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Organ donation in the ICU – a survey on next of kin response in two Swiss academic centres

Nebiker Mathias[ab*], Bloch Andreas[b*], Fedakar Pelin[b], Christen Lucienne[a], Hurni Anita[a], Carré Delphine[c], Cluzet Sylvie[c], Eckert Philippe[c], Schefold Joerg C.[b]

[a] Department of Medicine, Centre of Transplantation, Inselspital, Bern University Hospital, University of Bern, Switzerland
[b] Department of Intensive Care Medicine, Inselspital, Bern University Hospital, University of Bern, Switzerland
[c] Department of Intensive Care Medicine, Lausanne University Hospital, University of Lausanne, Switzerland

Summary

AIM OF THE STUDY: In the Swiss population, attitudes to organ donation are mostly positive. However, a high refusal rate by the next of kin may be observed. We aimed to investigate potential underlying reasons.

METHODS: In two independent Swiss tertiary care academic centres 167 next of kin were confronted with potential organ donation, over a period of 18 to 24 months. Of these, 147 could be contacted and were asked ≥6 months later to participate in a *post-hoc* survey (72-item questionnaire). Aspects related to conversations, time and care in the intensive care unit (ICU), underlying concepts for organ donation, impact on mourning, and other potential influencing factors were addressed.

RESULTS: The overall return rate was 66%. Seventy four of 77 (96%) next of kin stated that the request for organ donation was appropriate and they agreed to address the issue. Personal attitudes of next of kin regarding organ donation correlated with the decision for or against organ donation ($p < 0.0001$). Thirteen percent (8/62) reported that conversations with ICU physicians changed their decision. In 56% (18/32) of reports when organ donation was refused, the next of kin stated that presence of a documented will might have changed their decisions. Mourning was reported to be impaired by the request for organ donation in 8% (6/71), facilitated in 14% (10/71) and not affected in 77% (55/71) of cases. Twenty-seven percent (16/59) indicated that an opt-out policy for organ donation would subjectively have facilitated their decision and 81% (34/42) of consenting next of kin stated that an objection law should be put into place ($p < 0.0001$).

CONCLUSIONS: In this observational study, the majority of the next of kin stated that addressing organ donation did not affect mourning. Presence of a presumed will could likely facilitate grief and provide comfort for affected families. (Trial registration: ClinicalTrials.gov. Identifier: NCT 03612024. Date of registration: 24 July 2018.)

Introduction

Solid organ transplantation is an established therapy for end-stage organ failure [1, 2]. In Switzerland, federal law regulates organ and tissue transplantation, as well as organ donation via an opt-in system [3]. It is common sense that next of kin are always asked for consent to organ donation, even in the presence of a presumed positive patient will for organ donation. In clinical practice, an existing written or known presumed will of the patient is usually adhered to by the next of kin. In the case of a potential donor without written consent to organ donation and no next of kin available for consenting, organ donation is unlawful.

There is a growing mismatch between the limited number of donated organs and the increasing number of patients on transplantation waiting lists [4]. In Switzerland, the organ donation rate per million population (pmp) was 17.2 in 2017 [5]. Apart from Germany (9.7 pmp), all neighbouring countries have substantially higher rates: Austria 24.7 pmp, France 28.7 pmp, Italy 28.5 pmp [6]. Thus, a Swiss national action plan was implemented by the Federal Department of Health in 2014 to improve education/training, to establish national guidelines / checks, to clarify financial structures and to conduct public campaigns with the ultimate goal of increasing donation rates [7].

Refusal rates following a request for organ donation are high [4]. Interestingly, surveys on general attitudes towards organ donation in Switzerland reveal an acceptance rate of 92%, and 81% are willing to donate organs posthumously [8], whereas a consent rate of only about 30–40% is observed in many Swiss hospitals [9], including the participating institutions. As the underlying reasons are unclear, we collected answers and experiences from families confronted with organ donation after brain death (DBD) via a questionnaire-based investigation. Aspects related to conversations, time and care in the intensive care unit (ICU), underlying concepts (including the concept of brain death), impact on mourning, and other potential factors that might influence decision making were addressed.

* Equally contributing first authors

Correspondence:
Dr Mathias Nebiker, MD, Kantonsspital Aarau, Tellstrasse 25, 5001 Aarau, mathias.nebiker@ksa.ch

Methods

The questionnaire was developed in Bern and offered to the five Organ Donation Networks in Switzerland. Data were collected in the adult ICUs of two Swiss tertiary care academic centres (Department of Intensive Care Medicine, University Hospital of Bern and Department of Intensive Care Medicine, Lausanne University Hospital [CHUV]), with a catchment area of about 3–3.5 million inhabitants. At the time of the study, a donation after brain death (DBD) programme, but not donation after cardiac death (DCD), was established in Bern, whereas in Lausanne, both programmes were implemented. The 72-item questionnaire (German and French versions available) was designed in an exploratory manner by the team in Bern with the support of an external psychologist. The questionnaire addressed issues regarding conversations, time and care in the ICU, underlying concepts (including the concept of brain death), impact on mourning, and other potential factors relevant for decision-making (the questionnaires provided in the appendix in the PDF version of the manuscript).

All deaths in the ICU over a period of 18 months (Bern January 2016 to June 2017 and Lausanne July 2016 to December 2017) were screened for whether or not organ donation (DBD) was requested. In the event of a request, contact details of the primary contact person (next of kin) were recorded. At least 6 months after the death and following provision of written information, next of kin were contacted by telephone by an intensivist or by transplant coordinating staff, who requested permission to send the anonymous questionnaire. Subsequently the questionnaire was mailed in paper form to each family. If no contact by telephone was possible after several attempts (usually three times), the questionnaire was sent with an additional explanatory letter. No reminders were sent. No financial benefits applied. The need of approval by the local competent ethics committee of human research was waived in Bern (Nr. KEK-2017-00943). In accordance with the recommendations of the ethics committee of Canton de Vaud, no approval was required in Lausanne.

Clinical routine during organ donation evaluation

The following clinical routine applied to potential organ donors in both institutions: according to guidelines and federal law, the family was first informed about the medical condition of the patient, including disclosure of the futile prognosis, or even brain death. In a second family meeting, the concept of brain death was explained as a prerequisite for organ donation. If the patient's will regarding organ donation was available in written form, the next of kin were informed. In situations where written consent existed but the next of kin disagreed with organ donation, no organ was donated, although federal law places the patient's will higher than that of next of kin . In these circumstances, organ donation is considered inadmissible and may complicate the next of kin grieving process.

If brain death had not yet occurred, the next of kin were informed that maintenance of ICU care would be established for a maximum of 48 hours. From the moment of brain death, another 12–20 hours are typically required for organ evaluation and allocation, and planning of solid organ retrieval.

Statistical analysis

For statistical analysis, GraphPad Prism 6, GraphPad Software, USA was used. Data are presented as numeric values (n) or means with percentages, as appropriate. Contingency tables were analysed using a chi-square test or Fisher's exact test. A two-tailed p-value of <0.05 was considered statistically significant.

