**PARTICIPANT INFORMATION SHEET**

**FOR SIGNIFICANT OTHERS**



**Study Title: The Relations Study**

We would like to invite you to take part in our research study. Joining the study is entirely up to you. Before you decide, it is important to know why the research is being done and what it will involve. Take time to read this information sheet and speak to your family and others about it if you wish. We would be happy to answer any questions about the study. Please take time to decide if you would like to take part.

|  |  |
| --- | --- |
| **Why is the study being done?** | Research shows that parents who use drugs are often involved with many different health and social care services. These services should work together, along with the parents and other family/carers, to provide the right kind of help, at the right time, in the right way. This includes **family/carer support** and systems of care that are acceptable, supportive, and based on good evidence. However, we know that this is not always the case. This can lead to very different outcomes for families – some good, some not good.  Our study aims to:   * Find out much more about how the whole system works from the point of view of parents and other family members/carers, and * Understand how relations between families/carers and services can lead to different outcomes, and how to make the system better for everyone in the future.   The project includes 30 parents and their families from different areas in the UK – Scotland and England, as well as health and social care services. |
| **Who can take part?** | **You have been asked to take part because you are a family member, or significant other, of a parent who is using opioids or on opioid replacement treatment.** Your own views and experiences on being part of the family, or involved with the family, is important. The research team would like to include you in the study to hear about your experiences. |
| **Do I have to take part in the study?** | No. It is up to you to decide. Your involvement in the study is entirely **voluntary**. If you do agree to take part, we will ask you to sign a **consent form**. If you join the study, you are **free to withdraw** at any time, without giving a reason. If you do withdraw from the study, it will not affect the standard of care that you or the family taking part in the study receive, or your legal rights. |
| **If I take part, what will it involve?** | You will be invited to take part in a one-off interview with the researcher. The interview will last about one hour and will be arranged at a time that is convenient for you. Interviews can be in-person, online (video call), or by phone. With your permission, the researcher will audio-record your interview so they can type it up word for word later.  **The interview will be relaxed and informal, like a conversation.** The researcher will want to talk to you about **different topics** such as important life events in your family, your role within the family, your views on how drug use has affected the family, your experiences of accessing help and support from health and social care agencies, and ideas about how services could be improved for you and your family. |
| **Will I get expenses for taking part?** | Yes, we will give you a **£25 gift voucher *of your choice*** for a supermarket or high street shop for taking part in an interview. |
| **What are the benefits of taking part?** | Taking part in the study may not directly benefit you or your family. However, we hope that the information you provide will help to improve services for parents who use drugs and their families in the future. The study aims to empower families by ***giving you a voice*** and by making your lives more visible and understood. |
| **What are the potential risks of taking part?** | There are no major risks in taking part in this study. However, the study does involve talking about some sensitive topics. Sometimes people can become upset when they discuss personal issues that they feel strongly about, or which are important to them. The researcher will ensure that your thoughts and feelings are respected at all times and will arrange additional help and support if you need it.   |  | | --- | | **COVID-19**  Please note: Because of COVID-19, the researcher must make sure that any contact with you is safe, to protect you and your family, and also the researcher. Before any face-to-face contact, the researcher will check that everything is safe for the visit to go ahead. If not a telephone or online video call will be arranged. | |
| **Will my taking part in the study be kept confidential?** | Yes. All the information you provide for the study will be kept strictly **confidential**. However, there are some circumstances where information ***must be shared*** - for example, if a child or vulnerable adult is identified as being at risk of serious harm, or where details of an unsolved serious crime are disclosed, or where you are at immediate risk of harm yourself. In these cases, we will talk to you about our need to share information. |
| **What happens when the study is finished?** | After you finish your interview with the researcher, your involvement in the study will end. |
| **What will happen to the results of the study?** | The results will be written up in a report to the funder. We willsend you a plain English summary if you wish. We will also publish the results in academic journals and present the findings at conferences or other events for professionals and the public. In addition, we plan to present the findings in other countries, and we have a website so the public can read about the study.  The study website link is: [https://relations.stir.ac.uk](https://relations.stir.ac.uk/) |
| **Who is the funder and sponsor of the research?** | This study has been funded by the *Economic and Social Research Council.*  Project reference number: *ES/S015809/1*  The *University of Stirling* is the study Sponsor. |
| **Who is doing the research?** | The research project is being done by a large team of researchers based in Scotland, England and overseas.  **The Chief Investigator is Professor Anne Whittaker**  Address: NMAHP Research Unit, Pathfoot Building, University of Stirling, Stirling, FK9 4LA. Telephone/text: 07487 593413  Email: [anne.whittaker@stir.ac.uk](mailto:anne.whittaker@stir.ac.uk)  ***The researchers who will conduct interviews are:***  Calum Lindsay, Dr Melanie Dembinsky (Scotland)  Dr Landon Kuester and Dr Lucy Cullen (England) |
| **Who has approved this study?** | All research in Health and Social Care is looked at by an independent group of people, called a *Research Ethics Committee*, to protect your interests. This study has been reviewed and given a favourable opinion by the NHS North of Scotland Research Ethics Committee (Reference: 21/NS/0029). |
| **What if I want independent advice?** | If you would like to discuss the study with someone who is not directly involved in the project, please contact: ***Dr Emma France***, Associate Professor,  NMAHP Research Unit, Pathfoot Building, University of Stirling, Stirling, FK9 4LA.  Email: [emma.france@stir.ac.uk](mailto:emma.france@stir.ac.uk) |
| **What if something goes wrong?** | In the unlikely event that something goes wrong and you are harmed during the research and this is due to someone‘s negligence then you may have grounds for a legal action for compensation against the University of Stirling who is sponsoring this study but you may have to pay your legal costs.  If you wish to make a formal complaint about the study please contact:  ***The Complaints Investigations Co-ordinator***, Academic Registry & Governance Services, University of Stirling, Stirling, FK9 4LA.  Email: [complaints@stir.ac.uk](mailto:complaints@stir.ac.uk) |
| **How do I contact the research team?** | If you would like to discuss the study with the team, please call or text:  ***Professor Anne Whittaker,*** Telephone/text: 07487 593413  ***Calum Lindsay*** Telephone/text: 07468375346  ***Dr Melanie Dembinsky*** Telephone/text: 07795092280 |

