

Family Reported Experiences Evaluation FREE Study Questionnaire

*The FREE Study aims to help improve intensive care in the NHS
using the experiences of family members*

Completing this questionnaire

Today's date

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Did you complete this questionnaire
(please tick)

Alone

With help

Approximately how many times
did you visit your family member* in the ICU

times

** For this study a "family member" is anyone with a close familial, social or emotional relationship to the patient and is not just the next-of-kin.*

Please post your completed questionnaire in the stamped, addressed envelope provided

Your opinions about your family member's recent admission to the Intensive Care Unit (ICU)

- Your family member was a patient in the ICU.
- The questions that follow ask **YOU** about your family member's recent ICU admission.
- We understand that there were probably many doctors, nurses and other staff involved in caring for your family member. We know that there may be exceptions but we are interested in **your overall assessment** of the quality of care delivered.
- We understand that this was probably a very difficult time for you and your family members. We would appreciate you taking the time to provide us with your opinion.
- Please take a moment to tell us what was done well and what could be done to make the ICU better. Please be assured that all responses are confidential. The doctors and nurses who looked after your family member will not be able to identify your responses. If needed, you may add comments to the questionnaire to explain your answer.

About you

Please complete the following to help us know a little about you and your relationship to the patient.

- Q1 I am Male Female
- Q2 I am years old
- Q3 I am the patient's Wife Husband Partner Friend
 Mother Father Sister Brother
 Daughter Son Aunt Uncle
 Niece Nephew Grandmother Grandfather
 Other If Other (please specify):
- Q4 Are you the patient's next of kin? Yes No
- Q5 Before this most recent event, have you been involved as a family member of a patient in an ICU (Intensive Care Unit)? Yes No
- Q6 Do you live with the patient? (If the patient has died, did you live with the patient?) Yes No
- If **NO**, then on average how often do you see the patient? More than once a week
 (If the patient has died, how often did you see the patient?) Once a week
 Every 2 weeks
 Once a month
 Every 2 to 3 months
 Every 4 to 6 months
 Once a year
 Less than once a year
- Q7 How would you rate your knowledge of the patient's health issues prior to them coming to the ICU?
 Excellent Very good Good Fair Poor
- Q8 How would you rate the ease of travelling from your home to the hospital?
 Excellent Very good Good Fair Poor

Satisfaction with care

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

How did we treat your family member (the patient)?

Q1 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

Q2 Symptom management?

· How well the ICU staff assessed and treated your family member's symptoms

a - Pain

Excellent Very good Good Fair Poor N/A

b - Breathlessness

Excellent Very good Good Fair Poor N/A

c - Agitation

Excellent Very good Good Fair Poor N/A

How did we treat you?

Q3 Consideration of your needs?

· How well the ICU staff showed an interest in your needs

Excellent Very good Good Fair Poor N/A

Q4 Emotional support?

· How well the ICU staff provided emotional support

Excellent Very good Good Fair Poor N/A

Q5 Concern and caring by ICU staff?

· The courtesy, respect and compassion you were given

Excellent Very good Good Fair Poor N/A

Satisfaction with care cont.

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

Teamwork

Q6

Co-ordination of care?

The teamwork of all the ICU staff who took care of your family member

Excellent Very good Good Fair Poor N/A

Nurses

Q7

Skill and competence of ICU nurses?

How well the nurses cared for your family member

Excellent Very good Good Fair Poor N/A

Q8

Frequency of communication with ICU nurses?

How often nurses communicated to you about your family member's condition

Excellent Very good Good Fair Poor N/A

Doctors

Q9

Skill and competence of ICU doctors?

How well doctors cared for your family member

Excellent Very good Good Fair Poor N/A

The ICU

Q10

The atmosphere (mood) of the ICU was?

Excellent Very good Good Fair Poor N/A

The Waiting Room

Q11

The atmosphere (mood) in the ICU Waiting Room was?

Excellent Very good Good Fair Poor N/A

Level/amount of health care

(For Q12, please pay attention to the order of the responses)

Q12

Some people want everything done for their health problems while others do not want a lot done. How satisfied were you with the **LEVEL** or **amount** of health care your family member received in the ICU?

