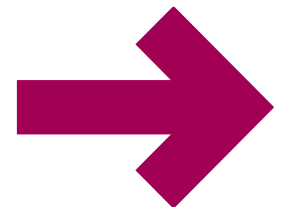


**Yorkshire and the Humber  
Renal Network**

**Transplant Forum**

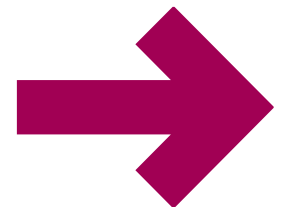
**15 May 2015, 09:30-12:15**



# Welcome & Introductions

**Dr John Stoves**

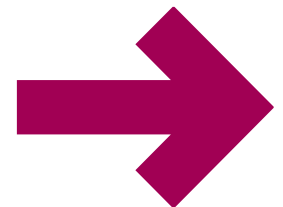
Consultant Nephrologist, Bradford Teaching Hospitals NHS FT  
Renal Clinical Lead, Yorkshire & the Humber Strategic Clinical  
Network



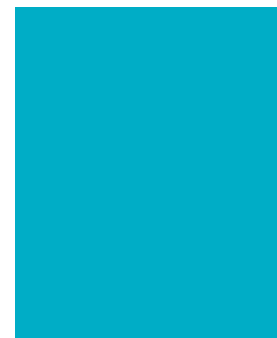
# Review of Previous Meetings and Actions

**Dr John Stoves & Dr Richard Baker**

Consultant Nephrologist, Bradford Teaching Hospitals NHS FT  
Renal Clinical Lead, Yorkshire & the Humber Strategic Clinical  
Network and Consultant Nephrologist, Leeds Teaching Hospitals  
NHS Foundation Trust

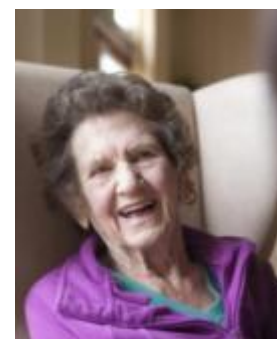
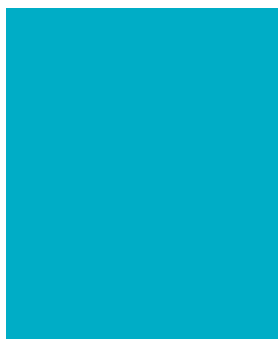


# Strategic Clinical Network for Yorkshire and the Humber Transplant Forum



Wakefield

15<sup>th</sup> May 2015



## Strategic Clinical Networks

*SCNs operate as engines for change across complex systems of care, maintaining and or improving quality and outcomes. They bring primary, secondary and tertiary care clinicians together with commissioners, partners from social care, the third sector and patients*

*SCNs are nationally mandated, hosted by NHS England and will receive funding for their core functions*



# A profile for Nephrology within a regional CVD Network

- Promote current and future regional priorities for Nephrology
- Strengthen links with primary care, CCGs and Collaborative Commissioning Groups – SYCOM, NEYCOM, 10CC
- Liaise with renal units, National Clinical Director, SCN renal leads, specialty leads (cardiac, diabetes, stroke), CRG leads
- Involve patients and patient representatives

# A profile for Nephrology within a regional CVD Network

- Renal Clinical Expert Group, LIGs/ CVD Strategy Groups
- Summarise care quality indicators – Public Health England QOF, Renal Registry/HES/NHSBT, Service Specifications (best practice, current initiatives, barriers to change)
- MDT regional forums (AKI, transplant, home therapies and shared care, conservative care)
- Support from the Clinical Senate and AHSN

## Key renal priorities for Yorkshire and the Humber in 2014-15

- Acute Kidney Injury
- Access to Renal Transplantation
- Assessing and managing variation



## Not forgetting ....

- Shared haemodialysis care
- Home therapies
- Conservative and palliative care
- Work Force Planning
- Care Planning
- Primary Care capacity, quality and expertise
- E-consultation
- Anaemia Management
- Emergency Planning
- Capacity Planning for Dialysis
- Transport
- Dialysis Away From Base
- Education (undergraduate, postgraduate, multidisciplinary)

## ... and other areas of interest

- Shared Decision Making – YoDDA
- Adolescent Link Worker/ Adult Support Worker
- Greener healthcare - procurement
- Sharing of patient electronic medical records between primary and secondary care

