

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

**Report for 2018/2019
(1 April 2014 - 31 March 2019)**



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 2018/19*. 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. 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 therefore 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 21 August 2019.**

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 would simply not be possible without organ donation. And it's thanks to the generosity of donors and their families and the careful coordination and hard work of all the medical teams involved, that this act is made possible every day.

Last year saw a UK record once again with 1,600 total deceased organ donors in the UK. 121 of them were from black, Asian and minority ethnic (BAME) communities – an increase on the 114 donors after death from these ethnic backgrounds in 2017/18.

The number of BAME deceased organ donors has increased by 51% over the last 5 years, from 80 in 2014/15 to 121 in 2018/19. Last year they represented 8% of all deceased organ donors. Significantly, there were more Asian deceased donors (56) last year than ever before. In addition to the 121 donors after death, last year saw 149 people from BAME communities becoming living donors, donating a kidney or part of their liver to someone in need. Although increases over the last few years are encouraging, BAME communities are still underrepresented among those donating.

The number of patients on the kidney transplant waiting list are falling year on year, and thousands of lives are being saved and improved through the gift of organ donation. But we need more people from our BAME communities to be prepared to donate in life or after death. 31% of people on the transplant waiting list are from BAME communities.

In the UK there is a high proportion of people from these 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. Blood and tissue types need to be a match for the transplant to be a success and people from the same ethnic group are more likely to be that match.

It is really encouraging to see that consent rates for organ donation amongst BAME families have risen over the last five years, with 42 percent now saying 'yes' to donation. However, there remains a huge 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 - as only around half as many families from these communities' support donation compared to families from a white background.

Despite the encouraging increase in families agreeing to donate after death, there is still much work to do to debunk the myths surrounding organ donation when it comes to the whole process, and whether it is supported within certain faiths and cultures. We know from ethnicity data given when people register their decision to opt out that those who make that choice are much more likely to be from a black, Asian or minority ethnic background.

While it is absolutely everybody's right to opt out if they don't want to be an organ donor, we are concerned that many people are making this decision based on misinformation, because they are worried about the donation process itself or don't think that their faith or beliefs will be respected.

We know from our surveys that black and Asian families are less likely to discuss organ donation and are much more likely to decline to donate organs for lifesaving transplants due to lack of knowledge or correct information.

Not knowing what their relative wanted is one of the biggest reasons given by BAME families for saying no to donation when approached by specialist nurses, meaning opportunities for lifesaving transplants are being missed because families are reluctant to discuss the topic of organ donation.

With the law changing in England and Scotland next year, it is really important that we work hard to ensure that people have the information they need to make the decision that's right for them and their family.

Providing community education, faith and cultural engagement, and targeted awareness raising campaigns are all part of our plans, working with partners, stakeholders and the Government, to address the stark underrepresentation of BAME people who become organ donors or have opted in via the NHS Organ Donor Register. The campaign to explain the change in law to opt out in England includes a specific focus on BAME communities and has been developed jointly by NHS Blood and Transplant and the National BAME Transplant Alliance (NBTA). We anticipate that this targeted approach will have a positive impact on these figures next year.

We hope that the ability to now state on your record when opting into the Register that you want the NHS to speak to your family and anyone else appropriate to ensure that organ donation goes ahead in line with your faith or beliefs, will reassure people that their faith or beliefs will be respected throughout the process. Specialist nurses work very hard to address any concerns and ensure that any end of life care decision is respected within the process, and donors and their families are treated with dignity and respect throughout.

We are 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 those willing to donate.



Millie Banerjee
Chairman
NHS Blood and Transplant



Kirit Modi
Hon. President
National BAME Transplant Alliance
(NBTA)

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SUMMARY

1 SUMMARY

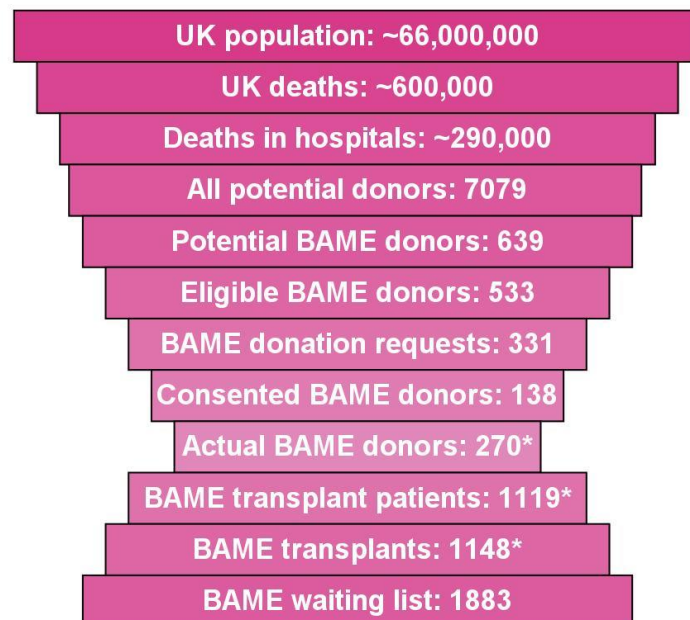
Organ Donor Register

- 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; 6.3% of opt-ins with ethnicity reported in 2014/15 and 7.1% in 2018/19.
- All minority groups were under-represented in ODR registrations, with total BAME representing 7.1% of opt-in registrations compared with 10.8% of the UK population being BAME.
- Relative to the UK population, there is over-representation in 118,000 opt-outs with ethnicity reported, for all but white and Chinese people. In particular, 56% of these opt-outs were made by Asian people.
- More ODR opt-in registrations are reporting ethnicity – up from 22% in 2014/15 to 33% last year.

Potential organ donors

- Referral rates to specialist nurses of potential white and BAME organ donors are increasing and are comparable: 99% 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 potential donors (44% DBD, 38% DCD) than for white potential donors (77% DBD, 65% DCD). Overall (DBD and DCD combined), consent rates were 42% for BAME and 71% for white potential donors last 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.

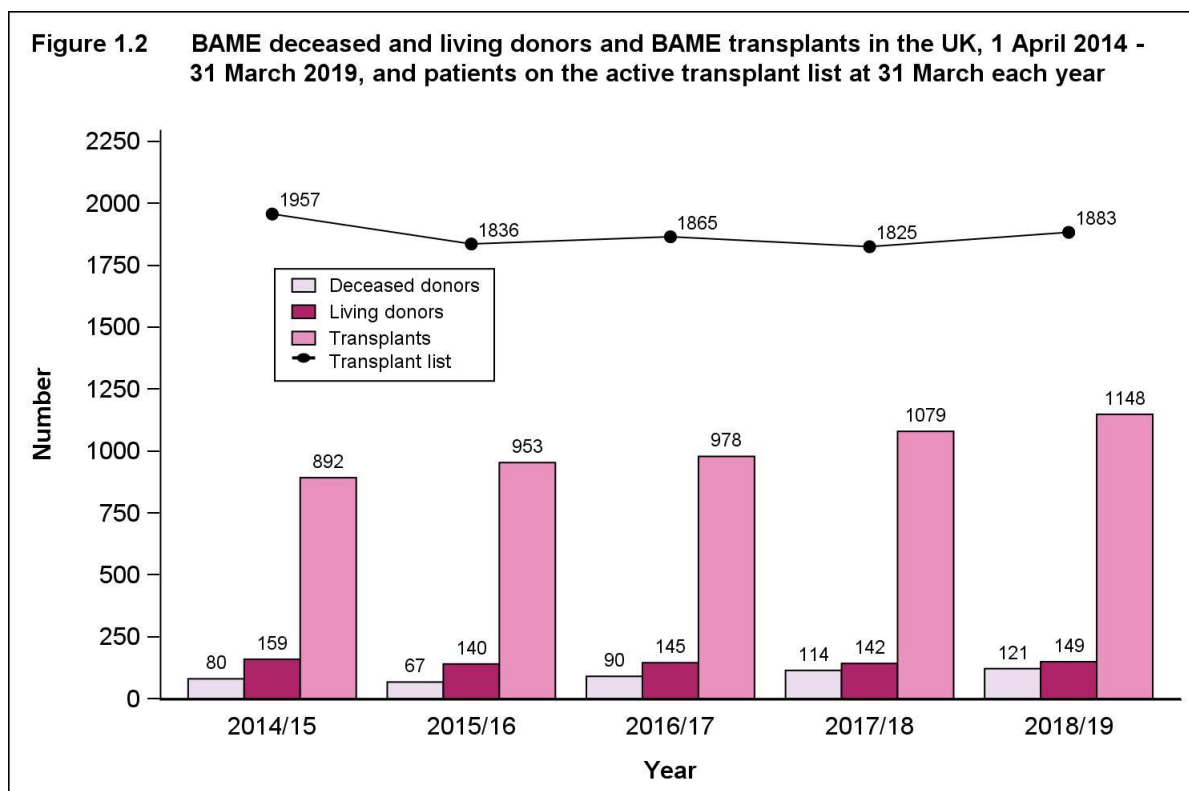
Figure 1.1 UK potential organ donor population, by BAME communities
1 April 2018 - 31 March 2019



*Please note that 149 living donors have been included in this figure

Organ donors, transplant recipients and transplant waiting list

- The number of BAME deceased organ donors has increased by 51% over the last 5 years: from 80 in 2014/15 to 121 in 2018/19, representing 8% of all deceased organ donors. In particular, there were more Asian deceased donors (56) last year, than ever before (previous maximum was 39 in 2013/14).
- The number of BAME living donors has remained at approx. 140-160 per year, and represented 14% of all living organ donors last year. There have been fewer white living donors this year than last, but more black and Asian living donors. There were 83 Asian living donors, the highest number in the last 5 years.
- The number of transplants in BAME people has increased by 29% over the last 5 years, with 1148 transplants in BAME people last year, representing 23% of all transplants.
- There were 1883 BAME people on the active organ transplant list at 31 March 2019, down 4% from 2014/2015 and representing 31% of the list.
- In 2018/19, Asian people represented 4% of deceased donors (DD), 13% of DD transplants and 17% of the transplant waiting list; black people represented 1% of DD, 13% of DD transplants and 11% of the list.
- In 2018/19, Asian people represented 8% of living donors (LD) and 9% of LD transplants; black people represented 2% of LD and 3% of LD transplants.
- Five years after being listed for a transplant (all organs), 73% of white and 70% of BAME people have been transplanted, while 9% of white and 7% of BAME people have died on the list without transplant.
- Median waiting times to transplant show that, generally, white patients wait less time than BAME patients, with the exception of pancreas and non-urgent adult hearts. Black patients or those of 'Other' ethnic minority groups tend to wait the longest.
- The majority of transplant donors 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 19% of BAME people have received a transplant. Five years after listing, 75% of white and 69% 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 965 days for black, 830 days for Asian, 810 days for other BAME and 640 days for white people). Over time, it is predicted that waiting times across ethnic groups will be more comparable with the introduction of the new kidney offering scheme in 2019.
- In 2018/19, Asian people represented 3% of deceased kidney donors (DD), 17% of DD kidney transplants and 19% of the transplant waiting list; black people represented 1% of kidney DD, 11% of DD transplants and 12% of the list.
- Proportionally and numerically more deceased donor kidney transplants were in Asian (433 transplants, 17% of all transplants) and black patients (270 transplants, 10% of all) last year than ever before.
- 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.
- The majority of kidney transplants from living donors (LD) are from donors of the same ethnicity as the recipient for Asian patients (65% of donors were Asian) and black patients (51% of donors were black).

Other organs

- One year after listing for transplant:
 - **Pancreas and pancreas/kidney:** 31% of white and 38% of BAME patients have received a transplant, while 5% of both have died on the list.
 - **Liver:** 65% of white and 70% of BAME patients have received a transplant, while 7% and 6% have died on the list, respectively.
 - **Cardiothoracic:** 48% of white and 36% of BAME patients have received a transplant, while 16% and 22% have died on the list, respectively.
- In 2019, Asian people represented:
 - **Pancreas and pancreas/kidney:** 4% of donors, 4% of transplants and 6% of the transplant list.
 - **Liver:** 4% of donors, 5% of transplants and 8% of the transplant list
 - **Cardiothoracic:** 4% of donors, 8% of transplants and 8% of the transplant list
- In 2019, black people represented:
 - **Pancreas and pancreas/kidney:** <1% of donors, 9% of transplants and 7% of the transplant list.
 - **Liver:** <1% of donors, 3% of transplants and 3% of the transplant list
 - **Cardiothoracic:**<1% of donors, 2% of transplants and 3% of the transplant list

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 ODR figures have been adjusted to reflect the removal of duplicate records in recent months and thus numbers of registrations and people on the ODR will not match those in previous reports.

It should also be noted that considerable work has been undertaken in early 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 2018/19 were the Driver and Vehicle Licensing (51%), online registrations (26%), GP registrations (19%), Boots Advantage card (2%) and NHSBT leaflets (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, 33% of registrations to the ODR in 2018/19 have their ethnicity recorded compared to 22% in 2014/15. This increase in reporting is largely due to increased online registrations where ethnicity can be recorded.

Table 2.1 shows the number of opt-in registrations per year by ethnicity from 1 April 2014 to 31 March 2019. In 2018/19, 92.9% of registrations with ethnicity recorded were by white people, 3.3% from Asian, 1% from black, 0.3% from Chinese, 1.9% from mixed race and 0.6% from other ethnic groups.

Table 2.2 shows the number of opt-out registrations per year by ethnicity from 1 April 2016 to 31 March 2019. Opt-out registrations were first recorded on the ODR in June 2015. In order to have complete data across each financial year, data reported from 1 April 2016 are shown in **Table 2.2**. Initially, 80% of opt-outs were registered by white people however the proportion dropped to 8% in 2017/18. Even though, the number of opt-out registrations by white people has been fairly constant over this time period. In the last year, the majority of opt-out registrations were from Asian (54%) and black people (20%).

Table 2.1 Ethnicity of all ODR opt-in registrations by year of registration¹, 1 April 2014 - 31 March 2019

		2014/15		2015/16		2016/17		2017/18		2018/19	
		N	%	N	%	N	%	N	%	N	%
White	British	186,072	85.3	395,204	86.9	301,917	84.9	381,028	85.1	400,442	85.5
	Irish	8,235	3.8	12,209	2.7	9,502	2.7	9,929	2.2	11,645	2.5
	Other	10,241	4.7	20,923	4.6	20,140	5.7	23,681	5.3	23,123	4.9
	Total	204,548	93.7	428,336	94.2	331,559	93.2	414,638	92.6	435,210	92.9
Asian	Indian	4,775	2.2	7,150	1.6	6,443	1.8	8,726	1.9	9,495	2.0
	Pakistani	638	0.3	1,242	0.3	1,362	0.4	1,635	0.4	1,546	0.3
	Bangladeshi	156	<0.1	339	<0.1	328	0.1	464	0.1	430	0.1
	Other	1,195	0.5	2,898	0.6	2,992	0.8	4,096	0.9	3,965	0.8
	Total	6,764	3.1	11,629	2.6	11,125	3.1	14,921	3.3	15,436	3.3
Black	Caribbean	885	0.4	1,655	0.4	1,458	0.4	1,890	0.4	1,888	0.4
	African	884	0.4	1,725	0.4	1,617	0.5	2,387	0.5	2,325	0.5
	Other	122	<0.1	246	<0.1	248	0.1	307	0.1	331	0.1
	Total	1,891	0.9	3,626	0.8	3,323	0.9	4,584	1.0	4,544	1.0
Mixed	White/Black African	1,128	0.5	2,339	0.5	707	0.2	964	0.2	967	0.2
	White/Black Caribbean	403	0.2	853	0.2	2,041	0.6	2,635	0.6	2,803	0.6
	White/Asian	1,157	0.5	2,429	0.5	2,086	0.6	2,771	0.6	2,768	0.6
	Other	905	0.4	2,010	0.4	1,812	0.5	2,501	0.6	2,590	0.6
	Total	3,593	1.6	7,631	1.7	6,646	1.9	8,871	2.0	9,128	1.9
Chinese	598	0.3	1,207	0.3	1,114	0.3	1,513	0.3	1,391	0.3	
Other	860	0.4	2,142	0.5	1,985	0.6	3,134	0.7	2,721	0.6	
Total reported		218,254	100.0	454,571	100.0	355,752	100.0	447,661	100.0	468,430	100.0
Not reported		763,476	77.8	921,336	67.0	1,004,320	73.8	872,308	66.1	941,691	66.8
TOTAL OPT-IN REGISTRATIONS (incl. known duplicates/deaths)		981,730		1,375,907		1,360,072		1,319,969		1,410,121	
TOTAL OPT-IN REGISTRATIONS (excl. known duplicates/deaths)		857,638		1,014,142		925,794		1,024,664		1,230,560	

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 2019							
		2016/17		2017/18		2018/19	
		N	%	N	%	N	%
White	British	17,004	74.2	19,704	6.9	20,736	18.6
	Irish	199	0.9	322	0.1	315	0.3
	Other	1,161	5.1	2,916	1.0	2,422	2.2
	Total	18,364	80.2	22,942	8.0	23,473	21.0
Asian	Indian	585	2.6	39,327	13.7	7,720	6.9
	Pakistani	1,018	4.4	105,791	36.8	31,968	28.6
	Bangladeshi	371	1.6	50,782	17.7	17,221	15.4
	Other	519	2.3	10,554	3.7	3,471	3.1
Total	2,493	10.9	206,454	71.8	60,380	54.1	
Black	Caribbean	357	1.6	21,269	7.4	9,333	8.4
	African	739	3.2	19,903	6.9	10,888	9.7
	Other	82	0.4	3,459	1.2	1,591	1.4
	Total	1,178	5.1	44,631	15.5	21,812	19.5
Mixed	White/Black Caribbean	84	0.4	1,954	0.7	928	0.8
	White/Black African	65	0.3	788	0.3	437	0.4
	White/Asian	74	0.3	1,819	0.6	634	0.6
	Other	110	0.5	3,160	1.1	1,264	1.1
Total	333	1.5	7,721	2.7	3,263	2.9	
Chinese		162	0.7	304	0.1	295	0.3
Other		375	1.6	5,510	1.9	2,476	2.2
Total reported		22,905	100.0	287,562	100.0	111,699	100.0
Not reported		2,407	9.5	22,659	7.3	12,626	10.2
TOTAL OPT-OUT REGISTRATIONS (incl. known duplicates/deaths)		25,312		310,221		124,325	
TOTAL OPT-OUT REGISTRATIONS (excl. known duplicates/deaths)		25,201		303,362		122,019	

Given the increase in proportion 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 registrations, it is possible to see differences relative to the current population of the UK (Appendix, **Table I**).

