

Participant Information Sheet

Study Title: The decision-making behind transferring dying patients home from critical care units: families' perspective

Researcher: Yanxia Lin

Ethics number: 18845

Please read this information carefully before deciding to take part in this research.

What is the research about?

I am Yanxia Lin, a Postgraduate research student from the Faculty of Health Sciences, University of Southampton. I have worked as a nurse for 2 years in Intensive care unit (ICU) and my experiences during that time have motivated me to undertake research into the decision-making of transferring a patient home to die from critical care.

Where someone spends the last days or weeks of their life is one of the biggest decisions they and their family have to make. While many patients prefer to die at home, the process can be difficult and challenging. The aim of this study is to explore and understand families' experiences of deciding whether or not to take their dying relative home which it is hoped will inform ways to help this practice and improve experiences for both patients and their relatives.

Who is funding the research?

This research is funded by the China Scholarship Council.

Why have I been chosen?

You have been invited to take part in this study because:

- you are an adult family member (over 18 years old) of a relative in critical care unit;
- you have been involved in making the decision of taking your relative home from critical care;
- you would like to share your experiences with the researcher.

Do I have to take part?

No. You can choose whether or not to take part in this study. If you decide to take part, you are free to leave at any time. If you do not want to take part you do not need to do anything more.

What will happen if I take part?

If you would like to take part in the research, please

1. Read through the information available on the website (Participant information sheet for more details)

2. Click on the link at the bottom of the page
3. Read through the consent form
4. Give your consent by ticking the box
5. Now you are ready to start the survey

The survey consists of three sections:

1. Section 1 asks you to share your experiences by writing them into the space provided. If you would like to email your experience separately, please do so by emailing me at yl8g14@soton.ac.uk. There are two follow up questions where you can add further information if you wish.
2. Section 2 has eight questions which asks about your background information;
3. Section 3 has five questions which asks about the patient's background information.

The completion of the questions may take you around 10 minutes.

Are there any benefits in my taking part?

There are no expected benefits to taking part in this research. Sometimes people do feel that sharing their experiences can make them feel better, however. Also some people like to participate in research that could help give a greater understanding of the patient and relative experience and potentially improve care for future patients.

Are there any disadvantages to take part?

It is not anticipated that there will be any risks to you taking part in the study. Sometimes people find it painful or difficult to recall their experiences. If there is anything you prefer not to share, this is fine and you do not have to. Only write the information that you are happy to give us.

Are there any risks involved?

You may feel upset as a result of recalling your experiences. If you don't want to continue the participation, you can leave at any time.

If you need support, please go to the below resources for help:

UK:

Cruse Bereavement Care

+44808 808 1677

<http://www.cruse.org.uk/>

USA:

Samaritans' 24/7 Crisis Services

+1(877) 870-4673

<http://samaritanshope.org/>

Will my participation be confidential?

Yes. All information which is collected about you during the course of the research will be kept strictly confidential. Any paperwork with your personal details on it will be stored in locked filing cabinet separate from your participant research number. Electronic data will be stored on a password-protected university computer. Only the research team and regulatory authorities (for monitoring the quality of the research) will have access to the data. Some of your direct quotes may be used in reports of the study's findings but details which identify you will not be included with these quotes. Once the study has ended, the documents will be archived for 10 years in a locked place which only people involved in the study can unlock, they will then be disposed of securely.

What happens to the findings of the study?

Findings will be used to improve the practice and families' experiences of taking a dying relative home. Specifically, these will be shared through project report, publications and conference presentations. However, you will not be named or be able to be identified in this information. If you would like to have information about this research project when we have completed it, a lay summary of our findings will be available on the research website.

What happens if I change my mind?

You can leave the study at any time. You can also withdraw the data you provide before it is analysed.

What happens if something goes wrong?

In the unlikely event that you have any concern or complaints with the participation, you can contact the University of Southampton's Research Governance Office at Rginfo@soton.ac.uk.

Where can I get more information?

If you have any questions or want to know more, you can contact:

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