# Key Priorities

## Access to Renal Transplantation

Hatfield Hall  
Stakeholder Event  
30<sup>th</sup> September 2013



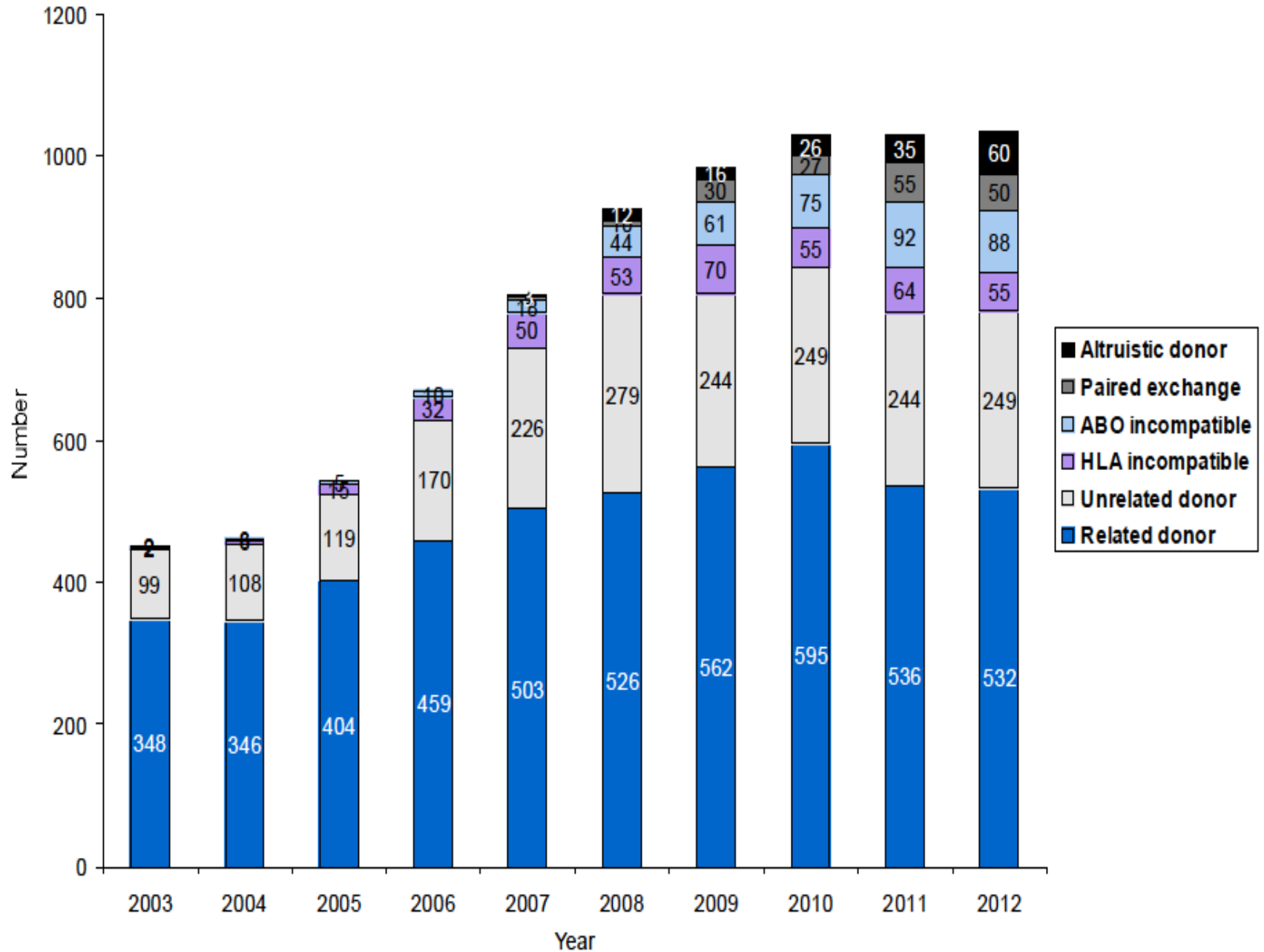
# Access to Renal Transplantation

- A regional MDT forum
- Issues of mutual interest
  - Donor and recipient assessment pathways
  - Timely Listing
  - Waiting list reviews
  - Annual consent and surgical review
  - Immunological assessments
  - Primary care communication
  - Transitional care

# Access to Renal Transplantation

- Case reviews
- Audit
- Telephone clinics
- Patient involvement
- Currencies/ tariff
- Repatriation of medicines

# Figure 1 Living kidney donor transplants in the UK, 2003-2012



# National Black, Asian and Minority Ethnic Transplant Alliance (NBTA)



## **NHS BT**

People from BAME communities only constitute 5% of organ donors despite representing 27% of those on the transplant waiting list

## **NBTA Forum: Moving Forward Together**

The NBTA is hosting a forum to showcase the work of the NBTA to date and to develop key 'big wins' to support national strategies. By sharing positive examples of BAME donation work we hope to demonstrate what has been achieved to date and what can be done going forwards to help make a real difference to the lives of BAME people affected by serious, life threatening conditions. The outcome from the day will, in particular, influence the implementation of the NHSBT Transplant 2020 strategy .

# Access to Renal Transplantation

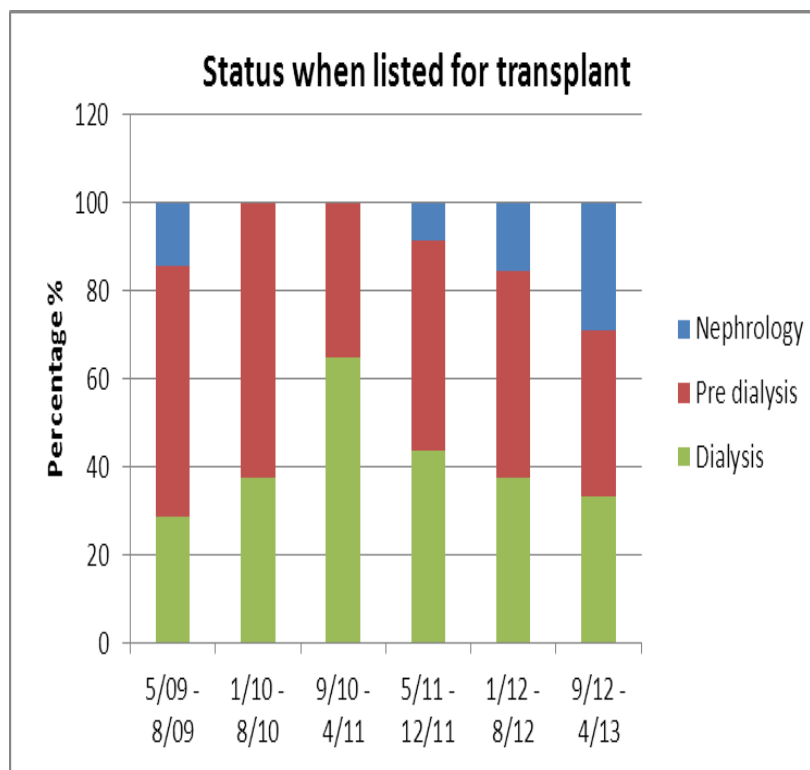
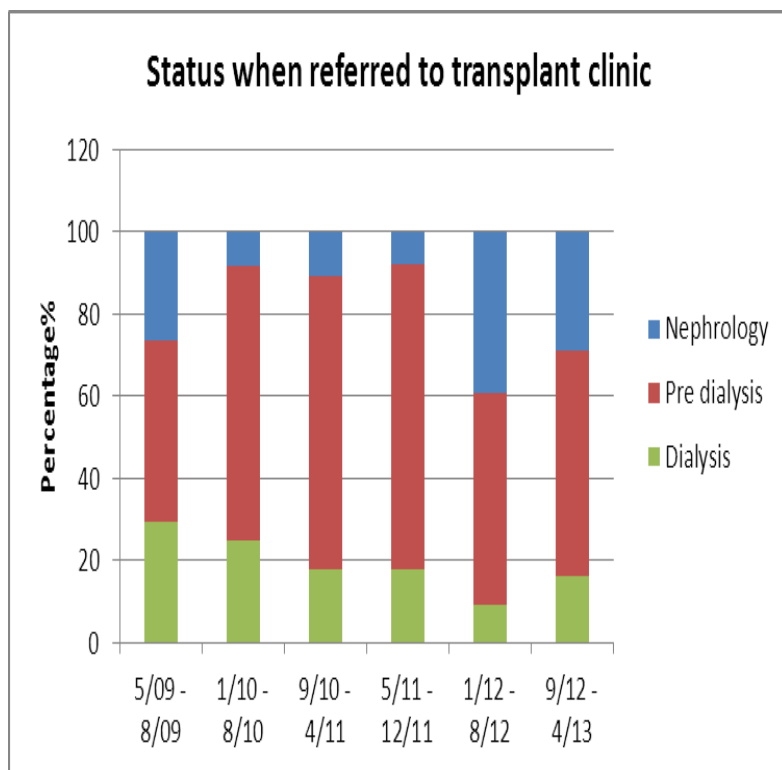
Access to Transplant and Transplant Outcome Measures (ATTOM) is an **NIHR** funded research programme, supported by the Department of Health, Renal Association, British Transplantation Society, UK Renal Registry, Scottish Renal Registry and NHS Blood and Transplant. ATTOM is a non-interventional, prospective, cohort study that aims to recruit all patients aged 18-75 years starting dialysis, receiving a transplant and a similar number of matched patients active on the transplant waiting list, from all dialysis and transplant centres in the UK over a one year period. The study aims are:

- To improve equity of access to kidney and pancreas transplantation across the UK

- To optimise organ allocation to maximise the benefit, from kidney and kidney-pancreas transplantation.



