PARTICIPANT INFORMATION SHEET (CARER CYP) NHS

Title of Study: Mixed methods investigation into provision of family rooms and support for parents admitted to psychiatric inpatient units and their children.

IRAS ref: 340906

PLEASE KEEP A COPY OF THIS INFORMATION SHEET FOR YOUR RECORDS

Section: Taking Part

Invitation Paragraph

We are inviting the child/young person you care for take part in this research project. We are sharing information about the project with you so you can discuss it with them and help them decide if they want to take part. If they are aged 15 or under, we will ask you to consent for them to take part, so it is important that you understand the project too. Please discuss the study with others if you wish. If you have any questions you can contact us using the contact details at the end of this information sheet.

What is the purpose of the study?

The aim of this study is to understand the experience of family visits when a parent is treated in a mental health inpatient hospital.
We are specifically interested in how we can improve the experience of these visits for parents and carers and children.
This will involve carrying out interviews with children and young people, parents, carers of children who visited a parent in hospital and healthcare professionals.

Who is responsible for this study?

This study is the responsibility of Dr Abby Dunn at the University of Sussex.

Chloe Elsby-Pearson from Sussex Partnership NHS Foundation Trust is Lived Experience Co-ordinator for the study.

It also involves collaborators at the University of Surrey, Surrey and Borders Partnership NHS Trust and Sussex Partnership NHS Foundation Trust.

Why has the child I care for been invited to take part?

They have been invited to participate because they visited their parent during their stay in an inpatient mental health hospital.

Do they have to take part?

Participation is voluntary and they do not have to take part. We will describe the study in this information sheet and then you will have a week to think about its contents with the child you care for. Please contact us if there is anything that is not clear, if you have any questions, or if you would like more information.

What does taking part involve?

If you decide to take part, you will be given this information sheet to keep and you and the child you care for will be invited to have a short conversation with the research team where you can find out more about the project and we can decide whether it is a good fit for you. After that, you will be asked to sign an online consent form to confirm your agreement for them to participate. They will be asked to sign a form assenting to take part. You will be given a copy of these forms to keep. The child you care for will then take part in an online interview. The interviews will be scheduled at a convenient time for you.

The interview will involve asking the child you care for to draw a picture which reflects their visit to hospital – it can take any form they wish. They can do this using an online drawing tool or on paper. We will ask them to show us the picture and describe it. We will also ask them questions about visiting their parent in hospital and how it could be improved.

The interview will be video-recorded and later transcribed by the research team for analysis. After the interview an anonymised (with all identifying data removed) transcript of the interview will be produced (automatic transcription through Microsoft teams, transcription software, and/or transcription by a researcher), after which the audio recording of the interview will be deleted.

What happens if the child I care for does not want to take part or if they change their mind?

They are free to withdraw from the study at any time, without giving a reason. You/they can withdraw their data (information about you/the child and the transcript of the recording of the interview) up to the point at which it is anonymised (one month after the interview takes place).

What are the possible benefits in taking part?

We hope that it will be a positive experience for the child you care for. Their input will contribute to improving the experiences of families visiting mental health inpatient units. To thank them for their time we give them a £10 voucher after the interviews have taken place.

Are there any potential risks involved?

A possible disadvantage to taking part in the study is that thinking about visiting a parent in hospital might be upsetting. To reduce the risk of this happening we are asking quite broad questions and we will remind all children and young people taking part that they don't have to answer any questions which make them feel uncomfortable. We have written the questions with children who have had similar experiences. We will also encourage the child you care for to bring anything to the interview which makes them feel more comfortable. A debrief sheet providing information about what happens next in the project along with signposting to support resources will be provided.

Are there limits to confidentiality?

Should the child you care for disclose information which indicates they themself or someone else is at risk of harm we may have to contact the appropriate services. In this case we will have to disclose their identity. We would discuss this with you first.

How is the project being funded?

This research is funded by the National Institute for Health and Care Research (NIHR) under award number NIHR207868.

What will happen to the results of the study?

We will produce a final report summarising the main findings. This will be available on our project website (http://inpatientfamilies.org)

This research may be published in peer reviewed academic journals under open access conditions. This means the article can be read for free online by anyone who wishes to. The findings will be presented to stakeholder groups and at conferences.

