

A thick blue wavy line that starts on the left, dips down, and then rises towards the right, spanning the width of the slide.

Can we use the guidelines to drive best practice in donor follow up?

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Clinical Lead- Living Donation

UK LKD Network Meeting, February 2020

Caring Expert Quality

Overview

- Why do we follow donors up at all?
- What does the data tell us?
- What do we need to improve?
- What could we do differently?



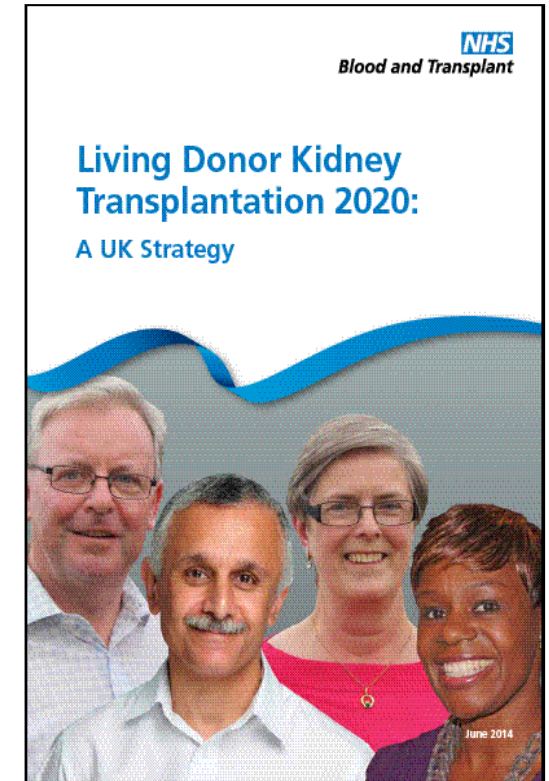
Why do we follow donors up at all?

European Legal/Regulatory Framework

- **EU organ Donation Directive 2010/53/EU**
 - Donor registry/record, follow-up systems (Art 15)
 - https://ec.europa.eu/health/sites/health/files/blood_tissues_organs/docs/directive_2010_45_en.pdf
- **Council of Europe**
 - Resolution CM/Res(2017)1 on principles for the selection, evaluation, donation and follow-up of the non-resident living organ donors
 - https://www.edqm.eu/sites/default/files/cmres_2017_1_on_principles_for_selection_eval_donation_and_follow_up_of_nrld.pdf
 - Resolution CM/Res(2015)11 on establishing harmonised national living donor registries with a view to facilitating international data sharing
 - https://www.edqm.eu/sites/default/files/resolution_on_establishing_harmonised_national_living_donor_registries_with_a_view_to_facilitating_international_data_sharing_2015_11.pdf

We committed to

- Increase living donor kidney transplantation (LDKT)
 - Address unwarranted variation
 - More options for LDKT
 - More living donors
- Improve recipient outcomes
 - Increase pre-emptive LDKT
 - Maximise UK living kidney sharing scheme (UKLKSS)
 - Disincentivise travel outside UK for a transplant
- Look after donors
 - Remove unwarranted barriers to donation
 - Ensure the best outcomes and donor experience

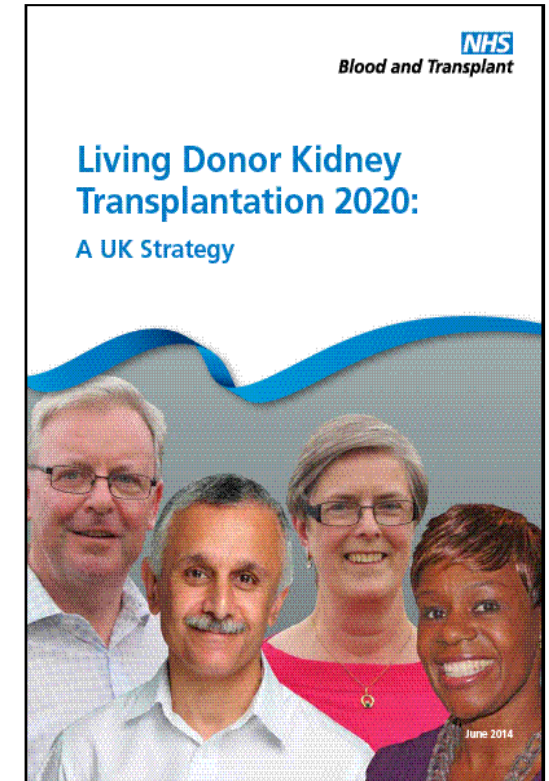


“To match world class performance in living donor kidney transplantation”

Measurable Outcomes

1. Global benchmarking

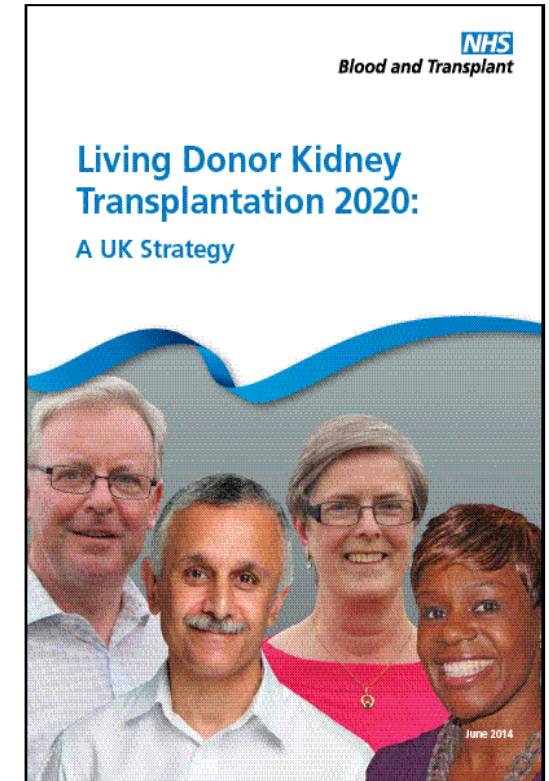
- a. LDKT rates of 26 per million population (pmp) across the UK with less variance and equivalent rates in each UK country
- b. Adherence to evidence based clinical practice guidelines by monitoring donor death and serious complication rates as defined within the guidelines
- c. 100% data capture for donation episode and 80% for life-long follow in the UK and pan EU (in development) living donor registry.



