

25 October 2023

THE PREVALENCE, SEVERITY & MEASUREMENT OF PAIN IN CYSTIC FIBROSIS – A SURVEY PILOT STUDY

Individual Living with Cystic Fibrosis Participant Information Sheet

What is this research about? This research, The Prevalence, Severity and Measurement of Pain in Cystic Fibrosis (CF), is investigating the occurrence and types of pain in adults living with CF. There is a current gap in the scientific literature describing pain in CF and no standardised tools specifically designed for people living with CF. This research hopes to confirm the significance of pain and provide preliminary information to develop a standardised CF pain scale.

My name is Anastasia Ward, and as part of my doctoral degree researching genomic variations in CF, I am investigating the different symptoms reported by people living with CF. Specifically, we want to understand better one of the most commonly reported symptoms - pain. In this study, we want to compare the difference in pain reported by those living with CF and those who are not. I am conducting this research under the supervision of Dr Nedeljka Rosic, Dr Keith Chee Ooi, and Dr Ramil Mauleon.

Inclusion and exclusion criteria: You are eligible to participate in this study if you are over the age of 18 and have been clinically diagnosed with CF. However, you are not eligible for this study if you have been diagnosed by your healthcare practitioner as being cognitively impaired.

What is this research about? This research is investigating the occurrence and types of pain in adults living with CF. There is a current gap in the scientific literature describing pain in CF and no standardised tools specifically designed for people living with CF. This research hopes to confirm the significance of pain and provide preliminary information to develop a standardised CF pain scale.

What does this research involve? The research involves only the completion of an anonymous online survey via software called Qualtrics. No identifying information is required. This survey contains 42 questions and will take approximately 20 - 30 minutes to complete. In this survey, we will ask you to recall past complaints or issues related to your physiological health. If you have any difficulties using a computer or the online survey platform, you may like to complete this survey with a friend or carer. However, it is very important that the answers provided are your answers and not those of your friend or the person who is providing assistance. This study is voluntary, and you may stop and withdraw at any time.

What are the risks associated with this research? This research has been assessed as low risk. However, if any question makes you feel uncomfortable or causes you distress, you are free to skip that question, take a break or withdraw from the research completely by closing down the survey. If you need additional support, please contact Lifeline on **13 11 14** or Beyond Blue on **1300 22 4636**. For online support, visit www.headtohealth.gov.au

My responsibilities to you. All data is collected anonymously to ensure privacy and confidentiality. When the analysis of the data is conducted, only group data will be reported. If you choose to be contacted after the completion of the survey as part of a follow-up research project(s), you will be provided with a new link to a separate page where you can leave your contact details, so your survey remains anonymous. The contact information you provide will be collected and stored securely by a member of the current research team. It will not be shared with anyone within or outside of Southern Cross University.

Inquiries: Please direct any inquiries to the student researcher Anastasia Ward (a.ward.22@student.scu.edu.au) or the Principal Supervisor, Dr Nedeljka Rosic (nedeljka.rosic@scu.edu.au).

Informed Consent: As this is an anonymous survey, no consent form is required. Completion and submission of the survey is implied consent.

Feedback to Participants: If you would like to receive a summary of the research findings on completion of the study, please click on the Feedback link at the end of the survey; this will take you to a separate page, not connected to the survey, where you can enter your email address. Again, your personal information will not be shared within or outside of Southern Cross University.

Ethics Approval: This research has been approved by the Human Research Ethics Committee at Southern Cross University. The approval number is 2023/026.

If you have concerns about the **ethical conduct** of this research or the researchers, write to the following:

*The Ethics Complaints Officer
Southern Cross University
PO Box 157
Lismore NSW 2480
Email: ethics.lismore@scu.edu.au*

All information is confidential and will be handled as soon as possible.

By clicking the link provided below to begin the survey, you are giving your consent to participate in this study. If you do not consent, please do not continue.

If you would like to complete the survey, please [**CLICK HERE >**](#)