If you decide to take part in the study, please keep a copy of this information sheet and please read the **appendix** on the following page, which tells you about how we will use information about you for the study and how to get further advice about data protection and your privacy rights.

**Thank you for taking the time to read this information sheet.**

**Appendix: Data Protection and Use of Your Information**

|  |  |
| --- | --- |
| **How will we use information about you?** | We will need to use information from you for this research study. The research team will use this information to do the research.  This information will include your name, age, address, contact details (telephone numbers), gender, ethnicity, and relationship with the parent participating in the study.  We will also ask you to provide information on the following:   * Your general health and wellbeing * The health and wellbeing of your family * The health and social care services that you are involved with * The impact of drug use on the family and related issues e.g. childcare, access to treatment, relations between family members, and social issues like housing, employment, welfare benefits and legal consequences.   **We will keep all information about you safe and secure.** We will follow UK laws and privacy rules. This means that your information will be treated in accordance with the *General Data Protection Regulation* (GDPR) and the *Data Protection Act* 2018.  Once we have finished the study, we will keep some of the information 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.  ***Personal data:*** All your ‘personal identifiable information’ will be kept securely on University computers. Only research project staff, based at the University, will be able to access this information, and it will be destroyed within one year of the end of the study.  ***Anonymity – protecting your identity:*** When you join the study, you will be given a unique identification or ‘ID’ code. This will be written on your consent form. We will then use your ID code on all your research records *instead of your real name*. Your name and any other information you provide for the research that might identify you, your family or another person will be removed or changed so no one can be recognised.  ***Audio recordings:*** If you agree to an audio-recorded interview with the researcher, they will use a secure device to record it. They will download the recording as soon as possible onto the University secure computer system and then delete the recording from the device.  With your permission, we will use a University approved **professional ‘transcription’ service** to type up your audio-recording, word for word. The researcher will check the written record of your interview and ‘anonymise’ it. This means that if we use any direct quotes from your interview, no one will know it is you. The name of the **professional service** we will use is Syntax Secretarial Solutions: [www.syntaxsecretarial.com](http://www.syntaxsecretarial.com)  ***Research data:*** All other information about you, including the researcher’s own notes about you and your family, will be stored securely on University computers and only research project staff will be able to access this information – we call this research data **‘pseudo-anonymised data’** because it does not contain any names or information that would identify people. This data will be stored securely for up to 10 years after the end of the study in line with University rules on storing research data. |
| **What are my choices about how my 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.  We need to manage your information in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about you.  ***Future research studies:*** If you agree to take part in the study, we will ask your consent to store your pseudo-anonymised research data for future ethically approved studies. If you agree, access to your data would be strictly controlled and stored in the **UK Data Service** (<https://ukdataservice.ac.uk/>). |
| **Where can I find out more about how my information is used?** | You can find out more about how we use your information  • by asking one of the research team  • by ringing us on 07487 593413  • by sending an email to [nmahp.relations@stir.ac.uk](mailto:nmahp.relations@stir.ac.uk)  If you would like more information on how we manage your data in the University of Stirling, please see our **Privacy Notice**: [www.stir.ac.uk/privacy](https://eur03.safelinks.protection.outlook.com/?url=http%3A%2F%2Fwww.stir.ac.uk%2Fprivacy&data=04%7C01%7Cemma.coles%40stir.ac.uk%7C7e13cc47a55b49a3790f08d90328ff07%7C4e8d09f7cc794ccb9149a4238dd17422%7C0%7C0%7C637544296890542052%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C1000&sdata=8EoAMhuvZSJTt6nyoZXzoHBNYBIhing8NYQ3pOsdDs0%3D&reserved=0)  If you have concerns about data protection please contact:  ***Data Protection Officer***, University of Stirling, Stirling, FK9 4LA.  Email: [data.protection@stir.ac.uk](mailto:data.protection@stir.ac.uk)  If you are not happy with their response or believe they are processing your data in a way that is not right or lawful, you can complain to the **Information Commissioner’s Office** (ICO) ([www.ico.org.uk](http://www.ico.org.uk) or 0303 123 1113). |