



Blood and Transplant

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

**Report for 2020/2021
(1 April 2016 - 31 March 2021)**

PREFACE

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

This report provides information related to organ donation and transplantation within the white and Black, Asian, Mixed Race and Minority Ethnic (BAME) communities in the UK. It is published as a supplementary report of the *Organ Donation and Transplantation Activity Report 2020/21*. In this report BAME is defined as Black, Asian, Mixed Race 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 2015 to 31 March 2016. 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 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.

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 7 July 2021.**

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 the 31 March 2020 and 2021 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



The last 12 months have been the most challenging in our history due to the Covid-19 pandemic. The whole of the NHS was put under intense pressure and the effects were also seen in organ donation and transplantation.

However, with a great team effort across clinical teams, and incredible support from donor families and living donors who said yes in some of the most difficult circumstances, organ donation and transplantation activity continued for the most urgent patients during the first wave of Covid-19 and returned to pre-covid levels rapidly throughout the summer.

Despite this, there was still an overall decline in organ donation and transplantation last year, impacting on both living and deceased donation. Last year there were 1,180 total deceased organ donors in the UK and 8.4% of them were from Black, Asian, Mixed Race and Minority Ethnic communities.

Over the course of the year, we saw a total of 146 donors from a Black, Asian, Mixed Race and Minority Ethnic background; 84 deceased donors and 62 living donors.

For living donation, the number of donors fell by 58% which meant that only 444 patients received a transplant via a living donor, accounting for 27% of the total number of organ donors. 14% of living donors came from a Black, Asian, Mixed Race or Minority Ethnic background.

Transplant operations were also reduced during the pandemic due to intensive care capacity, staffing pressures and most crucially, for the safety of patients who are immunosuppressed and vulnerable to infection. Despite this, 2,947 transplants were still able to take place – 767 of these in patients from Black, Asian, Mixed Race or minority ethnic backgrounds.

For many patients in need of a transplant often the best chance of a match will come from a donor from the same ethnic background. More specifically, kidney donors and recipients are matched by blood group and tissue type, and people from the same ethnic background are more likely to be a match. Over the last year the number of deceased donor kidney transplants has also fallen due to Covid-19 across all ethnic groups, and we expect numbers of patients waiting for a transplant to rise.

Overall, there has been an improvement in waiting times for transplants for all ethnicities, although Black patients are waiting still almost a year longer for a kidney transplant compared to White patients. One year after being listed for a kidney transplant, 35% of White patients had received their transplant whereas only 19% of Black, Asian, Mixed Race or minority ethnic patients had received a transplant. And it still remains that around 6% of Black, Asian, Mixed Race or minority ethnic patients have died waiting for an organ.

This shows the continued imbalance between the need for transplants in our Black and Asian communities and the availability of suitable organs. In total, when approached about organ donation in the hospital over the course of this year, 39.5% of Black, Asian, Mixed Race or minority ethnic families agreed to support donation going ahead, compared to 69% of white families. Many of these families approached can still find it difficult because organ donation is not something they have discussed with their relative. Others still have concerns about whether organ donation can go ahead in line with their religious beliefs.

Despite the challenges of the last year, it is reassuring to see that there has been an increase in the proportion of opt-in registrations from Black, Asian, Mixed Race and Minority Ethnic communities added to the NHS Organ Donor Register (ODR) over the past 5 years; from 6.8% of opt-ins with ethnicity reported in 2016/17 up to 9.2% in 2020/21. Though encouraging, we still need more people from our communities to be willing to donate in life or after death. People from Black, Asian, Mixed Race and Minority Ethnic backgrounds are still disproportionately represented amongst those who have opted out. Even though there is an increase in people choosing to register their support for organ donation, there is still much work to do to debunk the myths surrounding organ donation when it comes to the whole process, and how organ donation is supported within certain faiths and cultures.

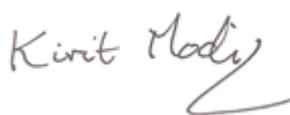
NHS Blood and Transplant and the National BAME Transplant Alliance (NBTA) have been working in partnership over a number of years to address these barriers and give confidence to these communities in not only gaining knowledge of organ donation but how to tackle the topic with their loved ones. This partnership has led to the establishment of the Community Investment Scheme and the Living Transplant Initiative; these are now well-established programmes which empower Black, Asian, Mixed Race and Minority Ethnic community groups to promote organ donation in targeted groups through grassroots networks.

Working together with partners, stakeholders, community groups and the NHS to provide education, faith and cultural engagement is more important than ever before, especially in a time where many health inequalities have been highlighted by the pandemic. The new ten year strategy, 'Meeting the Need' recently published by the NHS Blood and Transplant, included Diversity and Inclusion as a key theme and we look forward to continuing to work together to ensure this strategy is implemented and continue to save and improve more lives through organ donation and transplantation.

Support for donation has continued to stay strong, despite the country navigating its way through a pandemic and transplants have continued to proceed in the most difficult circumstances. But most importantly, more people from Black, Asian, Mixed Race and minority ethnic backgrounds are discussing their organ donation decision with their loved ones and ultimately enabling more donations and life-saving transplants to go ahead.



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SUMMARY

SUMMARY

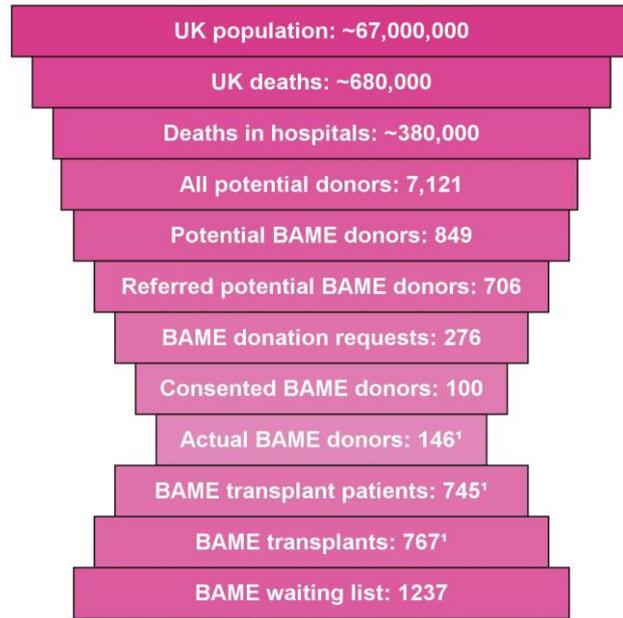
Organ Donor Register

- There has been an increase in the proportion of opt-in registrations from BAME communities added to the Organ Donor Register (ODR) over the past 5 years; 6.8% of opt-ins with ethnicity reported in 2016/17 and 9.2% in 2020/21.
- All minority groups were under-represented in ODR registrations; BAME represent 9.2% of opt-in registrations compared with 14.0% of the 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 416,710 opt-outs with ethnicity reported, for all but white people. In particular, 73% of these opt-outs were made by white people, followed by 16% made by Asian people, mostly of Pakistani origin (7.9%).
- The number of ODR opt-in registrations with ethnicity reported has fallen – from 25% in 2019/20 to 20% last year. In 2020/21, the proportion of ODR opt-out registrations with ethnicity reported was 83%.

Potential organ donors

- Referral rates to specialist nurses of potential white and BAME donors after brain death (DBD) last year were comparable, ranging from 97 to 99%, but were lower for potential BAME donors after circulatory death (DCD): 83% for white donors and 77% for BAME donors.
- Family consent/authorisation is much lower for BAME potential donors (35% DBD, 37% DCD) than for white potential donors (81% DBD, 67% DCD). Overall (DBD and DCD combined), consent rates were 39.5% for BAME and 70% for white potential donors last year, similar to the previous year.

Figure 1.1 UK potential organ donor population, by BAME communities, 1 April 2020 - 31 March 2021



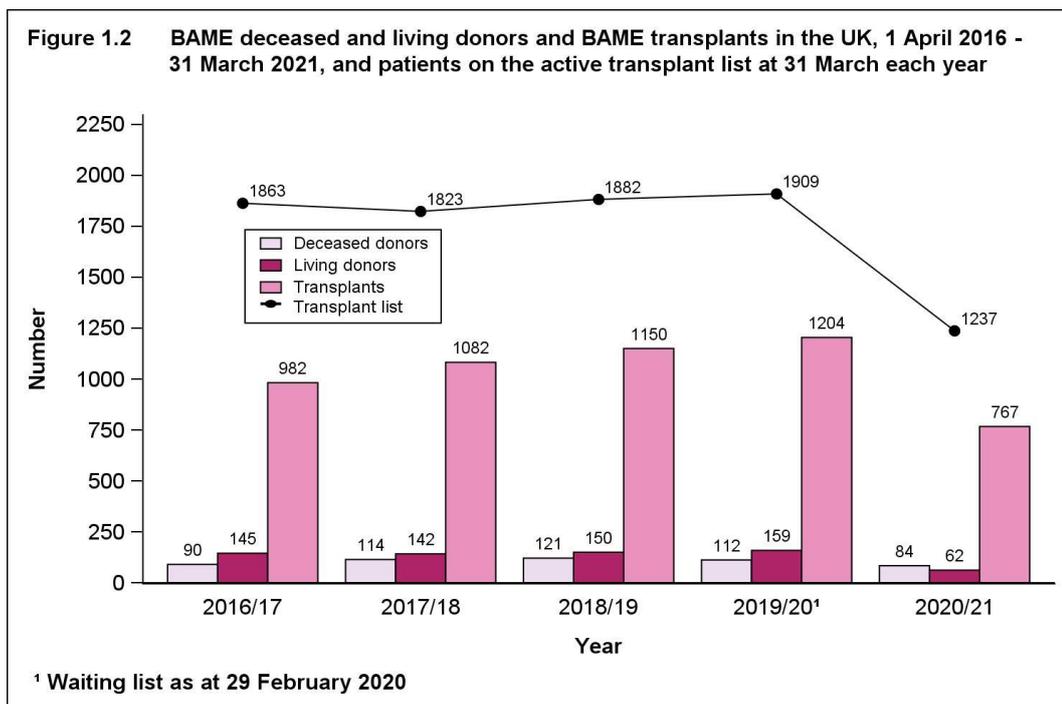
¹ Please note that 62 living donors have been included in this figure

- The main reasons BAME families gave for declining consent/authorisation for organ donation were 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 show 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 fell by 25% from 112 in 2019/20 to 84 in 2020/21. Restrictions implemented at the start of the COVID-19 pandemic will have contributed to this fall.
- The number of BAME living donors had remained at approx. 140-160 per year between 2016/17 and 2019/20, representing 14% of all living organ donors. COVID-19 also had an impact on living donation with BAME living donors falling by 61% to 62 donors in 2020/21. This is in line with the fall in white living donor numbers.
- The number of transplants in BAME people had increased by 23% over the previous 4 years, representing 25% of all transplants. The numbers fell from 1204 in 2019/20 to 767 in 2020/21 due to COVID-19.
- There were 1237 BAME people on the active organ transplant list at 31 March 2021, down from 1909 as at 29 February 2020 due to COVID-19 suspensions.



- In 2020/21, Asian people represented 3% of deceased donors (DD), 13% of DD transplants and 17% of the transplant waiting list; black people represented 2% of DD, 7% of DD transplants and 9% of the list, similar to the previous year.
- In 2020/21, Asian people represented 8% of living donors (LD) and 10% of LD transplants; black people represented 2% of LD and 4% of LD transplants, similar to the previous year.
- One year after being listed for a transplant (all organs), 45% (N=1768) of white and 27% (N=293) of BAME people have been transplanted. Five years after listing, 78% (N=3084) of white and 74% (N=795) of BAME people have been transplanted, while 8% (n=303) of white and 7% (N=74) 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 a 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.

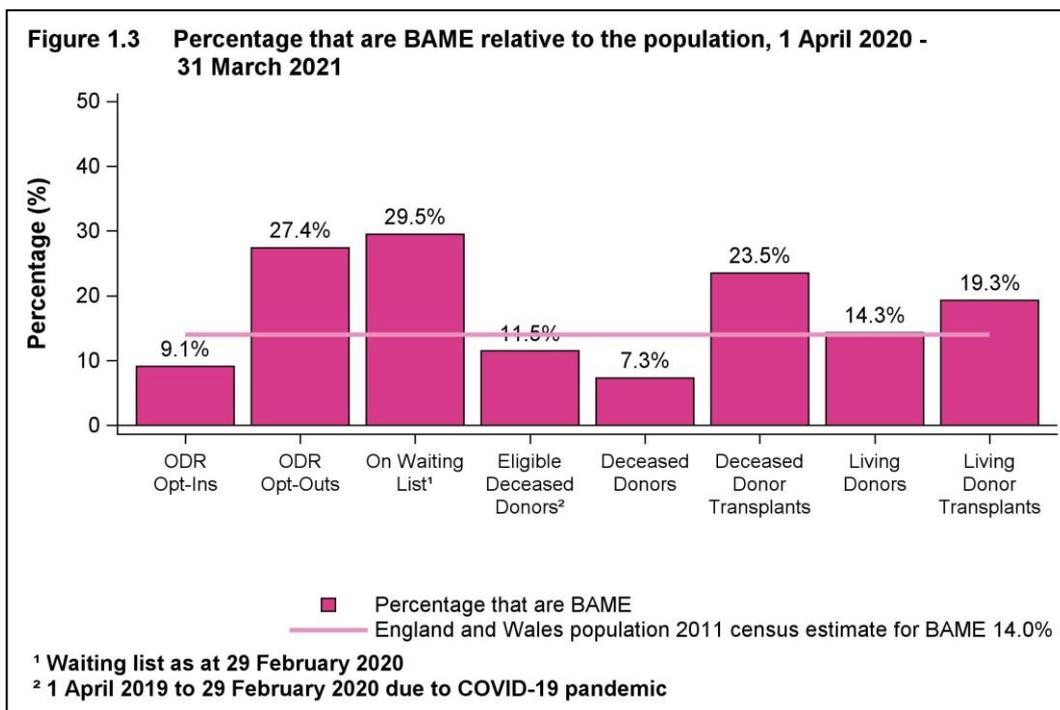
Kidney

- The number of deceased donor kidney transplants has fallen due to COVID-19 for all recipient ethnic groups.
- One year after being listed for a kidney transplant, 35% of white and 19% of BAME people have received a transplant. Five years after listing, 80% of white and 74% of BAME people have been transplanted while 6% of both white and 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 824 days for black, 682 days for Asian, 678 days for other BAME and 527 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 revised kidney offering scheme in 2019.
- In 2020/21, Asian people represented 3% of deceased kidney donors (DD), 16% of DD kidney transplants and 19% of the transplant waiting list; black people represented 1.4% of kidney DD, 9% of DD transplants and 10% of the list.
- 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 46% 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-race ethnicities who mostly received a living donor kidney from a white person.

Other organs

- One year after listing for transplant:
 - **Pancreas and pancreas/kidney:** 31% of white and 41% of BAME patients have received a transplant, while 2% and 3% have died on the list, respectively.
 - **Liver:** 69% of both white and BAME patients have received a transplant, while 6% and 8% have died on the list, respectively.
 - **Cardiothoracic:** 48% of white and 50% of BAME patients have received a transplant, while 10% and 13% have died on the list, respectively.
- In 2021, Asian people represented:
 - **Pancreas and pancreas/kidney:** 2% of donors, 3% of transplants and 6% of the transplant list.
 - **Liver:** 3% of donors, 9% of transplants and 13% of the transplant list.
 - **Cardiothoracic:** 3% of donors, 8% of transplants and 8% of the transplant list.
- In 2021, black people represented:
 - **Pancreas and pancreas/kidney:** 2% of donors, 5% of transplants and 2% of the transplant list.
 - **Liver:** 2% of donors, 3% of transplants and 3% of the transplant list.
 - **Cardiothoracic:** 3% of donors, 6% of transplants and 4% of the transplant list.

Figure 1.3 shows an over-representation of BAME people relative to the population of England and Wales for ODR opt-outs, those on the waiting list, deceased donor transplants and 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 drop in the proportion of ODR opt-outs by BAME people from 74% of opt-outs to 27% and a drop in deceased donor transplants from 27% to 24% in 2020/21.



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.

The primary sources of opt-in ODR registrations in 2020/21 were the Driver and Vehicle Licensing (64%), online registrations (15%), GP registrations (12%), Boots Advantage card (6%) and Other (3%).

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 20% of people registering on the ODR in 2020/21 have their ethnicity recorded.

Table 2.1 shows the number of opt-in registrations per year by ethnicity from 1 April 2016 to 31 March 2021. In 2020/21, 91% of registrations with ethnicity recorded were by white people, 4% from Asian, 1% from black, 0.4% from Chinese, 3% 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 and in Scotland on 26 March 2021, 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 2018 to 31 March 2021. Most opt-out registrations are entered online and as a result have a higher proportion of people reporting their ethnicity (87% in 2020/21). In the last year, there has been a reduction in the number of opt-out registrations, and the proportional breakdown by ethnicity is very different to 2019/20. In 2020/21, the majority of opt-out registrations were among white people (73%), followed by Asian people (16%) and black people (6%).

