# Supplemental Digital Content (SDC)

## Missing data

**Case-control variable**

0.24% (*n* = 3) were missing a data on case-control status (transplant type: i) living-donor or ii) deceased-donor transplant). This was as a result of the questionnaire code not being entered by participants who chose to complete the questionnaire online. Participants for whom case-control status was not recorded were more likely to also have missing data for age (2/3 had age missing, chi2 p <0.001), sex (2/3 had sex missing, chi2 p <0.001), and ethnicity (2/3 were missing ethnicity, chi2 p <0.001).

**Exposure variables**

**No. of potential donors/relatives**

4.03% (*n* = 50) participants had recorded no family members – this may mean that they have no living relatives or that the data is missing due to participants not wishing to complete this section. Record of this varied with age (chi2 p <0.001): older participants age 60-69 years were more likely to have recorded no family members which might suggest that the data is not missing but that no relatives exist. Those with missing data for age, sex, ethnicity, and transplant type were also more likely to have missing data for this variable.

When focusing on individuals with recorded demographic data, no pattern of missingness with age (chi2 p = 0.17), sex (chi2 p = 0.89), but maybe with ethnicity (chi2 p = 0.001) – suggested that nonwhite ethnic patients’ data more likely to be missing/blank and with transplant type (chi2 p = 0.003) suggesting recipients of deceased-donor kidney transplants were more likely to have missing data for potential donors. Again, as with age, this may suggest that the data is not missing but that no relatives exist.

**PAM score**

1.21% (*n* = 15) missing overall.

Those with missing data for age, sex, and ethnicity were not more likely to have missing data for this variable. No pattern of missingness with age (chi2 p = 0.51), sex (chi2 p = 0.55), or transplant type (chi2 p = 0.55) was observed but there was a pattern of missingness with ethnicity (chi2 p = 0.04). Black participants were more likely to have missing data than participants from other ethnic groups.

**Social support**

9.03% (*n* = 112) missing overall – these are the most sensitive questions on the questionnaire.

Those with missing data for age, sex, ethnicity and transplant type were more likely to have missing data for this variable. When focusing on individuals with recorded demographic data, no pattern of missingness with age (chi2 p = 0.47), sex (chi2 p = 0.53), or transplant type (chi2 p = 0.08), but maybe with ethnicity (chi2 p <0.001) – suggested that nonwhite participants were more likely to have missing data.

**Education**

6.69% (*n* = 83) missing overall – not bad for sensitive information.

Those with missing data for age, sex, ethnicity, and transplant type were more likely to have missing data for this variable. When focusing on individuals with recorded demographic data, no pattern of missingness with age (chi2 p = 0.47), sex (chi2 p = 0.12), or transplant type (chi2 p = 0.17) but maybe with ethnicity (chi2 p <0.001) – suggested that black patients’ and those from “other ethnic groups” are more likely to have missing data.

**Employment**

4.03% (*n* = 50) missing overall.

Those with missing data for age, sex, ethnicity, and transplant type were more likely to have missing data for this variable. When focusing on individuals with recorded demographic data, no pattern of missingness with age (chi2 p = 0.21), sex (chi2 p = 0.54), or transplant type (chi2 p = 0.36) but maybe with ethnicity (chi2 p = 0.001) – suggested that black, mixed-ethnicity and other ethnic groups’ patients’ data more likely to be missing/blank.

**Income**

35.89% (*n* = 445) missing overall – most sensitive question.

Those with missing data for age and sex were more likely to have missing data for this variable. When focusing on individuals with recorded demographic data, no pattern of missingness with ethnicity (chi2 p = 0.90) or transplant type (chi2 p = 0.20) but maybe with sex (chi2 p = 0.003) – suggested that women were more likely to have missing/blank data, and with age (chi2 p = 0.001) – suggestion of a U shaped-curve in that the oldest and youngest age groups were more likely to have missing/blank data (includes “would rather not answer.”)

**Covariates**

**Age**

2.74% (*n* = 34) missing overall.

Those with missing data for sex, ethnicity, and transplant type were more likely to have missing data for this variable. When focusing on individuals with recorded demographic data, no pattern of missingness with sex (chi2 p = 0.05), ethnicity (chi2 p = 0.97) or transplant type (chi2 p = 0.89).

