NHS
Blood and Transplant

Communication of Risk and Consent in Transplantation

RINTAG(18)31

02/10/2018

Objectives

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- Describe the projects within the ‘Communication of Risk and Consent in Transplantation’ working group
- Transplant Risk/benefit Assessment and Communication (TRAC) tool
- Best practice consent videos

Background

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- Changing donor demographics has led to increasing use of ‘marginal’ donors
- Greater need for individual assessment of risks/benefits of transplant due to large variability in recipient and donor population
- Perception that more ‘risky’ transplants are taking place and continued evaluation of outcomes is required
- How can we improve communicating this risk / benefit relationship to both patients and clinicians?

Key questions

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- How do we currently communicate transplant risk / benefit to our patients?
  - Patient information leaflets, videos etc.
  - Communication with healthcare professionals in clinic
  - Limited tools available for individualised communication of risk
  - How *should* we be communicating risk/benefit to our patients?
- How well do we as clinicians know the risk of transplantation and which variables are of significance?
- What information is relevant when consenting patients?

General principles

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- Tool must be (relatively) easy to use and interpret

- Must consider variation in literacy and numeracy rates amongst patient groups

- Note: current NHS literature aimed at a literacy age of 11

- Should be trustworthy and statistically sound

- Absolute risk should be clearly demonstrated to avoid misinterpretation

- Methodology should be transparent and easily accessible

- Should act as a helpful aid to clinicians when making clinical decisions

- Clear indicator that ‘acceptable tolerable risk’ will vary for each individual patient, tool itself not to include clinical recommendations

- Can demonstrate to clinicians which variables are of statistical significance

A Patient Journey

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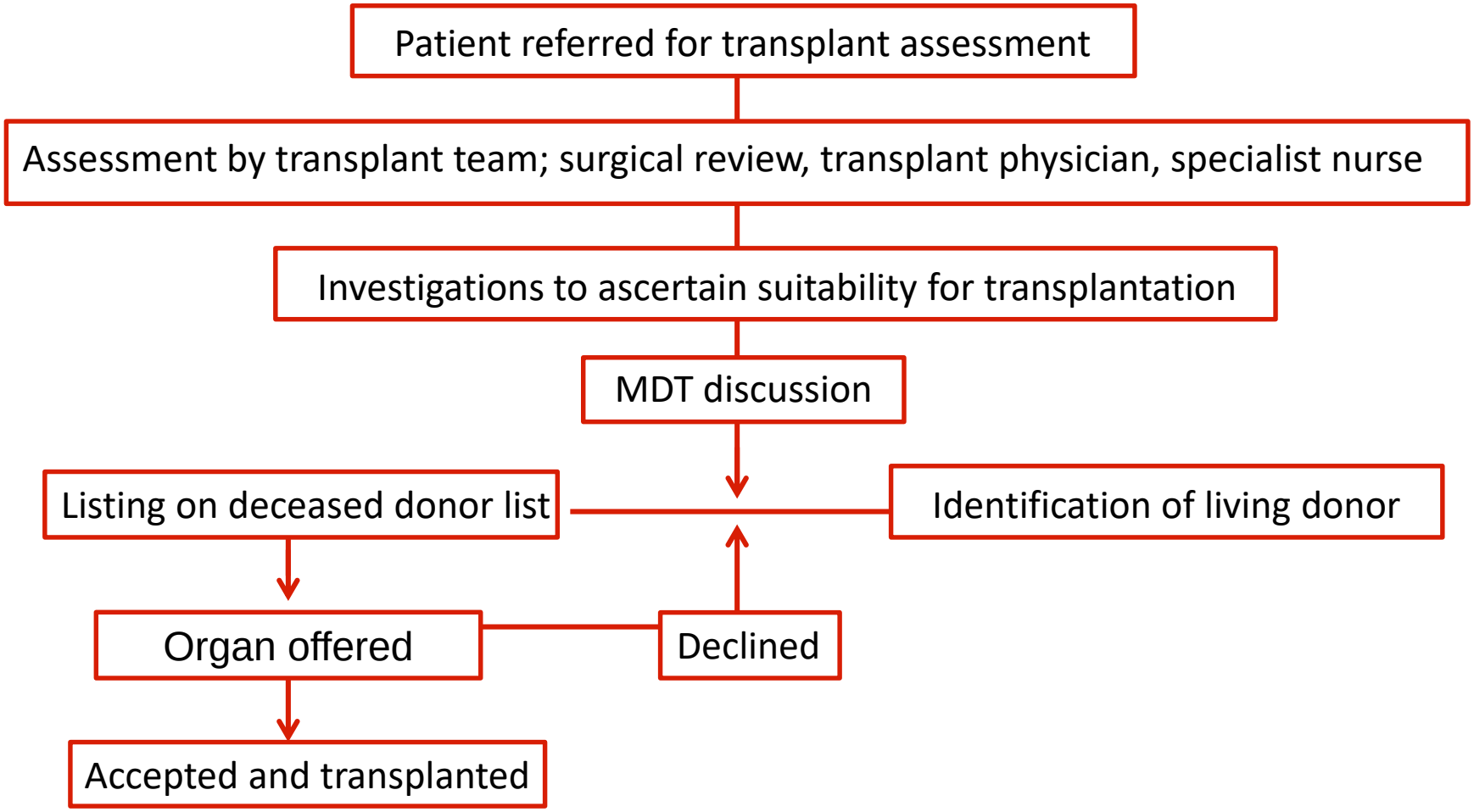
(Example for an elective kidney transplant recipient)



