



Blood and Transplant

**OPT OUT SUMMARY REPORT
ODR REGISTRATIONS AND
CONSENT/AUTHORISATION RATES**

June 2021

Key messages

- Opt out legislation has been implemented in Wales (2015), Jersey (2019), England (2020) and Scotland (2021). New legislation is progressing in Northern Ireland, Guernsey and the Isle of Man and NHSBT is working closely with the Governments to support the legislation development and implementation.
- Scotland has the highest proportion of opt in registrations on the ODR, 51.0%.
- Wales has the highest proportion of opt out registrations on the ODR, 6.2%. Since the implementation of the new legislation in Scotland, the proportion of opt out registrations has increased from 0.5% to 2.6%.
- There has been a significant fall in the number of donation decision conversations (family approaches), across all nations in 2020/21 due to the COVID pandemic, although consent/authorisations rates remain consistent.
- Northern Ireland and Scotland have the highest deceased donor consent/authorisation rates during 2020/21, 78.9% and 73.3%, respectively.
- Funnel plots for 2020/21 indicate that deceased donor consent/authorisation rates are not significantly different across the UK nations.
- Separate DBD and DCD funnel plots demonstrate that Scotland has a higher DBD authorisation rate than England. DCD consent/authorisation rates are consistent across the UK.
- Where deemed consent/authorisation applies, the UK consent/authorisation rate is 66.7%.

Introduction

This report presents information relating to the introduction of opt out legislation across the UK and includes data from the NHS Organ Donor Register (ODR) and the UK Potential Donor Audit (PDA).

ODR data includes all registrations as at the month end and data are recalculated each month.¹

PDA data comprise all audited patient deaths in UK Intensive Care Units (ICUs) and Emergency Departments, excluding patients aged over 80 years and patients who died on a ward. Paediatric ICU data are included however neonatal ICU data have been excluded from this report.

This report tracks trends in ODR registrations and deceased donor consent/authorisation rates across the four UK nations following changes in legislation relating to organ donation in the UK. ODR registration data are provided in the Appendix for the Crown Dependencies (Jersey, Guernsey, Isle of Man) but data relating to PDA activity are too small to be published (<5).

Current legislation status

Nation	Current legislation (proposed)	Implementation
Wales	Opt out - Deemed consent	1 December 2015
Jersey	Opt out - Deemed consent	1 July 2019
England	Opt out - Deemed consent	20 May 2020
Scotland	Opt out - Deemed authorisation	26 March 2021
Isle of Man	Opt in (Opt out - Deemed consent)	2021 (proposed)
Guernsey	Opt in (Opt out - Deemed consent)	2021 (proposed)
N. Ireland	Opt in	Opt out legislation under consideration

¹ If someone has asked to be removed from the register this will be accounted for. Removals data include deaths.

PDA definitions

Eligible donors after brain death (DBD) - patients confirmed dead by neurological death tests, with no absolute medical contraindications to solid organ donation.

Eligible donors after circulatory death (DCD) - patients who had treatment withdrawn and imminent (controlled) death was anticipated, with no absolute medical contraindications to solid organ donation.

Donation decision conversation - family of eligible donors asked to make or support patient's organ donation decision. This includes clarifying an opt out decision.

Consent/authorisation ascertained - family supported opt in decision, deemed consent/authorisation, or where applicable the family or nominated/appointed representative gave consent/authorisation for organ donation.

Consent/authorisation rate - the percentage of donation decision conversations where consent/authorisation was ascertained.

Deemed consent applies if a person who died in Wales, Jersey or England has not expressed an organ donation decision either to opt in or opt out or nominate/appoint a representative, is aged 18 or over, has lived in the country in which they died for longer than 12 months and is ordinarily resident there, and had the capacity to understand the notion of deemed consent for a significant period before their death.

Deemed authorisation applies if a person who died in Scotland has not expressed, in writing, an organ donation decision either to opt in or opt out, is aged 16 or over, has lived in Scotland for longer than 12 months and is ordinarily resident there, and had the capacity to understand the notion of deemed authorisation for a significant period before their death. Note that, in Scotland, a patient who has verbally expressed an opt in decision is included as a deemed authorisation, whereas a patient who has verbally expressed an opt out decision is not included.

Consent/authorisation groups:

- Expressed opt in – patient had expressed an opt in decision. Opt in decisions can be expressed in writing or via the ODR in all nations and verbal opt in decisions are also included in Wales, England and Jersey. Verbally expressed opt in decisions are not included in Scotland.
- Deemed consent/authorisation – patient meets deemed criteria specific to each nation as described above. In Scotland, this includes patients who have verbally expressed a decision to opt in.
- Expressed opt out – patient had expressed an opt out decision. Opt out decisions can be expressed verbally, in writing or via the ODR in all nations.
- Other – patient has expressed no decision or deemed criteria are not met. Paediatric patients are included in this group.

Organ Donor Register (ODR)

The number of opt in and opt out ODR registrations per million population (pmp) are presented in **Figure 1**, comparing ODR activity across the UK nations. Population estimates are the latest Office for National Statistics (ONS) estimates based on the 2011 Census figures. The total number of opt in and opt out registrations in each nation, the proportion of the population registered and the number of registrations pmp are provided in **Table 1**. **Figure 2** shows the trends over time, since 1 April 2015, in the numbers of monthly ODR registrations in the four UK nations. Equivalent data for the Crown Dependencies are included in the Appendix.

