UCL
GREAT ORMOND STREET
INSTITUTE OF CHILD HEALTH

Great Ormond Street
Hospital for Children
NHS Foundation Trust

The role of the UK Renal Registry

Stephen Marks
Consultant Paediatric Nephrologist

Great Ormond Street Hospital for Children NHS Foundation Trust
and UCL GOS Institute of Child Health, London, UK

EMEESY Network Annual Education Day, Nottingham, UK
Friday 27 September 2019

Potential conflicts

- Current positions
  - Chair of Audit and Informatics / Registry Committee for
    - British
    - Association for
    - Paediatric
    - Nephrologists

Introduction

- What is the registry ?
- Do we need the registry ?
- What data can we get from the registry ?
- What can you do for the registry ?
- What can the registry do for you ?
- Who pays for the registry ?

Definitions

- Registry
  - /ˈrɛdʒɪstri/
  - *noun*
- 1. a place where registers or records are kept
- "MI5 maintains a large registry of files on individuals and organisations"
- 2. registration

Definitions

- Registry
  - /ˈrɛdʒɪstri/
  - *noun*
- 1. a place where registers or records are kept.
- "MI5 maintains a large registry of files on individuals and organizations"
- 2. registration

- A software application for capture, managing and providing access to condition specific information for a list of patients to support organised clinical care
  - tools that disease management programmes use to tract patients with chronic conditions

History

- UK Renal Registry (UKRR) is non-profit organisation, part of the Renal Association
  - registered with the Charity Commission
- One of few high quality clinical databases open to requests from researchers
- UKRR collects, analyses, reports on data
  - 71 adult and 13 paediatric renal centres
  - mandated in England through NHS National Service Specification
  - Chief Executive of each Trust is responsible for adherence to this contract

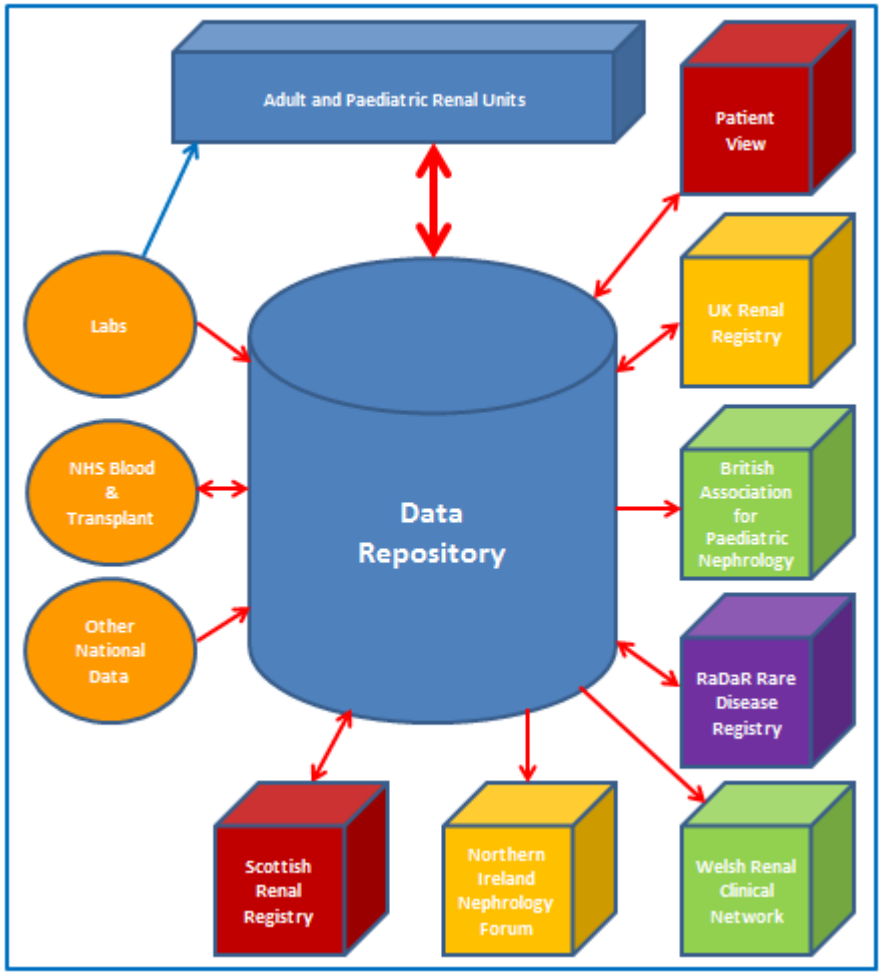
Funding

- Annual capitation fee levied on renal replacement therapy (RRT) patients
  - £27.50 per patient in England
  - £22.50 in Wales and Northern Ireland
  - levied as separate fees for the UKRR and PatientView on dialysis and transplant patients and representing less than 0.08% of average annual cost of treating patients

Data

- Some projects and collaborations receive funding through linkages with other organisations or grants for R&D
- Renal Registry Data Set Specification (RRDSS) defines the data collected
- Data are collected on a quarterly basis via an automatic download from renal unit databases
  - hange significantly in the future with the launch of UKRDC

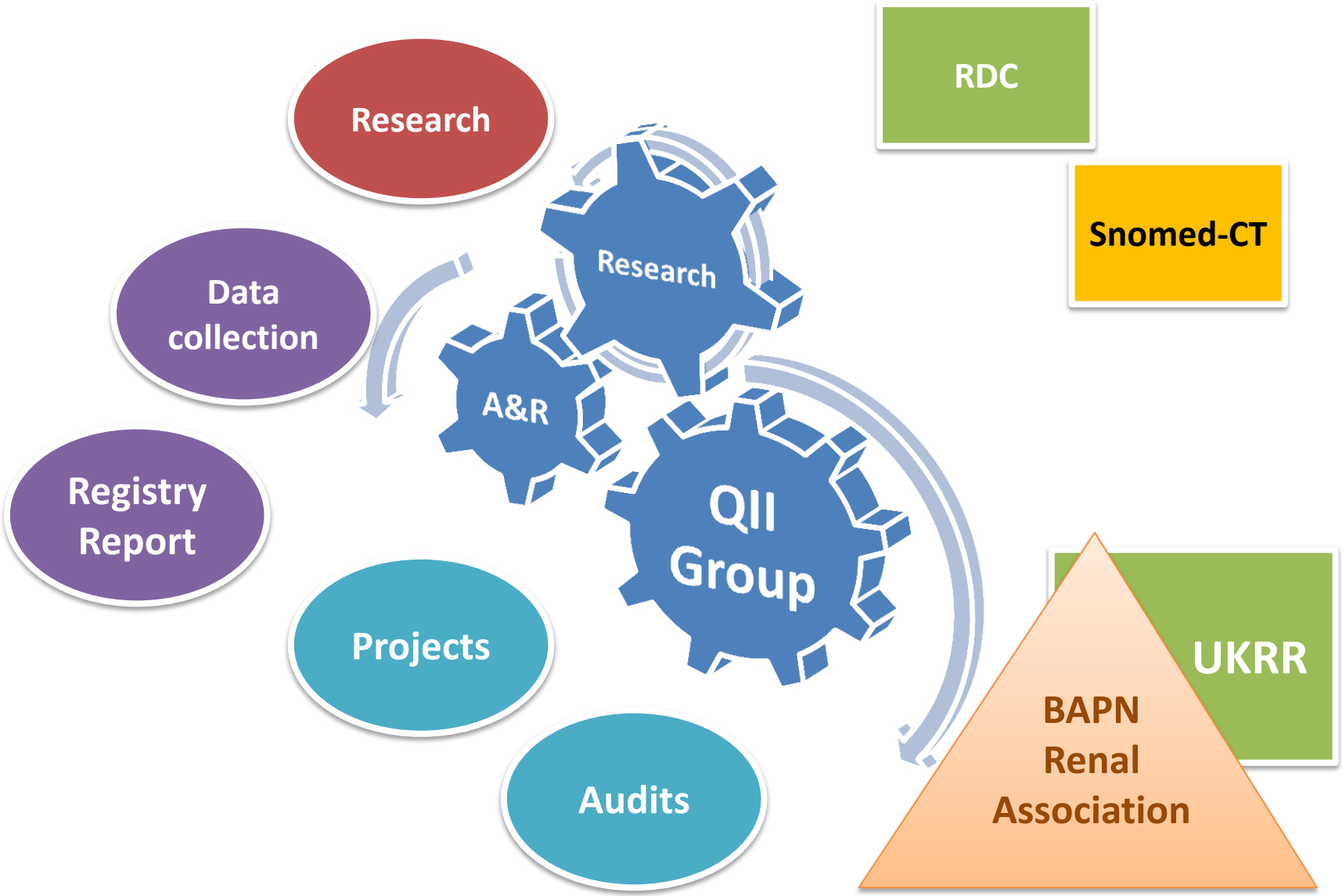
UK Renal Data Collaboration (UKRDC)



UK Renal Data Collaboration (UKRDC)

- Data are published annually in the UK Renal Registry Annual Report
  - online and *Nephron* submission
  - report is used by a variety of stakeholders
  - purpose is to act as a source of data for audit and benchmarking against the quality of care standards created by RA etc.
- Data and reports held by UKRR are a shared resource
  - used to develop further research into kidney disease and improve quality of care for patients

BAPN subgroups



UK Renal Registry

- Collecting data nearly 20 years
- Data on RRT patients expanding to CKD 4-5 and AKI (treated within renal units) Mandatory
- Annual chapters in UKRR report (Nephron)
  - 2018 results published online (quarterly)
  - analysis and interpretation published in Nephron
- Ongoing projects
- Publications
- ERA-EDTA Registry publications

Variable RRT Reporting

- Data collection — *Different systems, EPR*
  new items, PRD
- Data extraction — *Responsibility of the units*
  software, companies
- Data verified — *Missing data, outliers….* *UKRR*
- Data analysis — *Which analyses & which standards*
  QI, Clinical standards, research groups….
- Reporting and publishing — *Online results where RA standards*
  Summary published in Nephron

Standards *(Limitations)*

• Height, weight & BMI	*(Insuff data steroids, rhGH)*
• BP	*(Insuff medication, Echo)*
• Ca, PO4, PTH	*(Different PTH assays)*
• Bicarbonate	*(Different ranges)*
• Hb	
• Iron stores	*(Insuff data, diff measures)*
• Lipids	*(Insufficient data)*
• CV risk factors	

