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

You are being invited to take part in a research 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 parents. We will be investigating similarities and differences between lesbian, gay, bisexual, queer, nonbinary, intersex, and/or transgender (LGBTQIA+) pregnant persons and heterosexual pregnant persons whose gender matches with their assigned sex at birth (cisgender).

What is involved in the study?
If you chose to participate in the study, the first activity you will be asked to complete is an online survey, which will be done while pregnant. Your responses will be confidentially linked with your health records on a secure database seen only by the study team. You will be asked to complete a second follow-up survey after birth. It is expected that each of the online surveys will take approximately 20-30 minutes.

How did you determine who to recruit for the project?
The study team reviewed information on active pregnant people, with support of the clinical staff at the hospital, to determine who might be eligible for the project.

Why was I selected to participate in the eligibility questionnaire?
You have been invited to take part in the survey, since you are an active antenatal patient (i.e., pregnant person) who is a patient at a participating hospital site.

Why was I selected to participate in the main study?

Selection for the study is based off the answers that you have given in the screener questionnaire. The inclusion criteria for the study are:

- A legal adult of reproductive age (18-49)
- Currently pregnant and receiving care at one of the participating hospitals

How are you recording consent for the project?
You will be asked to complete an online form at the beginning survey one. This statement of consent includes both surveys and access to your medical records. If you chose to revoke that consent, you are welcome to do so at any point in the study to have it excluded from the data analysed as best we can.

If I don't give consent, will you still access my medical records to include in the study?
No – your medical records will not be used unless you provide consent and participate in the study. This can mean both doing nothing or deciding after starting the study that you've chosen to no longer participate. In either case you will be excluded from any subsequent study activities.

Why do you need to access my medical records?
Rather than asking you to look up information like blood pressure, height, weight, or other similar bits of information, the study is using medical records to provide the most accurate information possible.

If you want to know more about the types of information that we are gathering from participant's medical records, these will be listed under the "Methods" section of the study website at https://www.homepages.ucl.ac.uk/~stnvkll/.

How long do I have to decide if I want to participate in this study?
You can take all the time that you need to decide if you want to be involved. The only limitation is that if you want to participant, you will need to take the first survey during your pregnancy and the second survey after you give birth. Thus, you will not be able to join the study if you are no longer pregnant at the time you try to complete survey one.

What will I be asked to do if I take part in this study?
There will be two surveys that you will be asked to complete over the course of the study. The first survey will be while you are receiving pregnancy care. For the second survey, you will be reminded approximately one month after your due date that you need to complete.

Sub-study: If you are a patient at UCLH, as part of the first survey you may be asked if you are interested in participating in a sub-study. If asked, you will be sent more information about the sub-study activities before deciding if you want to participate. The decision to participate or not participate in the sub-study in no way impacts your participation in the main study.

Future Projects: We may be following up with participants in the future. If you are willing to be contacted, please select the option in the survey to share your contact information. By selecting this option, it would be mean we would be able to store just enough information to link responses over time.

Can I still participate in the study if I experience a miscarriage, stillbirth, or any kind of loss within my pregnancy?
If you would like to continue with the 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 the second survey will need to be completed approximately 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 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 study. You may find that thinking through the questions is interesting and provides new perspectives on your lived experiences, but this will vary for each participant. By taking part in the study you will be helping to improve what is known about pregnancy and childbirth among diverse communities 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 that will be covered in the survey questions are similar to topics discussed in everyday conversations that you might have with family and friends. These may also include topics covered by the news and social media as well. There will be a brief description of the questions you will be answering at the start of each section.

When answering questions in the surveys about your daily life you may experience uncomfortable emotions or discontent. We suggest taking your time with the survey, taking it in a safe and comfortable space. There are recommended points to take a break within the survey in case you do need to step away and come back at a later time.

For privacy purposes, we recommend using an individual email address for communication and survey reminders. Additionally, while completing the surveys you may also wish to position yourself where no-one is able to see your screen. After completing each survey, you may wish to clear your browser history if you are concerned about it being on the computer you used.

