NHS
Blood and Transplant

National Organ Utilisation Conference 2022
New Perspectives in Organ Utilisation

Friday 27th May

Welcome to the conference. We will be starting shortly.

*Visit the **conference website** to view the agenda and pre-recorded presentations*

Why not log into Mentimeter, which we will be using during today's session?

Using your smartphone or tablet, go to www.menti.com and enter the code **2919 9319**

NHS
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Welcome & Introduction

Professor Derek M Manas

Goals for the day

NHS Blood and Transplant

- Hear fresh perspectives on organ utilisation
- Reflect on national OU issues
- Inform broader transplant audience about utilisation projects
- Consider the impact of culture on utilisation
- An update on the work of the Organ Utilisation Group

Housekeeping

NHS Blood and Transplant

If you have any comments during the presentations, please use the Teams chat during the Q&A sessions

We will be seeking your input via “Menti” during the session – have your phone/tablet handy!

Attendees will be muted during the sessions

This session is being recorded (if you have any concerns, please let a member of the team know)

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“About you” Menti

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Keynote Speakers

Ian Currie

Professor Greg Snell

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Abdominal NRP

Ian Currie

NRP

What does it mean?

- NO’ RIGHT PAL
- NOT REALLY PRACTICAL

NRP

Blood and Transplant

What does it mean?

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- NOT REALLY PRACTICAL

Normothermic Regional Perfusion

NRP

NHS Blood and Transplant

What does it mean?

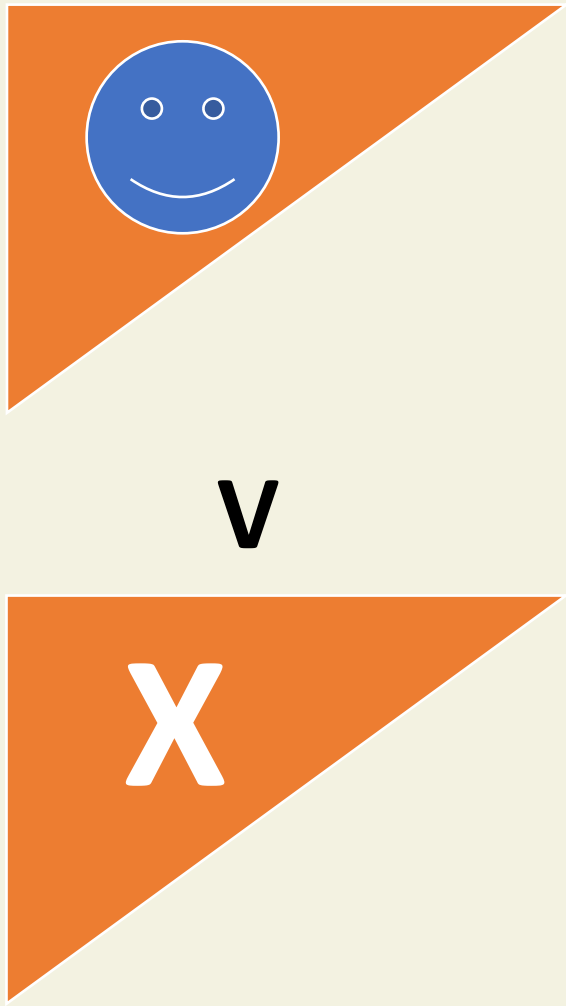
- NO' RIGHT PAL
- NOT REALLY PRACTICAL

Normothermic Regional Perfusion

NICE RESULTS, PEOPLE

Why NRP?

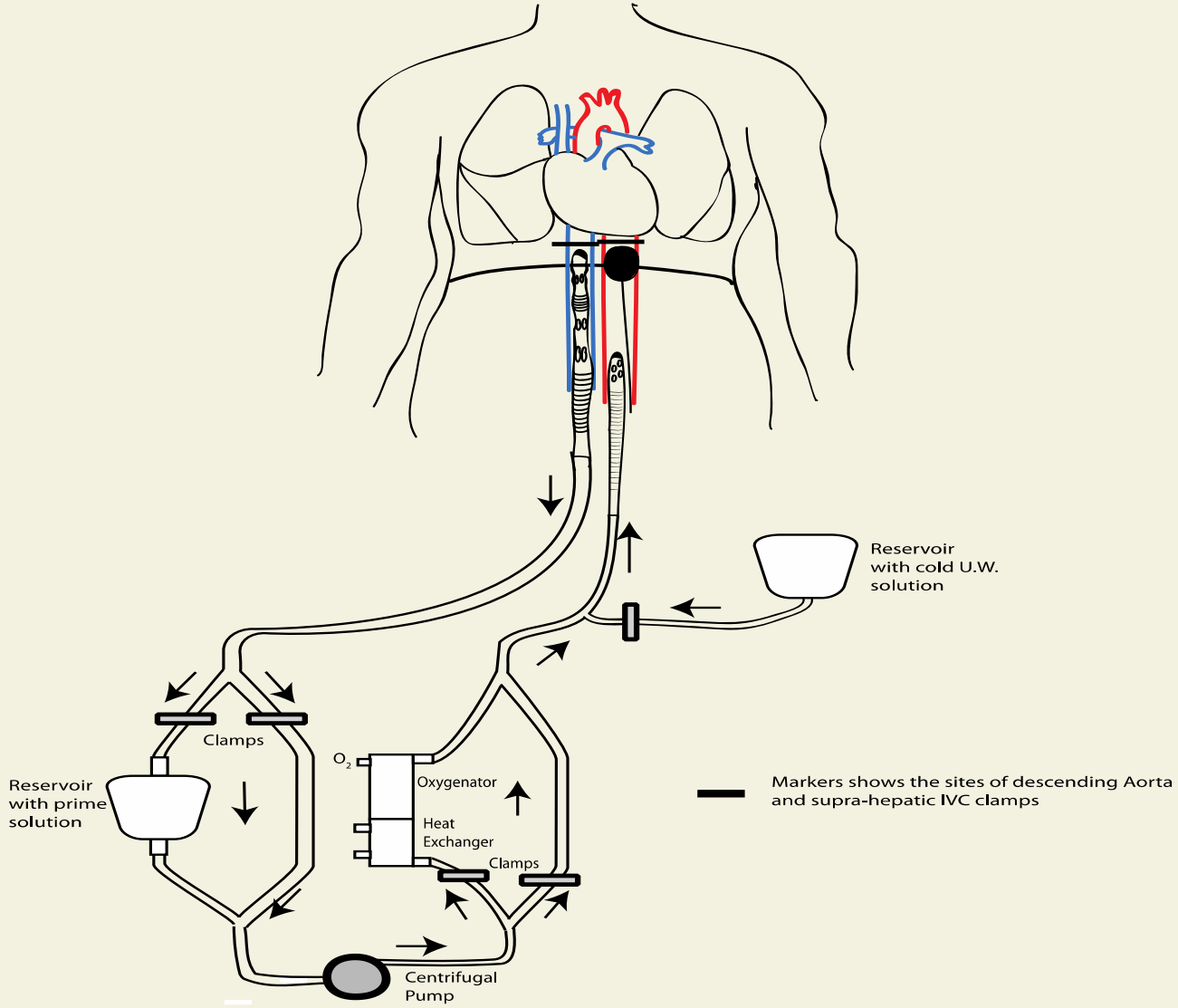
NHS Blood and Transplant



- DBD liver (50% of UK donors)
  - 1-2% non-function
  - 1% cholangiopathy
  - **80%** of liver transplants
- DCD liver (50% of UK donors)
  - 2-4% non-function
  - 5-20% cholangiopathy
  - Re-graft rate in UK is 27%
  - **20%** of transplants

How do we do NRP?

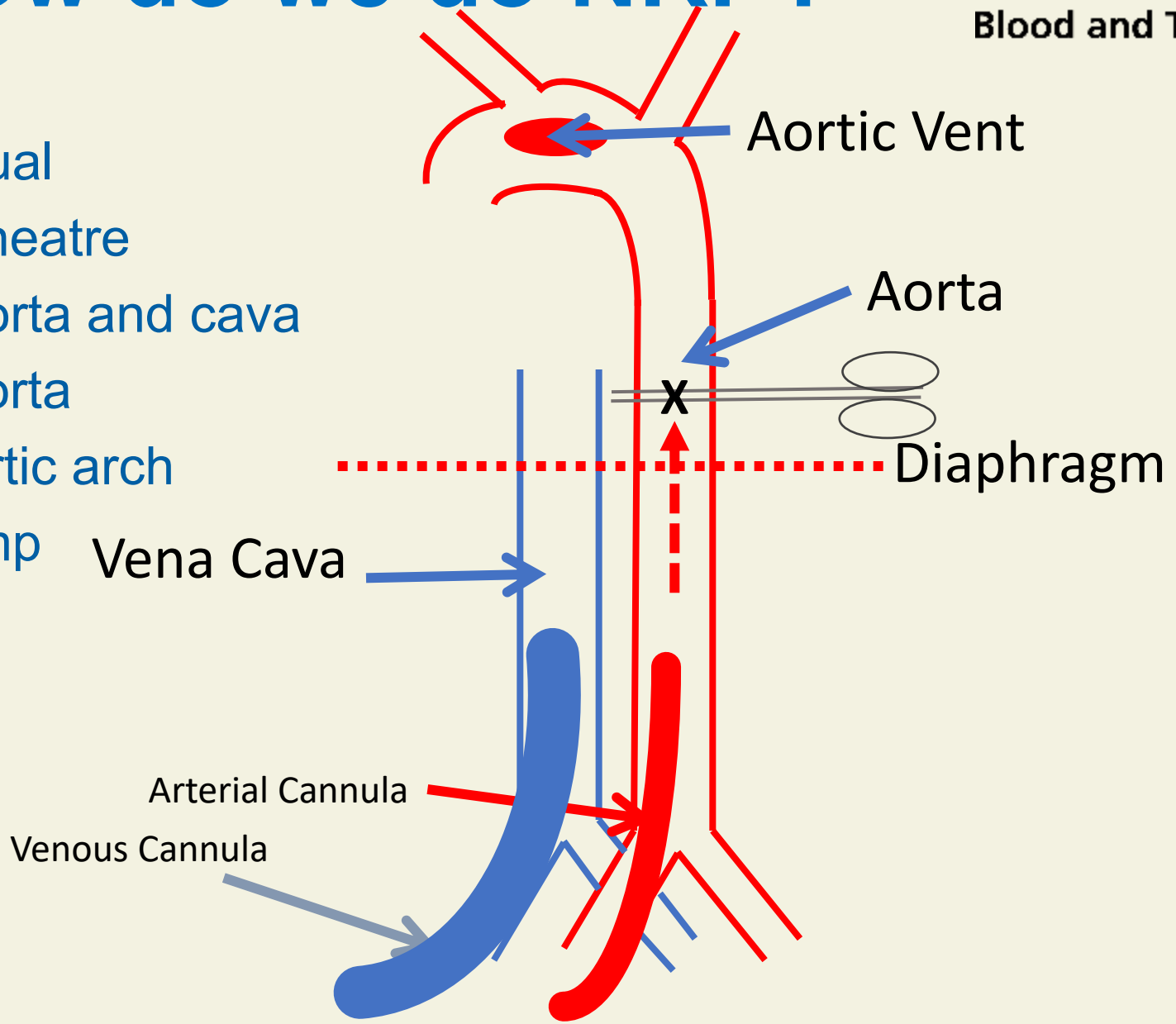
NHS Blood and Transplant



How do we do NRP?

NHS Blood and Transplant

- WLST as usual
- Transfer to theatre
- Cannulate aorta and cava
- Clamp the aorta
- Open the aortic arch
- Start the pump



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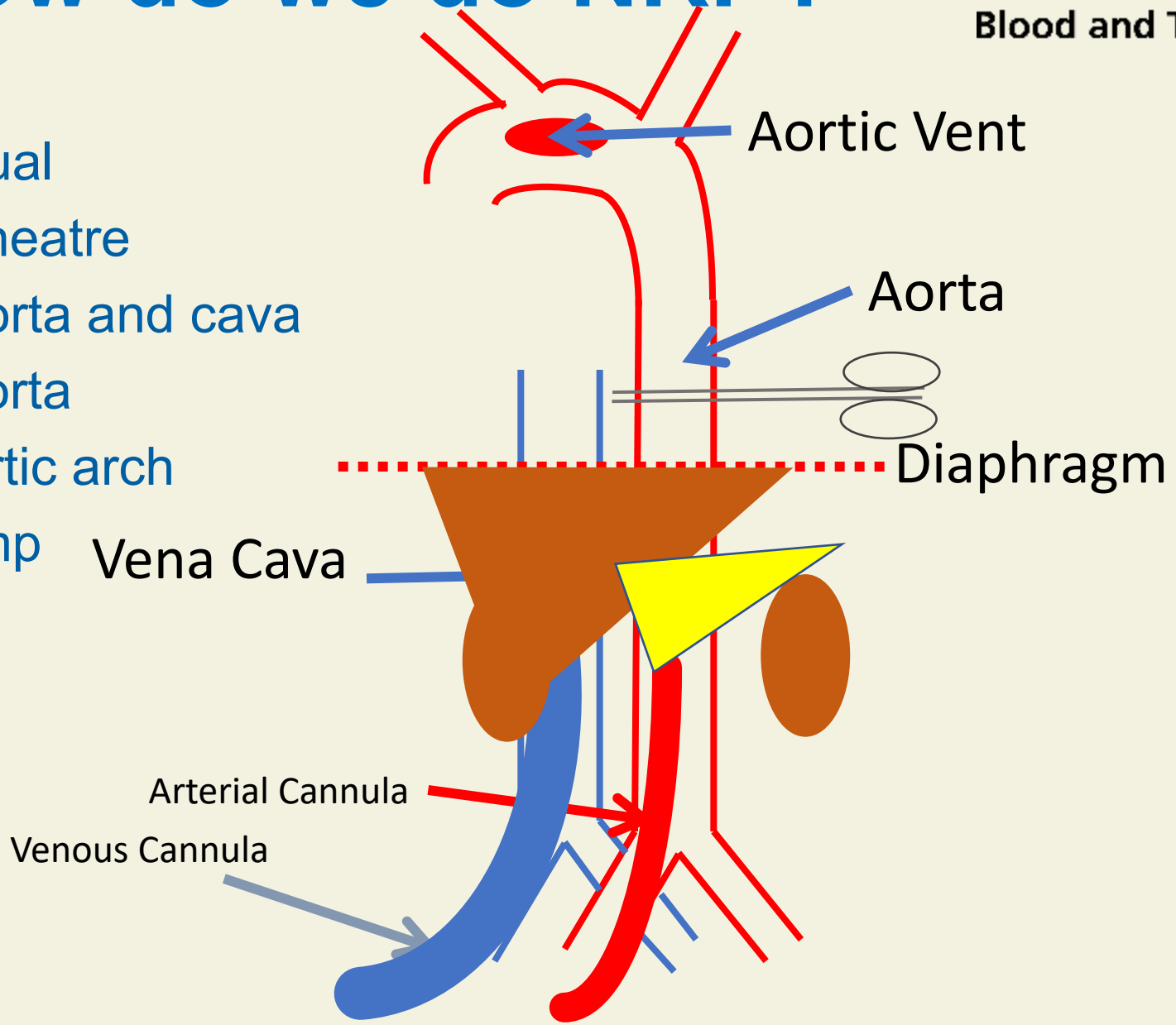

Oxygen uptake by organs

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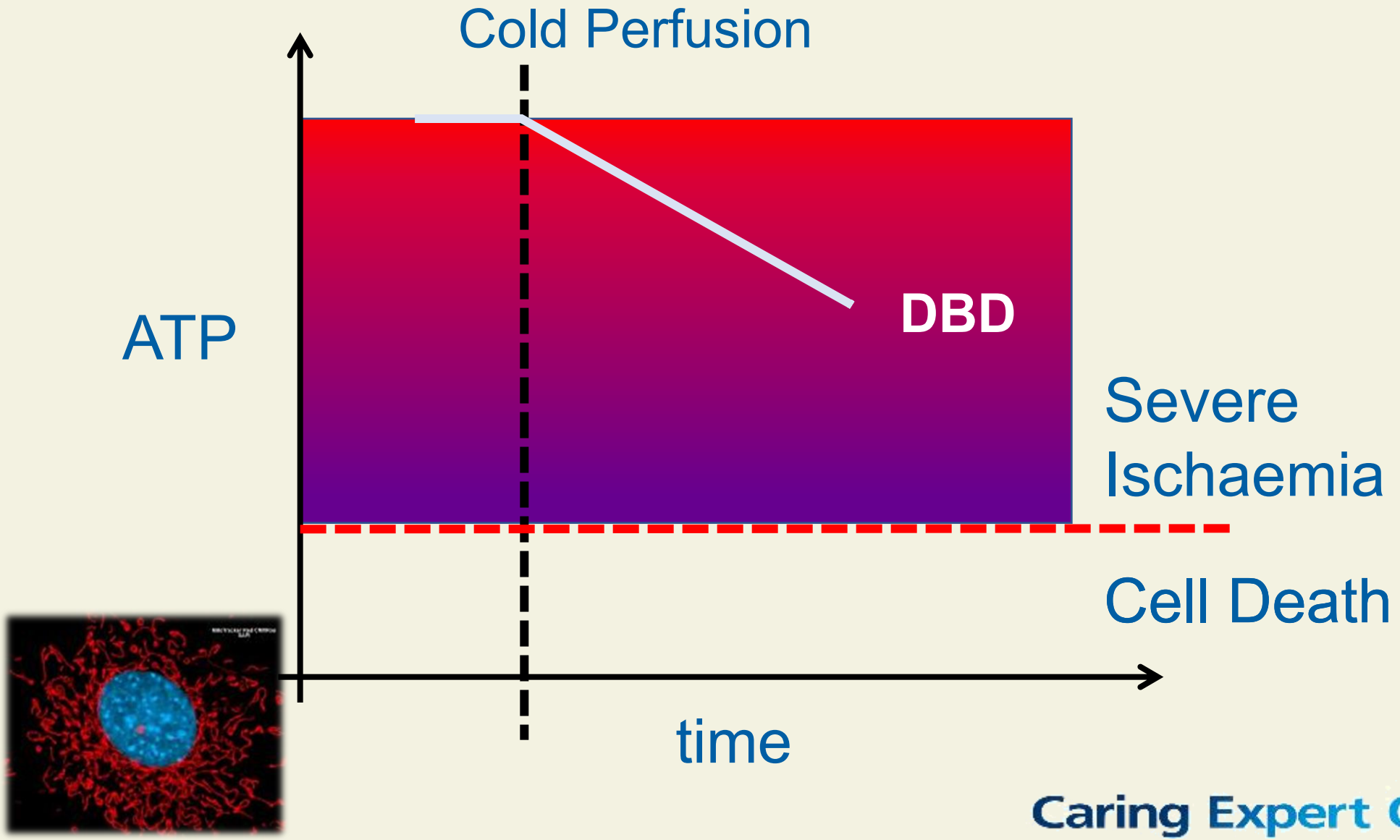
Better theatre environment

NHS Blood and Transplant

How does it work?

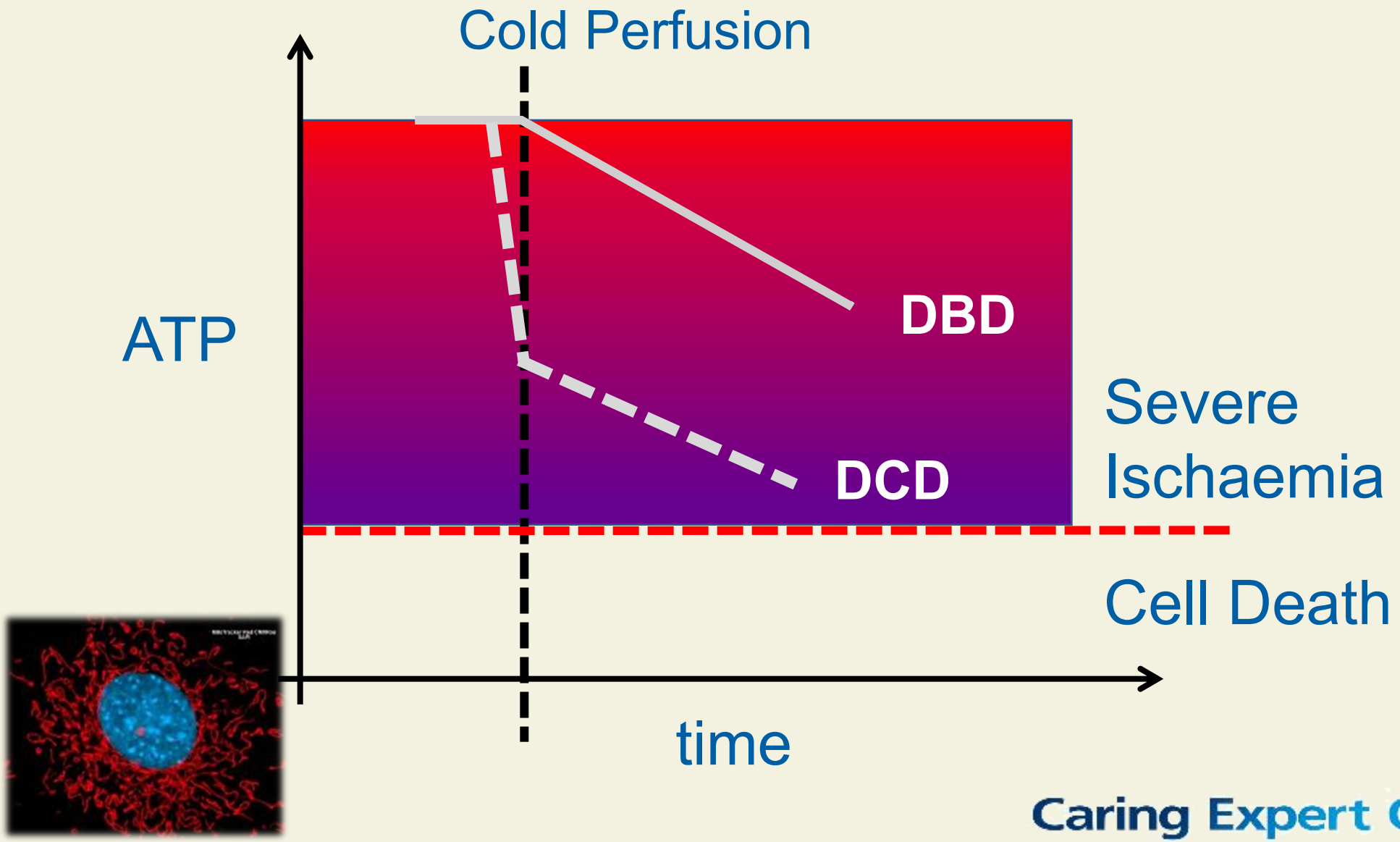
NHS Blood and Transplant



Caring Expert Quality

How does it work?

NHS Blood and Transplant



Caring Expert Quality

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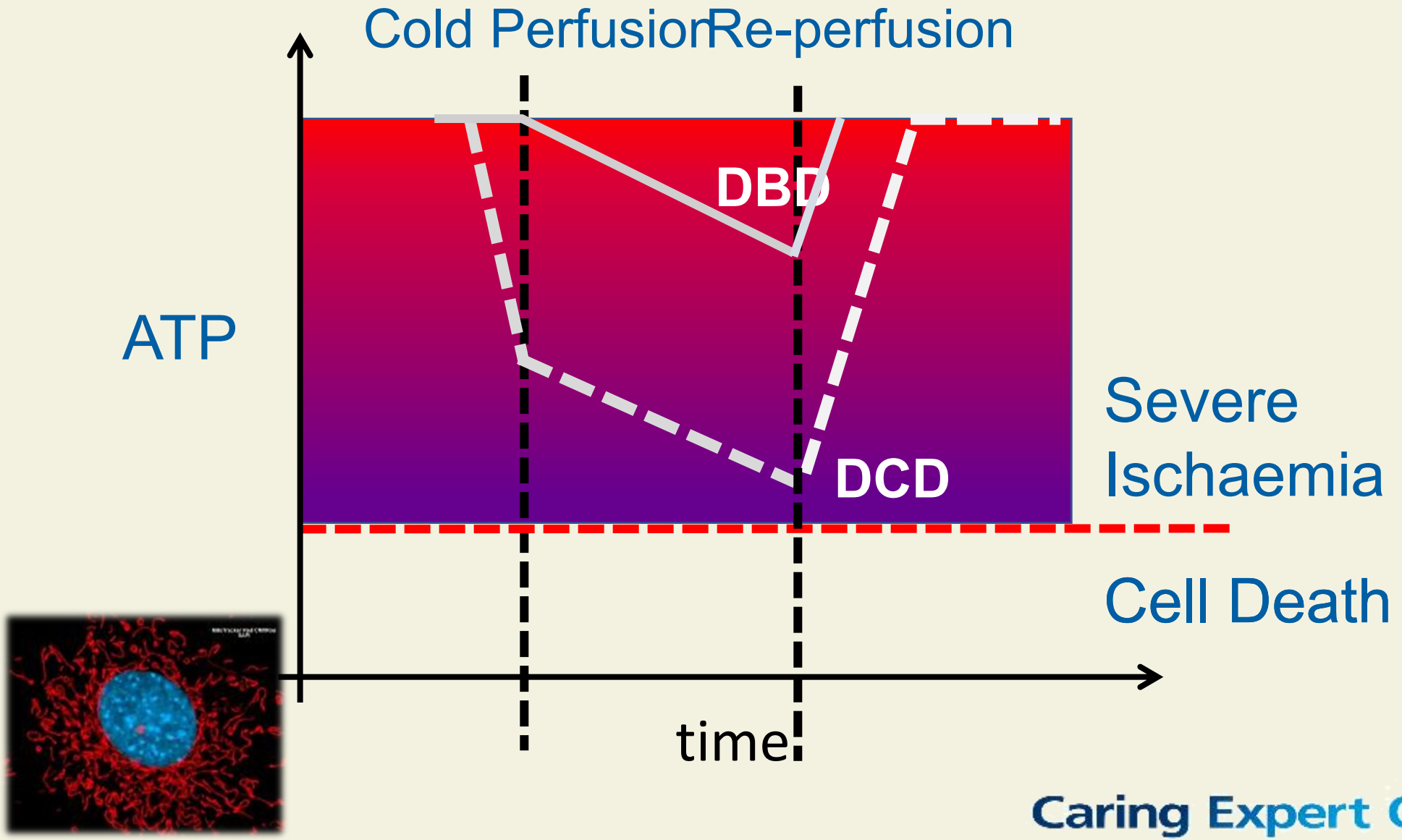
NHS Blood and Transplant



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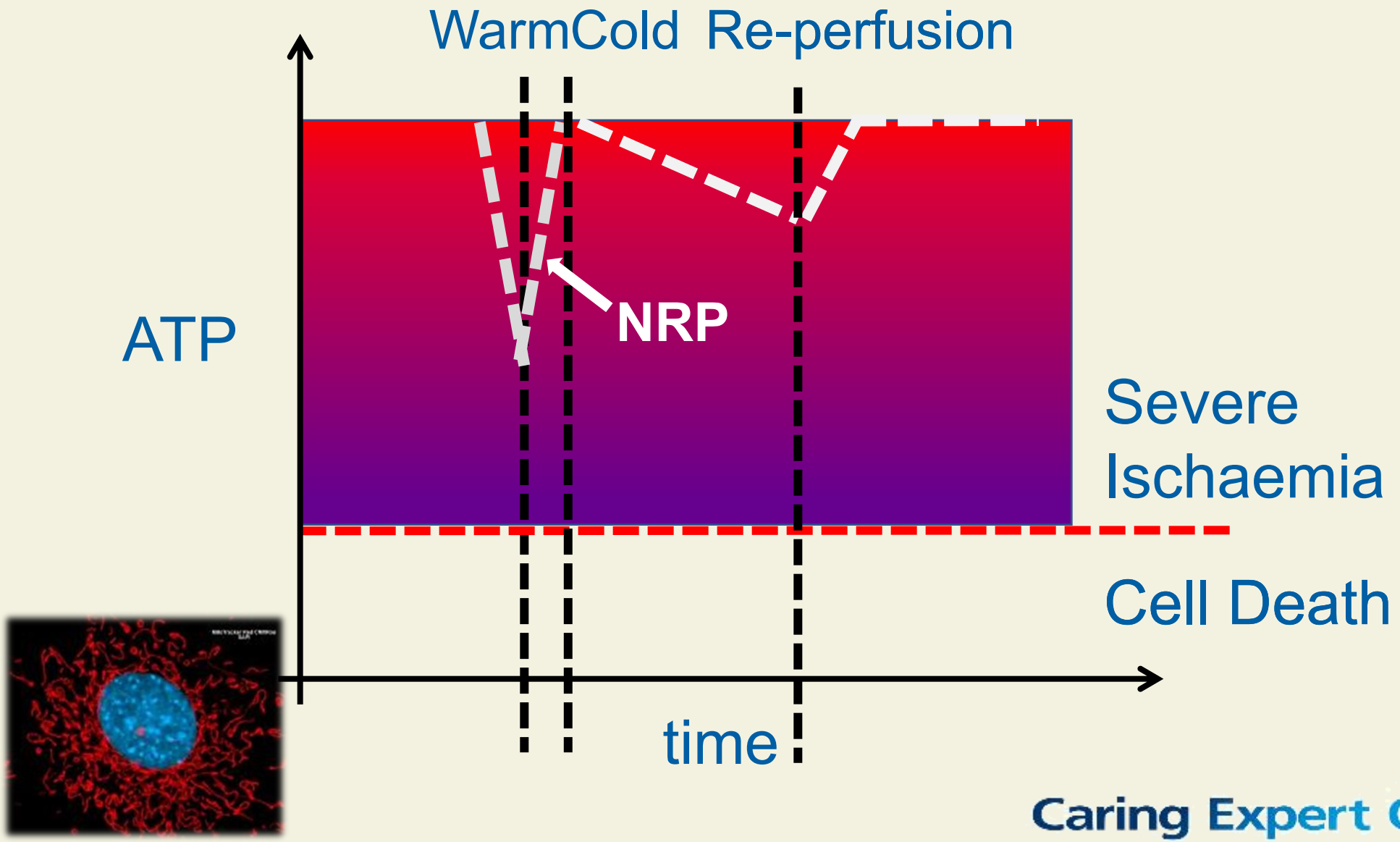
How does it work?

NHS Blood and Transplant



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Graft Selection

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NORMOTHERMIC REGIONAL PERFUSION

BLOOD RESULTS		RANGE	0	30'	60'	90'	120'
VENOUS GASES	pH	7.35-7.45	6.94	7.44	7.54	7.63	7.6
	H+	35-45	114	35.8	28.5	23.6	24.5
	pCO2	4.5-6.0	21.6	5.95	4.00	3.71	3.83
	pO2	5.0-8.0	5.43	19.9	54.35	31.0	54.6
	HCO3	22.0-28.0	22.2	29.5	31.0		—
	BE	-3 - +3	2.2	6.7	8.0	8.1	7.6
	Na+	135-145	139	136	138	137	137
	K+	3.6-5.0	5.5	5.6	5.7	5.9	5.9
	Ca2+	1.15-1.3	0.62	0.78	0.80	0.78	0.79
	Gluc	3.6-5.8	5.3	6.3	6.3	7.1	7.9
	Lact	0.6-1.4	10.5	8.5	8.6	8.0	6.9
	Hct	35-48	17.9	21.1	20.7	16.8	21.2
	Hb	115-180	119	78	60	59	102
	Sats	70-80%	46.3	69.5	86.2	—	—

BLOOD RESULTS		RANGE	0	30'	60'	90'	120'
ARTERIAL GASES	pH	7.35-7.45	7.15	7.49	7.59		
	H+	35-45	71.2	31.9	26.5	24.1	24.0
	pCO2	4.5-6.0	12.9	5.06	4.23	3.84	3.70
	pO2	11.0-15.0	40.2	51.1	44.7	52.0	45.1
	HCO3	22.0-28.0	26.1	not on pump	not on pump	not on pump	—
	BE	-3 - +3	4.6	6.7	7.5	8.2	7.3
	Na+	135-145	139	138	136	138	136
	K+	3.6-5.0	5.4	5.7	5.6	6.0	5.9
	Ca2+	1.15-1.3	0.73	0.77	0.76	0.77	0.79
	Gluc	3.6-5.8	4.9	6.3	6.2	7.1	7.7
	Lact	0.6-1.4	9.7	8.6	8.8	8.1	6.6
	Hct	35-48	17.9	21.1	20.7	16.8	21.2
	Hb	115-180	135	77	41	22	123
	Sats	>94%	99.8	—	—	—	—

BLOOD RESULTS		RANGE	0	30'	60'	90'	120'
BIOCHEMISTRY / FBC	Bili	3-21	65	6	7	7	7
	ALP	50-250	52	72	77	71	72
	ALT	10-50	1277	1522	1470	1315	1387
	AST	10-40	2462	2652	2569	2364	2395
	Urea	2.5-6.6	5.1	6.7	7.8	8.8	9.5
	Creat	60-120	49	57	62	62	63
	Hb	115-180	52	62	77	60	68
	WCC	4-11	10.3	5	3.9	2.7	2.6
	Plat	150-400	173	150	147	141	140
	Cultures			NFG			NFG

Sources; Rachel Hogg, Statistics, NHSBT

NHS Blood and Transplant

NHS Blood and Transplant

QUARTERLY REPORT ON NRP RETRIEVALS

1 April 2015 - 31 December 2021

As at 8 April 2022

RAG(22)08

NHS BLOOD AND TRANSPLANT

RETRIEVAL ADVISORY GROUP

DCD KIDNEYS RETRIEVED WITH OR WITHOUT NRP – ACTIVITY AND OUTCOMES

NRP v DCD; Retrieval and Tx

NHS Blood and Transplant

Table 1 Number of livers and kidneys offered, retrieved and transplanted

		NRP		Non-NRP	
		SBP 50mmHg to NRP ≤30 mins	SBP 50mmHg to NRP >30 mins	SBP 50mmHg to cold perfusion ≤30 mins	SBP 50mmHg to cold perfusion >30 mins
Number of donors		130	21	693	71
Liver	Number offered	129	21	637	62
	Number retrieved (% of offered)	99 (77)	15 (71)	287 (45)	13 (21)
	Number transplanted (% of offered)	80 (62)	12 (57)	197 (31)	4 (6)
Kidney (at least one)	Number offered	130	20	689	71
	Number retrieved (% of offered)	127 (98)	20 (100)	672 (98)	71 (100)
	Number transplanted (% of offered)	118 (91)	20 (100)	578 (84)	55 (77)

Cohort

This report presents data on UK adult (≥16) proceeding DCD donors that were attended by Cambridge or Edinburgh only between 1 January 2011 and 31 December 2020.

