NHS
Blood and Transplant

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

Report for 2017/2018
(1 April 2013 – 31 March 2018)

CONTENTS

1 EXECUTIVE SUMMARY

This report provides information related to organ donation and transplantation within the 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 2017/18*. This report defines BAME as Black, Asian, and minority ethnic (used to refer to members of non-white communities in the UK).

There has been a small increase in the proportion of opt-in registrations from BAME communities added to the Organ Donor Register (ODR) over the past 5 years; 5.6% of opt-ins in 2013/14 and 7.2% in 2017/18. Many BAME groups are poorly represented on the ODR relative to the current UK population.

Black, Asian and minority ethnic (BAME) groups represent 11% of the UK population (ONS mid-2011 estimates). Asians represent 5.1% of the UK population while 2.5% of the population are Black and 3.2% are from other minority ethnic groups. In contrast, at the end of the 2017/18 financial year, 35% of the total number of patients on the waiting list for a kidney transplant were BAME, reflecting a demand for kidney transplantation in excess of that for White patients. This is believed to be attributable to a higher burden of diabetes and kidney disease associated with the BAME communities. For other organs the demand is in line with that for the White population.

Allied to the higher demand for kidney transplantation for BAME patients, 28% of kidney transplants in 2017/18 were in BAME recipients. This demonstrates a gap between the need for transplantation (35% of the waiting list) and the number of transplants taking place for BAME patients. This explains the longer waiting time to kidney transplant for BAME patients (approx. 2½ years, compared with 2 years for White patients). This disadvantage for BAME patients arises partly from the need to match kidney donors and recipients according to blood and tissue types. Blood and tissue types differ across ethnic groups and the fact that only 7% of deceased organ donors in the UK are from minority ethnic groups makes it very difficult to find suitable matching kidneys for BAME patients on the transplant list. In response to this challenge, the UK Kidney Allocation Scheme that was introduced in 2006 included measures to help all disadvantaged patients who wait a long time for transplant. This made a difference for BAME patients and the subsequent increase in deceased donor numbers has also contributed to fewer BAME patients on the kidney transplant list and a fall in median waiting time for BAME patients than reported six years ago (for patients registered 2005-2009) from 4 to 2½ years. White patients have seen a smaller fall in median waiting time in the same period (from 3 years to 2 years). The Kidney Allocation Scheme has been reviewed and revised over the last 2 years and changes are planned for 2019 that will further help to achieve more equitable waiting times.

For other organs there is a need to match blood groups, but less or no requirement to match tissue types and thus BAME patients can more readily be matched to suitable donors and the waiting times are not longer than for White patients. Transplant rates are also broadly in line with demand as reflected by the transplant waiting lists.

The question thus arises for kidney patients about how, in addition to changes in kidney allocation, donor rates from BAME communities can be increased so that BAME patients can achieve more equitable access to kidney transplantation.

The data in this report show that the number of BAME deceased donors has increased, but numbers are still small: 114 (7%) BAME organ donors in 2017/18. The number of eligible BAME organ donors identified in the Potential Donor Audit indicates little increase in eligible DBD (20%) and 7 additional eligible DCD donors in 2017/18. In contrast there has been a 38% increase in the number of consented/authorised BAME DBD donors (from 64 in 2016/17 to 103 in 2017/18), with one additional consented/authorised BAME DCD donor.

The DBD and DCD consent/authorisation rates for BAME donors have increased by 6% and 4%, since 2013/14, respectively. However, despite these increases, only half as many families support organ donation relative to families of white potential donors.

In terms of living organ donation, the figures show a fall in both Asian and Black living donors, both in terms of absolute numbers of donors and as a proportion of all living organ donors. The reasons for this trend are not clear but living kidney donor transplantation is an important option for those in need of a transplant, particularly as it can mean that months or years of dialysis may be avoided.

While the increase in DCD BAME consent/authorisation rate is very positive for the many BAME patients on the transplant lists, more work needs to be done to further increase the possibilities for transplant for BAME patients. Importantly, the consent/authorisation rates for organ donation in BAME communities need further effort to increase, while the advantages of living kidney donation may also need to be the subject of awareness campaigns.

2 INTRODUCTION

This report provides information related to organ donation and transplantation within the 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 2017/18*. 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 registrants on the NHS Organ Donor Register (ODR), deceased and living organ donors, transplant recipients, patients on the transplant lists and waiting times to transplant. Trends in relation to potential organ donors, including donation consent/authorisation rates[1], 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 is available.**

The information reported is from the last 5 financial years, unless otherwise stated.

3 ORGAN DONOR REGISTER (ODR)

The primary sources of ODR registrations in 2017/18 were the Driver and Vehicle Licensing Agency (50%), online registrations (35%), GP registration[2] (12%), Boots Advantage card (2%) and NHSBT leaflets (1%).

Most sources of registration onto the ODR 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, 34% of registrants to the ODR in 2017/18 have their ethnicity recorded compared to 22% in 2013/14. This increase in reporting is largely due to increased online registrations where ethnicity can be recorded.

Table 1 shows the number of opt-in registrations per year by ethnicity from 1 April 2013 to 31 March 2018. In 2017/18, 92.6% of registrations with ethnicity recorded were from White ethnic groups, 3.3% from Asian, 1.0% from Black, 0.3% from Chinese, 2.0% from Mixed, and 0.7% from other ethnic groups. Ethnicity was not reported for 66% of all registrations. While it is estimated that 10.8% of the current UK population is BAME (using the 2011 census data from the Office for National Statistics (ONS)), only 5.6% of ODR registrants of known ethnicity in 2013/14 were BAME with an increase to 7.2% in 2017/18, reflecting an under-representation of BAME communities on the ODR.

[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

[2] Please note that a back-log of registration activity made via Scottish GP Services is not accounted for in these figures. These registrations will be uploaded in due course and reflected in future reports.

Table 1 Ethnicity of all ODR opt-in registrations by year of registration[1], 1 April 2013 - 31 March 2018

		2013/14		2014/15		2015/16		2016/17		2017/18	
		N	%	N	%	N	%	N	%	N	%
White	British	197,988	87.6	186,072	85.3	395,204	86.9	301,917	84.9	381,028	85.1
	Irish	5,772	2.6	8,235	3.8	12,209	2.7	9,502	2.7	9,929	2.2
	Other	8,573	3.8	10,241	4.7	20,923	4.6	20,140	5.7	23,681	5.3
	Total	**212,333**	**93.9**	**204,548**	**93.7**	**428,336**	**94.2**	**331,559**	**93.2**	**414,638**	**92.6**
Asian	Indian	4,897	2.2	4,775	2.2	7,150	1.6	6,443	1.8	8,726	1.9
	Pakistani	696	0.3	638	0.3	1,242	0.3	1,362	0.4	1,635	0.4
	Bangladeshi	126	<0.1	156	<0.1	339	<0.1	328	0.1	464	0.1
	Other	1,057	0.5	1,195	0.5	2,898	0.6	2,992	0.8	4,096	0.9
	Total	**6,776**	**3.0**	**6,764**	**3.1**	**11,629**	**2.6**	**11,125**	**3.1**	**14,921**	**3.3**
Black	Caribbean	981	0.4	885	0.4	1,655	0.4	1,458	0.4	1,890	0.4
	African	861	0.4	884	0.4	1,725	0.4	1,617	0.5	2,387	0.5
	Other	96	<0.1	122	<0.1	246	<0.1	248	0.1	307	0.1
	Total	**1,938**	**0.9**	**1,891**	**0.9**	**3,626**	**0.8**	**3,323**	**0.9**	**4,584**	**1.0**
Mixed	White/Black Caribbean	425	0.2	403	0.2	853	0.2	2,041	0.6	2,635	0.6
	White/Black African	1,212	0.5	1,128	0.5	2,339	0.5	707	0.2	964	0.2
	White/Asian	1,178	0.5	1,157	0.5	2,429	0.5	2,086	0.6	2,771	0.6
	Other	848	0.4	905	0.4	2,010	0.4	1,812	0.5	2,501	0.6
	Total	**3,663**	**1.6**	**3,593**	**1.6**	**7,631**	**1.7**	**6,646**	**1.9**	**8,871**	**2.0**
Chinese		577	0.3	598	0.3	1,207	0.3	1,114	0.3	1,513	**0.3**
Other		792	0.4	860	0.4	2,142	0.5	1,985	0.6	3,134	**0.7**
Total reported		**226,079**	**100.0**	**218,254**	**100.0**	**454,571**	**100.0**	**355,752**	**100.0**	**447,661**	**100.0**
Not reported	(% not reported)	820,224	(78.4)	763,476	(77.8)	921,336	(67.0)	1,004,320	(73.8)	872,308	(66.1)
TOTAL OPT-IN REGISTRATIONS		**1,046,303**		**981,730**		**1,375,907**		**1,360,072**		**1,319,969**	

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

Given the increase in proportion of 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 registrations, it is possible to see differences relative to the current population of the UK (Appendix, **Table I**). **Table 2** shows data on percentage of the ODR registrations in 2013/14 and 2017/18 against the percentage of the general population.

Table 2 BAME opt-in registrations on the ODR vs the UK population

Ethnicity	2013/14 % of the ODR registrations[1]	2017/18 % of the ODR registrations[1]	2011 % of the population[2]
Asian – Indian	2.2	1.9	2.3
Asian - Pakistani	0.3	0.4	1.6
Asian - Bangladeshi	<0.1	0.1	0.6
Black African	0.4	0.5	1.2
Black Caribbean	0.4	0.4	1.0
Chinese	0.3	0.3	0.7
Mixed race	1.6	2.0	1.7
Other ethnicity	0.4	0.7	1.6
Total BAME	5.6	7.2	10.8

[1] Where ethnicity reported
[2] Source – Office for National Statistics

The data suggest that many BAME groups are poorly represented on the ODR relative to the current UK population.

4 DECEASED ORGAN DONORS, TRANSPLANT RECIPIENTS AND TRANSPLANT WAITING LIST PATIENTS

In this section data capture does not allow for a detailed breakdown of ethnicity. Overall <1% of recipients and donors did not have ethnicity recorded. **This report only includes donors and recipients where ethnicity is reported.**

Figure 1 and **Table 3** demonstrate the proportion of all deceased donors and transplants made up by BAME donors and recipients in the UK in the last five financial years. The proportion of deceased donor transplants for a BAME recipient has increased from 20.2% of transplants in 2013/14 to 22.5% in 2017/18. The proportion of BAME deceased donors in the UK was only 7.3% in 2017/18, however this proportion is higher than the previous five years.