The current UK population 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 registrations in 2014/15 and 2018/19 against the percentage of the general population. In 2014/15, 6.3% of ODR registrations of known ethnicity were BAME which has increased to 7.1% in 2018/19. It is estimated that 10.8% of the current UK population is BAME, reflecting an under-representation of BAME communities on the ODR.

Table 2.3 BAME opt-in registrations on the ODR vs the UK population			
Ethnicity	2014/15 % of the ODR registrations¹	2018/19 % of the ODR registrations¹	2011 % of the population²
Asian-Indian	2.2	2.0	2.3
Asian-Pakistani	0.3	0.3	1.6
Asian-Bangladeshi	0.0	0.1	0.6
Asian-Other	0.5	0.8	0.6
<i>Asian-Total</i>	<i>3.1</i>	<i>3.3</i>	<i>5.1</i>
Black-African	0.4	0.5	1.2
Black-Caribbean	0.4	0.4	1.0
Black-Other	0.0	0.1	0.2
<i>Black-Total</i>	<i>0.9</i>	<i>1.0</i>	<i>2.5</i>
Chinese	0.3	0.3	0.7
Mixed race	1.6	1.9	1.7
Other ethnicity	0.4	0.6	0.8
Total BAME	6.3	7.1	10.8

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:

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 comparable in 2018/19 (86.3% and 84.3%, respectively).

Figure 3.1 presents the DBD and DCD referral rates for white and BAME communities. There has been an increase in the referral of BAME potential DCD donors to a SN-OD from around 77% to 92%, a similar rise has occurred for potential white DCD donors. The referral rates for both BAME and white potential DBD donors are now 99%.

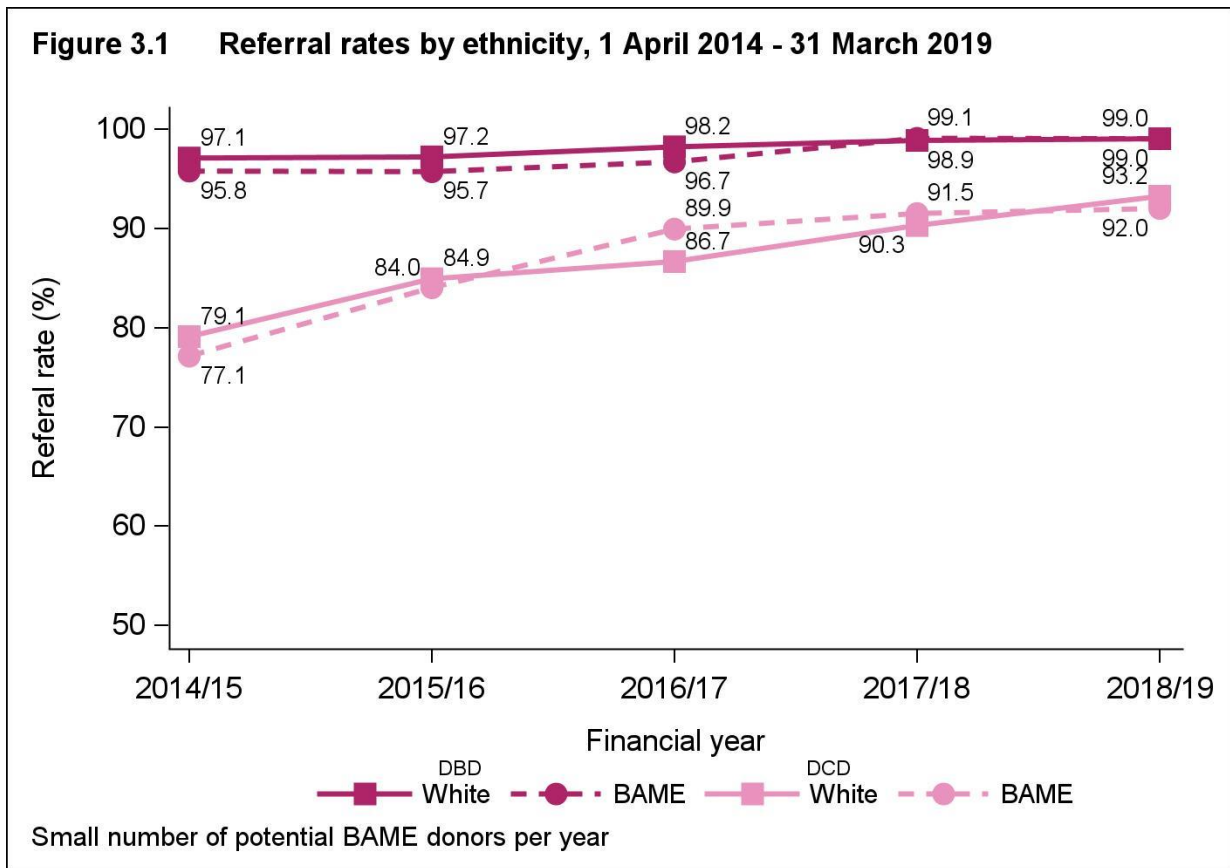


Figure 3.2 shows the number of eligible DBD donors and eligible DBD donors with consent ascertained over time for white and BAME communities, **Figure 3.3** shows the overall DBD consent/authorisation rates. Similarly, **Figure 3.4** and **Figure 3.5** illustrate the same information for DCD donation,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

Figure 3.2 demonstrates that there has been an increase in white eligible and eligible consented/authorised DBD donors in 2018/19 whereas for BAME communities there has been a slight decrease in comparison to 2017/18. There has been no impact on the overall DBD consent/authorisation rates for white and BAME communities as shown in **Figure 3.3**.

Figure 3.4 shows that there has been a fall in white eligible DCD donors although the number of eligible consented/authorised DCD donors has remained constant in 2018/19. This has not affected the white DCD consent/authorisation rate as it has gradually increased over the past 5 years. Similarly, for BAME communities, DCD consent/authorisation rates have also improved over time despite a small number of eligible and eligible consented/authorised DCD donors. There is a large drop from eligible DCD donors to consented/authorised DCD donors as a result of many families not being approached for organ donation consent/authorisation due to the DCD screening process which precludes unsuitable donors from solid organ donation.

Figure 3.2 Eligible DBD donors and eligible consented/authorised DBD donors by ethnicity, 1 April 2014 - 31 March 2019

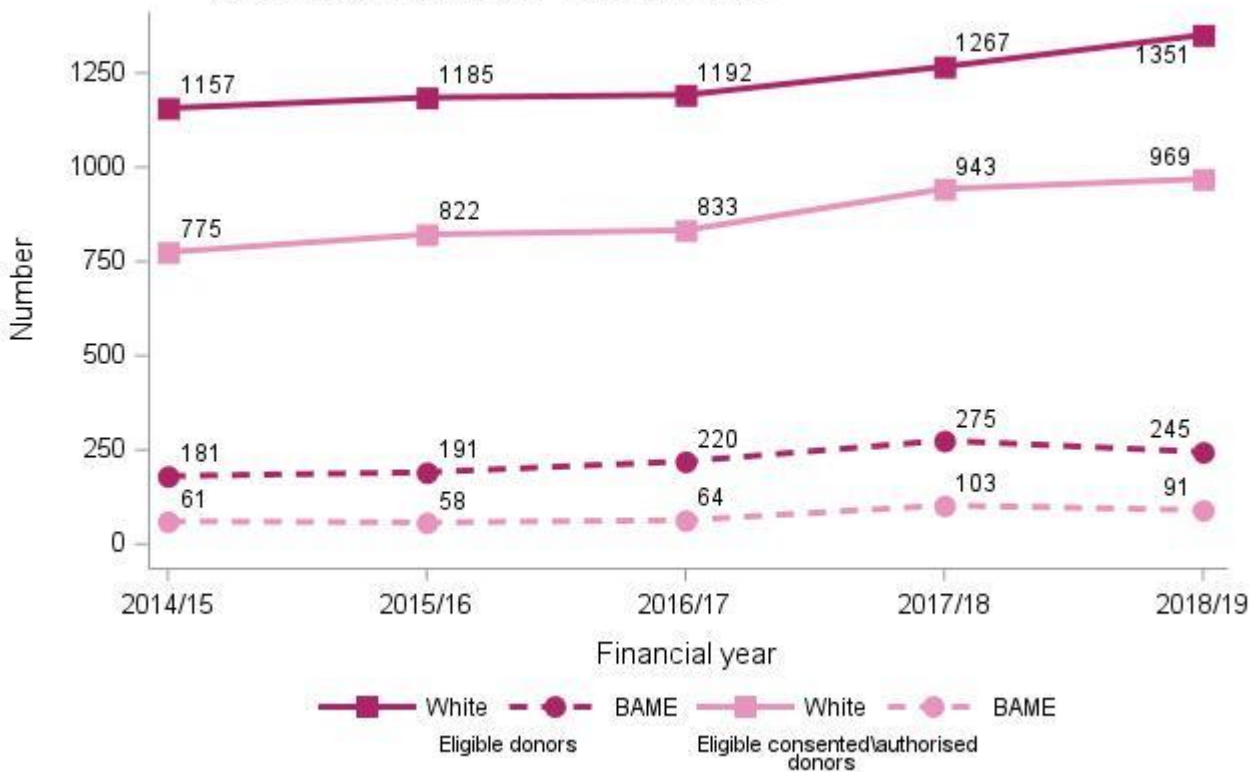
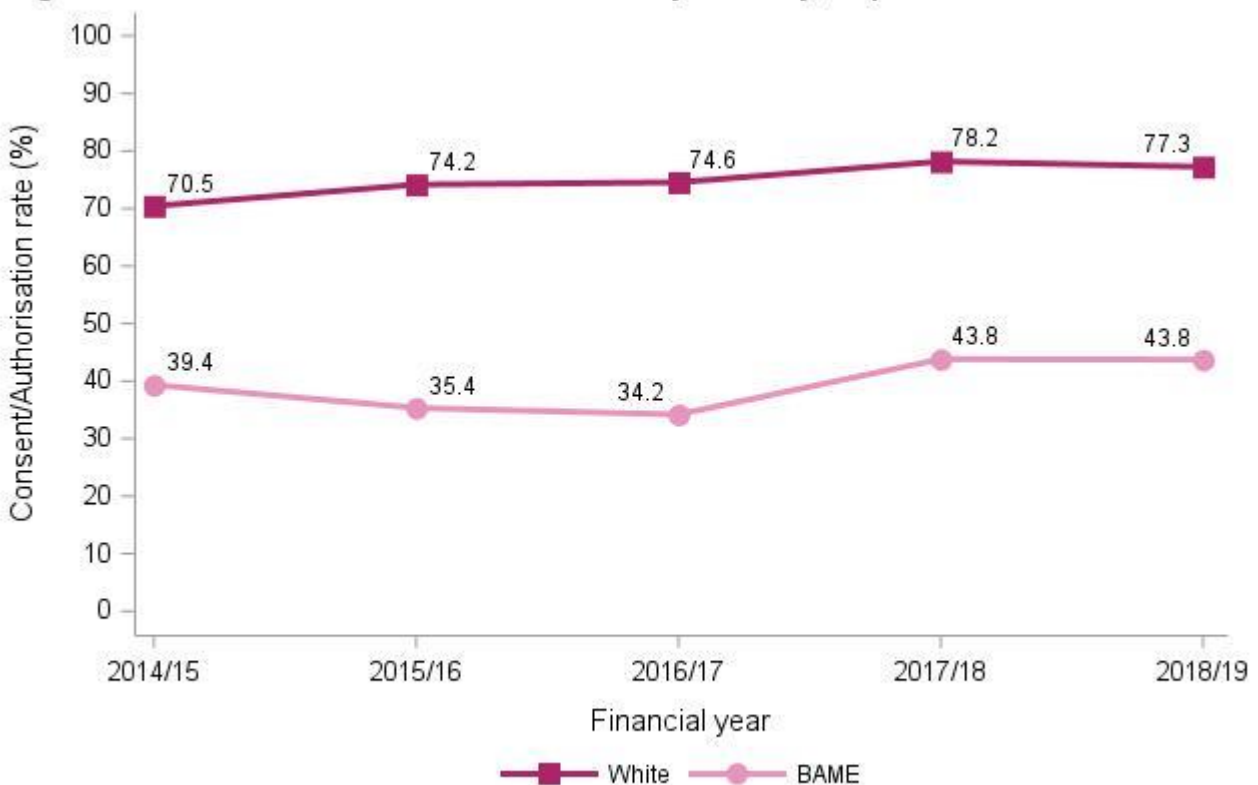


Figure 3.3 DBD consent/authorisation rates by ethnicity, 1 April 2014 - 31 March 2019



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 2014 - 31 March 2019

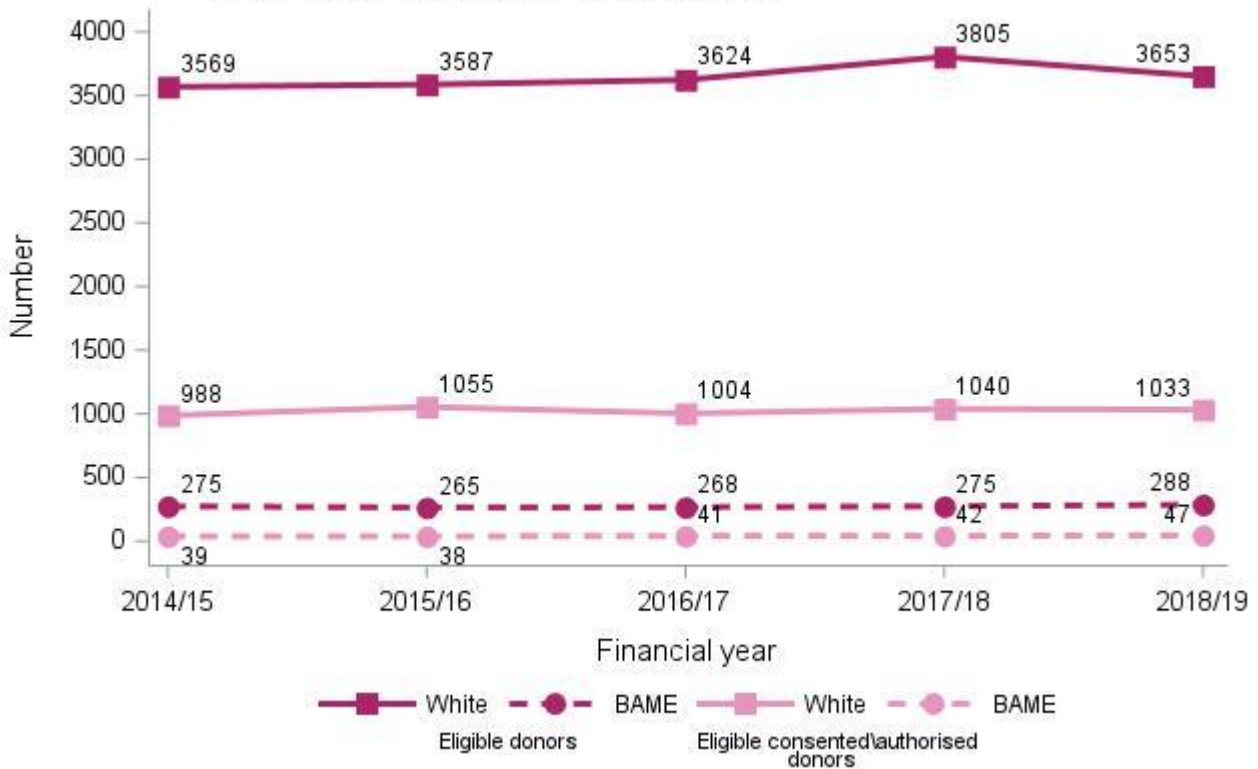
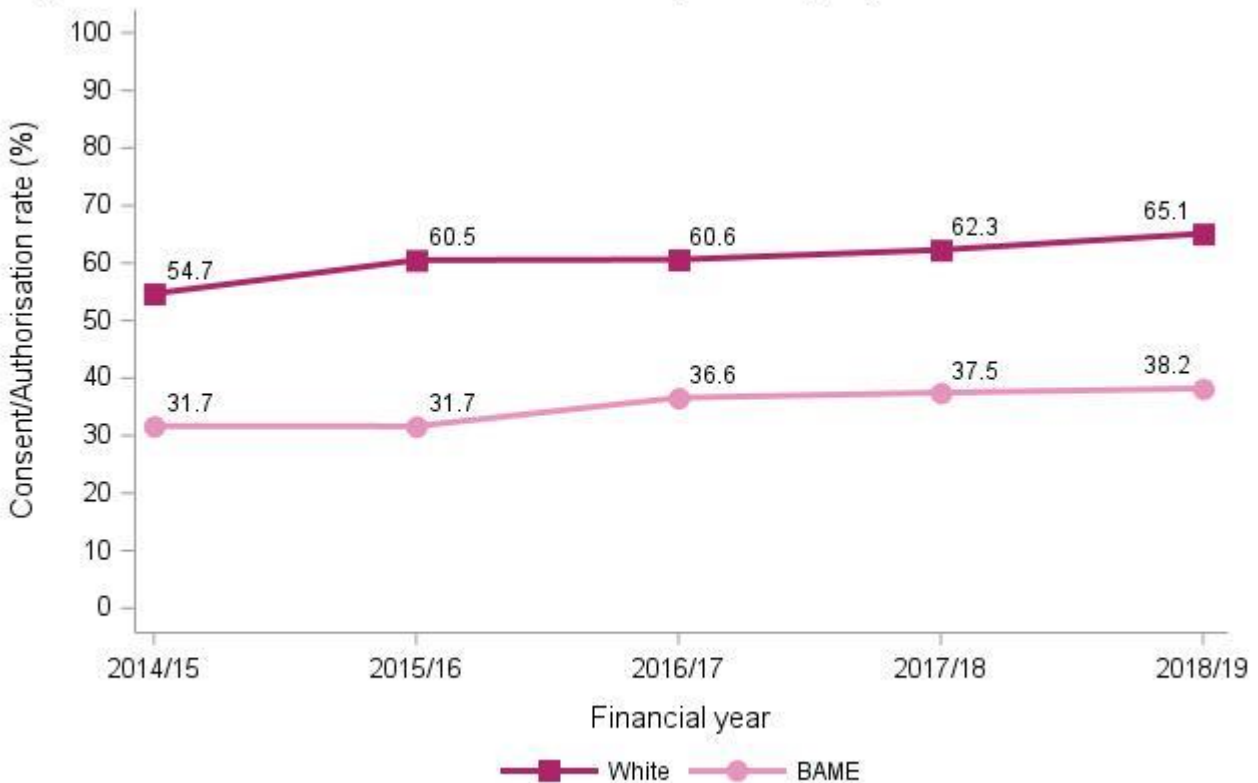


