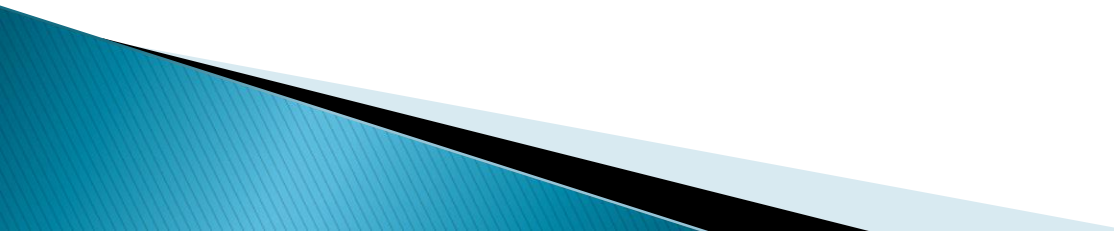


# Donor follow-up: more than a paper exercise?

## Developing a Donor Reported Experience Measure (DREM)

Dr Janine Hawkins, Senior Research Fellow;  
Ms Amanda Busby, Statistician, Dr David Wellsted, Statistician;  
Ms Beth Rider, Researcher; Prof. Ken Farrington, Consultant Nephrologist

# Overview of session

- ▶ Why measure donor experience?
  - ▶ DREM development and validation
  - ▶ Pilot results
- 

# Why measure donor experience?

## The donor perspective

- ▶ Donating a kidney involves detailed process of investigation, major surgery, and a significant period of recovery
- ▶ There are documented overall benefits for the individual donor and wider society, but living donor surgery entails risks– including a small risk of death
- ▶ Removal of a kidney inevitably causes physical harm to the donor and the potential lifelong impact on health and well-being must be fully considered for every individual

# Why measure donor experience?

## Psychological issues

- ▶ After donation donors generally consider it a positive experience – regrets are low. Most report better QoL than general population
- ▶ A small minority experience reduced QoL, more fatigue and relationship changes – predisposing factors are higher BMI, smoking and higher expectations re health consequences. Depression and fatigue more prevalent in females
- ▶ Potential donors must be made aware of these possible outcomes and must be followed up appropriately post-donation

# Why measure donor experience?



## Why does access vary across centres?

- Variation in acceptance of living donors
- Variation in process – work up
- Variation in clinical population
- Clinician attitude to LDKT?
- Healthcare staff and system capacity?

Arunachalam C et al. NDT 2013;28(7): 1952-60

[bristol.ac.uk](http://bristol.ac.uk)

