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Donor Reported Outcome Measures (DROMS)

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Background



Blood and Transplant

UK TRANSPLANT REGISTRY	 Blood and Transplant
<h3>DONOR REPORTED OUTCOME MEASURES (DROMS) SURVEY</h3>	
<p>Please return data to ODT Hub: Information Services along with Kidney Living Donor Assessment Pre- and Post- Operative (FRM4190) form or Kidney Living Donor Assessment Follow-Up (FRM4191) form as appropriate.</p> <p>ODT Hub: Information Services NHS Blood and Transplant Fox Den Road Stoke Gifford BRISTOL BS34 8RR</p> <p>Data will be collected at the following time points: Pre-donation (on completion of work up), 1 year and 5 years post donation.</p>	
DONOR DETAILS Section 1	
Surname _____	Date of birth <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
Forename(s) _____	
ODT donor number (if applicable) _____	
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DONOR REPORTED OUTCOME MEASURES (DROMS) SURVEY	
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.	
ABOUT YOUR DONATION (Please answer all questions unless indicated) Section 2	
1. How would you rate your health on a scale of 1-10 where 1 is "very poor" and 10 is "excellent"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
2. How would you rate your need to sleep on a scale of 1-10 where 1 is "almost all the time" and 10 is "as much as I expect"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
3. How would you rate the way you feel about your eating on a scale of 1-10 where 1 is "poor" and 10 is "great"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
4. Do you feel that your health has had a negative impact on your family or social life on a scale of 1-10 where 1 is "significant effect" and 10 is "not at all"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
5. How positive are you about your future on a scale of 1-10 where 1 is "not at all" and 10 is "very positive"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
6. Overall, what do people in your life think of you related to your decision to donate, on a scale of 1-10 where 1 is "they think very poorly of me" and 10 is "they think very highly of me"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
7. What is your view of your body image on a scale of 1-10 where 1 is "poor" and 10 is "excellent"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
8. What is your partner's perception (if applicable) of your body image on a scale of 1-10 where 1 is "poor" and 10 is "excellent"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
9. How would you rate your overall mobility on a scale of 1-10 where 1 is "poor" and 10 is "excellent"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
10. How would you rate your overall ability to cope with everyday activities such as working, housekeeping or travelling on a scale of 1-10 where 1 is "poor" and 10 is "excellent"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
11. How would you rate your overall ability to exercise on a scale of 1-10 where 1 is "poor" and 10 is "excellent"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	
12. How would you rate your overall ability to engage in leisure activities on a scale of 1-10 where 1 is "poor" and 10 is "excellent"? Please circle: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10	

What is DROMs?

- 20 point questionnaire survey to capture self-reported **outcomes** from living donors to add to clinical information collected in UK Living Donor Registry
 - **Pre**-nephrectomy (after completion of assessment)
 - Post nephrectomy at 1 and 5 years

Developed by:

- Members of the donor safety and welfare workstream on behalf of the LDKT 2020 Strategy Implementation Group (SIG)
- Work stream chaired by Vassilios Papalois with representation from
 - Living donors
 - Clinical colleagues
 - NHSBT representatives
- Questionnaire survey developed and refined with support from Vassilios' PhD student, work stream and SIG members

Implementation

- UK-wide from January 2019
- Communication via the UK Living Donation Network
- Pre-op data collection on all donors who have completed assessment and undergo nephrectomy from 1st January 2019
- 1 & 5 year follow-up to be collected on all donors with pre-nephrectomy data submitted

First year data

First year (Pre-donation)

Total number of questionnaires completed:	494	
Total number of living donors in 2019:	1009	
Proportion of living donors in 2019 that completed a DROM questionnaire:	458	45%
Questionnaires completed after donation (answered Q19 or Q20):	144	30%

First year (Pre-donation)

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Limitations

- Manual data collection
 - Paper form based system; IT solution required to support on-line submission, data entry and analysis
- Incomplete data
 - DROMS requires living donor coordinators to initiate and return pre-nephrectomy data so that donors are eligible for post-nephrectomy follow-up
 - DROM and DREM follow-up data currently limited to donors who attend a transplant or non-transplanting centre at 1 and 5 years post donation

Summary

- DROMS questionnaire implemented in January 2019
- To date, this has been completed by nearly 500 donors, however 30% of these were filled out at the incorrect time point
- More valuable data will be available when looking at the change in responses within individual patients from pre-donation to post-donation

Acknowledgements

LDKT 2020 Strategy Implementation Group (SIG)

Vassilios Papalois

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