What should I do if I experience stress while taking part in the 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

Most of these support services are available to all pregnant people. However, the language may centre cisgender, heterosexual individuals.

Will my doctor or midwife know that I am participating in the study?
No, your choice to participate in the study is confidential. Even if your provider is the one who refers you to the study, there will be no disclosure of participation if you chose to follow through.

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 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.

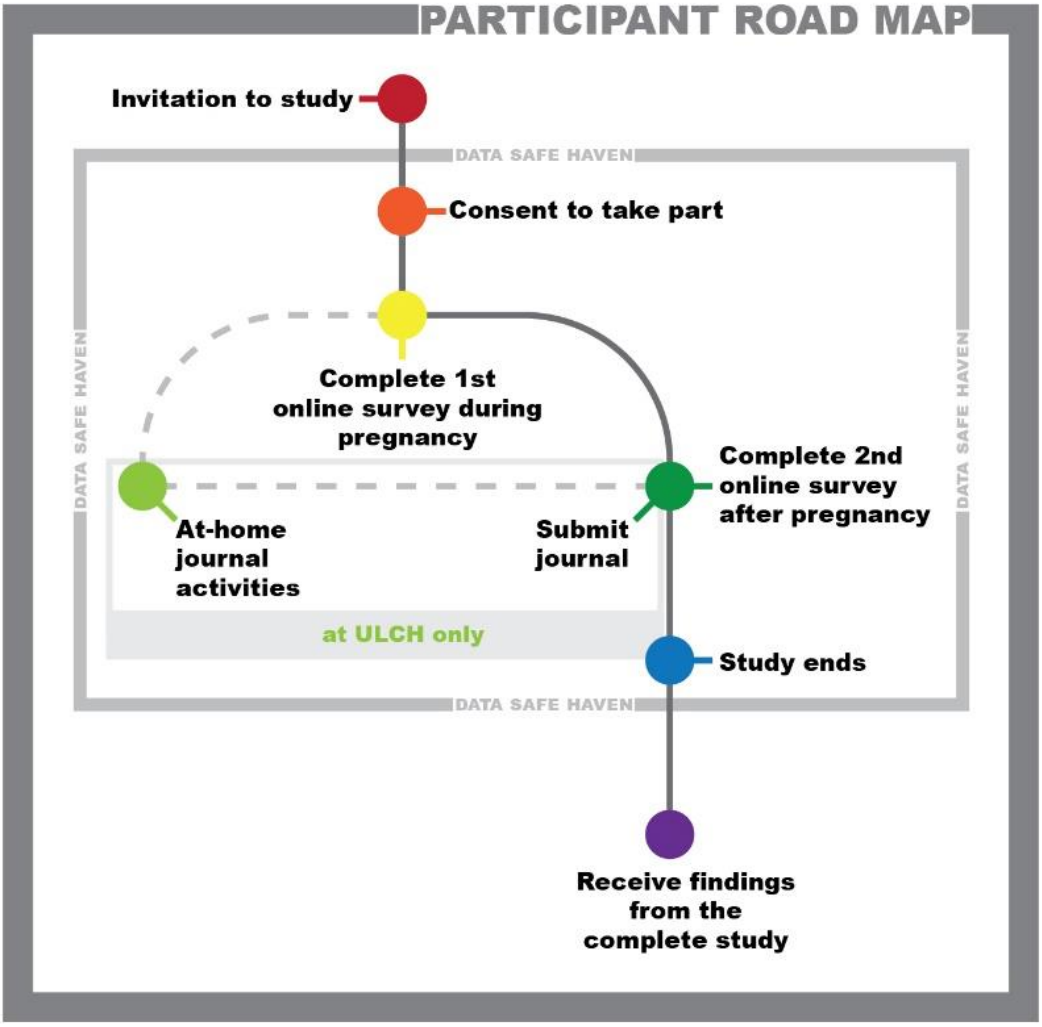
What happens if I decide I don't want to participate after enrolling?
You are welcome to opt-out of the study at any time, so long as your information is still linked to personal data. Please notify the study team at stnvkll@ucl.ac.uk that you have chosen to leave the study and wish your data to be removed.