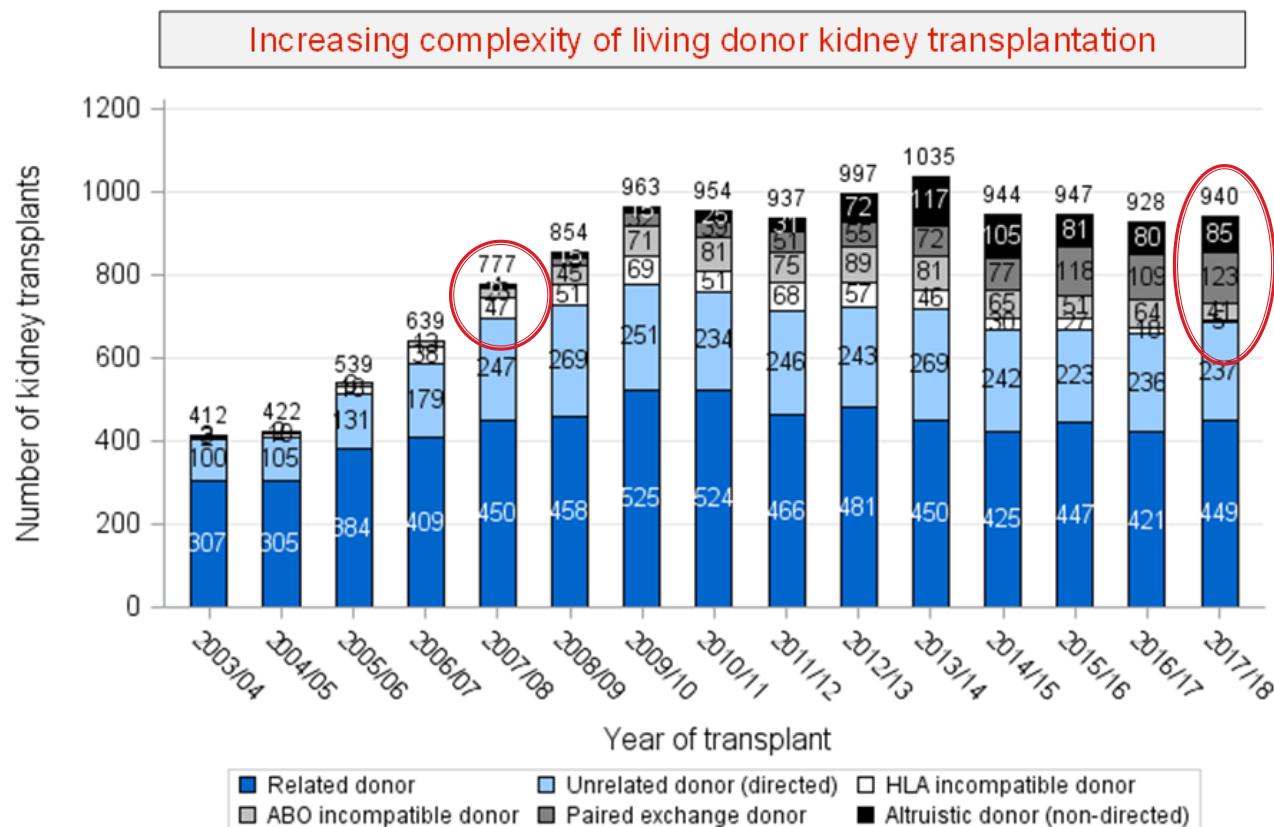
Access to and availability of LDKT in the UK  
Dr Pippa Bailey, Clinical Lecturer in Renal Medicine  
RTSM, January 2019

# Why measure donor experience?

## Adult living donor transplants



Blood and Transplant



The latest trends in organ donation and kidney transplantation in the UK  
Matthew Robb, NHS Blood and Transplant; RTSM, January 2019



# Why measure donor experience?



NEWS UK POLITICS US POLITICS VOICES SPORT CULTURE **INDY/LIFE** INDYBEST LONG READS INDY100 VOUCHERS PREMIUM CLIMATE BLOGS

News > UK > Home News

## Kidney transplants on the rise in UK thanks to change to sharing scheme

More altruistic donors are now on kidney sharing scheme, leading to increase in transplants in 2019

Rory Sullivan | Tuesday 21 January 2020 08:01 |







The number of patients receiving a **kidney transplant** from altruistic donors has risen by 60 percent from 2018 to 2019, following a change that allows donors to be routinely added to a kidney sharing scheme.

It is thought that this change, which took place in January 2018, is behind the spike in kidney transplants — with more non-directed altruistic donors (NDADs) now donating via the Living Kidney Sharing Scheme (UKLKSS).

# Why measure donor experience?

## REVIEW ARTICLE

### THE EXPERIENCE OF DONATING AND RECEIVING A KIDNEY: A SYSTEMATIC REVIEW OF QUALITATIVE STUDIES

Laura Rota-Musoll <sup>1,5</sup>, Mireia Subirana-Casacuberta <sup>2,5</sup>, Ester Oriol-Vila<sup>3</sup>, Mercè Homs-Del Valle<sup>3</sup>,  
Esmeralda Molina-Robles <sup>3,5</sup>, Serena Brigidi <sup>4,5</sup>

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<sup>5</sup>*Research group on Methodology, Methods, Models and Outcomes of Health and Social Sciences (M3O), Faculty of Health Science and Welfare, Centre for Health and Social Care Research (CESS), University of Vic-Central University of Catalonia (UVIC-UCC), Vic, Spain*

Rota-Musoll L., Subirana-Casacuberta M., Oriol-Vila E., Homs-Del Valle M., Molina-Robles E., Brigidi S. (2019). The experience of donating and receiving a kidney: A systematic review of qualitative studies. *Journal of Renal Care*. 1–21. <https://doi.org/10.1111/jorc.12309>



