Communicating risk and consent in transplantation

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NHS Blood and Transplant

Drivers for Change

- Change in risk for recipients due to changing donor landscape
- Need to support clinicians in use of higher-risk organs
- Montgomery and other cases have impacted on risk appetite
- Innovative ways of conveying information
- Appropriate recording of discussions with patients

Donated organs are second hand

Patient given kidney from 25-a-day smoker

Sarah-Kate Templeton

March 4 2018, 12:01am, The Sunday Times

The kidney the patient received failed, and she cannot undergo a further transplant
ALAMY

A transplant patient who was not told the organ she was being offered came from a 25-a-day smoker with high blood pressure wants guidelines changed so that full medical details of donors are disclosed.

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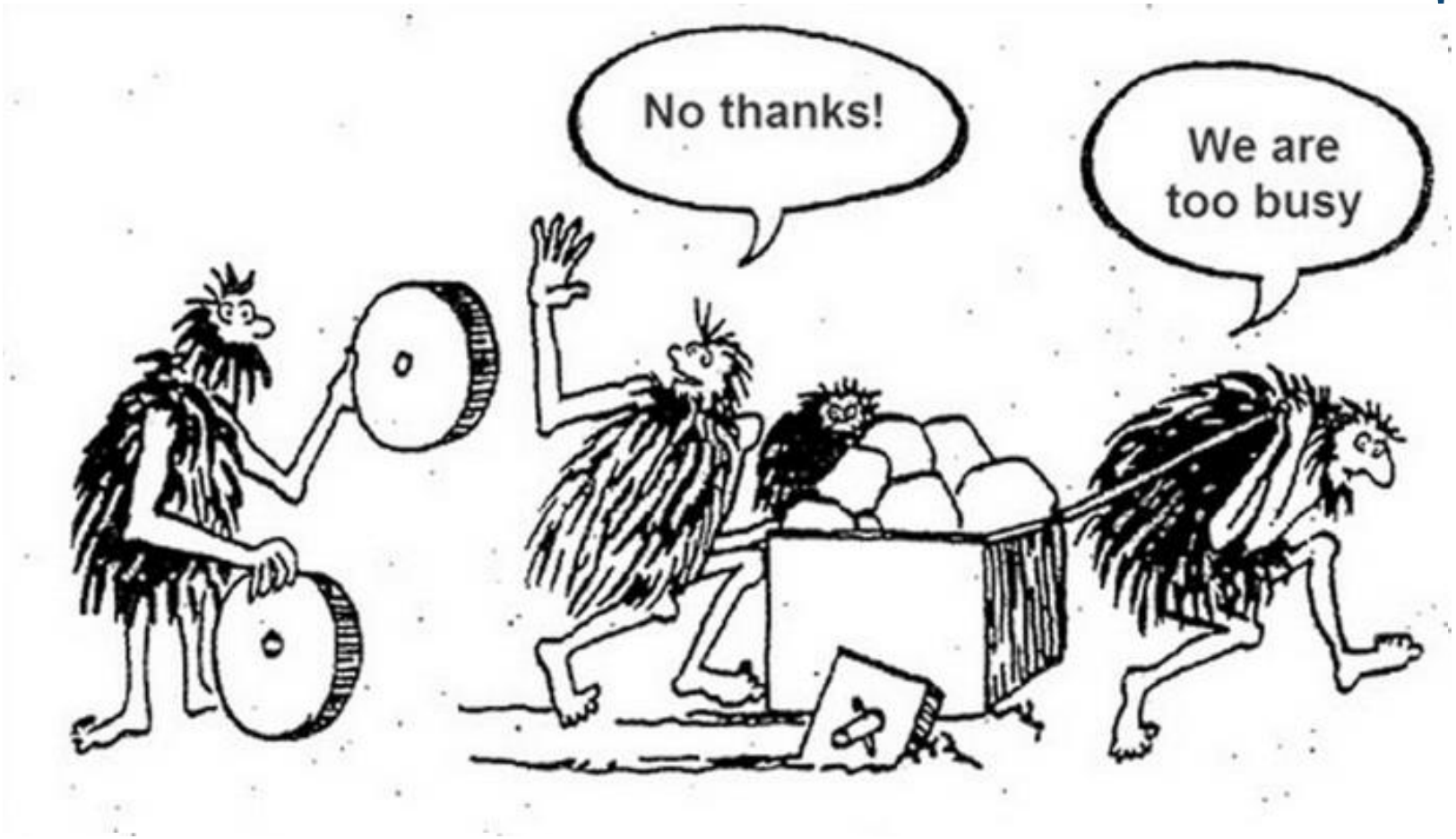
Transplant patients died after receiving kidneys with rare parasitic worm