Table 2.1 Ethnicity of all ODR opt-in registrations by year of registration¹, 1 April 2016 - 31 March 2021

		2016/17		2017/18		2018/19		2019/20		2020/21	
		N	%	N	%	N	%	N	%	N	%
White	British	301,917	84.9	381,028	85.1	400,442	85.5	268,290	83.9	174,513	81.2
	Irish	9,502	2.7	9,929	2.2	11,645	2.5	8,384	2.6	3,845	1.8
	Other	20,140	5.7	23,681	5.3	23,123	4.9	18,033	5.6	16,983	7.9
	Total	331,559	93.2	414,638	92.6	435,210	92.9	294,707	92.2	195,341	90.9
Asian	Indian	6,443	1.8	8,726	1.9	9,495	2	6,957	2.2	5,146	2.4
	Pakistani	1,362	0.4	1,635	0.4	1,546	0.3	1,259	0.4	929	0.4
	Bangladeshi	328	0.1	464	0.1	430	0.1	348	0.1	306	0.1
	Other	2,992	0.8	4,096	0.9	3,965	0.8	3,167	1.0	2,800	1.3
	Total	11,125	3.1	14,921	3.3	15,436	3.3	11,731	3.7	9,181	4.3
Black	Caribbean	1,458	0.4	1,890	0.4	1,888	0.4	1,439	0.5	874	0.4
	African	1,617	0.5	2,387	0.5	2,325	0.5	1,730	0.5	1,360	0.6
	Other	248	0.1	307	0.1	331	0.1	273	0.1	334	0.2
	Total	3,323	0.9	4,584	1.0	4,544	1	3,442	1.1	2,568	1.2
Mixed	White/Black African	707	0.2	964	0.2	967	0.2	777	0.2	710	0.3
	White/Black Caribbean	2,041	0.6	2,635	0.6	2,803	0.6	1,980	0.6	1,328	0.6
	White/Asian	2,086	0.6	2,771	0.6	2,768	0.6	2,054	0.6	1,529	0.7
	Other	1,812	0.5	2,501	0.6	2,590	0.6	2,030	0.6	1,699	0.8
	Total	6,646	1.9	8,871	2.0	9,128	1.9	6,841	2.1	5,266	2.5
Chinese	1,114	0.3	1,513	0.3	1,391	0.3	1,056	0.3	866	0.4	
Other	1,985	0.6	3,134	0.7	2,721	0.6	1,921	0.6	1,702	0.8	
Total reported	355,752	100.0	447,661	100.0	468,430	100	319,698	100.0	214,924	100.0	
Not reported	1,004,320	73.8	872,308	66.1	941,998	66.8	975,177	75.3	846,998	79.8	
TOTAL OPT-IN REGISTRATIONS (incl. known duplicates/deaths)	1,360,072		1,319,969		1,410,428		1,294,875		1,061,922		
TOTAL OPT-IN REGISTRATIONS (excl. known duplicates/deaths)	925,794		1,024,664		1,230,560		1,039,485		827,777		

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 2018 - 31 March 2021

		2016/17		2017/18		2018/19		2019/20		2020/21	
		N	%	N	%	N	%	N	%	N	%
White	British	17,004	74.2	19,704	6.9	20,736	18.6	161,410	23.0	274,165	65.8
	Irish	199	0.9	322	0.1	315	0.3	1,857	0.3	3,327	0.8
	Other	1,161	5.1	2,916	1.0	2,422	2.2	16,740	2.4	25,202	6.0
	Total	18,364	80.2	22,942	8.0	23,473	21.0	180,007	25.7	302,694	72.6
Asian	Indian	585	2.6	39,327	13.7	7,720	6.9	46,090	6.6	13,094	3.1
	Pakistani	1,018	4.4	105,791	36.8	31,968	28.6	207,420	29.6	32,717	7.9
	Bangladeshi	371	1.6	50,782	17.7	17,221	15.4	78,960	11.3	12,160	2.9
	Other	519	2.3	10,554	3.7	3,471	3.1	31,140	4.4	10,002	2.4
	Total	2,493	10.9	206,454	71.8	60,380	54.1	363,610	51.9	67,973	16.3
Black	Caribbean	357	1.6	21,269	7.4	9,333	8.4	38,930	5.6	9,560	2.3
	African	739	3.2	19,903	6.9	10,888	9.7	71,392	10.2	14,541	3.5
	Other	82	0.4	3,459	1.2	1,591	1.4	8,654	1.2	2,607	0.6
	Total	1,178	5.1	44,631	15.5	21,812	19.5	118,976	17.0	26,708	6.4
Mixed	White/Black Caribbean	84	0.4	1,954	0.7	928	0.8	6,159	0.9	2,784	0.7
	White/Black African	65	0.3	788	0.3	437	0.4	2,632	0.4	1,146	0.3
	White/Asian	74	0.3	1,819	0.6	634	0.6	3,900	0.6	1,955	0.5
	Other	110	0.5	3,160	1.1	1,264	1.1	7,883	1.1	3,498	0.8
	Total	333	1.5	7,721	2.7	3,263	2.9	20,574	2.9	9,383	2.3
Chinese	162	0.7	304	0.1	295	0.3	1,256	0.2	2,413	0.6	
Other	375	1.6	5,510	1.9	2,476	2.2	16,486	2.4	7,539	1.8	
Total reported	22,905	100.0	287,562	100.0	111,699	100.0	700,909	100.0	416,710	100.0	
Not reported	2,407	9.5	22,659	7.3	12,626	10.2	153,191	17.9	85,757	17.1	
TOTAL OPT-OUT REGISTRATIONS (incl. known duplicates/deaths)	25,312		310,221		124,325		854,100		502,467		
TOTAL OPT-OUT REGISTRATIONS (excl. known duplicates/deaths)	25,201		303,362		122,019		821,701		483,684		

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 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 reported was 2011. **Table 2.3** shows data on percentage of the ODR opt-in registrations in 2016/17 and 2020/21 against the percentage of the general population for England and Wales. In 2016/17, 6.8% of ODR opt-in registrations of known ethnicity were BAME which has increased to 9.2% in 2020/21. 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 opt-in registrations on the ODR vs the population for England and Wales

Ethnicity	2016/17 % of the ODR registrations¹	2020/21 % of the ODR registrations¹	2011 % of the population²
Asian-Indian	1.8	2.4	2.5
Asian-Pakistani	0.4	0.4	2.0
Asian-Bangladeshi	0.1	0.1	0.8
Asian-Other	0.8	1.3	1.5
<i>Asian-Total</i>	<i>3.1</i>	<i>4.3</i>	<i>6.8</i>
Black-African	0.5	0.6	1.8
Black-Caribbean	0.4	0.4	1.1
Black-Other	0.1	0.2	0.5
<i>Black-Total</i>	<i>0.9</i>	<i>1.2</i>	<i>3.3</i>
Chinese	0.3	0.4	0.7
Mixed race	1.9	2.5	2.2
Other ethnicity	0.6	0.8	1.0
Total BAME	6.8	9.2	14.0

¹ Where ethnicity is reported
² Source - Office of National Statistics
Note some rounding effects

POTENTIAL ORGAN DONORS



3 Potential organ donors

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:

Neurological death suspected patients who meet all of the following criteria: invasive ventilation, Glasgow Coma Scale 3 not explained by sedation, no respiratory effort, fixed pupils, no cough or gag reflex. Excluding those not tested as cardiac arrest occurred despite resuscitation, brain stem reflexes returned, or below 37 weeks corrected gestational age.

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, 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 comparable in 2020/21 (83.1% and 83.2%, respectively).

Figure 3.1 presents the DBD and DCD referral rates for white and BAME communities. The referral rates for BAME and white potential DBD donors are 97.5% and 99%, respectively and 77% and 83% for DCD donors.

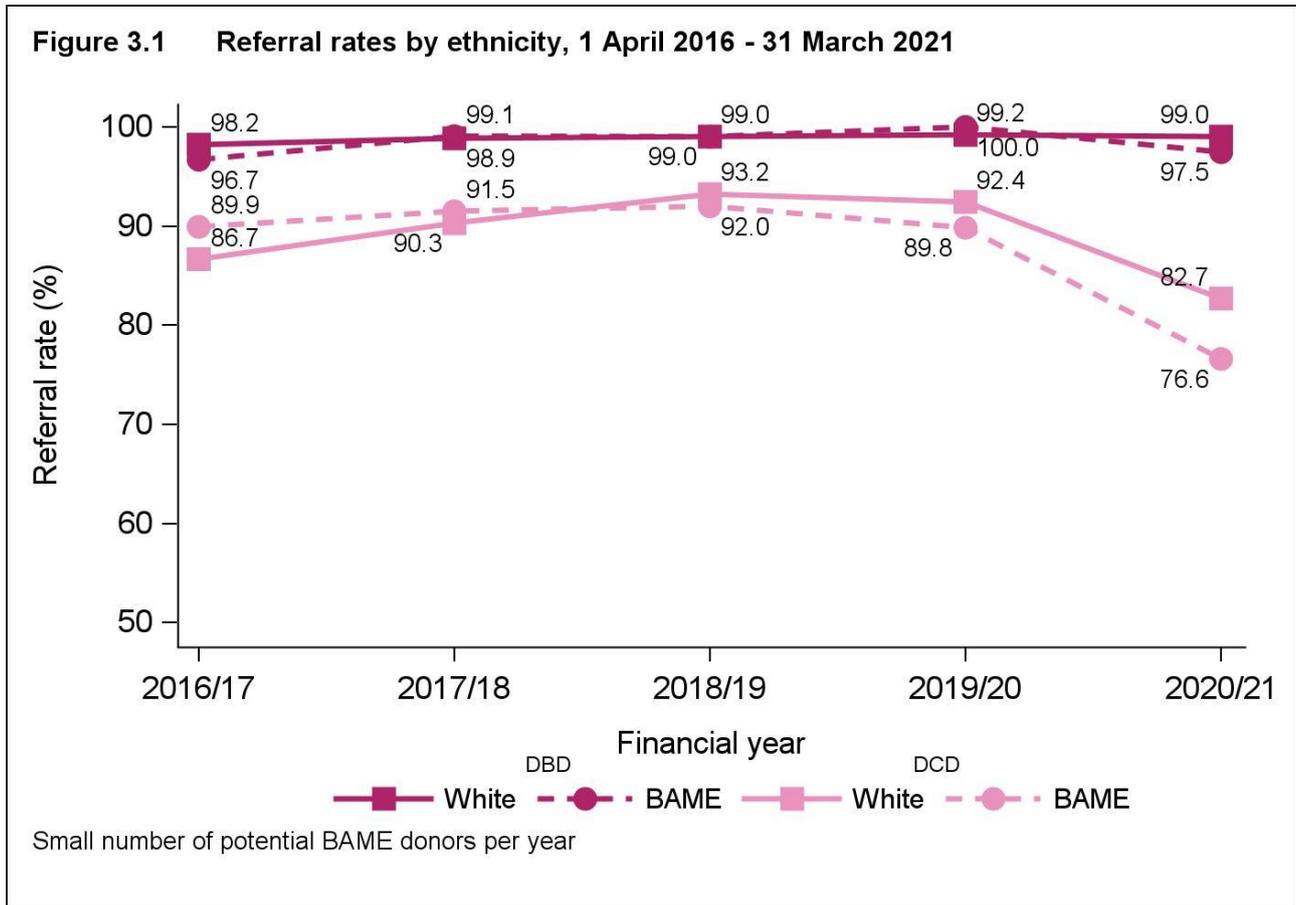


Figure 3.2 shows the number of eligible DBD donors and eligible DBD donors with consent ascertained over time for white and BAME communities, **Figure 3.3** shows the overall DBD consent/authorisation rates. Similarly, **Figure 3.4** and **Figure 3.5** illustrate the same information for DCD donation,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

Figure 3.2 demonstrates that, due to COVID-19, the number of white and BAME eligible DBD donors has fallen to 1098 and 277 respectively and that the number of white and BAME eligible consented/authorised DBD donors has fallen to 816 and 66 respectively.

Whilst there is a large pool of eligible DCD donors, additional DCD assessment and screening processes identify those unsuitable for organ donation and preclude them from the donation process. In combination with lower consent/authorisation rates, this results in fewer consented/authorised DCD donors as shown in **Figure 3.4**.

The impact of COVID-19 has also meant that both the number of eligible DCD donors and eligible consented/authorised DCD donors have fallen considerably.

Figure 3.2 Eligible DBD donors and eligible consented/authorised DBD donors by ethnicity, 1 April 2016 - 31 March 2021

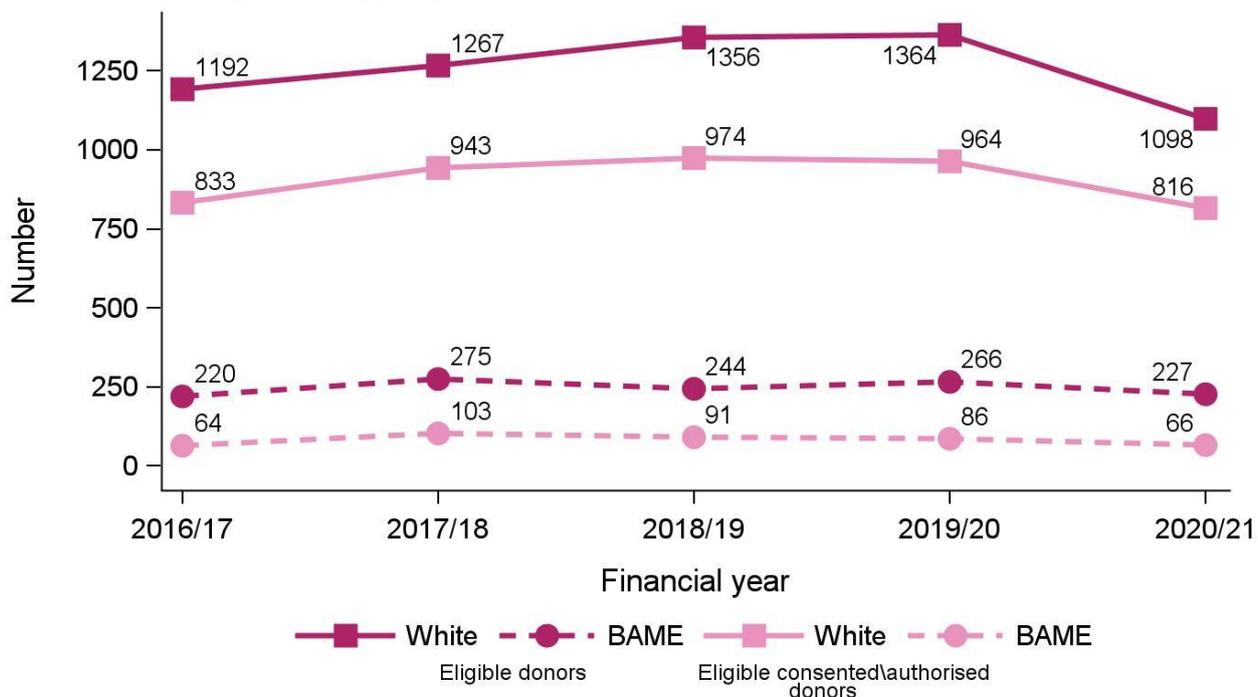
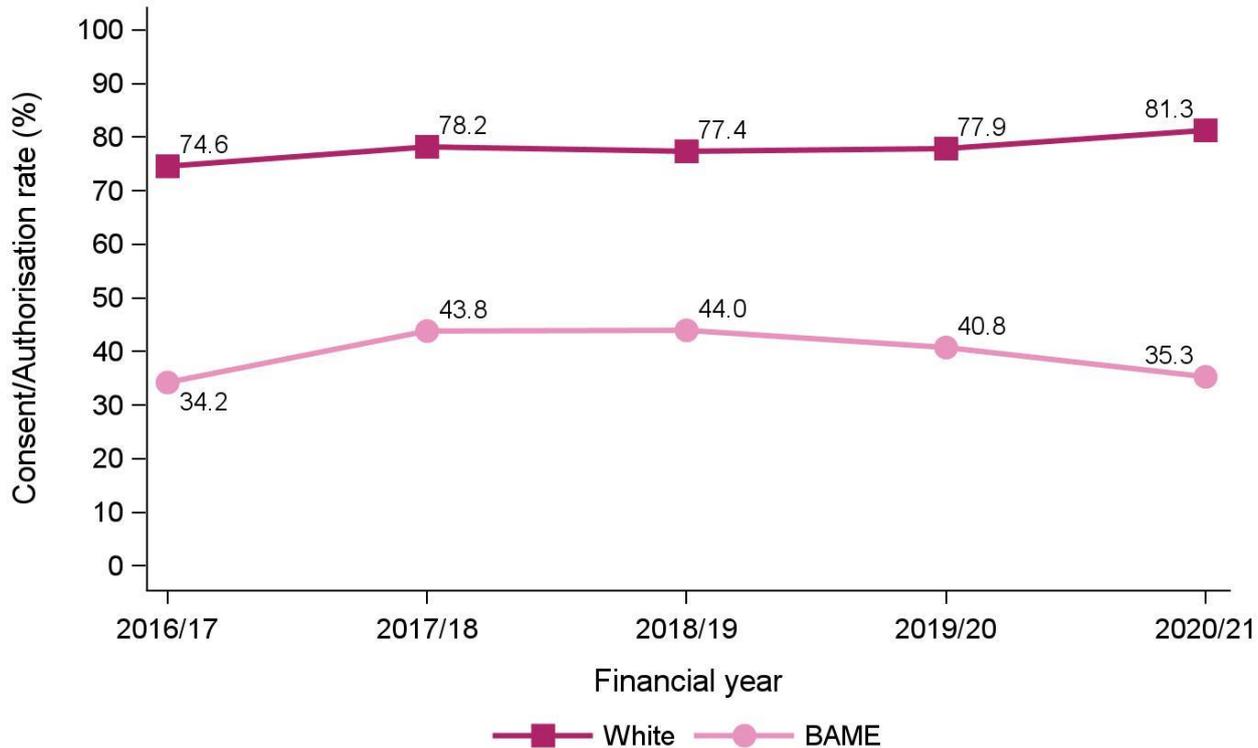


Figure 3.3 DBD consent/authorisation rates by ethnicity, 1 April 2016 - 31 March 2021



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

Figure 3.4 Eligible DCD donors and eligible consented/authorised DCD donors by ethnicity, 1 April 2016 - 31 March 2021