Figure 1 BAME donors and recipients as a percentage of all deceased donors and deceased donor transplant recipients in the UK, 1 April 2013 - 31 March 2018

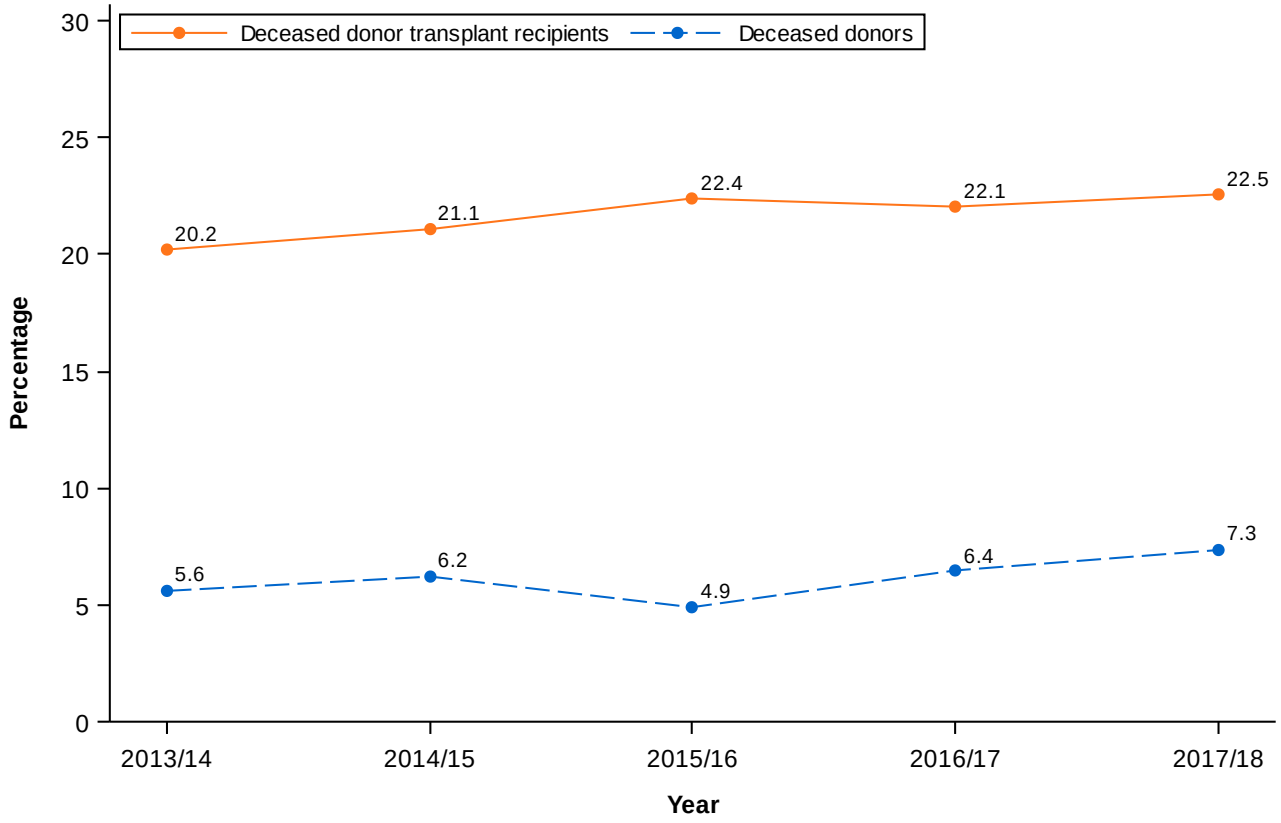


Table 3 **BAME deceased donors and deceased donor transplants in the UK, 1 April 2013 - 31 March 2018, by financial year**

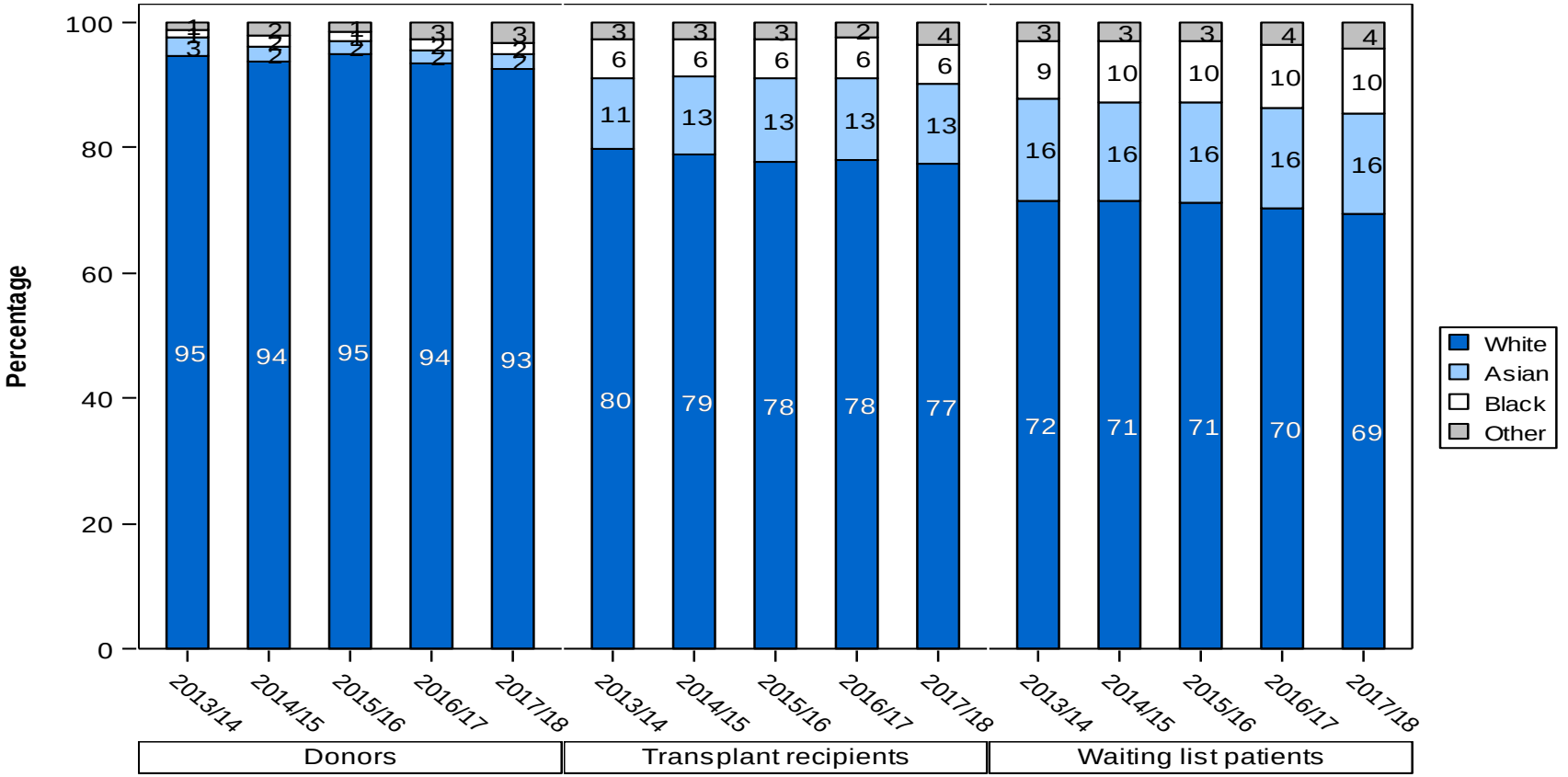
Financial year	Number of BAME recipient transplants	% of total transplants[1]	Number of BAME deceased donors			% of total donors[1]
			DBD	DCD	Total	
2013/14	706	20.2	54	17	71	5.6
2014/15	701	21.1	54	26	80	6.2
2015/16	782	22.4	49	18	67	4.9
2016/17	811	22.1	62	28	90	6.4
2017/18	901	22.5	83	31	114	7.3

[1] Where ethnicity reported

The ethnicity of deceased organ donors and recipients (where ethnicity is known) in each year from 2013/14 to 2017/18 and patients on the transplant list at 31 March each year is shown in **Figure 2** which includes White donors and recipients and **Figure 3** which shows only the ethnic minority groups. The information for all patients (where ethnicity is known) in this time frame is separated by organ in **Figures 4 to 7**.

