



# Communicating Risk: Complexity

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**‘Medicine used to be simple,  
ineffective, and relatively safe.  
It is now complex, effective, and  
potentially dangerous.’**

**Cyril Chantler**

**Consultant Paediatrician & Nephrologist**

# Risk used to be simple





# Risk & consent for clinicians

## Montgomery v Lanarkshire Health Board (2015)

- Need for doctors to discuss with potential transplant candidates the options that exist for their treatment
- Advise the patients of alternative treatments and associated risks



# Challenges in calculated risk taking

Every patient's need is unique in transplant

## 1. Chance of transplant

- CRF status

## 2. Risk of donor

- Transmission of diseases
- Variability of quality of donor

## 3. Risk of alternative is significant

- Progressive medical co-morbidities affecting transplant options
- Risk of death on waiting list



# Opportunities

- Counseling can ensure *shared decision making* is enhanced
- ↑ marginal recipient listing
- ↑ marginal organ usage
- Appropriate risk appetite for the patient



# What does risk mean to patients:

## Heuristics

- Short cuts that patients take to understand and perceive risk
- Has impact on recall of risk over longer period
- Significance for patients on transplant list
  - may wait long periods



# Vicarious risk

## What motivates clinicians to take risks?

- Fame/Notoriety
  - Can be double edged sword!
  - Danger of a common waiting list with varied risk appetite
- How does our perception of risk & vicarious values ultimately influence patients?

‘What would you do doctor?’





# Pancreas Transplantation

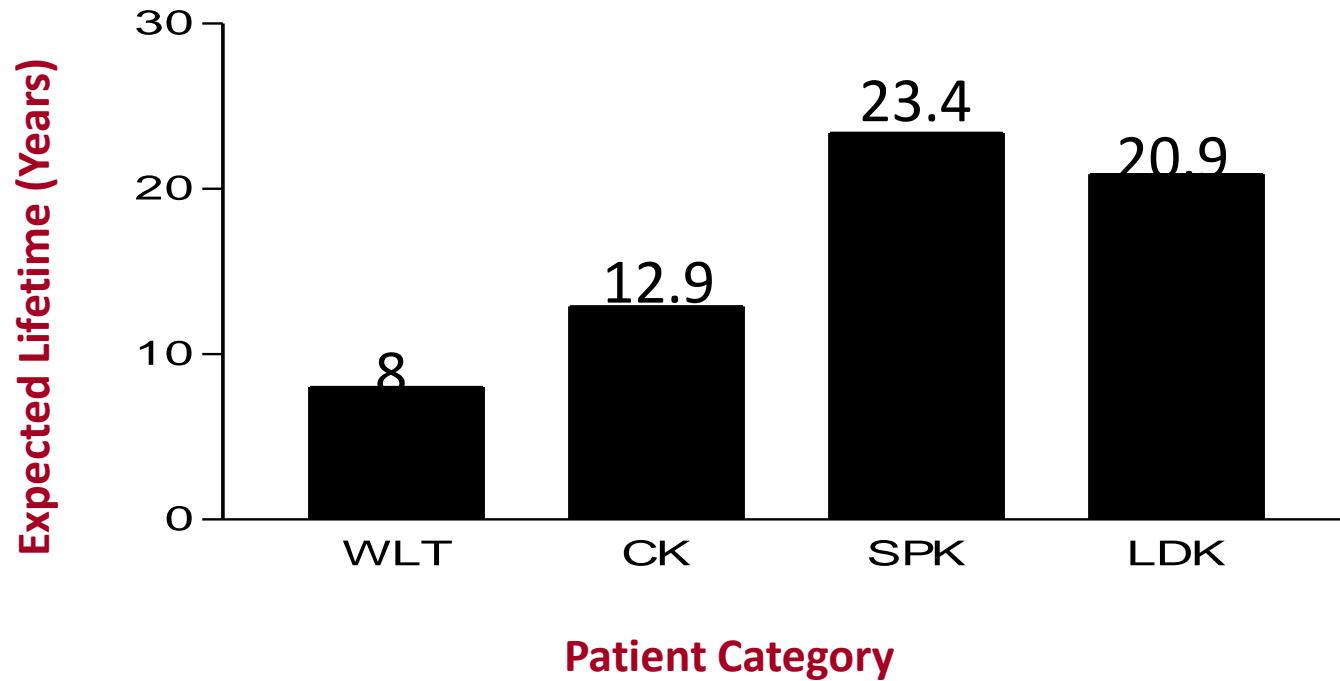
## Is it a life saving operation?

