

Questionnaire on family experiences of ICU quality of care

(name of actual ICU)

This questionnaire is about experiences that you and your family member (the patient) had during his or her stay in the Intensive Care Unit (ICU). We are interested in your experiences because we want to improve the care received by patients and family members.

Some of these questions may be difficult to answer because you may not have had all these experiences. Other questions may be hard to answer because they remind you of a difficult emotional time. Please feel free to skip questions that you find too difficult to answer.

The questions that follow ask **YOU** about your family member's ICU admission. We understand that you might perceive that care varied in time and between caregivers but we are interested in **your overall assessment** of the quality of care we delivered. Your responses will be used to improve our ICU care.

As we are currently developing the questionnaire, you will for each question also be asked to assess whether you find it relevant and understandable. At the end there are two short additional questionnaires that ask about which impact being a family member to an ICU patient has had on you.

If you want to elaborate on your answers or to add additional comments, this will be much appreciated and can be done in the comment boxes at the end of each part of the questionnaire.

When the term ICU staff is used, it concerns nurses, doctors, and other personnel from the ICU

Please fill in the questionnaire and return it in the enclosed pre-paid envelope. If you do not wish to participate you can just return the questionnaire blank.

If you have any questions, please feel free to call (*name, phone number and e-mail address on local investigator*).

Thank you.

ABOUT YOU

In this section, we would like to ask a few questions about you

1. How old are you?

2. What is your gender?

Male

Female

3. How are you related to your family member (the patient)?

I am his/her spouse or partner

I am his/her child

I am his/her sibling

I am his/her parent

I am another relative

I am his/her friend

Other (please specify) _____

PART 1: SATISFACTION WITH CARE

In this section, we would like to ask some questions about your overall experience of the care provided to your family member (the patient) and to you

Please check one box that best reflects your views. If the question does not apply to your family member's stay, then check the "not applicable" box (N/A).

HOW DID WE TREAT YOUR FAMILY MEMBER (THE PATIENT)?

1. Concern and caring by ICU staff: The courtesy, respect and compassion your family member (the patient) was given

- Excellent
- Very good
- Good
- Fair
- Poor
- N/A

Is the question relevant?

Yes Partially No Don't know

If partially or no, what could be altered?

Is the question understandable?

Yes Partially No

If partially or no, what could be altered?

2. Symptom treatment: How well the ICU staff assessed and treated your family member's symptoms

- 2 a. Pain**
- Excellent
 - Very good
 - Good
 - Fair
 - Poor
 - N/A

Is the question relevant?

Yes Partially No Don't know

If partially or no, what could be altered?

Is the question understandable?

Yes Partially No

If partially or no, what could be altered?

(continued)

2. Symptom treatment: How well the ICU staff assessed and treated your family member's symptoms

2 b. Breathlessness

- Excellent
- Very good
- Good
- Fair
- Poor
- N/A

Is the question relevant?

Yes Partially No Don't know

If partially or no, what could be altered?

Is the question understandable?

Yes Partially No

If partially or no, what could be altered?

2 c. Agitation

- Excellent
- Very good
- Good
- Fair
- Poor
- N/A

Is the question relevant?

Yes Partially No Don't know

If partially or no, what could be altered?

Is the question understandable?

Yes Partially No

If partially or no, what could be altered?

HOW DID WE TREAT YOU?

3. Atmosphere of the ICU: How well the involved ICU staff made you feel that your presence was appreciated

- Excellent
- Very good
- Good
- Fair
- Poor
- N/A

Is the question relevant?

Yes Partially No Don't know

If partially or no, what could be altered?

Is the question understandable?

Yes Partially No

If partially or no, what could be altered?

4. Consideration of your needs: How well the involved ICU staff showed an interest in your needs

- Excellent
- Very good
- Good
- Fair
- Poor
- N/A

Is the question relevant?

Yes Partially No Don't know

If partially or no, what could be altered?

Is the question understandable?

Yes Partially No

If partially or no, what could be altered?

5. Emotional support: How well the involved ICU staff provided emotional support

- Excellent
- Very good
- Good
- Fair
- Poor
- N/A

Is the question relevant?

Yes Partially No Don't know

If partially or no, what could be altered?

Is the question understandable?

Yes Partially No

If partially or no, what could be altered?

6. Presence at the bedside. The possibilities to be present at the bedside

- Excellent
- Very good
- Good
- Fair
- Poor
- N/A

Is the question relevant?

Yes Partially No Don't know

If partially or no, what could be altered?

Is the question understandable?

Yes Partially No

If partially or no, what could be altered?

7. If you have comments to your responses or other experiences (good or bad) from the ICU we could learn from, please add them here.

PART 2: SATISFACTION WITH INFORMATION AND DECISION-MAKING AROUND CARE OF CRITICALLY ILL PATIENTS

In this section, we would like to ask some questions about the information you received and how you feel about your involvement in decision making related to your family member's health care.

INFORMATION NEEDS

1. Ease of getting information: Willingness of ICU staff to answer your questions

- Excellent
- Very good
- Good
- Fair
- Poor
- N/A

Is the question relevant?