“To match world class performance in living donor kidney transplantation”

Risks to Delivering LDKT 2020

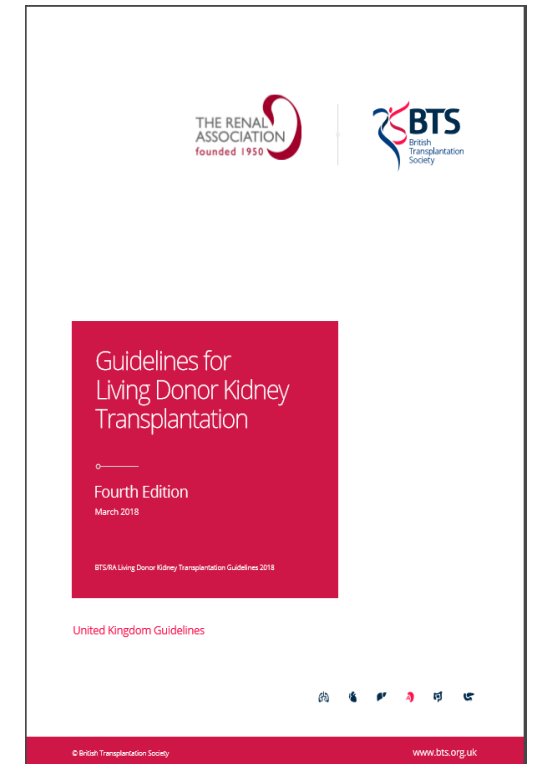
- Delivery dependent upon
 - Effective leadership within the wider transplant community – healthcare professionals, health departments, commissioners, other authorities, NHS Blood and Transplant and patient associations
 - Engagement from society and the wider transplant community
 - National commissioning for LDKT in all four UK countries to support integrated, UK-wide practice
 - Streamlining of organisational processes and clinical pathways to support best clinical practice



“To match world class performance in living donor kidney transplantation”

What do the guidelines say?

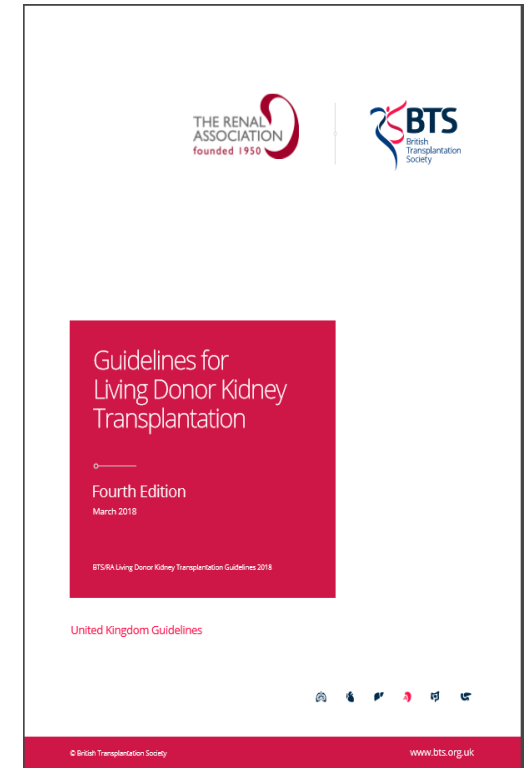
*‘The **continued success of living donation** depends upon ensuring the **safety and excellent long-term outcomes** of the donor. In particular, **donors must be reassured that the risk both of** developing progressive **CKD and of premature cardiovascular death remain low** following nephrectomy’.*



BTS/RA UK Guidelines, 4th Edition, 2018
https://bts.org.uk/wp-content/uploads/2018/07/FINAL_LDKT-guidelines_June-2018.pdf

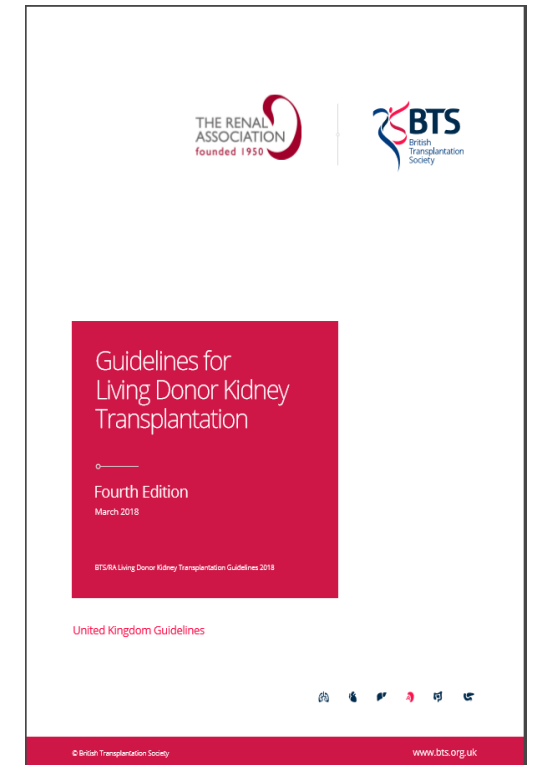
What do the guidelines say?

