

Organ Transplantation and Consent



Cambridge University Hospitals

NHS Foundation Trust



UNIVERSITY OF
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Outline

- What is consent
- The legal environment
 - Montgomery vs Lanarkshire
- Understanding risk
 - Risk vs probability
 - Perceptions of risk
 - Risk in transplantation
 - Absolute vs relative risk
- Risks in transplantation
 - Recipient
 - Donor
 - Immunosuppression
- Communicating risk
 - Timing: when to do it
 - Presenting information
 - Numeracy and literacy



What is consent?



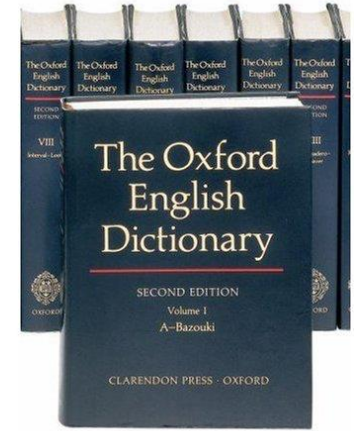
Oxford English Dictionary

- Consent:

“Voluntary agreement to or acquiescence in what another proposes or desires; compliance, concurrence, permission”

- Informed consent:

- *Law*: permission granted in the knowledge of the possible consequences;
- *Medicine*: consent to a medical or surgical procedure given after all relevant information (esp. regarding potential risks and benefits) has been disclosed to the patient or the patient's guardian

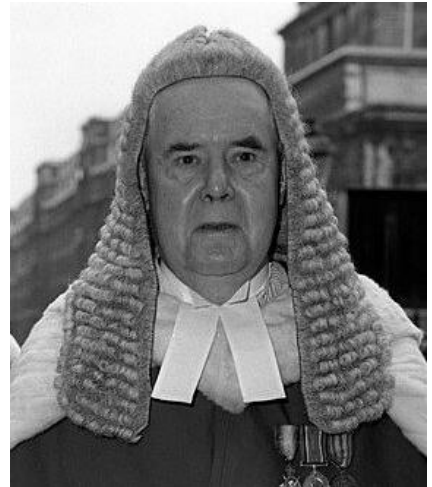
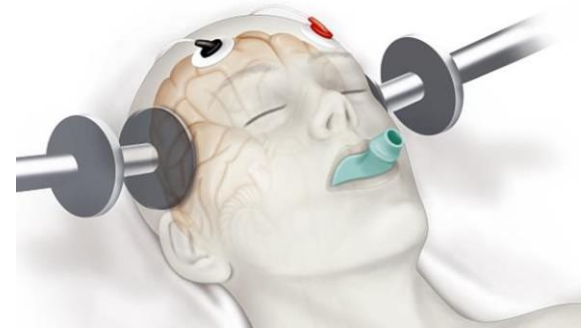


Permission granted in the knowledge of
the possible consequences

What risks should be disclosed?

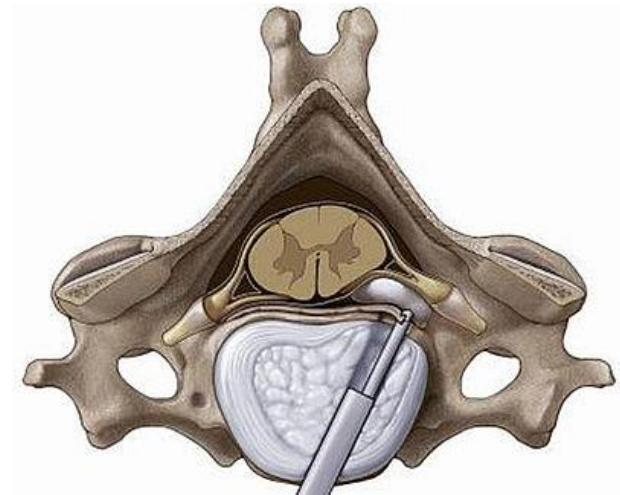
Bolam vs Friem Hospital Management Committee 1957: the Bolam Test

- John Bolam underwent electroconvulsive therapy without muscle relaxant and without restraint
 - He sustained many injuries including a pelvic fracture
 - He sued the hospital
- In summing up the case, Justice McNair said:
“There is no breach of standard of care if a responsible body of similar professionals support the practice that caused the injury, even if the practice was not the standard of care.”



Sidaway v Board of Governors of the Bethlem Royal Hospital 1985

- Amy Doris Sidaway underwent cervical cord decompression
 - Neurosurgeon did not mention risk of paraplegia, which was <1%



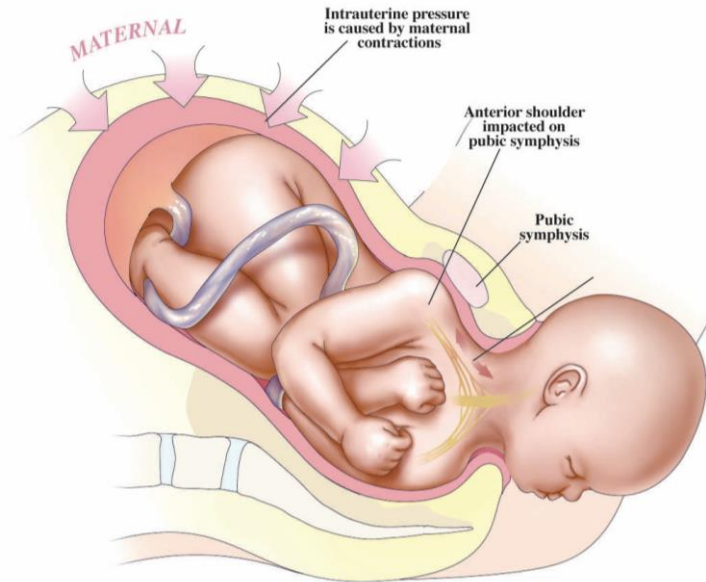
Sidaway v Board of Governors of the Bethlem Royal Hospital 1985

- Amy Doris Sidaway underwent cervical cord decompression
 - Neurosurgeon did not mention risk of paraplegia, which was <1%
- Lord Diplock stated "we are concerned here with volunteering unsought information about risks of the proposed treatment failing to achieve the result sought or making the patient's physical or mental condition worse rather than better. The only effect that mention of risks can have on the patient's mind, if it has any at all, can be in the direction of deterring the patient from undergoing the treatment which in the expert opinion of the doctor it is in the patient's interest to undergo. To decide what risks the existence of which a patient should be voluntarily warned and the terms in which such warning, if any, should be given, having regard to the effect that the warning may have, is as much an exercise of professional skill and judgment as any other part of the doctor's comprehensive duty of care to the individual patient, and expert medical evidence on this matter should be treated in just the same way. **The Bolam test should be applied"**

Montgomery vs Lanarkshire Health Board 2015

Supreme Court, Lord Neuberger presiding

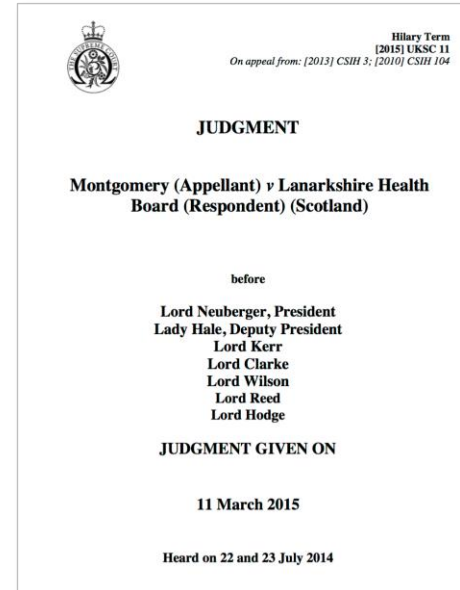
- Plaintiff: Nadine Montgomery
 - Molecular biologist; mother & sister were doctors
- 5 feet tall & diabetic
 - Women with diabetes have tendency to big babies with wide shoulders
- Not warned of 9-10% risk of shoulder dystocia
 - And that Caesarean section would avoid this risk
- Baby born with cerebral palsy



Montgomery vs Lanarkshire Health Board 2015

Supreme Court, Lord Neuberger presiding

- 'The doctor is ... under a duty to **take reasonable care** to ensure that the patient is aware of **any material risks** involved in any recommended treatment, and of **any reasonable alternative** or variant treatments.'
- 'The test of materiality is whether, in the circumstances of the particular case, **a reasonable person in the patient's position would be likely to attach significance to the risk**, or the doctor is or should reasonably be aware that the particular patient would be likely to attach significance to it.'



