‘The role of patients’ relatives in decision-making in Intensive Care’

Many thanks for completing this questionnaire. It asks for your own personal opinion on how you see your role as someone accompanying a patient in ICU. Please see the information leaflet for further information about the study.

**You can answer as many or as few of the questions as you wish. Where there is a choice of answers, please tick all those which apply. Feel free to add any further comments if you would like to.**

1. **About your relationship with the patient**
2. What is your relationship with the patient? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
3. How long has the patient been in ICU? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
4. Is the patient able to communicate with you? YES ❑ NO ❑
5. Do you know the patient’s opinion concerning their treatment? YES ❑ NO ❑
6. If ’YES’, can you describe in your own words what you have discussed?

(This may include their views on being ill, what treatment they would or would not want, personal views, religious background, views on death etc.)

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1. Does the patient have an Advance Directive? YES ❑ NO ❑ Don’t know ❑
2. **Your role in the decision-making process**
3. What has your role *been so far* (your actual experience)?

|  |  |
| --- | --- |
| * To listen and be told what the clinical team have decided?
 | ❑ |
| * To say what ***you* *believe*** is the best for the patient? *For example, your personal opinion on what you would want for the patient.*
 | ❑ |
| * To say what ***you* *think*** the patient would ***want***? *For example, you think the patient would or would not want a particular treatment because of what they have said / how they have acted in the past (even though you may not agree with it).*
 | ❑ |
| * To say to the clinical team what you ***know*** the patient wanted in the circumstances? *For example, you know there is an Advance Directive or the patient has told you explicitly in the past.*
 | ❑ |

1. What do you think your role *should* be (what you would like your role to be)?

|  |  |
| --- | --- |
| * To say to the clinical team what you **know** the patient wanted in the circumstances?
 | ❑ |
| * To say what ***you* *think*** the patient would **want** (the patient’s opinion)?
 | ❑ |
| * To say what ***you* *believe*** is the best for the patient (your opinion)?
 | ❑ |
| * To listen and be told what the clinical team have decided?
 | ❑ |
| * Not sure. Something else? Please give details if you can.

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1. **Your relationship with the clinical team**
2. Has the clinical team discussed any proposed treatment with you? YES ❑ NO ❑
3. Has the clinical team asked you if you know the *patient’s* wishes? YES ❑ NO ❑

If ‘YES’, how do you think this information influenced the treatment decision?

1. Did the clinical team ask you for your own *personal* views? YES ❑ NO ❑
2. In your own words, what is your experience of your involvement in treatment decisions? What mattered most to you?

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**About you:** If you are happy to do so, please tell us:

Are you: Male ❑ Female ❑ Prefer not to say ❑

Age range? 18-34 years ❑ 35-54 years ❑ 55-74 years ❑ 75+ years ❑

Are you: Employed ❑ Retired ❑ Unemployed ❑ Unpaid carer ❑ Other ❑

**Next steps…**

Would you be willing to speak with a member of the research team at a later date to further discuss your experience so we can better understand the decision-making process? If you would like to be involved, please provide your contact details (name, e-mail address or telephone number) or you can contact the researchers directly.

Your name:

Your email address:

Your telephone number: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Thank you for participating in this study**

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