Very dissatisfied Slightly dissatisfied Mostly satisfied Very satisfied Completely satisfied

Family satisfaction with decision making around care of critically ill patients

Instructions for family members of critically ill patients

This part of the questionnaire is designed to measure how you feel about your involvement in decisions related to your family member's health care.

In the Intensive Care Unit (ICU), your family member may have received care from different people. We would like you to think about all the care your family member received when you are answering the questions.

Please tick **one** box that best describes your feelings...

Information needs

Q1 Frequency of communication with ICU doctors?

· How often doctors communicated to you about your family member's condition

Excellent Very good Good Fair Poor N/A

Q2 Ease of getting information?

· Willingness of ICU staff to answer your questions

Excellent Very good Good Fair Poor N/A

Q3 Understanding of information?

· How well ICU staff provided you with explanations that you understood

Excellent Very good Good Fair Poor N/A

Q4 Honesty of information?

· The honesty of information provided to you about your family member's condition

Excellent Very good Good Fair Poor N/A

Q5 Completeness of information?

· How well ICU staff informed you what was happening to your family member and why things were being done

Excellent Very good Good Fair Poor N/A

Q6 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

Family satisfaction with decision making around care of critically ill patients cont.

During your family member's stay in the ICU, many important decisions were made regarding the health care he or she received.

*For the following questions, pick **one** answer from each of the following set of ideas that best matches your views.*

If your family member was able to make decisions for themselves while in the ICU, then some questions may not be applicable to you; in that case, please tick Not applicable...

The process of making decisions

Q7 Did you feel included in the decision-making process?

- I felt very excluded
- I felt somewhat excluded
- I felt neither included nor excluded
- I felt somewhat included
- I felt very included
- Not applicable

Q8 Did you feel supported during the decision-making process?

- I felt totally unsupported
- I felt slightly unsupported
- I felt neither supported nor unsupported
- I felt supported
- I felt very supported
- Not applicable

Family satisfaction with decision making around care of critically ill patients cont.

Q9 Did you feel you had control over the care of your family member?

I felt really out of control and that the health care system took over and dictated the care my family member received

I felt somewhat out of control and that the health care system took over and dictated the care my family member received

I felt neither in control nor out of control

I felt I had some control over the care my family member received

I felt that I had good control over the care my family member received

Not applicable

Q10 When making decisions, did you have adequate time to have your concerns addressed and questions answered?

I could have used more time

I had adequate time

Not applicable

Family satisfaction with decision making around care of critically ill patients cont.

If your family member died in the ICU, we would like to ask you your opinion on how things went in those final days.

We know it may be difficult to answer these questions but we would greatly value your input so we can improve the care we provide to dying patients.

Please answer the following questions (11-13)...

If your family member did not die, please go to question 14.

- Q11 Which of the following best describes your views:**
- I felt my family member's life was prolonged unnecessarily
 - I felt my family member's life was slightly prolonged unnecessarily
 - I felt my family member's life was neither prolonged nor shortened unnecessarily
 - I felt my family member's life was slightly shortened unnecessarily
 - I felt my family member's life was shortened unnecessarily

- Q12 During the final hours of your family member's life, which of the following best describes your views:**
- I felt that he/she was very uncomfortable
 - I felt that he/she was slightly uncomfortable
 - I felt that he/she was mostly comfortable
 - I felt that he/she was very comfortable
 - I felt that he/she was totally comfortable

- Q13 During the last few hours before your family member's death, which of the following best describes your views:**
- I felt very abandoned by the health care team
 - I felt abandoned by the health care team
 - I felt neither abandoned nor supported by the health care team
 - I felt supported by the health care team
 - I felt very supported by the health care team

Family satisfaction with decision making around care of critically ill patients cont.

Q14 How satisfied were you with the amount of control you had over the care of your family member?

Very dissatisfied Slightly dissatisfied Mostly satisfied Very satisfied Completely satisfied

Q15 Do you have any suggestions on how to make care provided in the ICU better?

Q16 Do you have any comments on things we did well?

Q17 Please add any comments or suggestions that you feel may be helpful to the staff of this ICU

We would like to thank you very much for your participation and your opinions.