The legal position: summary

- Reasonable doctor vs. reasonable patient
- No longer sufficient to tell a patient what a “reasonable doctor” might say
 - Bolam/Sidaway
- Requirement now is to tell a patient what a “reasonable patient” would want to know
 - Montgomery



Understanding Risk

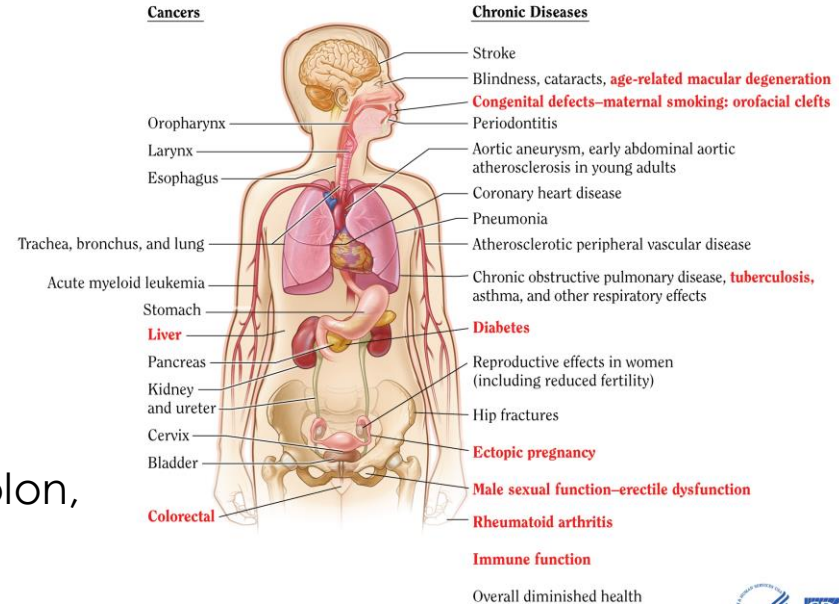


Who smokes?

- Reduces life expectancy by 7 years
- 25x more likely to get Lung Cancer
- 2-4x more likely to get CVA or MI
- Many cancers more common
 - Kidney, ureter, bladder, cervix, larynx, oesophagus, stomach, pancreas, liver, colon, rectum...
- Other problems more common in smokers
 - Impotence
 - Progression of diabetic complications

Risks from Smoking

Smoking can damage nearly every part of your body





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Wigan transplant patient given lungs of 30-year smoker

The father of a woman who died after a double lung transplant said she would have been "horrified" to discover the organs were from a smoker of 30 years.

Cystic fibrosis sufferer Lynsey Scott, of Wigan, died months after surgery at Wythenshawe Hospital last year.

Allan Scott said she was not told that the donor smoked and is calling for patients to be given more information.

The University Hospital of South Manchester (UHSM) NHS Trust said it had followed national guidelines.

Ms Scott, 28, who was born with cystic fibrosis, underwent the surgery in February 2009 to prolong her life after her condition deteriorated.

She died a few months later in July. Tests later concluded the primary cause of death was pneumonia.



Lynsey Scott died a few months after her lung transplant

SEE ALSO

- Woman dies after lung transplant
13 January 10 | Kent
- Organ transplants' hidden risk
24 November 09 | Health

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Smoking and donation: facts

- 50% of deceased donors are smokers
 - That's why they die young
- Smoker's lungs do less well than non-smoker's lungs
 - 48% survival at 5 years c.f. 58% at 5 years
 - The more cigarettes the worse the outcome
- Recipients who accept lungs from donors who smoke live longer
 - 25% waiting list mortality for a lung transplant

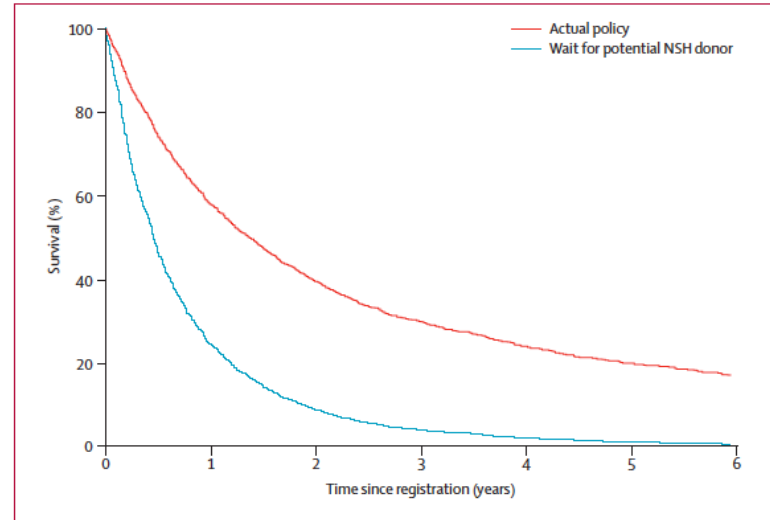
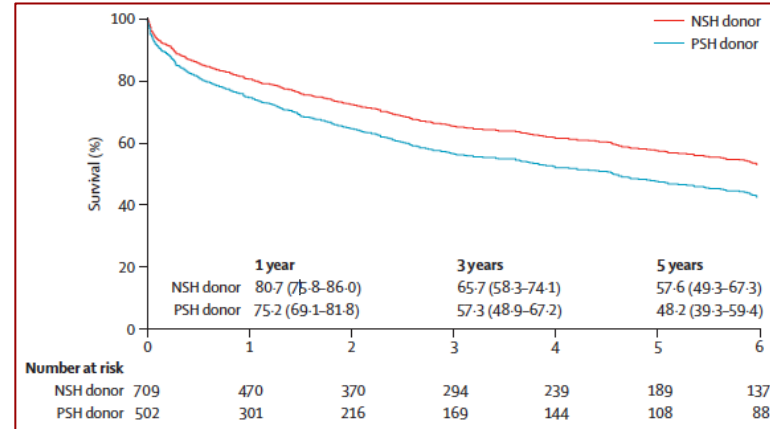


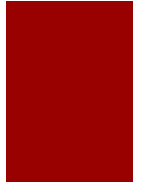
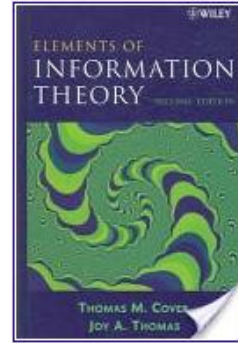
Figure 4: Actual survival from waiting-list registration for patients with a diagnosis of pulmonary fibrosis listed between 1999 and 2003, and an estimated survival if lungs from donors with positive smoking histories were excluded from the donor pool and patients chose to wait for lungs from donors with negative smoking histories
NSH=negative smoking history.

Informed consent and risk

- Information

- A reduction in uncertainty
- Knowledge of a possible event and its likelihood

- How likely is an event?



Probability and Risk

- Probability

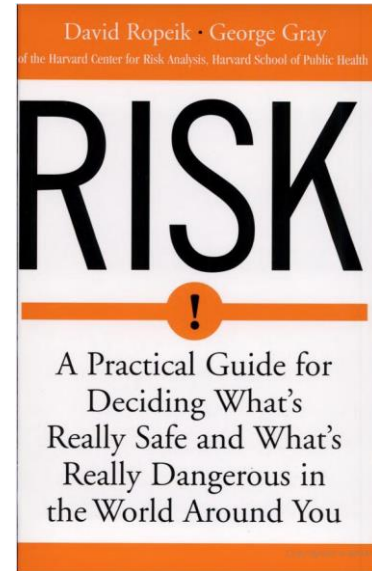
- the chance of an event occurring

- Risk

- Implies not only the chance of an event occurring, but also that the event has a consequence

- In medicine, risk implies harm,


Risk = probability x harmful consequence



What is an important risk?

- One that is common
 - high probability
- One that has a seriously harmful consequence,
 - e.g. death
- One that matters to the patient
 - Even if a small probability

Risk = probability x harmful consequence



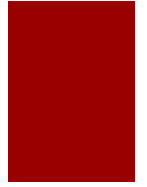
		Impact →				
		Negligible	Minor	Moderate	Significant	Severe
Likelihood ↑	Very Likely	Low Med	Medium	Med Hi	High	High
	Likely	Low	Low Med	Medium	Med Hi	High
	Possible	Low	Low Med	Medium	Med Hi	Med Hi
	Unlikely	Low	Low Med	Low Med	Medium	Med Hi
	Very Unlikely	Low	Low	Low Med	Medium	Medium

Perception of risk



- Two sorts of risk
 - Actual risk – objective likelihood of event occurrence
 - Perceived (or emotional) risk
 - Based on belief of event occurrence,
 - Affected by emotion not fact
 - Illustrated well by gambling, where chance of winning over estimated
- Lottery risk
 - Chance of winning jackpot (6 numbers): 1 in 14 million
 - Chance of winning £10 (3 numbers, £10): 1 in 57
 - *“the lottery is a tax on people who are bad at maths”*

Which is more likely to kill you, a routine anaesthetic or a parachute jump



Perception of risk - 2

- Prior experience
 - Risks of events that are perceived as well understood (familiar) or as less severe are readily dismissed
 - E.g. an anaesthetic for a non emergency operation*
 - events perceived as not understood (unfamiliar) are viewed as more consequential, more severe
 - e.g. a parachute jump*
- Numbers close to zero, e.g. $\leq 1\%$
 - Perceived as no risk.



* Both have a 1 in 100 000 risk of death.



TAKING RISK

There's a fine line between taking a calculated risk and doing something dumb.

