

Developing BAME Aspects of the Organ Donation and Transplantation Strategy

What do the data tell us?

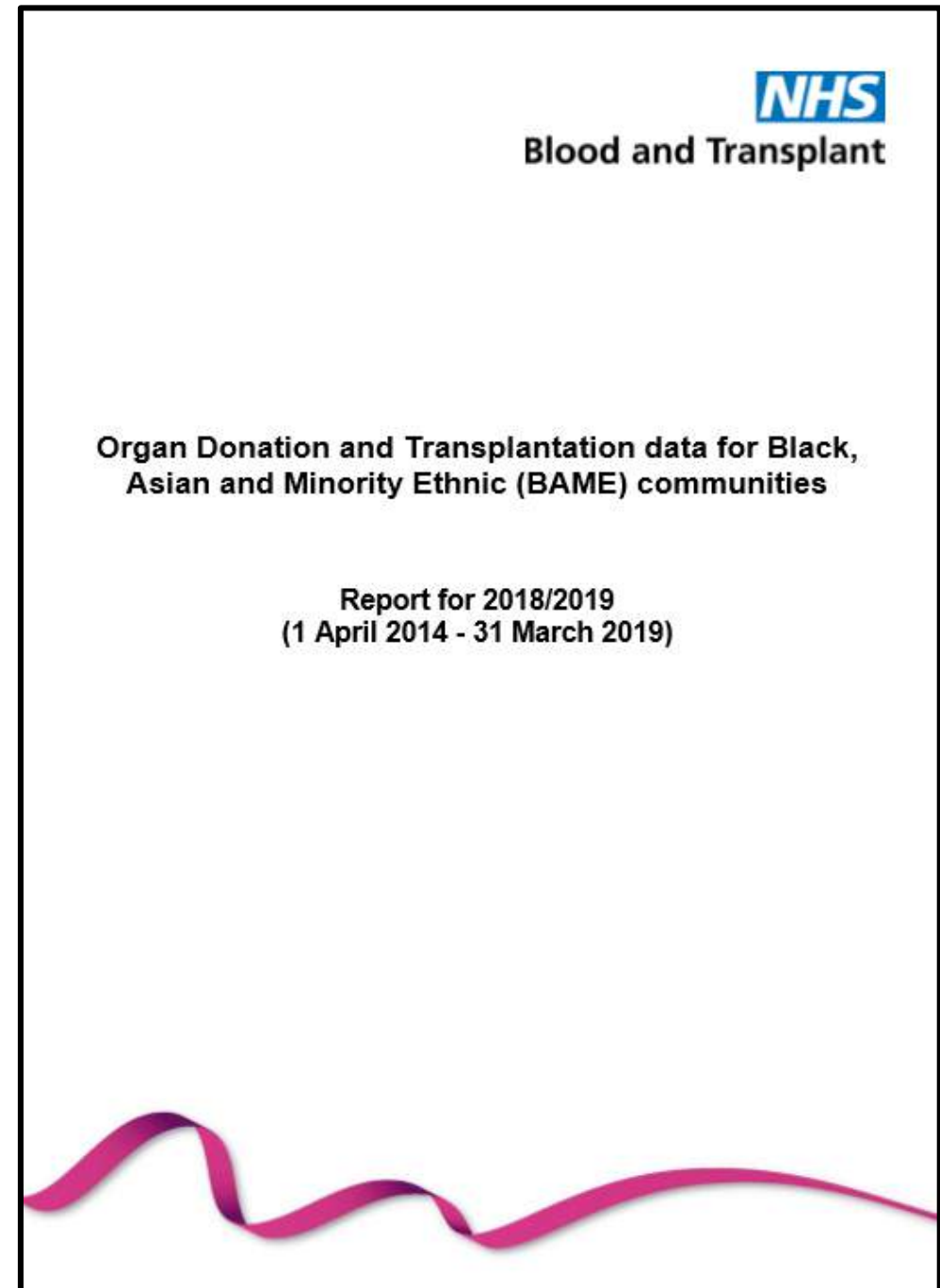
Improving data on ethnicity and religion



Yes I donate
ORGAN DONATION

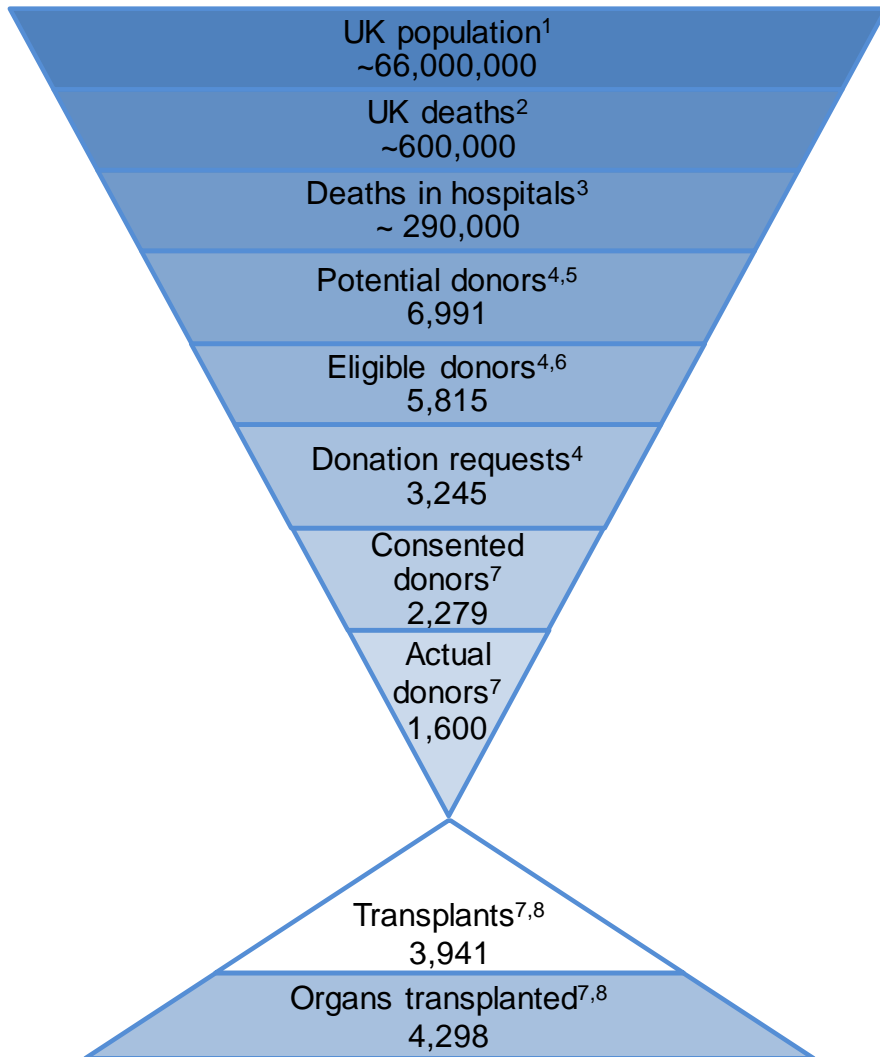
What do the data tell us?