Results

Overview and characteristics of next of kin

As shown (figure 1), a total of 167 interviews on organ donation were analysed. Twenty next of kin could not be contacted for technical reasons (invalid address / telephone number, or death). A total of 147 families were contacted. Twenty-five next of kin refused to participate and 122 questionnaires were sent. Eighty-one questionnaires were returned and analysed, corresponding to a retrieval rate of 66% (fig. 1). Detailed data are given (table 1). Sixty-three percent (22/35) of the next of kin consenting to organ donation returned the questionnaire, and 68% (59/87) of next of kin refusing organ donation did so. Responses were analysed according to availability (see appendix in the PDF version of the manuscript). Most participants were female (n = 44, 54%). The following relationships to the deceased person applied: husband/spouse n = 34 (42%), parent n = 23 (28%), sibling n = 12 (15%), daughter/son n = 11 (14%), not specified n = 1 (1%). The personal attitude towards organ donation was declared as: consenting 55 (68%), dismissive in 10 (12%) and undecided in 14 (17%); 2 gave no response (2%). Out of all questionnaires, 49 (60%) covered next of kin who consented to organ donation and 32 (40%) were from next of kin who refused organ donation. The presumed will of the deceased patient was known in 50 cases (62%), comprising 15 written documents (donor card, patient directive) and 41 volitions; multiple answers were possible to this question. In 72% of cases (n = 58), the final next of kin decision on organ donation corresponded to the presumed will, whereas in one single case the decision taken by the next of kin did not match the presumed patient will. In that case, the next of kin declared that the patient was not aware that waiting for brain death would prolong treatment on the ICU. In Lausanne, fewer next of kin rejecting organ donation participated in the survey (only French-speaking) compared with Bern (German- and French-speaking): Lausanne 18 consenting, 5 refusing; Bern 31 consenting, 27 refusing. All results of the questionnaire are provided in the appendix in the PDF version of the manuscript.

Organisational aspects and conversations on organ donation

Ninety percent of next of kin (72/80) reported that they were provided with sufficient time to be with their loved one during the ICU stay. Further, 94% (75/80) felt well cared for during the time in the ICU. Thirty-eight percent (30/78) claimed that, at least partly, the period of waiting to see the patient was too long. Additionally, 40% (32/80) indicated that the waiting period until they could talk to an ICU physician was at least partly too long. This perception appeared significantly more often in the group refusing organ donation (p = 0.0028). In 83% (66/80) the aspect

of potential organ donation was first addressed in the ICU, whereas in 11 cases (14%) the issue was first addressed either by the emergency department (n = 5) or by telephone (n = 6). In 41/79 (52%) of cases, potential organ donation was discussed in the first meeting with physicians. Forty-seven percent (35/74) of the organ donation requests occurred during off-hours, in the evening or during the nighttime.

Ninety-six percent (74/77) of the next of kin reported that it was appropriate that organ donation was addressed. Ninety-nine percent (66/67) stated that they agreed with the physician's obligation to address the issue of organ donation. Sixteen of 59 (27%) indicated that an opt-out policy to organ donation would have facilitated their decision and 34/38 (89%) who consented to organ donation stated that an objection law should be put into place. This was statistically significantly different ($p < 0.0001$; Fisher's exact test) from the group not consenting to organ donation (in this group, eight responses [35%] were in favour of an opt-out policy).

Emotional aspects including mourning

In 10/79 cases (13%), the next of kin were still hoping for medical improvement at the time of the organ donation request. Twenty-eight of 77 (36%) stated their surprise that organ donation was asked for and in 13/77 cases (17%) they felt upset by this question. With regard to the concept of brain death, 71/78 (91%) agreed that explanations were necessary. Fifty-nine percent (44/75) were convinced that a person who is declared "brain dead" has in fact actually died / is dead.

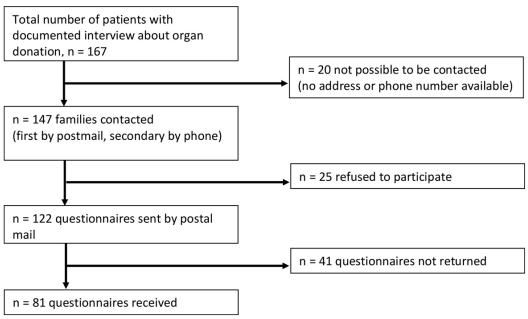

Figure 1: Study flow chart illustrating the sequence of next of kin contact and questionnaire delivery.

Five of 71 (7%) reported that the request impaired their mourning process, whereas 10/71 (14%) felt that it facilitated mourning and 55/71 (77%) reported no effect on mourning. In one case the mourning process was considerably impaired by the organ donation request. Details on consenting vs non-consenting next of kin are given in table 2. No significant differences were observed concerning mourning with regard to consenting and the knowledge of the presumed will of the deceased person (table 3).

Influence on consenting

Fifty-four of 62 next of kin (87%) reported that conversations with ICU physicians did not influence their decision regarding organ donation, whereas 8/62 (13%) indicated that it did change their decision. In cases of rejection of organ donation (n = 32), 4/32 responses (13%) signalled that having more time could have influenced their decision, and 6/32 (19%) stated that better explanation of the organ donation process might have changed their decision. In 18/32 cases (56%), the next of kin stated that an existing documented will of the deceased person might have changed the decision. Knowledge of the presumed will of the deceased patient and/or the language did not significantly affect consenting; however, personal attitudes regarding organ donation differed significantly between the groups with/without organ donation (table 4).

Discussion

The current study aimed to investigate in a detailed fashion next of kin decision making in regard to organ donation. In Bern, the refusal rate was higher than in Lausanne, with more interviews conducted in Berne (10.5% of deaths in Lausanne compared with 22.7% in Bern). In the light of potential differences in concepts of when to approach families, we rather focused on next of kin responses and not on potential centre-specific differences, which may be particular challenging to interpret. After analysing questionnaire-based responses from two independent academic centres in a descriptive fashion, we observed that the vast majority of the next of kin reported that being asked for organ donation was acceptable and did not affect mourning. They judged that the presence of a presumed will facilitated grief and provided help for families confronted with

Table 1: Characteristics and numbers of the interviews with next of kin regarding consent/refusal of organ donation.

		Lausanne	Bern	Total
Numbers of deaths in ICU		506	503	1009
Consent to organ donation	All interviews	53	114	167
	Yes	27	32	59
	No	26	82	108
Missing contact data	Total	6	14	20
	Yes	0	3	3
	No	6	11	17
Refuse to participate	Total	12	13	25
	Yes	4	3	7
	No	8	10	18
Questionnaire mailed	Total	35	87	122
	Yes	24	26	50
	No	11	61	72
Returned questionnaire	Total	22	59	81

a decision as to whether to donate. Furthermore, we identified potential intra-hospital organisational aspects that might affect the final decision.

Previous investigations have pointed to the fact that "in-hospital reasons" may be at least partly responsible for increased refusal rates [10–13]. We found that prolonged waiting time, i.e., time from first contact of the next of kin to meeting a physician, appeared as a potential factor that might affect refusal rates. In general, time until a treating physician was available for consultation consistently appeared in the survey as an important and potentially related factor. Thus, it appeared that the underlying communication concept of organ donation may be important, and this could also be reflected by the fact that in some cases, next of kin decisions changed during the process of considering organ donation. Although the exact underlying reasons remain unclear due to the observational nature of this investigation, we demonstrated that the final decision to donate may not be static for some next of kin. The scientific con-

Table 2: Comparison of the groups consenting / refusing organ donation (according to available data, no answer in italics).

