TRANSPLANTS = 25 NOV 2021 – LEILA NOTES ON CURRENT VERSION

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