Figure 3.5 DCD consent/authorisation rates by ethnicity, 1 April 2014 - 31 March 2019



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.

Table 3.1 DBD and DCD consent/authorisation rates from the Potential Donor Audit by Organ Donation Services Team (ODST) and ethnicity, 1 April 2014 - 31 March 2019

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	590	565	76.3	2330	1041	64.0	68.3
London	678	645	70.4	1278	626	60.5	65.5
Midlands	668	619	74.6	2485	1208	57.6	63.4
North West	798	752	75.1	2573	1003	61.6	67.4
Northern	423	403	72.2	1377	553	61.5	66.0
Northern Ireland	262	244	66.8	557	237	56.1	61.5
Scotland	493	463	74.1	1274	708	50.7	59.9
South Central	428	409	79.5	1411	635	61.1	68.3
South East	637	591	74.8	1528	751	66.2	70.0
South Wales	227	219	79.5	814	395	60.0	66.9
South West	433	394	82.2	1042	573	62.3	70.4
Yorkshire	515	481	76.5	1569	730	61.6	67.5
Total	6152	5785	75.1	18238	8460	60.5	66.4
BAME							
Eastern	88	74	39.2	135	73	42.5	40.8
London	476	422	40.3	457	194	40.7	40.4
Midlands	151	118	33.1	278	97	22.7	28.4
North West	95	82	35.4	105	42	19.0	29.8
Northern	11	11	63.6	28	12	41.7	52.2
Northern Ireland	4	3	33.3	7	5	60.0	50.0
Scotland	19	14	35.7	25	14	28.6	32.1
South Central	47	41	53.7	81	46	32.6	42.5
South East	138	120	45.8	126	54	37.0	43.1
South Wales	5	4	75.0	19	8	37.5	50.0
South West	15	12	50.0	27	14	42.9	46.2
Yorkshire	63	48	22.9	83	31	35.5	27.8
Total	1112	949	39.7	1371	590	35.1	37.9

In general, the data show that families of BAME eligible donors are much less likely to consent to organ donation. Around half as many families of BAME eligible donors support organ donation compared with families of white eligible donors: DBD consent - 75% white vs 40% BAME and DCD consent - 61% white vs 35% BAME for 1 April 2014 to 31 March 2019.

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 some increase in consent/authorisation rates for white and BAME communities. Families of Asian and black ethnic minority potential donors tended to consent/authorise organ donation less than families of other ethnic groups.

Table 3.2 Consent/authorisation (Con/auth) rates for families approached (app) for organ donation by ethnicity and financial year, 1 April 2014 - 31 March 2019										
Ethnicity	2014/15		2015/16		Financial year 2016/17		2017/18		2018/19	
	App	Con/auth rate %	App	Con/auth rate %	App	Con/auth rate %	App	Con/auth rate %	App	Con/auth rate %
White	2906	60.7	2851	65.8	2773	66.2	2875	69.0	2840	70.5
Asian	144	34.0	148	29.7	145	26.9	155	38.1	167	39.5
Black	76	32.9	81	29.6	93	36.6	97	34.0	90	32.2
Chinese/East Asian	19	26.3	10	30.0	18	22.2	24	29.2	18	50.0
Mixed	15	53.3	16	43.8	21	81.0	29	79.3	17	64.7
Other	24	54.2	29	62.1	22	50.0	42	54.8	39	59.0
BAME	278	36.0	284	33.8	299	35.1	347	41.8	331	41.7

Table 3.3 shows the reasons given by a family when declining consent/authorisation for organ donation, by ethnicity from 1 April 2014 to 31 March 2019. 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.

Table 3.3 Reasons for family's refusal to give consent/authorise to organ donation by ethnicity, 1 April 2014 - 31 March 2019												
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	1061	22.2	57	11.4	46	15.8	6	9.8	9	28.1	8	11.8
Family were not sure whether the patient would have agreed to donation	783	16.4	62	12.4	39	13.4	11	18.0	8	25.0	10	14.7
Family felt the length of time for donation process was too long	636	13.3	15	3.0	5	1.7	2	3.3	3	9.4	2	2.9
Family did not want surgery to the body	466	9.7	41	8.2	18	6.2	7	11.5	2	6.3	6	8.8
Other	381	8.0	32	6.4	19	6.5	2	3.3	2	6.3	9	13.2
Family felt the patient had suffered enough	374	7.8	14	2.8	11	3.8			1	3.1		
Family were divided over the decision	230	4.8	28	5.6	15	5.1	3	4.9	1	3.1	1	1.5
Strong refusal - probing not appropriate	224	4.7	27	5.4	16	5.5	2	3.3	1	3.1	2	2.9
Family felt the body needs to be buried whole (unrelated to religious or cultural reasons)	217	4.5	27	5.4	29	9.9	6	9.8	2	6.3	6	8.8
Family did not believe in donation	164	3.4	30	6.0	21	7.2	3	4.9	2	6.3	3	4.4
Family concerned that organs may not be transplanted	79	1.7	4	0.8	2	0.7						
Family wanted to stay with the patient after death	76	1.6	4	0.8			2	3.3				
Family felt it was against their religious/cultural beliefs	50	1.0	151	30.1	59	20.2	17	27.9	1	3.1	19	27.9
Family had difficulty understanding/accepting neurological testing	18	0.4	3	0.6	4	1.4						
Family concerned that other people may disapprove/be offended	10	0.2	4	0.8	4	1.4					1	1.5
Families concerned about organ allocation	7	0.1			3	1.0						
Family concerned donation may delay the funeral	6	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	4783	100.0	502	100.0	292	100.0	61	100.0	32	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 from 1 April 2014 to 31 March 2019. The number of BAME transplant recipients has increased year on year and the number of BAME patients on the transplant list has been fairly constant throughout this time. Each year there are consistently more BAME living donors than BAME deceased donors.

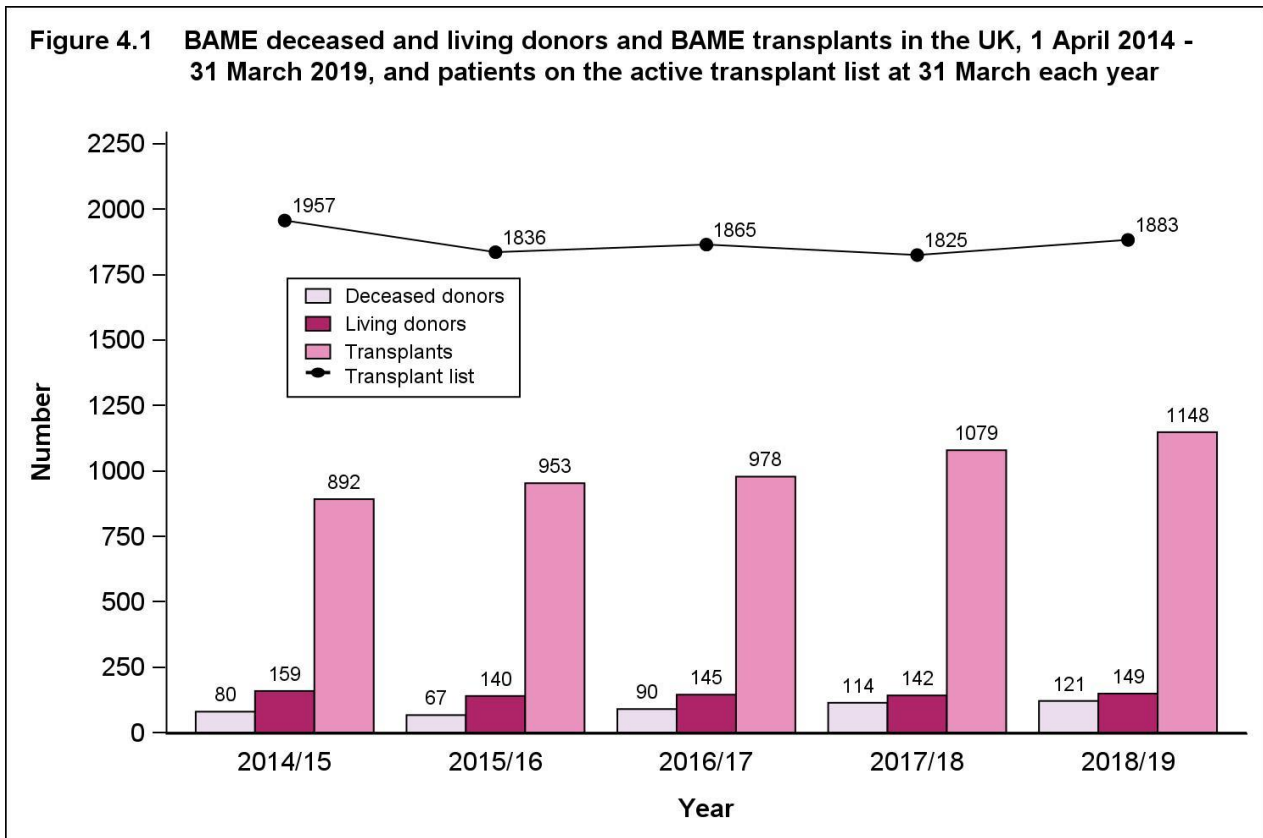


Table 4.1 shows a further breakdown of the number of living and deceased BAME donors, transplants and those on the transplant waiting list from 1 April 2014 to 31 March 2019. Rates per million population (pmp) of the total population are also shown. Last year, BAME patients accounted for a third of patients on the transplant waiting list, approximately a quarter of all transplants and 10% of donors were from BAME communities.

	Financial year				
	2014/15	2015/16	2016/17	2017/18	2018/19
Waiting list	6835	6389	6296	5954	5988
BAME waiting list	1957	1836	1865	1825	1883
BAME % of waiting list	28.6	28.7	29.6	30.7	31.4
BAME on waiting list per million population of total UK population (pmp)	29.6	27.8	28.2	27.6	28.5
Total donors	2370	2442	2443	2620	2628
Total BAME donors	239	207	235	256	270
BAME % of donors	10.1	8.5	9.6	9.8	10.3
BAME donors pmp	3.6	3.1	3.6	3.9	4.1
Deceased donors	1282	1363	1398	1555	1589
Deceased BAME donors	80	67	90	114	121
<i>DBD BAME donors</i>	<i>54</i>	<i>49</i>	<i>62</i>	<i>83</i>	<i>91</i>
<i>DCD BAME donors</i>	<i>26</i>	<i>18</i>	<i>28</i>	<i>31</i>	<i>30</i>
BAME % of deceased donors	6.2	4.9	6.4	7.3	7.6
Deceased BAME donors pmp	1.2	1	1.4	1.7	1.8
Living donors	1088	1079	1045	1065	1039
Living BAME donors	159	140	145	142	149
BAME % of living donors	14.6	13	13.9	13.3	14.3
Living BAME donors pmp	2.4	2.1	2.2	2.2	2.3
Total transplants	4385	4555	4709	5044	4939
Total BAME transplants	892	953	978	1079	1148
BAME % of transplants	20.3	20.9	20.8	21.4	23.2
BAME transplants pmp	13.5	14.4	14.8	16.3	17.4
Deceased donor (DD) transplants	3316	3494	3673	3996	3910
BAME DD transplants	702	784	809	902	969
BAME % of deceased donor transplants	21.2	22.4	22	22.6	24.8
BAME DD transplants pmp	10.6	11.9	12.3	13.7	14.7
Living donor (LD) transplants	1069	1061	1036	1048	1029
BAME LD transplants	190	169	169	177	179
BAME % of LD transplants	17.8	15.9	16.3	16.9	17.4
BAME LD transplants pmp	2.9	2.6	2.6	2.7	2.7
Unknown ethnicity was excluded					

Figure 4.2 and **Table 4.2** shows 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 defined as died. It 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.

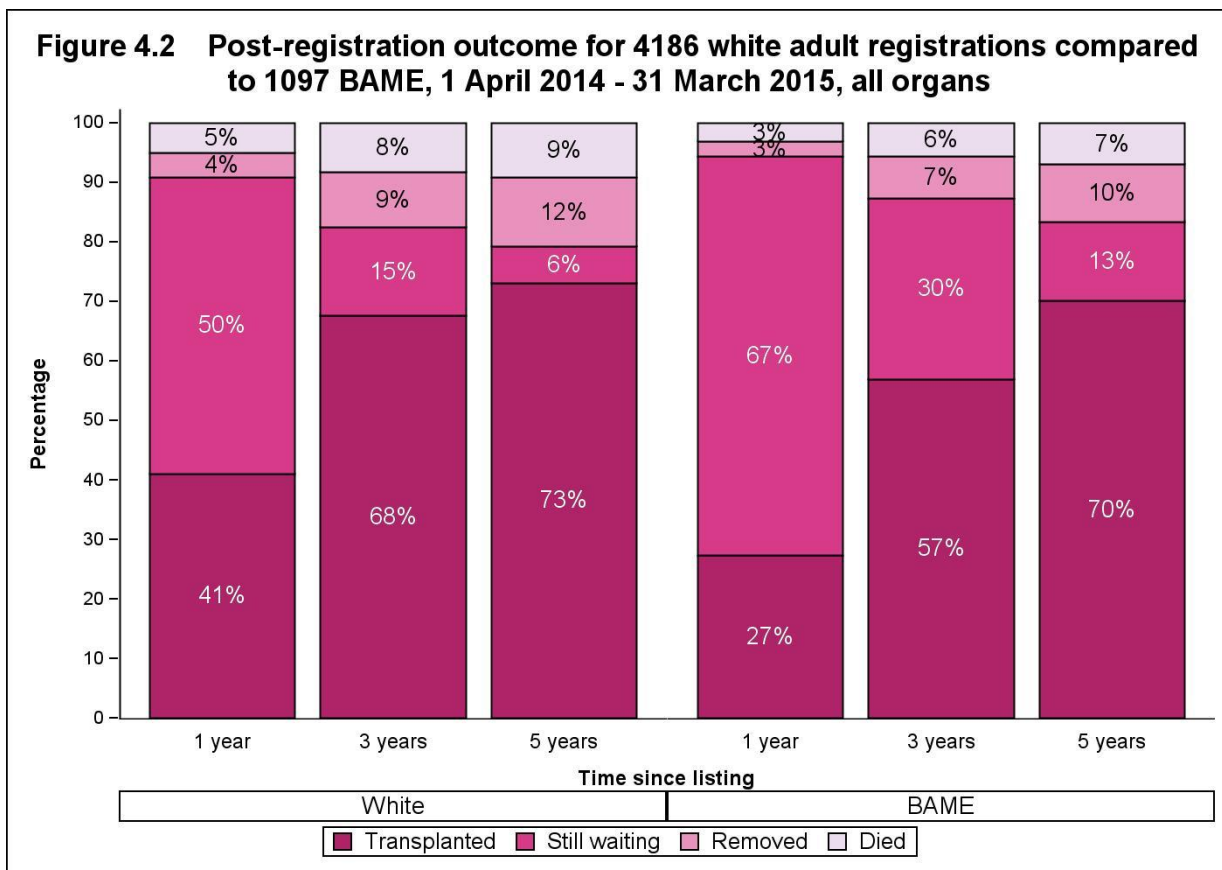


Table 4.2 Post-registration outcome for 4186 white adult registrations compared to 1097 BAME, 1 April 2014 - 31 March 2015, all organs