# Timely Transplant Listing



## Proposals for discussion

- A regional MDT Transplant Forum to share best practice from referral through work-up processes to post-transplant care
- Review the findings of the ATTOM study
- Support the work of BAME

# A Yorkshire and the Humber Transplant Forum for sharing and developing best practice

Sharing successes, challenges and barriers to  
change from multidisciplinary teams across the  
region and beyond

**2 meetings in 2014**

## First meeting topics

- Making the link between Transplant 2020 Strategy, the NBTA and local communities
- Harmonisation of living donor and recipient work-up pathways
- Timely listing for renal transplantation

## First meeting topics

### **Making the link between Transplant 2020, the NBTA and local communities**

- Kirit Modi, NKRF and NBTA
- Sadaqa Project in Birmingham
- Peer Educators
- Patient-led media campaign – TV, radio, newspapers
- Stakeholder meeting for a community-based project

## First meeting topics

### **Harmonisation of living donor and recipient work-up pathways**

- patient champions - ATTOM
- evening clinics
- primary care based altruistic pathway
- BAME focus

## First meeting topics

### **Timely listing for renal transplantation**

- Early referral
- Streamlined pathways for live donor and recipient
- A consistent regional approach to ensure timely surgical consent
- Structures, processes, relationships with other departments
- New bottlenecks
  - Dental screening
  - Cancer screening
  - BMI thresholds, weight management clinic

## Second meeting topics

- Patient perspectives, progress with NBTA, northern forum
- Cardiovascular risk assessment tools
- Surveillance to detect and treat post-transplant CMV and polyoma virus infection
- A consent model for potential renal transplant recipients
- CPEX protocols and reports



## Next steps agreed at last meeting

- Longitudinal metrics – pre-emptive listing for transplant
- Patient satisfaction surveys – sharing of resources
- Patients as champions and peer educators
- Telephone clinics
- Medicines management and medicines reconciliation
- Young Adult Worker
- Clinical guidelines for the acute admitting medical team

## Topics for today

- Progress with BK virus screening post-transplant
- Transplant currencies
- Repatriation of immunosuppressive medications
- IT developments
- Consent clinic update
- Measuring and reporting outcomes
- BTS, ATC and KPAG updates

# BK DNA PCR monitoring post-transplant

- All new renal transplant recipients
- 1,2 and 6 months or when transplant dysfunction
- BK, CMV, EBV, adenovirus .....
- Results in 7 days ....
- Initial findings
- Other centres?
- Scheduling

# Transplant Currencies

- Thank you for all your input into this work so far. As a quick update after our initial discussion a number of you volunteered to test and pilot the proposed template. We had several iterations of this template to improve and understand the underlying requirements and subsequently undertook some preliminary analysis of the data.
- Following this initial exercise we opened this invitation further and have received additional applications to supplement this original data. We have completed the analysis on the information submitted and would like to present them back to you on 29<sup>th</sup> April so we can plan the next steps.

# Transplant Currencies

- With regard to telephone clinics there are a number of options available in the reference cost returns for the Finance department to record outpatient activity, this includes new and follow up but also there is provision for face to face and non-face to face. You could use the outpatient follow up non face to face contact to record this (361).
- A normal tariff price is build-up of an average cost from all the national returns submitted so there will be occasions where those who are at the forefront of such developments should be in a position of receiving a greater proportion of tariff until the system catches up.

# Repatriation of immunosuppressive medications

- Home delivery
- Other medicines from primary care
- Prograf conversion/ BHLY
- Where switching within a transplant or renal unit from one critical dose immunosuppressant to another occurs, it is recognised that support will be needed to facilitate this change. Resultant savings must be shared across the NHS including the unit where the switch is undertaken.

## IT developments

- Transplant Outcome and Review screen
- Living donor pathway
- Consent clinic in Leeds
- Valganciclovir dosing
- Scheduling of BK virus testing
- Direct reporting of BK DNA PCR results into BHLY
  - Read coding/ unmapped results

- Patient Details
- Timeline & Summary
- Medications
- Biochemistry
- Haematology
- Virology & Immunisations
- Other Investigations
- Haemodialysis
- Low Clearance
- Conservative Managem...
- Peritoneal Dialysis
- Dialysis Access
- Transplant
- Live Donor Data
- Transplant Record...
- Paediatric
- Paeds to Adult Care
- Anaemia Management
- Dietetics
- Patient Trials
- Letters
- Reports & Interfaces
- Patient Charts**

Help & Info Dock zone

Transplant Record and Outcome

Transplant date  Created By

ODT Donor ID  Donor type  Tx type

Donor virology	Antibody/Antigen	PCR
CMV IgG	<input type="text"/>	<input type="text"/>
HBsAG	<input type="text"/>	<input type="text"/>
HBcAB	<input type="text"/>	<input type="text"/>
HCV	<input type="text"/>	<input type="text"/>
HIV	<input type="text"/>	<input type="text"/>
EBV	<input type="text"/>	<input type="text"/>
HTLV	<input type="text"/>	<input type="text"/>
Toxoplasmosis	<input type="text"/>	<input type="text"/>