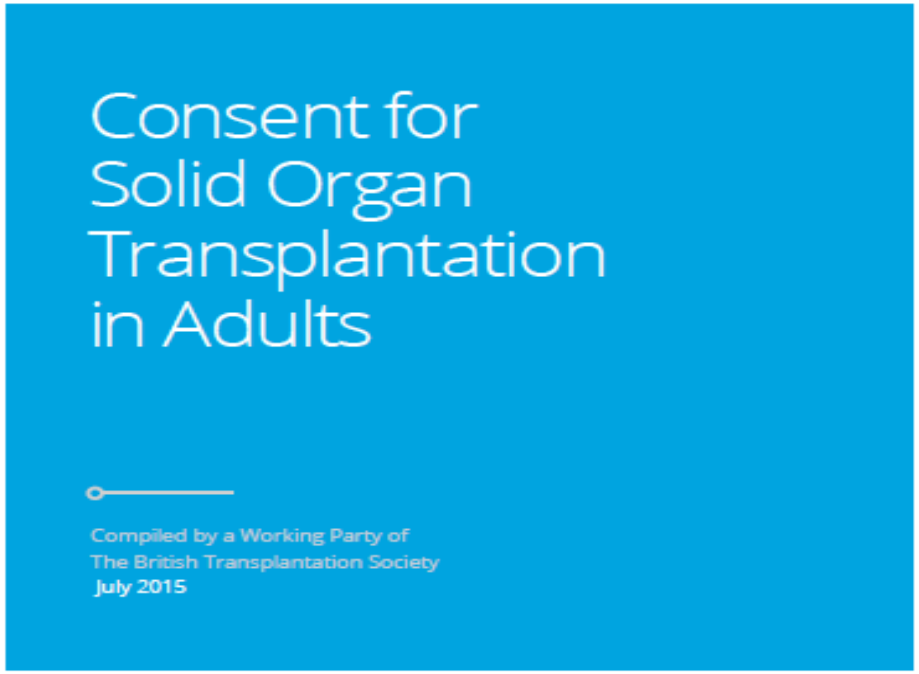
Doctors not to blame for neglect as two men suffered 'unintended consequences' of operation, coroner rules

Existing guidance



Existing guidance

Existing guidance



British Transplantation Society Guidelines

ODT/BTS workshop

To bring together stakeholders to seek their views on consent and communication of risk to patients in organ transplantation

- Challenges
- Barriers
- Timing
- Participants
- Organ specific information
- Documentation
- Use of technology
- Training

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Consent and risk communication

