

OPT OUT SUMMARY REPORT ODR REGISTRATIONS AND CONSENT/AUTHORISATION RATES

May 2022

Key messages

- Opt out legislation has been implemented in Wales (2015), Jersey (2019), England (2020) and Scotland (2021). New legislation is due to be implemented on 1 January 2023 in Guernsey, in spring 2023 in Northern Ireland and is making progress in the Isle of Man. 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, 52.3% of the population. Northern Ireland also has a high proportion of the population registered as an opt in, 51.1%.
- Wales has the highest proportion of opt out registrations on the ODR, 6.2%. England and Scotland have similar proportion, 3.5% and 3.0%, respectively.
- UK consent/authorisation rates have fallen to 65.7% in 2021/22 from a high of 69.3% in 2020/21. This declining trend is observed in all four UK nations.
- Where deemed consent/authorisation applies, the UK consent/authorisation rate has fallen from 66.7% in 2020/21 to 59.3% in 2021/22.
- Funnel plots for 2021/22 indicate that deceased donor consent/authorisation rates in England, Wales and Scotland are in line with the national average but Northern Ireland has a consent rate that is significantly higher.
- 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.

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 in (Opt out - Deemed consent)	1 January 2023
N. Ireland	Opt in (Opt out - Deemed consent)	Spring 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 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.

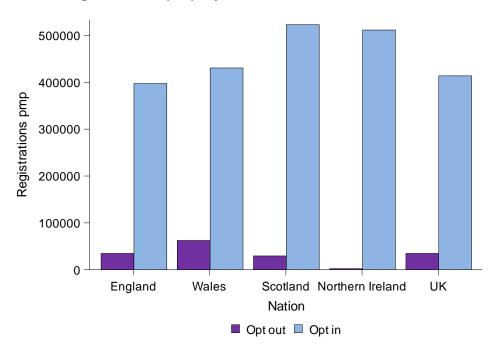


Figure 1 - ODR registrations pmp by 31 March 2022

Table 1 - ODR	registrations pmp	at 31	March 2022
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Nation	Opt-i	n registratior	າຣ	Opt-out registrations			
Nation	Ν	%	pmp*	Ν	pmp*		
England	22467602	39.7	397305	1969860	3.5	34834	
Wales	1364623	43.0	430480	198030	6.2	62470	
Scotland	2859714	52.3	522800	161625	3.0	29548	
N. Ireland	971644	51.1	511392	4370	0.2	2300	
UK	27750074	41.4	413686	2335905	3.5	34823	

* Population estimates are the mid-2020 estimates based on ONS 2011 Census figures

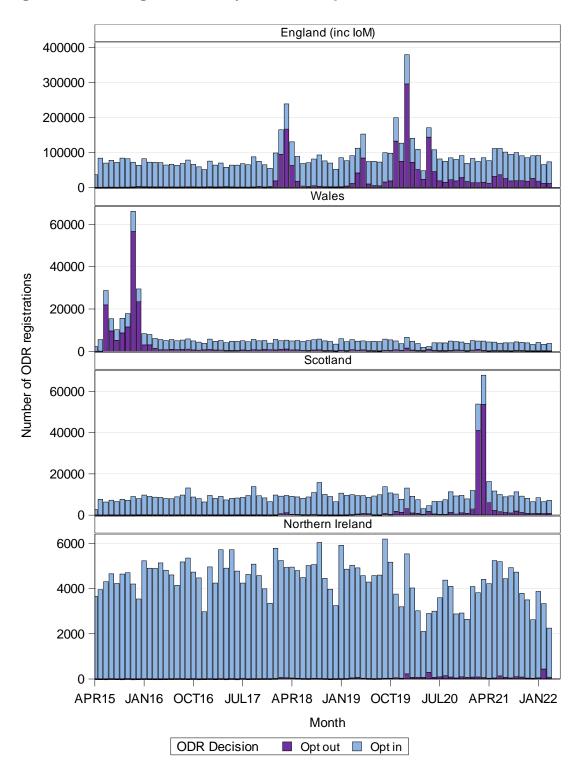


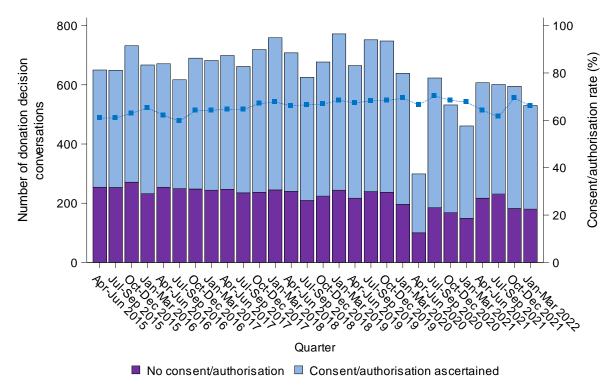
Figure 2 - ODR registrations by decision, April 2015 to March 2022

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.