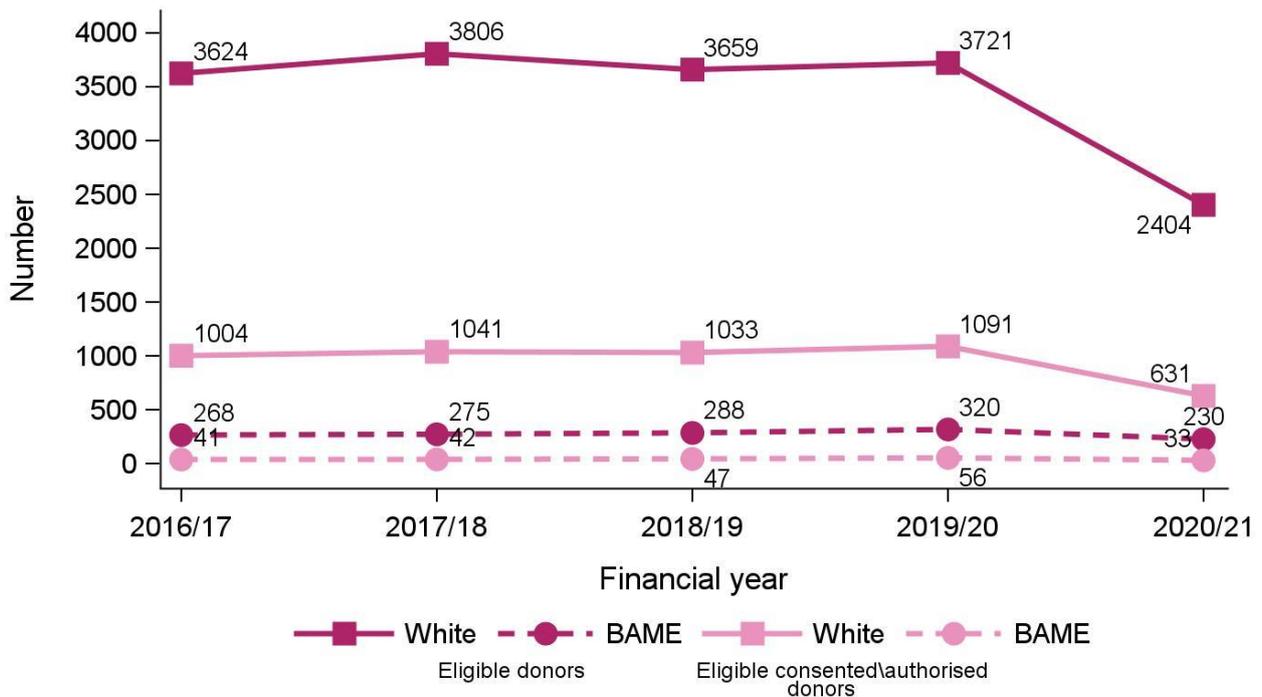
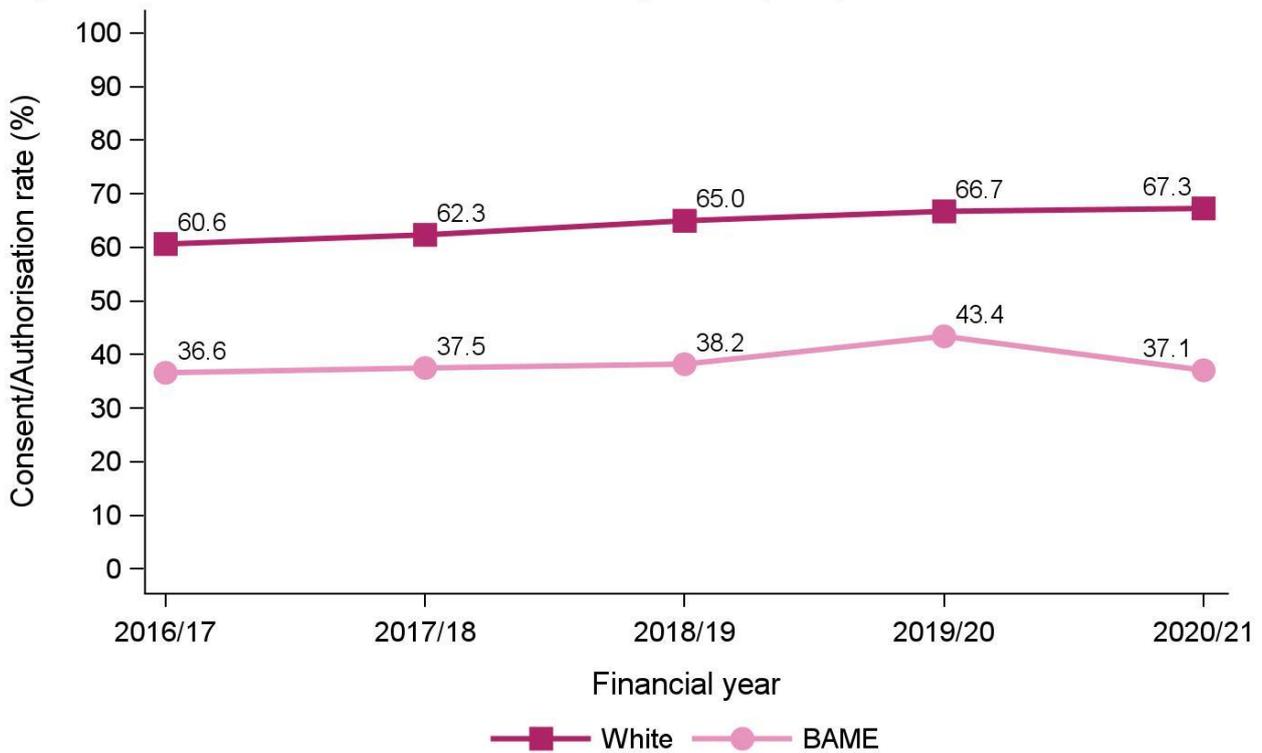


Figure 3.5 DCD consent/authorisation rates by ethnicity, 1 April 2016 - 31 March 2021



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

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 2016 to 31 March 2021. 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 2016 - 31 March 2021							
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	572	542	78.6	2355	958	67.8	71.7
London	662	626	73.3	1181	604	64.7	69.1
Midlands	681	617	77.3	2305	1086	61.1	67.0
North West	868	801	78.5	2596	952	65.1	71.3
Northern	446	426	72.8	1265	454	62.6	67.5
Northern Ireland	248	228	71.1	441	176	61.9	67.1
Scotland	513	469	77.8	1160	604	54.5	64.7
South Central	454	435	82.8	1423	578	63.8	72.0
South East	612	559	78.7	1341	616	69.2	73.7
South Wales	248	234	79.5	655	275	69.5	74.1
South West	431	392	84.7	895	472	65.3	74.1
Yorkshire	542	495	77.6	1597	714	64.3	69.7
Total	6277	5824	77.8	17214	7489	64.1	70.1
BAME							
Eastern	93	78	44.9	145	67	44.8	44.8
London	528	457	40.0	434	190	40.5	40.2
Midlands	175	134	32.1	280	91	35.2	33.3
North West	100	82	32.9	118	40	25.0	30.3
Northern	15	15	60.0	28	9	44.4	54.2
Northern Ireland	11	8	50.0	9	6	50.0	50.0
Scotland	24	18	44.4	24	11	18.2	34.5
South Central	51	43	46.5	73	37	40.5	43.8
South East	151	129	48.1	132	61	41.0	45.8
South Wales	9	8	75.0	20	10	50.0	61.1
South West	14	11	27.3	22	10	50.0	38.1
Yorkshire	61	44	22.7	96	33	33.3	27.3
Total	1232	1027	39.9	1381	565	38.8	39.5

Families of BAME eligible donors consent/authorise organ donation at a rate of 40% for DBD donation and 39% for DCD donation compared with families of white eligible donors who consent/authorise organ donation at a rate of 78% for DBD donation and 64% for DCD donation from 1 April 2016 to 31 March 2021.

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 an increase in consent/authorisation rates for white people from 66% to 75%. The consent/authorisation rate for BAME communities has fallen from 42% to 36% over the last year back to similar rates seen in 2016/17.

Table 3.2 Consent/authorisation (Con/auth) rates for families approached (app) for organ donation, by ethnicity and financial year, 1 April 2016 - 31 March 2021

Ethnicity	2016/17		2017/18		Financial year 2018/19		2019/20		2020/21	
	App	Con/auth rate %	App	Con/auth rate %	App	Con/auth rate %	App	Con/auth rate %	App	Con/auth rate %
White	2773	66.2	2876	69.0	2849	70.4	2873	71.5	1938	74.5
Asian	145	26.9	155	38.1	166	39.8	165	34.5	129	30.2
Black	93	36.6	97	34.0	90	32.2	98	39.8	76	27.6
Chinese/East Asian	18	22.2	24	29.2	18	50.0	21	52.4	14	35.7
Mixed	21	81.0	29	79.3	17	64.7	20	50.0	17	64.7
Other	22	50.0	42	54.8	39	59.0	36	69.4	40	57.5
BAME	299	35.1	347	41.8	330	41.8	340	41.8	276	35.9

Table 3.3 shows the reasons given by a family when declining consent/authorisation for organ donation, by ethnicity from 1 April 2016 to 31 March 2021. 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's refusal to give consent/authorise to organ donation by ethnicity, 1 April 2016 - 31 March 2021

Consent/authorisation refusal reason	Potential donor ethnicity											
	White		Asian		Black		Chinese/ East Asian		Mixed		Other	
	N	%	N	%	N	%	N	%	N	%	N	%
Patient had previously expressed a wish not to donate	1018	25.6	80	16.0	51	17.1	7	11.9	2	6.3	10	13.5
Family were not sure whether the patient would have agreed to donation	626	15.7	47	9.4	44	14.8	10	16.9	7	21.9	13	17.6
Family felt the length of time for the donation process was too long	545	13.7	9	1.8	7	2.3	2	3.4	3	9.4	2	2.7
Family did not want surgery to the body	402	10.1	51	10.2	17	5.7	6	10.2	2	6.3	9	12.2
Family felt patient had suffered enough	324	8.1	21	4.2	12	4.0	2	3.4	3	9.4	1	1.4
Other	315	7.9	34	6.8	20	6.7	1	1.7	5	15.6	7	9.5
Family divided over the decision	186	4.7	19	3.8	13	4.4	2	3.4	3	9.4	2	2.7
Family felt that the body should be buried whole (unrelated to religious/cultural reasons)	147	3.7	24	4.8	25	8.4	5	8.5	2	6.3	5	6.8
Strong refusal - probing not appropriate	131	3.3	20	4.0	10	3.4	1	1.7	1	3.1	2	2.7
Family did not believe in donation	121	3.0	28	5.6	18	6.0	5	8.5	2	6.3	3	4.1
Family wanted to stay with the patient after death	46	1.2	2	0.4	1	0.3						
Family felt it was against their religious/cultural beliefs	44	1.1	151	30.2	66	22.1	18	30.5	2	6.3	20	27.0
Family concerned that organs may not be transplantable	42	1.1	4	0.8								
Patient had registered a decision to Opt Out	9	0.2	2	0.4	5	1.7						
Family had difficulty understanding/accepting neurological testing	9	0.2	1	0.2	4	1.3						
Family concerned about organ allocation	6	0.2			2	0.7						
Family concerned other people may disapprove/be offended	5	0.1	4	0.8	2	0.7						
Family concerned donation may delay the funeral	3	0.1	3	0.6								
Family believe patient's treatment may have been limited to facilitate organ donation	1	0.0			1	0.3						
Total	3980	100	500	100	298	100	59	100	32	100	74	100

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 the 2019/20 financial year) from 1 April 2016 to 31 March 2021. Waiting list figures at the 31 March 2020 and 2021 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, thus 29 February 2020 is used as a more representative date for the number of patients on the active transplant list at year end for 2019/20.

There were 672 less active BAME patients at 31 March 2021. There was a 36% fall in the number of BAME transplant recipients in 2020/21 and a 25% fall in the number of BAME deceased organ donors due to COVID-19. Similarly, due to COVID-19, there was a 25% fall in the number of white deceased organ donors, with a 27% fall in the number of white transplant recipients. There is also a 61% reduction in the number of living donors, in line with the drop in white living donors.

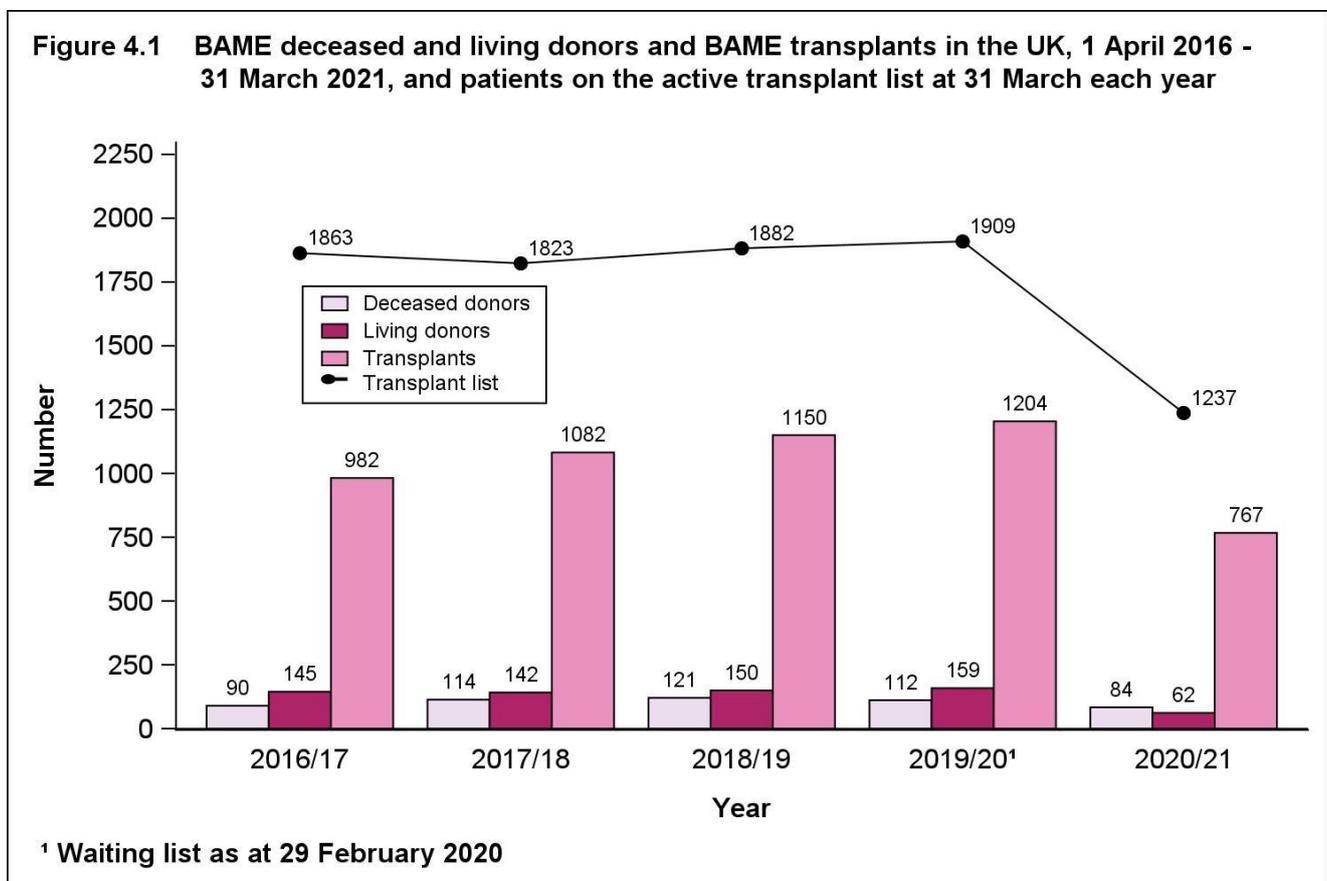


Table 4.1 shows a further breakdown of the number of living and deceased BAME donors, transplants and those on the transplant waiting list from 1 April 2016 to 31 March 2021, where totals exclude those with ethnicity not recorded. Rates per million population (pmp) of the total population are also shown. Last year, BAME patients account for a third of patients on the transplant waiting list, a quarter of all transplants and 9% of donors were from BAME communities.

	Table 4.1 Number of donors, transplants and waiting list in the UK, by financial year and BAME, 1 April 2016 - 31 March 2021				
	Financial year				
	2016/17	2017/18	2018/19	2019/20	2020/21
Waiting list ¹	6291	5949	5984	6040	4189
BAME waiting list ¹	1863	1823	1882	1909	1237
BAME % of waiting list	29.6	30.6	31.5	31.6	29.5
BAME on waiting list per million population of total UK population (pmp)	27.8	27.2	28.1	28.5	18.5
Total donors	2442	2619	2634	2621	1579
Total BAME donors	235	256	271	271	146
BAME % of donors	9.6	9.8	10.3	10.3	9.2
BAME donors pmp	3.5	3.8	4	4	2.2
Deceased donors	1398	1555	1589	1566	1144
Deceased BAME donors	90	114	121	112	84
<i>DBD BAME donors</i>	62	83	90	76	61
<i>DCD BAME donors</i>	28	31	31	36	23
BAME % of deceased donors	6.4	7.3	7.6	7.2	7.3
Deceased BAME donors pmp	1.3	1.7	1.8	1.7	1.3
Living donors	1044	1064	1045	1055	435
Living BAME donors	145	142	150	159	62
BAME % of living donors	13.9	13.3	14.4	15.1	14.3
Living BAME donors pmp	2.2	2.1	2.2	2.4	0.9
Total transplants	4712	5044	4941	4749	3344
Total BAME transplants	982	1082	1150	1204	767
BAME % of transplants	20.8	21.5	23.3	25.4	22.9
BAME transplants pmp	14.6	16.1	17.2	18	11.4
Deceased donor (DD) transplants	3676	3996	3910	3710	2903
BAME DD transplants	812	904	971	1010	682
BAME % of deceased donor transplants	22.1	22.6	24.8	27.2	23.5
BAME DD transplants pmp	12.1	13.5	14.5	15.1	10.2
Living donor (LD) transplants	1036	1048	1031	1039	441
BAME LD transplants	170	178	179	194	85
BAME % of LD transplants	16.4	17	17.4	18.7	19.3
BAME LD transplants pmp	2.5	2.7	2.7	2.9	1.3

Those with unknown/unreported ethnicity were excluded
Per million population of total UK population in 2019
¹ Waiting list as at 31 March, except 2019/20 (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 2015 and 31 March 2016. 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.

