

17/49/42 supp material 13: National Survey questionnaire

Section/ Question ID	Question	Response Format
Demographics		
1	What is your age?	18-29 30-39 40-49 50-59 60-69 69+ Prefer not to say
2	Please indicate if you identify as:	Male Female Prefer not to say
3	Please indicate which ethnic group you most identify with	White British White Irish Other white White and black Caribbean White and Black African White and Asian Other Mixed Indian Pakistani Bangladeshi Other Asian Prefer not to say Other (please specify)
4	Which clinical setting do you currently work in? (Please DO NOT specify your institution, as this information could potentially be used to identify you)	Palliative Care Hospice Care Other (please specify)
5	What is your current role? (Please state below but DO NOT specify your institution, as this information could potentially be used to identify you)	Free text
6	How many years have you worked in palliative or hospice care settings? Please indicate number of years below	Free text
Perceptions:		
(Questions in this section ask about your views toward organ and tissue donation in general, and eye donation in particular)		
7	Are you currently registered to be an organ/tissue donor?	Agree Not sure Disagree
8	Have you stipulated any organ and/or tissues that you do not want to donate?	Agree Not sure Disagree
9	If yes, please indicate below which organs	Free text

	or tissues you have indicated that you do not want to donate	
Please indicate whether you agree or disagree with the following statements		
10	Discussing eye donation is too distressing for a patient and/or their family	Agree Not sure Disagree
11	I feel confident in starting a conversation about eye donation with a patient and/or their family	Agree Not sure Disagree
12	Eye donation should be discussed routinely with eligible patients and/or their families	Agree Not sure Disagree
13	It is not my role to raise the option of eye donation with patients and/or their families	Agree Not sure Disagree
14	It is important that patients know that they may be eligible for eye donation	Agree Not sure Disagree
15	I am concerned about how patients and/or family members might respond to the option of eye donation being raised with them.	Agree Not sure Disagree
16	If you wish to add any comments regarding how you felt about the option of eye donation, please use the space below	Free text
17	Are you aware that eye donation is an option that patients can choose as part of end-of-life planning?	Yes No Other (free-text response)
18	Does your clinical setting actively encourage the option of eye donation being discussed with patients and/or their families?	Yes No Other (free-text response)
Practice		
(The following questions are about your knowledge and current practice relating to the option of eye donation as part of end-of-life care)		
19	Do staff within your clinical setting routinely discuss the option of eye donation in meetings (e.g., team, case conference, multi-disciplinary team meeting (MDT)?	Yes No Other (free-text response)
20	Do staff within your clinical setting routinely discuss the option of eye donation in end-of-life care planning conversations with patients and/or family members?	Yes No Other (free-text response)
21	Does your service routinely check the Organ Donor Register status of patients at the point of admission?	Yes No Other (free-text response)
22	Please summarise the process for checking Organ Donor Register status in your service (if unsure please write 'unsure')	Free text

23	Does your clinical setting have clinical guidelines in written form that include eye donation?	Yes No Other (free-text response)
24	Does your clinical setting have information in written form that staff can refer to if eye donation is raised by a patient or family member	Yes No Other (free-text response)
25	Does your clinical setting include eye donation in its admission documentation?	Yes No Other (free-text response)
26	Please comment below if you would like to share any thoughts on discussing the option of eye donation with patients and/or families.	Free text
27	Which of the following best describes your current practice?	I never discuss eye donation with patients or families I discuss eye donation only when the subject is raised by patients or families I routinely discuss the option of donation with patients and families Other (free-text response)
28	At what point in a patient's care should the option of eye donation be discussed? (Please select all that apply).	Before admission During admission During in patient stay During advanced care planning Never Other (free-text response)
29	How many times in the past year have you raised the option of eye donation with a family member?	0 1-5 6-10 11-15 15-20 More than 20
30	Reflecting back on the last time you discussed eye donation with a patient and/or relative, how did you feel having that conversation?	I have never discussed eye donation with a patient or family member Somewhat uncomfortable Very uncomfortable Neither comfortable nor uncomfortable Somewhat comfortable Very comfortable
31	If you have had a discussion with a family member, was this discussion pre or post death of the patient? (Please select all that apply)	Pre-death Post-death I have not had a discussion with a family member
32	Who do you think should raise the issue of eye donation with a patient or family member? (Please select all that apply)	It is my role The GP should have this conversation The Consultant referring the patient to Palliative Care Other palliative care specialist (e.g. CNS) A donation specialist All of the above Other (free-text response)
33	Please summarise why you think the people above should raise the issue of eye donation with a patient or family member.	Free text
34	Is there a donation link person in your service?	Yes No Don't know

