**Participant Information Sheet**

**Study Title**: **An Interpretative Phenomenological Analysis: What have been the experiences of family members who have been involved in the process of repatriating an individual with a Learning Disability and/or ASD back to Guernsey following an off-island specialist residential or hospital placement?**

**Researcher**: **Rebecca Wallace**

**ERGO number: 63185**

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

**What is the research about?**

My name is Rebecca Wallace and I am currently a second-year student studying on the Doctorate in Clinical Psychology programme at the University of Southampton. The research is a student project aiming to explore the experiences of family members who have been supporting an individual to move back to Guernsey following an off-island hospital or residential placement. I am keen to learn more about how this transition has been for family members in order to help improve services in Guernsey. It is my hope that in better understanding the experiences of family members, recommendations can be made in order to better support individuals when returning to local services.

**Why have I been asked to participate?**

You have been approached to participate in this study as you have been identified as a family member who has had caring responsibility of an individual who has returned to Guernsey following an off-island placement. I would therefore be really interested in hearing about your experiences with this process. I anticipate that there will be roughly 5-8 participants in total included in the study. Other participants included in this study will have had similar experiences to you.

Prior to the interview taking place, all attempts will be made to gain consent from the individual you have cared for in order for you to take part in the interview and they will be asked to sign a separate consent form. If the individual is unable to provide consent, you will be asked to provide consent on their behalf. You will also need to consent to participating in the interview yourself by signing the participant consent form.

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

If you chose to take part in the research, you will be asked to contact the researcher and you will have the opportunity to ask the researcher any questions that you may have about the research and to arrange an interview appointment time that will be convenient for you. All interviews will take place in Guernsey. You will have the option of either attending an interview at an agreed community location, organising the interview at your home or attending the interview via a virtual platform such as Zoom or MS Teams. Before starting the interview, you will be provided with a participant consent form and asked to sign the form if you agree to take part in the interview. The interview appointment will last for approximately one hour and will be conducted by interviewer (the researcher). You will be asked to reflect on your experiences and the experiences of the individual following their move back to Guernsey. The interview will be recorded using a secure Dictaphone device so that your experiences can be fully understood by the researcher. You will be asked to consent to the interview being recorded prior to starting the interview. Once you have completed the interview, you will be offered a £25 gift voucher and you will be provided with a debrief form that will explain a little more about the study.

Following completion of the interview, the recording on the Dictaphone will be transferred to a password protected computer and the Dictaphone recording will be destroyed. The audio recording will then be carefully transcribed in order for the researcher to better understand your experiences. Once all of the interviews have been completed, the researcher will explore common themes that may have arisen across all interviews in order to fully understand the experiences of all of the participants. A report will then be written up and will be submitted to the University of Southampton as part of the Doctorate in Clinical Psychology qualification.

**Are there any benefits in my taking part?**

Your participation in the study will be greatly appreciated and will help improve understanding of your experiences and help to offer recommendations for service improvements. In order to reimburse you for your time following your participation in the study, you will be offered a £25 voucher.

**Are there any risks involved?**

It is not expected that the interview will cause you any distress. However, if you do find that you become upset during the interview or once the interview has concluded, please do contact the researcher who will be able to provide you with information about support services.

**What data will be collected?**

At the beginning of the interview, you will be asked some personal information including your gender, your date of birth and your relationship to the individual that you care for. This information will be gathered in order to better understand the context of your experiences. However, all interviews will be referred to by using pseudonyms in the final report ensuring that any reader of the report will not be able to identify who you are.

All of your personal data will be handled securely during the interview process and when analysing the interviews. A secure encrypted Dictaphone will be used during the interview and once completed, your interview recording will be transferred to a password protected computer and the Dictaphone recording will be destroyed. Once your interview has been transcribed, the audio recording will be deleted. Your signed consent form will be kept in a lockable cabinet.

**Will my participation be confidential?**

Your participation and the information we collect about you during the course of the research will be kept strictly confidential.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

The interview will be recorded using a secure, encrypted Dictaphone and once the interview has finished, the audio file will be transferred to a password protected computer and the audio recording on the Dictaphone will be destroyed. The interview will then be transcribed, and the audio recording will be deleted. A professional transcription service will be used. The Data Protection Act (2018) has led to transcription services reviewing their policies regarding the protection of sensitive information. As a consequence, your interview data will be kept confidential by asking the service to sign a Non-disclosure agreement (NDA) meaning that the service will agree not to share your information with anyone else. All names will be replaced by pseudonyms in the written report so individual interviews will be kept anonymous. However, Guernsey is made up of a small community and therefore it may be possible to link certain information provided in the interview to an individual. All paper-based consent forms will be stored in a locked cabinet. As the research forms part of a student project, the researcher will be supervised by a member of the University faculty and by the Clinical Psychologist working in the local Adult Disability Team. They will also have access to the interviews for supervision purposes.

**Do I have to take part?**

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

**What happens if I change my mind?**

You have the right to change your mind and withdraw without giving a reason and without your participant rights being affected. You will have the right to withdraw the data from your interview for up to two weeks after the interview. Your interview recording will be destroyed at this point and will not be used in the final report. After this point the interview will be transcribed and therefore, withdrawal of your data will no longer be possible. Should you wish to withdraw, you can do so by contacting the researcher via their email, rjw406@soton.ac.uk.

**What will happen to the results of the research?**

Once all interviews have been transcribed and analysed, the results will be written up in a report and submitted to the University of Southampton for consideration of being awarded a Doctorate in Clinical Psychology. The completed project will then be published in a suitable journal. If you would like to receive a copy of the results, you will be invited to contact the researcher at the end of the study.

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent. However, direct quotes taken from your interview may be used in research write up and subsequent publication and/or presentations given about the research.

**Where can I get more information?**

If you require further information, please do not hesitate in contacting the researcher via their email address (rjw406@soton.ac.uk).

**What happens if there is a problem?**

If you have a concern about any aspect of this study, you should speak to the researcher who will do their best to answer your questions. The researcher can be contacted via email (rjw406@soton.ac.uk).

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Alternatively, you can contact the States of Guernsey Customer Care Team (01481 725241).

**Data Protection Privacy Notice**

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, ‘Personal data’ means any information that relates to and is capable of identifying a living individual. The University’s data protection policy governing the use of personal data by the University can be found on its website (<https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page>).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at <http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf>

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University’s policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason (‘lawful basis’) to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the ‘Data Controller’ for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

The States of Guernsey, Health and Social Care will keep identifiable information about you from this study for 10 years after the study has finished.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University’s data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University’s Data Protection Officer (data.protection@soton.ac.uk).

**Thank you for taking the time to read the information sheet and considering taking part in the research.**