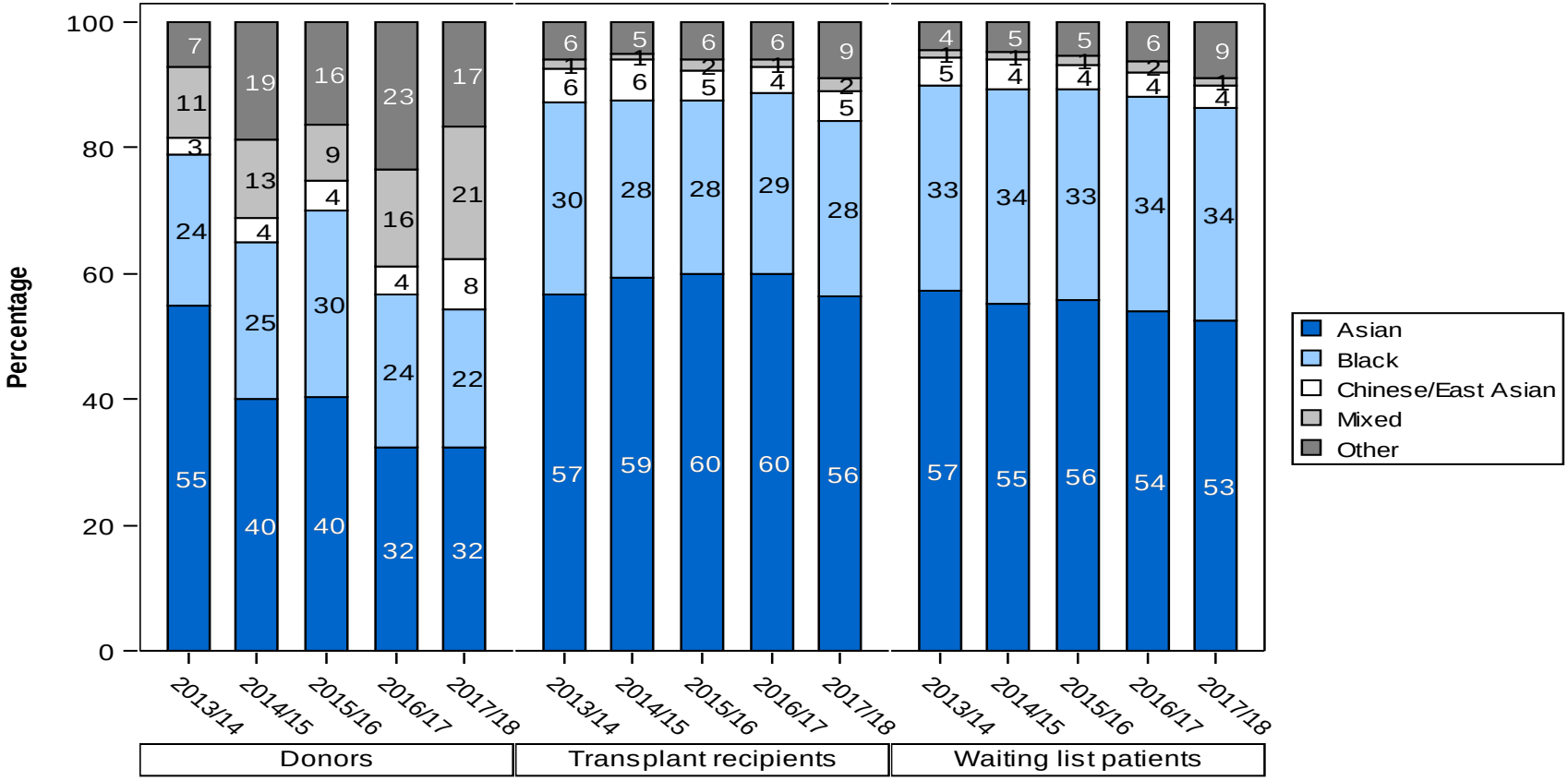
Overall there has been an increase in the number of deceased BAME organ donors over the last 5 years (**Figure 3**) from 71 in 2013/14 to 114 in 2017/18 (61% increase). There has also been a notable increase in the number of transplant recipients from BAME background: an increase of 28% from 706 recipients in 2013/14 to 901 recipients in 2017/18. Alongside the increasing numbers of ethnic minority patients receiving a transplant is a fall in the number of patients on the transplant lists. In 2013/14 there were 1,960 BAME recipients on the waiting list and in 2017/18 the number had decreased by 7% to 1,825. **Figure 2** and **Figure 3** demonstrate that the make-up of the ethnic minority patients listed and transplanted has changed very little over the time period analysed. However, the ethnic-make up for BAME deceased donors has fluctuated (**Figure 3**).

Figure 2 Deceased donors, transplant recipients and patients on the waiting list (as at 31 March) (including White people),1 April 2013 - 31 March 2018



	Donors					Transplant recipients					Waiting list patients				
	2013/14	2014/15	2015/16	2016/17	2017/18	2013/14	2014/15	2015/16	2016/17	2017/18	2013/14	2014/15	2015/16	2016/17	2017/18
White	1245	1202	1296	1308	1441	2784	2615	2711	2865	3097	4946	4878	4553	4430	4130
Asian	39	32	27	29	37	400	417	469	486	508	1123	1082	1026	1009	959
Black	17	20	20	22	25	215	197	216	234	251	637	668	614	634	615
Other	15	28	20	39	52	91	87	97	91	142	200	207	196	222	251

Figure 3 **Deceased donors, transplant recipients and patients on the waiting list (as at 31 March) (excluding White people),1 April 2013 - 31 March 2018**



	Donors					Transplant recipients					Waiting list patients				
	2013/14	2014/15	2015/16	2016/17	2017/18	2013/14	2014/15	2015/16	2016/17	2017/18	2013/14	2014/15	2015/16	2016/17	2017/18
Asian	39	32	27	29	37	400	417	469	486	508	1123	1082	1026	1009	959
Black	17	20	20	22	25	215	197	216	234	251	637	668	614	634	615
Chinese/ East Asian	2	3	3	4	9	39	45	36	32	43	91	88	73	73	68
Mixed	8	10	6	14	24	9	7	14	12	19	21	25	25	33	22
Other	5	15	11	21	19	43	35	47	47	80	88	94	98	116	161

Table 4 is a summary of all deceased donor transplants in 2017/18 by country of transplant, ethnicity of recipient and organ transplanted. 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.

Table 4 Deceased donor transplants, 1 April 2017 - 31 March 2018, by country of transplant and organ

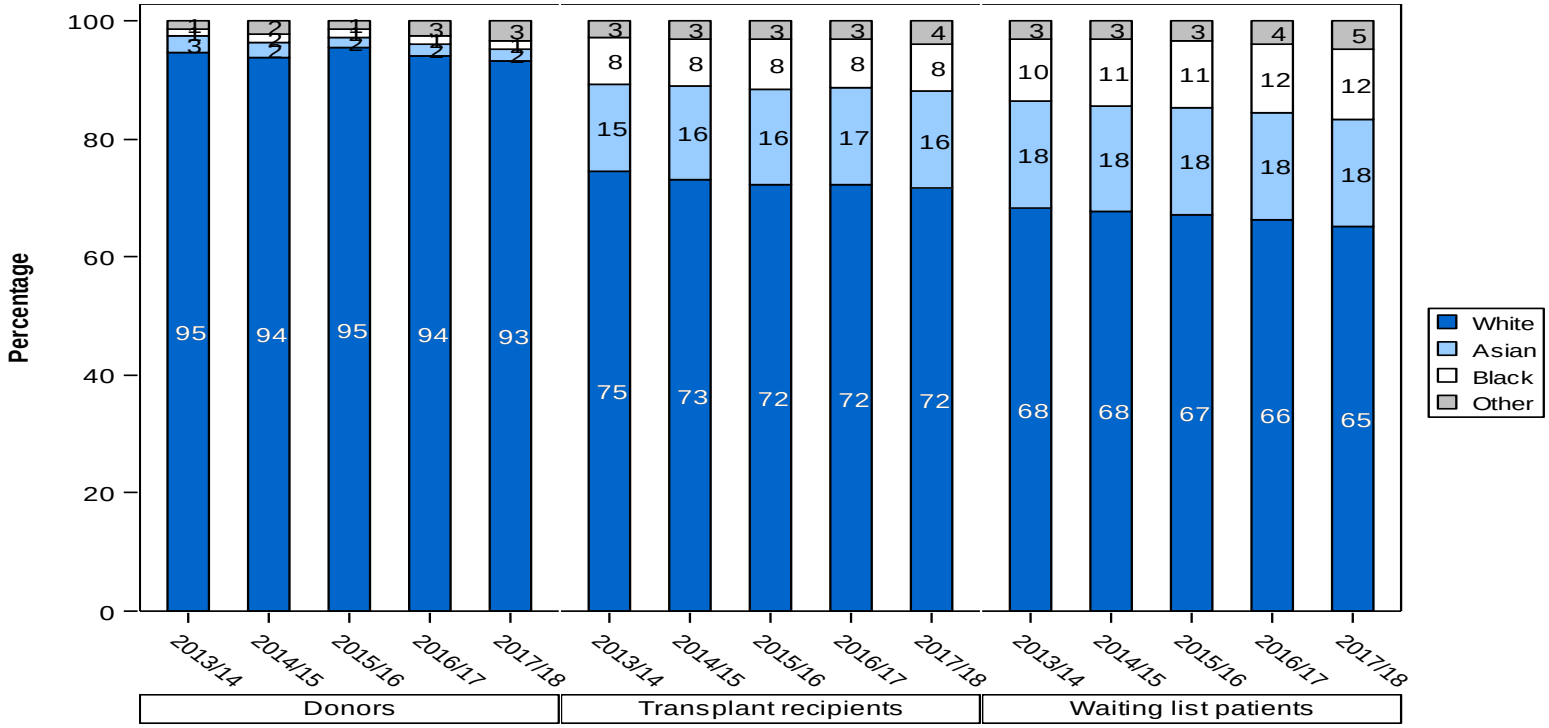
Country of transplant	Transplants (N)								
	Kidney	Pancreas[1]	Kidney/Pancreas[2]	Heart	Lung	Liver	Intestinal	Multiorgan[3]	**Total**
England									
White	1360	26	125	152	190	760	6	43	**2662**
Asian	382	1	14	15	6	59		9	**486**
Black	194		5	15	3	26		2	**245**
Chinese/East Asian	30		1		1	8			**40**
Mixed	11		2	2	1	2			**18**
Other	47			1		28		1	**77**
Wales									
White	43	1	6						**50**
Asian	2								**2**
Black	2								**2**
Mixed	1								**1**
Scotland									
White	188	11	16	11		97			**323**
Asian	13		1			5			**19**
Black	4								**4**
Chinese/East Asian	1					1			**2**
Other	1								**1**
Northern Ireland									
White	63								**63**
Chinese/East Asian	1								**1**
Other	2								**2**

[1] Includes 22 islet transplants
[2] Includes 4 simultaneous islet and kidney transplant
[3] Includes 12 heart/lung transplants, 2 liver, bowel and pancreas transplants, 12 multivisceral transplants, 5 modified multivisceral transplants, 22 liver and kidney transplants, 1 heart and liver transplant and 1 lung and liver transplant.

Kidney statistics

There has been an 46% increase in deceased BAME kidney donors from 68 to 99 donors over the last 5 years, thus representing 7% of all deceased kidney donors with known ethnicity in 2017/18. There has been a slight increase in the proportion of BAME patients registered for a kidney transplant: 32% compared to 35% of all patients on the list at 31 March 2013/14 and 2017/18, respectively. There has also been a small increase in the proportion of BAME patients receiving a kidney transplant: 25% of all kidney transplants in 2013/14 compared with 28% in 2017/18.