Outcome	1 year		3 years		5 years	
	N	%	N	%	N	%
White						
Transplanted	1718	41.0	2830	67.6	3061	73.1
Still waiting	2088	49.9	621	14.8	254	6.1
Removed	169	4.0	391	9.3	492	11.8
Died	211	5.0	344	8.2	379	9.1
BAME						
Transplanted	300	27.3	625	57.0	769	70.1
Still waiting	735	67.0	333	30.4	146	13.3
Removed	28	2.6	77	7.0	106	9.7
Died	34	3.1	62	5.7	76	6.9

Table 4.3 Median waiting time to transplant in the UK

Ethnicity	Number of patients registered	Waiting time (days)	
		Median	95% Confidence interval
Adult kidney			
White	6648	640	622 - 658
Asian	1591	830	782 - 878
Black	923	965	914 - 1016
Other	288	810	735 - 885
TOTAL	9584	706	689 - 723
Paediatric kidney			
White	136	222	182 - 262
Asian	68	397	271 - 523
Black	13	517	138 - 896
Other	14	738	447 - 1029
TOTAL	235	287	200 - 374
Adult pancreas			
White	848	348	330 - 366
Asian	59	279	185 - 373
Black	44	370	272 - 468
TOTAL	972	346	330 - 362
Adult liver			
White	2385	97	89 - 105
Asian	178	116	90 - 142
Black	72	129	74 - 184
Other	56	97	63 - 131
TOTAL	2698	99	91 - 107
Paediatric liver	220	107	84 - 130
Adult never urgent heart			
White	382	1298	702 - 1894
Asian	22	403	190 - 616
Black	19	742	85 - 1399
Other	7		
TOTAL	431	1085	611 - 1559
Adult ever urgent heart			
White	612	29	25 - 33
Asian	59	36	18 - 54
Black	22	71	28 - 114
Other	17	34	24 - 44
TOTAL	716	30	26 - 34
Paediatric never urgent heart	37	463	0 - 1044
Paediatric ever urgent heart	207	79	55 - 103
Adult lung			
White	1271	283	249 - 317
Asian	46	1191	279 - 2103
Black	15	731	369 - 1093
Other	6		
TOTAL	1344	289	252 - 326

Median waiting time not reported for fewer than 10 patients

¹ Patients registered 1 April 2012 - 31 March 2016

² Patients registered 1 April 2013 - 31 March 2017

³ Patients registered 1 April 2014 - 31 March 2017

⁴ Urgent waiting time only

⁵ 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 2014/15, there has been a gradual decrease in the number of deaths on the waiting list across all organs, from 565 to 431 in the last financial year. BAME patients accounted for 20% of those who died waiting for a transplant in 2018/19.

Table 4.4 Number of deaths on the transplant waiting list, by financial year, organ and ethnicity, 1 April 2014 - 31 March 2019											
Ethnicity	2014/15		2015/16		2016/17		2017/18		2018/19		
	N	%	N	%	N	%	N	%	N	%	
Kidney											
White	234	79.6	246	75.9	249	78.1	224	73.7	208	75.6	
Asian	41	13.9	36	11.1	39	12.2	40	13.2	37	13.5	
Black	13	4.4	32	9.9	26	8.2	30	9.9	16	5.8	
Other	6	2.0	10	3.1	5	1.6	10	3.3	14	5.1	
Unknown	3	.	5	.	1	.	5	.	5	.	
Total	297	100.0	329	100.0	320	100.0	309	100.0	280	100.0	
Pancreas											
White	27	93.1	27	96.4	22	88.0	24	85.7	17	94.4	
Asian	2	6.9	1	3.6	.	.	
Black	.	.	1	3.6	2	8.0	2	7.1	.	.	
Other	1	4.0	1	3.6	1	5.6	
Unknown	1	.	
Total	29	100.0	28	100.0	25	100.0	28	100.0	19	100.0	
Liver											
White	88	84.6	90	86.5	88	92.6	60	82.2	40	85.1	
Asian	10	9.6	8	7.7	5	5.3	6	8.2	6	12.8	
Black	5	4.8	4	3.8	1	1.1	4	5.5	1	2.1	
Other	1	1.0	2	1.9	1	1.1	3	4.1	.	.	
Unknown	2	.	
Total	104	100.0	104	100.0	95	100.0	73	100.0	49	100.0	
Cardiothoracic											
White	118	87.4	107	87.7	111	91.7	97	93.3	73	88.0	
Asian	10	7.4	8	6.6	8	6.6	4	3.8	7	8.4	
Black	6	4.4	7	5.7	2	1.7	3	2.9	2	2.4	
Other	1	0.7	1	1.2	
Unknown	.	.	1	
Total	135	100.0	123	100.0	121	100.0	104	100.0	83	100.0	
Total											
White	467	83.1	470	81.3	470	83.9	405	79.6	338	79.9	
Asian	63	11.2	52	9.0	52	9.3	51	10.0	50	11.8	
Black	24	4.3	44	7.6	31	5.5	39	7.7	19	4.5	
Other	8	1.4	12	2.1	7	1.3	14	2.8	16	3.8	
Unknown	3	.	6	.	1	.	5	.	8	.	
Total	565	100.0	584	100.0	561	100.0	514	100.0	431	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 2014 to 31 March 2019). 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 2014 - 31 March 2019

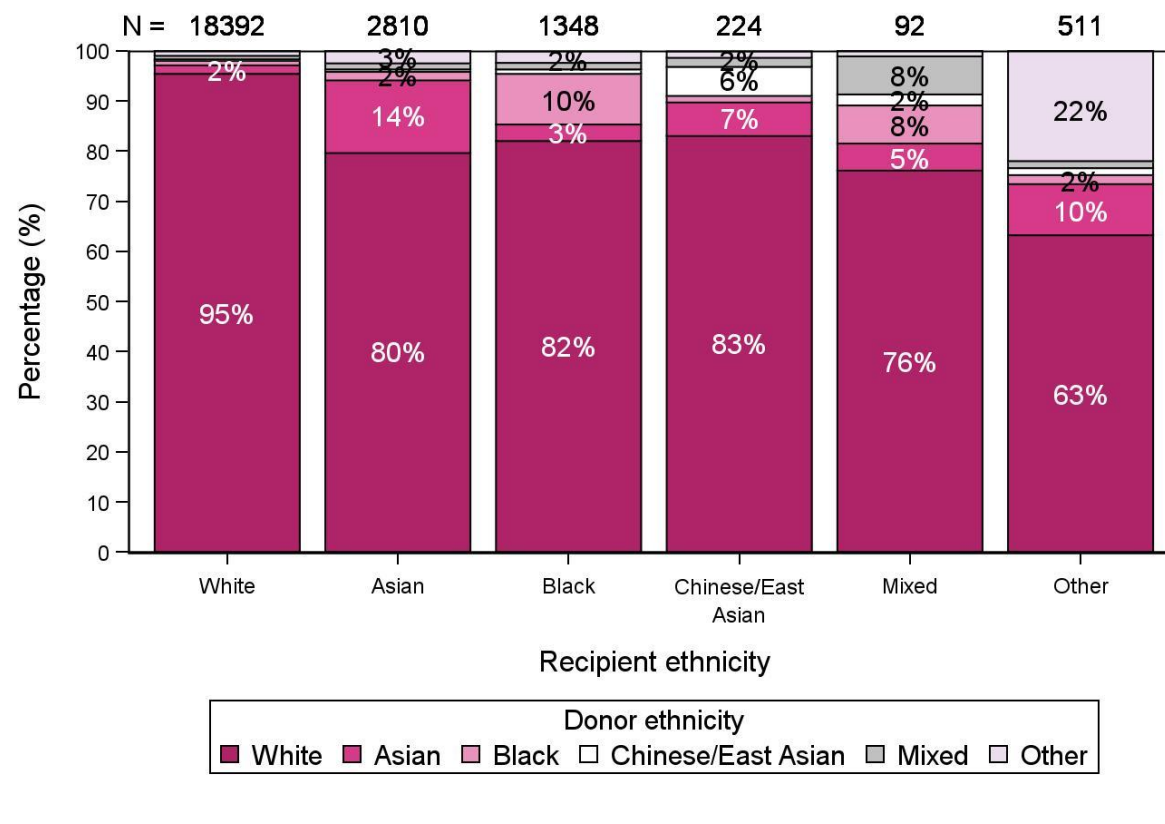


Table 4.5 Donor to recipient ethnicities for all transplants in the UK, 1 April 2014 - 31 March 2019

Donor ethnicity	Recipient ethnicity												Total N
	White		Asian		Black		Chinese/East Asian		Mixed		Other		
	N	%	N	%	N	%	N	%	N	%	N	%	
White	17545	95.4	2237	79.6	1106	82.0	186	83.0	70	76.1	323	63.2	21467
Asian	305	1.7	407	14.5	45	3.3	15	6.7	5	5.4	52	10.2	829
Black	160	0.9	47	1.7	136	10.1	3	1.3	7	7.6	9	1.8	362
Chinese/East Asian	51	0.3	13	0.5	12	0.9	13	5.8	2	2.2	7	1.4	98
Mixed	132	0.7	34	1.2	18	1.3	4	1.8	7	7.6	7	1.4	202
Other	199	1.1	72	2.6	31	2.3	3	1.3	1	1.1	113	22.1	419
Total	18392	100.0	2810	100.0	1348	100.0	224	100.0	92	100.0	511	100.0	23377

Deceased organ donors, deceased donor transplant recipients and patients on the transplant list at 31 March each year are shown by ethnicity from 2014/15 to 2018/19 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**; these charts have some 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, transplants and patients on the waiting list (as at 31 March)
1 April 2014 - 31 March 2019**

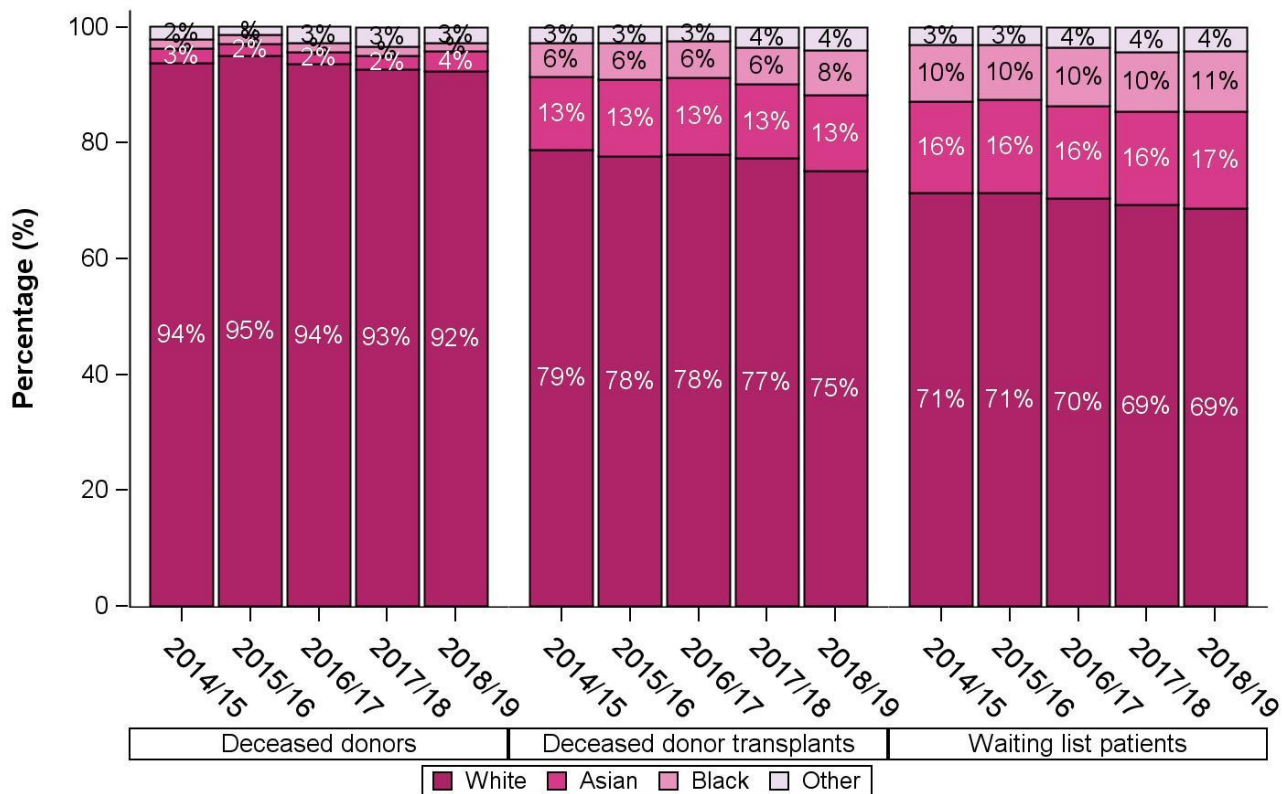


Figure 4.5 BAME communities - Deceased donors, transplants and patients on the waiting list as at 31 March, 1 April 2014 - 31 March 2019

