



PSYCHIATRY

Participant Information Sheet

Young people with experience of being in hospital under the Mental Health Act

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Please let us know if you need this Information Sheet in a different size, font, or format.

Title of Study: The involuntary psychiatric hospitalisation of people under 18: Why does this happen, what is it like, and how could it be avoided?

Department: Division of Psychiatry

Name and Contact Details of the Researcher:

Dr Susan Walker (susan.walker@ucl.ac.uk)

Name and Contact Details of the Principal Investigator:

Professor Sonia Johnson(s.johnson@ucl.ac.uk)

This study has been approved by the UCL Research Ethics Committee: Project ID number: 5650/002

1. Invitation Paragraph

You are being invited to take part in a research project.

Before you decide whether to take part, it is important for you to understand:

- why the research is being done, and
- what your part in it will involve.

Please take time to read the following information carefully. Discuss it with others if you wish.

Please ask us if there is anything that is not clear or if you would like more information.

2. Why is the research being done?

This study is part a PhD looking at the use of the Mental Health Act among people under 18 years old.

The overall aim of the research is to understand more about which young people are admitted to hospital involuntarily and why, in the hope that this will highlight how these admissions could be avoided and how the experience could be improved when it cannot be prevented. In addition, we know that certain groups are more likely to experience psychiatric treatment against their will than others (e.g., those from Black and Minority Ethnic groups) and it is hoped that the findings from this work will start to address these inequalities in access to mental health care.

3. Why have I been invited to take part?

You have been invited to take part in this research because you are aged 16-25 and have experience of being admitted to psychiatric hospital under Section 2 or Section 3 of the Mental Health Act before you were 18 years old.

Very little is known about the experience of being in hospital under the Mental Health Act as a child or adolescent. Young people we have talked to about this research have said that it is important to talk to people who have been in hospital involuntarily before they were 18 so we can learn more about these experiences and what can be done to prevent or improve them.

4. Do I have to take part?

It is up to you to decide whether to take part in the study.

If you decide not to take part you do not have to give a reason and it will not affect your legal rights, or any care or support you receive.

You can withdraw any time up to 2 weeks after the interview (by this time the interview will have been written out and made anonymous) without giving a reason and without it affecting your legal rights, or any care or support you receive. If you do withdraw after the interview, you would still be entitled to receive the £20 voucher.

If you decide to withdraw you will be asked what you wish to happen to the data (information) you have provided up to that point. For example, you could ask for it to be destroyed or it could remain as part of the study.

5. What happens next if I do agree to take part?

- We will give you information about the study

After expressing interest in the study, you will be emailed a copy of this Participant Information Sheet and will be invited to have a telephone call or video call (depending on your preference) with the researcher (Dr Walker) and ask any questions you have. You will be provided with as much time as you need for this: it typically takes about 15 minutes. If you would prefer not to discuss the information sheet, that is fine.

- You will have time to decide whether to take part

After at least 48 hours, Dr Walker will email or telephone you (depending on your preference) to ask if you would like to take part in the study.

- If you want to take part, we will ask for your consent

You will be invited to give consent on Microsoft teams or on the telephone by having each statement on the consent form read out to you and asking you to say out loud if you agree with the statements. This will be audio recorded (or video recorded, if you decide to have the camera on during the call) and saved as an audio (sound only) file, as a record of informed consent.

You will be asked if you would be happy for your contact details to be retained. This is so 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 similar studies.

- We will ask you to complete a personal details form

You will also be sent a link to an online form to fill out with some details about yourself. These questions (with the exception of your age) will be voluntary.

- Online one-to-one conversation about your experiences

A time will be arranged with you to take part in a conversation with Dr Walker on Microsoft Teams, or via a free telephone number.

In this conversation you will be asked some broad questions about:

- your experience of being in hospital under the Mental Health Act,
- what happened in the run-up to this,
- what you think could help improve the experience, and
- what could be done to avoid involuntary admissions taking place.

You do not have to answer any questions or talk about anything that you would prefer not to.

We will send you a copy of the topic guide (the questions we will be asking) in advance.

The interview will last between one hour and one hour 30 minutes, but you are welcome to take breaks if you wish or to stop at any point.

- Thank you token

To thank you for your time given to the study, you will receive a £20 e-voucher.

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

The interview and your consent to take part in the study will be recorded online. You can choose to turn off your video if you prefer to be audio-recorded only. If you choose to take part in a video call, we will change this video file to a sound only file before being transcribed. If you choose to phone in to an interview on Teams, using the 0800 freephone telephone number, the interview will be recorded on Teams as a sound file.

The audio files of the interviews will be transcribed by a company approved by UCL which is compliant with General Data Protection regulations (GDPR), and an agreement will be in place about sharing data and processing (managing) data. The transcription company will be asked to sign a confidentiality agreement.

When the recording is transcribed, your personal information will be anonymised so that no one will be able to link it back to you.