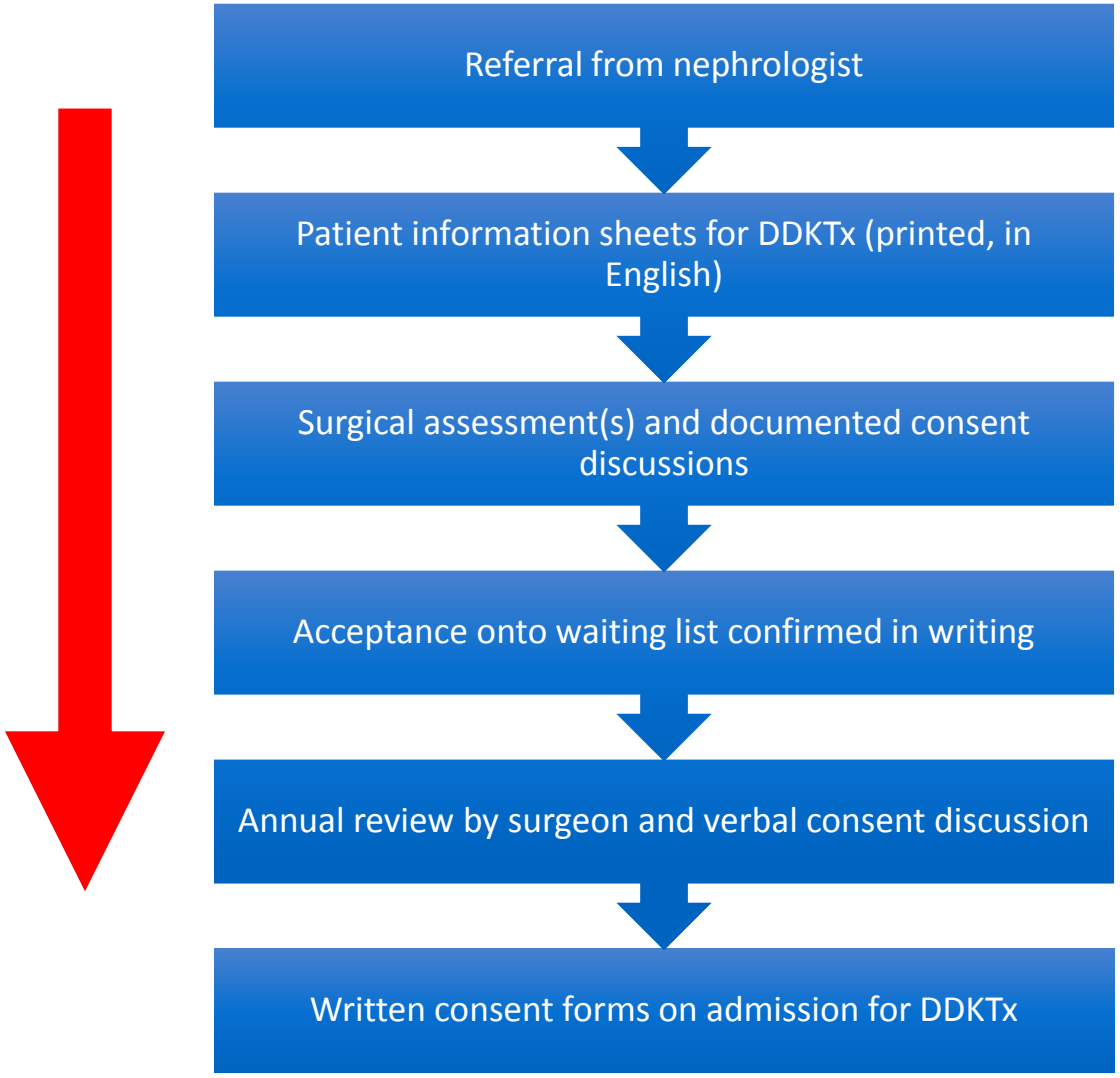
Key aspects

- Quality of information
- Communication
- Development of relationship
- Trust
- Shared decision making

PANDA

- Personalised
- Absolute
- Numerate
- Decision
- Aid

The Edinburgh approach



- Longitudinal process
- Different individuals?
  - Nephrologist
  - Surgeon
  - Co-ordinator/nursing staff
- Mode of delivery
- Medical and surgical consent?

- Organ offers/declines

What matters to me…

- Individual variation
- Different appetite for risk, and for desire to understand risk

