

OPT OUT SUMMARY REPORT ODR REGISTRATIONS AND CONSENT/AUTHORISATION RATES

May 2024

Key messages

- Opt out legislation has been implemented in Wales (2015), Jersey (2019), England (2020), Scotland (2021), Guernsey (2023), and most recently Northern Ireland on 1st June 2023 and is making progress in the Isle of Man. NHSBT is working closely with the Governments to support the legislation development and implementation.
- Northern Ireland and Scotland have the highest proportion of opt in registrations on the ODR, 54.8% and 52.9% of the population, respectively.
- Wales has the highest proportion of opt out registrations on the ODR, 6.0%. England and Scotland have a similar proportion of opt out registrations, 3.8% and 3.3%, respectively.
- UK consent/authorisation rates have continued to fall, in 2023/24, to 60.5% from a high of 69.3% in 2020/21.
- Comparing 2023/24 and 2022/23 only Northern Ireland has an improving authorisation rate, 66.4% and 64.9% respectively.
- Funnel plots for 2023/24 indicate that the deceased donor consent/authorisation rates are in line with the national average across all four nations, i.e, all nations are statistically similar.
- Separate DBD and DCD funnel plots demonstrate that DBD and DCD consent/authorisation rates are in line with the national average across all four UK nations.
- Where deemed consent/authorisation applies, the UK consent/authorisation rate was 51.3%. In Scotland a verbally expressed opt-in is recorded as a deemed authorisation. Relative to England, Wales and Northern Ireland, the adjusted deemed authorisation rate in Scotland is 55.2%.

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
Guernsey	Opt out - Deemed consent	1 January 2023
N. Ireland	Opt in (Opt out - Deemed consent)	1 June 2023
Isle of Man	Opt in (Opt out - Deemed consent)	Opt out legislation in progress

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, England or Guernsey 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, Jersey and Guernsey. 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 and deemed criteria are not met.
 Paediatric patients are included in this group. In Scotland, this group includes patients who have verbally expressed a decision to opt in but do not meet deemed authorisation criteria.

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 2021 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 six monthly ODR registrations in the four UK nations. Equivalent data for the Crown Dependencies are included in the Appendix.

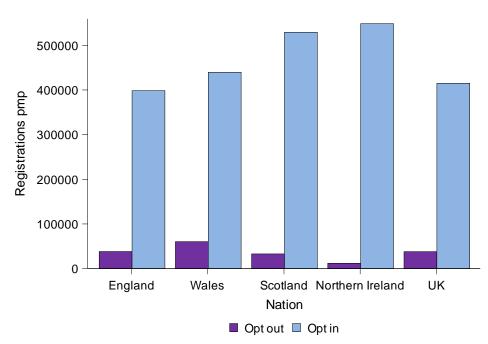


Figure 1 - ODR registrations pmp by 31 March 2024

Table 1 - ODR registrations pmp at 31 March 2024

Nation	Opt-i	n registration	S	Opt-out registrations			
Nation	N %		pmp*	Ν	%	pmp*	
England	22754769	39.8	398438	2182640	3.8	38218	
Wales	1375688	44.0	439517	189004	6.0	60385	
Scotland	2883913	52.9	529158	179440	3.3	32925	
N. Ireland	1047504	54.8	548431	22366	1.2	11710	
UK	28148363	41.5	414862	2576027	3.8	37966	

* Population estimates are the mid-2022 estimates based on ONS 2021 Census figures

