

Communication of Risk and Consent

Lorna Marson on behalf of the Risk and
Consent working group

What is the problem?

- Changes in donor landscape → changes in recipient risk
 - Montgomery and other cases affect clinicians' risk appetite
 - Can be difficult to frame discussions about risk within the context of local/national data
 - BUT: better documentation of individual patient preferences can support better decisions on the night...
- AND support the use of higher-risk organs

We do have existing guidance...

- e.g. Royal Colleges, GMC, NHSBT, BTS

...but we don't follow it

- Patient education – “one size fits all”, inherently biased
- Surgical assessment and verbal consent – wide local variation, lacks structure, patient preference not captured
- Patient information sheets - written in English, not individualized, no checklist, not evidence-based
- Patients rarely included in discussions about individual offers
- Annual review - often by trainee surgeons
- Consent form signed on admission - often supervised by trainee surgeons

How are we addressing this?

- Scoping workshop held in November 2017 with wide stakeholder representation
- Key messages:
 - Patient information is poorly accessible
 - many patients consult Google for health-related concerns
 - many patients are daunted by the length of consent forms
 - Pockets of good practice nationally not shared or universally adopted

Communication of Risk and Consent Executive Team

John Forsythe, Lorna Marson, Chris Callaghan, Maria Ibrahim, Liz Armstrong,
Steve Wigmore, Rachel Hilton, Claire Williment

Patient information tools (Written/ Videos)

Lead: Chris Callaghan

Organ Specific Working Group
Chairs

Kidney – Matt Wellberry Smith

Liver – Derek Manas

Pancreas – Chris Watson

Heart – Jayan Parameshwar

Lung – Jas Parmar

Bowel – Neil Russell

Transplant Risk and Consent tool

NHSBT

Lead: Lisa Mumford

Maria Ibrahim

Chris Callaghan

Jenny Mehew

Winton Centre

Alexandra Freeman

Lelia Finikarides

David Spiegelhalter

Mike Pearson

Consent Framework

Liz Armstrong

Review of NHSBT/ Consent for Solid Organ Transplantation in Adults Guidelines, July 2015

Chris Callaghan

Rachel Hilton

Patient information tools

- To aid provision of information to patients at the time of listing
- Allow clinician and patient to work together to ensure that patients understands risks of transplantation in a way and context that is relevant to them
- Assist conversation rather than replace it
- A variety of formats available

Patient information tools

“When taking consent clinicians must take reasonable care to ensure that the patient is aware of any material risks involved, and of any reasonable alternative or variant treatments”

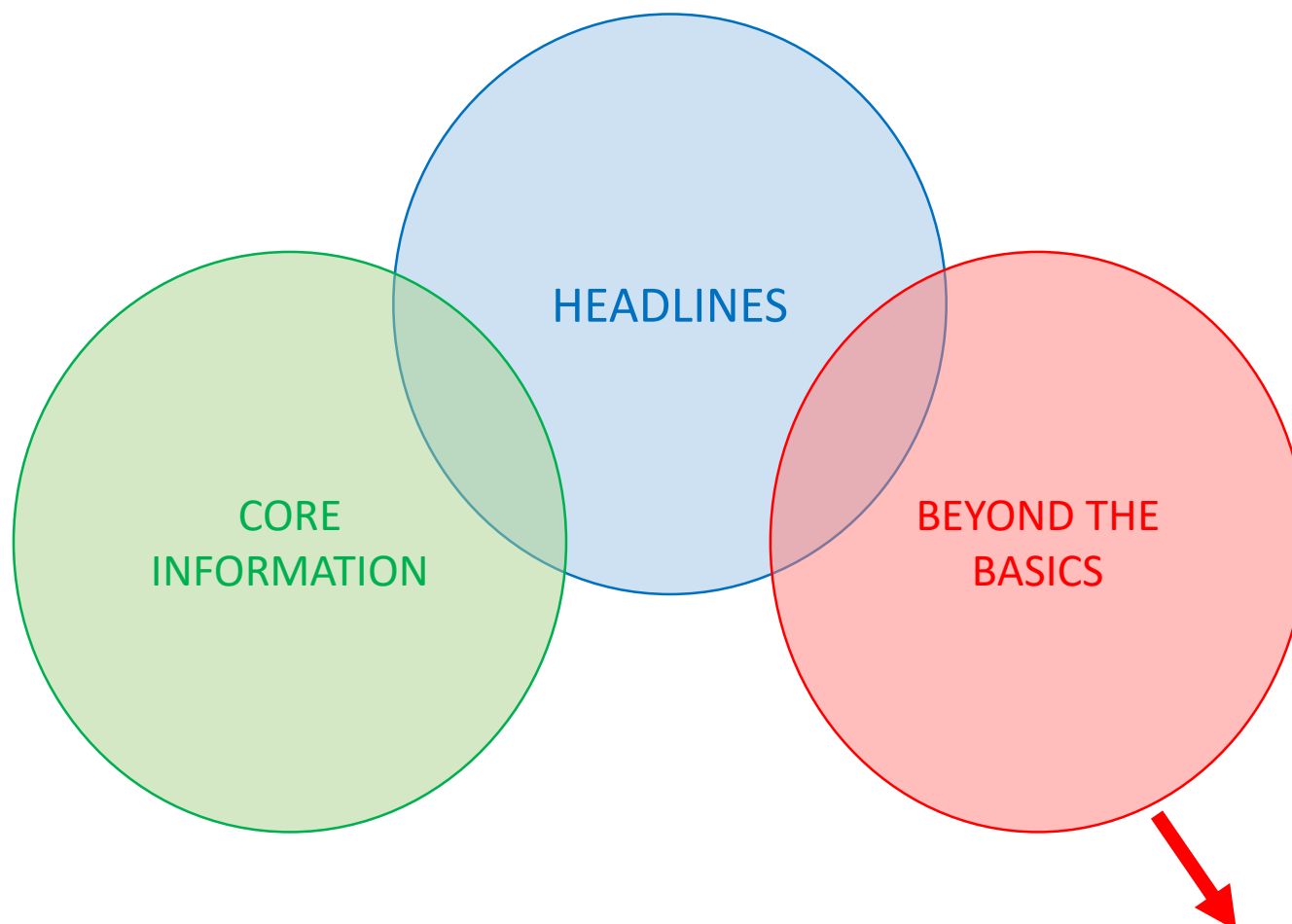
From clinicians:

- Easily accessible evidence base for clinicians and patients
- In line with good GMC practice
- Tailored/ person specific
- Should not ‘overburden’ the patients
- Triple layered approach
 - Headlining
 - Core Information
 - ‘Beyond the basics’

From patients/lay member groups:

- Give the information more than once
 - by more than one healthcare professional
 - in more than one way
- Careful use of language
- Time to consider and question
- Information to be given in a variety of ways
 - written, online, contact points
 - Impaired vision
 - Illiteracy and innumeracy

Patient information tools



Consistent presentation
style throughout

Links to more detailed
information, centre-specific



Catheter

- You will need a bladder catheter after the transplant. This is a soft plastic tube which connects your bladder, (where urine is stored inside your body normally) to the outside world.
- This is usually only in for a few days but occasionally it needs to be in for a few weeks.

CORE
INFORMATION

Catheter

- The catheter tube is placed through the penis in a man, and through the urethra (where urine comes out) in a woman
- A bladder catheter is used for monitoring how much urine the transplant is making, and to and to help protect the join between the transplant and your bladder.
- Typically a catheter is kept in for around 5 days after the transplant

BEYOND
THE BASICS

Catheter

- If the bladder is very small, or if joining the transplant urine pipe (ureter) to the bladder was particularly difficult, the catheter may need to stay in for longer
- The bladder can be very small if you are not making urine, which is the case for many long term dialysis patients

<https://exploretransplant.org/my-transplant-coach/>

Transplant Risk and Assessment Calculator Tool

In collaboration with the Winton Centre for Risk and
Evidence Communication, University of Cambridge

What is Predict?

Predict is an online tool that helps patients and clinicians see how different treatments for early invasive breast cancer might improve survival rates after surgery.

It is endorsed by the American Joint Committee on Cancer (AJCC).

> Start Predict



What does Predict do?

Predict asks for some details about the patient and the cancer. It then uses data about the survival of similar women in the past to show the likely proportion of such women expected to survive up to fifteen years after their surgery with different treatment combinations.



Who is Predict for?

Predict is for clinicians, patients and their families.
Patients should use it in consultation with a medical professional.



Where can I find out more?

To read more go to [About Predict](#).

Reset

Age at
diagnosis



- 55 +

Age must be between 25 and 85

Post
Menopausal?



Yes No Unknown

ER status



Positive Negative

HER2 status



Positive Negative Unknown

KI-67 status



Positive Negative Unknown

Tumour size
(mm)



- 5 +

Tumour grade



1 2 3 Unknown

Detected by



Screening Symptoms Unknown

Positive nodes



- 1 +

Micrometastases



Yes No Unknown

Enabled when positive nodes is zero

Treatment Options

**Hormone
Therapy**



☒ No ☐ Yes

Available when ER-status is positive

Chemotherapy



☐ None ☐ 2nd gen ☒ 3rd gen

Trastuzumab



☒ No ☐ Yes

Available with chemotherapy when HER2 status is positive

Bisphosphonates



☒ No ☐ Yes

Available for post-menopausal women

Results

Table Curves Chart Texts Icons

These results are for women who have already had surgery. This table shows the survival percentages based on the information you have provided

5 10 15 years after surgery.

Treatment	Additional Benefit	Overall Survival %
Surgery only	-	77%
+ Hormone therapy	5.1% (3.0% – 6.3%)	82%
+ Chemotherapy	4.1% (3.1% – 5.1%)	86%
+ Trastuzumab	2.3% (1.6% – 3.2%)	89%
+ Bisphosphonates	1.0% (0.4% – 1.5%)	90%

If nobody died from breast cancer 94% would survive 10 years. [i](#)

Show ranges?

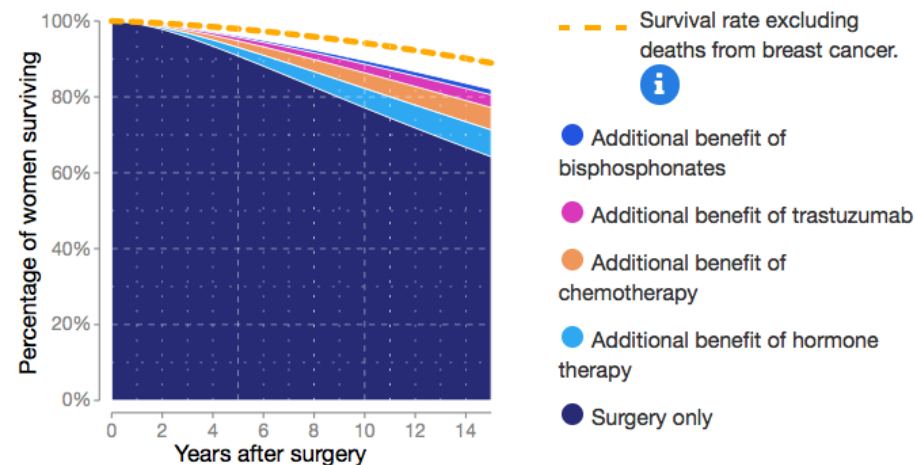


Yes No

Results

Table Curves Chart Texts Icons

These results are for women who have already had surgery. This graph shows the percentage of women surviving up to 15 years. These results are based on the inputs and treatments you selected.



Results

Table Curves Chart Texts Icons

These results are for women who have already had surgery. This display shows the outcomes for 100 women based on the inputs and treatments you have selected

5 10 15 years after surgery.