- Core information
- Layered approach

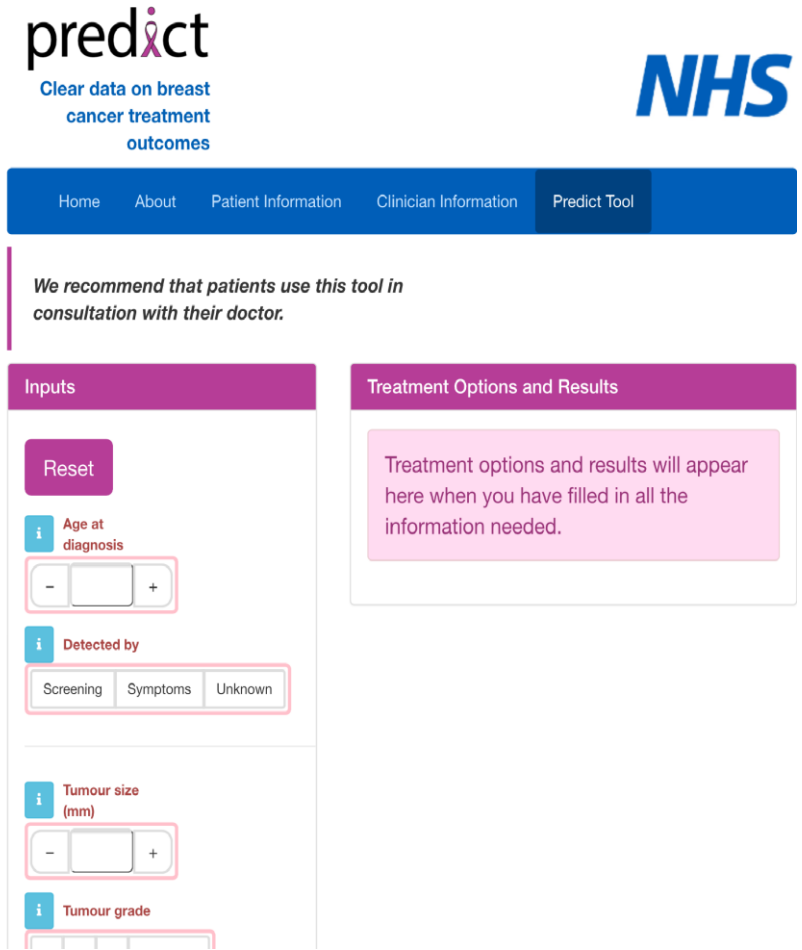
Information Provision

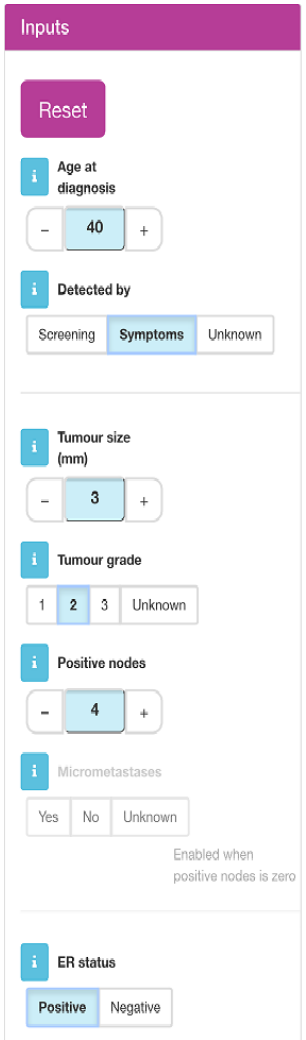
- Current best practice

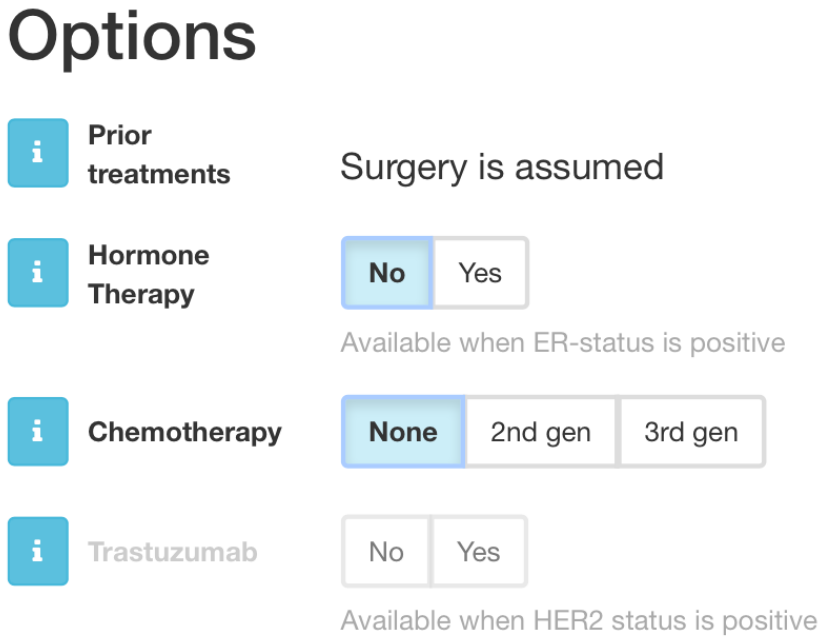
- Individual organ groups
  - Core information
  - Layers beyond that

- Toolkit
  - Written information
  - DVDs
  - Infographics
  - Data

  - Based on national data
  - Inclusion of local data







Winton Centre, Cambridge

Results

Table | Curves | Charts | Texts | Icons | Adverse effects mockup

This table shows the survival percentages based on the information you have provided.