Figure 1 - ODR registrations pmp by 31 March 2021

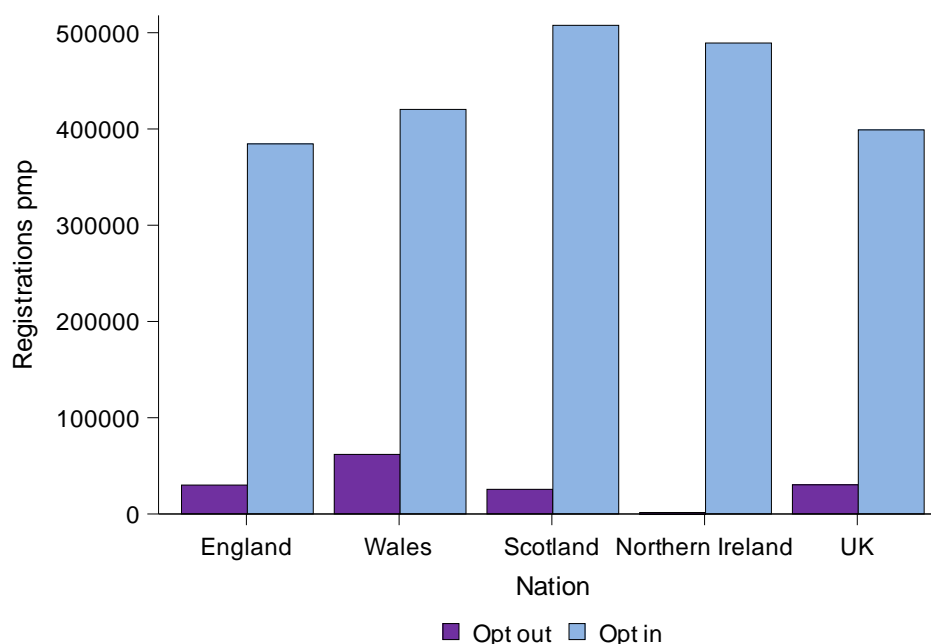
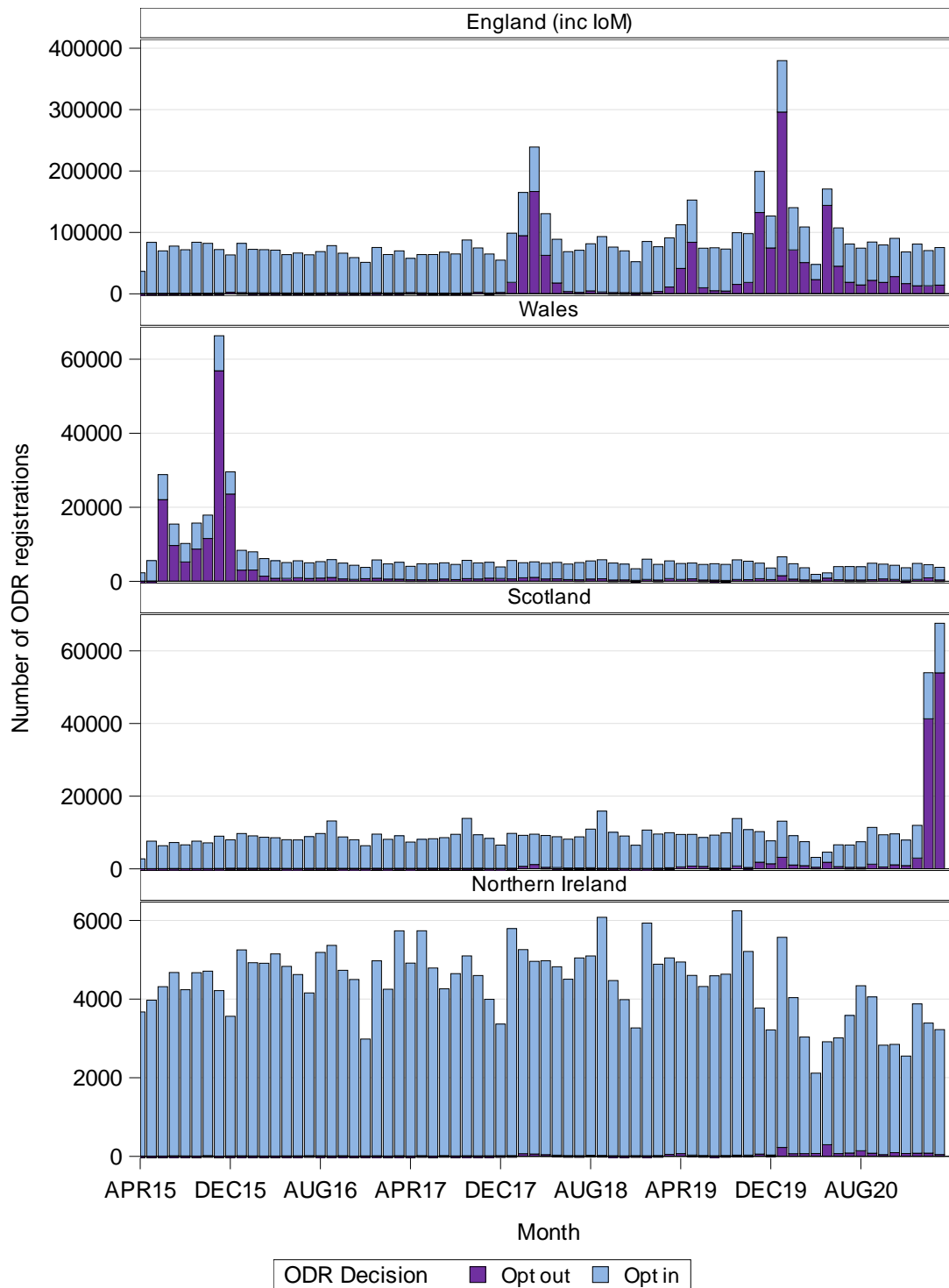


