

Surrogacy Reform: An Examination of Health and Law

Researcher: Zaina Mahmoud

The following is a brief summary of the research project. Please take time to consider the information carefully and discuss it with friends, family, others or ask the researcher any questions you may have.

This research project seeks to examine whether the current regulatory framework is fit for purpose through an exploration of the lived experiences of surrogates. In doing so, the aim is to create and sustain a culture and environment that promotes the health and wellbeing of surrogates by developing an alternative legal framework of surrogacy regulation, informed by those experiences. As surrogacy laws in the UK are under review, demonstrated by the Law Commission's inclusion of surrogacy regulation in their Programme of Law Reform. The aim of this project is to feed into their reports and consultation papers as it progresses.

The research questions are as follows:

1. How has the current regulatory framework for surrogacy affected surrogates' experiences in the UK and in California?
2. How could the UK legal framework change as to promote the reproductive rights, health, and wellbeing of surrogates?
3. Is it feasible to adopt a contractual legal framework, such as the Californian approach, for surrogacy arrangements in the UK, whilst safeguarding the health and wellbeing of surrogates?

Purpose of the research

While the practice of surrogacy has benefitted from advances in medical technology and progressive reductions in associated stigmas, current surrogacy regulation, as enshrined in the UK Surrogacy Arrangements Act 1985, has failed to keep pace. Only informal surrogacy arrangements, whereby the parties are forced to rely on trust rather than legal security for fulfilment, are permitted. Jurisdictions where commercial surrogacy is legal, notably California, provide an apt comparator as to how the law may be changed, as well as the difficulties that may be faced along the way.

This project will provide opportunities for extensive engagement with publics involved in surrogacy, as well as meaningful impact on future regulation of surrogacy. Reaching out to surrogacy organisations, fertility support groups, and LGBT+ family groups for the qualitative empirical research component allows for an open dialogue with underrepresented demographics about their understanding of reproductive agency, thereby informing improvements into surrogates and would-be-surrogates' reproductive rights and health and wellbeing, as well as elucidating the prevalence of surrogacy. A qualitative investigation will enable an honest expression of the surrogates and would-be-surrogates within the legal context, furthering the goal of improving reproductive rights, and creating a healthier public.

Limited research has been conducted into the experiences of surrogates and little is known about the demographics of surrogates in the UK. In addition to looking at the relation between the lived experiences of surrogates and its effect on reproductive agency, their health and wellbeing, this research will address the lacuna in qualitative empirical research in this field by exploring and comparing the intersection of

surrogates' and would-be-surrogates' experiences with the socio-cultural legal structure of both jurisdictions.

Why have I been approached?

The aim of this project is to ensure that research produced is in the interest of the stakeholders, and to ensure that the reform proposals take into account the experiences of surrogates. As such, advertising through social media, face-to-face at the Fertility Fair and Fertility Fest, and other such engagement was done in order to reach the surrogacy community. Additionally, information regarding this project may have been obtained through dissemination by various surrogacy organisations, or other surrogates, or online at www.surrogacyreform.com.

The anticipated number of participants is between around 6-8 in each jurisdiction, resulting in a total of 12-16 surrogates interviewed.

What would taking part involve?

Taking part in this research project involves consenting to participating in an interview, the transcription of which will be analysed.

The interview will be informal, and I will ask a series of questions to gain an understanding of your experience as a surrogate, and how the law has affected your decision, health, and wellbeing. These questions will be open-ended, allowing you to tell me in your own words what surrogacy means to you and what you understand the regulations to be. Additionally, questions asked will provide you with the opportunity to provide information about how surrogacy has played a part in your life, your health, your relationships, and the like.

With your consent, the interview will be recorded and transcribed, as to provide the opportunity to analyse in a way that allows for patterns to emerge out of the data. Following the interviews and data analysis, you will have the opportunity, if you so choose, to discuss the findings, and give feedback and engage with the research, in line with a reflexive approach to research. You will also be provided with a link containing the final findings of the research.

Your information will be anonymised following the interview, with all identifiable information removed. When discussing the interview, no names will be used: instead, "Mx (random letter)" will be used, with that random letter not representing your first or last names. Any other identifying information will be altered, to ensure the utmost respect for privacy.

What are the possible benefits of taking part?

By taking part in this study, you will have the opportunity to share your experiences as a surrogate, thereby contributing to the academia surrounding surrogacy. This research project aims to demonstrate the importance of stakeholders' experiences and knowledge when looking at law reform, as such, your contribution will be in keeping with such an approach. Additionally, given the reflexive nature of this project, you will be engaging with the research and co-creating the findings. Sharing your experiences is an excellent way to engage with the public discussion on surrogacy.

What are the possible disadvantages and risks of taking part?

Utmost care will be taken during the interview to ensure that the questions asked do not evoke any negative emotions. There is the possibility that discussing your experiences as a surrogate may result in some emotional distress, and as such, if at any time you would like to pause, take a break, or stop the interview entirely, please let me know and do so. I will be providing a leaflet with a list of various emotional support agencies and websites, for your information. There will also be a list available online, at www.surrogacyreform.com.

What will happen if I don't want to carry on with the study?

If at any point during the study you would like to withdraw your participation, you may do so without having to give a reason. This withdrawal must take place prior to the end of fieldwork, and an email will be sent informing you of this date. If this is the case, your data will be destroyed and will not be part of this research.

How will my information be kept confidential?

The University of Exeter processes personal data for the purposes of carrying out research in the public interest. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection

Data obtained from the interviews will be protected and stored according to the GDPR, such that any identifiable personal information will only be recorded on the consent form, which will be kept separate from the interview data, which will be anonymised following the interview. Your privacy will be respected and all efforts to ensure confidentiality in the storage and publishing of data will occur.