NHSBT BAME report at www.odt.nhs.uk



Overview of organ donation and transplantation in the UK

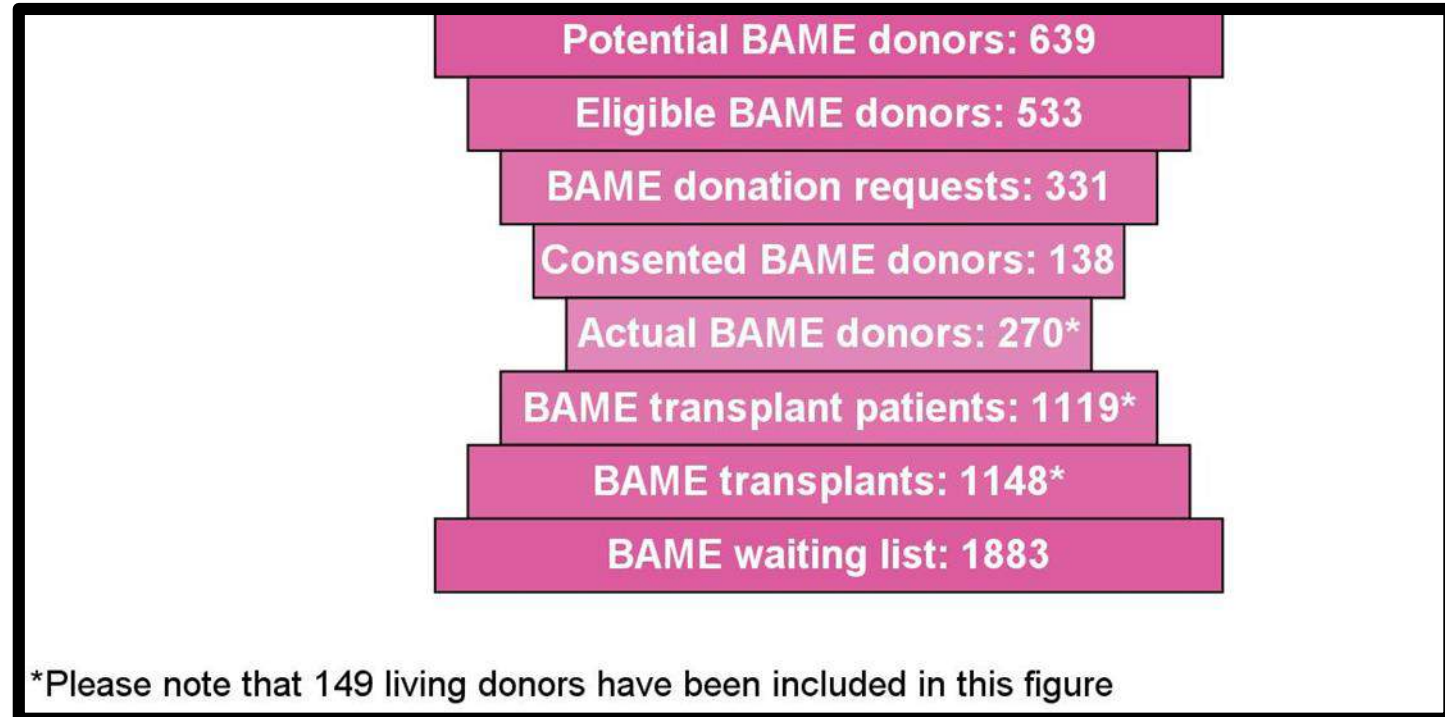
Overview



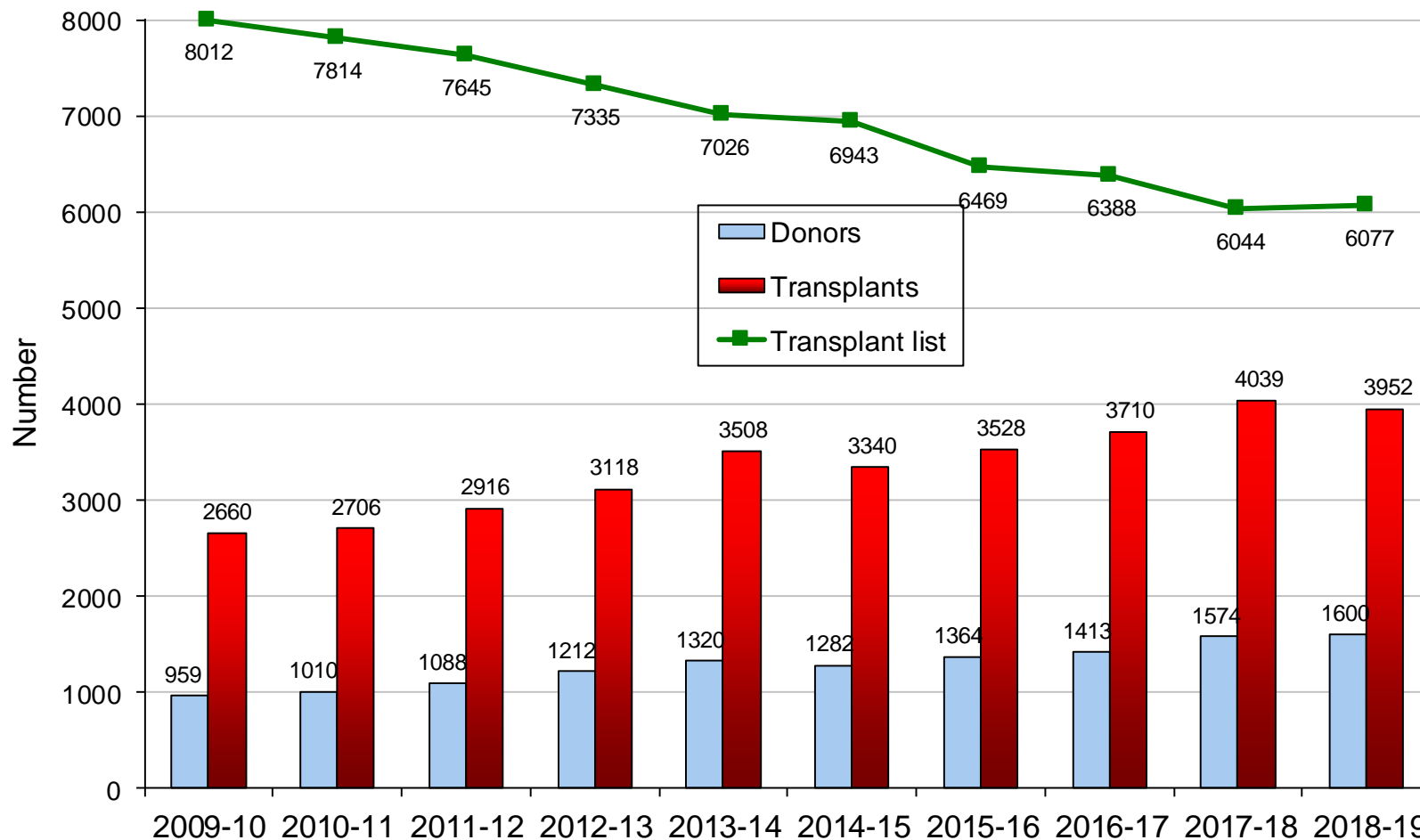
Only about 6,000 of 600,000 (1%) people who die each year, die in circumstances suitable to become organ donors

Of these, 1,600 (27%) became organ donors in 2018/19

These organ donors enabled approx. 4,000 deceased donor transplants to happen



All patients - Deceased donors, transplants and transplant waiting list



Over the last ten years

24% fall in waiting lists

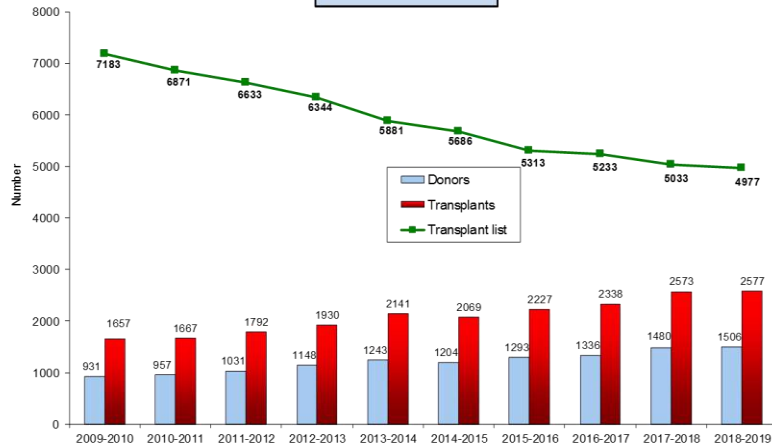
49% increase in transplants (all organs)

67% increase in deceased organ donors

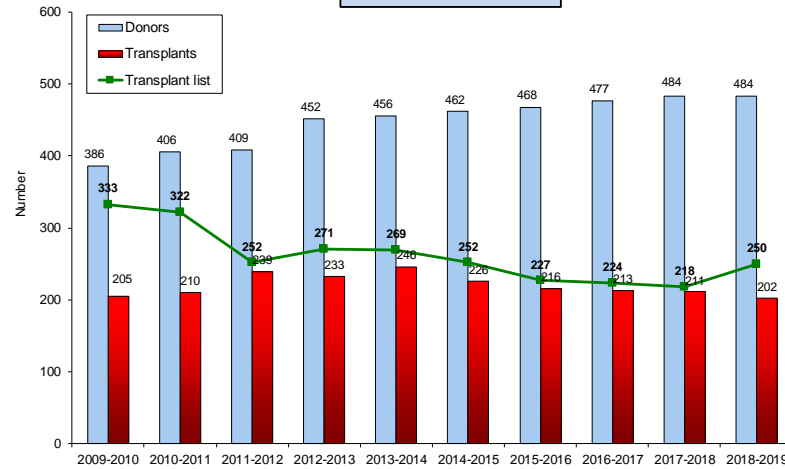
98% increase in donors since Organ Donation Task Force 12 years ago