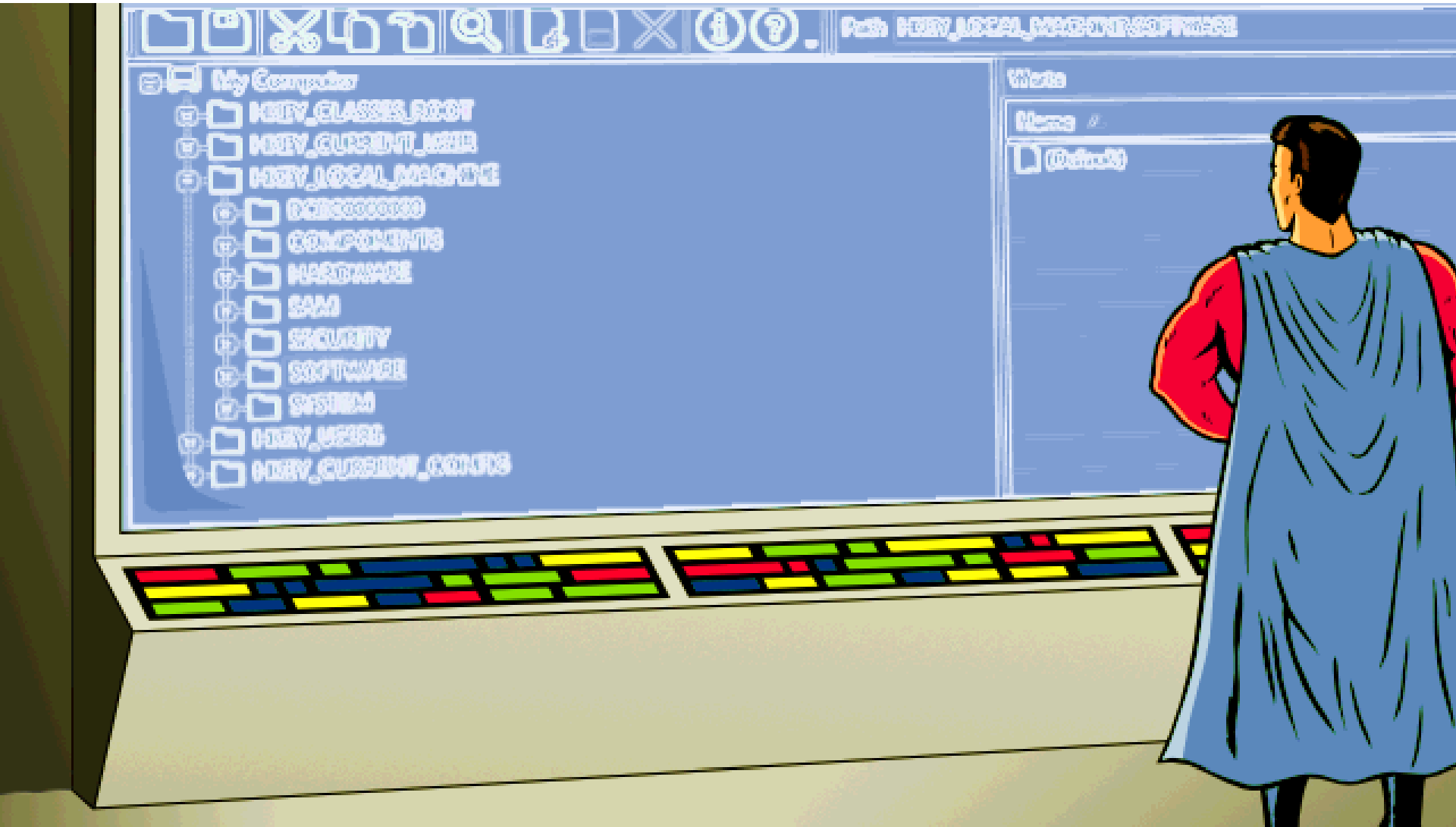
BAPN A&R Projects

1. Anaemia
2. Infants
3. Co-morbidity
4. Death on RRT audit
5. Changes in GFR post-transplant

UK Renal Registry 21st Annual Report Data to 31 December 2017

- 8,001 incident and 64,887 prevalent patients with ESKD on RRT in the UK
- Simpler, greener, predominantly online report, where the audit measures presented are directly linked to guidelines.
- Chapters have been re-designed to reflect treatment types (HD, PD and transplant) stage (incidence and prevalence), rather than biomedical parameters
  - reduced clinical commentary

Do we need registries and audit in 2019?



UK Renal Registry 21st Annual Report

Data to 31/12/2017

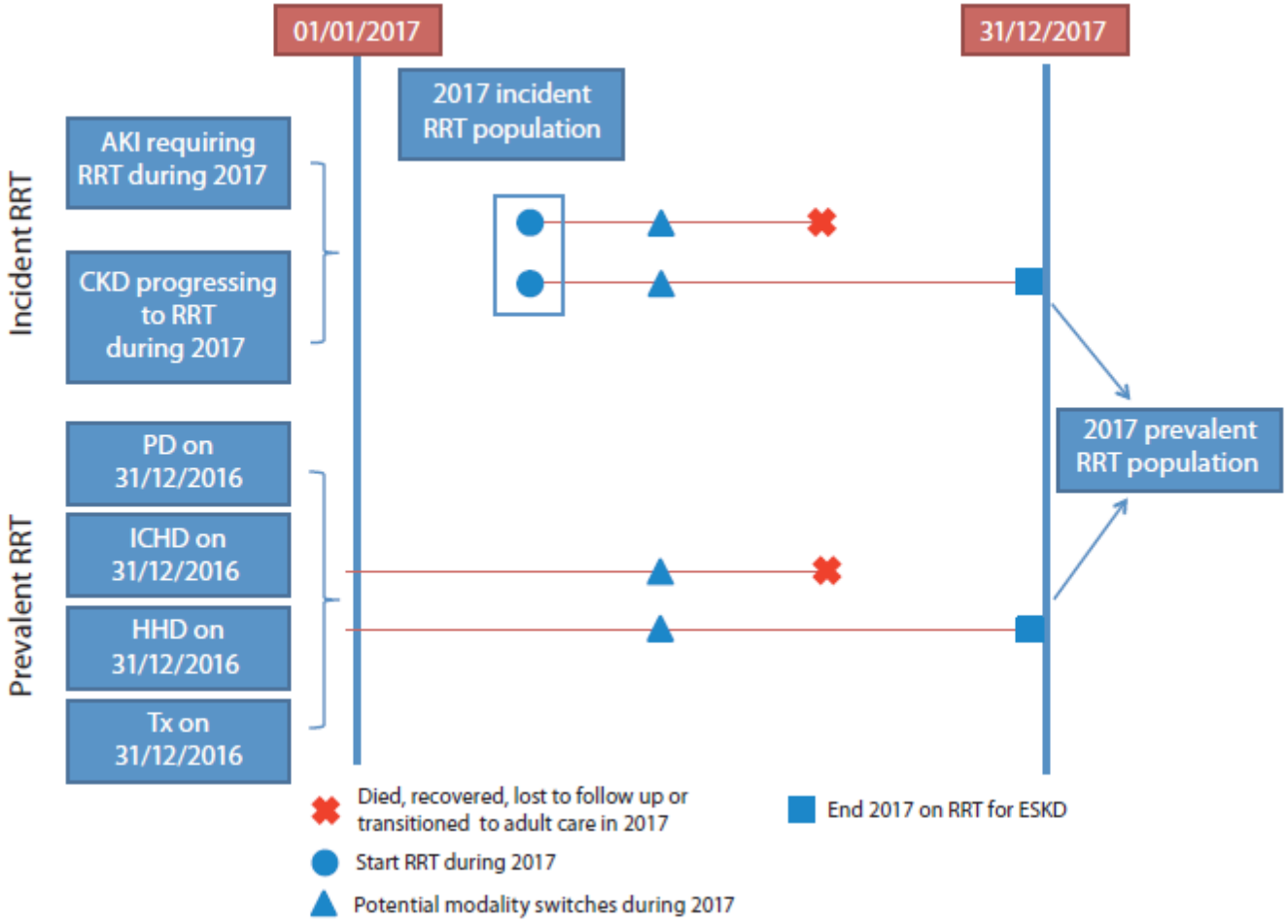
Chapter 7

Children on renal replacement therapy (RRT) for end-stage kidney disease (ESKD) in the UK in 2017

Definitions

- Incident population
  - patients who started RRT during 2017 and remained on RRT for at least 90 days
- Prevalent population
  - patients who were on RRT at end of 2017, aged < 18 years and still under paediatric nephrologist
- Five year populations
  - patients who started RRT and remained on RRT for at least 90 days in 2003-7, 2008-12, 2013-17

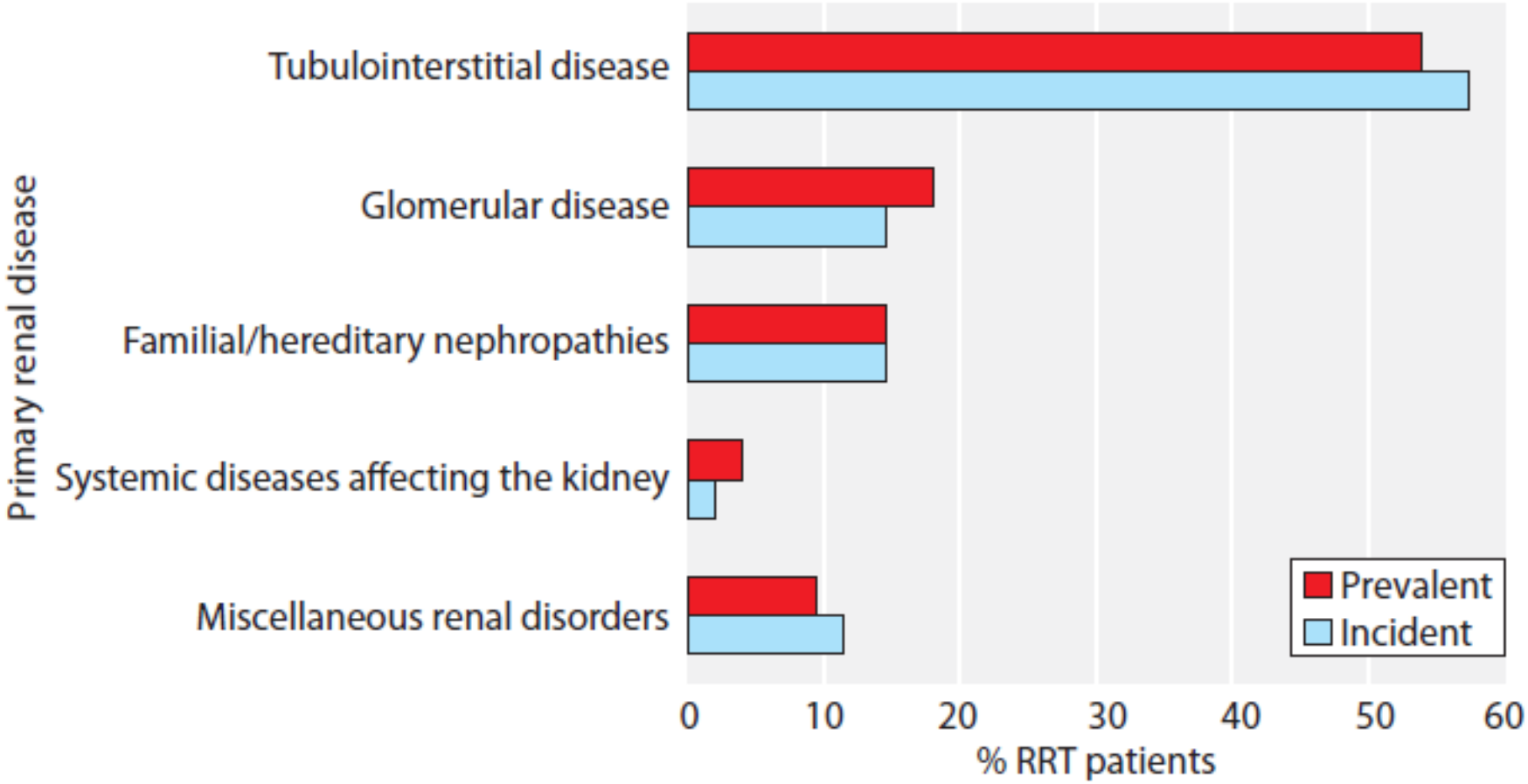
Pathways for incident and/or prevalent paediatric ESKD > 90 days of RRT