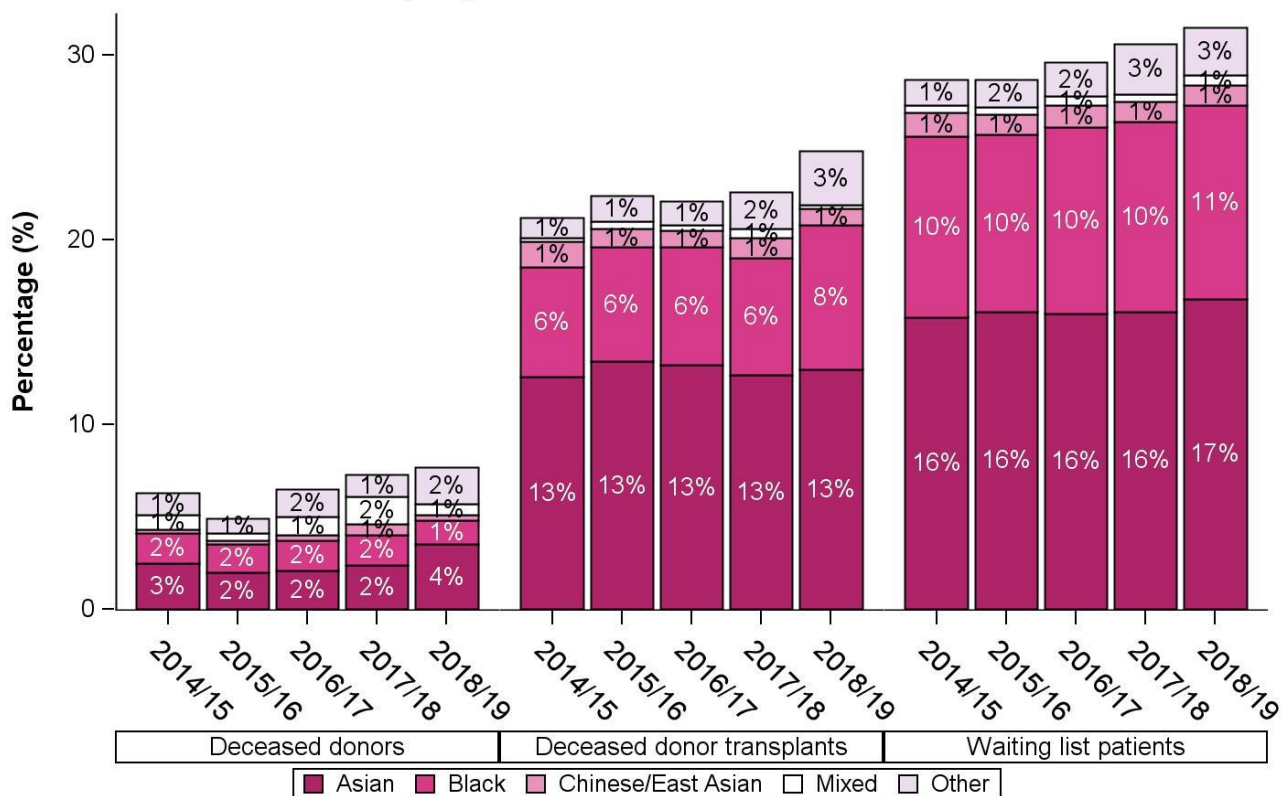


Figure 4.6 Living donors and transplants, 1 April 2014 - 31 March 2019

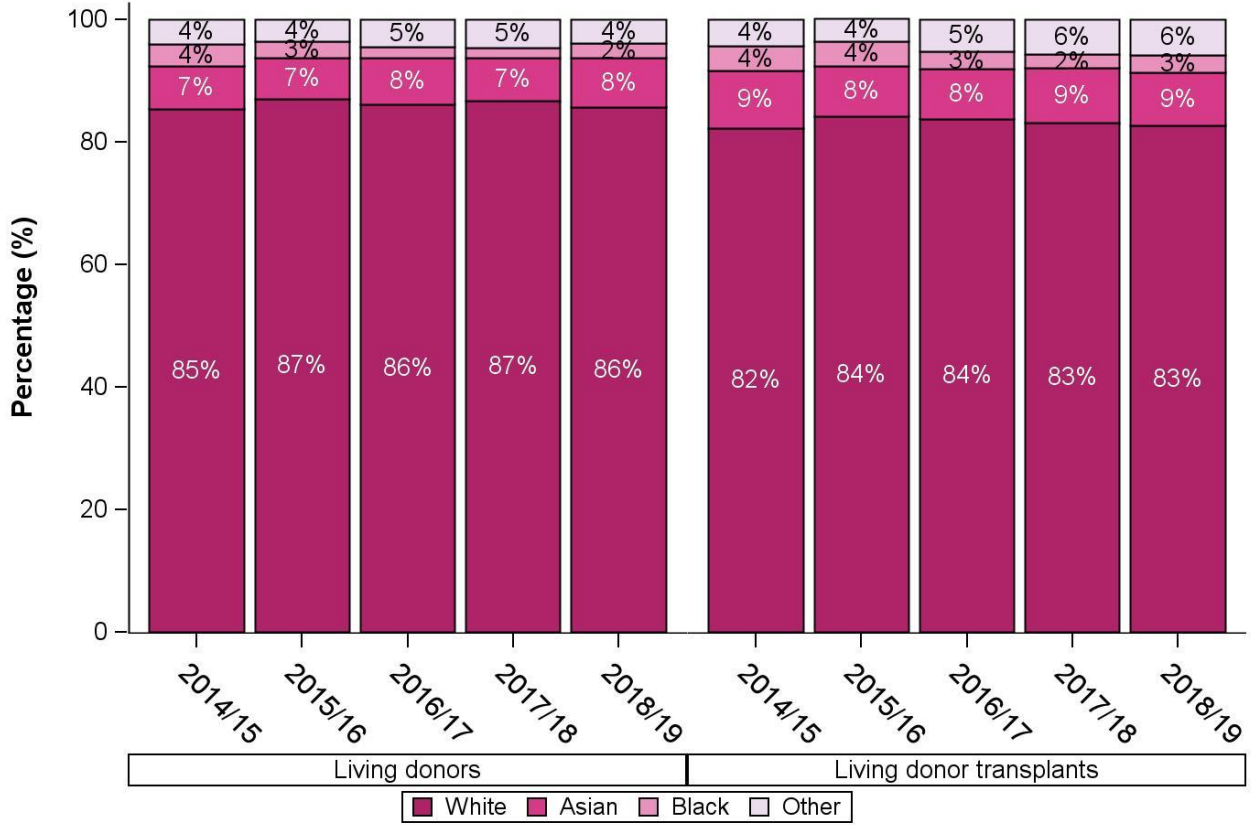


Figure 4.7 BAME communities - Living donors and transplants, 1 April 2014- 31 March 2019

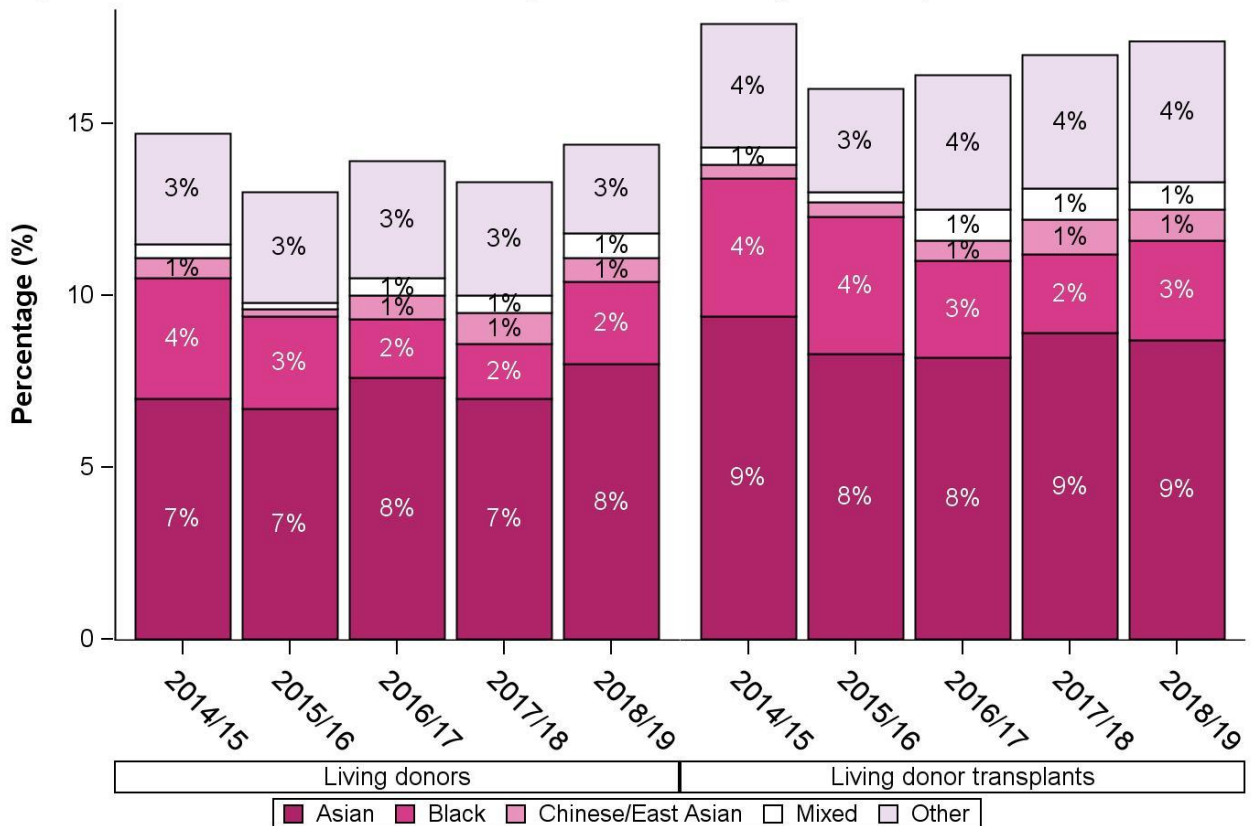


Table 4.6 Number of donors, transplants and waiting list patients in the UK, by ethnicity and financial year, 1 April 2014 - 31 March 2019

Ethnicity	2014/15		2015/16		Financial year 2016/17		2017/18		2018/19	
	N	%	N	%	N	%	N	%	N	%
Deceased donors										
White	1202	93.8	1296	95.1	1308	93.6	1441	92.7	1468	92.4
Asian	32	2.5	27	2.0	29	2.1	37	2.4	56	3.5
Black	20	1.6	20	1.5	22	1.6	25	1.6	20	1.3
Chinese/East Asian	3	0.2	3	0.2	4	0.3	9	0.6	4	0.3
Mixed	10	0.8	6	0.4	14	1.0	24	1.5	9	0.6
Other	15	1.2	11	0.8	21	1.5	19	1.2	32	2.0
Deceased donor transplants										
White	2614	78.8	2710	77.6	2864	78.0	3094	77.4	2941	75.2
Asian	418	12.6	467	13.4	483	13.2	507	12.7	510	13.0
Black	197	5.9	217	6.2	234	6.4	253	6.3	305	7.8
Chinese/East Asian	45	1.4	36	1.0	32	0.9	44	1.1	35	0.9
Mixed	7	0.2	14	0.4	12	0.3	19	0.5	7	0.2
Other	35	1.1	50	1.4	48	1.3	79	2.0	112	2.9
Waiting list										
White	4878	71.4	4553	71.3	4431	70.4	4129	69.3	4105	68.6
Asian	1082	15.8	1026	16.1	1009	16.0	959	16.1	1006	16.8
Black	668	9.8	614	9.6	634	10.1	615	10.3	630	10.5
Chinese/East Asian	88	1.3	73	1.1	73	1.2	68	1.1	63	1.1
Mixed	25	0.4	25	0.4	33	0.5	22	0.4	31	0.5
Other	94	1.4	98	1.5	116	1.8	161	2.7	153	2.6
Living donors										
White	929	85.4	939	87.0	900	86.1	923	86.7	890	85.7
Asian	76	7.0	72	6.7	79	7.6	75	7.0	83	8.0
Black	38	3.5	29	2.7	18	1.7	17	1.6	25	2.4
Chinese/East Asian	6	0.6	2	0.2	7	0.7	10	0.9	7	0.7
Mixed	4	0.4	2	0.2	5	0.5	5	0.5	7	0.7
Other	35	3.2	35	3.2	36	3.4	35	3.3	27	2.6
Living donor transplants										
White	879	82.2	892	84.1	867	83.7	871	83.1	850	82.6
Asian	100	9.4	88	8.3	85	8.2	93	8.9	90	8.7
Black	43	4.0	42	4.0	29	2.8	24	2.3	30	2.9
Chinese/East Asian	4	0.4	4	0.4	6	0.6	10	1.0	9	0.9
Mixed	5	0.5	3	0.3	9	0.9	9	0.9	8	0.8
Other	38	3.6	32	3.0	40	3.9	41	3.9	42	4.1

Unknown ethnicity was excluded

Table 4.7 summarises all deceased donor transplants by country of residence, ethnicity of recipient and organ transplanted in 2018/19. 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 2018 - 31 March 2019,

Country of residence	Transplants (N)								Total
	Kidney	Pancreas ¹	Kidney/ Pancreas ²	Heart	Lung	Liver	Intestinal	Multiorgan ³	
England									
White	1306	29	110	124	131	655	8	19	2382
Asian	410		8	19	5	45		3	490
Black	248		17	8		27			300
Chinese/Oriental	20			1		10			31
Mixed	5			1					6
Other	57		4	5	1	40		1	108
Wales									
White	102	2	10	6	6	28		3	157
Asian	5			1		1			7
Chinese/Oriental	1								1
Other						1			1
Scotland									
White	154	7	14	9	13	113			310
Asian	7			2	1	1			11
Black	3		1						4
Chinese/Oriental	3								3
Other	2								2
Northern Ireland									
White	44		2	6	4	33			89
Asian	2								2
Black	1								1
Mixed	1								1

¹ 20 islet transplants

² 8 simultaneous islet and kidney transplant

³ 4 heart/lung transplants, 1 liver/bowel/pancreas transplant, 6 multivisceral transplants, 4 modified multivisceral transplants and 11 liver and kidney transplants
71 unknown UK addresses, 8 overseas and 1 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, 19% 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 waiting on the list.

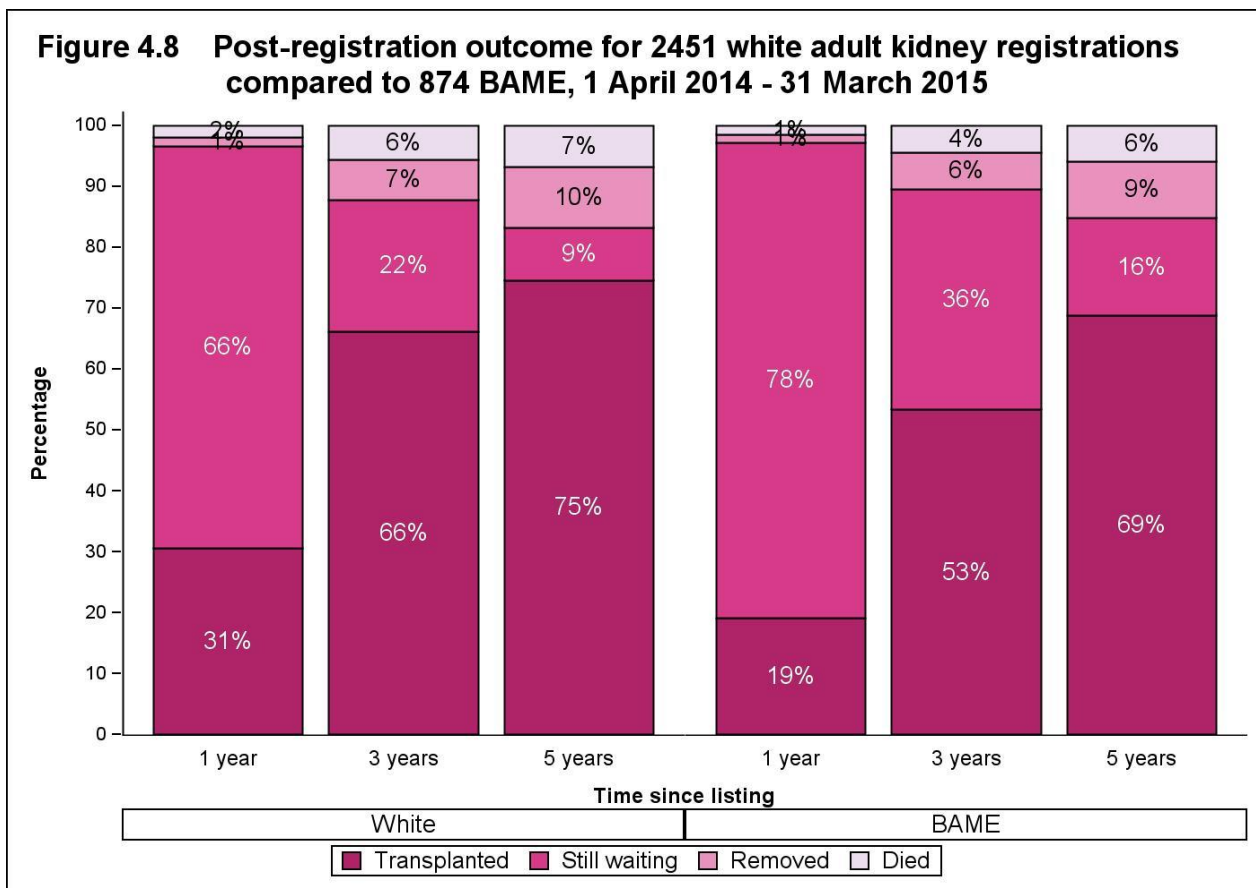
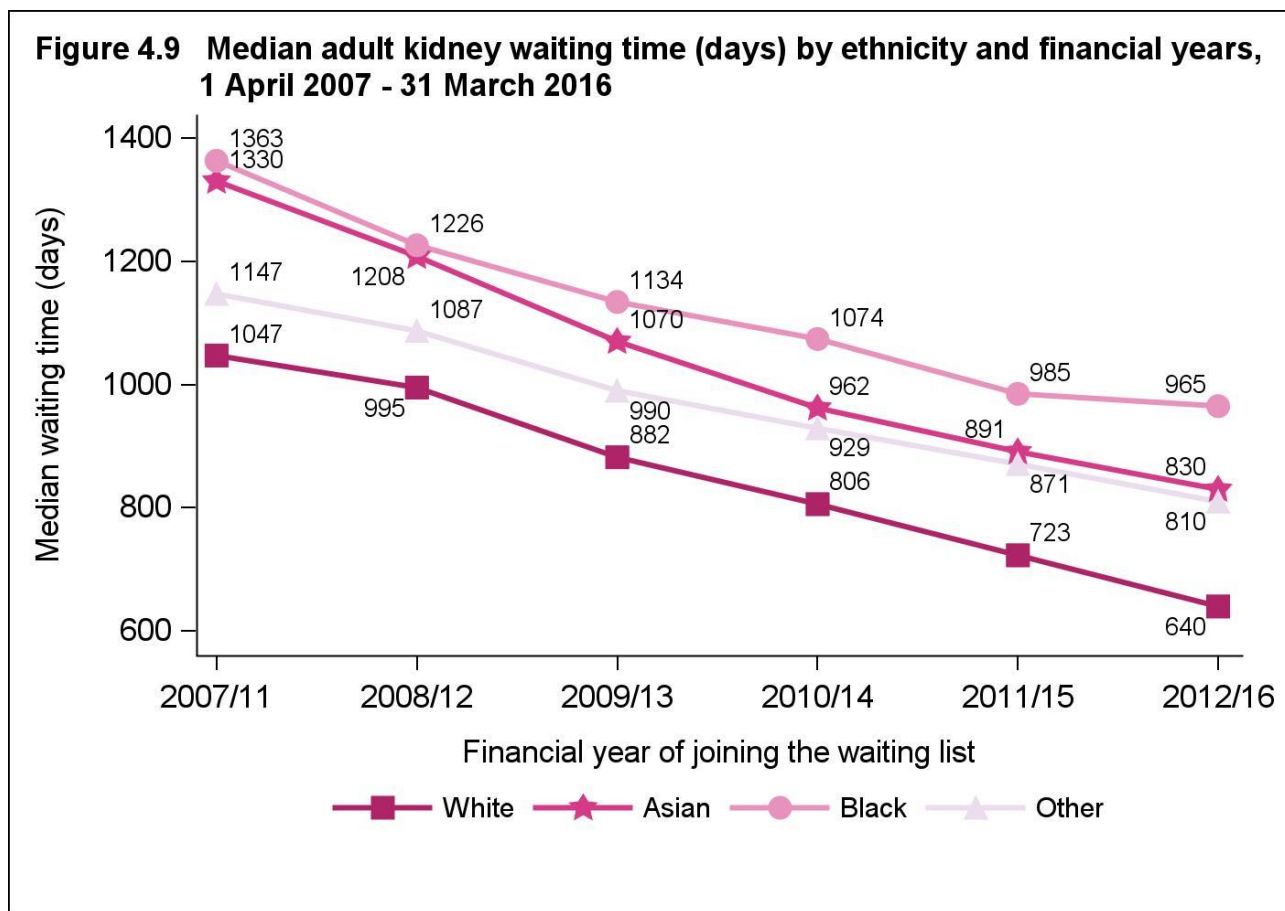


Table 4.8 Post-registration outcome for 2451 white adult kidney registrations compared to 874 BAME, 1 April 2014 - 31 March 2015

Outcome	1 year		3 years		5 years	
	N	%	N	%	N	%
White						
Transplanted	750	30.6	1623	66.2	1828	74.6
Still waiting	1619	66.1	529	21.6	213	8.7
Removed	35	1.4	163	6.7	243	9.9
Died	47	1.9	136	5.5	167	6.8
BAME						
Transplanted	167	19.1	466	53.3	601	68.8
Still waiting	683	78.1	317	36.3	141	16.1
Removed	11	1.3	53	6.1	81	9.3
Died	13	1.5	38	4.3	51	5.8

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 2016. 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 latest financial year, **Figure 4.10** shows that 7% of deceased kidney donors are from BAME communities whilst BAME patients represent 31% 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 2014 to 31 March 2019. 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.

