



Information Sheet for Young People (Ages 16–18)

Study Title: Provision for Parents on Psychiatric Inpatient Units (POPI)

IRAS ref: 340906

Why are we doing this study?

Sometimes parents need to spend time in hospital to get support for their mental health. We want to understand what it's like for young people when they visit their parent during this time. We hope your experiences will help us improve how visits are managed and supported for other families in the future. We are speaking to parents, young people, carers, and healthcare professionals so we can understand different perspectives.

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.

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.

Why have I been asked to take part?

You have been invited because you are aged under 18 and have visited a parent in a mental health hospital at some point between now and July 2021.

What will I be asked to do?

If you take part, you will be invited to a 30–60-minute online conversation (video call) with a member of our research team at a time that works for you.

We are using a 'Draw, Write, Tell' approach – this means you can draw or write about your experiences before talking about them. You can do this on paper or on the screen.

You can have a parent or carer with you during the session if you would like. The conversation will be audio-recorded so we can write it up later.

After the interview we can share your digital drawing with you (if you would like to have it) and we will send you a voucher to thank you for taking part.

After your interview 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.

Do I have to take part?

No – taking part is your choice. If you say yes, you can still change your mind later without giving a reason.

You can also skip any questions you don't want to answer and stop the interview at any time. If you decide to withdraw, you can ask us to delete your interview up to one month after it takes place, before your information is anonymised.

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.

Are there any benefits to taking part?

Your experiences will help us understand and improve how visits to parents in hospital are managed and supported. We will give you a £10 voucher to thank you for your time.

Are there any risks?

Some questions may feel personal or bring up difficult memories. You do not have to answer anything that makes you uncomfortable. We can pause or stop the interview at any point. We will give you information about organisations you can contact if you would like support.

How will my information be used?

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

University of Sussex privacy notice.

What will happen with the results?

We will write a report about what we find and share it on our project website. We may also publish the results in journals and talk about them at conferences, but no one will be able to identify you from this.

What if I have questions or a problem?

If you are unsure about something or have a question, you can contact the research team (details below). If you are unhappy with how you have been treated, you can make a complaint to the University of Sussex Research Governance team at researchsponsorship@sussex.ac.uk.

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.net, 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.

Contact details

Chief Investigator: Dr Abby Dunn – abby.dunn@sussex.ac.uk

Research team email:

parentprojects@sussex.ac.uk

Website: <http://inpatientfamilies.org>

Phone: 07350 440728

Things you can do if you feel upset:

- Talk to someone you trust (like a parent, carer, or friend)
- Do something that makes you feel calm – like drawing, playing, or watching something you like

- Cuddle a pet or soft toy
- Spend time in your favourite place or with your favourite person

If you ever feel sad, worried or just want to talk, here are some people who can help:

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