- **Counselling and consent of potential living kidney donors** must include **acknowledgement** that the **baseline risk of ESRD is increased by donation** (A1)
- **Discussion with potential donors must be informed by those factors known to increase ESRD risk post-donation**, including donor age, sex, race, BMI, and a family history of renal disease (A1)
- **Risk calculators predicting lifetime ESRD risk** may help **inform the consent process**. (C2)



What do the guidelines say?

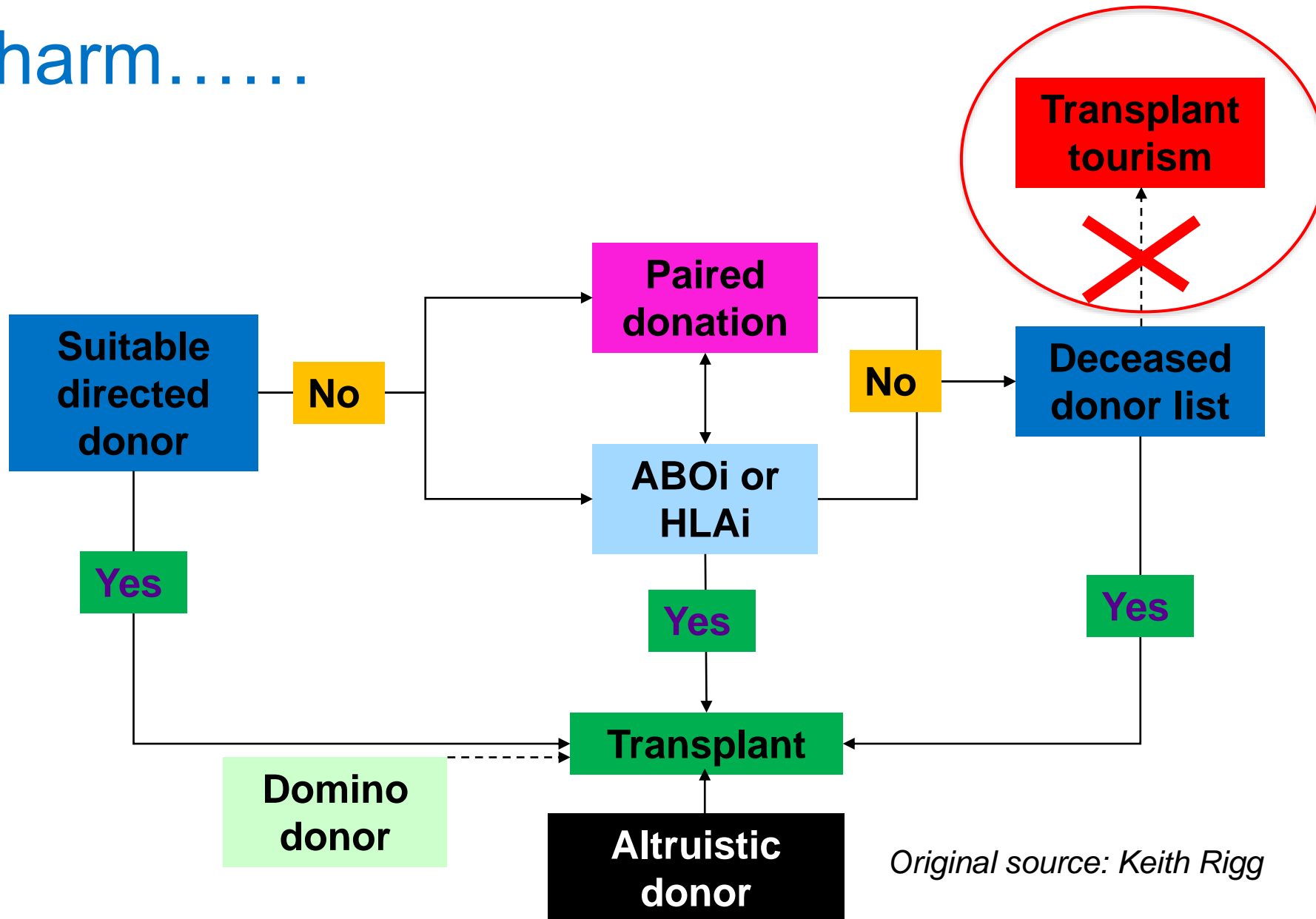
- The risk of ESRD in living donors **mandates lifelong follow-up after donor nephrectomy**. For donors who are resident in the UK, this can be offered locally or at the transplant centre according to the wishes of the donor, but such **arrangements must secure the collection of data for submission to the UK Living Donor Registry**. (B1)
- Donors who are **non UK residents and travel to the UK to donate** (privately or to a NHS entitled recipient) are not entitled to NHS follow-up but **must be given advice about appropriate follow-up** before returning to their country of origin. (C1)