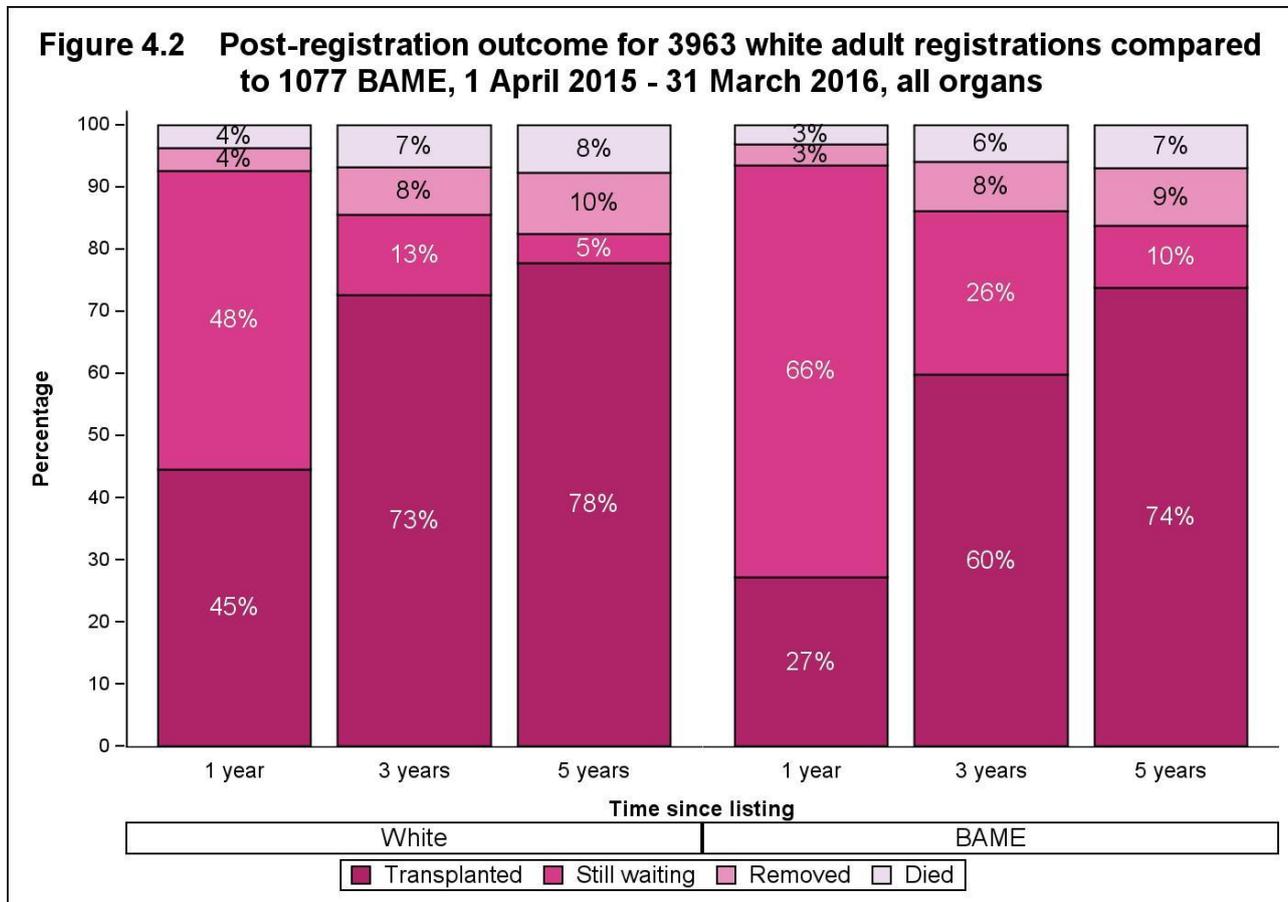


Table 4.2 Post-registration outcome for 3963 white adult registrations compared to 1077 BAME, 1 April 2015 - 31 March 2016, all organs

Outcome	1 year		3 years		5 years	
	N	%	N	%	N	%
White						
Transplanted	1768	44.6	2876	72.6	3084	77.8
Still waiting	1906	48.1	513	12.9	187	4.7
Removed	144	3.6	307	7.7	389	9.8
Died	145	3.7	267	6.7	303	7.6
BAME						
Transplanted	293	27.2	644	59.8	795	73.8
Still waiting	715	66.4	284	26.4	107	9.9
Removed	36	3.3	85	7.9	101	9.4
Died	33	3.1	64	5.9	74	6.9

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 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	7200	527	511 - 543
Asian	1749	682	643 - 721
Black	1009	824	770 - 878
Other	399	678	596 - 760
TOTAL	10472	589	575 - 603
Paediatric kidney¹			
White	147	202	141 - 263
Asian	78	399	322 - 476
Black	18	628	161 - 1095
Other	16	501	305 - 697
TOTAL	260	258	188 - 328
Adult pancreas²			
White	769	360	332 - 388
Asian	61	372	285 - 459
Black	56	414	374 - 454
Other	18	178	116 - 240
TOTAL	911	364	341 - 387
Adult liver³			
White	1652	70	62 - 78
Asian	124	87	57 - 117
Black	43	81	21 - 141
Other	61	36	21 - 51
TOTAL	1927	72	64 - 80
Paediatric liver³	142	74	54 - 94
Adult never urgent heart⁴			
White	406	2279	-
Asian	31	1473	-
Black	16	742	177 - 1307
Other	4	-	-
TOTAL	458	2279	-
Adult ever urgent heart^{4,5}			
White	676	35	30 - 40
Asian	73	37	14 - 60
Black	39	40	0 - 92
Other	13	34	21 - 47
TOTAL	808	35	31 - 39
Paediatric never urgent heart⁴	40	414	196 - 632
Paediatric ever urgent heart⁴	217	88	72 - 104
Adult lung⁴			
White	1378	351	308 - 394
Asian	58	1191	355 - 2027
Black	18	735	-
Other	5	-	-
TOTAL	1465	365	319 - 411

Median waiting time not reported for fewer than 10 patients

- Median and/or 95% confidence interval cannot be estimated due to insufficient numbers of patients transplanted

¹ Kidney-only patients registered 1 April 2014 - 31 March 2018

² Pancreas-only and kidney/pancreas patients registered 1 April 2015 - 31 March 2019

³ Liver patients registered 1 April 2018 - 31 March 2020

⁴ Cardiothoracic patients registered 1 April 2013 - 31 March 2018

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

The number of deaths on the transplant waiting list broken down by financial year, organ type and ethnicity are shown in **Table 4.4**. Over the last year, there has been an increase in the number of deaths on the waiting list across all organs, from 458 to 527. BAME patients accounted for 26% of those who died waiting for a transplant in 2020/21.

Table 4.4 Number of deaths on the transplant waiting list, by financial year, organ and ethnicity, 1 April 2016 - 31 March 2021										
Ethnicity	2016/17		2017/18		2018/19		2019/20		2020/21	
	N	%								
Kidney										
White	250	77.9	227	73.0	229	74.8	209	75.2	231	67.2
Asian	39	12.1	42	13.5	43	14.1	38	13.7	72	20.9
Black	27	8.4	31	10.0	18	5.9	22	7.9	36	10.5
Other	5	1.6	11	3.5	16	5.2	9	3.2	5	1.5
Unknown	1		5		5		4		3	
Total	322	100.0	316	100.0	311	100.0	282	100.0	347	100.0
Pancreas										
White	22	88.0	24	85.7	19	95.0	14	87.5	20	90.9
Asian			1	3.6			2	12.5	2	9.1
Black	2	8.0	2	7.1						
Other	1	4.0	1	3.6	1	5.0				
Unknown					1				1	
Total	25	100.0	28	100.0	21	100.0	16	100.0	23	100.0
Liver										
White	88	92.6	61	81.3	45	86.5	41	83.7	63	87.5
Asian	5	5.3	7	9.3	6	11.5	6	12.2	5	6.9
Black	1	1.1	4	5.3	1	1.9	2	4.1	3	4.2
Other	1	1.1	3	4.0					1	1.4
Unknown					2		6		1	
Total	95	100.0	75	100.0	54	100.0	55	100.0	73	100.0
Cardiothoracic										
White	111	91.7	103	92.8	86	87.8	94	89.5	71	84.5
Asian	8	6.6	4	3.6	8	8.2	6	5.7	9	10.7
Black	2	1.7	4	3.6	2	2.0	4	3.8	3	3.6
Other					2	2.0	1	1.0	1	1.2
Total	121	100.0	111	100.0	98	100.0	105	100.0	84	100.0
Total										
White	471	83.8	415	79.0	379	79.6	358	79.9	385	73.8
Asian	52	9.3	54	10.3	57	12.0	52	11.6	88	16.9
Black	32	5.7	41	7.8	21	4.4	28	6.3	42	8.0
Other	7	1.2	15	2.9	19	4.0	10	2.2	7	1.3
Unknown	1		5		8		10		5	
Total	563	100.0	530	100.0	484	100.0	458	100.0	527	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 2016 to 31 March 2021). 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 2016 - 31 March 2021

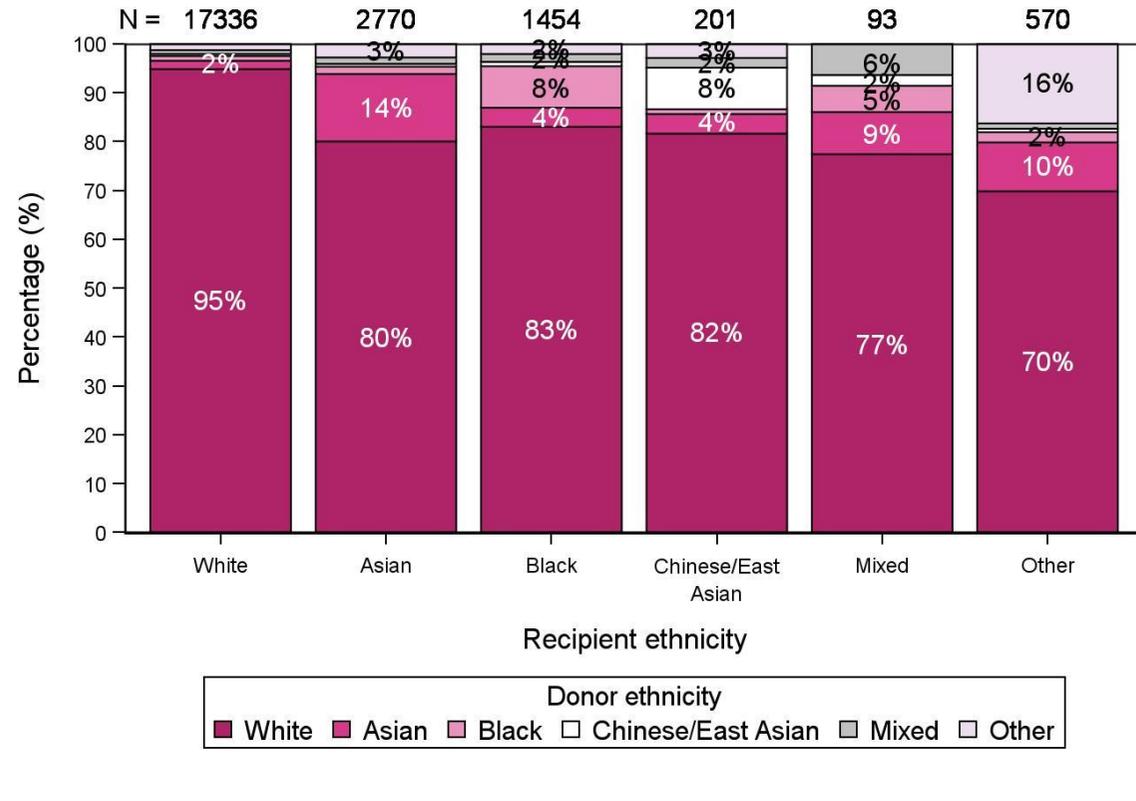


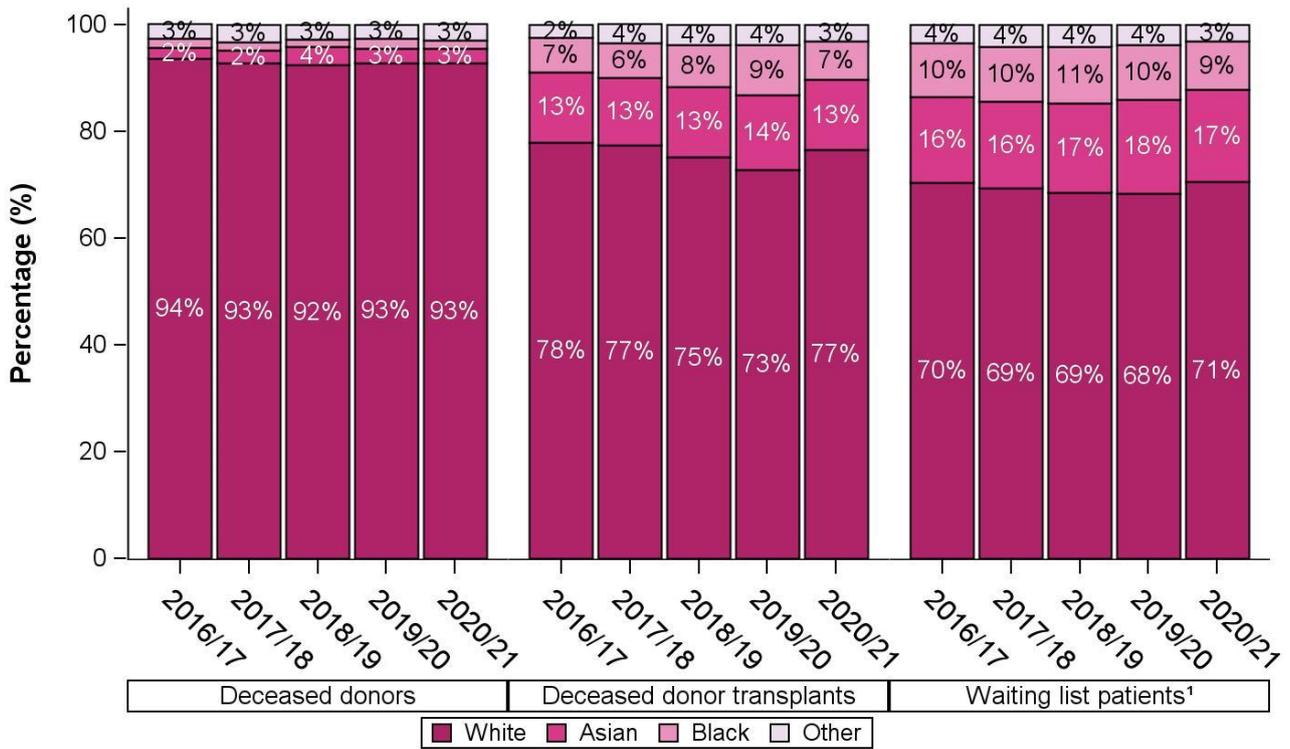
Table 4.5 Donor to recipient ethnicities for all transplants in the UK, 1 April 2016 - 31 March 2021

Donor ethnicity	Recipient ethnicity												Total N
	White		Asian		Black		Chinese/ East Asian		Mixed		Other		
	N	%	N	%	N	%	N	%	N	%	N	%	
White	16428	94.8	2217	80.0	1207	83.0	164	81.6	72	77.4	398	69.8	20486
Asian	301	1.7	382	13.8	57	3.9	8	4.0	8	8.6	57	10.0	813
Black	179	1.0	41	1.5	123	8.5	2	1.0	5	5.4	12	2.1	362
Chinese/East Asian	62	0.4	18	0.6	13	0.9	17	8.5	2	2.2	4	0.7	116
Mixed	131	0.8	35	1.3	23	1.6	4	2.0	6	6.5	6	1.1	205
Other	235	1.4	77	2.8	31	2.1	6	3.0	0	0.0	93	16.3	442
Total	17336	100.0	2770	100.0	1454	100.0	201	100.0	93	100.0	570	100.0	22424

Deceased organ donors, deceased donor transplant recipients and patients on the transplant list at 31 March each year (with the exception of 2019/20) are shown by ethnicity from 2016/17 to 2020/21 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.

