

Data Release Agreement *Blood and Transplant*

Agreement for use of data from the UK Transplant Registry

This agreement relates to the use of data from the UK Transplant Registry and requirements of the General Data Protection Regulations 2018, the Data Protection Act 2018, the Human Rights Act 1998 and the Common Law Duty of Confidentiality.

1. The following agreement applies where data/information are supplied to you by NHS Blood and Transplant for a particular study or NHS Blood and Transplant data is provided to you through a pass-through entity ("PTE") such as the UK Renal Registry.
2. The data/information referred to in point 1 above may include:
 - ◆ Data/information held in any electronic format or on paper
 - ◆ Data/information that are part of a verbal discussion
3. Once the information has been supplied, you are responsible for ensuring it is kept safe and secure.
4. All information must be treated as confidential and must not be disclosed to any other persons without authorised agreement from Statistics and Clinical Research, NHSBT.
5. Any information provided must only be used for the specific purposes that it was originally supplied and not used for any other purpose/study.
6. With reference to the Data Protection Act (2018), Section 171, you must not attempt, nor permit any third party to attempt, to re-identify any individual from the data, including through data linkage, inference, or matching with other datasets. If you become aware of, or reasonably suspect, that any individual has been identified, you must: (a) not use, disclose, or record this information in any way; and (b) notify NHSBT without undue delay.
7. Approval must be obtained from the relevant NHSBT review group or the PTE prior to any publication relating to the study for which the data were provided. Abstracts will be reviewed by the group in a period of between 2 and 4 weeks, and appropriate action must be taken on any issues raised by the group. No review period is defined for manuscripts, but the group will endeavour to respond in a reasonable timeframe. **An abstract or paper must not be submitted without prior approval.**
8. The data must be deleted or disposed of in a safe and secure manner in line with legislation after a maximum of three (3) years from receipt of data unless otherwise agreed by Statistics and Clinical Research, NHSBT.

9. The study must be supported by the relevant Clinical Director unless the public organ transplant dataset has been requested.
10. Any breach of the terms of this agreement may result in information not being supplied in the future.
11. You are responsible for ensuring that you adhere to the standards of this agreement.
12. NHSBT will not directly disclose any data which has not been pseudo-anonymised to you.
13. Should any accidental disclosure of patient identities by NHSBT occur, **you must report this to NHSBT within 1 working day.**
14. This Agreement will last for three (3) years from the last date of signature unless terminated earlier in accordance with clause 15.
15. You can terminate this Agreement by giving written notice to NHSBT of your intention to terminate.
16. This Agreement and all matters relating to it shall be governed by and in accordance with the Laws of England and Wales, Scotland and Northern Ireland and subject to the exclusive jurisdiction of the courts of England.

Please complete and sign:

Signed: _____

Print Name: _____

Institution: _____ **Date:** _____

For completion by the unit Clinical Director where appropriate

Signed: _____

Print Name: _____

Institution: _____ **Date:** _____

Please return:

By email statistical.enquiries@nhsbt.nhs.uk