Table 1 - ODR registrations pmp at 31 March 2021

Nation	Opt-in registrations			Opt-out registrations		
	N	%	pmp*	N	%	pmp*
England	21643178	38.7	386623	1691057	3.0	30208
Wales	1323995	42.2	421654	194967	6.2	62091
Scotland	2771874	51.0	509536	139838	2.6	25706
N. Ireland	924762	49.2	491895	2876	0.2	1530
UK	26750559	40.3	402627	2030703	3.1	30564

* Population estimates are the mid-2019 estimates based on ONS 2011 Census figures

Figure 2 - ODR registrations by decision, April 2015 to March 2021



Potential Donor Audit

In this section, data from the PDA are presented.

- **Figures 4a to 4d** provide, for each nation, a breakdown of the number of donation decision conversations by whether consent/authorisation was ascertained or not. The overall consent/authorisation rate is also presented. There is greater variation in the quarterly rates for Wales, Scotland, and Northern Ireland due to the smaller number of donation decision conversations compared to England.
- **Table 2** provides consent/authorisation rates for the last five years by nation.
- **Figure 5** provides DBD and DCD consent/authorisation rates by each nation for the same time period.
- **Table 3** provides consent/authorisation rates for the four consent/authorisation groups for the most recent period.

Figure 4a - Quarterly deceased donor consent rates in England, April 2015 to March 2021

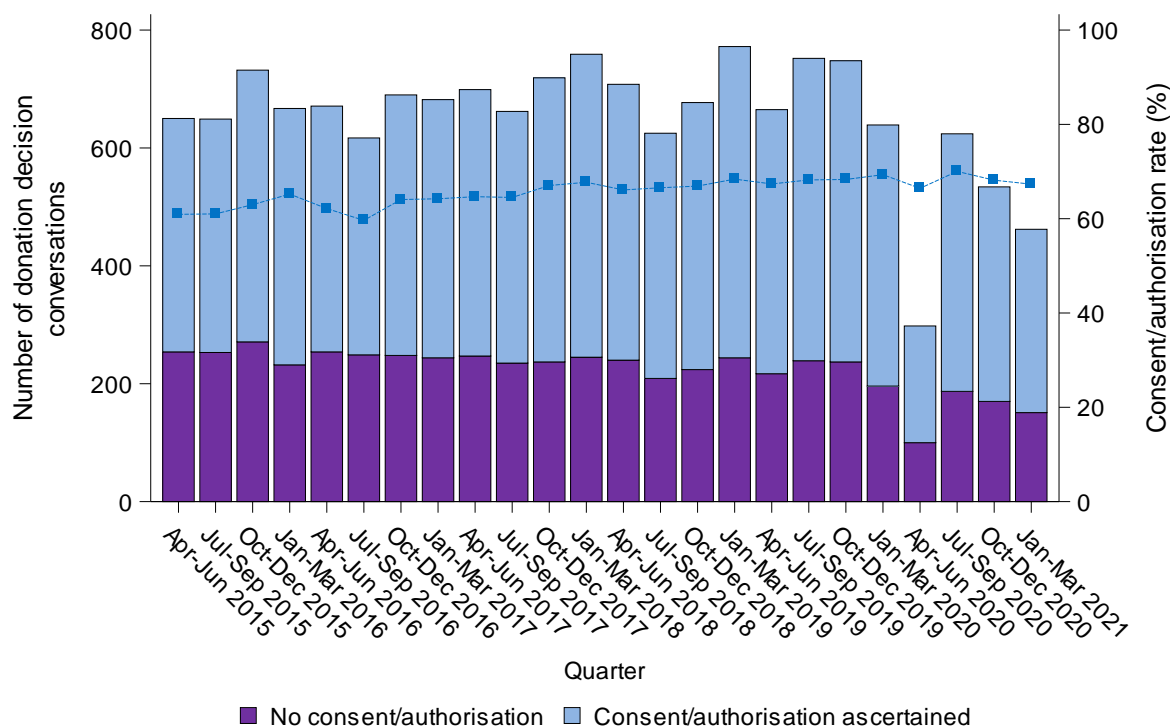


Figure 4b - Quarterly deceased donor consent rates in Wales, April 2015 to March 2021