NRP; Is Organ Damage Worse?

NHS Blood and Transplant

	Liver		Kidney	
	DCD	NRP	DCD	NRP
Organs retrieved	257	155	1303	394
Damage (% of reported)				
None	203 (84%)	137 (95%)	1120 (88%)	334 (86%)
Mild	22 (9%)	6 (4%)	85 (7%)	30 (8%)
Moderate	13 (5%)	1 (1%)	50 (4%)	18 (5%)
Severe	3 (1%)	0 (0%)	13 (1%)	6 (2%)

NRP; Is Organ Damage Worse?

NHS Blood and Transplant

	Pancreas		Lung	
	DCD	NRP	DCD	NRP
Organs retrieved	118	39	71	18
Damage (% of reported)				
None	94 (89%)	34 (94%)	51 (78%)	16 (100%)
Mild	4 (4%)	1 (3%)	8 (12%)	0 (0%)
Moderate	3 (3%)	0 (0%)	4 (6%)	0 (0%)
Severe	5 (5%)	1 (3%)	2 (3%)	0 (0%)

ITU stay

NHS Blood and Transplant

		Cambridge			Edinburgh		
		Total	Total Reported	Median (IQR)	Total	Total Reported	Median (IQR)
ITU Stay	NRP	79	73	2 (2-4)	44	41	2 (2-2)
	DCD	133	130	3 (2-5)	34	32	3 (2-5)

Liver Outcomes

NHS Blood and Transplant

Table 3 Graft survival (%) for liver transplants by time between systolic BP reaching 50mmHg to start of perfusion

Donor type	Number of patients	1-year survival (95% CI)
NRP		
SBP 50mmHg to NRP ≤30 mins	70	97.0 (88.4-99.2)
SBP 50mmHg to NRP >30 mins	11	90.0 (47.3-98.5)
Log-rank p-value		0.3073
Non-NRP		
SBP 50mmHg to cold perfusion ≤30 mins	190	87.2 (81.5-91.2)
SBP 50mmHg to cold perfusion >30 mins	4*	-
Log-rank p-value		-
Overall		
Overall NRP	81	96.0 (88.2-98.7)
Overall non-NRP	194	87.0 (81.3-91.0)
Log-rank p-value		0.0215

*Survival rates for groups with less than 10 transplants are not presented due to small numbers

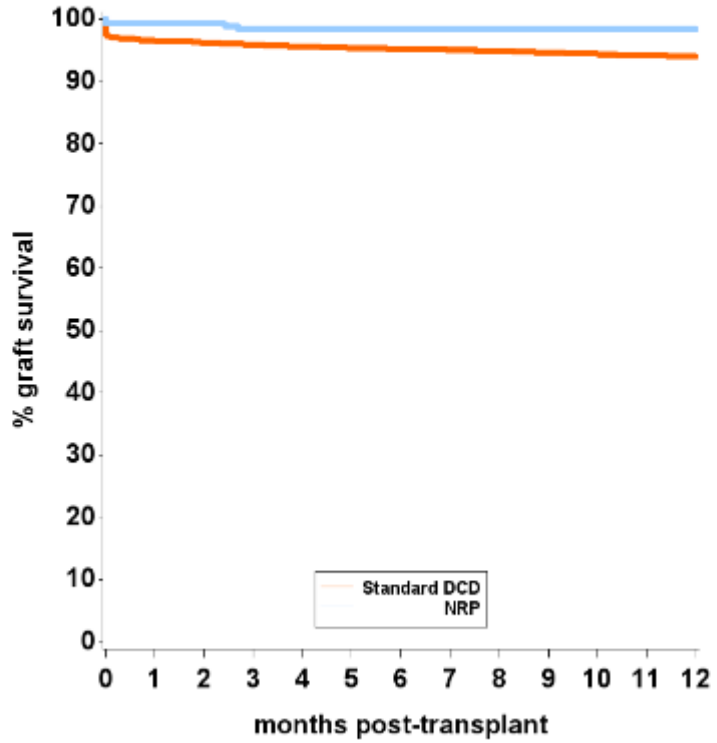
Table 2 Transplant survival (%) for liver transplants by time between systolic BP reaching 50mmHg to start of perfusion

Donor type	Number of patients	1-year survival (95% CI)
NRP		
SBP 50mmHg to NRP ≤30 mins	70	94.1 (85.0-97.7)
SBP 50mmHg to NRP >30 mins	11	90.0 (47.3-98.5)
Log-rank p-value		0.6631
Non-NRP		
SBP 50mmHg to cold perfusion ≤30 mins	190	84.7 (78.8-89.1)
SBP 50mmHg to cold perfusion >30 mins	4*	-
Log-rank p-value		-
Overall		
Overall NRP	81	93.6 (85.3-97.3)
Overall non-NRP	194	84.5 (78.6-88.9)
Log rank p value		0.0337

*Survival rates for groups with less than 10 transplants are not presented due to small numbers

NRP v DCD; 1 year graft survival

Figure 1 Kaplan-Meier graft survival function for DCD first kidney only transplant recipients by NRP status, 1 April 2016 – 31 March 2021



Kidney outcomes

NHS Blood and Transplant

Table 1 Number of kidneys retrieved and transplanted, by NRP status, 1 April 2016 – 31 March 2021

Method	Number of kidney donors	Number of kidneys retrieved	Number of kidneys transplanted	% transplanted (of retrieved)
Standard DCD	2613	5176	4390	85%
NRP	198	394	345	88%
Total	**2811**	**5570**	**4735**	**85%**

Centre Effect?

NHS Blood and Transplant

Table 2 DCD kidney transplants, by recipient centre and NRP status, 1 April 2016 – 31 March 2021

Recipient centre	Number of transplants	Standard DCD		NRP	
		N	% at centre	N	% at centre
Belfast	132	128	97	4	3
Birmingham	203	181	89	22	11
Bristol	172	170	99	2	1
Cambridge	478	391	82	87	18
Cardiff	144	144	100	0	-
Coventry	65	60	92	5	8
Edinburgh	135	97	72	38	28
Glasgow	212	174	82	38	18
Great Ormond Street	1	1	100	0	-
Guy's	298	281	94	17	6
Leeds	295	282	96	13	4
Leicester	183	162	89	21	11
Liverpool	156	149	96	7	4
Manchester	456	431	95	25	5
Newcastle	162	158	98	4	2
Nottingham	152	143	94	9	6
Oxford	391	372	95	19	5
Plymouth	88	85	97	3	3
Portsmouth	119	118	99	1	1
Sheffield	98	87	89	11	11
St George's	138	135	98	3	2
The Royal Free	133	131	99	2	2
The Royal London	160	156	98	4	3
WLRTC	232	226	97	6	3
Total	**4603***	**4262**	**93**	**341**	**7**

* Includes 133 dual kidney transplants

Graft Outcomes; Kidney

NHS Blood and Transplant

Table 3 One year graft survival rates following DCD first kidney only transplant, by NRP status, 1 April 2016 – 31 March 2021

Method	Number of transplants	1 year survival (95% CI)
Standard DCD	3471	94.0 (93.1-94.8)
NRP	256	98.4 (95.8-99.4)
Log-rank p-value		0.0059
Total	**3727**	**94.3 (93.5-95.0)**

Table 4 Mean eGFR at 12 months following DCD first kidney only transplant, by NRP status, 1 April 2016 – 31 March 2021

Method	Number of transplants	Mean eGFR
Standard DCD	2929	46.2
NRP	196	55.3
Total	**3125**	**46.8**

Risk adjusted eGFR; 7.6ml/min greater with NRP

NRP; liver graft utilisation in Ed.

NHS Blood and Transplant

- Donor age expansion
  - 30% of our NRP livers are >60 yrs (same as DBD)
- Functional warm ischaemic time increased
  - Extends >30mins (<30 mins for DCD)
- No Primary Non-Function as yet (5.2% in DCD)
- No Cholangiopathy as yet (26.0% in DCD)
- 8hrs CIT with ‘easy’ transplants in DCD versus 12 hours CIT with re-do’s/very sick for NRP

Conclusions

- Less Organ Damage for all organs
- Extended donor acceptance
- Greater CIT
- Shorter ITU stay
- Much better graft survival for liver and kidney
- 15% Better egfr at 1 year

NHS
Blood and Transplant

NRP

Nice Results People

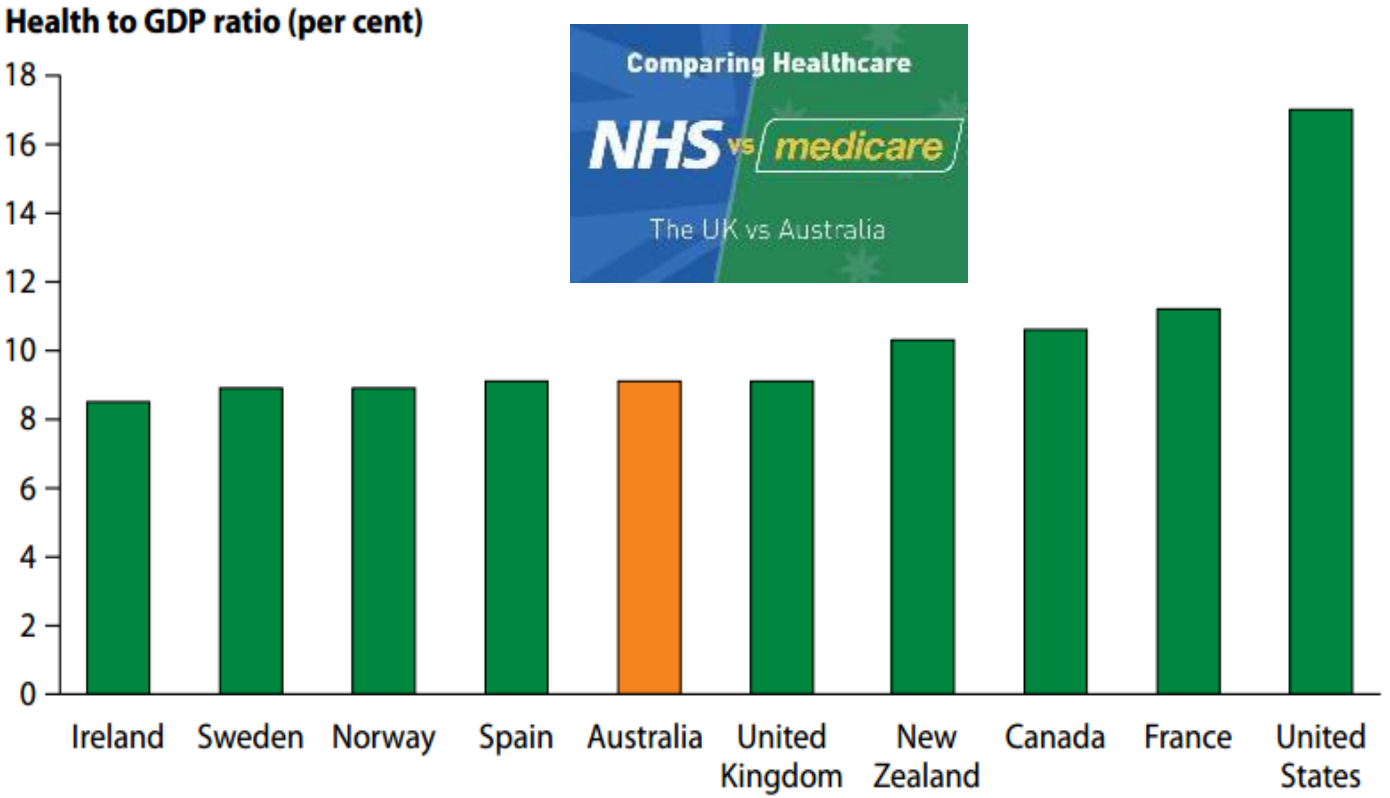
Where do donor lungs for transplantation come from?: the Australian experience

Prof Greg Snell

Medical Head,
Lung Transplant Service, Alfred Hospital
Melbourne, Australia

g.snell@alfred.org.au

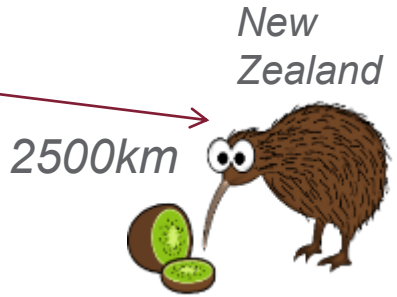
1) Why am I talking to you?



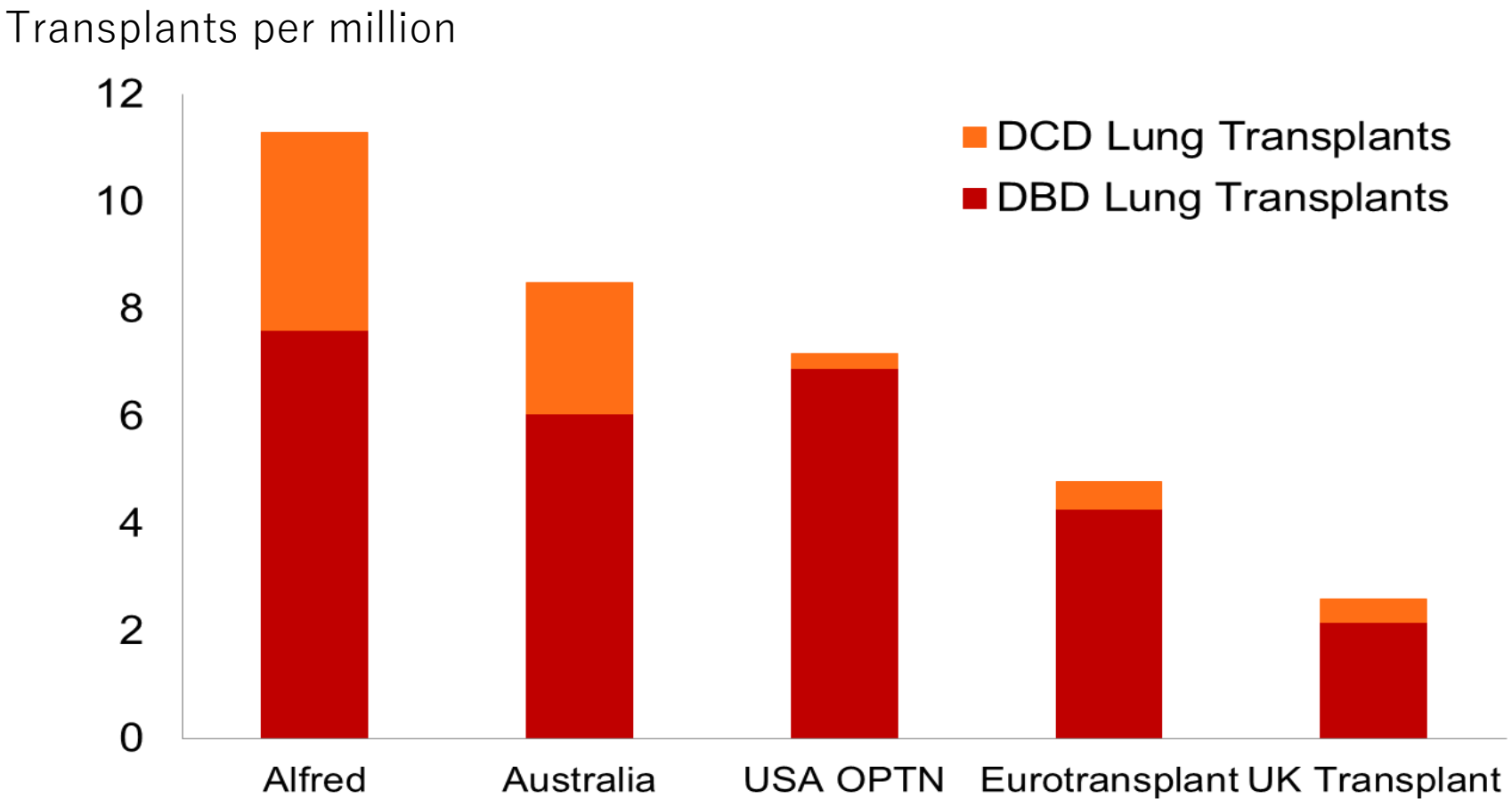
Source: AIHW 2013a.

Health expenditure as a proportion of GDP, selected OECD countries, 2011

Alfred DBD & DCD donor lung referrals

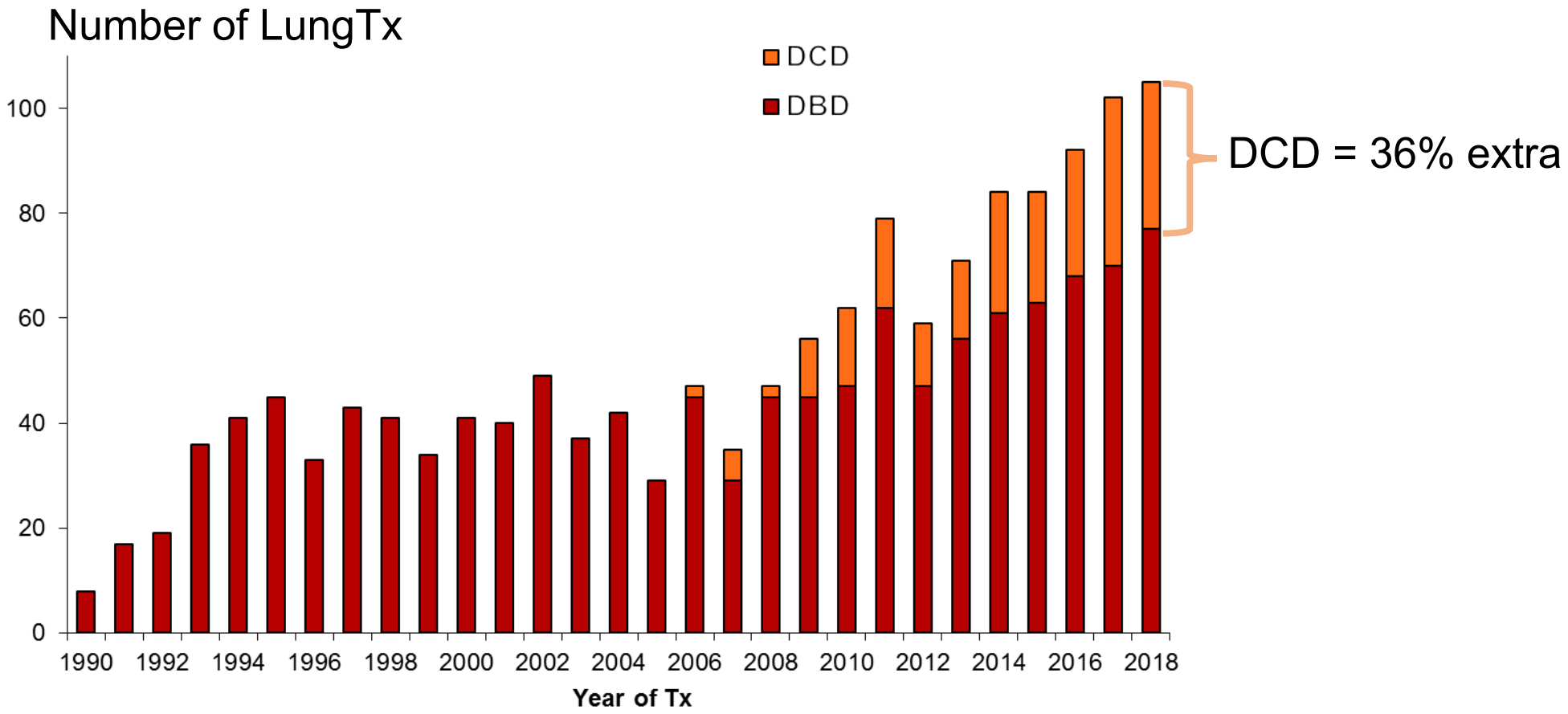


DBD & DCD lung Tx activity

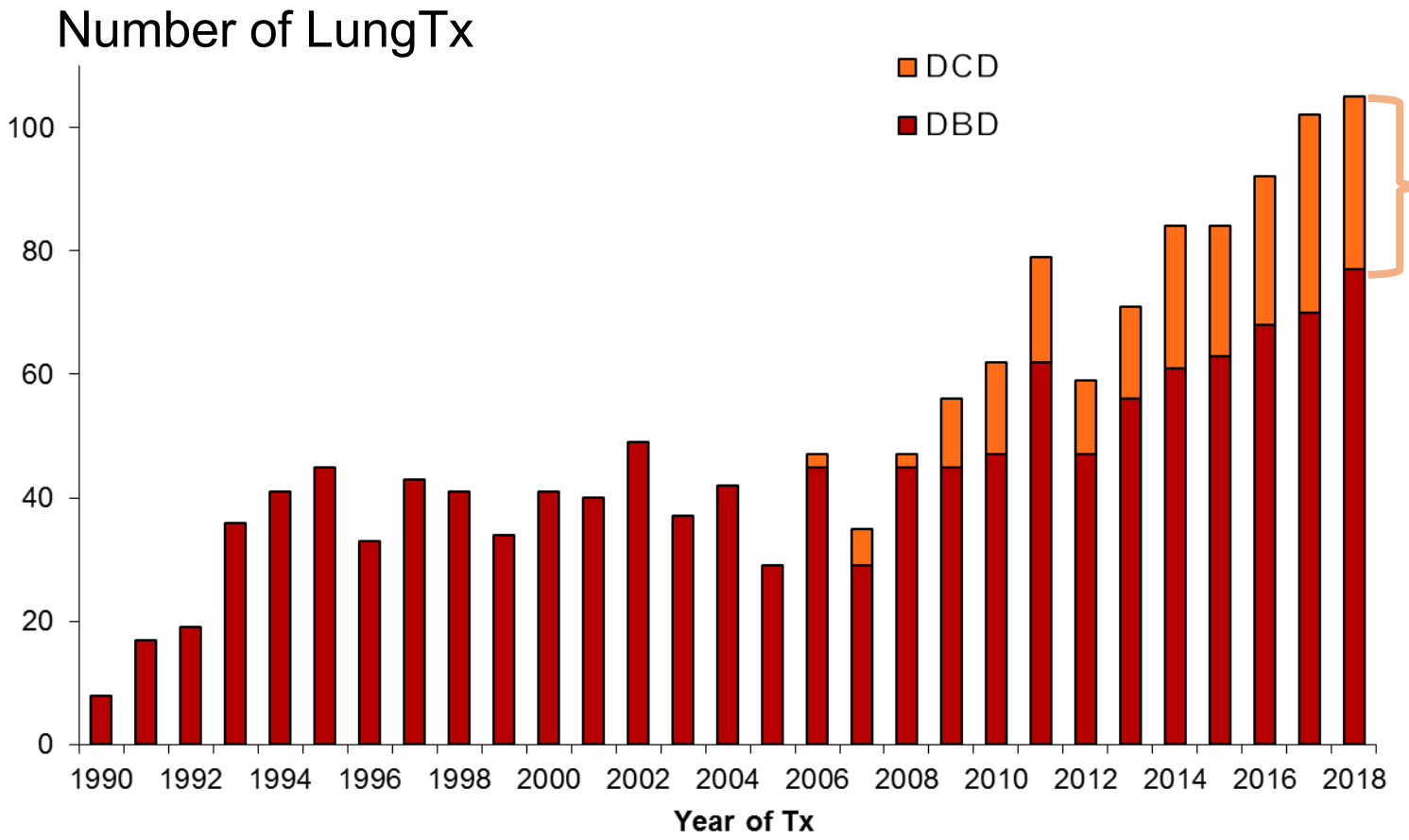


ODR 2018 22 24

Alfred DBD & DCD Lung Tx



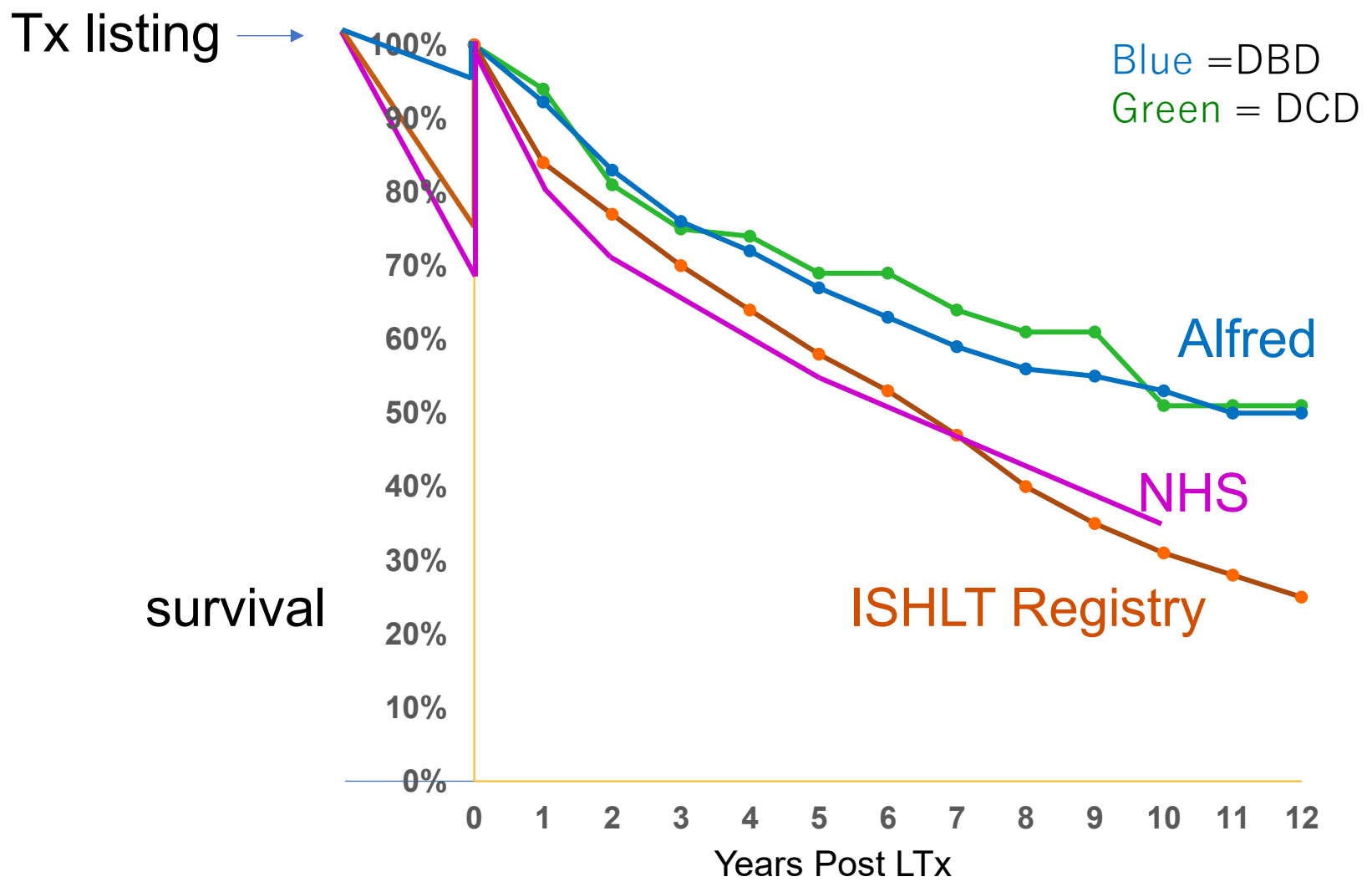
Alfred DBD & DCD Lung Tx



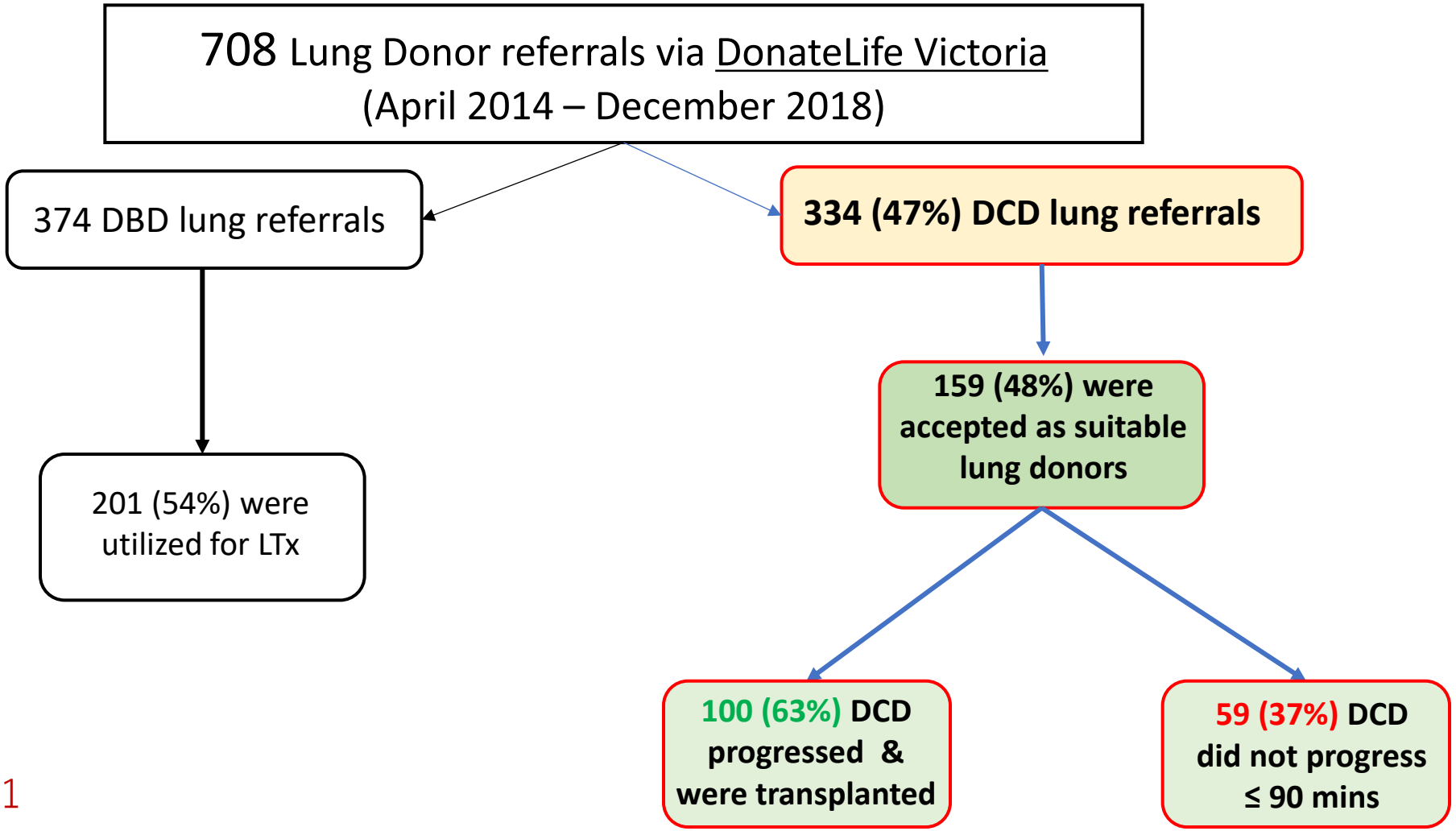
DCD = 36% extra

2018 **UK** = 164 Lung Tx
DCD = 26% extra

Alfred, NHS, ISHLT Registry survival

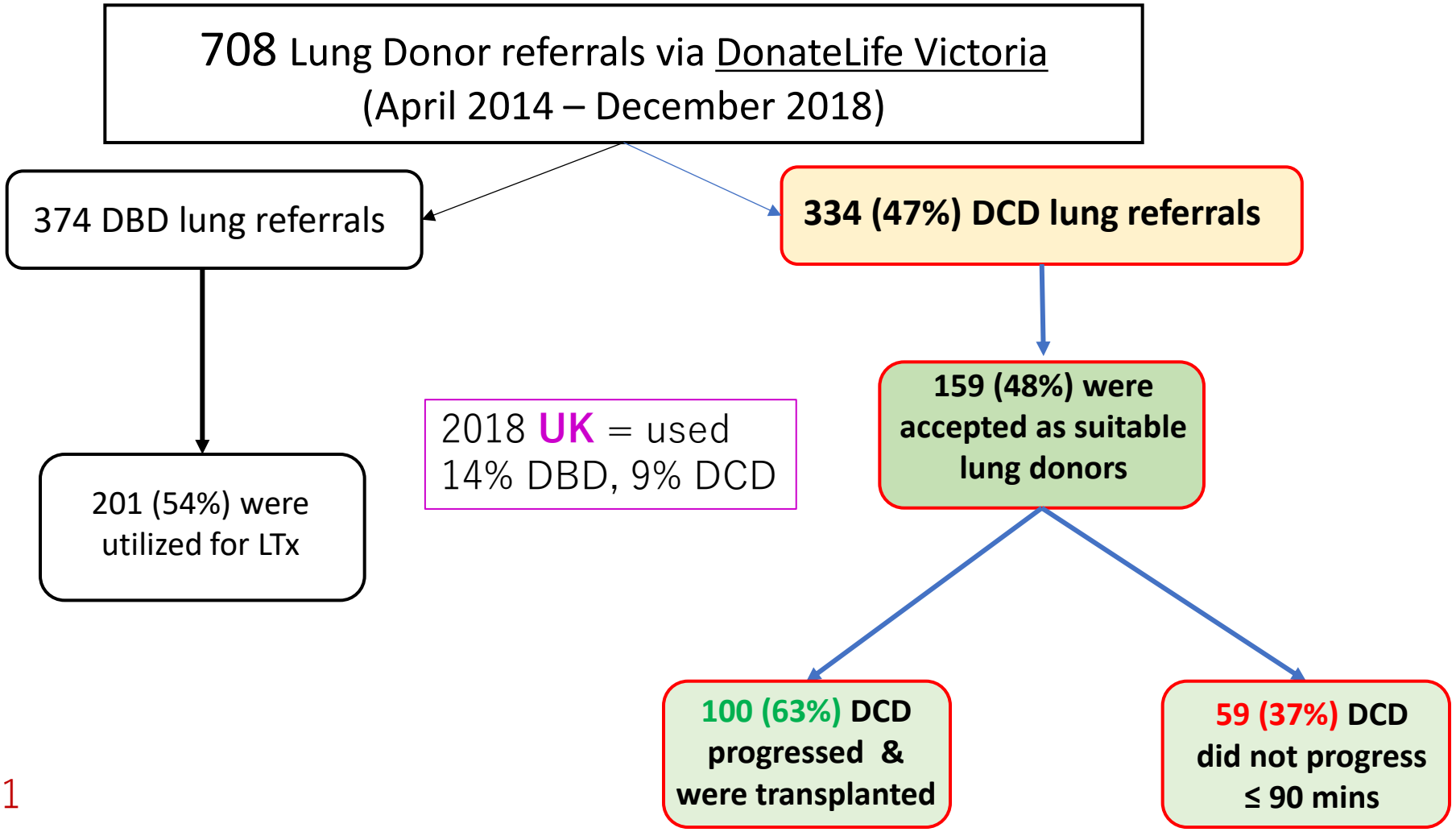


Alfred DCD lung donor referrals



Okahara 2021

Alfred DCD lung donor referrals



Okahara 2021

2) Alfred donor lung strategies & acceptability criteria

Lungs for donation & transplant (1)