Figure 4 Kidney statistics, 1 April 2013 - 31 March 2018

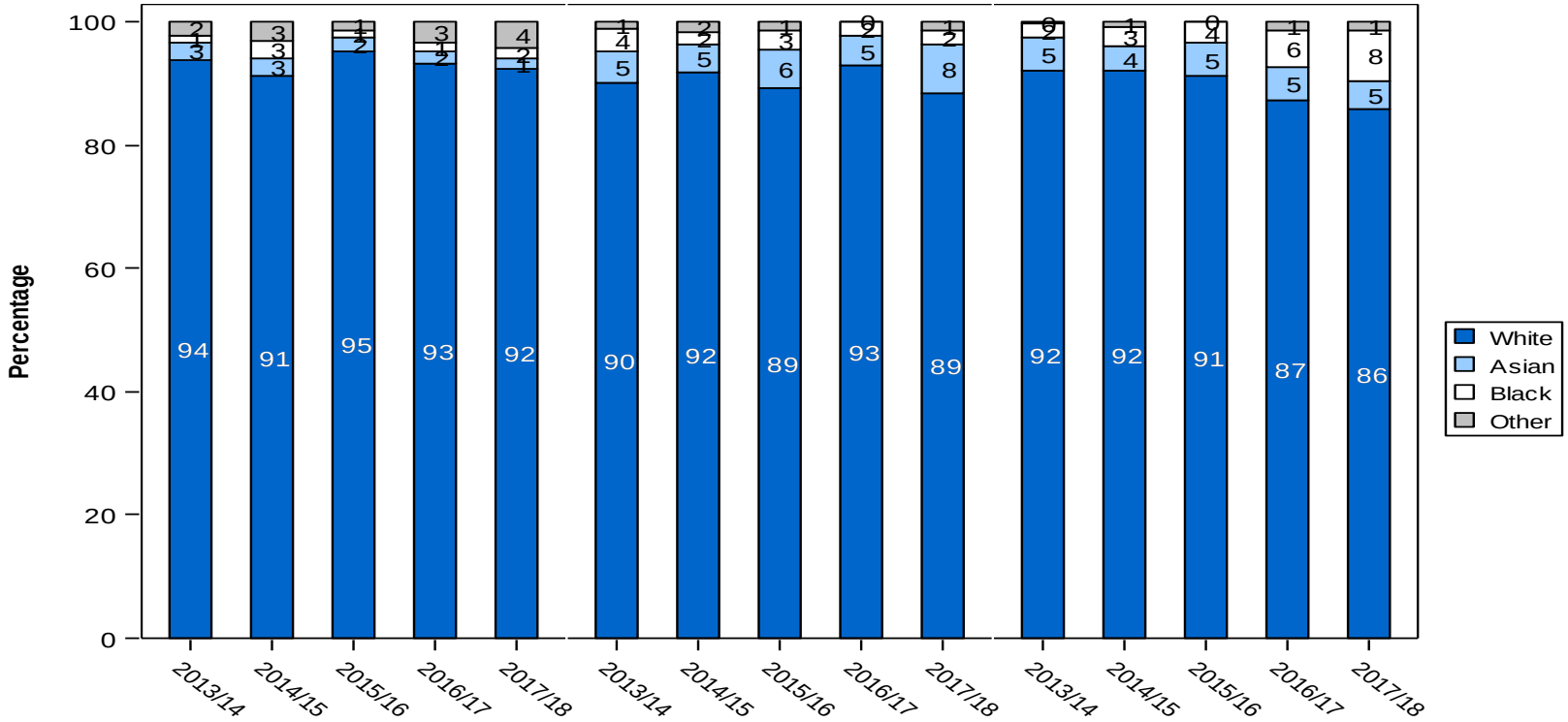


	Donors					Transplant recipients					Waiting list patients				
	2013/14	2014/15	2015/16	2016/17	2017/18	2013/14	2014/15	2015/16	2016/17	2017/18	2013/14	2014/15	2015/16	2016/17	2017/18
White	1174	1130	1232	1243	1363	1592	1497	1589	1661	1815	3942	3785	3487	3416	3223
Asian	35	29	25	27	30	311	328	352	384	417	1039	990	944	923	897
Black	15	19	17	17	19	171	161	184	189	207	605	631	580	600	590
Other	18	26	18	34	50	59	64	71	70	98	182	176	178	204	240

Pancreas and kidney/pancreas statistics

Over the last 5 years the proportion of BAME pancreas donors has remained relatively stable between 5-9% (22-41 donors per year). The number of BAME patients on the pancreas waiting list as at 31 March (including kidney/pancreas patients) has increased from 21 (8%) in 2013/14 to 31 (14%) in 2017/18. The number of BAME pancreas or kidney/pancreas transplant recipients has remained constant at 24 in 2013/14 (10%) and 2017/18 (11%).

Figure 5 Pancreas and kidney/pancreas statistics, 1 April 2013 - 31 March 2018

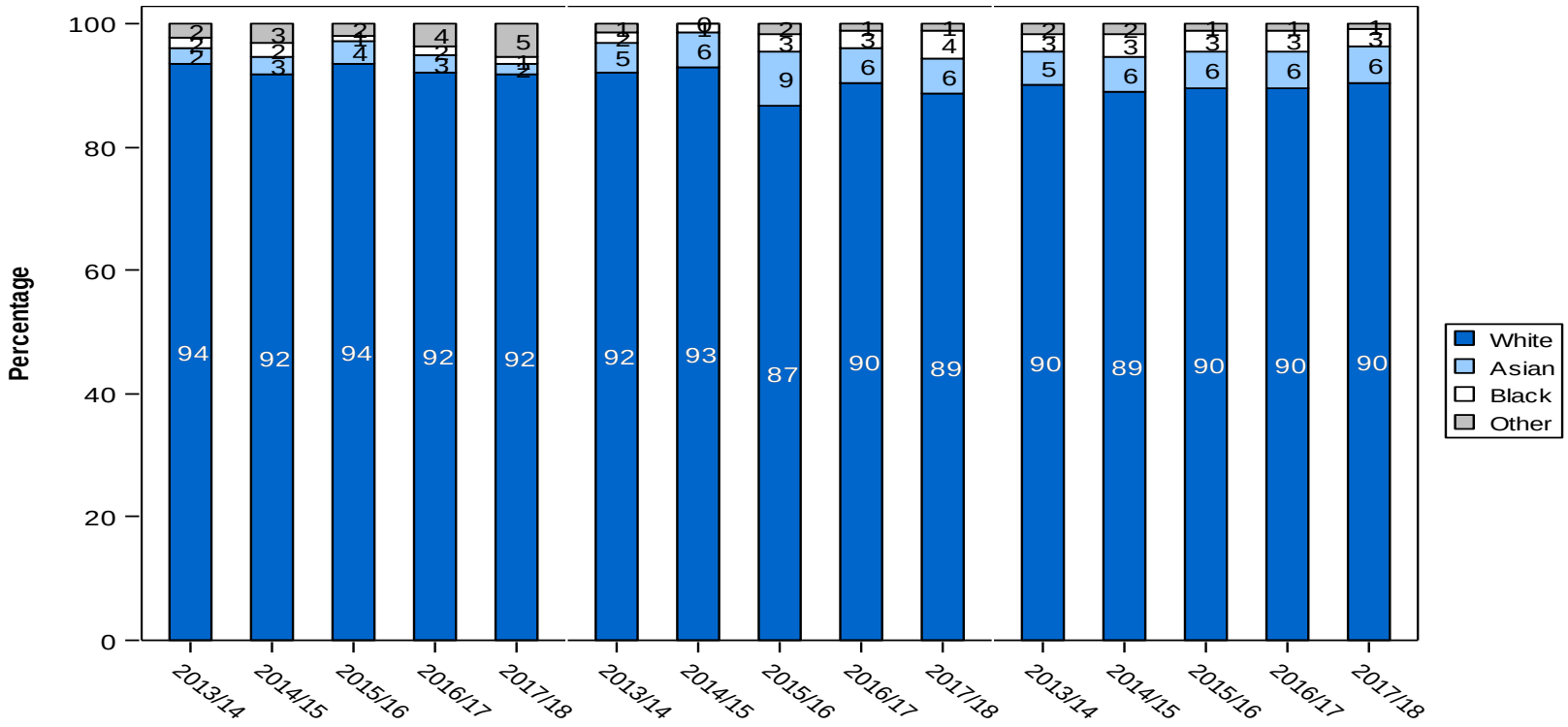


	Donors					Transplant recipients					Waiting list patients				
	2013/14	2014/15	2015/16	2016/17	2017/18	2013/14	2014/15	2015/16	2016/17	2017/18	2013/14	2014/15	2015/16	2016/17	2017/18
White	428	422	445	441	443	220	203	191	194	185	243	230	206	193	187
Asian	13	14	10	9	7	12	10	13	10	16	14	10	12	12	10
Black	5	12	6	7	8	9	4	7	5	5	6	8	8	13	18
Other	10	15	6	16	21	3	4	3	0	3	1	2	0	3	3

Cardiothoracic organ statistics

The proportion of cardiothoracic (heart and/or lung) BAME donors has fluctuated between 6% and 8% of all cardiothoracic organ donors (22-30 donors per year) between 2013/14 and 2017/18. The proportion of cardiothoracic organ transplants for BAME patients has increased from 8% to 11% over the five years, while the proportion of BAME recipients on the waiting list as at 31 March has remained constant at approximately 10%.