All patients - Deceased donors, transplants and transplant lists

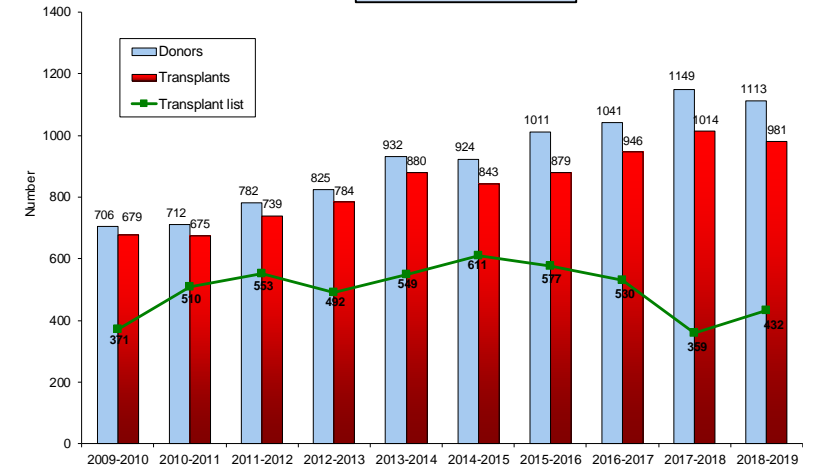
KIDNEY



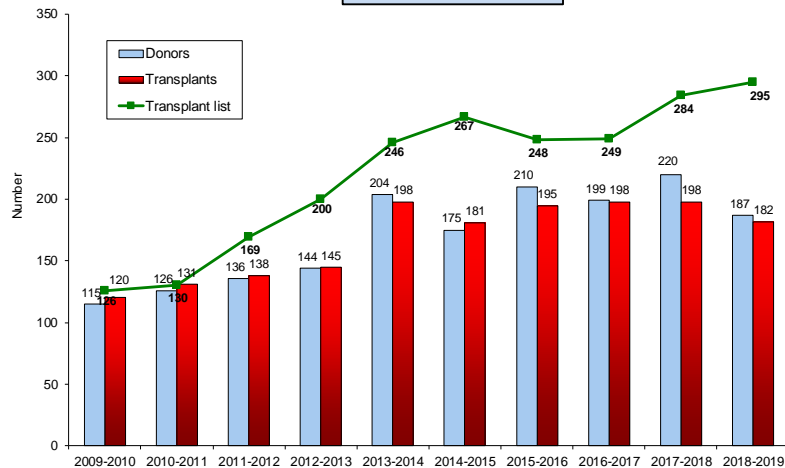
PANCREAS



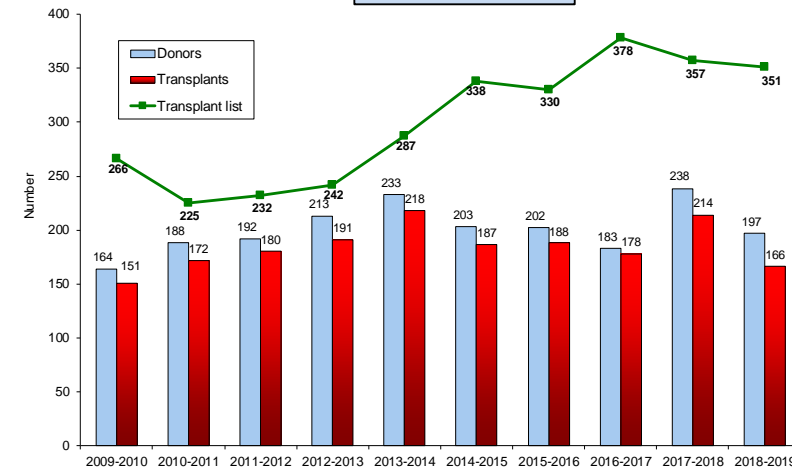
LIVER



HEART



LUNG



Organ Donor Register

BAME opt-in and opt-out registrations

Table 2.3 BAME opt-in registrations on the ODR vs the UK population

Ethnicity	2014/15 % of the ODR registrations ¹	2018/19 % of the ODR registrations ¹	2011 % of the population ²
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

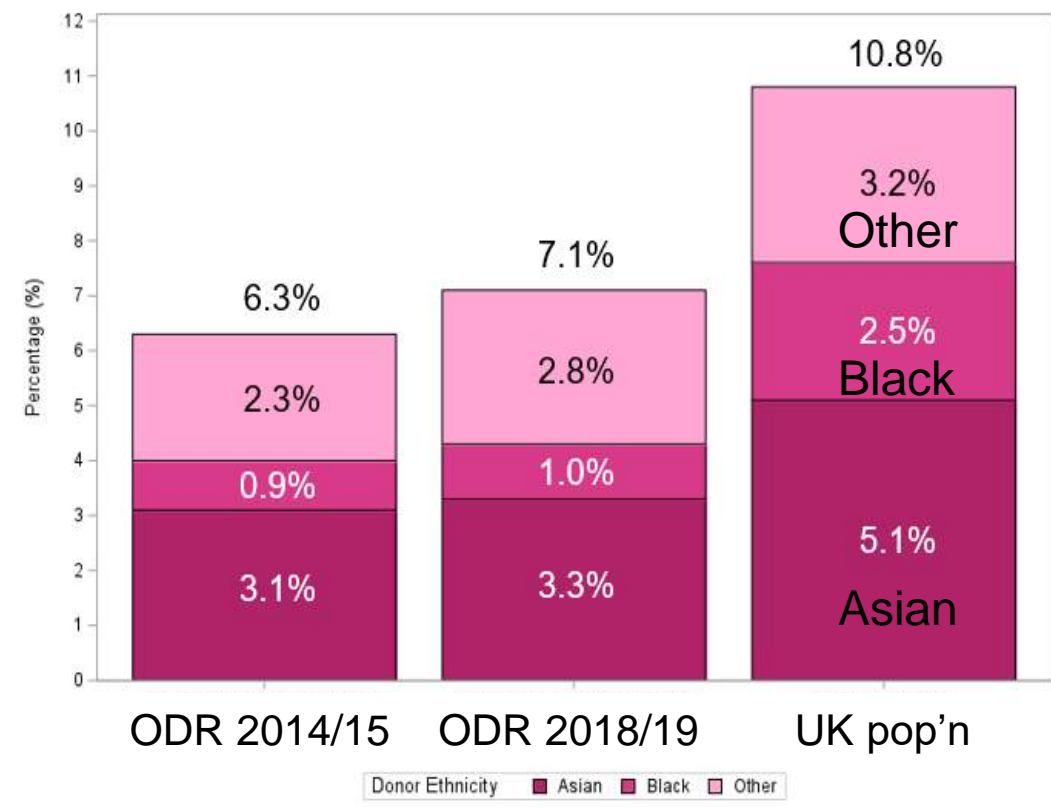
BAME opt-in and opt-out registrations

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BAME ODR opt-in registrations



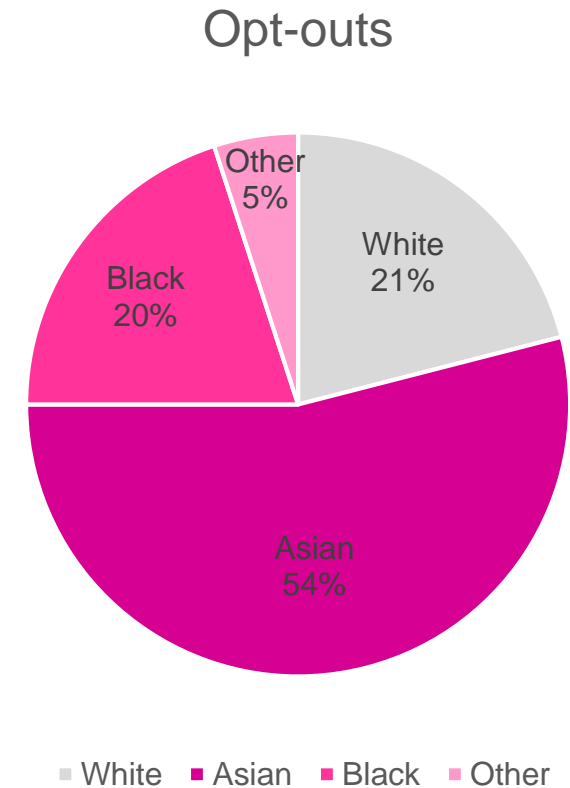
Note - More ODR opt-in registrations are reporting ethnicity – up from 22% in 2014/15 to 33% last year



BAME opt-in and opt-out registrations

Table 2.3 BAME opt-in registrations on the ODR vs the UK population				Opt-out
Ethnicity	2014/15 % of the ODR registrations ¹	2018/19 % of the ODR registrations ¹	2011 % of the population ²	% of opt outs in 2018/19
Asian-Indian	2.2	2.0	2.3	6.9
Asian-Pakistani	0.3	0.3	1.6	28.6
Asian-Bangladeshi	0.0	0.1	0.6	15.4
Asian-Other	0.5	0.8	0.6	3.1
Asian-Total	3.1	3.3	5.1	54.1
Black-African	0.4	0.5	1.2	9.7
Black-Caribbean	0.4	0.4	1.0	8.4
Black-Other	0.0	0.1	0.2	1.4
Black-Total	0.9	1.0	2.5	19.5
Chinese	0.3	0.3	0.7	0.3
Mixed race	1.6	1.9	1.7	2.9
Other ethnicity	0.4	0.6	0.8	2.2
Total BAME	6.3	7.1	10.8	79.0

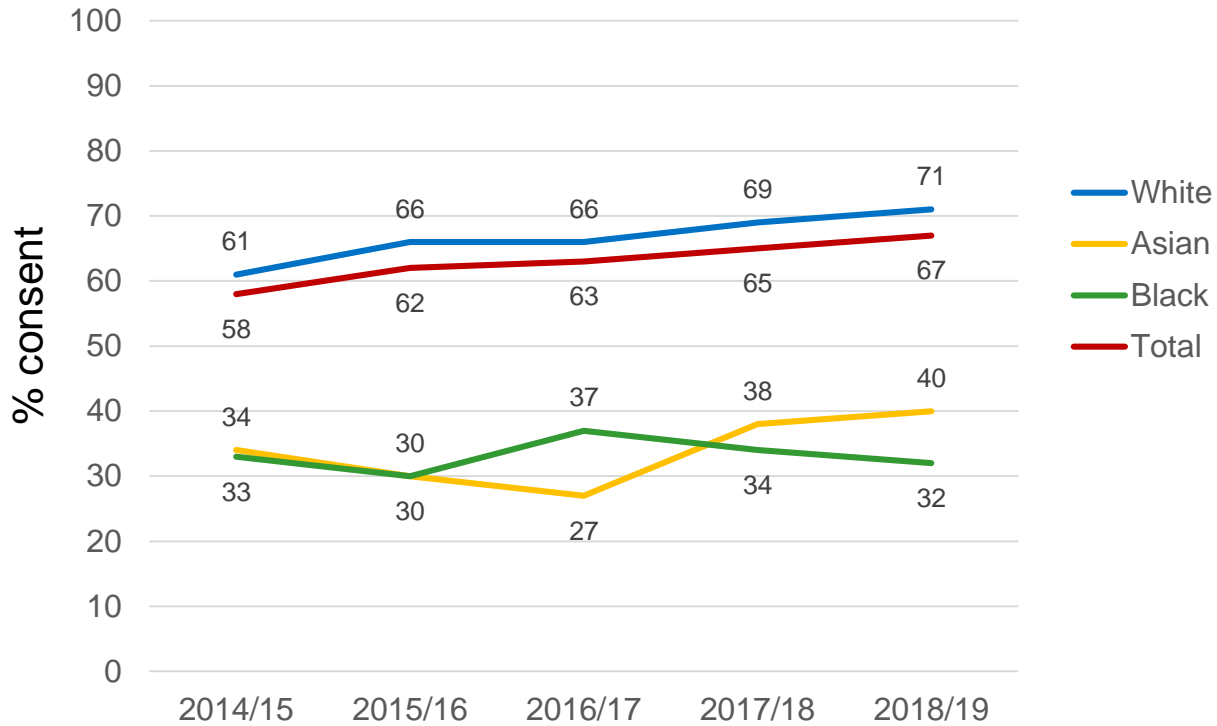
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 Note some rounding effects



