



## **Participant Information Sheet for Lived Experience Experts**

UCL Research Ethics Committee Approval ID Number: \_\_\_\_\_

### **YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET**

#### **Title of Study: An Exploration of the Role of Lived Experience in Researching Health Systems and Creative Health**

This research will investigate the role of people with lived experience in health research and use their responses to inform how to improve creative health research for those with lived experience.

**Department: Arts and Sciences**

**Name and Contact Details of the Researcher(s): Hanna Morris email: [uclqhm1@ucl.ac.uk](mailto:uclqhm1@ucl.ac.uk)**

**Name and Contact Details of the Principal Researcher:**

**Professor Helen Chatterjee [h.chatterjee@ucl.ac.uk](mailto:h.chatterjee@ucl.ac.uk)**

#### **1. Invitation Paragraph**

You are being invited to take part in a Masters student research project that is investigating the role of lived experience experts in research. Lived experience experts are people with direct experience and understanding that has come from having lived through something personally. Their “expertise” comes from their experience and can inform researchers. They are also known in abbreviated/shorter form as LEXperts (Lived experience experts). Before you decide whether to take part? it is important for you to understand why the research is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. 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. Thank you for reading this.

#### **2. What is the project’s purpose?**

This research dissertation is part of the Mobilising Community Assets for Health Inequalities (MCA) research project led by Professor Helen Chatterjee. The dissertation will focus on the role of lived experience experts (LEXperts) in researching health care systems and creative health. Lived experience experts are people with direct experience and understanding that has come from having lived through something personally. This means lived experience experts offer a unique viewpoint when it comes to shaping health and care policies, as well as designing and delivering services. This research project aims to look into the most appropriate and sensitive ways, as defined by Lived experience experts themselves, of including people with lived experience in creative health research.

**3. Why have I been chosen?**

You have been chosen for this research because you have lived experience. To take part you need to be a lived experience expert, age 18-70. If you are not a lived experience expert or available during the time frame specified, then you will not be eligible to take part.

**4. Do I have to take part?**

Taking part in the study is entirely voluntary and refusal to agree to participate will involve no penalty or loss of benefits to which you are otherwise entitled.

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Participants have the right to withdraw at any time without prejudice to their job or wellbeing and without providing a reason. Existing data already provided by the participant, at the point of withdrawal, will be securely deleted.

**5. What will happen to me if I take part?**

You will take part **in a one-time interview** with the researcher **or complete a short survey**. The survey should take **no more than 10 minutes** and the **interview should take no more than an hour**. You will be asked a series of questions relating to your experience as a lived experience expert in health research. Your information from this interview will then be stored in the UCL server password protected and only used for the purposes of this research. You will not be identifiable and all your answers will be anonymised. You have up to 1 month after the initial date of interview or survey completion to withdraw your consent and involvement in this research with no penalty to you. You can provide an email to be contact with the results of the study if you so wish.

**6. Will I be recorded and how will the recorded media be used?**

There will be an audio and/or video recording /transcript of your interview via teams made during this research. It will only be used for the purposes of the analysis by the researcher at UCL. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings. These recordings will be kept securely. After the research is complete the recordings will be securely deleted.

**7. What are the possible disadvantages and risks of taking part?**

There is a chance that participants could feel uncomfortable or upset in recalling their experiences. If there is discomfort caused by the questions, time will be given for a break and, participants will be informed that they can discontinue at any time.

**8. What are the possible benefits of taking part?**

Not all research has benefits for the participants. Whilst there are no immediate benefits for participating in the project, it is hoped that this work will improve the research environment for lived experience experts, creating access to future treatment and helping to shape future research.

**9. What if something goes wrong?**

Complaints will be handled by the lead researcher Professor Helen Chatterjee. If you have a complaint about something occurring during or following participation in this research (a reportable serious adverse event) please reach out to Professor Helen Chatterjee and we will provide you with the necessary support. If you have a complaint regarding your treatment by researchers again, please contact Professor Helen Chatterjee. Your complaint will not effect you detrimentally. Furthermore, if you feel your complaint has not been handled satisfactorily (e.g. by the Principle Researcher or the supervisor) please contact the Chair of the UCL Research Ethics Committee – [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)

#### **10. Will my taking part in this project be kept confidential?**

All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications.