Figure 6 Cardiothoracic statistics, 1 April 2013 - 31 March 2018

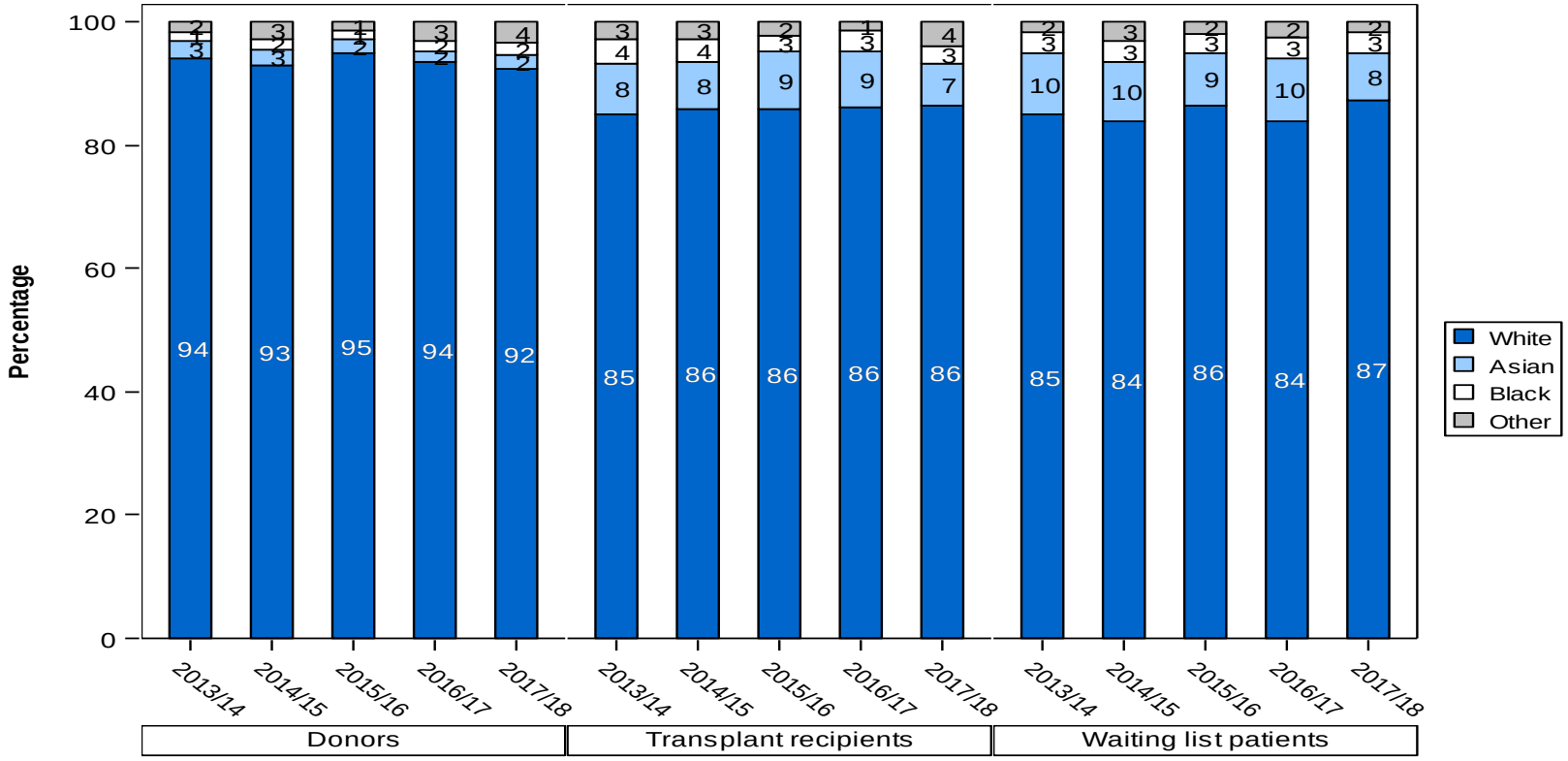


	Donors					Transplant recipients					Waiting list patients				
	2013/14	2014/15	2015/16	2016/17	2017/18	2013/14	2014/15	2015/16	2016/17	2017/18	2013/14	2014/15	2015/16	2016/17	2017/18
White	320	287	303	281	335	377	337	329	340	364	473	534	517	560	577
Asian	8	9	12	8	6	19	21	34	21	24	28	35	34	37	39
Black	6	7	3	5	4	7	5	11	11	18	15	21	19	21	17
Other	8	10	6	11	20	6	0	6	4	5	9	11	7	7	6

Liver statistics

The number of BAME liver donors has increased from 55 in 2013/14 to 87 (58% increase) in 2017/18, while the proportion of BAME liver donors is largely unchanged at 6% to 8%. The proportion of liver transplants that are for BAME patients has remained constant at approximately 14%. The proportion of BAME patients on the liver transplant list as at 31 March has fallen slightly from 15% in 2013/14 to 13% in 2017/18.

Figure 7 Liver statistics, 1 April 2013 - 31 March 2018



	Donors					Transplant recipients					Waiting list patients				
	2013/14	2014/15	2015/16	2016/17	2017/18	2013/14	2014/15	2015/16	2016/17	2017/18	2013/14	2014/15	2015/16	2016/17	2017/18
White	876	858	958	964	1048	748	723	753	815	873	466	512	505	445	309
Asian	27	25	22	17	25	72	65	83	84	69	55	60	50	54	27
Black	13	16	15	18	22	34	30	22	32	28	19	20	18	18	12
Other	15	25	15	31	40	25	24	20	14	40	9	19	11	13	6

Waiting times to transplant

Median waiting times (in months) are provided for adult and paediatric patients for each organ to transplant in **Table 5**. This shows longer waiting times for ethnic minority patients to receive a kidney transplant: adult White patients have an average (median) waiting time of 723 days (approximately 2 years), whereas adult Asian and Black patients have median waiting times of around 2½, 891 days and 985 days respectively. These waiting times are shorter than reported six years ago (for patients registered 2005-2009): waiting times then were 3 years for White patients and 4 years for all minority ethnic groups. Minority paediatric kidney patients also wait longer for transplant, while minority pancreas patients wait a shorter time than white patients. For cardiothoracic organ transplants the small number of minority patients registered for urgent heart transplantation does not lead to meaningful estimates of waiting times, however Black 'ever urgent' heart patients wait on average 44 days longer than White 'ever urgent' heart patients. The longest median waiting time for adult lung recipients is for Asian patients at 1191 days (approximately 3 years), while White patients only wait on average approximately 8 ½ months (261 days). Finally, for liver transplantation, Asian and White patients both wait approximately 4 months, while Black patients wait an average of 5 months for transplant.

Median waiting times are determined by including all patients joining the list in a given time period and using Kaplan-Meier survival estimates to allow the inclusion of patients not transplanted 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.

Table 5 Median waiting time to transplant in the UK

Ethnicity	Number of patients registered	Waiting time (days) Median	95% Confidence interval
Adult kidney[1]			
White	6492	723	703 - 743
Asian	1515	891	846 - 936
Black	879	985	926 - 1044
Other	274	871	796 - 946
TOTAL	**9303**	**782**	**764 - 800**
Paediatric kidney[1]			
White	143	228	176 - 280
Asian	68	366	209 - 523
Black	18	323	0 - 668
Other	10	498	181 - 815
TOTAL	**243**	**277**	**212 - 342**
Adult pancreas[2]			
White	870	353	334 - 372
Asian	57	279	204 - 354
Black	42	316	220 - 412
Other	13	278	78 - 478
TOTAL	**997**	**348**	**332 - 364**
Adult never urgent heart[1]			
White	321	1280	707 - 1853
Asian	17	344	188 - 500
Black[5]	15	-	-
Other	7	-	-
TOTAL[6]	**361**	**1065**	**548 - 1582**
Adult ever urgent heart[1,4]			
White	494	27	23 - 31
Asian	41	43	29 - 57
Black	16	71	64 - 78
Other	12	38	24 - 52
TOTAL	**568**	**29**	**25 - 33**
Paediatric never urgent heart[1]	**32**	**463**	**0 - 1642**
Paediatric ever urgent heart[1,4]	**160**	**70**	**46 - 94**
Adult lung[1]			
White	1027	261	227 - 295
Asian	38	1191	284 - 2098
Black	11	603	385 - 821
Other	5	-	-
TOTAL	**1087**	**274**	**239 - 309**
Adult liver[3]			
White	2376	132	121 - 143
Asian	199	118	93 - 143
Black	78	150	51 - 249
Other	51	75	34 - 116
TOTAL	**2706**	**130**	**120 - 140**
Paediatric liver[3]	**214**	**107**	**79 - 135**

Number of registered patients may not add up to totals, as ethnicity might not be reported for all patients
Median waiting times are not reported for fewer than 10 patients
[1] Patients registered 1 April 2011 - 31 March 2015
[2] Patients registered 1 April 2012 - 31 March 2016
[3] Patients registered 1 April 2013 - 31 March 2016
[4] Urgent waiting time only
[5] Median and/or 95% confidence interval cannot be estimated

5 LIVING DONORS AND RECIPIENTS

The ethnicities of living organ donors and recipients in each year from 2013/14 to 2017/18 are shown in **Figures 8** and **9.** The information for living donors is summarised below in **Table 6**.

Kidneys represent the vast majority of living organs donated and transplanted. The figures show an overall fall in living donation in both Asian and Black communities, both in terms of absolute numbers of donors and as a proportion of all living organ donors. The reasons for these trends are not clear.

There has been a total of about 490 non-directed, altruistic kidney donors in the UK in the last 5 years. These living donors donate a kidney to someone not known to them to help transform or save a life. Four of these donors were Asian with a further two mixed race altruistic donors.

In 2017/18, there were more *living* BAME donors (133) than *deceased* BAME donors (114). While for transplant recipients, in 2017/18 there were fewer BAME living donor transplant recipients (168, 16% of all living donor transplant recipients) compared to BAME deceased donor recipients (901, 22.5% of all deceased donor transplant recipients).

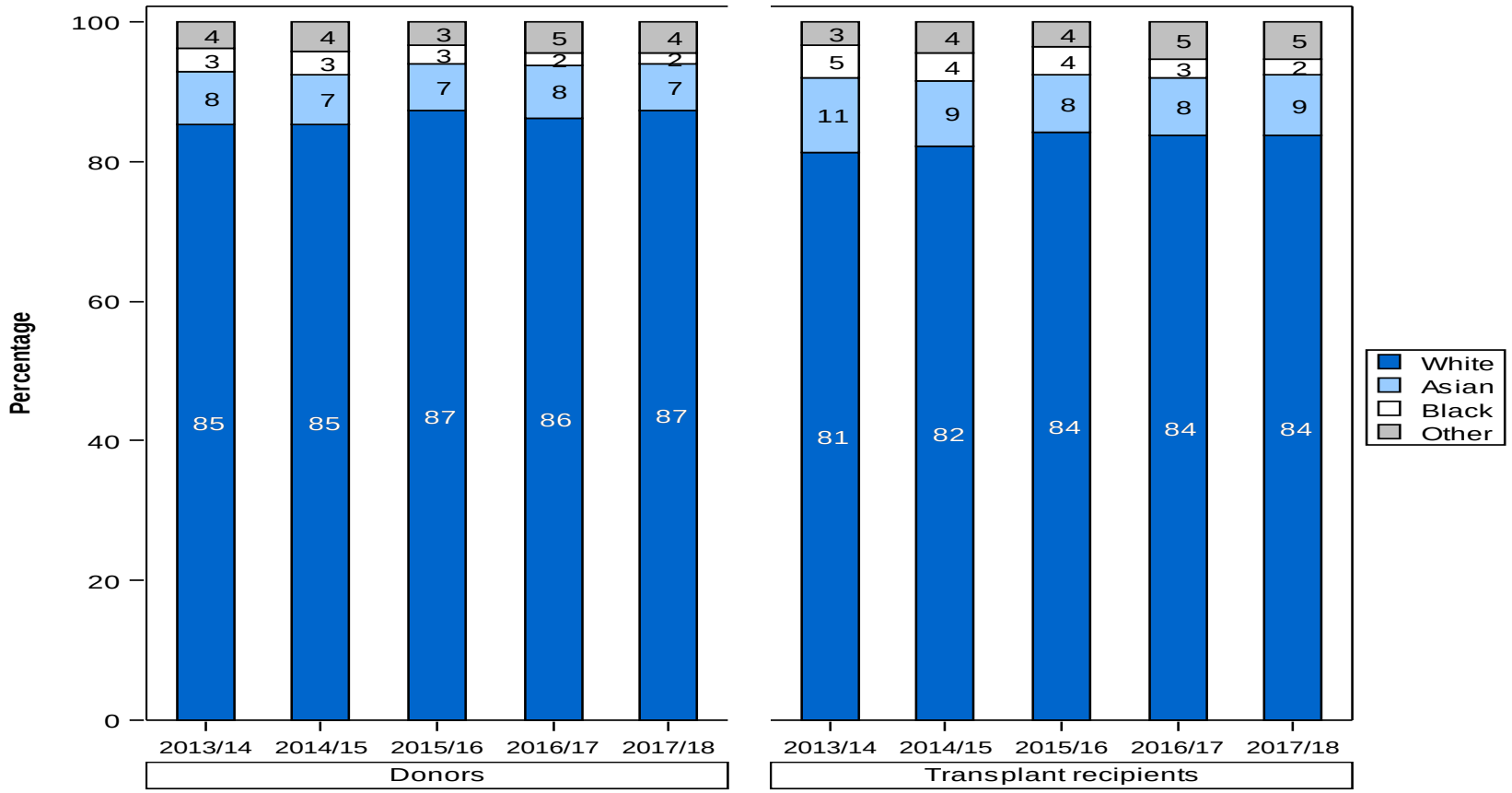
Table 6 **BAME living donors as a percentage of total living donors in the UK, 1 April 2013 - 31 March 2018, by financial year**

Financial year	Asian N	Asian % of total living donors[1]	Black N	Black % of total living donors[1]	Other N	Other % of total living donors[1]
2013/14	87	7.6	38	3.3	44	3.8
2014/15	76	7.0	38	3.5	45	4.1
2015/16	72	6.7	29	2.7	36	3.3
2016/17	79	7.6	17	1.6	47	4.5
2017/18	69	6.6	17	1.6	47	4.5

[1] Where ethnicity reported

Figure 8 shows all living donors and living donor transplant recipients and demonstrates that about 13% of living donors are BAME in 2017/18, with a higher proportion (16%) of living donor recipients from BAME groups.

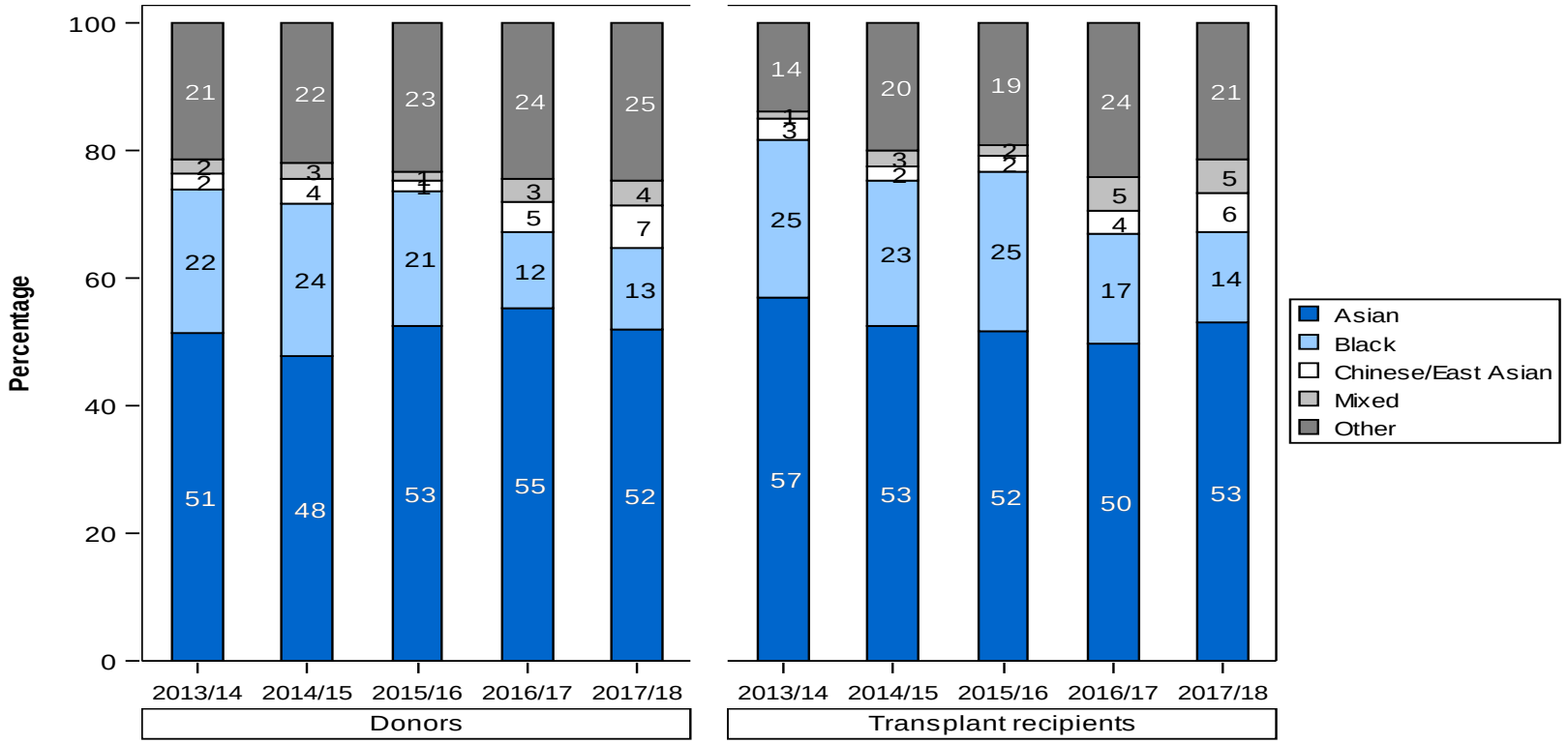
Figure 8 Living donors and transplant recipients, 1 April 2013 - 31 March 2018



	Donors					Transplant recipients				
	2013/14	2014/15	2015/16	2016/17	2017/18	2013/14	2014/15	2015/16	2016/17	2017/18
White	977	929	939	899	915	904	879	892	868	865
Asian	87	76	72	79	69	118	100	87	84	89
Black	38	38	29	17	17	51	43	42	29	24
Other	44	45	36	47	47	38	47	39	55	55

Figure 9 shows only BAME donors and transplant recipients. There has been a noticeable decrease in the number of Black and Asian living donors and patients receiving a living donor transplant from 2013/14-2017/18, but an overall increase in the number of other BAME donors and recipients. The reason for these trends is not known.

Figure 9 Living donors, transplant recipients (excluding White people), 1 April 2013 - 31 March 2018



	Donors					Transplant recipients				
	2013/14	2014/15	2015/16	2016/17	2017/18	2013/14	2014/15	2015/16	2016/17	2017/18
Asian	87	76	72	79	69	118	100	87	84	89
Black	38	38	29	17	17	51	43	42	29	24
Chinese/ East Asian	4	6	2	7	9	7	4	4	6	10
Mixed	4	4	2	5	5	2	5	3	9	9
Other	36	35	32	35	33	29	38	32	40	36

6 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 representative approached for formal organ donation discussion where consent/authorisation was ascertained.

Figures 10 and 11 show an overview of the number of eligible donors, and eligible donors with consent ascertained, over time for White and BAME groups for the DBD and DCD donation processes, respectively.

Figure 10 shows an increase in the eligible pool of potential White DBD donors (and consequently in consented White donors), with a small such increase for BAME DBD donors.

In eligible DCD donors, **Figure 11** shows a small increase for White eligible donors but little change elsewhere.

Figure 10 Eligible DBD donors and eligible consented/authorised DBD donors by ethnic origin, 1 April 2013 – 31 March 2018

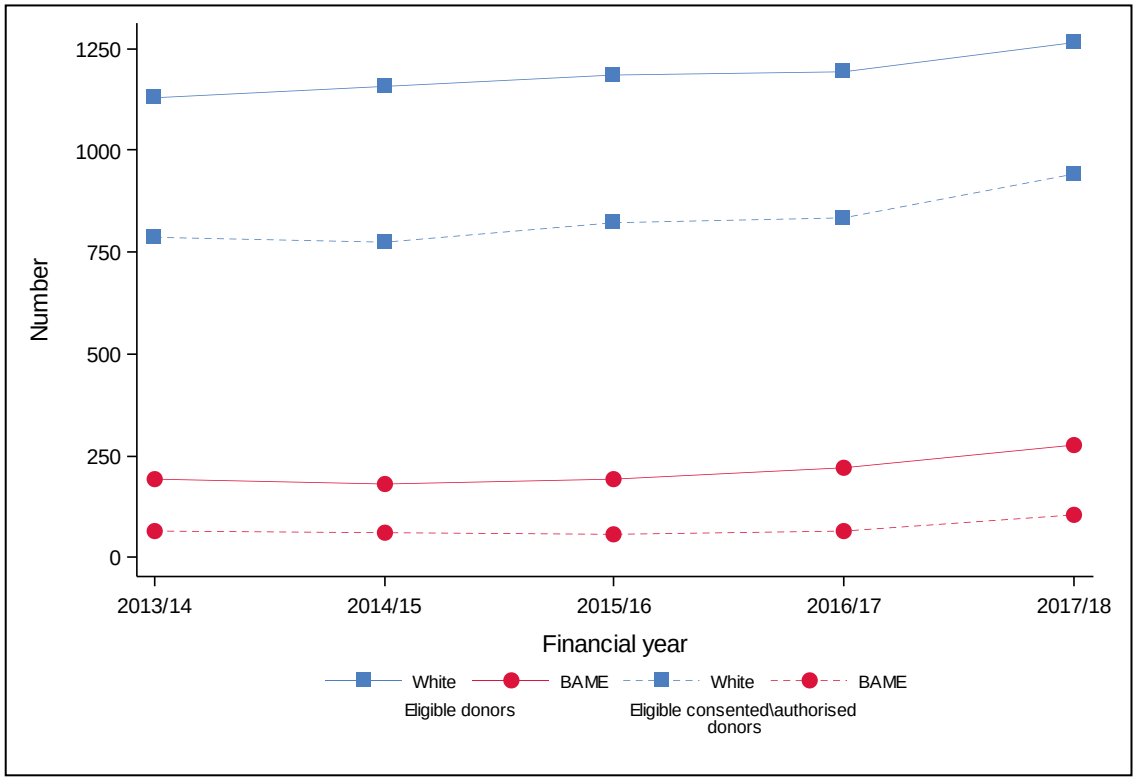


Figure 11 Eligible DCD donors and eligible consented/authorised DCD donors by ethnic origin, 1 April 2013 – 31 March 2018