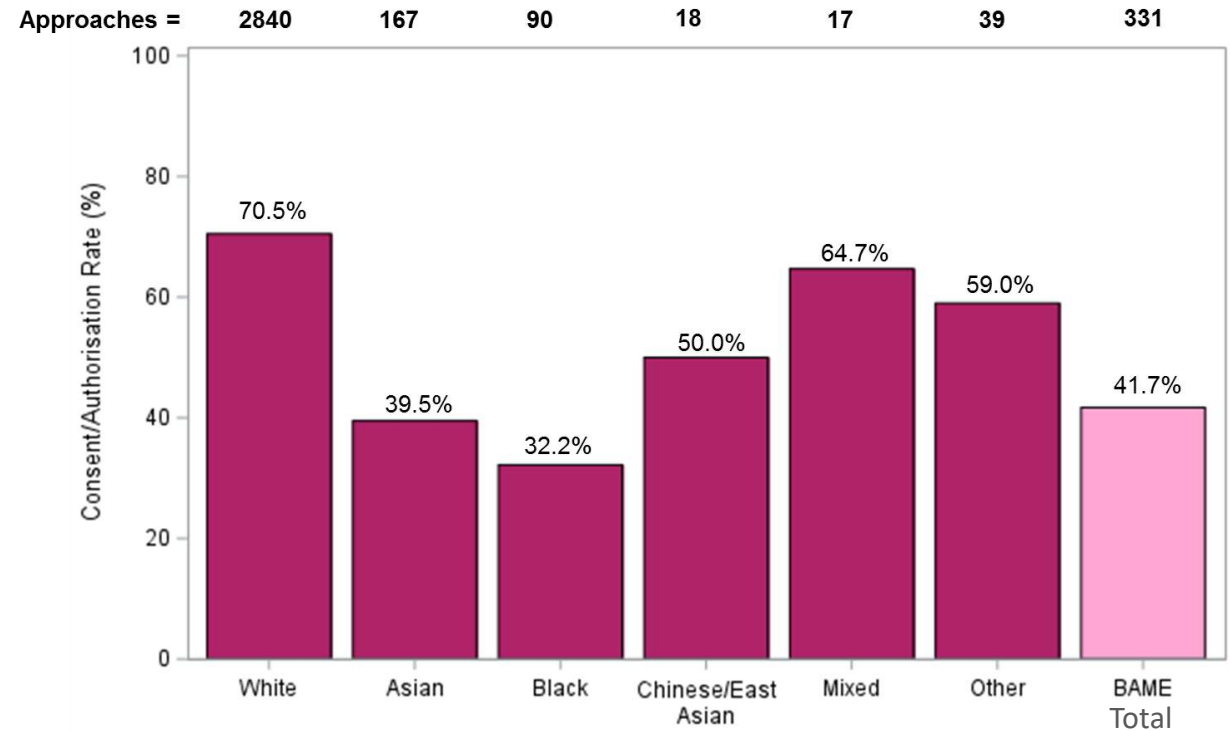
Family consent rates

Consent rates

Consent rates over time, by ethnicity

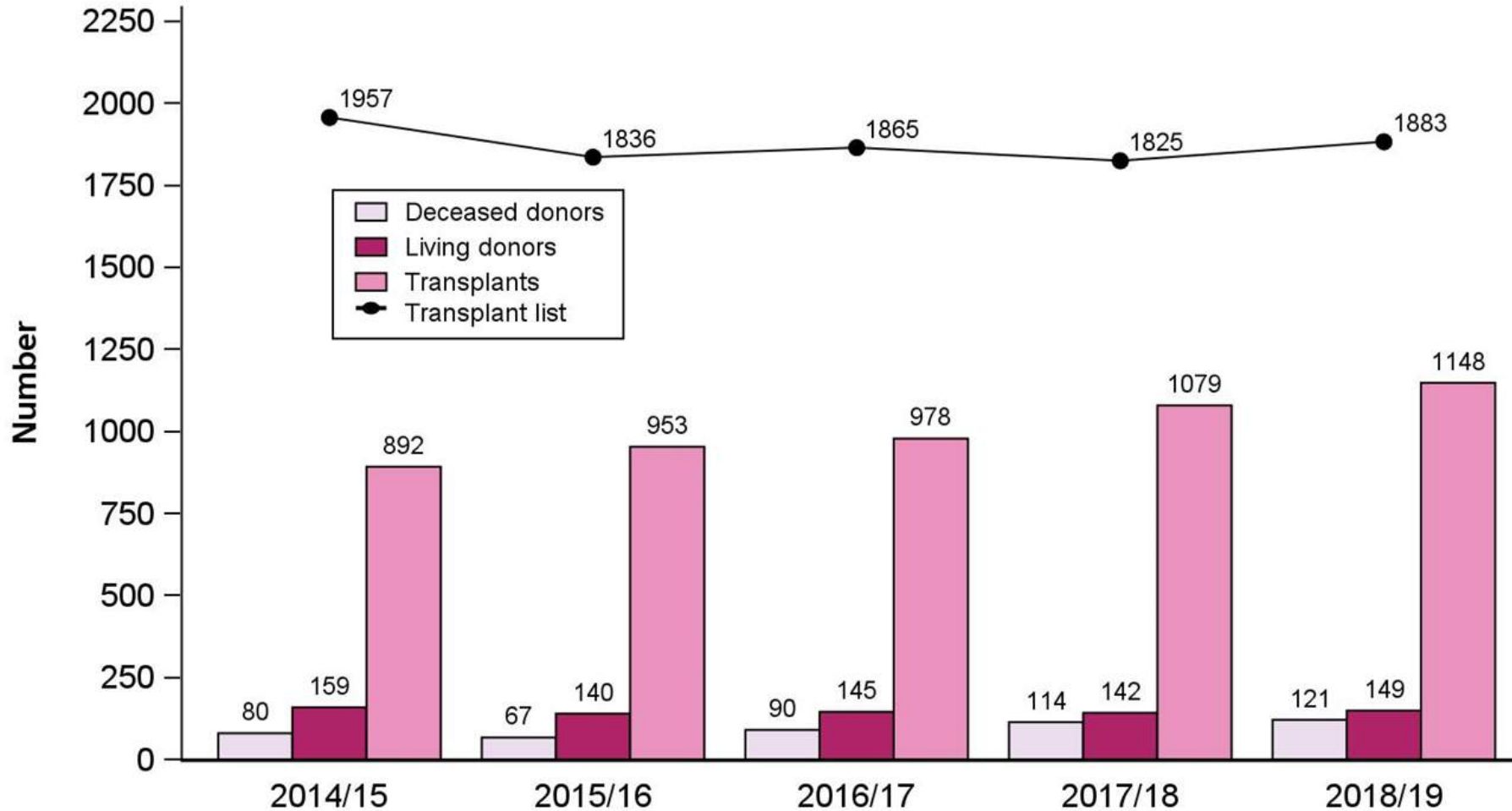


Consent rates by ethnicity – 2018/19



Organ donors and transplants

BAME donor, transplant and waiting list summary



Over the last five years

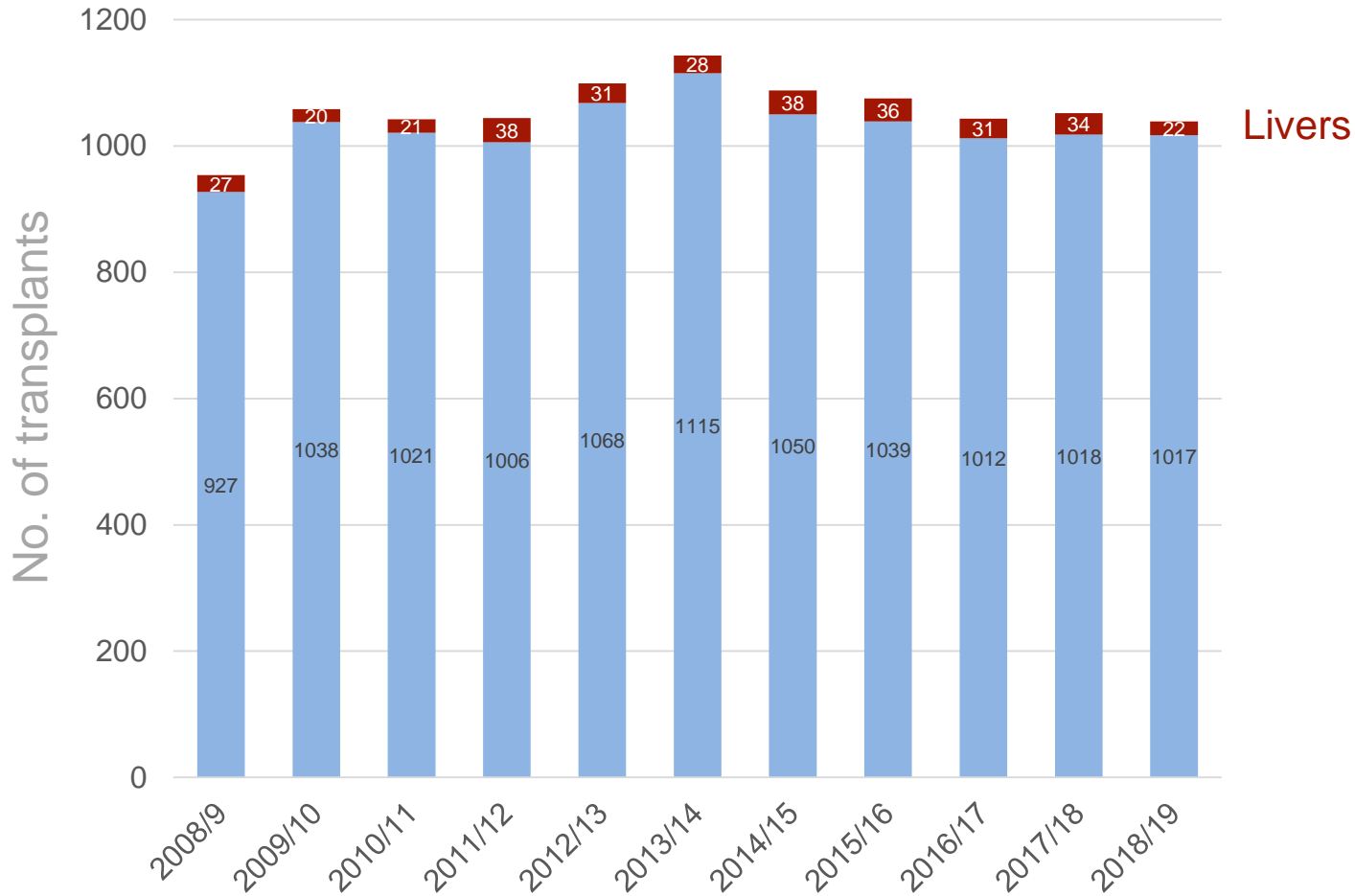
4% fall in waiting lists

29% increase in transplants (all organs)

