

NHS BLOOD AND TRANSPLANT

Recent trends in reasons why families did not support organ donation

Introduction

1. Since the introduction of deemed consent in Wales, nearly four years ago, and with the publicity surrounding the forthcoming implementation of opt out legislation throughout other UK nations members of the donation community have expressed concern that there has been an increase in the number of cases where '*patient previously expressed a decision not to donate*' is cited as the reason not to support organ donation. This paper presents recent trends in reasons why families did not support organ donation.

Data

2. Data were obtained from the national Potential Donor Audit (PDA) on all family approaches of eligible DCD and DBD patients between 1 January 2013 and 31 August 2019 and reasons why the patient's family decided not to support donation.

Results

Figure 1 Reasons for family not supporting donation of all families not supporting donation, Jan 2013 – Aug 2019

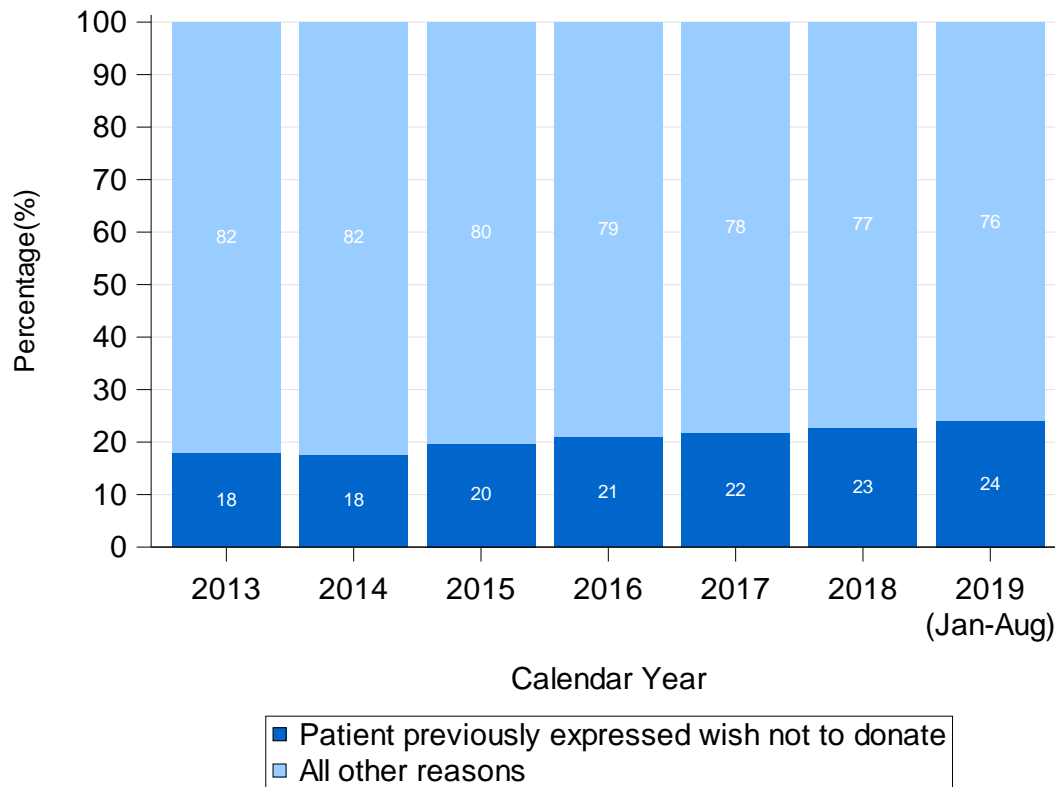


Table 1 Summary of reasons for not supporting donation Jan 2013 – Aug 2019

Reason for family not supporting donation	2013 - 2015		Jan 2016 – Aug 2019	
	Total	%	Total	%
Patient previously expressed a decision not to donate	738	18.4	917	22.3
Family were not sure whether the patient would have agreed to donation	592	14.8	659	16.0
Family concerns over post mortem intervention	549	13.7	592	14.4
Family felt the length of time for donation process was too long	454	11.3	493	12.0
Other	347	8.7	332	8.1
Family felt the patient had suffered enough	312	7.8	280	6.8
Strong refusal - probing not appropriate	288	7.2	146	3.5
Family were divided over the decision	216	5.4	186	4.5
Family felt it was against their religious/cultural beliefs	169	4.2	228	5.5
Family did not believe in donation	157	3.9	162	3.9
Family concerned that organs may not be transplanted	70	1.7	48	1.2
Family wanted to stay with the patient after death	60	1.5	46	1.1
Family had difficulty understanding/accepting neurological testing	25	0.6	12	0.3
Family concerned that other people may disapprove/be offended	16	0.4	10	0.2
Families concerned about organ allocation	7	0.2	7	0.2
Patients treatment may be or has been limited to facilitate organ donation	6	0.1	1	0.0
Refused virology testing although patient wished to donate	1	0.0	0	0.0
Total	4007		4119	

3. **Figure 1** shows the proportion of families not supporting donation over the past seven years where “*Patient previously expressed decision not to donate*” was reported as the reason for family not supporting donation. This has increased each year for the past five years from 18% in 2014 to 24% in the first eight months of 2019. However, as a proportion of all approaches this has remained unchanged at just under 8%.
4. **Table 1** compares the total number of cases reporting each reason for not supporting donation for two time periods, 2013-2015 and Jan 2016 – Aug 2019. The six most common reasons for not supporting donation are the same across both periods, with “*Patient previously expressed a decision not to donate*” being the most common (18.4% and 22.3% respectively). The citing of “*Strong refusal – probing not appropriate*” as the reason for family not supporting donation fell from 7.2% to 3.5% in the latter period.
5. In 2013-2015 there were 313 (7.8%) cases where the patient’s ODR opt-in decision was overruled. In Jan 2016 – Aug 2019 there were 331 (8.0%) cases where the patient’s ODR opt-in decision was overruled. The most common reason for over ruling the patient’s decision across both time periods was “*Family felt the length of time for donation was too long*” (27.8% in 2013-2015 and 30.8% in Jan 2016 - Aug 2019).

6. **A1** in the appendix shows the total number of cases for each reason for not supporting donation in Jan 2016 – Aug 2019 by ODR status. “*Patient previously expressed a wish not to donate*” and “*Family were not sure whether the patient would have agreed to donation*” were much less common when the patient was ODR opt-in registered (7.9% ODR opt-in vs 23.5% no ODR opt-in) and (3.6% ODR opt-in vs 17.1% no ODR opt-in) respectively. These tables also show that when a patient was ODR opt-in registered “*Family concerned that organs may not be transplanted*” was more common (3.9% ODR opt-in vs 0.9% no ODR opt-in).
7. **A2** in the appendix shows the total number of cases for each reason for not supporting donation in Jan 2016 – Aug 2019 by SNOD/SR presence. When a SNOD was present “*Other*” (5.5% SNOD/SR vs 16.4% no SNOD/SR) and “*Strong Refusal - Probing Not Appropriate*” (2.8% SNOD/SR vs 6.1% no SNOD/SR) were less frequently reported as the reason for not supporting donation. When a SNOD was present it was more common for “*Family felt the length of time for donation process was too long*” (12.9% SNOD/SR vs 8.9% no SNOD/SR) and “*Family felt it was against their religious/cultural beliefs*” (6.3% SNOD/SR vs 3.0% no SNOD/SR) to be given as the reason for not supporting donation.
8. **A3** shows the number of cases for each reason for not supporting donation in Jan 2016 – Aug 2019 by donor type. It was more common for families of DBD not to support donation for the reasons “*Family concerns over post mortem intervention*” (18.7% DBD vs 11.9% DCD) and “*Family felt it was against their religious/cultural beliefs*” (10.0% DBD vs 3.0% DCD). Families of DCD patients were more likely to not support donation for the reason “*Family felt length of time for donation process was too long*” (4.9% DBD vs 16.0% DCD).

Summary

9. The proportion of refusals reporting “*Patient previously expressed decision not to donate*” as the reason for family not supporting donation has increased from 18% to 24% between 2014 and 2019. However the proportion of all approaches has remained around 8%.
10. The six most common reasons for families not supporting donation were unchanged between the periods 2013-2015 and Jan 2016 – Aug 2019. In 2013-2015 It was more common for “*Strong refusal – probing not appropriate*” to be given as the reason for not supporting donation.
11. In 2013-2015 there were 313 (7.8%) cases where the patient’s ODR opt-in decision was overruled. In Jan 2016 – Aug 2019 there were 331 (8.0%) cases where the patient’s ODR opt-in decision was overruled.
12. There are differences in the reasons for not supporting donation when comparing the patient’s ODR status, SNOD presence and donor type.

Appendix

A1 Reasons for not supporting donation by ODR status, Jan 2016 – Aug 2019				
	No ODR Opt In/ ODR Unknown		ODR Opt In Known	
Reason for family not supporting donation	N	%	N	%
Patient previously expressed a wish not to donate	891	23.5	26	7.9
Family were not sure whether the patient would have agreed to donation	647	17.1	12	3.6
Family concerns over post mortem intervention	544	14.4	48	14.5
Family felt the length of time for donation process was too long	391	10.3	102	30.8
Other	291	7.7	41	12.4
Family felt the patient had suffered enough	252	6.7	28	8.5
Family felt it was against their religious/cultural beliefs	220	5.8	8	2.4
Family were divided over the decision	167	4.4	19	5.7
Family did not believe in donation	147	3.9	15	4.5
Strong refusal - probing not appropriate	137	3.6	9	2.7
Family concerned that organs may not be transplanted	35	0.9	13	3.9
Family wanted to stay with the patient after death	39	1.0	7	2.1
Family had difficulty understanding/accepting neurological testing	11	0.3	1	0.3
Family concerned that other people may disapprove/be offended	9	0.2	1	0.3
Families concerned about organ allocation	6	0.2	1	0.3
Patients treatment may be or has been limited to facilitate organ donation	1	0.0	0	0.0
Refused virology testing although patient wished to donate	0.0	0	0	0.0
Total	3788		331	

A2 Reasons for not supporting donation by SNOD/SR presence, Jan 2016 – Aug 2019

Reason for family not supporting donation	SNOD/SR Present		SNOD/SR Not Present	
	N	%	N	%
Patient previously expressed a wish not to donate	705	22.4	212	21.8
Family were not sure whether the patient would have agreed to donation	495	15.7	164	16.9
Family concerns over post mortem intervention	511	16.2	81	8.3
Family felt the length of time for donation process was too long	406	12.9	87	8.9
Other	172	5.5	160	16.4
Family felt the patient had suffered enough	192	6.1	88	9.0
Family felt it was against their religious/cultural beliefs	199	6.3	29	3.0
Family were divided over the decision	166	5.3	20	2.1
Family did not believe in donation	102	3.2	60	6.2
Strong refusal - probing not appropriate	87	2.8	59	6.1
Family concerned that organs may not be transplanted	45	1.4	3	0.3
Family wanted to stay with the patient after death	41	1.3	5	0.5
Family had difficulty understanding/accepting neurological testing	9	0.3	3	0.3
Family concerned that other people may disapprove/be offended	9	0.3	1	0.1
Families concerned about organ allocation	7	0.2	0	0.0
Patients treatment may be or has been limited to facilitate organ donation	0	0.0	1	0.1
Refused virology testing although patient wished to donate	0	0.0	0	0.0
Total	3146		973	

A3 Reasons for not supporting donation by donor type, Jan 2016 – Aug 2019

Reason for family not supporting donation	DBD		DCD	
	N	%	N	%
Patient previously expressed a wish not to donate	334	22.3	583	22.3
Family were not sure whether the patient would have agreed to donation	248	16.5	411	15.7
Family concerns over post mortem intervention	281	18.7	311	11.9
Family felt the length of time for donation process was too long	73	4.9	420	16.0
Other	89	5.9	243	9.3
Family felt the patient had suffered enough	78	5.2	202	7.7
Family felt it was against their religious/cultural beliefs	150	10.0	78	3.0
Family were divided over the decision	84	5.6	102	3.9
Family did not believe in donation	67	4.5	95	3.6
Strong refusal - probing not appropriate	56	3.7	90	3.4
Family concerned that organs may not be transplanted	12	0.8	36	1.4
Family wanted to stay with the patient after death	7	0.5	39	1.5
Family had difficulty understanding/accepting neurological testing	10	0.7	2	0.1
Family concerned that other people may disapprove/be offended	7	0.5	3	0.1
Families concerned about organ allocation	4	0.3	3	0.1
Patients treatment may be or has been limited to facilitate organ donation	0	0.0	1	0.0
Refused virology testing although patient wished to donate	0	0.0	0	0.0
Total	1500		2619	