

OPT OUT SUMMARY REPORT ODR REGISTRATIONS AND CONSENT/AUTHORISATION RATES

OCTOBER 2020

Key messages

- Opt out legislation has been implemented in Wales (2015), Jersey (2019) and England (2020). Implementation of new legislation is planned for Scotland, Guernsey and the Isle of Man in 2021.
- Scotland has the highest proportion of opt in registrations on the ODR, 50.2%.
- Wales has the highest proportion of opt out registrations on the ODR, 6.1%.
 Opt out registrations remain low in nations without out opt legislation.
- 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 73.1%, 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 DBD and DCD consent/authorisation rates are consistent across the UK.

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 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 in (Opt out - Deemed authorisation)	26 March 2021 (proposed)
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

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¹ If someone has asked to be removed from the register this will be accounted for and any backlog registrations will appear accurately. Removals data includes 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 registered 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.

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. ODR registrations for the Crown Dependencies has also been included. Population estimates are the mid-2018 estimates based on Office for National Statistics (ONS) 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 and three Crown Dependencies.

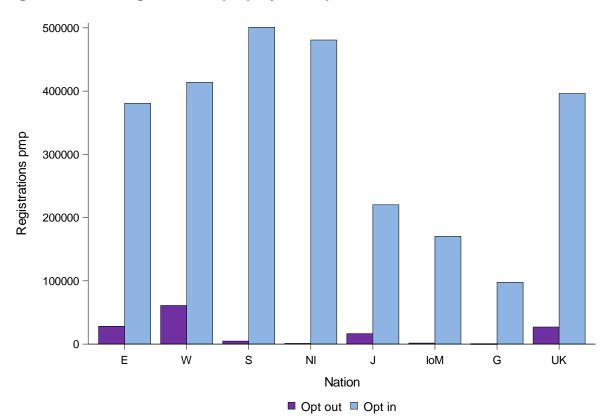


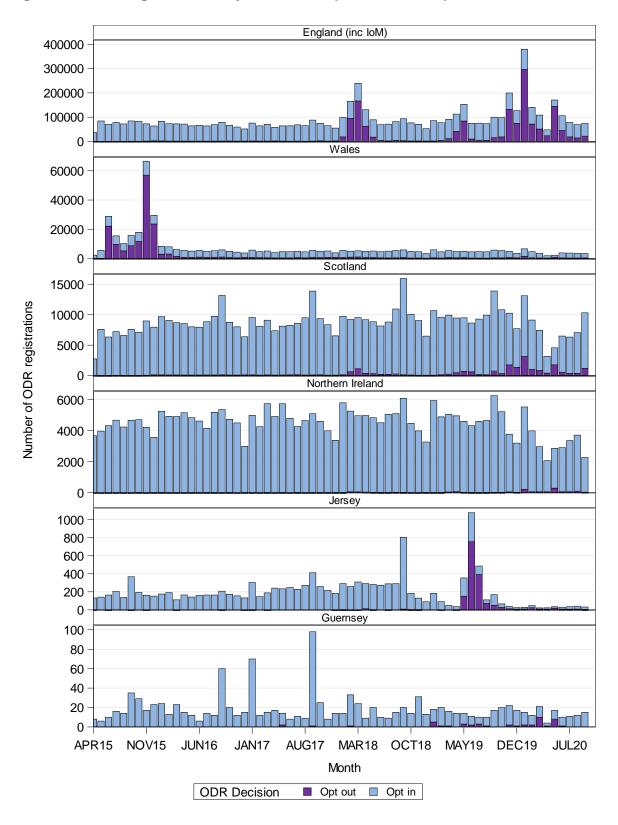
Figure 1 - ODR registrations pmp by 30 September 2020

Table 1 - ODR registrations pmp at 30 September 2020

Nation /	Opt-in registrations			Opt-out registrations			
Crown dependency	N	%	pmp*	N	%	pmp*	
	21308359	38.1	380642	1575039	2.8	28136	
England							
Wales	1299803	41.4	413950	191728	6.1	61060	
Scotland	2724752	50.1	500874	25959	0.5	4772	
N. Ireland	903957	48.1	480828	2244	0.1	1194	
Jersey	22025	22.0	220250	1652	1.7	16520	
Isle of Man	13632	17.0	170400	133	0.2	1663	
Guernsey	6831	9.8	97586	50	0.1	714	
UK	26325357	39.6	396228	1796864	2.7	27045	

^{*} Population estimates are the mid-2018 estimates based on ONS 2011 Census figures

Figure 2 - ODR registrations by decision, April 2015 to September 2020



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. Data on the Crown Dependencies has been excluded due to the small numbers. **Figure 5** provides DBD and DCD consent/authorisation rates by each nation for the same time period.

