TRANSPLANTS = 25 NOV 2021 – LEILA NOTES ON CURRENT VERSION

Add in on the front page

“This tool was created with help and input from transplant patients and their partners, as well as clinical teams at transplant centres in England.

Front page

**You need an internet connection to access the tool for the first time, but once you have visited the site once, you can access it offline (just don’t close the browser).**

**The tool can produce a pdf / printout of the results.**

**The tool should be used with your transplant doctors or specialist nurses.**

This is a communication tool. It should help patients understand risks and benefits of transplantation and help health care professionals explain these risks and benefits.

The tool takes details about transplant patients and produces results that are personalised to that patient. The results are displayed in the form of graphs and charts.

If you are a patient using the tool, be aware that the tool will ask for some medical information such as blood group, or recent test results. The tool will be less accurate if you don’t have all the relevant information.

The tool is suitable for lung patients who are over 16 years old and kidney patients who are over 18 years old.

This is because we use past data from NHS transplant registry. Fewer children have transplants than adults and there is not enough data yet to make a tool for children.

**How does the tool work?**

The tool will calculate:

* What is my likely waiting time for a transplant?
* How long might my transplant last?

The tool takes information about you, such as age, blood group, disease, and it looks at people who had these same characteristics, and shows what happened to these people.

For example, how many people ‘like you’ received a transplant within one year of being listed.

It is not showing you what will happen to you, it is showing you what happened to people like you, in the past.

It’s important to remember that the tool cannot take into account everything about you, for example, whether you have other health conditions.

There are many factors that can influence how well a transplanted organ does, for example taking your medication properly, diet and whether you exercise.

If you want to know more about the models and data behind the tools, go to the xxx tab or link.

Data about transplant patients were used to create statistical models. When you enter information into the tool, the calculator looks at these models and produces results.

KIDNEY only - Changes to the UK Kidney Offering Scheme in September 2019 are not reflected in these models

***For all the tools – under the inputs we need a link to an area that explains about the factors we didn’t include or did***

*LUNGS*

*“Patient inputs that were considered but not included in the tool e.g. antibody status”*

*Recipient Antibody Status – not currently collected by NHS BT*

*Recipient Height or TLC – BMI is included in model. In the model building, height was found to be significant for time to transplant and BMI for time to death on list (but not height), so decision was made to go with BMI as it includes height.*

*O2 need or use / NIV / Frailty / 6 minute walk test - 6 minute walk completeness for cohort used = 84% so would reduce cohort even further to include as we would remove all patients completely from the modelling if they had this missing. Home oxygen use (y/n) is collected but when we did the original project for this, we were told it was not relevant to include. NIV not collected.*

*FEV1, Transfer Factor - FVC is included in model*

*Comorbidities (coronary artery disease, renal dysfunction, diabetes) - Coronary artery disease collected only as primary disease so not available for inclusion. eGFR and diabetes was considered when constructing the models originally and were not significant.*

*Time on ventilator / mechanical support - Time on support not captured and very low numbers for on ventilator as it is only collected for patients in hospital at transplant – 9 (0.8%) of cohort were on ventilator at transplant.*

*KIDNEYS*

*Recipient BMI - Tested and not found to be significant in model*

*Creatinine - Although we can get terminal creatinine for donor, we don’t know how many were on filtration in ITU – this would give a falsely low creatinine and be misleading.*

*Comorbidities (cardiovascular disease, vascular disease, stroke, MI) - Not collected, looked into those that are, have a high proportion of missing data.*

*Remove Donor BMI - Removing factors that have been shown to be significant will make the model less robust*

LUNGS

* “Home page / Organs” can the font of this be bigger at the top of the page?
* Are we happy calling them TRAC tools?
* Choose your transplant centre – line space above header (feels squished)
* First thing I see when click Birmingham is WAITING TIMES button which is good (shows me where I am clearly)

**USEFUL INFORMATION**

* Useful information – weird that there’s a Useful information button AND you can click on the useful information words?
* Explain that the pdf download is technical information not useful information
* Retitle that area

LUNG TRANSPLANT TOOL – MORE INFORMATION

Additional information if you’re a patient click here

Additional technical information about the tool click here

* **What might happen if you are listed for a transplant?**

The displays here show how many people might have a transplant, or still be waiting for a transplant or sadly died or been removed from the waiting list.

We used data from people on the transplant waiting list in the past.

We took all the transplant patients who had the same characteristics as you (same age, blood group, disease and so on) to show on average, what happened to them.

These results are averages. There are other factors not included here, for example whether or not you have other health conditions, that may make your result higher or lower.

