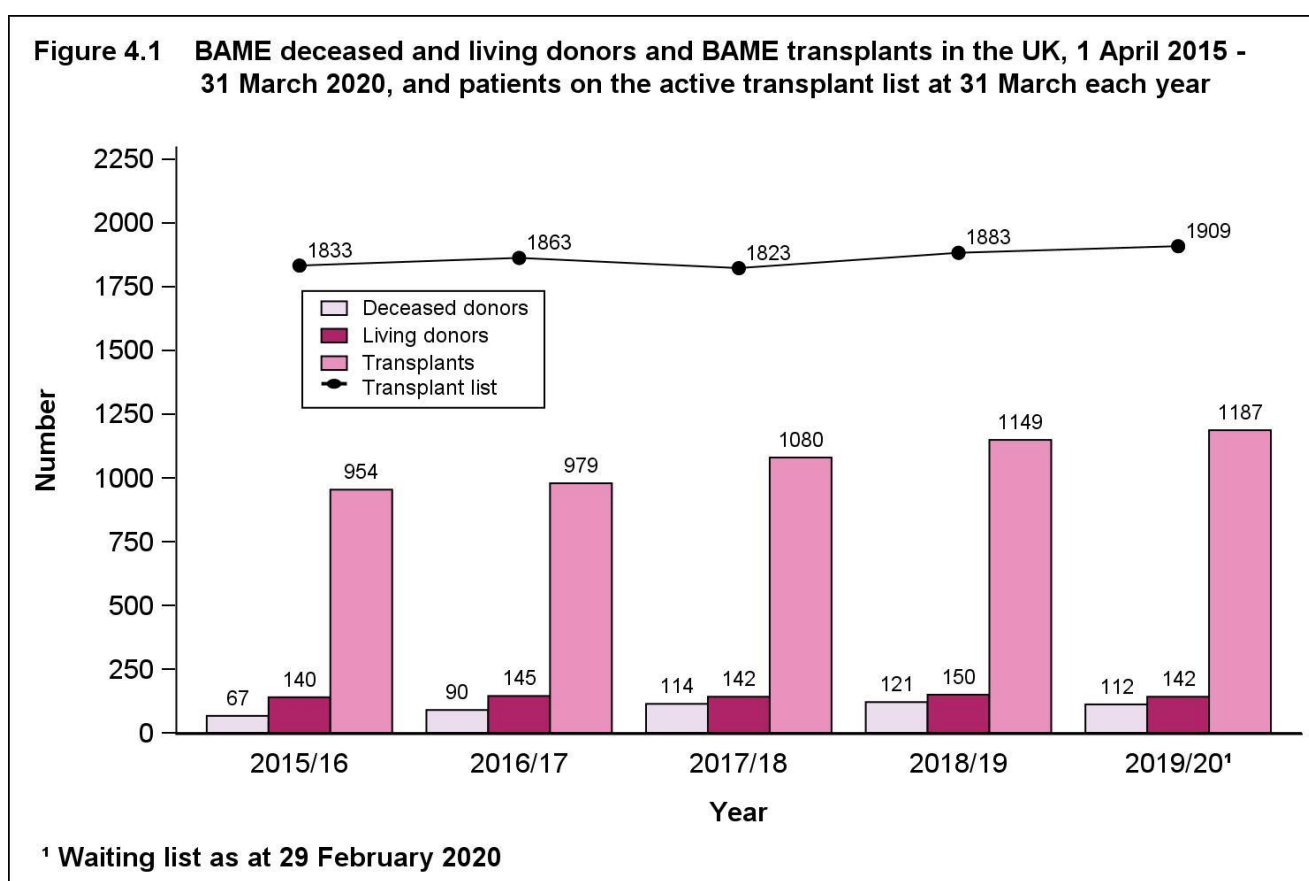
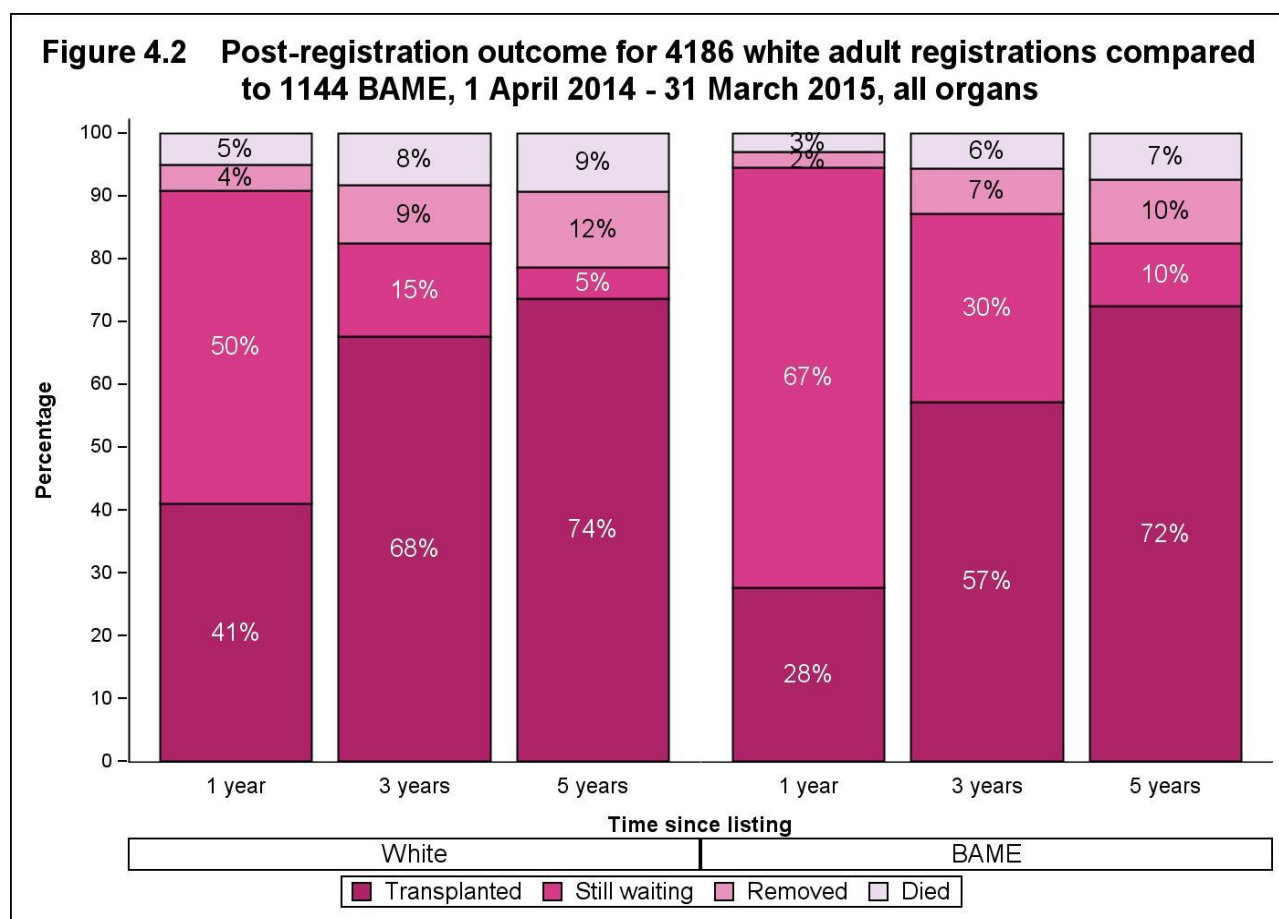


Table 4.1 shows a further breakdown of the number of living and deceased BAME donors, transplants and those on the transplant waiting list from 1 April 2015 to 31 March 2020, where totals exclude those with ethnicity not recorded. Rates per million population (pmp) of the total population are also shown. Last year, BAME patients accounted for a third of patients on the transplant waiting list, a quarter of all transplants and 10% of donors were from BAME communities.

Table 4.1 Number of total and BAME donors, transplants and waiting list patients in the UK, by financial year, 1 April 2015 – 31 March 2020					
	Financial year				
	2015/16	2016/17	2017/18	2018/19	2019/20
Waiting list ¹	6383	6291	5949	5988	6040
BAME waiting list ¹	1833	1863	1823	1883	1909
BAME % of waiting list	28.7	29.6	30.6	31.4	31.6
BAME on waiting list per million population of total UK population (pmp)	27.6	28.0	27.4	28.3	28.7
Total donors	2442	2442	2619	2634	2564
Total BAME donors	207	235	256	271	254
BAME % of donors	8.5	9.6	9.8	10.3	9.9
BAME donors pmp	3.1	3.5	3.9	4.1	3.8
Deceased donors	1363	1398	1555	1589	1566
Deceased BAME donors	67	90	114	121	112
<i>DBD BAME donors</i>	<i>49</i>	<i>62</i>	<i>83</i>	<i>90</i>	<i>76</i>
<i>DCD BAME donors</i>	<i>18</i>	<i>28</i>	<i>31</i>	<i>31</i>	<i>36</i>
BAME % of deceased donors	4.9	6.4	7.3	7.6	7.2
Deceased BAME donors pmp	1	1.4	1.7	1.8	1.7
Living donors	1079	1044	1064	1045	998
Living BAME donors	140	145	142	150	142
BAME % of living donors	13.0	13.9	13.3	14.4	14.2
Living BAME donors pmp	2.1	2.2	2.1	2.3	2.1
Total transplants	4554	4709	5044	4941	4694
Total BAME transplants	954	979	1080	1149	1187
BAME % of transplants	20.9	20.8	21.4	23.3	25.3
BAME transplants pmp	14.4	14.7	16.3	17.3	17.9
Deceased donor (DD) transplants	3493	3673	3996	3910	3710
BAME DD transplants	785	810	903	970	1010
BAME % of deceased donor transplants	22.5	22.1	22.6	24.8	27.2
BAME DD transplants pmp	11.8	12.2	13.6	14.6	15.2
Living donor (LD) transplants	1061	1036	1048	1031	984
BAME LD transplants	169	169	177	179	177
BAME % of LD transplants	15.9	16.3	16.9	17.4	18.0
BAME LD transplants pmp	2.5	2.5	2.7	2.7	2.7
Those with unknown/unreported ethnicity were excluded					
Per million population of total UK population in 2018					
¹ Waiting list as at 31 March for 2016–2019 and 29 February 2020					

Figure 4.2 and **Table 4.2** show post-registration outcomes (transplanted, still waiting, removed from the list or died waiting on the list) for all organs after one year, three years and five years for white patients compared to BAME patients registered between 1 April 2014 and 31 March 2015. Liver patients that were removed from the list because their condition deteriorated were grouped with those who died. This figure illustrates that BAME communities tend to wait for an organ longer than white patients, however, proportionally fewer are removed from the transplant list or die waiting for a transplant.



Outcome	1 year		3 years		5 years	
	N	%	N	%	N	%
White						
Transplanted	1717	41.0	2830	67.6	3085	73.7
Still waiting	2089	49.9	621	14.8	209	5.0
Removed	169	4.0	391	9.3	506	12.1
Died	211	5.0	344	8.2	386	9.2
BAME						
Transplanted	316	27.6	655	57.3	829	72.5
Still waiting	766	67.0	343	30.0	115	10.1
Removed	28	2.4	82	7.2	116	10.1
Died	34	3.0	64	5.6	84	7.3

This pattern is further demonstrated in **Table 4.3** which gives the median waiting time to transplant for adult and paediatric patients for each organ. Generally, white patients wait less time than BAME patients with the exception of adult liver, pancreas and non-urgent adult hearts. Black patients or those of other ethnic minority groups tend to wait the longest across all organs.

Table 4.3 Median waiting time to transplant in the UK

Ethnicity	Number of patients registered	Waiting time (days)	
		Median	95% Confidence interval
Adult kidney¹			
White	6957	573	557 - 589
Asian	1688	736	695 - 777
Black	982	900	845 - 955
Other	334	743	676 - 810
TOTAL	10082	633	619 - 647
Paediatric kidney¹			
White	151	222	170 - 274
Asian	78	384	260 - 508
Black	15	540	233 - 847
Other	18	560	448 - 672
TOTAL	265	291	206 - 376
Adult pancreas²			
White	812	348	322 - 374
Asian	54	347	261 - 433
Black	49	414	326 - 502
Other	15	186	168 - 204
TOTAL	939	352	329 - 375
Adult liver³			
White	849	65	54 - 76
Asian	52	89	56 - 122
Black	19	59	25 - 93
Other	41	37	22 - 52
TOTAL	976	65	54 - 76
Paediatric liver³	69	77	48 - 106
Adult never urgent heart⁴			
White	396	1798	1080 - 2516
Asian	24	506	0 - 1222
Black	17	742	86 - 1398
Other ⁶	5		
TOTAL	443	1487	909 - 2065
Adult ever urgent heart^{4,5}			
White	636	31	27 - 35
Asian	74	33	22 - 44
Black	27	68	1 - 135
Other	15	34	24 - 44
TOTAL	758	32	28 - 36
Paediatric never urgent heart⁴	32	463	0 - 951
Paediatric ever urgent heart⁴	214	77	54 - 100
Adult lung⁴			
White	1354	322	285 - 359
Asian	55	592	289 - 895
Black	16	735	526 - 944
Other ⁶	3		
TOTAL	1434	336	299 - 373

Median waiting time not reported for fewer than 10 patients

¹ Kidney-only patients registered 1 April 2013 - 31 March 2017

² Pancreas-only and kidney/pancreas patients registered 1 April 2014 - 31 March 2018

³ Liver patients registered 1 April 2018 - 31 March 2019

⁴ Cardiothoracic patients registered 1 April 2012 - 31 March 2017

⁵ Includes registrations and waiting time on super-urgent list where applicable

⁶ Median and/or 95% confidence interval cannot be estimated

The number of deaths on the transplant waiting list broken down by financial year, organ type and ethnicity are shown in **Table 4.4**. Since 2015/16, there has been a gradual decrease in the number of deaths on the waiting list across all organs, from 585 to 397 in the last financial year. BAME patients accounted for 18% of those who died waiting for a transplant in 2019/20.

