Study Title:
Legacies and Futures: Gestational Parents' Experiences with Vulnerability and Resilience as it Influences Neonatal Health (student study – sub-study)

You are being invited to take part in a research sub-study as part of a PhD degree project. Before you decide whether or not 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 the following information carefully. Talk to others about the study if you wish and ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Research Project Summary:
This project is focused on getting a better understanding of mental and physical health and well-being during pregnancy and postpartum recovery. While there have been similar studies in the past, this study provides a unique combination of survey results along with patient health records to help fill-in some of the missing gaps that can help improve care for all pregnant persons. We will be investigating similarities and differences between lesbian, gay, bisexual, queer, nonbinary, intersex, and/or transgender (LGBTQIA+) pregnant people and heterosexual pregnant people whose gender matches with their assigned sex at birth (cisgender).

How did you determine who to recruit for the sub-study?
Active patients at UCLH who participated in survey one of the main study were invited to consider participating in the sub-study.

Why was I selected to participate in the sub-study?
Participants that are interested in the sub-study will have the composite scores from the resilience and risk/vulnerability questions reviewed from survey one. This will be to make sure that they are more extreme (either high or low) versions of the scores to help better understand your experiences. While we are looking for more extreme score, there is no weight to the scores themselves outside of deciding who will make up the sub-sample of thirty (30) people. To be clear, this means that there are no right or wrong answers, the sub-study is just focusing on the extremes.

How are you recording consent for the project?
You will be asked to complete an online form confirming your consent before completing the journal information form. This records your consent to complete the journal activity in addition to the online surveys. A copy of the consent form that you complete for the sub-study will be sent to you after completion.

How long do I have to decide if I want to participate in this sub-study?
You will need to complete the sub-study before your second survey. Ideally you will need to decide at the end of your first survey, but you can email the study team (stnvkll@ucl.ac.uk) to opt-in at almost any point between survey one and two. We will let you know if it is still possible to take part in the sub-study when you email.

What will I be asked to do if I take part in this study?
You will be asked to complete a journal activity at home. This can be either downloaded or mailed to you depending on your preference. Each packet will include directions on how to complete and submit the journal activities.

There is a set of directions that will come with the journal. Within the journal, there are prompts to guide you if you are stumped on what you want to include within the journal. Activities within the journal have no right or wrong way to be completed, so how they are completed are up to what information and approach you feel best reflects what you want to share with the study team.

Can I still participate in the sub-study if I experience a miscarriage, stillbirth, or any kind of loss within my pregnancy?
If you would like to continue with the sub-study after experiencing a loss, you are welcome to stay within the study and share your experiences with the study team. The timeline for participating within the study will still align with your gestational due date. This means that you will be given a reminder to submit your journal one month after your gestational due date. If you do experience a loss and want to have the study timeline change, you contact the study team (stnvkll@ucl.ac.uk) to make that request.

If at any point you no longer feel comfortable participating in the sub-study, you are also able to leave the study by emailing (stnvkll@ucl.ac.uk).

Are there any benefits of taking part in the study?
There are no direct personal health benefits to participating in this sub-study. The potential benefits of the sub-study include the benefits of journaling for your mental health, but this may vary for each participant. For benefits beyond individual participants, by taking part in the study you will be helping to improve what is known about pregnancy and childbirth in a way that should help to improve guidelines and policies.

What are the possible risks and disadvantages of taking part?
There are no known risks for participating study, since there are no changes to your pregnancy care. The topics of the prompts that will be covered in the journal activity are similar to what you would discuss with family or friends, or see on the news or in social media about the stages of pregnancy and childbirth. Additionally, what you feel comfortable sharing in your journal is up to you.

As for the contents of the journal, you will be responsible for how you chose to keep your journal, so you will need to be aware of how you are storing the physical or digital journal and who may have access to it while you are completing the activities. We recommend selecting the version of the journal activity that you are best able to keep safely (e.g., a digital version kept with a password or a paper version that can be locked away).

