

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

INTRODUCTION

- 1 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

- 2 Of the 2217 patients across the United Kingdom that have been listed for a pancreas or islet transplant at some point in time since April 2008, 96.8% 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**.
- 3 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 reported and these are highlighted in the Appendix; Oxford (94%). When looking at registrations in the past three years, these centres remain significantly below expectations.

ACTION

- 4 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.

Table 1 Pancreas/Islet patient consent levels as recorded on the UK Transplant Registry, for patients registered, 1 April 2008 to 31 July 2016

Level of Consent	Number of Patients	
	N	(%)
Full	2019	94.0
Assumed	128	6.0
Total	2147	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 July 2016

Patient Registration Centre	Number of Patients	Outstanding consent	
	N	N	(%)
Bristol	6	0	100
Cambridge	210	1	99.5
Cardiff	111	0	100
Edinburgh	231	3	98.7
Guy's	287	0	100
King's College	8	0	100
Manchester	351	9	97.4
Newcastle	117	9	92.3
Oxford	740	46	93.8
Royal Free	12	0	100
WLRTC	144	4	97.2
Total	2217	72	96.8

Appendix 2 Pancreas/Islet 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	Outstanding consent	
	N	N	(%)
Bristol	4	0	100
Cambridge	92	1	98.9
Cardiff	36	0	100
Edinburgh	107	0	100
Guy's	121	0	100
King's College	2	0	100
Manchester	139	9	93.5
Newcastle	44	4	90.9
Oxford	262	43	83.6
Royal Free	3	0	100
WLRTC	32	0	100
Total	842	57	93.2

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 July 2016

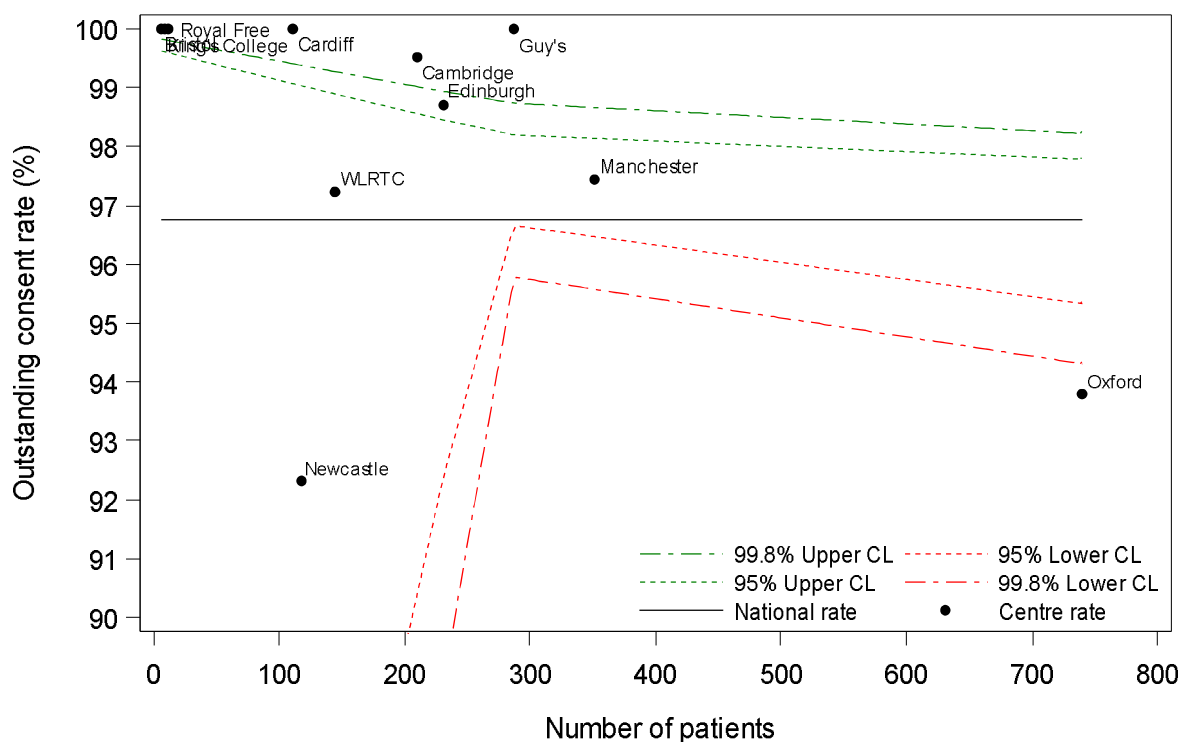


Figure A2 Pancreas/Islet patient consent rates for the use of personal information as recorded on the UK Transplant Registry, for patients registered 1 April 2013 to 31 July 2016