Table 4.4 Number of deaths on the transplant waiting list, by financial year, organ and ethnicity, 1 April 2015 - 29 February 2020											
Ethnicity		2015/16		2016/17		2017/18		2018/19		2019/20	
		N	%	N	%	N	%	N	%	N	%
Kidney											
	White	246	75.9	250	78.1	226	73.6	225	76.3	192	78.0
	Asian	36	11.1	39	12.2	41	13.4	39	13.2	31	12.6
	Black	32	9.9	26	8.1	30	9.8	16	5.4	14	5.7
	Other	10	3.1	5	1.6	10	3.3	15	5.1	9	3.7
	Unknown	5		1		5		5		4	
	Total	329	100.0	321	100.0	312	100.0	300	100.0	250	100.0
Pancreas											
	White	27	96.4	22	88.0	24	85.7	19	95.0	13	92.9
	Asian					1	3.6			1	7.1
	Black	1	3.6	2	8.0	2	7.1				
	Other			1	4.0	1	3.6	1	5.0		
	Unknown							1			
	Total	28	100.0	25	100.0	28	100.0	21	100.0	14	100.0
Liver											
	White	90	85.7	88	92.6	61	81.3	45	86.5	38	84.4
	Asian	9	8.6	5	5.3	7	9.3	6	11.5	5	11.1
	Black	4	3.8	1	1.1	4	5.3	1	1.9	2	4.4
	Other	2	1.9	1	1.1	3	4.0				
	Unknown							2		6	
	Total	105	100.0	95	100.0	75	100.0	54	100.0	51	100.0
Cardiothoracic											
	White	107	87.7	111	91.7	99	92.5	77	87.5	74	90.2
	Asian	8	6.6	8	6.6	4	3.7	8	9.1	4	4.9
	Black	7	5.7	2	1.7	4	3.7	2	2.3	3	3.7
	Other							1	1.1	1	1.2
	Unknown	1									
	Total	123	100.0	121	100.0	107	100.0	88	100.0	82	100.0
Total											
	White	470	81.2	471	84.0	410	79.3	366	80.4	317	81.9
	Asian	53	9.2	52	9.3	53	10.3	53	11.6	41	10.6
	Black	44	7.6	31	5.5	40	7.7	19	4.2	19	4.9
	Other	12	2.1	7	1.2	14	2.7	17	3.7	10	2.6
	Unknown	6		1		5		8		10	
	Total	585	100.0	562	100.0	522	100.0	463	100.0	397	100.0

Figure 4.3 and **Table 4.5** display donor ethnicities for each recipient ethnic group for all transplants in the UK over the last 5 years (1 April 2015 to 31 March 2020). It shows that most ethnicities receive an organ from a white donor (living or deceased). There is also evidence of ethnicity matching between donor and recipient, with the second most common donor ethnicity being the same as the recipient's ethnicity for most BAME groups.

Figure 4.3 Donor to recipient ethnicities for all transplants in the UK, 1 April 2015 - 31 March 2020

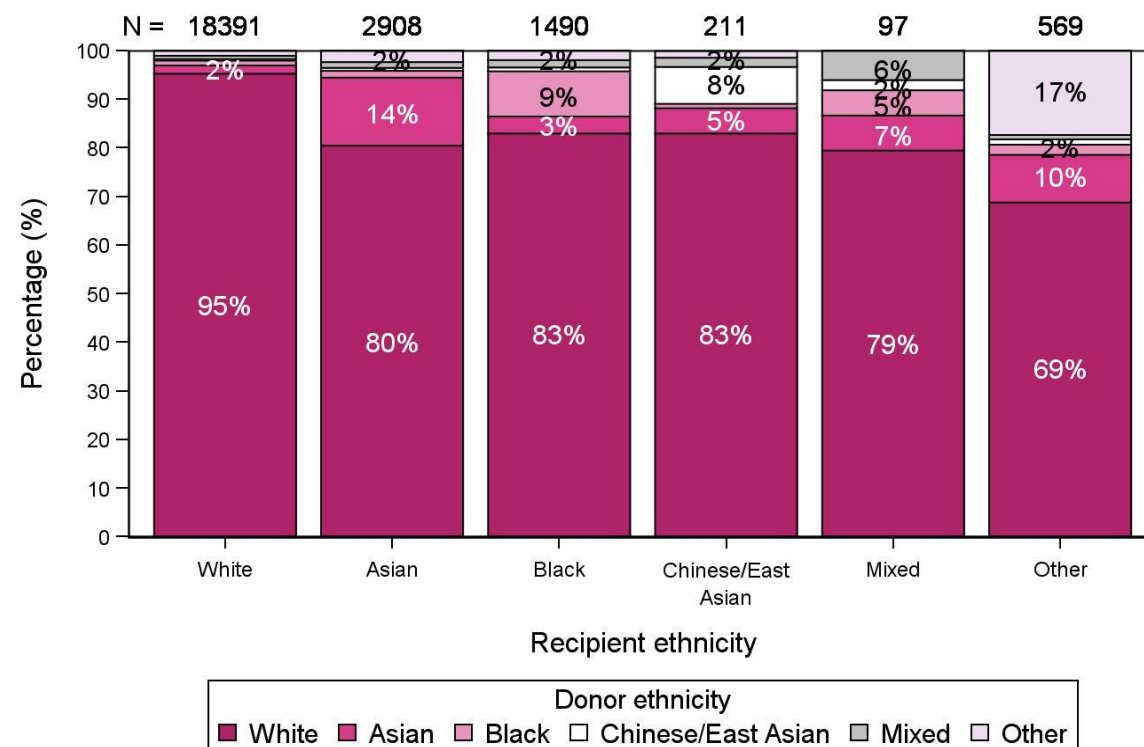


Table 4.5 Donor to recipient ethnicities for all transplants in the UK, 1 April 2015 - 31 March 2020

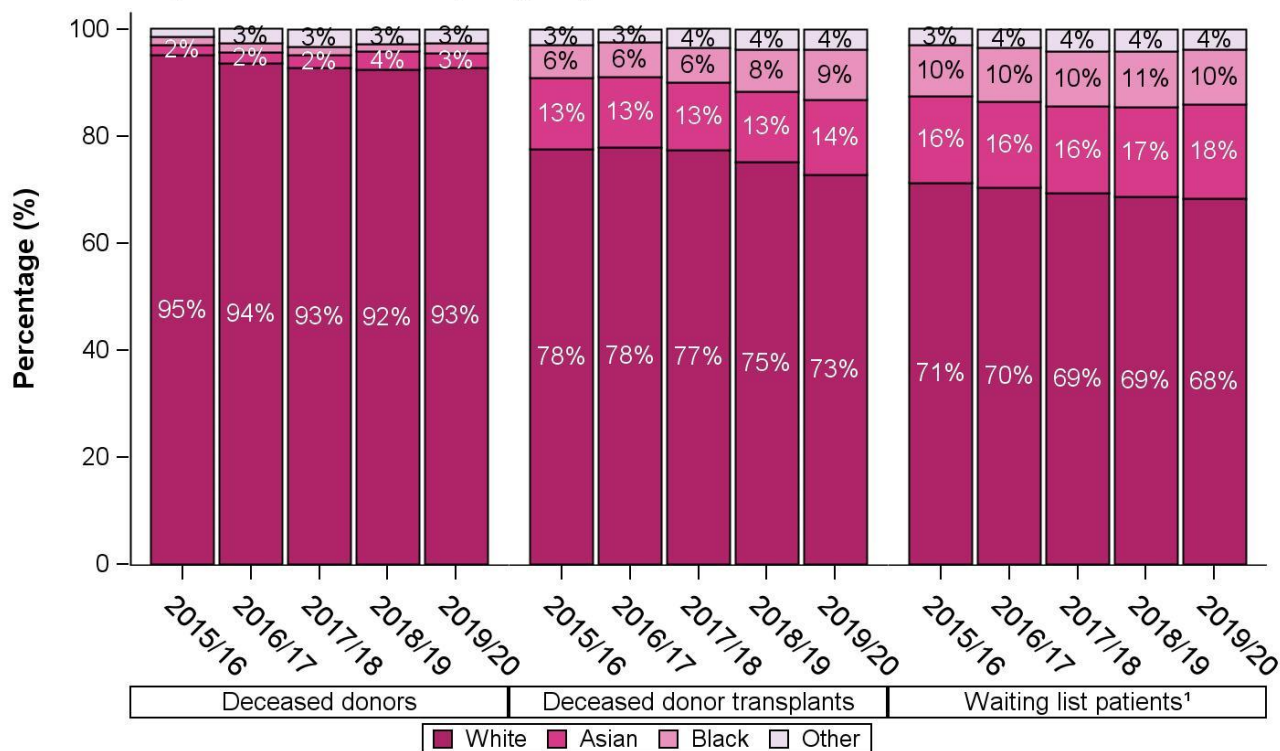
Donor ethnicity	Recipient ethnicity												Total
	White		Asian		Black		Chinese/ East Asian		Mixed		Other		
	N	%	N	%	N	%	N	%	N	%	N	%	
White	17511	95.2	2337	80.4	1235	82.9	175	82.9	77	79.4	391	68.7	21726
Asian	315	1.7	406	14.0	52	3.5	11	5.2	7	7.2	56	9.8	847
Black	176	1.0	42	1.4	138	9.3	2	0.9	5	5.2	12	2.1	375
Chinese/East Asian	60	0.3	16	0.6	12	0.8	16	7.6	2	2.1	6	1.1	112
Mixed	128	0.7	36	1.2	22	1.5	4	1.9	6	6.2	5	0.9	201
Other	201	1.1	71	2.4	31	2.1	3	1.4	0	0.0	99	17.4	405
Total	18391	100.0	2908	100.0	1490	100.0	211	100.0	97	100.0	569	100.0	23666

Many patients became suspended from the active transplant list as transplant centres reacted to the COVID-19 pandemic in March 2020, thus 29 February 2020 is used as a more representative date for the number of patients on the active transplant list at year end this year.

Deceased organ donors, deceased donor transplant recipients and patients on the transplant list at 31 March each year (with the exception of this year) are shown by ethnicity from 2015/16 to 2019/20 in **Figure 4.4** and **Figure 4.5** where **Figure 4.4** includes all patients and **Figure 4.5** only includes ethnic minority groups. Similarly, **Figure 4.6** and **Figure 4.7** display this information for living donors and living donor transplant recipients receiving a kidney or liver. Numbers relating to **Figures 4.4 to 4.7** are shown in **Table 4.6**; numbers in these charts are subject to rounding effects.