Discharge handover

Induction medications

**Biopsy d** **Biopsy report**

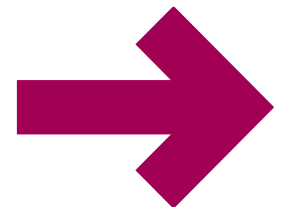
Number of stents



# Sharing Outcome Data Across the Region

**Dr John Stoves**

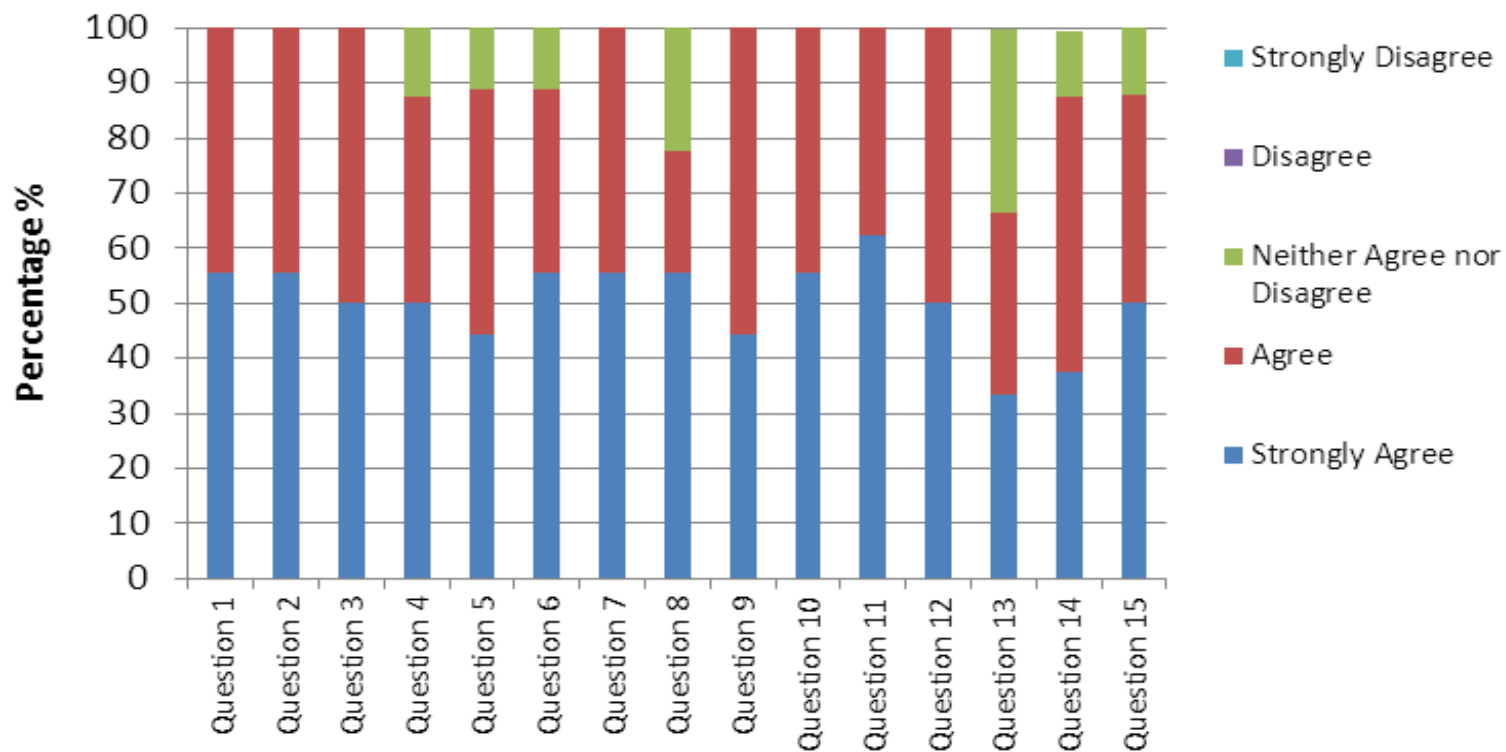
Consultant Nephrologist, Bradford Teaching Hospital NHS Foundation Trust and Renal Clinical Lead, Yorkshire & the Humber Strategic Clinical Network



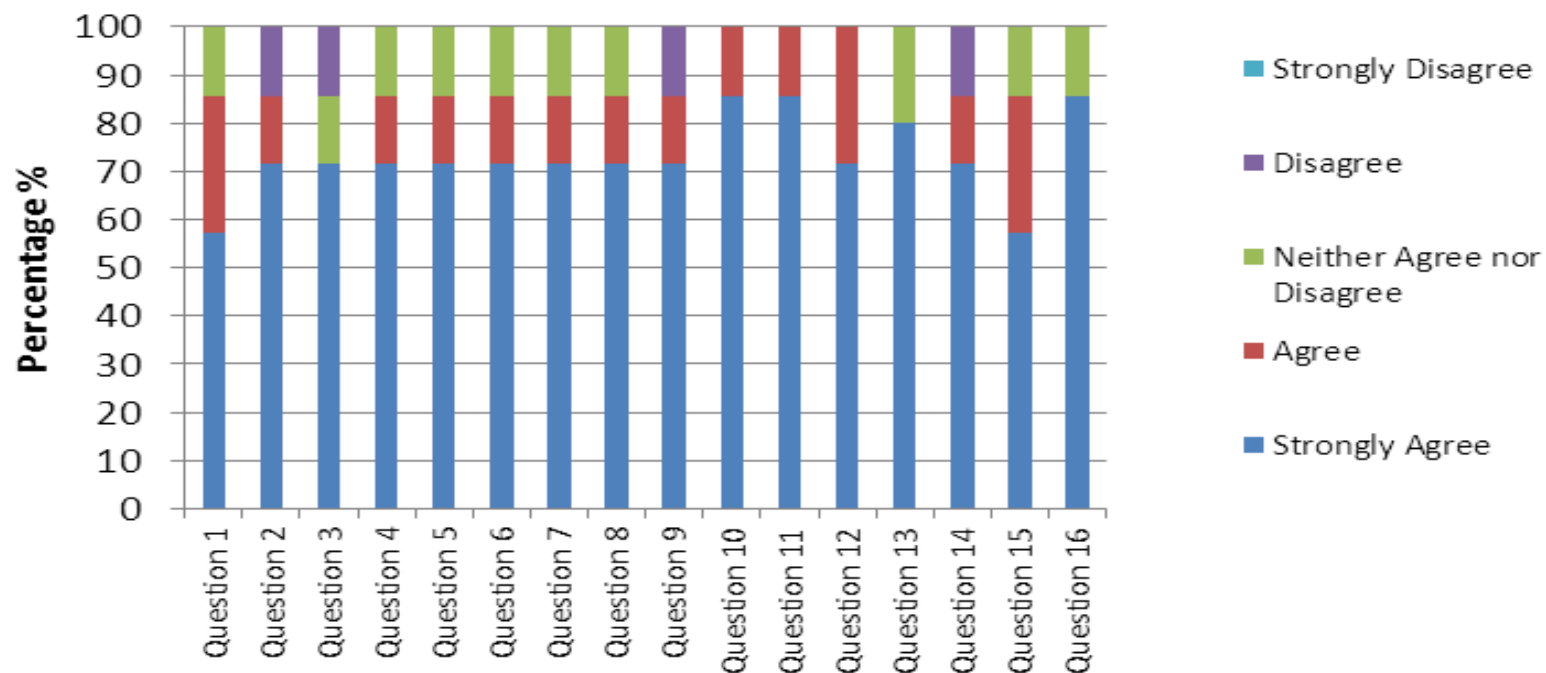
# Measuring and reporting outcomes

- Pre-emptive listing for transplantation
- Patient satisfaction surveys – including the new consent clinic
- Centre-specific outcomes
- BHLV Quick Reports

