

Helping patients make difficult choices

These tools show transplant patients personalised outcomes such as likelihood of getting a transplant (waiting time) and how long that transplant might last.

How did we create these tools?

Through **User Centred Design (UCD)**.

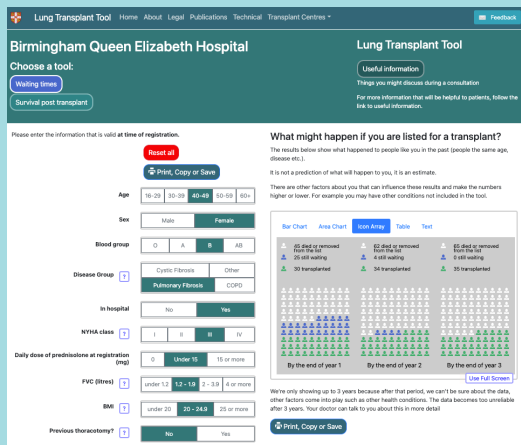
We **spoke to ~20 clinicians** to understand the assessment and listing process for transplantation.

We **observed ~50 clinical encounters** between patients and doctors, specialist nurses and other healthcare professionals to understand how outcomes and risks are currently communicated to patients.

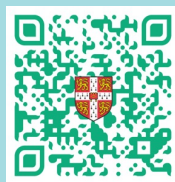
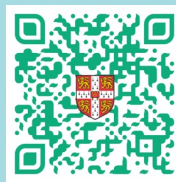
We conducted in **depth interviews** with **~60 patients & families** and asked about their experiences & what they wanted to know. Patients varied; some were not yet on the transplant list, some currently waiting for a transplant, others had had a transplant.

We created versions of the tool, testing it with **~45 patients** and **~20 clinicians** in an iterative fashion, amending based on feedback and re-testing.

“Statistics would help me explain to my family.”



“I think the numbers are really confusing. By the time I had got home I had forgotten what the doctor had said - It's a lot to take in...by the time they've finished talking to you, you just want to go home...you're just frightened.”



Adaptable design process

Our design process meant we could be adaptable and react to unexpected findings or feedback during development.

Our dedicated Winton Centre team could incorporate new features to the tool design: for example helpful pages for use during consults; medication lists; hospital visit schedules; 'donor decisions' and so on.

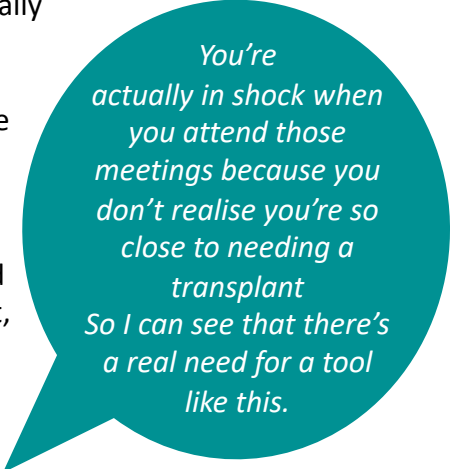
An adaptable tool *"Simply add your data and input fields"*

The tools were created to be adapted for other uses. We have already used the application to create a tool for kidney cancer outcomes.

We MIT-licensed the codebase to make a partially configurable application. This can take Cox Proportional Hazards models (with competing risks adjustment) for any situation and produce the same graphics and lay-out to help communicate these to patients and clinicians. The models give results stratified by patient characteristics entered into the app, generated immediately in text, table, icon array, bar chart, and survival curve formats

These apps are written in clojurescript and compiled to javascript to be run inside a web browser. They load from a URL provided by a simple static web server delivering files from a web directory containing all the data it needed.

This means that **no user data is ever transmitted to any other system** as the whole calculation is done in the browser, so it is easy to satisfy GDPR requirements. Results can appear on screen, in print, or as QRcodes for later reference. The apps run on any modern browser, either on desktop or mobiles devices. They are published as 'Progressive Web Apps' which means they can later run offline (e.g. in hospitals with poor wifi) and installed on device which support the PWA standard.



*You're actually in shock when you attend those meetings because you don't realise you're so close to needing a transplant
So I can see that there's a real need for a tool like this.*

Source code is available for

- Kidney cancer app at <https://github.com/wintoncentre/kcp.git>.