**Participant Information Sheet**

**Study Title**: Exploring adolescents’ and young adults’ experiences of seeking information about chronic pain using the internet and social media: a qualitative interview study

**Researcher**: Anna Hurley-Wallace

**ERGO number:** 56803

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 give verbal consent.

**What is the research about?**

This study aims to explore the experiences of adolescents and young adults when searching for information about chronic pain on the internet and social media. This project is being run by Anna Hurley-Wallace, who is studying towards a PhD in Psychology (and is funded by a University of Southampton PhD studentship).

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

You are aged between 16-24 years, live in the UK, and are currently experiencing persistent or chronic pain. Some examples of chronic pain include fibromyalgia, persistent headaches, joint pain, and many more.

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

This is an interview study, which will be conducted online. If you decide to take part, you will be invited to a 10-minute screening interview. Based on your responses, you may then be invited to a longer interview lasting approximately 1 hour, at a later date.

For the screening interview, Anna will greet you, and will ask you if you have read and understood this information sheet and the consent form. Anna will read the consent questions to you and you will be asked to confirm your consent on a recording. The recording will then be turned off and Anna will ask you some demographic questions (e.g. age, sex, gender), and questions about your pain.

For the main interview, Anna will greet you, and you will be asked if you are still happy to take part in the interview. From this point, the interview will be audio and/or video recorded (depending if you choose to use the video function or not). The interview will last for up to approximately 1 hour. Anna will use an interview topic guide to help steer the conversation. At the end of the interview, the recording will be stopped, and you will have an opportunity to ask any questions you may have, off the record. Anna will read a closing statement (debrief), and you will also be sent a copy of this by email.

**How can I take part in an online interview?**

These interviews will be conducted online using Microsoft Teams. You do not have to download Teams to take part; you have the option to use the web-browser version of Teams or download the app, as you prefer. Sign-up is free (https://www.microsoft.com/en-gb/microsoft-365/microsoft-teams/group-chat-software). You do not have to go on video if you do not want to.

To join the online meeting, you can click the link in the invite email (‘Join Microsoft Teams Meeting’); this link can also be accessed in your calendar (Outlook, Google, etc.).

Recordings from the interview get uploaded automatically to Anna’s personal account on Microsoft Stream. No one else can see these recordings – your recording will be written-up (transcribed) and given a fake name.

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

Participants (apart from University of Southampton psychology undergraduate students) will be given a £20 Love 2 Shop e-voucher on completion of the study, to thank each person for their time. This reward will not be given for the screening interview if you do not complete the main interview.

University of Southampton Psychology students will be awarded 12 research participation credits for taking part in this study. One research participation credit will be awarded as a token to students who participate in the screening and do not pass.

This study may help improve our current understanding of the internet needs of adolescents and young adults with persistent and chronic pain conditions.

**Are there any risks involved?**

There are no known physical risks of taking part in this study.

This study explores experiences of chronic pain, which may provoke negative thoughts or feelings in some people who take part. The NHS have lots of online resources available that may help you deal, both mentally and/or physically with pain: <https://www.nhs.uk/live-well/healthy-body/10-ways-to-ease-pain/>

**What data will be collected?**

This study will collect interview data (video and audio recording in Microsoft Stream), which will be written-up (transcribed) and pseudonymised, so that you cannot be identified from the transcription.

We will also collect personal data including data about your health, sex, gender, ethnicity, age, and postcode; this is because we might analyse the results by splitting the data up into various categories. Data about your pain condition (collected in the screening interview) will also be used to help us describe the group of people we interviewed.

**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.

Interview data (video and audio recording in Microsoft Stream) will automatically generate a base transcript. This base transcript will be checked by Anna and the video recording will be used to help clarify and finalise field notes. An audio-only version of the recording will be sent to an external provider to be professionally transcribed. The professional transcription will then be pseudonymised (names removed and replaced with a fake name), before being imported to NVivo for thematic analysis.

Pseudonyms and other personal data will be kept in a password protected data key file, on the University of Southampton OneDrive, that only the research team may access.

The raw recording and base transcript from the interview will be deleted once the professional transcription has been completed and checked, and field notes have been finalised.

Pseudonymised data (transcriptions) will be uploaded to the University of Southampton data repository, Pure, when the study is complete. This information will be stored by the University of Southampton for 10 years.

**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 answer some verbal consent questions to show you have agreed to take part. If you would like to take part, please get in touch with Anna at A.Hurley-Wallace@soton.ac.uk.

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

You have the right to change your mind and withdraw at any time without giving a reason and without your participant rights being affected. You can contact any member of the research team if you decide you want to withdraw. You may withdraw your data within 2-weeks of the interview if you wish. After 2-weeks, you will no longer be able to withdraw your data from the study.

If you want to withdraw from the study during the interview, you can do this by letting the interviewer know; the recording will be stopped and you can choose whether you are happy for us to keep the data collected up until that point, or you can alternatively ask for your data to be destroyed/ deleted. Please note that if you do not complete the whole study (main interview), you will not receive the £20 e-voucher reward.

**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.

Results from this study will be written-up and submitted to a relevant academic journal for publication. This research will be also be written-up as a paper in Anna’s PhD thesis.

Lay summaries of the research findings will be provided to any collaborating charities and organisations, as well as to people who took part in the study, on request.

**Where can I get more information?**

If you would like more information about this research or the study results, you could contact:

Anna Hurley-Wallace (PhD student in Psychology); A.Hurley-Wallace@soton.ac.uk

Dr Felicity Bishop (Research supervisor - primary); F.L.Bishop@soton.ac.uk

Dr Sarah Kirby (Research supervisor – secondary); Sarah.Kirby@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 researchers who will do their best to answer your questions.

Anna Hurley-Wallace; A.Hurley-Wallace@soton.ac.uk

Dr Felicity Bishop; F.L.Bishop@soton.ac.uk

Dr Sarah Kirby; Sarah.Kirby@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).

**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 up to 10-years after 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).

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