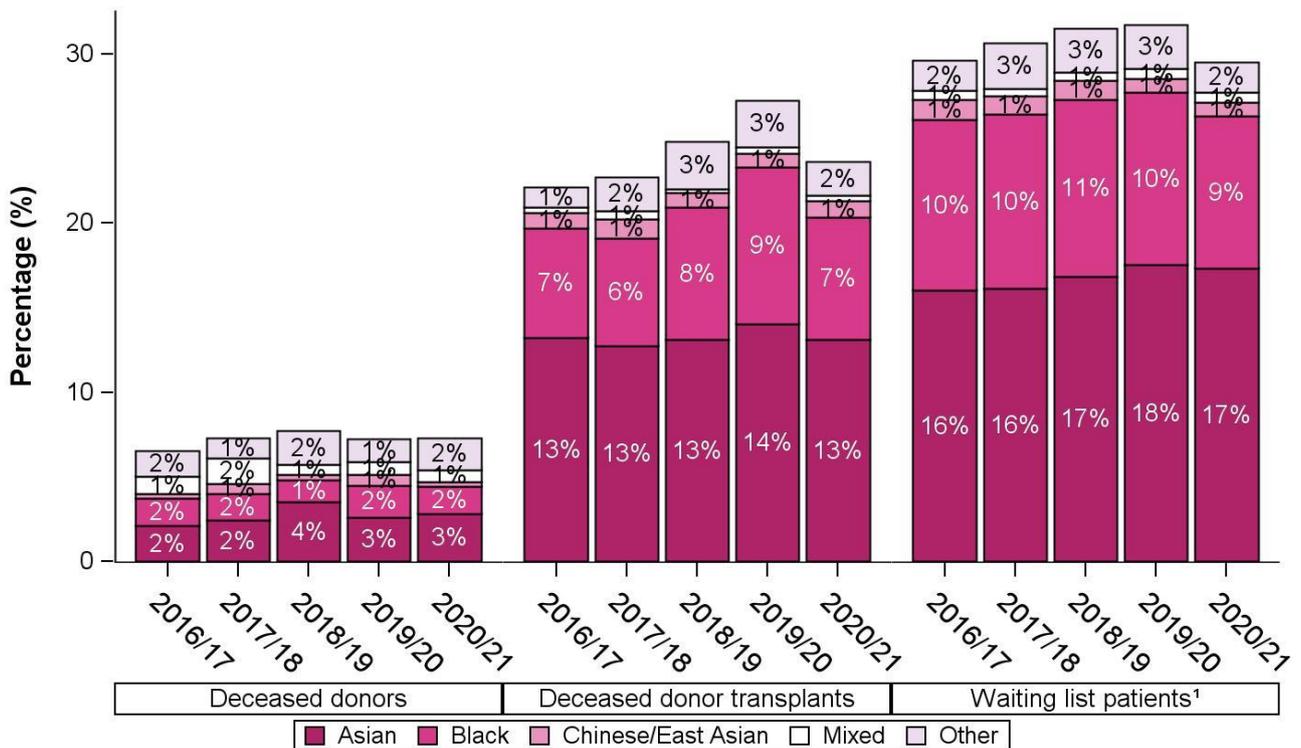
The figures illustrate that there are proportionally more BAME living donors than BAME deceased donors. There are proportionally more BAME people on the list for transplant than there are among people transplanted, reflecting an inequity of access to transplant for some organs.

Figure 4.4 Deceased donors, deceased donor transplants and patients on the waiting list (as at 31 March each year), 1 April 2016 - 31 March 2021



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 2016 - 31 March 2021



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

Figure 4.6 Living donors and transplants, 1 April 2016 - 31 March 2021

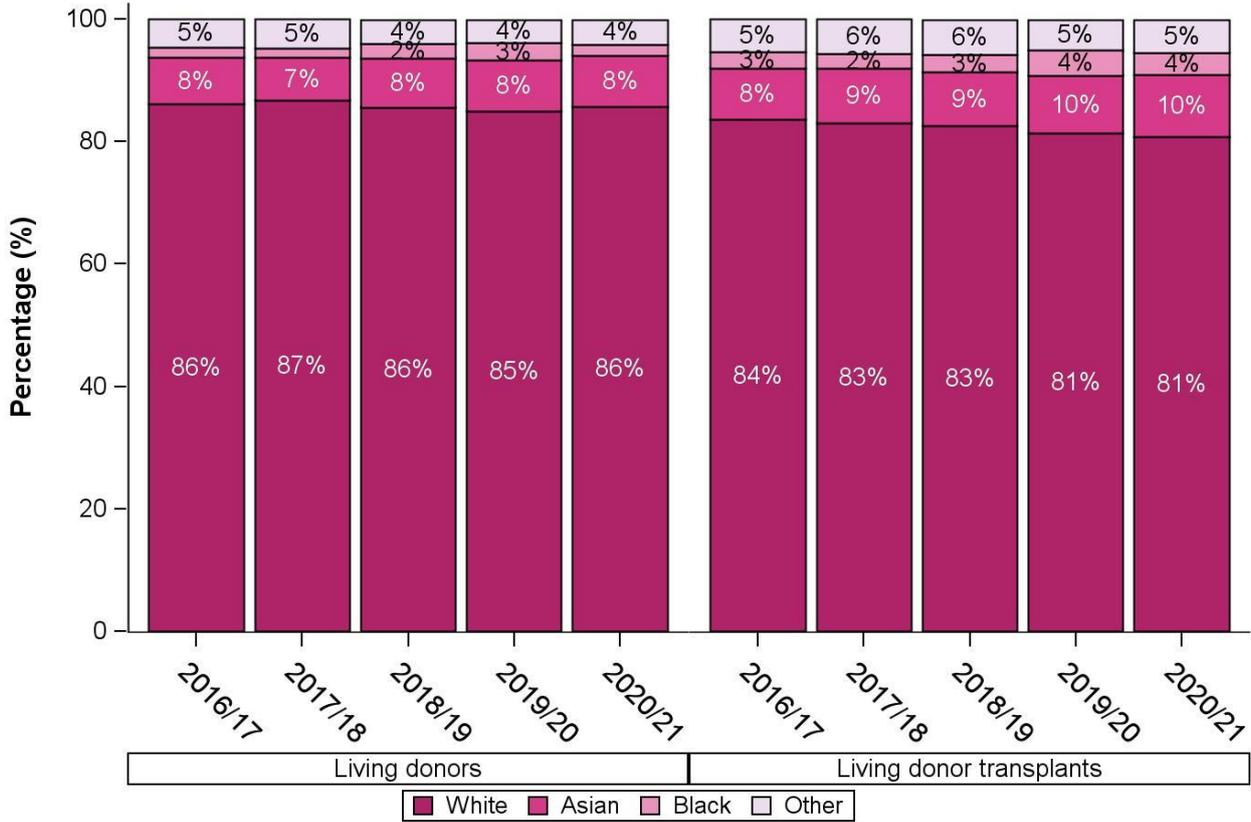


Figure 4.7 BAME communities - Living donors and transplants, 1 April 2016 - 31 March 2021

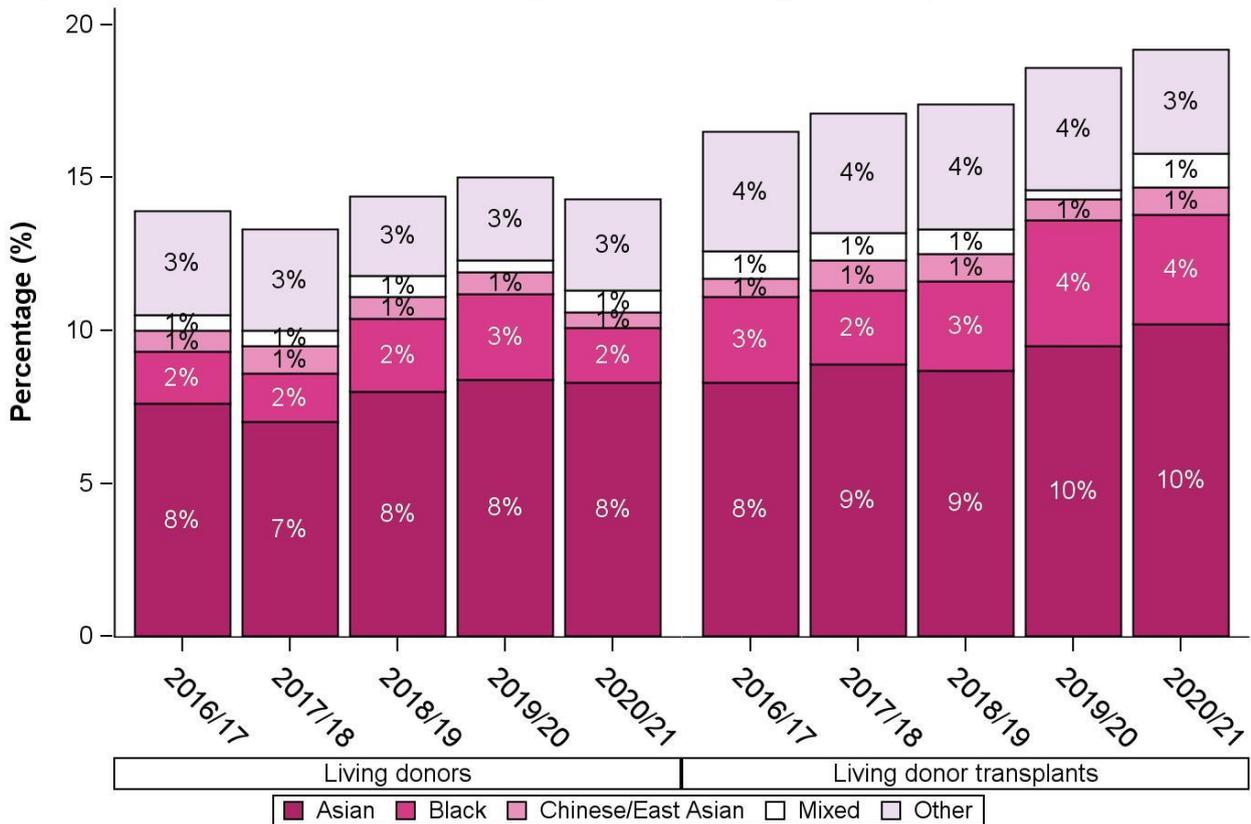


Table 4.6 Number of donors, transplants and waiting list patients in the UK, by ethnicity and financial year, 1 April 2016 - 31 March 2021

Ethnicity	2016/17		2017/18		2018/19		2019/20		2020/21	
	N	%	N	%	N	%	N	%	N	%
Deceased donors										
White	1308	93.6	1441	92.7	1468	92.4	1454	92.8	1060	92.7
Asian	29	2.1	37	2.4	56	3.5	40	2.6	32	2.8
Black	22	1.6	25	1.6	20	1.3	30	1.9	18	1.6
Chinese/East Asian	4	0.3	9	0.6	4	0.3	10	0.6	4	0.3
Mixed	14	1.0	24	1.5	9	0.6	12	0.8	8	0.7
Other	21	1.5	19	1.2	32	2.0	20	1.3	22	1.9
Deceased donor transplants										
White	2864	77.9	3092	77.4	2939	75.2	2700	72.8	2221	76.5
Asian	485	13.2	508	12.7	513	13.1	519	14.0	379	13.1
Black	238	6.5	254	6.4	305	7.8	345	9.3	209	7.2
Chinese/East Asian	32	0.9	43	1.1	35	0.9	29	0.8	28	1.0
Mixed	12	0.3	19	0.5	7	0.2	15	0.4	8	0.3
Other	45	1.2	80	2.0	111	2.8	102	2.7	58	2.0
Waiting list										
White	4428	70.4	4126	69.4	4102	68.5	4131	68.4	2952	70.5
Asian	1008	16.0	958	16.1	1006	16.8	1057	17.5	725	17.3
Black	633	10.1	614	10.3	629	10.5	615	10.2	376	9.0
Chinese/East Asian	73	1.2	68	1.1	63	1.1	47	0.8	34	0.8
Mixed	33	0.5	22	0.4	31	0.5	35	0.6	25	0.6
Other	116	1.8	161	2.7	153	2.6	155	2.6	77	1.8
Living donors										
White	899	86.1	922	86.7	895	85.6	896	84.9	373	85.7
Asian	79	7.6	75	7.0	84	8.0	89	8.4	36	8.3
Black	18	1.7	17	1.6	25	2.4	30	2.8	8	1.8
Chinese/East Asian	7	0.7	10	0.9	7	0.7	7	0.7	2	0.5
Mixed	5	0.5	5	0.5	7	0.7	4	0.4	3	0.7
Other	36	3.4	35	3.3	27	2.6	29	2.7	13	3.0
Living donor transplants										
White	866	83.6	870	83.0	852	82.6	845	81.3	356	80.7
Asian	86	8.3	93	8.9	90	8.7	99	9.5	45	10.2
Black	29	2.8	25	2.4	30	2.9	43	4.1	16	3.6
Chinese/East Asian	6	0.6	10	1.0	9	0.9	7	0.7	4	0.9
Mixed	9	0.9	9	0.9	8	0.8	3	0.3	5	1.1
Other	40	3.9	41	3.9	42	4.1	42	4.0	15	3.4

Unknown ethnicity was excluded

Table 4.7 summarises all deceased donor transplants by country of residence, ethnicity of recipient and organ transplanted in 2020/21. 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 2020 - 31 March 2021,

Country of residence	Transplants (N)								Total
	Kidney	Pancreas ¹	Kidney/ Pancreas ²	Heart	Lung	Liver	Intestinal	Multiorgan ³	
England									
White	953	9	55	99	64	498	1	18	1700
Asian	268		3	17	2	56		3	350
Black	159		5	9	6	24			203
Chinese/East Asian	21					5			26
Mixed	5		1	1		1			8
Other	40			2	1	9	1		53
Wales									
White	48		8	6	4	27			94
Asian	4								4
Scotland									
White	149	4	10	21	7	64		1	257
Asian	21					5			26
Black	5								5
Chinese/East Asian	1								1
Other	1					1			2
Northern Ireland									
White	131		1	3	3	28			166
Black	1								1
Chinese/East Asian	1								1
Other	2					1			3

¹ Includes 10 islet transplants

² includes 11 simultaneous islet/kidney transplants

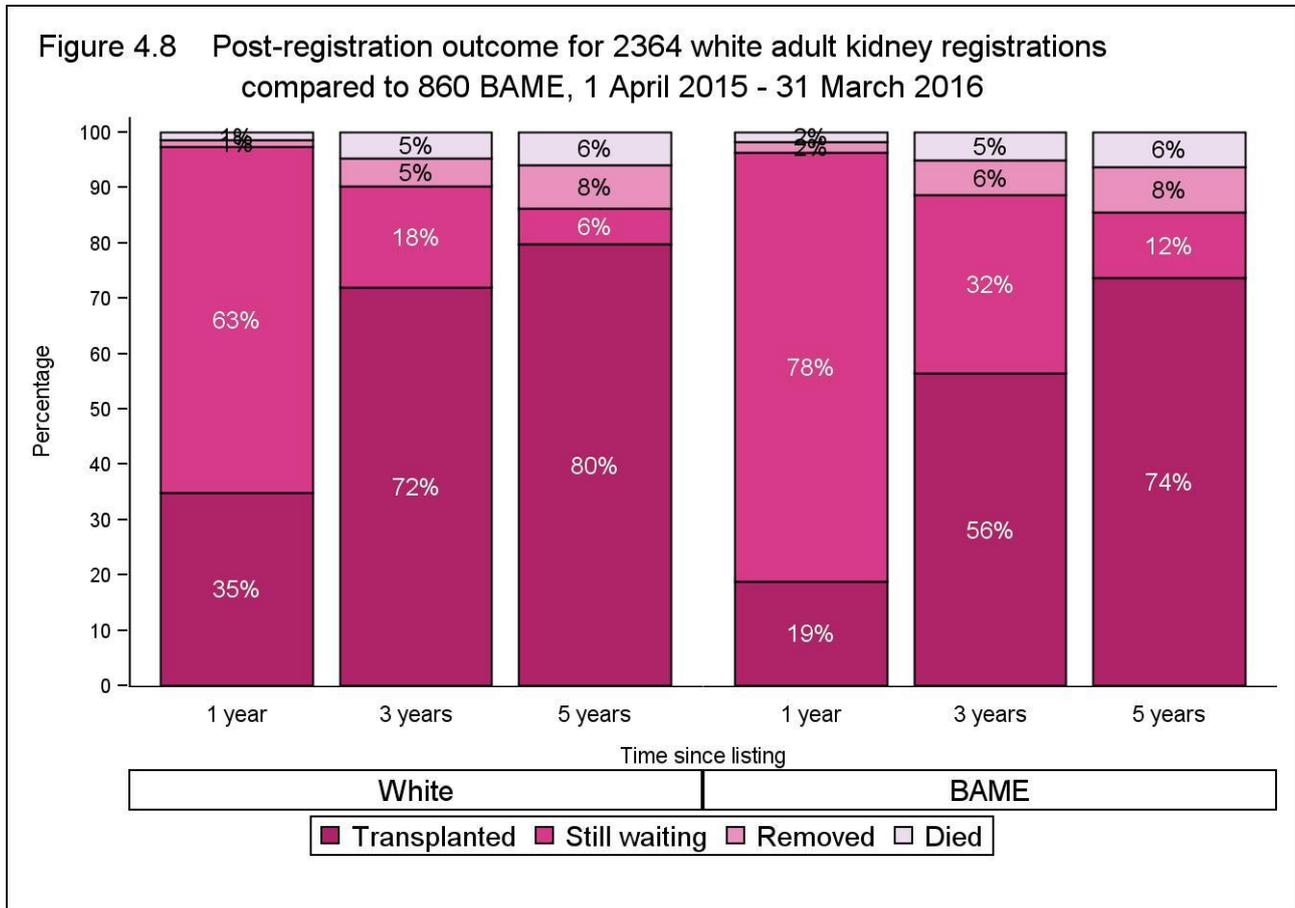
³ Includes 2 heart/lung transplants, 5 multivisceral transplants, 5 modified multivisceral transplants, 7 liver and kidney transplants, 2 heart and liver transplants, 1 lung and liver transplant