**ABOVE INPUTS**

* Make the sentence “please enter the inputs that are valid at time of registration” MUCH BIGGER (same size if we can as “what might happen if you are listed..”)
* Change sentence to

“Enter information that is correct at time of registration on the waiting list “

* Disease buttons – can we put “other” where COPD is? (depending on screen size, COPD becomes a BIG button
* Change IN HOSPITAL to “is the patient currently an in-patient in hospital?”

**IN BLUE – pop up box wording**

* NYHA CLASS – New York Heart Association Classification.

Class I – for example shortness of breath when walking or climbing stairs

Class II – for example mild shortness of breath that limits ordinary activities

Class III – only comfortable at rest, limited in doing normal activities such as walking short distances (20m – 100m)

Class IV – symptoms even at rest, usually bedbound patients.

* FVC

Forced vital capacity. A measure of lung function.

* BMI – Body Mass Index

Weight (in kg) divided by height (in metres) squared

e.g.

weight 70 kg

height 1.57m x 1.57m = 2.4649

70 ­÷ 2.4649 = BMI 28.4

Or use an online calculator like this <https://www.nhs.uk/live-well/healthy-weight/bmi-calculator/>

* POP UP BOX - Previous thoracotomy ?

Has the patient ever had any thoracotomy procedures?

* Display – don’t need “outcomes after listing” at the bottom
* Add an extra TEXT visualisation if we can?

If we took an example of 100 transplant patients, who input the same information as you into the tool, we would expect:

**After 1 year** **31 of them to have received a transplant**

**67** of them to still be waiting for a transplant

**2** of them to have died or been removed from the list

**After 2 years**  **67 of them to have received a transplant**

**23** of them to still be waiting for a transplant

**10** of them to have died or been removed from the list

**After 3 years** **75 of them to have received a transplant**

**3** of them to still be waiting for a transplant

**22** of them to have died or been removed from the list

**SURVIVAL**

* Need a header above inputs

**Enter inputs that are correct today. The results will show outcomes as if the patient receives a transplant today.**

* FVC pop up – same as waiting times
* Cholesterol – total cholesterol
* Make the word DONOR bigger – maybe say “Characteristics of DONOR”
* Donor / Recipient TLC mismatch **–**

Donor to recipient calculated total lung capacity mismatch.

Total Lung Capacity is the volume (measured in litres) that the lungs can hold.

TLC mismatch means the difference in lung capacity between the donor and the recipient.

This figure is usually calculated when the characteristics of the donor is known.

* CMV –

Is an abbreviation for Cytomegalovirus, a common virus. Has the donor had this virus?

If the donor is positive for CMV it means the recipient will receive some medication after transplant.

KIDNEY

* Primary renal disease – change to “Primary kidney disease”

POP UP

What is the patient’s primary kidney disease

* SENSITISATION POP UP

**Sensitisation refers to the level of antibodies the patient has in their blood.**

It is calculated with a tool like this one from NHS BT <https://www.odt.nhs.uk/transplantation/tools-policies-and-guidance/calculators/>

Patients can have antibodies due to for example pregnancy, previous organ transplants or blood transfusions.

Sensitisation is measured in cRF which stands for calculated reaction frequency.

The cRF is calculated by finding the percentage donors from a pool of 10,000 in the UK that are expected to be *in*compatible.

This pool of 10,000 is updated annually by NHS BT.

Sensitisation is the percentage of recipients who have identical blood group (A, B, AB or O) to the donor pool that are HLA incompatible. This means sensitisation takes into account antibodies and blood group.

So cRF of 85% means this patient is compatible with 85% of the donor pool.

* MATCHABILITY

This means whether it will be ‘easy’, ‘difficult’ or ‘moderate’ to match the patient to a donor.

NHS BT has a tool for calculating matchability.

The tool uses antibodies and blood group to calculate how easy it will be to match a patient to the donor pool of 10,000 people.

KIDNEY SURVIVAL

* HLA MISMATCH

HLA stands for Human Leukocyte Antigen.

HLA are proteins on the surface of white blood cells and other tissues.

When people have the same HLAs they are said to be a match.

There are many different types of HLAs so matching can be to differing degrees. Patients can match ‘a lot’ or ‘a little’.

HLA mismatch means how likely a patient is to be matched based on these HLA proteins.

* CENTRE

This refers to which of the 23 UK adult transplant centres the patient will be receiving their transplant. This is not always the dialysis centre at which they will be followed up.

DONOR characteristics

Hypertension –

Did the donor have high blood pressure as recorded by NHS BT