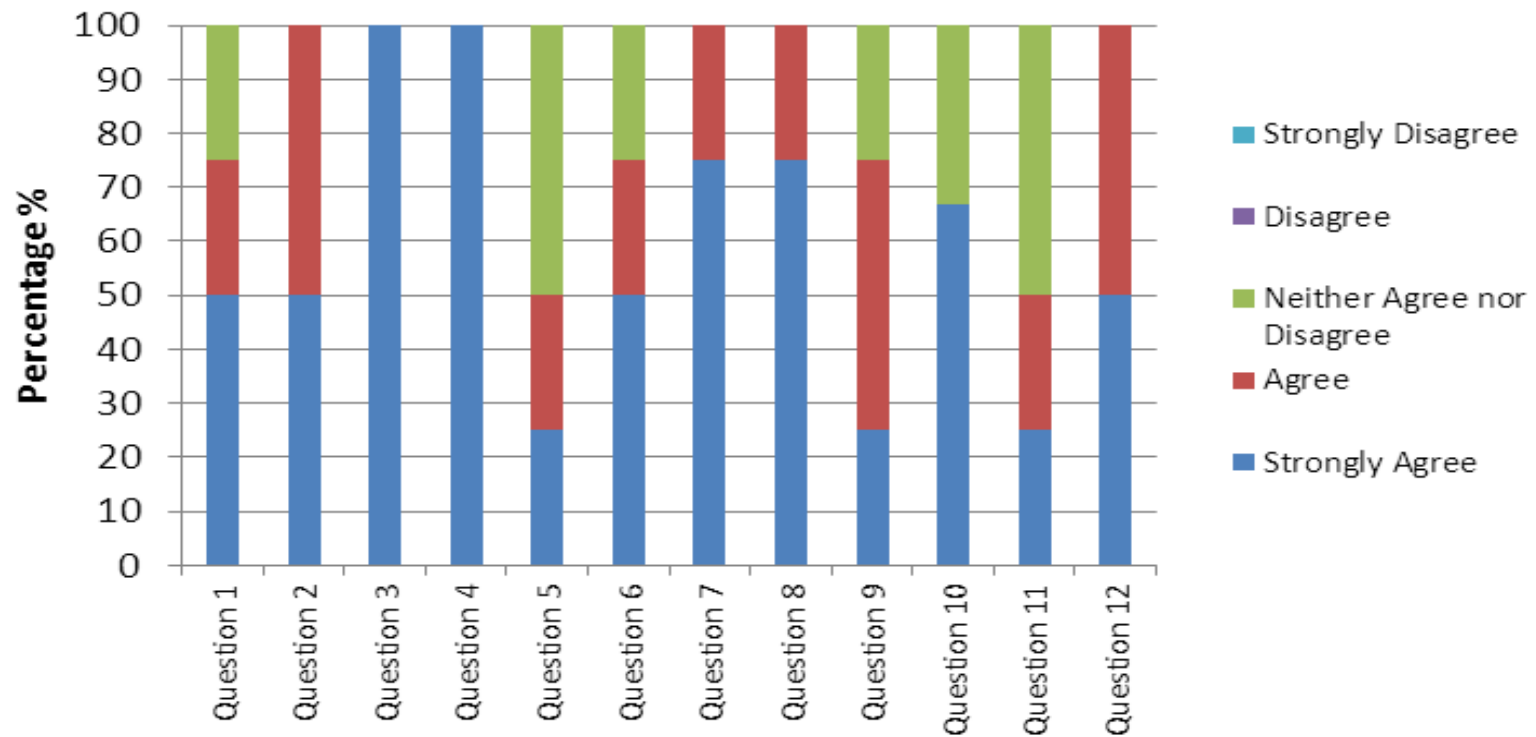
## Transplant Assessment Survey

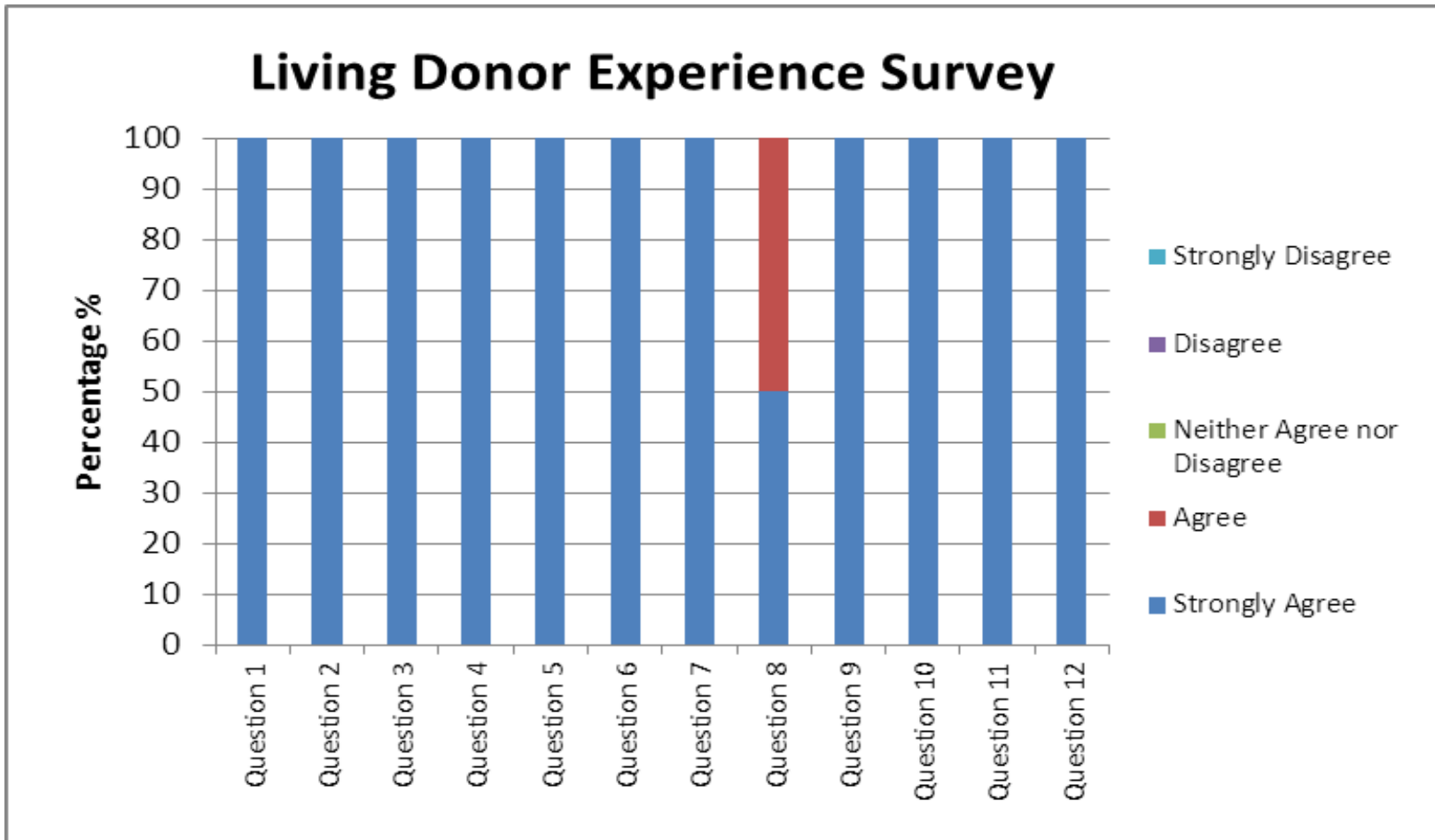


## 90 days Post Transplant Survey



## Annual Post Transplant Survey



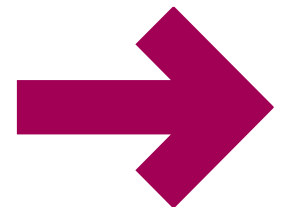


# Patient Comments

# The Consent Model and Patient Pathway in Yorkshire and the Humber

**Dr Matthew Wellberry-Smith**

Consultant Renal Physician, Leeds Teaching Hospital NHS Foundation  
Trust

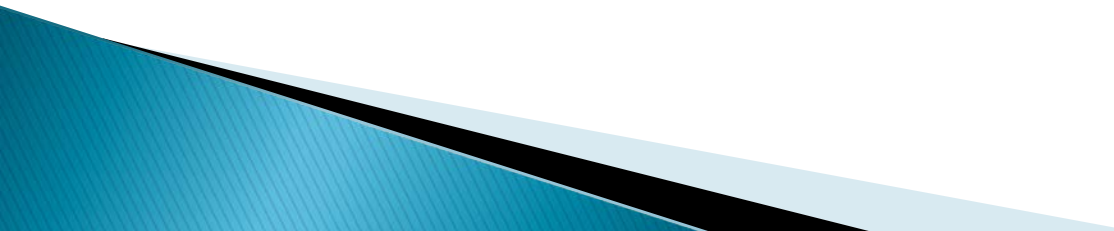





# Update on the Renal Transplant Listing / Annual Review clinic

M Welberry Smith

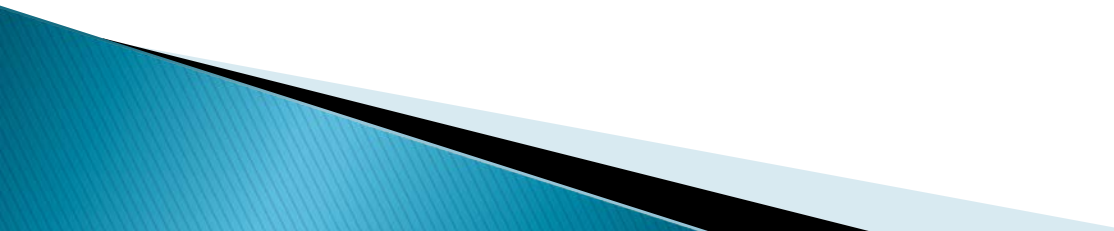
# Outline

- ▶ Drivers
  - ▶ Mechanics / practicalities
  - ▶ Outcomes
- 

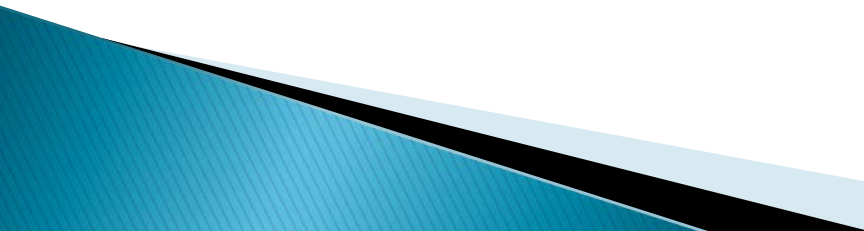
# Drivers

- ▶ Doing the best for our patients
  - ▶ Avoiding poor outcomes
    - Death
    - Poor graft outcomes / early graft loss
  - ▶ Making the best use of precious resource
  - ▶ National Guidance
  - ▶ i.e. Quality care!
- 

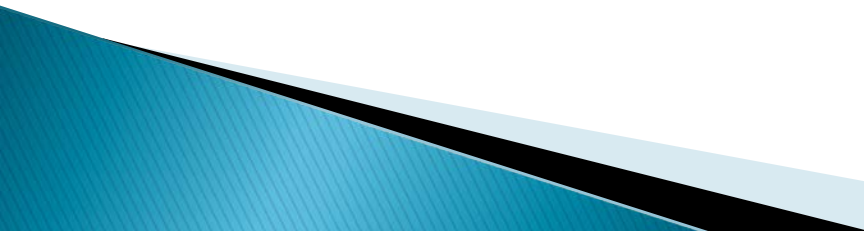
# Outstanding issues when last presented

- ▶ Venue
  - ▶ Date / time
  - ▶ Up and running
  - ▶ Remains a work in progress to develop over time
- 

# Anecdotes

- ▶ Recently listed
  - ▶ Clear classic history of longstanding cardiac chest pain, not investigated further than baseline ECG.
  - ▶ Intermittent claudication with no MRA
    - Suspended pending investigations
- 

# Mechanics

- ▶ Pre-listing
    - Proforma
    - Fax across + relevant results
    - BHL Y entry
    - Transfer PACS images
    - All at least 48h before appt
    - (Note this is deliberately separate to the listing MDT)
  
  - ▶ Prior to annual review – the same
- 