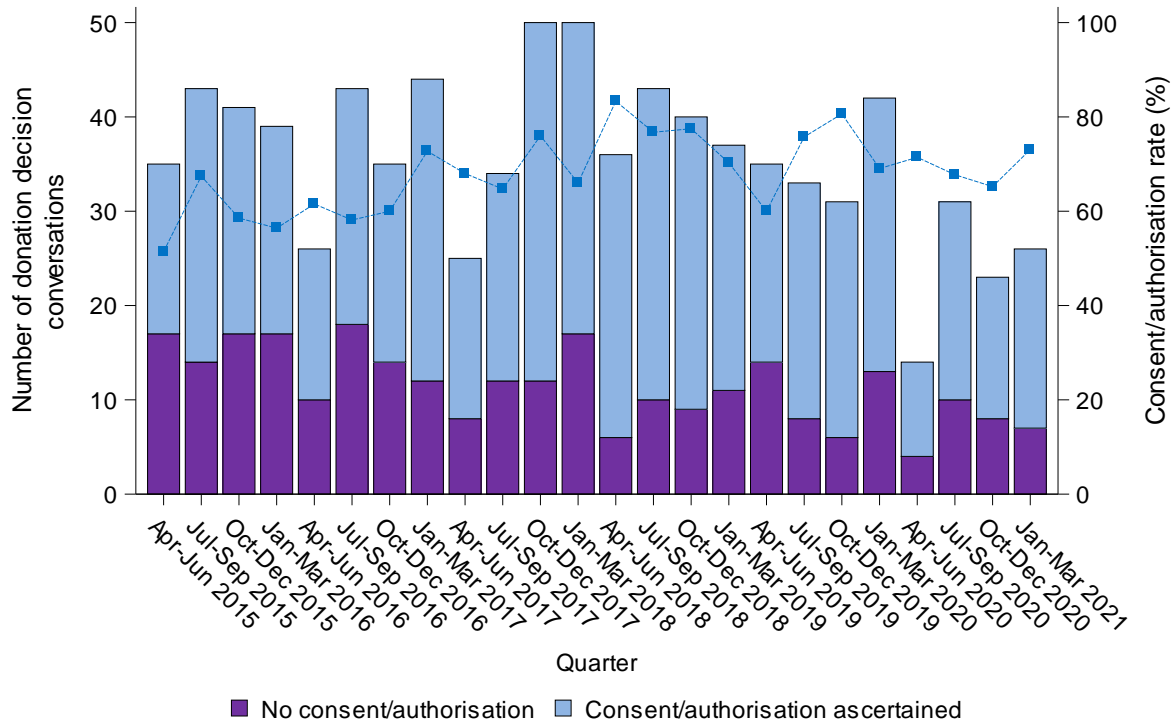


Figure 4c - Quarterly deceased donor authorisation rates in Scotland, April 2015 to March 2021

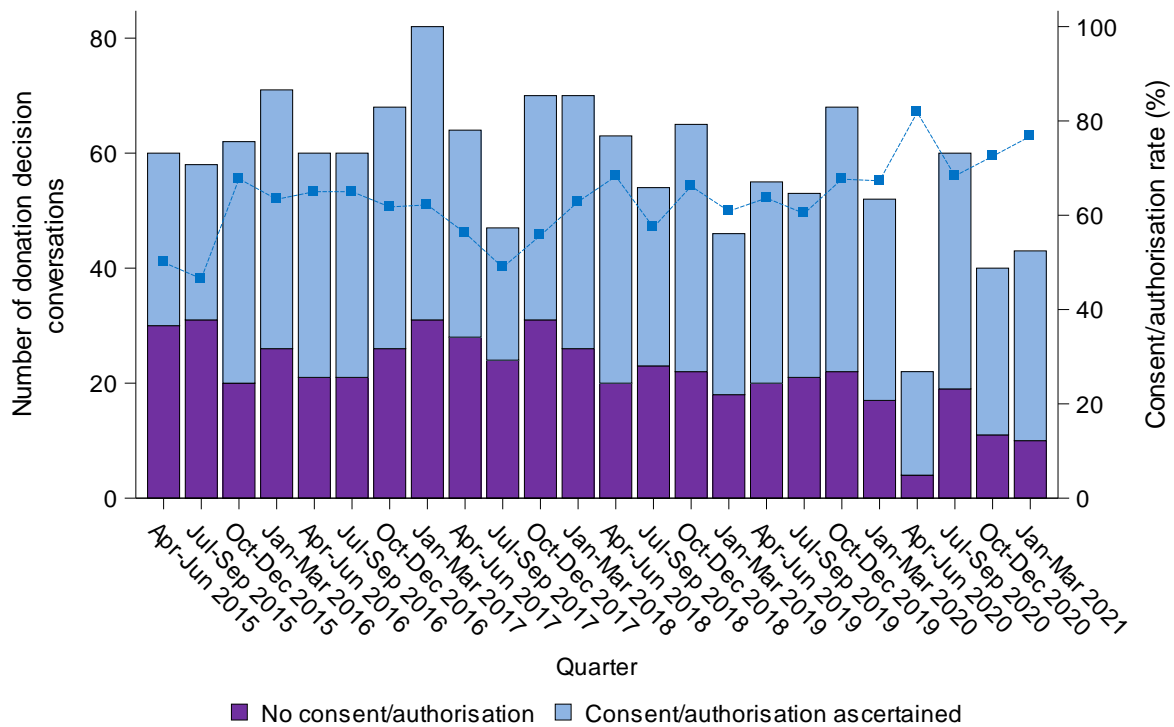


Figure 4d - Quarterly deceased donor consent rates in Northern Ireland, April 2015 to March 2021