- Unusual amongst transplant options as alternative Rx's:
  - Islets
  - Kidney alone (live & deceased)
  - Glucose control

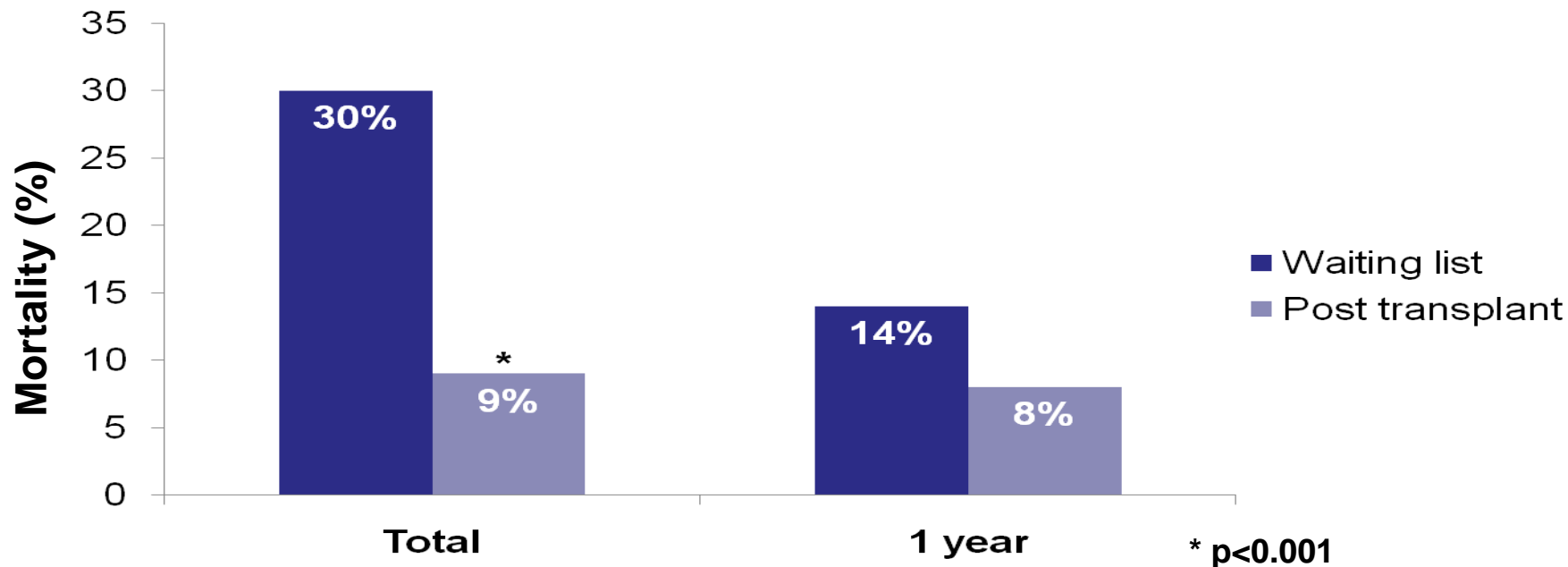


# What is the baseline preferred Rx for T1DM?

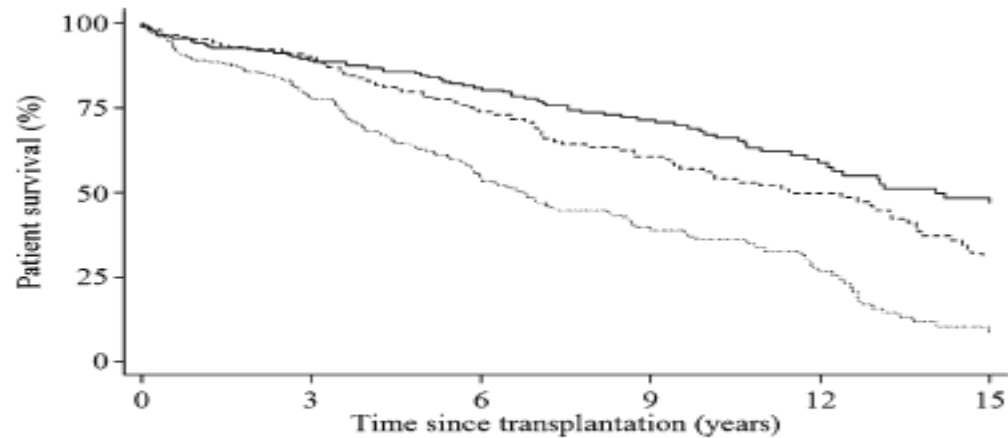
- A. SPK (E. KTA)
- B. LD (F. IAK)
- C. LD & PAK
- D. SIK



# Pancreas Mortality: Waiting List vs. Transplantation



Mortality in Diabetes: Pancreas Transplantation Is Associated with Significant Survival Benefit.  
van Dellen, D et. al. *Nephrol Dialysis Transplantation*, 2013 May;28(5):1315-22.