Audit measures relevant to RRT

Audit guideline	Audit criteria	Related analysis/analyses
The Renal Association: Treatment of adults and children with renal failure: standards and audit measures (2002)	Height and weight to be monitored at each clinic visit and plotted on the growth charts of healthy children and adolescents	Figures 7.6–7.13
	Blood pressure during PD or after HD to be maintained at <90th percentile for age, sex and height. Blood pressure in Tx patients to be maintained at <90th percentile for age, sex and height	Tables 7.14, 7.15, figures 7.14, 7.15
	Serum phosphate and calcium should be kept within the normal range. Parathyroid hormone (PTH) levels should be maintained within twice the upper limit of the normal range but, contrary to adult standards, may be kept within the normal range if growth is normal	Table 7.17
	Serum bicarbonate concentrations should be 20–26 mmol/L	Table 7.17
	Typically maintain the aspirational haemoglobin range 100–120 g/L for young people and children aged ⩾2 years and 95–115 g/L for children <2 years, reflecting the lower normal range in that age group	Table 7.17
National Heart Lung and Blood Institute and Kidney Disease Improving Global Outcomes (2013)	Screening children at risk of secondary dyslipidaemias including those with CKD	Table 7.15

Primary renal diseases



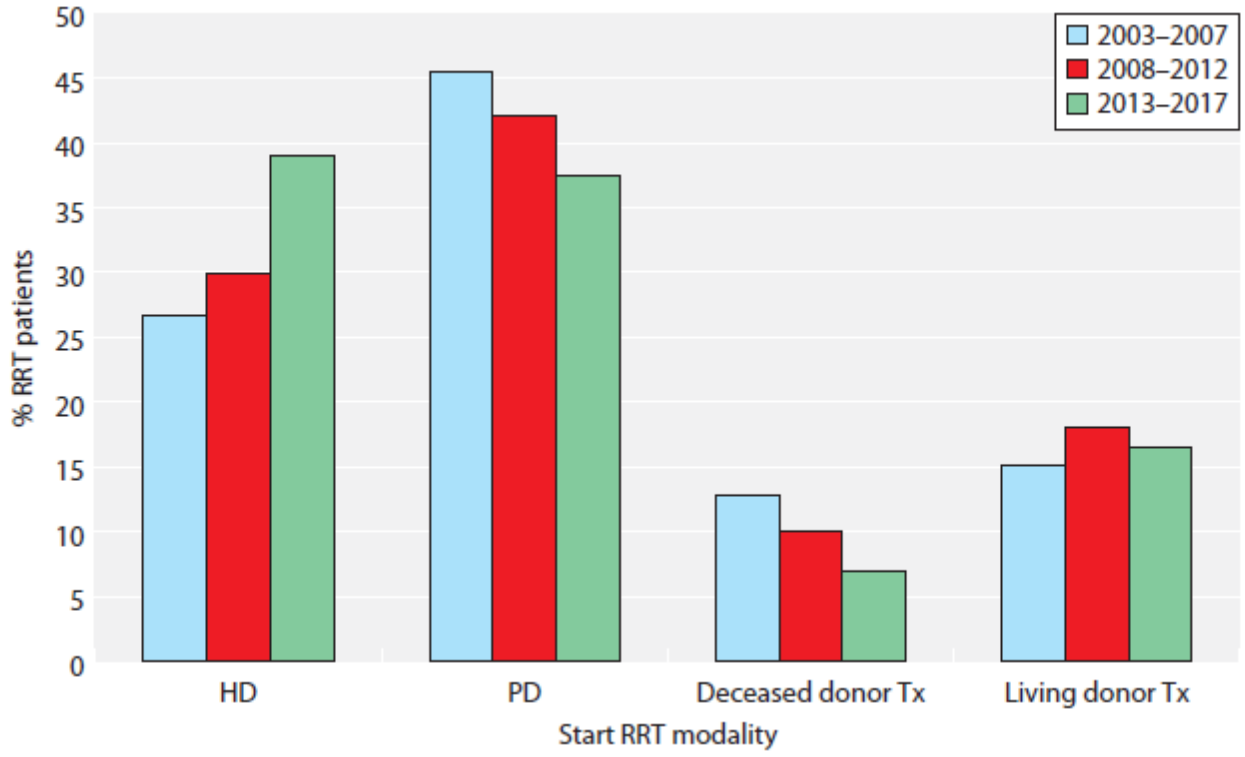
Key findings - 1

- 99 patients aged <16 years started RRT for ESKD in the UK in 2017 compared to 112 patients in 2016
- RRT incidence in patients aged <16 years was 7.9 pmarp
- 966 patients aged <18 years had received RRT for ⩾90 days at UK paediatric renal centres on 31/12/2017, compared to 964 patients in 2016
- RRT prevalence in patients aged <16 years was 64.8 pmarp. 76.3% had a functioning Tx (45.1% living donor and 31.2% deceased donor), 13.1% were receiving HD and 10.6% were receiving PD
- Tubulointerstitial disease accounted for >50% of all primary renal diseases (PRDs) in prevalent paediatric patients, with a high male : female ratio (3.4 : 1)
- Between 2003 and 2017, a third of patients aged <16 years who were referred early received a pre-emptive Tx
- At the time of transfer to adult services, 84.4% of paediatric patients had a functioning kidney Tx

Key findings - 2

- The median height z-score for children on dialysis was −1.9 compared with −1.1 for those with a functioning Tx
- The median weight z-score for children on dialysis was −1.1 compared with −0.1 for those with a functioning Tx
- The median systolic blood pressure z-score for children on dialysis was 1.0 compared with 0.4 for those with a functioning Tx
- Of those with complete data, 71.4% of the prevalent paediatric RRT population had 1 or more risk factors for cardiovascular disease; 6.0% had 3 risk factors
- 53.3% and 55.6% of prevalent HD patients achieved systolic blood pressure (SBP) and diastolic blood pressure (DBP) values <90th percentile, respectively
- 60.0% and 66.7% of prevalent PD patients achieved SBP and DBP values <90th percentile, respectively
- 82.9% and 76.5% of prevalent Tx patients achieved SBP and DBP values <90th percentile, respectively.

Start modality at RRT presentation

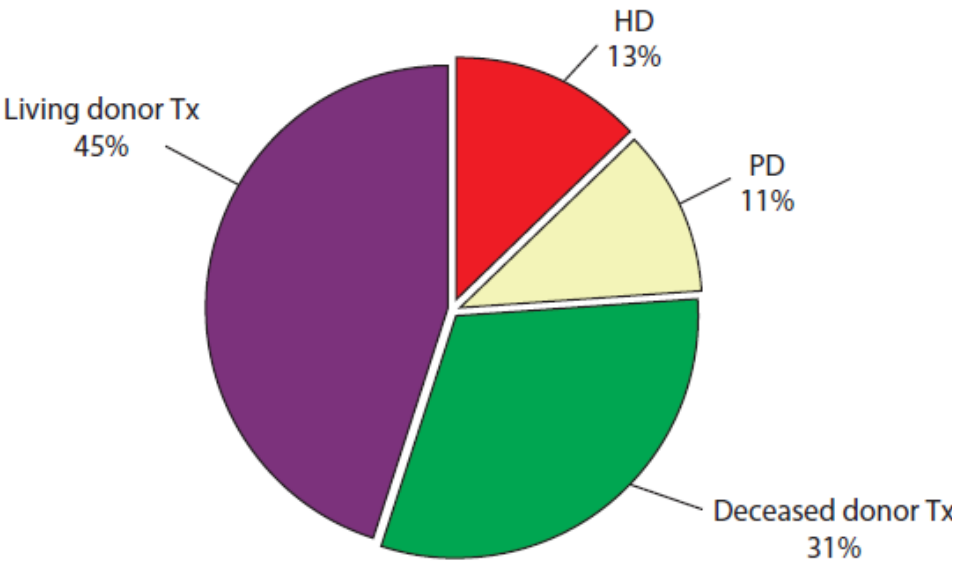


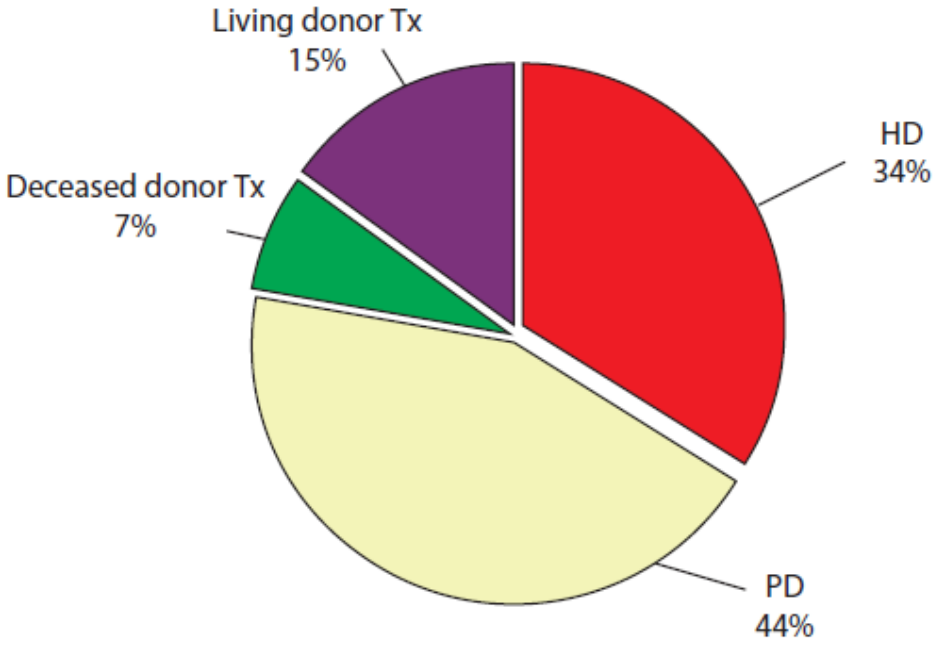
Pre-emptive transplantation rates

	N on RRT	*N* (%) with pre-emptive Tx
Total cohort analysed (2003–2017)	1,241	420 (33.8)
Time period		
2003–2007	386	136 (35.2)
2008–2012	404	151 (37.4)
2013–2017	451	133 (29.5)
Sex		
Male	793	290 (36.6)
Female	448	130 (29.0)
Ethnicity		
White	886	335 (37.8)
South Asian	212	49 (23.1)
Black	54	6 (11.1)
Other	74	23 (31.1)
Age at start of RRT (yrs)		
3 mths–<2	137	6 (4.4)
2–<4	148	42 (28.4)
4–<8	236	101 (42.8)
8–<12	284	105 (37.0)
12–<16	436	166 (38.1)
PRD		
Tubulointerstitial disease	679	295 (43.4)
Glomerular disease	233	17 (7.3)
Familial/hereditary nephropathies	190	65 (34.2)
Miscellaneous renal disorders	93	26 (28.0)
Systemic diseases affecting the kidney	38	15 (39.5)

97 patients were excluded because aged <3 months; 369 patients were excluded because late presenters

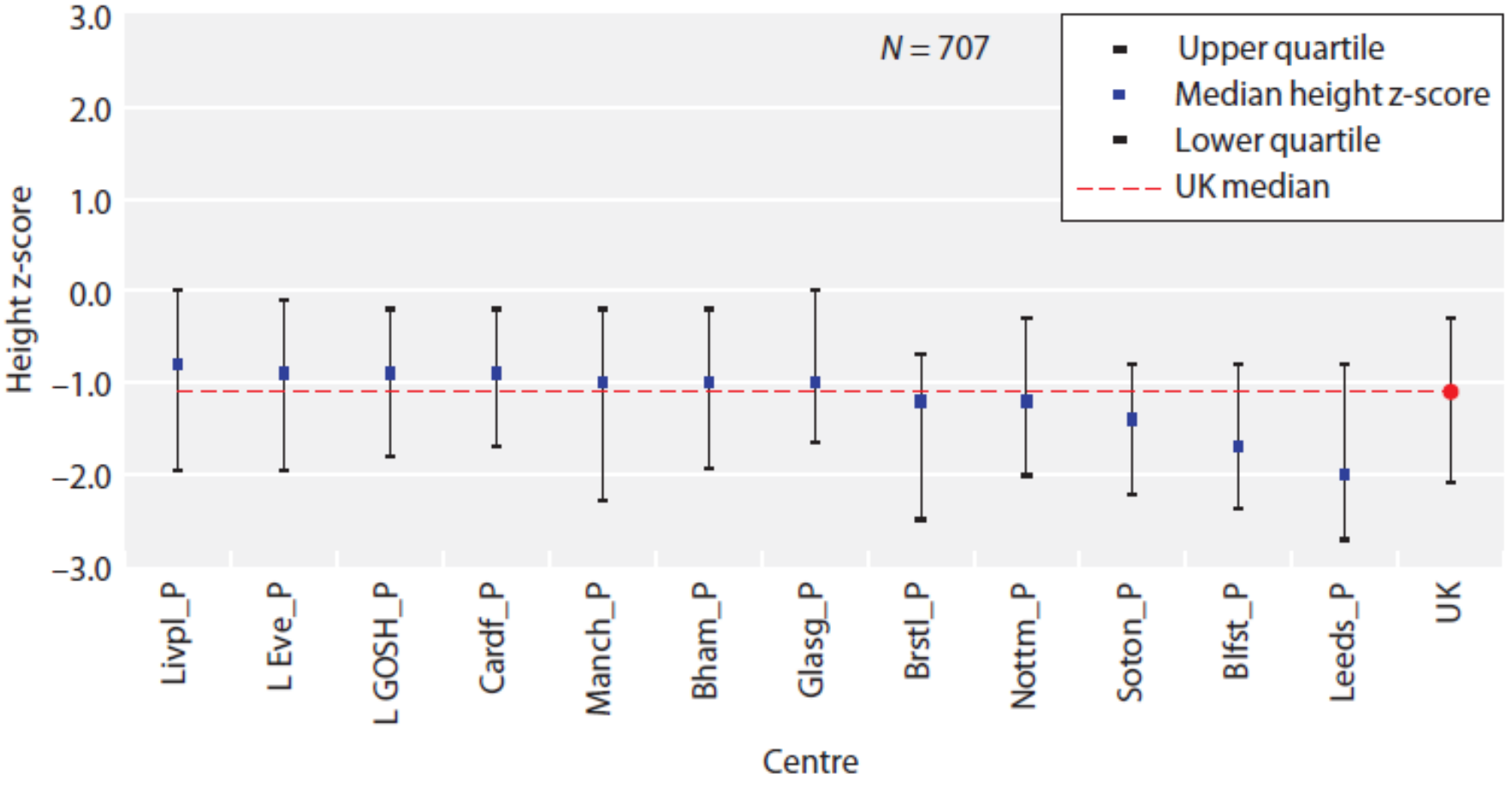
Overall RRT modality and commencement of RRT



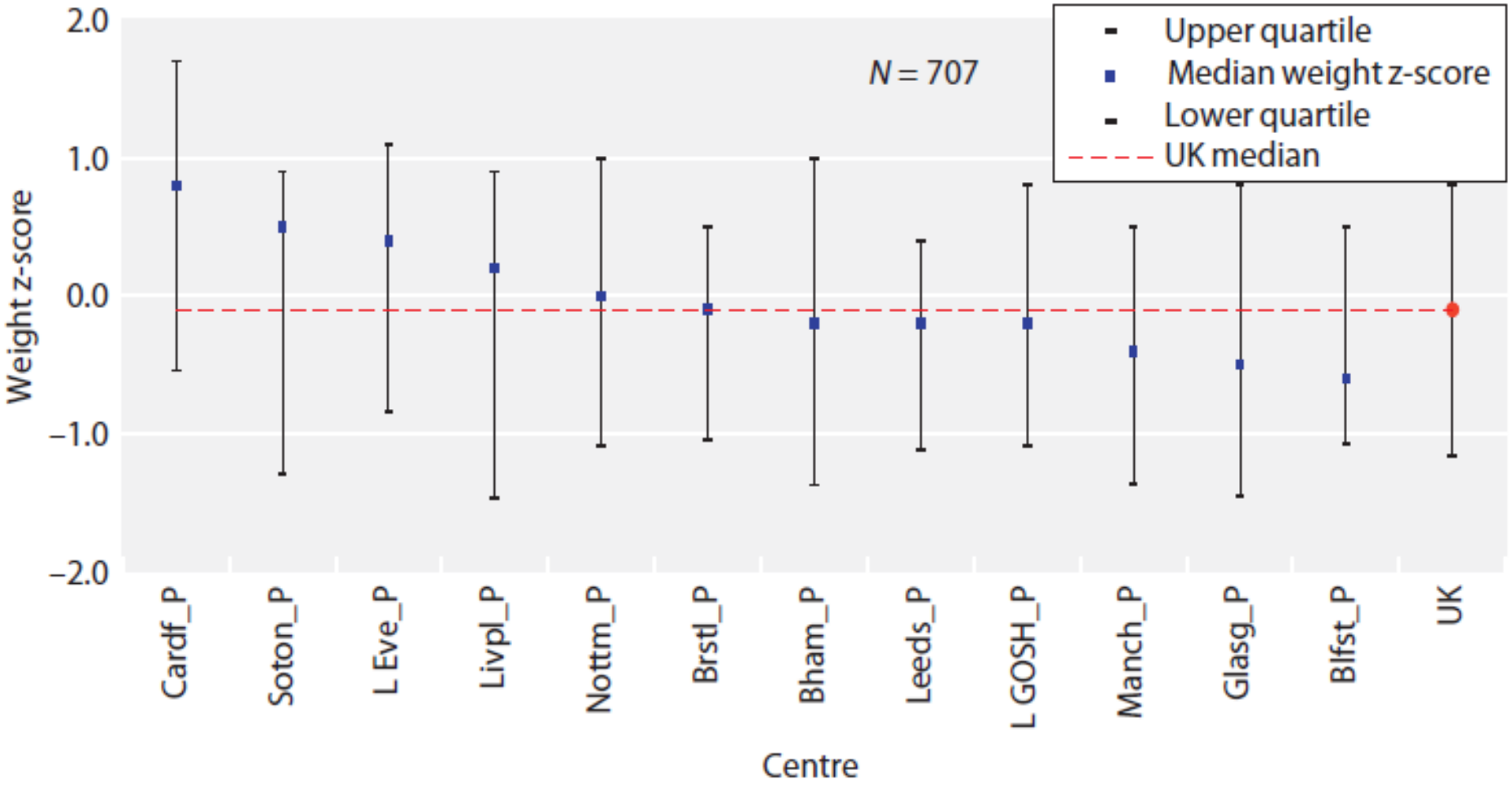


The usual suspects

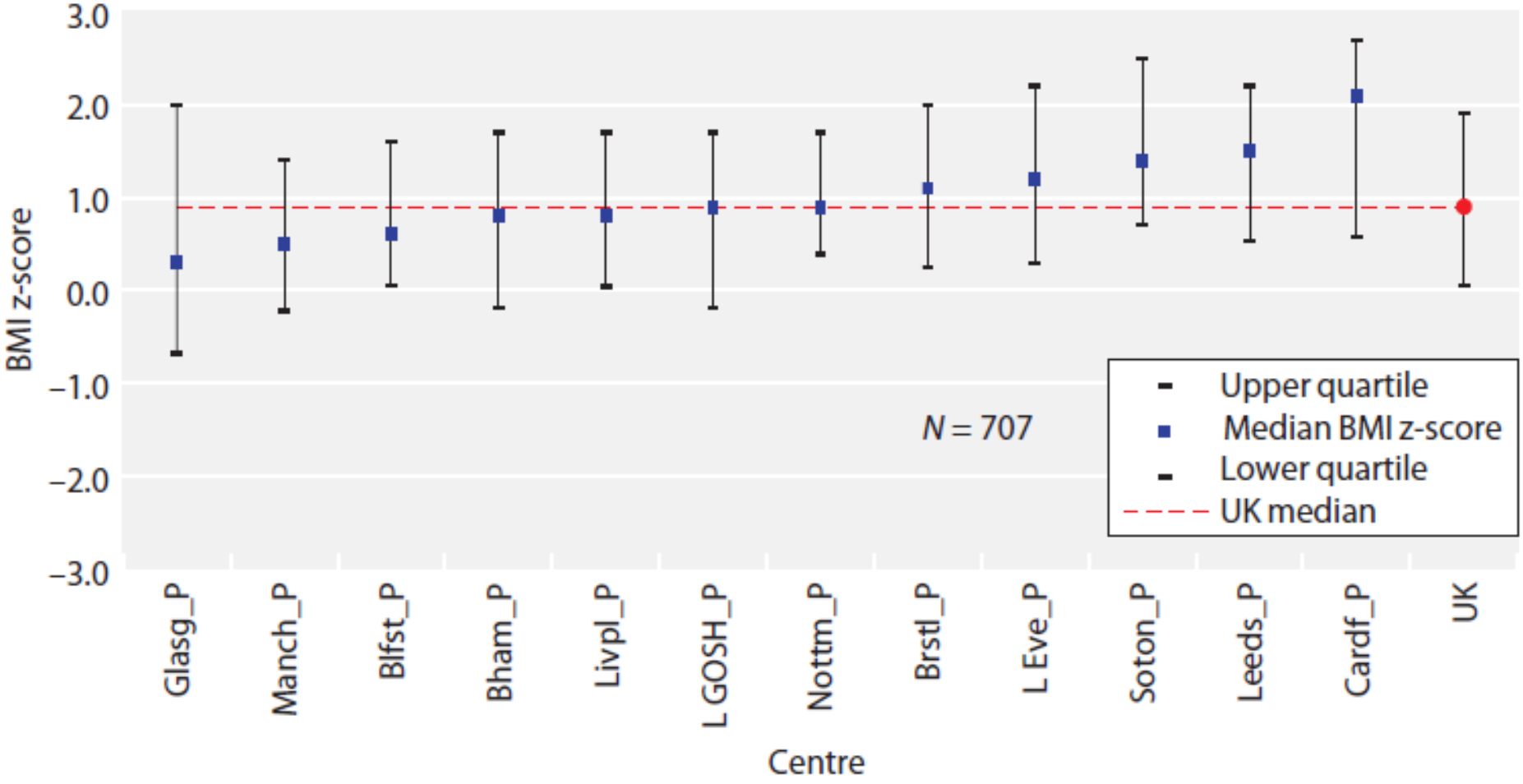
Height of paediatric transplant recipients



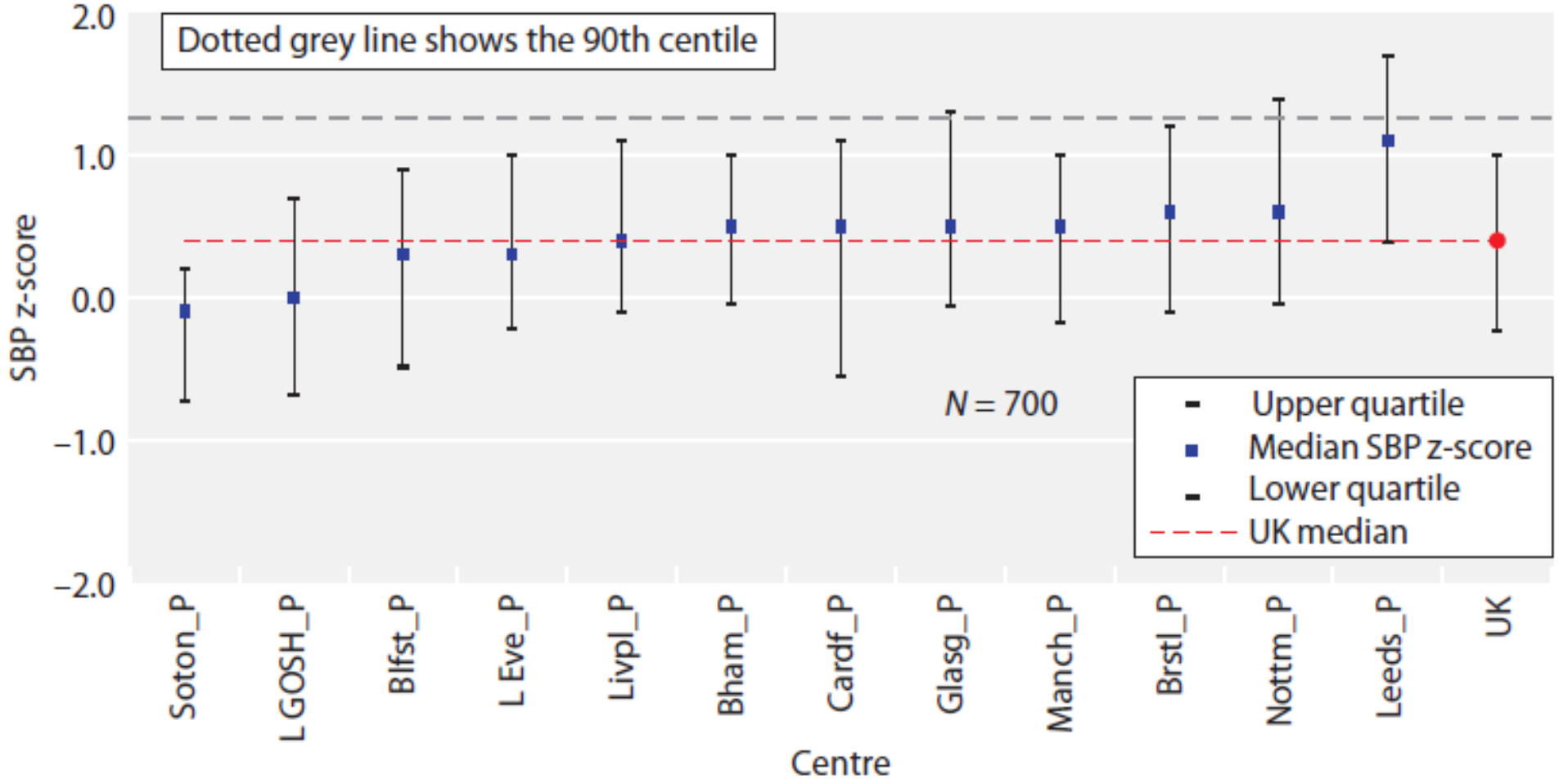
Weight of paediatric transplant recipients