Figure 4.10 Kidney statistics (waiting list as at 31 March), 1 April 2014 - 31 March 2019

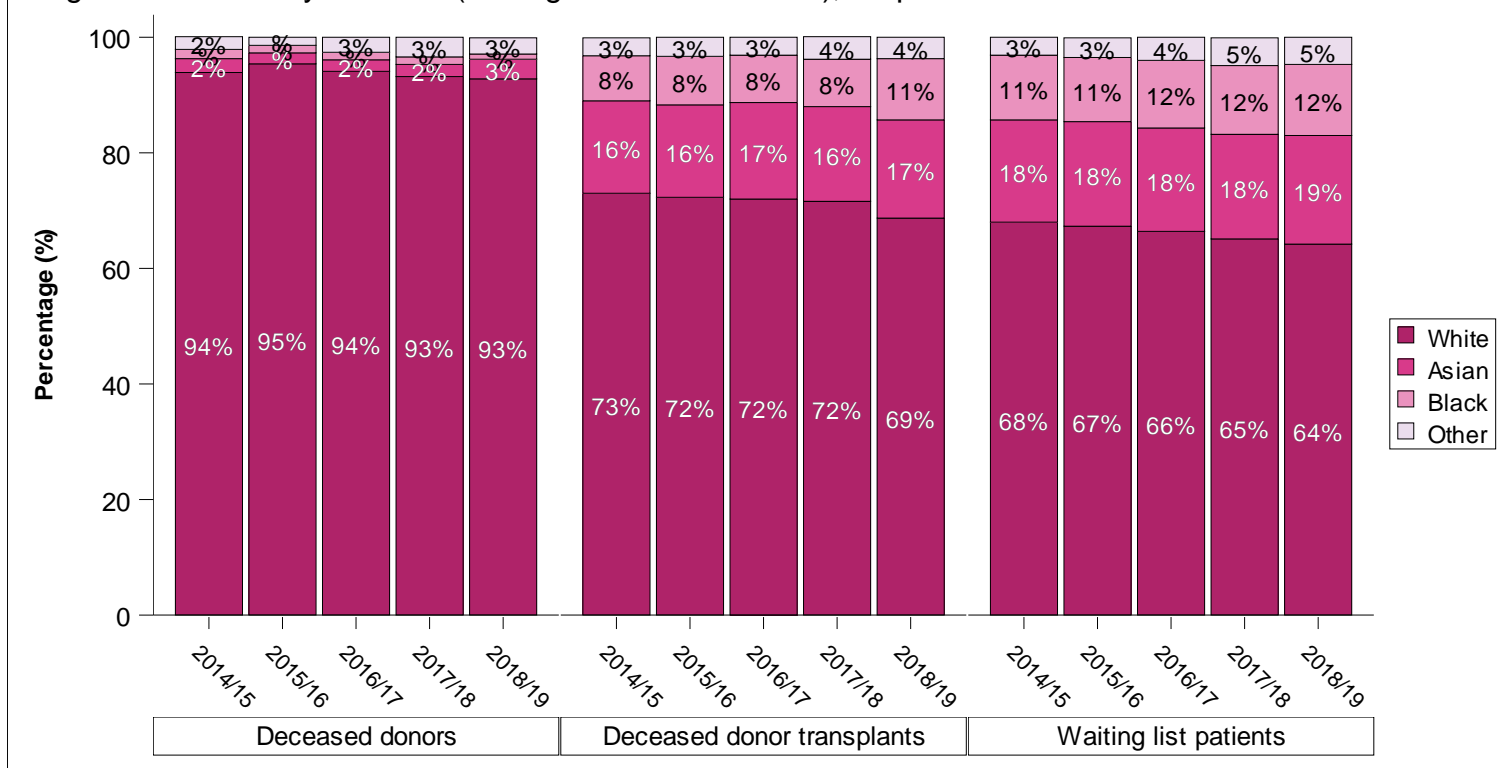


Table 4.10 Kidney statistics (waiting list as at 31 March), 1 April 2014 - 31 March 2019

Ethnicity	Deceased donors					Deceased donor transplants					Waiting list patients				
	14/15	15/16	16/17	17/18	18/19	14/15	15/16	16/17	17/18	18/19	14/15	15/16	16/17	17/18	18/19
White	1130	1232	1243	1363	1389	1497	1587	1661	1816	1751	3824	3519	3416	3223	3149
Asian	29	25	27	30	51	329	352	384	417	433	995	948	923	897	921
Black	19	17	17	19	14	161	185	190	207	270	631	581	600	590	602
Chinese/East Asian	3	3	3	9	3	33	27	24	33	24	81	70	71	67	59
Mixed	10	6	14	23	8	5	11	9	14	6	21	23	27	20	27
Other	13	9	17	18	31	26	34	38	51	64	75	86	106	153	145
Total	1204	1292	1321	1462	1496	2051	2196	2306	2538	2548	5627	5227	5143	4950	4903

Figure 4.11 Deceased donor to recipient ethnicities for kidney transplants in the UK, 1 April 2014 - 31 March 2019

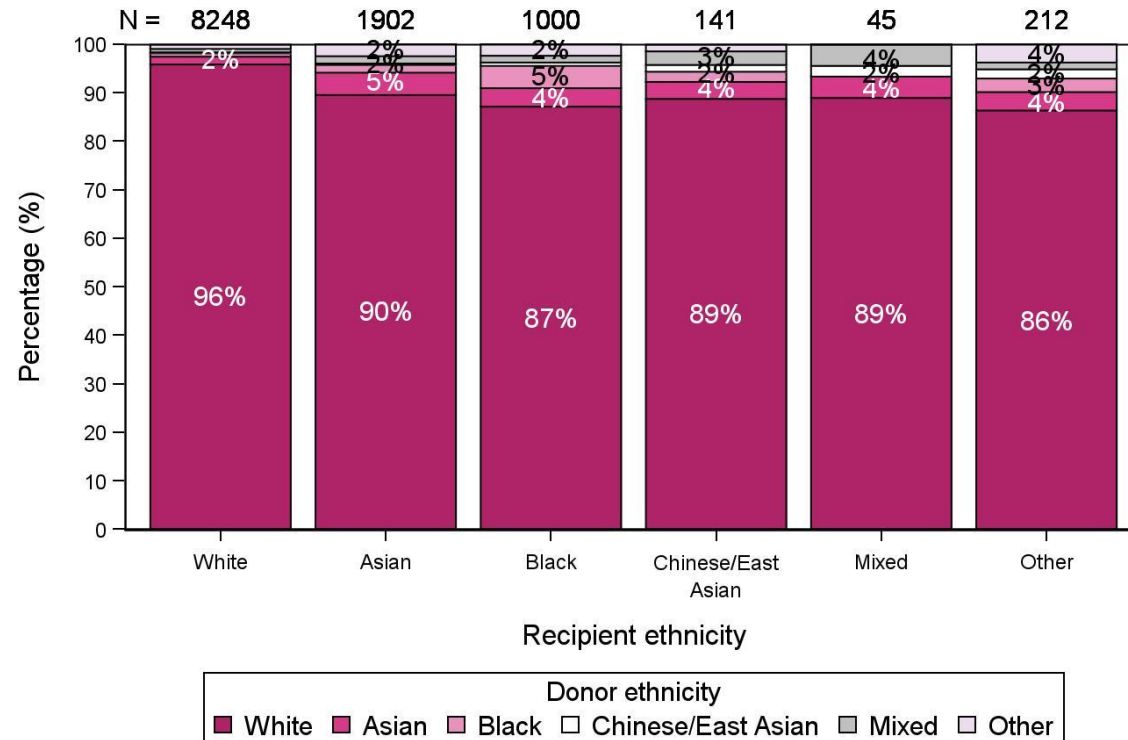


Table 4.11 Deceased donor to recipient ethnicities for kidney transplants in the UK, 1 April 2014 - 31 March 2019

Donor ethnicity	Recipient ethnicity												Total N
	White		Asian		Black		Chinese/East Asian		Mixed		Other		
	N	%	N	%	N	%	N	%	N	%	N	%	
White	7905	95.8	1703	89.5	871	87.1	125	88.7	40	88.9	183	86.3	10827
Asian	135	1.6	88	4.6	38	3.8	5	3.5	2	4.4	8	3.8	276
Black	55	0.7	30	1.6	46	4.6	3	2.1	0	0.0	6	2.8	140
Chinese/East Asian	18	0.2	6	0.3	7	0.7	2	1.4	1	2.2	4	1.9	38
Mixed	59	0.7	28	1.5	14	1.4	4	2.8	2	4.4	3	1.4	110
Other	76	0.9	47	2.5	24	2.4	2	1.4	0	0.0	8	3.8	157
Total	8248	100.0	1902	100.0	1000	100.0	141	100.0	45	100.0	212	100.0	11548

Figure 4.12 Living donor to recipient ethnicities for kidney transplants in the UK, 1 April 2014 - 31 March 2019

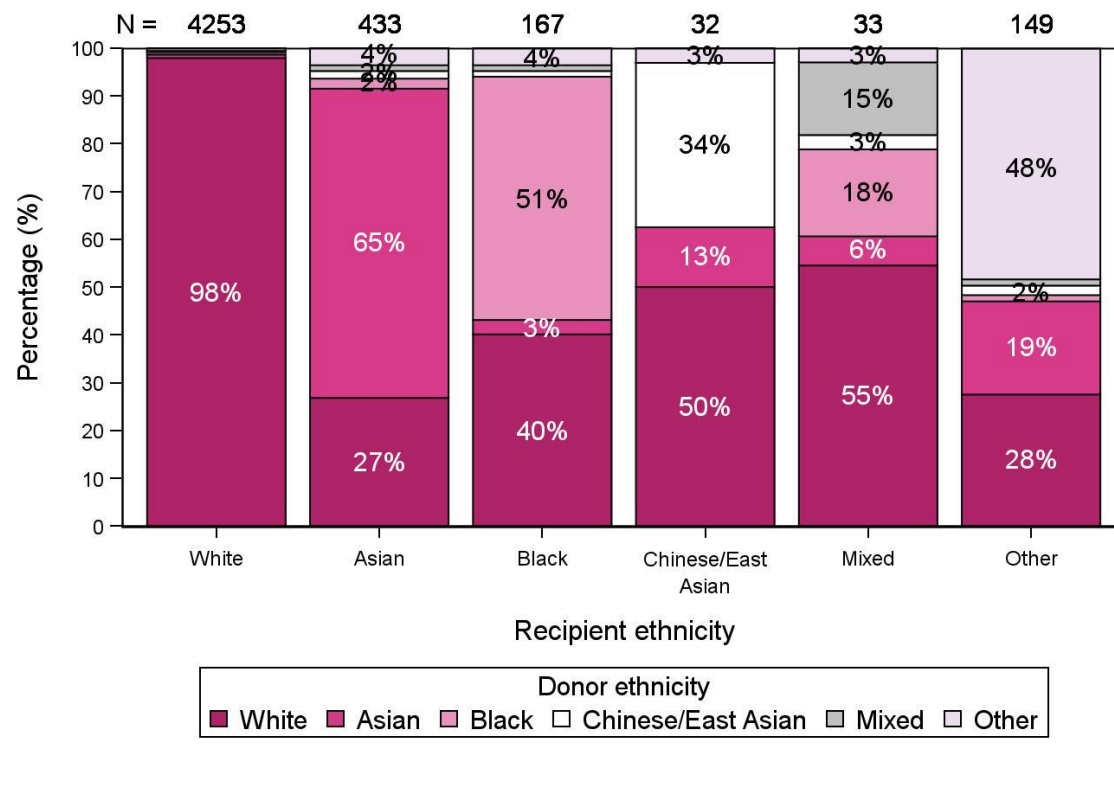


Table 4.12 Living donor to recipient ethnicities for kidney transplants in the UK, 1 April 2014 - 31 March 2019

Donor ethnicity	Recipient ethnicity												Total N
	White		Asian		Black		Chinese/East Asian		Mixed		Other		
	N	%	N	%	N	%	N	%	N	%	N	%	
White	4163	97.9	116	26.8	67	40.1	16	50.0	18	54.5	41	27.5	4421
Asian	29	0.7	280	64.7	5	3.0	4	12.5	2	6.1	29	19.5	349
Black	19	0.4	9	2.1	85	50.9	0	0.0	6	18.2	2	1.3	121
Chinese/East Asian	7	0.2	7	1.6	2	1.2	11	34.4	1	3.0	3	2.0	31
Mixed	7	0.2	5	1.2	2	1.2	0	0.0	5	15.2	2	1.3	21
Other	28	0.7	16	3.7	6	3.6	1	3.1	1	3.0	72	48.3	124
Total	4253	100.0	433	100.0	167	100.0	32	100.0	33	100.0	149	100.0	5067

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 2014 to 31 March 2019. BAME living donor transplant recipients mostly received a kidney from family or friends (related/unrelated). In the last 5 years, there have been 5 Asian and 2 other ethnic minority altruistic BAME donors.

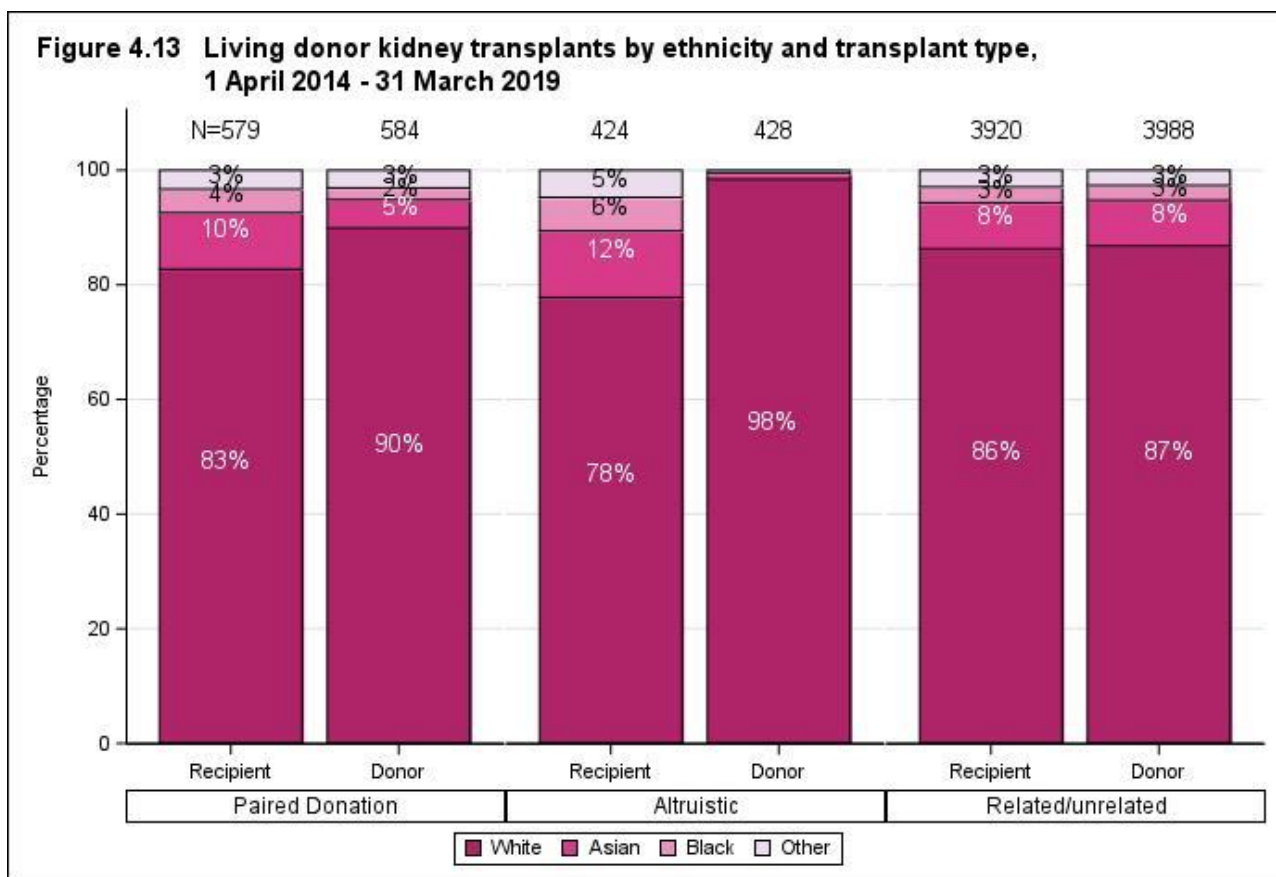


Table 4.13 Living donor kidney transplants by ethnicity and transplant type, 1 April 2014 - 31 March 2019

Type of living donation	Ethnicity	Recipient		Donor	
		N	%	N	%
Paired Donation	White	479	82.7	525	89.9
	Asian	57	9.8	29	5.0
	Black	24	4.1	12	2.1
	Other	19	3.3	18	3.1
	Unknown	6	.	1	.
	Total		585	100.0	585
Altruistic	White	330	77.8	421	98.4
	Asian	49	11.6	5	1.2
	Black	25	5.9	.	.
	Other	20	4.7	2	0.5
	Unknown	4	.	.	.
	Total		428	100.0	428
Related/unrelated	White	3383	86.3	3460	86.8
	Asian	315	8.0	319	8.0
	Black	108	2.8	104	2.6
	Other	114	2.9	105	2.6
	Unknown	72	.	4	.
	Total		3992	100.0	3992

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 21 BAME pancreas patients listed, 86% were transplanted within 5 years. This rate is higher than for white patients, although 14% had died waiting on the transplant list. The numbers of BAME patients is very small so results should be interpreted with caution.