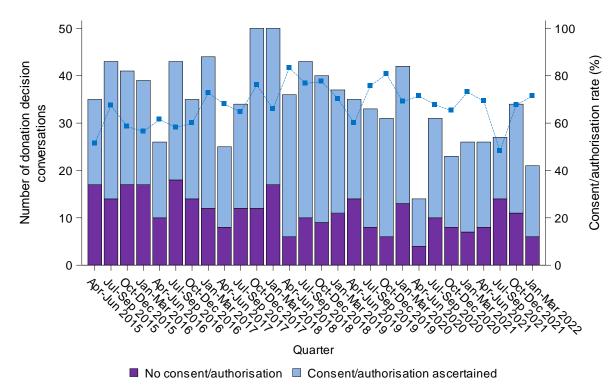
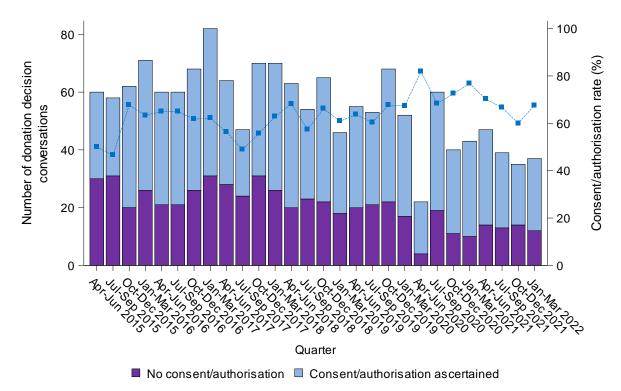
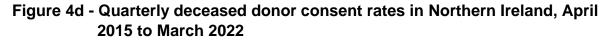


Figure 4b - Quarterly deceased donor consent rates in Wales, April 2015 to March 2022

Figure 4c - Quarterly deceased donor authorisation rates in Scotland, April 2015 to March 2022





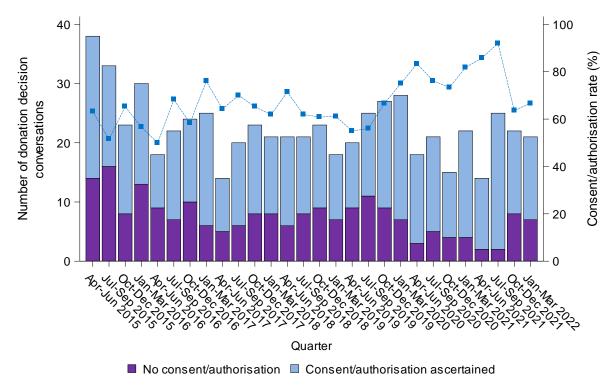


Table 2 - Donation decision conversations and consent/authorisation rate, by nation and financial year, April 2017 – March 2022

Nation	2017/18		2018/19		2019/20		2020/21		2021/22	
	Ν	%	Ν	%	Ν	%	Ν	%	Ν	%
England	2839	66.0	2782	67.0	2804	68.3	1915	68.6	2333	65.3
Scotland	251	56.6	228	63.6	228	64.9	165	73.3	158	66.5
Wales	159	69.2	156	76.9	141	70.9	94	69.1	108	63.9
N. Ireland	78	65.4	83	63.9	100	64.0	76	78.9	82	76.8
UK*	3333	65.5	3253	67.2	3280	68.0	2251	69.3	2684	65.7

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

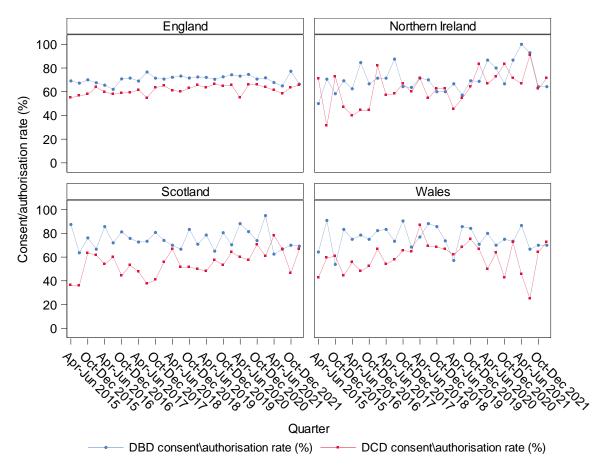


Figure 5 - Quarterly DBD/DCD consent/authorisation rates, April 2015 to March 2022

 Table 3 - Donation decision conversations and consent/authorisation rate, by

 nation and consent/authorisation group, April – March 2022

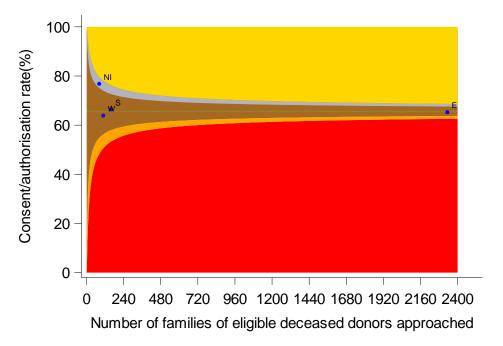
Nation	-	Expressed Deemed opt in consent/ authorisation		Expressed opt out		Other		
	Ν	%	Ν	%	Ν	%	Ν	%
England	1018	92.3	796	57.8	289	0.0	230	53.5
Scotland*	64	85.9	53	79.2	24	0.0	17	47.1
Wales	45	91.1	39	61.5	16	0.0	8	50.0
N. Ireland	39	97.4			4	0.0	39	64.1
UK**	1167	92.1	889	59.3	333	0.0	295	54.6

* Patients who expressed a verbal opt in decision are included as deemed authorisation in Scotland. **Total numbers include 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.

