

# Demographic Health of Organ Donation (Deceased) and the Organ Donation Register

## Appendix

# Appendix A: An increase in expressed opt-outs and opt-outs on the ODR is contributing to more families not providing support for donation to go ahead

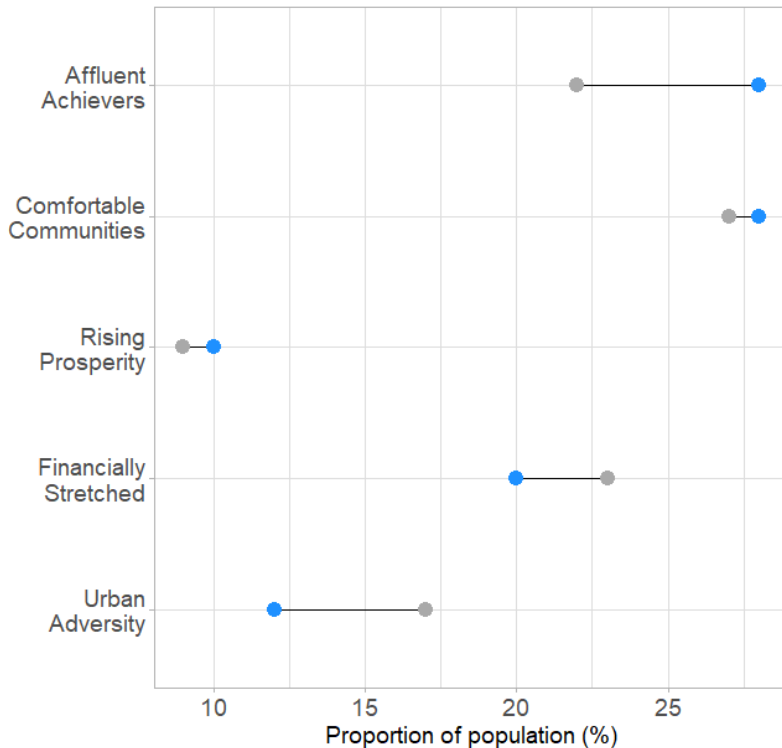
Primary reason why family did not support organ donation Source: Potential Donor Audit 2019/20 and 2021/22	2019/20		2021/22		% change
	N	%	N	%	
<b>Reasons contributing to an <u>increase</u> in families not supporting donation</b>					
Patient had previously expressed a decision not to donate	253	25.4%	273	29.6%	7.9%
Family felt it was against their religion/cultural beliefs	52	5.2%	63	6.8%	21.2%
Patient had registered a decision to opt-out	N/A	N/A	43	4.7%	100.0%
Strong refusal - probing not appropriate	27	2.7%	36	3.9%	33.3%
Family concerned other people may disapprove/be offended	1	0.1%	4	0.4%	300.0%
<b>Reasons contributing to a <u>decrease</u> in families not supporting donation</b>					
Family felt the length of time for the donation process was too long	129	13.0%	100	10.9%	-22.5%
Family were not sure whether the patient would have agreed to donation	140	14.1%	99	10.7%	-29.3%
Family did not want surgery to the body	98	9.9%	81	8.8%	-17.3%
Family felt patient had suffered enough	90	9.1%	68	7.4%	-24.4%
Other	81	8.1%	66	7.2%	-18.5%
Family felt the body should be buried whole (unrelated to religious reasons)	35	3.5%	25	2.7%	-28.6%
Family divided over decision	39	2.9%	24	2.6%	-38.5%
Family did not believe in donation	27	2.7%	23	2.5%	-14.8%
Family wanted to stay with the patient after death	10	1.0%	7	0.8%	-30.0%
Family concerned that organs may not be transplantable	7	0.7%	5	0.5%	-28.6%
Family had difficulty understanding/accepting neurological testing	3	0.3%	2	0.2%	-33.3%
Family concerned donation may delay the funeral	2	0.2%	2	0.2%	0.0%
Family concerned about organ allocation	1	0.1%	0	0.0%	-100%
<b>TOTAL</b>	<b>995</b>	<b>-</b>	<b>921</b>	<b>-</b>	<b>-7.4%</b>