The audio recordings from the interviews will be obtained through use of University-provided devices, protected securely and deleted following transcription. All the aforementioned will be contained in the consent form, and will be reiterated prior to the interviews. These will be stored separately. Additionally, I will ensure that the data will not breach anonymity you or any of the other participants in any way, and I will remove any identifying features from the transcript (names, addresses, occupations, etc.)

The research process will be designed with data protection in mind, such that the "raw data" and anonymised data will be kept separate and securely. Your name, location, ages, etc. will be anonymised in the publishing, such that any names used will be limited to 'Mx' and a randomly chosen letter that will in no way correspond with your first or last names. Any other identifying information will be omitted or altered in order to respect privacy.

The observation notes taken during the interview will be kept in a paper booklet, with the handwritten data from the interviews coded with only the date/time of the interview and without any personal identifiers present. The audio recordings of the interview will be recorded and stored on University-provided devices. Prior to the start of the interview, I will start the recording with identification of the date and anonymised ID (Mx [random letter]), and this will be recorded in the booklet with the observation notes. The consent form and any other personal identification will be stored in a loose-leaf format, with each form kept in separate envelopes, clearly marked 'private and personal' in a locked filing cabinet at the Wellcome Centre.

Following the interviews, the information obtained from the consent forms and the transcriptions, will be entered into password-protected encrypted documents and saved on the University's U:Drive, and not on any personal laptops/iPads/phones/etc. Following completion of the interview transcription, the audio recordings and original paper observation booklet will be destroyed. All data until then will be kept securely in locked cabinets at the Wellcome Centre. The data from the interviews will be kept for up to 8 years following the conclusion of this research project.

Will I receive any payment for taking part?

As a token of appreciation for your participation, you will be offered a £20 voucher to Amazon, love2shop, or a donation to a registered charity of your choice. You will be entitled to this token even if you decide to withdraw your participation.

What will happen to the results of this study?

The findings from this study will be published in the PhD thesis, as well as form the basis for other academic publications, and conferences. The PhD thesis will be deposited online, in the University of Exeter Repository. I will be updating www.surrogacyreform.com with a list of publications related to the findings from the research, to ensure dissemination of the information.

Who is organising and funding this study?

This study is part of my PhD, conducted under the supervision of Professor Anne Barlow, Professor Rebecca Probert, and Professor Katrina Wyatt. The funding for the PhD, and consequently this study, is the Wellcome Trust, through the Wellcome Centre for Cultures and Environments of Health.

Who has reviewed this study?

This project has been reviewed by the Research Ethics Committee at the University of Exeter.

Further information and contact details

If you would like to contact the research team for further information, or if you would like to take part, please email z.mahmoud2@exeter.ac.uk or go to www.surrogacyreform.com.

If you would like to voice a concern about the research project, please email z.mahmoud2@exeter.ac.uk or the SSIS Ethics team, ssis-ethics@exeter.ac.uk.

Thank you for your interest in this project!

Participant Consent Form

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I confirm that I have read the information sheet dated May 29, 2019 for the above project. I have had the opportunity to consider the information provided, ask questions and have had these answered satisfactorily

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my legal rights being affected.

I understand that relevant sections of the data collected during the study, may be looked at by members of the research team, individuals from the University of Exeter, Wellcome Centre for Cultures and Environments of Health or the Wellcome Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

I understand that taking part involves interview transcripts, later anonymised, to be used for the purposes of :

- (a) Inclusion in an archive for a period of up to 8 years
- (b) Shared with other researchers for use in future research projects
- (c) Published in academic publications
- (d) Public engagement activities

I agree to be contacted following conclusion of the interviews, as to discuss the findings, and give feedback and engage with the research, in line with a reflexive approach to research.

I agree to take part in the above project.

PARTICIPANT NAME

SIGNATURE

DATE

RESEARCHER NAME

SIGNATURE

DATE

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There is the possibility that discussing your experiences as a surrogate may result in some emotional distress. The following is a non-exhaustive list of emotional support agencies for your information:

Anxiety UK: self-help and information

British Association for Counselling and Psychotherapy: find counsellors in your area

Marriage Care: support for marriage and family relationships

Mind: advice and support for anyone experiencing a mental health problem

Relate: relationship counselling organisation

Samaritans: 24 hour confidential support for those experiencing distress or despair

TalkWorks: NHS talking therapy service

Women's Aid: ending domestic violence against women and children

Thank you for your participation in this interview study. Your experiences are invaluable and will be instrumental in my doctoral thesis. As you may already be aware, the Law Commission is in the midst of a consultation period, and the data from this interview may feature in my response to their consultation questions, as it is vital that surrogates' experiences and voices are taken into account.

The findings from this study will be published in my doctoral thesis, as well as form the basis for other academic publications, and conferences. The PhD will be deposited online, in the University of Exeter Repository. Additionally, I will be updating www.surrogacyreform.com with a list of publications related to the findings from the research, to ensure dissemination of the information.

These interviews are expected to end by September 30, 2019; an email confirming this date will be sent. If you would like to withdraw your participation, please email me (z.mahmoud2@exeter.ac.uk) and I will confirm your withdrawal. If you would like to voice a concern about the research project, please email me (z.mahmoud2@exeter.ac.uk) or the SSIS Ethics Team (ssis-ethics@exeter.ac.uk).

Once all interviews are complete, you will be invited to an informal session where you will have the chance to reflect on the findings, give feedback, and engage with the research.