BTS/RA UK Guidelines, 4th Edition, 2018

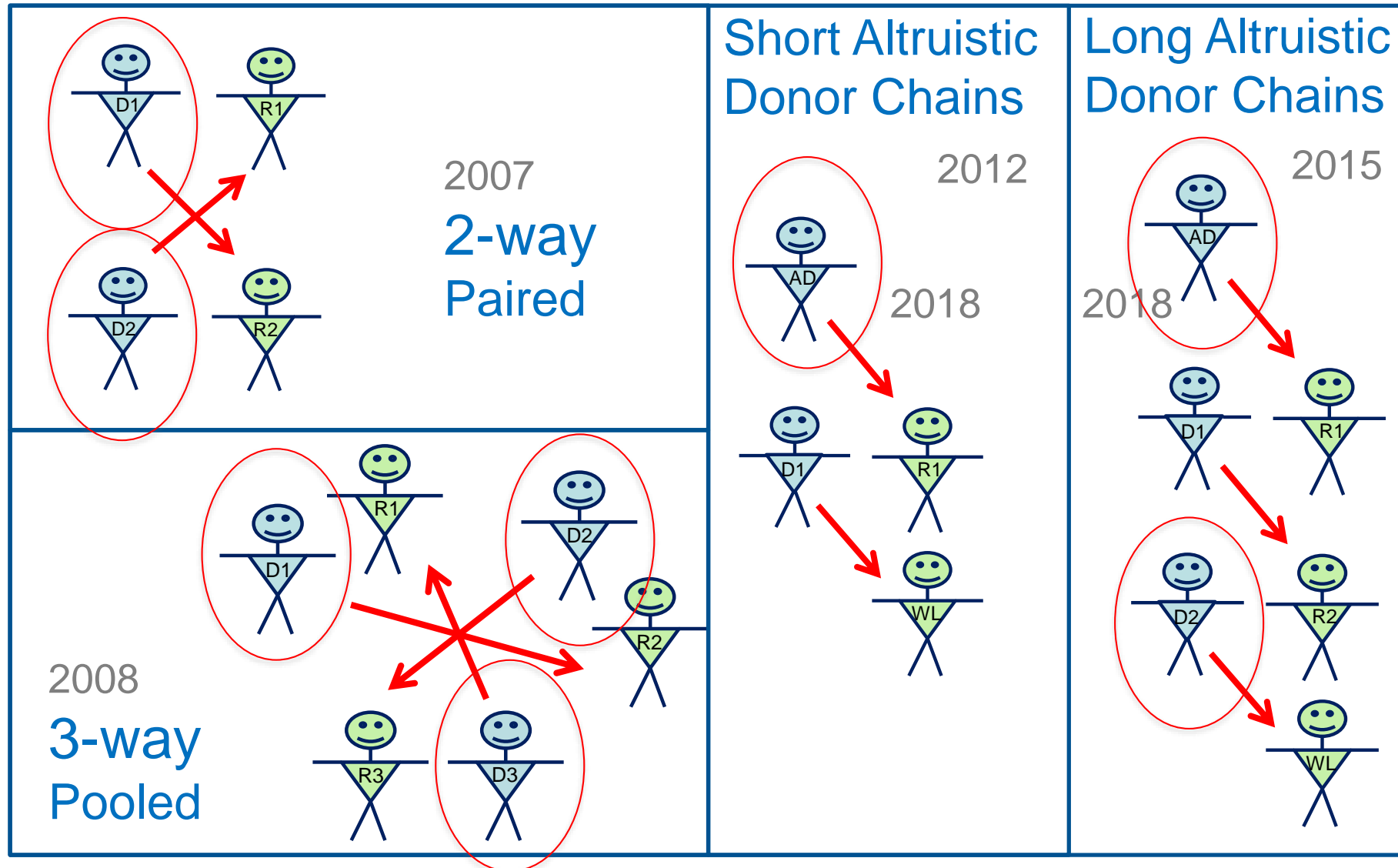
https://bts.org.uk/wp-content/uploads/2018/07/FINAL_LDKT-guidelines_June-2018.pdf

Do no harm.....



Original source: Keith Rigg

UK Living Kidney Sharing Scheme



January 2019

January 2020

- Self-reported **experience**
 - **Assessment**
 - **Hospital stay**
 - **After donation**
- Collected in UK Living Donor Registry
 - **Post donation:** 1 year anniversary

What does the data tell us?