Number at risk		0	3	6	9	12	15
LDK	171	140	99	66	41	20	
SPK	222	168	129	90	51	33	
DDK	237	147	84	44	22	5	

Survival by treatment modality or era

Survival (%)

		1 year	3 year	5 year	10 year
Patient survival	SPK	94	89	85	67
	LDK	95	90	79	56
	DDK	89	78	63	36

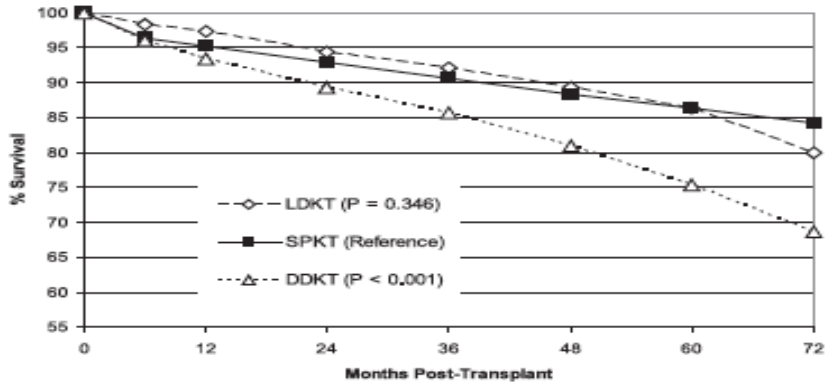
Improved patient survival with simultaneous pancreas and kidney transplantation in recipients with diabetic end-stage renal disease.

J.P Lindahl et. al. *Diabetologia* (2013) 56: 1364-71

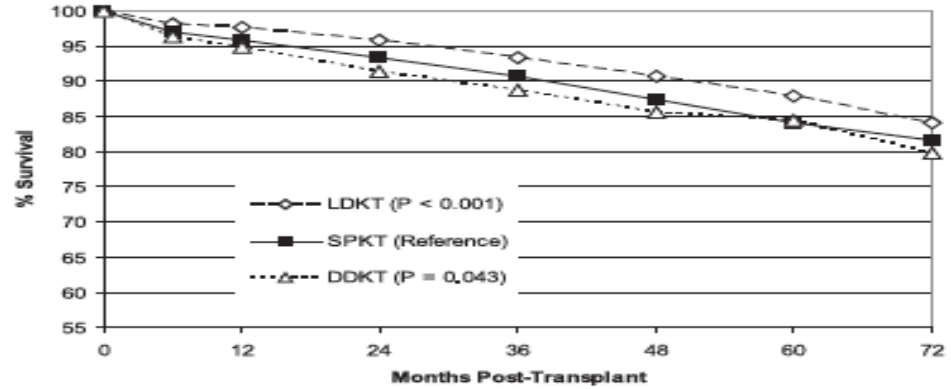


# The opposite results!

Although DDKTx definitively worse!



**Patient Survival**



**Death Censored Kidney Survival**

Living donor kidney versus simultaneous pancreas-kidney transplant in type 1 diabetics: An analysis of the OPTN UNOS database

B. Young et. al. Clin J Am Soc Nephrol(2009) 4: 845-52



# How much risk are individuals prepared to take?

Patients for themselves?

Vicariously by HCP's?