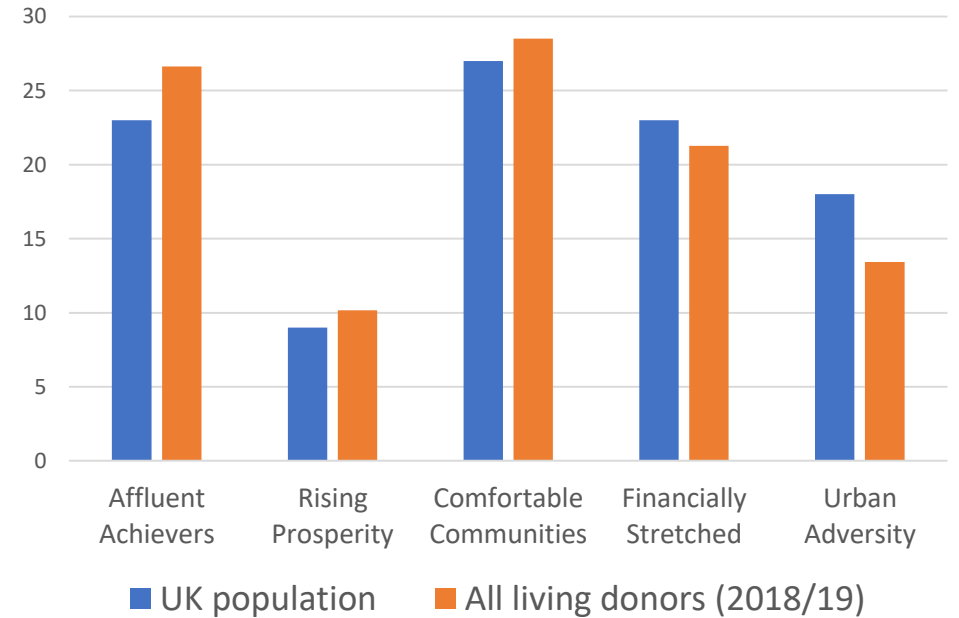
6% fall in living donors

51% increase in deceased organ donors

UK Living Donor Kidney & Liver Transplants

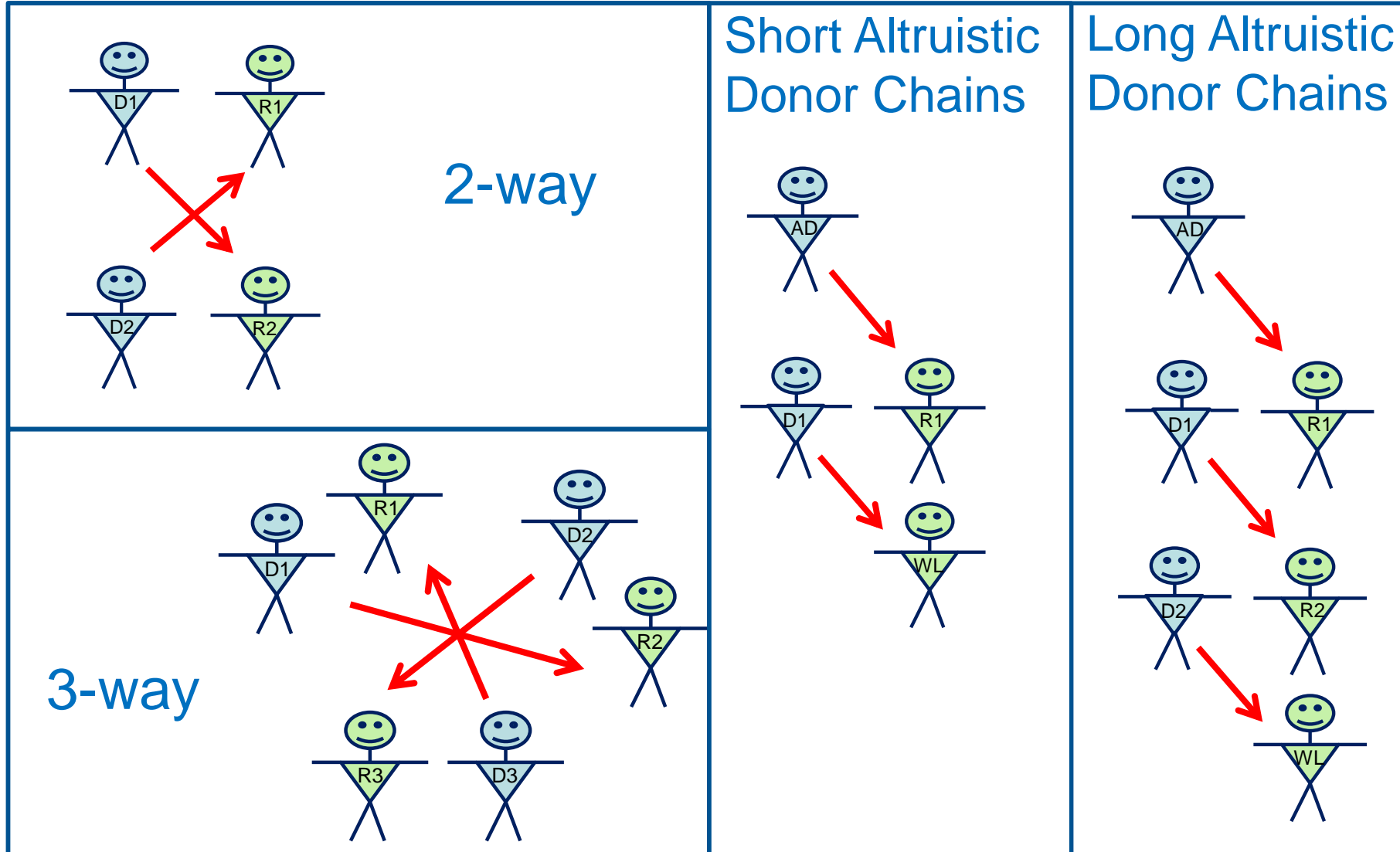


ACORN segmentation



Includes adult and paediatric patients and transplants in private hospitals

Living kidney sharing scheme – exchange types



UK scheme - largest in Europe – benefitting BAME patients

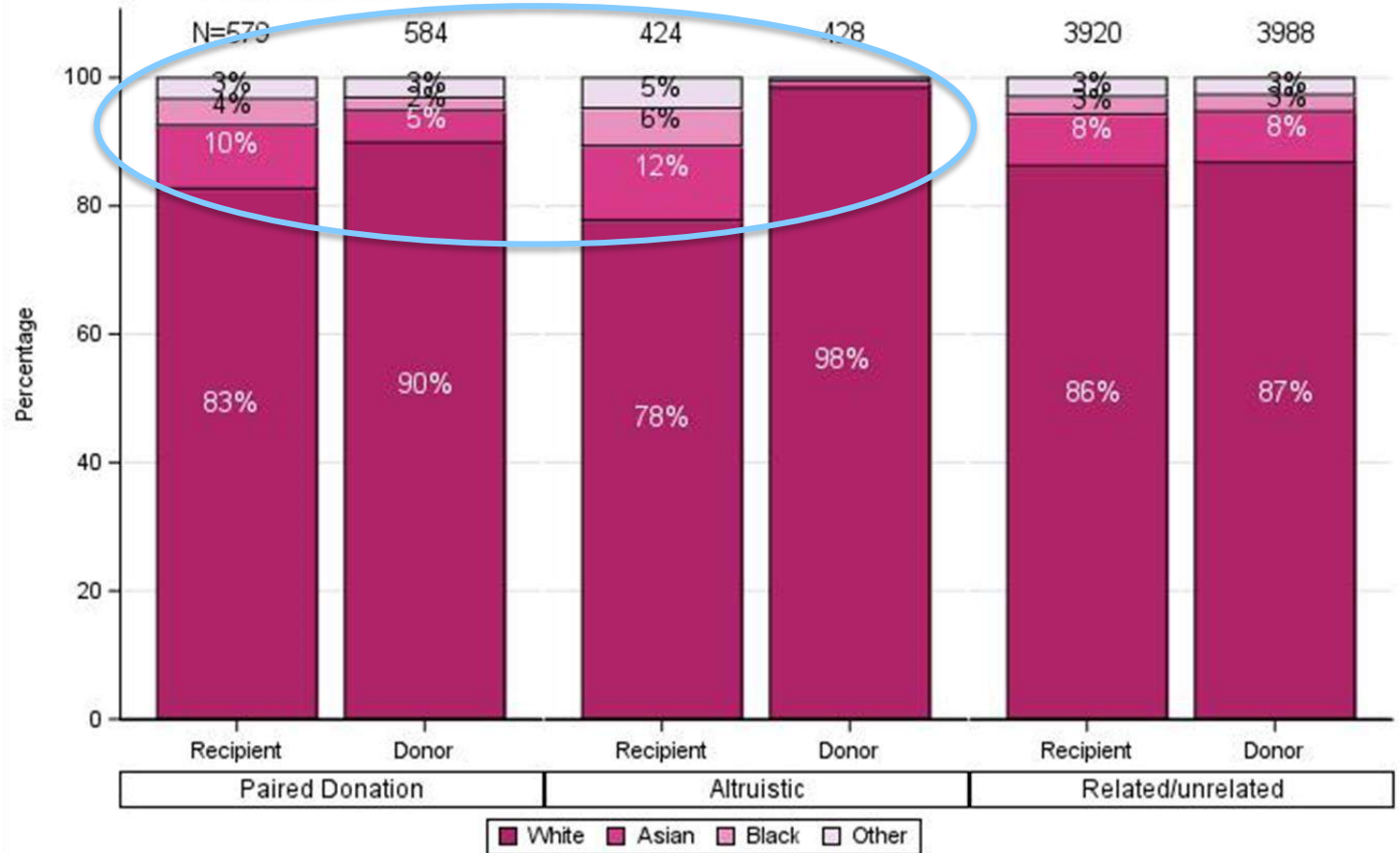


European Network for Collaboration on Kidney Exchange Programmes (ENCKEP)

- Large, advanced programmes
- New, smaller programmes
- Programmes in development
- Countries with no programme

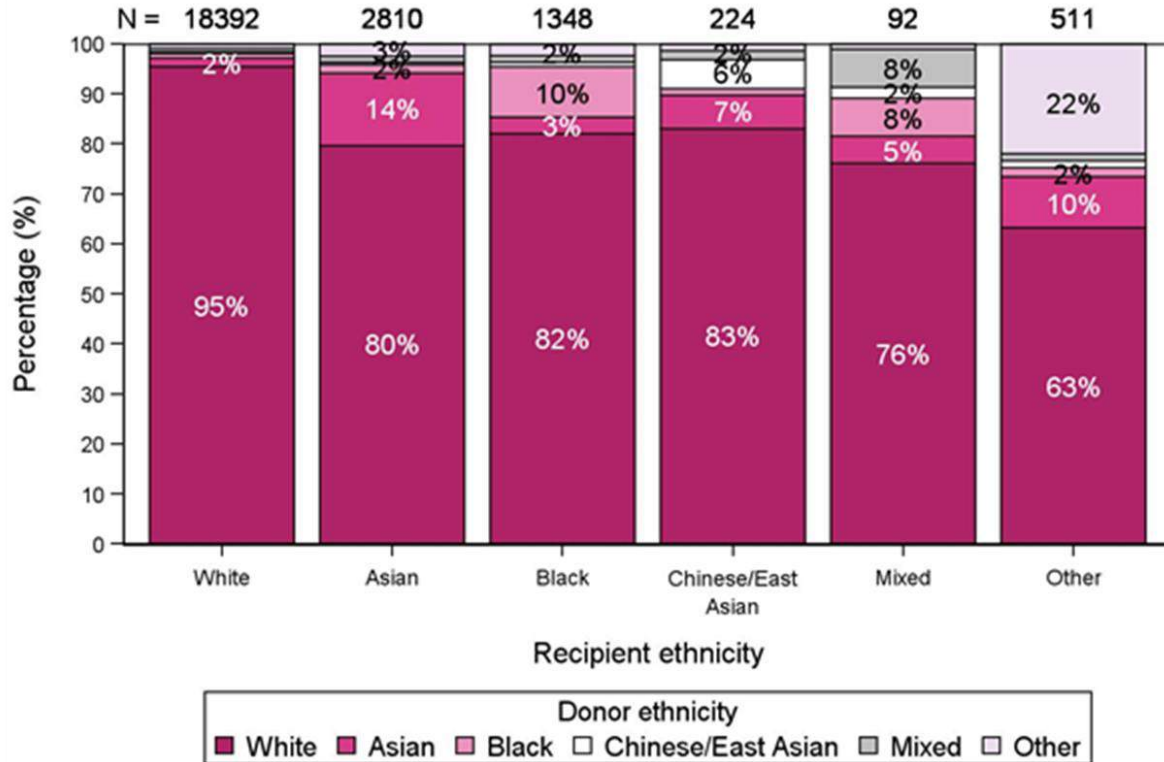


Living donor kidney transplants by ethnicity and transplant type, 1 April 2014 - 31 March 2019

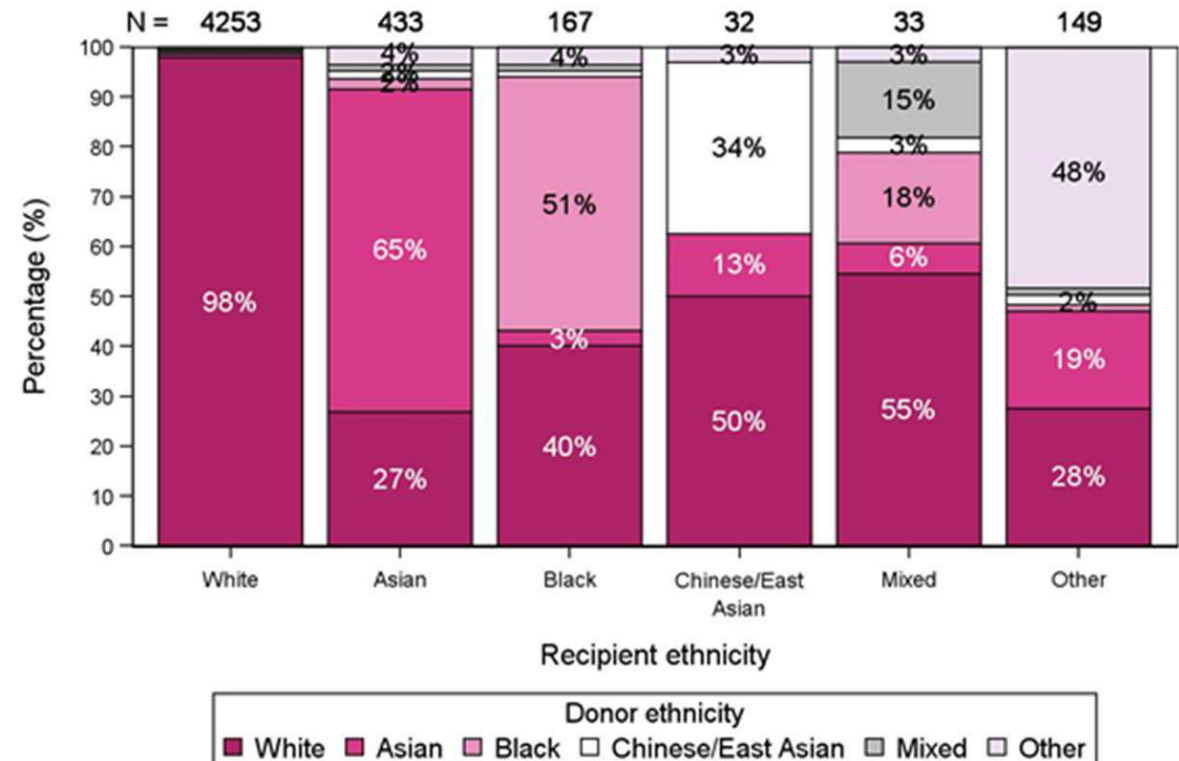


Donor-recipient ethnicities for kidney transplants, 2014-19

All transplants



Living donor transplants



Vast majority of BAME patients receive a transplant from a white donor – except in the case of living donor transplantation

Waiting times to transplant

Median waiting times (months) to adult DD organ transplant

All patients – over time

Organ	Waiting time - months	
	2012/13 report	2018/19 report
Kidney	38	23
Liver	5	3
Pancreas	12	11.5
Lung	9.5	9.5
Non-urgent heart	34*	36
Urgent heart	1*	1

Waiting times generally falling or remaining constant



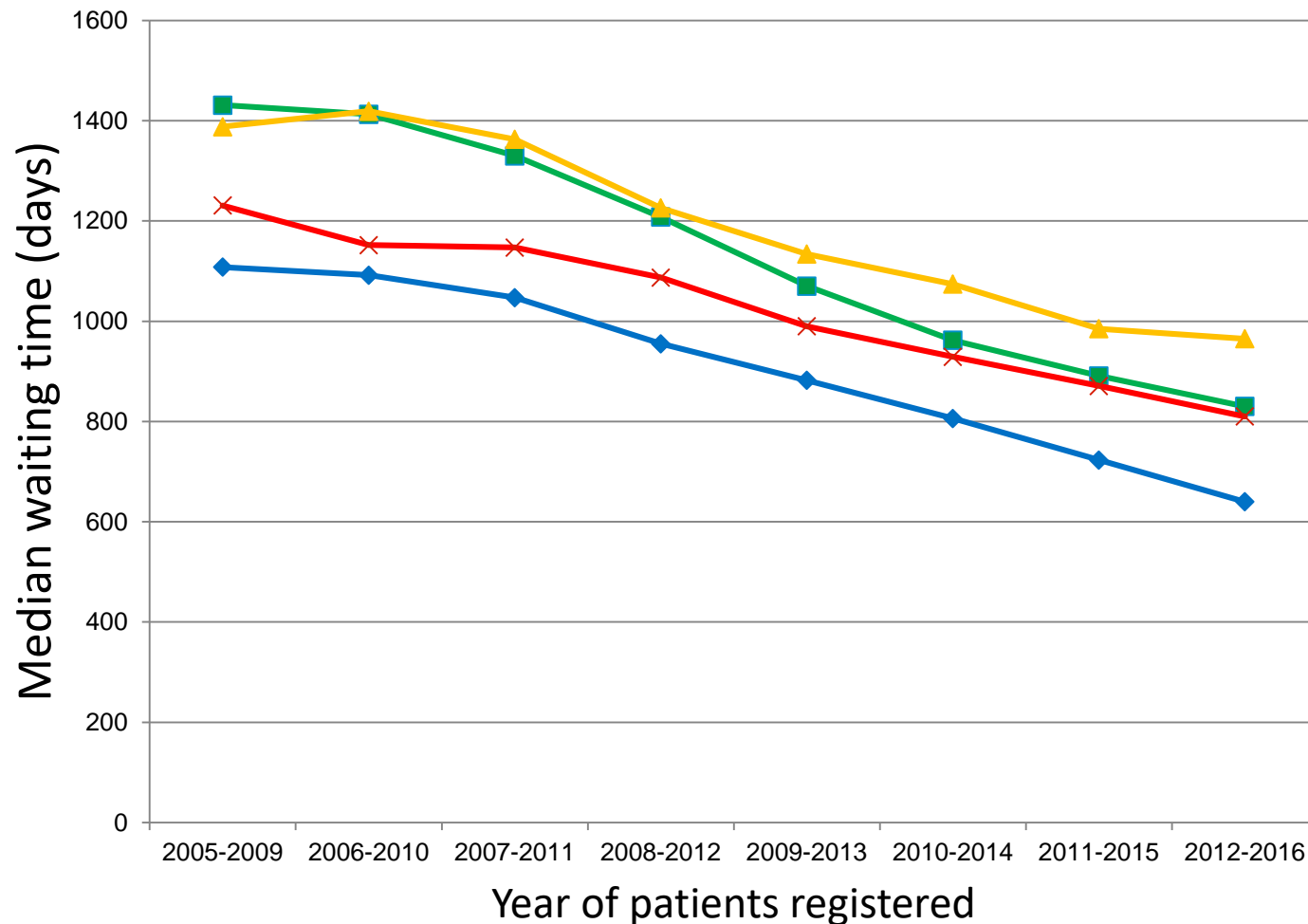
All patients – by ethnicity

Median waiting time to transplant in the UK (months)				
Organ	White	Asian	Black	Other
Adult Kidney	21	28	32	27
Paediatric Kidney	7	13	-	-
Adult Pancreas	12	9	12	-
Adult Liver	3	4	4	3
Adult Never Urgent Heart	43	13	-	-
Adult Ever Urgent Heart	1	1	2	-
Adult Lung	9	40	-	-

Note – 40 months wait for Asian lung patients is based on 46 patients and 13 months for never urgent heart on just 22 patients

