



UCL Research Ethics Committee Approval ID: 16059/012

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".



The lawful basis that will be used to process your personal data are: 'Public task' for personal data and 'Research purposes' for special category data. Your personal data will be processed so long as it is required for the research project. We will anonymise or pseudonymise the personal data you provide and will endeavour to minimise the processing of personal data wherever possible. Personal data will be stored separately to study data to ensure anonymity throughout this study.

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](mailto:data-protection@ucl.ac.uk).

If you are interested in taking part in the study, please email Dr Kathy Chant ([neopace@ucl.ac.uk](mailto: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 contact Dr Katie Gallagher on the details above.

Thank you for reading this information sheet and for considering taking part in this study.

We would also like to make sure that you have details of Sands and Together for Short Lives, organisations that provide support to families experiencing neonatal death or palliative care. Help and support is there for you if you need it:

<i>Providing specialist advice and support for bereaved families</i>	<i>Providing specialist advice and support for families caring for a child with life-limiting or life-threatening conditions</i>
<p>The Sands helpline is for anyone who has been affected by the death of a baby and wants to talk to someone about their experience.</p> <p>Tel: 0808 164 3332 Email: <a href="mailto:helpline@sands.org.uk">helpline@sands.org.uk</a></p>	<p>The Together for Short Lives helpline is for parents or carers looking after a child or young person who has a life limiting or life threatening condition, offering support and someone to talk to about their experience.</p> <p>Tel: 0808 8088 100 Email: <a href="mailto:helpline@togetherforshortlives.org.uk">helpline@togetherforshortlives.org.uk</a></p>