- Many myths:
  - ‘Not many are good enough to use’
  - ‘Too damaged by processes leading up to to death (eg donor smoking, trauma, aspiration), resuscitation & ICU complications (eg infection, fluid management)’
  - ‘Frail little sponge’
  - ‘Not many lung transplants needed or done’
  - ‘Lung transplants don’t work’

Lungs for donation & transplant (1)

- Many myths:
  - ‘Not many are good enough to use’
  - ‘Too damaged by processes leading up to to death (eg donor smoking, trauma, aspiration), resuscitation & ICU complications (eg infection, fluid management)’
  - ‘Frail little things’
  - ‘Not many lung transplants needed or done’
  - ‘Lung transplants don’t work’

BUSTED

Lungs for donation & transplant (2)

- It turns out:
  - Lungs are useable in approx. 50% of all donors that yield any organ for Tx
  - Lungs can recover from fluid, bruising, consolidation, asthma, aspiration quickly
  - Lungs contain O_2 at time of death = ischaemia resistant (eg no post-arrest damage syndrome per se). Lungs survive 2hrs post arrest with NO support.
  - Ex-vivo lung assessment & resuscitation is possible
  - Many lungs needed
  - Lung transplants do work & save lives

Lung donor criteria for LungTx

	Conventional	Alfred Extended
Age	<55yrs	<75yrs
CXR	normal	SLTx if unilateral changes BLTx if bilateral changes repeat post-bronch/PEEP etc
ABG	>300mmHg	>250mmHg repeat post-bronch/PEEP etc
General	no aspiration	
	no secretions	
	-ve gram stain	accept if PaO_2/CXR ok
	<20pk year Hx	<30pk year Hx
	DBD	DCD

Williams Sem Resp Med 2001

Westall Curr Resp Rep 2013

‘Ideal’ donor criteria are rarely met

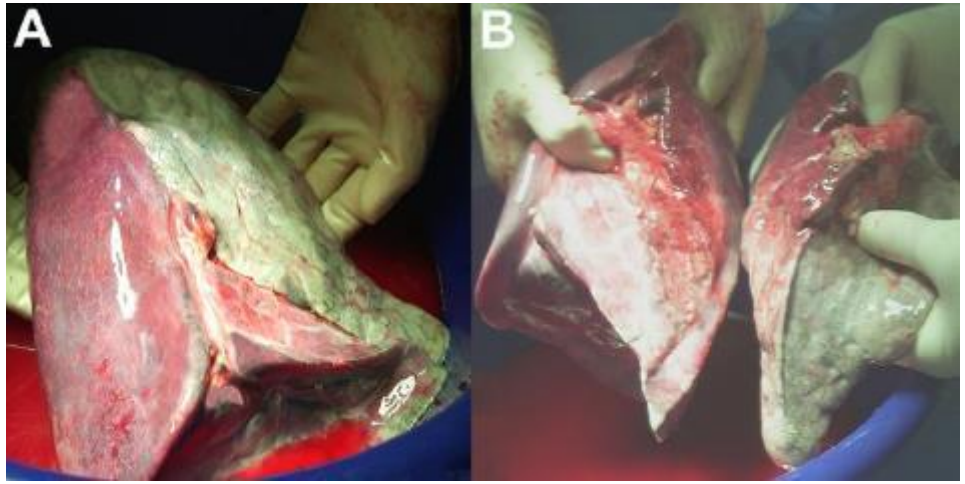
Age <55yrs	77/130 = 60%
CXR normal	42/130 = **33%**
ABG > 300mmHg	128/130 = 99%
No aspiration	72/130 = **59%**
No asthma	107/130 = 83%
Non-smoker	56/130 = **43%**
No secretions	11/130 = **9%**

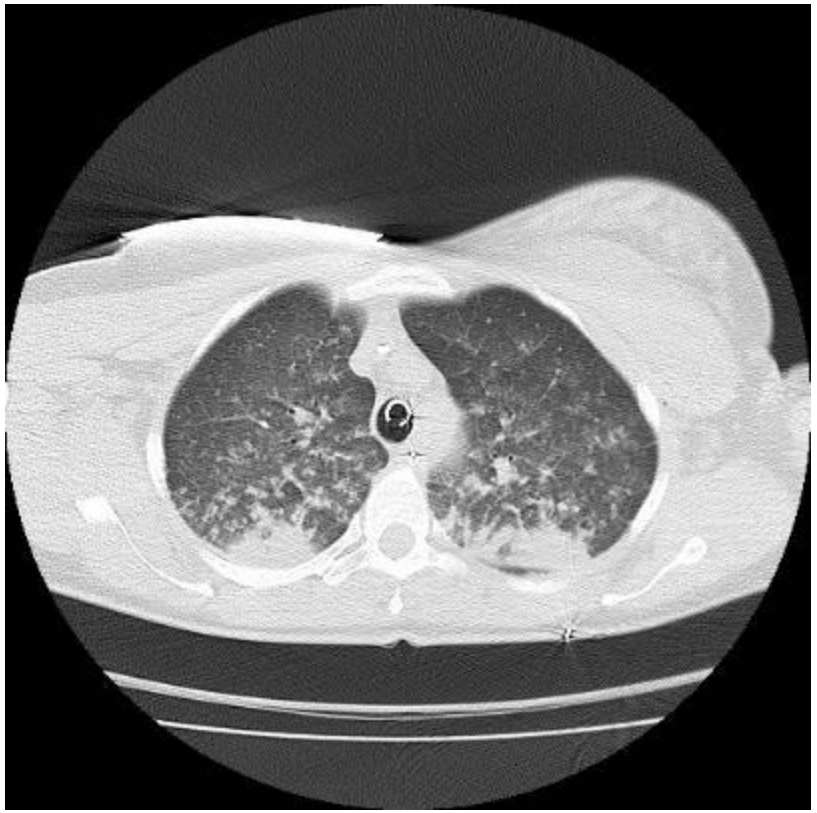
→ <5% of all donor offers ‘ideal’

→ <10% of all donors used ‘ideal’

Kotecha 2018

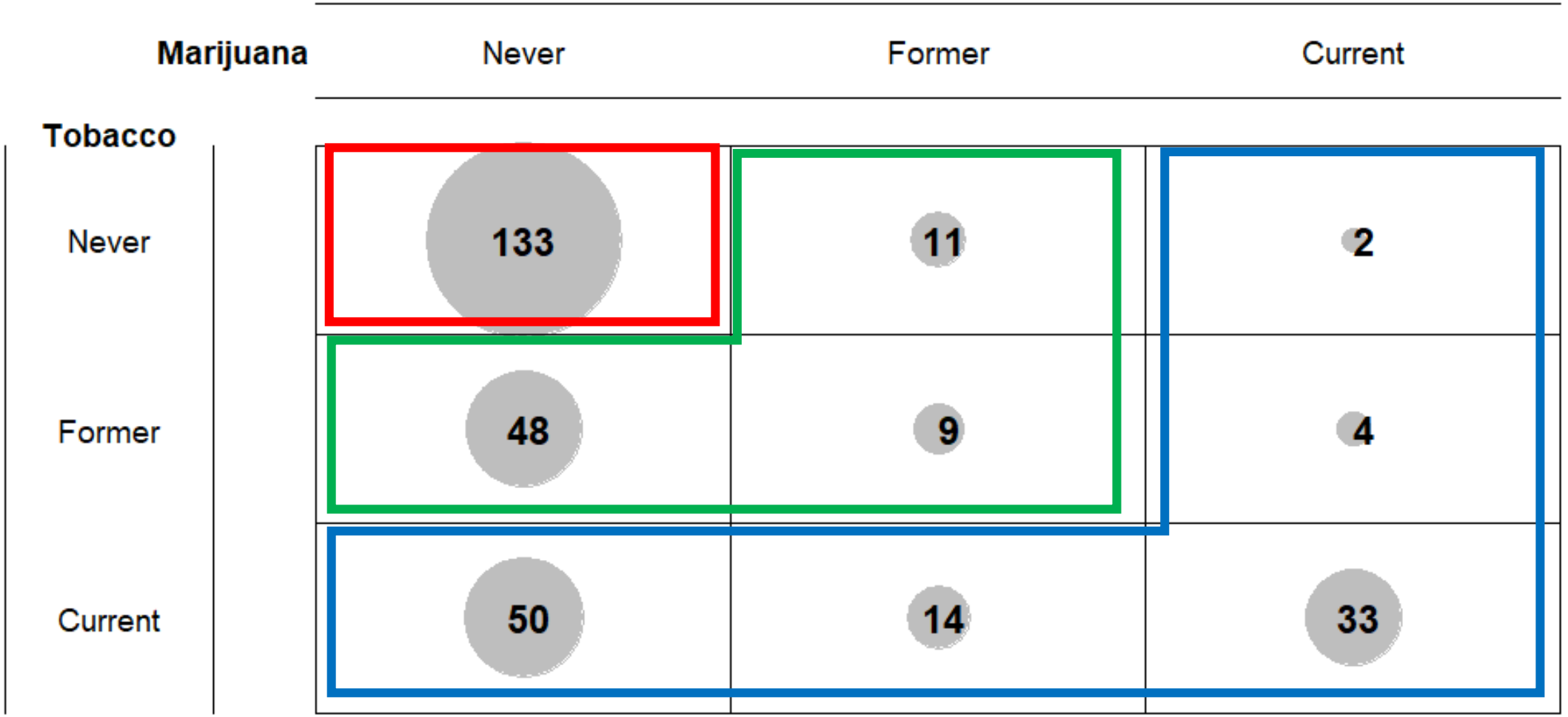
Lungs that worked





Donor smoking history (n=304)

Never smoker; 133
Former smoker; 68
Current smoker; 103



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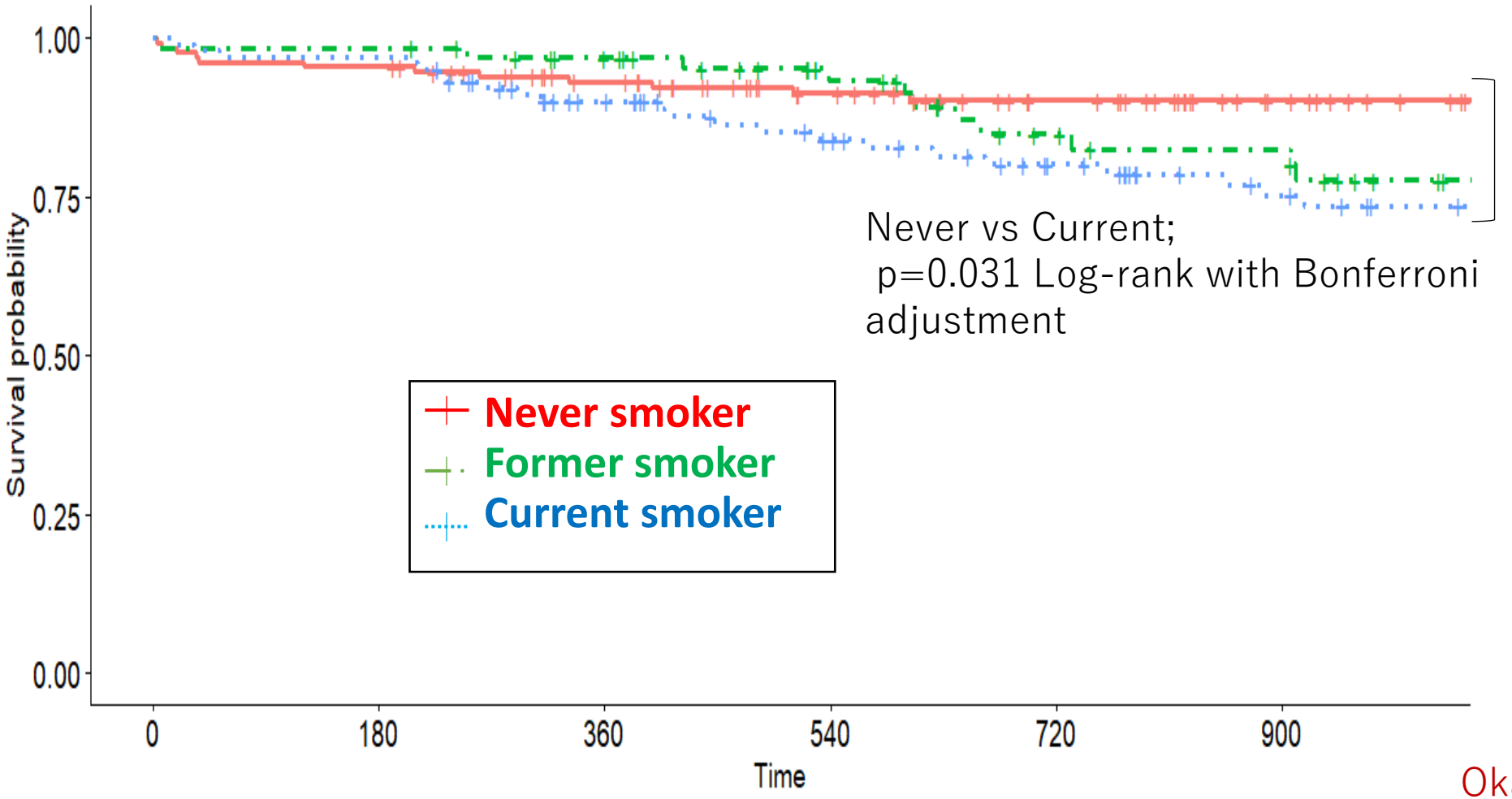
3-year LTx survival vs donor smoking history

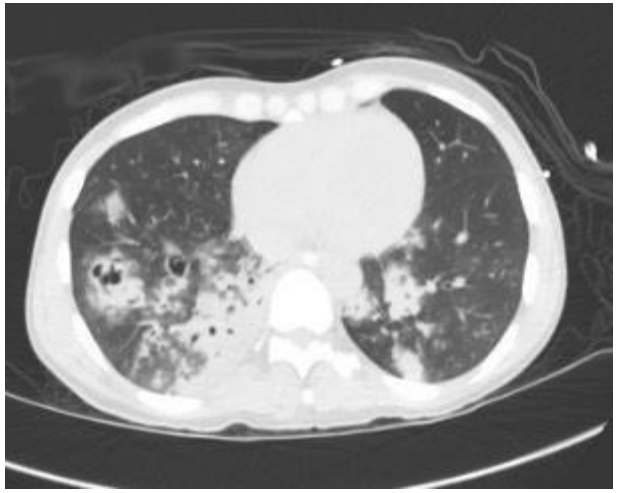


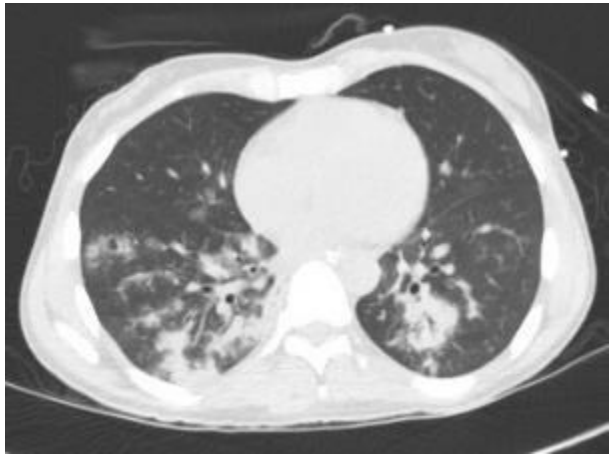
Okahara 2020

3) Alfred donor lung refusals

Lungs that wouldn't work!

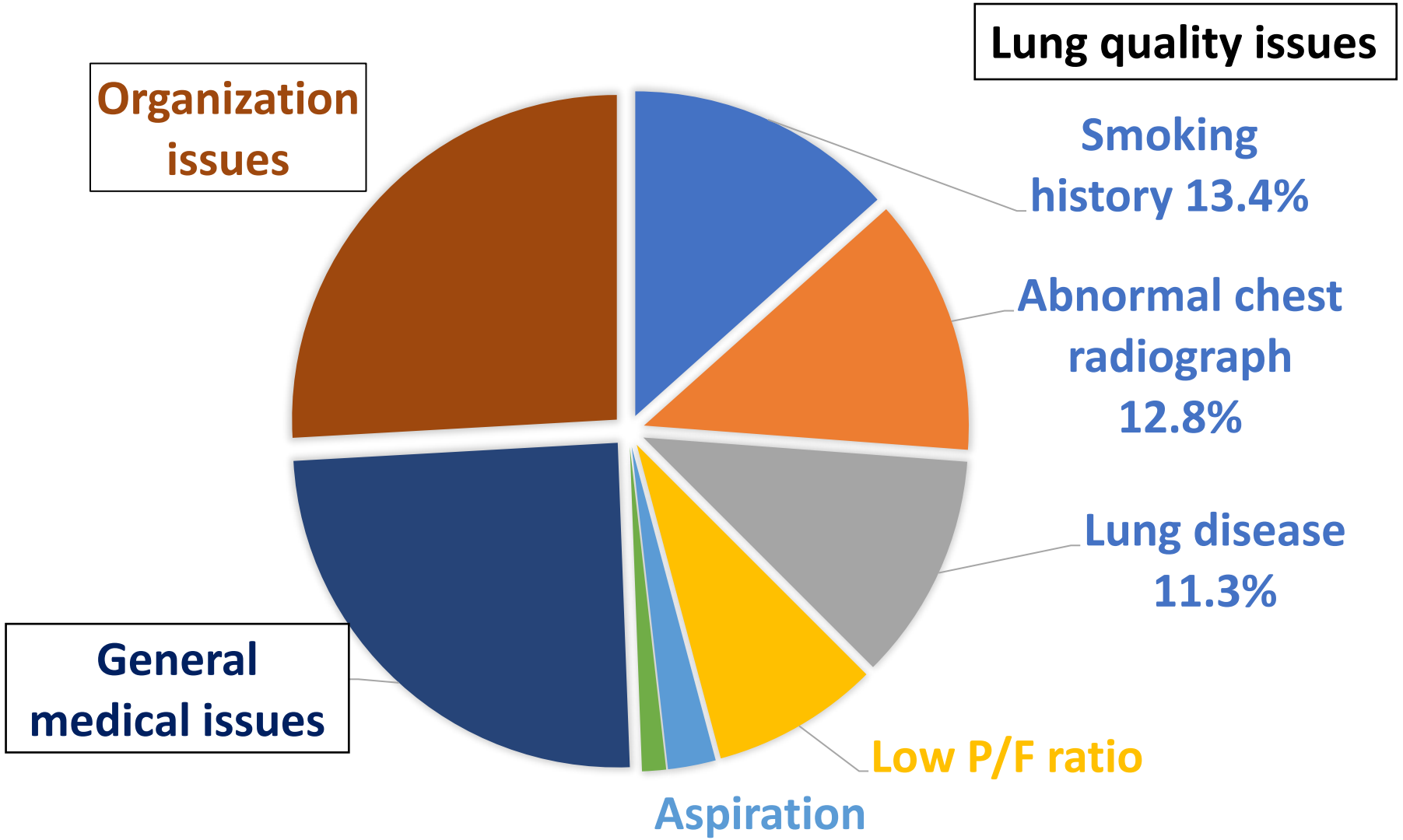
28 yr marijuana smoker



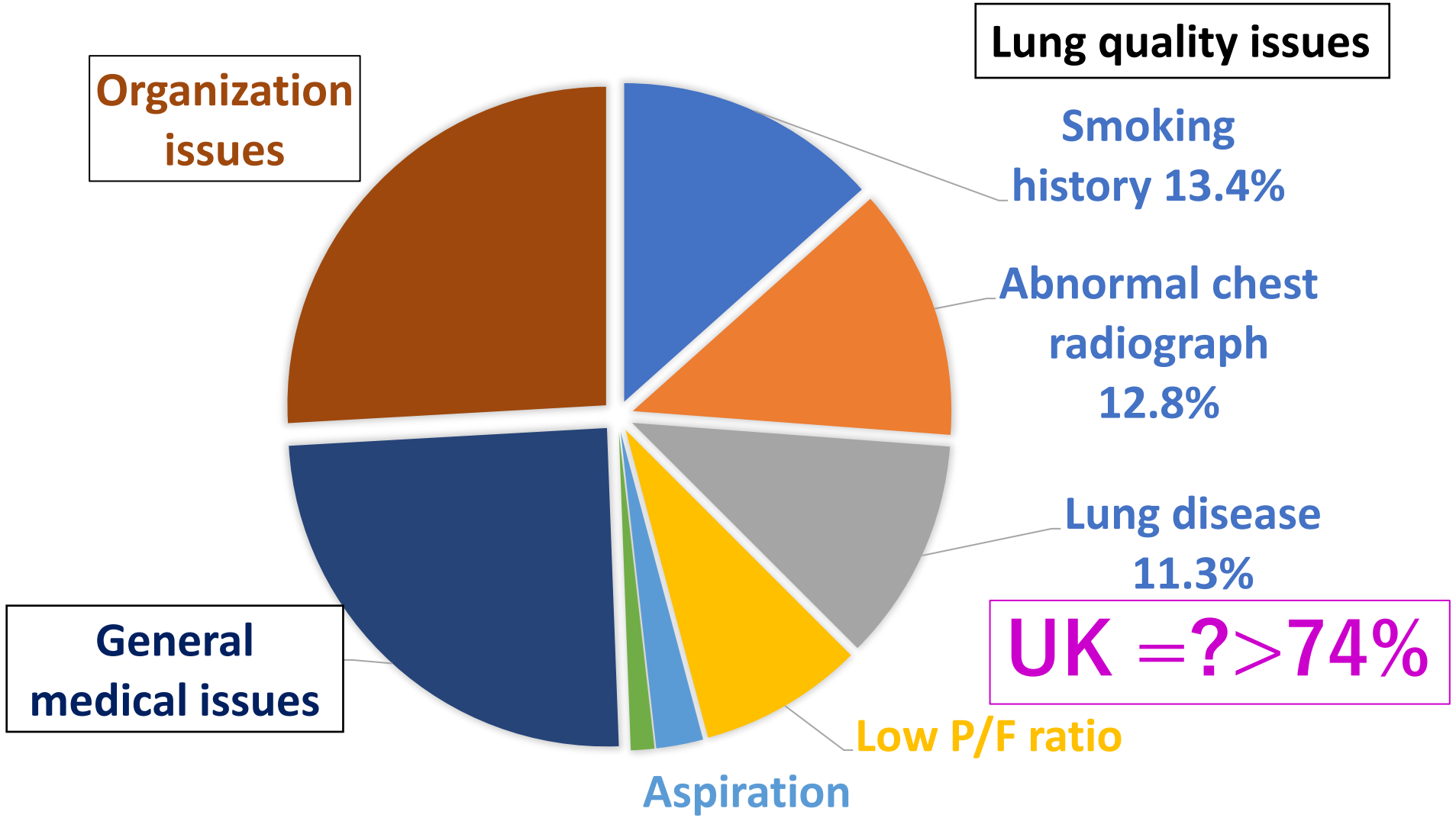


35 yr tobacco smoker

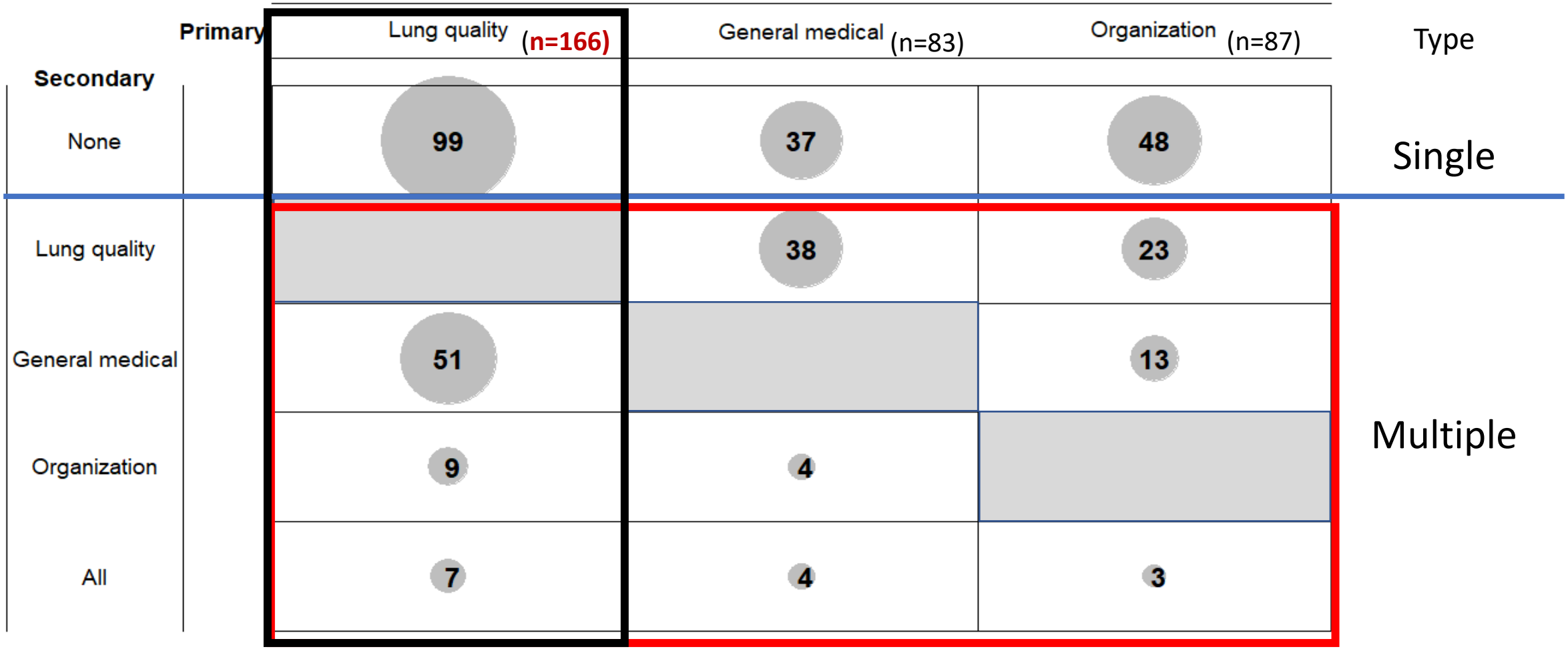
Primary reason for lung Tx donor lung refusal (n=376)



Primary reason for lung Tx donor lung refusal (n=376)



Refusals commonly have major comorbidities (n=336)



152 donors (45%) had ≥2 reasons for refusal

Okahara 2020

Declined lung donor refusal categories

Lung quality issues	General medical issues	Organization issues
Abnormal arterial blood gases (low P/F ratio)	Advanced age	Logistics (Operating room, Timing, Staff, Distance, Transport issues)
Abnormal chest imaging (X-ray/CT) including Pulmonary edema	Active infection (Pulmonary/Systemic)	ABO/X-match incompatible
Lung disease (COPD, IP, Pulmonary fibrosis etc)	High risk behaviour/drug use	Size incompatible
Aspiration	Hepatitis C	Withdraw of consent
Smoking history	Other disease (pulmonary embolism, ECMO)	
Other (including trauma with lung contusion)	Cancer	

Yellow box = ? fixable

Potential for EVLP assessment for refused donors

	Possible EVLP cases	EVLP Eligibility details (from trials) ~ 60% of our cases!							
		P/F ratio <300	Abnormal CXR	DCD	Age >55 years	Multiple transfusion	Aspiration	Extra assessment	Timing assistance
n=366									
Lung quality issue	**n = 52**	25	47	24	21	5	16	-	-
(Realistic)	**(16)**	(11)	(14)	(7)	(12)	(0)	(3)		
General medical issue	**n = 4**	1	1	1	3	1	0	3	-
Organization issue	**n = 10**	4	5	8	5	2	1	-	10

= 8-18% of refused donors could have been assessed with EVLP
= **4-9%** 'extra' transplants (50% conversion expected using EVLP)

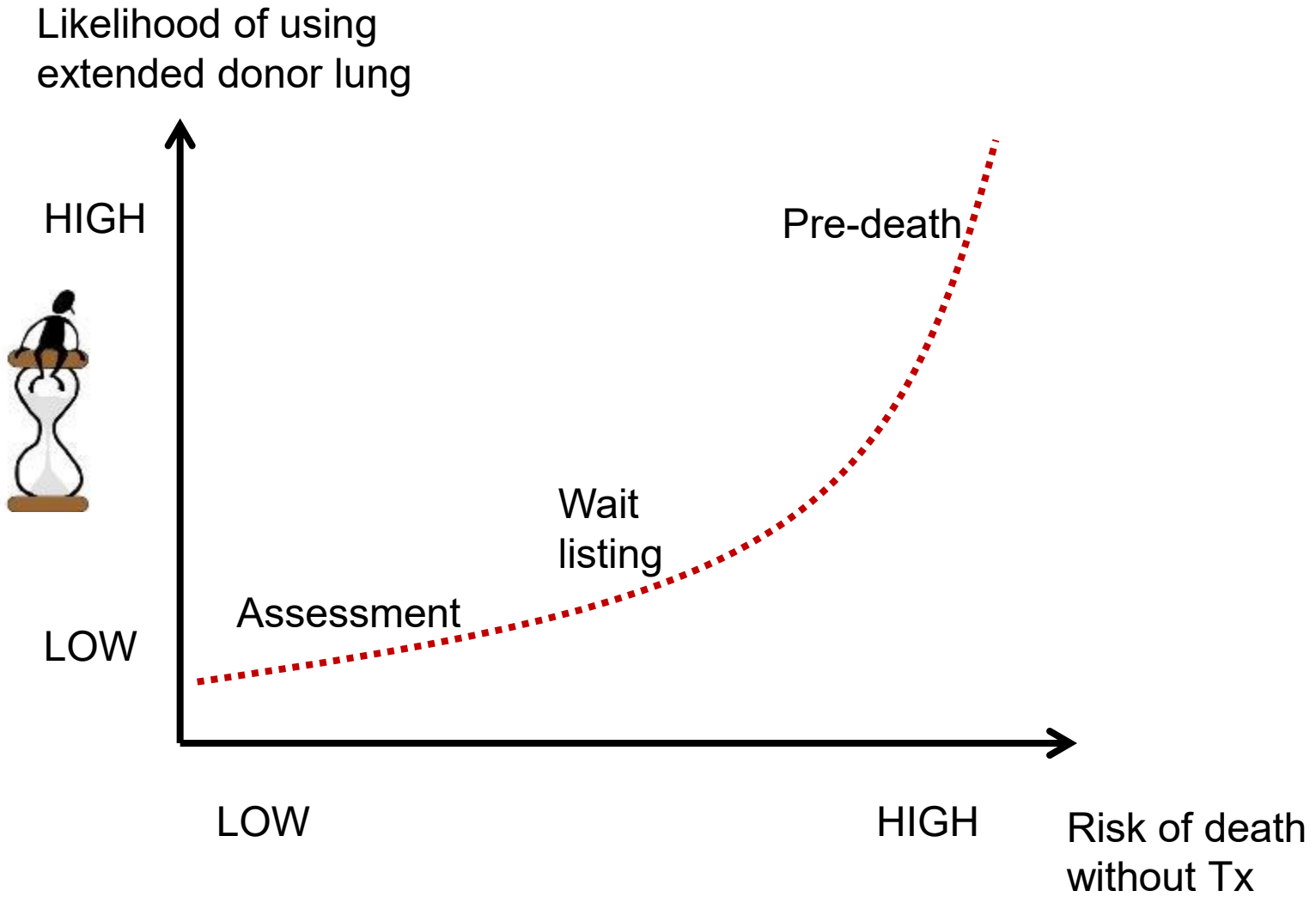
Okahara 2020

4) Donor lung suggestions & strategies

The ICU donation team & ‘extended’ donors

- ICU has a lung donor Mx Guideline
- Lung Tx Team Donor lung ‘Helpline’
- Not all potential donors (or recipients) are equal in terms of the Tx team :
  - Greater Tx team desperation for sick recipients
  - Size makes a bigger difference than for other organs
  - Blood Gp O, average height, will have lots of potential recipients
  - We do single lungs too!
- If the lungs might be improved & used then ‘extra’ work may help:
  - -Suction, bronchoscopy, fluid removal, proneing
  - -Serious antibiotics in 100% of lung donors
  - -Repeat ABGs & CXR
  - -CT chest
- Suggest regular debrief/followup between teams after donation to give +ve/-ve feedback

Tx teams ‘extended’ donor lung use strategy- what the Intensivist wont know



The Lung Tx Team & ‘extended’ donors (1)

- Lung Tx Team Donor lung ‘Helpline’ – best a physician
- Potential channel for Tx Physician feedback re: donor concerns/thoughts to Donation Team & Intensivist, (surgeon to sleep/operate)
- Assume donor lungs work, recipients are the problem! Think of resuscitating donors
- Never completely trust anyone on donor acceptability
- Know your Lung Tx waiting list
- Balance potential recipient & team needs via Tx Physician to Tx surgeon discussions ie use senior staff
- Tx Unit ICU 24/24 Intensivist in ICU
- Tx Unit culture of support for decisions
- Audit 100% of cases rejected

Suggestions to increase donor lung utilisation

- Communicate- lung ‘Helpline’ ie Tx physicians do more work
- Resuscitate lung(s)
- Accept bruising, aspiration story, asthma, Cigs <30pk years
- Accept imperfect numbers/features
- Consider very good/excellent donors up to 75 years
- Lung only organ donors are possible
- EVLP is not the answer
- Get senior staff involved
- Benchmark/Audit UK real reasons for not accepting lungs

5) Conclusion

Australian lung donor journey conclusion

- Working across a whole continent, we use arguably the world's highest proportion of donor lungs, but there are still lots out there…. (another talk!)
- As shown in the Australian donation system, communication & increased involvement of **physicians & intensivists** have the largest role to play
- Guidelines, audit, definitions & benchmarking are required

Acknowledgements:

Australian Government
Organ and Tissue Authority

donate life

ANZICS

MONASH University

Lungitude FOUNDATION

Special thanks: Dr Shuji Okahara, A/Prof Bronwyn Levvey

NHS
Blood and Transplant

Keynote Speakers:
Q&A

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A Patient Journey

Vicky Gerovasili
Dr Hannah Kilbride
Robert Burns
Steph Thomson
Dr Agimol Pradeep

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A Patient Journey: Introduction

Vicky Gerovasili

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A Patient Journey: Referring Physician Perspective

Dr Hannah Kilbride

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A Patient Journey: Patient Perspective "Who is really taking the risk?"