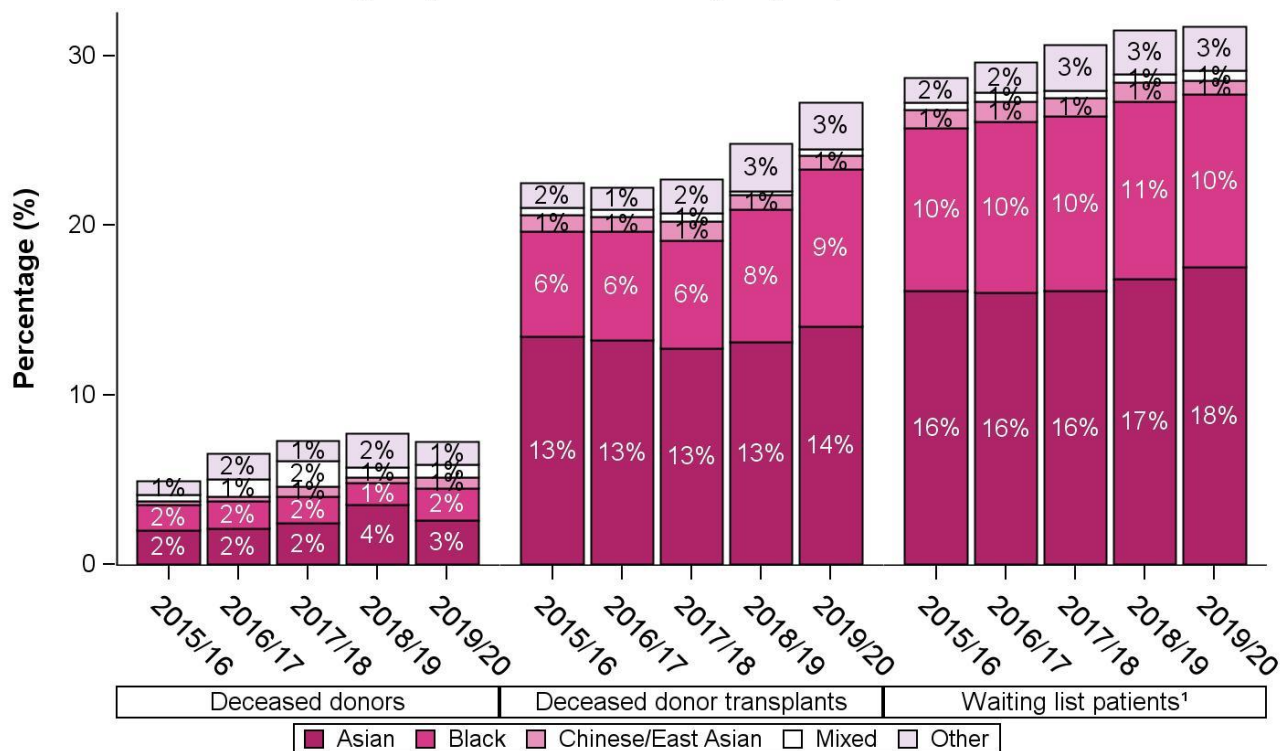
The figures illustrate that there are proportionally more BAME living donors than BAME deceased donors. There are proportionally more BAME people on the list for transplant than there are among people transplanted, reflecting an inequity of access to transplant for some organs.

Figure 4.4 Deceased donors, deceased donor transplants and patients on the waiting list
(as at 31 March each year), 1 April 2015 - 31 March 2020



¹ Waiting list as at 29 February 2020 for 2019/20

Figure 4.5 BAME communities - Deceased donors, deceased donor transplants and patients on the waiting list
(as at 31 March each year), 1 April 2015 - 31 March 2020



¹ Waiting list as at 29 February 2020 for 2019/20

Figure 4.6 Living donors and transplants, 1 April 2015 - 31 March 2020

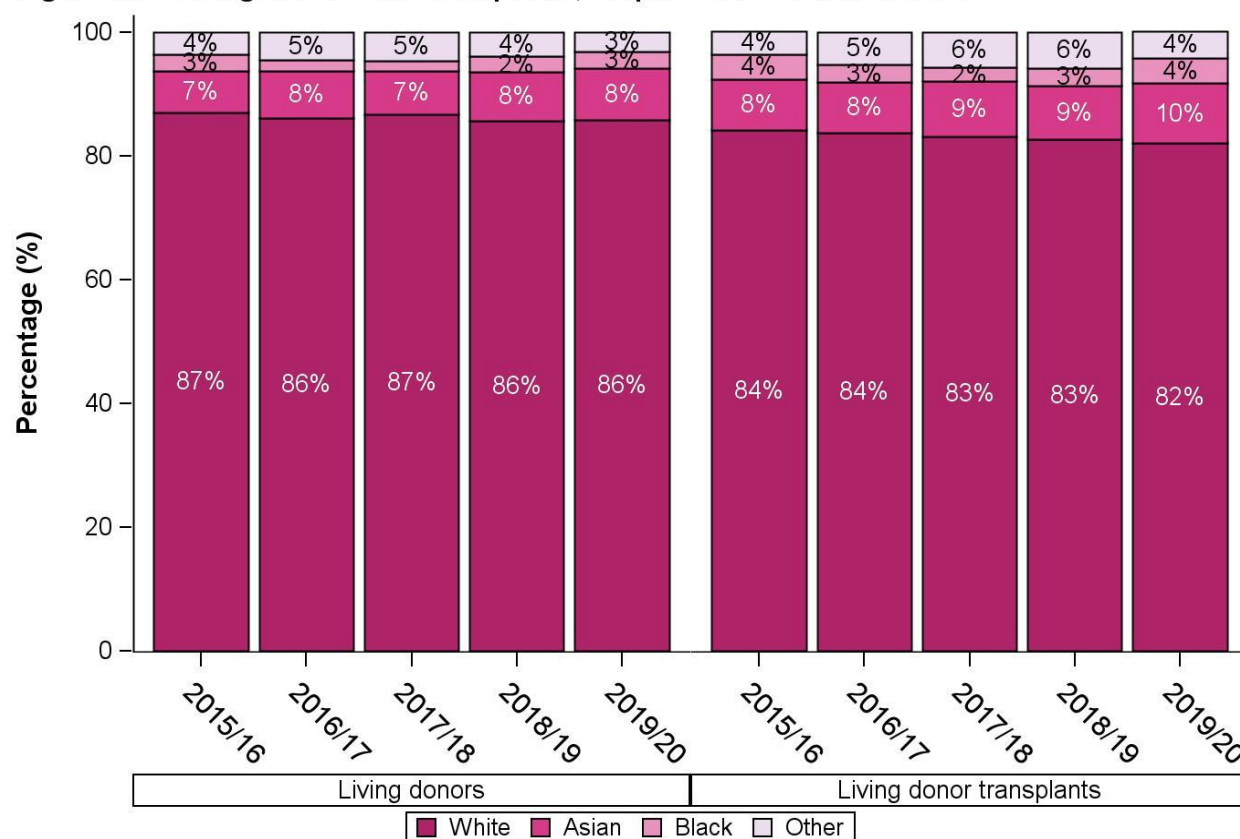


Figure 4.7 BAME communities - Living donors and transplants, 1 April 2015- 31 March 2020

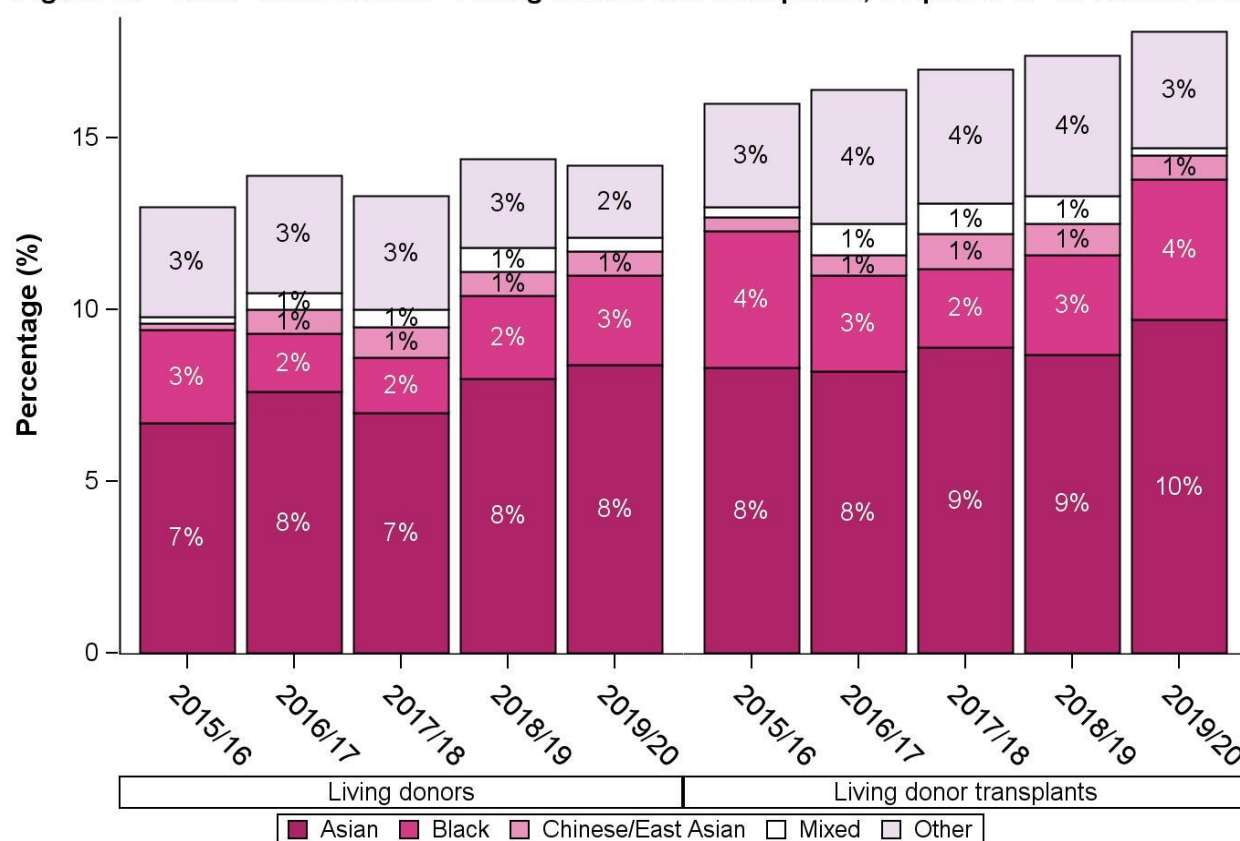


Table 4.6 Number of donors, transplants and waiting list patients in the UK, by ethnicity and financial year, 1 April 2015 - 31 March 2020

Ethnicity	Financial year									
	2015/16		2016/17		2017/18		2018/19		2019/20	
	N	%	N	%	N	%	N	%	N	%
Deceased donors										
White	1296	95.1	1308	93.6	1441	92.7	1468	92.4	1454	92.8
Asian	27	2.0	29	2.1	37	2.4	56	3.5	40	2.6
Black	20	1.5	22	1.6	25	1.6	20	1.3	30	1.9
Chinese/East Asian	3	0.2	4	0.3	9	0.6	4	0.3	10	0.6
Mixed	6	0.4	14	1.0	24	1.5	9	0.6	12	0.8
Other	11	0.8	21	1.5	19	1.2	32	2.0	20	1.3
Deceased donor transplants										
White	2708	77.5	2863	77.9	3093	77.4	2940	75.2	2700	72.8
Asian	467	13.4	484	13.2	507	12.7	512	13.1	519	14.0
Black	217	6.2	235	6.4	254	6.4	305	7.8	346	9.3
Chinese/East Asian	36	1.0	32	0.9	44	1.1	35	0.9	29	0.8
Mixed	14	0.4	13	0.4	19	0.5	7	0.2	14	0.4
Other	51	1.5	46	1.3	79	2.0	111	2.8	102	2.7
Waiting list¹										
White	4550	71.3	4428	70.4	4126	69.4	4105	68.6	4131	68.4
Asian	1025	16.1	1008	16.0	958	16.1	1006	16.8	1057	17.5
Black	612	9.6	633	10.1	614	10.3	630	10.5	615	10.2
Chinese/East Asian	73	1.1	73	1.2	68	1.1	63	1.1	47	0.8
Mixed	25	0.4	33	0.5	22	0.4	31	0.5	35	0.6
Other	98	1.5	116	1.8	161	2.7	153	2.6	155	2.6
Living donors										
White	939	87.0	899	86.1	922	86.7	895	85.6	856	85.8
Asian	72	6.7	79	7.6	75	7.0	84	8.0	84	8.4
Black	29	2.7	18	1.7	17	1.6	25	2.4	26	2.6
Chinese/East Asian	2	0.2	7	0.7	10	0.9	7	0.7	7	0.7
Mixed	2	0.2	5	0.5	5	0.5	7	0.7	4	0.4
Other	35	3.2	36	3.4	35	3.3	27	2.6	21	2.1
Living donor transplants										
White	892	84.1	867	83.7	871	83.1	852	82.6	807	82.0
Asian	88	8.3	85	8.2	93	8.9	90	8.7	95	9.7
Black	42	4.0	29	2.8	24	2.3	30	2.9	40	4.1
Chinese/East Asian	4	0.4	6	0.6	10	1.0	9	0.9	7	0.7
Mixed	3	0.3	9	0.9	9	0.9	8	0.8	2	0.2
Other	32	3.0	40	3.9	41	3.9	42	4.1	33	3.4

Unknown ethnicity was excluded

¹ Waiting list as at 31 March for 2016–2019 and 29 February 2020

Table 4.7 summarises all deceased donor transplants by country of residence, ethnicity of recipient and organ transplanted in 2019/20. 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 BAME deceased donor transplant recipients live in Northern Ireland, Scotland or Wales.