#### **11. Limits to confidentiality**

Please note that assurances on confidentiality will be strictly adhered to unless evidence of wrongdoing or potential harm is uncovered. In such cases the University may be obliged to contact relevant statutory bodies/agencies. Should this be the case, we would inform you of any decisions that might limit your confidentiality.

Furthermore, please note that confidentiality may not be guaranteed due to the limited size of the participant sample.

#### **12. What will happen to the results of the research project?**

Results will be used in the final dissertation project for this Masters degree and by the Mobilising Community Assets programme. You are entitled to a copy of the dissertation if you so wish. The date for release will be around September. You will not be identified in the dissertation or in any report or publication.

#### **13. Local Data Protection Privacy Notice**

**Notice:**

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

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in research studies, click [here](#)

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data used will be as follows:

Name  
Gender  
Age  
Occupation  
Email address

The lawful 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.* Personal data will be held in a password protected UCL server until December 2024. 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.

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).

***Detail any intended recipients of personal data if not explained elsewhere, and also advise if any personal data will be transferred outside the EEA, and if so to where.***

Only researchers involved in the project will have access to the data. No data will be transferred outside the EEA

**14. Who is organising and funding the research?**

UCL

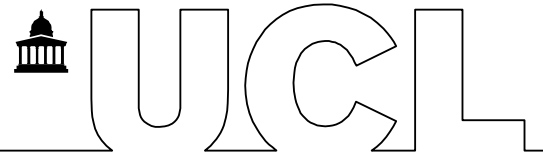
**16. Contact for further information**

If you have any issues or further questions, please contact Professor Helen Chatterjee. Email [h.chatterjee@ucl.ac.uk](mailto:h.chatterjee@ucl.ac.uk)

You will be given a copy of the information sheet and, if appropriate, a signed consent form to keep and remember.

**Thank you for reading this information sheet and for considering to take part in this research study.**

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## **PRIVACY NOTICE**

### **1. Introduction**

#### **UCL Masters student survey into Lived Experience in health research**

We respect your privacy and are committed to protecting your personal data.

Please read this Privacy Notice carefully – it describes why and how we collect and use personal data and provides information about your rights. It applies to personal data provided to us, both by individuals themselves or by third parties and supplements the following wider [UCL privacy notice](#)(s):

- [General privacy notice](#) when you visit UCL's website
- [Student privacy notice](#)
- [Staff privacy notice](#)
- [Research participants for health and care purposes privacy notice](#)

We keep this Privacy Notice under regular review. It was last updated on 16 Nov 2018.

### **2. About us**

UCL Masters student studying Creative Health at University College London (**UCL**).

UCL, a company incorporated by Royal Charter (number RC 000631), is the entity that determines how and why your personal data is processed. This means that UCL is the 'controller' of your personal data for the purposes of data protection law.

### **3. Personal data that we collect about you**

Personal data, or personal information, means any information about an individual from which that person can be identified. It does not include data where the identity has been removed (anonymous data).

We may collect, use, store and transfer different kinds of personal data about you. This may include:

- Your name and contact details should you wish to share these with us; and
- Details about your age and gender.

### **4. How we use your personal data**

We will only use your personal data when the law allows us to. Most commonly, we will use your personal data in the following circumstances:

- To complete and evaluate this survey
- To invite you to take part in further research and evaluation

Where the processing is based on your consent, you have the right to withdraw your consent at any time by contacting us using the details set out below. Please note that this will not affect the lawfulness of processing based on consent before its withdrawal.

We may also use anonymised data, meaning data from which you cannot be identified, for the purposes of:

- Service evaluation; and
- Education and research

Anonymised data may also be used in published reports or journals and at conferences.

#### **5. Who we share your personal data with**

Your personal data will be collected and processed by our staff and UCL (Access to your personal information is limited to staff who have a legitimate need to see it for the purpose of carrying out their job at UCL).

#### **6. Lawful basis for processing**

Data Protection Legislation requires that we meet certain conditions before we are allowed to use your data in the manner described in this notice, including having a "lawful basis" for the processing. The basis for processing will be as follows:

- Legitimate interests. The processing of your personal data may be necessary for the purposes of the legitimate interests pursued by us, except where such interests are overridden by your interests or by fundamental rights and freedoms which require protection of personal data [Note: read [UCL's guidance on legitimate interests](#)]

For special category personal data, the following lawful bases for processing will be used:

#### **7. International transfers**

We will not transfer your personal data outside of UCL.