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

4.2 Kidney

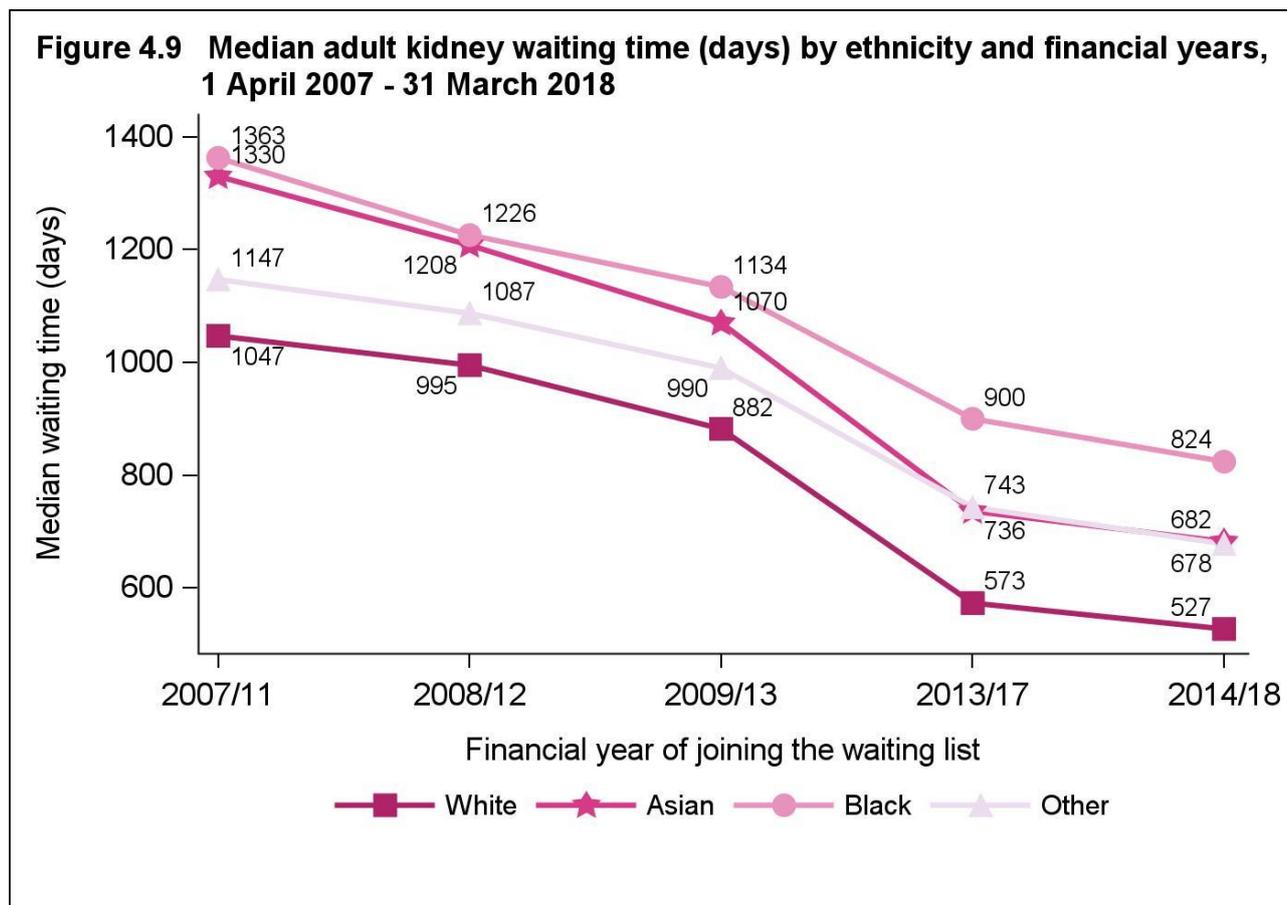
The vast majority of transplants are for patients who require a kidney either from living or deceased donation. Post-registration outcomes, median waiting times, donor to recipient ethnicities, deceased and living donor transplants are detailed in this section.

Figure 4.8 and **Table 4.8** show post-registration outcome comparisons for white and BAME adult kidney patients registered from 1 April 2015 to 31 March 2016. Post-registration, 19% of BAME kidney patients compared to 35% 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 waiting on the list.



Outcome	1 year		3 years		5 years	
	N	%	N	%	N	%
White						
Transplanted	825	34.9	1699	71.9	1886	79.8
Still waiting	1479	62.6	434	18.4	152	6.4
Removed	25	1.1	121	5.1	186	7.9
Died	35	1.5	110	4.7	140	5.9
BAME						
Transplanted	162	18.8	485	56.4	633	73.6
Still waiting	667	77.6	277	32.2	103	12.0
Removed	16	1.9	54	6.3	70	8.1
Died	15	1.7	44	5.1	54	6.3

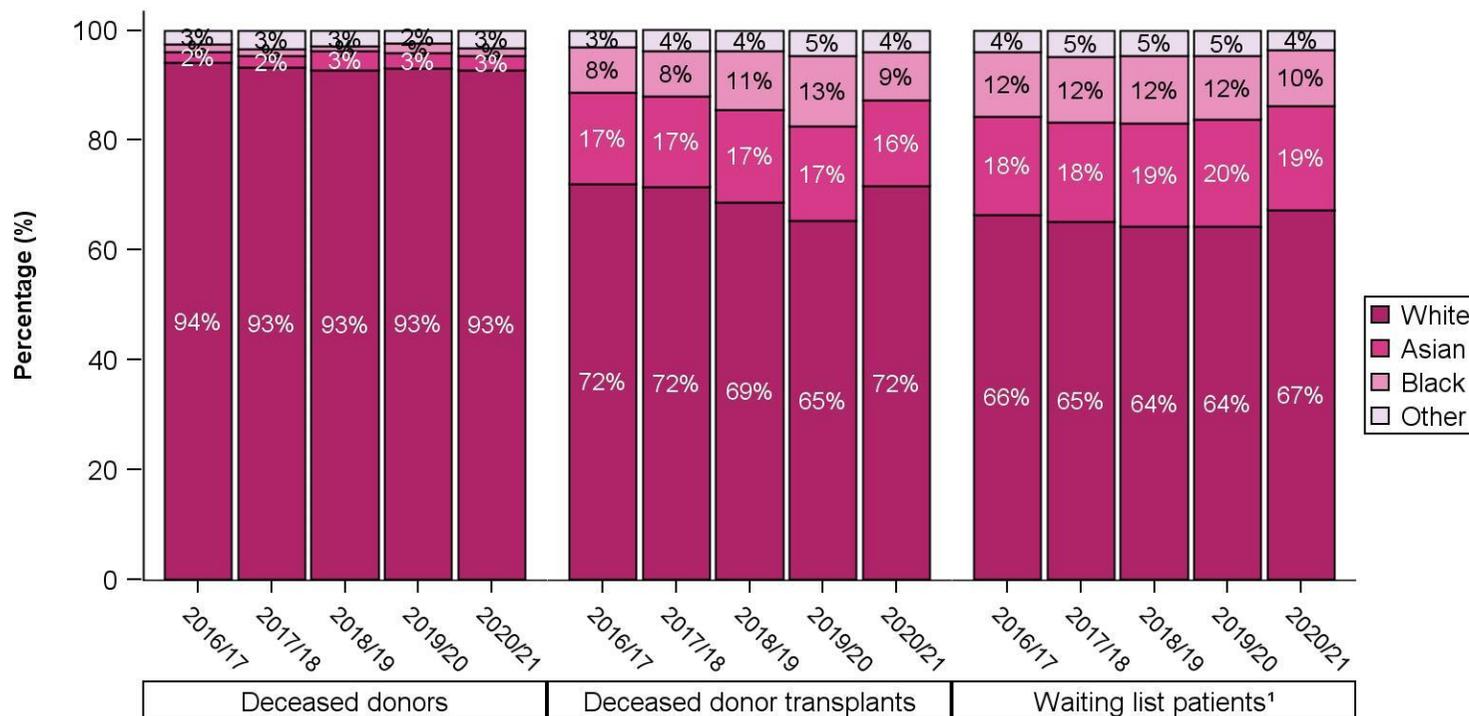
Figure 4.9 gives the adult median waiting time for a kidney transplant in days, by ethnicity and financial year group from 1 April 2007 to 31 March 2018. It shows an overall decline in waiting times for all ethnicities, although black patients are waiting ten months longer for a transplant than white patients.



In the last year, **Figure 4.10** shows that 7% of deceased kidney donors are from BAME communities whilst BAME patients represent 28% of transplants and account for 33% 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 2016 to 31 March 2021. 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.

Figure 4.10 Kidney statistics (waiting list as at 31 March each year), 1 April 2016 - 31 March 2021



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

Table 4.10 Kidney statistics (waiting list as at 31 March), 1 April 2016 - 31 March 2021

Ethnicity	Deceased donors					Deceased donor transplants					Waiting list patients				
	16/17	17/18	18/19	19/20	20/21	16/17	17/18	18/19	19/20	20/21	16/17	17/18	18/19	19/20	20/21
White	1243	1363	1389	1367	996	1661	1811	1743	1589	1361	3414	3220	3149	3139	2327
Asian	27	30	51	39	28	384	418	433	419	297	922	896	921	955	662
Black	17	19	14	27	15	194	207	270	311	170	599	589	601	569	351
Chinese/East Asian	3	9	3	10	4	24	32	24	26	23	71	67	59	45	32
Mixed	14	23	8	9	8	9	14	6	11	6	27	20	27	31	20
Other	17	18	31	16	22	35	52	64	77	43	106	153	145	147	72
Total	1321	1462	1496	1468	1073	2307	2534	2540	2433	1900	5139	4945	4902	4886	3464

Figure 4.11 Deceased donor to recipient ethnicities for kidney transplants in the UK, 1 April 2016 - 31 March 2021

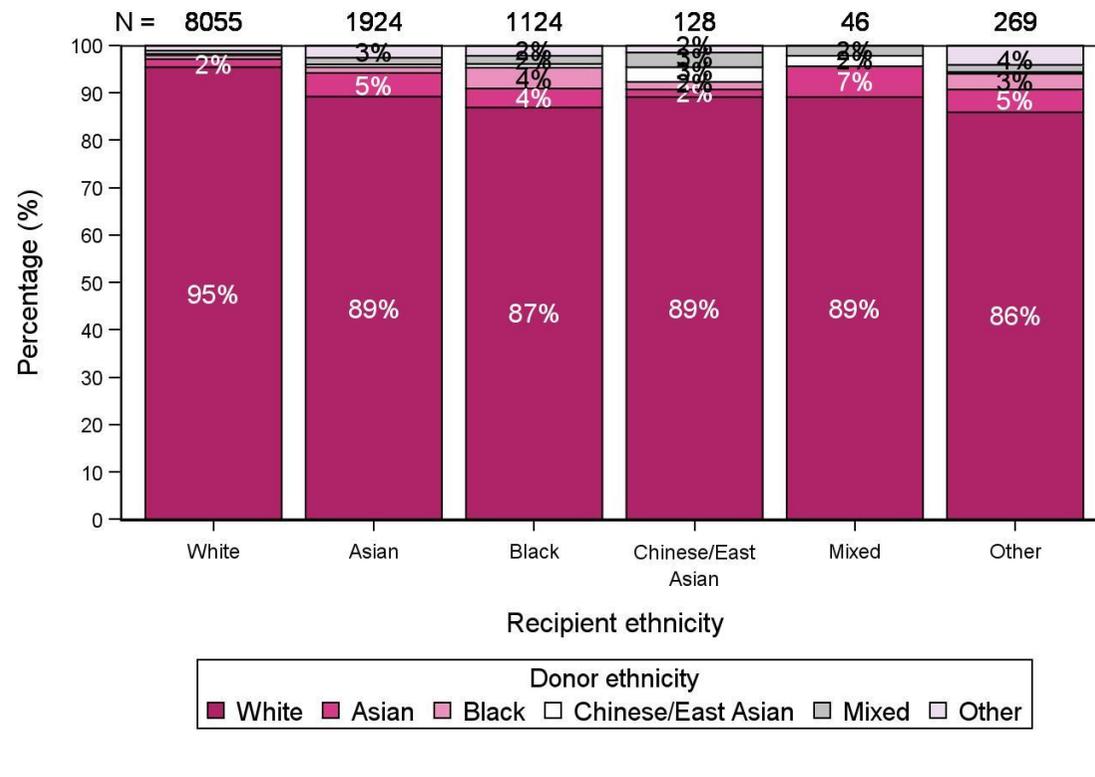


Table 4.11 Deceased donor to recipient ethnicities for kidney transplants in the UK, 1 April 2016 - 31 March 2021

Donor ethnicity	Recipient ethnicity												Total N
	White		Asian		Black		Chinese/ East Asian		Mixed		Other		
	N	%	N	%	N	%	N	%	N	%	N	%	
White	7681	95.4	1716	89.2	977	86.9	114	89.1	41	89.1	231	85.9	10760
Asian	135	1.7	97	5.0	45	4.0	2	1.6	3	6.5	13	4.8	295
Black	62	0.8	24	1.2	50	4.4	2	1.6	0	0.0	9	3.3	147
Chinese/East Asian	25	0.3	11	0.6	9	0.8	4	3.1	1	2.2	1	0.4	51
Mixed	56	0.7	26	1.4	19	1.7	4	3.1	1	2.2	4	1.5	110
Other	96	1.2	50	2.6	24	2.1	2	1.6	0	0.0	11	4.1	183
Total	8055	100.0	1924	100.0	1124	100.0	128	100.0	46	100.0	269	100.0	11546

Figure 4.12 Living donor to recipient ethnicities for kidney transplants in the UK, 1 April 2016 - 31 March 2021

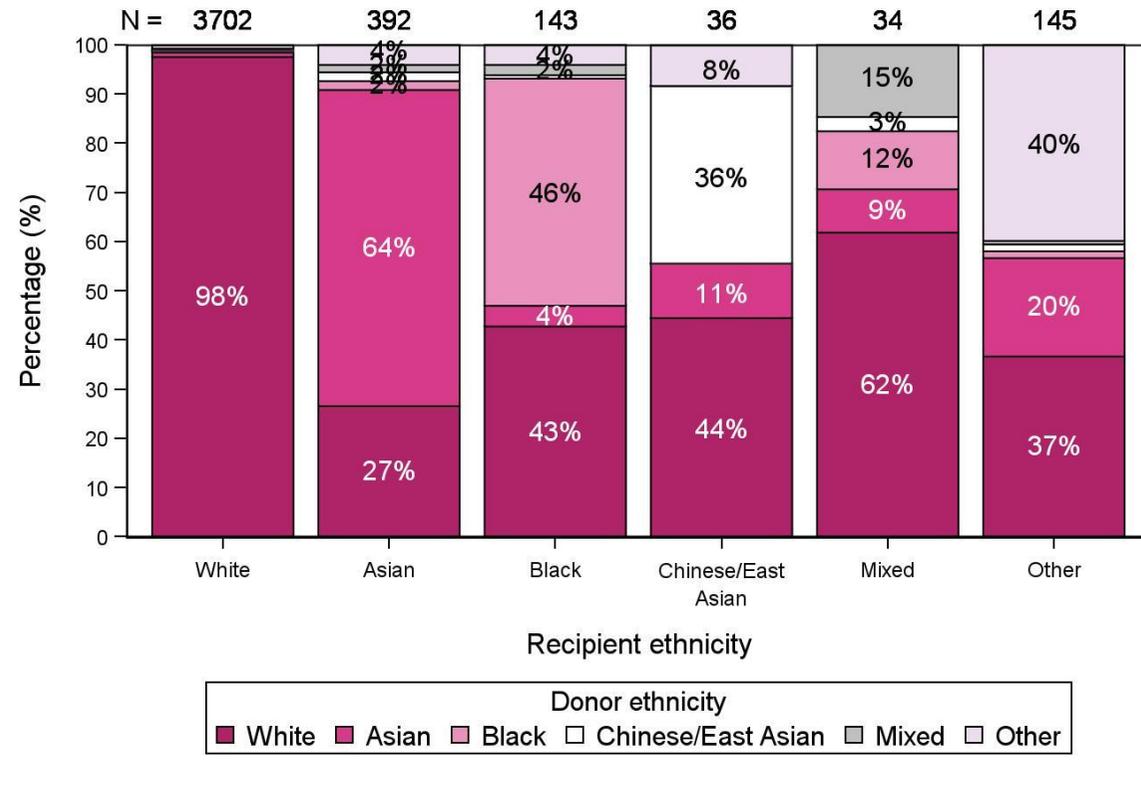


Table 4.12 Living donor to recipient ethnicities for kidney transplants in the UK, 1 April 2016 - 31 March 2021

Donor ethnicity	Recipient ethnicity												Total N
	White		Asian		Black		Chinese/ East Asian		Mixed		Other		
	N	%	N	%	N	%	N	%	N	%	N	%	
White	3611	97.5	104	26.5	61	42.7	16	44.4	21	61.8	53	36.6	3866
Asian	34	0.9	252	64.3	6	4.2	4	11.1	3	8.8	29	20.0	328
Black	14	0.4	7	1.8	66	46.2	0	0.0	4	11.8	2	1.4	93
Chinese/East Asian	8	0.2	7	1.8	1	0.7	13	36.1	1	2.9	2	1.4	32
Mixed	9	0.2	6	1.5	3	2.1	0	0.0	5	14.7	1	0.7	24
Other	26	0.7	16	4.1	6	4.2	3	8.3	0	0.0	58	40.0	109
Total	3702	100.0	392	100.0	143	100.0	36	100.0	34	100.0	145	100.0	4452

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 2016 to 31 March 2021. 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 2 other ethnic minority altruistic BAME donors.