Risk taking requires a knowledge of the risk



- There are known knowns.
 - These are things we know that we know.
- There are known unknowns.
 - That is to say, there are things that we know we don't know.
- But there are also unknown unknowns.
 - There are things we don't know we don't know.

Donald Henry Rumsfeld, 1932-2021.
U.S. Secretary of Defence under Presidents Ford and Bush Jnr.
The man who started the war in Afghanistan

Factors affecting outcome in transplantation

- The donor
 - Donor organ recovery
 - Warm and cold ischaemic time
 - Logistical issues, e.g. patient & organ transport; theatre access; cross match
- The transplant surgery
- The recipient
 - Post transplant care
 - Immunology
 - Immunosuppression



Outcome measures in transplant: Survival

- Graft survival

- How long did the transplant last?
- e.g. kidney transplantation

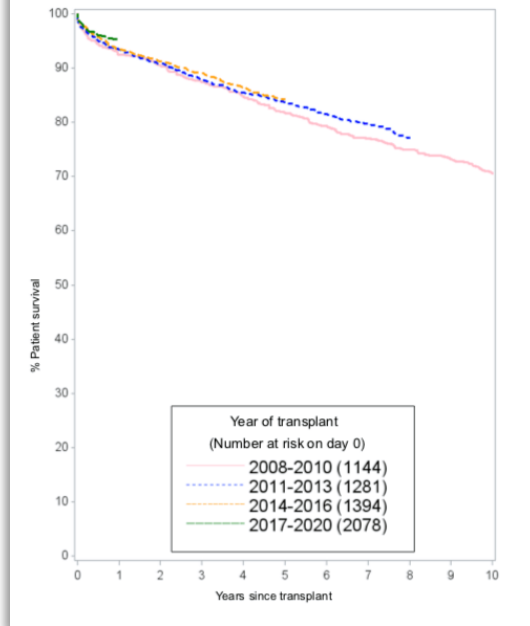
- Patient survival

- How long did the patient survive
- Equates to graft survival for heart and lung transplantation

- Time points

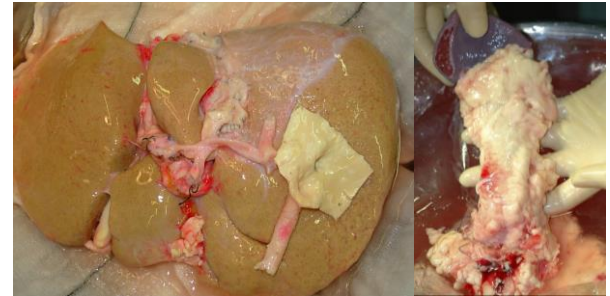
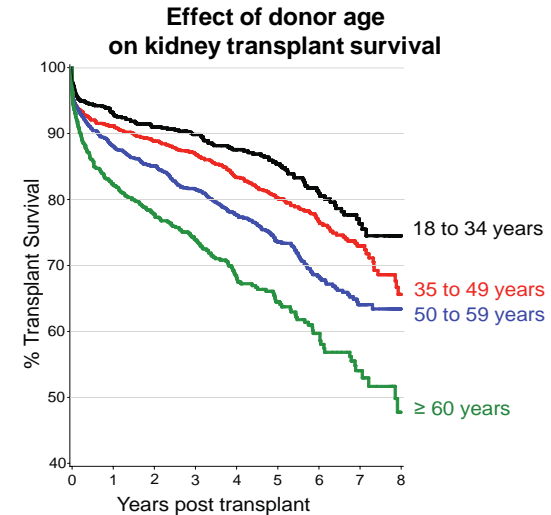
- 1 or 3 months: surgical factors
- 12 months: marker of “long term” outcome
- **Years:** what the patient wants to know is how long will I survive once I am listed

Figure 11.16 Long-term patient survival after first elective adult liver only transplant from donors after brain death, 1 January 2008 – 31 December 2020



Known knowns: Donor factors affecting outcome

- Factors common to all organs
 - Donor age
 - Cause of death – trauma vs CVA
 - Ischaemic time
- Organ specific factors
 - HLA mismatch – heart, lung and kidney
 - Smoking – lung
 - Hypertension – kidney
 - Obesity – Liver, pancreas
 - ...



Risk indices to predict donor organ outcome

- Multiple variable analysis of donor factors affecting outcome
- Analysis of thousands of donors
- “Risk” Index to aid:
 - Acceptance of donor organ
 - Allocation of donor organ
 - Audit of outcomes

American Journal of Transplantation 2006; 6: 783-790
© 2006 The Authors
Blackwell Publishing

Journal compilation © 2006 The American Society of
Transplantation and the American Society of Transplant Surgeons
doi: 10.1111/j.1500-4143.2006.01242.x

Characteristics Associated with Liver Graft Failure: The Concept of a Donor Risk Index

S. Feng¹*,
J.L. Bragg²,
J.D. Paine³
and F.M.

American Journal of Transplantation 2010; 10: 837-848
Wiley Periodicals Inc.

Journal compilation © 2010 The Authors
Transplantation and the American Society of Transplant Surgeons
doi: 10.1111/j.1500-4143.2009.02996.x

Systematic Evaluation of Pancreas Allograft Quality, Outcomes and Geographic Variation in Utilization

D. A.
R. A.

CLINICAL AND TRANSLATIONAL RESEARCH

A Comprehensive Risk Quantification Score for Deceased Donor Kidneys: The Kidney Donor Risk Index

Panduranga S. Rao,^{1,2,3} Douglas E. Schaebel,^{2,3} Mary K. Guidinger,^{2,4} Kenneth A. Andreoni,⁵
Robert A. Wolfe,^{2,4} Robert M. Merion,^{2,6} Friedrich K. Port,^{2,4} and Randall S. Sung^{2,6}

CLINICAL AND TRANSLATIONAL RESEARCH

A Simplified Donor Risk Index for Predicting Outcome After Deceased Donor Kidney Transplantation

Christopher J. E. Watson,¹ Rachel J. Johnson,² Rhiannon Birch,² Dave Collen,² and J. Andrew Bradley³

Background. We sought to determine the deceased donor factors associated with outcome after kidney transplantation and to develop a clinically applicable Kidney Donor Risk Index.
Methods. Data from the UK Transplant Registry on 7620 adult recipients of adult deceased donor kidney transplants between 2000 and 2007 inclusive were analyzed. Donor factors potentially influencing transplant outcome were investigated using Cox regression, adjusting for significant recipient and transplant factors. A United Kingdom Kidney Donor Risk Index was derived from the model and validated.
Results. Donor age was the most significant factor predicting poor transplant outcome (hazard ratio for 18–39 and 40–49 years relative to 50–59 years was 0.78 and 1.49, respectively, $P < 0.001$). A history of donor hypertension was also associated with increased risk (hazard ratio 1.36, $P = 0.001$), and increased donor body weight, longer hospital stay before death, and use of acetaminophen were also significantly associated with poorer outcomes up to 3 years posttransplant. Other donor factors including donation after circulatory death, history of cardiovascular disease, diabetes history, and terminal creatinine were not significant. A donor risk index based on the five significant donor factors was derived and confirmed to be prognostic of outcome in a validation cohort (concordance statistic 0.62). An index developed in the United States by Rao et al., *Transplantation* 2009; 88: 231–236, included 15 factors and gave a concordance statistic of 0.63 in the UK context, suggesting that our much simpler model has equivalent predictive ability.
Conclusions. A Kidney Donor Risk Index based on five donor variables provides a clinically useful tool that may help with organ allocation and informed consent.

Keywords: Kidney transplantation, Deceased donation, Graft survival.
(*Transplantation* 2012;93: 314–318)

The severe shortage of deceased donor (DD) organs available for transplantation has led to increased use of kidneys from suboptimal donors with potentially less good transplant outcome. Categorizing such kidneys according to anticipated outcome is important because it enables clinicians to be better informed when making decisions

about organ allocation and allows appropriate counseling of potential recipients.

Kidneys from suboptimal donors are variously referred to as marginal, extended criteria, or expanded criteria organs. While the criteria for a “marginal” organ are not well defined, expanded criteria kidneys have been carefully defined based on an analysis of data held by the Scientific Registry of Transplant Recipients (SRT) (1). Expanded criteria kidneys are those which have a relative risk of graft loss greater than 1.7 when compared with kidneys from young donors (aged 10–39 years) with a normal creatinine at death (less than 1.5 mg/dL) and without a history of hypertension or death from a cerebrovascular accident (CVA). However, the binary division of donor kidneys into those of standard and expanded criteria is an oversimplification. For example,

This work was supported by NHS Cambridge Biomedical Research Centre. The authors declare no conflicts of interest.

