

NHS BLOOD AND TRANSPLANT

National Organ Donation Committee

Summary of consented donors with no known date of death

Introduction

1. In light of the General Data Protection Regulation (GDPR) and proposed changes to the Potential Donor Audit (PDA) a question was raised regarding the completeness of date of death for patients referred for organ donation. Depending on the number of cases involved concerns were raised regarding the duty of care to all patients who enter the donation process and the possible impact on staff resource to locate any missing data. This paper investigates the numbers of patients with no known date of death to assess the scale of issue.

Data

2. Data on all patients referred for organ donation between 1 April 2016 and 31 March 2018 were obtained from the Referral Records where the patient's death date was unknown.
3. Of the 6617 consented patients between 2016 and 2018, 141, 2% have an unknown date of death. The number of patients with no recorded death date by Organ Donation Services Team (ODST) are reported in **Table 1**. The total number of cases per year ranges from 41 to 55 and three teams (North West, South Central and Yorkshire) have the highest number of cases each year.

Table 1 Number of consented patients with no known death date by ODST, 2016-2018

ODST	2016	2017	2018	Total
Eastern	2	3	0	5
London	2	0	0	2
Midlands	0	5	2	7
North West	15	11	16	42
Northern	3	1	1	5
Northern Ireland	0	1	0	1
Scotland	0	0	1	1
South Central	6	9	17	32
South East	3	1	1	5
South Wales	0	0	1	1
South West	5	5	4	14
Yorkshire	9	5	12	26
Total	45	41	55	141

4. **Table 2** presents the number of patients with no known death date by unit in which the patient died. The majority of cases (65%) are recorded as having died on an ICU or HDU. Unit type has not been reported in 33 (23%) cases.

ODST	ICU/HDU	Ward	Other	Not reported	Total
Eastern	1	0	0	4	5
London	1	0	0	1	2
Midlands	6	0	0	1	7
North West	33	1	1	7	42
Northern	4	0	0	1	5
Northern Ireland	1	0	0	0	1
Scotland	1	0	0	0	1
South Central	19	5	1	7	32
South East	2	1	1	1	5
South Wales	1	0	0	0	1
South West	4	2	1	7	14
Yorkshire	19	1	2	4	26
Total	92	10	6	33	141

Summary

5. The number of cases of consented patients with no known death date is small, equating to just 2% between 2016 and 2018. The number of cases per year in each team is very small, 5 or less in most teams. Three teams have a higher number of cases, but there are no more than 17 cases per year in any one team.
6. The small numbers involved indicate that it should be possible to follow-up all cases to track down death date or discharge date in the exceptional case where the patient was discharged alive.

Action

7. Members are asked to consider a suitable follow-up process for cases where no death date has been recorded. A regular data report to identify all such cases within each team could be established to assist this process.