5 **10** years after surgery

Treatment	Additional Benefit	Overall Survival %
Surgery only	-	90%

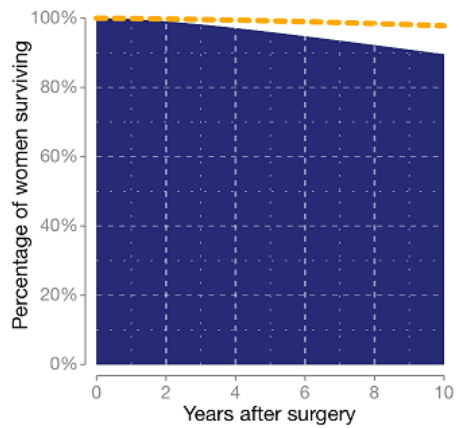
If these women were cancer free, 98% would survive 10 years.

Show ranges? Yes **No**

Results

Table | Curves | Charts | Texts | Icons | Adverse effects mockup

This graph shows the percentage of women surviving up to 10 years. These results are based on the inputs and treatments you selected



Survival of these women if they were free of cancer

Surgery only

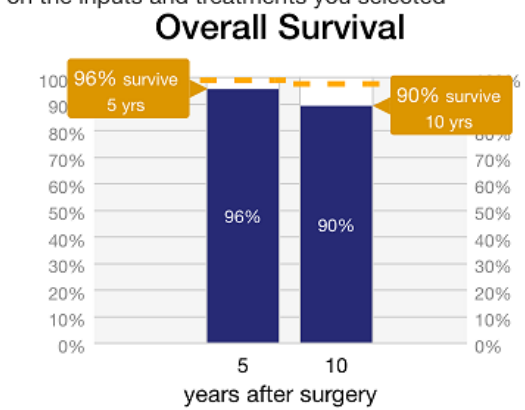
Surgery only

Results

Table | Curves | Charts | Texts | Icons

Adverse effects mockup

This graph shows the percentage of women surviving at 5 and 10 years. These results are based on the inputs and treatments you selected



Survival of these women if they were free of cancer

Surgery only survival is 96% at 5 years and 90% at 10 years

Results

Table | Curves | Charts | Texts | Icons

Adverse effects mockup

Based on the information you have entered:

5 | 10 years after surgery

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

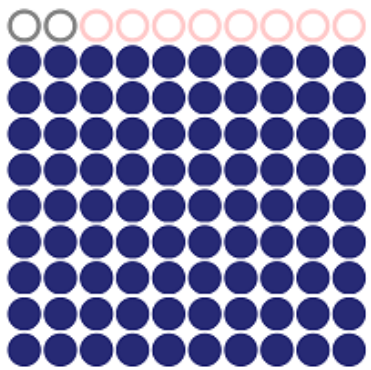
Of the women who would not survive, 2 would die due to causes not related to breast cancer.

Results

Table | Curves | Charts | Texts | Icons | Adverse effects mockup

This display shows the outcomes for 100 women. These results are based on the inputs and treatments you selected.

5 **10** years after surgery



2 deaths due to other causes

8 breast cancer related deaths

90 survivors with surgery alone

Results

Table | Curves | Charts | Texts | Icons | Adverse effects mockup

Mockup 1 | Mockup 2 | Mockup 3

The table shows information on the adverse effects you may experience if your treatment includes Bisphosphonates. The data is based on women of a similar age. It does **not** take account of dosage, or of interactions between treatments.

Adverse effect	Likelihood	Severity
Nausea	2%	
Joint Pain	10%	
Inflammation	10%	

Bisphosphonates have an additional survival benefit of 2% at 5 years and 5% at 10 years.

Links to more info:

Macmillan

Moving forwards

- Best practice exemplars
- Organ specific information
- Development of toolkits
- Nationally available resource
- Training in communicating risk and consent

Risk and consent working group

- John Forsythe
- Lorna Marson
- Chris Callaghan
- Rachel Hilton
- Steve Wigmore
- Pedro Catarino
- Claire Williment
- Liz Armstrong