PARTICIPANT INFORMATION SHEET (HCP) 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 would like to invite you to participate in this research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. 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?

This study aims to explore how families experience visiting a parent in a psychiatric hospital. We are particularly interested in the views of healthcare professionals who work on adult inpatient units, to understand current practice and how the environment or procedures could be improved. Findings will inform the development of a 'Family Visit Pack' – a set of guidelines, templates, and resources to support visiting arrangements and promote wellbeing during family visits.

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, North Staffordshire Combined Healthcare NHS Trust, Somerset NHS Foundation Trust and Sussex Partnership NHS Foundation Trust.

Why have I been invited to take part?

You have been invited to participate in this study because you currently work, or have recently worked (within the past two years for a minimum of six months), on an adult psychiatric inpatient unit and are familiar with family visiting practices.

Do I have to take part?

Participation is voluntary. You will have at least 7 days to review this information sheet before deciding. You are free to ask any questions or request additional information. Please contact us if there is anything that is not clear, if you have any questions, or if you would like more information.

What will happen to me if I decide to take part?

If you decide to take part, you will be given this information sheet to keep and will be asked to sign an online consent form to confirm your agreement to participate. You will be given a copy of this consent form to keep.

We will then invite you to take part interview (online or over the telephone). The interviews will be scheduled at a convenient time for you. The interviews will be scheduled at a convenient time for you. The interview will be audio/video-recorded. An anonymised (with all identifying data removed) transcript of your interview will be produced (automatic transcription through Microsoft teams, transcription software, and/or transcription by a researcher), after which the audio recording of your interview will be deleted.

After the interview there is an optional debrief conversation.

What happens if I do not want to take part or if I change my mind?

You are free to withdraw from the study at any time, without giving a reason. You can withdraw your data (information about you 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?

While there are no direct personal benefits, your insights will contribute to improving the experiences of patients who are parents and families visiting psychiatric units.

Are there any potential risks involved?

A possible disadvantage to taking part in the study is that some interview questions may prompt reflection on difficult experiences. In order to reduce any potential risks, you are not required to answer any question you find uncomfortable. Debriefing information and signposting to support resources will be provided.

Are there limits to confidentiality?

Should you disclose information which indicates you or someone else is at risk of harm we may have to contact the appropriate services. In this case we will have to disclose your identity.

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 your 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

What is personal data?

How will we use information about you?

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

This information will include:

- your name
- 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 your name or contact details. Your data will have a code number instead.

The University of Sussex is responsible for looking after your 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 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 data will not be shared outside the UK.

How will we use information about you 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 took part in the study.
We will keep your study data for a maximum of 10 of 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 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.

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 more about how your information is used?

You can find out more about how we use your information 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 or the Somerset NHS Foundation Trust patient advice and liaison service (PALS). PALS can be contacted by telephone (01823 343536) or email: pals@somersetft.nhs.uk. North Staffordshire Combined Healthcare NHS Trust's PALS can be contacted by telephone (0800 389 9676) or email: PatientExperienceTeam@northstaffs.nhs.uk.

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 healthcare professionals:

- NHS Staff Support Line (by Samaritans): 0800 069 6222
- Practitioner Health (for doctors and dentists): www.practitionerhealth.nhs.uk
- Your NHS Trust's Occupational Health and Wellbeing Services

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