Table 4.7 Deceased donor transplants by country of residence, organ and ethnicity, 1 April 2019 - 31 March 2020

Country of residence	Transplants (N)								
	Kidney	Pancreas ¹	Kidney/ Pancreas	Heart	Lung	Liver	Intestinal	Multiorgan ²	Total
England									
White	1170	24	96	126	118	625	5	28	2196
Asian	390		10	19	9	66		5	499
Black	284		17	4		29		1	335
Chinese/East Asian	23					3			26
Mixed	8		1	3		1			13
Other	68		3		1	22	1		95
Wales									
White	75		10	4	10	36		1	136
Asian	5								5
Black	4					1			5
Chinese/East Asian	2								2
Mixed	1								1
Other	1								1
Scotland									
White	158	10	23	12	9	66		1	280
Asian	12			1		1			14
Black	5								5
Chinese/East Asian	1								1
Other	5					1			6
Northern Ireland									
White	42	2	1	3	6	30		1	85
Asian	1								1
Black	1								1

¹ Includes 23 islet transplants

² Includes 5 heart/lung transplants, 8 multivisceral transplants, 6 modified multivisceral transplants, 15 liver and kidney transplants, 1 heart and kidney transplant, 1 heart and liver transplant and 1 lung and liver transplant

67 unknown UK addresses, 4 overseas and 8 from Ireland were defined as the country of transplant

4.2 Kidney

The vast majority of transplants are for patients who require a kidney either from living or deceased donation. Post-registration outcomes, median waiting times, donor to recipient ethnicities, deceased and living donor transplants are detailed in this section.

Figure 4.8 and **Table 4.8** show post-registration outcome comparisons for white and BAME adult kidney patients registered from 1 April 2014 to 31 March 2015. Post-registration, 20% of BAME kidney patients compared to 31% of white patients are transplanted in the first year. BAME patients are waiting longer for a kidney compared to white patients but have a lower death or removal rate, with a higher rate of patients remaining waiting on the list.

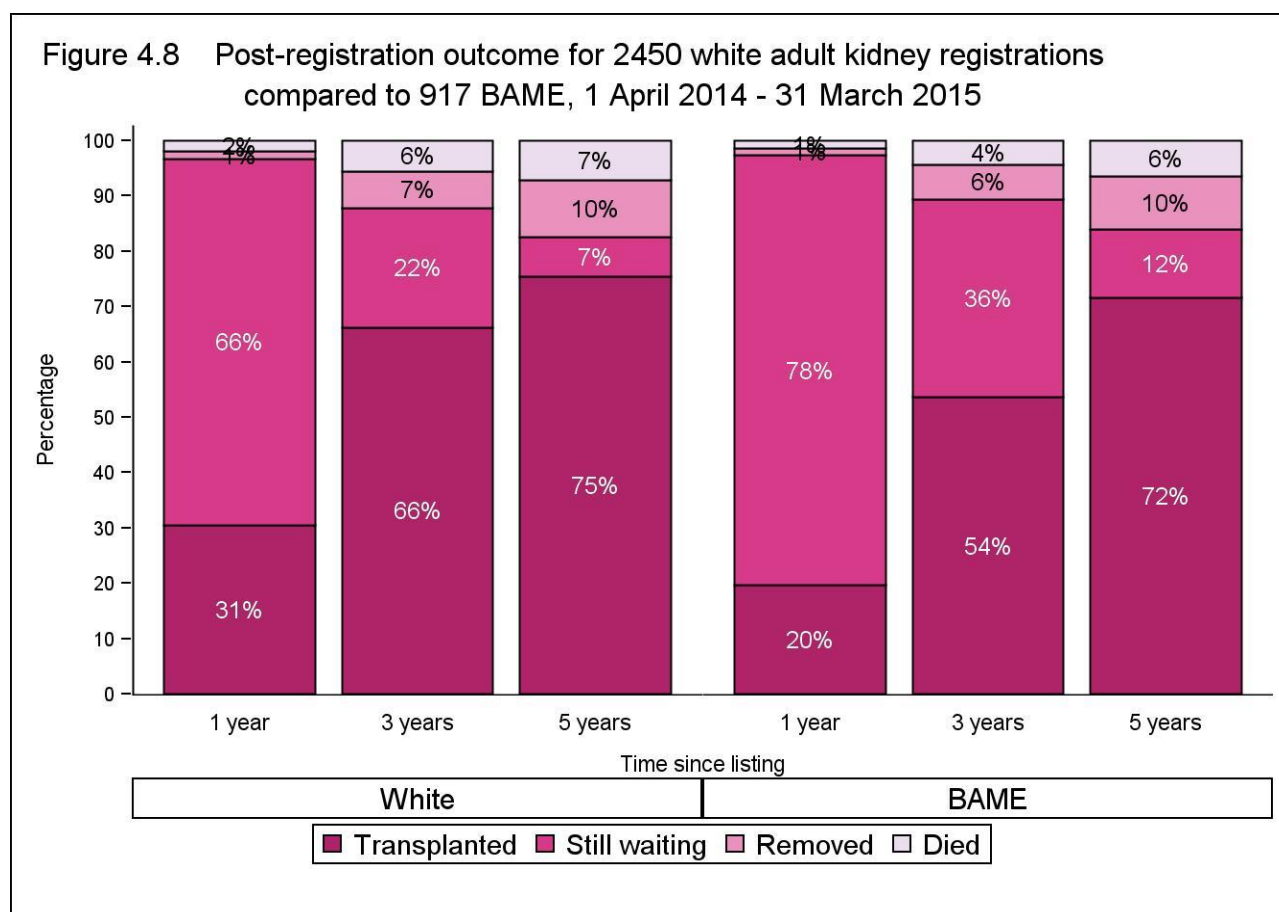
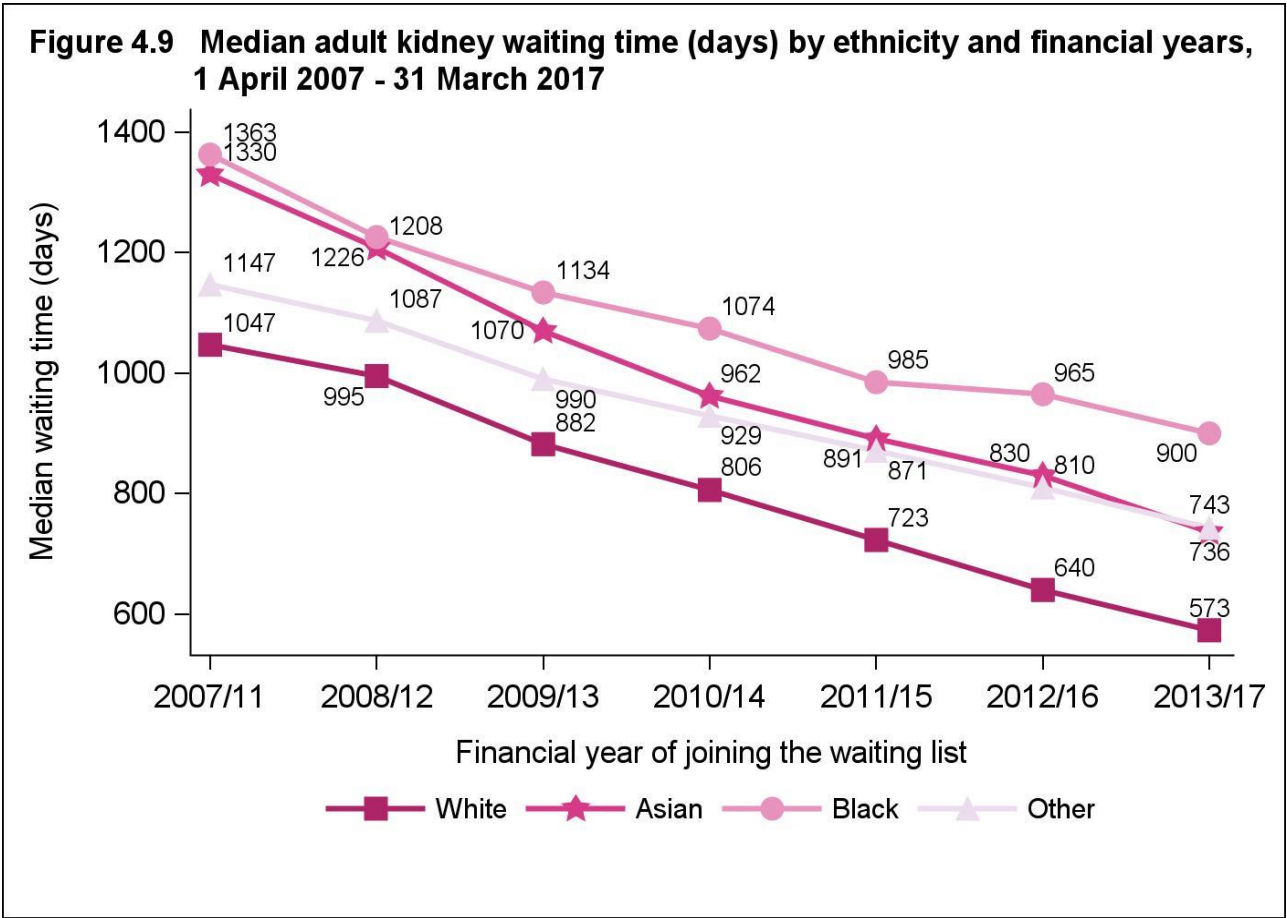


Table 4.8 Post-registration outcome for 2450 white adult kidney registrations compared to 917 BAME, 1 April 2014 - 31 March 2015

Outcome	1 year		3 years		5 years	
	N	%	N	%	N	%
White						
Transplanted	749	30.6	1623	66.2	1849	75.5
Still waiting	1619	66.1	528	21.6	175	7.1
Removed	35	1.4	163	6.7	253	10.3
Died	47	1.9	136	5.6	173	7.1
BAME						
Transplanted	180	19.6	492	53.7	657	71.6
Still waiting	713	77.8	328	35.8	113	12.3
Removed	11	1.2	57	6.2	88	9.6
Died	13	1.4	40	4.4	59	6.4

Figure 4.9 gives the adult median waiting time for a kidney transplant in days, by ethnicity and financial year group from 1 April 2007 to 31 March 2017. It shows an overall decline in waiting times for all ethnicities, although black patients are waiting almost a year longer for a transplant than white patients.



In the last year, **Figure 4.10** shows that 7% of deceased kidney donors are from BAME communities whilst BAME patients represent 35% of transplants and account for 36% of the kidney transplant waiting list. **Table 4.10** provides the numbers for **Figure 4.10**.

Figure 4.11 and **Table 4.11** display deceased donor to recipient ethnicities for kidney transplants in the UK from 1 April 2015 to 31 March 2020. Likewise, **Figure 4.12** and **Table 4.12** show the living donor to recipient ethnicities. Generally, BAME kidney transplant recipients receive white donor organs. However, for living donor transplants, recipients are much more likely to receive a kidney from someone of the same ethnicity with the exception of Chinese/East Asian or mixed race.

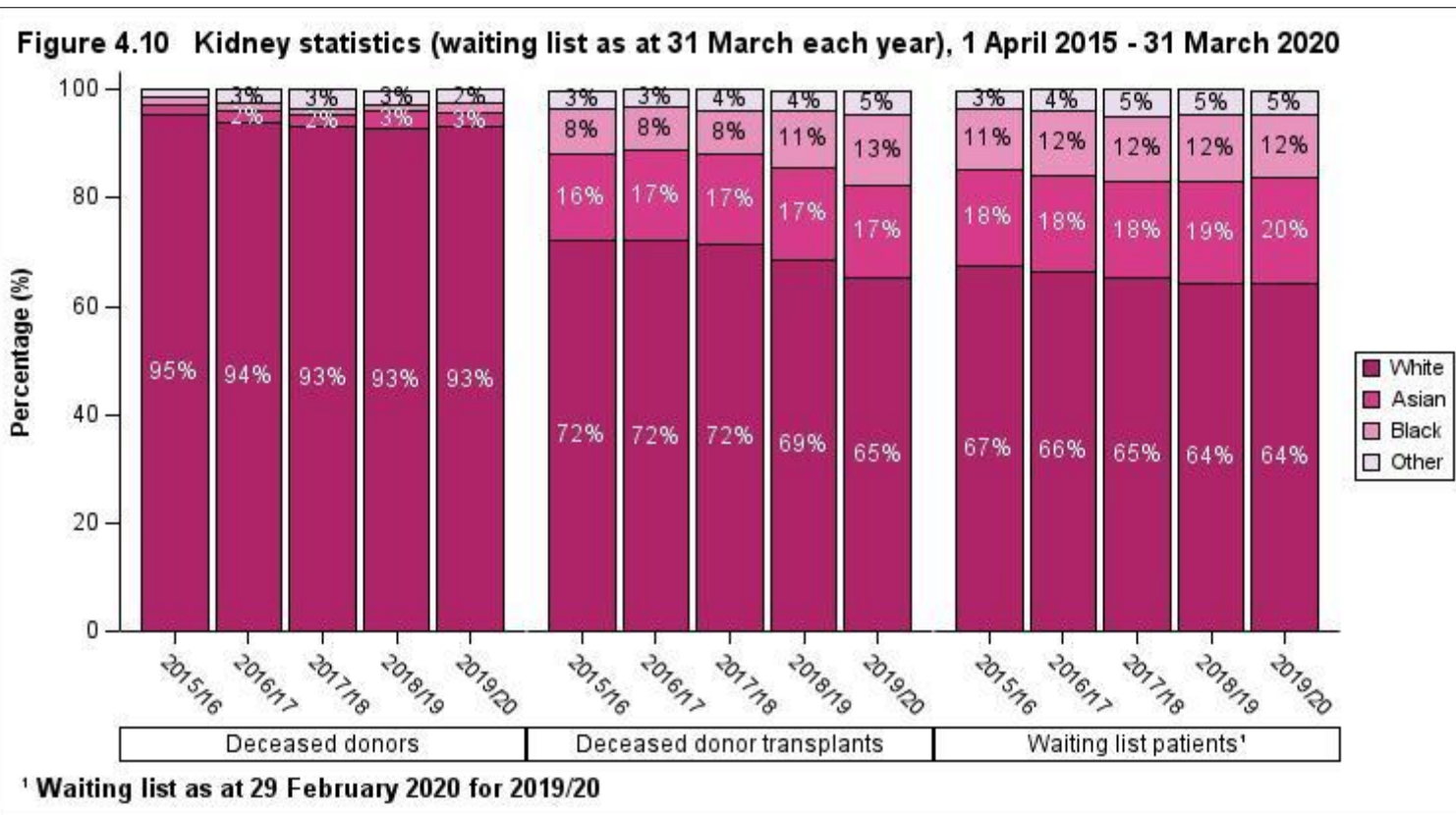


Table 4.10 Kidney statistics (waiting list as at 31 March 2016–2019 and 29 February 2020), 1 April 2015 - 31 March 2020