Figure 6.1 Number of Living Kidney Donors, 1 April 2004- 31 March 2018

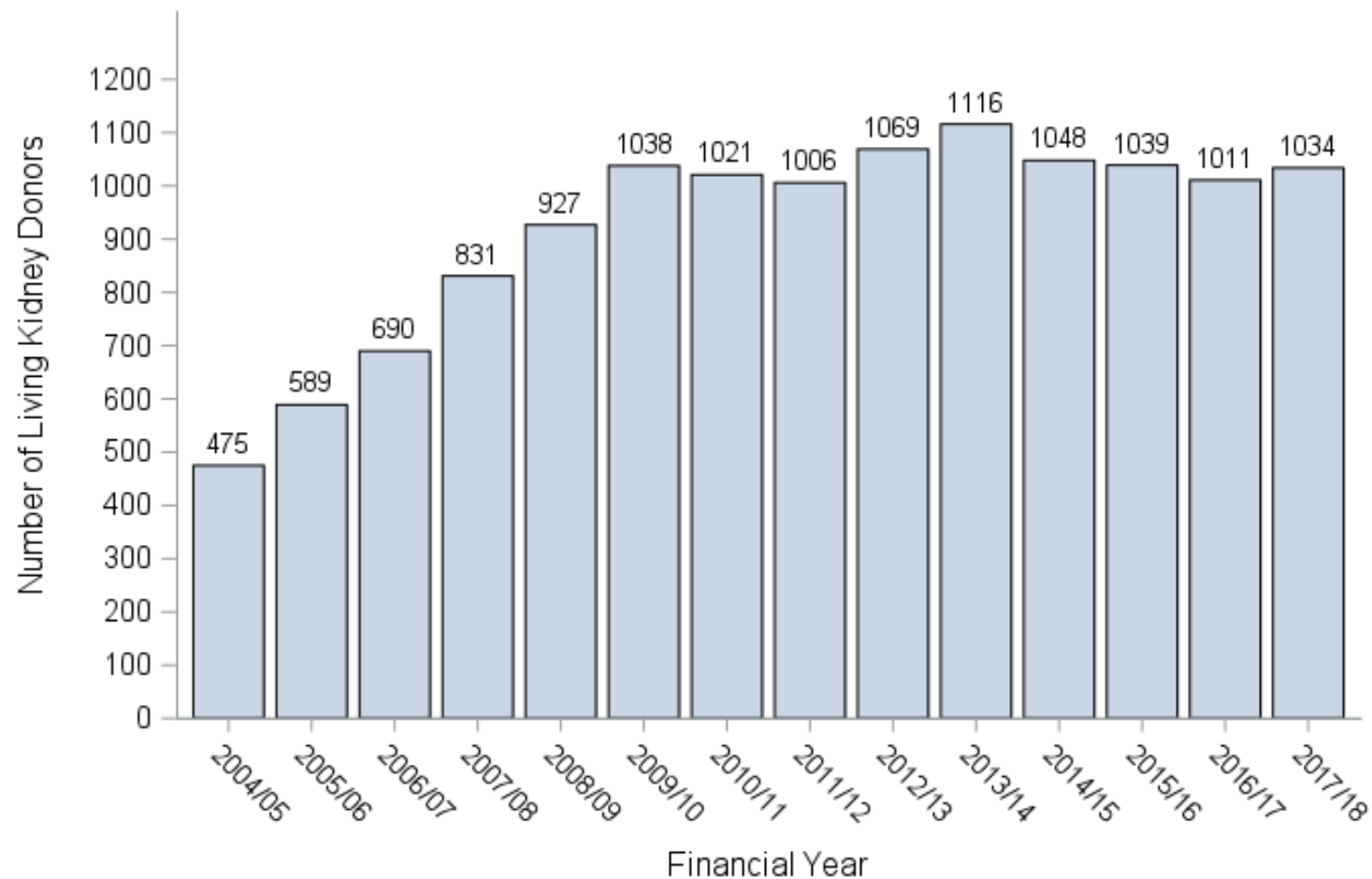
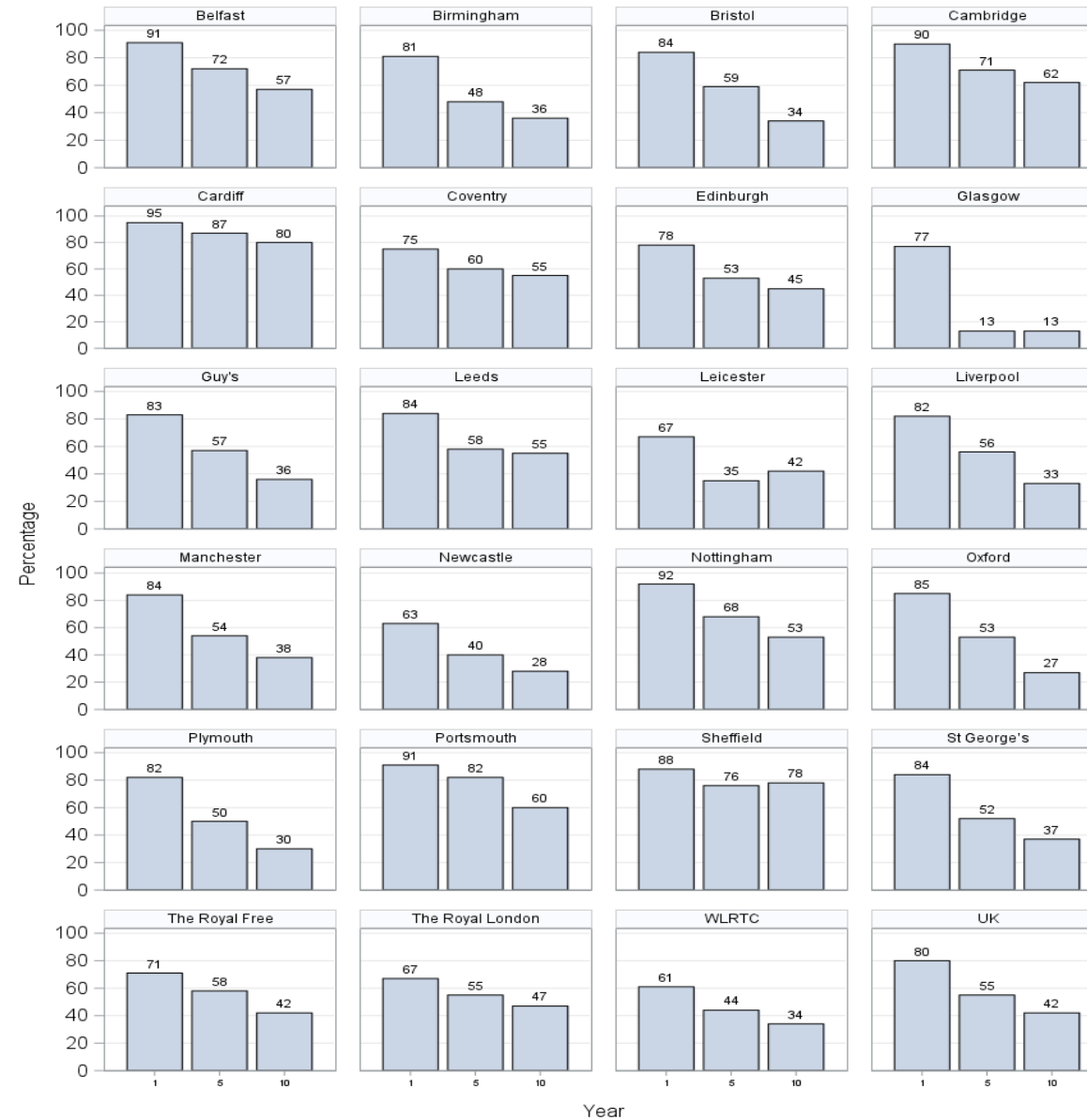