At what points could use of a risk/benefit tool developed using NHSBT data be most clinically useful?

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What are we currently working on?

- Transplant Risk/benefit Assessment and Communication (TRAC) tool

- Best practice consent videos

Development of the TRAC tool

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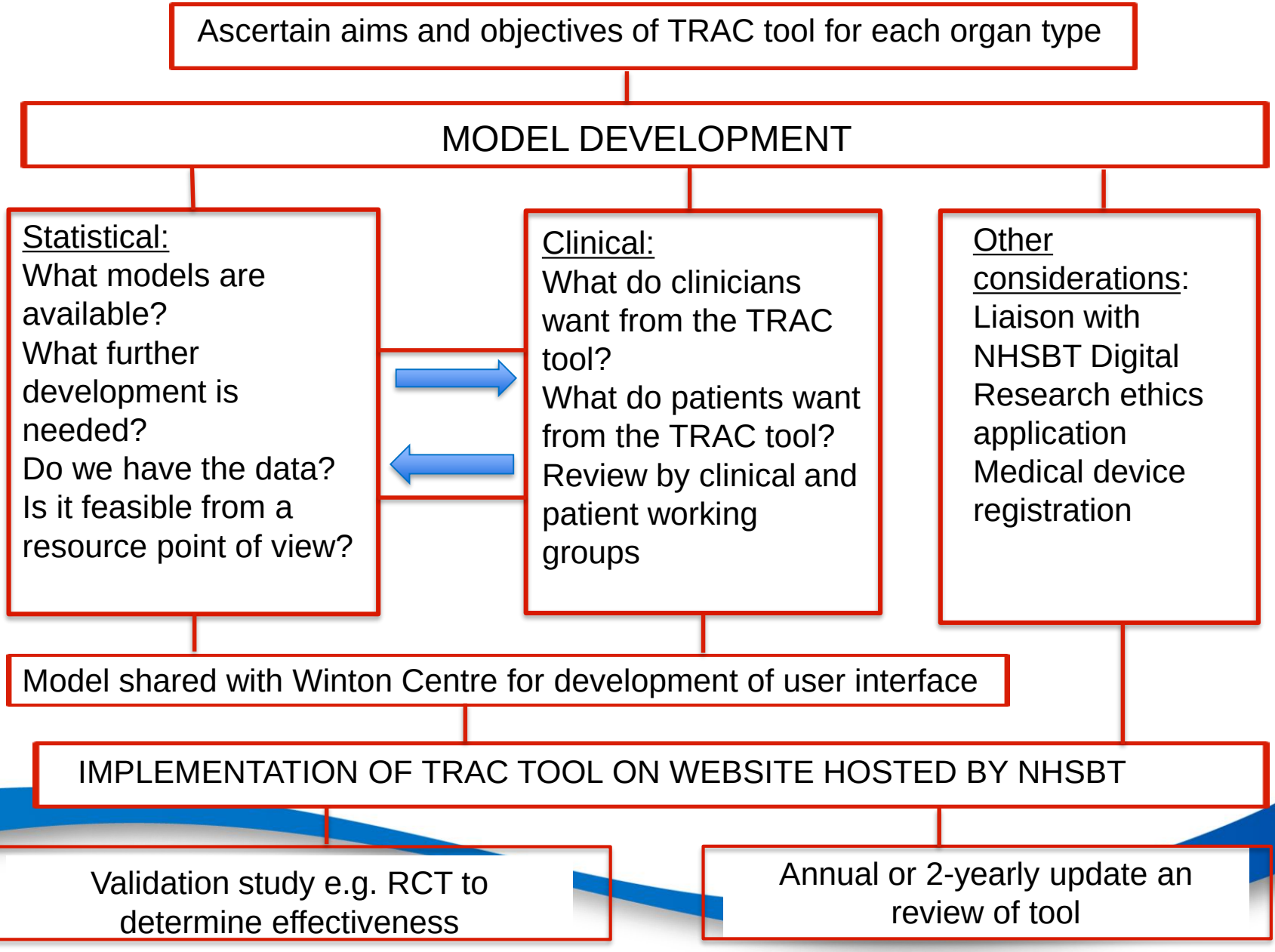