Ethnicity	Deceased donors					Deceased donor transplants					Waiting list patients				
	15/16	16/17	17/18	18/19	19/20	15/16	16/17	17/18	18/19	19/20	15/16	16/17	17/18	18/19	19/20
White	1232	1243	1363	1389	1367	1586	1660	1812	1743	1589	3516	3414	3220	3149	3139
Asian	25	27	30	51	39	352	385	417	433	419	947	922	896	921	955
Black	17	17	19	14	27	185	191	207	270	312	579	599	589	602	569
Chinese/East Asian	3	3	9	3	10	27	24	33	24	26	70	71	67	59	45
Mixed	6	14	23	8	9	11	10	14	6	10	23	27	20	27	31
Other	9	17	18	31	16	35	36	51	64	77	86	106	153	145	147
Total	1292	1321	1462	1496	1468	2196	2306	2534	2540	2433	5221	5139	4945	4903	4886

Figure 4.11 Deceased donor to recipient ethnicities for kidney transplants in the UK, 1 April 2015 - 31 March 2020

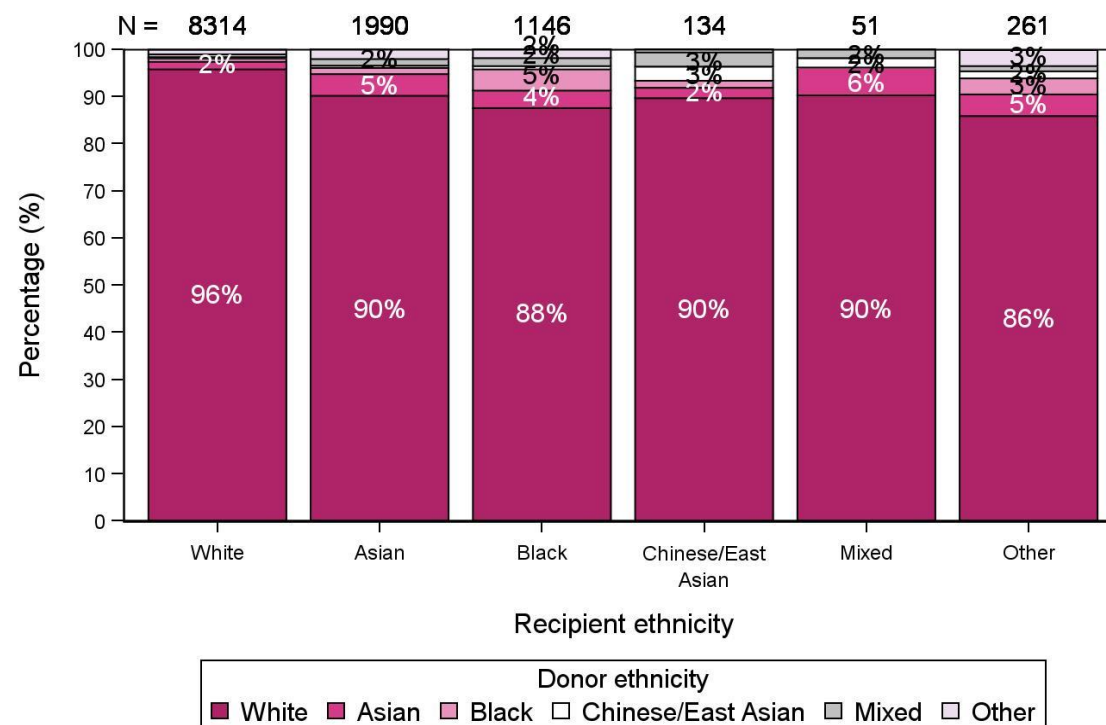


Table 4.11 Deceased donor to recipient ethnicities for kidney transplants in the UK, 1 April 2015 - 31 March 2020

Donor ethnicity	Recipient ethnicity												Total
	White		Asian		Black		Chinese/ East Asian		Mixed		Other		
	N	%	N	%	N	%	N	%	N	%	N	%	
White	7957	95.7	1792	90.1	1003	87.5	120	89.6	46	90.2	224	85.8	11142
Asian	136	1.6	91	4.6	42	3.7	3	2.2	3	5.9	12	4.6	287
Black	62	0.7	26	1.3	52	4.5	2	1.5	0	0.0	9	3.4	151
Chinese/East Asian	24	0.3	9	0.5	8	0.7	4	3.0	1	2.0	4	1.5	50
Mixed	54	0.6	27	1.4	19	1.7	4	3.0	1	2.0	3	1.1	108
Other	81	1.0	45	2.3	22	1.9	1	0.7	0	0.0	9	3.4	158
Total	8314	100.0	1990	100.0	1146	100.0	134	100.0	51	100.0	261	100.0	11896

Figure 4.12 Living donor to recipient ethnicities for kidney transplants in the UK, 1 April 2015 - 31 March 2020

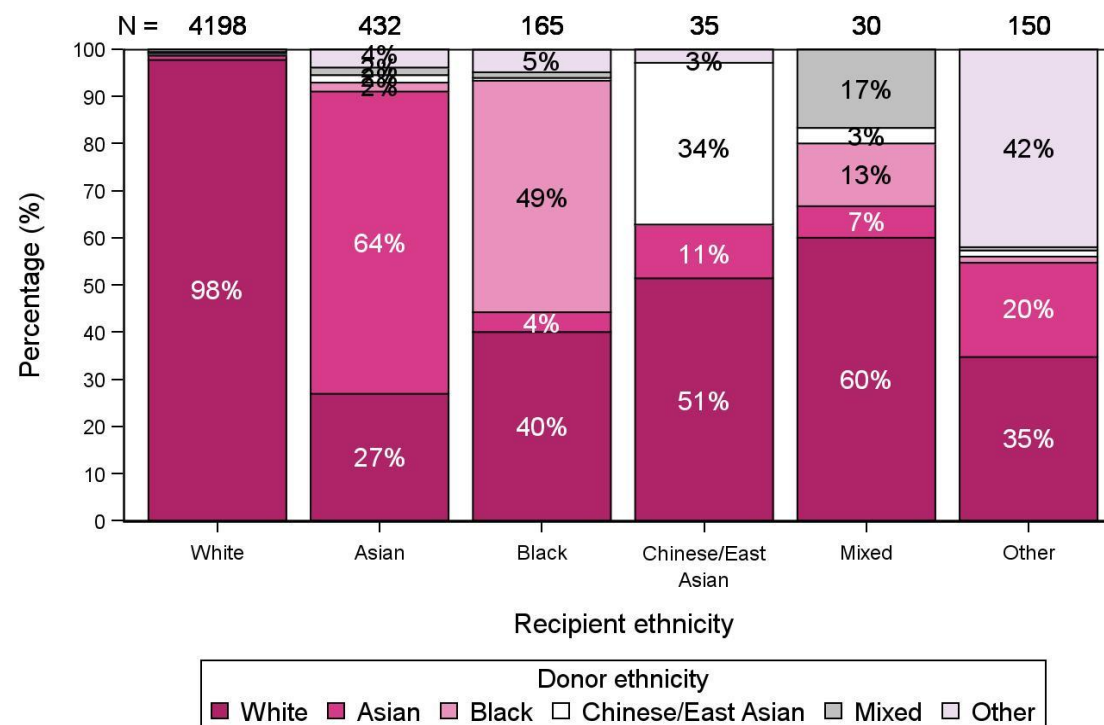
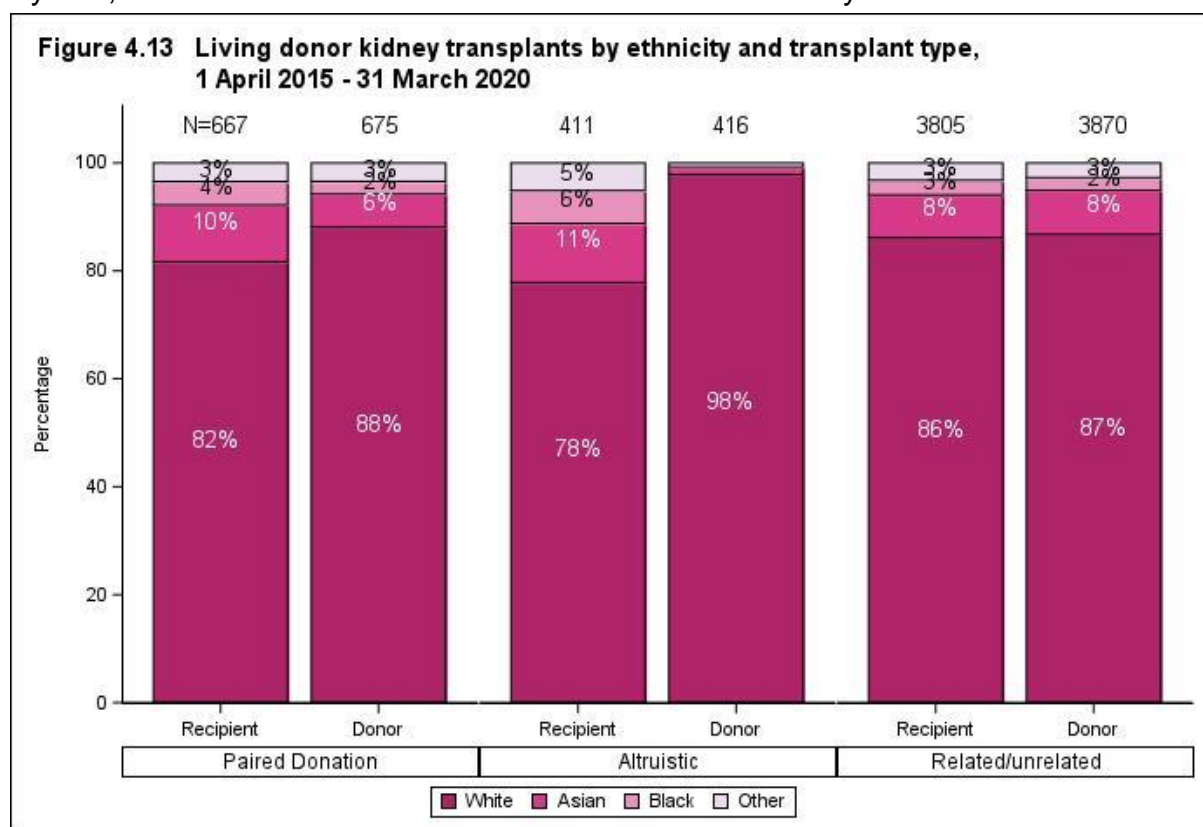


Table 4.12 Living donor to recipient ethnicities for kidney transplants in the UK, 1 April 2015 - 31 March 2020

Donor ethnicity	Recipient ethnicity												Total
	White		Asian		Black		Chinese/ East Asian		Mixed		Other		
	N	%	N	%	N	%	N	%	N	%	N	%	
White	4101	97.7	116	26.9	66	40.0	18	51.4	18	60.0	52	34.7	4371
Asian	37	0.9	277	64.1	7	4.2	4	11.4	2	6.7	30	20.0	357
Black	16	0.4	8	1.9	81	49.1	0	0.0	4	13.3	2	1.3	111
Chinese/East Asian	9	0.2	7	1.6	1	0.6	12	34.3	1	3.3	2	1.3	32
Mixed	7	0.2	7	1.6	2	1.2	0	0.0	5	16.7	1	0.7	22
Other	28	0.7	17	3.9	8	4.8	1	2.9	0	0.0	63	42.0	117
Total	4198	100.0	432	100.0	165	100.0	35	100.0	30	100.0	150	100.0	5010

Figure 4.13 and **Table 4.13** break down adult living donor kidney recipients by transplant type and ethnicity for the same time period from 1 April 2015 to 31 March 2020. BAME living donor transplant recipients mostly received a kidney from family or friends (related/unrelated). In the last 5 years, there have been 6 Asian and 3 other ethnic minority altruistic BAME donors.