	Consent yes n = 49	Consent no n = 32	p-value
The question regarding organ donation did upset me			
– Yes	4 / 8%	9 / 32%	0.0109*
– No	45 / 92%	19 / 68%	
– *No answer*	*0*	*4*	
Do you believe that a person who has been declared braindead is really dead?			
– Fully applies	30 / 68%	14 / 45%	0.1327†
– Partly applies	12 / 27%	14 / 45%	
– Does not apply	2 / 5%	3 / 10%	
– *No answer*	*5*	*1*	
The request for organ donation affected my mourning process: the process was…			
…considerably impaired	0 / 0%	1 / 4%	0.1507†
…impaired	3 / 7%	2 / 7%	
…not impaired	32 / 73%	23 / 85%	
…facilitated	9 / 20%	1 / 4%	
– *No answer*	*5*	*5*	

Available data (percentages) are given. * Fisher's exact test; † chi-square test

Table 3: Effect of consent, personal attitude towards organ donation and presumed will (if available) on the mourning process (71 answers, no answer = 10).

	Mourning process impaired	Mourning process facilitated	Mourning process not impaired	p-value
Consent to / rejection of organ donation process: (no answer = 0)				
– Consent	3 / 50%	9 / 90%	32 / 58%	0.133*
– Rejection	3 / 50%	1 / 10%	23 / 42%	
Personal attitude towards organ donation: (no answer = 2)				
– I would donate	2 / 50%	10 / 100%	38 / 84%	0.003*
– I wouldn't donate	1 / 25%	0 / 0%	7 / 16%	
– I don't know	1 / 25%	0 / 0%	0 /0%	
The presumed will of the deceased person was… (no answer = 0)				
…known	4 / 67%	8 / 80%	33 / 60%	0.475*
…not known	2 / 33%	2 / 20%	22 / 40%	

Data available (percentages) are given. * Chi-square test.

Table 4: Language, personal attitude, knowledge of presumed will of the next of kin, and correspondence of the final decision with the presumed will.

	Consent yes n = 49	Consent no n = 32	p-value
German speaking	21 / 47%	24 / 53%	0.006*
French speaking	28 / 78%	8 / 22%	
Personal attitude towards organ donation:			
– I would donate	44 / 92%	11 / 35%	<0.0001†
– I wouldn't donate	0 / 0%	10 / 32%	
– I don't know	4 / 8%	10 / 32%	
– *No answer*	*1*	*1*	
The presumed will of the patient was…			
…known	32 / 64%	18 / 36%	0.4858*
…unknown	17 / 55%	14 / 45%	
Did the final decision correspond to the presumed will:			
– Yes	37 / 79%	21 / 68%	0.3198†
– No	0 / 0%	1 / 3%	
– Not known	10 / 21%	9 / 29%	
– *No answer*	*2*	*1*	

Data available (percentages) are given. * Fisher's exact test; † chi-square test.

cept of brain death and potential organ donation may be viewed as important to next of kin confronted with the request for organ donation [14–16].

We observed that the existence of a presumed will may have facilitated decision making, and that this could influence the mourning process and might provide comfort to the next of kin. A considerable number stated that the decision whether to donate might have been different if a known presumed will had existed (56%, n = 18, of all those rejecting organ donation in the interview). Thus, it appeared that presence of a presumed will may lead to both increased organ donation rates and family relief. As the presented data are – to the best of our knowledge – the only currently available data for Switzerland, we speculate that an opt-out policy on organ donation would affect donation rates [17, 18].

Our study has important limitations that deserve discussion. First, the retrieval rate of the (not formally validated) questionnaire was 66%, which might impose a bias on our findings. Also, the group consenting to organ donation taking part in the survey was larger than the group refusing organ donation. Second, the study was performed in two academic centres and had an observational design, with all the inherent limitations driven by study design. Centre-specific differences in procedures and the proportions of participants might impact on our results. However, the questionnaire might be adopted by additional centres, enabling future multicentre comparisons. Also, excluding next of kin confronted with donation after cardiac death might be problematic, as the proportion of such donors in Switzerland increased in recent years and comparison with donation after brain death may be difficult. Third, and importantly, we deliberately designed the analysis in an anonymised fashion to provide participants with the highest level of data protection. However, this prevented us from drawing conclusions on exact patient-related factors, such as age, ethnicity or underlying pathologies leading to brain death. This was considered out of the scope of the current analysis and might be pursued in subsequent studies.

Conclusions

In this observational study including the primary next of kin of deceased individuals who qualified for potential organ donation, the majority stated that addressing the question of organ donation did not impact the mourning process. Furthermore, we identified potential intra-hospital organisational aspects such as waiting time that might affect the final decision. Finally, the next of kin judged that existence of a presumed will would have facilitated grief and might have provided help for families confronted with a request for organ donation.

Availability of data and materials

All data generated or analysed during this study are included in this published article and its supplementary information files in the appendix in the PDF version of the manuscript.

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Disclosure statement

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Appendix: Supplementary information

Supplementary file 1: Table providing all responses to the questionnaire.

Supplementary file 2: Questionnaire in English.

Supplementary file 3: Questionnaire in German.

Supplementary file 4: Questionnaire in French.