What should I do if I experience stress while taking part in the sub-study?
If you experience stress, we recommend pausing what you are doing and that you consider speaking to someone that can help you with handling the stress. You may also find support via one of these helplines:

The National Childbirth Trust
Website: https://www.nct.org.uk
Support line: 0300 330 0700

Gingerbread: Single parents, equal families
Website: https://www.gingerbread.org.uk
Helpline: 0808 802 0925

Mind
Website: https://www.mind.org.uk
Infoline: 0300 123 3393

Samaritans
Website: http://www.samaritans.org/
Helpline: 08457 90 90 90

Switchboard LGBT+ helpline
Website: https://switchboard.lgbt/
Helpline: 0300 330 0630

These support services are available to everyone who is pregnant. However, the general language used may centre on cisgender, heterosexual individuals.

Will my doctor or midwife know that I am participating in the study?
No, your choice to participate in the sub-study is confidential.

Is there any influence on my healthcare by participating in the study?
There will be no change in care that you receive by taking part in the sub-study. As your participation will be confidential, healthcare received will not be impacted in any way directly by the study itself or your participation status.

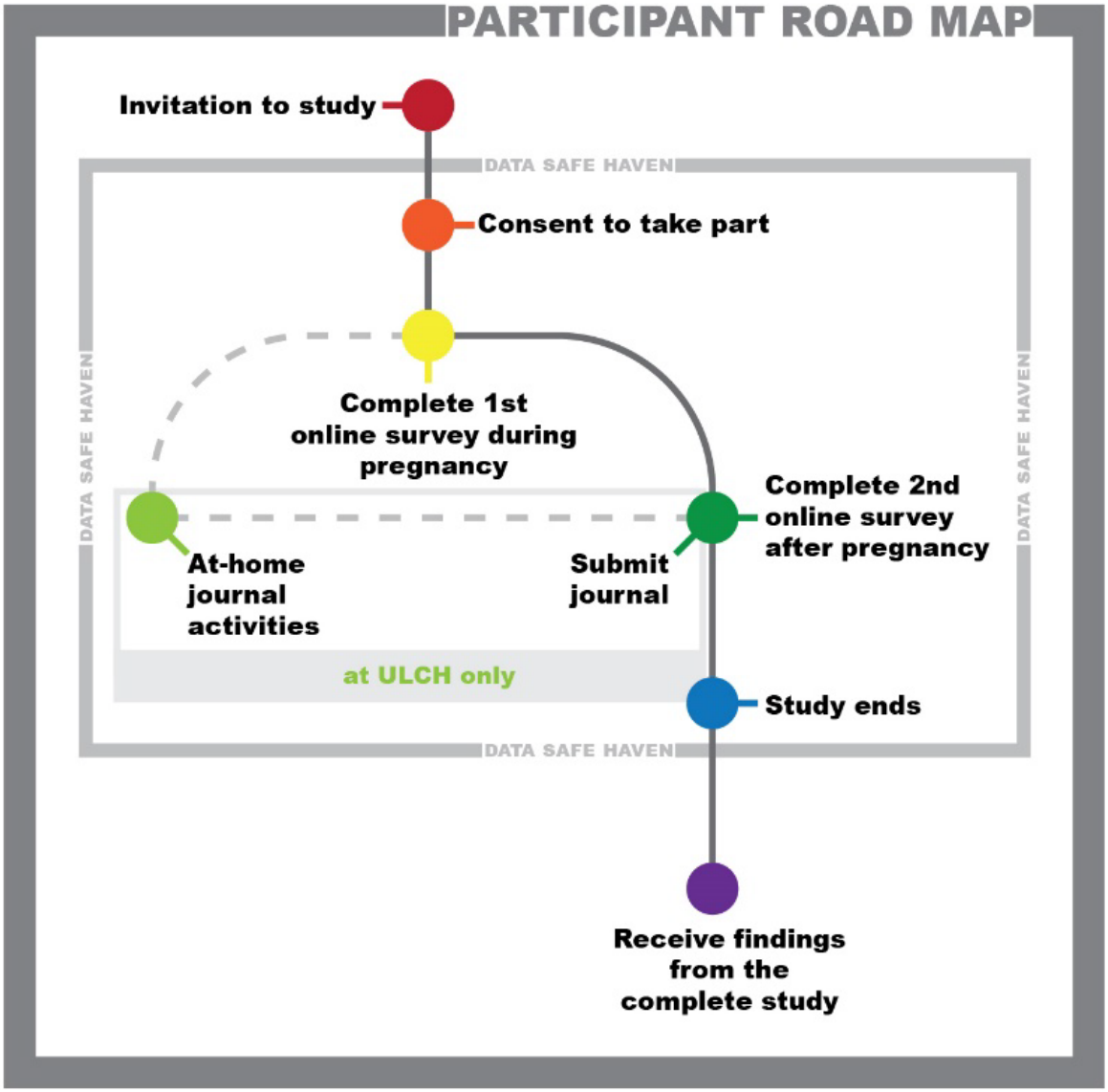
What happens if I decide I don't want to participate after enrolling?
You are welcome to opt-out of the sub-study at any time, so long as your information is still linked to personal data. Please notify the study team at stvnkll@ucl.ac.uk that you have chosen to leave the study and wish your data to be removed.