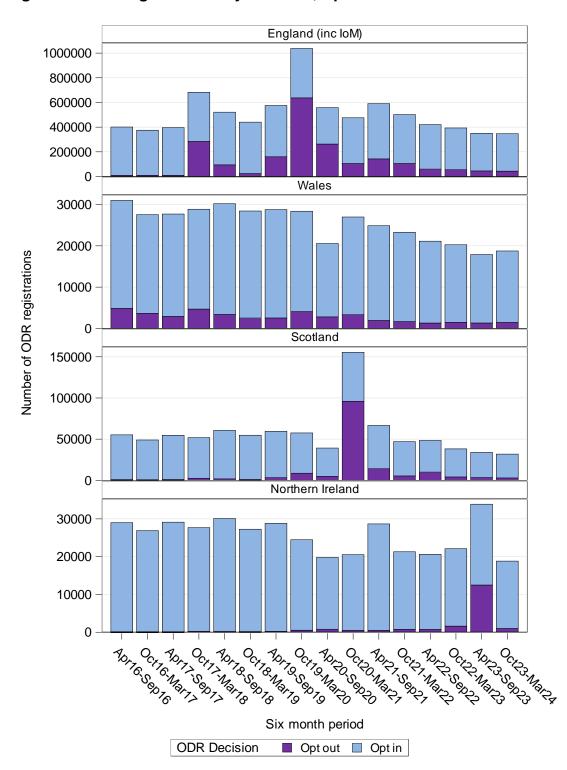


Figure 2 - ODR registrations by decision, April 2016 to March 2024

Potential Donor Audit

In this section, data from the PDA are presented.

- Figures 3a to 3d 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 six-monthly 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 4** 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. It is noteworthy that, in Scotland, patients who have verbally expressed an opt in decision are recorded as deemed authorisations but expressed opt in decisions elsewhere in the UK.

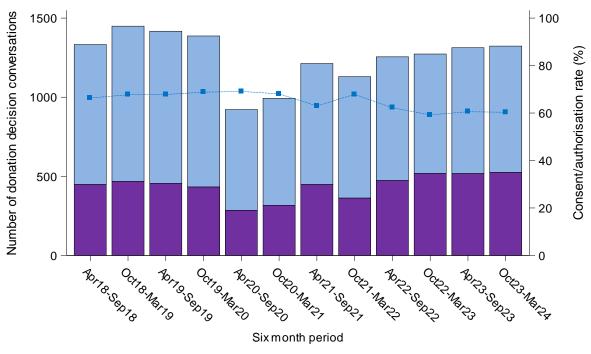
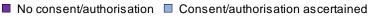


Figure 3a – Six-monthly deceased donor consent rates in England, April 2018 to March 2024



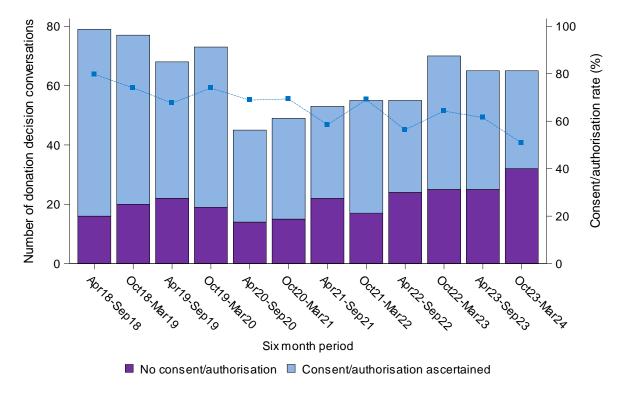
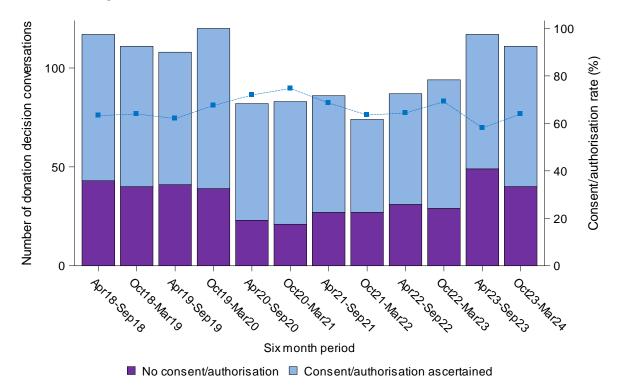


Figure 3b – Six-monthly deceased donor consent rates in Wales, April 2018 to March 2024

Figure 3c – Six-monthly deceased donor authorisation rates in Scotland, April 2018 to March 2024