TRAC development

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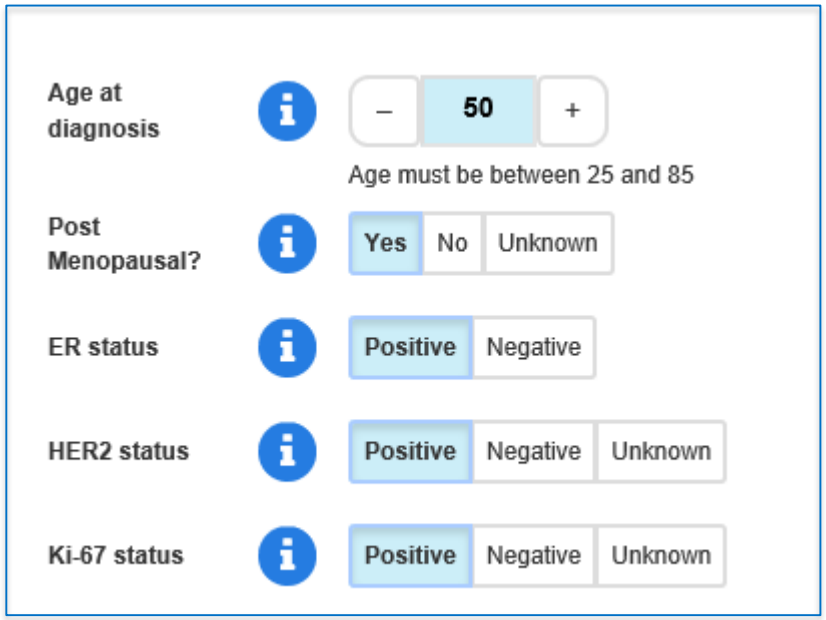
Examples from breast cancer ‘NHS Predict’ website, developed by Winton Centre:

Input:



TRAC development

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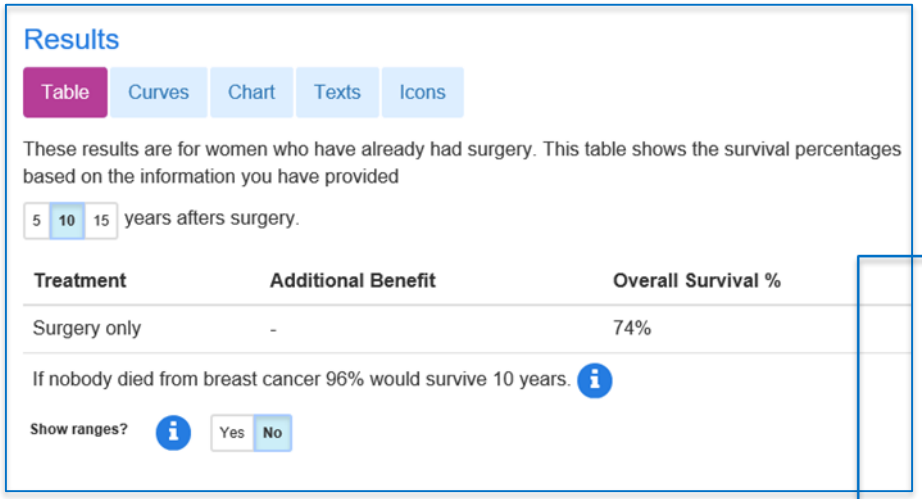
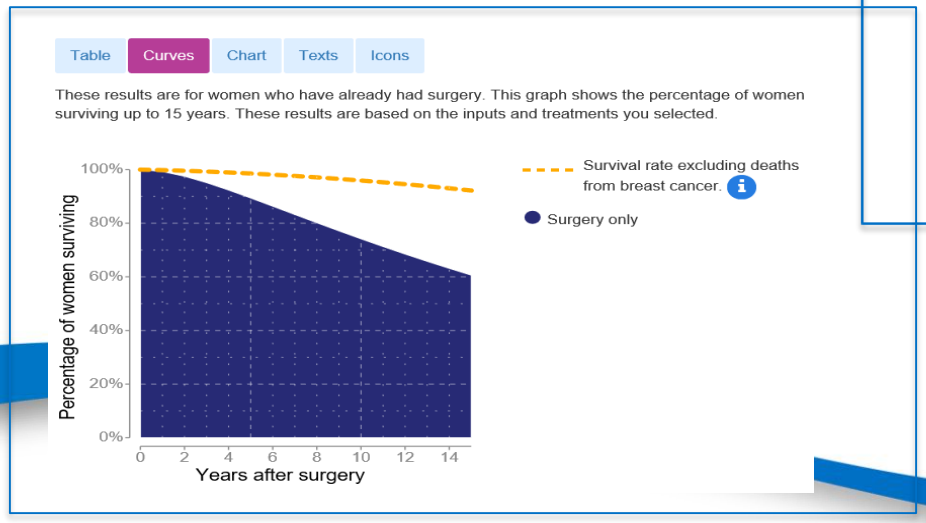
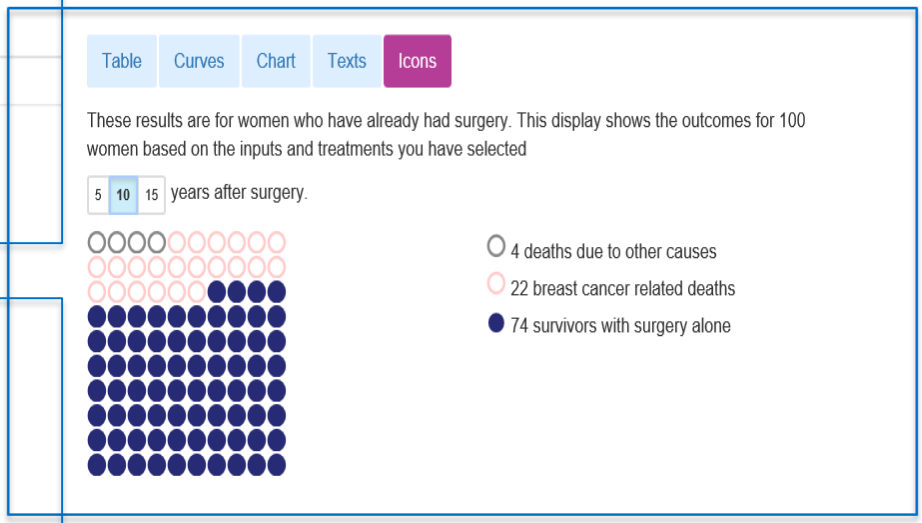
Output:







Example of survival graphs: John Hopkins IRD Kidney Transplant Calculator

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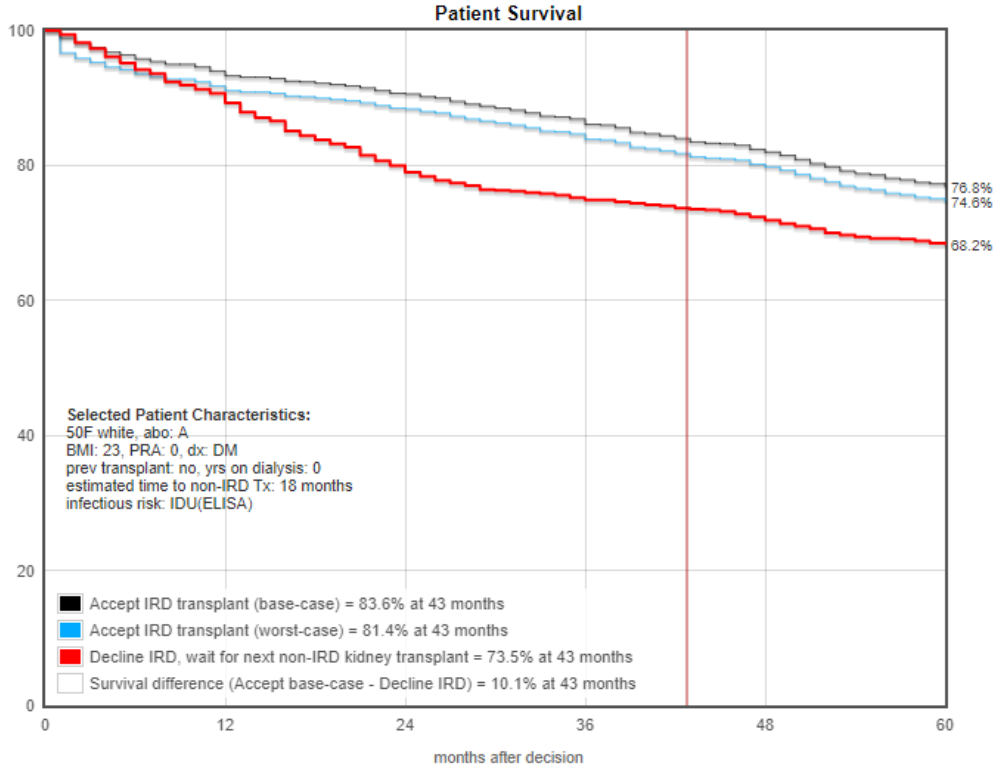

base-case estimate: mortality risk (if seroconverted) increased by 4.12% HIV, 3.42% HCV per year
worst-case estimate: mortality risk (if seroconverted) equivalent to immediate (100% chance) death

Recipient Characteristics:

Age: (20-75)	50
Gender:	female
ABO:	Type A
Ethnicity:	White
BMI: (19-39)	23
PRA: (0-100)	0
Renal failure diagnosis:	diabetes mellitus
Previous transplant:	no
Years on waitlist:	0
Estimated time remaining until non-IRD transplant *:	18 months

* This is time in addition to the time the patient may have already waited. eg: if a patient has spent 1 year on the waitlist, and the estimated time remaining until a non-IRD transplant is 18 months, the patient is expected to have waited 30 months since listing, before a non-IRD transplant.