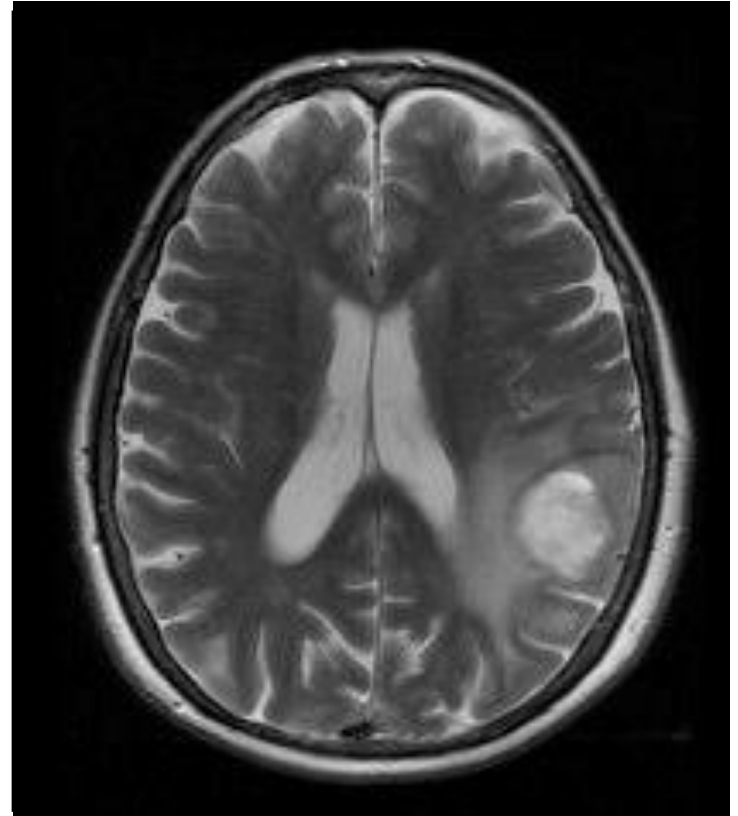
¹ University Department of Surgery, Addenbrooke's Hospital, Cambridge, and the NHS Cambridge Biomedical Research Centre, Cambridge, United Kingdom.

² NHS Blood and Transplant, Bristol, United Kingdom.

³ Address correspondence to: Christopher J.E. Watson, M.D., University of Cambridge Department of Surgery, Addenbrooke's Hospital, Cambridge CB2 0QQ, United Kingdom.
E-mail: cje20@cam.ac.uk

Known unknowns: Donor associated risks

- Mode of death
 - Carbon monoxide poisoning
- Transmission of Infection
 - Definite risk
 - Hepatitis B or C pos
 - HIV positive
 - High risk behaviour
 - Sex workers; Prisoners; iv drug use
 - "seronegative infectious window"
- Transmission of cancer
 - Primary brain tumour
 - Rarely transmitted (1% for grade 4)
 - History of previous cancer



Selection of donors in an era of organ shortage

Figure 2.1 Number of deceased donors and transplants in the UK, 1 April 2013 - 31 March 2023, and patients on the active transplant list at 31 March

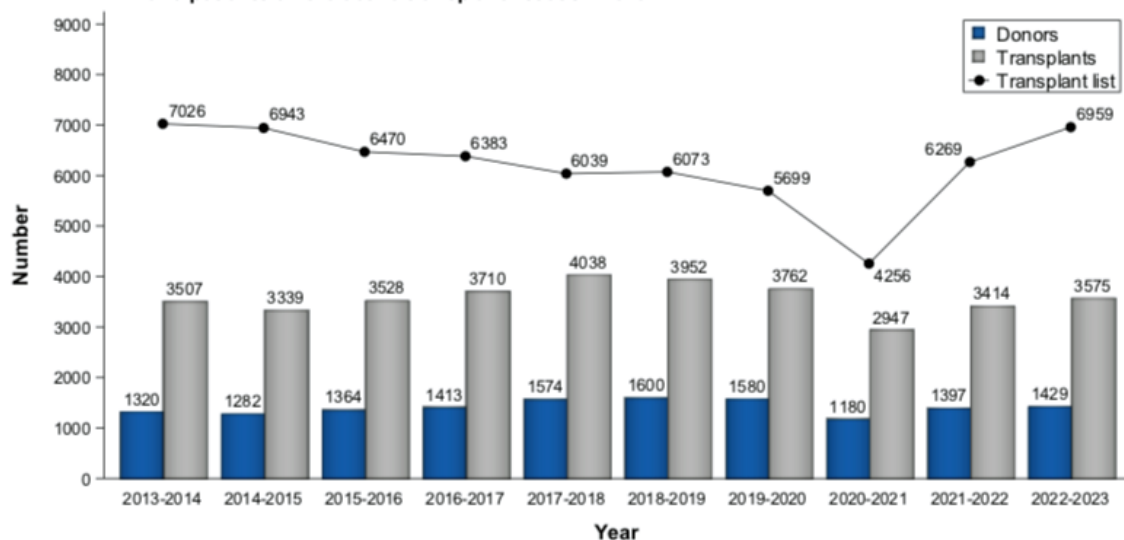


Figure 7.5 Post-registration outcome for 260 first non-urgent lung only registrations made in the UK, 1 April 2019 - 31 March 2020

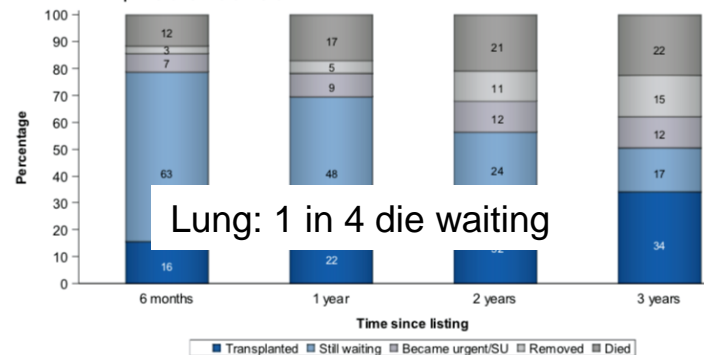
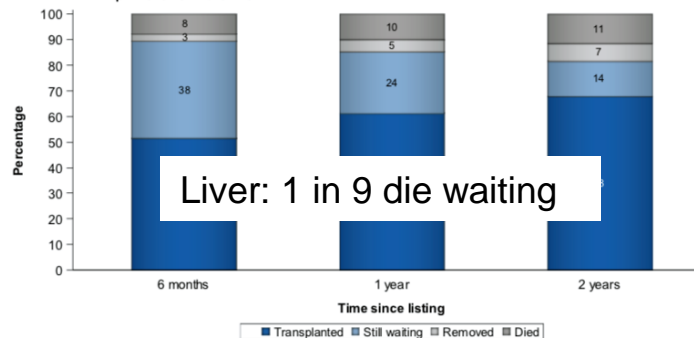


Figure 8.2 Post-registration outcome for 946 new elective liver only registrations made in the UK, 1 April 2020 - 31 March 2021



Embracing risk

- Risk in normal life
 - Tends to be avoided
 - Most of us are risk averse
- But
 - Organ failure involves risk
 - Transplantation involves risk
 - Delaying transplantation involves risk



Absolute vs Relative Risk

- Absolute risk
 - Risk of death with this transplant: 10 in 100
 - Risk of death on waiting list: 15 in 100
- Relative risk
 - Comparing risk on waiting list versus risk of accepting donor, e.g. 1.5 times more likely to die if wait for lungs from non-smoker than if have the next lung.

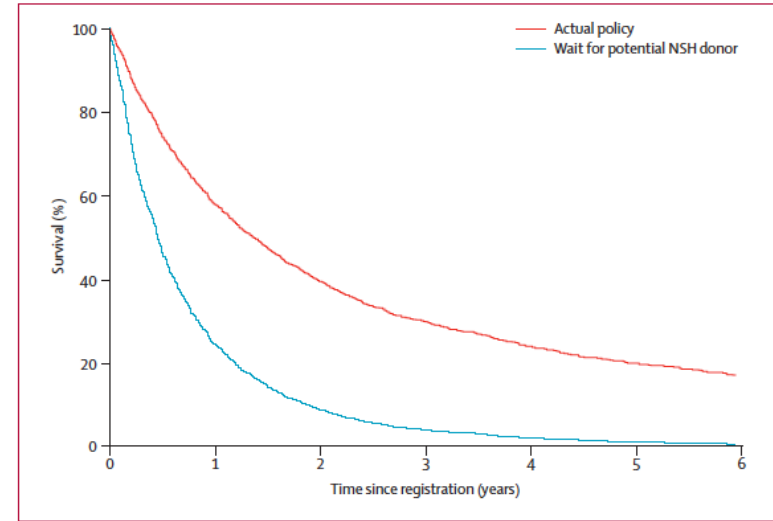


Figure 4: Actual survival from waiting-list registration for patients with a diagnosis of pulmonary fibrosis listed between 1999 and 2003, and an estimated survival if lungs from donors with positive smoking histories were excluded from the donor pool and patients chose to wait for lungs from donors with negative smoking histories|
NSH=negative smoking history.