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 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?
This project is being undertaken as part of PhD enrolment, which means that the project ideally ends with a written thesis written detailing the research background, study methods, and results. There is the possibility of other publications in academic journals. In either case, we will notify you of these publications via email and we will do our best to post publications to the study website as each becomes available. 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 main 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 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?
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

Imperial College Healthcare
Email: imperial.PALS@nhs.net
Hammersmith and Queen Charlotte's & Chelsea Post and Phone:
PALS manager, Hammersmith Hospital, Du Cane Road London W12 0HS

Tel: 020 3313 3322

St. Mary's Hospital Post and Phone:
PALS manager, Ground Floor, Clarence Wing, St Mary's Hospital, South Wharf Road, London W2 1NY

Tel: 020 3312 7777

For more information, you can visit:
https://www.imperial.nhs.uk/patients-and-visitors/help-and-support/feedback-compliments-and-complaints/pals

University Hospitals Sussex NHS Foundation Trust
Post:
PALS, Royal Sussex County Hospital, Eastern Road, Brighton, BN2 5BE

Tel:
Royal Sussex County Hospital: **01273 664511** or **01273 664973**.
Princess Royal Hospital: **01444 448678**

Email: uhsussex.pals@nhs.net

For more information, you can visit: https://www.bsuh.nhs.uk/your-visit/help-and-support/patient-advice-and-liaison-service-pals/

King's College Hospital
Post:
Patient Advice and Liaison Service, King's College Hospital NHS Foundation Trust, Denmark Hill, London SE5 9RS

Online contact form: https://www.kch.nhs.uk/contact/pals

Tel: **020 3299 3601**, 9am to 4.30pm, Monday to Friday (not bank holidays)

Email: kch-tr.palsdh@nhs.net

For more information, you can visit:
https://www.kch.nhs.uk/patientsvisitors/help-and-support/pals

Barts Health NHS Trust
The Royal London and Mile End – the Patient and Family Contact Centre, ground floor, Stepney Way atrium
10am-5pm, Monday-Friday
Tel: 0203 594 2040
Email: RLHpals.bartshealth@nhs.net / bartshealth.familycontact@nhs.net

Newham University Hospital – zone 1, St Andrews Wing
9.30am-4.30pm, Monday – Friday
Tel: 0207 363 9292
Email: nuhpals.bartshealth@nhs.net

Whipps Cross University Hospital – junction 4 in the main building
9.30am-4.30pm, Monday – Friday
Tel: 0208 535 6438
Email: WXpals.bartshealth@nhs.net

St Bartholomew's Hospital - Kenton Lucas Building - ground floor
9.30am-4.30pm, Monday – Friday
Tel: 0203 465 5919
Email: SBHpals.bartshealth@nhs.net

For more information, you can visit: https://www.bartshealth.nhs.uk/pals

Epsom and St Helier University Hospitals NHS Trust
St Helier Hospital
Tel: 020 8296 2508
Monday – Friday, 10am – 4pm

Epsom Hospital
Tel: 01372 735243
Monday – Friday, 10am – 4pm

Email: est-tr.PALS@nhs.net

Textphone (via Text Relay): 08001 020 8296 2508

Text message (deaf and hard of hearing only): 07975 232021

For more information, you can visit: https://www.epsom-sthelier.nhs.uk/pals

Guy's and St Thomas' NHS Foundation Trust
Post:

PALS, St Thomas' Hospital, Westminster Bridge Road, LondonSE1 7EH

Tel: 020 7188 8801

Email: pals@gstt.nhs.uk

For more information, you can visit: https://www.guysandstthomas.nhs.uk/patients-and-visitors/patients/your-care/pals.aspx

Homerton University Hospital NHS Foundation Trust
Post:
PALS, Homerton University Hospital NHS Foundation Trust, Homerton Row, London E9 6SR