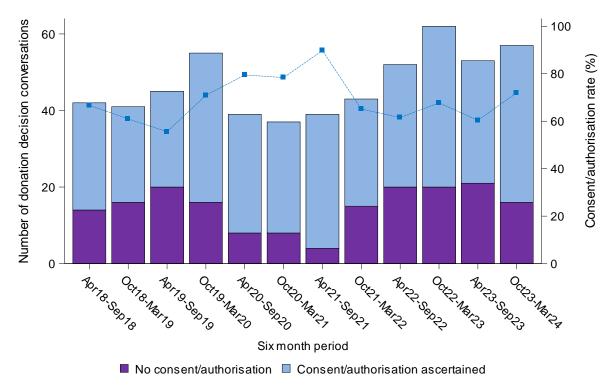


Figure 3d – Six-monthly deceased donor consent rates in Northern Ireland, April 2018 to March 2024

 Table 2 - Donation decision conversations and consent/authorisation rate, by

 nation and financial year, April 2019 to March 2024

Nation	2019	/20	0 2020/21 2021/22		/22	2022/23		2023/24		
	Ν	%	Ν	%	Ν	%	Ν	%	Ν	%
England	2804	68.3	1915	68.6	2343	65.3	2528	60.7	2636	60.4
Scotland	228	64.9	165	73.3	160	66.3	181	66.9	228	61.0
Wales	141	70.9	94	69.1	108	63.9	125	60.8	130	56.2
N. Ireland	100	64.0	76	78.9	82	76.8	114	64.9	110	66.4
UK*	3280	68.0	2251	69.3	2696	65.7	2952	61.3	3107	60.5

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

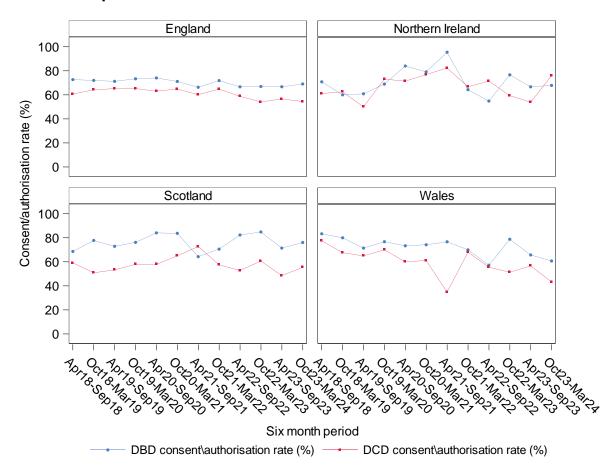


Figure 4 – Six-monthly DBD/DCD consent/authorisation rates, April 2018 to March 2024

Table 3 - Donation decision conversations and consent/authorisation rate, by
nation and consent/authorisation group, April 2023 to March 2024

Nation	Expressed Deemed opt in consent/ authorisation		ent/	Expressed opt out		Other		
	Ν	%	Ν	%	Ν	%	Ν	%
England	1118	89.8	966	50.1	291	0.3*	261	39.8
Scotland**	85	82.4	75	62.7	33	0.0	35	62.9
Wales	50	88.0	43	53.5	23	0.0	14	42.9
N. Ireland	55	90.9	23	60.9	9	0.0	23	39.1
UK***	1309	89.3	1109	51.3	356	0.3	333	42.3

* 1 case where formal consent was given but donation did not proceed as further information became available that the patient had verbally expressed a decision not to donate.

** 17 patients who expressed a verbal opt in decision are included as deemed authorisation in Scotland. In Scotland a verbally expressed opt-in is recorded as a deemed authorisation. Relative to England, Wales and Northern Ireland the adjusted expressed opt in rate in Scotland is 83.9% and the adjusted deemed authorisation rate is 55.2%.

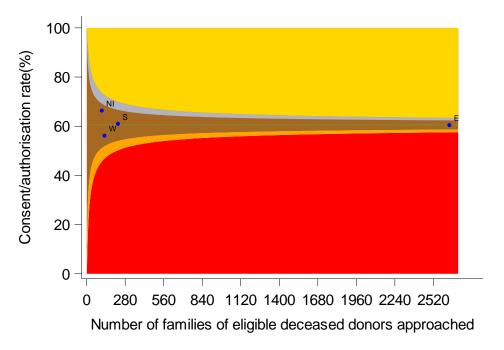
***Total numbers include cases from the Crown Dependencies.

A funnel plot is displayed in **Figure 5a** 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 5b** and **5c**, comparing separate DBD and DCD consent/authorisation rates, respectively.