Figure 6.5 Percentage of donors with follow-up reported, by centre



15 centres achieve >80% follow-up at 1 yr.

1 centre achieves >80% follow-up after 1 yr.

Serum Creatinine*

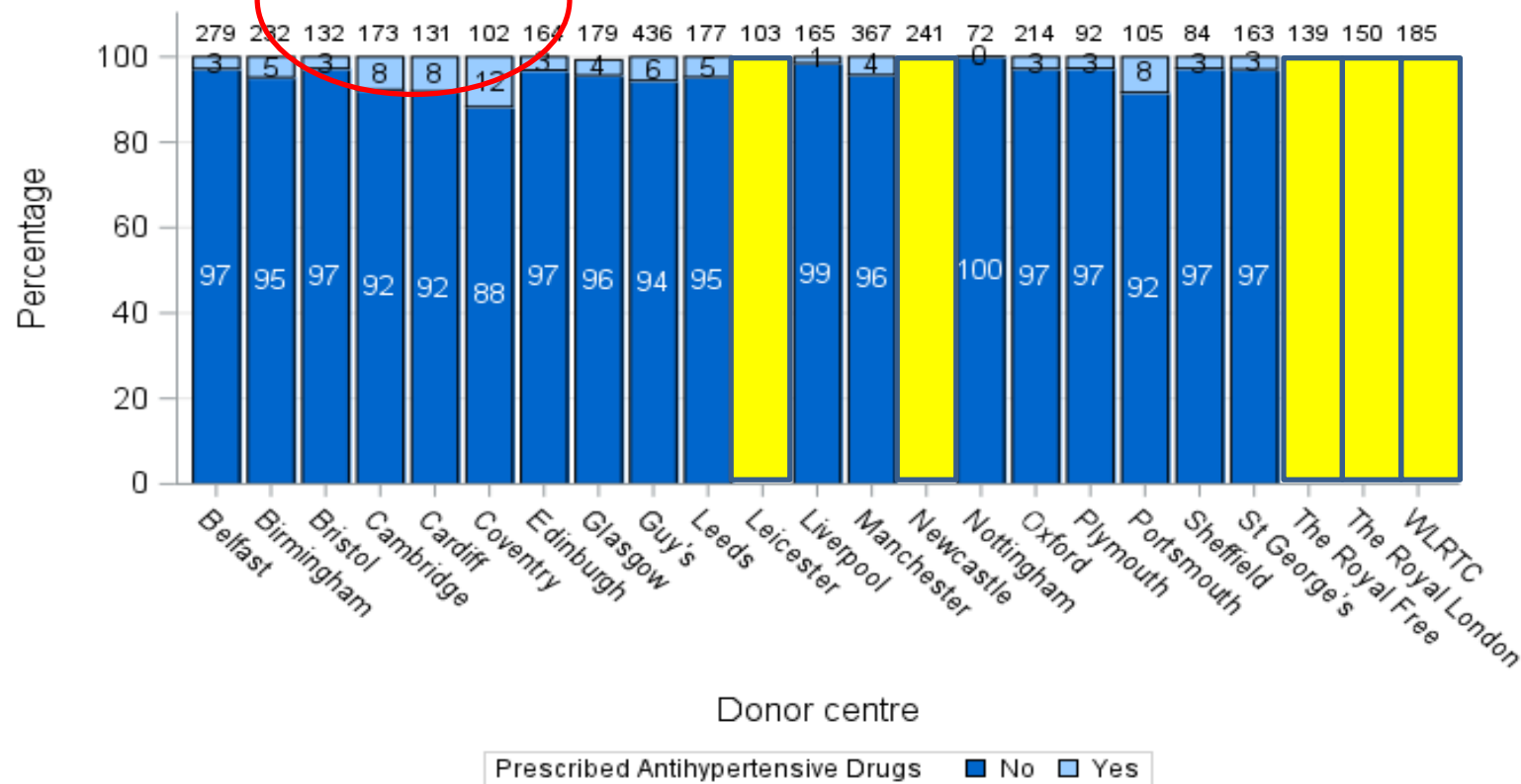
Donor Follow-up	No. of eligible donors (2004-2018)	% data returned	Variation in % rate across UK centres
1 year	4085	80%	61-93%
5 year	5222	55%	13-87%
10 year	3487	41%	13-80%

**Annual report on Living Donor Kidney Transplantation 2018/19, NHSBT
UK LKD Network Newsletter, September 2019, Issue 8*

<https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/16950/edition-8-quarterly-uk-living-donor-network-september-2019.pdf>

Blood Pressure

Figure 6.2 Percentage of Donors Prescribed Antihypertensive Drugs at 1 Year Follow-up Donations 1 April 2014- 31 March 2018