Figure 4a - Quarterly deceased donor consent/authorisation rates in England, April 2015 to September 2020

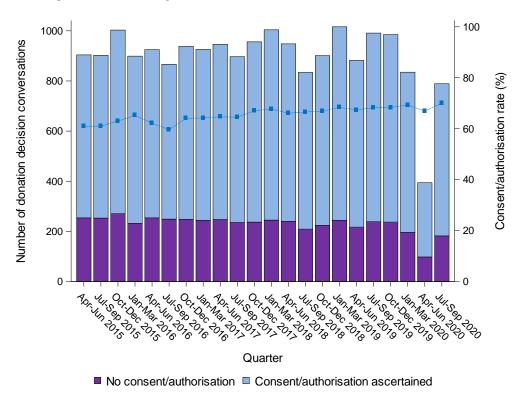


Figure 4b - Quarterly deceased donor consent/authorisation rates in Wales, April 2015 to September 2020

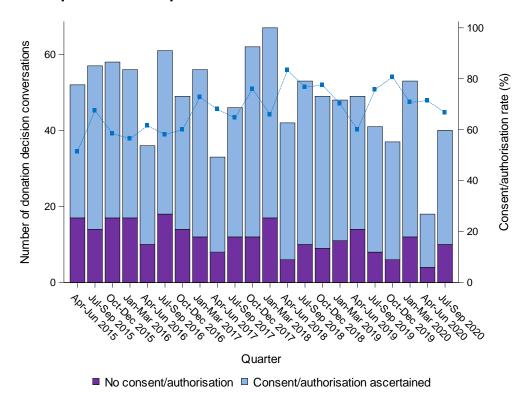


Figure 4c - Quarterly deceased donor consent/authorisation rates in Scotland, April 2015 to September 2020

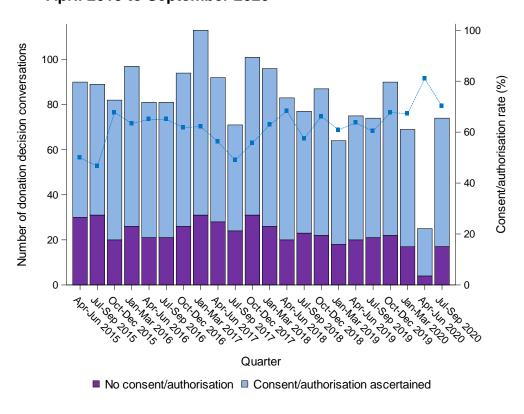


Figure 4d - Quarterly deceased donor consent/authorisation rates in Northern Ireland, April 2015 to September 2020