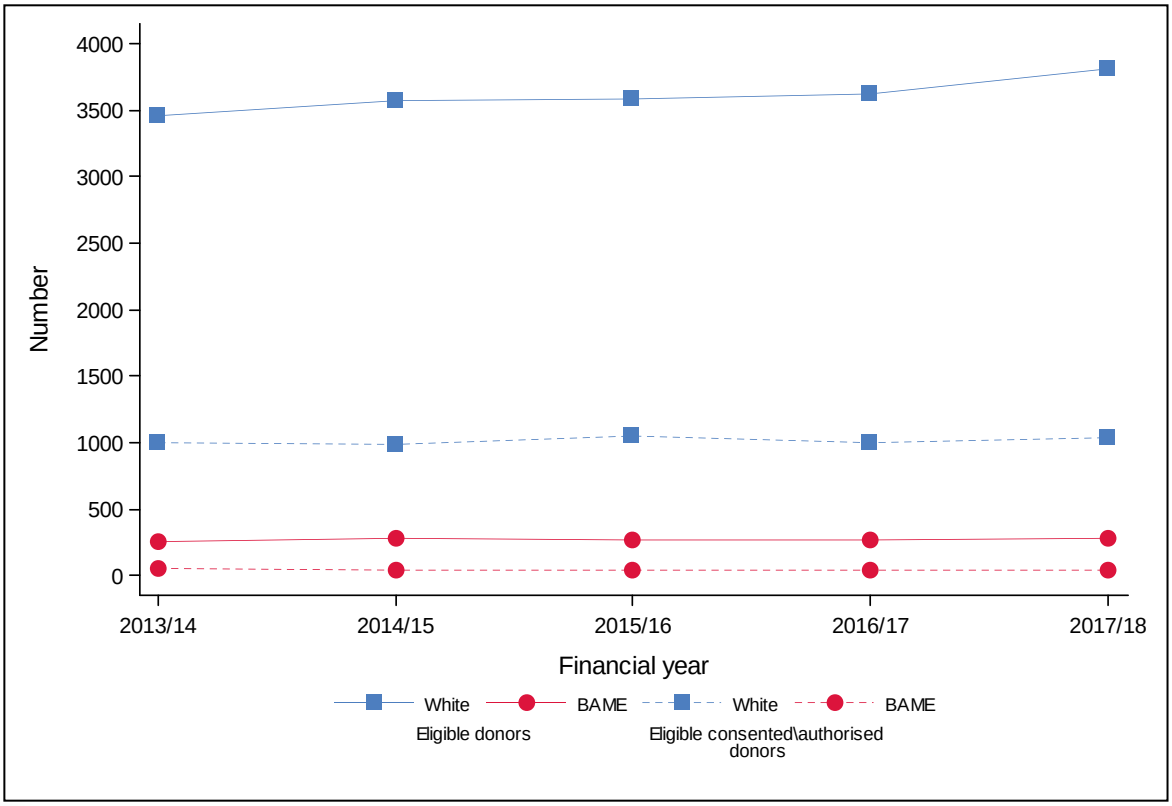


Table 7 shows the consent/authorisation rates separately for White patients and patients from ethnic minority groups broken down by the Organ Donation Services Teams (ODSTs) in the UK.

Table 7 DBD and DCD consent/authorisation rates from the Potential Donor Audit, 1 April 2017 to 31 March 2018, by Organ Donation Services Team (ODST) and ethnicity

	White eligible donors					Eligible donors from ethnic minority groups					All
ODST	Number of eligible DBD donors whose family were approached	DBD consent/ authorisation rate (%)	Number of eligible DCD donors whose family were approached	DCD consent/ authorisation rate (%)	Overall consent/ authorisation rate (%)	Number of eligible DBD donors whose family were approached	DBD consent/ authorisation rate (%)	Number of eligible DCD donors whose family were approached	DCD consent/ authorisation rate (%)	Overall consent/ authorisation rate (%)	Overall consent/ authorisation rate (%) [1]
Eastern	127	81.1	218	66.1	**71.6**	19	52.6	17	47.1	**50.0**	**69.4**
London	140	70.0	130	61.5	**65.9**	123	48.0	36	33.3	**44.7**	**57.5**
Midlands	119	78.2	220	61.4	**67.3**	19	21.1	19	36.8	**28.9**	**63.2**
North West	198	82.8	204	63.7	**73.1**	14	42.9	5	-	**31.6**	**70.5**
Northern	70	72.9	116	57.8	**63.4**	3	-	3	-	**-**	**62.9**
Northern Ireland	38	68.4	35	60.0	**64.4**	1	-	1	-	**-**	**66.2**
Scotland	83	78.3	148	48.0	**58.9**	6	-	3	-	**-**	**56.6**
South Central	83	80.7	135	62.2	**69.3**	6	-	8	-	**50.0**	**66.9**
South East	120	80.8	116	65.5	**73.3**	27	44.4	8	-	**42.9**	**69.3**
South Wales	48	83.3	68	72.1	**76.7**	0		1	-	**-**	**70.5**
South West	81	81.5	113	58.4	**68.0**	3	-	3	-	**-**	**66.7**
Yorkshire	97	74.2	167	70.7	**72.0**	14	21.4	8	-	**40.9**	**69.7**
TOTAL	**1204**	**78.2**	**1670**	**62.3**	**69.0**	**235**	**43.8**	**112**	**37.5**	**41.8**	**65.5**

[1] Includes 108 families approached where the ethnicity was not known or not reported.
Consent/authorisation rates not reported where N<10

Tables II and III in the Appendix show more detailed data by ethnic group from both the DBD and DCD organ donation processes, respectively. The data in these tables are used to produce **Figures 12** to **14**.

Figure 12 shows the neurological death testing rate over time for White and BAME potential DBD donors. There are no distinct differences for White and BAME potential donors in terms of neurological death testing, though overall over the last 5 years, the neurological death testing rate has increased.

Figure 12 Neurological death testing rate by ethnic origin (DBD only), 1 April 2013 – 31 March 2018

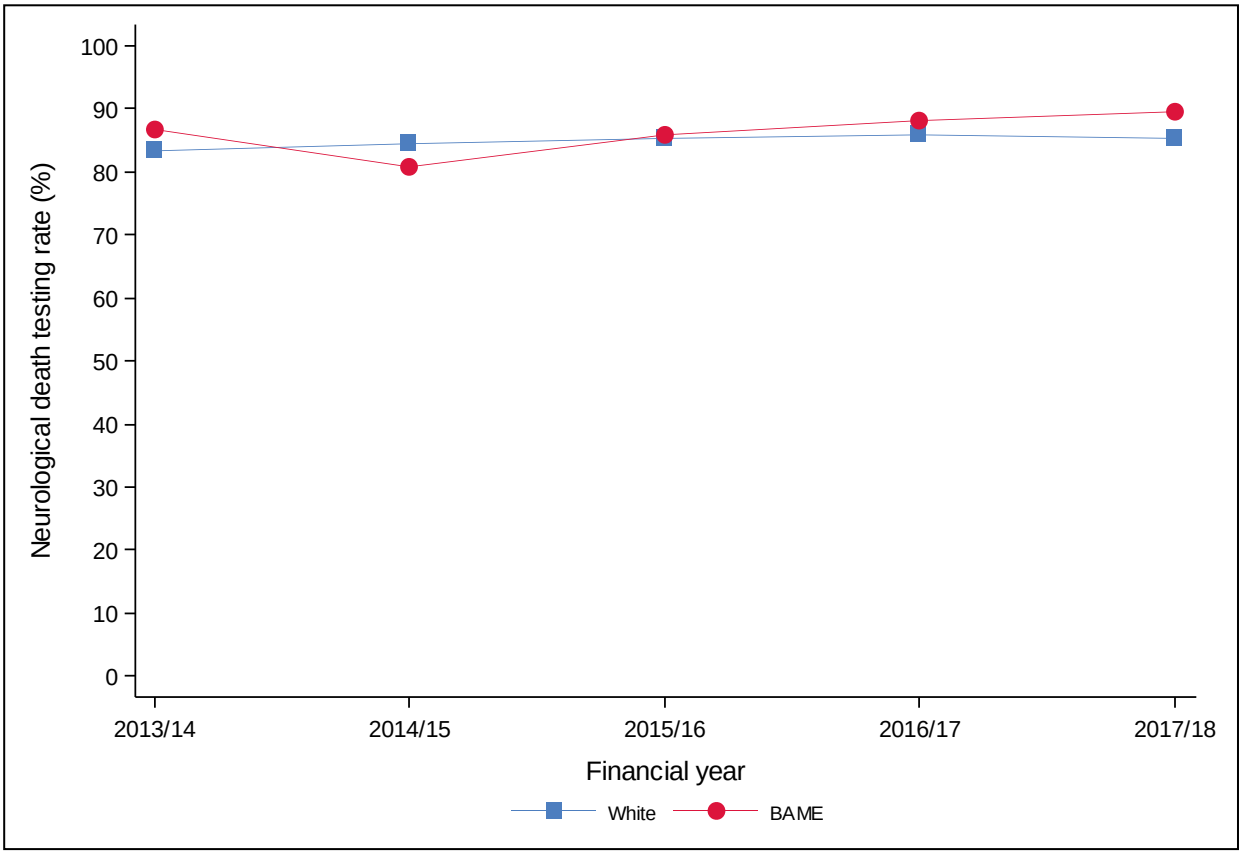


Figure 13 presents the DBD and DCD referral rates for White and minority ethnic groups. There has been an increase in the referral of BAME potential DCD donors to a SN-OD (from around 77% to 92%), a similar rise has occurred for potential White DCD donors. The BAME DCD referral rate now exceeds the White (92% and 90% respectively). The referral rates for both BAME and White potential DBD donors are now 99%.