What the patient must know, & understand: Absolute vs Relative Risk

- The risks for that individual associated with waiting
- Any additional risks that the donor poses
- Chance of another transplant offer (and when) if decline the initial offer
- Risk of death while waiting the extra time



Annual Risk of Death

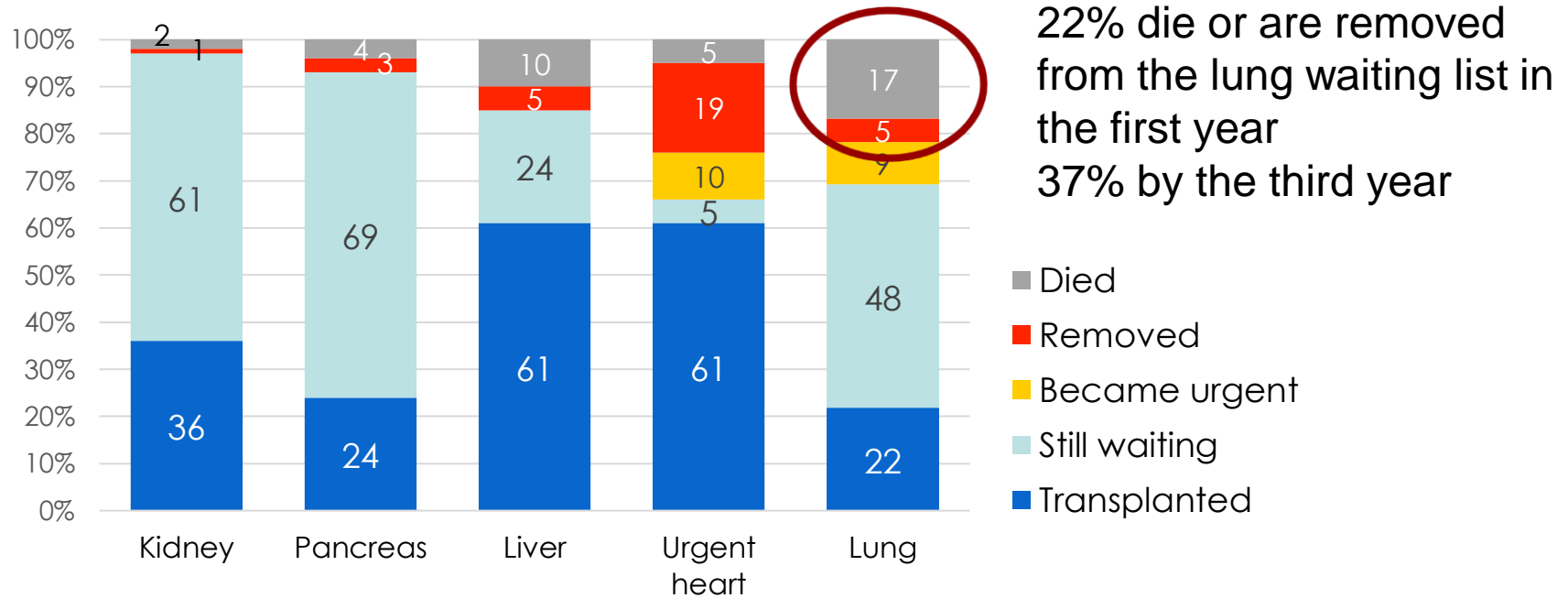


- Lung transplant waiting list: 170 per 1000
- Annual mortality rate in England & Wales:*
 - Age 25-34: 0.8 per 1000
 - Age 35-44: 1.5 per 1000
 - Age 45-54: 3.6 per 1000
- Serving in Afghanistan: 171 per 1000 per yr**

*Data for men. ONS data for 2005. <http://www.ons.gov.uk/>

** Blastland & Spiegelhalter: The Norm Chronicles

Patient outcomes one year after joining the transplant waiting list



Formula 1 motor racing is safer than waiting for a lung



Mark Webber, Valencia, 2010
"Red Bull gives you wings"



Romain Grosjean flaming crash 2020

Everyday risk: My risk of death in travelling to Bristol to give this talk

- Cambridge to Bristol: 340 miles return trip
- By motorbike: 49 in 1,000,000
 - 1 micromort per 7 miles
- By car: 1 in 1,000,000
 - 1 micromort per 333 miles
- By train or commercial plane: 0.045 in 1,000,000
 - 1 micromort per 22 million miles
 - By light aircraft: 1 micromort per 44000 miles



How to present the concept of risk



Communicating risk

- Nothing is safe
 - There is a risk of death on waiting list
- Organs are not new
 - All donor organs are all second hand
“from someone who died”
- Avoid emotive terms
 - “suboptimal”
 - “marginal”
 - “high risk”


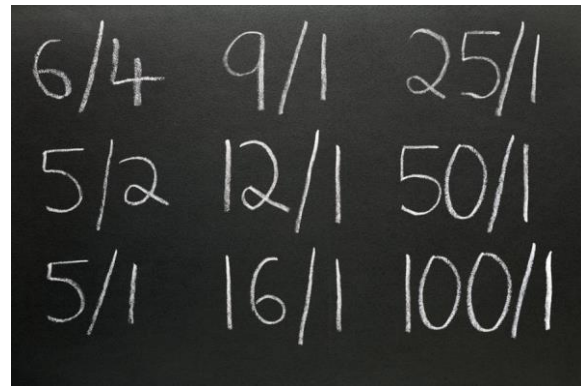


“You’re what we call ‘high risk.’”

Numeric description of risk

Possible numeric formats

- Percentages, e.g. 10%
- Frequencies, e.g. 10 in 100
- Odds, e.g. 10 to 1
- Classical probabilities 0.0 to 1.0



IMPLIED PROBABILITY	FRACTIONAL ODDS
99.01%	1/100
80.00%	1/4
75.00%	1/3
66.67%	1/2
55.56%	4/5
50.00%	1/1
45.45%	6/5
40.00%	3/2
33.33%	2/1
13.33%	13/2
5.00%	19/1

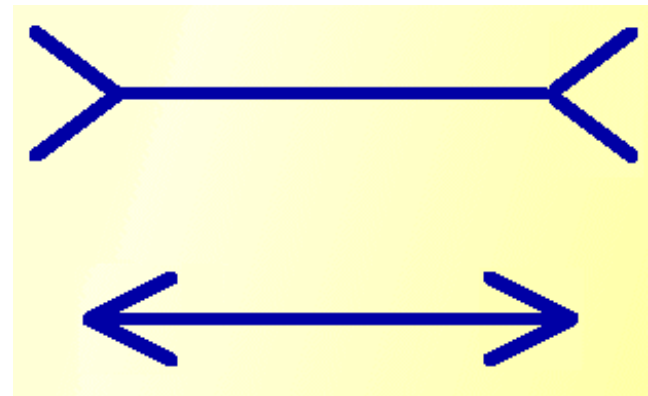
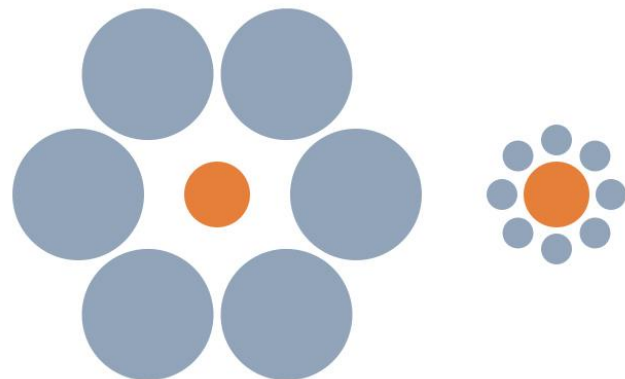
Which is bigger?