# Mechanics

- ▶ Attendance a requirement for listing
  - “Active subject to Leeds review”
  - Review in Leeds (aim) within 6/52
- ▶ 2x DNAs to annual review clinic = suspension
  - (though clearly only if no good reason!)
- ▶ **But note** option to formally opt out, by signing specific form via local nephrology team (to be returned to Leeds transplant coordinators)

# Proforma

Please note: It is a requirement of registration on the Renal Transplant Register that all patients attend an annual review in Leeds. New activated patients are registered 'subject to review' until they have attended clinic. Failure to attend two consecutive appointments will result in automatic suspension on the Renal Transplant Register.

New activation clinic

Annual review clinic

Will your patient require an interpreter? Y  N  Language \_\_\_\_\_

Will your patient require transport? Y  N  Transport with Escort  Wheelchair access

Most recent clinic letter attached (please include diagnosis list)

Previous Renal Transplant Y  N

If yes, Date of Transplant \_\_\_/\_\_\_/\_\_\_ Date of graft failure \_\_\_/\_\_\_/\_\_\_

Reason: \_\_\_\_\_

Smoker Y  N  Ex-Smoker  If yes or previous smoker, No. per day \_\_\_ for \_\_\_ years

Most recent Newcastle Score: \_\_\_\_\_

Date assessed: \_\_\_\_\_

Current exercise tolerance \_\_\_\_\_ yards

Claudication Y  N  Distance \_\_\_\_\_ yards Comments \_\_\_\_\_

Cardiac symptoms/events

Chest pain  SOB  NSTEMI / MI  Date \_\_\_/\_\_\_/\_\_\_

ECG  MRS/other stress test  Coronary Angiogram

(results attached)

Respiratory symptoms/events

SOB  Persistent Cough  Haemoptysis

Chest x-ray  CT

(results attached)