Donor Characteristics:

Infectious Risk Behavior:	Intravenous drug users
Serology Testing Used:	ELISA

Survival curves clearly interpretable, shows change over time

Lay representative feedback: useful for interpretation for clinicians in conjunction with patients

Best practice consent videos

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- Development of digital educational videos
- Aim to be realistic, informative and easily interpretable
- Dialogue between clinicians and patients
- Potential use of animation

Best practice consent videos

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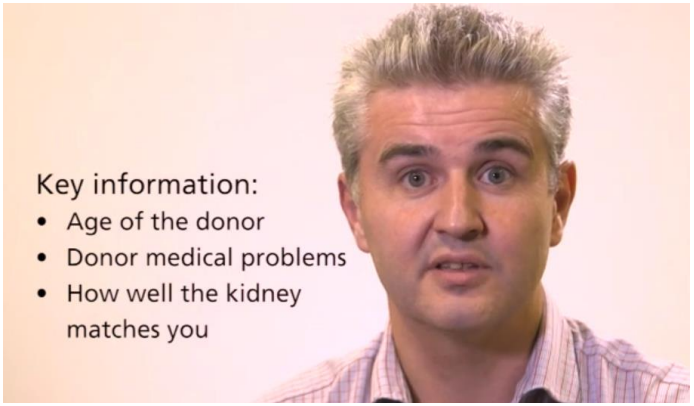
Royal Free Hospital:

(kidney transplantation)



John Hopkins:

(pancreas transplantation)