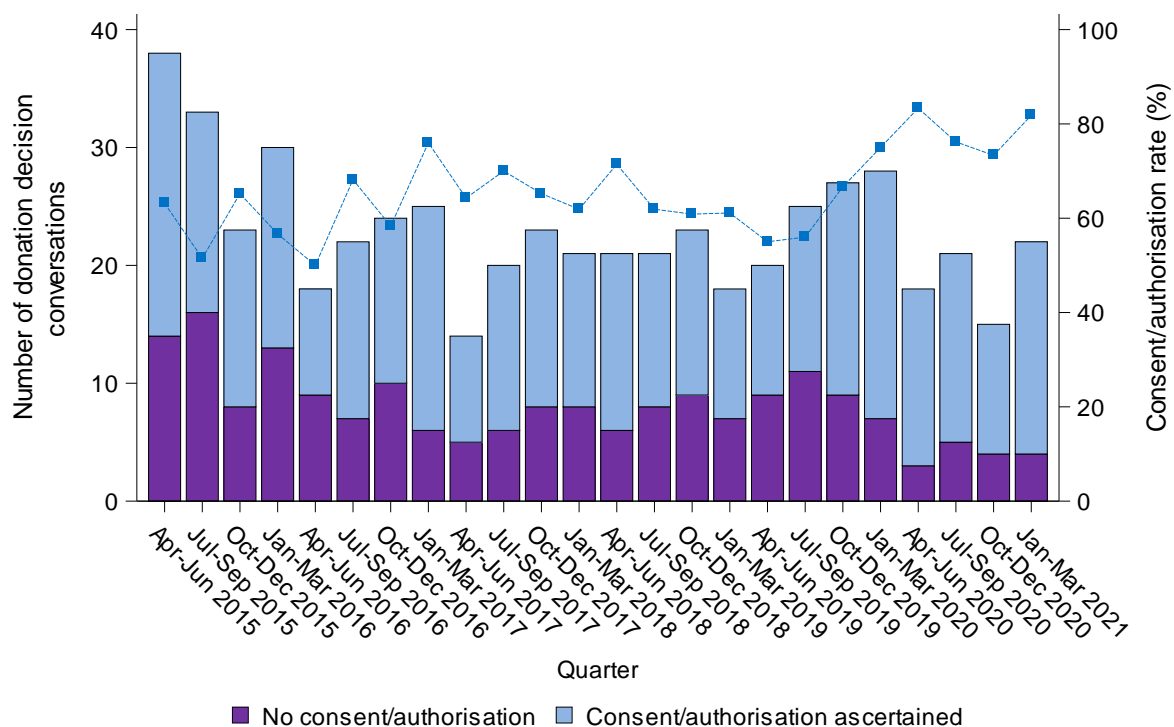


Table 2 - Donation decision conversations and consent/authorisation rate, by nation and financial year, April 2016 – March 2021

Nation	2016/17		2017/18		2018/19		2019/20		2020/21	
	N	%	N	%	N	%	N	%	N	%
England	2660	62.6	2839	66.0	2782	67.0	2804	68.3	1918	68.3
Scotland	270	63.3	251	56.6	228	63.6	228	64.9	165	73.3
Wales	148	63.5	159	69.2	156	76.9	141	70.9	94	69.1
N. Ireland	89	64.0	78	65.4	83	63.9	100	64.0	76	78.9
UK*	3176	62.8	3333	65.5	3253	67.2	3280	68.0	2254	69.1

*Includes cases from the Crown Dependencies reported in **Appendix A1**.

Figure 5 - Quarterly DBD/DCD consent/authorisation rates, April 2015 to March 2021