35	If yes, what is the position of the link person or champion in your service? (Please describe their position, but DO NOT add personal information such as names or institutions)	Free text
Legislation governing eye donation - knowledge and experience of changes		
<p>(The next set 39of questions will ask you about recent changes to legislation governing organ and tissue donation in England. This is commonly referred to as a move from an 'opt in' to an 'opt out' system (and also known as 'Max and Keira's Law'). Please answer these questions to the best of your knowledge, without undertaking additional reading or source checking (i.e. searching for answers online).</p>		
Please indicate your response to the following statements:		
36a	Patients in England are assumed to consent to organ and tissue donation unless they opt out.	(Agreement scale) True False Unsure
36b	In the case of a patient 18 years or older with mental capacity, family/next of kin (NoK) cannot refuse donation unless the patient had indicated their wish to opt out prior to death.	(Agreement scale) True False Unsure
36c	Patients can opt out of donating specific organs or tissues while maintaining a wish to donate others.	(Agreement scale) True False Unsure
37a	I am aware of the procedure for opting out of organ and tissue donation in England.	(Agreement scale) Strongly Disagree Somewhat disagree Neither Agree nor Disagree Somewhat agree Strongly Agree
37b	I am aware of the procedure for specifying organs and tissues that I do/do not wish to donate.	(Agreement scale) Strongly Disagree Somewhat disagree Neither Agree nor Disagree Somewhat agree Strongly Agree
37c	I am confident in my ability to talk through with patients and/or families the necessary processes for opting out of organ or tissue donation in England.	(Agreement scale) Strongly Disagree Somewhat disagree Neither Agree nor Disagree Somewhat agree Strongly Agree
38	Please summarise your current understanding of the processes for opting out of organ or tissue donation, providing as much detail as you would to a patient or family member/NoK in your service.	Free text
39a	Overall, the move to the opt out system has affected my clinical practice...	Rating Scale) Very negatively Somewhat negatively Neither positively nor negatively

		Somewhat positively Very positively
39b	Overall, the move to an opt out system has affected patients and families/NoK within my service...	Rating Scale) Very negatively Somewhat negatively Neither positively nor negatively Somewhat positively Very positively
40	Following your answer to the question above, please describe below the impact that the move to an opt out system has had on your clinical practice, and/or the patients and families/NoK within your service. (if none or if you are unsure, please write 'unsure' below)	Free text
41	Have you received any information regarding the move to opt out legislation? (e.g., from your institution, or from other bodies such as NHS Blood and Transplant)	Yes No
Please indicate your current level of satisfaction with the below aspects of information provision regarding introduction of opt out legislation.		
42a	For the information I have received regarding general implications of the legislation changes, I am...	Satisfaction scale) Completely unsatisfied Somewhat satisfied Neither satisfied nor unsatisfied Somewhat satisfied Completely satisfied
42b	For the information I have received regarding specific implications of the legislation changes for my service, I am...	
43	Do you have any further comments regarding the information you have received, or outstanding information needs in relation to the new legislation (opt out)? (If none please enter 'none')	
44	Overall, how effective do you believe the new opt out system will be in increasing supply of eye tissue?	Rating Scale) Not at all effective Not very effective Somewhat effective Highly effective
45	Do you have any other comments regarding the move to opt out legislation governing tissue and organ donation in England, relating to donation of eye tissue? (if none, please enter 'none')	Free text
Preferences		

(The following questions are about provision and needs relating to knowledge and training about eye donation).

46	Have you received any in-service training about eye donation?	Yes No
47	Who provided the training?	My employer (e.g. hospital or hospice) Other (free-text response)
48	How long ago did you undertake the training?	In the last 6 months 6-12 months 13-24 months More than 24 months
49	Did the training provide you with the information you needed to be confident in discussing eye donation with patients/ family members?	Yes Somewhat No
50	Do you have any further comments on the positive or negative aspects of the training and/ or information provided?	Free text
51	If you feel that you have unmet knowledge or training needs relating to eye donation please describe these below (if none, please enter 'none')	Free text
52	Do you know where to find out information about eye donation if you need to?	Yes No
53	Please describe below the information currently available to you regarding eye donation. (e.g., policies and procedures, information for patients and families etc.) (if unsure, please write 'unsure')	Free text
54	Please indicate below where this information about eye donation is held in your organisation. (if unsure, please write 'unsure')	Free text
55	What further information would you like to have regarding eye donation?	Free text
Flash Quiz		
56	How long after death can eye donation take place?	
57	What are definite contraindications for eye donation?	
58	Is there anything that needs to happen before eye donation can take place?	
Of the following evidenced based barriers to eye donation in palliative and hospice settings, which do you view as being the most influential?		
60a	Health care providers are reluctant to discuss the option of eye donation due to concerns that they will cause distress	Please rank your responses from 1 = least influential to 5 = most influential 1 = least influential, 5 = most influential
60b	Health care providers lack knowledge in what needs to be done to organise eye donation	Please rank your responses from 1 = least influential to 5 = most influential 1 = least influential, 5 = most influential
60c	Patients and family members are unaware of eye donation as an end-of-life option	Please rank your responses from 1 = least influential to 5 = most influential

		1 = least influential, 5 = most influential
60d	The option of eye donation is not 'embedded' as a routine part of end-of-life care clinical practice	Please rank your responses from 1 = least influential to 5 = most influential 1 = least influential, 5 = most influential
60e	Personal attitudes toward eye donation undermine clinical guidance and local policy about raising this option	Please rank your responses from 1 = least influential to 5 = most influential 1 = least influential, 5 = most influential
61	In your view what are the key barriers to eye donation? (If unsure, please enter 'unsure').	Free text