Other investigations/events

MRA (pelvic or lower limb)  Previous DVT  Left / Right (circle) Date \_\_\_/\_\_\_/\_\_\_

Previous anaesthetic complications Y  N

Previous abdominal surgery Y  N  Type \_\_\_\_\_ Date \_\_\_/\_\_\_/\_\_\_

Details \_\_\_\_\_

(results attached)

PACs images required/sent Y  N

BHLY update complete Y  N

Any other new or relevant clinical information

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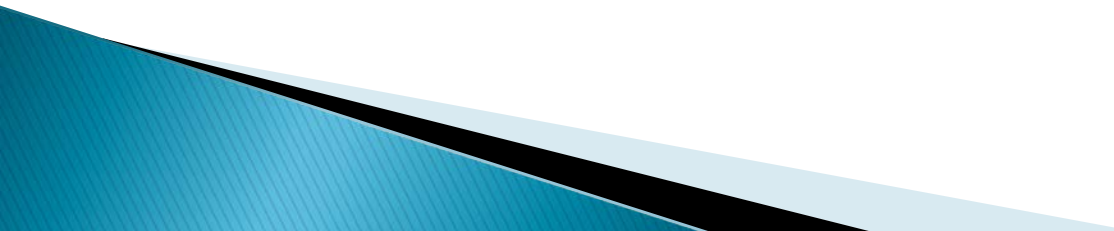


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Please ensure this referral and all relevant information has been submitted to the renal transplant office in Leeds one week prior to your recipient's appointment. This can be faxed on 0113 2384124 or via email [leeds@bcr.nhs.uk](mailto:leeds@bcr.nhs.uk) or [leeds@bcr.nhs.uk](mailto:leeds@bcr.nhs.uk)  
Please make sure you have received confirmation of receipt.



# Surgical consent – specific points

- ▶ Surgical risks
  - ▶ Dual and en-bloc considerations
  - ▶ Need for 3<sup>rd</sup> party vessels
- 

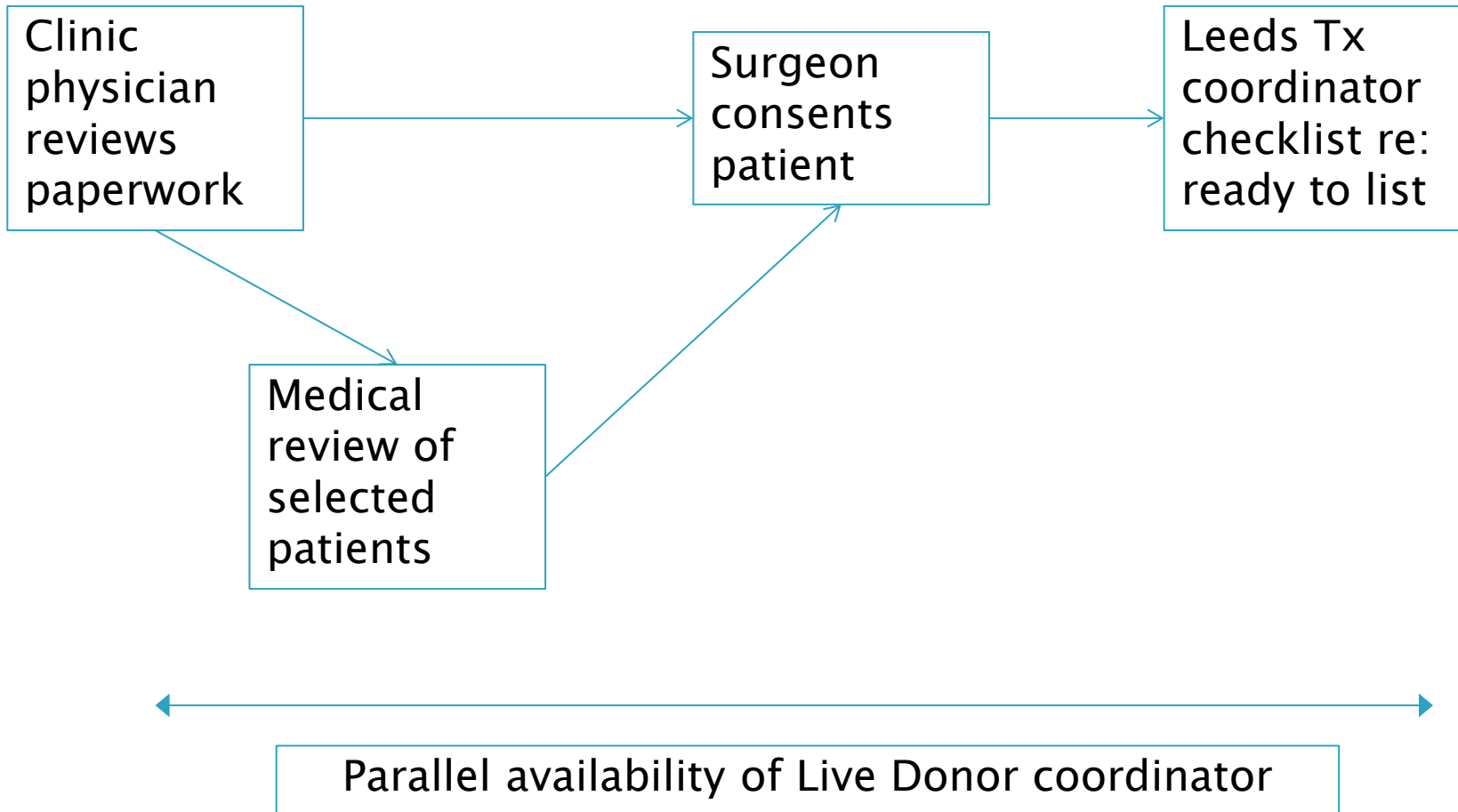
# For listing: Pre-clinic

Patient watches DVD (with family)

Pre-clinic paperwork

- Proforma
- BHLy Tx assessment screen
- Completed locally 1 week before appointment