Type of living donation	Ethnicity	Recipient		Donor	
		N	%	N	%
Paired Donation	White	545	81.7	595	88.1
	Asian	70	10.5	41	6.1
	Black	29	4.3	16	2.4
	Other	23	3.4	23	3.4
	Unknown	9		1	
	Total	676	100.0	676	100.0
Altruistic	White	320	77.9	407	97.8
	Asian	45	10.9	6	1.4
	Black	25	6.1		
	Other	21	5.1	3	0.7
	Unknown	5			
	Total	416	100.0	416	100.0
Related/unrelated	White	3278	86.1	3358	86.8
	Asian	302	7.9	315	8.1
	Black	103	2.7	92	2.4
	Other	122	3.2	105	2.7
	Unknown	66		1	
	Total	3871	100.0	3871	100.0

4.3 Pancreas and kidney/pancreas

This section focuses on pancreas and kidney/pancreas transplantation, reporting on post-registration outcomes and deceased pancreas donors, transplant recipients and transplant waiting list. The number of pancreas or kidney/pancreas transplants per year are small for BAME patients.

Figure 4.14 and **Table 4.14** shows post-registration outcome comparisons for white and BAME adult pancreas patients registered from 1 April 2014 to 31 March 2015. Of the 23 BAME pancreas patients listed, 87% were transplanted within 5 years. This rate is higher than for white patients, although 13% had died waiting on the transplant list. The number of BAME patients is very small so results should be interpreted with caution.

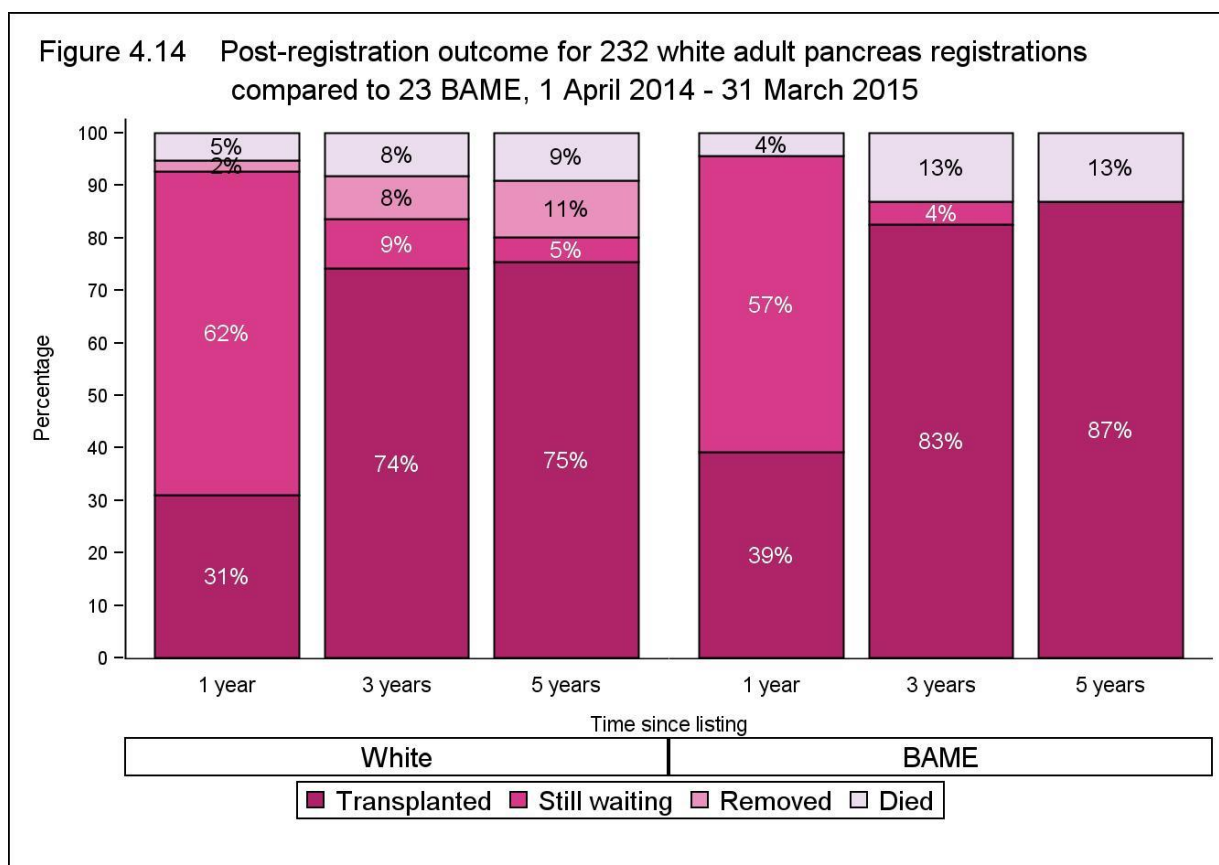


Table 4.14 Post-registration outcome for 232 white adult pancreas registrations compared to 23 BAME, 1 April 2014 - 31 March 2015						
Outcome	1 year		3 years		5 years	
	N	%	N	%	N	%
White						
Transplanted	72	31.0	172	74.1	175	75.4
Still waiting	143	61.6	22	9.5	11	4.7
Removed	5	2.2	19	8.2	25	10.8
Died	12	5.2	19	8.2	21	9.1
BAME						
Transplanted	9	39.1	19	82.6	20	87.0
Still waiting	13	56.5	1	4.3	0	0.0
Removed	0	0.0	0	0.0	0	0.0
Died	1	4.3	3	13.0	3	13.0

Figure 4.15 shows in the last financial year that 8% of deceased pancreas donors are from BAME communities whilst BAME patients represent 16% of transplants and 14% of the pancreas or islet transplant waiting list. **Table 4.15** shows the numbers in **Figure 4.15**.

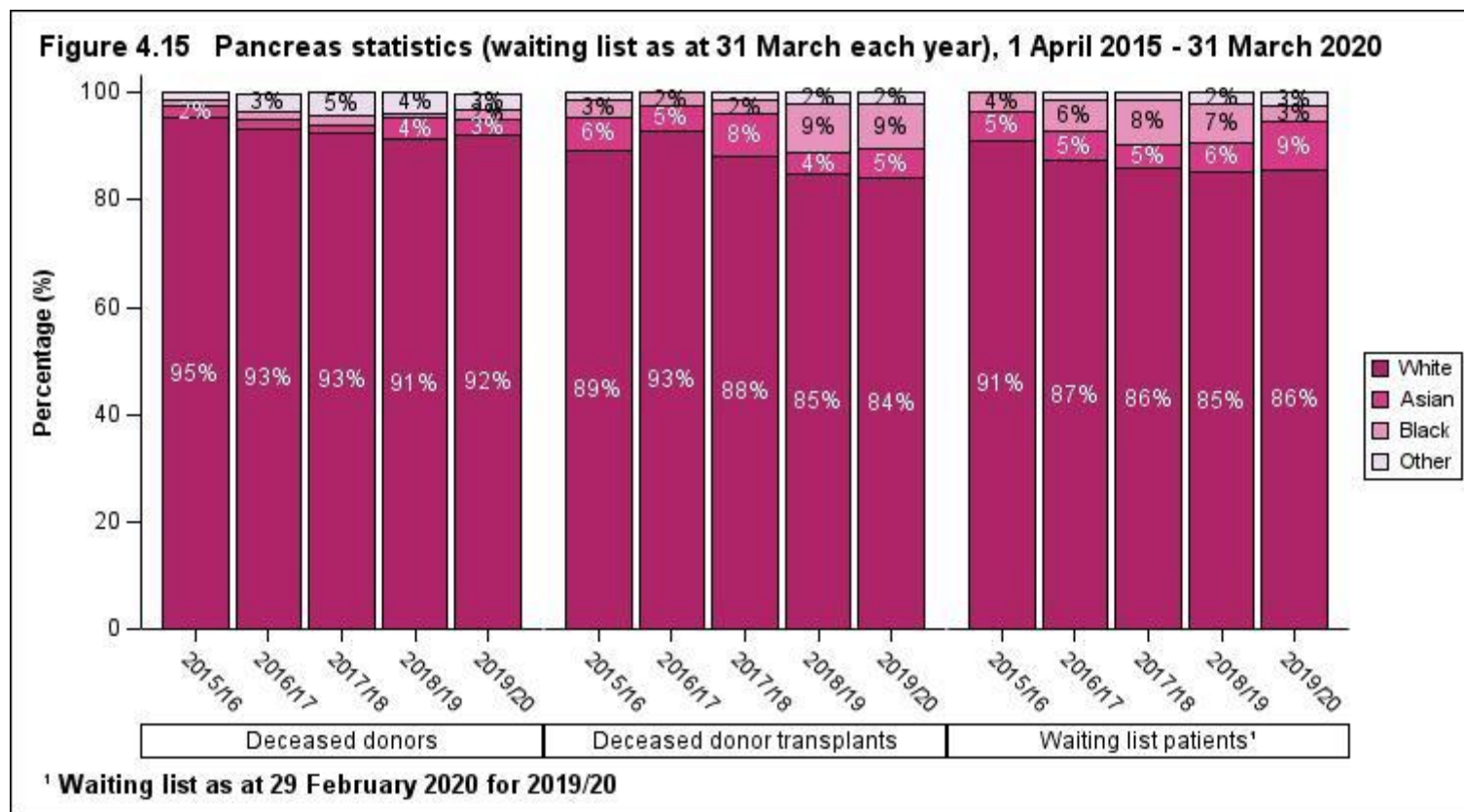


Table 4.15 Pancreas statistics (waiting list as at 31 March 2016–2019 and 29 February 2020), 1 April 2015 - 31 March 2020

Ethnicity	Deceased donors					Deceased donor transplants					Waiting list patients				
	15/16	16/17	17/18	18/19	19/20	15/16	16/17	17/18	18/19	19/20	15/16	16/17	17/18	18/19	19/20
White	441	433	435	423	408	191	193	181	166	166	206	193	187	213	202
Asian	10	8	6	18	13	13	10	16	8	10	12	12	10	14	21
Black	6	7	8	4	9	7	5	5	18	17	8	13	18	18	7
Chinese/East Asian		2	4	1	5	1		1							2
Mixed	2	6	9	3	3			2		1		1			1
Other	4	8	8	14	5	2			4	3		2	3	5	3
Total	463	464	470	463	443	214	208	205	196	197	226	221	218	250	236

4.4 Liver

This section focuses on liver transplantation reporting on post-registration outcomes, median waiting times and deceased liver donors, transplant recipients and transplant waiting list. Figures for living liver donation have not been reported on separately due to the small number of BAME recipients.

Figure 4.16 and **Table 4.16** shows post-registration outcome comparisons for white and BAME adult liver patients registered from 1 April 2014 to 31 March 2015. Liver patients that were removed from the list because their condition deteriorated were defined as having died. A higher proportion of BAME patients are transplanted compared to white patients at each time point post listing. White liver patients were more likely to be removed from the list or die waiting for a transplant.