Robert Burns

Heart Transplant Patient
Cardiothoracic Transplant Patient Group Chair

Patient Perspective – Who is really taking the risk?

NHS Blood and Transplant

- What is risk?
  - “the possibility of something bad happening” (*Cambridge Dictionary*)
- Need heart transplant something bad has already happened
- Risk in this context is something even worse happening;
  - Risk mitigation – reduce chance
  - Reduce trauma

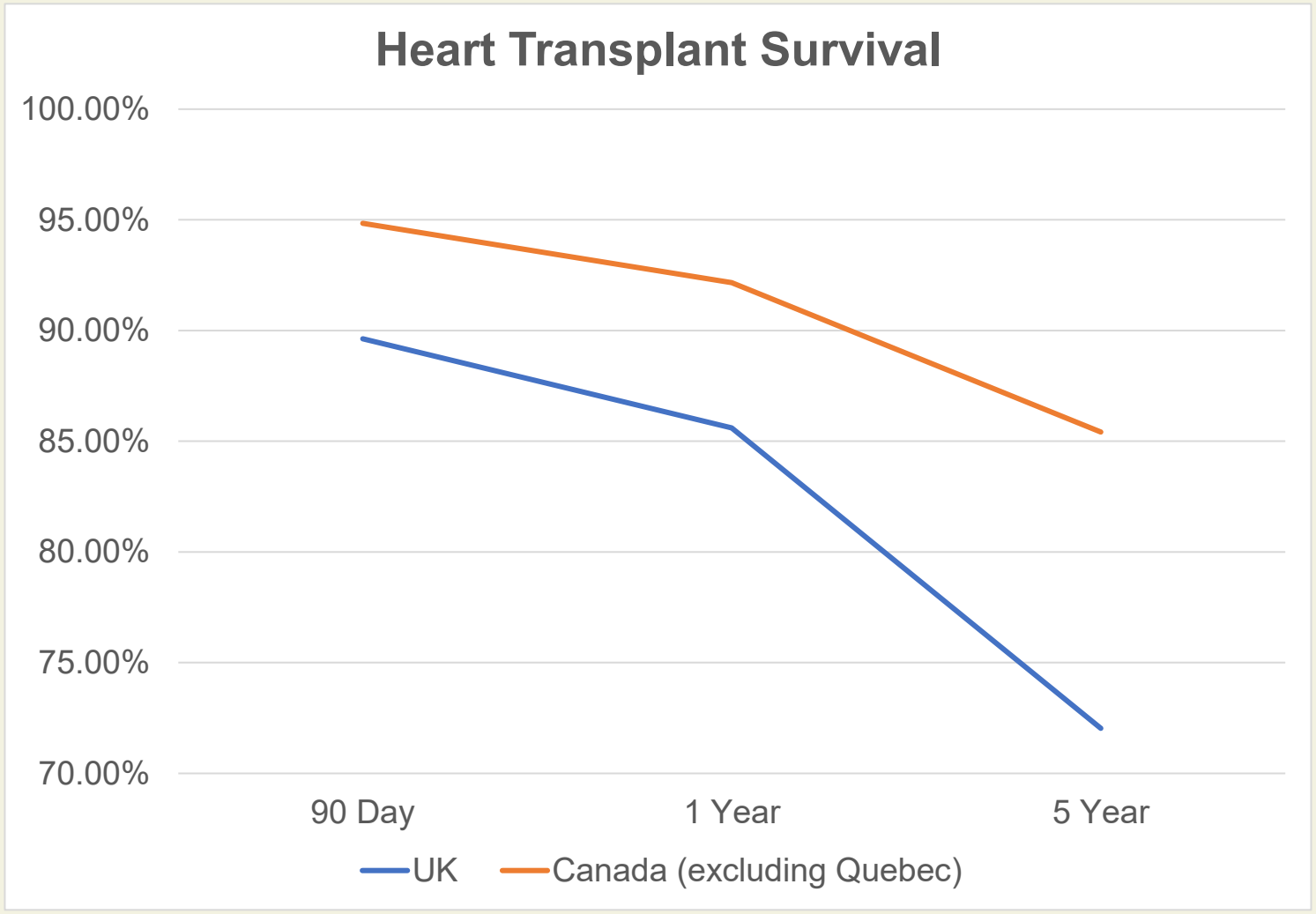
Improve Organ Utilisation

NHS Blood and Transplant

- What is utilisation?
  - “the act of using something in an effective way” (Cambridge Dictionary)
- Two fold;
  - Use - Increase donation to transplant %
  - Effective - Recipient to live a long and happy life

What is Survival Like?

NHS Blood and Transplant



What is Quality of Life Like?

NHS Blood and Transplant

- ➔Not currently measured
- ➔Anecdotally many transplant patients struggle (physically and mentally)

Factors influencing effectiveness?

NHS Blood and Transplant

- Acceptance criteria
- Transplant timing
  - Referral timing
  - Waiting time
- Patient optimisation
- Post transplant care
  - Hospital phase
  - Life long care

Factors influencing effectiveness?

NHS Blood and Transplant

- Acceptance criteria ✓
- Transplant timing
  - Referral timing ?
  - Waiting time X
- Patient optimisation X
- Post transplant care
  - Hospital phase ✓
  - Life long care X✓

Factors influencing effectiveness?

NHS Blood and Transplant

- Acceptance criteria ✓
- Transplant timing
  - Referral timing ?
  - **Waiting time X**
- **Patient optimisation X**
- Post transplant care
  - Hospital phase ✓
  - Life long care X✓

UK Heart Transplants

NHS Blood and Transplant

- 163 Heart transplants 2020-21 (4.8% SOT)
- 80% Heart transplants from urgent / super urgent list
- Pathway urgent / super urgent patients
  - Wait in hospital, frequently months even years, by 1 year 71% received a transplant
  - Completely life changing for whole family
- Routine Patients – by end year 3 just 17% transplanted from routine list

Experience waiting for urgent heart transplant

NHS Blood and Transplant

- Typically 20-30 patients all the time
- Isolation
- Institutionalisation
- Boredom
- Deconditioning
- Chronic sleep deprivation

What is the impact of this?

NHS Blood and Transplant

- Sub optimal for the transplant
  - Poor mental state
  - Exhausted
  - Family and financial challenges
  - Physically deconditioned

How do we optimise patients?

NHS Blood and Transplant

- Shorter waiting times
- Prehabilitation programs
- Appropriate inpatient environments
- Stimulation and family support

Summary / Key Messages

NHS Blood and Transplant

- Patients are in a high risk situation
  - Risk reductions
  - Support
- Improve Utilisation
  - Use – increase conversion from donation to transplant
  - Effective – Patient optimisation and excellent aftercare

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Blood and Transplant

A Patient Journey: Specialist Nurse for Organ Donation Perspective

Steph Thomson

Scotland Team – Paediatric Lead

NHS
Blood and Transplant

Things that impact Organ Utilisation

- Before Authorisation (consent)
- During formal Authorisation
- After Authorisation

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Blood and Transplant

Before Authorisation

- Timing of referral – earlier is better
- Is this hospital familiar with Donation?
- Access to the right people – medical/nursing, relatives
- Access to the right information – social, medical
- General donor pool – deteriorating health??

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Authorisation/consent formal discussion

- Timing – are the family ready for you to discuss donation?
- DBD/DNC – Has the patient been OR could they be tested?
- Should the family be offered DCD if DBD/DNC has been confirmed?
- Why might relatives be reluctant to agree to retrieval of specific organs/tissues?
- Asking the tricky questions

Procurator Fiscal/ Coroner

- May need guidance form Forensic Pathologist before agreeing to donation/ retrieval of specific organs

- Work ongoing within our organisation to help them understand things better from our perspective in the hope they will give consent/ impose fewer restrictions

Post Authorisation/consent

- Availability of services within donating hospital
  - Cardiac monitoring
  - Echocardiography – in and out-of-hours
  - Expertise of operator – trainee, consultant, technician
  - Ability to interpret and comprise a suitable report
  - Ability to transfer images to potential accepting centres
  - Availability of scout

Post Authorisation/consent

- Donor Optimisation
  - Knowledge base of SNOD
  - Ongoing project looking at improvement
  - Availability of transplant surgeon/RcPoCs for advice
  - Time – can ICU support this patient for longer?
  - Family – are the family comfortable with length of process being extended?

Post-Authorisation/consent

- Screening/Offering
  - Donor blood group – potentially offering to fewer potential recipients
  - BBV – more donors with BBV, offering to specific groups
  - Screening – donor may have screened in but then organs are not accepted when offered.

Post Authorisation/consent

- Acceptance by transplant centres
  - Multiple offers
  - May already have ongoing surgery
  - Location – distance between donating/receiving centre
  - Logistics – timings, weather, availability of transport

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Theatre

- Availability of space and personnel
- ? Night-time retrieval
- Intra-operative and backbench findings
- Availability of Histopathology – in/out-of-hours
- Late declines and fast-track

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Conclusion

- Lots of challenges for the SNOD at each stage throughout the donation process
- Always keen to try our best to achieve a good outcome for both donor family and recipients
- Projects ongoing to support us to improve as we move forward

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Blood and Transplant

NHS
Blood and Transplant

A Patient Journey: Recipient Coordinator Perspective

Dr Agimol Pradeep BEM

Transplant Recipient Co-Ordinator
King's College Hospital, London

NHS
Blood and Transplant

Role of Transplant Recipient Coordinator

To **support and guide the recipient through their transplant pathway**

Begins when a patient is referred for consideration of an organ transplant

Follows the recipient though the whole process into long term post transplant follow up care

Caring Expert Quality

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Blood and Transplant

There are over 250 Recipient Transplant Co-ordinators in the UK

Based at 27 transplanting units

Caring Expert Quality

Role of a Recipient Coordinator

- Screen referrals and discuss with Consultants and decide assessment pathway
- First telephone contact with the patient
- Gathering information for patient's assessment
- Organising the transplant assessment
- Talking to and educating the patient and their family about transplantation

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When I talk with the patient key points to remember are:

1. Listen first for what he/she wants to tell
2. Be vigilant - identify for what he/she does NOT want to tell
3. Acknowledge what he/she cannot tell

Caring Expert Quality

Role of Transplant Recipient Coordinator

NHS Blood and Transplant

- Collating the results from assessment investigations and discuss in MDT
- Point of contact for the patient at all stages of the assessment
- Preparing the patient for listing
- Listing the patient on the transplant waiting list
- Monitoring the patient whilst listed
- Suspending the patient from the waiting list when necessary
- Co-ordinating the transplant operation

Role of Transplant Recipient Coordinator

NHS Blood and Transplant

- Post transplant education before discharge from the hospital
- Preparing the recipient and their family for discharge
- Telephone advice
- Monitoring the recipient in clinic post transplant
- Help with internal and national transplant Audits

Transplant Assessment

Psychosocial evaluation is one of the key part of our assessment

- Support
- Financial support / housing
- Compliance with medications and hospital appts
- Knowledge deficits
- Anxiety / depression or mental health concerns
- Substance abuse

On call Commitment

NHS Blood and Transplant

Point of contact	Donor offers	Communicate	Patient Contact
Point of contact for NHSBT Hub, SNOD's, MDT members, patients and family	Screen through potential donor offers and discuss with Consultant on call and relevant members of the team	Communicate with NHSBT Hub and SNOD regarding decision.	Contact Patient and notify regarding a potential offer

On call Commitment

NHS Blood and Transplant

Organise transport for patient and organ

Organise admission including ward and ITU bed

Organise pre transplant admission, investigations and review

Organise any special treatment if required prior to transplant

On call Commitment

NHS Blood and Transplant

Communicate	Organise	Transfer	Communicate	Post Transplant
Communicate with SNOD and update Transplant Surgeon accordingly re; retrieval and timing	Organise Transplant Team and any necessary tests or investigations (example: donor organ biopsy)	Transfer patient to Theatre (most satisfying and rewarding part of our role)	Communicate with patients' family and act as point of contact during the surgery	Post transplant - update records and family

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Recipient Coordinator Role in Organ Utilisation

NHS Blood and Transplant

Patient advocates

Point of contact, rapport made with patient and families provide them confidence to notify us re; any concerns or worries. We make them feel valued.

Critical thinking skills and clinical knowledge:

Familiar with waiting list and able to navigate around according to the patient needs and donor characteristics. Knowledge on donor grafts and high risk donors, confident in counselling patients on the same

Access and networking with MDT members:

Expertise and confidence to reach out for help and guidance. Example: to discuss re; marginal or high risk donor offer

Caring Expert Quality

Recipient Coordinator Role in Organ Utilisation

NHS Blood and Transplant

Communication, Organisational and Interpersonal skills:

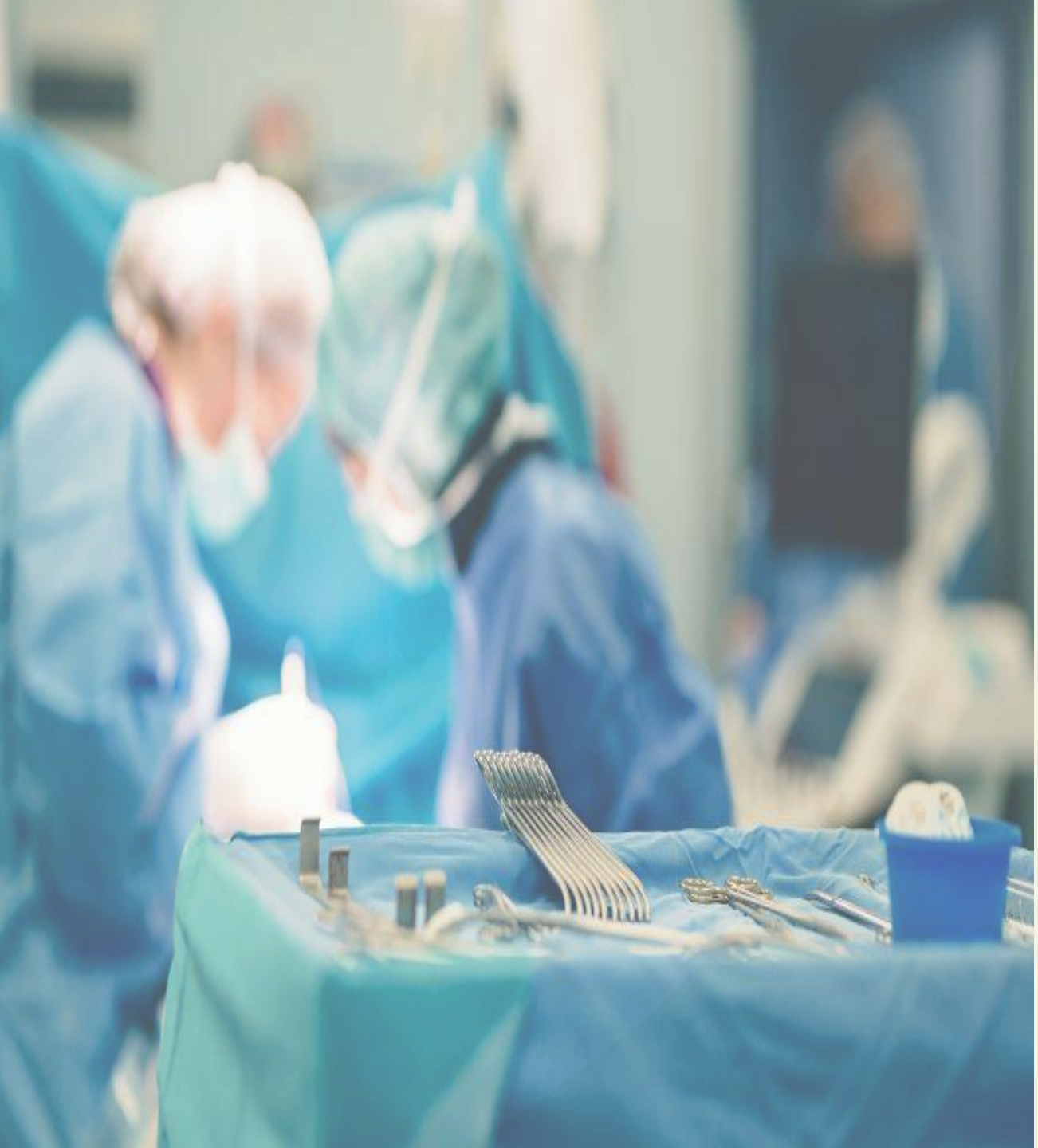
Example: Utilised an organ which was declined by all centres on history. On visualisation NORS surgeon felt differently & informed the transplant coordinator. Communicated same with on call Surgeon and co-ordinated from the patient aspect and organised transplant team in timely manner, and successfully transplanted the organ.

Leadership and Negotiation Skills:

Accountable for whole transplant process.
Often, have to lead conversation with SNOD's, other Transplant centres and MDT members with logistical issues to avoid; organ decline due to lack of resources & complex transplants happening during out of normal working hours.

Patient outcome is important:

Communicating donor characteristics with the care team.
Example CMV status, positive perfusion fluid result etc, which may impact recipient outcome.



Organ utilisation: *It's all about avoiding the patient missing that precious life saving opportunity*

Thank you for listening

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A Patient Journey:
Q&A

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Morning Break

11.35 – 11.45

Sessions will resume promptly at 11.45.

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Culture:
Organ Utilisation

Helen McManus
Lead for Education & Culture

Derek Manas
OTDT Medical Director NHSBT

Organ Lead CLUs

Caring Expert Quality

Rank the following priorities for the organ utilisation programme:

Aims today:

Case study

Promote discussions

Listen to cultural challenges

Recognise any cultural successes

Journey

NHS Blood and Transplant

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Culture

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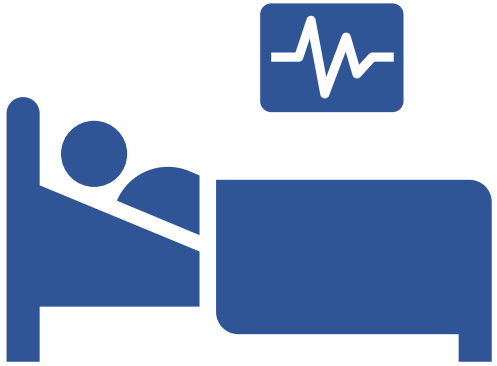
Blood and Transplant

"Culture is the way we do things around here. It is the norms, rituals, expected behaviours and unwritten rules within a work organisation"

"Culture is vital because it shapes our behaviour and values at work"

Professor Michael West Head of Thought Leadership, The King's Fund

Caring Expert Quality



NHS Blood and Transplant

Case study

48-year-old - Sub arachnoid haemorrhage

Consent for Donation after Circulatory Death (DCD)

Heart

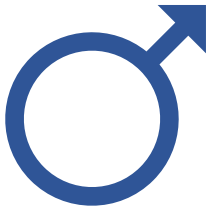
Lungs

Liver

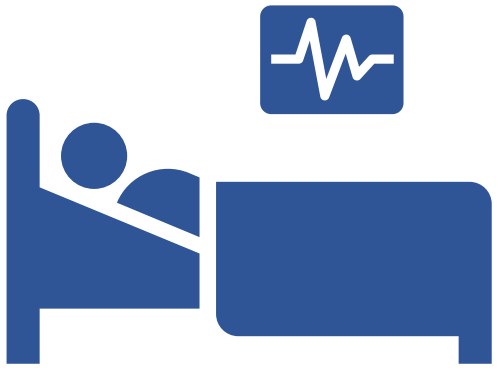
Kidneys

Pancreas

Eyes



Referral, assessment & consent



Case study

NHS Blood and Transplant

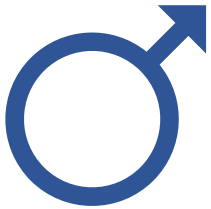
48-year-old - Sub arachnoid haemorrhage

Downtime 28 mins

Heart function - echo – ejection fraction 59%, normal LV function, good systolic function

Donor type – DCD

Ventilated – 48hrs

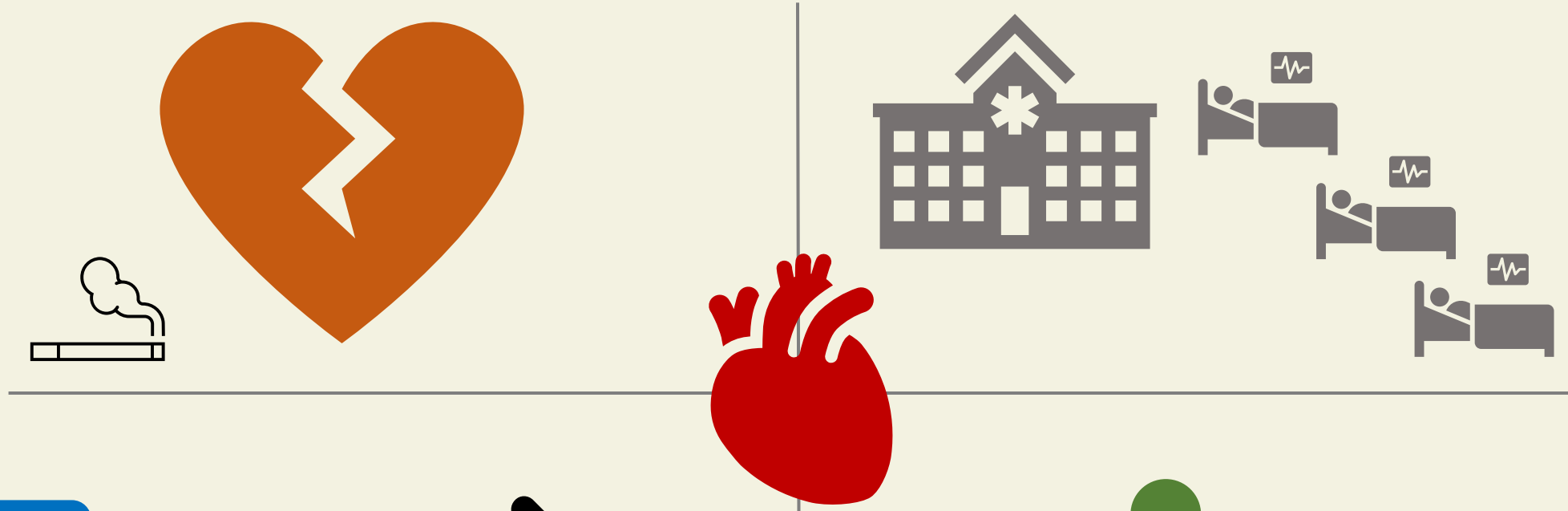


Offering & acceptance

Post donation

Mentimeter

NHS
Blood and Transplant



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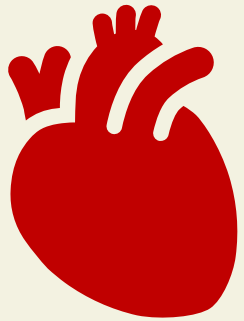
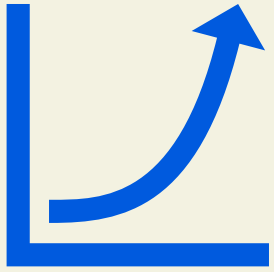
Caring Expert Quality



Culture

NHS
Blood and Transplant

Culture



NHS
Blood and Transplant

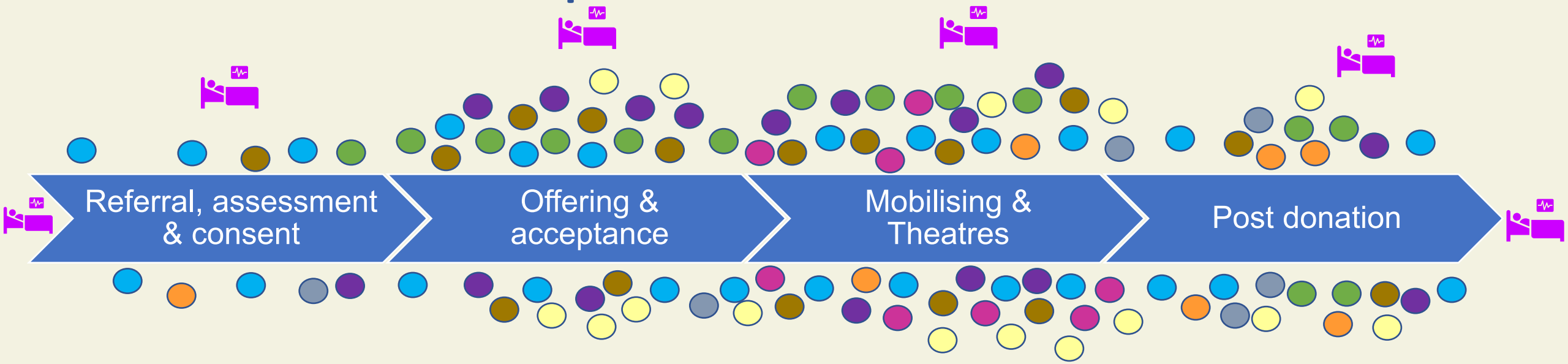
PaO2 at offering was 42kPa

Mentimeter

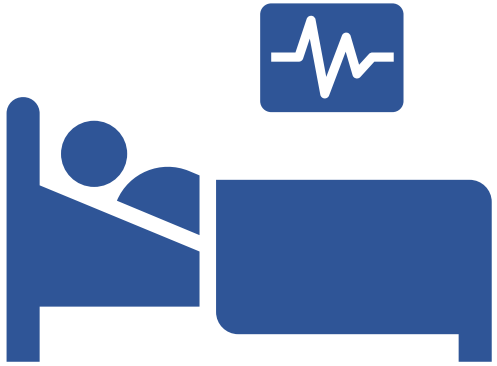
183 cm

The donation process

NHS Blood and Transplant



- NHSBT HUB
- CT RPOC
- Tissue & eye services (TES)
- Transplant surgeons/physicians
- Specialist nurses
- Abdominal RPOC
- Donor family care services
- NORS
- Recipients

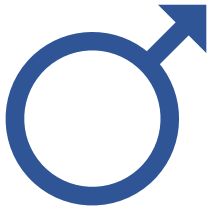


NHS Blood and Transplant

Case study

48-year-old - Sub arachnoid haemorrhage

2014 – episode of renal colic – CT showed normal bladder and kidneys, and 3mm calculi in L kidney

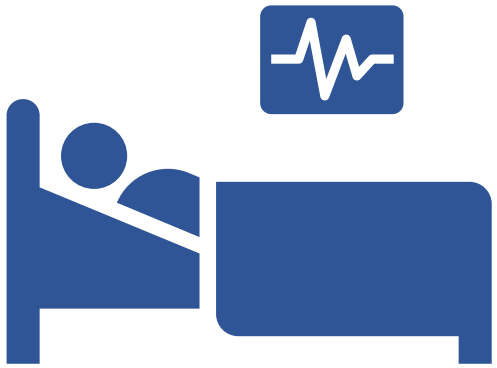


Offering & acceptance

Caring Expert Quality

Blood group B +

Mentimeter



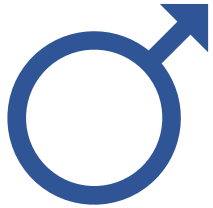
Case study

48-year-old - Sub arachnoid haemorrhage

Resuscitated - 28 minutes

Drinks a bottle of wine & 2 beers per night

BMI 26.2



Mobilising & Theatres

Post donation

NHS
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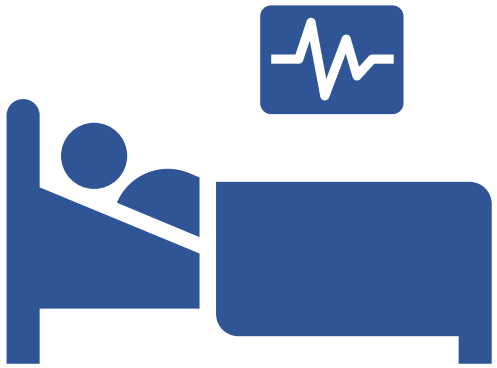
Mentimeter



NHS Blood and Transplant

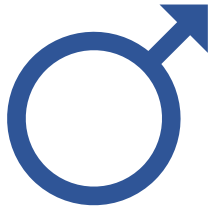
Case study

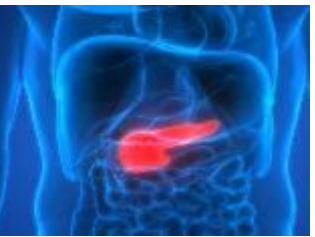
48-year-old - Sub arachnoid haemorrhage

Past medical history

No diabetes – but family history of type I & II diabetes

Donor type - DCD

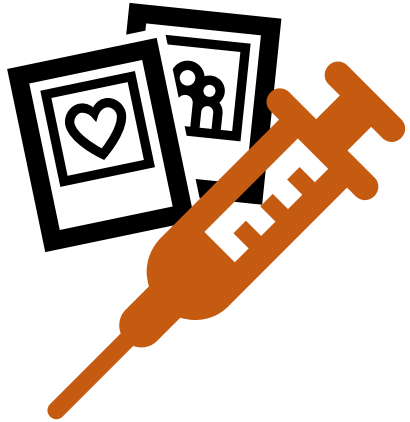


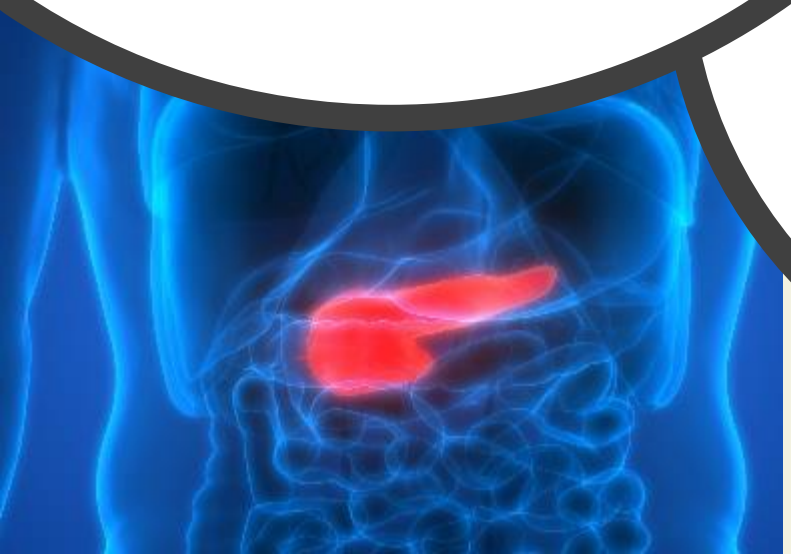


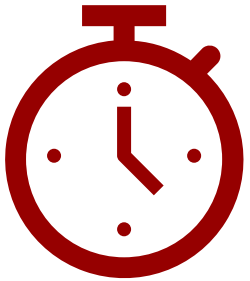
Offering & acceptance

Post donation

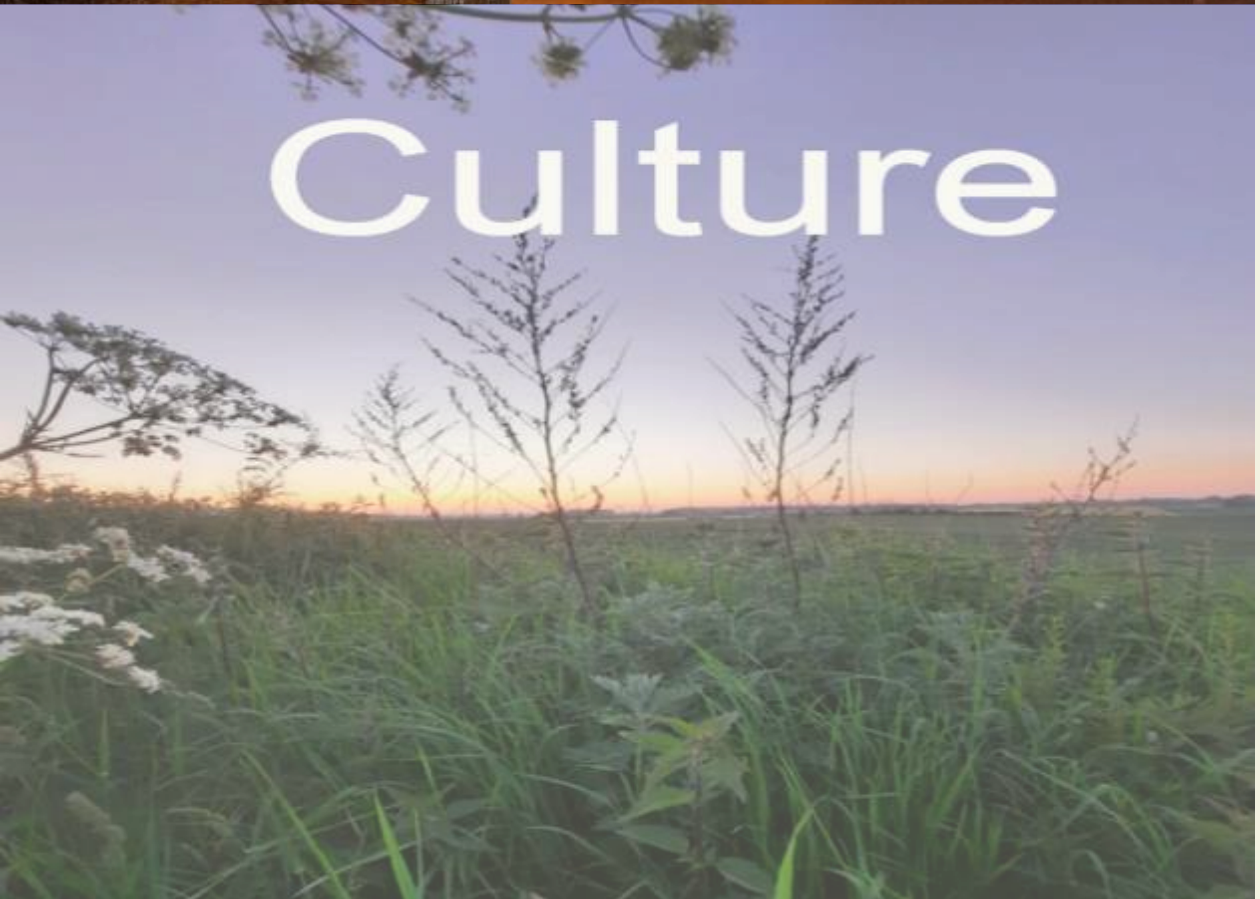
Mentimeter





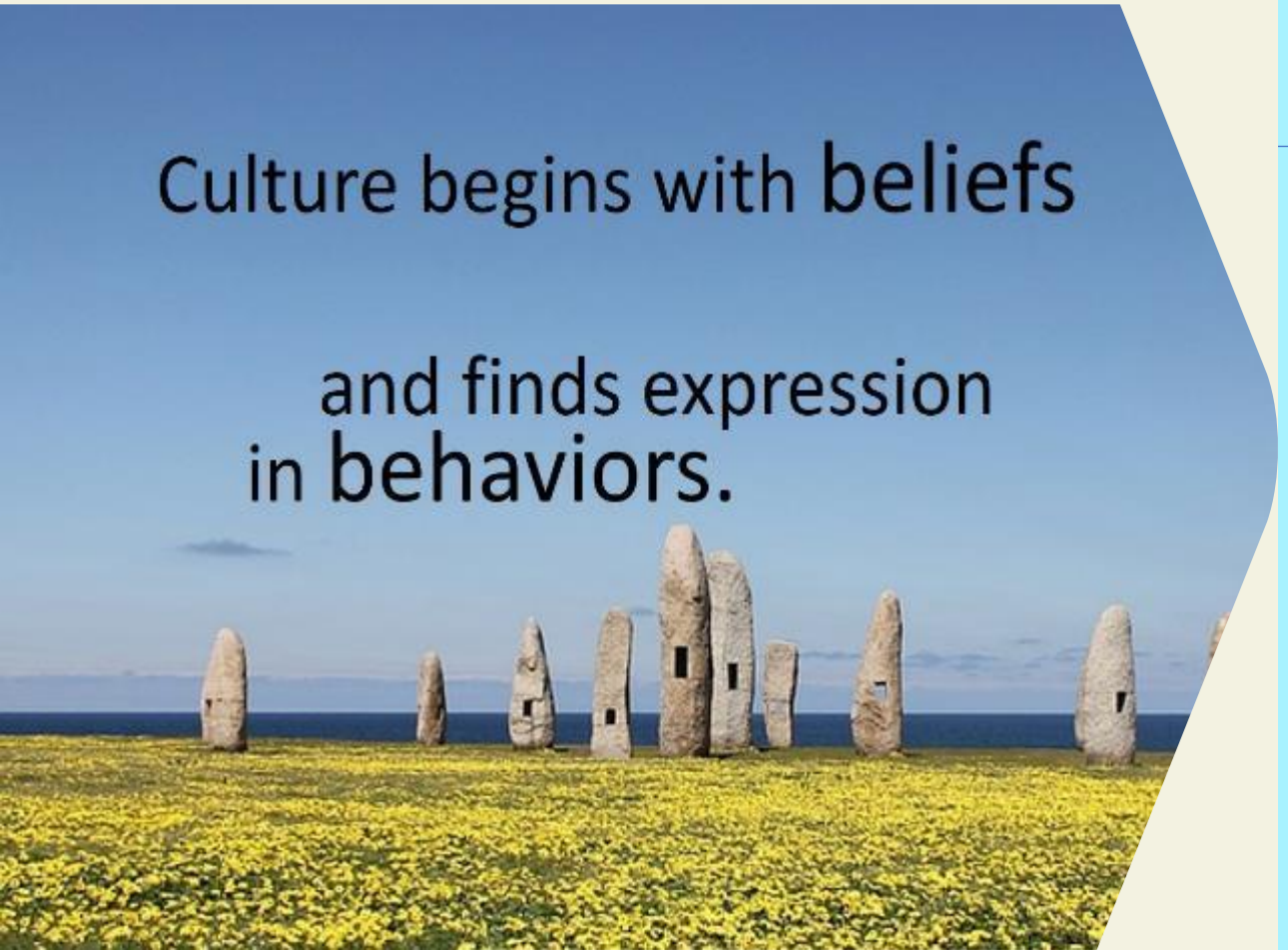


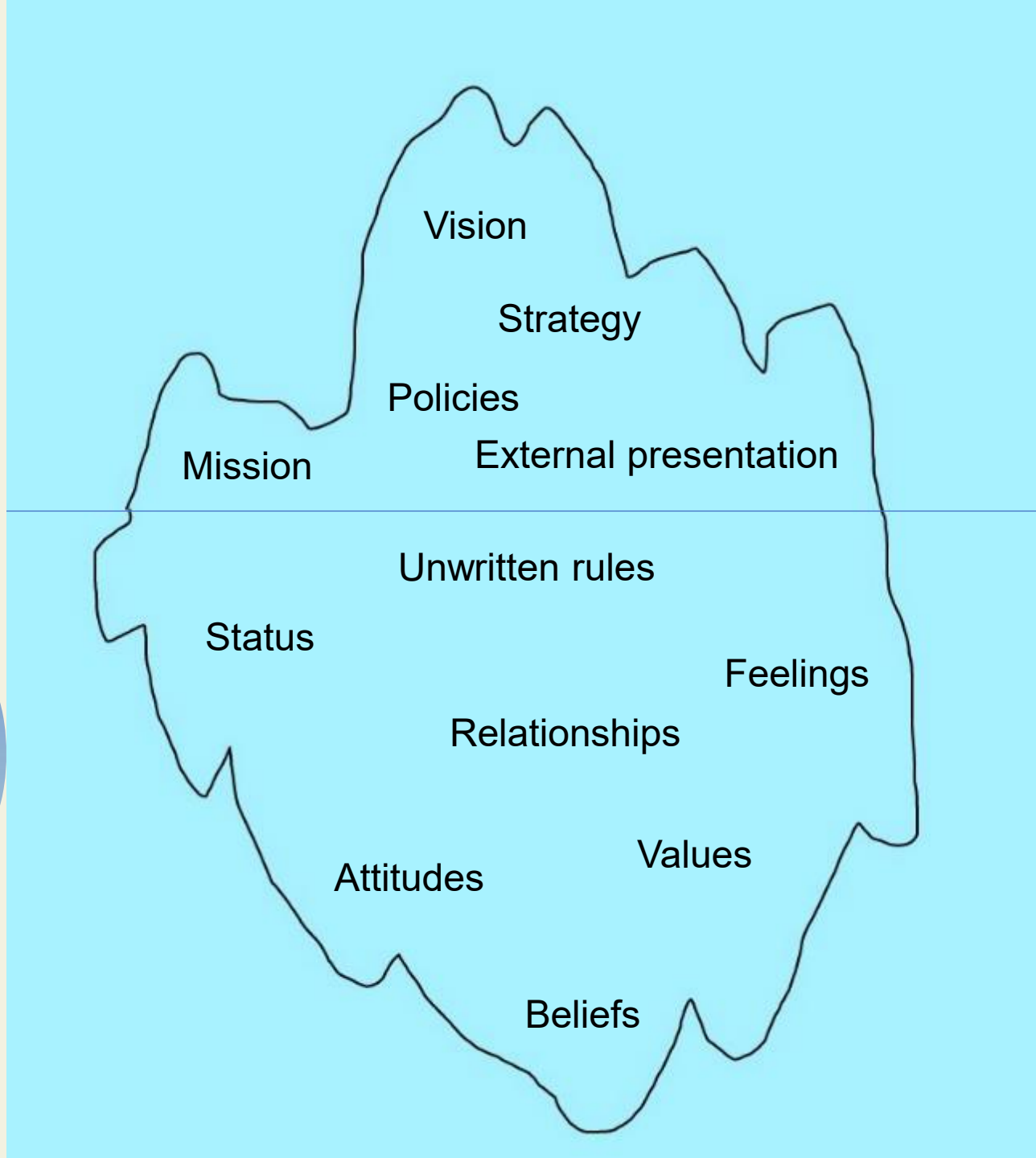

RESULTS


Culture


Vision and Values
Goals and Performance
Learning and Innovation
Support and Compassion
Equity and Inclusion
Team Work
Culture & Leadership

Culture - iceberg

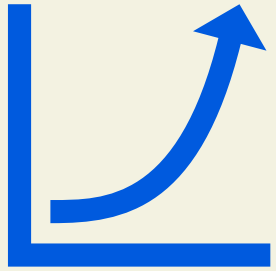


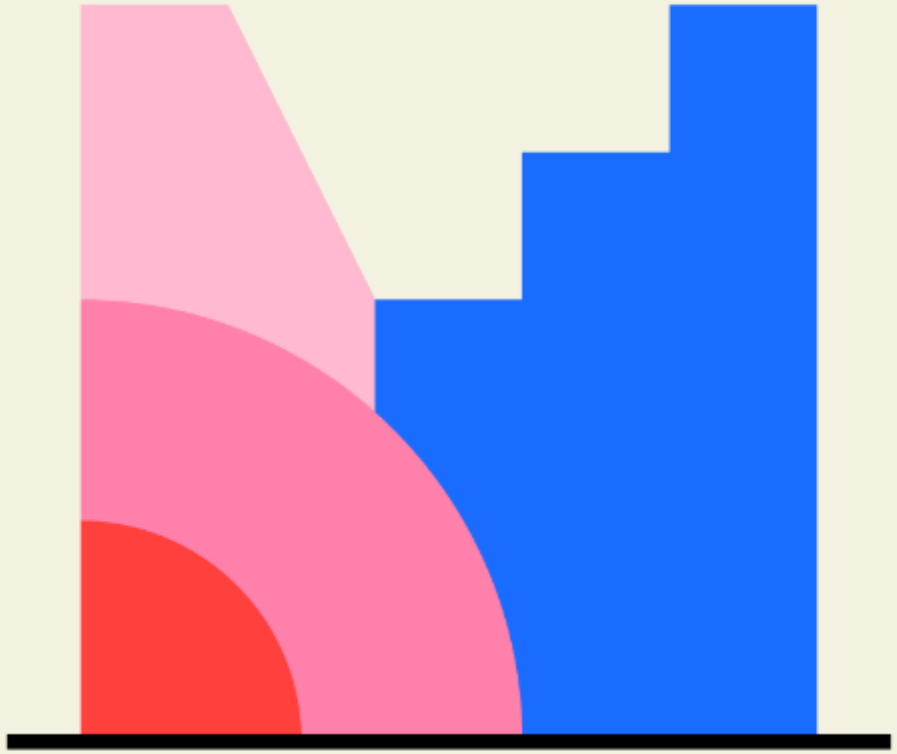


NHS
Blood and Transplant

Culture

Culture





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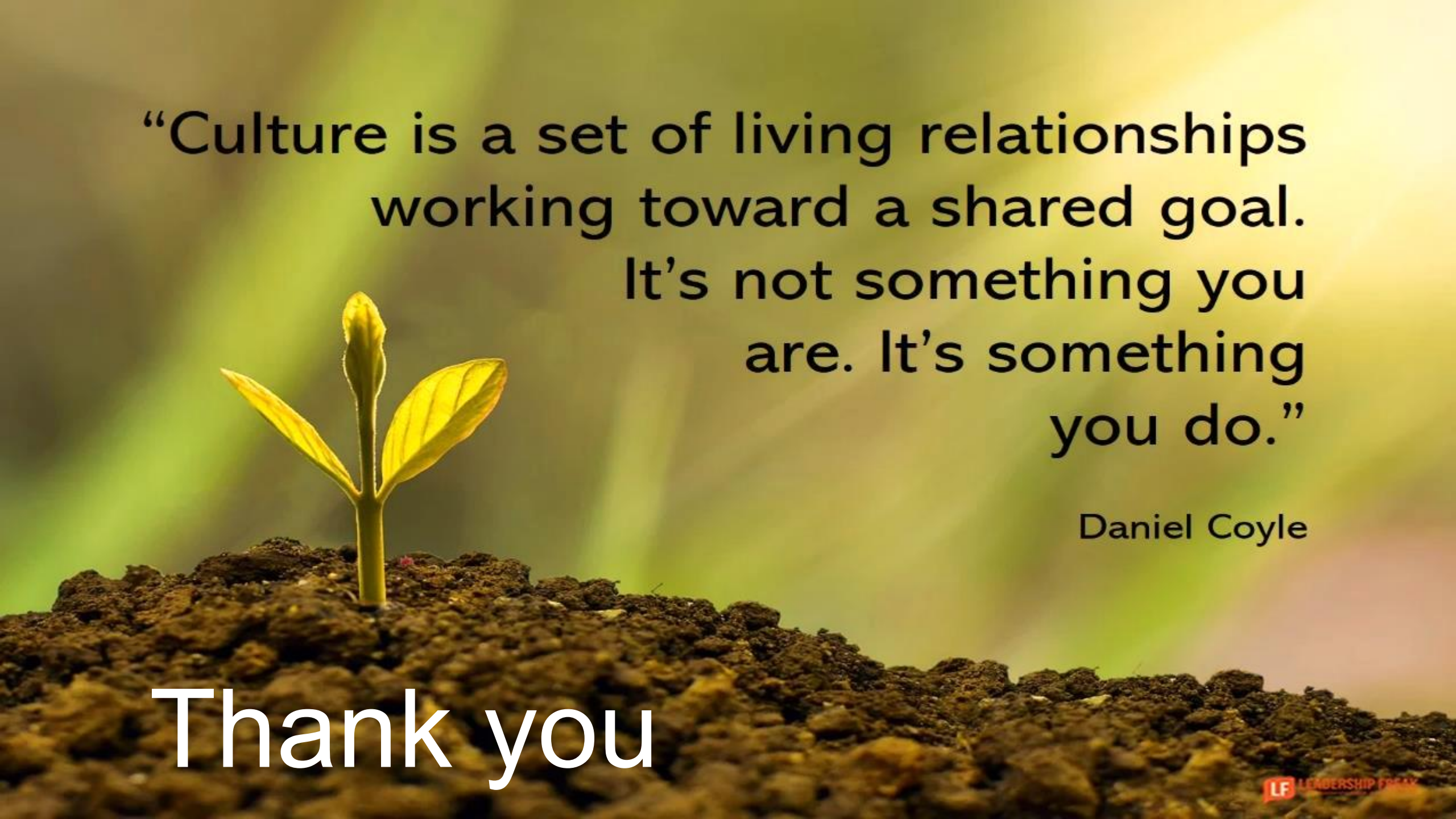

“Culture is a set of living relationships working toward a shared goal. It’s not something you are. It’s something you do.”
Daniel Coyle
Thank you

NHS
Blood and Transplant

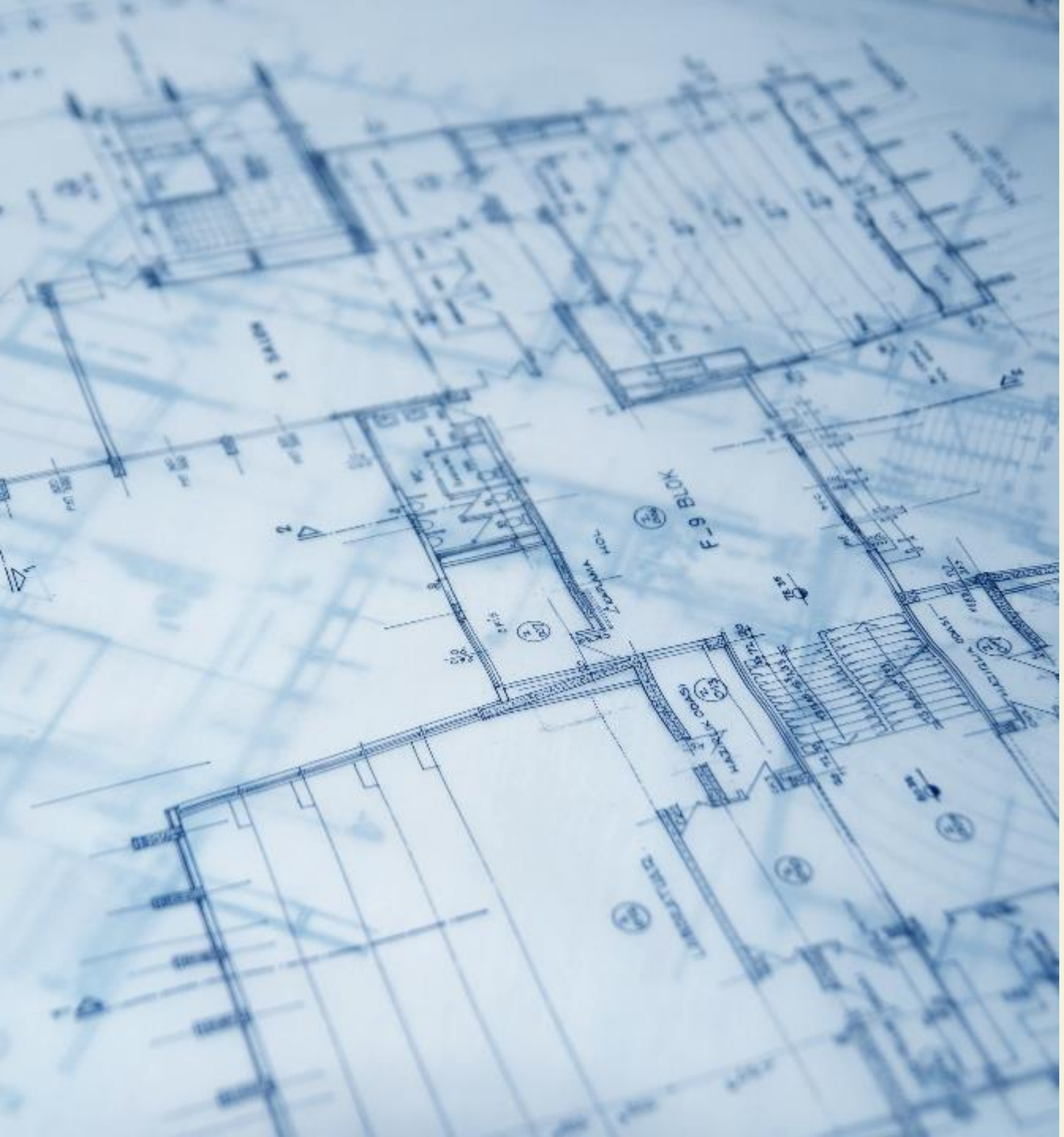
Lunch Break

Sessions will resume promptly at 13.25.

NHS
Blood and Transplant

Afternoon Session: Welcome & Introduction

Diana Garcia Saez



NHS
Blood and Transplant

Projects Showcase

Diana Garcia Saez

Richard Baker

Sue Madden

Liz Armstrong

Laura Ellis-Morgan

NHS
Blood and Transplant

Clinical Leads for Organ Utilisation (CLUs)

Diana Garcia Saez

Overview of CLU 2.0

NHS Blood and Transplant

Overall aims

1. Maintain momentum and enthusiasm from CLU 1.0 and the National OU Conference May 2021
2. Complete local and national projects from CLU 1.0
3. Ideas and perspectives for new local and national projects
4. Further engagement with R-CLODS and Trust/Board OD(T)C
5. Provide basis for successful business case for long-term funding (CLU 3.0)

Key changes from CLU 1.0

Five Organ Lead CLU appointed by the Organ Utilisation Programme in August 2021


Aaron Ranasinghe, B'ham

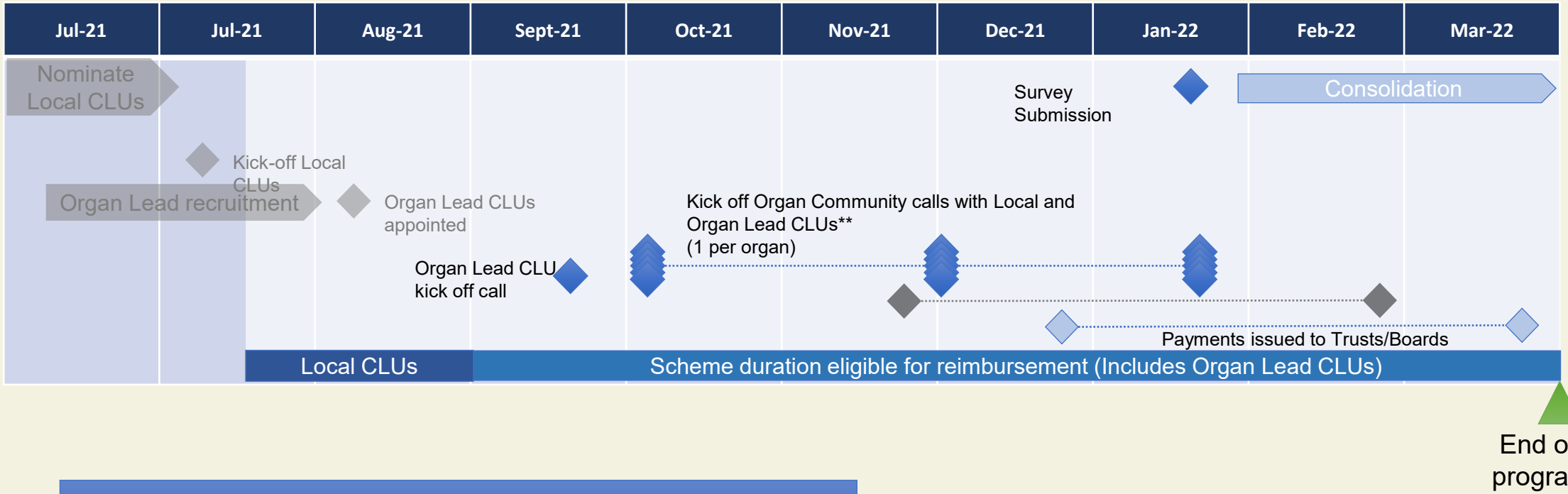

Vicki Gerovasili, Harefield


Raj Prasad, Leeds


David van Dellen, Manchester


Nick Inston, B'ham

NHS Blood and Transplant



Funding to continue during Q1 2022-2023.

Key

- NHSBT activity
- CLU activity
- Trust management activity

Kidney CLU scheme

Kidney units = 23

NHS Blood and Transplant

Figure 1 Number of kidneys from UK deceased donors offered, retrieved and transplanted, 5 February 2020 to 17 May 2022

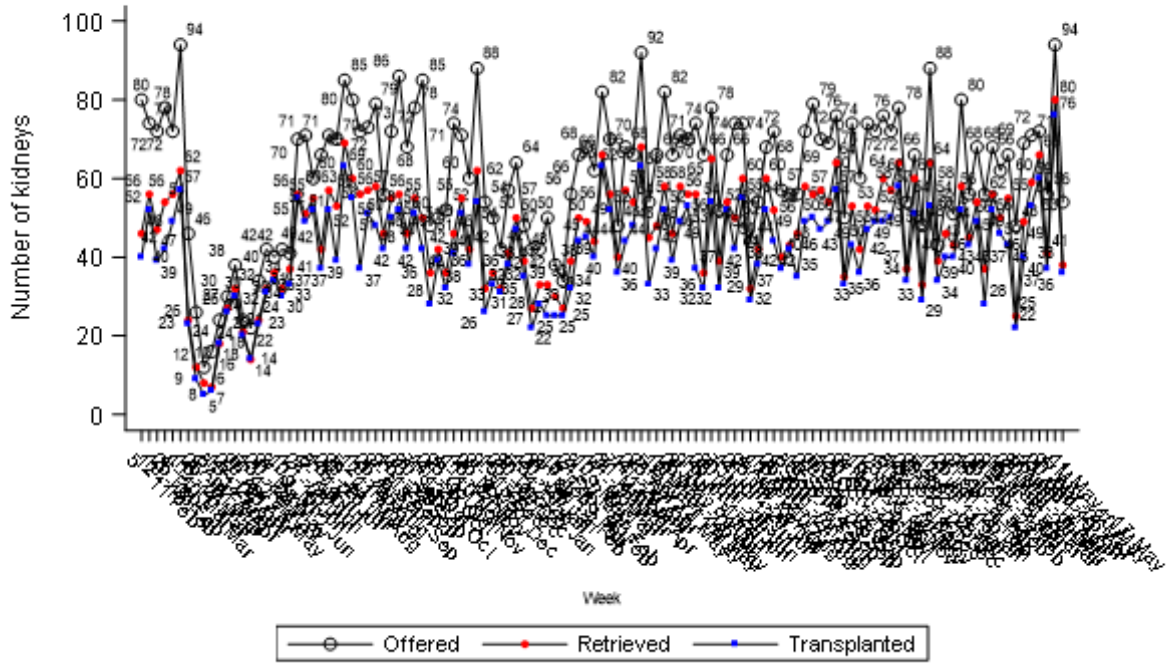
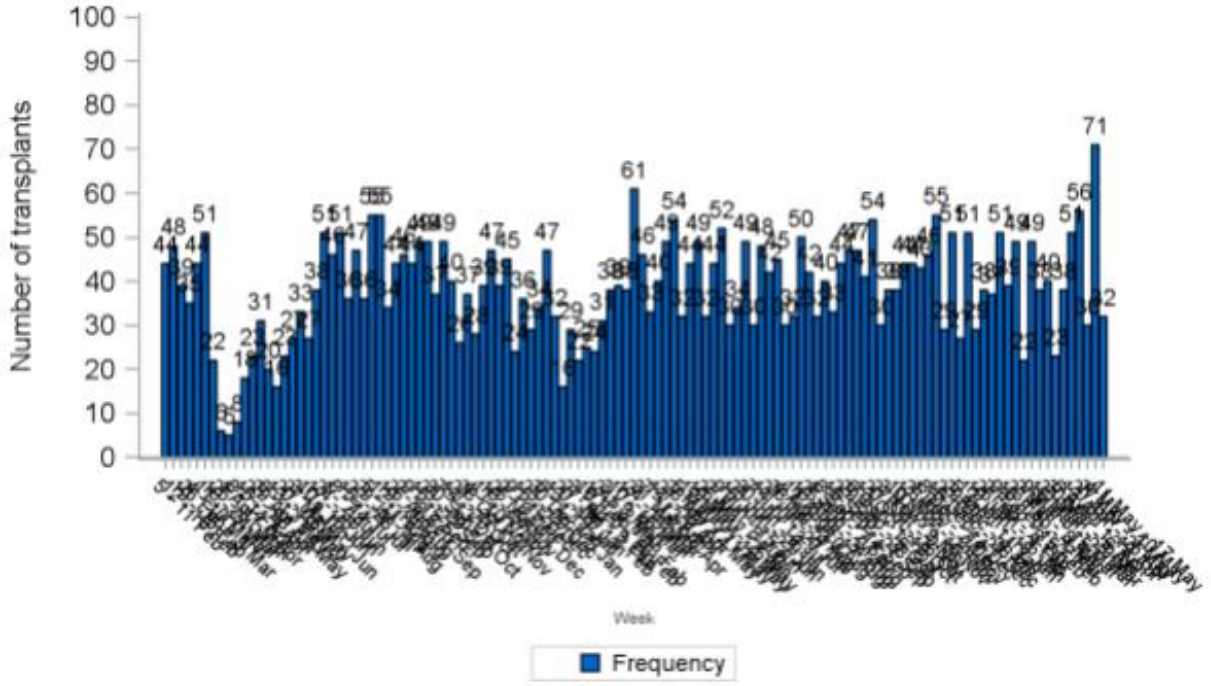


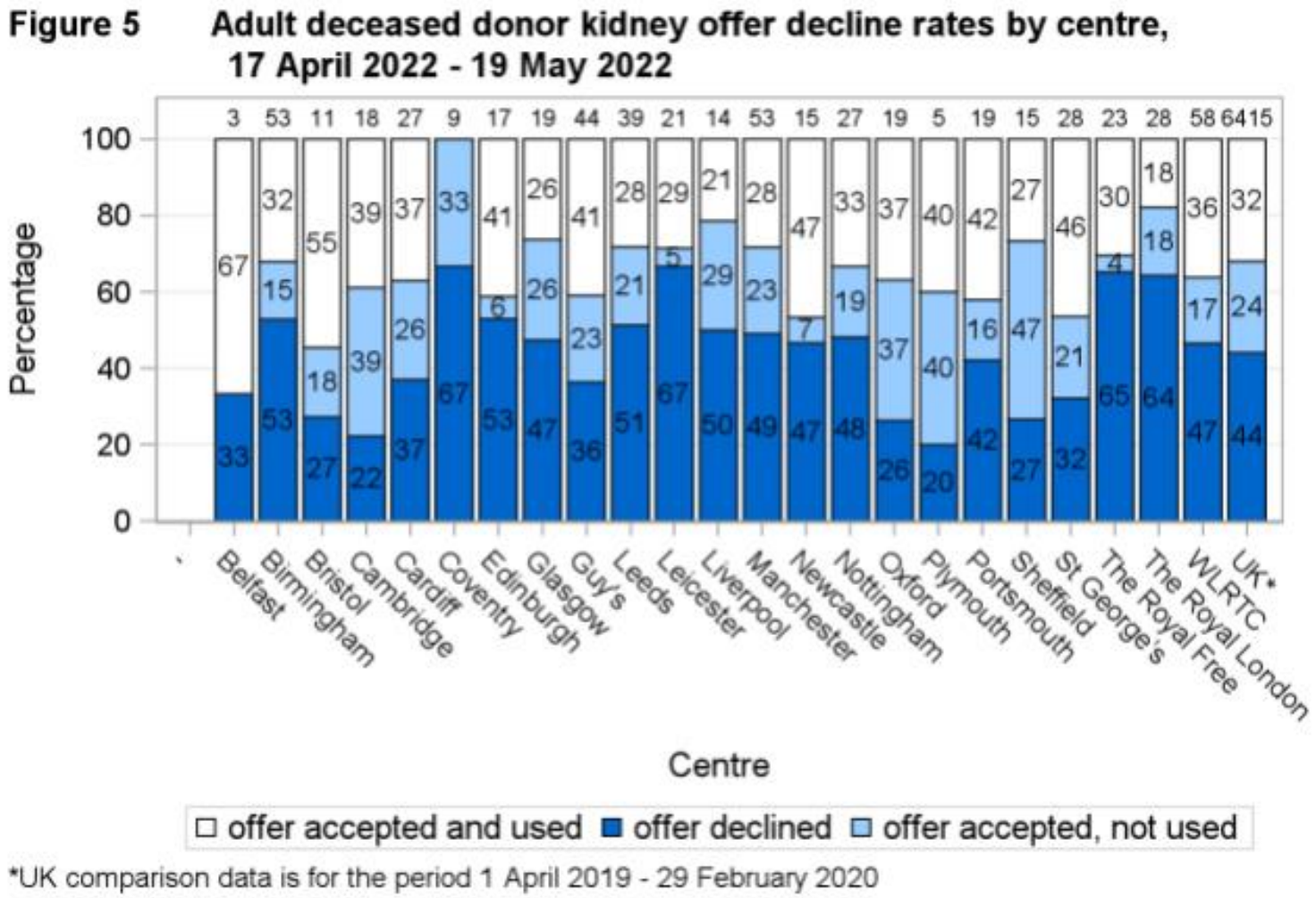
Figure 2 Number of deceased donor kidney transplants performed in the UK, 5 February 2020 to 17 May 2022



- From COVID to COVID recovery
- Offers back to where they were and transplant activity is up

Kidney CLU scheme

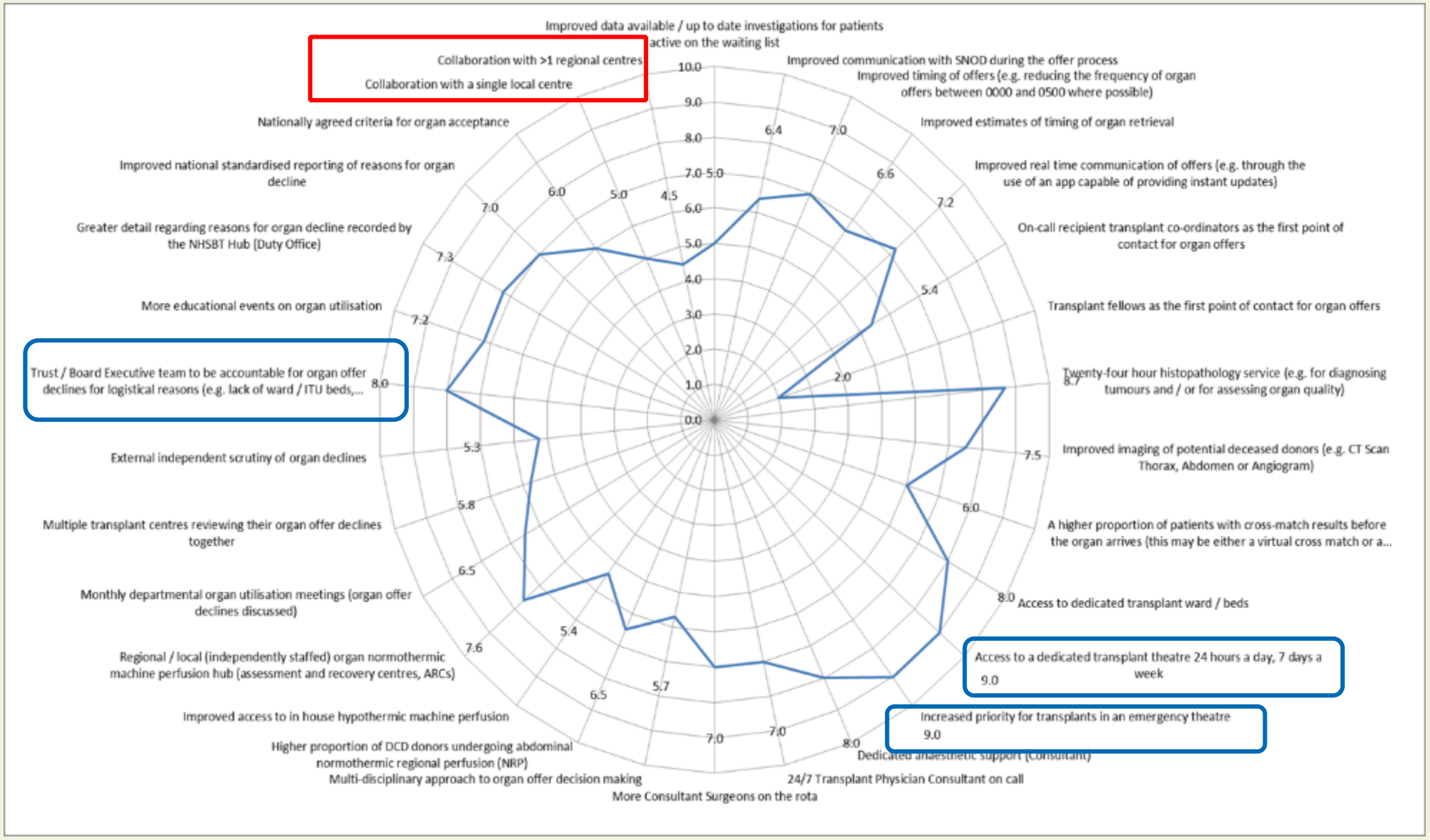
NHS Blood and Transplant



- But utilisation is still challenged

National survey on **Interventions for OU**

NHS Blood and Transplant



Kidney CLU scheme

NHS Blood and Transplant

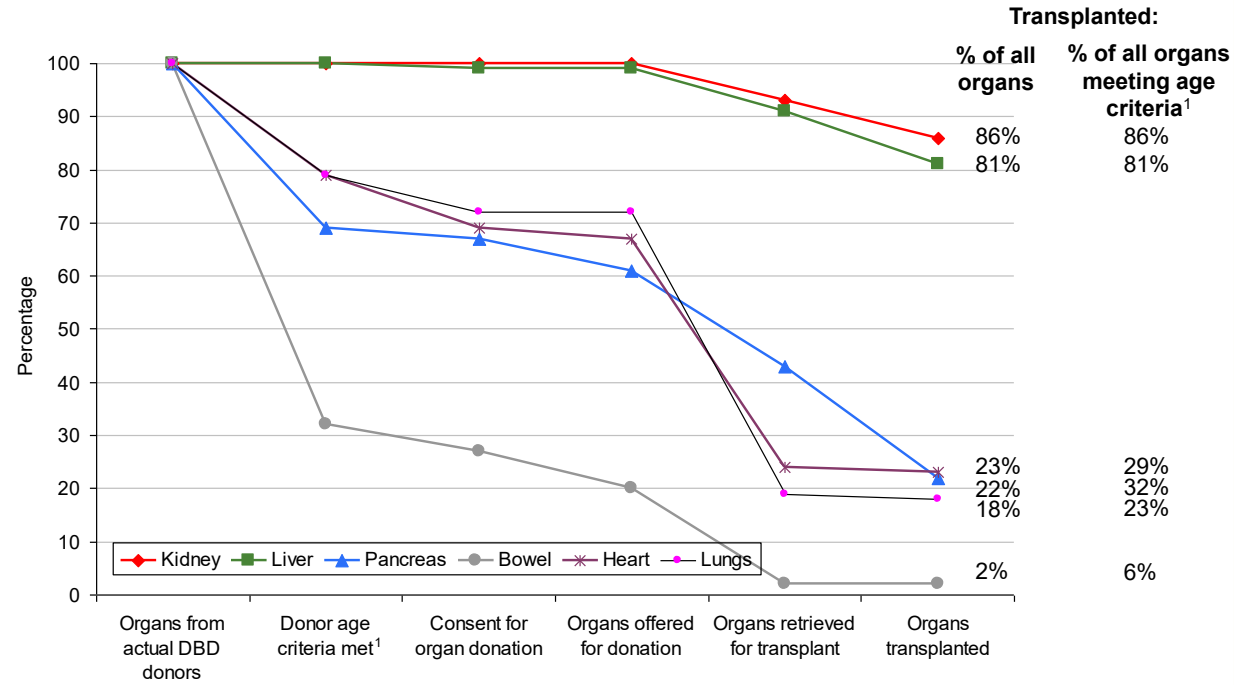
- Many issues appear to be local
- Common issues are facilities (Theatre/wards/anaesthetics/staffing)
- Accountability of Exec board suggests clinical teams trying but not being supported
- Collaboration not supported as the answer