# For listing: In clinic



# For listing: After clinic

All patients taken  
to Leeds MDT

# Annual consent: Pre-clinic

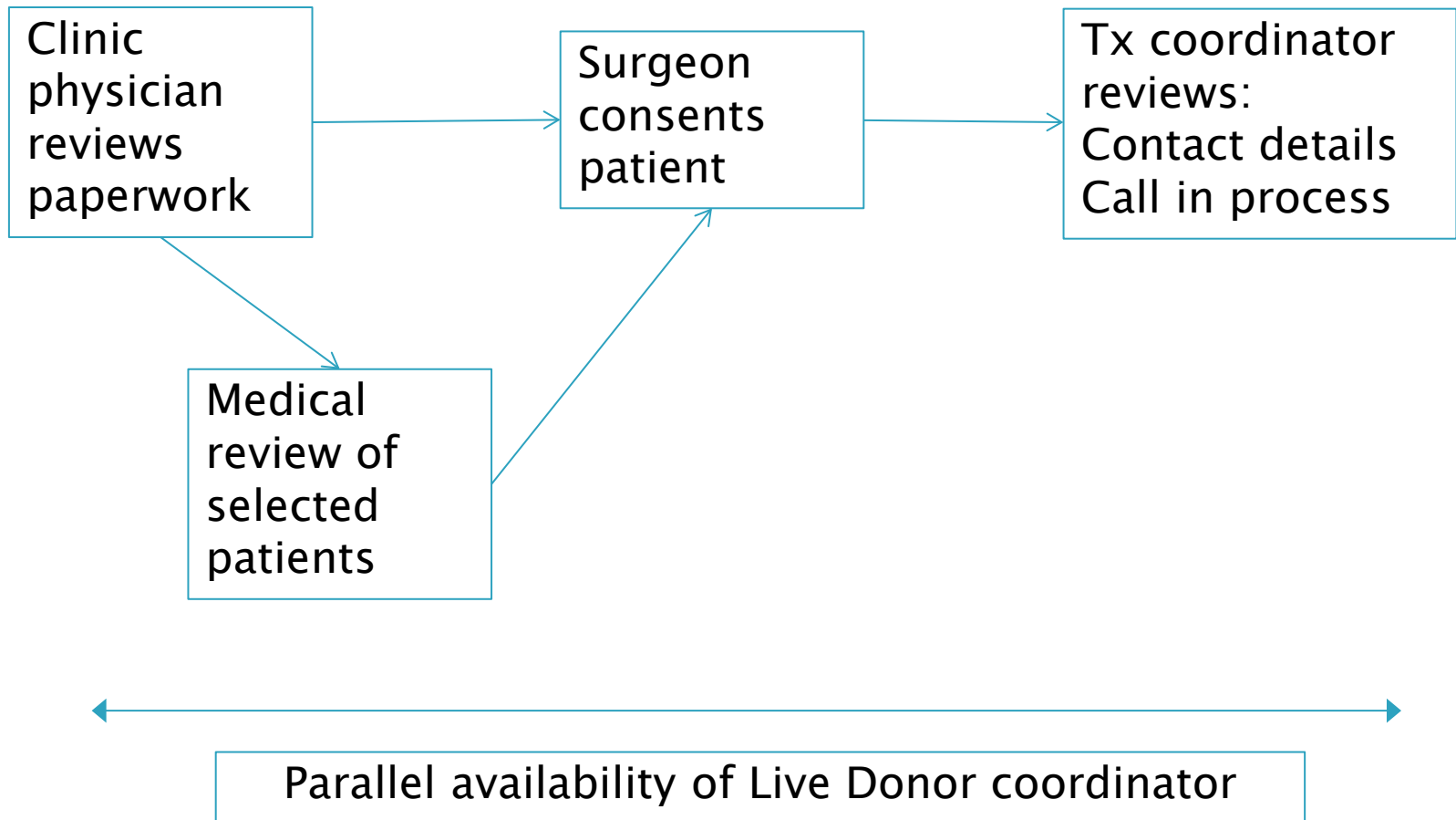
Patient watches DVD (with family)

Local pre-clinic paperwork update

(1 week before appointment)

?new clinical events

# Annual consent: In clinic



# For both listing and annual review

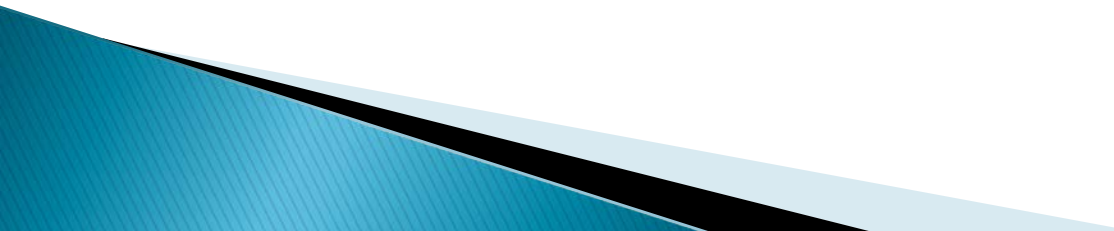
- ▶ Where new clinical event(s) or reasons for re-testing / reconsideration are identified:
  - Test(s) proposed then performed locally
  - Result to Leeds Tx coordinators
  - Review at Leeds MDT
  - Decision on listing / next move

# Outcomes


- ▶ Doing the best for every patient
  - The people we call for transplant are fit to receive one; we don't call people who will suffer
- ▶ Making the best use of every organ
  - Allocating organs appropriately



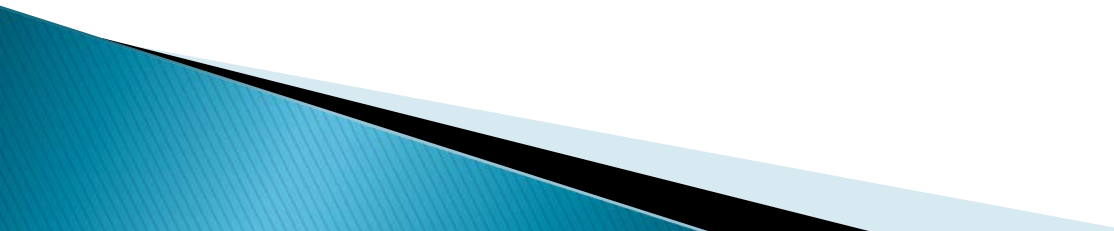
# Metrics – measuring the utility of a consent / waiting list clinic

- ▶ Patients removed from list
  - ▶ Extra tests ordered (and outcomes of reviewing them)
- 

# Worth the effort?

- ▶ Hard to be sure, but anecdotes good so far!
  - ▶ Audit
  - ▶ 2 year “run in” and annual audits planned
  - ▶ Intangibles are usually unmeasurable
    - (e.g. possible improvements in satisfaction from correctly managed expectations?)
- 

# Outline

- ▶ Drivers
  - ▶ Mechanics / practicalities
  - ▶ Outcomes
- 



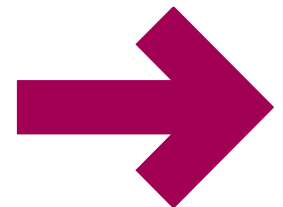
Leeds Transplant  
Centre

# Discussion / Questions

# BTS, ATC and KPAG Update

**Dr Richard Baker**

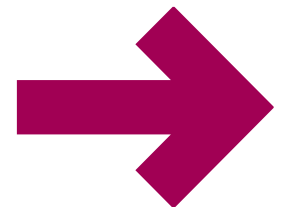
Consultant Nephrologist, Leeds Teaching Hospitals NHS  
Foundation Trust



# Next Steps & Closing Remarks

**Dr Richard Baker**

Consultant Nephrologist, Leeds Teaching Hospitals NHS  
Foundation Trust



# Thank You for Attending!

## Don't forget to complete your evaluation forms!

