**Perspectives on enhancing consent and recruitment in Intensive care units:**

**The PERSPECTIVES Study**

**Family member Participant Information Leaflet**

We are inviting you to take part in an interview about your views and experiences of research within the intensive care unit (ICU). Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read this leaflet carefully. You are welcome to contact us for more information, or if there’s anything that you don’t understand.

Feel free to discuss this with your friends and family if you wish. We would like to note that you do not have to accept this invitation and should only agree to take part if you want to.

**Who is doing the study?**

This study is being organised by researchers at the University of Liverpool and funded by the Economic and Social Research Council (http://www.esrc.ac.uk/). An Advisory Group of people who have experience of ICUs as doctors, researchers, patients and relatives, are advising on the study.

**What is the purpose of the study?**

This study is exploring your views of clinical research studies that take place in an ICU. Your views are very important to us and will help doctors and nurses improve the ways that patients and family members are invited to take part in clinical research studies in the future. The study will run until March 2019.

**Why have I been chosen to take part?**

You have been invited to take part in an interview because we would like to explore your views in more detail. We are inviting people from a range of backgrounds and with a variety of different perspectives about research in an ICU setting. While your family member was a patient in the ICU, you may have been approached about a medical research study on their behalf. Even if you had not been asked to take part in a particular study, we are still interested in your general views on research in the ICU.

As part of this study we will also be interviewing ICU researchers, nursing and medical staff in ICUs.

**Do I have to take part?**

It is completely up to you. If you do decide to take part, we will ask you to complete a consent form, either on paper or over the phone, to say that you agree to participate. If you decide later on that you wish to withdraw then you can leave the study at any time and you do not have to give a reason.

**What will happen if I take part?**

We will ask you to take part in a one-to-one interview with a trained researcher. This will last about an hour and involve the researcher asking you about your experiences of being invited to take part in a clinical research study. It doesn’t matter whether you agreed to participate or not – we are interested in your perspectives either way. The researcher will also ask about your general views of research in the ICU. With your permission, the interviews will be audio-recorded.

Should you lose capacity during the course of this study, we will keep the data already collected from you.

**Are expenses and/or payments provided?**

We do not anticipate that participants will incur any costs from participating in this study, aside from the time being interviewed. As a token of appreciation we will offer participants a £25 shopping voucher for taking part.

**Where will the research take place?**

The interviews will usually be carried out face-to-face in your home, or over the phone/Skype, at a date and time of your choosing. If you do not want to be interviewed, but still want to contribute to the study, you can take part by email or letter. Please just contact [RESEARCHER NAME].

**Are there any risks in taking part?**

We do not expect there to be any risks or discomfort from being interviewed in this study. If there are any questions that you do not wish to answer please just let the interviewer know and s/he will move on to the next question. You can also stop the interview or leave the study at any point – you do not need to give a reason.

**Are there any benefits in taking part?**

You will be helping us to better understand patient recruitment and consent in ICU research studies, including what is done well, and what could be improved.

**What if I am unhappy or if there is a problem?**

If you are unhappy or there is a problem, please let us know by contacting the lead researcher, Bridget Young, at University of Liverpool on 0151 794 5525 (byoung@liv.ac.uk), or [NAME OF LOCAL PI] on [CONTACT DETAILS FOR LOCAL PI]. They will try to help. If you are still unhappy or prefer to speak to someone else, then you should contact the University of Liverpool’s Research Governance Officer at ethics@liv.ac.uk . Please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

**Will my participation be kept confidential?**

All the information that you give us will be kept strictly confidential. Interviews will be transcribed (typed out) by a professional agency. Transcripts will have all identifying information removed (e.g. person, place or study names) before being analysed and stored, and only authenticated researchers will have access to them. The information you provide will be stored in locked filing cabinets or password protected computers. Anything about you, including any quotes which are used in the write-up of the study, will have all identifying details removed so that you will remain anonymous. With your permission, brief sections of the interview recording will be played at presentations about of the findings of the study to help the audience understand your quote. These sections will not contain any information that could identify you. If you do not want any audio clips of your interview used in this way, you can opt out via the consent form.

During the study the research data (consent forms, anonymised interview transcripts, study notes, and your contact details) will be kept in locked filing cabinets and/or password protected University of Liverpool computers. With your permission, when the study is completed your data will be archived at the University of Liverpool for possible use in future approved research. Before archiving all identifying information will be removed, and only authenticated researchers will have access to the data.

**What will happen to the results of the study?**

After the study has finished, the results will be written up and published in academic journals and presented at conferences. We will make a summary of the findings available to you at the end of the study if you would like us to. The researcher will ask you about this as part of the interview. You can also have a copy of the full research report if you would like it.

**How can I find out more?**

Just get in touch with a member of the Perspectives study team, Katie Paddock or [NAME OF RESEARCHER] on [EMAIL ADDRESS]. They will be happy to answer any questions you might have.

**Thank you for reading this. This information sheet is for you to keep**