Figure 14 shows consent/authorisation rates and demonstrates an increase across the board, but most noticeably for BAME DBD donors: 38% in 2013/14 rising to 44% in 2017/18.

Figure 13 Referral rate by ethnic origin, 1 April 2013 – 31 March 2018

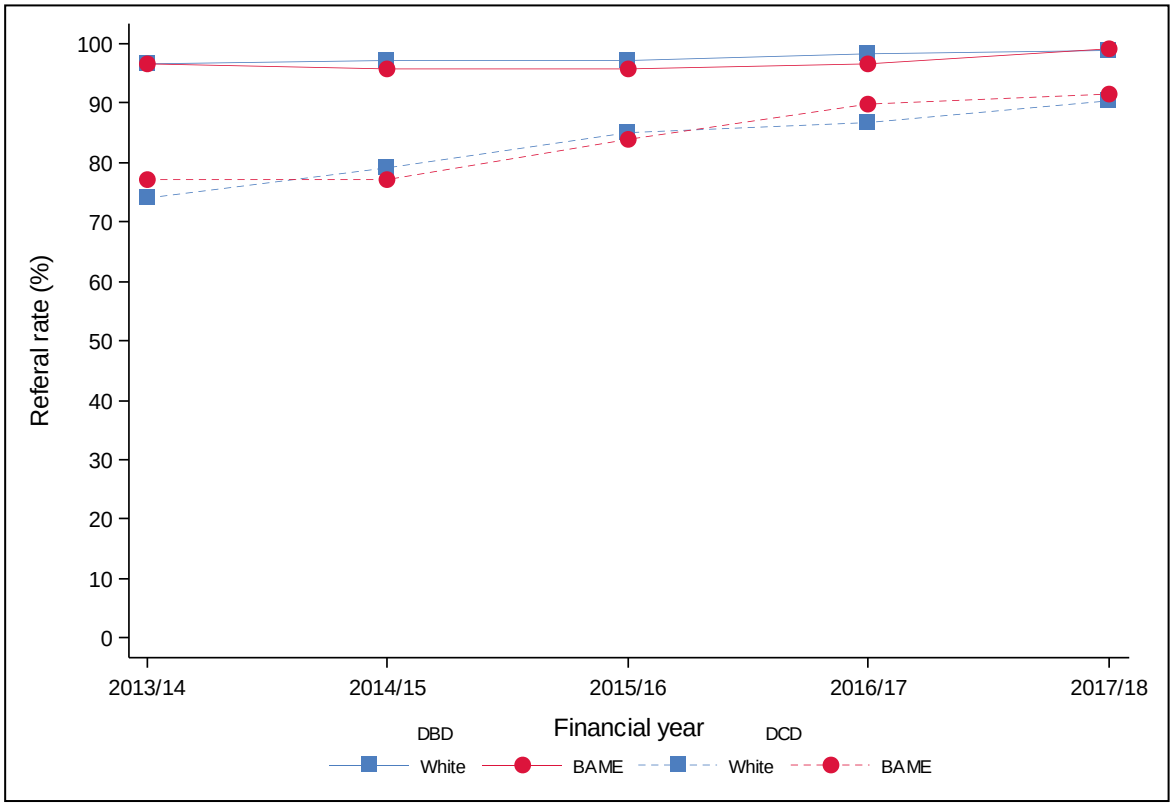
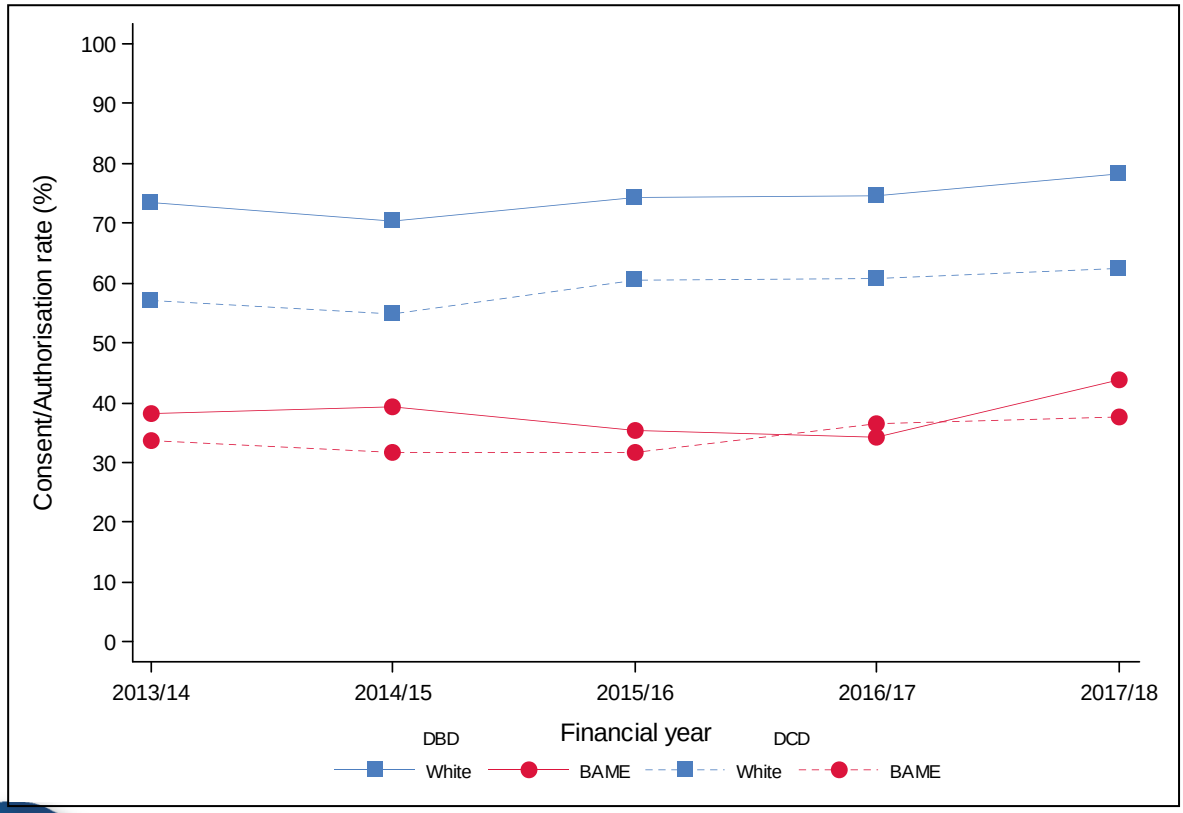


Figure 14 Consent/authorisation rate by ethnic origin, 1 April 2013 – 31 March 2018



Overall, the data show that, in general, families of BAME eligible donors are much less likely to agree to organ donation. Only about half as many families of BAME eligible donors support organ donation compared with families of White eligible donors: DBD - 78% White vs 44% BAME and DCD - 62% White vs 38% BAME in 2017/18. Overall, there has been some increase in consent/authorisation rates for White and BAME eligible donors since 2013/14; this is most notable for BAME DBD donors (38% to 44% over five years).

APPENDIX

Table I UK population by ethnicity, mid-2011 estimates (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**
Indian	1,438	2.3
Pakistani	1,041	1.6
Bangladeshi	377	0.6
Other Asian	378	0.6
Total Asian	**3,234**	**5.1**
Black Caribbean	649	1.0
Black African	792	1.2
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 Ethnic	515	0.8
Total Other	**2,030**	**3.2**
TOTAL	**63,533**	**100.0**

Source - Office for National Statistics

Table II National data from the NHSBT Potential Donor Audit for donation after brain death, 1 April 2013 – 31 March 2018[1]

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 (%)
	White	1420	1182	83.2	1371	96.5	1068	786	73.6
2013/14	BAME	242	210	86.8	234	96.7	168	64	38.1
	Unknown	55	31	56.4	33	60	22	7	31.8
	White	1436	1214	84.5	1394	97.1	1100	775	70.5
2014/15	BAME	236	191	80.9	226	95.8	155	61	39.4
	Unknown	62	40	64.5	51	82.3	29	23	79.3
	White	1459	1244	85.3	1418	97.2	1108	822	74.2
2015/16	BAME	233	200	85.8	223	95.7	164	58	35.4
	Unknown	55	33	60	43	78.2	24	11	45.8
	White	1446	1243	86	1420	98.2	1117	833	74.6
2016/17	BAME	272	240	88.2	263	96.7	187	64	34.2
	Unknown	69	49	71	57	82.6	35	29	82.9
	White	1564	1336	85.4	1645	98.8	1204	942	78.2
2017/18	BAME	322	288	89.4	319	99.1	235	103	43.8
	Unknown	68	52	76.5	64	94.1	32	21	65.6

[1]All 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 2013 – 31 March 2018[1]**

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 (%)
	White	5859	4341	74.1	1763	1005	57
2013/14	BAME	432	333	77.1	140	47	33.6
	Unknown	910	435	47.8	89	21	23.6
	White	5539	4381	79.1	1806	988	54.7
2014/15	BAME	481	371	77.1	123	39	31.7
	Unknown	741	404	54.5	90	19	21.1
	White	5469	4644	84.9	1743	1055	60.5
2015/16	BAME	413	347	84	120	38	31.7
	Unknown	618	411	66.5	79	20	25.3
	White	5245	4545	86.7	1655	1004	60.7
2016/17	BAME	407	366	89.9	112	41	36.6
	Unknown	581	425	73.1	67	24	35.8
	White	5356	4837	90.3	1670	1041	62.3
2017/18	BAME	388	355	91.5	112	42	37.5
	Unknown	537	423	78.8	76	32	42.1

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