#### **8. Information security**

We have put in place appropriate security measures to prevent your personal data from being accidentally lost, used or accessed in an unauthorised way, altered or disclosed. We have established procedures to deal with any suspected personal data breach and will notify you and any applicable regulator of a breach where we are legally required to do so.

#### **9. Data retention**

We will only retain your personal data for as long as necessary to fulfil the purposes we collected it for, including for the purposes of satisfying any legal, accounting, or reporting requirements.

We will keep your personal data according to the [Records Retention Schedule](https://www.ucl.ac.uk/library/about-us/records-office/records-retention) (or paste <https://www.ucl.ac.uk/library/about-us/records-office/records-retention> into your browser).

## **10. Your rights**

Under certain circumstances, you may have the following rights under data protection legislation in relation to your personal data:

- Right to request access to your personal data;
- Right to request correction of your personal data;
- Right to request erasure of your personal data;
- Right to object to processing of your personal data;
- Right to request restriction of the processing your personal data; and
- Right to request the transfer of your personal data

If you wish to exercise any of these rights, please contact the [Data Protection Officer](#).

## **Contacting us**

You can contact UCL by telephoning +44 (0)20 7679 2000 or by writing to: University College London, Gower Street, London WC1E 6BT.

Please note that UCL has appointed a Data Protection Officer. If you have any questions about this Privacy Notice, including any requests to exercise your legal rights, please contact our Data Protection Officer using the details set out below:

Data Protection & Freedom of Information Officer [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

## **11. Complaints**

If you wish to complain about our use of personal data, please send an email with the details of your complaint to the [Data Protection Officer](#) so that we can look into the issue and respond to you.

You also have the right to lodge a complaint with the Information Commissioner's Office (**ICO**) (the UK data protection regulator). For further information on your rights and how to complain to the ICO, please refer to the [ICO website](https://ico.org.uk/) (or paste <https://ico.org.uk/> into your browser).



## CONSENT FORM FOR *LIVED EXPERIENCE EXPERTS SURVEY*

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

**Title of Study: An Exploration of the Role of Lived Experience in Researching Health Systems and Creative Health**

**Department: Arts and Sciences**

**Name and Contact Details of the Researcher(s): Hanna Morris. Email: uclqhm1@ucl.ac.uk**

**Name and Contact Details of the Principal Researcher: Professor Helen Chatterjee h.chatterjee@ucl.ac.uk**

**Name and Contact Details of the UCL Data Protection Officer: \_\_\_\_\_**

**This study has been approved by the UCL Research Ethics Committee: Project ID number: \_\_\_\_\_**

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

**I confirm that I understand that by ticking/initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.**

		Tick Box
1.	*I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction	
2.	*I understand that I will be able to withdraw my data up to 1 month after the date of completing the survey.	
3.	*I consent to participate in the study. I understand that my personal information age and professional role will be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing.	
4.	<p><b>Use of the information for this project only</b></p> <p>*I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified (<i>unless you state otherwise, because of the research design or except as required by law</i>).</p> <p>I understand that my data gathered in this study will be stored anonymously and securely. It will not be possible to identify me in any publications.</p> <p>OR</p> <p>Anonymity is optional for this research. Please select from the following 2 options:</p>	



	<p>(a) I agree for my real name and role/affiliation to be used in connection with any words I have said or information I have passed on.</p> <p>(b) I request that my comments are presented anonymously but give permission to connect my role/affiliation with my comments (but not the title of my position).</p>	
5.	*I understand that my information may be subject to review by responsible individuals from the University Lead researcher Professor Helen Chatterjee for monitoring and audit purposes.	
6.	*I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, [without my employment or my legal rights being affected]. I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise.	
7.	I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.	
8.	I understand the direct/indirect benefits of participating.	
9.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	
10.	I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	
11.	N/A	
12.	I agree that my anonymised or pseudonymised research data may be used by others for future research. [No one will be able to identify you when this data is shared.]	
13.	I understand that the information I have submitted will be published as a report and I wish to receive a copy of it. Yes/No If so, please leave your contact details at the end of this form.	
14.	<p>I consent to the information provided in the survey to be used for the purposes of this research. The information will:</p> <p>EITHER</p> <ul style="list-style-type: none"> <li>- Be destroyed after data collection and anonymised reporting.</li> </ul> <p>OR</p> <ul style="list-style-type: none"> <li>- Stored anonymously, using password-protected software and will be used for specific research purposes.</li> </ul>	
15.	I hereby confirm that I understand the conditions under which I am taking part as specified in the Information Sheet and explained to me by the researcher.	
16.	<p>I hereby confirm that:</p> <p>(a) I understand the exclusion criteria as detailed in the Information Sheet and explained to me by the researcher; and</p> <p>(b) I do not fall under the exclusion criteria.</p>	
17.	I agree that my GP may be contacted if any unexpected results are found in relation to my health.	
18.	I have informed the researcher of any other research in which I am currently involved or have been involved in during the past 12 months.	
19.	I am aware of who I should contact if I wish to lodge a complaint.	
20.	I voluntarily agree to take part in this study.	
21.	<p>Use of information for this project and beyond will be used for the specific research purposes and no other reason. All information gathered from participants will be stored securely on the encrypted and password secured UCL server.</p> <p>I understand that other authenticated researchers will have access to my anonymised pseudonymised data.</p>	
22.		