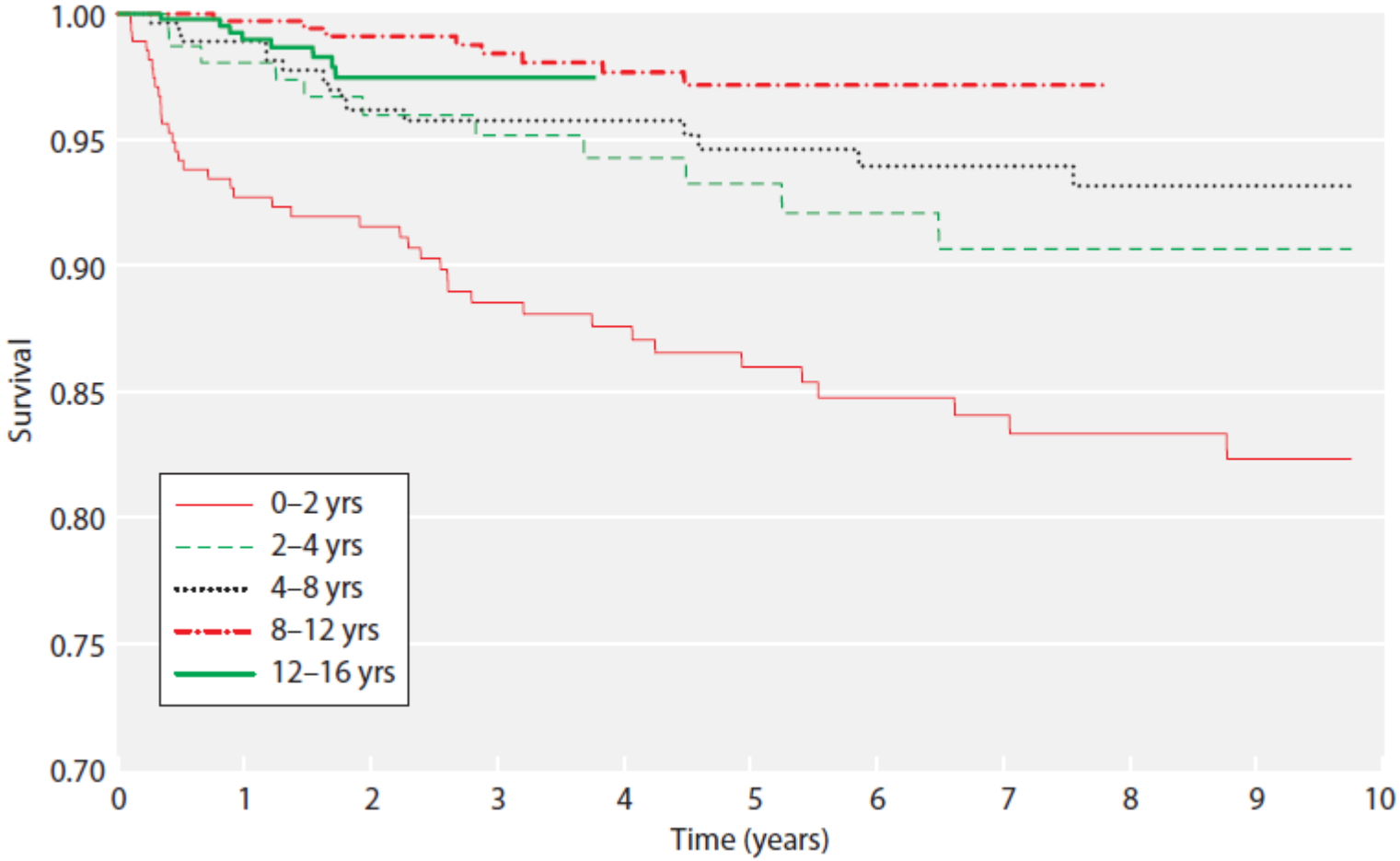
BMI of paediatric transplant recipients



SBP in paediatric transplant recipients



KM survival of incident children



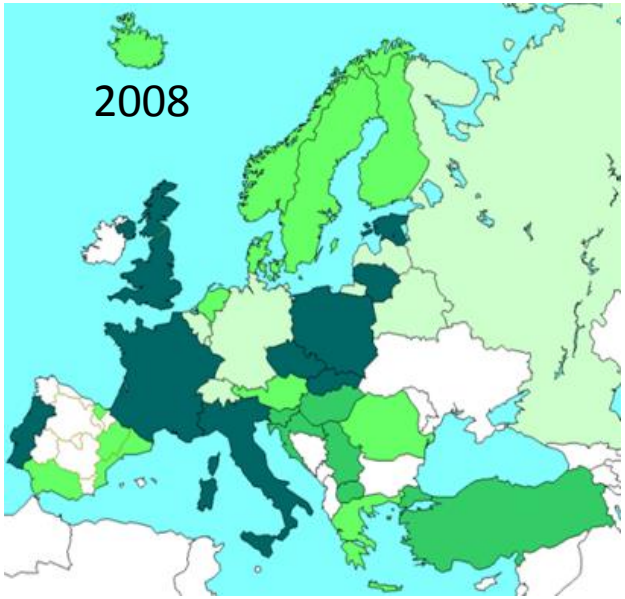
KEEP CALM AND DON'T MENTION BREXIT

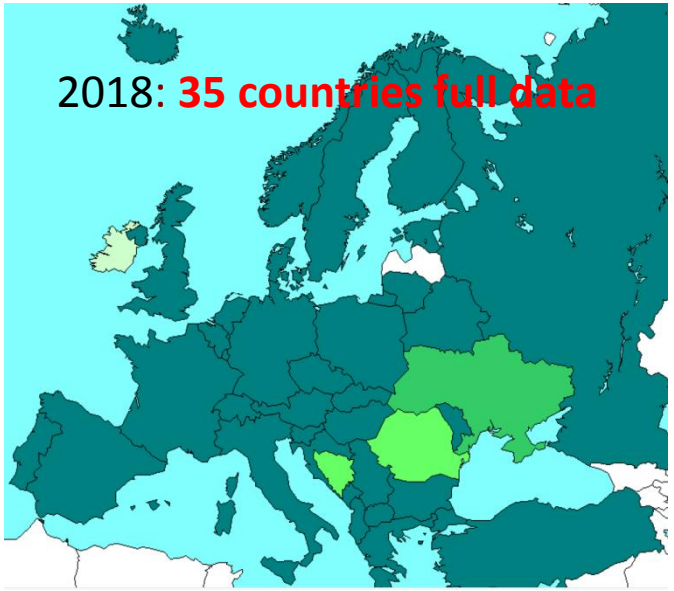
ERA-EDTA Projects

1.	Timing of dialysis	Manish Sinha
2.	Outcomes after transplantation	Stephen Marks
3.	Co-morbidities	
4.	Anthropometry	Heather Maxwell
5.	Graft loss among young children	Nick Ware
6.	Change in trends and outcomes	Tamara Mallett
7.	Antihypertensive medication	Dean Wallace
8.	Risk of infection post transplant	Mohan Shenoy
9.	Neurogenic bladder	Malcolm Lewis
10.	eGFR decline among adolescents	Alex Hamilton


Iceland
Sweden
Finland
Norway
Russia
Est.
Latvia
Lithuania
Den.
Ireland
UK
Belarus
NL
Bel
Germany
Poland
Ukraine
Cz. Rep.
Lux.
France
Slovak.
Austria
Swit.
Hungary
Mol.
Slo.
Cro.
Italy
Romania
Port.
Serbia
Bulgaria
Spain
Mac.
Tur.
Alb.
TURKEY
Greece
Malta
Cyprus

