

**NHS BLOOD AND TRANSPLANT  
ORGAN DONATION AND TRANSPLANTATION DIRECTORATE**

**KIDNEY ADVISORY GROUP**

UPDATE ON CONSENT RATE FOR PATIENT DATA HELD WITHIN ODT

**INTRODUCTION**

- Members will be aware that the NHS Blood and Transplant (NHSBT) Patient Consent Scheme for obtaining explicit consent for use of personal data for purposes of registration, organ allocation and transplant follow-up has been in place since October 2005. Each month, transplant centres with outstanding consent are issued a report to help identify those patients where consent should be obtained.

**KIDNEY PATIENT CONSENT RATES**

- Of the 31781 patients across the United Kingdom that have been listed for a kidney transplant at some point in time since April 2008, 97.6% have their level of consent for the use of their personal data recorded on the UK Transplant Registry. The patient consent rates achieved by each centre are summarised in **Appendix I** and visualised in **Figure A1**. For those who have their level of consent known, the level recorded is shown in **Table 1**.
- NHSBT remains grateful for the efforts made by centres to ensure the continued success of this statutory scheme. There remains however some registration centres that are falling significantly short of the expected levels of consent and these are highlighted in the Appendix; Royal London (76%), Manchester (94%) and Newcastle (92%). When looking at registrations in the past three years, these centres remain significantly below expectations.

**ACTION**

- For centres with consent rates lower than 98%, representative members are kindly requested to feed this audit back to the centre and ensure that the necessary actions are taken to obtain their patients' level of consent and report this to NHSBT. ODT Information Services remain committed to supporting centres with these returns and should you require further assistance, please do not hesitate to contact [odtdatasupportteam@nhsbt.nhs.uk](mailto:odtdatasupportteam@nhsbt.nhs.uk).
- Centres are requested to ensure a robust process is in place to make certain that consent is obtained in every case prior to patient listing.

<b>Table 1      Kidney patient consent levels as recorded on the UK Transplant Registry, for patients registered, 1 April 2008 to 31 January 2017</b>			
	Level of Consent	Number of Patients	
		N	(%)
	Full	29555	95.3
	Refused	1	0
	Assumed	1452	4.7
	Incapable	5	0
	Total	31013	100

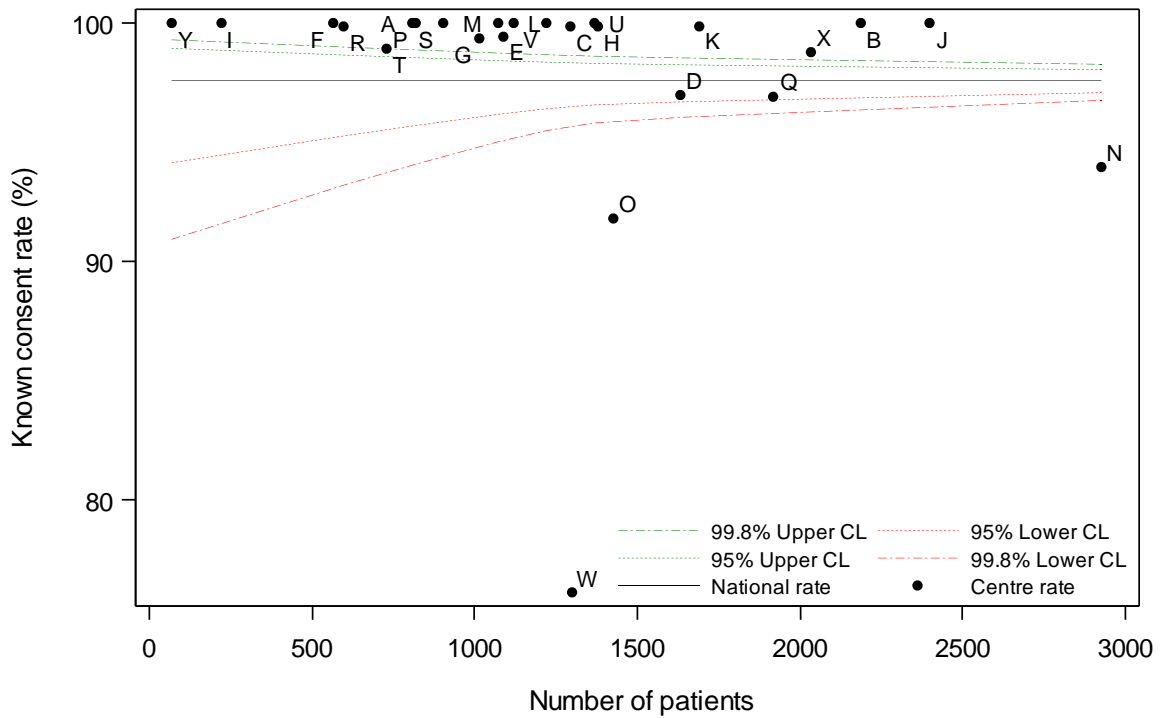
**Appendix 1 Kidney patient consent rates for the use of personal information as recorded on the UK Transplant Registry, for patients registered 1 April 2008 to 31 January 2017**

