



The Chronic Pain  
And Romantic  
Relationships Study

Edge Hill  
University



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# The Chronic Pain and Romantic Relationships Study

## Information Sheet for Young Person with Chronic Pain:

### Part 1 (Survey)

#### Core Project Team

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#### Introduction

Thank you for reading this information sheet. You are being invited to take part in a study that explores how young people with chronic pain and their partners navigate romantic relationships. We are interested in finding out about how having chronic pain can influence and challenge romantic relationships and the ways that young people with chronic pain and their partners work around those challenges. We also wonder if chronic pain has any positive effects on romantic relationships.

We define chronic pain as **“pain that has lasted for 3 months or more, regardless of whether the person has a formal diagnosis”**. There are lots of different ways of describing a romantic relationship and our definition is very open. We define a romantic relationship as **“a relationship between two young people that extends beyond platonic (‘just good friends’) friendship”**. We hope that young people in different forms of romantic relationship will be interested in taking part.

Before you make your decision to take part in the study or not, it is important for you to understand why this study is being done and what it will involve. Please take your time to read the following information carefully and discuss it with others if you wish. If anything is not clear to you or if you would like more information then please feel free to ask a member of the research team, whose details are at the end of this sheet.

There are two parts to this study. You can just participate in Part 1 or in both parts of the study. This information sheet concentrates on Part 1, but it provides a bit of information about Part 2.

This study is being undertaken in the United Kingdom (UK) and in Canada.

#### What is the purpose of this project?

The study aims to explore how young people with chronic pain and their partners navigate romantic relationships. We hope the project will help us understand more about the impact that chronic pain can have on young people and their partners. We hope that this could help health professionals provide better support in future.

#### Who can take part in this project?

You are eligible to take part if you are a young person (aged 18-25yrs) and you have chronic pain and you live in either the UK or Canada and you are involved in a romantic relationship. We hope to involve about 114 young people in the project.

## What will happen to me if I decide to take part in Part 1?

Part 1 of the study is an anonymous survey which you will be able to complete online. This will take you about 10 minutes to complete. The survey will ask you questions about yourself (for example, age, where you live, relationship status, pain characteristics). The survey will also mean you will be completing questions about your emotional/psychological wellbeing and your romantic relationship. If there are any questions you feel uncomfortable about answering, you can skip those questions.

## Do I have to take part in the study?

No, you don't have to take part. It is entirely up to you to decide whether or not you take part in Part 1 of this study.

Because the survey is anonymous, once you have submitted the survey you will not be able to withdraw from the study as we have no way to link your answers to you. We will only be able to contact you if you share your name and email because you are interested in taking part in Part 2.

## How do I give consent to take part?

If you are willing to take part in Part 1 of this study, then you can give your consent online. The first part of the online survey document will have the same information as in this Information Sheet and this will help you to make the decision about whether to take part or not. If you decide to take part, you will need to answer some questions to make it clear you know what you are agreeing to do. Once you have answered all of these questions and have agreed to take part, you will be able to access the survey.

## What are the disadvantages and risks of taking part?

We do not think that there are any disadvantages for you taking part in this project. We will take great care of the information that you tell us. We have chosen the questions carefully and we do not anticipate that the survey will be distressing to answer.

However, there is a chance that you could become upset when answering questions about your pain and your wellbeing. If you do get upset, then you might find it helpful to talk to a friend or someone you are close to. We have also created a **'Helpful Information Sheet'**. This sheet says 'Thanks' and provides contact details of organisations that you might find helpful. You will be prompted to download a copy of this sheet just after you have given your consent to take part and before you actually start the survey.

## What are the possible benefits of taking part?

There are no direct benefits for you if you take part in the survey, although we hope that you will find it interesting. The information that you share with us could help make things better for other young people with chronic pain.

## What happens when the research study stops?

Once you have taken part in Part 1 of the study you will not need to do anything else, unless you are interested in being involved in Part 2 of the study. We plan to have finished the study by February 2022 and written all the reports by May 2022.

### **Will my taking part in this study be kept confidential?**

All the information that is collected during the study will be kept strictly confidential and your name and other personal details will not be shared in any final reports, presentations, or articles we write. Any personally identifiable data (e.g., your contact information) will be deleted once data collection is completed but we will keep anonymised data (e.g., from your survey) for 10 years. Data from the study will be stored securely in a dedicated folder on the Edge Hill University cloud-based OneDrive (only members of the research team will be able to access this folder).

More details about how we look after the information can be found by clicking here ([link to GDPR statement in UK](#)).

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

We plan to write articles and present the work to help us share our ideas with other professionals in the UK and Canada and around the world.

If you would like to find out about the results of the study, you can find information about the study via [10.25416/edgehill.c.5433378](https://10.25416/edgehill.c.5433378).

### **Who is funding this study?**

This study is being funded by an internal funding award [CYPF28] from the Health Research Institute at Edge Hill University in the UK. The research team will not receive any personal payments for undertaking this research.

### **Who has reviewed the study?**

The study has been reviewed by the Health-Related Ethics Committee at Edge Hill University [ETH2021-0227] and University of Bath [21-237] in the UK, The University of Ottawa Research Ethics Board [H-10-21-7549] in Canada.

### **Who can I contact if I want to take part or want more information?**

If you would like to take part or would like further information about the study, then please contact:

In the United Kingdom

- Bernie Carter: email [bernie.carter@edgehill.ac.uk](mailto:bernie.carter@edgehill.ac.uk) or
- Abbie Jordan: email [a.l.jordan@bath.ac.uk](mailto:a.l.jordan@bath.ac.uk)

In Canada

- Paula Forgeron: email [paula.forgeron@uottawa.ca](mailto:paula.forgeron@uottawa.ca)

If you are based in the UK and have any concerns about the research and wish to speak to someone independent, please contact: FAO Philip Bentley, URESC Secretary, [research@edgehill.ac.uk](mailto:research@edgehill.ac.uk)

If you are based in Canada and have any concerns about the research and wish to speak to someone independent, please contact, Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5 Tel.: (613) 562-5387 Email: [ethics@uottawa.ca](mailto:ethics@uottawa.ca)

## And, finally.....what happens in Part 2 of the study?

If you want to know more about the web-based interview (Part 2), we can send you more details. But just so you know a little bit about it we are sharing an overview of what we are planning to do next

If you decided to take part in Part 2 of the study, we would ask you **and your partner** to talk to us about your relationship. We'd like to talk to both of you about how chronic pain influences your relationship, what challenges it creates for both of you and whether there are any good things that occur because of having to take chronic pain into account. The interview will take place remotely (e.g., Zoom, telephone) and we'd like to talk to you together.

To help make sure that we talk about things that are important to you, we will ask you and your partner to take some photographs or identify some images that illustrate for you some of the great parts of your relationship and some of the times that are trickier. We'd start the interview by asking you to talk about the photos or images you chose as this means we start talking about things that are really important to you and your partner.

You won't have to answer questions you feel uncomfortable with and only need to share as much as you want.

If you are interested, you can contact one of the researchers on the list on the previous page and you can also tick the box and share your email address just before you complete and submit your survey. **If your partner is not interested, then we may still invite you to take part in an interview.**

## GDPR statement

To access the GDPR statement please click [here](#).

## Edge Hill University Privacy Policy

If you wish to know more about Edge Hill University's privacy policy, please click [here](#).

**Thank you very much for your time in reading this information leaflet and for thinking about taking part in Part 1 of the study.**