The transcripts will be stored on the academic institution's computer as a password protected document and will be accessible by the UCL research team only. This will be stored separately from the demographic information form, and the sound file recording of you giving consent.

Sound files of your interview will be destroyed within one month of the interviews being transcribed. We will retain a sound file recording of you giving consent to take part in the interview, in line with UCL's data protection guidelines.

7. What personal and special category data will be collected about me?

Prior to the interview you will be asked to complete a secure online form with some questions about you. This will ask for your first name, age, sex, ethnicity, region where you live, approximate date of first involuntary hospitalization, dates of any subsequent involuntary hospitalisation, dates of any voluntary hospitalisations, age at the time of first involuntary hospitalisation, living situation (at the time of first involuntary hospitalisation), education/employment status (at the time of first involuntary hospitalisation), mental health diagnosis (at the time of first involuntary hospitalisation) and whether this has changed since then.

These questions are being asked so that we can understand more about the things that might make it more likely for a young person to be admitted to hospital against their will.

However, other than your age (which we need to ensure that you are legally able to consent to the study yourself) these questions will all be voluntary and there will be an option not to answer them.

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

It is possible that you may find some of the interview questions upsetting, as we will be talking about your experiences of being in hospital involuntarily. We hope that this won't be the case, and young people who have helped in the design of this study have said that they think young people would like an opportunity to talk about their experiences.

At the end of the interview, Dr Walker will talk to you briefly about how you are feeling and tell you about resources from organisations that offer support, or other ways to obtain support. You will be offered a phone call a few days later to see how you are following the interview.

If you do start to feel distressed during the interview, the interview will be stopped, and we will talk about how you are feeling. You can decide if you would like to continue the interview, do the interview another time, or no longer take part in the study. If you are unable to continue the interview at that time, you will be encouraged to contact your GP/mental health service provider if appropriate. You will be offered resources from organisations that offer support, or other ways to obtain support. In addition, Dr Walker is a Consultant Child and Adolescent Psychiatrist with a lot of experience of supporting young people in difficult situations. Dr Walker will offer to call you a few days later to see how you are.

9. What are the possible benefits of taking part?

As a thank you for taking part in the study, you will receive a £20 voucher.

Whilst there are no other immediate benefits for people participating in the project, it is hoped that the findings from the study will improve the care of others in a similar situation.

10. What if something goes wrong?

If you wish to raise a complaint or have any concerns, please contact Dr Susan Walker in the first instance: susan.walker@ucl.ac.uk.

If you continue to have concerns, please contact Professor Sonia Johnson: s.johnson@ucl.ac.uk. (Dr Walker's PhD supervisor)

If you are not satisfied that your concern has been resolved, complaints may ultimately be referred to the chair of the Research Ethics Committee at UCL: (ethics@ucl.ac.uk).

11. Will my taking part in this project be kept confidential (private)?

The audio-recording of your consent to take part in the study, the personal details form and your interview will be separately and securely stored on the UCL cloud-based (online) secure storage system in line with UCL's data protection guidelines.

We will remove anything that may identify you in the interview transcripts so that no information can be linked back to you. The transcripts will be stored on the academic institution's computer as a password protected document and will be accessible by the UCL research team only.

The interview sound files will be destroyed within one month of being transcribed.

If the researchers would like to use a direct quote from you in a publication they will use a fake pseudonym, that is a fake name, or a participant number.

12. Limits to confidentiality

Confidentiality will be maintained as far as it is possible, unless during your conversation the researcher hears anything which makes them worried that you or someone else might be in immediate danger of harm to their safety. In this case, the researcher will have to inform appropriate emergency services, but will tell you that they are going to do this.

13. What will happen to the results of the research project?

The findings will be submitted for publication in a peer-reviewed journal, that is a journal that has all papers reviewed by experts in that field before it is accepted for publication. The findings may also be shared in other forums including conferences, stakeholder groups and social media. Participant anonymity will always be maintained.

The data gathered in this study will be securely archived for 10 years on the UCL cloud-based (online) secure storage system.

14. Local Data Protection Privacy 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 (any information that can be used to directly or indirectly identify you), and can be contacted at data-protection@ucl.ac.uk

A data controller is: is the organisation that decides how and why personal data is processed (managed) within the law of the two main acts.

This 'local' privacy notice (detailed information about what UCL are doing with personal data they hold) 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 (General Data protection regulations) and DPA (Data Protection Act) 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data to be collected are listed above in section 7.

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.

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.

15. Who is organising and funding the research?

The study is organised by a researcher from the Division of Psychiatry, UCL. Young people with lived experience have been involved in the design of the study and the creation of the information and consent sheets as well as the recruitment advert. The study is funded by a grant from National Institute of Health Research (NIHR), study reference number: DRF-2017-10-147

16. Contact for further information

You can contact: Dr Susan Walker or Professor Sonia Johnson.
Email: susan.walker@ucl.ac.uk, s.johnson@ucl.ac.uk

You will be given a copy of this information sheet and a copy of the consent form to keep.

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