Best practice consent videos

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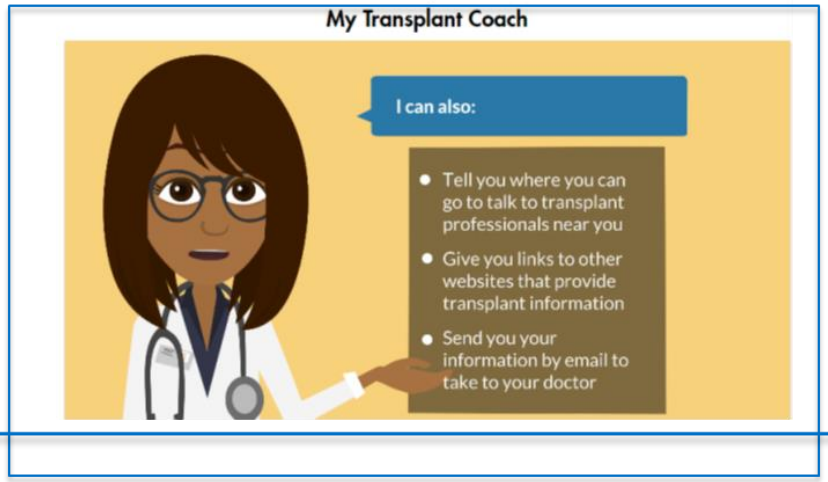
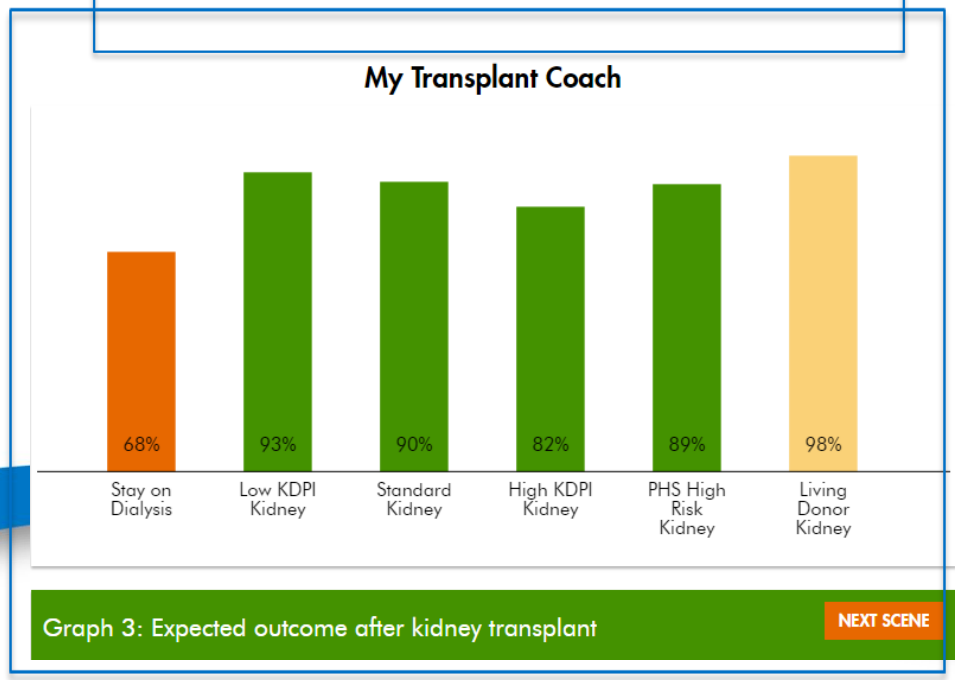
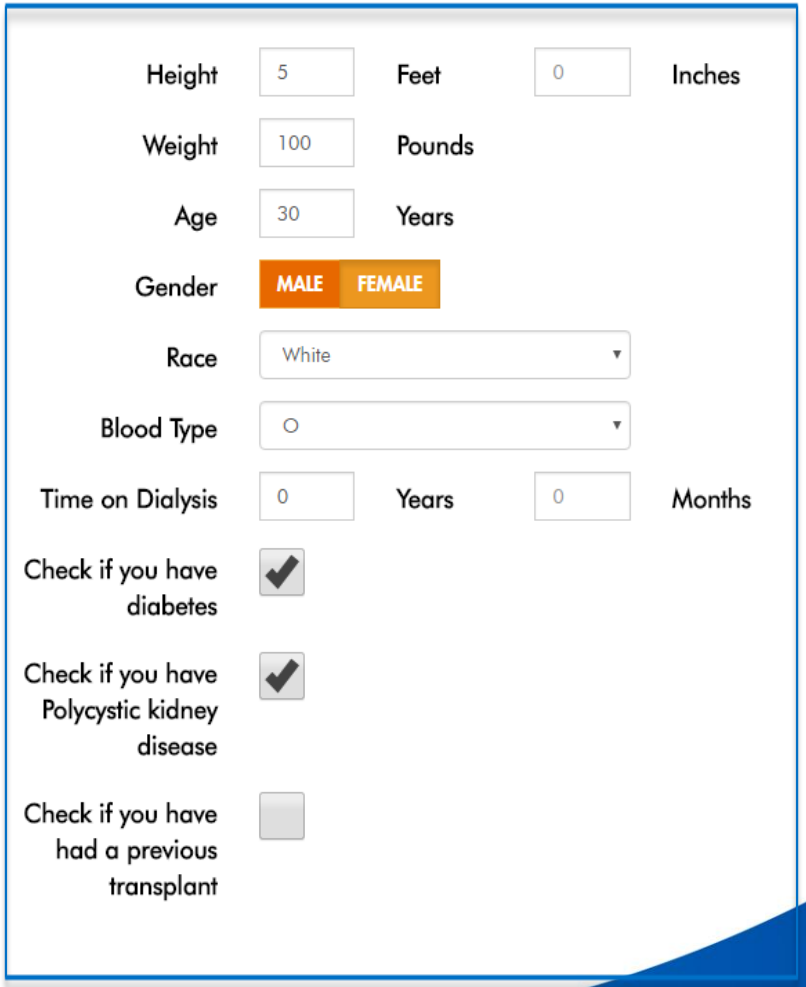
University of Emory:







Summary

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- Scope for expansion of current UK risk/benefit communication tools
- Variety of mechanisms by which this can be achieved
- Key clinically important communication messages to be identified
- Optimisation of shared decision making