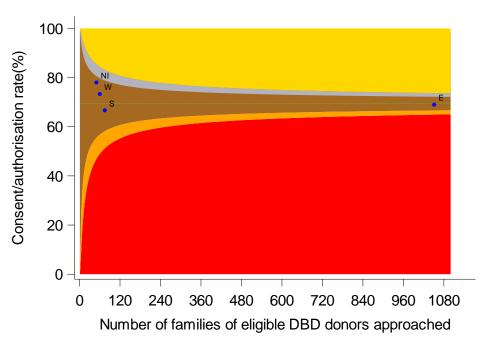
It is important to note that, in these plots, the UK rate is dominated by the consent rate in England, such that these funnel plot compare rates in Wales, Scotland and Northern Ireland with the equivalent rate in England. Additionally, these are unadjusted funnel plots so any differences in patient mix, 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.

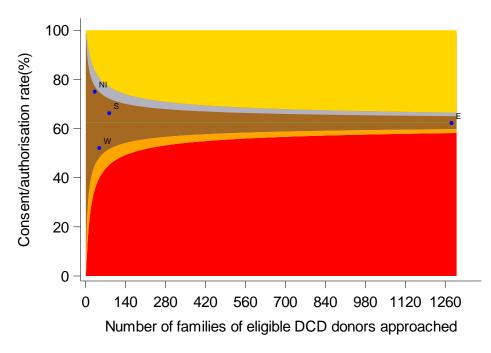
Figure 6a - All deceased donor consent/authorisation rates by nation, April 2021 to March 2022











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May 2022

Appendix



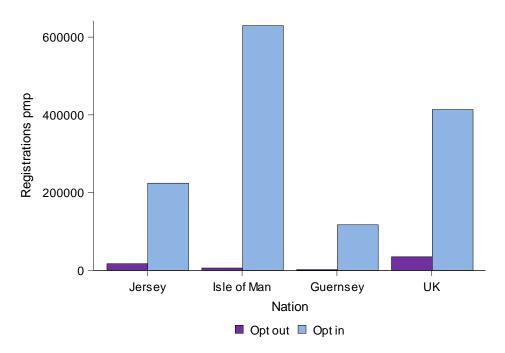


Table 1 - Crown Dependency ODR registrations pmp at 31 March 2022

Crown	Opt-iı	n registration	IS	Opt-out registrations			
dependency	Ν	%	pmp*	Ν	%	pmp*	
Jersey	22428	22.4	224280	1723	1.7	17230	
Isle of Man	56656	63.0	629511	553	0.6	6144	
Guernsey	7042	11.7	117367	120	0.2	2000	
UK	27750074	41.4	413686	2335905	3.5	34823	

* Population estimates are the mid-2020 estimates based on ONS 2011 Census figures

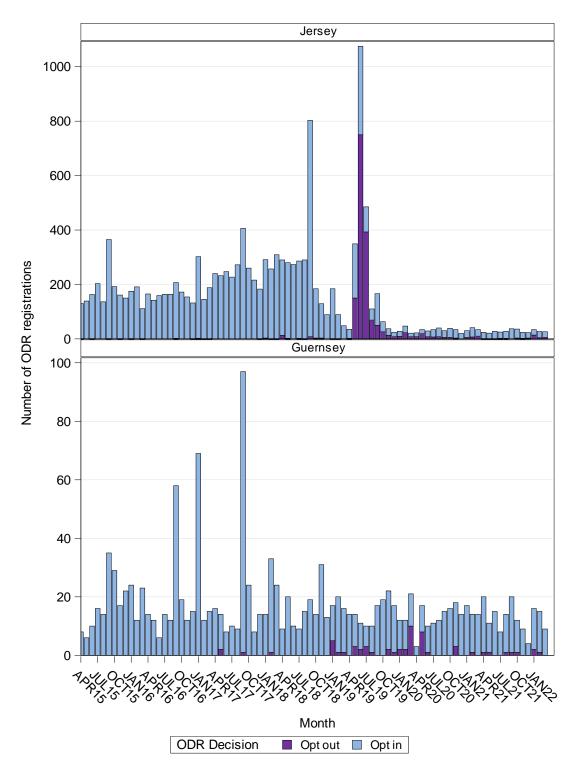


Figure 2 - Crown Dependency ODR registrations by decision, April 2015 to March 2022

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 three out of 14 donation decision conversations where criteria for deemed consent were met.