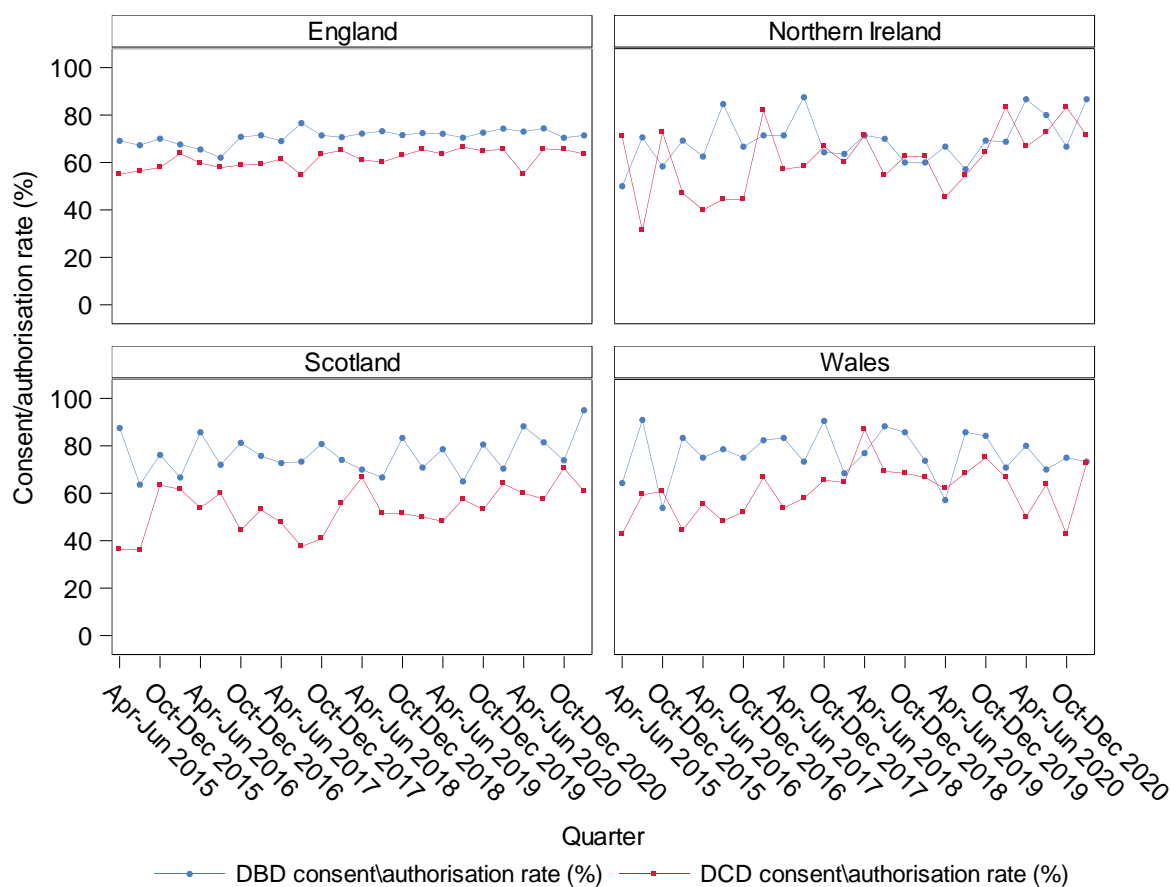


Table 3 - Donation decision conversations and consent/authorisation rate, by nation and consent/authorisation group, April 2020 – March 2021

Nation	Expressed opt in		Deemed consent/authorisation		Expressed opt out		Other	
	N	%	N	%	N	%	N	%
England	840	92.4	521	66.6	187	0.0	370	50.5
Scotland	85	94.1	2	100.0	16	0.0	62	62.9
Wales	39	97.4	29	65.5	15	0.0	11	72.7
N. Ireland	29	96.6	.	.	5	0.0	42	76.2
UK*	993	92.8	553	66.7	223	0.0	485	54.8

*Includes cases from the Crown Dependencies.

A funnel plot is displayed in **Figure 6a** comparing the deceased donor consent/authorisation rate between the four UK nations. Each nation is represented on the plot as a blue dot. The UK rate is shown on the plot as a green horizontal dashed line, together with 95% and 99.8% confidence limits for this rate. These limits form a 'funnel', which is shaded using the gold, silver, bronze, amber, and red (GoSBAR) colour scheme. If a point lies within the 95% limits, shaded bronze, then that nation has a rate that is statistically consistent with the UK rate. If a point lies outside the 95% confidence limits, shaded silver or amber, this serves as an alert that the nation may have a rate that is significantly different than the UK rate. When a point lies above the upper 99.8% limit, shaded gold, this indicates that the nation has a rate that is significantly higher than the UK rate, while a point that lies below the lower limit, shaded red, has a rate that is significantly lower than the UK.

It is important to note that, in these plots, the UK rate is dominated by the consent rate in England, such that these funnel plot compare rates in Wales, Scotland and Northern Ireland with the equivalent rate in England. Additionally, these are unadjusted funnel plots so any differences in patient mix, between the four nations, have not been accounted for.

Equivalent funnel plots are also presented, in **Figures 6b** and **6c**, comparing separate DBD and DCD consent/authorisation rates, respectively.

Figure 6a - All deceased donor consent/authorisation rates by nation, April 2020 to March 2021