# Why measure donor experience?

## REVIEW ARTICLE

### THE EXPERIENCE OF DONATING AND RECEIVING A KIDNEY: A SYSTEMATIC REVIEW OF QUALITATIVE STUDIES

*The experience of kidney donors is shown to be a positive one, both before and after the donation, although it involves certain difficulties and stressors and a perception of deficiency in the health system*

# Why measure donor experience?

## REVIEW ARTICLE

### THE EXPERIENCE OF DONATING AND RECEIVING A KIDNEY: A SYSTEMATIC REVIEW OF QUALITATIVE STUDIES

#### D1: Donation as a positive experience

- ▶ Motivation to improve life of recipient
- ▶ Donate with conviction
- ▶ Coping strategies
- ▶ Personal growth


#### D2: Difficulties and stressors of donor

- ▶ Personal investment
- ▶ Economic impact
- ▶ Physical impact
- ▶ Mental impact
- ▶ Overcoming opposition


#### D3: Deficiencies in the health system

- ▶ Lack of information
- ▶ Lack of attentiveness

# Summary – Why measure DE?

- ▶ Donation involves a detailed pathway of investigation, surgery and recovery;
  - ▶ There is increased likelihood of negative outcomes amongst certain donor groups;
  - ▶ There is variability in access to living donors across centres in the UK;
  - ▶ LDKT is increasing in complexity....including more altruistic donors
  - ▶ The experience of LD includes difficulties and stressors as well as positives, with particular challenges with information and attention during assessment and follow up
- 

# DREM – development and validation

UK TRANSPLANT REGISTRY 

**DONOR REPORTED  
EXPERIENCE MEASURES  
(DREMS) SURVEY**

Please return data to ODT Hub:  
Information Services along with  
Kidney Living Donor  
Assessment Follow-Up  
(FRM4191) form as appropriate.  
Data will be collected at 1 year  
post donation.

ODT Hub: Information Services  
NHS Blood and Transplant  
Fox Den Road  
Stoke Gifford  
BRISTOL  
BS34 8RR

**DONOR DETAILS** Section 1

Surname \_\_\_\_\_ Date of birth (DD/MM/YYYY)

Forename(s) \_\_\_\_\_

ODT donor  
number \_\_\_\_\_

Dear Donor,

We would be grateful if you could complete this short survey to help us understand more about your donation experience. Your information will be held by NHS Blood and Transplant in the UK Living Donor Registry to help monitor the wellbeing of kidney donors over time and also inform people who are considering donating a kidney about what to expect.  
Thank you for your support.

**ACCESSING THE LIVING DONOR PROGRAMME (Please answer all questions unless indicated)** Section 2

1. How easy was it to find out about living donation?  
Please circle: Not at all 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

2. How easy was it for you to make contact with the living donor team?  
Please circle: Not at all 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

3. How would you rate the speed of response once you contacted the living donor team?  
Please circle: Very poor 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 Excellent Don't know ☐ Not applicable ☐

4. How welcoming was the response to your initial enquiry?  
Please circle: Not at all 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 Extremely Don't know ☐ Not applicable ☐

FRM5365/1 (Donor Reported Experience Measures (DREMS) Survey) Effective: 16/12/19 Page 1

- 12 month development process:
  - LDKT 2020 Strategy Patient and Public Engagement Workstream 'brainstorm' session on DREM
  - Fixed time work group
  - Fixed time work group and University of Hertfordshire
  - Draft DREM ready for pilot

Accessing the LD programme (4);  
Your donor assessment (13);  
Your hospital stay (10);  
After your donation (6);  
General feedback (8);  
About you (4)

# DREM development and validation

- ▶ Pilot survey in August 2019
  - 101 donors / 9 centres in the UK
    - Transplanting / non-transplanting
    - Geographical spread
  - Randomly sampled 'n' through the door
- ▶ Use that data to:
  - Evaluate the scale's measurement properties
  - Recommend improvements

# DREM development and validation

- ▶ Looked at %'s responses and means
  - For response profiles (eg high NA / DK)
- ▶ Factor analysis
  - For internal reliability and factor structure (how responses cluster together in groups of questions)
- ▶ Overall response to domains



# DREM validation

- ▶ The factor analysis indicates that the scale has very high internal reliability (alpha 0.9).
- ▶ The 5 factors which largely coalesce around the 5 domains of the scale indicate good validity