Service is based at the main entrance to the hospital, Monday to Friday 9.30am – 4pm

Tel: 020 8510 7315 (Textphone: 07584 445 400)

Email: huh-tr.pals.service@nhs.net

For more information, you can visit:
https://www.homerton.nhs.uk/patient-advice-liaison-service-pals/

Kingston Hospital NHS Foundation Trust
Officers available Monday – Friday from 9am to 5pm

Tel: 020 8934 3993

Email: khft.pals@nhs.net
For more information, you can visit: https://kingstonhospital.nhs.uk/feedback/patient-advice-and-liaison-service/

Lewisham and Greenwich NHS Trust
University Hospital Lewisham and Lewisham Community Services
Tel: 020 8333 3355
Email: pals.lewisham@nhs.net

Queen Elizabeth Hospital
Tel: 020 8836 4592
Email: pals.qeht@nhs.net

For more information, you can visit: https://www.lewishamandgreenwich.nhs.uk/pals/

Royal Free London NHS Foundation Trust
Barnet Hospital PALS
Tel: 07929 790604/07929 790603 – Mondays (9.30am – 4.00pm)
Tel: 0208 216 4924 Tuesday – Friday (9am – 4pm)
Email: bcfpals@nhs.net
Post: PALS, Barnet Hospital, Wellhouse Lane, Barnet EN5 3DJ

Chase Farm Hospital PALS
The Patient Experience Team are available from Monday to Friday 10am to 4pm
Tel: 020 8375 1328
Email: rf-tr.cfhpals@nhs.net

Royal Free Hospital PALS
Tel: 020 7472 6446/6447; (020 7472 6445 – 24 hour service)
SMS: 447860023323
Email: rf.pals@nhs.net

For more information, you can visit: https://www.royalfree.nhs.uk/contact-us/patient-advice-and-liaison-service-pals/

St George's University Hospitals NHS Foundation Trust
Pals is offering face-to-face appointments by appointment only, please contact using the following information:

Tel: 020 8725 2453

Email: PALS@stgeorges.nhs.uk

For more information, you can visit:
https://www.stgeorges.nhs.uk/patients-and-visitors/help/

West Hertfordshire Hospitals NHS Trust
The PALS team are available between 8am to 4pm, Monday to Friday

Tel: 01923 217198

Email: westherts.pals@nhs.net

For more information, you can visit:
https://www.westhertshospitals.nhs.uk/patientservices/pals.asp

Whittington Health NHS Trust
Post:
PALS Office, The Whittington Hospital, Magdala Avenue, London N19 5NF

Tel: 020 7288 5551 (Monday – Friday 9.30am to 4.30pm, closed between 1-2pm)

Email: whh-tr.whitthealthPALS@nhs.net

For more information, you can visit:
https://www.whittington.nhs.uk/default.asp?c=1341

When contacting them, please quote the study number (IRAS: 264198) at the footer of this information sheet.

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 on cisgender, heterosexual individuals.

How will we use information about you?
We will need to use information from you and from your medical records for this research project.

This information will include your contact details and date of birth to make sure we match your responses to your medical records. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have if we have already assigned the data a coded number.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study. The data will be kept on a secure server known as a Data Safe Haven. We will only use your information for future research if you consent to participate.

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 study?
All research in the NHS is reviewed by an independent group of people, called a Research Ethics Committee (REC) which is there to protect your safety, rights,

wellbeing and dignity. This study has been reviewed by the London - Central Research Ethics Committee (20/LO/0551) and the Health Research Authority (HRA) in accordance with UK regulations.

How have patients and the public been involved in this study?
Prior to the start of the study, the public was surveyed to get their opinion on the study taking place. Within this same activity, respondents were asked their opinion about the recruitment method. Asking both about emailing before consent and in how frequently we should email before marking someone uninterested. Feedback from these activities shaped how the study is being conducted. Community members also helped to shape the contents of the recruitment email that you were sent inviting you to the study.

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 to let you know 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 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.