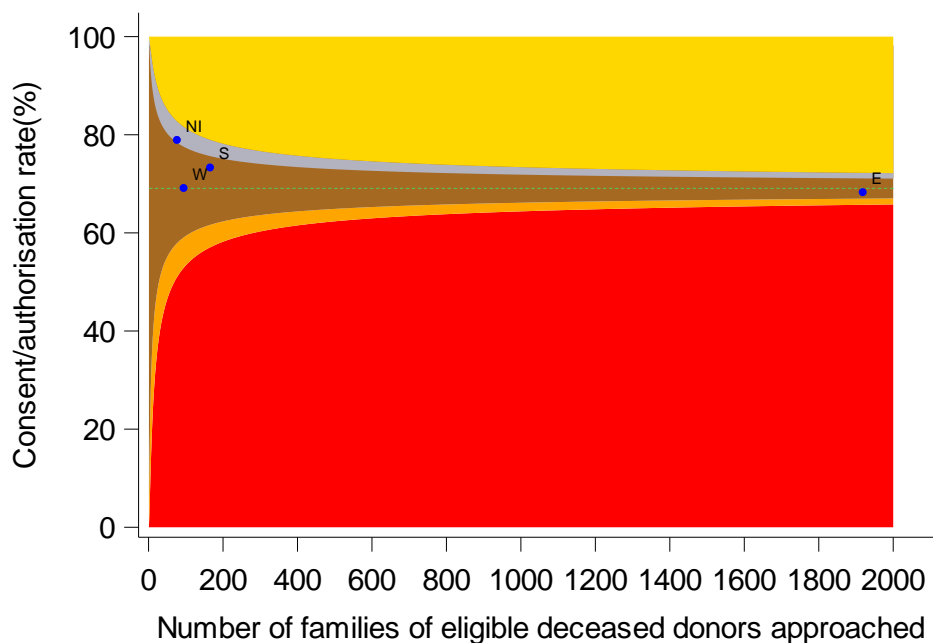


Figure 6b - DBD consent/authorisation rates by nation, April 2020 to March 2021

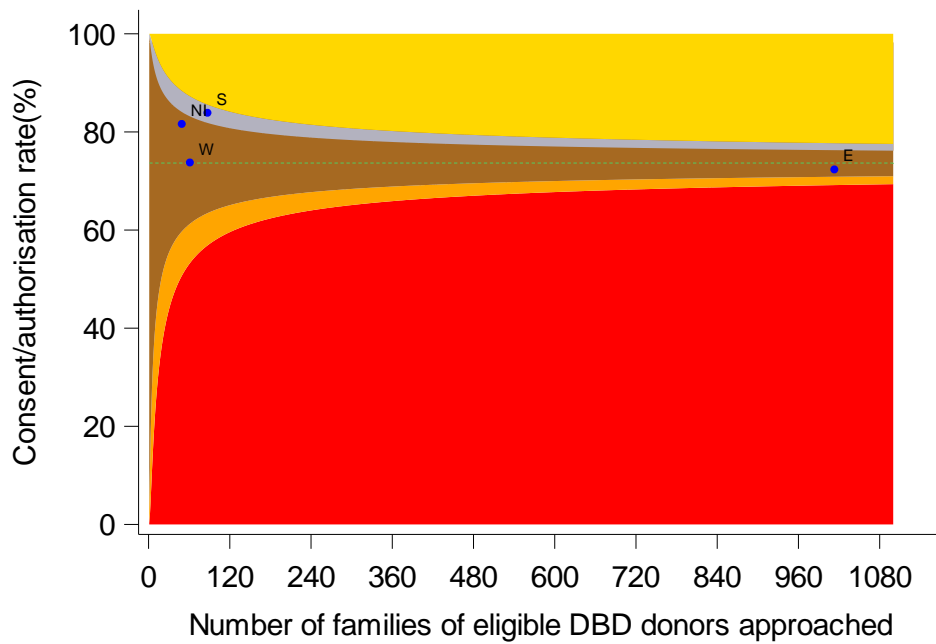
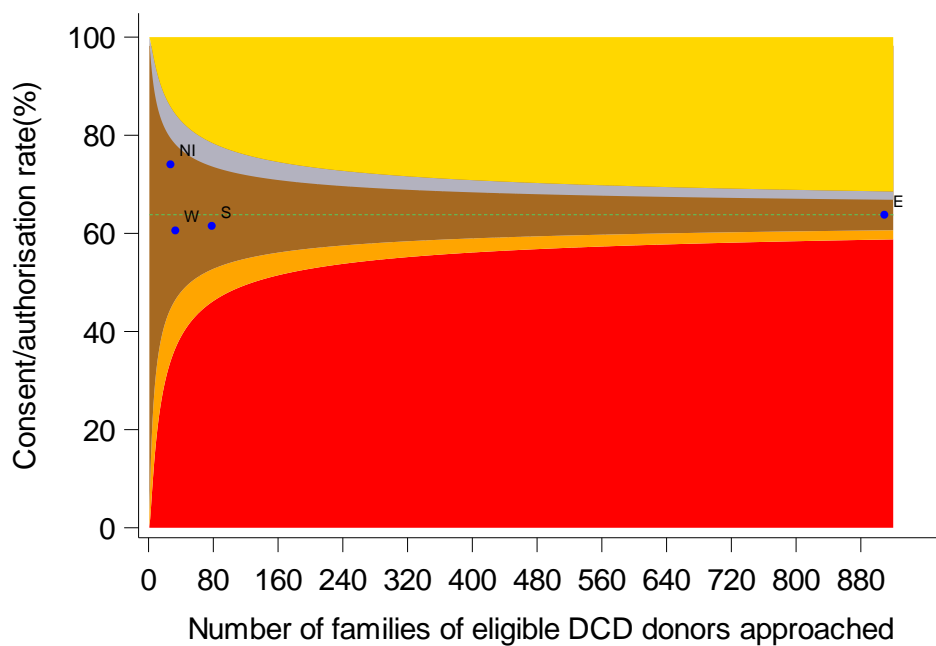