Table 8: Factor Loadings

Question	Factor1	Factor2	Factor3	Factor4	Factor5
Q11	0.19	0.06	0.15	0.88	0.15
Q12	0.11	-0.06	0.20	0.91	-0.06
Q13	0.10	-0.04	0.14	0.91	-0.04
Q14	0.31	-0.09	0.05	0.82	-0.06
Q21	0.38	-0.04	0.44	0.22	-0.33
Q22	0.41	-0.08	0.75	0.19	-0.18
Q23a	0.57	-0.07	0.65	0.02	-0.39
Q23b	0.45	-0.07	0.68	0.17	-0.30
Q23c	0.21	-0.10	0.72	0.31	-0.04
Q23d	0.27	-0.01	0.59	0.06	0.16
Q23e	0.11	-0.08	0.69	0.12	0.02
Q23f	0.39	0.06	0.67	0.37	0.12
Q23g	0.58	0.10	0.72	0.11	0.11
Q23h	0.53	0.08	0.74	0.07	0.18
Q26	0.17	-0.01	0.24	0.10	0.04
Q31	0.44	0.08	0.52	0.20	-0.01
Q33a	0.97	0.07	0.17	0.12	-0.01
Q33b	0.89	0.05	0.28	0.21	0.08
Q33c	0.97	0.07	0.17	0.12	-0.01
Q33d	0.88	0.05	0.24	0.08	0.08
Q33e	0.97	0.08	0.17	0.12	-0.01
Q33f	0.88	0.08	0.15	0.10	-0.01
Q34	0.85	0.09	0.37	-0.03	-0.03
Q35	0.97	0.07	0.15	0.14	0.00
Q41	0.33	0.48	-0.18	0.20	0.43
Q44	0.08	0.11	-0.01	0.08	0.26
Q46	0.16	0.54	0.03	-0.06	0.49
Q52a	0.08	0.96	0.04	-0.04	0.08
Q52b	0.08	0.96	0.03	-0.05	0.07
Q52c	0.44	0.80	-0.24	0.09	0.07
Q52d	0.06	0.93	0.04	-0.06	0.05
Q52e	-0.01	0.77	0.00	-0.02	-0.02
Q52f	-0.01	0.71	-0.02	0.03	-0.05
Q53	-0.10	0.78	-0.01	-0.03	-0.23

Note: Factor loadings above .4 are marked. Q26, Q41 and Q44 indicate cross-loading

# DREM validation

## ▶ Recommendations:

- Replace yes/no with 1-10 where possible
- Some question re-wording
  - Two questions on support (high 'not applicable')
  - To whom did you donate?
    - Add 'friend'
    - Clarify 'child'

## ▶ Outcome:

- A DREM with high internal reliability and five strong experience domains, that performs well as a measure of donor experience

# Donor rating of donor services (n=101)

- ▶ Responses to most questions typically positive
  - Top end of the scale (8,9,10) used more than bottom and mid points
- ▶ Overall rating of care is positive (8.9)
  - Access to the living donor programme (9.1)
  - General feedback (9.1)
  - After your donation (8.3)

	Section	N	Mean (standard deviation) range		
1	Accessing the living donor programme	88	9.1	(1.2)	3.0 – 10.0
2	Your donor assessment	95	8.9	(.8)	5.4 – 9.8
3	Your hospital stay	94	8.9	(1.2)	4.9 – 10.0
4	After your donation	94	8.3	(.9)	4.0 – 9.0
5	General feedback	94	9.1	(1.2)	5.0 – 10.0
	Overall	95	8.9	(.8)	5.5 – 9.8

# Acknowledgements

- ▶ The DREM working group: Lisa Burnapp, Fiona Loud, Matthew Robb, Jan Shorrocks, Lisa Silas
- ▶ DROM development team
- ▶ Patients and others contributing to the PPE workstream



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# Why measure DE?

- ▶ Patient experience is closely related to QoL and health-related outcomes, working to ensure a positive patient experience is at the focus of the NHS reform (1)
- ▶ Investing in quality improvement from a patient perspective offers positive implications towards the sustainability of healthcare services, including minimizing healthcare utilization (2)
- ▶ Patient experience allows providers to monitor extent to which fundamental standards of healthcare quality have been met, through objective reporting (3)

**For positive change**

