UCL INSTITUTE FOR WOMEN'S HEALTH
ACADEMIC NEONATOLOGY

Pilot study exploring frequency of decision making for withdrawal of life sustaining treatment
Name of Principal Investigator:

Health Care Professionals Information Sheet: the survey

Background

There is a paucity of information regarding the frequency of decision-making conversations for withdrawal of life sustaining treatment (WILST) for infants on the neonatal unit, how decisions are made, or the outcomes for the babies themselves. A prospective pilot survey is therefore being undertaken within 2 neonatal networks to explore the incidence and outcomes of neonatal life support decisions to refine data collection for a national study. The unit where you work is part of this pilot study, and so you will be asked to document information on episodes where discussions take place concerning WILST. For each infant included in the study data will be collected to capture the following information:

- Who is involved in the decisions to withdraw life sustaining treatment?
- What factors prompt the conversations around potentially withdrawing life sustaining treatment?
- What are the outcomes of these conversations for the infant?
- Is palliative care offered to infant and families?
- How is parental support and palliative care documented in the infant's notes?

What does the study involve?

Participation in the study will involve completing a survey which captures the information above. Data collection will be prospective and over a period of 9 months. When an infant on a neonatal unit is identified who meets the eligibility criteria, you or your colleagues will be asked to register this infant onto a database hosted securely within a dedicated study website. The hospital number of the infant will be used to generate a Unique Personal Identifier (UPI) code within the NHS computer network. You can then use this UPI to enter information onto a dedicated, secure website about decision making throughout the infants journey, minimising the chances of double counting a baby and ensuring that the personal details of the infant remain anonymous. A telephone number and email address will be available should you encounter any problems with the website or the survey. Each time a conversation around life sustaining treatment occurs, we would like you to document this on the database. The outcomes for the baby at discharge will also be documented (morbidity and mortality). Once uploaded onto the database, the research team will store the information securely. Access will be strictly password protected to those within the research team with appropriate safeguards. Paper copies of the questions on the database will be made available to you within the neonatal unit to orientate you to the study website and highlight the questions you will be asked.

Which Infants will be eligible?

Infants will be eligible for the study if they meet the following inclusion criteria:

- Any infant where withdrawal of life sustaining treatment is discussed with parents
- Any infant who died after live birth, both in the neonatal unit and labour unit

Do you have to take part?

It is up to you to decide whether or not to take part. Your willingness to complete the survey will be classed as implied consent and so you will not be required to sign a consent form. Please do not hesitate to contact the research team if you have any questions.

What if something goes wrong?

If you have any complaints about the study, please contact the chief investigator, Professor Neil Marlow, on the details below.

Will my taking part in this study be kept confidential?

You will be asked to enter your details, including job role, at the end of the survey. This information will be optional and will allow us to determine who is compiling the information as part of the study. All information which is collected about you during the course of the research will be kept on a password protected database and is strictly confidential. All information will be confidentially archived by University College London for 7 years following the end of the study.

What will happen to the results of the research study?

The results will contribute towards the development of national survey to document the incidence and outcome of difficult decision making for infants on the neonatal unit, and also forms part of a wider study exploring parental support in the neonatal unit. Results will be published in academic journals and conference presentations. If you wish to see a copy of these articles results, please inform Dr Neil Marlow.

Who has reviewed the study?

To ensure that this study meets required ethical standards, it has been reviewed and approved by the NHS Research Ethics Committee and the Research & Development department at University College London.

Thank you for your time. Please do not hesitate to contact the research team if you have any questions.

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