Figure 6c - DCD consent/authorisation rates by nation, April 2020 to March 2021



Appendix

Figure A1 – Crown Dependency ODR registrations pmp by 31 March 2021

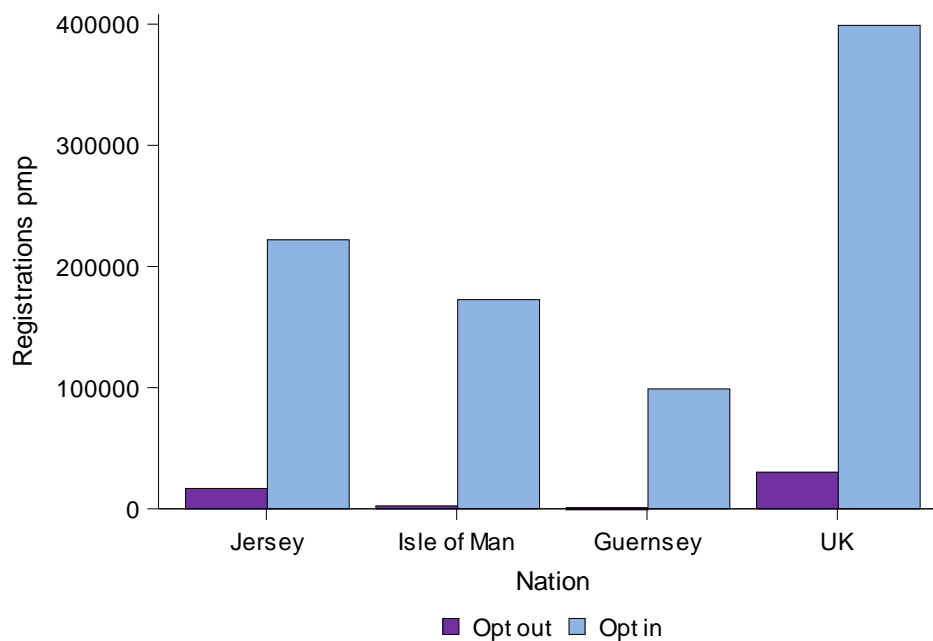
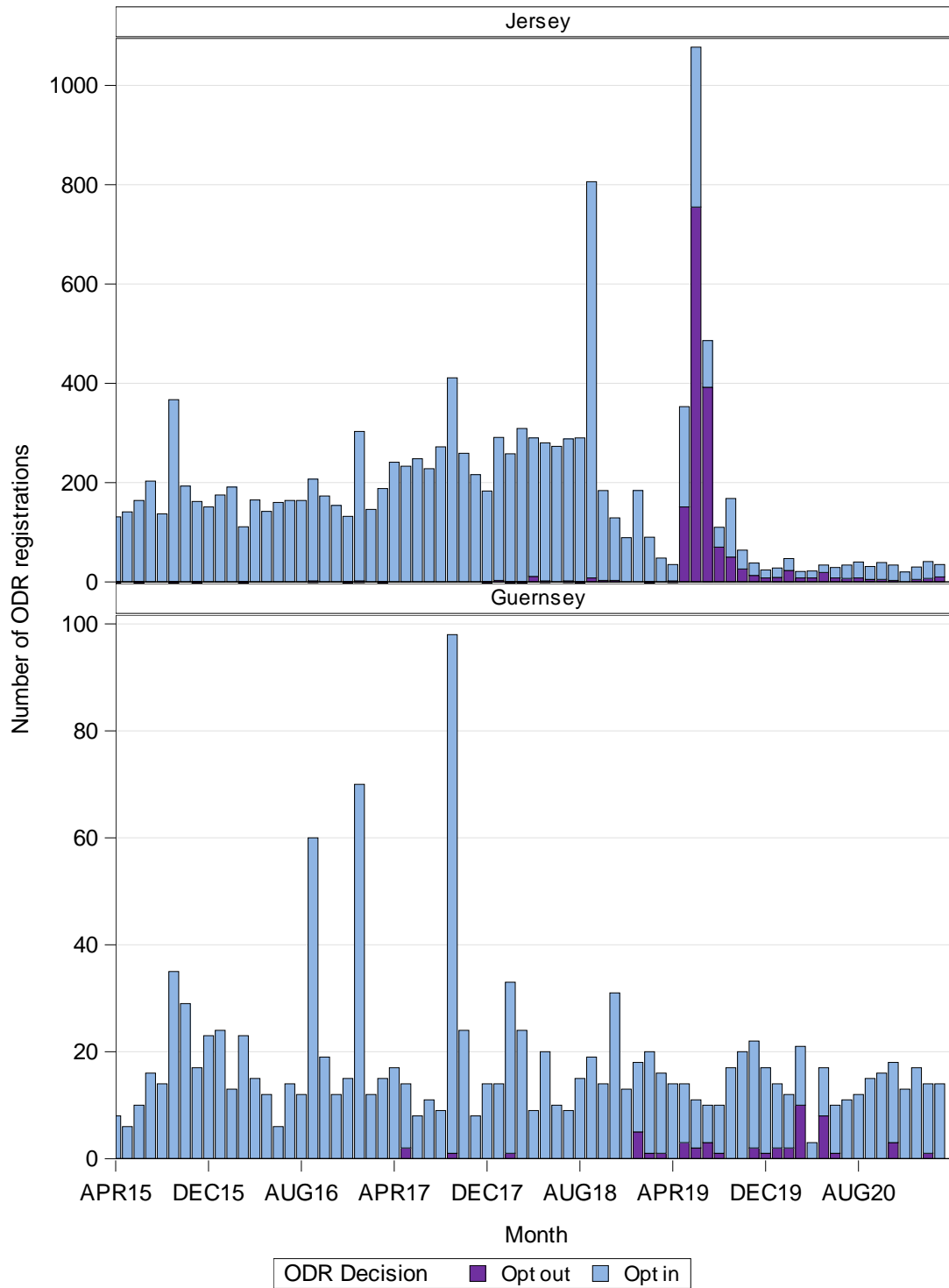


Table 1 - Crown Dependency ODR registrations pmp at 31 March 2021

Crown dependency	Opt-in registrations			Opt-out registrations		
	N	%	pmp*	N	%	pmp*
Jersey	22201	22.2	222010	1682	1.7	16820
Isle of Man	13811	17.3	172638	197	0.2	2463
Guernsey	6928	9.9	98971	56	0.1	800
UK	26750559	40.3	402627	2030703	3.1	30564

* Population estimates are the mid-2019 estimates based on ONS 2011 Census figures

Figure 2 - Crown Dependency ODR registrations by decision, April 2015 to March 2021



Consent rate data for the Crown Dependencies are excluded due to small numbers. Since the introduction of opt out legislation in the Jersey, there have been two out of 11 donation decision conversations where criteria for deemed consent were met.