- The total number of eligible deaths has reduced between 2019/20 and 2021/22 by -19%.
- However the total number of families not donating has reduced by only -7.4%. A greater proportion of families are not supporting donation
- The reasons that families do not support donation, as logged by our specialist nurses, has changed since before the Opt-Out law change.
- Many reasons that relate to indecision about donation, or concern with the donation process, have reduced their contribution to families declining
- However there has been an increase in the Patients declaring a decision to opt-out, either previously to family or via the register. These reasons previously accounted for a third of families declining (33%) but are now almost half of families (45%)

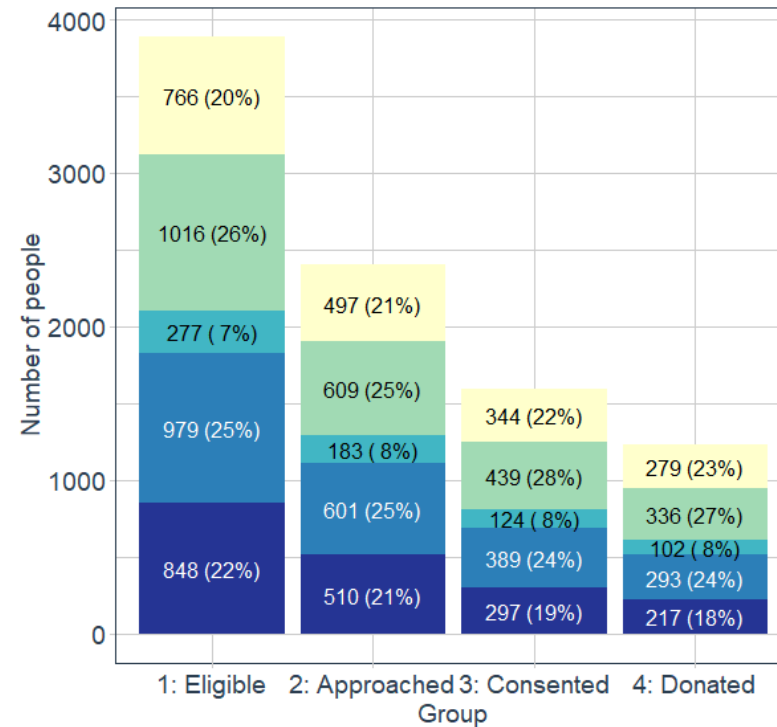
# Appendix B: The lowest socio-economic groups are underrepresented on the ODR, more likely to be eligible donors, but less likely to consent

- The opt-in NHS ODR does not adequately represent sub-populations with high number of eligible donors – there are almost three times as many people from the affluent achievers ACORN group who have opted-in for organ donation as there are from urban adversity, despite the groups being equally represented in the number of eligible deaths
- The pool of eligible donors is not representative of the general population, in particular the Urban Adversity group is overrepresented in the eligible pool. However, the urban adversity group is not overrepresented at the stage of ‘donated’ due to lower consent rates

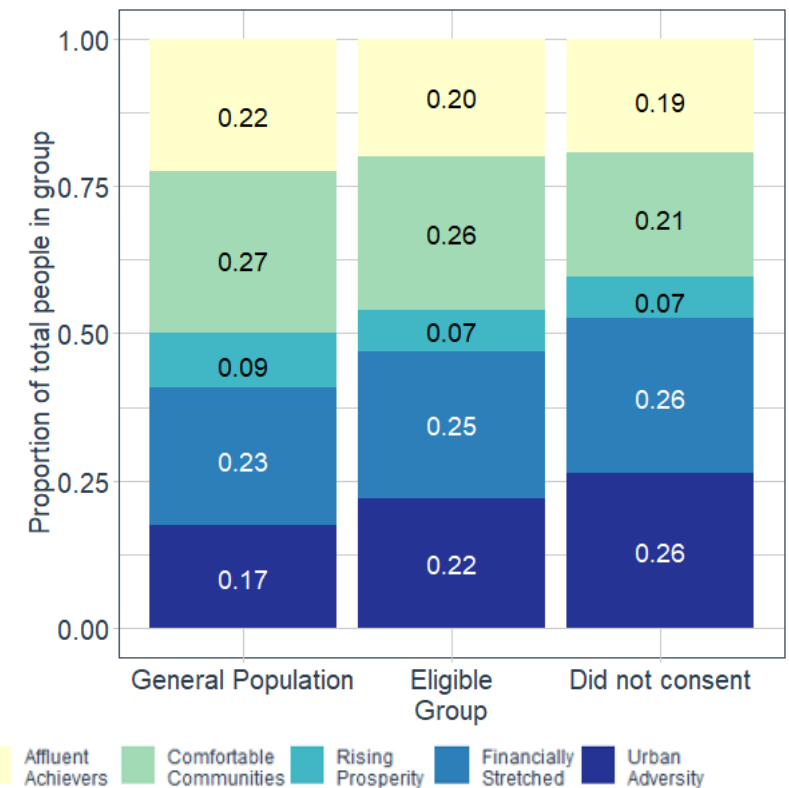
Proportion of the population on the ODR (blue) as of 31/05/2022 and in the UK (grey)



Proportion of people at each stage of donation by ACORN group (2021/22)



Proportion of people in eligible donor pool and did not consent group compared to general population (2021/22)

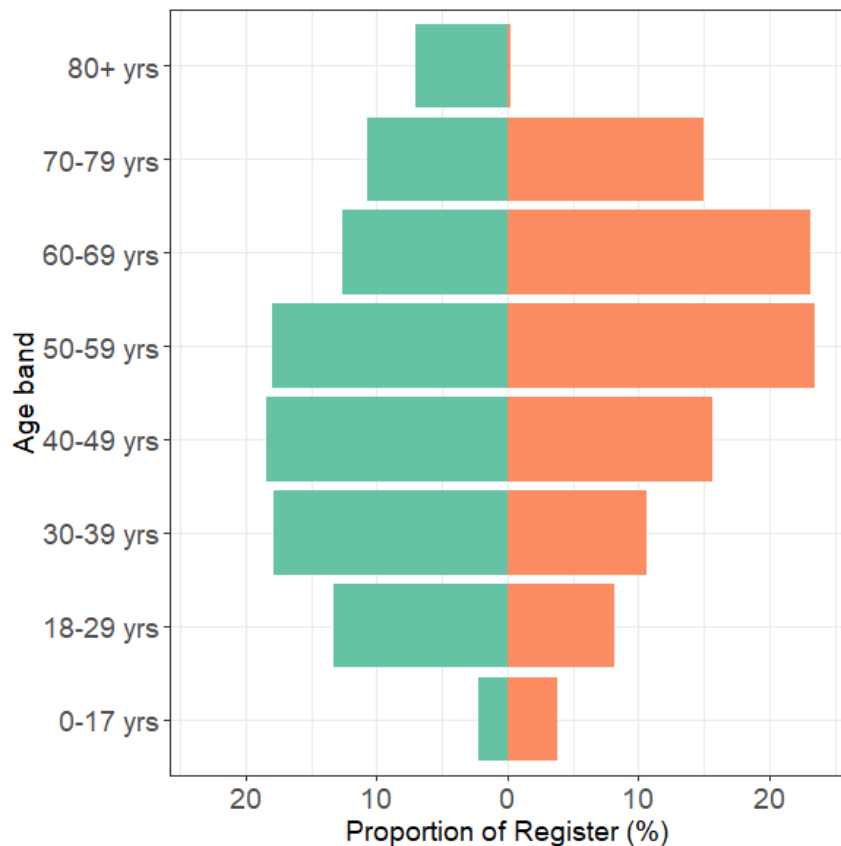


Acorn category: Affluent Achievers, Comfortable Communities, Rising Prosperity, Financially Stretched, Urban Adversity

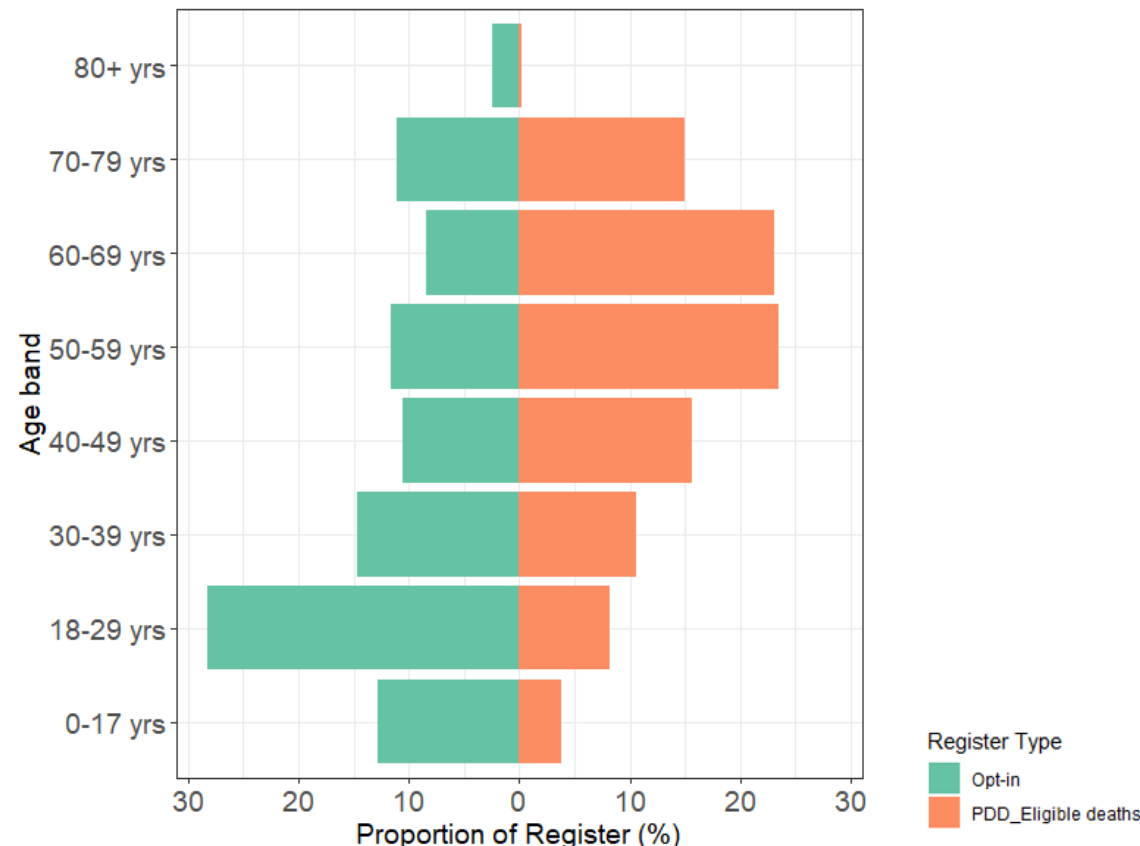
# Appendix C: Our long-term partnership with the DVLA has led to the NHS ODR being overrepresented in younger age groups compared to the age of the eligible donor pool

- Roughly 45% of all eligible deaths and actual donors are aged between 50-69 years old, yet comprise 19% of annual of opt-ins on the ODR last year.
- People tend to register their decision for the first time when they are younger, 43.5% are aged between 16 and 30 years old at the point of registration, whilst we don't have age break down by registration method, it can be assumed this is due to the DVLA given 64% of registrations come via this route

Current age of all opt-in registrants (as of September 2022) and age of PDD eligible deaths (2021/22)



Age of opt-in registrations (01 April 2021 – 26 Sept 2022 ) and PDD eligible deaths (2021/22)



Register Type  
■ Opt-in  
■ PDD\_Eligible deaths

# Appendix D: Whilst not directly comparable, those OTDT teams with the lowest consent rate are also the regions with the lowest proportion of the population registered an opt-in decision

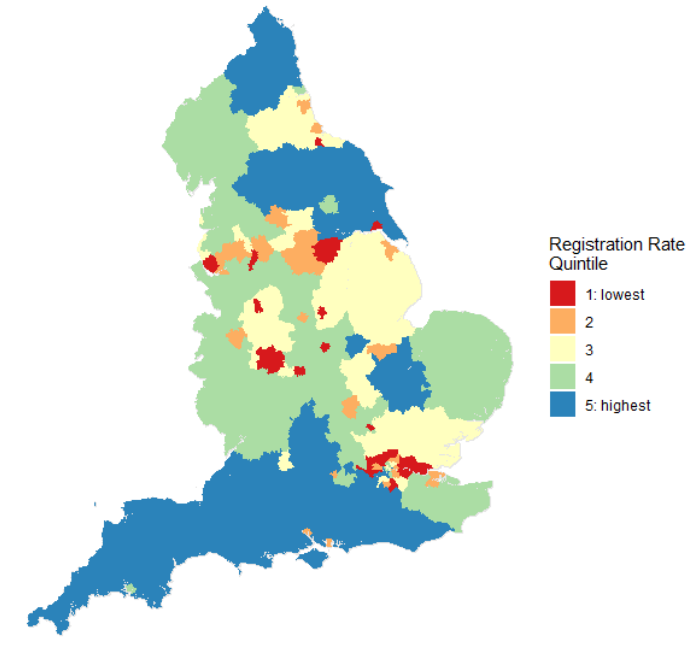
- The regions with lowest proportion of the population on the ODR are London, the Midlands and the north-west, which correspond to the OTDT regions with the lowest overall and/or deemed consent rate have the lowest overall and deemed consent rate.
- ODR data is available by NHS region and OTDT regions do not have the exact same geographical areas so a direct comparison can not be made. The North West OTDT region for example includes north Wales.

% of the population registered a decision by NHS region (ODR figures as of 31 January 2023)			
NHS Region	% opt-in	% opt-out	% recorded a decision
London	32.4%	6.6%	39.0%
North West	36.3%	3.6%	39.9%
Midlands	36.5%	4.0%	40.5%
South East	44.9%	2.3%	47.1%
North East & Yorkshire	43.8%	3.6%	47.4%
East of England	44.6%	3.0%	47.6%
Wales	44.9%	6.4%	51.4%
South West	50.9%	1.9%	52.8%
Northern Ireland	52.6%	0.3%	53.0%
Scotland	53.2%	3.2%	56.4%

Consent rate by OTDT Regional Teams, ranked by deemed consent (YTD consent rate as of 31 January 2023)			
OTDT Region	Overall consent rate	Deemed consent rate	Expressed opt-in consent rate
London	51%	45%	91%
Midlands	55%	51%	84%
North West	64%	53%	94%
Eastern	62%	57%	93%
South Central	63%	57%	91%
Yorkshire	61%	60%	90%
Northern	69%	61%	89%
South Wales	66%	63%	89%
South East	65%	65%	88%
South West	68%	69%	90%
Scotland	67%	76%*	84%
Northern Ireland	61%	N/A	82%

English ODR Registration

ODR all decisions on 26/09/22  
Population: 2021 census



\* Scotland class 'expressed opt-in' as on the ODR only. Therefore those who have shared their decision verbally would be class under deemed consent, hence why their deemed consent rate is higher.

# Appendix E: People of minority ethnic heritage are underrepresented on the opt-in ODR and as donors, but overrepresented on the opt-out ODR and in need of a transplant, leading to health inequalities in waiting times

- There are proportionally more minority ethnic patients on the list for transplant than there are among people transplanted, reflecting an inequity of access to transplant for some organs. Currently, 80% of Black and Asian patients receive a transplant from a White donor.
- Through our attitudinal tracker we know that significant barriers to organ donation exist amongst minority ethnic groups relating to faith culture and family, which is reflected in a lower willingness to donate (61% vs 75% White population) and a lower consent rate (40% vs 71% White donors)

**Percentage that are from minority ethnic groups relative to the minority ethnic population, April 2021 – March 2022**