OUG report is eagerly awaited

Pancreas CLU scheme

NHS Blood and Transplant

Challenges in pancreas transplantation



- Utilisation of organs…… (poor yield)
- Retrieval quality
- Physical assessment of organs
- Objective assessment of donor factors
- Prolonged time to asystole/DCD donors
- Islet utilisation

Pancreas CLU scheme

NHS Blood and Transplant

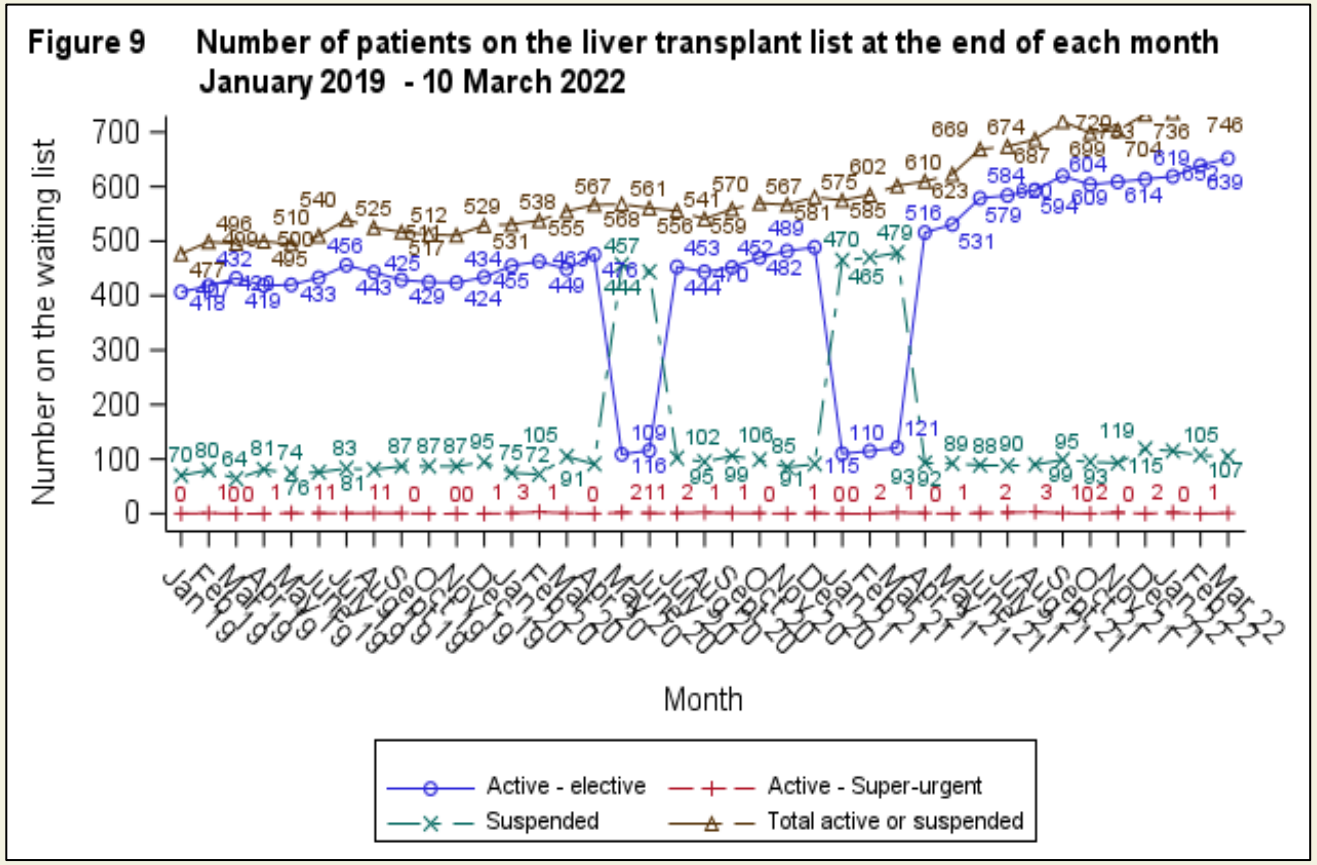
Interventions to increase Pancreas utilisation

- Pancreas imaging – to identify objective assessment criteria at retrieval
- Delphi assessment of organ offers – planned Delphi to look at donor criteria
- Prolonged asystole for DCD donors – assessing if we can wait longer than 30 mins for asystole in donors
- Work on improving quality of organ donors – retrieval education
- Early identification of which donors suitable for islet and solid organ offers

Liver CLU scheme

NHS Blood and Transplant

What are the main utilisation challenges



Marginal Grafts
New Indications

Variations
Within Centres
Between Centres
"Culture"

Surges in activity
Declines on Logistics

Allocation policies

Liver CLU scheme

NHS Blood and Transplant

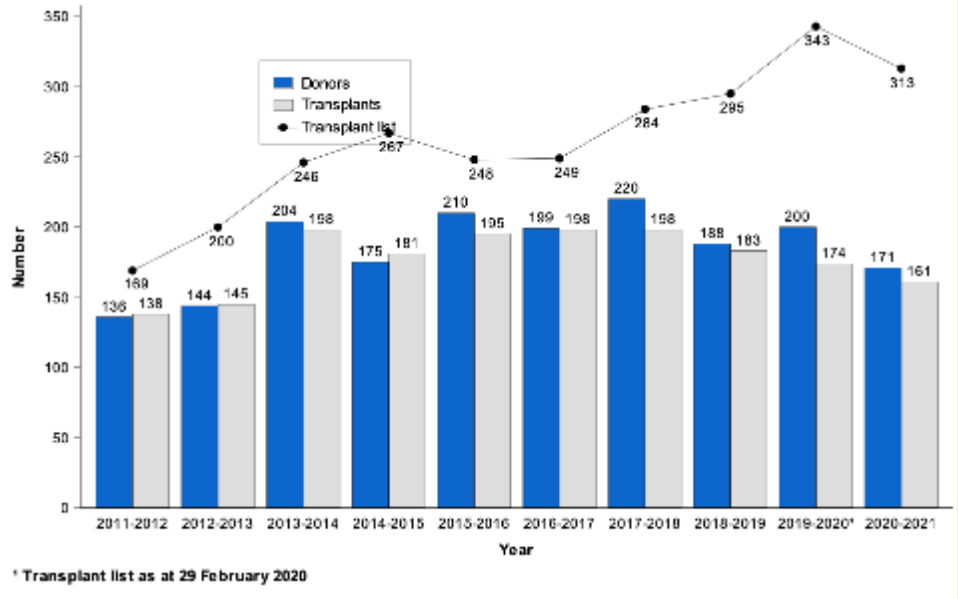
Interventions to increase Liver utilisation

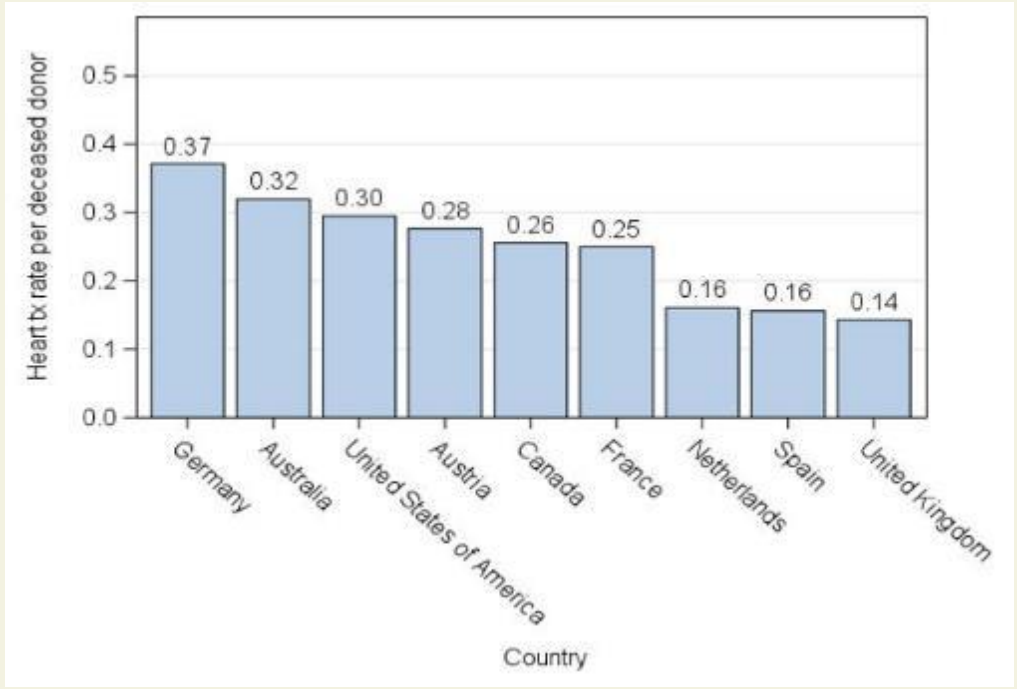
- Engagement – Working Closely with LAG – Joint document to OUG, Dashboards,
- Changing culture – Liver Offer Review Schemes, Centre based utilisation groups
- Reducing Variation – DCDs, right lobe grafts
- National audit on reasons for turning down organs
- Novel Technology – NMP, HMP, NRP

Heart CLU scheme

NHS Blood and Transplant

What are the main utilisation challenges





- Organ optimisation
- Data transfer and availability
- Workforce planning/ Staff shortages

Heart CLU scheme

NHS Blood and Transplant

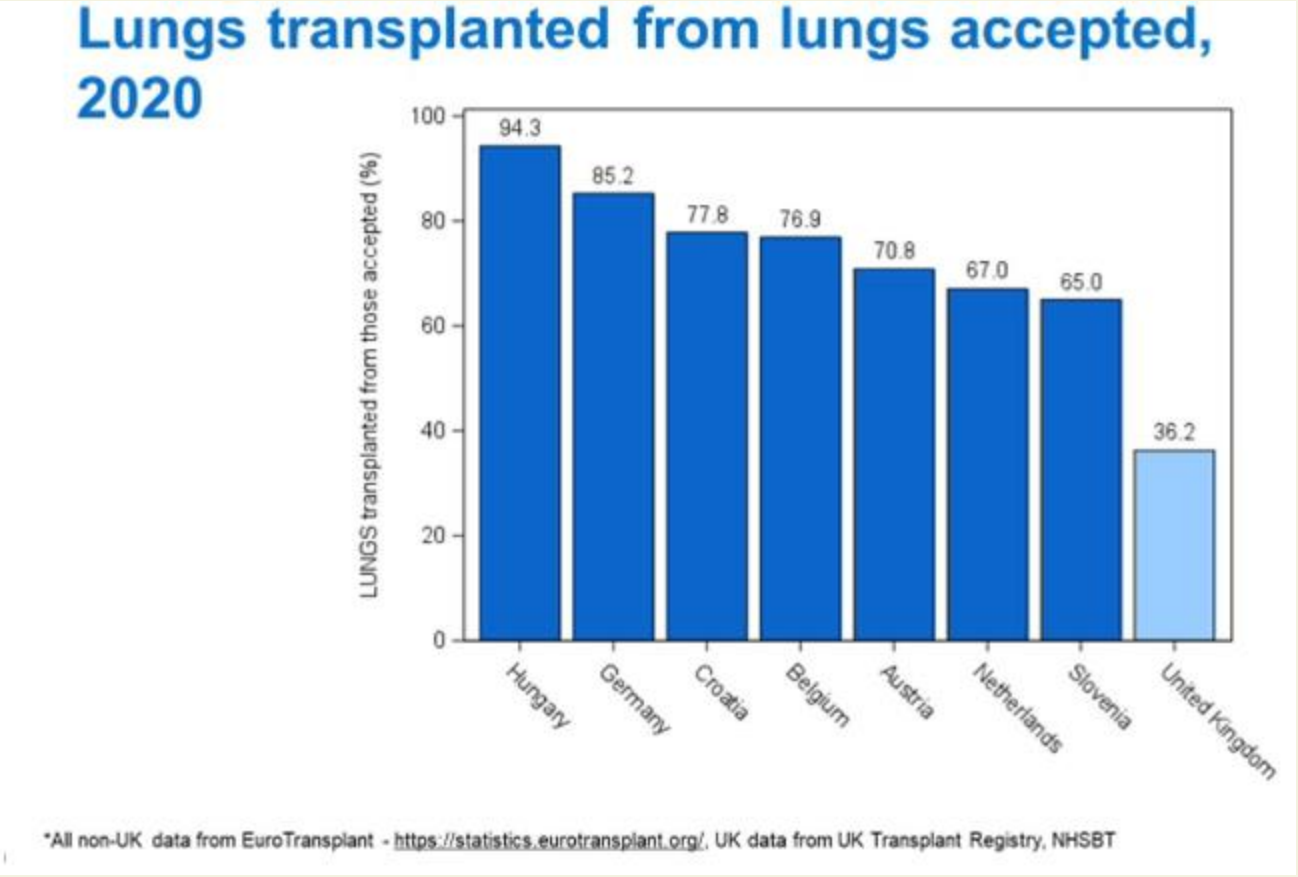
Interventions to increase Heart utilisation

- Every centre now seems to have donor offer review meetings
- Double consultation with respect to organ turndown
- Centres engaging through the CLUs in National Surveys
- Local projects (Machine preservation, ‘Heart champions for echocardiography’, coronary angiography)
- **Agreed Higher quality donor heart criteria**
- **Heart Offer Review schemes–** Go live date 23rd May

Lung CLU scheme

NHS Blood and Transplant

What are the main utilisation challenges



- Workforce / Lung Tx Surgeons Job Plans
- Lack of Theatre / ITU staff to run 2 Tx in parallel
- Increasing complexity of retrievals / Retention and recruitment
- Increasing recipient complexity
- Joint Heart & Lung Tx Rota disadvantages Lung Tx
- COVID 19

Lung CLU scheme

NHS Blood and Transplant

Interventions to increase Lung utilisation

- Virtual donor optimisation pilot scheme - Birmingham CLU
- “Blind the people” - Collaborative acceptance between surgeons and physicians at Royal Papworth
- Streamlining the process of lung donor to recipient size matching - Harefield CLU
- Reinforce donor audits at all centres
- **Agreed Higher Lung Donor Quality Criteria**
- **Lung Offer Review schemes – Go Live date 16th May 2022**

NHS Blood and Transplant

48 Tx physicians/ surgeons dedicated to improving OU
Led by **5** Organ Lead CLUs and **2** National Clinical Leads

31 local CLU projects and **3 national** projects in progress

National survey on **Interventions for Organ Utilisation**
145 responses from 27 units

Offer review schemes recommenced for Kidney & Pancreas and initiated for Liver, Heart and Lung
Led by Organ Lead CLUs

17 Organ Community Calls
4 Organ lead CLU calls

1 all CLU call
Information sharing between CT and Abdo organ groups

- Transplant Physicians group
- Trainees in CLU scheme
- Metrics

Presentation to **NHSBT Chief Executive** by Organ Lead CLUs showcasing the CLU scheme

CLUs have developed and implemented **local action plans** for improving OU

Self-appraisals submitted to Organ Lead CLUs

CLU 2.0 Evaluation Survey

NHS Blood and Transplant

28 responses were received from CLUs at **18 transplant units** in March - April 2021

- Kidney (14), Liver (5), Pancreas (5), Heart (6) , Lung (6)

Key Barriers	
Access to theatres and ICU beds	• Limited access to theatre (out-of-hours) • Competition with conventional waiting list
Staffing	• No transplant trainees or consistent junior support • Inadequate surgical and coordinator staffing
Risk taking and culture	• **Small units**, more conservative • The unit's **risk taking behaviour** variation in assessment of donors
Technology	• Very **limited access** to NRP / No organ perfusion service • Access to good quality echocardiogram

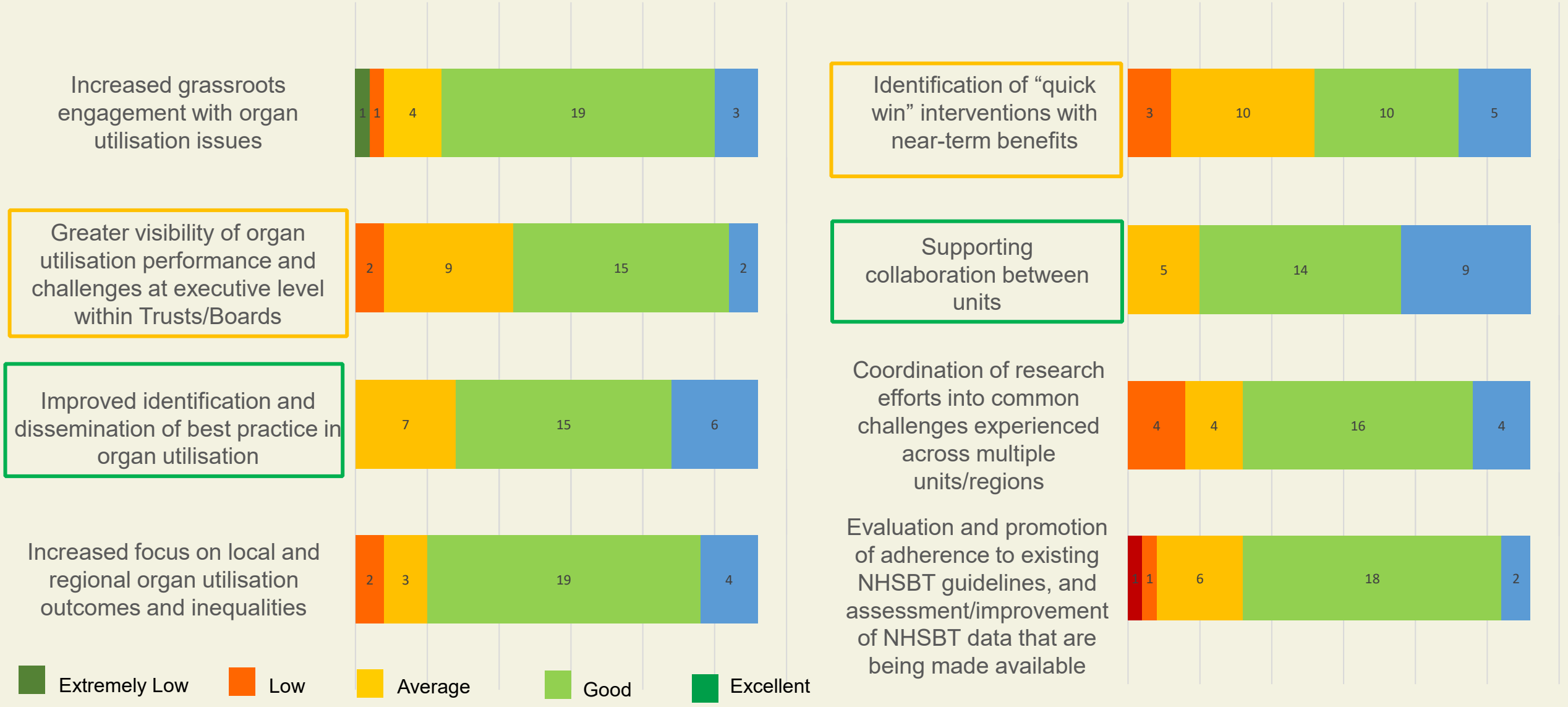
79%

respondents felt **more empowered** since becoming a CLU to address some of these barriers

Andrea Pereira, Hugh Laverty

Evaluate the impact of the scheme in relation to the expected benefits

NHS Blood and Transplant



Acknowledgments

- Aaron Ranasinghe, David van Dellen, Nick Inston, Raj Prasad and Vicky Gerovasili
- Chris Callaghan
- Claire Williment
- **OUP:** Jessica Jones, Tom Nicholson, Andrea Pereira, Celine Haines, Jonathan Green, Hugh Laverty, Joel McGrath, Helen McManus, Agimol Pradeep
- **NHSBT Stats team:** Sue Madden, Sally Rushton, Roderick Jaques
- Dale Gardiner
- Advisory Group chairs

Acknowledgments

- **Heart CLU:** Asif Shah, Harikirshna Doshi , Jacob Simmonds, Fernando Riesgo, Marius Berman, Vipin Mehta
- **Lung CLU**: Arun R Nair, Jacob Simmonds,, Amit Adlakha, Espeed Khoshbin, Pradeep Kaul, Vipin Mehta
- **Kidney CLU:** Neil Russell, Tim Brown, Khalid Sharif, Liam McCarthy, Sanjay Sinha, John O'Callaghan, Somaiah Aroori , Aimen Amer, Nicholas Barnett, Rhana Zakri, Zia Moinuddin, Ravi Pararajasingam, Rupesh Sutaria, Adnan Sharif, Andrew Jackson, Hemant Sharma, Sanjay Mehra, Anusha Edwards, Abbas Ghanzanfar, Stuart Falconer, Reza Motallebzadeh, Ismail Mohamed, Laszlo Szabo, Rowland Storey.
- **Liver CLU:** Andrew Butler, Liam McCarthy, Khalid Sharif, Colin Wilson, Miriam Cortes-Cerisuelo, Thamara Perera, Shahid Farid, David Nasralla
- **Pancreas CLU:** Gavin Pettigrew, Sanjay Sinha, Aimen Amer, Nick Barnett, Rhana Zakri, Zia Moinuddin, Rowland Storey

NHS
Blood and Transplant

Assessment & Recovery Centres (ARCs)

Dr Richard Baker

AMD Clinical Governance
Renal Consultant, St. James's Hospital Leeds

Organ Assessment and Recovery Centres

NHS Blood and Transplant

Why should we implement ARCs now?
The **supply of marginal organs is increasing**, and evidence suggests that machine perfusion can help to improve the post-transplant outcomes of marginal organs. Organ transplant waiting list has increased due to COVID-19 and ARCs provide the opportunity to **increase the number of transplants** per year.

UK heart utilisation is low, just 29% of offered hearts are transplanted. Current technology (Transmedics OCS) machine allows for hearts to be **perfused for up to 12 hours at the upper limit.**

UK lung utilisation is the lowest of all solid organs - just 12% of offered DCD lungs and 22% of DBD are transplanted. The Toronto ORC model has demonstrated that marginal lung Assessment, Repair and Preservation is feasible with current technologies and resulted in a 100% increase in lung transplant activity since launched.

Utilisation of offered DCD livers is low, at just 29%. 6 transplant centres across the UK have begun using ESMP across the UK. There is strong evidence in the literature to suggest that **liver function can be repaired using ESMP.**

The supply and demand for Kidneys is the highest of all organ types in the UK. **Medical management costs for the Kidney are very high,** thus the opportunity cost of not transplanting a kidney is high. Kidney dialysis costs c.£30,000 per year.

ARC Drivers

24hrs

Up to 24 hours of ex-situ organ preservation time for certain organs

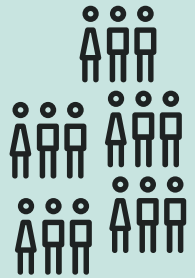
48%

Of offered primary organ types organs are utilised
(DBD 53%, DCD 40%)

ARC Outcomes

400+

Additional transplants per year by year 5



£1.4b

In QALY benefit to the UK economy over 10 years

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ISSUES FOR ARCs

- In Situ perfusion (ANRP)?
- Criteria for intervention
- Which model?
- Offering
- Transport
- Specification and protocol for intervention
- Viability assessment
- HTA
- Research

IN SITU

EX SITU

Risk Profile

DONOR

DBD
DCD

(T)ANRP

TRANSPORT

COLD

STATIC

WARM

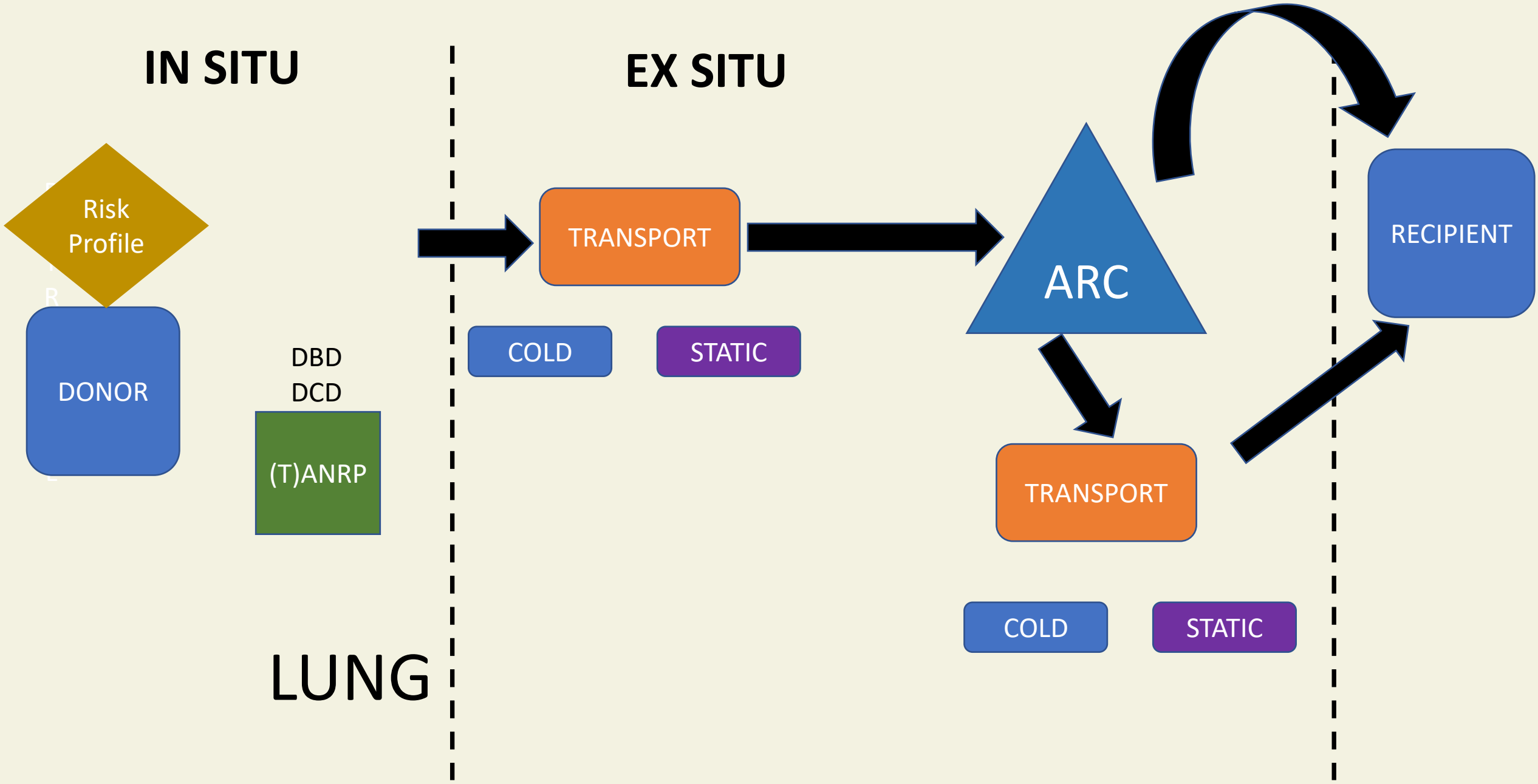
PUMPED

OXYGENATED ?

ARC

TRANSPORT

RECIPIENT


IN SITU
EX SITU
Risk Profile
DONOR
DBD
DCD
(T)ANRP
LUNG
TRANSPORT
COLD
STATIC
ARC
TRANSPORT
COLD
STATIC
RECIPIENT

IN SITU

EX SITU

Risk Profile

DONOR

DCD

(T)ANRP

TRANSPORT

WARM

PUMPED

OXYGENATED

ARC

RECIPIENT

Liver

DEVICE	CIRCULATION	OXYGEN	TEMPERATURE
	Perfusion	Yes	
	Perfusion	Yes	
	Perfusion	Yes	

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ISSUES FOR ARCs

- In Situ perfusion?
- Criteria for intervention
- Which model?
- Offering
- Transport
- Specification and protocol for intervention
- Viability assessment
- Tactical Data Solution – Perfusion and short term outcome
- HTA
- Research

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Risk Communication Tools

Sue Madden

Risk Communication Tools

NHS Blood and Transplant

- Developed by NHSBT Statistics and Clinical Research team in collaboration with the Winton Centre for Risk and Evidence Communication, at the University of Cambridge
- Designed to help clinicians communicate risks and benefits of transplantation to their patients in an easy to understand format
- Help to visualise possible outcomes for patients from the point of listing or the point of transplant for deceased donor transplantation
- Provide useful information to clinicians when consenting patients
- https://www.odt.nhs.uk/

for Clinicians

Advice for clinical staff involved in facilitating organ and tissue donation in the UK

See the advice

- Read our coronavirus advice to transplant patients
- Frequently asked questions about transplants during coronavirus

Communicating risk to potential recipients

NHS Blood and Transplant, in collaboration with the Winton Centre, have developed online tools to help clinicians communicate the risks and benefits of transplantation to patients.

» Access the tools

Commonwealth Tribute to Life project

NHS Blood and Transplant is seeking support from Commonwealth nations for a memorandum of understanding on organ donation and transplantation which reflects our shared values.

» Read the ambition

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

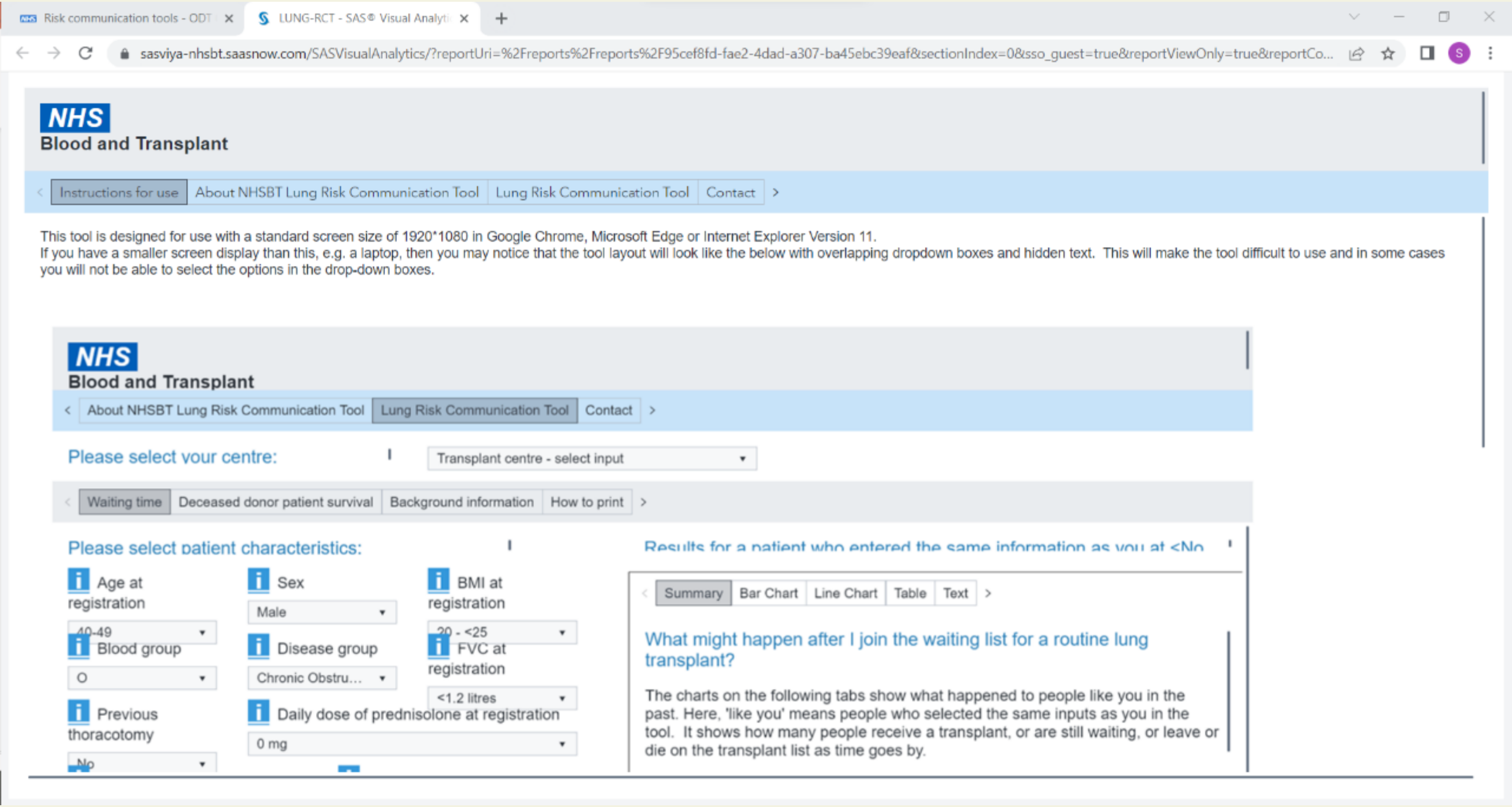
To help decision making when considering a pancreas transplant.

