**Family member questionnaire**

**Perspectives on enhancing consent and recruitment in intensive care studies:**

**The PERSPECTIVES survey**

***OFFICE USE ONLY*** *Please write in BLOCK CAPITALS*

STUDY NAME:

ICU STAY (DAYS):

DISCHARGE DATE: / /

DATE SURVEY GIVEN: / /

PARTICIPANT ID:

We are inviting you to take part in a questionnaire about your **views of clinical research studies** in the intensive care unit (ICU). Your views are very important to us, even if you have not been involved with a clinical research study. The information you provide will help doctors and nurses to improve the ways that patients and families are invited to take part in ICU research studies in the future. This questionnaire is being organised by researchers at the University of Liverpool, and is funded by the Economic and Social Research Council (ESRC).

The information you give us will be treated in strict confidence and used only for research purposes. Data will be archived (stored) at the University of Liverpool for possible use in future approved studies but we will always make sure no one can be identified from this data.

You can take part in this questionnaire without giving us your name/contact details. If you are willing for us to contact you further about the Perspectives study, there’s a sheet at the end of the questionnaire for providing your name and contact details. We will always keep your name/contact details separate from the questionnaire so your answers cannot be linked to you by anyone outside the Perspectives study team. When our study is over we will destroy all contact details we hold for you. To find out more, or if there is a problem, please contact the researcher, Katie Paddock on 0151 795 5421 or Perspectives@liverpool.ac.uk, who will be happy to help.

Please place the completed questionnaire in the envelope provided and hand it to the member of staff who gave it to you, or return to us in the envelope provided (no stamp needed). Alternatively, you can complete the questionnaire online at **https://perspectives.moresurvey.de**

**Notes: We refer to people agreeing to take part in research as giving ‘consent’**

**When we refer to ‘family members’ we mean the people close to you (e.g. friends), as well as relatives**

**We kindly request only THREE family members per patient complete a questionnaire**

**Are you**: Male  Female  Other 

**Your age:**

18-24 25-34 35-44 45-54 55-64 65-74 75+

**What is your relationship to the patient?** *They are your…*

…Son/Daughter  …Brother/Sister  …Mother/Father 

…Spouse/Partner  … Friend  … Other 

**So far, how long was your family member’s most recent stay in the Intensive Care Unit (ICU) at this hospital?** *Please give in number of days*

1. **Apart from this questionnaire, while your family member was a patient in the ICU, did anyone ask you about the possibility of him/her taking part in a clinical research study in the ICU?**

Yes  No  Unsure 

***Go to question 2 Go to question 6 Go to question 6***

1. **Do you know the name of the clinical research study you were asked to consent for on behalf of your family member? Or what it was about? If yes, please write it below. Please do not include this questionnaire survey in your answer:**
2. **How was information about the clinical research study given to you?**

(*Tick all that apply)*

Written  Verbal  Neither  Unsure 

*Please turn over*

1. **Did you agree (consent) for your family member to take part in the clinical research study?**

Yes  No  Unsure 

1. **These questions are about your experience of clinical research studies in the ICU, apart from this questionnaire:**

*Please turn over*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **How much do you agree or disagree with the following statements?** *(Tick one box per question)* | StronglyDisagree | Disagree | Neither Agree nor Disagree | Agree | StronglyAgree |
| 1. Overall, the information about the clinical research study was clear
 |  |  |  |  |  |
| 1. I was given little opportunity to ask questions about the clinical research study
 |  |  |  |  |  |
| 1. It was hard to take in the information about the clinical research study
 |  |  |  |  |  |
| 1. I was given enough time to think about whether or not my family member should take part in the clinical research study
 |  |  |  |  |  |
| 1. I felt pressure to agree for my family member to take part in the clinical research study
 |  |  |  |  |  |
| 1. The person who talked to me about the clinical research study was approachable
 |  |  |  |  |  |
| 1. I was informed of the risks and benefits of the clinical research study
 |  |  |  |  |  |
| 1. I trusted the person who talked to me about the clinical research study
 |  |  |  |  |  |
| 1. Deciding on behalf of my family member whether or not he/she should take part in the clinical research study was hard
 |  |  |  |  |  |
|  | StronglyDisagree | Disagree | Neither Agree nor Disagree | Agree | StronglyAgree |
| 1. The person who talked to me about the clinical research study was knowledgeable about it
 |  |  |  |  |  |
| 1. I felt comfortable in making a decision about whether my family member should take part in the clinical research study
 |  |  |  |  |  |
| 1. I would be willing for my family member to take part in clinical research studies in the future
 |  |  |  |  |  |