All responses to the □uestionnaire.														
	Question	Response	Number(s) of answers	Response	Number(s) of answers	Response	Number(s) of answers	Response	Number(s) of answers	Response	Number(s) of answers	Response	Number(s) of answers	
1	**care provided by intensive care unit (□C□□): general impression**													
1.1.	Did the nursing staff introduce themselves?	☐ yes	77	☐ no	2	no answer	2							
1.2.	Did the medical staff introduce themselves?	☐ yes	79	☐ no	0	no answer	2							
1.3	The ICU staff was made a competent impression.	☐ fully applies	76	☐ partly applies	2	☐ does not apply	0	no answer	3					
1.4.	I had enough time to ask questions.	☐ fully applies	72	☐ partly applies	7	☐ does not apply	1	no answer	1					
1.5.	The ICU staff made a compassionate impression.	☐ fully applies	68	☐ partly applies	9	☐ does not apply	1	no answer	3					
1.6.	Me and my family felt well cared for at the ICU.	☐ fully applies	75	☐ partly applies	4	☐ does not apply	1	no answer	1					
1.7.	The information provided by the ICU doctors was	☐ comprehensible	70	☐ partly comprehensible	10	☐ incomprehensible	1							
1.8.	My next of kin received the best possiblecare before he/she died.	☐ fully applies	73	☐ partly applies	2	☐ does not apply	0	no answer	6					
1.9.	I/we had to wait too long until I/we could visit the patient.	☐ fully applies	10	☐ partly applies	20	☐ does not apply	48	no answer	3					
1.1	I/we had to wait too long until I/we could talk to an ICU doctor.	☐ fully applies	12	☐ partly applies	20	☐ does not apply	48	no answer	1					
1.11	During the stay at the ICU I had enough time to be with my next of kin.	☐ fully applies	75	☐ partly applies	4	☐ does not apply	1	no answer	1					
1.12	The premises during the conversations were adequate.	☐ fully applies	70	☐ partly applies	7	☐ does not apply	1	no answer	3					
1.13	At what time of day was the first conversation regarding possible organ donation held?	☐ in the morning	15	☐ in the afternoon	24	☐ in the evening	22	☐ at night	13	no answer	7			
2	**conversation(s) regarding organ donation**													
2.1	Where was organ donation first addressed?	☐ at the emergency unit	6	☐ on the telephone	5	☐ at the ICU	66	☐ at another hospital	0	☐ others	3	no answer	1	
2.2	Who first addressed organ donation?	☐ I/we	8	☐ doctor	65	☐ nursing staff	3	no answer	5					
2.3	□rgan donation was discussed already in the first meeting with the ICU doctors.	☐ yes	41	☐ no	38	no answer	2							
2.4	Was the question regarding organ donation surprising?	☐ yes	28	☐ no	49	no answer	4							
2.5	Did this question upset you?	☐ yes	13	☐ no	64	no answer	4							
2.6	Did you find it appropriate that organ donation was addressed?	☐ yes	74	☐ no	3	no answer	4							
2.7	Conversations about organ donation were (multiple answers possible)	☐ too short	0	☐ too long	1	☐ adequate in length	74	☐ comprehensible	70	☐ incomprehensible	3	no answer	2	
2.8	□nce the question about organ donation had been raised, were you aware that the situation was medically hopeless?	☐ yes	76	☐ no	2	no answer	3							
2.9	Were you still hoping for a medical improvement when organ donation was discussed?	☐ yes	10	☐ no	69	no answer	2							
2.10	During the conversation about organ donation, were there any issues that bothered you (e.g. too many people, language, other reasons)?	☐ yes	9	☐ no	70	no answer	2							
2.12	My personal attitude towards organ donation is:	☐ I would want to donate	55	☐ I do not want to donate	10	☐ undecided	14	no answer	2					
2.13	My own next of kin know my wishes regarding organ donation.	☐ yes	65	☐ no	13	no answer	3							
2.14	I have expressed my wishes in written form.	☐ yes	35	☐ no	42	no answer	4							
3	**the term □brain death□**													
3.1	The term □brain death□was familiar to me before the disease of my next of kin.	☐ yes	58	☐ no	22	no answer	1							
3.2	The term □brain death□was explained to me/us.	☐ yes	73	☐ no	8									
3.3	I understood the concept of "brain death□after the conversation.	☐ fully applies	57	☐ partly applies	14	☐ does not apply	9	no answer	1					
3.4	I was able to memorize the concept of brain death.	☐ fully applies	48	☐ partly applies	25	☐ does not apply	3	no answer	5					
3.5	Did you find the explanations regarding brain death necessary?	☐ fully applies	71	☐ partly applies	7	☐ does not apply	0	no answer	3					
3.6	Do you believe that a person who has been declared braindead is really dead?	☐ fully applies	44	☐ partly applies	26	☐ does not apply	5	no answer	6					
3.7	After the explanations on brain death, I was better able to understand the fact that my next of kin was dead despite □normal□physical appearance	☐ yes	67	☐ no	7	no answer	7							
4	**decision on organ donation**													
4.1	Has an organ donation been agreed to?	☐ yes	49	☐ no	32									
4.2	The wishes of my next of kin regarding organ donation were known.	☐ yes	50	☐ no	31									
4.3	(provided that known): The wishes were	☐ discussed by word of mouth	41	☐ Donor card	9	☐ Advance directive	5	☐ written	10					
4.4	The final decision taken correspond to the presumed will of the next of kin.	☐ yes	58	☐ no	1	☐ unknown	19	no answer	3					
□	**in case the □hises of the deceased □ere not follo□ed**													
5.2	In case an organ donation was rejected, which of the following could have had an influence on the decision?	☐ more time	4	☐ better explanation of the process	6	☐ a documented will of my next of kin	18							
5.4	Within the family - was there any unanimity regarding the suspected wishes?	☐ yes	61	☐ no	7	no answer	13							
5.5	Within the family, were there different views on what the presumed wishes were?	☐ yes	8	☐ no	57	no answer	16							
5.6	Would you/the family still come to the same decision today?	☐ yes	65	☐ no	4	no answer	12							
5.8	Do you agree with physicians□legal obligation to address the issue of organ donation?	☐ yes	66	☐ no	1	no answer	14							
5.9	Should everyone become an organ donor, provided they have not objected to organ donation during their lifetime (so-called objection law)?	☐ yes	42	☐ no	19	no answer	20							
5.10	Would an existing objection law (or opting-out system) have facilitated the decision?	☐ yes	16	☐ no	43	no answer	22							
5.11	Did the conversation change the decision regarding organ donation?	☐ yes	8	☐ no	54	no answer	19							
5.12	I felt pressurised during the conversation.	☐ yes	5	☐ no	58	no answer	18							
□	**recommendations follo□-up**													
6.3	I would like to receive aftercare as a next of kin.	☐ yes	13	☐ no	56	no answer	12							
6.4	If "yes:□	☐ involving a personal meeting	10	☐ involving meeting other affected next of kin	4	☐ other	1							
6.5	The request for organ donation affected my mourning process: the process was	☐ considerably impaired	1	☐ impaired	5	☐ not impaired	55	☐ facilitated	10	no answer	10			
□	**□uestions regarding transplant coordination in case of organ donation approval**													
7.1	I remember the transplant coordinator.	☐ yes	35	☐ no	18	no answer	28							
	The assistance provided by the transplant coordination service was													
7.2	… professional	☐ fully applies	40	☐ partly applies	1	☐ does not apply	0	no answer	40					
7.3	… has met my needs	☐ fully applies	33	☐ partly applies	6	☐ does not apply	0	no answer	42					
7.4	… compassionate	☐ fully applies	31	☐ partly applies	1	☐ does not apply	4	no answer	45					
7.5	… an additional burden	☐ fully applies	1	☐ partly applies	6	☐ does not apply	30	no answer	44					
7.6	I felt under pressure when I had to decide which organs/tissues to donate.	☐ yes	4	☐ no	45	no answer	32							
7.7	Did the process of organ donation correspond to what transplant coordination services had explained?	☐ yes	43	☐ no	3	no answer	35							
7.8	Were there any deviations (e.g. timing, information flow)?	☐ yes	3	☐ no	38	no answer	40							
	Are you aware that a donor's next of kin can always contact transplant coordination services													
7.9	… regarding information about the recipient(s) (in an anonymised fashion)?	☐ yes	33	☐ no	15	no answer	33							
7.1	… in case anything is still unclear during the organ donation process?	☐ yes	27	☐ no	19	no answer	35							
7.11	Transplant coordination services defaults to calling next of kin one year later. Such a phone call	☐ is appreciated	24	☐ is fine with me	17	☐ is not necessary	4	☐ is disturbing	2	no answer	34			
□	**personal information**													
8.1	I am the deceased's:	☐ spouse	34	☐ parent	23	☐ son/daughter	11	☐ sibling	12	no answer	1			