- 6 deaths due to other causes
- 5 breast cancer related deaths
- 1 extra survivors due to bisphosphonates
- 2 extra survivors due to trastuzumab
- 4 extra survivors due to chemotherapy
- 5 extra survivors due to hormone therapy
- 77 survivors with surgery alone

Table Curves Chart Texts Icons

These results are for women who have already had surgery. This display shows the outcomes for 100 women based on the inputs and treatments you have selected

5 10 15 years after surgery

77 out of 100 women are alive at 10 years with surgery only.

- 82 out of 100 women treated (an extra 5) are alive because of hormone therapy.
- 86 out of 100 women treated (an extra 9) are alive because of hormone therapy, and chemotherapy.
- 88 out of 100 women treated (an extra 11) are alive because of hormone therapy, and chemotherapy, and trastuzumab.
- 89 out of 100 women treated (an extra 12) are alive because of hormone therapy, and chemotherapy, and trastuzumab, and bisphosphonates.

Of the women who would not survive, 6 would die due to causes not related to breast cancer.

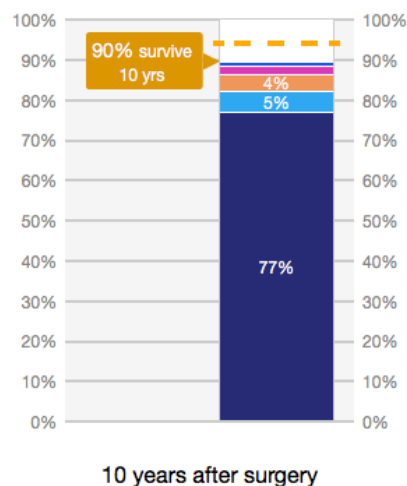
Results

Table Curves Chart Texts Icons

These results are for women who have already had surgery. Based on the inputs and treatments you selected, this graph shows the percentage of women surviving

5 10 15 years after surgery.

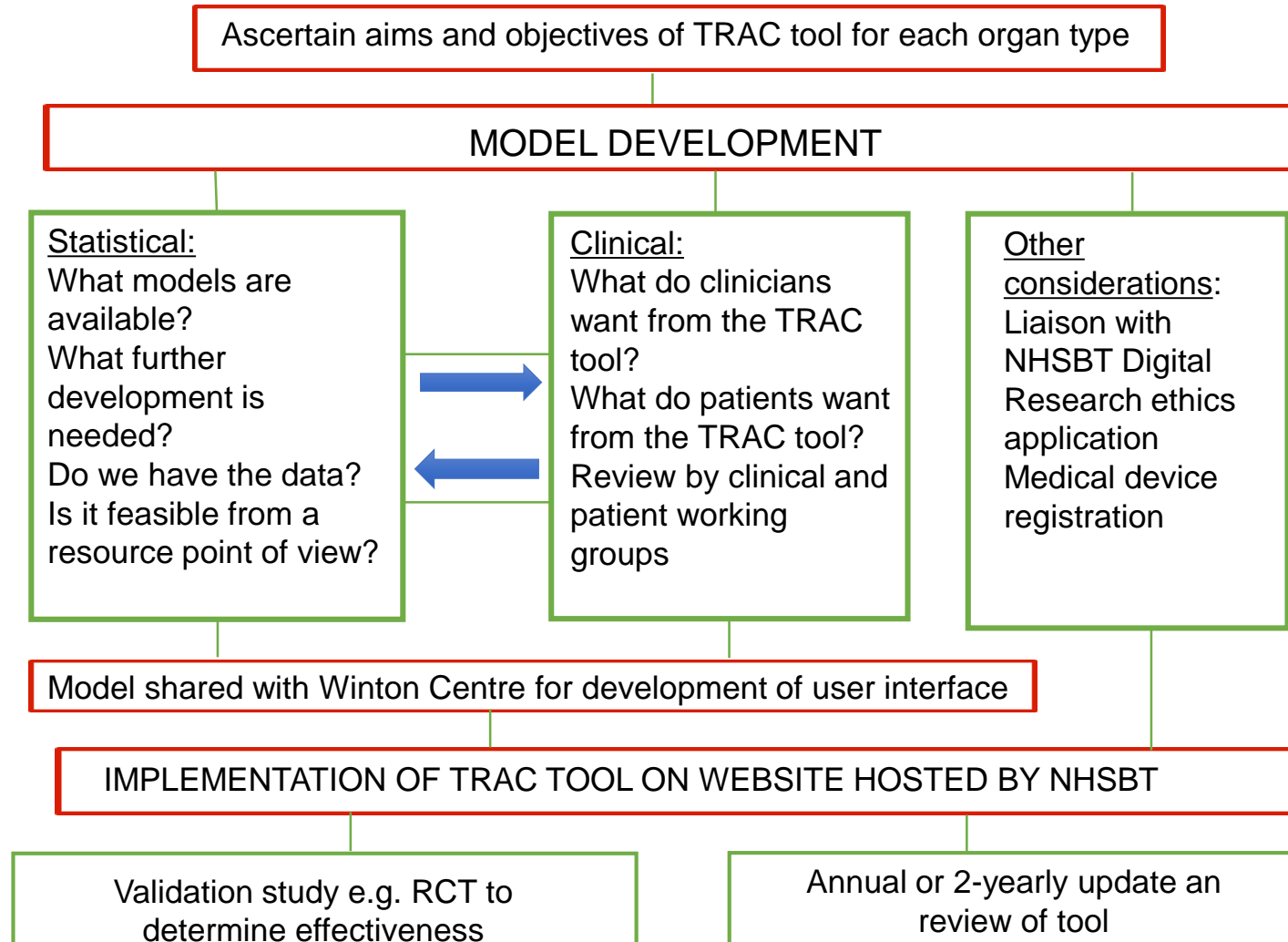
Overall Survival



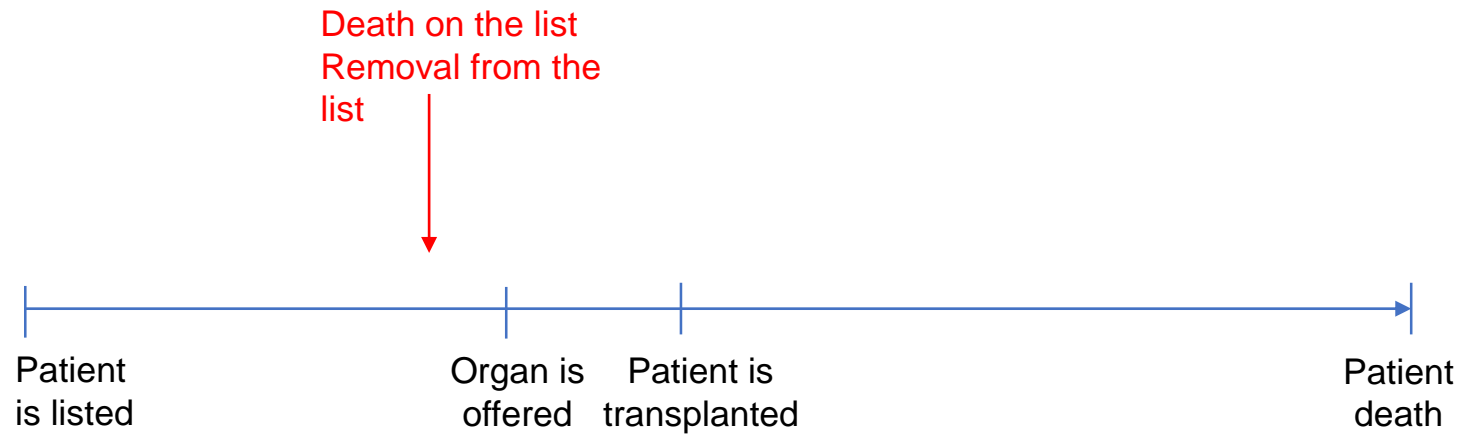
--- Survival rate excluding deaths from breast cancer. **i**

- Additional benefit of bisphosphonates is 1% at 10 years.
- Additional benefit of trastuzumab is 2% at 10 years.
- Additional benefit of chemotherapy is 4% at 10 years.
- Additional benefit of hormone therapy is 5% at 10 years.
- Surgery only survival is 77% at 10 years.