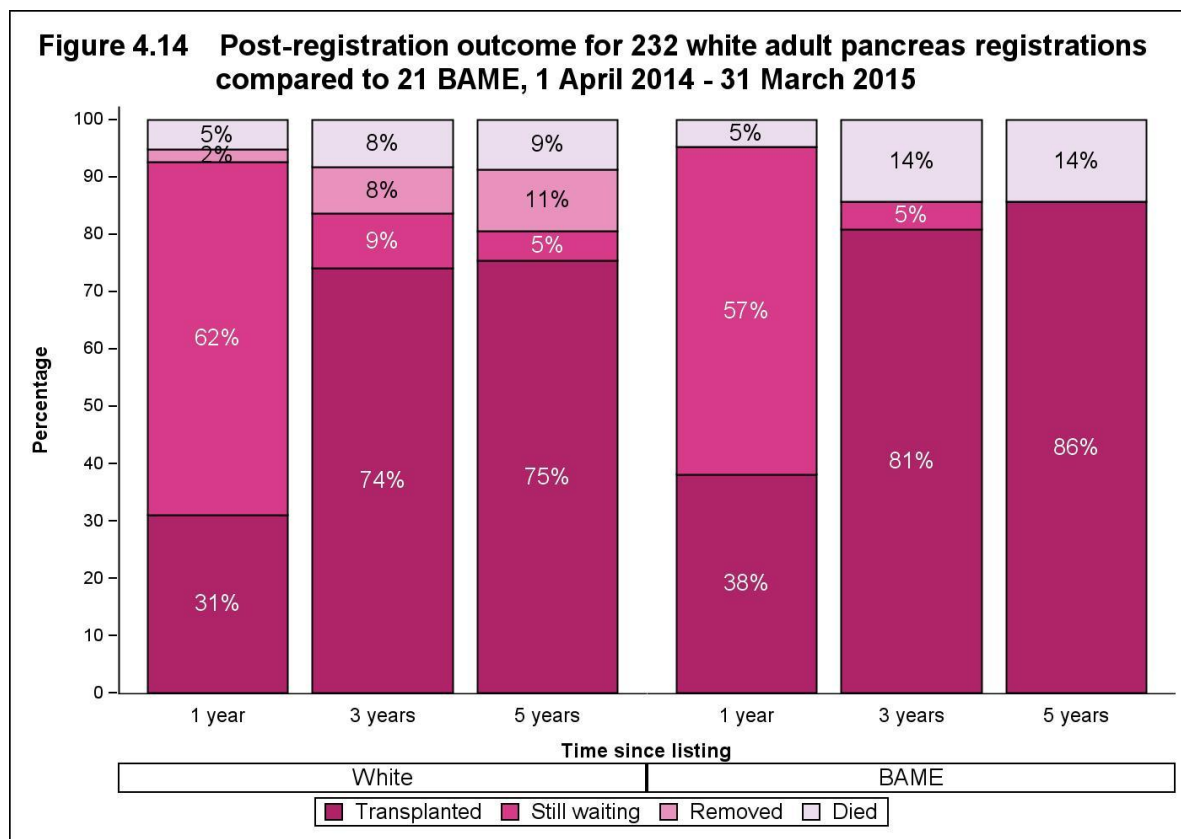


Table 4.14 Post-registration outcome for 232 white adult pancreas registrations compared to 21 BAME, 1 April 2014 – 31 March 2019

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	12	5.2
Removed	5	2.2	19	8.2	25	10.8
Died	12	5.2	19	8.2	20	8.6
BAME						
Transplanted	8	38.1	17	81.0	18	85.7
Still waiting	12	57.1	1	4.8	0	0.0
Removed	0	0.0	0	0.0	0	0.0
Died	1	4.8	3	14.3	3	14.3

Figure 4.15 shows in the latest financial year that 9% of deceased pancreas donors are from BAME communities whilst BAME patients represent 15% of transplants and 15% of the pancreas or islet transplant waiting list. **Table 4.15** shows the numbers in **Figure 4.15** .

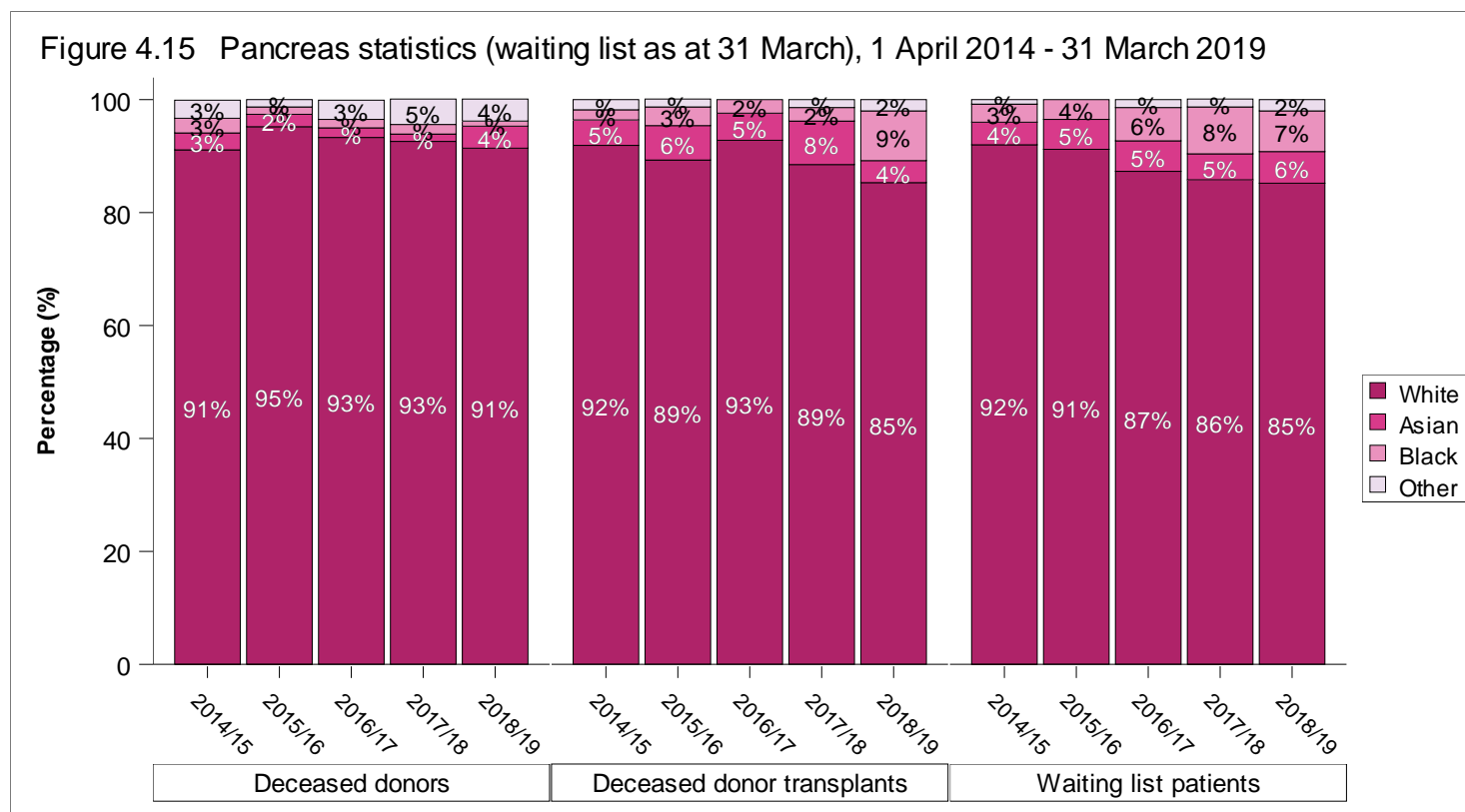


Table 4.15 Pancreas statistics (waiting list as at 31 March), 1 April 2014 - 31 March 2019

Ethnicity	Deceased donors					Deceased donor transplants					Waiting list patients				
	14/15	15/16	16/17	17/18	18/19	14/15	15/16	16/17	17/18	18/19	14/15	15/16	16/17	17/18	18/19
White	421	441	433	435	424	204	191	194	185	174	230	206	193	187	213
Asian	14	10	8	6	18	10	13	10	16	8	10	12	12	10	14
Black	12	6	7	8	4	4	7	5	5	18	8	8	13	18	18
Chinese/East Asian	2		2	4	1	1	1		1		2				
Mixed	6	2	6	9	3	1			2				1		
Other	7	4	8	8	14	2	2			4			2	3	5
Total	462	463	464	470	464	222	214	209	209	204	250	226	221	218	250

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.

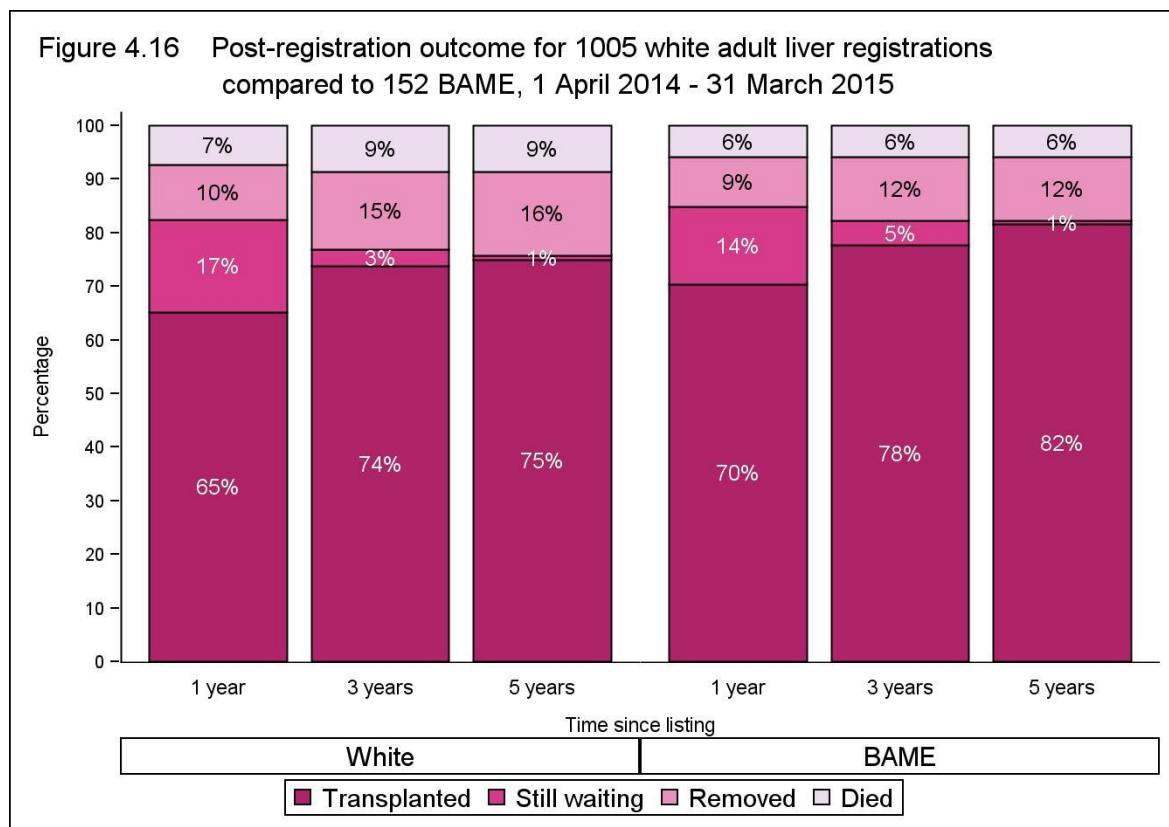
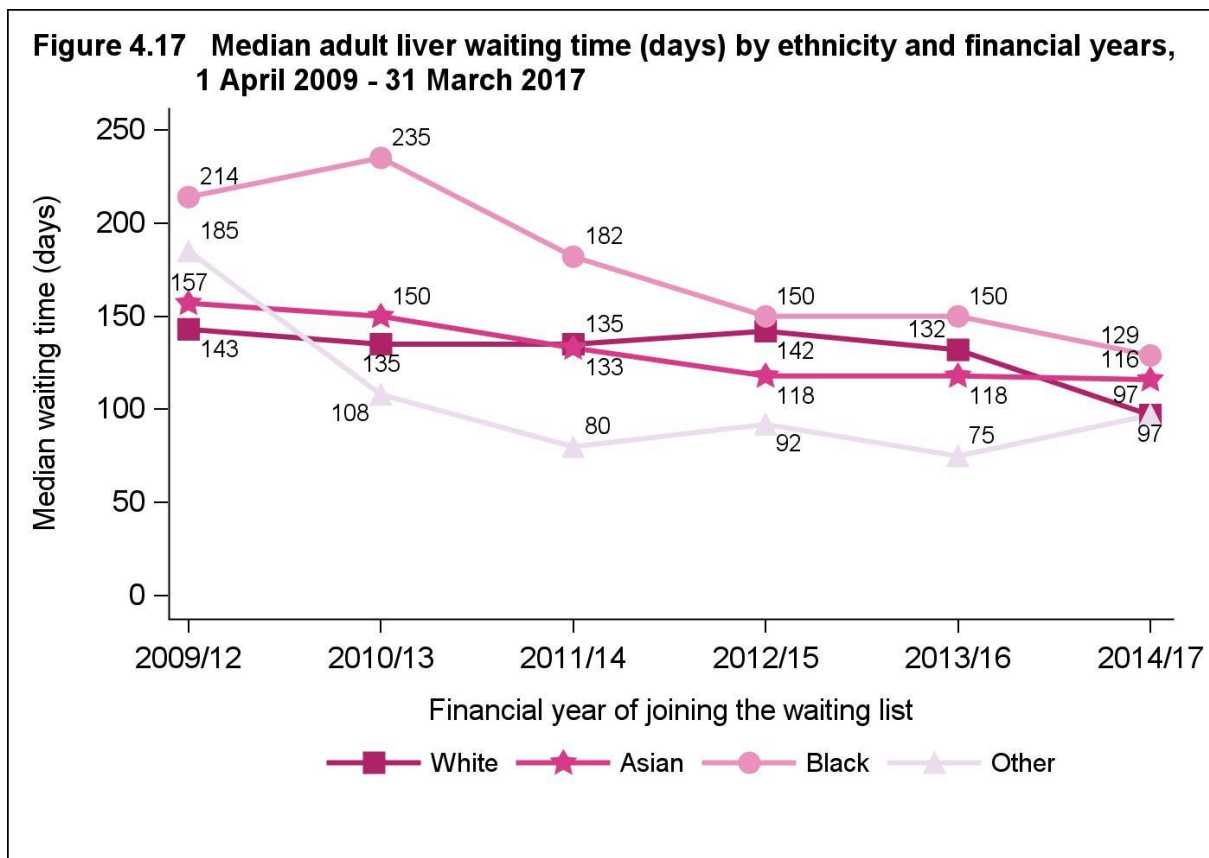


Table 4.16 Post-registration outcome for 1005 white adult liver registrations compared to 152 BAME, 1 April 2014 - 31 March 2015

Outcome	1 year		3 years		5 years	
	N	%	N	%	N	%
White						
Transplanted	655	65.2	742	73.8	753	74.9
Still waiting	174	17.3	30	3.0	8	0.8
Removed	102	10.1	147	14.6	158	15.7
Died	74	7.4	86	8.6	86	8.6
BAME						
Transplanted	107	70.4	118	77.6	124	81.6
Still waiting	22	14.5	7	4.6	1	0.7
Removed	14	9.2	18	11.8	18	11.8
Died	9	5.9	9	5.9	9	5.9

Figure 4.17 gives the adult median waiting time for a liver in days by ethnicity and financial years from 1 April 2009 to 31 March 2017. It shows an overall decline in waiting times for all ethnicities; black ethnic minority groups are waiting 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.