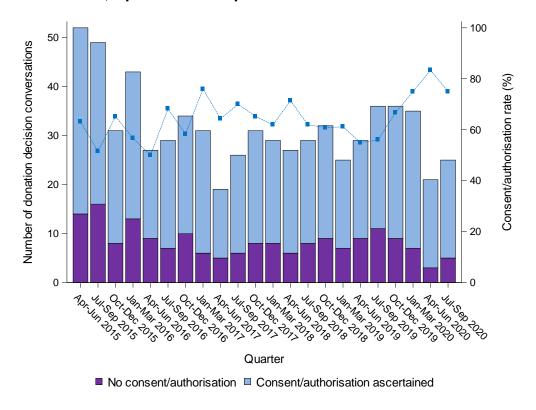
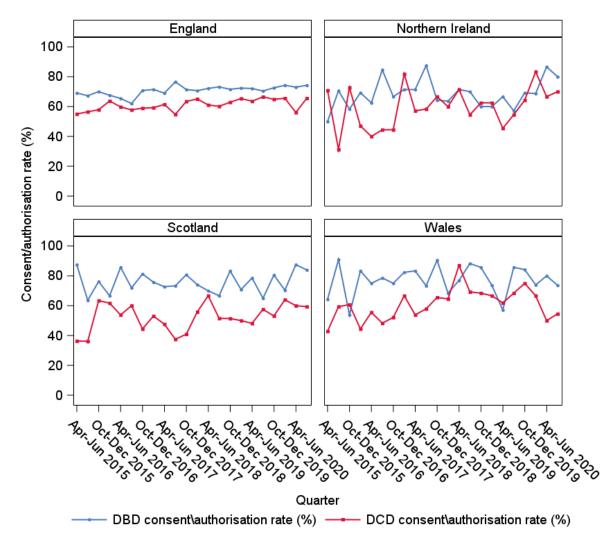


Table 2 - Donation decision conversations and consent/authorisation rate, by nation and financial year, April 2016 – September 2020

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	903	69.0
Scotland	270	63.3	251	56.6	228	63.6	228	64.9	78	73.1
Wales	148	63.5	159	69.2	156	76.9	140	71.4	44	68.2
N. Ireland	89	64.0	78	65.4	83	63.9	100	64.0	38	78.9
UK	3176	62.8	3333	65.5	3253	67.2	3279	68.1	1064	69.6

^{*} Data for the Crown Dependencies are excluded due to small numbers (<5)

Figure 5 - Quarterly DBD/DCD consent/authorisation rates, April 2015 to September 2020



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 September 2020

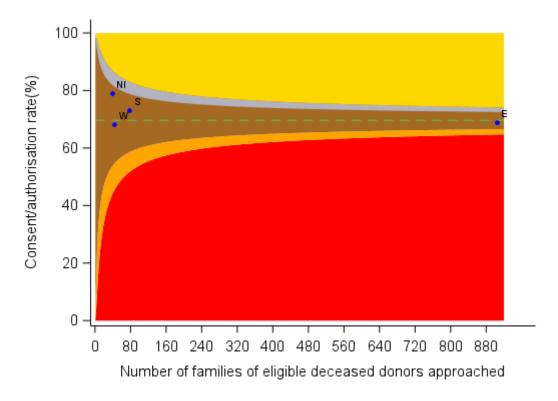


Figure 6b - DBD consent/authorisation rates by nation, April 2020 to September 2020

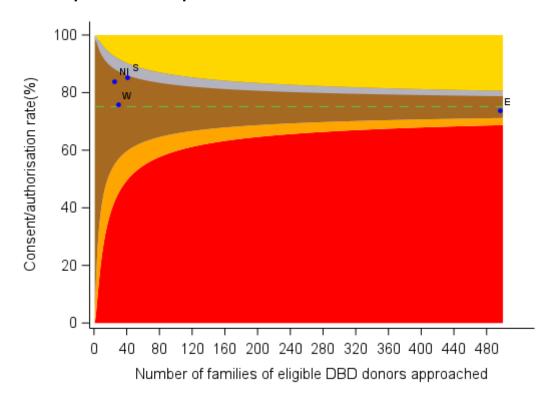
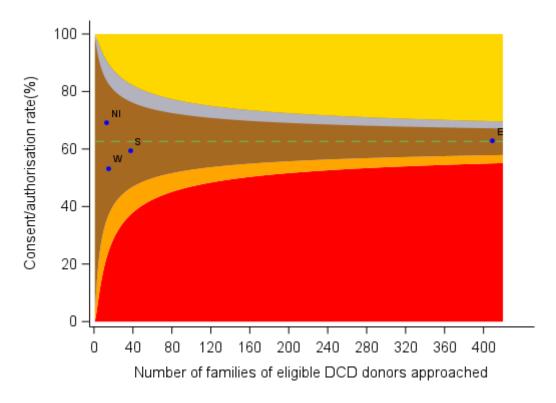


Figure 6c - DCD consent/authorisation rates by nation, April 2020 to September 2020



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