I am participating in the study, but am not able to or wish to not continue. Can I leave the study?
Yes, you are welcome to leave the study at any time. All you have to do is let the study team know that you no longer plan to participate by emailing us at stnvkll@ucl.ac.uk. You are welcome to leave the study at any time, but it might not always be possible to remove your data.

If I leave the study and do not want my data to stay, when and how can I make sure that my data are not used?
If you would like to retract your data from the study, you will be able to do so as long as we are still able to connect you with your data. Once all of the data for the study is collected this identifiable data will removed (i.e., pseudonymisation) and we won't be able to tell what data is yours. You are welcome to request your data to be removed

from the study up until this point (anticipated to be March 2023, but this may change). To make this request, you can email the study team at stnvkll@ucl.ac.uk and we will let update you on how/if your data was able to be removed from the study.

How will the information I provide be handled by the study team?
Any information you share as part of the sub-study is kept safely with any risk to you as low as possible. The data will be stored on a password protected and encrypted university server called the *Data Safe Haven* and only the researchers named below will have access.



Will there be any publication of the information found in the study?
Yes, there will be publication of findings from this sub-study. This sub-study is part of a project being undertaken as part of PhD enrolment. This means that the project ideally ends with a written thesis written detailing the research background, study methods, and results. Additionally, findings will be submitted for publication in

academic journals at the least. If you are interested in being notified about the findings, you can ask to join the project mailing list through the study website.

How will my participation in the sub-study be reflected in any of the publications?
Quotes from participants will be used within the publications. It will however not be possible to know who said what and who participated, since the study data is being pseudonymised. Instead, quotes will be attributed to a randomly generated participant identification label.

How can I be sure that my data is being safely handled?
This project is taking extra steps to ensure the safety and security of participants' information. More information about the UCL General Research Participant Privacy is available online at: https://www.ucl.ac.uk/legal-services/privacy/ucl-general-research-participant-privacy-notice. You are also welcome to contact the Data Protection Office at UCL at data-protection@ucl.ac.uk if you have further question.

Is there any gift or compensation for participating in the study?
Currently, we will not be able to compensate you for participating in the study.

What if something goes wrong with the sub-study?
If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your research doctor if you would like more information on this. In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence, then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to the David Frost (d.frost@ucl.ac.uk) who is the Chief Investigator for the research and is based at UCL**.** The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions, contact details are at the end of the document. If you remain unhappy and wish to complain formally, you can do this via the hospital's Patient Advisory Liaison Service (PALS).

