

NHS BLOOD AND TRANSPLANT
ORGAN DONATION AND TRANSPLANTATION
BOWEL ADVISORY GROUP
PUBLICATION OF A TRANSPLANT DATA SET

NHSBT have in place a means of handling external requests for national data in support of studies and research. This includes an approvals process by the relevant Steering / Research group. This process ensures that there is no duplication of effort with work already being undertaken and enables studies reliant on data that are not routinely available to be avoided. Advice is often given on how to enhance proposed studies, including the provision of statistical support in some cases.

By contrast, data from UNOS are made routinely available by means of a simple request process with a small charge in respect of shipping costs of the disk where appropriate.

It has been suggested for a number of years that UK Transplant Registry data should be made available in a similar way and it has now been agreed as part of ODT's Information Management Strategy that national data will be made available in a small number of standard datasets that are updated on an annual basis.

There are some risks associated with this strategy eg misinterpretation of data, duplication of studies, but it would mean that national data would be readily available to a wider group of researchers, including an international audience, and that could bring significant benefits. That said, it has been agreed that a single, initial data set is provided that contains only basic data relating to transplants over a number of years. No patient or centre identifiable data will be included.

Agreed initial transplant dataset:

All organs transplants 1995 – 2011

Donor characteristics – type (living, DBD, DCD), age group, sex, cause of death

Recipient characteristics – age group, sex, primary diagnosis

Transplant information – year, organ(s) transplanted, transplant number, CIT, HLA mismatch (where appropriate), urgency status of recipient (where appropriate)

Graft and patient survival times and censoring indicators (as appropriate for each organ)

The timing for provision of the dataset has not yet been agreed but is likely to be towards the end of the current financial year. The data would be requested / downloaded via the website.