

**NHS BLOOD AND TRANSPLANT
KIDNEY ADVISORY GROUP
PATIENT CONSENT SCHEME AUDIT**

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 29950 patients across the United Kingdom that have been listed for a kidney transplant at some point in time since April 2008, 98% 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**. 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 (79%), Manchester (96%), Newcastle (93%) and Oxford (96%). 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. 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.

Level of Consent	Number of Patients	
	N	(%)
Full	27903	95.1
Refused	1	0.0
Assumed	1434	4.9
Incapable	4	0.0
Total	29342	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 July 2016

Patient Registration Centre		Number of Patients N	Consent Known %	Outstanding Consent N
A	Belfast	756	100	0
B	Birmingham	2067	100	0
C	Bristol	1221	100	0
D	Cambridge	1528	99.5	8
E	Cardiff	1023	99.8	2
F	Coventry	537	100	0
G	Edinburgh	948	99.2	8
H	Glasgow	1299	100	0
I	Great Ormond Street	206	100	0
J	Guy's	2261	100	0
K	Leeds	1593	99.9	1
L	Leicester	1079	100	0
M	Liverpool	1014	100	0
N	Manchester	2745	95.6	120
O	Newcastle	1327	93.0	93
P	Nottingham	773	100	0
Q	Oxford	1804	95.6	79
R	Plymouth	564	100	0
S	Portsmouth	846	100	0
T	Sheffield	686	98.8	8
U	St George's	1286	100	0
V	The Royal Free	1161	99.8	2
W	The Royal London	1220	78.5	262
X	WLRTC	1944	98.7	25
Y	Private	62	100	0
Total		29950	98.0	608

Appendix 2 Kidney patient consent rates for the use of personal information as recorded on the UK Transplant Registry, for patients registered 1 April 2013 to 31 July 2016

Patient Registration Centre		Number of Patients N	Consent Known %	Outstanding Consent N
A	Belfast	361	100	0
B	Birmingham	780	100	0
C	Bristol	431	100	0
D	Cambridge	609	98.7	8
E	Cardiff	363	99.4	2
F	Coventry	233	100	0
G	Edinburgh	399	98.7	5
H	Glasgow	610	100	0
I	Great Ormond Street	84	100	0
J	Guy's	877	100	0
K	Leeds	658	99.8	1
L	Leicester	366	100	0
M	Liverpool	423	100	0
N	Manchester	1227	90.8	113
O	Newcastle	579	92.6	43
P	Nottingham	284	100	0
Q	Oxford	747	90.1	74
R	Plymouth	203	100	0
S	Portsmouth	342	100	0
T	Sheffield	276	99.6	1
U	St George's	569	100	0
V	The Royal Free	495	99.6	2
W	The Royal London	573	54.3	262
X	WLRTC	746	99.9	1
Y	Private	48	100	0
Total		12283	95.8	512

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 July 2016

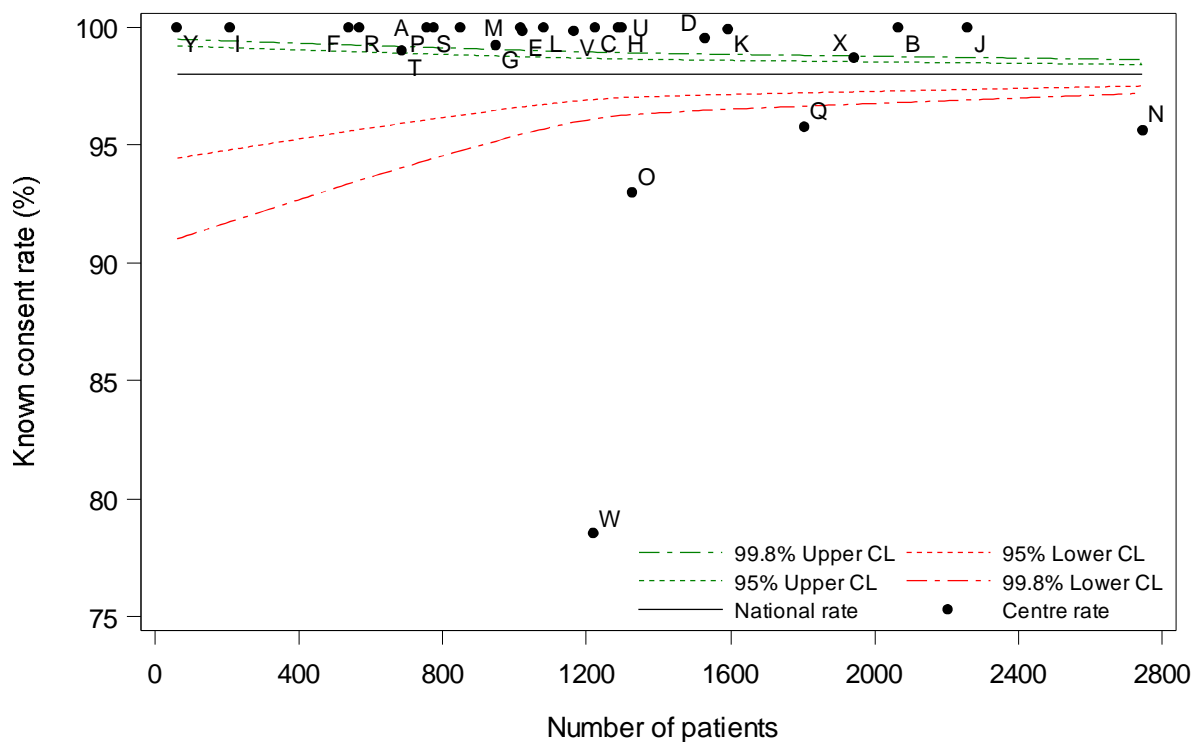


Figure A2 Kidney patient consent rates for the use of personal information as recorded on the UK Transplant Registry, for patients registered 1 April 2013 to 31 July 2016