1. **These questions are about your views on clinical research studies involving ICU patients when they are too ill to make decisions for themselves.** Please complete these questions whether or not your family member has been involved in a research study in the ICU.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **How much do you agree or disagree with the following statements?** *(Tick one box per question)* | StronglyDisagree | Disagree | Neither Agree nor Disagree | Agree | StronglyAgree |
| 1. All ICU patients should take part in clinical research studies, unless a doctor advises against it
 |  |  |  |  |  |
| 1. Clinical research in the ICU is important to help other patients in the future
 |  |  |  |  |  |
| 1. I assume that treatments given to my family member on the ICU have already been thoroughly tested in clinical research studies
 |  |  |  |  |  |
| 1. I would only agree for my family member to take part in a clinical research study if their own health might benefit
 |  |  |  |  |  |
|  | StronglyDisagree | Disagree | Neither Agree nor Disagree | Agree | StronglyAgree |
| 1. When an ICU patient is too ill to decide for themselves, it is acceptable for a member of their family to decide whether the patient should be included in a clinical research study
 |  |  |  |  |  |
| 1. When an ICU patient is too ill to decide for themselves, and time is too short to contact a family member, it is acceptable for doctors to decide whether the patient should be included in a clinical research study
 |   |  |  |  |  |
| 1. When an ICU patient is too ill to decide for themselves, and there are no known family members to contact, then it is acceptable for doctors to decide whether the patient should be included in a clinical research study
 |  |  |  |  |  |
| 1. When an ICU patient is too ill to decide for themselves, and there is a known family member, but they cannot be reached, then it is acceptable for doctors to decide whether the patient should be included in a clinical research study
 |  |  |  |  |  |
| 1. When an ICU patient is too ill to decide for themselves, it is acceptable for a doctor to ask a family member over the phone for an opinion on whether the patient should be included in the clinical research study
 |  |  |  |  |  |
| 1. If I was too ill to make a decision for myself, I would be upset if a doctor had consented on my behalf for me to be included in a clinical research study

*Please turn over* |  |  |  |  |  |
|  | StronglyDisagree | Disagree | Neither Agree nor Disagree | Agree | StronglyAgree |
| 1. If I was too ill to make a decision for myself, I would be upset if a family member had consented on my behalf for me to be included in a clinical research study
 |  |  |  |  |  |

**7. We would value any comments or suggestions you have about recruitment and consent to clinical research within the ICU. Please use the space below:**

*Please turn over*

**Thank you for taking the time to complete the questionnaire**

As part of this survey we will be interviewing about 60 of the people who return the questionnaires, to learn more about their perspectives on ICU clinical research. If you are interested in the possibility of taking part in these interviews, please tick the box below and provide your name and contact details.

As a token of appreciation we will offer a £25 shopping voucher to everyone who takes part in an interview. We only have a small research team and so we hope you will understand if we are unable to interview everyone who expresses an interest.

Please also tick the box and give us your contact details if you’d like us to let you know about the study findings when these are available.

Only the Perspectives research team will have access to your name and contact details. These will be stored separately from your questionnaire and in accordance with Data Protection guidelines. We will destroy any contact details we hold for you once the study is completed.

**I agree to being contacted by the Perspectives research team for the purpose of:**

1. being contacted about the possibility of taking part in an interview with a researcher 
2. receiving a summary of findings of the questionnaire (expected in 2019) 

**Name** *(BLOCK CAPITALS)*

**Address:** *(BLOCK CAPITALS)*

**Postcode:**

**Phone: Mobile:**

**Email:**

If you have a preference about when over the next few weeks/months we should contact you about a possible interview, please give details below:

**Today’s date: / /**

*Please contact me in:* 2 – 4 weeks  5 – 8 weeks  9 – 12 weeks 

*The Perspectives Study, University of Liverpool, IPHS, Waterhouse Building, Block B (2nd floor), Brownlow St, Liverpool, L69 3GL*