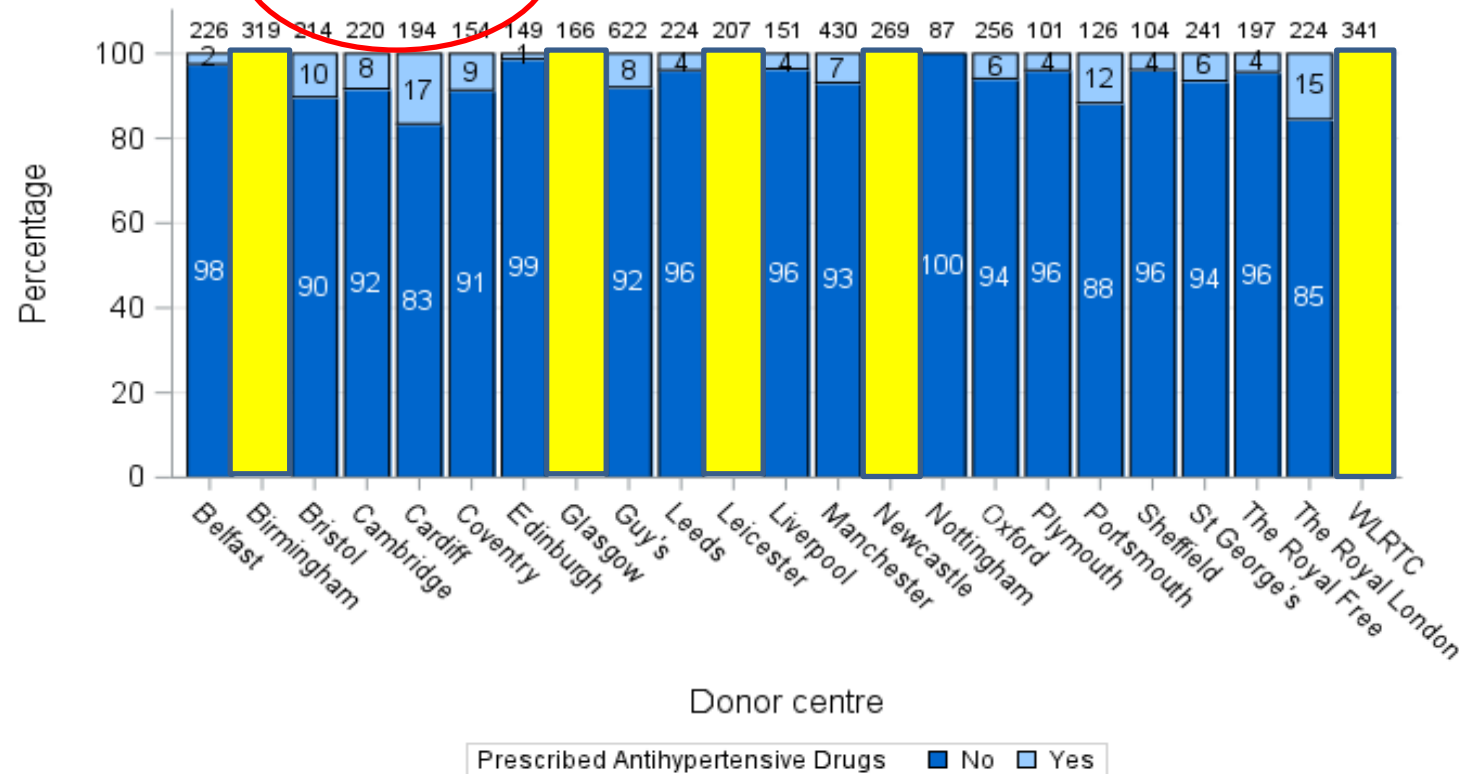
Percentages are omitted where less than 75% of data reported

Blood Pressure



Blood and Transplant

Figure 6.3 Percentage of Donors Prescribed Antihypertensive Drugs at 5 Year Follow-up Donations 1 April 2009- 31 March 2014



