UCL Research Ethics Committee Approval ID: 16059/012
UCL Data Protection Registration: Z6364106/2023/05/142
Name of Principal Investigator: Dr Katie Gallagher (katie.gallagher@ucl.ac.uk)
Name of Co-Investigators: Professor Neil Marlow, Professor Myra Bluebond-Langner, Alex Mancini
Name of researcher: Dr Kathy Chant

You have been invited to take part in a study. Before you decide whether to take part it is important for you to understand why the study is being done and what it will involve. Please take time to read the following information carefully and discuss with others if you wish to. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part.

Death in the first 28 days of life, or 'neonatal death', represents the highest number of deaths in children under 5 in the UK. Each year 1,200 babies unfortunately die during this period, with most neonatal deaths happening on neonatal units, where babies receive treatment from specialist doctors and nurses. For many families, conversations will have taken place with their baby's healthcare team to decide whether to continue treatment, or whether to provide palliative, or end-of-life, care.

What constitutes good palliative and or end-of-life care, however, is unclear and professionals often provide different treatment to different families, reporting different outcomes in their research. This means we cannot compare whether one approach to neonatal end-of-life care is better than another. Creating a common, or 'core' set of outcomes from which to measure neonatal end-of-life care would allow us to develop measures of good practice and improve the care of families. These outcomes must reflect the needs of all families involved; this is particularly relevant for Black and Asian families whose infants are at higher risk of neonatal death, for reasons we do not yet fully understand. A core outcome set will identify care to be reported in all research exploring neonatal palliative and end-of-life care.

This is an observational study. That means that no interventions or treatments will take place. We would like to do a single 30-60 minute interview, conducted either over the phone or through video conferencing software (MSTeams). A researcher with previous experience of interviewing families and neonatal healthcare professionals will conduct the interviews. To ensure that we capture what you would like to tell us correctly, we will record the interview, with your consent. The physical recording will be deleted once we have downloaded the written transcript of the conversation. During the interview we will ask you about your personal experience of working with families receiving neonatal palliative, or end-of-life, care and what you think is important to measure when providing such care.

We are asking you to consider taking part as a healthcare professional or researcher who works with families in any setting providing neonatal palliative and/or end-of-life care, or bereavement support. We would like to learn from your experiences of what you feel is important to measure when considering best practice in neonatal palliative and/or end-of-life care.

It is up to you to decide whether or not to take part. If you decide to take part, you are free to withdraw at any time and without giving a reason. You may decline to answer any question you do not want to answer, or not answer an interview question by saying "pass". To take part, we ask you to consent to recording the interview and so it is worth considering whether you feel comfortable with this aspect of the study.

If you decide to take part, there will be a 'cooling off' period of 4 weeks following the interview, should you decide within this time that you no longer want to participate. In this time period, you will still be able to withdraw your data without having to give a reason. The recording will be pseudonymised for these 4 weeks and will then be deleted. Following this, we will be unable to remove your data and it will be included in the analysis.

You will not receive any direct benefit from being in this study, however information learned from this study may help families whose baby requires palliative, or end-of-life, care in the future, and the healthcare professionals who work with them. There are no medical risks if you take part in this study.

If you are interested in taking part in the interview, we will ask you to contact one of our researchers; Dr Kathy Chant (

We will keep all data about you safe and secure. We will also follow all privacy rules. At the end of the study we will save some of the data in case we need to check it. We will write our reports in a way that no-

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

If you are interested in taking part in the study please email Dr Kathy Chant (neopace@ucl.ac.uk) a member of the research team to arrange a time for the interview which is convenient for you. Should you require any further information, either prior to your participation or following your participation, please conta