Questionnaire for next of kin

1. care provided by intensive care unit (ICU): general impression

1.1. Did the nursing staff introduce themselves? ☐ yes ☐ no
1.2. Did the medical staff introduce themselves? ☐ yes ☐ no
1.3 The ICU staff was made a competent impression. ☐ fully applies ☐ partly applies ☐ does not apply
1.4. I had enough time to ask questions. ☐ fully applies ☐ partly applies ☐ does not apply
1.5. The ICU staff made a compassionate impression. ☐ fully applies ☐ partly applies ☐ does not apply
1.6. Me and my family felt well cared for at the ICU. ☐ fully applies ☐ partly applies ☐ does not apply
1.7. The information provided by the ICU doctors was ☐ comprehensible ☐ partly comprehensible ☐ incomprehensible
1.8. My next of kin received the best possiblecare before he/she died. ☐ fully applies ☐ partly applies ☐ does not apply
1.9. I/we had to wait too long until I/we could visit the patient. ☐ fully applies ☐ partly applies ☐ does not apply
1.10 I/we had to wait too long until I/we could talk to an ICU doctor. ☐ fully applies ☐ partly applies ☐ does not apply
1.11 During the stay at the ICU I had enough time to be with my next of kin. ☐ fully applies ☐ partly applies ☐ does not apply
1.12 The premises during the conversations were adequate. ☐ fully applies ☐ partly applies ☐ does not apply
1.13 At what time of day was the first conversation regarding possible organ donation held?
☐ in the morning ☐ in the afternoon ☐ in the evening ☐ at night

2. conversation(s) regarding organ donation

2.1 Where was organ donation first addressed?
☐ at the emergency unit ☐ on the telephone ☐ at the ICU ☐ at another hospital ☐ ____________
2.2 Who first addressed organ donation? ☐ I/we ☐ doctor ☐ nursing staff
2.3 Organ donation was discussed already in the first meeting with the ICU doctors. ☐ yes ☐ no
2.4 Was the question regarding organ donation surprising? ☐ yes ☐ no
2.5 Did this question upset you? ☐ yes ☐ no
2.6 Did you find it appropriate that organ donation was addressed? ☐ yes ☐ no
2.7 Conversations about organ donation were (multiple answers possible) ☐ too short ☐ too long ☐ adequate in length ☐ comprehensible ☐ incomprehensible
2.8 Once the question about organ donation had been raised, were you aware that the situation was medically hopeless? ☐ yes ☐ no
2.9 Were you still hoping for a medical improvement when organ donation was discussed? ☐ yes ☐ no
2.10 During the conversation about organ donation, were there any issues that bothered you (e.g. too many people, language, other reasons)? ☐ yes ☐ no
2.11 If yes, please specify (free text): ____________
2.12 My personal attitude towards organ donation is: ☐ I would want to donate ☐ I do not want to donate ☐ undecided
2.13 My own next of kin know my wishes regarding organ donation. ☐ yes ☐ no
2.14 I have expressed my wishes in written form. ☐ yes ☐ no

3. the term "brain death"

3.1 The term "brain death" was familiar to me before the disease of my next of kin. ☐ yes ☐ no
3.2 The term "brain death" was explained to me/us. ☐ yes ☐ no
3.3 I understood the concept of "brain death" after the conversation. ☐ fully applies ☐ partly applies ☐ does not apply
3.4 I was able to memorize the concept of brain death. ☐ fully applies ☐ partly applies ☐ does not apply
3.5 Did you find the explanations regarding brain death necessary? ☐ fully applies ☐ partly applies ☐ does not apply
3.6 Do you believe that a person who has been declared braindead is really dead? ☐ fully applies ☐ partly applies ☐ does not apply
3.7 After the explanations on brain death, I was better able to understand the fact that my next of kin was dead despite "normal" physical appearance. ☐ yes ☐ no

4. decision on organ donation

4.1 Has an organ donation been agreed to? ☐ yes ☐ no
4.2 The wishes of my next of kin regarding organ donation were known. ☐ yes ☐ no
4.3 (provided that known): The wishes were ☐ discussed by word of mouth ☐ written down (☐ organ donation card ☐ living will ☐ ____________)
4.4 The final decision taken correspond to the presumed will of the next of kin. ☐ yes ☐ no ☐ unknown
4.5 Why did the deceased support/not support organ donation (e.g. bodily integrity, desire to help other people)? ____________

5. in case the wishes of the deceased were not followed

5.1 What led to the differing decision? (free text) ____________
5.2 In case an organ donation was rejected, which of the following could have had an influence on the decision?
☐ more time ☐ better explanation of the process ☐ a documented will of my next of kin
5.3 Other: (free text) ____________
5.4 Within the family - was there any unanimity regarding the suspected wishes? ☐ yes ☐ no
5.5 Within the family, were there different views on what the presumed wishes were? ☐ yes ☐ no
5.6 Would you/the family still come to the same decision today? ☐ yes ☐ no
5.7 If not, why? (free text) ____________
5.8 Do you agree with physicians' legal obligation to address the issue of organ donation? ☐ yes ☐ no
5.9 Should everyone become an organ donor, provided they have not objected to organ donation during their lifetime (so-called objection law)? A conversation with the next of kin would still take place. ☐ yes ☐ no
5.10 Would an existing objection law (or opting-out system) have facilitated the decision? ☐ yes ☐ no
5.11 Did the conversation change the decision regarding organ donation? ☐ yes ☐ no
5.12 I felt pressurised during the conversation. ☐ yes ☐ no
5.13 If yes, to what extent: (free text) ____________

6. recommendations/follow-up

6.1 What could/should be done differently? (free text) ____________
6.2 I missed the following aspect during the ICU stay: (free text) ____________
6.3 I would like to receive aftercare as a next of kin. ☐ yes ☐ no
6.4 If "yes": ☐ involving a personal meeting ☐ involving meeting other affected next of kin ☐ other ____________
6.5 The request for organ donation affected my mourning process: the process was
☐ considerably impaired ☐ impaired ☐ not impaired ☐ facilitated

7. Questions regarding transplant coordination in case of organ donation approval

7.1 I remember the transplant coordinator. ☐ yes ☐ no

The assistance provided by the transplant coordination service was

7.2 … professional ☐ fully applies ☐ partly applies ☐ does not apply
7.3 … has met my needs ☐ fully applies ☐ partly applies ☐ does not apply
7.4 … compassionate ☐ fully applies ☐ partly applies ☐ does not apply
7.5 … an additional burden ☐ fully applies ☐ partly applies ☐ does not apply
7.6 I felt under pressure when I had to decide which organs/tissues to donate. ☐ yes ☐ no
7.7 Did the process of organ donation correspond to what transplant coordination services had explained? ☐ yes ☐ no
7.8 Were there any deviations (e.g. timing, information flow)? ☐ yes ☐ no

Are you aware that a donor's next of kin can always contact transplant coordination services

7.9 … regarding information about the recipient(s) (in an anonymised fashion)? ☐ yes ☐ no
7.10 … in case anything is still unclear during the organ donation process? ☐ yes ☐ no
7.11 Transplant coordination services defaults to calling next of kin one year later.
Such a phone call ☐ is appreciated ☐ is fine with me ☐ is not necessary ☐ is disturbing
7.12 Additional remarks regarding the assistance provided by transplant coordination services: (free text) ____________