* 2014/15 report

Median waiting time to adult kidney transplant



Ethnicity

- Black patients
- Asian patients
- Other patients
- White patients

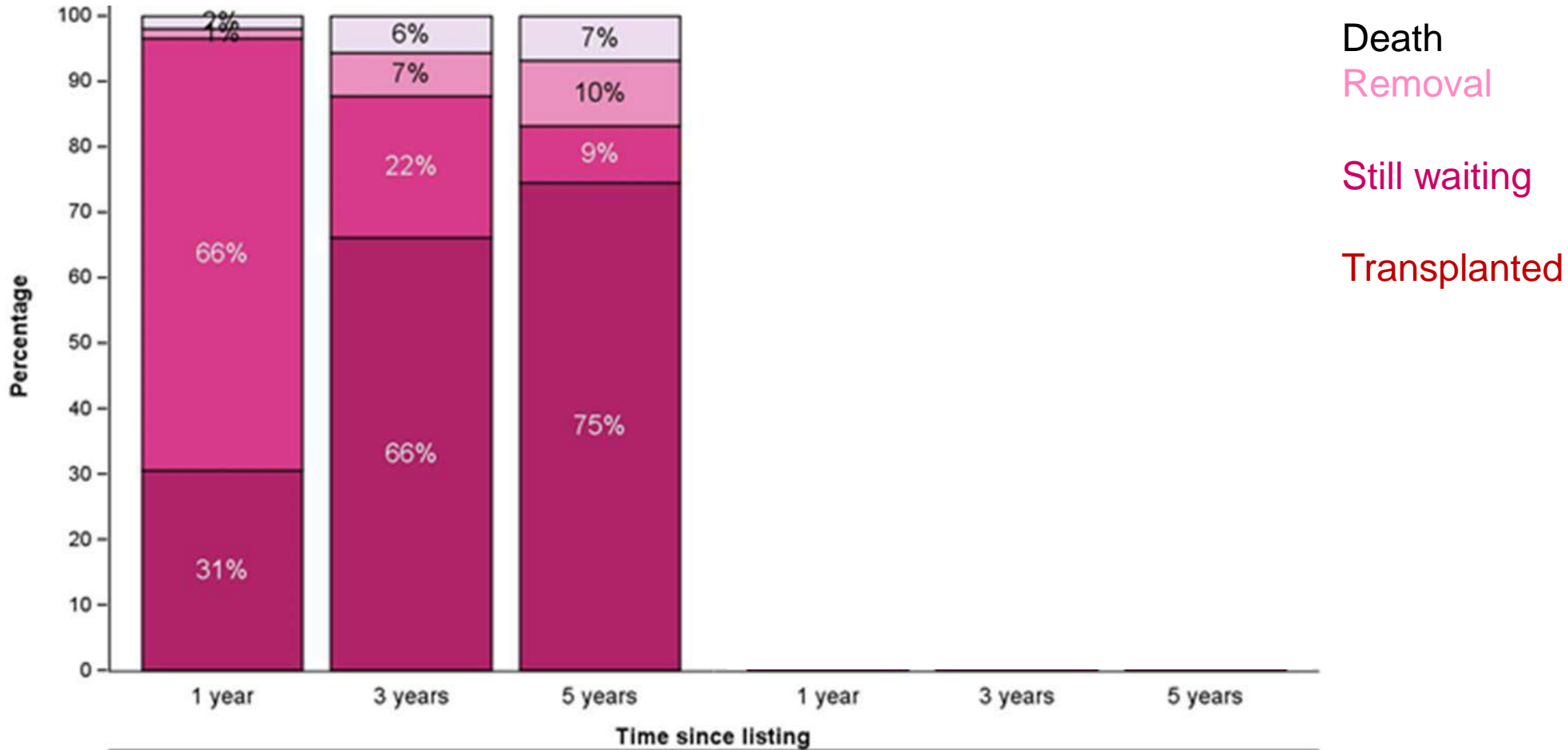
Current median wait time

- 32 months
- 28 months
- 27 months
- 21 months

Outcome of listing for adult kidney transplant

White patients

BAME patients

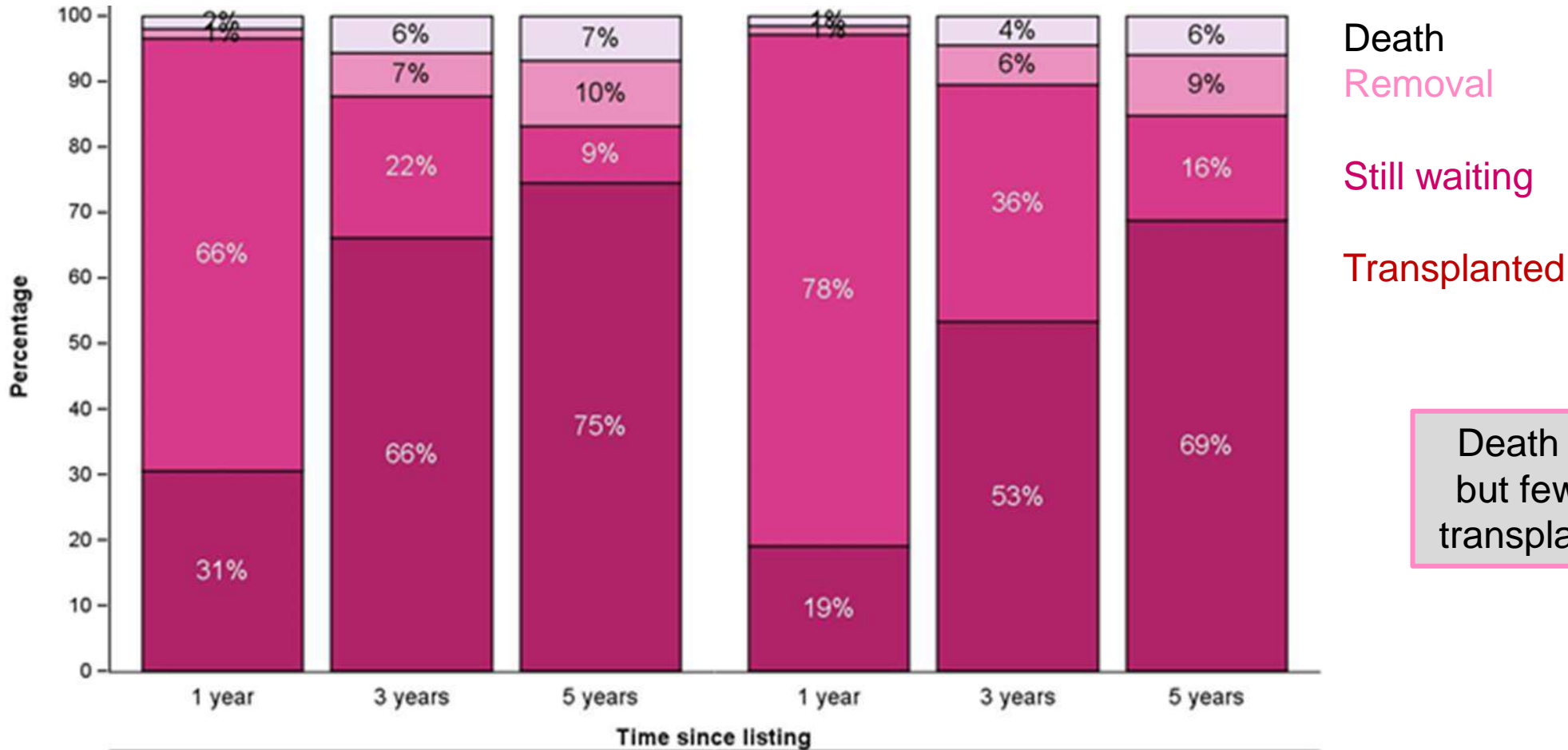


Post-registration outcome for 2451 white adult kidney registrations compared to 874 BAME, 1 April 2014 - 31 March 2015

Outcome of listing for adult kidney transplant

White patients

BAME patients

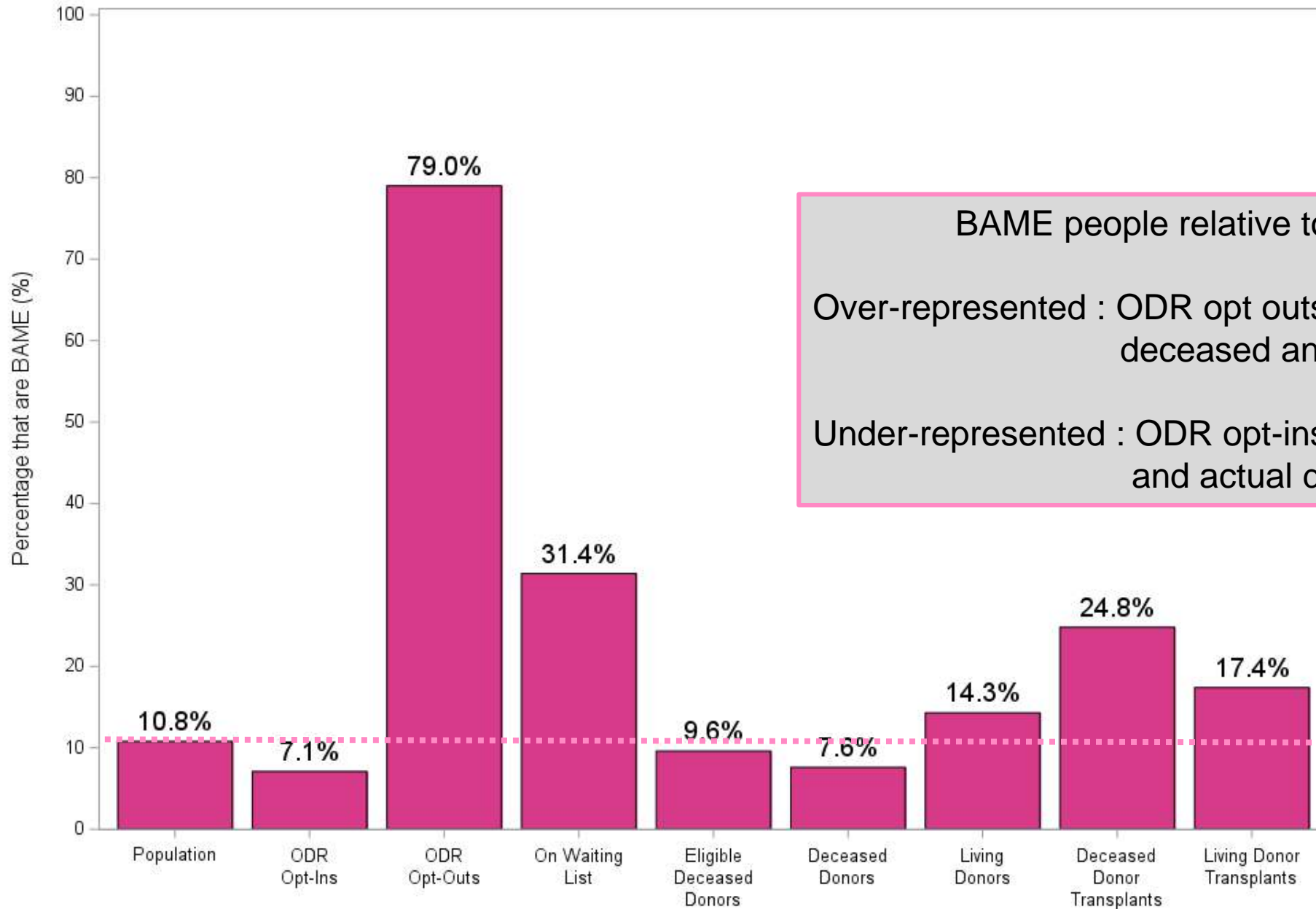


Death rates comparable, but fewer BAME patients transplanted within 5 years

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

Data Summary

BAME summary, 2018-19



BAME people relative to population estimate

Over-represented : ODR opt outs, waiting list, living donors, deceased and living donor transplants

Under-represented : ODR opt-ins, eligible deceased donors and actual deceased donors

UK population estimate 2011

Improving data on ethnicity and religion

Data collection – Organ Donor Register

Religion

Christian (Protestant, Catholic, Other), Muslim, Buddhist, Hindu, Sikh, Jewish, Other, None

Ethnicity

White – British, Irish or Other

Asian – Indian, Pakistani, Bangladeshi, Other

Black – Caribbean, African, Other

Mixed – White/Black African, White/Black Caribbean, White/Asian, Other

Chinese

Other

Good level of detail
in ODR data
collection

HOWEVER.....

- Not compulsory to report ethnicity or religion and some ODR registration sources do not give the option to report it at all – last year, ethnicity reported for:
 - 33% opt-ins
 - 90% opt-outs
- Ethnicity of people registering on the ODR is captured but is not then linked to the main ODR database so we cannot account for duplicates/ deaths etc and cannot report ethnicity of those currently on the ODR

Sources of ODR opt-in registrations in 2018/19:

- Driver and Vehicle Licensing (47%)
- Online registrations (34%)
- GP registrations (16%)
- Others (3%)

Data collection – Potential Donor Audit

Ethnic origin

- 1 = White
- 2 = Asian or Asian-British
- 3 = Black or Black-British
- 4 = Chinese / Oriental
- 6 = Mixed
- 7 = Other
- 9 = Unknown

Religion

- 1 = Christian
- 2 = Muslim
- 3 = Buddhist
- 4 = Hindu
- 5 = Sikh
- 6 = Jehovah's Witness
- 7 = Jewish
- 8 = None (atheist)
- 98 = Other
- 99 = Unknown

Potential donors:

Ethnicity and religion are not well reported as information difficult for Specialist Nurse to obtain from patient notes (<40% complete)

Is more detailed data capture realistic?

Data collection – donation and transplantation

Data capture is basic:

Ethnic origin

- 1 = White
- 2 = Asian or Asian-British
- 3 = Black or Black-British
- 4 = Chinese / Oriental
- 6 = Mixed
- 7 = Other
- 9 = Unknown

Actual organ donors:

Ethnicity reported and >99% complete
Religion not collected

Transplant recipients:

Ethnicity reported and >98% complete
Religion not collected

- Ethnicity is well reported in donors and recipients
- Often ethnicity is reported as White and BAME only, due to small numbers
- More detailed data capture would relate to even smaller numbers and may be difficult to interpret meaningfully, but could add some insights?

Summary

Final Summary

What do the data tell us?

- Over the last 5 years
 - 4% fewer BAME patients on the transplant lists
 - 29% more BAME transplants
 - 6% fewer BAME living donors (LD)
 - 51% more BAME deceased donors (DD) - to 121 last year
- Last year
 - 8% of DD and 25% of DD transplant recipients were BAME
 - 14% of LD and 17% of LD transplant recipients were BAME
 - 31% of people waiting for a transplant were BAME
 - Family consent rates were 42% for BAME potential donors, much lower than for white potential donors (71%)
 - 7% of ODR opt-ins and 79% of ODR opt-outs were BAME

Improving data on ethnicity and religion

Data Source	Ethnicity - Detailed?	Ethnicity - Complete?	Religion - Collected?	Religion - Complete?
ODR	✓	✗	✓	✗
Potential Donors	✗	✗	✓	✗
Donors	✗	✓	✗	
Recipients	✗	✓	✗	

Most ethnicity data collection is at high level
 Very limited data collection on religion
 Potential for improvements?

Thank you



Yes I donate
ORGAN DONATION