Patient Registration Centre		Number of Patients N	Consent Known %	Outstanding consent N
A	Belfast	807	100	0
B	Birmingham	2185	100	0
C	Bristol	1294	99.8	2
D	Cambridge	1632	96.9	50
E	Cardiff	1091	99.5	6
F	Coventry	564	100	0
G	Edinburgh	1016	99.3	7
H	Glasgow	1381	99.9	2
I	Great Ormond Street	221	100	0
J	Guy's	2400	100	0
K	Leeds	1690	99.9	2
L	Leicester	1121	100	0
M	Liverpool	1075	100	0
N	Manchester	2926	93.9	178
O	Newcastle	1428	91.8	117
P	Nottingham	818	100	0
Q	Oxford	1920	96.9	60
R	Plymouth	598	99.8	1
S	Portsmouth	901	100	0
T	Sheffield	728	98.9	8
U	St George's	1366	100	0
V	The Royal Free	1222	100	0
W	The Royal London	1297	76.1	310
X	WLRTC	2031	98.8	25
Y	Private	69	100	0
<b>Total</b>		<b>31781</b>	<b>97.6</b>	<b>768</b>

**Appendix 2 Kidney patient consent rates for the use of personal information as recorded on the UK Transplant Registry, for patients registered 1 February 2014 to 31 January 2017**

Patient Registration Centre		Number of Patients N	Consent Known %	Outstanding consent N
A	Belfast	351	100	0
B	Birmingham	692	100	0
C	Bristol	392	99.5	2
D	Cambridge	558	91	50
E	Cardiff	323	98.1	6
F	Coventry	184	100	0
G	Edinburgh	369	98.9	4
H	Glasgow	537	99.6	2
I	Great Ormond Street	77	100	0
J	Guy's	814	100	0
K	Leeds	601	99.7	2
L	Leicester	293	100	0
M	Liverpool	388	100	0
N	Manchester	1055	84.8	160
O	Newcastle	549	88.5	63
P	Nottingham	264	100	0
Q	Oxford	732	93	51
R	Plymouth	178	99.4	1
S	Portsmouth	311	100	0
T	Sheffield	257	98.8	3
U	St George's	508	100	0
V	The Royal Free	434	100	0
W	The Royal London	484	41.5	283
X	WLRTC	642	99.8	1
Y	Private	43	100	0
<b>Total</b>		<b>11036</b>	<b>94.3</b>	<b>628</b>

**Figure A1** Kidney patient consent rates for the use of personal information as recorded on the UK Transplant Registry, for patients registered 1 April 2008 to 31 January 2017



**Figure A2** Kidney patient consent rates for the use of personal information as recorded on the UK Transplant Registry, for patients registered 1 February 2014 to 31 January 2017

