



Parent Information Leaflet
Parents' experiences of difficult neonatal decision making – a research study

Dear Parent

We are sorry to approach you at such a difficult time, but we would like to learn how we might improve the ways in which we provide support for parents, such as yourselves, as part of a research study. We would like to study how doctors talk about difficult issues with parents, so that we can use this information to help us design improved training of doctors in communication.

Taking part in the study will involve video recording the side-room conversations that you will have with your baby's doctors in relation to your baby's treatment. To do this we place a small discrete video recorder in the room and switch it on when the conversation begins, after the doctor has confirmed with you that you are agreeable. The recordings will be anonymised so that your identity is not revealed when presented in research environments or in training: names will be removed from the audio recordings, the sound of your voice will be changed, and finally your video image will be distorted by using software to convert it into an outline so that your face will not be recognisable. The data will be held on a secure database for seven years following the end of the study. Should you wish to keep a copy of the audio recording of the conversation we will provide you with one on a small audio-player. The video is removed to preserve confidentiality for all parties. If you decide to withdraw from the study and ask us to do so, we will destroy these research records, and confirm to you that we have done so.

Our results will form part of a wider study that may be published in academic journals and conference presentations and used to help design our training. We can make these materials available to you if you wish.

We have been given approval to conduct this study from two agencies: the Research and Development department at our hospital trust, and the Research Ethics Committee for City & East London, which has oversight of the ethical aspects of our proposals. If you have any complaints about the study, please get in contact with Professor Neil Marlow using the details below, who leads the overall study.

Before making up your mind about participation, you may wish to discuss this study with your partner, and other family and friends. You may also ask questions to any member of our research team. You are under no obligation to take part in this study but if you feel able to help and wish to participate in this study please let one of your baby's doctors or nurses know.

Please feel free to get in touch with a member of the research team if you have any questions at all:

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Thank you for your time in reading this information. We wish you and your family all the very best in the time ahead.