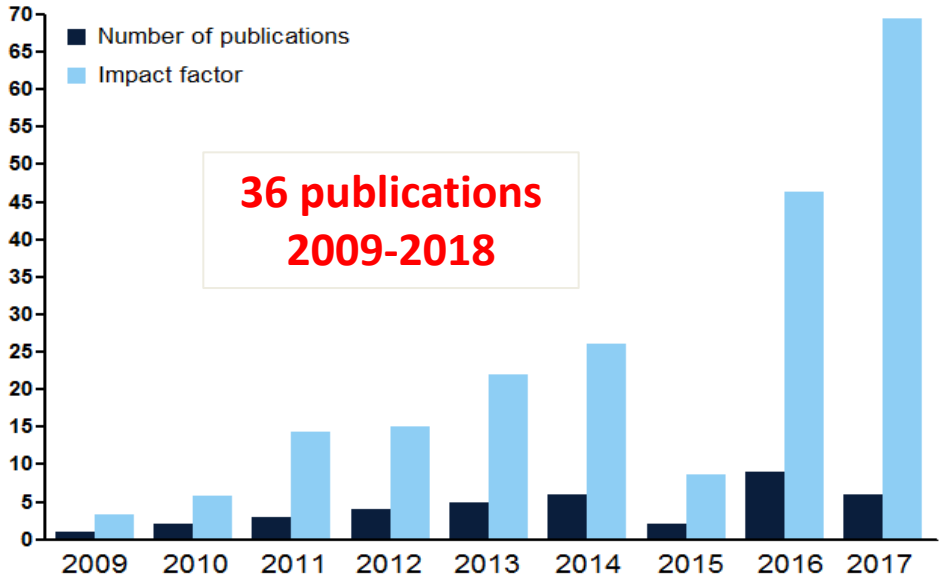
ESPN/ERA-EDTA registry



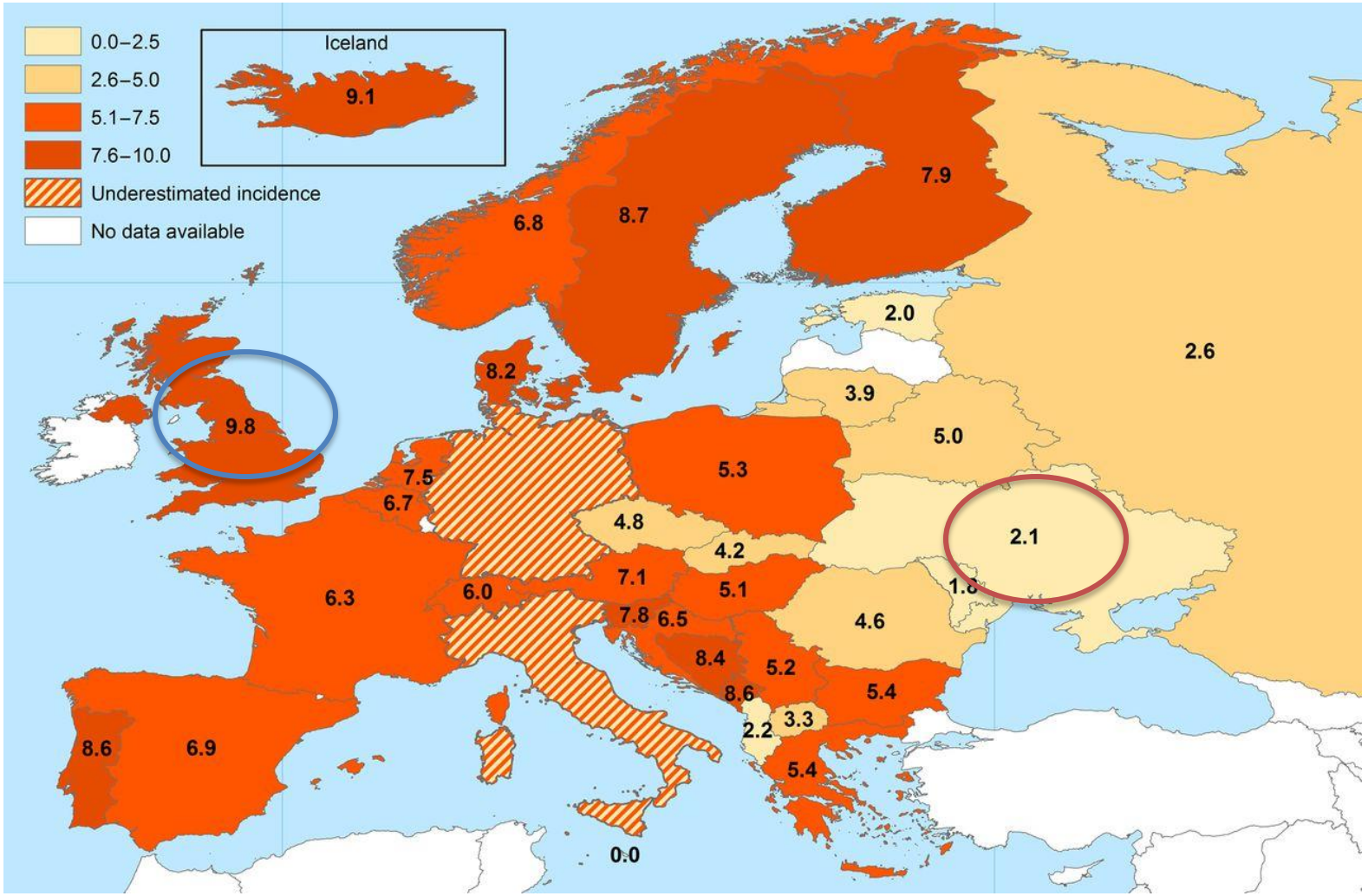


Extended data collection

Limited data collection



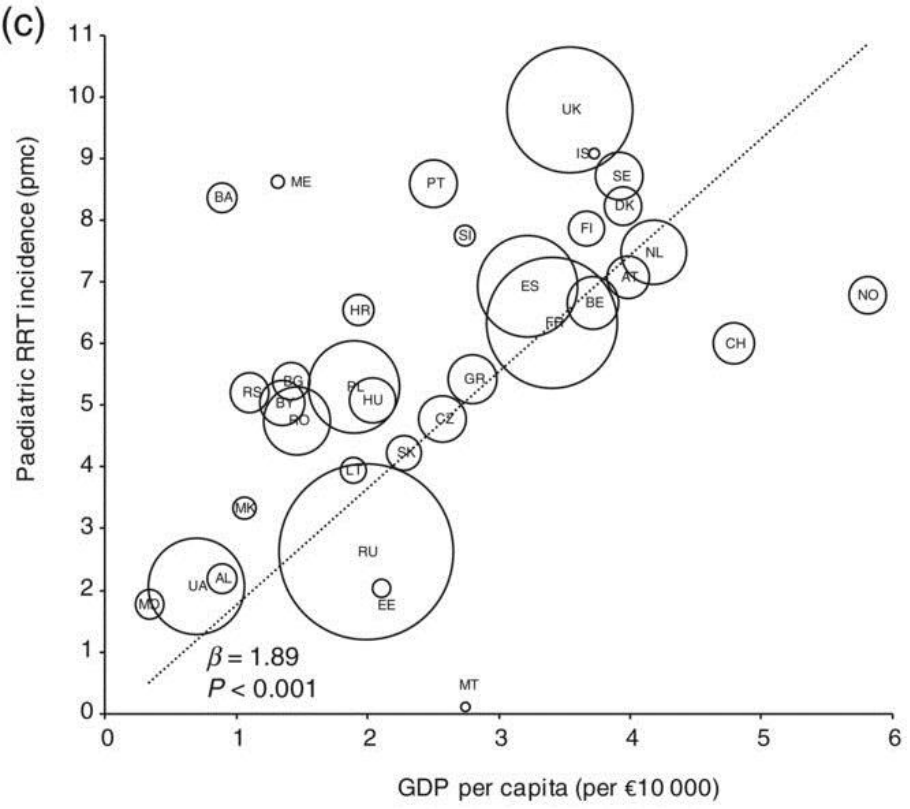
Paediatric RRT incidence per million children in 2007–2011: Average = 5.2

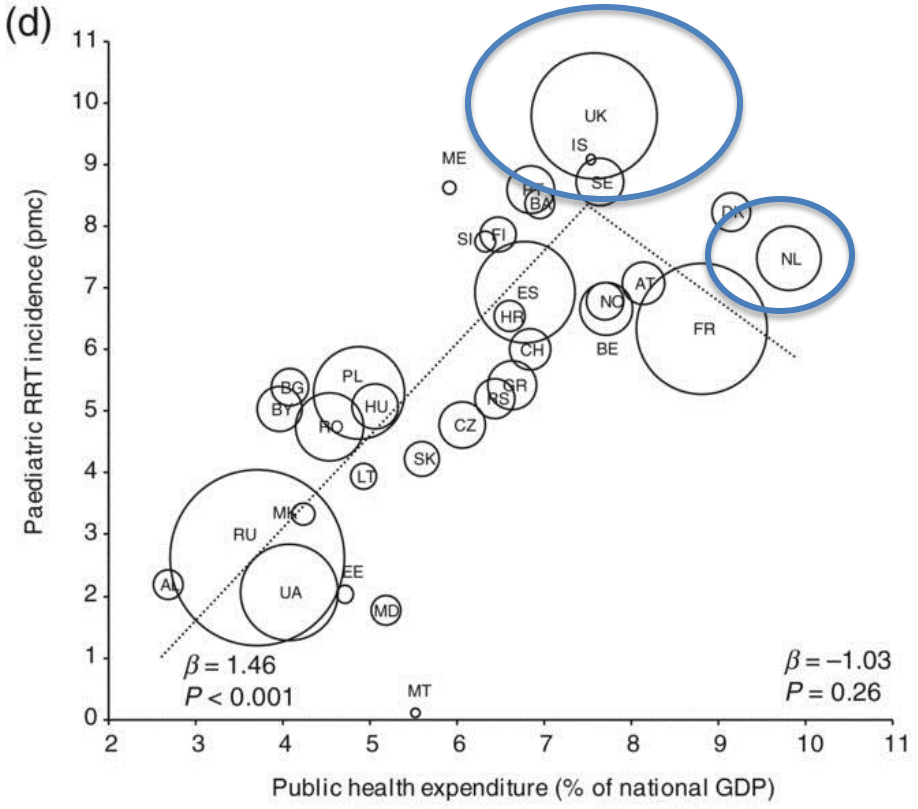


USRDS 2014: Incident ESRD children (0-18y) = 12 pm children

Chesnaye NC et al. Nephrol. Dial. Transplant. 2015;30:1377-1385

RRT incidence negatively associated with GDP/public health expenditure & certain optimum public health expenditure



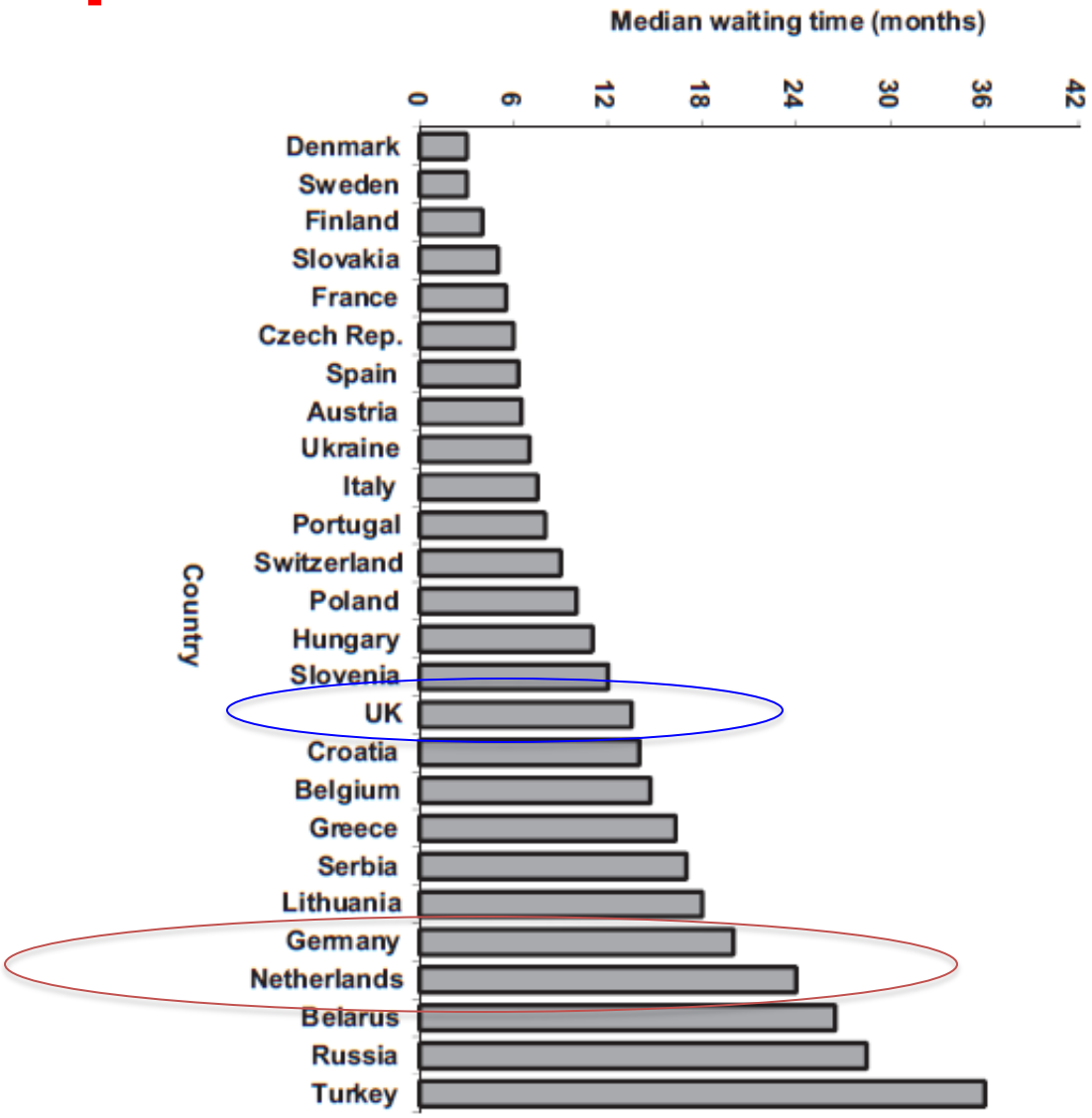


Chesnaye NC et al Nephrol Dial Transplant 2015

Mortality disparities in mortality between countries

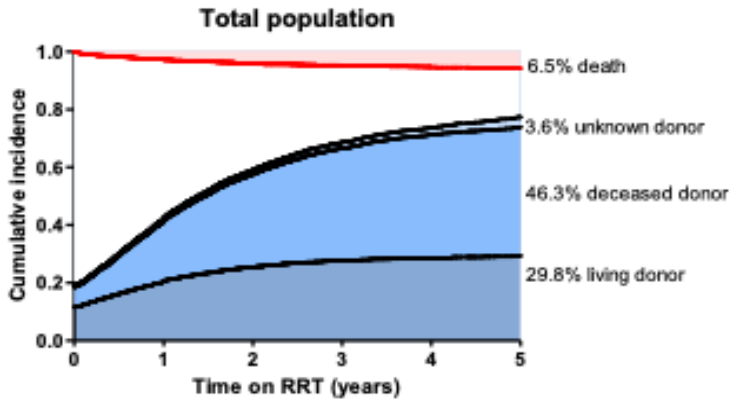
Chesnaye NC et al Lancet. 2017 May 27;389:2128-2137

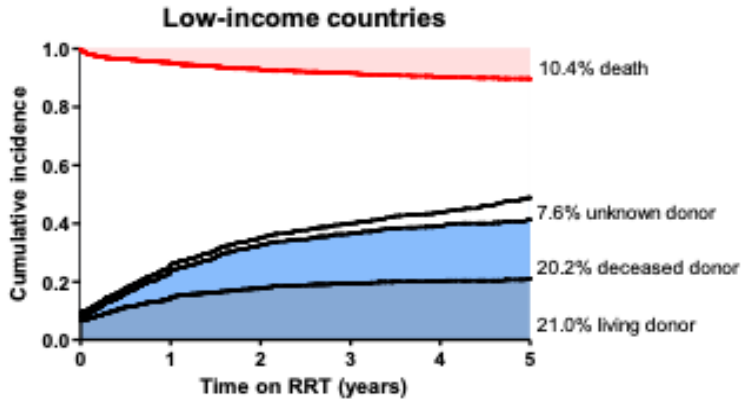
Disparities in Paediatric Renal Transplantation in Europe: waiting time