University College London Hospital
PALS can be accessed by visiting the office at either UCH Monday to Friday (closed all day Wednesday), or the NHNN Wednesday to Friday 9am – 4pm

Post:
PALS, Ground Floor Atrium, University College Hospital, 235 Euston Road, London NW1 2BU

Online contact form:
http://www.uclh.nhs.uk/PandV/Helpandsupport/PALS/Pages/OnlineformforcontactingthePALSteam.aspx

Tel (main hospital): 02034473042
Tel (NHNN): 02034483237

Email: Uclh.pals@nhs.net

For more information, you can visit:
https://www.uclh.nhs.uk/PandV/Helpandsupport/PALS/Pages/Home.aspx

When contacting them, please quote the study number (IRAS: 264198).

What if I feel like I need help or support?
If there are any issues that you feel like have impacted your mental health, please consider speaking with an independent support service:

The National Childbirth Trust
Website: https://www.nct.org.uk
Support line: 0300 330 0700

Gingerbread: Single parents, equal families
Website: https://www.gingerbread.org.uk
Helpline: 0808 802 0925

Mind
Website: https://www.mind.org.uk
Infoline: 0300 123 3393

Samaritans
Website: http://www.samaritans.org/
Helpline: 08457 90 90 90

Switchboard LGBT+ helpline
Website: https://switchboard.lgbt/
Helpline: 0300 330 0630

These support services are available to everyone who is pregnant. However, the general language used may centre cisgender, heterosexual individuals.

How will we use information about you from the sub-study?
The information you share through the sub-study will be used in combination with the main study data that is provided in the two online surveys and your medical records.

What are your choices about how your information is used?
You can stop being part of the sub-study at any time, without giving a reason and without withdrawing from the main study.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- through this study website
- by sending an email to stnvkll@ucl.ac.uk

Local Data Protection Privacy Notice

Notice:
The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk. UCL's Data Protection Officer can also be contacted at data-protection@ucl.ac.uk.

Your personal data will be processed for the purposes outlined in this notice.

The legal basis that would be used to process your personal data will be performance of a task in the public interest.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible. Only authorised members of the research team will have access to your personal information. The anonymised data set will be kept for [10 years] after the end of the project, after which it will be reviewed to determine whether it would be appropriate to delete it.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

Your data will not be transferred to third parties.
You will be given a copy of this information sheet and consent form for your records.

For more information, please read our privacy notice: https://www.ucl.ac.uk/legal-services/privacy/participants-health-and-care-research-privacy-notice

Who is organising and funding this study?
This study has been organised by University College London and funded by the UBEL Doctoral Training Partnership (ESRC).

Who has reviewed this sub-study?
This sub-study has been reviewed as part of application IRAS 264198 by London – Central Research Ethics Committee (20/LO/0551). Details of this review are noted in the main study PIS online at https://www.homepages.ucl.ac.uk/~stnvkll/PIS

How have patients and the public been involved in this study?

During the planning of the study, members of the community were asked to review the journal activity materials and provide feedback. This feedback has been incorporated into the materials.

What if relevant new information becomes available?
Please check the web site for any updates of new, relevant information. We will also be notifying participant via the email provided for the study of any updates.

We also invite you to join the mailing list and let us know if you are interested in being contacted when any presentation or publication come out of the study. Our Twitter will also be posting updates, find us @LegaciesFutures.

Who can I contact if I have any further questions or concerns about the sub-study?
You can reach out to the study team at stnvkll@ucl.ac.uk with any questions or concerns that you have. Kate Luxion is the student researcher in charge of coordinating the study, so will be able to assist you with any questions you have.

Further information and contact details
Kate Luxion
stnvkll@ucl.ac.uk

David Frost
d.frost@ucl.ac.uk

S. Melissa Whitten
melissawhitten@nhs.net

Thank you for taking the time to read this information sheet and for your participation in this study. Please keep this information for future reference.