8. personal information

8.1 I am the deceased's: ☐ spouse ☐ parent ☐ son/daughter ☐ ____________
8.2 I am: ☐ female ☐ male
8.3 Further comments you would like to let us know: ____________

Fragebogen f□r Angeh□rige

1. Betreuung durch □ntensivstation: genereller Eindruck

1.1. Hat sich das Pflegepersonal der Intensivstation vorgestellt? ☐ Ja ☐ Nein
1.2. Hat sich das □rztliche Personal der Intensivstation vorgestellt? ☐ Ja ☐ Nein
1.3 Das Personal der Intensivstation empfand ich als kompetent. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
1.4. Ich hatte gen□gend □eit meine Fragen zu stellen. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
1.5. Das Personal der Intensivstation nahm emotional Anteil. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
1.6. Ich und meine Angeh□rigen f□hlten sich auf der Intensivstation gut betreut. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
1.7. Die Informationen durch die □rzte der Intensivstation waren ☐ verst□ndlich ☐ teilweise verst□ndlich ☐ unverst□ndlich
1.8. Mein Angeh□riger wurde optimal betreut, bevor er/sie starb. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
1.9. Es kam vor, dass ich/wir zu □lange□ warten mussten, bis ich/wir ans Bett konnte/n. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
1.10 Es kam vor, dass ich/wir zu □lange□ warten mussten, bis wir mit dem Arzt der Intensivstation ein Gespr□ch f□hren konnten. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
1.11 Ich hatte auf der Intensivstation gen□gend □eit, um bei meiner/m Angeh□rigen zu sein. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
1.12 Die R□umlichkeiten w□hrend den Gespr□chen waren angemessen. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
1.13 □u welcher Tageszeit fand das erste Gespr□ch hinsichtlich einer m□glichen □rganspende statt? ☐ morgens ☐ mittags ☐ abends ☐ nachts

2. □espr□ch□e□, in denen nach Organspende gefragt □urde

2.1 Wo wurde das Thema □rganspende erstmals angesprochen? ☐ Notfallstation ☐ telefonisch ☐ Intensivstation ☐ anderes Spital ☐ □□□□□□□□□□
2.2 Das Thema □rganspende wurde erstmals durch wen angesprochen? ☐ durch uns Angeh□rige ☐ Arzt ☐ Pflege
2.3 Das Thema □rganspende wurde bereits im **ersten** Gespr□ch mit den □rzten thematisiert. ☐ Ja ☐ Nein
2.4 War die Frage nach □rganspende □berraschend? ☐ Ja ☐ Nein
2.5 Haben Sie diese Frage als schlimm empfunden? ☐ Ja ☐ Nein
2.6 Finden Sie es angemessen, dass man die Frage nach □rganspende stellt? ☐ Ja ☐ Nein
2.7 Ich empfand die Gespr□che zur □rganspende (mehrere Angaben m□glich) ☐ zu kurz ☐ zu lang ☐ lang genug ☐ verst□ndlich ☐ kompliziert
2.8 War Ihnen zum □eitpunkt der Frage nach □rganspende bewusst, dass medizinisch die Situation f□r Ihre/n Angeh□rige/n aussichtlos war und keine weitere Hilfe m□glich war? ☐ Ja ☐ Nein
2.9 Hatten Sie noch Hoffnung auf eine medizinische Besserung als die □rganspende besprochen wurde? ☐ Ja ☐ Nein
2.10 Als □ber die □rganspende gesprochen wurde, gab es etwas, was sie gest□rt hat (z. Bsp. zu viele Personen, Sprache, …)? ☐ Ja ☐ Nein
2.11 Falls ja (Freitextfeld): □□
2.12 Meine pers□nliche Einstellung zur □rganspende ist: ☐ Ich w□rde spenden wollen. ☐ Ich w□rde nicht spenden wollen. ☐ Ich weiss es nicht.
2.13 Meine Angeh□rigen kennen meinen Willen. ☐ Ja ☐ Nein
2.14 Ich habe meinen Willen schriftlich festgelegt. ☐ Ja ☐ Nein

3. □um Begriff □Hirntod□

3.1 Der □Hirntod□ war mir bereits vor der Erkrankung meines Angeh□rigen bekannt. ☐ Ja ☐ Nein
3.2 Der □Hirntod□ wurde erkl□rt. ☐ Ja ☐ Nein
3.3 Den □Hirntod□ habe ich nach dem Gespr□ch verstanden. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
3.4 Ich konnte mir das □onzept des □Hirntodes□ merken. ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
3.5 Fanden Sie die Erkl□rungen bez□glich □Hirntod□ notwendig? ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
3.6 Glauben Sie, dass man dann wirklich tot ist? ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
3.7 Durch die Erkl□rungen zum □Hirntod□ verstand ich die Situation, dass mein Angeh□riger trotz □normalem□ Aussehen tot ist, besser. ☐ Ja ☐ Nein

4. Entscheidung Organspende

4.1 Wurde einer □rganspende zugestimmt? ☐ Ja ☐ Nein
4.2 Der Wille meines Angeh□rigen war bekannt. ☐ Ja ☐ Nein
4.3 Sofern bekannt: Der Wille war ☐ m□ndlich besprochen ☐ schriftlich dokumentiert (☐ Spenderausweis ☐ Patientenverf□gung ☐ □□□□□□□□□□)
4.4 Entsprach der getroffene Entscheid dem mutmasslichen Willen des Angeh□rigen? ☐ Ja ☐ Nein ☐ nicht bekannt
4.5 Warum war der □erstorbene □f□r□ oder □gegen□ die □rganspende? (Freitext, z. Bsp. Unversehrtheit des □□rpers, Wunsch anderen Menschen zu helfen, …)
□□

□. Falls nicht dem □ unsch des □erstorbenen entsprochen □urde

5.1 Was hat dazu gef□hrt, dass anders entschieden wurde? (Freitext) □□□□□□□□□□□□□□□□□□□□□□□□□□□□□□
5.2 Falls eine □rganspende abgelehnt wurde, was h□tte die Entscheidung allenfalls beeinflusst?
☐ mehr □eit ☐ bessere Erkl□rung des Ablaufs ☐ der dokumentierte Wille meines Angeh□rigen
5.3 Anderes (Freitext): □□
5.4 Innerhalb der Familie gab es Einstimmigkeit bez□glich mutmasslichem Willen. ☐ Ja ☐ Nein
5.5 Innerhalb der Familie gab es verschiedene Auffassungen □ber den mutmasslichen Willen. ☐ Ja ☐ Nein
5.6 W□rden Sie heute den gleichen Entscheid f□llen? ☐ Ja ☐ Nein
5.7 Falls nein, warum? (Freitext) □□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□
5.8 Sind sie mit der gesetzlichen □erpflichtung des Arztes einverstanden, dass er/sie das Thema □rganspende ansprechen muss? ☐ Ja ☐ Nein
5.9 Sollten alle □rganspender/in werden, sofern sich die Person zeitlebens nicht dagegen ausgesprochen hat (sogenannte Widerspruchsl□sung / vermutete □ustimmung)? Ein Angeh□rigengespr□ch w□rde auch in diesem Fall stattfinden. ☐ Ja ☐ Nein
5.10 H□tte eine bestehende Widerspruchsl□sung in Ihrem Fall den Entscheid erleichtert? ☐ Ja ☐ Nein
5.11 Hat das Gespr□ch den Entscheid bez□glich □rganspende ge□ndert? ☐ Ja ☐ Nein
5.12 Ich f□hlte mich w□hrend des Gespr□ches unter Druck. ☐ Ja ☐ Nein
5.13 Falls ja, inwiefern: (Freitext) □□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□□