# INDIVIDUAL PERSPECTIVE

**What do we do for  $n=1$ ?**





# SPK assessment referral

## (07/15)

- **T1DM 25 years**
  - 50u Insulin/day
- **2° complications**
  - ESRF (eGFR 10ml/min)
  - Hypoglycaemic unawareness
  - Peripheral neuropathy
  - Retinopathy



- **Medical History**

- 2X previous CVA's

- cerebellar & occipital infarcts - resulting in significant balance issues

- brainstem ischaemia

- Epilepsy

- 50u Insulin/day

- **Dual anti-platelet therapy**

- (stroke physicians resistant to stopping)



- **Cardiac History**

- **Echo**

- Good biventricular function
- LV diastolic dysfunction

- **Myoview**

- Some diffuse evidence of reversible ischaemia

- **Angiogram**

- Small vessel disease

- **CPET**

- AT 11.79ml/kg/m<sup>2</sup>
- VO<sub>2</sub>max 13.4 (32% predicted)



# What Tx Option should he be offered?

**A. SPK** (E. IAK)

**B. Find a LD**

**C. Find a LD & PAK**

**D. Kidney alone**



- **Surgical MDT X3**
- **Anaesthetic MDT X1**
- **Pass for SPK**
  - with caveat of high risk
- **Called in for transplant**
  - Cancelled on day due to high risk

# Who is protecting themselves here?

Where does the shared responsibility of MDT  
end & personal responsibility begin?

What risk can patient take on themselves?





- Further MDT discussion
  - (total elapsed time 18/12)
- Happy to activate with view that high risk
- Consider SIK



# What Tx Option should he be offered?

**A. SPK**

**(E. KTA)**

**B. Find a LD**

**(F. IAK)**

**C. KTA**

**D. SIK**





# Activated For SIK– 03/17

- 26yo F donor – Trauma
- HLA 1:2:1
- Kidney TIT 10h31min
- D2: islet transplant (wt 70 kg)
  - 250 000 Islet/eq
  - Viability 88%; purity 90%



- 2<sup>nd</sup> transplant performed
- Alive with dual functioning grafts
- No hypoglycaemic unawareness
  
- Cr: 180umol/l
- Insulin requirements: 8u/day (from 50)
- C-peptide: 1159pmol/l



# Risk with caveats?

Is getting 2<sup>nd</sup> prize.....

(even if it's quite good)

good enough?



Can we make patients settle for 2<sup>nd</sup>  
place for their own good?



# Who should be the eventual arbiter with respect to risk?

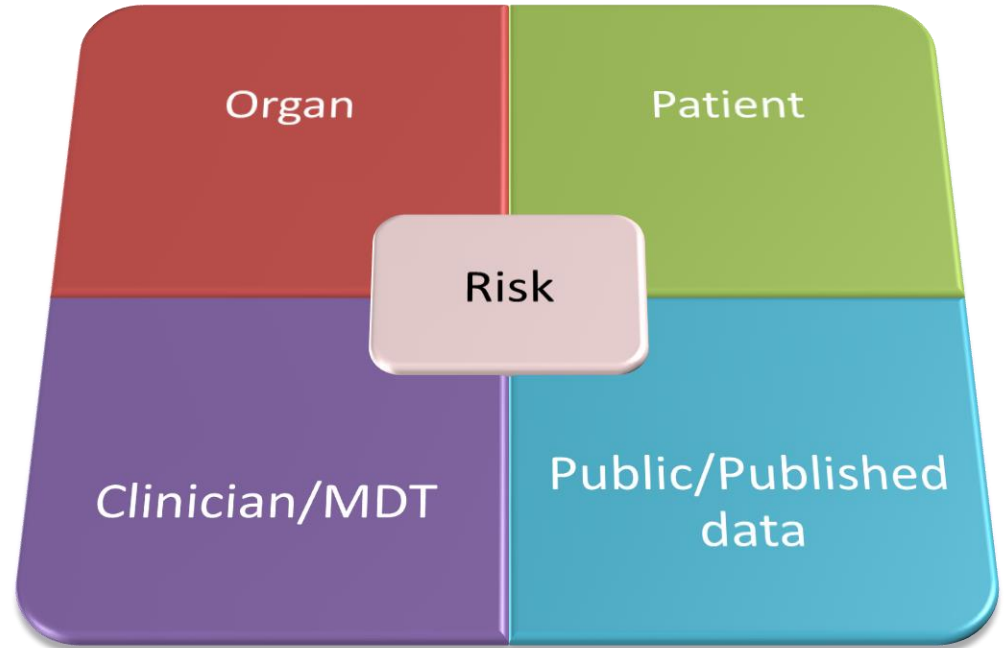
(pick 1 as they may be in conflict with each other!)

- A. Patient**
- B. Responsible clinician**
- C. MDT**
- D. Wider community (advisory committees; exceptional listing mechanisms)**



# Conclusion

- Risk's importance heightened by recent legislative changes
- 1. Perception of risk**
  - 2. vicarious decision making**
  - 3. patient/clinician risk appetite**  
requires consideration





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