In the latest financial year, **Figure 4.18** shows that 9% of deceased liver donors are from BAME communities whilst BAME patients represent 13% of transplants and 13% of the liver transplant waiting list. **Table 4.18** shows the numbers in **Figure 4.18**.

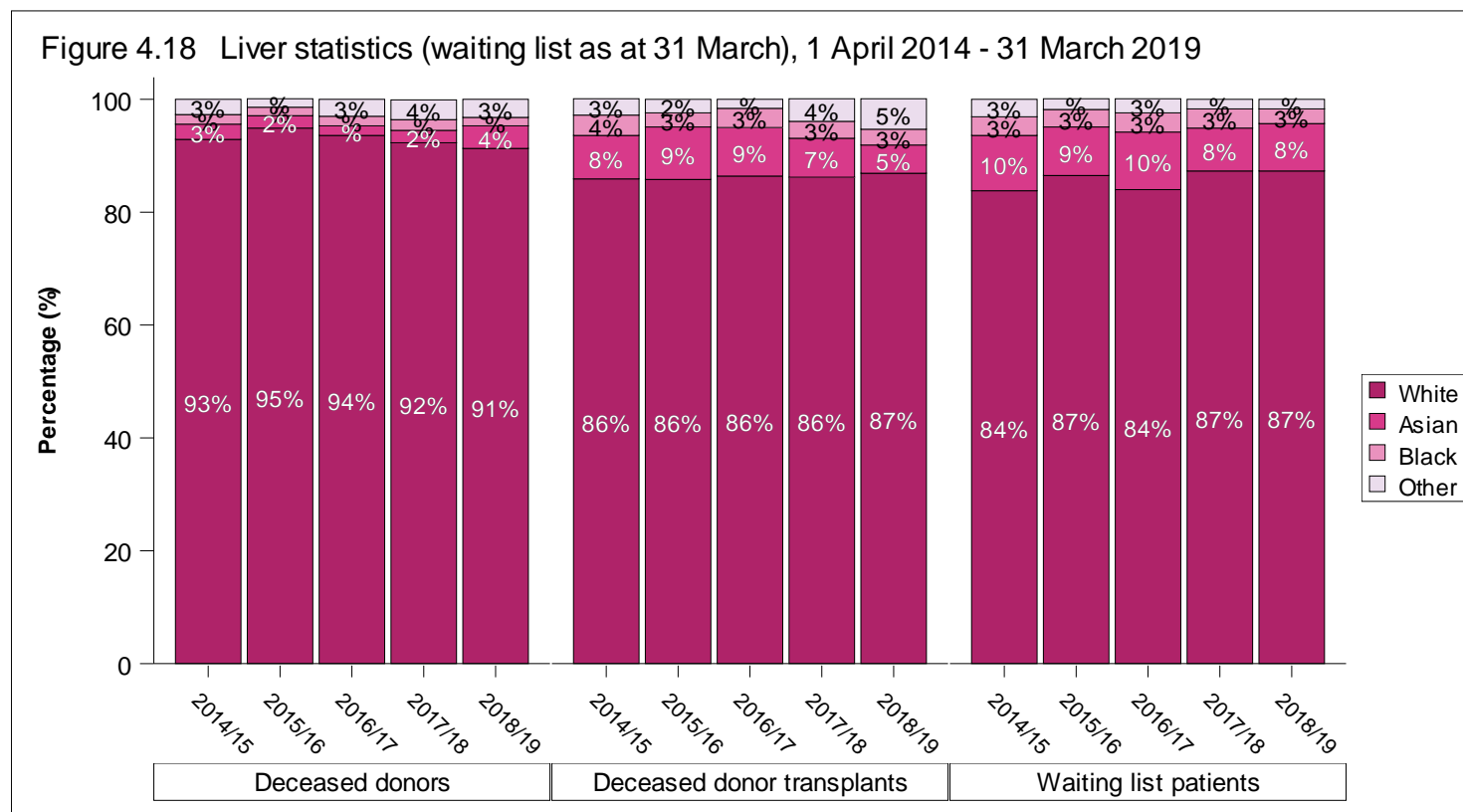


Table 4.18 Liver statistics (waiting list as at 31 March), 1 April 2014 - 31 March 2019

Ethnicity	Deceased donors					Deceased donor transplants					Waiting list patients				
	14/15	15/16	16/17	17/18	18/19	14/15	15/16	16/17	17/18	18/19	14/15	15/16	16/17	17/18	18/19
White	858	958	964	1047	1008	723	754	814	868	840	512	505	445	309	365
Asian	25	22	17	25	44	65	82	81	69	48	60	50	54	27	35
Black	16	15	18	22	17	30	22	32	30	27	20	18	18	12	11
Chinese/East Asian	2	3	4	6	3	13	8	6	10	10	4	1	1		3
Mixed	9	5	12	18	8	2	1	2	2		2	2	4		
Other	14	7	15	16	24	9	12	7	28	42	13	8	8	6	4
Total	924	1010	1030	1134	1104	842	879	942	1007	967	611	584	530	354	418

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.

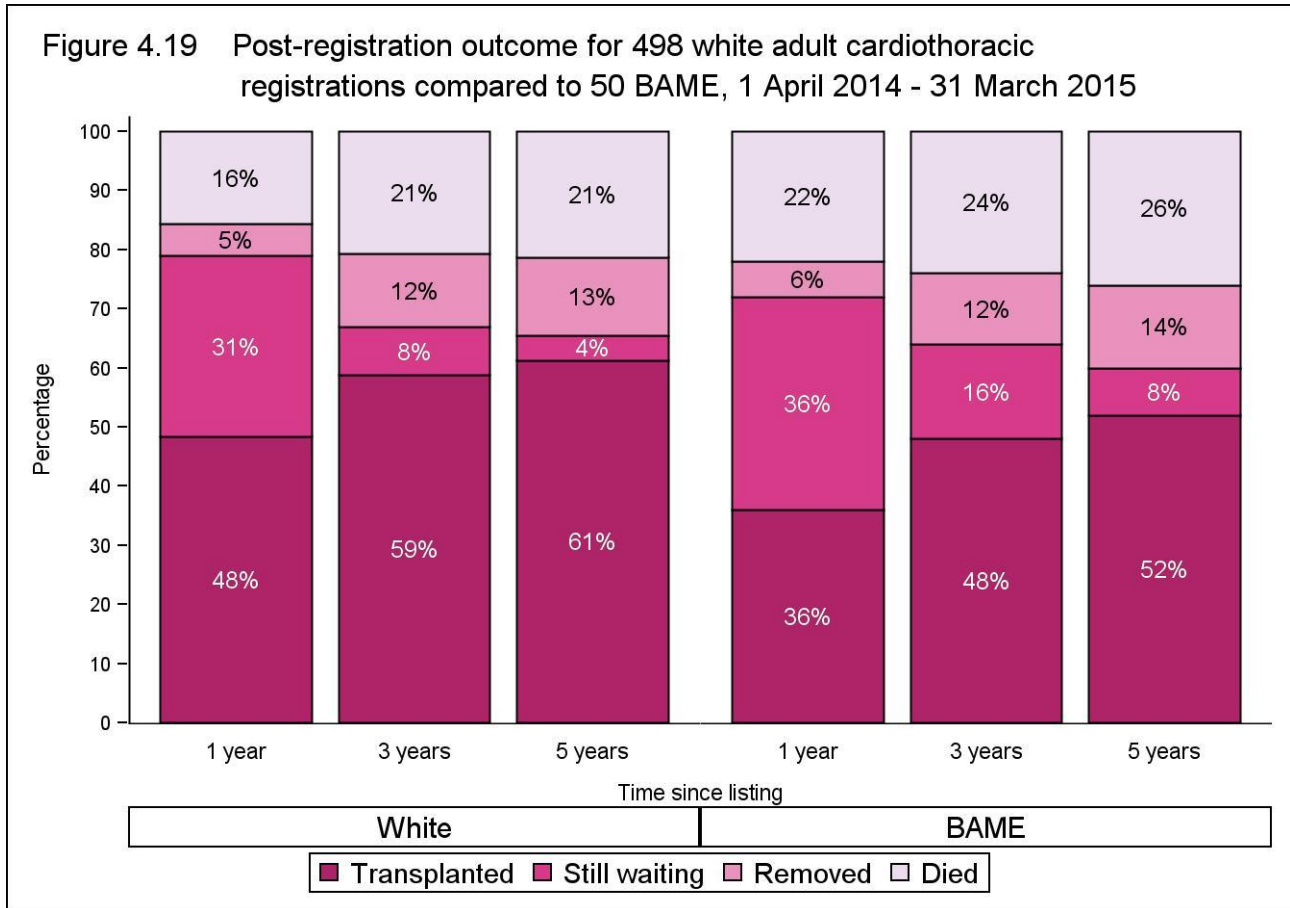


Table 4.19 Post-registration outcome for 498 white adult cardiothoracic registrations compared to 50 BAME, 1 April 2014 - 31 March 2015

Outcome	1 year		3 years		5 years	
	N	%	N	%	N	%
White						
Transplanted	241	48.4	293	58.8	305	61.2
Still waiting	152	30.5	40	8.0	21	4.2
Removed	27	5.4	62	12.4	66	13.3
Died	78	15.7	103	20.7	106	21.3
BAME						
Transplanted	18	36.0	24	48.0	26	52.0
Still waiting	18	36.0	8	16.0	4	8.0
Removed	3	6.0	6	12.0	7	14.0
Died	11	22.0	12	24.0	13	26.0

In the latest financial year, **Figure 4.20** shows that 9% of deceased cardiothoracic donors are from BAME communities whilst BAME patients represent 13% of transplants and 12% of the liver transplant waiting list. **Table 4.20** shows the numbers in **Figure 4.20**.

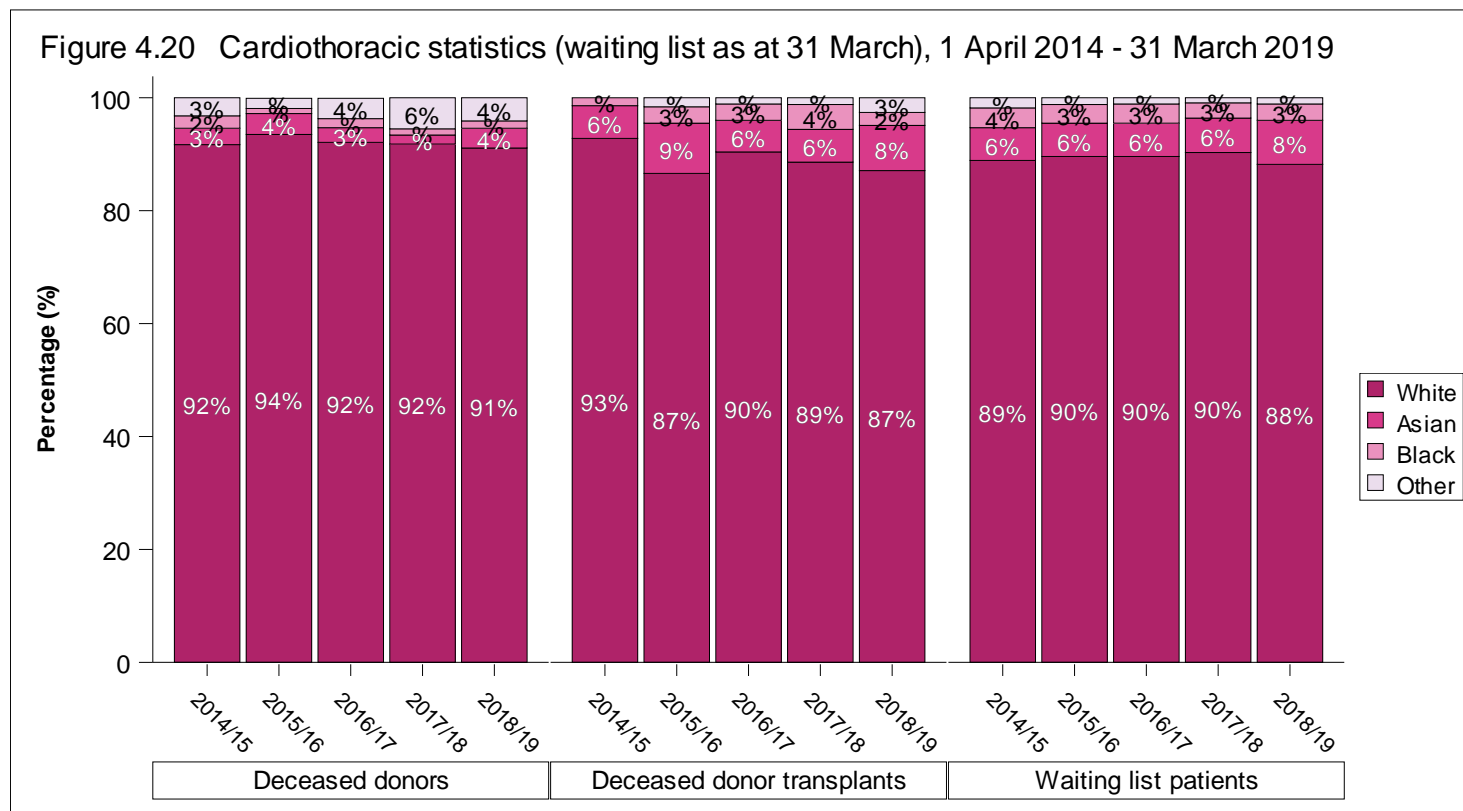


Table 4.20 Cardiothoracic statistics (waiting list as at 31 March), 1 April 2014 – 31 March 2019

Ethnicity	Deceased donors					Deceased donor transplants					Waiting list patients				
	14/15	15/16	16/17	17/18	18/19	14/15	15/16	16/17	17/18	18/19	14/15	15/16	16/17	17/18	18/19
White	287	304	280	335	286	337	329	340	364	304	534	517	560	577	569
Asian	9	12	8	6	11	21	34	21	24	28	35	34	37	39	50
Black	7	3	5	4	4	5	11	11	18	8	21	19	21	17	19
Chinese/East Asian	3		1	3	3		1	2	1	1	3	2	1	1	
Mixed	4	4	6	9	2		2	1	3	1	3	1	3	2	4
Other	3	2	4	8	8		3	1	1	7	5	4	3	3	3
Total	313	325	304	365	314	363	380	376	411	349	601	577	625	639	645

APPENDIX



Table I UK population by ethnicity, mid-2011 census data estimates per thousands

Ethnicity	N (thousands)	%
White British	52,423	82.5
White Irish	1,529	2.4
Other White	2,746	4.3
Total White	56,698	89.2
Asian-Indian	1,438	2.3
Asian-Pakistani	1,041	1.6
Asian-Bangladeshi	377	0.6
Other Asian	378	0.6
Total Asian	3,234	5.1
Black-African	792	1.2
Black-Caribbean	649	1.0
Other Black	130	0.2
Total Black	1,571	2.5
White & Black Caribbean	351	0.6
White & Black African	143	0.2
White & Asian	318	0.5
Other Mixed	276	0.4
Chinese	427	0.7
Other ethnicity	515	0.8
Total Other	2,030	3.2
TOTAL	63,533	100.0

Source - Office of National Statistics

Table II National data from the NHSBT Potential Donor Audit for donation after brain death, 1 April 2014 – 31 March 2019¹

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 (%)
2014/15	White	1436	1214	84.5	1394	97.1	1100	775	70.5
	BAME	236	191	80.9	226	95.8	155	61	39.4
	Unknown	62	40	64.5	51	82.3	29	23	79.3
2015/16	White	1459	1244	85.3	1418	97.2	1108	822	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	1633	1410	86.3	1617	99.0	1254	969	77.3
	BAME	306	258	84.3	303	99.0	208	91	43.8
	Unknown	65	47	72.3	62	95.4	31	22	71.0

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 2014 – 31 March 2019¹

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 (%)
2014/15	White	5539	4381	79.1	1806	988	54.7
	BAME	481	371	77.1	123	39	31.7
	Unknown	741	404	54.5	90	19	21.1
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	5356	4836	90.3	1669	1040	62.3
	BAME	388	355	91.5	112	42	37.5
	Unknown	538	424	78.8	77	32	41.6
2018/19	White	5123	4776	93.2	1586	1033	65.1
	BAME	450	414	92.0	123	47	38.2
	Unknown	401	349	87.0	43	19	44.2

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