□. Empfehlungen □Nachbetreuung

6.1 Was k□nnte / sollte man anders (bzw. besser) machen? (Freitext) □□□□□□□□□□□□□□□□□□□□□□□□□□□□□□
6.2 W□hrend der Betreuung auf der Intensivstation hat mir folgender Aspekt gefehlt: (Freitext) □□□□□□□□□□□□□□□□□□□□□□□□□□□□□□
6.3 Eine Nachbetreuung der Angeh□rigen w□rde ich in Anspruch nehmen. ☐ Ja ☐ Nein
6.4 Falls ja: ☐ in Form von pers□nlicher Betreuung ☐ Treffen mit anderen Angeh□rigen in □hnlicher Situation ☐ anderes □□□□□□□□□□
6.5 Durch die Anfrage zur □rganspende wurde mein Trauerprozess ☐ nachhaltig beeintr□chtigt ☐ beeintr□chtigt ☐ nicht beeintr□chtigt ☐ erleichtert

□. Fragen zur Transplantationskoordination im Falle einer □ustimmung zur Organspende

7.1 Ich kann mich an die Transplantationskoordinatorin erinnern. ☐ Ja ☐ Nein

Die Betreuung durch die Transplantationskoordination war
7.2 … professionell ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
7.3 … hat meinen Bed□rfnissen entsprochen ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
7.4 … empathisch ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
7.5 … eine zus□tzliche Belastung ☐ trifft voll zu ☐ trifft teilweise zu ☐ trifft nicht zu
7.6 Ich f□hlte mich unter Druck bei der Entscheidungsfindung, welche □rgane/Gewebe gespendet werden d□rfen. ☐ Ja ☐ Nein
7.7 Entsprach der Ablauf der □rganspende dem, wie es die Transplantationskoordination erkl□rt hatte? ☐ Ja ☐ Nein
7.8 Gab es Abweichungen (z. Bsp. zeitlicher Ablauf, Informationsfluss)? ☐ Ja ☐ Nein

Ist Ihnen bekannt, dass sich die Familie des Spenders/ der Spenderin jederzeit bei der Transplantationskoordination melden kann
7.9 … f□r Ausk□nfte zu den Empf□ngern (anonymisiert)? ☐ Ja ☐ Nein
7.10 … falls etwas beim □rganspendeprozess nicht optimal gelaufen ist? ☐ Ja ☐ Nein
7.11 Nach einem Jahr werden die Angeh□rigen telefonisch von der Transplantationskoordination kontaktiert, dieser Anruf
☐ wird gesch□tzt ☐ geht in □rdnung ☐ braucht es nicht ☐ ist eine st□rende Belastung
7.12 Freitext zur Betreuung durch die Transplantationskoordination: □□□□□□□□□□□□□□□□□□□□□□□□□□□□□□

□. Eigene Angaben

8.1 Das eigene □erh□ltnis zur verstorbenen Person: ☐ (Ehe)Partner/in ☐ Mutter/□atter ☐ Sohn/Tochter ☐ □□□□□□□□□□□□□□□□□□□□
8.2 Das eigene Geschlecht: ☐ weiblich ☐ m□nnlich
8.3 Weitere Bemerkungen, die im Formular nicht erw□hnt sind, k□nnen Sie hier - oder falls mehr Platzbedarf bestehen auf der R□ckseite - erg□nzen:
□□

□uestionnaire □l□intention proches

1. Prise en charge au□soins intensifs: impression générale

1.1. Le personnel soignant s’est-il pr□sent□? ☐ □ui ☐ Non
1.2. Les m□decins se sont-ils pr□sent□s? ☐ □ui ☐ Non
1.3 J’ai jug□ le personnel des soins intensifs comp□tent. ☐ tout □ fait ☐ en partie ☐ pas du tout
1.4. J’ai eu suffisamment de temps pour poser mes questions. ☐ tout □ fait ☐ en partie ☐ pas du tout
1.5. Le personnel des soins intensifs a pris en compte mes □motions. ☐ tout □ fait ☐ en partie ☐ pas du tout
1.6. Mes proches et moi nous sommes sentis bien pris en charge. ☐ tout □ fait ☐ en partie ☐ pas du tout
1.7. Les informations donn□es par les m□decins □taient ☐ compr□hensibles ☐ en partie ☐ incompr□hensibles
1.8. Mon proche a b□n□fici□ d’une prise en charge optimale avant son d□c□s. ☐ tout □ fait ☐ en partie ☐ pas du tout
1.9. Il est arriv□ d’attendre □trop□ longtemps avant de voir mon/notre proche. ☐ tout □ fait ☐ en partie ☐ pas du tout
1.10 Il est arriv□ d’attendre □trop□ longtemps avant de pouvoir parler avec le m□decin des soins intensifs. ☐ tout □ fait ☐ en partie ☐ pas du tout
1.11 J’ai eu suffisamment de temps pour □tre aupr□s de mon proche dans le service des soins intensifs. ☐ tout □ fait ☐ en partie ☐ pas du tout
1.12 Les locaux utilis□s pour les entretiens □taient adapt□s. ☐ tout □ fait ☐ en partie ☐ pas du tout
1.13 A quel moment eut lieu le premier entretien abordant un possible don d’organes? ☐ matin ☐ midi ☐ soir ☐ nuit

2. Entretien□s□durant le□uel la □uestion du don d□organes a été abordée

2.1 □□ le sujet du don d’organes a-t-il □t□ abord□ pour la premi□re fois?
☐ Urgences ☐ au t□l□phone ☐ aux soins intensifs ☐ dans un autre h□pital ☐ □□□□□□□□□□□□□□□□
2.2 Qui a th□matis□ le don d’organes en premier? ☐ nous (proches) ☐ M□decin ☐ Personnel soignant
2.3 Le sujet du don d’organes a-t-il □t□ abord□ avec les m□decins lors du **premier** entretien d□j□? ☐ □ui ☐ Non
2.4 La question concernant un □ventuel don d’organes □tait-elle inattendue? ☐ □ui ☐ Non
2.5 Cette question a-t-elle □t□ per□ue comme douloureuse? ☐ □ui ☐ Non
2.6 Trouvez-vous ad□quat de poser la question concernant un don d’organes? ☐ □ui ☐ Non
2.7 J’ai v□cu l’entretien sur le don d’organes (plusieurs r□ponses possibles) ☐ trop court ☐ trop long ☐ assez long ☐ compr□hensible ☐ compliqu□
2.8 Au moment de la question concernant le don d’organes, □tait-il clair pour vous que la situation de votre proche □tait, d’un point de vue m□dical, sans espoir? ☐ □ui ☐ Non
2.9 Aviez-vous encore de l’espoir d’une am□lioration de la situation lors de l’entretien sur le don d’organes? ☐ □ui ☐ Non
2.10 Avez-vous □t□ d□rang□ par quelque chose lors de l’entretien (par ex. trop de personnes pr□sentes, langue, …)? ☐ □ui ☐ Non
2.11 Si oui (texte libre): □□
2.12 Ma position personnelle quant au don d’organes est: ☐ Je serais d’accord de donner mes organes. ☐ Je ne serais pas d□accord. ☐ Je ne sais pas.
2.13 Mes proches connaissent mes volont□s. ☐ □ui ☐ Non
2.14 J’ai consign□ mes volont□s par □crit. ☐ □ui ☐ Non