A

- 1 1 in 1000
- 2 74 in 100
- 3 20 in 50
- 4 9 to 1 against
- 5 12% patients die

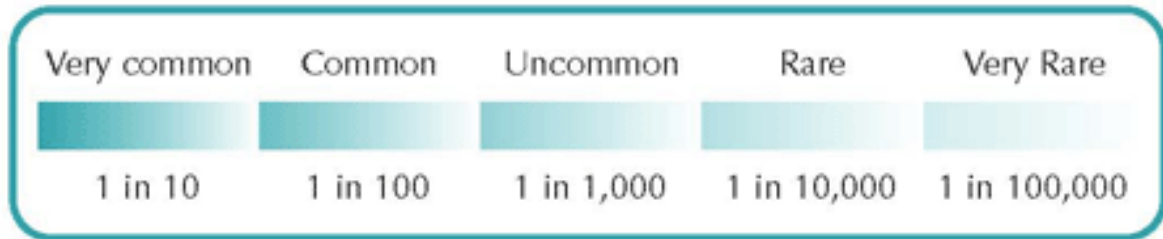
B

- 10 in 10000
- 3 in 4
- 40%
- 1 in 10
- 7 out of 8 patients survive



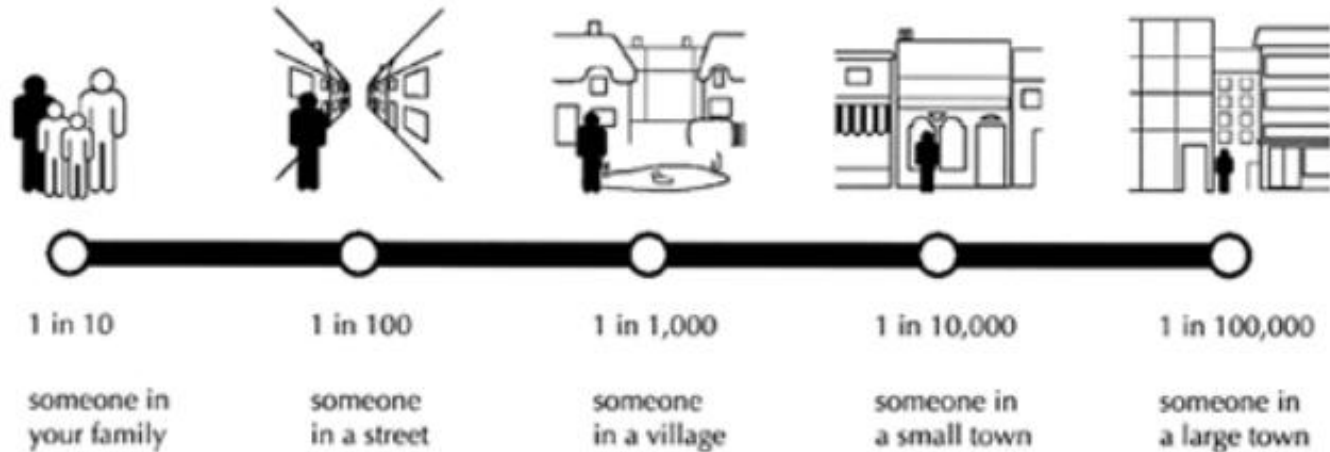
Descriptive terms

- Avoid descriptive terms such as:
 - “common”, “rare”, “possible”, “unlikely”
 - Different perceptions between healthcare professional and patient
- Standardise terminology
 - As in figure below*



How common: Making frequencies meaningful

The following diagram may help you decide how you feel about a risk:



In 2018: Cambridge 129,000; Oxford 154,600; Bristol 459,300
Teversham: 3000

Making frequencies meaningful



- 8 in 100:
 - Chance of drawing an Ace from a deck of cards
 - Chance of dying in the first year after a liver transplant
 - Chance of a deceased donor kidney failing in the first year
- 2 in 100
 - Chance of getting £10 on the lottery
 - Chance of dying following a kidney transplant if you're under 60 and not diabetic
- 1 in 100
 - The chance of your premium bond winning in a year



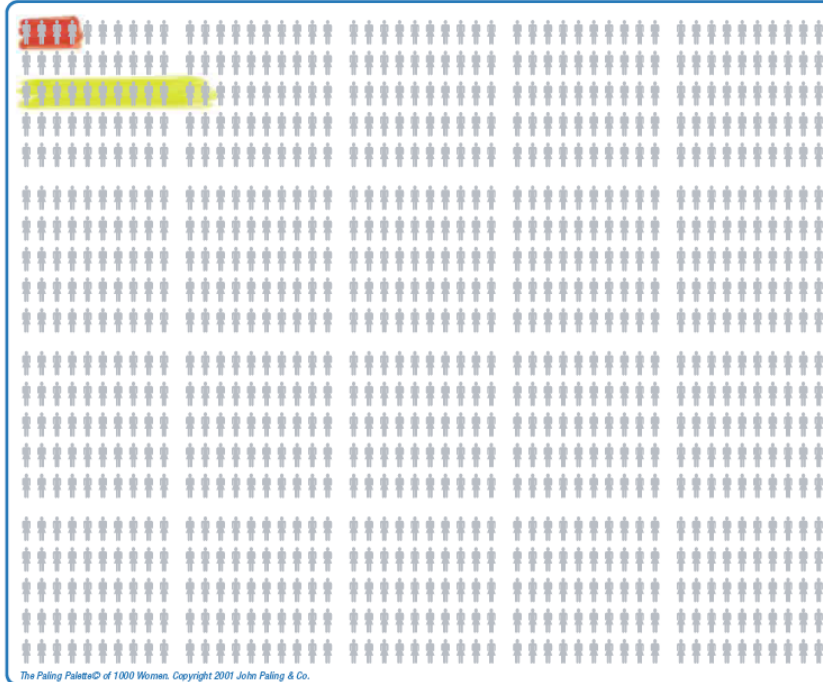
4/1000
12/1000

One Thousand People

- Pictures to Help You

See
Your
Odds

We can only show you averages. It is impossible to predict whether your results will be positive or negative.

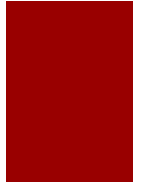


Odds for a 39 year old woman of producing a child with Downs Syndrome or other chromosome abnormality 12 out of 1000

Odds of a woman having a miscarriage as a result of amniocentesis 4 out of 1,000

Data from Hook EB, Cross PK and Schreinemachers DM. Chromosome abnormality rates at amniocentesis and in live born infants. JAMA 249(15):2034-8

Recommendations for numeric estimates



- Actual frequencies
- Consistent denominator
 - 5 in 100 vs. 11 in 100 rather than 1 in 20 vs. 1 in 9

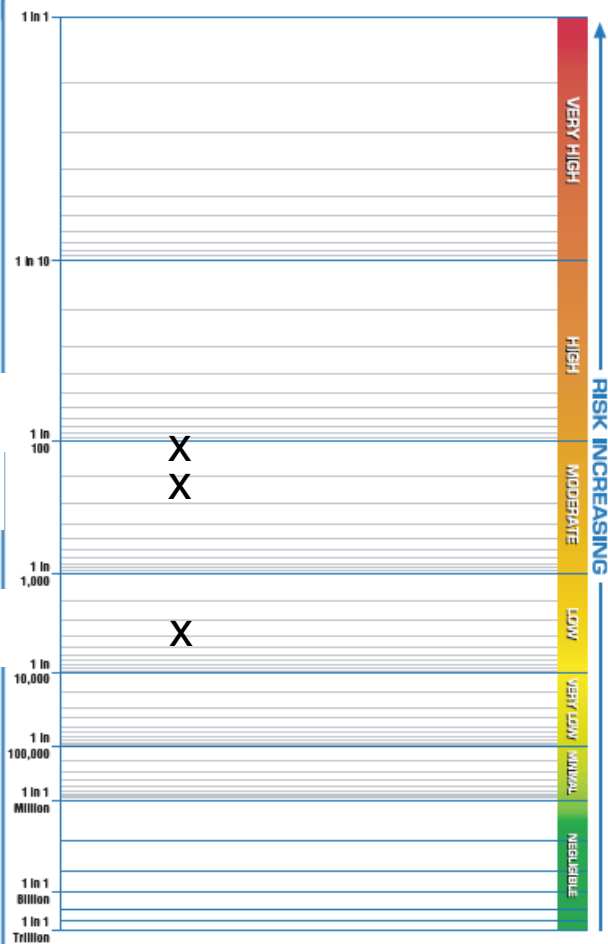
Numerator
Denominator

- Whole numbers, not decimals
- Numerator
 - Some perceive risk by size of numerator, so 10 in 100 is greater than 1 in 10.
Influences choice of denominator
- Avoid logarithmic scales
 - No one understands them

Odds of
Specific Risks

The Paling Perspective Scale®

Helping People Put Life into Perspective

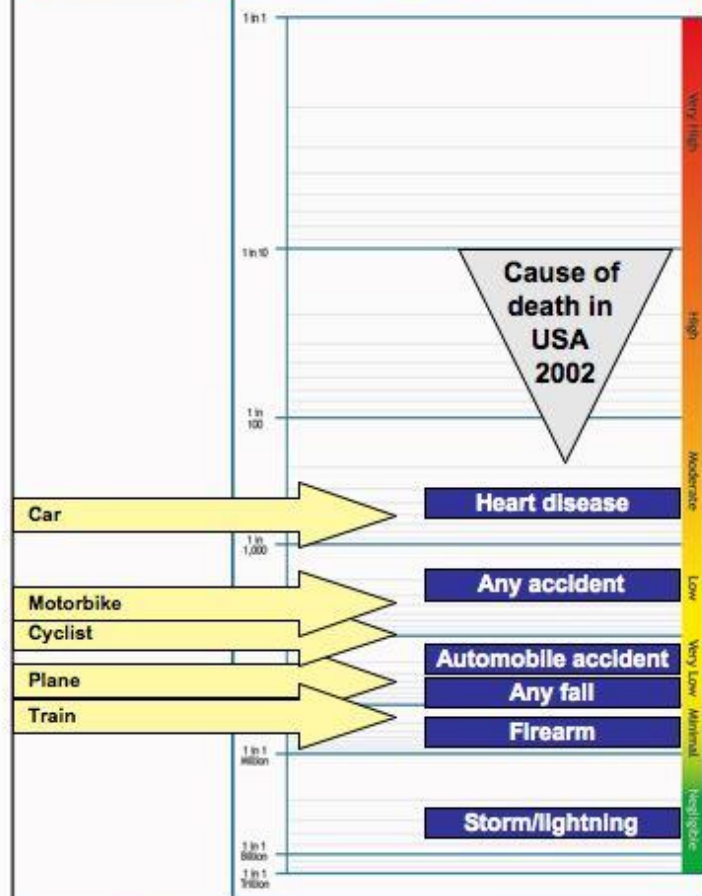


Kidney recipient
Live liver donor

Live kidney donor

The Higher the Point,
The Higher the Likelihood

The Paling Perspective Scale®



THE PALING PERSPECTIVE SCALE
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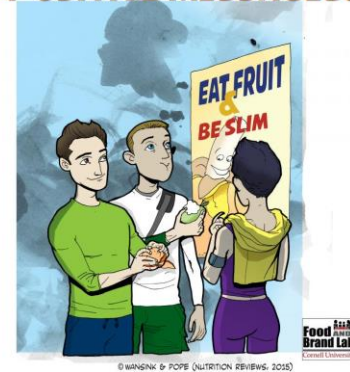
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WHICH HEALTH MESSAGES WORK?

