**Patient Participant Information Sheet**

**Study Title**: Exploring the effects of social network dynamics on patients receiving ‘Hospital at Home’ care in a rural environment.

**Researcher**: Jack Gillham

**ERGO number: 26874**

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?**

This is a student PhD project conducted by Staff Nurse Jack Gillham under the supervision of principal research fellow Dr Ivaylo Vassilev and senior research fellow Rebecca Band. This project is about the Hospital at Home service you have recently used. It focuses on how the service works, who makes it work for you and what can be done to improve it for future patients.

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

We are asking everyone being treated by the ‘Hospital at Home’ service at the Dorset County Hospital to take part.

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

You will be given time to consider before being asked to give written consent by the researcher, who is also a staff nurse from the ‘Hospital at Home’ team.

Once this is done you will be given the first of two questionnaires to complete on your own. These can be completed online **(link below)** or on paper and returned in the FREEPOST envelope provided. It is your choice whether you choose to complete online or via post. If you choose the online option the researcher will give you the link to the website. The questionnaire should take about 30 minutes to complete.

The online questionnaire can be found at: https://www.isurvey.soton.ac.uk/37641

You may not hear anything from the research team until you are prompted via your preferred contact route to complete the second questionnaire 12 weeks later. You will be sent this in the post or informed of the web address. This will have lots of, but not all of, the same questions as the first. Again, this can be returned in an pre-addressed FREEPOST envelope if you opt for the postal option. You are welcome to change from online to paper (or vice-versa) if you wish. This questionnaire should also take about 30 minutes to complete.

Finally, you may be approached to take part in an interview with the researcher. This will be an informal discussion about the answers to the questionnaire, how you cope at home with or without support from family and friends, and your experience with the Hospital at Home service. This will take about an hour. This can take place face-to-face or via the telephone depending on your preference.

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

There may not appear to be any immediate benefits to taking part. However, taking part in this research will help gather information on the Hospital at Home service which can help to improve it, and others like it, and therefore improve any future care and treatment you or your family may receive from it.

**Are there any risks involved?**

The questions within the research ask you about the relationships you have with friends and family, and how they help you cope with your health. You may find talking about this emotional. During interviews, please to tell the researcher if you are feeling distressed and wish to pause, stop or withdraw from the study.

The study will take up to 2 hours (2x 30 minute questionnaires, 1x 1 hour interview) of your time.

**What data will be collected?**

All data will be collected by the PhD student researcher and Hospital at Home staff nurse, Jack Gillham

* The researcher will look at the doctor’s records from your current admission to Hospital at Home service to obtain your current medical diagnosis and any other ongoing health problems.
* You will be asked to complete two very similar questionnaires. The first when you are discharged, and the second 12 weeks later. The questionnaires will ask you about how you having been coping at home, what help you have received and from whom, and what effect this has had on your health.
* If you are approached to take part in an interview, the researcher will ask you questions about your time with, and since discharge from, the Hospital at Home service to get more detail about the answers to your questionnaires. This will focus on your ability to cope with or without support from family, friends and healthcare staff. The interviews will be audio recorded, transcribed word-for-word, anonymised so you cannot be identified and then the audio recordings will be deleted.

The University of Southampton will use your name and contact details, may contact you about the research study, will make sure that relevant information about the study is recorded for your care, and will oversee the quality of the study. Individuals from the University of Southampton and regulatory organisations may look at your research records to check the accuracy of the research study.

The only people in the University of Southampton who will have access to information that identifies you will be people who need to contact you to or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

**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 questionnaires will be stored in a locked filing cabinet and digital information will be stored on encrypted devices in locked offices. Your data will be anonymised and assigned a pseudonym. Audio recordings will be deleted once transcribed.

All anonymised data is required to be kept for 10 years once the research has been completed but will remain anonymised throughout.

The initial questionnaire will ask for contact details for the purpose of arranging interview. This will be stored securely and not shared with any other parties.

**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** or **discontinue** at any time without giving a reason and without your participant rights or ongoing and future care being affected. The contact details for the research team can be found at the bottom of this letter.

If you **discontinue** you will not take any further part in the study but agree that all your information can be included in the study. If you **withdraw** from the study, only the information about you that has been made anonymous will be used and only for the purposes of achieving the objectives of the study only.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

If you can no longer take part due to health needs and/or cannot give consent to continue your data will be treated as if you have chosen to **withdraw.**

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

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.

The results of the study will be written up and may be published. The results may also be discussed at conferences. These will never include the names of people who have taken part, only code names or numbers. You can have a results summary if you wish.

**Where can I get more information?**

More information can be obtained from any members of the research team.

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

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions.

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](mailto:rgoinfo@soton.ac.uk)).

Jack Gillham (Staff nurse and PhD student researcher)

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Dr Ivaylo Vassilev (Chief investigator, principal research fellow and Academic Supervisor to Jack Gillham)

Email: [I.I.Vassilev@soton.ac.uk](mailto:I.I.Vassilev@soton.ac.uk)

Dr Rebecca Band (Senior research fellow and Academic Supervisor to Jack Gillham)

Email: [R.J.Band@soton.ac.uk](mailto:R.J.Band@soton.ac.uk)

As the sponsor for the PhD project, The University of Southampton can be contacted:

Email: [rgoinfo@soton.ac.uk](mailto:rgoinfo@soton.ac.uk)

Telephone: 02380595058

**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.

The University of Southampton is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you until the research has finished. The unidentifiable data will be kept for 10 years

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 until the study has finished after which time any link between you and your information will be removed.

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](mailto:data.protection@soton.ac.uk)).

**Thank you.**

Thank you for taking the time to read the information sheet and considering taking part in the research. We will contact you to find out if you would like to take part soon.