

## NHS BLOOD AND TRANSPLANT

### BOWEL ADVISORY GROUP

#### INTESTINAL TRANSPLANT FORM RETURNS

##### BACKGROUND

- 1 183 patients have received an intestinal transplant in the UK since 1991. As of 21 September 2014, 116 (63%) of these patients were not recorded as deceased on the UK Transplant Registry (UKTR), however follow-up data are not recorded for all of these patients.
- 2 On 22 July 2013 a dedicated intestinal transplant follow-up form went live which allows centres to submit survival data to the UKTR via ODT Online. The follow-up intervals are 3 months, 1 year and then annually. Up to date follow-up data are vital to inform analyses of UK intestinal transplant patients.
- 3 The Intestinal Transplant Record Form went live on 1 July 2008 and centres are requested to return these data within 7 days of transplant.

##### DATA AND METHODS

- 4 111 intestinal transplants were performed between 1 April 2009 and 31 August 2014. Intestinal Transplant Record Form return rates for these transplants were calculated by transplant centre.
- 5 Follow-up data are expected for 103 patients who received an intestinal transplant prior to 31 March 2014 and who, according to the UKTR, have not died. The UKTR was interrogated to determine if any follow-up information had been returned for these patients (via any kind of NHSBT follow-up form). If follow-up had been returned, the latest follow-up interval that was recorded and the number of full years since the transplant were compared to determine if the data were up to date or not. A window of almost 4 months was used in this calculation to allow for reasonable delays.

##### RESULTS

- 6 **Table 1** shows the Intestinal Transplant Record Form return rates for each centre. A total of 20 forms (18%) have not yet been returned; most of these transplants were carried out at Cambridge in the first few years after the introduction of the form. Cambridge and King's College have three outstanding forms each for transplants carried out in the last 5 months. Birmingham and Oxford have returned a high proportion of forms (96% and 93% respectively).
- 7 **Table 2** shows the follow-up data return rates for each centre, out of those patients that are not recorded on the UKTR as deceased. Overall, the UKTR holds survival information for 76 (74%) of the 103 patients and in 58 cases (76%) this information is up to date. Cambridge and Oxford have very good follow-up return rates; 94% respectively and all of the follow-up data they have returned are up to date. Birmingham have not provided any survival data for 18 (40%) out of 45 patients and only 41% of the data they have provided are up to date. King's College have returned data for 2 (25%) out of 8 patients.

**ACTION**

- 8 Members are kindly requested to feed the information presented in this report back to their transplant units in order that more complete and timely data are submitted to the UKTR.

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**Table 1**      **Intestinal transplant record form return rates by centre for intestinal transplants carried out between 1 April 2009 and 31 August 2014**

| Year of transplant | Birmingham |           |                | Cambridge |           |                | King's College |           |                | Oxford    |           |                |
|--------------------|------------|-----------|----------------|-----------|-----------|----------------|----------------|-----------|----------------|-----------|-----------|----------------|
|                    | TxS        |           | Forms returned | TxS       |           | Forms returned | TxS            |           | Forms returned | TxS       |           | Forms returned |
|                    | N          | N         | %              | N         | N         | %              | N              | N         | %              | N         | N         | %              |
| 2009/10            | 9          | 8         | 89             | 5         | 1         | 20             | 3              | 3         | 100            | 4         | 4         | 100            |
| 2010/11            | 7          | 7         | 100            | 6         | 0         | 0              | 3              | 3         | 100            | 2         | 2         | 100            |
| 2011/12            | 6          | 6         | 100            | 8         | 7         | 88             | 2              | 2         | 100            | 5         | 5         | 100            |
| 2012/13            | 2          | 2         | 100            | 5         | 5         | 100            | 2              | 2         | 100            | 5         | 5         | 100            |
| 2013/14            | 3          | 3         | 100            | 16        | 16        | 100            | 0              | 0         | -              | 7         | 5         | 71             |
| 2014/15*           | 1          | 1         | 100            | 3         | 0         | 0              | 3              | 0         | 0              | 4         | 4         | 100            |
| <b>Total</b>       | <b>28</b>  | <b>27</b> | <b>96</b>      | <b>43</b> | <b>29</b> | <b>67</b>      | <b>13</b>      | <b>10</b> | <b>77</b>      | <b>27</b> | <b>25</b> | <b>93</b>      |