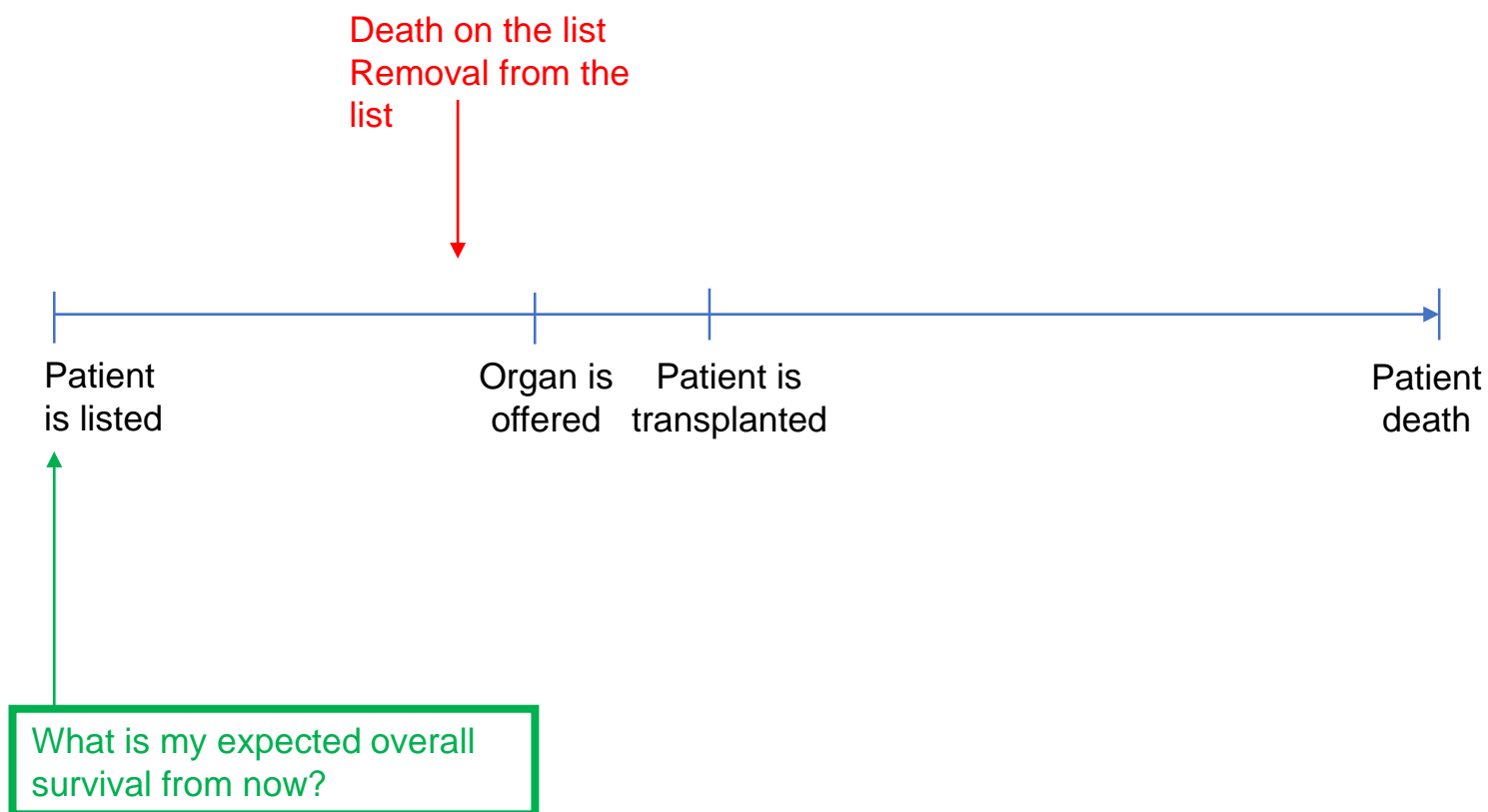
Development of the TRAC tool



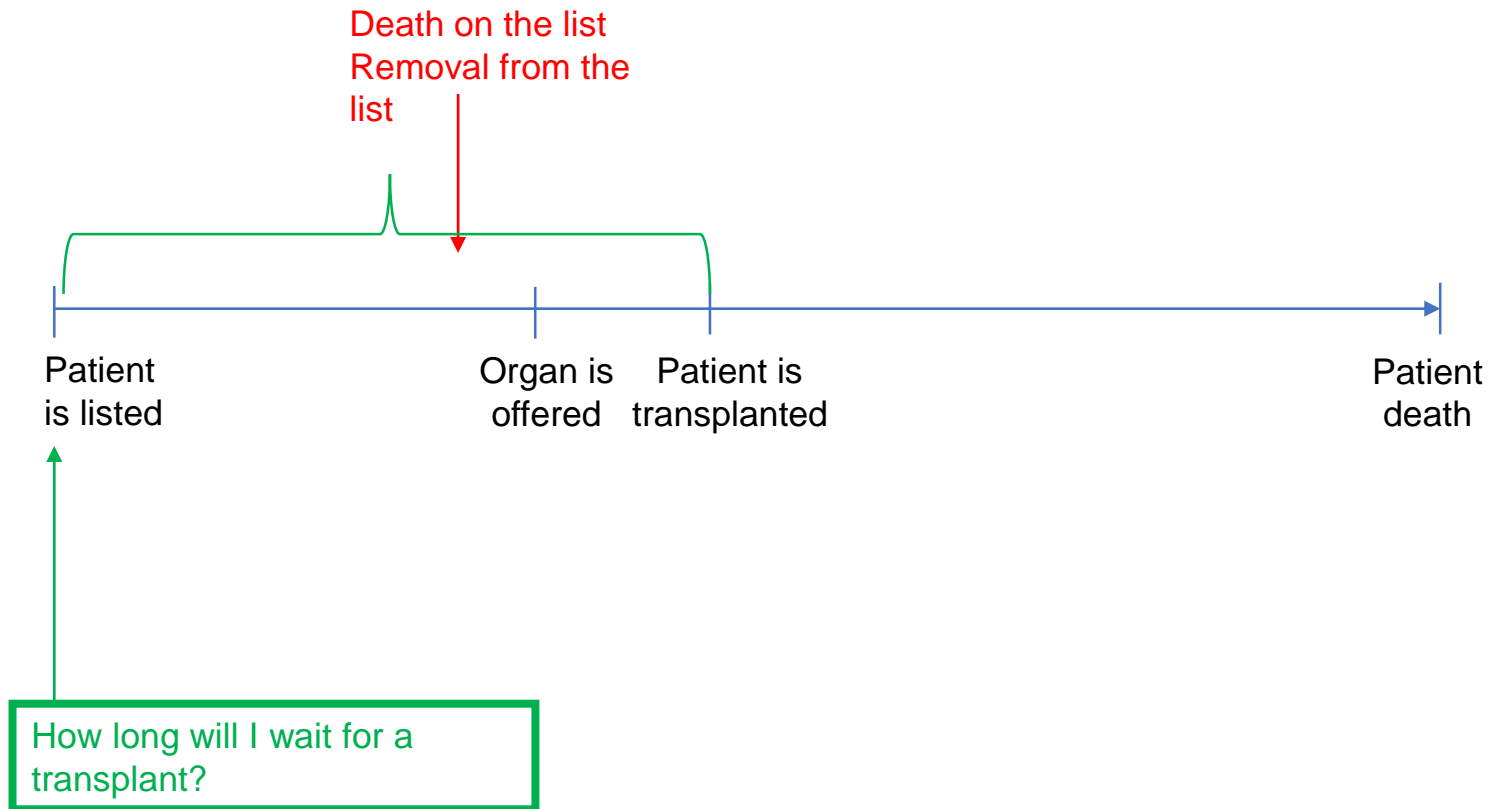
Patient Outcomes



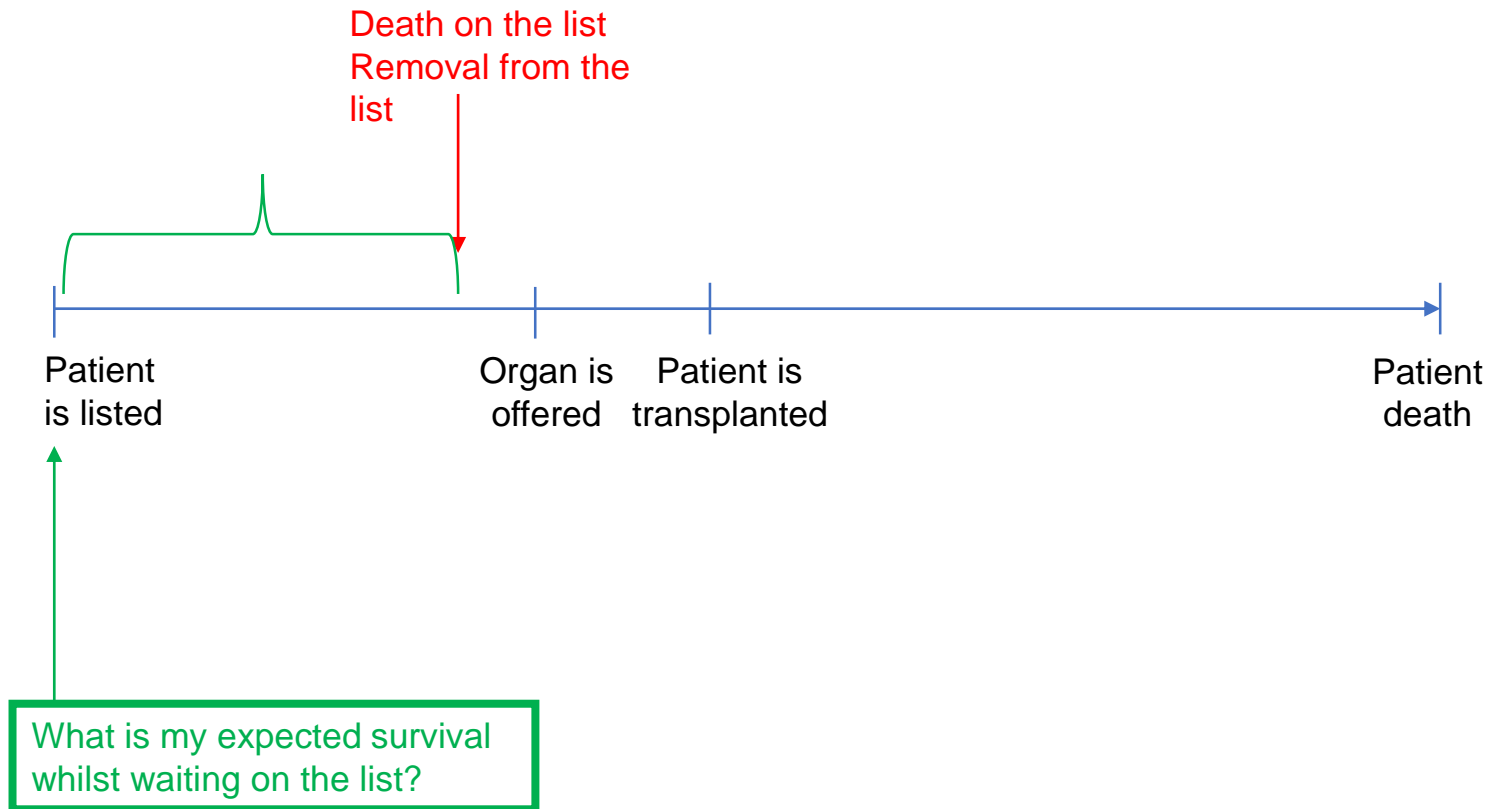
Survival from Listing



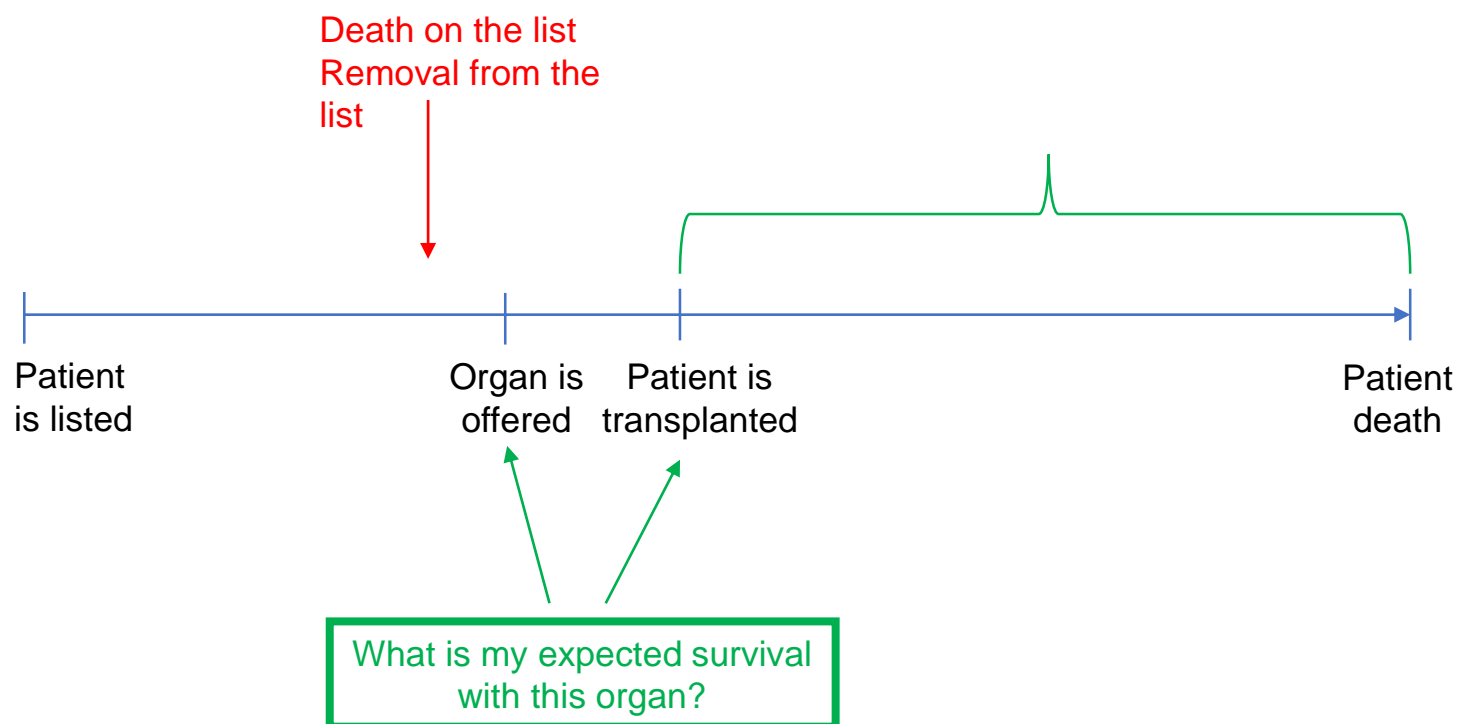
Time to Transplant



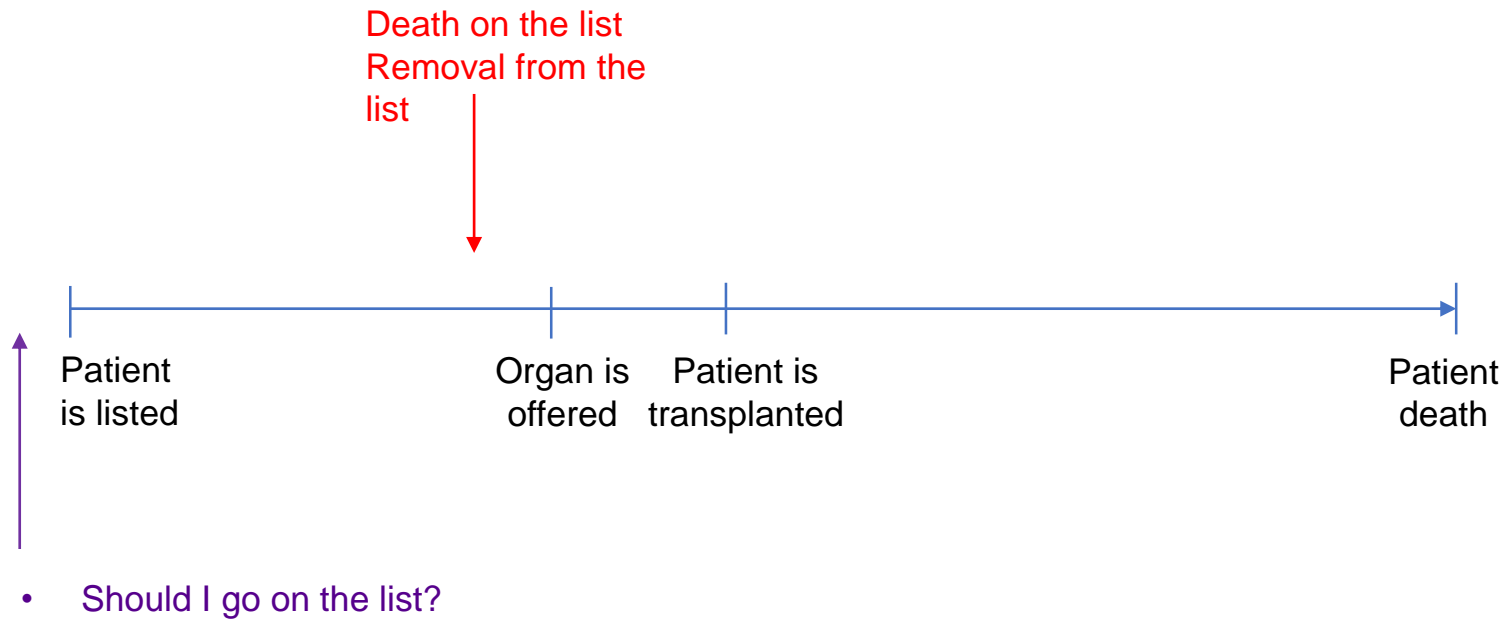
Survival on the list



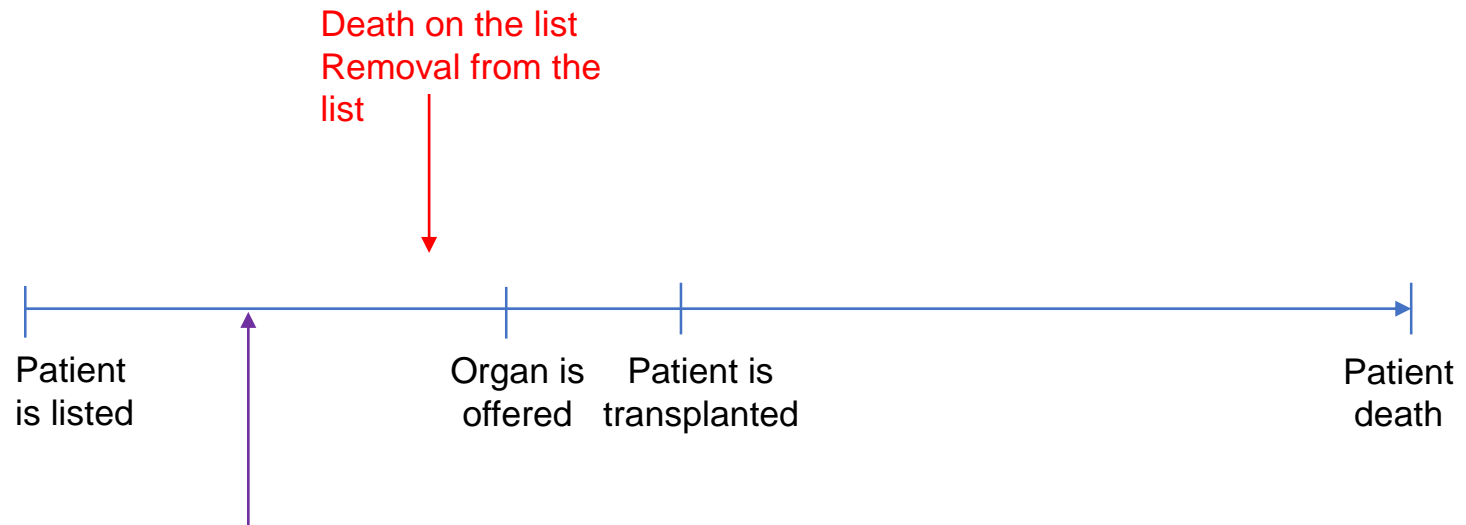
Post-transplant survival



What we cannot answer

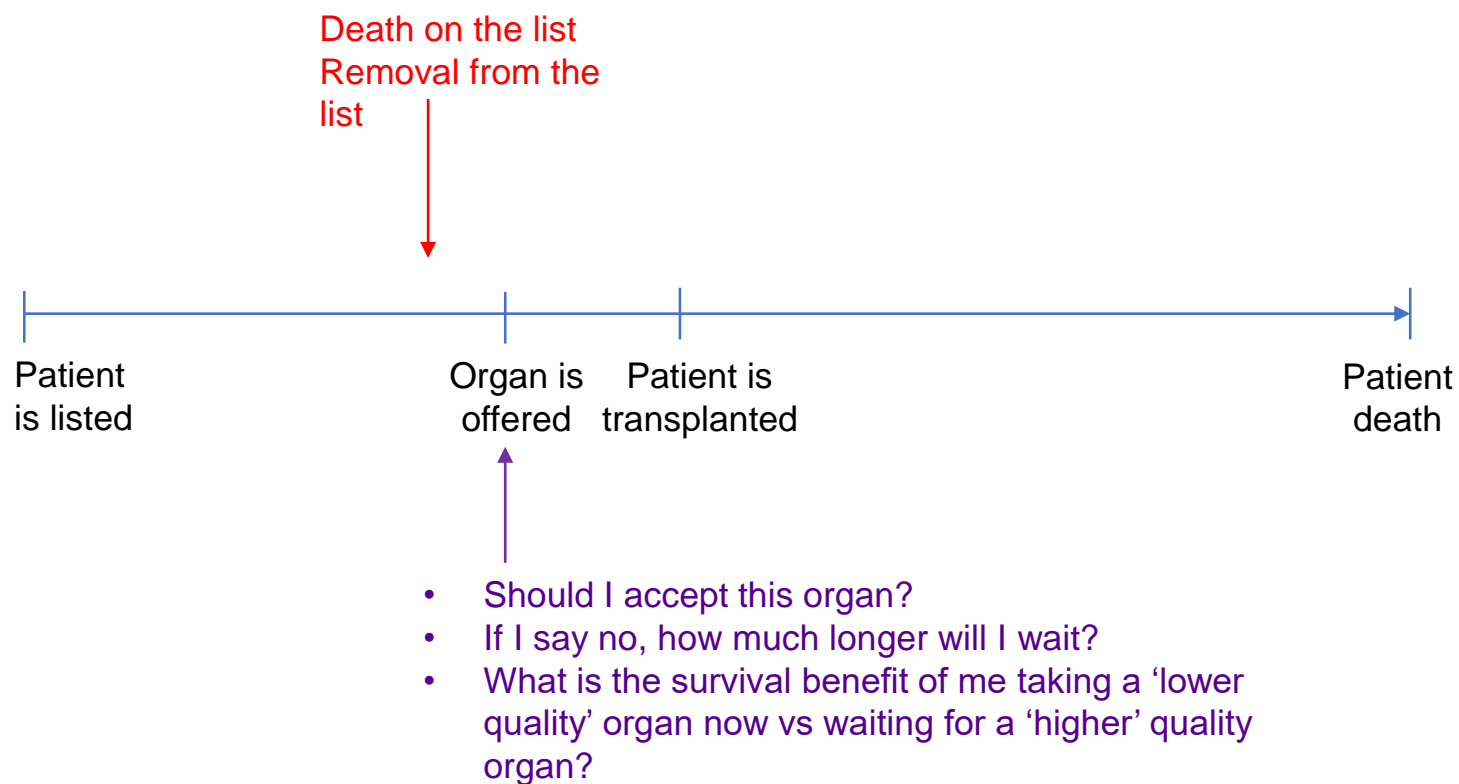


What we cannot answer



- What are my expected outcomes now? (post-listing)

What we cannot answer



Summary of Models

	Lung	Liver	Kidney	Heart	Pancreas
Survival from listing	✓	✓	✓	✓	✓
Time to transplant	✓		✓		
Survival on the list	✓	✓			
All competing risks from listing	✓				
Post-transplant survival	✓	✓	✓	✓	✓