» Access the tool

Instructions for use

These tools are 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 include overlapping drop-down boxes and hidden text.


Risk communication tools - ODT
LUNG-RCT - SAS® Visual Analyti
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NHS
Blood and Transplant
Instructions for use
About NHSBT Lung Risk Communication Tool
Lung Risk Communication Tool
Contact
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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
About NHSBT Lung Risk Communication Tool
Lung Risk Communication Tool
Contact
Please select your centre:
Transplant centre - select input
Waiting time
Deceased donor patient survival
Background information
How to print
Please select patient characteristics:
Age at registration
40-49
Sex
Male
BMI at registration
20 - <25
Blood group
O
Disease group
Chronic Obstru...
FVC at registration
<1.2 litres
Previous thoracotomy
No
Daily dose of prednisolone at registration
0 mg
Results for a patient who entered the same information as you at <No
Summary
Bar Chart
Line Chart
Table
Text
What might happen after I join the waiting list for a routine lung 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.

What is NHSBT Lung Risk Communication Tool?

The NHSBT Lung Risk Communication Tool (Lung-RCT) is an online personalised calculator that can help doctors and nurses communicate risk and benefit about transplantation to patients, and can help patients more easily understand the numbers and statistics presented to them in clinic. It helps visualise possible outcomes for patients from the point of listing or point of transplant for deceased donor lung transplantation.

What does Lung-RCT do?

Lung-RCT is a communication tool designed to aid discussions between patients and clinicians. It will help clinicians and patients to visualise outcomes based on data for patients with similar characteristics in the past.The calculator asks for some details about the patient and presents results in the form of graphs and tables and charts based on those details.

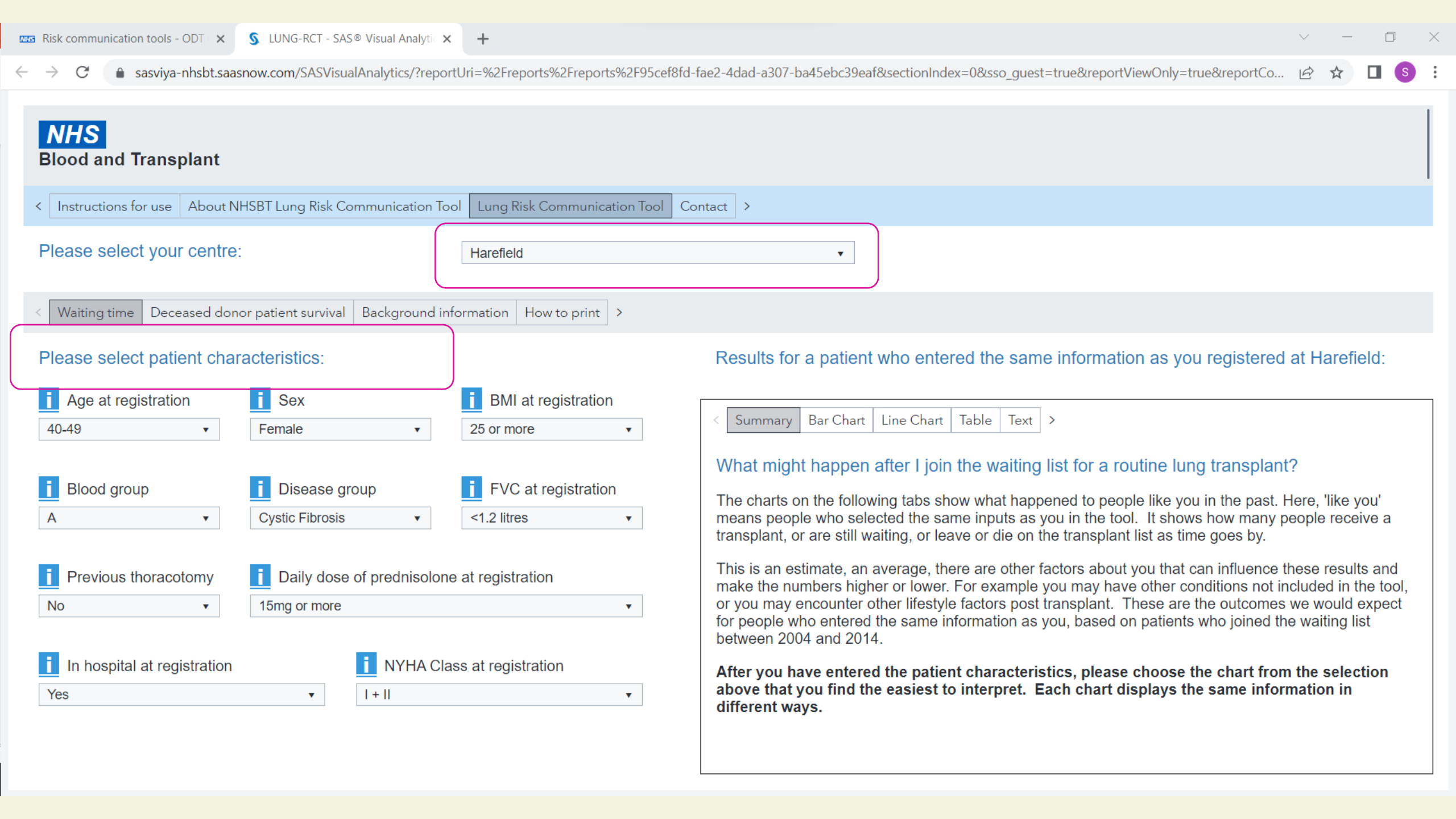
Currently the results presented for lung patients are: waiting time (from the point of listing) and chance of getting a transplant whilst acknowledging the risk of death on the list or removal from the list, also survival of the individual after receiving a transplant.To create the results presented, data about patients in the past were used to build statistical models. When you enter details into Lung-RCT, the calculator looks at these models and extracts results based on what happened to people “like this”.

Who is Lung-RCT for?

The Lung-RCT has been designed to be used by clinicians with patients and their families. It is a communication tool and should not be used by itself to make decisions.

Patients should use Lung-RCT in consultation with a medical professional.

Only adult (aged ≥16 years) patients have been used to the develop the tool; it is not suitable for paediatric patients due to the small number of patients involved which would not generate robust models. Patients who were not eligible for National Health Service (NHS) treatment and adult patients registered (for clinical reasons) on a paediatric waiting list were not included. Patients registered on another organ transplant list (eg, kidney list) either before, during or after their lung registration were also not included. The results from the Lung-RCT will therefore not be suitable for patients from outside the UK or for those patients who fall outside these inclusion criteria.


Risk communication tools - ODT
LUNG-RCT - SAS® Visual Analyti
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NHS
Blood and Transplant
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Harefield
Waiting time
Deceased donor patient survival
Background information
How to print
Please select patient characteristics:
Age at registration
40-49
Sex
Female
BMI at registration
25 or more
Blood group
A
Disease group
Cystic Fibrosis
FVC at registration
<1.2 litres
Previous thoracotomy
No
Daily dose of prednisolone at registration
15mg or more
In hospital at registration
Yes
NYHA Class at registration
I + II
Results for a patient who entered the same information as you registered at Harefield:
Summary
Bar Chart
Line Chart
Table
Text
What might happen after I join the waiting list for a routine lung 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 waiting list between 2004 and 2014.
After you have entered the patient characteristics, please choose the chart from the selection above that you find the easiest to interpret. Each chart displays the same information in different ways.

Risk communication tools - ODT | LUNG-RCT - SAS® Visual Analyti

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NHS
Blood and Transplant

Instructions for use | About NHSBT Lung Risk Communication Tool | Lung Risk Communication Tool | Contact

Please select your centre: Harefield

Waiting time | Deceased donor patient survival | Background information | How to print

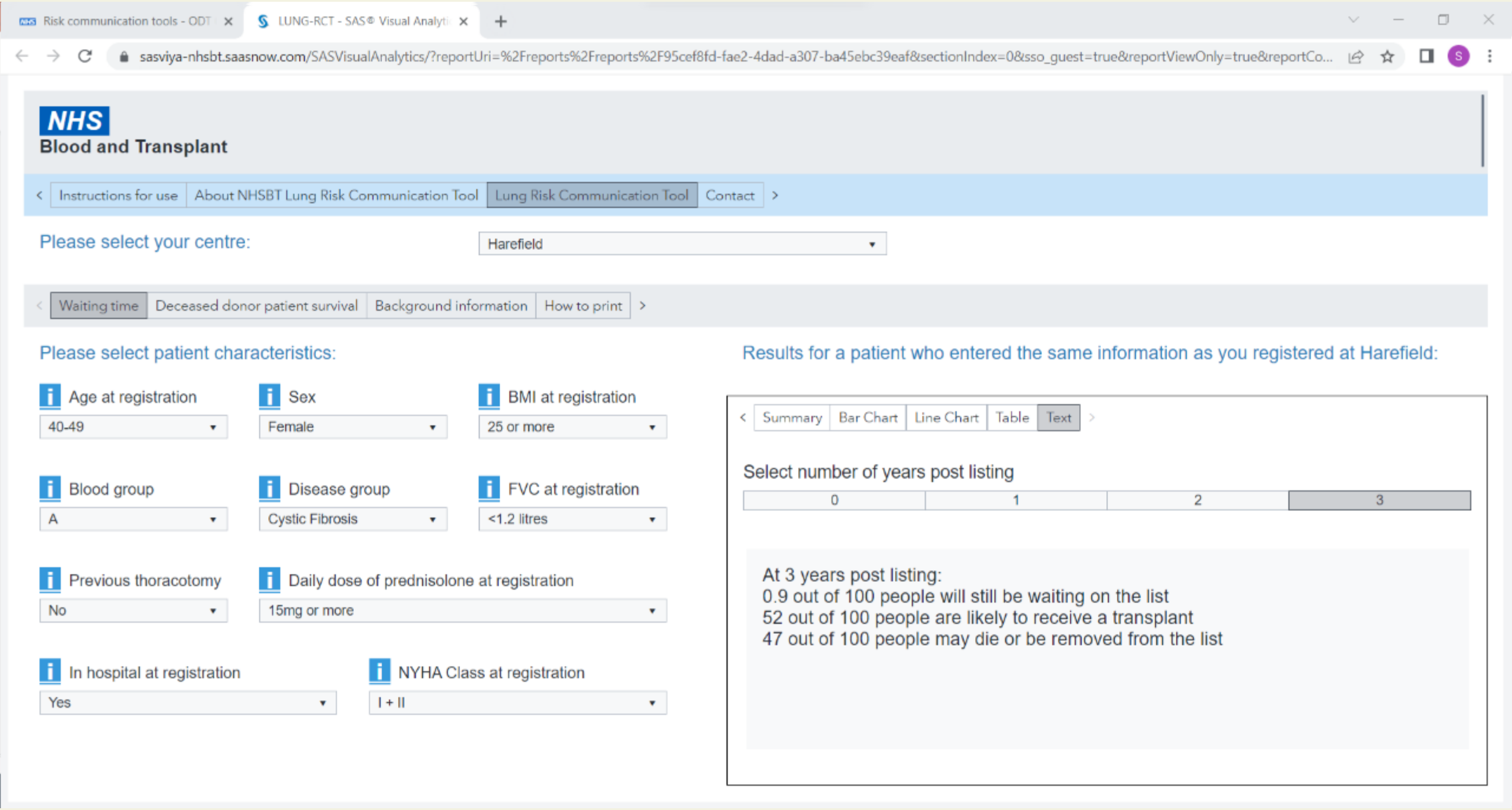
Please select patient characteristics:

- Age at registration: 40-49
- Sex: Female
- BMI at registration: 25 or more
- Blood group: A
- Disease group: Cystic Fibrosis
- FVC at registration: <1.2 litres
- Previous thoracotomy: No
- Daily dose of prednisolone at registration: 15mg or more
- In hospital at registration: Yes
- NYHA Class at registration: I + II

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

Summary | Bar Chart | Line Chart | Table | Text

About how long do these people stay on the list?


Risk communication tools - ODT
LUNG-RCT - SAS® Visual Analyti
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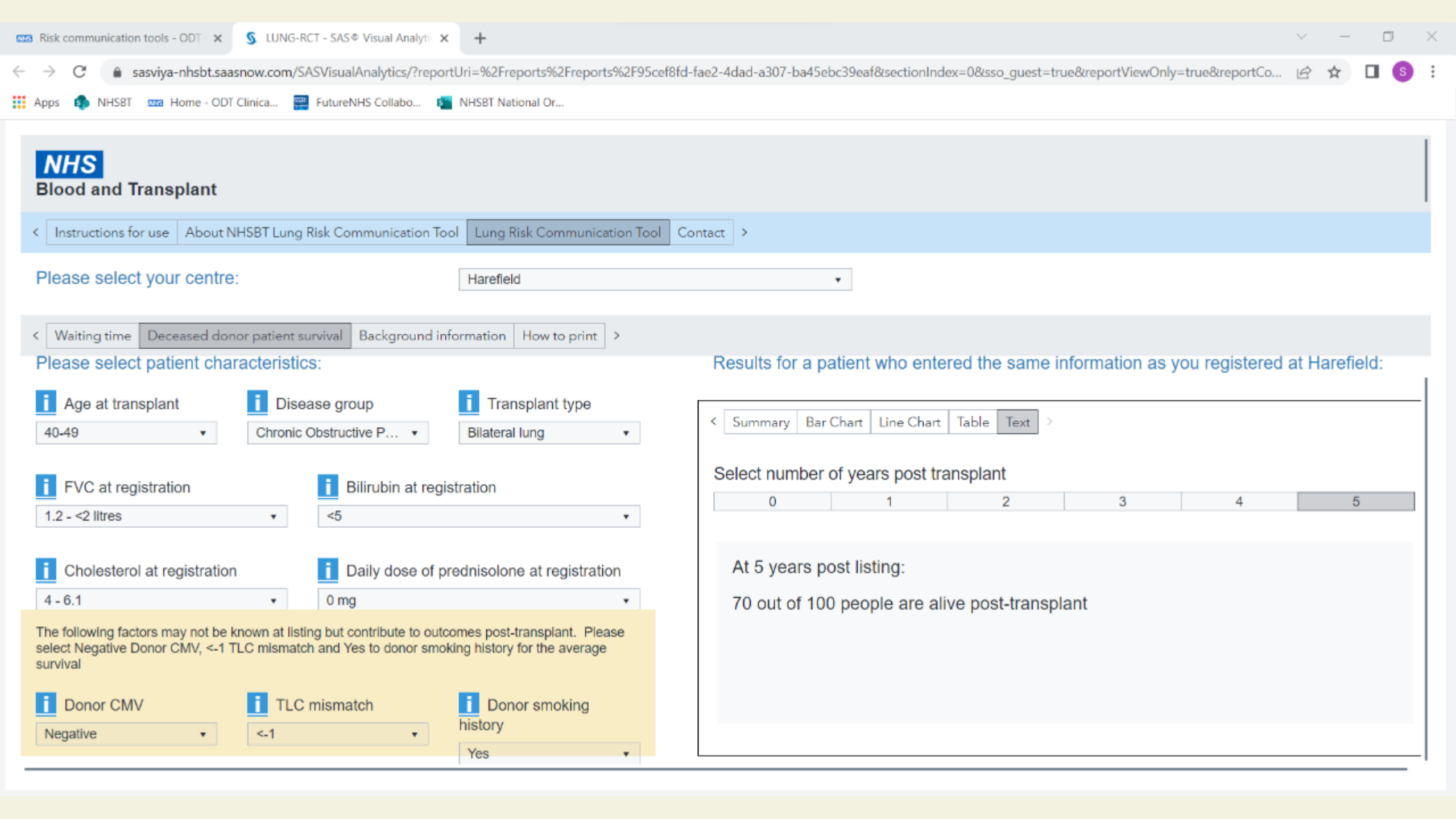
NHS
Blood and Transplant
Instructions for use
About NHSBT Lung Risk Communication Tool
Lung Risk Communication Tool
Contact
Please select your centre:
Harefield
Waiting time
Deceased donor patient survival
Background information
How to print
Please select patient characteristics:
Age at registration
40-49
Sex
Female
BMI at registration
25 or more
Blood group
A
Disease group
Cystic Fibrosis
FVC at registration
<1.2 litres
Previous thoracotomy
No
Daily dose of prednisolone at registration
15mg or more
In hospital at registration
Yes
NYHA Class at registration
I + II
Results for a patient who entered the same information as you registered at Harefield:
Summary
Bar Chart
Line Chart
Table
Text
Select number of years post listing
0
1
2
3
At 3 years post listing:
0.9 out of 100 people will still be waiting on the list
52 out of 100 people are likely to receive a transplant
47 out of 100 people may die or be removed from the list


Risk communication tools - ODT
LUNG-RCT - SAS® Visual Analyti
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Apps
NHSBT
Home - ODT Clinica...
FutureNHS Collabo...
NHSBT National Or...
NHS
Blood and Transplant
Instructions for use
About NHSBT Lung Risk Communication Tool
Lung Risk Communication Tool
Contact
Please select your centre:
Harefield
Waiting time
Deceased donor patient survival
Background information
How to print
Please select patient characteristics:
Age at transplant
40-49
Disease group
Chronic Obstructive P...
Transplant type
Bilateral lung
FVC at registration
1.2 - <2 litres
Bilirubin at registration
<5
Cholesterol at registration
4 - 6.1
Daily dose of prednisolone at registration
0 mg
The following factors may not be known at listing but contribute to outcomes post-transplant. Please select Negative Donor CMV, <-1 TLC mismatch and Yes to donor smoking history for the average survival
Donor CMV
Negative
TLC mismatch
<-1
Donor smoking history
Yes
Results for a patient who entered the same information as you registered at Harefield:
Summary
Bar Chart
Line Chart
Table
Text
Select number of years post transplant
0
1
2
3
4
5
At 5 years post listing:
70 out of 100 people are alive post-transplant

NHS
Blood and Transplant

Patient Information Website

Liz Armstrong

Projects:

Patient information website

NHSBT Second National Organ Utilisation Conference

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 be 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

NHS
Blood and Transplant

BTS
British Transplantation Society

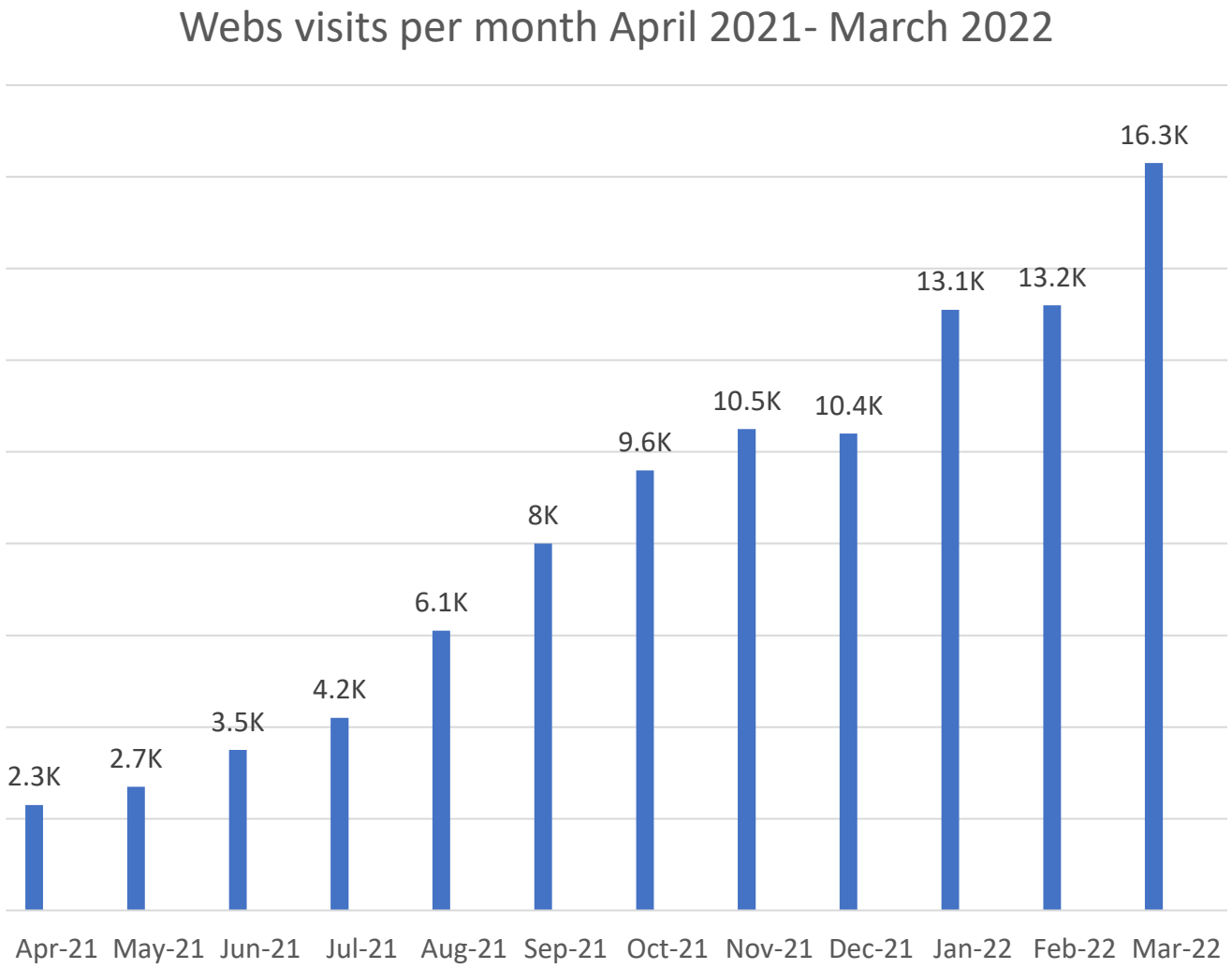
Communication of Risk and Consent

https://www.nhsbt.nhs.uk/organ-transplantation/


Having a liver transplant
Share


Having a heart transplant
Share

Patient information website - dashboard



Location of users

TOWN/CITY OF WEB VISIT

	Town/City	Web visits	% of web visits
1.	London	14,496	16.0%
2.	Birmingham	2,530	2.8%
3.	Glasgow	1,691	1.9%
4.	Manchester	1,544	1.7%
5.	Croydon	1,324	1.5%
6.	Leeds	1,294	1.4%
7.	Bristol	1,163	1.3%
8.	Liverpool	1,083	1.2%
9.	Edinburgh	951	1.1%
10.	Cambridge	790	0.9%
11.	Cardiff	733	0.8%
12.	Newcastle upon Tyne	731	0.8%
13.	Sheffield	694	0.8%
14.	Nottingham	629	0.7%
15.	Dublin	600	0.7%
16.	Sydney	553	0.6%
17.	Coventry	494	0.5%
18.	Belfast	455	0.5%
19.	New York	449	0.5%
20.	Oxford	442	0.5%
21.	Norwich	365	0.4%
22.	Plymouth	352	0.4%
23.	Southampton	341	0.4%
24.	Reading	338	0.4%
	Grand total	90,481	100.0%

1 - 5000 / 5207

COUNTRY OF WEB VISIT

	Country	Web visits	% of web visits
1.	United Kingdom	68,209	68.3%
2.	United States	11,683	11.7%
3.	India	3,140	3.1%
4.	Australia	1,454	1.5%
5.	Canada	1,336	1.3%
6.	Ireland	885	0.9%
7.	Pakistan	838	0.8%
8.	Philippines	565	0.6%
9.	Hong Kong	459	0.5%
10.	Germany	456	0.5%
11.	South Africa	447	0.4%
12.	United Arab Emirates	365	0.4%
13.	Netherlands	364	0.4%
14.	Saudi Arabia	360	0.4%
15.	Malaysia	348	0.3%
16.	Egypt	341	0.3%
17.	Singapore	335	0.3%
18.	South Korea	297	0.3%
19.	New Zealand	296	0.3%
20.	Spain	296	0.3%
21.	France	294	0.3%
22.	Italy	272	0.3%
23.	Indonesia	264	0.3%
24.	Sweden	238	0.2%
	Grand total	99,916	100.0%

1 - 184 / 184

Thanks to…

- Chris Callaghan
- Kam Rai
- Clare Giltrow
- Organ specific working group chairs and all members
- Digital, Date and Technology Services & Donor Experience Teams
- OTDT Clinical Team

NHS
Blood and Transplant

Digital Infrastructure for Utilisation

Laura Ellis-Morgan

Digital Infrastructure for Organ Utilisation

diuprojectmailbox@nhsbt.nhs.uk

NHS Blood and Transplant

The Digital Infrastructure for Organ Utilisation (DIU) project will develop IT infrastructure to underpin:

- **The ARCs (Assessment & Recovery Centres) initiative**
- **Robust donor and organ assessment**
- **Secure media sharing**

Project Phase 1

- **EOS Replacement -** Allowing external users to easily search for and view donor data
- **Secure Media Sharing-** Allowing external users to safely view media related to a donor (image, video etc.)

Project Phase 2 [Indicative]

- **Digital Accept/Decline (of offers)-** Digital assignment of an organ offer to a centre. Digital acceptance or decline of an organ by a centre
- **Machine Perfusion Data Collection and Storage-** Management of machine perfusion/ARC data in relation to a donor record
- **HTA-A Form Digitisation-** Digitisation of the process managing HTA-A form data
- **Body Map Digitisation-** Digitisation of donor body-map data

Transition State 1 Drivers:

Data Security

Existing & impending cyber security risks with current EOS platform

Existing risk of compromised patient confidentiality/safety through the lack of an auditable, secured image-sharing system

User Experience

Existing risk of "near misses" and critical incidents with the current EOS platform

Poor user experience on the existing EOS platform, originally built in 2007

Project Phase 3 [Indicative]

- **Digital Workflow System-** Provision of key retrieval timings to permitted users via a digital platform
- **DCD Observations-** Provision of DCD observation data to permitted users via a digital platform
- **Transplant Offer Management (TOM)-** Assessment of the existing TOM application for functionality which can be implemented on the EOS Replacement. Provision of external facing APIs for Trust system integration to support retrieval of donor and offer data from NHSBT for presentation in Trust systems.

DIU Strategic Goals:

Collaborate with partners

- Deliver an electronic offering system that supports sharing of data between NHSBT and its partners and helps to increase organ utilisation

Modernise our operations

- Invest in core IT platforms by replacing the aging and unsupported EOS platform
- Replacement of manual and paper-based processes by digitising the HTA-A form and body map
- Drive continuous performance improvement using data by enabling the sharing of key workflow timings and DCD observation data with 3rd parties

Drive Innovation

- Integrate NHSBT systems with the perfusion machines to support the implementation of Assessment and Recovery Centre (if this requirement is brought into scope in future transition states)
- Improving patient outcomes by improving organ utilisation and efficacy (through provision of efficient decision-aiding platforms)

NHS
Blood and Transplant

Organ Utilisation Group: Overview

Professor Steve Powis

Remit

NHS Blood and Transplant

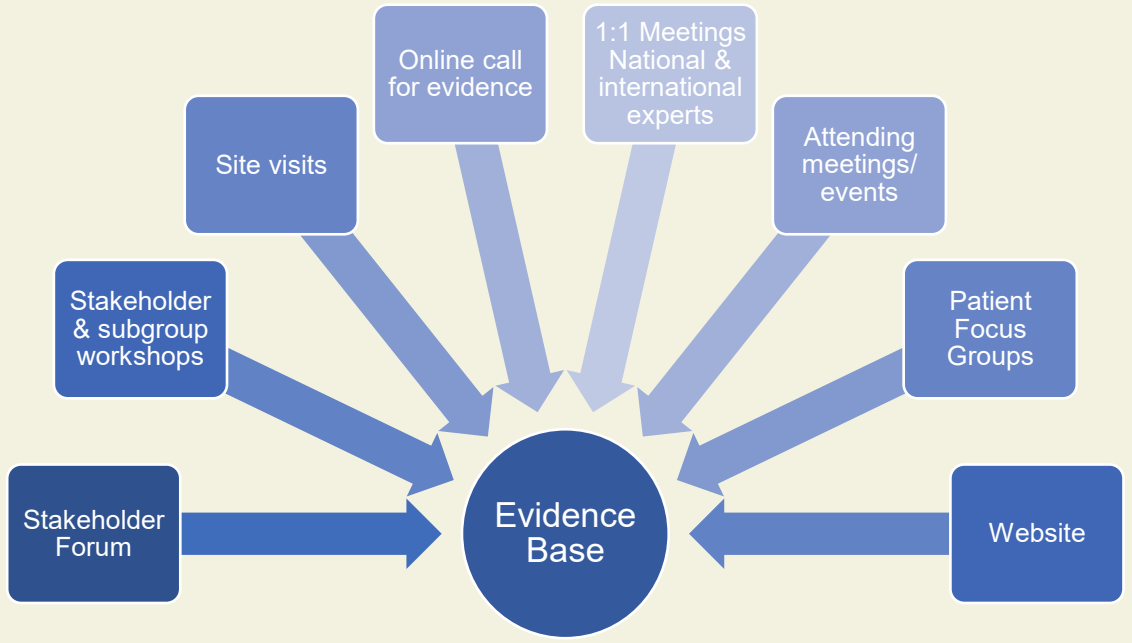
- Established by the Department of Health and Social Care to make recommendations on how to:
  - Deliver improvements in the number of organs that are accepted and successfully transplanted for adult and paediatric patients
  - Optimise the use of the existing skilled workforce, investment and infrastructure
  - Provide equity of access and patient outcomes
  - Reduce unwarranted variations in practice
  - Support innovation
- Remit in England only, but acknowledge patients cross UK borders and any recommendations for change may impact on other UK countries. Recommendations shared with UK Ministers
- Transplantation of organs from living and deceased donors
- Paediatric and adult services
- Task-and-finish group – will be disbanded after recommendations are provided

Approach & Engagement

NHS Blood and Transplant

- Multi-disciplinary representation on the Organ Utilisation Group
- Subgroups to bring in additional expertise and insight (membership not limited to England)
- 97 responses to online call for evidence
- 248 responses to patient survey
- 4 patient focus groups
- 58 delegates at stakeholder workshop
- Meetings with 6 countries
- 10 site visits
- National and international evidence base review
- Stakeholder Forum to share information, seek views/ comments on direction of travel and drafts.