Yes Partially No Don't know
If partially or no, what could be altered?

Is the question understandable?

Yes Partially No
If partially or no, what could be altered?

2. Understanding of information: How well ICU staff provided you with explanations that you understood

- Excellent
- Very good
- Good
- Fair
- Poor
- N/A

Is the question relevant?

Yes Partially No Don't know
If partially or no, what could be altered?

Is the question understandable?

Yes Partially No
If partially or no, what could be altered?

3. Honesty of information: Perceived honesty of information provided to you about your family member's condition

- Excellent
- Very good
- Good
- Fair
- Poor
- N/A

Is the question relevant?

Yes Partially No Don't know
If partially or no, what could be altered?

Is the question understandable?

Yes Partially No
If partially or no, what could be altered?

4. Completeness of Information:

4.a. How well ICU staff informed you about **what was happening** with your family member.

- Excellent
- Very good
- Good
- Fair
- Poor
- N/A

Is the question relevant?

Yes Partially No Don't know
If partially or no, what could be altered?

Is the question understandable?

Yes Partially No
If partially or no, what could be altered?

4.b. How well ICU staff informed you about **why things were being done** to your family member.

- Excellent
- Very good
- Good
- Fair
- Poor
- N/A

Is the question relevant?

Yes Partially No Don't know
If partially or no, what could be altered?

Is the question understandable?

Yes Partially No
If partially or no, what could be altered?

5. Consistency of Information: The consistency of information provided to you about your family member's condition (Did you get a similar story from the doctor, nurse, etc.)

- Excellent
- Very good
- Good
- Fair
- Poor
- N/A

Is the question relevant?

Yes Partially No Don't know

If partially or no, what could be altered?

Is the question understandable?

Yes Partially No

If partially or no, what could be altered?

6. Overall quality of information:

6a. The overall quality of information provided to you by **doctors**

- Excellent
- Very good
- Good
- Fair
- Poor
- N/A

Is the question relevant?

Yes Partially No Don't know

If partially or no, what could be altered?

Is the question understandable?

Yes Partially No

If partially or no, what could be altered?

6b. The overall quality of information provided to you by **nurses**

- Excellent
- Very good
- Good
- Fair
- Poor
- N/A

Is the question relevant?

Yes Partially No Don't know

If partially or no, what could be altered?

Is the question understandable?

Yes Partially No

If partially or no, what could be altered?

PROCESS OF DECISION-MAKING

The decisions doctors made in regard to tests, surgery, treatments etc.

7a. Inclusion in the decision-making processes. How well the staff involved you in major decision-making processes.

- Excellent (go to question 8)
- Very good (go to question 8)
- Good (go to question 8)
- Fair (go to question 7b)
- Poor (go to question 7b)
- N/A (go to question 10)

Is the question relevant?

Yes Partially No Don't know
If partially or no, what could be altered?

Is the question understandable?

Yes Partially No
If partially or no, what could be altered?

7b. If you found inclusion in the decision-making processes fair or poor, was it because:

- You were involved too much?
- You were not involved enough?
- Other reasons (please specify)

Is the question relevant?

Yes Partially No Don't know
If partially or no, what could be altered?

Is the question understandable?

Yes Partially No
If partially or no, what could be altered?

8. Support during the decision-making processes: How well ICU staff supported you when major decisions were made

- Excellent
- Very good
- Good
- Fair
- Poor
- N/A

Is the question relevant?

Yes Partially No Don't know
If partially or no, what could be altered?

Is the question understandable?

Yes Partially No

If partially or no, what could be altered?

9. When major decisions were made, did you have adequate time to have your concerns addressed and questions answered?

I had adequate time

I could have used more time

Don't know

Is the question relevant?

Yes Partially No Don't know

If partially or no, what could be altered?

Is the question understandable?

Yes Partially No

If partially or no, what could be altered?

10. If you have comments to your responses or other experiences (good or bad) from the ICU we could learn from, please add them here.

PART 3: SATISFACTION WITH QUALITY OF CARE FOR DYING PATIENTS

In this section, we would like to ask some questions about your experiences of the quality of care provided to your family member in the last days of his/her life

1. How often did your family member appear to have his/her pain under control?

- All the time
- Most of the time
- A good bit of the time
- Some of the time
- A little bit of the time
- None of the time
- Don't know
- N/A

Is the question relevant?

Yes Partially No Don't know
If partially or no, what could be altered?

Is the question understandable?

Yes Partially No
If partially or no, what could be altered?

2. Did your family member receive help from a mechanical ventilator (respirator) to breathe?

- Yes
- No (go to question 3)
- Don't know (go to question 3)

Is the question relevant?

Yes Partially No Don't know
If partially or no, what could be altered?

Is the question understandable?

Yes Partially No
If partially or no, what could be altered?

2a. How often did your family member appear comfortable on the ventilator

- All the time
- Most of the time
- A good bit of the time
- Some of the time
- A little bit of the time
- None of the time
- Don't know

Is the question relevant?

Yes Partially No Don't know
If partially or no, what could be altered?

