Communication of Risk and Consent in Transplantation

02/10/2018
Objectives

• 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

• 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

• 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

• 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

(Example for an elective kidney transplant recipient)

Patient referred for transplant assessment

Assessment by transplant team; surgical review, transplant physician, specialist nurse

Investigations to ascertain suitability for transplantation

MDT discussion

Listing on deceased donor list

Identification of living donor

Organ offered

Declined

Accepted and transplanted

At what points could use of a risk/benefit tool developed using NHSBT data be most clinically useful?
What are we currently working on?

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

• Best practice consent videos
Development of the TRAC tool

- Ascertain aims and objectives of TRAC tool for each organ type

**MODEL DEVELOPMENT**

- **Statistical:**
  - What models are available?
  - What further development is needed?
  - Do we have the data?
  - Is it feasible from a resource point of view?

- **Clinical:**
  - What do clinicians want from the TRAC tool?
  - What do patients want from the TRAC tool?
  - Review by clinical and patient working groups

- **Other considerations:**
  - Liaison with NHSBT Digital
  - Research ethics application
  - Medical device registration

**MODEL DEVELOPMENT**

- Model shared with Winton Centre for development of user interface

**IMPLEMENTATION OF TRAC TOOL ON WEBSITE HOSTED BY NHSBT**

- Validation study e.g. RCT to determine effectiveness
- Annual or 2-yearly update and review of tool

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

Input:

- Age at diagnosis: 50
- Post Menopausal?: Yes
- ER status: Positive
- HER2 status: Positive
- Ki-67 status: Positive
TRAC development

Output:

Results

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Additional Benefit</th>
<th>Overall Survival %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery only</td>
<td></td>
<td>74%</td>
</tr>
</tbody>
</table>

If nobody died from breast cancer 96% would survive 10 years.

Show ranges? Yes No

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.

16 deaths due to other causes
22 breast cancer related deaths
74 survivors with surgery alone

Survival rate excluding deaths from breast cancer.
Example of survival graphs: John Hopkins IRD
Kidney Transplant Calculator

Survival curves clearly interpretable, shows change over time

Lay representative feedback: useful for interpretation for clinicians in conjunction with patients
Best practice consent videos

• Development of digital educational videos

• Aim to be realistic, informative and easily interpretable

• Dialogue between clinicians and patients

• Potential use of animation
Royal Free Hospital: (kidney transplantation)

John Hopkins: (pancreas transplantation)
Best practice consent videos

University of Emory:

My Transplant Coach

- I can also:
  - Tell you where you can go to talk to transplant professionals near you
  - Give you links to other websites that provide transplant information
  - Send you your information by email to take to your doctor

Graph 3: Expected outcome after kidney transplant
Summary

- 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