3. Le concept de la □mort cérébrale□

3.1 Je connaissais l’expression □mort c□r□brale□ avant d’y □tre confront□. ☐ □ui ☐ Non
3.2 L’expression □mort c□r□brale□ nous a □t□ expliqu□e. ☐ □ui ☐ Non
3.3 J’ai compris l’expression □mort c□r□brale□ suite □ l□entretien. ☐ tout □ fait ☐ en partie ☐ pas du tout
3.4 J’ai pu retenir le concept de la □mort c□r□brale□. ☐ tout □ fait ☐ en partie ☐ pas du tout
3.5 Selon vous, les explications concernant la □mort c□r□brale□ sont-elles n□cessaires? ☐ tout □ fait ☐ en partie ☐ pas du tout
3.6 Croyez–vous alors que les gens sont r□ellement d□c□d□s? ☐ tout □ fait ☐ en partie ☐ pas du tout
3.7 □ travers les explications de la □mort c□r□brale□, j'ai compris que mon proche □tait mort, malgr□ son apparence □normale□. ☐ □ui ☐ Non

4. Décision concernant le don d□organe

4.1 Un don d'organes a-t-il □t□ approuv□? ☐ □ui ☐ Non
4.2 La volont□ de mon proche □tait connue. ☐ □ui ☐ Non
4.3 Si connue: La volont□ avait □t□ ☐ discut□e ensemble ☐ consign□e par □crit (☐ carte de donneur ☐ directives anticip□es ☐ □□□□□□□□□□□□)
4.4 La d□cision finale correspond-elle □ la volont□ pr□sum□e du patient? ☐ □ui ☐ Non ☐ inconnu
4.5 Pourquoi le d□funt □tait-il □pour□ ou □contre□ le don d'organes? (Texte libre, p.ex : int□grit□ du corps, souhait d’aider quelqu’un d’autre, …):
□□

□. Dans le cas o□ la volonté de la personne décédée n□était pas connue

5.1 Qu’est-ce qui vous a aid□ □ prendre une d□cision? (texte libre) □□□□□□□□□□□□□□□□□□□□□□□□□□□□□□
5.2 Dans le cas o□ le don d’organes a □t□ refus□, qu’est-ce qui aurait pu influencer votre d□cision?
☐ Plus de temps ☐ Plus d’explications quant au processus ☐ Avoir la volont□ □crite de mon proche
5.3 Autre (Texte libre): □□
5.4 La famille □tait-elle unanime concernant la volont□ pr□sum□e de votre proche? ☐ □ui ☐ Non
5.5 Y avait-il des divergences dans la famille quant □ la volont□ pr□sum□e? ☐ □ui ☐ Non
5.6 Prendriez-vous aujourd’hui la m□me d□cision? ☐ □ui ☐ Non
5.7 Si non, pourquoi? (Texte libre) □□
5.8 □tes-vous d’accord avec l’obligation l□gale du m□decin d’aborder le sujet du don d’organes? ☐ □ui ☐ Non
5.9 Est-ce que tout un chacun devrait □tre consid□r□ comme donneur d’organes, □ moins qu’il ne s’y soit oppos□ de son vivant – connu comme le r□gime du consentement pr□sum□? Tout en incluant □galement une discussion avec les proches. ☐ □ui ☐ Non
5.10 Est-ce que le r□gime du consentement pr□sum□ aurait facilit□ votre d□cision? ☐ □ui ☐ Non
5.11 Avez-vous chang□ d’avis suite □ l’entretien portant sur le don d’organes? ☐ □ui ☐ Non
5.12 Je me suis senti(e) sous pression durant l’entretien. ☐ □ui ☐ Non
5.13 Si oui, dans quelle mesure? (Texte libre) □□

□. □ecommandations □le suivi

6.1 Que devrions-nous am□liorer? (Texte libre) □□
6.2 Lors de la prise en charge aux soins intensifs, certains aspects ont-ils manqu□? (Texte libre) □□
6.3 J’aurais souhait□ b□n□ficier d’un accompagnement. ☐ □ui ☐ Non
6.4 Si oui: ☐ Sous la forme d’un entretien personnel ☐ Rencontre avec d’autres proches ayant v□cu une situation similaire ☐ autre □□□□□□□□□□□□
6.5 Suite □ la question du don d’organes, mon processus de deuil a □t□ ☐ durablement alt□r□ ☐ alt□r□ ☐ n’a pas □t□ influenc□ ☐ facilit□

□. □uestions relatives □ la coordination de transplantation en cas de consentement au don d□organes

7.1 Je me rappelle de la coordinatrice de transplantation. ☐ □ui ☐ Non

La prise en charge par la coordinatrice de transplantation □tait
7.2 … professionnelle ☐ tout □ fait ☐ en partie ☐ pas du tout
7.3 … a r□pondu □ mes besoins ☐ tout □ fait ☐ en partie ☐ pas du tout
7.4 … empathique ☐ tout □ fait ☐ en partie ☐ pas du tout
7.5 … une charge suppl□mentaire ☐ tout □ fait ☐ en partie ☐ pas du tout
7.6 Je me suis senti/e sous pression lorsqu’il a fallu d□cider quels organes allaient □tre donn□s. ☐ □ui ☐ Non
7.7 Le processus de don d’organes a-t-il □t□ expliqu□ en d□tail par la coordinatrice de transplantation? ☐ □ui ☐ Non
7.8 Ya-t-il eu des diff□rences (p.ex. timing, flux d’information)? ☐ □ui ☐ Non

Saviez-vous que la famille du donneur/euse pouvait en tout temps contacter la coordination de transplantation
7.9 … pour avoir des informations quant aux receveurs (anonymement)? ☐ □ui ☐ Non
7.10 … dans le cas o□ quelque chose ne s’est pas d□roul□ de la mani□re optimale dans le processus du don d’organes? ☐ □ui ☐ Non
7.11 Apr□s un an, les proches sont contact□s par t□l□phone par la coordination de transplantation, cet appel
☐ est appr□ci□ ☐ est ok ☐ n’est pas n□cessaire ☐ est une g□ne suppl□mentaire
7.12 Texte libre pour la prise en charge par la coordination de transplantation: □□

□. Données personnelles

8.1 Lien de parent□ avec la personne d□c□d□e: ☐ Epoux-se/partenaire ☐ M□re/P□re ☐ Fils/Fille ☐ □□□□□□□□□□□□□□□□□□□□
8.2 Genre: ☐ Femme ☐ Homme
8.3 Des commentaires suppl□mentaires peuvent □tre ajout□s ci-apr□s ou au verso:
□□