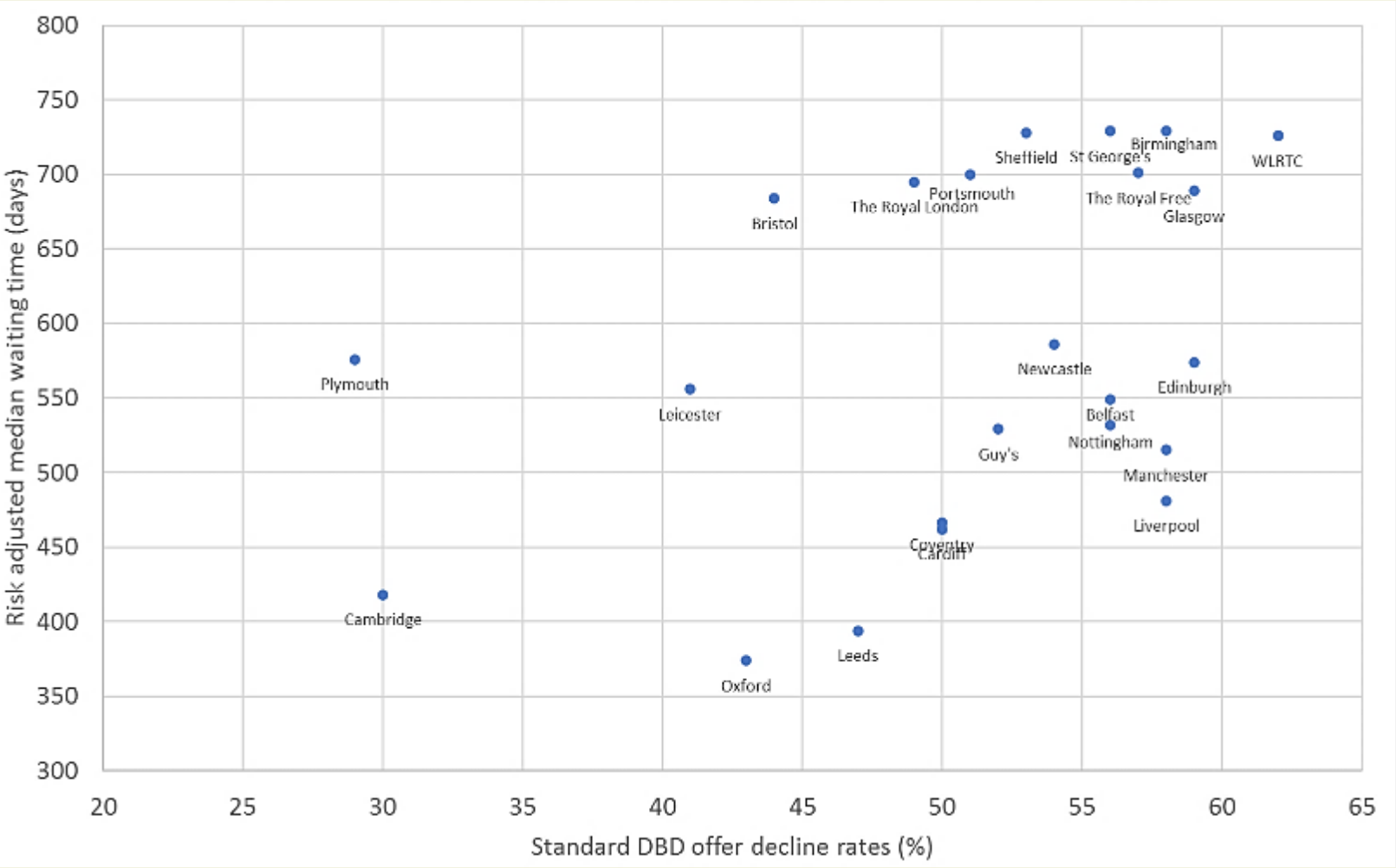
OUG Subgroups	
Standards	Commissioning
Workforce	Systems Architecture & Data Handling



New Analyses - Decline rate impact on waiting list

NHS Blood and Transplant

Adult kidney adjusted waiting time by DBD standard offer decline rates

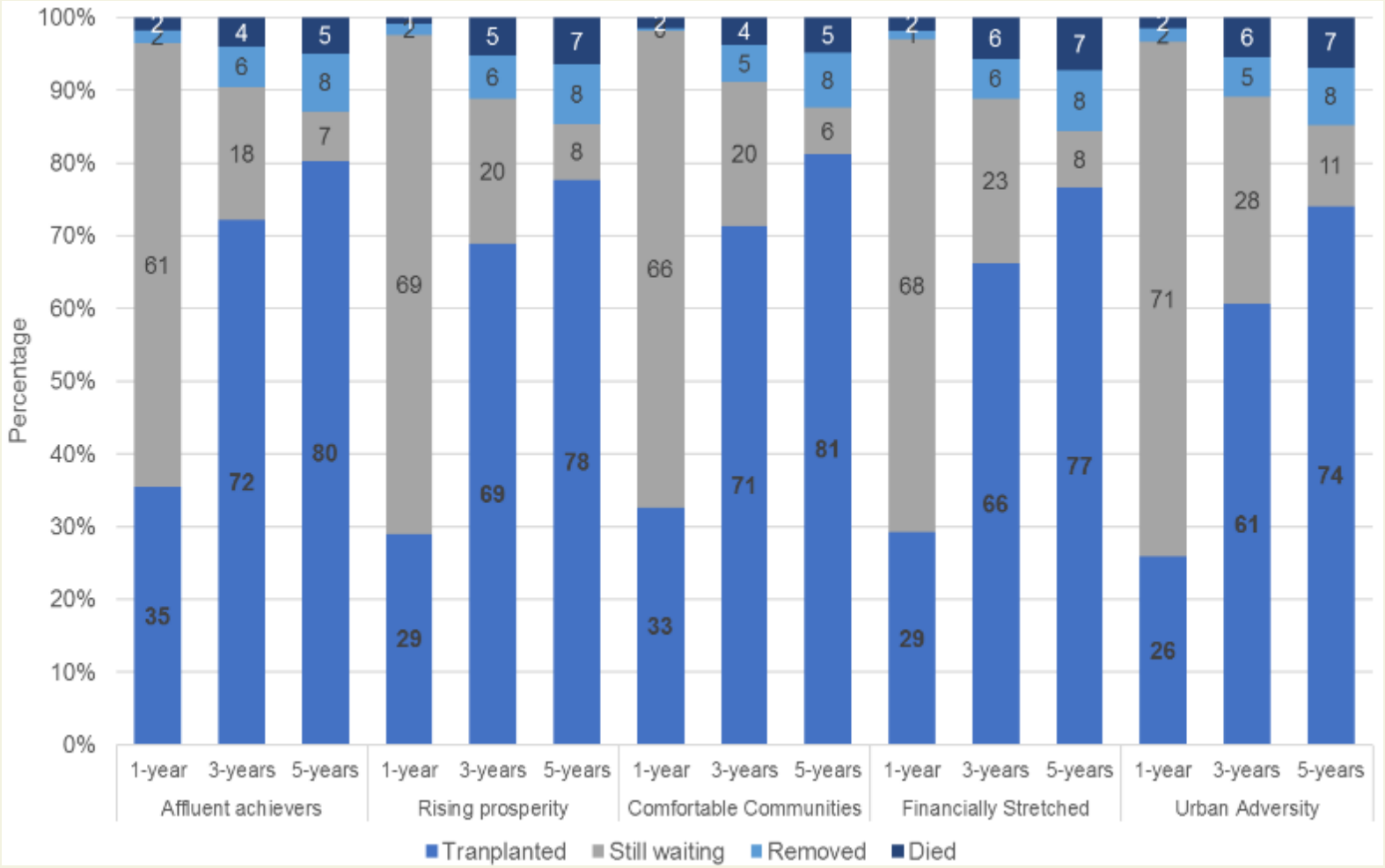


Using Pearson's correlation coefficient, it was found that a centre's standard DBD kidney offer decline rate and risk-adjusted waiting time for kidney transplantation have a significantly linear relationship ($r=0.4$, $p=0.05$).

New Analyses – Acorn impact on waiting times

Blood and Transplant

Post-registration outcome for new adult kidney only registrations made in the UK, 1 April 2015 – 31 March 2016, by Acorn category

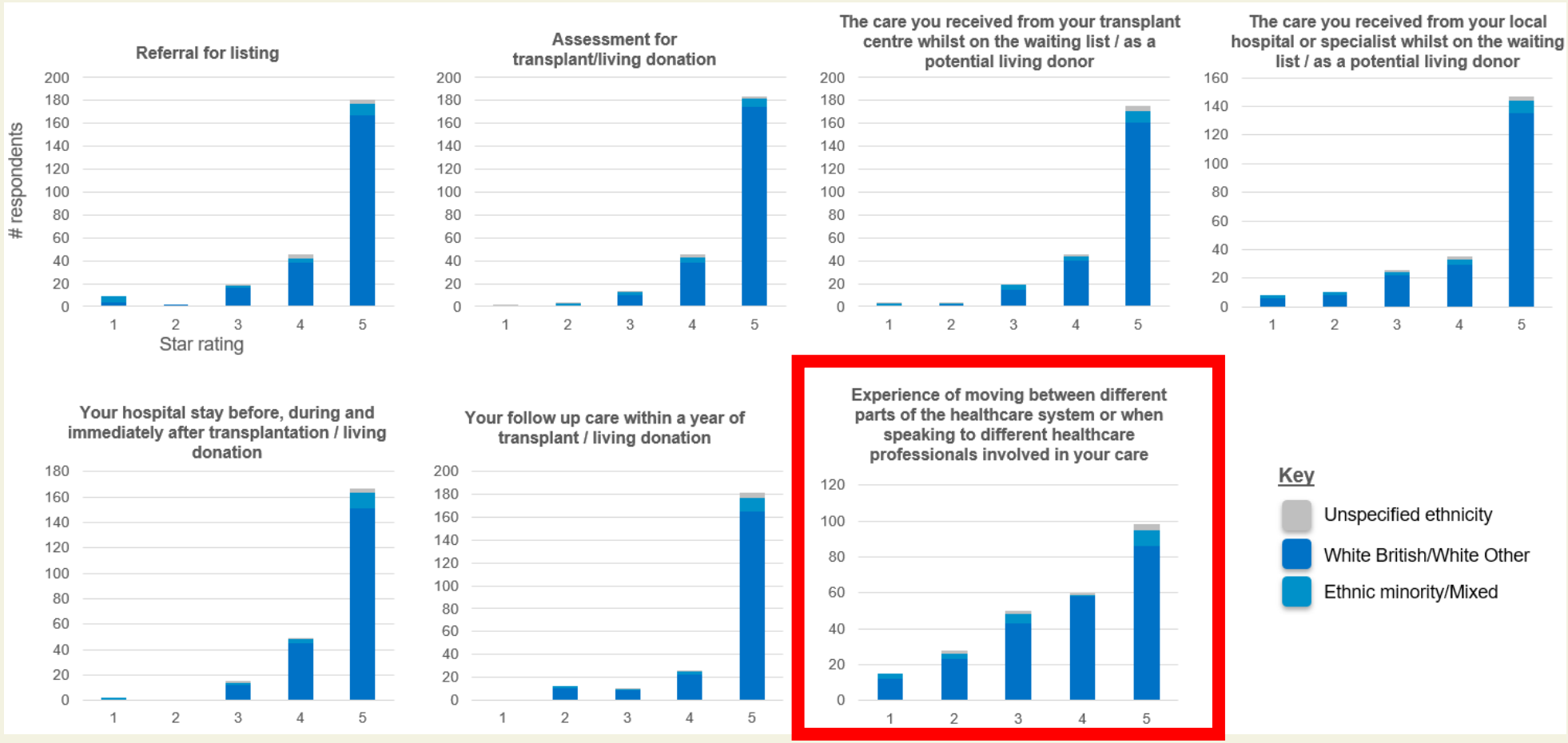


- UK Transplant Registry postcodes – 98% accurate.
- Proportion of patients transplanted/ waiting/ removed one, three and five years after joining the list by acorn category.
- 35% of patients in the affluent achiever's category are transplanted within 1 year compared to 26% in the urban adversity category
- 80% of affluent achievers have received a transplant compared to 74% of urban adversity after 5 years.

New Analyses – Patient survey & Focus Groups 'Mind the Gap'

NHS Blood and Transplant

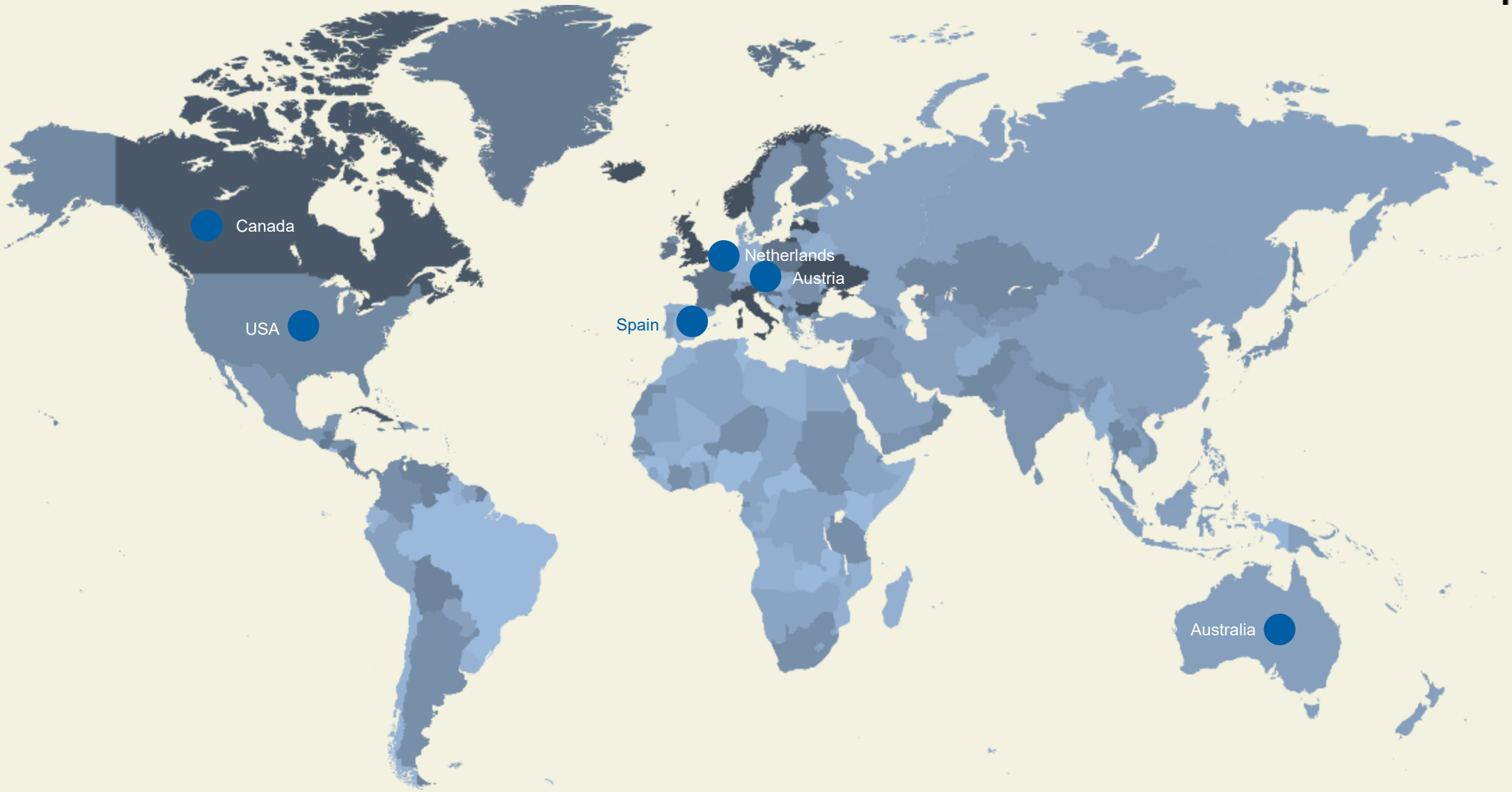
OUG Patient Survey



Keep watching – Fiona Loud will cover in more detail in next presentation

Evidence - International Meetings

NHS Blood and Transplant



Similarities & Cautionary Tales

NHS Blood and Transplant

Similarities

- Maximising utilisation potential – a shared issue
- Risk appetite and centre variation – not possible to eliminate, but should seek to reduce the amplitude
- Utilisation rates driven by local enthusiasts
- Few instances of any national level oversight of the whole care pathway
- Workforce burnout and recruitment/ retention issues especially post pandemic

Cautionary Tales

- 70% acceptance rates in EuroTransplant for hearts, but no quality control on outcomes
- Reporting measures that focus on chastising poor outcomes increases risk averse behaviour
- Large number of centres means increase in transplant, competition etc, but also means that some centres have very low transplant rates due to small waiting lists

Lessons Learned

- **Resourcing:**
  - Agreements, preferably formal contracts, minimise organ declines
- **External scrutiny:**
  - for severely underperforming Units, with Trust management involved
  - Benchmarking and outcome measures are key to driving improvements
- **Support:**
  - Always have 2nd opinion regarding an organ decline
  - Don't disincentivise those who accept higher risk donors. Challenge those who don't accept standard criteria donors
  - Nationally trusted source of advice for complex cases or concerns regarding risk/ safety issues
  - Support those who take risks
  - Annual training programmes, informed by evaluation of any common issues
- **Incentivise:**
  - focus on monitoring adherence to best practice, rather than only criticising best practice
  - Set measures that incentivise
  - Have metrics that are patient-focussed – supports patient involvement and incentivises Units
  - If a centre accepts a high-risk organ then they don't go to the bottom of the list for the next organ

Innovation

NHS Blood and Transplant

- Developing predictive analytics to address risk aversion and prevent inappropriate offers
- Use GPS tracking of organs in transit, to support resource planning and inform future improvements
- Looking to standardise biopsy imaging
- Establishing a new matching system to help those with longer wait and highly sensitised patients, with built in simulation to explore likely outcome.
- All dialysis patients are required to be considered for transplant within 12 months.
- Undertaking a mapping exercise to look at donation and transplantation across the country, to identify problems and solutions
- 70% of DCD donors have NRP. Looking to establish DCD Hearts and TANRP
- Provides a mobile ECMO team for DCD procedures
- Focussing on shared decision making with patients
- Using advanced tissue typing to ensure organ goes to the right patient, with machine perfusion to ensure it is in the best possible state

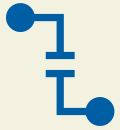
Summary of feedback – Key Challenges

NHS Blood and Transplant

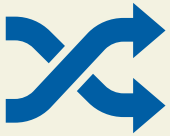
Patients

The psychological and social support of patients

Inequity of access (ethnic; geographic; lifestyle)



Disjointed service



Inconsistency in advice

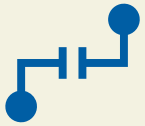
Poor communication and data

Clinicians

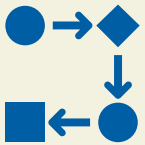
Managing and reducing staff fatigue & increasing recruitment and retention

Innovation and machine perfusion

Access to theatres and beds in wards and intensive care units



Disjointed commissioning



Length of the donation, offering and allocation processes

Data access and imaging

Direction of Travel

NHS Blood and Transplant

NOTE – Recommendations are not yet finalised.

Patient centred focus, involvement, choice, information and education along the whole care pathway, PROMs, PREMs

Collaboration with other units and centres through a buddying scheme and building on lessons learned through COVID

The use of innovation and novel technologies, such as machine perfusion

Standardisation and strategic direction and leadership with national oversight

Improved access to data, to inform patient and clinical decision making and resource allocation

Workforce sustainability, resilience and training to meet current and future needs

Message from Maria Caulfield

”Last week marked the second anniversary of Max and Keira’s Law, which introduced opt out as the legal basis for consent for donation. As we see consent rates increasing, it is important that we make the best use of every donated organ, with all patients on the waiting list across the country being given the same opportunities for a life-saving transplant.

We need to build on the collaboration developed across transplant communities throughout the pandemic. We also need to build on the progress we have made with innovations such as machine perfusion.

I am grateful to the Organ Utilisation Group for leading the way with this important work. I look forward to seeing the recommendations and working with all those across the NHS to deliver improvements, which will place the UK back as a world-leader in this life-saving treatment, keeping the quality of patient care and the need for equity at the core of everything we do.”

Maria Caulfield, Parliamentary Under Secretary of State
(Minister for Patient Safety and Primary Care)

Next steps

NHS Blood and Transplant

- Steer from Ministers on draft recommendations then publish
- Implementation
  - Few ‘quick wins’
  - Commitment and drive from Government, commissioners, NHSBT, Trusts, Transplant Teams, Patient Group, Royal Colleges, NHS Digital…
  - Implementation oversight group to align approach and monitor progress

NHS
Blood and Transplant

Organ Utilisation Group: Q&A

Please go to www.menti.com on your smartphone or tablet and enter code **2919 9319**

NHS
Blood and Transplant

Organ Utilisation Group: Patient Feedback

Fiona Loud

Hilaria Asumu

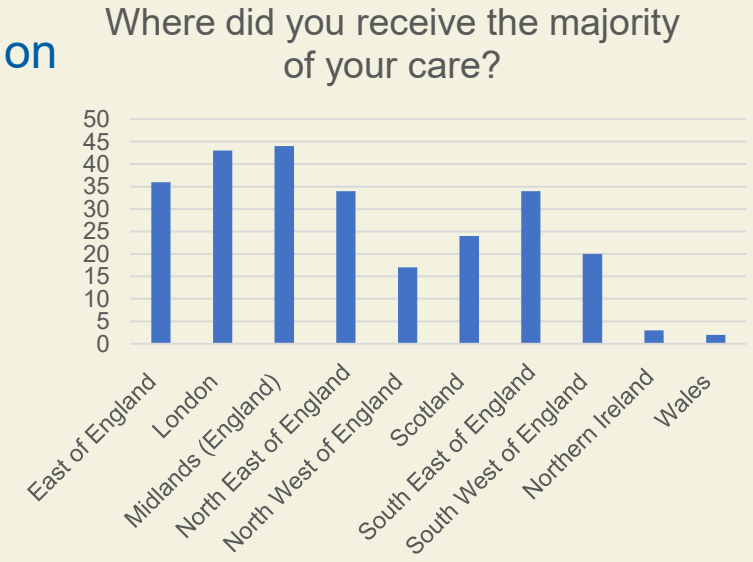
Patient Engagement: Survey

NHS Blood and Transplant

A survey was shared in February 2022 to further hear from people who are waiting for, or have had, transplants, plus their families and carers, and capture those “less heard voices” and their experiences of transplant services. We asked for them to rate different aspects of their care using a 1 to 5 star rating. The survey was anonymous and covered both deceased and living donation.

Demographics

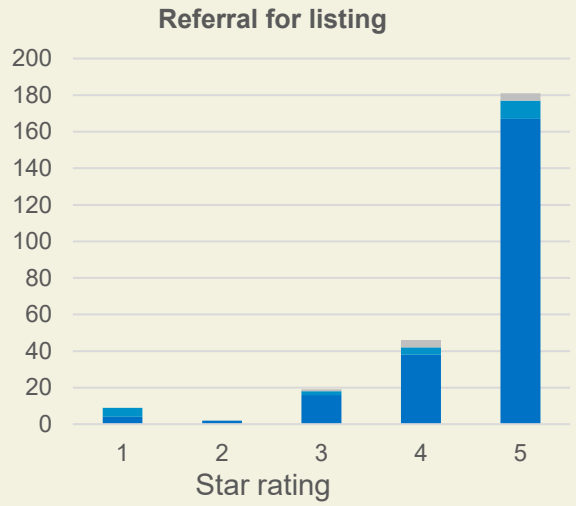
- **258 responses** were received from people from **10 regions** across the UK.
- There were **193** respondents that had received a transplant and **26** who were on the waiting list.
- **42** people answered as family members / carers of those either on the waiting list or have received a transplant.
- The majority (**252**) were answering as or on behalf of an adult, with **6 people** answering on behalf of a child.
- **19** respondents had received a kidney / liver transplant from a living donor
  - Of these respondents, **14 people** received their organ from a family member or friend, and **1 person** received their organ from someone who responded to a media/social media appeal

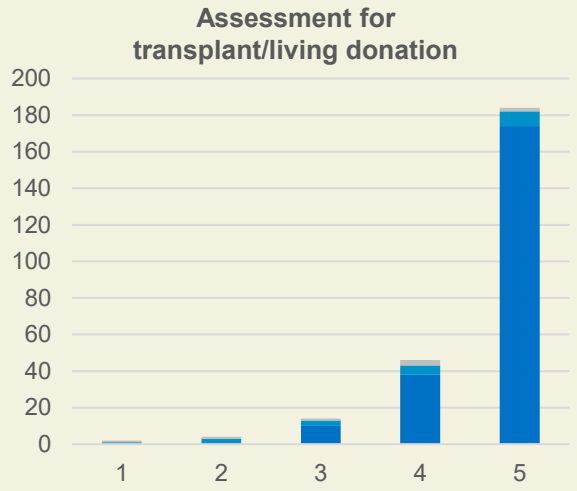


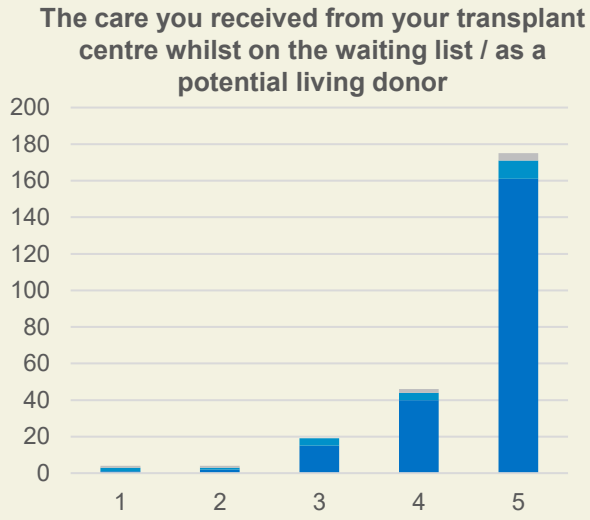
Patient Engagement: Survey

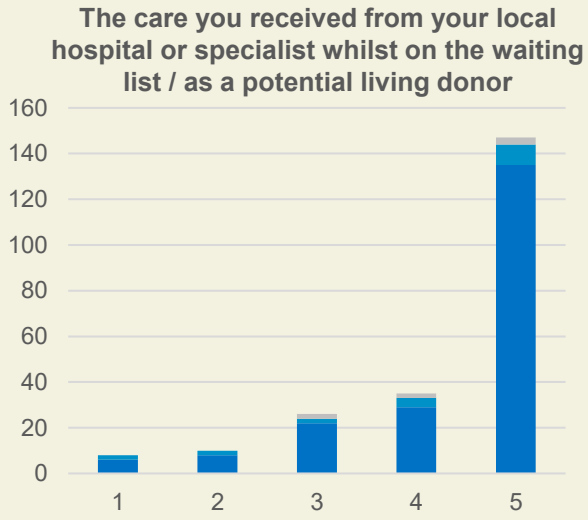
Experience ratings for pathway stages by respondent ethnicity (5 “star” scale)

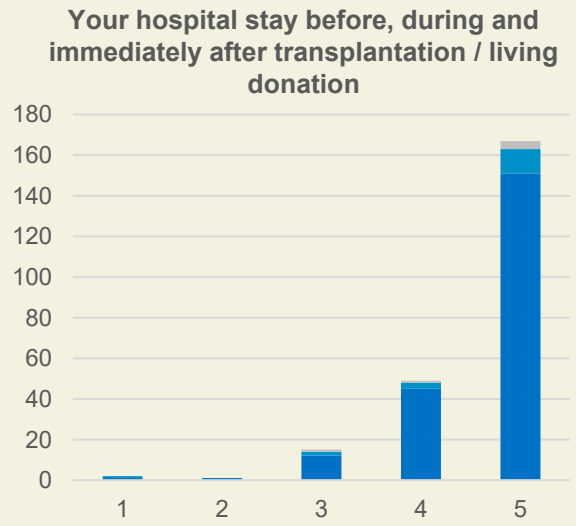
NHS Blood and Transplant

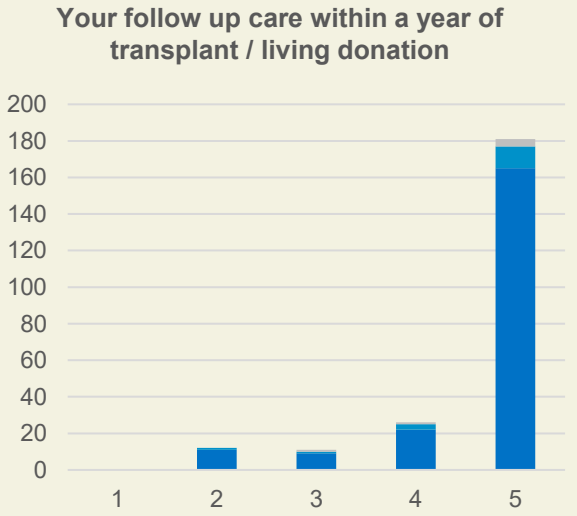












Key

- Unspecified ethnicity
- White British/White Other
- Ethnic minority/Mixed

Patient Engagement: Survey

Further comments

NHS Blood and Transplant

The care my son received before receiving a transplant was amazing.

The clinical and nursing provision was very good and sensitive.

Both myself and my family have received amazing care from the transplant team. My post transplant team are the most exceptional, caring and amazing team who I have ever had the fortune to meet.

I found it very hard to talk to anyone as I saw a different person every time.

Transplant itself was fine in terms of the surgery but the information given re. what would happen and when etc. was very poor.

System and communication was disjointed.

After the transplant, having to travel 2 hours in hospital transport at 6am 2 times a week was a huge demand.

Services offered were not uniform. Some are better than others, generally satisfactory.

Patient Engagement: Focus Groups

NHS Blood and Transplant

- **Focus Group 1: Kidney**
  - 1 Asian; 5 Black; 2 White delegates
  - 1 parent of paediatric patient with special needs
  - 1 representative of adult special needs patient
  - 2 male and 6 female delegates
- **Focus Group 2: Lung**
  - Pre- and post-transplant
  - 1 male and 4 female delegates
  - 1 representative of a patient who had been a child at the time of listing
- **Focus Group 3: Kidney**
  - Pre - and post-transplant
  - 6 Black delegates
  - 2 delegates on the waiting list
  - 2 male and 4 female delegates
- **Focus Group 4: Liver**
  - Pre - and post-transplant
  - 8 delegates
  - 4 male and 4 female delegates
  - Experience of transplant during COVID
- Difficulties experienced in identifying patients willing to engage and participate.

Patient Engagement: Focus Groups

NHS Blood and Transplant

General feedback

- General happiness with initial care (dialysis; Cystic Fibrosis services)
- Disjointed service, with patients getting lost in the system and medical records not being shared effectively, which compromise patient care/ safety
- Lack of psychological support for patients and their families, which had a strong adverse impact on their experience, relationships and well-being
- Disparity in the level of care offered between different centres
- Poor communication, meaning some patients were concerned and confused
- Inconsistency in advice received
- Many patients explained how they had to fight to get the care they need

They never look at a patient as a whole.

The team became like an extended family.

They were on my side. They want you to survive and will do everything in their power to help you

I felt lonely and saw no-one and had no support. I felt forgotten.

You rely on peers to support you, as you don't want to trouble the nurses.

Patient Engagement: Focus Groups

NHS Blood and Transplant

Kidney Focus Group

- Lack of compassionate care
- Belief from many patients that the level of care offered is dictated by ethnicity of the patient
- Concerns regarding provision of pain medication with several patients reporting being left in agony for long periods of time.
- Medical data is not shared effectively between teams and services, meaning that some patients received care that they believed risked their safety.
- Inconsistency in advice and poor communication regarding living donation (e.g. who could be a donor, options for donors from family who are overseas)

Just because he has special needs, he shouldn't be denied the right to live.

I was on the transplant waiting list but am suspended now. I don't want to go back on the list as I don't trust them with my life.

There are some wards I refuse to go on because of malpractice. I'm scared to go to sleep in case they make a mistake.

The Doctors stick together and don't admit their mistakes.

Patient Engagement: Focus Groups

NHS Blood and Transplant

Lung Focus Group

- Generally good support for cystic fibrosis patients pre-transplant.
- General (but not universal) positive feedback about commitment and approach taken by transplant teams.
- No reliable source of information for ‘every day’ queries from patients – e.g. diet, contraception, welfare benefits.
- Inconsistency in experience regarding referral approach

As far as I’m concerned they’ve just let me go. I am completely unsupported with my CF and my depression.

The false alarms gave me a boost and helped me keep my head above the water until the final call came. I knew that they were thinking about me.

I’m so thankful to be on the list and considered for a transplant.

The false alarms were upsetting.

Patient Engagement: Focus Groups

NHS Blood and Transplant

2nd Kidney Focus Group

- Dedicated, compassionate and attentive transplant teams
- Level of information received was great and professionalism was outstanding
- The service they received varied, highlighting the lack of equity
- Medical data is not shared effectively between teams and services – inconsistency of communication
- Moving between parts of the system was difficult, but the care received once integrated was good
- Little support and flexibility for those with competing priorities and obligations (e.g., work, studies)

They asked very obvious questions when they could have checked my notes, I felt like I was being tested.

They were always making sure I was okay, checking up on me and making sure I understood everything that was going on.

When I got the information [regarding my transplant] I was so excited at how everything would happen, they were so encouraging.

It's not easy being a patient when you're a student, I need to work really hard to provide for myself, and there is little support.

Patient Engagement: Focus Groups

NHS Blood and Transplant

Liver Focus Group

- Workup was great, with the team checking in often
- Collaboration between transplant centres worked really well
- Transplant centre takes responsibility for the post-transplant care (immunosuppressants, bloods etc.)
- Took a bit of time to get contacted and on the system after moving centres
- Liver care is a postcode lottery
- Kept feeling as if they were forgotten about, which got a lot worse during COVID

I was treated really really well, I have nothing but praise, for the coordinators as well

Care was absolutely first class; I couldn't complain about a single thing.

Communication between the hospitals was ridiculous – it was by letter and the visibility of info wasn't consistent.

There should be a gentler way on how to convey the news of transplant when you're not expecting it – it left me frazzled.

The care and advice given wasn't consistent across different centres.

Patient Engagement:
Ethnic minority perspective

NHS Blood and Transplant

Hilaria Asumu

Hilaria is a kidney disease and transplant patient. She received her transplant in 2018. She became an Ambassador for Organ Donation with NHS Blood and Transplant, and also a peer educator with Kidney Research UK.

Hilaria is actively involved in the black African community in Greater Manchester and other counties across the UK. She is the chair of WSH BME Kidney Network and works as an advocate for African-Caribbean kidney patients and their families navigating government institutions like the police, social services, the workplace, hospitals, schools for children etc.

NHS
Blood and Transplant

Afternoon Break

Royal Papworth Hospital
NHS Foundation Trust

Delivering positive change

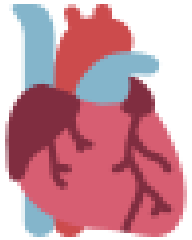
Stephen Posey
Chief Executive

Royal Papworth Hospital NHS Foundation Trust

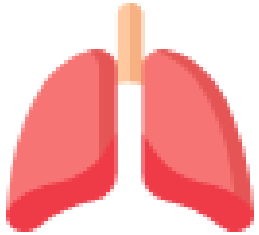
Compassion
Excellence
Collaboration

Royal Papworth Hospital
NHS Foundation Trust

About us

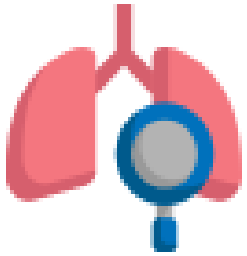


Largest specialist cardiothoracic hospital in UK



The UK's main heart and lung transplant centre

Elective care



Leading centre for cystic fibrosis

Emergency cardiology care

Largest sleep study centre in the UK

Royal Papworth Hospital
NHS Foundation Trust

Papworth

1979	UK’s first successful heart transplant operation takes place
1984	Europe’s first successful heart-lung transplant is performed
1986	World's first heart, lung and liver transplant takes place
2001	UK national centre for pulmonary endarterectomy established
2011	UK’s first Total Artificial Heart patient discharged home
2015	Europe's first successful heart transplant via donation after circulatory death (DCD)

Since 1979, we have carried out around 3,000 heart, lung and heart-lung transplants, with world-leading survival rates, the shortest waiting lists and an increasing number of patients living 30+ years post-transplant.

Royal Papworth Hospital
NHS Foundation Trust

Working within the context of our environment:

- **Demand**
- **Finance**
- **System**
- **Workforce**

Royal Papworth Hospital
NHS Foundation Trust

- Know your governance structures
- Learn from best practice
- Engage with your leadership team
- Understand the wider context
- Listen to patients, staff and communities

These things will help when proposing developments and prioritisation of transplants and organ utilisation

Royal Papworth Hospital
NHS Foundation Trust

Thank you

Comments and questions welcomed

Compassion
Excellence
Collaboration

NHS
Blood and Transplant

Lessons from a CEO: Q&A

Please go to www.menti.com on your smartphone or tablet and enter code **2919 9319**

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Wrap up & Session Close

Diana Garcia Saez

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Recap: Final Reflection

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Thank you!