Figure 5a - All deceased donor consent/authorisation rates by nation, April 2023 to March 2024





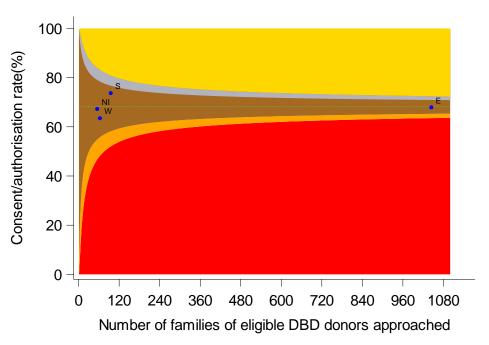
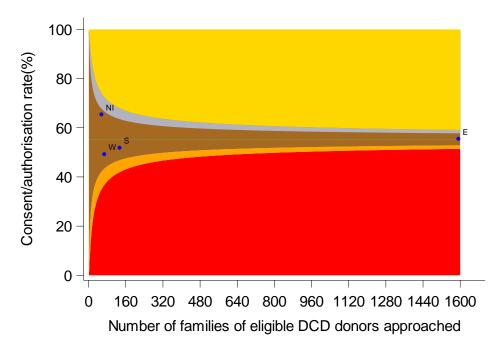


Figure 5c - DCD consent/authorisation rates by nation, April 2023 to March 2024



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May 2024

Appendix

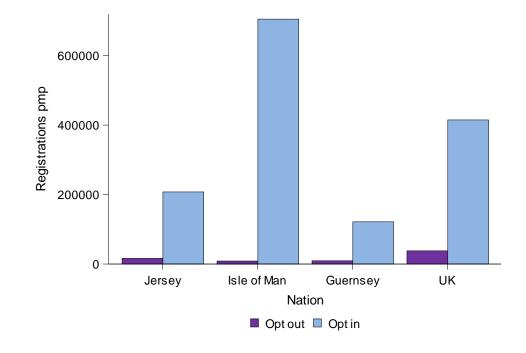


Figure A1 – Crown Dependency ODR registrations pmp by 31 March 2024

Table A1 - Crown Dependency ODR registrations pmp at 31 March 2024

Crown	Opt-i	n registratio	าร	Opt-out registrations			
dependency	Ν	%	pmp*	Ν	%	pmp*	
Jersey	22831	20.8	207555	1788	1.6	16255	
Isle of Man	56411	70.5	705138	692	0.9	8650	
Guernsey	7292	12.2	121533	554	0.9	9233	
UK	28148363	41.5	414862	2576027	3.8	37966	

* Population estimates are the mid-2022 estimates based on ONS 2021 Census figures

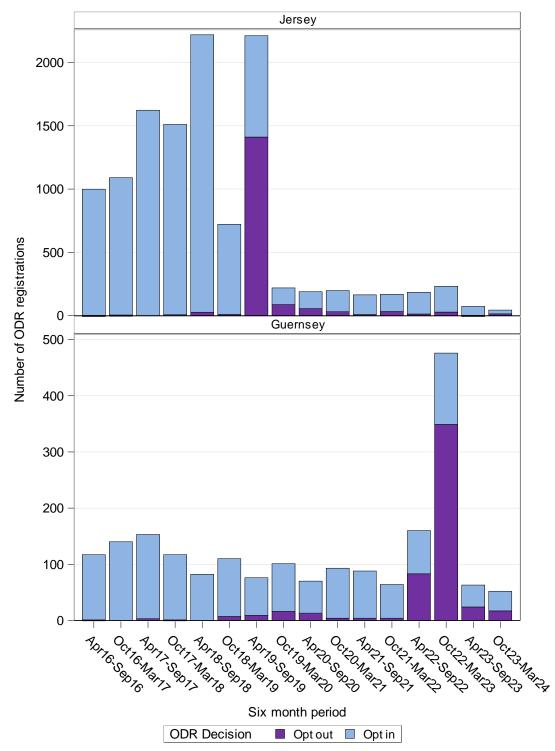


Figure A2 - Crown Dependency ODR registrations by decision, April 2016 to March 2024

Consent rate data for the Crown Dependencies are excluded due to small numbers. Since the introduction of opt out legislation in Jersey, there have been seven out of 22 donation decision conversations where criteria for deemed consent were met.