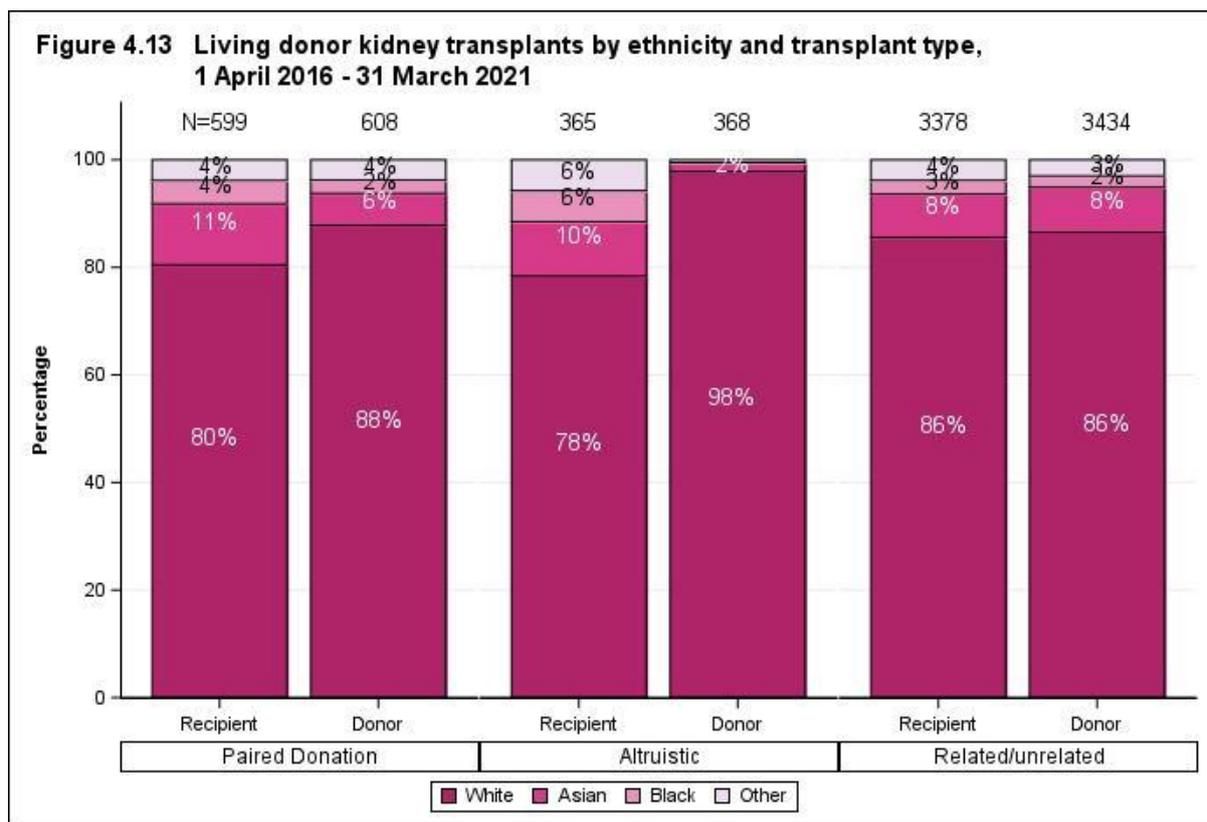


Table 4.13 Living donor kidney transplants by ethnicity and transplant type, 1 April 2016 - 31 March 2021

Type of living donation	Ethnicity	Recipient		Donor	
		N	%	N	%
Paired Donation	White	482	80.5	534	87.8
	Asian	68	11.4	36	5.9
	Black	26	4.3	15	2.5
	Other	23	3.8	23	3.8
	Unknown	10		1	
	Total		609	100.0	609
Altruistic	White	286	78.4	360	97.8
	Asian	37	10.1	6	1.6
	Black	21	5.8		
	Other	21	5.8	2	0.5
	Unknown	3			
	Total		368	100.0	368
Related/unrelated	White	2891	85.6	2970	86.5
	Asian	271	8.0	288	8.4
	Black	87	2.6	73	2.1
	Other	129	3.8	103	3.0
	Unknown	56			
	Total		3434	100.0	3434

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 2015 to 31 March 2016. Of the 34 BAME pancreas patients listed, 74% were transplanted within 5 years. This rate is lower than for white patients, although fewer had died waiting on the transplant list. The number of BAME patients is very small so results should be interpreted with caution.

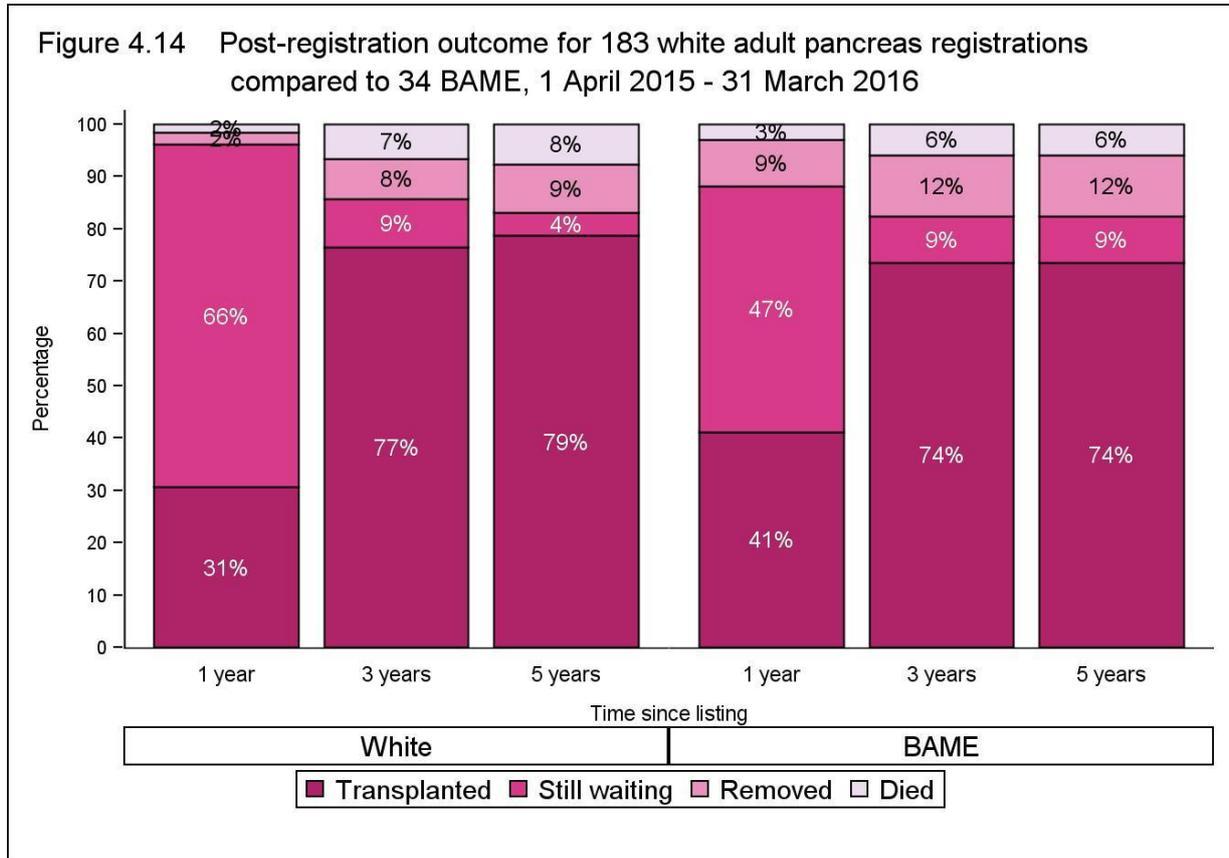
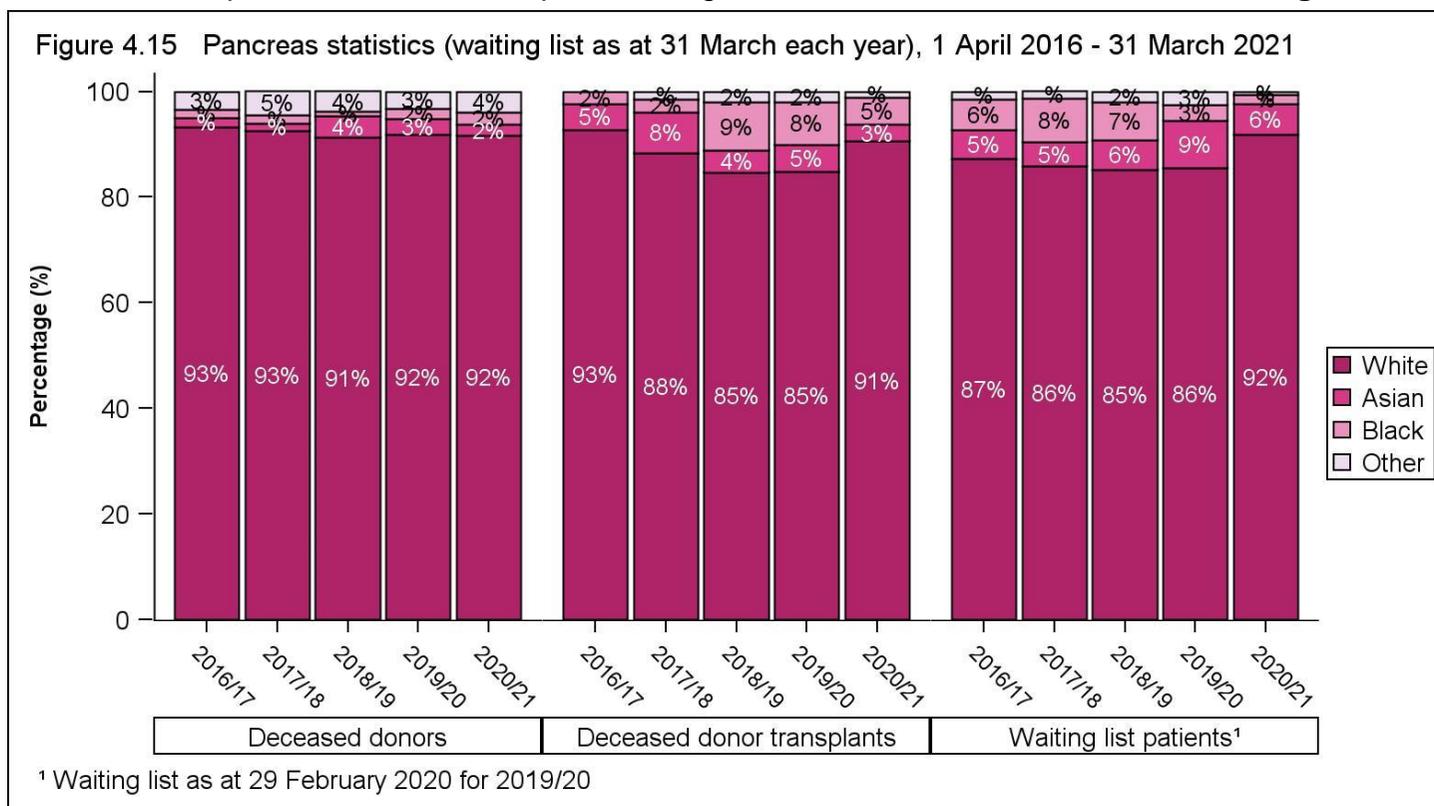


Table 4.14 Post-registration outcome for 183 white adult pancreas registrations compared to 34 BAME, 1 April 2015 - 31 March 2016

Outcome	1 year		3 years		5 years	
	N	%	N	%	N	%
White						
Transplanted	56	30.6	140	76.5	144	78.7
Still waiting	120	65.6	17	9.3	8	4.4
Removed	4	2.2	14	7.7	17	9.3
Died	3	1.6	12	6.6	14	7.7
BAME						
Transplanted	14	41.2	25	73.5	25	73.5
Still waiting	16	47.1	3	8.8	3	8.8
Removed	3	8.8	4	11.8	4	11.8
Died	1	2.9	2	5.9	2	5.9

Figure 4.15 shows in the last financial year that 8% of deceased pancreas donors are from BAME communities whilst BAME patients represent 9% of transplants and 8% of the pancreas or islet transplant waiting list. **Table 4.15** shows the numbers in **Figure 4.15**.

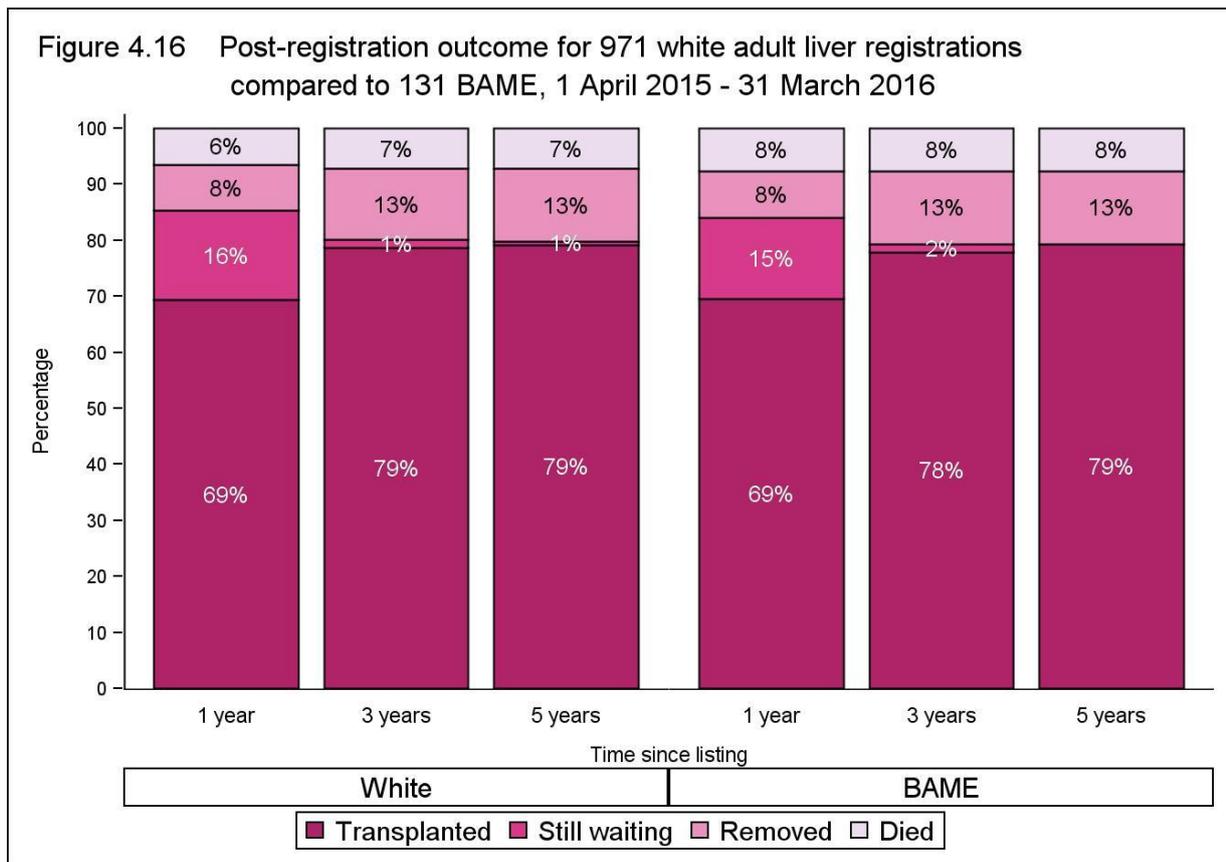


Ethnicity	Deceased donors					Deceased donor transplants					Waiting list patients				
	16/17	17/18	18/19	19/20	20/21	16/17	17/18	18/19	19/20	20/21	16/17	17/18	18/19	19/20	20/21
White	433	435	423	409	188	193	181	166	167	87	193	187	213	202	158
Asian	8	6	18	13	4	10	16	8	10	3	12	10	14	21	10
Black	7	8	4	9	5	5	5	18	16	5	13	18	18	7	3
Chinese/East Asian	2	4	1	6			1							2	
Mixed	6	9	3	3	3		2		1	1	1			1	
Other	8	8	14	5	5			4	3		2	3	5	3	1
Total	464	470	463	445	205	208	205	196	197	96	221	218	250	236	172

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 2015 to 31 March 2016. 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.



Outcome	1 year		3 years		5 years	
	N	%	N	%	N	%
White						
Transplanted	673	69.3	764	78.7	769	79.2
Still waiting	155	16.0	14	1.4	6	0.6
Removed	80	8.2	123	12.7	126	13.0
Died	63	6.5	70	7.2	70	7.2
BAME						
Transplanted	91	69.5	102	77.9	104	79.4
Still waiting	19	14.5	2	1.5	0	0.0
Removed	11	8.4	17	13.0	17	13.0
Died	10	7.6	10	7.6	10	7.6

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 2020. It shows an overall decline in waiting times for all ethnicities; Asian and black patients now wait a similar time for a transplant compared to white patients. 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.