Anonymised quotes from the interview may be used in these publications.

You will be sent a summary of the results of the study if you indicate you would like to receive one.

Who has reviewed this study?

This research has been reviewed by an independent group of people, called an Ethics Committee. This study was reviewed and given a favourable opinion by the East Midlands - Derby Research Ethics Committee (REC reference: [**26/EM/0005**]) which indicates it is ethical, safe and respects the rights of people taking part.

Section: Your personal data

How will we use information about you or the child you care for?

We will need to use information from you/the child for this research project.

This information will include:
- The name of the child you care for
- your contact details.

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 the name of the child you care for or your contact details. The data will have a code number instead.

The University of Sussex is responsible for looking after this information. We will share your information related to this research project with the following types of organisations:
- Regulatory bodies and ethics committees
- Other researchers and institutions (in an anonymised form where you cannot be identified).

We will keep all information about you/the child you care for safe and secure by:
- Anonymising the data
- Keeping any identifiable information in a separate password protected file

- Storing information about you on a secure University of Sussex-hosted online platform.

Your/the child's data will not be shared outside the UK.

How will we use information about you or the child you care for after the study ends?

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 or the child that you care for took part in the study.
We will keep study data for a maximum of 10 years. The study data will then be fully anonymised and securely archived or destroyed. Identifiable data will be retained for a maximum of 12 months post-study on a secure university server before being destroyed.

What are your choices about how information about you or the child you care for is used?

The child that you care for can stop being part of the study at any time, without giving a reason, but we will keep information about them that we already have.

You have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.

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. To facilitate this, your anonymised data will be stored in the Figshare data repository where it can be accessed by other researchers in an anonymised form.

Where can you find out how the information about you or the child you care for is used?

You can find out more about how we use the information about you or the child you care for as follows:

- our leaflet www.hra.nhs.uk/patientdataandresearch and website information
- by asking one of the research team
- by sending an email to parentprojects@sussex.ac.uk or dpo@sussex.ac.uk

Section: Further information

What if you have a query or something goes wrong?

If you are unsure about something you can contact the research team for further advice using the contact details at the bottom of this information sheet.

However, if your query has not been handled to your satisfaction, or if you are unhappy and wish to make a formal complaint to someone independent of the research team, then please contact:

Head of Research Ethics, Integrity and Governance
Research & Enterprise Services
University of Sussex
Email: researchsponsorship@sussex.ac.uk

The University of Sussex has indemnity cover in place which may respond to its legal liabilities in respect of this study.

If you wish to complain or have any concerns about any aspect of the way you have been treated during the course of this study then you should follow the instructions given above.

You can also follow the NHS Complaints Procedure. Details can be obtained from the NHS SPFT patient advice and liaison service (PALS). PALS can be contacted online (https://www.sussexpartnership.nhs.uk/about-us/contact-us/feedback-advice-and-complaints) or by telephone (0300 304 2198) or email: spft.pals@nhs.netor, or the NHS SABP patient advice and liaison service (PALS). PALS can be contacted online (https://www.sabp.nhs.uk/contact/pals) or by telephone (01372 216202) or email: rxx.palsandcomplaintssabp@nhs.net

Who should I contact for further information?

If you have any questions or require more information about this study, please contact me using the following contact details:

Chief Investigator: Dr Abby Dunn, abby.dunn@sussex.ac.uk
Research mailbox: parentprojects@sussex.ac.uk
Website: http://inpatientfamilies.org
Phone: 07350 440728

Support and resources

If you feel you would benefit from support, the following organisations may be helpful:

Support for parents and carers:

- Mind: 0300 123 3393 or www.mind.org.uk
- Rethink Mental Illness: 0808 801 0525 or www.rethink.org
- Family Lives (parenting support): 0808 800 2222 or www.familylives.org.uk
- YoungMinds Parent Helpline: 0808 802 5544 or www.youngminds.org.uk

Support for children and young people:

- Childline: 0800 1111 or www.childline.org.uk
- YoungMinds Textline: Text YM to 85258
- The Mix (under 25s): 0808 808 4994 or www.themix.org.uk

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