\* 1 April 2014 – 31 August 2014

**Table 2** Follow-up data return rates by centre for patients who received an intestinal transplant prior to 1 April 2014 and are not recorded on the UKTR as deceased

| Year of transplant | Birmingham |  |                         |           |                               | Cambridge |           |                         |           |                               | King's College |  |                         |          |                               | Oxford   |          |                         |           |                               |
|--------------------|------------|--|-------------------------|-----------|-------------------------------|-----------|-----------|-------------------------|-----------|-------------------------------|----------------|--|-------------------------|----------|-------------------------------|----------|----------|-------------------------|-----------|-------------------------------|
|                    | Pts        |  | Follow-up data returned |           | Up to date follow-up returned | Pts       |           | Follow-up data returned |           | Up to date follow-up returned | Pts            |  | Follow-up data returned |          | Up to date follow-up returned | Pts      |          | Follow-up data returned |           | Up to date follow-up returned |
|                    | N          |  | N                       | %         | N                             | %         | N         | %                       | N         | %                             | N              |  | N                       | %        | N                             | %        | N        |                         | N         | %                             |
| 1996/97            | 0          |  | 0                       | -         | 0                             | -         | 1         | 0                       | 0         | 0                             | 0              |  | 0                       | 0        | -                             | 0        | -        | 0                       | 0         | -                             |
| 1998/99            | 3          |  | 3                       | 100       | 0                             | 0         | 2         | 1                       | 50        | 1                             | 50             |  | 0                       | 0        | -                             | 0        | -        | 0                       | 0         | -                             |
| 1999/00            | 1          |  | 1                       | 100       | 1                             | 100       | 0         | 0                       | -         | 0                             | -              |  | 0                       | 0        | -                             | 0        | -        | 0                       | 0         | -                             |
| 2000/01            | 1          |  | 1                       | 100       | 0                             | 0         | 0         | 0                       | -         | 0                             | -              |  | 0                       | 0        | -                             | 0        | -        | 0                       | 0         | -                             |
| 2001/02            | 1          |  | 1                       | 100       | 0                             | 0         | 0         | 0                       | -         | 0                             | -              |  | 0                       | 0        | -                             | 0        | -        | 0                       | 0         | -                             |
| 2004/05            | 3          |  | 3                       | 100       | 1                             | 33        | 0         | 0                       | -         | 0                             | -              |  | 0                       | 0        | -                             | 0        | -        | 0                       | 0         | -                             |
| 2005/06            | 4          |  | 3                       | 75        | 1                             | 25        | 0         | 0                       | -         | 0                             | -              |  | 0                       | 0        | -                             | 0        | -        | 0                       | 0         | -                             |
| 2006/07            | 3          |  | 3                       | 100       | 1                             | 33        | 0         | 0                       | -         | 0                             | -              |  | 0                       | 0        | -                             | 0        | -        | 0                       | 0         | -                             |
| 2007/08            | 2          |  | 2                       | 100       | 1                             | 50        | 2         | 2                       | 100       | 2                             | 100            |  | 0                       | 0        | -                             | 0        | -        | 0                       | 0         | -                             |
| 2008/09            | 5          |  | 3                       | 60        | 1                             | 20        | 3         | 3                       | 100       | 3                             | 100            |  | 0                       | 0        | -                             | 0        | -        | 2                       | 2         | 100                           |
| 2009/10            | 5          |  | 1                       | 20        | 1                             | 20        | 3         | 3                       | 100       | 3                             | 100            |  | 2                       | 1        | 50                            | 0        | 0        | 1                       | 1         | 100                           |
| 2010/11            | 7          |  | 3                       | 43        | 3                             | 43        | 5         | 5                       | 100       | 5                             | 100            |  | 2                       | 0        | 0                             | 0        | 0        | 1                       | 1         | 100                           |
| 2011/12            | 5          |  | 2                       | 40        | 0                             | 0         | 3         | 3                       | 100       | 3                             | 100            |  | 2                       | 0        | 0                             | 0        | 0        | 5                       | 5         | 100                           |
| 2012/13            | 2          |  | 1                       | 50        | 1                             | 50        | 2         | 2                       | 100       | 2                             | 100            |  | 2                       | 1        | 50                            | 0        | 0        | 2                       | 2         | 100                           |
| 2013/14            | 3          |  | 0                       | 0         | 0                             | 0         | 13        | 13                      | 100       | 13                            | 100            |  | 0                       | 0        | -                             | 0        | -        | 5                       | 4         | 80                            |
| <b>Total</b>       | <b>45</b>  |  | <b>27</b>               | <b>60</b> | <b>11</b>                     | <b>24</b> | <b>34</b> | <b>32</b>               | <b>94</b> | <b>32</b>                     | <b>94</b>      |  | <b>8</b>                | <b>2</b> | <b>25</b>                     | <b>0</b> | <b>0</b> | <b>16</b>               | <b>15</b> | <b>94</b>                     |