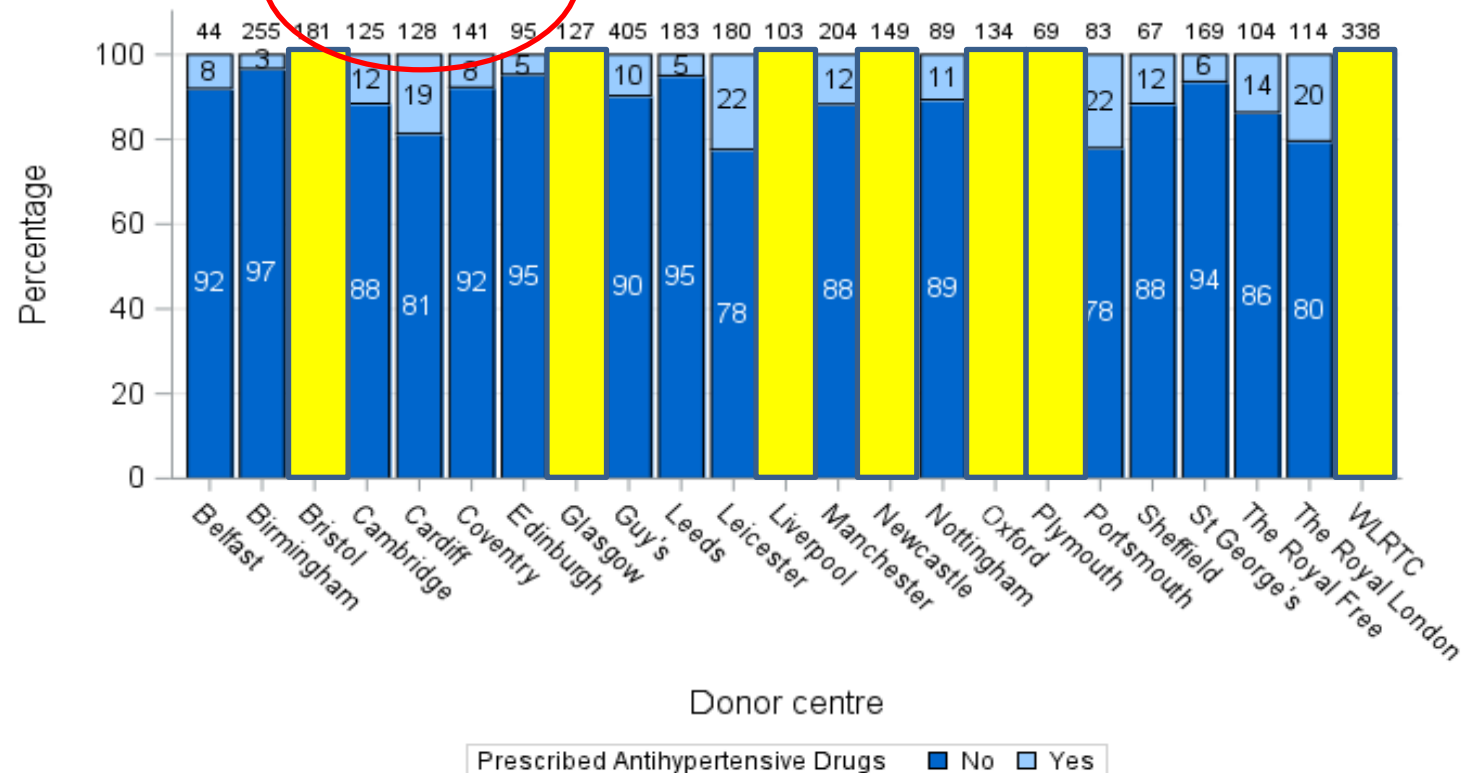
Percentages are omitted where less than 50% of data reported

Blood Pressure



Blood and Transplant

Figure 6.4 Percentage of Donors Prescribed Antihypertensive Drugs at 10 Year Follow-up, Donations 1 April 2004- 31 March 2009



Percentages are omitted where less than 35% of data reported

What do we need to improve?

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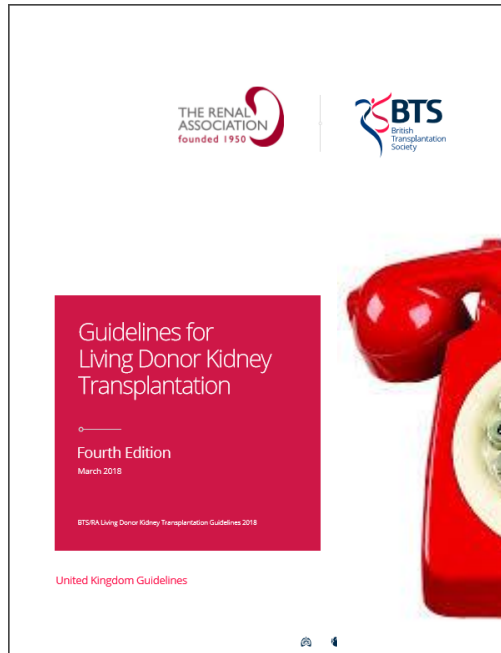
Challenges

- Completeness of registry data
 - Clinical
 - Self-reported
 - Paper-based system; manual collection and analysis
- Accurate time points for data collection and timely reporting to NHSBT
 - Anniversary visits
- Increasing number of donors in follow-up
 - Centre-based; face to face visits

What could we do differently?

A decorative graphic at the bottom of the slide consisting of two overlapping wavy bands of blue, with the top band being a lighter shade than the bottom one.

Consider.....



Setting up a Skype Clinic

A practical guide



**Toolkit:
Part 1**

Elements and requirements

**Toolkit:
Part 2**

Where to perform follow-up and by whom

**Toolkit:
Part 3**

How to perform follow-up

BTS/RA UK Guidelines Chapter 10, pp254
https://bts.org.uk/wp-content/uploads/2018/07/FINAL_LDKT-guidelines_June-2018.pdf



Acknowledgements

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LDKT 2020 Strategy Implementation Group

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DROM/DREM

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JOIN US!

Our membership is open to everyone working professionally in the field of transplantation, whatever your role. It includes clinicians from a wide range of specialities, basic scientists, scientists working in Histocompatibility and Immunogenetics, nurses, donor coordinators, professions allied to medicine and ethicists and more.

There are significant opportunities and professional benefits for members and we strongly encourage all those working in the field to join us to ensure that we are truly representative of the sector and to help make our voice even stronger.

The voice of transplantation professionals in the UK, providing leadership, representation and guidance for the benefit of our patients.

This purpose is supported by four strategic objectives:



ADVANCE

To advance scientific and clinical research and innovation relevant to the practice of transplantation.



INFLUENCE

To influence public opinion and operational strategy relevant to transplantation.



PROMOTE

To promote excellence in professional standards and ethics across the multi-disciplinary transplant community.



CONTRIBUTE

To contribute to the advancement of transplantation, from organ donation to long-term follow up, to maximize patient and graft outcomes for all organs.

Become a member:

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Congress 2020

4th-6th March, ICC Belfast

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