**If you would like your contact details to be retained so that you can be contacted in the future by UCL researchers who would like to invite you to participate in follow up studies to this project, or in future studies of a similar nature, please tick the appropriate box below.**

<input type="checkbox"/>	Yes, I would be happy to be contacted in this way	<input type="checkbox"/>
<input type="checkbox"/>	No, I would not like to be contacted	<input type="checkbox"/>

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature



## CONSENT FORM FOR LIVED EXPERIENCE EXPERTS INTERVIEW

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

**Title of Study: An Exploration of the Role of Lived Experience in Researching Health Systems and Creative Health**

**Department: Arts and Sciences**

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Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

**I confirm that I understand that by ticking/initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.**

		Tick Box
1.	*I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction	
2.	*I understand that I will be able to withdraw my data up to 1 month after the date of the interview.	
3.	*I consent to participate in the study. I understand that my personal information age and professional role will be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing.	
4.	<p><b>Use of the information for this project only</b></p> <p>*I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified (<i>unless you state otherwise, because of the research design or except as required by law</i>).</p> <p>I understand that my data gathered in this study will be stored anonymously and securely. It will not be possible to identify me in any publications.</p> <p>OR</p> <p>Anonymity is optional for this research. Please select from the following 2 options:</p>	

	(a) I agree for my real name and role/affiliation to be used in connection with any words I have said or information I have passed on. (b) I request that my comments are presented anonymously but give permission to connect my role/affiliation with my comments (but not the title of my position).	
5.	*I understand that my information may be subject to review by responsible individuals from the University Lead researcher Professor Helen Chatterjee for monitoring and audit purposes.	
6.	*I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, [without my employment or my legal rights being affected]. I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise.	
7.	I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.	
8.	I understand the direct/indirect benefits of participating.	
9.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	
10.	I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	
11.	N/A	
12.	I agree that my anonymised or pseudonymised research data may be used by others for future research. [No one will be able to identify you when this data is shared.]	
13.	I understand that the information I have submitted will be published as a report and I wish to receive a copy of it. Yes/No If so, please leave your contact details at the end of this form.	
14.	I consent to my interview being audio/video recorded and transcribed, and understand that the recordings and transcripts will be: EITHER - destroyed after data collection and anonymised reporting. OR - Stored anonymously, using password-protected software and will be used for specific research purposes.	
15.	I hereby confirm that I understand the conditions under which I am taking part as specified in the Information Sheet and explained to me by the researcher.	
16.	I hereby confirm that:  (a) I understand the exclusion criteria as detailed in the Information Sheet and explained to me by the researcher; and  (b) I do not fall under the exclusion criteria.	
17.	I agree that my GP may be contacted if any unexpected results are found in relation to my health.	
18.	I have informed the researcher of any other research in which I am currently involved or have been involved in during the past 12 months.	
19.	I am aware of who I should contact if I wish to lodge a complaint.	
20.	I voluntarily agree to take part in this study.	
21.	Use of information for this project and beyond will be used for the specific research purposes and no other reason. All information gathered from participants will be stored securely on the encrypted and password secured UCL server.  I understand that other authenticated researchers will have access to my anonymised pseudonymised data.	
22.		

**If you would like your contact details to be retained so that you can be contacted in the future by UCL researchers who would like to invite you to participate in follow up studies to this project, or in future studies of a similar nature, please tick the appropriate box below.**

<input type="checkbox"/>	Yes, I would be happy to be contacted in this way	<input type="checkbox"/>
<input type="checkbox"/>	No, I would not like to be contacted	<input type="checkbox"/>

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature