

NHS BLOOD AND TRANSPLANT

PANCREAS 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.

PANCREAS/ISLET PATIENT CONSENT RATES

- Of the 2333 patients across the United Kingdom that have been listed for a pancreas or islet transplant at some point in time since April 2008, 96.5% 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. When looking at registrations in the past three years, one registration centre is falling significantly short of the expected levels of consent reported and this is highlighted in the Appendix; Oxford (83%).

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	2126	94.3
Assumed	128	5.7
Total	2254	100

Appendix 1 Pancreas/Islet 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	Consent Known	Outstanding consent
	N	%	N
Bristol	5	100	0
Cambridge	228	98.2	4
Cardiff	116	99.1	1
Edinburgh	246	98.8	3
Guy's	310	100	0
King's College	7	100	0
Manchester	367	95.9	15
Newcastle	124	91.9	10
Oxford	770	94.3	44
Royal Free	12	100	0
WLRTC	148	97.3	4
Total	2333	96.5	81

Appendix 2 Pancreas/Islet 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	Consent Known	Outstanding consent
	N	%	N
Bristol	1	100	0
Cambridge	86	95.3	4
Cardiff	27	96.3	1
Edinburgh	98	100	0
Guy's	118	100	0
King's College	1	100	0
Manchester	104	86.5	14
Newcastle	38	89.5	4
Oxford	229	83	39
Royal Free	1	100	0
WLRTC	30	100	0
Total	733	91.5	62

Figure A1 Pancreas/Islet 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

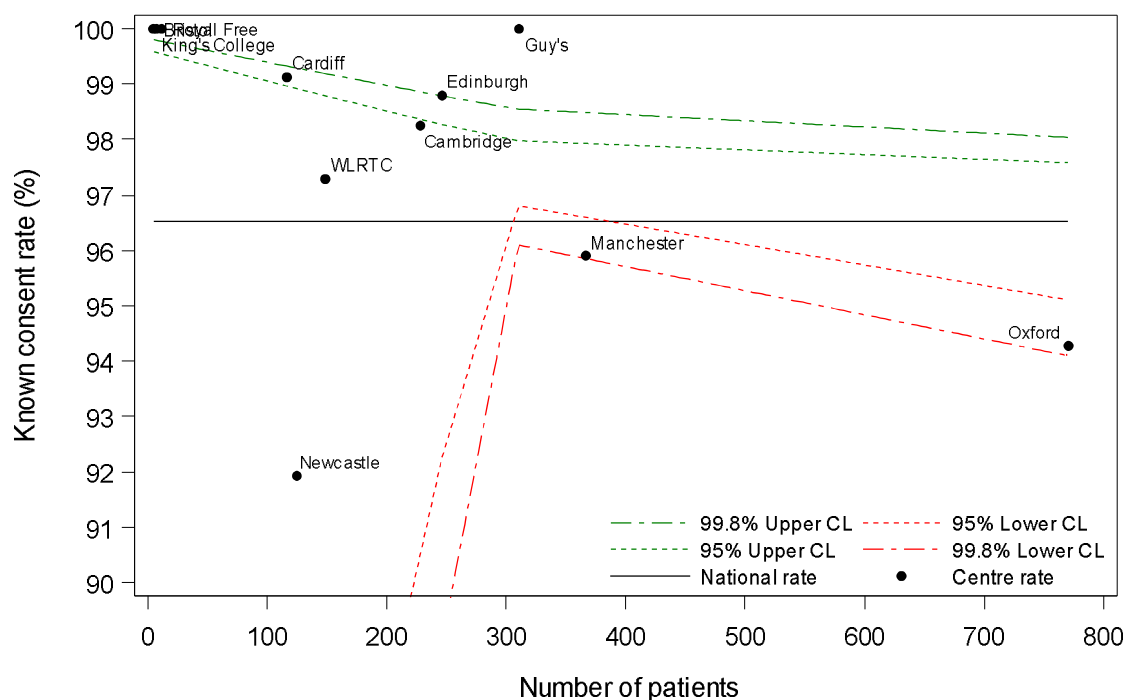


Figure A2 Pancreas/Islet patient consent rates for the use of personal information as recorded on the UK Transplant Registry, for patients registered 1 February 2014 to 31 January 2017