Is the question understandable?

Yes Partially No
If partially or no, what could be altered?

3. How often did your family member appear to keep his/her dignity?

- All the time
- Most of the time
- A good bit of the time
- Some of the time
- A little bit of the time
- None of the time
- Don't know

Is the question relevant?

Yes Partially No Don't know
If partially or no, what could be altered?

Is the question understandable?

Yes Partially No
If partially or no, what could be altered?

4. Do you think that your family member got the emotional support he/she needed?

- Yes
- Partially
- No
- Don't know

Is the question relevant?

Yes Partially No Don't know
If partially or no, what could be altered?

Is the question understandable?

Yes Partially No
If partially or no, what could be altered?

5. Do you think that your family member got the spiritual support he/she needed?

- Yes
Partially
No
Don't know

Is the question relevant?
Yes Partially No Don't know
If partially or no, what could be altered?

Is the question understandable?
Yes Partially No
If partially or no, what could be altered?

6. Please rate the overall care your family member received from all doctors, nurses and other health care professionals during the last several days of his or her life while in the ICU. (Circle the number)

| | | | | | | | | | | | | |
|---------------------------|---|---|---|---|---|---|---|---|---|---|----|--------------------------|
| Worst care possible | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Best care possible |
|---------------------------|---|---|---|---|---|---|---|---|---|---|----|--------------------------|

Is the question relevant?
Yes Partially No Don't know
If partially or no, what could be altered?

Is the question understandable?
Yes Partially No
If partially or no, what could be altered?

7. Did your family member discuss his or her treatment preferences regarding end-of-life care (for example, resuscitation or intensive care) with a doctor (GP or hospital doctor) before admittance to the ICU?

- Yes
No
Don't know

Is the question relevant?
Yes Partially No Don't know
If partially or no, what could be altered?

Is the question understandable?
Yes Partially No
If partially or no, what could be altered?

8. Did your family member discuss his or her treatment preferences regarding end-of-life care with the ICU staff during the ICU stay?

- Yes
- No
- Don't know

Is the question relevant?

- Yes Partially No Don't know
If partially or no, what could be altered?
-

Is the question understandable?

- Yes Partially No
If partially or no, what could be altered?
-

9. Was the end-of-life care according to the wishes of your family member?

- Yes
- Partially
- No
- Don't know

Is the question relevant?

- Yes Partially No Don't know
If partially or no, what could be altered?
-

Is the question understandable?

- Yes Partially No
If partially or no, what could be altered?
-

10. Did you feel your family member's life was prolonged unnecessarily?

- Yes
- Partially
- No
- Don't know

Is the question relevant?

- Yes Partially No Don't know
If partially or no, what could be altered?
-

Is the question understandable?

- Yes Partially No
If partially or no, what could be altered?
-

11. Did you feel you got the chance to say goodbye to your family member?

- Yes
- Partially
- No
- Don't know

Is the question relevant?

Yes Partially No Don't know
If partially or no, what could be altered?

Is the question understandable?

Yes Partially No
If partially or no, what could be altered?

12. If a decision was made to limit life sustaining treatment, did you agree with the decision?

- Strongly agreed
- Agreed
- Neither agreed or disagreed
- Disagreed
- Strongly disagreed
- Don't know
- N/A (go to question 15)

Is the question relevant?

Yes Partially No Don't know
If partially or no, what could be altered?

Is the question understandable?

Yes Partially No
If partially or no, what could be altered?

13. Which part did you experience you had in connection with the decision to limit life sustaining treatment?

- The patient made the decision
- The doctors made the decision without involving me (and/or my family)
- The doctors made the decision after discussing it with me (and/or my family)
- The decision was made jointly between the doctors and me (and/or my family)
- I (and/or my family) made the decision after being informed of the situation by the doctors
- I (and/or my family) made the decision alone
- Don't know

Is the question relevant?

Yes Partially No Don't know
If partially or no, what could be altered?

Is the question understandable?

Yes Partially No
If partially or no, what could be altered?

In (*name of country*) the legislation states that decisions to limit life sustaining treatment must be made by the patient or the doctors. Families have no legal right or duty to make decisions.

14. If you disregard the legislation, which part would you have wished to have in connection with the decision to limit life sustaining treatment?

- That the doctors made the decision without involving me (and/or my family)
- That the doctors made the decision after discussing it with me (and/or my family)
- That the decision was made jointly between the doctors and me (and/or my family)
- That I (and/or my family) made the decision after being informed of the situation by the doctors
- That I (and/or my family) made the decision alone
- Don't know

Is the question relevant?

Yes Partially No Don't know
If partially or no, what could be altered?

Is the question understandable?

Yes Partially No
If partially or no, what could be altered?

15. If you have comments to your responses or other experiences (good or bad) from the ICU we could learn from, please add them here.

**Thank you for taking the time to complete this survey.
Please put it in the stamped, self-addressed envelope and mail it to us
as soon as possible.
Thank you again for your help.**

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Name and contact information

euroQ2. European Quality Questionnaire.

Questionnaire on family experiences of ICU quality of care