**Sex**

1.69% (*n* = 21) missing overall.

Those with missing data for age, ethnicity, and transplant type were more likely to have missing data for this variable. When focusing on individuals with recorded demographic data, no pattern of missingness with age, ethnicity or transplant type (chi2 p = 0.75).

**Ethnicity**

2.42% (*n* = 30) missing overall.

Those with missing data for age, ethnicity, and transplant type were more likely to have missing data for this variable. When focusing on individuals with recorded demographic data, no pattern of missingness with age (chi2 p = 0.73), or transplant type (chi2 p = 0.94), but maybe with sex (chi2 p = 0.03) – women more likely to have missing data, but numbers very small.

# SDC Tables

**Table S1. Logistic regression analysis: likelihood of having a higher level of knowledge (>7/10 points) over lower level of knowledge (≤7/10 points) in DDKT recipients only.**

|  |  |  |
| --- | --- | --- |
| **Exposure variable** | **Unadjusted model**  **OR [95% CI]** | **Adjusted modela**  **OR [95% CI]** |
| **Education**   * **No university education** * **University level education** | Reference  2.39 [1.79-3.19] | Reference  2.76 [2.16-3.53] |
| **Income**   * **Household income <£2000/month** * **Household income ≥£2000/month** | Reference  1.90 [1.22-2.97] | Reference  1.77 [1.14-2.75] |

aadjusted for sex, age, ethnicity (binary)

**Table S2. Logistic regression analysis: likelihood of having a higher level of patient activation (PAM level 3 or 4) over a lower level of patient activation (PAM level 1 or 2)** **in DDKT recipients only.**

|  |  |  |
| --- | --- | --- |
| **Exposure variable** | **Unadjusted model**  **OR [95% CI]** | **Adjusted modela**  **OR [95% CI]** |
| **Education**   * **No university education** * **University level education** | Reference  1.93 [1.31-2.88] | Reference  2.15 [1.33-3.49] |
| **Income**   * **Household income <£2000/month** * **Household income ≥£2000/month** | Reference  1.95 [1.23-3.11] | Reference  1.84 [1.22-2.78] |

aadjusted for sex, age, ethnicity (binary)

**Table S3. Logistic regression analysis: likelihood of having a higher level of perceived social support (≥30/36 points) over a lower level of perceived social support (<30/36 points)** **in DDKT recipients only.**

|  |  |  |
| --- | --- | --- |
| **Exposure variable** | **Unadjusted model**  **OR [95% CI]** | **Adjusted modela**  **OR [95% CI]** |
| **Education**   * **No university education** * **University level education** | Reference  0.72 [0.53-0.98] | Reference  0.76 [0.57-1.02] |
| **Income**   * **Household income <£2000/month** * **Household income ≥£2000/month** | Reference  1.78 [1.29-2.45] | Reference  1.80 [1.27-2.53] |

aadjusted for sex, age, ethnicity (binary)

**Table S4. Responders and nonresponders.**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Total invited**  *N* = 3103(%) | **Participants**  *n* = 1240 (%) | **Nonparticipants**  *n* = 1863 (%)a |
| **Sex** |  |  |  |
| Male | 1902 (61) | 705 (57) | 1197 (64) |
| Female | 1201 (39) | 514 (41) | 687 (37) |
| Missing | 0 | 21 (2) | 0 |
| **Renal Transplant type** |  |  |  |
| Live-donor | 1462 (47) | 672 (54) | 790 (42) |
| Deceased-donor | 1641 (53) | 565 (46) | 1076 (58) |
| Missing | 0 | 3 (0.2) | 0 |

aAs % were rounded up to the nearest whole number some totals are more than 100%. We could not analyze response by age as people were sampled by age at transplant and then asked to enter their current age in the questionnaire.

**Table S5. Responders compared to national denominator population (data from NHS Blood and Transplant).**

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Characteristics** | | **Study DDKT recipients**  **%** | **National population of DDKT recipients 2013-2017**  **%** | **Chi2**  **p-value** | **Study LDKT recipients**  **%** | **National population of LDKT recipients 2013-2017**  **%** | **Chi2**  **p-value** |
| **Sex (%)** | **Male**  **Female** | 58  42 | 62  38 | 0.56 | 58  42 | 59  41 | 0.89 |
| **Age (years)** | **50-59** | 28 | 26 | 0.75 | 27 | 23 | 0.51 |
| **60-69** | 24 | 22 | 0.74 | 25 | 15 | 0.08 |
| **Ethnicity (%)** | **White**  **BAME/Other** | 82  18 | 73  27 | 0.13 | 89  11 | 83  17 | 0.22 |

Individuals with missing data for each characteristic excluded from figures to allow direct comparison to published NHS Blood and Transplant data

**Table S6. Likelihood of participants reporting that financial concernsa meant that relatives were unable to donate.**

|  |  |  |
| --- | --- | --- |
| **Exposure variable** | **Unadjusted model OR [95% CI]** | **Adjusted modelb OR [95% CI]** |
| **IMD rank quintile (per +1 quintile level in IMD rank)** | 1.05 [0.84-1.30] | 1.11 [0.91-1.34] |
| **Education**   * **No university education** * **University level education** | Reference  0.92 [0.68-1.25] | Reference  0.79 [0.54-1.15] |
| **Income** **per +£1000 increase in monthly household income after tax** | 0.93 [0.85-1.01] | 0.94 [0.88-1.00] |

aAlthough participants were not specifically asked for further details on their financial concerns for donors, these may have resulted from a lack of awareness of the reimbursement process on the recipient’s part, and/or inadequate information provision from healthcare workers when discussing treatment options with transplant candidates. badjusted for sex, age, ethnicity (binary)

**Table S7. Multivariable logistic regression analysis: likelihood of receiving a LDKT over a DDKT – missing explanatory variables imputed.**

|  |  |  |
| --- | --- | --- |
| **Exposure variable** | **Unadjusted model OR [95% CI]** | **Adjusted modela OR [95% CI]** |
| **Number of potential donors (per +1 potential donor)** | 1.00 [1.00-1.01] | 1.00 [1.00-1.01] |
| **Patient activation PAM level (per +1 level in PAM)** | 1.35 [1.27-1.44] | 1.32 [1.23-1.43] |
| **Patient activation**  **PAM level 1 (lowest)**  **PAM level 2**  **PAM level 3**  **PAM level 4 (highest)** | Reference  1.12 [0.71-1.77]  1.78 [1.37-2.32]  2.26 [1.82-2.80] | Reference  1.04 [0.65-1.64]  1.68 [1.26-2.26]  2.06 [1.61-2.64] |
| **Social support** | 1.06 [1.04-1.09] | 1.06 [1.04-1.08]b |
| **Transplant knowledge** | 1.58 [1.49-1.67] | 1.59 [1.49-1.69] |
| **Education**   * **No university education** * **University level education** | Reference  1.37 [1.08-1.75] | 1.48 [1.17-1.87] |
| **Income** **per +£1000 increase in monthly household income after tax** | 1.14 [1.10-1.18] | 1.14 [1.10-1.18] |

aAdjusted for sex, age, ethnicity (binary) bfor this analysis a recipient’s number of potential donors was also included as a confounder.

**Table S8. Comparison with participants in ATTOM study.**

ATTOM study - 72% of invited participants in final analysis

Bailey et al study - 40% of invited participants in final analysis

|  |  |  |
| --- | --- | --- |
|  | **ATTOM participants**  **Likelihood of LDKT over DDKT**  **Unadjusted OR (p-value)** | **Participants in Bailey et al study**  **Likelihood of LDKT over DDKT**  **Unadjusted OR (p-value)** |
| **No qualifications**  **University** | Reference  0.39 (p <0.001) | Reference  0.46 (p = 0.02) |
| **School level education**  **University education** | Reference  0.73 (p = 0.009) | Reference  0.72 (p = 0.05) |

|  |  |  |
| --- | --- | --- |
|  | **ATTOM participants**  **Likelihood of LDKT over DDKT**  **Adjusted OR (p-value)** | **Participants in Bailey et al study**  **Likelihood of LDKT over DDKT**  **Adjusted OR (p-value)** |
| **No qualifications**  **University** | Reference  0.55 (p <0.001) | Reference  0.48 (p = 0.03) |
| **School level education**  **University education** | Reference  0.76 (p = 0.01) | Reference  0.69 (p = 0.001) |