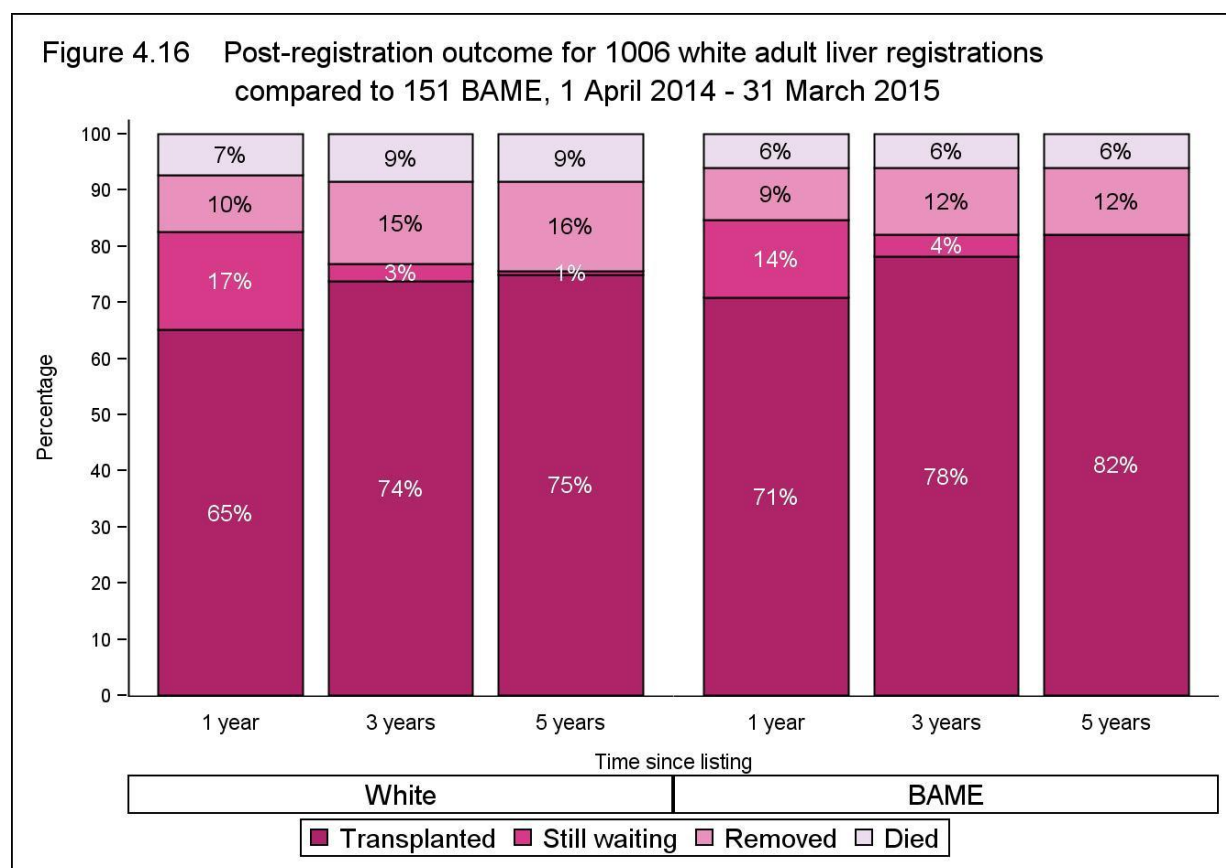


Table 4.16 Post-registration outcome for 1006 white adult liver registrations compared to 151 BAME, 1 April 2014 - 31 March 2015

Outcome	1 year		3 years		5 years	
	N	%	N	%	N	%
White						
Transplanted	655	65.1	742	73.8	754	75.0
Still waiting	175	17.4	31	3.1	7	0.7
Removed	102	10.1	147	14.6	159	15.8
Died	74	7.4	86	8.5	86	8.5
BAME						
Transplanted	107	70.9	118	78.1	124	82.1
Still waiting	21	13.9	6	4.0	0	0.0
Removed	14	9.3	18	11.9	18	11.9
Died	9	6.0	9	6.0	9	6.0

Figure 4.17 gives the adult median waiting time for a liver in days by ethnicity and financial year from 1 April 2009 to 31 March 2019. It shows an overall decline in waiting times for all ethnicities; Asian patients are waiting almost a month longer for a transplant compared to white patients and other ethnicity groups. Throughout this time period, other ethnicity groups consistently waited less time for a liver transplant although they are a smaller cohort of patients and so waiting times may vary.

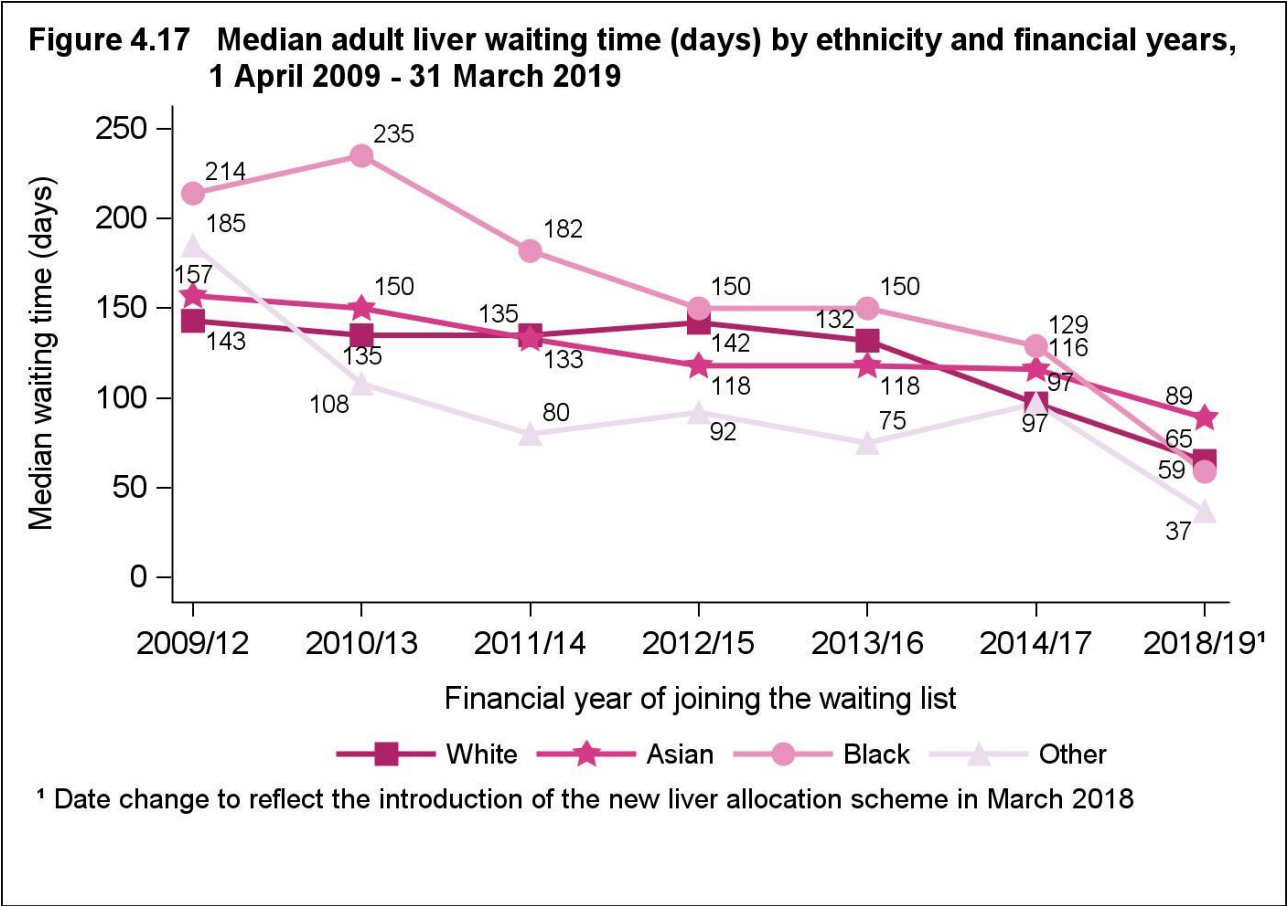


Figure 4.18 shows that 8% of deceased liver donors are from BAME communities whilst BAME patients represent 14% of transplants and 15% of the liver transplant waiting list in 2019/20. **Table 4.18** shows the numbers in **Figure 4.18**.

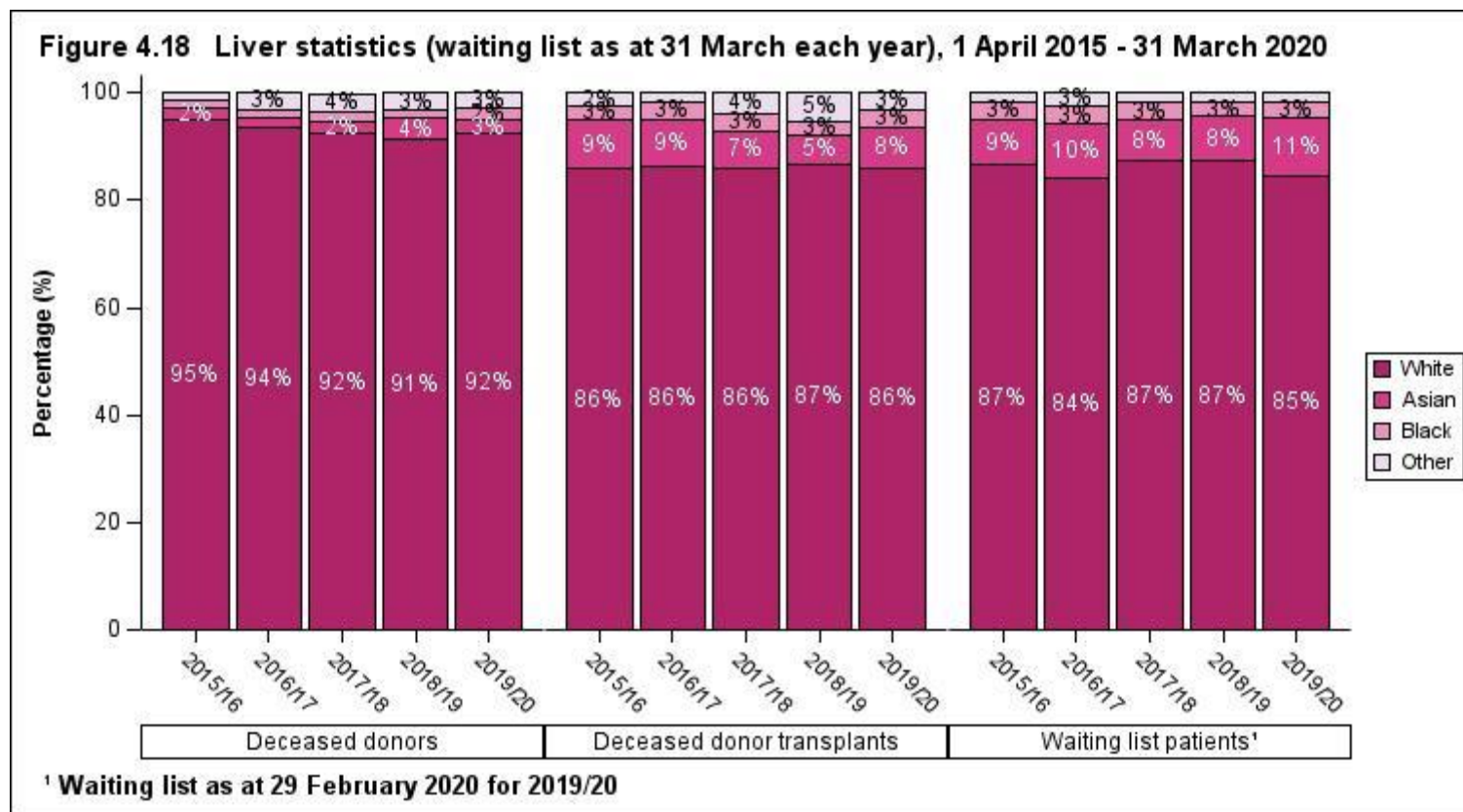


Table 4.18 Liver statistics (waiting list as at 31 March 2016–2019 and 29 February 2020), 1 April 2015 - 31 March 2020

Ethnicity	Deceased donors					Deceased donor transplants					Waiting list patients				
	15/16	16/17	17/18	18/19	19/20	15/16	16/17	17/18	18/19	19/20	15/16	16/17	17/18	18/19	19/20
White	958	964	1047	1008	1030	753	813	867	839	773	505	445	309	365	379
Asian	22	17	25	44	29	82	81	69	50	68	50	54	27	35	48
Black	15	18	22	17	26	22	32	31	27	31	18	18	12	11	14
Chinese/East Asian	3	4	6	3	8	8	6	10	10	3	1	1		3	2
Mixed	5	12	18	8	8	1	2	2		1	2	4			1
Other	7	15	16	24	15	12	7	28	41	23	8	8	6	4	4
Total	1010	1030	1134	1104	1116	878	941	1007	967	899	584	530	354	418	448

4.5 Cardiothoracic

This section focuses on cardiothoracic transplantation reporting on post-registration outcomes and deceased cardiothoracic donors, transplant recipients and transplant waiting list.

Figure 4.19 and **Table 4.19** shows post-registration outcome comparisons for white and BAME adult cardiothoracic patients registered from 1 April 2014 to 31 March 2015. BAME cardiothoracic recipients wait longer for a heart or lung compared to white patients and have a higher chance of death or removal from the list.