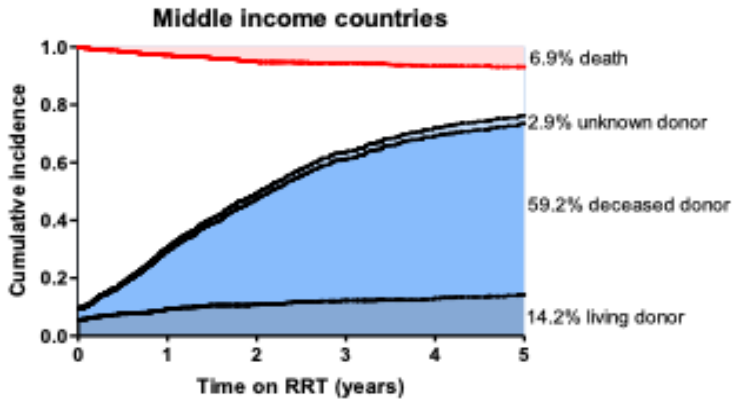


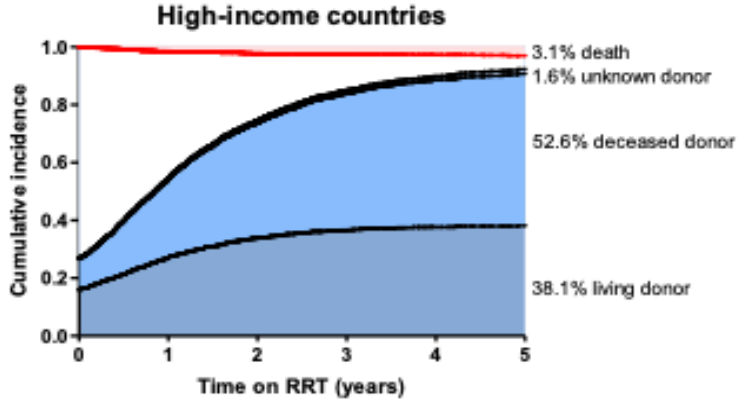
Harambat J, Am J Transplantation 2013; 13: 2066–2074

Relatively low access to transplant in EU low-middle income countries: 37 countries 2007-2015 < 20y







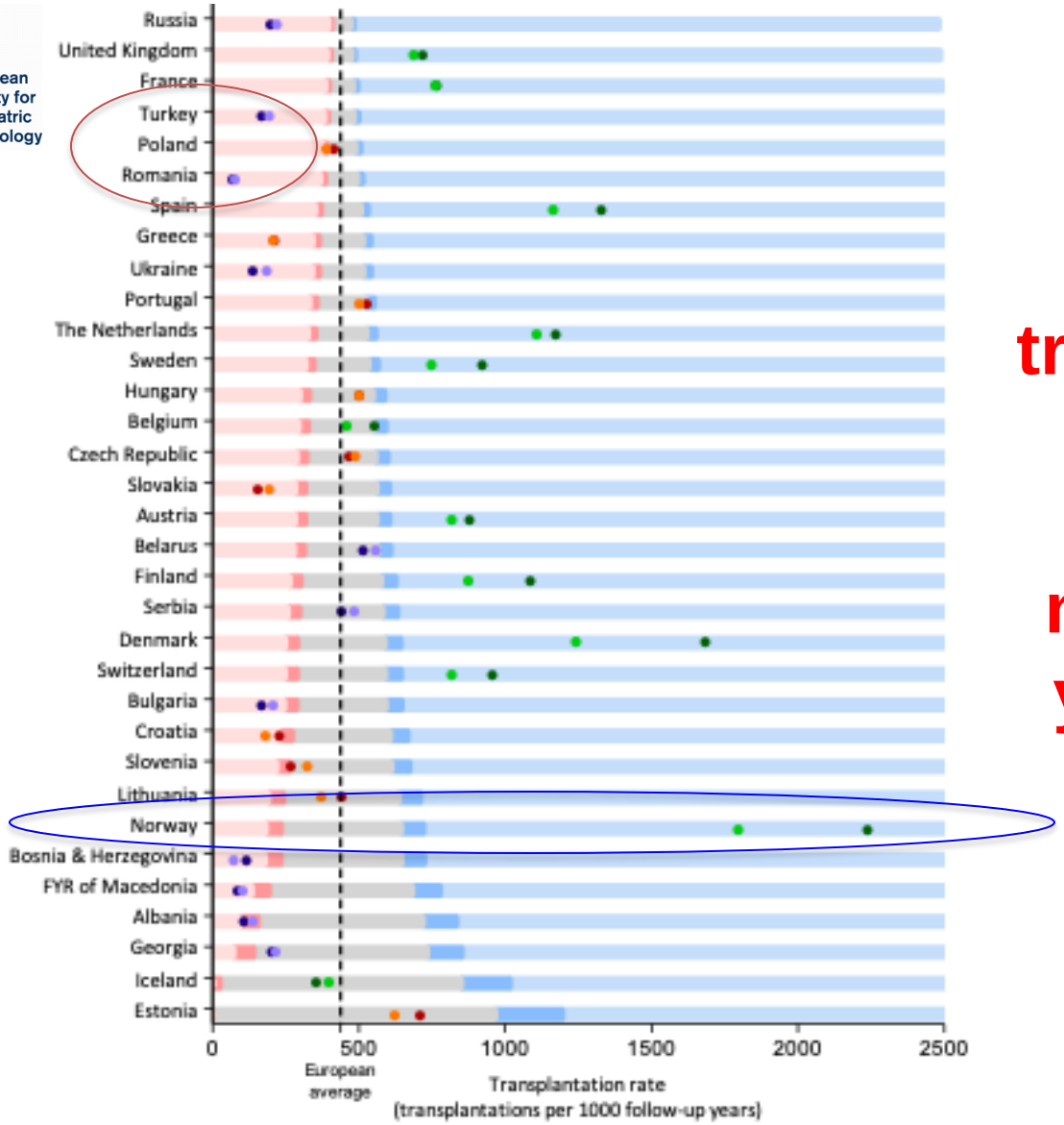


GDP -> 66% variation in tx rates.

Tx 76 & 58 % less likely in low-income/ middle-income countries compared to high- income

Bonthuis et al, Lancet under review

european society for paediatric nephrology



5 year transplantation rate by country (transplant numbers/1000 per year of follow-up)

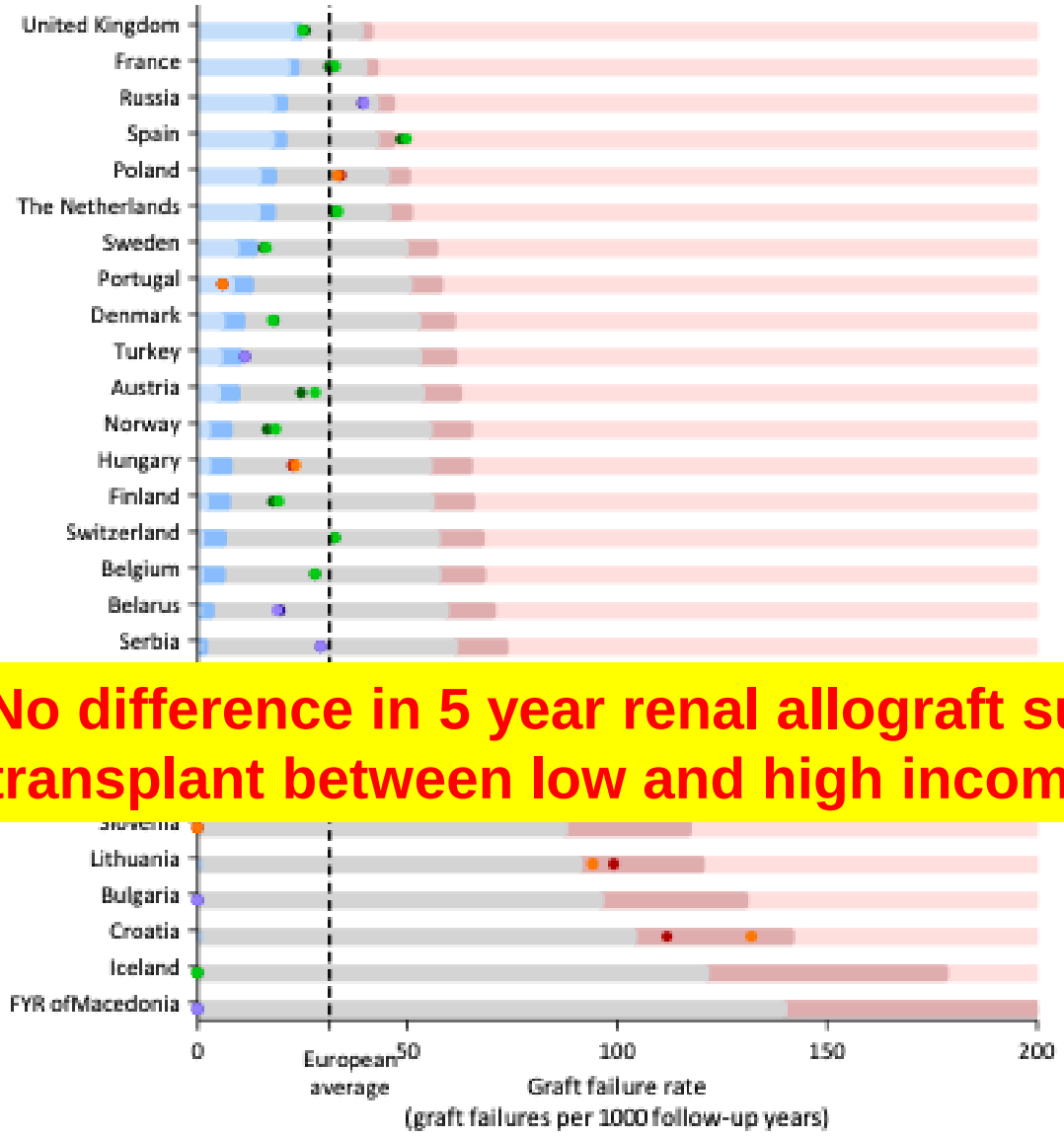
Bonthuis et al, Lancet under review

european society for paediatric nephrology

Leading European Nephrology

5 year graft failure rate by country

No difference in 5 year renal allograft survival after transplant between low and high income countries



Bonthuis et al, Lancet under review

Take home messages

- In an ideal world, every child entering hospital would automatically get data entered clinically which could be used for audit and research
- Benchmarking of clinical cases
  - ?related to funding
- Collaborative working between units within
  - UK
  - Europe
  - Internationally

Steve's immune system picked the absolute worst time to reject his new hair transplant.