**PARTICIPANT INFORMATION SHEET FOR PARENTS**



**Study Title: The Relations Study**

We would like to invite you to take part in a 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. Please take time to read this information sheet and speak to your family and others about it if you wish. We will talk to you about the study and can answer any questions if something is not clear. Please take time to decide if you would like to take part.

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| **Why is the study being done?** | Research shows that parents who are prescribed drugs like methadone or suboxone, or who use drugs like heroin, are often involved with many different health and social care services. These services should work together, along with parents and families, to provide the right kind of help, at the right time, in the right way. This includes family support and systems of care that are acceptable, non-discriminatory, supportive, trustworthy, 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 of care works *from the point of view of parents and families themselves*, and * Understand how *relations* between parents and services can lead to different outcomes for families, and how to make the system better for everyone in the future. |
| **Who can take part?** | The project aims to include 30 families from two different areas in the UK – Scotland and England. This will allow us to compare different families and family experiences, different types of help from services and different ways of delivering services.  ***You can take part in the study if:***  **1. You are a parent, aged 18 years or older, who lives in Scotland.**   * This includes mothers and fathers who are living with their child/children, or their partner’s children. * We would also like to include parents who are **not** living with their children, but who have regular contact with them, or plan to do so in the near future – for example, your child/children may be living with a relative or they may be in foster care or residential care. * Mothers and fathers who are expecting a baby.   **2. You are prescribed opioid substitution therapy for the treatment of a drug problem – for example, Methadone or Buprenorphine (Suboxone, Subutex, Buvidal).**  We understand that people often take different types of drugs (legal and illegal). If you are taking other drugs in addition to opioid substitution therapy, you can join the study too. If in doubt, talk to the research team and they can see if it is possible to include you in the study. |
| **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 decide to take part, we will ask you to sign a **consent form**. If you do decide to take part, 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 your family receive, or your legal rights.  The consent form will also ask if you are happy for **your child/children to be involved in the study**. If you agree, we will always respect their wishes if they show they are not happy with this. By law, children who are **able to make their own mind up** about whether to be involved in research, must be asked to provide their consent too. We have **information sheets** to explain the study to children of different ages. We will show you these and talk to you about the consent process if this applies to your children. |
| **If I take part, what will it involve?** | The study uses a research method called ‘**ethnography**’. Put simply, ethnography is a way of trying to understand how society works by studying people in their own environment. This is done by using methods such as talking to people about their lives, seeing what they do, who they spend time with, and seeing what happens to them over time. Ethnography tries to understand what life is like for people, and how their lives are shaped by the world they live in.  Ethnography is often used to try and understand complex social issues from the point of view of the people it most affects. The focus of this study is about drug use, parenting and family life and the way governments and services respond to parents who use drugs and their families.  In this study, we would like to gain a better understanding of your life as a parent who uses drugs. We are keen to learn more about your views and experiences of health and social care services and how professionals affect your life and the life of your family.  **Although ethnography usually involves the researcher spending quite a long time with people, it is entirely up to you how little or how much you do with the researcher. If you only want to speak to the researcher once, or just a few times, that is okay. If you would like to do more, for longer, that is also okay. The research team can be very flexible. We plan to involve parents in the study up to the end of 2022.**  After you join the study, the researcher will be keen to find out about you, your family and friends, and the services you are involved with. Because each parent and family are unique, the researcher may suggest different kinds of things that you could do – everything from a one off interview, or series of interviews with the researcher, to other kinds of joint activities. **Here are some examples to give you an idea:**  The researcher could talk to you about:   * Your relationships with different family members and your friends. * Your opinion about different services you’re involved with. * Your drug taking history and drug treatment. * Your experience of becoming a parent or parenting. * Your child, their development and education. * Your own upbringing and views about parenting and family life.   **The researcher will suggest different ways to meet and talk**, for example:   * You could arrange to talk with the researcher on the telephone, by video call, or face-to-face * Meet up in a local café for a coffee and a chat. * Seeing you and your family at home. * Walk around your neighbourhood or go to the local shops with you. * Go with you to see your parents, brothers and sisters, or other relatives. * Call you on your mobile phone before or after an important event. * Go with you to see your health worker, drug worker, support worker or social worker. * Accompany you to do everyday things like going to the chemist, going to the park or school with your kids, or visiting the housing department or jobcentre.   The kinds of things you do with the researcher, and the way you communicate with them, will be discussed and agreed in advance, so it fits in with your normal routines and responsibilities.    If you would like to do more than a one off interview, the researcher may suggest making a regular time, at a time that suits you, to have private one-to-one conversations. This will allow the researcher to find out more about your personal views on certain topics or things that happen in your life. The researcher might suggest using things like photos, diaries or media stories as talking points.  **To give you an idea of how the researcher could work with you over time, here is a rough guide…**    ***Starting off – the first couple of weeks…***  Due to the COVID-19 restrictions, the researcher might start off by talking to you on the phone or online (video call). If it is safe to do so, the researcher will suggest meeting you in person and may visit you and your family at home, or somewhere else. They might suggest a **‘go-along’ or ‘walk and talk’ interview** where they chat to you when you are out and about.  To begin with, the researcher might ask questions to find out about your health and social circumstances and they will want to know about the kind of agencies you are involved with. This will help the researcher build up a good picture of you, your family and what’s happening in your life.  ***The first few months…***  The researcher may ask you if they can accompany you to your appointments with different professionals and services, and will talk to you about the kind of help you receive and want. They will be interested to see how different professionals and services treat you, what they expect you to do, or not do, and how they respond to your needs and the needs of your family over time. The researcher may also ask if they can accompany you when you are going about your daily routines, like going to the shops, paying bills, visiting family and friends, taking your kids to school or nursery, or visiting them. If you are taking different kinds of drugs and medication, they will be keen to hear your views about this.  ***On-going contact…***  The researcher may ask if they could talk to different members of your family, especially if they are involved with services as well. They might have views and experiences of their own that they would be willing to share, or you might be keen for us to speak to someone in particular about an important issue. Depending on your situation, the researcher might also want to accompany you to more agency appointments, especially if important decisions are being made about your treatment and care, or the care of your family.  ***Finishing up – the last month…***  The researcher will let you know when they have to end the research and they may ask you to do a final check on the information you have provided for the study. They will also want to talk to you and your family to reflect on your experience of being involved in the research. They will invite you to get involved in the final part of the study where we will present the results to different groups of people, including parents and families and professionals.   |  | | --- | | **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 each face-to-face contact, the researcher will check that everything is safe for the visit to go ahead. | |
| **What are the benefits of taking part in the study?** | Taking part in this study may not result in any direct benefit to you or your family. However, we hope that the information you provide will help to improve services for parents who use drugs in the future. The study aims to empower parents and their families by ***giving you a voice*** and by making your life more visible and understood. |
| **What are the potential risks of taking part in the study?** | We do not think there are any major risks in taking part in this study. However, the study involves talking about sensitive topics and 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 we can arrange additional help and support if you need it. |
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|  | The study involves everything from a one off interview with the researcher to you possibly spending a considerable amount of time with the researcher, which can be quite a commitment. However, the researcher will always put your wishes first, so we will do our best to avoid causing you any inconvenience.  If you do agree to ongoing contact with the researcher, but for any reason, you do not stay in contact with the research team for a period of at least four months, we will assume you no longer wish to take part in the study and we will not contact you again. |
| **Will I get expenses for taking part?** | Yes, you will be offered a **£30 voucher per month for every month** you and your family remain in the study and in contact with the researcher. The value of the monthly voucher is to cover your time on the project and any out-of-pocket expenses that you might have for taking part e.g. travel, drinks, food, or child care if you need it. The type of voucher will be for a supermarket or high street shop of *your choice*. The researcher will ask you what voucher you want.  If you would prefer to just take part in a one off interview, we will offer a **£25 voucher for each interview** you take part in, limited to once a month**.**  If you need a **data sim card** to take part in telephone or online calls, or a **mobile device** to make online calls, then the research team can provide this for you. |
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| **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 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 circumstances, we will talk to you about our need to share information, and with whom. |
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| **Who will know I am taking part in the study?** | With your consent, we will write to your **GP and your other key workers** to let them know that you and your family are taking part in the study. This could include, for example, your drug worker, health visitor or social worker – or anyone you see regularly who you would be happy to tell.  The letter we send to your GP and other key workers will tell them about the study and will let staff know that the researcher may ask to attend appointments with you. However this would only be done if **you** agree and if **they** agree too.  ***Contacting other people to find you:*** We would like to keep in touch with you until the end of the study if possible. However, sometimes this is difficult if you change your phone number or address. With your permission, we will try to contact you via other people who might be able to help us find you. We will ask you to fill in a form with the names and contact numbers of your preferred contacts - for example, you might be happy for us to ask your GP or a family member. |
| **What happens when the study is finished?** | After you finish your last interview or meeting with the researcher, your involvement in the study will end. The researcher will invite you to attend a **special event** where the results of the study will be presented and discussed. The research team may also invite you to take part in making creative outputs to tell the public about the learning from the study e.g., art, music and animations that expresses the results of the research. |
| **What will happen to the results of the study?** | The results of the study will be written up in a report to the funder. We willsend you a copy 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 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)  ***Other UK project staff include:*** Dr Polly Radcliffe, Dr Emily Finch, Prof. Jane Callaghan, Dr Hannah Carver, Dr Alison Munro, Dr Amy Chandler, Dr Emma Wincup and Prof. Avril Taylor.    ***International project staff include:*** Prof. Thomas McMahon, USA; Prof. Miriam Boeri, USA; Dr Amy Salmon, Canada; Dr Fiona Martin, Canada; and Dr Anna Olsen, Australia.  ***The researchers on the study are:***  Dr Dembinsky and Mr Lindsay (Scotland)  Dr Landon Kuester and Ms 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 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 contact us, please call or text:  ***Professor Anne Whittaker,*** Telephone/text: 07487 593413  ***Dr Melanie Dembinsky,*** Telephone/text: 07795 092280  ***Calum Lindsay,*** Telephone/text: 07468375346 |

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**

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| **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, date of birth, address and contact details (telephone numbers), gender, and ethnicity.  We will also ask you to provide personal information on the following:   * Your marital/relationship status and name of partner (if applicable). * Name/date of birth of your children, and address if they live elsewhere. * Information on your social circumstances such as: housing status, training/education, employment status, household income/welfare benefits, criminal justice history and child care history (including parental responsibilities and rights, child welfare orders). * Information about the health and social care services that you are involved with e.g. the name and contact details of your GP, drug worker, social worker etc.   We will also record information that you tell us about your:   * family history/upbringing and life circumstances * drug use/drug treatment (current/past) * significant physical/mental health problems/treatment * significant health and wellbeing issues for your child/children.   Lastly, we will ask you to provide the name and contact details of people who might know about your whereabouts if we are unable to contact you.  **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, another person, or the services you use, will be removed or changed so no one can be recognised.  ***Audio recordings:*** If you agree to audio-recorded interviews 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-recordings, 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 services** we will use: TP Transcription, gTYPE and 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 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). |