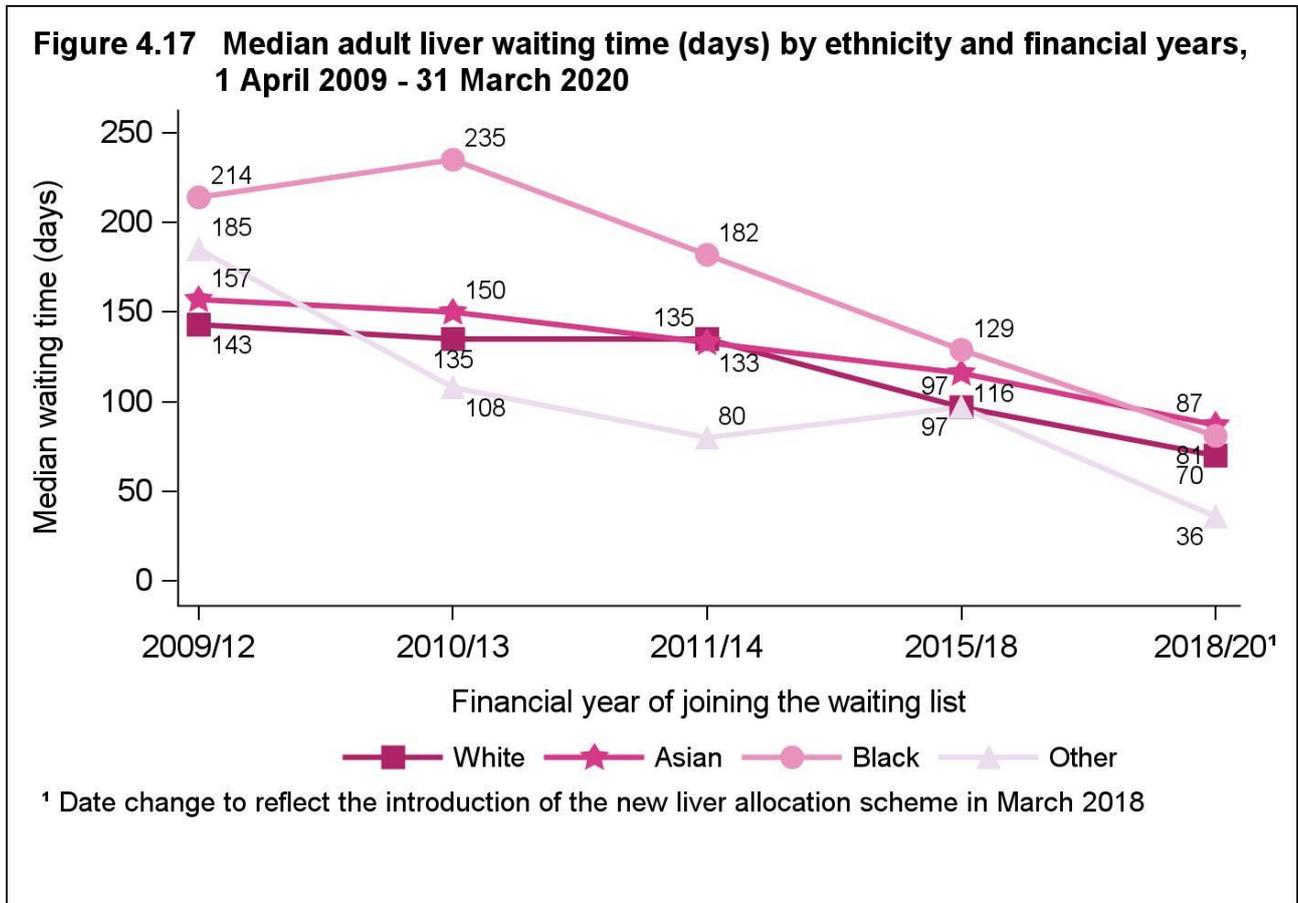
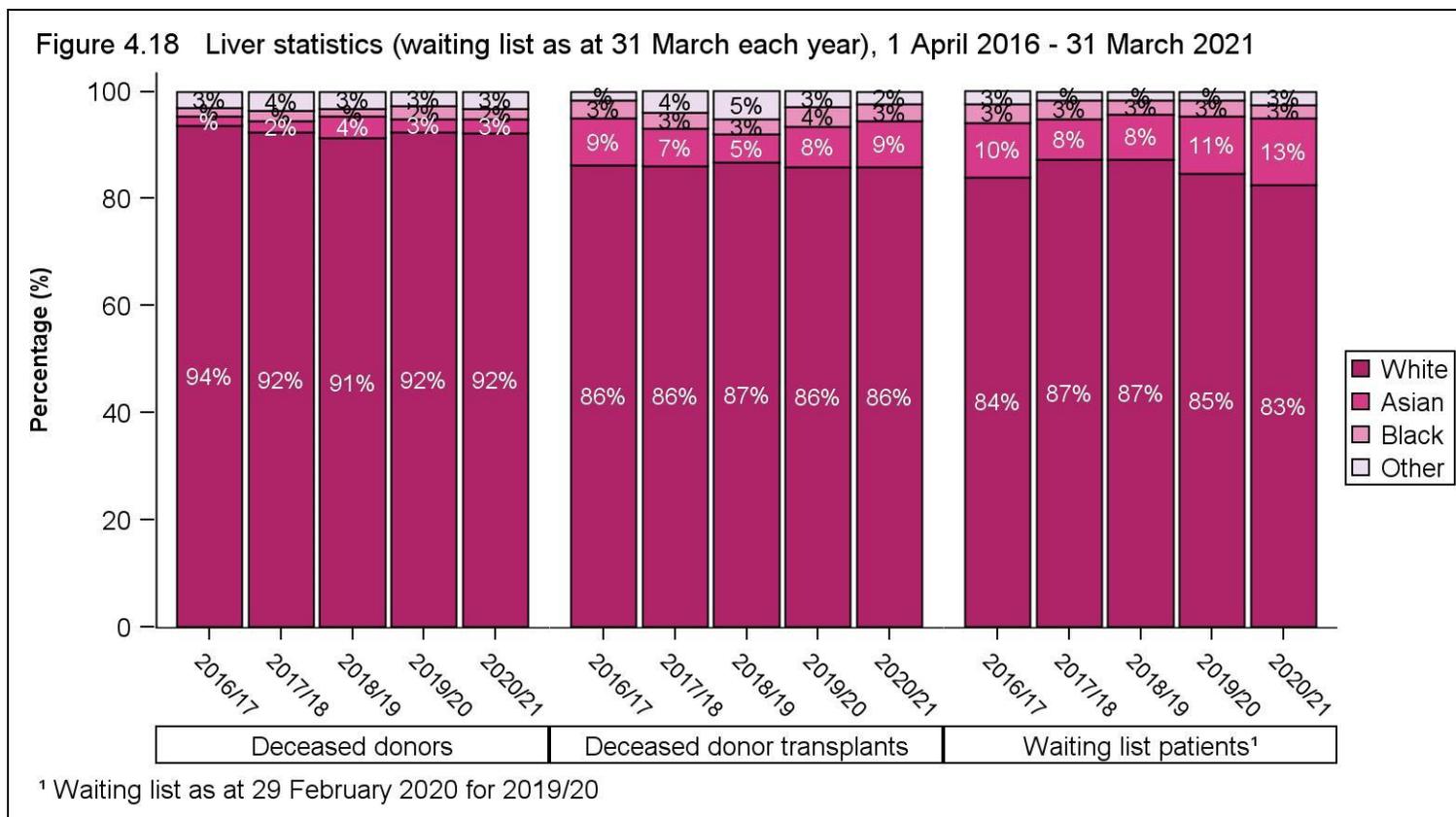


Figure 4.18 shows that 8% of deceased liver donors are from BAME communities whilst BAME patients represent 14% of transplants and 17% of the liver transplant waiting list in 2020/21. **Table 4.18** shows the numbers in **Figure 4.18**.



Ethnicity	Deceased donors					Deceased donor transplants					Waiting list patients				
	16/17	17/18	18/19	19/20	20/21	16/17	17/18	18/19	19/20	20/21	16/17	17/18	18/19	19/20	20/21
White	964	1047	1008	1030	779	813	867	838	772	628	445	309	365	379	99
Asian	17	25	44	29	22	83	69	51	68	63	54	27	35	48	15
Black	18	22	17	26	17	32	31	27	32	24	18	12	11	14	3
Chinese/East Asian	4	6	3	8	4	6	10	10	3	5	1		3	2	
Mixed	12	18	8	8	6	2	2		1	1	4			1	2
Other	15	16	24	15	17	7	28	41	23	11	8	6	4	4	1
Total	1030	1134	1104	1116	845	943	1007	967	899	732	530	354	418	448	120

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 2015 to 31 March 2016. BAME cardiothoracic recipients wait a similar time for a heart or lung compared to white patients but have a higher chance of removal from the list.

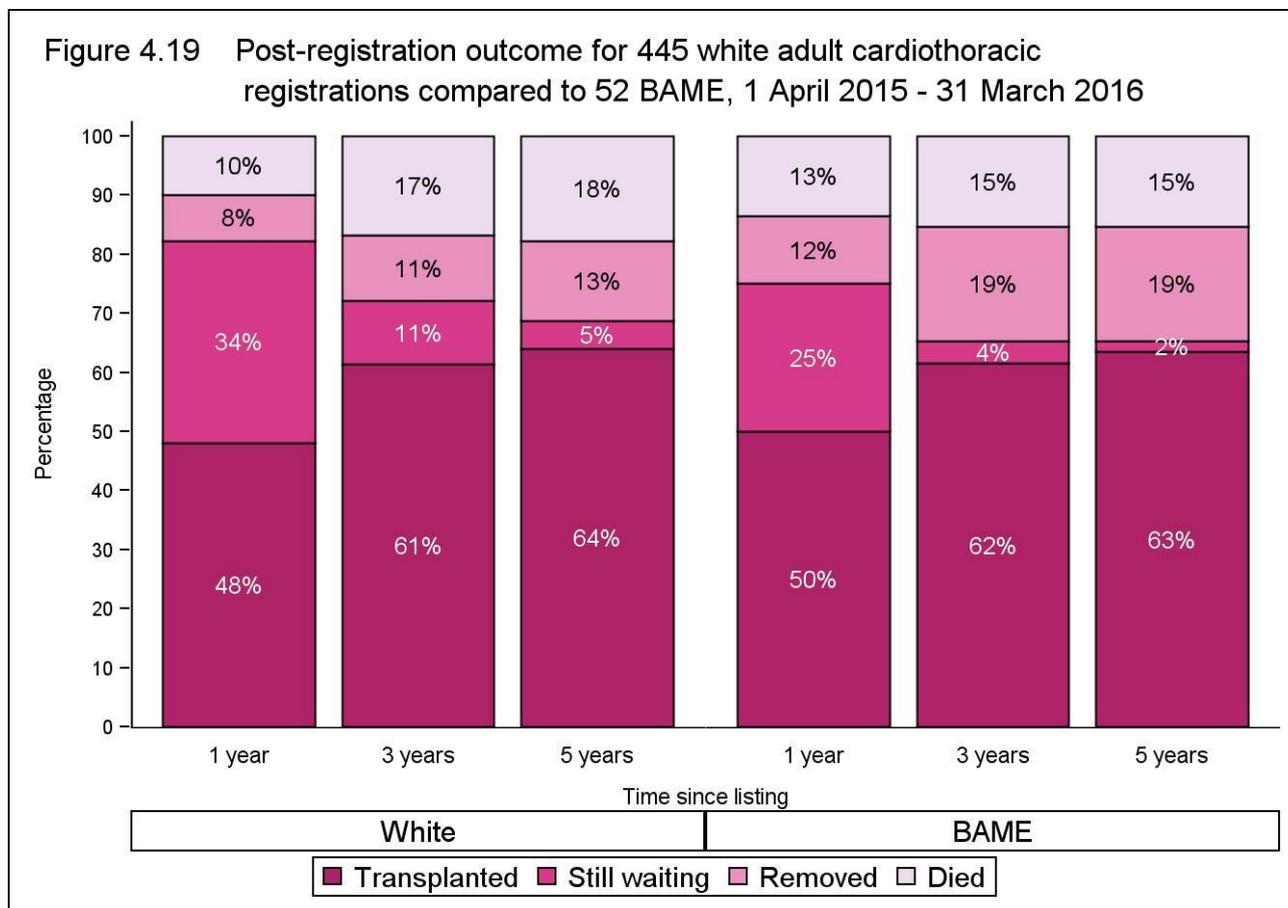


Table 4.19 Post-registration outcome for 445 white adult cardiothoracic registrations compared to 52 BAME, 1 April 2015 - 31 March 2016

Outcome	1 year		3 years		5 years	
	N	%	N	%	N	%
White						
Transplanted	214	48.1	273	61.3	285	64.0
Still waiting	152	34.2	48	10.8	21	4.7
Removed	35	7.9	49	11.0	60	13.5
Died	44	9.9	75	16.9	79	17.8
BAME						
Transplanted	26	50.0	32	61.5	33	63.5
Still waiting	13	25.0	2	3.8	1	1.9
Removed	6	11.5	10	19.2	10	19.2
Died	7	13.5	8	15.4	8	15.4

In the last financial year, **Figure 4.20** shows that 13% of deceased cardiothoracic donors are from BAME communities whilst BAME patients represent 15% of transplants and 13% of the liver transplant waiting list. **Table 4.20** shows the numbers in **Figure 4.20**.

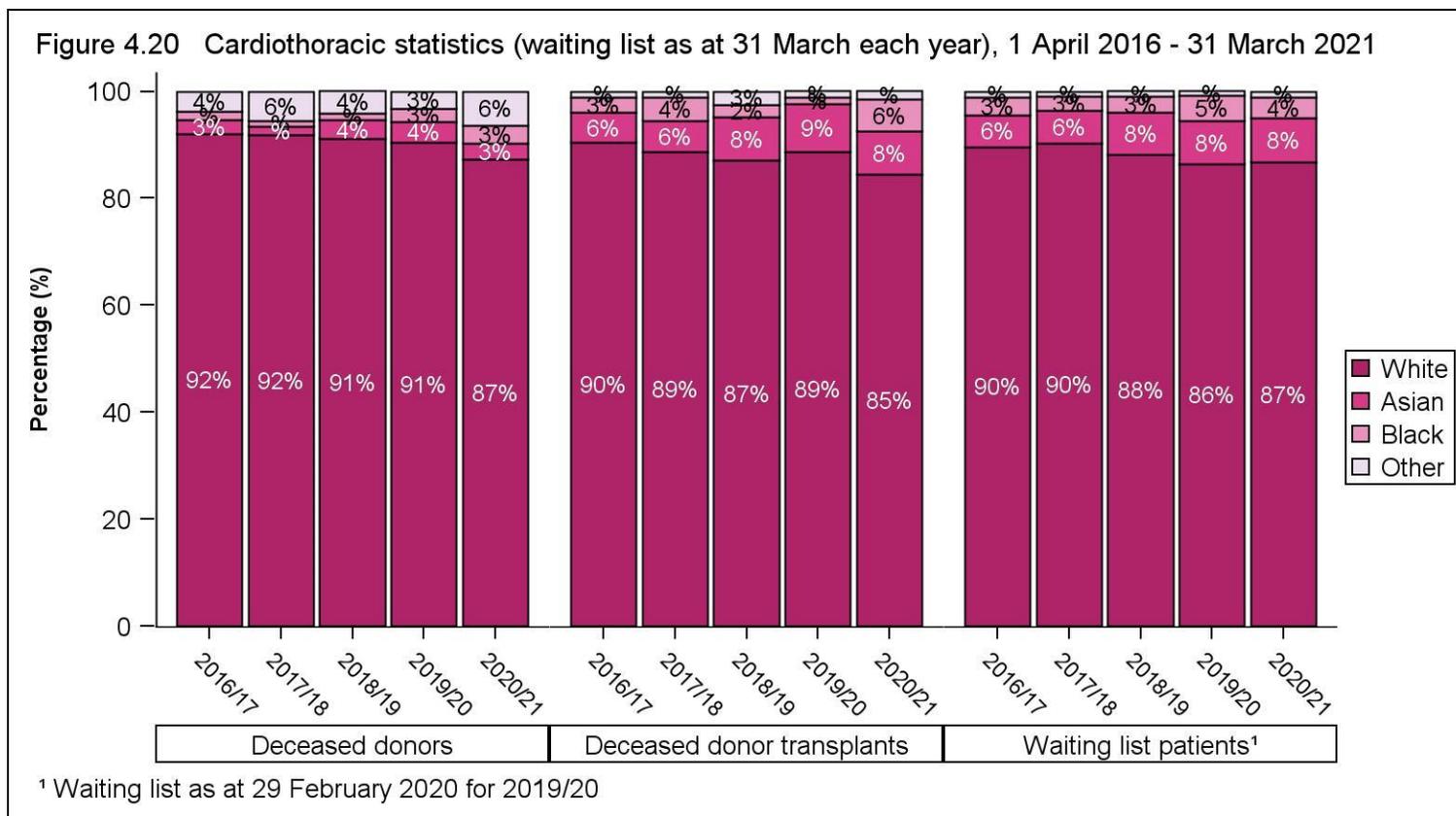


Table 4.20 Cardiothoracic statistics (waiting list as at 31 March), 1 April 2016 - 31 March 2021

Ethnicity	Deceased donors					Deceased donor transplants					Waiting list patients				
	16/17	17/18	18/19	19/20	20/21	16/17	17/18	18/19	19/20	20/21	16/17	17/18	18/19	19/20	20/21
White	280	335	285	287	205	340	364	304	297	212	559	577	566	595	504
Asian	8	6	11	12	7	21	24	28	30	20	37	39	50	55	48
Black	5	4	4	8	8	11	18	8	4	15	21	17	19	33	22
Chinese/East Asian	1	3	3	1	1	2	1	1			1	1			1
Mixed	6	9	2	4	3	1	3	1	3	1	3	2	4	3	3
Other	4	8	8	5	11	1	1	7	1	3	3	3	3	3	3
Total	304	365	313	317	235	376	411	349	335	251	624	639	642	689	581

APPENDIX



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

Ethnicity	N (thousands)	%
White British	45,135	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	100.0

Source - Office of National Statistics

Table II National data from the NHSBT Potential Donor Audit for donation after brain death, 1 April 2016 – 31 March 2021

Financial Year	Ethnic origin	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 (%)
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	White	1630	1434	88.0	1617	99.2	1238	964	77.9
	BAME	322	281	87.3	322	100.0	211	86	40.8
	Unknown	44	29	65.9	38	86.4	19	12	63.2
2020/21	White	1426	1185	83.1	1412	99.0	1004	816	81.3
	BAME	315	262	83.2	307	97.5	187	66	35.3
	Unknown	68	43	63.2	58	85.3	20	10	50.0

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

Table III National data from the NHSBT Potential Donor Audit for donation after circulatory death, 1 April 2016 – 31 March 2021

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 (%)
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	White	5322	4919	92.4	1635	1091	66.7
	BAME	482	433	89.8	129	56	43.4
	Unknown	492	371	75.4	48	23	47.9
2020/21	White	4730	3911	82.7	938	631	67.3
	BAME	641	491	76.6	89	33	37.1
	Unknown	557	372	66.8	20	4	20.0

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