EXPERTS PREFER NEGATIVE ONES BUT
THE PUBLIC FOLLOWS POSITIVE MESSAGES.

Framing

- Positive and negative framing
 - Doctors tend to concentrate on negative risk
 - 5 in 100 chance of death
 - Patients want to know success
 - 95 in 100 chance of survival
- Positive framing
 - Evidence suggests more effective in persuading patients to take “risky” treatment



Numeracy

= numerical literacy

- Patient numeracy very poor
 - 60% of patients innumerate in US transplant study*
 - 45% of population in the UK had numeracy at a level expected of primary school children in UK in 2022.
- Healthcare professionals
 - may not be good either

*Elisa Gordon, Northwestern. ATC presentation.

Telegraph.co.uk

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Fifth of school leavers 'illiterate and innumerate'

One in five teenagers is practically unemployable after leaving school lacking the English and maths skills needed for everyday life, research suggests.

By Graeme Paton, Education Editor
Published: 3:24PM BST 07 May 2010

The number of 16- to 19-year-olds rendered functionally illiterate or innumerate has failed to improve over the last two decades, the study said, despite billions spent attempting to raise standards in the three-Rs.

Teenagers' reading ability has barely changed since 1960, it was claimed, leaving thousands of young people struggling to "partake fully in employment [and] family life".

The conclusions – in research from Sheffield University – come amid continuing fears over levels of basic skills.

Last month, a cross-party committee of MPs said that the number of school leavers without a job or college place had failed to improve "despite one policy strategy after another".

It will also raise doubts over Labour claims that school standards have risen dramatically in the last 13 years.

On Friday, the National Union of Teachers warned that more action was needed to tackle the "long tail of underachievement" in schools.

In the latest study, academics assessed evidence relating to levels of basics skills among young people between 1948 and 2009.

It said the latest data suggested 22 per cent of 16- to 19-year-olds were now functionally innumerate, while 17 per cent were illiterate.

Related Articles

- 900,000 young classed as 'Neets'
- School homework is 'polluting family life'
- Private and state school gap 'widening under Labour'
- Labour has failed to reduce 'Neets', say MPs
- Neets figures 'to top one million for first time'
- OECD: UK has more 'Neets'

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Graeme Paton

Whizz Online Maths

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Back to school

Dread your kids asking for help with their maths homework? We can help!

Our **Family Maths Toolkit** contains over 200 free activities for families to do together.

It's all linked to what they learn at school. So you'll be helping your kids, and boosting your own confidence at the same time!

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You can
support your
child with
maths even
if you struggle.



I want to improve my maths

We can all feel better about
numbers

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I want to support children with maths

Helping kids feel confident with
numbers

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I want to support my staff

Boost staff confidence, skills
and progression

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Get on with numbers so you can get on in life

National Numeracy is an independent charity with a vision for everyone in the UK to get on with numbers so they can get on in life.

Which is the best way to convey risk?

- Evidence mixed
- Many studies favour graphical representation
- Some suggests people are less risk averse with numbers rather than bar graphs or icons
- Depends on
 - Cognitive ability of patient
 - Age
 - Level of education

* Stone et al. J Exp Psych:Appl 1997; 3: 243. Timmermans et al. Pat Edu Coun 2004;54:255

** Lipkus et al. J Natl Cancer Inst Monogr 1999;25: 149

Challenges in communicating risk

- Personalise risk
 - Statistics are for populations
 - How typical of the population is the patient?
 - 2% of patients die after a kidney; 5% if they are diabetic
 - How closely does the patient associate himself with the risk
 - e.g. if 5 in 100 may get a donor cancer, emphasise that the patient may be one of the 5 or one of the 95
- Communicating interactions
 - How do multiple risks interact
- Communicating small probabilities
 - Less than 1% tends to be ignored



Giving the information?

■ Who?

- Nurse
- Doctor
- Peers – fellow patients

■ How?

- A process, not an event
- With information to take away
 - Booklets
 - Videos
 - Websites
 - NB: Literacy



Summary

- Informed consent
 - relies on a **dialogue** between an **informed patient** and healthcare professional
 - demands communication of the risks and benefits of the **choices** available
- **Good communication** of risk is essential
 - Treatment options and associated risks
 - Organ quality
 - Donor disease
 - Transplant complications
- **Multiple modalities** of risk information are probably best
 - Information at time of listing
 - Reiterated during waiting period
 - Confirmed at time of transplant

NHSBT risk communication tools

NHS
Blood and Transplant

[Instructions for use](#) [About NHSBT Kidney Risk Communication Tool](#) [Kidney Risk Communication Tool](#) [Contact](#)

This tool is designed for use with a standard screen size of 1920*1080 in Google Chrome, Microsoft Edge or Internet Explorer Version 11.
If you have a smaller screen display than this, e.g. a laptop, then you may notice that the tool layout will look like the below with overlapping dropdown boxes and hidden text. This will make the tool difficult to use and in some cases you will not be able to select the options in the drop-down boxes.

NHS
Blood and Transplant

[Instructions for use](#) [About NHSBT Kidney Risk Communication Tool](#) [Kidney Risk Communication Tool](#) [Contact](#)

Please select your centre:

[Waiting time](#) [Deceased donor patient survival](#) [Deceased donor graft survival](#) [Living donor patient survival](#) [Living donor graft survival](#) [Background information](#) [How to print](#)

Please select patient characteristics:

i Age at registration
60-59

i Sex
Male

i Ethnicity
White

i Blood group
O

i Matchability score
1-3 Easy

i Highly sensitised
cRF >=85%
cRF <85%

i Graft Number
First kidney transplant

i On Dialysis at registration?
Yes

i Primary renal disease - diabetes?
No

[Summary](#) [Bar Chart](#) [Line Chart](#) [Table](#) [Text](#)

What might happen after I join the waiting list for a kidney transplant?

The charts on the following tabs show what happened to people like you in the past. Here, 'like you' means people who selected the same inputs as you in the tool. It shows how many people receive a transplant, or are still waiting, or leave or die on the transplant list as time goes by.

This is an estimate, an average, there are other factors about you that can influence these results and make the numbers higher or lower. For example you may have other conditions not included in the tool, or you may encounter other lifestyle factors post transplant. These are the outcomes we would expect for people who entered the same information as you, based on patients who joined the

NHS
Blood and Transplant

[Home](#) [Kidney](#) [Lung](#) [Heart](#) [Liver](#) [Pancreas](#) [Small bowel](#) [Resources](#) [Contact](#)

Welcome to the patient information area for organ transplantation
Have your find guidance and advice to help you decide if a transplant is the right treatment for you

Kidney
The kidney is the most commonly transplanted organ.
[Learn about kidney transplants](#)

Lung
There are three types of lung transplant: single, double or heart-lung transplants.
[Learn about lung transplants](#)

Heart
The first heart transplant programme in the UK began in 1979.
[Learn about heart transplants](#)

Liver
Survival rates for liver transplants are higher than ever.
[Learn about liver transplants](#)

Pancreas
A pancreas transplant lets people with diabetes live free from insulin injections.
[Learn about pancreas transplants](#)

Small bowel
Small bowel transplants are used to treat irreversible intestinal failure.
[Learn about small bowel transplants](#)

WHAT'S

NHS
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Risk communication tools

These tools are to help decision making when considering a transplant.

Patients should only use these tools in consultation with a medical professional.

Please note that these tools are only accessible via Google Chrome, Microsoft Edge or Internet Explorer Version 11 browsers.

