

NHS BLOOD AND TRANSPLANT
CARDIOTHORACIC ADVISORY GROUP
TRANSPLANT RISK COMMUNICATION TOOLS

BACKGROUND INFORMATION AND UPDATE

1. Over recent years, NHSBT have been undertaking a project to improve the information that is available to patients on the risks and benefits of organ transplantation.
2. One part of this project was to develop a Patient Information Website to help patients gain a greater understanding of the process of transplantation and make better informed choices. This went live recently: <https://www.nhsbt.nhs.uk/organ-transplantation/>.
3. The other part of this project is to develop organ specific Risk Communication Tools that use data from the UK Transplant Registry held by NHSBT to convey information about an individual's risks, using past data on patients like them. For this project, NHSBT have been collaborating with the Winton Centre for Risk and Evidence Communication, at the University of Cambridge. The tools are designed to aid clinicians and patients in decision-making at different points in the transplantation process.

Specifically:

- To communicate clinically relevant and statistically significant factors which influence patient and graft outcomes following listing for transplantation.
 - To help develop patients' understanding of the risks and benefits associated with transplantation and convey possible outcomes in an understandable way to a wide variety of patients via a user-friendly interface.
 - To provide useful information to clinicians when consenting patients, using NHSBT data to ascertain modelled outcomes.
4. NHSBT do not currently have access to data on patients who do not join the transplant list, so the tools are focussed on outcomes on the waiting list (risk of death vs chance of receiving a transplant) and outcomes following transplantation (survival post-transplant). These organ specific tools are at different stages of development:

Organ	Outcome	Stage
Lung	Waiting list outcomes	Live
	Patient survival post-transplant	Live
Kidney	Deceased donor waiting list	User testing
	Deceased donor patient survival post-transplant	User testing
	Deceased donor graft survival post-transplant	User testing
	Living donor patient survival post-transplant	User testing
	Living donor graft survival post-transplant	User testing
Liver	Elective waiting list outcomes	Modelling
	Patient survival post-transplant	Model built
Pancreas	Waiting list outcomes	Modelling
	Patient survival post-transplant	Model built
Heart	Urgent waiting list outcomes	Modelling
	Non-urgent waiting list outcomes	Modelling
	Patient survival post-transplant	Model built

5. In each organ area, the Statistics and Clinical Research team are working closely with clinicians to ensure the models that are used for these tools are clinically relevant (within the constraints of the data available) as well as statistically valid.
6. User testing is being co-ordinated by NHSBT. Surgeons, physicians and recipient co-ordinators at each centre are being contacted to give feedback on these tools where relevant to their organ area. Feedback is being collated and incorporated, where possible, into the tool to improve user experience.
7. The aim is for all organ specific tools to be accessible on the NHSBT website and to be used in a clinical setting by the end of 2021, in collaboration between a patient and clinician. The Lung Communication Tool is now live on the ODT website.

Sally Rushton and Lisa Mumford
Statistics and Clinical Research

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