Transplant Benefit Score (donor:recipient specific)		✓			

Consent Framework

Organ transplants have many benefits, but also have some risks. It is important that you and your family understand these benefits and risks before you are placed on the national transplant list. In the UK, NHS Blood and Transplant maintain the transplant list, and sets guidance on many aspects of organ and tissue transplantation. This poster provides information from NHS Blood and Transplant and the British Transplantation Society on what you and your family can expect from the transplant team looking after you.

Communicating Risk and Consent in Organ Transplantation

Care will be co-ordinated & integrated, encompassing practical and (when necessary) psychological support if you are referred for transplant assessment

Information & education will be communicated using a variety of formats tailored to the needs of all communities

Assessment and consent discussions, where appropriate, will involve your family and friends and members of the transplant team. Discussions will be tailored to the individual patient to enable shared decision making around listing for transplantation and risk

Decisions made will be confirmed in writing with regards to transplantation and risk

Annual review of patients on the transplant waiting list will include a review of decision making around transplant choices and risk, taking into account changes to their clinical condition. A consultant will lead discussions and decisions will be confirmed in writing.

If you have any questions about the benefits and risks of organ transplantation, please speak to a member of the transplant team looking after you.

Consent

Discussions will be written and recorded, including up to date documentation of the key points of the discussion, hard copies or web links and any further information provided to you.

Review of guidelines

Consent for Solid Organ Transplantation in Adults



Compiled by a Working Party of
The British Transplantation Society
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Acknowledgements

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 - Chris Callaghan
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 - Kidney – Matt Wellberry Smith
 - Liver – Derek Manas
 - Pancreas – Chris Watson
 - Heart – Jayan Parameshwar
 - Lung – Jas Parmar
 - Bowel – Neil Russell