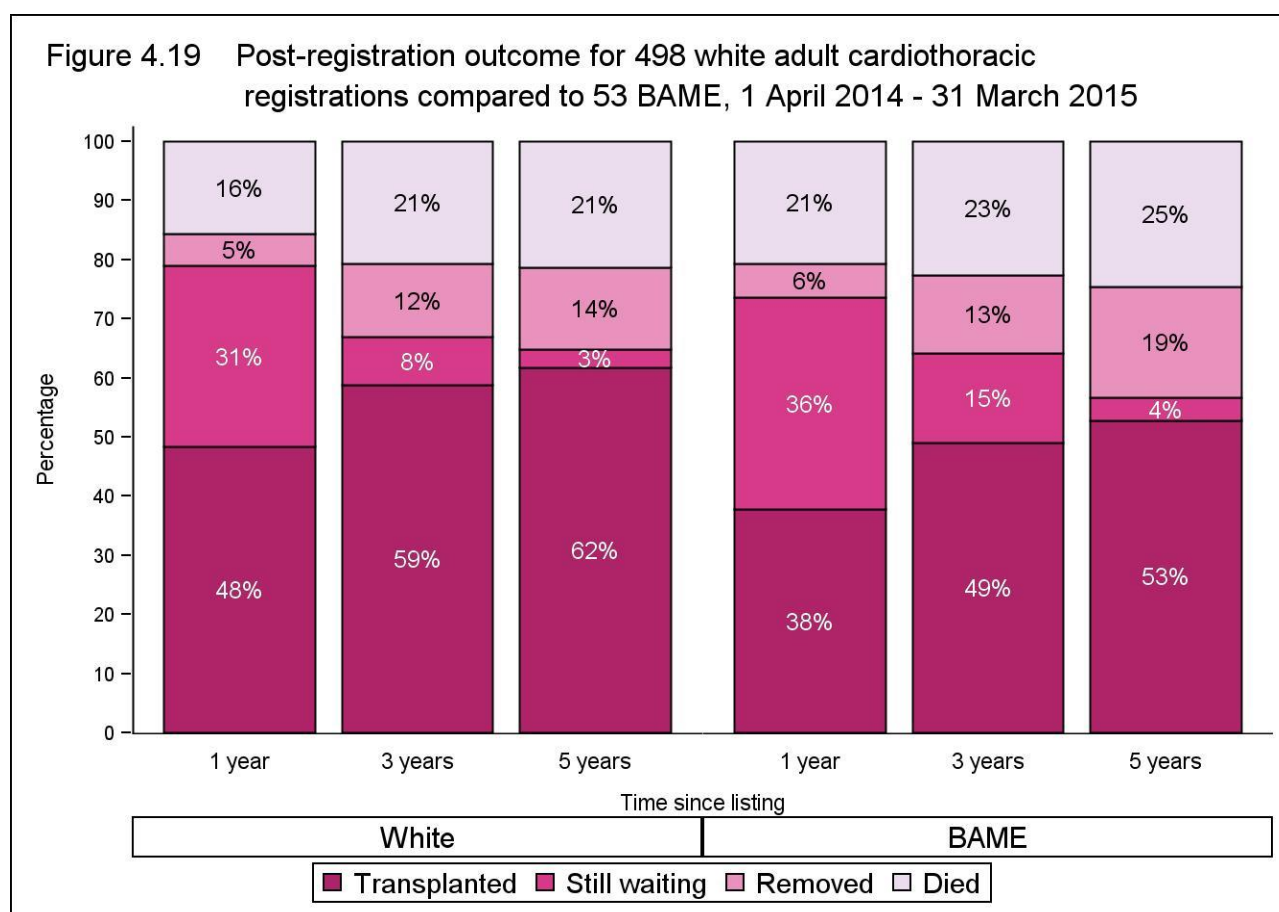


Table 4.19 Post-registration outcome for 498 white adult cardiothoracic registrations compared to 53 BAME, 1 April 2014 - 31 March 2015

Outcome	1 year		3 years		5 years	
	N	%	N	%	N	%
White						
Transplanted	241	48.4	293	58.8	307	61.6
Still waiting	152	30.5	40	8.0	16	3.2
Removed	27	5.4	62	12.4	69	13.9
Died	78	15.7	103	20.7	106	21.3
BAME						
Transplanted	20	37.7	26	49.1	28	52.8
Still waiting	19	35.8	8	15.1	2	3.8
Removed	3	5.7	7	13.2	10	18.9
Died	11	20.8	12	22.6	13	24.5

In the last financial year, **Figure 4.20** shows that 9% of deceased cardiothoracic donors are from BAME communities whilst BAME patients represent 11% of transplants and 14% of the liver transplant waiting list. **Table 4.20** shows the numbers in **Figure 4.20**.

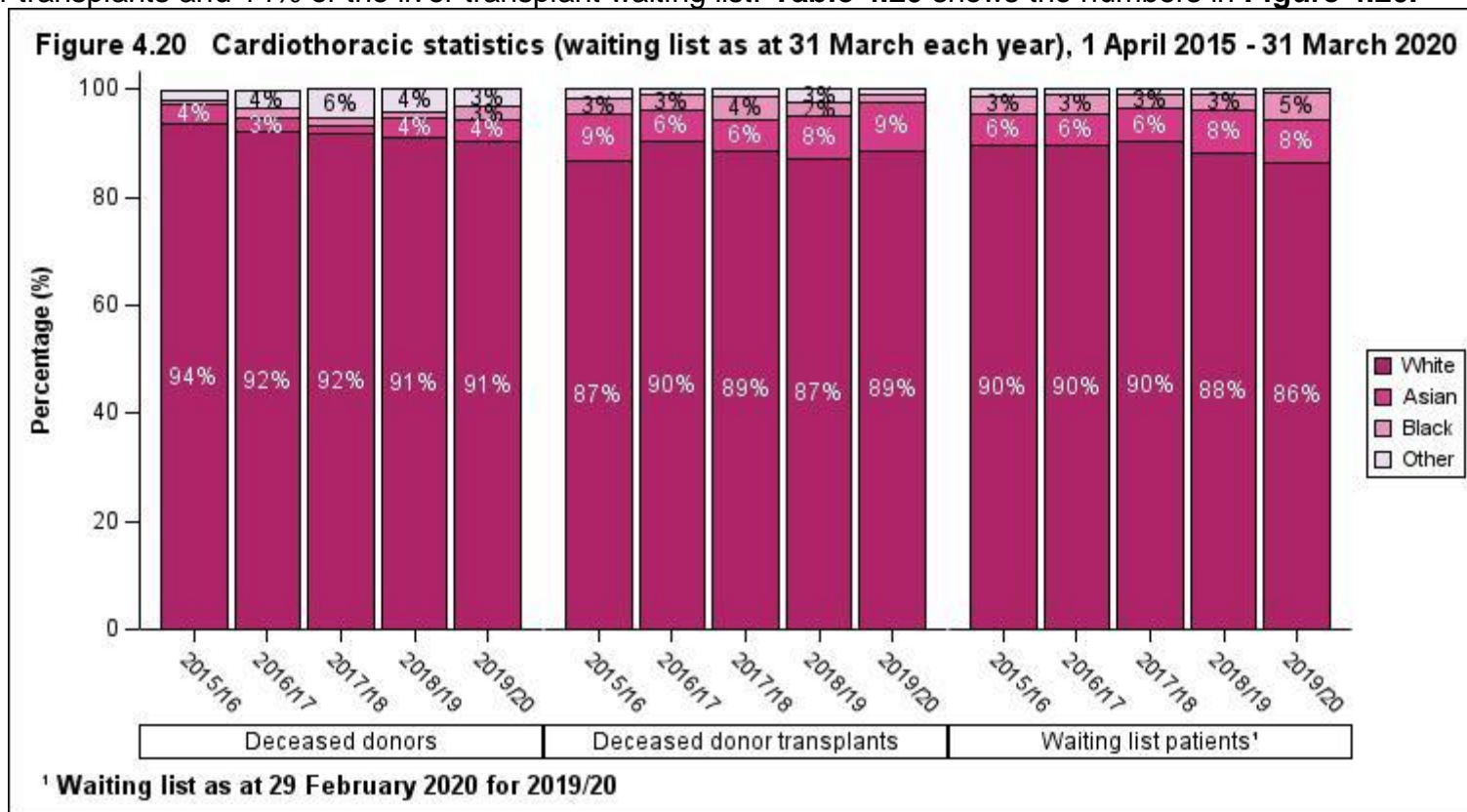


Table 4.20 Cardiothoracic statistics (waiting list as at 31 March 2016–2019 and 29 February 2020), 1 April 2015 - 31 March 2020

Ethnicity	Deceased donors					Deceased donor transplants					Waiting list patients				
	15/16	16/17	17/18	18/19	19/20	15/16	16/17	17/18	18/19	19/20	15/16	16/17	17/18	18/19	19/20
White	304	280	335	285	287	329	340	364	304	297	517	559	577	569	595
Asian	12	8	6	11	12	34	21	24	28	30	34	37	39	50	55
Black	3	5	4	4	8	11	11	18	8	4	19	21	17	19	33
Chinese/East Asian		1	3	3	1	1	2	1	1		2	1	1		
Mixed	4	6	9	2	4	2	1	3	1	3	1	3	2	4	3
Other	2	4	8	8	5	3	1	1	7	1	4	3	3	3	3
Total	325	304	365	313	317	380	376	411	349	335	577	624	639	645	689

APPENDIX

**Table I Population of England and Wales by ethnicity, mid-2011
census data estimates per thousands**

Ethnicity	N (thousands)	%
White British	43,135	80.5
White Irish	531	0.9
Other White	2,544	4.5
Total White	48,209	86.0
Asian-Indian	1,413	2.5
Asian-Pakistani	1,125	2.0
Asian-Bangladeshi	447	0.8
Other Asian	836	1.5
Total Asian	3,821	6.8
Black-African	990	1.8
Black-Caribbean	595	1.1
Other Black	280	0.5
Total Black	1,865	3.3
White & Black Caribbean	427	0.8
White & Black African	166	0.3
White & Asian	342	0.6
Other Mixed	290	0.5
Chinese	393	0.7
Other ethnicity	564	1.0
Total Other	2,182	3.9
TOTAL	56,076	14.0

Source - Office of National Statistics

Table II National data from the NHSBT Potential Donor Audit for donation after brain death, 1 April 2015 – 31 March 2020¹

Financial Year	Ethnic origin	Number of patients where neurological death was suspected							
		Number of patients where neurological death was suspected	Number of patients that were neurological death tested	Neurological death testing rate (%)	Number of patients where neurological death was suspected that were referred to the SN-OD	DBD referral rate (%)	Number of eligible DBD donors whose family were approached	Number where consent /authorisation ascertained	DBD consent /authorisation rate (%)
2015/16	White	1458	1243	85.3	1417	97.2	1107	821	74.2
	BAME	233	200	85.8	223	95.7	164	58	35.4
	Unknown	55	33	60.0	43	78.2	24	11	45.8
2016/17	White	1446	1243	86.0	1420	98.2	1117	833	74.6
	BAME	272	240	88.2	263	96.7	187	64	34.2
	Unknown	69	49	71.0	57	82.6	35	29	82.9
2017/18	White	1566	1338	85.4	1548	98.9	1206	943	78.2
	BAME	322	288	89.4	319	99.1	235	103	43.8
	Unknown	68	52	76.5	64	94.1	33	21	63.6
2018/19	White	1638	1415	86.4	1622	99.0	1259	974	77.4
	BAME	305	257	84.3	302	99.0	207	91	44.0
	Unknown	65	47	72.3	62	95.4	31	22	71.0
2019/20 ²	White	1510	1329	88.0	1499	99.3	1155	892	77.2
	BAME	293	259	88.4	293	100.0	195	81	41.5
	Unknown	41	26	63.4	35	85.4	17	10	58.8

¹All data for neonatal ICUs has been excluded from this data.

² 1 April 2019 – 29 February 2020 due to COVID-19 pandemic

Table III National data from the NHSBT Potential Donor Audit for donation after circulatory death, 1 April 2015 – 31 March 2020¹

Financial Year	Ethnic origin	Number of patients for whom imminent death was anticipated	Number of patients for whom imminent death was anticipated that were referred to the SN-OD	DCD referral rate (%)	Number of eligible DCD donors whose family were approached	Number where consent /authorisation ascertained	DCD consent /authorisation rate (%)
2015/16	White	5469	4644	84.9	1743	1055	60.5
	BAME	413	347	84.0	120	38	31.7
	Unknown	619	411	66.4	80	20	25.0
2016/17	White	5245	4545	86.7	1656	1004	60.6
	BAME	407	366	89.9	112	41	36.6
	Unknown	581	425	73.1	69	24	34.8
2017/18	White	5357	4837	90.3	1670	1041	62.3
	BAME	388	355	91.5	112	42	37.5
	Unknown	538	424	78.8	77	32	41.6
2018/19	White	5131	4783	93.2	1590	1033	65.0
	BAME	450	414	92.0	123	47	38.2
	Unknown	401	349	87.0	43	19	44.2
2019/20 ²	White	4862	4530	93.2	1540	1022	66.4
	BAME	419	388	92.6	122	53	43.4
	Unknown	389	314	80.7	47	23	48.9

¹All data for neonatal ICUs has been excluded from this data.
² 1 April 2019 – 29 February 2020 due to COVID-19 pandemic