On this page:

- [Access the tools](#)
- [Instructions for use](#)
- [Give us your feedback](#)

Access the tools

Lung Risk Communication Tool
To help decision making when considering a lung transplant.
[Access the tool](#)

Kidney Risk Communication Tool
To help decision making when considering a kidney transplant.
[Access the tool](#)

Ron Stratton Liver Risk Communication Tool
To help decision making when considering a liver transplant.
[Access the tool](#)

Heart Risk Communication Tool
To help decision making when considering a heart transplant.
[Access the tool](#)

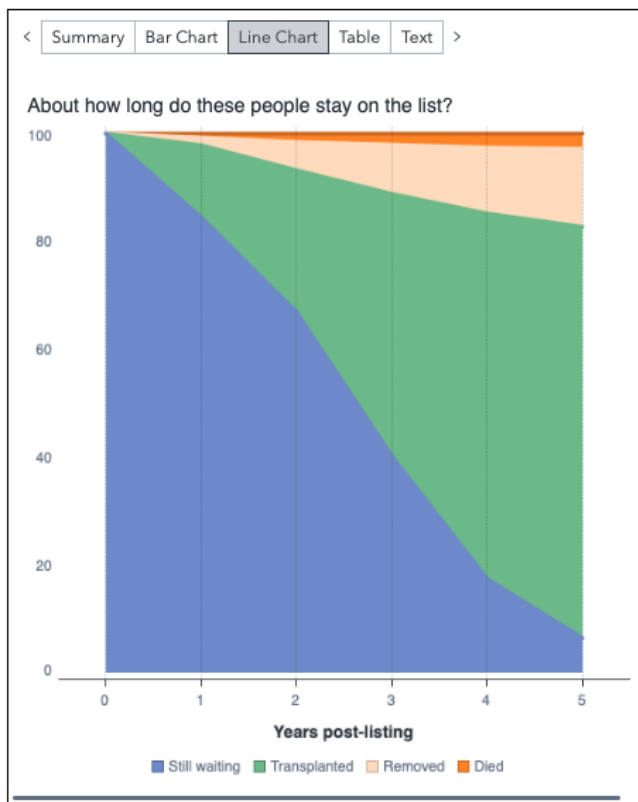
Pancreas Risk Communication Tool
To help decision making when considering a pancreas transplant.
[Access the tool](#)

Kidney waiting list

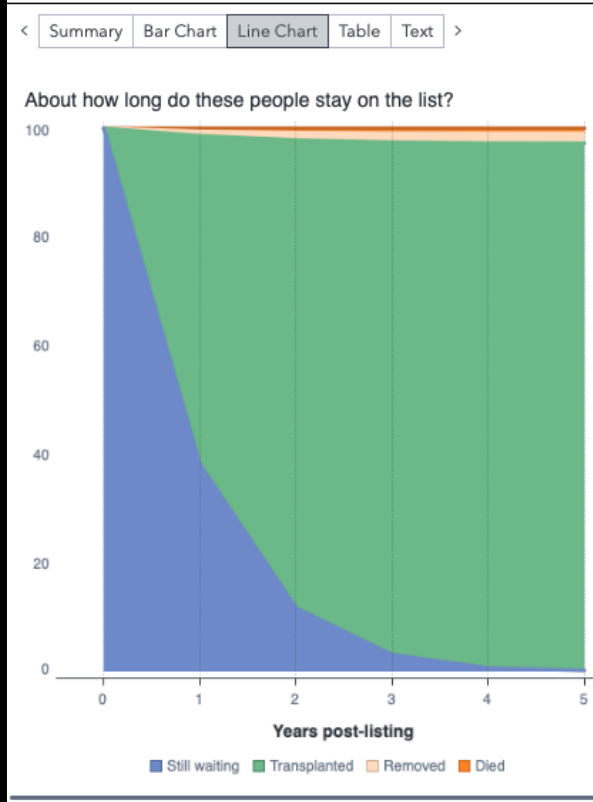
Please select patient characteristics:

Age at registration 30-39	Sex Male	Ethnicity White
Blood group O	Graft Number First kidney transplant	
Matchability score 1-3 Easy	On Dialysis at registration? Yes	
Highly sensitised cRF <85%	Primary renal disease diabetes? No	

Results for a patient who entered the same information as you registered at Birmingham:



Results for a patient who entered the same information as you registered at Cambridge:

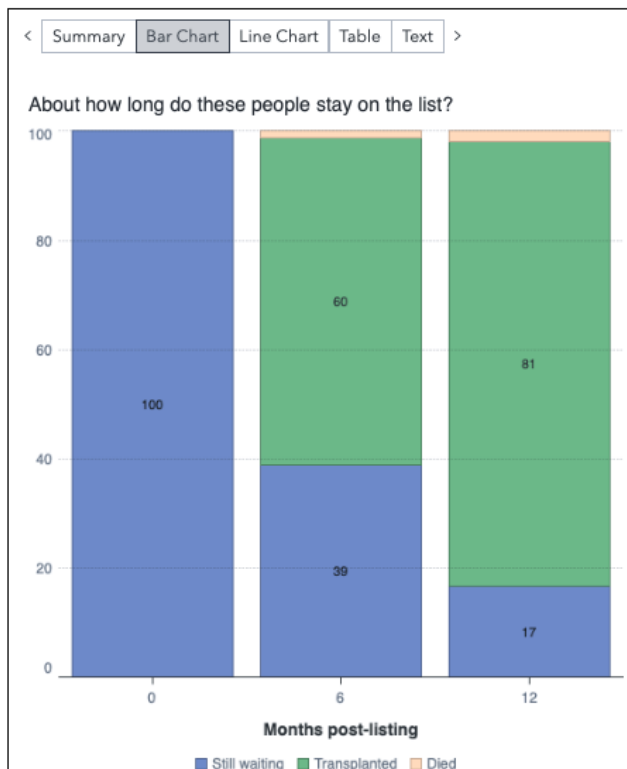


Liver waiting list

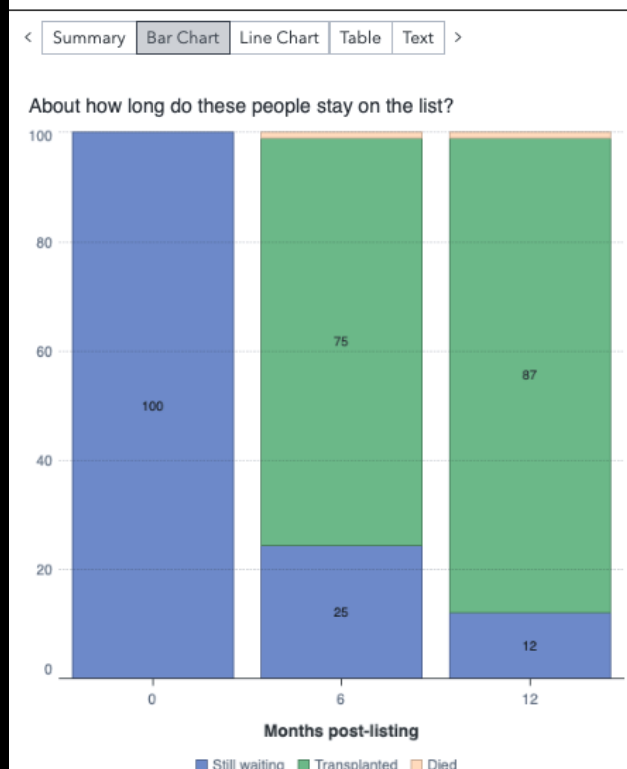
Please select patient characteristics:

Age at registration 30-39	Sex Male	BMI at registration 25-29
Blood group O	Disease group PSC	Previous abdominal surgery No
INR at registration 1.4-1.5	Bilirubin at registration 90 or more	Sodium at registration 136 or more
Albumin at registration 31-34	Creatinine at registration <=90	Inpatient at registration Outpatient

Results for a patient who entered the same information as you registered at Kings College:



Results for a patient who entered the same information as you registered at Royal Free:

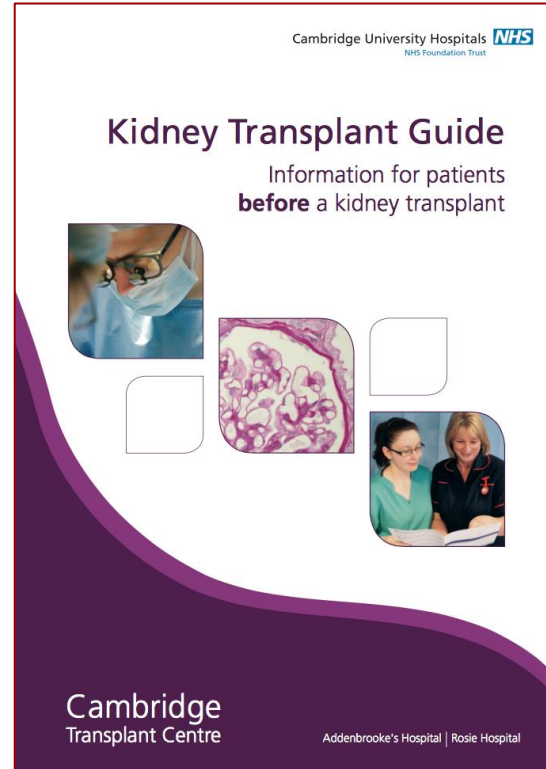




How do I do it?

3 stages

- Written information
 - Patient booklet
 - An information sheet
 - The consent form
- The clinic appointment
- The repeat appointment
 - Completion of assessment
 - Reviews on the waiting list



Are they listening?



Hearing, not listening

- East Anglian Renal Meeting
- Talk about pancreas transplantation, risks and benefits
- Deborah: “If you had told me that before the transplant I would never have had it”
 - She had had all the information we give
- 10 years after transplant
 - Qualified as a nurse
 - Married
 - 1 child

